

# IMPACT OF POLYCYSTIC OVARY SYNDROME ON THE REPRODUCTIVE HEALTH OF WOMEN -A SOCIOLOGICAL STUDY

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**Abstract**—A woman's health in any household in India is given importance mainly during pregnancy, and the immediate postpartum period that follows it, leaving huge gaps in their healthcare. Women today face numerous health issues in their everyday life which are related to PCOS i.e. Polycystic Ovaries Syndrome. Currently, it is the most common endocrine disorder affecting 1 out of 10 women of reproductive age in India with more than 1 million cases each year. The most common symptoms include amenorrhea, hirsutism, infertility, obesity, acne vulgaris and androgenetic alopecia.

PCOS as a condition has an effect on three aspects of a woman's quality of life, i.e. social, health and economic. In a developing country like India where the socio-cultural environment is borderline conservative in its approach, and to make matters worse, the cost of dealing with a condition like PCOS is not something every woman can afford, there are serious social and economic ramifications in the life of a woman with PCOS. The approach of the research will be based on the social construction of illness and theories related to the concept of stigma. Health is a relative concept that varies according to age, lifestyle, personal circumstances, environment, culture, etc. but what counts as health is a social construct- a result of individual, social and cultural interpretations and perceptions. The purpose of this research is to study the level of awareness about PCOS, its effect on the reproductive health of women and how that effect brings undesirable alterations in a woman's social (relationship between infertility and marriage) and economic life.

## INTRODUCTION

A woman's health in any household in India is given importance mainly during pregnancy, and the immediate postpartum period that follows it, leaving huge gaps in their healthcare. Women today face numerous health issues in their everyday life which are related to PCOS i.e. Polycystic Ovaries Syndrome. It is slowly gaining the reputation of an everyday name amongst women in our country, especially in the urban sectors and primarily the metropolitan cities like Delhi, Bangalore etc. It is one of the most common hormonal disorders among women of reproductive age. Polycystic means "many cysts" and PCOS causes the formation of clusters of small, pearl-sized cysts on the surface of the ovaries (Wardhan, Rashmi, 2016). The cysts are fluid-filled and contain immature eggs. Women with PCOS produce

higher amount of male hormones known as androgens, which contribute to some of the symptoms of the condition.

## CAUSES

Till date, the medical science has been unable to pinpoint any certain cause or condition that leads to PCOS. However, the three major medical scenarios that are highlighted for causing it are:

1. **Insulin resistance:** The pancreas produces the hormone insulin to control the level of sugar in the blood. It helps in the transfer of glucose from the blood to the cells where it is broken down for the production of energy. A body which is insulin resistant is not affected by the naturally produced insulin and thus the body produces extra insulin to compensate. An increased level of insulin leads to over production of testosterone by the ovaries which hinder the formation of follicles (sacs in the ovaries where eggs are formed) and eventually the process of ovulation as well. Resistance to insulin also causes a body to gain weight which in turn worsens the symptoms of PCOS because the excess fat content in the body leads to an increase in the insulin production.
2. **Hormonal Imbalance:** Women diagnosed with the condition of PCOS have commonly shown an imbalance in the following hormones-
  - *Testosterone* is considered a male hormone but the female body also produces it in small amounts
  - *Luteinizing Hormone (LH)* stimulated the process of ovulation but an increased level of this hormone may have an adverse effect on the ovaries.
  - *Sex Hormone-Binding Globulin (SHBG)* is a protein present in the blood which binds itself to testosterone, reducing its effect. Thus, low levels of this hormone may trigger symptoms of PCOS.
  - *Prolactin* is the hormone which helps in the production of milk in the breast glands. An increase in the level of this

hormone has shown an adverse effect in some cases of women with PCOS.

3. Genetics: Even though the specific gene associated with PCOS has not yet been identified, there is a general agreement among experts that there might be a genetic link to this condition. Thus, if there is a family member with PCOS like mother, sister or aunt, one is quite susceptible to the condition themselves.

### IMPACT

PCOS, in today's time is one of the most complex metabolic maladies to exist with no start or end point. Instead, it exists in the form of a vicious circle where ironically, cause can take place of the effect and vice versa at any two given points on the circle. The impact of this condition is a never ending list; however it may be narrowed down to the following:

Physical or Biological:

- Irregular or no menstrual periods
- Acne
- Excess facial and body hair growth (hirsutism)
- Fatigue
- Weight gain
- Alopecia
- Impaired glucose tolerance by the age of 30
- Type 2 diabetes
- Sleep apnea
- Decrease in sex drive
- Infertility
- Barrier to effective breastfeeding
- Cardiovascular disease
- Hypertension
- Endometrial cancer
- Ovarian cancer
- Breast cancer

Psychological:

- Anxiety
- Mood swings
- Stress
- Eating disorders
- Depression
- Self esteem issues

- Body image issues
- Phobias

### Social:

- *PCOS as a taboo topic*- The topic of menstruation is considered as a taboo in majority of Indian households even today, and since PCOS is directly connected to it, the latter has consequently become a tabooed disease as well (Sharma, S., & Mishra, A. J., 2018). This approach along with a serious lack of awareness regarding the issue is a huge inconvenience while dealing with the physical symptoms let alone the psychological ones which are simply labeled as 'a phase', leaving the woman to deal with them with her own devices.
- *Infertility*- The issue of fertility from woman's perspective is not just any medical issue or a physical ailment but has an immense social connotation to it as well. It is both a personal as well as a social mountain climb for a woman trying to conceive. There are various aspects to this situation from a societal point of view:
  - i. Communal: The pressure from the community as a whole to fulfill one's role as woman by giving birth to a child has dire consequences for a woman who has no control over the situation. Not only is she excluded from social interactions and gatherings, but she is further forced to feel incomplete, inadequate and less of a woman. This behavior reinforces her social isolation whether self-imposed or imposed by her family members.
  - ii. Economic: The cost of fertility treatments takes a toll on the budget of an average Indian family. When PCOS gets involved, things get complicated and expensive by ten folds, because the treatment not only revolves around fertility medication but PCOS as well; this in itself carries the potential of a dozen medical issues. This implies regular visits to not only a fertility specialist but a gynaecologist, endocrinologist, dietician, psychologist (to keep a check on stress and anxiety levels) and various other experts.
  - iii. Religious: Religion plays a significant role as a deciding factor in the treatment that is met out to a woman on the basis of her ability to conceive a child, especially in a country like India. According to a Hindu mythologist, Devdutt Patnaik, in Hinduism it is crucial to have children (especially male) so as to achieve Moksha (salvation). It is instructed in Islam for a man to marry a woman who can bear him numerous children of which he can boast on the day of resurrection. In Bible, childless women are termed as 'Barren' (Sharma, S., & Mishra, A. J., 2018).
  - iv. Domestic abuse: The inability to bear a child is one of the leading causes of domestic violence against women

in India. This can manifest in both physical and psychological manner. In the Indian society, when a woman fails to bear a child, she is often harassed by her in-laws and relatives by being called a 'Baanj' to emphasize her worthlessness as woman.

- v. Marital relations: Infertility forces a couple and not just the woman to bear the brunt of the societal pressures, resulting in scarred relations between a husband and a wife which mostly leads to a divorce. A divorce based on infertility of a woman acts as a stigma for any future relations she might have with a man.
- *Job dissatisfaction:* The various hormonal imbalances causes frustration and anxiety and frequent spells of depression hampering the quality of work a woman puts in her job, leading to a sense of dissatisfaction. Menstrual cycle is not only vital for the uterus of a woman but also her brain as the irregularity dislocates her mind's focus from her goals.
  - *Sexual dissatisfaction:* It is observed that women with PCOS are less satisfied with their sexual life. Whether it is because of depression or body image issues or infertility or hormonal imbalance, the doctors are not sure about the trigger cause (Brady, C., Mousa, S. S., & Mousa, S. A., 2009).
  - *Identity crisis:* The presence of a normal functioning uterus in a woman's body is so integral to her self as a physical, social and sexual being that when something happens out of the ordinary in that organ, it not only has an impact on her biological health but her psychological and social health as well. First the anxiety and depression hampers her quality of work which makes her question her role as a functioning citizen of the society. Next, the sexual dissatisfaction and infertility not only makes her feel less of a wife worthy of a loving and providing husband but strengthens the notion of being incomplete when she fails to bear a child to her husband (Sanchez, N., & Jones, H., 2016). Lastly, the excess facial and body hair growth, acne and weight gain simply become the visual ramifications of her already deteriorating identity crisis as a woman.

#### **PROBLEM STATEMENT - BACKGROUND AND SIGNIFICANCE**

Currently, PCOS is the most common endocrine disorder affecting 1 out of 10 women of reproductive age in India (Shekokar P.S, 2017) with more than 1 million cases each year. The most common symptoms include amenorrhea (an abnormal absence of menstruation), hirsutism (abnormal growth of hair on a woman's face and body), infertility, obesity, acne vulgaris and androgenic alopecia (a common form of hair loss in both men and women). It is a stigmatizing condition that not only has an adverse effect on a woman's

biological health but also her identity, mental health and quality of life. Other than the biomedical aspects of this disorder, the other aspects have been completely overlooked, like social, economic, psychological etc (Sanchez N., 2014).

According to the Ontario Social Development Council (1997), Quality of Life is the product of the interplay among social, health, economic and environmental conditions which affect human and social development. The fundamental indicators to measure Quality of Life are:

- Social
- Health
- Economic
- Environmental

PCOS as a condition has an effect on three aspects of a woman's quality of life, i.e. social, health and economic. Although the health aspect is being extensively worked on since the past few decades, little has been done to address the social and economic aspects of the condition. In a developing country like India where the socio-cultural environment is borderline conservative in its approach, and to make matters worse, the cost of dealing with a condition like PCOS is not something every woman can afford, there are serious social and economic ramifications in the life of a woman with PCOS.

#### **LITERATURE REVIEW**

Primarily considered as an endocrinological disorder, recent studies have proved that PCOS is a hormonal, metabolic and psychosocial disorder that has a direct impact on a patient's quality of life. There is documentation of decrease in the quality of life because of mood disturbances, weight gain, acne, decreased sexual drive etc. Not paying attention to aspects of PCOS like depression will eventually cause delay in the treatment of "primary" issues like infertility and hyperandrogenism. Thus, the emphasis has now shifted firstly, towards a more holistic approach in dealing with the emotional turmoil that accompanies PCOS and secondly, towards an early diagnosis as well as long term management so as to increase the chances of a patient to live a healthy active life (Brady, C., Mousa, S. S., & Mousa, S. A., 2009).

The Indian Fertility Society reported the prevalence of PCOS in 3.7%-22.5% women in India. Women with PCOS experience higher levels of anxiety and depression than the general populace. According to International research, it has an unfavorable effect on the quality of life of women (QOL). There has been an increase in the focus on this aspect as it truly reflects the impact of the condition on a patient's life. The Indian perspective on the QOL is however completely unexplored. The recent approach in tackling PCOS is to understand the symptoms from the patient's point of view so as to isolate the symptoms that cause the maximum impact and target novel therapies towards them, so as to improve the

overall outcome (Chaudhari, A. P., Mazumdar, K., & Mehta, P. D., 2018).

The economic cost of the treatment of PCOS in women in the US is \$4 billion annually, including the assessment of the condition and treating the issues related to it such as hirsutism, diabetes, infertility etc. Despite the heavy costs, there is a serious lack of awareness about the issue. A significant constraint to agency (Agency refers to the ability of individuals to construct their own lives through the choices and actions they make) and health that has received minimal attention in PCOS research is socioeconomic status. For example, low socioeconomic status in childhood has been found to increase the risk of PCOS in adulthood either due to lack of awareness or the inability to afford medical care (Sanchez N., 2014).

According to an article published in the DailyO (an online blog platform created by the India Today Group), out of every ten women diagnosed with PCOS in India, six are teenagers. Despite being discovered as early as 1935, there is a lack of awareness about the condition in India. A study conducted by the Department of Endocrinology and Metabolism, AIIMS, reported that 20%-25% of Indian women of reproductive age are suffering from PCOS. 30%-50% women have a fatty liver whereas 60% are obese. Nearly 70% have developed insulin resistance, 40%-60% have glucose intolerance and 60%-70% have high levels of androgens. The extent of this condition has spread so far that it forced the hand of an agency like the Indian Council of Medical Research (ICMR) to conduct a nationwide survey (Shekokar P.S, 2017).

Evidence demonstrates that 20% of obese women with PCOS will develop an impaired glucose tolerance by the age of 30 years and also the prevalence of type 2 diabetes in them is seven times higher than the controls. The combination of these two conditions leads to an increased risk of cardiovascular disease in women with PCOS. Due to their life time reduction in ovulation rate they are generally at a low risk of ovarian cancer but the usage of ovulation induction treatment will eventually create a risk. In a study of 217 women the proportion of women with positive family history of breast cancer was significantly higher in women with PCOS compared with controls (Daniilidis, A., & Dinas, K., 2009).

A field work study conducted on women with PCOS in the Outpatient Department (OPD) of a government hospital in Jammu, in the form of interviews, to study the socio-cultural impact of PCOS on women belonging to the economically weaker section (EWS) of the society, discusses the lack of awareness about the condition and the social stigma surrounding it. The stigma is not only because of the fact that PCOS is directly related to menstruation but also because of the infertility that is a major consequence of the condition, rendering a woman incapable of playing the role socially constructed for her. In this context, one of the respondents replied, "My mother-in-law treats me like a domestic maid. She says that I am good for nothing as I couldn't provide them

with a grandchild, so I can at least be useful in the domestic chores of the family."

The taboo around the topic of menstruation in the Indian society acts as a roadblock in an early diagnosis of PCOS or even in preventing the condition. In a country like India, where women are socialized in such a way that they refrain from discussing the topic of their sexuality and biological changes in their bodies, PCOS has become a tabooed disease. Failure of being able to explain their state, women with PCOS feel marginalized and even isolated (Sharma, S., & Mishra, A. J., 2018).

## RESEARCH OBJECTIVES

- 1) To study the level of awareness about PCOS.
- 2) To study the impact of PCOS on infertility.
- 3) To study the effect of PCOS on the economically weaker women.
- 4) To study the part PCOS plays in the social life of women.
- 5) To study the relationship between infertility and marriage.

## METHODOLOGY

This study will combine both qualitative and quantitative data collection methods and tools. Thus the study would employ triangulation method. This study is based on the field work that will be conducted through interview schedule followed by Focus Group Discussion (FGD). The interview schedule would be semi-structured. Further, a case study approach would be employed for in-depth study of the women with PCOS.

## DATA COLLECTION

Data will be collected from both primary as well as secondary sources. Primary sources will include interview through interview schedule from the outdoor patient at hospitals. Respondents would be in the age group between 18-38years, government and private hospital gynecologists, experts in IVF clinics. Secondary sources of data collection will include published books, journals, newspaper articles, magazine articles, government published reports.

## UNIVERSE OF THE STUDY

Study place will include hospitals and IVF clinics in Delhi.

## SAMPLE DESIGN

Sampling design taken will be non-probability sampling. Snowball sampling will be used under non-probability sampling.

## SAMPLE SIZE

Sample size taken will be 200 respondents from Delhi.

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