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Building a family after donor conception

Ethical and empirical perspectives

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I am indebted to a great number of people who helped me to realise the results I achieved during the past four years.

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Universally, becoming a parent is seen as one of the main goals in life. Raising a helpless little human to an autonomous adult brings, among many other things, joy, happiness, fear, worries, frustration, pride, busy days and sleepless nights. Becoming a parent can without a doubt be seen as one of the most life-changing events in a person’s life. For some people, the path to parenthood is a challenge. Fertility problems block their child wish to come through. Luckily, many solutions are available to overcome involuntary childlessness. Using donated gametes is one of them. For those families, several dynamics occur that are absent in other families. They need to deal with questions that other families are not confronted with. In this dissertation, I will go in to some normative and psychological issues concerning family building via gamete donation. For four years I had the opportunity to delve into the topic of parenthood after assisted reproduction with gamete donation. I was able to read and think about ethical issues and I had the chance to study the views, experiences and opinions of the people involved in the practice. This dissertation is the result of four years of work. It represents my own process of thinking about parenthood via gamete donation. This dissertation discusses by no means in detail every ethically relevant aspect of this topic. However, I attempt to discuss what I believe are some of the main issues surrounding this field.

In a sense, writing a doctoral dissertation is similar to climbing a mountain. Of course, the views from my office didn’t come near to the views in the mountains, and yes, writing a dissertation requires nothing but a chair (or something similar) and a computer. Nonetheless, on one point the similarities are striking. From the moment a climber leaves basecamp, he knows difficulties might cross his path. The snow conditions might not be as expected, the weather might change drastically during the ascent, the route might be more difficult than expected, fear might suddenly overwhelm the climber or the friendly roommate in the mountain refuge might turn out to be a snorer. Difficulties also like to appear whilst writing a doctoral dissertation. I can
honestly say that Murphy probably had a laugh almost every time I submitted a manuscript to a journal. Also at my first encounter with an ESHRE talk, he was there enjoying himself, leading to a personal aversion of everything that looks like presenting in front of a reasonable audience. However, with persistence, many of these hitches can be overcome and the mountain can be conquered, and so can be reaching the end of writing a doctoral dissertation. Writing this doctoral dissertation was sometimes demotivating, difficult, boring, lonely, and at some points, a lot more difficult than climbing. But at other times it was equally fun, enriching, challenging and enormously freeing. Either way, the last four years have transformed me, for the better and the worse.
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Section 1

Introduction and background
The child wish: when ART comes in

Universally, parenthood is undeniably regarded as one of the most important goals in life. For most people in most societies, parenthood is included in their life plan and is considered to be central to their identity (Boivin et al., 2007). In many cultures, having children is a confirmation of one’s masculinity and femininity and it is seen as an expression of the couple’s unity. There are many possible motivations for choosing the path of parenthood. Having children is said to bring happiness and being a parent is seen as a valuable act in life. The fulfilment of one’s identity and continuity (passing on one’s genes) are also seen as reasons for opting into parenthood (Bos et al., 2003).

However, not all couples who intend to have children will also achieve this goal spontaneously. Some will need medical help to resolve underlying fertility problems. The World Health Organization recognizes infertility as a public health issue worldwide (Boivin et al., 2007). Infertility is clinically defined as ‘a disease of the reproductive system defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse’ (Zegers-Hochschild et al. for the World Health Organization and the International Committee for Monitoring Assisted Reproductive Technology, 2009). As age is a determining factor for a successful conception and pregnancy, a woman aged 35 or older is considered infertile after six months of unsuccessfully attempting a pregnancy. According to this definition, infertility is a broad concept. In practice, a distinction can be made between infertility and subfertility. Many couples who fail to conceive after 12 months are sub fertile: they may still achieve a pregnancy without medical assistance in the future. Another distinction can be made between primary infertility, which is the inability to conceive, and secondary infertility, which is defined as a failure to conceive after a previous conception (Keye, 2006). In this dissertation, infertility is used in the broad sense: everyone who experiences difficulties in having children and needs to appeal to assisted reproduction is infertile.

When having a baby does not go smoothly

An estimated 10-15 % of couples is affected by infertility, which makes this one of the most common diseases for people at their reproductive age (between 20 and 45 years old) (ASRM Fact Sheet, 2014). Physiological causes in either the man or the woman are
responsible for 20-35% of the infertility cases. For 25-40% of cases, the problem lies with both partners and in 10-20% the infertility remains unexplained (ESHRE ART Fact Sheet, 2014). Next to physiological causes, lifestyle factors such as smoking, obesity and stress are associated with increased risk of infertility (ESHRE ART Fact Sheet, 2014). Several techniques and medical treatments have been developed to help infertile couples. Non-invasive methods include advice about the timing of intercourse or drug therapy to promote ovulation or prevent miscarriages (Harvard Medical School, 2009). Other couples need to appeal to more advanced medical techniques such as in vitro fertilization (IVF) or intracytoplasmic sperm injection (ICSI) where a woman’s oocytes are removed from her ovaries and combined with sperm in a laboratory. When embryos develop, these are transferred to the woman’s womb (HFEA, 2012). Since the birth of the first IVF baby Louis Browne in 1978, it is estimated that more than 5 million IVF babies followed since then worldwide (Adamson et al., 2013). Each year, an estimated 1.5 million Artificial Reproduction Techniques (ART) cycles are performed worldwide, which result annually in the birth of an estimated 350,000 babies (ESHRE, 2014). In Belgium, more than 3 % of all babies born are conceived by ARTs. In the USA, this is estimated to be slightly more than 1% of total births (ESHRE, 2014).

A considerable part of the infertile couples cannot use their own genetic material. In such cases, material of a third party can be used. Sperm, oocyte or embryo donation can help a couple to conceive a child that is partly genetically or biologically related to them. In the United States, it is estimated that 40,000 children are born annually via donor insemination (Thorn, 2006). In Belgium, in 2011, an estimated 13,000 women were inseminated with donor sperm and an estimated 300 women received a donor egg (Belrap, 2014).

Given the value that is attached to parenthood, it is not surprising that infertility has a massive impact on the individual’s and couple’s psychological wellbeing and stability. Both men and women report on the psychological burdens of infertility in the form of anger, grief and depression, guilt, stress, isolation, loss and a sense of personal failure (Dunkel-Schetter & Lobel, 1991; Mason, 1993; Cousineau & Domar, 2007). The most difficult emotion for couples to handle is the loss of control over one’s life (Cousineau & Domar, 2007). Infertility becomes the centre of daily tasks and discourse, often leading to an exclusion of other important aspects of life (Cousineau & Domar, 2007). For men, reduced sexual desire and satisfaction, and feelings of personal and sexual inadequacy were found after infertility diagnosis (Ramezanzadeh et al., 2006; Irvine, 1996). For women, failure talk is often reported with regard to sexual and reproductive functions, and a reduction of self-esteem in the sense that their body cannot do what other women seem to do without any difficulty (Petok, 2006; Daniluk, 1998). Lengthier treatment seems to increase marital distress, which, for women, is accompanied with a negative impact on sexual functioning (Petok, 2006, Cousineau & Domar, 2007). Overall, stress seems to be a larger problem for women than for men (Petok, 2006; Henning and
Strauss, 2002). Data on the impact of infertility on the couple and the impact on the marital relationship has not been conclusive (Cousineau & Domar, 2007). On the one hand, marital stress seems to increase in couples who do not conceive within the first year compared to couples who do (Benazon et al., 1992). On the other hand, studies have shown that generally, marital relationships remain stable (Edelmann et al., 1994). For most couples, infertility seems to be a temporarily life crisis.

**Alternative families**

Infertility does not only affect heterosexual couples. Lesbian and gay couples and singles may not have medical reasons for assisted reproduction, but they cannot achieve a pregnancy on their own either. To differentiate this inability to conceive spontaneously from medical infertility, sometimes the term social infertility is used. A study conducted in 2012 showed that 3.5% of the adults in the US identified as lesbian, gay, bisexual or transgender, which comes down to 8.2 million people in the US (Gates & Newport, 2012). Of these, an estimated 650,000 same-sex couples are living in the US with 19% of them raising children, with 27% for lesbian couples specifically (The Williams Institute, 2010). These data include biological children, adopted children and foster care children. Unlike heterosexual couples who often only find out about infertility after months of trying to conceive naturally, these couples know in advance that having children on their own is not possible. When such couples opt for medical aid to fulfil their child wish, they know that, in the case of lesbian couples, a gamete donor, and for gay couples also a surrogate, will be necessary.

**Zooming in on third party reproduction**

Along with the development of reproductive techniques, ethical questions and discussions have been raised from the start. Several examples of such ethical debates can be given. For instance, arguments were advanced against the moral acceptability of the reproductive techniques. The argument goes that by using such techniques, procreation is separated from sexual intercourse, disrupting the ‘natural order’ of things. Italy for instance rejects gamete donation based on this motivation. Another example of a hugely important moral consideration is the welfare of the child. It is for instance argued that with ARTs and the practice of gamete donation, families can be formed which cannot guarantee the child’s well-being: frozen sperm that was stored from a man who died, can be used to inseminate the widow. In the ethical debate, it is argued that the right to procreate should always be balanced with the well-being of the
future child, meaning that the resulting child should have a reasonably happy life (Pennings, 1999). Another example of a moral objection raised against ARTs, is the fear for designer babies and eugenics. To what extend should would-be parents be able to choose their donor and accompanying characteristics? Should would-be parents be able to create embryos and pick only the boys or girls, or choose the blond or brown haired child? A recent debate in this regard discusses the moral acceptability of the so-called ‘three parent babies’, where DNA of three persons is used during an IVF treatment in order to prevent mitochondrial diseases (HFEA, 2014; Human Genetics Alert, 2013). Other ethical debates include for instance the status of the embryo, the importance of genetic ties, the acceptability of surrogacy, access to infertility treatment, fertility preservation, and surplus embryos and their destiny.

With this dissertation, I aim to contribute to the ethical and empirical bioethical debates that focus on third party reproduction, particularly with regard to heterosexual and lesbian families. Third party reproduction is used as a general term incorporating sperm and oocyte donation, but leaving out surrogacy arrangements. The term is alternated with synonyms such as gamete donation or the gamete donation practice throughout this dissertation. In order to situate the topics I touch upon in this dissertation in the literature about third party reproduction, three main debates are outlined in this introduction.

(1) Third party reproduction challenges the traditional view on parenthood. This raises questions about the definition of parenthood and, consequently, about what makes someone a parent and gives this person parental rights and responsibilities. Several normative accounts of parenthood and their problems are explored.
(2) For a long time, the use of gamete donation was shrouded in secrecy. An important ethical debate nowadays concerns the question whether children should be told about their conception method. The debate focusses on the discrepancy between the right of the child to be informed and the right of the parents to keep this information private.
(3) Even though a donor transfers his parental rights and obligations to the intending parents, he or she contributes to the existence of a child. The question is whether a donor, knowing that his or her genetic make-up is partly present in the child, should have the responsibility of being available when the child becomes older and has questions about his or her genetic roots. This debate centres around the anonymity and open-identity systems, with the interests of two parties opposing: the child’s right to information about the donor and the donor’s right to privacy.
References


Chapter 1

Third party reproduction: a challenge to the traditional accounts of parenthood and kinship
The genetic and biological accounts of parenthood are probably the most intuitive and the most prominent throughout history, reflecting the idea that parenthood results from creating a child with one’s own genetic material and gestating it. It is not surprising that the law still reflects such a conception of parenthood. In most countries, the mother who gave birth to the child is automatically the legal mother. In marriage, the husband of the legal mother automatically becomes the legal father. The rationale behind this legislation is that the woman who gives birth to the child is evidently also the genetic mother and the woman’s partner is, presumably, the genetic father. With the development of ARTs, this - for a long time self-evident - link between genetics and parenthood was severed, hereby challenging the traditional view on what constitutes parenthood. Imagine the following case: a couple desperately wants to have a child of their own. After trying for 3 years and several medical examinations later, it turns out both spouses are infertile. The man cannot produce sperm and the woman cannot produce good quality oocytes both due to a genetic disorder. For the woman, this disorder has affected her capacity to carry an embryo to term as well. Adoption is not an option for them, so they decide to search for two donors and a surrogate. The donor sperm and donor oocytes are successfully united and one embryo is transferred to the surrogate’s body. This woman subsequently gives birth to a healthy baby boy. The baby is handed over to the couple and they start raising the little boy (Hill, 1991). Who is entitled to parenthood in this case? Instead of two, now at least five parties are entitled to claim parental rights and duties (not to mention the partners of the donors and surrogate). In what follows, an overview of the ethical considerations concerning what makes someone a parent is given.

1.1 Accounts of parenthood

In the search towards a conclusive definition of parenthood, several views have been developed in the literature. There are those who ground parental rights and responsibilities in genetics and biology, accounts known as geneticism and gestationalism, and those who argue that parenthood arises from non-genetic or social grounds, accounts known as voluntarism, intentionalism and causalism. All these accounts can be considered as ‘monistic definitions’ of parenthood: they argue that there is a single basis for parenthood. Several problems arise from each of these accounts. As an answer to these problems, a pluralistic account was proposed. Advocates of this account argue that each basis given by the monistic definitions is a sufficient basis, rather than a necessary one. By making each basis a sufficient condition
for parenthood, several bases can be defended as a ground for parenthood. This account of parenthood defends both genetic and social grounds for parenthood. However, also this account faces an obvious problem.

1.1.1 Monistic accounts of parenthood and their problems

1.1.1.1 Parenthood based on genetic and biological grounds

**Geneticism**

A geneticist account of parenthood states that parental rights and obligations arise solely from the genetic relationship between the parents and the child. Several arguments were given by advocates, mainly revolving around the property argument and the causal geneticism argument.

*Property argument.* The first argument in favour of a geneticist account was based on the idea that a person ‘owns’ the products, processes, and organs of his or her own body, and consequently, has property rights over his or her own genetic material (Hill, 1991; Kolers & Bayne, 2001; Hall, 1999). Since a child is a product of one’s genetic material, a genetic parent receives the rights over this child.

Opponents pointed out several problems with this argument. First, since a child is a genetic composition of two persons, one would only own half of the child (Hill, 1991). In practice, this would be rather inconvenient since one cannot make decisions for only half of the child. Second, it is not clear how rights over one’s own gametes can be transferred to rights over a child. A new human being comes into existence: claims over its components are not the same as claims over the new human being (Kolers & Bayne, 2001). Thirdly, parental rights and responsibilities are not simply property rights, since property rights do not depend on social obligations (Kolers & Bayne, 2001). One can own a mobile phone and choose to never look at it or destroy it. This is allowed since you bought the phone and you have the private property rights over the phone. Parental rights are clearly of a different sort: such rights are directly connected to the well-being of the ‘owned’. In addition, in contrast to property rights, the value of ‘the property’ (meaning, the child) does not depend on its rarity or importance. Moreover, parental rights and responsibilities change over time since the child grows up to become an adult. Property rights do not change over time as long as the ownership does not (Kolers & Bayne, 2001).

*Causal geneticism.* A second argument given by advocates of geneticism claims that genetic ties are not a matter of choice. Begetting a child is the same as causing a child to exist, and one is morally accountable for the things one causes (Nelson, 2000). Callahan (1992) defended the argument by claiming that genetic ties intrinsically lead to
obligations. We cannot choose to either acknowledge or transfer them: causing a child means agreeing to parental duties. The genetic account thus leaves aside the intentions of people. The rationale behind this position is that children are helpless and dependent on others when they are born. Since genetic parents are the direct cause of the existence of the child, they bear this responsibility. This does not necessarily rule out adoptive parents or stepparents: one can pick up parental duties voluntarily. The difference is that a genetic relationship automatically leads to parenthood (Fuscaldo, 2006). The question is why the genetic parents in these cases, such as adoption, are not seen as the moral parents of the child. If parental obligations are inherent to genetics, why can they be transferred so easily in the case of adoption or newly constituted families? Causal geneticism thus faces several problems. Kolers and Bayne (2001) tackle this argument by showing that the idea that pure genetics cause a child to exist is false, or at least controversial. The question is when a child is brought into existence. Some identity theories argue that one exists from the first moment of consciousness (when the relevant part of the brain is formed). They state that it is not entirely clear when this moment takes place, but argue that, by the time this part of the brain has developed, the gestational mother is as much responsible for the existence as the genetic parents (Kolers & Bayne, 2001). Fuscaldo (2006) also argues that a difficulty arises from the causal geneticism argument. She questions what can be seen as the cause of a child’s existence: is it the donor, the embryologist who fertilizes the woman’s oocyte, the clinician who transfers the embryo back into the woman’s body? Parenthood defines a unique relationship between a person and a child. She argues that a causal account generates too many parents and that it is therefore not plausible.

Implications for donors. Proponents of the causal geneticism account argue that from their account, it follows that donors have parental duties and rights. The fact that a donor has no intention of raising the children resulting from his or her gametes, that the receiving couple does not want him or her to take up parental rights and responsibilities and that society excuses him from any obligations and rights, is not relevant (Callahan, 1992; Benatar, 1999). According to them, building new families through gamete donation is morally wrong because donors fail to fulfil their parental responsibilities. However, Bayne (2003) stated that it does not automatically follow from the account that donors have parental responsibilities. Even if geneticism were defendable, donors should still not be responsible. He argues that donor families should be regarded as exceptions to the standard routine to parenthood. According to him, it is permissible that someone transfers his or her parental responsibilities and rights to another individual (or institution) as long as he or she has good reasons to believe that this individual will carry out these responsibilities adequately. Consequently, by agreeing to the donation contract, a donor transfers his parental liability. Of course, one could argue that donors cannot know with certainty that his or her recipients will be responsible parents and
that therefore, they cannot transfer their rights. However, in practice, recipients of donor material always receive counselling. This counselling session should detect possible problems with regard to parental responsibilities. It can be assumed that all people starting ART treatment via gamete donation will be responsible parents. Donors can therefore transfer their rights.

Also Fuscaldo (2006) argues that a person cannot be held responsible for everything he causes, especially not for unforeseeable actions. To make her point, she presents a case report based on an incident that occurred during the civil war.

According to Dr T.G. Capers of Vicksburg, on 12th May 1863, during a battle, a young soldier friend of his was hit in the scrotum by a bullet that carried away his left testicle. The same bullet apparently penetrated the left side of the abdomen of a young woman nursing the injured nearby. To her surprise, 278 days later, the woman gave birth to a healthy baby boy. The infant was shortly after operated on to remove a malformed bullet. Dr Capers concluded that this was the same bullet that carried away the testicle of his young friend and, with some spermatozoa on it, penetrated the ovary of the young woman. (Fuscaldo, 2006, p. 67)

She believes that, although the two persons can be seen as the cause of the existence of the child, they cannot be forced to carry parental obligations. Indeed, conception happened out of their control.

**Gestationalism**

The gestational account of parenthood argues that parental rights and responsibilities arise solely from gestating and giving birth to the child. This does not mean that fathers cannot be parents in a moral sense. Their moral status as a parent arises indirectly from the relationship the father has with the mother, instead of the relationship with the child (Rothman, 1989). Three arguments are discussed.

**Maternal bonding argument.** The first argument is based on the idea that during the pre- and postnatal relationship between the mother and the child, a deep bond is developed. From this bond, a parental claim arises (Hill, 1991). One can wonder what exactly the implications of such a bond are for parental rights. A first problem is that it is unclear how this bond differs qualitatively from the bonding process developed by others (e.g. the father). Secondly, it is not certain that such an intrinsic bond even exists. We know that parents, whether they are the natural parents or the adoptive parents, love their child. This so-called ‘intrinsic bond’ seems to be present in the case of adoption as well (Hill, 1991).

**The relinquishment argument.** The second argument concerns the effects on the mother when she has to relinquish her child. Evidence shows that when new mothers are separated from their child (even for only a short period of time), feelings of anxiety
develop (Hock et al., 1989). Again, it is not clear how this influences granting parental rights and why psychological harm in case of relinquishment would not be equally harmful for others (e.g. the father), meaning that the mother has no exclusive right to parental responsibility.

The physical involvement argument. The physical contribution of a birth mother to the existence of a child cannot be overlooked. It is argued that this involvement should be the basis for granting parental rights to the birth mother. The physical involvement generates property rights to the child (Hill, 1991). First of all, this argument faces the same problems as already mentioned above: parental rights differ from property rights. Secondly, one could argue that a genetic contribution would also count as physical involvement. In that case, not only gestation would lead to parental rights, such rights would also follow from a genetic link.

Implications for surrogacy. From the gestational account it follows that the gestational host has moral priority to the parental status (Hill, 1991). This means that in case of surrogacy, the primary parental status goes to the surrogate mother. Opponents argue that this account does not necessarily imply a moral priority for the surrogate mother. As in the case of the geneticist account and the implication for donors, it can be argued that surrogacy should be regarded as an exception to the standard practice. By agreeing to a contract in which the surrogate declares to carry the child to term in order to hand the child over to the intending couple, she gives up her priority as a parent. A counterargument can be developed to each of the above arguments (Hill, 1991). With regard to the maternal bonding argument, a surrogate mother knows in advance that she will not be recognized as the mother of the child. The maternal bonding should be given less weight since attachment to the child can be precluded. With regard to the relinquishment argument, one should evaluate possible regrets in the light of contractual agreement made between the surrogate and the couple. In addition, the possible harm done to the surrogate when relinquishing the child should be weighed up against the possible harm done to the intending couple when not receiving the child. With regard to the physical involvement argument: the physical involvement of the surrogate gives her property rights over the child, and as these property rights would be considered the same as parental rights, it follows from there that she transferred her property rights – and, parental rights - to the new owners by contractual agreement.

1.1.1.2 Parenthood based on social grounds

Voluntarism

Several people voluntarily take up a parental role with accompanying rights and responsibilities. Adoptive parents are a clear example. The promise to take up parental
obligations, implies that one is willing to fulfil this promise. Therefore, a voluntary commitment to parenthood implies the acceptance of parental responsibilities (Weinberg, 2008). However, the obvious problem here is the voluntariness of parental obligations. One can choose freely to fulfil parenthood or not. Such an account implies an arbitrary basis for parenthood: many children will be left without or with too many parents when this is regarded as the basis.

**Intentionalism**

As an answer to the problems posed by the traditional views on parenthood for third party reproduction and surrogacy, a new account was introduced (Van Zyl, 2002). The intentional account of parenthood defends the position that the parents of the child are those people who intended to create the child, regardless of any biological connection. In this case, parental obligations and rights arise from the mental states of persons and the contracts between individuals rather than from genetic or biological ties (Hill, 1991). This account gives expression to the procreative liberty that was made possible by the ARTs and gamete donation: procreation became a conscious choice without the need of biogenetic ties. Schultz (1990) argued that, to include the new families created by ARTs, the law should refrain from the traditional accounts of parenthood and should purely accept intention as the basis for determining parenthood. Hill (1991) also argued that the moral parent should be determined by intentions. He argued that intentional parents are the first cause of the existence of a child; their desire and intention to rear a child starts the chain of creating a child for instance by searching for a donor. Without the intention of the parents, the child would not exist. This creates a unique causal relationship, from which parental rights and obligations rise. Moreover, while a combination of genetic progenitors and a gestational host are necessary to bring the child into existence, no specific progenitor is necessary. Any biological progenitor would do to create the child, but if it were not for the particular intentional parents, the child would not exist (Hill, 1991).

Although this account offers a solution for non-traditional families, several problems still remain. First, this account can be used to exclude people from parental duties and rights (Van Zyl, 2002). In cases where ARTs are used to conceive a child, conscious thought has indeed taken place before conception. Nevertheless, many pregnancies are still unplanned and unintended. With intention as the single basis for parenthood, parents of unintended children could not be held responsible for them. This account allows people to procreate without intending to be a parent and thus, be free of any parental duties and rights. At the same time, parents who unintentionally created a child, cannot claim parental rights and responsibilities. A child could be left with no parents (Fuscaldo, 2006). Second, anyone can claim parental responsibility by showing
intent, hereby including people who intuitively should not be the parents of a particular child (Roberts, 1983).

Bayne and Kolers (2003) refute Hill’s arguments. First, they reject the intentional parents as prime movers, because other people such as eager grandparents might be the prime movers in orchestrating a pregnancy. Second, they agree that but for the orchestration of the intended parents, the child would not exist. However, they reject the position that the intended parents are the only necessary cause of a particular child’s existence since particular biological progenitors are also necessary: each person’s genetic material is essential to that person. Particular gametes will create a particular child. Hill’s but for-argument is not limited to intentional parents, it also includes the genetic and gestational parents as having parental rights and responsibilities. Nonetheless, Bayne and Kolers argument fails to counter intentionalism because the providers of gametes may not have the intention the create a child.

Causalism

Another ground for parenthood was given by causalists who defend that parenthood results from being the cause of the existence of the child. A first interpretation was given by Munson (1988) who made a distinction between multiple agents who were part of the causal chain that lead to the existence of the child, and the initial causal agents, who started the chain that lead to the existence of the child. He argues that one cannot be held morally responsible for every consequence one contributes to. Therefore donors and medical doctors for instance are not morally responsible for the child and consequently do not have parental rights and responsibilities. The problem with this account is that it is often unclear who or what exactly is the initial cause: grandparents, parents, the bottle of wine or the electricity breakdown? Although Munson’s interpretation offers an account that is closely related to our intuitions with regard to the donor and other actors who contribute to the existence of the child, it remains too vague to pin down who exactly should be held responsible for the child.

Another interpretation was given by Fuscaldo (2006), calling her account ‘candidate parenthood’. Like Munson, Fuscaldo argued that merely being part of the causal chain that leads to the existence of the child is not enough to generate parental rights and responsibilities: however, instead of narrowing the causal account down to the initial cause, her account requires the notions of freedom and foreseeability. She argued that parenthood follows when the creation of a child was a foreseeable consequence of a free action. This also implies that donors are responsible for the child, since it is foreseeable that from freely donating gametes, a child will be created. However, she adds that not everyone is equally responsible for the existence of a child, meaning that degrees of responsibility exist. Nonetheless, the problem with this account remains that it creates too many parents. The foreseeable consequence of a child can be incurred by genetics,
gestation and intention. This account does not offer a solution when a conflict arises between all parties who freely contributed to the foreseeable existence of the child.

1.1.2 A pluralistic account of parenthood

Clearly, every monistic account of parenthood faces problems due to their monistic nature. A monistic definition based on genetics fails to include the social intentional parents. The gestational account fails to include intentional families using a surrogate and fails to ground fatherhood and accompanying rights and responsibilities in the relationship the father has with the child. The intentionalist account fails to include those couples who conceive an unintended child and causalists create too many parents.

To solve this, a more inclusive account of parenthood in which one or more criteria are regarded as sufficient rather than necessary for parenthood was suggested by Bayne and Kolers (2003). They argue that handling a sufficiency view leaves open the possibility that all accounts constitute a part of the puzzle, implying that genetic, gestational and intentional parents are all parents and therefore, all have rights and responsibilities towards the child (Bayne & Kolers, 2003). They argue that the underlying assumption in all these accounts seems to be a correct basis for parenthood: being the cause of a child is the key basis for parenthood. A causal account of parenthood is necessarily pluralistic, since several activities make significant causal contributions. By taking such a pluralistic account, they recognize the implication that a child can have a number of parents.

Although such an account has the advantage of including several types of parents, the obvious problem is that no priority is given to a basis of parenthood and that when a conflict arises, no solution can come from this account. When we recall the example of the little boy brought into existence by the help of his donors, his gestational mother and his intentional parents, custody could be claimed by all these parties. In practice, this would not be possible, nor would it be in the best interest of the child. This could result in either too many parents or in every responsible party pointing at each other, leaving the child with no parent (Weinberg, 2008).

1.2 Conflicting values

The institutionalization of gamete donation has changed the focus of what constitutes parenthood. Also the development of adoption and foster care programs shows that an evolution in the view on parenthood has taken place. By evaluating such practices as
morally acceptable, Western societies have accepted that parental relationships need not be grounded in genetic ties. By offering such treatments and programs, the importance of genetic ties is downgraded and social parenthood is promoted. Remarkably, during the course of treatment with gamete donation, a conflict seems to rise between on the one hand, downgrading genetic ties, and on the other hand, underlining the importance of the genetic ties. First of all, third party reproduction is often only offered after a long series of unsuccessful treatment with own gametes. Long, expensive and, for the woman, physically burdensome treatments with own gametes are preferred in order to have a genetically own child, while donor insemination is a relatively easy way to conceive. Already in the first stage of assisted reproduction, society underlines the value attached to genetic ties. When own material cannot be used (and only then), a choice must be made when the couple still wants to have children. The two most common options are adoption and third party reproduction. Many couples choose third party reproduction because then at least one of the two parents can still have a genetic link with the child (van den Akker, 2001a, 2001b, 2006). This shows that genetic relatedness is still seen as important. In a way, the use of donor gametes and its motivation reflect opposite values. When the decision is taken to use gamete donation to have a child, very often, physical characteristics of the future social parent (for instance eye and hair colour, height and weight, blood type) are ‘matched’ with the donor. The idea is that by doing that, the child will look like a combination of the two parents. By offering to match the social parent with the donor, the assumption seems to be that physical resemblances – which are a symbol of genetic relatedness – are actually important, and that a genetic relationship should be pretended, or simulated. The social parent may not have genetic ties with the child, but at least he or she looks like a genetic parent. Another motivation for donor matching is that it facilitates secrecy.

One explanation for this conflict between these two values can be found in the societal view on kinship and relatedness. For a long time, a couple could only become parents by virtue of biological processes, therefore, the social recognition as parents could only result from the biological link (for fathers, the assumed biological link in marriage) between parents and their children (Strathern, 1999). Although anthropological analyses often argue that kinship is a symbolic cultural system, the normative idea of kinship in society attaches great significance to ‘blood ties’ (Nelkin & Lindee, 1995). The transference of biogenetic ties between parents and child is culturally perceived to constitute a bond of relatedness (Carsten, 2004). Nelkin (2006) argued that genetics are increasingly seen as providing the essence of true personhood. The blood bond between parents and a child is ‘proved’ by visual characteristics (Becker, 2000). Similarities between the parents and the child, either physical, psychological or social, are sought and underlined by both the parents and the social environment in order to confirm kin ties and relatedness. This sort of dialogue is called “resemblance talk” and is
an important expression of the cultural norm about kinship (Becker et al., 2005). Matching the donor can be seen as a way to invoke social recognition for the social parent, and as a way to take over the role of the genetic link: kinship is actively created as if it would be based on a genetic link (Becker et al., 2005; Burr, 2009; Scheib et al., 2000). Instead of developing an alternative view on kinship and family ties, the importance of the presence of a genetic link is reinforced, while couples opting for donor gametes have shown their acceptance of an alternative model to adapt the societal normative model of kinship (Becker et al., 2005). Studies show that such couples de-emphasize the importance of genetic links and tend to focus more on social relationships and the child in itself instead of comparing it as ‘familiar’ to the parents (Becker et al., 2005). Third party reproduction challenges the societal normative view on kinship and family ties, but it seems that the societal view is not adapting. Rather, couples using third party reproduction have to deal with their deviation from the norm.

In conclusion, it is clear that third party reproduction has a major impact on the moral norms surrounding parenthood. The separation of the genetic link from parenthood raises questions about what makes someone a parent and on what basis parental obligations and rights should be allocated. Moreover, this separation seems to conflict with our intuitive account of kinship and family ties. Even though third party reproduction is morally accepted by most people in Western society, the importance of genetics for kinship is not entirely put aside. On the contrary, while promoting a practice which detaches parenthood from genetics, exactly the importance of genetic ties seems to be underlined.

1.3 References


Chapter 2

The involvement of four parties: sharing information
Fulfilling one’s child wish through gamete donation means the involvement of two extra parties (apart from the couple): the medical team and the donor. When a child is born, a fourth party is added. When the couple is not seen as a unit but as two separate persons, five parties are involved with all their own specific interests. In natural conception, no one but the couple is involved in the process: all decisions before and after pregnancy are made by the couple itself. They do not need to consider the possible interests of someone else but themselves (and their future child). When two external parties are involved, the question rises about who needs to be informed about what. Several ethical debates exist, ranging from what information the recipient couple should receive before conception about the donor, to what information a hospital should obtain from the donor, and who needs to be informed about the conception method. In this introduction, I focus on the last question and discuss two closely related debates. The first debate concerns the disclosure of the conception method to the child. The second debate concerns the kind of information about the donor that should be available to the child. Both debates are closely related since the question about secrecy precedes the flow of information from the donor to the child: if the child is not informed about the conception method, information about the donor is not relevant. Often, both debates are mixed up and it is assumed that anonymity precedes secrecy and identifiability invokes openness. However, both debates should be clearly distinguished: using an anonymous or identifiable donor does not determine secrecy or disclosure. A couple can perfectly use an identifiable donor but choose never to disclose the conception method or a couple can use an anonymous donor and choose to tell the child about his or her origins.

In both debates, each party has his or her own rights, obligations and interests, which often results in opposite outcomes. Deontological and consequentialist approaches present two different ways of thinking about the rights of the parties involved. The consequentialist approach holds that choices, which include actions or certain behaviour, need to be morally assessed on the grounds of their effects. More precisely, this means taking into account the benefits and harms done to all parties involved. Deontologists evaluate actions by their conformity to the moral norm. If an action affecting a party’s interests is in itself morally bad, regardless of the consequences, it is argued that this action should not be taken. In the following, arguments presented by both approaches are discussed.
2.1 Sharing the conception method: secrecy and disclosure

The first application in clinical practice of sperm donation was around the 1930s. For many years, the use of donor material was shrouded in secrecy. Medical doctors advised their patients to never disclose details about the deviant conception method to either the environment or the child (Allan, 2012). The use of sperm donation was linked with masturbation and intrusion of the marital vowels. The practice was heavily morally charged: sperm donation was a taboo and the child and environment should not be informed about the conception method (Frith, 2001a; Cook et al., 1995a). Over the years, the demand for gamete donation grew and the practice became more and more accepted. From the 1980s, the disclosure debate was stimulated by this increased acceptance of the practice. The veil of secrecy became questioned and voices were raised in favour of more openness about the conception method. Two important factors determining this shift were the openness in the adoption practice, where this was found to be in the best interest of the child, and the greater emphasis on children’s rights (Haimes, 1988; UN Conventions on the Rights of the Child, 1989). Nowadays, openness towards the child, preferably at an early age, about the use of gamete donation is more and more being advised to patients (Klock, 2013). Nonetheless, in the end the parents can still decide whether or not they will disclose the information.

2.1.1 Parents

Notwithstanding the trend towards openness over the years, studies show that most heterosexual couples choose to keep the conception method secret, with study outcomes ranging from 54% to 81% (Nachtigall et al. 1998; Golombok et al. 2002; Owen & Golombok 2009). Although more and more couples express their intention to disclose when questioned before conception, final outcomes prove otherwise. The actual disclosure tends to be postponed and eventually abandoned because barriers such as discomfort and anxiety developed (Gottlieb et al., 2000; Nordqvist & Smart 2014; Klock 2013; Cook et al. 1995b; Daniels et al., 2009). Many heterosexual couples who intended to disclose, do not do so (Gottlieb et al., 2000; Lindblad et al., 2000; Lalos et al., 2007). These data contrast with data from lesbian and single mothers, where secrecy is more difficult to maintain due to the absence of a father (Landau & Weissenberg, 2010; Murray & Golombok, 2005; MacCallum & Golombok, 2004; Stevens et al., 2003). The nature of gamete donation allows for the option of secrecy: a pregnancy and birth occur so it is possible to ‘disguise’ the donor conception, pass the child off as biologically and genetically related to the parents and to appear as a ‘normal’ family (Frith, 2001a). This is exactly one of the reasons that is often given by parents in support of their choice for
secrecy: the wish not to stand out in the crowd and to blend in as a normal family, particularly in relation to the child. Secrecy is chosen so that the child would feel ‘normal’ and have a normal childhood (Readings et al., 2011). In relation to this, secrecy is often preferred out of fear that the child would be rejected by the environment, or to protect the father or mother against deteriorating relationships if the child would no longer accept the social parent as a parent (Rowland, 1985; Nachtigall, 1993; Daniels & Taylor, 1993). Other reasons given by parents are that there is no need to tell, that the information is seen as a personal matter, or that disclosure is pointless when no further information about the donor can be given (Readings, 2011; Brewaeys et al., 1997). Additionally, protection of the child is often mentioned: protection against frustration or a sense of loss that might be experienced when no information is available about the donor, or protection against possibly upsetting information (Readings, 2011; Brewaeys et al., 1997).

Nonetheless, a group of parents does indeed disclose the conception method to their child at a relatively young age (before adolescence). Data differ from 8.6% in a European study by Golombok et al. (2002) to approximately 30% (New Zealand) or 50% (UK) in more recent studies (Daniels et al., 2009; Readings et al., 2011). This might indicate a shift towards more openness within families. One of the arguments given against secrecy is that there is always the possibility of unexpected disclosure. Parents need to keep the secret and this can weigh on them psychologically. It has also been argued that secrecy may jeopardize family communication which might result in the distancing of family members (Papp, 1993; Imber-Black, 1998). A gap might develop between those who know and those who do not know (Clamar, 1989). Parents who disclose the information give similar reasons for their decision. An important consideration given by these parents is that they want to be open and honest with the child (Blyth et al., 2001; Readings et al., 2011). Children ought to know about ‘their’ story, and this is proof of how wanted the child was. Keeping the information a secret would be morally wrong. Other reasons that are given are that the child has the right to know, that there is no reason not to do so, and to protect the child from an unexpected disclosure (Lycett et al., 2005; Readings, 2011). It is often argued that if the child finds out at a later time, this will destroy the child’s trust in the parents.

In conclusion, parents can decide whether to disclose or not for a number of morally relevant reasons. In the ethical debate about what should be done, several arguments are given. In the following, two arguments are discussed.

Right to privacy

Studies of the opinions of the parents themselves show that the privacy of the parents should not be treated lightly. Information about the use of ART and the specific conception method can be regarded as highly personal and intimate information about
the couple. Such information contains sensitive knowledge about one’s health and about the lack of genetic contribution of one parent. Disclosing such information means exposing one’s personal life. Because of the sensitive nature of the information, it can be argued that the couple has the right to keep it private and not disclose it to the child or environment. Privacy can be defined as “the condition of not having undocumented personal knowledge possessed by others” (Parent, 1983) or as “the right of individuals to limit access by others to some part of their persons” (Gostin, 1995). Privacy means protecting information from others. Several arguments are given in support of the right to privacy of the parents. Infertility can have a devastating effect on the well-being and self-image of a person. Disclosing such information could be detrimental for the person’s well-being (Pennings, 2001a). Also, the information can be embarrassing for either the mother or the father. Keeping the information private would also protect the man or woman from social stigma (Nachtigall, 1993).

**Right to autonomy**

The arguments based on the autonomy of the parents are closely related to the arguments based on the right to privacy. Parents are autonomous actors and their decisions regarding reproduction should be respected. It is argued that, as long as the child will have a reasonable quality of life, an intervention on their decisions should not be allowed (Pennings, 2001b). The argument against full parental autonomy is that the disclosure decision will affect the well-being of the child. In the early days, disclosure was thought to have a detrimental effect on the well-being of the child and the family. Nowadays, it is argued that telling the child is in his or her best interest and that secrecy is harmful for the child. However, in most decisions concerning their child, full parental autonomy is respected even though these decisions might have a serious impact on the child’s well-being: parents are free to decide to move, change school or spend a lot of time working (Pennings, 2001b). An intervention in the disclosure decision is even harder to justify when compared to the context of genetic counselling where the risks of having an affected child are communicated to the parents, but the decision is left to the parents. The consequences in such cases are far more severe than the consequences of disclosure or non-disclosure (a thorough analysis of this argument will be given in chapter 6). If we respect the parents’ autonomy in these cases, their autonomy should also be respected in the case of the disclosure decision. Parents should either be free to choose or they should be guided towards a decision in all situations where the child’s welfare is at stake.
2.1.2 Children

At this moment, not much is known yet about the impact of disclosure on the child and family relationships in general (Golombok et al., 2011). This is due to the secrecy that has surrounded gamete donation for decades and the high secrecy rates up until now in heterosexual couples. It is impossible to investigate the opinion of children who are not informed about the donor conception without revealing the secret. Nevertheless, studies have been conducted on the wellbeing of these children with results showing that children who are not informed have positive relationships with their parents and develop normally, which shows that this specific family secret does not always have an impact on the child’s life (Golombok et al. 2002; MacCallum et al., 2007). Of children who are aware of their donor conception, it appears that age and the manner of disclosure have an impact on the reaction of the children, with people finding out at a later age, particularly if the disclosure happened by accident or under adverse circumstances, reporting more negative reactions such as anger and feelings of betrayal (Jadva et. al., 2009; Turner & Coyle, 2000). In chapter 6, a thorough analysis is made of the empirical data available at this moment regarding the impact of disclosure and secrecy on the child. In the ethical debate, the arguments supporting the interests of the child centre around the child’s rights.

Right to privacy

Most definitions of privacy are formulated in a negative sense: a right to limit access to certain information about oneself. The right of parents not to disclose as discussed previously is an example of this interpretation. Privacy can also be defined in a positive sense (Pennings, 2001a). This interpretation starts from the right not to know: privacy not only means the right to limit access to information of an individual to others, but also to limit access to information from others to the individual (Council of Europe, 1996; Laurie, 1999). This means that a person has the right not to know certain facts about him- or herself which might lead to an adaptation of the picture of him- or herself in a troublesome way. This right is often discussed with regard to medical information or information concerning one’s genetic make-up: no one is obliged to take a genetic test and everyone has the right to decline the offer of information about one’s health. It is argued that if a person has the right not to know such information, that person also has the right to obtain information that might result in a more correct image of the self (Pennings, 2001a). Information about one’s conception method offers insight into one’s genetic origins and the relationships with one’s parents. This information is highly valued in society: the family and one’s place in the family is regarded as crucial information for one’s identity. Most often, the ideal family is defined as a mother and a
father with genetically related children. When the family composition is deviant from this norm, a child should be informed to correct his or her self-image.

From this, two arguments can be developed depending on the ethical theory that is chosen (deontological or consequentialist). Consequentialist argue that although information about the conception method indeed contributes to a more complete self-image, it does not necessarily increase a person’s psychological wellbeing (Pennings, 2001a). Correct information about one’s genetic make-up is not necessary to live a happy live. This is clear from misattributed paternity cases: a number of people (both children and fathers) are not aware of the misattribution of paternity, but they are nevertheless happy and live normal lives. In contrast, according to the deontological approach, the moral norm is that a person ought to have access to information that might complete his identity. To conform to the norm, a donor conceived child should receive identifying information about the donor, whatever the consequences.

**Human Rights and the UN Convention on the Rights of the Child**

The positive interpretation of privacy is also covered by the human right to respect for identity and private life. This right prescribes that everyone should have access to details about their identity as individual human beings (European Court of Human Rights, 1989). The Human Rights and the UN Convention of the Rights of the Child are often quoted in the larger debate concerning disclosure and information exchange in the context of gamete donation. Especially in the debate about the right of the child to receive information about the donor, these rights are used in support of the child. Nonetheless, three rights apply to the disclosure debate as well: article 13 which generally prescribes a person’s right to information, article 2 which provides protection against discrimination, and article 7 which gives the child the right “[... as far as possible [...] to know [...] his parents’. It is easy to see why article 13 supports the claim that children have the right to be informed about their conception method. According to article 2, withholding information about the conception would discriminate donor offspring since information about the conception method is routinely provided to all persons who are raised by their genetic parents. In the case of donor conception, questions about the usefulness of this information for the child are posed and secrecy is maintained. Not sharing this particular information is discriminatory towards the donor conceived children. Article 7 prescribes the right of the child to know his or her parents. This particular right is actually applied to the anonymity debate. However, the right implies openness towards the child about his or her conception. If the child has the right to know his or her parents, and assuming that this means that a child should have access to information about the donor, a child should also have the right to be informed about the conception method. Several counterarguments are given to these rights. However,
these rights will be discussed more thoroughly in the following part concerning the anonymity debate. All counterarguments will be discussed in that part.

2.2 Exchanging information between the donor and the family: anonymity and identifiability

Next to the information exchange between the parents and the child about the donor conception, information can also be exchanged between the donor and the family and the other way around. The main ethical debate in this regard focusses on the anonymity and identifiability of the donor: should donors remain anonymous or should they release information about themselves, and if so, what information should they release? The question can also be reversed to whether donors should receive information about their donor offspring. In chapter 5, this question is analysed. As in the secrecy and disclosure debate, the interests of several parties are involved: the child, the donor and the parents, although the focus lies particularly on the first two parties. Opposing rights and interests are at stake, with different outcomes depending on which interests are prioritized. The current legal situation regarding the information exchange differs across countries, which shows that balancing all interests is a difficult exercise and several outcomes can be defended.

2.2.1 Legal situation

Anonymity

For a long time, together with keeping secret the use of gamete donation, the donor’s identity was safeguarded. This practice of anonymity was chosen because of the stigma surrounding infertility (particularly male infertility), the accompanying possible social rejection of the practice and the possible consequences this could have for both the families and the medical profession (Blyth & Frith, 2008). Nowadays, the global legal situation still centres around anonymity. All but 11 countries in which gamete donation is permitted endorse anonymity either by allowing it or by imposing it (Janssens et al., 2011). In an anonymous system, no identifying information about the donor can be obtained by the child or parents, or from the child by the donor. In some of these countries the law allows that some general non-identifying information is exchanged. In Belgium, for instance, very little non-identifying information is released in the form of ‘matching’ the donor to the social parent. The social parent’s physical characteristics,
such as eye and hair colour, are used to select a donor. This means that recipients can assume that the donor has for instance brown eyes and brown curly hair. Such information is very vague. In Spain, both parents and child have the right to obtain general non-identifying information about their donor. Also, in exceptional cases when the life of the child is endangered, the identity of the donor may be released on the condition that this release averts the danger for the child (Pennings, 2002).

Open-identity

In 1984, Sweden was the first country to remove the anonymity of the donor. Several countries followed this example during the 1990s such as Austria, Switzerland, New Zealand, a number of Australian jurisdictions. Others followed later on such as The Netherlands, Finland and the UK (Frith, 2001a; Janssens et al., 2011; Lalos et al., 2007). In the United States, no federal legislation exist that either prohibits or allows anonymous or identifiable donation. The policies concerning the exchange of (non-)identifying information differ from centre to centre. Most centres offer partial access to information, which means non-identifying information is available (Pennings, 2002). However, data show that open-identity programs are on the rise (Scheib & Cushing, 2007).

An open-identity system obliges donors to agree with a release of his or her identifying information and it allows the child, when mature, to receive identifying information about the donor (Daniels & Lalos, 1995). In some countries, also non-identifying information is included in the exchange. The age of the children varies, with some countries releasing the information when the child turns 16 and other countries preferring the age of 18. When the child reaches the prescribed age, the information becomes available via registers. This means that children are able to access the information if they want to, but they are not forced: children have the right, but not the duty to obtain information. This interpretation of the child's right has as a consequence that when the parents decide to keep the conception method secret, the child will never be informed about the available information. An open-identity system only has meaning when the conception method is shared (Shenfield & Steele, 1997). To forestall this problem, a suggestion was made by Warnock in 1987 to place the donor conception on the birth certificate. Up until today, only the state Victoria (Australia) has implemented this in their regulation (VARTA, 2014).

While in the majority of such open-identity countries, the information exchange goes in one direction (from donor to child), New Zealand and Victoria foresee an information exchange in the other direction. Donors are allowed to receive identifying information about the offspring born from their donation, but only if the child agrees to this exchange (New Zealand Government, 2004; Victorian Registry of Birth Death and Marriages, 2008). In the UK, donors are entitled to non-identifying information about
their donor conceived children such as the number of children born from their donation, their sex and year of birth (Human Fertilisation and Embryology Authority, 2009).

**Other information exchange systems**

Next to the anonymous and open-identity legislations, other systems exist. In Iceland, both the anonymous and open-identity track are offered to both the parents and donor (Frith, 2001). This so-called ‘double track’ system incorporates the potential wishes and interests of both parents and donor. Such a system recognizes that several morally acceptable perspectives exist in this discussion and leaves the decision to the actors in the field, in contrast to anonymous or open-identity systems which impose one option that is regarded as inherently better than others (Pennings, 1997). This system thus allows an information exchange, but only when consent is given by both parties.

In a couple of countries (for instance, Belgium), yet another system is legally allowed. For oocyte donation, known donation is a widespread practice next to the anonymous system. This known donor is generally a sister or sometimes a friend of the recipient. There are two options. The recipient can choose to use her sister’s or her friend’s oocytes herself. This is called known (intra-familial) donation. The second option is that the sister’s oocytes are offered to the centre in return for oocytes donated by another donor (who is also someone’s known donor). In that case, a known-anonymous donation takes place (Laruelle et al., 2011). The reason for allowing this system is the continuous shortage of oocyte donors with long waiting lists as a consequence. When a recipient brings her own donor, she does not depend on the availability of an anonymous donor. In case of known donation, the exchange of information between the recipient, the child and the donor is inevitable. However, this system does not necessarily result into openness, which means that the child may know the donor in a different capacity than as its genetic parent (Greenfeld & Klock, 2004). In case of known-anonymous donation, no information is released between the recipient and the anonymous donor.

Apart from the official paths, commercial companies (sperm banks that sell sperm over the Internet) have developed separate rules about the exchange of information. The most famous example of such a network of companies is Cryos International. Couples can choose their donor from a list and order sperm. The information exchange from donor to parents is available already before conception. Donors are presented in a catalogue, with a standard profile containing information about their medical and physical characteristics. Donors can choose to extend this profile by adding a social and educational history, religion, sexual orientation, and skills such as language, music, and sports. A donor can also add an audiotape or a written message with his or her motivation for donating his or her gametes. In most American clinics such profiles are given to the parents before conception as well, meaning that they can make a choice
Based on the profile of a donor. In such cases, a large amount of non-identifying information is exchanged.

Not only systems to exchange information between parents, children and donors exist, also systems to share information between donor siblings – children conceived with the same donor – and their families have been developed. The most successful worldwide registry is the USA-based Donor Sibling Registry (DSR), founded in 2000 (Freeman et al., 2009), which at the moment (November 2014) has more than 44000 registered parents, donor children and donors and some 11700 connected donor half-siblings and/or donors (Donor Sibling Registry, 2014). Through this registry, not only half-siblings and accompanying families can be traced, the donor can also be searched for: when a donation was made in an anonymous system, no information is exchanged via the official ways. In those cases, donors and families can sign up on the registry hoping to find a match.

Clearly, several systems exist each emphasizing the interests and rights of other parties. While an anonymous system underlines the interests of the donor and the protection of the family integrity, an open-identity system emphasizes the rights of the donor conceived children to information about their genetic roots and the benefits of openness and honesty in families. What interests are exactly at stake here? What rights can be used to support the possible release of information?

2.2.2 Children

Respect for identity and private life and the best interests of the child

Respect for identity and private life is considered to be a human right (UN Convention on the Rights of the Child, 1989). It has been argued that denying such information can be harmful for the child (Turner, 1993). Not having access to knowledge about one’s genetic parents can have a detrimental effect, which was named ‘genealogical bewilderment’ (Sants, 1964). This term was originally used for adopted children, but it was argued that this equally applied to donor conceived offspring (McWhinny, 1996; Haimes, 1988). This analogy between adoption and gamete donation was one of the prime movers behind the shift towards more openness and the exchange of information. Based on the adoption context, identifying information about the donor was said to be essential for the child to obtain a fuller sense of his or her identity (Blyth, 1998; Scheib & Cushing, 2007). Consequently, it was often argued that because of the need of this information for a fuller self-image, identifying information was in the best interest of the child. The UN Convention included the best interest of the child in article 3 as a general principle: the child’s best interest should be a primary consideration in all actions concerning children. The problem here is what is in the child’s best interest. Proponents of open identity and disclosure use evidence from the literature on adoption
to support the position that children are harmed when they do not have identifying information about their donor. However, it can be questioned whether both contexts are comparable (Shenfield, 1994). The position in the family of a child conceived through gamete donation differs a lot from an adopted child: a donor conceived child does not have to deal with feelings of abandonment and most of them still have a genetic link with one of their parents. The meaning of genetic (un)relatedness is different for donor conceived children than for adopted children (Golombok, 1998). Therefore, we should be careful in generalizing possible consequences for both contexts. In addition, even if knowing one’s donor would contribute to one’s self-image, this information is not necessary for one’s psychological wellbeing (Pennings, 2001a). Many donor conceived people do not have information about the donor and seem to be perfectly happy. Also, reasons for children to desire information about their donor can often be brought down to mere curiosity, rather than to a search to complete their identity (Vanfraussen, et al., 2001; Rumball & Adair, 1999, Jadva et al., 2010). For some, not having access to such information results in frustration while for others, it is unimportant (Ravelingien et al., 2013). All this shows that these children do not need the identity of the donor to complete their own identity. On the contrary, some have argued that it is in their best interest not to know anything about their genetic origins (hereby promoting anonymity) because this would differentiate them from other children (Primarolo, 1990). In conclusion, at the moment, it is not clear what would be in the best interest of the child.

Human Rights and the UN Convention on the Rights of the Child

It has been argued that children have an absolute right to know their donor, whether or not this knowledge would be in their best interest. As for the disclosure debate, the Convention on the Rights of the Child (UN Convention on rights of the Child, 1989) was one of a prime movers for a legislative change for gamete donation. The European Convention of the Protection of the Human Rights and Fundamental Freedoms (Council of Europe, 1950), and the European Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine (Council of Europe, 1996) also contain themes used in support of a shift towards open-identity systems (Blyth, 1998). Changing legislation to oblige donors to release identifying information about themselves was the result of trying to meet the formal rights of the child.

The most frequently cited rights in support of releasing identifying information about the donor to the child are article 7 of the UN Convention, the right to know his or her parents, and the right to respect for family and private life (Council of Europe, 1950 art 8; UN Convention on the Rights of the Child, 1989 art 18). As previously mentioned, the right to know one’s parents implies disclosure. Strangely enough, these two main
arguments face the most obvious critiques. With regard to the right to know one’s parents, the question is whether knowing one’s donor falls under this right. The problem lies in the definition of ‘parents’ (Frith, 2001b). Most countries treat the donor as a person who transfers his or her parental rights and obligations towards the recipient, implying that the donor is not seen as a parent of the child. Therefore, it is hard to see why this right would say anything about a child having the right to information about his or her donor. With regard to the right to respect for family and private life, one could wonder in which sense a donor can be seen as part of the family life of the child: creating a family relationship is not the intention of a donation program. Moreover, the ‘relationship’ between a donor and his offspring is not recognized by law as a family relationship (Blyth, 1998). It is difficult to defend the child’s right to information about the donor on this basis.

Two rights offer a better basis in support of the right to information about the donor. The first right involves the protection against discrimination (UN Convention on the Rights of the Child, 1989 art 2; Council of Europe, 1996 art 1). As explained when discussing the secrecy/disclosure debate, most other children automatically have information about their genetic parents. Not allowing donor conceived children to have access to this information, would be discriminating. Indeed, on this basis, it can be argued that children should be able to know the identity of their donor. Speirs (1998) argued that the consequence of this right would indeed lead to questions about the use of gamete donation. When a certain practice results in discrimination of one of the parties involved, maybe the practice itself should be questioned. A second right in support is the general right to information (UN Convention on the Rights of the Child, 1989 art 13; Council of Europe, 1950 art 10, Council of Europe, 1996 art 10). When donor offspring are denied information even when official records are available, this right is breached. It is easy to see why this right would lead to an open-identity system. However, both rights touch upon the most crucial problem of this rights-based discourse: the rights of the child conflict with the right to privacy of the parents and the donor. Even when the child has a right to identifying information about the donor, a balance must be made between the rights of the other parties involved. The most controversial point in using the Convention and other fundamental rights to support the particular situation of donor conceived children is that these rights were not written with gamete donation in mind (Frith, 2001a). We should consequently be careful to draw decisive conclusions about disclosure or identifiability from these rights.

Possible consequences

Creating the possibility for donor conceived children to meet their donor by releasing identifying information can have several consequences which should also be taken into account. Opponents of an open-identity system argue that such a system suggests that
the genetic relationship between the donor and the child is important and consequently that knowing one's genetic roots is important. By underlining the importance of genetic ties, greater curiosity is developed, a more significant place is given to the donor in the child’s mind and a greater drive to contact him or her is established (Fortescue, 2003). This focus is opposed to what the practice of gamete donation stands for. Also, practical implications arise in the form of expectations. The child's expectation of type and frequency of contact might differ a great deal with the idea of the donor. Conversely, this concern applies to donors as well: they might want to have regular contact while the donor conceived child only wants to meet once. A third concern that might be stipulated is that donors are matched physically with the recipient family, but not socially. A child might end up meeting a man or woman with a wealthier or poorer background than itself. Negative feelings about him- or herself and towards the parents might be developed by the child. It has also been suggested that the ‘real-life’ distinction between the biological and non-biological father could create confusion for donor offspring. Instead of completing the child’s identity, this would only fragment notions about paternity and identity (Grace et al., 2008; Rose, 2004). Only one study about donor offspring who have met the donor has been conducted so far. Jadva et al. (2010) conducted a study about the experiences of offspring concerning their contact with the donor. The authors showed that such meetings were a positive experience overall. Also, the search for the donor was reported as not having a negative impact on the relationship with the parents. These data show that when offspring and donors get in touch and both agree to meet, this might result into positive experiences. Nonetheless, further research is necessary to draw general conclusions about experiences of contact with the donor. Moreover, these data were obtained through children who searched for their donor via the Donor Sibling Registry. Although many children already signed in on this registry, this remains a minority within the large group of donor conceived children. We should be careful in generalizing the results of these studies to the whole pool of donor conceived children. In addition, we should keep in mind that these data show the experiences after arranging a meeting. It is possible that many donors do not want any contact years after their donation. The experiences of donor conceived children who do not succeed in contacting the donor should also be investigated and taken into account.

2.2.3 The donor

Right to privacy

The revelation of his or her identity to the offspring might have several consequences for the donor. It opens up the possibility to be contacted by offspring. This contact might also lead to the disclosure of the man or woman as a donor to his or her family
and environment. The possibility exists that a donation of this kind was not shared with family members. The coming out of a person as a donor, can have a big impact on the donor’s relationships. When the donor did inform the family members, this family faces several years in which it is not clear whether a donor conceived child will ever turn up. Also, the presence of a real individual conceived via the donor’s material might disturb his or her family life. Another point of consideration is that the family constitution of the donor might change between the moment of donation and the moment of a request for contact. The donor may have remarried and may not have told his new family about the donation, the donor may have lost a child in the meantime, or the donor was not able to have a child of his or her own due to medical problems with his or her spouse (Fortescue, 2003). Since identifiable information about the donor can be considered as revealing intimate information about oneself and his or her family, the donor has a right to privacy. One could argue that therefore, a donor should be respected in his or her wish to block the information flow to the offspring.

**Possible consequences**

Very often it is argued that installing an open-identity system would diminish the recruitment of sperm and egg donors (Fortescue, 2003; Pennings, 2001c; Craft & Thornhill, 2005). The reduction of the donor candidates would even jeopardize the whole donation practice. Initially, studies conducted in several countries seemed to confirm this fear by showing that current donors would not donate when anonymity would be abolished with results such as 80% (Denmark, UK), 59% (USA) and 74% (Belgium) (Pedersen et al., 1994; Schover et al., 1992; Baetens et al., 1999; Cook & Golombok, 1995). However, a cautious interpretation of these data is warranted since these studies reflect the opinion of donors who chose to donate in an anonymous system. This means that the data are biased towards donors preferring anonymity. What these data actually say is that in the pool of anonymous donors, a significant part would not be donating in an identifiable system (Pennings, 2001c). When this point is taken into account when interpreting the data, the findings become more comprehensible. It was argued that another type of donor would be attracted by an identifiable system and that these donors would neutralize the decline in the existing donor pool (Pennings, 2001c). Indeed, research indicates that the number of donor candidates did not fall back, because a ‘new type’ of donor stepped in (Blyth & Frith, 2008). Several studies showed that older men in relationships who already had children of themselves were attracted by the new system. This is in contrast to the usual student population, which involves young, single and heterosexual men (Daniels and Lalos, 1995; Daniels et al., 1996; Janssens et al., 2006; Thorn et al., 2008). It was argued that an identifiable system brings forward the more ‘responsible’ donor (Yee, 2009). However, other studies contested this new profile by showing that single heterosexual men were more likely to donate in such
a system than married men (Frith et al., 2007). Another study conducted in the
Netherlands showed that single men without a child wish were more prepared to
donate in an identifiable system (Trommelen et al., 1999). In a report published by the
Human Fertilization and Embryology Authority (HFEA), a similar trend was found. The
proportion of the youngest donor group (aged 25 or younger) increased from 15% to
22% of the total amount of sperm donors, while the proportion of older groups
decreased in 2013. The study also showed that the number of donors with own children
is decreasing since 2005 (HFEA, 2014). Next to the heterosexual men, gay men were also
found to be more interested to donate in an identifiable system (Riggs, 2008; Ripper,
2008). More important than the profile, are the expectations these men have when
donating. While the married men were more inclined to a one time meeting with their
donor offspring, the single heterosexual and gay men indicated to be open for an
ongoing relationship (Godman et al., 2006; Riggs, 2008; Ripper, 2008). Not so much the
fear for a decrease in donor candidates is grounded, it is more important to guard the
motives and expectations of the new donors who present themselves. We should be
careful in creating a system where donors are attracted because of paternal motives.
This could lead to unrealistic expectations about the relationship with the child and
could possibly become a threat for the parents of the child.

Next to the impact of the shift on donor recruitment, also the impact of actual
contact on the donors should be investigated. Not much literature exists so far on the
viewpoint of the donor in this regard. So far, no study exists on the experiences of
donors who donated in an identifiable system after contact with either donor offspring
or the parents of the donor offspring. Studies focus in this regard on the experiences of
the donor offspring and parents. A study by Kirkman et al. (2014) investigated the
expectations of Australian donors who donated before mandatory release of identifying
information was installed. Expectations ranged from wanting no contact and fearing
contact, to accepting the need of the donor offspring to know the donor, personal
interests in the offspring and desiring a relationship with the offspring. Jadva et al.
(2011) conducted a study about initially anonymous donors who agreed to release their
identity to their offspring later on. All the donors included in this study reported
meeting offspring as a positive experience and as having positive consequences.
Although no information is available yet on identifiable donors, the current data show
that when contact takes place under these circumstances (with agreement of the
donor), this leads to positive experiences. It is however not yet clear how such meetings
will develop with the new type of donor and his specific expectations. Other important
findings from the current studies towards donors who agree to subsequent contact with
their offspring concerns the donor's wellbeing, their wish for information about the
number of children born from their donation, or even the wish for identifying
information. In the open-identity debate, the focus lies solely on the information
exchange from the donor towards the offspring. However, it is equally important to investigate what the interests of the donor are in information about his or her offspring. In chapter 5, arguments in favour of an information exchange in the direction of the donor are scrutinized.

2.2.4 Parents

The right to autonomy

In the anonymity/open-identity debate, the focus is particularly on the children and the donor, since the discussion involves an information exchange between these two parties. The parents seem to be a forgotten group in this discussion. However, it is unclear why this party should not also be taken into account here. The most important interest of the parents is their autonomy. The right to autonomy means, as already defined above, making autonomous informed decisions and being respected for these decisions. For this particular discussion, that means that parents have the right to decide how they build their family. This implies that parents should be able to choose autonomously what type of donor (anonymous, identifiable, or known) they want to use to build that family. The right to choose how to build one’s family implies inevitably that they should be able to take decisions that will have an impact on the child’s life. This should not pose a problem. Most of the time, parents have the right to make decisions that can have a big impact on the child’s life. When it comes to donor conception, suddenly this autonomy is no longer respected. Parents can only opt for the system that is legal in their country. When they do not agree, they have to cross borders to another country where a different system applies (Van Hoof & Pennings, 2012). However, this is only possible for people who have the necessary financial resources (Janssens et al., 2006).

Possible consequences

The goal of an open-identity system is to provide donor conceived children with the right to information about their genetic origin (Lampic et al., 2014). Forcing would-be parents into an open-identity system has proven not to be as effective as hoped to reach this goal. Gottlieb et al. (2000) showed for the Swedish situation that for couples conceived between 1985 (when anonymity was abolished by law) and 1997, secrecy was preferred by 89% of the parents, with only 41% having the intention to disclose the donor conception to the child. As already discussed, the intention to tell does not always result in actual telling. Moreover, it can be hypothesized that an open-identity system might even support secrecy. The threat a donor poses to the intimacy of a family becomes more real by releasing identifiable information. This hypothesis is supported
by a study of Brewaeys et al. (2005) who showed that when would-be parents had the choice between an anonymous or non-anonymous donor, 37% would opt for an anonymous donor mostly because of the fear of interference of an identifiable donor. On the other hand, a compulsory anonymous system might also lead to more secrecy in different ways. It can be hypothesized that parents will be more prepared to share the conception story with their child when enough information on the donor is available. This hypothesis is supported by several studies showing that parents who intend to disclose are more in favour of identifiable donors (Lycett et al., 2004; Scheib et al., 2003; Hunter et al., 2000). In that case, parents who had to agree to an anonymous donor might have disclosed if the donor would have been identifiable. In both systems the possibility exists that parents are forced into secrecy even when they do not intend to do so, because of the type of donor. When the aim is to reach more openness surrounding the practice of third party reproduction in order for donor conceived children to find out information about their genetic origins, the parents’ wishes should be respected. The implications of an open-identity system on the parents should not be overlooked in this debate. As already discussed, the motivation and expectations of donors attracted by such a system differ from the donors in an anonymous system, with procreation being a more important motive than altruism (Janssens et al., 2006; Thorn et al., 2008). The effects have yet to be investigated, but it could be argued that an open-identity system may result in interference of the donor in the recipient families and may add to the complexity of multiple familial relationships (Janssens et al., 2006; Saywer, 2010).

Not all parents will experience the possibility to meet the donor as a threat. The number of parents enrolling for the Donor Sibling Registry who look for their child’s donor and/or donor siblings proves this point. Until now, one study was conducted about the experiences of parents who looked for their child’s donor and these parents generally reported positive experiences (Freeman et al., 2009). However, the implications of the open-identity system have yet to be fully investigated, so no final conclusions about the psychosocial impact of the system can be made.

2.3 Balancing rights

The deontological theories use rights to support an outcome in favour of the child, the donor and the parents. This discourse faces several problems. First, as shown above, some of the rights do not support the argument they aim to support. Second, as already mentioned in the secrecy debate, these rights were not made with gamete donation in mind. The problem with this rights-based discourse in general is that it does not
explicitly support one party in favour of another: it is not clear whether the conflict should be resolved in favour of the child, the donor or the parents (Blyth, 1998). In this regard, an important distinction should be made between prima facie rights and actual rights (Pennings, 2001b). With regard to the secrecy debate (but this also applies to the anonymity debate), the child can have a prima facie right to information, which means that the child is justified to receive certain information, in this case, information about his or her conception method. A prima facie right is binding and obligatory until it conflicts with another prima facie right, which in this case is the parents’ right to privacy. This means that the original prima facie right still counts – the child does not lose his or her right to information – however, this right can be overridden by the other prima facie right. This means that a child might have a prima facie right to information about his or her donor conception, but this does not mean the child also has the actual right. Rights are not absolute rules: when several parties are involved with different rights, it is impossible to acknowledge all rights because this would lead to contradicting outcomes. In the secrecy and disclosure discussion, the parents’ right not to tell and the child’s right to be informed each support a different outcome. In the anonymity and open-identity debate, the donors’ right to privacy conflicts with the children’s right to information about their roots, and this again conflicts with the parents’ right to autonomy. To decide which right should have priority, a balance must be made by evaluating the empirical evidence available.

In both debates, the focus is often solely the best interest of the child. However, take for instance the anonymity debate, it is unclear how information about the donor is necessary for the development of the child’s identity. It is clear that some donor conceived children want information about the donor, for instance because of curiosity about physical similarities or shared interests. When we look at the parents and the donor, an open-identity system imposes a role on the donor that might not be the desired role for either of the parties. Indeed, data show that the type of donor changes in an open-identity system. It seems that this change is motivated by the assigned role to the donor. Some donors welcome the possibility to be contacted by their offspring while others do not. With regard to the parents, although for some the involvement of a donor is seen as an enrichment of family relationships, for others it is seen as a threat and an intrusion of their family life. So far, a wide spectrum of opinions is found for all three parties and it is not clear why one opinion should be prioritized. In order not to impose a particular system, the double track system would offer a solution (Pennings, 1997). Instead of forcing all parties into a certain system, let the parties make their own choice. Donors can choose to donate anonymously or identifiable, and parents can choose to pick an anonymous or an identifiable donor. A double track system respects the parents’ autonomy and the donors’ right to privacy. Such a system recognizes moral pluralism and supports a morality that is reached by agreement of the parties involved (Pennings, 1997). Given the lack of evidence about the best interest of the child, the
choice should be left to the parents themselves, especially in an area as personal as reproduction (Leenen, 1993). This might turn out to be the best for all parties involved, instead of forcing them into a system in which they might not feel comfortable (Shenfield & Steele, 1997). Hereby, the interests of the child are indirectly recognized as well. The argument against a double track policy stating that this does not take into account the child’s interest is thus not entirely valid. Another counterargument is that such a system would install discrimination because some children would have access to information about the donor and others would not. It is unclear how this would not also be an argument against an anonymous or an open-identity system. The same discrimination applies here since parents still have the authority to decide about the disclosure to the child.

2.4 References


Chapter 3

The focus of this dissertation: four viewpoints considered
In this doctoral dissertation, each party involved in third party reproduction is highlighted separately by one or two particular research questions. My doctoral research is twofold: I include a normative section where theoretical analyses are made based on already existing empirical data, and an empirical section where the (normative) views of the actors involved in third party reproduction are investigated. In the normative part, the points of view of the donors (chapter 5) and the counsellors (chapter 6) are considered. In the empirical part, the views of parents (chapter 7 and 8) and children (chapter 9) are scrutinized. In the following, I briefly explain what is discussed in each chapter and how my research adds to the literature on third party reproduction.

**Normative research**

**Donors: information exchange from the child to the donor**

As shown previously, anonymous gamete donation was long the preferred practice. Since a few decades, a new focus on the rights and interests of donor-conceived children has led a number of countries to shift towards an open-identity system. However, this evolution appears to overlook whether information exchange could also be of interest to the other parties involved, in particular the gamete donors. In this chapter, the question is analysed whether donors should be granted a right to some information about the offspring conceived by their donations. Five arguments are offered - along the same lines of the arguments given in favour of granting information to the donor conceived children - which donors could use in support of such a claim: (1) It can be of great importance to the donors’ and their own children’s health that they receive medical information (in particular, evidence of an unsuspected genetic disease) about the donor offspring; (2) basic information (such as whether any children were born) could be a way to acknowledge donors for their altruistic behaviour; (3) general information (information about the child’s wellbeing) about the donor offspring could ease the donors’ potential concern about and sense of responsibility for the offspring; (4) an extended profile could provide an important enrichment of the donors’ identities; (5) identifying information would be useful for donors who want to contact the donor offspring. We will show that arguments (1) and (2) prove to be sufficient reasons for granting donors a right to certain information. Argument (4) can be defended with regard to another type of information than the one that is claimed.
Counsellors: giving advice in the secrecy and disclosure debate

In the above section, I showed that much discussion exist on whether the conception method should be disclosed to the child or not. Both arguments in favour and arguments against disclosure have been presented. For a long time, secrecy was advised. Nowadays, a shift towards openness seems to be developing. The question is, however, whether such a directive counselling approach is ethically justified. In this chapter, an analysis is made by balancing the two underlying principles of autonomy for the parents (non-directive approach) and beneficence for the child (directive approach). We analyse the arguments and evidence available at this point that support the beneficence principle. This analysis shows that no sufficient arguments can be given in favour of the beneficence principle; the parents’ autonomy should not be overridden.

Empirical research

Parents

(a) The grounds for parenthood

In the first chapter, an overview of normative theories about the grounds of parenthood was given. Clearly, a large variety of normative theories exists on what should be the basis of parenthood. In this chapter, a study about the moral reasoning of the parents involved in the field on the basis of parenthood and parental rights and responsibilities is presented. Via a hypothetical scenario, we investigated their arguments and views with regard to the grounds of parenthood. For this study, we aimed at including a large variety of parents. We focused on lesbian couples post and during treatment, and on heterosexual couples post treatment who had a child either via anonymous sperm donation or via (known-) anonymous oocyte donation. The aim was to add new insights from the stakeholders to the normative debates concerning parenthood. Looking into the moral experiences of the people involved can enrich current moral frameworks with views that were overlooked by ethicists. The study shows that the people use traditional grounds such as intentionalism and geneticism, as well as new grounds such as the relationship between the partners.
(b) The influence of the genetic link on the experience of parenthood

One of the central topics in the literature on parenthood after treatment via gamete donation, is the relevance of genetic ties for parenthood. To enrich normative analyses and descriptive background theories, a qualitative analysis is presented on how lesbian couples experience and deal with the difference in genetic relatedness in their family and to what extent parenthood and being a parent depends on a genetic link. Previous research showed that lesbian couples handle the difference with regard to genetic relatedness, for instance, by creating a narrative about physical resemblances or by focusing on the social bond and its influence on children. The difference with regard to the genetic link brought up complex and context-specific experiences for these parents. Generally, the genetic link was described as irrelevant: equality between both parents was presented as a given. However, some experiences of difference due to the presence of one genetic link were found.

Children: the influence of the genetic link on the definition of family concepts

In the last chapter, a qualitative study is presented that explores how children (9 to 10 years old) from lesbian families define the three actors involved in the building of their family: the biological mother, the non-biological mother and the donor. The aim of this research is to outline how a child conceived via third party reproduction (sperm donation) makes sense of his or her family relationships, and to what extent this is influenced by the (non-)existence of a genetic link. Two findings stand out. First, the biological and non-biological mother were described as equal parents. Second, the concepts ‘non-biological mother’ and ‘donor’ were defined by looking at the heteronormative concepts of ‘mummy’ and ‘daddy’. With regard to the donor, the comparison with a ‘daddy’ turned out to be complex due to the conflict between the role as a progenitor and the lack of a social relationship.
Chapter 4

Methodological background to this dissertation
4.1 General background

This doctoral dissertation is the result of a larger interdisciplinary research project. The aim was to gain a better understanding of social and genetic parenthood. Three departments of the Ghent University were part of the project: the department of Philosophy and Moral science, the department of Experimental-Clinical and Health Psychology and the Centre for Reproductive Medicine of the Ghent University Hospital. Each department was represented by a supervisor, and one or more researchers. The involvement of these three parties was necessary for the approach that was chosen for this research, which is increasingly known as an empirical bioethics approach. First, I will discuss the approach in general. Then, I will focus on the goal of this research project and the methods used for the studies included in this dissertation.

4.1.1 The development of empirical bioethics

The bioethical field is a relatively young research field that is booming since the late 1960s (Borry et al., 2005). Although theology and philosophy shaped the bioethical movement a great deal, the field was essentially interdisciplinary, with important contributions from physicians, lawyers, nurses and social scientists. Nonetheless, the relationship between the human sciences and ethics did not run smoothly. Data gathering was unknown to ethicists, and the methods used in ethics were unknown to social scientists. Although an interdisciplinary approach was aimed for, a gap existed between the normative and the empirical research. One of the reasons for the difficult cooperation can be found in the distinction between descriptive and normative ethics. While descriptive ethics (sociology, psychology, anthropology,...) aims at describing people’s values, rules and norms – they describe the ‘is’ -, normative ethics discusses what is morally acceptable – they describe the ‘ought’ (Borry et al., 2005). Therefore, ethicists believed that the empirical data gathered by social sciences were not useful for ethical reflection. In the medical field for instance, this lead to a top-down applied ethics approach with ethicists arguing about principles and rules that were then applied in practice. Practical recommendations concerning for instance abortion and euthanasia were made by people who did not have enough understanding of what was going on in practice. This form of applied ethics was criticized in recent years as too abstract, too general, too speculative and insensitive to reality (Ives, 2008; Borry et al., 2005).
The empirical bioethics approach developed and is still developing in response to this ‘traditional’ or ‘philosophical’ bioethics. The theory-driven focus is gradually replaced by an ethical approach that is more grounded in practical reality. The empirical bioethics approach seeks a way to contextualize moral theory by combining both empirical data and moral theory (Musschenga, 2005). The aim is to create an ethical analysis in which moral theories, principles and rules are developed, justified and investigated together with real-life experience of the actors involved in the field. One could say that the ultimate goal of empirical ethics is to improve the contextuality of ethics (Haimes, 2002). Real-life experiences are thus used to inform ethical theories: the ‘is’ of the world is used to inform the debate about the ‘ought’ of the world (Ives, 2008). Empirical research contributes to that goal by showing the socially constructed nature of the issues discussed in bioethics (Light & McGee, 1998). Instead of ethicists thinking about solutions and how practical ethical dilemmas should be solved in their ivory towers, the aim is to get them out of their tower into the practice in cooperation with other experts in the field such as psychologists and social scientists, in order to enrich their views on how dilemmas should be solved. Ethics is about people, not just about good arguments (Ives, 2008).

### 4.1.2 The value of including empirical data into practical ethics

The objections against this method can be summarized in the fear of a loss of normativity due to the use of empirical data as a single basis of normative judgments (van der Scheer & Widdershoven, 2004). The deduction of normative statements from descriptive statements is seen as a great difficulty. Several responses to this critique can be offered. Ives (2008) argued that empirical bioethics should not be confused with some forms of social science in which the experiences of people are merely documented. The leading idea behind this approach is not to investigate what people think, but why people think what they think, which is then again subject to critical analysis. The moral reasoning behind people’s ideas, arguments, accompanying inconsistencies and their explanations of these inconsistencies are the topic of investigation. An ethical analysis should at least in part start from an understanding of the ethical considerations made by the actors in the field. Of course, the empirical bio ethicist’s task is to evaluate these normative values; when people value something, this does not mean they should value it. The mere data gathering should not be used as the single truth and should not define policy. The data gathering is there to inform ethical analysis, not to govern ethical analysis. The critique that an empirical bioethical approach would lead to relativism is not grounded either. Even though empirical bioethics works with behaviour and phenomena that are contextualized, the normative judgments following are not
Empirical research can at least in four ways contribute to ethics (Musschenga, 2005). First of all, empirical data give us insight into the actual conduct of the people involved in the field. An example of this is the literature on secrecy and disclosure about the conception to the child. Empirical data gives us insight into what people actually do (telling or not telling) and more importantly, why (MacDougall et al., 2007). This information adds to the ethical rights discussion, as shown in the introduction. A second reason why empirical data are valuable for practical ethics, is the identification of relevant issues that were not present (or largely underestimated) in the purely normative analysis. Ethicists can be informed about moral considerations which escaped their attention, the empirical data hereby enriching the normative analysis. An example of this is the research by Provoost et al. (2009) on the status of the embryo. Their research showed that parents saw the embryo as an embodiment of the couple; this symbolic value had a great influence on their decisions regarding the donation of their spare embryos to another couple or for scientific research. This moral consideration was not included in the ethical literature before. Thirdly, empirical data give insight into the institutional aspects of a context relevant for the practicality of ethical guidelines. In the discussion of single embryo transfer, empirical data showed that for actors in the field, the reimbursement system determined their view on the system: patients who need to pay a large amount of money for an IVF cycle, want a maximum chance of success in return, thus favouring a multiple embryo transfer and ignoring the possible negative consequences of this choice (Porter & Bhattacharya, 2005). Empirical research showed that financial factors can play a role in people's decision making process. Fourth, adding empirical research creates an insight into the description of the actual moral opinions and reasoning patterns of the people involved in the practice. An example of this is the study of Ives et al. (2008b) which demonstrated that fathers who were separated from their children tended to focus on genetic constructions of fatherhood since they are unable to use their caring relationship as a basis for claiming parental status. The value of an empirical bioethics approach lies thus in enriching ethical theories with new information that would otherwise not have been taken into account in the ethical debate.

Van der Scheer and Widdershoven (2004) suggested a way to combine both descriptive and normative disciplines and called it integrated empirical-ethical research. This can be seen as the hybridization of the two fields in which normative rules are formulated on the basis of empirical research. The most frequently used integrating model, however, is the Wide Reflective Equilibrium (WRE) (Daniels, 1996). The distinction between integrating models and the other traditional models is that integrating models are interactive and embedded in the specific practice. While other models build on pre-existing data, integrating models gather data specifically for the
purpose of informing ethical debate. This allows the researchers to delve deeper into
the normative concerns and constructions of the participants by challenging their
views, pointing out inconsistencies, bringing up counterfactual cases and using thought
experiments (Ives et al., 2008b). Since this is an emerging field in full development, no
standard or traditional methods are available (Ives, 2008).

4.2 An empirical bioethics approach to parenthood

Our research project consisted of a normative and an empirical part. In this dissertation,
I followed that idea by distinguishing a normative and empirical section. The goal of the
project was to eventually integrate normative (the views of ethicists and policy makers)
and empirical (the views of the major agents involved) research by using the WRE.

4.2.1 Normative part

For the normative part, literature searches were conducted towards both normative and
empirical papers on parenthood after medically assisted reproduction and all related
ethical topics. This literature search started at the beginning of the project and was
continued during the whole project. Familiarizing with the already existing data and
moral discussions and scrutinizing the principles, arguments and background theories
used in the academic and political discussions on medically assisted reproduction with
donor material were seen as important factors in reaching three goals. First, the aim
was to actively add to the normative literature by developing new normative analyses
that integrated the already existing empirical research. Second, reading about the
already existing normative research on this topic helped the team to pin down which
topics should be included and which focus should be maintained in our own interview
guides. It also helped the team to think about concepts, arguments and moral reasoning;
this was useful background information to investigate the participants’ own moral
reasoning about certain topics.

The final goal of the project was to integrate the normative and empirical part
using the WRE (Daniels, 1996). The aim of WRE is to enrich already existing ethical
frameworks with considerations of the people involved in the field. Participation in a
real practice (for instance, gamete donation), makes people experts. They therefore
might have views, opinions, or moral considerations which are overlooked by ethicists.
After critical examination of people’s views, the resulting new insights might be added
to the ethical framework. The WRE consequently starts from the moral judgements of a
person or group of persons that are confronted in daily life with moral problems. To include those moral judgements made in ‘the best circumstances’, a selection is made based on (1) cognitive conditions and (2) specific moral conditions. The cognitive conditions include for instance being fully informed, being rational or not being influenced by emotions during moral judgment. The specific moral conditions depends largely on the moral theory. A utilitarian will demand thinking about the consequences of an action, while a deontologist will demand thinking about motives and rules. One specific moral condition that is generally agreed upon, is impartiality. The aim of applying such conditions is to reach a set of well-considered moral judgements. These well-considered moral judgements are then summarized into moral principles, which are again tested in specific situations to see whether they lead to acceptable judgements. This method of justification is repeated until a balance is reached. However, to prevent a summary of moral judgements and a mere descriptive ethics, an independent and external third set of beliefs, namely background theories, is added. This third set is used as an independent support for the moral principles (instead of the mere support of the well-considered judgements). They include philosophical, sociological, anthropological and psychological theories. By adding background theories to the balance, the method moves from a representation of the people's capacity to make moral judgements to a justified framework. The aim is thus to reach a moral framework that is a balance between well-considered moral judgements made by people in specific situations, moral principles and background theories. The following example can clarify the above. Think about the ethical framework of directed gamete donation. Imagine that from an interview study, the following well-considered moral judgement can be derived: “Donor X has the right to decide that recipient Y cannot receive his gametes”. This can be justified by the rule “a donor has the right to select or screen the recipients of his or her donation”. To investigate the coherence between the moral judgement and the justifying principle, we go back to our judgements in daily life, change the situation and see whether the principle still counts. For instance, the situation can be changed to organ donation. Either you agree with the judgement that also organ donors should be allowed to select the recipients, or you disagree and the principle is no longer defensible. The next step is then to specify the initial principle into one that includes the gamete donation context and excludes the organ donation context. The grounds for making a difference should be made clear. For instance, the initial principle can be changed into “a gamete donor has the right to select his or her recipients” on the grounds that donating gametes leads to the creation of a human being while donating organs only has implications for the recipient. Again, this specified principle should be tested in other situations. The aim of the final principle is to incorporate all relevant moral judgements with the greatest coherence. At the same time, the principle should be justified by one or more background theories. A background theory that supports the principle of recipient selection is that of
responsibility for one’s gametes and for the children following from one’s gametes. In practice, the moral judgements on recipient selection by donors differ. Recipient selection by the donor is not accepted by everyone. The aim is then to make a well-justified choice between both positions. Therefore, we should also work towards an equilibrium starting from the opposite moral judgement “Donor X has no right to choose recipient Y instead of recipient Z” and an accompanying opposite principle “a donor has no right to select or screen the recipients of his or her donation”. The main background theory supporting this principle is the theory of fair allocation of scarce goods. The equilibrium with the least contradictions or contra-intuitive judgements, and the most coherence between the moral judgements, is the preferred option.

In this dissertation, I attempt to contribute to such an equilibrium on parenthood after assisted reproduction with gamete donation by focusing on the experiences and moral reasonings of families built via gamete donation. Three chapters are included adding to the empirical literature and which can used as background information in a WRE.

4.2.2 Epistemology: social constructivism

The research project was conceptualized within a specific epistemological position in which knowledge is a compilation of human-made constructions, not the neutral discovery of an objective truth. This postmodern position underpins a social constructivist approach and involves a radical questioning of positivism by claiming that knowledge and truth are not fixed, but are culturally and historically local (Burr, 2003; Gergen, 1999). Social constructivism is based on the belief that versions of knowledge are produced through the daily interactions between people in the course of social life and do not reflect an objective observation of the world (Burr, 1995). Thus, what we see and experience is never a direct reflection of an external reality but is instead a negotiated creation of meaning.

Taking this epistemological stance as a starting point seems to explain perfectly why in the WRE as an ethical justification theory, we can rely on the well-considered judgements of the people. Several opponents of the WRE have argued that the well-considered judgements cannot be seen as reliable or credible and that the WRE is not able to point out and exclude the ‘bad’ moral judgements (Brandt, 1979; Hare, 1988; Singer, 1974). In addition, all our judgements are influenced by personal, cultural, political and religious systems. Therefore, the reliability of the constructed framework cannot be guaranteed, according to opponents, in the sense that the framework cannot be seen as an independent and rational theory. A constructionist approach counters these critiques with defining ethics as a framework for practical use in society, a useful moral code, rather than a search for an ‘ethical truth’ or an ‘objective ethical
framework’ to justify moral acts or judgements. If we want to reach such a goal, it is reasonable to include the everyday and common moral judgements into the ethical framework. These judgements justify the construction of new principles, instead of having a probability of being ‘true’.

However, if one accepts this epistemology and the combination with the WRE, inevitably, one should recognise and accept moral pluralism. Common sense and moral judgements are tradition-bound. Consequently, a moral framework only applies to the particular moral society. The framework is not fit for solving problems between different moral societies, or even within each society. A framework that aims to do that, should try to include all elements and beliefs of the different societies into one WRE. The problem is thus that constructivism understands moral objectivity as a social agreement that is accepted by everybody. Reaching such a common ground seems to be an unrealistic goal. The coherence that is prescribed by the WRE consequently does not necessarily lead to a useful system when combined with social constructivism.

Using this epistemological framework has several implications for the interpretation of the data we gathered during the project. First of all, because parenting is a social construction, it is highly culturally determined and it needs to be considered within its broader societal and cultural context. Although having children is desired and expected in all cultures, the meanings attached to parenthood and children vary from culture to culture (Hynie & Hammer Burns, 2006). For people from collectivist cultures, the family is the most important social unit, with parental obligations and relationships prevailing over spousal relationships. Therefore, infertility may be extremely stressful because it signifies a failure to fulfil one’s social role and obligations. In patrilineal African societies, childless women are blamed for the couple’s infertility and may be cast out of their community and excluded from inheriting property or participating in family life (Hynie & Hammer Burns, 2006). Within a social constructivism approach, one tries to pay attention to those broader social discourses that provide people with the words to think and talk about their experiences. Secondly, consistent with our epistemological position, we aimed to capture people’s meaning-making processes about their experiences and therefore we applied a qualitative research design. Qualitative research best fits experiential and explorative research questions and enables to study persons as meaning-making beings (Smith et al., 2009). Finally, a qualitative researcher cannot be an objective, politically neutral observer who stands outside and above the social world. The process of exploring how participants make sense of their personal and social world is inevitably influenced and complicated by the researcher’s own conceptions (Smith & Osborn, 2008) and theoretical and epistemological commitments (Braun & Clarke, 2006). A so-called “double hermeneutic” is involved: the researcher is trying to make sense of the participants trying to make sense of their world (Smith & Osborn, 2008). This dynamic interaction between researcher and participant is central to the constructivist paradigm.
4.2.3 Empirical part

In order to gain a thorough image of the views and opinions of the actors themselves on social and genetic parenthood after medically assisted reproduction, a large variety of participants was included. In the first place, we concentrated on parents post treatment and would-be parents in treatment during the time of the interview. We included lesbian and heterosexual (would-be)parents who used sperm donation and heterosexual (would-be) parents who used anonymous, known-anonymous or known donation. We also included heterosexual (would-be) parents who used their own gametes. Secondly, we focused on the children of the post treatment parents and lastly, we included the known oocyte donors of the parents that were interviewed. For this doctoral dissertation, five interview studies were analysed. The results are presented in the empirical part of this dissertation: chapter 7 incorporates four interview studies, namely heterosexual parents through anonymous sperm donation and known-anonymous oocyte donation and lesbian parents after and during treatment with anonymous sperm donation, chapter 8 presents a study towards lesbian parents through anonymous sperm donation, and chapter 9 includes an interview study with these lesbian parents’ children. I will explain some features of the participants, the interviews we conducted and how we analysed the data, followed by some reflections on the validity of these qualitative studies. More detailed information on the methods for each particular study will be presented in the chapters.

Participants

All participants were recruited via the Department of Reproductive Medicine of the Ghent University Hospital. We purposefully sampled a maximum of 10 couples, in line with the literature on qualitative methods, in order to guarantee sufficient in-depth engagement with each individual case (Smith & Osborn, 2008). Also the practical reason of time lead to the choice for this number, since we chose to focus on a large variety of sub groups rather than on a larger group of participants per sub study. During recruitment it became clear that even reaching the set number of 10 couples was difficult for some sub studies. No data ‘saturation’ technique was used; the addition of new data to the analysis until there is nothing new or relevant to emerge was not applied. The department’s counsellor was involved in the recruitment process as she had met each couple during a counselling session before they started treatment. She contacted all participants by phone based on the same recruitment protocol. Besides the perspective of parents, we also attempted to capture the children’s perspective. Again, a set number of 10 children was agreed upon. These children were recruited via the parents. After each interview, the parents were asked whether their child (aged 7 to 10 years) would also want to participate in the study and whether the parents themselves...
would agree to this interview. During the course of the project, it became clear that the recruitment of children was very difficult. Few parents were willing to let their child participate, mainly due to the secrecy concerning the donor conception. We were able to recruit a maximum of 7 children in the lesbian families, with all other groups only providing 1 to 3 children. Lastly, we included the known donors of the families who used known donation. These donors were contacted after the interview with the couple had taken place and the interviewer had informed them about the upcoming recruitment of the known donor, which in all cases, was the mother’s sister. All known donors agreed to participate. All studies were approved by the Ethics Committee of the Ghent University Hospital.

Interviews

Data were collected through semi-structured in-depth interviews. This form of interviewing allows the researcher and the participant to introduce new issues, to modify initial questions in the light of the participants’ responses and to probe interesting and important areas which arise (Smith & Osborn, 2008). The interview was supported by an interview schedule that covered the following topics: the experience of the fertility treatments, the experience of the genetic versus non-genetic tie between parents, the meaning of the donor, the experience of parenthood and the assumed rights and responsibilities of the different parties. The interview guides were constructed by the research team that consisted of psychologists, ethicists, a midwife and professionals part of the reproductive field. An overview of the existing literature, as well as theoretical and practical insights were used to construct the interview guide. For instance, bidirectional models advancing the child’s agency (De Mol & Buysse, 2008a; De Mol & Buysse, 2008b) influenced our interview schedule. The bidirectional framework ads the child-to-parent direction of influence to the widely accepted parent-to-child influence within the context of an intimate, long-term parent-child relationship (De Mol & Buysse, 2008a; De Mol & Buysse, 2008b). As a result, questions about the way the children reacted to the knowledge of their genetic origin were included, as well as how processes differed among multiple children in the same family (by probing). Several pilot studies were conducted in order to test and to fine tune the guides. During the data collection, the guides were evaluated on for instance clarity of the questions, word choice, or whether the questions lead to the information we wanted. Final guides can therefore differ slightly with regard to certain questions and wording (the guides are included as appendices). The interview topics were put in an appropriate sequence meaning that more sensitive topics were introduced later in the interview. This sequence was set up for two reasons: it allowed the respondents to (1) become relaxed and comfortable and (2) to mention certain issues spontaneously, before the interviewer introduced them (Smith & Osborn, 2008). The latter could
indicate that the issues are not merely experienced as relevant by the interviewer, but indeed particularly by the participants. We chose to use a semi-structured interview guide for several reasons. First of all, we wanted to cover a large amount of information, going from experiences about the treatment to normative reasoning about parental rights and responsibilities. The semi-structured guide was meant as a support for the interviewer not to forget certain topics. Second, our team included two interviewers which both did interviews within one sub study. The use of a semi-structured guide maintained as much uniformity as possible within one group with regard to topics. Nonetheless, the interviewers were free in how they used the guide during the interview. The sequence of the topics was not strict, on the contrary, the interviewer was free to adapt the sequence according to what the participants said. The participants partially guided the interview.

Only conjoint interviews were conducted in order to obtain couples’ shared constructions and to observe interactions between the partners. As argued by Bjornholt and Farstad (2012), conjoint interviews provide a “common reflective space”, which enables partners to complement and contradict each other; they can challenge and reinforce each other’s ideas. By interviewing couples together, the researcher can observe family practices and dynamics as they occur in family life and topics of disagreements can be identified (Bjornholt & Farstad, 2012).

**Analysis**

The data were analysed using an inductive thematic analysis method (as presented by Braun & Clarke, 2006). We chose this method because it provides a flexible research tool suited for a large and complex data set. Also, this method is compatible with the constructionist paradigm of the research project. Cases were analysed in a cumulative way, with a focus on the content of the people’s experiences. The coding process was iterative, allowing the researcher to move back and forth during the analysis.

For the studies included in this dissertation, the analyses consisted of a phased process, starting with familiarizing with the data and memo writing. The transcripts were then screened with the research question in mind and relevant text units were coded inductively. From these codes, higher level codes and themes were derived. During this process, a team of auditors was invited to challenge the initial codes and themes via alternatives and counterexamples (Hill et al., 1997). The structure of the themes was written down in an analysis report which was extensively examined and discussed by the auditor team. Through discussions, the final structure of the themes was agreed upon. To improve data analysis, discussions and intensive trainings with the whole team were organised in order to learn from each other and to become aware of alternative view points on the matter.
While in quantitative research exact numbers can be given to ensure the reliability and validity of the analysis, in qualitative research it is much more complex to verify the validity of the findings. The researcher plays a much more central role and is inevitably involved in the research. To ensure the reliability and validity of an analysis, the ‘credibility’, ‘transferability’ of the data and ‘reflexivity’ towards the data should be taken into account. In the following, our attempts to strengthen the validity of our research through these three methods will be explained.

**Credibility.** The credibility of qualitative research is referred to by Kvale and Brinkmann (2009) as ‘defensible claims’: are the claims faithful to the data? In order to enhance the credibility of the research, two steps were taken. First, we worked in an interdisciplinary team to discuss the data collection method and analysis. Our team engaged in intensive training and collaboration in order to learn from each other, challenge views and findings and to become aware of alternative interpretations. For every analysis, an internal auditor (usually from a different discipline) and an external auditor (the supervisor) was involved. The auditing consisted of a detailed analysis of the research report that was provided by the analyst. Based on the report, the auditors questioned the constructed categories and challenged the analysis via alternatives and counterexamples until final themes were agreed upon (Hill et al., 1997). Further, we tried to increase the transparency of our interpretative work by providing analysis reports with the identified themes, illustrated by quotes of the participants. The interpretation of the quotes was presented transparently, enabling the reader to identify how interferences were made (Hill et al., 1997). Second, data triangulation was applied to achieve multiple ways of understanding (Daly 2007; Hill et al., 1997). We established triangulation of data sources by including at a large variety of participants (heterosexual couples and lesbian couples), and data analysis methods by using both thematic analysis and interpretative phenomenological analysis.

**Transferability.** Transferability is known as the ‘qualitative counterpart’ of the term ‘generalizability’. In the context of qualitative studies, it means that research findings can be transferred to other contexts (Kvale & Brinkmann, 2009). Instead of aiming at statistical generalizability, the aim is to enhance theoretical generalizability; i.e. the extent to which knowledge produced in one situation can be transferred to other situations (Hill et al., 1997; Kvale & Brinkmann, 2009). The eventual goal of qualitative research is to provide a rich, contextualized understanding of human experiences, that results in idiographic and local insight of particular persons in a particular context, which is not generalizable nor universal (Marecek, 2003). During team discussions, we constantly reminded each other of the very specific context of our data. For one, the participants were recruited in Dutch-speaking Belgium which means that the patients we recruited should be contextualized in the context of anonymous gamete donation.
Another example is the recruitment of the children of the lesbian families. By coincidence, all children turned out to be boys. During team discussions, we wondered whether the results would have been different if more girls had been included. More generally, we often discussed the topics we investigated, such as genetic relatedness or secrecy and disclosure, in relation to other contexts such as adoption or reconstituted families.

**Reflexivity.** Reflexivity is defined as a process in which your own position as researcher is taken into consideration. Reflexivity needs to be applied throughout all the steps of the research process. In the first phase of this project, a phase of ‘settling in’ the research field was implemented. In order to get closer to the participant’s world and to try to take an insider’s perspective, each team member did a short internship in the Department of Reproductive Medicine in Ghent. We followed patients during the different phases of their treatment and learned about the implications of certain techniques for the couple. Seeing the work that is done in the laboratory, listening to patients during their first counselling session, but especially experiencing a live insemination learned me about the massive impact and importance of reproductive techniques on people’s lives. At that point, I was overwhelmed by the experience, but it opened my eyes for the reality of the practice I had been reading about before. Parallel with this process, the literature regarding different topics on parenthood after ART was reviewed. Second, reflections on one’s orientation and assumptions were made explicit by means of a Socratic dialogue held in our research team and by keeping track of personal reflections in a diary. We often discussed rather informally our own ideas about gamete donation and related topics such as disclosure to the child. Not only did I discuss this in the research team, I often talked about my opinions and struggles with the practice of gamete donation with friends and family. These discussion helped me to get insight into my own views on the matter. Third, in the data collection phase, I was reflective of my own position as young, female researcher without children and discussed the meaning that gamete donation or anonymous donation would have for myself with my team members, friends and family. Finally, regarding data interpretation, presuppositions were identified by the internal and external auditors and reflected upon by the analyst. It is believed that knowing one’s presuppositions prevents the design of narrow research questions, problematic reactions during the interview and interpretation biases during the analysis. As a result, the position of the researcher becomes more self-conscious (Parker, 2005).
4.3 References


Section 2

Normative analyses
Chapter 5

The right of the donor to information about children conceived from his or her gametes

Based on published journal articles:

5.1 Introduction

As already previously discussed in the introduction, over the past two decades, there has been a remarkable trend towards more openness in the practice of gamete donation (Janssens et al., 2011). In these so called ‘open-identity’ countries, donors are no longer allowed to donate anonymously. Instead, they have to consent to the release of their identity to the children conceived from their gametes if they request this once they become mature.

This shift towards identifiable donation is the result of a new focus on the rights and interests of donor-conceived children (Scheib & Cushing, 2007). However, this evolution appears to focus exclusively on this party. Policy makers seem to overlook whether information exchange could also be of interest to the other parties involved, in particular the gamete donors. As it stands today, donors rarely receive information about the result of their donation. Therefore, it would be useful to scrutinize the donors’ perspective on the practice of gamete donation. It is not clear why donors would not be justified to receive information about their donor offspring, similarly to their donor offspring who are justified to receive information about the donor. We need to analyse whether donors also have an interest in receiving some kind of information about the offspring conceived by their donations and whether they consequently have a right to such information.

5.2 Possible arguments in favour of the donor

As a first step of our analysis, we distinguish between various types of information that a donor could claim.

- Basic information: this would include information about the outcome of the donation, in particular the number and sex of the donor offspring;
- Medical information: this would involve medical and genetic facts about the donor offspring;
- Phenotypic information: this information type would contain a description of the general body characteristics of the donor-conceived children, such as hair and eye colour, length and weight;
Extended donor child profile: this is a counterpart of the extended donor profile and would consist of elements like a personality description, information about the child’s interests and hobbies, and perhaps a letter to the donor;

Identifying information: the name and contact details of the donor child. Such information would be given in addition to some of the information types mentioned above.

Remarkable is that in some countries such as Belgium, policy already allows the exchange of the above information for a particular group of donors, namely for the group of known donors. In practice, this group mainly consists of oocyte donors. These are sisters, nieces or close friends of the recipient women (in rare cases, the mother). The allowance of such known donors developed in support of the constant shortage of oocyte donors. Because of the particular personal relationship between the donor and the recipient, it is evident that the donor has all information about her donor child. The donor indeed knows the child. In case of an anonymous or identifiable donor, however, the ethical judgement of this information exchange is clearly very different: it is not seen as self-evident. It should therefore be investigated whether such donors should also be able to receive information about their donor offspring.

We identify five arguments on which donors could base their claim for a right to some type of information about the offspring conceived by their donations:

Medical information, in particular evidence of an unsuspected genetic disease, about the donor offspring can be of great importance to the donors’ and their own children’s health.

Donors should be acknowledged for their altruistic behaviour. Basic information is a minimal reward for their donation.

General information about the donor offspring should be given as a means to ease the donors’ potential concern about and sense of responsibility for the offspring.

An extended profile can provide an important enrichment of the donors’ identities.

The open-identity system creates a ‘new’ type of donor – one that desires contact with the donor offspring. Identifying information enables such contact.

In what follows, we analyse all arguments and evaluate whether or not a donor is justified to claim the proposed information.
5.2.1 Desire versus need

Whether a donor can claim one or several of these information types depends on two conditions. First, we have to take into account the weight of the donors’ interests in obtaining such information. Are these interests related to the recognised needs of a person? After all, a mere desire for something does not necessarily point to important needs that must be addressed. A right cannot be based on a mere desire (Savulescu, 1999). “At the root of rights are interests” (Freeman, 1996). It should be investigated first what the effect of (not) granting a right would have on the quality of life of the person (suffering, social contacts, knowledge, development of skills,…), independent of that person’s personal desire. When the quality of life would be highly increased when certain information is released, or when the quality of life would be severely decreased when certain information is not released, it would be justifiable to grant the right to such information. It is important to distinct the need from a desire, since it is perfectly possible for a person to desire something he or she does not need or which even opposes his or her interests, or the other way around, it is possible for a person not to desire what he or she actually needs. The evident question is then when the threshold between a desire and a need is crossed and when it is not (Savulescu, 1999). A clear line cannot be drawn. Nonetheless, we can investigate whether the release of certain information about the donor offspring would have a positive effect on the donors’ quality of life.

A second condition is that we must take into account that the interests of the donor potentially oppose with the interests of the other parties involved, namely the parents and the children. A balance should be made between the donors’ positive right to privacy (the right to information which contributes to the development of his or her identity) and the parents’ and children’s negative right to privacy (the right to withhold the release of personal information to a third person). In what follows, we will analyse the proposed arguments and evaluate the weight of the underlying interests.

5.3 Analysis of arguments

Five arguments will be discussed. The first two arguments are top-down, meaning that the arguments follow from an ethical reasoning about the possible interests of the donor. The three other arguments are based on the wishes of donors themselves. In these cases, it will be investigated whether sufficient ethical justification can be found to grant a right to such information.
5.3.1 Medical information about the donor offspring for the benefit of the donors’ health

The importance of exchanging medical information became clear in the US in 2009 when a sperm donor passed on a lethal genetic heart disease to some of the donor offspring. This condition was discovered when one of the offspring died of the disease. The medical information was then passed on to the other offspring so they could be examined, and treated if necessary, and regular observation was made possible (Jones, 2009). The exchange of medical information from donor to donor-conceived children is now increasingly accepted as a means for securing their health (Ethics Committee of the American Society for Reproductive Medicine, 2009; McGee et al., 2001; Ravitsky, 2012). But this line of reasoning might be just as convincing for the donor: not exchanging medical information might endanger to donors’ quality of life.

We can identify at least three reasons why donors could claim an equal right to medical information about the donor offspring. The first reason has to do with their own wellbeing. If a donor-conceived child develops a genetic disease and this information is passed on to the donor, the donor can be tested for the disease. At best, adequate measures can then be taken to prevent the disease. If the donor were to develop the disease, at least appropriate treatment could be started timely. Releasing information about one’s genetic make-up could also inflict damage, for instance when nothing can be done about a life-threatening disease or when no treatment is available. One could argue that this argument only applies to preventable diseases, or diseases for which early treatment is advantageous. However, one could also argue that the donor should be informed anyway so at least he or she knows what is coming. The second reason has to do with the donors’ reproduction. With medical information about their donor offspring, donors could make informed reproductive decisions about whether or not they should have children of their own, and about the need for prenatal or preimplantation diagnosis. Finally, this information could also benefit the donors’ own children. They have an interest in this information for the same reasons as the donor: it could lead to a suitable treatment if needed and it could help them make informed reproductive decisions in the future. In addition, donors and their own children have an interest in medical information about the donor offspring to prevent the small but existing risk of incest. When the partner of a donor’s own child was conceived via gamete donation, the hospital should provide information on whether the gametes that were used were not his- or her selves. Of course, no information should be released of the actual donor.

In other donation contexts – for instance with blood and tissue donation – relevant medical information is already passed on to the donor. In these practices, there are international guidelines concerning the release of information that benefits the donor’s wellbeing (Knoppers et al., 2006). The current wisdom is that blood and tissue donors...
should be informed if tests reveal a relevant medical condition. This reasoning is also applied in the context of medical scientific research. All persons need to be informed when information relevant to their health is found. Both the Council for International Organizations of Medical Sciences and the Council of Europe prescribe this right of the participants. Three basic ethical principles form the basis of this right: respect for an individual, wellbeing and justice (Knoppers et al., 2006). It is unclear why the same reasoning should not apply for gamete donors, particularly because their interest in this type of information can be met without intruding the rights and interests of the offspring and their parents. After all, medical information can be made anonymous and be passed on by for instance the fertility centre or general practitioner. That way, the anonymity of the child is protected. To conclude, it would be reasonable to provide gamete donors information about genetic disorders exhibited by the donor offspring.

5.3.2 Basic information as a way to reward the donors

The practice of gamete donation is often compared with the act of giving someone a gift. Donors are seen as altruistic helpers who do the recipients a favour. Particularly in those donation settings where they do not receive payment, the question arises whether donors do not deserve to be rewarded for this gift, on top of whatever social recognition they may receive. Particularly for oocyte donors, the physical burden they endure supports the idea of some kind of compensation. There are other comparable donation contexts in which the donors are rewarded for their altruistic behaviour by granting them relevant feedback. For instance, people who donate to charity usually receive information about how their money was put to use and what their donation has helped to achieve. Also, within scientific research, it is common practice that participants are informed about the results of the research (Fernandez et al., 2003; Knoppers et al., 2006). This appears to be a good way to acknowledge their role and not to treat them as a mere ‘means to an end’. For gamete donors too, information about the ‘result’ of their donation could be an appropriate form of reciprocity (Pennings, 2005). Given that the main motivation of donors is to help other couples have a child of their own, the minimum feedback they deserve is information about whether, and if so, how many, children were born from their donation. Indeed, several studies show that both sperm and egg donors ask questions about the outcome of their donation, such as the number or sex of the offspring (Cook & Golombok, 1995; Frith et al., 2007; Kalfoglou & Geller, 2000; Purewal & van den Akker, 2009). By granting them this type of information, we would allow them to feel positive about their donation, because this way at least they would know whether or not they actually helped other couples.
There is a second reason why donors should receive such basic information. This information offers identifiable donors in particular more than just recognition for what they have done. The Ethics Committee of the American Society for Reproductive Medicine (2009) states that “this information can offer psychological closure to the donor, caution the donor that contact may later occur, and give donors who already have children the opportunity to consider the impact of future contacts on their children and/or partner” (p. 26). A study conducted by Kalfoglou and Geller (2000) shows that some egg donors wish to receive information about the outcome of the donation precisely for this last reason. Therefore, it could be argued that basic information is also important for the psychological wellbeing of the donors.

5.3.3 General information about the donor offspring’s wellbeing in response to the donors’ concerns

Both egg and sperm donors wonder about the wellbeing and whereabouts of the offspring conceived by their donations. One study on ‘egg-sharing’ donors reports that they often think about the donor offspring (Gürtin et al., 2012). Another study showed that some egg donors feel somewhat responsible for the donor offspring and are worried about the parenting style of the parents (Jordan et al., 2004). Other studies indicate that sperm donors as well worry about the wellbeing of the donor offspring (Jadva et al., 2011; Daniels et al., 2005). Jadva et al. (2011) and Baetens et al. (2000) report that some donors would even feel morally obliged to help the child if this were to be necessary. These concerns can be explained by the fact that the donors helped create the child. Our society is in general highly sensitive to the needs and wellbeing of children, so it is not surprising that this concern heightens when it involves children who carry part of your genes.

Granting donors general information about the offspring conceived by their donations could be a way to reassure them about the children’s wellbeing. Indeed, based on this same motivation, during the 1970-80’s, in the practice of adoption, arguments were raised in favour of allowing birth parents (often birth mothers) to participate in the choice of the adoption parents and to gain information about the development of the child (Wolfram, 2008). Studies conducted in the US showed that birth parents were concerned about their adopted child and desired a more active involvement in the adoption process and life of the child (Wolfram, 2008). This concern was one of the motivations for the development of an ‘open adoption’ system.

The question is, however, whether a donor needs identifying information to reduce these potential concerns, as was proposed in the adoption context. Although gamete donation is comparable to the practice of adoption in the sense that both birth parents and gamete donors have a genetic child that is raised in another family, there is also an
important difference. Donors do not have to cope with negative feelings about giving up the child. Therefore, donors do not have the same interests in contact with the offspring as the birth parents and there is much less ground for granting them identifying information about the donor offspring. Nonetheless, it could suffice to give donors anonymous feedback on the general wellbeing of the donor offspring, for instance through a rating scale that covers various welfare issues, as used in scientific research about the psychological wellbeing of children (Golombok et al., 2011). This information could be updated every 5 to 10 years. This anonymous information could then be passed on to the donor.

Problems with this argument

The proposed argument seems to suppose that a concern is a sufficient reason for granting donors a right to the information. As previously discussed, a concern is not sufficient as a basis for a right. Some remarks should be made in answer to the argument. First of all, only a part of the total donor pool is concerned about his or her donor offspring. Second, it is questionable whether donors who wish for this information but do not receive it, would lose quality of life. Of course, donors who wish for such information and do receive it, will be happier. However, all this should be balanced with the impact of the suggested psychological tests on the family. It is most likely that in practice, such tests would result in negative feelings such as feelings of being controlled, constantly being reminded of the existence of the donor, feelings of liability to the donor, or the possibility of endangering the secret about the use of gamete donation. Some donors’ concern about the wellbeing of their donor offspring does not weigh against the possible negative impact on the family. Donors who are concerned should be comforted by trusting the screening programs of the reproductive centre. Thirdly, it is not certain that such anonymous general information about the donor offspring would be able to ease the donors’ concern. More effectively would be to inform the donor before conception with information about the recipient family. By granting donors such information, they are given a mere passive role; they cannot influence the selection procedure. However, this practice could even indulge more concerns in the case when the donor would not agree with the recipient family. One could argue then, to solve this concern, that donors should have an influence on the selection of the recipients. When donors are able to select their recipient family, they could ensure themselves of a good and caring family for their donor offspring. This would be similar to the policy in some countries where the recipient family can choose their donor. Nonetheless, for several reasons directed gamete donation seems to be a bridge too far. First, the general rule that donors relinquish all rights and duties is breached. Second, when the distribution of gametes is left to the donors, this might
conflict with distributional justice (Pennings, 1995). In conclusion, donors are not justified to claim general information about their donor offspring.

5.3.4 Phenotypic and extended information about the donor offspring for the enrichment of one’s identity

One can easily imagine that a gamete donor may now and then wonder about his or her donor offspring, for instance about whether they share certain physical or personality traits. Some studies confirm that there is curiosity among donors about physical resemblances, and this appears to be a major motivation for them to inquire about the donor offspring (Jadva et al., 2010; Kalfoglou & Geller, 2000; Scheib et al., 2005). A curiosity about resemblances in personality traits was found as well (Daniels et al., 2005). However, as explained above, mere curiosity about the donor offspring is no sufficient reason to pass on information to the donor. A right to information must be based on a significant interest. According to advocates of the current open-identity gamete policies, this is undoubtedly the case for donor offspring. Even though their wish to know more about the donor also appears to stem mainly from curiosity (Jadva, et al., 2009; Jadva et al., 2010; Scheib et al., 2005), they do get the opportunity to fulfil this curiosity. In some countries, they are granted phenotypic information, an extended donor profile or even identifying information because this is said to be important in terms of the development of their identity (Daniels, 1998; McWhinnie, 2001; Velleman, 2008). With information about their second genetic parent, it is argued, they are able to gain a better insight in who they are, in particular in those aspects of their identity that are ‘unique’ and those that they have in common with one or both progenitors. If this is a valid reasoning, does a similar argument not apply equally for the donor? After all, donors too share 50% of their genes with the offspring conceived by their donations. They too could discover similarities and differences, both physically and behaviourally, and use this information for a more correct perception or an enrichment of their identity (Kaebnick, 2004). One could thus argue that donors should receive phenotypic information and extended profiles of the donor offspring. An obvious problem is that children change over time. A solution could be to collect the information when the donor-conceived child reaches the age of eighteen. At that age, his or her personality traits and physical characteristics will have reached a more or less stable point. Alternatively, information could be exchanged when the child is still younger, but provide an update every five years. Since donors typically have more than one donor-conceived child, they would receive several extended profiles and various types of phenotypic information. This should make it easier for donors to discover similarities or differences between themselves and the donor offspring.
Problems with this argument

However, there appear to be more differences than similarities between both cases. First, contrary to the donor offspring, donors generally do know (about) both their parents and therefore have been able to develop a personal identity based on sufficient information about their genetic origin. This is exactly what the donor offspring are looking for. Both parties are in effect seeking a different kind of feedback. The Law Reform Committee (2012) puts it as follows: “While some donors may feel that knowledge of their donor-conceived children is important, the identity of a donor’s offspring is not central to a donor’s self-identity. The donor knows who his or her family is, and where he or she came from” (p. 105). Second, donors are adults. This means that their identity is already formed. Therefore, the information can no longer be useful for the actual development of his or identity, at least not in the way it could help the donor offspring who are often children or teenagers. Moreover, donors can access the information they need by having children of their own and by watching them grow up. The impact caused by the lack of this ‘genetic’ information is much bigger for the donor offspring than it is for donors. Furthermore, there is a certain danger involved in exchanging this information with donors: it concerns personal information about a child. The idea that such information is passed on to a stranger without the child’s explicit consent (because the child is too young to understand) and possibly against his or her will is a severe breach of the child’s right to privacy (and also of the parents). The donors’ interest at stake is not a sufficient argument to grant them phenotypic information or extended profiles of the offspring.

Another type of information

Nonetheless, although there is an asymmetry in the need for phenotypic and extended information between donor and offspring, there is another sense in which information about one’s donor offspring could complement the donors’ identity, and here the information can remain anonymous. One could argue that the mere fact of procreation in itself creates an extra dimension to the identity of a person. Knowing that you are a ‘mother’ or a ‘father’ (in the strict biological sense), that you have procreated, can be important for a person and creates an extra meaning to one’s self-image (Robertson, 1994). Moreover, having children in itself can be valuable because it is a form of ‘self-replication’. It is a way to make your own person live on when you pass away (Dillard, 2010). A study by Janssens et al. (2006) shows indeed that some identifiable sperm donors donate with procreative reasons. For them, the mere knowledge that they did reproduce, that children have resulted from the donation, could already contribute to their identity and be sufficient for them to feel satisfied about the donation. Therefore it could be argued that for this reason basic information should be passed on to donors.
5.3.5 Identifying information about the donor offspring for donors who want contact

Donors within an open-identity system differ from anonymous donors in that they must be available in the future if the donor offspring were to desire contact. This change of expectations attracts sperm donors with a different profile and different motivations (Daniels et al., 2005; Pennings, 2001). Anonymous sperm donors appear to be mainly single heterosexual young men, most commonly motivated by altruism or financial reimbursement (Cook & Golombok, 1995; Janssens et al., 2006; Thorn et al., 2008). Studies show that this profile alters when anonymity is abolished. If one changes the conditions and laws about gamete donation, the recruited donor profile will change too (Pennings, 2005). With the change towards open-identity systems, new donor profiles do indeed appear: according to some studies, particularly older married men with children are now prepared to donate (Daniels, 2007; Daniels & Lalos, 1995; Human Fertilisation and Embryology Authority, 2005). Results of another study contest these findings and show a greater willingness for contact among single donors than donors who are in a relationship (Godman et al., 2006).

This last finding makes sense. The system of open-identity donation is highly suited, apart from the altruistic motivation, for men who choose to donate precisely because it offers the opportunity to have contact with one’s donor offspring (Ripper, 2008). For some, an open-identity system is seen as attractive because they have a desire for future contact (Riggs, 2008; Ripper, 2008). A study shows that a considerable part of the new group of donors is therefore homosexual (Riggs & Russell, 2011). They appear to see their donation as a way to have genetic children and to meet them. Riggs and Russell (2011) state that “gay men, in general, are more willing to be identified, and that while donating for altruistic reasons, may also donate as a way of staking an identity claim to paternity if it is perceived that there are no other options available in this regard” (p. 267).

From the point of view of donors who wish to play a part or have a say in the donor offspring’s life, it is logical to desire information that enables them to contact the offspring. However, we cannot just grant them a right to identifying information based on a desire. On the one hand, this could harm the interests of the other parties involved if they are not willing to be contacted. This is especially the case when the social parents have not informed the child about its donor conception. Even a request by a donor for contact could have disastrous consequences for the family in such circumstances. On the other hand, donors simply do not have an interest in receiving identifiable information: these donors have a desire to receive identifying information, but this does not imply that there is a need for them to receive this information. By not receiving this information, they are not likely to be harmed. However, there is no obvious reason why it should be prohibited either. If all parties desire contact, the possibility of mutual identity exchange could be offered, while not granting a particular right to it. This could
for instance be accomplished by creating an online register to which both the gamete donor and the offspring can subscribe if contact is desired. Only when the donor child also registers on his own initiative and consent, should the exchange of identifying information be made possible. This system is already being used in the United Kingdom in the form of the UK Donor Link and in the USA in the form of the Donor Sibling Registry.

Nonetheless, a particular danger must be brought to attention. It is possible that the donors have high expectations about the contact which the donor offspring and their parents may not be willing to meet up to. There are at least two ways to prevent this kind of situation. For one, we could screen donor candidates in advance in terms of their personality, expectations, coping skills and perspective on donation. According to Sydsjö et al. (2012) and Sydsjö et al. (2011), who conducted a study on the personality traits of current identifiable donors in Sweden, preventive screening resulted in the recruitment of mature and stable donors. However, this screening can only partially filter the donors’ motivations. An additional solution would be to offer psychological counselling to those donors who wish to contact the donor child, so that unrealistic expectations can be identified and dealt with in time.

5.3.6 Different interpretations of having a right

Donors seem to be justified to claim the right to two types of information: medical information and basic information. It is important to point out in detail what exactly this right would entail. At least four different interpretations of what ‘having a right’ entails can be distinguished (Räikkä, 1998). Räikkä mentions an obligation to give information, an obligation not to prevent a person from obtaining information, an obligation to give information whether or not the person asks and an obligation not to prevent a person from obtaining information whether or not the person asks. In this regard, it should be remembered that not all donors want the information they are entitled to. In addition, passing on the information donors are entitled to can have negative consequences. Receiving information about one’s genetic make-up can have negative consequences when nothing can be done about the disease. When basic information about one’s donation is given and no children have resulted from the donation, this could have negative consequences for the donor. It is easy to imagine that when someone decides to help other couples and the donation did not result in a child, this is no pleasurable news. Therefore, having a right should be clearly distinguished from having an obligation to receive information. The right entails a possibility - information should only be passed on to those donors who ask for it – not a duty. The right should entail an obligation not to prevent a person from obtaining information. They have, as is the case in other medical contexts (for instance, paternity cases) a right
not to know (Knoppers et al., 2006). In practice, information could be gathered in a register that is available for the donor when he or she wishes, instead of automatically sending him or her the information. Hereby, the right is respected, but not forced upon the donor. At the moment of donation, the possible channels through which information can be obtained can be explained. Either way, donors should be informed about the possibility of receiving negative news. In addition, accompanying measures such as counselling, should be offered when needed.

5.4 Conclusion

Our analysis shows that gamete donors are justified to claim a right to two types of information about the offspring conceived by their donations. Information about genetic disorders can be important for the donors’ and their own children’s health. Basic information about the offspring can be regarded as an appropriate reward for their altruistic behaviour. Such information can also play a role in the enrichment of their identity by confirming their procreation. In contrast, both general information about the child’s wellbeing and an extended profile cannot be granted to the donor due to the lack of a need. Finally, it can be argued that a possibility to get in touch should be offered when all parties involved agree. However, arguments in defence of a right to identifying information about the donor offspring have not been found.

5.5 References


Chapter 6

Donor conception disclosure: directive or non-directive counselling?

Based on submitted journal article:
6.1 Introduction

It is widely agreed among health professionals, as well as medical and governmental organizations and associations, that couples using Assisted Reproductive Techniques (ART) should be offered counselling (Boivin 2003; HFEA 2012). It differs from country to country whether this counselling is mandatory or not. The European Society for Human Reproduction and Embryology (ESHRE) and the American Society for Reproductive Medicine guidelines (ASRM) (the two largest professional societies) prescribe that counselling should be offered at all stages of ART treatment (Strauss & Boivin, 2001; Boivin et al., 2001; ASRM, 2013). Counselling can be seen as a process which takes place between a counsellor and a patient “in a private and confidential setting to explore any difficulty, distress or dissatisfaction with life that the client may be experiencing. Counselling can increase a client’s ability to make choices and change aspects of their situation” (British Infertility Counselling Association, 2013, para. 1.1). Counselling in the context of infertility treatment covers many specific tasks such as information giving, implications and decision-making counselling, support counselling and therapeutic counselling (Strauss & Boivin, 2001). In this chapter, the focus is on the approach that should be used during implications and decision-making counselling: should the counsellor assist the patient in making decisions according to the patient’s own values (the non-directive counselling approach), or should the counsellor direct the patient to a decision that is seen as the most appropriate, even if this decision does not correspond with the patient’s own values (the directive counselling approach)? Here, we will focus specifically on the much debated topic of donor conception (DC) disclosure. For a long time, a directive approach pro secrecy was used in counselling sessions (Nachtigall, 1993; Allan, 2012). Patients were advised not to tell their child(ren) and environment about the use of donor material. Nowadays, both a directive and a non-directive approach are defended, with the directive approach now favouring disclosure, and this preferably at an early age (HFEA, 2012; Australian and New Zealand Infertility Counsellors Association, 2012; Peterson et al., 2012; Hertz, et al., 2013; Klock, 2013). The defence of the directive approach in this counselling context is rather remarkable for two reasons. First, psychosocial counselling is generally considered to be non-directive: in the psychosocial field it is agreed that patients should not be directed towards a certain behaviour. Counselling otherwise is seen as manipulative and unprofessional (British Association for Counselling and Psychotherapy, 2013). Second, both in law and ethics it is considered that parents should be able - in most cases - to make decisions concerning the well-being of their child free from external intervention (McHaffie et al.,
This parental responsibility - which includes both rights and duties - towards a child is based on the supposition that parents will act in the best interests of their child. In a medical setting, this can be translated for instance into the right to an informed consent on the child’s behalf (British Medical Association, 2008). A directive counselling approach promoting openness interferes with the privacy and autonomy of the parents, hereby challenging this general belief in the parental autonomy. In the following, we will discuss whether this exception to the non-directivity rule is ethically justifiable for the specific topic of DC disclosure.

Defining the two approaches

First, it should be clarified what is meant by ‘non-directive’ and ‘directive’ counselling. While there is no single accepted definition of these two approaches, an agreement exists on how to differentiate both approaches and what they generally stand for (Oduncu, 2002; Xafis et al., 2014). Non-directive counselling is seen as an approach by which the counsellor takes a neutral position in order to facilitate the weighing of pros and cons of an action by the patient(s) (Klock, 1997, 2013; Sachs & Hammer Burns, 2006). Patients are provided with information in order to make a decision in accordance with their own personal views and beliefs; they are not influenced by the opinion of the person communicating that information (Hayden, 2005; Kirklin, 2007; Xafis et al., 2014). Non-directive counselling “may include the offer of information but does not involve giving advice or directing a client to take a particular course of action” (British Infertility Counselling Association 2013, para. 1.1). Directive counselling can, consequently, be defined as the opposite. In this approach, the counsellor directs the patients towards a goal that does not originate in them and that may not correspond with their own beliefs. The counsellor has a clear goal in mind and tries to convince the patients to comply to his or her advice (Kessler, 1997; Bernhardt, 1997). Such advice can be convincing for patients who regard their counsellor as an “expert” or an “authority”, someone who knows “what is best”. A counsellor can be directive in many ways. An option can be favoured overtly, or it can be communicated in a more subtle way by putting an unbalanced focus on only one position (Xafis et al., 2014). For instance, a counsellor who were to say: “It is best you do this” or “If I were you, I would do that,” would be using a directive approach because the position he or she favours is openly promoted. An example of more subtle directive counselling in the context we wish to discuss here would be a counsellor who only explains the risks of non-disclosure, and withholds mentioning risks of informing the child about the donor conception (or vice versa). An extreme version of directivity is when a certain decision is said to be a condition for access to treatment. The approach can thus be seen as a continuum with on the one end counsellors giving one-sided/biased advice or guidance regarding a certain decision, and on the other end threatening not to offer treatment if the patient does not agree with certain conditions.
In this chapter we hold a strict dichotomy between non-directive and directive counselling for the sake of the argument. In practice, this distinction is often not so clear. However, the practice is not the focus of this analysis. We take the normative position that is presented in the guidelines as a basis.

6.2 Counselling and the disclosure decision: guidelines and opinions

As already mentioned, the guidelines and recommendations of several associations and organizations in the ART-field differ in terms of how counsellors should approach couples seeking ART and gamete donation with regard to the decision whether or not to disclose the conception method to the child.

6.2.1 Counsellors’ positions

**Non-directive counselling**

With regard to directive counselling in general, it is argued that recommending certain behaviour (in this case, disclosure) is detrimental because it shuts the door to future counselling when the patients do not follow the counsellor’s opinion (Klock, 2013). A neutral position is also deemed important because the counselling session should be an opportunity for the couple to freely discuss their thoughts and feelings without feeling judged (Sachs & Hammer Burns, 2006). If the counsellor imposes his or her view, patients may feel uncomfortable and sense a conflict with their own opinion (Klock, 1997, 2013). Another consideration in favour of this neutral position has to do with the effectiveness of directive counselling (Klock, 2013). We do not know whether couples actually follow the recommendations the counsellor gives regarding for instance the disclosure decision. It is possible that the patients will say they agree just to avoid problems or further questions. Patients might feel constrained to discuss their difficulties regarding the disclosure decision and could be driven to hold back their own opinion and intentions.

With regard to counselling on the topic of DC disclosure, Kainz (2001) said that “the therapist should remain neutral and help the couple come to their own decision regarding disclosure” because “at this point, there is no evidence in the literature that there is a ‘best’ option for all couples” (Kainz, 2001, 484). The Counselling Special Interest Group of the Canadian Fertility and Andrology Society recommends counselling
concerning “the implications of privacy/secrecy and openness and the level of disclosure recipients are comfortable with” (Canadian Fertility and Andrology Society Counselling Special Interest Group, 2009, 31). In this case, it is not clear whether the counsellor should provide specific advice, particularly because the starting point of the guideline is that disclosure is the better option (they argue that enough evidence is available to support this).

**Directive counselling**

The second position is represented by a group of mental health professionals who support the idea of promoting openness. Their arguments question the moral value of privacy and they warn for the possible harms to the psychological well-being of both the parents (the burden of a secret) and the child (the awareness that something is not right) (Daniels et al., 2011). A secret can create a barrier to open communication in the family and there is always the risk of accidental discovery at a later, unsuspected and possibly inappropriate time, which could be particularly damaging for the child (Turner & Coyle 2000). In contrast, disclosure, and specifically disclosure at an early age, is said to be best for the development of the child’s self-concept and identity (Kirkman, 2003; Landau, 1998; McGee et al., 2001). Informing children about their conception is thought to render them capable of forming a ‘correct’ identity based on all the information available regarding their own life (Horowitz et al., 2010). This view is for instance supported by the Australian and New Zealand Infertility Counsellors Association (ANZICA). According to ANZICA, the recipient parents “need to tell the offspring themselves about circumstances of their conception” (Australian and New Zealand Infertility Counsellors Association, 2012, para. 6). Peterson et al. (2012) also state in this regard that “counselors can assist couples in understanding the importance of disclosing the nature of the conception to the child” (p. 246).

### 6.2.2 Guidelines and legislations

Several guidelines from numerous instances have been developed on the topic of DC disclosure, while only few legislations concern this topic. Focussing on the guidelines first, in a report on the ethical aspects of information sharing after DC, the Nuffield Council on Bioethics (2013) argues that openness is not intrinsically valuable. The Council takes the view that openness towards donor conceived children is important as long as it contributes to the quality of family relationships. According to the Council, the decision whether or not to disclose should be made by the parents because it depends on their social context whether openness is valuable or not. If parents believe that non-disclosure is the better option for their particular situation, this should be respected and supported by the counsellor (Nuffield Council on Bioethics 2013).
Nonetheless, the Council also adds that it will “usually be better for children to be told, by their parents and at any early age” (Nuffield Council on Bioethics, 2013, 102). Hereby, a directive stance is taken with regard to what should be considered by the parents. Along the same lines, the German guidelines on psychosocial counselling take an ambiguous position on what approach should be used during counselling. On the one hand, they underline the parents’ autonomy in the disclosure decision. On the other hand, early disclosure is recommended to avoid family secrets (Thorn & Wischmann 2009). The American Society of Reproductive Medicine (ASRM) is also ambiguous about the counselling approach that should be used. For instance, the Ethics Committee of the ASRM states that “it is the recipient parents' choice whether to disclose the fact of donor conception to their offspring” (Ethics Committee of ASRM, 2013, 4). However, the Committee also states that “although whether to reveal the fact of donor conception to offspring has long been the subject of debate, more recently a strong trend in favor of encouraging disclosure has emerged (1–3). The Ethics Committee finds that disclosure to the child of the fact of donor conception [...] may serve the best interests of offspring” (Ethics Committee of ASRM, 2004 2013, 1).

Along with organizations, some legislators have also decided upon the issue. For instance, in Victoria, Australia, it is now mandatory to offer pre-treatment counselling that includes the advice that children conceived via donor insemination should be told about their donor origin (Thorn, 2006; Blyth, 2012). The HFEA provides similar regulation. In its Code of Practice, the authority states that “the centre should tell people who seek treatment with donated gametes or embryos that it is best for any resulting child to be told about their origin early in childhood” (HFEA, 2012, guidance note 20.7). Our question regarding the justification indirectly also affects the evaluation of the legislation on this topic: if directive counselling cannot be justified, then legislation obliging counsellors to provide directive counselling is also unjustified.

### 6.3 Balancing two ethical principles

The discussion about non-directive and directive counselling can be seen as a balancing of two ethical principles: the principle of autonomy versus the principle of beneficence (Oduncu, 2002; De Wert et al., 2012). Advocates of the principle of autonomy refer to respect for an individual’s right to self-determination and the need to provide all the relevant information available in an unbiased way so that the patient can make an informed and free decision. In the genetic context, the support for this principle and consequently, the non-directive approach, developed in part as a reaction to the coercive policies used in for instance Nazi Germany and the accompanying fear for
eugenics (Oduncu, 2002). In the psychosocial context, it was Carl Rogers (1942) who first used the term to define his patient-centred therapy, characterized by the idea that counsellors can only assist the patient during their decision-making process, but cannot influence the outcome. Rogers specifically used this term to show his rejection of the medical model, which was based on the beneficence principle. This principle states that the well-being of a person should be protected at all times and that active steps should be taken towards achieving it. The beneficence principle is nowadays still often adhered to by health care providers who consider a certain behaviour as beneficial for their patients (and their future child). For instance, most health care providers take a directive stance about taking folic acid when a woman is trying to get pregnant (Oduncu, 2002; Bonte et al., 2014).

When two principles conflict, a balance must be made in order to decide which principle should be preferred (Beauchamp & Childress, 2013). Since advocates of advising openness challenge the highly valued autonomy of the parents, it is up to them to show why the beneficence principle is morally preferable to the autonomy principle. Beauchamp and Childress proposed six ethical conditions to guide such balancing, which are sound and practical rules to weigh the principles at stake here:

1. Better reasons exist to act according to the overriding principle rather than to the overridden principle.
2. The goal of breaching one principle in favour of another must have a reasonable chance of success.
3. The breach must be the smallest breach possible and its proportion must be in line with the goal.
4. No alternatives for a breach must be available.
5. The consequences of the breach must be as small as possible.
6. All parties affected by the breach must be treated impartially.

### 6.4 Analysis of the conditions

#### 6.4.1 Condition 1: better reasons for the overriding principle

Advocates of the directive approach have to show that the child’s well-being is promoted when it is informed at an early age about his or her donor conception and that it is harmed when not informed or only informed late in life. If this is the case, better reasons exist for following the beneficence principle and consequently,
overruling the parents’ autonomy. In the following, an analysis is made of the arguments given by advocates of the directive approach. First, we discuss the health risk when a child is not informed or only informed late in life. Then, we zoom in on different aspects with regard to psychological harm done to children when the information is not disclosed, or not in a timely fashion.

(a) Health risk

Children can be medically harmed when the DC is not disclosed or only disclosed at a later time (for instance, after the child has reproduced). Uninformed donor conceived offspring make wrong assumptions about their genetic heritage because they believe their social father is also their genetic father. When a genetic predisposition is overlooked because of the lack of correct genetic information, the consequences can be severe. An inaccurate diagnosis can be followed by inappropriate treatment. Disclosure about the donor conception can be necessary for a better diagnosis of emerging conditions, for preventive actions, and for making informed decisions about one’s reproduction (Ravitsky, 2012).

It is impossible to know how many children are medically harmed by not being (timely) informed about their DC. Proper genetic screening of the donor is prescribed by guidelines for reproductive centres (ASRM, 2013; Association of Biomedical Andrologists, 2008; ESHRE Task Force on Ethics and Law, 2014). Of course, the hope to thereby avoid harm presupposes that donors are properly screened for the most common genetic disorders and that they provide truthful and extensive information about their family medical history. In the US, screening differs significantly among centres (Sims et al. 2010). Daar and Brzyski (2009) argue that a substantial number of centres does not follow the guidelines. Also, even if screening is done properly, a rare genetic condition may be overlooked, a genetic condition may manifest only years after donation or donors may not be entirely honest or complete when the anamnesis is investigated. The occasional cases where a genetic disease was found despite genetic screening illustrate this (Maron et al. 2009). Nonetheless, we can assume that the probability of such risk of medical harm caused by secrecy is low given that donors are screened for the most common genetic disorders and asked to provide extensive information about their family medical history. Moreover, openness about the donor conception is not going to improve this situation much. Apart from the fact that the child knows that it should not look at the father for genetic information, no useful information comes from being informed about the donor conception.

Another important aspect is the possibility of consanguineous relations when donor conceived children are not informed (Landau, 1998). One could argue that disclosing the DC intercepts incestuous relationships between donor conceived persons. However, the first question that needs to be addressed is the probability of such relations. Serre et al.
(2014) investigated the probability of consanguineous events in France where a maximum of 10 children per donor is allowed (comparable to other countries using an anonymous system). They showed that even when both the current number of pregnancies and the current number of donor descendants were ten times higher, the risk of such relations would still be lower than the risk associated with rare first-cousin relationships. Promoting openness about the donor conception out of fear for consanguinity is not grounded since the probability is too low. Moreover, as in the case of the medical risk, it is unclear how openness would prevent such relationships. Being informed about one’s donor conception does not mean that one is informed about the donor’s file number or identifying information in order to be able to compare donors. In addition, parents should not solve the problem of possible at-risk relationships; this should be done by restricting the number of children per donor. At this moment, the number of offspring is set in an arbitrary manner while norms should be decided on the basis of, among other elements, realistic consanguinity risk estimates (Janssens et al., 2011).

(b) Psychological risk: knowledge about the conception

The case of non-disclosure

Some papers claim that a certain degree of psychological harm is done to the child when the DC is never revealed. For instance, the child could suffer psychologically if he or she is aware that something is not right or that something is kept secret from him or her (Daniels et al., 2011). It is argued that family secrets, such as the use of donor material, may have a negative impact on family dynamics in general. There is an unequal distribution of power with the person aware of the secret having more power than the person for whom the secret is concealed. Also, with the two parents being aware of something the child does not know, the child is excluded from the coalition between his or her parents, which can deteriorate relationships (Sleipan et al., 2012; Turner & Coyle, 2000; Baran & Pannor, 1993). First of all, parents always have more power than their children until a certain age. The unequal distribution of power is a given in a parent-child relationship. Second, not all family secrets are harmful. Many people and families conceal a secret, it is inherent to human interaction (Vangelisti & Caughlin, 1997; Imber-Black, 1993). Recent research has shown that whether or not a secret is harmful, depends on the motivation for keeping the secret. Caughlin & Afifi (2004) found for instance that when the motivation for avoiding a topic was the protection of the relationships, a diminishment in negative association between avoidance and dissatisfaction appeared. Third, the probability of this harm cannot be measured since such effects can only be reported by those who found out. However, several studies have shown that children who are not informed have positive relationships with their parents and develop normally, which shows that this specific family secret does not
always have an impact on the child’s life (Golombok et al., 2002; Brewaey et al., 1997; MacCallum et al., 2007; Lycett et al., 2004; Nachtigall et al., 1997; Shenfield & Steele, 1997). We should be careful in generalizing all secrets as harmful (Shenfield & Steele, 1997). In this regard, a distinction should be made between never revealed secrets and secrets that are disclosed at a later and possibly inappropriate time, or by inappropriate people. Secrets such as the use of donor material may indeed be harmful when they are revealed in anger (Snowden & Snowden, 1993). In that case, not the secret itself (the use of donor material), but rather the fact that the parents ‘betrayed’ their child can be damaging for the child. This is often accompanied with feelings of frustration when they are not able to receive information on their donor (McWhinnie, 2001; Kirkman, 2004).

It is often argued that the adoption context illustrates the harm caused by non-disclosure (Feast, 2003). However, in that context, the shift in legislation (the move towards open adoption) was immediately linked to the provision of identifying information about the birth parents (Feast, 2003; Haimes, 1988). It was the lack of such information that was claimed to be damaging for the adopted child, causing a so-called ‘genealogical bewilderment’ and identity problems, and not the secrecy itself (McWhinnie, 1984; Baran & Pannor, 1993). A distinction should be made between the ‘secrecy or openness’ discussion and the ‘anonymous or identifiable donor’ discussion. If lessons can be learned from the adoption context, it may only be about providing information about the donor and not about possible harm caused by secrecy. Moreover, it is under discussion whether both contexts are similar and we should be careful to generalize possibly problematic consequences (Horowitz et al., 2010). As Shenfield (1999) already pointed out, “children born of gamete donation have been wanted long before their conception by their psychosocial parents. An adopted child, by contrast, was first abandoned by two biological parents before adoption by the psychological parents” (Shenfield 1999, 8). Both adopted and donor conceived children need to deal with their genetic origins. On top of that, adopted children need to deal with their social origins, while donor conceived children do not, meaning that the context and background adopted children need to deal with (being abandoned) differs a great deal from the context and background of a donor conceived child.

The case of disclosure

While gamete donation seems to be a widely accepted method of reproduction in Western society, openness about the conception method is not unproblematic for every single person. Western society still highly values genetic ties, and genes are seen as the primary basis for kinship (Edwards, 2009). This means that families using sperm or egg donation are still potentially subject to stigmatization. There are some indications that stigmatization is slowly decreasing in Western countries. The number of people who disclose or at least have the intention to disclose is rising compared to for instance
30 years ago. The attitude towards gamete donation is also changing. However, at the same time, the number of disclosers is still low which might indicate that people still fear stigmatization. Data on this point are hard to gather; it is not clear at all whether or not social stigmatization has disappeared within Western society. Outside the Western world, there are many communities where donor conception is not accepted (Nuffield Council on Bioethics, 2013). This is for instance the case in Muslim communities where the ‘lineage’, as traced through the paternal line, is considered highly important. In British South Asian communities it is for this reason feared that the family and social environment will reject donor conceived children as soon as the DC is known. In addition, in these families, infertility raises questions about manhood and masculinity (Culley & Hudson, 2007). Consequently, non-disclosure can serve as an important protection for the child and the family against the stigma surrounding infertility and other detrimental effects of openness about the DC (Nuffield Council Bioethics, 2013). The broader social environment is clearly an important factor in deciding whether or not it is best to disclose. This concern regarding stigmatization is frequently raised by parents as a justification for non-disclosure and should not be dismissed without argument (Thorn, 2006; Horowitz et al., 2010).

(c) Psychological risk: timing

The case of late disclosure

Several studies show that some children, in case of late (and (un)intended) disclosure, develop psychological problems due to the feeling of ‘betrayal’. This revelation may lead to long and frustrating searches for the donor or for donor information (Lalos et al., 2007). The impact of late disclosure may be severe. However, we have no idea what proportion of donor conceived children is at risk, since we do not know how many donor conceived offspring find out about their conception method at a late age. It is possible that many more people find out about their DC at a later age but do not have a problem with it. We should keep in mind that the current research on the donor conceived persons’ attitudes towards their DC disclosure only involves biased samples. Individuals who are aware of their DC but do not have a problem with it and did not have a problem with the method or timing of disclosure will probably remain under the radar. Donor conceived people who are angry or discontent are more likely to contribute to websites, networks or internet forums and participate in studies. Moreover, revealing the donor conception, even at a later time, can also have positive effects on the family relationships. In a few cases of accidental discovery of non-paternity in a medical context, it was found that the (unintended) disclosure was appreciated by the parties involved and did not disrupt family relationships (Ravelingien & Pennings, 2013).
The case of early disclosure

Defenders of directive counselling for DC disclosure assume that early disclosure will be beneficial or will at least prevent possible future harm to the child. Recent studies do indeed show that, in case of early disclosure (prior to adolescence), the children appear to accept the information, integrate it into their life story and have positive reactions to the disclosure decision (Hewitt, 2002; Jadva et al., 2009). Nonetheless, possibly negative effects of early disclosure on the child and his or her family should not be overlooked. In Jadva et al. (2009), for instance, some adults who were told during childhood reported that they felt confused, frustrated or upset about being a donor conceived child. We should be careful in considering early disclosure as beneficial by definition.

6.4.2 Condition 2: reaching the goal

Another condition for allowing a breach of the autonomy principle is that the goal of this breach has to have a reasonable chance of success. Advising the parents to disclose the information, does not mean they will actually disclose (Klock, 2013). It is possible that parents feel uncomfortable with disclosure and say that they will disclose to please the counsellor, but never have the intention to actually disclose. The counselling approach is only rarely mentioned in research papers about disclosure decisions of the parents. Visser et al. (2012) reviewed papers that reported on counselling in gamete donation. The review showed that only five studies specified the use of a directive counselling approach pro (early) openness by the counsellor. This was for instance the case in a study by Rumball and Adair (1999), early openness was advised by the counsellor. In this study, 181 of 308 participants completed a questionnaire on disclosure attitudes. Of these 181 participants, 127 had not told their child (minimum one year old) about the donor conception but 98 participants declared an intention to disclose in the future. In another study by Hammarberg et al. (2008) where a directive approach was used with regard to the disclosure decision, 41% of the parents stated that the counselling had some impact on their disclosure decision, with 26% reporting no impact at all.

Although little is known about the counselling approach, most studies show that the majority of heterosexual parents do not plan to disclose the DC to their child with study outcomes ranging from 54% to 81% (Nachtegall et al., 1998; Golombok et al., 2002; Owen & Golombok, 2009). In addition, the intention to disclose is not necessarily the same as actual disclosure. During pre-treatment counselling, a couple might be convinced of disclosure, but the actual decision to disclose might be postponed and eventually abandoned during the life of the child because barriers such as discomfort and anxiety rise (Gottlieb et al., 2000; Nordqvist & Smart, 2014; Klock, 2013; Cook et al., 1995; Daniels et al., 2009). Most of the heterosexual couples who intend to disclose, do not do so
The combination of the empirical evidence on actual disclosure and the uncertain effect of promoting openness, raises doubts about the reasonable chance of success of a directive approach.

6.4.3 Condition 3, 4 & 5: proportionality, necessity and consequences

The following three conditions are treated together, because they all aim at minimizing the breach. In this regard, the following question should be answered: Is advising parents to disclose the information among the smallest breaches possible to achieve the goal of informing children about their donor conception? One smaller breach to reach this goal would be to raise awareness by sensitisation actions, for instance via advertisements, posters and brochures. The “Time to Tell” campaign held in 2006 in Victoria, Australia is an example of such a sensitisation action with the goal of spreading information about the benefits of disclosure and about the donor-linking service. Electronic and print media information was spread, and community education activities were organised (Johnson et al., 2012). This promotion of the donor registers resulted in an increase of applicants for the registers, and an increase in uptake of resources concerning how to disclose from the website.

Both sensitisation campaigns and directive counselling are directive, albeit on a different scale. Nonetheless, there is a difference between both actions with regard to their nature, with sensitisation actions being impersonal and indirect. Parents are not personally addressed and large-scale campaigns can more easily be ignored, thus resulting in a smaller breach of their autonomy. However, due to this impersonal and large scale nature, there is no room for, for instance, personal advice about how to tell. DC disclosure can be a delicate subject to discuss and when openness is promoted, personal advice adjusted to each particular family would be preferable. In addition, the effects of the campaign are unknown in the sense that it is impossible to measure whether more parents disclosed the donor conception to their children after the campaign. The only conclusion that can be drawn is that, given for instance the increase in uptake of resources from the website, there was a need for information. Sensitisation actions, could be proportional even if fewer children were informed about their DC than in case of directive counselling because they also involve a smaller breach of the parental autonomy. However, they still assume that good is done to the children, and this, as we argued above, is uncertain.

Another option to inform children about their donor conception, would be adding the information to their birth certificate (Blythe et al., 2009). This interventionist approach would ascertain that children are informed because the disclosure would not depend on actions of the parents. In this case, the parents’ autonomy is breached more severely than in the directive approach. To justify this, it should be demonstrated - in
line with the severity of the breach – that a high risk of serious harm to the child exists when it is not informed. From the analysis above, it is clear that no sufficient evidence so far is available for even a lesser degree of risk to the child. This means that a fortiori a more severe breach of the parents’ autonomy cannot be justified.

Following the above, one could argue that sensitisation campaigns are preferable to directive counselling since they imply a smaller breach of parental autonomy but they also are less likely to convince parents to disclose. However, the decisive element in the balance will remain the demonstration of the positive effects of disclosure on the child.

6.4.4 Condition 6: impartial treatment of all parties

The last condition prescribes a consistent policy regarding the breach of a principle. The advocates of a directive approach propose a breach of the autonomy of the parents. To fulfil the sixth condition, all parents who have valuable information about the child’s conception should be treated equally. Not only parents using donor insemination should be affected, also adoption parents should be included. In the adoption context, an open policy is already implemented. Parents are stimulated to tell their child about its adoption. Another large group of parents that should be included are the mothers (and fathers, if informed by the mother) in misattributed paternity cases (Ravelingien & Pennings, 2013). Also in this context at least one of the parents possesses, in most cases, valuable information about the child’s conception. Therefore, it could be argued that, also in this context a directive approach pro openness should be applied.

6.5 Conclusion

The aim of this analysis was to investigate whether or not a directive counselling approach is ethically justified in the context of DC disclosure. Although, in general, a non-directive approach is adopted within the context of medically assisted reproduction, some counsellors favour a directive approach pro early openness when it comes to the specific topic of donor conception. To decide whether or not the DC disclosure context can indeed be an exception to the rule, the two underlying principles of autonomy and beneficence should be balanced. To allow a breach of the autonomy principle, several conditions should be satisfied. Following this analysis, two conditions are not fulfilled. With regard to the first condition, so far, the evidence available in favour of promoting openness is insufficient. The risk of non-disclosure should not be
overestimated and the risk of disclosure should not simply be put aside. At this moment, there are no better reasons for advising openness than for respecting the parents’ own beliefs and wishes. Moreover, studies about the intention to disclose show that the desired effect of a directive counselling approach may not have a reasonable chance of success, thus failing the second condition.

Following this analysis, at this moment, directive counselling - whether in favour of disclosure or secrecy - is ethically unjustified. In practice, this means that counsellors should aim to counsel ‘as neutrally as possible’, paying equal attention to the possible (psychological and medical) harms of secrecy as well as of disclosure. Counsellors should point out the possible dangers of keeping a secret on the one hand and disclosing personal information on the other hand, as well as the possible consequences of timing.

6.6 References


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Section 3

Empirical Research
Chapter 7

The basis for parental rights and duties.

Perspectives of couples after gamete donation treatment
7.1 Introduction

Medical developments in the reproductive field have enabled a disconnection between genetic, gestational and social ties. This introduced a variety of non-traditional families that challenged the traditional basis for attributing parental rights and responsibilities. The question of (what should be) the ‘new’ basis of parenthood has been of interest to a number of disciplines. From a psychological point of view, a large number of studies were conducted on the effect of this disconnection on the families’ wellbeing (Golombok et al., 2012; Blake et al., 2014; Turner & Coyle, 2000; Vanfraussen et al., 2002; Brewaeys, 1996). In the sociological and anthropological disciplines, one looked at the changing notions of family and kinship (Nordqvist, 2010, 2012, 2014; Edwards & Salazar, 2009; Edwards et al., 1999). From a philosophical point of view, the question was raised about the moral basis of parenthood and parental rights and duties. Roughly speaking, two approaches have been developed in an attempt to answer this question, a theoretical normative approach and an empirical approach (Ives et al., 2008).

As shown in the introduction of this dissertation (chapter 1), many divergent moral grounds for parenthood have been suggested and defended, ranging from voluntary grounds, to causal, intentional or genetic grounds, with some accounts being monistic and others pluralistic. All these theoretical accounts try to pin down a sound basis for granting parental duties and rights by offering theoretical arguments. Then the theories are applied to the practice. Following the geneticism account for instance, genetic ties are the sole basis of parental duties and rights. This is translated into the argument that donors should take up certain parental duties and rights towards the children who are conceived with their gametes. In contrast, the empirical approach to the moral question of the basis of parental rights and responsibilities does not aim to answer the question with a theoretical construction based on ethical principles. This approach looks into the moral judgements of the people who participate in the practice. For instance, the constructions of biological and social fatherhood by fathers have been explored (Ives et al., 2008; Hargreaves, 2006; Kirkman, 2004; Snowden et al., 1983). One of the findings of Ives et al. (2008) was the distinction between the father-as-carer and the father-as-progenitor. Many of the fathers interviewed did not have contact with their child and those who did, have had to gain the right through court. The genetic link was considered as a unique bond that made a man the real dad in contrast to a stepdad (a non-biological father). However, at the same time, the father-as-carer was valued much more highly than the father-as-progenitor. Being there for the child involved commitment, whereas being the progenitor was considered to be a purely biological
relationship. In evaluating the role of the father, the father-as-carer was considered as the good father.

While the empirical approach provides valuable insights into how people in the field think about moral concepts, this merely achieves a descriptive ethics. Similarly, while the philosophical approach adds valuable theoretical insights, it misses the social context. If we want to apply our moral framework to the real world (for instance, via policy), we need to include the perspectives of the people in the field. A combination can be achieved via the WRE, as explained in the methodology of this dissertation.

In this chapter, we aim to offer new insights into the grounds for parenthood and the basis of parental rights and responsibilities by focussing on the moral views of the people involved in the field. We performed a qualitative study of the opinions and reasoning of couples who used third party reproduction to fulfil their child wish. Via a hypothetical scenario (see further), we investigated their considerations about what is relevant for granting parental rights and duties. The aim of this study is consequently twofold. We want to (1) offer data to contextualize the current philosophical theorizing on this subject and (2) to provide empirical evidence that can be used in support of an ethical argument. In this chapter, an overview and discussion is given of the results of our data analysis. The contribution of these results for the normative framework is discussed in the general discussion of this dissertation.

7.1.1 Parenthood and the accompanying rights and responsibilities.

Parenthood and parental rights and responsibilities are often mentioned together, as if parenthood is the same as parental rights and duties and vice versa. However, this presupposition is open for debate. According to Bayne and Kolers (2003), first of all, a distinction should be made between ‘natural’ parenthood and legal parenthood, with the first defined as grounded in a natural relationship with the child and the second implying rights and responsibilities. They argue that a relationship between both concepts exist. ‘Natural’ parenthood makes someone liable for parental responsibilities and parental rights. However, neither rights nor responsibilities are necessarily granted to a ‘natural’ parent. Custody is for instance not always granted to the natural parents. In addition, natural parenthood is not necessary for being granted rights and responsibilities towards a child. For instance, grandparents can receive visitation rights to their grandchild. However, Bayne and Kolers argue that natural parenthood does indeed generate a likelihood of legal parenthood.

Another discussion in this regard concerns the acquisition of parental rights and responsibilities. One position is that rights and responsibilities are always acquired together. This is called the ‘parental package’ thesis and is defended by Bayne and Kolers (Bayne and Kolers, 2003). They argued that if parenthood generates both rights
and responsibilities, it generates these all together. One cannot be granted merely all the parental rights or merely all the responsibilities. The ‘no parental rights’ thesis and the ‘priority’ thesis contest that assumption. The first thesis argues that parents only have duties, and no rights over their children although they can make decisions about how to discharge the duties they have to the child (Montague, 2000). The argument goes that if parents would have rights over their children, they would have a discretion as to ‘whether or not’ (instead of only ‘how’) they could discharge their parental obligations. Rights would offer the opportunity to disregard the parental duties. The ‘priority’ thesis, in contrast, argues that parents do have parental rights, but that they are subordinate to their duties. Parents have rights over their children because they are bound by duties towards their child (Blustein, 1982). Archard (2010) argues that the terminology used in the parental package thesis should be clearer. A distinction should be made between ‘responsibilities’, which is defined as hands-on, day-to-day rearing of the child, and ‘obligations’, which should be understood as the duty to ensure that the child is adequately cared for, not as a duty to take care of the child himself. Parental rights and obligations are not necessarily acquired together. He argues for instance that a rapist whose victim conceived and gave birth has acquired obligations towards that child but does not acquire rights. Moreover, once acquired, rights and obligations do not necessarily go together. People can lose their rights but keep their obligations to the child. An abusive parent loses his or her right to custody but maintains his or her financial obligations towards the child (Archard, 2010).

7.2 Method

Participants

For this analysis, four interview studies were included. We focussed on lesbian couples post treatment (group 1) and during or immediately after (group 2) treatment with anonymous sperm. We also included post treatment heterosexual couples; one group had been treated with anonymous sperm (group 3) and one group had been treated with anonymous or known-anonymous oocytes (group 4).

The participants of group 1 were the same as in chapter 8. For the participants’ characteristics, I refer to the method in that chapter. The participants of group 2 were recruited in January 2013 based on a list of lesbian couples (n = 17) who started treatment only a few months before the interview took place (which was between November 2012 and February 2013). The sample was completed with two couples who had an ICSI treatment between November 2012 and January 2013. Couples were eligible
when they came for their first child as a couple, were pregnant or had the intention to continue with the fertility treatment, were counselled by the same person who did the recruitment, had the Belgian nationality and were Dutch speaking. Nine couples could not be included due to different reasons: no correct phone number (1), did not call back after receiving info about the study protocol (1), the partner refused (1), too occupied (1), partner was native French speaking (1), overwhelmed by the change to IVF (1), pregnant and not willing to be involved in hospital related issues (1) or refused without an explicit reason (2). The aimed total of 10 couples was reached for this group.

The participants of group 3 were recruited between June and October 2013 based on a list of heterosexual couples (n=31) who were accepted for treatment (and subsequently treated) with anonymous sperm donation between 2002 and 2005 and who met the same inclusion criteria as group 1: Belgian citizenship; Dutch-speaking; at least one child via donor insemination between seven and ten years old at the time of the interview. The couples were enlisted according to the year of birth of their first-born; couples with the eldest children were contacted first. Seven couples could not be included due to wrong phone number (5), being unreachable (1), and no response after receiving limited info about the study protocol on voice mail (1). Twelve couples refused participation because they wanted to keep the method of conception a secret (7), because they perceived it as a closed chapter (1), or because it was a sensitive topic for the male partner (3) or for both (1). One woman refused because she lost her partner and one couple pulled out after initial consent (busy schedule). All the couples that refused participation planned not to disclose the sperm donation to the child. All eligible couples needed to be contacted in order to be able to include 9 couples and 1 individual participant. In this last couple, the man refused participation.

The participants of group 4 were recruited between October 2013 and February 2014, also based on a list of heterosexual couples (n=21) who were accepted for treatment (and treated) with anonymous or known-anonymous oocytes between 2002 and 2006. They met the same inclusion criteria as group 1 and 3. The same recruitment protocol was maintained. Again, all eligible couples needed to be contacted to be able to include

<table>
<thead>
<tr>
<th>Sexual Orientation</th>
<th>Timing interview</th>
<th>Type of donation</th>
<th>Nr</th>
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</thead>
<tbody>
<tr>
<td>Group 1</td>
<td>Lesbian couples</td>
<td>Post treatment</td>
<td>Anonymous sperm donation</td>
</tr>
<tr>
<td>Group 2</td>
<td>Lesbian couples</td>
<td>During treatment</td>
<td>Anonymous sperm donation</td>
</tr>
<tr>
<td>Group 3</td>
<td>Heterosexual couples</td>
<td>Post treatment</td>
<td>Anonymous sperm donation</td>
</tr>
<tr>
<td>Group 4</td>
<td>Heterosexual couples</td>
<td>Post treatment</td>
<td>(Known-)anonymous oocyte donation</td>
</tr>
</tbody>
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six couples and three individual participants. One couple had separated but agreed to individual interviews. In another couple, the partner refused to participate but he joined his partner at the end of the interview. The partner was present during the part of the interview relevant for this analysis. Four couples could not be included because they were unreachable (wrong phone number). Eight couples refused participation for several reasons: wanting to keep the method of conception a secret (4), the woman thought her partner would not want to participate (1), divorce (2) or they perceived it as a closed chapter (1). One last couple pulled out after initial consent. Tables 1 and 2 provide more detailed information about the participant groups. An informed consent form was signed by both partners at the time of the interview. The studies were approved by the Ethics Committee of the Ghent University Hospital.

**Table 2. Participants' characteristics**

<table>
<thead>
<tr>
<th>Group 1</th>
<th>n</th>
<th>Biological mother (34-47)</th>
<th>Non-biological mother (37-52)</th>
<th>Children (1-9)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Sara</td>
<td>Lisa</td>
<td>Mia &amp; Kim</td>
<td>Timothy, Lynn</td>
</tr>
<tr>
<td>2</td>
<td>Mia &amp; Kim</td>
<td>Mia &amp; Kim</td>
<td>Tom, Eva</td>
<td></td>
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<tr>
<td>3</td>
<td>Rose</td>
<td>Liz</td>
<td>Angela</td>
<td>Travis, Rian, Antonio, Milo</td>
</tr>
<tr>
<td>4</td>
<td>Nicole</td>
<td>Angela</td>
<td>Ben, Jessica</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Mary</td>
<td>Monica</td>
<td>Charlie</td>
<td></td>
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<td>6</td>
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<td>Beth</td>
<td>Lydia</td>
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<td>8</td>
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<td>Sandy</td>
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<td>Lexi</td>
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<td>Annie</td>
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<td>2</td>
<td>Emily</td>
<td>Ruby</td>
<td></td>
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<tr>
<td>3</td>
<td>Lola</td>
<td>April</td>
<td></td>
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<tr>
<td>4</td>
<td>Ada</td>
<td>Frances</td>
<td></td>
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<td>5</td>
<td>Myriam</td>
<td>Patricia</td>
<td></td>
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<td>6</td>
<td>Kelly</td>
<td>Marilyn</td>
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<td>Ruth</td>
<td>Tamara</td>
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<td>8</td>
<td>Klara</td>
<td>Bo</td>
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<td>9</td>
<td>Molly</td>
<td>Abigail</td>
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### Group 3

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<td>Brooke</td>
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<td>3</td>
<td>Jessica</td>
<td>Samuel</td>
<td>Sienna, Laura</td>
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<td>4</td>
<td>Amelia</td>
<td>Matt</td>
<td>Sebastian, Gus</td>
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<td>5</td>
<td>Candice</td>
<td>Patrick</td>
<td>Isaac, Joshua</td>
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<td>Harry</td>
<td>Uma</td>
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<td>Oliver</td>
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<td>8</td>
<td>Charlotte</td>
<td>Luke</td>
<td>Daphne, Thomas</td>
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<td>9</td>
<td>Jillian</td>
<td>Oscar</td>
<td>Elaine, Dylan</td>
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<tr>
<td>10</td>
<td>Rebecca</td>
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<td>Ramses, Lorcan</td>
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Pseudonyms are given to protect the privacy of the participants

Years of age, range

### Group 4

<table>
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<tr>
<th>n</th>
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<th>Biological father (36-57)</th>
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<tr>
<td>1</td>
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<td>2</td>
<td>Alexa</td>
<td>Casper</td>
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<td>3</td>
<td>Stella (ex-partner Aiden)</td>
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<td>Cliff</td>
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<td>4</td>
<td>Yolanda</td>
<td>Redmond</td>
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<td>5</td>
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<td>Chad</td>
<td>Lewis</td>
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<td>Melanie</td>
<td>Erik</td>
<td>Savannah, Violet</td>
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<tr>
<td>7</td>
<td>(ex-partner Stella)</td>
<td>Aiden</td>
<td>Cliff</td>
</tr>
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<td>8</td>
<td>Xenia</td>
<td>Raoul</td>
<td>Morgan</td>
</tr>
<tr>
<td>9</td>
<td>Madison</td>
<td>Lucas</td>
<td>Olivia, Shawn</td>
</tr>
</tbody>
</table>

Interviews

Couple interviews were conducted by two psychologists of the research team between March 2013 and February 2014 at a location of the couples' preference: the Ghent University Hospital or their own home. The interviews were semi-structured and lasted approximately 50-120 minutes. They were audio-taped and transcribed with participants' consent. Transcripts were checked for accuracy, first by a team member and then by the interviewer. Pseudonyms were used in order to protect the anonymity of the participants. The interview guides are added as appendices in this dissertation.

This chapter presents the analysis of responses to a hypothetical scenario of a gamete mix-up in an IVF lab that resulted in a baby and three adults with different links to the child: one person with a genetic and a social link to the child (A), one person with only a
social connection to the child (B) and one person with only a genetic link to the child (C). The scenario was used as an elicitation technique to allow an exploration of participants’ views and moral reasoning regarding the grounds of parenthood. It was introduced as fictional and was read aloud while the participants could read along on their own sheet. Several features of the scenario were installed purposely: (1) the child was very young to rule out solutions depending on the child’s own preference; (2) each of the protagonists separately claimed parental rights to enable the consideration of each aspiring parent; (3) the gender (and the names) of the protagonists were not specified to allow for various and unsolicited interpretations with regard to gender; (4) the baby and a (distant) location were named (both fictional) to make the scenario more tangible.

Baby Jeff was born late 2011 to A and B following an IVF-treatment at an American clinic. A and B were overjoyed but their relationship broke down a year later. They parted in friendship and agreed on a week-on/week-off co-parenting arrangement. Later that year, it became clear that a mistake had been made in the lab of the American clinic. A was genetically linked to Jeff, B was not. Instead of the gametes of B, the lab used the gametes of another person (C) who underwent an IVF-treatment in the same clinic. All three parties were notified by the hospital and all three now request parenthood.

Following the assumption of Bayne and Kolers (2003) that parenthood carries both rights and responsibilities together, we posed a general open question about parenthood: ‘What (if any) type of parenthood would you attribute to each of these persons and why?’ To facilitate the discussion on this complex topic, the participants were offered cards with a non-exhaustive number of parenthood statuses and/or parental rights (also blank cards were offered to allow other resolutions) they could give to each of the protagonists: ‘full parenthood’, ‘co-parenthood’, ‘no parenthood, but sporadic contact’ and ‘no parenthood, no contact’. The participants were invited to think out loud and questions were asked based on what they said or did. They were explicitly asked not to base their response on what was legally possible but to elaborate on how they would respond to a situation like this. We hereby aimed at revealing their moral views.

**Analysis**

For a description of the analysis, I refer to the methodology of this dissertation (chapter 4).
7.3 Findings

Below, we describe the elements and criteria considered relevant by the participants as they dealt with the scenario and decided about granting parental status or rights. Quotes and participants’ own wording (including gender specific personal pronouns) are used to support the findings.

7.3.1 Framing the problem

The spontaneous first reactions to the scenario were nearly always related to the challenging nature of the case. “Boy, I sure find that a difficult question” (Frances). Many participants sighed when referring to the troublesome situation pictured in it. However, they dealt with the scenario in an open way, frequently challenging each other’s views and stimulating further reflection. After reading the scenario, participants typically started framing the problem in their own words. A lot can be learned from their guesses and presumptions (e.g. the way they filled in missing facts) and from what they spontaneously mentioned as relevant, straightforward or problematic.

In this phase, most participants spontaneously questioned the decision of the hospital to disclose the mix-up, with many thinking that “the best thing would be if the hospital kept quiet”. Especially those who already had children via DI doubted whether telling was the right thing. Interestingly, most of the lesbian participants specifically questioned the disclosure to C while almost none questioned the disclosure to A and B. Some thought it was better not to inform C because he would be confused or because it would disrupt the co-parenting arrangement of A and B. Several participants initially thought (or wondered whether) C was an anonymous sperm donor. In that case, the interviewer clarified this by pointing at the text of the scenario.

Participants’ first elucidations showed that almost all of them automatically supposed that A was a woman while the other two were men. When further quizzed about gender, it was considered as something that was or ought to be irrelevant, although some admitted that this information could influence how people would deal with a case like this. The bond between a mother and a child was considered “somewhat more significant” than that between a father and a child.

Whilst examining the scenario, many participants revealed their views on allowing more than two parents. Solutions with three parents were sometimes looked into but seldom considered realistic. Often, emotional expressions showed a negative attitude towards the idea, describing it as “bizarre”, “complicated” or even “unhealthy” for the child. One woman described the multi-parent family as a “weird blended family”. Tamara even thought that the fact that Jeff already had two parents should be reason enough
for C not to claim parenthood. Further elaborations largely dealt with the welfare of the child and practicalities of how such a family would be organized. When the three-parent family was considered a possibility, it was based on the principle of justice. Edmond and Yolanda, for instance, took into account that none of the actors had “asked for it” (the mix-up) to happen and that all three consciously chose to have a child.

Several participants talked about the partner of C, as “there were not just three persons involved but four”, albeit not always with a clear impact on the outcome of the deliberation. When talking about the possibility that C’s partner also wanted Jeff, Molly said: “Yes, that one just has to do another [IVF] attempt, you know. Well, sorry, it is very sad for that lady but...”.

Most participants started their exploration by spontaneously pointing to an unproblematic party. They all viewed A (sometimes together with B) as the party whose parental status was not or should not be questioned. Most lesbian couples treated A as an individual party and said that it was “self-evident” and “logical” that A should be granted parenthood. Even if, later on in their discussion, B and C were considered parents, this was never in a similar self-evident way as for A who was “the mother anyway”. Somehow, the mix-up changed B’s and C’s grounds for parenthood while leaving A unaffected. Most heterosexual couples saw A and B self-evidently as parents, hence considering only C to be the problematic party. “In any case, A and B are co-parents”. By considering A and B as a couple, an equal parental status was granted.

JOSEPH: A and B are symmetrical, purely mathematically seen, so they need to get the same.

7.3.2 Preconditions for assigning parenthood and parental rights or responsibilities

In their search for a solution for the problem presented in the scenario, the participants discussed, next to criteria for parenthood (see further), some preconditions. Each precondition can be seen as some sort of goal. Granting or withholding parenthood status or parental rights was not only the result of criteria, it was the result of the combination of the criteria and the preconditions that they wished to be fulfilled. First, the preconditions that we found are explained. The criteria for parenthood are discussed further on.

7.3.2.1 The age of the child and the welfare of the child argument

In trying to determine parenthood, some participants referred to the best interest of the child: “you have to consider the child”, or “you should put yourself in the child’s place”. This was not a basis for a solution but a normative statement about what would be a good
way to solve the problem. For some, the child’s wellbeing was paramount because they considered Jeff “the most important person”. This argument was used especially when dealing with the position and rights of C, whereby the interests of C (who wanted to see his child) were perceived as being in conflict with those of Jeff (who would benefit from the continuation of family life).

In most interviews, it appeared that Jeff’s age, while not directly decisive, was taken into account and used to support several arguments. Jeff’s young age meant that he could not be asked for his opinion. While some thought this made the case more difficult, others said it rather simplified it. Participants who had children sometimes said it was a good thing that the child was too young to realize what was going on. Several participants suggested that Jeff should decide once he was old enough. Mostly, the child’s age was a factor in the precondition welfare of the child. The precondition was used to support an argumentation based on criteria for parenthood (such as the social link or the genetic link). The precondition could be used in two lines of reasoning with very different outcomes for the protagonists B and C. Firstly, it was used in favour of granting parenthood to A and B because “they already raised him for a year” and taking Jeff away would be too disruptive for the child. Secondly, it was used in favour of allowing C into Jeff’s family because Jeff would easily adapt to the new situation as “he was only one”. In this line of reasoning, Jeff’s young age and his lack of comprehension of the situation seemed to open up possibilities that otherwise would not have been there. Jeff’s bond with his original parents (or with B) was not yet very strong and so it would not be too disruptive to diminish the parental roles of A and B in favour of C. In this respect, age was used as an indicator of to what extent the earlier family should be considered as a solidified construction and how well the child was aware of his family and had grown into it.

When C was given no or a very limited status or rights, participants’ arguments were mostly or even exclusively based on considerations about the child’s best interests.

AIDEN: I think it is in the interests of the child that you do not pull apart this world as it has been built.

Interestingly, when these participants had more nuanced positions, leaving some room for (later) contact with C, this was based on the same argument.

MADISON: If the child were to really need it, then try.

In this case, the welfare of the child was used usually in combination with an emphasis on the criterion genetic link: because of this link, C and Jeff would want to know each other and be involved in each other’s life. Thus, granting C parental status and rights would be also in Jeff’s best interests.
7.3.2.2 Distributive justice by allocating parenthood

About half of the couples, especially aspiring parents, considered it relevant to know whether C had children “of his own”. It was part of an attempt to take the context into account. This was considered important, it could “make this into something totally different”. On the one hand, it was used as a predictor for C’s desire.

PATRICK: It just changes the situation, because of the fact that C would not have a child, he will want co-parenting.

On the other hand, it was used as a criterion for allowing C to have contact with Jeff, based on a form of distributive justice.

MAYA: If this one has no children at all and he also has a strong child wish and he knows that her, or his material is in a baby, than he is a little bit entitled to contact.

In contrast, if C had children apart from Jeff, it diminished his right to parenthood over Jeff. This points to an instrumental view of children. Although not spelled out as such, the underlying idea was that Jeff was somehow interchangeable by having other children or that the wish of being a parent to Jeff could be fulfilled by being a parent to other children. So, as a solution, “C could go for another round of IVF”, according to some.

7.3.2.3 Maintaining the status-quo

Several participants indicated that the former situation (before the disclosure of the mix-up) was to be treated as a given. Overall, participants showed a tendency to confirm the given situation. Lola, for instance, argued that the hospital appointed B as a parent just by giving this person a child.

LOLA: I think, well, the hospital offered this dad a child and then I think ‘this guy now has him [Jeff] as his child’, right? Probably registered or so.

Also for another woman, the agreement between A and B should be taken into account.

KATE: See, it had been agreed. Already before, so I think that... it can stay the way it was. Gosh, I would leave it as it was, A and B co-parenting.

7.3.3 Criteria for parenthood

Below, we describe the criteria as used by the participants. These include both known criteria found in the literature and additional criteria. We focussed on the participants’ reasoning and their use of criteria rather than on the outcome of their deliberation. Many criteria were used in ways that appeared entwined.
MONICA: I would say, that person [A] has been engaged in it from the start, and is genetically linked to that child. Then, I think, well, that is the parent, right. Both genetically as from the start, she is the parent, or he is the parent. And those two? Well, too bad this guy [C] was not there from the start but he is a genetic parent and he wants that child. And that guy [B] was there from the start, so he already had a share of that upbringing, thus, to me, he is equally as much a parent, see.

Below, we try to disentangle these accounts while also examine how criteria were linked.

### 7.3.3.1 Gestation and birth

In five interviews, participants briefly mentioned gestation and birth as criteria for parenthood, saying that also for a non-genetic parent it was important to somehow share the experience of pregnancy. This shared experience (which C lacked) was considered an important albeit not essential element. This had almost certainly been influenced by the fact that most participants presumed the mix-up happened with sperm and not eggs, hence making A the genetic and gestational mother of Jeff.

### 7.3.3.2 Causal grounds

Only few references were made to clear causal links. Some pointed to A and B as “initiators” who “in principle, were the parents” but also for C causal links were mentioned to argue in favour of some parental rights “because he also took steps with his wife”. In most of these quotes it was difficult to distinguish causation from intention.

LOLA: Actually, this is still the couple that made the child. You know, in their head, and made the decision ‘we are going to make a child in that way’.

Quotes that leaned more to intention as a criterion were categorised as intentionalist accounts (see below). These quotes stressed the conscious decision that preceded the steps taken.

In their deliberation about the parenthood status of the protagonists, almost all participants mentioned the accidental mix-up as significant. The mix-up was used to support a variety of positions and arguments, often in relation to causation (and responsibility) and/or intentionality (see below). A first line of thought was that participants thought that the mix-up showed that the protagonists were not responsible for the outcome as it was the clinic and not them that made the mistake and caused the existence of this child. One group of participants focussed exclusively on A and B: they did not intend for this to happen and for C “to show up”. Therefore, they were not responsible and should not be obliged to share parenthood with C. The same criterion also applied to C but this was not mentioned by them. Other participants pointed out that also C “could not be blamed” for what happened and, therefore, was entitled to some
(often limited) form of parental status or rights, for instance a right to receive information about the child.

MATT: Because he is entitled to that. It was not his fault that it was switched.

Others recognized this and showed sympathy for C, but considered this element too insignificant to be a basis for granting parenthood, especially when it was C’s “only argument”.

A second line of thought was that, since the mix-up was an accident, “it might as well not have happened”. The gametes “might as well” have been from A and B and “had it not come to light, nobody would have known”. Thus it was ok to simply ignore it in favour of the status-quo. Elly thought that the mistake somehow strengthened C’s claim. Because he had been harmed he had the right to be protected from further harm even if that meant allowing him some form of parenthood status or rights.

ELLY: It’s absolutely not done, that, when you make a mistake like this, you don’t even allow this person to see the child.

However, this line of reasoning was also used (by others) to the benefit of B; for instance when Lola said that, because of this mistake “B’s child was stolen from him” and it “would not be right to steal it even more” by granting rights to C or diminishing the rights of B.

7.3.3.3 Genetic link

For many participants the genetic link was an important element. The genetic link between C and Jeff was expressed in a variety of ways going from C being called the (genetic or biological) father or parent, to C “having something to do with the child”. Many women used several labels concurrently and struggled to label C: “you cannot really call that the father but...” (Clara). For many, a genetic link was (part of) a basis for parenthood but the weight attached to it varied. It appeared difficult to determine what exactly should be granted to C: for one woman a genetic link “clearly meant parenthood” while for others, it meant having a right to at least getting to know Jeff. Many thought C should be allowed at least some form of parental status or rights “because it is his material”, or “because in the end, it is a part of you”.

The fact that B was not genetically linked to the child, although he initially presumed he was, was considered a loss and “a blow for B” (and A). B “lost” his genetic link to Jeff and thereby also lost (part of) his ground for parenthood. Although many participants sympathised with B, for some, the consequences of losing a genetic link were clear and far-reaching. Marie said B, “spoken bluntly, had nothing to do with it” and Liz even though B “was absolutely nothing” in terms of parental status. Anni said that B “should act sensibly now” since “in the end Jeff was not his child”. According to her “B had to consider [the best interests of] the child” while she did not request such an approach from C. These
spontaneous remarks about B’s lack of a ground for parenthood appeared to be rather intuitive and were mostly made in the first instances of dealing with this case. Despite the fact that all couples had one partner who did not share a genetic link with their (future) child, many participants attached a lot of meaning to the genetic link. However, while the genetic link was presented by many as unequivocal, it was also clearly difficult for them to put their finger on the exact impact this should have in the search for a solution. Interestingly, in seeing the genetic link as a ground for parenthood, several non-genetic parents somehow dismissed themselves as parents. This can be illustrated with a slip of the tongue of Oliver. At one point, Oliver said that C had limited rights based on his genetic link although he did attribute parenthood to C in some way. He suggested the following solution for C.

**OLIVER:** So, sending a picture every other month and an email with ‘everything is fine with our child. With your child.’

When Oliver went on to consider how difficult and confusing this must be for Jeff, he dismissed B as a parent based on the lack of a genetic link, despite being in the same situation in relation to his own child.

**OLIVER:** What if that child once realizes that ‘Ooh, I am going to person B. That is my parent.’ No, no, that is not your parent. No, these are. C is your father or mother.

**CYNTHIA:** But no. You know, it’s the same, you are the father of our little June, you know.

**OLIVER:** OK, but... no, I am speaking purely biologically, you see.

In one couple, the non-genetic mother was clearly bothered by the weight attached to the genetic link by her partner, Sara.

**SARA:** [C] is a parent, that’s biologically. Agreed, a mistake has been made, but he is a parent, end of story. He has a right to it.

This was the only couple where such irritations occurred. Over the course of the discussion, the genetic mother, who ascribed full parental status to C and first suggested to exclude B from parenthood, later disconnected the parental status from parental rights. By the end of the discussion, she wanted a full parenthood status for C but only would agree to sporadic contact between C and Jeff while B could be allowed to play the role of a parent devoid of such a status, on the condition that the relationship between B and Jeff remains positive (see below, ‘the social link with Jeff’). Conceivably, while she clearly attached a lot of weight to the genetic link, this unusual resolution was part of an attempt to soothe her partner by making a compromise between her views and those of her partner.
In contrast to what was mentioned above, others thought that the genetic link was “absolutely not relevant” or could not be a (good) basis for parenthood because it was “not worth that much”. To explain this view, Frances and Ada used two arguments: (1) genetic material could be donated and (2) a hundred mistakes like the mix-up could be made, resulting in “a hundred children out there and one could not start co-parenting all of them”. A woman who also followed this line of thought described C as “having nothing to do with it”. For Erik also, a genetic link did not generate rights.

ERIK: Now, we come to the question, ‘what about that genetic material? Is it a reason to contact someone? Is it a, uhm, bond?’ For me, it is not a reason. You see, do we know, all of us, for sure that our parents are our parents? As long as we do not take a DNA-test, we cannot know. And I do not feel an urge to do that. My parents told me that they were my parents. And until today, that appeared sufficiently true (laughs).

7.3.3.4 Social link

When the social link was deliberated as a possible ground for parental status or rights, several participants pointed to C’s lack of a social bond which jeopardized C’s entitlement to parenthood. The participants also discussed this element in relation to A and B who did share this bond, although here, some differences were found between the groups studied.

In the heterosexual couples, the social bond that A and B shared with Jeff and their share in Jeff’s upbringing were seen as fundamental to offer equal parental status and rights to A and B. The social link was considered more important than the genetic link. Therefore, A was not granted a higher status or more rights than B. Very often, this argument was combined with an account of (shared) intention.

For the lesbian couples, however, the social link was generally used to determine the outcome for B but not for A. The latter could imply that A’s case was already firm enough based on the genetic link with Jeff whereas for B this had to be examined. Most participants attached great value to the social link although, in spite of being in a similar situation themselves, not all of them thought this would be a convincing basis for parental status or rights. Molly thought the social link was the most important criterion. She said it would be “hell for B if the child were to be taken from him” only because, “by accident”, “not his cells” were used. Her partner, however, disagreed.

ABIGAIL: Well, he [B] thinks it is his child but it is not his, right. Whatever is inside the child is not his.
MOLLY: Just the cells. But the upbringing that this child already had? You can hardly say to B ‘well, so you raised it for a year but uhm, it is not yours. So, bye bye.’
ABIGAIL: Yes, I think that is a difficult one.
MOLLY: I don’t! (laughs).

The fact that B had spent the first year of Jeff’s life “raising him as his own child”, meant a lot for the majority of the participants. B had committed himself to Jeff’s upbringing, an engagement that was fundamental according to some. The duration of that social contact was significant and, because of that, he had somehow “earned” parenthood and Jeff should be considered “his child”. For others, this social bond was not a (significant) ground for parenthood because it could not outweigh the lack of a genetic link. The social and the genetic link were perceived as two competing criteria with different outcomes for this scenario. Sara, who considered the genetic link the most important element, agreed that the social link meant something, although not as a basis for parenthood. When she suggested that B could be allowed to continue this commitment, she installed a condition: the ongoing good relationship with Jeff:

SARA: But from the moment it goes wrong, or it no longer works for one of the parties, then I think you should not oblige your child to go to someone, in the end, he does not even share a biological link with. Then, what has been, was fine, but at that point, it is finished.

For some, the social link was not important in itself but in combination with an intention. The fact that B “loved the child” and the expectation that this would continue in the future (despite the lack of a genetic link) supported B’s claim for parenthood because he would still want the child.

When combined with intention, the continuation of B’s relationship with Jeff depended upon his reaction since perhaps he would “not want the child any more”. This shows that the disclosure of the mix-up had two consequences for B. One the one hand, his claim for parenthood was weakened as a result of the disappearance of his genetic ground and, in contrast to A’s straightforward case, B’s claim had to be examined. On the other hand, compared to A, B did lose status but gained freedom of choice. So, while the loss of a genetic link was seen as a potential reason for B to end his relationship with Jeff, the loss also allowed him to voluntarily discharge himself from parenthood.

NELLY: When all of a sudden, he hears that, genetically, he has nothing to do with it, he could say ’yes, but you know, it is not mine, do as you please with it’.

7.3.3.5 Intention

The majority of participants referred to intention (to have a baby) as a criterion for parenthood. They also saw the intention of the protagonists as the most important element in differentiating the scenario from a donor conception situation. Their explanations contained many different types of intention: to create a child, to create a child in a specific situation/with a specific person, or to create a genetically related child. Again, most participants’ reasoning was not in compliance with the parity
principle: they did not use this criterion in an equivalent way for B and C. In fact, only few participants noted that both B and C had a similar intention, namely to conceive with their own genetic material.

LYZ: They chose for it, all three of them, you know.
MARTHA: Well no, because C actually has nothing to do with it, right. It was a mistake.

Participants who thought intention was important, pointed at the causal role of intention: “Because it started with that intention” and “because the origin and the wish were here [pointing to A & B]”. For some participants, the mix-up revealed that C did not have the intention to have this particular child (with A) and should therefore not be granted parenthood. His involvement was based on a mistake, a weak basis for parenthood.

SANDY: Because it was initially not intended for that material to be used for A, you know. It was just an unfortunate mistake.

These participants used this argument to deny C (substantial) parental status or rights but did not mention that A and B also lacked this intention (to use these particular gametes).

All but a few lesbian participants thought that B’s intention was more important than his lack of a genetic link. At the time, they said, B made a careful decision to be a parent, acted upon it by going to the hospital, and later fulfilled his responsibilities towards Jeff. They believed this was a clear basis for parenthood, frequently stating that B deserved parenthood more than C.

Many other participants pointed at the relevance of C’s intention: he was going through IVF himself and had a “clear wish to make a child”, and “gave his material with the aim of becoming a father”. However, only few acknowledged that, C had the same intention as A and B and also had acted upon it. C’s intention was mentioned in negative wordings, to show that “he did not consciously choose” to end up in this mistake. C had not given his genetic material in order for A to conceive, unlike a gamete donor, who they thought could definitely not claim parental status or rights. This difference was considered extremely important.

LEILA: But, see, that person did not consciously choose to not have contact with his child or to... This is not a donor.

The fact that this was not done by him but to him gave C some entitlement to, albeit limited, parental status or rights.

Interestingly, for many participants, especially the heterosexual couples, intention was treated differently when it was “a couple’s shared intention” for a parental project compared to an individual intention.
MARILYN: We talk about the individual wish to have a child, you know. Pfff, you start from the individual. But you do it together.

At the time of conception, A and B shared an intention and “chose to conceive a child together”. This shared intention entitled them to an equal share of parental status or rights: “the child was meant for them”. Although C also had the intention to make a child, it was clearly not a shared intention with A.

PATRICIA: Eventually C is someone who also, you know, stepped into the story but not into that story between those two persons and that child.

According to this view, C had the right intention (to make a child) but not with the right partner. This extra requirement gave B the obvious advance over C. None of the participants specified why they demanded this shared intention with A (the parent with a straightforward case).

OSCAR: He [C] has something to do with it, but not in that relationship of those two [A and B]. Those two chose to have a child together.

7.3.3.6 Voluntary acceptance of parenthood

For some participants, the outcome of the dilemma depended upon B’s reaction to the mix-up.

SARA: The question is, B, well, how does B react to the message ‘this is not your child’.

Some even thought that B should be allowed to decide the matter as he desired. Whereas some participants were convinced that B would want to continue his parenthood project with Jeff, others questioned this: he could reject the child as “not his” or “not wanting to have anything to do with him”.

For some, in case C wanted the child, “you could not just ignore him”. In addition to his genetic link with Jeff, C’s voluntary acceptance was required in order to receive parental status or rights. Only for one parent, Sara, C’s intention was not seen as required because sharing genes was enough. Other participants who talked about C’s desires thought this was clearly decisive. Only if C wished so, and on the basis that he was genetically linked to Jeff, should he be allowed some (mostly rather limited) form of parental status or rights.

MARTHA: Well, everything depends on this guy, right? If he says ‘I really want full parenthood’, then they really need to chat, I think.

However, the participants thought it was not self-evident that C would want to be Jeff’s parent: perhaps he did not want the child “because he already had one” (with the right
woman), for instance. Sometimes this seemed like an easy way out of this puzzle or a playful way to escape further deliberation.

LEILA: Perhaps one of them backs off. Then it will be easier [laughs].

7.3.3.7 The relationship with the undisputed parent

Several lesbian (but none of the heterosexual) participants mentioned the (lack of a) relationship between the protagonists as relevant. Two women thought that B was entitled to some form of parenthood because “those two had been in a relationship”. When Anni suggested to create a co-parenting arrangement between A and C, her wife Ysa objected.

YSA: But there is nothing of a relationship between A and C? You cannot… co-parenthood, I think, between two people who completely don’t know each other.

The (lack of a) relationship was related to views about intention as a criterion: some women thought that the lack of a relationship with A would have a discouraging effect on C’ acceptance of a parental role: because it was not “a child with the right woman” and also because “C did not even know the woman”. B’s past relationship with A and their separation were thought to be relevant by some. B’s status was somehow weakened because of that.

JOSEPH: Had A and B still been together, then it was evident, then it was A and B. But now A and B broke up. That’s A, B and C, that’s a triangle. But C and A never had a relationship. That really is a drawback for the baby.

7.3.3.8 Being there from the start

The parenthood project was sometimes described as a story where you could (or could not) be part of from the start. Partly, this depended on your own choice, which pointed to some overlap of this criterion with voluntarism. Rather than the mere duration of a parent-child relationship, they pointed to the continued relationship from the start of this story: those who were “there from the start” or who “had always been there” should be allowed a parental status.

MONICA: I would ascribe full parenthood to the genetic parent. Because, yes because he/she is both genetically… and was right there, fully present, from the moment of birth.

7.3.3.9 Identifying yourself as a parent

Knowing that you were a parent or perceiving yourself as a parent, was sometimes considered a ground for parental status. The fact that B considered himself as Jeff’s
parent, in a way, made him become Jeff’s parent. B “presumed it was his child” and always saw Jeff in that way “so in their mind, and their experience and the way they feel it, it is their child” (Tamara). For these participants, resolving the case merely based on the genetic link would not prevent B from still perceiving Jeff as his child. For them, this was evidenced that, on other than genetic grounds, Jeff therefore still was B’s child. Conversely, not knowing that there was a child out there, for C, could be a reason not to be recognized as a parent.

7.4 Discussion

7.4.1 Thinking about criteria for parenthood

One of the main results of the analysis of the hypothetical scenario was that the grounds for parenthood mentioned by the respondents were supplementary in the sense that many criteria counted at the same time. Moreover, criteria were selected with the aim of reaching a goal, such as the welfare of the child, or distributive justice.

In a sense, assigning parenthood or parental rights or responsibilities can be compared to a slot machine. A particular sequence of criteria and preconditions led to a certain outcome which could be parenthood, parental rights, or explicitly none of these. Criteria and preconditions could be grounds both for attributing parenthood and for withholding parenthood, depending on the combination they were part of. Three criteria described in the literature returned systematically in the participants’ arguments: the genetic link, the social bond, and intention. Especially the genetic link and intention were often the basis of the combinations. For instance, the genetic link was combined with criteria and preconditions such as intention, causation, the welfare of the child or distributive justice. In a similar way, the criterion intention was combined with criteria as a genetic link, causation (for C) or a social bond (for B). A few combinations were fixed. For the lesbian couples, to be an undisputed parent, the combination of a genetic and a social link was necessary and sufficient (this was the case for A). For the heterosexual couples, an intention or a social link in combination with the criterion of ‘commonality’ was necessary and sufficient for equal parenthood (see further).

The pluralistic account presented by the participants differed from Bayne and Kolers’ suggestion (Bayne and Kolers, 2003). For them, a pluralistic account means that several grounds are sufficient to grant parenthood, leading to possibly more than two parents. However, their account does not involve such complex combinations of criteria, and includes much fewer criteria than the number mentioned by the participants.
Arguments undermining their own position

There were substantial differences between participants (irrespective of their own link with the child) in the weight attributed to the genetic link. For the heterosexual couples, the genetic link was considered irrelevant for A and B, while for C, the link was hugely important in the sense that this was seen as a ground for giving this actor parental rights. Also for the lesbian couples the genetic link was considered an important criterion for determining parental rights. One would expect that these couples (who have a one-sided genetic link with their child) would diminish the importance of genetics and emphasize the social bond. Indeed, that idea was found in the entire interview when they were talking about their own situation. However, when they were thinking about the hypothetical scenario, many couples profoundly challenged either their own or their partner’s status. Some couples described a view that, when applied to their own situation, disqualified either themselves or their partners as parents. A discrepancy existed between talking about their own situation and talking about the baby Jeff case. Moreover, most couples did not notice this inconsistency. Only in one couple, this led to irritation in the non-biological mother. However, it could be argued that this discrepancy is not surprising since context has an influence on the moral judgement. “Context” can be defined as a particular set of circumstances that determines what is acceptable and what is not (Walker, 2003). Different contexts can differ with regard to what is considered morally acceptable or not. The difference between the hypothetical case and their own situation was the mistake made by the hospital. According to the participants, this mistake gave C another status than the donor in their own situation. In addition, because of this mistake, the status of the non-biological parent (B) was different than the status of the non-biological parent in their own situation. In the participants’ own situation it was decided beforehand that there would be a biological and a non-biological parent.

A different mind-set with regard to the grounds of parenthood

Another interesting finding was the difference between the lesbian couples and the heterosexual couples with regard to who they saw as the ‘obvious parents’ and who they saw as the problematic party. Most lesbian couples automatically granted maximum rights to A. Granting rights to parents with only one of the two ties was considered much more difficult. In contrast, for the heterosexual couples, the obvious parents were in almost all cases A and B. For them, only C was the problematic party. The lesbian couples seemed to be focussing more on the ties between one adult and the child, while for the heterosexual couples, the commonality (shared intention and social bond) between the partners was considered most important, disregarding the link between each party and the child. Lesbian couples regarded A and B as separate protagonists with each a particular link with the child and the heterosexual couples seemed to
consider A and B as a couple, meaning one unit with an equal relationship to the child. This idea returned when the couples talked about the position of A and B. For the lesbian couples, B was equally entitled to parenthood as A because of their particular relationship (the relationship with the undisputed parent); when the relationship ended, B lost his/her equal position. This was not the case for the heterosexual couples. A and B were put in an equal position because of the shared history with the child. When the relationship ended, B’s position did not change towards the child.

An explanation for this difference between lesbian and heterosexual couples is hard to find. A possible explanation could be a different approach towards third party reproduction by both groups. While heterosexual couples might see it as that ‘the couple’ is going for treatment, lesbian couples might consider it as that the birthmother is going for treatment and the non-biological mother is supporting her. This might be explained by the difference in cause of treatment (medical versus social cause). However, from the experiences of the lesbian mothers it was clear that this was not the case. The lesbian couples emphasised the engagement of both mothers in the ‘project’ of having children. Another explanation might be the different legal situation for both groups. In heterosexual couples, the woman’s husband automatically becomes the father of the child, while this was not the case for lesbian non-biological mothers (until recently). This might create a different perception of B. However, with regard to their own situation, the legal difference between both mothers did not influence their perception of the non-biological mothers as a parent.

7.4.2 Thinking process

Moral reasoning

Looking at the participants thinking process, we found that the participants’ idea about the impossibility of three parents was clearly reflected in their reasoning. The conclusion that three parents with equal rights and responsibilities was not possible in practice was often decided beforehand. During their reasoning about A, B and C, they noticed that if they followed their own arguments (intention to have a child means parenthood), the three adults should be granted parental rights and responsibilities. To avoid that conclusion, a specification was then added. The intention was narrowed down to intention to have a child with A. That way, B could remain parent and C was excluded. One couple concluded that, according to their arguments, all protagonists should be given parenthood based on their arguments, although they did not regard it as a practical solution.

Another finding that stood out in the participants’ moral reasoning was that at times criteria were not used consistently. Certain criteria were for instance applied to one protagonist but not to the other. The parity principle was not respected by the couples.
Bayne and Kolers (2003) defined this principle as follows: “the condition that makes one person a parent should, biology permitting, make anyone a parent.” (p. 225). For instance, the criterion of ‘intention to have that particular child’ was considered relevant for C. Because this criterion was absent, no parenthood status should be given. However, neither A nor B had the intention of having that particular child so the same criterion was not present for A and B as well. The argument was however not applied to them. This shows that people’s moral reasoning is at times not consistent. This should be taken into account when incorporating their arguments into theory. This raises questions about the value of people’s views and the status of their judgements. It, for one, shows that people’s moral judgements should not be given too high an epistemic status and that they should not be taken for granted without critical review. This will be discussed more thoroughly in the general discussion of this dissertation.

**Absent considerations**

All couples reflected on grounds for parenthood and parental rights, with A (and B) often entitled to parenthood and C often entitled to parental rights (more precisely, contact). Their definition of ‘parenthood’ was investigated during the interview before the discussion of the hypothetical case. All couples described being a parent and ‘parenthood’ as having rights and responsibilities towards a child. They often gave examples of nourishment, education and health care. However, we did not elaborate on the definition of parenthood when discussing the hypothetical case. Possibly, another definition would have been given in that context. Next to this parental package view, in most of the cases, parental rights were granted separately (without the responsibilities) to a protagonist (often C). In that sense, the couples’ view matched Archard’s opinion that one can perfectly well have obligations towards a child, without having rights, and the other way around (Archard, 2010). The couples only reflected on possible parental rights. None of the couples mentioned that certain criteria would be the ground for obligations towards the child. The influence of our four cards should not be underestimated in this regard. We offered cards with either parenthood or with separate rights and no separate responsibilities/obligations. Nonetheless, none of the couples reflected on the distinction.

Another interesting finding is that the couples, as they dealt with the scenario, took the perspectives of the three adults into account but only rarely mentioned the perspective of the child. For instance, when they spoke about the social link, they almost exclusively talked about what the child (and the parent-child relationship) meant for the adult (B) but they barely considered this from the child’s point of view. The few couples who did mention the child’s interests, used it as a precondition. The age of baby Jeff in this scenario is an explanation for the minor attention for the child’s
interests. Some couples made remarks about the young age and that, because of the age, the child’s opinion could not be taken into account.

### 7.4.3 Limitations

A first limitation of this study is that the hypothetical case discussions were planned at the end of the interview. This sometimes led to shorter time spend on this issue because both participants and interviewers were tired. Secondly, all findings are the result of moral reasoning about an hypothetical scenario. Caution is needed when making assumptions about how participants would (re)act in real life. Third, partners will have influenced each other’s views. However, a clear advantage of partner interviews is that the partners often quizzed each other’s views thereby stimulating each other to give the question further thought and deepening the conversation, which resulted in richer data (Bjornholt & Farstad, 2012). Fourth, data should be interpreted with the knowledge that four cards with options were offered beforehand.

### 7.4.4 Wider implications of the findings

The aim of this research was to gather insights into the perspectives of people who had used/who were using donor gametes on the criteria for parenthood and parental rights and responsibilities. This information should help to (1) contextualize the current philosophical theories on this subject and (2) to provide empirical evidence that can be used in support of an ethical argument. Therefore, in the following, we sum up those points that can be taken on board by philosophers.

A first point that can be derived from these data is that people take a complex pluralistic stance towards the grounds for parenthood. Almost none of the couples presented one criterion as a basis, on the contrary. Different criteria were used together, with outcomes depending on the combination of criteria and preconditions. Most couples had the intuition that the genetic link with the child was important for parental rights. Two other criteria that are widespread in the literature were inextricably linked to parenthood by the participants, namely the social bond and intention. Next to those three, many other criteria were mentioned. In addition, they took into account several preconditions such as the baby’s age and welfare, or C’s family background. The data showed a complex knot of criteria. It seems that the pluralistic accounts of parenthood fit better with the moral reasoning of the people involved than the monistic accounts, but that the account (as described by Bayne and Kolers) should be broadened with more criteria. Secondly, a shared experience or relationship with the child (shared social bond or shared intentions) seemed to be one of the main grounds for parenthood. This idea of ‘shared history’ is a new criterion that is not present in the
theoretical literature. This finding shows the value of looking into a couples’ relation to the child (the couple as whole), instead of each protagonist’s relationship with the child. This finding enriches the current theories and should therefore be looked into in more detail.

7.5 References


Nordqvist, P. (2012). 'I don't want us to stand out more than we already do': lesbian couples negotiating family connections in donor conception. Sexualities, 15, 644-661.


Chapter 8

Parental (in)equality and the genetic link in lesbian families

Based on published journal article:
8.1 Introduction

As previously discussed, couples using third party reproduction challenge the classic Western notion of biogenetic parenthood since one parent has no genetic link with the child(ren) (Haimes & Weiner, 2001). Parenthood and kinship ties are until today often seen as having a genetic and/or biological basis. One major expression of this cultural norm is the resemblance talk (Becker et al., 2005). Physical resemblances are seen as a proof of kinship and, thus, as a support for the genetic relatedness (Hargreaves, 2006). In a society where parental roles and positions are often determined by genetic ties, these couples have to develop their own view on the importance of genetic ties and social connectedness with regard to parenthood and have to develop other deterministic factors for parental roles.

Studies showed that these couples deal with this challenge in several ways. Sometimes, ‘proof’ of a connection between the child and both parents is created by matching certain characteristics of the donor to those of the social parent (Becker et al., 2005; Burr, 2009; Scheib et al., 2000; Nordqvist, 2014). In addition, these couples compensate for this lack of a ‘full’ genetic connection by privileging social ties and valuing nurture over nature (Hargreaves, 2006; Frith et al., 2012). Narratives about physical resemblances are created and the focus is put on the social bond and its influence on children (Goldberg et al., 2008; Golombok et al., 1997; Jones, 2005; Nordqvist, 2010; Nordqvist, 2014; Vanfraussen, 2003). For lesbian couples, passing on the non-biological mother’s last name to the child appears to create a kinship link between the social parent and the child (Nordqvist, 2012).

In this chapter, the focus lies specifically on lesbian families and the meaning of the genetic link they give for parenthood. The lesbian family is particularly interesting exactly because of the typical family structure which includes a non-biological mother. Being a female co-parent implies two things. First, she has no biological and genetic link with the child(ren) while the biological mother has. Second, she is a female partner and this does not fit into the societal definition of what constitutes parenthood (Vanfraussen et al., 2003). This becomes clear in the constraints of language. In contrast to heterosexual couples, the role of the non-biological mother can be described as “in the netherworld” (Muzio, 1999). The lesbian non-biological mother is ‘invisible’ both linguistically and legally, in Western society (de Kanther, 1996). She needs to define her role as a parent socially, as a care-giver, instead of basing it on biological notions (Dalton & Bielby, 2000). In this chapter, our aim is to investigate how these couples experience one mother’s genetic relatedness to her child(ren) while the other mother
has no genetic link, whether or not they experience this as a difference, whether or not this influences the mothers’ position, and how they deal with this difference. The mother that has a genetic and biological link with the child is referred to as the biological mother and the mother that has no such link is referred to as the non-biological mother.

Ideas about genetics and blood ties are complex and rarely present a watertight logical reasoning. People’s attitudes towards biogenetic ties are not ‘rational’, on the contrary, they are often contradictory and fragmented (Bestard, 2009). In this study we want to carefully map these couples’ attitudes. Investigating these couples’ views on the meaning of the genetic link for parenthood offers a valuable insight into the views of the actors themselves on what constitutes parenthood. Such information can contribute to the ethical literature on the definition of parenthood.

### 8.2 Method

**Participants**

<table>
<thead>
<tr>
<th>n</th>
<th>Biological mother (34-47) (^b^)</th>
<th>Non-biological mother (37-52)</th>
<th>Children (1-9)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Sara</td>
<td>Lisa</td>
<td>Timothy, Lynn</td>
</tr>
<tr>
<td>2</td>
<td>Mia &amp; Kim</td>
<td>Mia &amp; Kim</td>
<td>Tom, Eva</td>
</tr>
<tr>
<td>3</td>
<td>Rose</td>
<td>Liz</td>
<td>Ben, Jessica</td>
</tr>
<tr>
<td>4</td>
<td>Nicole</td>
<td>Angela</td>
<td>Travis, Rian, Antonio, Milo</td>
</tr>
<tr>
<td>5</td>
<td>Mary</td>
<td>Monica</td>
<td>Charlie</td>
</tr>
<tr>
<td>6</td>
<td>Lauren</td>
<td>Jill</td>
<td>Walter</td>
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<tr>
<td>7</td>
<td>Beth</td>
<td>Lydia</td>
<td>Neil, Florence</td>
</tr>
<tr>
<td>8</td>
<td>Kate</td>
<td>Sandy</td>
<td>Kenny, Marilou</td>
</tr>
<tr>
<td>9</td>
<td>Martha</td>
<td>Lexi</td>
<td>Bart, Mathilda</td>
</tr>
<tr>
<td>10</td>
<td>Ysa</td>
<td>Annie</td>
<td>Brenda, Geena, Louise</td>
</tr>
</tbody>
</table>

\(^a^\)Pseudonyms are given to protect the privacy of the participants  
\(^b^\)Years of age, range

The participants were recruited in October 2012 based on a list of lesbian couples (n=42) who were accepted for treatment (and subsequently treated) with anonymous sperm donation between 2002 and 2004 and who met the following inclusion criteria: Belgian citizenship; Dutch-speaking; at least one child via donor insemination between seven and ten years old at the time of the interview. Couples who opted for intra-partner oocyte donation were excluded in order to obtain a homogeneous sample of couples (where one parent has a genetic link and the other does not) with a similar experience.
(donor insemination and parenthood). The women were enlisted according to the year of birth of their first-born. Couples with the eldest child were contacted first. To reach the goal of 10 couples, sixteen women had to be contacted. Reasons for not including the six other couples were: inadequate contact information or language difficulties (5) and no response after receiving information about the study protocol (1). An informed consent form was signed by both partners at the time of the interview. The study was approved by the Ethics Committee of the Ghent University Hospital. Table 3 provides more detailed information about the participants’ characteristics.

**Interviews**

The participants were interviewed at home (n = 9) or at the fertility clinic (n = 1), according to their own preferences. The interview duration ranged from 90 to 120 minutes. The interviews were recorded and transcribed verbatim. Anonymity was ensured by replacing all the names of persons and places by either pseudonyms or a single letter.

The interview was divided into two parts. The first part included open-ended questions about the couples' experiences and perceptions of the treatment. The second part included more specific questions to investigate moral reasoning about certain topics. Topics such as what is parenthood and how is it experienced, the importance of resemblances, the importance of genetic and social ties and questions about the donor were touch upon. With regard to the donor, their opinion on donor anonymity and open identity were discussed, as well as their perception of the donor with specific questions about the rights and obligations of the donor and the selection of the donor. To end this part, a hypothetical scenario was presented to investigate their reasoning about parental rights and obligations in combination with the presence or lack of genetic and social ties with the child. This chapter focuses on one specific question we asked during the second part of the interview to investigate their perceptions about the genetic link: “You (to the genetic mother) have a genetic link with your children, you (to the non-biological mother) do not. How is that for you (to the couple)?”. Other parts of the interview were also included when relevant to our research question. The interview guide is added as an appendix in this dissertation.

**Analysis**

For a description of the analysis, I refer to the methodology of this dissertation (chapter 4).
8.3 Findings

We identified two major themes which offered a better insight into how lesbian couples experience the difference in genetic relatedness and how they deal with it. The first theme represented the general opinion that prevailed in all interviews, namely that the genetic link was not relevant in their family and did not create a difference between the parents. The second theme comprised the couples’ experience of differences due to the fact that one mother was genetically related to her child(ren) while the other mother was not. Figure 1 gives an overview of the themes and subthemes. The size of the circles shows which themes were more present in the couples’ experiences: the bigger the circle, the more present the theme was.

![Figure 1: thematic map](image)

8.3.1 The genetic link as irrelevant: equality between parents

The general view put forward in all interviews was that the genetic link was not a relevant issue for them as parents. The mothers had the feeling that they were equal as
parents and that the presence of a genetic link with one of the mothers did not play a role. Both biological and non-biological mothers shared this general perception and they supported each other in explaining this to the interviewer.

8.3.1.1 Equality as a given

Several couples clarified that they did not make a distinction between each other. They explained it as that it “doesn’t make a difference” or referred to the genetic link as something that did not matter.

NICOLE and ANGELA together: It doesn’t matter.
NICOLE: Not for us.
ANGELA: No.

Along the same lines, one non-biological mother said that she did not feel like she had to put more effort in the parenting because she was ‘merely’ the non-biological mother; she felt as much a mother as the biological mother. While it was often claimed that genetics was irrelevant for their parenting, one couple stressed their equality by drawing resemblances. They gave examples of ways in which the children were like the non-biological mother. Resemblances are typically seen as something exclusive to genetics and blood ties. By talking about resemblances between the non-biological mother and the children, the participants created a link between them that was equal to the genetic link between the genetic parent and the children.

INTERVIEWER: You've also mentioned similarities between you and the children, especially with Angela?
NICOLE: Yes, the spaghetti with brown sugar.
ANGELA: Yes, like even in what they [the children] eat, and uhm, how they talk. Derek is exactly like me when he talks, you know, in his pronunciation and things..
NICOLE: yeah, indeed.

Most couples also described the irrelevance of genetic relatedness by talking about how they perceived their relationship with their child(ren). They both viewed the children as equally ‘theirs’. Phrases such as ‘they couldn’t be more mine’ and ‘we simply have two kids’ were used by both partners. Some couples explained that the decision to have a child was a joint decision and that this was more important than the genetic grounds of parenting. This joint intention not only made them parents, it made them equal parents.

MARY: We made those decisions together back then, and I consider Charlie as much as Monica’s son, as I consider him my son.

This position was generally supported by factual statements. However, some couples also presented equality as a goal, hereby taking a normative position. Lisa and Sara, for
instance, were convinced that parents should be equal. Lisa (non-biological mother) said: ‘If you know in advance, or if - in the back of your mind - you still think it makes a difference, then you better not even start.’ In another interview, it was mentioned that equality was achieved by, for instance, having the non-biological mother take care of the baby (e.g. changing diapers) from the moment he was born.

LAUREN: From the moment he was born...
JILL: ...Getting up in the middle of the night, walking around with him, changing his diapers, yes, everything really.
LAUREN: I tell her ‘this is your moment to bond, go on, go change his diapers!’
JILL: Yes, then I just took part in raising him, we both did that.

8.3.1.2 Confirmation of parental equality

Some couples not only talked about how they viewed the genetic link and its relation to parenthood, they also mentioned the behaviour of others which, according to them, proved their parental equality.

Children

Two couples took their children’s opinion into account, saying that the children did not distinguish between the mothers. They saw their children’s behaviour as a confirmation of their equality as parents.

ANGELA: The children don't give me the feeling that she is the natural mum and that I'm merely the mommy, that-. They don't know any better. Well, of course they know that Nicole is the natural mum, but for me there really is no difference, at all. And I think that's because of the boys. If the boys were to keep more distance from me, maybe then it would be different.

Social environment

Some couples focussed on how they thought the wider social context perceived them and brought up the reaction from other people to support their equality. Four couples explained that strangers in the street saw the non-biological mother as the ‘real mother’ (the biogenetic mother) because of the perceived physical resemblances between her and the children. This was experienced as ‘good’ or ‘nice to hear’ by both mothers, but especially by the non-biological mother. Angela, for instance, said ‘Oh, when they say that they (the children) look like me, you feel more involved.’ Later on she added ‘yeah, it is something extra, like, you know, I didn't give birth, but they do look like me.’ This established her status as a full-fledged parent, because she was put at the same level as the biological mother.
LEXI: And she [a stranger in the street] went like: ‘Oh, is that your daughter?’ And I said: ‘Well, yes.’ But I didn’t mention … and then: ‘Oh, but she really looks like you’. And it was like ‘Oh, okay’ (laughs). And that was a bit, yes… (Lexi and Martha laugh).

MARTHA: … And there I was, completely left out of it. While I’m the one that did all the hard work! (laughing)

LEXI: Yes, that was like: ‘Alright, that’s good’. It was funny, too.

MARTHA: She was so proud!

LEXI: Yeah, I was.

8.3.2 The genetic link as relevant: the experience of a difference

Apart from the general view that they were and should be equal as parents, some experiences of a difference due to a one-sided/partial genetic relatedness were also mentioned in the interviews. Some couples described these experiences explicitly, while others mentioned them only subtly. Nearly all mothers said that they considered these experiences as insignificant and explained that equality prevailed.

Differences were mainly reported by the non-biological mothers, but to a lesser degree also by the biological mothers. The non-biological mothers described more negative feelings, experiencing the genetic link as something they lacked. The biological mothers outlined more positive feelings, emphasizing the genetic link as something valuable they had on top of the social bond.

8.3.2.1 The genetic link as a valuable extra

Three non-biological mothers explained their perception of the genetic link and described how it created a difference between them and their partner. They stated that genetic relatedness was a special feeling they would never experience; it was something on top of the social bond that both mothers had with their children. Monica, for instance, phrased this idea and also explained that the genetic link was something ‘fundamental’.

MONICA: I can't imagine the bond between a mother and her child. You know, I'm convinced that what she [genetic mother] experiences is something quite different from what I have with Benjamin (son). [...] To me, Benjamin is my son, but I mean, yes, the deeper meaning of it, you know. [...] flesh and blood is, yes, I cannot descri-, that bond, it’s like it’s on a higher level, I don’t know how to explain it.

Anni explained that she recognized several physical characteristics (hereditary traits) of the biological mother in the children. She regretted that she would never have such resemblances due to the absence of a genetic link for her.
When talking about these particular experiences, the mothers immediately added that they were rare, that these thoughts only popped up sometimes or in specific situations and that they did not bother them much. For instance, Lydia continued: ‘And then I think ‘oh, well, that’s a pity’, but then I immediately think ‘it is what it is’. Monica clarified that: ‘it’s not that it’s constantly on my mind, no.’

Experiences with regard to the genetic link were also mentioned by some of the biological mothers. In contrast to the non-biological mothers, these experiences were positive. Beth, for instance, described the presence of a genetic link as ‘a nice feeling’ that she regarded as valuable in some way. At the same time, like the non-biological mothers, she stressed that these feelings were rare and that she often forgot that her partner did not have such a link. By doing this, she confirmed the general framework that both parents were equal (cfr. Theme 1).

BETH: It gives me a very good feeling, but, so for me, it's pleasant that, that there is such a bond. But that doesn't mean I experience that, that ... (looks for words), that does not imply that I think ‘and she does not have that bond’, you know. But I do enjoy it myself. It gives me a good feeling, that that genetic bond exists. (short pause). But, I would not, you know, at times I almost think that she also has that [genetic bond]. Like you almost forget that ‘Oh no, that’s not the case at all’.

Two biological mothers also mentioned differences due to hereditary traits. In their experience, recognizing characteristics of themselves in their child was a valuable privilege for the biological mother. Kate, for instance, explained it as ‘special’ to recognize physical traits of her father and other family members in her son.

8.3.2.2 Challenges to parental equality

In the first theme we described how parents found confirmation of their equality as parents in their environment. At the same time, they also mentioned cues that pointed towards the value of a genetic link and consequently also to the difference between them as parents.

Children

Even though parents generally had the feeling that the children approached them as equal parents, some couples reported that the behaviour of the children made them feel unequal. The couples described that their child at times preferred to be with the biological mother. They found an explanation for this particular behaviour in the presence of the genetic link.

LYDIA: Well, yes, sometimes I notice that Florence tends to favour you. And then I think, you know, had she come out of my belly, she might have favoured me because I, because there is a kind of, connection, something, between flesh and
blood. I don't know. So that does cross my mind sometimes when I see her going on 'Oh mummy this' and 'mummy that'.

Again, a nuance to this experience was added.

LYDIA: But it's only, it's only for a fraction of a second that you notice, that you think or feel like that, and then it is gone. Nothing, uhm, nothing special you know (laughs).

Society

Although the couples had the possibility to use donor insemination to start a family, the law only considered the birthmother as the legal mother. If the non-biological mother wanted to be recognised as a legal parent, she needed to adopt her child. According to them, this situation imposed an inequality on the mothers. Not being the legal parent had practical consequences such as not being able to make important decisions in case of illness of the child or in case something happens to the biological mother, and not being able to bequeath one’s possessions to the child. Four non-biological mothers adopted the children to avoid these consequences. However, regardless of this imposed legal inequality, they still felt equally worthy as a mother.

SARA: Imagine that something happens to me, you’re never sure. Also with regard to inheritance, now the children can also inherit from you… and also, what if they are seriously ill and some very important decisions have to be taken, she would never have been able to take them […] that were all juridical things, because, for us, for our feeling, that was not necessary.

LISA: No, that was not necessary.

Donor

Four non-biological mothers perceived the donor, who was a necessary factor to have the child, as another challenge to their equality as parents. In this respect, the choice for anonymous donation was very important. A known donor might have interfered and could have received the status of a ‘real parent’ or the second parent because of his genetic link with the children. The non-biological mothers believed that they would then come third in line. As for the donor, the genetic link was thus suddenly seen as an unconditional right to parenthood. In contrast to their initial views on the irrelevance of the genetic link for the two mothers as parents, this genetic link determined his position towards the child.

JILL: I would say no. Because I always feel pushed back a bit. I don't have a natural...

LAUREN: ... You're afraid of losing your position...

INTERVIEWER: Can you explain what you mean exactly with 'being a step behind'?
JILL: That's why I'm glad we quickly agreed to choose someone anonymous. Because I said 'I'd be one step behind'. (...) imagine, if the father gets involved, imagine that he calls tomorrow and says: ‘Look, I want to meet Andy (son)’, then, yes, I'd be one step behind. Then it's the mother and the father, the natural biological mother and father, so yes, I'm pushed aside. You know, that's how I would feel.

8.4 Discussion

Participants’ meaning making of genetic relatedness seemed to be complex and context-specific. The couples’ experiences of the difference in genetic relatedness turned out to be inextricably linked with how they view themselves as parents, and thus, the development of their parental identity.

Our findings in the first place showed that these couples thought of parental equality as a given. The focus on joint parental decisions and experiences with their children and the social environment were meant to support this equality idea. Previous studies have shown that equality in daily parenting practice is an important factor in the creation of these families (Vanfraussen et al., 2003; Dunne, 2000; Chan et al., 1998). Chan et al. (1998) investigated the division of labour between heterosexual and lesbian families using donor insemination and found that the child-care tasks were divided more equally in the lesbian families. The authors also showed that equality was highly valued and desired more in lesbian families than in heterosexual families. This was confirmed by a study conducted by Vanfraussen et al. (2003) who showed that in lesbian families, both children and parents described the mothers as equally involved as parents. In addition, this study showed similar results with regard to the importance of the absence of a biological link. As in our study, the absence did not prevent the mother from taking and receiving an equal parental role. However, our study revealed a tension in the sense that some couples mentioned equality as a goal, hereby adopting a normative position. This same tension also became clear when one couple described their search for similarities between the non-biological mother and the children in order to establish a balance with the physical similarities the biological mother had with their children. One may wonder why striving and searching for equality is necessary when it is already perceived to be there. Nonetheless, this actively striving for equality is not an exceptional practice in lesbian families. A more technical approach is sometimes used to achieve equality, namely intra partner donation: one woman donates the eggs and the other carries the pregnancy (Pelka, 2009). This technique makes it possible for lesbian prospective
parents to both participate biologically in the creation of a child (Dondorp et al., 2010; Marina et al., 2010).

Together with the equality in parental roles, the one-sided/partial genetic relatedness appeared to be a source of experiences of a difference in parental roles and positions. These experiences were influenced by several factors, which can all be traced back to a difference in genetic relatedness.

First, factors within the family were mentioned. Non-biological mothers talked about missing the genetic link, or seeing the genetic link as an extra bond on top of the social bond. Biological mothers enjoyed having a genetic link with the children, and considered genetic resemblances as valuable. Couples also talked about the (rare) favourising behaviour of the children. Preference for the biological mother in some situations, stressed the idea that there might be a difference between both mothers, a difference that was traced back by the non-biological mother to biological relatedness.

Second, also factors from outside the family played an important role in these experiences. External factors influenced the (perceived) parental position of the non-biological mother. First of all, at the time these couples were in treatment and gestated their children, the law made a distinction between the mothers by only seeing the genetic mother as the legal mother. The non-biological mother had to adopt the child in order to obtain this legal status. If she did not adopt the child, this had consequences in daily practice. For instance, she would not be allowed to sign school documents. Similar findings were presented by Nordqvist (2012). In her study, she showed that the legal status was perceived as a societal factor which imposed a difference on the two mothers. A second external factor that revealed experiences of a difference was the donor. Our findings showed that lesbian mothers found it difficult to deal with the genetic link when it concerned the link between the donor and their children. In the light of the general equality narrative, it is remarkable that some parents would grant the donor an unconditional right to parenthood if he were to turn up. The genetic link between the donor and their children seemed to have another status than the genetic link in their own family. For them as parents, the genetic link was not relevant for parenthood, but for the donor, it was the one sufficient element for claiming parenthood and the associated rights and duties. This suggests that these lesbian parents find genetic relatedness in their family and the presence of a genetic link for an anonymous donor with their children difficult to handle. The same reasoning was found by Nordqvist (2012b; 2014) and Donovan and Wilson (2008) who’s data showed that the decision against known donation was motivated by the threat the donor would form to the equality between both mothers.

Several experiences seem to pop up during the course of these family lives which can be expected to have an impact on the perceived parental position. One could expect that a non-biological mother would feel second-best when the children seem to favourise the biological mother, or when a biological link is highly valued. However, overall, the
couples stressed that these experiences of a difference detracted nothing from the parental equality. These statements can be understood in two ways. One is that the parents indeed did not bother about the difference in genetic relatedness. The few times a difference popped up were considered insignificant and not worth the attention. The second hypothesis is that a difference was in fact experienced and that these statements should be seen as part of their ‘functional’ narrative to deal with the rather uncomfortable experiences of a difference. People construct coherent life stories in order to make sense of their lives (McAdams, 2006). This means that events that relate to the desired outcome are highlighted and events that do not fit the story are minimized or completely left out (Polkinghorne, 2004). The family narrative has to be ‘manageable’ and functions as a way of dealing with complexities and contradictions (Crossley, 2007; Polkinghorne, 2004).

Limitations and clinical implications

First, we should take the context of the interview into account where the participants talked to both the interviewer and the partner. The downplaying of the difference with regard to genetic relatedness with the child(ren) can be understood as an attempt to protect the family cohesion in front of the other mother, and more importantly, not to offend the other mother by telling either positive or negative experiences related to the genetic link. Second, our study does not allow to compare the experiences and attitudes of homosexual and heterosexual families. Parental gender, however, may be a possible influencing factor. As a consequence, our findings only tell us something about the experiences of lesbian parents. It would be interesting to conduct the same research for heterosexual parents to see whether genetic relatedness in this case also triggers experiences of a difference. This study confirms what has also been found in other studies, namely that people’s views and attitudes may change over the years in reaction to the child’s development and the social environment. Counselling should try to make this clear to patients starting treatment with donor gametes.

8.5 References


Chapter 9

Two mothers and a donor: exploration of children’s family concepts in lesbian households

Based on journal article accepted for publication:
9.1 Introduction

Plenty of research has been done focusing on the social and psychological development of children in lesbian families, often in comparison to children growing up in heterosexual families (Biblarz & Stacey, 2010; Brewaeys, 2001; Golombok & Badger, 2010; Malmquist et al., 2014; Patterson, 2006). These studies have shown that there are no significant differences between both groups with regard to child outcomes such as psychological adjustment, development during primary school, and academic achievements. They have also shown that children growing up in lesbian families function well in terms of family identity and relationships (Tasker, 2005; Tasker & Golombok, 1995; Rosenfeld, 2010; Wainright et al., 2004).

Next to these outcome studies, other research has been focusing specifically on the experiences of the children growing up in lesbian families. Several studies concentrated on their experiences regarding the donor conception. Topics such as disclosure, the image they have of and their curiosity towards the donor were investigated before (Jadva et al., 2010; Vanfraussen, et al., 2001, 2002). Vanfraussen et al. (2001) suggested that especially boys were interested in information about ‘who the donor is’. The difference between sexes may be due to the family structure, characterized by the absence of a father, and their search for a male role model. However, Vanfraussen et al. (2003) showed that the wish for information about the donor was mainly driven by curiosity and was not linked to the quality of the parent-child relationship.

Defining family concepts

There is a lack of research looking at how children growing up in lesbian families define family concepts. In contrast, the definitions of children from heterosexual families have been studied extensively. Piaget (1928) was one of the first to ask young boys about their family concept. He concluded that children’s concepts of family were subject to developmental changes. While young children (aged 7 to 8) concentrated on cohabitation, older children (aged 11 to 12) had a broader definition, focusing more on biological relations irrespective of the cohabiting facet. More recent research showed that children have a complex image of family, not so much focusing on biological ties and the nuclear family, but centering more around affective ties (Anyan & Pryor, 2002; Morrow, 1998; Rigg & Pryor, 2007). The focus on such emotional relationships exceeded gender, age and ethnicity (Morrow, 1998).
When it comes to research on how children from lesbian families talk about family structure, two ‘new’ – in contrast to children growing up in heterosexual families – elements come up: the absence of a father and the existence of a donor. In some families, the donor is an abstract concept, whereas in other families, this donor takes a prominent place in the family. Tasker and Granville (2006) asked children raised in lesbian families with a known donor how they defined their network of family relationships. One of the findings was that children had a clear idea about the differences between a donor and a father, although some donors clearly had the role of a father in some of the families. Malmquist et al. (2014) focused specifically on the children’s father concept, and to a minor extent on their donor concept when this was in relation to talk about fathers. They showed that these children described difficulties defining the father concept, one of the reasons being that they did not have a father. When children described the concept, they explained that a father was basically someone like a mother. Particularly interesting is that similar research with children from heterosexual families showed different results, namely that mothers were associated with caring and nurturing characteristics, while fathers were linked to sports and play (Oliveira-Formosinho, 2009). Perlesz et al. (2006) conducted a multigenerational qualitative study towards how children, their lesbian parents and their grandparents defined family. They found that during the development of the child, the understanding of and view on their parents being lesbian, changed, as well as how they handled information about their family structure in their social environment. Fear for being bullied lead them to be more careful in explaining their family structure to peers: being more conscious of the hetero-normative society leads to more secrecy about their ‘not normal’ family.

This study aims to contribute to the literature on family and parental concepts held by children growing up in lesbian families. We explore in detail the concepts the children construct regarding the three actors involved in the building of their families: the biological mother, the non-biological mother and the donor. In comparison with children growing up in heterosexual families, these children have two uncommon concepts they need to understand and define, both for themselves and for their social environment: a non-biological mother and a donor. Because these concepts are absent in the majority of families, it is particularly interesting to study the definition of these concepts in this particular family type.
9.2 Method

Participants

The focus of this chapter is on the lesbian parents’ children. We were able to recruit six boys (aged 9 to 10), and one girl (aged 7). The girl was the sister of one of the boys. These siblings were interviewed separately. All other children had at least one younger sibling who was not included in this study due to the age restriction. The interview with the girl was eventually not included in the analysis because it contained little information. This was probably due to her young age in combination with her shy personality. All children were aware of the anonymous donor conception. An informed consent form was signed by both mothers before the interview took place.

Interviews

The interviews were performed by either H.V.P., a psychologist of the research team or V.P., a bioethicist and social health scientist with experience in interviewing children who was also part of the team. All children were interviewed at their home. In one interview, the child’s parents were present due to practical reasons. The interview duration ranged from 20 to 50 minutes. The interviews were recorded and transcribed verbatim and checked for accuracy. Anonymity was ensured by replacing all the names of persons and places by either pseudonyms or a single letter.

The semi-structured interview consisted of three main successive themes: the family, the conception story and the donor. To start, an elicitation technique inspired by the Apple Tree Family, a technique for mapping children’s view on family relationships, was used (see Tasker & Granville, 2011). A drawing of a tree and small cards in the shape of apples were offered to the child. The tree was presented as the child’s ‘family’. The children were invited to write down their own name on an apple and place it somewhere on the sheet with the drawing. Then they were asked to think about who belonged to their family. They were invited to place an apple for each of these persons on the sheet. They were informed that they could choose freely whether they wanted to place this apple in the tree, or in any other place they saw fit. The results of this exercise were used further on in the interview as a tool for defining the concepts of biological and non-biological mother and as a point of reference for further questions about the child’s family. At the start of the second part of the interview, an apple for the donor was offered only to children who had mentioned a donor in their conception story. The children were asked to put the apple somewhere on the sheet (the tree, or any other place). Based on what the children chose to do with this apple, the concept was discussed. The interview guide is included as an appendix in this dissertation.
For a description of the analysis, I refer to the methodology of this dissertation (chapter 4).

9.3 Findings

Four themes were identified offering insight into the children’s concepts of those who were involved in the building of their family: the biological mother, non-biological mother and donor. The first theme focuses on the children’s experience of their particular family structure within a heterosexual society. The second theme comprises the children’s views on the concept of a biological mother. The third theme explains how the children defined the concepts of the non-biological mother. Finally, the fourth theme describes the more complex definition of the meaning and role of the donor.

9.3.1 A two-mother-family in a heterosexual society

The first theme is related to the societal context in which children’s parental concepts are shaped. Already at a young age, these children learned that their family structure was not common. Especially in the school environment, the children were confronted with questions about their particular family structure. Peers had wondered about the reason for having two mothers instead of a mother and a father, and had asked the child to explain this. Tom mentioned that such questions had been addressed to him.

TOM: Uhm, yes, sometimes they ask if it’s true that I have two mums. Yeah, they think it’s a bit strange. And, uhm, most of them don’t understand how that’s even possible.

Tom was confronted with the exceptionality of his family structure and was called to explain. By describing it as weird and asking for a reason, the peers presented Tom’s family structure as deviating from the norm.

Not only the presence of two mothers, also the method of conception was a source of unclarity for peers. Ben, for instance, described that peers asked him questions such as ‘But, how come you were born?’, since there was no father. Again, such questions made the family structure look different from ‘how it should be’. Nonetheless, he dealt with this by explaining how his family was formed.

In Timothy’s case, simply looking at his social environment made him aware that his family structure was different.
TIMOTHY: I used to think that, uhm, it wasn’t normal to have a dad and a mummy (...) So I thought that gays and lesbians were normal, not the hetero’s.

Int: When did that change? When did you stop thinking that?

Timothy: Well, once I got older, I started thinking about it, because everyone I knew had a mummy and a dad. So I wondered whether I was really normal. But I am normal, a normal boy, who also comes from a mummy and a dad.

The confrontation with the heterosexual social context made him change his idea about what a family was supposed to look like: suddenly his family structure was not normal anymore. He then seemed to find ‘normality’ in the way he was conceived. He transformed his family structure in a certain way to a heterosexual one by focusing on his biological mother and donor, and called the latter ‘daddy’. By labelling the donor as a daddy, his family structure was like everyone else’s. Whether he actually saw the donor as a daddy did not matter at this point. Labelling the donor as daddy was more convenient because it made his family look more normal.

All children mentioned that at some point their social environment confronted them with their two-mother-household. Nevertheless, this did not make them question their two mothers as parents. On the contrary, the exercise with the apple tree at the start of the interview made it clear that both mothers were firmly mentioned together and put in the tree together. No distinction was made between the mothers, they were presented as equal and without considering biological or social relationships. The equality between the two mothers was self-evident and no doubts about the status of one of the mothers as a parent were raised.

9.3.2 The meaning and role of the biological mother

When they were asked to define ‘biological mother’, all children mentioned two characteristics: caring for the child and a biological/causal link. With the biological/causal link we mean that children referred to the idea that ‘I came out of her belly’ or ‘she made me’. It was not always clear whether the children talked about a biological (gestational) link, a genetic link or some kind of causal link. Some children addressed both characteristics, other children mentioned only one. Four children described the caring element in the sense that the biological mother was someone who takes care of you, prepares food, buys clothes and watches over you. In this regard, Kenny defined the biological mother as ‘a personal babysitter.’ Ben addressed the element of care and what can probably be seen as a causal link between him and this mother:

BEN: Yes, uhm, a mummy means that, uhm, actually she should take care of you, because you can’t exist without parents, and without a mummy. […] But, uhm, yeah, the mummy takes care of you, makes your meal, changes your diapers when you're little, ... she made you really, it is important, a mummy.
Three children defined the biological mother in terms of the presence of a biological link. Timothy did this in a descriptive way by saying ‘So actually, your mummy made you.’ The two other children described this in a normative way. The link was considered unique, since they did not share this with their other mother. This made her special. According to Walter, for instance, it gave the mother the status of ‘real mother’. He described his biological mother as ‘my real mummy, the one who gave birth to me.’ By defining the biological mother in this particular way, a difference between the two mothers was created: when there is a ‘real mother’, then there must also be someone that is not real, or less real. This description was in contrast to his initial parental concept. In the exercise with the apple tree, he had presented the parents as equal. Also for Kenny, both parental concepts were not so clear. On the one hand, the biological mother was characterized by ‘care’, which was also the case for the non-biological mother – suggesting similarity - and on the other hand, the biological mother was someone special because of the biological link, which suggested a distinction.

9.3.3 The meaning and role of the non-biological mother

While the concept of the biological mother was defined in itself, the concept of the non-biological mother was defined by all children through a comparison with another parental concept. Three children explained the role and meaning of the non-biological mother by comparing her to the biological mother. For Tom and Timothy, the non-biological mother was similar to the biological mother because she also took care of the children.

TOM: Uhm, yeah, that’s a bit the same [as a biological mother]... but yes. A different name, and she usually does different things, like other work. And yeah, she also takes care of us all the time.

Walter, too, defined non-biological motherhood in reference to a biological mother. However, he defined a non-biological mother through the difference with a biological mother, namely the biological link. The non-biological mother was defined as the wife of his mother, and as someone who had adopted him and had promised to take care of him. The non-biological mother was seen as someone who equally provided care, but who had a different ‘status’. The status of real mother was reserved for the person with a biological link (see previous theme). Again, this contrasted with his initial presentation during the exercise with the apple tree where both parents were described as equal.
WALTER: and mom, that’s actually the wife of mummy. And yes... she, uhm, promised by law or something that she would take care of me too. [...] But she’s, uhm, actually not my real mummy, but yeah.

The father as a reference

Four children used the father figure as a reference to explain the concept of the non-biological mother. They justified the comparison by pointing out similar traits between both actors, which were often common characteristics of what fathers are and do in their opinion. Kenny, for instance, explained that he sometimes labelled his non-biological mother with ‘daddy’ because ‘she’s also really funny, making jokes all the time. Like most dads.’ He added that he did not say this out loud, which could indicate that he did not want his parents to hear it because he expected it to be hurtful or inappropriate. Ben also mentioned humour as a basis for comparison between the non-biological mother and a father. Apart from that, he considered his non-biological mother as someone like a daddy on the grounds of caretaking.

BEN: Uhm, a mom is like, uhm, not really a replacement, but she, instead of a dad, - and together with the mummy – raises you. And she of course is also really nice and, uhm, looks after you, like a dad really.

Travis described his non-biological mother as similar to a daddy on the basis of drinking beer and being equally stern. Two children raised the gender difference and clarified that the non-biological mother and a daddy were therefore not completely the same.

BEN: But a mom is something else still, because she’s a girl too, and a dad is a boy, so that’s actually different.

9.3.4 The meaning and role of the donor: a complex issue

Five children were aware of the man ‘behind the seeds’. The other child, Travis, did not include the donor in his conception story. Consequently, no questions about the donor concept were asked in this interview. Only Walter mentioned the donor spontaneously from the beginning, during the exercise with the apple tree. All other children were offered an apple for the donor later on in the interview after they had mentioned him during their explanation of the conception story.

For the five children who were aware of the involvement of a donor, the donor concept appeared to be complex. Offering an apple for the donor created a possibility to talk about who the donor was and what his position in the family structure was. The place of this apple differed among the children: some children placed the apple next to the apple of the parents, other children made a clear distinction between the top of the tree (where well-known family members were placed) and the trunk (where the donor
was placed). However, they had one thing in common in their explanation: they all made a comparison with daddies. Most of the children also used the term ‘daddy’ to refer to the donor. Nonetheless, it was clear that the children were searching for the right terminology. One child talked about ‘\textit{that mister’}, indicating a distant relationship in combination with a polite way of putting it. All other children used the term ‘daddy’, but showed discomfort in using this specific term. Tom, for instance, initially named the donor ‘daddy’, but immediately corrected himself and explained that the donor was not a real daddy. The donor was differentiated from those men who met the conditions to receive the label of daddy in society.

\textsc{INTERVIEWER:} Do you know where, from whom the seed came, where it came from?
\textsc{TOM:} Yes, from my daddy. I mean, not my real dad. Somebody gives his little seed to the doctor. And then, uhm, yes, that’s with a syringe. I think. And that’s a bit the same then.

Two elements were indicated by the children which explained their difficulties with the terminology, and by extension, the position of the donor in the family structure. On the one hand, donors and daddies have a kind of causal or biological relationship with the child in common. On the other hand, donors do not have a social relationship with the child while fathers have. For most children, the combination of these two elements made it difficult not only to label the donor, but also to understand the donor concept and to point out where in the family structure the donor should be positioned. This became particularly clear when the children were asked to place an apple for the donor.

\textsc{TOM:} Hm, he belongs a bit out of the tree.
\textsc{INTERVIEWER:} [...] Okay, so the mister should be more here, next to the sheet of the paper. And why is that?
\textsc{TOM:} Well, I don’t know him. It is a kind of family, I guess, but yeah, I never see him, I don’t know him.
\textsc{INTERVIEWER:} So, what do you mean when you say ‘a kind of family’?
\textsc{TOM:} Well, it’s a kind of, uhm, well, we don’t know him, but he is a small part. Without him, my sister and I wouldn’t be here.

On the one hand, the donor was thought of as some sort of family member, but on the other hand, the lack of a social relationship excluded him from the family structure. However, not including him at all was impossible, because without the donor, Tom would not exist. This idea of the donor as a progenitor was also mentioned by Ben. For him, the donor was not the same as a daddy because he was unknown. Nonetheless, the donor deserved a special place in the apple tree.

\textsc{BEN:} Yeah, the ground is hard and colder. The mister really doesn’t belong there. And in the crest it’s nice and warm. And to me, life has the same meaning, that’s
life, from, our trunk. And, he could also have a place near the roots, [...] it is because of the roots that the tree can live and, it is because of him that I live, and my sister too, and our family.

Timothy too placed the donor in the trunk of the tree. Both children created the same metaphor to show that the donor was a necessary condition for them and their family to exist, but that this did not make him a member of the family.

For Timothy and Kenny, the social relationship predominated in attributing a role to the donor and therefore, he was not considered part of the family. For both children, if there were to be a social relationship with the donor, that would change his status. They explained that, if the donor were known and present in their lives, he would be a daddy. The combination of the two elements would make the donor a father. For Kenny, the donor would then be positioned next to his biological and non-biological mother. He said that if the donor were present, then ‘that would be a daddy. Then I would have a mummy, daddy and mom.’ Timothy added an extra condition. He said: ‘If my mom wasn’t here, then of course I would call him daddy. But now I would just name him by his first name.’

For Walter, the lack of a social relationship did not matter. For him, although the donor lived in another country and was not known, he was his daddy. First of all, he introduced him spontaneously in the interview as his daddy. While he was explaining having a biological and non-biological mother, he added ‘And, then there’s my daddy. But I don’t know his name. Because we never knew him, he lives in Denmark.’ In talking about the donor further on in the interview, Walter repeatedly referred to him as his daddy. When Walter was asked to place the apple for the donor, he put it next to the apples for his mothers. He explained this action simply by saying that the donor was his father. Two reasons for this comparison could be found. First, it appeared that for Walter, the fact that the donor had a biological relationship with him, was reason enough to consider the donor as a daddy. A second explanation can be found in the birth story that his mothers had told him. For his mothers, it was a conscious choice to introduce (and label) the donor as a daddy. It is likely that this contributed to Walter’s reasoning and word use.

9.4 Discussion

Defining family-specific concepts through hetero-normative references

As part of a heterosexual society, these children had been confronted with the exceptionality of their particular family structure. Especially peers tend to ask questions about the two mothers and the conception method (Vanfraassen et al., 2002). The
children were urged to think about the meaning and role of the three actors who were involved in the creation of their family, and particularly about who the non-biological mother and donor was, and how these actors related to other family members. The first striking element in the definition of these two concepts was that all children referred to the hetero-normative mother and father concept. One interpretation is that the children looked at society (particularly at their peers) and found no immediate model for their non-biological mother or donor. In contrast to the concepts typical for their family structure, the concepts ‘mummy’ and ‘daddy’ were clear: everywhere they looked, they found examples of mothers and fathers. To explain their own family concepts, they fell back on these two more familiar concepts. The non-biological mother was defined by referring to either what is known as a ‘mother’ in society, or by referring to the father concept. Malmquist et al. (2014) found that children from lesbian families defined fathers as similar to mothers. One of the explanations the authors gave to these particular descriptions was that such children’s images of daddies were vague. Therefore, they used “a more familiar maternity discourse” (p.130) in order to define a ‘daddy’. This could also be the case for the non-biological mother: the more familiar mother-father discourse was used to define their non-biological mother.

In a similar way to the non-biological mother concept, the donor was defined through a comparison with the more familiar concept of ‘daddy’. For defining, naming and positioning the donor in the family structure, the father concept appeared to be the closest concept to make a comparison with. The donor namely gave seeds to one of the mothers, and the child himself was the result. In this regard, a donor is very similar to a father. However, in this comparison, difficulties arise. The lack of a social relationship is a major difference with the father concept, a difference that is not present in the definition for the non-biological mother. The findings show that the children have difficulties with defining the concept exactly because of this opposition between ‘progenitor’ and ‘unknown’. This difficulty is also reflected in the search for a correct label for the donor: the term ‘daddy’ was frequently used, but most children were clearly uncomfortable using this word because it did not cover the subject. Some of them alternated this term with ‘that mister’ or ‘that man’. Also Malmquist et al. (2014) found a complex balance between the use of the word ‘daddy’ and other names such as ‘seed daddy’ or ‘that man’. The authors concluded that the labelling by the parents probably has a huge influence on the image the children create of the donor. However, most children’s parents in our study did not label the donor as ‘daddy’. They used terms such as ‘that friendly man’, or ‘the man who gave seeds’. The children themselves labelled the donor as ‘daddy’, which indicates again that ‘daddy’ for them seems the best available term to describe what a donor is.

Another striking element in the definition of the donor was mentioned by two children. The donor was differentiated from a father because of the current lack of a social relationship. However, if the donor were to be known or present, his status would
change from ‘unknown man’ to ‘daddy’. This confirms the fear of lesbian parents about using a known or identifiable donor. The parents’ fear is that a known donor would become the second parent, and that the non-biological mother would come only third in line (Nordqvist, 2012). Two children mentioned that the position of the donor would change when he would be known. This finding indicates that there might be some ground for this fear.

Equality and difference between the two mothers

Most children saw both mothers as equal parents, without considering the difference in biological ties. They all made this initially clear by mentioning both parents together during the exercise with the apple tree. Some children confirmed this equality during their descriptions of the non-biological mother by describing her role in terms of what a biological mother was. In emphasizing similar characteristics and activities, equality was installed. Also the definitions of the non-biological mother in terms of a daddy can be indicative of considering the two parents as equal. A father is generally seen as a parent equal to a mother. Another explanation could be that children from lesbian families do not gender differentiate between parents (Malmquist et al., 2014). The distinction between a father, a biological mother and a non-biological mother might not be as strict in their experience. In this regard, it should be kept in mind that all findings are the result of specific questions that were asked during the interview. The distinctions between the mothers might be artificial, because they were asked about the concepts separately and in a specific order. The concept of a biological mother was discussed first, and the concept of the non-biological mother was explored afterwards. Nonetheless, by focusing on the concepts separately, valuable information was shared that would not have been discussed without this specific focus. These findings show that aside of similarities (which were presented as self-evident), differences between the mothers were also mentioned. Two children mentioned their mothers together in the exercise with the apple tree, and presented them as ‘my parents’. During the discussion of the individual concepts, however, distinctions arose. For Kenny, equality and difference in parenting status went hand in hand. The parents were equal, although the biological link made the mother special. Walter made a clear distinction during his discussion of the individual concepts. He described the mother with a biological link as the real mother, and the non-biological mother as the mother’s wife who promised to take care of him. The biological link was therefore seen as an unconditional right to parenthood, and as intrinsically more valuable than adoption. His story might be interpreted as contradictory and confusing. However, it is not uncommon for children to say one thing at a certain point and something else at a later moment. People’s reasoning about blood ties are complex and rarely follow watertight logical reasoning (Bestard, 2009). In this regard, it is perfectly possible that Walter and Kenny believe that
their parents are equal as well as different, and that the biological link is simultaneously special and irrelevant.

**Limitations and clinical implications**

Similar to the remark about the structure and sequence of the questions about the mothers, it should be noted that the information gained about the donor in relation to the exercise with the apple tree resulted from offering an apple for the donor. The findings are also based on the opinions of boys only. Gender differences may translate into differences in understanding kinships roles with girls generally having a more sophisticated view on relationships (Borduin et al., 1990). Lastly, although rich information was found in these data, we should keep in mind that this study involved six children.

Apart from these limitations, valuable findings that contribute to the literature about family structure and the children’s view on concepts as biological mother, non-biological mother and donor are presented. First of all, we found that the mothers were seen as equal parents and biological links are not taken in consideration. Secondly, the two family structure-specific concepts ‘non-biological mother’ and ‘donor’ were defined by looking at the hetero-normative concepts of ‘mummy’ and ‘daddy’. For the concept of the non-biological mother, this worked well. For the donor, more difficulties were described. This comparison turned out to be complex and confusing due to the conflict between the role as a progenitor and the lack of a social relationship. Considering the clinical implications, this study shows that children in this specific family context might find it difficult to define their donor and to situate him in or outside their family structure. Confusion may arise about the difference between the donor and a father, and explaining or comparing the donor in terms of a daddy adds to this difficulty. It might be relevant for counsellors to adopt this insight in their counselling session with the parents about disclosure to the child.

### 9.5 References


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Section 4

General discussion and conclusion
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General discussion and conclusion
10.1 Integrating normative and descriptive research

The aim of the project was to add new insights to the literature on social and genetic parenthood through an empirical bioethics approach. This approach aims at contextualizing normative theory by combining moral theory and empirical data (Musschenga, 2005). Real-life experiences are used to inform ethical theories. In the normative section of this dissertation, normative analysis and empirical data available in the literature were combined in the sense that empirical data were used to support and clarify the normative analyses. The existing data helped us to come to a normative analysis on the right of donors to information and on the justifiability of a directive counselling approach on sharing the donor conception. In the empirical section of this dissertation, we analysed the empirical data we collected ourselves. We gathered insight into families’ experiences with a one-sided genetic link (the lesbian parents), the positioning and meaning of the donor (the children) and couples’ moral grounds for parenthood (couples’ views on the hypothetical scenario). The value of these studies lies in that they offer an insight into the real-life moral reasoning of the people who deal with social and genetic parenthood every day. These data can be used as background information to inform normative theory.

The ethicists’ task

When we want to integrate our empirical findings into a normative framework (via for instance, the WRE), the question arises of how we can move from the empirical data to normative conclusions. One of the steps in that process involves the evaluation of people’s views. We should keep in mind that the opinions and moral judgements of the actors might contain contradictions or might be biased. It is the task of an ethicist to review these judgements and select what is described as ‘well-considered’ judgements in order to confront these with already existing rules and background theories. Exactly this process improves the credibility of the integration of empirical data. According to De Vries and Van Leeuwen (2010), it all has to do with identifying non-biased moral judgements. To successfully select such judgements, ethicists should be open to a large variety of moral experiences, they should gain a relevant moral sensitivity to the subject and gather moral experiences of people in the field until saturation is reached. An example of such a biased moral judgement can be found in the analysis of the couples’ views on the hypothetical case. An inconsistency appeared when an argument was used for protagonist C (he was not granted parenthood), but this same argument
was not used for the other protagonists A and B, while the argument also applied to
them. The inconsistency might be explained by a bias: the couple might identify with A
and B, therefore protecting those protagonists from anything that would block them
from obtaining parenthood. This is not the only example of a biased moral judgement.
In a sense, all judgements made by the participants can be expected to be biased. They
all are part of a specific situation which influences their judgements: participants used
an anonymous or known donor, are (non-)biological mothers or fathers, are part of a
lesbian or heterosexual family,… A critical stance towards empirical data when used as
background information for normative theories is thus appropriate.

A valuable contribution

Empirical data can contribute in several ways to normative theories (Musschenga, 2005).
One such valuable contribution is that empirical data offer an insight into the actual
moral opinions and reasoning patterns of the people involved in the practice. One of the
things that became clear through the interviews with the lesbian parents was the value
of having an anonymous donation system in Belgium. This was described via moral
judgements on the rights of the donor (he had none), their view that contact with the
donor should not be possible and that the child should only receive non-identifying
information about the donor. One of the functions that can be linked to these moral
judgements is the protection of the non-biological mother as a parent. These findings
should be treated cautiously since we recruited parents who opted for anonymous
treatment (assuming that they knew that known donation was possible). We miss out on
the people who sought treatment elsewhere because they did not accept anonymity. In
that sense, our data are biased. Nonetheless, in light of a rising trend towards open-
identity donors, it is interesting to look into the moral reasoning of the people who
choose for an anonymous system.

A second contribution of empirical data is the identification of relevant issues that
were not present (or largely underestimated) in the purely normative analysis.
Examples of this can be found in the analysis of people’s views on the grounds for
parenthood and parental rights and responsibilities. The empirical data we gathered
showed that the moral grounds that were considered relevant by the couples were
much more complex than the grounds described in current normative literature.
Moreover, a new moral ground was introduced by the couples: the commonality in
intention or social bond is not present in the normative literature as a ground for
parenthood.

Exactly in these ‘encounters with experience’ lies the value of integrating empirical
data into normative work: data confronts the ethicist with real life situations and the
impact that certain ethical frameworks can have on the lives of people (Ives and Draper,
Integrating the views of actors in the field can result in the inclusion of voices that might otherwise be left out.

10.2 Sharing information: the unanswered question

The discussion on information sharing is complex, but this should not be surprising. In this particular context, the interests of parents, children, donors and professionals are involved, leading to two major discussions: the secrecy and disclosure debate on the one hand, and the anonymity and identifiability debate on the other hand. In the literature, there seems to be a one-sided focus on the rights and interests of the child, and an accompanying one-sided focus on the importance of openness and open-identity systems. A child born via gamete donation never had a choice in the decision to participate in this practice, while donors and parents did. In addition, a child is a vulnerable human being that is not able to speak for itself. A child cannot protect his or her own autonomy. Due to this diminished autonomy, they are entitled to protection (Klitzman, 2012). In the UK’s Children’s Act (1989, section 1) it was noted that the child’s welfare should always be of paramount consideration. Hereby, the child was elevated to a higher moral status than other human beings. Today, this allows interventions on parental decision making, such as fines for taking children out of school in term-time for a holiday. While in general parents still autonomously make the decisions with regard to the child, a shift can be noticed towards an emphasis on the child’s welfare. Even though serious consideration to the interests of the child is understandable, it should not lead to a neglect of the other parties. As already discussed in the introduction of this dissertation, the interests of all parties should be heard in order to reach a balance. This balance might not lead to an equal distribution of rights for all parties in the end, but all parties should at least be considered equally.

Balanced criteria for all parties

In chapter five, we argued that a right (to information) should only be granted when a need exists for what the right offers, a mere desire is not sufficient. For instance, empirical data showed that donors were curious about or had a desire for certain information about their donor children, such as medical information, an extended profile or information about the donor children’s wellbeing. We argued that some of the information that was desired, was not a need (for instance, an extended profile). Therefore donors should not be granted a right to that information.
If we use this criterion of ‘need’ to grant a right in the donors’ case, it would only be fair to apply the same criterion to donor conceived children. Similarly as in the donors’ case, we should differentiate the children’s desires and needs. Of course, it is possible that based on this criterion, children are justified to receive more information from their donor than their donor from them. While the outcome of the analysis should be no means be the same for all parties, the criterion to grant rights should.

An example of information that is increasingly being claimed to be a right for donor conceived offspring is identifying information. Nonetheless, we know from studies that children are interested in such information mainly out of curiosity (Jadva et al., 2010; Vanfraussen et al., 2003). This suggests that some information that is described as the child’s right at this moment, is not based on a need. Further research on the needs and desires of all parties should be conducted in order to grant the information each party is justified to receive. An analysis of the current arguments in favour of granting information to donor conceived children should be made in order to determine which criterion is used and whether or not this criterion should be revised.

Due to the lack of sufficient empirical evidence, directive advice to parents to either disclose or to keep it secret to the child cannot be justified. Nonetheless, counsellors do have a responsibility to advise parents in what they should consider. That way parents can make an informed decision. Following Appleby et al. (2012), three types of considerations should be communicated to be taken into account by the parents: medical welfare, family welfare and rights. The medical welfare involves considerations about the child’s interests in its genetic make-up in relation to medical risks. The family welfare involves considerations concerning the welfare of the biological and non-biological parents, and the siblings in relation to disclosure. With regard to the rights, parents should be encouraged to reflect upon their views on their child’s rights (for instance to be informed) and their own rights (for instance to keep the information private). More specific considerations such as timing of disclosure or the impact of disclosure on the extended social environment should also be discussed. Overall, we should accept that at this moment, no conclusive advice about disclosure can be given. The preferable option is the option that is chosen by the parents.

This is not the only question we have no answer to at the moment. Also with regard to anonymity we should be careful about which systems we implement. The future has yet to show the effects of an open-identity system on the donor children and their families, and on the donors and their families. In the UK for instance, the entitlement of donor conceived offspring to receive identifying information about their donor will not come into effect until 2023 since the open-identity system was installed in 2005 (Freeman et al., 2012). Caution should thus be maintained when anonymity is abolished.
and an open-identity system becomes the only option for parents. It could be argued that parents should be respected in their autonomy and be able to choose for themselves. In a double track system, both parents and donors can choose to opt into an anonymous or identifying system.

One could argue that policy should wait for the scientific evidence before applying a certain system. However, the precautionary principle cannot be applied in this context (Pennings, 2012). Policy cannot wait for the scientific evidence. A ‘catch-22’ would arise: we can only decide upon questions following from the donation practice (e.g. disclosure, open-identity) when we have scientific evidence about what the best option is, but we cannot obtain this evidence because we cannot implement certain decisions as long as we have no evidence. Scientific research should thus be conducted in order to be able (1) to make decisions about future consequences rising from the practice and (2) to evaluate the existing policy and review it if needed.

One interesting question then is whether parents should be forced into one system even when sufficient data become available on for instance the impact on the wellbeing of the child. Imagine that conclusive data are found which show that psychological harm is done to children conceived with an anonymous donor. If as a consequence of this finding, anonymity is abolished, only the interests of the children are taken into account. However, moderate harm to the child might not outweigh a strong violation of the autonomy of the parents. A balance would be more appropriate with parents being able to make the deliberation themselves, even if this means that the decision is not completely in the interests of the child. This happens all the time; divorce is a good illustration.

10.3 Building a family through gamete donation: dealing with the unfamiliar.

An unfamiliar third building block

Building a family via gamete donation means dealing with the donor, not only at the start of the treatment, but also years after treatment when for instance the conception story is explained and children start asking questions, or when physical characteristics appear in children that do not match family members. The donor is an essential element in the building process. Without the donor, these families would not exist. An interesting dynamic occurs when the donor is deemed a fundamental building block, but is considered irrelevant when it comes to parenting the child. Both studies on the lesbian families (parents and children) show such a dynamic. For the children, this
became clear through their struggle with terminology. The donor was seen as a party that made their family possible. In that sense, a special status was granted. However, this special status conflicted with the unimportance of the donor during the children’s life. The donor as a necessary building block seemed to lead them to the term ‘dad’, but this word conflicted with the actual status. For the parents, an opposite duality became clear through the struggle of the non-biological mother with the position of the donor in relation to her own position as a parent. While the children pictured the donor as an important person for the creation of their family and as an irrelevant person in their family at the same time, the non-biological mothers saw the donor as an insignificant (but necessary) building part who could claim parental rights if he would turn up. They described the donor as if he could be the second parent, and they would become third in line. Interestingly, this idea was also found in the experiences of some children. Two children positioned the donor as a mere creator, not as a father. However, if this man would turn up, he would be given the position of a father. An important difference between the children and the parents was that the children would see him as an equal parent to both mothers, while the non-biological mothers would see him as better positioned than themselves.

Often the parents are treated as a unity in discussions and research. In this dissertation, I also considered the parents as one party. However, our findings show that differences in experiences of biological and non-biological parents can be present and that it might produce richer findings when the parents are seen as separate parties. The experiences of the non-biological mothers seemed to differ greatly at certain points from the biological mothers with regard to the donor. The distinction applied to the status of the parent, with non-biological mothers as the ‘weaker’ party in the sense that they experienced a threat, while biological parents did not. Although not relevant in all discussions, in psychological research this distinction might lead to new insights into the dynamics that occur in families using gamete donation.

An ambiguous position towards the genetic link

The studies on the lesbian families (parents and children) showed an ambiguous position towards the importance of a genetic link. Even though the social ties were described as much more important than genetic ties, at times, it became clear that the genetic link was considered essential. For the parents, experiences of the donor as a hypothetical threat seemed to show that the genetic link was seen as an irreversible, powerful bond that put the donor in a special position towards the child. The genetic link was not only valued in relation to the donor. Some non-biological mothers also explained experiences of a difference due to a one-sided genetic link. Some children explained a similar idea with regard to the one-sided biological bond. They described that bond as more valuable than the social bond. The struggle with the importance of
the genetic link also became clear from the analysis of the hypothetical scenario. That study showed that for most couples, the genetic link was highly valued for protagonists A and C as a basis for either parenthood or parental rights. At the same time, the genetic link was considered irrelevant for protagonists A and B.

The ambiguous status of the genetic link was a recurrent theme throughout the studies. It illustrates the contradiction in the practice of gamete donation. The genetic link is downgraded and social bonds are presented as the sole relevant ties, but at the same time, the genetic link seems to be of the highest importance. For some people, even though they opt for gamete donation, genes and genetic bonds are still granted a special status. In a sense, this is actually not surprising. In most cases, people who choose gamete donation consider a biological link with their child important (Murray and Kaebnick, 2003). Often, people start medical treatment with their own gametes to evolve into treatment with donated gametes when a partner’s gametes turn out not to be eligible for conception. Gamete donation is after all a practice that offers the closest solution to having a genetically related child when natural conception fails. In that sense, it is ‘logical’ that a duality exists. Trying to convince people that genes are ‘just’ genes and that a child is raised by its residential parents seems to fail to recognize the parents’ concerns. Acknowledging that a genetic bond might have a special meaning does not need to endanger the practice of gamete donation. Not only parents might be ambiguous about the importance of the genetic link, also for donor conceived children such a duality might exist. The genetic link might be downgraded to recognize the non-biological parent, but at the same time, children might have physical, personal or medical characteristics of the donor which highlights the importance of the genetic link. A clinical implication is that counselling sessions should integrate this discussion and point out this duality to aspiring parents in order to prepare them for possible conflicting feelings and experiences for their own and their children. This also has implications for policy. The ambiguity in couples’ views on the genetic link shows that the trend towards an open-identity system where the donor and child have the possibility to keep in touch, might not be the best system for everyone. The anonymity creates a distance between the donor and the family and protects them from the possible threat the donor might pose. By minimising the information about the person that is genetically related to the child but is unwanted in the family, parents and children are able to deal with the situation.

An unfamiliar future: long-term impact

Gamete donation is a long-lasting process that starts with the decision to use gametes and evolves over time. Some people, such as lesbian couples, know in advance that they will need to appeal to gamete donation if they want to have genetically related children. Other people need to get used to the idea. Either way, people most likely accept the
consequences (e.g. one-sided genetic link) before starting treatment. Counselling before and during the treatment helps people to consider those consequences and points out possible difficulties they will be confronted with later in life, such as the disclosure decision.

However, while couples might initially come to terms with the consequences, this is challenged when the child enters their lives and grows up. Parents are confronted with the consequences in real life. This may change the way they perceive the donation or the experience of living in a donor family. Our studies showed for instance experiences of a difference due to the one-sided genetic link, or due to children’s behaviour towards the biological mother. While the genetic link was seen as irrelevant for parenting and one’s parental status, children challenged this view with their behaviour. Another example is the changing disclosure attitude. The disclosure decision is discussed during the counselling session(s) that take place before or during the treatment. However, attitudes can change and new questions and uncertainties might rise as the child grows up. Discussing disclosure options without already having the child and without knowledge about how the child would react to certain types of information, is rather difficult. It is not surprising that attitudes change years after the initial counselling session due to the development of the child and other environmental influences.

The long-term impact of the treatment should not be overlooked. Questions and issues that were dealt with at the start of the treatment during counselling might come up again. The emphasis of the current counselling practice seems to be on pre-treatment and during treatment sessions. However, we should be aware of the possible need of counselling many years after the treatment.

10.4 Social acceptance

In Western society, medical help to fulfil a child wish is no longer a secret practice. In the scientific field, a lot of medical and psychological research is being conducted and a rich ethical debate accompanies the developments. Also outside the scientific world, more popularising debates are often held concerning the social, psychological and ethical aspects of gamete donation. This seemingly has created a more open climate about the practice. However, we have no idea about the acceptance of donor families in social practices, for instance at school or with friends and family. We should not forget that only medical doctors and other specialists in the field take part in public discussions and conduct research in the field, meaning that the image of acceptance that is created is biased.
There are some indications that families built via gamete donation are increasingly being accepted by their environment. One example is the growth in the number of families who decide to tell their child about its donor conception. Compared to for instance 30 years ago, the openness about the use of donated gametes clearly has increased. A second dynamic is the possibility for alternative families such as same sex couples, singles or older couples to make use of the practice. These couples have no other option than telling their child due to the lack of a father figure or due to age-related natural restrictions. The fact that these couples are allowed to use the practice indicates a social acceptance. However, we should be careful not to generalize. While lesbian couples are open about the donor conception, several studies show that the majority of heterosexual couples did not and still do not disclose the donor conception (Nachtigall et al. 1998; Golombok et al. 2002; Owen & Golombok 2009, MacCallum & Golombok, 2007). The rising number of lesbian families might create the wrong impression about the number of people who decide to disclose. Another example is the rising number of donor offspring and donors who register themselves on websites such as Donor Sibling Registry (UK) to get in touch with donors, offspring or half-siblings. Particularly the communication about the search is relevant in this case. Jadva et al. (2010) showed that approximately 60% of the participants had told their friends about their search for the donor or their siblings, and 79% had told their mother. Only 29% of offspring from heterosexual families had told their father about their search for the donor. The data indicate a social taboo to talk about the donor conception. In addition, the openness varies largely among cultures (Inhorn & Van Balen, 2002), with Australia and New Zealand as strong advocates of openness. Many countries such as Belgium or France apply an anonymous system. An open climate is much less present in those countries. Moreover, caution should be maintained when talking about the open climate in countries such as Australia. While on an institutional level openness is promoted and highly valued, empirical data showed that this open climate does not seem to be embraced by the people themselves (Kovacs et al., 2012; Durna et al., 1997).

While we have a clear view on the evolution in policy and on the ethical debate concerning this topic, we have no idea about local evolutions in stigmatization and social acceptance. Only Nachtigall et al. (1997) provide data which suggest that the social stigma about male infertility is one of the reasons the donor conception is not disclosed in heterosexual families. Hudson et al. (2009) concluded that we have limited information on the current ‘public’ perceptions of the practice of gamete donation, with ‘public’ meaning the people who do not need to appeal to medically assisted reproduction via donated gametes. Stigmatization might occur on different levels, such as within families (for instance grandparents who make a difference between ‘own’ grandchildren and the grandchildren conceived via gamete donation) or in the wider social environment (at work, at school, neighbours,...). In this regard, the study of the children revealed interesting findings. These children experienced problems in
explaining their family constitution (having a donor and not having a father) to peers. Reactions of peers showed a difficulty to understand the situation. An explanation might be that our society still imposes hetero-normative family concepts and that children are not familiar with alternative families. This lack of understanding creates a difference between ‘us’ (those having a father) and ‘them’ (those having something else than a father or nothing). In that sense, it would be interesting to investigate children from heterosexual couples who used gamete donation with regard to their experiences with peers. The children in our study had to explain two anomalies. Apart from the donor, also the presence of two mothers needed to be explained.

The gamete donation practice increases the number of alternative families. People should be sensitized about new family formations. Such families should be integrated in policy in order to raise public acceptance. An example of acceptance of alternative families was the recent change in legislation in Belgium with regard to the legal parental status of the non-biological mother in lesbian families. Giving these mothers the same rights as the fathers in heterosexual couples is a step forward in the social acceptance of alternative families. Research should be conducted on the social acceptability of families using gamete donation in order to be able to anticipate properly on trends and evolutions at the level of the actors themselves.

In conclusion, the practice of gamete donation involves several moral debates, many of which have not yet reached a conclusion, and some of them might never reach a conclusion. It is necessary to closely monitor further evolutions in the field, especially as donor children grow up in different contexts. There are many complex ethical issues surrounding gamete donation, but it has the potential to fulfil a profound lifelong dream for many people.

10.5 References


Het ouderschap wordt universeel als één van de belangrijkste doelen in het leven gezien. Voor veel mensen kan de kinderwens niet worden vervuld zonder medische hulp. Infertiliteit wordt gedefinieerd als een ziekte gekenmerkt door het uitblijven van een klinische zwangerschap na 12 maanden of meer van onbeschermdeslachtsgemeenschap. Tien tot vijftien procent van de koppels op reproductive leeftijd wordt geconfronteerd met deze ziekte. Voor een grote groep van deze mensen volstaat een medische behandeling zoals IVF of ICSI met eigen materiaal om een kind te verwekken. Voor anderen zal dit geen soelaas brengen. In deze gevallen kan er worden overgegaan op het gebruik van donornormateriaal (sperma-, eicel-, of embryodonatie). Het is net deze groep waarop wordt ingezoomd in deze verhandeling.

Wanneer gedoneerde gameten worden gebruikt om de kinderwens te vervullen, zijn er meestal twee partijen extra betrokken bij het proces: de medici en de donor. De betrokkenheid van 4 partijen (naast eerstgenoemden ook de ouders en het kind) creëert een complexe verhouding van wensen, verwachtingen, rechten, belangen en plichten van alle partijen. Het hoeft dan ook niet gezegd dat de praktijk een bron van veel ethische discussies is. De verhandeling poogt bij te dragen aan deze ethische en empirisch bio-ethische literatuur over gametendonatie. Elke partij wordt belicht, ofwel vanuit een normatief standpunt, ofwel vanuit een empirisch standpunt.

De splitsing van genetische en sociale banden tussen ouders en kind zorgt ervoor dat een nieuwe invulling nodig is voor de morele grond voor ouderschap. Wat maakt van iemand een ouder, of op welke basis kan iemand ouderlijke rechten en plichten claimen? Er werden verschillende visies en argumenten gegeven in de literatuur als antwoord op deze vraag. Monistische visies stellen dat er één grond is voor ouderschap. Zo verdedigt het geneticisme dat de genetische link tussen ouder en kind de enige grond is voor ouderschap. Het intentionalisme stelt dan weer dat de intentie om een kind te

Uitdaging voor de morele basis voor ouderschap

De splitsing van genetische en sociale banden tussen ouders en kind zorgt ervoor dat een nieuwe invulling nodig is voor de morele grond voor ouderschap. Wat maakt van iemand een ouder, of op welke basis kan iemand ouderlijke rechten en plichten claimen? Er werden verschillende visies en argumenten gegeven in de literatuur als antwoord op deze vraag. Monistische visies stellen dat er één grond is voor ouderschap. Zo verdedigt het geneticisme dat de genetische link tussen ouder en kind de enige grond is voor ouderschap. Het intentionalisme stelt dan weer dat de intentie om een kind te
verwekken en op te voeden de grond is voor ouderschap. Als antwoord op deze monistische visies, kwam de pluralistische visie. Deze visie stelt dat er meerdere gronden zijn voor ouderschap en bijhorende rechten en plichten.

**Uitwisselen van informatie**

De betrokkenheid van vier partijen en de aard van de praktijk doet de vraag rijzen wie over wat moet geïnformeerd worden. De ethische discussies focussen zich op de informatie-uitwisseling tussen de ouders en het kind enerzijds en de informatie-uitwisseling tussen het gezin en de donor anderzijds. Het eerste debat richt zich op de vraag over onthulling of geheimhouding naar het kind toe. Het tweede debat gaat over de anonimiteit of identificeerbaarheid van de donor. In beide debatten hebben alle betrokken partijen een belang. In het onthullingsdebat staat het recht van de ouders op privacy tegenover het recht van het kind om geïnformeerd te worden over informatie die zijn/haar leven aanbelangt. In het anonimiteitsdebat staan de belangen van donoren, kinderen en ouders eveneens tegenover elkaar. Om tot een oplossing te komen moeten al deze belangen tegenover elkaar worden afgewogen. Om tot een goed evenwicht te komen, kunnen we beroep doen op empirische gegevens over bijvoorbeeld de impact van het al dan niet vertellen of de impact van contact met de donor in het gezin.

**Informatie-uitwisseling van het kind naar de donor**

Lange tijd was de praktijk van gametendonatie anoniem. Donoren doneerden anoniem om in de toekomst niet geconfronteerd te kunnen worden met de kinderen resulterend uit hun donatie. Sinds een paar decennia wordt deze anonimiteit in vraag gesteld door een focus op de rechten en belangen van de kinderen. Een aantal landen hebben reeds de overstap gemaakt naar een open-identiteitssysteem waarbij de donor identificeerbaar wordt voor het kind vanaf een zekere leeftijd (meestal 18 jaar) indien het kind dit wenst. Opvallend aan deze beweging is dat er bijna uitsluitend aandacht is voor de belangen van het kind. De belangen van andere partijen worden niet in rekening gebracht. In dit hoofdstuk focussen we ons net daarom op de belangen van de donor. Als het kind recht heeft op bepaalde informatie van de donor, dan heeft de donor wellicht ook recht op informatie over de kinderen resulterend uit zijn/haar donatie. In dit hoofdstuk gaan we op zoek naar argumenten die donoren zouden kunnen gebruiken om bepaalde informatie te claimen.
Counselen over al dan niet onthullen aan het kind

Eén van de grote ethische discussies draait rond de vraag of het kind al dan niet moet op de hoogte worden gesteld van de conceptiemethode. Voor een lange tijd werd geheimhouding aangeraden aan het koppel. Op dit moment is er een verschuiving aan de gang waarbij meer en meer geadviseerd wordt om net wel te onthullen. Een eerste vraag die hierbij moet gesteld worden is of een dergelijke directieve aanpak, waarbij een actie wordt aangeraden aan de ouders, wel geëtudeerd is. In dit hoofdstuk maken we een analyse van twee principes die elk onderliggend zijn aan een specifieke counseling aanpak: het principe van autonomie (onderliggend aan een niet-directieve aanpak) en het principe van weldoen (onderliggend aan een directieve aanpak). We maken een analyse van de empirische data die op dit moment voorhanden zijn die het principe van weldoen, en dus een directieve aanpak, ondersteunen. De analyse toont dat er op dit moment niet voldoende empirisch bewijs is om een directieve aanpak te verantwoorden. De autonomie van de ouders mag niet geschonden worden en bovendien is er geen bewijs dat onthulling het welzijn van het kind bevordert.

De morele grond voor ouderschap volgens koppels die gebruik maakten van gametendonatie

In dit en volgende hoofdstukken wordt er een analyse van empirische data die ingezameld werden voor het onderzoek waarvan deze verhandeling deel uitmaakt. In dit eerste empirische hoofdstuk dat handelt over de ouders houden we een ruime focus aan naar zowel heteroseksuele als lesbische ouders na de behandeling, alsook lesbische koppels tijdens hun behandeling. Zoals reeds aangehaald daagt de praktijk van gametendonatie de traditionele gronden van ouderschap uit door de opsplitsing van genetische en sociale banden. Om deze normatieve theorieën te verrijken, maken we in dit hoofdstuk een analyse van de gronden die deze ouders aangeven voor ouderschap. Genetische en intentionele gronden worden vaak vermeld, maar ook nieuwe gronden, zoals de relatie tussen de partners, werden aangehaald. De koppels nemen een pluralistische houding in ten aanzien van ouderschap en tonen dat zeer veel criteria recht kunnen geven op ouderschap.

De invloed van een eenzijdige genetische link op ervaringen van ouderschap

In het tweede empirische hoofdstuk over de ouders zoomen we in op de lesbische ouders met een studie naar hun ervaringen met de eenzijdige genetische link. We weten
uit voorgaand onderzoek dat deze ouders het verschil in genetische link opvangen door te concentreren op het belang van sociale banden en de impact hiervan op kinderen. Uit onze data bleek dat de genetische link vaak als irrelevant werd beschouwd. Toch bleken er, voornamelijk bij de niet-genetische moeders, af en toe ervaringen van verschil op te duiken. Zo beschouwden sommige niet-genetische moeders de genetische link als waardevol of speciaal, of werd er voorkeursgedrag naar genetische moeder opgemerkt, wat dan werd verklaard door de aanwezigheid van de genetische link. Ook externe factoren initieerden ervaringen van verschil, zoals de adoptieprocedure om de wettelijke ouder te kunnen worden van het kind.

Familieconcepten bij kinderen van lesbische koppels

In het laatste empirische hoofdstuk ligt de focus op de kinderen van de lesbische koppels en op hoe zij omgaan met hun gezinsstructuur. We maken een analyse van hoe zij de concepten ‘genetische mama’, ‘niet-genetische mama’ en ‘donor’ definiëren. Twee opvallende bevindingen kwamen naar voren. Ten eerste werden beide moeders als gelijkwaardig beschouwd. De kinderen maakten geen onderscheid tussen een genetische moeder en een niet-genetische moeder. In hun beleving was een dergelijke opsplitsing niet relevant. Ten tweede, om de concepten ‘niet-genetische moeder’ en ‘donor’ te definiëren, grepen de kinderen terug naar de heteronormatieve concepten ‘mama’ en ‘papa’. In het geval van het concept ‘donor’ bleek dit vrij complex. Er ontstond een conflict tussen de donor als verwekker (zoals een papa) en de donor als een afwezig en onbekend persoon (niet zoals een papa).

Conclusies

In de huidige literatuur is er een trend naar een eenzijdige focus op de rechten en belangen van het kind. Hoewel het kind een kwetsbare partij is en dus speciale aandacht verdient, mogen we de andere partijen niet uit het oog verliezen. De donor blijkt, net zoals het kind, belang te hebben bij bepaalde informatie van zijn/haar donorkinderen. Het is onduidelijk waarom deze belangen zomaar aan de kant zouden mogen worden geschoven. Bovendien verdienen alle partijen dezelfde behandeling; de criteria voor het al dan niet toekennen van recht op informatie moeten voor alle partijen dezelfde zijn.

Verder onderzoek is nodig naar de effecten van het al dan niet onthullen van de conceptiemethode aan het kind en de effecten van identificeerbare donoren op de gezinnen. Er is op dit moment te weinig informatie om een algemeen geldend antwoord te geven op de vragen resulterend uit beide debatten. De beste optie (onthullen of niet; anonieme donor of niet) is de optie die de ouders zelf kiezen na een informerende counseling sessie.
Gametendonatie is meer dan een behandeling alleen. De impact op het gezin op lange termijn mag niet worden onderschat. Een kind verwekt via gametendonatie groeit op en confronteert de ouders op allerlei manieren met de praktijk. Fysieke gelijkenissen met de donor, interesses die ouders niet bij zichzelf terugvinden, maar ook rechtstreekse vragen over de donor (als het kind is ingelicht), brengen de donor jaren na de donatie terug op het toneel. Onze data toonden eveneens dat de eenzijdige genetische link voor ervaringen van verschil kan zorgen jaren na de donatie. Eén van de moeilijkste vraagstukken waarmee ouders worden geconfronteerd is de onthulling naar het kind. Aan het begin van de behandeling worden koppels gecounseld over deze vraag. Toch is het niet onlogisch dat gedurende de jaren de mening van de ouders verandert, of dat het karakter van het kind een andere aanpak vraagt dan de initiële overeengekomen aanpak. De evolutie van ervaringen en visies op de praktijk en de gevolgen van ouders mag niet vergeten worden. Counseling mag niet stoppen bij een succesvolle behandeling.

De gametendonatiepraktijk omvat meerdere ethische discussies waarvan vele nog geen conclusie hebben bereikt. Toch is het belangrijk evoluties verder op te volgen. De praktijk heeft het potentieel om de levensdroom van zeer veel mensen waar te maken.
English summary

Background

Universally, parenthood is undeniably regarded as one of the most important goals in life. However, not all couples who intend to have children will also achieve this goal spontaneously. An estimated 10-15% of couples is affected by infertility, which makes this one of the most common diseases for people at their reproductive age (between 20 and 45 years old). A considerable part of the infertile couples is not able to use their own genetic material. In such cases, material of a third party can be used. Sperm, oocyte or embryo donation can help a couple to conceive a child that is partly genetically or biologically related to them.

The involvement of four parties (parents, child, donor, medical team) creates a complex web of wishes, expectations, rights, responsibilities and interests of all parties. It is not surprising that the practice is a source of ethical discussions. This dissertation aims at contributing to this ethical and empirical bio-ethical literature. Each party involved will be investigated, either from a normative or an empirical point of view.

A challenge to the moral grounds of parenthood

With the development of ARTs, the - for a long time self-evident - link between genetics and parenthood was severed. What exactly makes someone a parent then? Several moral grounds and argument were presented in the literature. Monistic theories argue that there is one moral ground for parenthood. A geneticist account of parenthood states for instance that parental rights and obligations arise solely from the genetic relationship between the parents and the child. The intentional account of parenthood defends the position that the parents of the child are those people who intended to create the child, regardless of any biological connection. In answer to the monistic theories, a pluralistic account was developed. This theory argues that there can be more than one moral ground for parenthood. None of the grounds is necessary, all grounds are sufficient.
Exchanging information

Because of the involvement of four parties, the question rises about who needs to be informed about what. The ethical debates centre around the information exchange between the parents and the child (disclosure debate), and the information exchange between the family and the donor (anonymity debate). In both debates, all parties have their own interests. In the disclosure debate, the parents’ right to privacy conflicts with the child’s right to information about his/her own life. In the anonymity debate, the interests of the donor, the parents and the child are in conflict with each other. To reach a solution, the interests of all parties should be balanced. To reach such a balance, empirical data on for instance the impact of (non-)disclosure or the impact of contact with the donor should be taken into account.

Information exchange from the child to the donor

Anonymous gamete donation was long the preferred practice. Since a few decades, a new focus on the rights and interests of donor-conceived children has led a number of countries to shift towards an open-identity system. However, this evolution appears to overlook whether an information exchange could also be of interest to other parties, in particular the gamete donors. In this chapter, the question is analysed whether donors should be granted a right to some information about the offspring conceived by their donations. Five arguments are offered - along the same lines as the arguments given in favour of granting information to the donor conceived children - which donors could use in support of such a claim.

Giving advice in the secrecy and disclosure debate

Much discussion exist on whether the conception method should be disclosed to the child or not. For a long time, secrecy was advised. Nowadays, a shift towards openness seems to be developing. The question is, however, whether such a directive counselling approach is ethically justified. In this chapter, an analysis is made by balancing the two underlying principles of autonomy for the parents (non-directive approach) and beneficence for the child (directive approach). We analyse the arguments and evidence available at this point that support the beneficence principle. This analysis shows that no sufficient arguments can be given in favour of the beneficence principle and we concluded that the parents’ autonomy should not be overridden.
The grounds for parenthood

A large variety of normative theories exists on what should be the basis of parenthood. In this chapter, a study about the moral reasoning of the parents involved in the field on the basis of parenthood and parental rights and responsibilities is presented. Via a hypothetical scenario, we investigated their arguments and views with regard to the grounds of parenthood. For this study, we aimed at including a large variety of parents. We focused on lesbian couples post and during treatment, and on heterosexual couples post treatment who had a child either via anonymous sperm donation or via (known-) anonymous oocyte donation. The aim was to add new insights from the stakeholders to the normative debates concerning parenthood. Looking into the moral experiences of the people involved can enrich current moral frameworks with views that were overlooked by ethicists. The study shows that the people use traditional grounds such as intentionalism and geneticism, as well as new grounds such as the relationship between the partners.

The influence of the genetic link on the experience of parenthood

One of the central topics in the literature on parenthood after treatment via gamete donation, is the relevance of genetic ties for parenthood. To enrich normative analyses and descriptive background theories, a qualitative analysis is presented on how lesbian couples experience and deal with the difference in genetic relatedness in their family and to what extend parenthood and being a parent depends on a genetic link. Previous research showed that lesbian couples handle the difference with regard to genetic relatedness, for instance, by creating a narrative about physical resemblances or by focusing on the social bond and its influence on children. The difference with regard to the genetic link brought up complex and context-specific experiences for these parents. Generally, the genetic link was described as irrelevant: equality between both parents was presented as a given. However, some experiences of difference due to the presence of one genetic link were found.

The influence of the genetic link on the definition of family concepts

In the last chapter, a qualitative study is presented that explores how children (9 to 10 years old) from lesbian families define the three actors involved in the building of their family: the biological mother, the non-biological mother and the donor. The aim of this research is to outline how a child conceived via third party reproduction (sperm donation) makes sense of his or her family relationships, and to what extend this is influenced by the (non-)existence of a genetic link. Two findings stand out. First, the
biological and non-biological mother were described as equal parents. Second, the concepts ‘non-biological mother’ and ‘donor’ were defined by looking at the heteronormative concepts of ‘mummy’ and ‘daddy’. With regard to the donor, the comparison with a ‘daddy’ turned out to be complex due to the conflict between the role as a progenitor and the lack of a social relationship.

**Conclusions**

In the current literature, there seems to be a one-sided focus on the rights and interests of the child, and an accompanying one-sided focus on the importance of openness and open-identity systems. Even though serious consideration to the interests of the child is understandable, it should not lead to a neglect of the other parties. We argued that the donor was justified to receive certain types of information about his/her donor conceived children. Moreover, all parties should be considered equally: the criteria to grant a right to information should be equal for all parties. More research should be conducted on the effects of (non-)disclosure and identifiable donors on the families and donors. At this moment, we lack sufficient information to come to a general solution in both debates. The preferable option is the option that is chosen by the parents (and donors).

Gamete donation is a long-lasting process that starts with the decision to use gametes and evolves over time. While couples might initially come to terms with the consequences, this is challenged when the child enters their lives and grows up. Parents are confronted with the consequences in real life. One of the most difficult questions parents are confronted with is the disclosure decision. While this is discussed during the counselling session(s) that take place before or during the treatment, attitudes can change and new questions and uncertainties might rise as the child grows up. The long-term impact of the treatment should not be overlooked. Questions and issues that were dealt with at the start of the treatment during counselling might come up again. We should be aware of the possible need for counselling many years after the treatment.

In conclusion, the practice of gamete donation involves several moral debates, many of which have not yet reached a conclusion, and some of them might never reach a conclusion. There are many complex ethical issues surrounding gamete donation but it has nevertheless the potential to fulfil a profound lifelong dream for many people.
Appendices
# Appendix 1  
## Interview guide lesbian couples – retrospective study

The order of the questions depends on what the participants bring up during the interview. The participants guide the interview partially.

Symbol O: Questions are in first instance asked to the couple to invite them to talk about both (and shared) experiences. Then, the differences within the couple are investigated by asking the question to each participant separately. These differences are then fully explored.

Symbol *: The specific term used by the participants is copied by the interviewer. When the concept still needs to be introduced, neutral terms are used.

<table>
<thead>
<tr>
<th>Aim/technique</th>
<th>Questions/themes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Introduction</strong></td>
<td>Suggestion: You were invited for an interview because you have a child conceived via medically assisted reproduction. Not much research has been done to the experiences of these families themselves so far. That is why we invited you; during this interview we would like to get to know your experiences and opinions as parents.</td>
</tr>
<tr>
<td></td>
<td>[Informed consent ]</td>
</tr>
<tr>
<td></td>
<td>[Point out the possibility of taking a break, skipping questions, thinking about questions,...]</td>
</tr>
<tr>
<td></td>
<td>[Point out that no answer is right or wrong]</td>
</tr>
<tr>
<td><strong>Experiences</strong></td>
<td><em>(Origins of) the child wish</em></td>
</tr>
<tr>
<td></td>
<td>How did your child wish start?</td>
</tr>
<tr>
<td></td>
<td>Which options did you consider to fulfil your child wish?</td>
</tr>
<tr>
<td></td>
<td>Can you tell me a bit more about this decision process?</td>
</tr>
</tbody>
</table>
When themes are mentioned by the participants that were not included in this guide, these are further explored. [summarizing and feedback.]

Moral reasoning

<table>
<thead>
<tr>
<th>Moral reasoning</th>
<th>Now, we will go in to some things in more detail. When you’d rather not talk about certain things, you can always say so.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experiences of parenthood</td>
<td></td>
</tr>
<tr>
<td>‘Mattering’</td>
<td></td>
</tr>
<tr>
<td>How do you know that you, as parents, matter to your child*?</td>
<td>How do you see the donor* (evolution)? What does this donor* mean to you?</td>
</tr>
<tr>
<td>Genetic versus social</td>
<td></td>
</tr>
<tr>
<td>You are both parent to your child. You (to the genetic mother) have a genetic link with your children, you (to the non-biol mother) do not. How is that for you (to the couple)?</td>
<td>Do you sometimes talk about the donor* in your family or not really?</td>
</tr>
<tr>
<td>How do you see the role of the donor* towards your child? What duties, rights or responsibilities does he have for you?</td>
<td>Imagine that you could have received more information on the donor*, what information would you like to have received?</td>
</tr>
<tr>
<td>Do you notice a difference in daily life? Or in specific contexts? How do other</td>
<td>Imagine that your child* wants certain information about the donor* in the future, what information should your child* be</td>
</tr>
<tr>
<td>Information-anonymity</td>
<td></td>
</tr>
<tr>
<td>You used an anonymous donor. How was that for you?</td>
<td></td>
</tr>
<tr>
<td>Did you consider using a known donor, a friend for instance?</td>
<td></td>
</tr>
<tr>
<td>The following three questions are hypothetical and it is possible you have never thought about them before. This is no problem.</td>
<td>What do you expect from the reproductive centre with regard to the donor selection?</td>
</tr>
<tr>
<td>What do you think about the financial reimbursement for donors?</td>
<td></td>
</tr>
<tr>
<td>Perception of the donor</td>
<td></td>
</tr>
<tr>
<td>If it were possible, would you have liked to choose your donor* or not?</td>
<td>If you could choose your donor*, which characteristics would be relevant to make a choice?</td>
</tr>
<tr>
<td>If you would be informed about the number of offspring of your donor*, and this number would be high, what would this mean to you?</td>
<td>What do you expect from the reproductive centre with regard to the donor selection?</td>
</tr>
<tr>
<td>How come you would have liked more information?</td>
<td>What do you think about the financial reimbursement for donors?</td>
</tr>
<tr>
<td>Hypothetical scenario</td>
<td>To further elaborate your personal opinions in more detail, I brought a story with me that we made up. I would like to ask some questions about the story (see below). The aim is to get a better insight into your opinions, so you should answer what you think, not what can be done legally. I will read the story out loud, and you can read with me on this sheet.</td>
</tr>
</tbody>
</table>

Semantic differential scale

<table>
<thead>
<tr>
<th>Semantic differential scale</th>
<th>Do you sometimes talk about the donor* in your family or not really?</th>
</tr>
</thead>
<tbody>
<tr>
<td>How do you see the donor* in your family or not really?</td>
<td></td>
</tr>
<tr>
<td>Did you consider using a known donor, a friend for instance?</td>
<td></td>
</tr>
<tr>
<td>The following three questions are hypothetical and it is possible you have never thought about them before. This is no problem.</td>
<td></td>
</tr>
<tr>
<td>What do you think about the financial reimbursement for donors?</td>
<td></td>
</tr>
</tbody>
</table>
people deal with it? offered according to you?

Imagine that the donor* was able to let you know that he would like to be in contact with you (now, this is not possible). What would your reaction be?

Ending

[Thank participants for participating]
[Offer information about the possibility for medical and psychological help]
[Explain the interview study towards children and give informed consent when interested.]
Semantic differential scale

A “semantic differential scale” is offered to the participants. They are invited to situate their answer on the scale. The range of possibilities between the two extremes are not named, so the participants are free to fill these in themselves. No scores are used to prevent a feeling of right and wrong answers. This scale is used to ask about attitudes and opinions, and as a tool to open up a certain subject for discussion.

1) How do you see the donor*?

Someone offering cells

2) What exactly did you receive of the donor*?

Some cells

A child with personality traits
Hypothetical scenario

The participants are offered following story to investigate their ideas about parenthood and the importance of genetic ties. This story is used for several groups. The sexes of the individuals in the story are not defined. When the participants ask about this, their question is reversed (they are asked to fill in the sex) or they are asked whether this would influence their answer.

When the story is read out loud by the interviewer (participants can read with the interviewer on a separate sheet), the participants are invited to think about a solution for all individuals in the story. Cards are offered to help them with ‘full parenthood’, ‘co-parenthood’, ‘no parenthood, but sporadic contact’ and ‘no parenthood, no contact’. Each option can be put with each individual. They are asked to discuss out loud their decisions and the reasons for their decisions.

Baby Jeff was born late 2011 to A and B following an IVF-treatment at an American clinic. A and B were overjoyed but their relationship broke down a year later. They parted in friendship and agreed on a week-on/week-off co-parenting arrangement. In 2012 it was clear that a mistake had been made in the lab of the American clinic. A was genetically linked to Jeff, B was not. Instead of the material of B, the lab used the material of another person (C) who underwent an IVF-treatment in the same clinic. All three parties were notified by the hospital and all three now make a claim the child/parenthood
Appendix 2  
Interview guide children from lesbian families

<table>
<thead>
<tr>
<th>Aim/technique</th>
<th>Questions/themes</th>
</tr>
</thead>
</table>
| **Introduction** | *The interviewer introduces herself as a researcher. Suggestion: “I am a researcher and I conduct research on how all sorts of families can look like – with mummies, daddies and children – and how the children in all those families were created. I wonder how this is in your family, how your family was created. I don’t know much about those things, but I would like to learn a lot about it. And that is why I wanted to come and talk with you.”*  
If you have any questions, you can always ask them to me. When you want to take a break, or when you don’t want to talk about something, or when you want to think about something first, that is all possible. There are no right or wrong answers. I am very curious about what you think. |
| **Apple tree (see below)** | *Child is offered a sheet with a drawing of a tree, cards in the shape of apples and a pencil*  
I would like to know who belongs to your family – who really belongs to you – and that is why I brought some kind of apple tree. You can write your name on an apple and put it somewhere on the drawing or the sheet, where ever you want. Now, you can add other apples for all the people who belong to your family. You can choose where you put the apples. So, who belongs to you? To your family?  
**Probe:** should anyone else be in the tree?  
**Probe:** why can x be in the tree?  
*(! The donor is only discussed when the child mentions him spontaneously, he is not introduced here)  
[Questions about the meaning of ‘belonging to me’: reversing the question and asking to the child ‘does he/she belongs to you? If he/she belongs to you, he/she can be in the tree’]* |
| **Experiences** | *Concept family/ parenthood (and feelings)*  
You have an apple for your mummy*  
| *Similarities*  
Some children look like their mummy*,  
| *Birth story*  
Formerly, your mummy* and mom* |
(biological mother). But, what exactly is that, a mummy*? What do mummies* do? (little alien’)

And a mom* (non-biol mother), what is that exactly? What do moms* do?

You have a mummy* and a mom*, some children have a daddy. Can you tell me what a daddy is? What do daddies do, you think?

How do you know, or how can you tell that you are the child of your mummy* and mom*?

How could other people know that you are the child of your mummy* and your mom*?

How can you know you matter to your mummy* and mom*?

some children look like their mom*, some children look like both of them and some children do not look like either of them. How is that with you? What do you think of that? You like it, or not? Why is that?

Are there other people you look like, or not? (siblings?)

were alone (pointing at apple tree). Back then, they had no children. And then, you came. Do you know how you came, were created? Can you tell me a bit about that?

Probe: Who told you about how you were created?

Probe: Do you talk about this at home sometimes? Do you know how other children are created? In whose tummy have you been? And how did that work? (Probe: from who was the egg? Where did the seed come from?) How did that work with your brother(s)/sister(s)?

What do you think about that? Do you talk about this sometimes? Of not yet? Or how does it work with you? How is that for you, (not) talking about that?

(discussion is open for feelings surrounding the donor and feelings surrounding two mothers)

1 Imagine that a little alien would come to the Earth to investigate this world and at the alien’s planet, no mummies* and moms* and daddies* exist. How would you explain what mummies* and moms* are to this little alien? And how could this little alien know, “Ah, those are X’s mummy* and mom*”.
| Resuming Apple tree (see below) | Let’s turn back to the apple tree [resume what we did in part 1]. We also talk with other children and then we give them also an apple for the donor* and we ask them where this apple should be placed. If you would have an apple for the donor*, what would you do with it? Where would you place it? Why can the donor* be there?

What do you know about the donor*?

What does the donor* mean to you?

Do you think about the donor* sometimes, or not? Some children think a lot about the donor*, other children think about him sometimes, others never think about the donor*. How is that for you? Probe: what do you then?

I find this all very interesting. I am learning a lot from you. I didn’t know much about all this.

If you could know something about the donor*, would you like to know something and what would this be? Imagine you had a crystal ball or a magical box, what would you like to know?

[I Underline that interviewer has no information about the donor]

| Environment | Have you ever told about all this to one of your friends, or not? Or in class? What did you tell?

(discussion is open for feelings surrounding the donor and feelings surrounding two mothers)

What did the children think about it? Did they say anything, ask something, or not? And your teacher?

Did another adult talk about this with you already, or not? Probe: did you talk about it with your grannie or grandpa? What do you think then? Have you spoke about it with your brother/sister? How is that for you?

| Summarizing and feedback | [Summarize] Is that correct? Did I forget something?

Are there any questions you want to ask me? Or things you would like to know?

[I Underline that interviewer has no information about the donor]

| Ending | [Thank child for participation.] |
### Appendix 3  Interview guide heterosexual couples – anonymous sperm donation – retrospective study

<table>
<thead>
<tr>
<th>Aim/technique</th>
<th>Questions/themes</th>
</tr>
</thead>
</table>
| **Introduction** | *Suggestion:* You were invited for an interview because you have a child conceived via medically assisted reproduction. Not much research has been done to the experiences of these families themselves so far. That is why we invited you; we would like to get to know your experiences and opinions as parents.  
[Informed consent]  
[Point out the possibility of taking a break, skipping questions, thinking about questions,...]  
[Point out that no answer is right or wrong] |
| **Experiences** | *(Origins of) the child wish*  
How did your child wish start?  
Which options did you consider to fulfil your child wish?  
Can you tell me a bit more about this decision process?  
How did you experience the meeting with the counsellor?  
What did you tell to your social environment (or didn’t you tell anything?)  
What did you tell to your child now?  
How did the professionals have for you?  
Can you tell me a bit more about this decision process?  
What meaning did the treatment have for you, as a couple?  
What meaning do they have for you now?  
What role did the professionals have for you?  
How did you experience the meeting with the counsellor?  
What reaction or responses did you receive from your environment?  
What did you tell to your social environment (or didn’t you tell anything?)  
What did you tell to your child now?  
How did the professionals have for you?  
Can you tell me a bit more about this decision process?  
What meaning did the treatment have for you, as a couple?  
What meaning do they have for you now?  
What role did the professionals have for you?  
How did you experience the meeting with the counsellor?  
What reaction or responses did you receive from your environment? | *(Experiences with the treatment)*  
How did you experience the treatments?  
What meaning do they have for you now?  
What role did the professionals have for you?  
How did you experience the meeting with the counsellor?  
What reaction or responses did you receive from your environment?  
Did you tell your child about its conception?  
How come you did (not)?  
Are you aware of whether your child* has ever spoken about this with other people/children?  
What do you think the donor* means to your child*?  
What meaning did the treatment have for you, as a couple?  
What meaning do they have for you now?  
What role did the professionals have for you?  
How did you experience the meeting with the counsellor?  
What reaction or responses did you receive from your environment?  
Did you tell your child about its conception?  
How come you did (not)?  
Are you aware of whether your child* has ever spoken about this with other people/children?  
What do you think the donor* means to your child*? | *(Meaning couple)*  
What meaning did the treatment have for you, as a couple?  
What meaning do they have for you now?  
What role did the professionals have for you?  
How did you experience the meeting with the counsellor?  
What reaction or responses did you receive from your environment?  
Did you tell your child about its conception?  
How come you did (not)?  
Are you aware of whether your child* has ever spoken about this with other people/children?  
What do you think the donor* means to your child*? | *(Environment/ family narratives)*  
What meaning did the treatment have for you, as a couple?  
What meaning do they have for you now?  
What role did the professionals have for you?  
How did you experience the meeting with the counsellor?  
What reaction or responses did you receive from your environment?  
Did you tell your child about its conception?  
How come you did (not)?  
Are you aware of whether your child* has ever spoken about this with other people/children?  
What do you think the donor* means to your child*? | *(Well-being child)*  
Did you tell your child about its conception?  
How come you did (not)?  
Are you aware of whether your child* has ever spoken about this with other people/children?  
What do you think the donor* means to your child*? | *(Similarities)*  
Do you experience any similarities or differences between you and your child* or not really?  
Do you recognize yourself in your child* in some way or not? O  
Do others sometimes speak about this?  
What meaning does the absence/presence of similarities has for you? |

*When themes are mentioned by the participants that were not included in this guide, these are further explored.  
[summarizing and feedback.]*
Moral reasoning

Now, we will go in to some things in more detail. When you’d rather not talk about certain things, you can always say so.

<table>
<thead>
<tr>
<th>Experiences of parenthood</th>
<th>‘Mattering’</th>
<th>Meaning donor</th>
<th>Information-anonymity</th>
<th>Perception of the donor</th>
<th>Hypothetical scenario</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parenthood is a concept with a lot of definitions. However, not one decisive definition has been given so far. That’s why we wanted to ask you. Parenthood in general, what does this mean for you? At which moment you had the feeling ‘now, I’m a parent’?</td>
<td>How do you know that you, as parents, matter to your child?</td>
<td>How do you see the donor? Has there been an evolution in how you see the donor? What does this donor mean to you?</td>
<td>You used an anonymous donor. How was that for you? Did you consider using a known donor, a friend for instance?</td>
<td>If you would have been allowed to choose certain characteristics of the donor at the time of your treatment, would you have liked that? Why (not)? What characteristics would you consider important?</td>
<td>To further elaborate your personal opinions in more detail, I brought a story with me that we made up. I would like to ask some questions about the story (see below). The aim is to get a better insight into your opinions, so you should answer what you think, not what can be done legally. I will read the story out loud, and you can read with me on this sheet [see appendix 1].</td>
</tr>
<tr>
<td>Genetic versus social</td>
<td>You are both parent to your child. You (to the mother) have a genetic link with your children, you (to the father) do not. How is that for you (to the couple)? O Do you notice a difference in daily life? Or in specific contexts? How do other people deal with it?</td>
<td>[Semantic differential scale, see appendix 1] Do you sometimes talk about the donor in your family or not really? Do you sometimes think about the donor?</td>
<td>What duties, rights or responsibilities does he have towards your child for you?</td>
<td>Imagine that you could have received more information on the donor, what information would you like to have received? O How come you would have liked more information?</td>
<td>At this point, we didn’t determine the gender. What if A would be male and B would be female? In other words, B has no genetic link, but has carried the child? Would it make a difference or not?</td>
</tr>
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<td></td>
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<td></td>
<td>What duties, rights or responsibilities does he have towards your child for you?</td>
<td>Imagine that your child wants certain information about the donor in the future, what information should your child* be offered according to you?</td>
<td>Imagine that the donor* was able to let you know that he would like to be in contact with you (now, this is not possible). What would your reaction be?</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>What duties, rights or responsibilities does he have towards your child for you?</td>
<td>Imagine that your child* wants certain information about the donor in the future, what information should your child* be offered according to you?</td>
<td>Imagine that the donor* was able to let you know that he would like to be in contact with you (now, this is not possible). What would your reaction be?</td>
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<tr>
<td>Ending</td>
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<tr>
<td>Thank participants for participating</td>
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<tr>
<td>Offer information about the possibility for medical and psychological help.</td>
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<tr>
<td>Explain the interview study towards children and give informed consent when interested.</td>
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</tbody>
</table>
Appendix 4 Interview guide heterosexual couples – anonymous or known-anonymous egg donation – retrospective study

Note to this guide:

In this study, two groups of participants were included. Some participants opted for anonymous donation, and others for known-anonymous donation. To include the experiences and reasoning about both donors (the anonymous donor from whom they received and the known donor they brought with them ‘in return’) for the participants who used known-anonymous donation, we added specific questions to the guide. These questions are underlined. The abbreviations “K-A donation” and “K-A donor” is used to refer to the known-anonymous donation.

<table>
<thead>
<tr>
<th>Aim/technique</th>
<th>Questions/themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>Suggestion: You were invited for an interview because you have a child conceived via medically assisted reproduction. Not much research has been done to the experiences of these families themselves so far. That is why we invited you; we would like to get to know your experiences and opinions as parents.</td>
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<tr>
<td></td>
<td>[Informed consent]</td>
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<tr>
<td></td>
<td>[Point out the possibility of taking a break, skipping questions, thinking about questions,…]</td>
</tr>
<tr>
<td></td>
<td>[Point out that no answer is right or wrong]</td>
</tr>
<tr>
<td>Experiences</td>
<td>(Origins of) the child wish</td>
</tr>
<tr>
<td>-------------</td>
<td>-----------------------------</td>
</tr>
<tr>
<td>How did your child wish start?</td>
<td>How did you experience the treatments?</td>
</tr>
<tr>
<td>Which options did you consider to fulfil your child wish?</td>
<td>How did you experience the meeting with the counsellor?</td>
</tr>
<tr>
<td>Can you tell me a bit more about this decision process (decision K-A donation)?</td>
<td></td>
</tr>
</tbody>
</table>

When themes are mentioned by the participants that were not included in this guide, these are further explored. [summarizing and feedback.]

<table>
<thead>
<tr>
<th>Moral reasoning</th>
<th>Experiences of parenthood</th>
<th>Genetic versus social</th>
<th>Meaning anonymous egg donor</th>
<th>Information-anonymity</th>
<th>Perception of the anonymous egg donor</th>
<th>Negotiations, relationship, engagements with the K-A donor</th>
<th>Hypothetical scenario</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parenthood is a concept with a lot of definitions.</td>
<td>You are both parent to your child. You (to the mother) have a genetic</td>
<td>(questions about the donor from whom they received)</td>
<td>Both anonymous and known egg donation are offered (ever considered this?). You used an anonymous</td>
<td>If you would have been allowed to choose certain characteristics of the donor* at the time of</td>
<td></td>
<td>To further elaborate your personal opinions in more detail, I brought a story</td>
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<tr>
<td>However, not</td>
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</tbody>
</table>

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one decisive definition has been given so far. That’s why we wanted to ask you.

Parenthood in general, what does this mean for you? At which moment you had the feeling ‘now, I’m a parent’?

Do you notice a difference in daily life? Or in specific contexts? How do other people deal with it? What does the genetic link mean to you?

Do you sometimes talk about the donor* in your family or not really? Do you sometimes think about the donor*?

What duties, rights or responsibilities does he have towards your child for you?

What does the anonymous egg donor* mean to you? Has there been an evolution in how you see the donor*?

Do you think that you could have received more information on the donor*, what information would you like to have received?

How come you would have liked more information?

Imagine that your child* wants certain information about the donor* in the future, what information should your child* be offered according to you?

Imagine that the donor* was able to let you know that he would like to be in contact with you (now, this is not possible).

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>What does the K-A donor* mean to you (contact, engagements...)?</td>
<td></td>
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<tr>
<td>Did you share the K-A donation with your environment? Do you know whether your K-A donor* has ever mentioned this her environment?</td>
<td></td>
</tr>
<tr>
<td>How do you see the role of your K-A donor* towards your child (contact)?</td>
<td></td>
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<tr>
<td>What do you think about the financial reimbursement for donors?</td>
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<tr>
<td>With the K-A donor?</td>
<td></td>
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<tr>
<td>What does this anonymity mean to you?</td>
<td></td>
</tr>
<tr>
<td>The following three questions are hypothetical and it is possible you have never thought about them before. This is no problem.</td>
<td></td>
</tr>
<tr>
<td>What do you expect from the reproductive centre with regard to the donor selection?</td>
<td></td>
</tr>
<tr>
<td>What do you think about the financial reimbursement for donors?</td>
<td></td>
</tr>
<tr>
<td>What duties, rights or responsibilities does he have towards your child for you?</td>
<td></td>
</tr>
<tr>
<td>What does this anonymity mean to you?</td>
<td></td>
</tr>
<tr>
<td>The following three questions are hypothetical and it is possible you have never thought about them before. This is no problem.</td>
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</tr>
<tr>
<td>What do you expect from the reproductive centre with regard to the donor selection?</td>
<td></td>
</tr>
<tr>
<td>What do you think about the financial reimbursement for donors?</td>
<td></td>
</tr>
<tr>
<td>What do you think about the financial reimbursement for donors?</td>
<td></td>
</tr>
</tbody>
</table>
**Semantic differential scale**

1) **How do you see the donor***?

<table>
<thead>
<tr>
<th>Someone offering cells</th>
<th>_______________________________</th>
<th>Mother</th>
</tr>
</thead>
</table>

2) **What exactly did you receive of the donor***?

<table>
<thead>
<tr>
<th>Some cells</th>
<th>_______________________________</th>
<th>A child with personality traits</th>
</tr>
</thead>
</table>

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**Ending**

[Thank participants for participating]

[Offer information about the possibility for medical and psychological help]

[Explain the interview study towards children and give informed consent when interested.)]
Appendix 5  Interview guide lesbian couples – prospective study

<table>
<thead>
<tr>
<th>Aim/technique</th>
<th>Questions/themes</th>
</tr>
</thead>
</table>
| Introduction                       | **Suggestion**: You were invited for this interview because you currently are in treatment at the fertility centre of the Ghent University Hospital. Not much research has been done to the experiences of the families in treatment so far. That is why we invited you; during this interview we would like to get to know your experiences and opinions as parents.  
  [Informed consent]  
  [Point out the possibility of taking a break, skipping questions, thinking about questions,...]  
  [Point out that no answer is right or wrong] |
| Experiences                        | **(Origins of) the child wish**  
  How did your child wish start?  
  How do you experience the treatment process?  
  How do you experience this as a couple?  
  **Decisions**  
  Who will carry the child?  
  What does this mean for you?  
  Did you consider other options (adoption)??  
  How is this for you?  
  Did you ever consider using a known donor?  
  **Environment**  
  Have you told your environment about your current treatment or not really? How come you chose (not) to tell?  
  What reaction or responses do you receive from your environment?  
  **Thinking about the future**  
  How do you picture your future family?  
  For instance, do you think about having more than one child, what are your ideas about who will carry the child, do you have any ideas about the donor,...?  
  **Disclosure**  
  Do you think you will disclose the conception method to your child or not? What are your views on that now?  
  When themes are mentioned by the participants that were not included in this guide, these are further explored.  
  [summarizing and feedback.] |

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Moral reasoning

<table>
<thead>
<tr>
<th>Parenthood</th>
<th>Selection/views on heritability</th>
<th>Information-anonymity</th>
<th>Donor: role and meaning</th>
<th>Hypothetical scenario</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parenthood is a concept with a lot of definitions. However, not one decisive definition has been given so far. That’s why we wanted to ask you. Parenthood in general, what does this mean for you? What exactly is ‘a parent’?</td>
<td>Did you record certain preferences for the donor selection? You already mentioned that X* will carry the child. One of you will have a genetic link with the child, the other will not. How do you see that? What does ‘a genetic link’ entail for you exactly?</td>
<td>The following three questions are hypothetical and it is possible you have never thought about them before. This is no problem. Imagine that your child* wants certain information about the donor* in the future, what would your reaction be? What information should be available to your child?</td>
<td>How do you see the donor* (image and meaning)? [Semantic differential scale] What duties, rights or responsibilities does the donor* have towards your child according to you?</td>
<td>To further elaborate your personal opinions in more detail, I brought a story with me that we made up. I would like to ask some questions about the story (see below). The aim is to get a better insight into your opinions, so you should answer what you think, not what can be done legally. I will read the story out loud, and you can read with me on this sheet. Imagine A would die, how would you deal with the situation then?</td>
</tr>
</tbody>
</table>

Ending

[Thank participants for participating]
[Offer information about the possibility for medical and psychological help]
[Explain the interview study towards children and give informed consent when interested.]
Semantic differential scale

What exactly will you receive from the donor*?

Some cells ____________________________________________________________ a child with personality traits