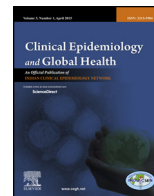




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Original research article

## Tabooed disease in alienated bodies: A study of women suffering from Polycystic Ovary Syndrome (PCOS)

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### ABSTRACT

**Objectives:** To study socio-cultural impact of PCOS on Indian Women especially those belonging to Economically Weaker Section (EWS).

**Methodology:** It is a field work based study in which females suffering from PCOS were interviewed in the Outpatient Department (OPD) of a Government Hospital in Jammu. Majority of the respondents belonged to EWS and did not know anything about PCOS. Semi-structured interview schedule was used to interview patients who visited OPD for the treatment. Entire data were collected from 15th November 2016 to 31st December 2016. Information provided by respondents is used as narratives in the present study. Theories of stigma and social construction of illness have been used to analyse respondents' approach towards the disease and the way they perceive the onset of PCOS.

**Results and discussions:** Entire discussion part has been sub-divided into: PCOS as a tabooed disease; infertility: a major consequence of PCOS; Lack of awareness about the disease; and social construction of PCOS. Respondents are found to have a grave concern about the disease due to their inability to adhere to the socially constructed role of a woman. Since, menstruation is still a tabooed topic of discussion in many parts of Indian society, hence they abstain from discussing about irregularity of periods till situation goes out of hand. Married women are marred by the stigma of infertility and unmarried ones fear future infertility.

**Conclusion:** Lack of awareness and compulsion to fulfil socially expected role of a woman, women suffering from PCOS, in this part of India, aim only at becoming pregnant (in case of married women) and normalising their monthly periods (in case of unmarried females). However, there is need to spread awareness about PCOS and encouraging women to adopt knowledge, attitude and practice approach to manage this disease.

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### 1. Introduction

Polycystic Ovary Syndrome (PCOS) is not a much talked of disease in some sections of Indian society. Present study deals with the prevalence of this disease in one such section. Around 10.97% of Indian female population is suffering from PCOS as compared to 6.3% in Sri Lanka and 2.4% in China.<sup>1</sup> This huge variation in the number of patients as compared to other Asian Countries may be due to the fact that India is the world capital of diabetes and, PCOS and diabetes share a symbiotic relation with each other.<sup>2</sup> According to a study conducted by Metropolis in India, 25.88% and 18.62% women are suffering from this disease in eastern and

northern parts of the country respectively.<sup>3</sup> This study also concluded that such leviathan prevalence of PCOS owes its existence to the ignorance and lack of awareness among youngsters. In addition to genetic pre-disposition, environmental factors in the form of sedentary lifestyle, socio-psychological stress and excess consumption of fatty and junk food also contribute a lot to the onset of this disease.<sup>4</sup> So now-a-days prevalence of this disease is mainly due to the change in lifestyle. According to Ayurveda, PCOS is related to the presence of toxins and impurities in Rakht (blood) and Rasa (lymph) Dhatu (elements) of the female body.<sup>5</sup>

Present study deals with the prevalence of PCOS amongst women, majority of whom belonged to Economically Weaker

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Section (EWS),<sup>c</sup> in Jammu city of the Jammu and Kashmir state in India. It aims at studying their social and medical approach towards the disease. The current study explores how the social construction of PCOS aggravates socio-psychological stress caused to the patient on account of this disease. It also examines how stigma is being attached to this disease, thereby, exacerbating their pathological ailments.

This disease is referred to as 'Tabooed' because of its direct association with menstruation and bodies of women have been denoted alienated due to the indifferent behaviour of women and society towards their illnesses. It has been found in a study of women in rural India, who also belonged to EWS, that 92% of the women had one or more gynaecological or sexual disorders, and only 8% of them had undergone medical examination and treatment in the past.<sup>6</sup> Maternal deprivation in the form of healthcare and nutrition, affects women and their off springs. This undernourishment of the mothers has adverse health effects for women themselves throughout their lifespan. And their children also fail to remain untouched by incessant falling health in their lives.<sup>7</sup> This can further be highlighted by taking example of women suffering from leucorrhoea. Women associate leucorrhoea with *Sharam* (embarrassment) and abstain from reporting it unless the situation becomes unbearable.<sup>8</sup> In a study on Iranian women, it has been found that lack of genital hygiene was the main reason for the high prevalence of this disease.<sup>9</sup>

## 2. Review of literature

Existing literature shows onset of various socio-cultural and metabolic anomalies in the lives of those suffering from PCOS. This disease holds its ground in the gene pool of the patient however present lifestyle manifests it thereby afflicting coming generations with PCOS like diseases. Neel<sup>10</sup> proposed a hypothesis in which he attributed onset of type-II diabetes to the thrifty nature of human gene pool. He proposed that this thrifty nature was helpful for human beings during hunting and gathering days when food availability was occasional. However, in present society due to food abundance, thrifty genotype results in the accumulation of fat in the human body, which always remains unused. This unused fat results in the onset of diseases like diabetes mellitus. Speakman,<sup>11</sup> criticised genetic thriftiness and proposed that it was genetic drift which made human beings susceptible to obesity and related lifestyle diseases. Hence, all human beings (and in present study only females) are equally susceptible to lifestyle diseases like diabetes, PCOS etc.<sup>49</sup> state that hyperandrogenemia is per se an important characteristic feature of PCOS. Its prevalence is attributed to the genotype of the patient. In their study, they concluded that presence of hyperandrogenemia was more prominent as compared to anovulation. PCOS is the resultant of genetic predisposition, and environmental factors (in the form of eating habits and physical inactivity) help in the physical manifestation of this disease.<sup>12</sup> Main symptoms of this disease are partial anovulation medically known as oligomenorrhoea and hyperandrogenism.

Restrictions imposed on menstruating women are due to socio-genic and psycho-genic approach of the society especially males.<sup>51</sup> Different meanings are provided to menstrual events and thus women are forbidden from indulging in different works. Crawford<sup>13</sup> analysed folk stories associated with menstruation and found that evil spirit resides in the blood of a menstruating woman and thus menstruated blood can affect environment of a woman.

This evil spirit enters into the body of a menstruating woman in the form of a lizard, a serpent or a bird. Thus, women in Portugal used to wear drawers during menstruation to protect themselves from these animals. According to Paula Weidiger,<sup>14</sup> some people believe that menstrual taboos are meant to protect men from the real danger which is the menstruating women. Teenage girls who feel the need of discussing menstruation in their peer group tend to opt for certain euphuisms and circumlocution so that they should not break the norm of keeping menstruation talks under cover.<sup>15</sup> In India, restrictions imposed on menstruating women vary from curbing their entrance into religious places to keeping them away from pickle jars. In a study conducted by Bhatt and Bhatt,<sup>16</sup> 44.8% women in the study (majority of them being housewives) preferred to have frequent periods as it provided them relief from the household and religious chores. Women belonging to lower social strata tend to hide everything related to their reproductive lives, even from their immediate kins.<sup>17</sup>

Similarly, lack of awareness about the disease and infertility pose a challenge for the sufferers. Worldwide infertility is associated with different psychological disorders. Infertility leads to sadness, anger, depression, hurt, embarrassment and humiliation amongst couples.<sup>18</sup> Body image dissatisfaction and sufferings from depression have been found to be very high in childless women.<sup>19</sup> Some people believe that women with PCOS can never conceive. However, doctors hold a different attitude towards this statement, because, in some cases, women with PCOS get pregnant even without any medical assistance and in some cases, just a little medical assistance prove to be helpful.<sup>20</sup>

## 3. Methodology

### 3.1. Sampling and ethical approval

The present study investigated awareness of and after effects of PCOS on women, majority of whom were belonging to EWS in Jammu city of Jammu and Kashmir state in India. Field work was done by the first author by interviewing thirty five patients suffering from PCOS at Shri Maharaja Gulab Singh (SMGS) Hospital. Sample size of the study may look small but according to George and Thomas,<sup>21</sup> an appropriate sample size for a phenomenological study can be between 6–12 persons. According to Creswell<sup>22</sup>, sample size of 20–30 respondents is sufficient for a qualitative study. Ethical approval for data collection was sought from the Ethical Committee of the Government Medical College, Jammu which is the parent hospital of SMGS hospital. The first author used to sit with the gynaecologist in the Out Patient Department (OPD) of gynaecology department of the hospital where females suffering from various gynaecological and obstetrical diseases visited to consult doctor.

### 3.2. Procedure

Tools employed for the research include purposive random sampling and thirty five patients were interviewed using semi-structured interview schedules. Approach of the patients towards the disease was also analysed using quasi participant observation method. Since, purposive sampling is clubbed with quasi participation method; hence it brings in the use of triangulation method to study the entire process. Triangulation is the method of using two or more theories, data sources, methods or investigators to conduct a research and can be used in qualitative as well as quantitative research.<sup>23</sup> In addition to the application of these tools, viewpoints of three gynaecologists (two from allopathy and one from Ayurveda) have also been included to substantiate the study.

<sup>c</sup> According to Ministry of Housing and Urban Poverty Alleviation (Government of India), any household with annual income up to Rs. 300,000 is categorised as person belonging to EWS [52].

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