



!

" # \$! %
&% % ' !! (
)

\$: %! !

" : !

4 0
7 !
;
9 /

4
7
;
9

94
97
9;
99
98
95 #
9E
9G \$

9
8
E
F
44
49
48
45

8 !!
5
E : H ! %

4E
77
79

1. Background

Within the UK, approximately 25,000 children have been born using donated gametes (eggs and sperm) or embryos since 1991. However, research exploring public attitudes to new reproductive technologies (NRTs) and third party assisted conception in particular, is limited and has largely focused on the experiences of (mostly white, middle class) individuals and couples who are users of NRTs or on the motives of (mostly white) egg and sperm donors. There is a small body of work which explores 'lay' or 'public' perceptions of third party assisted conception more generally. This reveals a general consensus that technological 'help', including treatments which use donated genetic material, should be offered to couples so that they can become parents (Kazem et al 1995; Edwards 1998; Kailasam, Sykes & Jenkins 2001).

As far as minority ethnic communities in the UK are concerned, there is evidence to suggest that British South Asian communities may differ from white communities in the meanings which are attached to the experience of childlessness. Such differences may also influence ideas about the acceptability and appropriateness of infertility treatments (Culley et al 2006). The ways in which infertility and infertility treatments are publicly understood is likely to have an impact of the experiences of childless couples and those seeking treatment (Miall 1994). It is important, therefore, to have some understanding of how communities perceive gamete donation.

An additional important aspect of the context of this study is the current acute shortage of gamete donors, especially egg donors, from 'non-white' ethnic groups (Golombok & Murray 1999). This has been exacerbated by the ending of donor anonymity from April 2005 (HFEA 2006). South Asian couples, therefore, face very long waiting times for treatment. A project which explores the views of members of South Asian communities is therefore very timely.¹

2. Aims

The study aimed to: examine the public understandings of gamete donation amongst British South Asian communities and to explore issues regarding the willingness of South Asian women and men to consider donating or receiving gametes through altruistic or other means.

3. Methods

In order to ensure that the project was as inclusive as possible, a team of bi-lingual community facilitators were recruited to work with the core research team. The facilitators, all of whom have previous research experience and are trained interpreters, were given additional training on using the focus group method and on the substantive topic. The facilitators were members of a research advisory group and were involved in organising and hosting the engagement event. The study was approved by the Faculty of Health and Life Sciences Human Research Ethics Committee at De Montfort University and adhered to the British Sociological Association Ethical Code of Conduct for researchers.²

3.1. Literature review

An extensive review of the published academic literature on public perceptions of gamete donation was carried out as part of this study. The team also collected UK published Asian (English language) newspaper and magazine items which discussed gamete donation. The results of the academic literature review are to be published in the journal *Public Understanding of Science*.

3.2 Focus groups and interviews

Fourteen single sex focus groups with a total of 100 participants of Indian, Pakistani and Bangladeshi origin were conducted.

Bangladeshi

designed to elicit their views on the 'community' discourses surrounding gamete donation. The guide for the focus groups was developed in consultation with the facilitators and an advisory group which included user representatives, academics, members of South Asian communities, counsellors and clinicians. 'Vignettes' were used in the focus groups in order to give people some information about gamete donation, to 'depersonalise' the issue, and to generate discussion through a consideration of the stories. The vignettes were developed in partnership with infertility counsellors drawing from their practice experience. Five of the groups were conducted by facilitators in South Asian languages (two in Punjabi, two in Bengali [Sylheti dialect] and one in Urdu), and nine groups were conducted in English by two members of the core research team. The participants were asked about the importance of children, their attitudes to fertility treatment and in particular how they felt people in their own communities would respond to a number of issues concerning the use of donated eggs and sperm and willingness to act as donors of eggs and sperm in a number of different contexts. The participants also discussed issues of disclosure to children, how they felt about donor anonymity, and the payment of donors. In addition to the focus groups, semi-structured interviews were conducted with 20 key informants including: practitioners (4), counsellors (1), support group and user organisation representatives (7), and community representatives (8) to provide additional context to the focus group discussions.

3.3 Community Engagement Event

The team also held a highly successful community engagement event: 'Making Parents: Infertility Awareness and South Asian Communities' at a South Asian community centre in the city of Leicester in March 2006. Attendees included members of South Asian communities, as well as representatives of the following organisations: British Fertility Society, British Infertility Counselling Association, Infertility Network UK, National Gamete Donation Trust, Donor Conception Network, Human Fertilisation and Embryology Authority, Afiya Trust, ACeBabes, Daisy Network, Ujala Resource Centre Leicester, Eastern Leicester Primary Care Trust, Leicester Centre for Ethnic Health Research, and the Leicester Adoption Agency. In addition to presentations on infertility and its treatment from clinicians and support groups, the team presented preliminary findings from the study for discussion amongst participants, and generated feedback and further data from a series of small group discussions.

4. Findings

This section gives a brief summary of key findings, drawing mainly on the focus group data. It is important to point out that the complex, sophisticated and often ambivalent and contradictory views expressed by the same participants, sometimes within the same focus group, represent shifting 'opinions' and views which depend on the specific question being addressed and the specific vantage point from which rTd (g)Tijj 6.06254 0 Ttd ((e)Tijj 4429138 20116

marriage so that no one points a finger at me and has any doubt that I am a man or not. It's a question of proving my manhood.

Infertility is however, seen as something amenable to medical treatment, though few participants had knowledge of treatments beyond a general

genetic link to his children. This was seen as less important in the case of women. As this Bangladeshi woman argued

I think, in tradition, whether a child has his mother's characteristics doesn't matter much, but it, he, the child, has to have the father's characteristics. And father's side family characteristics.

Both men and women stressed the fact that in the case of donated eggs, the man would maintain a genetic link and the female would establish a form of connection to the child through the process of pregnancy and birth. In this way, the use of donated eggs was less threatening to the status quo. Women would be able to 'cope' with the fact of having their own gametes substituted, since they would carry the pregnancy, 'nurture' the foetus and thereby generate a 'biological' link between mother and child.

With a woman, at least she's carrying it for nine months, she's nurturing it...you know, in her stomach, so she's got that bond. (Indian woman)

I think once, once you're sort of pregnant and carrying the child, you just think of it as your own baby, yours and your husband's regardless of how it got there, whether it came from the donor. But, you just tend to think of it as your baby and once it's born, it's your baby. (Indian woman)

Women in particular, also felt that South Asian men might have great difficulty on an emotional level, in accepting a non-biologically related child, whereas women were regarded as more nurturing and able to bond with a child to which they had given birth, despite its genetic origins. Several participants suggested that the man could potentially reject the child if he had not played what was perceived as a central role in its creation. One man of Indian origin commented

I think the father may react to the child in a different way. He would think that this child is not conceived by his sperm, so he would keep some distance with this child. Whereas the mother, will not, because she would have gone through all natural processes by keeping the child in her womb for nine months and all that.

It was felt that when going through the inevitably difficult circumstances of raising a child, the man might begin to resent the donor-conceived child when the 'going got tough'. Some participants drew analogies with adoption and with step-children. As this woman of Indian origin explained:

It's easier for women to accept children, rather than vice versa. For men to accept [step-children], it's much, much harder.

It was also felt that for South Asian men, the use of donated sperm would represent an affront to their masculinity and would have the effect of revealing a basic and highly stigmatising 'defect'. This also has implications for potential disclosure of treatment, which are discussed below.

4.3 Choosing donors and choosing gametes

Most participants felt that it was important to 'match' the donor with the characteristics of the recipient family. In many cases, this was expressed in terms of the importance of a physical resemblance. However, many people also stressed the importance of cultural connections and ethnic identities, which they perceived could be carried in the donor eggs or sperm especially. So for some participants, especially older ones, it was important that parents could 'relate' to a donor through shared cultural heritage. The Muslim and Hindu participants particularly, felt that the donor should be from the same cultural and especially religious background as the recipient family. As this man of Bangladeshi (Muslim) origin expressed it:

My community, colour, lifestyle. He will have a history, same as my family.

Muslim women too, expressed a similar view,

If you're Muslim, you'd want a Muslim background, because you just don't want anybody.

A minority of participants also felt, however, that eggs from a 'white' donor might also be acceptable to childless couples, and that this option should be offered. It was pointed

If your relationship [with the family donor] breaks down, then they can be really bad to you, and it could become like 'that's my child, give it here – I've changed my mind'.

In discussing family donation more generally, people referred to the practice of 'informal fostering or informal adoption' whereby children are 'shared' within South Asian families, as a relatively common (historically at least) 'solution' to childlessness (see later). These analogies were made to both support the idea of family donation, and also to point out the potential problems.

4.4 Disclosure and the management of information

Participants discussed whether or not a South Asian couple using donated eggs or sperm would be likely to share this fact with the family, the community and whether or not they would or should disclose to any ensuing offspring the fact that they had been conceived in this way. The debates here, as in much of the research, were complex, ambivalent and often contradictory, representing the complex ethical and practical issues involved in such decisions (Becker 2002).

People discussed the risks of secrecy and the dangers of disclosure of treatment; the risks and benefits in telling offspring about their conception, and the advantages and disadvantages of identifying donors, including the pros and cons of using family donors.

Most participants suggested that a couple would be highly unlikely to reveal the use of donated gametes if at all possible. Few people felt that a couple would be open about the nature of the treatment, and many felt that it might not even be disclosed within the family. It was felt that knowledge of the use of such treatment could lead to problems for the couple in the wider community and considerable stigma for the child concerned, raising difficulties for marriage prospects, for example. It was felt, by some that the child would be discriminated against and potentially ostracised. This was most forcefully expressed by the Pakistani and Bangladeshi participants.

This is not an issue that can be broadcast. I think the majority will take it negatively. Best thing is to keep it secret. (Bangladeshi man)

Recent policy changes promote a culture of ‘openness’ in third party assisted conception (HFEA 2004). However, our findings suggest that there may be different approaches to, and consequences of, disclosure in different cultural/religious contexts and it is important that professionals acknowledge the socio-cultural context of users.

417103Tj(e)Tj1.60035410 Td (f)Tj3.5854 /R3121 90 7 3.24191 0 Td (i)Tj21.01291 0 Td D

4577864519 Td ((e)Tj6.0034 0aTd (e)Tj 5.28312 0

guaranteed never to meet any child born as a result of the donation. However, for many the possibility of an offspring 'turning up' at some future point in time was regarded as too emotionally difficult as well as being potentially highly disruptive to existing personal and social relations. They were therefore concerned about the ending of donor anonymity. Whilst some initially commented that they would consider egg donation as an altruistic act, to relieve the suffering

4.6 A

4.7 Religion and gamete donation

Religion was significant in the st

imperative and third party donation is seen to confuse issues of kinship, descent and inheritance and effectively destroy a child's lineage. Sperm donation is regarded as zina (adultery) (Inhorn 2005) and a child born by forbidden methods is a laqith, an illegitimate child.³

For Muslim women and men, new reproductive technologies are framed within a discourse of risk which is primarily interpreted through their existing value and belief systems in which Islam plays a key role. The groups with Hindu and Sikh participants were marked by the absence of a religious discourse, with few participants reporting any specifically religious objections to either receiving or donating gametes. It is also important to note, however, that there is a difference between official representations of religious ideas, and the experience of religion as 'lived'. It would be incorrect to assume that someone who identifies themselves as Muslim would not wish to consider using donated gametes in treatment, or donating gametes for the use of others.

This study highlights the importance for some communities, of locating knowledge in relation to understandings of religious teachings. An understanding of the religious context of gamete donation is significant for infertility clinicians, counsellors and support groups. Infertility counsellors and groups who support the process of disclosure, such as Donor Conception Network, need to consider the provision of culturally sensitive support to families in making decisions about sharing information.

4.8 Public profile of gamete donation

The need for gamete donors has a low public profile in South Asian communities. None of our participants had seen any request for donors and few were aware of the processes involved in becoming a donor. This was especially acute in the case of egg donation. None of our participants had ever been made aware that there was a shortage of donors from minority ethnic communities, despite a recent national publicity campaign. Equally, few people were aware or had seen any information about the removal of anonymity or payment of donors.

There was no clear consensus on the issue of whether or not donors should be paid. Several men in particular, felt that a financial incentive should be offered and that this

would increase the number of potential donors coming forward. As this Indian man commented

It depends on the market as well. If you get a lot of response, then you would not think of paying for it. But if there are not many donors available to meet demand, then you will have to pay.

Most of those who expressed an

The culturally and religiously specific ways in which some members of South Asian communities perceive gamete donation have been demonstrated. This study highlights the importance of locating knowledge in relation to understandings of cultural practices. An understanding of the religious and broader cultural context of gamete donation is significant for infertility clinicians, counsellors and support groups.

Given a strong desire for children, infertile couples and individuals from South Asian communities may wish to access this form of infertility treatment and it is important that service providers are aware of the broader cultural context of family and gender relationships. The research suggests that despite many reservations, the degree of stigma attached to childlessness will lead some infertile couples to use third party assisted conception, although they may face many dilemmas in doing so. Less concern generally was expressed about the use of donated eggs than donated sperm. There was extensive discussion of the dilemmas and difficulties in the management of information in particular. Disclosure of treatment and disclosure of donation were regarded by most participants as highly risky actions and the pros and cons of disclosure were widely debated.

The study also suggests that recruitment of egg donors from South Asian communities may remain challenging, especially following the ending of donor anonymity. Although acting as an egg donor was viewed as a highly altruistic act, and several women expressed their admiration for women who gave such a 'gift', it was nevertheless seen as involving a number of serious and long-term emotional and relational risks, which many felt would deter potential donors. There is evidence, however, that some men may be prepared to become altruistic sperm donors. Men were slightly less concerned than women about the possibility of being contacted by offspring in the future. Women are perhaps more likely to donate within the family, though here too many concerns were raised about this practice and the findings underline the importance of making sure that culturally sensitive counselling is available to women who are considering this.

The findings reported here should not be regarded as representing an essential and fixed 'South Asian perspective' on gamete donation, but as offering some potentially important aspects of how the specific participants in this study explored this issue interactively, at a

particular point in time. It is also important to point out that although the study has demonstrated some culturally specific ways of framing considerations of gamete donation, there are many similarities with the way in which concerns have been expressed by 'white' populations. Other studies have identified concerns about possible incest, disruption of family relationships and 'parental' responsibilities of donors (Hirsch 1999, Edwards 1999) and concerns relating to donor anonymity and payment (Lui & Weaver 1996, Westlander et al 1998, Lyall et al 1998) which are not dissimilar to those raised by the participants in this study.⁵

Recommendations

The public profile of gamete donation needs to be raised so that a dialogue can effectively take place between stakeholder groups. For those who wish to encourage altruistic gamete donation, particular efforts are required to inform South Asian communities about the need for donors and to actively engage with communities. Efforts need to be made to include those who are often excluded from mainstream publicity activities. All engagement materials should be culturally inclusive and it is essential that community members are involved in the design of any intervention.

Infertility service providers should consider the potential additional concerns about the process of using donated gametes which South Asian men and women might have, especially in relation to decisions to use family donors; decisions to disclose treatment and decisions to inform children of the means of their conception. Counsellors have an important role to play in this process and infertility counsellors need to ensure that they are working in a culturally sensitive way.

Organisations which offer general support to families undergoing fertility treatment, and those which support disclosure to offspring such as Donor Conception Network need to provide culturally informed and sensitive support.

Notes

1. Data from the 2001 census shows that there are 2.3 million of South Asian (Indian, Pakistani, Bangladeshi and 'Other Asian') origin in the UK. This represents 4% of the total population of England and Wales.
2. <http://www.britsoc.co.uk>.
3. Formal legal adoption, as it is known in the West is also not tolerated for similar reasons, although the fostering of needy children is encouraged in Islamic scriptures. The position in the Shi'a branch of Islam is less certain, with some evidence of a tolerance of gamete donation, surrogacy and adoption as legitimate ways to 'save infertile marriages' (Inhorn 2005).
4. The research team have produced a strategy for raising the profile of gamete donation in minority ethnic communities which is attached as an appendix.
5. For an overview of the research literature on 'public' perceptions of gamete donation see Hudson et al. (forthcoming).

Appendix

? # & # ! # 0 % ! ! *



Appendix

! ' "

! |

* " | | ! #

* | ! ? &

& # # # \$: " # # # @

: ! # 0 \$ / !) ! !! ' "

#

*

