DONOR ANONYMITY

Prospective parents’ intentions regarding disclosure following the removal of donor anonymity

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Abstract

This short survey of UK infertility counsellors was designed to determine whether the removal of donor anonymity resulted in noticeable changes in prospective parents’ stated intentions regarding disclosure of their origins to any children conceived through donor conception. Members of the British Infertility Counselling Association working in Human Fertilisation and Embryology Authority (HFEA) – licensed centres, before and after the legal changes, were sent a short questionnaire that included space for free comments (take-up: 62%). Three-quarters reported changes. Of these, two-thirds said prospective parents were more likely to say they would disclose, while less than a tenth said prospective parents were less likely do so. Where no changes were noted, this was primarily because the majority of prospective parents had stated their intention to be open even prior to the legal changes. Possible influences on intentions included: the culture within the centre, moves towards openness within the wider society, and parents’ lack of confidence regarding how to go about disclosure. Follow-up studies are needed to improve understanding of whether influences on decision making carry through to patterns of actual disclosure; whether involvement in counselling affects outcomes; and whether access to professional assistance at the time of planned disclosure is helpful.

Keywords: Decision making, disclosure, donor anonymity, infertility counsellors

Introduction

There are no large-scale studies reporting on patterns of disclosure following donor conception. Smaller studies suggest that numbers of parents who disclose appear to be rising. However, it is likely that some who state their intention to disclose at the point of treatment or later may not, in fact, carry that out, while others who indicate that they will not disclose may go on to do so (Golombok et al., 2002a, 2006; Murray & Golombok, 2003). In other words, actions do not necessarily follow prior intentions. There also appears to be some differences in patterns of disclosure according to the type of donated gamete treatment used, though caution is necessary with such a limited research base (Golombok et al., 2002b, 2006; Scheib et al., 2003).

Views held within the professional community (the medical community in particular) within actual and prospective parents and within past donors about the appropriateness of disclosure appear divided. The research evidence base into its impact on child and family well-being is small and, again, there are no large-scale studies. What there is suggests that children and young people who are donor conceived fare well regardless of whether or not they have been told of the nature of their conception (Golombok et al., 2006). However, researchers urge caution, as many of the offspring studied have yet to attain adulthood and/or cope with disclosure, whether accidental or planned (Golombok et al., 2002a, 2002b, 2004; Blyth, 2005), and some studies have reported difficulty in recruiting, or maintaining the involvement of, families where disclosure has not taken place; this may skew the findings (Golombok et al., 2005). Reports from families where openness is practiced from early in the child’s life suggest that social and emotional well-being can be attained (Lorbach, 2003; Daniels, 2004; Lycett et al., 2005) and that parenting may be enhanced (Lycett et al., 2004), though again these reports draw on small numbers.

There is a small, but growing, body of research and other evidence that indicates support for greater
openness from, and disquiet among, donor-conceived people who are aware of their origins but denied access to information held by medical practitioners or the state. This can take the form of emotional distress, concern regarding medical disadvantage owing to an incomplete family medical history, and concerns about the denial of a perceived human right to information about oneself (Donor Conception Support Group of Australia, 1997; Whipp, 1998; Cordray, 1999; Turner & Coyle, 2000; Gollancz, 2001; Kirkman, 2004; McWhinnie, 2006). However, it is likely that many of those conceived with the use of donated gametes, especially where the climate of secrecy was or still is very strong, remain unaware of their status. Recruitment to studies is limited to those who know their status and are traceable.

Views are therefore likely to be formed and maintained on the basis of personal beliefs, values or clinical experience. Claims of evidence-based policymaking have been disputed as drawing on standards that would not be considered robust enough for medical or scientific matters (Blyth et al., 2004).

Since the first major report into assisted conception in the mid 1980s, the UK has seen many public debates regarding the removal of donor anonymity (Warnock, 1984). Following a lengthy period of activity, which included pressure group activity from coalitions of professional and service user led organizations, a court case brought under the Human Rights Act 1998 by a donor-conceived adult and a donor-conceived minor (Rose and Another v. Secretary of State for Health and Human Fertilisation and Embryology Authority [2002]) and a national consultation (Department of Health, 2001), the UK Parliament voted to end the anonymity of gamete donors with effect from 1 April 2005 (Human Fertilisation & Embryology Authority [Disclosure of Donor Information] Regulations, 2004; Wincott & Crawshaw, 2006). One reason cited for opposing the removal of anonymity was the concern that parents would be less likely to disclose to their child(ren) the nature of their origins because of fear of rejection in favour of an identifiable donor (House of Commons Science and Technology Committee, para 157:2005). No existing research evidence has been identified thus far as documenting such a fear. Although a small number of clinicians has reported informally that this concern is present during medical consultations, others state that their clinical experience suggests that such fears are not widespread. Indeed, one earlier study suggested that lack of information about the donor was a reason given by some parents for not telling children about their conception (Cook et al., 1995).

This paper reports on a survey of infertility counsellors to determine whether there had been any changes in the professed intentions of prospective parents around disclosure following the removal of donor anonymity.

Materials and methods

The British Infertility Counselling Association (BICA) is the only professional organization specific to infertility counselling in the UK. Its membership comprises infertility counsellors within and outside of centres licensed by the Human Fertilisation and Embryology Authority (HFEA), together with others working actively in allied research and education. Agreement was secured through the BICA Executive to conduct a short survey with those of its members working in HFEA-licensed centres. No ethics approval was required.

Members working in licensed centres before and after the removal of anonymity were emailed a short questionnaire through the BICA Information Officer. This comprised three multiple-choice questions and space for free comments. Two reminders were sent. Recipients were able to decide whether to return the completed questionnaire anonymously or with identifiers.

Analysis was performed using SPSS together with manual thematic analysis of the free comments.

Results

There are currently 86 centres offering licensed treatment in the UK (HFEA, 2007) and BICA has 83 of its members working in these. Of these, six did not have email addresses and twelve email addresses were returned as ‘undeliverable’. From the 65 members who received the survey, the take-up rate was 62% (40). Approximately 92.5% (37) of respondents were infertility counsellors in licensed centres, while the remaining 7.5% (3) were nurses.

Changes noted in prospective parents’ intentions to disclose to their children the nature of their conception

Approximately 75% (30) of respondents had noticed a change in prospective parents’ intentions about disclosure since the lifting of anonymity. A few commented that this reflected (and perhaps accelerated) a general move towards openness in preceding years. As seen in Figure 1, 67% (20) of those who noticed a change reported that prospective parents were more likely to say that they intended to disclose than had been the case previously; 7% (2) found that prospective parents were less willing to disclose; 3% (1) said that most prospective parents were now undecided. Of the remaining 23% (7), there were...
mixed reports including: prospective parents who were more prepared to disclose but expressed concerns about later rejection at age 18; prospective parents who were unsure how to go about disclosure; and prospective parents who were going abroad either for speed of treatment (and thus prepared to use anonymous donors, if necessary) or for use of an anonymous donor. Two respondents felt that some prospective parents who would have opted for non-disclosure prior to the changes were now more likely to say they would disclose, albeit reluctantly. Finally, one respondent worked in a centre where there had been an increase in the numbers of known donors being used, especially by single women and same-sex couples (hence presumably sperm donors). Although the majority in these latter categories would have opted for openness prior to the changes, the use of known donors meant that any children conceived could now also know the identity of their donor from infancy.

The responses of those who had not seen any changes are shown in Figure 2.

Of the 33% (10) of respondents who had not noticed any changes, 80% (8) reported that most prospective parents still said they intended to disclose. Of these, 30% (3) found that prospective parents asked more questions and engaged in fuller discussion than had been the case previously. Only 10% (1) found that most prospective parents still did not intend to tell, and another said that prospective parents were still evenly divided between telling or not. In other words, where the removal of anonymity had appeared to prompt changes to prospective parents’ approaches to disclosure, these were predominantly in the direction of openness.

By combining the numbers of counsellors who reported overall intentions to disclose (i.e. whether or not this constituted any change since the removal of anonymity), the differences between intentions to tell 70% (28) and ‘other’ categories 30% (10) becomes even greater, as illustrated in Figure 3.

**Free comments**

A number of respondents 45% (18) offered additional comments, some of which echoed those set out previously. These included the use of overseas treatment opportunities (and the influence of sperm shortages in the UK), and the reluctant acceptance of disclosure by some. Additional responses fell into three broad themes:

(i) influence of the culture within the centre
(ii) influence of moves towards openness within the wider society
(iii) parents’ need for help with how to disclose.

(i) Influence of the culture within the centre. A small number of respondents reported that the culture in the centre where they worked was not conducive to promoting full reflection by prospective parents. One remarked that, ‘I feel I am dealing not only with the client’s issues but also the personal issues of the clinic staff as well’.

There were other accounts where the legal changes had prompted what were seen as beneficial changes to
the centre’s culture. In one centre, such changes had led to all those contemplating the use of donated gametes now being seen by the infertility counsellor. Despite apprehension being expressed frequently prior to counselling, many prospective parents later expressed appreciation of the time and space this offered for reflection. Another respondent felt that counselling should be mandatory and conducted over more than one session as, in their experience, where counselling was ‘thorough, challenging but empathic, people will often re-evaluate their position’.

Although it was clear from several comments that the respondent favoured greater openness, this was not universal. For example, one respondent felt a ‘twin track’ approach would have been preferable.

(ii) Influence of moves towards openness within the wider society. Several respondents commented on how perceived changes towards openness within the wider society were encouraging prospective parents to move towards disclosure. In keeping with this, more prospective parents were making a positive choice to be open rather than defensive, the latter being driven by perceived risk of having their ‘secret’ exposed later. One reported that most prospective parents opted for openness once they fully understood how the HFEA Register worked, and then felt relieved insofar as, for example, ‘Typical remarks are “Well that’s that really. If your child could find out anyway then we need to be the ones to tell them”’. However, there were also suggestions that it continued to be more difficult for men than women to contemplate disclosure. One respondent reported that, for some couples, telling their own parents (i.e. prospective grandparents) was a key barrier to disclosure. Another pointed to particular difficulties that were encountered among members of some minority ethnic communities because of worries about stigmatization. Some couples remained adamantly opposed to disclosure.

(iii) Parents’ need for help with how to disclose. It was clear that some respondents saw their role as educative as well as providing help with decision making. This is in line with the current HFEA Code of Practice (HFEA, 2007). Some found that prospective parents wanted to ‘tell’, but were unsure how to go about doing so and at what age. In these cases, discussions were less to do with whether or not to tell, but ‘how’ and ‘when’. Several respondents referred to the usefulness of the Donor Conception Network materials for parents and families (http://www.dcnetwork.org) when engaging in such dialogue.

One respondent commented at some length on prospective parents’ concerns about the lack of future support services for them as a family. This was seen within the context of how difficult it seemed for most prospective parents to engage fully in discussion about the range of parenting skills that they might need to support their child’s needs, including openness, when ‘they are typically struggling to balance hope on the one hand with anticipated loss and actual loss on the other’. In other words, the uncertainty about whether a pregnancy would result from treatment got in the way.

Another reported that a number of prospective parents speculated that they would welcome the availability of non-identifying information about the donor to assist them with parenting during a child’s childhood and teenage years, especially if they found themselves with a very curious child.

Discussion

This short survey has limitations that should be taken into account when interpreting the findings. Although it achieved a high take-up rate, it was conducted primarily with one sector of the multi-disciplinary team within HFEA-licensed centres. At 45% (18), less than half of the respondents offered any free comments, so it is not known how far these represent the experiences or views of the remainder. It is likely that some prospective parents who inform the infertility counsellor that they intend to tell their child of the nature of their conception will not, in the end, do so. Regardless of how explicitly the rules of
confidentiality are stated (for example, the content of counselling sessions cannot normally be disclosed to the treating clinician), some prospective parents will fear that they may be refused treatment if they say what they perceive to be the ‘wrong’ thing.

With these limitations in mind, the findings presented here indicate that, contrary to fears among some professionals and policymakers, there has been a move towards disclosure in the stated intentions of prospective parents since the removal of anonymity. For some prospective parents this appears to have come about with reluctance, and this group may be at particular risk of delaying or avoiding disclosure. However, where disclosure intentions accord with personal beliefs or with norms within the wider society, barriers to actual disclosure may be low. Where the use of anonymous donors through overseas treatment conflicts with prospective parents’ personal beliefs or the broader norms within their community or wider society, this carries the potential for later distress among parents and their children, and/or may complicate the decision-making process surrounding disclosure (Merricks, 2007). Follow-up studies are warranted. A more detailed survey would indicate the extent to which the themes identified from the free comments are present in a larger study population, as well as identifying any additional themes. Studies that add understanding to whether the barriers and drivers identified influence actual disclosure patterns are needed, as are studies that examine whether exposure to counselling affects disclosure patterns.

Of concern are accounts of prospective parents’ needs for ongoing professional support with parenting tasks around disclosure and subsequent management, given that such services are not available at present. This reflects studies with parents that suggest uncertainty about how to tell may prove a major inhibitor to disclosure (Kirkman, 2003). This finding is especially pertinent in light of the imminent opening of the HFEA Register of Information, in 2008, to those who consider that they may have been donor conceived. There is an urgent need for intervention studies in this area.

Finally, the finding that a small number of respondents reported that many prospective parents continue not to intend to disclose while the majority reported otherwise warrants further study. This may reflect different cultures operating within different centres, different patient profiles or something else.

In conclusion, infertility counsellors see large numbers of people contemplating the use of donated gametes as their route to parenthood. They do so within strict boundaries of confidentiality, and as part of a service designed to enable patients to make a fully informed choice. These confidentiality rules may make prospective parents more likely to disclose their actual intentions to this group of professionals than to others in the treatment team. The group of counsellors approached were all in post before and after the removal of anonymity, so were in a position to note any changes to their practice experience. Despite fears that the removal of anonymity may increase the numbers of prospective parents who were not willing to disclose their use of donor conception to the child, this is not apparent from this short survey.

References


Rose and Another v. Secretary of State for Health and Human Fertilisation and Embryology Authority [2002] EWHC 1593.


