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WHAT IS OUR FAULT? THE BURDEN OF INFERTILITY ON WOMEN BELONGING TO LOWER -INCOME GROUPS

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ABSTRACT This article explores the struggles of women from lower income groups in accessing Assisted Reproductive Technologies. This study, conducted in Maulana Azad Medical college based in Delhi, where we interviewed women to understand their take on ARTs. A qualitative study by nature, we highlighted issues such as delay in treatment, emotional and physical violence from home and secondary infertility. The main findings throw light on the stratification of class in the tragedy of childlessness.

KEYWORDS : assisted reproductive techniques, childlessness, parenthood, infertility in India

INTRODUCTION

In many cultures' parenthood is considered important and childless men, and women in particular, are often stigmatized (Makuch, M. Y. et al.,2011). Childlessness is a major life problem for many people mainly because it is associated with strong psychological consequences (Van Balen et al., 2002; Van Balen et al., 2009), like, anxiety, distress, depression, low self-esteem, emotional turmoil, feelings of blame and guilt and reduced libido. The situation with childless elderly people is difficult due to lack of social contact and emotional support. Not only that, childless couples may have difficulty communicating how they feel while interacting with friends and peers with children, and perceive negative attitudes from their social world (Dyer,2007; Schmidt, 2009).

There has been rapid evolution and discovery of novel pathways to parenthood like artificial insemination, oocyte cryopreservation, surrogacy, uterus transplantation, and assisted reproductive treatments (ART) (Sharma et al., 2018). ARTs are most widely recommended as successful and common treatments in most countries and include a wide range of procedures involving in vitro handling of human oocytes, sperms or embryos for establishing a pregnancy (Butler P et al.,2003).

Infertility has remained a social taboo since ages and is still not accepted as a public health challenge. With changing times and rapid developments taking place in the field of modern science, our philosophies have evolved eventually but the desire of the child, remain a major concern for most of the couples facing infertility. In parallel to the development of new ART procedures, modern societal changes have occurred in the process of family formation calling for an enhanced ethical debate and re-evaluated legislations. Infertility is a serious health issue worldwide, affecting approximately 8%–10% of couples worldwide. Of 60–80 million couples suffering from infertility every year worldwide, probably between 15 and 20 million (25%) are in India alone (Katole A et al.,2019).

However, in developing countries, infertility care and access to ART has received little attention and are neglected by governments. Services are either frequently unavailable or available at high cost for majority of the population (Vayena et al., 2009). This could either be attributable to the fact that infertility is less prioritized over other life-threatening health problems (Nachtigall, 2006) or the idea that ART demands high technology in a scenario with limited resources. In India the percentage of budget spend on health is lower than its other counter parts such as Bhutan, Nepal, and Sri Lanka.

The factors which makes India a unique case study are as follows; a) When it comes to dealing with infertility issues there is lack of awareness, b) Absence of enough infrastructure which can provide services across different economic group, c) Various important reproductive issues which are directly linked to infertility ailments are not being discussed at the public policy platform. Present study shed light on one segment of huge issue of infertility among lower income groups in India. The burden-of-infertility is an extremely complex problem to assess and varies between countries, because of different social, cultural and religious beliefs (Habbema et al., 2008). The last decade has seen increase in the number of infertility patients across the globe and with the increase in the number of infertility patients, there has been rise in the "Assisted Reproductive Technology" center in different parts of the world. According to a survey by the Indian Council of Medical Research (ICMR), including 13 districts and a sample of 37,570 women, the prevalence of primary infertility in urban areas is 4% and is 3.7% in rural areas. District Level Household and Facility Survey (DLHS) data from India (2007–2008) reported infertility in 8% of the married women reiterating infertility has become a major medical concern for sizeable amount of the young population in all types of demographical settings in India, urban as well as rural. (Deshpande PS et al.,2019)

The present article presents partial findings from a bigger study and have taken under consideration the following two objectives:

- To study the desire and pressure of conceiving among couples and their dynamics among those living in urban areas in Delhi
- To study different means and choices for treatment for infertility with respect to sociocultural, and economic background of couples

Methods

This study is a part of Ph.D. thesis submitted by the first author to University of Delhi. The present study was conducted in Maulana Azad Medical College, New Delhi (India) where 140 patients were interviewed. This mixed method study was done using snow ball sampling, and only a part of the qualitative findings is presented in this article. The study was conducted after obtaining permission from the head of department of IVF and Reproductive Biology centre. Ethical consent was obtained from the patients, questions and motive of the study was also explained to them. The name of the respondents is changed for the purpose of anonymity. Semi-structured questionnaire was prepared which addressed their socio-economic background, years of marriage, age at marriage, occupation of their husband, their obstetrics history or any other illness history and the duration for which they were taking the treatment. Due to certain limitation we have used descriptive statistics to show some of the important findings.

RESULTS

The findings have been broadly explained under the following themes using a Knowledge, Attitude and Practice (KAP) model: a) Knowledge of female patients regarding their infertility issue b) Perception of factors compounding infertility treatment, and c) Attitude of the patient in dealing within fertility and its consequences

Knowledge of female patients regarding their infertility issue

The issue of infertility becomes graver and sensitive for a female patient, particularly for those belonging to lower socioeconomic background. In a male-dominated society, it is usual to believe that women are the cause of infertility, as a result of which they often have to go through emotional crisis and the domestic violence. However, the situation turns upside down and gender biases when a male suffers from infertility. According to a study, 50% women who suffered from infertility had to face violence from their partners (Bondade et al., 2018). One patient named Asha (name changed); a young lady of 25 years of age had come all the way from Meerut for her treatment to the hospital where this data was collected. According to her, she was married off early at the age of 17 and was living in a joint family with

her husband. After trying for some time, when they were not able to conceive, they went for a check-up in Meerut itself and found that her husband was suffering from infertility. Following this, she came to Delhi with her husband for treatment and to sustain herself, she worked as part-time maid. On being asked about her husband's opinion about this she said *"he was least bothered while the other members of the family had been blaming her because of which she had to come for a treatment"*. Although the shortcoming was in the husband, he was not interested in getting himself treated. To support herself and her treatment, she was working as part time maid. Even though she knew that the problem lies with her husband, she was trying to find light at the end of the tunnel just to experience motherhood.

When it comes to knowledge about their own health condition, 34 female patients said that they did not have any problem before coming to the centre, 32 patients complained of cyst and other issues, 29 of them said that they were having blockage in the tube, in 17 patients both the partners were having problem, 14 had a miscarriage and 14 said that their husband was having low sperm count or oligospermia. Almost two-third of the study population was referred by their relatives or their treating doctors to the present facility. Almost 70% of the patients said they had family pressure because of which they have come for the treatment. Husbands of around 80% of the patients worked in private sector and most of the earnings went into managing their households. Hence undergoing such an expensive treatment for infertility was a challenge.

Perception of factors compounding the infertility treatment among female patients

Gomati (name changed) complained in disappointment regarding the infrastructure of the present facility where the interview was being conducted "There is no sitting place for our husbands and relatives who are accompanying us. Most of the time we have to bring our own water or buy it from here as there is not provision for drinking water". This makes it really difficult for us to come here for a whole day visit. Many patients complained that there was no redressal mechanism in public health facilities and nobody was ready to listen to them or their problem. They have to opt to public facilities as they didn't have the option to go for private institutions due to financial constraints. Sujata (name changed) who was waiting for her turn with the other patients also expressed her dissatisfaction regarding the drawbacks of public health facilities. She was 32 years old and married for 14 years. Her husband was working in a private firm. On being asked if she has sought treatment elsewhere previously, she said that they were showing in a private hospital. On being probed further, she said *"it was very expensive for us and hence we had to forgo the treatment"*. For past two months they were coming (both husband and wife) to this public health facility for her treatment. But here there were a lot of challenges that they had to face. There were long que of patients waiting for their turn and most of them had a similar complain that doctors were not ready to listen to them or did not give enough time to a single patient to hear them out. On an average, a patient had to wait for 3-4 months for just getting the diagnostic tests done. The whole procedure became physically and emotionally tiring for the patients and their respective families as well. As the OPD hours were between 2P.M to 4P.M., these patients used to start off from their home very early in the morning in order to reach the facility on time. All the patients said that they were certain that they will get the desired results. In spite of these critical concerns, these patients were bound to try their luck in public health care facilities because they were not financially capable of seeking treatment from a private institution. But at the same time, these atrocities cannot be overlooked.

Attitude of the patient and their family in dealing with infertility and its consequences

There were patients who were trying for a child for more than ten years. For them the present facility was the last resort and, they have come with lot of hopes. Gyatri (name changed) was in her late thirties and was trying for a child for the past 11 years. Most of these patients got married at an early age and on contrary to the working-class population, they also go through early pregnancy and tend to have larger families. during the study, it was observed that patients who got married early were either trying for long and had then come for treatment to try for ART or they were facing secondary infertility. Secondary infertility is the inability to become pregnant or to carry a baby to term after previously giving birth to a baby. The idea of family continues to be seen from the perspective of society. Many couples who were facing secondary infertility wanted to have more children mainly because of two reasons, a) either their first child was a girl, or b) if something happens to the previous child at least they should have one more. In deciding the ideal number of children, family and societal pressure plays an important role.

Kanti (name changed) was 28 years old and married for 10 years. She was having an 8-year-old male child and have had 2 abortions afterwards. On being asked about the reason for another child, she said that, *"both my brother in laws have 3 children, so my family members suggested that we should also have one more"*. Views like family pressure and desire for a male child was commonly seen among our study sample, especially for those who faced secondary infertility.

Table 1: Secondary infertility cases among patients

Age	Age at Marriage	Years of Marriage	Previous Children	Age of the Child	Previous Health Issue	Period of Trying	Reason behind trying for second child
28	15	13	1	9	No	2	wanted son
25	13	12	1	8	irregular periods	1	wanted more children
28	18	10	1	8	miscarriage twice	5	wanted more children
26	19	5	1	4	period with less flow	1	wanted male child
25	23	2	1	1	ovarian cyst with miscarriage	1	wanted more children
25	18	7	1	5	white discharge, weakness inflammation	2	wanted male child
32	24	8	1	died	tube block	3	previous child died
25	18	7	1	6	cyst, weakness in body and issue in periods	4	wanted more children
25	20	5	1	still birth	None	4	childlessness
27	23	4	1	3	miscarriage and thyroid	2	wanted more children
29	20	9	1	died	white discharge, weakness, inflammation	7	previous child died
37	20	17	1	3	Cyst in ovaries fibroid, painful, period	2	wanted more children
27	20	7	1	6	hormonal issue	4	wanted more children

Table 1 shows the various reasons behind patients seeking treatment for secondary infertility crisis. Only 15% (2 out of 13) of the cases were such who were childless while the rest were trying for another child. Reasons like miscarriage, thyroid, ovarian cyst, hormonal issues were common among patient dealing with secondary infertility.

Most of our study patients coming to Maulana Azad Medical College and Hospital, had previously gone to other private clinics before coming to the present facility. Average age at marriage was 21 years and duration of marriage was 7 years. There was barrier from the side of family as well such as discord in family relations, communication gap between husband and wife and economic issues. Almost all the patients said that they didn't wanted to go for adoption as they wanted their own child.

Pushpa (name changed) and her husband, both 38 years old and were married for 10 years. They were facing difficulty in having a child and had consulted in a private hospital earlier. She was getting treated for irregular menstrual cycle but after taking those medicines, her menstruation cycle completely stopped. They came to Maulana Azad for treatment. Their only source of income was from her husband's shop. They were clueless about adoption and from where they can adopt a child. There were various cases similar to Pushpa who were clueless regarding their situation. Most of the time there were misconceptions regarding adoption. Various patients didn't know where to approach for adopting and later in life will the adopted child accept them as parents.

DISCUSSION AND WAY FORWARD

New reproductive technologies (NRT) have indeed opened up new avenues for the problem of infertility but at the same time it has arisen

some of the important questions regarding who can access the ART services and who cannot? Also, we must not be unrealistic with our expectations from such assisted reproductive therapies. Most of the patients who were interviewed in this study belonged to the lower economic class where sustaining their daily needs was a challenge. Some of the patients also said that they had to relocate from their native place or even stay away from their husband to get themselves treated. Some of them also had to take up part time jobs to support their treatment. Frequent visits to clinic, travelling for long duration became added burden for the female patients. They had to come early for getting tested and then again had to wait for the report. In many cases they won't get their results on time. The struggle becomes evident among economically weaker sections where women are economically dependent on their husband and subject to domestic abuse in various forms. Our public sector struggles to provide answer to all infertility cases as there are relatively more critical medical problems to deal with.

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