



Donor Conception

Parents Disclosing Donor Conception to Their
Children: **What Does the Literature Tell Us?**

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Each year in Australia, more than six hundred children are created through the help of donor sperm, eggs, or embryos (Waters, Dean, & Sullivan, 2006; Wolf, 1996), although it is impossible to know how many more babies are born after private arrangements with a sperm donor. Almost 9% of the 29,720 treatment cycles of assisted reproduction in Australia and New Zealand in 2003 used donor insemination (Waters et al., 2006). In the United Kingdom, more than 37,000 babies have been born from donated sperm, eggs, or embryos (Human Fertilisation and Embryology Authority, 2004), and over 1800 children are known to have been conceived by donor insemination (DI) in the UK between 1999 and 2001 (Lycett, Daniels, Curson, & Golombok, 2004). Although no official figures are available from the United States, similar estimates have been made, proportionate to the population (Lycett et al., 2004). Despite such high levels of donor-assisted conception internationally, donor insemination, in particular, continues to be a process clouded in secrecy. Limited public awareness has been reflected in sometimes controversial and often changing legislation.

Since its initiation in the early twentieth century, DI has been considered a very private process which should be kept secret, even 'forgotten'. According to some authors (e.g. Turner & Coyle, 2000), this view was strongly encouraged by clinicians, who recommended that parents should not disclose to their children the processes by which they were created. If it became necessary to acknowledge a lack of biological connection, it has been claimed that parents were advised to tell their children that they were adopted (Rowland, 1985). The shameful association of sperm donation with masturbation and marital unfaithfulness remains an undercurrent in attitudes to donor insemination (Kirkman, 2004b).

The secrecy and shame associated with such procedures was often reflected in legislation. For example, until 1977, the United Kingdom classified babies born as a result of DI as illegitimate, requiring parents either to adopt their child or to ensure that no-one knew that donated semen had been used (Cohen, 2004; Smart, 1987). Consistent with the culture of secrecy associated with DI, it was usually considered unnecessary to keep records of donors; information about the donor was certainly not made available to donor-conceived people or parents.

However, social and professional attitudes have changed over the years, with the pace of change recently accelerating. Activism by donor-conceived adults and donor-conception support groups, commentary by counsellors and other professionals, and an increasing body of research have contributed to a growing sense that people conceived with donor

sperm, eggs, or embryos, like adopted people, have the right to know about their genetic origins and to have access to information about their biological parents.

Despite the growing support for 'telling', there is evidence that the majority of parents, especially heterosexual couples who have used DI, do not disclose the use of a donor to their children (Baetens, Devroey, Camus, Van Steirteghem, & Ponjaert-Kristoffersen, 2000; Brewaeys, 2001; Brewaeys, Golombok, Naaktgeboren, de Bruyn, & van Hall, 1997; Cook, Golombok, Bish, & Murray, 1995; Durna, Bebe, Steigrad, Leader, & Garrett, 1997; Golombok, Brewaeys et al., 2002; van Berkel, van Der Veen, Kimmel, & te Velde, 1999). In a review of research on DI families published from 1980 to 1995 (Brewaeys, 1996), it was found that between 47% and 92% of parents intended not to disclose to their children; it was difficult to discern a trend to greater disclosure. A European study that included 94 families with children conceived by DI revealed that parents had not told their children (aged, on average, 6 years) of their donor origins, with most parents reporting that they had no intention of ever disclosing this information (Golombok et al., 1996). Six years later, fewer than 9% of children in this study had been told of their donor origins (Golombok, Brewaeys et al., 2002). A similar result was found in Sweden where, despite legislation giving donor-conceived people access to identifying information about their donor and support of disclosure by clinics, only 11% of DI parents had told their children; a further 41 % intended to tell (Gottlieb, Lalos, & Lindblad, 2000).

Some studies have found that many parents do not disclose (or plan not to disclose) their origins to children conceived by egg donation (Murray & Golombok, 2003), even if they tend to disclose more often than DI parents ((Golombok, Murray, Brinsden, & Abdalla, 1999; Greenfeld & Klock, 2004; Khamsi, Endman, Lacanna, & Wong, 1997; Murray, MacCallum, & Golombok, 2006; Söderström-Anttila, Sajaniemi, Tiitinen, & Hovatta, 1998). Nevertheless, there is some evidence, in both DI and egg donation parents, of an increasing tendency towards intent to disclose (Golombok, Lycett, MacCallum, & Jadva, 2004).

Changing Legislation

Some countries have made legislative changes to discourage or outlaw anonymous gamete and embryo donation (see Frith, 2001; Lycett, Daniels, Curson, & Golombok, 2005; van den Akker, 2006), with the clear intent of making it possible for donor-conceived people to learn about their donors. Legislation in Victoria, Australia, for example, mandates the maintenance of two registers which formally record all births from donor

conception in the State as well as information about donors of sperm, eggs, and embryos. Identifying information can be released to donor-conceived people from the age of 18 (Infertility Treatment Authority, 2004; Szoke, 2004). The Infertility Treatment Authority, the body established to administer these central registers, also maintains two voluntary registers which formally record applications for the exchange of information between donor and donor-conceived person where the conception took place before the mandatory registers were established (Infertility Treatment Authority, 2004).

Sweden, in 1985, was the first country to make legislative provisions for the person conceived by sperm donation to have information about the donor (Gunning, 1998; Pedersen, Nielsen, & Lauritsen, 1994). New Zealand legislation ensures that clinics use only donors who are willing to be identified, in the future, to people conceived from their gametes or embryos (see Daniels & Lewis, 1996). The UK has had legislation since April 2005 that allows people conceived from future donor procedures to have greater access to both identifying and non-identifying information about their donors upon reaching the age of 18 (Human Fertilisation and Embryology Authority, 2005); in the Netherlands, since June 2004, donor-conceived people have been able to retrieve such information once they turn 16 (Brewaeys, de Bruyn, Louwe, & Helmerhorst, 2005).

Different legislative provision may apply to egg donation, which is or has been forbidden by law in a range of European and Scandinavian countries (Gunning, 1998; Söderström-Anttila, Foudila, & Hovatta, 2001).

Donor Perspectives

Historically, at least to the 1990s (Cook & Golombok, 1995; Pedersen et al., 1994), sperm donors were young, single men motivated by payment, with anonymity taken for granted. Egg donors, at least outside the US, tend to be motivated by altruism (Khamsi et al., 1997; Kirkman, 2003a). In the US, high prices are paid for donated eggs (Kalfoglou & Gittelsohn, 2000).

Studies of the attitudes of sperm donors to the prospect of being identified to donor-conceived people suggest that some men would certainly be deterred from donating but others would be encouraged to donate (e.g. Adair & Purdie, 1996; Cook & Golombok, 1995). A review (Daniels, 1998) of studies of the attitudes of Australian sperm donors revealed that, even in the 1980s, a majority of donors were willing to consider the possibility of being identified to donor-conceived people, a result echoing an earlier international review of research (Daniels, 1989). A telephone poll of 32 men who had

been altruistic, anonymous donors in the UK between 1988 and 2002 found that at least half would still have been willing to donate even had they been identifiable to people conceived from their sperm (Daniels, Blyth, Crawshaw, & Curson, 2005).

Clinics' recruitment strategies appear to play a role in donors' willingness to be identified (Daniels, 1998). In the UK, for example, clinics that paid their donors were more likely to attract donors who valued their anonymity, whereas those who relied on altruism tended to attract donors prepared to be identified to the people conceived as a result (Blyth, Crawshaw, & Daniels, 2004).

It is becoming evident that sperm donors may change their views about the meaning of their donation as the years go by (Daniels et al., 2005). Young men who once donated anonymously (for pocket money) may come to think about possible descendents, perhaps after having children of their own, and become willing to be identified to the donor-conceived person who is searching for them (Kirkman, 2004a).

Although egg donors are often known to their recipients, an investigation at a clinic in England found that few egg donors gave any information about themselves beyond profession and interests (Abdalla, Shenfield, & Latache, 1998), which will be all that is available for donor-conceived adults to discover at 18.

'Double track' system

Some clinics, especially in the US, offer donors the option of being anonymous or not, and parents the option of choosing a known or anonymous donor. Those who support this system argue that it caters for individual needs (Frith, 2001; Pennings, 1997; Scheib, Riordan, & Shaver, 2000); others respond that, while catering for the needs of donors and recipients, it gives no choice to donor-conceived people (Kirkman, 2005; McWhinnie, 2001).

The 'double-track' system provides the opportunity to compare parents' intentions to disclose to their children. Parents who choose known donors are not only more likely to intend to tell their children about their donor-assisted conception than those who choose anonymous donors (Brewaeys et al., 2005), but may also be distinguished by other characteristics. An investigation in the Netherlands found that recipients who chose donors willing to be identified to a person conceived from their sperm tended to be better educated, financially better off, and more able to cope with male infertility than were those who chose anonymous donors (Brewaeys et al., 2005).

Disclosure and Sexuality

In studies of donor-assisted conception, it has generally been found that lesbian couples and single women are more likely to choose identifiable donors and to report higher rates of disclosure intentions than heterosexual couples (Brewaeys, De Bruyn, & Helmerhorst, 2003; Leiblum, Palmer, & Spector, 1995; Scheib, Riordan, & Rubin, 2003). For example, almost all of the participating lesbian couples a Dutch study chose identifiable donors but fewer than two-thirds of heterosexual couples did so (Brewaeys et al., 2005); and, in the UK, most of the participating solo mothers intended to be open with their children about their DI conception, whereas fewer than half of the mothers in heterosexual relationships planned to tell (Murray & Golombok, 2005). The high levels of disclosure among DI mothers who are single women or part of a lesbian couple has been attributed to the desire to explain the absence of a father (Brewaeys et al., 2005; Golombok, Jadva, Lycett, Murray, & MacCallum, 2005). It has also been suggested that such families are spared the stigma associated with male infertility and the need to protect the social father, a concern that is often noted in heterosexual families as a reason for not disclosing to their children (Brewaeys et al., 2005; Golombok et al., 2005).

However, there is evidence that heterosexual couples may be increasingly likely to choose an identifiable donor where choice is possible. In the Netherlands, a double-track system was instituted in 1994 and continued until anonymous donation ended in 2004. In 1996, only 13% of heterosexual couples chose an identifiable donor; by 2002, 47% did so (Brewaeys et al., 2003). The most common reason given by parents was that they thought their child had the right to find out about the donor, although most hoped the child would not want to do so.

Reasons for non-disclosure

Parents explain the choice not to tell their children about donor conception as arising from a range of often complex reasons. The most common are concerns about the child's well-being, including that children will be distressed to learn that they are not genetically related to their fathers and that they will be unable to learn anything about their donors; fear that parent-child relationships will be disrupted; desire to protect the infertile parent from stigma; and the belief that there is no need to tell (Adair & Purdie, 1996; Cook et al., 1995; Kirkman, 2003b; Lindblad, Gottlieb, & Lalos, 2000; Lycett et al., 2005; McWhinnie, 1995; Murray et al., 2006). (There is some evidence that stigmatisation of the infertile father may be diminishing as a reason for non-disclosure: Lycett et al., 2005.) Uncertainty

about how best to tell (the most appropriate age for the child and what words to use) is another evident barrier to disclosure (Cook et al., 1995; Kirkman, 2003b; Leiblum & Aviv, 1997; Rumball & Adair, 1999), and parents may keep postponing the moment until it seems too late (Golombok, MacCallum, Goodman, & Rutter, 2002).

It has also been found that some parents conceal the use of a donor so that they do not lose their status as a 'normal' family (Brewaeyts et al., 2005). Others fear that their family will be ostracised or their children rejected by their grandparents and other members of the extended family; this is especially so for parents who have used DI rather than egg donation (Golombok et al., 2004). Some parents of DI children appear to have convinced themselves that a spontaneous conception occurred (Klock & Maier, 1991; Lycett et al., 2005), rendering disclosure of DI (in their eyes) unnecessary. One study found that the main distinction between parents who disclosed to their children and those who did not was whether they defined the matter as one of honesty (disclosers) or confidentiality (non-disclosers) (Nachtigall, Becker, Quiroga, & Tschann, 1998).

Family Secrets

There is an influential claim that secrets in families can have a detrimental effect on family relationships (Imber-Black, 1993); secrets about donor-assisted conception have been included in this assessment (Baran & Pannor, 1993; Landau, 1998). Donor-conceived people who discovered their conception as adults, often under adverse circumstances (such as during a family argument or soon after the father's death) often report having felt an indefinable sense of being outsiders in their families and continuing resentment at parental lies (Kirkman, 2003b; Turner & Coyle, 2000).

It is well established that, even in families where secrecy is upheld and children are brought up believing that they are genetically descended from both parents, someone outside the family has usually been told about the donor conception (Brewaeyts et al., 2005; Durna et al., 1997; Golombok et al., 1999; Gottlieb et al., 2000; Greenfeld & Klock, 2004; Leiblum & Aviv, 1997; Murray & Golombok, 2003). This arises from one or both parents' need to discuss the difficulties they are confronting in trying to conceive and to seek help in making decisions about possible ways of having children. The adults' need for support and advice has obvious consequences in increasing the likelihood that their children will be informed by someone else that they were donor-conceived.

Reasons for Disclosure

Among the reasons given by parents who tell their children about their donor-assisted conception is that they want to avoid having someone else disclose the information or preclude accidental disclosure as a result of technological advances, such as blood tests or genetic tests that reveal the biological incompatibility of parent and child (Kirkman, 2003b; Lindblad et al., 2000; Lycett et al., 2005). Parents who have disclosed or plan to do so tend to state that they value openness and honesty in families and that their children have a right to know as much as possible about their genetic history (Adair & Purdie, 1996; Kirkman, 2003b; Lindblad et al., 2000; Lycett et al., 2005; Murray et al., 2006). The 'right to know' incorporates a basic human right to have information about one's family, the need for knowledge that could be medically relevant (such as the presence of inherited disorders), and the desirability of avoiding marriage (and the conception of children) with a close blood relative.

Effects of Disclosure on Donor-Conceived People and Their Families

The limited information available on donor-conceived people who have known about their conception from an early age suggests that, on the whole (although not invariably) they deal well with the information (Kirkman, 2003b; Rumball & Adair, 1999; Scheib, Riordan, & Rubin, 2005). When children learn before puberty (the crucial stage for identity formation), the fact of being donor-conceived can be incorporated into their developing sense of who they are, rather than requiring an adjustment to their established understanding of self. This applies to families of lesbian couples (Chan, Raboy, & Patterson, 1998; Vanfraussen, Ponjaert-Kristoffersen, & Brewaeys, 2002) as well as to heterosexual couples and single women. One study suggests that curiosity about the donor is accompanied by acceptance of being donor-conceived and good parental relationships (Scheib et al., 2005).

The relatively few donor-conceived people who learnt as adults and have participated in public discussion tend to describe less acceptance of their conception and may be angry with their parents for deceiving them, but the search for their donor does not seem to be a search for a father; on the whole, their social father fulfils that role (Donor Conception Support Group, 1997; Hewitt, 2002; Kirkman, 2003b; Turner & Coyle, 2000).

Parents have reported satisfaction with having told their children (Scheib et al., 2005); no reports were found of parents who regretted having done so. Some parents, however,

worry that their children may, in the future, become too interested in the donor, to the detriment of the parents (Lycett et al., 2005).

Studies of donor-conception families, whether they are comparisons of those who disclose with those who do not or compare families with children conceived in other ways (Brewaeys et al., 1997; Golombok et al., 2005; Murray et al., 2006), tend not to reveal problems that can unequivocally be attributed to disclosing or not disclosing donor conception. A study that found more positive parent-child relationships in disclosing families in comparison with non-disclosing families discerned no suggestion of dysfunction in the latter (Lycett et al., 2004).

Conclusion

The literature on parents telling their children that they were donor-conceived (and on associated matters such as donor anonymity) presents a picture of complex human relationships and multi-layered meanings of genes, infertility, identity, and family. The decision to disclose and the ramifications of doing so (or not doing so) are far-reaching (e.g. Donor Conception Support Group, 1997; Hewitt, 2002; Kirkman, 2003b; McWhinnie, 2001; Turner & Coyle, 2000). In donor-assisted conception, the often-competing demands of genes and relationships in defining the family can pull parents towards both disclosure and secrecy (Kirkman, 2004a), contributing to the complexity of decisions about telling.

It has been argued that parental disclosure to children is not a single event but a continuing process (e.g. Rumball & Adair, 1999). Approaching the topic as a matter of disclosure is less helpful, it has been suggested, than thinking of it as including the child in stories about building the family (Daniels & Thorn, 2001; see Kirkman, 2003b; Rumball & Adair, 1999).

Because of the history of secrecy in donor-assisted conception, the difficulty of finding properly matched or random samples, and the young age of the children concerned, it is hard to draw any reliable conclusions about the effects of disclosure. It is not feasible to conduct rigorous studies of the effects of non-disclosure because of the impossibility of identifying the population of affected families and the ethical problems raised by studying them. It would be highly inappropriate for it to be the researcher who reveals the story of donor conception; the explanation for inclusion in the research and the questions asked at interview could hardly avoid such a revelation.

The movement towards identifiable donors and the emphasis on the needs of donor-conceived people represents an acknowledgment of children's rights rather than a change in practice in response to evidence. Even in America, where donor-assisted conception (in common with many other aspects of modern life) is likely to remain unregulated, the professional body of reproductive medicine specialists recommends that donor-conceived people should be informed by their parents about their conception (Ethics Committee of the American Society for Reproductive Medicine, 2004). Their reasons give weight to human rights and the testimony of donor-conceived adults. Where once the urgent desire of people to become parents was paramount, there is now recognition of the life-long ramifications for their children and a growing sense of responsibility to ensure the best outcome for all.

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