To know or not to know? Dilemmas for women receiving unknown oocyte donation

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Submitted on December 23, 2011; resubmitted on March 6, 2012; accepted on March 9, 2012

Background: This study aims to provide insight into the reasons for choosing an unknown oocyte donor and to explore recipients’ feelings and wishes regarding donor information.

Methods: In-depth interviews were carried out with 11 women at different stages of treatment. Seven were on a waiting list and four have given birth to donor oocyte babies. The interviews were analysed using interpretative phenomenological analysis.

Results: The choice of unknown donor route was motivated by a wish to feel secure in the role of mother as well as to avoid possible intrusions into family relationships. The information that is available about unknown donors is often very limited. In the preconception phase of treatment, some participants wanted more information about the donor but others adopted a not-knowing stance that protected them from the emotional impact of needing a donor. In the absence of information that might normalize her, there was a tendency to imagine the donor in polarised simplistic terms, so she may be idealized or feared. Curiosity about the donor intensified once a real baby existed, and the task of telling a child was more daunting when very little was known about the donor. A strong wish for same-donor siblings was expressed by all of the participants who had given birth.

Conclusions: This qualitative study throws light on the factors that influence the choice of unknown donation. It also highlights the scope for attitudes to donor information to undergo change over the course of treatment and after giving birth. The findings have implications for pretreatment counselling and raise a number of issues that merit further exploration.

Key words: oocyte donation / IVF / qualitative / decision making / assisted conception counselling

Introduction

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

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

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

The capacity to make a choice depends on whether both kinds of donation are available. Given the physically invasive nature of donating oocytes, donor oocytes of either kind are often in short supply. For example, in the USA, Greenfeld et al. (1998) reported that 34% of recipients used an unknown donor because there was no known donor available to them. Some authors have claimed that where a known donor is available, most recipients would prefer to use this option (Greenfeld et al., 1998; Baetens et al., 2000) because it...
alleviates concerns about the unknown donor’s genes. However, the Kirkland et al. (1992), finding that only 26% of their UK participants would accept a known donation suggest that concerns about having a known donor can be equally strong.

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

In addition, within the practice of unknown donation, there is considerable variation in how it is carried out, particularly regarding the matching process. For example, in the clinic in Belgium where the Baetens et al. (2000) study took place, a shortage of donors meant that the only criterion for matching donors to recipients was ethnicity. Such a limited capacity for matching may well account for the low uptake of unknown donation reported in this study. In contrast, in the USA, where there is a long-established market in donor oocytes, matching and selection of unknown donors are widely available and there is a two-track system of future identity release or full anonymity. Not surprisingly, the USA is a destination for couples who desire long-term anonymity and are willing to travel (Hughes and Dejean, 2010).

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

The practice of oocyte donation in the UK and many other parts of the world has been modelled on the much older practice of sperm donation. In the past, donor insemination (DI) clinics provided only basic biometric information about donors and usually encouraged couples to keep their treatment secret. In spite of changes in legislation about donor identity release, most oocyte recipients in the UK only receive a very limited amount of information about their donor. This includes physical characteristics, marital status, religion, health history and occupation. A study that looked at the amount of additional biographical material voluntarily left by donors on the donation form found that most donors offered minimal extra information (Abdalla et al., 1998). Likewise, in Australia, most recipients are provided with only basic information and there are no guidelines that stipulate what should be stored or released (Rodino et al., 2011). The situation is different in the USA, where it is common practice to provide more detailed background information (Heinemann-Kuschinsky et al., 1995; Lindheim et al., 2000). About half of recipients report having seen a photograph of their donor (Klock and Greenfeld, 2004).

In this field, qualitative research has complemented quantitative research and has highlighted areas that merit further investigation. A UK clinic-based study found that a preference for unknown donation was linked to the wish to avoid interference in the mother–child relationship (Konrad, 2005). Some of the participants in this study also expressed a strong wish for more information about their donor. A USA study shows that where recipients have the capacity to choose a donor, this is experienced as reassuring and empowering and facilitated the process of acceptance (Becker, 2000). The narrative of ‘gift’ has been identified as being widely used by recipients even in non-altruistic donation (Kirkman, 2003; Konrad, 2005). Studies that took place following the birth have shown a tendency to diminish the role of the donor (Hallebone, 1991; Murray and Golombok, 2003; Konrad, 2005). The perception of the baby as their ‘own’ child can be used to justify not telling the child about the donation (Murray and Golombok, 2003; Konrad, 2005).

New reproductive technology gives rise to complex situations that need to be negotiated. Research into this process lags well behind the technological advancements themselves. It has been observed that psychosocial research in oocyte donation is still in its infancy (Hershberger, 2004; van den Akker, 2006), and although there is some existing research, there is a need for further studies that can help enlighten women considering embarking on oocyte donation as well as informing health professionals in the field. Little has been published on the factors that might influence the choice of unknown donation or on the impact of donor information on recipients. There is also a need for studies aimed at establishing what kind of information might be in donor families’ best interests. This study aims to provide insight into the reasons for choosing an unknown oocyte donor and to explore recipients’ feelings and wishes regarding donor information.

Materials and Methods

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

A total of 11 women were interviewed. The aim was to conduct an in-depth exploration of the women’s personal experiences, and the fact that father’s were not interviewed does not reflect an underestimation of their significance. Seven of the participants were on the waiting list for treatment at the Lister Clinic, one of the larger Assisted Conception clinics in London that specializes in oocyte donation. Because of the length of time that can be involved prior to conception, a longitudinal study was not possible. In addition, therefore, a smaller group of four women who had given birth to a donor child within the last 2 years were recruited from the Donor Conception Network (DCN), which is a national self-help organization for donor-conceived families. Ethical approval at the Lister Hospital, Tavistock Clinic and Birbeck College was granted and information and consent forms were administered to those who wished to take part.

Because IPA uses comparatively small sample sizes, it is important that samples are as homogeneous as possible. The samples were selected from the group of women who form the majority of donor oocyte recipients in the UK; that is women in their 30s or 40s who are in a stable relationship, of White British origin, in the middle to higher socio-economic groups and whose partner would be the genetic father.
Participant details

All of the 11 participants were married and opted for an unknown oocyte donor with their husbands as the genetic father. Their names have been changed in order to preserve confidentiality.

WL group

Seven participants (Alison, Bridget, Clare, Deborah, Rita, Sylvia and Theresa) were recruited from the WL for treatment at the Lister Clinic, in London. Their age range was 33–44 years. Five of the women had previously undergone infertility treatments, ranging from one attempt at IVF to 10 years of IVF. In addition, Deborah also had a failed oocyte donation treatment at a different clinic. Bridget and Clare both suffered from premature menopause in their 20s and this was their first experience of infertility treatment.

DCN group

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

Interviews and analysis

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

The interviews were all carried out by S.J.S.-S. and took place in the participants’ own homes, except for one which took place in a clinic setting. The interviews lasted ~2 h and were audio-tape recorded with the participants’ consent and then transcribed.

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

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

Results

The choice of unknown donation

The women described feelings of loss and powerlessness in relation to needing donor oocyte treatment. For example, Kate experienced her need for a donor as ‘emasculating’. IVF treatment was emotionally and physically exhausting and some of the participants had experienced treatment failures previously.

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

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

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

Theresa also wants to avoid interference from a donor:

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

The donor, as a third person, was perceived as a potential intruder who might undermine a sense of themselves as a couple creating a baby and also reinforce personal feelings of inadequacy.

Five of the women had actually had offers from potential known donors, three from family members and two from a friend or colleague. It can be difficult within a family to decline such an offer. Lily turned down offers from her two of her sisters and wished that their mother could have been more understanding of her decision.

Lily’s concerns about known donation were intensified because she does not have a particularly good relationship with either of her sisters. She worried that she might not love the baby as a result:

if I had a child who was like that, I’d sort of be irritated as I am by my sisters!

Bridget initially thought that she would accept her sister’s offer, but then changed her mind:

I just suddenly thought, I don’t want anybody else involved other than me and Martin. I don’t want to run the risk of somebody ever turning round to me and saying that’s my child.

The potential for a known donor to make a claim on a child is a very powerful concern. Bridget is also worried about the impact on her relationship with her husband and wants their creation of a baby to be what she calls a ‘private affair’.

Rita had a work colleague who had offered to donate to her and her husband. But she worried about the donor changing her mind or losing her existing children:

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

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

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

But for a child to turn round to me and say, ‘well you’re not my mum anyway’ is one thing, but (…) for them to know who their genetic mother is, I just think that would be really (…) difficult.
All these concerns contribute to a vision of long-term insecurity in a known donor situation. Opting for an anonymous donor allowed them to feel more in control of their future situation. Their anxieties reflect fears about future sources of loss such as the possibility of losing the child’s love.

Some of the women asked their potential donors if they would donate to the clinic pool in order to move them up the WL and release anonymous donor oocytes for them. This might seem like a pragmatic solution, but in each case the donors were not prepared to donate to an anonymous couple because they wanted to know where their eggs were going. Bridget was particularly upset that her sister did not feel able to donate for her rather than to her. This led her to think that oocyte donation is very different from sperm donation:

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

This perception held true for the other participants as well. Their anticipatory fears were that in the presence of a known donor their identity as the baby’s mother might be jeopardized and that the donor might intrude into the relationship they have with the baby’s father. It is as much about how a donor’s presence in their lives might make them feel, as it is about what a known donor might do in reality.

The process of reaching a decision about the type of donation they wanted to pursue involved projecting themselves into the future. Bridget described how emotionally draining it is to have to do this:

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

Knowing and not knowing

Although an unknown donor was felt to be a much safer option in terms of protecting the mother–child relationship, the lack of information raised concerns about what might emerge in the child. There was wide variation in how much the women were preoccupied by the screening and matching process. Their concerns also varied at different times and stages of treatment.

The reality of UK oocyte share programmes is that recipients are given basic biometric information, such as the donor’s height, eye colour, hair colour, weight and age. Given the shortage of donors, there is not much scope for choice. Clare and Deborah felt content with only to know what is referred to as the ‘basics’. The information they are given often includes whether the donor has a pre-existing child or not as Marilyn described:

we were literally given height, hair colour, eye colour, the fact she had a child.

Some of the participants want to know more. Rita worried about HIV risk, while Alison and Bridget were more concerned about qualities such as intelligence, personality and sense of humour.

Alison felt particularly strongly that the categories on the clinic donor matching form were too basic:

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

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

this is my health history and everything and I don’t want anything to do with you during the time.

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

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

Oh, I don’t want to know, it’ll be my baby, so I don’t want to know. It was like sweeping it under the carpet.

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

Marilyn was also ambivalent about having more information:

it’s hard to know (...) sometimes you want more information, but it isn’t always (pause) you don’t often feel better when you get it.

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

Knowing about a donor makes the need for a donor more real and this can be painful. Jinny unexpectedly became very upset when she was matched with a donor who had similar eye colour to her but was much shorter than her:

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

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

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

I was too scared to ask (...) I just thought, ‘oh, I don’t want to know, in case they say ‘no’.
Prior to conceiving with their child’s donor, all the participants had experienced a failed attempt or attempts, either with the same or different donor. Kate was matched to four different donors before she succeeded.

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

Having initially preferred not knowing much about the donor, as the time for implantation approached, Lily became increasingly concerned by ‘the fear of the unknown’. In particular, she was worried about the child having features that she might find hard to love and as a result she and her husband decided to seek treatment in the USA where it is possible to choose donors on the basis of comprehensive information. Lily did not choose a donor who was a facial or physical ‘identikit’ of herself; what was important to her was that there was enough information for her to feel that: ‘I trust the person she is’.

**Imagining the donor**

For Lily, having a lot of information facilitated a feeling of trust in the donor. In the absence of detailed information, the other participants found themselves imagining the donor. Alison had been matched with a ‘large’ donor because the clinic had categorized her as ‘large’ on the basis that she is tall, although she is slim. She was upset:

I don’t want a large donor. You know, ‘cos I had visions of someone who weighs twenty stone.

Anxiety-provoking visions of the donor were experienced by some of the others as well. Kate recalled worrying about the donor during her pregnancy:

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

Jinny’s experience was even stronger than Kate’s and she projected her worst fears onto the blank screen of the unknown donor. She remembered being anxious in pregnancy:

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

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

In the absence of information that might normalize and humanize the figure of the donor, there is a tendency for her to be imagined in a black or white form. The participants also conjured up idealized pictures of their donors, as a counter to her opposite form. For example, Bridget imagined the donor as an Earth Mother figure, who values:

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

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

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

Once the babies were born, these kind of anxieties were quickly dispelled and all the participants with babies spoke of strong loving feelings towards their newborns, for example, Marilyn:

He was a beautiful baby and I just thought, he’s lovely, the minute I saw him.

Any earlier fears about whether they would feel like the real mother were also not realized. The physical process of producing a baby and the ease with which these participants bonded with their newborns gave rise to a strong sense of identity as the baby’s mother.

However, this does not mean that they do not think about the donor, as she is present in their thoughts. They imagine what she is like as a person when they perceive particular qualities in their children. They all felt that they might see the donor in their child. Jinny looks at her baby and wonders ‘if your donor’s got a quirky smile?’ She even thinks she would recognize the donor, if she ever bumped into her, because her daughter’s smile is so distinctive. Kate thinks that her son’s sensitivity has come from his donor: ‘neither of us are particularly sensitive like Theo’.

Marilyn talked about her son’s ‘sweet’ temperament and his good looks and these make her wonder about her donor’s personality and looks:

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

Marilyn also drew on her knowledge that her egg share donor has a pre-existing child to reassure herself that her donor would not be so devastated if her own treatment had failed:

She’s probably in a good place - she’s got a child, she’ll be less, feeling less desperate.

**The wish to know more**

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

whether thoughts would creep in later and that you really wished you had known that person (…) and whether the baby was going to take after them in any respect.

For the women in the DCN group, who had actually given birth, the wish to know more about their donor assumes greater prominence, much as Theresa described. As her daughter began to grow up, Jinny felt that the information she has about her donor is not enough:

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

Kate found herself beset by thoughts that play on the economic inequality at the heart of egg sharing and which mean that the donor receives subsidized or free IVF in return for her oocytes. She found herself pre-occupied by the question of her donor’s social class:
trying to get your head round what sort of person is she? (...) you sort of go mad thinking about things like this - does she live in a council flat? And it’s horrible snobby things that go through your mind, but you just don’t know, who this person is.

Kate knew nothing in reality that can dispel these thoughts. Looking back when her twins were in their second year, she felt that having an unknown donor had been hard for her to deal with. She now wishes it has been possible to have her sister as a known donor:

I would have probably have preferred that to this sort of unknown person.

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

They must know what education they have, what subjects they’ve done, (...) would be lovely to know what her interests were (...) They must know more than me.

In contrast, Lily has pages of information about her donor. Although she feels she knows a lot about the donor, following the birth of the twins, she began to regret choosing a clinic where there was no option for future donor identity release. If her twins want to know the identity of their donor in the years to come, this will not be possible. Like the others, she shifted towards wanting to know more on behalf of her children.

The wish for same donor siblings

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

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

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

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

but she’ll be thirty something now I don’t know if she’ll want to donate or whether she’s still there.

Jinny envisaged that she would not be so anxious a second time round and also hoped that if her donor agreed, she could have more information about her.

The experience of loving the babies they had given birth to alleviated any ‘stranger anxiety’ that the participants previously felt about the donor. Even though she is unknown, she does not feel as unknowable as she did before their birth. In a way, a sense of familiarity had been created. Starting again with a different unknown donor would generate more anxiety.

The prospect of telling a child

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

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

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

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

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

The issue of whether a child will understand their motives in choosing an unknown donor is a different kind of concern from the fear of the child’s rejection which dominated their pretreatment thinking.

Looking back to how at the preimplantation stage, she protected herself from hearing about her donor’s childbearing history, Jinny regretted how much her thinking was dominated by a fear that

I might not be successful and I wasn’t really thinking straight - that I might want to know to tell Anna.

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

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

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

Kate and Lily both have something that was written by their donors which expresses their altruistic wishes in donating. They envisaged that it will be important for them to show this to their children when they are old enough to understand. It was reassuring to have the donor’s motives documented like this as Lily said:

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

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

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

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

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

While a lack of information can foster a self-protective illusion of not needing a donor, it can also give rise to considerable anxieties at a later stage. Examples here are fears of the donor being ugly or freakish. These preoccupations are a form of ‘stranger anxiety’. The unknown donor functions as a ‘blank’ screen onto which the recipients can project their fears. Under ordinary circumstances in pregnancy, couples do not know what their baby will look like, but knowing about their own genetic heritage may facilitate reassuring assumptions. Fears about the donor and the baby’s appearance have also been reported in the counselling literature on DI. Clinical experience with DI couples suggest that negative fantasies about the donor early in pregnancy may be particularly strong when the couple has very little or no information about the donor (Thorn, 2006). Even when anxieties about the donor are not intense, there may still be a lingering preoccupation with what the donor is like and who he is (Snowden and Mitchell, 1981). Following the birth, most of the participants here wondered what kind of person their donor was and found it hard to personify her. The lack of information is felt at this point to be a disadvantage and is something that might become an impediment to disclosure.

The donor’s motives for making the donation are rated as an important piece of information in Rodino’s et al. (2011) study. It assumes increased significance in the process of telling a child as it facilitates the construction of a narrative. Recognition of the centrality of narratives to the production of human meaning is associated with the work of Bruner (1986). Narratives can be particularly important in helping people to deal with ambiguous and traumatic experiences and form an important part of the process of navigating life transitions. The depersonalized donor is difficult to fit into a narrative because it is hard to imagine what kind of person she is. In the absence of knowledge about her, the donor may be experienced as a figure out of a fairy story. Incidental bits of information that the participants have been told about their donor can also assume increased significance as they piece together a picture of her. This piecing together of partial bits of information has been described in adoptive families, both before the arrival of a child (Sandelowski et al., 1992) and after (Treacher and Katz, 2000). Similarly in adoption, there may be very limited information about the birth mother and even less about the genetic father. These information gaps give rise to fantasies about the birth mother and, in time, to adopted children’s fantasies about themselves (Treacher and Katz, 2000). They also make the task of constructing a narrative for the child more difficult. Following the birth of a child, access to additional information about a donor might make the process of disclosure less daunting, as Pennings (2000) has suggested.

In the absence of a sense of what kind of person their donor is, the women in this study were also led to wonder about her in relation to characteristics that they perceive in their child or children. In an account of the counselling needs of oocyte recipients, Rosenthal (1998) wrote that the recipient may experience the ‘ghost of the donor’ as present in their lives. The impression from the women in this study, is that the donor is a present feature in their minds. This is very different from the findings of Murray and Golombok (2003), whose study suggests that giving birth to a baby might make it easier for recipients to ‘forget’ the use of a donor. In contrast, the experience of the recipients here suggests that a lack of information gives rise to a conceptual gap around which attributions about difference can be made. Positive attributions do not give rise to anxieties in the way that negative ones do, but they have the potential, over time, to undermine a mother’s sense of her own self-worth. Konrad (2005) also describes a tendency to idealize the donor. It may be that when it is difficult to normalize her, the tendency is towards an
overly positive or negative view. This kind of black and white thinking has previously been recognized in adoption as a form of the 'family romance' on the one hand or of 'bad blood' on the other (Brinich, 1990; Treacher, 2000).

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

Important changes over the time span of treatment have also been illustrated in known oocyte donation studies (Lessor, 1993; Lessor et al., 2004). These studies of sister-to-sister donation reveal how much the experience changes for both donor and recipient, as time progresses and the idea of a baby becomes more real. A marked shift in couples' attitudes over time has also been shown in an IVF study about surplus embryo donation in which couples showed a tendency to reverse their previous decision to donate surplus embryos once a baby is born, because they perceive their spare embryos differently (DeLacey, 2005). What these studies, and the study here suggest, is that the process of giving birth is transformative. Having a real baby as opposed to a desired baby, gives rise to a marked shift in attitudes and a different perspective for oocyte-recipient mothers.

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

Acknowledgements
We acknowledge the assistance provided by Mr Hossam Abdalla, Clinical Director at the Lister Fertility Clinic in London, UK. Most important of all, we thank the participants themselves for taking part in the study.

Authors’ roles
S.J.S.-S. was the main researcher and carried out the interviews. E.J.S. organized recruitment at the Lister Hospital. J.A.S. supervised the research project and was involved in the design of the study as well as overseeing the analysis of the data. All the authors contributed to the writing of the paper.

Funding
A grant was awarded by the Tavistock Clinic Research Committee to fund transcribing of audiotapes.

Conflict of interest
None declared.

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