

## **Infertility and Assisted Reproductive Technology in India: A Study of Socio-Cultural, Political and Legal Issues and Current Practices**

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### **Abstract**

*Motherhood in Indian society defines a woman's identity even before marriage because the preparations for a self-sacrificing life begin long before she is married. There are social, cultural and family pressures that impinge on couples (who can afford it) to use advanced technology. The repeated use of this technology is also encouraged by physicians as it is commercial and profit-making. In Indian society, where fertility is valued to the extent that womanhood is defined as motherhood, ART give hope to the infertile even though only a few can afford it. Couples that come from the higher socioeconomic group, in the search to have their own biological child, can now have a child through high technology options like IVF. Assisted reproductive technology (ART) has grown by leaps and bounds in the last few years. India has one of the highest growths in the ART centers and the number of ART cycles performed every year. There is no standardization of protocols and reporting is very inadequate. There are only ART guidelines and no law still exists. Furthermore, the moral, ethical and social issues raised by ART are unresolved. The total absence of monitoring and self-regulation can lead to the misuse of ART and related technologies. Our first and the biggest challenge is to document the tremendous work being done in India.*

**Key words:** *Infertility, Assisted Reproductive Technology, IVF.*

### **I. Introduction**

To procreate had been cherished dream of mankind since long. Couples start dreaming about their future life with kids' immediately after marriage or in some cases after some time. Not all couples succeed in starting a family when they wish for it and couples in India also face difficulties related to reproduction. Research studies quote that 25 % of total couples suffering with

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infertility are in India alone.<sup>1</sup> According to World Health Organization estimate the overall prevalence of primary infertility in India is between 3.9% to 16.8%.<sup>2</sup>

As per DLHS<sup>3</sup> in India around 8.8% of currently married women in reproductive age group had infertility problems, with wide variation ranging from 14 % to 3%. At the national level, around 6% women have primary infertility where as 2% have secondary infertility.<sup>4</sup>

Since ancient times, many Indian couples have suffered from infertility and have gone to great lengths to have a baby. Infertility touches all aspects of affected couples life. However in India, infertility is a particularly important problem since it is associated with specific social, cultural and religious aspects stemming from the long and varied history of the country and the importance of religion in the life of all Indians. In most areas of the women's wellbeing is reported to be more affected by infertility than men. In developing countries position of women is defined by their reproductive capacity and their failure to do so due to any reason leads to social and cultural repercussions for them. Women express consistently lower scores on mental health, social functioning and emotional behaviour domains in quality of life and experience higher levels of stigma than men.<sup>5</sup>

As in many developing countries, in India too infertility treatment is not part of the reproductive health services offered. There is no public health programme that focuses on infertility in the Indian context, though the International Conference on Population and Development (ICPD) programme of action states that reproductive health services should include prevention and appropriate treatment of infertility.<sup>6</sup> The Ninth Five-Year Plan (1997–2002) document of the

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<sup>1</sup> Prasad R. Infertility and Treatment Seeking Behavior among women of EAG states in India. *India 2014: Population and Development*. 87-10.

<sup>2</sup> Available at National health portal, <https://www.nhp.gov.in/disease/reproductive-system/infertility>.

<sup>3</sup> District Level house hold survey.

<sup>4</sup> Unisa S. Infertility and treatment seeking in India. Findings from District level house hold survey. *Facts, Views & Vision in Ob Gyn.* (2010 ) at 59-65.

<sup>5</sup> Sheoran P, Sarin J. Infertility in India: social, religion and cultural influence. *Int J Reprod Contracept ObstetGynecol*( 2015);4:1783-8.

<sup>6</sup> Programme of action. International Conference on Population and Development, Cairo, 1994:Para 7.6.

Government of India has included infertility in the comprehensive reproductive and child health package.<sup>7</sup>

## **II. Social-Cultural Construction of Motherhood in India**

Society seems to influence the experiences of women with infertility. The way they perceive importance of motherhood depends a great deal on the societal messages and beliefs. In Indian society, infertility is taken as women's problem and she is blamed for not able to procreate. As a dutiful wife she is expected to start a family immediately after marriage and when fails to do so, she is blamed for her role failure and often subjected to negative remarks and blame from in laws and neighbours.<sup>8</sup>

The identity of a woman in India is formed in relation to the values, meanings and symbols of Indian society. The meanings and values of the cultural identity are internalized. The ideology of motherhood differs according to the socio-cultural context, ethnicity, and class. In India, which is mostly a patriarchal society, motherhood has connotations of respect and power. Here, the "mother goddess" as mother is highly revered. A woman is considered "complete" or "real" only when she becomes a mother. She proves her womanhood in this way and feels secure in her marriage because it is believed to bond the marital relationship.

The ideology of motherhood is related to the way families are structured on kinship practices and depends on the variations in them. Ideas about womanhood and motherhood are linked to family and marriage. Family organization and marriage are important to understand reproduction and motherhood. Kinship is also important in understanding inheritance, rights over children, authority and responsibility of members of the family or kin-group. The way the patriarchal family is structured is one of the major causes of inequality between men and women and of the understanding that motherhood is one of the major roles of a woman in society.

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<sup>7</sup>Edited by EFFY VAYENA PATRICK J. ROWE P. DAVID GRIFFIN, Current Practices and Controversies in Assisted Reproduction, Report of a meeting on "Medical, Ethical and Social Aspects of Assisted Reproduction" held at WHO Headquarters in Geneva, Switzerland 17–21 September 2001, World Health Organization Geneva 2002.

<sup>8</sup>Id.

The mothering role of women is reproduced in society irrespective of whether women become mothers or not and the ideology of motherhood is dependent on the way a society constructs it. Motherhood is seen to be positively significant in many traditional societies, since women's reproductive capacity is something which women consider their source of power, and as defining their identity and status. It is also considered a resource for women who are denied the experience. This is true of childless women who centre their whole life on the fact that they cannot become mothers or bear children and have to pay a social cost for it. The ideology of motherhood in Indian society explains why fertility is so important. Feminine identity is defined by the ideology of motherhood, being fertile is important and infertility is a huge problem.

### **III. Socio-Cultural Context and Consequences of Infertility/Childlessness in Indian Society**

Since a woman is defined by her fertility, she internalizes the motherhood role to the extent that if she is infertile, she feels worthless. Then she proceeds to do all she can to reverse the situation. The experience of infertility/childlessness is usually marked by anxiety and fear, societal pressures to conceive and social stigmatization, and various trials of various treatments. Infertility is a major problem in the context of important domains of social life such as kinship, inheritance, marriage and divorce patterns.

It is a threat to a woman's identity, status and economic insecurity, it may lead to identity dilemmas, lowered self-esteem, frustration and a sense of powerlessness. There are many reasons for the importance given to biological children in society:

1. It is assumed that the desire to have children is normal and parenthood is part of the natural order of things.
2. Some childless women might not be that enthusiastic about motherhood but want a child to satisfy their in-laws or husband, or experience pregnancy, childbirth or parenthood.
3. Some are under external pressures to have children (as in India). For some, it makes them feel part of daily life and for some couples a child is like an achievement.

4. For some men, having a child is proving their sexual potency.
5. It is important for women, because for them there is a link between femininity and fertility. Motherhood also gives women a female adult identity and a reputation of a responsible human being.
6. Children provide emotional satisfaction, make life interesting and provide a reason for living.
7. People also want children because it is almost like a biological need, as they want to see a part of themselves in their child.
8. Some want to be able to spend the wealth they have acquired or achieved on someone, and a biological offspring is the best person to spend it on. Having a child for some couples affirms their love for each other as a child is seen as a binding factor.
9. A child is also looked upon as someone who helps an urban middle-class housewife spend her time, since the child occupies her and gives her status in society, she also has something to talk about with other women.
10. A poor woman has children for economic reasons too. The more children she has, the more earnings there are for the family as a whole. So children are precious resources for her, as she usually cannot send them to school.
11. Moreover, children seem to be the central point of discussion for mothers, so a childless mother feels excluded and her childlessness becomes more obvious.

Jindal and Gupta<sup>9</sup>, through their study, reiterated that in India the social pressure to become parents is even more because of the joint family system and the influence of elders. If the couple is infertile, there is loss of status and prestige. Among the women that they studied, social problems increased with the duration of marriage or duration of infertility, while these decreased with increase in age, education and income of the husband. The problems were inversely related to education and economic independence. Insistence on a male

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<sup>9</sup> Jindal UN, Gupta AN. Social problems of infertile women in India, INTERNATIONAL JOURNAL OF FERTILITY, 1989, at 33&34..

child was responsible for such problems in both primary and secondary infertility cases when the first offspring was female. Poverty and illiteracy emerged as important socioeconomic determinants of these problems.

#### **IV. Effect of Religion on Infertile Women**

Unisa<sup>10</sup> feels that childless women are kept purposely from celebrations of newborn children and celebrations of first pregnancies, as their presence is considered inauspicious. Many people expressed the opinion that a childless couple should also not bless a newly married couple as that might result in the newly married couple's childlessness. After a few years of marriage, a childless woman avoids ceremonies. Actual and anticipated rude comments at social functions forced many women in this study into becoming social recluses. Women considered themselves to be a source of bad luck. Unisa pointed out that the women themselves had low self-esteem as a result of these negative social attitudes .

Society has fixed a right time for motherhood and fatherhood and that it was too late for women to become mothers after they were 25 years old. These concerns related to lack of adult identity (male and female), also proving their capability of motherhood, status in the family, the stigma of late motherhood and lack of security in old age. Children are valued by women because they continue the patrilineal family line and helped them establish a relationship with the elders in the family.<sup>11</sup>

#### **V. Psychosocial Consequences**

Feelings of losing control over their body and their life are expressed by some women who are childless. For many women, conception becomes a preoccupation resulting in anxiety, despair, depression and various other psychological problems. This adds to the problems that already exist. They feel

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<sup>10</sup> Unisa S. Childlessness in Andhra Pradesh, India: treatment seeking and consequences. *Reproductive Health Matters*, 1999, 7:54–64.

<sup>11</sup> Mulgaonkar VB. A research and an intervention programme on women's reproductive health in slums of Mumbai. Mumbai, Sujeevan Trust, 2001.

sad, disappointed and exhausted by the intensity of their emotions because this problem has taken over their lives.<sup>12</sup>

Some women who are infertile feel constantly preoccupied with their body, waiting for a sign of something going wrong or right. There is anxiety with the onset of menstruation and it is viewed not as a sign of femininity, but as a failure. There is concern whether the pregnancy will continue or not, or preoccupation with the cause of infertility, or with unexplained infertility. In-depth interviews conducted with infertile couples undergoing treatment have revealed that women express disappointment at failing expectations and that treatments allow hope but also defer final acceptance of infertility. Since this experience damages self-esteem it might have repercussions on other relationships of the woman. In India, women often complain of being ridiculed by their in-laws for not being able to conceive. They feel rejected by their partners because they are made to feel incomplete and the threat of someone else coming on the scene looms large.<sup>13</sup> One of the few psychosocial studies of infertile couples in India revealed that infertility is a life crisis and a stressful experience with invisible losses, especially for women.<sup>14</sup> They experience marital and psychological instability, and stress and strain, including deterioration in the quality of life. The crisis is long lasting and not much is known about the strategies adopted by infertile couples to cope with their childlessness. In the study, 77% of couples had alterations in sexual response (reduction of sexual happiness), which also has implications for the marital relationship.

The couples coped with infertility by involving themselves in religious practices such as praying and visiting religious places, by caring for others in the family,

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<sup>12</sup> Gupta J. *New reproductive technologies, women's health and autonomy: freedom or dependency?* New Delhi, Sage Publications, 2000.

<sup>13</sup> Widge A. *Beyond natural conception: a sociological investigation of assisted reproduction with special reference to India* [Thesis]. New Delhi, Jawaharlal Nehru University, 2000.

<sup>14</sup> Desai P, Shrinivasan V, Hazra M. Understanding the emotions of infertile couples. *Journal of Obstetrics and Gynaecology of India*, 1992, 42:498–503.

fostering relatives' children and some by being involved in social organizations. Some couples also expressed the positive freeing aspects of childlessness.<sup>15</sup>

## **VI. Treatment-Seeking Behaviour of Infertile/ Childless Couples in India**

Though there are many consequences of infertility, the obvious commonly expressed consequences include fertility-seeking behaviour which includes treatment mostly from traditional healers.<sup>16</sup><sup>17</sup> More recent studies have also identified allopathy as one of the more popular treatments that are sought besides traditional treatments.<sup>18</sup> Although infertility treatment is available in government hospitals, there is often poor coordination between gynaecologists, infertility specialists, surgeons and laboratory technicians. Couples who can afford the cost of ART such as in vitro fertilization (IVF) are using them increasingly.

Women usually initiated the first contact with a physician. The reasons for couples delaying seeking medical advice were because of the fear of a final definitive diagnosis and partly because of the dread of the emotional stress and physical discomfort of the tests they would have to undergo. Some also felt that in seeking medical attention they were admitting failure in their efforts to conceive.

## **VII. Assisted Reproductive Technologies: Social, Physical and Psychological Costs**

There are social, cultural and family pressures that impinge on couples (who can afford it) to use advanced technology such as IVF, gamete intrafallopian transfer

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<sup>15</sup>Edited by EFFY VAYENA PATRICK J. ROWE P. DAVID GRIFFIN, Current Practices and Controversies in Assisted Reproduction, Report of a meeting on "Medical, Ethical and Social Aspects of Assisted Reproduction" held at WHO Headquarters in Geneva, Switzerland 17–21 September 2001, World Health Organization Geneva 2002.

<sup>16</sup>Kakar DN. Traditional healers in North India: a case study. *Nursing Journal of India*, 1983, 74:61–63.

<sup>17</sup> Gupta AN, Dhall GI, Dhaliwal LK. Epidemiology of infertility in Chandigarh. In: Shah Ratnam S, Soon Teoh E, Anand Kumar C, eds. *Advances in infertility and sterility*. Singapore, Parthenon Publishing, 1983:103–109

<sup>18</sup> Unisa S. Childlessness in Andhra Pradesh, India: treatment seeking and consequences. *Reproductive Health Matters*, 1999, 7:54–64.



(GIFT) and intracytoplasmic sperm injection (ICSI). It has been suggested that some childless women go through procedures such as IVF repeatedly, although they believe that it is not beneficial, is invasive and has risks of physical and psychological damage. They do, however, repeat the treatments due to a sense of being responsible for reproductive failure and because of the constant valorisation of motherhood as a woman's most important role. The repeated use of this technology is also encouraged by physicians as it is commercial and profit-making.<sup>19</sup>

The ambiguity towards the experience with IVF cycles has been revealed by many studies. However, it is believed that IVF focuses exclusively on biological reproduction and curtails any potential for the redefinition of parenthood or infertility. In so doing, it reinforces the notion of the "natural" bond between a mother and her biological children as well as reinforces the idea that the only desirable structure of social relations between adults and young children is the nuclear family or indeed one's own biological children.<sup>20</sup>

### VIII. Seeking ART in the Indian Context

In Indian society, where fertility is valued to the extent that womanhood is defined as motherhood, ART give hope to the infertile even though only a few can afford it. Couples that come from the higher socioeconomic group, in the search to have their own biological child, can now have a child through high technology options like IVF. In India where there is a stigma against infertility and childlessness, this is perceived as a great scientific achievement. Most couples who opt for treatment are very apprehensive about the societal reaction to their childlessness. As in the West, the need for a child in India is not so much of a biological need but is a social one.<sup>21</sup>

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<sup>19</sup> Crowe C. Women want it: in vitro fertilization and women's motivation for participation. In: Spallone P, Steinberg DL, eds. *Made to order: the myth of reproductive and genetic progress*. Oxford, Pergamon, 1987:84–93.

<sup>20</sup> Ibid

<sup>21</sup> Widge A. *Beyond natural conception: a sociological investigation of assisted reproduction with special reference to India* [Thesis]. New Delhi, Jawaharlal Nehru University, 2000.

According to data available with healthcare private equity firm Quadria Capital, although infertility affects nearly 28 million couples seeking children, only 1 per cent of them are seeking treatment. The total demand for IVF cycles, primarily used for treatment of infertility, was 100,000 in 2015 and is expected to touch 260,000 by 2020 at a compound annual growth rate (CAGR) of over 20 per cent, throwing up a plethora of opportunities for both domestic players and foreign chains wanting to either establish or strengthen their presence in the burgeoning IVF market.<sup>22</sup>

“The IVF market is estimated to be underpenetrated by 9-12 times than the addressable demand in the key cities such as Delhi, Mumbai and Bangalore, and provides a huge opportunity for penetration of IVF centres across the country,” says Amit Varma, managing partner at Quadria Capital. “The IVF market is highly fragmented with both domestic and a handful of foreign companies offering services,” he adds.

According to Srinivasan, overestimates of infertility help justify the industry’s and the medical practitioners’ existence, but in a large country with a large population it is a substantial number and requires attention. IVF and other ART are promoted today for all forms of infertility. The Institute for Research in Reproduction (IRR) began work on an IVF programme in 1982 to provide subsidised IVF. Besides, the services in the private sector are mostly market driven. According to an infertility specialist in Delhi, as private specialists invest a lot in acquiring hi-tech equipment, the costs of service are therefore high (personal communication). According to another infertility specialist, IVF clinics are mushrooming in India.

There are nearly 1,000 centers offering IVF across the country, a few centres also exist in the public sector. An evaluation of the public sector ART centres is proposed, following which the existing ones may be strengthened with trained and interested staff. The mushrooming of private centres combined with the lack of public sector centres has created a situation of exploitation of helpless, childless couples.

On the other hand still there exists a social stigma around IVF treatment in India. Being a conservative society, social and religious concerns prevent people

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<sup>22</sup>Paramita Chatterjee, “IVF: Fertile Ground”, available at <http://www.businessworld.in/article/IVF-Fertile-Ground/08-08-2016-104172/>

from seeking IVF treatment. There is still a section of society which is unaware of the positives of this treatment. While the market for IVF is growing, many people still refuse to accept the scientific facts behind IVF. Family succession in case the child doesn't carry family genes, treating the child as multi-parental creation, and child's emotional safety are some of the key taboos existing in the society. Additionally, third-party donors, whether they provide eggs, sperms, embryos or surrogacy, are anathema, especially to people with religious and social reservations.<sup>23</sup>

### **IX. The Socio-Political Context**

It is political in the sense that it is in the overpopulated state's interest to control fertility and not be concerned about infertility. In India, infertility appears to be an unimportant question for policy-makers and women's groups alike. As an example, none of the programmes of the national reproductive health policy has focused on implementing preventive and curative services for infertility treatment. Infertility seems to be a relatively unimportant issue, as it affects only a few couples in an "overpopulated" country. Among them, even fewer couples, those of a certain class group, are able to access ART. These are the primary reasons that the voice of the childless woman is absent in the feminist and policy debates surrounding reproductive technology in India. Hence, neither the issue of infertility nor the implications of ART are given any value. However, irrespective of the number, or the class of women who are affected by infertility, or have access to infertility treatment, the infertile or the childless woman is a focus for patriarchal power and this has major social repercussions for the woman.

### **X. Legal Framework of Assisted Reproductive Technology in India**

Assisted reproductive technology (ART) has grown by leaps and bounds in the last few years. India has one of the highest growths in the ART centers and the number of ART cycles performed every year. Very soon India will be the leader in the world of ART in terms of a number of cycles. With the advances of technology and availability of techniques even in tier II and tier III cities our country, the results still vary dramatically. There is no standardization of

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<sup>23</sup> Ibid.

protocols and reporting is very inadequate. Furthermore, there are only ART guidelines and no law still exists. Our first and the biggest challenge is to document the tremendous work being done in India.<sup>24</sup>

As a result, questions have been raised on the effectiveness, safety, availability and costs of these procedures, as well as many ethical and legal aspects of their use.

ART still has some safety problems and risks that need to be described and evaluated so that current clinical policies and laboratory procedures can be revised, if necessary. Confidence, Credibility or trust in ART is needed, not only for couples who need to undergo treatment but also for professionals who provide treatment and for the society at large, as well as for legislators and resource allocators.

In India, there is no legislation dealing with the assisted reproductive system. No legislation currently regulates ART in India. In 2002, the Indian Council of Medical Research (ICMR) laid out guidelines for surrogacy. Further, in 2005, the ICMR issued the 'National Guidelines for Accreditation, Supervision and Regulation of ART Clinics in India' (ICMR Guidelines), which inter alia, prescribed the conditions that ART clinics need to comply with. Both the above initiatives did not have any legislative backing. Thereafter, the Assisted Reproductive Technology Bill (ART Bill) was first proposed in 2008, with the final version being brought out in 2017.

#### **X.I. The Indian Council for Medical Research Guidelines for ART Clinics and Surrogacy in India:<sup>25</sup>**

It is necessary to follow ICMR guidelines in ascertain the therapeutic and research values of the AR procedure.

**Informed consent:** After duly counselling the couple/oocyte/semen donor, an informed and written consent should be taken from both the spouses as well as the donor. They should be explained that:

1. The various risks in simple language that they can understand.

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<sup>24</sup>Narendra Malhotra, Duru Shah, Rishma Pai, H. D. Pai, and Manish Bankar, "Assisted reproductive technology in India: A 3 year retrospective data analysis", *J Hum Reprod Sci.* 2013 Oct-Dec; 6(4), Indian society of assisted reproduction,p. 235–240.

<sup>25</sup> ICMR Guidelines on Biomedical Research on Human Participants 2006.

2. The possibility of multiple pregnancies and their risk, ectopic gestation, increased rate of spontaneous abortion, premature births, higher perinatal and infant mortality, growth and developmental problems, possible side effects of the drug used.
3. There is no guarantee on the success/failure of the procedure.
4. About the cost to the patient of the treatment proposed and of an alternative treatment, if any.
5. There may be possible disruption of the patient's domestic life which the treatment an expenses may cause;
6. About the possible deterioration of gametes or embryos associated with storage, and possible pain and discomfort;
7. About the advantages and disadvantages of continuing treatment after a certain number of attempts.
8. Informed consent should include information regarding use of spare embryos. It should be made clear whether embryos that are not used for transfer could or could not be used for research purposes or implanted in another woman's womb, or preserved for use at a later date or destroyed.
9. Consent may be withdrawn at any time before implantation.
10. Specific consent must be obtained from couples who have their gametes or embryos frozen, with regard to what should be done with them in case of death, or if any of the parties becomes incapable of varying or revoking her or his consent.
11. Abortions should never be encouraged for research purposes.

**Selection of Donor:** The semen bank assumes the responsibility in selection of the suitable donor on following terms:

1. Complete physical examination of the donor should be done; the donor should be healthy with reasonable expectation of good quality eggs or sperms and preferably with proven fertility record.
2. The physical characteristic and mental make-up of the donor should match as closely as possible to that of the spouse of the recipient,

especially with reference to colour, eyes and hair, height and build, religious and ethnic background, and education and ABO blood type.

3. Blood group of the proposed donor and donee should be tested with respect to Rh compatibility.
4. No donor suffering from any sexually transmitted disease (e.g. syphilis, gonorrhoea, chlamydia, herpes, HIV etc.), infectious disease (e.g. hepatitis B and C, HIV) or genetically transmissible disease. Sexually transmitted diseases should be ruled out within a week of obtaining the seminal fluid.
5. It is essential that donated semen is cryo-preserved and used only after 6 months as this would enable the centre to retest the donor after 6 months for HIV and eliminate the potential risk of HIV transmission in the 'window' period of HIV infection.
6. Identity of the donor as well as the recipient should be protected from each other. However, all the records of the donor must be preserved for at least 10 years and should be confidential.
7. Confidentiality of the entire procedure and its outcome is advisable and therefore, no relative should be accepted as a donor in order to avoid identification and claims of parenthood and inheritance rights.
8. Any information about clients and donors must be kept confidential. No information about the treatment of couples may be disclosed to anyone other than the accreditation authority or persons covered by the license, except with the consent of the person(s) to whom the information relates, or in a medical emergency concerning the patient, or a court order.
9. Written consent and an undertaking of the donor should be taken towards unrestricted use of sperms or oocytes for AR and he/she will not attempt to seek the identity of the recipient. In case the donor is married, the written consent of the spouse should also be taken, if possible.

10. It is also desirable to restrict the use of semen from the same donor to a maximum of 10 pregnancies to avoid the possibility of an incestuous relationship occurring among the offspring's at a later date.
11. In case of the oocyte donor, incurring any health problems related to the process of donation, the costs of the subsequent health care should be borne by the potential recipient couple irrespective of whether they receive oocyte donation as planned or not.
12. In case of unused surplus/ spare embryos, consent of the concerned couple should be obtained to cryopreserve such embryos for donation to other needy couples. The ownership rights of such embryos rest with the couple concerned.
13. Respect for the embryo's moral status can be shown by careful regulation of conditions of research, safeguards against commercial exploitation of embryo research, and limiting the time within which research can be done on embryo up to 14 days' growth i.e. when the primitive streak appears.<sup>26</sup>

While the guidelines attempt to incorporate some issues related to social justice and gender inequality, they still fall short on many fronts. The ethical guidelines should go beyond technicalities and build effective safeguards so that the unequal power relationship between the providers and users of new technology is minimised. The guidelines should also keep in mind the unequal gender balance and ensure that the rights of women users of these technologies are not compromised in any manner.

The very title 'National guidelines for accreditation, supervision and regulation of ART clinics in India' makes it clear that the ICMR, the apex body in India for the formulation, coordination, and promotion of biomedical research, has limited itself to creating red tape on the running of clinics. It is critical to envision future trends and lay down an ethical framework for biomedical research, especially in the new frontier of human reproduction that could change

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<sup>26</sup>B. L. Chaudhary , "Assisted Reproductive Techniques Ethical and Legal Issues", J Indian Acad Forensic Med. October-December 2012, Vol. 34, No. 4

the very face of humanity. This role, it seems, is not one that the ICMR is ready to play.<sup>27</sup>

## XI. Recommendations

World Health Organization in a meeting on “Medical, Ethical and Social Aspects of Assisted Reproduction” held at WHO Headquarters in Geneva, Switzerland prescribed the following recommendations and some recommendations specify the group or entity that would be expected to take the appropriate action:<sup>28</sup>

- There must be specific and uniform definitions of terms commonly used in ART.
- Guidelines need to be developed for the establishment of national and international ART registries.
- National ART surveillance programmes should be developed.
- National and international data on twin and higher-order multiple pregnancy rates resulting from ART and other forms of infertility treatment should be published.
- ART statistics need to emphasize the birth rates of healthy infants as well as rates of malformations, neonatal morbidity and mortality, and abnormalities of pregnancy.
- Malformation rates should include those associated with abortion, stillbirth and live birth.
- Moral, ethical and social issues raised by ART should be resolved.
- Consumers of ART services should work closely with professionals and with governments to document.

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<sup>27</sup>Laxmi Murthy, Vani Subramanian, “ICMR guidelines on Assisted Reproductive Technology: lacking in vision, wrapped in red tape”, Indian Journal of Medical Ethics, Vol IV No 3 July-September 2007.

<sup>28</sup> Current Practices and Controversies in Assisted Reproduction, Report of a meeting on “Medical, Ethical and Social Aspects of Assisted Reproduction” held at WHO Headquarters in Geneva, Switzerland 17–21 September 2001.



- Prior to treatment, patients undergoing ART procedures should be counselled about the implications of disclosure and nondisclosure to the child of its genetic origins. Subsequently, parents should have access to support when they are considering being open with the child about his/her genetic origins.

- Further studies should be conducted on the effects on the child of secrecy and disclosure about his/ her genetic origins resulting from gamete or embryo donation.

- Procedures need to be established to ensure continuing multidisciplinary debate to shape the ethical framework of ART.
- Procedures should be developed to allow stored embryos, for which there will be no clinical use, to be used for research or discarded. This research could be used to improve ART or the understanding of embryo development, but must be legally permissible and carried out only with the prior informed consent of the donors.
- Newly introduced procedures, as well as those currently used in ART, should be followed by surveillance of all treated individuals and offspring and include child development.
- Policy-makers and health staff should give attention to infertility and the needs of infertile patients.
- Governments should improve education in infertility and reproductive health for the general public and health care professionals.
- A gender perspective needs to be applied by health care providers to infertility management and treatment.
- Infertility management should be integrated into national reproductive health education programmes and services.
- Physicians should provide adequate investigation facilities and treatment for the infertile couple in a culturally sensitive and ethically acceptable manner.
- Where appropriate, traditional healers should be included in the dialogue between patients and health care providers concerning the treatment of infertility.

- Where public funding is insufficient, alternative sources of funding for public sector ART programmes should be sought.
- Cost-effective options, including the establishment of national networks of satellite clinics to screen and refer appropriate couples to specialist centres, should be examined as a means of improving access to ART.
- ART should be complementary to other ethically acceptable, social and cultural solutions to infertility.
- Public awareness of infertility and its causes should be increased to improve preventative behaviour and to diminish the stigmatization and social exclusion of infertile men and women.
- The dissemination of public information on the options for treatment of infertility, including adoption and the ethical and legal issues involved, should be improved.
- Infertility should be recognized as a public health issue worldwide, including developing countries.
- Research is needed on innovative, low-cost ART procedures that provide safe, effective, acceptable and affordable treatment for infertility.

## **XII. Conclusion**

Motherhood in Indian society defines a woman's identity even before marriage because the preparations for a self-sacrificing life begin long before she is married. It is still the most important goal for a woman. Infertile women often complain of being ridiculed by their in-laws for not being able to conceive. Some couples use AI and ART. Since IVF has been introduced in India it has given desperate couples great hope and a chance to have their own baby instead of going through endless treatments without any hope. In the search to have one's own biological child, couples that belong to the higher socioeconomic groups can now have a child. In the present context of consumerism and market-oriented technologies, the private health care sector and the pharmaceutical and genetic engineering companies use the slogan of "help for the infertile", but it is

the companies that stand to gain. There are hardly any subsidised clinics in India and the government hospitals do not offer these advanced technologies. Preventive and curative services for infertility are not a priority. Furthermore, the moral, ethical and social issues raised by ART are unresolved. The problems posed for parenthood, when the legal parent of a child born to a woman who is neither its genetic nor social mother have not been confronted in India. These technologies are offered as a choice. However, in a country such as India, where modern and/or hi-tech infertility treatment depends on the couple's/woman's ability to pay, there is not much choice. Moreover, due to the lack of regulation and laws there are concerns about the lack of professionalism and the safety of the treatments offered. The total absence of monitoring and self-regulation can lead to the misuse of ART and related technologies. Legal battles regarding ART and/or surrogate motherhood have been going on in the West, but it will not be long before similar problems are faced by the Indian society. A set of rational and consistent policies to manage ART is required. There should be a focus on non-technological solutions such as preventive measures for infertility, adoption of children of all sexes, raising consciousness to reduce the social pressures for biological parenthood and on protesting against perverse uses of ART. The reality of the childless woman is complex. Experiences of infertile women with reproductive medicine are not very pleasant but they still want to use the technology, sometimes because it helps them negotiate their position in the patriarchal family. Also, an overemphasis on the negative impact of these technologies distracts attention from the politics and organization of health care in general, from the legal system, from political struggles over the nature of sexuality, parenthood and the family, and from the impact of the varied material and cultural circumstances in which people create their material lives. The problem of women's health in India has to be looked at within a general context of poverty, class and gender inequalities and unequal access to resources. The health and well-being of women are important as a value. The politics and organization of health care in general, the legal system, the nature of sexuality, parenthood and the family and the present economic structures all are important related issues that impinge on a childless woman.