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Research Article

Experiences of Young Women with PCOS: A Qualitative Study

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A B S T R A C T

Polycystic ovary syndrome (PCOS) is a noteworthy medical issue alluded to as a standout amongst the most widely recognized endocrine disorders in women of reproductive and conception age, yet it is a condition that is open to a great extent uninformed of and that healthcare service providers don't appear to completely grasp. Though PCOS has its roots in the biological factor, it is also important to understand the psychological and social perspective. Thus, the present paper has attempted to use a biopsychosocial model to explain the aspects of PCOS to understand its essential features, which may occur over time. Therefore, this perspective is essential to understanding to what extent PCOS Therefore, understanding the extent to which physical, social, and psychological attributes affect PCOS is essential. by physical, social, and psychological attributes. It is becoming increasingly clear that PCOS is now so prevalent and found to be associated with several aspects of mental health and psychological well-being, including mood disorders like depression and anxiety, eating disorders, self-esteem issues, and body dissatisfaction with physical appearance. Therefore, in order to understand the relevance of the psychosocial factors contributing to the behavioral or lifestyle changes of young women suffering with PCOS, a focus group discussion was conducted with the aim to qualitatively assess the psychosocial factors and lifestyle changes of women diagnosed with PCOS over a span of time with the aim to study them by exploring and understanding the psychosocial experiences of young women with PCOS.

Keywords: PCOS, Bio-Psychosocial Model, Health Psychology

Introduction

Polycystic ovary syndrome (PCOS) is one of the most common hormonal disorders among women of reproductive age. The condition is present in 12–21% of women of reproductive age and up; further, 70% of women with PCOS remain undiagnosed (Boyle & Teede, 2012). It was first reported by Sten and Leventhal in 1935. PCOS is classified as a syndrome because it is a heterogeneous disorder, i.e., not all of the women with PCOS will express all of the symptoms associated with the disorder. The term "polycystic" refers to multiple cysts in the ovaries seen in several women who are diagnosed with this condition.

Polycystic ovary syndrome (PCOS) is a major public health problem referred to as one of the most common

endocrine disorders in women of reproductive age, yet it is a condition the public is largely unaware of and that health care providers do not seem to fully understand. PCOS is characterized by a spectrum of symptoms, including irregular or no menstrual periods, excess hair growth on the face and body (hirsutism), weight gain, acne, ovarian cysts, and thinning of the hair on the scalp.[1] The short- and long-term health problems associated with PCOS are significant and include obesity, type 2 diabetes, cardiovascular disease, obstructive sleep apnea, complications during pregnancy, impaired fertility, and increased risk of endometrial cancer.[5] Just as concerning is the fact that PCOS can be a stigmatizing condition[6] that affects a woman's identity,[6,7] mental health,[8] and health-related quality of life;[9–12] all these aspects associated with PCOS have received less attention than the biomedical aspects of the condition. [13]

The Contemporary Perspective of Health: The Bio-Psycho-Social Model

The biopsychosocial model given by George Engel (1977) proposes not that biomedical factors are unimportant, but that they are not sufficient to understand health and illness. As the name suggests, the model recognizes the importance of psychological and social factors in diseases, illness, and health, alongside the biological variables. This model then proposes health not as the absence of disease but instead as a state of functioning and well-being that encompasses both physical and mental aspects of an individual. This is the model that informs the definitions of WHO mentioned in the sections earlier. The following sections brief the three major components of the model.

The Role of Biological Factors

The biological factors include the genetic materials and processes by which we inherit characteristics from our parents. It also includes the function and structure of the person's physiology. For example, does the body contain structural defects, such as a malformed heart valve or damage in the brain, that impair the operation of these organs? Does the body respond effectively in protecting itself, such as by fighting infection? The efficient, effective, and healthful functioning of the systems depends on the way the components in the physiology operate and interact with each other.

The Role of Psychological Factors:

Behaviour and mental processes such as cognition, emotion, and motivation are under the focus of psychological factors. Cognition is a mental activity that encompasses perceiving, learning, remembering, thinking, interpreting, believing, and problem-solving. Emotion is a subjective feeling that affects and is affected by our thoughts, behaviour, and physiology. Motivation is the process within individuals that gets them to start some activity, choose its direction, and persist in it. All of these components impact our health and illness in a countless number of ways. For instance, an example of cognition affecting health would involve the following: for instance, if a person strongly believes that life is not worth living without the things he/she enjoys and she/he turns out to be someone who enjoys smoking cigarettes, then she/he would not quit to reduce his/her risk of getting cancer or heart disease. Similarly, regarding emotion and its impact, people whose emotions are relatively positive are proven less disease-prone and more likely to take good care of their health and to recover quickly from an illness than are people whose emotions are relatively negative. The same can be said about motivation also; many people are motivated to do what important people in their lives want them to do. Parents who quit smoking because their child pleads with them to protect their health are an example.

The Role of Social Factors

People live in a social world, and as we interact with people, we affect them, and they affect us in turn. For example, adolescents often start smoking cigarettes and drinking alcohol as a result of peer pressure (Murphy & Bennett, 2004). The closest and most continuous social relationships for most people occur within the family, and children often learn many health-related behaviours and ideas from their parents, brothers, and sisters. On a broader level, our society and community affect the health of individuals by promoting certain values of our culture, such as that being fit and healthy is good. The mass media—television, newspapers, and so on—often also reflect these values. The significant influence of communities/societies is suggested in the research finding that they differ in the extent to which their members practise certain health-related behaviours, such as smoking cigarettes or consuming fatty foods (Diehr et al., 1993).

Polycystic Ovary Syndrome (PCOS)

Polycystic ovary syndrome (PCOS) is one of the most common hormonal disorders among women of reproductive age. The condition is present in 12–21% of women of reproductive age and up; further, 70% of women with PCOS remain undiagnosed (Boyle & Teede, 2012). It was first reported by Sten and Leventhal in 1935. PCOS is classified as a syndrome because it is a heterogeneous disorder, i.e., not all of the women with PCOS will express all of the symptoms associated with the disorder. The term "polycystic" refers to multiple cysts in the ovaries seen in several women who are diagnosed with this condition. The ovaries in the female reproductive system contain follicles. Each follicle contains one undeveloped egg. While several follicles begin to develop in each cycle, normally one follicle becomes "dominant" and the egg matures within the enlarging follicle. This egg is then released and moves

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to the fallopian tube. The follicles that do not release a mature egg disintegrate. In many cases with PCOS, this process gets adversely affected.

Bio-Psycho-Social Perspective of PCOS

The bio-psycho-social model sees health and illness as a result of the interplay between biological, psychological and social factors. PCOS, one of the most common endocrinology-related disorders affecting women of reproductive age, must be understood through the lens of this model.

Although the causes identified for PCOS so far have been largely biological (hormonal imbalance and genetics), its effects on women are clearly more than just biological. It is becoming increasingly clear that PCOS is associated with several aspects of mental health and psychological well-being, including mood (e.g., depression and anxiety), eating disorders, self-esteem, body dissatisfaction, and physical appearance. The co-morbidity associated with depression is particularly alarming. Women with PCOS are more likely to suffer from depression than women without PCOS, and the severity of depressive symptoms tends to be higher in women with PCOS than in controls. Further, anxiety is co-morbid with depression and potentially under-diagnosed in women with PCOS. In fact, women with PCOS tend to have higher levels of anxiety as well as higher scores on symptoms such as poor sleep, worry about unimportant matters, phobias, and pain compared with controls (i.e., women without PCOS matched for age, body weight, and body mass index). Depression can also affect mental health in the long term, considering that women with PCOS tend to be at higher risk of a major depressive episode, recurrent depressive episodes, and suicide attempts. There may be social implications of PCOS as well. For example, stigma associated with PCOS-related hirsutism leads women to avoid activities that expose the body (e.g., swimming) or involve social contact. Women with PCOS have been found to be at an increased risk of social phobia (Manson et al., 2008).

Given this evidence, treatment for PCOS cannot be simply medical. Psychological dimensions of women's experiences must be addressed. Practitioners need to consider how PCOS symptoms and related medical conditions affect or underlie mental health symptoms in women with PCOS. For example, type 2 diabetes, obstructive sleep apnea, and vitamin D deficiency associated with PCOS can result in fatigue and tiredness. A biopsychosocial perspective of PCOS is also central to developing multidisciplinary programmes that assess both the physical and mental health outcomes associated with PCOS. These multidisciplinary programmes must address concurrently many factors seen to contribute to the management of PCOS, such as life changes in diet and exercise patterns (especially to combat obesity) and learning stress management and emotional regulation.

Social support must also be built into the programmes, as it has been found to be beneficial for women with PCOS. Roessler et al. (2012) examined the psychological impact of a group-oriented approach to disease management and health behaviour in women with polycystic ovary syndrome (PCOS). Seventeen overweight PCOS women were randomised in a crossover design of eight weeks of high-intensity aerobic exercise followed by eight weeks of group counselling (n=8) or vice versa (n=9). Interpersonal communication and emotional and relational aspects were observed and analysed throughout the period, focusing on changes in health behaviour. The most salient findings showed supportive relationships expressed as group cohesion, exchange of narratives of illness and of disorder-specific aspects. Individual relationships between the participants were important for changes in behaviour, especially those generating feedback from the other participants and reducing social isolation. The results were most encouraging in the group that had initial counselling sessions before the physical intervention. It can be concluded that group counselling sessions focusing on supportive relationships followed by high-intensity aerobic training have beneficial effects on wellbeing, health and exercise behaviour for women with PCOS.

PCOS to a large extent has been studied from a clinical perspective. However, the nature of the syndrome, its manifesting symptoms and the subsequent life experiences of the women mandate a study which is holistic and which would focus on the psychosocial aspects of the syndrome. The current study is one of the very few studies which made an attempt to qualitatively understand the experience of PCOS among women. The following literature has been reviewed and presented to highlight key areas of concern and spheres of impact with respect to PCOS.

One of the earliest and most significant studies on women's own experience of the syndrome was by Kitzinger & Willmott.[12] Interviews were conducted with 30 women (21-42 years) as a part of the study. Thematic analysis of the interviews revealed pervasive reports of feeling 'freakish', 'abnormal', and not 'proper' women. These feelings were found to be related to three symptoms commonly experienced by women with PCOS: 'excess' hair growth; irregular, absent or disrupted periods; and infertility. The authors asserted that smooth, hairless bodies and faces, regular menstruation and the capacity to bear children were associated with femininity, and as a result of their symptoms, women expressed feeling 'different' from other women and less 'feminine'. The results discussed within a feminist framework suggest that polycystic ovarian syndrome is a deeply stigmatising condition, 'a theft of

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womanhood', with far-reaching implications for all women, whether or not they conform to 'feminine' norms.

In more recent times a study on 12 women (18-23 years) with PCOS in England brought about the following themes regarding the experience of PCOS: concerns for older self, feeling physically inferior, coping with symptoms, patient-provider relationship, seeking usable information and support, and coming to terms with a chronic condition. The above-noted aspects of experiences are an outcome of a semi-structured interview. Further, it was found that these women faced numerous physical, social, and emotional challenges on a daily basis.[20] Similarly, another study on the lived experiences of Danish women with PCOS provides further insights into the problems that they experienced and how they coped with PCOS. The interviews with 21 participants (20-35 years) revealed that they were highly influenced by society's femininity norms. Many of them perceived their bodies as "different" because of the symptoms of PCOS, namely, hirsutism. Further, they used different strategies to live up to body ideals and cope with the symptoms. Moreover, hirsutism had a decisive negative influence on the women's everyday lives, particularly with regard to male partners and sexual relations.[13]

Four significant themes emerged from a study that explores the experience of women living with polycystic ovary syndrome and the co-morbidities, and they are as follows: change (to life plans such as marriage and changing nature of condition and symptoms); support (healthcare professionals, education and relationships); co-morbidities (living with other conditions and depression, self-harm and suicidal ideation); and identity (feminine identity and us and them). The findings also highlight the need for screening of women with polycystic ovary syndrome for depressive disorders. Totally, 10 participants with polycystic ovary syndrome took part in Skype™ interviews, and the same was analysed using thematic analysis.[21] Williams, Sheffield & Knibb[22] conducted another study to explore the impact of polycystic ovary syndrome on women's lives using photovoice. 9 participants (20-45 years) photographed objects related to their quality of life and made diary entries explaining each photograph. Three major themes emerged from thematic analysis of the diaries: control (of symptoms and polycystic ovary syndrome controlling their lives), perception (of self, others, and their situation), and support (from relationships, health care systems, and education). The control is seen in terms of the ability to manage symptoms and also in terms of the syndrome's control over regular life activities. There is, further, a differential perception of participants about themselves and their femininity. The frustration regarding the unresponsive health care systems and alternatives found on the internet and the way women make use of the sources available is also seen. One important aspect found in the study is the positive approach by a few women towards the condition. It illuminates the positive aspects of living with polycystic ovary syndrome and the role pets and social networking sites play in providing support for women with polycystic ovary syndrome. Participants in such studies have described how certain situations or behaviours helped them to develop a more positive outlook and gain a sense of challenge rather than threat vis-à-vis the situation.

At a more specific level, the study by[2] sought to identify the information needs of women with PCOS during different periods of their lives, how and where they obtain this information, and the consequences of this information for future treatment and health outcomes. In-depth qualitative interviews regarding the information needs with 10 South Australian women diagnosed with PCOS (28-38 years) found that the internet proved to be a most versatile and beneficial source of information for women with PCOS, if its limitations are taken into consideration. In their path to diagnosis women predominantly found themes related to feelings of frustration about the delays in diagnosis, lack of information and an unwillingness of health professionals to take their symptoms seriously. Further, women considered that some doctors did not know very much about PCOS, and most were not satisfied with this information. As an outcome, women with PCOS make use of the Internet for their health information, as well as to network with other sufferers. The Internet also provides initial anonymity, an arena to discuss sensitive issues, and a reciprocal support network that can be further developed once trust is gained.

Focusing on the alternative mechanisms devised by women with PCOS in need of information,[10] conducted a study on 50 participants to consider the experiences of women living with polycystic ovary syndrome who access and participate in an online support group discussion forum dedicated to issues surrounding this condition. Thematic analysis of these interviews revealed a number of empowering and disempowering experiences associated with online support group participation. The empowering processes reported by members of the group included: Connecting with others who understand; Access to information and advice; Interaction with healthcare professionals, treatment-related decision-making, and improved adjustment and management. In terms of disempowering processes, two were described by group participants: Reading about the negative experiences of others and feeling like an outsider.

Other studies have highlighted the dissatisfactions and perceptual changes in interpersonal relationships and sexual life. For instance, a study by Taghavi et al. (2015) aimed to generate an in-depth understanding of the health-related quality of life of Iranian women with PCOS. Twenty

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Iranian women (21-34 years) were interviewed, and data were subjected to thematic analysis. Women reported substantial effects of PCOS on their quality of life, with themes generated from the data related to sexual-physical problems (an unsexualised self: loss, change and pain; and being pained and painful) and exposure and invasion: the rejecting and invading social world (concealing and avoiding and public property: public scrutiny) and diminished self and diminished life (infertile as inferior and exhausted mind and body), respectively. Another qualitative study also explored and documented the perceptions of women with PCOS about their disorder and quality of life. The study conducted semi-structured interviews with open-ended questions with 23 women (18-40 years) with PCOS. The study revealed that there were impacts of the syndrome at the physical (inconvenience and pain), mental (anxiety, frustration, and depression), emotional (embarrassment, shame and inferiority), cognitive (inability to cope), interpersonal (reduced social interaction) and intrapersonal (altered perceptions of self, body and image) levels. In addition, women with PCOS across studies have reported that they do not feel their body is sexually appealing, showing that PCOS symptoms might be negatively associated with self-esteem, body satisfaction, and/or fear of negative appearance evaluation.[6] Further, results showed that infertility affected the relationships of the couples because the infertile spouse felt guilty and considered separating or getting divorced for not being able to give a child to his partner.[1]

On a very simple note, theme analysis across studies to a large extent points at various psycho-social dimensions hitherto neglected in the study and understanding of PCOS. Most research carried out till now on PCOS studies has generally tended to focus on the biological perspectives only. However, very few, though increasingly the qualitative research studies as mentioned in the current literature review, have given attention and emphasis to the psychosocial aspects. The aspects related to sexual and physical health, psychological distress, body dissatisfactions and feminine identity concerns are common themes running across all the research. These understandings reiterate the fact that the study of PCOS is incomplete without its complementary psychosocial aspects. Having said so, the Indian literature has a paucity of such qualitative understandings of the syndrome. The current research is an attempt to fill the lacuna in the existing knowledge base.

Method

Design

This was an exploratory qualitative study seeking to understand the physical, psychological and social experiences of young women with PCOS, in the context of syndrome. A single focus group discussion was employed to understand the experiences of women with PCOS.

Sample

There was total 8 participants who were recruited through purposive sampling (it is also known as judgmental sampling). It is a non-probability technique that involves conscious selection by the researcher of certain people to include in the study. Participants are selected because they have particular characteristics that are of interest to the researcher. In the current study, women were selected for the focus group discussion if they were diagnosed by a health care specialist and were currently facing at least 2 symptoms of PCOS. All the participants were in the age group of 18-24 years and were unmarried. Details of the participants are provided in Table 1 below.

Table 1.Participants details

S.No	Age	Year of PCOS Diagnosis	Present Education/ Vocation
1	20	19	Under graduate student
2	19	17	Under graduate student
3	18	17	Under graduate student
4	18	13	Under graduate student
5	18	17	Under graduate student
6	18	17	Under graduate student
7	19	16	Under graduate student
8	18	17	Under graduate student

About the Measures

In order to develop the tool i.e. Semi structured interview, various qualitative and quantitative studies were reviewed and discussed by the students. These included studies from different parts of the world including the UK, Iran and India. Researchers engaged in the 'reflexivity' exercise wherein they discussed their own experiences with PCOS and how these experiences influenced their approach towards this research. Through this approach, various dimensions of PCOS were identified. Review of literature and group discussion indicated 4 themes around which questions could be developed:

- The journey from initial symptoms to the actual diagnosis
- Impact on life
- Sources of support and information
- Future

Questions were developed in each theme by researchers in small groups. Once the list was ready, it was read and reread to eliminate repetitions; ensure that questions were relevant to the objective of the study; were clear, sensitively worded and not leading. Questions were broad and open ended in nature, in order to be able to elicit large amount

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of information. Interview schedule used for the FGD is attached at the appendix of the report.

Discussion and Interpretation

The study was aimed to explore several nuances of PCOS, from the initial symptoms to the actual diagnosis, impact on one's life, do they have good support system, and also how well the medical professionals are equipped with knowledge and information. The analysis of focus group discussion resulted in 8 major themes. They are discussed in detail, accompanied with the verbatim in the upcoming sections.

Theme 1: The Myriad Reactions

There were significant differences and also similarities observed among the immediate reactions exhibited by the participants. Predominantly individual participants were seen responding with an inability to draw the distinction between the pubertal changes and symptoms of PCOS. This is evident when one participant reported the following: *"During adolescence, you have acne, so I didn't realize that I have PCOD."* Similar reactions were emerging from other participants also, and it was seen that almost every participant went up to a professional seeking remedy for the acne, assuming it was an adolescent hormonal change issue. Also, at this point the family members were not worried much. But post-diagnosis, a different picture emerges. The individual responses can be grouped under two broad categories. One wherein the individual was aware of the disorder beforehand and had someone in the family who had undergone similar experiences, and the second where the individual was unaware of the disorder. In the first case, where the participants were in the know of the disorder, the initial perceptions of the individual were less worried. They had the wherewithal to deal with the disorder. But when they did not know about it, they were frightened and more worried, and the misconceptions and lack of sufficient explanation by the doctors made it even more difficult for them to handle it. The following account substantiated the argument— *"I was scared, so I didn't really know what it was, and it wasn't explained properly, like what exactly is happening or how long it's going to take or what it means, things like that. So, it was scary…obviously the doctors didn't help."* And *"I got scared that I might just become infertile."* The family members were, however, seen to be reacting in similar patterns. For those who had members of the family already experiencing PCOD, they were more worried about their daughter's health and future, more so if the symptoms were severe. Those for whom the disorder was entirely new were apprehensive about a lot of possible complications that could develop as an outcome. Also, most of the participants in the current sample had manifestations of symptoms in moderate levels, and hence the panic and fear of the future were not very drastic.

Theme 2: Concerned When Known, Indifferent When Unknown

Doctors play a very important role in dealing with PCOS and in its treatment. It is essential that communication of clinical evidence fosters understanding (Epstein et al., 2004). Further, Heisler et al. (2002) evaluated closely related communication-based predictors: patients' perceptions of participatory decision-making, informing patients, and understanding. They found that self-reported, improved outcomes of diabetes self-management were closely related to informing patients and patient understanding. Despite such evidence for the importance of communication on the doctor's part, the current sample reports a majority of instances against it.

Just like the individual reactions, doctors' support and warmness differed in one respect—whether they knew the person personally or not. If the doctors knew the person on personal accounts such as family friends, then the warmth and support extended by the doctors were huge. This support was very significant in bringing about a positive attitude towards dealing with the disorder and reducing apprehension about the future. But when the doctors were unknown to the individuals, there was no emotional support extended. They were treated just at a biological level and given pills as a remedy. The following accounts exemplify the statement, *"So my family doctor lives far away, so at first I went to a popular doctor, and she treated me as if I were just another patient with PCOS, but my family doctor reassured me"; "I was treated just as any other patient; there wasn't any emotional investment or anything."*

Overall, the doctors were also seen to provide very little information and also in a less detailed fashion. They were on most occasions not providing sufficient information, leaving the participants in a confused mindset. The doctors also did not explain the possible future complications and the side effects of the pills they are about to take. On the other hand, some doctors, those who knew the patients beforehand personally, did mention the side effects, the commonness of the disorder, the possible complications that can arise, and the necessary changes in lifestyle. For instance, two participants reported the following: *"My doctor emphasized the fact of the statistics of the disorder; she told me that it is a lifestyle disorder and that I needed to change my habits, stop eating junk food, and indulge in exercise."* Also, only one doctor was seen to be suggesting alternatives to allopathic treatment. For instance, the participant reported, *"The homeopathic medicine will have no side effects, but the allopathic one will have side effects," and she listed them down.* As mentioned before, the role of doctors in the span of PCOS is very significant. However, in recent times, there has been a greater emphasis on illness rather than disease,

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and a doctor not paying attention to a person's subjective experiences with the illness can result in dissatisfaction. Dissatisfaction with doctors regarding the length of time it takes to diagnose polycystic ovary syndrome (PCOS) and disappointment at the lack of supporting information are also extremely common in literature on PCOS,[7] just as seen in the current study also.

Theme 3: Prescriptions and Proscriptions

A major similarity across participants emerged in terms of their prescribed changes in lifestyle. Unanimously, all of them had been given instructions regarding changing sleep cycles, managing weight, and intake of a balanced diet. The following accounts substantiate the observation— *"I basically try to sleep for at least six hours daily. I usually go to the gym and do yoga, and I try to control my diet. "I need to wake up on time and sleep on time, all that." "I need to lose approximately 5-10 kgs of weight for my menses to be normal."* Also, for those participants who had comorbid psychological conditions, the doctors rendered advice specific to their condition. For instance, the following account by the participant proves the claim— *"I have been through psychiatric disorders; my gynecologist talked to the psychiatrist, and they told me to lower my stress levels and take pills and medicines and said that's how PCOS will get cured. Doctors said PCOS won't go away when I have stress and all".*

The doctor's advice was in line with emphasizing the importance of lifestyle modifications and day-to-day changes in dealing with it. In line with the current study, research findings suggest that exercise and nutritional counseling may benefit the metabolic and reproductive abnormalities associated with PCOS (Bruner et al., 2006). Also, short-term weight loss has been consistently successful in reducing insulin resistance and restoring ovulation and fertility. Modifying additional lifestyle factors, including alcohol consumption, psychosocial stressors, and smoking, is also crucial in the long-term treatment of PCOS (Norman et al., 2002). Further, exercise is found to be especially critical since it increases the efficiency with which the body disposes of glucose, increases the sensitivity of cells to insulin, and reduces hyperandrogenism. In addition, it increases the likelihood of weight loss or weight maintenance, which is associated with improved clinical outcomes.[9] Additional benefits of exercise include improved blood circulation, reduced blood pressure, increased levels of "good cholesterol," stronger muscles, and a positive effect on mood.

Theme 4: The Spectrum of Impact

PCOS is across literature seen to impact several aspects of one's life. Studies have shown that the similar symptoms and manifestations could bring about different levels of impact and disturbances. For example, Sheehan (2004) observed how the same levels of hirsutism can result in different levels of distress. Another study highlighting the need for individual treatments is by Bernard et al. (2007)[3], on the different levels of success regarding acne treatments based on women's perceptions of their acne. In the current study, around seven significant dimensions of impact were elicited. They are emotional states and impact perceptions of body, performance, career, lifestyle, marriage, and family. Mood swings, though at mild levels, were reported by a few participants; the symptoms were more severe for those with comorbid psychological conditions. But otherwise, not everyone reported impacts on mood as an outcome of PCOS. The reports of participants substantiate the claim—"I *had very small mood swings, like when I would have my period. "So, two years ago I was diagnosed with depression, so at that time I did not link it to PCOD, nor did my doctor, but now I understand the link."* In general, however, it can be inferred from participants' accounts that they all could have faced some frustration and related negative impact on mood due to the outcomes of PCOS on other aspects that shall be mentioned in the following sections, such as impact on self-image, career, etc. For example—"It *didn't affect my mood much, but like, uh...it's like...it generally affects your decisions about life, about the opportunities I've wanted, and stuff like if you're not confident otherwise, so that way it has affected me."*

The next major impact was seen on perceptions of the self and the body. Irregular menstruation is a primary symptom of PCOS; in addition to this, other physical symptoms commonly associated with PCOS include weight gain, hirsutism, infertility, acne, insulin resistance, etc. (Keegan et al., 2003; Rasgon et al., 2003). In Indian women, symptoms like anovulation and infertility, obesity, insulin resistance, thyroid dysfunction, hirsutism, acne, and baldness are common. (Ramanand et al., 2013). Somewhat in line with the previous studies, the participants reported the effect of weight gain to be significant in affecting their perceptions toward their bodies. For example, *"When I put on weight, it affected my self-esteem and my self-confidence a lot. "* Hirsutism, one of the most predominant symptoms of PCOS, did not, however, manifest prominently in the current sample. Only one participant reported major impacts of hair growth. However, even that participant reported overcoming the strain caused by it over time with increasing confidence. Self-esteem and self-concept were also impacted in another important way wherein the symptoms of PCOS were seen to be causing difficulties in enjoyment or performance, like other individuals who do not have the disorder. So then individuals report feelings of not wanting to be women and also sometimes feeling bad about being women. The following accounts by participants exemplify the above inference: *"Whenever I'm on my*

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periods, I always get thoughts like 'Why am I a girl? I mean every time I get on the first days, the pain is so unbearable. I cannot do certain things, like, as simple as, hanging out or even going outside the bedroom." Research suggests that PCOS (particularly with hirsutism or infertility) can lead to a loss of sense of womanhood or femininity.[21,12] However, unlike the previous studies, none of the participants in this study believed that their identity as a woman had been impacted in any way.

The other equally significant area of impact perceived by participants was career and academic performance. Though none reported that it could have any stark bearing, all of them agreed to the regular adjustments and compromises they might have to make due to PCOS. This in turn, they felt, could possibly impact performance in academics or in a future career. For example, participants reported the following: *"If you have an important task to complete that may affect your investment in your future if you get a job," and "Extreme pain and mood swings might affect my job."* Thus, when pain and muscular cramps due to PCOS peaked, participants reported feeling dysfunctional. This brief period is when they feel like a contributor in impacting performance.

Participants overall also reported a significant controlling effect of PCOS on their lives. Lifestyle changes came across as a significant and major area of impact. Though almost all participants retrospectively took the changes to be in a positive manner, all of them initially did feel a huge sense of loss due to PCOS. In later stages, they recognize that changes done by them are indeed helpful for the larger good also. For example, the following participant account exemplifies the above claim—" Earlier *I used to sleep at 3 AM and wake up at 6 AM. No, I sleep at 12 AM and wake up by 6-7. Also started exercising, like I exercise for about one and a half hours daily and six days a week. "I take at least three proper meals... and I go to the gym"; "I think twice before consuming anything. I eat more carbs and more proteins instead of junk.* These accounts highlight the positive outlook taken by the participants towards the lifestyle modifications, even though perceived as constricting.

Another area of impact that significantly emerges across literature as impacting an individual due to PCOS is marriage and family-related concerns. Stigma associated with PCOS is also a cause for concern. Given the emphasis on motherhood and its equation with womanhood in India, if women with PCOS are infertile, a stigma of not being able to fulfill a woman's role as a mother may have negative consequences for her psychological and physical health (Manlove, 2001). Married women are marred by the stigma of infertility, and unmarried ones fear future infertility. (Sharma & Mishra, 2017). However, the current sample of participants did not convey such concerns predominantly. One participant reported feeling scared of being infertile, but largely it was seen that they were not really concerned about those aspects. It turned out that the participants themselves felt a bit immature to answer that question, as it was a bit far-fetched, and none had really given a serious thought to marriage and family. However, on deeper probing, some participants felt that there could be minor issues of adjustment that might have to be made, but otherwise no other serious impact. The following verbatim seconds the interpretation variations made: "*It would be a bit of an adjustment issue"; "I don't think it will literally affect your life drastically, but yes, to some degree"; "I don't think it should have any impact."*

Theme 5: Coping With the 'Cystorhood' Life

Coping mechanisms undertaken to deal with PCOS, though largely similar across literature, also have a few culture-specific differences. Psychological support is especially important given that women are diagnosed in adolescent years. Adolescents with PCOS are susceptible to poor mental health and additional chronic conditions (eg, type 2 diabetes) if their symptoms are untreated or poorly managed. In addition, such services need to be affordable, given the high prevalence of PCOS in India—with estimates ranging from 9.3% in Andhra Pradesh (Nidhi et al., 2011) to as high as 22.5% in Mumbai (Joshi et al., 2014). These statistics show the importance of coping mechanisms to be undertaken. However, the current sample did not report having to undertake drastically different and difficult coping mechanisms, as for almost all of them, the symptoms were manifest at milder levels. So, the specific coping mechanisms varied from none to almost very generic adaptations. Such as self-talk, music, etc., the participants' accounts are as follows: *"Self-talk always helps"; "Since I have very small mood swings, I would do things which calm me down, like I used to listen to music or have a shower."* Also, the physical symptoms such as excessive hair growth were not prominently manifest. Those physical aspects that needed coping were acne and weight gain. Thus, we can see how the participants moved from initial perceptions of ambiguity and dubiousness towards PCOS to later accepting it as a part of their life and taking it in their stride.

Theme 6: Impacts of Comparison

Comparison and its impact are stark in coming to terms with PCOS. Knowing that the symptoms are common in it has helped many participants deal with initial fright post-diagnosis. In the current study, also, this positive impact was seen. Knowing that it was common made the participants take a more proactive and positive stance towards PCOS. Also, comparison favoured the participant when the individual with whom they compared also had similar symptoms. Participants reported making combined

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and coordinated efforts to keep up their exercise regime and diet. For example, *"I had two friends from the college only who really worked hard and put their efforts into exercising… so they motivated me to push forward"; "Like she eats really healthy food, so she keeps asking me whether this is healthy or not";* "*Initially I felt negative, but when I found my best friend also had PCOS, we supported each other and ended up going to the gym together."* However, comparison turned sour when the participants found that they have symptoms different in nature or intensity from others who have PCOS. In such situations comparison leads to more negative orientations towards PCOS. For example, *'So when I ask my friends who are suffering from PCOS, "Do you have some kind of pain or problems like that?" they always say "no", and those are the days when I feel really low and like someone is wrong with me.'* These accounts show similar efforts at comparison could lead to drastically different outcomes depending on what the nature of symptoms experienced by the individuals under question is.

Theme 7: Support Systems

Support systems in the form of family, friends and other sources play a significant role in dealing with PCOS in the long term. In the current study, family was found to be an incredible source of support. Though some participants reported indirect victimisation occasionally, they also asserted that family was indeed supportive. However, it was noted that one participant mentioned that older members of the family were unable to understand her and provide support. While emotional and social support was abundant, informational support seemed to be lacking. As previously mentioned, doctors – the most credible source of information – were not seen to provide sufficient information. Thus, participants reported having the need to turn to other sources such as the internet, TV, friends and books. The internet, among these, was the most popular choice; however, it is also exercised cautiously by the participants. For example, *"Fortis gave out pamphlets. I actually got to know about the psychological effects of PCOS from there"; "Whatever doubts we have, we usually consult the internet only"; "You've got to use your own discretion when it comes to the internet and check it from multiple sources. Like if I came across something like infertility, I would ask my mother and doctor; I wouldn't just believe it."* These accounts highlight the need for credible informational support and also the paucity of it in the current context. Online support groups are functional big time in serving as emotional and informational support systems in countries abroad. However, in India this construct doesn't seem to have quite emerged at a large scale. Nevertheless, one participant reported a modicum of support group in the form of a WhatsApp™ group. This group was created and managed by the doctor and included individuals with PCOS in a particular locality and functioned similarly to a support group.

Theme 8: Context Based Suggestions of the Participant

Lifestyle changes including a healthy diet, a balanced sleep pattern, regular exercise and avoiding junk, and appropriate stress management were broadly the suggestions imparted by the participants. For instance, the participants reported the following: *"You have to exercise; you really cannot let go of that. You have to pay attention to your diet"; "You cannot take too much stress, because stress kind of really aggravates your hormones, and PCOD does get affected"; "Yoga personally has really helped me with PCOD. "* These suggestions highlight the broader nature of the impact of PCOS beyond just biology. The changes suggested are almost all in the psycho-social realms. Thus, PCOS as a disorder involves biological, psychological, and social aspects.

Understanding the Experiences through the Bio-Psychosocial Model

As can be seen in the diagram, micro-level processes consist of biological factors such as hormonal imbalance, insulin resistance, and genetics. These factors result in the physical changes such as irregular menstruation, acne, weight, body hair and hair loss, skin darkening, etc. The person can also have comorbidities with diabetes, thyroid, infertility, and so on. But biological mechanisms cannot solely explain PCOS. It has been found that stress also causes PCOS. PCOS can also impact the emotions of the person and can result in anxiety, depression, frustration, etc. Thoughts related to future complications, reproductive concerns, and whether to change doctors can also impact the experience of women with PCOS. In addition, motivation also plays an important role because that will determine whether the patient will make the required lifestyle changes to manage PCOS or not. These micro-level processes interact with each other and also with the broader macro processes. All these micro-level processes are embedded in a macro system that consists of the social system comprising the patient's family, peers, doctors, and society/culture in general. A social system, while providing the support that is required, can also impact people by contributing to anxiety and frustration. Thus, through this study and using the biopsychosocial model, one can arrive at a holistic understanding of PCOS. In our current sample, it could be said that the biological factors played a prominent role in shaping the experiences of the participants. Whatever discourse emerged came about under this dimension only, majorly. The psychological systems seem to play the next most important role. As previously mentioned, the distress and frustration caused by the condition are quite prominently prevailing. Finally,

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the social systems seem to interact and moderate the interactions between the other two levels. Strong familial support systems made the experience more manageable for the current set of participants.

Implications: The study will help future researchers to identify how treatment can be provided to individuals suffering from PCOS and what measures and treatment can be done to overcome its root cause.

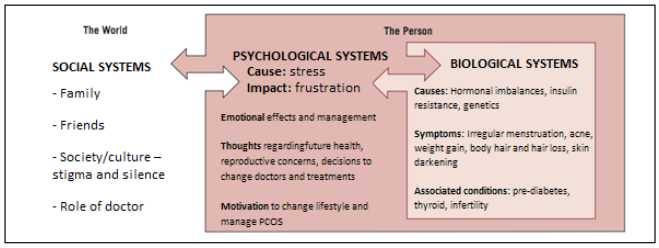

Figure 1.PCOS as a psycho-social experience can be diagrammatically conceptualized as following

Conclusion

This study looks at PCOS through a biopsychosocial perspective, which considers the interplay of biological (physiology, medications, and genetics), psychological (emotions and attitudes, beliefs, and stress management), and social (family, peers, and culture) factors to result in health and the experience of an illness. The biopsychosocial model also takes into account the systems perspective, which believes that, within a system (like our body), all levels of organisation are linked to each other in a hierarchical manner. A change in any one level will result in a change in other levels; thus, micro-level and macro-level processes are interlinked, and a change in one will result in a change in the other. This means that the physical, social, and psychological levels will all interact with each other to produce the complete experience of PCOS, the elaboration of which was presented in the previous section.

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