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DISCLOSURE OF GENETIC ORIGINS: PARENTAL EXPERIENCES AND ATTITUDES IN THE UK AND BRAZIL

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THESIS SUBMITTED IN FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

UNIVERSITY OF WARWICK,

DEPARTMENT OF PSYCHOLOGY,

FEBRUARY 2018

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ACKNOWLEDGEMENTS

There are a number of people who have been fundamental to the creation of this thesis, and I would like to extend my appreciation to the following people in particular:

Bourn Hall Clinic, Cambridge, and the Donor Conception Network, for recruiting embryo donation and double donation families.

Adoption Focus, for their help contacting and recruiting adoptive families.

My PhD supervisor, Fiona MacCallum, for providing endless guidance, patience, inspiration and encouragement over the last four years.

Andrea Seixas Magalhães, for welcoming me into Pontifical Catholic University of Rio de Janeiro to complete the Brazilian aspects of this thesis, and for her warmth, positivity and guidance throughout.

Lia Mara Netto Dornelles, for her help with my FAPERJ application and her support during the Brazilian research included in this thesis.

My wonderful, supportive friends, for providing me with much needed distraction and laughter.

My parents, Jayne and James Doherty, for their unconditional love and support throughout my PhD, and always.

The professionals who participated and shared their experiences of working with patients.

Finally, but most importantly, all the families who kindly shared their experiences with warmth, hospitality, and generosity.

DECLARATION

This thesis is submitted to the University of Warwick in support of my application for the degree of Doctor of Philosophy. It has been composed by myself and has not been submitted in any previous application for any degree.

LIST OF ABBREVIATIONS AND GLOSSARY OF TERMS

DCN (Donor Conception Network) – The Donor conception network is a UK-based support network that advocates openness and facilitates the sharing of information between donor-conceived children and their families.

DD (Double donation) - Double donation occurs when the sperm from a male donor and an egg from a separate female donor are fertilised to create an embryo

Disclosure – 'Disclosure' is a term used to share information with others, i.e. family and friends too, however for the context of this thesis, disclosure means sharing information with donor-conceived children

ED (Embryo donation) – Embryo Donation *usually* occurs as a result of 'surplus' embryos arising from the IVF treatment of heterosexual couples using their own gametes to conceive

FC (Female couples) – In the context of this thesis, female couples refers to a lesbian couple that conceive using donor conception

HC (Heterosexual couple) - In the context of this thesis, heterosexual couple refers to a female-male couple that conceive using donor conception

SMC (Single mothers by choice) - In the context of this thesis, single mothers by choice refers to single women who conceive using donor conception

ABSTRACT

Embryo donation (ED) and double donation (DD) are fertility treatments whereby resulting children are raised by parents to whom they are genetically unrelated. The main similarity between ED/DD and adoption is the lack of genetic parent-child relationships, and the main difference is the presence of the gestational link in ED/DD families, which provides an option of concealing genetic origins. This thesis consists of one large study followed by three subsidiary studies, with the overall aim of exploring the disclosure of genetic origins in the UK and Brazil, and the support available to assist parents with this process.

In Study I, 36 ED/DD parents, and 27 adoptive parents were interviewed to determine if and how they disclosed to their children, and identify the support that they received to manage this process. In Study II, 30 UK-based infertility counsellors completed an online survey to ascertain how they engage in disclosure-related issues with patients seeking embryo donation/double donation treatment. In Study III, 19 Brazilian parents, who conceived a child using donated sperm or eggs, completed an online survey to explore if and how they disclosed to their children, and whether they felt supported with this process. In Study IV, 24 Brazilian fertility professionals completed an online survey to determine how they engage with parents seeking treatment with donated gametes. Overall, adopters were more confident in the process of adoption revelation, and received more support in order to achieve this, compared to ED/DD parents. Findings highlight the complex nature of disclosing donor conception, and identified that Brazilian parents experience similar challenges compared to those in the UK. Disparities were found in the disclosure-related support provided both across and within these two country contexts. From these results, recommendations for how parents could be better supported with disclosure-related issues are given.

INTRODUCTION

The advancement of ED/DD treatment means that it is possible for parents to conceive and then rear children to whom they are not genetically related. For this reason, parallels have been drawn between ED/DD families and adoption; however, there are also a number of differences, the most striking one being the gestational relationship shared between ED/DD mothers and their children.

ED/DD are the fastest growing form of fertility treatment, yet there has been no research investigating in detail the disclosure processes used by ED/DD parents, and the level of support available for patients seeking these treatments. The first purpose of this thesis is to examine exactly what parents tell their children when they have been conceived by ED/DD, and how they are supported with this process. (Studies I and II). This process is typically referred to as 'disclosure' and within the context of this thesis refers to the sharing of details of conception to children who are donor-conceived. The inclusion of a sample of adoptive parents provides an opportunity to see the similarities and differences between how these parents share information, and the support available to them. Research on the outcomes of Brazilian parents who have conceived using donated gametes is scarce, and no studies have explored disclosure in this context. Therefore, the second purpose of this thesis is to explore donor conception in the Brazilian setting with particular focus on how parents experience the disclosure process, and if and how they felt supported with disclosure (Studies III and IV).

To put these studies into context, the thesis starts by discussing the background of donor conception and the implications of conceiving a child using donated gametes, in both the UK and Brazil (Chapter 1). The laws and regulations surrounding disclosure, and what is known about donor-conceived families, in both the UK and Brazil are explored in Chapter 2. Chapter 3 examines the disclosure-related support available for donor-conceived families in the UK and Brazil. Chapter 4 compares ED/DD to adoption, with specific focus on disclosure and disclosure support. At the end of chapter 4, the rationale and details for all four studies are introduced. Chapters 5 to 8 cover the four empirical studies of

the thesis, from I to IV in order. Finally, Chapter 9, presents overall conclusions, discusses implications in terms of the national context, and recommends changes to current practice.

RATIONALE FOR INCLUDING A UK AND BRAZILIAN COMPARISON

I was awarded a FAPERJ Fellowship, which enables UK-based PhD students to spend time at a Brazilian University conducting research that will form part of their PhD thesis. Consequently, I spent six months at Pontifical Catholic University of Rio de Janeiro (August 2015 – February 2016) collecting data presented in Studies III and IV.

I was motivated to apply for this fellowship because in 2013 a Brazilian Researcher, Dr Dornelles, undertook a six-month placement at Warwick University and shared an office with me. Dr Dornelles and myself had a mutual interest in donor conception and we had several detailed discussions on the similarities and differences of donor conception practice in the UK and Brazil. Dr Dornelle's informed me that there is very little Brazilian research on the disclosure of donor conception and the disclosure-related support available. My supervisor during this Fellowship was Dr Andrea Seixas Magalhães, a Brazilian Researcher who works at PUC University in Rio de Janeiro. Both Dr Magalhães and Dr Dornelles helped me to establish important contacts with fertility professionals, Researchers, Psychologists and infertility counsellors in Brazil. These relationships were integral to shaping the research questions as well as providing practical support and assistance with parent recruitment and literature reviews.

CHAPTER 1 - DONOR CONCEPTION

This chapter puts the emergence of, and current practice relating to, donor conception treatments into context. Information on donor conception practices in the UK will be followed by details regarding the Brazilian setting.

Infertility is commonly termed as the inability for a heterosexual couple (HC) of reproductive age to conceive after having unprotected sexual intercourse for at least one year (Zegers-Hochschild et al., 2009). Recent figures estimate that infertility affects around one in seven HCs living in the UK (National Institute for Health and Care Excellence, 2013). Couples unable to conceive naturally may explore family building options, two of which are adoption (see Chapter 4), or Assisted Reproductive Technologies (ART). There are several forms of ART including Intrauterine Insemination (IUI), *In Vitro* Fertilization (IVF) and Third Party Assisted Reproduction (i.e. sperm donation, egg donation and ED/DD), a form of fertility treatment that involves fertilising gametes (sperm and eggs) outside of the body.

1.1 DONOR CONCEPTION IN THE UK

IVF provides an opportunity for HCs to conceive their own genetic child with medical help; nevertheless, it does not cure infertility and some HCs may still be unable to conceive using their own gametes; for example, a man may be azoospermic. Some intended parents might require the use of donated genetic material; resulting in specialised forms of fertility treatment termed 'donor conception'. Donor conception is a process whereby sperm or eggs from individual donors, or an embryo from a donor couple are provided for use in the fertility treatment of others (the recipients). It provides HCs an opportunity to experience pregnancy and childbirth when there may be no alternative, and offers female couples (FCs), and single mothers by choice (SMCs), a chance to create a family by using donated sperm.

1.1.2 TYPES OF DONOR CONCEPTION

There are four different types of donor conception; sperm donation, egg donation, double donation (sperm and egg) and embryo donation:

Sperm donation

This occurs when the egg of a woman (recipient) is fertilised with the sperm of a man (sperm donor), who is not her partner. It is the oldest Third Party ART with the first documented papers on this dating back to 1945 (Barton, Walker, & Wiesner, 1945) and does not have to involve IVF techniques. Heterosexual couples *usually* undertake treatment with donated sperm due to a male infertility problem[1], whereas FCs and SMCs use treatment with donated sperm due to the absence of a male partner. If treatment is successful, children will be genetically related to the mother who carried and gave birth to him/her, and will also be genetically linked to the sperm donor. In the UK, despite the lack of genetic relationships, the male partner is the legal father of any resulting child (HFE Act, 1990).

Egg donation

Egg donation is when the egg of one woman (egg donor) is donated to another woman (recipient) and fertilised with the sperm of the recipient's partner. The first pregnancies reported from donated eggs were in the mid-1980s (Craft, McLeod, Bernard, Green, & Twigg, 1981; Lutjen et al., 1984; Trounson, Leeton, Besanko, Wood, & Conti, 1983), thus it is a more recent development than sperm donation. Egg donation *usually* occurs when there is a female fertility problem, such as poor egg quality or no eggs at all[2], and provides a unique opportunity for infertile women to experience pregnancy and childbirth. The resulting child is genetically connected to his/her father, and the egg donor, but is not genetically connected to the mother who carries and gives birth to the

[1] It might also be recommended due to a heritable medical condition in the male partner

[2] It might also be recommended due to a heritable medical condition in the female partner

child. In the UK, the recipient is regarded as the legal mother of any resulting child (HFE Act, 1990).

Embryo donation

The first birth after successful ED treatment was in Australia in 1983 (Trounson et al., 1983), five years after the emergence of IVF. Embryo Donation usually occurs as a result of 'surplus' embryos arising from the IVF treatment of HCs using their own gametes[3] (MacCallum & Golombok, 2007). There are increasing numbers of embryos in storage (Hoffman et al., 2003) which may be stored for up to 10 years (HFE Act, 1990). Those who have stored embryos may encounter difficulties deciding what to do with them, and may delay the decision (Nachtigall, Becker, Friese, Butler, & MacDougall, 2005). Their options are: to donate their embryos to scientific research, store them with the possibility of using them in the future, dispose of them, or donate them to a couple/individual who is experiencing infertility. If the latter option is chosen, this results in ED.

Double donation

Double donation occurs when the sperm from a male donor and an egg from a separate female donor are fertilised to create an embryo. The fundamental difference between ED and DD is that for DD treatment the sperm donor and egg donor are *usually* unknown to each other but their gametes are purposefully put together to create an embryo for a recipient; as opposed to embryo donors, who are normally a couple who have attempted IVF.

Embryo donation / double donation families

Heterosexual couples tend to resort to ED/DD treatment when other ART attempts have been unsuccessful. If ED/DD treatment is successful, neither parent is genetically related to their resulting child, instead their child is genetically linked to the couple who donated their embryo, or to the sperm and egg donor in DD. Female couples, or SMCs *usually* attempt ED/DD when previous treatments with donated sperm and their own gametes have been

[3] There may also be incidences where there are surplus embryos as a result of donor sperm treatments used by FCs/ SMCs. In these cases both parties may agree to their embryo being donated.

unsuccessful. When treatment is successful, the genetic make-up of these families is the same as for HCs.

Structurally, ED and DD are equivalent; however, there is a clear distinction between embryo donors, and individual sperm and egg donors. Sperm and egg donors have an intention for their gametes to be used in another persons' fertility treatment from the outset; in contrast, ED occurs as a result of couples, or individuals having their own course of fertility treatment in an attempt to conceive, and whilst they may later decide to donate their embryos, their initial intentions are different (Blyth, Frith, Paul, & Berger, 2011). From a psychological perspective, this is important because an embryo is a product of the couple attempting to create a child, which they may perceive as meaningful and symbolic of their relationship (de Lacey, 2007).

1.2 NUMBER OF TREATMENTS INVOLVING DONATED GAMETES/EMBRYOS

A recent report identified that 48,477 fresh[4] IVF cycles were performed in 2013 (HFEA, 2014). Of these cycles, 5% involved donated sperm, 4% involved donated eggs and less than 1% involved ED/DD. Therefore, almost one in ten fresh IVF cycles used donated gametes, however, these figures do not take into account treatment involving sperm donation that does not require IVF technologies, so absolute figures are higher. Whilst the overall numbers of treatments involving donated gametes are increasing, the proportions of donor conception treatments have remained broadly steady since 2012 (HFEA, 2014).

[4] This report is concerned with fresh IVF treatments, and does not include frozen treatments which is why the number of IVF treatments reported in the 'Egg and Sperm Donation in the UK: 2012-2013' in 2013 are lower than those reported in 'Fertility Treatment 2014 Trends and Figures' (which also refers to numbers of treatments in 2013).

1.2.1 NUMBER OF TREATMENTS BY DONATION TYPE

Sperm donation

In 2014, 2,691 fresh IVF cycles involved the use of donor sperm; this is a 6.5% increase compared to 2,527 cycles in 2013, and similar escalations have been identified yearly since 2011 (HFEA, 2016). Donated sperm in the form of donor insemination[5] is also increasing; in 2014, 4,675 DI cycles were performed, an increase of 1.1% compared to 4,624 in 2013, Overall, in 2014, 7,366 treatment cycles involved donor sperm compared to 7,151 in 2013, representing an overall increase of 3% (HFEA, 2016).

Egg donation

The number of cycles using freshly donated eggs with partner sperm has increased substantially (47.9%) over the past five years from 1,262 in 2009 to 1,866 cycles in 2013 (HFEA, 2014) then remained steady during 2014 (HFEA, 2016).

Embryo donation/double donation

The number of IVF cycles using both donated eggs and donated sperm (either DD or ED) has increased dramatically. In 2009, 256 ED/DD cycles were performed (HFEA, 2014) compared to 743 cycles in 2014 (HFEA, 2016). This represents a rapid 190.2% increase in ED/DD treatments from 2009 to 2014, demonstrating that ED/DD treatments are the fastest growing form of donor conception treatment.

1.2.2 NUMBER OF TREATMENTS ACCORDING TO FAMILY TYPE

In 2013, 6,285 patients received treatment that involved using donated gametes; most were HCs (64%) but significant proportions were FCs (21%) and SMCs (15%) (HFEA, 2014). Overall, increases in the numbers of treatments performed in 2013, compared to 2012, were identified across all three family types (HFEA, 2014). These figures are not a complete representation of the

[5] Donor insemination is the process of placing semen, from a donor, into a woman's vagina to assist her in getting pregnant and does not involved IVF techniques.

number of treatments involving donated gametes. First, the HFEA report focuses on the numbers of *fresh* IVF treatments, yet a significant proportion of IVF cycles use frozen embryos. Out of the 13,353 frozen cycles in 2013, 2% involved frozen donated embryos (HFEA, 2014), resulting in an additional 267 treatments in 2013 alone. Second, the figures do not include treatment details for the growing population of people who receive cross-border fertility care i.e. travel overseas for treatment. It is difficult to ascertain exactly how many people receive fertility treatment abroad or how many UK children result (Nygren, Adamson, Zegers-Hochschild, & De Mouzon, 2010). Third, unlike egg or ED, sperm donation can easily be performed outside of the clinical setting, through informal arrangements between friends, on 'introduction websites' and social media forums, which are not recorded by the HFEA. Between 1991, and 2011, over 35,000 children in the UK have been born as a result of registered egg, sperm or ED treatment (HFEA, 2011). However, it is likely that there are considerably more donor-conceived children in the UK.

1.3 CONSEQUENCES OF SUCCESSFUL TREATMENT

Introducing donors into the family building equation has potential psychological, legal, practical and social implications,

1.3.1 SPERM/EGG DONATION

Lack of genetic relationship to one parent

A consequence of donor conception is that the resulting child will not share a genetic relationship to his/her mother or father[6]. However, the experience of pregnancy and childbirth provides parents with an option of whether or not to tell their children about the involvement of a third party (sperm or egg donor) in their conception, and how this means that they are genetically unrelated to their children. This can be a difficult issue for parents to contemplate, and if and how parents disclose this is discussed fully in 2.1 and 2.3.

[6] When FCs and SMCs, use a sperm donation, they have a child who does not have a 'father', but instead is genetically linked to a sperm donor.

Genetic connections to donor 'siblings'[7]

In the UK, up to 10 different families can be created from the gametes of one donor[8], resulting in the likelihood that several genetically linked children will grow up in different families and may be completely unaware of each other's existence. Parents may experience difficulties determining if and how to tell their children about the possibility of donor siblings, discussed fully in 2.3.

1.3.2 EMBRYO DONATION/DOUBLE DONATION

Embryo donation was initially considered advantageous over sperm or egg donation because neither parent is genetically related to their child so it was thought that the couple's contribution to the conception was more balanced (Trounson et al., 1983). From a genetic structural stance this is true; however, there are unique psychological consequences of having a child as a result of ED/DD treatment.

Lack of shared genetic relationship with both parents

ED recipients will raise a child who is not genetically related to either parent, but who is fully genetically related to the couple who donated their embryo. The lack of genetic relationships is the same for DD treatment; children are genetically related to two separate donors. As in sperm or egg donation, ED/DD recipients can decide whether or not to reveal the use of ED/DD treatment to their children (discussed fully in 2.4).

Likelihood of FULL donor 'siblings'

For ED, the donor couple may have their own children, and/or may have donated other 'surplus' embryos to be used in the treatments of other couples or individuals. In these scenarios, children sharing the same donor couple are raised in separate families: the donor family and the recipient family(ies). For

[7] The author is aware that 'siblings' is a contentious term; however, because adoptive families are also discussed throughout this thesis, for purposes of consistency ' siblings' is used as a term to make comparisons between children sharing the same genetic information. This is not to make any assumptions about the equivalency of donor 'siblings" and children raised as siblings.

[8] Human Fertilisation and Embryology (HFE) Act 1990 (as amended by the HFE Act 2008)

DD treatment, half donor 'sibling's would arise, as in sperm or egg donation; however, there is the potential for a greater number due to the use of both egg and sperm donation.

Summary of donor conception in the UK

There is evidence of rising numbers of treatments involving donated gametes (HFEA, 2016) and, ED/DD is the most rapidly growing form of donor conception (HFEA, 2014, 2016). Data provided by the HFEA are valuable, but do not necessarily reflect the true number of people living in the UK who receive treatment with donated gametes, meaning that an ever-increasing number of UK born children are conceived using donated gametes.

1.4 DONOR CONCEPTION IN BRAZIL

1.4.1. INFERTILITY IN BRAZIL

There are around 47 million women of reproductive age (15–49 years of age) in Brazil and approximately four million infertile couples (Santos, Uga´, & Porto, 2008); which transpires to a rate of infertility in around one in ten Brazilian couples. The increase in demand for fertility treatment identified in the UK in recent years is also found in Brazil, and one reason for this is the postponement of maternity until after the age of 30 (Garcia & Bellamy, 2015). During the decade between 2000 and 2010 the numbers of women aged forty years old, or over, seeking fertility treatment in Latin America increased from 14.8% to 23% (Zegers-Hochschild, Schwarze, Crosby, & Souza, 2011).

The Latin Network of Assisted Reproduction (REDLARA) is a scientific and educational institution that brings together over 90% of the fertility clinics across Latin America. In the most recent REDLARA report (Zegers-Hochschild, Schwarze, Crosby, Musri, & Urbina, 2016) data from 56 Brazilian fertility clinics show that 24,613 treatments were undertaken in Brazil. In comparison, in 2012 (Zegers-Hochschild, Schwarze, Crosby, Musri, & Souza, 2015), data from 57 Brazilian clinics revealed that 21,452 cycles were performed, representing an increase of 18% between 2012 and 2013.

1.4.2. DONOR CONCEPTION TREATMENTS

Sperm donation has been performed in Latin America for nearly half a century (Golombok, Scott, Appleby, Richards, & Wilkinson, 2016), but REDLARA reports do not provide information on the number of treatments that use donated sperm because these procedures are not registered. In terms of egg donation, recent Brazilian data (Zegers-Hochschild et al., 2016) states that in 2013, 1738 cycles used donated eggs. This is a substantial 48.5% increase compared to 2012, where 1170 treatment cycles used donated eggs (Zegers-Hochschild et al., 2015). In consideration of ED/DD, 5,833 frozen embryo transfers were performed in 2013 (Zegers-Hochschild et al., 2016), however this figure is based on both own embryos *and* donated embryos, therefore the exact number of ED/DD treatments remains unknown. Furthermore, the exact number of fertility clinics in Brazil is also unknown (Souza, 2014).The Brazilian Society of Assisted Reproduction[9] lists 136 fertility clinics, and a recent report listed 200 Brazilian fertility clinics (IFFS Surveillance, 2013). These conflicting accounts suggest that there are considerably more clinics than the 56 that contributed to the most recent REDLARA report (Zegers-Hochschild et al., 2016). Therefore, it is probable that the actual number of treatments are considerably higher than those reported.

1.5 UK AND BRAZIL COMPARISONS

Table 1 compares donor conception figures in Brazil and the UK, as far as the data is available.

Table 1: Comparison of donor conception treatments in the UK and Brazil

	Brazil	UK
Treatment cycles	24,613	64,600
Embryo donation treatments in 2014	Unknown	743
Treatment with donated eggs in 2013	1,738	1866
Treatment with donated sperm in 2013	Unknown	2,527
Treatment with donated sperm in 2014	Unknown	2,691

As identified in Table 1, 24,613 cycles were performed across Brazil in 2013 (Zegers-Hochschild et al., 2016), which is significantly fewer than the 64,600

[9] www.sbra.com.br

cycles in UK (HFEA, 2016). The general population of Brazil is much greater than the UK, (Worldometers, 2017) so it would be reasonable to assume that the number of cycles performed in Brazil would also be proportionally larger; yet from recorded figures, this does not appear to be the case. Perhaps many infertile Brazilian HCs do not seek treatment due to the high cost of infertility treatment in Brazil (L. M. Dornelles, personal communication, April 24 2017). Overall, where information is available, data demonstrates that the number of treatments using donated gametes in both the UK and Brazil are increasing; however, data on the number of people in both the UK and Brazil, who have received treatments with donor conception, is not complete and as such, it is likely that many more conceptions involving donated gametes occur in both of these country contexts.

CONCLUSIONS

The development of IVF techniques, and the willingness of donors to provide their sperm, eggs or embryos to be used in the fertility treatment of others, has created possibilities for many people, to create and build families of their own, where otherwise it may have been impossible. There is evidence of increasing numbers of donor conception treatments in both the UK and in Brazil, and as such more donor-conceived children are being born. Treatment with donated gametes has legal, ethical and psychological implications; specifically the resulting children lack a genetic relationship to one or both of their parents. However, children share genetic relationships with their donor(s) and possibly their donor 'siblings'. Because a pregnancy is established, and childbirth is experienced, this leaves parents with an option about if, what and how to reveal details about their conception to their children. These aspects will be explored in detail in Chapter 2, along with the legal differences between donor conception practices in the UK and Brazil.

CHAPTER 2 - DISCLOSURE OF DONOR CONCEPTION

Parents face important decisions about whether or not to tell their child details about their donor conception, such as the lack of genetic relationships to parents, and how this means that their children are genetically related to others. Parents who decide not to tell their children will raise children who are unaware that one, or both of their parents are, in fact, not their genetic parent. Parents who decide to tell their children face further choices including what, when and how to tell; a process commonly referred to as 'disclosure[10]'.

2.1 DO PARENTS DISCLOSE?

2.1.1 DISCLOSURE RATES OF SPERM AND EGG DONATION

Disclosure intentions were collected from 111 parents who conceived during the 1980s using DI in the UK, Spain, Italy and the Netherlands. No parents had disclosed to their children by the time they were early school age (Golombok et al., 1996) and 82% had decided never to tell. A follow-up revealed that less than 9% of the UK sample had told their child by early adolescence (Golombok et al., 2002), and no further parents had disclosed by age 18 (Owen & Golombok, 2009). Therefore the overwhelming majority of parents did not disclose to their children at this time, also consistent with American findings (Klock & Maier, 1991; Nachtigall, Becker, Quiroga, & Tschann, 1998). The first UK study to explore the disclosure intentions of egg donation recipients included a sample of 41 DI and 21 egg donation families who had a child aged between three and eight years old (Golombok, Murray, Brinsden, & Abdalla, 1999). None of the DI families had told their child about their origins and only one egg donation couple had done so. A follow-up at age 12 (Murray, MacCallum, & Golombok, 2006) revealed that 35% of egg donation families had either disclosed or were planning to, in comparison to 11% of DI families. The higher disclosure rate in egg donation families has also been found elsewhere (van den Akker, 2006). One reason for this may be because whilst she lacks a genetic relationship, the

[10] 'Disclosure' is a term used to share information with others, i.e. family and friends too, however for the context of this thesis, disclosure means sharing information with donor-conceived children.

egg donation mother has a biological relationship with the child through pregnancy; however, conversely the fact that there is a biological relationship between an egg donation child and mother has been cited as the reason some parents feel that disclosure is unnecessary (Golombok et al., 2004; Shehab et al., 2008).

Intentions do not always result in disclosure

A longitudinal UK study, comprising 50 DI parents and 51 egg donation parents, interviewed parents when their children were aged one (Golombok et al., 2004) and found that 46% of DI parents and 56% of egg donation parents intended to tell their children about their conception. However, in a follow-up, when children were aged seven years old, only 28% of DI parents and 41% of egg donation parents had started disclosure (Readings, Blake, Casey, Jadva, & Golombok, 2011), thus demonstrating that disclosure intentions and actions are not always the same (discussed fully in 2.3.1).

Disclosure rates of single mothers by choice and female couples

In comparison to HCs, SMCs and FCs tend to be more likely to disclose because they may need to explain the absence of a father and because there is no social father to protect (Murray & Golombok, 2005). The decision to become a SMC is usually one of a well-planned nature (Murray & Golombok, 2005), which is also true for FCs; this thorough consideration could also contribute towards openness. In light of this, research has shown disclosure intentions of sperm donation to be almost 100% (Klock, Jacob, & Maier, 1996), however it is unknown if this remains true when donated eggs have also been used in the fertility treatment of SMCs or FCs in the form of DD.

2.1.2 DISCLOSURE OF ED/DD TREATMENT

There are now several studies on the disclosure rates of sperm and egg donation, however much less is known about disclosure of conception where neither parent is genetically related to their offspring

Embryo Donation

MacCallum and Golombok (2007)conducted the first UK study to explore the disclosure intentions of 21 families who had a child aged between two and five years, conceived using anonymously donated embryos. Two mothers had commenced disclosure, five planned to in the future, and five were undecided. However, the most common response, provided by nine mothers, was the decision to never tell their child. Seventeen mothers were followed up when their children, aged between five and nine years old (MacCallum & Keeley, 2008). Only three had disclosed, four intended to, and two were unsure, but again, the most frequent response from eight mothers (47%) was the decision to never disclose. Thus in the latter study, 42% of parents had either disclosed or were inclined to do so, which is comparable to findings of egg donation parents (Murray et al., 2006); however, due to the small numbers of ED families available to interview it cannot be ascertained whether they might be more or less likely to disclose compared to egg or sperm donation. Nonetheless, the majority of ED parents were still non-disclosing.

There are no other studies on ED disclosure in UK families; however, a Finnish study (Söderström-Anttila, Foudila, Ripatti, & Siegberg, 2001)found that 69% of 27 couples that had received ED treatment thought that children should be told about their conception. Only 11 couples actually had a child at the time of participating and of these parents, only 41% (*n*=4) had decided to reveal ED conception to their children, therefore the majority of parents were not planning to disclose, or were uncertain of their plans. This demonstrates that whilst overall, intended parents might think that it is best for children to be told, when it comes to the prospect of disclosing to their own children, some parents are less certain. These two studies revealed very similar proportions of parents who have, or intend to disclose ED conception to their children (41% vs. 42%), so disclosure rates appear consistent across the UK and Finland.

Double Donation

Only one study looked exclusively at parents who have conceived using both donated sperm and eggs. Landau, Weissenberg, and Madgar (2008) interviewed

11 SMCs in Israel, where ED is prohibited; so the only option for SMCs to experience pregnancy is to use donated sperm and donated eggs. At the time of the interview 11 children were under four years old and three were over four years old. None of the mothers had started to disclose, but all planned to do so in the future, although how and when is unknown.

2.1.3 REASONS FOR DISCLOSURE DECISION IN ED FAMILIES

Initially, disclosure literature primarily focused on whether parents were going to tell or not, rather than exploring the reasons that contributed towards their decision-making process (Daniels, Grace, & Gillett, 2011)**,** however recent studies have explored why parents reach their decisions. Such reasons are based on MacCallum and Golombok's study in 2007, because ED (and DD) is the focus of this thesis; however, where relevant, sperm or egg donation studies have also been incorporated. MacCallum and Golombok (2007) placed participants into a 'disclosing' group (those who had told, or who were planning to tell) comprising 7 (33%) parents, or a 'non-disclosing' group (parents were had definitely decided not to disclose, or who were unsure of their plans) comprising 14 (66%) parents.

Reasons for non-disclosure

Non-disclosers felt that disclosure would be more harmful than it is beneficial, with four main reasons identified. First, worries were expressed about protecting the child; this stemmed from two fears: 1) that it would be confusing and upsetting for children to learn about their conception, 2) that children would be upset that they would not be able to trace their donors due to the anonymous nature of their donation. These two reasons have also been provided by egg and sperm donation families (Golombok et al., 1999)**;** as well as concern that children might be discriminated against by others (Applegarth, Kaufman, Josephs-Sohan, Christos, & Rosenwaks, 2016; Lycett, Daniels, Curson, & Golombok, 2005), or that disclosure would negatively impact upon the emotional well-being of their child (Golombok et al., 1999; Rumball & Adair, 1999).

Second, ED mothers (MacCallum & Golombok, 2007) thought that disclosure could harm parent-child relationships, leading children to feel outside of the family, so protected family relationships by not disclosing. Similar findings have been reported when egg or sperm donation has been used (Murray & Golombok, 2003) in order to protect the non-genetic parent from rejection (Lycett et al., 2005; Nachtigall, Pitcher, Tschann, Becker, & Szkupinski Quiroga, 1997). In ED/DD families, parents may worry that disclosure could result in children rejecting *both* non-genetic parents (MacCallum & Golombok, 2007).

Third, ED mothers (MacCallum & Golombok, 2007) justified non-disclosure on the grounds that the mother carried the child, and that both parents were present before conception and have raised their child. These parents placed less importance on genetics and more on the rearing of children. This has also been found in non-disclosing sperm and egg donation families (Applegarth et al., 2016; Lycett et al., 2005), who felt that genetics had little or no bearing on their child's life.

Finally, MacCallum (2009) found that one mother did not disclose because she did not know what to tell her child, feeling that it was complex information that would be very difficult to explain. Some ED parents also experienced difficulty in finding the 'right' times and choosing appropriate words to disclose (MacCallum & Keeley, 2012) this issue is fully explored in 2.3.3.

Reasons for disclosure

Two reasons were identified for disclosure. First, to avoid children accidentally finding out from someone else (MacCallum & Golombok, 2007); all parents had told at least one other person so this was indeed a possibility. Egg and sperm donation families have also provided accidental disclosure as a reason for disclosing (Lalos, Gottlieb, & Lalos, 2007; Lycett et al., 2005; McGee, Brackman, & Gurmankin, 2001), and perceived accidental discovery as negative because children are likely to feel betrayed, or they might find out in an inappropriate and potentially damaging manner. Second, many disclosers felt that their children had a 'right' to know about their conception and placed importance on children having correct medical history background, and thought that children

deserved honesty (MacCallum & Golombok, 2007). Similar findings have also been identified elsewhere (Applegarth et al., 2016; Lycett et al., 2005; Rumball & Adair, 1999).

Reasons for the disclosure decision of ED are solely based on the experiences of mothers, and under the framework of anonymity. Therefore it is uncertain how similar or different these views are to the fathers, and if these would alter when identifiable donors had been used.

2.1.4 DOES DISCLOSURE HAVE A NEGATIVE IMPACT?

Effects of secrecy within families

Family secrets can increase levels of anxiety (Lane & Wegner, 1995), and can be particularly damaging when concerning biological parentage (Smart, 2009). One of the first studies to explore the feelings of donor-conceived adults was a questionnaire study of 16 DI offspring from the UK, USA, Australia and Canada (Turner & Coyle, 2000). All were aged between 25 and 55 years old at participation, so were conceived between the 1940's and 1970's. Many participants felt that their life was a 'lie' and had mistrust towards their parents for their lack of honesty about their conception. Information is unknown about the participants' age at the time of discovery or, how exactly they were told, so exactly which aspects these adult donor-offspring found upsetting are uncertain. Nevertheless, they felt that their needs and interests were not prioritised when their families kept information hidden from them, stressing the negative impact of doing so. More recently, eight adults conceived using the same anonymous sperm donor, suddenly discovered details about their conception from aged 11 upwards (Blyth, 2012a). In most instances, disclosure occurred because mothers wanted to reassure their offspring that they would not inherit a serious health condition, due to recent death or illness in a family member. Participants were generally shocked by this revelation and were concerned about the impact of this prolonged secrecy on family relationships.

Benefits of early disclosure on child's acceptance

There is growing evidence to suggest that when donor-conceived children are told about their conception prior to adolescence, and in gradual stages, then they appear to accept this. Jadva, Freeman, Kramer, and Golombok (2009) found that donor-offspring told during adulthood reported more negative attitudes towards their conception compared to those told during childhood or adolescence[11]. Scheib, Riordan, and Rubin (2005) studied 29 DI adolescents, aged 12 – 17 years old, who were aware of their origins. Most (n = 22, 75.9%) could not recall the age that they first heard about their conception, reporting that they had always known, and seven participants learnt this information aged between four and nine. Almost all participants felt comfortable about their conception, and on the whole, knowledge of their conception had neutral or positive effects on parent-child relationships. These two studies contrast sharply with the negative responses found in donor offspring who discovered details about their conception later in life, supporting the benefits of early disclosure. Another benefit is that it removes the possibility of offspring discovering that they were donor-conceived in an unplanned manner, which can negatively impact upon parent-child relationships (Blyth, 2012a).

Comparisons of relationships in disclosing and non-disclosing families

Golombok et al. (2011) found that non-disclosing DI mothers showed less positive interaction in comparison to a control group of mothers who conceived naturally, suggesting that lack of communication about donor conception reduces positive mother-child interactions. In support of this, Lycett, Daniels, Curson, and Golombok (2004) found that parents favouring disclosure demonstrated more positive parent-child relationships, and had fewer parent-child arguments than non-disclosers. However, in both of these studies the quality of parent-child relationships in non-disclosing families was still within the normal range, and positive family relationships were still experienced. A

[11] A significant relationship was not found between positive emotions and age of disclosure. Therefore offspring were not more likely to respond more positively if they are told when they are younger, but were less likely to respond negatively.

systematic review of 17 publications compared donor-conceived offspring aged 11 to 17 years old with naturally-conceived offspring (Ilioi & Golombok, 2015). Findings identified that regardless of disclosure status, donor-conceived adolescents were equally well adjusted, and also had positive relationships with their parents. Embryo donation families also appear to be faring well. When children were aged two to five years old, warm parent-child relationships were formed and children did not show any raised levels of emotional or behavioral problems (MacCallum & Golombok, 2007) and similar outcomes were identified when children were aged between five and nine (MacCallum & Keeley, 2012).

Overall, disclosure status does not appear to impact negatively upon children's development, or well-being and appears to be advantageous over non-disclosure. However, UK research discussed thus far has considered only anonymous donations; in the UK, donors now must be identifiable, and the potential impact of this is considered in Section 2.2.

2.1.5 THEORERICAL ARGUMENTS FOR AND AGAINST DISCLOSURE

The aim of this thesis is not to present a case for and against disclosure, but rather to ensure that appropriate support is available for parents to disclose to their children, should they wish to. It is worth noting that not all Researchers feel that disclosure is in the best interests of children. Guido Pennings recently wrote a controversial[12] paper (Pennings, 2017) questioning why Researchers consistently recommend disclosure, despite the lack of empirical evidence of differences in psychological well-being of donor-conceived offspring in non-disclosing or disclosing families. He concluded that Researchers often ignore their own findings when making suggestions for disclosure, which he implies they do so based on moral grounds rather than research based ones and that there is no evidence that disclosure is in the best interests of children. Another argument against disclosure is protecting the privacy of parents who have used donor conception to conceive. In their paper, Patrizio, Mastroianni and

[12] Three Researchers who specialise in Donor conception, wrote letters to the editor in response to this paper, defending their recommendations that disclosure is in the best interests of children.

Mastroianni (2001) question why infertile people using donor conception should feel obligated to disclose when fertile people enter into adulterous relationships and conceive children, yet are not honest with these children about their biological heritage.

Whilst these two viewpoints are acknowledged, this section briefly touches on a couple of theoretical underpinnings behind possible benefits of disclosure**.** The similarities between ED/DD and adoption are discussed fully in Chapter 4; however, it is important to note here two key theories learnt from adoption research, that may also be applicable to donor-conceived offspring. First, 'genealogical bewilderment' was originally introduced by Sants (1964) who identified that some adoptees experienced stress and 'incompleteness' as result of not knowing relevant details about their background. Sants argued that the sense of isolation from past generations experienced by some adopted individuals is not experienced by offspring raised by their natural parent(s), who have the continuity of their genetic background. It is possible that donor-conceived offspring might experience similar feelings if details of their genetic origins are kept hidden from them. Second, research on the identity formation of adopted individuals also provides a useful basis for exploring identity development in donor-conceived offspring. According to Erikson (1958), adolescence as a time of great productivity in identity formation. Grotevant (1997) studied the process of identity development in adopted individuals and found that during this process, it is common for adopted individuals to feel that part of themselves is missing, which is typically in relation to the lack of available information about their birth family. As discussed in Section 2.2.2, some donor conceived offspring wish to have access to details of their donors. Together, having access to information about genetic donors and openness about one's genetic origins may go some way to reducing any possibly sense of genetic bewilderment that might be felt by some donor-conceived individuals and help them to develop a strong sense of 'self'.

2.2 UK LEGISLATION ON DISCLOSURE

2.2.1 CURRENT LEGISLATION

The HFE Act (1990) legislated that all gametes involved in donor conception treatment were to be from anonymous donors[13]. In 2004, the Act was updated[14] and donor anonymity was removed; consequently when donor-conceived children born after 1st April 2005 turn 16 years old they can request non-identifying information about the donor such as ethnicity, physical characteristics, medical history, year and country of birth and the number and gender of any children that their donor(s) might have had; and from age 18 then they can request identifying information about their donor(s), such as their full names and last known address. The latest amendment[15] allows donor-conceived offspring, aged 17 and over, to access identifying information about donor 'siblings' on the premise that both parties agree to this information being shared. The updated act further states that it is best for donor-conceived children to be told about their conception during early childhood, based on evidence of emotional damage of finding out later in life.

2.2.2 REASONS BEHIND REMOVAL OF ANONYMITY

To encourage disclosure

It has been suggested that donor anonymity supported non-disclosure (Daniels & Taylor, 1993) which is evidenced by parents giving anonymity as a reason for non-disclosure (see 2.1.3). Previously, the focus was on adults fulfilling their wish to have a child, but more recently, the needs of donor-conceived offspring are attended to.

[13] There are however instances where donor-offspring have made contact with their donor relatives through informal channels such as 'The Donor Sibling Link' and the Donor Conceived Register

[14] The Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations, 2004)

[15] The Human Fertilisation and Embryology Act 2008

To encourage early *disclosure*

As stipulated in current UK law, early disclosure is now deemed to be in the child's best interests. This was based on growing evidence that when donor-conceived offspring are told about their conception before adolescence and in gradual stages then they appear to accept this (see 2.1.4). Another benefit is that it removes the possibility of children accidentally discovering that they were conceived differently, which as discussed (see 2.1.4) can have negative consequences.

An increasing number of intended parents wanted identifiable donors

Another contributing factor was the increased availability of fertility treatment for non-traditional families including SMCs, and FCs, who now form a significant proportion of treatments involving the use of donor sperm (section 1.2.2) and tend to prefer identifiable donors over anonymous donors because it provides their children with an opportunity to know more information about their donor and possibly meet them in the future (Scheib, Riordan, & Rubin, 2003).

To provide donor-offspring a chance to know their donor relatives

Some donor-conceived offspring are interested to know information about their donor relatives (Jadva et al., 2009; Scheib et al., 2005) to give them a fuller understanding of themselves; whilst not impossible through unconventional avenues[16] this is difficult to do when donors remain unknown.

2.2.3 THE IMPACT OF THE LAW CHANGE ON DISCLOSURE

UK legislation now *encourages* disclosure through the use of identifiable donors and also advises parents that disclosure is best (see 3.1.1). It does not, however, impose mandatory disclosure, so parents can decide whether or not to reveal this to their children. As explained by Ravitsky (2010), four components need to be in place in order for children to know details relevant to their donor conception. The first three aspects: 1) right to full medical history, 2) right to information relevant to development of identity and 3) right to donor's identity,

[16] Such as the Donor Sibling Link or the Donor Conceived register

are implemented by UK legislation. However, these are only possible if parents implement the fourth aspect: the disclosure of donor-conception. It has now been over a decade since the removal of donor anonymity, but little is known about the impact of identifiable donors on parents' disclosure decisions in the UK.

The impact of identifiable donors

UK Law is now reflective of other countries that support openness through the use of identifiable donors. Sweden was the first country to pass legislation about disclosure, since then other countries, including: Austria, Switzerland, Netherlands, New Zealand, Norway, Finland and Australia (Western Australia and Victoria states) only offer identifiable donors (Lalos et al., 2007). An early Swedish study found that only one, out of 92 couples, planned to disclose when they had used anonymously donated sperm (Milsom & Bergman, 1982). In 1985, Sweden banned anonymity and a later study found that 52% of parents who used identifiable sperm donation had either already disclosed, or planned to do so (Gottlieb, Lalos, & Lindblad, 2000). It cannot be concluded whether the increased number is due to the use of identifiable sperm, but it does suggest that in Sweden, parental attitudes towards disclosure changed over time. However, in Belgium, parents who had conceived using donated eggs were no more, or less likely to disclose to their children whether an anonymous or identifiable donor was used (Laruelle, Place, Demeestere, Englert, & Delbaere, 2011). Thus, the impact of identifiable donation on disclosure rates is inconclusive.

Only one study (Freeman, Zadeh, Smith, & Golombok, 2016) has explored the impact of identifiable donors in the UK. Semi-structured interviews were conducted with 31 SMCs and 47 heterosexual mothers in a couple, who had children aged four to eight years old conceived using identifiable sperm donors. At the time of the study 55% of SMC's and 36% of coupled mothers had begun to disclose. For coupled mothers, the disclosure proportions were not dissimilar to a comparable UK study using anonymously donated sperm which identified a disclosure rate of 28% at aged seven (Readings et al., 2011). Therefore, the use

of identifiable donors does not appear to have resulted in a marked increase in disclosure. One reason for this could be that parents are not receiving adequate support to guide them through the disclosure process (see 3.1.4 for full discussion), and because a formalised system of disclosure is absent (Frith, 2001).

Overall, although some studies show that parents who used identifiable donors are more inclined towards disclosure, it remains unclear exactly if and how the use of identifiable donors has shaped these trends, and if indeed parents are more likely to disclose if they have used identifiable donors, especially in the context of ED/DD.

2.3 THE 'PROCESS' OF DISCLOSURE

Parents in favour of disclosure face challenges such as when and how to share information with their children about the family building methods used.

2.3.1 THE DISCLOSURE DECISION

Couple disagreement

As discussed, there are an array of reasons behind parents' decision for disclosure and non-disclosure. An added complexity is that members of a couple might experience different feelings to their partner about disclosure. Such differences have been identified in 28% of couples who have used donor sperm (Daniels, Lewis, & Gillett, 1995), 18% of egg recipient couples (Klock & Greenfeld, 2004) and 14% of ED recipient couples (MacCallum, 2009). These figures show a similar proportion of couple disagreement, regardless of their contribution of gametes. Studies have shown that when differences occur, mothers tended to defer to the fathers' wishes of non-disclosure and in disclosing families, fathers tended to defer to their partner's wish to disclose (Daniels et al., 1995; Shehab et al., 2008). Either approach may ultimately leave one member of the couple feeling that their thoughts and feelings about disclosure are not considered. Hargreaves and Daniels (2007) found that couples who held conflicting views were unlikely to have received infertility counselling, which could have been an opportunity to discuss and work through their disclosure intentions (see 3.1 for details of counselling).

Disclosure intentions might change over the course of time

A longitudinal study in New Zealand highlights the dynamic nature of disclosure intentions. Daniels et al. (2011) interviewed 12 parents who had not planned to disclose, but now wished to tell their adolescent/adult aged DI-conceived offspring. The most prominent reasons why parents now felt compelled to disclose was because they thought it was important for their offspring to have complete information about their medical background, concerns that their offspring might unintentionally start a romantic relationship with a donor sibling, or that their offspring might accidentally find out from others. They felt

like they had betrayed their children and wished that they had disclosed sooner. This sense of regret was also found in other studies (Jadva et al., 2009; Lalos et al., 2007; Mac Dougall, Becker, Scheib, & Nachtigall, 2007) where parents felt that the prospect of disclosure felt more difficult as their child became older.

2.3.2 WHEN DO PARENTS BEGIN TO DISCLOSE

An American study (Mac Dougall et al., 2007) focused on the methods of disclosure of 112 couples (48 DI, 64 egg donation) that either had already started to tell their child about their conception, or planned to do so. Two strategies were identified:

'**Seed-planting strategy'** is when parents commence disclosure during early childhood, because they deem it important for children not to remember the day that they were told and want them to feel as though they have 'always known'. Parents felt that this minimises the chances of breaking their child's trust because they 'waited too long' to tell. Conversations typically started when children were aged three to four years old, usually in response to children asking questions about where they came from. By revealing a simple, age appropriate story that gradually unfolds over time, and within usual family activities, it was hoped that it would be 'no big deal'. Mac Dougall et al. (2007) found that some parents used this strategy as an attempt to 'practice' using the words; an approach also identified by Blyth, Langridge, and Harris (2010). The seed-planting approach has also been found in a UK study where most disclosing parents had started the process before their children were four years old (Blake, Casey, Readings, Jadva, & Golombok, 2010).

In contrast, '**Right time strategy'** is the belief that there is an ideal 'window of opportunity' in a child's ability to be able to receive and understand information pertaining to their donor conception, and parents felt that they would know when this 'right time' emerged. Parents generally considered it pointless telling their child until they were able to understand some basic details of reproduction, and tended to start the process between the age of six and seven years old.

In the Mac Dougall et al. (2007) study, around two thirds of the 38 disclosing couples had used the seed-planting strategy, and a smaller proportion of parents opted for the 'right time' strategy. Lalos et al. (2007) found similar findings whereby around a third of parents (36%, *n* = 8) wanted to first explain how children are normally conceived, before they started to explain donor conception, whereas the majority used a 'fairy-tale' approach (i.e. seed planting).

Difficulties finding the right time

Some parents delay disclosure because they think that their child is too young to understand details about their conception (Readings et al., 2011; Rumball & Adair, 1999). In a study of 108 egg recipients in the UK, USA, Australia and Canada (Blyth, Kramer, & Schneider, 2013) children being 'too young' was the most common reason for non-disclosure and the eldest child deemed too young was eleven years old. Researchers have found that the longer that parents wait to tell their children, the more difficult it is to do so (Daniels et al., 2011; Jadva et al., 2009; Lalos et al., 2007).

Couples might feel differently about when to share information

Mac Dougall et al. (2007) found that mothers tended to have a greater preference for early disclosure compared to fathers. In their study, approximately a quarter of parents used a combination of both seed-planting and right time disclosure strategies. The researchers speculated that this served as a compromise when couples had a difference in opinion on when to disclose; as such, they shared some information early and waited for the 'right time' to discuss more detailed information. Couple disagreements with regards to timing have been provided as a reason for delaying disclosure (Applegarth et al., 2016), and if this remains unresolved, may ultimately result in non-disclosure.

Relationship between delaying disclosure and anxiety

Non-disclosing parents have been found to have higher levels of distress compared to their disclosing counterparts (Golombok, Blake, Casey, Roman, &

Jadva, 2013; Ilioi & Golombok, 2015; Salter-Ling, Hunter, & Glover, 2001). Mac Dougall et al. (2007) found that parents who disclosed earlier were more comfortable with their disclosure decision, compared to those adopting the right-time strategy, who experienced higher levels of apprehension and uncertainty. Honesty featured highly in the motivations for disclosure; therefore the researchers conjectured that early disclosure allowed parents to act on this honesty earlier. In support of this Applegarth et al. (2016) found that non-disclosing parents regretted delaying disclosure, whereas parents who disclosed before their children were aged seven had the least anxiety and were most comfortable about their disclosure decision. Therefore, not only is early disclosure recommended for children, it also appears to benefit parents.

2.3.3 WHAT DO PARENTS TELL THEIR CHILDREN?

The content of parent's disclosure narratives, in MacDougall et al's study were examined and five themes identified:

"The helper" – this is the revelation that parents needed help to be able to have a baby, which was received from a donor, or doctor, or both. The donor was usually presented positively, e.g. *'a nice person gave us sperm (or eggs) and a doctor helped us to have you.'* The helper narrative has also been found elsewhere (Blake et al., 2010; Hahn & Craft-Rosenberg, 2002).

"Spare parts" – is when parents explain that they had something '*missing*' or '*broken',* or that their bodies '*worked differently*' compared to others, so '*spare parts*' were needed. E.g. '*daddy's sperm was broken, so we got sperm from a doctor*'.

"Families are different" – is when parents explain that there are different ways to make a family, and that donor-conception is one of these. Parents expose their children to different family configurations either within the community, or through books or media sources. This approach allows parents to express that their children came about in a purposeful way, and serves to foster a sense of similarity between children who are created 'differently'. This theme has also been identified elsewhere (Lalos et al., 2007).

''Labor of love'' – is the sharing of information about the desire to have children, which motivated donor conception. Examples include that children were wanted '*so badly'* and that their parents '*love them so much*' – and '*worked so hard*' to have them. Mac Dougall et al. (2007) suggested that if children are aware of how much they were wanted then they might be more accepting of their parent's decision to opt for donor conception.

"Nuts and bolts" - this approach was generally intended to be used by parents who have not yet disclosed, anticipating that they would describe the technical details pertaining to the biology of the donor conception to their children. Examples include: '*we used a donor's sperm' or 'a donor egg*' '*which was placed inside mommy and then you grew*.' This theme was also found in a UK study (Blake et al., 2010).

Parents used one or more of these approaches, beginning with basic information and adding more complex details as their children grow older (Mac Dougall et al., 2007). DI parents were more inclined to opt for the "spare parts" narrative whereas egg donation parents tended to favor the "helper" version. The authors alluded that this could be because egg donation is more invasive and risky compared to DI, so the helper version is more appropriate. On the other hand, the physically innocuous process of sperm donation makes it seem more like providing a 'spare part'. Ultimately, to facilitate children's understanding of all details of their conception, a combination of all of these techniques should be incorporated. However, it is unknown how 'seed-planters' add more information into their story to help their children to understand the more complex elements.

Difficulties knowing how to disclose

Parents may experience uncertainties about what to tell their offspring and how to share this information. This doubt stems from difficulties finding appropriate terminology to match their child's level of understanding, and concerns that their children will ask difficult questions (Isaksson, Skoog-Svanberg, Sydsjö, Linell, & Lampic, 2016). Mac Dougall et al. (2007) found that many parents were

frustrated trying to find comfortable vocabulary to discuss the use of a sperm/egg donor, and wanted assistance to build up phrases to describe the biological aspects of donor-conception, whilst maintaining their own role as the social parents. Parents often seek reassurance that they are telling in the 'best' or 'right' way (Blake et al., 2010), or seek 'definitive answers' about what to tell their children, or wanted someone to tell them what to say (Mac Dougall et al., 2007), indicating that they think that there is a correct way to disclose. In Daniels et al. (2011), some parents even asked the interviewer for guidance about how they could begin to disclose, emphasising their uncertainties about how to do so. Ultimately, reservations about how to discuss donor conception with their children may result in non-disclosure, or partial disclosure (see 2.3.4).

Difficulties with Terminology

Donor offspring in SMCs are more likely to refer to the donor as 'dad' or 'father' (Jadva et al., 2009; Scheib et al., 2005) than children in two-parent households who tend to use ' biological/birth father' and 'donor' (Scheib et al., 2003). Zadeh, Freeman, and Golombok (2016) found that SMCs carefully considered how they would distinguish the donor from a daddy. Some did this by explaining that a daddy is someone who brings the child up, or who is 'around'; others explained how the donor was not a 'day-to-day daddy' or a 'normal dad'. Scheib et al. (2003) suggest that HCs are faced with a unique scenario, not relevant in other family types, of explaining that their child has both a sperm donor and a father, or an egg donor and a mother. The complexities involved could be even more salient in ED/DD conception where children may have both a mother and an egg donor, and a father and a sperm donor.

2.3.4 LAYERS OF DISCLOSURE

Previously, disclosure was often thought as a dichotomy between secrecy and honesty; parents would either tell their children about their donor-conception, or they would not. However, when researchers explore the content of the

information that disclosing parents have shared with their children, it is apparent that sometimes, important details are missing.

Sharing information about IVF

Upon examining qualitative data, Readings et al. (2011) found that some 'disclosing' parents, had just discussed the use of fertility treatment, and did not explain that they had used donated eggs or sperm to their seven-year-old child. These parents considered that they had been open with their children, and branded details pertaining to donated gametes as either irrelevant, inappropriate for a seven year old to know, or unnecessary to share. The authors suggested that divulging information about IVF served two purposes. First, it acts as a stepping-stone to ease children, or/and parents into full disclosure; these parents may think that their children are not ready to learn all information about their conception, or they themselves may feel uncomfortable discussing the topic. Second, often the use of IVF is widely known amongst family and friends, but the use of donor gametes may not be. So disclosing IVF can be used as a mask to conceal the use of donated gametes, and as such, avoid full disclosure. Similar findings were identified in interviews of Swedish parents (Isaksson et al., 2016).

Who are the donors?

Another example of incomplete disclosure is the absence of specific information relating to the donors. Blake et al. (2010) found that whilst the majority of DI (n = 7, 70%) and egg donation (n = 7, 54%) parents referred to the involvement of donor, a significant proportion of parents had not explicitly told their children about the involvement of someone else. Furthermore, Rumball and Adair (1999) found that in DI families, the least common theme, provided by just four parents (7%), was an explanation about biological versus social parents. In support of this, Mac Dougall et al. (2007) found that to protect their role as the 'real' parents, parents minimised the importance of the donor.

Future contact with donors

Forty one percent of disclosing mothers in the UK who had used identifiable sperm had told, or planned to reveal the possibility of future contact with their donor (Freeman et al., 2016). Another UK study (Zadeh, Freeman, & Golombok, 2015) interviewed 46 SMCs who conceived using donated sperm in the UK between 2003 and 2009, and had a child aged between four and nine years old. Mothers represented the donor in one of two ways: 'donor presence' or 'donor absence'. 'Donor presence' was when mothers thought the donor was significant in family life and described him as a gift-giver, a gene-giver or a potential partner. 'Donor absence' was when parents described the donor as unknown, part of a process, or 'out of sight and out of mind'. Although there was some deviation, 'donor presence' was predominantly used when identifiable donors had been used, and 'donor absence' for anonymous donors. The focus of this paper was centred on mother's own interpretation of the donor, as opposed to how mothers tell their children about the donor. Nonetheless, it underlines the different representations of the donor, and how this may impact how parents describe the donor to their children. No studies have explored in detail if and how parents tell their children about future contact with donors.

The existence of donor siblings

Freeman, Jadva, Kramer, and Golombok (2009) explored parents' reasons for searching for their child's donor siblings via the Donor Sibling Registry; a US-based registry that enables contact between families who share the same donor. 505 parents had successfully located donor siblings, and 34% (n = 233) had told their child about the search, but the majority of children had not been told. However, most parents (68%, n = 309) who had not told their children about their search had a child less than seven years old, so the young age could be a reason for not sharing this information. In support of this, Scheib and Ruby (2008) found that one parent wanted to wait until she felt that her child was able to understand the differences between her own family and the donor family. Studies on how parents share information about donor siblings is lacking, but nonetheless these two studies reveal important insights into the

complex nature of telling children about their donor-siblings.

2.3.5 HOW OFTEN DO PARENTS TALK TO THEIR CHILDREN?

Frequency of conversations

Parents vary in the frequency that they talk to their children about their conception. But on the whole, parents view disclosure as an on-going process, were aware that their children did not yet understand all relevant details (Blake et al., 2010; Blyth et al., 2013; Lycett et al., 2005; Mac Dougall et al., 2007)and felt a sense of responsibility to help their children to understand the 'implications' of their donor conception story (Nordqvist, 2014).

Initiation of conversations

Van Parys et al. (2016) found that parents engaged in conversations about donor-conception directly in response to their children's questions, but did not tend to initiate discussions themselves. Discussions can take the form of a bi-directional approach; there was evidence from these interviews that parents adapt their communication according to the questions asked. However, some children may be less likely to ask questions, so it is less clear how their understanding would develop. A Swedish study comprising 30 parents who conceived using identifiable sperm found that parents thought that it was important to keep the story 'alive', and did so by engaging in discussions surrounding donor conception as and when opportunities arose (Isaksson et al., 2016). Making the most of opportunities arising links in with Lycett et al. (2005) findings that some parents wanted discussions to feel natural, spontaneous and not forced.

2.3.6 HOW DO DONOR-OFFSPRING UNDERSTAND WHAT THEY HAVE BEEN TOLD?

A longitudinal UK study explored donor-offspring's understanding of their conception at aged seven and ten years old. Short interviews were conducted with 12 children (6 egg donation and 6 DI) when they were aged seven (Blake et al., 2010). Four children demonstrated some basic understanding of their

conception, but the majority did not. The follow up study when children were aged ten years old (Blake, Casey, Jadva, & Golombok, 2013) found that understanding tended to increase with age. However, only just over half of the children could tell a simple story about their conception, and the remaining still had either little or no understanding. The authors concluded that children tended to provide more detailed responses aged 10, compared to when they were aged seven. This is reinforced by research on naturally conceived children, who begin to develop an understanding of biological inheritance aged seven upwards (Gregg, Solomon, Johnson, Zaitchik, & Carey, 1996; Williams & Smith, 2010). Studies are lacking on the comprehension of older children, and if and how they learn full details about their conception.

Summary of disclosure process in egg or sperm donation

Families that have used donated sperm or egg tend to use one of two disclosure strategies: parents either tell their children early so that they have 'always known' or wait for the 'right time' when they believe that their children have the required comprehension. Findings demonstrate that some parents engage in partial disclosure, and do not reveal full details to their child. If and how parents add full details over time is unknown. These studies show the complex nature of revelation and how full and relevant details are frequently missing.

2.4 DISCLOSURE PROCESS IN ED/DD

Specific details concerning what and how parents tell their children when they have been conceived through ED/DD treatment are sparse.

2.4.1 WHEN DO ED/DD PARENTS DISCLOSE?

At the follow-up UK study of ED mothers when children were aged five to nine years old (MacCallum & Keeley, 2012), only three (18%), out of 17 mothers had told their child about the donor conception, with four mothers (24%) intending to do so in the future. The three disclosing parents told at aged one, three and four, and the two parents, who intended to disclose, planned to do so when their child was aged thirteen or fourteen. The other two mothers did not specify an

intended age and planned to disclose when their children began to ask questions in relation to where they came from, or how babies are made.

2.4.2 WHAT DO ED/DD PARENTS TELL THEIR CHILDREN

The shared information in the three disclosing mothers in the MacCallum and Keeley (2012) study was examined. One told her children about 'magic sparks':

> *There were three magic sparks put in and two of them weren't able to make a baby but you, you were the other spark.* (p. 746)

She then added**:**

> *I haven't actually talked about the magic spark coming from two other people who couldn't keep her as their baby because I felt that was just ... too difficult to bring in.* (p. 746)

Therefore, she has not explicitly told her daughter what the magic sparks are, and has omitted the fact that two other people - the donors - were involved in her conception*.* The second mother's son is aware that he is a 'fertility baby' but did not elaborate on exactly what she has told him:

> *[The child] knows he's a fertility baby ... he doesn't really understand what it is.* (p. 746)

The third mother told her daughter that she needed to borrow some eggs, but did not elaborate if she informed her where the eggs came from:

> *If you said to her 'what's a donated embryo?' she would say 'Mummy had to borrow some eggs for me to be made'.* (p. 746)

As identified in egg and sperm donation families, these ED parents had also engaged in only partial disclosure. The researchers reported that these three mothers planned to share full information with their children in the future, but it is unknown how they planned to do so, and if indeed they did. In the Israeli study (Landau et al., 2008), all DD mothers planned to reveal the use of a sperm donor, but it was unclear whether mothers will tell their children about the egg

donor's involvement in their conception, hence they may also be engaging in partial disclosure.

Two studies in New Zealand provide further insights into the disclosure of ED treatment. In the first, interviews were conducted with 13 potential ED recipients (Goedeke & Payne, 2009). All but one participant valued the relevance of genetic connections between donors and their potential child, accentuated the child's right to access information about his/her origins and believed that disclosure was imperative to the child's sense of identity and wellbeing. In the second study, 22 ED donors and 15 ED recipients were interviewed (Goedeke, Daniels, Thorpe, & Du Preez, 2015). On the whole, participants also saw knowledge of genetic background as critical for physical and psychological well-being, and the development of a 'healthy sense of identity'. Further, they felt that ED created social ties between both parties; they considered themselves extended family and thought that donor siblings were particularly relevant. Relatedly, a concern commonly expressed by recipients in a Finnish study (Söderström-Anttila et al., 2001) was deciding how and when to talk to children about donor siblings. Two couples planned to contact the clinic psychologist for guidance with this.

No other studies have explored the disclosure of ED/DD, therefore exactly what and how parents tell their children about their conception remains unidentified.

2.4.3 SUMMARY OF DISCLOSURE IN THE UK

UK disclosure rates pre 2005, when gametes were anonymously donated, were low. There is evidence to suggest higher disclosure rates when identifiable donors have been used, but little is known about this in the UK context. Even less is known about the process of disclosure in ED/DD families, with only one UK study exploring, in brief, what ED parents tell their children (MacCallum & Keeley, 2012). The notion of partial disclosure is evident across several studies and indicates that rates of full disclosure may indeed be lower than anticipated.

2.5 DISCLOSURE COMPARISONS IN BRAZIL AND THE UK

2.5.1 LEGISLATION IN BRAZIL

The donation of gametes was first regulated in Brazil in 1992, under the Federal Medical Council through resolution 1358 (Conselho Federal de Medicina, 1992). In this initial resolution it was declared mandatory that secrecy be maintained for both the donors and the recipients; this has remained constant in the subsequent resolutions (Conselho Federal de Medicina, 2010, 2013, 2015). Unlike the UK, no Brazil legislation provides information, guidelines or recommendations about disclosing donor conception to any resulting child. The lack of regulation of ARTs in Brazil has been criticized due to the lack of information pertaining to the best interests of donor-conceived children (Medeiros & Verdi, 2010).

2.5.2 DISCLOSURE RATES IN BRAZIL

Only one article has been located on the attitudes of Brazilian parents who received treatment using donated eggs (Burgos et al., 1998). Fifty-eight intended parents from Chile, Brazil and Columbia completed a semi-structured questionnaire. The majority used anonymous egg donors (87%), and the remainder used eggs donated from family members. Most parents (n = 44, 76%) did not intend to disclose the involvement of donated gametes to their children, and a smaller proportion (n = 14, 24%) were unsure of their future plans. No intended parents were definitely considering disclosure, which is a finding similar to UK parents at that time (Golombok et al., 1996). The most common reasons for non-disclosure in Burgos et al's study were that the children were 'theirs' regardless of their origin, or that parents felt that it would be harmful for their child to know that they are donor-conceived. Again, these are similar to those found in UK studies. However, in light of the fact that anonymous donors are still used in Brazil, in comparison to the UK that only offer identifiable donors, the prospect of disclosure may be more difficult today for Brazilian parents. Burgos et al. (1998) study was conducted over two decades ago. There are several UK studies that explore disclosure, which have established that more recently, parents are more inclined to disclose – whether this is also true

for Brazilian parents has not been studied. Thus it is unknown if Brazilian parents tell their children about their donor conception, how they share information with their children, and whether or not the difficulties faced by Brazilian parents are similar to those experienced by parents in the UK.

CONCLUSIONS

Until recently, the vast majority of HCs did not disclose, however, now an increasing number of parents are telling their children about their donor conception. However, parents have been found to engage in different levels of disclosure, which brings about the question: what constitutes as disclosure? Little is known about how parents share information with their children about ED/DD conception. With the growing evidence supporting openness, and knowledge that ED/DD is the fastest growing form of donor conception treatment, it is important to seek to understand why some parents are reluctant, or hesitant to share information with their children about their conception, and to consider the difficulties that parents face when they contemplate disclosure. Chapter 3 examines these disclosure-related difficulties, and identifies the support available for intended parents seeking treatment with donated gametes in the UK and Brazil.

CHAPTER 3 – DISCLOSURE-RELATED SUPPORT

3.1 COUNSELLING SUPPORT

Until the past 20 years, infertility professionals advised parents to keep details about donor conception a secret and not to tell the child, or indeed anyone else (Bloom, 1957). Disclosure was considered harmful to children and parent-child relationships (Leader, Taylor, & Daniluk, 1984; Mahlstedt & Greenfield, 1989). Given the historical context, it is not surprising that the majority of parents endorsed non-disclosure (see 2.1.1). However, over the past decade, there has been a culture change, and early disclosure is now considered to be in the best interests of donor-conceived offspring (Nuffield Council on Bioethics, 2013). This concept is now endorsed by UK legislation, (Human Fertilisation and Embryology Authority, 2004), which also details support provisions to facilitate parents with this process.

3.1.1 UK LEGISLATION ON COUNSELLING PROVISIONS

When the HFE Act (1990)was implemented, the importance of counselling support in fertility clinics was recognised by stating that intended parents must be offered: *"...a suitable opportunity to receive proper counselling about the implications of taking the proposed steps, and have been provided with such relevant information as is proper*' (section 13.6). However what exactly was meant by 'proper' and 'relevant information' was not specified. In 2005, two key changes were implemented (Human Fertilisation and Embryology Authority, 2004). First, the introduction of identifiable donors (see 2.2.1), and second, that fertility clinics should: '*Encourage and prepare patients to be open with their children from an early age about the circumstances of their conception'*. More recently, section 13(6C) of the HFE Act (1990)(as amended by the Human Fertilisation and Embryology Act 2008: implemented on 1 October 2009) requires fertility clinics to provide information about:

> *'(a) the importance of informing any resulting child at an early age that the child results from the gametes of a person who is not a parent of the*

child, and

(b) suitable methods of informing such a child of that fact'.

Legislation does not provide details on how clinics should encourage and prepare intended parents to disclose early, nor stipulate that this is solely the responsibility of infertility counsellors. It is mandatory for clinics to offer counselling prior to treatment with donated gametes, but it is not obligatory for patients to take up this offer; therefore, who would be responsible to assist intended parents with issues of disclosure, if the offer of counselling were declined, is ambiguous. Nonetheless, infertility counsellors are ideally placed to discuss disclosure related issues; so how do fertility counsellors support parents and what impact does this support have on parents' disclosure decisions?

3.1.2 STUDIES ON DISCLOSURE SUPPORT IN THE UK

Studies identifying counselling support for intended parents seeking gamete donation treatment are scarce and lack detail about the content covered during these sessions. Salter-Ling et al. (2001) found that only around a third (*n* = 7, 35%) of the 20 couples that attended infertility counselling prior to their DI treatment, remembered discussing the disclosure of DI conception to their children. This highlights that disclosure was not routinely discussed; however, this study was conducted prior to legislation changes, so may not be an accurate indication of current support.

Of the studies that focus on counselling support post-legislative change, one obtained survey responses from 108 egg donation recipients, 33 (30.6%) of whom used both donor eggs and donor sperm and lived in Europe, America, Australia and Canada (Blyth et al., 2013). Sixty-seven respondents gave details about the disclosure advice they received during counselling. Of these parents, only 47 (70.1%) were told to disclose early in life. The remaining parents were advised either to disclose during adolescence (*n* = 1, 1.5%), not at all (*n* = 2, 3%), or did not receive any disclosure advice (*n* = 17, 25.3%). Respondents had children of a range of ages, so it is unlikely that the lack of disclosure encouragement can be accounted for simply by changes in professional culture.

Issues less routinely covered during counselling were that it is likely that their child would be curious about their genetic origins (*n* = 31, 46.3%), the importance of knowing that one is donor-conceived (*n* = 24, 35.5%, the possibility that children could have donor siblings (*n* = 23, 34.4%), the existence of the Donor Sibling Registry (*n* = 5, 7.5%) and information about support groups (*n* = 17, 25.4%). These findings raise some important issues about the content of counselling sessions. In particular, the lack of discussion on the consequences of using donated gametes, such as disclosure and the possibility of donor siblings. Furthermore, few parents were informed about relevant donor conception groups, which could assist with their onward disclosure journey.

A second survey focused on 214 patients who had received fertility treatment in a UK clinic (Wilde & Parsons, 2014). Fifty percent of participants had attended counselling sessions, but 33% were not offered any counselling, despite this being a mandatory legal requirement. This violates the HFEA Code of Practice that '*the centre should make patients aware that the offer of counselling is routine*' (section 3.2). The majority (61%) of parents, who were aware about the availability of counselling sessions, did not feel that the potential benefits were made transparent; 45% of patients gave this as a reason for non-attendance. Most (70%) patients who received counselling found it helpful, leaving a substantial number who did not feel that it was of benefit. Limited information is available why parents felt this way; some suspected that they were being assessed, or that it was a hurdle to get through in order to access treatment. The authors concluded that the need for support is demonstrated by the 62% of respondents who sought support elsewhere and that fertility clinics need to do more to provide appropriate emotional support.

In the most recent study, 865 participants who had received fertility treatment in a UK clinic were surveyed (Payne & van den Akker, 2016). Forty-four percent of respondents attended counselling sessions at their fertility clinic. Most (75%) attenders thought that it was useful in the following ways[17]: it helped them to understand the facts (31%), helped to explore/deal with their feelings (26%),

[17] Parents could select more than one response, hence why the total is more than 100%

someone impartial to talk to (20%), someone who understood/normalised feelings (17%), and helped to accept situation/face future (11%). The most common responses received from parents who did not find counselling helpful were: counselling was on the wrong focus/at the wrong time (39%), it was a tick box exercise (25%), and counsellor was not supportive (24%). Only 22% of participants in this study had used donated sperm, eggs or embryos, so it is unclear if findings would differ if focused solely on this patient group.

These studies have revealed important insights into fertility counselling in the UK. First, that although counselling should be offered, and patients should be informed to disclose early, according to participants, these two matters do not always occur. Second, parents are not reaping the benefits of counselling and the fact that many respondents had sought support elsewhere exemplifies this. However, these studies only look at the parent self-report data, which might not be an accurate indictor of the support as a whole. In summary, there are no UK studies that specifically look at support available for parents receiving treatment with donated gametes that take into account support available from the perspective of the clinics as well as the parent.

3.1.3 COUNSELLING SUPPORT FOR ED/DD

As discussed, ED/DD treatment has *additional* factors to explain, such as telling children that they might have full genetic 'siblings' and that they are not related to either parent[18]. As such, intended parents seeking ED/DD treatment may have different needs and therefore need to be differently managed by fertility counsellors. Research on ED families in the UK (MacCallum & Keeley, 2012) concluded that parents could benefit from practical assistance, such as material that explains the benefits of early disclosure and how they could talk to their children about their conception. No studies have focused on the disclosure support available for ED/DD parents in the UK; however, two studies conducted in New Zealand shed some light on this from the perspective of fertility counsellors working with ED recipients.

[18] In two parent families

The ED practice in New Zealand is different to that in the UK; since 2005, potential ED donors and recipients in New Zealand must participate in individual and joint counselling to discuss issues related to ED. During these sessions, counsellors facilitate and encourage communication between the two families with the intention to discuss the prospective child's rights to obtain information about his/her genetic background, and to manage expectations and plans about the on-going sharing of information and contact between families (Goedeke & Payne, 2009). As such, counsellors in New Zealand are in a unique position whereby they have a responsibility to actively balance the needs of the donor family, the recipient family and any resulting offspring.

To determine how counsellors perceive their roles and responsibilities when working with ED recipients, interviews were conducted with infertility counsellors. The two studies (Goedeke, Daniels, & Thorpe, 2016; Goedeke & Payne, 2010) each included a different sample of nine counsellors. Common themes were identified across the two studies. One of the main focuses of counselling sessions is the future child. To ensure that intended parents think about the long-term consequences, counsellors facilitate conversations about future scenarios, by asking intended parents to explore the 'what ifs' related to successful treatment. However, they were attentive to the difficulties of asking intended parents to hypothetically consider future scenarios when they are still protecting their own hopes. All counsellors were dedicated to encouraging intended parents to be open with their children. But a further, and possibly more complex, task was ensuring that intended recipients had actually processed the importance of openness, and not inaccurately claimed to do so in order to have treatment. Counsellors were mindful that some future scenarios are unknown, and that they do not always have all of the answers. To this end, counsellors believed that ongoing support should be available.

By actively guiding and empowering intended parents to confront topics that they have either avoided or not contemplated, counsellors hoped to provide clarity for intended parents and reinforce that they are making the right decision. Counsellors wanted the process to be a helpful experience that allowed patients to find a resolution, whether that is to end treatment, or to

decide that they wish to go ahead with treatment with their eyes wide open about future possibilities. However, due to the outcomes of ED being largely unknown, some counsellors expressed uncertainty and caution about how they proceed, referring to ED as 'extreme treatment' warranting significant implications counselling.

Overall, these New Zealand counsellors considered ED as having significant long-term consequences. Engaging in thoughts about future scenarios provides a space for potential recipients to decide if ED treatment is right for them, whilst also ensuring that the interests of the potential child are paramount. Whilst mindful of the differences in practice between the UK and New Zealand, the meaningful dilemmas and challenges raised are relevant to both. These include ensuring that intended parents are willing to disclose, the ambiguity of future scenarios, and the difficulties of considering the 'what ifs' prior to receiving successful treatment.

3.1.4 DOES SUPPORT IMPACT THE DISCLOSURE DECISION?

UK guidance stipulates that parents should be encouraged to disclose (Human Fertilisation and Embryology Authority, 2004), yet it remains largely unknown what impact this has had on parents' disclosure decisions; only one UK study provides some insight. Lycett et al. (2005) recruited recipients from a DI clinic that actively encouraged parents to disclose. At the time of study, when children were aged between four and eight years, only six out of 46 parents (13%) had told their child about their conception, and a further 12 (26.1%) planned to do so in the future. The most common response was either non-disclosure (n = 20, 43.5%) or uncertainty about future plans (n = 8, 17.4%). The authors concluded that the clinic's philosophy of openness had little impact on the decision to disclose; however, the manner in which intended parents were encouraged to disclose is not reported, so it is unclear what support was provided and what further support may have been needed. Furthermore, participants had used anonymous donors, which could account for, or contribute to the low rates of disclosure.

Studies looking at the impact of support on the disclosure decision have been conducted in New Zealand, where by 1994 clinic guidelines were to advise parents that it is best to tell their children of their origins (Daniels, Blyth, & Landau, 2004). Purdie et al. (1992) explored the disclosure intentions of DI recipient couples that had attended disclosure counselling. The majority (83%) either definitely planned to tell their child, or were inclined to; this is a much higher proportion than contemporaneous UK studies (Golombok et al., 1996; Golombok et al., 1999), implying that the ethos of openness in New Zealand may have contributed towards parents' increased rates of disclosure. However, another later New Zealand study (Rumball & Adair, 1999) found that even though all parents were advised to disclose early, the majority of parents had not begun to do so by the time their child was aged six years old, because they were unsure how to proceed. This is reminiscent of the difficulties that will be explored in Section 2.3.1, and presents the question: what use is encouragement alone if it is not paired with disclosure guidance and practicalities of undertaking this?

There are a number of reasons why encouragement may not result in disclosure:

Parents might not wish to disclose

As discussed, there are complex reasons behind parents' disclosure decisions. Therefore, if intended parents' own views do not align with the advice then they are likely to follow their own convictions and opt for non-disclosure (Hershberger, Klock, & Barnes, 2007). In the same way, if parents feel inclined to disclose, but have not received advice to do so, then they may indeed still disclose. This is illustrated by a Swedish study, where just under half of the disclosing parents did not recall being encouraged to disclose but had done so regardless (Lalos et al., 2007).

Inconsistent advice from fertility professionals

Different professionals working within the same clinic may provide inconsistent disclosure advice. A Swedish study (Lalos et al., 2007) identified that half of the

women (53%, *n* = 10) and three quarters of the men (77%, *n* = 13) who received DI treatment, felt that they had received unclear, and sometimes contradictory disclosure advice from fertility professionals. Only two out of 19 couples felt that both members of the couple had clearly been encouraged to disclose. An American study found that mental health professionals consistently encouraged openness, but that guidance received from doctors was more variable (Shehab et al., 2008). Similarly, Swedish gynaecologists and obstetricians were inclined to view disclosure negatively, despite this contrasting with legislation that promotes disclosure (Svanberg, Sydsjo, Selling, & Lampic, 2008). Given the discrepancy between the previous practice of advising parents to maintain secrecy and recent movement towards openness, it might be that some professionals' views have not adapted to this change, and if so, their attitudes of non-disclosure may be reflected back to patients. Current attitudes of professionals working within UK clinics are undocumented, but a recent report (Nuffield Council on Bioethics, 2013) states the need for a culture change within clinics whereby *all* clinicians value the benefits of counselling and disclosure.

The timing of infertility counselling

Research has consistently shown that many parents felt that discussions about disclosure, prior to receiving successful treatment, were premature. For instance, egg donor recipients were not ready to explore the implications of disclosure at the time of their treatment (Hahn & Craft-Rosenberg, 2002), however, at the time of participating in research (6 months to 5 years after they had given birth) parents now felt able to consider these issues. Although the need for pre-treatment counselling was recognised, parents also thought that counselling should be available after they had a child, when they are experiencing living with their disclosure decision. In the UK, Salter-Ling et al. (2001) found that prior to receiving treatment all patients received counselling, but in retrospect, they reported that their main focus at this time had been to become pregnant, not to consider disclosure. Once treatment was underway, several participants described a desire to then see a counsellor to discuss disclosure. This suggests that an opportunity to discuss this both before, and during treatment would benefit intended parents. Similar results were found in

a study exploring DD treatment in Israel (Landau et al., 2008). Information on whether or not counselling sessions were attended is absent, but at the time of treatment, most parents had not thought about the significance of having a donor-conceived child. However, in the first few years of their child's life, parents' attentions turned to the consequences of their treatment, such as the possible existence of donor-siblings and how children will react to knowing that their donors are anonymous.

As discussed, parents' thoughts and feelings of disclosure may change over the course of time. Therefore, several researchers suggest that infertility counselling should be available post-treatment, when it may be particularly valuable for parents who are unsure about if, how and when to disclose to their child (Lalos et al., 2007; MacCallum & Golombok, 2007). Applegarth et al. (2016) went beyond this and proposed that fertility centres could follow up families when their children reach ages three, six and nine years to ensure that they are getting appropriate disclosure-related support at each stage.

Infertility counsellors face ethical dilemmas

A study in Australia and New Zealand revealed that infertility counsellors share similar views on the timing of counselling (de Lacey, Peterson, & McMillan, 2015). They thought that pre-treatment discussions are sometimes not as meaningful, and that disclosure support would be most suitable after a successful pregnancy has been achieved. Furthermore, some counsellors described experiencing an 'ethical dilemma' when taking intended parents through a hypothetical journey, particularly when numerous attempts of unsuccessful treatment have occurred. By definition, implications counselling is a non-directive manner of aiding individuals to explore and understand their decisions (Blyth, 2012b). As such, counsellors should maintain neutrality on disclosure, paying equal attention to both disclosure and non-disclosure (Raes, Ravelingien, & Pennings, 2014). Yet, the very nature of legislation that promotes openness may put some counsellors in a compromising situation whereby they feel torn by their professional responsibility to respect the decisions of patients, and their legal responsibility of ensuring that the best interests of the future

child are accounted for; a predicament acknowledged by counsellors in New Zealand (Goedeke et al., 2016).

Patients need more than just encouragement

As discussed, parents may experience a range of difficulties associated with disclosure, so encouragement alone might not be enough to guarantee disclosure. Parents may desire detailed information, for example, in a Swedish study, 425 heterosexual gamete donation recipients were asked if they were satisfied with the disclosure information that they had received (Isaksson et al., 2011). The majority were, but around one quarter reported not receiving any, or enough support, and one third had a desire to receive more information or further support. In another Swedish study, parents who received successful DI treatment and now had a young child were asked to prepare advice for fertility professionals (Lalos et al., 2007). An accumulation of their responses established the need for: 1) contact with other families who have been through treatment; 2) guidance on disclosure issues, particularly when to tell their child; and 3) clinics to be aware of the psychological aspects of treatment, not just medical ones.

3.2 OTHER DISCLOSURE-RELATED SUPPORT IN THE UK

In the recent UK survey, (Payne & van den Akker, 2016) 28% of respondents sought support from Fertility Network UK, and 45% did so through another organization[19], or sought online support via general Facebook groups, twitter, and fertility blogs and forums. This demonstrates the volume of parents who feel the need to access additional support, however, few studies have looked at this aspect specifically.

[19] Examples included Fertility Friends, Fertility Zone, NGDT , DCN, HFEA, Mindful Muma to be/Embrace Fertility, The Miscarriage Association, Gateway Women, The Dove Cote, Mumsnet, NetMum'sHealthUnlocked

3.2.1 BOOKS FOR DONOR-CONCEIVED FAMILIES

One of the most common sources of support is via books that can be shared with children. Several UK studies (Blyth et al., 2010; Nordqvist, 2014; Salter-Ling et al., 2001) found that some parents used the book *My Story* (Infertility Research Trust, 1991) to aid them with disclosure. Parents in New Zealand (Hargreaves & Daniels, 2007) have also used 'My Story' and another book entitled: 'How I Began' (New South Wales Infertility Social Workers Group, 1988), which provide scripts to present the concept of donor conception to their young children. Parents also used these books as a foundation to create their own personalised books about their child's conception. Mac Dougall et al. (2007) noted that many parents reported difficulties finding disclosure-related resources; either the books were not relevant for their specific situation, or they did not match their children's level of development at the time they wished to disclose. Other studies have revealed similar frustrations and found that parents would like information about disclosure scripts and the effectiveness of different approaches (Hahn & Craft-Rosenberg, 2002; Lalos et al., 2007). There is however, a range of books designed for parents to read to their donor-conceived children, which are collated on a website[20] maintained by Librarian, Patricia Sarles (Sarles, 2017). Currently, there are over 30 books written in the English language listed here, specifically for gamete donation families. However the extent of parents' awareness of, and utilisation of, these books remains largely unknown, as is whether or not fertility counsellors routinely tell intended parents about such books.

3.2.2 SUPPORT FROM OTHER PARENTS

A commonality across both non-disclosing and disclosing parents is the desire to have contact with other parents in a similar situation. Peer support normalises the donor experience, and as such reduces feelings of isolation and stigma and provides a platform to share information from the personal, lived experiences of other parents (Thorn & Daniels, 2007). The desire for peer contact is evidenced by the growth in the number of donor conception support

[20] http://booksfordonoroffspring.blogspot.co.uk

groups in countries including Australia, Canada, New Zealand, UK and the USA (Daniels, 1997). However, parents have reported difficulties in finding other parents dealing with the same issues (Mac Dougall et al., 2007). Further, due to the pro-disclosure philosophy of support groups, parents contemplating non-disclosure have reported challenges finding someone to discuss issues with (Thorn & Daniels, 2007). Parents who intend to disclose, or who are unsure what to do, think that it would be beneficial to talk to others who have gone through the process (Hahn & Craft-Rosenberg, 2002; Mac Dougall et al., 2007; Rumball & Adair, 1999), but if and how they do this remains largely unknown. Whilst not negating parents' own responsibility to research support groups, fertility clinics are in an ideal position to inform intended parents of relevant and local groups. However, as discussed, counsellors are not routinely doing this.

3.2.3 UK BASED SUPPORT GROUPS

There are several UK based support groups including the Infertility Network[21] and Fertility Friends[22] but arguably the most popular for donor-conceived families in the UK is the Donor Conception Network (DCN). DCN advocates openness and facilitates the sharing of information between donor-conceived children and their families. As well as providing a platform for parents to meet others in a similar situation, DCN also have a number of resources designed to help parents to share information with their children. DCN have over 2,000 members; this is substantially less than the number of treatments performed that involve donated gametes (see 1.2), which suggests that either many parents do not feel the need for peer or disclosure-related support, or that parents are not aware of DCN's existence.

Two studies have looked at the impact of DCN on disclosure decisions. Salter-Ling et al. (2001) recruited couples through DCN and through fertility clinics. When asked about their disclosure intentions, all 20 DCN participants planned to disclose; however, only three (13%) of the 25 clinic participants planned to

[21] http://www.infertilitynetworkuk.com/support
[22] http://www.fertilityfriends.co.uk

do so. It is difficult to ascertain whether couples that are more likely to disclose join DCN, or if DCN influenced parents to consider disclosure; however, a study conducted by Crawshaw and Montuschi (2014) revealed that DCN had a positive influence on disclosure decisions. Survey data was collected on 79 participants who were considering building their family by using donated gametes and attended a DCN-ran Parenthood preparation workshop designed to facilitate decision-making, and prepare parents on strategies of early disclosure. On the whole, participants valued meeting others in a similar situation, were encouraged to disclose when they otherwise might not have done, and were equipped with ideas about how they could disclose and education on the benefits of early disclosure.

3.2.4 CONCLUSIONS OF DISCLOSURE SUPPORT IN UK

Counselling support

Little is known about UK counselling practice for patients seeking treatment with donated gametes, and post-legislation change, studies either do not exclusively look at parents in the UK (Blyth et al., 2013), or do not focus solely on families who have used donated gametes (Payne & van den Akker, 2016; Wilde & Parsons, 2014). Nonetheless, not all participants reported being offered counselling, or felt that the benefits of attendance were made clear. A substantial proportion of patients did not find counselling beneficial because they thought that they were being assessed, viewed it as tick-box-exercise, or felt that counselling was on the wrong focus at the wrong time. What was also striking was that patients are not routinely encouraged to disclose early, despite this being a requirement of UK law, or encouraged to consider full repercussions of their treatment (i.e. the possibility of donor-siblings). It is therefore unsurprising that parents experience difficulties such as determining when to disclose, and deciding how to reveal the possibility of donor siblings to their children.

Evidence from New Zealand (Goedeke et al., 2015; Goedeke & Payne, 2010) demonstrated that fertility counsellors considered ED to have significant long-

term consequences, and to require specialised counselling. They felt responsible to ensure that the interests of the future child are paramount, and did so by engaging patients into thoughts about possible future scenarios, which was accompanied with dilemmas and challenges. Overall, the fact that counsellors in New Zealand consider ED treatment to have such important consequences brings attention to if and how intended parents in the UK can fully prepare themselves for the implications of ED treatment, when mandatory counselling is not imposed. What, if any, impact counselling has on disclosure is inconclusive. Inconsistent advice by fertility professionals (Lalos et al., 2007) makes it difficult to observe the exact impact. Whilst counselling might encourage disclosure, without information on how to do so, and on-going support with the process, parents are often left perplexed about how to proceed.

Alternative disclosure support

Post-treatment resources have the potential to reduce any disclosure related dilemmas and obstacles encountered; however, research on these is sparse. From the few studies that have been conducted, parents reported difficulties with finding appropriate books (Mac Dougall et al., 2007). Parents seek solace from other parents in a similar situation to them, but difficulties have been experienced when trying to find like-minded people to discuss issues of non-disclosure (Thorn & Daniels, 2007). This could potentially be avoided if the consequences of non-disclosure are fully covered during counselling sessions. Support groups such as DCN provide measureable disclosure benefits, such as helping parents feel confident with their disclosure decision, and providing them with tools (Crawshaw & Montuschi, 2014). Despite these benefits, infertility counsellors do not routinely inform intended parents about the availability of support groups (Blyth et al., 2013).

There has been a recent call to improve psychological support for fertility patients globally (Blyth, 2012b) but approaches to counselling vary across countries. The following section looks at Brazil, and how it compares to the UK.

3.3 DISCLOSURE SUPPORT IN BRAZIL AND UK COMPARISONS

The availability and content of counselling in other countries is relevant for two reasons. First, so that intended parents worldwide have the opportunity to access support in relation to their treatment. Second, parents who received their treatment outside of the UK may not have been offered counselling prior to their treatment because counselling may not be available in that country. A recent study (Blyth, 2012b) identified the counselling practice in 16 countries, including England and Brazil, and found great variation in the procedures and practices of fertility counselling. Findings conclude that there is an international need to strengthen the practice of counselling, including the legal mandating of counselling and ensuring that appropriately trained and accredited professionals are available to provide support.

3.3.1 LACK OF COUNSELLING LEGISLATION IN BRAZIL

Unlike the UK, there is no legislation in Brazil that includes information or guidelines about providing counselling support for intended parents seeking treatment with donated gametes, nor is disclosure promoted in any of the resolutions. Therefore, it is the decision of individual clinics whether or not to make emotional support available. Some fertility clinics have Psychologists whose role is to provide emotional support for intended parents receiving fertility treatment and to determine what content is covered during these sessions. However, the majority of fertility clinics do not have a Psychologist, and instead other fertility professionals, such as Doctors or Nurses, provide informal support to intended parents (L. M. Dornelles, personal communication, April 24 2017).

3.3.2 EMOTIONAL SUPPORT FOR GAMETE DONATION

The only research located identifying the support that Brazilian parents received when receiving gamete donation treatment is the Burgos et al. (1998) questionnaire study. Fifty-eight donor egg recipients were asked about the level of support that they received during their treatment. Only 37% received psychosocial counselling before their treatment; however, 67% of participants

stated the desire for psychological support both before and throughout the treatment cycle, and 14% suggested a need for post-treatment psychosocial counselling. Again, this supports the notion of having a counselling service that is available beyond treatment, although, the reasons why recipients wanted this support are not stated. Further, it is unknown whether the 63% of parents who did not receive counselling was because it was unavailable, or whether they did not attend for another reason. Nonetheless, this reveals that a large proportion of egg donor recipients in Brazil were not accessing counselling.

A small group of Brazilian Psychologists meet several times a year to discuss issues relating to fertility treatment and disclosure (L. M. Dornelles, personal communication, April 24 2017). They present findings at conferences in Brazil (i.e. the yearly Brazilian Congress on Human Reproduction) and aim to raise awareness about the need for psychological support for ART, particularly gamete donation. This recent movement suggests that the importance of emotional support for donor conception families is increasingly acknowledged.

3.3.3 ADDITIONAL SUPPORT AVAILABLE FOR BRAZILIAN PARENTS

Several Brazilian authors have written books[23] designed for parents to read to their donor-conceived children. The majority have been written by Brazilian Psychologists specialising in infertility, demonstrating an awareness that parents benefit from scripts and guidance on how they can share information with children about their conception. There are no support groups in Brazil (L. M. Dornelles, personal communication, April 24 2017), so if and how parents seek disclosure-related advice is unknown.

3.4 CONCLUSIONS OF DISCLOSURE SUPPORT IN BRAZIL

Unlike the UK, Brazilian legislation does not stipulate the need for clinics to provide counselling provisions to intended parents seeking treatment with donated gametes, nor does it require fertility professionals to promote disclosure. Research on counselling support in Brazil is limited but there does

[23] Located on website maintained by Librarian, Patricia Sarles (http://booksfordonoroffspring.blogspot.com.br/search/label/Portuguese)

appear to be a recent shift whereby the need for support is receiving more attention (Dornelles, MacCallum, Lopes, Piccinini, & Passos, 2014; Lopes, 2014). However, this is mostly from the perspective of the emotional impact of infertility, as opposed to support needed to assist with issues of disclosure or non-disclosure. A few books providing guidance on disclosure are available, but overall, the level of disclosure-related support available for intended parents, is unknown.

CONCLUSIONS

Now that the importance of informing donor-conceived offspring about their origins is enshrined in UK law, infertility counselling has the potential to increase parents' confidence in disclosure. However, if and how counsellors prepare ED/DD recipients to disclose and, if and how these families access any additional forms of disclosure support are not known. In terms of genetic structure, ED/DD families are irrefutably comparable with adoptive families; therefore Chapter 4 compares disclosure practices and disclosure-related support between these two family types.

CHAPTER 4 - ED/DD AND ADOPTION COMPARISONS

Prior to the existence of reproductive technologies, a solution to childlessness was to adopt a child. There are some similarities between adoptive and ED/DD families, but also some clear differences. This chapter draws upon these comparisons paying particular attention to disclosure patterns, and the disclosure-related support available for these two family types. Before comparing the two family types, a summary of the development of adoption is provided.

A brief history of adoption

Adoption, in the sense of providing a home for other people's children and caring for them on a short-term or permanent basis has always existed, but had no legal foundations in UK until the establishment of the Department for Education (1926). At this time, focus was on fulfilling the needs of infertile couples by providing a means to create a family, and little consideration was given to the needs of that particular child (Gheera, 2014). During this era, secrecy shrouded adoption, and adopters were discouraged from revealing adoption to their child. The Adoption of Children Act 1949 (Department for Education, 1949) was the driving force behind a more developed system led by social workers in an attempt to protect children from harmful birth families. A 'clean break –fresh start' was considered best for the child, which meant that all contact with their birth family ceased post-adoption and parents were still not encouraged to disclose (Gheera, 2014). The subsequent Adoption Act 1976 (Department for Education, 1976), recognised the importance of adoptees having access to information about their origins and the interests of the child become increasingly important. Legislation stated that once the adopted person reached aged 18, they had the right to obtain a copy of their birth certificate, and any other necessary information pertaining to their adoption, and adopters were consequently encouraged to disclose. Current practice strongly emphasises adoptive parents to disclose early and fully (Department for Education, 2002).

4.1 SIMILARITIES AND DIFFERENCES OF ED/DD AND ADOPTION

Researchers have argued the differences and similarities between ED[24] and adoption. Some reason that ED more closely resembles adoption than it does gamete donation (Kirkman, 2003; Nordqvist & Smart, 2014), whereas others suggest that that ED belongs somewhere between adoption and tissue donation (de Lacey, 2005).

4.1.1 SIMILARITIES

Strong desire to become parents

The fundamental aim of intended adopters and intended ED/DD recipients is to create a new, or add to an existing family. Many adoptive parents have experienced difficulties with infertility (Kupka et al., 2003; van den Akker, 2001) so adoptive and ED/DD parents have often embarked on a similar pathway to parenthood, including failed attempts at natural conception, and commencing infertility treatment.

Genetic relationships

In both family-types, parents raise children to whom they are not genetically connected. Therefore their children share genetic relationships with their birth parents/donors, and there is also a likelihood that adopted/ED[25] children have full genetic siblings. These relationships may or may not be viewed as meaningful by all parties, however ED recipients in New Zealand considered these connections to be both important and ongoing (Goedeke et al., 2015). In particular, ED siblings growing up in separate families were thought to be significant. Donors and recipients planned how contact between siblings would be established, which included: phone calls, occasional contact for special events, emails and social media. No research has yet been conducted on ED/DD children's perspectives of these relationships. In contrast, there is an extensive

[24] ED, as opposed to DD, because donated embryos already existed from the donor couple, unlike DD which consists of creating an embryo through combining donated eggs with donated sperm

[25] This is less likely for DD due to an donor egg and donor sperm being sourced from two separate people who were not part of a couple

body of research on how adoptees perceive relationships with their birth families, and how birth family contact can enhance the adoptee's sense of identity (Crawshaw, 2002; Feast, 2003; Haimes, 1988; Sobol & Cardiff, 1983; Triseliotis, 1973).

Approaches to ED

There has been an emergence of 'embryo adoption' in both the USA ('Snowflakes', as discussed in Section 4.1.2) and in New Zealand. In New Zealand, practitioners and legislators view ED as "Embryo adoption". Indeed most of the donors and recipients in Goedeke et al.'s study (Goedeke et al., 2015) viewed ED as markedly different from gamete donation, and more similar to adoption. First, participants noted that like adoption, the child is '*completely not theirs' (p5).* Second, unlike egg or sperm donation, a child resulting from ED treatment would have '*fully-fledged, full genetic siblings' (p5);* a consequence considered important by both donors and recipients. Drawing strong parallels between adoption and ED, i.e. *'No different from a normal adoption' (p5)* provided a family-building framework that donors and recipients could relate to. Despite using such metaphors, participants acknowledged that they were not equivalent, and for them, ED was preferential to adoption. From the recipients' perspective, ED provided an opportunity to experience pregnancy, childbirth and parenting a young child, who they could shape the development of, and attach and bond with during gestation and beyond.

Infertility counsellors in New Zealand also viewed the implications of ED as being analogous to those of adoption (Goedeke et al., 2016), and drew upon these parallels in their counselling practice to ensure they do not '*repeat the mistakes of adoption*' (p. 414). In respect of this, counsellors thought that ED children should be informed of their background, and that they should have access to details about their donors. They were, however, mindful of the distinctions between adoption and ED, so they did not view them as identical.

In summary, the adoption analogy can help recipients to make sense of their method of family creation, and may provide a useful paradigm for counsellors when working with ED patients. However, the context of ED in New Zealand

more closely resembles adoption, compared to ED practice in the UK, so it is unknown if these views would be upheld by UK recipients. Also, it is unknown if DD recipients also draw upon the adoption metaphor, and in which ways.

4.1.2 DIFFERENCES

There are some very clear differences. In the UK, the HFEA acknowledges that an embryo should be granted 'respect' compared with other human tissues, due to having 'special status', but that an embryo should not be given the same status as a person. In contrast adoption involves establishing parentage, and from this fundamental distinction, other differences arise.

Gestational relationship

All categorical differences between adoptive and ED/DD parents stem from the gestational relationship shared by ED/DD parents and their children, and the absence of this between adoptive parents and their children. By childbearing and parenting from birth, ED/DD parents have an opportunity to appear like families who have conceived using their own gametes (Hill & Freeman, 2011; Keenan, Gissler, & Finger, 2012). The gestational period can also serve as a shield to conceal ED conception, and therefore provides parents with an option of whether or not to disclose to their child (Widdows & MacCallum, 2002). Furthermore, the emphasis on gestation may help ED/DD parents to feel that their child is 'theirs' from the very offset (MacCallum, 2009).

Assessment of intended parents

Due to the resemblance between ED and adoption, researchers have questioned whether the same safeguarding procedures should be implemented for these two family types (Bernstein et al., 1996). In New Zealand (Goedeke et al., 2015) some ED donors were surprised about the lack of assessing suitability of ED recipients, compared to the rigorous procedures implemented in adoption. In the UK, the assessment of adoptive parents is very different to that of ED/DD parents. For intended adopters, because a child already exists, parents are selected to meet the needs of each particular child, which varies depending on the history of the child and their family. For that reason, children are 'matched'

to an appropriate adoptive parent(s) deemed suitable to meet their needs. As part of this process, intended adopters are required to participate in detailed, lengthy assessments where information is gathered on their personality, relationship history, motivations, and how they feel about adoption (MacCallum & Widdows, 2012). This in-depth approach is in disparity to the criteria placed on intended ED/DD parents. The only requirement is that treatment will not be granted unless the welfare of any child born has been taken into account (HFE Act, 2008). Guidance is vague, but clinics should collect background information on the social and medical history of intended parents, and if concerns are raised then additional information can be sought from GPs or Social Services.

The legal status of parenthood

Under UK law, ED/DD parents are the sole legal parents from the offset the HFE Act (1990). The legalities of adoption are more complex and require consent from birth parents, or a termination of parental rights by court. Therefore the child will have already been 'parented' by a number of other people including birth parents and foster families. Children then typically live with their new adoptive family for at least several months before they are granted full parental rights (MacCallum & Widdows, 2012).

Contact with birth parents/donors

A significant development in adoption has been the emergence of open adoptions (Grotevant, Perry, & McRoy, 2005; Grotevant & McRoy, 1998) where on-going contact between the birth child and their birth family is encouraged on the premise that it is thought to promote child wellbeing (Triseliotis, 2011). Some children will have no contact with their birth family at all, but where contact exists, it ranges from the exchange of information in letters sent via the adoption agency, to regular meetings between the birth family and the adoptive family. Either approach has the potential to provide adoptive parents with more information about birth parents, such as a detailed overview of their child's genetic and social background. In contrast, ED/DD offspring in the UK will not have contact with their donor relatives until he/she reaches 18 years old, but this requires the offspring being told. However, in America, contact between

ED/DD offspring and their donors may occur sooner. For example, 'Snowflakes' is an embryo adoption programme based in the USA whereby ED donors can select a recipient couple and negotiate on-going contact between the two families (Collard & Kashmeri, 2011).

4.2 DISCLOSURE IN ADOPTION

4.2.1 THE HISTORY OF SECRECY

In the past, adopters commonly kept information about adoption a secret and did not inform their child about their adoptive status, resulting in many adoptees being shocked when they later discovered their parents had not been open with them (Sorosky, Baran, & Pannor, 1978). Furthermore, adoptees unaware of information relating to their birth family were vulnerable to emotional, identity and behavioral difficulties (Brodzinsky, 2006; Grotevant, 1997; Grotevant et al., 2005). Today, information-sharing in a developmentally appropriate manner is considered important for positive parent–child relationships and the psychological well-being and identity formation of the adoptee (Brodzinsky & Pinderhughes, 2002). In support of this, adult adoptees who experienced open communication within their families reported more satisfaction with their adoption experience (Howe & Feast, 2000), felt closer to their adopters (Sobol, Delaney, & Earn, 1994) and had fewer insecurities and emotional difficulties (Brodzinsky, Smith, & Brodzinsky, 1998). The disclosure of adoption is now viewed as morally compulsory (Palacios & Sánchez-Sandoval, 2006),but as in ED/DD conception, there is no legal mandate to disclose.

4.2.2 THE DISCLOSURE PROCESS

When do adopters disclose?

Most families begin the process of disclosure between two and four years old (Brodzinsky & Pinderhughes, 2002; Brodzinsky et al., 1998). However, whilst young children might know that they are 'adopted', what they understand about

this term is rather limited. Brodzinsky, Singer, and Braff (1984) conducted interviews with 200 adopted children between the ages of four and 13 years old. When aged around four or five-years-old, children demonstrated little, or no understanding that being adopted is any different to children who live with their birth families. By around six-years-old, children could differentiate between these two family types, but could only usually explain adoption by repeating what they had been told, rather than formulating their own understanding. It was not until around eight to 11 years, that children displayed a deeper understanding of adoption, and could acknowledge the relevance of genetic relationships. Brodzinksy (2011) notes that between the ages of six and 12, children begin to realise that birthparents may have other options rather than just placing their child for adoption, and may begin to question their connection to two different families.

Reasons for early disclosure

Harrigan (2010) conducted 11 in-depth interviews with adoptive mothers which explored how and why parents tell their young children 'adoption stories'. The first reason was to build familiarity*;* the story helped children to grow a sense of awareness about adoption from a young age. This was important so that children were never surprised by this fact in the future. The second reason was that telling the adoption story provided an opportunity for parents to become acquainted with adoption-related talk; they acknowledged that this is not an easy or smooth process and that the early delivery of the adoption story allowed information articulation without worrying that they might say something inappropriate or unclear. Brodzinksy (2011) supports this and notes that early disclosure *'normalises'* the term adoption for both the child, and the parents who may experience anxiety when initially discussing adoption.

Disclosure as a process

Adopters view disclosure as an on-going occurrence rather than a one-off event. However, Jones and Hackett (2007) found that they were often uncertain when to discuss certain aspects of adoption. Their children demonstrated a range of curiosity about their adoption, with some seeking answers from an early age,

and others seemingly disinterested. They did not want to pursue communication too insistently due to concerns that it might upset, or embarrass their child. Howe and Feast (2003) found that if an adoptee does not ask questions, or raise discussions about their origins, it does not necessarily mean that they do not wish to discuss it. This highlights one of the predicaments that adopters might encounter: they may risk revealing precise details of adoption before their child is emotionally or cognitively able to take this information on, but could also risk the perception that they are concealing important information. In respect of frequency, Brodzinsky (2005) suggested that it is one-dimensional to adopt a "more is better" approach to adoption communication, because children's needs differ over time, and instead the *quality* of communication is more important.

How do adopters disclose to their children?

In terms of the quality of communication, openness in adoption consists of two aspects: 'structural openness' - the contact and sharing of information between the adoptive family and the birth family; and 'communication openness' - discussion within the adoptive family about the adopted child's birth family, history, and other adoption related facets (Brodzinsky, 2006). Wrobel, Kohler, Grotevant, and McRoy (2003) developed the Family Adoption Communication (FAC) Model: a theory-based design that attempts to explain the evolution of family communication about adoption. It found that adoptees might withhold information from their children for a number of reasons, including: how much information they possess about the birth family, how comfortable they feel sharing information, parents' own goals, beliefs and values, their relationship with their child, children's curiosity and questioning, children's developmental stage. Overall, the FAC model considers some of the complex decisions experienced by adoptive parents throughout their child's adoptive journey, particularly with regards to the delivery or withholding of information. It does, however, not account for the emotional aspects of adoptive communication, which has been explored by other researchers.

Why might adoptive parents decide to withhold information?

In support of the FAC model, research has found that adopters worry that children's reaction to certain new knowledge could affect family dynamics, self-esteem or sense of security; so withholding information serves as a protection mechanism (Brodzinsky & Pinderhughes, 2002). Interviews with 20 adoptive parents (MacDonald & McSherry, 2011) revealed that although they thought that honesty was imperative, they were cautious about what level of information they shared, often referring to the child's birth family history as 'huge', 'disturbing' and a 'burden' for the child[26]. They found it difficult to strike the balance between sharing complex and potentially emotional topics, whilst still promoting their child's self-esteem. Adopters were aware that their child only grasped a basic understanding of adoption but felt that it was age-appropriate and considered themselves as 'gatekeepers', keeping more complex details safe until their children were old enough to understand.

4.2.3 THE CREATION OF CHILD-FRIENDLY STORIES

Storytelling is deemed imperative because it acts as a tool to begin to form the child's sense of their own identity (Galvin, 2003) and can impact upon their self-worth (Friedlander, 1999). Jones and Hackett (2007) interviewed 10 UK couples that had adopted children ranging from seven to 26 years old. Participants told a minimum of three stories: the adoptive parents', the adopted child's, and the birth parents', which dealt with a range of complex, and sometimes competing motivations, feelings and experiences[27]. The stories reflected happiness, welcomed the child into the family, and conveyed information about birth families. In another study, 11 in-depth interviews examined what and how mothers disclosed to their children aged three to 17 years old (Harrigan, 2010). Analysis revealed disparity in the method and frequency of storytelling, but a theme common in all families was that the story was told in an interactive manner that ensured that children were actively

[26] This is likely to be more problematic today when large numbers of adoptions follow neglect/abuse, rather than in the 1960s when adoptions frequently occurred as a result of the pregnancy of unmarried women

[27] Additional stories may include information about time spent in foster care

involved. Parents did not deem the story as complete, but rather one that requires developing over the course of time, supporting the notion of disclosure as a process. In terms of story evolution, participants did not alter the original content, but instead added details according to children's reactions, questions or developmental stage. The stories had two overarching aims: to positively reinforce feelings about adoption, and to help the child build a complete life history.

Positively reinforcing adoption

Adoption stories can positively reinforce perceptions in several ways (Harrigan, 2010). First, by reinforcing the birth parents' positive intentions that adoption was a result of love and concern of the well-being of the child. Second, adopters reinforced positivity by telling children about the 'great lengths' they went to in order to adopt, to demonstrate how wanted they are. Third, the permanent nature of the adoptive family was emphasised to reassure children that these relationships are of a lasting nature. Fourth, parents stressed their desire to become parents to demonstrate how much thought had gone into the process. Finally, the special qualities of the child were emphasised, and how it was that particular child that adopters were looking for. However, presenting adoption in a positive manner does not come without challenges, specifically when sharing information relating to the rejection of a child by a birth mother or father, whilst attempting to maintain positivity and honesty (Jones & Hackett, 2007).

Building a complete history.

Harrigan (2010) also found that adoption stories allowed parents to fill in any potential gaps in their child's history, and to generate a sense of completeness. To this end, adopters felt that it was vital to tell the story from the very beginning, so that their child could develop a true understanding of their adoption. They did not want to leave their child to fill in any 'blanks' and thought that adding untrue elements of fantasy would be deceiving their children. Therefore, they only engaged in sharing factual information, and did not fabricate or speculate upon unknown information.

4.2.4 DISCLOSURE COMPARISONS BETWEEN ADOPTION AND ED/DD

There has been little research directly comparing disclosure processes in adoption and ED/DD. In the MacCallum and Keeley (2012) UK study, all 24 adoptive mothers had told their child about their adoptive status, whereas only three ED mothers (18%) had begun to disclose to their child. The study also included a sample of IVF mothers, who were much more inclined to disclose compared to ED mothers, thus the authors concluded that the key issue influencing non-disclosure in ED mothers was explicitly the use of third-party conception. On examining the content of what parents had told their children, almost all adopters had used the term 'adopted' with their child, and provided some information about what this means i.e. *'She is aware that she isn't our blood child, she does know that.'* (p.746). Around a half of the adopters explicitly discussed pregnancy and felt that their children had understood that 'tummy mummies' are different from social mummies. In comparison, ED mothers provided fewer details of genetic relationships, and as discussed, none of three disclosing mothers had specifically referred to the use of other people in their conception.

4.3 MANDATORY SUPPORT AND RESOURCES FOR ADOPTERS

4.3.1 ADOPTION TRAINING AND LIFE STORY BOOKS

Adopters must attend a training programme, including a mandatory group with other intended adopters, to educate them for the skills that they will need as an adoptive parent, and equip them with advice and prepare them for how they can help children to understand their background. Upon placement, adoptive parents are provided with a Life Story Book (LSB), containing information about their child's history, typically including drawings, photos, family trees, and written text narrating the story. In the UK, it is considered compulsory for children to receive a LSB as they enter their adoptive family (Department for Education, 2014). As well as being considered a 'right' so that adoptees have appropriate information about their history (Feast, 2010), LSBs facilitate conversations about adoption (Jones & Hackett, 2007).

Whilst having the potential to be useful, some adopters have expressed concerns over incompleteness, inaccuracies, and the overall poor quality of the LSB (Selwyn, Wijedasa, & Meakings, 2015). Watson, Latter, and Bellew (2015) conducted focus groups or telephone interviews with 40 adoptive parents who had children ranging from two to 15 years of age. Although all adopters should have received an LSB, this was not always the case. One father and his partner created their own book based on materials provided by the adoption agency. Upon reflection, this couple were pleased that they were not provided with a book because they thought deeply over every picture and every word, and had complete control over the final product. On the whole, parents welcomed the idea of LSBs, and particularly liked that they contained photos of birth family members. Those most satisfied felt that their LSBs were age appropriate, explained the story well, and avoided using 'fairytales'; reinforcing the concept that adopters do not wish to fabricate information. Unsatisfied parents felt that the LSB lacked a storyline, was poorly produced and contained unsuitable or inappropriate information. This could be because LSBs are a simplified version of the truth, which often neglect the birth parents' perspective (Baynes, 2008). In particular, LSBs frequently overlook the role of the birth father in the child's history (Baynes, 2008; Ryan, 2000). If LSBs do not contain accurate and complete information about the birth family, representing both the birth father and the birth mother, then an adoptee might struggle to gain a comprehensive understanding of their background.

Adopters should be educated and prepared by their social workers on how engage their child in their LSB (Ryan & Walker, 2007). However, when this was assessed (Watson et al., 2015), support ranged from no training at all, to beneficial sessions where adopters were shown example LSBs and could discuss issues with other adoptive parents. Adopters were aware that every child is different, nonetheless, they would have liked to be told an approximate ideal age of when to start using the LSB. They also would have liked training on how to use it, how to respond to any questions that their children might ask, the best way to update the book (Watson et al., 2015) and how to discuss difficult issues (Jones & Hackett, 2007).

4.3.2. ADDITIONAL SUPPORT/ RESOURCES

In addition to the support from state authorities, there are many web-based resources that can help parents to discuss life story history with their children. One of these is a computer based tool developed in the UK entitled 'In My Shoes', which uses images, videos, sound and speech and takes children through a series of modules that encourage them to share experiences and emotions with others (Calam, Cox, Glasgow, Jimmieson, & Groth Larsen, 2000). Many adopters access alternative adoption-related support, including Joy Rees training[28], psychotherapy sessions on LSBs, play therapy, social worker support and drop-in sessions ran by the adoption team (Watson et al., 2015). In addition, a wealth of books[29] cover a variety of adoption related topics such as the timing of disclosure, advice on sharing information (particularly that of a difficult nature), useful conversation techniques, example scripts, guides on how to make a LSB, questions that children are likely to answer alongside explanations and age-appropriate answers, as well as story books designed for parents to read with their children.

Support groups

Adoption UK[30] is an online support group providing a variety of links, articles and resources that adopters may access. They run regular workshops entitled 'Telling about adoption', which include interactive material on the importance of disclosure, age-appropriate explanations, exploring child identity, development, and the practicalities of life story work. Other popular groups that provide a plethora of on-going disclosure support include: CoramBAAF[31], After Adoption[32], Families that Last[33], First 4 Adoption[34] and Family lives matters[35].

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[28] Joy Rees Training is comprehensive support on Life Story Books of adopted children.
[29] Listed on websites:
http://booksfordonoroffspring.blogspot.co.uk/search/label/adoption
http://corambaaf.org.uk/bookshop

[30] https://www.adoptionuk.org
[31] http://corambaaf.org.uk
[32] http://www.afteradoption.org.uk
[33] http://www.familiesthatlast.org.uk/support
[34] http://www.first4adoption.org.uk/adoption-support/adoption-support-services/#

4.3.3 SUPPORT COMPARISONS BETWEEN ADOPTION ED/DD

One of the main differences in the disclosure-related support available is that it is mandatory for adopters to attend preparation sessions, which amongst other aspects, equips them with the tools and techniques to disclose to their child, and for adoptive children to receive a LSB. In comparison, ED/DD parents are merely invited to attend a counselling session prior to treatment, which is not a mandatory requirement. Whether ED/DD parents do indeed attend these sessions, and if and how they are prepared for the complexities of disclosure during these voluntary sessions are unknown. There are also far fewer alternative resources available for ED/DD parents compared to adoptive parents. This could be due to the higher frequency[36] of adoptions that occur, or because ED/DD is a much newer family building option.

SUMMARY OF ED/DD AND ADOPTION COMPARISONS

There is a wealth of information exploring how adoptive parents disclose to their children. The process typically begins early in the child's life around the ages of two and four years old (Brodzinsky & Pinderhughes, 2002; Brodzinsky et al., 1998). Therefore adoptive parents do not appear to have the same difficulties as donor-conceived families when determining when to first begin disclosure. Adopters feel that early disclosure is imperative (Harrigan, 2010) and view disclosure as an on-going process rather than a one-off event; a pattern shared by donor-conceived families, but which may or may not be employed by ED/DD families. One of the difficulties faced by adopters is that they want to be honest and truthful, but may choose to withhold potentially difficult and complex information in an attempt to protect their children from harm (Brodzinsky & Pinderhughes, 2002; MacDonald & McSherry, 2011). As such, adoptive parents not only have to decide when to begin to tell their child about their background, but also need to determine if and when to tell their

[35] http://www.familylives.org.uk/advice/your-family/fostering-adoption-kinshipcare/how-to-tell-your-child-they-are-adopted/

[36] In the UK, 5,821children were adopted during the year March 2014 and March 2015 (BAAF website; CORAM BAAF, 2016), compared to the 743 ED/DD treatments cycles performed in 2014 (HFEA, 2016).

child additional information as they become aware of it through either the birth family or adoption services. It could be speculated that ED/DD parents are less likely to obtain new information, due to the inability to contact the donors until ED/DD offspring are aged 18, so are unlikely to encounter this prospect.

Adopters used a minimum of three stories incorporating information from the perspectives of the adoptive parents', the adopted child, and the birth parents (Jones & Hackett, 2007). Adopters wanted their children to feel loved by their birth parents, and that adoption was a well thought out decision, of a permanent nature (Harrigan, 2010). Further, they emphasised the importance of the truth and giving their children a complete history, to avoid their children inventing fantasies (Harrigan, 2010; Watson et al., 2015). It could be argued that adoptive parents have a more 'complex' story to tell by incorporating information from all parties in the adoption journey. It is unclear whether ED/DD parents would employ a similar technique and incorporate information about all parties involved: themselves as parents, their child and also the donors.

CONCLUSIONS

ED/DD and adoptive families share significant parallels, and key milestones in adoption, particularly the importance of information about one's history, have helped shape donor conception practice. Now that ED/DD offspring can access identifying information about their donors, the differences between adoption and ED/DD are diminishing further. Overall, there has been a change in climate from one of secrecy to one of openness in adoption and donor conception; however, it is unknown if this has also extended to the disclosure of ED/DD.

THE CURRENT STUDIES

RATIONALE FOR UK STUDIES

ED/DD is the most rapidly growing form of donor-conception treatment; however, no UK studies have explored disclosure intentions of parents under the framework of identifiable donors, or the process of disclosing ED/DD conception to their children (see Chapter 2). With UK law promoting disclosure, and growing evidence supporting the importance of openness, it is imperative to understand why some parents are reluctant, or hesitant to share information with their children. Information on the support available for ED/DD recipients is also lacking (see Chapter 3). Studies I and II assess: 1) how parents make disclosure related decisions, 2) how parents manage the process of disclosure, 3) disclosure-related difficulties that parents encounter, and 4) the current level of support available. As adoption has much higher disclosure rates, and more established support practices, comparisons between the two family types will identify whether it is the lack of genetic connections that is problematic, or something more specific to the nature of ED/DD. Study I examines this from the perspective of the parents themselves, whereas Study II focuses on the perspective of infertility counsellors.

STUDY I: PARENT INTERVIEWS: PARENTS' EXPERIENCES OF SHARING INFORMATION WITH THEIR CHILDREN ABOUT THEIR CONCEPTION

A qualitative approach, comprising questions carefully prepared based on the literature review, in the form of in-depth, semi-structured interviews, was chosen in order to obtain detailed data. The inclusion of a cohort of adoptive parents, allows a detailed comparison between these two family types, with particular focus on how parents tell their children about the lack of genetic links to their parent(s) and shared genetic links to their birth family/donor relatives.

Aims

The first aim was to identify if and how ED/DD parents disclose to their children, and the reasons behind their decision, and to compare this with adoptive families. The second aim was to ascertain the extent to which parents felt supported with disclosure related issues.

STUDY II: COUNSELLING SURVEY: HOW ARE PARENTS SUPPORTED WITH THE PROCESS OF DISCLOSURE?

UK legislation states that parents must be offered a 'suitable opportunity' to attend counselling prior to receiving ED/DD treatment (see Chapter 3). Infertility counsellors are ideally placed to prepare intended parents for the process of disclosure. However, there is no existing data on the extent that counsellors encourage and prepare intended ED/DD parents to disclose, and whether clinics allow on-going access to support post-treatment (see Chapter 3). An anonymous online survey consisting of a combination of multiple-choice and open-ended questions was used to gain information from infertility counsellors about their experience of disclosure-related counselling.

Aim

To identity how infertility counsellors in the UK encourage and prepare ED/DD recipients to disclose to their children

RATIONALE FOR BRAZILIAN STUDIES

Research on gamete donation is a relatively recent development in Brazil, and no research has identified whether or not parents disclose, how parents reach this decision, and any disclosure-related difficulties that they might encounter. The importance of support for donor gamete recipients is becoming increasingly recognised around the globe; however, Brazilian legislation does not stipulate disclosure advice or recommendations on how infertility professionals should work with gamete donation recipients (see Chapter 3). Studies III and IV were designed to find out how Brazilian parents experience disclosure and to identify the disclosure-related support available to them.

STUDY III: WHAT DO BRAZILIAN PARENTS SAY TO THEIR DONOR-CONCEIVED CHILDREN AND HOW DO THEY FEEL SUPPORTED WITH THIS PROCESS?

An anonymous online survey design, consisting of a combination of multiple choice and open-ended questions was chosen to capture the experiences of Brazilian parents who have created their family using donor conception. Due to the secretive nature of donor conception in Brazil, and the lack of existing research, parents who had used either donated sperm, eggs or embryos in their treatment were included to reach as many parents as possible.

Aims

The first aim was to identify whether or not parents disclose to their children, the reasons behind their decision, and to ascertain how parents disclose. The second aim was to determine if and how parents felt supported with disclosure-related practicalities, and to identify any areas of support that they may need.

STUDY IV: HOW DO BRAZILIAN FERTILITY CLINICS SUPPORT PARENTS WITH DISCLOSURE?

An anonymous online survey design consisting of a combination of multiple-choice and open-ended questions was chosen to acquire information on the emotional[37] support available for patients seeking treatment with donated gametes in fertility clinics in Brazil.

Aims

The overall aim of this study was to identify the support available to Brazilian parents who are seeking treatment with donated gametes, with particular focus on how intended parents are supported with disclosure-related implications

Ethical approval

Ethical approval for these four studies was received from the ethics committee at the University of Warwick (see Appendix 1).

[37] Counselling has been termed as 'emotional support' because not all practitioners in Brazil who provide support of this nature are qualified counsellors

CHAPTER 5 - STUDY I

5.0.1 STUDY I OVERVIEW

No UK research has looked at exactly what children are told when they have been conceived by ED/DD treatment, and how they are supported with this process. The inclusion of adoptive parents allows a detailed exploration of exactly what parents tell their children about their conception/adoption, and how parents are supported with disclosure-related implications.

Aims

The first aim was to identify if and how parents disclose to their children, and the reasons behind their decision. The second aim was to ascertain the extent to which parents felt supported with disclosure-related issues

Research questions

The specific research questions are as follows:

1. The disclosure decision
    i. What proportion of parents disclosed to their children?
    ii. What are the reasons for their disclosure decision?
    iii. How do parents feel about their decision?

2. The process of disclosure
    i. How are disclosure-related conversations initiated?
    ii. How frequently do conversations occur?
    iii. What are the common themes in the narratives that parents tell their children?
    iv. What do children understand?
    v. What do parents find difficult?
    vi. Do parents have any worries or concerns about the future?

3. Disclosure-related support
    i. What support did parents receive from their fertility clinic/adoption services to help them with the process of disclosure?
    ii. Did parents access any disclosure support elsewhere?
    iii. What further support, if any, do parents need to assist them with the disclosure process?

5.0.2 MATERIALS AND METHODS

PARTICIPANTS

Out of the twenty-seven adoptive parents, seventeen were mothers and ten were fathers (63% vs. 37%). In comparison, out of thirty-six ED/DD parents, thirty-one were mothers and five were fathers (86.1% vs. 13.8%).

ED/DD parents

Thirty-six parents, from 31 different families, who had a child as a result of ED/DD treatment were recruited through one fertility clinic, and one UK-based support group (DCN[38]). So that confidentiality could be maintained, parents initially received a participant information leaflet from the fertility clinic, informing them about the study (see Appendix 2). All parents who had a child aged between three and nine years old inclusive, as result of ED/DD treatment, were invited to participate. This age range was chosen because based on previous research (Mac Dougall et al., 2007; MacCallum & Golombok, 2007) it was anticipated that parents would not start talking to their children until around the age of three, and a maximum age of nine years meant that all children would have been conceived post UK legislation change. A total of eighteen letters were sent to eligible parents, and nine of these parents

[38] As discussed in section 3.2.3, DCN is a UK based support groups that advocates openness and facilitates the sharing of information between donor-conceived children and their families.

participated in this study, representing a response rate of 50%. Participants responded directly to the Researcher who then initiated contact.

Due to the sensitive and often secretive nature of fertility treatment, it proved difficult to find fertility clinics to agree to help to recruit parents. To purposefully sample for parents who were open to disclosure, participants were also recruited through DCN, via an advert (see Appendix 3) placed in their monthly newsletter asking parents who had a child up to nine years old inclusive, as a result of ED/DD treatment, to participate. Parents who had a child aged less than three years old were also included at this point, for two reasons. First, because it became apparent from initial parent interviews that some parents started to disclose to their children before they were three years old. Second, the addition of younger children allowed more recent experiences of implications counselling to be explored, providing a more accurate representation of current counselling support. A total of twenty-nine parents responded to the advert, and twenty-seven of these parents participated in this study. Thus 75% (n = 27) of ED/DD parents who participated in this study were recruited through DCN, and 25% (n = 9) parents were recruited through the fertility clinic. Nineteen parents received their treatment in the UK, and 17 parents received their treatment abroad.

Adoptive parents

Adopters were recruited via a UK adoption service. All parents who had an adoptive child aged between three and nine years inclusive, who had been placed with them for a minimum of one year, were invited to participate. Parents were sent an email via the adoption service (see Appendix 4) and were asked to contact the researcher directly. Thirty-one parents responded, and twenty-seven of these parents participated in this study, representing 17 different adoptive families.

5.0.3 DEMOGRAPHIC CHARACTERISTICS

Demographic characteristics rated on interval scales were compared using Independent Samples T-Tests and categorical demographic characteristics were compared using χ^2 analyses (see Table 2 for a summary of demographic information). Target child1 refers to the first child that parents had that fits the study criteria.

Table 2. Demographic Characteristics of ED/DD and adoptive families

	Adoption ***n*** **= 27**		**ED/DD** ***n*** **= 36**			
	Mean	**SD**	**Mean**	**SD**	***t***	***p.***
Age of parents						
At interview (years)	45.4	4.86	48.4	3.35	-2.93	.015
When had target child 1 (years)	38.3	5.02	43.7	2.62	-5.51	.000
Age of target child 1 (months)	84.4	21.4	56.3	28.61	4.27	.000
No. of fertility treatments	1.1	1.85	6.3	4.09	-6.12	.008
	N	**%**	**N**	**%**	χ^2	***p.***
Family Structure					21.13	.000
Couples	26	96.3	18	50		
Single mothers	1	3.7	18	50		
Children					7.64	n.s.
Number of boys	14	41.2	32	59.3		
Number of girls	20	58.8	22	40.7		
Parents					24.3	.000
Mothers	17	63	31	86.1		
Fathers	10	37	5	13.8		

Parent demographics: comparisons between ED/DD group and AD group

There were group differences in the age of the parents at the time of interview; ED/DD parents were significantly older than adopters. There were also group differences in the age that parents had target child1; ED/DD parents were significantly older than the adopters at the time that they became a parent to target child1. There were also group differences between the number of mothers and fathers who participated in each group. There were also significant group differences between the family structures of each group. Out of the twenty-seven adoptive parents, twenty-six were in a couple at the time they adopted their child, and one was SMC, whereas of the thirty-six ED/DD parents, eighteen were in a couple at the time of treatment, and eighteen were SMCs.

Finally, ED/DD parents attempted significantly more fertility treatments before they successfully became pregnant with target child 1, compared to adopted children.

Children demographics

There were eighty-eight children, 46 boys, and 42 girls (52.3% vs. 47.7%). The age of the first target child varied between groups, with ED/DD children being significantly younger than adoptive children; this is unsurprising due to the inclusion of ED/DD children aged under three-years-old.

5.0.4 PROCEDURE

When each participant made contact with the researcher by phone, or email, they were informed about details of the study and had the opportunity to ask any questions. The researcher then sent the relevant Participant Information Leaflet (see Appendix 2 and 5) to the participant, and after reading it a date was arranged for the researcher to visit participants in their home to conduct the interviews. Where relevant, both members of a couple were invited to participate. All interviews were conducted one-to-one, so when both members of a couple participated, it was in two separate interviews. Before the interviews commenced, participants were asked to read and sign the consent form (see Appendix 6). The length of interviews ranged from 50 minutes to 180 minutes,

and the average length was approximately 80 minutes. The same researcher (ND) conducted all interviews and the supervisor (FM) listened to 10% of the interviews for quality assurance purposes.

Interviews were conducted with 100% of the mothers in this study, and in families where a father was present, with 68.2% of fathers. Fewer fathers participated due to work commitments or because they were less keen to participate.

5.0.5 INTERVIEW MEASURES

Semi-structured interviews were chosen to illicit detailed information about parents' experiences of disclosure and disclosure related support. ED/DD interviews were loosely based on previous research conducted by the PhD supervisor (FM) (MacCallum & Golombok, 2007) but were extensively developed in order to account for recent legislative changes of donor conception, and included the addition of a section exploring disclosure-related support. The adoption interviews remained as consistent to ED/DD interviews as possible, but terminology was altered where necessary to ensure that the interview was relevant to adoptive parents[39].

Fathers' interviews were adaptations of mothers' interviews, however information regarding demographic background was not included because this information was collected from coupled mothers. Interviews (see Appendix 7 and 8 for the mothers' interviews) focused on the following four main areas of interest:

i) Background information

Demographic information was obtained about the family-type, how families were created, and the motivations behind ED/DD treatment/adoption.

[39] i.e. referred to birth parents as opposed to donors, and adoption training as opposed to infertility counselling.

ii) The disclosure decision

Questions explored parents' disclosure decision, how they arrived at their decision, and any difficulties or concerns that had encountered when making their decision. Non-disclosing parents were asked about their future intentions, to determine if they were planning to disclose.

iii) The process of disclosure

Disclosers were asked questions that addressed when they began the process of disclosure, how discussions regarding disclosure occur, the narratives that they tell their children, and the reactions shown by their child. Non-disclosers were asked questions to identify if they have told their children any details about their conception. Further questions ascertained whether parents encountered any difficulties regarding disclosing or non-disclosure.

iv) How are parents supported with the disclosure process

Questions identified the disclosure-related support parents received during the adoption process or at the time of ED/DD treatment. Further questions addressed whether parents have accessed any additional support, if and how it helped them with the disclosure process, and whether they felt satisfied with the support available.

5.0.6 DATA ANALYSIS

Before discussing data analysis, the position of the researcher is briefly discussed. Elliott, Fischer, and Rennie (1999) raise the significance of owning one's own perspective whilst conducting qualitative research. The researcher has prior experience of working with adoptive families, which prompted interest in research on alternative family formations. The researcher is also an experienced interviewer, and by employing a non-judgmental approach of active listening and probing is likely to have helped participants to provide honest accounts of their unique perspectives and experiences.

Thematic analysis was chosen as the preferred method of analysis because it examines and records patterns within data, and allows qualitative data to be

presented systematically in order for themes to be generated. All parent interviews were audio recorded and transcribed verbatim. The interviews of adopters and ED/DD parents were analysed separately following the thorough step-by step thematic analytical method as described by Braun and Clarke (2006). First, transcripts were read and re-read so that the researcher (ND) could become familiar. Second, the researcher (ND) began to systematically generate initial codes throughout the entire dataset of interviews; these codes were defined as 'disclosure' and 'support', the two main threads and areas of interest in this thesis. Third, once these initial codes had been generated, the data was then organised into meaningful groups, by clustering similar codes. Fourth, once similar codes were grouped together, each code was carefully considered by exploring the relationships between codes within the same group; this led to the creation of themes, and subthemes. Fifth, the themes and subthemes were reviewed, refined and finalised, according to the data and relationships within each theme. Sixth, during this final stage, the themes and subthemes were assigned meaningful names. Stages three, four, five and six were performed in collaboration with the supervisor (FM).

The data of ED/DD parents who had a child under three years old, and those with children aged between three and nine years old, were initially analysed separately. However, once thematic analysis was performed, it became apparent that the same themes were generated across these two groups; therefore they were merged together and formed one group referred to as 'embryo donation/double donation parents'. There are instances where age of the child becomes relevant, specifically when considering how parents felt supported during their clinic counselling (i.e. the younger the child, the more recently parents attended implications counselling) and in such instances, comments are made about the age of the child.

Justification of data analysis decisions

Epistemological position

A realist epistemological position was taken because the qualitative analysis performed reports experiences, meanings and the reality of participants. This meant that experiences, motivations and meaning could be interpreted in a straightforward way due to the assumption of a largely unidirectional relationship between experience and language and meaning (Braun & Clarke, 2006). This realist approach allows us to expand our understanding on parents' experiences of discussing genetic origins with their children, a key aim of Study I.

Type of analysis conducted

A deductive approach was employed because the research was driven by the Researchers' interest in the topic area and pre-planned research questions, which together shaped the topics covered in the semi-structured interviews. Whilst the whole dataset was read and acknowledged in the early stages of becoming familiar with the data, only data relevant to 'disclosure' or 'support' were extracted during the coding process. This means that to some extent there remains a story to tell with data that was not coded; however, for the purposes of this thesis it was deemed unnecessary to code information that was not relevant to 'disclosure' or 'support'. This approach provided a less rich description of the dataset as a whole, but allowed a more detailed analysis of these two aspects of the data. 'Disclosure' comprised of the following five areas: the disclosure decision, how children are being told, what children are being told, which aspects parents need to develop and worries and concerns about the future. 'Support', comprised the following three areas: did parents feel encouraged and prepared to disclose, how do parents address the need for additional support and how could support be improved?

Types of themes

A semantic approach was taken because the research was interested in exactly *what* parents are actually saying to their children and their own experiences of the support received, rather than looking at explanations *beyond* what participants have said. Further, the analysis provides broader meanings and implications of the data as well as discussing findings in relation to previous literature and legislation.

What constituted a theme?

For the context of this analysis, a theme was determined by an observance of a patterned response in the data that represents and captures important aspects of the data in relation to the research question. In line with Braun and Clarke (2006), the themes were not solely determined by their frequency within the dataset, although each theme was represented a number of times across the dataset. More specifically, a theme was determined by how important the data was to the research questions, which was founded upon Researcher judgement[40].

A code follows all extracts and contains information about the parent/family type that each quote belongs to. For adoptive parents, the codes are follows:

MC = Mother in Couple, **FC** = Father in Couple, **SMC** = Single Mother, Age of child = a number is provided which reflects the age of child in years.

For ED/DD parents, the following codes are used:

Disclosure status:	ND = not disclosed, D = disclosed
Family type:	FC = coupled father, MC = coupled mother SMC = single mother
Age of child:	A number is provided which reflects the age of child in years, or months (m)
Donation location:	AB = abroad, UK = United Kingdom
Donation type:	DD = double, ED = embryo, U – parent unsure

[40] The PhD student in collaboration with her PhD supervisor

Donor information: A = both anonymous, I = both identifiable donors

IA = one identifiable /one anonymous

Section 5.1 provides details of disclosure status of adoptive and ED/DD families. Section 5.2 and 5.3 address the first aim of Study I, and Sections 5.4 and 5.5 address the second aim of Study I.

5.1 STUDY I RESULTS – DISCLOSURE STATUS

5.1.1 DISCLOSURE STATUS OF ADOPTERS VS ED/DD FAMILIES

All adopters (*n* = 27, 100%) had started the process of disclosing to their children; in contrast, although most ED/DD parents (*n* = 28, 77.8%) had started to disclose, eight parents (22.2%) had not.

5.1.2 DISCLOSURE STATUS BREAKDOWN OF ED/DD FAMILIES

'Disclosers' are parents who have begun disclosure, and included four parents with young children (aged 7 to 29 months) who had not yet started to tell, but definitely planned to[41]. 'Non-disclosers' are parents who have not told their children details about their conception and do not definitely plan to do so in the future; this includes parents who are unsure of their future plans.

Table 3 displays the demographic characteristics of disclosing parents versus non-disclosing parents. There were no significant group differences between the ages of disclosing and non-disclosing ED/DD parents at the time of the interview, or the age when they had target child. There were significant group differences between the family structures of disclosing and non-disclosing parents. Non-disclosers comprised seven parents who were in a couple, and one SMC; and disclosing parents comprised 10 parents in a HC, one lesbian couple and 17 SMCs. Therefore, SMCs were more likely to disclose, and parents in a HC were less likely to do so. Significant group differences were also identified in respect to treatment location; more non-disclosers received treatment in the UK, compared to abroad. Interestingly disclosers were significantly more likely to have one or more anonymous donor compared to non-disclosers. Therefore using identifiable donors did not increase the likelihood of disclosure.

[41] The level of intention was evident in the fact that they had attended DCN workshops, had purchased books to help them to talk to their children about their conception, had considered how they will begin to disclose, and intended to do so before their children were three years old.

Table 3. Demographic Characteristics of ED/DD parents according to disclosure decision

	Non-disclosing (*n* = 8)		**Disclosing (*n* = 28)**			
	Mean	**SD**	**Mean**	**SD**	***t***	***p.***
Age of parents						
At interview (years)	49.1	1.81	48.2	3.67	-.641	0.05
When had Child 1 (years)	43.6	1.68	43.7	2.86	.120	0.263
Age of Child 1 (months)	65.6	20.44	53.68	30.34	-1.043	0.098
Age of Child 2 (months)	65.6	10.8	41.8	21.5	-3.591	0.374
	N	**%**	**N**	**%**	χ^2	***p.***
Family Type					**15.111**	***0.002***
Couple	7	87.5	11	39.3		
Single mother	1	12.5	17	60.7		
Treatment location					**13.111**	***0.004***
UK	7	87.5	14	50		
Abroad	1	12.5	14	50		
Donors					**19.704**	***0.001***
Both identifiable	12	85.7	10	25		
One identifiable	0	0	8	20		
Both anonymous	2	14.3	22	55		

5.2 STUDY I RESULTS - DISCLOSURE OF ADOPTION

5.2.1 THE DISCLOSURE DECISION

5.2.1.1 REASONS FOR DISCLOSURE

All adopters were asked to explain the reasons why they had decided to disclose. Two themes were identified:

1. **'I DIDN'T WANT HER TO THINK WE'D LIED TO HER'**
    I. Don't want child to feel adoption is shameful
2. **PROVIDING A 'SENSE OF THE WHOLE'**

THEME 1 - 'I DIDN'T WANT HER TO THINK WE'D LIED TO HER'

Adopters felt that there would be negative consequences if children were not told, and subsequently discovered that they were adopted. Future revelation of adoption could result in children feeling that they had been lied to; thus honesty was favoured:

> *I think the thing I always refer to in my own mind is, you don't want to divulge that in the future and then have them feel like they've been lied to* **FC/daughter-7**

> *I think you always ought to be honest..... I didn't want her to think that we'd lied to her. And also if you hide stuff about adoption, it's always going to be found out.* **MC/daughter-8**

Don't want child to feel adoption is shameful

Within the context of honesty, parents did not want their children to feel that adoption is 'shameful', suggesting that they saw adoption as stigmatised. Adopters thought that keeping adoption a secret could lead to children believing it is shameful, so openness would minimise these negative feelings:

> *I think it's like, well why? Are you, is it a secret? Is it a shameful thing? So we don't want her to feel like that.* **MC/daughter-3**

I don't want her to ever feel that anything was kept from her. Um, and that, anything is secretive and therefore... wrong, naughty or dirty or anything like that. **MC/daughter-4**

THEME 2 - PROVIDING A 'SENSE OF THE WHOLE'

Adopters felt that knowledge of one's adoptive background is important for their children's sense of identity and helped children to feel a sense of completeness:

I think it's highly important just to be, just to have a sense of the whole. Not to have any kind of fantasy about what's gone on but also to have a real, real sense of this is who I am... **MC/son-9/daughter-6**

This sense of wholeness was also identified in adoption literature in where adopters thought that it was important not to leave children to fill in any blanks that might result in the creation of fantasies (Harrigan, 2010).

5.1.1.2 WHY TOLD EARLY

All adopters had begun disclosure by the time children were four years old. This is in line with findings elsewhere (Brodzinsky & Pinderhughes, 2002; Brodzinsky et al., 1998). In this study, parents either started at the time of adoption placement, or when children first began to ask questions relating to where they came from[42]. One theme identified why parents opted for early disclosure:

1. **SO THAT CHILDREN FEEL THAT THEY HAVE 'ALWAYS KNOWN'**
   - **I.** Lessens the impact
   - **II.** Particularly compared to teenage years

[42] For some children, the process of disclosure had already started before they were placed with their adoptive parents, thus in these cases adoptive parents continued to develop the conversation surrounding their adoption.

THEME 1 - SO THAT CHILDREN FEEL THAT THEY HAVE 'ALWAYS KNOWN'

Parents disclosed early because they believed that it is better for children to have 'always known' that they are adopted. If children cannot remember the day they were told, they will grow up being aware that they are adopted, and that this would feel natural to them:

> *You need to tell them as softly as possible, and the only way to do that is to tell them about it as early as possible so that they don't remember ... If you've always known it's the most natural thing.* **FC/daughter-3**

Lessens the impact

Parents thought that the impact of the discovery of one's adoption increases with the age of the child, therefore will lessen if children feel like they have 'always known' that they are adopted:

> *I think in order to soften that impact as much as humanly possible, if she can never remember the day that she found out, then that's got to be good....* **FC/daughter-3**

Although adopters were aware that further details would need to be discussed in the future, they believed there would be no shock about adoption per se:

> *At some stage you've got to have that conversation, if you do it at the point where, like <son> it becomes second nature... there's no big shock about it.*
> **FC/son-8**

Particularly compared to teenage years

The impact of finding out about one's adoptive origins was considered greatest during teenage years, so adopters actively avoided the potential consequences of this by disclosing early. This is reflected in this mother's view of the 'hideous' nature of learning about adoption during adolescence:

> *I just think the idea that you know that it might be something that you just sit down and tell him when he's 13 just sounds like the most hideous thing you could ever do and guaranteed to have a massive impact.*
> **MC/daughter-7**

Section summary

The fact that all adopters have disclosed, and have done so early, demonstrates that they are aware of the negative consequences of discovering one's adoption later in life. It is likely that adopters were aware of the negative impact of children finding out that they are adopted in teenage years, via information shared during their adoption preparation, and this issue being prevalent in TV shows such as 'Long lost Family' and '15,000 kids and counting'. Reasons for early disclosure demonstrated by adopters in this study are in line with previous findings (Harrigan, 2010).

5.2.2 HOW ARE CHILDREN BEING TOLD?

Parents were asked about the initial conversations that they had with their children about adoption, and how on-going conversations are managed.

5.1.2.1 HOW DID THE CONVERSATION FIRST START?

Two themes were identified in the ways that parents first began having adoption-related conversations with their children:

1. **BY STORYTELLING**
2. **BY CHILDREN ASKING QUESTIONS**
   - **I.** 'Was I in your tummy'?
   - **II.** Where did I come from?

THEME 1: BY STORYTELLING

The conversation usually began by engaging in storytelling about when they first became a family. This mother's experience is reflective of how parents began 'drip feeding' information to their children:

> *We started drip-feeding him...it's always oh you lived there before you lived here so that's always been from day one. And we used to say she looked after him until the social worker found mummy and daddy so we've always had that talk.* **MC/son-6**

Storytelling has proven to be popular amongst adopters elsewhere (Galvin, 2003; Jones & Hackett, 2007) because it can help adoptees to begin to form a sense of identity (Galvin, 2003), and it is also a frequent form parent-child interaction.

THEME 2: BY CHILDREN ASKING QUESTIONS

Other parents reported that the conversation first started in response to questions asked by their children. Two sub-themes identified the type of questions:

'Was I in your tummy'?

Children commonly asked questions relating to pregnancies and if they were in their mother's tummy:

> *The first time I think we talked about pregnancies etc. was when my friend was pregnant ... And then obviously the natural question was, 'was I in your tummy then?' Um.. 'No, darling. You weren't'. So we sat down and went through that she wasn't in my tummy...* **MC/daughter-5**

Where did I come from?

Children also asked questions relating to where they came from, as described by this father:

> *She's asked me and she's asked <wife>, who built me? ...Did you build me mummy? Did daddy build me? And we'd say, well, no. Mummy and daddy didn't build you, a man and a lady built you. And that's how it went first..* **FC/daughter-3**

5.1.2.2 HOW ARE CONVERSATIONS MAINTAINED?

Most parents do not usually have a structured way of discussing adoption with their children, and instead employed a variety of strategies to try to build discussions on adoption into every day routines. Two over-arching themes were identified:

1. **BY HAVING NATURAL CONVERSATIONS**
    I. Instigating discussions in the car
        i. Avoid eye contact
        ii. Promotes a contained conversation
    II. By children asking questions

2. **BY USING RESOURCES**
    I. Every day resources
        i. Families are different
        ii. Representations of adoption
    II. Personalised resources
        i. Instigate conversation about key events
        ii. Instigate conversation about birth family

THEME 1: BY HAVING NATURAL CONVERSATIONS

Most parents tried to discuss adoption in a 'natural' manner, in every-day conversations, as opposed to finding a specific time to sit down for this purpose:

> *It's very natural, and it'll sometimes come out of the blue when you're in the middle of the supermarket, and you're like, what do I do? But then you think, it's fine. We'll just go somewhere quiet and have a chat. So it's all, it's done just quite naturally, not a deliberate sit down and talk about stuff.*
> **MC/son-8**

Instigating discussions in the car

One way that natural conversations occur is whilst in the car, an approach used by both parents and children. There are two benefits associated with engaging discussions in this context:

Avoid eye contact

First, the car facilitates parent-child conversation without having to have eye contact, which could be viewed as awkward when discussing emotional issues. This father shares a recent experience:

You can have good conversations side by side in the car when you're not having to look at each other, and she had talked about it a couple of times and I said, you talked about it a bit recently, and I just want to check, you're okay aren't you, and you do know that you can ask us anything? **FC/daughter-8**

Promotes a contained conversation

Second, a vehicle provides a contained environment that promotes the engagement of conversation, and allows a natural conclusion once the destination has been reached:

We'll be on our way to somewhere and we'll have a chat about something important and the other good thing about that is it can then, we can then move because you arrive at your destination and go off and do what you were meant to do. **MC/daughters aged 7 and 8**

These parents did not want to make adoption a 'big deal' and generally assumed that children were uncomfortable, or reluctant to discuss adoption related issues.

By children asking questions

In some families, conversations *usually* begin as a result of children asking questions. These parents tend to be led by their children's pace, rather than proactively information sharing. Again, emphasis was on the importance of conversations just being a part of their 'normal' routine:

I think it usually comes from him. .... so he initiates conversations but it, it's never, we don't have time, it just happens as part of normal-normal conversation.. **MC/daughter-7**

I'm led by her really. So if she's talked about it I'll make sure that she understands that the door is open, and if she's got any questions. **FC/daughter-8**

However, a potential pitfall of this approach, is just because children do not ask questions, does not mean that they do not wish to discuss their adoption (Howe

& Feast, 2003). Therefore, these parents could risk assuming that their children do not want to talk about adoption when indeed they do, or risk their children assuming that their parents were avoiding this topic.

THEME 2: BY USING RESCOURCES

Parents use two different types of resources to facilitate adoption conversations. First, those found in everyday life, including children's TV programmes, films, and books. Second, real-life resources including photos, LSBs and letter contact.

Everyday resources

The majority of parents used everyday resources as an opportunity to talk to their children about their adoption, complementing the theme of keeping conversations natural:

> *If you ever say to her lets sit down and have a talk or something, she would be like wow no chance, 'cause she thinks its, she's like is it about my behaviour.... But.. something might be in a book or on tv or we see something and she might say something, and I'll say 'yeah remember when'.....* **MC/daughter-4**

Everyday resources allow parents to highlight the similarities of analogies presented in stimuli, and make comparisons with their children's life. Parents did this in three ways:

Families are different

Adopters explained how resources facilitate discussion on the concept that all families are different. This mother uses books to explain the varied nature of families:

> *There's one on adoption by Todd Carr...which says, you know, families come in all shapes and sizes, two mums, two dads, sometimes children are adopted....* **MC/daughter-6**

Representations of adoption

Many resources designed for children also contain characters that have adopted children, or animals, which can be used to discuss issues such as why children are not with their birth parents, or why they look different to their adopters:

> *There's another one in a family and the mum, the daughter says to the mum, 'mummy why is my hair a different colour to yours?' And she says to her, well because we chose you..* **FC/daughter-3**

> *So we were sat watching <Disney's Meet The Robinsons> and the at end, he goes back to the time where his birth mum had left him on the doorstep... I said well 'you do know that, you know, it's like you and you know, you've got things in common with this film'.* **MC/sons-8 and 7**

Personalised resources

Photos, LSBs and letter contact with birth family, all contain personal information pertaining to adoption. Children and/or their parents use these to discuss adoption in two different ways:

Instigate conversation about key events

Photos visualise important events in the adoption process including when children were born, the day that adoption was approved, or when children first lived with their adoptive parents. Families used images to trigger discussion of these events:

> *<Referring to photo> That was the day that we went to see the judge and they know that an they've all got a picture in their bedroom of us with the judge erm so they have a-a constant memory of that and it, and they often talk about it.* **MC/daughters-7 and 8**
>
> *She'd get it out <referring to life story book> and say can we look at big book about me? So we'd go through.. She loves to see her scan photos when she was, and that would then stimulate discussion.* **MC/daughter-5**

Instigate conversation about birth parents

Photos and letter contact are also used as a way to instigate discussions about birth parents:

She often asks, 'can I see their photo', or I say 'would you like to see their photos?' So she knows, she looks like [birth dad] actually. She knows that. So we tried to sort of make it quite light because she's only little.
MC/daughter-6

So we wrote last year and we got them, told them what we were doing and then asked them what do you want us to put in this letter? Is there anything you would like to add? So tell them we're sitting in the paddling pool. **FC/sons-4 and 6**

Resources create parent-child dialogue that engages children in discussion of concepts related to adoption. The importance of taking interactive approaches to actively involve children in the process has also identified in adoptive parents elsewhere (Harrigan, 2010).

5.1.2.3 FREQUENCY OF CONVERSATIONS

The actual frequency of conversations varied between families, with some parents reporting that at times adoption can be discussed as often as daily, or as infrequently as a couple of times a year. Nonetheless, all adopters viewed disclosure as a continuous process. Two contrasting themes identified how adopters attempt to balance how often conversations occur:

1. **KEEPING CONVERSATION 'ALIVE'**
    I. So that children do not forget
    II. To help children to accept

2. **DON'T WANT TO FORCE CONVERSATION**
    I. Assume that children feel uncomfortable
    II. Don't want child to feel rejected

THEME 1: KEEPING CONVERSATION 'ALIVE'

Many adopters saw it as important to keep discussions about adoption alive, and two sub-themes identify the benefits of this:

So that children do not forget

First, they felt that it would be easy for their young children to forget details about their adoption, which seems plausible considering that children appeared confused about some aspects of their adoption (see 5.2.4.1). Therefore parents thought that it was important to trigger their children's memory:

> *She'll have no memory of going to a foster carers, and her memory of coming to us.... We have to keep that memory alive.* **MC/daughter-3**

To help children to accept

Keeping the conversation 'alive' was also viewed as helping children become more acquainted with the idea that they are adopted, as this mother explains:.

> *You've got to repeat it as often as you can, they've got it accept it. ...So it's that kind of drip- drip-drip on the right occasion with the right example for him to belong more to the idea that he's adopted.* **MC/son-8**

THEME 2: DON'T WANT TO 'FORCE' CONVERSATION

In contrast, some parents did not want to push adoption discussions onto their children, so instead left the initiation of conversations to their child, which served two purposes:

Do not want children feel uncomfortable

Parents using this approach tended to assume that their children were not comfortable talking about their adoption. Parents did not elaborate why this is so, but as this mother explains, she lets her daughters determine the frequency of conversations:

> *I don't want to force them into talking about anything that they're not comfortable talking about so I kind of jump on any opportunity they give me so they tend to in their own subtle ways they'll let me know when they want to talk about it.* **MC/daughters-7 and 8**

Don't want child to feel rejected

Some parents were concerned that talking about adoption could be upsetting for their children, so to minimise this they avoided initiating discussions. This mother felt emotional talking about her fear of her daughter feeling rejected, and considers more frequent conversations with her daughter in the future:

> *I do worry about her feeling rejected, and I can't do anything about that.. So I probably don't bring it up because of that... I just don't want to bring up hurtful feelings for her...*I think maybe I should bring it up more. <mother is upset> **MC/daughter-8**

Section Summary

Overall, this highlights some of the complex decisions that adopters make when determining the frequency of adoption-related discussions. In line with research by Jones and Hackett (2007) adopters in this study were concerned about discussing adoption frequently enough so that they do not forget, but not wanting to pursue conversations too intently in case this upsets or disturbs their child.

5.2.3 WHAT ARE CHILDREN BEING TOLD?

5.2.3.1 THEMES IN ADOPTION NARRATIVES

Three themes identified the commonalities in the narratives that adopters use to discuss adoption:

1. **BIRTH PARENTS**
    I. The role of tummies
    II. Couldn't meet children's needs
    III. Birth parents as loving

2. **PEOPLE INVOLVED IN THE PROCESS**
    I. The Judge
    II. Social workers
    III. Foster carers

3. **ROLE OF ADOPTIVE PARENTS**
    I. Child needed new parents
    II. They wanted a child
    III. The day we met
    IV. How special child is

THEME 1 - BIRTH PARENTS

Birth parents were present in all narratives. Three subthemes identified how they were represented:

The role of tummies

First, parents explain to their children how they were in someone else's tummy:

> *You weren't in my tummy you were in [birth mother]'s tummy* **MC/son-8**

> *Wasn't in my tummy, was in another lady's tummy* **MC/daughter-5**

This helps parents to put the relevance of birth mothers into context, and inexplicitly provides information relating to children's genetic connections with their birth mother. Similarly, MacCallum and Keeley (2012) found that around a

half of the adopters in their study explicitly discussed pregnancy, and thought that children understood that 'tummy mummies' differ from social mummies. Information relating to birth fathers was predominantly lacking in the narratives, possibly because often there is limited or no information available about him (see 5.2.4.1).

Birth parents couldn't meet children's needs

Parents usually provided an explanation of why children no longer live with their birth parents, which revolved around them being unable to meet their children's needs. Examples include:

> *She couldn't look after you* **MC/daughters-5 and 7**
>
> *Weren't doing the mummy and daddy job* **MC/daughters-8 and 7**
>
> *They couldn't keep you safe* **MC/son-8**

Some parents provided specific reasons to explain *why* birth parents could not meet their needs, which were centred on parents being 'unwell/ill/sick, or too young to look after their children:

> *She really loved you because she was, tried to look after you, but unfortunately, she became ill* **MC/daughters-5 and 7**
>
> *They were very young when they had her, they weren't able to give her a good home* **MC/daughter-8**

Birth parents as loving

Some adopters were cautious to ensure that birth parents were not perceived in a negative light. They did not want their child to feel any sense of rejection by their birth parents, and wanted to reassure their children that their birth family loved them:

> *Parents didn't want to give you up* **FC/son-8**
>
> *I tell her mummy loved her* **MC/daughter-8**

Harrigan (2010) also found that some adopters also wanted their children to know that their birth parents' intentions were out of love and concern for their child.

THEME 2 - PEOPLE INVOLVED IN THE PROCESS

The second theme was the incorporation of information about the roles of three characters involved in the adoption process:

The Judge

First, some parents included information about the people who were involved in the process of deciding that children could no longer live with their birth parents. The most common person featuring in this 'decision' was the Judge:

> *The clever judge and the social worker decided that um.. she needed to go and live with somebody else.* **MC/daughter-5**

> *Judge said that you needed to find a new family.* **MC/daughters-8 and 7**

Social workers

Second, some parents told their children about the involvement of social workers, both in the decision process, and also how they tried to help birth parents to make 'better choices':

> *The social workers decided that you had to go to foster care and they wanted you to get a forever family and we came along.* **MC/son-8**

> *The social workers tried to help them and tried to get them to make good choices and better choices.* .... **MC/daughters-8 and 7**

Foster carers

Third, some children were reminded that they previously lived with the foster carers who were described as a stepping-stone facilitating the bridge between children living with their birth parents and their adoptive parents. This also served to explain to children why they did not remain with their foster carers:

The foster carer couldn't keep her forever, cus she was an older lady on her own, and (<child> needed a mummy and daddy, and so, um, so they found us. **MC/daughter-5**

You lived there before you lived here.. <foster carer> looked after him until the social worker found mummy and daddy. **MC/son-6**

THEME 3 - ROLE OF ADOPTIVE PARENTS

The final theme was information about how the adoptive family was created, categorised by four sub-themes:

Child needed new parents

The reasons why children no longer live with their birth parents, and how this decision was made, appeared in most narratives. This lends itself to explaining how they needed new parents and this is how they became a family:

We came along because she needed a new mummy and daddy. **MC/daughter-8**

They were looking for the right person to be your mummy. **SM/son-6**

Emphasis was placed on how they were the 'right' parents for that particular child, and how that child was the 'right' child for them.

They wanted a child

Less routinely, parents focused on how they wanted a family, and how their child fulfilled this desire:

I was looking for a little boy. **SM/son-6**

Wanting a family not being able to have, erm, babies in my own tummy, but that we REALLY still wanted to have our own forever family. **MC/son-9/daughter-6**

The day we met

Some adopters also included details about when their relationship first began:

> *When you first became mummy and daddy's little girl.* **MC/daughter-5**

> *When you came to live with mummy and daddy.* **FC/daughter-3**

How special child is

Parents used narrative telling as an opportunity to explain to children how special they are:

> *He was that person that special boy. So, we, you know we just continually reinforce that.* **MC/son-9/daughter-6**

> *We were, we were sort of dreaming of a little girl, and then you came along and the dream came true.* **MC/daughter-5**

Parents thought that it was important to reinforce children's qualities and to positively frame both the child and the nature of adoption, and in turn counteract any negative feelings that children may have about being adopted. This positive presentation of adoption in a positive manner was also identified by research elsewhere (Harrigan, 2010).

Section summary

The inclusion of information about birth parents, the adopted child and the adoptive parents reflects findings by Jones and Hackett (2007) whereby adopters were found to tell stories from these three perspectives. Parents built the narrative on a framework that allowed them to be truthful with their children, but provided a structure whereby more refined details could be added over time. This is in consonance with findings elsewhere (Harrigan, 2010; Watson et al., 2015) where although parents were aware that their children did not fully understand the details of their adoption, they valued the significance of sharing information in an age appropriate (discussed fully in 5.2.4) and honest manner.

5.2.4 WHICH ASPECTS DO PARENTS NEED TO DEVELOP?

Specific areas that parents wished to develop, and the difficulties encountered when sharing information with their children, are explored in this section.

5.2.4.1 CHILDREN'S UNDERSTANDING

Parents discussed difficulties in relation to explaining the consequences of adoption, and four themes were extracted:

1. **DON'T UNDERSTAND THE IMPLICATIONS**
    I. Importance of filling in the gaps

2. **WHO IS MY BIRTH FATHER?**
    I. Lack of information about birth father
    II. Lack of understanding about reproduction

3. **WHY COULDN'T THEY LOOK AFTER ME?**

4. **BIRTH SIBLINGS**
    I. Child not emotionally ready
    II. Unsure how to introduce information

THEME 1: DON'T UNDERSTAND THE IMPLICATIONS

Although parents reported that most children knew that they were 'adopted', they were unable to makes sense of the more complex elements of their adoption, such as why they are no longer living in their birth family, and the relationship that they share with birth siblings:

> *She understands that she's adopted.. She understands...that her birth parents didn't think that they were going to be able to look after her, so she went to live with... I don't think she's looked closely at all the implications of that. But she's 8 years old, so I wouldn't expect her to.* ***FC/daughter-8***

> *She's aware that the lady whose tummy she was in had two more babies, but she doesn't really understand that means they're my half-sisters.* **MC/daughter-4**

Parents were not concerned that their children did not yet understand the finer details of their adoption because they thought that their children were currently too young, and that their understanding would develop as they grew older. This is congruent with literature that established children are unable to demonstrate a deeper understanding of their adoption until between the ages of eight and eleven years old (Brodzinsky et al., 1984) and only begin to acknowledge the relevance of genetic relationships and question their connection between the two different families between six and twelve years old (Brodzinksy, 2011).

Importance of filling in the gaps

Filling in the 'gaps' as children develop, in order to help them gain a full and accurate understanding of all elements of their adoption, was viewed essential:

> *There's no big reveal, there's nothing left to tell them. We've told them in suitable language so when they're a little bit older we'll obviously go into a bit more detail about you know scenarios and everything but at the moment we just kind of use you know age appropriate language.* **FC/sons-6 and 4**

THEME 2: WHO IS MY BIRTH FATHER?

Most parents felt that their children had some, albeit limited, understanding of their birth mother, which is consistent with the role of tummies being prevalent throughout narratives. However, children had less understanding of the birth father, and his relevance to their lives. This is unsurprising considering that information regarding the birth father is commonly missing from parent-child narratives. Two subthemes identify why this is so:

Lack of information about birth father

Most adopters had less information about the birth father than the birth mother. Thus, parents encountered difficulties telling their children about him:

> *It would be good to know a little bit more about him. Because we gonna have to say that all we know is a name, we don't know anything more. We don't really know if that his name is accurate or not.* **MC/daughter-4**

Social services often have less knowledge about the birth father compared to the birth mother, which means that material about him is frequently lacking from LSBs (Baynes, 2008; Ryan, 2000). It is therefore understandable that adopters experience difficulties discussing this with their children, and children demonstrate little understanding about their birth fathers.

Lack of understanding about reproduction

Birth mothers are easier to explain to children who have limited awareness of sexual education, but it is increasingly difficult to explain the birth father's role without prior reproductive education. Some adopters explained that because their children currently lack understanding about reproduction, they have not yet made the connection that a birth father was a necessary part of the equation:

> *She's never said anything about the father, she doesn't quite get the birds and the bees yet. So she hasn't figured out that there had to be a dad involved.* **MC/daughter-4**

> *I don't think she's clipped on that there's a dad in the equation... I need to get help with what to say anything more because I haven't got it, mm, it's a difficult one.* **MC/daughter-8**

Most parents refer to the birth mother as 'tummy mummy', however there is not an equivalent term to describe the birth father, so some adopters had difficulties finding appropriate terminology to discuss him. Some parents found it 'uncomfortable' or 'difficult' to bring the birth father into this narrative. One reason for this is because information relating to reproduction is currently absent from parent-child dialogues, however Brodzinksy (2011) recommended that children are told simple facts relating to reproduction and childbirth.

THEME 3: 'WHY COULDN'T THEY LOOK AFTER ME?'

Parents commonly reported that their children questioned the whereabouts of birth parents and why they no longer live with them. Parents attempt to discuss adoption in an 'age appropriate' manner and deem some of the information relating to birth parents as shocking, or disturbing, and thought it would be

harmful or inappropriate to subject young children to negative information. To strike the balance between protecting children from potentially harmful details, yet still being open and honest, parents spare children from information that they feel that they do not need to know at this stage:

> *She would ask questions about her adoption and we try to be as open and honest as possible but there are some things she just doesn't need to know, that are too hurtful for her.* **MC/daughter-8**

> *Why couldn't they look after me properly? Why couldn't they keep me safe?... That's what I find really difficult because as I said, I don't want to lie, but at the same time, they're not ready to know enough information.* ***MC/son-8***

> *We're a bit...a bit lenient with the truth. A bit sort of we don't tell them everything. Such as the, you know, dad's too drunk to look after you..... we'll tell them as much as we know, but at the age they are now, I don't think they need to know every detail.* **FC/daughters-7 and 8**

These findings are in line with FAC model (Wrobel et al., 2003)whereby adopters purposely withhold certain elements of the adoption story that they do not believe are appropriate to their children's developmental stage, or to protect their children from information that could affect their self-esteem or sense of security (Brodzinsky & Pinderhughes, 2002). Again, adopters tailored details in an age appropriate fashion so that they do not frighten or upset their children, whilst still maintaining a version of the truth. This reiterates findings by Jones and Hackett (2007) whereby adopters discussed adoption in a manner that allowed them to be open and honest, but was structured so that more complex details could be added over time.

THEME 4: BIRTH SIBLINGS

The final theme was the complexities encountered in explaining the relationships between children and their birth siblings, which was particularly prominent in families where there is no contact between birth siblings. Two

sub-themes identified why most parents have not yet told their children about their birth siblings:

Child not emotionally ready

Many parents thought that their children were not emotionally ready to learn details about their birth siblings, but that it was vital to share this information in the future:

> *I would like very much to do it and we will do it eventually. But it's very hard ...I'd like him to be a lot more stable emotionally before I introduce that....they do not affect his daily life and I still think there will be sometime until he is a lot more stable and then we will be able to talk about these things slowly.* **MC/son-8**

Concerns about children's readiness were more deeply exemplified where one, or more, birth sibling still lived with their birth families, which could heighten adoptees' sense of rejection. Some parents felt that this would be difficult information for their children to handle:

> *They don't know that they have a younger brother again because they're not emotionally ready to understand why their brother's still with their birth mum and they're not….* **MC/daughters-7 and 8**

Unsure how to introduce information

All adopters thought that it was imperative that children ultimately learned details of birth-siblings, but some felt unsure how they would approach this and would benefit from some support and guidance on how to do so in the future**:**

> *She will have to know that, yeah... I haven't thought about ages, no. To be really honest I haven't... I have, but I don't know the answer, yeah. And that's really why we're gonna need some support and guidance on it***.**
> **MC/daughter-4**

> *I need to get my head around introducing to <child>, (laughs) which is a difficult one. 'Cause she'll be like oh why can't I see my sisters?' We haven't quite got past that bridge really.* **MC/daughter-4**

5.2.4.2 TERMINOLOGY

Parents faced challenges when determining what terminology to use to explain adoption to their children and two themes were identified:

1. **DON'T WANT CHILDREN TO GET CONFUSED**
2. **TOUCHY ABOUT 'MUMMY'**

THEME 1: DON'T WANT CHILDREN TO GET CONFUSED

First, some parents felt that using birth 'mummy' would be confusing for their children because they already have a (adoptive) mummy:

> *I think with adoption they always used to say all these different suggests, birth mummy or tummy mummy, but I didn't want to use that because I'm mummy, and I didn't want it to get confusing.* **MC/daughter-8**

However, another mother, considers that her daughter might now need the language 'tummy mummy' to help her to understand how she is connected to her birth parents:

> *We use their first names. We always have done. Occasionally I've said tummy mummy to her recently, she just turned 6, so her understanding might be starting to shift a bit so she might need that kind of language to really get her head around what this all means.* **MC/daughter-6**

THEME 2: TOUCHY ABOUT 'MUMMY'

Second, some adoptive mothers were sensitive because they see themselves as being 'mummy', so felt uncomfortable when the birth mother if referred to as another form of mummy:

> *The one thing about that I've always been a little bit touchy about... I've always struggled to call her mummy.* **SMC/son-6**

This illustrates that even when language is relatively established, as it is in adoption, parents might still be uncomfortable about certain terms, or uncertain which terms are preferential to aid their children's understanding.

Section summary

Brodzinksy (2011) highlights the important of openness so that it does not undermine children's trust in their parents. Adopters in this study did not lie to their children, but instead shared information in an age appropriate manner that served to protect adoptees from potentially harmful information. As MacDonald and McSherry (2011) found**,** adopters in this study viewed some information pertaining to birth parents as 'disturbing' and harmful, and themselves as 'gatekeepers', withholding more complex details until they deemed that their children were old enough to understand.

5.2.5 WORRIES AND CONCERNS ABOUT THE FUTURE

Parents did not regret being open with their children about their adoption, but many were worried about the future consequences of this openness. One theme underpinned their concerns:

1. **HOW CHILDREN WILL FEEL**
    I. About being adopted
    II. About being 'part of the family'
    III. About birth family
    IV. Damage of non-disclosure

THEME 1 - HOW CHILDREN WILL FEEL

Adopters were concerned about how their children will feel in the future, and four subthemes underpinned this worry:

About being adopted

Some parents were concerned that their children might be subject to teasing or bullying by other children, because they are adopted. Parents wanted to install resilience in their children so that they could deal with this possibility:

> *Kids do get bullied, you know, so I want her to feel.., I just want it to be part of who she is but not all of who she is.... It doesn't define her but she defines it.* **MC/daughter-6**

> *Kids will find a chink in the armour and then they'll use it at some point in your life against you... hopefully we will give her the tools to just brush it aside or maybe not to brush it aside.* **FC/daughter-3**

About being 'part of the family'

Some adopters were worried that their children might not feel part of the family:

> *My other concern is that it is going to be a big thing because she feels so much part of the family, and it's like how will she respond to that?* ***FC/daughter-3***

> *You're so worried about them feeling secure and wanted you never quite know where those conversations are going to take you. I'm always a bit cautious about it.* **MC/daughter-8**

This signifies that some adopters anticipate that children will view genetic connections as important to creating family ties.

About birth family

Some parents were concerned how their children might feel when they discover potentially hurtful information about the background of their birth parents:

> *He's got to deal with the fact that not only his mum's history, all his siblings everywhere... and he's got to work out that actually one my birth dad didn't want me but he took my brother on. I don't know how, you know that's a lot for him to go through.* **MC/son-6**

These concerns exemplify why adopters currently avoid discussing the 'nitty gritty' details. Parents had also considered how they could prepare their children to meet their birth parents in the future, and felt anxious about the uncertainly of how, and if, this will happen, and any upset or disappointment that could result from this process:

Its SUCH an unknown area, I think for me, nearer the time, understanding the process will be helpful. ... I feel highly protective of the kids, that I don't want them to be, erm, upset or disappointed. **MC/son-9/daughter-6**

Obviously you have to do the best for them. I think I would like, before they went off to find them, hopefully I would find some more information from social services because the last thing I'd want to do is put my children in harms way of them, you know. **FC/son-8**

Parents expressed an interest in receiving more information about the birth parents and about the process of connecting with birth parents when adoptees turn 18, in order to help to prepare both their children, and themselves for this possible eventuality.

Damage of non-disclosure

Parents strongly believed that children should be told about their adoption during their childhood and could not fathom keeping this hidden from their children, something they considered would be very damaging to the child:

I can't believe some people don't tell their children until they're like, 18.... how in this day and age have you got to a place where you haven't sort of said. **MC/daughter-6**

It's inexplicable to me that people would conceal that information. How damaging a thing to find out subsequently. It would never occur to me for a minute to conceal stuff from her. **FC/daughter-8**

Concerns about non-disclosure exemplify the perceived negative consequences of concealing adoption.

Overall, this chapter highlights both the process of adoption disclosure, and difficulties that parents encounter along the way. The next section explores the process of ED/DD disclosure and makes comparisons with adoption.

5.3 STUDY I RESULTS - DISCLOSURE OF ED/DD

5.3.1. THE DISCLOSURE DECISION

5.3.1.1 REASONS FOR DISCLOSURE

Two themes accounted for parents' decision to disclose:

1. **'I DON'T THINK YOU CAN HAVE A FAMILY ON THE BASIS OF LIES'**
    I. Negative effect on children
    II. I'm very open as a person

2. **'A PART OF THEIR STORY, A PART OF THEIR LIFE'**

THEME 1 -'I DON'T THINK YOU CAN HAVE A FAMILY ON THE BASIS OF LIES'

The first theme centred on the desire to be honest. Parents considered that withholding of this information was a form of lying, and did not wish to deceive their children:

> *I don't think you can have a family on the basis of lies. You know, why you would, why would I… (mother is upset) I just couldn't, you know, not tell them.* **D/SMC/twin sons-3 (UK/DD/A)**

Within this framework, two sub-themes were identified:

Negative affect on children

First, most disclosers believed that if they did not disclose, then their children would, at some point, discover that they were donor-conceived; a view also shared by non-disclosing parents (see 5.3.3.4). Parents felt that it would negatively affect their children if they discovered their donor conception later in life because they would feel like they had been lied to:

> *To feel that their whole lives have been lies and… it just messes people up…... I don't think it's right, because even if…even if I hid it, he would sense that there was something there.* **D/SMC /son-8m (AB/DD/A)**

How could you, you'd feel your whole entire life had been based on a lie. People have been lying to you all of those years, so I don't, I couldn't not tell him. **D/SMC/son-5 (AB/DD/A)**

'I'm very open as a person'

Second, most disclosers described their character as being open and honest, therefore considered it in their nature to share information with their children:

OPENESS is the way forward, ABSOLUTELY the way forward.. I really related to that. Cos I'm very open as a person. **D/SMC/son-6 (AB/ED/A)**

I would be honest with them in every aspect of life so why would I conceal this bit? **D/FC/daughter-7 (UK/ED/I)**

THEME 2 - 'A PART OF THEIR STORY, A PART OF THEIR LIFE'

Many disclosers thought it fundamental for children to grow up with this knowledge to help them to understand their identity:

I think it is very important for them to know, because it's…just a part of their story, a part of their life.. it's not better, it's not worse, it's just different. **D/SMC/son-7 (UK/DD/I)**

I want to make sure that they understand, and have the information that they need to have. Yeah, it's kind of her information, isn't it? It's her heritage in some ways, or genetics maybe, rather than heritage. **D/SMC/daughter-2 (UK/DD/I)**

5.3.1.2. WHY TOLD EARLY

All disclosers had begun disclosure before their child was three years old, the majority doing so when their child was a baby. Parents who definitely intended to disclose, but had not yet started, planned to do so before their child turns three. Two themes identified why parents opted to disclose early:

1. **BENEFITS FOR CHILDREN**
    I. 'Wouldn't remember a point at which they were told'
        i. So it's not a shock
        ii. So children feel like they have always known

2. **BENEFITS FOR PARENTS**
    I. Practise language
    II. To desensitise

THEME 1 - BENEFITS FOR CHILDREN

One sub-theme identified the benefits of early disclosure for children:

'Wouldn't remember a point at which they were told'

Parents thought that if children were told when they are young, then they would not remember the day that they were told:

> *I've talked to them about it openly from the beginning… from when they were very-very small so they wouldn't remember a point at which they were told.* **D/MC/daughters-6 and 4 (AB/DD/A)**

Early disclosure was seen as building familiarity, which was considered beneficial in two ways:

So it's not a shock

First, if children cannot remember when they were first told that they are donor conceived, this will not come as a shock to them in the future, implying that it is a significant and otherwise potentially upsetting communication:

> *Is so-so important, it is part of their make up is part of their being and they just need to know and they need to know at an early age so that it's not a surprise to them when they're growing up* **D/MC/son-8 (UK/ED/A)**

So children feel like they have always known

Second, children will grow up with an awareness of their conception, a process that some disclosures viewed as 'subliminal learning':

> *We made the point of just talking openly, even before they were too old to probably comprehend fully what we were talking about…... It was you know like subliminal learning... You will remember hearing, having heard these words somewhere* **D/FC/daughter-7 (UK/ED/I)**

Not remembering the moment of disclosure establishes the view that there are potential negative consequences associated with learning that one is donor-conceived, so some ED/DD parents are using early disclosure is used in an attempt to reduce this impact. Sharing information during early childhood is in agreement with current UK legislation (see 2.2.1).

THEME 2 - BENEFITS FOR PARENTS

Early disclosure was also viewed to benefit parents, as identified by two subthemes:

Practise language

It provides parents with the chance to explore what language they will use to explain ED/DD to their children. This allows parents a window of opportunity to become acquainted with ED/DD-related talk before their children are able to comprehend the language. Donor conception terminology can be difficult (see 5.3.4.1); therefore early disclosure creates an important rehearsal period that increases parents' comfort:

> *You yourself need to, almost practice, or rehearse telling them, so that you feel completely comfortable, and also I suppose trying out different words and different ways of telling them so that you feel very COMFORTABLE with it... that's a good opportunity to do that on a 3 week old baby because they're not responding.* **D/SMC/twin sons-3 (AB/DD/A)**

Disclosers anticipated that disclosure would not be an easy or smooth process so the early delivery of information allowed participants to articulate information without concern of saying something unclear or unsuitable.

To desensitise

Some parents initially found it incredibly emotional to tell their children about their conception, so used early disclosure as a unique opportunity to 'desensitise'. Parents allowed themselves to be emotional when talking to their young babies, so that they could be more in control of their emotions as their children become increasingly aware of what they are told:

> *I used to talk to him when he was a baby more for my own benefit because for the first few times that you talk about it it's really emotional actually... you almost need to desensitise yourself about it cos obviously you don't want to be getting all emotional talking to-to them about it.*
>
> **D/SMC/sons-3 and 2 (AB/DD/A)**

Disclosers were aware that their own attitudes to donor conception might impact how children perceive it and therefore did not wish to be emotional discussing this when their children were older because this might portray donor conception as something displeasing.

5.1.3.3 REASONS FOR NON-DISCLOSURE

Five themes described the reasons for non-disclosure:

1. **REJECTION BY FAMILY**
2. **'THEY'LL HAVE NOTHING TO FIND OUT'**
3. **'THEY'RE MINE THAT'S IT'**
4. **DON'T WANT CHILDREN TO FEEL 'DIFFERENT'**
5. **CHILDREN ARE TOO YOUNG**
    I. Too young to understand
    II. Too young to be told

THEME 1 - REJECTION BY FAMILY

Some non-disclosers described 'difficult' family relationships, and were concerned that other family members would reject their children, if they were aware of the circumstances of their conception. As a result, they thought that it

would be better for no one to know, including their children. This father illustrates this with reference to his mother:

> *I don't want her to know.... she doesn't treat my children very nicely now, so, goodness me what will she do to them, how would she treat them, if, they weren't tied, like blood to me.* **ND/FC/twin daughters-6 (UK/U/I)**

Similarly, this mother was worried that her older, naturally conceived son, would reject her younger ED conceived sons:

> *You know him and <twins> don't really get on.. if that was to come out now it would be awful .... 'you're not my brother and you're this and you're that'. So you know, it made it makes it even harder to want to…* **ND/MC/twin sons-7 (UK/ED/I)**

These fears show the perceived stigma attached to donor-conception, and that genetics are viewed as relevant for family relationships. These concerns could mean that parents have not completely come to terms with their infertility and could benefit from some support to work through their feelings.

THEME 2 - 'THEY'LL HAVE NOTHING TO FIND OUT'

Some parents gave the use of anonymous donors as a reason for non-disclosure. One couple had a son born under the legislative framework of anonymity, whereas their daughters were born subsequently using identifiable donors. Both partners felt that it would be unjust and difficult for their daughters to be able to trace their donors, but not their son:

> *We got a legal issue, that the law change, so we have <son> who can't find, there's no information to find… There's <daughters> who have access through the law, to find some, limited information…., I just don't know how <son> would cope.* **ND/FC/twin daughters-6 (UK/U/I)**

The only non-disclosing SMC received anonymous treatment abroad, and therefore thought that disclosure was futile:

It kind of makes it a little bit harder now .. it makes you feel god is there any point in telling them because they won't be able to find out.
ND/SMC/twin sons-7 (UK/ED/I)

These findings are congruent with that view that anonymity increases parents' reluctance to disclose, and in theory, support the suggestion that parents might be more likely to disclose if they have identifiable donors (see 2.2.3). However, some disclosers also used anonymous donors, but still revealed the use of ED/DD treatment to their children, therefore anonymity is not the only prerequisite for non-disclosure.

THEME 3 - 'THEY'RE MINE THAT'S IT'

Non-disclosers placed more emphasis on the importance of the social family, and social aspects of parenting, over the relevance of genetic origins. They felt their children were 'theirs' regardless of genetics, and that there is no need to tell otherwise. Both members of this couple describe their feelings on this issue:

I don't know how the situation would arise if it ever came to light, when they're 18, 20 I don't know. .... No. No. You know as far as I'm concerned they're mine, that's it. **ND/FC/twin sons-5 (UK/U/I)**

I planned not to tell them… Really, they are our children um you know we are their mum and dad. **ND/MC/twin sons-5 (UK/U/I)**

MacCallum and Golombok (2007) also found that some ED parents justified non-disclosure on the basis that they have raised their child from pregnancy, and placed more emphasis on the importance of rearing children, than on genetics.

THEME 4 - DON'T WANT CHILDREN TO FEEL 'DIFFERENT'

Another reason for non-disclosure was because parents did not want their children to feel 'different' because they are donor-conceived:

And not that I would tell them now because I would hate them to go to school and feel different. **ND/MC/twin sons7 (UK/ED/I)**

I don't want them being labelled as being different, you don't know what's going to come up against them then in school…. **ND/SM/twin sons-7 (AB/DD/A)**

Again, this reinforces the perception that there are negative connotations associated with donor-conception.

THEME 5 – CHILDREN ARE TOO YOUNG

Some parents provided the child's young age as a reason for non-disclosure; these parents tended to be more uncertain whether they would maintain non-disclosure in the future. This parent explains how she is just taking it 'one step at a time':

We've never really gone down that, that road… 'Cause they are, they are young still…. And that does bring up the question again about telling them but yeah it hasn't really come in to conversation because you know they are still so young…. As I say I've just taken it one step at a time.

ND/MC/twin sons-5 (UK/U/I)

Another mother thought that her seven-year-old twins were currently too young to cope with the emotional elements of disclosure. She doesn't want to 'dump' this on them, again reinforcing that she views donor conception as negative; she contemplates telling them when they are adults:

I thought well maybe when they get older maybe when they're grown up … so I have thought in my head IF we do, I'll wait until they're adults and tell them. I couldn't dump that on them now as children. **ND/MC/twin sons-7 (UK/ED/I)**

Uncertainty concerning the 'best' age to disclose, and the belief that doing so during adulthood might be preferential, is contrary to findings from literature and UK legislation that endorses early disclosure, and demonstrates that some non-disclosures were unaware of the benefits of the early delivery of this information.

5.3.3.4. DID I MAKE THE RIGHT DECISION?

All disclosers felt that openness was the right thing to do, yet in contrast, non-disclosers were less certain, and often made spontaneous reflections on their decision, deliberating between thinking that they have done the 'right thing', and being uncertain if they have. Two themes accounted for this ambiguity:

1. **CHILD MIGHT FIND OUT IN THE FUTURE**
    I. Medical reasons
    II. Triggers
    III. Other people knowing

2. **'AS THEY GET OLDER IT BRINGS MORE IMPLICATIONS'**

CHILD MIGHT FIND OUT IN THE FUTURE

First, non-disclosers were concerned that the use of ED/DD might come out in the future. This non-disclosing couple initially described that they had made the 'right choice' not to disclose:

> *We've made a decision not to tell them….. Before they were born.... and we haven't changed our mind, since. In fact, I think for me, it's been more compounding not to.* **ND/MC/twin daughters-6 (UK/U/I)**

> *You can't worry about these things and cover all the eventualities,….. so I think we've made the right choice.* **ND/FC/twin daughters-6 (UK/U/I)**

However, later in the interview this same couple expressed doubts about their decision. The father felt that there could be a 'fall out' *when* their children find out about their conception:

> *I think inevitably, there will be, yes, fall out when they do find out. But.. I think there's fall out equally, there's fall out if you do know. It works both ways….. Neither solution is perfect… but once your research (*to interviewer) *is done, you'll be able to decide which we should have done* **ND/FC/twin daughters-6 (UK/U/I)**

This implies that he thinks that their children will find out at some point in the future, and also that he thinks that there is a 'right' way for children to be told, demonstrating both doubt about non-disclosure and also the perception that both approaches have disadvantages. Most non-disclosers thought that there was a possibility that their children would unintentionally find out about their conception, and three sub-themes highlight why this is so:

Medical reasons

Some non-disclosing parent worried that a medical emergency could result in the accidental revelation of donor conception:

> *The only time that I have a wobble about it, is if I ever think about that if they ever get seriously ill... I think that's the only time that makes me feel really like.. Oh God!* **ND/MC/twin daughters-6 (UK/U/I)**

Triggers

Non-disclosing parents also worried that there might be a 'trigger' that makes children question their conception. This father explains his concerns:

> *We have an issue with you know, <son> has brown eyes, I have blue, uh grey eyes, (wife) has blue eyes, how do you get a brown eye child? It's possible, but it's rare... But.. there are you know, some triggers, that he might think.* **ND/FC/twin daughters-6 (UK/U/I)**

Other people knowing

Around half of the non-disclosing parents had told at least one other person about their child's conception, and were concerned that their child might find out from this person:

> *You think, God, that was actually a massive piece of information you've given to somebody and that's a lot to expect them to keep that contained and not tell anyone else'* **ND/FC/son-3 (UK/ED/I)**

Non-disclosers acknowledged that circumstances might appear where it is in the best interests of the child to be open. As such, they do not intend to disclose, but were mindful that new events may be encountered that may cause them to

re-evaluate. This has been identified in non-disclosers elsewhere, which Lindblad, Gottleib, and Lalos (2000) categorised as 'unexpected circumstances may arise'.

THEME 2: 'AS THEY GET OLDER IT BRINGS MORE IMPLICATIONS'

Non-disclosers acknowledged that they feel different now compared to at the time of treatment. All non-disclosing parents made the decision not to disclose prior to the birth of their children. However, now that they are actually parents they consider the consequences of this decision, particularly with regards to how their children would feel if they found out, and feeling that disclosure is indeed the 'right' thing to do:

> *One of the things I worry about as well is I think I HAVE to tell them.. it's the right thing to do and that I'm not going to be here forever and maybe they will have some family out there that you know would be nice for them to have.* **ND/MC/twin sons-7 (UK/ED/I)**

Some mothers in non-disclosing couples felt more inclined to tell their children in the future, compared to their male partners who were more reluctant to do so. This topic heightened emotions in mothers during interviews and evidences the importance of couple counselling (discussed in detail in 5.5).

Section summary and comparison with adopters

Irrespective of their disclosure stance, most parents thought that children would ultimately discover that they are donor-conceived. Disclosing parents ensured that this would never be a shock by starting the process early. However, for non-disclosing parents, this worry is still alive and contributes towards doubt over their decision to keep information about conception concealed. Parents generally felt that there are negative consequences associated with being donor-conceived. Disclosers are taking actions to minimise feelings of 'difference', such as linking with other donor-conceived children, whereas non-disclosers are not. The opinion that children are too young to deal with

disclosure contrasts with UK legislation and indicates that non-disclosers would benefit from advice on the timing of disclosure.

Non-disclosers were generally unsure of their future plans, and were uncertain about how to proceed. In comparison, all adopters were confident with their decision, they did not consider non-disclosure to be an option. Both disclosing ED/DD and adoptive parents disclosed early because they thought that it was important for children to be unable to remember the day they were told about their conception/adoption, and that the early delivery of this information would help children to understand their identity. ED/DD parents acknowledged that sharing information about donor conception is not an easy or smooth process and that the early delivery of this allowed them to articulate information without worrying that they might become emotional or say something inappropriate or unclear. Adopters did not provide this as a reason; perhaps they felt more confident at delivering information because adoption revelation was covered during their adoption training, whereas ED/DD parents were unprepared for this process.

5.3.2 HOW ARE CHILDREN BEING TOLD?

5.3.2.1 HOW ARE CONVERSATIONS INITIATED?

Three themes identified how parent-child discussions relating to donor conception are instigated in disclosing families:

1. **BY USING BOOKS**
2. **BY MAKING LINKS BETWEEN SIMILAR FAMILIES**
3. **BY CHILDREN ASKING QUESTIONS**
    I. Donors
    II. Biology

THEME 1: BY USING BOOKS

Most disclosers used books as a tool to broach conversations, and particularly liked this method because it can form a part of everyday routines, without

specifically sitting down to discuss donor-conception. This was important for parents, and corresponds with the desire to have 'natural' conversations:

> *I will occasionally bring it up, if it, if it seems to fit in with something we're talking about, but I don't tend, I wouldn't generally instigate it, out of the blue.* **D/SMC/twin sons-3 (AB/DD/A)**

THEME 2: BY MAKING LINKS BETWEEN SIMILAR FAMILIES

Contact with other donor-conceived families facilitated discussions by enabling parents to point out the similarities between other families, and their own. This strategy was particularly common for SMCs who wanted their children to be clear that they do not have a dad:

> *If it does come up I'll say things like, you know so and so, and so and so… they don't have a daddy in their family.* **D/SMC/son-5 (AB/DD/A)**

> *I'll often say to him... we're going to see, er, X, Y, and Z, do you remember they've also got families where they just live with their-they live with their mummy.* **D/SMC/son-7 (UK/DD/I)**

THEME 3: BY CHILDREN ASKING QUESTIONS

Discussions were also stimulated by children's questions, which tended to occur from around five years old. Two sub-themes identified the nature of questions:

Donors

First, almost all questions were based on clarifying information about donors, specifically who they are and their relevance:

> *'So do they know who I am? Do they have my address?' ... I said, 'no darling, they don't have your address either.' So he said, 'Good, 'cause I want to live with you.'* **D/SMC/son-7 (UK/DD/I)**

> *'Are they in our family' and I said 'No, they're not in your family, your family is <sibling>, and <sibling> and me and you. But it's not all those*

other people they just happen to share some of the ingredients that went into making you. **D/SMC/daughters-3 and 5 (AB/DD/IA)**

The presence of questions appearing from around the age of five-years-old is in line with adoptive children who begin to question the relevance of their connection between two different families around age six (Brodzinksy, 2011) and naturally conceived children who begin to understand biological inheritance aged seven upwards (Gregg et al., 1996; Williams & Smith, 2010).

Biology

Second, questions centred on biological aspects of donor conception, specifically human anatomy.

'*So I grew inside you mom'. And I said 'yes you did'. And that was very important to her.* **D/MC/daughter-7 (UK/ED/A)**

*They would ask 'what are sperms? And what are eggs'**?** And we would have to explain a little bit human anatomy ... there's no embarrassment telling a child, children, simple things so it helps.* **D/FC/daughter-7 (UK/ED/I)**

Parents thought that it was important to answer questions truthfully to help their children to develop a fuller picture of their conception. The presence of conversations relating to biology have also been found in studies looking at donor sperm or egg (Blake et al., 2010; Mac Dougall et al., 2007).

5.3.2.2 FREQUENCY OF CONVERSATIONS

Disclosing parents did not view disclosure as a one-off event and placed value on revisiting conversations with their children to aid understanding. Two themes identified how conversations are regulated:

1) **DON'T WANT IT TO DEFINE CHILDREN**
2) **KEEPING IT ON THE RADAR**
   I. So that children do not forget
   II. Because children do not understand

Disclosers described the complexity of carefully managing the frequency of conversations to get the correct balance.

THEME 1: DON'T WANT IT TO DEFINE CHILDREN

First, parents did not want to talk about donor conception too often because they do not want it to be the most prominent characteristic:

> *I would say probably haven't said anything about it for several months.. I don't want to flog it to death you know I don't wanna sort of be constantly talking about it because ..it's part of how they came into this world but it's not the thing that defines them.* **D/MC/daughters-6 and 4 (AB/DD/A)**

THEME 2: KEEPING IT ON THE RADAR

Second, parents were equally concerned about initiating discussions often enough to keep it on the 'radar'; this serves two purposes:

So that children do not forget

Regular conversations served to trigger memory to ensure that children do not forget that they are donor-conceived:

> *I think it's important just to keep that open and not to forget to keep doing it because they don't understand….Otherwise it kind of might be forgotten*
> **D/MC/son-4 and daughter-2 (AB/DD/A)**

Because children do not understand

Parents were aware that their children did not understand all details relevant to their conception; so on-going conservations provide opportunities to add more detail to help their children's comprehension flourish:

> *We started at an early time so it would never be a shock to them BUT it's we have to sort of remind us to keep doing that because it's obvious they don't really understand.* **D/MC/son-4 and daughter-2 (AB/DD/A)**

> *As <child> gets more understanding of reproduction ... It will make it easier. I'm just drip-feeding a wee bit you know, when the big conversation does come through that he understands it more*. **D/FC/son-8 (UK/ED/A)**

Section summary and comparison with adopters

Parents were aware that their children did not understand the finer details of their conception, but planned to aid their understanding by speaking truthfully and drip-feeding information; a view also shared by adopters. Adopters and disclosing ED/DD parents thought that it was important to have 'natural' conversations; however, adopters placed more emphasis on this and generally assumed that their children were reluctant to discuss their adoption. Adopters used an abundance of resources to discuss key events and conceptions surrounding adoption, whereas ED/DD parents utilised fewer resources because children's TV programmes and films do not contain child-friendly analogies relating to donor-conception. Instead, ED/DD parents tended to engage in discussions as a result of their children's questions, or by pointing out the similarities between other donor-conceived families.

Both adopters and disclosing ED/DD parents accentuated the importance of keeping the conversation 'alive' because they were mindful that their young children could forget, and did not yet understand all details. They were, however, wary about raising the subject of adoption/conception too frequently. For ED/DD parents, this was because they did not want their children's conception to be a 'big deal', or define their children. Adopters were more concerned about 'forcing' a conversation that they thought their children were reluctant to have, or anxious that raising conversations could lead to their children feeling rejected.

5.3.3. WHAT ARE CHILDREN BEING TOLD?

5.3.3.1 NARRATIVES OF DISCLOSING PARENTS

Each ED/DD story was unique, but five themes were identified across narratives:

1. **CHILD WANTED**
   I. Happy because have child

2. **PARENTS NEEDED HELP**
   I. 'Mummy and daddy couldn't have babies'
   II. 'Didn't know a man that I loved enough'
   III. Couldn't do it alone

3. **'TWO KIND PEOPLE'**
   i. Gametes
   ii. Grateful to donors
   iii. Anonymity
   iv. Identifiable donors

4. **DOCTORS AND NURSES**
   i. Presented in a positive way
   ii. Grateful to doctors/nurses

5. **TUMMIES**

THEME 1: CHILD WANTED

Most parents emphasised their desire to have a baby and stressed how 'wanted' their children were:

> *Mummy really wanted to have a baby, actually for me the key thing about starting off like that it, that's what I want him, them to understand.*
>
> **D/SMC/sons-2 and 4 (AB/DD/A)**

> *I said well you were a tiny tiny-tiny little dot and I really wanted to have you so much and so did daddy and we were trying so hard.*
>
> **D/MC/daughter-9 (UK/ED/A)**

This theme has also been identified by Mac Dougall et al. (2007) and defined as 'labor of love'. Information is shared with children about how desired they were, and the 'great lengths' that parents went to in order to have their child. Mac Dougall et al. (2007) suggested that the emphasis on how wanted children were might make them more accepting of their donor conception.

Happy because have child

A sub-theme of this desire was how happy they were to become parents:

> *How lucky I am, how lucky he is, because he helped me make a family*
>
> **D/SMC/son-2 (AB/DD/A)**

> *Mummy stopped crying. She smiled and smiled and smiled, because she was so happy. And that's how we became a family.* **D/SMC/son-7 (UK/ED/I)**

Overall, this theme provides parents with an opportunity to positively reinforce their children's conception by the definition of ED/DD treatment as a well thought out decision, and not one of an impulsive nature.

THEME 2: PARENTS NEEDED HELP

Parents incorporated information that they needed help in order to conceive, which formed three sub-themes:

'**Mummy and daddy couldn't have babies**'

All HCs referred to the fact that both 'mummy' and 'daddy' needed help to have a baby:

> *Mummy's eggs didn't work and Daddy's sperm didn't work anymore... there are some really kind people out there who give their eggs and sperm to erm mummy's and daddy's who want to have a baby but who can't.*
>
> **D/MC/daughters-6 and 4 (AB/DD/A)**

> *Mummy and daddy couldn't have babies and that made mummy and daddy very sad.* **D/FC/daughter-7 (UK/ED/I)**

'Didn't know a man that I loved enough'

Single mothers by choice have a slightly different story to tell, and usually included information about how they could not find a man to have a baby with:

> *Didn't know a man that I loved enough to-to-to try to have a baby with.*
>
> **D/SMC/daughter-8 (AB/DD/A)**

> *I wanted to have you know, children very much and I looked around for somebody who could be their Daddy and couldn't find anybody.*
>
> **D/SMC/daughters-5 and 2 (AB/DD/IA)**

Couldn't do it alone

However some SMCs instead centred the story around their inability to make a baby on their own:

> *When mummy wanted to have a baby and she couldn't do it on her own, she went to, she went a long way away on an aeroplane to a very special erm, hospital*. **D/SMC/son-4 (AB/DD/A)**

> *Sometimes a mummy can't make a baby but she can grow a baby erm so the doctor.* **D/SMC/sons-2 and 4 (AB/DD/A)**

Telling children that help was needed to conceive serves two purposes. First, it provides basic information relating to the biology of procreation. Second, it conveys details about family structure; specifically the absence of a father in SMCs. The importance of ensuring that donor offspring in SMC families are aware that they do not have a father has been noted elsewhere (Zadeh et al., 2015).

THEME 3: 'TWO KIND PEOPLE'

Donors were present in all narratives in some form of another, and were frequently portrayed as being kind, generous and altruistic in nature. Most parents did not specifically use the term 'donors', but the fact that two people were involved was unequivocal. Examples include: '*two kind people'*, *'a kind couple'*, '*a lady who did a nice thing and a man who did a nice thing*' and

'*Generous man and a generous woman*'. Scheib et al. (2003) suggested that HCs are faced with the predicament of explaining that their children have a sperm donor and a father, or an egg donor and a mother; this complexity could be even more prominent in ED/DD conception where children may have both a mother and an egg donor, and a father and a sperm donor. However, this did not appear to be the case in that HCs presented the donors in the same manner as SMCs. Four sub-themes illustrate how the donors were portrayed:

Gametes

Parents told their children that the 'donors' provided their gametes in order to help them to have a baby:

> *These very kind people who were also looking to have children and needed help. They had lots of eggs to spare and they said that they would like to help other people and you were one of these eggs.* ***D/MC/daughter-8 (UK/ED/A)***

A variety of terminology was used to discuss gametes (see 5.3.4.1 for details) but nonetheless, this provides some important information related to the biology of donor conception. Mac Dougall et al. (2007) described this theme as 'nuts and bolts' whereby technical details pertaining to the biology of the donor conception are conveyed to children.

Grateful to the donors

Many parents expressed tremendous gratefulness towards the donors and wanted to pass these sentiments on to their children:

> *We'll always be REALLY-REALLY grateful to them and I you know I've said to the girls things like erm .. I would just LOVE to be able to hug our donors and say thank you so much* **D/MC/daughters-6 and 4 (AB/DD/A)**

However, a potential problem with this could be that they raise their children's hopes and expectations of the donors, which in turn might result in their children being disappointed if they meet their donors and they are not as they expected, or if donor-offspring are unable to meet their donors in the future. Furthermore, the element of gratefulness could imply that donor-conceived

children should be grateful for their existence, which may unintentionally put pressure on donor-offspring to feel this way.

Anonymity

When anonymous donors had been used, some parents began to let their children know that it is unlikely that they will be able to meet their donors in the future:

> *I sort of positioned them like kind of fairy fairies almost like special little fairies who came and gave this amazing gift of erm donor egg and donor sperm these kind amazing people then they've kind of fluttered off and we won't we will never know who they were.* **D/MC/daughters-6 and 4 (AB/DD/A)**

> *There ARE some kind people who we will never know' and that's REALLY important because it was anonymous* **D/MC/daughters-6 and 5 (AB/DD/A)**

Parents who shared this information did so in the interests of transparency; they did not want any aspects hidden from their children and also did not want their children to potentially be disappointed when they later discovered that they could never meet the donors. However, not all parents who used anonymous donors had yet begun to explain this (discussed in 5.3.4.1).

Identifiable donors

When identifiable donors have been used, a few parents had informed their children about the possibility of future contact:

> *... you may become friends with them in the future or get on with them really well or form a different relationship, with them whatever that might be but they won't ever be part of our family, you know, our unit.*
>
> **D/SMC/daughters-3 and 5 (AB/DD/IA)**

> *I explained to him, we don't know them, at the moment.. But when you're eighteen, you'll be able to get some information, if you want and then you might be able to track them down.* **D/SMC/son-7 (UK/DD/I)**

Just over half of the children in this study had at least one identifiable donor, yet the possibility of meeting donors in the future was absent from most narratives. Similar findings were found when identifiable sperm had been used and only 41.2% of disclosing mothers had discussed, or planned to reveal the possibility of future contact with their donor (Freeman et al., 2016). This aspect could be largely lacking due to parents' worries and concerns about future contact with the donors (see 5.3.5.1), due to the young age of children at the time of the study, or because parents view this aspect as currently unimportant.

THEME 4: DOCTORS AND NURSES

Medical professionals were present in most narratives, and were described as actively helping parents to create a baby. The inclusion of details about fertility staff might assist young children to conceptualise an otherwise unfamiliar story because they are likely to be aware of doctors/nurses. Professionals were presented in two ways:

Presented in a positive way

First, like donors, medical professionals were also portrayed in a positive way:

> *Really clever doctors and nurses.* **D/MC/son-5 (UK/ED/I)**

> *A special erm, hospital where there was some really clever doctors and nurses.* **D/SMC/daughter-4 (AB/DD/A)**

Grateful to doctors/nurses

Second, some parents expressed appreciation of the medical professionals who provided necessary input in order for them to have children:

> *Mummy loves you so much, mummy is so grateful to the doctors and nurses and donors, who made it possible for her to have you.*
>
> **D/SMC/son-7 (UK/ED/I)**

The **'helper'** narrative identified by parents in this study with respect to both donors and medical staff has frequently been found elsewhere in sperm/egg donation studies (Blake et al., 2010; Mac Dougall et al., 2007).

THEME 5: TUMMIES

All parents provided a simple explanation of how gametes were 'put' or 'mixed' together and placed in 'mummy's tummy' by doctors/nurses:

> *The man gave a seed to the doctor and the lady gave an egg to the doctor and the doctor put the together and made a teeny tiny baby and he put the baby in mummy's tummy and that baby was you and you grew and grew*
> **D/SMC/sons-2 and 4 (AB/DD/A)**

The act of growing and developing inside tummies was emphasised, which may serve to reinforce parent-child connections whereby despite the genetic relationship, children were still in their mothers' tummy and are therefore linked to their parents. Also, young children are likely to be familiar with the role of tummies in pregnancies through seeing other women with babies in their tummy.

Overall, these themes are reflective of those used by sperm/egg donation parents (Blake et al., 2010; Mac Dougall et al., 2007; Zadeh et al., 2016) and establish that ED/DD parents present conception in a similar way. The key difference is that ED/DD parents discuss the use of *two* donors, as opposed to one in sperm/egg donation.

5.3.3.2 NARRATIVES OF NON-DISCLOSING PARENTS

Some non-disclosers had told their children *partial* information about being conceived differently, as illustrated by two themes:

1. **USE OF IVF**
2. **THE USE OF A SPERM DONOR**

THEME 1: USE OF IVF

One couple told their children that they were conceived using IVF, however did not plan to reveal the use of donors, hence did not intend to fully disclose the lack of genetic relationship:

> *The girls know they're IVF, but.. I haven't really told them the ins and outs cus they're quite little…. But <son>.... I mean he knows about the facts of life anyway, and he knows that daddy had cancer, and that we had to have our children conceived in a different way. And he knows about.. You know the little petri dish with an egg, and the sperm goes in.*. **ND/MC/twin daughters-6 (UK/U/I)**

THEME 2: THE USE OF A SPERM DONOR

The only non-disclosing SMC had told her children about the use of a male donor, but had not explained that a female donor was also needed. She was uncertain if she would disclose this in the future:

> *Mummy was looking for a nice daddy and I say to them I had to go to the doctor and he helped me and he got the seed and you know. So I've told them kind of the truth themselves so whether that transpires in them telling someone you know so be it.... So I haven't made up any story about their daddy or anything like that.* **ND/SMC/twin sons-5 (AB/DD/A)**

As this mother stated, she has told her children 'kind of the truth'. The revelation of partial information helped these non-disclosers to think that they had not been completely dishonest with their children, which could serve to protect their own sense of integrity, but could also be used as a mask that shields full details of their children's conception, as also identified by Readings et al. (2011)in sperm/egg donation families.

Section summary and comparison with adopters

Adopters and ED/DD parents have comparable information to convey to their children, which was evident in some of the similarities between themes

identified in their narratives. However, ED/DD parents generally included more details about the donors' role, compared to adoptive parents, who provided less information about the birth parents. This is surprising considering that adopters have more information about birth parents through the possibility of contact, and information from social services, compared to the limited information that ED/DD parent have about donors.

The role of tummies was present in the narratives of both sets of parents; from the perspective of ED/DD parents, they deemed it was important for their children to know that they shared this connection and that they are 'their' child regardless of the lack of genetic connections. In contrast, adopters thought it was fundamental for children to know that they grew in another lady's tummy; this helped to connect children to their birth family. ED/DD narratives also included more biological aspects, such as basic elements of conception and gametes. Adopters did not include such details, perhaps because they are less pertinent to the adoption story. Emphasis was placed on how wanted their children were; however, adopters focused on how 'special' their children were, an aspect not specified by ED/DD parents. Adopters were generally concerned that their children might feel unwanted by their birth parents; therefore reinforcing their children's special qualities may serve to raise their self-confidence. Overall, ED/DD parents expressed more gratitude compared with adoption. It is feasible that this is because in adoption, the involvement of others requires less 'help', and birth parents did not normally make a free choice, so gratitude is not appropriate.

Finally, some non-disclosers engaged in partial information, as identified in studies elsewhere (Isaksson et al., 2016; Readings et al., 2011). To some extent, some adopters also engaged in partial disclosure by absenting the birth father and his role in this process, whereas disclosing ED/DD parents univocally referred to the use of two donors.

5.3.4 WHICH ASPECTS DO PARENTS NEED TO DEVELOP?

Disclosers felt responsible to help their children to comprehend all details surrounding their conception.

5.3.4.1 CHILDREN'S UNDERSTANDING

Four themes identified areas of development that disclosers wanted to help their children to understand:

1. **DO NOT UNDERSTAND THE IMPLICATONS**

2. **LACK OF GENETIC CONNECTEDNESS**
    I. Not genetically connected to parents
    II. How lack of genetic connection makes them different to other children
    III. Siblings conceived in a different manner

3. **EXPLAINING ANONYMITY**
    I. Not comfortable about using anonymous donors
    II. Concerns about how children will feel

4. **DONOR SIBLINGS**
    I. Children are too young to understand
    II. Do not know how to tell

THEME 1: DO NOT UNDERSTAND THE IMPLICATONS

Parents who had children of an age where they were able to communicate to a reasonable level, reported that their children were able to repeat a simple story about their conception, but were not able to fully comprehend the significance of what they were told and how this impacts them both now and in the future:

> *I think at the moment they just know that there were donors that gave eggs and sperm and they know the words but they don't know erm what it actually means the implication of it.*
>
> **D/MC/daughters-6 and 4 (AB, DD, A)**

> *< Child> is able to tell the story a very simple story about how the erm we you know you need an egg and a seed to make a baby ... BUT he doesn't understand the implication.* **D/MC/son-4 and daughter-2 (AB, DD, A)**

Parents reinforced the importance of adding more complex details over the course of time to help their children's understanding to flourish.

THEME 2: LACK OF GENETIC CONNECTEDNESS

The majority of parents were aware that their children do not understand the significance of genetic links, and within this context three sub-themes were extracted:

Not genetically connected to parents

A few parents have started to explain to their children that they are not genetically related to their parent(s) by discussing biological aspects such as making physical parent-child comparisons. However, parents felt that their children do not yet fully understand what this means:

> *<Child> said something the other day about her having brown hair and not having red hair that made me realise that she's sort of forgotten again .... they're so young they don't YET understand that that means we're not biologically connected.* **D/MC/daughters-6 and 4 (AB/DD/A)**

Parents' interpretation of their children's understanding are in accordance with findings that most seven-year-olds demonstrated little or no understanding of their conception (Blake et al., 2010), and naturally conceived children do not begin to understand biological inheritance until aged seven upwards (Gregg et al., 1996; Williams & Smith, 2010).

How lack of genetic connection makes them different to other children

Most children do not yet understand that they were conceived differently to the 'norm':

He won't understand that that doesn't happen as the norm ... I don't think at four he really processes what he's told, or realises he's any different to what anybody else. **D/SMC/son-5 (AB/DD/A)**

Disclosers planned to gradually introduce information to set the 'scene' so that children feel like they have always known about this:

I don't think that bit's really sunk in, but again, trying to kind of set the scene gradually for, you know, there are some children conceived to single mums who are genetically connected to their mums, and some that aren't.... that will come quite a lot LATER for them, in terms of them really understanding it. **D/SMC/twin sons-3 (AB/DD/A)**

Siblings conceived in a different manner

Some disclosers have children conceived through different methods of conception. For instance, this mother has a son conceived using her own eggs and donor sperm, and daughters who were born as a result of ED treatment. She has started explaining the differences to her children:

She's aware that she's different from <first child> funnily enough you know he's told her you know 'I'm from mummy's eggs and you're from some other ladies'. Which upset her. And I told her all the benefits (laughs) you know there's schizophrenia in my family baby there's not schizophrenia in your donors. **D/SMC/daughters-3 and 5 (AB/DD, IA)**

She focussed on the benefits of ED conception, in the hope that her daughter would adopt the same positive views towards her conception, rather than focusing on the lack of genetic connections. But most parents in this predicament want to be open with their children and anticipate that this will be difficult. The next mother conceived her first child as a result of ED treatment; however, her second child was conceived naturally. She does not know how to explain this to her children, which is causing her anguish because she is concerned that her child might perceive genetic connections as important and not feel an equal part of the family:

<First child> is going to come to the realisation that there is a difference between the two, and so I'm now trying to write <first child> a story for the next bit, to sort of in child-friendly language as best I can... That's the bit that I find really hard because deep down I really wanted them to be genetically related, and I'm really struggling. **D/MC/son-5 (UK/ED/I)**

THEME 2: EXPLAINING ANONYMITY

Most parents felt that their children were unaware of the relevance of their donors. This is unsurprising because although donors were depicted in the narratives, specific information about how they are genetically relevant was largely lacking. Over half of the children, whose parents were involved in this study, were conceived using at least one anonymous donor. As discussed, some parents had already started to explain to that this means that they will never be able to meet their donors. Two subthemes identify why some parents have yet to explain this aspect to their children:

Not comfortable about using anonymous donors

Most disclosers reluctantly used anonymous donors because treatment abroad was more affordable and had shorter waiting times, but they would have preferred to use identifiable donors:

I would've much preferred to have used known, you know, identifiable donors. But, you know, that meant waiting another 2 to 4 years to have a child, and I just, you know. I just wasn't, I was at the end of the road already. **D/SMC/son-6 (AB/ED/A)**

Therefore it is understandably difficult for parents to explain anonymity to their children, when non-identifiable donors were not their preferred choice.

Concerns about how children will feel

Some parents were worried about how their children will feel about not being able to trace their donors in the future (discussed further in 5.3.5.1); this concern was provided as a reason both for telling about anonymity and for not doing so. Ultimately parents planned to discuss anonymity, and delayed doing

so to protect their children from potential harm in the short-term, suggesting that they perceive that their children will find this upsetting:

> *That's really not ideal at all and I do worry about that for the children ... but you know at the time I just felt that I didn't feel like I could do anything else personally.* **D/MC/son-4 and daughter-2 (AB/DD/A)**

THEME 3: GENETICALLY LINKED DONOR 'SIBLINGS'

A small number of children have already been told about genetically linked donor siblings; however, two sub-themes identified why the majority of parents had not yet shared this information:

Children are too young to understand

Parents general felt that their children were not currently old enough to understand the differences between the 'social' family and the 'biological' family, and thought that children would be unable to grasp the potential significance of donor 'siblings' until they can comprehend these differences:

> *That's another step in the story that they perhaps, they're a way off getting their heads around ... understanding that the donors could also donate to other people and those people would share a genetic connection. Because I think for them at the moment, family is VERY much about the people that you live with, and the people that you see.* **D/SM/twin sons-3 (AB/DD/A)**

Research elsewhere has similarly demonstrated that parents are hesitant to tell their children about their donor siblings when they have been located because they deemed their children too young to be able to understand the intricacies of these relationships (Freeman, et al., 2009; Scheib & Ruby, 2008).

Do not know how to tell

Some parents were unsure how to broach discussion about donor siblings:

> *Two-two half siblings erm and so I, I erm it's a bit of information is relevant for the girls they don't know that and that is the only the ONLY thing that I*

haven't said to them so far and I'm not happy about it. ...and I'm not sure what to do about it ... I'm not sure how to word it.

D/MC/daughters-6 and 4 (AB/DD/A)

There are two further reasons for the complexities of telling children about their donor siblings. First, parents tell their children a simple narrative about their conception, however, donor siblings are not directly linked to *how* children were conceived, but rather a consequence that provides another layer**.** Second, parents were often unaware whether there are donor siblings because this information was not provided by their clinics; without this knowledge it is difficult for parents to share accurate information.

5.3.4.1 'I DON'T ALWAYS KNOW WHAT LANGUAGE TO USE'

Many disclosing parents experienced difficulties when determining what terminology to use, as identified by three themes:

1. **DONORS**
2. **DONOR SIBLINGS**
3. **SEED VS SPERM**

THEME 1: DONORS

The label 'donor' helped parents to define this role, whilst diminishing aspects relating to parenting. This was relevant for SMCs in particular, who appreciated the need for careful phrasing so that their child understands that the donor is not their "dad'':

I had to think really carefully about how I would frame that for him and what words I would use, so I say that he's got, well he's got two donors.. to me, he hasn't got a dad. To me he's got a donor **D/SMC/son-6 (AB/ED/A)**

A UK-led study also found that SMCs carefully considered how they could distinguish the donor from a daddy (Zadeh et al., 2016). However, not all parents wanted to use the word 'donor' at this stage and some parents, particularly those with younger children, instead used phrases such as '*a little bit of a man and a little bit of a woman'* or '*a kind man and a kind lady who gave*

mummy all the bits and pieces'. This mother explains her reluctance to use 'donor':

> *I haven't used the word "donor", because I think until, from my point of view until she gets really a little bit older and she can get the concept. I don't want her sort of saying I don't have a daddy I have a donor, because I think that sounds really...* **D/SMC/daughter-2 (UK/DD/I)**

To this end, a 'daddy' is something tangible that young children can relate to because of their context within families, whereas children will have no prior knowledge of what a 'donor' is. Also, other children are likely to be unfamiliar with this term, so parents might want to try to protect their children from drawing attention to the fact that they are conceived differently. Couples did not experience the same difficulties with regards to labelling the male donor, perhaps this is because two parents are present, so they do not fear that their children might feel like they are 'missing' something: a dad.

THEME 2: DONOR SIBLINGS

Most parents referred to other children who share the same donors as 'siblings'; however, some expressed serious discomfort with this term, particularly parents who had children in their family who were genetically unrelated to each other. The lack of genetic relationships between siblings who grow up in a family together, and those who are genetically linked siblings growing up in a different family, create a tension for parents that they find hard to explain:

> *He's got a sibling, she's right here so I don't.. He might feel differently to this when he, you know, because the chances are that there are genetic, there are, I can't even think of them as, I don't even think of them as siblings. They are other children in the world that have the same genetic material as him.* **D/SMC/son-6 (AB/ED/A)**

This second mother also has genetically un-related siblings and describes that her issues with the word sibling because it questions the relationship between her two children:

I'm really uncomfortable with the whole donor sibling thing you know they're not siblings they are children that are born you know as a result of the same donor... the whole donor sibling in inverted commas, if that makes people siblings then that should, then what does it make my two?

D/SMC/sons-3 and 2 (AB/DD/A)

Perhaps because in ED, the difficulties of explaining donor siblings are even more salient because children will share the same two donors, as opposed to one donor for sperm/egg donation or DD.

THEME 3: SEED VS SPERM

Some difficulties were experienced in labelling male gametes; however, parents did not express any particular nuisances with female gametes and used 'egg(s)' or 'embryo(s)' interchangeably. One reason for this is because most children can relate to the word 'egg' because it is likely to already be in their vocabulary, in relation to animals or food, whereas 'sperm' is not a word that young children would usually be familiar with. Generally, parents with younger children preferred to use 'seed' and parents with older children were more partial to using 'sperm', however preferences varied. For some, 'seed' was favoured because it is a word that their young children are likely to already be familiar with through their knowledge of plants, or because they feel uncomfortable using the word 'sperm', seeing it as an 'awkward' word for young children to know:

Sperm's a bit awkward [laughs]. It's not like you sort of bandy that word around the school playground normally, so it's a bit tricky really.

D/SMC/daughters-5 and 2 (AB/DD/IA)

Yet other parents avoided using 'seed' because they thought it has the potential to confuse children:

I don't tend to use the seed analogy and stuff because I find that's soo confusing actually personally .... I just find it's confuses things, they're not plants **D/SMC/twin sons-4 (UK/DD/I)**

Section summary and comparison with adopters

Non-disclosers minimised the relevance of genetic relationships, however, disclosers viewed genetic connections as important, and thought that it was imperative for their offspring to know details about the donor relatives that they share genetic links with. Nonetheless, considerable dilemmas were encountered; without children being developmentally able to comprehend what they are told, explaining the differences between 'social' and 'genetic' family is potentially complicated. Children's understanding is relatively consistent across adoptive and ED/DD families; children were able to repeat the story of their adoption/conception, but were predominantly unable to interpret what this actually means. Both sets of parents emphasised the importance of 'drip feeding' to help their children to fill in the 'gaps' in order to understand over the course of time.

Genetic connections regarding 'siblings' were viewed as being particularly challenging, and both sets of parents expressed uncertainty about what and how to tell their children about these links. Disclosing ED/DD parents who had not revealed details about genetic siblings withheld this information because they felt that their children were not yet able to comprehend these relationships. Meanwhile adopters sometimes reserved sharing this because they wanted to protect children from feeling rejected by their birth parents in situations where birth siblings and parents lived together. Thus, adopters were lenient with the truth in order to protect their children.

Both adoptive and ED/DD parents experienced difficulties with terminology, however for ED/DD parents, the intricacies of language choice were more prominent. One reason for this is because the terminology of ED/DD is still relatively new compared to adoption. Furthermore, adopters are equipped with phrases during their training that they can use to talk to their children, whereas ED/DD parents did not receive the same manner of support. Nonetheless, both sets of parents experienced difficulties determining language for the donors/birth parents. They wanted their children to be clear about these

relationships, and attempted to use language that children can relate to, whilst minimising potential harm or confusion.

5.3.5 WORRIES AND CONCERNS ABOUT THE FUTURE

Almost all parents, regardless of their disclosure decision, expressed worries and concerns how children will feel in the future, and what other parents are doing.

5.3.5.1 HOW CHILDREN WILL FEEL

Two themes were identified within this framework:

1. **ABOUT BEING DIFFERENT**
   - I. Reactions in teenage years
   - II. Other children being unkind
2. **ABOUT DONOR INFORMATION**
   - I. Inability to trace donors
   - II. Preparing children for the unknown

THEME 1: ABOUT 'BEING DIFFERENT'

Some disclosing parents were concerned that their children might feel different and/or distressed about their conception

> *The worry is always that it will cause them some distress, you know, because you don't want your children to feel in any way upset or sad or hurt or you know, so that would be my only concern, is that they're, they're growing up slightly DIFFERENT to a lot of the other children they will come across.* **D/SMC/twin sons-3 (AB/DD/A)**

Parents were particularly concerned about two aspects:

Reactions in teenage years

Most disclosers worried how their children will feel as they enter adolescence, and their need for understanding their identity forms:

I just have worries about how he is going to, because it's, you know, it's unpredictable isn't it? You can't predict how he is going to adapt into teenage-hood and then adulthood and how he's going to deal with it.

D/SMC/son-5 (AB/DD/A)

Other children being unkind

Some disclosing parents were concerned that other children may be unkind to their children because they are donor-conceived. This fear indicates that, like non-disclosing parents, some disclosers perceived that there is stigma associated with being donor conceived:

Children usually use points of difference to be unkind to each … you know... <child's> Mummy and Daddy aren't even her real Mummy and Daddy, something like that. **D/MC/daughters-6 and 4 (AB/DD/A)**

THEME 2: ABOUT DONOR INFORMATION

Parents also worried how children might feel about their donors, and two subthemes were extracted:

Inability to trace donors

Where anonymous donors had been used, parents were apprehensive about how their child might feel about the inability to trace them, and how this might impact on their offspring's emerging sense of identity:

The only area that I retain any element of uncomfortable-ness about it, if you like, is that one about the anonymity aspect... I wonder if, when they get older, they will want more information than they have.. I suppose I just feel potentially a little bit sad for them. **D/SMC/twin sons-3 (AB/DD/A)**

A different mother hoped that unlike children who have been conceived using identifiable donors and the uncertainties this entails, her children might feel a sense of clarity by knowing that they will never have future contact with donors. Nonetheless, she still worried how her children would feel:

It's quite clear you know my answer to them is you can't, we will never know.... So it's quite clear and in the way there is clarity in that no, rather than when you are 18 you might be able to you know. I worry how they'll feel about that **D/SMC/daughter-4 and son-2 (AB/DD/A)**

Preparing children for the unknown

Parents who used identifiable donors also worried about how their children might feel in the future. Their concerns centred on whether, or not, the donors would welcome future contact, thus parents were cautious not to raise their offspring's hopes too much:

I can tell him what he'll be able to-what he can expect...But obviously, I don't know his donors…I have to…in managing that, to try and prepare him for… the unknown, we just don't know. **D/SMC/son-7 (UK/DD/I)**

Parents experience worries irrespective of whether or not they have used identifiable donors. Although the nature of worries differs, concerns about what impact donors will have on children's feelings in the future were universal. Isaksson, Sydsjo, Skoog Svanberg, and Lampic (2014) also found that disclosers were apprehensive about who the donors are, what they are like, and what might happen in the future with regards to possible contact. Hahn and Craft-Rosenberg (2002) identified similar concerns and suggested that parents would benefit from counselling and coping strategies to manage possible future scenarios

5.3.5.2 ARE OTHER PARENTS TELLING?

Regardless of their disclosure stance, most parents were concerned about whether or not other parents were disclosing, and two themes were identified:

1. **IS EVERYONE ELSE TELLING?**
2. **IMPACT OF LYING**

THEME 1: IS EVERYONE ELSE TELLING?

Most non-disclosers were particularly concerned about whether other parents were telling their children. One mother became emotional when describing her uncertainty of the future. She wished to disclose, but was not sure how she would do so. She wanted to seek reassurance from the researcher that other parents felt similar to her and that other parents were also not disclosing:

> *I do think about when I'm going to tell them and HOW I'm going to tell them because I will eventually but you know. I don't know I mean you you're in a obviously you have spoken to a lot of people, you know, I don't know what other people's situation is.. is what I'm saying kind of what some people are saying?* **ND/MC/twin sons-7 (UK/ED/I)**

A couple of other non-disclosing parents were also emotional during the interviews, especially when considering whether to tell their children in the future. This level of emotion suggests insecurity of non- disclosure. None of the non-disclosing families knew of, or had any contact with other donor-conceived families so were unaware whether their feelings, and actions, are the same as other parents. In contrast, almost all disclosers know other donor-conceived families who they could to talk to, share ideas and make comparisons with.

THEME 2: IMPACT OF 'LYING' TO CHILDREN

The majority of disclosing parents were incredibly concerned about the possible repercussions of non-disclosure. They strongly thought that children should be told, and viewed the concealment of ED/DD conception as deceitful and dishonest:

> *They have the right to know how they came about because you're telling a really fundamental lie otherwise, aren't you? Or even if you're lying by omission. I think it can be really detrimental to them in later life, not to know. Because they're going to find out somehow.*
>
> **D/SMC/son-5 (AB/DD/A)**

You must be honest with children. Yeah. Wow, what a mistake if you don't. What a mistake, what a betrayal...it's a terrible thing to do to your children because they will probably find out. **D/SMC/twin sons-8 (UK/DD/IA)**

Some non-disclosers actually considered that concealment was indeed lying to their children, and were considerably emotional thinking about how their children might feel about this and how it might affect parent-child relationships:

The uncertainness about what lies ahead in time in terms of letting him know, you know historically where he's come from and stuff like that…. So that's the only difficulty I feel, personally. … It's almost like keeping a big secret, it's almost like lying isn't it. **ND/MC/son-3 (UK/ED/I)**

I feel it would break my heart to tell them because it would be like saying you know you're not really ours and your whole life has been a lie, which makes me feel (mother gets upset). **ND/MC/twin sons-7 (UK/ED/I)**

Non-disclosers fundamentally thought that disclosure was the 'right' thing to do. Therefore there is discord between what they think is best, and what they are actually doing i.e. maintaining non-disclosure. This fits in with literature (Golombok et al., 2013; Ilioi & Golombok, 2015) where disclosing parents demonstrated less anxiety compared to non-disclosers, or those who disclosed later (Mac Dougall et al., 2007).

Section summary and comparison with adopters

Disclosing ED/DD parents and adopters worried how their children will feel once they fully understand all details about their conception/adoption. Specific concerns were expressed that they would experience negative reactions for being 'different', and that children will be upset when they understand the lack of genetic connections. They wanted to install resilience in their children so that they can deal with this in the future. Non-disclosing ED/DD parents were also concerned about their children's feelings, from the perspective of the impact of learning they are donor-conceived. This was difficult for non-disclosers to contemplate because they generally thought that disclosure was the 'right' thing

to do; yet they were maintaining non-disclosure, which caused anxiety. Parents were apprehensive about suitably preparing their children for the possibility of meeting their birth families/donors. Based on their history of providing inadequate care, adopters were worried that birth parents might cause their children harm and wanted to minimise this whilst preparing their children for all eventualities. ED/DD parents were anxious about the 'unknown', in particular, how children might feel about not being able to trace their anonymous donors, and the potential disappointment if donors do not want future contact. Finally, parents were concerned about what other parents in a similar circumstance to them were doing. Non-disclosers wanted reassurance that other parents were also not disclosing, whereas disclosers were concerned about the repercussions of donor conception concealment. Adopters had less concerns about this overall, perhaps this is due to the assumption that adoptive parents will disclose.

Overall, this section raised some important findings about the complex nature of disclosure. The implications of this and recommendations for current practice are made in Chapter 9. The following chapter focuses on the disclosure-related support for adoptive families.

5.4 STUDY I RESULTS - SUPPORT FOR ADOPTERS

5.4.1 DID PARENTS FEEL ENCOURAGED AND PREPARED TO DISCLOSE?

Parents were asked questions relating to if and how their adoption training encouraged and supported them with aspects of disclosure.

5.4.1.1 THE DECISION MAKING PROCESS

All parents were advised that it was best to be open with their child about their adoption, and two themes were identified:

1. **DO IT QUICKLY**
2. **DO IT VERY OFTEN**

THEME 1: DO IT QUICKLY

Parents were told was that it is best to be open with their children from a 'very early age':

> *It was just about being honest and telling them from a very early age that's what you have to do ..you have to support your children.* **MC/son-6**

> *Well they always just said be open and honest and, erm, we use the word adoption from the very, you know, before <child> was speaking.*
> **MC/sons-8 and 7**

'Do it very often'

Parents were also advised to discuss adoption frequently:

> *You should do it as quickly as possible and that you should do it very often.*
> **MC/son-8**

Adopters acted upon this advice, as evidenced by the fact that all adopters in this study had disclosed, had done so early and viewed adoption dialogue as an on-going process.

5.4.1.2 PREPARATION TO DISCLOSE

Parents were asked what disclosure-related support they received, and two themes were identified:

1. **LIFE STORY BOOK**
   I. Helps to tell children about birth family
   II. Is not always appropriate

2. **'BIGGEST GAP IN KNOWLEDGE'**
   I. Age-related disclosure
   II. Not prepared for children's questions
   III. No-one can prepare you

THEME 1: LIFE STORY BOOK AS USEFUL

The most important tool that parents gained from their adoption training was being provided with an LSB. Two sub-themes were extracted:

Helps to tell children about birth family

First, LSBs provide visual and written information that helps to fill in the 'blanks' and allows children to gain a better understanding of their adoption and of their birth family:

> *That was really helpful that we'd got something that we could give them as comprehensive a picture as, from birth to being sort of adopted by us, is that we could fill in as many blanks as possible.* **FC/son-8**

> *<Child> still reads the books a lot, she has a life story book and she reads that. And even now she'll just pick that up and read it... she just makes sense of it in her own head.* **FC/daughter-8**

Overall, parents found LSBs particularly helpful because it provided them with background information about their birth family that otherwise would have remained unknown. This in itself helped to fulfil children's curiosity and facilitated adoption-related conversations, also identified by Jones and Hackett (2007).

Is not always appropriate

But not all parents reaped the same benefits; some felt that the content was inappropriate for a young child because it contains some potentially harmful information about birth parents.

> *His life storybook is REALLY graphic about his dad. I'm not very comfortable (laughs) with that or happy with that really.... It's completely inappropriate, it's you know.... it's at least a 12 if not an 18.* **SMC/son-6**

This parent is in the same predicament, but felt that the LSB might be beneficial for future use:

> *We got this gargantuan photo album that's got completely inappropriate for a child of her age when she came, it probably was meant to be a resource that we could use I guess when the time is ready.* **MC/daughter-6**

Information deemed to be inappropriate has previously been identified in adoption research (Watson et al., 2015), and raises attention to the need for LSBs to be 'child-friendly'.

THEME 2: 'BIGGEST GAP IN KNOWLEDGE'

Whilst most parents felt that LSBs provided useful material, some felt that they lacked advice on *how* they could talk to their children:

> *Do you know, they didn't. And that's probably our biggest gap in knowledge at the moment...I don't really recall that element being discussed!* **FC/daughter-3**

Three sub-themes identify the areas of support that parents felt were lacking:

Age-related disclosure

First, as discussed, parents were aware that disclosure is a process that requires the inclusion of more detailed information over the course of time. However, they were uncertain *when* to add more complex information:

I don't remember them saying "at this age do this". ...I think it's a case, it was sort of you know, age appropriate, be open and honest, tell them as much as they need to know at that time, erm, I can't remember any specifics how it was. **MC/daughter-3**

All children are different and therefore it might be difficult to give exact age-appropriate advice, nonetheless approximate age-related guidelines would be appreciated.

Not prepared for children's questions

Second, parents did not feel that their adoption training prepared them for the different questions that their children might ask:

I think the emphasis was much more on understanding how a, how a child who's adopted might feel, there wasn't a lot of emphasis on answering questions....I didn't feel prepared for questions they might ask.
MC/daughter-7

The pre-empting of questions and uncertainty of how to answer them could be a reason for delaying the sharing of more complex information as discussed, and demonstrates that adopters would benefit from scripts that they could use to answer their children's questions.

No one can prepare you

Third, whilst aware of the areas of support that they would like to be developed, some parents felt that no amount of adoption training could truly prepare you to talk to your child:

I think, really, no one can sort of prepare you for when the child is sat in front of you and you've got to tell them something. **MC/daughter-4**

This father also shares a similar view, and thinks that adoption preparation is 'clever' because it provides a template, but leaves parents to fill in the details:

They could probably tell you lots of things how to deal with things, but then a child will probably ask you a question that's completely left of centre and

you're like, well this didn't come up how do I deal with this.. I think they're quite clever so they give you broad-brush strokes and then it's left for you to fill in with the little brush strokes. **FC/son-8**

Section summary

Overall, adopters were clear that they had been advised to disclose early and to discuss disclosure frequently, but felt that they lacked preparation about how to share the more detailed and complex elements of their children's adoption story. As discussed in 4.3, adoption training should prepare adopters for how they can help children to understand their background, however, not all adopters felt equipped to answer their children's questions, and discuss disclosure in an age-appropriate manner.

5.4.2 HOW DO ADOPTERS ADDRESS THE NEED FOR ADDITIONAL SUPPORT?

All adopters had either accessed additional support, or knew how they could access this if they wanted to. Two themes were extracted:

1. **'REAL ADOPTERS WITH REAL KIDS, GOING THROUGH REAL SITUATIONS'**
2. **NO CURRENT NEED FOR SUPPORT**
    I. Aware that might need support in the future
    II. Would know where to go if needed future support

THEME 1: 'REAL ADOPTERS WITH REAL KIDS, GOING THROUGH REAL SITUATIONS'

Most adopters had on-going contact with other adoptive families via support groups, such as Adoption First and Adoption UK. The most common form of support was through informal online groups such as those created on Facebook, by adoptive parents and for adoptive parents. Parents tended to access support groups to discuss issues with other adoptive parents, who are in a similar situation to them and understand their experiences:

We've got a lot more from <facebook group> that than we've got from social services over the last four years. Urm because that's real, real people, real adopters with real kids going through real situations just as we are, urm it's not textbook, it's reality and that's a lot more help. **FC/daughters-7 and 8**

They run erm various support groups you know, just nights where, erm, you know, or coffee mornings, you know, nights where we get together ... they're really good cos they, it's nice to be in a room with like other people and other people understand what you're talking about, you know. **MC/sons-8 and 7**

Emphasis was placed the importance of peer support for adoption in general, as opposed to specific disclosure-related support. As discussed in 4.3, there are a range of support groups, however parents in this sample preferred informal peer support such as those accessed through online groups.

THEME 2: NO CURRENT NEED FOR SUPPORT

Many parents did not presently feel the need to access support, but two sub-themes identified their perceived future needs.

Aware that might need support in the future

Most adopters could foresee a potential need to access support in the future, particularly when their children enter their teenage years:

At the moment we're in a position where we feel comfortable talking about it, urm the point will come, there may be a point in the future when he becomes a teenager, where that, you know we may need further assistance. **FC/son-8**

Parents did not elaborate on why this was so, but it is plausible that they were made aware during the adoption preparation as some adoptees gain a greater understanding of their adoption, they might feel a sense of rejection or might experience difficulties understanding their identity.

Would know where to go if needed future support

If the situation should arise where support was needed, all adopters felt confident that they would be able to find appropriate support:

> *I mean I think there's lots of, I would know where to go if I needed it and I, I certainly wouldn't be you know, I'd be very active in finding, in anything if we needed.* **MC/daughter-7**

> *Adoption UK that we're members of and we get their newsletter and updates and they're full of these things are running... so it's not as if I'm totally isolated and I'd think oh shit where would I go?* **FC/daughter-7**

Section summary

Overall, whether or not they are active participants, adopters were aware of the support network and systems that surround them. No adopters were uncertain if and how they could seek advice or information if necessary. Parents did not utilise all of the different forms of support available as identified in 4.3, such as Joy Reece training and play therapy, because they did not currently need disclosure-related support.

5.4.3 HOW COULD SUPPORT BE IMPROVED?

As discussed, adopters generally felt that information relating to *how* to talk to children about the more complex details of adoption was lacking during their training. Many of these parents remained unsure how to help children to fully understand all details surrounding their adoption, and three themes were identified:

1. **HELPING CHILDREN TO UNDERSTAND WHY THEY ARE NOT WITH THEIR BIRTH FAMILY**
2. **HOW TO PREPARE CHILDREN TO MEET BIRTH FAMILY**
3. **KNOWING HOW MUCH INFORMATION TO GIVE**

THEME 1: HELPING CHILDREN TO UNDERSTAND WHY THEY ARE NOT WITH THEIR BIRTH FAMILY

First, parents were aware that they needed to progressively reveal all details about why children were removed from their birth parents. Nonetheless, some adopters found this difficult to broach because they felt that some of the information could be harmful and they contemplate seeking advice in the future to facilitate this:

> *I will find that quite hard to tell her, that her mum was a prostitute.... if I wanted support about that, I could just ring up and say could someone have a chat with me <child>'s been asking questions about such and such, I know they'd be there.* **MC/daughter-4**

> *I'm going to have to start doing a bit of research and getting some support around what point do I start telling them more....I want to work up to them knowing as much as they possibly can...* **MC/son-8**

THEME 2: HOW TO PREPARE CHILDREN TO MEET BIRTH FAMILY

Most parents felt uncertain about how to best prepare children to meet their birth family, and would like more information about how they could do so:

> *I think that there should be you know something you can access from time to time to update yourself and talk through, talking to your child .... And to talk to him about things like, like meeting with his sister, knowing how to prepare for that.* **SMC/son-6**

Knowing how much information to give

Parents attempt providing information in an age-appropriate manner, yet not imparting too much information that could be distressing for their children to hear. This mother's view describes the challenges in striking this balance, and how she will be seeking guidance on how to manage this equilibrium:

> *It's a tricky one in knowing how far to go, how much to say, you know. But it's going to be tricky.... We will definitely be looking for some guidance, either by buying a book about it or going on a seminar, Barnado's have various seminars, so....* **MC/daughter-3**

Section summary

These findings reinforce parents' desire to protect children from harmful information, whilst still longing to be truthful with them. Although adopters reported difficulties accomplishing this, they generally felt that they would be able to find support to guide them through this process.

SUMMARY OF ADOPTION SUPPORT

Overall, this section highlights the adoption support available and reinforces the difficulties that parents encounter throughout all stages of the disclosure process. Adopters felt unsure how to answer their children's questions, and how they can help their children to understand details about their birth family; specifically why they no longer live with their birth parents, and the possibility of future contact. On the whole, adopters wanted to protect their children from harmful information, and were sometimes unsure about how they could do that whilst remaining open and honest. Although adopters experienced these uncertainties, they felt that certain that they could seek answers to their questions by accessing support groups, attending seminars or looking up information online or via books. The next section explores the ED/DD disclosure-related support and makes comparisons with adoption support.

5.5 STUDY I RESULTS - SUPPORT FOR ED/DD PARENTS

COUNSELLING ATTENDANCE

Out of the 36 ED/DD parents in this study, 63.8 % (*n* = 23) attended implications counselling at their clinic before their treatment, comprising six non-disclosers (75%) and 17 disclosers (60.7%). Therefore, a higher proportion of non-disclosers participated in clinic counselling sessions, demonstrating that attendance did not necessarily make parents more inclined to disclosure. Eight parents (22%) attended privately arranged independent counselling; all were disclosing parents. Overall, nine (25%) parents (seven disclosing, and two non-disclosing) did not attend either clinic or private counselling prior to their ED/DD treatment.

5.5.1 DID PARENTS FEEL ENCOURAGED AND PREPARED TO DISCLOSE?

Parents were asked questions about the issues discussed during clinic counselling sessions, and the extent to which they felt encouraged and prepared to disclose their children.

5.5.1.1 WERE PARENTS ENCOURAGED TO DISCLOSE?

Three themes were identified:

1. **COUNSELLING HAS NO BENEFIT**
    I. Counselling as an assessment
    II. Counselling for clinic's benefit

2. **'YOU WILL TELL THE CHILDREN WON'T YOU'**

3. **INFORMATION LACKING ON THE PROS AND CONS OF DISCLOSURE**
    I. Would like disclosure literature
    II. Would like contact with other parents
    III. Would like a list of trained fertility counsellors

THEME 1: COUNSELLING HAS NO BENEFIT

The majority of parents, both disclosing and non-disclosing, did not find counselling beneficial. Two sub-themes identified reasons why these sessions were not helpful:

Counselling as an assessment

Parents viewed counselling as an 'assessment' that they needed to pass, rather than a valuable opportunity to explore their thoughts, feelings and concerns about treatment. They felt 'guarded' and under pressure to give the 'right' answers:

> *She <counsellor> was like a policewoman, and therefore I was going in to sit some type of assessment that I had to pass. There was no way I was going to be really telling that woman anything about, you know, what I really felt.* **D/SMC/son-7 (UK/DD/I)**

> *I felt like I was being assessed, and if I couldn't give the right answers, then I…then I wouldn't be allowed to do the treatment, so I was a bit guarded.* **D/SMC/daughter-7m (AB/DD/IA)**

As a result, some parents were not completely honest with counsellors about their feelings and therefore disclosure was not explored deeply. The perception of counselling being an assessment was also identified in a recent UK study of patients accessing fertility treatment (Wilde & Parsons, 2014) suggesting that this is something that is uniformly felt by parents receiving a range of treatments.

Counselling for clinic's benefit

Some parents referred to counselling as a 'tick box' procedure intended for the clinic's benefits, rather than to help intended parents:

> *I spent a lot of hundreds of pounds on having counselling sessions that were not for me….you're undergoing a counselling session to satisfy someone else.* **D/SMC/daughters-3 and 5 (AB/DD/IA)**

> *It was all like just ticking a box, she was rubbish, but that just felt yeah it was what it was as well. It was for me to jump through a hoop as much as them.* **D/SMC/daughter-4 and son-2 (AB/DD/A)**

This raises potential concerns about how counselling is viewed from the parents' perspective. If intended parents feel that counselling is for the clinic's benefit, then it is unlikely that they will fully engage with counselling services; as these findings demonstrate. Similar conclusions were also drawn from a recent counselling survey of patients who had used a variety of fertility treatments, mostly using their own gametes (Payne & van den Akker, 2016), demonstrating that although ED/DD treatment has greater, life-long consequences, compared to other forms of treatment, ED/DD patients do not receive more comprehensive support to aid them.

THEME 2: 'YOU WILL TELL THE CHILDREN WON'T YOU'

Most parents were advised that it is in the best interests of their children to be told about their conception, but several parents were dubious about <u>why</u> openness was recommended. Although counsellors usually enquired about parents' disclosure intentions, parents felt that in-depth discussions relating to the disclosure decision were missing.

> *I think the first one said 'so you will tell the children won't you' (laughs) and I was like 'yes'. You know, that felt a bit like another tick box thing*. **D/SMC/daughter-4/son-2 (AB/DD/A)**

THEME 3: INFORMATION LACKING ON THE PROS AND CONS OF DISCLOSURE

Both disclosing and non-disclosing parents felt uninformed about why they were advised to disclose. Disclosers have since undertaken their own research to find out why this was recommended, but non-disclosing parents remain unaware why disclosure was endorsed, and think that a discussion on the pros and cons would have helped them to make an informed decision:

> *We encourage parents'. But why? We'd like to know why? Why?.. Yeah, God there's a huge gap missing. … Let us know why, give us the pros and cons you know so hopefully we can make a good based decision upon that but…. that was definitely missing I think and still is*. **ND/MC/son-3 (UK/ED/I)**

This mother's partner agrees and would also have liked more evidence on why it is in the best interests of the child to be told:

> *I don't know how I feel about it really. ….Hence why…We could've done with some direction. People advise you and say we think it's in the best interest of the child to tell them and then that's it…. Yeah, give us a bit more support in that, in that part.* **ND/FC/son-3 (UK/ED/I)**

Would like disclosure literature

One suggestion to combat the lack of information was to be provided with literature and case studies on the issues of disclosure versus non-disclosure:

> *I felt it was a bit superficial to be honest. I just think it was, skirted round the issues really.. we weren't given any books to read, we didn't look at any case studies.. I think perhaps we should've been given something to read about people who tell and people who don't tell,* **D/MC/son-5 (UK/ED/I)**

Would like contact with other parents

Another suggestion was that clinics could help to link parents in a similar situation:

> *I think maybe it would've been good for us to meet other people who'd done it*. **D/M/son-5 (UK/ED/I)**

This was viewed as particularly beneficial because disclosing parents could act as mentors to guide ED/DD recipients through their experiences. As discussed, most disclosers are in contact with other donor-conceived families, whereas non-disclosers do not know other donor-conceived families and would gain from this experience in a number of ways, including when to begin the disclosure process, identifying how they could disclose, and reassurance from

other parents regarding their children's reaction to disclosure. Counsellors could have facilitated this process by informing patients about support groups; however this did not occur. Other studies have likewise found that clinics do not routinely tell intended parents about relevant support groups (Blyth et al., 2013).

Would like a list of trained fertility counsellors

A further suggestion, from another disclosing parent, was that it would be useful to be provided with a list of trained fertility counsellors, whom they could contact if they experienced any disclosure-related repercussions in the future:

> *It would be useful to have a list of appropriately trained counsellors who understand some of the issues, the repercussions of telling versus not telling. And who can talk you through what you're most comfortable with in terms of how you approach this whole subject.* **D/SMC/daughters-3 and 5 (AB/DD/IA)**

Infertility counsellors are ideally placed to provide intended parents with information on how they could access future counselling support, such as a list of counsellors available listed on the British Infertility Counselling website, however, this did not occur for parents in this sample. Overall, whilst most parents felt that disclosure was recommended, they did not receive enough information about *why* openness was endorsed.

5.5.1.2 WERE PARENTS PREPARED FOR THE PROCESS OF DISCLOSURE?

Parents did not feel prepared on the practicalities of ED/DD revelation, as identified by these two themes:

1. **UNPREPARED FOR <u>WHEN</u> TO TELL**

2. **UNPREPARED FOR <u>THE PRACTICAILITIES OF TELLING</u>**
    I. 'Where the hell do you begin?'
    II. Role-play would be beneficial

THEME 1: UNPREPARED FOR WHEN TO TELL

No parents reported that they received advice on the timing of disclosure. Disclosing parents had begun the process early, yet non-disclosers were still unsure about when the best time to disclose is. This was a concern to this mother:

> *What's a good age, how do you break a subject like that?... you know at a time before they become devastated and not so that they become devastated that you didn't tell them before if you know what I mean? So yeah, it's an absolute worry to us.* **ND/MC/son-3 (UK/ED/I)**

She felt that knowledge of donor conception could come as devastating news to her child if he found out later, suggesting that although she is aware that disclosing later in life can have negative consequences, she is unaware of the benefits of early disclosure. A different non-disclosing mother contemplates that it might be better to disclose to her offspring when they are adults:

> *How early do you tell a child that and how do you explain that? ... I would like to think that maybe when twins are older then I will tell them the truth as well, that's going to be a really difficult one isn't it, but I think they will handle is better as adults then as children* **ND/MC/twin sons-7 (UK/ED/I)**

She was told by her clinic that she would know if and when the 'right' time appeared. However, she now reflects that in fact she does not know when this 'right time' is:

> *I spoke to the Dr about it and he said well you know you'll sort of know if and when is the right time erm and I sort of said will we?* **ND/MC/twin sons-7 (UK/ED/I)**

She remains uncertain and feels that she needs some help to decide what to do:

> *I don't know the answer... I suppose really I should have some counselling and get someone to help me decide what to do, you know for them the best thing for them.* **ND/MC/twin sons-7 (UK/ED/I)**

Generally, non-disclosing parents did not plan to disclose, but now that their children are several years old they are now potentially more open to discussing and exploring disclosure. This further supports the reality that disclosure intentions are dynamic and are likely to change over time as donor-offspring grow older (Daniels et al., 2011) and raises issues about the timing of counselling (fully discussed in 5.5.5.4).

THEME 2: THE PRACTICALITIES OF TELLING

Regardless of their disclosure decision, parents did not feel equipped with the practicalities of *how* to tell children about their conception, as illustrated by two subthemes:

'Where the hell do you begin?'

No parents reported discussing the practicalities of disclosure during counselling, but the absence of this dialogue is particularly relevant to non-disclosers, who are uncertain of their future plans and do not know how they would begin the process of ED/DD revelation:

> *Where the hell do you begin? You know, what are the right things to be said?* **ND/MC/son-3 (UK/ED/I)**

Similarly, another non-disclosing mother was also unsure how she would approach disclosure and reflects that it might have been better to have just told her sons from the start:

> *Maybe it would be better to go on and do it and just be straight from the beginning maybe. You are erm you know a donated embryo, it doesn't sound very nice does it? ...There is no easy way to say that is there*?
> **ND/MC/twin sons-7 (UK/ED/I)**

Some non-disclosing parents became emotional discussing this topic, and would benefit from on-going advice and support on the practicalities of how they could tell their children, so that they were prepared to do so should they wish to in the future. Not knowing how to start disclosure has consistently been cited as a reason for delaying disclosure, and ultimately not disclosing (Blyth et al., 2013;

Daniels et al., 2011; Jadva et al., 2009; Lalos et al., 2007; Triseliotis, 2011). Parents' concerns about *how* they could instigate discussions could be minimised or completely eradicated if the benefits of early disclosure were explored fully with intended parents during their clinic counselling.

'Coaching on how to do it'

Disclosing parents were concerned about whether they are telling their child in the 'right' manner, and felt that engaging in role-play with their counsellor would have been a useful strategy to practically prepare them for disclosure-related discussions with their child:

> *Almost even like role-playing with them like you're gonna say, how you're gonna say it… how would you talk back to that, what's the other side of that one, how would you? You know, what does your more rational side say about that? Things that a counsellor can help*. **D/SMC/son-7 (UK/DD/I)**

> *Kind of role-playing it, really...it would be very good to be able to... you know, have a bit of kind of coaching, on how to do it, or what has worked for other people, you know*. **D/SMC/daughters-5 and 2 (AB/DD/IA)**

5.5.1.3 HOW COULD COUNSELLING BE MORE BENEFICIAL?

Two themes identified the reasons why parents did not reap the full benefits of counselling:

1. **TIMING OF COUNSELLING**
    - I. 'I didn't need any more counselling I needed a baby'.
    - II. Counselling after a pregnancy has been established

2. **ONE IS NOT ENOUGH: OPTIMAL NUMBER OF COUNSELLING SESSIONS**
    - I. More time needed to consider the implications
        - i. Particularly the disclosure decision

THEME 1: TIMING OF COUNSELLING

All parents who attended implications counselling at their clinic did so *before* their treatment, however, regardless of their disclosure status, most parents did not feel that this was the most suitable time to fully explore the implications of disclosure. Two sub-themes identified why this was so:

'I didn't need any more counselling I needed a baby'

All parents attempted ED/DD treatment after numerous unsuccessful fertility treatments, often spanning several years. Consequently, they found it difficult to consider the possibility that their ED/DD treatment would result in a successful pregnancy. Therefore, at the time of their pre-treatment counselling they did not feel that they were in a position to fully focus on disclosure-related implications in a realistic way:

> *The difficulty was when I was going through the implications counselling, I kind of thought this is never gonna happen anyway, we have five missed you know chances of becoming pregnant …. So it seemed a bit premature to me, to go through all of that because there is no guarantee that I was gonna become pregnant.* **D/MC/son-8 (UK/ED/A)**

> *And she was saying well if you're crying now, how do you think you'll be when the baby is born? Well I said I don't know how I'm going to be….. I haven't even got pregnant yet, you know I can't even think… think about that.* **ND/MC/twin daughters-6 (UK/U/I)**

Counselling after a pregnancy has been established

Parents felt that they would most benefit from counselling support *after* they have found out that their treatment was successful, and/or during the first few years of their child's life. This is because it would then be about a tangible being, rather than a 'what if' scenario:

> *It would then would be about the existing child rather than a potential situation with all the worry entailed in that.* **D/SMC/twin sons-4 (UK/DD/I)**

They felt that post-treatment counselling would allow them to fully explore issues that were presented in pre-treatment implications counselling, when they would be in a more suitable position to be able to consider these:

> *To reiterate a lot of the stuff that discussed during implications counselling because it's now a live issue, this is now happening, it's real, it's not a fantasy world 'oh will I ever become pregnant?'.* **D/MC/son-8 (UK/ED/A)**

This non-disclosing parent, whose child is aged three, now feels ready to engage with counselling:

> *I think you…partially feel that it's never going to work and you're going down that road but when it's there suddenly you're faced with all these 'what's going to happen in the future?' …. I could probably do with some more counselling really*. **ND/FC/son-3 (UK/ED/I)**

The timing of counselling and parents' wish to attend post-treatment have consistently been shown as desirable by parents who have used sperm/egg donation (Applegarth et al., 2016; Lalos et al., 2007; MacCallum & Golombok, 2007) and deemed necessary by infertility counsellors in New Zealand who are experienced at working with ED recipients (Goedeke et al., 2016; Goedeke & Payne, 2010). The experiences of ED/DD parents in this study support the view that they would also benefit from both pre and post-treatment counselling.

THEME 2: 'ONE IS NOT ENOUGH': OPTIMAL NUMBER OF COUNSELLING SESSIONS

Most parents attended only one clinic counselling session, and the maximum number of sessions that parents attended was three. The fact that many parents therefore engaged with counselling for just one hour prior to their treatment may be among the reasons why parents did not fully benefit from counselling Two sub-themes identified the advantages of a greater number of counselling sessions:

More time needed to consider the implications

Parents appreciated that ED/DD has a number of implications and consider it as a 'big' thing to do. This mother, who attended the maximum number of sessions in this sample, did not think that three sessions was enough time to fully consider the consequences:

> *Three sessions to me seems nothing, it's such a big thing to do, it's not, it's not having your own, your, you know, your own genetic baby, you know, it's completely different.* **D/MC/son-5 (UK/ED/I)**

This mother was shocked that she only had to attend one session:

> *It astounds me, you only actually have to go one hour, of what they call counselling. It's not really counselling…. I do wonder how much…people go into this without even really thinking about it.* **D/SMC/son-8m (AB/DD/A)**

This is congruent with the experiences of infertility counsellors in New Zealand (Goedeke et al., 2016; Goedeke & Payne, 2010) who considered ED to have significant long-term consequences that require substantial counselling.

Particularly the disclosure-decision

In particular, parents thought that more sessions were needed to fully explore issues of disclosure. This disclosing mother thinks that counselling should be an on-going process because parents are often unaware if they are doing the 'right' thing:

> *I think it would be good if counselling was an on-going…. Most people have got nothing, you're very much trudging through it in the dark not knowing if you're doing the right thing*. **D/MC/son-5 (UK/ED/I)**

Congruent with this, this non-disclosing father thinks that he and his wife would have benefitted from deeper exploration:

> *Has been a huge amount debate as you can imagine between [wife] and ourselves whether um we tell <Child> later on but [counsellor] advised that it's something we seriously think about doing for the sake of the child. And I*

think that's something we could have really done with exploring more in conversation. **ND/FC/son-3 (UK/ED/I)**

Section summary and comparisons with adoption

In accordance with UK legislation, clinics should encourage parents to begin the disclosure process during early childhood; however, this did not occur for parents in this sample, leaving non-disclosing parents in particular, perplexed about how to proceed. This contrasts sharply with the experiences of adopters who were all told that it is best to tell their children as soon as possible. Embryo/double donation parents would benefit from advice and information on age-related disclosure, which would be especially valuable for non-disclosing parents who think that their children are currently 'too young', and contemplate that disclosure during adolescence or adulthood might be better. Parents thought that more counselling sessions should be available, demonstrating that they value counselling, but that counselling was not presented in a way that was most efficient for their needs. It is clear that parents considered ED/DD treatment to have unique and life-long implications, and they wanted the opportunity to consider these, but at a time when a pregnancy had been established, so that they could realistically engage with disclosure-related issues. Overall, ED/DD parents received insufficient counselling that left them unprepared for the complex process of disclosure.

5.5.2 HOW DO PARENTS ADDRESS THE NEED FOR ADDITIONAL SUPPORT?

The majority of parents would benefit from additional support to address their disclosure-related issues. Whilst to some extent their need for further support is similar, how disclosing and non-disclosing parents address their needs differs. Disclosers were extremely resourceful at seeking out alternative forms of support, whereas non-disclosing parents did not seek out any additional support, and were unaware of the support that is actually available. Therefore this section predominately focuses on disclosing parents, resulting in four themes:

1. **ACCESSING A PRIVATE COUNSELLOR**
    I. To discuss implications of using donated eggs
    II. For emotional support
    III. To explore disclosure

2. **LINKING WITH OTHER DONOR-CONCEIVED FAMILIES**
    I. Emotional support
    II. Sharing ideas and information
    III. So that children do not feel different

3. **DONOR CONCEPTION NETWORK RESOURCES**
    I. Workshops
        i. Convinced to tell
        ii. Prepared for how to disclose
    II. Books
        i. Not suitable for every family type
        ii. Unsuitable for young children

4. **CREATIVE SOLUTIONS TO LACK OF SUITABLE RESOURCES**
    I. Adding extra information into existing books
    II. Creating a photo book

THEME 1: ACCESSING A PRIVATE COUNSELLOR

Whilst the majority of parents did not perceive clinic counselling as useful, the fact that several parents accessed private counselling reinforces the perceived value of counselling per se. Those who independently arranged counselling, were all disclosing parents, and accessed these sessions prior to ED/DD treatment, or after they found out that their treatment was successful. Three subthemes identified the reasons why parents sought these sessions:

Parents, who accessed independent counselling *prior* to treatment, did so to discuss issues related to using donated eggs, or for emotional support:

To discuss implications of using donated eggs

This was specifically relevant for SMCs who were relatively comfortable with the idea of using donated sperm; however, the addition of using donor eggs was a more complex decision because they had not previously considered that they would be required. They wanted to explore this via counselling, to ensure that they felt comfortable before starting treatment:

> *When I found out that I would need egg donation, for me that was, as I said, the big decision, so I sought out a, erm, a local counsellor...a fertility counsellor …. she was brilliant.* **D/ SMC/twin sons-3 (AB/DD/A)**

> *I remember the counsellor saying to me, you know, whatever you do, you've got to be comfortable with the decisions you make, because you…if you're not, you'll transmit that to him*. **D/SMC/son-8m (AB/DD/A)**

This reiterates that for some parents, the use of DD/ED treatment is viewed as a highly significant one that requires considerable thought and exploration.

For emotional support

Almost all parents described how infertility had an impact on their emotional well-being, which led some disclosers to seek support from someone 'impartial'

> *I was perhaps becoming conscious that <my friends> didn't want a blow-by-blow account of, you know, of every little up and down along the way. ... I think the counsellor made a really important role in being that sort of objective, outside of the family support.* **D/SMC/twin sons-3 (AB/DD/A)**

> *I would see her fortnightly and it was just an offloading, just so I could talk and get upset and I did get a bit depressed at one point*. **D_/SMC/twin daughter and son-2 (AB/DD/A)**

To explore disclosure

Parents, who sought counselling *after* successful treatment, did so to explore disclosure. Like non-disclosing parents, they also experienced worries regarding sharing information with their children:

> *I was going through the whole, 'ah, if its sperm and egg how do I tell them? What do I tell them?' you know, it's more complicated because then it, it's not just a sperm donor but, you know explaining the egg donor although I'm actually there.* **D/SMC/twin sons-3 (AB/DD/A)**

> *She was marvellous and I think also hearing from her about stories about people she was dealing with who completely you know, screwed up breaking down because they found out late about their own parentage and I didn't want that to happen to <child> and I wanted to be as clear from the start as possible*. **D/MC/daughter-7 (UK/ED/A)**

Overall, independent post-treatment counselling clarified two main aspects. First, debating the negative consequences of non-disclosure helped them to realise that disclosure was the right decision for them. Second, discussions on how they could talk to their child about their conception prepared them for this future event. Prior to treatment, independent counselling was accessed by SMCs only, and not by HCs. Due to needs pre-treatment being related to emotional aspects, this could be because couples went through the treatment together, so can support each other emotionally, whereas SMCs do not have this shared experience. All family types accessed post-treatment counselling when their attention shifted to aspects related to disclosure, as such disclosure-related issues impacted both SMCs and HCs.

THEME 2: LINKING WITH OTHER DONOR-CONCEIVED FAMILIES

A second way that disclosing parents address their need for additional support is by making contact with other families who have donor-conceived children via the DCN or online forums, such as 'Fertility Friends' and 'Infertility Network'. Three sub-themes identified how contact with donor-conceived families was beneficial:

Emotional support

Like independent counselling, emotional support from other parents was also accessed only by disclosing SMCs, who sought this pre-treatment, or once a pregnancy was established, in an attempt to 'bond' with other parents going through treatment at a similar time, and to share treatment-related worries:

> *We were all going the treatment at the same time and that's why fertility friends was great because we you know you kind of bond.* **D/SMC/sons-3 and 2 (AB/DD/A)**

> *Certainly from talking to other, you know, people on Fertility Friends.. we're really quite nervous when they were pregnant about how they were going to feel about having a donor egg baby, and you know, we could all sort of reassure each other*. **D/SMC/daughters-5 and 2 (AB/DD/IA)**

Sharing ideas and information

Linking with other parents provides a platform for information sharing about issues of disclosure, particularly from parents who have been through a similar situation, which is considered the 'best' source of information and knowledge:

> *Other women in the same situation as me but particularly those that are a little bit further on as their children are a bit older have become probably the BEST sort of information and knowledge around talking to the children in particular.* **D/SMC/twin sons-3 (AB/DD/A)**

Sharing experiences and making comparisons also served to reassure parents about the responses and reactions of their children:

> *I'm very lucky that… got two good friends, who have used donation to conceive, but I feel quite lucky in that we can actually chat to each other and sort of compare our children's responses, and compare what we're doing at the moment and how that's going*. **D/MC/son-5 (UK/ED/I)**

Non-disclosers have not established relationships with other parents who have donor-conceived children, but thought that these links would be constructive

because they considered the experiences of parents who have been through the process to be more meaningful than discussions with counsellors as both members of this non-disclosing couple describe:

> *We need to get it from people who have actually been through that process...get their positive and negatives. How they've dealt with it, you know... how they've gone about that why they've made the decisions that they've made….* **ND/FC/son-3 (UK/ED/I)**

> *Somebody who's been through this before. It's going to be more beneficial to us than somebody per se, counsellor sitting there you know going… to give you all the time in the world but they're not going to know because they've not been through it.* **ND/MC/son-3 (UK/ED/I)**

So that children do not feel different

Support groups were also potentially of benefit to children. Disclosers hoped that providing an opportunity for children to know other families conceived in a similar way would minimise the chance of children feeling 'unusual and 'different'':

> *He's going to be unusual..his story will be very different to other children's stories. Which is why it's really important for me and we do have a network and he sees other children in the same position.* **D/SMC/son-5 (AB/DD/A)**

> *I think it's so important for the children to know that a come across other children from similar circumstances...to know there's other children like them and they can meet them and see them it's not just them.* **D/MC/son-4/daughter-2 (AB/DD/A)**

Some non-disclosers gave 'difference' as a reason for non-disclosure, but contact with other donor-conceived families would establish reference points to reassure parents and their children. However, as identified in other research (Blyth et al., 2013), parents in this study were largely uninformed by their fertility clinic about the existence of support groups, and generally found them by independent research.

THEME 3: DONOR CONCEPTION NETWORK RESOURCES

As well as providing an opportunity to meet other donor-conceived families, parents who accessed DCN received disclosure support and advice. Two types of resources prepared and facilitated disclosers to be open with their children

DCN Workshops

As discussed in 3.2.3, DCN run several workshops intended for donor-conceived parents; most disclosing parents in this study attended at least one of these.

'Convinced us we needed to tell'

Workshops were usually attended during pregnancy in order to explore information disclosure. Some attendees said that the workshop convinced them to disclose to their child:

> *I think when we went to that weekend it really convinced us we needed to tell, you know, any child we might have and how important that was*.
>
> **D/MC/daughter aged 2 (AB/DD/A)**

Information on how to talk to children

Attending workshops also helped parents to consider how to talk to their child in the 'right' way, again highlighting the perception that there is indeed a correct way to discuss disclosure:

> *It's all about – when you're a parent of donor-conceived children – learning how to say things in the right way … you can practice all this language, this is sort of what the DCN sort of invite you to do.* **D/SMC/son aged 8 months (AB/DD/A)**

Parents also reported that these workshops helped to prepare them how to answer their children's future questions:

> *The reason that I go to all the meetings and the, you know, is to, you know, so that I'm as informed as I can be so that when he does come to me with the difficult questions*. **D/SMC/son-6 (AB/ED/A)**

These findings are reflective of research by Crawshaw and Montuschi (2014) that found that attending workshops encouraged disclosure where parents were unsure, and prepared parents with advice on the practicalities of early disclosure.

DCN Books

As discussed in 3.2.1, DCN have a range of books designed for parents to read to their children, which parents generally think are useful. However, there were two reasons why some parents were unsatisfied with the books available:

Not suitable for every family type

Parents felt that the selection of books were not always applicable for their particular situation, and as this mother explains, she would like it if books were available to cover all family types:

> *From a user's point of view those-those books are INCREDIBLY useful and it would be it would be amazing if there was one specific to every circumstance. So for example, my girls are my girls are donor egg and donor sperm. But the only books available were about donor egg.*
> **D/MC/daughters-6 and 4 (AB/ DD/A)**

Unsuitable for young children

At the time of the interviews, DCN books attempted to cover a variety of different family types all in the same book[43]. As a result, parents had to skip through irrelevant pages; something that parents deemed was an unsuitable approach for young children:

> *The one we've got flips between a twin scenario they the they try to be all things to all erm users and if you're telling a child a story you can't have a page that erm says if you're twins turn to page whatever because a child wants to look at every page of the book… and that doesn't quite work that side of it.* **D/MC/daughters-6 and 4 (AB/DD/A)**

[43] DCN have since created a new set of books whereby parents can enter details online to personalise a storybook according to their family type and treatment used.

Other findings on sperm/egg donation families also found that parents were disappointed by, or frustrated with the lack of resources available (Lalos et al., 2007; Mac Dougall et al., 2007). However, as discussed in 3.2.1 there are a plethora of books available, of which parents were largely unaware. This could be avoided if counsellors provided intended parents with a list of suitable books that they could utilise.

THEME 4 - CREATIVE SOLUTIONS TO LACK OF SUITABLE RESOURCES

Parents applied creative approaches to construct a personalised story for children, as illustrated by two sub-themes:

Adding extra information into existing books

First, the addition of extra information, or adaptation of current books, allowed parents to create a suitable story that covered the family structure and donation type specifically relevant to their children. This mother describes how adding extra material into an existing DCN book helped to convey important information about her children's conception:

> *It doesn't talk about erm going abroad and … they didn't they didn't have one for lesbian parents with double donation so we just sort of had to add that into the story.* **D/MC/son-4 and daughter-2 (AB/DD/A)**

Creating a photo book

Second, the creation of a personalised photo book provided a unique tool to help children to understand their ED/DD conception. The benefit of this is that it can be used to explain details relating to donor conception that might be missing from DCN books, and can tell the exact story that parents wish to share. This mother explains how she uses this book:

> *When I first made it they were FASCINATED by it, they wanted to read it every night. They mostly just wanted to look at the picture of me with the big fat tummy. Er, and they liked the airplane, there's a picture of an airplane as I sort of fly off to the clinic.* **D/SMC/twin sons-3 (AB/DD/A)**

Section summary and adoption comparisons

Disclosers sought support to address their needs, whereas non-disclosers did not, and their needs remained present. One prominent difference between disclosing ED/DD parents and adopters was that several ED/DD parents accessed independent counselling because they considered ED/DD treatment a 'big' decision, and to help them to decide whether or not to disclose. Adopters did not seek this support, which implies two things. First, all adopters were advised to disclose during their adoption training and were made aware of the benefits of being open, whereas ED/DD parents were not. Second, adopters were acquainted with the consequences of non-disclosure, whereas some ED/DD parents were less familiar with this.

Some disclosers designed photo books to help their children to understand details about their conception. This approach is similar to LSBs used by adopters; however, adopters were encouraged to use LSBs as a disclosure method, but ED/DD parents were not advised of the benefits of visually representing donor conception. Peer support was deemed important, however, adopters sought this to share experiences with other parents in a similar position to them, whereas ED/DD parents were inclined to pursue support for reassurance and advice regarding disclosure. This reinforces that ED/DD parents have a greater need for disclosure related support, compared to adopters.

5.5.3 WHAT SUPPORT IS CURRENTLY LACKING?

Whilst disclosing ED/DD were clearly active about addressing their needs, three themes identified their unmet needs:

1. **SUPPORT FOR COUPLES**
    I. Difference in feelings about disclosure-decision
    II. Difference in feelings about how to disclose
2. **SUPPORT FOR PARENTS WHO RECEIVED TREATMENT ABROAD**
3. **HELPING CHILDREN TO UNDERSTAND**

THEME 1 - SUPPORT FOR COUPLES

Two areas of support were reported as needed in relation to how couples manage disclosure.

Difference in feelings about disclosure-decision

First, some non-disclosing couples had opposing views on disclosure; in these instances mothers were more inclined to tell, and fathers less so. This mother feels that she and her husband would have benefitted from talking about their different feelings:

> *Has been a huge amount debate as you can imagine between [husband] and ourselves whether um we tell <Child> … I think that's something we could have really done with exploring more in conversation… for me I just want to be really honest. You <husband> feel differently about it don't you? It's a real bone of contention isn't it?* **ND/MC/son-3 (UK/ED/I)**

Her husband reflects on their clinic counselling, and also wishes that they had received more support to talk about their feelings:

> *I wish we'd have more support in talking to somebody about all of our feelings…you know I think we kind of worked through it ourselves really….* **ND/FC/son-3 (UK/ED/I)**

This mother and her husband had planned never to tell their children:

> *My husband and I said we would never tell them when we first you know conceived you know that we would bring them up as our own and we would never ever mention it. You know and to be fair we haven't....*
>
> **ND/MC/twin sons-7 (UK/ED/I)**

However, she is now more open to disclosure, but her husband wants to maintain secrecy. She was distressed about this issue and describes her feelings:

> *I don't think my husband really wants to... I feel it would break my heart to tell them because it would be like saying you know you're not really ours and your whole life has been a lie (***ND/MC/twin sons-7 (UK/ED/I)**

Overall, this illustrates the complex nature of decision-making, and how this is exemplified when couples have opposing views.

Difference in feelings about <u>how</u> to disclose

Second, even when couples fundamentally agree that disclosure is best, and have started the process, they can hold different views on how, and what they would like to tell their child. This disclosing mother would have liked a counsellor to facilitate a conversation between herself and her husband about their feelings on disclosure, something she considered would have been especially valuable during the first couple of years after her son was born:

> *Sitting down with a counsellor and just talking about our feelings …. just to facilitate the discussion amongst ourselves so that we could then facilitate discussion with <child>. I think that would have been really, really useful.. during that first year -first two years maybe yeah. But it just wasn't available*. **D/MC/son-8 (UK/ED/A)**

These examples demonstrate a need for on-going support to help couples to manage changing feelings and emotions relating to disclosure and further supports the dynamic nature of disclosure, even in disclosing couples.

THEME 2 - SUPPORT FOR PARENTS WHO RECEIVED TREATMENT ABROAD

Some parents were worried about parents who received their treatment abroad and did not have the opportunity to attend counselling, although parents who actually received treatment abroad did not express the same concerns. Overall, this implies that despite parents not finding counselling beneficial, they still see value in having the opportunity to attend UK based sessions:

> *Clinics abroad don't do implications counselling and I am worried, that really worries me. Because I think what if those couples come back and their pregnant with a baby and they start having doubts. I mean it's too late ... So I think the implications counselling is so-so important and it needs to be done even if couples go abroad.* **D/MC/son-8 (UK/ED/A)**

You give yourself a big responsibility when you do it, and I would imagine that people who go abroad and don't have to have any, it worries me that people go abroad and don't have to have any counselling for that child. **D/MC/son-5 (UK/ED/I)**

However, many parents assumed that UK counselling was mandatory and were unaware that not all clinics impose mandatory counselling, as such, it is likely that this concern would likely extend to any parent who does not receive pre-treatment counselling.

THEME 3 -HELPING CHILDREN TO UNDERSTAND

As discussed, disclosers were aware that their children do not yet fully understand the genetic relevance of ED/DD conception, however some parents had specific worries about how they will develop future understanding:

But the next challenge for us will be you know, having to explain to him a little bit more in depth, which I'll be asking for help for because I don't, I'm not, sort of beyond me. **D/MC/son-8 (UK/ED/A)**

I would actually LOVE to talk to a counsellor now actually, erm to just talk through how I'm going to deal with things. **D/SMC/twin daughters-2 (AB/DD/IA)**

There'll be a lot of challenges ahead around all of that. So I guess that kind of counselling at different points would help with just sort of thinking through, trying to get a bit of clarity really around that. **D/MC/daughter-2 (AB/DD/A)**

These examples elucidate that parents would benefit from engaging with an experienced counsellor to decide how to progress the disclosure-story in the future.

Section summary and comparison with adopters

Even several years after ED/DD conception, parents have continued needs centred on the continuing sharing of information, and developing their children's understanding. Couples experienced additional complexities that are not relevant in SMC families, who solely control the sharing of information and do not have a partner who might feel differently. In comparison, coupled adopters did not report opposing views, perhaps because it is customary for adopters to disclose, so there was less potential for disagreements. Overall, adopters had fewer unmet needs and felt comfortable that they could find the answers to these by doing some research, in comparison to ED/DD parents.

OVERALL SUMMARY

Adopters received superior disclosure support at their adoption training, compared to ED/DD parents pre-treatment. Consequently, adopters had fewer needs and felt comfortable that they could find the support to meet them, whereas ED/DD parents had a range of existing needs and were less certain how these could be met. Overall, findings highlight areas of support that are lacking and recommendations for future counselling practice are made in Chapter 9.

CHAPTER 6 - STUDY II
COUNSELLING SUPPORT - THE CLINIC'S PERSPECTIVE

Chapter 5.5 explored how ED/DD recipients perceived the support that they received. This chapter looks specifically at the level of counselling support available in UK clinics, according to the counsellors themselves.

6.1 STUDY II OVERVIEW

Current UK legislation states that fertility clinics should 'encourage' and 'prepare' intended parents to be open with their children about their method of conception from a young age, and that all clinics have to offer counselling to prospective parents. Patient self-report data[44] shows that a sizeable proportion of patients did not reap the potential benefits of counselling because either they reported not being offered counselling, thought that the counsellor was assessing them, viewed it as tick-box-exercise (Wilde & Parsons, 2014) or felt that counselling focused on wrong aspects at the wrong time (Payne & van den Akker, 2016). Legislation does not include information about *how* clinics should provide disclosure related support and as discussed, ED/DD treatment has additional implications, which are likely to require specialised counselling, compared to other forms of infertility treatment.

UK-based research has focused solely on patient-report data, no published research has explored if and how infertility counsellors themselves engage with intended parents seeking ED/DD treatment in the UK, and the extent to which they encourage and prepare patients to disclose to their children

Aims

The main aim of this study was to identify how fertility counsellors engage with intended parents seeking ED/DD treatment. Specifically, to explore the extent to which they encourage disclosure, and prepare intended parents for the practicalities of this.

[44] These patients accessed a range of fertility treatments, not specifically just those using donated gametes

Research Questions

1. How is counselling offered and attended by intended parents seeking ED/DD treatment?
2. How routinely are issues relating to the disclosure-decision discussed?
3. How routinely are specific disclosure-related issues discussed?
4. What post-counselling support is available for intended ED/DD parents?

6.2 METHODS AND MATERIALS

Participants

Fertility counsellors were recruited through the British Infertility Counselling Association website[45], which contains a comprehensive list of fertility counsellors in the UK, and their contact details. Eighty-eight fertility counsellors were located and were invited by email to participate in an anonymous online survey. A total of thirty of these counsellors completed this survey, representing 34.1% of the total number of fertility counsellors available. All participants were female, but due to the anonymous nature of this study, there is no further demographic information to report.

Procedure

Fertility counsellors were contacted by email (see Appendix 9), which contained information about the study and how they could participate. Participation was anonymous, however counsellors were provided with the Researcher's contact information should they wish to ask any questions. Approximately six weeks after sending the initial email, a follow-up email asked counsellors to complete the survey if they had not already done so but wished to. Data collection started on 25.11.2013 and ended on 25.09.2014.

Survey measures

This study was a questionnaire design whereby an online survey was created specifically to ascertain the content of counsellors' discussions with intended

[45] http://www.bica.net/find-a-counsellor/

parents who are planning to receive ED/DD treatment. The survey consisted of a mixture of option choices and open-ended text boxes (see Appendix 10), and questions addressed the following topics:

1. How is counselling offered and attended?

Questions identified the accessibility and uptake of implications counselling, the number of free sessions available, when counselling sessions are usually attended, and how couples engage in sessions.

2. How routinely are issues relating to the disclosure-decision discussed?

Questions identified counsellors' own opinions on disclosure, and if the following areas are routinely discussed during counselling: patients' disclosure intentions, the pros and cons of disclosure, possible implications of non-disclosure/disclosure, how both members of a couple feel about disclosure, and the possible future scenarios of their decision.

3. How routinely are specific disclosure-related issues discussed?

Questions identified how routinely the exact process of disclosure is discussed with specific focus on age-related disclosure, and the exploration of how to respond to questions that the potential future child might ask. Further questions explored if and how the following implications are discussed: the possibility that the child could have donor siblings, and the possibility that child may, or may not, want contact future with donors.

4. What post-counselling support is available?

Finally, questions focused on the extent of availability of further support for intended parents after they have attended counselling session(s).

6.3 FINDINGS

The majority of data obtained was qualitative data and where relevant, this data has been reported in terms of frequencies and percentages. Qualitative data obtained from open-ended responses was limited and whilst this data was not substantial enough to perform qualitative analysis, qualitative responses have

been included to further support quantitative data. The majority of participants worked in a fertility clinic based in the UK (*n* = 22, 73.3%), and the remainder (*n* = 8, 26.7%) were UK based independent fertility counsellors. Clinic-based counsellors completed the whole survey, whereas independent counsellors only answered questions that were relevant to their practice[46], and did not respond to questions that were not relevant to them[47]

6.3.1 HOW IS COUNSELLING OFFERED AND ATTENDED?

Do clinics impose mandatory counselling?

Counsellors were asked whether their clinic imposes mandatory implications counselling for parents to attend prior to receiving ED or DD treatment, and had the option to respond 'yes', 'no' or 'do not insist but strongly recommend'. The majority of counsellors (*n* = 23, 76.7%) said that it is mandatory for parents to attend counselling, and the remaining counsellors (*n* = 7, 23.3%) 'do not insist but strongly recommend' counselling before ED/DD treatment. It is encouraging that no counsellors responded 'no'; however, the outcome of not insisting upon counselling means that almost one quarter of parents can decide whether or not to attend.

What proportion of ED/DD patients attend counselling?

Responses ranged from 10% to 100%, and counsellors reported that the mean percentage of attendance is 78%. However, a closer look at the data revealed that the response of one-hundred-percent was only provided when mandatory counselling was imposed by clinics. When the responses for mandatory counselling were removed, the overall counselling attendance was instead a much lower rate of 49.3%. Consequently, when provided with a choice, around half of intended ED/DD parents attend counselling. This raises concerns about the remaining proportion that do not attend counselling, specifically whether they have fully considered the unique situation of ED/DD treatment, especially the possibility of sharing details about their children's conception.

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[46] Therefore not all questions have a total response rate of *n* = 30

[47] i.e. those relating to the number of free counselling sessions that they offer, because private counsellors do not offer free sessions

Number of 'free' counselling sessions

The number of free counselling sessions available for intended parents ranges from one to five or more sessions. Typically, parents are entitled to three free sessions, however some clinics provide just one (*n* = 4, 18.2%) or two (*n* = 4, 18.2%) sessions for free.

Two counsellors provided additional comments for this question and stated that unlimited free counselling sessions are provided:

> *As many as required, with info about counselling availability all through till the child is 18yrs*
> *Number of free counselling sessions can be increased if appropriate at discretion of counsellor*

In contrast, this counsellor feels that not enough free counselling sessions are provided:

> *Not enough to explore underlying issues that may be concerning e.g. negative attitude towards donor or donation.*

These responses highlight the variation in the number of free counselling sessions between clinics, and thus how the counselling support available for parents can be determined by where receive their treatment.

Can intended parents pay for additional counselling if they require more sessions?

All 22 clinic-based counsellors said that intended parents could pay for additional counselling if they desire more sessions, or that additional sessions are provided for free. Therefore, the number of counselling sessions available appears to be unlimited, however whether or not these are included within the cost of treatment varies between clinics.

When can free counselling be accessed?

All counsellors said that free counselling *can* be accessed *before* treatment, however the availability of free counselling declined over the course of time, with fewer free sessions available during treatment (*n* = 21, 95.5%), during pregnancy (*n* = 20, 90.9%) and even less so after pregnancy (*n* =19, 86.3%).

When is counselling usually accessed*?*

Most counsellors (*n* = 27, 90%) reported that counselling is usually attended *before* treatment, and the remaining counsellors (*n* = 3, 10%) responded that counselling is usually accessed *during* treatment. Furthermore, some counsellors explained in their comments that whilst counselling can be accessed at any time, it is very rare that parents attend counselling after their treatment:

> *They are told they can come back at any point 'later' for counselling if they wish to, though this rarely happens*
> *Rarely accessed during or after although this is available*

Do couples attend counselling together?

Counsellors were asked two questions about how they engage with couples when receiving ED/DD treatment. The first was whether or not counsellors *insist* that both members of a couple (where applicable) are present for counselling sessions. In response, the majority of counsellors (*n* = 28, 93.3%) do insist that both members of a couple attend, whereas the remaining two counsellors (6.7%) do not. Counsellors were also asked how couples *usually* engage with counselling; all counsellors usually engage with both members of a couple together, and in addition, nine counsellors (30%) *usually* see both members of a couple separately as well. No counsellors reported that they usually just see intended parents separately.

6.3.2 HOW ROUTINELY ARE ISSUES RELATING TO THE DISCLOSURE DECISION DISCUSSED?

For the following topics, counsellors could select one of five options: 'always', 'usually' 'sometimes' 'only if I think it's an issue' or 'only if initiated by parents'. Table 4 illustrates professionals' responses.

Do counsellors think parents should disclose to their children?

Most counsellors thought that it is 'always' (*n* = 20, 66.7%) or 'sometimes' (*n* = 4, 13.3%) best to disclose. One counsellor (3.3%) remained 'neutral' and two (6.67%) thought that it is 'sometimes best not to disclose'. No counsellors report thinking that it is 'always best not to disclose'. Three counsellors (10%) did not provide a response either way and instead selected 'rather not say'. Only two-thirds of counsellors thought that it was always best to disclose, therefore, if counsellors themselves do not think that this is the best approach, it might be difficult for them to fully endorse and encourage disclosure.

Table 4. How UK counsellors explore the disclosure decision

	Always		**Usually**		**Only if considered an issue**		**Only if raised by parents**		**Never**	
	n	%	*n*	%	*n*	%	*n*	%	*n*	%
Exploring the decision										
Disclosure intentions	24	80	3	10	2	6.7	1	3.3	0	0
Pros and cons of decision	25	83.3	3	10	1	3.3	1	3.3	0	0
Possible implications of disclosure	25	83.3	3	10	1	3.3	1	3.3	0	0
Possible implications of non-disclosure	24	80	3	10	2	6.7	1	3.3	0	0
How both members of couple feel about disclosure decision[48]	21	70	7	23.3	1	3.33	1	3.33	0	0
Exploring future scenarios										
Possible future scenarios of disclosure	22	73.3	6	20	1	3.3	1	3.3	0	0
Possible future scenarios of non-disclosure	24	80	3	10	2	6.7	1	3.3	0	0

[48] One counsellor did not provide a response to this question

How do counsellors explore the disclosure decision?

Five questions explored how counsellors engage with intended ED/DD parents about their disclosure decision. As illustrated by Table 3, the majority of counsellors routinely explored patients' disclosure intentions, and the pros and cons of disclosing. Slightly more counsellors discussed[49] the potential implications of disclosure compared to the potential implications of non-disclosure (*n* = 28, 93.3% vs. *n* = 27, 89.9%). The issue explored less frequently was how both members of a couple feel about the disclosure decision, with just two thirds of counsellors always discussing this.

It is reassuring that most counsellors are routinely discussing disclosure intentions, and the pros and cons of disclosure. However, considering that intended parents should be 'encouraged' to be open with their children, the fact that approximately one out of every six counsellors do not engage in this discussion in all instances, raises potential concerns. Salter-Ling et al. (2001) found that only one third of DI couples in the UK, had talked about their disclosure decision with counsellors; however, this study was conducted prior to UK legislation endorsing disclosure, therefore it is unsurprising that this was infrequently discussed.

How are future scenarios explored?

Two questions identified how counsellors engage in the exploration of possible future scenarios. The possible future scenarios of non-disclosure are discussed slightly more frequently[50] compared to future scenarios of disclosure (*n* = 24, 70% vs. *n* = 22, 73.3)**.** Most counsellors explore the future consequences of disclosure versus non-disclosure; however around a quarter of counsellors do not always do this.

[49] Always or usually
[50] Participants selecting 'always'

6.3.3 HOW ROUTINELY ARE DISCLOSURE-RELATED ISSUES DISCUSSED?

Questions focused on how routinely professionals engage with intended parents about the process of disclosing to their children, and the consideration of the particular implications of disclosure. Table 5 illustrates professionals' responses.

Table 5: How UK counsellors explore the disclosure processes and implications

	Always		**Usually**		**Only if considered an issue**		**Only if raised by parents**		**Never**	
	n	%	*n*	%	*n*	%	*n*	%	*n*	%
Process of disclosure										
Age-appropriate disclosure	23	76.6	1	3.33	2	6.7	4	13.3	0	0
How to respond to children's questions	20	66.6	3	10	4	13.3	3	10	0	0
Implications of disclosure										
Possibility that child could have donor siblings[51]	24	82.9	4	13.8	1	3.4	0	0	0	0
Child might want donor contact	25	83.3	3	10	1	3.33	1	3.33	0	0
Child might never want donor contact	23	76.6	1	3.33	1	3.33	2	6.7	0	0

The process of disclosure

Two areas identified the extent that intended parents are prepared for the process of disclosure. First, around three quarters of counsellors 'always' discuss age-appropriate ways of talking to children about the use of ED/DD treatment, leaving around a quarter of participants who do not do this with all intended parents. Second, two thirds of counsellors 'always' discuss how to respond to any questions that any resulting child might ask; however, this means that a third of counsellors do not always explore this aspect with parents.

[51] One participant did not provide an answer for this question.

Overall, a sizable minority of counsellors do not always prepare intended parents with ways they can tell their child about their conception, which is surprising considering the stipulation in UK legislation.

Implications of disclosure

How counsellors engage in discussion regarding the consequences of disclosure are separated into three different aspects. Around three quarters of counsellors 'always' explore all three of these aspects: the possibility of genetically linked siblings, the possibility that children might want to contact their donor in the future and the possibility that children might not want future contact with their donors. Overall, these responses are substantially higher than those reported by Blyth et al. (2013), where only a third of egg and DD recipients reported discussing the possibility that their future child could have donor siblings, and just under half reported discussing the likelihood that their children would be curious about their genetic origins.

6.3.4 POST-COUNSELLING SUPPORT

Finally, the extent of further support that is available for intended parents after their counselling session(s) was explored. Counsellors could select all applicable options: 'direct parents to support groups', 'provide parents with additional books and/or leaflets to take away', 'parents can access additional free counselling', 'parents can pay for additional counselling' or 'no further support'. All counsellors reported that parents could access extra support after their treatment; however, the type of after support available varied. The most common forms of additional support were directing parents to support groups (n = 20, 66.7%), providing additional books and/or leaflets to take away (n = 20, 66.7%) and accessing free additional counselling (n = 20, 66.7%). Half of the counsellors (n = 15, 50%) said that parents could pay for additional counselling if required. Overall, one third of counsellors do not direct parents to support groups, or provide additional books and/or leaflets to take away. The accessiblity of further counselling also varied; free counselling is available in two thirds of clinic, and in the remaining clinics patients must pay for these sessions. In respect of the inconsistency of after-treatment support, another

recent UK survey (Wilde & Parsons, 2014) found that 62% of patients sought support outside of the fertility clinic, demonstrating that the majority of parents feel the need for further help.

SUMMARY OF FINDINGS AND CONCLUSIONS

These findings raise important implications about how counselling is offered and attended by intended parents seeking ED/DD treatment, and makes comparisons to the key findings of Study I.

How counselling is offered and attended

When provided with a choice, only half of intended ED/DD parents attend clinic counselling. This raises alarms about whether non-attenders have fully considered the outcomes of successful ED/DD treatment, in particular issues relating to the disclosing to their future child. Study I found that parents viewed ED/DD treatment as a 'big' decision that has substantial implications, and expressed serious concerns about parents who do not fully consider these prior to treatment. This draws attention to whether mandatory counselling should be imposed in all clinics, an issue fully examined in Section 9.4. The number of free counselling sessions varied substantially between clinics, and one counsellor spontaneously commented that not enough free sessions are provided to fully explore all relevant issues. This is particularly pertinent because parents in Study I did not think that enough counselling sessions were provided for them to fully realise the outcomes of successful treatment. However, all clinics either allowed parents to pay for additional counselling sessions, or provided unlimited free sessions, but parents were unaware that they could access on-going sessions. The accessibility of free counselling declining over the course of time is contrary to the needs of parents, who would most benefit from counselling support *after* a pregnancy is confirmed. Nonetheless, post-treatment counselling is largely available in most clinics, but ED/DD parents were unaware of this.

The disclosure decision

Only two-thirds of counsellors thought that it is 'always' best to disclose, and not all counsellors routinely discussed parents' disclosure intentions, the pros and cons of disclosure and the potential implications of parents' disclosure decisions. This is contrary to UK legislation that states that parents should be encouraged to disclose. It is therefore unsurprising that ED/DD parents felt uninformed about the benefits of disclosure. The issue least routinely explored was how both members of a couple feel about the disclosure decision. However, non-disclosing ED/DD parents experienced differences between their own feelings and that of their partners, which could be resolved by discussing this during counselling. Furthermore, the possible future scenarios of non-disclosure were not always discussed, however, Study I highlights that non-disclosure created considerable anguish for some parents, so this is an important issue to discuss.

Disclosure-related issues

The lack of routine guidance on approaches to disclosure by a substantial proportion of counsellors is concerning for three reasons. First, ED/DD parents were often unsure how to answer their children's questions. Second, non-disclosers were uncertain how they could begin the disclosure process. Third, UK legislation stipulated that patients should be prepared to disclose and this is not always occurring. If these aspects were always discussed during counselling, parents would be better prepared for the process of disclosure. Most, but not all, counsellors explored issues relating to donor relatives. ED/DD parents experienced difficulties telling their children possibility of genetic 'siblings', and the prospect of future contact with donors was a prominent concern. Parents would be better prepared for these issues if they were reflected upon more during counselling.

Post-treatment support

Post-treatment support was available in all clinics; however, the extent of further support varied extensively between clinics. One third of counsellors do not direct parents to support groups, or provide them written information to

take away. ED/DD parents would benefit from being informed about the post-treatments options available to them to help them through all aspects of disclsoure, and written information would alliow reflection and consideration on the information discussed at a later stage.

Overall, findings highlight the current variation in counselling practice in the UK, and demonstrate that the support that parents can receive varies between infertility counsellors/clinics. What is striking is ED/DD parents did not recall any discussions about the pros and cons of treatment, or the process of how they could talk to their child. In comparison, most counsellors reported regularly discussing these issues. This raises important issues about how counselling is offered, and how this support is actually perceived by ED/DD patients. The implications of this for current counselling practice are fully considered in Chapter 9.

CHAPTER 7 - STUDY III
WHAT DO BRAZILIAN PARENTS TELL THEIR DONOR-CONCEIVED CHILDREN AND HOW DO THEY FEEL SUPPORTED WITH THIS PROCESS?

7.1 STUDY III OVERVIEW

An anonymous online survey design, consisting of a combination of multiple choice and open-ended questions was chosen to capture the experiences of Brazilian parents who have created their family using donor conception. Due to the secretive nature of donor conception in Brazil, and because no studies of this nature have been conducted before, parents who had used either donated sperm, eggs or embryos in their treatment were included in an attempt to reach as many participants as possible.

Aims

The first aim was to identify whether or not parents disclose to their children, the reasons behind their decision, and to ascertain how parents disclose. The second aim was to determine if and how parents felt supported with disclosure-related practicalities, and to identify any additional areas of support that they may need.

Research questions

1) The practicalities of disclosure:
    i. Do parents tell their children about the use of donor conception treatment?
    ii. What are the reasons for parents' disclosure decisions?
    iii. When parents have started to tell, what and how are they disclosing?
    iv. What commonalities are present in the narratives that parents tell their children?
    v. What do parents feel their children understand?

2) Disclosure related support
    i. If and how were parents supported with the practicalities of disclosure?
    ii. What additional disclosure-related support do parents need?

7.2 METHODS AND MATERIALS

Recruitment

Contact details were obtained for 136 fertility clinics listed on the Brazilian Society of Assisted Reproduction website[52]. These clinics were sent an email containing the aims of the study to see if they would be willing to help recruit parents who have a child, of any age, conceived using donated gametes. Positive responses were received from eight[53] individuals working in fertility clinics, all of whom were Psychologists. Psychologists contacted parents who fulfilled the criteria, informing them about the research and providing the link to the online survey (see Appendix 11). Where possible, both members of a couple were invited to participate. Data collection started in October 2015 and ended in July 2016

Participants

Nineteen parents completed the survey; the majority (*n* = 16, 84.2%) were mothers and three (15.8%) were fathers. Participants were aged between 32 and 51 years old (mean = 41.2 years). Most were in a heterosexual couple (*n* = 16, 84.2%) and three were in a female couple (15.8%). Thirteen had conceived using donated eggs (72.2%) and five had used donated sperm (27.8%); one participant did not provide information about donation type. All parents had at least one donor-conceived child, ranging from one month old to 14 years old (mean = 5 years old).

[52] http://sbra.com.br
[53] Response rates from fertility clinics were low: some fertility clinics replied stating that they would feel uncomfortable contacting recipients to participate

Survey measures

This study used an anonymous online survey consisting of a combination of multi-choice and open-ended questions, based on questions used in the semi-structured interviews conducted in Study I. Questions were adapted[54] to account for the differences in the practice of gamete donation in Brazil and the UK, and were translated from English into Brazilian Portuguese by a native speaker who is fluent in English (see Appendix 12 for English version). The survey consisted of four main sections:

1. Demographic information including age of parent and child, family configuration and type of donation used
2. Questions to explore parents' disclosure decision: whether or not parents have started to share information with their children about their conception and the reasons for parents' disclosure decision
3. Questions to explore the process of disclosure
4. Questions to determine if parents received emotional support from their fertility clinics or elsewhere, and the extent of this support

Data analysis

Open-ended survey responses were translated from Portuguese into English, by a researcher[55] fluent in both languages. The English version was then analysed using the thematic analysis principles identified by Braun and Clarke (2006), following the procedures described in 5.0.6. Where relevant, quantitative information is also presented in the form of frequencies and percentages. Each extract contains a code that provides information about the family type, treatment type and age of child:

FAMILY TYPE - MC – Mother in couple, **FC** – Father in couple, **SSFC** –female couple
DONATION TYPE - DE – Egg donation, **SD** – Sperm donation, **U** – unknown
AGE OF CHILD – m – months old, **y** – years old

[54] To account for the fact that in Brazil, donation is anonymous. The terminology was also altered to reflect sperm and egg donation, not just ED/DD treatment.
[55] Dr Lia Mara Netto Dornelles

7.3 FINDINGS

The majority (*n* = 14, 66.6%) of parents had not disclosed to their children. Most non-disclosing parents (*n* = 7, 50%) were unsure about whether or not they would disclose in the future, five (35.7%) did not plan to disclose and two parents (14.3%) intended to do so. The remaining seven parents (33.3%) had started to share information with their children about their conception. Reasons for their disclosure decisions are discussed, and where relevant, extracts are provided to illustrate each theme.

7.3.1 THE DISCLOSURE DECISION

7.3.1.1 REASONS FOR NON-DISCLOSURE

Parents provided reasons for non-disclosure and the following four themes were extracted:

1. **CHILDREN MIGHT WANT TO FIND THEIR GENETIC PARENT**
2. **CHILD MIGHT NOT CONSIDER THEM AS THE 'REAL' PARENT**
3. **GENETICS ARE IRRELEVANT**
4. **NOTHING WOULD BE GAINED FROM OPENNESS**

THEME 1: CHILDREN MIGHT WANT TO FIND THEIR GENETIC PARENT

As discussed, donation in Brazil is anonymous. Some parents were concerned that if their children were aware of their donor-conception status, then they might wish to search for their 'biological mother'

> *He may get curious and start looking for his biological mother! It's unnecessary all this anxiety!* ***(MC/DE/9m)***

> *I am worried about his wanting to know about his biological mother. (****MC/DE/6y)***

Parents felt uneasy about this, and thought that it would create 'unnecessary' anxiety, however it is unclear exactly where this anxiety stemmed from; whether parents thought that their child might be distressed over their inability

to trace their anonymous donor(s) or whether parents were anxious about the impact that their children seeking donors would have on the parent-children relationships. Mothers only, and only when donated eggs had been used in treatment, provided this as a reason for non-disclosure. Only a small number of fathers participated in this study, so it is unclear whether fathers were not concerned about children wanting to find their donors, or whether this difference is simply accounted for by the few male participants. Gamete donation parents in the UK were also found to be reluctant to tell when anonymous donors were used, however their concerns were predominately based on how their children would feel, and less so about parents' own insecurities (see 2.1.3).

THEME 2: CHILD MIGHT NOT CONSIDER THEM AS THE 'REAL' PARENT

Some parents did not disclose due to concerns that their child might reject them if he/she was aware that they were not the biological parent:

> *I am concerned that he may not consider me his father* ***(FC/DS/6y)***

> *I am concerned that he likes me less if he gets to know he is not genetically connected to me* ***(FC/DS/7y)***

Fathers provided this reason when sperm donation had been used only; mothers did not share this view when donated eggs had been used. This suggests that fathers have more insecurity in terms of being seen as the 'real' parent, when they lacked a genetic relationship with their child. Perhaps mothers felt more secure about being perceived as the 'real' mother because they experienced a biological connection to their child; this is in line with UK based research whereby mothers gave their gestational connection as a reason for non-disclosure (Lycett et al., 2005).

THEME 3: GENETICS ARE IRRELEVANT

Non-disclosing parents viewed genetics as unimportant, and therefore felt that it was unnecessary to disclose:

Because today the origin of the egg makes no difference to me. For me it was only a cell ***(MC/ED/7m)***

*I don't think it is necessary…he is my son... and that is what matters****…(MC/ED/7y)***

However, whilst they felt that genetics were unimportant, genetics were indeed relevant for some parents because they were the very reason why they were hesitant to disclose: i.e. concerns that they might not be considered as the 'real' parent, or that children might want to trace their donors. Likewise, viewing the social aspects of parenting as more important than genetics were found elsewhere (Applegarth et al., 2016; Lycett et al., 2005).

THEME 4: NOTHING WOULD BE GAINED FROM OPENNESS

Some parents did not disclose because they did not feel that it was important for their children to know details about their conception:

*I doubt the benefit he may have knowing about the donation (****FC/DE/2y)***

I do not see the importance or the need to know these details. ***(MC/DE/2y)***

This suggests that parents were unaware of any benefits of disclosure, perhaps because in Brazil there is a general lack of information available on the possible positive outcomes of disclosure.

7.3.1.2 WHAT COULD CAUSE PARENTS TO DISCLOSE IN THE FUTURE?

Non-disclosing parents, who do not intend to disclose, and those unsure of their plans, were asked if there was anything that could make them inclined to disclose in the future. The following two themes were identified:

1. **'BEING MORE CONFIDENT ABOUT HIS LOVE'**
2. **FOR MEDICAL PURPOSES**

THEME 1: 'BEING MORE CONFIDENT ABOUT HIS LOVE'

Some parents would be more included to disclose in the future if they were certain that their children would still love them:

> *Being more confident about his love* ***(FC/DS/6y)***

> *If I am much more confident that he is going to keep loving me* ***(FC/DS/2y)***

This illustrates the fear that their children would reject them if they knew that they were genetically unrelated.

THEME 2: 'FOR MEDICAL PURPOSES

Other parents could be inclined to disclose if their offspring developed any serious medical conditions in the future:

> *I fear only on health issues. He may develop an illness linked to their genetics.* ***(MC/DE/2y)***

> *Only in the case of an illness that I could not donate or help* ***(MC/DE/1m)***

This demonstrates that even though these parents do not wish to disclose, they were aware that they might need to do so in the future if a medical emergency emerged. Which is in line with findings of non-disclosing ED/DD parents in Study I.

7.3.1.3 REASONS FOR DISCLOSURE

Disclosing parents explained why they had decided to disclose, and two themes were extracted:

1. **NEGATIVE IMPACT OF KEEPING SECRETS**
2. **CHILDREN HAVE A 'RIGHT' TO KNOW**

THEME 1: NEGATIVE IMPACT OF KEEPING SECRETS

The first theme was centered on the importance of openness; specifically, parents felt that concealing information about donor conception could

negatively impact family relationships:

> *Afraid that the secret could disturb our relationship* ***(MC/U/6y)***

> *I don't think it's healthy to keep a secret about <child's> conception* ***(MMC/DE/5m)***

This demonstrates that as found in UK studies of egg/sperm donation recipients. (Lycett et al., 2005) these Brazilian parents were aware that family secrets could negatively impact parent-child relationships and wanted to avoid this possibility**.**

THEME 2: CHILDREN HAVE A 'RIGHT' TO KNOW

Another reason for disclosure was the belief that children have the 'right' to know information about their history. Emphasis was placed on the importance of children having the correct information about their origins:

> *They know all about their history. It is a right of every individual and should not be denied.* ***(MMC/DS/10m)***

> *In my personal opinion... I think it's their right****. (MMC/DS/14y)***

A right to know has also been found in egg/sperm donation recipients elsewhere, whereby parents thought that their children deserved honesty (Applegarth et al., 2016; Lycett et al., 2005; Rumball & Adair, 1999).

7.3.2 THE PROCESS OF DISCLOSURE

All disclosers began to talk to their children about their conception before they were five years old. They did not elaborate on reasons why they started the disclosure process early, but this suggests that disclosing Brazilian parents are aware of the benefits of early disclosure.

7.3.2.1 HOW ARE CONVERSATIONS INITIATED?

Parents were asked how parent-child discussions relating to donor-conception occur, and three themes were identified:

1. **QUESTIONS FROM CHILDREN**
2. **IF PARENT WANTS TO INSTIGATE**
3. **USING STORY BOOKS**

THEME 1: QUESTIONS FROM CHILDREN

Conversations typically arise as a result of children asking questions about their family structure, or where they come from. This parent shares her experiences of an early conversation with her child:

> *When <child> was around 2 years, she/he used to sing a song at home that she/he learned at nursery for daddy's day that said "my daddy" and asked "Do I have a daddy?" and I answered "No, you have two mums".* ***(MMC/DS/14y)***

Van Parys et al. (2016) also found that parents engaged in conversations about donor-conception directly in response to their children's questions, and tended not to raise discussions themselves. However, some children may be less likely to ask questions, so it is unclear if and how these conversations would be initiated if this were so.

THEME 2: IF PARENT WANTS TO INSTIGATE

Conversations also occur if parents wish to talk about their children's conception. To this end, parents viewed disclosure as on-going parent-child dialogue:

> *If he asks me and if I want to talk more about his origin* ***(MC/U/6y)***

> *If I want, if he asks or if there is anything that makes him ask* ***(MC/DE/4y)***

THEME 3: USING BOOKS

Some parents use books to talk to their children about their conception:

> *I have talked about my desire to have him and for that I needed help as it says in the children's book.* ***(MC/DE/6y)***

I have told her/him a story from a children's book ***(MC/DE/7y)***

Information was not provided on if they found these books beneficial, and in which ways, but on the whole books can allow conversations to occur naturally and spontaneously, something that parents have reported is important (Lycett et al., 2005).

7.3.2.2 WHAT HAVE DISCLOSING PARENTS TOLD THEIR CHILDREN?

Disclosers provided examples of the narratives that they have told their children about their conception, resulting in three themes:

1. **THE DESIRE TO HAVE A BABY**
2. **HELP WAS NEEDED**
3. **ALL FAMILIES ARE DIFFERENT**

THEME 1: THE DESIRE TO HAVE A BABY

Most parents emphasised how much they wanted their child. This helped parents to let their children know that their conception was carefully planned:

That he was too much desired. ***(MC/DE/4y)***

That we wanted much to have a child. ***(MMC/DS/14y)***

This theme fits in with findings by Mac Dougall et al. (2007), parents express how loved and wanted their children are in the hope that they will accept their parent's decision to use donated gametes.

THEME 2: HELP WAS NEEDED

Some disclosing parents told their children about how a man, or women was needed in order to help them to have a child. This mother, who has the oldest child in the study, also included information about how a doctor helped:

That we wanted much to have a child but we needed the seed of a man and the seed of a woman to make this baby. As we didn't have a man in our family the doctor helped us to find a nice man that gave us this seed and

then he was born. ***(MMC/DS/14y)***

Two mothers had not yet started to disclose because their babies are just a few months old, but planned to explain that help to conceive was necessary:

> *I am going to try to tell him/her about my desire to have a child but it was impossible with my eggs and so I needed another woman's.* ***(MMC/DE/5m)***

> *We haven't talked about conception yet because he/she is a baby. But we intend to behave as natural as possible, commenting when asked and answering everything but only what is asked. For example: "That was the doctor who put a seed inside mommy's belly.* ***(MMC/DS/10m)***

The last extract does not yet provide information that a man was needed; if and how this female intended to reveal this in the future is not known. It could be possible that they plan to engage in partial disclosure, as established in other studies (see 2.3.4). Nonetheless, the 'helper' narrative is reminiscent of findings elsewhere (Blake et al., 2010; Mac Dougall et al., 2007).

THEME 3: ALL FAMILIES ARE DIFFERENT

The final theme was an explanation of different family configurations; female couples used this approach, likely to account for the absence of a father in their family dynamic:

> *Some children have two moms, some have two daddies, others have a mom and a daddy, some don't have either a daddy or a mom and her/his family is her/his grandma and grandpa or an uncle…Each family has its way and all of them are good, love each other and take care of their child.* ***(MMC/DS/14y)***

> *I will tell her/him that families are different. That love is what matters. That there are a lot of different families and that to build our family, just the way we wanted, it was necessary <to have> the help of another person whom we don't know.* ***(MMC/DS/10m)***

'Families are different' was also found by Mac Dougall et al. (2007)and Lalos et al. (2007) and helps parents to express that their children were conceived in a purposeful manner, and also creates parallels between children who are created 'differently' and serves to present donor conception as one, of many, different forms of creating a family.

7.3.2.3. WHAT HAVE NON-DISCLOSING PARENTS TOLD THEIR CHILDREN?

Non-disclosing parents had not shared any information with their children about their conception, and one theme was identified:

1. **UNSURE WHAT TO TELL**

THEME 1: UNSURE WHAT TO TELL

Some non-disclosers considered how they might disclose in the future. One parent, who intends to disclose, plans to read information to find out how she could talk to her child about his/her conception, and plans to use developmentally appropriate language:

> *I don't know. I am going to read about it and try to tell her when she starts asking…in a language she can understand.* ***(MC/DE/17m)***

Another non-discloser was unsure whether or not she would disclose in the future, but mentioned that she had not *yet* considered what she would say to her child, indicating that she has not completely ruled out the possibility:

> *I haven't thought about it yet.* ***(MC/DE/1m)***

This demonstrates that non-disclosers were generally unsure how they could initiate the disclosure process, and highlights that they would benefit from some guidance on this.

7.3.2.4 WHAT DO CHILDREN UNDERSTAND?

Parents provided information on their children's understanding of their conception, and one theme was identified, with three sub-themes:

1. **CHILDREN HAVE LITTLE UNDERSTANDING**
    I. Conversation should be treated in a 'natural' way
    II. Importance of answering questions
    III. Using age-appropriate language

THEME 1: CHILDREN HAVE LITTLE UNDERSTANDING

Most parents felt that their children currently understood very little about their conception, but considered this normal due to the young age of their children:

> *I suppose she/he understands a little because of her/his age.* ***(MC/U/6y)***

> *She is still little to understand much about her conception.* ***(MC/DE/5y)***

Given that the mean age of children, whose parents participated in this study, was five years old, their understanding appears to be in line with UK findings where the majority of seven-year-olds were unable to demonstrate basic understanding of their donor conception (Blake et al., 2010).

Three sub-themes were identified within the remit of children's understanding:

Conversation should be treated in a 'natural' way

First, emphasis was placed on the importance of having 'natural' conversations relating to their child's conception. One parent, who has the oldest child in the study, felt that her adolescent-aged offspring were fully aware of all relevant details pertaining to their conception. She further explained that in order to ensure that conversations are natural, it is imperative that parents are comfortable with the fact that they had used donated gametes:

> *Since they were little they have faced it naturally because we have dealt with it in a natural and calm way. It is necessary that this subject is*

> *resolved inside the adult's mind to be settled for the child. If the adult is insecure about it the child is not going to deal well with it. As it happens with any other aspect in life.* ***(MMC/DS/14y)***

Another parent, who has not yet started the process of disclosure, reiterated the importance of natural parent-child dialogue:

> *I do not think there is a time for it. These are questions that naturally arise with the complexity for each age. And they should be answered as naturally as doubts arise.* ***(MMC/DS/10m)***

Research has consistently shown that in accordance with these Brazilian parents, parents elsewhere like to treat discussions on donor conception in an unforced, natural and spontaneous way (Isaksson et al., 2016; Lycett et al., 2005).

Importance of answering questions

Second, parents felt that it was important to answer their children's questions as they arise, and to add additional details as their children grow older:

> *All details about his doubts when they appear.* ***(MMC/DS/10y)***

> *Tell him stories for children, answer his questions, try each time to talk a little bit more. I am waiting for him to grow to tell more.* ***(MC/U/6y)***

This further is supported by findings by Van Parys et al. (2016) where parents adapt their communication in response to the questions that children ask.

Using age-appropriate language

Third, parents felt that it is important to talk to their children in a language that is suitable for their age, and adding more complexity as their children's understanding develops:

> *Because he is a baby the language is still too much primitive. We show him his two mothers.* ***(MMC/DS/10m)***

Already explained. The truth adapted to each age....The truth, using an adequate language to her/his age. ***(MMC/DS/14y)***

Overall, parents used these methods in an attempt to help their children to gain a more comprehensive understanding of their conception. These approaches further demonstrate that disclosure is considered a linear process that becomes more detailed over the course of time.

7.4 SESSIONS OF EMOTIONAL SUPPORT

7.4.1 HOW AND WHEN WERE SESSIONS ATTENDED?

Around three-quarters of parents (*n* = 14, 73.7%) were offered emotional support at their clinic, and all but one parent attended these sessions, therefore around two thirds of parents (*n* = 13, 68.4%) attended sessions of emotional support. The high uptake of participation suggests that intended parents thought that attendance would be beneficial, and that they felt that they needed support. All but one parent *(n* = 12, 92.3%) received this support from the clinic's Psychologist, and the remaining parent (7.7%) engaged in emotional support from a Doctor within their clinic. Out of the six parents who did not attend emotion support sessions, this was mostly because they were not offered any (*n* = 5, 83.3%) although the remaining parent (16.7%) did not feel that they needed this support. Four of the six non-attenders (66.6%) wished that they have received sessions, and an additional parent independently sought independent counselling as this service was unavailable at her clinic; she found that this helped her to decide to disclose. Consequently, only one parent did not feel that they needed emotional support either at the time of their treatment, or at the present time.

Of the 13 parents who attended support, all attended a minimum of two sessions, and the maximum number attended was five or more (*n* = 4, 30.8%). Most parents (*n* = 9, 69.2%) received support *before* their fertility treatment, six (46.2%) did so *during* treatment, and two parents (15.4%) received support

after treatment[56]. Finally, most parents (*n* = 9, 69.2%) always attended sessions alongside their partner, two parents (15.4%) always attended their sessions alone, and two parents (15.4%) attended sessions both with their partner, and also alone.

7.4.2. DID PARENTS RECEIVE DISCLOSURE-RELATED SUPPORT?

Parents were asked if they received any information or advice about disclosing to their child.

Was the issue of disclosure discussed?

Approximately two thirds of counselling attenders (*n* = 9, 69.2%) discussed the disclosure decision in their sessions, three parents (23.1%) said that this was not raised, and one parent (7.7%) does not remember. Of the nine parents who discussed disclosure, most (*n* = 7, 77.8%) did not receive any advice, and only two parents (22.2%) were advised that it is best to be open with their children:

> *Whenever possible, speak the truth to him/her.* ***(MC/U/6y)***

> *That it should decide something that was totally comfortable for me. If I had doubts and uncertainties, the child would surely know something's wrong. It could not be a secret, a weight.* ***(MC/DE/7m)***

These extracts illustrate that some fertility professionals encourage disclosure, but these conversations were largely absent. It is therefore unsurprising that non-disclosers were generally uncertain about their disclosure plans, and unaware of the benefits of disclosure.

Did parents receive support on how they could disclose?

No parents received advice about how they could talk to their children about their origins. It is therefore predictable that non-disclosing parents are unsure about how they could initiate the disclosure process.

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[56] Parents could select more than one option which accounts for why the combined responses are greater than 100%

SUMMARY OF FINDINGS AND UK-BRAZIL COMPARISONS

The disclosure decision

Although most parents had not yet disclosed, when considering their future intentions, only a quarter of parents definitely did not intend to disclose. The finding that most parents had not completely ruled out disclosure is surprising considering the perceived nature of secrecy in Brazil. Non-disclosers did not think that openness would be fruitful, a concern commonly identified in non-disclosing parents in Study I, and likewise exploring the pros and cons of disclosure would help them to make a fully informed decision and raise awareness of the potential benefits of disclosure. Further, concerns were expressed that their children would not love them, or they would want to find their donors; reassurance from professionals could reduce these worries. They were also unsure how they could begin to disclose, and like non-disclosers in the UK, would benefit from example narratives and role-playing so that they have suitable resources to draw upon. Brazilian non-disclosers generally viewed genetics as irrelevant, a view also shared by non-disclosers in Study I, yet despite this view, they were concerned that their children would reject them for not being the 'real' parent. Reasons for disclosure were the same across both country contexts, with emphasis on the child's right to know about their conception, and the potential damage of secret-keeping.

Process of disclosure

Like UK parents, Brazilian disclosers started the process early, by using the 'seed-planting' technique (Mac Dougall et al., 2007). Overall, less emphasis was placed on using disclosure-related resources, which could be because Brazilian parents are unaware of available resources. UK ED/DD parents tended to use more creative approaches, such as creating storybooks and adding information into existing books. It is possible that this was because ED/DD is a potentially more complex story to explain, and perhaps Brazilian parents did not need to do this because the available books were suitable. In general, Brazilian parents were not apprehensive about the practicalities and complexities of disclosure, compared to UK parents. Again, this could be because in Brazil there is less

pressure to disclose, less guidance and no support groups, therefore parents cannot make peer comparisons and instead disclose in their own stride.

What are children told?

Key information in narratives were similar to those employed by UK parents in Study I, specifically the desire to have children, and details about the help that was needed. However, Brazilian parents placed less prominence on the actual donors, compared to UK parents. Due to the anonymous nature of Brazilian donors, parents may view the donors as less significant. Findings by Zadeh et al. (2016) support this; parents who used anonymous donors tended to 'absent' the donors, compared to parents who had used identifiable donors who portrayed the donors as being more 'present' and therefore more relevant. Brazilian parents also did not discuss gratefulness to the donors/medical staff in the same way that UK parents did. Perhaps this was because ED/DD parents were likely to have attempted infertility treatment for longer, and therefore felt more 'grateful' to the people who helped them to have children, or because the act of donating an embryo might be viewed as more meaningful than donated sperm or eggs. Not all disclosing Brazilian parents explicitly told their children that someone else (i.e. the donor) was needed in their conception. This could be accounted for by the young age of some children in this study, however if parents do not proceed to reveal full details then it is possible that parents might engage in partial disclosure (Blake et al., 2010; Readings et al., 2011). Disclosing parents felt that their children understood their conception to a developmentally appropriate degree, and emphasised the importance of having natural conversations, using age-appropriate language, and answering questions truthfully, so that their children's understanding will deepen. Employing these techniques reinforces that like UK parents, Brazilian parents view disclosure discussions as evolving.

Non-disclosers had not told their children anything about their conception, and were generally unsure how they could initiate the disclosure process. This is comparable to findings of Study I whereby non-disclosers were uncertain about how and when they could start disclosure. Brazilian non-disclosers did not

reflect on their decision regretfully like UK parents did, perhaps this is because there is less pressure on Brazilian parents to disclose, so they are more comfortable with their decision.

Emotional support

The uptake of emotional support when offered was high, and all but one parent who did not attend sessions wished that they had done so, illustrating the current need for support. How these sessions were attended varied, but couples tended to attend sessions together, and usually before their treatment. Again, this is consistent with findings in Study I. All attendees participated in a minimum of two sessions, whereas most UK parents attended only one session, therefore Brazilian parents had more access to sessions of support. For the majority of parents, the issue of disclosure was absent from these sessions. Whilst mindful of the differences between studies, this demonstrates a stark difference to findings from Study I where parents were routinely advised to disclose, and Study II where most counsellors reported discussing disclosure intentions. Like Study I, no Brazilian parents received support or advice on how they could talk to their children about their origins; however, the absence of this advice in Brazil is less surprising due to the lack of Brazilian guidance and legislation to this regard.

Overall, the Brazilian context is less supportive of disclosure, evidenced by the low disclosure rates and sparseness of disclosure support. Current practice in Brazil is similar to that in the UK before HFEA brought in mandatory counselling offer. Chapter 9 presents the implications of this study for Brazilian practice and legislation.

CHAPTER 8 - STUDY IV

HOW DO BRAZILIAN FERTILITY CLINICS SUPPORT DISCLOSURE?

8.1 STUDY IV OVERVIEW

An anonymous online survey design consisting of a combination of multiple-choice and open-ended questions was chosen to capture information on the emotional[57] support available for patients seeking treatment with donated gametes in fertility clinics in Brazil from the viewpoint of the clinics.

Aims

The overall aim was to identify the clinics' perspectives on the support available to Brazilian parents who are seeking treatment with donated gametes, with particular focus on how intended parents are supported with disclosure-related implications

Research questions

1) Are sessions of emotional support available, and if so are they offered and attended?
2) If and how routinely are issues relating to the disclosure-decision discussed?
3) If and how routinely are specific disclosure-related issues discussed?
4) What post-counselling support is available?

8.2 METHODS AND MATERIALS

Recruitment

All 136 fertility clinics that had contact details available on the Brazilian Society of Assisted Reproduction website were emailed details about the aims of the study and how they could participate (see Appendix 13). Six weeks after

[57] Counselling has been termed as 'Emotional support' because not all practitioners in Brazil who provide support of this nature are qualified counsellors

sending the initial email, a follow-up email was sent, reminding participants to complete the survey if they had not already done so but intended to. Data collection started October 2015 and ended July 2016.

Participants

Twenty-four[58] fertility professionals completed the survey; most (*n* =17, 70.8%) were Psychologists and the remainder were Doctors (*n* = 3, 12.5%), Nurses (*n* = 3, 12.5%) or clinic administrators (*n* = 1, 4.1%).

Survey measures

The anonymous online survey (see Appendix 14 for English version) was designed based on questions in the UK fertility counsellors' survey (Study II). Questions were adapted[59] according to the differing practices between these two countries, and translated into Brazilian Portuguese following the same procedures as stated in 7.2. The survey contained four main sections:

1) *How are sessions of emotional support offered and attended?*

Questions addressed: if clinics provide free sessions of emotional support; the proportion of patients that attend emotional support; if fertility professionals recommend that sessions of emotional support are attended; how patients are referred for emotional support; when sessions can be/are usually accessed; and how couples engage in sessions of emotional support.

2) *How routinely are issues relating to the disclosure-decision discussed?*

Questions identified professionals' own opinions on whether disclosure is preferential, and whether the following areas are routinely discussed during sessions of emotional support: patients' disclosure intentions, the pros and cons of disclosure, possible implications of non-disclosure/disclosure, and how both members of a couple feel about disclosure. Further, questions probed if

[58] Not all participants responded to every question, so sometimes the total number of responses is less than 24.
[59] Adaptations included: extending the invitation of participation to all fertility professionals due to the fact that very few fertility clinics have psychologists / counsellors, and changing questions to allow for all types of donor conception (not just ED/DD).

professionals routinely explore the possible future scenarios of disclosure/non-disclosure.

3) *How routinely are specific disclosure-related issues discussed?*

Questions focused on how counselling engages with discussing the process of disclosure, with specific focus on starting the process, and how to respond to questions that the potential future child might ask. Further questions explored if and how the following implications are discussed: possibility that child could have donor siblings, and the possibility that child may/may not want future contact with their donors.

4) *What post-counselling support is available?*

Finally, questions addressed what, if any further support is available for intended parents.

8.3 RESULTS

8.3.1 HOW ARE SESSIONS OFFERED AND ATTENDED?

How many free sessions do clinics provide?

Responses ranged from no free sessions, to a maximum of five sessions (mean = 3). In half of the clinics, patients could pay for additional sessions (n = 11, 50%), and seven clinics offered on-going free sessions of emotional support (n = 7, 31.2%).

What proportion of patients attends sessions of emotional support?

There was wide variation of attendance between clinics, with responses ranging from 10% to 100%. The mean response was 59%; therefore just under half of patients do not access sessions of emotional support. Six clinics made it compulsory for patients to attend sessions, so when mandatory attendance was removed, a smaller proportion (43.5%) of parents voluntarily attend these sessions.

Do professionals recommend that patients attend these sessions?

All respondents thought that intended parents should receive emotional support, and recommended between two and five (mean = 3) sessions prior to their treatment. This demonstrates that professionals thought that parents would benefit from attending these sessions, and did not think that attending just one session was enough.

How are participants referred for emotional support?

Referrals are usually made by the doctor or nurse (*n* = 12, 57.1%), or upon patient request (*n* = 2, 9.5%). Seven clinics routinely invite all patients receiving gamete donation treatment to attend sessions on either a mandatory (*n* = 6, 28.6%) or optional (*n* = 1, 4.8%) basis.

When can sessions of emotional support be accessed?

In all clinics, support was available both before, and during treatment. However, the accessibility of sessions declined over the course of time, with less availability during (*n* = 6, 27.7%) and after pregnancy (*n* = 6, 27.7%).

***When are sessions of emotional support usually accessed*?**

Support is usually accessed before (*n* = 13, 61.9%) or during (*n* = 6, 8.6%) treatment, which is in accordance of when it is most available. However, a couple of professionals reported that it is usually accessed at all stages (*n* = 1, 4.8%), or after treatment (*n* = 1, 4.8%).

Do couples attend sessions of emotional support together?

Two aspects of couple engagement were identified. First, all professionals thought that both members of a couple should attend sessions together, as opposed to separately. Second, both partners usually attend sessions together (*n* = 12, 57.1%), or attend sessions together and also individually (*n* = 9, 42.9%). No respondents reported that they usually see both members of a couple separately.

8.3.2 HOW ARE ISSUES RELATING TO THE DISCLOSURE DECISION DISCUSSED?

Do professionals think parents should disclose to their children?

Most participants were pro-disclosure and thought that it is 'always' best to be open with children (*n* = 16, 76.2%). The remaining respondents (*n* = 5, 23.8%) remained neutral; therefore no respondents were against disclosure.

Respondents were then asked a series of questions about how they routinely engage with intended parents on issues related to the disclosure decision. For each question, participants had the option to select 'always', 'usually' 'only if I think it's a problem', 'only if parents initiate discussion' or 'never'. Table 6 shows a collation of all responses.

Table 6. How Brazilian professionals explore the disclosure decision

	Always		**Usually**		**Only if considered an issue**		**Only if raised by parents**		**Never**	
	n	%	*n*	%	*n*	%	*n*	%	*n*	%
Exploring the disclosure decision										
Disclosure intentions	5	22.7	7	31.8	3	13.6	6	27.3	1	4.54
Pros and cons of decision	9	40.9	4	18.2	2	9.1	6	27.3	1	4.54
Implications of disclosure	7	31.8	6	27.3	3	13.6	5	22.7	1	4.54
Implications of non-disclosure	8	36.4	7	31.8	3	13.6	3	13.6	1	4.54
How couples feel about disclosure	9	40.9	6	27.3	2	9.1	5	22.7	0	0
Exploring future scenarios										
Future scenarios of disclosure	5	22.7	9	40.9	1	4.54	4	18.2	3	13.6
Future scenarios of non-disclosure	5	22.7	8	36.4	2	9.1	4	18.2	3	13.6

Do professionals explore the disclosure decision?

Just over half of participants either always, or usually explore disclosure intentions, therefore a substantial proportion of participants do not routinely do so. First, under two thirds of participants always or usually explore the pros and cons of the disclosure decision with the intended parents, however this leaves a substantial proportion of respondents who do not regularly discuss this. Study III revealed that non-disclosing Brazilian parents were unaware of the benefits of disclosure; if this topic was always considered during sessions of support then this could enable parents to make a better-informed decision. Second, the implications of non-disclosure were more frequently discussed than the implications of disclosure (*n* = 15, 68.2% vs. *n* = 13, 58.1%). It is unclear why this is so, but positive that most intended parents get to explore non-disclosure. Third, only two thirds of professionals usually or always explore how both individuals within a couple feel about the disclosure decision. So although all participants thought that couples should attend sessions together, they do not always facilitate and encourage both members of a couple to consider their feelings about disclosure.

Exploring future scenarios

The possible future scenarios of disclosure are discussed slightly more frequently[60] compared to future scenarios of non-disclosure (*n* = 14, 63.6% vs. *n* = 13, 58.1%). However in comparison to other issues related to the disclosure-decision, a larger proportion of respondents never discuss future implications (*n* = 3, 13.6%). This may result in some intended parents being left uncertain about the future consequences.

8.3.3 HOW ARE SPECIFIC DISCLOSURE-RELATED ISSUES DISCUSSED?

Questions focused on specific aspects of disclosure, and how routinely professionals engage with intended parents about sharing disclosure information with their children, and the consideration of the implications of disclosure. Table 7 illustrates professionals' responses.

[60] Participants selecting 'always' or 'usually'

Table 7. How Brazilian professionals explore the disclosure processes and implications

	Always		Usually		Only if considered an issue		Only if raised by parents		Never	
	n	%	*n*	%	*n*	%	*n*	%	*n*	%
Process of disclosure										
How to initiate disclosure	4	18.2	7	31.8	3	13.6	8	36.4	0	0
How to respond to child's questions	8	36.4	6	27.3	2	9.1	6	27.3	0	0
Implications of disclosure										
Child could have donor siblings	3	13.6	4	18.2	6	27.3	7	31.8	2	9.1
Child might want donor contact	3	13.6	4	18.2	2	9.1	12	54.5	1	4.54
Child can never have donor contact	5	22.7	6	27.3	2	9.1	9	40.9	0	0
How child might feel in the future	7	31.8	7	31.8	5	22.7	3	13.6	0	0

The process of disclosure

Two areas addressed if and how the process of disclosure is discussed. First, how intended parents could initiate disclosure was only routinely incorporated into sessions of emotional support by half of the professionals, whereas many only tended to discuss this if initiated by parents. Second, the exploration of how intended parents could answer children's questions occurred more frequently, with around two thirds of participants always or usually deliberating this issue with intended parents. It is however promising that no respondents reported that they never discuss the process of disclosure with intended parents.

Implications of disclosure

Consequences of disclosure were broken down into four separate aspects. First, the possibility that children could have donor siblings was always or usually raised by only one third of participants. Second, the possibility that the child might want to contact their donor(s) was also infrequently raised with only

around a third of participants always or usually discussing this. Third, the fact that children can never establish contact with donor (s) was only usually or always discussed by a half of the respondents. Finally, around two thirds of the professionals usually or always consider how children might feel in the future about their donor conception.

On the whole, Table 6 illustrates that the majority of professionals tend to wait until issues are raised by parents, rather than initiating discussions themselves. Topics most routinely discussed are how the child might feel in the future, and how intended parents could answer their questions. Issues less frequently discussed were related to the donor relatives, specifically the fact that children might have donor siblings, and also that children may wish to meet their donors, but would be unable to.

8.3.4 IS ONGOING SUPPORT AVAILABLE?

The final section of the survey explored the extent of further support that is available for intended parents. No additional support was available in three (13.6%) clinics, but varying degrees of support were available in all other clinics. The most common form was the sharing of books or leaflets on disclosure (*n* = 10, 45.5%). Less routinely, intended parents were directed to support groups (*n* = 4, 18.2%); there are no national support groups in Brazil, therefore it is assumed that these are support groups ran by individual clinics.

SUMMARY OF FINDINGS AND UK SUPPORT COMPARISONS

How sessions are offered and accessed

All respondents thought that patients should attend sessions of emotional support, signifying the perceived value of support. Similarities between the UK and Brazil were that the number of free sessions available varied between clinics, and that accessibility of support was less during, and after pregnancy. Fewer Brazilian patients attend sessions compared to patients in the UK (59% vs. 78%), which is expected given that UK legislation stipulates the importance of counselling, whereas Brazilian legislation does not. Nonetheless, the

substantial proportion of Brazilian patients who do not attend raises potential concerns about whether or not parents have fully considered the implications of using donated gametes. At some Brazilian clinics, as few as 10% of patients attend support sessions, indicating that some clinics place less value on emotional support or do not encourage patients to attend.

The disclosure decision

The framework of donor anonymity and the absence of guidance on emotional support is geared towards non-disclosure. Therefore, professionals who sanction disclosure might feel compromised between endorsing disclosure, and not having appropriate Brazilian legislation to support them with this. An infrequent topic discussed is intended parents' disclosure intentions. It is unclear why this is so, but given the secretive nature of donor conception in Brazil, it is possible that professionals wish to respect the privacy of their patient. Also, only two thirds of respondents routinely discuss the pros and cons of disclosure, however, Study III revealed that non-disclosing Brazilian parents were unaware of the benefits of disclosure; if this topic was habitually debated, parents could make better-informed decisions. Overall, UK counsellors routinely engage with discussions on the disclosure decision more than professionals in Brazil.

Disclosure-related issues

Most professionals waited for patients to raise issues relating to the process and implications of disclosure, rather than initiating discussions themselves; this is concurrent with Brazilian parents' experiences - no parents reported receiving disclosure advice. This is, however, in stark comparison to Study II, where most UK counsellors reported routinely discussing these aspects. Issues less frequently discussed were regarding the donor relatives. Again, due to donor anonymity, donors may be seen as less relevant and so are not considered an important part of the treatment process. Although disclosing Brazilian parents did not appear to be experiencing any current difficulties, non-disclosers would benefit from engaging with professionals about how they could talk to their child.

The availability of additional support

Similar additional support is available in the UK and Brazil, however, there was no evidence from Study III that Brazilian parents accessed extra support, so it is possible that they are unaware of its existence. Nonetheless, parents would benefit from post-treatment support, to provide reassurance that their children would still love them, and to explore the benefits of openness and the discussion of methods of disclosure.

Overall, professionals varied in the extent that they engaged with patients. Individual professionals tended to respond in the same direction to each question. This, alongside the varying number of free sessions of support, demonstrates that emotional support is largely determined by at which clinic patients receive their treatment; ranging from very little disclosure support, to a more comprehensive exploration of the disclosure decision, and the practicalities of disclosure. On the whole, it is promising that despite the lack of regulations pertaining to emotional support, only a small percentage of respondents never discuss these issues. However, if all professionals incorporated these aspects into their sessions, then parents would have appropriate information, and would be better prepared for the future.

CHAPTER 9 - DISCUSSION

This thesis had four main aims. First, to explore how parents disclose to their children conceived by ED/DD treatment in the UK. Second, to identify the disclosure-related support available in the UK for ED/DD recipients. Third, to see if and how Brazilian parents disclose donor conception to their children. Forth, to identify the disclosure-related support available in Brazil.

9.1 METHODOLOGICAL ISSUES

Before discussing the key findings and their implications for policy and practice, the limitations of these studies are acknowledged.

Study I

On the whole, UK based fertility clinics were reluctant to help with recruitment, as such, the pool of participants were limited to just one clinic, plus those recruited through DCN. As a result, the experiences of a small number of parents have been drawn upon. Participants recruited through DCN were pro-disclosure and therefore are not representative of all parents who have a child conceived through ED/DD. Nonetheless, the aim of this study was to see how the process of disclosure is experienced, rather than focusing on disclosure rates. Parents were interviewed only once, so the findings provide a snapshot of individuals' experiences at that moment in time. However, because parents had children of a range of ages, overall parent experiences were captured during the first few years of children's life. The age of children differed between adoptive and ED/DD parents; adopters had children who were aged three to nine-years-old, and ED/DD parents had children aged up to nine years old. However, as discussed in 5.0.2, when responses of ED/DD parents who had a child aged up to three were compared with those who had children over the age of three, the same themes were present. It is therefore not anticipated that including a younger range of children for ED/DD parents has impacted upon any differences detected between adoptive and ED/DD parents.

Study II

Just 30, out of a possible 88 infertility counsellors completed the survey, representing around one third of the infertility counsellors available. Therefore counsellors who did not complete the survey are unaccounted for, and they may be more or less likely to discuss disclosure-related implications. An anonymous online survey design was chosen due to time constraints, and it was thought that the anonymous nature of the survey would encourage more counsellors to participate. Whilst open-ended boxes were provided in an attempt to obtain more detailed responses, most counsellors provided minimal additional information and mostly resorted to selecting check boxes where appropriate. If counsellors were instead interviewed, it is possible that more detailed data could have been elicited through the clarification and probing of information. Another limitation is that several counsellors contacted the researcher to say that they rarely encountered patients seeking ED/DD treatment, and as such their responses were based on their relatively unfamiliar experience of this and therefore it is possible that if counsellors had more experience, they might have responded differently. Finally, adoption services were not asked to complete an online survey of the support that they provide adopters, so comparisons between the support available for ED/DD parents and adoptive parents is made based on parents' experiences alone.

Study III

Brazilian clinics were largely unwilling to assist with recruiting parents. Some clinics responded to the invitation to assist stating that they would feel uncomfortable contacting recipients because parents now wanted to 'forget' that they had treatment or that parents 'did not want to discuss their treatment', and participation would serve as a reminder of this. This in itself reveals important information about how donor conception is viewed in Brazil. All professionals who agreed to help with recruitment were clinic based infertility counsellors, who also reiterated parents' reluctance to both participate and to disclose to their children. As a consequence, this study drew on the experiences of a small magnitude of parents. An anonymous online study was chosen because the researcher was not fluent in Brazilian Portuguese, so

was unable to conduct interviews. Despite encouraging participants to provide detailed information in open text boxes, several parents provided very limited information to some of the survey questions, and therefore the data was not as rich as it might have been if an interview design was used.

Study IV

Many Brazilian clinics do not offer any form of emotional support. It is possible that these clinics were less inclined to complete this survey, and that the responses received were from clinics that do indeed offer emotional support. As a result, the responses received may not be representative of all clinics and might exaggerate the level of support available. Not all Brazilian clinics that do provide such support have fertility counsellors, so a range of professionals completed the survey. Nonetheless, the fact that a variety of professionals completed the survey is reflective of practice in Brazil. Once again, a key limitation of this study is its small number of participants.

9.2 KEY ED/DD AND ADOPTION COMPARISONS

Detailed comparisons between the findings of adoption and ED/DD parents have been made in 5.2 and 5.4; this section specifically focuses on how current practice impacts these two groups. First, training is mandatory for all adopters that, amongst other things, prepare them for disclosure. In contrast, counselling attendance is not mandatory for ED/DD parents, which significantly impacts the level of support received. Second, in accordance with UK legislation, clinics should encourage parents to begin the disclosure process during early childhood, and should be informed of the importance of doing so. However, ED/DD parents were often unsure why disclosure is endorsed, and did not feel that the benefits were made transparent. In particular, non-disclosers remained unaware of the benefits of early disclosure, and were perplexed about when to begin sharing information. This contrasts sharply with adopters, who were all told that it is best to tell their children as soon as possible. Third, UK legislation states that parents should be prepared for the process of disclosure, but ED/DD parents did not feel prepared; they thought that counselling was a tick box

exercise, did not think that enough sessions were available, and thought that counselling was on the wrong focus, at the wrong time, leaving non-disclosers hesitant about starting the process. In contrast, adopters were equipped with information and tools (i.e. LSB) during their training that prepared them to disclose. Finally, adopters had fewer current needs and were certain that they would be able to find the answers to these by undertaking independent research. In comparison ED/DD parents had a range of unmet needs including awareness of the benefits of disclosure, when and how they could begin the process, explaining more complex elements of ED/DD conception to their children, and preparing their offspring for the future.

9.3 IMPLICATIONS FOR ED/DD PRACTICE IN THE UK

One key issue with current legislation is that whilst it stipulates that parents should be encouraged to disclose and equipped with the skills to do so, it does not specify that this is solely the responsibility of counsellors. Without mandatory counselling, it is unclear who would be responsible for guiding intended ED/DD parents through this process. Findings demonstrate that the introduction of identifiable donors alone is not enough to convince parents to disclose**.** In accordance with recent UK findings on sperm donation (Freeman et al., 2016)**,** there was no evidence that ED/DD parents were more likely to disclose if they had identifiable donors. In fact, disclosers were more likely to have one or more anonymous donor compared to non-disclosers. Instead, the most relevant prerequisite to disclosure was parents' own thoughts, feelings and experiences relating to disclosure, which were largely determined outside of the clinic setting.

No parents felt that clinic counselling prepared them to be open, however, disclosing parents sought support from independent counsellors, or the DCN to help them to decide what to do. This illustrates that external support influenced parents' disclosure decisions and prepared them to disclose. Therefore, as in previous studies (Lycett et al., 2005; Rumball & Adair, 1999)**,** clinic support did not make parents more likely to disclose, despite this being an intention of

current legislation. In support of this, a higher proportion of non-disclosers participated in clinic counselling sessions, compared to disclosing parents, demonstrating that counselling attendance made little impact on their decisions. Several reasons account for why this is so. First, as identified elsewhere (Payne & van den Akker, 2016; Wilde & Parsons, 2014), parents viewed counselling as an assessment, and were concerned about saying the 'wrong' thing that might risk treatment, so were not completely honest with counsellors about their feelings. Second, they did not feel that the benefits of counselling were made clear to them, and considered counselling to be for the clinics' benefit, rather than their own. Which is also consistent with findings in other studies (Payne & van den Akker, 2016; Wilde & Parsons, 2014). Third, as found by Hahn and Craft-Rosenberg (2002) and Landau et al. (2008), ED/DD parents were also unable to fully consider disclosure prior to treatment, and although most clinics do offer post-treatment counselling (Study II), parents were unaware of this. Fourth, parents did not think that enough sessions were offered to fully consider the consequences of their treatment, and were unaware that the overall number of counselling sessions available is actually unlimited (Study II). Finally, parents lacked on-going support, despite the importance of this being emphasised in previous research findings (Lycett et al., 2005; Mac Dougall et al., 2007).

9.4 PROPOSED SOLUTIONS TO CURRENT UK PRACTICE

In light of these findings, two fundamental changes to counselling practice in the UK are proposed.

9.4.1 MANDATORY COUNSELLING SHOULD BE LEGISLATED

When provided with a choice, half of intended ED/DD parents do not attend implications counselling. However, parents considered ED/DD treatment to be a 'big' decision with significant long-term consequences, in support of this, infertility counsellors in New Zealand considered it necessary for ED recipients to require substantial counselling (Goedeke et al., 2016; Goedeke & Payne, 2010) . Overall, findings warrant that mandatory counselling would help to

prepare recipients for the life-long implications of ED/DD treatment**.** Mandatory counselling has previously been proposed by the British Fertility Society (2012) for all gamete donation treatments, however, considering the unique implications of ED/DD treatment, and the fact that adopters, who attend mandatory preparation, are more confident at disclosure, mandatory counselling is even more essential for ED/DD recipients.

During mandatory sessions, intended parents should receive appropriate support and information to enable them to make a fully informed decision. To this end, it is recommended that:

1) *Clinics provide more support to assist patients with the disclosure decision*

ED/DD parents were unsure *why* disclosure is advocated and would have liked information on the pros and cons of disclosure, and did not feel that the benefits of disclosure were transparent. In light of this, it is *recommended* that all intended ED/DD parents are provided with a list of the pros and cons of disclosure. Further, to fully understand why disclosure is encouraged, patients should be aware of the future consequences of non-disclosure. It is therefore *recommended* that all counsellors fully explore the consequences of non-disclosure. Non-disclosing mothers were generally more inclined to disclose in the future, compared to their male partners who were more reluctant to do so, which created substantial conflict. It is *recommended* that couples attend counselling sessions together and that they are encouraged to fully explore their possible contrasting feelings. Overall, these recommendations are in line with those made by Tallandini, Zanchettin, Gronchi, and Morsan (2016) advocating the need for information about the possible consequences of non-disclosure, the benefits of early disclosure, and developing the story over time.

2) *Clinics provide more support to guide parents through the process of disclosure*

Non-disclosers' uncertainty about the 'best' age to disclose, and the belief that it could be better to disclose during adulthood is contrary to UK legislation, indicating that they are naïve to the benefits of the early delivery of information. It is therefore *recommended* that the advantages of early disclosure are discussed during counselling sessions. In addition, as found in Study I, uncertainty about how to disclose is a common reason for delaying or avoiding disclosure, which is a common finding in other studies (Blyth et al., 2013; Daniels et al., 2011; Jadva et al., 2009; Lalos et al., 2007). Parents' concerns about *how* they could instigate discussions could be minimised or eradicated if patients were informed of the possible methods of disclosure. As discussed, there are a plethora of books available, however, parents were largely unaware of these resources. In light of these factors, it is *recommended* that counsellors show parents examples of disclosure literature including, personalised books that they could create to help parents with telling, existing books that they can use to talk to their children, and the exploration of potential future scenarios and answering future questions. In addition to this, it is vital that intended parents are provided with literature that they may take away with them and can refer back to in the future.

3) *Clinics should provide information about alternative on-going support*

Participants wanted a list of trained fertility counsellors who they could access for fertility related advice. In support of this, a recent survey found that 75% of respondents were unaware of the accredited specialist infertility counsellors listed on the BICA website (Wilde & Parsons, 2014). Therefore it is *recommended* that all intended parents are informed about the BICA website and how access to counsellors on here could benefit them in the future. One of the most beneficial forms of support utilised by disclosing parents was support groups, which provided a platform to share ideas amongst peers, and create links between donor-conceived families. Counsellors did not routinely inform intended parents about relevant support groups, and non-disclosing parents

remained unaware of their existence, but would unequivocally benefit from accessing them to assist with the disclosure decision and process. It is therefore *recommended* that counsellors inform patients about support groups.

4) Counsellors should attend training

To improve counselling, it is *recommended* that counsellors undergo training specifically on disclosure issues; this is suggested for three reasons. First, one third of counsellors did not think that it was always best to disclose. If counsellors themselves do not think that this is the best approach, then they might be hesitant to encourage patients to do so. Second, a substantial proportion of counsellors did not inform parents about the benefits of early disclosure, despite this being depicted in UK legislation. Third, a substantial proportion of counsellors do not prepare intended parents with methods of disclosure, which is also in disparity to UK legislation. In support of this recommendation, Lalos et al. (2007) found that parents received unclear and conflicting advice from fertility staff and concluded that staff should be educated and trained to provide a consistent and positive attitude towards disclosure.

9.4.2 PARENTS SHOULD BE ENCOURAGED TO ATTEND POST-TREATMENT COUNSELLING SESSIONS

Parents would benefit from post-treatment counselling, so that they are in a better position to realistically engage with disclosure-related issues. It is *recommended* that in addition to mandatory counselling, patients are strongly encouraged to attend counselling after a pregnancy has been established. During this second phase of counselling, information discussed during mandatory counselling should be reiterated and developed. As findings from Study I support, one area of focus should be on preparing intended parents to help their children to understand the more complicated elements of their conception including: the lack of genetic relationship to parents, shared relationships with donor relatives, and the possibility of future contact with donor relatives. It is *recommended* that counsellors provide support and guidance on these aspects, with particular focus on the implications of bringing up a child conceived by ED/DD treatment.

9.5 AREAS OF FUTURE RESEARCH IN THE UK

Most children in Study I were reported to be unable to comprehend genetic relationships, because either this information was currently absent, or they were not developmentally mature enough to understand genetics links. Research focusing on ED/DD offspring from aged eight and into adolescence would generate important information about when and how parents discuss the more sophisticated elements of disclosure, such as genetic links in relevance to their parents, and donors, and to explore if and how they are perceived as relevant.

No research has explored children's own understanding of ED/DD conception; therefore the second suggestion is to see how ED/DD children perceive their conception. This would generate information about ED/DD offspring's understanding, and highlight areas that need to be developed. The third suggestion is exploring how ED/DD families navigate discussions and prepare their offspring for the possibility of meeting their donor relatives. This aspect was of particular concern to ED/DD parents in Study I and will become a reality in 2022 when the first ED/DD offspring will have the opportunity to obtain identifiable information about their donors. Considerable support and counselling is likely to be needed to guide the donor and recipient families through this process. Interviewing ED/DD recipients and their offspring, would provide detailed information in anticipation of this future occurrence and findings would inform policies and practices about how this process could be suitably managed. The final suggestion is undertaking a research project to incorporate awareness of donor conception into the national curriculum. Many parents were concerned how their children would feel about being donor conceived, and were worried that their children would be subject to teasing because of their method of conception. The incorporation of information about donor conception in schools could raise awareness of alternative family building methods, and would help to normalise donor conception. Overall, this could reduce feelings of 'difference', and if it becomes a more acceptable and discussed topic in society, could provide non-disclosing parents with the confidence to disclose.

9.6 KEY FINDINGS AND RECOMMENDATIONS TO BRAZILIAN PRACTICE

Detailed comparisons between practices in the UK and Brazil have been made in Chapters 7 and 8; however, this section discusses how national frameworks affect these issues**.** Overall, the Brazilian context is less supportive of disclosure, as evidenced by the low disclosure rates and sparseness of disclosure-related support available in fertility clinics. Current Brazilian practice is similar to UK practice prior to the mandatory offer of counselling, and whilst findings show that UK practice needs to be further developed, it has taken a step in the direction that supports donor-conceived families. Based on the findings of Studies III and IV, Brazilian practice could be improved in the following ways:

1) *Emotional support should be available in all clinics*

The high uptake of participation in emotional support when offered suggests that patients thought that attendance would be beneficial, and that they desired support. The majority of non-attending parents wished that they have received support, but sessions were not available. The substantial proportion of Brazilian intended parents who do not attend these sessions raises concerns about whether or not parents have fully considered the implications of gamete donation treatment.

2) *Parents should be encouraged to attend sessions*

At some Brazilian clinics, as few as 10% of patients attend support sessions, therefore encouragement to attend is inconsistent across clinics. In light of this, it is recommended that all clinics encourage attendance by ensuring that patients are aware that support is available and are informed of the benefits of attendance. Further, patients should be made aware of the accessibility of, and benefits of attending support sessions at all stages of treatment and beyond.

3) *Emotional support should be more comprehensive*

For the majority of parents, conversations regarding disclosure did not occur. It is therefore unsurprising that non-disclosers were generally uncertain about

their disclosure plans, and unaware of the benefits of disclosure. Further, parents did not receive advice about how they could talk to their children about their origins. It is therefore foreseeable that non-disclosers were unsure how to initiate donor conception revelation. Patients seeking treatment with donated gametes should routinely be encouraged to explore the pros and cons of disclosure to help them to make a fully informed decision. All patients should also have an opportunity to discuss how they could disclose to their child, and should be shown books and information about how they could disclose. Overall, if all professionals incorporated an exploration of these aspects into their sessions, then parents would have the information to determine how they would like to proceed, and would better prepared for the disclosure process.

4) *The availability of post-treatment support should be reinforced*

Additional support is available in most clinics, but there was no evidence that parents were accessing any extra support, perhaps indicating that they are unaware of its existence. The availablity of post-treatment support should be made visable to all patients.

5) *Professionals providing emotional support should attend a training session*

Professionals would benefit from attending a training programme to provide all patients with a thorough and consistent approach. This is recommended because Brazilian professionals varied extensively in the degree that they engaged with patients. Professionals were reactive to discussing issues relating to the process of, and implications of disclosure, rather than proactively initiating discussions themselves. However, some intended parents might need a more hands-on approach.

6) *Brazilian legislation should consider the best interests of donor-conceived children*

Finally, and most crucially, current Brazilian practice promotes non-disclosure, which was evident by the large number of non-disclosers in Study III. In line with other national laws, the Federal Medical Council in Brazil should consider whether or not they think that it is in the best interests of donor-conceived children to learn details about their conception. The creation of a legal

framework would help infertility professionals to deliver more adequate patient support.

9.7 AREAS OF FUTURE RESEARCH IN BRAZIL

Native Portuguese speakers could conduct interviews with Brazilian parents who have received gamete donation treatment. This qualitative approach would allow more detailed data to be extracted to give a fuller picture of parents' experiences. Native Portuguese speakers could also conduct interviews with professionals providing emotional support to extract rich data from their experiences of working with patients seeking donor conception, and findings from this could help to inform Brazilian legislation geared towards improving the current status of support. Finally, it is clear that donor conception in Brazil is a subject shied away from in both research and society. An overall increased awareness of donor conception through the conducting of research and its outcomes would help to 'normalise' donor conception.

OVERALL CONCLUSIONS

Disclosure goes above and beyond conversations that parents usually have with their children about how they came into this world. As such, parents are implementing strategies about how to manage this and facilitate their children's understanding. Findings highlight the complex nature of sharing information with children, and identify that their needs are not always met by the current support available. If it is indeed the intention of UK legislation to encourage disclosure, then simply introducing identifiable donors, and providing parents with an option to attend counselling is not enough. Overall, more comprehensive support is needed in both Brazil and the UK to help parents to navigate their way through the process of disclosure.

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APPENDICES

APPENDIX 1 - ETHICAL APPROVAL

APPENDIX 2 STUDY I - PARTICIPANT INFORMATION LEAFLET (ED/DD)

APPENDIX 3 STUDY I - DCN RECRUITMENT EMAIL

APPENDIX 4 STUDY I - ADOPTION RECRUITMENT EMAIL

APPENDIX 5 STUDY I - PARTICIPANT INFORMATION SHEET ADOPTION

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APPENDIX 11 STUDY III - EMAIL FROM CLINICS TO PARENTS

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APPENDIX 13 STUDY IV - PROFESSIONALS RECRUITMENT EMAIL

APPENDIX 14 STUDY IV - PROFESSIONALS SURVEY

APPENDIX 1

7th March 2014

Warwick Medical School

PRIVATE
Nicola Doherty
Psychology
University of Warwick
Coventry
CV4 7AL

Dear Nicola,

Study Title and BSREC Reference: *An exploration of what parents say to their children when they do not share a genetic relationship* REGO-2013-576 AM01

Thank you for submitting a substantial amendment to the above-named project to the University of Warwick Biomedical and Scientific Research Ethics Committee, for Chair's Approval.

I am pleased to confirm that the changes that you wish to make to this study have been reviewed by one BSREC member and have been approved. This means that you may continue with your study.

I take this opportunity to wish you success with the study and to remind you any further substantial amendments require approval from the committee before they can be made. Please keep a copy of the signed version of this letter with your study documentation.

Yours sincerely,

P.P. Graham Hewitt

Dr David Davies
Chair
Biomedical and Scientific
Research Ethics Sub-Committee

Biomedical and Scientific Research Ethics Subcommittee
A010 Medical School Building
Warwick Medical School,
Coventry, CV4 7AL.
Tel: 02476-151875
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APPENDIX 2

THE UNIVERSITY OF WARWICK

PARTICIPANT INFORMATION LEAFLET

Study Title: An exploration of what parents say to their children when they do not share a genetic relationship

Investigator(s): **Nicola Doherty and Dr Fiona MacCallum**

Introduction

You are invited to take part in a Research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully. Talk to others about the study if you wish.

(Part 1 tells you the purpose of the study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study)

Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

PART 1

What is the study about?

We are interested in finding out more about the experiences of parents who have a child who is genetically unrelated to them, particularly what parents say to their children about their origins and what support parents have received regarding this. It is hoped that findings will be beneficial to other families in a similar position.

Do I have to take part?

It is entirely up to you to decide. We will describe the study and go through this information sheet, which we will give you to keep. If you choose to participate, we will ask you to sign a consent form to confirm that you have agreed to take part. You will be free to withdraw at any time, without giving a reason and this will not affect you or your circumstances in any way.

What will happen to me if I take part?

Once you have decided to participate, a time will be arranged for the researcher to visit you in your home, or at a location of your choice, for the research to be undertaken.

Your participation will involve a one to one interview with the researcher which will cover three main topics:

1) Information that you may have told your child about their donor conception
2) Information that you know about your child's donors
3) Your experiences of the support that you received.

You will also be asked to complete a questionnaire about how issues are discussed in your family.

It is anticipated that this will take no longer than two hours to complete. After your participation, you will not receive any further contact from the researcher unless you wish to receive a copy of the research summary report after the study has ended, or wish for your contact details to remain on file for potential participation in possible future research. Both of these options will be discussed with you prior to your participation.

What are the possible disadvantages, side effects, risks, and/or discomforts of taking part in this study?

During the interview you will be asked questions about your experiences of adoption and your thoughts and feelings about talking about adoption with your child, family and friends. If you feel uncomfortable at any stage during the research, you may ask for a particular question to be skipped, or for the interview to be ceased.

What are the possible benefits of taking part in this study?

This research will provide you with an opportunity to contribute to research in this area of parenting. It will also provide you with an opportunity to reflect on your own family circumstances, which you may find beneficial. Your knowledge and experience might benefit future parents who have, or are thinking of adopting a child.

Expenses and payments

You will not receive any payments for participating in this research, however if you decide for the research to take place in a location other than your home, then reasonable travel expenses will be reimbursed.

What will happen when the study ends?

Once data has been collected from all participants, data analysis will be undertaken. The findings of this research will be reported as part of the researcher's PhD thesis. Data will not be reported in any way that would allow identification of any participants.

Will my taking part be kept confidential?

Yes. We will follow strict ethical and legal practice and all information about you will be handled in confidence. Further details are included in Part 2.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm that you might suffer will be addressed. Detailed information is given in Part 2.

This concludes Part 1.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

PART 2

Who is organising and funding the study?

This research is funded by the Department of Psychology at the University of Warwick and will form part of the researcher's PhD project.

What will happen if I don't want to carry on being part of the study?

Participation in this study is entirely voluntary. Refusal to participate will not affect you in any way. If you decide to take part in the study, you will need to sign a consent form, which states that you have given your consent to participate.

If you agree to participate, you may nevertheless withdraw from the study at any time without affecting you in any way.

You have the right to withdraw from the study completely and decline any further contact by study staff after you withdraw.

What if there is a problem?

This study is covered by the University of Warwick's insurance and indemnity cover. If you have an issue, please contact Jo Horsburgh (details below).

Who should I contact if I wish to make a complaint?

Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed. Please address your complaint to the person below, who is a Senior University of Warwick official entirely independent of this study:

Jo Horsburgh
Deputy Registrar
Deputy Registrar's Office
University of Warwick
Coventry, UK, CV4 8UW.
T: +00 44 (0) 2476 522 713 E: J.Horsburgh@warwick.ac.uk

Will my taking part be kept confidential?

Yes, all data will be kept confidential. All personal details including names, contact details and addresses will be kept in a password protected file on the researcher's computer separate from all other data. A paper copy of personal details will be in a

locked cabinet in the researcher's office separate from all other data.

All of your responses during the research will not contain any personal information and will instead be labelled with a unique code. Only the researcher and the supervisor will have access to the file that contains your personal details and unique code. This will be stored in a password protected file separate from all other data.

When reporting findings of this research, we may include brief quotes from your interview, but will not include any personal details.

All information from your participation will remain confidential except where you might disclose issues concerning your own, or others, health, safety or well-being, in which case I may need to pass this information onto other professionals in accordance with the BPS Guidelines.

What will happen to the results of the study?

Results of this research will be written up and will form part of the researcher's PhD thesis. Papers may be submitted to journals for publication and may be presented at conferences.

Who has reviewed the study?

This study has been reviewed and given favourable opinion by the University of Warwick's Biomedical and Scientific Research Ethics Committee (BSREC): REGO-2013-576

What if I want more information about the study?

If you have any questions about any aspect of the study or your participation in it not answered by this participant information leaflet, please contact:

Nicola Doherty
Email: nicola.doherty@warwick.ac.uk
Phone: 07805 163 184

Thank you for taking the time to read this participant information leaflet.

APPENDIX 3

STUDY I - DCN RECRUITMENT EMAIL

Have you created a family by embryo donation or double donation?

Is your child aged up to nine years old?

If so, the Department of Psychology at the University of Warwick are looking to meet volunteers to discuss your experiences of embryo donation / double donation with you.

What does participation involve?
Participation will take approximately one hour and will consist of a one to one interview and answering some questions about how you communicate within your family. This can take place in your home, or at your choice of location, at a time convenient for you. We will follow strict ethical and legal practice and all information about you will be handled in confidence.

What are the benefits of participating?
Your contribution will be invaluable to a relatively unexplored area of research. Your knowledge and experience may be beneficial to other couples who have, or are planning on creating a family by embryo donation / double donation.

How can I find out further information?
If you are interested and would like further information, please contact the researcher Nicola Doherty on Nicola.Doherty@warwick.ac.uk or 07805 163 184.

Thank you,

Nicola

APPENDIX 4

STUDY I – ADOPTION RECRUITMENT EMAIL

Good Afternoon

Adoption Focus has been asked to help recruit adoptive parents for a research project to be conducted by the University of Warwick. This research is independent of Adoption Focus and participation is entirely at your discretion. More details are below and a leaflet is attached.

Who is conducting the research?
The Department of Psychology at the University of Warwick are looking to meet parents to discuss your experiences of adoption with you. The research is being conducted under the supervision of Dr Fiona MacCallum, who is known for her important research into non-genetically related families.

What does participation involve?
Participation will take no longer than two hours and will consist of a one to one interview and answering some questions about how you communicate within your family. This can take place in your home, or at your choice of location, at a time convenient for you. Strict ethical and legal practice will be maintained and all information about you will be handled in confidence.

What are the benefits of participating?
Your contribution will be invaluable and your knowledge and experiences may be beneficial to other parents in a similar position.

How can I find out further information?
If you may be interested and would like further information, please contact the researcher, Nicola Doherty who will give you more information about the study. Nicola can be contacted by email at Nicola.Doherty@warwick.ac.uk or by telephone on 07805 163 184.

APPENDIX 5

THE UNIVERSITY OF WARWICK

PARTICIPANT INFORMATION LEAFLET

Study Title: An exploration of what parents say to their children when they do not share a genetic relationship

Investigator(s): **Nicola Doherty and Dr Fiona MacCallum**

Introduction

You are invited to take part in a Research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully. Talk to others about the study if you wish.

(Part 1 tells you the purpose of the study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study)

Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

PART 1

What is the study about?

We are interested in finding out more about the experiences of parents who have a child who is genetically unrelated to them, particularly what parents say to their children about their origins and what support parents have received regarding this. It is hoped that findings will be beneficial to other families in a similar position.

Do I have to take part?

It is entirely up to you to decide. We will describe the study and go through this information sheet, which we will give you to keep. If you choose to participate, we will ask you to sign a consent form to confirm that you have agreed to take part. You will be free to withdraw at any time, without giving a reason and this will not affect you or your circumstances in any way.

What will happen to me if I take part?

Once you have decided to participate, a time will be arranged for the researcher to visit you in your home, or at a location of your choice, for the research to be undertaken.

Your participation will involve a one to one interview with the researcher which will cover three main topics:

1) Information that you may have told your child about their origins
2) Information that you know about your child's birth parents
3) Your experiences of the support that you received.

You will also be asked to complete a questionnaire about how issues are discussed in your family.

It is anticipated that this will take no longer than two hours to complete. After your participation, you will not receive any further contact from the researcher unless you wish to receive a copy of the research summary report after the study has ended, or wish for your contact details to remain on file for potential participation in possible future research. Both of these options will be discussed with you prior to your participation.

What are the possible disadvantages, side effects, risks, and/or discomforts of taking part in this study?

During the interview you will be asked questions about your experiences of adoption and your thoughts and feelings about talking about adoption with your child, family and friends. If you feel uncomfortable at any stage during the research, you may ask for a particular question to be skipped, or for the interview to be ceased.

What are the possible benefits of taking part in this study?

This research will provide you with an opportunity to contribute to research in this area of parenting. It will also provide you with an opportunity to reflect on your own family circumstances, which you may find beneficial. Your knowledge and experience might benefit future parents who have, or are thinking of adopting a child.

Expenses and payments

You will not receive any payments for participating in this research, however if you decide for the research to take place in a location other than your home, then reasonable travel expenses will be reimbursed.

What will happen when the study ends?

Once data has been collected from all participants, data analysis will be undertaken. The findings of this research will be reported as part of the researcher's PhD thesis. Data will not be reported in any way that would allow identification of any participants.

Will my taking part be kept confidential?

Yes. We will follow strict ethical and legal practice and all information about you will be handled in confidence. Further details are included in Part 2.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm that you might suffer will be addressed. Detailed information is given in Part 2.

This concludes Part 1.
If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

PART 2

Who is organising and funding the study?

This research is funded by the Department of Psychology at the University of Warwick and will form part of the researcher's PhD project.

What will happen if I don't want to carry on being part of the study?

Participation in this study is entirely voluntary. Refusal to participate will not affect you in any way. If you decide to take part in the study, you will need to sign a consent form, which states that you have given your consent to participate.

If you agree to participate, you may nevertheless withdraw from the study at any time without affecting you in any way.

You have the right to withdraw from the study completely and decline any further contact by study staff after you withdraw.

What if there is a problem?

This study is covered by the University of Warwick's insurance and indemnity cover. If you have an issue, please contact Jo Horsburgh (details below).

Who should I contact if I wish to make a complaint?

Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed. Please address your complaint to the person below, who is a Senior University of Warwick official entirely independent of this study:

Jo Horsburgh
Deputy Registrar
Deputy Registrar's Office
University of Warwick
Coventry, UK, CV4 8UW.
T: +00 44 (0) 2476 522 713 E: J.Horsburgh@warwick.ac.uk

Will my taking part be kept confidential?

Yes, all data will be kept confidential. All personal details including names, contact details and addresses will be kept in a password protected file on the researcher's computer separate from all other data. A paper copy of personal details will be in a locked cabinet in the researcher's office separate from all other data.

All of your responses during the research will not contain any personal information

and will instead be labelled with a unique code. Only the researcher and the supervisor will have access to the file that contains your personal details and unique code. This will be stored in a password protected file separate from all other data.

When reporting findings of this research, we may include brief quotes from your interview, but will not include any personal details.

All information from your participation will remain confidential except where you might disclose issues concerning your own, or others, health, safety or well-being, in which case I may need to pass this information onto other professionals in accordance with the BPS Guidelines.

What will happen to the results of the study?

Results of this research will be written up and will form part of the researcher's PhD thesis. Papers may be submitted to journals for publication and may be presented at conferences.

Who has reviewed the study?

This study has been reviewed and given favourable opinion by the University of Warwick's Biomedical and Scientific Research Ethics Committee (BSREC): REGO-2013-576

What if I want more information about the study?

If you have any questions about any aspect of the study or your participation in it not answered by this participant information leaflet, please contact:

Nicola Doherty
Email: nicola.doherty@warwick.ac.uk
Phone: 07805 163 184

Thank you for taking the time to read this participant information leaflet.

APPENDIX 6

STUDY I – CONSENT FORM

CONSENT FORM

(Biomedical and Scientific Research Ethics Committee) Study Number:

Patient Identification Number for this study:

Title of Project: An exploration of what parents say to their children when they do not share a genetic relationship

Name of Researchers: Nicola Doherty and Dr Fiona MacCallum

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated 09/04/2014 (version **1** for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. ☐
3. I agree that my interview can be audio recorded and I understand that all my responses will be kept confidential. ☐
4. I agree to take part in the above study. ☐
5. I would like a summary report of the study to be sent to me when the research is completed: YES/NO (delete as appropriate) ☐
6. I am happy for my personal details to remain on file after the study has finished for possible contact to participate in any future studies: YES/NO (please delete as appropriate) ☐

Name of Participant	Date	Signature
Nicola Doherty		
Name of person taking consent	Date	Signature

APPENDIX 7

STUDY I - INTERVIEW

ADOPTION

ID NUMBER: _____

DATE OF INTERVIEW: _____

HOUSEHOLD STRUCTURE

I'd like to begin by getting a few details about your family and who lives here with you.

(Obtain number of adults, number of children and relationships)

Name	Sex	D.O.B.	Age	Relationship/ Parentage	Method of conception

(PROBE: Were any of your children conceived by assisted reproduction, such as IVF, donor insemination or egg donation?

Are any of your children adopted or fostered? If yes, how old was the child when you became legal guardian?

Do either of you have any children who don't live with you?

Do you mind telling me how old you are? How old is your partner? (get d.o.b)

PARENTAL DESCRIPTION OF THE CHILD

I'd like to go on now and talk about your experiences of adoption, but first to help me get a picture of <child> in my mind I would like to ask you a few questions about what <child> is like

What does <child> look like?

What is <child's> personality like?

What is <child> is like to live with?

EXPERIENCE OF ADOPTION

Now I'd like to ask you about your experiences of adoption

When did you first decide you would like to have a child? **PROBE**

When did you first discover that you were having difficulties? **(if applicable)**

Did you find out what the problem was? **(When)**

Did you try fertility treatment?

If YES, PROBE

What treatment?

How many treatment sessions?

What made you decide to stop treatment?

Experience of adoption (cont.)

IF NO:

Did you consider IVF/embryo donation as an option for you **(PROBE)**

What made you decide against trying treatment?

ASK ALL

Now I would like to talk more specifically about your decision to adopt

What first caused you to consider adoption as an option for you?

Who initially suggested adoption as an option?

Did you have much previous knowledge of adoption donation before it was suggested?

Was it a joint decision to adopt?

Was one of you keener than the other at first?

What about by the time <child> was placed with you?

How did you feel when you were approved for adoption?

How long after did it take before <child> was placed with you?

How did you feel about having <child> home in the first few weeks after he/she was placed with you?
And how about now, how do you feel?

Where was <child> before he/she was placed with you? **PROBE** *(when taken off birth family, from birth?*

Do you know why <child> was placed for adoption?

TELLING OTHERS ABOUT ADOPTION

I'd like to turn now to how you feel about telling others about <child's> adoption

Before you adopted <child> did you and your partner discuss what you were going to tell people?

Did you agree?

Do you still agree about what to tell now that you have <child>?

TELLING CHILD

Is <child> aware that they are adopted?

IF NO:

Do you plan to tell him/her?

If yes…….

When do you think you will tell him/her?

What do you plan to tell him/her? **PROBE**

If no…..

What made you decide not to tell him/her? **PROBE**

Do you think you'll ever change your mind about telling him/her?

Are you and <partner> in agreement about not telling <child> PROBE
TELLING CHILD (if told)

IF YES:

Was child aware about their adoption before they were placed with you?

When was <child> told?

What made you decide to tell him/her?

What have you said to child? **PROBE**

Were you and <partner> in agreement about what to tell <child>?

How much does <child> understand?

Do you initiate discussions with your child about their adoption?

How often?

What kind of things do you say?

Does <partner> initiate discussions with your child about their adoption?

How often?

What kind of things does he/she you say?

Does <child> ask questions about his/her adoption?

How often?

What kind of things do he / she say?

And what are your responses?

Are you comfortable discussing adoption with <child>

Are you happy for <child> to freely discuss their adoption with others?

Do you think that it is <childs> information to share with others or yours?

How do you think you would feel if <child> wanted to contact their birth parents in the future?

What about if they wanted to contact any biological siblings that they may have?

EXPERIENCE OF SERVICES

Now I would like to ask you some questions about your experience of adoption services.

How supportive were adoption services generally?

How much did they involve both you and <partner>?

During your adoption training did they discuss disclosing to your child with you?

What about disclosing details of adoption to your family and friends?

What was their advice? **PROBE**

Did you find these sessions beneficial to you?

IF YES: in which ways

IF NO: why?

Do you think that it would be beneficial to be offered a session after your child has been placed with you so that you have the opportunity to discuss disclosing to your child, if you wish to?

Other than your social worker, are you aware of any other support groups / services that you could access to ask any questions or raise issues that you may have regarding disclosure?

IF YES:
Have you accessed them? Which ones?

APPENDIX 8

STUDY I - INTERVIEW

ED/DD

ID NUMBER: _____

DATE OF INTERVIEW: _____

HOUSEHOLD STRUCTURE

I'd like to begin by getting a few details about your family and who lives here with you.

(Obtain number of adults, number of children and relationships)

Name	Sex	D.O.B.	Age	Relationship/ Parentage	Method of conception

(PROBE: Were any of your children conceived by assisted reproduction, such as IVF, donor insemination or egg donation?

Are any of your children adopted or fostered? If yes, how old was the child when you became legal guardian/carer

Do you have any children who don't live with you?)

Do you mind telling me how old you are? How old is your partner? (get d.o.b)

PARENTAL DESCRIPTION OF THE CHILD

I'd like to go on now and talk about your experiences of embryo donation, but first to help me get a picture of <child> in my mind I would like to ask you a few questions about what <child> is like

What does <child> look like?

What is <child's> personality like?

What is <child> is like to live with?

1. EXPERIENCE OF EMBRYO DONATION/DOUBLE DONATION

Now I'd like to ask you about your experiences of conceiving a child

When did you first decide you would like to have a child? **PROBE**

When did you first discover that you were having difficulties?

Did you find out what the problem was? **(When)**

Did you try alternative fertility treatment initially?

If YES, PROBE

What treatment?

How many treatment sessions?

What made you decide to stop treatment?

Did you consider adoption as an option for you? (**PROBE** how far in the process they got if applicable)

What made you decide against adoption?

ASK ALL

Now I would like to talk more specifically about your ED/DD donation

What first caused you to consider embryo donation as an option for you?

Who initially suggested embryo donation as an option?

Did you have much previous knowledge of ED/DD before it was suggested?

Was it a joint decision to try ED/DD?

Were one of you keener than the other at first?

How about by the time you went for treatment?

Did you conceive first time?

How did you feel when you found out that the ED/DD was a success?

How long after you started treatment was it before you conceived <child>?

How did you feel about having <child> home with you in the first few weeks after birth?

And what about now, how do you feel?

TELLING OTHERS ABOUT CONCEPTION

I'd like to turn now to how you feel about telling others about how <child> was conceived.

Before <child> was born did you and your partner discuss what you were going to tell people?

Did you agree?

Do you still agree about what to tell now that you have <child>?

TELLING CHILD

Is <child> aware of the circumstances of how he/she was conceived?

IF NO:

Do you plan to tell him/her?

If yes…...

When do you think you will tell him/her?

What do you plan to tell him/her? **PROBE**

If no…..

What made you decide not to tell him/her? **PROBE**

Do you think you'll ever change your mind about telling him/her?

Are you and <partner> in agreement about not telling <child> **PROBE**

TELLING CHILD (if told)

IF YES:

When did you tell <child>?

What made you decide to tell him/her?

What have you said to child? **PROBE**

Were you and <partner> in agreement about what to tell <child>?

How much does <child> understand?

Do you initiate discussions with your child about their conception?

How often?

What kind of things do you say?

Does <partner> initiate discussions with your child about their conception?

How often?

What kind of things do you say?

TELLING CHILD (if told continued)

Does <child> ask questions about his/her conception?

How often?

What kind of things do he / she say?

And what are your responses?

Are you comfortable discussing how your child was conceived with <child>

Are you happy for <child> to freely discuss their conception with others?

Do you think that it is <child's> information to share with others or yours?

As you'll be aware, <child> will have access to identifying information about the donor(s) when they reach 18. How do you think you would feel if <child> wanted to contact their donors in the future?

What about if they wanted to contact any biological siblings that they may have?

TELLING CHILD (ASK ALL)

What are your thoughts on the removal of anonymity of donors?

How would you feel if the law made it compulsory for parents to tell children?

Do you think that having identifiable donors has had any impact in your decision of whether or not to tell your child about their conception?

Do you think that it's important for children to know details surrounding their conception?

Do you have any worries for the future regarding your decision of telling / not telling child the circumstances surrounding this conception?

EXPERIENCE OF CLINIC

Now I would like to ask you some questions about your experience of your clinic

How supportive were the clinic generally?

How much did they involve both you and <partner>?

Did you attend any counselling sessions that were offered to you?

IF NO: Any particular reason why not?

IF YES:

Did you attend these sessions together?

Did they discuss disclosing details of conception to your child with you during these sessions?

What about disclosing details of conception to your family and friends?

Did you feel that the clinic spoke to you about this with a particular slant? **PROBE** slant

What was their advice? **PROBE**

Did you find these sessions beneficial to you?

IF YES: in which ways

IF NO: why?

Do you think that it would be beneficial to be offered a counselling session after your child has been born so that you have the opportunity to discuss disclosing to your child, if you wish to?

Other than your clinic are you aware of any other support groups / services that you could access to ask any questions or raise issues that you may have regarding disclosure?

IF YES:

Have you accessed them?

Which ones?

APPENDIX 9

STUDY II - EMAIL TO CLINICS

Subject line: Counselling support for patients seeking embryo or double donation treatment

Dear <insert name of counsellor and clinic>

I am a PhD student at the University of Warwick researching the level of support and information that fertility clinics provide prospective parents when they seek treatment with donated embryos / double donation. You have been asked to participate in this research because your input would be invaluable to further our understanding of this relatively unexplored area of research.

To explore this, I have created a brief survey which I would be incredibly grateful if you would be able to take the time to complete. All responses are anonymous and there will be no way of linking the clinic with your answers. It should only take around 10-15 minutes of your time to complete the survey.

To find out further information and to participate please click on the following link:

https://www.surveymonkey.com/s/W8P5LHY

If you have any questions, please do not hesitate to contact me by email at Nicola.doherty@warwick.ac.uk or via the details below.

Thank you for your time,

Nicola Doherty

University of Warwick
Department of Psychology
Coventry
CV4 7AL

07805 163 184
Nicola.doherty@warwick.ac.uk

APPENDIX 10

Support and information provided by clinics for intended parents receiving treatment with embryo donation / double donation

When completing the survey please think specifically about your experiences of working with intended parents who are planning a child by embryo donation or double donation.

If you haven't worked with intended parents who have used embryo donation or double donation, please complete this survey thinking of what you would do in this circumstance.

Thank you

1. Please give your date of birth and the length of time you have been in the current role. These responses will only be used in the event of your wishing to remove your data from the study at a later date

What is your Date of Birth (DD/MM)

How many years have you been working in your counselling role for?

*** 6. Do you insist that intended parents receive counselling prior to treatment with donated embryos? (Please select ONE)**

- ○ Yes
- ○ No
- ○ Don't insist, but strongly recommend

7. How many counselling sessions do you offer for free? (Please select ONE)

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5 or more

Other (please specify)

8. Can intended parents pay for additional counselling if they require more sessions? (Please select ONE)

- ○ Yes
- ○ No

Other (please specify)

9. What do you estimate the counselling uptake to be?

Percentage .....

10. What is the average number of counselling sessions attended by intended parents?

Please enter number of sessions

11. When can intended parents access counselling for free? (Please select ALL that apply)

- [ ] Before treatment
- [ ] During treatment
- [ ] During pregnancy
- [ ] After pregnancy

Other (please specify)

12. When are counselling sessions usually attended? (Please select ONE)

- ( ) Before treatment
- ( ) During treatment
- ( ) During pregnancy
- ( ) After pregnancy

13. How frequently do you cover the following areas with intended parents prior to treatment with donated embryos? (Please select ALL that apply)

	Always	Usually	Only if I think it's an issue	Only if parents initiate discussion	Never
Assess implications of treatment	☐	☐	☐	☐	☐
Discuss about deciding on donors	☐	☐	☐	☐	☐
Explore meanings that both partners attribute to donors	☐	☐	☐	☐	☐
Explore motivation for embryo donation	☐	☐	☐	☐	☐
Discuss grieving inability to have a biologically related child	☐	☐	☐	☐	☐
Explore implications of differences and similarities between their feelings and those of their partner	☐	☐	☐	☐	☐
Explore impact of embryo donation on wider family and social relationships	☐	☐	☐	☐	☐
Discuss the possibility that child will have full genetically linked siblings raised in a different family	☐	☐	☐	☐	☐

Discontinuity of traditional biological and genetic connectedness in parent-child relationship	☐	☐	☐	☐	☐
Explore questions and feelings that might arise in further within child, self and partner	☐	☐	☐	☐	☐

Other (please specify)

* **14. During counselling sessions do you discuss adoption? (Please select ALL that apply)**

- ☐ Discuss whether parents have considered adoption
- ☐ Discuss pros and cons of adoption
- ☐ Discuss why embryo donation is preferred over adoption
- ☐ Only discuss adoption if intended parents initiate discussion

* **15. What is your own personal view on parents disclosing to their child? (Please select ONE)**

- ○ Always best to disclose
- ○ Sometimes best to disclose
- ○ Neutral
- ○ Sometimes best not to disclose
- ○ Always best not to disclose
- ○ Rather not say

* **16. Thinking about disclosure, when do you explore these areas? (Please select ALL that apply)**

	Always	Usually	Only if I think it's an issue	Only if parents initiate discussion	Never
Discuss pros and cons of disclosure	☐	☐	☐	☐	☐
Explore potential implications of non-disclosure	☐	☐	☐	☐	☐
Explore potential implications of disclosure	☐	☐	☐	☐	☐
Discuss future possible scenarios if decide to disclose	☐	☐	☐	☐	☐
Discuss future possible scenarios if decide not to disclose	☐	☐	☐	☐	☐

Explore disclosing to child	☐	☐	☐	☐	☐
Explore disclosing to family	☐	☐	☐	☐	☐
Explore disclosing to friends	☐	☐	☐	☐	☐
Discuss how to respond to questions that their child might ask	☐	☐	☐	☐	☐
Discuss age appropriate ways of discussing embryo donation with their child	☐	☐	☐	☐	☐
Consider that their child may want to contact biological parents in the future	☐	☐	☐	☐	☐
Consider that their child may never have contact biological parents in the future	☐	☐	☐	☐	☐
implications of differences and similarities between their feelings surrounding disclosure and those of their partner	☐	☐	☐	☐	☐

17. Do you insist on both partners (if applicable) being present for counselling? (Please select ONE)

- ○ Yes
- ○ No

18. How do you counsel intended parents receiving treatment with donated embryos? (Please select ONE)

- ○ Both parents together
- ○ separately
- ○ Both together and separately

19. After pregnancy is achieved as a result of emrbyo donation, is any further support available to parents? (Please select ALL that apply)

- ☐ Direct parents to support groups
- ☐ Provide parents with additional books/leaflets to take away
- ☐ Parents can receive additional free counselling
- ☐ Parents can pay for additional counselling
- ☐ No further support

Other (please specify)

20. This is the end of the questionnaire. If you have any additional comments please write them below. Thank you for your time.

APPENDIX 11

STUDY III - EMAIL FROM CLINICS TO PARENTS

Dear Sir / Madam,

We are investigating the experiences of parents who have set up their families through donor conception and would like to invite you to participate anonymously from our online survey.

Who is conducting the research?
This research is being conducted by Professor Andrea Seixas Magalhães, from the Department of Psychology of PUC-Rio and PhD student Nicola Doherty from the University of Warwick (UK).

Why is this research being conducted?
There is little research in Brazil investigating experiences of parents who constituted family through donation of gametes. Therefore, your contribution will be very valuable for this area of research. Their knowledge and experience can bring benefits to other parents who have or are planning to have children by donating gametes.

What does participation involve?
You can participate by responding to an anonymous online questionnaire about your gametes donation treatment experience. This questionnaire should take approximately 20 minutes to complete. We encourage both parents, when applicable, to complete the questionnaire separately. It is important to obtain data from the experience of fathers and mothers.

What happens to data?
The results will be analyzed, discussed and will form part of Nicola Doherty's doctoral thesis. In addition, they will be published in the form of articles in scientific journals and presented at conferences.

How can I participate?
If you wish to participate, access the link that will lead you to the anonymous questionnaire.

Https://www.surveymonkey.com/s/TXSDKJH

If you would like further information, please contact the research team.

Profa. Andrea Seixas Magalhães Email: andreasm@puc-rio.br (21) 99693-0442
Nicola Doherty Email: nicola.doherty@warwick.ac.uk (21) 98284-7066

Pontifical Catholic University of Rio de Janeiro (21) 3527-1185

Thank you!

APPENDIX 12

Experiences of parents who have created a child by donor conception

Thank you for choosing to participate in this survey.

This survey is designed to explore the experiences of parents who have created a family using donor conception. It is hoped that your participation in this survey will better inform others who have, or are planning on, creating a family by donor conception. Your responses are anonymous.

We're interested in as much information as you feel comfortable providing, so if you prefer not to answer a particular question, feel free to move onto the next. There is a mixture of multiple choice and open questions, so please chose the most applicable option, or provide details as appropriate.

If you have more than one child conceived through donor conception, please complete this survey based on your oldest child. Where applicable, it would be beneficial if both parents could complete this survey separately.

If you would like to provide any additional information there is a comments box at the end of the survey. Alternatively, you may wish to contact me via email on: nicola.doherty@warwick.ac.uk.

If you are happy to complete the survey then please continue below. If at any time you decide not to continue with the survey then please exit the survey and your details will not be saved.

Thank you for your time,

Nicola Doherty

Experiences of parents who have created a child by donor conception

1. What is your gender?

- ◯ Female
- ◯ Male
- ◯ Do not wish to diclose

Other (please specify)

2. How old are you?

3. What is your child's age? (if you have more than one child conceived donation treatment please base your responses to this survey on your oldest child)

4. Please could you select which treatment you used to conceive your child

- ◯ Sperm donation
- ◯ Egg donation
- ◯ Embryo donation
- ◯ Double donation using separate donors

Other (please specify)

5. Did you receive this treatment as part of a couple, or as a single person?

- ◯ As part of a couple
- ◯ As a single person

6. What first caused you to consider donation treatment as an option for you? (provide as much detail as you like)

TALKING TO YOUR CHILD ABOUT THEIR CONCEPTION

7. Is your child aware of the circumstances of how he or she was conceived?

- ◯ KNOWS SOMETHING
- ◯ YES
- ◯ NO

Other (please specify)

DO YOU PLAN TO TELL YOUR CHILD IN THE FUTURE

8. Do you plan to tell your child in the future?

- ◯ YES
- ◯ NO
- ◯ UNSURE

Experiences of parents who have created a child by donor conception

IF PLAN TO TELL CHILD IN THE FUTURE

9. What makes you in favour of telling your child in the future?

10. Why have you decided to tell your child in the future rather than now?

11. When do you think you will tell your child?

12. Why do you think you would chose that time?

13. Thinking about the future, what do you think that you will say to your child when you tell them about their conception?

IF YOU ARE UNSURE ABOUT TELLING YOUR CHIILD

14. Why do you think you are unsure about telling your child? (provide as much information as you like)

15. Is there anything in particular that could make you more in favour of telling your child?

16. Is there anything in particular that could make you more against telling your child?

Experiences of parents who have created a child by donor conception

IF YOU HAVE DECIDED NOT TO TELL YOUR CHILD

17. Why have you have decided not to tell your child? (provide as much detail as you like)

18. Is there anything in particular that could change your feeling on this issue?

Experiences of parents who have created a child by donor conception

CHILD KNOWS SOMETHING

19. When did you first talk to your child about their conception?

20. Exactly what have you said to your child about their conception?

21. Why did you decide to tell your child?

22. What do you think your child understands?

23. Do you think that you will add any more details to what you have already told your child?

24. How often do you start a conversation with your child about their conception?

- ◯ Daily
- ◯ Weekly
- ◯ At least once a month
- ◯ A few times a year
- ◯ Once or twice a year
- ◯ Never

Other (please specify)

25. What kind of things do you say?

Experiences of parents who have created a child by donor conception

26. Is there anything in particular that would cause you to start a conversation with your child about their conception?

27. How often does your child ask questions, or talk about his/her conception?

- ○ Daily
- ○ Weekly
- ○ At least once a month
- ○ Once or twice a year
- ○ Never

28. What kind of things does your child say?

29. And what are your responses?

30. How do you feel about talking to your child about their conception? (please elaborate on your answer in the box provided below)

- ☐ Not comfortable
- ☐ Somewhat comfortable
- ☐ Very comfortable

Please elaborate

31. Are you happy for your child to freely discuss their conception with others?

- ○ Not happy for child to discuss with others
- ○ Happy for child to discuss some details with others
- ○ Happy for child to discuss all details with others

Other (please specify)

Experiences of parents who have created a child by donor conception

32. Whose information do you think that it is to share with others? (please elaborate on your answer below)

- ◯ My information
- ◯ Child's information
- ◯ Both

Please elaborate

33. What about in the future, whose information do you think it will be to share? (please elaborate on your answer below)

- ◯ Mine
- ◯ Child's
- ◯ Both

Please elaborate

34. Are you aware if there are any other children conceived from the same donors that you used?

- ◯ Yes there are other children
- ◯ No there aren't any other children
- ◯ I am unsure

35. Is your child aware that there are other children with whom they share a genetic relationship?

- ◯ Yes
- ◯ No
- ◯ Not applicable

36. How do you think you would feel if your child wanted to contact any children who they may share a genetic relationship with in the future?

37. How do you think you would feel if your child wanted to contact their donors in the future?

Experiences of parents who have created a child by donor conception

TELLING CHILD

38. When did you tell your child?

39. Exactly what have you said to your child about their conception?

40. Why did you decide to tell your child?

41. What do you think your child understands?

42. Do you think that you will add any more details to what you have already told your child?

43. How often do you start a conversation with your child about their conception?

- ◯ Daily
- ◯ Weekly
- ◯ At least once a month
- ◯ A few times a year
- ◯ Once or twice a year
- ◯ Never

Other (please specify)

44. What kind of things do you say?

Experiences of parents who have created a child by donor conception

45. Is there anything in particiular that would cause you to start a conversation with your child about their conception?

46. How often does your child ask questions, or talk about his/her conception?

- ◯ Daily
- ◯ Weekly
- ◯ At least once a month
- ◯ Once or twice a year
- ◯ Never

47. What kind of things does your child say?

48. And what are your responses?

49. How do you feel about talking to your child about their conception? (please elaborate on your answer in the box provided below)

- ◯ Not comfortable
- ◯ Somewhat comfortable
- ◯ Very comfortable

Please elaborate

50. Are you happy for your child to freely discuss their conception with others?

- ◯ Not happy for child to discuss with others
- ◯ Happy for child to discuss some details with others
- ◯ Happy for child to discuss all details with others

Other (please specify)

Experiences of parents who have created a child by donor conception

51. Whose information do you think that it is to share with others? (please elaborate on your answer below)

- ◯ My information
- ◯ Child's information
- ◯ Both

Please elaborate

52. What about in the future, whose information do you think it will be to share? (please elaborate on your answer below)

- ◯ Mine
- ◯ Child's
- ◯ Both

Please elaborate

53. Are you aware if there are any other children conceived from the same donors that you used?

- ◯ Yes there are other children
- ◯ No there aren't any other children
- ◯ I am unsure

54. Is your child aware that there are other children with whom they share a genetic relationship?

- ◯ Yes
- ◯ No
- ◯ Not applicable

55. How do you think you would feel if your child wanted to contact any children who they may share a genetic relationship with in the future?

56. How do you think you would feel if your child wanted to contact their donors in the future?

Experiences of parents who have created a child by donor conception

COUNSELLING

57. Did you attend fertility counselling?

- ◯ Yes
- ◯ No

DIDN'T ATTEND COUNSLLING

58. Why didn't you attend counselling

- [ ] I didn't feel that I needed to
- [ ] I can't remember it being offered

Other (please specify)

Experiences of parents who have created a child by donor conception

DID ATTEND COUNSELLING

59. How many counselling sessions did you attend

- ◯ 1
- ◯ 2
- ◯ 3
- ◯ 4
- ◯ 5 or more

Other (please specify)

60. When did you attend these counselling sessions?

- ☐ Before treatment
- ☐ During treatment
- ☐ After treatment

61. Did you attend these sessions with your partner?

- ◯ Always
- ◯ Never
- ◯ Sometimes
- ◯ Not applicable

62. During these sessions, did you discuss about disclosing donor conception details to your child?

- ◯ Yes
- ◯ No
- ◯ Can't remember

63. If applicable, what advice did the counsellor give to you?

64. Did you find your counselling sessions beneficial

- ◯ Not at all
- ◯ Somewhat
- ◯ Mostly
- ◯ Very

Experiences of parents who have created a child by donor conception

65. If you would like to provide details of how counselling could be improved then please write comments in the box below

Experiences of parents who have created a child by donor conception

FINAL QUESTIONS

66. How would you feel if the law made it compulsory for parents to tell their children about their conception?

67. How important do you think it is for children to know details about their conception?

68. If you could give any advice to other parents planning on having a child by donor conception, what would that advice be?

69. Thank you for completing this survey. If you have any other comments to make, please write them in the comments box below. If you have any questions, please contact the researcher at Nicola.doherty@warwick.ac.uk

APPENDIX 13

STUDY IV – PROFESSIONAL RECRUITMENT EMAIL

I am looking for professionals who have emotional support to complete an online questionnaire about their experience working with patients who wish to start a family through donation of gametes. The questionnaire is anonymous and should take approximately 15 minutes to complete. Your cooperation will be very valuable to us.

Who is conducting this research?
This research is being conducted by Professor Andrea Seixas Magalhães, from the Department of Psychology of PUC-Rio and PhD student Nicola Doherty from the University of Warwick (UK).

Why is this research being conducted?
In Brazil, there is little research investigating experiences of emotional support to parents who plan to start a family through donation of gametes. Therefore, your contribution will be very valuable for this area of research.

What does participation involve?
You can participate by responding to an anonymous online quiz about your work experience with gametes donation. This questionnaire should take approximately 15 minutes to complete.

What happens to data?
The results will be discussed, will be part of the doctoral thesis of Nicola Doherty, will be published in the form of articles in scientific journals and presented at congresses.

How can I participate?
If you wish to participate, access the link that will lead you to the anonymous questionnaire.

Https://www.surveymonkey.com/s/VX7KJMN

If you wish to obtain further information, please contact Profa. Andrea Seixas Magalhães.

Profa. Andrea Seixas Magalhães Email: andreasm@puc-rio.br (21) 98284-7066

Nicola Doherty Email: nicola.doherty@warwick.ac.uk (21) 98284-7066

Pontifical Catholic University of Rio de Janeiro (021) 3527-1185

Thank you!

APPENDIX 14

Support provided by clinics for intended parents receiving treatment with

Thank you for choosing to participate in this survey.

This survey is designed to explore the counselling support available to parents when seeking treatment with donated gametes. Your responses are anonymous.

We're interested in as much information as you feel comfortable providing, so if you prefer not to answer a particular question, feel free to move onto the next. There is a mixture of multiple choice and open questions, so please chose the most applicable option, or provide details as appropriate.

If you would like to provide any additional information there is a comments box at the end of the survey. Alternatively, you may wish to contact me via email on: nicola.doherty@warwick.ac.uk.

If you are happy to complete the survey then please continue below. If at any time you decide not to continue with the survey then please exit the survey and your details will not be saved.

Thank you for your time,

Nicola Doherty

1. Please give your date of birth and the length of time you have been in the current role. These responses will only be used in the event of your wishing to remove your data from the study at a later date.

What is your Date of Birth (DD/MM)

How many years have you been working in your counselling role for?

2. Do you insist that intended parents receive counselling prior to donor conception treatment? (Please select ONE)

- ◯ Yes
- ◯ No
- ◯ Don't insist, but strongly recommend

3. How many counselling sessions do you offer for free? (Please select ONE)

- ◯ 0
- ◯ 1
- ◯ 2
- ◯ 3
- ◯ 4
- ◯ 5 or more

Other (please specify)

Page 1

Support provided by clinics for intended parents receiving treatment with

4. Can intended parents pay for additional counselling if they require more sessions? (Please select ONE)

- ◯ Yes
- ◯ No

Other (please specify)

5. What do you estimate the counselling uptake to be?

Percentage .....

6. What is the average number of counselling sessions attended by intended parents?

Please enter number of sessions

7. When can intended parents access counselling? (Please select ALL that apply)

- ☐ Before treatment
- ☐ During treatment
- ☐ During pregnancy
- ☐ After pregnancy

Other (please specify)

8. When are counselling sessions usually attended? (Please select ONE)

- ◯ Before treatment
- ◯ During treatment
- ◯ During pregnancy
- ◯ After pregnancy

Support provided by clinics for intended parents receiving treatment with

9. How frequently do you cover the following areas with intended parents prior to treatment with donated gametes? (Please select ALL that apply)

	Always	Usually	Only if I think it's an issue	Only if parents initiate discussion	Never
Assess implications of treatment	☐	☐	☐	☐	☐
Discuss about deciding on donors	☐	☐	☐	☐	☐
Explore meanings that both partners attribute to donors	☐	☐	☐	☐	☐
Explore motivation for treatment	☐	☐	☐	☐	☐
Discuss grieving inability to have a biologically related child	☐	☐	☐	☐	☐
Explore implications of differences and similarities between their feelings and those of their partner	☐	☐	☐	☐	☐
Explore impact of treatment on wider family and social relationships	☐	☐	☐	☐	☐
Discuss the possibility that child will have genetically linked siblings raised in a different family	☐	☐	☐	☐	☐
Discontinuity of traditional biological and genetic connectedness in parent-child relationship	☐	☐	☐	☐	☐
Explore questions and feelings that might arise in further within child, self and partner	☐	☐	☐	☐	☐

Other (please specify)

10. During counselling sessions do you discuss adoption? (Please select ALL that apply)

- ☐ Discuss whether parents have considered adoption
- ☐ Discuss pros and cons of adoption
- ☐ Discuss why treatment is preferred over adoption
- ☐ Only discuss adoption if intended parents initiate discussion

Support provided by clinics for intended parents receiving treatment with

11. What is your own personal view on parents disclosing to their child? (Please select ONE)

- ◯ Always best to disclose
- ◯ Sometimes best to disclose
- ◯ Neutral
- ◯ Sometimes best not to disclose
- ◯ Always best not to disclose
- ◯ Rather not say

12. Thinking about disclosure, when do you explore these areas? (Please select ALL that apply)

	Always	Usually	Only if I think it's an issue	Only if parents initiate discussion	Never
Discuss pros and cons of disclosure	☐	☐	☐	☐	☐
Explore potential implications of non-disclosure	☐	☐	☐	☐	☐
Explore potential implications of disclosure	☐	☐	☐	☐	☐
Discuss future possible scenarios if decide to disclose	☐	☐	☐	☐	☐
Discuss future possible scenarios if decide not to disclose	☐	☐	☐	☐	☐
Explore disclosing to child	☐	☐	☐	☐	☐
Explore disclosing to family	☐	☐	☐	☐	☐
Explore disclosing to friends	☐	☐	☐	☐	☐
Discuss how to respond to questions that their child might ask	☐	☐	☐	☐	☐
Discuss age appropriate ways of discussing donor conception with their child	☐	☐	☐	☐	☐
Consider that their child may want to contact biological parents in the future	☐	☐	☐	☐	☐
Consider that their child may never have contact donors in the future	☐	☐	☐	☐	☐
implications of differences and similarities between their feelings surrounding disclosure and those of	☐	☐	☐	☐	☐

Support provided by clinics for intended parents receiving treatment with their partner

13. Do you insist on both partners (if applicable) being present for counselling? (Please select ONE)

- ○ Yes
- ○ No

14. How do you counsel intended parents receiving treatment with donated embryos? (Please select ONE)

- ○ Both parents together
- ○ separately
- ○ Both together and separately

15. After pregnancy is achieved, is any further support available to parents? (Please select ALL that apply)

- ☐ Direct parents to support groups
- ☐ Provide parents with additional books/leaflets to take away
- ☐ Parents can receive additional free counselling
- ☐ Parents can pay for additional counselling
- ☐ No further support

Other (please specify)

16. This is the end of the questionnaire. If you have any additional comments please write them below. Thank you for your time. If you have any questions please contact the researcher on Nicola.Doherty@warwick.ac.uk