

Short Communication: Previous semen donors and their views regarding the sharing of information with offspring

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BACKGROUND: The UK government has decided to introduce, from 2005, rules that will allow donor-conceived persons to have access to identifying information concerning their donor. This has led to many concerns regarding future gamete donor recruitment. **METHODS:** Semen donors who had been recruited between 1988 and 2002 were invited to take part in a telephone interview. The interview sought these previous donors' views on issues associated with recruitment, attitudes regarding information sharing and views concerning the offspring. Responses regarding information sharing were compared with their views recorded at the time of recruitment. **RESULTS:** All 32 donors were recruited altruistically. Eighteen (56%) held the same views concerning the provision of identifying information as they did at the time of recruitment. Of those who had changed their views, eight (25%) expressed a willingness to be more open and four (12%) now wished to be anonymous having previously been unsure. Half of the donors would still have donated if they had been required to be identified to offspring, one-quarter would not have and one-quarter were undecided, although the majority of these said they may have donated under an open system. **CONCLUSION:** The study shows that it is possible to recruit identifiable donors at this clinic and this suggests that it may be possible for other clinics to do likewise.

Key words: assisted human reproduction/donor anonymity/donor recruitment/information sharing/semen donors

Introduction

On January 21, 2004, the Public Health Minister in the UK government announced that new rules would be initiated to allow people conceived from future sperm, oocyte and embryo donation to have access to greater information concerning their genetic origins. These rules will enable donor-conceived people to have access to the identifying and non-identifying information concerning their donor, once they have reached the age of 18 years. These provisions, which will come into force in April 2005, will not be retrospective.

A consultation process began in December 2001, when the Department of Health (2001) invited responses to its document, *Providing Information About Sperm, Egg and Embryo Donors*. Following the receipt of 237 submissions, the then Public Health Minister, Hazel Blears, announced to the 2003 Human Fertilisation and Embryology Authority annual conference the government's intention to introduce new rules concerning access to donor information (Blears, 2003). Recruitment of semen and oocyte donors has always been difficult (Blyth *et al.*, 2004; Novaes, 1998) and there has been considerable concern expressed that the new regulations

will make future gamete recruitment almost impossible. Dr Gillian Lockwood, Director of the Midland Fertility Clinic, was quoted as saying 'It is the opinion of most of the clinics that this will have quite significant consequences on reducing the supply of sperm and egg donors.' (Blakemore, 2004).

The arguments leading to this change in policy can be summarized as a growing concern for the interests, health and well-being of the children/adults conceived from gamete donation (Blank, 1998; Blyth *et al.*, 2004), the need to treat those conceived by donor gametes and embryos and those who have been adopted in the same way (Daniels, 2004b), and the need to consider the health and well-being of families who have received the assistance of donated gametes (Daniels, 2002, 2004a; Golombok *et al.*, 2004). There has also been a growing challenge to the protective and paternalistic stance adopted by professionals and policy makers regarding 'what is best' for patients (Haimes, 1998; Novaes, 1998).

These concerns do not seem to centre on the changes, but rather on the consequences of those changes. As a result, in January 2004 the current Public Health Minister announced that the next 6 months would be used to further research

and to engage with clinics and donors, prior to making any decision about the anonymity of future donors (Johnson, 2004).

Previous research on UK donor motivation highlights the link between methods of donor recruitment and the decision of donors to remain anonymous. For example, a study undertaken to assess the attitudes of potential donors (Lui *et al.*, 1995) found that the majority of respondents would not donate if their anonymity was not guaranteed. The majority of donors recruited were students within a system of recompense for travel expenses. Similarly, in a study by Cook and Golombok (1995), two-thirds of the donors participating in the survey stated that they would not donate semen if identifying information were to be released to offspring. Furthermore, the same number of donors indicated that they would not donate semen without payment. However, one-third of donors clearly stated that they would be willing to be identified to offspring and continue to donate. The average age of the participants in this study was 24 years, with 81% reported as single and 65% being students.

In a comparative study of semen providers from two UK clinics (Daniels *et al.*, 1996)—one in which no payment was made to donors and the second where a fee was paid to donors—contrasting views were documented to the questions of anonymity and identity release. Participants from both clinics were generally in favour of storing identifying information in a central register. However, 41% of donors from the first clinic—who were mainly married men with children of their own and with primarily altruistic motives—indicated that they were willing to continue donating if identifying information would be released to any resulting offspring. In contrast, donors (63%) from the second clinic—who were generally unmarried senior students and young professionals—were generally unwilling to provide semen under an identity release system. These studies question the view that anonymity is essential for the recruitment of semen donors by highlighting that particular recruitment strategies or policies of clinics for semen donation will attract donors with particular viewpoints.

This paper reports on one of the studies undertaken during that 6 month review period established by the Minister. This research was funded by the Department of Health. The research involved a follow-up study of men who had donated sperm at the Assisted Conception Unit of King's College Hospital (KCH), London, between 1988 and 2002. The donors' views regarding their willingness to be identified to offspring in the future had been recorded at the time of their recruitment. All donors at KCH are recruited altruistically, that is, without payment or reimbursement of expenses. The programme is different from most, if not all, other clinics in the UK because of its altruistic policies (National Health Service and private).

Materials and methods

Letters of invitation to participate in a telephone interview were sent to 77 of the 84 men who had given sperm for storage between 1988 and 2002 at KCH. Of the seven not sent letters, four were already

known to be lost to follow-up as a previous attempt had been made to contact them; one was not contacted for professional reasons; one had indicated that he wished for no further contact; and one was a known donor, who had moved overseas. To ensure confidentiality, the nature of the research and the reason they had been involved at KCH was not specified in the letter, but the letter was signed by the doctor who was in charge at the time of recruitment whom many had seen. The study was approved by the Ethics Committee of the Assisted Conception Unit at KCH.

Thirty-three replies (response rate 42.8%) were received and one of those said he did not wish to participate. All participants received the same semi-structured questionnaire seeking both quantitative and qualitative information by means of a telephone interview conducted by E.B. and M.C. of the research team. Content of the questionnaires was based on previous studies to ascertain donors' attitudes involving one or more of the authors (Daniels *et al.*, 1996; Lalos *et al.*, 2003).

Initial questions sought detailed demographic information (household composition at the time of donation; changes in household composition since donation; educational attainment; most recent/current employment; religion). Other topic areas explored in the interviews included: participants' reason(s) for becoming a donor; how they had learned of the need for semen donors; the partner's role in the decision to donate (where the participant had a partner at the time of donation); the degree to which participants had discussed their role as a donor with family, friends, acquaintances and any children; whether they had attempted to recruit other men as donors; their views on payment and reimbursement of expenses to donors; their views on making available any personal information about themselves to any offspring and what factors had been influential in their decision-making if they had changed their views since donation; their views on the potential implications of any change in UK legislation to remove donor anonymity and on the government's proposed Voluntary Contact Register. Donors' attitudes regarding possible identification at the time of donation were recorded at the clinic. Donors were also asked for their recollection of their thinking at the time of donation. There are some discrepancies between what was recorded at the clinic and what some participants remembered, and some who, when asked, were unable to remember. This will be explored in a further paper currently in preparation. All interviews were tape-recorded and transcribed. For the material reported in this paper, each of the two interviewers initially analysed the data from the interviews they conducted using a thematic analysis and then discussed their general themes. The data were subsequently re-examined to confirm the validity of these conclusions and, where appropriate, coded under more general categories. The substantive qualitative data are being analysed using NVivo software package for additional publications.

Results

Demographics

The age of donors at the time of donation ranged from 27 to 57 years (mean 40.3). More than three-quarters of the donors were living with a partner and children at the time of donation and just under three-quarters had higher education or professional qualifications. The holding of such qualifications is reflected in donors' current employment, which shows that again, just over three-quarters were in professional/associated professional and senior management positions. In comparison to household composition at the time of

Table I. Reasons for becoming a donor

Reason	<i>n</i>	%
General desire to help others	2	6.2
Specific desire to help others become parents	27	84.3
To expand own gene pool	3	9.3
Wanting others to share the joy of parenting/fortunate to have children	8	25
Felt they were good 'stock' to be a donor	5	15.6
Other	8	25

donating, most (22, 68.7%) were still in the same situation at the time of the interview. Seven of the 10 whose circumstances were no longer the same (21.8%) had changed due to children leaving home and the remaining three (9.37%) had had a change of partner. At the time of the telephone interview, 25 (78.1%) had children, the remaining seven (21.8%) having no children either before or since donating. All of the respondents donated exclusively to KCH.

Recruitment

Almost three-quarters of the donors (21, 65.6%) had become donors as a result of information via the media—television, radio, newspaper, magazine articles, and advertisements. Just under one-quarter (7, 21.8%) said that knowing someone who was infertile had been the factor leading them to approach KCH. One donor had been approached personally, i.e. to be a known donor.

Table I shows that the major motivating reason for becoming a donor was a desire to help others become parents and therefore be able to share the joy of parenting. Amongst the 'other' reasons given, there was a heavy emphasis on feeling needed/valued. More than one reason was offered by some respondents.

Of the 32 donors, five (15.6%) did not have a partner at the time of donation. Of those who did have a partner, the role of the partner in the decision to donate was described by nine (28.1%) as being significant, nine (28.1%) said that it was not significant, and seven (21.8%) stated that it was of no influence. Two respondents (6.2%) did not tell their partners, and seven (21.8%) stated that it was of no influence. This included one who could not remember. Overall, respondents felt that all the existing means of recruiting donors should continue to be used and expanded. Eight (25%) donors suggested that there should be more coverage of success stories in the media, and nine (28.1%) had suggestions for making the practical arrangements for donating easier. Several donors in their general comments strongly suggested that donors should know the outcome of their donations, as this would be an aid to recruitment.

Six (18.7%) donors had attempted to recruit others to become donors, but none of these approaches had been successful.

Respondents were questioned whether they thought donors should be reimbursed for expenses that may be incurred. The majority of donors (26, 81.2%) believed that travel/subsistence expenses should be paid, while six (18.7%) thought that expenses should include loss of earnings. Six (18.7%)

rejected the idea of payment of expenses. Twenty-four donors (75%) stated that they did not believe there should be payment for semen donations, while five (15.6%) said there should be, and three (9.3%) were unsure.

Attitudes regarding information sharing

Prior to their first donation, participants' views on identity disclosure were recorded at KCH. Twelve (37.5%) of these respondents said that they would have been happy to agree to being identified at this stage, five (15.6%) stated that they were pleased to have the assurance of anonymity, and 14 (43.7%) were recorded as being unsure. One respondent donated to friends only.

When questioned how they felt about being identified to offspring now or at some stage in the future, 18 (56.25%) stated that they still felt the same and 12 (37.5%) indicated that they felt different. Of the 12 (37.5%) respondents who stated that they felt different, eight (25%) expressed willingness to be open and four (12.5%) stated that they wished to be anonymous. Two respondents did not answer this question, one knew that his sperm had not been used but said that he would move more towards being identified, and the other donated to friends only.

Of the eight (25%) who now expressed a willingness to be open, seven (21.8%) had previously been unsure and one wished to be anonymous. Of the four (12.5%) who now wished to be anonymous, three (9.3%) had previously been unsure and one willing to be identified.

The reasons given by respondents who had moved towards openness included the experience of bringing up their own children, getting older, media coverage, greater awareness of implications of contact for offspring and their needs in general, and general life experiences. Several respondents claimed that having their own children had influenced their thinking in relation to information sharing. Reasons given by those who had moved towards anonymity included legal concerns, offspring 'knocking on the door', and implications for donors' family. Respondents were asked about possible government action to remove the anonymity of donors in the future. Fifteen (46.8%) respondents felt that this may deter prospective donors, 14 (43.7%) stated that they would strongly support this action, and three (9.3%) thought that it might improve donor recruitment. Nine respondents suggested that such a move should be made explicit to prospective donors at the time of donation.

Sixteen (50%) of the respondents indicated that they would still have donated if they had been required to be willing to be identified to offspring, whereas eight (25%) stated that they would not, or probably would not, donate under these circumstances. Of the eight (25%) respondents who were undecided, six (18.7%) indicated that they may have donated under an open system, and two (6.2%) stated that this was a decision they would need to make jointly with their wives.

Among the multiple reasons offered by respondents to explain their willingness to be identified was the view that the offspring had the right to know ($n = 11$), and an awareness that some offspring may want to know the identity of

the donor ($n = 14$). Three respondents claimed to like the idea of possible contact if offspring wanted this. The themes that emerged to explain a desire for anonymity included a fear of being 'hassled' by offspring in the future, e.g. for money ($n = 5$). Four had no desire for any ongoing responsibility to offspring, two respondents expressed the view that involvement ceased with the donation itself, and one expressed a fear of having to provide a possible relationship for offspring in the future. Several respondents expressed concerns of the impact on their own families.

Respondents were asked to comment on the Government's proposal to establish a Voluntary Contact Register for donors and offspring. Twenty-five (78.1%) saw this as a good idea in principle. Seven indicated that it would be important to have the involvement of intermediary services. Two expressed the need for confidentiality, three highlighted the importance of family/partner agreement, and two indicated a potential need in themselves to trace offspring. In addition, at various points in the interview process, a number of respondents expressed a need for intermediary services where there was to be any contact.

In response to a specific question concerning their willingness to place their name on a Voluntary Contact Register, 19 (59.3%) said that they would, four (12.5%) said that they would not, three (9.3%) said that they would provide non-identifying information only, two (6.2%) were undecided, and four (12.5%) donors did not answer the question. The respondents were asked about information sharing with their immediate family: 25 (78.1%) said that they informed their partners, 12 (37.5%) had told selected family members, nine (28.1%) claimed to be totally open regarding their participation, six (18.7%) had informed only one family member, four (12.5%) had decided not to tell any family, and one was unsure whether or not he had told his mother or siblings. Of the respondents who had disclosed to family members, 28 (87.5%) reported no adverse reaction, three (9.3%) said that there had been some adverse reaction, for example, one stated that there had been disapproval on religious grounds. Respondents were asked whether or not donors should inform their partners and/or children. Sixteen (50%) said that partners and children (if any) should be informed at donation, five (15.6%) said that partners should be informed but not necessarily the children, four (12.5%) believed that partners should be informed and the children when they are old enough, and one stated that neither partner nor children should be informed. Five (15.6%) respondents commented that it is a personal decision and therefore generalizations cannot be made in this case, one said that he thought it should not be a secret, and one commented that the decision should be up to the individual donor.

The donor and the offspring

When the respondents were asked if they ever thought about their donor offspring, 27 (84.3%) answered yes. Although some respondents said no when asked the question directly, they subsequently went on to describe ways in which they had thought about offspring, so these later responses were included. Many of the men who stated that they had thought

about their donor offspring said that it tended to be quite fleeting and was not a dominating/consuming experience for them. Seven donors (21.8%) knew that no conceptions had occurred as a result of the donations, and, of these, two (6.2%) said that they had thought about possible children before they knew the outcome of the donation.

Twenty-one (65.6%) wondered if there had been any offspring and eight (25%) wondered how they were in general terms. Other reasons cited by respondents included whether they are happy in a family, what their personality is like, whether they are healthy and what it would be like to meet them.

All 32 respondents believed that for those who know that they were conceived by donor insemination (DI), it might be important for them to have information concerning the donor. Eighteen (56.2%) felt this was important so that offspring could meet their identity needs, 16 (50%) felt that this was important to meet curiosity needs, eight (25%) thought that it was important for up to date medical information, six (18.7%) felt that it would help to cope with troubled emotional reactions to not knowing and three (9.3%) said that it is a modern trend to want to know biological parents.

Sixteen (50%) of the respondents felt that parents should inform the offspring that they were conceived as the result of DI. One said that parents should not inform, and one was undecided. Fourteen stated that it should be the parents' decision, with some indicating that they would or would not inform the offspring if they were parents. Twenty-seven (84.3%) respondents emphasized the importance of offspring being able to have contact with the donor either directly or by indirect means. Fourteen (43.7%) respondents felt that secrets are harmful/damaging to family well-being and a further seven (21.8%) stated that a family should not have secrets. Eight (25%) felt that secrets do not necessarily have to be harmful and several respondents expressed their concerns about accidental disclosure.

Discussion

At the time that this research was undertaken, the UK government was considering the position that it would adopt in relation to donor-conceived offspring having access to the identity of their donor once they had reached the age of 18 years. Having commissioned research and undertaken further consultation, the government has now made its decision to remove anonymity from 2005. In the lead up to that decision, and subsequent to it, there has been considerable concern expressed regarding the implications of such a development on donor recruitment. The results of this study show that it has been possible to recruit semen donors at KCH who are prepared to be identified to their offspring in the future. Over half (56.3%) of the respondents in the study indicated that they would still donate if they were required now or at some stage in the future to be identified to offspring. Eight respondents (25%) said that they would not or probably would not donate, and four (12.5%) were undecided. Of the four who were undecided, two (6.3%) indicated that they would need to consult with their families. This is in sharp contrast to

the other UK studies (Chauhan *et al.*, 1988; Golombok and Cook, 1994; Cook and Golombok, 1995; Lui *et al.*, 1995; Murray and Golombok, 2000). The Assisted Conception Unit at KCH has had a long-standing policy of offering relatively generous amounts of time to potential donors to discuss and explore their decision. Together with, and reinforced by, its policy of only accepting altruistic donations, this may be a significant factor in the views of the men who became donors and who took part in this study. Not all donors were willing to be identified but the majority were. KCH could be said to be 'ahead of its time' in terms of its approach. It may be that the differing results between this and other studies is a reflection of the recruitment policy and practices adopted by clinics.

One other UK study (Daniels *et al.*, 1996) which compared donors at KCH with donors from another clinic highlighted some important demographic differences between the donors in the two clinics. These differences seemed to be related to their views concerning willingness to be identified in the future. Some of the differences between the respondents in this present study and those in other studies may be accounted for by these demographic factors. Donors in this present study were older, more likely to be married, and had children of their own. Their reasons for donating were primarily altruistic (there was no monetary recompense, either payment or expenses).

A feature of this study was that the views expressed when first becoming a donor were able to be revisited in the light of current thinking and experience. Most studies present the views of current donors (Cook and Golombok, 1995; Lui *et al.*, 1995). This study is unique in that it provides evidence that over time more than one-third of these donors have reflected on their donation and that this reflection has led to a change in thinking. This is examined in a paper currently in preparation. Most of the arguments currently being presented regarding a decline in the availability of donors cite research that focuses on current donors only. The evidence from this study suggests that a longer-term view of donor attitudes regarding information sharing may be helpful. This is particularly significant given that the offspring will only be able to access the identity of the donor at the age of 18 years.

All of the donors whose semen had been used for treatment indicated that they thought about the offspring that would have resulted from their donation. For many of these it was a passing thought and was certainly not something that was dominating or consuming factor. In all, 21 (65.6 %) wondered if they had had any offspring and eight (25%) wondered about them in general terms. Their interest lay in knowing whether the offspring were in a happy family, what their personalities were like and whether they were healthy.

All 32 respondents believed that it might be important for the donor offspring, if they knew of their conception, to have access to information concerning the donor, and this is in line with the studies by Turner and Coyle (2000) and Hunter *et al.* (2000). Twenty-seven respondents (84.3 %) felt that it would be important for offspring to have contact with the donor either directly or by indirect means. There was also concern about family well-being in that 21 of the 32

respondents (65.5%) believed that secrets in families could be harmful and damaging. This is something that has been highlighted by Daniels (2002), Daniels, 2004a) in terms of the family-building approach. In terms of the use of donors, 75% of respondents supported the establishment of a voluntary register/contact system, and 19 (59.3%) indicated that they were prepared to place their names on such a list.

The government has now announced the establishment of UK DonorLink which will provide such an opportunity for donors and offspring to make contact. This organization was formally launched in April 2004.

The experience at KCH is important in terms of the consideration of new recruitment strategies following government legislation. No information is available on the costs of recruiting different kinds of donors nor of the level of effort that is involved, and therefore it is not possible to make any comparisons with other clinics. We would suggest, however, that recruitment of donors who are prepared to be identified in the future will require more effort in terms of counselling time and will certainly be challenging in terms of finding innovative ways of reaching out to groups of men who have demographic characteristics similar to those taking part in this study.

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