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Secrecy, disclosure and everything in-between: decisions of parents of children conceived by donor insemination, egg donation and surrogacy

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Abstract

This study examined families where children lack a genetic and/or gestational link with their parents. A total of 101 families (36 donor insemination families, 32 egg donation families and 33 surrogacy families) were interviewed when the child was aged 7 years. Despite a shift in professional attitudes towards openness, about half of the children conceived by egg donation and nearly three-quarters of those conceived by donor insemination remained unaware that the person they know as their mother or father is not, in fact, their genetic parent. By contrast, almost all the surrogacy parents had told their child how they were born. A majority of parents who planned never to tell their child about their conception had told at least one other person. However, qualitative data indicated that to categorize families as 'secret' or 'open' is inadequate. In fact many parents engage in 'layers' of disclosure about their child's conception, both with their child and with family and friends.

Keywords

disclosure; donor conception; secrecy; surrogacy

Introduction

For medical professionals involved in helping infertile couples to conceive, the successful birth of a healthy infant usually marks the end of professional involvement with the family. However, there is a small but growing body of research relating to the long-term outcomes for these families alongside an increasing number of support groups and networks for parents and offspring (e.g. Donor Conception Network, Infertility Network UK). It is now evident that the birth of a healthy child is not always the end of the story. Donor insemination (DI), egg donation (ED) and surrogacy parents go through quite different

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processes in order to conceive, but they are similar in that one of the child's commissioning parents is not their genetic parent, and/or the commissioning mother did not give birth to them.

The potential significance of this absent genetic and/or gestational link to the child may not be fully known until later life. Turner and Coyle's (2000) study of 16 adult DI offspring who learned of their conception in later life, highlights a number of potential negative outcomes, including familial mistrust, negative sense of distinctiveness in relation to others, concern about lack of genetic continuity and frustration in the search for information about their donor. Jadva *et al.* (2009) studied offspring born by DI who were members of the online Donor Sibling Registry and found that around half had felt confused or shocked at the time of finding out and 69% still felt curious about their conception at the time of study. Those told later in life reported more negative feelings regarding their donor conception than those told earlier. Furthermore, as Landau (1998) observed, there are implications for the parents too: when one parent is genetically related to the child while the other is not, there is an asymmetry in the parents' relationships with their child. This creates the potential for tension which could have an effect on family functioning. Clearly donor conception throws up some unique challenges and the way in which parents deal with information regarding their child's conception has repercussions for the child and the family as a whole.

Whilst donor insemination in particular has a long history, attitudes and practices relating to disclosing the method of conception have changed considerably over recent decades. Assisted reproduction technology professionals, like adoption professionals, initially advocated secrecy. Prior to the mid-1980s, parents were typically advised not to tell children of their parentage (Royal College of Obstetricians and Gynaecologists, 1987). However, a climate of openness has emerged among assisted reproduction technology professionals. The Human Fertilisation and Embryology Authority (HFEA) code of practice, for example, has included an enlarged section on the importance of informing children of their donor origins, since its seventh edition published in 2007 (HFEA, 2007). In addition, legislation has been enacted in a number of countries to give donor-conceived offspring the right to identifying information about their donor at the age of majority. In the UK, anonymous donation was abolished in April 2005, so future generations of donor-conceived children will have the right to identifying information about their donor at the age of 18. This climate of openness may be a result of the substantial body of research on the negative effects of secrecy in adoption, another form of non-genetic parenting (for example, Palacios and Brodzinsky, 2010). It may also be due in part to the increasing prevalence of assisted conception techniques, perhaps reducing the level of actual or perceived stigma attached to it.

Although there is plenty of evidence that the discovery of secrets such as adoption later in life is harmful for a child, there are not sufficient data so far for assisted conception families to conclude that successful withholding of the nature of the child's conception has any negative impact. There are obvious practical obstacles to studying such families as the children grow up. However, Lycett *et al.* (2004) found that mothers who were open with their child experienced less frequent and less severe arguments with their children and reported lower levels of conduct problems and less strain, although it is important to stress that these findings are cross-sectional and thus do not establish causation. It has been

suggested by family therapists that secrecy surrounding the circumstances of the child's birth will be detrimental to family relationships because it may interfere with the reciprocal relationship of trust or create boundaries between those who know and those who do not (Karpel, 1980). Some have argued that secrecy may interfere with the child's security of attachment (Lycett *et al.*, 2004) and in this way may have damaging consequences for the child's psychological wellbeing. McWhinnie (2001) reviews the debate surrounding secrecy and disclosure and concludes that secrecy is not in the child's best interests. She argues that it is not always easy to maintain the secret due to questions about medical history and family resemblance, so that, for the parents, 'the dilemmas and evasions last a lifetime'.

Why do some parents choose to tell while others do not? A study of intention to tell amongst DI parents (Salter-Ling *et al.*, 2001) found that parents who were undecided about telling their child were also significantly more distressed about their fertility difficulties than those who were planning to tell. Nachtigall *et al.* (1997) found that those who had disclosed to their child tended to be younger, have more than one child by DI and had lower scores on perceived stigma about DI than those who were undecided and those who had not disclosed. The authors suggested that these parents may feel more comfortable with their use of donor insemination and that younger parents may feel a greater obligation to disclose as a result of the change in attitudes towards openness.

Recent studies of DI families show quite consistent rates of telling or intention to tell, with most reporting between 30% and 40% (Rumball and Adair 1999; Lycett *et al.*, 2005; Daniels *et al.*, 2009). These are considerably higher than rates found by an earlier European study (Golombok *et al.*, 2002) of DI families, which found that only eight sets of parents (8.6%) had told their child about the DI at the age of 12, while a further nine (9.7%) planned to tell in the future. A follow-up of the UK sample at age 18 showed that no further children had been told about their genetic origins between early adolescence and early adulthood (Owen and Golombok, 2009). However, these were all heterosexual two-parent families. Higher rates of disclosure have been found for heterosexual solo mothers (Murray and Golombok, 2005; Landau and Weissenberg, 2010) and lesbian mothers (Stevens *et al.*, 2003; MacCallum and Golombok, 2004) than for heterosexual couples, partly as a result of having to explain the absence of a father.

Less is known about ED families than about DI families and still less about surrogacy families. The evidence from ED families generally suggests that ED parents may be slightly more open about the child's conception than DI parents. Proposed explanations for this difference have ranged from egg donation being a more socially acceptable procedure, to the idea that pregnancy and childbirth compensate in some way for the absence of a genetic relationship and the greater proportion of known donors which might make future contact between the child and the donor more likely than in donor insemination (Murray and Golombok, 2003; Vayena and Golombok, in preparation). Clearly, being open about a child's donor conception in most cases has the consequence of being open about one parent's infertility. ED and surrogacy families differ from DI families in that the fertility problem lies with the mother and not the father. It has been suggested that secrecy in DI families is mainly due to a desire to protect the infertile husband from the stigma of male infertility, which is thought to be more shameful than female infertility (Daniels and Taylor,

1993). Therefore, one would expect to find higher rates of disclosure in surrogacy and ED families than in DI families. Haimes (1993a) argued that egg donation is viewed in a familial, clinical and asexual context whereas semen donation is seen in an individualistic context of dubious sexual connotations. One may postulate that this too would make egg donation comparatively less shameful than donor insemination.

Recent studies of ED families have found quite variable rates of telling, from 29% of parents intending to tell their child about their conception (Murray and Golombok, 2003) to a US study by Klock and Greenfeld (2004) finding that 59% of ED parents planned to tell. A study of ED families conducted in Belgium found that 44% of couples intended to tell their child about the nature of their origins (Baetens *et al.*, 2000). Of course, intentions regarding telling and actual telling decisions may not be the same and few studies exist which report actual disclosure rates. In the first phase of the present study when the child was 1 year old – the most recent study of gamete donation children in the UK – 46% of DI parents and 56% of ED parents intended to tell their child about the nature of their conception (Golombok *et al.*, 2004).

Very few studies have examined the disclosure patterns of families created by surrogacy, partly because surrogacy still remains a relatively rare method of conception and is illegal in some countries. A study by MacCallum *et al.* (2003) of 42 couples with a child born by surrogacy found that all were planning to tell the child about the nature of their birth. The most common reason given for telling was that the child had the right to know the truth and secondly to prevent the disclosure coming from someone else. Van den Akker (2000) studied 29 women at various stages of surrogacy arrangements – not all completed – and found that 97% said they would disclose the surrogacy to their child. Another small UK study (Blyth 1995) of 20 commissioning parents found that all intended to tell their child about the surrogacy.

This is the first prospective study to look comparatively at parents' decisions in DI, ED and surrogacy families regarding telling their child and others about the method of conception. Previous investigations have examined the attitudes, decisions and decision-making processes of DI parents, but less attention has been paid to those of ED and surrogacy parents. In addition, few studies have been able to interview both the mother and father. The present paper reports on the level of agreement or disagreement between partners, due to a sizeable sample of fathers. The data were collected as part the fourth phase of a longitudinal study (Golombok *et al.*, 2004a and b, 2005, 2006a and b) enabling the same families to be seen over the course of 7 years to examine the extent to which the parents followed through with their original intentions regarding disclosure to the child. In-depth interviews were used to gain qualitative data with which to illustrate and explore the reasons behind the decisions made by parents.

Materials and methods

One hundred mothers and 73 fathers, constituting 101 families with a 7-year-old child, were interviewed. One family was a father-headed family as the mother had passed away. In 71

families, both the mother and the father were interviewed individually about the conception, enabling the extent of their agreement on disclosure to be analysed.

Of the children, 36 were conceived by donor insemination, 32 by egg donation and 33 by surrogacy, representing response rates of 72%, 63% and 79%, respectively, since the families first participated when the children were aged 1. Twenty-one of the 33 children born by surrogacy were born as a result of a genetic surrogacy arrangement, where the surrogate's own egg was used, and the remaining 12 by gestational surrogacy where the commissioning mother's egg was used. Fifty-four of the children were male and 47 female. The interviews were conducted as close as possible to the child's seventh birthday, between October 2006 and January 2009. The mean age was 89 months, ranging from 77 to 99 months.

The participants, when recruited for the first phase of the study, were all heterosexual couples. The DI and ED parents were recruited through nine UK fertility clinics. The surrogacy parents were recruited through the General Register Office of the UK Office for National Statistics and Childlessness Overcome Through Surrogacy (COTS), the UK surrogacy organization. By this fourth phase of the study, 86% of the children were still living with both parents.

Data from mothers and fathers were collected by means of standardized, semi-structured, investigator-based interviews using the approach developed by Quinton and Rutter (1988). Current 'telling status' was coded by trained interviewer as 'told', 'plans to tell', 'plans not to tell' and 'uncertain'. 'Telling' referred to parents having disclosed to their child that they were conceived by egg donation, donor insemination or surrogacy. In 71 families separate interviews were carried out with both the mother and the father, with both parents coded as having the same 'telling status' in 61 (85.9%) of these families. Where parents' responses differed, the mothers' interviews (of which there were more) were used to categorize the family's telling status, and these families were examined in more detail to reveal the nature of the difference. The mothers' interviews provided quantitative data for this study, while qualitative data from both mothers' and fathers' interviews were used to provide illustrative examples.

Ethical approval for the study was obtained from the University of Cambridge Psychology Ethics Committee.

Results

Extent of disclosure to child

The telling status at age 7 by family type is summarized in Table 1. Overall, 52 (51.5%) of the children had been told. The DI group had the lowest proportion of children who had been told ($n = 10$, 27.8%) and the surrogacy families had the highest, with 20 (95.2%) of the genetic surrogacy children and nine (75.0%) of gestational surrogacy having been told. All surrogacy parents who had not yet told their child (three gestational surrogacy families and one genetic surrogacy family) intended to do so in the future. The DI group had the highest

proportion of parents not planning to tell at all ($n = 14$, 38.9%), compared with only five (15.6%) ED parents planning not to tell.

Parents' intentions at age 1 compared with age 7

As shown in Table 2, the intentions of parents regarding disclosure when their child was aged 1 were compared with their intentions 6 years later. In total, 49 (70.0%) of parents who intended to tell at age 1 had told their child at age 7 and a further 20 (28.6%) of these still planned to tell. Couples who intended to tell their child when interviewed at age 1 were asked at what age they planned to do so. Whilst many were unsure, 36 (80.0%) of the 45 couples who gave an age said that they intended to talk to their child by the age of 5.

Twelve (80.0%) mothers who planned not to tell at age 1 still planned not to tell when interviewed at age 7. Of the 16 parents who, when interviewed at age 1, were uncertain whether or not to tell their child, seven (43.8%) were still uncertain and six (37.5%) had decided against telling. Only three had turned to a pro-telling stance by age 7; two (12.5%) had told and one (6.3%) planned to tell.

Agreement between parents regarding telling child

For the 71 families where both the mother and the father were interviewed about their child's conception, 61 (85.9%) reported the same telling intentions. Where the child had already been told, 38 (97.4%) couples appeared to be in agreement; a significantly higher proportion than in families where the child had not been told, where 23 (71.9%) of couples were in agreement (Fisher's exact test, $P = 0.004$).

Disagreement between parents in their intentions to tell occurred most often where one partner was coded as uncertain. In some cases it seemed that one parent, aware that they and their partner did not agree about whether or not to tell, would describe themselves as uncertain, meaning that they were unsure how the disagreement would be eventually resolved. For example: 'I would be more likely to talk to [child], maybe not now but in a couple of years' time, and talk it through with him but I don't think [husband] wants to do that, he doesn't want him to know anything, but I don't know, I'd have to ask [husband], I think we have a lot of talking to do about it' (ED mother).

Excluding the six cases of uncertainty on one side or other, there were four cases where the responses of the two parents were apparently incompatible. Two of these cases showed apparent lack of awareness of the child having been told already, where the mother had told and the father reported 'planning to tell', and another where the father said the child had been told but the mother was still planning to tell. Contradictory attitudes to disclosure were indicated in two cases, one where the mother planned not to tell and the father planned to tell, and another where the mother planned to tell whilst the father planned not to tell. In both cases the parents were apparently unaware of the discrepancy with the other parent's views.

Reasons behind decision

Parents were asked about their reasons for their decision regarding whether or not to tell their child about their conception. Their responses were coded according to clearly defined criteria. Fifty-one parents who had told, 18 who planned to tell and 17 who planned not to tell their child gave reasons for their decision, as shown in Table 3.

Reasons for having told child—Amongst mothers who had already told their child, the most cited reason was that they ‘wanted to be honest’, with 37 (72.5%) mothers expressing this as a reason. The second most cited reason was ‘child has right to know’, thirdly, ‘to avoid disclosure’ and fourthly ‘no reason not to’.

‘Child has a right to know’ was the most cited reason for DI mothers and one of the two most cited reasons for ED mothers. The other equally cited reason for ED mothers was that they ‘wanted to be honest’. The reason given most frequently by surrogacy parents was ‘to avoid disclosure’.

The qualitative data gave a more detailed picture of the motivations behind these parents’ decisions. With respect to the desire to be honest, some parents felt their child ought to know about their own ‘story’ and felt it was positive for their child to know. Some felt that knowing about the conception would show the child how ‘wanted’ they were: ‘I think it’s very important for children to know where they came from and it would be just wrong, morally wrong, to withhold that information from him’ (DI mother); ‘You know it’s not a shameful thing and there’s nothing for her to be ashamed of being born in that way, it’s something that she should be proud of really’ (gestational surrogacy mother).

Some parents who told did so because they felt that by telling in a positive, open way they could pre-emptively minimize stigma or shame that could be attached to the child’s conception. Others told their child as a way to avoid possible harm from disclosure in other circumstances or from other people: ‘I don’t like lies ... And I didn’t want it to be a sort of dirty secret’ (genetic surrogacy mother); ‘If you try not to tell them ever, if ever they find out, it destroys any trust they’ve got in you’ (genetic surrogacy father).

Reasons for not telling child—Overall, the most cited reason for planning not to tell the child, given by nine (52.9%) mothers was that there was ‘no need to tell’, secondly ‘to protect child’ and thirdly because they ‘see it as a personal matter’. Three (17.6%) mothers – all DI mothers – said they were not telling in order to protect their partner, compared with only one (5.9%) – an ED mother – not telling in order to protect herself. No surrogacy parents were intending not to tell their child. ED and DI parents did not differ in the distribution of reasons given for their decision not to tell.

The qualitative data provided more information about these parents’ thoughts and feelings. For those parents who were not telling in order to protect the child, some were concerned that their child would not feel ‘normal’ if they were told and they wanted them to have a normal childhood. This was particularly pertinent for the small number of families who had a naturally conceived child as well. Others felt that there was simply nothing to be gained

from telling. For example, one mother said ‘I can’t see the point of opening a can of worms when you don’t need to’ (DI mother).

Not many mothers elucidated exactly what they felt they might stand to lose, but some admitted to concerns about the effect disclosure might have on the relationship between the child and their parents, in particular the non-genetic parent: ‘Um I think as well that she might feel that [father] wasn’t her “dad” dad’ (DI mother).

Many mothers who had decided against telling because there was ‘no need to tell’ tended to minimize the importance of gametes, or genetics, in the making of a child. Genetics were often considered by these mothers as being considerably less important than nurture (parenting), and – in the case of ED mothers – than carrying the child in pregnancy: ‘I gave birth to her, I carried her for 9 months, we’re very much of the opinion that she’s very much my child as well, you know? Because obviously she fed from me, inside me, and I think her characteristics – although obviously there’s something in the genes – a lot of the characteristics she has I think she’s got from me’ (ED mother); ‘At the end of the day I’ve got quite a strong opinion that genes don’t make up the person, they say it’s how you bring them up, sort of thing, I think that’s very true’ (DI father).

Two mothers referred to the high incidence of naturally conceived children who are not in fact the child of the man they call ‘dad’: No ... no. I just think there’s so many dysfunctional families out there and half of them don’t know the father anyway’ (DI mother).

Some expressed the view that the mere act of telling the child made it more important than it should be: ‘to [father] it’s not an issue at all and he thinks that by flagging it up it makes it an issue, or he thinks that I’m going to make it more of an issue than it actually is’ (ED mother).

For a few parents who were not telling in order to protect the child, the concern was for the frustration or sense of loss that might be experienced by their child when they found themselves unable to learn about, or meet, the anonymous donor: ‘I wondered how I would feel if several years down the line I found out that the father I thought was my father wasn’t my natural father. Um, that would be fine if I then had the means to actually find my father, you know, the, the natural father, but if there’s no means then it just leaves a void in your life ... and I don’t think that’s fair to happen’ (DI mother); ‘I try to put myself in his position and if I if I was told and there was no way I could find out I think I’d be more frustrated than if I, you know, would be happy ignorant’ (DI father).

For some couples the pain of the infertility was still felt and appeared to have some impact on the decision not to tell their child: ‘I’m not sure how they would react now, because they’re older, and how [father] would feel about it, because he was really hurt at the time when he found out he couldn’t conceive naturally, it was a real, you know, struggle. I don’t know, it’s a hard decision to make and at the moment I suppose we’re chickening out a bit by not facing up to it’ (DI mother).

Another approach described by some parents in this category was that if their child asked them directly they would tell them the truth, but they had no intention of telling otherwise:

‘We just agreed that if anything sort of came up from the children in the future, you know if they queried anything then we would be honest. So but we don’t plan to tell them as such unless they ask ... It wouldn’t be a tragedy or the end of the world if she did find out but we’d rather she didn’t’ (ED mother).

Mothers were asked whether or not they had any concerns about not telling their child. Six (35.3%) reported no concerns about not telling, eight (47.1%) had minor concerns, two (11.8%) moderate concerns and one (5.9%) extreme concerns. Most concerns related to the child finding out about their conception by accident. The mother who was rated as having extreme concerns was worried about the child finding out from their neighbour. This neighbour had asked the mother directly whether the child had been conceived by DI and she had felt obliged to answer honestly, despite the agreement between her and her husband not to tell others: ‘I just felt awful, I felt so awful. I felt like I betrayed [father]. I felt as if almost all of a sudden this big secret has come out, and there’s someone outside of my family that now knows how [child] was conceived. and I wanted her to move away, my next-door neighbour, I wanted to move away, I just thought I really didn’t like it. I don’t know if you can understand that but I just felt really really, um ... vulnerable, I guess, not for my sake but for [child]’s’ (DI mother).

Three mothers mentioned concerns relating to organ donation, blood testing or genetic profiling, which might cause the information to be revealed in the future. In contrast to these fears relating to the negative effects of disclosure, two mothers expressed some concern about whether not telling was the right decision for the child: ‘[upset] Sometimes I’m worried that it will damage her. Not knowing her true roots. But then I think of her as my own now anyway ... Well she is mine. I don’t think ... She is mine’ (ED mother).

Reasons for planning to tell child—The most commonly given reason by parents who planned to tell but had not yet done so was that their child was too young, cited by 15 (83.3%) mothers. Qualitative data indicated that these parents tended to consider their child too young to understand the biology and were waiting for sex education before embarking on conversations about gametes. Some parents felt the child needed to be more settled, either socially, within the family, or academically, before they could be told without risk of set back.

The second most common reason was ‘to protect child’, an explanation which appeared to be closely linked to ‘child too young’, in that it was felt that until the child reached a certain age or level of understanding, they needed to be protected from information which they could not fully understand. For these parents, seven was viewed as too young an age to deal with information about their conception, and it was felt that they would handle it better emotionally when they are older. Others felt that the child was not old enough to understand the potential sensitivity of the subject and might tell other people, including peers, leaving themselves open to negative reactions or teasing: ‘I don’t know how to approach that bit. I just don’t want him to compromise himself, you know, without realizing’ (ED mother).

Thirdly, four mothers said that they ‘didn’t know what to tell’, and three that they were ‘waiting for their child to ask’.

Mothers were asked at what age they envisaged telling their child about their conception. Of the 18 mothers who responded to this question, the majority of 11 (61.1%) were unsure at what age they would tell: 'I don't know. When is ever the right time? But yeah I don't know' (DI mother).

Two mothers (11.1%) stated that they had planned to tell before age 7 and intended to do so soon. For one of these, a DI family, the father had died when the child was a toddler and the mother, having originally intended to tell at a young age, was nervous of giving the child more to deal with. A further two mothers (11.1%) planned to tell in the next year. Only two mothers mentioned ages above 10 years old, one suggesting 18 might be the right age and the other considering telling at 21: 'So many ups and downs can happen in the teenage years, I mean, just academic things, like you know, whether or not he wants to go to university, whether he wants to travel, all these things, I'd rather have them sort of all out of the way and I mean, you know 21 seems like one of those arbitrary ages, they've still got so much growing to do but there's still, there's a certain maturity which perhaps wasn't there at 18, at 16, you know, so it's just that as we've decided to kind of leave it, that would be the sort of age that I'd look at' (ED mother).

Disclosure to others

Parents were asked whether or not they had told anyone (beside the child) about the child's conception. Of the 99 families who answered this question, 85 (85.9%) had told at least one person. Seventy-nine (92.9%) of these families had told a member of the maternal family (grandparents or siblings), while only 61 (71.8%) had told a member of the paternal family.

Of the 47 parents who had not yet told their child or did not plan to, 33 (70.2%) had already told someone else. Of the 17 parents who intended never to tell their child about their conception, 10 (58.8%) had told someone else about the way in which the child was conceived.

All surrogacy families, genetic and gestational, had told someone else about the method of their child's conception, compared with 28 (87.5%) ED families and 24 (66.7%) DI families.

Partial disclosure to child and others

Despite having reported that they had told their children about their conception, closer inspection revealed that 16 out of the 21 (76.2%) families in genetic surrogacy arrangements had only told their child that they were carried by another woman and had not yet disclosed the use of the surrogate mother's egg. However, all said they would probably tell in the future. For example:

Genetic surrogacy mother: 'We've made it like a bread in the oven, "she just kept you warm until you were ready to come out", so no, it hasn't come up that biologically she's not mine.' (genetic surrogacy mother)

Interviewer: 'Does he know about the donor egg as well?'

Mother: No ... But, I think if he ever said to me, if he ever asked me that direct question, then I would be honest with him. But, um it's not really come up ... I don't know how important it is to tell him that. Because, I don't know, I don't know whether it is important. But I know that if it comes up, then I definitely will be honest.' (genetic surrogacy mother)

Although for the purposes of these analyses, these children had been 'told' about their conception, in that they knew they had been born to a woman other than their mother, they remain unaware of the absence of a genetic link between themselves and their mother. In addition to this, one child had been told about the surrogacy but not told the identity of the surrogate, who was an adult already known to the child.

Partial disclosure was not only found in surrogacy families. During the process of interviewing at age 7, it became evident that a number of gamete-donation parents planned to or had already told their child about the use of IVF, but had not yet or did not plan to tell their child about the use of a donor egg or spermatozoa: 'Well we've told him that he's an IVF baby but we weren't telling him what the problem was ... we'll only tell him if the time arose to tell him' (DI mother); 'He's asking all the questions, he knows the basic facts, and so I think soon we should explain that his um, the egg was fertilized outside the body, and wait a little bit longer to explain I'm not the biological mother' (ED mother).

In these cases, although the parents considered themselves to have been open, they had not in fact told about the donor conception. For these parents the donor gamete was often characterized as the 'nitty gritty', a level of information inappropriate for a 7-year-old, or even unnecessary at any age. Other parents stated that because they had told others about the use of IVF, they felt the child would need to be told about this too: 'The one thing we both agreed on was we wouldn't tell [the children], but that at some point we would explain IVF because enough people knew about that' (DI mother).

It is also possible that partial disclosure can act as a 'smoke screen' which can be used to avoid full disclosure: 'The only thing people have asked, because before we went down this line we had IVF and um, a lot of people said to me 'so how did you get pregnant in the end then?' and I said "oh yeah it was IVF", you know, or "fertility treatment" and that's all we say' (DI mother).

In addition, one couple who had used a known egg donor planned to tell the child about the donor conception, but not the identity of the donor, out of respect for the donor's wish to stay anonymous. Concerning disclosure to family and friends, disclosing some but not all of the details of the child's conception, was very common. For example, telling people about the use of fertility treatment but not gamete-donation, or telling about gamete donation but not the identity of the donor: 'We have talked to other people fairly openly about it, but, um, not the fact that he's an egg donation. So the fact that he's an IVF baby, we haven't told a lot of people that he was, um, an egg donation' (ED mother).

In many cases, this was because family and friends had been aware of the difficulties in conceiving and the time taken, so that some level of disclosure was unavoidable. For some parents, telling other people about the donor gamete was seen as unnecessary level of detail:

Interviewer: Did you tell your family everything about the surrogacy and the egg donation part of it or did you leave anything out?

Genetic surrogacy mother: No I mean we were going to but especially with my mum we didn't go into the nitty gritty because she didn't want to, you know.'

Discussion

Findings from this study have shown that whether or not to tell a child about their conception can be a difficult decision for parents and one that may be ongoing even when the child is 7 years old. Whilst the majority of parents spoke confidently about the choice they had made, the decision was still a dilemma for a minority of gamete-donation families. The decision can be particularly difficult where one partner has died, where the child has a naturally conceived sibling and for those who disagree with their partner about whether or not to tell. Mothers who are uncertain about the decision to tell when their child is a baby do not always resolve their uncertainty, with many remaining uncertain as their child grows older. The findings also indicate that these mothers are considerably more likely to have decided against telling when interviewed 6 years later than to have decided to tell.

A higher number of families were expected to have told their child about their conception, based on their responses at age 1, than had actually done so, particularly amongst gamete-donation families. Nevertheless, in comparison to previous gamete-donation studies (e.g. Golombok *et al.*, 2002; Murray and Golombok, 2003), the rates of disclosure are fairly high and may indicate a slight shift of attitudes in favour of openness, albeit currently reflected more in parental intentions than in actual disclosure patterns. Interviews with parents who had told their child indicate that whilst many had told because they felt the child had a right to know, nearly as many parents had told to avoid the possible negative effects of accidental disclosure. The risks of such a disclosure may have increased in recent decades due to genetic profiling and organ matching.

Of the three types of conception, surrogacy parents are much more inclined to disclose to their child than either type of the gamete-donation parents. DI parents continue to be the least inclined to disclose. ED parents are more similar to DI parents in both their decision and the reasons given for their decision, than they are to surrogacy parents. This is despite the fact that couples conceiving through egg donation have in common with surrogacy couples a fertility issue lying with the mother. However, it is clear from the qualitative interviews that surrogacy parents face a unique situation that has important differences to that of parents of children born by gamete donation. Firstly, in the case of gestational surrogacy, the child is genetically related to both parents, which cannot apply to ED or DI families. Secondly, all surrogacy parents have had to explain the arrival of a baby in the absence of a pregnancy, which makes non-disclosure to close family and friends nearly impossible. The fact that so many other people, both inside and outside the family, know about the surrogacy might then push these parents towards telling their children. Thirdly, the kind of explanation needed to tell a child that they were born through surrogacy differs significantly from that needed to tell a child about egg or sperm donation, and may not have to come after sex education. These interviews have shown that many surrogacy parents

employ terminology relating to ‘broken tummies’ which does not necessitate an understanding of human reproduction and the role of gametes (for a detailed analysis of the telling process in gamete-donation families, drawing on interviews with those parents who had already told their child when interviewed at age 7, see Blake *et al.* 2010). This might therefore facilitate talking to their children about their conception earlier than gamete-donation parents.

Both genetic and gestational surrogacy parents were more likely to have spoken to their child about their conception than gamete-donation parents. However, genetic and gestational surrogacy parents have different information to disclose in regards to the conception. For gestational surrogacy, where the child is genetically related to both parents, disclosure involves telling the child that they were carried by another woman, whereas genetic surrogacy may additionally involve disclosing the child’s genetic relationship with the surrogate. Despite this difference, this study’s findings have shown that disclosure in genetic surrogacy families has been similar to that in gestational surrogacy families, in that most parents have only told their child that they were carried by another woman and have not yet mentioned egg donation or genetic relatedness. Whilst this may be a consequence of the more difficult terminology required, the fact that over 40% of ED parents in this study have already told their child about their conception suggests that some explanation of gametes or genetic relatedness is not an impossible undertaking at the age of 7. The relative unwillingness of these parents to tell their child about the use of the surrogate’s egg at this point may indicate that, for them, the issue of maternal genetic non-relatedness is a more sensitive issue than the use of surrogacy itself. Interviews with some of these parents suggest that they have come to view the genetic element as almost irrelevant, a biological detail: a perspective directly comparable to that of ED and DI parents who have decided against telling their child about their conception. As regards to disclosure, therefore, genetic surrogacy families have some important commonality with gamete-donation families. It remains to be seen whether, and at what age, these parents will explain the full details and implications of the surrogacy to their child.

One unexpected aspect of this study was the fairly high rates of discrepancy between parents as to their intentions regarding disclosure to the child. When parents who had already told the child were excluded, 28.1% of parents gave different responses. In addition to those parents’ whose disclosure intentions were different, qualitative data from interviews with parents whose responses were the same indicated a certain amount of divergence in opinion. In these cases, the parents may agree for the purposes of this study’s analyses but do so as a result of one parent deferring to the other, rather than having the same preference. Therefore these findings may under-represent the number of parents holding different views on disclosure to their partners. Shehab *et al.* (2007) found that deferral of one parent to the other over disclosure to children was common in gamete-donation families. Moreover, they found that in disclosing couples men frequently deferred to their wives, whereas in non-disclosing couples women always deferred to their husbands. Gillett *et al.* (1996) examined the degree of congruence in the feelings of couples who had had a child by donor insemination. They found that, for both males and females, their feelings about DI did not correlate with their perceived view of their partners’ feelings, whether before, during or after

the treatment. It could be that different attitudes to assisted conception in the first place are partly responsible for the different attitudes to telling the child about their conception. These findings suggest that many couples would benefit from advice or joint counselling, not just during fertility treatment but later as well, in order to properly work through and reconcile their different views. Where the parents disagree, or agreement was reached by deferral, there may be a risk of the child being told of their conception later in life or without the knowledge of the other parent.

The implications of donor anonymity emerged as a factor in some parents' decisions not to tell their child, as they were concerned that the mystery of an anonymous donor would be harder for a child than not knowing anything at all. Indeed, some offspring born through anonymous donation who are aware of their conception have gone on to search for their donors through websites such as the Donor Sibling Registry (Jadva *et al.* 2010). With the abolition of anonymous donation in the UK in 2005, future parents may be more likely to tell their offspring about their conception. A US study of DI families (lesbian couples, single women and heterosexual couples), from a clinic in which donors were willing to have their identity released to offspring at age 18, found that 70% of DI parents had disclosed (Scheib, 2003). Similarly, a Dutch study found that, of couples who had chosen to conceive using an identity-registered donor (constituting 63% of heterosexual couples and 98% of lesbian couples), 93% intended to disclose to their child, compared with just 17% of couples who had chosen an anonymous donor (Brewaeys *et al.*, 2005).

The fact that nearly half of the parents who do not intend to tell their child have made that decision in order to protect the child is perhaps contentious, given that professionals increasingly suggest that withholding such information may be harmful for the child. This adds support to the conclusion of Golombok (1997) that 'the opinion of social policy makers that openness is beneficial for children contrasts sharply with the view of parents who prefer not to tell.' To what extent parents' expressed wishes to protect their child also conceal a need to protect themselves is hard to ascertain, although some of the qualitative responses do illustrate how the two can be entwined. A study by Snowden *et al.* (1983) concluded that whilst verbal expressions of concern by parents were most often directed towards their children, the overall impression was that secrecy was maintained because of the benefits it would bring to the parents, and in particular to the father.

The majority of parents who intended never to tell their child had told at least one other person about their child's conception. This mirrors results from Daniels *et al.* (2009) who also found 59% of DI parents had told someone else. Klock and Greenfeld (2004) found that a majority of ED parents had told other people about the conception, but that many regretted having done so. These figures suggest that for most families there is at least a small risk of the child finding out. Although many parents cited the desire to protect their child as the reason for not telling, and some expressed confidence that they could explain it all satisfactorily to their child were the information to come out accidentally, as Landau (1998) observed, 'parents may define a particular secret as protective, but the child, upon its disclosure, may regard it as intentional concealment'. Studies of individuals conceived using donor insemination who had found out about their conception later in life have been found

to feel more angry and negative about their conception than those told earlier (Jadva *et al.* 2009).

Qualitative data from this study of disclosure at age 7 has indicated that the categories of 'secrecy' and 'disclosure' do not tell everything about the extent to which parents share information about their child's conception. As discussed above, the majority of families in genetic surrogacy arrangements had only told their child that they were carried by another woman and had not yet disclosed the use of the surrogate's egg. Although these families fell into the 'told' category, their children do not yet know the full story and remain unaware of the absence of a genetic link between themselves and their mother. At least one surrogacy family had told about the surrogacy but not the identity of the surrogate. From this can be concluded that it is more appropriate to think in terms of layers of disclosure rather than a simple dichotomy of secrecy and disclosure. Layers of disclosure are not limited to surrogacy families. During the process of interviewing at age 7, it became evident that a number of gamete-donation parents planned to or had already told their child about the use of IVF, but had not yet or did not plan to tell their child about the use of a donor egg or spermatozoa. In addition, a few parents were considering telling their child about the use of gamete donation, but not the identity of the donor. Haimes (1993b) identifies three competing strategies for the management of genetic origins: (i) full secrecy; (ii) telling about method of conception but not revealing donor identity; (iii) and telling everything. The findings of this study suggest the picture is more complicated still, with many different layers of disclosure possible, and parents often engaging in different levels of openness with different people.

That parents engage in partial disclosure may suggest that IVF is easier to talk about in comparison to the more sensitive issue of genetic relatedness. Telling the child about the IVF may be a way for parents to ease themselves, or their child, into full disclosure. This set of interviews suggest that these layers of disclosure are undertaken according to the parent's perception of their child's maturity and understanding, but are also often affected by the parent's own comfort or discomfort in discussing the subject. Previous studies have shown that a gradual disclosure tailored to the child's level of understanding may be the most favourable approach, resulting in the telling process becoming a 'non-event' for the child (Rumball and Adair, 1999; Dudley and Naeve 1997) and this was a strategy consciously employed by some of the parents in this sample. Alternatively, for parents who do not plan to tell the child about the donor conception at any age, it may be that their use of IVF is so widely known amongst family and friends that secrecy with the child is not an option, whereas the use of a donor gamete may not be as widely known and can therefore more easily be kept secret from the child. It is also possible that partial disclosure to the child and to others acts as a 'smoke screen' which can be used by the parent to explain away any comments or questions that may have aroused suspicion.

Another attitude to information sharing which emerged from interviews with gamete-donation parents can be characterized as 'we won't tell but we won't lie'. These parents, who had decided not to tell their child about their conception, nonetheless also expressed the view that they would always be honest with their child, so that if their child asked them directly they would tell them the truth. This appears to be a position that allows the parent to

maintain a view of themselves as ultimately truthful with their children, in a society where secrecy in families is generally frowned upon, without, in all probability, disclosing the donor conception. Similarly, some parents talked of the small possibility of future scenarios, e.g. organ matching, where it might be in the best interests of the child to be open, and therefore suggested they could not rule out disclosure in the future. Linblad *et al.* (2000) categorized this response pattern as ‘unexpected circumstances may arise’, where parents who expressed their intention not to tell nevertheless acknowledge that new life circumstances could arise which would cause them to reconsider.

Daniels’ (1997) work in the area of gamete donation lead him to a similar conclusion relating to the dichotomy of secrecy and openness in the gamete-donation literature, stating that ‘In earlier writings, I also portrayed the issue as opposites, using the terms secrecy and openness. As a result of the value connotations associated with these words, as well as in recognition of the complexity surrounding the topic, I now discuss the topic in terms of information sharing and information exchange, thus moving away from the presentation of the issue in either/or terms.’

Future research is needed to follow those families where the parents have said that they intend to disclose the conception to their child but at age 7 had not yet done so. Will they tell, and if so at what age? For those parents who at age 7 had given their child some but not all of the information, in particular those who had not yet spelled out the absence of the genetic link for their child, it will be important to follow them as they tell their children the rest of the story. The process of partial disclosure could also inadvertently lead to the child’s finding out more information by themselves, the knowledge that they were born with the use of medical intervention raising further questions about their birth. Future research should also be aware of the possibility of disagreement or non-communication between parents about their intentions regarding telling their child, indicating that ideally both parents should always be interviewed, and separately. Moreover, the difference between telling intentions and reality should be recognized, as should the diversity in the meaning of ‘telling’, to ensure that the degree of openness in gamete-donation and surrogacy families is not overstated.

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Biography

Jennifer Readings was awarded a BA Hons. in Social and Political Sciences at the University of Cambridge. At present, she is working on a longitudinal study of families created using donor insemination, egg donation and surrogacy at the Centre for Family Research, University of Cambridge.



Table 1

Parents' decisions at age 7 regarding telling their child about their conception.

<i>Telling child status</i>	<i>Donor insemination</i>		<i>Egg donation</i>		<i>Genetic surrogacy</i>		<i>Gestational surrogacy</i>		<i>Total</i>	
	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>
Plan not to tell	14	38.9	5	15.6	0	0	0	0	19	18.8
Plan to tell in future	7	19.4	10	31.3	1	4.8	3	25.0	21	20.8
Told	10	27.8	13	40.6	20	95.2	9	75.0	52	51.5
Uncertain	5	13.9	4	12.5	0	0	0	0	9	8.9

Table 2

Parent's intentions at age 1 regarding telling their child, compared to responses at age 7

Response at age 7	Donor Insemination		Egg Donation		Genetic Surrogacy		Gestational Surrogacy		Total	
	n	%	n	%	n	%	n	%	n	%
At age 1, planned not to tell										
At age 7: Uncertain	1	10.0	1	20.0	0	0	0	0	2	13.3
Plan not to tell	8	80.0	4	80.0	0	0	0	0	12	80.0
Plan to tell	0	0	0	0	0	0	0	0	0	0
Told	1	10.0	0	0	0	0	0	0	1	6.7
At age 1, uncertain										
At age 7: Uncertain	4	44.4	3	42.9	0	0	0	0	7	43.8
Plan not to tell	5	55.6	1	14.3	0	0	0	0	6	37.5
Plan to tell	0	0	1	14.3	0	0	0	0	1	6.3
Told	0	0	2	28.6	0	0	0	0	2	12.5
At age 1, planned to tell										
At age 7: Uncertain	0	0	0	0	0	0	0	0	0	0
Plan not to tell	1	5.9	0	0	0	0	0	0	1	1.4
Plan to tell	7	41.2	9	45.0	1	4.8	3	25.0	20	28.6
Told	9	52.9	11	55.0	20	95.2	9	75.0	49	70.0

Table 3

Reasons for parents' decisions regarding telling their child about their conception.

Reasons for decision	Donor insemination		Egg donation		Genetic surrogacy		Gestational surrogacy		Total	
	n	%	n	%	n	%	n	%	n	%
Plan not to tell child										
To protect child	6	50.0	2	40.0	0	0	0	0	8	47.1
To protect mother	0	0	1	20.0	0	0	0	0	1	5.9
To protect father	3	25.0	0	0	0	0	0	0	3	17.6
To protect donor	0	0	0	0	0	0	0	0	0	0
To avoid disapproval	1	8.3	1	20.0	0	0	0	0	2	11.8
No need to tell	7	58.3	2	40.0	0	0	0	0	9	52.9
Don't know how to tell	0	0	0	0	0	0	0	0	0	0
Don't know what to tell	0	0	0	0	0	0	0	0	0	0
See it as a personal matter	4	33.3	0	0	0	0	0	0	4	23.5
Plan to tell child										
To protect child	1	25.0	4	40.0	0	0	1	33.3	6	33.3
To protect mother	0	0	1	10.0	0	0	0	0	1	5.6
To protect father	0	0	0	0	0	0	0	0	0	0
To protect donor	0	0	0	0	0	0	0	0	0	0
To avoid disapproval	1	25.0	0	0	0	0	0	0	1	5.6
No need to tell	0	0	0	0	1	100	0	0	1	5.6
Child too young	3	75.0	9	90.0	1	100	2	66.7	15	83.3
Waiting for child to ask	0	0	1	10.0	1	100	1	33.3	3	16.7
Don't know what to tell	2	50.0	2	20.0	0	0	0	0	4	22.2
Told child										
Child has right to know	7	70.0	10	76.9	13	68.4	4	44.4	34	66.7
To avoid disclosure	2	20.0	5	38.5	15	78.9	6	66.7	28	54.9
No reason not to tell	0	0	2	15.4	6	31.6	3	33.3	11	21.6
To avoid intermarriage	0	0	0	0	0	0	0	0	0	0
To comply with donor wishes	0	0	0	0	1	5.3	0	0	1	2.0

Reasons for decision	Donor insemination		Egg donation		Genetic surrogacy		Gestational surrogacy		Total	
	n	%	n	%	n	%	n	%	n	%
Had no choice	1	10.0	1	7.7	4	21.1	0	0	6	11.8
Wanted to be honest	0	0	10	76.9	11	57.9	6	66.7	27	52.9

n = number of parents who offered this explanation; % = *n* as a percentage of the number of parents in each telling category who were interviewed about the reasons for their decision. Total percentages exceed 100 as parents could give more than one reason.