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# **Women's experience of their fertility and being an egg donor recipient**

## **A Portfolio of Research and Therapeutic Practice**

**Simone Roggenkamp**

**A portfolio submitted for the degree of DPsych**

**City University London**

**Department of Psychology**

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This is dedicated to each of the eight participants who shared their journeys with me so honestly and generously. I hope I have done justice to your stories.

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### **Declaration**

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# Section A: Preface

This portfolio consists of three sections: a qualitative research study, a case study and an article, with the overall aim of exploring women's psychological experience of their fertility and reproductive health. The aim has been, across the three sections, to depict how women try to make sense of their fertility issues, the complexity of this experience, and how this impacts on other areas of their life. Fertility issues have been medicalised due to the rise of and focus on developing artificial reproductive techniques to assist people in conceiving: The focus has been on solving a medical problem with a medical solution, and less on the more psychosocial elements of infertility and artificial reproductive techniques. It is hoped that these three sections will help extend our understanding and insight into the experience of the psychosocial repercussions that fertility issues and egg donation can have for women.

The first section, section B, is an interpretative phenomenological analysis research study into women's psychological experience of being the recipient of donor eggs. The aim was to capture and give voice to the women's attempts at making sense of their experience as a donor egg recipient. Their experience was based around trying to negotiate being faced with a new reality of themselves as infertile, having to form new ideas about what constitutes family and motherhood, and having to negotiating their experience around doing something out of the ordinary. The study hopes to convey the complexity and ambivalence that they women faced because of their infertility and due to being an donor egg recipient, including their experience of egg donation as a potential threat to their concept of family and to their self-image, their experience of being faced with, and having to manage, the consequences of conceiving through egg donation, their perceived selfishness of undergoing egg donation, and their experience of getting to the point of choosing egg donation.

My initial interest in examining women's relationship and experience of fertility came from having experienced, from the side-lines, people going through fertility issues within my own close circle. Additionally, my interest was also evoked by a seeming increase in attention and awareness on the part of the media to fertility and artificial reproductive techniques, which mainly seemed to focus on the sociological and medical aspects of fertility, while little attention was given to the psychological aspects of being faced with infertility and having to come to terms with other ways of reproducing. At the same time, I was having several clients referred to me due to issues seemingly unrelated to fertility, only to discover during therapy that behind their difficulties were fertility-related struggles such as low self-esteem due to not conceiving and confusion as to whether romantic relationships were "the right ones to have children in". This suggested to me that fertility-related issues might play a larger role in people's existential struggles than I had imagined, and this evoked my interest. Researching fertility online it became clear that the majority of research had focused on infertility and IVF, but there appeared to be a paucity of research on egg donation, especially the experience of being the recipient of egg donation. It seemed that the predominant interest had been in ensuring that pursuing egg donation did not harm anyone: the donor, recipient or the child, and had therefore examined the psychological wellbeing of these individuals, but not the actual experience of what it was like to have a child with someone else's egg/genetic material. This was how the research question, *what is it like to be the recipient of donor eggs?*, of this study arose.

Section C consists of a case study which depicts my therapeutic work with a woman with endometriosis, as we try to build and create a strong therapeutic alliance in a growth-promoting environment, in which she could feel safe enough to get in contact with her inner feelings of shame from having endometriosis. The case study highlights the struggle of trying

to connect the body, the senses and the mind, and how this was achieved through Focusing (Gendlin, 1969). Though the focusing was used here to help the client explore her feelings regarding her endometriosis, the process of trying to help clients to get to their inner feelings, by creating a connection to their bodies again, and opening the mind up to hear and react to these feelings, is one I believe to be an essential part any therapy.

Following on from sections B and C's exploration of the meaning of fertility, section D focuses on donor egg recipients' experience of support before, during and after having a child. Again, little research has explored donor egg recipients' experience of support, whether psychological or not. The article captures the women's ambivalence and complex experience on the matter, and their attempts to figure out how best to manage. The article highlights how two particular stages – the time around the infertility diagnosis, and after having the child through oocyte donation (when the women realised the implications of this) – were the ones that felt the most difficult to manage, and when support was believed to be the most beneficial. The article is written with the intention of submitting it to the interdisciplinary and international journal of Patient Education and Counseling. The readership of the journal consists of health care professionals and health promotion researchers. The aim of the journal is to explore, illuminate and promote patient education, health care providers' education and improve communication between providers and patients. The aim of this journal fits with the intention of the article to explore and capture donor egg recipients experience of support in order to improving communication and understanding between health care providers and egg donor recipients. The intention to submit the article to an interdisciplinary journal, rather than a counselling psychology journal, is due to the findings of the article suggesting that not all recipients' wants or seeks counselling, and that therefore other clinical staff might need to play a greater role supporting and guiding



recipients, and therefore more focus is needed on promoting and improving other health care providers' communication and support to egg donor recipients.

Besides being linked through their focus on fertility, all three sections also encapsulate the women's experience of their own vulnerability, and their sense of ambivalence and distrust with regard to relying on others for support. The research shows the women's distrust of others due to feeling as though they are in a vulnerable position by being a donor egg recipient; in the case study, the struggle is for the client to not only face her own vulnerability, but also allow me in, to share this experience with her. The article depicts donor egg recipients' ambivalent feelings about receiving support.

It is hoped that this portfolio will not only reflect the women's experience of fertility, but will also bring insight into the role that counselling psychology can have in the area of fertility. As science-practitioners we have a unique opportunity and determination to not only improve and develop therapeutic practice, by continuing to be reflective, and being guided by research, but also (as scientists) we have the opportunity to give people a voice, and allow that voice to guide and inform policies. The science-practitioner stance is reflected in the portfolio. The practitioner aspect is reflected in the case study where the aim was to reflect upon and improve my practice by gaining a greater understanding of the client-practitioner relationship and the struggles we faced. The scientist aspect is reflected in the research, which aims to give a voice to donor egg recipient women, in order for us, as counselling psychologists, to extend our understanding about what aspects donor recipients might face and need support to process through counselling. Lastly, the article aims to give voice to the women's experience by conveying to other professionals, and other counselling

psychologists, what recipient women's experience of support might be, and thereby giving some insight into other ways in which we can better support them.

I feel that working on this thesis has helped me develop my identity as a counselling psychologist. It has allowed me to gain a greater insight into the different aspects of being a counselling psychologist. Prior to the research, I mainly saw myself as a practitioner; though my therapeutic work was based in science and theory, my primary role was as a therapeutic practitioner. Embarking on the research has helped open my eyes to the multiple roles a counselling psychologist can carry out, and how each of these has equal value.

## **References**

Gendlin , E. (1969). Focusing. *Psychotherapy: Theory, Research and Practice*, 6(1), 4-15.

# **Section B: Research: Women's experience of being the recipient of egg donation**

## **Abstract**

Thus far, the majority of the research into egg donation has focused on the donor-conceived children, their experiences and the implications for them. However, little is known about the recipient women's actual experience of being the recipient of donor eggs. Hitherto, the research has primarily employed quantitative research methods and has mainly focused on specific areas of egg donation such as deciding on treatment, donor selection, disclosure and the parent-child relationship. Yet without an insight into women lived experience of being a recipient of donor eggs, it is not possible to fully know what might be important to examine further. Interpretative phenomenological analysis was used to explore and describe the "lived experience" of what it is like for the participating women to have a child through egg donation. Eight women were interviewed when their children were between 1 and 8 years old. All the women were white British, between 38 and 50 years old at the time of the egg donation procedure, and varied in relationship status from married, living with partner, separated to single. The analysis resulted in the following four superordinate themes: "Threat", "Living with the consequences", "Selfish act" and "Doing what it takes". The discussion section explores the main themes in the women's accounts, including a more detailed exploration of "protection from stigma and from showing one's vulnerability";

“recipients’ experience of resemblance”; “recipients’ experience of egg donation as selfish”; and “recipients’ experience of support”, followed by an exploration of the clinical implications and limitations of the research, and suggestions for future research.

# **1 Introduction**

## **1.1 Overview**

To provide the reader with an easy-to-read structure the introduction has been divided into the follow sections: A general history of reproduction; Egg donation; Rationale for the research; Challenge of preconceptions; Adoption versus egg donation; Egg donation and ethics; Egg donation and psychological effects; Disclosure/non-disclosure; Egg donation and support; and lastly the link between counselling psychology and egg donation. Each section is meant to introduce the reader to the research and assumptions made about egg donation to date, and provide context for the following piece of research.

## **1.2 A general history of reproduction**

Each year more and more babies are born using Assisted Reproduction Technologies (ART) (International Committee for Monitoring Assisted Reproductive Technology, 2009). This seems to be due to greater public awareness of fertility treatments (Mosalanegad & Koolee, 2013, Edwards, 2014) and to women waiting to conceive till past age 30. In fact, there has been a doubling of the number of women in their 30s giving birth over the last 25 years (Cahill & Wardle, 2002). For some, waiting with conceiving till later in life is a conscious choice and is planned (Miller, 2005) due to women studying longer and becoming more career-minded, or wanting to settle down first. For others, there is a lack of awareness of the impact of age on fertility and this has been given as a reason for women waiting with conceiving till past 30 (Cousineau & Domar, 2007; Wyndham, Figueira, & Patrizio, 2012). The trend of waiting to conceive till past age 30 means that more women are struggling with their fertility, as a woman's chance of conceiving naturally declines rapidly after 35 (Appendix 1 & 2). Of course, difficulties conceiving can also be due to the partner's

infertility, however, for the purpose of this piece of research, where the focus is on women's fertility journey, infertility will only be regarded from the women's perspective.

Currently there are several ways of conceiving using reproductive technologies: Artificial insemination (AI), In vitro fertilisation (IVF), donation (sperm, egg and embryos) and surrogacy. AI consists of inseminating a woman with sperm as a way of increasing the chances that the sperm reaches the egg. This can either be done with her partner's sperm, so both parts are genetically linked to the child, or donated sperm (AID) in the case of male infertility, which results in the mother having a genetic link to the child and there being a genetic father and a social<sup>1</sup> father, or in the case of single women wishing to conceive, a genetic mother with an absent genetic donor father (Bos & van Balen, 2010). IVF consists of fertilising an egg and sperm in a laboratory, and then placing the fertilised egg in the woman's womb. In the case of donation, the procedure is the same as IVF but the sperm or egg, or both, is replaced by donated material, and then transferred into the woman who will carry the baby (Bos & van Balen, 2010), meaning therefore that either one or both parents are genetically unrelated to the child (Golombok, Readings, Blake, Casey, Mellish, Marks & Jadv, 2011), though the carrying mother will develop a biological link to the child through the fact of carrying it, but not a genetic link. Embryo donation, when an egg and sperm have already been fertilised together and an embryo is created, is relatively uncommon (MacCallum & Golombok, 2007), and occurs most often when a couple in fertility treatment

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<sup>1</sup> For the purpose of this piece of research, the woman receiving the donated egg is referred to as the recipient, the woman donating the egg is the genetic mother, and where donated sperm is also used, the man donating the sperm is known as the genetic father and the man who will raise the child is known as the social father.

donate one of their embryos. In surrogacy, a woman carries and gives birth to a child on behalf of someone else (Bos & van Balen, 2010). Here the child can either be genetically related, if the parents have donated material, or non-genetically related, if not. All of these methods mean that people who cannot conceive naturally, such as single women, homosexual couples, people past the reproductive age and people with various diseases that prevent conception, have the chance to conceive and create a family (Golombok, 2013). This piece of research will focus solely on egg donation, where the birth mother is not genetically related to the child, and either the partner's sperm or donated sperm is used.

### **1.3 Egg donation**

Since the first use of donor eggs in the 1980s (Bos & van Balen, 2010; Kirkman, 2003), their use has seen a constant increase (Richards, Pennings, & Appleby, 2012) due to greater awareness and demand. The rise in awareness of egg donation is not based on individuals; society as a whole is showing signs of greater awareness and openness. This is seen in the increase of media coverage of egg donation over the past 20 years (Fine, 2015).

Egg donation has the highest success rate of pregnancies and births compared to other fertility treatments (Hershberger, 2004). This is due to the possibility of using younger eggs than those that the woman seeking treatment would be able to provide (Stuart-Smith, Smith & Scott, 2011). Initially egg donation was intended for women with ovarian failure, but has with time become more prominent amongst women with age-related infertility (Sauer & Klein, 2011), women not wanting to pass on genetic abnormalities, or women who are infertile due to factors other than aging (Sachs & Hammer Burns, 2006).

#### 1.4 Rationale for the research

Infertility has in many ways been medicalised due to the rise of artificial reproductive techniques. The focus has been on solving a medical problem with a medical solution, and less on the more psychosocial elements of infertility and artificial reproductive techniques. It seems that this emphasis on the medical aspects above the psychosocial is slowly shifting, and more thought is being given to what the long-term psychosocial implications of ART, including egg donation, consist of, though this is yet to be fully examined (Cousineau & Domar, 2007; Sarasohn Glazer & Weidman Sterling, 2013). The rise in the numbers pursuing egg donation, together with an increase in awareness, have led to an increase in research in the area, and on the psychosocial implications. As technology progresses rapidly it raises the question as to whether we *should* just because we *can*. Without fully understanding the psychosocial implications, then, it is not possible to answer that question. Alongside the British Infertility Counselling Association (BICA), Counselling Psychologists can help enlighten people as to what psychosocial implications egg donation might have. Our focus is not merely on improving clinical practice but also on helping to inform policies and society about the ethical and psychological consequences of egg donation, and how we can best help people manage these consequences. As Counselling Psychologists we can help to inform the *should we*.

Thus far the majority of the research into egg donation has focused on the donor-conceived children, their experiences and the implications for them. However, little is known about the recipient women's actual experience of being the recipient of donor eggs. Hitherto the research has primarily employed quantitative research methods and has mainly focused on: the impact that assisted reproductive technologies might have on parenting and child development (i.e., Golombok, 2013); how partners decide on treatment (i.e., Ahuja, Mostyn



& Simons, 1997; McCarthy & Sheau-Huey, 2011); selecting a donor (i.e., Klock & Greenfeld, 2004); the role of donor in the child's life (i.e., Hart & Plath, 2011); how important might the missing genetic link be and what impact can this have; and disclosing the use of an egg donor either to family and friends or the children themselves (Kirkman, 2003).

Existing research has therefore focused on specific areas of the experience but not on capturing all of the experience. Yet without getting an insight into what the women's whole experience is like, it is not possible to fully know what might be important to examine further. It is therefore crucial that more research with a broader examination of what the experience is like for the women is conducted. A summary of the current thinking and research about egg donation will now be given in order to place this study within the context of the existing research, and to help justify why this piece of research was conducted.

### **1.5 Egg donation: challenge of preconceptions**

Since the advent of artificial reproduction techniques there have been objections and, for some, a complete rejection of the concept: first with AI, then with IVF in 1978, and then later with donation. Each time the objections have been the same: the deviation from marital sex is condemned (Richards, 2014) and the act of artificial insemination is viewed as unnatural (Sauer & Klein, 2011), and it is questioned as to where to draw the line (Richards, 2014). Common for those objections is that ART challenges our preconceptions about how the world should be. The same is true for egg donation which is also seen to challenge and question many of our current western preconceptions about the world, such as what constitutes a family, motherhood, how attachment is formed, the importance of having a genetic link, whether women will be able to connect with the child (Bos & van Balen, 2010), the power imbalance that non-disclosure will create (Bos & van Balen, 2010), the effects of

keeping a secret, and the effects on the child of being donor conceived. Furthermore, as egg donation does challenge preconceptions it is important to examine further how the recipient women of egg donation experience the potential negotiations of their preconceptions i.e., How do the recipient women experience and manage not being genetically related to the child? How does the lack of genetic relation impact their experience of family, motherhood and resemblance to the child?

### 1.5.1 Family

Fundamentally, egg donation challenges how the western world has traditionally viewed and defined family. Egg donation, and donation in general, questions what constitutes kinship and relatedness i.e., how a donor child is connected to the social parents, the genetic parents, and other siblings (whether these are genetic or social siblings) (Edwards, 2014). It seems that we humans have a need to put things in boxes. We need clarity of what is what. Who is related to whom. Egg donation complicates things as it makes it harder to judge connections from the outside (Edwards, 2014). The rise in popularity of egg donation therefore requires us to redefine the constitution of “the family unit”. It is no longer possible to assume genetic relatedness based on people defining themselves as belonging to a family. Kinship is no longer purely genetic, but can be divided into two types; kinship through genetics, and kinship through social connection (Braverman & Frith, 2014). An anthropological study asked people to discuss various aspects of ART (Edwards, 2014). The participants seemed to share a consensus about there being a biological and a social form of kinship. For some, their kinship consisted of both, i.e., being the genetic (biological) parent and being the social parent (bringing up the child), while for others, such as those with donor-conceived children, the kinship was seen to be formed through social relatedness. This could suggest that one’s view of what constitutes kinship greatly influences what reproductive technologies one might

consider, i.e., if one believes that kinship is based on genetics, then one might not be willing to pursue the donor route, whereas someone defining kinship as more socially determined might be more inclined to seek the donor route. On a macro level, egg donation also influences societal and cultural definitions of kinship (Edwards, 2014). Egg donation, which was first rejected by many due to the idea of “designer” and “test tube” babies, has since become more acceptable. This might not only be due to greater awareness around egg donation, but might also be linked to western societies having started to embrace and develop many new family models – divorced families, single parents, gay parents, families with step-siblings, half siblings, and so on. It seems that the increase in family models in western culture has created a shift in the way social relatedness is valued. This is, for example, seen in the social acceptance of people valuing and viewing their half-siblings, step-siblings or step-parents as equal to their genetic family. It has been suggested that in western society not having the genetic link is somehow viewed as making the connection more “fragile” (van Berkel, Candido, & Pijffers, 2007). This is interesting in the light of it becoming more socially acceptable to live in very diverse families, i.e., few question that a step-daughter can view her step-father as her father, though critics of egg donation argue that the genetic link is important for a child’s sense of self, for the attachment. By contrast, it has been argued that genes do not guarantee a bond (Lillehammer, 2014), or a sense of kinship. Lillehammer (2014) argues that it is perhaps impossible to choose one’s parents, but possible to choose one’s bond to them, regardless of whether they are genetic parents or not. It is not the genes but the bond that is built to one’s parents that matters in the child-parent relationship and in how one might define a family (Lillehammer, 2014).

It seems a particularly western concept to determine kinship through genetics, since in

many non-western cultures the formation of kinship is defined differently, for example, in Papua New Guinea and Zumbaguan, kinship is not determined by genetics or social parenting but through food and feeding (Edwards, 2014). This idea of feeding and food creating a form of kinship or bond could also be prominent for donor egg recipients as the opportunity to breastfeed could be seen as furthering bonding, and as a way of transferring something of the recipient mother into the child.

The different cultural views on the formation of kinship also underline the importance of more research into different religious and cultural backgrounds and their views and experience of egg donation (Edwards, 2014). As mentioned above, some cultures have a very different way of defining kinship from the traditional western definition, but there might also be some religious differences in terms of how a woman might experience egg donation. For some, religion is transmitted and is part of who you are from the onset; for others religion is nurture (Hudson & Culley, 2014). For example, in the Jewish community there is some debate about who is defined as the mother: the egg donor or the carrier (Edwards, 2014), and whether a child born through egg donation is even Jewish if the donor is not Jewish. This is due to the belief by some Jews that religion is passed on by the mother (Edwards, 2014). This therefore suggests that there could be cultural and religious influences on a woman's view of her egg donation journey. For this piece of research, the examination of the cultural and religious impact on the experience of egg donation is outside of the remit due to a difficulty in recruiting participants for the research.

Egg donation does not only challenge the concept of family due to the lack of a genetic link, but also because of the involvement of a third party, the donor. Egg donation raises the question as to what role and part the donor plays in the constitution of the family. The answer

to this would be expected to also be dependent on whether the donor is known to the recipient or is anonymous. It has been suggested that some egg donation recipients try to “de-kin” (Edwards, 2014) from the donor by distancing themselves from the meaning of the donation and viewing the donation as “merely a [donation of] bodily matter” (Edwards, 2014). This enables them to detach themselves from the donor by not attempting to create an image of them. Edwards (2014) and Howell (2006) talk about this process in terms of kinning and de-kinning. Once the egg is implanted in the social mother then the child is de-kinned from the genetic mother, and the kinning process between the social mother and the child begins. If these concepts of kinning and de-kinning are correct then that could suggest that the recipient women’s experience might focus on strategies and desires to de-kin the child from the donor, and ways of trying to form a closer bond with the child themselves.

### 1.5.2 Motherhood

Just as is the case with what constitutes a family, egg donation has also brought into question what constitutes a mother/motherhood. This seems to be due to, as Miller (2005) suggests, “The institution of motherhood in the Western world is, then, historically, socially, culturally, politically and, importantly, morally, shaped. In turn, it powerfully shapes our experiences as women” (3). Research has long suggested that people have been reluctant about having fertility treatments involving a third party due to this questioning of the ownership of “mother” (Purewal & Akker, 2006). As mentioned above, there has been a shift towards viewing social parenting as equal to, or even more important than, genetic parenting (Miall, 1994; Thornton, McNamare & Montague, 1994). Freeman, Bourne, Jadava, and Smith (2014) found that egg donors had no doubts as to who they viewed as the mother – the social mother. Freeman et al. (2014) stated that there is a discrepancy between how egg donors and sperm donors define themselves, in terms of parenthood, and that this might suggest a

difference in how parenthood is defined by men and women. It seems that for men, fatherhood is defined based on genetics, whereas for women, motherhood is not strictly defined by genetics, but also by the nurturing aspect, i.e., who cares for the child. Almeling (2014) supported this by showing that sperm donors did not make a distinction between genetic and social parenting, whereas egg donors did, and therefore did not view themselves as the mothers. This suggests that it might be easier for women to integrate the child and redefine their idea of motherhood and ownership of the child, as women might already have a view of motherhood as being more socially defined than genetically determined.

Not only has the definition of motherhood been questioned but also the quality of the parenting/parent-child relationship, raising the question of whether a mother will be better or worse depending on how the child has been conceived. Research suggests that there is greater parent involvement in ART families than natural conception families (Bos & van Balen, 2010), and a strong and warm attachment to the children (van Berkel, Candido, & Pijffers, 2007). This could be due to being highly motivated and willing to go through a difficult and draining process to achievement parenthood, and thereby being more appreciative of what has been gained (Bos & van Balen, 2010; van Berkel, Candido, & Pijffers, 2007). The parent/child relationship has been found to be as good, if not better, in families using egg donors than in families who have conceived naturally, which could be due to the increased desire and effort that has been put into conceiving (Golombok, Murray, Jadv, MacCallum & Lycett, 2004). However, it has been suggested that parents/mothers may develop an over-protective attachment to their children as they are aware how “lucky” they are (Berkel, Candido & Pijffers, 2007).

The importance of pregnancy and birth is not only seen as significant per se for the recipient women, but in terms of the legalities of motherhood giving birth is crucial. Under the 2008 Act (Human Fertilisation and Embryology Authority, 2008; McCandless & Sheldon, 2014) the birth mother is deemed the legal parent. This supports the notion that genes are not deemed to be as valuable as the act of birth, and supports the women's desire to have the opportunity to carry the child themselves. Despite this, it seems that genes are still seen to be very important, and this is suggested by the fact that many women go great lengths, and through multiple treatments, to conceive using their own material (McCandless & Sheldon, 2014).

Based on the research it seems that although socially, culturally, and for some, personally, egg donation might question the traditional idea of what constitutes a mother, for women undergoing egg donation, motherhood might not be perceived to be any different to motherhood through natural conception. However, the research so far seems to have been primarily quantitative, and therefore not able to capture the experience that the women had of motherhood.

### 1.5.3 Importance of a genetic connection

Another issue that egg donation challenges is the general importance of a genetic connection. The sections 'motherhood' and 'family' suggest that donor recipient women might not need the genetic connection to connect with a child, however, despite the greater acceptance of egg donation as a conception method, it seems that having a genetic child is still the most desirable method. It seems that there might be some discrepancy regarding how important the genetic link actually is, and how it is viewed (Appleby & Karnein, 2014). The desire for a genetic link is seen in women's repeated IVF attempts with their own eggs, despite being

informed of the low success rate, rather than pursuing egg donation, which has a higher success rate. This is quite interesting in the light of how, as previously mentioned, the structure of “family” is changing and becoming more diverse (Braverman & Frith, 2014; Edwards, 2014; Richards, 2014), and more and more families are not necessarily genetically related. This could have led to the assumption that the genetic connection does not have the same status as it used to. People’s pursuit of the genetic connection, first and foremost, suggests that although other family models are accepted, socially the ideal form of family is still a mother, father and genetic children (Witt, 2014). It has been suggested that the preference for the traditional family is due to the enduring belief that it is best, morally and psychologically, for the children to be part of the traditional family model (Witt, 2014). Some people believe that if a child cannot know their heritage, this is detrimental to their self-understanding (Velleman, 2005; Witt, 2014), and that to develop a functional self the child needs to be with their genetic parents (Bos & van Balen, 2010). However, the majority of the research does not support the view that children have to live with their genetic parents in order to develop a healthy self-identity (Bos & van Balen, 2010). Actually, what has been found to negatively impact the children’s sense of self is when the donor conception is not disclosed until later in the child’s life (Turner & Coyle, 2000; Golombok, 2002). The above research, combined with the research from the two previous sections, suggests that although the genetic connection is the most desirable, once the women realise their infertility then the genetic connection takes on a new and less important meaning (Appleby & Karnein, 2014; Richards, 2014).

The majority of the research regarding the effects of not being genetically connected has looked at the effects on the children, however, not much research has actually looked at the women’s experience of not being genetically related to their child. Rather, the focus has been



on whether the woman's relationship to a child changes according to whether or not they have the genetic link. Here research suggest that the missing genetic link does not have an impact on the relationship between parents and child or on the child's development (Golombok, 2013). However, it is worth noting that most of the research on this subject has been based on small sample sizes, and mainly been conducted with open disclosure families. The experience might be different for women in non-disclosure families.

#### 1.5.4 Resemblance

Another preconception challenge by egg donation is parent/child resemblance. The lack of the genetic link in egg donation means that recipients can no longer be sure that their child will bear any resemblance to them. Furthermore, in the US it is possible to select one's donor, whereas in Europe it is common for the clinic to select the donor. Many UK recipients seek treatment in the UK, Spain or Eastern European countries where clinics match the donor and recipient, and the recipient therefore has very little information as to whether, or how, the donor bears resemblance to the recipient. It has been suggested that being genetically related to your child gives the illusion that you know what to expect when it comes to the child's development, and that egg donation brings up a lot of questions about what the child will be like due to having an unknown involvement (Braverman & Frith, 2014). The issue of resemblance is also an issue with adoption, however, Becker, Butler and Nachtigall (2005) suggest that, with adoption, resemblance is not societally, or individually, expected. Perhaps the difference in expectations, for adoption and egg donation, comes back to the child being carried by the mother, which might give the assumption that the mother is able to influence the child through pregnancy. This needs to be examined further. It may be that society's expectation of a child resemblaning its carrying mother (though not genetically related) might also influence the recipients women's experience. With egg donation, therefore, there might

be a sense of uncertainty as it is not possible to “predict” what the child will look like or how their personality will develop. Braverman and Frith (2014) state that the child is perceived as being more “known” if it is possible to make assumptions about the child based on ourselves. This suggestion is supported by the fact that many recipients hope that the child will look like their partner, if the partner shares a genetic connection with the child, and by the fact that most recipients wish for a donor that bears some resemblance to themselves (Braverman & Frith, 2014). The desire for the child to bear a resemblance to one or both parents has been suggested to be not only due to wanting to “predict” aspects about the child, but also to enhance the chance of the child being “passed off” (Braverman & Frith, 2014, 134) as one’s own, in order to conceal the fact of egg donation and to not make the child stand out (Hudson & Culley, 2014). The extent to which physical resemblance matters might also be culturally determined. Hudson and Culley (2014) found that “sameness” mattered greatly in their study with British South Asian couples, which found that physical resemblance and joint religious beliefs were important. There was a sense of wanting close physical resemblance so the child could be passed off as their own and thereby be more easily integrated into the Asian community.

The research so far suggests that resemblance is important to egg donor recipients as it gives a sense of predictability, and an outward idea of belonging. However, more research needs to be done into the recipient women’s experience of what it is like to have an unknown factor, in the sense of them not being able to predict or guess what the appearance and attributes of their children will be. Additionally, insight is needed into whether and how the women’s experience of belonging is influenced by resemblance.

## **1.6 Adoption versus egg donation**

Egg donation has often been compared to adoption. Much of the early research used adoption as a way of predicting and suggesting what implications egg donation might have. This was due to their similarity because of the absence of a genetic link, and due to difficulties recruiting donor recipients, with a paucity of people disclosing and therefore not partaking in research. Adoption research was, for example, used to examine the potential importance of a genetic link for the parent/child relationship by comparing adopted children with naturally conceived children (Brodzinsky, 2005; Golombok, 2013). However, it was later suggested that a comparison between adoption and egg donation is impossible, as an adoptee has a pre-story before entering the family, which is often filled with complex and negative feelings, which might impact on the parent/child relationship and the child's wellbeing, above the influence of the missing genetic link (Golombok, 2013). Donor-egg conceived children, on the other hand, do not have this pre-story, and have not suffered the same abandonment as adoptees, making a comparison not appropriate. The impact of the pre-existing story on the child's psychological wellbeing and the family functioning has been supported by research that has found that adoptees are more at risk of psychological issues (Blake, Richards, & Golombok, 2014), though it has been argued that the effect of this when compared to children conceived naturally is small (Blake, Richards, & Golombok, 2014).

An important factor in why people view egg donation as more desirable than adoption (van den Akker, 2001) is the women's opportunity to experience pregnancy, and being part of the child's story from the beginning, rather than having a pre-existing story to be managed (Black, Richards, & Golombok, 2014; Overall, 2014, Sarasohn Glazer & Weidman Sterling, 2013). The ability to achieve pregnancy and childbirth is often seen as a crucial part of why women choose egg donation above adoption, as both are seen as a way creating a bond with

the child (Sarasohn Glazer & Weidman Sterling, 2013). The pre-story/pre-existing story of adoptees is, however, why some judge that, ethically, adoption is more correct than egg donation. Adoption gives an existing child the second-best option possible (Witt, 2014), whereas with egg donation a human is created based solely on one's own needs.

### **1.7 Egg donation and ethics – how far shall we take it?**

Egg donation does not only challenge the preconceptions that society holds about conception, it also creates new moral and ethical dilemmas, and many are still unanswered, such as is it ethical that just because “we can, we shall”? Where do we draw the line, and how do we draw the line? Who gets to choose whether woman A or B should be allowed to conceive through egg donation?

#### **1.7.1 Older parents**

Egg donation, together with other forms of donation and surrogacy, have rapidly led to an increase in “aged parenting” (Parks, 2014) due to it being possible for women of advanced maternal age, i.e., over 40 (Sauer & Klein, 2011) to conceive despite being past the natural reproductive age. Currently in the UK there is no legal age limit for women receiving donor eggs, however, most UK centres do not accept women above 50 years old (Infertility Guidance Service, 2016). The use of egg donation for women of advanced maternal age has sparked controversy and debate as it has raised the question of who should be able to benefit from the procedure (Parks, 2014; Sachs & Hammer Burns, 2006). Where do we draw the line? Reports of egg donation being used by women over 50 have confirmed some peoples' feelings of egg donation being unnatural and going against nature's ways (Sauer & Klein, 2011). The advocates for limiting “aged parenting” have argued that the woman and child are put under greater risk of health problems when the woman is older (Parks, 2014). However, it

has been argued that there is no greater risk for the mother or child whether the mother is in her 40s or 50s (Parks, 2014). Also, it has been argued that, regardless of whether the recipient is aged or not, egg donation raises some medically ethical questions, as there are medical risks for the mother and the donor due to the hormonal interference, and there might be some risk to the child's future health as a consequence of them being conceived through egg donation, which is yet to be fully examined (Blake, Richards, & Golombok, 2014).

Morally it has been argued that women past the age of reproduction should not be allowed to go down the egg donation route as it is not deemed fair to the children who will have to live with the possibility of losing their parents at a young age, or having to care for elderly parents at a young age. However, Parks (2014) argues that the possibility of death is not exclusive to aged parents, and that aged parents have a responsibility to ensure proper thought has gone into what will happen in their later years, and what impact that might have on the children they bring into the world. If this is done, then the moral argument for not supporting aged parenting falls through.

Again, to my knowledge there is no research into the recipient women's experience of being an older parent as well as having conceived through egg donation.

#### 1.7.2 Genetic sexual attraction

An interesting, yet relatively unexplored aspect of egg donation is the possibility of genetic unknown "incest", where a donated child might form a romantic attachment to a genetic unknown sibling (Edwards, 2014). Not only will this have genetic repercussions for future generations, as genetic diseases can occur when close family members mate, but it might also have psychological consequences for the donated child, as there can be a doubt as to whom

you might be related, and how people manage potentially finding out that a partner is genetically related to them. Recipient women's thoughts and concern in this area have gone unreported. It could be argued that genetic sexual attraction might also occur; to my knowledge there is no research that investigates this with regard to egg donation.

### 1.7.3 Egg donation and the invasion of a third party

There are also ethical and moral dilemmas in terms of third party involvement. With regards to the egg donation debate there has also been some controversy in relation to the donors donating their eggs. Currently in the UK there are two methods of donation: altruistically, where you donate due to altruistic reasons, or as part of an egg-sharing program, where a woman already undergoing IVF with her own eggs can choose to donate eggs to another woman in exchange for a discount on her treatment (Sauer & Klein, 2011).

For the women donating altruistically there has been some debate about how these women should be reimbursed for their time and efforts. Currently in the UK donors "can receive compensation of up to £750 per cycle of donation, to reasonably cover any financial losses incurred in connection with the donation, with the provision to claim an excess to cover higher expenses such as for travel, accommodation or childcare" (Human Fertilisation and Embryology Authority, 2016). As egg donation has increased in popularity this has led to a shortage of donors. The development of egg sharing grew from this shortage (Sauer & Klein, 2011), and has been argued to be a more ethically sound option as it does not require a donor to undertake unnecessary treatment, and also makes egg donation a less commercial route. However, others have argued that egg sharing is no more ethically correct, as where the woman is providing a service for the personal gain of a discount on the cost of treatment, then there is no way to guard against some women feeling "forced" to donate due to financial

need (Sauer & Klein, 2011). Due to the shortage of eggs, the concept of "fertility tourism" (Edwards, 2014, 54) has evolved and made egg donation a commercial undertaking in many countries outside the UK. The idea of egg donation becoming more commercial means that it raises new ethical dilemmas in terms of how to protect vulnerable people in foreign countries from being used as egg donors (Sachs & Hammer Burns, 2006).

In terms of the recipient/donor relationship there is some debate about how much information is wanted by the recipient about the donor, and the effect the information has on the recipients "relationship"/thoughts and ideas about the donor. Currently in the UK donors are asked to fill in demographic details i.e., name, address, religion, ethnicity, appearance, own number of children, medical conditions, academic background, skills and interests.

Additionally they are asked to write a brief statement about themselves which is given to the recipients. There are different tendencies abroad, where some countries have complete anonymity, and others, like America, have complete openness, and the recipients have the opportunity to select their own donor from a folder which contains photos and in-depth information about the donor. In the UK the identifying information about the donor is not released until after the child turns 18 and seeks it. Rubin et al. (2015) looked at the amount of information that the recipient wanted when they had to pick the donor, and found that recipients wanted some information to feel in control of the decision, but not too much that it would lead to more difficulty in choosing. This was primarily due to the fact that the more information given, the more the recipients started seeking for perfection. Also, it was suggested that too much information could lead to difficulty in keeping an emotional distance. Though these particular findings were with regard to picking the donor, which is not possible in Europe, such findings could suggest that recipients do form a kind of attachment to the donor – whether a close or distant attachment, and that this might be enhanced by the level of information received about the donor. Klock and Greenfield (2004) supported this

idea, by suggesting that the detail of donor information effects men's decision as to whether to disclose. Though the same effect was not found for women, in this particular study it might be the case that women's experience of the donor, and of disclosing, is affected by the level of information received about the donor. Both studies seem to the earlier proposed idea of some recipients needing to de-kin from the donor after the fact.

## 1.8 Egg donation and psychological effects

### *1.8.1 Psychological distress with coming to terms with infertility*

Research into infertility and the use of ART has suggested that many women experience high levels of distress in the process of coming to terms with the infertility or embarking on the ART route (Ahuja, Mostyn, & Simons, 1997; Williams & Zappert, 2014). Infertility is defined as the “inability of a couple to achieve conception or to bring a pregnancy to term after a year or more of regular, unprotected intercourse” (World Health Organisation, 1992). Research has suggested that infertility causes psychological difficulties such as “distress, anxiety and depressive symptoms” (Cassidy & Sintrovani, 2008; Edelman, Connolly, & Bartlett, 1994; Merari, Chetrit, & Modan, 2002), and has implications for mental and social wellbeing. It remains to be fully examined whether the social and psychological consequences of infertility have long-lasting effects for the women undergoing egg donation, despite conceiving. Do the consequences of not having been able to conceive naturally have lasting effects, and if so do they impact on the egg donation journey? When donor conception first emerged, some research was done into the psychological wellbeing of parents who had gone through fertility treatment (Blake, Richards, & Golombok, 2014). This suggested a small difference in psychological wellbeing depending on conception route (more references in Blake, Richards, & Golombok, 2014). However, van Berkel, Candido, and Pijffers (2007) described how egg recipients reported negative feelings, such as anxiety and uncertainty, and



felt more anxious about the future than IVF mothers. This suggests that some egg-recipient mothers do experience difficult feelings as a consequence of having gone down the egg donation route, and that these feelings are managed through denial and defensive reactions (van Berkel, Candido, & Pijffers, 2007).

It has been suggested that the high levels of distress are due to the women having to adapt their self-concept, involving accepting themselves as an infertile (Thorn, 2009; Kikendall, 1994). However, little has been reported about women's sense of self in relation to egg donation, and the transition from infertile to conceiving through egg donation. The potential struggle with, first, being faced with the negative repercussions of discovering one's infertility, and, secondly, having to accept an alternative path to conceiving, could both cause distress (Cousineau & Domar, 2007). As motherhood has been suggested to be central to many women's feelings about life/personal fulfilment, it has been assumed that the inability to conceive naturally will therefore influence women's views of themselves (Petok, 2014; Sachs & Hammer Burns, 2014). Thorn further supports this view by suggesting that the need to use donor eggs could be experienced as a sense of loss in terms of women's self-concept (Thorn, 2009). Silbergleid (2013), in her "donor egg essay", grapples with this idea as she explains how, despite now having conceived through egg donation, she feels her self-image has had to change as her "disease was not cured" but merely involved a different path. Kirkman (2003) suggested that women's experience of their journey to pregnancy is important as it impacts on how they construct their own narrative of who they are. Furthermore, a woman's struggle with the acceptance of her infertility, and the use of egg donation and subsequent effect on her self-concept, could have an impact on the way her children construct their own "narrative identity" (Kirkman, 2003, 2236). This suggests that egg donation might have a significant psychological impact on the recipient women's

emotional and psychological wellbeing. It could be argued that the above is also the case for women adopting, however, it is worth noting whether a difference could lie in the fact that egg donor recipients are infertile but then conceive, whereas women who adopt are infertile, and never conceive. Potentially the conception through egg donation could alleviate the negative feelings caused by ones' infertility, and therefore create a different experience. More research is needed into this area before any conclusion can be drawn.

The medical procedure that the recipient women have to embark upon can also be seen as a contributing factor to the high levels of distress. The procedure is invasive for the donor and the recipient as both have to embark on hormonal medication and intrusive medical procedures to ensure the donor's and recipient's ovulatory cycles are synchronised (Bosch, Reis, Domingo & Remohi, 2008). One study found that the majority of the donors and recipients found the procedure of the drug therapy and egg retrieval the worst part of the process (Ahuja, Mostyn, & Simons, 1997).

### 1.8.2 Loss

The theme of "loss" features heavily for egg donor recipients, as the women are having to come to terms with the loss of fertility (Applegarth, 2014) and the loss of the genetic link with the child (Sachs & Hammer Burns, 2014). The journey of egg donation often starts with a sense of loss from facing the reality of not being able to use one's own eggs, and having suffered repeated cycles of hope and failure (Sachs & Hammer Burns, 2006). Most do not expect to go down the egg donation route until faced with their infertility, in which it seems as if their "reality changes" (Sarasohn Glazer & Weidman Sterling, 2013, 18), as people are then forced between choosing a different means of conception, adoption or not having children. This means that when a woman embarks on egg donation, there is already a pre-

story, a story behind what has led her to seek egg donation. The journey leading to the decision to use egg donation is often filled with sorrow, failures, and attempts to try to accept a different reality. Again, this supports why psychology counselling should play a major role in the egg donation route. It seems that the difficult feelings can be both about the past, i.e., having to accept and manage a sense of loss, and about the future, and what implications their actions might have.

### 1.8.3 Personality

Smart (2015 cited in Fine, 2015, 159) suggested that how women negotiate and view donation is largely influenced by their personality and world view. She uses the metaphor of whether people view the glass half full or half empty. If half empty the focus continues to be on the negatives of donation, such as continuing to have a sense of loss and clinging onto differences, whereas if half full there is a more positive view of egg donation and the difficulties along the way are diminished (Fine, 2015). This suggests some individual differences in how women experience and manage the journey of egg donation, and why more research into women's experience of egg donation is important.

## 1.9 Non-disclosure/disclosure

One of the most discussed aspects around egg donation is the disclosure/non-disclosure question. Mainly this is due to the concern around the impact that non-disclosure would have on the children. It is a known fact that research and the majority of professionals support full disclosure to the child due to the importance of heritage in a child's development of their identity (Erikson, 1968; Richards, 2014), and with regard to the child having appropriate information about the possibility of genetically transmitted illnesses etc. Adoption literature suggests there are greater coping skills amongst adoptees when adoption is disclosed

(Brodzinsky, Smith, & Brodzinsky, 1998). Additionally, there has also been some debate regarding whether a child's right to know their heritage comes before or after a parent's right to choose whether to disclose or not due to their privacy rights and judgement of what is in the best interest of the child (Gollancz, 2001; McGee, Brakman, & Gurmankin, 2001; MacCallum & Golombok, 2007; Walker & Broderick, 1999).

Despite public encouragement for the parents to disclose, it is not a legal requirement to report that a child was conceived by donation on the child's birth certificate (Richards, 2014). Research studies have reported a wide variation in parents intention to disclose to their children, from between 29% and 88% (Murray & Golombok, 2003; Klock & Greenfeld, 2004; Pettee & Weckstein, 1993), and most parents do not disclose the use of egg donor to the children (Golombok, Murray, Brinsden, & Abdalla, 1999; Gottlieb, Lalos, & Lindblad, 2000). It has been suggested that this might be due to: uncomfortable feelings in relation to choosing the donation route (Richards, 2014; Appleby, Blake, & Freeman, 2012), a fear that it will damage the parent/child relationship, not wanting to cause upset about donor anonymity, while also protecting both parents and child from potential public stigmatisation (Nachtigall, Pitcher, Tschman, Becker, & Szkupinski Quiroga, 1997; Golombok, 2013, MacCallum & Golombok, 2007). Hahn and Craft-Rosenberg suggested that people disclose due to feeling like the child has a right to know, and not wanting to risk the child finding out alternative ways, parents who were undecided whether to disclosed were concerned about how and when to disclose, and to protect the child/parent relationship. The parents that did not disclose stated that there was no need for the child to know. There is sparse information about disclosure from the experience of the mothers, in terms of what it is like for the women to be caught in the dilemma as to whether to disclose or not. Salter-Ling, Hunter, and Glover (2001) found a link between parents who were unclear about whether to disclose and the

level of distress they had about their infertility. If undecided on whether to disclose then they were more likely to have more negative feelings about their infertility. Additionally, it has been suggested that although parents tend to focus on the impact disclosure will have on the child, actually the apprehension about disclosing is more related to protection of the parents (Readings, Blake, Casey, Jadv, & Golombok, 2011; Snowden, Mitchell, & Snowden, 1983).

There are several strategies that parents use when it comes to disclosing. Some take the approach of slowly giving the child more and more information about their conception, so the child has a sense of always knowing, while others decide not to disclose until the child becomes old enough to grasp what egg donation means (Blyth, Kramer, & Scheider, 2013; MacDougall, Becker, Scheib, & Nachtigall, 2007). MacDougall et al. (2007) found that parents were more anxious about disclosing if they had opted for the strategy of waiting until they felt the child was ready. Readings, Blake, Casey, Jadv, and Golombok (2011) suggested a third strategy in which parents take the position of not voluntarily disclosing to the children, but if asked directly, they would disclose. So an approach of “withholding, rather than hiding”. The research also found that not all the parents who intended to disclose actually did so, suggesting that it might prove a difficult decision for the parents. It is worth questioning whether parents who chose the strategy of waiting for the right time to disclose saw disclosure as more of a one-off event compared to parents who disclose gradually over time.

Research seems to suggest, therefore, that disclosure is quite a step for parents, and that there is a struggle as to whether or not to disclose. However, what the exact experience is like for the parents/mothers is still unclear, as research so far has found that parents tend to focus on the consequences for the children rather than themselves, though there is a sense of the non-

disclosure also being for the parents' benefit. This piece of research will hopefully extend the current understanding of the struggle of disclosure by focusing on the women's experience of whether or not to disclose.

### **1.10 Egg donation and support**

Within the literature there seems to be a consensus that infertility and fertility treatment can be very distressing and cause an array of emotional and psychological responses (Boivin & Takefman, 1996; Joy & McCrystal, 2015; Mahlstedt, 1994). Research has suggested that particularly stressful are: undergoing the treatment itself, having to make difficult decisions with regard to treatment, the rollercoaster of going through hopes and failures of treatment, normalising, preparing for the implications, and disclosure concerns and guidance on helping donor-conceived children to manage (Sachs & Hammer Burns, 2006). Due to this psychosocial impact, it has been suggested that counselling is advisable and should be available throughout and after treatment (Boivin, Appleton, Baetens, Baron, Bitzer, Corrigan, Daniels, Darwish, Guerra-Diaz, Hammar, Whinnie, Strauss, Thorn, Wischmann & Kentenich, 2001; Greenfeld, 1997). The Human Fertilisation and Embryology Authority (HFEA) regulates assisted conception in the UK and with the HFE Act 1990 made it a legal requirement for all licensed fertility clinics to offer counselling. The HFEA went even further with the HFE 2008 act in which it stated that counselling "should be routinely offered as part of the treatment process" and that counselling is distinct from "assessment of suitability of treatment, the provision of information to obtain consent and the normal relationship between clinic staff, patients and donors" (Joy & McCrystal, 2015, 87; The Human Fertilisation and Embryology Authority, 2016). The importance of separating counselling from assessment is supported by research suggesting that one of the reasons for the limited uptake of counselling for people going through infertility is due to their being cautious about showing any

ambivalence or uncertainty due to fear of treatment retraction (Coven, 2011). The NICE guidelines for fertility support the HFEA standpoint by recommending counselling and that this counselling should be sought from professionals independent of one's care. The British Infertility Counselling Association (BICA) was founded in 1988 to promote a high infertility counselling standard by ensuring that all counsellors are appropriately accredited according to the BICA scheme (see Crawshaw, Hunt, Monach, & Pike, 2013), which is supported by the HFEA guidelines as it requires infertility counsellors to be a member of the BICA or the equivalent. The BICA Guidelines for Good Practice in Infertility Counselling were produced in 2006 and 2007 with the latest addition in 2012. According to the guidelines the purpose of infertility counselling is to assist people in reflecting on, understanding and adjusting to the implications of the route taken and to provide support and assist in developing coping strategies (Crawshaw, Hunt, Monach, & Pike, 2013; Monach, 2013). Egg donation, like sperm and embryo donation and surrogacy, differs from other types of fertility treatment as it requires a greater focus on the meaning and significance of the treatment (Hunt, 2013), particularly an exploration around the implications of the lack of genetic link, potential issues regarding disclosure and the parent/child relationship (Hammarberg, Carmichael, Tinney, & Mulder, 2008). Boivin et al. (2001) suggest that there are certain specific objectives for third party reproduction including coming to terms with an alternative route, gender differences, suitability, disclosure, legal and medical aspects, role of the donor, and preparing for the procedure.

Several screening tools have been developed to identify fertility patients in need of psychological support such as SCREENIVE, FertiQoL and FertiSTAT (Peterson, Boivin, Norre, Smith, Thorn, & Wischman, 2012). The literature generally suggests that, once it has been confirmed who is in need of fertility counselling is often divided into implications

counselling (understanding the implication of the fertility route taken, in the case of egg donation, understanding the meaning of egg donation and its implications for all parties involved, disclosure issues, legalities and donor siblings) and, support and therapeutic counselling (centred around providing emotional support at stressful times and helping clients cope with the consequences and acceptance of their infertility and treatment (Cramond, 1998; The Human Fertilisation and Embryology Authority, 2015; Crawshaw, Hunt, Monach, Pike, & Wilde, 2013; Peterson, et al., 2012). A New Zealand study (Goedeke, Daniels, & Thorpe, 2016) into counsellors' experience of their role and responsibility with regard to embryo donation found that embryo donation was experienced by the clients as having long-term implications, and that these were difficult for clients to comprehend due to them being caught up in protecting their hopes; it was difficult for clients to even dare to believe that they would achieve pregnancy and have a child, let alone being able to look past the point of success. In the counsellors' view implication counselling was the predominant counselling form. This may also be the case for egg donation which bears many similarities to egg donation.

The BICA supports the HFEA statement that counselling for egg donation recipients should be routinely offered, and further recommends that a minimum of two sessions be made available by the clinic, that clinics provide written information regarding egg donation and which organisations people can contact, and that the legal status of the donor-conceived child is fully explained (Crawshaw et al., 2013). Furthermore, infertility counselling can also be seen as a way of ensuring informed consent – ensuring that people are fully aware of the implications and consequences of the decision they make (Joy & McCrystal, 2015), as counsellors can help to ensure that patients fully understand the medical, legal and psychosocial implications of their actions (Peterson et al. 2012).



Infertility counselling research has suggested that people undergoing IVF might wish for some counselling, whether prior to treatment or during it (Laffort & Edelman, 1994). Though there seems to be a wish for counselling amongst IVF patients, still relatively little is known about the effectiveness of the counselling that patients receive (Klerk et al., 2005; Marcus, Marcus, Marcus, Appleton, & Marcus, 2007), and the existing research seems somewhat contradictory. Some studies have reported high levels of satisfaction with the counselling regardless of whether it is mandatory or voluntary (Marcus et al., 2007; Stewart et al., 1992). Marcus et al. (2007) found that out of the 30% of people that participated in counselling, 50% of them reported a high satisfaction with the counselling, while the remaining were either indifferent (38%) or found it unhelpful (10%). Other studies have found infertility counselling to have little effect on levels of anxiety and depression regardless of whether the counselling took place pre-treatment, or once pre-treatment and once during treatment (Emery, Beran, Darwiche, Oppizzi, Joris, Capel, Guex, & Germond, 2003; Connolly, Edelmann, Barlett, Cooke, Lenton, & Pike, 1993). Additionally, despite some research suggesting a perceived need and wish for counselling, there seems to be a limited uptake of people actually seeking it (Joy & McCrystal, 2015; Klerk, Hunfeld, Duivenvoorden, den Outer, Fauser, Passchier, & Macklon, 2005). Reasons such as scheduling/time, lack of awareness of how to go about it, anxiety about treatment retraction if there are signs of treatment uncertainty, feeling unable to cope, and prohibitive costs have been given (Klerk et al., 2005; Boivin, Scanlan, & Walker, 1999; Pepe & Byrne, 1991; Marcus et al., 2007). The prospect of potentially negative encounters with other medical professionals has also been suggested as a reason why clients might not feel comfortable about speaking to a psychologist at the same clinic (Bartlam & McLeod, 2000). Infertility research has suggested that people often seek support online, but that those who rely solely on the internet versus a

combination of the internet and a social group show higher levels of distress (Cousineau & Domar, 2007). This suggests that appropriate support can help to de-scale the levels of distress. The idea of the helpfulness of peer support is supported by the Donor Conception Network (DCN) which was founded in 1993 by five sperm donor families to guide and support other donor families or prospective donor families. The DCN offers workshops, peer support and information about being a donor-conceived family.

There has been some discussion as to whether counselling should be made mandatory (Machin, 2011); in countries like Australia this is the case for donor recipients whereas in countries like the UK and Denmark counselling is advised but not mandatory (Hammarberg et al., 2008; Machin, 2011). The debate has been around the fact that although counselling can be helpful to aid recipients in managing the psychosocial aspects of gamete donation, not all want therapy, and that therefore other ways of supporting recipients might be found, such as via other professionals, primarily doctors and nurses (Machin, 2011). For recipients who do not engage with therapy, other professionals might be the only people they confide in, as they might choose not to disclose to family and friends. This gives other professionals a central role in supporting and guiding (Hammarberg, Astbury, & Baker, 2001). However, it has been suggested that doctors underestimate the emotional and physical distress that patients involved in reproductive treatment endure (Kopitzke, Berg, Wilson, & Owens, 1991), suggesting that it could be difficult for them to provide the appropriate support. Perhaps further support and education needs to be given to medical staff with regard to the psychosocial impact of infertility and infertility treatment in order to equip them with the means to provide suitable support and guidance. In the US there is ongoing discussion about how to create a more integrative approach to infertility treatment by providing counselling services onsite – to support patients as well as the medical team (Domar, 2015). The idea

behind the approach is for patients to have easily accessible daily support, provide physicians with social workers, and provide time guarantees for services. It also means that medical staff have access to new research in the area, get a view on the patient perspective and receive support in managing difficult situations (Domar, 2015).

Another interesting area within infertility counselling is cross border fertility treatment. This phenomenon is still relatively under-regulated and under-researched, yet more and more people are seeking treatment abroad (Joy & McCrystal, 2015), often due to shortage of eggs in their home country, shorter waiting lists elsewhere, and high costs and dissatisfaction with treatment in the home country (Culley, 2011). Egg donation is the most sought after fertility treatment abroad (Hunt, 2013). Blyth (2012) showed that infertility counselling varies across countries with regard to the qualifications and standards needed, and identified four areas which could be used to examine similarities and differences across countries: “The legal mandate for counselling; eligibility credentials for individuals carrying out professional counselling activities; different forms of counselling; and counselling practice in relation to specific elements of assisted reproduction treatment” (2012). The European Society of Human Reproduction and Embryology (ESHRE) has compiled cross border infertility counselling guidelines which can be used by all practitioners, though as of yet it is not a requirement to follow these guidelines and the extent to which they are used is unknown (Hunt, 2013). Further thought needs to go into how people who go abroad independently can access support, and ensure that UK clinics who refer abroad encourage people to seek counselling before travelling (Hunt, 2013).

This piece of research hopes to further explore how support or lack of support was perceived along the way.

### **1.11 Women's experience of egg donation**

There has been a paucity of research so far exploring women's experiences of conceiving by donor eggs. To highlight the psychosocial aspects of egg donation, Hersherberg (2007) conducted a systematic review of studies from 1983-2002, and found six areas which the research was centred around: motivation of recipients, desired donor characteristics, known versus unknown donor, recipient demographics, disclosure, and the parent/child relationship. The motivation of recipients for pursuing egg donation consisted of wanting to experience pregnancy and wanting a new born child. Interestingly the research also suggested that the recipients preferred egg donation to adoption due to a "mistrust of the adoption process" (Sachs & Hammer Burns, 2006, 332). Regarding donor selection and characteristics it seems that medical and genetic history, race, personality, appearance and intelligence is important for the recipients (Lindheim, Kavi & Sauer, 2000; Hersherberg, 2007; Sachs & Hammer Burns, 2006, 329). Regarding recipient demographics two studies have found that recipients are often "between 34 and 41 years old, white, well educated, financially secure, and experiencing above normal levels of marital satisfaction" (Hersherberg, 2004; Applegarth, Goldberg, Cholst, 1995; Golombok, Murray, Brinsden, & Abdalla, 1999), and that in general recipient showed good psychological health.

Only one qualitative study to date has looked at the overall experience of women having conceived with the assistance of egg donors. The study was divided into two, and both explored recipients' experiences using descriptive phenomenology, with the aim of understanding and describing their experiences. The women were between 33 and 46 years old, and all pregnant at the time of the interview. The first part of the study was reported by Hersherberg (2006) and examined recipient women's experience of egg donation. The following four themes emerged: 1. Acknowledging the desire for motherhood; 2. Accepting

and coming to terms with donor oocytes as a way to achieve motherhood; 3. Navigating an intense period of decision making; and 4. Living with the lasting legacy of achieving motherhood through oocyte donation (Hershberg, 2006, pp. 163-165). The theme “acknowledging the desire for motherhood” described the wish by the women to be in suitable relationship, and therefore delaying any attempts to conceive till later in life, and their wish to fulfil a lifelong dream of becoming a mother and a good parent. The second theme “accepting and coming to terms with donor oocytes as a way to achieve motherhood” captured their experience of realising their infertility, which was for some traumatic, and for others expected, due to waiting till past 40 to try and conceive. The theme also describes how the women’s reaction to egg donation changed over time, from initial rejection to acceptance, exacerbated by the wish to experience pregnancy. “Navigating an intense period of decision making” depicts the experience of women deciding on the donor as “surreal” (165), and the theme “living with the lasting legacy of achieving motherhood through oocyte donation” expressed the women’s concern about being aged parents, about the donor’s involvement, and the impact of the unknown genetic history of the donor. All of these aspects have helped to extend our understanding of the egg donation phenomenon. The findings from this study were similar to those of Thorn (2009) with regard to the idea that women need to modify their self-identities to include the fact that they are unable to conceive “naturally”, and that this impacts on how they view their femininity and their roles as mother and woman. All of the participants in Hershberg’s study were white British, well-educated, heterosexual, and married. As mentioned throughout, it has been argued that egg donation could be experienced differently depending on one’s cultural and religious background. The aim of this study was to recruit from a more diverse group than in Hershberg’s study, while trying to stay within the homogenous ideology of interpretative phenomenological analysis. Although the

recruitment process proved difficult, this study did recruit somewhat more diverse than the Hershberg study.

The second part of the study was reported by Hershberg, Klock, & Barnes (2007) and depicts the recipient women's experience of disclosure. Two themes emerged: "engaging in selective disclosure" and "responsibility toward the resulting child". The two themes encapsulate how whether the women chose to disclose or not, all engaged in selective disclosure, though the degree varied. The themes also suggested that the women had the child's best interest at heart when contemplating whether to disclose. The women's decision making was influenced by their "values and beliefs, and social and cultural influences" (291) and reiterated Hahn and Craft-Rosenberg, suggestion that people focus on the child's right to know, and the rights of close relations, and wanting to protect the children from finding out accidentally, shame, and not wanting the disclosure to cause harm. The women also expressed a desire to protect themselves and their children from stigma.

### **1.12 The study's link to Counselling Psychology**

As discussed, there is a paucity of research exploring women's experiences of being the recipient of egg donation. Although "fertility counselling" is evolving there is still a need for specialist support for this group of women. The fact that these women become pregnant with the assistance of egg donors, and are not themselves genetically related to the child they give birth to, will inevitably bring up specific psychosocial issues which are different from those experienced by women having other infertility treatments.

Much of the research on egg donation is about the children's welfare, disclosure and the parent/child relationship. There is some research on counselling and infertility but little research into the area of egg donation and counselling. The focus on the women's experience

is a start in giving some insight into how we, as counselling psychologists, can support the women better. To gain this insight, an understanding of what the experience is like for the women is needed, which is the focus of this piece of research.

Counselling psychology is important in helping the recipient of egg donation explore their options, and the meaning of the choices that they make (Braverman & Frith, 2014). There is a need to explore the lifelong implications that are undoubtedly part of choosing the egg donation route i.e., how do they feel about not being able to have a genetic child, what does it mean for them to go down the egg donation route, and how will they manage disclosure (Braverman & Frith, 2014).

As mentioned in Section 1.10, ‘egg donation and support’, the British Infertility Counselling Association (BICA) was founded in 1988 to ensure a high standard of counselling for everyone involved with infertility or engaged with infertility treatment, and its members include counsellors, psychologists and other medical professionals, among others.

Counselling Psychology is therefore not at odds with the BICA, rather, counselling psychologists might be an important addition to the membership of BICA to ensure a continued satisfactory level of counselling and knowledge within infertility counselling. Additionally, Counselling Psychologists wishing to specialise in infertility counselling should adhere to the BICA guidelines.

There are still many ethical and legal implications which have not yet been resolved, i.e., concerns about the child, donor’s and recipient’s wellbeing, how to regulate the cost and more commercial sides of egg donation, setting the boundaries as to how, who and what should be allowed (Sarasohn Glazer & Weidman Sterling, 2013). Counselling psychologists

play a role not only in helping to improve clinical practice, but also in gaining a greater understanding of the implications of egg donation in order to provide guidance, alongside other professionals and the BICA, as to how it should be managed and regulated, and how best to support professionals and recipients in this task. Sometimes the professionals are the only people that potential recipients confide in, as they might chose not to disclose to family and friends. This gives professionals a central role in supporting and guiding. Additionally, it has been suggested that doctors actually underestimate the emotional and physical distress that patients engaged in reproductive treatment endure (Kopitzke, Berg, Wilson, & Owens, 1991).

The aim of this study is therefore to further expand on egg donation research, in particular the “lived” experience of the recipient women, with the broad research question “what is women’s experience of being the recipient of donor eggs?” The aim is to broadly capture what these women’s experiences are in order to further our understanding of the phenomenon of “egg donation” and the implications it has.



## **2 Methodology<sup>2</sup>**

### **2.1 Chapter overview**

Firstly, this chapter will examine the relevance of Interpretative Phenomenological Analysis (IPA) to the research topic and question, and explain the rationale for using this method for the study. Secondly, an overview of IPA is given, including the study's epistemological stance. Thereafter, reflexivity is explored in terms of acknowledging my involvement in the research process. Finally, the recruitment process, the participants, the ethical considerations and the analysis are presented.

### **2.2 Research design**

This is a qualitative study looking at women's experience of being a recipient of donor eggs. Semi-structured interviews were used to explore eight women's experience of this phenomenon. Based on the study's aim to explore women's subjective experience of egg donation, the qualitative methodology of Interpretative Phenomenology Analysis (IPA) was used to interpret the findings.

### **2.3 Rationale for choice of methodology**

When deciding on what methodology to use for a study it is crucial to consider what the study wants to explore and achieve (Langdridge, 2007; Willig, 2009). This study explores and describes the 'lived experience' of what it is like for the participating women to have a child through egg donation: their thoughts and feelings during the process, including after their child was born. Furthermore, the study aims to get an insight into the subjective experience of each participant, while also looking for general themes across participants to

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<sup>2</sup> The methodology chapter is written in the first person to openly reflect the researcher's involvement in the research process.

help shed light on the experience of the women. With the research aims in mind, the broad research question emerged: “what is a woman’s experience of being the recipient of donor eggs like?”.

As this study is looking at women’s experience, a qualitative research method was deemed the most appropriate. The focus in qualitative research is on what an experience is like, what it feels like, how it is discussed, and how people engage in sense making from it (Willig, 2012, 5). Additionally, qualitative research can be used to focus on exploring a few in-depth experiences rather than focusing on a larger sample with a view to generalising the results (Willig, 2012).

Kvale suggests that, when it comes to choosing the most appropriate methodology for research, it is crucial to think of the methodology as “the way to the goal” (1996, 278, cited in Willig, 2009). Hence, the research question should inform one’s choice of methodology. The research question for this study is based on wanting to elicit and explore the subjective “lived experience” of what it is like to be a recipient of donor eggs, and IPA was therefore chosen as the most appropriate methodological approach. IPA permits an investigation of the women’s experiences, and an understanding of the phenomenon, egg donation, without focusing on any particular aspects of the phenomena.

It could also be argued that grounded theory would have been suitable. It has been suggested that IPA and grounded theory share many similarities such as the terminology used, the systematic analysis and the focus on examining people’s experiences (see Smith, 1995, 1999; Willig, 2009). However, grounded theory seeks to make more macro-level claims by producing theory and engages with developing the participants’ accounts further (Smith, et al., 2009), whereas IPA is much more focused on the micro-level by focusing on a

few people's detailed experience. In this study, IPA was deemed more appropriate than grounded theory because of the focus on exploring how women view their experiences of egg donation rather than on building a theory of this. This study wanted to take a more exploratory approach to the experience of using egg donation, which IPA allows, rather than a more explanatory approach, as grounded theory aims to do. Choosing to take an experiential approach, as opposed to focusing on building a theory or focusing on the narrative used, was done based on there being relatively little research on the area of egg donation, and it therefore seemed important to take a bottom-up approach in which themes could organically transpire, as opposed to my imposing certain areas. It could be argued that grounded theory, like IPA, allows for a bottom-up process, however, IPA, as suggested by the rapid increase of IPA research within psychology, fits well within the ethos of Counselling Psychology, with its focus on "giving voice and making sense of the experience" (Larkin, Watts, and Clifton, 2006).

Thematic Analysis (TA) was also considered as a possible tool of decoding. TA, like IPA, searches for themes and meaning in data, however, where IPA is theoretically and epistemologically bound in phenomenology, TA is not bound, and can be used across a range of theory and epistemologies (Braun & Clarke, 2006). The focus of TA is to find patterns or themes across whole data sets, whereas IPA seeks to firstly capture the themes individually, and then move across the data sets, thereby ensuring that a voice is given to each participant. For this piece of research, with the research question in mind, IPA was deemed more appropriate than TA due to the research question wanting to capture, in detail, the *experience* of egg donation, which is in line with the phenomenological epistemological stance of IPA, which holds the experience as the core (Holloway & Todres, 2003).

## 2.4 Overview of IPA

IPA is a recent and rapidly growing qualitative methodology (Smith, Flowers, & Larkin, 2009). The rise in IPA's popularity seems to be due the straightforward guidelines that the methodology offers, which makes it an easily accessible approach. It could be argued that IPA has two goals (Larkin, Watts, & Clifton, 2006). Firstly, it is concerned with understanding and describing peoples' experiences by examining in detail how people make sense of their experience. Secondly, it is interested in looking at the individual's experience in relation to the other participants' accounts, and the wider social, cultural and theoretical context, as well as the phenomenon.

As mentioned above, the focus of IPA involves eliciting an insight into people's views, and understanding a specific phenomenon (Willig, 2009). This is done by capturing the reflections that people make about their experiences, as these reveal peoples' attempt at making sense of their experience (Smith, Flowers, & Larkin, 2009). According to IPA "*an experience*" is defined by "something important which is happening to you" (Smith, Flowers, & Larkin, 2009, 2). "*An experience*" can be a moment of special importance, or a collection of moments that make up a common meaning. This study is looking at the participating women's experience of the separate moments/parts – making the decision, medical procedure, sense of self, view of the donor – that collectively make up the "*experience*" of egg donation. As with other qualitative methods, IPA is concerned with an in-depth exploration of peoples' subjective and individual experience of a particular phenomenon, "what the experience for *this* person is like, what sense *this* particular person is making of what is happening to them" (Smith, Flowers, & Larkin, 2009, 3). The aspiration is to gain insight (Conrad, 1987) into the participant's experience of the phenomenon: i.e., to get a sense of what it would be like to walk in the participant's shoes by aiming to get to the essence of their experience. This is done by attempting to explore and understand how people

make sense of that particular phenomenon (Larkin, Watts, & Clifton, 2006) through examining people's thoughts and perceptions on the matter.

IPA is influenced by the three pre-existing philosophical approaches of phenomenology, hermeneutics and ideography. IPA is phenomenological, and has been influenced by some of the great phenomenologists, such as Husserl, Heidegger and Gadamer, in its aims to explore peoples' "lived experience" by letting the phenomenon in question "show itself as itself" (Larkin, Watts, & Clifton, 2006, 108). IPA wants to capture what the human experience is like. However, IPA differs from descriptive phenomenology in its more interpretative (hermeneutic) angle (see Bramley & Eatough, 2005; Shinebourne & Smith, 2009). It is believed that it is possible in IPA for the researcher to be descriptive of a participant's experience while also being able to hypothesis about "what it means for the participants to have made these claims, and to have expressed these feelings and concerns *in this particular situation*" (Larkin, Watts, & Clifton, 2006, 104, italics in original). IPA is about being able to "give voice" (Larkin, Watts, & Clifton 2006, 102) to the participants' accounts whilst also being able to make sense of those accounts through a more interpretative lens. IPA differs from general phenomenology by not merely describing/"giving voice" to the participants' accounts of what the experience is like, but by also analysing what the accounts say about what that particular situation or experience means to them (Larkin, Watts, & Clifton, 2006). There are therefore two levels to the IPA analysis; what the experience is like and what it means to them.

As Smith, Flowers and Larkin state "[IPA] is phenomenological in attempting to get as close as possible to the personal experience of the participant, but recognises that this inevitably becomes an interpretative endeavour for both the participant and the researcher. Without the phenomenology, there would be nothing to interpret; without the hermeneutics, the phenomenon would not be seen." (2009, 37). This follows Heidegger's and Husserl's

understanding of phenomenology as it acknowledges that people are “part of reality” (Larkin et al., 2006, 105). It is not possible to understand ourselves without engaging with the world, and it is not possible to understand the world without acknowledging our involvement with the world (Larkin et al., 2006). Heidegger suggested that a person is always “a person in context” (Larkin et al., 106), therefore excluding a definite reality/truth, as a complete separation of ourselves from the world is impossible. Reality cannot be understood by its own but only as a function between the person and the world:

“Any discovery that we make must necessarily be a function of the relationship that pertains between researcher and subject-matter (person and world, subject and object etc.)” (Larkin et al., 2006, 107). IPA is therefore hermeneutic in its approach as it recognises the researcher’s role in helping to construct meaning out of the participant’s sense making. This is also referred to as the double hermeneutic (Smith & Osborn, 2003), as the researcher attempts to make sense out of the participant’s sense making. Consequently, IPA theoretically acknowledges that a first-person account is not completely possible. IPA researchers believe it is their aim to get as close to the participant’s experience as possible. They aim to see the world as the participants do, which is believed to be achievable through the researcher’s ability to be empathic and to create a safe environment in which participants feel comfortable in sharing their experiences, and for the researcher to remain reflexive during this process.

Additionally, IPA is an interpretative method in its ability to look at an individual’s experiences in relation to the other participants’ experiences in order to find potential commonalities. Furthermore, participants’ accounts are also considered within the wider social, cultural and theoretical context.

IPA is idiographic in its focus on the detail and the particular; the focus is firstly on the individual case and thereafter moves to examining the commonalities and differences across

a small number of cases. The idiographic level that IPA is based on is not, as commonly but erroneously thought, meant to only include the “study of individuals” but also includes the “study of the specifics” rather than the general (Larkin et al., 2006, 103). IPA studies therefore tend to focus both on specific people’s experiences and on a specific situation/event.

IPA looks at the particular phenomenon with regard to a particular group of people in a particular context. With regard to this study, IPA helps to give insight into the phenomenon of egg donation from the perspective of eight women who have gone through the process of having a child through egg donation, by firstly analysing each individual woman’s experience and thereafter looking for commonalities and differences across all the women to get to the essence of what appeared to be these eight women’s experience.

The focus on the detail and the particular means that IPA studies often employ small, purposive and homogenous samples sizes. However, the degree to which the sample is homogenous is dependent on the nature and constraints of the study (Langdridge, 2007). In this study, the sample is homogenous in that they are all women, who have experience of the same phenomenon i.e., having a child with the assistance of egg donation, and they are all in the late child-bearing age i.e., over 40 at time of birth.

It has been argued that due to the small sample size, and the chosen method, generalisation is not the aim. This has led to questions about the actual importance of the contribution of the findings of qualitative research (Pringle, Hendry, & McLafferty, 2011; Malim, Birch, & Wadeley, 1992). However, though generalisation is not the objective, it is possible to find commonalities across participants and these can help provide some insight into the phenomena (Pringle, Hendry, & McLafferty, 2011; Reid, Flowers, & Larkin, 2005).

Additionally, theoretical generalisation is possible by examining the findings against other research and literature, which can help to generate debate about the phenomenon in question.

## **2.5 Epistemological and ontological standpoint**

This research takes the phenomenological epistemological stance that it is possible to gain knowledge about people's subjective experience of their thoughts, perceptions and emotions (Willig, 2012). The aim of this study is to gain knowledge about how the women in the study viewed and experienced being the recipient of egg donation. The assumption this piece of research makes is that people are able to provide us with an insight into how they experience a particular phenomenon, by the way they talk about it. In this case, the study takes the stance that it is possible to gain insight into the quality and texture of participants' thoughts and feelings regarding their experience of being the recipient of donor eggs.

It is acknowledged that the researcher is involved in making meaning of the participants' experience. Though the aim is to get as close to the participants' experience as possible, it is accepted that the participants' experience can only be understood through the researcher's analysis.

Additionally, the study takes the viewpoint that due to people's different ways of thinking and assuming, the same world can be experienced very differently (Willig, 2009). It is therefore acknowledged that the eight women in this study might have a very different view of being the recipient of egg donation.

The ontological assumption of this study is that people are able to provide us with an insight into how they experience a particular phenomenon by the way they talk about it. Though the aim is to get as close to the participants' experience as possible, it is accepted that the participants' experiences can only be understood through the researcher's analysis. It is



recognised that the experiences the study is aiming to capture will be subjective, and that the study aims to understand the experiences described by the eight participants without aiming to obtain “the absolute truth”. This study therefore does not aim to capture universal truths, but rather aims to capture eight women’s individual subjective experiences of being the recipient of donor eggs. Consequently, this study takes on a relativist ontological position (Willig, 2001) in which no judgement is being made as to whether the participants are stating the objective truth.

## **2.6 Reflexivity**

Reflexivity is crucial in IPA due to its interpretative nature according to which the researcher is believed to be embedded in the data, e.g., the researcher influences the research process through their interaction with the interviewee, and the researcher is involved in making sense out of a participant’s own sense making. Reflexivity on the researcher’s part is therefore essential in analysing the researcher’s influence on the final outcome (Shaw, 2010).

Langdridge defines reflexivity as “the term for the process in which researchers are conscious of and reflective about the ways in which their questions, methods and very own subjective position [...] might impact on the psychological knowledge produced in a research study” (2007, 58-59). An instrumental part of the research is, therefore, for the researcher to continuously reflect on their own assumptions about the world, their investment in the research, and their interactions with the participants in order to get as close to the participants’ experience as possible (Finlay, 2003).

My interest and experience into infertility and the use of Assistive Reproductive Treatments (ART) was first elicited by the struggles with fertility experienced by my close friends and family. As I followed their journeys I began reflecting on the differences in how

people come to make the decision of using ART, the sorrows and heartaches when it does not succeed, the effect it has on a couple's view of themselves and each other, and the extent to which people feel comfortable sharing their infertility struggles with others. This sparked my interest in the psychological experience of infertility and infertility treatment, and the individual differences that there might be in how people experience the process. Despite my somewhat personal experience of infertility via my friends and family, I felt that I was sufficiently removed from their experiences that this would not negatively impact on the research. Also, none of my personal experiences have involved egg donation, and IPA does acknowledge that the researcher's own assumptions/"preconditions" (Willig, 2009, 69) will be embedded in the research, and that a researcher can therefore never interpret the material with complete objectivity. I have therefore remained reflexive during the research process by using a diary in which I have continuously reflected on my own thoughts, feelings and experiences about the interactions with the participants, the actual content of the participants' experience, and the hopes and expectations for the research and the findings. Additionally, following van Manen's (1990) ideas that assumptions are constantly being made, I have kept a field diary in which thoughts and feelings about the work were written pre- and post-interview in order to help me reflect on any particular biases I might have had which could have affected the interview or other parts of the research process.

Both diaries aided the bracketing of my own experience and thoughts, and helped me to separate these from the experience of the participants. It is generally accepted within qualitative research that it is impossible for a researcher to be neutral, which underlines the importance of staying reflexive throughout the process (Langdridge, 2007).

Before conducting any interviews, as recommended by Finlay (2003), I took time to examine my assumptions and expectations about the research by writing down all my initial

thoughts and expectations of themes (see appendix 2). This became especially important as during the early stages of research my own relationship broke down, which affected my own thoughts about my prospects of having children and my own fertility, and I therefore found myself being able to relate more personally to some of the themes in the women's stories, such as the struggle to find the right relationship, uncertainty, the unknown, etc. Both reflexive practices, the field diary and the mind map of initial assumptions and expectations, helped me to think about how I would feel if I could not have children naturally and if I needed the assistance of an egg donor, and aided me in bracketing my own assumptions and point of view.

My reflections after the first interview helped me to think about what I might be representing to some of the women as I am of child-bearing age. I reflected upon some of the thoughts the women might be having about me and my ability to have children. Although none of the women directly asked about whether I had children, many of them commented on how women should not leave it too late to have children. This felt to be both a reflection of their wish for having had children earlier, and also a reminder to me that I should not wait.

I feel that the epistemological stance of IPA sits comfortably with my identity as a counselling psychologist. This allows for the focus on examining people's feelings, perceptions and experiences, and has the underpinning belief that people have the ability to express their inner world. As a counselling psychologist, I am able to listen to clients' individual subjective experience, without judging whether it is the objective truth or not. I accept their experience as their own reality.

## **2.7 Recruitment**

The study set out to recruit eight women who had experience of achieving pregnancy through the assistance of egg donation within the past 10 years. The women were required to have had carried the child to term. Women who were currently pregnant through the use of egg donation, or who did not carry a child to term, were excluded from the research on the basis of the risk of potential negative psychological effects of participating. Additionally, to reduce the chance of recruiting vulnerable mothers such as those suffering from postnatal depression, an exclusion criterion of one year past birth was also added. No restrictions in terms of age, culture, social and marital status, or religion were made, as it was acknowledged that the recruitment process could be difficult due to the sensitive area of the research. Additionally, at the time of the research to my knowledge there had been no research which had suggested that a women's age, marital, cultural or religious status would greatly impact the women's experience of being the recipient of egg donation.

Due to the acknowledgement that recruitment of participants could prove difficult, various methods of recruiting were used. An advert (see appendix 3) for participants was put up on fertility chat rooms such as [www.fertilityfriends.co.uk](http://www.fertilityfriends.co.uk) and chat rooms for mothers such as [www.mumsnet.com](http://www.mumsnet.com). Additionally, adverts were put up in locations that potential interested mothers might frequent, such as cafes, universities and shops – with the permission of the owners. Participants were also recruited through the Donor Conception Network ebulletin, a monthly newsletter sent out to all members of the Donor Conception Network, and through word of mouth.

## **2.8 Participants**

In total fourteen women contacted me with an interest in participating; one through word of mouth, one through mumsnet.com, and twelve through the Donor Conception Network

ebulletin. Out of the fourteen women eight were individually interviewed. Due to the idiographic stance of IPA the participant number was deemed appropriate in order to collect sufficient data to achieve a thorough analysis (Kirkman, 2003) and is considered a sufficient number for an IPA study at doctoral level (Smith, Flowers, & Larkin, 2009). The remaining six were excluded from the study due to not fitting the criteria by either living abroad, not being able to attend a face-to face-interview or having children under the age of 1.

All the women made the first contact and were then contacted to ensure they met the criteria and did not show any signs of psychological distress. A pack with the information leaflet, including the areas that would be discussed in the interview, and the consent form was sent to the women that fitted the criteria, and they were asked to read these and decide whether they were interested in taking part.

All eight women consented to taking part and a date and location for the interview was arranged. All the women were given a choice of location and date for the interview. Six of the women were interviewed at their homes. A colleague of the researcher was made aware of the locations and times of the interviews, and was contacted at the beginning and end of the interview to manage any potential risk issues to do with going to the participants' homes. The last two participants were interviewed at City University.

Before the start of the interview each woman was asked to re-read the information sheet (see appendix 4), and the consent form (see appendix 5). Sufficient time was given for the participant to ask any questions they might have about the information sheet and the consent form. If no concerns were expressed the participant was asked to sign the consent form. All the participants filled out a brief biographical questionnaire about their age, cultural, socioeconomic and religious background, relationship status, number of children, number of children conceived through other kinds of assisted reproductive technology other

than egg donation, and number of children conceived through egg donation (see appendix 6). This was done in order to potentially put the research in the context of the backgrounds of the participants.

## **2.9 Interview schedule**

Based on the study's aim of capturing women's rich experience it was decided that semi-structured interviews would be the most appropriate data collection method. A semi-structured interview is often thought of as one of the most useful methods for collecting qualitative data as it enables the participant's individual experience to come to light by allowing for change and variation within individual accounts, while having some guidelines to help ensure the interviewee stays on topic (Smith, 1995; Smith, Flowers, & Larkin, 2009). There has been some criticism around using semi-structured interviews, such as the claim that the interviewer is not sufficiently visible when writing up the research, and that the interview is not acknowledged as an interaction (Potter & Hepburn, 2005). I stayed reflexive throughout the process by using a field diary in which thoughts and feelings about my interaction with the participant and the effects these might have had on the data collected were considered.

All the interviews took between 60 and 90 minutes.

The interview schedule was designed to be as neutral as possible in order to allow the participants' own experiences to come to light, while staying within the research topic (Smith & Osborn, 2003). The focus was on allowing the participants space and time to explore their experiences, while I, as the researcher, was being mindful of the theories and research which had helped inform the schedule. The interviews all started with the same broad question, "Could you tell me about your experience as an egg donor recipient in as much detail as

possible?”. This was to allow space for the first thing that came into participants’ minds. Furthermore, it aimed to ensure that the topic was approached in a way that felt comfortable for the participant, and allowed the participant to start from the point that they felt was the most appropriate (Smith & Eatough, 2009). Thereafter, the interviews loosely followed an interview schedule designed to explore participants’ overall experience (see appendix 7). The questions focused on the process of conception, including their experiences of the actual donation, the support that they received, and if and how they could have been better supported, their views and experiences about their pregnancy, their sense of self as a woman, mother and partner, their views on their mother/child attachment, and their views about their egg donor. Throughout the interview the aim was to help participants relate their experiences about the topic, while letting them share their experiences in their own way to capture the quality and richness of each person’s experience (Smith, Flowers, & Larkin, 2009). This meant that the interview could change for each participant. The interviews ended by asking whether the participants would like to add anything else.

After the interview the participants were given time to ask any questions they might have about the research, or to discuss the questions asked. The participants were also given a debriefing sheet (see appendix 8) with a list of potential sources for further psychological support should they require it. Time was also allowed for a brief discussion about how participants had found the experience of taking part, and if anything, in particular had surprised them.

## **2.10 Transcription**

The interviews were audio recorded and transcribed verbatim. The transcription followed the same notation code i.e., participants were given an alias, all identifiable information was replaced with a [child’s name], [place] or [job title] etc. As the study was interested in

capturing the essence of the participants' experience it was deemed appropriate to transcribe the data verbatim. This meant that vocal utterances, broken words or sentences and non-verbal communication were included in the transcripts (see appendix 9).

## **2.11 Analytic strategy**

The transcripts were analysed using Interpretative Phenomenology Analysis (IPA). The aim of IPA is to “capture the experience and meanings associated with a phenomenon rather than to identify people's opinions about it” (Willig, 2009, 67).

After each interview, I recorded any initial thoughts or themes that had occurred to me during the interviews. Later I recorded all the thoughts and ideas across the participants in order to compare my pre-ideas and thoughts to the final master themes and in an attempt to bracket biases (see appendix 10).

In line with Smith and Dunworth's (2003, 609) idea that “mentally hearing the voice of the participant during subsequent readings of the transcript assists with more complete analysis”, I listened to the interview several times, so I could fully emerge myself into the interview and the participant's experience. At that stage I wrote down any initial thoughts, feeling or images in a field diary to capture my initial observations/biases. The text was then analysed according to Smith, Flowers and Larkin (2009). Each text was read and re-read several times, and any initial observations and thoughts were written down in the right margin. All observations and thoughts were colour coded: yellow for descriptive comments, i.e., describing the content, rephrasing of the participant's comments, or important words; green for contextual comments, i.e., questions the text evoked, comparisons in the text, comparisons across participants and interpretations of the text; and pink for linguistic reflections, i.e., thoughts about the use of language. The text was then read again, including



my notes in the right margin, and emergent themes were identified, and written in the left margin. The emergent themes were then collected and some initial clustering of themes was produced.

After analysing each transcript in this manner, I came to the realisation that the emergent themes were too descriptive and did not truly capture the essence of the participants' experience. Instead I had captured a very descriptive, and slightly prescriptive, view of their experience. Also, due to the highly descriptive stance, in which I had not gone beyond the data, I had ended up with vast amount of emergent themes as I had not wanted to miss out any of their experience. My focus had been more on the P rather than the I. The next step therefore involved an attempt at getting closer to the essence of the experiences by being more interpretative and fluid in my way of analysing, and condensing the themes. This was done by, for each transcript, going through each of the early emergent themes and interpreting what having that experience *meant* to the participant while keeping in mind the research question of “what is this woman's experience of being the recipient of donor eggs?”. This process helped me to step away from the descriptive words the participant was using and get closer to the “sense” of that experience i.e., instead of “left with two options” it would become “acceptance of egg donation as a process”. Additionally, I focused only on parts that were relevant to the question. This meant that I disregarded material that did not directly answer the question of “what is the women's experience of being the recipient of egg donation?” such as dealing with the bodily changes of pregnancy or the difficulty of holding multiple roles as these were related to motherhood in general and not specific to recipients of egg donation.

This way of analysing helped to shift the focus away from the process the participants were going through and more to the experience they had of this process. After condensing the emergent themes, the condensed themes were clustered to capture the main categories of

meaning within each transcript. A summary for each participant's transcript was produced with the main clusters (see appendix 11). Finally, a joint summary of clusters/themes across the participants' transcripts was produced (see appendix 12) by cutting out each of the themes from each participant and grouping them together according to shared meaning i.e., "resemblance gives idea of belonging", "wishing for resemblance", "sadness for lack of connection" ended up being part of a grouping called "Not belonging", which became a subtheme for "threat to family unit". The groupings were done with the research question in mind, and the themes which did not directly answer the research question were disregarded, for example, "dramatic labour", "pregnancy as odd", since both were related to the general experience of pregnancy rather than giving an insight into what it is like to be the recipient of egg donation.

## **2.12 Ethics**

This study adhered to the BPS ethical guidelines *Code of Human Research Ethics* and *Code of Ethics and Conduct 2009*. Consequently, the study acknowledges that it has a duty to respect the autonomy and dignity of persons, maintain scientific integrity, uphold social responsibility and minimise harm. These principles were upheld by ensuring that the nature of the research was made clear to the participants before the interviews by way of the leaflets used to recruit participants. Furthermore, due to the sensitive nature of the study, and the fact that participants might not have openly spoken about their thoughts on this topic, they were given information about the areas to be discussed prior to the interviews taking place. It was hoped that this would help participants prepare for the interview and give them an idea of what to expect of it. It was made clear that all identifying details would be changed to maintain confidentiality; audio recordings were kept in a locked cabinet separated from any identifying information. Written consent was obtained from each participant before the

interview began and each participant was informed that they were free to withdraw from the study at any point. As this is a very personal and sensitive area to research, it is understood that emotional upset could have occurred during and after the interview, and each participant was therefore verbally de-briefed after the interview. Throughout the interview and the de-briefing, the researcher drew on her counselling psychology skills of empathy and listening, whilst being mindful that a researcher's role is different from that of a therapist. In addition, the participants were given the opportunity to receive a copy of their own transcripts and a chance to change or leave out anything in the transcript that they were not comfortable with. One participant requested the transcript, but did not want to make any changes. Furthermore, the participants were informed that they were welcome to contact the researcher at any time should they have any questions in the future about their interview or the research, however, none of the participants did so.

### **2.13 Validity**

Unlike quantitative research, which has fairly well-established and accepted ways of measuring the validity and reliability of the research, qualitative research is still in the infancy of trying to establish acceptable ways of judging its validity and quality. With the surge of qualitative research methods within psychology in recent times, an adequate way to judge its validity is required (Smith, Flowers, & Larkin, 2009; Yardley, 2000). Several researchers, such as Elliott, Fischer and Rennie (1999), and Yardley (2000, 2008) have come up with slightly different principles. To assess the validity and quality of this piece of research it will be assessed against Yardley's (2000) four principles of quality: *sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance*.

The first of Yardley's principles is *sensitivity to context*, which addresses the importance of the research being explored and understood in the context of existing research

and theory on the topic of investigation, ensuring that the analysis stems from the data. This principle considers the socio-cultural environment, the language used by the participant, and also entails an awareness of the impact that the researcher/participant interaction has on the participant's narrative. This piece of research has aimed to show sensitivity to context through its attempt to carry out a thorough literature review, and via an in-depth discussion section in which the themes of this research are discussed in relation to the existing research and theory around egg donation. Additionally, through reflexivity (see reflexivity section) the researcher/participant interaction was examined. In an attempt to eliminate any potential power imbalance between myself and the participant, the participants were encouraged to choose the time and location of the interview. The use of quotes throughout the analysis section ensures that the analysis stems from the data, and gives the reader an opportunity to check the participants' "voices" against my interpretations.

*Commitment and rigour* and *transparency and coherence* consist of ensuring the appropriate level of diligence of the research. This was achieved by providing a detailed description of the research process under "analytic strategy" – from the outset, through the recruitment phase, and to the analysis. Additionally, much consideration has gone into ensuring that the method, epistemology and research question/aim were coherent with each other.

The last principle is the *impact and importance* of the research. It is hoped that this piece of research will have both a theoretical and practical impact, by adding to the slowly increasing volume of research and knowledge within the egg donation area. Practically the aim is to create a greater awareness of how the topic of donor eggs should be addressed within the psychological and medical field.

## **2.14 Introduction to each participant**

Below is a short introduction to each of the participants which should give the reader a brief insight into each of the women's stories. Four areas have been highlighted for each of the women: Their journey to egg donation, whether the procedure was performed in the UK or abroad, the women's own perspective on the children's resemblance to them, and, finally, a brief statement about the anonymity of the donor. These areas were chosen based on the desire to provide the reader with some context with regards to the themes represented in the analysis section.

### **Laura**

Laura met her partner "late in life" and first attempted to conceive naturally, before proceeding to one IVF cycle. This attempt was unsuccessful, and Laura was informed that there was less than a 1% chance of her conceiving. She and her partner then decided on egg donation, and due to being informed of a long wait in UK, they decided to go abroad. Their first attempt with egg donation was unsuccessful, but Laura conceived on the second attempt with a new donor and her partner's sperm, when she was in her early 40s. She has one child, who at the time of the interview was around pre-school age, and despite several attempts has not been able to conceive again through egg donation. Laura and her partner have decided not to try for more children. According to Laura, the child bears resemblance to her partner (the biological father) and his side of the family, and has similar colouring to her. The donor is anonymous.

### **Maria**

Maria is married, and she and her husband conceived their first child naturally. She was unable to conceive again naturally due to having blocked fallopian tubes. Their second child

was conceived through egg donation, with her husband's sperm, when Maria was in her mid-40s. At the time of the interview the egg-conceived child was primary school age. The treatment was done abroad due to a long waiting list in the UK. According to Maria, her second child has a very Mediterranean look and does not resemble the rest of the family. The donor is anonymous.

### Angela

Angela is a solo parent and conceived twins through a double donation of egg and sperm when 50 years old. Angela had begun the egg donation journey while in a relationship, but the relationship broke down just before Angela made it to the top of the waiting list. After some consideration, Angela decided to go ahead as a solo parent. The procedure was done in the UK. At the time of the interview the twins were toddlers. According to Angela neither of the children look like her, but due to her being a solo parent she stated that people often assume the children look like the genetic father. The donors are anonymous.

### Linda

Linda was single until her 40s, when she met her current partner. After, briefly, trying to conceive naturally and nothing happening, Linda went for a fertility scan which showed that there was little chance of conceiving naturally. Linda successfully conceived twins through egg donation, who at the time of the interview were toddlers. The procedure took place abroad. According to Linda the children have some similarities to her husband, but also have stereotypical mannerisms from the country in which the donation took place. The children have a slightly darker skin than her, but this is consistent with her husband's skin tone. The donor is anonymous.

### Deborah

Deborah met her partner in her late 30s and after having unprotected sex for 18 months, she went to the doctors and was diagnosed with early menopause. She and her husband therefore decided on egg donation using her husband's sperm. They had the procedure done in the UK and conceived one child, who at the time of the interview was at primary school. Deborah stated that her son and her share eye colour and skin tone, and that there is also a resemblance to her husband. The donor is anonymous.

### Karen

Karen was 42 when she and her husband started trying for children. With a small chance of conceiving naturally, they decided on egg donation. They have conceived two children through egg donation and with her husband's sperm. The children were at primary and secondary school at the time of the interview. The donation was done abroad. In her interview, Karen highlighted the children's skin tone as being very different from hers, but that her child's skin tone fits with her husband's more Mediterranean appearance. The donor is anonymous.

### Kate

Kate is in a lesbian relationship with a woman who has a child in her early 20s. Kate did not realise until in her mid-40s that she wanted to have a child. Due to her age Kate was informed that there was a very small chance of conceiving with her own eggs, so she therefore decided on a double donation to conceive, and successfully conceived a child. At the time of the interview the child was pre-school age. According to Kate, there is a very close resemblance between her and her daughter despite not being genetically connected. The donors are anonymous.

Kirsty

Kirsty was in her early 40s when her and her husband started trying for a baby. They went through 19 cycles of IVF: first with her own eggs only, and then four attempts with donor eggs, until switching to also using donor sperm. Two children were conceived by donor egg and sperm, and they were primary school age at the time of the interview. Kirsty stated in the interview that there are some physical similarities between her and her children. The procedure was done in the UK and the donors are anonymous.



## 3 Analysis

### 3.1 Introducing themes

The analysis resulted in four superordinate themes which provide an insight into the participating women's experience of being the recipient of donor eggs: "threat", "living with the life-long consequences", "selfish act" and "doing what it takes". Figure 3.1 represent the superordinate themes along with the sub-themes. All of the themes overlap in some way or another, and at times it felt hard to clearly distinguish the themes and the meanings. In the end, this way of forming and representing the themes seemed the most appropriate as it provides an easy-to-read structure, and captures the essential meaning of the participants' accounts. A further discussion on the overlapping of themes can be found at the end of the analysis section.

"Threat" explores how egg donation can be experienced as a potential threat to the women's concept of family and their self-image. "Living with the consequences" captures the women's experience of the realisation and management of the consequences of being a donor recipient. "Selfish act" depicts how for some of the women the choice to undertake egg donation was experienced as a selfish act. "Doing what it takes" explores the recipient women's experience of getting to the point of choosing egg donation.



*Figure 3.1: Diagram of superordinate themes*

## 3.2 Threat

This superordinate theme captures how aspects of egg donation were perceived as a threat by the women, and is divided into two further themes: “threat to family” and “threat to self”.

### 3.2.1 Threat to family

“Threat to family” illustrates via “Belonging: you belong to me, whether we look alike or not”, “the struggle of disclosure” and “the spectre of the donor”, the women’s experience of how physical resemblance, the potential intrusion of the donor and having to disclose felt as a

potential threat to their family units, as all three themes contain aspects that could challenge the preconception that society holds of what constitutes family.

### *3.2.1.1 Belonging: you belong to me, whether we look alike or not*

All eight women touch upon the idea and importance of the child belonging, and whether a child was perceived to belong to a family seemed to be judged on three aspects: genetic connection, physical resemblance and a feeling of ownership. From the interviews, it seemed that the majority of the women were not particularly focused on the desire to pass on their genes and continue their heritage, instead their focus was on their experience of not sharing a physical resemblance with their children as a consequence of not being genetically connected. This appeared to be a very important aspect for the women, as physical resemblance was seen as helping to create and maintain the idea of the child belonging, both outwardly in others' eyes, and inwardly for themselves, so as not to be reminded of the missing genetic link to themselves and to others. This was true for the majority of the women whose child either bore a slight resemblance to them, or had a close resemblance to their husband, and was more pertinently clear for the women whose children had no resemblance to their parents.

Deborah supports the idea that external resemblance automatically gives the assumption that the child belongs to the family.

*Deborah, 2413: Well, I've always wanted him to look like Harry, (2) maybe with a smaller nose. (2) But [slight laugh] I've always wanted him, so that he doesn't look like. I mean a friend once put it, uhm, a phrase, something like a cuckoo in the nest, you know that they're all birds and then, but this is a cuckoo bird, and I remember being up, [emphasis] almost like. I really didn't like her saying that, like he wasn't*

*mine. (2) And suppose I, I really want him to look like Harry, because I thought he (2), we could pass him off as ours. Even though he is ours, but maybe it would be less complicated.*

Deborah reiterates the idea that close resemblance between the child and the parents makes it easier for the child to be passed off as their own. For Deborah, knowing that resemblance to herself is not possible, she goes for the next best thing; a resemblance between husband and son. The father/son resemblance can be used as a protection against a questioning of the family unit. At the end of the quote there is a sense of an acknowledgement of the child belonging, in terms of feeling like the child belongs, despite the lack of genetic links, suggesting that the “feeling” of belonging and “looking” like belonging are separate entities. A child can feel like yours, without looking like yours, however, physical resemblance means that others will not question the ownership: if there is resemblance then people assume relation. For Deborah resemblance makes matters less complicated, however, she later states that lack of resemblance can make disclosure easier as people are more inclined to have a sense of there being more to the story, or at least are more open to the disclosure, since they expect it.

There are several ways of interpreting the use of the term “cuckoo in the nest”. To me, the term highlights a sense of deceit. It could be argued that egg donation maintains a form of deceit towards the outside world of the “perfect family”. This is upheld by pregnancy and resemblance which hides the facts of a non-genetic connection. Deborah’s strong reaction to the term displays her discomfort with having her ownership of her son challenged.

Maria extends our understanding further with her experience of resemblance and belonging. She and her husband had gone abroad for the donation, and had been informed that the donor

bore a resemblance to her. However, when the child was born there was little resemblance and, as Maria stated:

*Maria, 2487: ... there was a feeling that she looked like she didn't belong to us as a couple, us as a family.*

There is a feeling of the child being the odd one out, not belonging, due to lack of resemblance. In Maria's account of her experience of the lack of resemblance there was a great deal of focus on the difficulties this creates for her daughter. Maria gave a very rational account of her own experience of this, and it felt as though she was slightly hiding behind her daughter's experience instead of facing her own difficult feelings. It could be argued that Maria might not have any difficult feelings regarding the lack of resemblance. However, as a parent, she would naturally be affected by her daughter's difficulties and this might impact on her experience of the resemblance as well. As the next exert will show, it seems that Maria does and did struggle with the lack of resemblance. This exert describes Maria's experience of seeing her daughter for the first time:

*Maria, 1398: ... there was a little kind of "oh" [said with higher pitch tone] moment [brief laugh], [I: mhm] but otherwise, yeah, no, just lovely, I mean, actually, I, I, I, I was going to say that, you know, just because she didn't look at all [said with slight emphasis] like my previous (1) my first child and ..hh [in breath] (1) not particularly, you know, recognisable recognizable to anyone else in my family, ..hh [in breath] uhm (1) having said that my sister who is now, who looks like you, she has got blonde hair, uhm (1) was born with jet black hair [I: mhm] (1) and loads [said with emphasis] of hair, I mean just ridiculous [said with emphasis] amounts of curly [I: mhm] black hair and now she's got dead straight blonde hair, [I: mhm] all of which has just happened naturally over time. So: o, uhm, so partly I was like (1), oh that's weird and then partly (1) thinking, if you looked at photos of Janice [Maria's sister] when she was a baby. She looks exactly like that. She's got loads*

*and loads of black hair. So:o [I: mhm] yeah it was kind of a little bit funny [I: mhm] but also yeah, a slight shock at the:e amount of, yeah, the fact that she was very dark [I: mhm] and then the fact that there was such a lot of hair*

There was clear surprise at the very distinct difference between what was expected and the reality of Maria's daughter's appearance, and there was a sense of having to try to come up with an excuse for the difference so that the daughter could still be passed off as having a "with-in family resemblance". This need to compare her daughter to her own sister suggested to me that Maria had a need to find, and potentially hide behind, a reasonable explanation for the difference in appearance. This suggests some level of discomfort. In addition, it is worth wondering whether Maria is not also indirectly affected by the somewhat negative feelings that her daughter has due to the lack of resemblance. The sentence "*all of which has just happened naturally over time*" (referring to her sister) could suggest a hope that her daughter's appearance would also change over time. Furthermore, the excerpt seems to capture a real ambivalence about her feelings: a sense of shock, alongside the need to try to keep up appearances by rationalising it.

Most of the women stated that they did not mind not looking like their children. Yet in the interviews there was a sense of sadness and loss around the lack of resemblance. For Linda, the experience of sadness and loss was related to never getting the opportunity to experience what it is like to share a resemblance; to recognise sides of one self in a child:

*Linda, 377: for me:e it doesn't feel like a huge loss. I kind of. I envied my partner a little bit because it is his sperm and I can see (1) his looks in them. And I can't really see mine and that would be amazing, you know, I would.... Genes kind of go on for generations. More pertinent is just;st (2) the immediate characteristics. You know looking at them, thinking, that must be amazing to see something really like yourself*

*in your kid... I am not gonna see that (1) uhm but certainly, you know, it is not an issue (1). Not when (1), not when you have wanted something so badly.*

Linda acknowledges that there is a loss, but the loss is downplayed, and she alludes to this being due to the fact that the gain of having a baby outweighs the loss. However, despite this, there is a sense of “missing out” by not getting the opportunity. Not getting to experience that side of parenthood in which aspects of one self are reproduced in one’s children. The importance of the resemblance is also seen in Linda’s search for parts of herself in the children, i.e., “*I can’t really see mine*”, to me, this suggests that Linda have not completely accepted that the children will not resemble her, and that potentially she is holding on to at some point being able to recognise herself in them.

Whereas for Linda the lack of resemblance was a loss in terms of not getting the opportunity to recognise herself in her children, for Karen the loss of lack of resemblance is focused on not getting to have that connection with her child. Furthermore, there is a sense of it being a reminder of what she could not pass on to her children. Maybe it is even a reminder of her own infertility.

*Karen, 972: ... for me it’s my child’s skin colour ..hh [ mhm] and these are external signals for us, [I: mhm] that our children are not genetically related to us. [I: mhm] And we talk about that aspect. Is like we’ve each kind of like got, got something that we picked up on. [I: mhm]. So, when we look at our child (2) that’s the bit that says (2) [slightly quieter] “not genetically related”. And that makes us all sad. [I: mhm]. You know, there’s a:a, there is sadness because that’s a [slight emphasis] loss. [I: mhm] We can’t have the gain without the loss*

There is an acknowledgement with the comment “can’t have the gain without the loss” that no other way was possible. There will always be a loss, but the gain is also there and the gain outweighs the loss. Many of the women echoed this, stating that the gain of having a child, a child that they bore, is greater than the sense of loss from not being genetically connected. The use of “us/we” in the quote suggests that this is a shared experience of donor recipients, perhaps there is also some comfort, for Karen, in sharing this experience with others.

Two of the women saw it as a positive that they had not passed on their genes as they were not completely satisfied with their own genes. However, through reflection on the rest of their interviews, it seems that the positive spin on not passing on their genes could be a defence against having no other options. Linda, in particular, did mention that if her eggs could be restored she would have a genetic child as well, suggesting that she has not fully accepted the idea of not having a genetic child, and that the dream will continue.

All the women mentioned looking for a shared resemblance, though knowing that, technically, a resemblance is not achievable. Deborah talked about sharing similar traits and physicality with her child. There is a sense of having passed something of herself to her son. This might suggest a deep-rooted desire and expectation in women to be able to recognise themselves in their children.

*Deborah, 1879: It’s really weird because (1) when he was [emphasis] born he had these blue eyes, and the donor had blue. They told us blue green, but when she filled out the pen portray, she just put blue. He’s now got green eyes, like me (2) and because he is got, olivine, we’re more olivine than, (1) I am not sort of like Mediterranean, but I’ve got slightly olivine tone then say you [I: mhm]and uhm, he has got that. [I: mhm] So something of me. He has (2) all my worse qualities. (2) He*



*is impatient (3), I'm inpat [cut off], he has got that from me, and I feel like I have given him (1) you know, all those sorts of ... So I suppose I have given him all of these (3), or we share them or what it is.*

The quote suggests that for Deborah there is a real sense of passing something on to her son. It feels as if there is a real need to think of herself as passing something on. Interestingly, she has only highlighted the areas in which they match and not the areas in which they differ. This focus on similarities only seems to suggest, to me, that shared resemblance provides a connection for the two of them. The commonalities give a sense of strengthening the experience of the donor-conceived son as her own. The desire to feel as if something is passed on from the mother to the child is an experience common to all the women, highlighting that the chance to experience pregnancy is one of the determining factors for choosing the egg donation route. The desire is to have that experience of having a baby grow inside of them, and also the opportunity to pass parts of themselves on to their children as a way of increasing a sense of connection, and giving them a purpose in the conception. This is particularly expressed by Linda:

*Linda, 489: ... imagining even if there are not the genes there is the stuff that's from me that's coming into them... [I: Mhm] when I talk about the vitamins and the acupuncture and doing the pregnancy yoga ... so that I could give them as much of good vibes and nutrients from me. [I: Mhm] Yeah:eah. which in a way was like my, you know, my only contribution seeing that it wasn't the genes*

Maria (1491) also speaks about looking for a physical resemblance in her child, although knowing her daughter would not look like her. Maria states that searching for resemblance is a connection point. Something to connect the two. Something that they share. Again reinforcing the idea that physical resemblance does play a great role in making it feel like the

child belongs. As Helen points out in her interview, there might be an evolutionary need for women to be able to recognise themselves in their children as a way of helping the bonding between mother and child which in evolutionary terms is essential for the child's survival.

However, all the women agreed that in terms of the love for their children and the feeling of the child belonging to them, the lack of resemblance made no difference:

*Angela, 659: a:and (2) I just, I can't help but love them, and, you know, [I: mhm]  
the fact that their donor just (2) I would say it makes no difference*

This suggests that the love and attachment the recipient women have for their children is not bound to the experience of whether the child resembles them or not.

To sum up, physical resemblance, or lack of, was experienced as a potential threat due to belonging being judged on genetic connection and physical resemblance by the women, and by others. It seems that the women's experience was somewhat mediated by how easy it was for the child to "passed off" as their own – for the women whose husbands donated sperm, and for solo parent Angela, it seemed easier to pass the children off as their own as they believed that people assumed the children to resemble the father and did therefore not question the women's lack of resemblance. However, all the women, regardless of relationship status and sexual orientation, looked for shared resemblance with their child despite the lack of genetic connection, and all seemed to share a sense of sadness around not having a shared genetic connection with the children.

### *3.2.1.2 The struggle of disclosure*

Disclosing came up in two ways: disclosing to the child and disclosing to others. Both aspects can be perceived as a threat to the family unit as the donation becomes a public

reality, and this in turn could question the definition of what family is, and the ownership of motherhood. Six of the participants had disclosed the egg donation route to their children, and two were yet to disclose but intended to do so in the near future.

The women who had disclosed felt that it was the child's *right to know* (Deborah, 2351) the truth about their conception and it seemed that disclosure was seen as a way of protecting the children from uncomfortable feelings by making the donation *a fact* (Karen 685). In this way the donation is always part of their story, and the chances of a later accidental revelation are avoided. Karen extends our understanding:

*Karen, 668-86: I wanted to create a, a situation for my child, where she'd never not known. [I: mhm] So that was very important to me because:se as a [job title] I wanted to make sure that, uh, we had a no shame scenario. [I: mhm] That, that it was just a fact, you know, the world is round, grass is green, [I: mhm] (2) I'm, you know, I'm created by donor egg, you know.*

It seems that for Karen modelling openness to the children would avoid any feelings of shame in the children regarding their conception. Secrecy appears to be experienced as being connected to feelings of shame and non-disclosure to the child, and in Karen's experience is linked to the parents having difficult feelings about the route of conception. The sense of wanting to model openness and pride with the conception towards the children was echoed by several of the women.

For the two women who had yet to disclose but intended to do so, their experience seemed to be filled with some uncertainty and anxiety around how and when they should tell the children. There seemed to be a sense of there being a right way to disclose and for them disclosure seemed to be seen as a one-off event, in which you tell the child and then they

know. Interestingly, for the women who had disclosed, the disclosure seemed to be experienced more as a process in which the child slowly understood more and more and started asking different questions to gain further understanding. Kate develops our understanding:

*Kate, 256-95: I want to. That's why I'm waiting, I'm waiting [I: mhm] till she is a bit older and I can explain to her that this is her information for her [slight emphasis on pronunciation], but it's not necessarily for her to talk to people on the bus about. [I: mhm] I also quite, even though I went on that workshop, I haven't quite worked out how to tell her; because you think like there is technical words like sperm. [I: mhm] [laughs loudly] I don't know, uhm, how to handle that [slight emphasis on pronunciation], [I: mhm] but I absolutely want her to fully know before it gets to any point. I don't want it. My dread would be in the playground, somebody coming up to her and her saying, what she says so far, when people say I've got mummy and a daddy, [I: mhm] she says I've got two mummies. So that's, that's the other side of this anyway, [I: mhm] the gay thing and the egg donor thing.*

In Kate's account, there seems to be a lot of anxiety, not only about how to disclose and when, but also some anxiety about the child not fully understanding the significance of the information and then sharing it prematurely with others. This slight uncomfortableness with the idea of the child sharing the information widely and randomly with others suggests that Kate herself perhaps does not feel comfortable with the information being shared. This suggests that the non-disclosure to the child could be a form of self-protection. At the same time, Kate seems to have an experience of having a time pressure in which she has to disclose before the daughter starts questioning the conception herself. Additionally, it seems that Kate's anxiety around her experience is heightened due to her having already made her daughter 'other' because of her sexual orientation and relationship status.

The majority of the women did not disclose to others while undergoing treatment as a way of self-protection from intrusion. For Karen, the non-disclosure was a way of protecting herself and allowing herself time and space to process her own emotions before having to manage others' reactions to her journey:

*Karen, 1814: Why I didn't want to tell people. Uhm, because, your:r, because the:e, every month when you get the (2) another failure, another failure, you almost, well, I almost felt like I had to kind of come to terms within myself, uhm, come to terms with the loss. Sometimes you have to kind of like, kind of inwardly digest it before you can, can tell somebody else because otherwise you then have to cope with [emphasised] their reaction to the loss*

From Karen, there was almost a sense of feeling uncomfortable about sharing her vulnerability with others. Laura extends our understanding further. Her non-disclosure was not only a form of self-protection from others' intrusion, but also protection against a sense of embarrassment of not being able to conceive, which she was unable to face:

*Laura, 146: I just couldn't handle it. Couldn't handle it. So, when it came to this next stage of the IVF, and (1) uhm:m the fact that we were going to go down this donor route. I just said, we had a conversation and I just said, I didn't want anyone knowing. So we never told anybody. [slight emphasis] Nobody. ... Whether it was the best choice or not, I'll never (1), I don't know, but it worked for me [I: mhm] because I wasn't able to cope with (2). I think there was probably a (2) a (1) an embarrassment [I: mhm] the fact that I wasn't able to conceive naturally so there was a sort of a (1), you know, [slight emphasis] yeah, an embarrassment, uhm, and I was angry and frustrated, and you know, I just wanted to keep it to myself.*

The repetition of “*I just couldn't handle it*” emphasises the difficulty in dealing with others' intrusion. It seems that Laura wants to hide the truth, not wanting it out in the open, as that

would mean having to face her own struggle with her infertility. Further supporting this, in the interview Laura several times mentioned not wanting to have others judging her, suggesting that she was not completely comfortable with her infertility, or perhaps with the route of egg donation. Laura's account suggests that open disclosure is only possible once women themselves are comfortable with their infertility and confident in the route taken.

Three of the women were open with others about the egg donation from the beginning:

*Kirsty, 1662: Yeah! I couldn't bear it to be secret about it. It just makes me feel ill [emphasis on pronunciation], you know, I just couldn't keep up with "oh, this person knows this much, that person knows that much, oh my god, I forgot to say that, I wouldn't have, did I say that to so and so or did I tell that", you know, I just couldn't keep, ...hh [in breath] couldn't keep in my head who knows what? I'd just much rather everybody knows everything.*

For Kirsty, there is a sense of openness being the healthiest option. Her use of "*It just makes me feel ill*" gives a physical manifestation of having to keep a secret. It seems easier being open about the egg donation than having to keep up with the secrets. Interestingly, throughout her account Kirsty reveals herself to be the most confident about her decision. Unlike the others, Kirsty did not appear to doubt her decision, and this seems to fit with the approach she has in terms of there being no point in keeping it secret. There is a willingness to own the route that she has taken and she seems comfortable with it. In comparison to Kirsty's account the majority of the other women, throughout their interviews, showed a greater ambivalence about the idea of egg donation, the consequence of having a child through egg donation and disclosing to others. That could suggest that caution with regard to disclosing to others might be linked to greater ambivalence in terms of being the recipient of

egg donation. Laura furthers this idea by highlighting her distrust of others to guard and manage her sensitive information.

*Laura, 772: I'm too embarrassed (1) I think (2) or (2) worried, uhm (2) I don't trust people or something. I don't know what it is about telling them about X... that she's an, an egg, an egg donor (1) child and ...hh I don't know whether I kind of in one way I kind of go, "well they don't need to know", but then why not be open about it?*

The quote highlights the uncertainty that Laura has and her feelings of ambivalence around disclosure. There is an acknowledgement that she is uncomfortable sharing it due to being embarrassed, and this seems to exacerbate the feeling of not being able to trust others. The egg donation is an uncomfortable secret rather than a fact. This is supported by the stumbling "egg donation" which could suggest again a discomfort about saying it out loud.

Deborah extends our understanding on the subject by expressing her discomfort about disclosing to others. For Laura the focus of her non-disclosure was her own ambivalent feelings, whereas Deborah's discomfort is focused on the potentially negative reaction of others. This is exacerbated by Deborah having had a negative experience disclosing to a new friend. Deborah describes her concerns:

*Deborah, 2146: they owe you, but they know something very intimate about you. They know something very intimate about you and I just (1). If they don't react in the right way, you're going to have to not like them and that's the first thing.*

There is a clear anxiety about whether people will tell others. Both Laura and Deborah seem to share a distrust of others to contain their information. The use of "owe you" seems to suggest that Deborah has a feeling of people having something on her. It gives her an

uncomfortable stance towards others. There is a fear, it seems, of others using it against her. This could suggest that Deborah still has some uncomfortable feelings about the route taken as it could be argued that egg donation can only be use “against” you if you are not completely comfortable with your decision. There is a sense of it being very risky having to disclose to others. You don’t know how they will react, and for Deborah it seems there is a feeling that this can sway the power balance. Making her less than. Deborah further supports this hypothesis later in the interview when she states that she felt comfortable disclosing to her next-door neighbour, as her next-door neighbour had a child with autism, and she would prefer an egg-donated child to an autistic child – suggesting that having an egg-donated child lessens your status. It seems that Deborah’s experience is based on being fearful about the judgement of others, and the subsequent negative social consequences. There is a feeling both with Deborah and Laura that they wish to keep it to themselves, and that it is not “need to know” information. Though Laura and Deborah have uncomfortable feelings about having to go down the donor route, it is important that this is not confused with regret around their choice. Both are excited about the end result, but have great sadness and shame about not being able to reproduce.

To sum up, this section highlighted how disclosing is experienced as a risky business by some of the women. There is some uncertainty as to whether it is possible to trust others to handle your information, and a couple of the women are scared that others will judge them or gossip. This suggests that disclosing to others can be seen as a threat due to the disclosure possibly endangering the women’s social status, or due to some of the women potentially having some unprocessed feelings about the route taken and therefore not feeling comfortable sharing. It might be interesting in future research to examine whether the women’s attachment patterns to others affect how they feel about disclosing to others. Perhaps the



women who have anxious or ambivalent attachment patterns are more likely to be suspect that others will react negatively to their information.

### *3.2.1.3 The spectre of the donor*

This theme explores the extent to which the donor is welcomed into the family or not. From the interviews it seems that the extent to which the women welcome the donor is related to whether the donor is perceived as a threat to their family unit or not. The donor was part of all of the women's consciousness – but the extent to which they thought, related and included the donor varied greatly. There was a division between the donor as depersonalised or personified. Half of the women gave a depersonalised account of the donors, whereas the other half described a nuanced relationship in which they had some thoughts about their donors and had an idea of what their donor might be like. Kate had created quite a rich image of the egg donor, despite having only minimal information. Laura and Maria both spoke of finding some comfort in the anonymity of the donor. For Maria, the donor was a depersonalised object outside of their family unit, which there was no need to include in the family. There was a sense, in the interview, of the donor being perceived as a means to an end.

*Maria, 931: ... they seem to make an effort to kind of draw that person into their family [I: mhm] and I, and we definitely don't do that. [I: mhm] (2) Yeah, I can't imagine. [I: mhm] I can't imagine why people want to do that and how they would be doing it. That doesn't seem right at all (1) to me... simply we don't know that person, anything about her at all [slight emphasis on pronunciation] ... it's like trying to bring an idea (1) of a person into your life and that's just (1) I don't [I: mhm] I can't. [I: mhm] Yeah (1) doesn't seem right.*

There is a strong objection to including the donor and a feeling of not wanting the donor's contribution to mean too much. There is a sense of Maria having quite strict emotional boundaries when it comes to the donor. The formulation of the rejection is rational, given she has so little information, and yet many of the other women created images and perceptions about the donors despite having the same amount of information, suggesting the depersonalised experience of the donor as a self-protection. It is easier to keep the donor on the outside of the family when there is no image of the donor. On the outside the donor does not intrude on the woman's territory and the boundaries are more stringent.

Laura further supports this idea of there being some comfort and protection from the donor being on the outside of the family: that anonymity provides protection against the donor invading their lives. There is a discomfort with the idea that the donor might become a part of their lives, or take up too much of the child's consciousness:

*Laura, 1820: I don't think it would be right for me to see a picture, never me, I'm never having the access ..hh, because I would have to show X [child] that picture. She's gotta live for this picture isn't she? She would live for it. She'd want to meet her, but she [emphasis] can't... there's no point. So, I don't think like I wish I knew more, because there's no point.*

*I: She would live for that picture.*

*Laura: Yeah, [higher pitch] I would say so.. adoption, they've got this picture, don't they, and they hang on to it forever, hoping that one day they meet this person again. "my God, I look so much like the person. It'd be so nice to meet her, so one step" and I'll go, well here's a picture of her, but you can't meet her. Maybe that wouldn't be fair on her*

From Laura's account it shows that she does not want to encourage inclusion. There is an assumption that a picture of the donor creates a greater connection as it reveals a close

resemblance, and that seems to come back to the idea of resemblance creating a greater feeling of connection. The expression “*live for*” is a very strong one which gives the sense of Laura being scared that such a picture would take over her life. That a connection, between donor and daughter, would be so strong it would threaten her position. Again there is this feeling of the donor being a threat that needs to be kept away, of not wanting the donor to intrude/invoke their lives. “*She'd want to meet her, but she [emphasis] can't*”. This sentence seems to symbolise not only the logistical impossibility but also Laura's determination for the two not to meet. Behind Laura's seemingly rational account there seems to be an experience of the donor as a threat. There is some anxiety about what it would mean if the donor were to enter their lives.

It seems that, for some of the women, there is a sense that if the child wished to know more about the donor, or wanted to meet the donor, this would equate to a rejection of them as a mother. It is almost a sense of “*if my child searches for someone else, then that must be because I am not good enough*”. Angela extends our understanding further on this point, as for her the idea of the children potentially wanting to meet the donor is also met with some ambivalent feelings.

*Angela, 504: I think for [slight emphasis] me the idea of them contacting. It's a kind of day that I expect to happen. [Me: mhm]. It is not a day:ay (1) that I will push (2), but it is a day that I expect to happen and I imagine I will have mixed feelings, I think, (2) I hope (1) that we have a solid enough relationship at that point (1) that it won't rock (1) [slight emphasis] me, and I won't feel unstable about it, I may need (2) to have my own therapy around that at the time and [I: mhm] (1) but I (1) for me, I'd hope that whatever I feel, and I think it will be mixed feelings, that I can manage, that I can self-soothe so that it doesn't kind of impact them, [I: mhm] uhm similarly, I don't want to become and say [increase in voice] 'oh, yes, you go off, you have a lovely of time' and and, you know, not not kind of show, pay interest to*

*how they might feel about it. So: o, I think, I might feel (1) calmer if I understand or, you know, less rocked (2) if I understand what their interest is, how, what that's about, they may not want to tell me. [I: mhm] But I think understanding their thoughts (1) and feelings about it [I: mhm] would help me [I: mhm] [slightly quieter] hopefully allay any fears I might have. [I: mhm] [increase in tone] I don't [slight emphasis] expect them to want to uh, run off and live with, you know, [I: mhm] [brief laugh] not that that will be an option anyway, you know, but but they will kind of just go and be (3) "wow it's wonderful". I want, I want them to be able to say what they think and feeling, for us all to be able to say what we think and feel about it.*

There is a sense for Angela of being prepared for the day, and of acknowledging her mixed feelings about them meeting. There seems to be some uncertainty with regard to the strength of the children's bond with her, going from "I think", to "I hope". This could be due to her children still being so young at the time of the interview and her therefore not feeling that she was sure of the attachment they had with her, so increasing her anxiety. However, many of the other women with older children also experienced anxiety and worry around the donor's involvement in their children's life. There is also a strong focus on needing to know why they want to meet. From the "I don't expect them to want to uh, run off and live with" there is an assumption that they will find the donor wonderful, and that therefore she is in a kind of competition with the donor. This creates the experience of the donor as a threat. Angela later states that she would find it difficult if the donor had managed to achieve all the things that she wanted in life, again comparing her own life to the donor's. There is a sense of competition with the donor based on a fear of the unknown, a feeling of not knowing who the donor is, or what their intentions are, of not having had the chance to talk about it. Karen further enhances our understanding on this point:

*Karen, 2801: A fear of the unknown, of what that might be and...*

*I: And if you have to put words into what the unknown might be?*

*Karen: ..hh I guess somebody else wanting a relationship [I: mhm] (2) with, with the child, you know that's kind of like, u:uh, how would that be, that's a bit ..hh bizarre. What would that mean, uhm (2) and what that mean to my child, how will it, how would that work out if there was somebody else and involved.*

Karen supports the idea that there is a fear of the unknown with regard to the unknown of the donor. It seems that Karen is experiencing the donor as a threat to her family unit with her statements: “*how would that work out*” “*what would it mean*”. There is an uncertainty around how you negotiate roles and boundaries if the donor is involved. This uncertainty seems to be creating some apprehension towards the donor.

Six of the eight women wanted to distance themselves from the donor and were not interested, or were ambivalent, about potentially having to let the donor in. However, Kate offered a very different scenario in which the donor would be welcomed into the family. In Kate's case there was an expectation that the donor would one day come to play quite an active role in her child's life.

*Kate, 1168: I also imagine that they might have a relationship after Marissa [daughter] is 18 because I'm very, very reassured that she is 27 [laughs] because I'm worried I'm 52 [I: mhm] and going to be very ancient when (1) Marissa [daughter] is in her 20s. [I: mmm] (2) And I have this fantasy that if they struck up a relationship (2) it will be nice for Marissa [daughter], th, th [cuts the words off] say after I died, [I: mhm] there will be somebody around (1) who is very strongly linked to her.*

From Kate's account it seems that she has a positive experience of having the donor involved. There is almost a comfort in thinking that one day the donor could act as almost a

surrogate parent. There is a wish to provide her daughter with support when she is no longer around. This, at first, seems linked to being an older parent. However, none of the other parents raised this point, despite all the participating women being between 40 and 50 when they conceived. Although Kate imagines that the donor could be an important addition to the family, it is worth noting that Kate sees this relationship as starting after her daughter turns 18, and later in the interview Kate states that she might feel differently if the donor were to seek contact now. This suggests that despite there being an openness towards the donor, this is only welcomed later in life when Kate cannot participate in her daughter's life in the same way. Having the first 18 years without the donor involvement will naturally mean that she and her daughter get to develop a close bond before the intrusion of the donor. There is also an assumption that having a genetic connection in some ways automatically creates a strong connection. Kate seems to have a very positive view of the capacity for all three of them to be connected while maintaining some boundaries.

This section highlighted how the donor was experienced as a threat by the recipient women with regard to their place within the family. It seems that the majority of the women felt more comfortable keeping the donor outside the family, at least until a strong firm bond had been created between them and their children, and this was deemed possible through anonymity.

### 3.2.2 Threat to self

“Threat to self” encapsulates how the majority of the women experienced a change to their sense of self, though this was not linked with having to go down the egg donation route, rather the change seemed to be as a consequence of them being faced with their infertility. Though a good deal of research has been done into infertility and women's sense of self, it was felt that this was still important to mention here, as it might be assumed that the women's

identity might have been impacted by having to pursue egg donation, so it is an interesting aspect that this piece of research suggests that it is not the egg donation that necessarily impact the women view of themselves but it is the fact that they are infertile that seem to have the great effect on the women's sense of self. Also, none of the women would have pursued the egg donation had it not been for their own infertility, and I would argue that their reaction to their infertility is a building block in their overall experience of being the recipient of egg donation. Egg donation is portrayed more as a solution to a problem than something that influenced their sense of self. The experience of getting to the point of deciding on egg donation is discussed in greater length under "doing what it takes", so in this section the focus is on how the women depicted their experience of egg donation in terms of their self-identity.

Six out of the eight women stated that the infertility had shaken them and their view of themselves. Most strong was Deborah's account of how the discovery of early menopause led her to change the way she viewed herself:

*Deborah, 1145: Yes, I was no longer (1) I had to (1) even now it's a bit difficult. I mean when I am with men, I am a bit of a flirt. And I have to sort of accept that I am not that woman that I used to be. I mean all men used to love me, because I was like really:ly, you know, appealing. I don't mean that so much, (1) you know (2) my looks, I was not, you know, I am not saying I some great beauty, but very entertaining to men. And I have to kind of remind myself not to flirt any more. ... I have to [emphasis] really come to terms with (2) that I'm not (2) that woman any (1) anymore, and that I couldn't prod [cut word off], and from the outside of I couldn't produce the eggs. (1)*

It seems that for Deborah being faced with the reality of having early menopause greatly influenced her experience of herself – from an attractive woman to unattractive due to her

inability to reproduce. This is also interesting with regards to egg donation as the fact that Deborah was able to carry a child to term, through egg donation, did not alter this negative self-image caused by her infertility. The infertility seems to stay with Deborah. The tremendous impact that the diagnosis of early menopause had on her is further supported by her stating that the early menopause is a secret:

[]

*Deborah, 1258: ... one of my secrets, and that's one of my secrets. And so that affected part of how I felt like I was. How was I really a woman? How am I really as a woman?*

This suggests an experience of having to hide her infertility, of being ashamed, for not only being infertile but more profoundly for going through an early menopause. Being post-menopausal is experienced as such a blow that it profoundly impacts her sense of self as a woman.

The idea that the discovery of infertility leads to a change in one's self-image was supported by several of the women. These women saw themselves as healthy, fit and younger than their actual age, and therefore it felt like a challenge to their sense of self when they were informed of their infertility. Karen illustrates this point:

*Karen, 90: ... thinking that everything would be f:fine, you know, I was, looked younger than my age:ge, [I: mhm] I was fit, uhm, you know, I've kind of read in the papers that women in their 40s having babies. Never occurred to me, that that wouldn't been, it wouldn't be me given that, you know, I was fit and healthy.*



It is clear that Karen, due to her sense of herself as healthy and fit, found it quite shocking to realise that this sense of self did not match the reality. “*I was*” suggests a change in her thinking about herself.

For Laura, the infertility caused her to lose a part of herself:

*Laura, 730: it's [higher pitch] hard not being able to have your own children. It's not easy... I have really [emphasis] really struggled to deal with it. I've lost a lot of confidence and, in myself, in this process, uhm, and I used to be a very, uhm, outgoing, bubbly (1) well I still am, but there's something missing*

Though Laura is not able to articulate what is missing, it seems that being infertile has profoundly affected her sense of self in a negative manner. There is a sense of having an experience of herself as “before” and “after”, which supports Karen’s use of “was”. Laura’s quote confirms that it is not the experience of egg donation that impacted on her self-identity, but rather her experience of being infertile.

Contrary to the other women’s accounts, Kirsty’s sense of self was not affected by her infertility diagnosis:

*Kirsty, 524: But maybe that's because I, you know, my infertility was related to age and therefore I was having to accept that, and I had, because I had been pregnant in my past, you know, [says the following quietly] I don't know, anyway, [back to normal speech speed] I just, I felt fine about it. [I: mhm] It didn't make me question my identity as a woman, [I: mhm] having to use an egg donor.*

For Kirsty having as she had previously conceived, though chosen to terminate the pregnancy, Kirsty had a sense of having already proven her womanliness, and therefore not struggling with accepting the infertility.

This section focused on the women's experience of their sense of self in relation to pursuing egg donation route. It seems that the egg donation did not directly affect the women's experience; instead it was the infertility that caused the greatest change in their experience of themselves. Interestingly, Deborah's experience suggests that conceiving a child through egg donation does not alter one's sense of self as infertile.

### **3.3 Living with the consequences**

This superordinate theme captures the women's experience of the realisation and management of the consequences of being a donor recipient in "living with the consequences: what have I done?" It also depicts their struggle between wanting to manage on their own and not being ready for professional support, while appreciating support around them, discussed under the theme "ambivalence about support". This theme is further subdivided into "I can manage on my own" and "good support helps smooth the journey".

#### **3.3.1 Living with the consequences: what have I done?**

For the majority of the women there seemed to have been a shift from focusing on having a child no matter what it took, without being particularly concerned with the potential long-term implication, to beginning to reflect on the implications more after having given birth.

Laura helps our understanding:

*Laura, 306: I actually didn't really think about the consequences or the future. I just was so... I was so [emphasis] desperate, and it sound like a [emphasis] horrendous word to use, [emphasis] desperate,*

From the quote and throughout Laura's interview it seemed that Laura's experience was clouded by a sense of "full steam ahead" while trying to conceive. Like being on board a train, but with the train going so fast that you do not notice what is outside, and then suddenly post-birth the train slowing down, revealing more clearly what is around you. Several of the women mentioned how there had been a shift in their reflections. From not seeing the consequences to understanding the consequences/implications of egg donation, for example, with Maria not believing that a lack of resemblance was an issue but then once in the process of egg donation realising the implications it can have and also that it is not possible to predict the child's possible reaction.

*Maria, 496: those kind of things that we didn't:t (1) I didn't think particularly would matter very much. Of course, you can't put yourself in the mind of the potential human being that you're making and realise actually it might matter very much to [increase in tone of voice] them*

This is supported by several of the women's accounts whose experience seemed to be influenced by a sense of anxiety about not knowing what the future would hold, not knowing whether there would be negative consequences of the egg donation. Though this might hold true for all parents – whether genetic, donor or adoptive – for the women who have egg-donated children concerns for the future seem particularly related to the uncertainty of how the children will cope with the story of their conception in the future. Maria illustrates this:

*Maria, 2657: So, my, my worry is that she:he will feel unhappy about it for some, for whatever reason, that it will be a source of unhappiness for her rather than something that she's not too bothered about [mhm] and that's my concern that it will have a kind of negative impact on her.*

It seems that there is some guilt about potentially causing her daughter upset due to her actions; that her actions might be the cause of the upset. This fits with the women's realisation, after the fact, of the lifelong consequences of egg donation, and how these will always be in the background. There is a sense of never being able to separate egg donation from any of the child's future issues. Maria supports this point as she is currently experiencing her daughter as unhappy, yet she is not able to pinpoint the cause:

*Maria, 2766: Well, I don't know. I mean, I suppose I struggle to find a re:ason. Why is she unhappy? Why is she anxious? Why is she (1) sad about things? She's not able to articulate, albeit she's still very young ..hh, uhm, so I'm scrabbling around to think of reasons, [I: mhm] why it might be. O:one potential reason might [emphasised] be that she is unhappy about (1) the knowledge that she has about her conception. [I: mhm] Actually, I don't think that is the case. I don't. [I: mhm] I think if that was the case, she might be able to say that because, you know, she knows about it, we:e talk about it. She knows we're very open to talking about it [...] So, I don't think it's that, but a small part of me thinks (1), it could have. I don't know. And it could. She doesn't know and I don't know.*

Though Maria states that she does not believe her daughter's unhappiness to be linked to egg donation, in the quote and in the interview there was a sense of uncertainty about whether the issues are egg-donation related. This quote highlights the struggle for Maria of not being sure whether egg donation is the cause. Though Maria rationalises the unhappiness and says that she does not believe egg donation to be the direct cause, it is worth wondering whether this might be due to not wishing to hold the responsibility for her daughter's unhappiness. It is better to rationalise that the unhappiness is not donor related, though no one knows the cause, then to accept and face the fact that her actions might have caused upset. Also, it is interesting how Maria states that her daughter would tell her, as they are open to talk about it, yet several times in the interview states that they hardly talk about the egg donation

conception, and that only Maria's family members are aware of the fact. This suggests that perhaps there is not a great openness in Maria's family. This, combined with Maria's very rational account of egg donation, could suggest that her daughter might not feel able to talk about it. Nevertheless, Maria's account shows her difficulty in isolating the potential effect that egg donation might have on her daughter.

The idea that the women potentially experience a sense of guilt towards the implications they have caused for the child is supported by Kate:

*Kate, 584: that's when I think I should have thought about this more, because for her I've done something, that gives her something that she has to manage (1) [I: mhm] and I feel sort of sad for her, that I haven't just made her life just completely smooth. [I: mhm] There is this thing. Well she's got to manage is she got two mums, that may or may not be a challenge in her world [I: mhm, mhm] and she's got to manage that, (2) th [cuts word off] (1) this, and what (1) impact it has on her.*

Kate supports the idea that there seem to be a realisation, after the fact, of not fully understanding and processing the consequences of her actions. Kate's quote supports the idea of a shift from prior to conception being solely focused on getting to the goal of having a child, to post-birth, and reflecting more deeply on what the consequences might be. The short-term goal of having a baby overshadows the long-term implications of making a person by egg donation. There also seems to be some guilt from Kate's perspective of having complicated her daughter's life in order to fulfil her own personal desire. Additionally, the guilt seems to be exacerbated for Kate due to her having an experience of already having complicated her child's life by being lesbian, suggesting that one's sexual orientation and relationship status could influence one's sense of guilt. Though that might be the case, the

women who were in heterosexual relationships also experienced a sense of guilt for giving their children something that they will have to manage. Maria extends the experience of guilt:

*Maria, 308: I'm not saying that I regret doing it, but I'm saying I think (2) we shou [cuts word off] we should have thought about the longer term [I: mhm] implications of doing it more than we did, [I: mhm] and I don't think we had (1) much encouragement to think about the long term [I: mhm] We had encouragement [I: mhm] to think about (1) the, the here and now and, and the getting pregnant and having a baby, [I: mhm] but it's almost like the process (1) stops at that, the point of success. [I: mmm yeah] The process stops and (2) clearly it doesn't. [I: mhm] The process begins then [I: mhm] really*

It seems as if, for Maria, there is an element of surprise about the difficulty that they have encountered. The quote suggests that there might have been a hope, at the beginning, that once the baby arrived, everything would be perfect, but instead there is a realisation that at that point the managing of the implications of egg donation have only just begun. As Maria states, the focus was on having the baby and the practical steps of egg donation but actually the process of processing the implications begins after the baby's arrival. That is when the women have to start managing what egg donation means for them and for the child. The women are suddenly facing challenging that perhaps they could not foresee beforehand, because, as Maria says, “*you can't put yourself in the mind of the potential human being you are making*” (496). For Maria, in particular there is a realisation that what she might not have felt was an issue could well be an issue to the child, e.g., the lack of resemblance. This is also supported by the earlier quote in which Maria is uncertain about the cause of her daughter's upset.

It seems there was a move from thinking “*selfishly*” about just wanting a child and not thinking properly about the implications of the birth to becoming more acutely aware of the implications that her actions have on her daughter. This suggests that it is difficult, prior to birth, to really reflect on the implications of egg donation. It is only possible to contemplate the abstract idea of the baby and what it will be like, and the reality might be quite different.

The idea of not properly being able to reflect on the implications beforehand is further extended by Maria. She talks about finding it too easy a journey, and not feeling as if there were enough barriers in the way to actually make her stop and reflect more deeply, again suggesting that she did not fully contemplate the consequences:

*Maria, 267: you're very focused on the process [I: mhm] and getting that right, and you're focused on having a baby, because that's what you want [I: mhm] to do (1) uhm, and that's marvellous of course, when that happens. [I: mhm] I suppose what we didn't think about, particularly and I think, perhaps other people perhaps don't is, is (1) babies don't stay babies [says with slight laughter] for very long. They grow up [I: mhm] and then, you know, all sorts of different things can happen to make you [I: mhm] (1) wonder, [says questioning] was that the right thing? [higher pitch in tone] I don't know. I still [I: mhm] you know, sometimes I think (1), you know, my daughter has a number of different kind of (1) issues now with behaviour and, and health and I think, gosh, (1) we perhaps didn't think about that quite (2) [I: mhm] enough.*

This passage reiterates the idea that it is possible to get blinded by the desire to have a child and not possible to fully contemplate the consequences. It is difficult to look into the future and know what to expect. It seems that for Maria the egg donation implication did not surface until the child became older and perhaps when Maria had to start seeing the donation from the child's perspective rather than her own. There is an acknowledgment of her uncertainty of

whether it was right to pursue the egg donation. The last part of the quote highlights the ongoing uncertainty about whether their actions have led to/will lead to difficulties for the child. To me, there is a sense of both guilt and regret in that quote. Guilt in form of the acknowledgement that they might have done something that has created difficulties for the child. Regret in terms of “*was that the right thing?*”, with Maria seemingly reflecting on the wisdom of the decision given her daughter’s current difficulties. The egg donation and the daughter’s difficulties have made Maria’s life more complicated. It seems that for Maria there is a sense of never being able to separate any “problem” her daughter has from the possibility of it being linked with egg donation. Life is seen through the egg donation lens. The presence of egg donation is always there. Never far from her mind.

### 3.3.2 Ambivalence about support

This theme has been divided into “I can manage on my own” and “good support helps smooth the journey”, and encapsulate the women’s struggle between wanting and not wanting support, managing and not managing, and finding ways of coping.

#### 3.3.2.1 *I can manage on my own*

Half of the women did not want, nor did they seek, professional support at the time, the reason being that they were determined that egg donation was right for them. There seemed to be a certainty about their route and what they wanted, and therefore a perceived sense of being able to cope. Almost a sense of “I am fine with it, so I do not need any support”. All but three explicitly stated that their thinking around professional support had changed over time, and some felt that they had not fully processed the possible implications at the time. Five of the women went abroad where there is no requirement for counselling before undertaking egg donation. Three undertook the procedure in the UK, but were only either



offered or required to attend one session. Four of the women undertook private counselling. The other four women stated that at the time they did not think counselling was needed, however, all but three of the women mentioned in their interviews (as discussed in the section 3.3.1) that after giving birth there was a realisation of the potential ramifications of their actions, and that counselling could be beneficial.

The rejection of psychological counselling seemed to be due to the women feeling certain of their decision to pursue egg donation. This certainty seemed to prevent the women from engaging with counselling as counselling was only seen as a place to discuss whether to proceed with egg donation. For Kirsty, there was a sense of not having anything to “unearth” (Kirsty, 1727), as she was comfortable with her decision. Several of the women supported Kirsty’s experience of not needing counselling. Kate extends our understanding further:

*Kate, 1848: they did offer, but I think it was going to be like a one-hour session just to throw around the idea...but as I said I didn’t because uhm, ..hh I have been in, I’m very, I’m, I’m quite familiar with my own process, [Me: mhm] I’ve been in therapy a lot and my partner also is a X [job title], [Me: mhm] so, I felt comfortable that, I know how to explore [I: mhm] my own stuff.*

For Kate, there is a trust in her own ability to cope, and not feel she needs others to help her examine her own process. There is, interestingly, also an idea of counselling as just being a place to “throw around the idea”. This supports the earlier hypothesis about counselling being perceived as a place only to ensure that you are embarking on the right track. It seems that counselling is not thought of as a place to explore the potential implications, and how one might manage these implications.

For Laura, not engaging with counselling was about not needing others:

*Laura, 2311-36: it didn't feel like I needed it (2) at the time. I kind of had [emphasis] my mind set on egg donation. I, I was just like, you know, this is my road, and I don't need to talk to you. I don't need anybody. I don't need anybody that's why I was like I don't need my [emphasis] family, I don't need my [emphasis] friends and I don't need a counsellor. I just need (2) my man and for this to work.*

From her account, there was a strong sense of not wanting to let others in. Feeling as if others were intruding in a very personal struggle. There is almost a sense of wanting to hide from others. This also, to me, suggests some uncomfortable feelings about her infertility and going down the donor route. Laura states that she “*was worried that I would be judged*” (1410). Almost a sense of not wanting to have to put your failings out in the open. It seems that Laura’s experience is based on withdrawing from others as a way of protecting herself.

Maria attended one counselling session. Though she found it useful, she did not, at the time, think more was needed. The focus of the session had been on whether to pursue egg donation rather than guidance on thinking ahead.

*Maria, 332: We had encouragement to think about (1) the, the here and now and, and the getting pregnant and having a baby, but it's almost like the process (1) stops at that, the point of success. The process stops and (2) clearly it doesn't. The process begins then... so the kind of longer-term implications ..hh [in breath] of how:oh, you kind of manage donor conception for your child and how they manage it as they get older, I think, we didn't have enough kind of information about that. I don't. I don't think so. I think it would've been better to ..hh [in breath] (1) just slow down a bit really and think through all of the implications a bit more*

For Maria, there was a sense of needing to reflect more on the longer-term implications. Thinking beyond just having a baby, thinking about what it would be like when the child is 5, 10 years old, etc., even though she acknowledges that she probably wouldn't have wanted more counselling at the time. There is a sense of it having all gone too fast. It seems that for Maria there was not enough time to properly process the implications, due to being seeped in the practicalities of egg donation, and therefore not having the space to properly process the consequences. It seems that for both Maria and Laura there was a sense of only realising the consequences of their decision after the event.

*Laura, 843: the first thing that we talked about was sort of what we've been through [Me: mhm] and that's all this, and my counsellor said, [clears throat], "you've been through a hell of a lot", you know, ..hh and its, we have never, and we've been through so much really, and you kind of take it in your stride but (3), you think you're taking it in your stride, [I: mhm] but you're not and I don't think that I've been dealing with it right.*

From Laura's quote, it seems that there is a lack of awareness about the toll it has taken to pursue egg donation. This lack of awareness or appreciation of the effect it has had on the women, the partners, the partnership, fit with the idea that women had of not needing therapy. Despite rejecting the idea of therapy, it seems that there is a need for it, but that the women's ability to see the need was clouded by the practicalities of trying to conceive. The inability to create the appropriate emotional space for therapy at the time of egg donation conception is supported by Deborah who, unlike the women mentioned so far, did attend frequent therapy sessions:

*Deborah, 2749: ... because I wasn't probably ready to explore all the issues like I said. I really probably was in [emphasis] such denial [I: mhm] about [emphasis]*

*everything before he came along. (3) uhm, so you [indiscernible] you think. I didn't think (2). [I: mhm] It was just all a big blank, [I: mhm] and before I had him, and I couldn't engage with it [emphasis] really [I: mhm] and I didn't really properly engage with him in there, as I said to you, it was just like ..hh I am providing you with a [increase in tone] warm safe place, and let's deal with everything when he comes out.*

Though Deborah attended therapy it felt impossible to engage. The comparison of therapy disengagement and child disengagement to me suggests a sense of Deborah at a form of emotional survival stage, where it is impossible to engage with anything. It seems that at that time she was just getting through. Maybe it was a form of defence in case it did not work or the effect of having been through so much.

This section suggested that some of the women did not engage with therapy at the time of the egg donor conception, and that this was largely due to not feeling the need as they perceived themselves as able to cope, or did not want to let others in. Also, there was a sense of not being able to open up and face one's own actions, and of being caught up in the practicalities and therefore not able to see beyond the immediate. All of this could be seen as a way of protecting oneself when in a vulnerable state. Most the women implicitly or explicitly stated that their view of support had changed over time, and that they felt better able to reflect on the implications of what they had done after having the children. This seemed to be irrespective of how old the children were at the time of the interview, and seemed to stem from the child going from being something abstract before it was born to becoming something concrete after the birth.

### 3.3.2.2 *Good support helps smooth the journey*

Despite half the women not seeking psychological counselling, or feeling the need for psychological counselling at the time, it seemed from the interviews that the majority of the women sought other forms of support, e.g., the Donor Conception Network, friends and family, or advice from the internet. Some also made a point of engaging in better self-care such as physical activity, and made a conscious effort to surround themselves with supportive and nourishing people. The fact that the women sought many different ways of being supported suggests that they did have an experience of needing support.

Unlike the women mentioned in the section above, Karen believed it to be of the utmost importance to engage with the implications of egg donation,

*Karen, 3076, 3131: once you have engaged with it, you can move on*

and did so through attending psychological counselling and through having a focus on self-care. For Karen, there was an acknowledgement that only through engaging with the emotional, physical and psychological implications of egg donation could you process and pack them away neatly. The engagement with the negative feelings of egg donation and her infertility was crucial in her being able to cope and manage. Though Karen at the beginning of the process of egg donation did not want others involved as she was anxious about having to manage their feelings as well as her own, she found other healthy ways to cope including therapy and an emphasis on self-care in the form of physical activities and surrounding herself with supportive people. There is an awareness, for Karen, of the importance of facing one's challenges and not hiding away from these. It seems that for her the process of engaging with her feelings has led her to a place of greater acceptance of egg donation than is

the case with some of the other women who have not engaged with their negative feelings. This was seen in Karen's very open and balanced view of egg donation in comparison to the perspective of some of the other women who displayed some discomfort and secrecy around the fact of conception.

One of the other ways in which some of the women sought support was through the internet. For Linda, who had a very strong negative initial reaction to egg donation, there was a need to normalise the process, which was done through the internet:

*Linda, 173-83: I did a lot of googling (1) and uhm, it was amazing like how the internet (1) works in that way because once I started seeing, uhm, what was out there, it also really helped my acceptance of (1) doing it. It felt completely normal suddenly. Because there are obviously 1000s of people talking about clinics... Anyway in doing it really helpful and did some, my first kind of internet chats and stuff*

This concept of others helping to normalise egg donation comes through in several of the women's accounts. For some, it was about hearing about or meeting other recipients. For others, it was about actually seeing what it meant to be a recipient of egg donation – to get an answer to the question “what is it like?” I would argue that the need to hear others normalise the process suggests that the women wanted to fit in. Hearing others' stories begins the process of normalising as the women then feel included in a group, rather than the being abnormal. This is supported by Linda's quote in which she says: “*Because there are obviously 1000s of people talking about clinics*”, which suggests that realising that there were many others in the same situation as her gave her some comfort.

The importance of feeling supported and heard by professionals consistently came up across the majority of the women. Most of the women had at some point felt badly treated by members of staff – this was especially the case with the delivery of the infertility diagnosis – and several of the women stated that the delivery of the news had been overwhelming, shocking and difficult to comprehend. Though the infertility pre-empts the egg donation, it could be argued that the way the women manage and cope with their infertility could have consequences for how they manage the implications of egg donation, and some of the negative psychological effects of being diagnosed as infertile might have impacted the women's psychological wellbeing even after conceiving through egg donation. Linda supports this experience:

*Linda, 126-36: it wasn't told to me particularly sensitively either so it was really extra devastating. They were very perfunctory you know in there. Like my partner said that was like the worst (slight laughter in voice) bedside manner he had ever ..hh.. seen. So it was really insensitive and kind of and I just thought "crikey", you know. Don't they realise when they are telling you that your eggs are no good. Just exactly what that kind of information feels like. It just felt like they didn't have an awareness of that*

Here Linda displays having had the experience of professionals not comprehending the effect that the diagnosis can have. For Deborah the way in which the information was given, alongside the diagnosis of early menopause, was such a blow that it left her in a state of being stuck.

*Deborah, 140: Because I have had this awful experience in X [UK location]. I just was a bit stuck there*

Both Linda's and Deborah's accounts show the negative influence that poor professional delivery can have.

On the other hand, it seemed that good support helped the women to feel better able to cope with the stress of going through the treatment. Linda later talks about getting a supportive and positive response from the doctor performing her procedure, which meant that she felt a greater confidence that it would work out and her levels of worry decreased.

*Linda, 690: ...but he just gave me this squeeze of the hand, it was very kind of grandfatherly. He was quite plump and he just said "you know this is a really good one" like that and I was just like God I just know that it is gonna be ok (brief laugh). It was like as if, It was like as if he could tell that it would be a positive outcome and that just really helped. Yeah;ah because obviously it is then it is like two and a half weeks before you hear, yeah; ah so I hung onto that.*

The doctor helped increase Linda's faith and trust in the process. Of course doctors have to be careful not to give false hope, but for Linda it seemed just having someone to believe in the success meant that she was better able to relax, and thereby give her body a greater chance of receiving the donated egg. The doctor's support seems to have changed her experience from uncertain and not in control to having a greater sense of hope and certainty. This illustrates the idea that professionals hold a very important position in helping recipients to manage their negative feelings, whether this is with regard to facing their infertility, or deciding what to do next, or when the women are undergoing treatment. From the women's perspective, it seems that this time is a very sensitive one and the appropriate support and guidance from the professionals helps diminish the difficulty in managing this challenging period.



Besides the professional support, it seems that Linda a strong need for reassurance, and she did things that were out of the ordinary for her in order to get this:

*Linda, 219-26: And we are not religious but I tell you what we went to every single church that we saw in that island, man... I mean we were just so:o. We were just so:o hoping.*

The superordinate theme “living with the consequences” suggests that although some women did not want psychological counselling, or felt unable to engage with it at the time, with hindsight they saw things differently. The fact that seven of the women stated that they later realised how important it was to engage with the emotional and psychological implications of egg donation suggests that support *is* needed, but perhaps other kinds of support need to be recommended before psychological support. The majority of the women stated that they wished there was more information about egg donation, and wished that doctors suggesting egg donation were better able to provide information, or guidance on how to find such information. Additionally, many of the women who went abroad for egg donation felt even more excluded as the clinics abroad do not offer counselling, and they felt they were left to themselves to find information and support.

### **3.4 Selfish act**

This theme depicts how for some of the women the choice of undertaking egg donation was experienced as a selfish act. For Angela, the sense of selfishness seems to lie in putting her own needs first. Of wanting something that biologically is not possible:

*Angela, 1579-93: I got to that point of being very selfish and wanting to have ..hh children and the experience of being a mother, I suppose, as a part of my:y [one word indiscernible], but it felt very [slight emphasis] strong [I: mhm] (3) what I*

*wanted (2) and this is why I think, we are similar beings, we are very self [cut word off]. We can be very selfish [brief laugh] [I: mhm] and that can for be good and bad.*

It seems that Angela is here trying to explain how strong her desire was for wanting to experience motherhood and have a child. It almost seems as if Angela is using her strong desire to justify what to her seems like a selfish act. The cut-off in her pronunciation of 'selfish' could suggest some discomfort with the concept of selfishness, or could perhaps be due to discomfort around putting herself in the "selfish" category. This hypothesis seems to be supported by her attempt to distance herself from her sense of being selfish by creating a 'we' – we are selfish. It is unclear what is meant by 'we' here – whether it is 'we' as in human beings or 'we' as in egg donor recipients.

For Linda, the egg donation seems to be experienced as selfish due to her perceiving it as a selfish alternative to a more altruistic route, i.e., adoption, or accepting nature's course of not being able to achieve pregnancy due to leaving it too late in life:

*Linda, 155: And I made a pact that, and I will still stick to it, you know, that I will foster [emphasis] or I will adopt [emphasis]. Because it also felt like a fairly selfish thing (1) to (1) know that there are so many babies or even more likely children that need to be cared for, but that I still wanted that feeling of being pregnant*

For Linda, the selfish act lies in having put her own desire to experience pregnancy above helping orphanage children. Putting her own needs first gives her the sense of being selfish. It seems that the idea of having a choice creates the sense of selfishness. Linda, like Angela, is uncomfortable with this experience of herself as selfish due to going through the donor route, and in order to manage this feeling she states that she will compensate for her selfish act by, in future, going down a more, to her, altruistic route, via adopting or fostering. (Note, however, that it has been suggested that people who adopt do not do so for altruistic reasons

but for the same reasons as an egg donor recipient, i.e., they want to become a parent.) Linda further expands on her experience of herself as being selfish, and therefore having to compensate by making “good” children:

*Linda, 1040-48: I really, when I think about the more selfish act of (1) making such, going through such palaver to have kids when, you know, people say “uh population control” and dududo or like all the kids that needs adopting and so on which is so true too (1) but (1) I just comfort myself with ..hh the idea that I hope:pe that we,e can:an create two beings that will just contribute to the planet in some way in a really positive way*

As egg donation was seen as a selfish act, it seemed that some of the women felt a need to justify their children’s existence by believing that their children would grow up to be an asset to society. Kirsty supports this point:

*Kirsty, 2536-82: and I think I will have (2) uhm (2) done my bit for humankind if (3) I:I (2) uhm (3) send out into the world two (2) functional [I: mhm] (2) kind, emotionally intelligent (2) human beings [I: mhm] to:o counteract the enormous [emphasis pronunciation] number of dysfunctional [emphasis in pronunciation] [I: mhm] unkind [slight emphasis in pronunciation] and emotionally illiterate human beings, [I: mhm] there are also out there on the planet because you need mo:ore good people [I: mhm] to:o uhm counteract the (2) terrible effect that (1) uhm:m dysfunctional people can have (2) on the lives of others. [I: mhm] And so if [emphasis in pronunciation] I manage to achieve that, if, if we manage to produce children who are like tha:at, [I: mhm] who grow up into people, who go out and in turn they get more children, [I: mhm] well then you’re going like this [makes signs with hands that good and dysfunctional people counter each other out] hopefully with good quality human beings,*

It seems that Kirsty has an experience of wanting and aiming to produce healthy functioning children as a way of compensating for the act. For Kirsty it seems that there is a need to justify one's actions and for her this is done by having a firm belief that her children will help to counteract the *dysfunctional* people. Additionally, it seems that the breaks in Kirsty's speech could suggest some uncertainty, maybe an uncertainty as to whether she can produce functional children, or maybe it is more of a questioning of whether producing functional children can actually "make up" for a sense of selfishness.

The idea of having to compensate for one's actions is also supported by Linda's statement of having made a pact to foster or adopt as a way of doing something good. This bargaining, in a sense, seems to be identifying egg donation as bad, and adoption as good. The women has to make the children good, balanced adults, as they have done something bad by putting their own needs before those of the world. Though it could be argued that all people who have children, either naturally or through adoption, who do not adopt for the sole purpose of giving orphanage children homes, are having children for the selfish purpose of wanting a family. Though perhaps the reason why the feeling of selfishness comes up for these women in this research is due because they have gone to greater lengths to conceive and thereby fulfil their desire for the chance to experience pregnancy. All the women that participated stated that egg donation rather than adoption was the preferred route because they wanted the experience of pregnancy.

### **3.5 Doing what it takes**

This theme describes the recipient women's experience of getting to the point of choosing egg donation. All the women viewed egg donation as a fix, however, for some it was easier to

accept as a fix than for others. Maria encapsulates this view of egg donation as a solution to a problem:

*Maria, 1012: we've got a problem, we've got a practical problem and this is a, uhm, practical solution (1) to our problem uhm, and it seemed (1) entirely sensible.*

It seemed that all of the women, once the decision was made, the egg donation was seen merely as a way of getting from A to B. For Maria, who was diagnosed with blocked fallopian tubes, a medical problem, it meant that a practical and medical solution was needed. Maria stated that a younger person would not be expected to live with that diagnosis so neither should she. To me, there is almost a sense of entitlement – why should I live without when others would not be expected to?

Laura's experience of getting to the point of acceptance of egg donation seems to be based on being desperate for a child:

*Laura, 304: I just was so:o (2) and I used this word at DCN, I was so [emphasis] desperate, and it sounds like a [emphasis] horrendous word to use, [emphasis] desperate ... At that point, all I wanted was to have my own baby, and I was, and I would do anything to have it.*

It is interesting that for Laura the word “desperate” has such a negative tone. With the use of the word “desperate” there is a sense of being helpless in the situation, and also having such a strong desire for a child that nothing else matters.

From all of the women there was a sense of strong determination, desperation and being focused on the goal, more than thinking about the egg donor route. For the majority, there

was a sense of *not having anywhere else to go* (Karen, 56) and also being so caught up in the process and being *on a roll* (Karen, 135) that they were not stopping to think about the consequences. This is further explored under “living with the consequences”, but the point is also valuable to make here as in many of the interviews there was a sense of only looking to the immediate future, of having your eyes fixed on the prize of having a baby. There is a sense of the when being more important than the how as the desperation for a child is driving the journey. All of the women had intended to conceive using their own eggs, and stated that they had wished for a genetic child at the onset, but when faced with the reality of not being able to conceive with their own eggs, or there being a very small chance, they all felt that egg donation was the next best thing. It was very clear throughout the interviews that there was an almost hierarchical *process of elimination* (Kirsty, 74) for the women when it came to conception. Kirsty captures this point:

*Kirsty, 117: perhaps you almost have to prove to yourself. That you can't do it. That it isn't going to work to do it that way, in order that you are never going to be left with any kind of, well what if, what if I had*

It seems here that it is important to be sure that no less invasive method could have worked. Particularly for Kirsty, as she states later in the interview, there is a need to ensure that she could not have had a genetic child. This seems to suggest that the greatest desire is for a genetic child, but as that is not a possibility, the next best option is egg donation. On the surface 's account gives the idea of the desire for the child being greater than concerns over the method by which the child comes into the world. Despite this, however (Kirsty went through over 15 IVF attempts with her own eggs before moving on to egg donation), it still seems to be a difficult process to get to the turning point of deciding to go another way. The

struggle, for Kirsty and also for the other women, was not about accepting egg donation as the route, but lay in having to accept themselves as infertile. Kirsty encapsulates this point:

*Kirsty, 260: it wasn't that I had a problem with egg donation, accepting that idea at all [with emphasis], I didn't at all. It was absolutely the first thing that I went to once I have decided "okay, well that's not going to work, now what? [I: mhm] So no problem with that, it was more just the idea of, of what you are letting go off [slight emphasis on each word] what you're having to accept isn't going to happen rather, rather than any difficulty embracing what you are going to do.*

For me, that quote conveys a huge sense of loss. The loss of not being able to reproduce oneself; the loss of letting go of one's hopes and dreams and of one's sense of self as fertile. Whereas most of the women found it relatively easy to accept egg donation, once their infertility had been accepted, a couple of the women, like Linda, found that it took longer to reach acceptance. Linda had a very strong reaction to egg donation, and was initially very *repulsed* by the idea and had quite vivid images of alien-like things being implanted, and expecting a baby to be taken from someone else and implanted into her. For Linda, deciding on egg donation was a process of allowing herself to get used to the idea, of grieving for what would not be, and of gaining more knowledge about egg donation to help normalise it by researching online, reading others' stories, and allowing time to pass.

*Linda, 173-83: I did a lot of googling (1) and uhm, it was amazing like how the Internet (1) works in that way because once I started seeing, uhm, what was out there, it also really helped my acceptance of (1) doing it. It felt completely normal suddenly. Because there are obviously 1000s of people talking about clinics... Any way in doing it really helpful and did some, my first kind of Internet chats and stuff*

For all of the women time was of the essence. They were all aged between 38 and 50 when they started contemplating egg donation and most of the women decided to go abroad due to the wait being too long in the UK. In the interviews, there was a real sense of it being full steam ahead. No time for stopping. A sheer determination for success. Karen compares it to long car journey:

*Karen, 297: kind of a bit like (1) doing a long car journey, you know, we're not going to stop for a coffee break. [Me: mhm] ..hh we've been driving for the 10 hours, we've got another hour to go, we are not going to stop to l [cut off] toilet, to the toilet, we're just going to go and get there*

The “hour to go” gives the idea of feeling very close to the finishing line. Almost a sense of “we will get there”. It seems that for Karen it was a journey where there was a sense of belief that it would work out. Not feeling like an endless journey – but a journey where you just have to push yourself a little further to get there. Her words “*just going to go and get there*” give the sense of sheer determination and focus on the goal, with the knowledge that once you are at the destination the extra push is worth it and feels immaterial. Karen supports this idea later in the interview, when she makes a comparison between the journey of egg donation and the idea of waiting for a bus for hours to go to a party. While you are waiting, you think you will never forget the wait, but then when you arrive at the party and are having fun, the journey becomes insignificant.

*Karen, 1457: the thought process of deciding (1) kind of like almost felt organic because. ..hh its, when you're on the journey (2), you find yourself in a place that you, yo, u, you wouldn't consider if you haven't have had the journey. So, if you are going through the jungle [I: mhm] ..hh and someone says, would you cross a river or not? Well if you are not even in the jungle, [I: mhm] you could say, “of course I wouldn't cross a river without a boat, that would be ridiculous”. [I: mhm] But*



*actually if you have been in the jungle for three weeks and you get to a river and you have no boat, [I: mhm]..hh you have a different view [smiles], [I: mhm] you just kind of like, you know, you're there, [I: mhm] and you're in it.*

*1537: So, we were just kind of like meandering along through our jungle and it was [slight emphasis] just, just kind of felt, you know, it was one more river that we had to cross*

For all of the women it seemed that adoption was not a consideration (Angela, 1240). There was a great desire from the women to have the experience of carrying the child. For some this was important due to it helping to strength the bond between mother and child, for others it was about just having the experience of a child growing inside of them. There was also an emphasis on egg donation providing the opportunity to bond with the child from the beginning. The child has no previous story. As Kirsty stated, *you are their story*.

The women's experience of reaching acceptance of the egg donation route emerged from a process of elimination, in which other possible routes were eliminated, a sense of desperation for a child which fuelled their determination, and a process of normalisation.

### **Similarities and differences across the four superordinate themes**

The analysis section has produced four superordinate themes: "threat", "living with life-long consequences", "selfish act" and "doing what it takes", which jointly capture these particular women's experiences of being egg donor recipients.

Though the themes have been grouped into the four superordinate themes, there seems to be an overarching experience across all four of the women with regard to feeling vulnerable, and somewhat under threat and therefore wanting to protect themselves and their children (which could be perceived to be a form of self-protection). This comes out with particular force in

the superordinate themes of “threat” and “living with the lifelong consequences”, where the women expressed being fearful of being judged, being distrusting of others, experiencing a degree of discomfort about being in a perceived vulnerable position, and experiencing feelings of shame, sadness and loss. This overarching theme of self-protection is discussed in greater detail in the discussion section.

The four themes were created with the intention of capturing the essential meaning of the participants’ experience. “Doing what it takes” represent the women’s experience of pursuing egg donation and being set on that idea as a solution to a problem, whereas “Living with the life-long consequences”, “selfish act” and “threat” are about the realisation and management of the meaning of having pursued ED. Though these three themes share the overlap of realisation and management, “living with the life-long consequences” captures the women’s experience of not fully reflecting nor understanding the implications of egg donation until after the child is born, and the struggle and ambivalence regarding support and relying on others, whereas “selfish act” captures a couple of the women’s experience of egg donation as a selfish alternative and therefore needing to compensate by creating good children. “Threat” captures the realisation, management and experience of the three specific areas of resemblance, the donor, and disclosure. It could be argued that there is some overlap between the themes of ‘living with the consequences’ and ‘selfish act’. Both themes mention the sense of egg donation in regard to the concept of selfishness – however, it is felt that these two themes were sufficiently different to warrant separation, as ‘living with the consequences’ focuses on there being a sense of questioning of actions; a later realisation that the women’s actions might have significant implications for their children. The aim was more for the theme to represent the change in the women’s mindset from before the child was conceived (solely focusing on getting pregnant and thinking of the immediate future) to after the birth

(shifting their attention and focus on to the more long-term psychosocial implications of their actions, on behalf of the child and themselves). In this way the theme was more about representing the shift in the women's experience and the women's sense of guilt for giving the child something to manage. In contrast, the theme of "selfish act" rather aims to capture the women's internal sense of selfishness due to putting their own needs first – before the needs of the world, existing orphans or even their own future children.

## **4 Discussion**

### **4.1 Overview**

This piece of research aimed to capture eight women's experience of being the recipient of donor eggs. The discussion section will explore the findings alongside existing research, followed by highlighting the limitations, including the researcher's reflections on the research process. Thirdly, areas for future research, and the implications this research has for medical professionals and counselling psychologists, will be explored.

The aim was not to be able to provide a generalisation about the women's experience of donor eggs; instead it is acknowledged that the research is showing one version of what the experience might be like. This version is not necessarily permanent, nor is it the same for other recipients of donor eggs.

### **4.2 Findings and existing research**

As stated previously, the aim of this piece of research was to encapsulate the women's overall lived experience of being the recipient of donor eggs, by capturing how the women made sense of this experience. Firstly, a brief account of the main themes in the women's accounts will be explored, thereafter four themes; Protection from stigma and from showing one's vulnerability; recipients' experience of resemblance; recipients' experience of egg donation as selfish; and recipients' experience of support, will be explored in greater detail. Due to the limited word count, not all the aspects of the women's experience can be discussed in detail, however, these four areas have been selected due to being very prominent in the women's accounts, and with a view to extending the existing research in the area.

#### 4.2.1 Overall experience

The women's overall experience as recipients of egg donation seemed to contain a lot of conflicting emotions such as disbelief, devastation, embarrassment, distrust, vulnerability, loss, acceptance, anxiety, hope, trust, desperation, pride, and joy.

All but one expressed a sense of *shock, disbelief, devastation, embarrassment and shame* on hearing of the fact of their infertility diagnosis, and therefore finding it difficult to disclose to others about the egg donation, as disclosing meant also having to inform others of their infertility. The shock seemed to arise from none of the women imagining themselves as infertile, suggesting that, regardless of age, women see themselves as fertile. This supports Wyndham, Figueira and Patrizio's (2012) suggestion that people are somewhat ignorant about their fertility, and the chances of conceiving later in life. The same women also expressed *difficulty in accepting* their infertility, and it seems that it was their infertility, rather than the egg donation route, which was the difficult aspect to accept and digest. The infertility seemed to shake the women's perception of themselves, and despite conceiving a child, for some of the women the negative effect of being diagnosed infertile stayed with them. The women's struggle with accepting their infertility could be argued to be linked to a sense of struggle in not living up to the "societal expectation of motherhood" (Bute, 2009, 753). Even in today's society motherhood and femininity are intrinsically linked, and childrearing is seen as the ultimate evidence of a woman's femininity (Letherby, 1999). Loss of fertility can therefore not only be perceived as a threat to a woman's identity as a woman, as it positions the infertile woman as "other" to the ideal, regardless of whether the woman conceives via an alternative route, but also as a threat to achieving the desired motherhood identity. According to the identity process theory (Breakwell, 1986; Turner & Coyle, 2000), whether one's identity is perceived to be under threat is dependent on how the threat

interferes with “the four major principles of identity: self-esteem, continuity, positive distinctiveness and self-efficacy” (Turner & Coyle, 2000, 2042). It seemed that for some of the women, such as Deborah, their identity as a woman was significantly impaired by the infertility, as it had a direct negative impact on their self-esteem, and created a negative distinctiveness.

All expressed a sense of *loss* regarding not being able to reproduce. For some, the loss was about not sharing a genetic link with their child; for others, it was about not getting the opportunity to recognise part of themselves in their children.

The practical process of egg donation was a time of *anxiety, hope, trust and feeling “on edge”*, as the women tried to manage the hopes and failures of the procedure.

Another pivotal area of the women’s experience of being a donor egg recipient was to do with being hit by the ramifications of the egg donation, after having children. There was a sense, from some of the women, of only really understanding the implications that egg donation can have after having the child, then questioning whether it was the right path taken and becoming anxious about the potential consequences for the child. Though many of the women focused on the consequences for the child, it could be argued that the ramifications for the child are shared with the parents, and that the women’s concern regarding the child’s reaction might reflect their own ambivalence and anxiety. It seems that many of the women became more worried about the future, and the unknown implications that might arise later. This led the women to feeling uncertain, unsure, and somewhat anxious.

Despite the women’s somewhat negative and ambivalent feelings, it seemed that all the women were happy with having pursued egg donation. The egg donation had helped fulfil

their dreams of a family, and was therefore, overall, seen a positive, as it was the only way that the women felt they would get to experience pregnancy, birth and caring for a child from birth, and achieve the sought-after mother identity

#### 4.2.2 Protection from stigma and from showing one's vulnerability

One theme seemed particularly prevalent in the women's experience of being a donor egg recipient: feeling vulnerable, and therefore wanting to protect themselves and their children. This comes out with particular force in the superordinate themes of "threat" and "living with the lifelong consequences", where the women expressed being fearful of being judged, being distrusting of others, experiencing a degree of discomfort about being in a perceived vulnerable position, and experiencing feelings of shame, sadness and loss. These feelings seem to have led the women to engage in many different self-protection strategies, such as rationalising the process, not disclosing to others, de-kinning from the donor and not wanting to engage with the implications of their actions. Though the aim of this research is not to provide an account of the strategies that the women engaged in, it seems that these strategies might help to inform us of the experience the women had as donor egg recipients, and could be argued to suggest that the women felt they were somewhat exposed.

The need to protect themselves seems to have come from a strong distrust of others. This is a yet unexplored area. To my knowledge no research has explored recipient women's experience of distrust to others. It seems that the women's distrust was due to feeling vulnerable and ashamed of their infertility. Most of the women reported feeling embarrassed by their infertility, like Deborah, who felt her early menopause was her secret. Some also explicitly or implicitly felt that by disclosing to others, it would give others something on them, that in some way they would own the women, suggesting that the women perceived

themselves to be in a weaker position than women who had conceived naturally. This is an important area to investigate further as it seems key to the women's experience. Interestingly, it seemed that for most the women it was not the egg donation route that caused discomfort with having to disclose, but rather the fact of having to own up to being infertile, as the egg donation was seen as a reminder of their infertility.

Furthermore, extensive research has suggested that disclosure is a particular difficult area for recipients, which this research suggests could be due to the women's feelings of distrust. This supports the research which has implied that parents do not disclose due to feeling uncomfortable about the egg donation route (Richards, 2014; Appleby, Blake, & Freeman, 2012). Perhaps by getting a greater insight into their distrust, this might further our understanding of the experience of disclosure.

The women's experience of wanting to protect themselves seems to fit with Goffman's stigma theory, in which he states that individuals try to adhere to societal standards, and that if they fail to do so they are left with ambivalent feelings: "the stigmatised individual in our society acquires identity standards which he applies to himself in spite of failing to conform to them, it is inevitable that he will feel more ambivalence about his own self" (cited in Sachs & Hammer Burns, 2006, 325). It is being on the outside of the norms which can cause stigmatisation (Sachs & Hammer Burns, 2006). It could be argued that egg donation is stigmatised due to its comparison to the conception pattern of the idealised family, though, as discussed in the introduction, there are many definitions of families. Yet the idealised family is still defined as one where "children should be conceived naturally, born to and raised by their two young heterosexual, married to each other, genetic parents" (Cutas and Chan, 2012, cited in Rauscher, Young, Durham, & Barbour, 2017, 551; Rauscher & Fine, 2012). The fear



of stigmatisation seems to fit with the women's experience of being an egg recipient, with the accompanying anxiety about being judged, suggesting an awareness of having done something outside the norm. Kate talks about her anxiety in terms of making her child more "other" due to pursuing the egg donation route. Not wanting to make her daughter more "other" could also be linked back to a sense of not wanting herself to be perceived as more "other". It has been suggested that stigmatised people find a way of coping with the stigmatisation through either "problem-focused coping" (Bos, Pryor, Reeder, & Stutterheim, 2013, 3) such as selective disclosure, affiliating oneself with others in the same boat, seeking peer support and activism, or "emotion-focused strategies" (Bos, Pryor, Reeder & Stutterheim, 2013, 3) such as downward social comparison. Most of the women seemed to engage with all of these activities: selective disclosure; though the women who were dubious about disclosure did not want children to be judged, it also seemed as if the women were anxious about being judged themselves. This supports the research suggesting that parents' apprehension to disclosure is more related to wanting to protect themselves *as well as* their children, than simply for the sake of the children (Readings, Blake, Casey, Jadvá, & Golombok, 2011; Snowden, Mitchell, & Snowden, 1983), and that non-disclosure is related to fear of societal stigma (Cook, Golombok, Bish, & Murray, 1995; Rumball & Adair, 1999). This supports previous research which has suggested that non-disclosure protects both parents and child from potential public stigmatisation (Nachtigall, Pitcher, Tschman, Becker, & Szkupinski Quiroga, 1997; Golombok, 2013; MacCallum & Golombok, 2007). The findings also support Hershberg, Klock and Barnes's (2007) idea of women being selective in whom they disclosed to. This degree of selectivity varied from some only telling the immediate family, to others who disclosed more openly. Additionally, these women's experience of disclosure supports the idea that two primary strategies exist when it comes to disclosing to the donor-egg conceived child: disclosing so that the child has always known,

or waiting for the right time (Blyth, Kramer, & Scheider, 2013; MacDougall, Becker, Scheib, & Nachtigall, 2007). From the women's accounts it seemed that those who had disclosed from the beginning were less anxious about the impact of the donor conception on both them and their children than the women who were waiting for the right time to disclose.

With regard to affiliating oneself with others in the same boat, and seeking peer support and activism, this came out in several of the women's accounts either in their involvement with the Donor Conception Network or with the use of the internet and chatrooms to explore other recipient women's accounts and stories. It supports the theory that one of the ways of managing stigmatisation is through finding others like yourself, in which you are not seen as the abnormal but the norm, i.e., the abnormal is determined by what is generally accepted to be normal. In wider society, and perhaps within friend groups, egg donation might be viewed as outside the general norm, whereas within friend groups who have also engaged with donation and support networks for egg donation, egg donation is seen more as the norm and therefore not stigmatised in the same way. The process of normalising through surrounding oneself with other recipient parents and highlighting the benefits of egg donation has been argued to be a way of managing stigma (Frieze, Becker, & Nachtigall, 2008).

With regard to downward social comparison, Festinger (1954) proposed the theory of social comparison in which it was suggested that people evaluate themselves by comparison to others – either upwardly or downwardly. Downward social comparison is a way of feeling better about oneself by comparing oneself to others less fortunate (Wills, 1981). This seemed especially to be the case for Deborah, who mentions having an experience of being less than others due to having pursued egg donation, and feeling more able to disclose to her neighbour who had a child with a disability, as the neighbour was worse off than Deborah. It could be

argued that Deborah attempts to free herself from public stigmatisation by disclosing to someone whom she views to be socially lower than her.

Sachs and Hammer Burns (2006) suggest that egg donation might remove the stigma that the women might suffer because of being infertile, with their achievement of pregnancy, but that the alternative route of egg donation might cause it owns stigmatisation for

breaking/redefining kinship, genes and motherhood, as discussed in the introduction.

However, this piece of research suggests that for most of the women who had negative feelings regarding their infertility, these feelings were not repaired despite conceiving through egg donation. The negative feelings seemed to stay with the women.

It also seems that the women's experience as a recipient meant they not only had to protect themselves from others' judgement but also had to protect themselves from their own negative feelings or ambivalence. This is again suggested by several of the women's very rational accounts. It seemed that some of the women used rationalisation as a way of protecting themselves from engaging with their potentially ambivalent feelings about egg donation. Maria presented with a very rational account of her experience of egg donation, though it seemed that, comparative to the other women, the egg donation had the greatest implications for her, as her daughter was experiencing difficulties, and the arrival of the donor-conceived daughter in the family with an already naturally conceived child seemed to have caused some family rupture as well. This rational account could therefore be a way of justifying to herself the actions taken, thereby protecting herself from fully engaging with her experience of egg donation. Another take on the rationalisation is provided by the cognitive dissonance theory (Festinger, 1957). Cognitive dissonance is an aversive state which occurs when there is a discrepancy between people's beliefs or attitudes and their behaviour

(Festinger, 1957; Jarcho, Berkman, & Liebermann, 2011; van Den Akker, 2001).

Rationalisation is here seen as an attempt to reduce cognitive dissonance by justifying one's action as it might not fit with one's attitude and the rationalisation thereby attempts to make the selected decision more desirable than alternatives (Jarcho, Berkman, & Liebermann, 2011). This seems to be the case for the women, who at first were all set on having genetic children as this was believed to be the most desirable outcome. However, when that option was removed, the women then seemed to reframe their attitudes towards alternative methods of conception through rationalisation and by changing their perspective on the importance of nature/nurture in order to achieve cognitive consistency.

#### 4.2.3 Experience of resemblance

Another prominent aspect of the women's experience of being donor egg recipients was resemblance to their children. Their experience consisted of: a sense of loss, a feeling of missing out, not wanting to stand out, the lack of resemblance as a constant reminder of their infertility, and yet a perception of the child as "their child".

##### *4.2.3.1 Loss and missing out*

The feelings of loss and missing out were centred around three aspects: not getting the chance to recognise parts of themselves in their children, not having a genetic link with their children, and never getting to experience what it would be like to have a genetic child. These aspects seemed to cause the recipient women to feel a deep sense of loss, and as for some a sense of missing out a part of parenthood. Though some of the women did mention that they wished to pass on their genes, for the majority the focus was more on being able to recognise themselves in their children.

#### *4.2.3.2 Not wanting to stand out*

Another central part of the women's experience of resemblance was about not wanting to stand out, i.e., wanting to be part of the norm, and wanting to avoid others' questions of kinship, and potentially public stigmatisation. Supporting Section 4.2.2: "Protection from stigma and from showing one's vulnerability" point regarding egg donor recipients fearing stigmatisation. In a quest to avoid public stigmatisation, maintain social approval and a wish to protect themselves from others' intrusion, physical resemblance is desired as it gives an automatic assumption of belonging, whereas lack of resemblance, or contradictory features, might cause others to wonder about the kinship. This supports Braverman and Frith's (2014) suggestion that physical resemblance matters in terms of the ability to "pass off" (134) the child as one's own, and that lack of resemblance is experienced as threatening to one's social status (Harrigan, Priore, Wagner & Palka, 2017). Harrigan, et al, (2017) explained resemblance's perceived threat to recipients through Face theory (see Brown, & Levinson, 1987; Cupach, & Metts, 1994; Goffman, 1967; Harrigan et al, 2017), which suggests that people strive to maintain a positive self-image (referred to as positive face) through "maintaining social approval, maintaining autonomy, maintaining respect and preventing rejection" (278), and that resemblance is therefore a way of ensuring social approval as others will not question ones' relation. Face theory seem to support the women of this study experience of searching for resemblance, both physical and psychological, and rationalising potential lack of resemblance, as a way of maintaining social approval and avoid rejection or stigmatisation.

#### *4.2.3.3 Reminder of infertility*

Physical resemblance was highlighted as being potentially, outwardly, the most prominent telltale sign of the lack of genetic connection, and ultimately an indirect way of indicating

that the parents had gone the donor route, or had had to go down alternative routes to achieve pregnancy, thereby highlighting the women's infertility. Of course, even with a genetic child, the child might not bear strong a resemblance to the mother. However, there seems to be greater attention given to the resemblance in cases of egg donation, as the mothers are aware that there is a reason behind the lack of resemblance, and that if there is some resemblance then it must be pure chance. The women had to process the lack of genetic connection to the children, and for some this was made more difficult as the lack of resemblance felt like a reminder of the non-genetic link, suggesting that resemblance is a reminder of what the women could not produce, a reminder of not having achieved the "perfect biogenetic family", and a reminder of their infertility. The wish to create a "perfect family" is illustrated by some of the women's long battle with trying to conceive, first naturally and then with assistance.

#### 4.2.3.4 *Feeling vs. looking*

Despite the preference for the child to resemble the family, the recipients' emotional attachment to the child was not affected. All the women saw the donor-conceived child as their own, and themselves as the mother. This suggests that regardless of a genetic connection or physical resemblance, a child can emotionally be perceived as one's own. It seemed that in the women's description of their experience there was a clear distinction between a physical "*looking*" and an emotional "*feeling*" sense of belonging. Though not all the women felt their child *looked* to belong to them, or the family, all the women agreed that they *felt* as if the child belonged, and that they were the child's mother whether the child looked like them or not. Additionally, all the women stated that the love for their children was not affected by the fact that they did not share a genetic link.

This suggests that the women's ability to bond with the child was not affected by not being genetically related, supporting previous research which has suggested that the parent/child

relationship in donor-conceived families is as good as in other types of conceived families (Golombok, Murray, Jadv, MacCallum & Lycett, 2004), and supports the viewpoint of Bowlby's attachment theory's that it is not necessarily the genetic connection, but the repeated positive interactions that cause the emotional attachment (Bowlby, 1964; Leon, 2002).

#### 4.2.4 Recipients' experience of egg donation as selfish

Another interesting aspect, and an as yet unexplored research area that this research has brought up, was selfishness. Some of the women described perceiving egg donation as a selfish act due to going to great lengths to conceive a child, when there are children who need adopting. The experience of egg donation as a selfish act seems to come from the women's sense of pursuing a route that they find more desirable, due to it fulfilling their wish to experience pregnancy and birth, rather than being solely focused on the welfare of the child, and on wanting to give a child a second chance in life. It seems that their experience is based around perceiving adoption to be a form of altruistic experience while egg donation is for their own egoistic benefit. However, adoption literature suggests that people do not adopt to "save" a child, but to fulfil their own desire to create a family. In this study however, it seems that some of the women saw adoption as a more altruistic route. Perhaps this is related to adoption, in more recent years, becoming more socially acceptable, whereas egg donation might be perceived as less socially acceptable.

The recipient women's experience of themselves as selfish led them to feel pressured to create "good children". There was a feeling that since they had done a "selfish" thing, they then had to make up for this. This suggests that further research is needed, not only to extend our understanding of recipient women's potentially selfish feelings, but also to understand

how these selfish feelings may or may not impact the parent/child relationship, or the child's experience of themselves. If recipients do feel their actions are selfish, and that their children have to make up for this by being good people, then perhaps this could affect the child's wellbeing due to the pressure on them to be good.

The idea of selfishness in artificial reproductive technology has been briefly discussed by Smajdor (2008) with regard to society judging late parenthood, where women choose to "postpone" attempts to conceive till later in life, as selfish. The word "postponing" in itself gives the idea of a deliberate choice, however, in the case of the women participating in this piece of research, it was not a conscious choice to wait until their 40s before attempting to get pregnant; the women either tried for years to conceive using their own genetic material, or felt that they had to be in the right circumstances in their life to have children. Smajdor's (2008) findings suggest there is a sense of perceived selfishness in terms of being an older parent, however, this study does not support those findings as the selfishness here was related to pursuing egg donation above adoption, and not about the women perceiving themselves as being past the reproductive age.

Further research is needed to extend our understanding on this point.

#### 4.2.5 Recipients' experience of support

One of the aims of this piece of research was to gain a greater understanding into donor egg recipients' experience of support, in order to extend the limited research in this area and gain a greater insight into how recipients can be supported more effectively in the future. This section will focus on three areas to help do just that: the women's experience of counselling, their experience of other professionals, and areas in which more support is needed.



#### *4.2.5.1 Experience of counselling*

Overall, the women's experience and need for support varied greatly; some of the women sought psychological therapy and felt it was important to engage with therapy; others did not feel the need to engage; and one did engage, but did not feel she could connect and open up at the time. This research supports previous research which found there to be a limited uptake of counselling, and that the sense of being unable to cope and a lack of awareness of how to get started are common reasons for not engaging (Joy & McCrystal, 2015; Klerk et al., 2005; Boivin, Scanlan, & Walker, 1999; Pepe & Byrne, 1991; Marcus et al., 2007). The women's decision regarding whether to attend therapy seemed to be based on whether they felt a need to discuss the egg donation decision and the implications of egg donation. All the women felt certain that egg donation was the right next step. While some felt it was important to engage with therapy as a way of facing their emotions and the implications of egg donation, others felt able to cope on their own. A couple of the women who did attend therapy described being too emotionally unavailable at the time to engage with therapy. It seems there was a sense of not being able to fully open up due to being in some denial. The exact reason for the denial is unclear from the accounts, however, it seems that the stress of going through the treatment journey did lead some of the women to withdraw from others, almost shutting themselves down. This might have been a way of sheltering themselves, and a way of coping, and suggests that people might retreat to survival mode, in which only the basic needs can be met, rather than opening up and facing the potential present and future repercussions, which feels too dangerous. Perhaps there was a fear of realising that it was not the right decision, or perhaps it is more about the fertility journey, and that repeated attempts are so exhausting that no emotional space is available to process one's emotional frame of reference. Adding to this point, it seems that for some of the women there was such a burning desire for a child that they assumed that once the child was born, then everything would be alright, though as one

of the women highlighted, it is only when the child comes that the repercussions of one's actions properly set in. It is at that point that the egg donation becomes reality. Perhaps aligned with Goedeke, Daniels and Thorpe's (2016) study, in which counsellors experienced clients as being unable to comprehend the long-term implications due to being caught in a mode of trying to protect themselves by not allowing themselves to believe success would be achievable, the women in this study were unable to comprehend the implications as they were unable to allow themselves to believe that they would have a child. This supports Hammarberg, Ashbury and Baker's (2001) suggestion that counselling should be continuous, and not a one-off, as it seems there are several stages at which support could be beneficial, i.e., the women who might feel unable to process the implications before or during treatment might need more support after the birth, as this might be the time when the repercussions properly set in.

This is furthermore supported by the fact that most of the women expressed how their view of counselling had changed over time, and several of the women, including some of the women who never attended therapy, felt that it might have been beneficial to engage with therapy, as after giving birth the implications of egg donation had become more real. The idea that the women's experience of the need for support might change over time is quite interesting, as although the women's perspective changed, none of them sought counselling later. It would be beneficial to examine further what stops recipient women from seeking further support after giving birth. A couple of the women in the present study mentioned not knowing who to contact, not properly contemplating seeking counselling or seeking support elsewhere, such as with the Donor Conception Network. The findings of this study suggest that more focus should be given to promoting counselling correctly; informing the women that the counselling offered is not only a place to discuss the decision but also a place to help and support them to thoroughly reflect on, and help equip them with, ways to manage the

inevitable implications of conceiving by egg donation, both for themselves and for their children, as well as how to seek counselling later in the process. Machin (2011) highlighted that as counselling is not mandatory, more importance should be placed on proactively seeking people in need of counselling. Instead of making counselling mandatory, it should be made more visible for those in need.

The women's view of counselling also seemed to be related to their past experiences and ideas around counselling. Some of the women had counselling-related jobs, and therefore saw it as a matter of course that they undertook counselling. Others had previously engaged in therapy, while yet others did not mention having engaged with therapy before. This might suggest that it is important to take into consideration recipients' past counselling experience when offering egg donation counselling. Future research could examine whether there is a correlation between past counselling experience and seeking therapy regarding egg donation.

#### *4.2.5.2 Experience of support from other staff*

The importance of feeling supported and heard by professionals consistently came up across the women's accounts. Most of the women had at some point felt badly treated by members of staff – this was especially the case with the delivery of the infertility diagnosis, with several of the women stating that the delivery of the news had been overwhelming, shocking and difficult to comprehend. Though the infertility pre-empts the egg donation, it could be argued that the way the women manage and cope with their infertility could have consequences for how they manage the implications of egg donation, and some of the negative psychological effects of being diagnosed as infertile might have impacted the women's psychological wellbeing even after having conceived through egg donation, thereby making the support from professionals even more important. On the other hand, it seemed

that good support from professionals helped the women to feel better able to cope with the stress of going through the treatment. The doctors were seen as being able to increase faith and trust in the process. Of course, doctors have to be careful not to give false hope, but it seemed that it might be invaluable for recipients to feel that someone believed in their possible success. This would lead them to feel more relaxed, and thereby with a greater chance of their bodies receiving the donated egg. The present study suggests that professionals hold a very important position in helping recipients to manage their negative feelings, whether this is with regard to facing their infertility, or deciding what to do next, or when the women are undergoing treatment. From the women's perspective, it seems that this time is a very sensitive one and the appropriate support and guidance from professionals helps diminish the difficulty in managing this challenging period. This supports Machin's (2011) suggestion that practitioners and nurses should play a greater role in supporting recipients as not all recipients will be interested in counselling.

There has been some debate around whether social and personal vulnerability is linked to the level of professional satisfaction. Sabourin, Wright, Duchesne and Belisle (1991) found that infertility patients with high levels of personal and social vulnerability felt less satisfied with clinic professionals, though Schmidt, Holstein, Boivin, Tjornhoj-Thomsen, Blaabjerg, Hald, Rasmussen and Nyboe Andersen (2003) found that personal/social vulnerability did not affect satisfaction. Schmidt et al.'s study found high levels of patient satisfaction, even with the absence of counselling, and suggests that counselling might not be needed if the service from other staff is good. This supports the present study's suggestion that more focus should be given to helping other professionals provide better support and compassion towards the recipients.

#### *4.2.5.3 Areas in which support is needed*

Based on the women's description of their experience of support it seems there are several ways in which counselling could help support the women. One of the aspects that the women struggled with, in particular, was being faced with the fact of their own infertility. The women's experience of themselves as infertile caused them to experience feelings of shame and embarrassment. There also seemed to be a clear sense of the women seeing themselves as "before" and "after". The women's sense of self seemed shaken, not by having to pursue egg donation, but due to their infertility. Interestingly, the fact that the women conceived, albeit through egg donation, did not seem to alter their view of themselves as infertile, suggesting that the processing ones' feelings regarding owns infertility is important, as one's self image is not rectified by conceiving through other methods. This is an important aspect to research further, and is important in terms of counselling: to be aware that donor egg recipients who attend counselling might be stuck with a view of themselves as infertile, and this might continue to impact their sense of self, despite conceiving through egg donation. As suggested by Sachs and Hammer Burns (2006), it therefore seems crucial that counselling is used to help recipients restore their, potentially, damaged sense of self and supports them to reach a point of acceptance of their infertility.

Another aspect that the findings suggest could be helpful for the women to explore further is not whether to proceed with egg donation, but contemplation of the implications of their decision. Though it might not be possible for the women to fully comprehend the impact the egg donation might have until the child is born, perhaps counselling can still be beneficial in educating, preparing and supporting the recipient women with regard to the psychosocial aspects of egg donation, as suggested by Greenfeld (1997). Additionally, the women in the present study seem to support Hammarberg, Carmichael, Tinney and Mulder's (2008)

findings that disclosure and the parent/child relationship is particularly useful to explore (Hammarberg, Carmichael, Tinney & Mulder, 2008), as the women struggled with disclosure, i.e., to whom, when, and why they should disclose.

Despite several of the women stating that their view on counselling had changed over time, and that more support would have been beneficial, it seems that most of the women were not ready to discuss egg donation at the time, and making counselling mandatory does not therefore seem appropriate.

Overall, the women's experience of support and feeling supported projected the sense that the women who were the most open and had engaged with a variety of coping strategies seemed to find it easier to disclose and talk about egg donation. This suggests that engaging with the implications of egg donation leads to a greater confidence and openness, and could possibly help reduce any potential distress, while acknowledging that not all feel the need for counselling or have the ability to engage with counselling. Furthermore, based on the women's poor experience with other medical professionals, it seems that more focus should be given on helping assist other professionals in ways to support recipient women, if counselling is not appropriate.

### **4.3 Limitations and reflexivity**

#### **4.3.1 Methodological limitations**

One of the methodological limitations with IPA is its dependence on language. Firstly, the findings are dependent on participants' language, and their ability to express their experience of a phenomenon using the language they have available. As Smith et al. (2009) state "our interpretations of experiences are always shaped, limited and enabled by, language" (194).

Willig (2009) argues that interviews depict how people “talk about” a phenomenon rather than their actual experience of it. Therefore the experience that IPA allows to emerge reveals the participants’ understanding of their experience (Smith, Flowers, & Larkin, 2009).

Secondly, the analysis is also dependent on the researcher’s language, i.e., the researcher’s ability to make meaning out of the participants’ words and then transform this meaning with their own words. On reflection, there were several times when I found the process of analysis using IPA very difficult. This was mainly due to English is not being my first language, and the analysis using IPA being very dependent on the words you use to convey the participants’ meanings. As a non-English mother tongue speaker, I understand the meaning they are making, but at times find it difficult to condense the meaning down to a word or a phrase in English. I was aware that there were times when someone with English as their first language might have used a different word, or interpreted the women’s experience differently based on their native understanding of English. This at times became quite a hindrance for me, as I would spend too long trying to find the perfect word, or doubting whether my use of English was correct.

Furthermore, IPA is dependent on the participants’ ability to access their experience – not only to communicate the experience, but actually for the participants to access it, get to the core of how they experienced a phenomenon, in this instance, egg donation. To rectify this, close attention was paid not only to how the women formulated their experience but also to other aspects such as non-verbal cues and metaphors. Additionally, it is also acknowledged that the experience the women disclosed was influenced by the interaction between them and the researcher.

The aim is not to generalise these findings, but to depict the experience these women had of egg donation and think of that in terms of how it should impact research to further our understanding of the egg donation phenomenon. Larger studies and multiple methodological approaches are needed to get a fuller picture of what the experience of being a donor egg recipient is like.

#### 4.3.2 Procedural limitations

As with any study, one of the limitations is recruitment, as the findings are based on the people that choose to come forward, and the sample is therefore not necessarily representative of donor egg recipients. Rozmarits and Ziebland (2004) have suggested that people choosing to participate might have had a particularly positive or negative experience and are therefore wanting to share their story. Despite a variety of recruitment methods, only fourteen women came forward with the intention to participate, and six were excluded from the study due to not fitting the criteria by either living abroad, not being able to attend a face-to-face interview or having children under the age of 1. This could suggest that the women who came forward might have had a specific reason for wanting to share their story, like Laura, who stated in the debriefing that she saw her participation as a way of starting to get used to talking about the conception.

An additional procedural limitation was the research schedule. All interviews began with the same broad, open question: “could you tell me about your experience as a donor egg recipient in as much detail as possible?”. This was to allow space for the first thing that came into participants’ minds. Furthermore, it aimed to ensure that the topic was approached in a way that felt comfortable for the participant, and allowed the participants to start from the point that they felt was the most appropriate (Smith & Eatough, 2009). However, the broad



question invited a specifically chronological description of their experiences, and some seemed overwhelmed as to where to begin. While analysing, it became clear that the data had more of a rational, descriptive feel to it, and why it was also, at times, very difficult to get to the “lived” experience. This could suggest that the way the questions were asked elicited more process-based answers and did not focus enough on the women’s experience, however, as discussed earlier, the rational accounts could also be a way of the women managing their feelings. It may also be that the rational accounts fit in with Smart’s (cited in Fine, 2015) idea about how personality might affect how one might view egg donation. Perhaps women who have a more rational world view, in general, are more likely to pursue the egg donation route, as it might be easier to accept egg donation from a rational perspective than an emotional one. At the time, I did not transcribe each interview in between the interviews, however, had I done this, I might have become more aware of the rational accounts that some of the women were giving. In the future, it might be helpful to transcribe each interview before the next in order to get an sense of whether or not the questions bring out the participants’ felt experience rather than their more rational account.

Another procedural limitation was the diverse recipient group. IPA advocates a relatively homogenous sample, and though the women did share many main similarities – all having undergone the egg donation procedure, all having successfully conceived and given birth to a child with the assistance of egg donation, all having an anonymous egg donor, all having a child over 1 years old at the time of the interview, all being of advanced maternal age, between 38-50 at the time of the procedure – there was also quite a few differences across the group such as their sexual orientation, relationship status, known/unknown sperm donor, and the age of the child at the time of the interview. Due to egg donor recipients representing a relatively small population size, and given the secrecy that is still present with regard to egg

donation, it was felt that the benefits of my novel research in this area outweighed the lack of homogeneity. Furthermore, due to the enduring paucity of research into women's experiences of being egg donor recipients it is not possible to determine whether or to what extent relationship status, sexual orientation or the age of the child impacted the women's experience of being a donor egg recipient. For this piece of research, it seemed that the diverse nature of the group at times exacerbated the experience, i.e., the women's experience of guilt of having given something for the child to manage was something shared by most of the women, but for the women not in heterosexual relationships or where the husband had not donated the sperm, this sense of guilt seemed heightened. Though it is possible to examine the differences and convergences within the data using IPA, the extent to which the differences impact the data is outside the remit of IPA, i.e., it is possible to capture that the women's relationships status might have impacted their experience but not to what degree. More research is needed to examine whether women's sexual orientation, relationship status, known/unknown sperm donor and the age of the child impacts significantly on the women's experience of being egg donor recipients.

#### **4.4 Final Reflexivity**

##### **4.4.1 Reflexivity on the research process**

One of the biggest challenges for me in the analysis process was my desire to give justice to the women's voices, and therefore finding it difficult to go beyond the data. Though as counselling psychologists we make interpretations of the clients' stories all the time, this felt very different in the research process as I was not able to check my understanding with the women participating. This meant that I, at times, felt scared that I was putting my interpretations and words "into their mouths" and that I was going too far beyond the data, which would mean that the women would not be able to recognise themselves in the

interpretations. My struggle with IPA reflects the struggle within IPA itself of charting the right course between staying true to the participants' accounts of a phenomenon while adding a deeper level of interpretation that adds to the richness of their experience but does not remove us from their voice. This was a continuous battle for me. One which I am yet to resolve. Larkin, Watts and Clifton (2006) also stated that students are at times not brave enough to fully engage with the interpretation needed for IPA. I would agree with this. It seems for me that part of my own process alongside the research was to develop a greater confidence and belief in my abilities as a researcher and as a counselling psychologist. Finding the balance between "giving voice" and "making sense" (Larkin, Watts & Clifton, 2006) is a difficult one for novice IPA researchers, however, as with most things, I am sure that my confidence with IPA will increase and the process of going beyond the data will feel more organic.

As mentioned earlier, IPA is very dependent on language, and I am aware that language has, at times, seemed like a particular barrier for me – it has often felt difficult to find my words. At the beginning of the research process I lived in the UK and the English language felt like my primary language, however, after moving back to Denmark halfway through the research process, I found myself struggling to find both my English and Danish words, making me, at times, feel inferior and incapable, and making the research process more of a struggle.

Perhaps due to this sense of not being able to find the right words I became very prescriptive and rigid, as I often felt I needed some clear guidance on how to cope with my struggle in finding my words. I felt caught in trying to do it right, often imagining that there must be a right way, a structured way. In a sense, IPA can be both prescriptive and structured, however, the structure lies in the guidelines of "how to do it" rather than in the words to use to describe an experience.

The sense of wanting to get it ‘just right’, and the difficulty in getting to the essence of the women’s experience of egg donation due to their somewhat processed and rational accounts, meant that the analysing process felt, at times, quite paralysing, and gave me the sense of being stuck, and almost drowning in the data.

#### 4.4.2 Reflexivity on the egg donation phenomenon

I had very conflicting thoughts about egg donation at the beginning of the research. On the one hand, I thought that egg donation would be viewed negatively by the women, and that the women would feel a continuous sense of failure for having to use the egg donation method. On the other hand, I hoped that egg donation would be perceived as being “just as good” as natural conception. This might have been exacerbated by the fact that during the early stages of research my own relationship broke down, which affected my own thoughts about my prospects of having children and my own fertility. I was especially affected by the women’s thoughts about wanting to be in the right relationship before conceiving, and some of the women’s frustration with not being able to find a suitable partner with whom to have children impacted me and my thoughts greatly. Perhaps this led me to, at the beginning, have a greater interest in egg donation being perceived as ‘just as good’. During the process my thoughts about egg donation changed and fluctuated. Currently, I am at the point where I acknowledge that most people, including myself, hope for a nuclear genetically related family, but that other ways can become acceptable to us when this is not possible. It seems that actually it is not about whether egg donation is better, worse or the same as natural conception, but perhaps more about having to get to a place of accepting of one’s fertility, and then accepting that egg donation is a different form of conception.

Additionally, due to the research, I have often found myself very frustrated with the media's portrayal of egg donation and reproduction in general. As I have been writing up my thesis there has been a campaign in Denmark about trying to encourage people to have children earlier in life, so infertility can be avoided. This campaign, amongst others, has often portrayed the idea of not conceiving earlier in life as a choice, and that people 'postpone' pregnancy so it fits better into their lives. I often found myself incredibly frustrated with this idea. My research, and my own experience, suggests that not conceiving earlier in life is not necessarily a choice. The women from this research felt a pressure to create the right circumstances, i.e., getting an education, having a job, and a partner, before having children. This is supported by Wyndham, Figueira and Patrizio (2012). However, their article also talks about conception in terms of 'delaying', 'postponing', all of which suggest that women are making a conscious decision not to conceive earlier.

#### **4.5 Future research**

Though this piece of research has helped to further our understanding into the concept of egg donation, and more specifically the recipient women's experience of egg donation, there are still many areas that need further research before an adequate picture of egg donation can be made.

To get a greater insight into how the phenomenon of egg donation is experienced, it seems crucial to examine the concept with a more diverse group. As mentioned in the introduction, some research has suggested that there could be cultural and religious differences in how egg donation might be experienced. More research is therefore needed to examine whether women's social, religious and cultural status might inform how they experience egg donation.

This could be done through a more comparative study, in which different cultural and religious beliefs were compared.

Different from Hershberg's study (mentioned in the introduction), where the interviews were conducted while the women were pregnant, in this study the interviews were conducted between 1 and 8 years after the birth, and that fact allowed us to see that there was movement in the women's thinking about and reflections on egg donation, from the stage of contemplating egg donation to their thoughts after having the child. It could also be argued that not interviewing the women until some of the children were older might mean that the intensity of the women's experience might be diminished due to the passing of time. My study might not therefore capture the strength of these feelings. Maybe more needs to be known about people considering egg donation. It seems that after the arrival of the baby the route to getting the baby becomes less important, so the women do not think about all the conflicting thoughts they had back then. But more knowledge about the period prior to choosing egg donation might give a greater insight into what support the women need at the time. Another area that could do with further examination is psychological support for women undergoing egg donation. This is a very under-investigated area. This research suggests that not all feel the need for or benefit from psychological counselling before undertaking the procedure. However, further research could be done with the women who undertake counselling, and those women who did not undertake counselling, to understand their reasons for not wanting to participate. This would provide an insight into whether and how psychological support could assist the women.

Another interesting point that the research raised was to do with the women's struggle with disclosure, and their distrust and anxiety about others handling their information. Some of the

women were more distrusting and affected by outside opinions than others, suggesting that it might be interesting to, in the future, examine whether the women's attachment patterns to others affect how they feel about disclosing to others. Perhaps the women who have anxious or ambivalent attachment patterns are more likely to be suspicious of whether others will react negatively to their information. This could be important information with regard to helping recipient women manage their feelings towards disclosing to others.

Additionally, an interesting question that this piece of research has left unanswered is regarding the selection process of egg recipients. Currently there are no criteria to prevent people from pursuing egg donation, and this seems slightly at odds with the rules for adoption, which requires a very lengthy and stringent acceptance process. Fine (2015) has already suggested that a more stringent selection process might be put in place in the future. This is an interesting concept, and it will be revealing to see what role psychologists/counsellors will come to play in assessing potential recipients, especially in the light of research which has suggested that there is a limited uptake of counselling for people going through infertility due to a fear of assessment (Bartlam & McLeod, 2000). This might mean that it will be even more difficult to get recipients to attend counselling. This will certainly be an interesting development to follow, and will require counselling psychologists to be particularly mindful of how to manage this balance between being an assessor and being someone who can help potential recipients work through the implications of egg donation.

It will also be worth following developments around the still unknown implications of the 2005 non-anonymity law. Not until 2023, when the first children born under this law are 18

and able to contact their donors, will we be able to examine the consequences of the non-anonymity, on the children and on the mothers.

## **4.6 Implications**

### **4.6.1 Implications for professionals working within the field of egg donation**

One of the aims of this piece of research was to help support and provide guidance to professionals who come into contact with egg recipients, such as doctors and nurses. These are the professionals who often have the most contact with recipients both before and during attempts at conceiving. Most of the women in this research sought a greater understanding and support from the professionals such as doctors and nurses along the way. Half of the women had had negative experiences with professionals, and all felt that this had had a negative psychological impact on their wellbeing. The desire from the women to feel better supported by the medical professionals is clear here. This suggests that more guidance and support should be given to medical professionals in how they deliver the news of infertility and what support they can offer the women, such as introducing them to the Donor Conception Network (DCN). Interestingly, though the Donor Conception Network provides great support and workshops, one of the women had never heard of the DCN, and stated after the interview that she wished hospitals were better at helping to inform them about what support services were available. Some of this sense of lack of support was more pertinent for the women who chose to go abroad. Here the women discovered that there was no support available. As it is not possible to regulate foreign clinics, perhaps the GP, or the doctor disclosing the infertility diagnosis, therefore has an even more central role at that stage in ensuring that people know what services are available to them. Perhaps a closer collaboration between GP practices and the DCN is needed.



#### 4.6.2 Implications for counselling psychologists

Bearing in mind the “science-practitioner” (Strawbridge & Woolfe, 2003) ethos of counselling psychology, there are several ways in which the discipline can influence the area of egg donation.

This piece of research suggests several ways in which therapeutic work could help recipients. The findings suggest that the women felt confident in their decision to pursue egg donation, and did not feel a need to question this in counselling; rather the women seemed to want help with reflection on future implications of egg donation, and support and guidance on how to manage certain scenarios such as disclosing to others and the child, as well as dealing with the effects that lack of resemblance might have on them and on their child. The counselling of recipient women should be about equipping them with the tools to manage the implications, rather than with coming to the decision of egg donation. Additionally, this research suggests that there was a change in the patterns of the women’s reflexivity, suggesting that counselling should not be thought of as a one-off event but should be offered at more intermediate stages. In the debrief several recipients suggested that therapy might be important at the stage of being told of one’s infertility, during the process of trying to conceive by donor eggs, after the birth, and then around the time that the women start disclosing to the child and others.

In terms of the actual modalities that could be the most helpful for donor egg recipients there is no research, to my knowledge, which has investigated what is the most beneficial. Sachs and Hammer Burns (2006) state that psychoeducation, support and assessment are essential in counselling donor egg recipients. Those three aspects are certainly important, however, the current study suggests that a humanistic therapeutic approach is also needed. Not only do the

women need some psychoeducation as to the practicalities of egg donation, but it seems that it is also crucial for the counselling psychologist to help the women rebuild their assumptions and beliefs about themselves, the world and others. The findings suggest that therapeutic work with donor egg recipients perhaps needs to focus on managing their distrust of others, feelings of vulnerability, their sense of loss, and on helping the women find coping strategies. The women's distrust of others seems particularly important. This might not only affect the women's relationship to others, but might also affect their attitude towards counselling. It is therefore important for counselling psychologists to create an environment in which recipients can openly explore their feelings. This might prove a challenge as most of the recipients did not want to engage with the implications of egg donation, or share their thoughts and concerns with others. However, with Kirkman (2003) suggestion that children model their narrative about conception on the narrative of their mothers, it is important to help and support the women in forming a healthy narrative of their infertility and the egg donation route. This is supported by Karen, who believed that she had to face the consequences on her own in order to be able to help her children face it themselves.

Though I have suggested several ways in which counselling psychology could benefit the area of egg donation, more research is needed in this area.

## **5. Conclusive thought**

This piece of research has through interpretative phenomenological analysis explored women's lived experience of being the recipient of donor eggs. The aim was to broadly capture their experience, and the analysis showed the complex, intrinsic, and at times conflicting experiences of these women. Broadly their experience consisted of navigating a new reality, facing their own vulnerability and devastation, feelings of distrust and worry, yet

a clarity about the pursuit of egg donation in order to achieve having a child. This research suggests that egg donor recipients' experiences are psychosocially complex, and that though not all recipients want support, in particular counselling, importance should be placed on making support available for the women in need, as egg donation does bring its own complications with it, and requires a life-long navigation of these, for the recipient women themselves, and for the recipient women on behalf of their children.

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## Appendixes

### Appendix 1 Decline of infertility statistics

Figures taken from:

Excellence, N. I. (2016, August 30). <https://www.nice.org.uk>. Retrieved from <https://www.nice.org.uk/guidance/cg156/chapter/figures-and-tables-to-support-chances-of-conception-and-embryo-quality-recommendations>

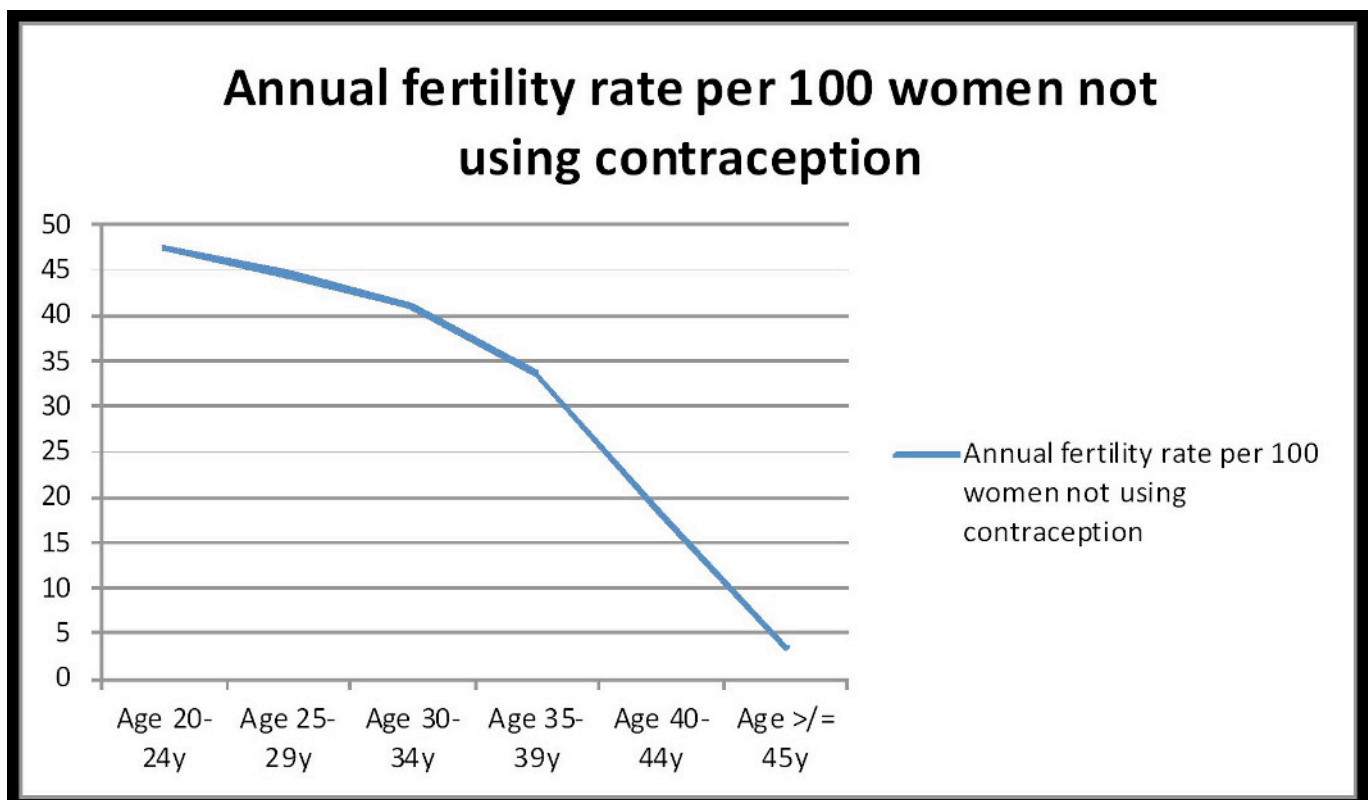
#### Appendix 1.1 Cumulative probability of conceiving a clinical pregnancy by the number of menstrual cycles

Cumulative probability of conceiving a clinical pregnancy by the number of menstrual cycles attempting to conceive in different age categories (assuming vaginal intercourse occurs twice per week)

<b>Age category (years)</b>	<b>Pregnant after 1 year (12 cycles) (%)</b>	<b>Pregnant after 2 years (24 cycles) (%)</b>
19–26	92	98
27–29	87	95
30–34	86	94
35–39	82	90

## Appendix 1.2 The effect of maternal age on the average rate of pregnancy

Calculated on the basis of studies in 10 different populations that did not use contraceptives.



## Appendix 2 Initial thoughts



## Appendix 3 Adverts

### Appendix 3.1 Advert for online chat rooms

#### **Research into the experience of women recipients of donor eggs**

I am a Trainee Counselling Psychologist at City University London and as part of my Doctoral training I am conducting research into women's experience of being a recipient of egg donation and how women feel about this experience. I am therefore looking for women who are interested in being interviewed about their experience. The interview will take place at a convenient location for you and will last approximately 60 minutes and will be audio recorded.

The travel costs to take part in the study will be covered by the researcher.

If you would like more information or would like to take part then please contact me via my email:

[REDACTED]

(Supervised by Dr. Karen Ciclitira, email [REDACTED])

*This study has been reviewed by, and received ethics clearance through the Psychology Department Research Ethics Committee, City University London. Ethics approval number [PSYCH(P/F) 14/15 107]*

*All personal information will be kept strictly confidential*

**Did you have a child through egg donation?**

**Would you be willing to talk to me about your experience in confidence?**

**I want your story to be heard.**

I am researching women's experience of being the recipient of egg donation and I hope this important research will change how services are provided and how people understand the area of egg donation. I am looking for women of all ages, cultures, social and marital status, who have become pregnant with the assistance of donor eggs, and carried the child to full term.

If you would like to take part in an interview about your experience, or wish to find out more, please contact me, Simone Roggenkamp, on 07770895629, or email me at [REDACTED]

This research is conducted as part of my doctorate in Counselling Psychology at City University, and have received ethic approval from City University [PSYCH(P/F) 14/15 107]. All personal information will be kept strictly confidential

Research into egg donation  
[REDACTED]  
Simone Roggenkamp

Research into egg donation  
[REDACTED]  
Simone Roggenkamp

Research into egg donation  
[REDACTED]  
Simone Roggenkamp

Research into egg donation  
[REDACTED]  
Simone Roggenkamp

Research into egg donation  
[REDACTED]  
Simone Roggenkamp

Research into egg donation  
[REDACTED]  
Simone Roggenkamp

Research into egg donation  
[REDACTED]  
Simone Roggenkamp

Research into egg donation  
[REDACTED]  
Simone Roggenkamp

Research into egg donation  
[REDACTED]  
Simone Roggenkamp

Research into egg donation  
[REDACTED]  
Simone Roggenkamp

## **Appendix 4 Information sheet**



### **Information Leaflet**

I would like to invite you to take part in this study. Please carefully read this information leaflet before deciding to take part in this research study. This leaflet contains information about why the study is conducted and what it would involve for you. This will help you decide whether or not you wish to part take in this project. If you require further information please do not hesitate to contact me.

### **What is the aim and purpose of this study?**

The aim of this study is to explore the experience of women recipients of donor eggs. Each year more and more babies are conceived and born with the assistance of women who donate their eggs. There has been research into various aspects of this topic such as parenting and child development, deciding on treatment, selecting a donor, disclosure of treatment and the impact of the missing genetic link. However, little research has been done into women's feelings around being the recipient of donor eggs. I am therefore looking for women who are interested in being interviewed about their experience.

The aim of the study is to help provide health services with richer knowledge and understanding of what it might be like for women who have conceived through egg donation.

### **Who is involved in organising this research?**

This research study is organised and conducted by Simone Roggenkamp, Trainee Counselling Psychologist, as part of her research thesis for City University London Counselling Psychology Doctorate programme. This research is supervised by Dr Karen Cicilitira, Psychotherapist and Lecturer.

### **Do I have to take part?**

Whether you choose to take part or not is up to you. If you decide to take part, your experience will help health professionals gain a better understanding of the experience of women that are the recipient of donor eggs. Your voice will also hopefully help health services improve current services and treatments available.

If you do decide to participate you will be contacted to meet with the researcher and asked to sign a consent form. Your personal information will be kept anonymous at all times during the research and

destroyed once study is completed. If at any point you wish to discontinue, you are free to withdraw from the study at any time without giving reasons. Taking part in this study will not affect the care that you receive now or in the future.

### **What will the study involve?**

Once you have contacted the researcher to let her know you are happy to participate. You will be invited to meet on one occasion to sign a consent form if you agree to consent and to take part in an interview. The interview will last between 60 - 90 minutes, in which you can leave at any time you wish. The interview will be audio recorded so that it can be transcribed. Once the interview has been transcribed all recordings will be destroyed.

### **Are there any risks or disadvantages of taking part?**

You may find talking about your experiences distressing; if you find yourself distressed at any point, please let the researcher know at any time. The researcher will be able to provide you with appropriate services and support that you will be able to access following the study, if required. Please note that you are able to discontinue at any point during the interview.

The disadvantage of the study is the time required to take part in the **one off** meeting in which the interview will take place. The researcher is aware that providing this time may be difficult, however, your time will be highly valued and will allow meaningful information to be gathered.

### **Are there any benefits to take part in the study?**

Although there may not be any direct personal gain, it is hoped that participating in the study will give you the opportunity to share and voice your experience in detail. As an appreciation of your time all travel costs to and from the interview will be paid by the researcher.

### **Will my information be kept confidential?**

All information collected from you will be kept strictly anonymous at all times. This means that no one reading the study will be able to recognise you as the participant. All names used in the interview will be deleted or reported using a code name.

### **Who has reviewed this study?**

The study has been approved by City University London Psychology Department Research Ethics Committee.

### **What happens to the results?**

Once all data have been collected, it will be written up as part of the doctorate in Counselling Psychology. This may then be submitted for publication in academic journals.



**What if there is a problem?**

If you would like to complain about any aspect of the study, City University London has established a complaints procedure via the Secretary to the University's Senate Research Ethics Committee. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is '*Women's experience of being the recipient of donor eggs*'.

You could also write to the Secretary at:

Anna Ramberg  
Secretary to Senate Research Ethics Committee  
Research Office, E214  
City University London  
Northampton Square  
London  
EC1V 0HB  
Email: [REDACTED]

**Contact details**

**Researcher:** Simone Roggenkamp, Trainee counselling Psychologist

**Email:** [REDACTED]

**Phone:** [REDACTED]

*Please do not hesitate to contact the researcher if you require further details or have any questions about the research. The researcher is very happy to answer them for you.*

**Thank you for reading this leaflet and considering taking part in the study.**



## Appendix 5 Consent form



### Women's experience of being the recipient of donor eggs

Ethics approval number: *PSYCH(P/F) 14/15 107*

#### The purpose and aim of study:

The aim of this study is to explore the experience of women recipients of donor eggs. Each year more and more babies are conceived and born with the assistance of women who donate their eggs. There has been research into various aspects of this topic such as parenting and child development, deciding on treatment, selecting a donor, disclosure of treatment and the impact of the missing genetic link. However, little research has been done into women's feeling around being the recipient of donor eggs. I am therefore looking for women who are interested in being interviewed about their experience.

The aim of the study is to help provide health services with richer knowledge and understanding of what it might be like for women who have conceived through egg donation.

Please initial box

1.	<p>I agree to take part in the above City University London research project. I have had the project explained to me, and I have read the participant information sheet, which I may keep for my records.</p> <p>I understand this will involve:</p> <ul style="list-style-type: none"><li>• being interviewed by the researcher</li><li>• allowing the interview to be audio recorded</li><li>• completing a questionnaire asking me about my demographics</li></ul>	
2.	<p>This information will be held and processed for the following purpose(s):</p> <p>I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports in the project, or to any other party. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation.</p>	
3.	<p>I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project until <b>31<sup>st</sup> July 2015</b> without being penalised or disadvantaged in any way. If you withdraw from the study all your data will be withdrawn and destroyed. Whether you agree or do not agree to have your data used for this study, your travel costs will still be covered for your participation in the interview.</p>	

4.	I agree to City University London recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on the University complying with its duties and obligations under the Data Protection Act 1998.	
5.	I agree to take part in the above study.	

Please note that you are welcome to receive a copy of your transcript with the opportunity to change or leave out anything that you do not feel comfortable with. In addition, if you would like to receive a summary of the findings when it is completed, then please feel free to ask me for these. Please confirm whether you would like to receive the summaries by:

☐

By Post

☐

By email

\_\_\_\_\_  
Name of Researcher  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Participant  
Date

\_\_\_\_\_  
Signature

## Appendix 6 Demographics



### Demographic information questionnaire

Participant ID: \_\_\_\_\_

Age: \_\_\_\_\_

Ethnicity origin (please circle)

White

Irish

Black/African/Caribbean/Black British

Mixed/multiple ethnic groups

Asian/Asian British

Other (please specify) \_\_\_\_\_

Prefer not to answer

Education (please circle)

Secondary Education, GCSE

Secondary Education, no GCSE

Some higher learning, no A Level or equivalent

Higher earning graduate, A Level or equivalent

Some college credit, no degree

Trade/technical/vocational training

Bachelor's degree

Master's degree

Doctorate degree

Prefer not to answer

Sexual orientation (please circle)

Heterosexual

Bisexual

Lesbian

Prefer not to answer

Marital status (please circle)

Married  
Divorced  
Widowed  
Domestic partnership  
Single  
Civil partnership  
Prefer not to answer

Religion (please circle)

Christian  
Muslim  
Hindu  
Sikh  
Jewish  
Buddhist  
Any other religion (please specify) \_\_\_\_\_  
No religion  
Prefer not to answer

Economic status (please circle)

Stay at home parent  
Full time work  
Part time work  
Self-employed  
Student  
Retired  
Unable to work  
Unemployed  
Prefer not to answer

Number of children and their ages: \_\_\_\_\_

Number of children conceived through assisted reproductive technology \_\_\_\_\_

Number of children conceived through egg donation \_\_\_\_\_

## **Appendix 7 Interview schedule**

### *Making the decision and coming to terms with using donor eggs*

- Could you tell me about your experience as an egg donor recipient in as much detail as possible?
- Could you please describe how you came to the decision to utilise egg donation?

### *Experience of sense of self/self-identity before and after*

- Please describe how your experience of having eggs donated has affected your feelings and thoughts about yourself.
- Please describe how your experience of being a donor egg recipient has affected your thoughts and feelings about yourself as a mother.
- Please describe how your experience of having eggs donated has affected how you view yourself as a partner/wife/girlfriend.

### *Experience of pregnancy*

- Please describe your experience of getting pregnant.

### *Donor criteria*

- What is your relationship to the woman who donated their eggs to you?
- (If they have not met) What information did you receive about your egg donor? And was this helpful?
- Could you describe the process of choosing your egg donor?
- Could you describe your feelings towards your egg donor?

### *Worries and fears*

- Please describe your main worries and fears regarding egg donation.

### *Mother/child attachment*

- Please describe any thoughts and feelings you might have regarding developing a relationship with your child.

### *Support/counselling*

- Did you receive any Counselling at any point – and if so could you tell me about this.
- Please describe a time where you felt you could have been better supported?

### *General*

- Is there anything else you would like to tell me about the subject matter which we have not yet discussed?

## Appendix 8 Debrief sheet



Thank you for taking part in the interview. The aim of the interview was to get an insight into your experience of being a recipient of egg donation by trying to capture how you made sense of the experience.

If the interview has raised any particular concerns for you then please note that you can contact any of the following counselling services for further support:

### **Fee paying services:**

#### **British Infertility Counselling Association**

[www.bica.net](http://www.bica.net)

Provides a list of potential counsellors specialising in infertility.

#### **The Bridge Centre**

One St Thomas Street

London Bridge

London SE1 9RY

Tel: 020 7089 1449

Email: [bridge@thebridgecentre.co.uk](mailto:bridge@thebridgecentre.co.uk)

Offers: Implications Counselling, support counselling and therapeutic counselling

#### **CRM CARE Fertility London**

Park Lorne,

111 Park Road,

London NW8 7JL

Tel: 0207 616 6767

#### **The London Women's Clinic, London**

113 - 115 Harley Street

London W1G 6AP UK

Tel: 020 7563 4309

Email: [tracey.sainsbury@londonwomensclinic.com](mailto:tracey.sainsbury@londonwomensclinic.com)

#### **London Fertility Centre**

Cozens House

112A Harley Street

London W1G 7JH

Tel: 02072240707

**Non-fee paying services:**

**Samaritans**

If you feel in distress the Samaritans provide a 24 hours a day phone counselling service.  
08457 909090

**City and Hackney Mind**

8-10 Tudor Road  
London E9 7SN  
02089 854239  
cityandhackneymind.org.uk

I hope you found the interview interesting should you have any questions or concerns regarding this study, its purpose or procedures, or if you have a research-related problem, please feel free to contact me via email: [REDACTED], or via phone: [REDACTED].

If you would like to complain about any aspect of the study, City University London has established a complaints procedure via the Secretary to the University's Senate Research Ethics Committee. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: *Women's experience of being the recipient of donor eggs*

You could also write to the Secretary at:

Anna Ramberg  
Secretary to Senate Research Ethics Committee  
Research Office, E214  
City University London  
Northampton Square  
London  
EC1V 0HB  
Email: [REDACTED]

## Appendix 9 Example of transcript

15218 Themes	L. No.	Linda's experience of being the recipient of egg donation	Exploratory comments
Pin prick	570	know.	
	571	I: Mhm	
	572	Linda: just never thought of it as a pin prick.	Thinking about the donor egg as a developed baby and not a small pin prick - seem to symbolise her movement from donor egg being something big and unimaginable to small and almost invisible.
	573	I: Mhm	Unaccepting → accepting
	574	Linda: Yeah;ah	
Monsters, Alien	575	I: Mhm	
	576	Linda: which was why, why it so quickly became this sort of more mon {cut the word off}, you	Acknowledging that her fantasies made the idea of egg donation monsters
	577	know, monsters kind of like alien <b>guggy</b> kind of	Donor egg - monsters, alien like, paranormal
Therapy	578	thing. {says loudly} but that was just because, it	→ ? Symbolises the procedure of egg donation as not normal/natural
	579	wasn't really, it was more that uhm .hh you know,	
	580	I studied quite a lot of, you know, uhm, kind of	Her co-ensuing studies made her more attentive to her dark thoughts
	581	psychotherapy and psychoanalytic ideas	
	582	I: mhm	
Attentive to dark thoughts	583	I: mhm	
	584	Linda: so I was quite...hh I was quite attentive to	
	585	the more darker <u>thoughts</u> .	Tentative to her dark thoughts

30

15218 Themes	L. No.	Linda's experience of being the recipient of egg donation	Exploratory comments
Brief thoughts	586	I: Mhm	
	587	Linda: You know, it wasn't like. It wasn't like	Brief temporal thoughts, not dwelling her daily existence but the thoughts were there if tended to.
	588	they were that prominent but it was more that	
	589	because I have been to therapy and I know it is	
	590	important to tend to those things I was	
Admit to her thoughts	591	I: Mhm	
	592	Linda: You know, I was just more aware of them.	
	593	but it wasn't like, you know they were sort of	
	594	flooding {brief laugh} my, my daily existence. But	Is she in control of it?
	595	it was just if I were to, to allow myself to really	Able to hold back some of her thoughts.
Foreign body inside (idea of self)	596	<u>admit</u> some of the, some of the more	Represses the more darker thoughts of egg donation
	597	unconsciously weirdy stuff I was feeling.	'Admit' ⇒ suggest some thoughts might be hard to admit to.
	598	I: Mhm	
	599	Linda: that would be what it was.	
	600	I: Mhm	
Foreign body inside (idea of self)	601	Linda: That kind of .hh having a foreign body	Initial thoughts of ED as a foreign body
	602	inside of me	Non-acceptant ⇒ foreign body, aborted fetus, alien, monsters, unnatural ↓

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15218 Themes	L. No.	Linda's experience of being the recipient of egg donation	Exploratory comments
	603	I: Mhm	
	604	Linda: Idea	
	605	I: Mhm	
Process of acceptance ↑	606	Linda: Yeah;ah...hh Whereas by the time I came to actually have the implantation	Acceptance ⇒ love, acceptance, seeing them as pin prick → stage of acceptance The fantasy of the implantation decrease with the acceptance of using egg donation
	607		
	608	I: Mhm	
For feelings of absolute love	609	Linda: I remember <u>feeling</u> totally different. Like I felt <u>absolute love</u> for them.	When accepted the idea and went ahead the feeling changed to love Absolute love ⇒ parent love?
	610		
	611	I: Mhm	
Love Being put together	612	Linda: because I had felt love from them from them moment that, uhm, they had been put together in the dish	The moment they were put together in the dish the negative thoughts about ED disappeared and there was only love. [What comes first the acceptance or love?]
	613		
	614		
	615	I: mhm	
Cur & alive reality ↓	616	Linda: You know, from that moment on they felt like, you know, <u>ours</u> and <u>alive</u> and stuff and it	Thought about them not being here's disappeared.
	617		

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15218 Themes	L. No.	Linda's experience of being the recipient of egg donation	Exploratory comments
Praying	618	was. We started praying and stuff from <u>then</u> , you know,	Moment put together there was feelings of love, ownership?
	619		Putting all their hopes & wishes into it succeeding, becoming religious -praying- doing all they can to make it successful.
	620	I: Mhm	
Whatever it takes.	621	Linda: and lighting candles and doing <u>whatever</u> you can do to <u>just make it ok</u> .	Willingness to do whatever it takes to succeed,
	622		
	623	I: Mhm	
powerful love change of feelings	624	Linda: But, you know, because of that really <u>powerful</u> , uhm reaction to, you know, <u>actually</u>	For the moment the eggs were harvested there was a change in her feelings towards the eggs.
Mixing the donor & partner	625	even from the moment the eggs was harvested from the <u>love</u> donor, you know it would be like	Describes the donor as 'love donor' maybe meant lovely? Romanticises the donor
	626	and my partner gave his sperm and then, you know, we got the news that they had been, you	
	627	know, put <u>together</u> , you know and then just those three days where they are doing their business.	Emphasis 'together' - my reflection of closeness, bond, love, possibility.
Waiting time	628	and then you get the news after that about	Waiting time-painless
	629		
	630		
	631		
	632		
	633	I: Mhm	
Survival of the strongest	634	Linda: You know, how many cells divisions and which ones are <u>strong</u>	→ strong enough for survival Survival of the fittest
	635		

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15218 Themes	L. No.	Linda's experience of being the recipient of egg donation	Exploratory comments
Feeling like a mother Maternal love	636	I: Mhm	
	637	K: and you know, you are already like, you know,	Becoming a mother Feeling like a mum from the moment the eggs & sperm were put together. Genetic link or vate is irrelevant now - now all that matters is success & maternal love.
	638	feeling a mum aren't you then {laughter}.	
The procedure Feeling involved At one with the idea Acceptance	639	I: Mhm	
	640	Linda: so, so I remember <u>really really</u> vividly the	Recalls the actual procedure of having the implant Emphasis on 'really' - to emphasise the beginning the strong emotions started then.
	641	uhm process of ..hh {deep in breath} of, you	
	642	know, the tube going <u>in</u> and them injecting the	Her following the procedure on screen - involving her.
	643	embryo, trying to show me on the screen where it	
open & ready to receive	644	kind of went into my ..hh my womb and uhm just,	
	645	just remember feeling <u>totally</u> at one with the idea	Feeling totally at one with the idea Acceptance.
	646	and totally	
	646	I: mhm	
Preparing her body	647	Linda: totally sort of, you know, ready to receive	open & ready to receive
	648	it	
	649	I: mhm	
	650	Linda: you know, I had done a lot of stuff with	Preparing her body
	651	diet and this thing called a moxa stick which kind	

34

15218 Themes	L. No.	Linda's experience of being the recipient of egg donation	Exploratory comments
Alternative medicine Best conditions = best chances	652	of help to heat up the womb.	changing her life style to make herself ready to receive the embryos.
	653	I: Mhm	
	654	Linda: Helps increase blood flow. This is a	Explaining all ways to ensure her body is ready. [Made me think of her body as a temple] Ensuring she has done all she can. It being her contribution.
When to implant	655	qualitative Chinese medicine, you know. So I, I	
	656	had a really <u>thick</u> uhm womb lining.	↑
	657	I: Mhm	
	658	Linda: because they measure that because a that is	important to hold onto the idea of being a fertile person Due to prep work she had the feeling of being very fertile - strong womb Living gives the idea of being fertile. Feeling fertile vs. actually being infertile. Denial?
'strangely fertile'	659	one of the things that help them determine ..hh	
	660	when to implant and stuff like that.	
	661	I: Mhm	
	662	Linda: when to go for the implantation, and so I,	
	663	you know I just felt very, yeah I thought, you	
	664	know, I felt <u>strangely fertile</u> even thought that	
	665	wasn't my own eggs	
	666	I: mhm	
	667	Linda: You know, and I think that, that was also	

35

15218 Themes	L. No.	Linda's experience of being the recipient of egg donation	Exploratory comments
Feelings of own fertility helped normalise it.	668	really something that really helped ma {cut the word off} make it feel more natural	Made the process feel more natural that she has contributed.
	669		The preparation = feeling more fertile = feel more natural.
	670	I: Mhm	
Prep strengthened the bond	671	Linda: Yeah;ah more like mine if you like.	Important that they felt like hers. Prep help strengthen the attachment to them.
Point of implantation	672	I: Mhm	
	673	Linda: Yeah;ah. {saying thoughtfully } the funny thing was. I don't know. I don't know why. maybe	
Service management	674	he did it with everyone it was a very good	
	675	psychological little trick but. the guy. the main	The importance of being psychological ready
	676	guy who did it, who was ..hh he was. He was	
	677	dealing with the eggs and tray	
	678		
	679	I: Mhm	
	680	Linda: And there was, and then there was a nurse	Recalling the time of the procedure.
	681	between him and the guy that actually took it in to	
	682	the pipette thing or whatever	Not aware of terminology
	683	I: {interrupts} Mhm	

36

15218 Themes	L. No.	Linda's experience of being the recipient of egg donation	Exploratory comments
Good rapport with medical staff.	684	Linda: it is, to insert it ..hh and the guy who is	
	685	like the main genet {cuts word off}, you know,	
	686	gynecologist guy or whatever, he, he was very	
	687	fluent in English and great, and we had a repore	
	688	with him and he was kind of sort of, the guy that	
	689	did the inserting I had never seen before	
	690	I: mhm	
	691	Linda: and never saw again. He was totally X	Describes him
	692	{nationality of the country the procedure was	
	693	performed in}. didn't speak any English.	
	694	I: Mhm	
reassurance from staff.	695	Linda: But he just gave me this squeeze of the	The importance of his looks in making him comfortable
	696	hand, it was very kind of grandfatherly. He was	
	697	quite plumb and he just said 'you know this is a	Looking for signs that it will be ok
	698	really good one' like that	Comfort
	699	I: Mhm	
Comforted 'It will be ok'	700	Linda: and I was just like God I just know that it	Comforting knowing it will be ok
	701	is gonna be ok {brief laugh}.	

37

15218 Themes	L. No.	Linda's experience of being the recipient of egg donation	Exploratory comments
Reassurance from staff belief in positive outcome	702	I: Mhm	
	703	Linda: It was like as if. It was like as if he could	Giving him supernatural powers of being able to predict the outcome. It being the sign she was looking for
	704	tell that it would be a positive outcome and that	
	705	just <u>really</u> helped (30:57).	
Waiting time	706	I: Mhm	
	707	Linda: Yeah;ah because obviously it is then it is	Waiting time uncertainty anxiety
	708	like two and a half weeks before you hear.	
	709	I: Mhm that's a long time	
	710	Linda: yeah;ah so I <u>hung</u> onto that.	Continuing to give her reassurance in the time of waiting. What the doctor said helped ease the wait. Also shows how much the doctors/staff matter in the process.
	711	I: Mhm	
	712	Linda: Thought everything had gone really well.	
	713	I: Mhm	
	714	Linda: Yeah;ah	
	715	I: okay thank you for that.	

38

15218 Themes	L. No.	Linda's experience of being the recipient of egg donation	Exploratory comments
Wanting to know more Acceptance Moving on Worry about the kids.	734	should be ok)	
	735	so uhm yeah;ah that <u>was</u> . That was all and I	Wanting to know about the donor: [why?] Difficult not knowing much about the donor.
	736	remember I wanting to find out <u>more</u> . Then I	
	737	thought okay just, you know, accept that was how	
	738	it <u>is</u> , and uhm, that wasn't too hard for me <u>but</u> , you	Having to accept the lack of knowledge.
	739	know, obviously I, I worry about how that is	but suggesting maybe it is easy for her to forget - maybe she would prefer not to forget 3rd person involvement
	740	gonna be for our kids.	
Feelings towards donor lovely payment for service	741	I: Mhm	Having to accept the lack of knowledge. Thinking about what it will be like for the children not to have much information.
	742	Linda: You know, knowing absolutely nothing.	
	743	I: Mhm	
	744	Linda: So, but literally that's it. I don't think we	Suggesting they can never find out more.
	745	could ever <sup>is now</sup> anything. Uhm, but my feelings	
	746	towards them are just like. Just think they're just	
	747	lovely and, you know, we didn't pay much but, we	Describes donor as lovely
	748	did <u>pay</u> enough if it was {hard to detect that	Feels like she is almost saying 'yeah they are lovely but we did pay for it' Cold - > serm@?
	749	sentence} uhm ok for them.	
	750	I: Mhm	

40

## **Appendix 10 Example of thoughts and ideas post interviews**

Post interview L:

Seems to be missing seeing herself in her children.

Queries what it would be like to see yourself in your children's mannerism and looks.

Wanting to match the donor to her own looks to superficially get the children to look like her did not take priority over just having a baby.

The end goal of having a baby was more important than what the baby would look like.

Shocked by own infertility

Took time to accept egg donation as an option

Looking for connections

Selfish act to use ED

Ambivalence about passing own genes on? See faults in other genes – so other genes might be better –

Envy about partner having the link

Uninformed lead to strong experience of egg donation at the start.

Emotional

Alien – initial view of egg donation

## Appendix 11 Example of emergent themes with quotes

Amended Emergent Themes ←	Emergent themes ←	Line	Key words, ←
Doubting own fertility	worried about own fertility	7-23	I had a sense in my 30s that I was going to have fertility problems', 'But I have this worry because I'd had chlamydia... And it can affect your fertility. And I just had this feeling; I was going to have problems... almost like an intuition
Doubting own fertility		38-49	I had a worry... I wasn't using contraception, (3) but I knew at the back of mind I wasn't going to become pregnant.
New relationship at the forefront	Happy in new relationship	32	And then I was single. And then I met X [name of partner] when I was 38. And I was so happy to meet him (1) and I was so happy to be with him,
New relationship at the forefront	Happy in new relationship	111	And then I sort of carried on my life (1) with my husband. We had a very nice life together and we're very happy
"brutal" delivery		52-65	Well it was [emphasis] awful. It was just brutal and terrible. Uhm, there was no sort of nice sugar-coating. It was simply how it was told
"brutal" delivery		140	Because I have had this awful experience in X [UK location]. I just was a bit stuck there
"Devastation"		84	I remember coming in from the doctor and cry my eyes out, a:and, (2) because I knew what it meant
"Devastation"		234	But what did I feel? I, I was, I was devastated (1) at the early menopause. I was devastated. Uhm (3) I, it sounds odd
"uh, that's disgusting"		97-99	you can go down the donor egg route, and I remember thinking, 'uh, that's disgusting', 'that's awful', 'that's weird', (2) it just was like [slight emphasis] 'no way', 'weirdness'.
Unknown territory		102-9	And there was not much about it in those days... but I didn't know about it
Unknown territory		120-23	the egg thing came up again. Because by this stage, I've met somebody (1) who had two friends who had done it and she put

			me in contact with them.
Unknown territory		326	a brave new world.
Unknown territory		337	I mean adopting might have felt more normal in the sense. (1) I think it was because it was so new (1) and I haven't heard of anyone doing it.
Unknown territory		2766	'oh, egg donor', I supposed I would have [increase in tone] liked much [emphasis] more information then,
Influenced by others positivity		125-31	...who had done it and she put me in contact with them....I went to see them both. A:and they were just like, this is so, just lovely and it's wonderful and (2) it was easy and you won't [increase in tone of voice] regret it
Influenced by others positivity		139	Going to see them it made it more real. Because I have had this awful experience in X [UK location]. I just was a bit stuck there.
Influenced by others positivity		161-69	I would have gone to X [foreign location]... And then a piece of luck happened. And the piece of luck was that (1) a friend of mine (1), his wife was going through IVF.... been to the most wonderful clinic (2) in X [location], called X [clinic in UK].
Influenced by others positivity		182	you must go see her
Realising wish for children		134	I thought I'd be okay without a child, but I now realise I wouldn't have been.
Stuck		140	I have had this awful experience in X [UK location]. I just was a bit stuck there
"brilliant" having procedure in UK		151-53	I sent off for the paper work, my husband didn't like it and I'm [slight emphasis] so pleased that he didn't like it, because I'm [slight emphasis] so pleased I did in England
"brilliant" having procedure in UK		161-69	It was a brilliant. (1) I would have gone to X [foreign location]. He was absolutely right

Egg sharing as "most wonderful ethic way of doing it"		179-80	it was the most wonderful ethical way of doing it,
Egg sharing as "most wonderful ethic way of doing it"		212	They wanted to donate their eggs (2), and uhm, that was how (1) I came to do it.
Acknowledging infertility		194-96	they said that, I think it was like a 40% success rate, (2) which is a lot better than, well, I wouldn't have had any success anyway with, uh, the IVF, even if I would have had it. It would have been naught percent.
Greater chance of success		189-93	So we went along there. ..hh And they said that, I think it was like a 40% success rate, (2) which is a lot better than,
Demands of eggs	Wanting clever genes	204-6	I didn't like to sounded of them; one was a PE teacher, and it wasn't, wasn't, uh. I wanted, I wanted like clever genes basically.
Demands of eggs		370	But by this stage she was now late (2) 30's. So it was like, I wasn't gonna have like the freshest eggs
Demands of eggs	Wanting clever genes	673-86	obviously we wanted, uhm:m (3) it's really important. I know it sounds awfully snobby, but we wanted s:s (1) I wanted someone clever. I didn't want a thick kid. I couldn't have dealt with that (2) uhm:m (1) because, you know, my husband is very clever, and I'm clever, and I just didn't wanna have a thicko. And I know that sounds awful, but was what we did, that was one of our things.
Demands of eggs	Pleased with heterosexual donor	768-96	that (1) a couple, a heterosexual couple. And the more I think about that the more I'm pleased. (2) That it is heterosexual and not a lesbian couple because it's genetic I think. And it is not that I have got anything against (1) gay people, but I don't want that risk then, of my child being a gay.(3) A:and (2) I'm not saying



			that there is anything not normal about being gay but it is unusual
Demands of eggs	Pleased with heterosexual donor	800-7	it will be more straightforward if (1) they are straight, because he is already (2) unusual in some ways,
Demands of eggs	Pleased with heterosexual donor	818-27	it would just be one more thing that might be, for him to have to deal with it, it might be different. ..hh uhm (3) So, and also there's a risk of him being, I think it is gen [cut word off], my take is that, I've seen in families, I've seen people. But it may not be I don't know.
Denial		236	it sounds odd. I will say it, (1) just tremendous amounts of denial. I couldn't engage with the fact that there was a baby at the end of it. And even when X [name of child] was born (1) I, they could have brought a (1) rabbit out,
Denial		248	I was obviously in some denial of having a baby
Never questioned ownership		264-4	a friend who wants to have a second baby, who is in her 40s and ..hh she, she worries that, she wouldn't feel like hers, she would be carrying someone else's baby, that's what she said, and I never felt like that. It always felt like my baby.
Nothing can prepare you for motherhood		252-63	they say nothing can prepare you for motherhood. Every other experience you have in life, you go into thinking I want to. You have some image of what it would be like, but I didn't have one.
Ambivalence towards donor		278-92	I felt (2) curiosity about the women. (2) But I knew. I felt some resentment towards the woman. So when I say resentment, let's say jealousy (3) that she was like producing all these eggs.

## Appendix 12 Example of clustering for one participant

### Clustering emergent themes

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→

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### Master themes

"secure attachment"	I have been a great mother	Change in attachment?/discrepancy in view of self as a mother?
I have been a great mother		
"could have pulled out a rabbit"	Not able to attach before birth	
Denial		

Happy in new relationship unknown territory	<i>Child not a priority</i>	Experience of coming to the decision
search for life partner above else		
not in touch with longing		
Preconception of conception		
Life continuing		
questioned ownership		
beforehand		
complicated		
uh, that's disgusting	<i>Unusual and unnatural</i>	
desperate act		
playing with nature		
Realising a wish for a child	Willingness to go ahead	
Accepting being on a journey		
Greater chance of success		
Acknowledging infertility		
Influence by others positivity		
Stuck		

<p>Dilemma of honesty</p> <p>Own shame</p> <p>Ambivalence towards others finding out</p> <p>openness with son</p> <p>Child's story to tell</p> <p>Wanting openness</p> <p>Easier to disclose if easily apparent</p> <p>Disclosing to everyone</p> <p>Told less and less</p> <p>Others not wanting the information</p> <p>Difficulties keeping track of disclosure</p>	<p><b>To disclose or not to disclose</b></p> <p><b>Anxiety of disclosing</b></p>
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<p>Sadness for lack of connection</p> <p>important for child to be perceived as part of family</p> <p>Not completely mine</p> <p>transferring something into them</p> <p>Favoured similarities to self</p> <p>Wish for resemblance to her</p>	<p><b>Sadness for lack of connection</b></p>
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<p>Who is the mother?</p> <p>Health</p> <p>Questioning son's religious status</p> <div data-bbox="178 1736 893 1863"> <p>wish for resemblance to her</p> <p>seeing unknown donor in her</p> <p>Who does the child look like</p> </div>	<p><b>A lot of questions/uncertainties/certainties become uncertain</b></p>
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<p>Demands of eggs</p> <p>"not clicking" with donor description</p> <p>Best not to pass bad genes on clever genes</p>	<p><b>Not wanting just any eggs</b></p>
<p>Denial</p> <p>"could have pulled a rabbit out"</p> <p>Not "ready to explore all the issues"</p>	<p><b>Denial</b></p>
<p>Feeling like a failure</p> <p>shame</p> <p>devastation</p>	<p><b>Negative experience of own womanhood due to menopause</b></p>
<p>Perfect boy</p> <p>child was meant to be</p>	<p><b>Child meant to be</b></p>
<p>Miracle</p> <p>Invincible</p> <p>Pure happiness</p>	<p><b>ecstatic</b></p>
<p>Not wanting unusual</p> <p>Becoming more common</p>	<p><b>Wanting child to fit in</b></p>
<p>likewise people important</p> <p>wished for more support from others</p>	<p><b>support important</b></p>
<p>Worried about sexual attraction</p> <p>worried about health</p>	<p><b>Worry</b></p>

Brutal delivery stuck devastation	Brutality
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egg sharing as ethical Importance placed on donor having altruistic motives	Motives important for feeling of donation
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Failure if no desire to meet donor positive towards donor siblings	Openness important
"Brilliant" procedure in UK trace heritage important	Tracing heritage important

"on edge" Stuck devastation	Difficult journey emotionally
Feeling like a failure shame devastation	Negative experience of own womanhood due to menopause
Denial	

Donor brought into their lives	Donor personalised
Failure if no desire to meet donor	

**The Professional Practice Component of this thesis has been  
removed for confidentiality purposes.**

**It can be consulted by Psychology researchers on application at  
the Library of City, University of London.**

## **Appendix**

### **1 Appendix Focusing manual**

This is going to be just to yourself. What I will ask you to do will be silent, just to yourself. Take a moment just to relax.

5 seconds

All right – now, just to yourself, inside you, I would like you to pay attention to a very special part of you. Pay attention to that Part where you usually feel sad, glad or scared.

5 seconds

Pay attention to that area in you and see how you are now. See what comes to you when you ask yourself, “How am I now?” “How do I feel?” “What is the main thing for me right now?” Let it come, in whatever way it comes to you, and see how it is.

30 seconds or less

If, among the things that you have just thought of, there was a major personal problem, which felt important, continue with it. Otherwise, select a meaningful personal problem to think about. Make sure you have chosen some personal problem of real importance in your life. Choose the thing which seems most meaningful to you.

10 seconds

1. Of course, there are many parts to that one thing you are thinking about – too many to think of each one alone. But, you can feel all of these things together. Pay attention there where you usually feel things, and in there you can get a sense of what all of the problem feels like. Let yourself feel all of that.

30 seconds or less

2. As you pay attention to the whole feeling of it, you may find that one special feeling comes up. Let yourself pay attention to that one feeling.

1 minute

3. Keep following one feeling. Don't let it be just words or pictures – wait and let words or pictures come from the feeling.

1 minute

4. If this one feeling changes or moves, let it do that. Whatever it does, follow the feeling and pay attention to it.

1 minute

5. Now, take what is fresh, or new, in the feel of it now and go very easy. Just as you feel it, try to find some new words or pictures to capture what your present feeling is all about. There doesn't have to be anything that you didn't know before. New words are best but old words might fit just as well. As long as you now find words or pictures to say what is fresh to you now.

1 minute

6. If 'the words or pictures' that 'you "now have"' make some fresh difference, see what that is. Let the words or pictures change until they feel just right in capturing your feelings.

1 minute

Now I will give you a little while to use in any way you want to, and then we will stop.

From Gendlin (1969). *Focusing. Psychotherapy: Theory, Research and Practice*, 6(1), 4-15.



# Section D: Article: Oocyte recipients’ experience of support

## **Abstract**

*Objective:* To capture oocyte recipient women’s experience of support.

*Method:* Eight recipient women took part in face-to-face semi-structured interviews. The data was analysed using Interpretative Phenomenological Analysis.

*Results:* The data presented stems from a study examining what women’s experience of being an oocyte recipient is like and resulted in four superordinate themes: “threat”, “living with the life-long consequences”, “selfish act” and “doing what it takes”. This article will report the three subthemes from the superordinate theme “living with the life-long consequences”, which were all related to the recipient women’s experience and need for support: “I can manage on my own”, “living with the consequences”, and “good support helps smooth the journey”.

*Conclusion:* This paper suggests that though counselling was seen as beneficial by some recipients, not all felt able or willing to engage in it. It seems that the recipient women felt the greatest need for support around the time of their infertility diagnosis, and after having the child through oocyte donation, as that seems to be the time when the women realised the ramifications.

*Practice implication:* Focus should be on promoting counselling as more than a place to contemplate whether to pursue egg donation, and on assisting and preparing other professionals, such as doctors and nurses, to give the appropriate support to oocyte recipients.

## **1 Introduction**

Since the first use of donor eggs in the 1980s, their use has seen a constant increase (Richards, Pennings, & Appleby, 2012). Despite the rise in oocyte donation, there is a paucity of research exploring oocyte recipient women's experience of support. This appears to be due to the medicalisation of infertility and artificial reproductive techniques, including oocyte, where the focus has been on solving a medical problem with a medical solution, and less on the psychosocial elements of infertility and artificial reproductive techniques. The fact that these women become pregnant with the assistance of egg donors, and are not themselves genetically related to the child they give birth to, will inevitably bring up specific psychosocial issues which are different from those experienced by women having other infertility treatments.

Within the literature there seems to be a consensus that infertility and fertility treatment can be very distressing and cause an array of emotional and psychological responses (Boivin, & Takefman, 1996; Joy & McCrystal, 2015; Mahlstedt, 1994), and that particularly stressful are: undergoing the treatment itself, having to make difficult decisions with regard to treatment, the rollercoaster of going through hopes and failures of treatment, normalising, preparing for the implications, and disclosure concerns and guidance on helping donor-conceived children to manage (Sachs & Hammer Burns, 2006). Due to this psychosocial impact, it has been suggested that counselling is advisable and should be available throughout and after treatment (Boivin, Appleton, Baetens, Baron, Bitzer, Corrigan, Daniels, Darwish, Guerra-Diaz, Hammar, Whinnie, Strauss, Thorn, Wischmann & Kentenich, 2001; Greenfeld, 1997). The Human Fertilisation and Embryology Authority (HFEA) regulates assisted conception in the UK and with the HFE Act 1990 made it a legal requirement for all licensed fertility clinics to offer counselling. The HFEA went even further with the HFE 2008 act in

which it stated that counselling “should be routinely offered as part of the treatment process” and that counselling is distinct from “assessment of suitability of treatment, the provision of information to obtain consent and the normal relationship between clinic staff, patients and donors” (Joy & McCrystal, 2015, 87; The Human Fertilisation and Embryology Authority, 2016). The importance of separating counselling from assessment is supported by research suggesting that one of the reasons for the limited uptake of counselling for people going through infertility is due to their being cautious about showing any ambivalence or uncertainty due to fear of treatment retraction (Coven, 2011). The British Infertility Counselling Association (BICA) was founded in 1988 to promote a high infertility counselling standard by ensuring that all counsellors are appropriately accredited according to the BICA scheme (see Crawshaw, Hunt, Monach, & Pike, 2013), and have published three editions of the BICA Guidelines for Good Practice in Infertility Counselling, with the latest addition in 2012. According to the guidelines the purpose of infertility counselling is to assist people in reflecting on, understanding and adjusting to the implications of the route taken and to provide support, and assist in developing coping strategies (Crawshaw, Hunt, Monach, & Pike, 2013; Monach, 2013). The BICA supports the HFEA statement that counselling for egg donation recipients should be routinely offered, and further recommends that a minimum of two sessions is made available by the clinic, that clinics provide written information regarding egg donation and what organisations people can contact, and that the legal status of the donor-conceived child is fully explained (Crawshaw et al., 2013). Furthermore, infertility counselling can also be seen as a way of ensuring informed consent – ensuring that people are fully aware of the medical, legal and psychosocial implications and consequences of the decision they will make (Joy & McCrystal, 2015; Peterson et al. 2012). Egg donation, like sperm and embryo donation and surrogacy, differs from other types of fertility treatment as it requires a greater focus on the meaning and significance of the treatment (Hunt, 2013),

particularly an exploration around the implications of the lack of genetic link, potential issues regarding disclosure and the parent/child relationship (Hammarberg, Carmichael, Tinney, & Mulder, 2008). Boivin et al. (2001) suggest that there are certain specific objectives for third party reproduction including coming to terms with an alternative route, gender differences, suitability, disclosure, legal and medical aspects, role of the donor, and preparing for the procedure.

Several screening tools have been developed to identify fertility patients in need of psychological support such as SCREENIVE, FertiQoL and FertiSTAT (Peterson, Boivin, Norre, Smith, Thorn, & Wischman, 2012). The literature generally suggests that, once it has been confirmed who is in need of counselling, fertility counselling is often divided into implications counselling (understanding the implication of the fertility route taken, in the case of egg donation, understanding the meaning of egg donation and its implications for all parties involved, disclosure issues, legalities and donor siblings) and, support and therapeutic counselling (centred around providing emotional support at stressful times and helping clients cope with the consequences and acceptance of their infertility and treatment) (Cramond, 1998; The Human Fertilisation and Embryology Authority, 2015; Crawshaw, Hunt, Monach, Pike, & Wilde, 2013; Peterson, et al., 2012).

It has been suggested that people undergoing IVF might wish for some counselling, whether prior to treatment or during it (Laffort & Edelman, 1994). Though there seems to be a wish for counselling amongst IVF patients, still relatively little is known about the effectiveness of the counselling that patients receive (Klerk et al, 2005; Marcus, Marcus, Marcus, Appleton, & Marcus, 2007), and the existing research seems somewhat contradictory. Some studies have reported high levels of satisfaction with the counselling regardless of whether mandatory or

voluntary (Marcus et al., 2007; Stewart et al., 1992). Marcus et al. (2007) found that out of the 30% of people that participated in counselling, 50% reported a high satisfaction with the counselling, while the remaining were either indifferent (38%) or found it unhelpful (10%). Other studies have found infertility counselling to have little effect on levels of anxiety and depression, regardless of whether the counselling took place pre-treatment, or once pre-treatment and once during treatment (Emery, Beran, Darwiche, Oppizzi, Joris, Capel, Guex, & Germond, 2003; Connolly, Edelmann, Barlett, Cooke, Lenton & Pike, 1993).

Additionally, despite some research suggesting a perceived need and wish for counselling, there seem to be a limited uptake of people actually seeking it (Joy & McCrystal, 2015; Klerk, Hunfeld, Duivenvoorden, den Outer, Fauser, Passchier, & Macklon, 2005). Reasons such as scheduling/time, lack of awareness of how to go about it, anxiety about treatment retraction if there are signs of treatment uncertainty, feeling unable to cope, and prohibitive costs have been given (Klerk et al, 2005; Boivin, Scanlan, & Walker, 1999; Pepe & Byrne, 1991; Marcus et al., 2007). The prospect of potentially negative encounters with other medical professionals has also been suggested as a reason why clients might not feel comfortable about speaking to a psychologist at the same clinic (Bartlam & McLeod, 2000).

Infertility research has suggested that people often seek support online, but that those who rely solely on the internet versus a combination of the internet and a social group show higher levels of distress (Cousineau & Domar, 2007). This suggests that appropriate support can help to de-scale the levels of distress. The idea of the helpfulness of peer support is supported by the Donor Conception Network (DCN) which was founded in 1993 by five sperm donor families to guide and support other donor families or prospective donor families. The DCN offers workshops, peer support and information about being a donor-conceived family.

There has been some discussion as to whether counselling should be made mandatory

(Machin, 2011); in countries like Australia this is the case for donor recipients whereas in countries like the UK and Denmark counselling is advised but not mandatory (Hammarberg et al., 2008; Machin, 2011). The debate has been around the fact that although counselling can be helpful to aid recipients in managing the psychosocial aspects of gamete donation, not all want therapy, and that therefore other ways of supporting recipients might be found, such as via other professionals, primarily doctors and nurses (Machin, 2011). For recipients who do not engage with therapy, other professionals might be the only people they confide in, as they might chose not to disclose to family and friends. This gives other professionals a central role in supporting and guiding (Hammarberg, Astbury, & Baker, 2001). However, it has been suggested that doctors underestimate the emotional and physical distress that patients involved in reproductive treatment endure (Kopitzke, Berg, Wilson, & Owens, 1991), suggesting that it could be difficult for them to provide the appropriate support. Perhaps further support and education needs to be given to medical staff with regard to the psychosocial impact of infertility and infertility treatment in order to equip them with the means to provide suitable support and guidance. In the US there is ongoing discussion about how to create a more integrative approach to infertility treatment by providing counselling services onsite – to support patients as well as the medical team (Domar, 2015). The idea behind the approach is for patients to have easily accessible daily support, provide physicians with social workers, and provide time guarentees for services. It also means that medical staff have access to new research in the area, get a view on the patient perspective and receive support in managing difficult situations (Domar, 2015).

Another interesting area within infertility counselling is cross border fertility treatment. This phenomenon is still relatively under-regulated and under-researched, yet more and more people are seeking treatment abroad (Joy & McCrystal, 2015), often due to shortage of eggs in their home country, shorter waiting lists elsewhere, high costs and dissatisfaction with

treatment in the home country (Culley, 2011). Egg donation is the most sought after fertility treatment abroad (Hunt, 2013). Blyth (2012) showed that infertility counselling varies across countries with regard to the qualifications and standards needed, and identified four areas which could be used to examine similarities and differences across countries: “The legal mandate for counselling; eligibility credentials for individuals carrying out professional counselling activities; different forms of counselling; and counselling practice in relation to specific elements of assisted reproduction treatment” (2012). The European Society of Human Reproduction and Embryology (ESHRE) has compiled cross border infertility counselling guidelines which can be used by all practitioners, though as of yet it is not a requirement to follow these guidelines and the extent to which they are used is unknown (Hunt, 2013). Further thought needs to go into how people who go abroad independently can access support, and ensure that UK clinics who refer abroad encourage people to seek counselling before travelling (Hunt, 2013).

This piece of research hopes to further explore how support or lack of support was perceived along the way. As no study has explored oocyte recipient women’s experience of support, prior, during, and post procedure.

## **2 Method**

### **2.1 Participant Characteristics**

Eight donor oocyte recipients, all Caucasian, between 38 and 50 years old at the time of the procedure, were interviewed. One of the women was a solo mother, one was in a gay relationship, two were living with a partner, three were married and one was separated, and all had children ranging from 1 to 12 years old at the time of the interview.

## 2.2 Procedure

Participants were recruited through online fertility chat rooms, the Donor Conception Network ebulletin, and through word of mouth. All the women made the first contact and were then contacted to ensure they met the criteria and did not show any signs of psychological distress. A pack with the information leaflet, including the areas that would be discussed in the interview. A consent form was sent to the women that fitted the criteria, and they were asked to read these and decide whether they were interested in taking part. All eight women consented to taking part and a date and location for the interview was arranged. All the women were given a choice of location and date.

Based on the study's aim of capturing women's rich experience it was decided that semi-structured interviews would be the most appropriate data collection method. Each interview lasted between 60 and 90 minutes. The interview schedule was designed to be as neutral as possible in order to allow the participants' own experiences to come to light, while staying within the research topic (Smith & Osborn, 2003). The interviews all started with the same broad question, "Could you tell me about your experience as an egg donor recipient in as much detail as possible?". Thereafter, the interviews loosely followed an interview schedule designed to explore participants' overall experience including: making the decision, self-identity, experience of pregnancy, donor criteria, worries and fears, attachment and support/counselling.

## 2.3 Data Analysis

This is a qualitative study looking at women's experience of being a recipient of donor eggs. Semi-structured interviews were used to explore eight women's experience of this



phenomenon. Based on the study's aim to explore women's subjective experience of egg donation, the qualitative methodology of Interpretative Phenomenological Analysis (IPA) was used, and the text was analysed according to Smith, Flowers and Larkin (2009).

## 2.4 Ethical Considerations

Ethical approval was obtained at City, University of London, and the study adhered to the BPS ethical guidelines Code of Human Research Ethics and Code of Ethics and Conduct 2009.

Each participant received an information sheet and a consent form prior to the interview. Due to the sensitive nature of the research, included in the introduction sheet was a list of the areas that would be discussed during the interview. Written consent was obtained from each participant prior to the interview, and after the interview a debrief sheet was given, and time was allocated for a brief discussion on how participants had found the experience of taking part, and if anything, in particular had surprised them. With permission, each interview was audio recorded.

All identifying information was changed to preserve the participants' anonymity.

## 3 Results

The following three areas emerged following an interpretative phenomenological analysis of the oocyte recipient women's experience of support.

### 3.1 I can manage on my own

Three of the eight recipient women did not want, nor did they seek, professional support at the time. The rejection of psychological counselling seemed to be due to the women feeling certain of their decision to pursue egg donation. This certainty seemed to prevent the women from engaging with counselling as counselling was only seen as a place to discuss whether to proceed with egg donation:

*Kate, 1848: they did offer, but I think it was going to be like a one-hour session just to throw around the idea [...] I felt comfortable that, I know how to explore [I: mhm] my own stuff.*

The quote suggests that one of the reasons for not attending counselling is the experience of trusting ones' own ability to cope, and not wanting or needing others to help in her examine her own process. There is, interestingly, also an idea of counselling as just being a place to "throw around the idea". This supports the above statement about counselling being perceived as a place only to ensure that you are embarking on the right track. It seems that counselling is not thought of as a place to explore the potential implications, and how one might manage these implications.

Several of the women supported the sense of not needing, nor wanting others involved:

*Laura, 2311: it didn't feel like I needed it (2) at the time. I kind of had [emphasis] my mind set on egg donation. I, I was just like, you know, this is my road, and I don't need to talk to you. I don't need anybody. I don't need anybody. I don't need anybody that's why I was like I don't need my [emphasis] family, I don't need my [emphasis] friends and I don't need a counsellor. I just need (2) my man and for this to work*

From her account, there was a strong sense of not wanting to let others in. Feeling as if others were intruding in a very personal struggle. There is almost a sense of wanting to hide from others, or at least withdrawing from others. There is a sense of nothing will help, expect, for the procedure to work, suggesting that once the procedure works then all the hardship will disappear. Also, this account seems to support the previous quote of the women trusting their own ability to cope.

For one of the women who did engage in therapy there was a sense of not being able to create the appropriate emotional space for therapy at the time:

*Deborah, 2749: ... because I wasn't probably ready to explore all the issues like I said. I really probably was in [emphasis] such denial [I: mhm] about [emphasis] everything before he came along (3) uhm, so you [indiscernible] you think. I didn't think (2). [I: mhm] It was just all a big blank, [I: mhm] and before I had him, and I couldn't engage with it [emphasis] really [I: mhm] and I didn't really properly engage with him in there, as I said to you, it was just like ..hh I am providing you with a [increase in tone] warm safe place, and let's deal with everything when he comes out.*

This quote suggests that, for some of the women, there was a sense of not being able to open up and face one's own actions. The comparison of therapy disengagement and child disengagement, to me, suggests a form of emotional survival stage, where it is impossible to engage with anything. It seems that at that time she was just getting through. Maybe it was a form of defence in case it did not work or the effect of having been through so much. Either way, it could be seen as a way of protecting oneself when in a vulnerable state.

### 3.2 Living with the consequences

For the majority of the women there seemed to have been a shift from focusing on having a child no matter what it took, without being particularly concerned with the potential long-term implications, to beginning to reflect on the implications more after having given birth, regardless of whether the women had engaged with counselling or not:

*Laura, 306: I actually didn't really think about the consequences or the future. I just was so... I was so [emphasis] desperate,*

There was a sense from some of the women of being clouded by a sense of “full steam ahead” while trying to conceive, and therefore not being able to stop and fully reflect on their actions. One of the women mentioned having a sense of it having all gone too fast, and not having enough time to properly process the implications, due to being seeped in the practicalities of egg donation.

*Maria, 218: I do think now though, on reflection, I think, perhaps we didn't think about it (I) enough. [I: mhm] I think it actually was probably too quick [I: mhm] and too easy ..hh and there were not (I), there were not kind of sufficient barriers in the way to kind of slow us down [I: mhm]and make us really think about, [say in a questioning tone] is this right? [...] you know, that's, that's my take on it now,*

From the quote, there is a sense of wishing that something had stood in their way. That something had made them reflect on the implications of their actions. It almost seems there is an admission that she was unable at the time to fully reflect on the implication at the time. This support the previous suggestion that the women might be clouded by a sense of “full steam ahead” while trying to conceive.

Additionally, a couple of the women felt that it was not possible, prior to having the child, to fully appreciate and understand what the consequences would be. One of the women mentioned how it is not possible to predict how your child might react to the implications, for example what you as a parent might not expect to be an issue for a child might turn out to be a significant aspect:

*Maria, 496: ... I didn't think particularly would matter very much. Of course, you can't put yourself in the mind of the potential human being that you're making and realise actually it might matter very much to [increase in tone of voice] them*

Several of the women felt some uncertainty about not knowing what the future would hold, not knowing whether there would be negative consequences of the egg donation. Though this might hold true for all parents – whether genetic, donor or adoptive – for the women who have egg-donated children concerns for the future seem particularly related to the uncertainty of how the children will cope with the story of their conception.

### 3.3 Good support helps smooth the journey

Despite half the women not seeking psychological counselling, or feeling the need for psychological counselling at the time, a few of the women who did seek counselling felt it to be of the utmost importance to engage with the implications of egg donation:

*Karen, 3076, 3131: once you have engaged with it, you can move on*

... and did so through attending psychological counselling and through having a focus on self-care. For Karen, there was an acknowledgement that only through engaging with the

emotional, physical and psychological implications of egg donation could you process and pack them away neatly.

The interviews also showed that the majority of the women sought other forms of support, e.g., the Donor Conception Network, friends and family, or advice from the internet, suggesting there was a perceived need for support. Some also made a point of engaging in better self-care such as physical activity, and made a conscious effort to surround themselves with supportive and nourishing people.

Several of the women sought ways of normalising egg donation by, for example, seeking information online, and joining chat rooms:

*Linda, 173-83: I did a lot of googling (1) and uhm, it was amazing like how the internet (1) works in that way because once I started seeing, uhm, what was out there, it also really helped my acceptance of (1) doing it. It felt completely normal suddenly. Because there are obviously 1000s of people talking about clinics...*

This concept of others helping to normalise egg donation comes through in several of the women's accounts. For some, it was about hearing about or meeting other recipients. For others, it was about actually seeing what it meant to be a recipient of egg donation – to get an answer to the question “what is it like?” I would argue that the need to hear others normalise the process suggests that the women wanted to fit in. Hearing others' stories begins the process of normalising as the women then feel included in a group, rather than the being abnormal. This is supported by L's quote in which she says: “*Because there are obviously 1000s of people talking about clinics*”, which suggests that realising that there were many others in the same situation as her gave her some comfort.

The importance of feeling supported and heard by professionals consistently came up across the women's accounts. Most of the women had at some point felt badly treated by members of staff – this was especially the case with the delivery of the infertility diagnosis – and several of the women stated that the delivery of the news had been overwhelming, shocking and difficult to comprehend:

*Linda, 126: it wasn't told to me particularly sensitively either so it was really extra devastating [...] So it was really insensitive and kind of and I just thought "crikey", you know. Don't they realise when they are telling you that your eggs are no good. Just exactly what that kind of information feels like. It just felt like they didn't have an awareness of that.*

Here the participant L displays having had the experience of professionals not comprehending the effect that the diagnosis can have. Though the infertility pre-empts the egg donation, it could be argued that the way the women manage and cope with their infertility could have consequences for how they manage the implications of egg donation. Some of the negative psychological effects of being diagnosed as infertile might have impacted the women's psychological wellbeing even after having conceived through egg donation, thereby making the support from professionals even more important.

On the other hand, it seemed that good support from professionals helped the women to feel better able to cope with the stress of going through the treatment. One woman spoke of a particular experience in which she had received a supportive and positive response from the doctor performing her procedure, which meant that she felt a greater confidence that the procedure would work out and her levels of worry decreased:

*Linda, 690: ...but he just gave me this squeeze of the hand, it was very kind of grandfatherly. He was quite plump and he just said "you know this is a really good one" like that and I was just like God I just know that it is gonna be ok (brief laugh). It was like as if, it was like as if he could tell that it would be a positive outcome and that just really helped.*

This doctor helped increase faith and trust in the process. Of course, doctors have to be careful not to give false hope, but the sense in this case was that it could be invaluable for recipients to feel that someone believed in their possible success and this could lead them to feel more relaxed, and thereby with a greater chance of their bodies receiving the donated egg. The doctor's support here seems to have changed this woman's experience from uncertain and not in control to having a greater sense of hope and certainty. This illustrates the idea that professionals hold a very important position in helping recipients to manage their negative feelings, whether this is with regard to facing their infertility, or deciding what to do next, or when the women are undergoing treatment. From the women's perspective, it seems that this time is a very sensitive one and the appropriate support and guidance from professionals helps diminish the difficulty in managing this challenging period.

## **4 Discussion and Conclusion**

### **4.1 Discussion**

The present study aimed to explore and capture oocyte recipients' experience of support before, during and after undertaking the procedure. The analysis suggested quite an ambivalent relationship to counselling and support: some wanted and sought counselling, others sought counselling but could not fully engage with it due to feeling emotionally unavailable, and others did not want or need counselling. There was a sense of not being able to open up and face one's own actions, and of being caught up in the practicalities and



therefore not able to see beyond the immediate. All of this could be seen as a way of protecting oneself when in a vulnerable state.

Though there was some consensus around the issue of the ramifications of oocyte donation not being clear until after having the child, and though some felt at a loss then as to how to manage this for themselves and their children (and that more psychological support could be beneficial then), the continued ambivalence for some of the women regarding support, and the fact that they did not seek counselling later, despite sensing a need, suggests that making counselling mandatory would not be beneficial for the women. This supports the notion that perhaps more attention should be given to thinking of other ways of supporting recipients, such as assisting other professionals in becoming better at helping recipients examine the ramifications and manage these (Machin, 2011). Doctors need support in providing potential recipients with more information, or guidance on how to find such information. Additionally, as many of the women went abroad for egg donation, there needs to be more awareness of how support can be provided to these women. Again, as the women will probably get the infertility diagnosis in England, and then seek to go abroad, more importance should be placed at the early stage of the women's treatment on doctors and nurses being able to provide the women with support, or guidance on where to seek support.

## 4.2 Conclusion

This paper suggests that although counselling was seen as beneficial by some recipients, not all felt able or willing to engage in it. It seems that the recipient women felt the greatest need for support around the time of their infertility diagnosis, and again after having the child through oocyte donation, as that seems to be the time when the women fully realised the

ramifications. A greater focus should be given to assisting other professionals to support recipient women.

#### 4.3 Practice implications

Based on the above conclusion it seems that mandatory counselling for recipient of egg donation is not necessarily appropriate. This paper would suggest that the focus should instead be on promoting counselling to recipients as not just a place where one can “throw around the idea” of egg donation but as something that can be beneficial in helping to prepare for the future implications that oocyte donation undoubtedly brings. Additionally, other clinical staff should be assisted in helping recipients feel supported and to provide them with further guidance on where to seek support. Furthermore, extra support should be given around the time of the infertility diagnosis and after having the child.

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## Appendix

### Appendix 1 Author Guidelines for Patient education and Counseling

Taken from: <https://www.elsevier.com/journals/patient-education-and-counseling/0738-3991/guide-for-authors#1001>

#### Aims and Scope

Patient Education and Counseling is an interdisciplinary, international journal for patient education and health promotion researchers, managers, physicians, nurses and other health care providers. The journal seeks to explore and elucidate educational, counseling and communication models in health care. Its aim is to provide a forum for fundamental as well as applied research, and to promote the study of the delivery of patient education, counseling, and health promotion services, including training models and organisational issues in improving communication between providers and patients.

Patient Education and Counseling is the official journal of the European Association for Communication in Healthcare (EACH) and the American Academy on Communication in Healthcare (AACH).

#### Manuscript Categories

During online submission, the author can select a category from the following list: Research Paper, Review Article, Short Communication, Reflective Practice, Discussion or Correspondence. The type of manuscript should be indicated in the cover letter.

**Research Papers** Preference is given to empirical research which examines such topics as provider-patient communication, patient education, patient participation in health care, adherence to therapeutic regimens, social support, decision-making, health literacy, physiological changes, health/functional status etc. Maximum 4000 words. Please note that manuscript word counts EXCLUDE the following: Abstract, acknowledgements, references, tables, figures, conflict of interest statements. Both descriptive and intervention studies are acceptable. Each Research Paper will also require a heading selected from the following to identify the section of the journal to which it best applies: Communication Studies, Patient Education, Healthcare Education, Healthcare and Health Promotion, Patient and User Perspectives and Characteristics, Assessment and Methodology.

#### Article structure

##### *Subdivision - numbered sections*

Divide your article into clearly defined and numbered sections. Subsections should be numbered 1.1 (then 1.1.1, 1.1.2, ...), 1.2, etc. (the abstract is not included in section numbering). Use this numbering also for internal cross-referencing: do not just refer to 'the text'. Any subsection may be given a brief heading. Each heading should appear on its own separate line.

Manuscripts should be organised as follows:

**Title page, Abstract, 1. Introduction, 2. Methods, 3. Results, 4. Discussion and Conclusion, References, Legends.**

**Discussion and Conclusion** should be headed as one section and divided into three parts.

Example: 4. Discussion and Conclusion, 4.1. Discussion, 4.2. Conclusion. 4.3 Practice Implications

### ***Introduction***

State the objectives of the work and provide an adequate background, avoiding a detailed literature survey or a summary of the results.

### ***Material and methods***

Provide sufficient detail to allow the work to be reproduced. Methods already published should be indicated by a reference: only relevant modifications should be described.

### ***Results***

Results should be clear and concise.

### ***Discussion and Conclusion***

Discussion and Conclusion should be headed as one section and divided into three parts.

Example: 4. Discussion and Conclusion, 4.1. Discussion, 4.2. Conclusion. 4.3 Practice Implications

### ***Practice Implications***

Articles should include a paragraph or paragraphs entitled 'Practice Implications' as part of the discussion and conclusion, which outlines the implications for practice suggested by the study. Authors should take care that these implications follow closely from the data presented, rather than from other literature. In the event that an article presents very preliminary data or conclusions, these paragraphs may be omitted

### ***Essential title page information***

- ***Title.*** Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible.

### ***Abstract***

A structured abstract, by means of appropriate headings, should provide the context or background for the research and should state its purpose, basic procedures (selection of study subjects, observational and analytical methods), main findings (giving specific effect sizes and their statistical significance, if possible), principal conclusions and practice implications. Abstracts should adhere to the following format: **Objective, Methods, Results, Conclusion, Practice Implications. The word limit for abstracts is 200.'**