Sharing genetic origins information in donor assisted conception: views from licensed centres on HFEA donor information form (91) 4

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Section 31 of the Human Fertilization and Embryology Act 1990 permits people born as a result of licensed treatments provided in the UK to seek certain information about their genetic origins held on the Human Fertilization and Embryology Authority (HFEA) Register of Information. The precise nature of such information is to be specified in Regulations that have yet to be determined by the Secretary of State. The Register comprises data submitted to the Authority by licensed centres on HFEA Donor Information Form (91) 4. This paper reports on a survey of views of licensed centres concerning the adequacy of this form and centres' experiences of gathering information from donors. The survey shows that centres' experiences vary considerably, and the authors argue that there is a case for the sharing of centres' experiences and dissemination of effective strategies. The paper further discusses the nature of information that might become available to individuals seeking information from the HFEA. While requests for non-identifying information concerning the donor cannot be made prior to 2010, any information made available then is inevitably dependent on current practice in centres. The authors conclude that current variability in practice does not best serve the interests of donor offspring who may seek information about their genetic origins.

Key words: anonymity/donor offspring/gamete donors/genetic origins information/policy

Introduction

The Human Fertilisation and Embryology Act 1990 requires centres providing licensed fertility treatment to maintain records of both the providers and recipients of donated gametes and embryos, and to provide this information to the Human Fertilisation and Embryology Authority (HFEA) for inclusion on the Authority’s Register of Information. Under Section 31 of the Act, donor offspring born since the introduction of the Act have a right of access to certain information held on the Register. The Act empowers the Secretary of State to specify the nature of such information, but specifically prohibits retroactive disclosure of the identity of the donor (Section 31 [5]), except in connection with legal proceedings in the event of a child being born with a congenital disability.

Although the Secretary of State has yet to determine the precise nature of the information to be made available to donor offspring, HFEA Donor Information Form (91) 4 provides for certain information about the donor to be recorded, including: height, weight, ethnic group, skin colour, eye colour, hair colour, occupation and interests. In addition, there is space for donors to provide: ‘a brief description of yourself as a person. This should be something which could be passed on to any child born as a result of your help. It may also be seen by the parents.’

Guidance issued to centres by the Authority suggests that such information could include ‘further information about the donor’s interests, family background, childhood, region of origin etc.’ and that centres should offer potential parents the opportunity to see any additional information provided by the donor prior to treatment (HFEA, 1994).

The Authority’s Code of Practice also advises centres to encourage donors: ‘to provide as much ... non-identifying biographical information about themselves as they wish, to be made available to prospective parents and any resulting child’ (HFEA 1995, 3.42, p. 19).

The study

This paper reports on a brief study undertaken by the British Association of Social Workers Project Group on Assisted Reproduction (PROGAR) by means of a postal questionnaire sent to the directors of all licensed treatment centres (119) in the UK at the end of October 1996.

Results

Replies were received from 53 of the 119 centres to which a questionnaire was sent, including six that also indicated that the centre did not recruit donors, an overall response rate of 45%. Responses to each of the five questions asked on the questionnaire are outlined below.

Do you feel that HFEA form 91 (4) provides adequate additional space for information to meet the needs of resultant children?

Of the 47 replies, 26 (55.3%) indicated that they considered the form provided adequate additional space for information to meet the needs of resultant children, while 14 (29.8%) did not think so and seven (14.9%) were ‘unsure’.

Do you feel that donors need guidance in completing this section of the form, e.g. sub-headings?

Irrespective of their views on the adequacy of space on the
form, 30 respondents (63.8%) considered that donors needed guidance on completion of the form, although a greater proportion of those who considered the form contained insufficient space for additional information – 11 out of a total of 14 (78.6%) – did so.

Can you describe the attitude of donors to providing additional information?

Respondents reported a range of attitudes of donors towards providing further information. Measured by the frequency with which they were mentioned, negative/cautious attitudes were more in evidence than positive ones, but a number of centres reported experience of donors with both positive and negative attitudes towards providing further information. Most frequently mentioned were: donors not being interested in, or attaching any importance to, providing further information; ambivalence; donors being unwilling to provide more than basic information about themselves; donors not knowing what information to provide about themselves, and donors fearing that ostensibly non-identifying information might, nevertheless, compromise their anonymity. An indication of the range of responses is provided by the following comments:

‘Our donors are egg donors and often have few interests beside their family so often they don’t know what to write.’

‘Generally they are very unsure as to what is required but are happy to acknowledge the possible future needs of the child.’

‘Once everything is explained they normally fill in extra info, i.e. why they donated.’

Strategies identified in connection with eliciting further information from donors included: explaining the rationale for requesting further information; providing encouragement; providing counselling, advice and guidance on what information could be supplied. Other responses came close to hinting that any further information provided by the donor might be ‘extracted’ rather than voluntarily given, as illustrated by the following response:

‘Not usually bothered. Most need persuasion to do this.’

Do you have other means of collecting information and/or other records that contain information on the characteristics of donors? If yes, can you describe these?

Twenty-seven centres (57.4%) indicated that they had additional means of collecting information about donors, 71.4% (10 out of 14) of those indicating dissatisfaction with the space for additional information on Donor Information Form (91) 4 being most likely to do so. However, where specific details were provided, most of the information collected related to the donor’s physical characteristics and/or medical history only. The 10 centres specifically seeking information about the donor’s social background or personal characteristics did so using a variety of methods, including: report from a counsellor; pen-pictures; social history; advice on areas of interest for the child, and a ‘dating agency’ style questionnaire [the latter comprising a two-sided A4 questionnaire requesting information about: physical build; education; religion; political leanings; interests (music, hobbies and leisure interests); personality checklist, and additional space for any further information].

In what way would you like to see the HFEA form improved?

Thirty respondents (63.8%) provided comments on improving the form, and only seven (14.9%) considered the form to be satisfactory in its current format. One respondent indicated that they were unsure how the form could be improved. Twelve of the 14 respondents who had indicated dissatisfaction with the space provided for additional information on the form (85.7%) offered suggestions for improving the form, as did 14 of the 26 respondents who had indicated satisfaction with the space available on the form (53.8%), although of the latter, one recommended abolishing the form altogether, and another proposed dispensing with the section for additional information. Most proposed improvements concerned the structure of the form, including the provision of more space for additional information, and the use of sub-headings, although other ideas included the use of a self-completion questionnaire format rather than requiring donors to write in prose.

Respondents’ suggestions about donor information that could explicitly be sought included: educational background; blood group; ethnic background; genetic history; family background; hobbies; religion; ‘a pen sketch’; motivation for donating; talents; skills, and whether the donor had children of his/her own. One respondent suggested space for the donor to leave a message for the child. Another that the use of structured questions might elicit more useful information. Several respondents commented on donors’ lack of clarity about the information that should be included, and that guidance, such as an information leaflet, advice from counsellors, and illustrative examples of the sort of information to be provided could be given to donors. One respondent expressed concern about the provision of detailed information and the risks of compromising the anonymity of the donor (in a centre operating in a sparsely populated area) while another was worried that detailed information such as the donor’s occupation could lead to moral judgements being made about the ‘worthiness’ of particular donors.

Discussion

Historically, treatment in the UK involving donated gametes has been characterized by both secrecy and anonymity. It is beyond the scope of the present paper to discuss the issue of donor anonymity per se. However, while the Human Fertilisation and Embryology Act 1990 stops short of retroactive removal of donor anonymity, its provisions allowing donor offspring access to information about their genetic origins represent a presumption that they will be told the truth about their conception.

Proposals from respondents to the questionnaire concerning the recording of information about donors also suggest an endorsement of information sharing (without which the availability of such information would be meaningless). Nevertheless, it is evident that this remains controversial (see, for example, McWhinnie, 1996; Johnson, 1997; Pennings, 1997; Shenfield and Steele, 1997; Wavell, 1997) and evidence from various studies in different countries (e.g. Brewaeys et al., 1993; Cook et al., 1995; Golombok et al., 1996; Brewaeys et al., 1997) indicates that most parents of donor insemination children do not intend to tell their child of the nature of their conception.
Various reasons have been advanced to explain parents’ reluctance to inform their children about their origins, including a desire to protect the donor, to protect the infertile/subfertile father, to protect family relationships and to protect the child (Daniels and Taylor, 1993; Cook et al., 1995; Brewaeys et al., 1997). For the purposes of the current debate, what is especially pertinent is the recognition of the potential influence on parents’ attitudes regarding disclosure of advice that might (or might not) be given by professional staff, lack of a ‘script’ for information sharing, and limited information about the donor that parents may share with their child(ren) (Cook et al., 1995; Brewaeys et al., 1997; Pennings, 1997).

Cook et al.’s recognition that: ‘DI parents were often conscious of the difficulty of providing an explanation in the absence of information about the donor’ (Cook et al., 1995, p. 555) reflects the dilemma faced by many parents of donor insemination children in the absence of information about the donor:

‘Ideally I don’t want to lie to my child or deceive her by failing to tell her the whole truth. It doesn’t seem right for me to decide that she doesn’t need to know the truth about her conception. Yet, if I do tell her about it when she’s old enough to understand, it could be too upsetting for her. After all, she would never be able to trace the donor if she wanted to. Why cause problems unnecessarily?’ (father of donor insemination daughter, cited in Lasker and Borg, 1989, p. 173).

While the decision whether or not to tell their donor-conceived children about their origins rests with parents, the evidence suggests that those providing treatment services could do more to advance the cause of information-sharing. For example, Cook et al. (1995) adversely compare the position of donor insemination parents with adoptive parents, citing the value for the task of telling adoptees about their origins of children’s story books explaining adoption. However, none of the donor insemination parents in their study appeared to be aware of the existence of similar books for young donor offspring, which have been readily available since at least 1988 (see, for example, Paul, 1988; Schaffer, 1988; Infertility Research Trust, 1991; Gordon, 1992; Wickham, 1992; Schnitter, 1995). Similarly, there is nothing in UK legislation or procedures preventing treatment centres attempting to collect much more information from donors than is specified in the current HFEA Donor Information Form (91) 4, such as the comprehensive donor information that is required to be collected under the Australian State of Victoria’s Infertility Treatment Act 1995.

The views of donors and donor offspring have recently been added to this debate. Available evidence indicates a range of responses towards information sharing on the part of donors, including potential cultural variations. It also suggests that the way in which centres approach information sharing themselves can influence donor attitudes (e.g. Purdie et al., 1994; Cook and Golombok, 1995; Daniels et al., 1997).

While the tradition of secrecy in donor assisted conception has inevitably limited the potential contribution donor offspring have been able to make to the debate, a small number of donor offspring have begun to make known their views, invariably indicating a wish not to be deceived about their origins (see, for example, Turner 1993; Donor Conception Support Group of Australia Inc., 1997; Whipp, 1998).

Conclusion

While only part of the overall, complex, picture regarding information sharing [see Daniels and Taylor (1993) and accompanying papers for a fuller discussion], Cook et al. (1995) findings suggest that the cause of information sharing might be advanced by the increased availability to parents of information about the donor. The current study supports earlier ones (e.g. Purdie et al., 1992; Daniels et al., 1997) concerning centres’ variable experiences and success in encouraging donors to provide information about themselves.

The survey did not investigate in detail the processes used by those centres where obtaining further information from donors appeared relatively unproblematic. However, ideas generated by respondents about the nature of information to be collected, and the ways in which centres can encourage donors to provide such information, might themselves contribute markedly to attitudes concerning information sharing in donor assisted conception. Further exploration of potentially successful strategies which can be shared with others needs to be undertaken.

Assuming that, as presently intended, the information to be released to donor offspring will not identify the donor, it necessarily follows that the only information about the donor to which donor offspring will have access will be that recorded on HFEA Donor Information Form (91) 4. Further, in the absence of subsequent access to the donor to supplement or amend this information, information that is not recorded at the point of contact between the centre and the donor will be irretrievably lost. At present, the interests of donor offspring who may want information about their genetic origins are not best served by the existing variability in information-gathering processes.

References


HFEA donor information-sharing form


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