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Infertility in India - levels, patterns and consequences: Priorities for social science research

Dr. Shireen J. Jejeebhoy

Objectives

Infertility has been relatively neglected as both a health problem and a subject for social science research in South Asia, as in the developing world more generally. The general thrust of both programmes and research has been on the correlates of high fertility and its regulation rather than on understanding the context of infertility, its causes and consequences. Yet, we know that infertility affects a relatively large number of couples at some point in their reproductive lives - globally, between 50 and 80 million couples [1]-- and has a variety of biological and behavioural determinants. Moreover, in pronatalist cultures such as those of India, and South Asia more generally, the consequences of infertility for women can be devastating.

The objective of this paper is to present a profile of the little that is available on the subject of infertility, and to identify social science research needs in the area of infertility.

Defining infertility

The lack of uniform definitions has hounded research on infertility. While it is clear that infertility, childlessness or sterility all refer to the inability of couples to conceive or bear children when desired, there tends to be some variation in the specific definitions adopted by clinicians, demographers and other researchers. Variation occurs largely in (a) the reference period used to establish infertility; and (b) in the classification of women who have experienced pregnancy but not a live birth.

For example, the WHO definition, drawn up by the Scientific Group on the Epidemiology of Infertility [2] has used a two year reference period:

- Infertility can be primary, if the couple has never conceived despite cohabitation and exposure to pregnancy (not contracepting) for a period of two years; primary infertility is also referred to as primary sterility;

- Infertility can be secondary, if a couple fails to conceive following a previous pregnancy, despite cohabitation and exposure to pregnancy (in the absence of contraception, breastfeeding or postpartum amenorrhoea) for a period of two years; this is also known as secondary sterility.

While WHO defines infertility as failure to conceive despite two years of cohabitation and exposure to pregnancy, many studies adopt their own definitions.

- Clinicians, and at least one community based study in Egypt [3] have used one year of unsuccessful efforts to conceive as the criterion for infertility.
- In contrast, community surveys measure infertility in terms of childlessness [4], [5]. Childlessness is defined as the proportion of couples who have not had a live birth by the time of interview, despite at least five years of cohabitation and exposure to pregnancy, and in the absence of contraception, breastfeeding or postpartum amenorrhoea. Unlike a couple with primary infertility, a childless couple also includes those who have successfully conceived but have failed to deliver a live birth. Similarly, secondary sterility in these studies refers to couples having difficulty bearing a second or higher order birth, despite usually *five* years of exposure, as in the definition above. The five year reference period is typically used, but not necessarily, in demographic surveys.

Measuring infertility

Estimates of the levels of infertility in any setting come from clinic based studies of community surveys of fertility. Both types of studies have limitations and different uses. Hospital based studies, for example, are unable to assess the levels of infertility in a particular setting but can provide extensive information on the patterns or causes of infertility prevailing in a particular clinic setting. In contrast, community based studies are better equipped to assess the levels of childlessness than its causes.

More particularly, hospital based studies are not representative of the community at large since patients visiting these hospitals are always self-selected and probably have experienced the problem for longer durations than others. Clinical studies of infertility are fraught with measurement problems and variations and difficulties in diagnosis, classification and treatment which makes comparison difficult. Another problem is sample loss; while clinical histories may be available for the entire sample, many individuals may refuse clinical examination or clinical procedures.

One clinic based study that used common definitions and methodologies was a multi-centric study sponsored by WHO [6] of over 8000 infertile couples in 33 medical centres in 25 countries in the developing and developed regions, and including Bombay, Chandigarh and Delhi. This study has been able to provide enormous insight into the aetiology of infertility and regional and cultural variations in patterns of infertility. In this study, a complete clinical history was to be taken for each partner and a full examination was to be performed, comprising a urogenital examination of and two semen samples from men, and a pelvic examination as well as hysterosalpingography or laparoscopy to estimate tubal patency among women. However, even in this design, despite uniform definitions and procedures, possibilities for bias exist: the sample was selective of couples who defined themselves as infertile, actively sought services and had good access to infertility services. Furthermore, the study experienced considerable sample loss: refusal to undergo clinical examinations or surgical procedures ranged from 22 percent in the developed country settings to 65 percent in African settings.

Community based studies have currently been more representative of the population, but have been limited in terms of insights into the patterns and causes of infertility. -In addition, definitions of infertility as assessed in community surveys vary somewhat with those in clinical studies; demographic surveys measure infertility as (a) childlessness after x years of marriage; and (b) the absence of pregnancy in sexually active couples. These measures underestimate the prevalence of infertility, for at least three reasons: 1) because in settings in which infertility is grounds for abandonment and divorce, surveys of currently married women will miss ever married women who are no longer married because of infertility; 2) because measures of childlessness ignore considerable secondary infertility; and 3) because some childless women misreport their childlessness; there is some evidence from the World Fertility Surveys that childless women do not admit their childlessness in surveys [7]. In particular, women who have adopted children are likely to be missed as infertile. On the other hand, they overestimate infertility, strictly defined, in that they can include women who have had a pregnancy but not a live birth.

Notwithstanding the difference in estimates rendered by differences in definitions and study populations, globally, it is estimated that about 8 percent to 12 percent of all couples experience some form of infertility during their reproductive lives. In a core of about five per cent of couples, the causes of infertility are attributed to anatomical, genetic, endocrinological or immunological factors. The remaining three percent to seven percent is the consequence of sexually transmitted diseases or of complications suffered post partum or post abortion [2]. Studies in developed countries suggest that about 15 percent of all couples experience primary or secondary infertility at some time in

their reproductive lives, and about half of these couples do not succeed in bearing (more) children [8].

There is very little evidence on the levels or patterns of infertility in India, and in South Asia more generally, and the little that is available is not necessarily reliable, and comes largely from measures of childlessness drawn from censuses and surveys, using varying reference periods. The recent NFHS, for example, estimates childlessness as 2.4 percent of currently married women over 40 in India [9]. The 1981 census of India [10], [11] estimates infertility to be in the range of 4-6 percent. Similarly, a global review of infertility from WFS and other sources [4], [5] estimates similar rates of infertility in other settings in South Asia (Bangladesh, 4 percent; Nepal, 6 percent; Pakistan, 5 percent; and Sri Lanka, 4 percent). Even a village level Study in Maharashtra observes an infertility rate of 6 percent [12]. Estimates for other regions of the world also fall, by and large, into the 3-6 percent band (Middle East, 3 percent; Latin America: 3 percent; Europe: 5 percent; North America: 6 percent; Caribbean: 6.5 percent). In contrast, estimates for Africa are higher (around ten percent) [5].

None of these measures of infertility includes the considerable secondary infertility prevailing in the region. One estimate of overall primary and secondary infertility in South Asia drawn on the basis of women at the end of their reproductive careers (aged 45-49) suggests a rate in the range of 10 percent: 8 percent in India, 10 percent in Pakistan, 11 percent in Sri Lanka, 12 percent in Nepal and 15 percent in Bangladesh [5].

Thus far, moreover, both community and clinic based studies have relied exclusively on quantitative methods and clinical diagnosis. Yet, the fact that little is known about the particular factors that may be associated causally with infertility in this region makes a qualitative focus and an in-depth case study design equally important. For example, an in-depth study of infertility in Egypt obtained critical insights into culturally specific determinants of infertility through ethnographic methods. Insights thus obtained were then used in the design of a standardized questionnaire, which itself contained a series of open-ended questions [13].

This study, which drew its sample from an infertility clinic, obtained an in-depth assessment of the individual's infertility and its correlates, with interviews lasting from two to four hours, using a standard but flexible questionnaire.

Determinants and correlates of infertility

While community based surveys give a broad idea of levels of infertility, they have not been designed to probe the determinants, aetiology or correlates of

infertility. The available information on the major causal factors underlying infertility come almost entirely from clinic based studies of couples seeking infertility treatment. And as a result of differences in definitions and terminology, results are often not comparable across studies.

The description of immediate causes of infertility described below come from the results of a multicentric study of infertility conducted by WHO [5], [6]. What is important is the fact that the immediate causes of infertility relate to both males and females, and that conditions that directly contribute to infertility vary widely by region and culture.

Identifiable factors affecting female infertility include: hormonal or endocrine disturbances (menstrual or ovulatory disturbances), tubal factors (occlusions, pelvic adhesions and other tubal abnormalities), acquired non-tubal factors (cervical or uterine disturbances), sexual dysfunction and congenital abnormalities. There is no demonstrable cause of infertility in the female partner for about one third of all infertile couples attending infertility clinics. The most common recognisable factors were endocrine disturbances (35 percent globally and 37 percent in Asia) and tubal factors (32 percent globally and in Asia). In contrast, sexual dysfunction, congenital abnormalities and acquired non-tubal factors accounted for no more than two percent, one percent and 12 percent globally and two percent, one percent and 15 percent respectively in Asia. Untreated reproductive tract infections, including pelvic inflammatory disease, sexually transmitted diseases, particularly chlamydia trachomatis and gonorrhoea, and botched or repeated abortions are also known correlates of infertility among women [14].

Among males, the commonest cause of infertility is oligozoospermia (semen contains too few spermatozoa), resulting from infectious factors, congenital factors, endocrine disturbances, immunological factors and varicocele, or idiopathic infertility (abnormal semen analysis results without etiological factors identifiable from history or physical examination). The distribution of major diagnoses in the WHO study suggests that almost of all men globally and 58 percent of Asian men have no demonstrable cause and another 25 percent (23 percent in Asia) revealed an abnormal semen analysis without etiological factors. The major identifiable causes of male infertility was varicocele, affecting roughly 10 percent of all infertile men and infectious factors affecting another five percent.

Knowledge of male infertility is very limited and effective treatment is rarely available. Among females, causes of endocrine disorders are also poorly understood but can be effectively treated by way of assisted fertilisation techniques [5].

There is considerable regional variation in both infertility levels and determinants. The single known factor responsible for both are differences in the prevalence of STDs. Among others, much of the available literature remains focussed on risk factors among western populations with particular attention to lifestyle issues such as over-exercising, smoking and alcohol consumption; but these factors are observed to be relatively unimportant in non-western settings [13]. Such significant regional and cultural variations in conditions that directly contribute to infertility underscore the need for culture specific studies of the sociocultural and behavioural correlates or determinants of infertility.

There is, unfortunately, very little research available on the sociocultural or behavioural correlates of infertility in South Asia.

A range of demographic, behavioural and sociocultural factors have been identified as potential determinants of infertility. Among the recognisable correlates of infertility are:

1. Sexually, transmitted diseases which account for an increasing proportion of infertility in developing countries. In particular, previous history of STDs is associated with such conditions as tubal factors in the female partner (in particular tubal occlusion or pelvic adhesions) and obstruction or gland infection in the male partner; the major STDs being gonorrhoea and chlamydia [5]. The results of the multicentric WHO study suggest that in Asia, among women with a demonstrable cause, almost half have probably become infertile as a result of either STDs or unsafe management of abortion or delivery. Among men with a demonstrable cause, about one in three is probably infertile as a result of STD experience.

There is considerable variation in the contribution of previous history of STDs to infertility, [1], [5], [6]. Its contribution has been, thus far, considerably lower among infertile couples in Asia than in Africa (13 percent and 46 percent among men in the WHO study). And, in Africa and other countries with high risk factors, upto two-thirds of infertile women who have never been pregnant are reportedly infertile because of a previous pelvic infection, mostly sexually transmitted [15]; this compares with roughly one-third in other settings. There is not much direct evidence from South Asia; a profile of an infertility clinic in Bangladesh finds that in 21 percent of all respondent couples, the husband had a low sperm count, and of these a large number were attributed to STDs [16].

Major risk factors then, aside from previous history of STDs, that are associated with infertility include number of sexual partners, contact with sex workers, history of STDs, recurrent vaginal infections, urinary tract infection, and male sexual dysfunctions [13].

2. Maternal health factors such as unhygienic delivery, postpartum infection, unsafe obstetric and abortion procedures are observed to be linked to sepsis and pelvic infections; severe malnutrition and anaemia are also observed to affect infertility; as do such morbidities as tuberculosis. Women's poor health and nutrition status can lead to repeated miscarriages and foetal wastage. The most commonly observed link is that between post-partum or post abortion complication and tubal blockages or pelvic infection that in turn cause infertility. For example, a hospital study in Delhi [18] finds a strong association between rates of pelvic infection and history of abortion. There is however some evidence also of the effect of maternal nutritional status on infertility; a study in Bangladesh finds a significant inverse relationship between weight, mid-arm circumference and incidence of sterility [17].

3. Age, adolescents are frequently observed to be temporarily infecund (adolescent sterility); so also, infertility increases among older women who become prematurely menopausal.

4. Lifestyle is sometimes held to be related to infertility -- smoking, alcohol consumption, drug use and even over exercise [13].

5. Side effects of previous contraceptive use: for example large numbers of women with pelvic infections in India had undergone vaginal tubectomy or minilaparotomy [18].

6. Marriage patterns: eg. cross cousin marriages [13].

7. Occupational patterns and exposure to noxious chemicals or pesticides in the work place [3], [13].

To this list we can add, as background determinants, the availability, accessibility and quality of reproductive health services, including information and referrals on the one hand, and levels of education, household economic status and women's autonomy on the other. There is, thus far, surprisingly little evidence available on these; one exception is a profile of infertile couples in an infertility clinic in Bangladesh that concludes that the majority of infertile couples are moderately educated but unemployed [16].

This list is by no means exhaustive, since determinants of infertility vary widely with culture. An example of how determinants of infertility vary by culture comes from a study in Egypt. This study reports that the most commonly observed factors included female ovarian, tubal and cervical factors and male factors -- each observed in 45 to 55 per cent of the infertile couples in the sample, with each infertile couple displaying on average about two factors [13].

However, the main risk factors associated with infertility were cervical electrocautery (a practice generally abandoned by modern medicine but continued in this region), male occupational exposure to noxious agents, male water-pipe smoking and close cousin marriage practices . Similarly, a study in China observed that infertility was higher where the male partner was engaged in cotton farming or smoked than among other couples; it was also higher in a low income setting than a high income one [19].

Consequences of infertility

Infertility also has severe consequences for men and particularly for women's wellbeing. Despite this, there is even less social science research on the consequences of infertility than on its determinants. Most of the evidence available is anecdotal and poorly documented. For example, in the South Asian setting, which prizes reproduction and in which women typically gain prestige and security in their husband's homes only after they have produced a son or two, few are unaware of the devastation infertility can cause for women's lives. The "blame" for infertility is unquestioningly placed on the woman. Consequences of childlessness are on several fronts but few of these consequences have been studied. Some of the more commonly expressed consequences of infertility include:

1. Health seeking or "fertility" seeking behaviour

Little is known about the fertility seeking behaviour of childless women and men. There is certainly anecdotal evidence that many childless couples turn to traditional healers or quacks. The preponderance of signs on rural highways across north India advertising dubious infertility services, gives an idea of the demand for such services and the evident success of quacks in' exploiting this demand. Such impressions are corroborated by a study in North India that finds that traditional healers are more commonly approached for such chronic non-incapacitating conditions as childlessness or impotency than for other conditions; and that treatment typically comprised the use of supernatural powers and occasionally, herbs [20]. Numbers are available from a study in Egypt -- also a patriarchal setting - substantiating the reliance on traditional medicine, particularly for women: Of the 768 couples reporting primary infertility in the sample, six per cent of the husbands, and 16 per cent of the wives sought care from traditional healers [3].

So also, large numbers of infertile men, and particularly women, do seek modern health services for infertility. Documentation however is poor, and little is known about the characteristics of those who seek services, the kinds of services received, expenses incurred and time spent in such treatment. The community

based study in Egypt, however, does look at some of these issues and its results are illuminating [3]. Of the primarily infertile couples, 43 percent of the husbands, compared to almost three in four wives (73 percent) sought medical treatment. A third of the wives, and seven percent of the husbands underwent surgery.

Increasingly utilised in India by infertile couples are sophisticated IVF technologies. These technologies exert a huge toll in terms of financial, physical and emotional costs, but are unlikely to prove successful in a large majority of cases -- one estimate suggests that no more than 5-10 percent of couples undergoing such treatment are successful.

Adoption is another fertility seeking consequence of infertility. In India traditionally, adoption has been seen as a last resort, to be explored when other treatments have been abandoned for their lack of success; more recently, adoption has become an increasingly acceptable behaviour but again, little is known about levels and patterns of adoption.

Unfortunately, a major limitation of community based investigations is that they are unable to shed light on the outcomes of treatment seeking for infertility, in terms of successful subsequent fertility, adoption or continued childlessness.

2. Marital instability

Better documented is evidence of abandonment or divorce of childless women by their husbands. For example, Cain's village level study [21] in Bangladesh concludes that one immediate consequence of reproductive failure is divorce; less commonly, a man will take on additional wives. Regardless of which partner is infertile, a woman's value as a potential spouse is severely reduced and if she remarries, it will be to someone who is less desirable than her first spouse; in addition, this process delays the start of childbearing and further reduces chances of fertility among women who can conceive [22]. Similarly, a study [23] on women's situation in Tamil Nadu and Uttar Pradesh finds that eleven percent of women in both states alike agree that a man should leave his wife if she fails to conceive; considerably fewer -- three percent -- agree to the reverse, that is, that a woman should leave her husband if he is unable to give her a child.

Studies of marital dissolution also observe that a leading cause of divorce is childlessness. For example, a study of the socioeconomic determinants of divorce in Bangladesh [22] concludes that the divorce rate is strongly associated with childlessness.

The consequences of divorce and desertion for infertile women's lives, their remarriage prospects and their economic security have rarely been studied.

3. Emotional harassment

Widespread but poorly documented except anecdotal is evidence of the severe emotional harassment experienced by large numbers of childless women in their marital homes. Harassment comes in many forms: ostracism from family celebrations, taunting and stigmatisation, negative attitudes, as well as beating, withholding of food and health care. One study of gynaecological morbidity in the slums of Baroda [23] has observed in focus group discussions and case studies that emotional harassment is often expressed by infertile women; for example, "My mother-in-law --- always fights with me and if she has her own way she will see to it that I am divorced and my husband remarried."

4. Self-esteem

Infertility is clearly a major event, and often perceived as a crisis. Studies have highlighted the low self-esteem, security and self-confidence that prevails among the childless. Women in particular suffer the deleterious consequences of infertility. The inability to perform their roles as child bearers and rearers, and the common misconception that infertility is always the shortcoming of the female is observed to take a huge toll on the woman in terms of loss of self-esteem, grief, and feelings of failure [24]. Incidents reported in India in which the presence of childless women at joyful occasions is perceived as inauspicious must reinforce feelings of inferiority. Yet, few of these consequences have been studied in the south Asian context.

Priority areas for social science research on infertility

The general focus of social science research in South Asia has been on the determinants and correlates of high fertility rather than on the levels, causes and consequences of infertility. The sparse information we have on levels of infertility comes as a by-product of information on fertility rather than from research specifically designed to assess the context of infertility. Figure 1 provides a conceptual framework outlining the correlates and consequences of infertility. What is required are studies that focus exclusively on infertility and its context: its immediate and background causes and correlates; attitudes to infertility and of infertile women and men to infertility; and consequences of infertility in terms of health and health seeking, marital disruption and relations, emotional harassment and so on. Locally assessed causes and consequences of infertility need to be taken into account. Despite the huge amount of anecdotal literature on

the consequences of infertility, especially for women's wellbeing, little social science research has addressed these issues in South Asia.

FIGURE 1 : Infertility: Correlates and Consequences

CORRELATES	MEASURES	CONSEQUENCES
<p>Age Parity Obstetric and gynaecological morbidity</p> <ul style="list-style-type: none"> • Unhygienic delivery • Complications at delivery • Post partum infection • Unsafe abortion • Severe malnutrition • Severe anaemia <p>Sexual behaviour</p> <ul style="list-style-type: none"> • Number of partners • History of STDs • Contact with sex workers <p>Previous contraceptive history</p> <ul style="list-style-type: none"> • Complications <p>Socioeconomic and cultural factors</p> <ul style="list-style-type: none"> • Occupational exposure to noxious chemicals, pesticides, close cousin marriage <p>Life style</p> <ul style="list-style-type: none"> • Alcohol consumption drug use 	<p>Primary infertility Secondary infertility Childlessness</p> <p>Male</p> <ul style="list-style-type: none"> • Oligozoospermia resulting from infections, congenital, endocrine disturbance, • immunological factors • varicocele • Sexually transmitted infections • unknown causes <p>Female</p> <ul style="list-style-type: none"> • Hormonal or endocrine disturbance • Tubal factors • Pelvic adhesions • Blockages • Acquired non-tubal factors • Congenital abnormalities unknown 	<p>Health</p> <ul style="list-style-type: none"> • Physical and mental <p>Fertility seeking behaviour</p> <ul style="list-style-type: none"> • Treatment seeking general, conservation medical use of sophisticated technologies • Recourse to quacks and godmen <p>Marital instability</p> <ul style="list-style-type: none"> • Divorce • Second wife abandonment • Economic insecurity <p>Harrassment</p> <ul style="list-style-type: none"> • Violence • Verbal abuse <p>Self-esteem and negative attitudes</p> <ul style="list-style-type: none"> • Attitudes of others to infertile women • Feelings of inferiority, low self-esteem • Attitude of adoption, childlessness

At the same time, much needs to be accomplished in the area of services and information. Referral networks for infertility treatment and counselling are rarely available, and what is available is of dubious quality. Worse, little is done to dispel the myth, in programme messages and information campaigns, that it is women who are responsible for infertility.

Conclusion

The overarching priority of programmes and unfortunately, social science research has been on the levels, correlates and regulation of high fertility rather

than on understanding the context of infertility, its causes and consequences. As a consequence, there is little reliable information on the levels, patterns, determinants or consequences of infertility in South Asia on the one hand; and health services in this region rarely provide services, reliable information or even sympathetic counselling and referrals to infertile couples, on the other. Rigorous social science research on the context of infertility would be an important first step in highlighting the extent of the problem, its causes and its consequences for wellbeing, especially that of women, as well as for programme needs.

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