

Full Title:

Parents dilemmas in sharing donor insemination conception stories with their children

Short Title:

Telling conception stories

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Abstract

Parents of children conceived by gamete (sperm or egg) donation often find it challenging to share donor conception stories with their children. This paper reports findings of a qualitative study of families with children conceived by donor insemination (DI) in New Zealand, a country where the policy and practice of sharing information in DI is advanced. Almost all parents had told or planned to tell their children about their origins, but some parents faced considerable dilemmas around disclosure. Parents need to be given support and guidance as they inform their children about their donor family history.

Introduction

Secrecy and anonymity have long surrounded the medical practice of donor insemination, ostensibly to protect the interests of the parties involved: the clinicians, donors, recipients, and children (Daniels, 1998; Daniels and Taylor, 1993; Haines, 1993). Elaborate devices used to preserve the anonymity of donors highlight the significance attached to genetic ties in Western societies and how this is linked to ideas about family, intimacy, and social relations more generally (Edwards, 1998; Haines, 1992; Hargreaves, 2006). Secrecy and anonymity have been used as tools for protecting families from the stigma of male infertility, and children from the stigma of being ‘different’ (i.e. not conceived ‘naturally’), from the possible harm of finding out that their father is not their ‘real’ father, or the confusion that could result from having two ‘fathers’ (Blyth and others, 1998; Haines, 1993).

Arguments in favour of paternalistic protection of children’s interests, however, have been increasingly criticised by both professionals and the families involved. Adults

conceived by DI also have spoken out against the secrecy, lies and deceit surrounding their conception (Blyth and others, 1998; Donor Conception Support Group, 1997; Franz and Allen, 2001; Hewitt, 2002; Turner and Coyle, 2000). As a result, in recent years the issue of whether or not children should be told of their donor origins has become one of the most controversial in donor-assisted conception (Daniels, 1997; Klock, 1997; Shenfield, 1997; Weil, 1997). Proponents of information sharing have raised issues about the psychological harm caused by deception and secrecy in families, against deceiving human beings about a fundamental aspect of their identity, and the children's 'right' to know their genetic origins (Baran and Pannor, 1989; Blyth and Landau, 2004; Daniels, 2002; Daniels, 2004b; Daniels and Taylor, 1993; Landau, 1998). Arguments in favour of information sharing also have been fuelled by changes in attitude towards adoption (Cohen, 1996). This has led to policy and legislative changes in several countries, such as New Zealand, Australia and more recently in the United Kingdom to remove gamete donor anonymity (Department of Health, 2004). Under regulations instituted by the Human Fertilisation and Embryology Authority, individuals conceived with the use of donated gametes after 31 March 2005 will have the right to obtain identifying information about their donors when they reach the age of 18 (Human Fertilisation and Embryology Authority, 2004).

Removal of donor anonymity and support for children's 'right' to know their donor origins have far-reaching implications for all parties concerned. Questions arise about whether or not parents will decide to share their donor family history with their children, and if they do, how they will frame the story of their child's 'origins' (Daniels and Thorn, 2001). Legal support for children's rights to be able to identify

donors also raises questions about the implications for parents of sharing this sensitive information with their children, and whether health professionals should actively promote disclosure. If so, how can they best support and guide parents to share the family building history with their children (Daniels, 2004a)?

This paper reports findings from a qualitative study of families with children conceived by DI in New Zealand. The aim of the paper is to discuss parents' decision-making in relation to telling their children about their donor origins, their reasons for telling or not telling and the dilemmas they face around disclosure.

Whilst many of the participants had told their children or planned to tell them about their donor origins, the aim of the paper is elucidate the dilemmas and obstacles that parents encounter, highlighting the need for parental support and for understanding the social context of parents' decision-making. The implications for policy and practice in this area are explored in the context that children in a number of western countries will have the legal right to identify donors when they reach maturity, and therefore should be informed of their donor origins.

After outlining the research methods, the paper describes the social and political context of information sharing in New Zealand. The section reporting results is divided into two parts: the first focuses on the experiences of parents who have told their children about their DI origins, their reasons for telling and the process of telling. The second part examines the particular dilemmas encountered by parents who have not told their children. The paper concludes by discussing the implications for policy and practice and further research in this area.

Methods

This qualitative study was carried out in New Zealand by the first author, to meet the requirements of a PhD in Sociology. Details of the research methods used and some of the families interviewed have been reported elsewhere (Hargreaves, 2006). The research involved carrying out 52 semi-structured interviews as follows:

- Eighteen conjoint interviews with heterosexual couples where the reason for using DI was male-factor infertility; all were New Zealand Europeans, except one father who was Maori;
- Two interviews with married women with children conceived by DI whose husbands did not participate;
- Four interviews with separated or divorced mothers of children conceived by DI;
- Two interviews with lesbian couples, and the known donor to one of these couples.
- Fourteen interviews with extended family members including four conjoint and three with individual grandparents, five conjoint and two with individual aunts and uncles;
- Interviews with 11 health professionals working in two DI programmes, including medics, laboratory scientists, nurses and counsellors;
- Children were not formally interviewed for this study; most were very young, ranging in age from 7 months to 12 years. Informal interviews took place, either during or after parents' interviews, with five children conceived by DI aged from 8 to 12 years.

Participants were necessarily self-selected; only those willing to talk to a researcher about this personal and sensitive area of their lives are included in the study. The experiences of the participants are therefore not generalisable to the whole population of families with children conceived by DI. However, it is likely that there will be similarities between the stories of participants and families who did not participate in the study, as people who embark on similar experiences at a particular time and place draw on a set of shared discourses to interpret and make decisions about their lives (Williams and Popay, 1994).

Most participants were recruited through two New Zealand fertility clinics, and the New Zealand Infertility Society (now Fertility NZ). Two lesbian couples and the donor of one of these couples were recruited through personal contacts. Extended family members were recruited by asking the parents interviewed if they were willing to ask other family members to be involved in the study. Semi-structured interviews took place in people's homes and fertility clinics, lasted 1 1/2 – 2 hours and took the form of guided conversations (Fielding, 1993). Interviews were fully transcribed and all participants given pseudonyms to protect their identities and ensure confidentiality. Interview transcripts were analysed with the use of QSR NUD*IST software to identify recurring themes and the similarities and differences between the views and experiences of participants. Ethical approval for the study was granted by the National Ethics Committee on Assisted Human Reproduction (NECAHR).

Information sharing in New Zealand

New Zealand has come to be regarded as a “leader” in information sharing about DI (Daniels, 2004b; Daniels and Lewis, 1996). This was primarily fuelled by a move

towards open adoption, with the Adult Information Act 1985, and New Zealand's biculturalism. This means that New Zealand Maori cultural perspectives, including the importance of whakapapa, the ability of Maori to trace their genealogical histories for several generations (Christchurch City Libraries, 2006), are taken into consideration in the formulation of policy and practice in New Zealand. Ultimately, the active encouragement by health professionals over the past 15 years has been instrumental in the development of the 'right to know one's genetic origins' as a dominant discourse in New Zealand society (Daniels, 2004a).

In the absence of legislation or any formal policy governing assisted human reproduction in New Zealand, in the early 1990s, most New Zealand fertility clinics began moving towards a policy of information sharing, recruiting only donors who were willing to be identified in the future to DI offspring. This reflected support for the beliefs that secrets were harmful in families, and that it was in children's 'best interests' to know their genetic origins. However, if children wished to identify donors, clinics could not guarantee that they would be able to in the future because agreements with donors were not supported in law. In these circumstances, many donors wanted to have some measure of control over when and how any offspring would be able to contact them, and often stipulated their views on this in their anonymous donor profiles given to recipient couples after the birth of a child. With the enactment of the Human Assisted Reproduction Technology Act 2004, however, clinics are required to set up procedures for recording donor and birth details which can be accessed by offspring (New Zealand Government, 2004).

Findings

Parents who had told their children about their donor family history

Most parents participating in this study had shared information with family members and close friends about their infertility and use of DI. Most parents had also told their children about their DI origins. Six couples, with children ranging in age from 7 months to 9 years, who had not disclosed to their children, said they planned to do so in the future. Only one parent, a mother whose husband chose not to participate in the research, had no plans to inform her 7 year-old child of his donor family history.

Parents' disclosure to children was associated with information sharing with other family members and close friends, a strong conviction that children had the right to know their origins, and the use of models and age-appropriate scripts for telling advised by fertility clinic counsellors. Almost all disclosing parents had attended clinics that actively advocated information sharing with children. Most parents indicated that clinic staff had advised disclosure to children when they were young. Parents also believed the decision to tell was theirs, and that they were not pressured to tell.

Parents reported a variety of reasons for telling their children. The majority told their children about their DI origins before the child was two years old. Some parents chose to tell their children about their origins from birth, explaining that this was a way of practising telling before their child understood anything about it. One father said that they had told their children from the beginning to avoid having secrets or relationships "based on a lie". Other parents thought that it was important to know one's family heritage and how one came to be born.

Several parents also wanted their children to have the sense that they had “always known” about their donor origins. One father said that in this way it would “just become another part of life” and not “an issue”. They did this by telling their children stories about how they came to be part of their family, by reading children’s books written as a tool for parents to tell, such as ‘My Story’ (Cooke, 1991) and ‘How I Began’ (New South Wales Infertility Social Workers Group, 1988), or by developing their own personalised story books based on these books. These story books provide useful ‘scripts’ for introducing the notion of donor conception to young children. Although not available when this research was carried out, the Donor Conception Network in the UK has since developed a series of resources to support parents in telling their children, at different ages, about their donor-assisted conceptions (Montuschi, 2006). Some parents had told their children when they were between 3-5 years old in response to questions such as how they were “made”. Like other parents, they had disclosed when “it just seemed right” (Rumball and Adair, 1999).

Sharing their donor family history with their children was part of a journey for parents. For some it began with the desire to be secretive, but then evolved to one where the focus became the interests of the child. Stephanie, the mother of three children conceived by DI, Liam, aged 12 years, Marcus, aged 9 and Louise, aged 7, reflected on the journey:

Stephanie: We just went through all the traditional paths ... that we weren't going to tell a soul. But it's just so unrealistic. Well, it's like all of those things, it's a grieving process. And then, as you go through the grieving process, and then you decide, yes, this is what you're going to do, and you're going to do it under these circumstances, and then you go on a bit further

and you think, well, that's not very practical, and it's just an evolution. And I look at Liam now, and I think he is a person in his own right. He has rational thought, and all of those things, and he has an absolute right to know.

Another couple decided to begin telling their daughter about her donor conception when she was five years old, using 'My Story' as a model for her own life story. They had decided she should be the first to know about her donor conception because they had a relative who had been traumatised by discovering unexpectedly at his 21st birthday that he was adopted. Only after telling their daughter had they told their older naturally-conceived son and their parents.

Unlike couples who had told their children when they were very young, Brendan and Mary had made the conscious decision to tell their children, Jason and Clare, when they were 10 years and 8 years respectively. When they had fertility treatment Brendan and Mary had not been encouraged by fertility clinic staff to tell their children about their means of conception, but they later received a letter from the clinic informing them that they were now advocating that children be told. They had purchased a children's book as an aid to disclosure, talked to their children and asked them if they had any questions, but none were forthcoming. Mary recalled the difficulties of telling after years of secrecy:

Mary: It was a terrible issue for *us*, for *me*. I found it really hard to tell them. I just worried about it for months and months. But once they were getting older I thought well this is something that's there... they've got a right... it's a selfish reason not to tell them. As much as you feel that you're giving away something when you tell them, it's your selfish reasons. You're not thinking about their feelings, and their right to know these sorts of things. Because it's their

body, and how would you feel if you were in the same situation? I think if I was in the same situation I would want to know.

Parents who had not told their children about their donor family history

In contrast to parents who had shared information with their children about their donor family history, parents who had not told their children were more likely to be secretive with others, have difficulties communicating with spouses or other close family members, hold conflicting views about secrecy and disclosure, and to have received no formal counselling in the fertility clinic about information sharing, including child development models or scripts for telling.

Andrew and Annie, parents of two daughters aged 5 and 2 years had received no formal counselling when attending the fertility clinic for treatment, but had been told by a clinician that it was “better to tell than not to tell children of their origins”.

Andrew had decided not to tell anyone about his infertility, and had refused to talk even to his wife about it for several years, which caused a great deal of stress in their marriage (Hargreaves, 2006). Although she disagreed with his position, out of loyalty to her husband, Annie had also told nobody. Annie had 18 inseminations to conceive her second child and attributed the difficulty she had in conceiving to the stress in her marriage. Andrew nonetheless believed he had a moral duty to tell his children about their DI origins, but having always kept it a secret the prospect of telling was causing him significant anxiety.

Andrew: It was easy at the time, but as time went on it became more difficult, and I guess what has become more difficult is my realisation that I have to tell my kids. I went and saw my doctor

six months ago or eight months ago, to talk about the issue... I was getting stressed, stressed to hell about the whole issue. And he basically said, well, it's my choice.

Adding to his stress, Andrew constructed the event of 'telling' the children as a major event to be confronted at a fixed point in time, instead of a process (Hajal and Rosenberg, 1991). He had decided he should tell his children when his eldest daughter was 7 years old. In contrast, Annie took a more child-centred view and perceived disclosure as part of on-going healthy parent-child relations.

Annie: Oh, I just think it's about *them*, isn't it? It's not natural not to tell them. It didn't ever enter our minds not to tell them really. You've got to be honest with them. I mean, they're our children. If you can't be honest with your children, well you've got a big problem I think.

Non-disclosure to children was also associated with concerns about rejection by children and other close family members, the perceived stigma of male infertility and use of donor sperm to conceive. Steve, father of Justin and Leanne, twins aged 4 years, was also secretive about their means of family building. His wife, Jane, however, found secrecy "the most difficult thing about DI" and had "blurted out" her secret on some occasions. Steve and Jane claimed not to have discussed their views on disclosure with each other, but clearly were conflicted about telling. Insisting that the twins would eventually be told, Steve nonetheless said that he thought that disclosing to the children had the potential to "tear families apart". He claimed that his adopted niece had "rejected" his sister, her adoptive mother, in favour of her birth mother. Jane also had fears of rejection. She had not told her parents about the children's origins because she had felt rejected by them on a previous occasion. She also feared that the children might reject their father.

Jane: I sort of don't really like to have to tell the children that their father's not actually their genetic father because I sort of feel that I'd hate him to get hurt. But he could possibly say that he's not hurt, but to me I sort of feel that that side of it is quite difficult.... It's sort of a stigma thing too isn't it? It's just like adoption, but I think with adoption less, yeah, with adoption it's a bit different.

Steve and Jane were also conflicted about when was the 'best' time to tell their children. When asked what he thought was a suitable age to tell the children, Steve replied:

Steve: Probably about 10 years of age, a bit older; when they're starting to get more comprehension of what's happening around them in the world because their on-going education sort of thing. But at the moment they want to know a lot of questions about everything. They drive you batty. I mean to say, the fish up and died the other night, and they just didn't want to accept the fact. Why did it die?

Jane questioned Steve's view because her children were already asking her questions about how they came to be born.

Jane: Justin and Leanne actually often say, "Who's your mum and who's your daddy?" and "Who's my daddy?" and I go, "Oh, all right..." as if I'm telling a lie. Where did I come from, type thing, and that's when I feel, wouldn't it be good to be able to sort of pop it out? I think that could be quite an opportunity to tell them, and then I think, "Well is it too early?"

Other parents who said they planned to disclose to their children in the future included parents with young babies. Richard and Belinda, parents of Madison, aged 7 months, had discussed the issues around disclosure with a counsellor and in anticipation of

telling had bought a children's book about DI. In contrast, disclosure was a distant abstraction for Tania and Mark who had received no formal counselling when undergoing fertility treatment. Tania said they had found it difficult to communicate with their parents about their use of DI, and claimed that their parents did not seem to understand that they had used another man's sperm to conceive their child. Tania also said she thought of her 9 month-old son as her husband's child rather than anyone else's and had not been interested in receiving the profile containing non-identifying information about the donor from the clinic. Tania also felt unequipped to tell their son about his donor 'origins':

Tania: [Clinic staff] sort of said that it was important that the child knew, and to perhaps bring it up like an adopted child, but I honestly received no information about how you might tell the child... I mean we'll sorta certainly tell him, but I've never really thought about what the consequences would be [she laughs]. Since he was born I've said to him, "you're a special wee baby," but you don't think about... I don't think... because he's only a baby and he's too young to understand, and he'll probably be ten years old before he'll really understand what we mean.

Henry and Prue said they had not yet told their sons Jack, aged 8 years, and Luke aged 6 years about their donor family history. They thought that the boys were too young to tell, and were not sure how they would approach the topic. Prue said the boys had not asked any questions about the "facts of life" which might have provided an entrée to disclosure. Like other parents, Henry thought that nine or ten years old would be a "good time" to tell. However, he and Prue were not looking forward to it, anticipating having to answer "a hundred questions".

Telling their children about how they built their family was not a priority for Joe and Ella, parents of three sons aged 8, 5 and 3 years old. Their first baby, a daughter conceived by DI, was stillborn, and Ella said they had kept returning to the clinic in the hope of having another daughter. Joe, unlike other men in the study, said he would talk to “anyone” about his infertility and their children’s donor conceptions; it was part of his “therapy”. Ella expressed concern that he had told so many people because she did not want her sons to find out about their donor origins from others. When asked whether they thought their children should know about how their family was built, Joe and Ella said:

Joe: I think so, yeah. It's going to come out eventually; better it come from our mouths than somebody else's.

Ella: The thing is, at what age to tell them.

Joe: It's one of those things you haven't thought too much about. We will tell them eventually, I suppose by the time they're 10 or 11 and they know the facts of life...that they'll be told.

Only one parent said she did not plan to tell her child about his donor family history. Meredith, the mother of Daniel, aged 7 years, said she had not told because she wanted to protect her son, who was also an only child, from feeling “different” from other families. She said he was a very sensitive boy who “doesn’t let something go, and get on with the next thing.” Meredith said she had received no counselling about disclosure; the focus of her treatment was on carrying a baby to term after recurrent miscarriages. On some level, Meredith was prepared to leave it to ‘fate’ as to whether Daniel found out or not about his donor family history. If he found out, it would be the “right time”, she said.

Discussion

The high numbers of parents in this study who had begun sharing the story of their donor family history with their children or said they planned to tell them in the future reflects the findings of other New Zealand studies (Purdie and others, 1992; Rumball and Adair, 1999). However, it contrasts with other international studies investigating parents' disclosure patterns, which have found that most parents did not intend to tell their children about their donor family history (Daniels, 1988; Golombok and others, 2002; Leiblum and Aviv, 1997; Lycett and others, 2004, 2005; Nachtigall and others, 1998; van Berkel and others, 1999). Even in Sweden, the first country to introduce legislation, in 1985, enabling children conceived by DI to identify donors upon reaching maturity, a study found that only 52 per cent of parents had told (11 per cent) or intended to tell (41 per cent) their children about their DI origins, suggesting that legislation alone is not sufficient to change personal attitudes in a population (Gottlieb and others, 2000). More recent European studies suggest a move towards higher levels of disclosure to children, but the question remains how many parents who indicate that they will disclose, do so in practice (Brewaeys and others, 2005; Lycett and others, 2004, 2005).

Parents, who had disclosed, gave similar reasons to those in other studies of disclosure patterns, including avoiding accidental discovery and a desire for openness (Lycett and others, 2005). Most of these parents preferred talking to their children from babyhood about the 'different' means of conception. In contrast, making decisions about disclosure to children was fraught with conflict and ambivalence for many of the couples that had not yet told their children about their donor family history. This was particularly true for couples with conflicting views on secrecy and

disclosure, or who had encountered difficulties with family relationships, or in conceiving and carrying babies to term. This supports the finding of Daniels and others (1995) that the dynamics between couples can sometimes lead to struggles around decision-making.

The decisions of parents such as Andrew and Annie and Steve and Jane not to share information with others about their children's donor-assisted conception reflect arguments supporting the maintenance of secrecy in DI: the desire to protect the recipient family and particularly the male from the stigma of male infertility and use of donor sperm, fear of rejection from others including family members and children themselves, and the inability to fulfil culturally sanctioned reproductive roles (Daniels and Taylor, 1993; Hargreaves, 2006). The mother who said she had no plans to tell her son about his DI conception indicated her desire to protect her son, but her husband declined to be interviewed, so his views on disclosure are unknown. In contrast to their husbands, Annie and Jane, both found the secrecy around infertility and DI to be burdensome and expressed the desire to share the information about their use of DI at least with close family and friends. These findings raise the issue of possible gender differences in the perceived need or desire for secrecy, which might be usefully explored with couples in counselling sessions in fertility clinics prior to the commencement of DI treatment, and in future research.

Parents anticipating a 'right time' to tell appeared to be waiting for a time when they thought their child would understand the complex concepts related to biological relatedness and heredity. Other research has shown that parents had chosen to wait because of their children's ages and perceived inability to understand (Rumball and

Adair, 1999). These findings suggest that parents have their own particular ideas about child development that might be explored when working with them. The notion of waiting for the ‘right time’ to tell and having no particular plans to tell, however, illustrates that ‘telling’ is by no means straightforward, even as a concept, “let alone as a feature of interaction within actual families” (Haimés and Timms, 1985:82). It also raises the question whether the parents will eventually tell their children and under what circumstances. Solomon and others (1996) contend that children below the age of 7 years are unable to fully understand the concepts of biological inheritance. However, waiting until children understand runs counter to advice given in some clinics that children should be told using age-appropriate scripts *before* they understand. This is the position adopted by the Donor Conception Network in the United Kingdom in material given to would-be parents (Donor Conception Network, 2005; Montuschi, 2006). Parents can also benefit from learning from other people’s experiences of sharing this information with others in a similar position through such networks and support groups (Daniels, 2004a).

Most of those who were still waiting for the appropriate time to tell had sons, which raises the question of whether couples find it more difficult to tell boys than girls. Reluctance to tell boys may relate to claims that girls are more interested in where babies come from and therefore ask more questions about it, providing an opportunity to tell. Equally, it may reflect concerns about the possible implications of the social father’s male infertility for their sons who may consequently identify with or possibly reject their social fathers as inadequate. Such claims, however, may be socially constructed, highlighting the need to take account of social context when working

with parents. Future research in this area might usefully explore possible differences in telling boys and girls about their donor conceptions.

One of the major barriers to disclosure is the lack of well-established and acceptable scripts for telling children their donor family history (Daniels and Thorn, 2001).

These can be found in the children's books written to help parents frame the story of DI conception from an early age and the resources developed more recently by the Donor Conception Network (Cooke, 1991; Daniels, 2004a; Montuschi, 2006; New South Wales Infertility Social Workers Group, 1988). Not only do parents need access to these scripts for telling, they also need to be able to match age-related child development issues, and suitable scripts for answering the types of questions raised by children at different times, which requires some specialist knowledge (McWhinnie, 1996). The lack of knowledge about what constitutes appropriate age-specific information might lead parents to think that they should wait until the child can cognitively grasp the concept of biological relatedness. But this, in turn, begs the question of how parents are to know *when* their children are cognitively competent.

Conclusion

The decision of most parents to disclose to their children about their DI origins reflects the current philosophy of New Zealand fertility clinics, which has been shaped by the ideology that children have the 'right' to know their genetic origins, and that secrets in families are frequently never secrets and can be damaging.

Decisions about secrecy and disclosure, however, are embedded in complex sets of

social relations and professional practices, and therefore involve taking account of the interests of all significant parties concerned.

As more countries introduce legislation to end anonymity for gamete donors, giving children/offspring the legal right to find the identity of the donor, issues around secrecy and disclosure and the complexities of when and how to disclose are pressing issues for all concerned. We recommend that parents' social context for making decisions about disclosure is taken into account during counselling or information-giving sessions. We also recommend that they be given access to scripts and the experiences of parents that will help them to understand that disclosure is not a single event, but an on-going conversation, and that these scripts need to be matched to children's levels of understanding and parents' comfort levels. More research is needed to understand children's perception of their donor family history and their views on disclosure. What significance do they attach to biological and social ties? How do children conceptualise donors, and to what extent do they share these constructions with their parents?

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