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1 **HUMAN REPRODUCTION (ACCEPTED)**

2

3 **“WHAT SORT OF PERSON IS SHE?” CHOOSING THE UNKNOWN EGG**

4 **DONOR AND THE IMPACT OF NOT KNOWING.**

5

6

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20

21 **Abstract**

22

23 ***Background***

24 This study aims to provide insight into the reasons for choosing an unknown egg  
25 donor and to explore recipients' feelings and wishes regarding donor information.

26 ***Method***

27 In-depth interviews were carried out with eleven women at different stages of  
28 treatment. Seven are on a waiting list and four have given birth to donor egg babies.

29 The interviews were analysed using Interpretative Phenomenological Analysis.

30 ***Results***

31 The choice of unknown donor route is motivated by a wish to feel secure in the role of  
32 mother as well to avoid possible intrusions into family relationships. The information  
33 that is available about unknown donors is often very limited. In the pre-conception

1 phase of treatment some participants want more information about the donor but  
2 others adopt a not-knowing stance that protects them from the emotional impact of  
3 needing a donor. In the absence of information that might normalise her, there is a  
4 tendency to imagine the donor in a black or white form, so she may be idealised or  
5 feared. Curiosity about the donor intensifies once a real baby exists and the task of  
6 telling a child feels more daunting where very little is known about the donor. A  
7 strong wish for same donor siblings was expressed by all of the participants who had  
8 given birth.

### 9 *Conclusions*

10 This qualitative study throws light on factors that influence the choice of unknown  
11 donation. It also highlights the scope for attitudes to donor information to undergo  
12 change over the course of treatment. The findings have implications for pre-treatment  
13 counselling and raise a number of issues that merit further exploration.

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## 1 **Introduction**

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3 Egg donation is a form of in-vitro fertilisation (IVF) treatment that enables an infertile  
4 woman with impaired or absent ovarian function to become pregnant. There are two  
5 routes to achieving this; one involves a known donor who is often a family member or  
6 a close friend. The second route involves receiving eggs from an unknown donor  
7 whose identity may remain anonymous or be available for release once a child  
8 reaches the age of 18 .

9

10 The choice of unknown donation has been reported as allowing recipients '*to impose*  
11 *their own identity patterns onto future children*' (Bertrand-Servais et al,1993). It has  
12 also been reported as being motivated by a wish for control and an avoidance of  
13 complex relationship issues with a known donor (Hershberger et al 2007). Konrad  
14 (2005) has argued that the function of anonymity in egg donation is '*to preserve the*  
15 *form of the true gift*'.

16

17 Studies that measure the preference rates for known or unknown donation suggest that  
18 there may be wide variation between countries where egg donation is practised. For  
19 example in the UK, Kirkland et al (1992) found a strong preference for anonymity  
20 whereas Baetens, et al (2000), in Belgium, report that two-thirds of their participants  
21 prefer to have a donor who is known to them. Laruelle et al (2011) have identified a  
22 variation according cultural background, with European or North African couples  
23 being more likely to opt for unknown donation.

24

25 The capacity to make a choice depends on whether both kinds of donation are  
26 available. Given the physically invasive nature of donating eggs, donor eggs of either

1 kind are often in short supply. For example, in the USA, Greenfeld et al, (1998),  
2 report that 34% of recipients used an unknown donor because there was no known  
3 donor available to them. Some authors have claimed that where a known donor is  
4 available most recipients would prefer to use this option (Greenfeld et al,1998;  
5 Baetens et al, 2000) because it alleviates concerns about the unknown donor's genes.  
6 However, the Kirkland et al (1992) finding that only 26% of their UK participants  
7 would accept a known donation suggests that concerns about having a known donor  
8 can be equally strong.

9

10 Within Europe there is wide variation in the legislation and practice surrounding egg  
11 donation, particularly regarding donor identity release, financial compensation for  
12 donors and upper age limits for recipients. Known donation is not permitted in  
13 France, Denmark and Spain and egg donation is not available at all in both Italy and  
14 Germany (Baetens et al, 2000). This situation has led to the rise of cross border  
15 treatments (Pennings, 2004; Shenfield et al, 2010). French couples wanting to use a  
16 known donor often travel to Belgium for treatment (Pennings et al 2009).

17

18 In addition, within the practice of unknown donation there is considerable variation in  
19 how it is carried out, particularly regarding the matching process. For example, in the  
20 clinic in Belgium where the Baetens et al study (2000) took place, a shortage of  
21 donors meant that the only criteria for matching donors to recipients was ethnicity.  
22 Such a limited capacity for matching may well account for the low uptake of  
23 unknown donation reported in this study. In contrast, in the USA, where there is a  
24 long established market in donor eggs, matching and selection of unknown donors is  
25 widely available and there is a two track system of future identity release and full

1 anonymity. Not surprisingly the USA is a destination for couples who desire long  
2 term anonymity and are willing to travel (Hughes & Dejean, 2009).

3

4 The situation in the UK is that anonymous eggs are mainly sourced through egg share  
5 schemes (Ahuja et al,1997; Blyth et al, 2004). These are run by clinics who offer  
6 subsidised IVF treatment to infertile women under the age of 35 in return for donating  
7 some of their own eggs. The law regarding donor identity release in the UK was  
8 altered in 2005 (HFEA, 2004) so that donor children, if they so choose, will have the  
9 right to find out the identity of their donor once they reach 18 years. There is  
10 however no requirement for parents to tell their children about their origins. (Murray  
11 & Golombok, 2003).

12

13 The practice of egg donation in the UK and many other parts of the world has been  
14 modelled on the much older practice of sperm donation. In the past, Donor  
15 Insemination (DI) clinics provided only basic biometric information about donors and  
16 usually encouraged couples to keep their treatment secret. In spite of changes in  
17 legislation about donor identity release, most egg recipients in the UK only receive a  
18 very limited amount of information about their donor. This includes physical  
19 characteristics, marital status, religion, health history and occupation. A study that  
20 looked at the amount of additional biographical material voluntarily left by donors on  
21 the donation form found that most donors offered minimal extra information (Abdalla  
22 et al, 1998). Likewise, in Australia most recipients are provided with only basic  
23 information and there are no guidelines that stipulate what should be stored or  
24 released (Rodino, 2011). The situation is different in the USA, where it is common  
25 practice to provide more detailed background information (Heinemann-Kuschinsky et

1 al, 1995; Lindheim et al, 2000). About half of recipients report having seen a  
2 photograph of their donor (Klock & Greenfeld, 2004).

3

4 Qualitative research has the potential to complement quantitative research and can  
5 highlight areas that merit further investigation. A UK clinic based study found that a  
6 preference for unknown donation was linked to the wish to avoid interference in the  
7 mother child relationship (Konrad, 2005). Some of the participants in this study also  
8 expressed a strong wish for more information about their donor. A USA study shows  
9 that where recipients have the capacity to choose a donor, this is experienced as  
10 reassuring and empowering and facilitated the process of acceptance (Becker, 2000).  
11 The narrative of 'gift' has been identified as being widely used by recipients even in  
12 non-altruistic donation ( Konrad, 2005; Kirkman, 2003). Studies that took place  
13 following the birth, have shown a tendency to diminish the role of the donor  
14 (Hallebone, 1991; Murray & Golombok, 2003; Konrad, 2005). The perception of the  
15 baby as their 'own' child can be used to justify not telling the child about the donation  
16 (Murray & Golombok, 2003; Konrad, 2005).

17

18 New reproductive technology gives rise to complex situations that need to be  
19 negotiated. Research into this process lags well behind the technological  
20 advancements themselves. It has been observed that psychosocial research in egg  
21 donation is still in its infancy (Hershberger 2004; van den Akker, 2006) and although  
22 there is some existing research, there is a need for further studies that can help  
23 enlighten women considering embarking on egg donation as well as informing health  
24 professionals in the field. Little has been published on the factors that might influence  
25 the choice of unknown donation or on the impact of donor information on recipients.

1 There is also a need for studies aimed at establishing what kind of information might  
2 be in donor families' best interests. This study aims to provide insight into the  
3 reasons for choosing an unknown egg donor and to explore recipients' feelings and  
4 wishes regarding donor information.

5

6

## 7 **Materials and Methods**

8 The qualitative methodology used is Interpretative Phenomenological Analysis (Smith  
9 et al, 2009). This approach seeks to understand the personal world of participants  
10 through exploring feelings, beliefs and attitudes and feelings is well suited to an in-  
11 depth exploration of subjective experience. IPA has been used to examine a number  
12 of areas in human reproduction (Provoost et al, 2009; Duncan et al, 2001; Turner &  
13 Coyle, 2000). The relatively small sample size in IPA allows for close analysis of  
14 each case, so that consideration can be given to individual participant's meaning  
15 making processes as well as cross group analysis. (Smith, 2004; Brocki & Wearden  
16 2006).

17

18 A total of eleven women were interviewed. The aim was to conduct an in-depth  
19 exploration of the women's personal experiences and the fact that father's were not  
20 interviewed does not reflect an underestimation of their significance. Seven of the  
21 participants were on the waiting list for treatment at the Lister Clinic, one of the main  
22 Assisted Conception clinics in London that specialises in egg donation. Because of  
23 the length of time that can be involved prior to conception a longitudinal study was  
24 not possible. In addition therefore a smaller group of four women who had given birth

1 to a donor child within the last 2 years were recruited from the Donor Conception  
2 Network, which is a national self-help organisation for donor conceived families.  
3 Ethical approval at the Lister Hospital, Tavistock Clinic and Birkbeck College was  
4 granted and information and consent forms were administered to those who wished to  
5 take part.

6  
7 Because IPA uses comparatively small sample sizes, it is important that samples are  
8 as homogeneous as possible. The samples were selected from the group of women  
9 who form the majority of donor egg recipients in the UK; that is women in their  
10 thirties or forties who are in a stable relationship, of White British origin, in the  
11 middle to higher socio-economic groups and whose partner would be the genetic  
12 father.

13

#### 14 *Participant Details*

15 All of the eleven participants are married and have opted for an unknown egg donor  
16 with their husbands as the genetic father. Their names have been changed in order to  
17 preserve confidentiality.

18

#### 19 *Waiting list (WL) Group*

20 Seven participants (Alison, Bridget, Clare, Deborah, Rita, Sylvia and Theresa) were  
21 recruited from the waiting list for treatment at the Lister Clinic, in London. The age  
22 range is 33-44 years. Five of the women have previously undergone infertility  
23 treatments, ranging from one attempt at IVF to ten years of IVF. In addition, Deborah  
24 has also had a failed egg donation treatment at a different clinic. Bridget and Clare,

1 both suffered from a premature menopause in their twenties and this is their first  
2 experience of infertility treatment.

3

4 Donor Conception Network (DCN) Group

5 Four participants who had given birth to an egg donor child within the last 2 years  
6 were recruited from the DCN membership. The age range is 37-44. All of the  
7 women experienced at least one unsuccessful donor egg IVF cycle prior to  
8 conceiving. The children are between the ages of 18 and 23 months, there were 2 sets  
9 of twins and 2 singletons in the group. Kate and Marilyn received treatment in UK  
10 egg share programmes. Two of the women had travelled abroad for treatment, Lily to  
11 the USA and Jinny to Spain.

12

13 *Interviews and Analysis*

14 The interviews were semi-structured. Participants were asked about their previous  
15 history of infertility treatment, their decision to enter into egg donation treatment and  
16 about their choice of anonymous donation. Thoughts and feelings about the donor  
17 were explored, in particular their hopes, anxieties and fears, in relation to her and any  
18 possible or actual children. In addition the participants who had given birth to a child  
19 were asked about their experience of pregnancy, childbirth and their relationship to  
20 their babies.

21

22 The interviews were all carried out by SSS and took place in the participants' own  
23 homes, except for one which took place in a clinic setting. The interviews lasted  
24 about two hours and were audio-tape recorded with the participants' consent and then  
25 transcribed.

1

2 Transcripts were then analysed individually before any cross group analysis took  
3 place. This is in line with the idiographic principles of IPA, and means that themes  
4 are generated and clustered for each participant. Once this process is complete  
5 themes are then clustered across the group. This technique allows for similarities and  
6 differences to emerge. The four stage process of data analysis is described in further  
7 detail in Smith and Osborn (2008).

8 Where there are particularly long quotations, some material may have been omitted  
9 for reasons of space. The notation (...) marks an editorial elision.

10

11

## 12 **Results**

13

### 14 **The Choice of Unknown Donation**

15

16

17 The women describe feelings of loss and powerlessness in relation to needing donor  
18 egg treatment. For example, Kate experiences her need for a donor as ‘*emasculating*.’  
19 IVF treatment is emotionally and physically exhausting and some of the participants  
20 have experienced treatment failures previously.

21

22 All them have considered the possibility of having a known donor and they all decide  
23 to opt for the unknown route. Their concerns for the most part involve fears that a  
24 known donor might undermine their identity as the baby’s mother and/or disrupt their  
25 relationship with their partner.

26 For example, Sylvia envisages that a known donor could be an unwanted reminder of  
27 her infertility:

1           *"knowing the person, I think it would be a constant reminder that this was not*  
2           *my egg."*

3

4 Theresa also wants to avoid interference from a donor:

5           *"we didn't want anyone outside having any involvement in the baby. If it was*  
6           *going to be our baby we wanted it to be someone that we didn't know."*

7

8 The donor, as a third person, is perceived as a potential intruder who might undermine

9 a sense of themselves as a couple creating a baby and also reinforce personal feelings

10 of inadequacy.

11

12 Five of the women have actually had offers from potential known donors, three from

13 family members and two from a friend or colleague. It can be difficult within a family

14 to decline such an offer. Lily turned down offers from her two of her sisters and

15 wishes that their mother could have been more understanding of her decision.

16

17 Lily's concerns about known donation are intensified because she does not have a

18 particularly good relationship with either of her sisters. She worries that she might

19 not love the baby as a result:

20           *"if I had a child who was like that, I'd sort of be irritated as I am by my*  
21           *sisters!"*

22

23

24 Bridget initially thought that she would accept her sister's offer, but then changed her

25 mind:

26           *"I just suddenly thought, I don't want anybody else involved other than me*  
27           *and Martin. I don't want to run the risk of somebody ever turning round to me*  
28           *and saying 'That's my child.'"*

29

30 The potential for a known donor to make a claim on a child is a very powerful

31 concern. Bridget is also worried about the impact on her relationship with her husband

32 and wants their creation of a baby to be what she calls a *"private affair"*.

1

2 Rita has a work colleague who has offered to donate to her and her  
3 husband. But she worries about the donor changing her mind or losing her existing  
4 children:

5 *“you can feel completely differently once you even embark on the drugs, or if*  
6 *something happened to your child and (...) you’ve got somebody (..) that’s*  
7 *partly you out there (...) it’s very complex.”*

8

9 Deborah who has turned down an offer from a sister-in-law also thinks about “*the*  
10 *worst case scenario*”, of a known donor losing her own children. There is the added  
11 complexity of the donor’s family as well. Rita was concerned that her potential donor  
12 did not want her parents to know about the donation because they “*might think it was*  
13 *a grandchild they hadn’t had.*”

14

15 Looking into the future, Bridget thinks the existence of a known donor would make it  
16 harder to deal with any rejecting feelings a child might express:

17

18 *“But for a child to turn round to me and say, ‘well you’re not my mum*  
19 *anyway’ is one thing, but (...) for them to know who their genetic mother is, I*  
20 *just think that would be really (...) difficult.”*

21

22 All these concerns contribute to a vision of long-term insecurity in a known donor  
23 situation. Opting for an anonymous donor allows them to feel more in control of their  
24 future situation. They anxieties reflect fears about future sources of loss such as the  
25 possibility of losing the child’s love.

26

27 Some of the women ask their potential donors if they will donate to the clinic pool in  
28 order to move them up the waiting list and release anonymous donor eggs for them.

29 This might seem like a pragmatic solution but in each case the donors are not

1 prepared to donate to an anonymous couple because they want to know where their  
2 eggs are going. Bridget is particularly upset that her sister did not feel able to donate  
3 for her rather than to her. This has led her to think that egg donation is very different  
4 from sperm donation:

5 *“women tend to think about the fact that if they donate eggs, their children*  
6 *will be running round somewhere else.”*

7  
8 This perception holds true for the participants as well. Their anticipatory fears are  
9 that in the presence of a known donor their identity as the baby’s mother might be  
10 jeopardised and that the donor might intrude into the relationship they have with the  
11 baby’s father. It is as much about how a donor’s presence in their lives might make  
12 them feel, as it is about what a known donor might do in reality.

13

14 The process of reaching a decision about the type of donation they want to pursue  
15 involves projecting themselves into the future. Bridget describes how emotionally  
16 draining it is to have to do this:

17 *“you have to put yourself through thinking what would happen if you became*  
18 *pregnant and at the end of the day you may well not become pregnant, so it’s*  
19 *quite an emotionally exhausting time.”*

20

21

22

### 23 **Knowing and Not Knowing**

24

25 Although an unknown donor is felt to be a much safer option in terms of protecting  
26 the mother child relationship, the lack of information can raise concerns about what  
27 might emerge in the child. There is wide variation in how much the women are  
28 preoccupied by the screening and matching process. Their concerns also vary at  
29 different times and stages of treatment.

1

2 The reality of UK egg share programmes is that recipients are given basic biometric  
3 information, such as the donor's height, eye colour, hair colour, weight and age.

4 Given the shortage of donors there is not much scope for choice. Clare and Deborah  
5 feel content only to know what is referred to as the "basics". The information they  
6 are given often includes whether the donor has a pre-existing child or not as Marilyn  
7 describes :

8 *"we were literally given height, hair colour, eye colour, the fact she had a*  
9 *child"*

10

11 Some of the participants want to know more. Rita worries about HIV risk whilst  
12 Alison and Bridget are more concerned about qualities such as intelligence,  
13 personality and sense of humour.

14

15 Alison feels particularly strongly that the categories on the clinic donor matching  
16 form were too basic:

17 *"when you are given a piece of paper that's filled in fourteen seconds flat and*  
18 *it's either large, small, green, blue, whatever, it just seemed nonsense."*

19

20

21 Alison and Rita are the most ambivalent about unknown donation and they express  
22 similar ideas about an ideal donor situation. Rita wishes for a donor who might say:

23 *" this is my health history and everything and I don't want anything to do with*  
24 *you during the time."*

25

26 Their ideal would be a situation in which it was possible to know a lot about the donor  
27 but be guaranteed no involvement whilst the child is growing up.

28

1 But in some cases, not knowing is felt to be protective. Lily recalls her first  
2 experience at a UK clinic. When she was told about a potential donor's  
3 characteristics, her instinctive response was:

4 *“Oh, I don't want to know, it'll be my baby, so I don't want to know”. It was*  
5 *like sweeping it under the carpet.”*  
6

7 At this stage Lily's impulse was to minimise her knowledge about the donor as a self-  
8 protective mechanism in order not to disrupt a feeling that it will be her baby. It  
9 seems that having recently been diagnosed with a premature menopause, she was not  
10 yet ready to deal with the genetic loss involved in having an egg donor child. Much as  
11 feelings of loss influence the women's preference for the unknown donor route, these  
12 feelings can also determine how much the participants want to know about a donor at  
13 a given time.

14

15 Marilyn is also ambivalent about having more information:

16 *“it's hard to know (...) sometimes you want more information, but it isn't*  
17 *always (pause) you don't often feel better when you get it.”*  
18

19 What she is highlighting is that information requires emotional processing and that  
20 there may be times when not knowing is preferable. Both Marilyn and Jinny express a  
21 wish to protect themselves at the start of treatment by not knowing too much about  
22 the donor for fear of having their hopes raised and being disappointed if treatment  
23 fails.

24

25 Knowing about a donor makes the need for a donor more real and this can be painful.

26 Jinny unexpectedly became very upset when she was matched with a donor who had  
27 similar eye colour to her but was much shorter than her:

1           *“I was quite brave about most things and I don’t know why I was so silly (...).*  
2           *And I just can’t believe I focused on this stupid thing.”*

3

4   Having coped with much bigger losses, including several miscarriages, and a recent  
5   failed IVF treatment with a taller donor, she finds it hard to understand the  
6   irrationality of her response. Her case illustrates the potential for donor information to  
7   trigger a grief reaction that may be linked to previous unresolved losses.

8   Jinny decided that she did not want to be told about whether her donor had an existing  
9   child or if she had donated to someone else before. Information about a donor’s  
10   reproductive history can be a prognostic indicator and previous evidence of fertility  
11   indicates a higher chance of a successful donation. Jinny felt very anxious about  
12   whether the treatment would work for her this time and she chose not to know  
13   because she did not want to risk hearing anything negative:

14           *“I was too scared to ask (...) I just thought, ‘oh, I don’t want to know, in case*  
15           *they say no’.”*

16

17   Prior to conceiving with their child’s donor all the participants have experienced a  
18   failed attempt or attempts, either with the same or different donor. Kate was matched  
19   to four different donors before she succeeded.

20   Given this, it is not surprising that the main preoccupation is being successful rather  
21   than having access to information. After a long wait, Marilyn felt relieved to have a  
22   donor at all. She describes the donor information they were given as ‘vague’ but  
23   adds: *“I think we were just happy to have the quality eggs.”*

24

25   Having initially preferred not knowing much about the donor, as the time for  
26   implantation approached, Lily became increasingly concerned by *“the fear of the*  
27   *unknown”*. In particular she is worried about the child having features that she might  
28   find hard to love and as a result she and her husband decide to seek treatment in the

1 USA where it is possible to choose donors on the basis of comprehensive information.  
 2 Lily did not choose a donor who was a facial or physical ‘identikit’ of herself, what  
 3 was important to her was that there was enough information for her to feel that: *‘I*  
 4 *trust the person she is’.*

5

### 6 **Imagining the donor**

7 For Lily, having a lot of information facilitated a feeling of trust in the donor. In the  
 8 absence of detailed information, the other participants find themselves imagining the  
 9 donor. Alison has been matched with a ‘large’ donor because the clinic have  
 10 categorised her as ‘large’ on the basis that she is tall, although she is slim. She is  
 11 upset:

12 *“I don’t want a large donor. You know, ‘cos I had visions of someone who*  
 13 *weighs twenty stone.”*  
 14

15 Anxiety provoking visions of the donor are experienced by some of the others as well.

16 Kate recalls worrying about the donor during her pregnancy:

17 *“What if she’s really ugly! You know it’s the things that you think about.*  
 18 *Ridiculous really, but (..) you do worry.”*  
 19

20 Jinny’s experience is even stronger than Kate’s and she projects her worst fears onto  
 21 the blank screen of the unknown donor. She remembers being anxious in pregnancy  
 22 that:

23 *“the donor might look strange, the donor might have a beaked nose or,*  
 24 *something odd (...) I didn’t imagine the donor could be pretty or nice. (...)*  
 25 *When I heard she was short, she had to be dwarf and I just magnified anxiety*  
 26 *about it; the fact that I didn’t know.”*  
 27

28 In her imagination Jinny conjures up a witch-like figure with a beaked nose.

29 In the absence of information that might normalise and humanise the figure of the  
 30 donor there is a tendency for her to be imagined in a black or white form. The

1 participants also conjure up idealised pictures of their donors, as a counter to her  
 2 opposite form. For example, Bridget imagines the donor as an Earth Mother figure,  
 3 who values:

4 *“the experience of motherhood and (...) would like to be able to offer the*  
 5 *opportunity for other women who can’t. I mean it is an incredibly giving thing*  
 6 *to do.”*

7

8 Lily thinks that without the information on her donor, she would have been much  
 9 more anxious during pregnancy:

10 *“I always remember someone saying that they felt their babies were going to*  
 11 *come out with blue flashing lights saying, ‘I’m different, I’m from donated*  
 12 *eggs’. (...)I never had any of those worries (...), because I had the security of*  
 13 *knowing what their donor is like.”*

14

15

16 Once the babies are born these kind of anxieties are quickly dispelled and all the  
 17 participants with babies speak of strong loving feelings towards their newborns,  
 18 for example, Marilyn:

19

20 *“He was a beautiful baby and I just thought, he’s lovely, the minute I saw*  
 21 *him.”*

22

23 Any earlier fears about whether they would feel like the real mother are also not  
 24 realised. The physical process of producing a baby and the ease with which  
 25 these participants bond with their newborns give rise to a strong sense of  
 26 identity as the baby’s mother.

27

28 However, this does not mean that they do not think about the donor, as she is  
 29 present in their thoughts. They imagine what she is like as a person when they  
 30 perceive particular qualities in their children. They all feel that they might see the  
 31 donor in their child. Jinny looks at her baby and wonders *“if your donor’s got a*

1 *quirky smile?*” She even thinks she would recognise the donor, if she ever bumped  
 2 into her, because her daughter’s smile is so distinctive. Kate thinks that her son’s  
 3 sensitivity has come from his donor: *“neither of us are particularly sensitive like*  
 4 *Theo.”*

5 Marilyn talks about her son’s *‘sweet’* temperament and his good looks and these make  
 6 her wonder about her donor’s personality and looks:

7 *“he’s got a lovely personality (...) I wonder if his genetic mother looked like*  
 8 *this, or what she’s like, whether she’s a very lovely woman (...) because I*  
 9 *don’t know where his characteristics have come from.”*

10  
 11

12 Marilyn also draws on her knowledge that her egg share donor has a pre-existing child  
 13 to reassure herself that her donor won’t be so devastated if her own treatment has  
 14 failed:

15 *“She’s probably in a good place - she’s got a child, she’ll be less, feeling less*  
 16 *desperate.”*

17  
 18  
 19

## 20 **The wish to know more**

21

22 At the start of her treatment, Theresa who is in the WL group, envisaged a potential  
 23 for feelings about unknown donation to undergo changes at a later stage:

24 *“whether thoughts would creep in later and that you really wished you had*  
 25 *known that person (...) and whether the baby was going to take after them in*  
 26 *any respect.”*

27

28 For the women in the DCN group, who have actually given birth, the wish to know  
 29 more about their donor assumes greater prominence, much as Theresa describes. As  
 30 her daughter begins to grow up, Jinny feels that the information she has about her  
 31 donor is not enough:

1           *“ light, brown hair, very fair skin, blue eyes and she hasn’t got the same blood*  
 2           *group, I wish I knew more about her, I really do.”*  
 3

4 Kate finds herself beset by thoughts that play on the economic inequality at the heart  
 5 of egg sharing and which mean that the donor receives subsidised or free IVF in  
 6 return for her eggs. She finds herself pre-occupied by the question of her donor’s  
 7 social class:

8           *“trying to get your head round what sort of person is she? (...) you sort of go*  
 9           *mad thinking about things like this - does she live in a council flat? And it’s*  
 10           *horrible snobby things that go through your mind, but you just don’t know,*  
 11           *who this person is.”*  
 12

13 Kate knows nothing in reality that can dispel these thoughts. Looking back when her  
 14 twins are in their second year, she feels that having an unknown donor has been hard  
 15 for her to deal with. She now wishes it has been possible to have her sister as a  
 16 known donor:

17           *“I would have probably have preferred that to this sort of unknown person.”*  
 18

19 Jinny’s account is particularly dominated by wishing she knew more about her  
 20 daughter’s donor. This is complicated by the fact that she thinks she could have asked  
 21 for more information at the time of treatment. Her regret about this is accompanied by  
 22 a feeling that knowledge is being withheld by the clinic:

23           *“They must know what education they have, what subjects they’ve done, (...)*  
 24           *would be lovely to know what her interests were (...) They must know more*  
 25           *than me.”*  
 26

27 In contrast, Lily has pages of information about her donor. Although she feels she  
 28 knows a lot about the donor, following the birth of the twins, she begins to regret  
 29 choosing a clinic where there was no option for future donor identity release. If her  
 30 twins want to know the identity of their donor in the years to come this will not be

1 possible. Like the others she shifts towards wanting to know more on behalf of her  
2 children.

3

#### 4 **The wish for same donor siblings**

5

6 At the outset of treatment the focus is on getting pregnant and having a baby but once  
7 this is achieved a more complicated issue arises - that of building a donor conceived  
8 family. All the women in the DCN group speak of their wish to try again with the  
9 same donor. Lily and Marilyn have been able to do this because they had some frozen  
10 embryos stored at the clinic. Marilyn's embryo transfer was unsuccessful but Lily  
11 conceived and is expecting a third baby. She is thrilled that her twins will have a full  
12 blood relative.

13

14 Kate and her husband decided to approach the clinic to ask if their donor would  
15 donate to them again, but the response was negative. She is very sad about this but is  
16 also realistic about why the donor might not want to do it:

17 *“well I'm glad we asked the question, because we talked about it for months,*  
18 *(..) I mean she's got two children, it would be so difficult to do, I mean all*  
19 *those injections, it's a hell of a commitment, why would she want to do it?”*

20

21

22 Jinny has a friend whose Spanish donor donated to her a second time and this has  
23 given her hope. She has been plucking up courage to approach the clinic and ask  
24 them to approach her donor:

25 *“but she'll be thirty something now I don't know if she'll want to donate or*  
26 *whether she's still there.”*

27

28

1 Jinny envisages that she would not be so anxious a second time round and also  
2 hopes that if her donor agrees she can have more information about her.

3

4 The experience of loving the babies they have given birth to has alleviated any  
5 ‘stranger anxiety’ that the participants previously felt about the donor. Even though  
6 she is unknown, she does not feel as unknowable as she did before their birth. In a  
7 way, a sense of familiarity has been created. Starting again with a different unknown  
8 donor would be a more anxious-making process.

9

### 10 **The prospect of telling a child**

11

12 All the participants within both groups say that they intend to be open with their  
13 children about the fact of the donation. However for the women in the DCN group,  
14 following the birth, the issue of lacking information about the donor and being unable  
15 to answer a child’s questions about her makes the task of disclosure feel more difficult  
16 than it otherwise would be.

17

18 For Jinny being unable to give her daughter much information stirs up feelings of  
19 guilt:

20 *“I can feel guilty, the responsibility, isn’t it, you’re creating a life outside of*  
21 *yourself really and I think you have a duty of care in a way and duty to give*  
22 *her as much information as possible.”*

23

24

25 Marilyn also raises a concern about whether her son might question their decisions:

26 *“I just have to hope that we can explain it to him in such a way that he*  
27 *understands why we made the decisions we did and that we will have a good*  
28 *enough relationship with him that he feels OK about that.”*

29

1 The issue of whether a child will understand their motives in choosing an unknown  
2 donor is a different kind of concern from the fear of the child's rejection which  
3 dominated their pre-treatment thinking.

4  
5

6 Looking back to how at the pre-implantation stage, she protected herself from hearing  
7 about her donor's childbearing history Jinny now regrets how much her thinking was  
8 dominated by a fear that

9 *"I might not be successful and I wasn't really thinking straight - that I might*  
10 *want to know to tell Anna."*  
11

12 Marilyn was told that her donor had a pre-existing child:

13 *"my first thought was always she must be fertile, she must have fertile eggs."*

14 This information initially alleviated anxieties about her own treatment but following  
15 the birth, it features as a piece of missing information about her son's half brother or  
16 half sister.

17

18 Kate and Lily both have something that was written by their donors which expresses  
19 their altruistic wishes in donating. They envisage that it will be important for them to  
20 show this to their children when they are old enough to understand. It is reassuring to  
21 have the donor's motives documented like this as Lily says

22 *"Her reasons for doing the donation were nice, I mean she'd had a cousin*  
23 *who was infertile - for the children when they're older, it's nice to know that*  
24 *she's doing it for a nice reason."*  
25

26

27 Information like this has the potential to take on considerable significance because it  
28 will become part of the narrative the recipients tell their children in future.

29  
30

1

**2 Discussion**

3 The strong preference for unknown donation found in this study has also been  
4 reported in larger surveys that have found a majority opting for anonymously donated  
5 eggs (Kirkland et al, 1992; Applegarth et al,1995). In this group of women, any  
6 concerns they have about unknown genetic material are heavily outweighed by their  
7 anxieties about the presence of a known donor in their lives. The intense feelings of  
8 loss and powerlessness that arise from being infertile create a situation in which  
9 participants feel vulnerable and insecure. At the outset of treatment these feelings  
10 dominate their thinking and influence their decision making. They feel that a known  
11 donor might reinforce feelings of inadequacy and undermine their identity as mother.  
12 They also express concerns that she might change her mind in the future and want  
13 more involvement with the child. In this context the donor is represented as a third  
14 party who might intrude into their lives. The wish to protect themselves from any  
15 further experiences of loss or disempowerment means that unknown donation is  
16 perceived as the most secure route to motherhood.

17

18 The wish to be protected from the donor seems to be a feature of both egg and sperm  
19 donation. Studies of couples in donor insemination treatment suggest a preoccupation  
20 with protecting themselves from the donor (Cook et al,1995; Lorbach, 2003). In a  
21 study of lesbian parents, Touroni and Coyle (2002) also identified a dominant theme  
22 of a need for control and autonomy, involving a desire not to have to deal with the  
23 donor who was feared as a *'potentially threatening and disruptive outsider'*.

24

1 The experience of the participants in this study suggests that prior to implantation  
2 there may be a dilemma about knowing about the donor. Information requires  
3 psychological processing and has the potential to throw up feelings that can be  
4 difficult to manage. At this stage recipients may be struggling to accept their own  
5 infertility and the outcome of their treatment remains uncertain. It is increasingly  
6 recognised within the field of Health Psychology, that decision making in relation to  
7 medical technology has a strong emotional component to it. Potentially life-changing  
8 decisions are often not made in a rational way (Smith et al, 2002). For some of the  
9 women in this study, limiting the reality of the donor at this stage, helps them to cope  
10 with the emotional demands of treatment. A pattern of defensive denial in egg  
11 recipients has been identified in other studies (Weil et al,1994; Murray &  
12 Golombok,2003). Konrad (2005) also describes an “*active not knowing*” in her  
13 study. However, this is not the case for all of the participants and anxieties about  
14 donor matching mean that some wanted access to more information than was  
15 available . Ahuja et al (1997) found that 67% of UK egg recipients had concerns  
16 about donor screening and matching and other studies have also reported the wish to  
17 know more about an unknown donor (Mahlstedt & Probasco, 1991, Pettee &  
18 Weckstein 1993 and Applegarth et al., 1995). Most studies look at issues such as the  
19 wish for donor information at a single point in time. One of the things that this study  
20 shows is how much scope there is for attitudes to the donation process to change over  
21 time.

22  
23 Whilst a lack of information can foster a self-protective illusion of not needing a  
24 donor it can also give rise to considerable anxieties at a later stage. Examples here are  
25 fears of the donor being ugly or freakish. These preoccupations are a form of ‘stranger

1 anxiety'. The unknown donor functions as a 'blank' screen onto which the recipients  
2 can project their fears. Under ordinary circumstances in pregnancy, couples do not  
3 know what their baby will look like, but knowing about their own genetic heritage  
4 may facilitate reassuring assumptions. Fears about the donor and what the baby's  
5 appearance have also been reported in the counselling literature on DI. Clinical  
6 experience with DI couples suggest that negative fantasies about the donor early in  
7 pregnancy may be particularly strong where the couple has very little or no  
8 information about the donor (Thorn, 2006). Even where anxieties about the donor are  
9 not intense, there may still be a lingering preoccupation with what the donor is like  
10 and who he is (Snowden & Mitchell, 1981). Following the birth, most of the  
11 participants here wonder what kind of person their donor is and find it hard to  
12 personify her. The lack of information is felt at this point to be a disadvantage and is  
13 something that might become an impediment to disclosure.

14

15 The donor's motives for making the donation are rated as an important piece of  
16 information in Rodino's (2011) study. It assumes increased significance in the  
17 process of telling a child as it facilitates the construction of a narrative. Recognition  
18 of the centrality of narratives to the production of human meaning is associated with  
19 work of Jerome Bruner (1986). Narratives can be particularly important in helping  
20 people to deal with ambiguous and traumatic experiences and form an important part  
21 of the process of navigating life transitions. The depersonalised donor is difficult to fit  
22 into a narrative because it is hard to imagine what kind of person she is. In the  
23 absence of knowledge about her, the donor may be experienced as a figure out of a  
24 fairy story. Incidental bits of information that the participants have been told about  
25 their donor can also assume increased significance as they piece together a picture of

1 her. This piecing together of partial bits of information has been described in adoptive  
2 families, both before the arrival of a child (Sandelowski et al, 1992) and after  
3 (Treacher & Katz, 2000). Similarly in adoption there may be very limited  
4 information about the birth mother and even less about the genetic father. These  
5 information gaps give rise to fantasies about the birth mother and, in time, to adopted  
6 childrens' fantasies about themselves (Treacher & Katz 2001). They also make the  
7 task of constructing a narrative for the child more difficult. Following the birth of a  
8 child, access to additional information about a donor might make the process of  
9 disclosure less daunting, as Pennings has suggested (2000).

10

11 In the absence of a sense of what kind of person their donor is the women in this study  
12 are also led to wonder about her in relation to characteristics that they perceive in  
13 their child or children. In an account of the counselling needs of egg recipients,  
14 Rosenthal (1998) writes that the recipient may experience the '*ghost of the donor*' as  
15 present in their lives. The impression from the women in this study, is that the donor  
16 is a present feature in their minds. This is very different from the findings of Murray  
17 and Golombok (2003), whose study suggests that giving birth to a baby might make it  
18 easier for recipients to 'forget' the use of a donor. In contrast, the experience of the  
19 recipients here suggests that a lack of information gives rise to a conceptual gap  
20 around which attributions about difference can be made. Positive attributions do not  
21 give rise to anxieties in the way that negative ones do, but they have the potential,  
22 over time, to undermine a mother's sense of her own self-worth. Konrad (2005) also  
23 describes a tendency to idealise the donor. It may be that when it is difficult to  
24 normalise her, the tendency is towards an overly positive or negative view. This kind  
25 of black and white thinking has previously been recognised in adoption as a form of

1 the 'family romance' on the one hand or of 'bad blood' on the other (Brinich, 1990;  
2 Treacher, 2000).

3 The painful realisation that they may find it difficult to have another child with the  
4 same donor is another example of an issue that was not even on the horizon at the  
5 outset of treatment but assumes great significance, once they have a child. The wish to  
6 have same donor siblings was expressed by all the participants in the group who had  
7 given birth. There appear to be two elements to this issue. One is an alleviation of a  
8 form of 'stranger anxiety' in relation to the donor and the other involves future  
9 kinship issues for the children and a wish to avoid creating a genetically disparate  
10 family. The question of future siblings is mentioned in some handbooks about DI  
11 treatment (Snowden & Snowden, 1993; Vercollone et al,1997) but it does not feature  
12 in the gamete donation research literature. In the practice of egg sharing eggs are  
13 simultaneously allocated between the donor and recipient. This means that there are  
14 fewer spare embryos so future attempts for full siblings may not be possible. The  
15 wish for donor related siblings was a strong finding in this study. It is an issue that  
16 should be raised prior to treatment and in egg sharing needs special consideration.

17

18 Important changes over the time span of treatment have also been illustrated in known  
19 egg donation studies (Lessor,1993; Joseph et al, 2004). These studies of sister to sister  
20 donation reveal how much the experience changes for both donor and recipient, as  
21 time progresses and the idea of a baby becomes more real. A marked shift in couples'  
22 attitudes over time has also been shown in an IVF study about surplus embryo  
23 donation in which couples showed a tendency to reverse their previous decision to  
24 donate surplus embryos once a baby is born, because they perceive their spare  
25 embryos differently (de Lacey, 2005). What these studies, and the study here suggest,

1 is that the process of giving birth is transformative. Having a real baby as opposed to  
2 a desired baby, gives rise to a marked shift in attitudes and a different perspective for  
3 egg recipient mothers.

4

5 This study provides an ‘inside view’ of egg donation treatment using an unknown  
6 donor. The relatively small size of the study allows for an in-depth attention to the  
7 participants’ subjective experiences and helps to generate an understanding of some  
8 of the complex issues that arise. Findings from qualitative studies such as this are not  
9 generalisable because of the small numbers and the findings need to be considered in  
10 this light. Nevertheless the study highlights factors that may influence the choice of  
11 unknown donation and suggests that the amount of information that is available may  
12 be a determinant of the whole experience for the recipient. It also demonstrates the  
13 scope for attitudes to donor information to undergo change over the course of  
14 treatment. The findings have implications for pre-treatment counselling and raise a  
15 number of issues that merit further exploration.

16

17 **Key Words:** *egg donation/ IVF/ qualitative/ decision making/ assisted conception*  
18 *counselling.*

19

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3 Sue Stuart-Smith was the main researcher and carried out the interviews. Elizabeth J  
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6 analysis of the data. All the authors contributed to the writing of the paper.

7

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