SHORT COMMUNICATION

Disclosure patterns of embryo donation mothers compared with adoption and IVF

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Abstract Attitudes towards information sharing in donor conception have changed in recent years in some parts of the world, with a move towards openness. This study follows up a sample of embryo donation mothers, examining their current disclosure patterns and comparing them with adoptive and IVF mothers to investigate any influence of the method of family creation. This study compared 17 mothers with an embryo donation child aged 5–9 years with 24 mothers with an adopted child and 28 mothers with a genetically related IVF child. Embryo donation mothers were far less likely to share information with the child; 43% were inclined towards disclosing, compared with all adoptive mothers and nearly 90% of IVF mothers. Furthermore, embryo donation and IVF mothers who had disclosed had often only given partial explanations of the child’s conception. Differences between embryo donation and adoption in particular should be taken into account when advising embryo recipients.

Introduction

Since the development of assisted reproductive techniques, the issue of sharing information about the conception with the child has been contentious, particularly in third-party conception, where the child lacks a genetic and/or gestational relationship with one or both intended parents. One such situation is embryo donation where neither of the recipient couple will be genetically related to the resulting child, although the intended mother carries the child and gives birth.

Those in favour of full disclosure regarding the child’s conception have often drawn parallels with adoption. From the 1960s onwards in Western cultures, there has been a shift in adoption towards a more child-centred structure, including encouraging adoptive parents to be open with the child. Today, adoption workers stress the importance of telling the child from a young age. Consequently, most adoptive parents begin to share the circumstances of the adoption when the child is aged between 2 and 4 years (Brodzinsky et al., 1998).
Similarly, the climate surrounding donor conception has changed over the last 20 years in Western countries, and a number of jurisdictions, including the UK, have moved to allow donor offspring access to donors’ identities. Parents’ behaviour seems to have been influenced by this shift. A study of assisted reproduction families with children conceived from 1999 onwards found that 47% of donor insemination parents and 72% of oocyte donation parents were inclined towards disclosure when the child was aged 7; a significant increase over earlier reports (Readings et al., 2011). Furthermore, Soderstrom-Antilla and colleagues (2010) studied oocyte donation families with children born between 1992 and 2007 and found a change in parental attitudes towards greater openness across this 15-year period.

Genetically, embryo donation families do resemble adoptive families. However, legally, practically and psychologically, there are vast differences between embryo donation and adoption (MacCallum, 2007). Existing research implies that these differences are reflected in parents’ disclosure patterns. In the UK, interviews with 21 embryo donation mothers with a child aged 2–5 years found the large majority (67%) were inclined towards non-disclosure to their child (MacCallum and Golombok, 2007). In comparison, a group of adoptive parents were significantly more likely to disclose the method of family creation (MacCallum, 2009).

Of further interest is what the story told to the child entails. Readings et al. (2011) demonstrated that there is not a simple dichotomy between ‘disclosure’ and ‘secrecy’, but a number of gamete donation parents engage in ‘partial disclosure’, such as telling the child about the use of IVF but not donor gametes. Similarly, a group of Israeli single mothers, who had conceived using unrelated donor oocytes and spermatozoa, were all planning to share the fact of the sperm donation with their children, but not necessarily also the oocyte donation (Landau et al., 2008). The lack of genetic relatedness between the social parents and the child seems to be the omitted detail.

The current report follows up the previously studied UK embryo donation families to examine parents’ disclosure patterns during middle childhood, comparing embryo donation mothers with adoptive mothers. This allows an examination of whether the change in law in 2005 (after the first study phase) to give donor-conceived individuals access to the identity of their donors (Human Fertilisation and Embryology Authority, 2004) has affected parents’ viewpoints. A second comparison group of IVF mothers was included to investigate if the lack of the genetic link specifically influences disclosure. Where mothers had begun disclosure, the content of information shared was explored.

**Results**

**Extent of disclosure**

Only three embryo donation mothers (18%) had told their child about the donor conception. Four (24%) planned to disclose and two (12%) were uncertain, but the most frequent response, from eight embryo donation mothers (47%), was that they definitely would not tell. Conversely, all 24 adoptive mothers (100%) had talked to their child about the adoption. Regarding IVF, one parent (4%) had decided not to tell (the father whose partner was deceased) and two (7%) were undecided, whereas 12 mothers (43%) were intending to disclose and 13 (46%) had already told. Across the three groups, 64 (93%) mothers had maintained their stance as reported in the first phase of the study. Those who had changed their minds were split more or less evenly between moving towards and away from openness.

**Content of information shared**

For the three embryo donation mothers, the terminology used varied, but in all cases the full details of the conception had not been discussed. One mother had described the process to her child from a very early age (before 2 years) as follows: ‘The story goes like this: “there were three magic sparks put in and two of them weren’t able to make a baby but you, you were the other spark.”’ However, she went on to say: ‘I haven’t actually talked about the magic spark coming from two other people who couldn’t keep her as their baby because I felt that was just … too difficult to bring in.’ Another mother had used the word ‘fertility’ but without a full explanation: ‘[The child] knows he’s a fertility baby … he doesn’t really understand what it is’. The third mother had used the word ‘embryo’, but it was unclear if she had explained that this related to both parents, since spermatozoa was not mentioned. ‘If you said to her “what’s a donated embryo?”, she would say “Mummy had to borrow some eggs for me to be made.”’ All these mothers were in favour of full disclosure and said they would share more information as the child got older, but at this stage the children remain unaware of the full connotations of their conception.

In contrast, the adoptive mothers had nearly all used the term ‘adopted’ with the child, and given some information as to what it means for parentage: ‘She is aware that she isn’t our blood child, she does know that.’ About half of the adoptive mothers explicitly referred to pregnancy; children seemed to grasp the concept of ‘tummy mummies’ as being separate from social parents: ‘He knows he’s adopted, he knows he came from another lady’s tummy and he knows that we’ve adopted him.’

**Materials and methods**

Recruitment for the initial study was through four fertility clinics and three adoption services (for full details see MacCallum et al. (2007)), with response rates of over 70%. All participants were then asked to take part in the follow up and 87% agreed. Seventeen mothers with a child conceived by embryo donation, 28 mothers with a child conceived by IVF (using the parents’ own gametes) and 24 mothers with an adopted child, were interviewed when the child was aged 5–9 years. In one IVF family, the mother had died so the father was interviewed. Mothers reported on whether they had: (i) told their child about the assisted conception/adoption; (ii) planned to disclose in the future; (iii) were uncertain; or (iv) planned not to tell. Disclosing mothers were asked at what age they had told or planned to tell. Interview transcripts of mothers who said that they had told the child were analysed to extract qualitative information.
For the IVF mothers, there was no lack of genetic relationship to get across. Explanations of IVF conception differed in the level of detail. The most common explanation (used by seven of the 13 disclosing IVF mothers) was the most basic, simply stating that the parents had needed some unspecified medical assistance: ‘They’re aware that we both had to go to hospital because I couldn’t fall pregnant and we had some help from a doctor.’ Three of the other mothers had told the child a little about the mechanics of IVF, but in vague terms, such as referring to ‘test tubes’: ‘I’m not so sure that she’s clear in her mind because she was saying about being born in a test-tube, so she’s not quite got the understanding yet, and I wouldn’t want to go into anything very detailed.’ The remaining three IVF mothers gave their children more specific information, describing spermatozoa, eggs, embryos and the IVF process: ‘They know already about both stories of the birds and the bees and natural conception and IVF conception.’

The content of disclosure followed the same pattern as the extent of disclosure, whereby the adoptive mothers were most likely to have given full explanations, the embryo donation mothers tended to give only part of the information, and the IVF mothers were somewhere in between these two.

**Age of disclosure/planned disclosure**

For the 40 disclosed parents, the age at which children had been told ranged from birth (or ‘always told’) to 5 years (mean = 25.5 months). The age of intended disclosure for embryo donation and IVF parents ranged from 8 to 16 years (mean = 11.5 years). Half of the parents who planned to tell did not give a specific age, saying that they would disclose the facts when the child spontaneously asked relevant questions, such as how babies are made.

**Discussion**

The embryo donation mothers were far less inclined towards information sharing than either adoptive or IVF mothers. The key factor influencing embryo donation mothers’ disclosure patterns seems to be not the lack of a genetic link, or the use of assisted reproductive technology, but explicitly the use of third-party conception. Comparisons with gamete donation and IVF mothers are as private about this issue as donor insemination parents and more so than oocyte donation parents. Thus, embryo donation disclosure rates may be specifically related to the lack of a genetic link on the paternal side, as suggested by the mother who had mentioned only donor eggs. There was no obvious change of mothers’ attitudes since the first phase of the study, despite the change in UK law. Studying embryo donation families with children conceived after April 2005 could investigate whether the legal changes have influenced parental disclosure decisions prospectively.

Analysis of the content of the shared information showed that, as in the study by Readings et al. (2011), several ‘disclosing’ embryo donation and IVF mothers had only given partial information. In particular, few details of genetic relationships were given in embryo donation, compared with adoption. Adoptive parents are equipped with scripts and props with which to explain adoption at a child-friendly level. The adoptive mothers’ reports show how they use these, especially the distinction between themselves and the ‘tummy mummy’. Explanations of embryo donation and IVF are more difficult, entailing an understanding of gametes. Therefore, these mothers may be following the ‘seed-planting’ strategy of disclosure (MacDougall et al., 2007), where information is shared at an age-appropriate level and built on as the child develops. The aim is for the child to feel that they have ‘always known’. This approach is only successful if the full information is revealed over time, and it is unclear yet how much detail the participating mothers will add later.

Some embryo donation and IVF mothers were planning to disclose in the future, with the mean age reported as 11.5 years. These mothers have chosen the ‘right-time’ disclosure strategy (MacDougall et al., 2007), believing that a certain level of cognitive ability is required to comprehend the information. Some mothers felt that the child would first need some understanding of the mechanics of sexual conception. A similar tendency to postpone disclosure was found in a group of Israeli single mothers with children conceived through sperm donation (Landau and Weissenberg, 2010). However, experience from disclosing mothers suggests basic level information can be shared from an early age. Indeed, research has shown that donor offspring themselves prefer the ‘seed-planting’ strategy of early disclosure (Jadva et al., 2009). If regulatory bodies wish to encourage successful information sharing, there needs to be an increase in availability and awareness of materials explaining donor conception in child-friendly terms, such as the ‘Telling and Talking’ booklets (Donor Conception Network, 2006).

The sample of embryo donation mothers studied was small, limiting the strength of the findings, although it reflects the infrequent usage of this treatment in the UK, with a birth rate of just 35 children per year on average over the preceding decade (Human Fertilisation and Embryology Authority, personal communication). To increase the representative nature of the sample, the participating clinics were from different geographical regions. Bearing this caveat in mind, the diverging disclosure patterns of embryo donation and adoptive families do highlight how these two processes of non-genetic parenthood differ. They are not viewed in the same way by participants (MacCallum, 2009) nor by groups who set reproductive guidelines (Ethics Committee of the American Society for Reproductive Medicine, 2009). The advice from the UK regulatory body, the Human Fertilisation and Embryology Authority (HFEA) to parents of donor-conceived offspring explicitly compares donor conception to adoption (Human Fertilisation and Embryology Authority, 2009). Such comparisons may not be helpful. Wider distribution of supportive materials discussing age-appropriate disclosure approaches and findings on positive outcomes of disclosure could be a better way forward.

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References


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