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Assisted Reproductive Technologies and Socio-ethical Issues: Analysis of Risk Perception among the Different Social Groups in India

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The paper analyses the debates on assisted reproductive technologies (ARTs) and explores the risk perception of four major actors (scientists, practitioners, women's' rights group and patients) on ART on the basis of in-depth interviews of key informants and critical analysis of secondary literature in reproductive and social sciences, websites contents of ART clinics and research reports by non-governmental organisations. Our analysis shows that even the scientific actors use the language of social actors and invoke political and economic issues like 'human rights', 'declining population rate', 'accessibility and availability of ART' to promote and defend the ARTs. Whereas women's rights group view risk in the potential of ARTs to reinforce the patriarchal norms, notions of motherhood, social compulsion to have children and thus sustaining the notions of patriarchal family and furthering the exploitation of women's bodies and reproductive capacities. The findings provide useful insight into the various dimensions of risk associated with the assisted reproductive technologies.
[Key Words:** Assisted Reproductive Technology; ART; Risk; Risk perception; Socio-ethical Issues; Social Groups; India**]

Introduction

World Health Organization (WHO) report estimated that 60 to 80 million couples globally suffer from infertility (Rutstein & Shah 2004). In India 8.8 percent women face lifetime primary/secondary infertility problem, out of which three-fourth suffered from primary infertility (Ganguly & Unisa 2010). It is indicated that childlessness in India is primarily due to the problem of infertility and not because couples choose to remain childless (Tripathi 2011). If this is the demand side of the picture, the supply side of the picture is more alarming. There is no reliable data on the number of Assisted Reproductive Treatment (ART) clinics - major sources of infertility treatment in India. Surrogacy, which is part of the ART industry, is also increasing at an alarming

rate. It is argued that India is turning in to a 'surrogacy outsourcing capital' of the world. The demand and supply side of infertility treatment are raising important issues related to the efficacy of technology, health risks, socio-economic and ethical-legal problems.

Despite the growing demand and supply of ART, there is very little understanding on perception of risk associated with ART by different stakeholders and the socio- ethical challenges it is throwing up in the society**.** This paper aims to fill up this gap by capturing the risk perceptions of different stakeholders on ART. The first section of the paper critically analyses the scientific and technological claims of ART widely used in India. The second section of the paper dwells upon the social science literature to understand the risk perception of various stakeholders, particularly the women's right group. The third section outlines the risk perception of patient groups, fourth section offers an analysis of debates on ARTs in reproductive medicine and outlines the risk perceptions of practitioners and the last section paper provides discussion and conclusions of the study.

Assisted Reproductive Technologies (ARTs)

ARTs can be broadly divided into two groups: *In vitro* techniques and *In vivo* techniques. *In vivo* techniques are the simplest techniques where conception is facilitated inside the body. *In vitro* techniques are complex techniques where the gametes are taken out of the body and fertilization takes place outside the body. In-vitro Fertilization (IVF) involves natural in-vitro fertilization (NIVF) and stimulated in-vitro fertilization (SIVF). In NIVF the IVF cycles are completely natural. In NIVF ovum release is not induced by an external agent but by closely following its natural cycle and retrieving it laproscopically. In SIVF clomiphene citrate is used in conjunction with human menopausal gonadotropin (HMG) to stimulate and sustain spontaneously recruited follicles for ovum harvesting (Zayed, Lenton & Cooke 1997:2408).

The main technique of IVF is Intra Uterine Insemination (IUI) which includes extraction of sperms from seminal fluid and after wash directly injecting in the uterus of women. With subjects of treatment requiring low level of follicle stimulating hormone (FSH) and with the absence of highly specialized techniques like egg collection and culture, Stimulated Intra Uterine Insemination (SIUI) is considered very cost effective in comparison to SIVF. Both techniques, however, raise some socio-ethical issues.

Socio-ethical issues and ART

Scholars have raised various socio-ethical issues related to ART. Feminist scholars have looked at ART treatment from a women's rights point of view and have argued that the market and the prevailing patriarchal structure of the society are forcing ART treatment on women (SAMA 2006). They have focused mainly on the social and health implications of ART on women as they are on the receiving end of ARTs. Problematizing the commercialization of reproduction by the ART industry, Sarojini, Marwah & Shenoi (2011) have shown how 'women' in procreative capacity are packaged and tailor made

according to the needs of the 'customer' with the right mix of technology and market. The ART also poses the risk of technology being enforced upon women unnecessarily (Shah 2009).

It has been noted that how media has played important role in constructing a credible image for ART practitioners among public and how 'metaphysical explanations become culturally acceptable coping mechanisms for the clinicians and their patients, as they both struggle to make sense of the uncertain nature of assisted conception'(Bhardwaj 2006). It has been also reported that the infertile couple secretly resort to ART to escape the social stigma of infertility as well as to conceal the origin of progeny (Bharadwaj 2003). The basket of technologies in ART throws up a host of ethical issues. For instance, the In-Vitro Fertilization technique involves ethical issues like bypass natural conception, life is created outside the body, excess fertilization of embryos, uncertainty about discarded embryos, equitable access to all sections of the population, destruction and manipulation of life through research on embryos and selection of embryos through sex determination(Chaudhary 2012).

The regulatory framework for ART technologies is still in the nascent stage in the country. *The Ethical Guidelines for Biomedical Research,* published by ICMR (Indian Council of Medical Research) in 2000, was the first official document to be referred for the regulation of ART in India. However, these guidelines are not legally binding on the ART clinics. These guidelines were incorporated in the ART (Regulations) Bill in 2008, ART (Regulations) Bill 2010, and ART (Regulations) Bill 2013. The ART (Regulations) Bill defines the functions and powers of the authorities to regulate ARTs and lays down the rules and procedures in constituting the authorities. The bill bans ovum or sperm donation among family members, relatives and friends and mandates semen banks and the clinic to keep the identity of the donor confidential. However, even after eight years since the first draft of the regulation bill appeared in the public domain, the latest version of the bill ART (Regulations) 2016 is still pending as there has been no consensus on the risk associated with ART. The union cabinet's recent approval to introduce the Surrogacy (Regulation) Bill 2016 in the parliament has elicited multiple responses from various stakeholders. Therefore, understanding the 'risk framework' will be an apt platform to converge the voices of different stakeholders.

Material and Methods

The study is based on comprehensive analysis of secondary literature and primary data collected from in-depth interviews with a representative group of practitioners, scientists, policy makers, women's rights activist and patients. The risk frame of the various stakeholders were analyzed from the interview conducted and a literature survey of scientific articles on ART published in journals, and opinion published by practitioners on websites maintained by the infertility clinics in India and the interviews and reports published by women's and health rights groups. In our study we have selected four important

stakeholders in ART: women's groups, doctors, patients and scientists /researchers.

The data for analysis of patients risk frames is mainly derived from a study, based on interview of 25 women, conducted by SAMA- a women's right group (SAMA 2006).The patients include couples/individuals who had undergone assisted reproductive treatment. The respondents belonged to the age group of 22-46. Majority of the respondents in the study defined themselves as belonging to "middle class families". The authors also conducted an in-depth interview with the male counterpart of the couple, who had undergone ART treatment in March, 2010. The respondent identified himself as a graduate, aged 42, and businessman. The respondent has undergone treatment for six years. The source of data for the analysis of practitioner's risk frames are the websites maintained by infertility clinic. Three websites of infertility clinics in Mumbai, Hyderabad and Bengaluru were consulted. Only those websites, which discuss different risks of ART, were chosen. One of the websites maintained by Dr. Malpani infertility Clinic, Mumbai claims to be ranked in the best five infertility clinics in India by the *Outlook Magazine* in 2005. Another website maintained by Dr. Rama's Institute for Fertility, located in Hyderabad with a branch in Bengaluru claims to have nineteen years of experience and catered services to infertile couples from at least twenty countries. The websites of infertility clinics do not provide any information on the number of patients they treat. The views regarding the risks of different techniques are presented in the form of Frequently Asked Questions (FAQ) either authored in the name of chief physician or without giving the name of the author. Details of different techniques are also provided in the website in a combination of simple and technical language and the speciality of the particular clinic in that technique. The source of data for analysis of scientist's risk frames is derived from the scientific publications on ARTs in reputed journals like *Human Reproduction*, *Journal of Human Reproductive Sciences* and *Journal of Assisted Reproduction and Genetics*. The authors also conducted interview with two scientists who were aware of the latest developments in the area of assisted reproduction.

Risk Perception of Social Actors

Risk has two dimensions: the probability and/or the consequence of occurrence of an event (Adams, 1995). However, the perception of risk is not only limited to technical parameters and probabilistic number but also to our psychological, social and cultural context (Nelkin 2001).Different stakeholders have different perception about risk and social, legal and ethical issues associated with ART.

Feminists' Views on ART

The feminist debates on ART starts with Shulamith Firestone's arguments that 'development of birth-technology is potentially liberating for women, because it could free them from the burden of biological motherhood' (Zipper & Sevenhuijsen 1987:120). Naomi Chan(2009) argued that reproductive technologies could rescue women from social dilemma enforced

on them due to the possession of reproductive capacities The ART is seen as the way out from coerced 'baby vessel' to voluntary motherhood and from compromising the career out of social compulsion to become mother at young fertile age. For Stanworth (1987) ARTs are the means for men to wrest not only the control of reproduction but reproduction itself and its implications include: deconstruction of motherhood- in the place of the single biological mother there will be 'ovarian mothers' who supply eggs, 'uterine mothers' who give birth to children and 'social mothers' who raise them, delegitimizing genetic parenthood and its separation from 'the sexual act' and marriage.

Stanworth(1978:35) does not see reproductive technologies as an invasion of human body but emphasizes the creation of 'political and cultural condition in which the technologies can be employed by women to shape the experience of reproduction according to their own definitions.'. The argument that reproductive technologies are imposed on women is countered on the grounds that the infertile women and lesbians utilize ART for achieving pregnancy (Petchesky 1987:77). Historical evidences show that the women were not passive receptors of 'male' reproductive technologies, the 'market' for pills, sterilization, IVF, amniocentesis and high-tech pregnancy monitoring facilities resulted from the shared situation of reproductive demands by men and women rather than a mere victimization of women (Petchesky1987:72). This position, however, is opposed by feminist scholars like Maria Mies and Gena Corea, who view development of ART like IVF as patriarchal exploitation of women's bodies (Zipper & Sevenhuijsen1987:120).

The separation of mode of reproduction from the mode of procreation facilitated by conceptive technologies has created not only new objects like ova, sperms, wombs or embryos for sale but also new historical subjects like women willing to sell or donate their egg or womb, couples contracting their biological reproduction to another women, couples willing to donate extra embryos for another couple (Gimmenez 1991).Thus, there is no consensus among feminists whether ART is a liberator for women or a tool for commodification of their body and their further exploitation and subjugation.

Risk Perception of Women's' Rights Groups

Women's right groups like Saheli Resource Center for Women, AIDWA and SAMA articulate women's right in social, economic and political domains. SAMA is the most vocal group to raise the women's voice on ARTs and have placed their views in the public domain. *SAMA* in its study has shown how private ART clinics and practitioners exploit the social compulsion of patients for having a child in India. Following statements validate this point:

The field of assisted reproduction is unique in the sense that it capitalizes on individual vulnerability and the social pressure to have a child' (SAMA 2006:55)

The practices in ART are problematized by women's' group when moral judgments intervene in the decision-making on scientific issues. For instance, the following statements noted by SAMA (2006:58) convey the risk in

such emerging practices: 'The articulation of the service providers were more guided by their notions of morality in who should donate eggs rather than medical reasons.' Thus, there is no attempt on the part of the providers, to question this social pressure. Rather it is reinforced by their perception of infertility, "as a major issue in our society", and by finding technological solutions to a social problem. By promoting these technologies, they believe that they are actually providing a "solution to those couples who are desperate to have their own children".

This type of logic reinforces the subjugation of women to social inequalities and patriarchal values. Women's groups have also questioned the notion that ART is the only solution to infertility and denying people any other options. SAMA pointed out the potential risk of ART in discouraging people to seek other socially relevant options like adoption: 'Among the 15, eight providers were of the view that adoption is the last resort, considered only when all other treatment options fail. However, three other providers felt that, people who were open to adoption would not come in for treatment at all and adoption cannot be imposed on couples as a viable action' (SAMA 2006:31).

It seems that though there is a provision for adaptation in the ART bill, practitioners deliberately avoid encouraging couple to go for adoption as it may affect their business. They exploit the social and economic vulnerability of women. A women's right activist, in the interview, articulated similar concerns: 'Because of the social pressure on women exerted by her family, the compulsion to take the help of technology becomes imminent; you know. ...why is that options like adoption are not being promoted. I think somewhere the whole idea of market and the role it plays is real' (Interview with a Women's right activist)

It was also noted that not only the economically vulnerable but well off women are also exploited. The easy availability of ART puts pressure on women and her family to take up the technology. Therefore, one may notice that not only the surrogacy or the ovum donation but the unregulated expansion of ART also forces women to have children. The ART also opens the possibility for eugenics as it is evident from the following response: 'you have come across a kind of marketing, you know the kind of promotion...showing those sort of designer babies, you know, all those information through the website...all those promotional blue-eyed babies, blond hair...it is kind of drawing people to those ideas or notions of accepting beauty '(*Interview with a Women's right activist*).

Such responses show that practitioners also promote notions of beauty like offering babies of desired traits, which the respondent calls "designer babies". The health of the women undergoing ART treatment was also a major concern of women's right activists. The health risks of retrieving large number of eggs, multiple pregnancies and the ethical risks posed by left over embryos and stem cell research. In fact retrieving a large number of eggs requires hyper stimulation of ovaries through intake of hormonal drugs, which often entails serious medical complication for women. Often more than two embryos are

implanted to improve chances of pregnancies. In this case, the women had to undergo foetal reduction, which again poses many health risks. Another pertinent question raised is what happens to the spare embryos? Are they sold or donated for research or simply discarded? SAMA (2010) in its study pointed out that there is no information whether they are supplied to IVF clinics for stem cell research or for something else. Thus, one can see that the use of left over eggs and embryos is the basic ethical risk of appropriating women's reproductive materials

Risk Perception of Patients

The most important risk perceived by the patients is related to the economic liability incurred during treatment. The information given on websites of infertility treatment clinics includes only the cost of particular treatments like IVF or ICSI. The actual cost of treatment can be understood only by including the money spent on different diagnostic tests and medicines and other hidden expenses like travelling and lodging cost and the loss of income from the lost working days during the treatment. It is not only money but also the feeling of severe stress when women are required to go through the tiring and repeated processes of diagnosis and treatment. The psychological risks involved with medical technologies are often not accounted for. Another patient interviewed by SAMA shared her experience in the following words: 'What has been difficult in this entire process is that it has been mentally exhausting. I am a person with a fighting spirit but I have gone through moments of utter desperation and depression and I feel that the world has come to a halt. Once the IVF cycle fails, you feel utterly dejected and don't really know how to explain the whole thing to yourself and others. You feel frustrated. It is not easy going through this process.' (SAMA 2006:62)

The information asymmetry is another problem; patients are not given proper information about treatments, risks involved or options other than ART. Mostly uneducated and rural women do not have any idea of treatment process that they undergo. The processes are explained to their male counter parts or technical jargons are used in such a way that finally the patients do not bother to ask in detail about the treatments. This also indicates lack of transparency in the functioning of the clinic.

Risk Frames of Practitioners

How doctors/ practitioners articulate the risk associated with ART could be understood through the analysis of their responses given on their websites in the form of an FAQ for potential customers. One of the infertility clinic's websites shows the general information related to the risk of oocyte freezing technique in the following words: There have been studies on mouse as well as human oocytes, & it suggest that there is no damage of intricate structures with in the egg, or structures responsible for organizing the chromosomes [the genetic building blocks with in the egg]. There have been healthy babies born from this technique, but the safety of oocyte freezing is still to be proven. (*Dr. Rama's Institute for Infertility, Hyderabad*)

The above statements suggest that the uncertainty of different ART techniques forms the basis to practitioner's riskframes.The following statement was given under the heading 'Risks associated with Assisted Hatching (AH). It is an advanced technique in IVF. The risk frame converges both risks to the embryo and to the mother. 'If not done with expertise the procedure can damage/kill the embryo itself. Some centres have reported a slight increase in the incidence of identical twins (monozygotic). This is so because while making a hole in the zona, the embryo may sometimes split into two giving rise to monozygotic twins. However, there has been no reported increased incidence of birth defects in children born as a result of this procedure. Rare side effects to the mother from the accompanying steroid and antibiotic may be there. (*Advanced Fertility Centre, Bangalore*).

The above statements attempt to down play the risk. The term 'rare side effects' symbolizes how practitioners underestimate certain types of risks. Contrary to the patients, feminists and the civil society's understanding of risk, the scientists' risk frames are based on 'technical uncertainty' but they also invoke social issues for promoting ART as it is evident from the websites of ART clinics. The ART clinics point out two types of social risks: sex-selection and socio-psychological issues that children and parents may face later in life. .

The risk frame articulated is social, because of the pre-natal diagnostic techniques widely used in India for determining the sex of the foetus leading to gender based selective abortion. Some practitioners also raise the issue of age of the patients opting for the ART. SAMA(2007) in its later study reported that a women of fifty years might be able to give birth to a baby without complications, but the problem is that when the couple get their child at around 50 years of age and by the time their child is even 10 years, they would be around 60 years of age and that might be physically strenuous for them to bring up the child. The huge age difference between the parents and the child (generation gap) might also be problematic for both of them in future. The practitioners perceive a potential social and psychological risk with increase in the age of couples/ individuals undergoing ART treatment. Considering the age related issues, the ART Bill formulated in India has put an upper age limit of 45 years for women seeking ART.

Debates on Art in Reproductive Science and Risk Perceptions of Practioners

Debates in reproductive science on issues related to ART are based on the 'uncertainty of therapies', techniques and drugs. A key inference on the characteristic of risk that can be made from the analysis of practitioners' discourse on risk is its omnipresence in human activity. Take for instance this statement, 'in a world where each step we take entails some risk, the actual risk of Creutzfeldt-Jakob disease (CJD) being transmitted is extremely minute or even zero' (Kemmann 1998:1777). Scientific actors do acknowledge risk, but the way they acknowledged them itself down plays the risk. The risk is given a

generality, one that is inherent in human enterprise and hence science is also not devoid of it.

In reproductive medicine, the risk related to ART has been articulated into four categories: Health risk, rates of success, efficacy of therapy and economic risk. However, these risks are not separate watertight compartments rather they overlap and reflect connections in understanding ART. Analysis of these risks in the following paragraphs provides a glimpse of major debates in the field.

1. Health Risk: The health risks to mother arises from multiple pregnancies, pregnancy induced hypertension (PIH), pre-eclampsia, polyhydramnios, gestational diabetes, maternal morbidity due to increased incidence of dystocia and caesarian sections and postnatal problems like isolation and depressive illness(Ombelet 2007:192). The risk of bleeding, ectopic pregnancy, heterotopic pregnancy, miscarriage and Ovarian Hyper Stimulation Syndrome (OHSS) rise with the increase in number of treatment cycles (Klemetti et al. 2005). The risk of ovum donation to the donor increases with the increase in age, the donors are vulnerable to the risk of Down's syndrome and risk of lowering fertility, which has led countries like Spain to restrict the age of ovum donation to 35 years (Marina, et.al. 1999:2773). Thus, a key inference from analysis of the above literature emerges that the uncertainties of therapies and drugs are reflected in the health risk articulation of practitioners.

2. Success Rate: Success rate can be a useful analytical tool in risk articulation and understanding the major debates because they act as a link between health risks and economic exploitation. Couples are wooed to infertility centers by projection of success rates. The ambiguities in defining success rates are used by infertility clinics to project themselves as good and exploit the couples.

The multiple pregnancy rates across the world were estimated to be 20 per cent in 1993(De Mouzon & Lancaster, 1995) which is an indication of importance of success rate in ART. To increase the possibility of pregnancy large numbers of oocytes are retrieved (Felberbaum, Ludwig & Diedrich 1998:1778) and many oocytes are fertilized in-vitro and transferred in the uterus. Health risks in ART have a linear relationship with success rates. Hyper stimulation for ovum retrieval is a major debate in the field of ART. Most of the practitioners accept that knowledge about the safety of hyper stimulation is primitive, since it's after effects will be manifested only in a long course of time (Edwards, Lobo & Bouchard, 1996:917).

Multiple pregnancies are a major cause of maternal and fetal morbidity and the premature deliveries. A major share of health care cost in ART is related to multiple pregnancies as the obstetric care costs vary from 2.1, 4.5 and 7 times greater for twins, triplets and quadruplets respectively, compared to singletons (Ombelet 2007). Multiple pregnancies in effect are iatrogenic to both mother and children. Practitioners defend transplanting multiple embryos by arguing that maximum number of embryos should be transplanted to optimize the chances of conception particularly in special situation like older women

(Adonakis, 1997:2544). On the other hand there are studies that show that health of children conceived through IVF can be improved through promotion of single embryo transfers (Klemetti 2006).

The debate on the success rate informs us two possibilities in ART: the possibilities of controlling and exploitation of technology. The ambiguity and uncertainty is more exposed in debates on therapeutic efficacy.

3. Therapeutic Efficacy: The debate on using recombinant FSH over urine derived FSH for ovulation induction therapy provides insights in to larger issues related to therapeutic efficacy and economic efficacy of assisted reproductive treatment. FSH is basically a gonadotropin hormone which stimulates the release of ovum from ovaries. Postmortem pituitary extracts and the urine of postmenopausal women were the original source of gonadotropins for therapeutic use (Balen, Hayden & Rutherford 1999:1411). Pharmaceutical companies began to explore the possibilities of genetic technologies when the problems of supply, collection, transport, storage and processing of urine compounded with the increase in the demand for FSH.

An analysis of debates on the therapies using urine derived FSH and recombinant FSH reveals that there are two groups of scientific actors one supporting the urine based FSH and other supporting recombinant FSH. Scientists favoring the recombinant version of FSH suggest the advantages like homogeneity, unlimited supply, low risk of infection, purity and specificity (ibid:1412).Some scholars also argued that the pure product is always preferred to an impure product. Human products carry a risk of infection by slow-viruses; they carry a risk of immunogenicity and had repeatedly demonstrated to be uneven in biological potency (Gleicher, Vietzke & Vidali, and 2003:477).

However, the biggest disadvantage of rFSH is the increased price of the product compared to the urine derived FSH (uFSH). The average cost of drug per treatment cycle using rFSH was more than double compared to using uFSH (Jacob et al.1998:1785-1786). One reason for the variation in the cost between both the products is that urinary gonadotropins have come off the patent production and can be sold like generic medicine on the other hand recombinant formulations are recent innovations and are highly protected by patent regimes (Gleicher, Vietzke & Vidali 2003:476). Scientists who support urinary gonadotrophins contest the therapeutic efficacy of rFSH and argue that not a single case of contamination of urinary gonadotropins in clinical use has been reported over the past thirty years which is a credible period for action of slow viruses if they were present. Recombinant products have the potential biological risk of introducing animal viruses into humans. Comparative studies on the therapeutic efficacy of uFSH and rFSH are limited in number and not substantial enough to arrive at any conclusion.

A review paper analyzing the studies that project recombinant gonadotropins as 'super drugs' argue that the surge in the study reports on recombinant gonadotropins was not of use to practitioners and these reports

have 'blurred the line between scientific information giving and marketing' (Meniru 1998:1410).

4. Economic Risks: Economic risks are analyzed by experts as the comparative costs and benefits of different strategies used in treatment. The economic risk associated with using u-FSH is seen in scientific journals on two grounds. Firstly, the lower therapeutic efficacy leading to increased treatment cycles and secondly the scarcity of raw materials for u-FSH compared to r-FSH, which escalates the cost of u-FSH. According to Mantovani, Belisari & Szucs (1999) lower therapeutic efficacy of u-FSH poses economic risk by increasing the number of treatment cycles, which leads to loss of employment days of the couples, expense in traveling which increase the overall societal cost for treatment. There is a tendency here to separate the different risks of a particular treatment and view the economic risk in isolation. Lower therapeutic efficacy in ART becomes different from other treatment because it leads to repetition of the treatment cycle leading to the use of same drugs repetitively which could lead to increase the health risks.

The risk articulation in the literature of reproductive medicine shows that practitioners and scientists perceive risk based on the uncertainty of therapies, techniques and drugs used in assisted reproductive treatment. The debates also indicate that a point of contention among scientists is manipulation of research for commercial interest which shows how it plays out in ART in promoting techniques, therapies and drugs which are not really necessary or its efficacy is ambiguous. The perception of risk is not always technical; social issues are invoked to project certain risks to counter moves from any corner to regulate ART.

Discussion

One of the strategies adopted is to contextualize the infertility problem in human rights framework is related to the questioning of rationale for denying the overweight women from infertility treatment. The 'adherence to rigid BMI cut off values in denying access to fertility treatment may represent adoption of utilitarian values at the cost of individual welfare'. The policy decision for restricting obese women from availing infertility treatment is based on utilitarian values which compromise the individual welfare to save the public money. Pandey, Maheswari & Battacharya,(2010:817) argue: 'what is unethical to these scientists is the restriction of a needy person from availing treatment – an infringement of individual right to lead a healthy life and procreate.'

Some scholars legitimize the use of ART in context of 'baby friendly policies' are linking it with declining fertility rate and declining gross domestic product (Taylor 2007:121-128). They have also advocated for inclusion of ART facilities through public health programme. Political strategies of legitimization include formation of country specific support groups or self-help groups by infertile couples, which are coordinated by umbrella organizations at regional and global levels like the International Consumer Support for Infertility (ICSI) which provides the platform for patient support groups from

39 countries all over the world (Dill 2007:148). In India the presence of patient support groups for ART is not documented by scholars. Our online search revealed the existence of organizations like '*Infertility Friends*' *(www.infertilityfriends.org)* who claim to be India's first infertility support group. Their website claims that the group was started by one of Mumbai's famous infertility clinic- *Malpani Infertility Clinic*. However, there is no credible information about the activities or the support they provide to infertile couples.

The analysis of the literature on ART in reproductive medicine and social sciences suggests that the articulation of risk by actors in scientific and social realm is based on uncertainty in therapies, techniques and drugs. While social actors relate the uncertainty of ART to both technological risk and social risk, scientific actors relate the uncertainty of techniques, therapies and drugs only to 'health risks' and 'economic risks'. However, this risk perception based on the uncertainty among the practitioners is not reflected in their public articulation and its translation in to policy. Though the perceptions of scientific actors and social actors on risks of ART shows coherence in general analysis, an in-depth analysis reveals the tensions between the social actors and the scientific actors. Assumptions on the risk of ARTs are contested even with in the same group of the actors.

Policies excluding certain groups from assisted reproductive treatment are problematized in human rights framework. The strategies in countering criticisms and attempts to regulate ART range from using scientific facts to project new technological innovation as 'user friendly' and 'promoting the welfare of women'. Nonetheless stringent regulatory measures are defended in the name of patients' rights and human rights so that women are not excluded from the accessibility of ART treatment through public health programme.
Legislations like restricting ART for obese women, which have come up based on scientific studies, are opposed by presenting contradictory studies by the practitioners suggesting the mutability of expert knowledge in scientific discourse. Practitioners counter feminists' argument that ovum donation is exploitative by using scientific studies suggesting that most of the donors are educated and are primarily motivated by altruistic considerations. It suggests that donations of these kinds do not have a scope for exploitation. On the other hand, practitioners try to differentiate 'ovum donation' and 'sperm donation' from 'organ donation'.

The debates over using recombinant drugs and urine derived drugs, shared ovum programmes versus third party donation and the number of embryos to be implanted provide insights in to the major themes of debates among ART practitioners and scientists. It can be inferred that the scientists are divided over the issue of success rate in ART treatment. While a group of practitioners promote strategies and techniques to increase success rate, the opponent groups emphasize the need for improving the quality of treatment. The debate owes significance considering the social, health and economic

implications for couples/individuals undergoing the treatment. The practitioners risk frames are analysed in a cost-benefit framework and advocated to patients to take the decision themselves. The patients' risk frame suggests that the patients do not perceive the technologies as inherently risky. Rather they perceive risk in their day to day negotiations with the expert, their economic condition, their roles in their personal and public life while seeking ART to have a child and above all the possibility of technical failure which threatens their very purpose of undergoing all the hardships.

The recently approved the surrogacy (Regulation) Bill 2016 proposes a blanket ban on commercial surrogacy while allowing altruistic surrogacy on fulfilment of certain condition. The main controversial provisions in the bill include ban on surrogacy services for single parents, live-in partners, homosexuals and unmarried couples (Live Mint 2016) and in case of heterosexual couples, they can commission only their relatives as surrogate mother and payment of money to surrogate mother other than medical bills is prohibited (The Hindu 2016). The bill also prohibits couple having biological or adopted children, Foreign nationals and oversees Indians are barred from commissioning surrogates. Practitioners have accused the government of banning surrogacy in India 'in the garb of morality and righteousness' (Bakshi 2016). Practitioners have also condemned the bill for ignoring the condition of infertile couple who have not succeeded in conceiving after repeated cycles of IVF).

The experts have also doubted about the feasibility of arranging relatives as surrogate mothers. Members of the opposition political parties have accused the bill to be exclusionary and discriminating as it prohibits surrogacy services for single parents, live-in partners, homosexuals and unmarried couples (Sibal 2016). They also point out that the bill violates fundamental rights guaranteed by the constitution such as Article 14- "equality before the law or the equal protection of the laws within the territory of India" and Article 7 and 16 of the United Nations Universal Declaration of Human Rights(UDHR) (ibid). The above Articles of UDHR call for equality before the law and the right of men and women of full age to found a family. Womens' rights activists have responded to the surrogacy bill 2016 reiterating their apprehensions that the state engagement with surrogacy and ART is in line with the agenda of promoting 'heteronormative family, marriage and patriarchal obsession with "own" biological children' (Sarojini, Sneha and Deepa 2016).

Conclusion

Our study shows that the risk perceptions of actors' depend on how they relate to ART. The relationship to technology is grounded in a socio-cultural and political context shaped through their lived experiences. Scientific actors use the language of social actors and invoke political and economic issues like 'human rights', 'declining population rate', 'accessibility and availability of ART' to promote and defend the ARTs. Scientific actors invoke the support of patient groups and lobbying groups to promote the ART. Whereas practitioners

invoke social issues in articulation of risks in particular context to counter the efforts to regulate the use of the ART.

What we witness in the regulatory policy making is that the risks perceptions of 'experts' easily make way into policies while those of 'non experts' are side-lined. This results in regulatory policies that amplify risk perception of some actors related to ART. We think the need of the hour is to initiate forums for dialogue between different actors that will echo the different risk perceptions. Further, we suggest that a dialogue process will strengthen the participation of different stakeholders and facilitate an informed regulatory policy making process.

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