

## Negotiating boundaries: Accessing donor gametes in India

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### Abstract

*Background:* This paper documents how couples and providers access donor materials for conception in the Indian context and perceptions about using them. The objective is to facilitate understanding of critical issues and relevant concerns.

*Methods:* A postal survey was conducted with a sample of 6000 gynaecologists and in-depth interviews were conducted with 39 gynaecologists in four cities.

*Results:* Donor gametes are relatively more acceptable than a few years ago, especially if confidentiality can be maintained, though lack of availability of donor materials is sometimes an impediment to infertility treatment. Donor sperms are usually accessed from in-house or commercial sperm banks, pathology laboratories, IVF centres, professional donors, relatives or friends. There is scepticism about screening procedures of sperm banks. Donor eggs are usually accessed from voluntary donors, friends, relatives, egg sharing programmes, donation from other patients, advertising and commercial donors. There are several concerns regarding informed consent for using donated gametes, using relatives and friends gametes, the unregulated use of gametes and embryos, record keeping and documentation, unethical and corrupt practices and commercialisation.

*Conclusion:* These issues need to be addressed by patients, providers and regulatory authorities by providing information, counselling, ensuring informed consent, addressing exploitation and commercialisation, ensuring monitoring, proper documentation and transparency.

*Key words:* Infertility, India, donor, gametes, assisted reproductive technologies, ART.

### Introduction

The 'mothering role' of women is seen to be central in many traditional societies, including in India where there seems to be no space for infertile couples as part of the governing definition of the family. The system of patriarchal descent, patrilocal residence, property inheritance, lineage and caste are responsible for the extreme importance given to fertility in Indian society. Childlessness is a life crisis for many couples, with many visible and invisible losses. Infertility affects more than 80 million people worldwide (Daar and Merali, 2002). In India the estimates of primary and secondary infertility are 3% and 8%, but expected to be higher as this evidence is dated (WHO, 1980). Infertility affects women's identity, status and security and they experience

stigmatisation, isolation and powerlessness. Childless women are more vulnerable to blame, mental and physical violence, threats of abandonment, divorce and social exclusion (Singh, Dhaliwal and Kaur, 1996). They are under psychological, familial and community pressure to have their own biological child (Singh and Dhaliwal, 1993; Widge, 2001). They seek treatment, including assisted reproductive technologies (ARTs), if affordable. Adoption is not popular though some couples grudgingly adopted before ARTs were introduced (Bharadwaj, 2003). Surrogacy is still uncommon in India, though some couples are using this option nowadays.

The first scientifically documented IVF baby was born in India in 1986 which heralded the growth of ARTs, mostly in the private sector. Treatments are expensive, the sector is highly commercialised and

the market thrives on couples' desperation to have their own 'biological' child. ARTs could involve the use of donated gametes and couples may have to use donated sperm, eggs or embryos to facilitate reproduction. This paper focuses on how couples and providers access donor materials for conception in the Indian context and perceptions about using them. Specifically it focuses on general concerns about using donated gametes, how they are accessed, informed consent, costs, concerns of providers and couples, ethical dilemmas and unethical practices. It originates from a study inspired by earlier research that explored women's experiences of childlessness and ARTs in India (Widge, 2001). As these issues have been mostly addressed by the media in India, this paper is an initial step in the exploration and documentation of these issues and could facilitate our understanding of critical issues and relevant concerns.

Gamete and embryo donation is a sensitive subject especially in societies where extreme social and cultural importance is given to genetically related children (Kirkman, 2008). Health professionals and regulatory bodies are important collaborators in this venture to address ethical aspects and other concerns. The issues that have been debated till date globally are socio-psychological responses and attitudes of recipients and donors, donor anonymity, payment to donors, commercialisation of gametes and embryos, proper recruitment and screening of donors, quality of the gametes and limiting the use of donors to reduce the risk of consanguinity. Some other issues have also included assessment and screening of recipients, avoidance of transmission of genetic diseases to the recipients and offspring, the information given to and welfare of the future child, informed consent, conflicts of interests between the various actors and appropriate regulatory mechanisms (ESHRE, 2002; Dickens, 2002). Recently the United Kingdom's HFEA scheme on payment for egg sharing for stem cell research has raised concerns among clinicians and activists (Roberts and Throsby, 2008).

Ideally couples would like to have their own biological child but sometimes it is not possible to have a completely genetically linked child and patients have to accept a partial genetic link or a gestational link (Halman *et al.*, 1992). Couples also have to deal with a shortage of gametes in most societies but providers and patients find ways to overcome this shortage (Fathalla, 2002).

In some societies religion and law prevent couples from using donated gametes but in many they are ethically and legally accepted and in some the restrictions are ignored in the desperation to have a child (Borrero, 2002; Inhorn, 2002). Some couples

travel abroad to access donor gametes and ARTs that are not accessible in their own, for legal or other reasons (Dickens, 2008). It is broadly understood that gamete and embryo donation are safe, cost effective and beneficial for infertile couples. But their use has given rise to contentious issues and an understanding of the science, guidelines, ethical and legal and social implications of these procedures is required for them to be used safely and effectively (Borrero, 2002). So far it has been difficult to find an international consensus on how to deal with these issues as there are social, cultural, religious differences, but each society needs to develop and implement its own statutes.

#### *a) Sperm donation*

The majority of sperm donors are men between the ages of 18-40 who donate anonymously or are known donors either altruistically or for a financial incentive (HFEA, 2007). Some donors donate at different sperm banks or via the internet but there are concerns that using the same donor sperm may lead to recessive, disease-causing genes and unrealised consanguinity. Known sperm donors donate to relatives and friends. The laws regarding sperm donation vary in different countries. Sperm donors and recipients are usually anonymous to each other. However, a recipient may receive non-identifying details about the donor such as height, weight, hair colour and education. Recipients have concerns regarding physical attributes, health status, education, occupation, family background and interests of donors (Purdie, 1992). Recently the law in certain countries has given rights to people conceived through sperm donation to access varying levels of information about their biological father, after a certain age. The morality and ethics of sperm donation has caused much heated debate but despite these issues, sperm donation has been acceptable because it enables couples to have children. There are shortages of sperm donors and banks struggle to access donors (National Gamete Donation Trust, 2008). Shortages have led to men offering free sperm on the internet (which not recommended for health reasons and the possibility of exploitation, women going abroad and a smaller donor pool (Collier, 2010).

#### *b) Egg donation*

Egg and embryo donation has been used to treat infertility for a variety of conditions. Sources of donated oocytes include donations from infertile women usually between the ages of 25-35 years, already undergoing egg collection, altruistic donations from relatives or friends or commercial donations from non infertile women or from egg sharing

programmes in IVF clinics (Leeton *et al.*, 1986). Use of egg donors is regulated in many countries but the high demand for donors has led to waiting lists and shortages. The increased international demand for donor eggs has triggered a surge of egg donation and even international travel for fertility treatment (Storrow, 2005) and even mail order oocyte donation, which raises ethical issues of possible exploitation of underprivileged women (Heng, 2006). Egg donation is a cumbersome procedure and for some, it goes against socio-cultural norms. There are also cultural differences in the willingness to donate oocytes (Purewal and Akker, 2005). Payments to donors has been considered as ethically acceptable but there are arguments against payment that consider inequality, co modification and exploitation of donors (Steinbock, 2004; Shanley 2002).

### *c) The Indian context*

Using donated sperm in India is usually a matter of secrecy as couples do not want their infertility revealed and disturb the social and biological connection between the mother, father and child (Bharadwaj, 2003). It has been suggested that the use of donated gametes is taken lightly by the medical community and there are practices like sperm mixing, transplantation of embryos without consent or the discarding of embryos by mistake in India (Aquil, 2006). Donor sperm being used in artificial insemination and IVF without the couple's knowledge have also been reported (Srinivasan, 2004).

The Indian Council of Medical Research in its guidelines for regulation of ART clinics in India, states that no ART procedure will be done without the spouse's consent; use of sperm or eggs donated by a relative or known friend of either the wife or husband shall not be permitted; the ART clinic will be responsible to obtain sperm from appropriate banks and eggs and provide the couple with information on height, weight, skin colour, educational status, profession, family background, freedom from known diseases like Hepatitis B or AIDS, ethnic origin and the DNA fingerprint (if possible). They also state that semen mixing is not permitted; the ART clinic cannot be party to any commercial element in donor programmes or gestational surrogacy and that the child has the right to seek information about the genetic parent or surrogate when the child reaches the age of 18, but the donors identity will not be revealed until then. According to the Ministry of Health and Family Welfare, these guidelines have been formulated to protect patients as they believe that several ART clinics are functioning without adequate infrastructure to deliver these services and these services are 'highly questionable' (ICMR, 2005).

## **Methods**

This research was funded by grants from the Ford Foundation (India), UNFPA (India) and Soros Foundation and conducted with members of the Federation of Obstetricians and Gynaecological Societies of India (FOGSI), which is a large specialist organisation with 16,000 members. The research was approved by the ethics committees of the London School of Hygiene and Tropical Medicine and FOGSI in India and informed consent of all interviewees was obtained.

In the first phase a postal survey was conducted with a nationally representative sample of 6000 gynaecologists practicing in the public and private sectors randomly selected out of a list of all FOGSI members. The purpose was to explore the range of infertility services that are being offered in these sectors. The survey focussed on background information, services offered (including donor related), referrals for ARTs and adoption and impediments to effective infertility treatment. Despite reminders, the final response rate was 8% yielding 470 responses: 365 (78%) from the private sector, 55 (12%) from the public sector and 49 (10%) from those who practice in both. This was sufficient to sustain rudimentary statistical analysis, though obviously the achieved sample may not be representative. The data were analysed using SPSS, frequency tables were generated and tests of significance were conducted for some variables.

In the second phase, in-depth interviews were conducted with 39 providers (27 from the private and 12 from the public sector respectively) in two major cities (New Delhi and Mumbai) and two medium cities (Agra and Nashik) in India. These providers were randomly selected from those who responded to the survey and agreed to be interviewed. In-depth interviews were conducted and taped with informed consent and categories of responses were coded and analysed using thematic content analysis with the help of excel worksheets. Relationships between themes were then analysed. The interview guides focused on the following: patient related information; barriers to prompt care seeking for women/couples; quality of treatment; screening process; cost and affordability; patients information on infertility and information provided to patients; informed consent procedures; sex preference; strengths and weaknesses of ARTs and opinion of ART practitioners; reasons for rejection; success rates; coping strategies of patients; adoption and problems associated with infertility services. They also focussed on donor issues: access, screening, choices of donors, reasons for acceptance or rejection of donated materials, transactions between donor and recipient, third

party donation issues of concern, number of embryos transferred, use of spare embryos; access to and use of surrogates and perception of regulatory guidelines regarding donated materials. The paper focuses mainly on the information from the in-depth interviews on the above mentioned donor related issues.

## Results

A quarter of the providers surveyed said that they have a donor programme at their facilities. 68% of providers offered artificial insemination by husband at their clinics, less than 1% offered artificial insemination by donor, 19% offered oocyte donation, 23% have sperm banking facilities, less than 1% offer embryo donation and 12% allow surrogacy arrangements.

Most providers felt that donor gametes are acceptable to two thirds of the cases of those who need to use them. But acceptability is usually after counselling and reflection on the available options. 44% of the providers surveyed said that donor insemination was acceptable to their patients, whereas 37% felt that there was a negative attitude towards donor insemination. A quarter of the providers felt that lack of availability of donor materials was one of the impediments to infertility treatment.

### *a) Accessing donor sperm*

Most gynaecologists said that they access donor sperms from sperm banks or pathology laboratories, or ask their patients to access them directly and some collaborate with IVF centres to access them. A few providers were uncomfortable with patients accessing their own samples from a laboratory, a relative, friend or from anyone known to the patient though this was acceptable to some others. Most ART specialists said that they access their samples from commercial sperm banks or have their own banking facilities. Some allow patients to access their own donors or samples, some have access to professional donors and some use spare samples from current patients and/or from health workers in their facility.

Most providers were of the opinion that patients sometimes want their own family members to donate sperm. Many reported that they were approached by patients to use the father or brother-in-law's sperm because of caste, lineage and property concerns. This was usually unacceptable to providers as they felt it could create future inter-generational problems or confusions about parentage. Some felt that donor sperm of a distant relative, friend or brother was acceptable if they worked out a mutual arrangement between them. They expressed concern that some

providers are not apprehensive about using sperm from any source as there are no checks. Several providers reported the practice of using fresh or mixed semen and expressed concerns about the medical status of the donor and the quality of the sperm in such a context. They also reported that the repeated use of the same sperm donor in the same geographical area was a problem as it could have cross-genetic implications.

An ART specialist reported a case of what she called *ART incest* where the clinic was approached by a couple who had lost their son and wanted to use their daughter's eggs and the father's sperm to have a son. Besides genetic implications, she felt this would create major kinship dilemmas for the couple and the future child.

### *b) Sperm bank protocols*

Some providers were sceptical about protocols followed by sperm banks, quality of sperm samples and checks and audits. Some reported that screening procedures were adequate but those who were unsure about their protocols have their own sperm banks and prefer to conduct their own screening for general infections, biochemistry, family, sexual and drug history, allergy, thalassemia, HIV, Hepatitis B, and VDRL.

### *c) Accessing donor eggs*

Providers suggest that most couples access eggs from commercial donors (some providers have a donor list and the patients can choose on the basis of criteria such as colour, height etc.), voluntary donors (e.g. employees of the hospital or clinic), friends and/or relatives, through egg sharing programmes in IVF clinics, donation of spare eggs or embryos by patients and through advertising on the internet (one of the ART specialists has photographs and profiles of egg donors on his website). Some providers encourage patients to arrange their own donors. There are usually few voluntary anonymous donors. Some ART specialists expressed concerns about egg sharing as that may reduce chances for both the donating and recipient couple. There is a huge demand for eggs and supply is usually a problem as egg retrieval is a physically and medically complicated procedure. Commercial egg donation is a new concept in India, and some providers expressed concern about exploitation of such donors. Currently only few centres in major cities have access to such donors.

### *d) Use of spare embryos*

Most providers transfer three embryos and either cryo-preserve spare ones, discard them, use them for another couple or for research.



e) *Acceptance of donor gametes: relevant concerns*

Providers reported that couples' main apprehension about using donor sperm was the lack of a genetic link and the man's concern about his status in the joint family. A provider shared a case of a couple where the husband, even after agreeing to using donor sperm, abandoned his wife. Though most providers felt that there has been a change in attitude towards using donated gametes, especially if secrecy can be maintained, the use of donated materials is still perceived as socially unacceptable. Some felt that couples did not focus as much on caste and colour as before, in the desperation to have a child. But concerns are expressed about education, professional status, religion and medical history of the donor. One of the providers explained...

*....couples are so hardened by the process of going through infertility testing and treatment that they usually don't ask too many questions about the donated sample and they will be ready for donor eggs, donor semen, donor 'everything'.*

A few providers maintained that that donated materials are not accepted easily by uneducated and conservative patients and if they do, it is usually a time consuming process. There are some patients who prefer to remain childless or choose not to use donated materials due to religious concerns.

Concerns regarding donor eggs are fewer though patients are worried about religion, physical characteristics, background, family, medical history and some about caste. One of the ART providers offers information on seven criteria i.e. height, built of the patient, colour of eyes, colour of hair, blood group, social background and educational status. If recipients require more information they are provided with information about marital status, number of children and husband's status.

f) *Costs of gametes*

Most providers said that the cost for donor sperm range between Rs. 200-600 (5-15 USD) per sample but it has also been reported in the media that sperm donors receive up to Rs. 5000 (125 USD) and an egg donor between Rs. 10000-20000 (250-500 USD) per sample, which doctors disguise as travelling expenses (Dutta, 2002). Patients acquire sperm samples directly from the banks or pay the providers. If couples are willing to participate in the clinic's egg-sharing programme, the costs are reduced by Rs. 10000-20000 per IVF cycle for the woman who is donating the eggs. As egg donors are not easily available and commercial donors are few, most clinics encourage egg sharing. If donors are from the

family or friends, they make their own monetary arrangements, if any.

g) *Providers' perceptions about using gametes from relatives and friends*

More than half of the providers, who allow the use of donated material in their practice, felt that the recent guidelines by the ICMR that do not allow the use of relatives or friends gametes, were acceptable as the use of such materials may lead to problems within the families about paternity and property. A private provider shared her opinion.

*...I am not sure of using a friends sperm is acceptable as there could be problems later. A woman I know was deserted by her husband as he started living with the woman who had a child with his donated sperm.*

Some providers disagreed with the guidelines as they felt that lineage and shortage issues can be taken care of if relatives' sperm and/or eggs are used.

h) *Ethical dilemmas/unethical practices*

Most providers said that the use of relatives' sperm and secrecy about the use of donor sperm from either the husband, wife or the family, was an ethical dilemma in their practice. A provider expressed one such dilemma:

*I was approached by someone who wanted me to conduct the test on his friend as he was azoospermic, so that his in laws don't doubt his fertility.*

Some providers felt that the practice of using spare eggs and embryos without informed consent of couples and the use of untested fresh or mixed semen was unethical. They felt strongly that that ARTs may become a racket because of the unethical use of donated gametes. Recently subsidiary businesses supporting the ART industry have emerged, for e.g. consultants (who may not have clinical and practical knowledge), offering services to set up a gamut of infertility services including supply of technical personnel and professional donors (persn. comm. with provider).

i) *Other concerns*

In general, providers expressed concerns about the unregulated use of gametes, embryos and stem cells, lack of or incomplete informed consent, record keeping and documentation. Some providers allowed the free use of donor gametes irrespective of the guidelines. Most suggested a strong regulatory mechanism to monitor and discourage unethical practices, but some felt that providers should practice self-regulation. The need for a national law on sperm banking

was expressed and some disapproved of the guidelines regarding keeping DNA records for 40 years and access to donor information to the child after 18 years of age. They felt record-keeping is cumbersome and revealing the identity to the child maybe difficult in Indian society as children may find it socially unacceptable that they have two parents. Donors who have donated several times may find themselves in an awkward situation and donation of gametes may be reduced.

## Discussion

Most concerns with the use of donated gametes discussed in other contexts are emerging in India. Data from this study indicate that ICMR's guidelines are not being followed adequately as providers are guided by the desperate need of their patients and their demands, profit motives and the decreasing supply of gametes.

The boundaries between who is an acceptable child (biologically related or not) and who is an acceptable donor and what is morally and ethically acceptable seem to have blurred in the desperate need to have a child. Couples seem to have fewer concerns about using donated gametes and are less focused that before on issues of caste and colour. Having a child is relatively more important over donor gamete related complications and recipients are so overwhelmed by the current situation of childlessness that they are unable to think clearly about the personal and social consequences of their decisions. Providers objections regarding guidelines on anonymous gamete donors include consequences of shortage of gametes, commercialisation and corrupt practices. Though there are arguments for and against donor anonymity, they feel it is tempting to accept donor anonymity (Dickens, 2002; Pennings, 2000). It could be hard to judge whether known donors are motivated by pressure or financial motivation in the context of the commercialised and unregulated private health sector care in India where there is inadequate counselling and informed consent. On the other hand it has been argued that donor anonymity would lead to a vicious cycle of paid donation and result in the exploitation of donors and recipients in India (Dutta, 2002). In some countries new systems of recruiting gamete donors are being tried out like the mirror exchange system where the male partner donates sperm and is guaranteed a reduced waiting time for donor oocytes. This could also work the other way and may avoid ethical objections raised against other incentives to attract donors (Ferraretti *et al.*, 2006).

Regarding the use of relatives' gametes, there are arguments for and against it, about securing the

stability of the family, fear of the unknown origin of the genetic material versus creating complications of paternity, later rejection by a partner, accusations of adultery, and family tensions. In such a context there are many issues to consider (Nikolettos *et al.*, 2003; Frith, 2001; Marshall, 2002). Using the father-in-law's sperm could possibly create confusion in kinship structures and conflict within relationships and the family. Patients seem to be unaware of such consequences and sometimes may succeed in negotiating with providers they are usually focused on having a child. Besides there are issues of inequality in the family regarding gender and property or using a relatives' sperm in the present may result in the husband's rejection of a wife in the future or in accusations of adultery. But using a relative as a egg donor could be a positive option, for example, most women would feel comfortable using their sister's eggs. The issue is difficult to resolve and needs further exploration in the specific context of the family dynamics in India. Currently the situation requires that patients are provided with adequate counselling and made aware of consequences that may impinge on their or their future child's life.

The proper recruitment and screening of donors could avoid transmission of genetic diseases and HIV to recipients and offspring. Using low quality gametes are of concern as some sperm banks, and providers may not be following protocols. Practices of using fresh or mixed sperm have been reported, which are medically unacceptable. It has also been suggested that there is a semen racket in India as many banks do not have adequate facilities of preservation, screening and many do not follow WHO guidelines (Ghosh, 2006). Sufficient screening procedures minimise risks for the receiver and the offspring and need to be followed (Garrido, 2002). Recruitment and counselling of gamete donors has to be done in an open and transparent and informative manner. Unless guidelines are implemented with proper monitoring, these practices are likely to continue. Proper record keeping is key because of the repeated use of the same donor samples, as that increases the risk of consanguinity. Information provided to recipients about the donors may be misleading or inadequate and donor gametes could be used without informed consent of the wife and/or husband. Therefore it is critical that complete and transparent information is provided and informed consent of the involved parties is obtained.

## Conclusion

ARTs have the capacity to alter established family structures and bring to fore many emotional and ethical issues. The definition of the traditional family

has changed in many parts of the world and the boundaries are being expanded to include arrangements for parenting that are accompanied by complex social and ethical issues which need to be considered (Seibel, 1996). The above mentioned issues need to be addressed by patients, providers and regulatory authorities by providing information, counselling, ensuring informed consent, addressing exploitation and commercialisation, ensuring monitoring, proper documentation and transparency. Proper regulation of ARTs may restrict choices for couples and providers but is critical in protecting vulnerable users. It is important that the current specific social and cultural context be kept in perspective, democratic values respected, and to find a way of using these technologies wisely as they affect current and future generations.

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