



Public Perceptions of Gamete Donation in British South Asian Communities

Executive Summary

Dr. Lorraine Culley
Nicky Hudson

De Montfort University, Leicester.



Acknowledgements

This study was funded by the Economic and Social Research Council's Science in Society Programme*

We would like to thank all the participants who willingly shared their views with us.

Research Team:

Dr. Lorraine Culley (Principal Investigator)

Nicky Hudson

Professor Mark Johnson

Mary Seacole Research Centre, De Montfort University, Leicester

Dr. Frances Rapport, *University of Wales Swansea*

Dr. Adi Bharadwaj, *University of Edinburgh*

*Grant ref: RES-160-25-0044.

Faculty of Health and Life Sciences, De Montfort University,
Leicester 2006

Public Perceptions of Gamete Donation in British South Asian Communities

Executive Summary

Aim

To examine the public understandings of gamete donation amongst British South Asian communities.

Methods

Single gender focus groups (10 female, 4 male) with people of Indian, Pakistani and Bangladeshi origin in 3 cities (n=100); interviews with 20 key informants; community engagement event.

Key Findings

Using donated sperm and eggs:

- ❑ There was a general acceptance of IVF to treat infertility with the couples' own gametes. However, third party assisted conception was seen to encompass many potential risks for the individuals and families who used donated gametes. Less concern was expressed about the use of donated eggs than the use of donated sperm. A genetic link with the father was considered important. Pregnancy and birth gave women an alternative bond with the child conceived via egg donation.
- ❑ Disclosure of treatment (including to offspring) and disclosure of donation were regarded by most participants as highly risky actions given a general social disapproval of third party assisted conception and most felt that treatment would not be disclosed. However, many participants felt that the child had a 'right' to know about the nature of his or her conception and that 'accidental' disclosure could be damaging.
- ❑ Discussions with Muslim participants demonstrated a significant concern for the religious acceptability of gamete donation. A variety of views were expressed, but most were of the opinion that the third party assisted conception was not permissible in Islam. No religious objections were discussed by Hindu or Sikh participants.

Donating sperm and eggs:

- ❑ There is a low public profile of gamete donation in South Asian communities. Very few participants were aware of a shortage of donors.
- ❑ Donation was viewed as a highly altruistic act, and many could see the necessity and advantages of using donated gametes for couples facing the stigma of infertility.
- ❑ Many women felt that they would maintain an emotional interest in the donated egg, which could cause them problems on a long term basis. Women were not generally deterred by the physical aspects of egg donation.

- ❑ Intra-family or ‘known’ donation raises many important ethical issues, and the research suggests a degree of ambivalence around this, for women especially. Several women suggested that they would consider donating to help family members, but would need to discuss the potential implications. Some counsellors, clinicians and community representatives expressed some concerns about the possibility of social pressure on women to act as family donors.
- ❑ Men were less concerned with potential emotional problems of donation, but some expressed concerns about possible economic consequences or implications for inheritance.
- ❑ The removal of donor anonymity was troubling to many (especially women), who were concerned by what they saw as the prospect of a child ‘turning up’ on their doorstep. This possibility was viewed as a major disincentive for egg donors especially, since women are perhaps more vulnerable than men to social stigma and ostracism for apparently transgressing cultural norms. However, a small number of male participants were willing to consider donation even in the context of the ending of anonymity.
- ❑ There was no clear consensus on the issue of whether or not donors should be paid.

Key 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.
- ❑ Additional and more inclusive public consultation by the HFEA and other relevant bodies on this and related issues is needed. Consultation techniques need to be more proactive, using alternatives to “traditional” public consultation methods. Focus groups and citizens juries could be organised in collaboration with a range of community based groups and used in place of, or alongside, existing methods of consultation.

For a copy of the full report of this research, please contact:

Nicky Hudson
Research Fellow
Faculty of Health and Life Sciences
De Montfort University
The Gateway
Leicester
LE1 9BH

T: 0116 2078766

E: nhudson@dmu.ac.uk