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## **REPRODUCTIVE HEALTH AND WELL-BEING: ANALYSIS OF KANGRA**

### ***Abstract***

*Stigma due to infertility affects different aspects of women's lives across the globe, particularly in a patriarchal Indian society, where it further relegates them to a lower social status. The rationale of the paper is to unfold the situation of infertility caused by Polycystic Ovarian Syndrome (PCOS) in a traditional rural population of Kangra district in Himachal Pradesh, India. The paper focuses on the identification of the PCOS case percentage, consequences of infertility, and suggestive measures to mitigate the socio-psychological impact of PCOS. Due to under-reportage of PCOS at the local public and private hospitals, the study adopted snowball method to identify women experiencing infertility. Rotterdam Criteria with available clinical evidence was employed for screening of PCOS women. Out of 167 PCOS affected women, 54.4% were found to be experiencing infertility wherein 9.58% women happened to have primary infertility while secondary infertility was found to be higher i.e. 44.91%. The qualitative data informed that the affected women, despite being the victim of the disease were not engaged in the decision making process which severely affected their situation.*

**Keywords:** *Reproductive Health, Gender, Well-Being, Stigma, Family.*

### **Introduction**

In a traditional Indian society, marriage is irrefutably the predominant institution for raising children (Perelli-Harris et al., 2012), and motherhood is considered to be a natural and primary course for married women. Therefore, the desire to have children is regarded significant for a successful marital life. However, the inability to bear children is deemed to be a misfortune, affecting and altering the life course of married individuals. At large the concordance between body processes and social processes is maintained in the social structure by acceptance of the given codes of conduct specific to a culture. Ortner (1972:5) pointed out that due to women's reproductive capacities, they are rendered an integral and dominant part of nature, as compared to men.

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This is also the reason that women's reproduction is central in shaping their womanhood. The individual accepting the codes of behaviour get idea of cultural expectations about gender roles from their environment i.e. their society's value and belief about the categories (Blackstone 2003: 335). The fulfilment or non- fulfilment of these gendered expectations impacts the well-being of the individuals respectively. Thus, in case of women with infertility, the non-fulfilment of the expected roles of womanhood, puts their identity in predicament.

Across the world, infertility<sup>1</sup> has been relatively neglected, especially due to global politics revolving around high fertility and measures to control it. The consequences of infertility would impact women of those cultures where womanhood is deeply linked or seen synonymous to motherhood while childless women are often discriminated against and stigmatized (Inhorn 2003:1842). This paper is an attempt to situate the intersection between gender roles, fertility, patriarchy and decision making with a backdrop of infertility due to PCOS and its impact on the life of women's mental well-being. The concept of bodies becomes important as subjectivities in its social meaning become important to unfold gender constructs and images, and idealized nature and roles.

In India, the prevalence of infertility, in general, is calculated to be around 3.9 to 16.8%, and approximately 3.7% in Himachal Pradesh (World Health Organization [WHO] as mentioned in National Health Portal, NHP 2016). Polycystic Ovarian Syndrome (PCOS), being the most prevalent endocrine condition across the world, and is also one of the common causes of infertility. A study by Gill, Tiwari, & Dabadghao (2012) estimated 3.7% prevalence of PCOS in North India. On the other hand, studies that have been conducted on PCOS (between 2011 to 2017) anticipated its prevalence in India to be ranging from 3.7 to 22.5 per cent (Ganie et al. 2019:333). The discrepancies in data can be grounded on the criteria used to record prevalence. In the Indian context, PCOS is associated with the changes in socio-cultural, political and economic scenarios post the liberation of the Indian economy in year 1991 (Pathak 2020:49).

### **PCOS and Infertility**

The evidence of infertility cannot be singularly corroborated to urbanisation in developed countries as cases are reported from underdeveloped or developing countries and traditional societies as well (Harpending 1994 : 385). Among many, Polycystic Ovarian Syndrome (PCOS) has become a most common cause of primary infertility<sup>2</sup> and secondary infertility<sup>3</sup> (Basir et al. 2019:203), stemming from the endocrine imbalance (Eggers, Sabine, & Hashimoto 2007:169). Many scholars have described it through various manifestations or symptoms such as irregular or no menstrual cycle, excess hair growth on the face and body (hirsutism), weight gain, acne, ovarian cysts,

and thinning of the hair on scalp, insulin resistance etc. (Ehrmann 2005: 1223; Speroff, Glass & Kase 2005: 465; National Institutes of Health Evidence, NIHE 2012).

Infertility is reported to be ten times more common among women with PCOS in comparison to the healthy controls (Hart & Doherty 2015:919). Since the PCOS affected women have impacted ovarian quality and function, it poses a greater risk of infertility or secondary infertility (Hart & Norman 2006:751; Hart & Doherty 2015:918) and higher risk of miscarriage ( Homburg 2006 : 281).

### **PCOS, Infertility and Mental Well being**

In patriarchal societies, infertility among traditional women contributes to the psychological burden, and is often associated with lower social status; lowered self-perception; lowered autonomy in making decisions; divorce; and physical and emotional violence (Syamala 2012 :18). Motherhood is taken to be natural for women, and any deviations are discouraged (Goffman 1963:6). Many scholars believe that the ill body is a focal point to explore the socio-cultural and politico-economic issues where the body of women affected with PCOS can be perceived as a 'social body' from a socio- political perspective (Pathak 2020 :49).

Infertility, besides the physical consequences of PCOS and subsequent lowered body image satisfaction (Himelein & Thatcher 2006: 613), leads to adverse effects that women might experience in different spheres of their daily life such as low social contact and self-esteem that converge into mental trauma, stress, depression (Kerchner, Lester, Stuart & Dokras 2009 :207), and risk of other psychiatric disorders (Cesta et al. 2016 :196).

The major impact on the mental well-being of the affected women can be correlated to their social environment where the role of family pressure has already been explored by many scholars (Ramesh & Dinesh 2020: 308). Unfortunately, the male infertility is culturally 'invisible' (Barnes 2014:2), and the blame for childlessness often falls upon women, who have to face the associated stigma unevenly.

Generally, reproductive decision making may either be unilateral or collective in nature, taken up openly, or may be secretly or imposed in a coercive way. In the Indian context, the reproductive decision making rests not just with the couple but with other members of the family as well. The stress culminates as culturally women are expected to bear children immediately after formalisation of marriage. As a consequence, women with PCOS facing issues in conceiving, start experiencing pressure from their affinal families. This is because in many cultures across the world, fertility and upbringing children endows a better status and power to women in the social structure while childless women experience discrimination, derogation, and

ostracization (Riessman 2000 :111). The impact of PCOS associated stigma and individual's production of self-image is realized on the well-being of these women who may get engaged in different practices of seeking social support. In practice impacted well-being of the PCOS affected women are hardly discussed with the sick throughout the treatment which makes them more vulnerable (de Niet et al. 2010 :1501).

### **Methods of Data Collection**

This cross-sectional study was conducted between year 2018 and 2019. The sample size of the study included 167 PCOS affected women from the rural villages of Kangra district of Himachal Pradesh (a state in North India). The participants were in the age group between 18 years to 45 years. The study utilised a mixed method approach combining qualitative methods such as medical biographies, in-depth interviews, life histories, case studies, narratives etc., whereas an interview schedule was employed to collect quantitative data. Face-to-face interviews were employed to explore the possibility of finding illiterate participants as well. The quantitative and qualitative data were arranged in three data sets (i) macro data such as demographic details, percentage of PCOS, cases of infertility and sub- infertility, miscarriages, etc. from interview schedule; and (ii) in-depth data from life histories and case studies. Since the local medical institutions reported only a few cases, the participants were recruited through snowball method utilising the social network of midwives, Accredited Social Health Activists (ASHAs)<sup>4</sup> and *anganwadi* workers. The anthropometric measurements were collected using standard techniques of Weiner and Lourie (1981). Stature and body weight measurements were recorded to the nearest 0.1 cm and 0.5 kg. The descriptive statistical analysis was done by using SPSS Statistical Software version 20.0.

### **Inclusion Criteria**

The individuals fulfilling all three Rotterdam criteria (2004) along with clinical diagnostic evidences were included in the study.

### **Exclusion Criteria**

The individuals with medical history of chronic diseases such as cardiovascular disease, diabetes, etc. and of thyroid were also excluded from the study.

### **Findings**

Table no. 1 depicts that out of 167 PCOS affected women, 16 (9.6 %) women were having primary infertility and 75 (44.9%) were suffering from secondary infertility. The comparative historical research delineated that high fertility is desired by all known great religions of the world and since the

indicator of fertility or infertility of a couple revolve around women's conception, fecundity rituals are most often correlated to the female sex (Eggers, Sabine, & Hashimoto 2007). In the patriarchal traditional societies, a women's identity is generally established with and revolves around motherhood (Riessman 2000; Eggars & Kirchengast 2001).

In case of infertility, the cultural values and norms pile up stress on the affected women. Despite being a sufferer, women do not have much of a say and generally become peripheral in the reproductive decision-making process. For the present study, some cases of primary infertility were interviewed in which the reproductive decisions rested not with the women but with her family leading to various kinds of stresses, as can be witnessed from the following case study.

*Case Study 1:* A 40 years old married woman had a clinical history of irregular menstrual cycle, who got diagnosed with PCOS in year 2001. She was a housewife. Her height was 160 cm and her weight was 65kg (BMI 25.39). Her waist circumference was 99 cm. In her case, the diagnosis of PCOS was confirmed with the presence of irregular menstrual cycles and polycystic ovaries via conducted ultrasound. She was not aware of PCOS in the beginning and got to know about it only after the doctor's diagnosis. Just after her marriage, at the age of 20 years, she tried to conceive for two years but was unable to get pregnant. She also reported that they were not using any birth control so the inability to conceive remained a puzzle for them. Due to the persistence of the same issue, both the husband and wife went to see a local doctor. She reported that after examination of both it was found that she was suffering from PCOS.

After diagnosis, in 2001, she underwent regular hormonal treatment, recommended by the doctors but even after a long span of 19 years, the couple have not been able to bear a child. It confirmed that her infertility was both, a symptom and a consequence of PCOS. Her diagnosis with PCOS brought her multiple stressors but reported to have never experienced stress because of other secondary elements such as weight gain and hirsutism as much as she experienced it because of infertility. The one which affected her well-being, the most, was her family's and society's behaviour and attitude towards her. She reported that, after diagnosis, her husband became indifferent to her and continued to blame her for their childlessness. It made her unhappy and slipped into depression because of it. It affected her relationship with her husband so deeply that they barely communicated. Their sexual relationship also got affected because of it.

Her failure to accomplish the 'expected' brought her dishonour in the family and society. While her family pushed her to the periphery, her co-sister and her children became centre of their attention which also progressed her depression. The cultural norms where barren women are not allowed to perform or participate in various rituals, produced the feeling of alienation, which

negatively affected her quality of life and lowered her self-esteem. She did not feel like a 'complete woman'. She reported that her family and husband have turned down any of her suggestions to have a child via modern day reproductive technology such as In-Vitro Fertilisation (IVF).

On the other hand, in cases of secondary infertility (for example, Case study 2) women did not experience stigma related to childlessness. This is primarily because, prior to infertility, they had birthed a child. However, women with secondary infertility shared other components (such as stress and depression) with infertile women.

*Case Study 2:* In another case, in which the woman (height 152.4cm, weight 50 and BMI 21.5, waist circumference 75) had PCOS symptoms, secondary infertility was reported. The woman pretended that she was content and happy with her life. After bringing to note that every female in their family had at least two children, when she was asked about her reason to stick to only one child, she started crying. It was realised that her pretension was a strategic management of her depression and fact about herself to maintain her role as a dedicated wife and daughter-in-law, and to conceal something which could generate stigma or empathy. She had a son and pretended to be satisfied with the number of children they wanted in their family. Later she told that she did conceive a second time after her first son was born. But since her husband did not want her to continue the pregnancy, he imposed his decision on her coercively and compelled her to abort the child.

After one year of abortion, when family counselled him and suggested them to have another child, the couple affirmed with the family's suggestion and tried to conceive but the woman was unable to conceive. Later when they consulted a local doctor, she got diagnosed with PCOS associated secondary infertility. With diagnosis, the doctor prescribed her some medicines but despite it she could not conceive. She reported that after some time, they went to a local shaman as they believed that their infecundity could be a consequence of killing an unborn child and the curse of it might have been affecting them but their state remained the same.

In the study population, unmarried women (n=31) with PCOS shared their concerns related to fertility, reproductive health, motherhood, and prospective marital issues that may arise due to PCOS (for example, case study 3).

*Case Study 3:* A girl of 26 years (height 165, weight 50, BMI 18.4 waist circumference 65) with a clinical history of irregular menstrual cycle i.e. oligomenorrhea, was about to get married after a year. She was lean with 1.61m height and 46kg weight. The girl showed her concern regarding irregular periods, when other female members of her family socialized her about the ways of conduct post marriage and of marital life. Later when she was taken to the doctor, she was diagnosed with PCOS. She immediately started her

medication for the same but showed her concern regarding her fertility. She also showed her concern about the effects of PCOS on the quality of ovum which could affect the health of the future children.

### **Discussion**

Polycystic ovary syndrome (PCOS), being an endocrinopathy, is an ailment that affects women's fertility in their reproductive period. Through the case studies above, it is revealed that women in Indian context do not have reproductive decision making power where dominance of other's decisions impacts their well-being in totality. In this cross-sectional study, out of the total 167 women with PCOS with an age range between 18-45 years and a mean age of  $30.78 \pm 6.7$  years, 9.58% women happened to have primary infertility and 44.91% women had secondary infertility. For the given sample size, there were 30 (18%) women out of the total PCOS patients who happened to have at least one or a maximum of three miscarriages.

Given the frequency of infertility in PCOS patients, the author has tried to address the social and psychological consequences of infertility; and associated concerns and decision making processes via presented case studies. During research study, it was found that most of the participants were lean but had the issue of central obesity. Most of the participants were not seeking treatment, and the one seeking it was not fully aware of the consequences of the disease.

### **Conclusion**

Through the present study it was found that out of 167 participants, 54.4% were experiencing infertility (either primary or secondary) due to PCOS, wherein a proportionately larger number of women experienced secondary infertility which remains relatively inconspicuous in the national statistics but have similar psychological consequences. PCOS negatively affected all aspects of their life. Reflecting on these negative impacts of PCOS in these cases, it can be said that PCOS is not only a medical condition rather a bio-social problem. It is important to point out that along with medication to treat the disease, there is a dire need to facilitate medical counselling for both, i.e. the affected women and their families, especially in rural areas, to work on physical as well as socio- cultural consequences of PCOS and their mitigation. In this view, interventions including counselling and capacity building of the family members will help in establishing a strong family support system for women; and encourage the affected women to develop a positive attitude, fight against the stigmatization and other social atrocities. Therefore, in rural areas as in urban, emotional social support groups should be created to provide regular emotional support and counsel women to improve their mental well-being.

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### **Ethical Approval and Participant Consent**

This study was approved by the Ethical Clearance Committee, University of Delhi. Informed consent was obtained from all individual participants included in the study and anonymity was maintained.

### **Limitation of research**

The study could be conducted with a larger sample size, to have a better view of population wide prevalence. The cases of deviations in Luteinising Hormone (LH) and Follicle Stimulating Hormone (FSH) level were excluded in study.

**Table 1: Percentage distribution of infertility among women participants with PCOS.**

Infertility	Count (N)	Percentage (%)
Primary Infertility	16	9.58
Secondary Infertility	75	44.91
Total	91	54.49
Miscarriages (1 or more)	30	17.96

### **Notes**

1. Infertility is a disease of the reproductive system defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse (see National Health Portal, NHP 2016; Zegers- Hochschild et al. 2009: 9).
2. Primary Infertility synonymous to infertility which means that the couple has never conceived (see National Health Portal, NHP 2016).
3. The Secondary infertility means that the couple has experienced a pregnancy before and failed to conceive later (see National Health Portal, NHP 2016).
4. Accredited Social Health Activist (ASHA) workers act as an interface between the community and the public health system who facilitate health care needs of local people (National Health Mission, 2021). Accessed at <https://nhm.gov.in/index1.php?lang=1&level=1&sublinkid=150&lid=226>.

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