



Research Article

Exploring the experiences of Indian women in diagnosis and treatment of PCOS/PCOD

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Abstract

Polycystic Ovary Syndrome (PCOS)/Polycystic Ovary Disorder (PCOD) can have a substantial influence on the quality of life, which is why research into its diagnosis and treatment, with a special emphasis on the issues faced by women in the context of healthcare, is critical. The study's goal was to explore and understand the experiences of Indian women with PCOS/PCOD regarding their diagnosis and treatment. The data was collected from 12 women in their early twenties with PCOS/PCOD with the help of snowball sampling. The interviews were narrative, and the data was subjected to reflexive thematic analysis (Braun & Clarke, 2006, 2019). The main 3 themes were-1) Communicating about the diagnosis, 2) Experiences with the healthcare professionals, and 3) Treatment and Acceptance. The study concluded with the need for sensitizing healthcare professionals to the problems of women with PCOS/PCOD, also making them aware of the psycho-social impact of it on women's lives. The limitation of this study is the homogeneity of the sample as the participants were mainly women who were educated and belonged to high-income families, which restricted the kind of experience and responses the researcher got in the study. This study can be used in making various interventions for women with PCOS/PCOD.

Keywords:

PCOS/ PCOD, Quality of life, Obesity, Women's health & well-being

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Introduction

Polycystic Ovary Syndrome (PCOS) is the most prevalent endocrine disorder that is found in women in their reproductive age. It causes the ovaries to become enlarged and filled with cysts in the outer layer and abnormalities in the metabolic rate. If not treated properly, it can have chronic implications across the lifespan. Different symptoms are seen in different women; menstrual irregularities, weight gain or weight loss, body and facial hair, and hormonal acne are the common

symptoms seen in women.^[1] A woman might be genetically prone to having PCOS however it is only the interplay of environmental factors with genetic factors that causes the typical metabolic and menstrual problems, as well as the ultimate presentation of the PCOS phenotype.^[2] The Rotterdam diagnostic criteria are currently applied, and a diagnosis of PCOS is given if two of the following conditions are present: irregular or absent ovulation, increased levels of androgenic hormones, or polycystic ovaries.^[3,4]

According to a systematic review, the prevalence rate of PCOS is close to 10 percent among Indian women.^[5] By providing effective patient counselling, it is possible to provide a healthy future for women. The visible symptoms such as hirsutism (terminal hairs in a male pattern distribution),^[6] acne, frontal and temporal balding, menstrual dysfunction and obesity or the potential consequences like infertility are perceived as very stigmatizing by many women and can lead to stress and psychiatric morbidities.^[7] These symptoms are painful and considered as unfeminine.^[8] The majority of research in the past on this area has focused majorly on the pathophysiology of the syndrome.

Women need to be functional and reproductive to be truly feminine in nature. Still, it challenges the idea of being feminine and being a woman^[8] as symptoms like facial hair or an absent menstrual cycle make women question their femininity. It acts as a major stressor in the lives of women, because of the symptoms and how they are seen in society. A bunch of studies have established that women with PCOS are more likely to experience depressive symptoms than women without PCOS^[9,10]; it is associated with mood disturbances.^[11] Thus, in patients with PCOS, disease-related changes in appearance like hirsutism and weight gain,^[11] irregular or absent menstrual periods, and infertility appear to considerably affect the quality of life.^[12] A longitudinal study found that women with PCOS have a low health-related quality of life and life satisfaction till their late reproductive years.^[13]

Women with PCOS have voiced extreme displeasure with the information offered, the diagnostic process, and the treatment received; numerous studies have shown a considerable increase in emotional distress after diagnosis.^[14] A

poll of women with PCOS recruited through specialist clinics indicated that the majority were unsatisfied with oral contraceptives as treatment, with the majority responding that they would prefer other treatments.^[14,15] A prompt diagnosis could support women to increase access to medical care and encourage them to adopt healthier lifestyle choices to reduce the chances of PCOS-related metabolic and cardiovascular issues.^[16, 17,18] A study found dissatisfaction with diagnostic experience among Indian women in terms of the sensitivity of the Healthcare professionals as well as the information provided by them.^[19] Coping with a lifestyle disease is affected by various types of individual predispositions which further effect one's coping style; it was observed that emotional coping strategies was highly correlated with the quality of life among women with PCOS.^[20]

Rationale

The presence of physiological symptoms and low quality of life makes evaluation of women's emotional state and experiences an important part of their assessment and treatment. In the last decade we have seen a lot of quantitative research focusing on the quality of life and well-being of women with PCOS. There are a few studies that have captured the experiences of Caucasian women through a qualitative lens however there is a scarcity of qualitative research in the Indian context. Women of different cultural origins and races may have quite different experiences with PCOS symptoms, its diagnosis, and management, as well as its impact on Quality of life.^[19] This study focuses on the experiences of Indian women with PCOS/PCOD during diagnosis, treatment, and management. It contributes to the expanding corpus of qualitative studies that examine the lives of women with PCOS/PCOD and makes us understand the symptoms and lives of women with these symptoms. It also sheds light on the individual differences among women with PCOS and the way they cope with the syndrome.

Method

The current study took place in Delhi, the capital of India during the period of September 2021-December 2021. The constructivist paradigm was taken by the researchers due to the qualitative nature of the study.

Objectives

To explore and understand the experiences of Indian women with PCOS/PCOD in diagnosis and treatment.

Research design

An exploratory qualitative research design was used in the current study. In-depth narrative interviews were conducted with 12 participants. To explore more about the experiences of women with PCOS, a pilot study was conducted before the actual study. Unstructured interviews of two women with PCOS were conducted. They were transcribed and analysed. The major themes were observed and more literature was explored in similar areas.

Participants

There were 12 participants in the study in the age group of 19-26 years. The women were diagnosed with PCOS/PCOD. All the participants were unmarried and belonged to middle-class and upper-middle-class families. The women were college-going students or working professionals. The data was collected in the Delhi NCR region.

Sampling procedure

Snowballing was used as a sampling technique because the sample was a hard-to-reach population. Details regarding the research project were sent via social media platforms like LinkedIn, Instagram and WhatsApp. The participants responded to this information through calls or texts; the purpose of the study was explained to the participants and their availability for the interviews were asked to set the time slots. Before the narrative investigation began, consent was obtained, rapport was built, and compliance with all ethical standards was guaranteed. Narrative interviews were conducted through video calls as the study was done in the pandemic post the second wave in India.

Data collection

The inquiry method that was employed was narrative interviewing. The interviews were both videotaped and written down. Open-ended questions were created after a thorough literature study and extensive deliberations with the supervisor. These questions centered on the experiences from diagnosis to the present time and

how this disorder has affected their other aspects of life; their experiences with the healthcare professionals. To get the participants to elaborate on their experiences, the researcher applied probing strategies such as silence, prompting sentences, and nonverbal attention skills. Furthermore, probing strategies allowed the researcher to explain unclear information. The length of audio taped interviews varied from 25 to 50 minutes.

Data Analysis

The data was analysed using the Reflexive Thematic Analysis Framework.^[21,22,23] It's a technique for finding, evaluating, and summarising themes or patterns in data. This methodology is thorough, rigorous, up to date, and offers a versatile strategy for the given work. i.e. qualitative data.^[21,22] The method involves six steps 1. Familiarising with the data was done by transcribing and reading and re-reading the data. 2. Creation of codes-qualitative analysis is a constant moving back and forward between data reading, coding, reflecting, reading, recoding, and interpreting. Therefore, the important portions from the interview were highlighted as a part of the first step of coding, followed by creation of codes. 3. Searching for themes-this involves understanding the overlapping, lower levels, and higher levels of themes and sub-themes. 4. Reviewing themes and 5. Defining and naming themes-the themes were further reviewed, named, and described, including which one entails, and then finally, 6. Reporting the findings.

Each Interview script was thoroughly read by the researcher. The researcher went ahead and examined the interview data as soon as she received each transcript. The researcher then contrasted this study with earlier interviews that had been examined. The thematic analysis thus reflected not only individual interviews but also the differences between each participant's lived experience and the others.

Results

The researchers came out with three main themes 1. Communicating about the diagnosis, 2. Experiences with healthcare professionals, and 3. Treatment and acceptance, the further sub themes can be seen in Table 1. The section further discusses these themes in a more detailed way with the help of verbatims and existing literature.

Table 1 : Themes and sub-themes

Themes	Sub-themes
Communicating about the diagnosis	The initial communication about the disorder Different reactions to diagnosis Limited communication by the professionals
Experiences with the healthcare professionals	The experiences of the subjects concerning medical professionals and their ways Lack of empathy
Treatment and Acceptance	Alternative Treatment Coping with the disorder Individual predispositions like locus of control, sense of agency and self-efficacy Part of self

- Communication about the diagnosis** - The initial communication was seen as an experience which had a great impact on the participants, they responded to the diagnosis differently. Limited explanation by the healthcare professionals during the diagnosis was seen as an overarching theme that majority of the participants shared; this resulted in a state of confusion, anxiousness and going after different sources of information which could be reliable or not.

A 22 year old participant shared - "pehle wale doctor ne kuch nahi bataya tha jiski wajah se mujhe or mumma ko samajh hi nahi aa raha tha ki hota kya hai phir 1 saal around ke baad humare current doctor ne detail mai bataya ki kya hota hai or kaise manage hota hai.. ki darne ki bilkul zarurat nahi hai (first doctor didn't tell us anything because of which my mother and I were very confused about what exactly is this disorder... then around 1 year later our current doctor told us about the syndrome in detail and how it can be managed and that there is nothing to worry about.)".

A 20 year old participant shared her experienced "doctor ne toh bus physiology explain kari thi or kuch nahi bataya (doctor only explained about the physiology of the syndrome)" when the participant further asked her doctor she said, "aap medicine khao thode time phir dekhte hai (you eat the medicine for an year and then we'll see)."

A 22 year old shared that it took her around a year to wrap her mind around the whole diagnosis and understand what it is doing to her body.
- Experiences with the healthcare professional** - The theme covers different types of experiences the participants had with the healthcare professionals.

A participant shared her experience of changing multiple doctors as she felt body shamed by all of them. She was quoted saying - "she (doctor) used to say do a lot of physical exercise and I feel disappointed I mean how can I do the exercise when I am not at all feeling energetic how stupid of you...".

A participant shared her experience of her initial diagnosis when she was 19 years old saying -and the first thing she basically told me was one of the very major things that I remember from that session is she asked me to get married and have kids as much as I want to before 30 because after that I will have implications I was just an 18 years old so I just panicked..."
- Treatment and acceptance** - It covers about the alternative treatments the participants shared about and the treatment. Participants had different ways of coping and accepting the situation and individual pre-dispositions played a major role in this process.

When asked about her current treatment plans one of the participants said "... I'll switch to Ayurveda or homeopathy." explaining about how she and her mother don't think allopathy is working and believe that alternate treatments will work better.

A 23-year-old participant had lost all hope and faith in the treatment and felt that there is nothing that can happen now. She was quoted

saying that - “ab kuch nahi ho sakta yaar (nothing can happen now)”; due to this thought she had stopped taking medicine and preventive measures.

A participant while explaining about her diagnosis and initial experience said - “umm I felt like this is not me and everyone is lying to me and I just felt very away from my body because I was not used to seeing myself like that...”; another participant said “I felt very unattached to myself”

A participant stated “I see PCOS as something that I have to carry with me I like it or not”.

Discussion

Polycystic Ovary Syndrome is the most prevalent endocrine disorder that is found among women in their reproductive age. The diagnosis of this lifestyle disease has suddenly increased in India due to the increasing awareness around women's reproductive health and the increase in the obesity and lifestyle index. The visible symptoms or the potential consequences are perceived as very stigmatizing by many women and can lead to stress. This study was done to explore the experiences of women with PCOS in India. A thorough literature review was done to understand PCOS, its symptoms and its effect on women. A pilot study was conducted to understand the experiences of women and to explore the domains and then structure the interview questions.

The first theme “Communication about the Diagnosis” talks about the experiences of the participants around the time of the diagnosis covering the period of prognosis and the aftereffects of the diagnosis. It was seen in multiple cases that the doctor's communication about the disorder played a major role in how the participants took up the treatment procedure and followed it or not. A participant was noted saying that her doctor just told her that she has PCOS, said that it was very prevalent nowadays and prescribed her medications. She had no choice but to come back home and google which lead to more increased anxiety when she saw symptoms like infertility and a lot of facial hairs. This above phenomenon has been termed as 'Cyberchondria' which is defined as searching for symptoms about medical conditions repeatedly which further results in increased health anxiety.^[24] Women who were able to cope with the

diagnosis had a good experience with their healthcare professionals who told them about the syndrome in detail, its prevalence rate, its effect on one's life and the its further treatment and management. The diagnosis that occurs in adolescence must be taken sensitively as there are a lot of other changes going on around the life of the girls at this time, if the doctors are not able to make the girls aware or don't give knowledge about the symptoms and other aspects of treatment the patients try to find the answers through google or other external sources which makes it even worse and the same was seen in the cases of the participants. The time of prognosis and diagnosis was seen as a major contributing factor to how well an individual was able to cope with the syndrome and the majority of women showed dissatisfaction with their diagnosis experiences.^[15,19,25,26]

The second theme covers the “Experiences with the Healthcare professional” of all the participants. Majority of participants felt that their doctors were very dismissive about their problems like mood swings and lethargy and the only thing they told them was to lose weight which made the participants feel ignored and their bodies restricted to the weight. Majority of the participants shared their experiences with the doctors where they felt they were body-shamed. Changing or switching multiple doctors was seen as a pattern in most participants as they wanted a medical professional who could empathize with their situation, act in a more sensitive way and provide them with a holistic treatment rather than just oral contraceptive pills. There is ample literature from Western countries that have shown similar themes where the participants shared their experiences with the healthcare professionals and how participants felt ignored and demeaned by them.^[25-27]

The third theme “Treatment & Acceptance” talks about the treatment of PCOS/PCOD of the subjects, and how there were some points of commonality that affected the participant's journey. The theme also talks about the alternate treatment participants went looking for after diagnosis. These alternative ways of treatment like Homeopathy or Ayurveda because they were tired of take so many medications for such a long time and felt that these medicines are doing them more harm than good. Three participants shared about their belief that having a healthy and stress-free lifestyle is the only treatment for this syndrome.

There were some individual characteristics like Locus of control that effected the women's acceptance of the disorder and the way they dealt with the disorder. The disorder requires an individual to make lifestyle changes like proper sleep, regular exercise, intake of a balanced diet, and stress management; women who felt that they had achieved control over PCOS had first accepted PCOS as part of self, and they had an internal locus of control. Every participant in the study stated that she needed to or eventually needed to learn how to live with PCOS.

The first and foremost treatment in PCOS/PCOD is healthy lifestyle changes, being able to enforce these changes requires certain sense of acceptance about the disorder and an internal locus of control, a faith in themselves one will be able to achieve it. A 23-year-old participant had lost all hope and faith in the treatment and felt that there is nothing that can happen now. A similar pattern was seen in all the 12 participants; individuals who were able to cope with the syndrome properly had the belief that making dietary changes or exercising regularly were in their control and by doing that they will be able to improve their symptoms. Studies have shown the role of Locus of control in health behaviours and health related outcomes.^[28-29] Accepting the condition as part of self was also seen as a major stage that the participants went through. Each participant was at a different stage in terms of perceiving the syndrome as part of the self. Initially, during the diagnosis, the participants felt unattached and in denial. The majority of the participants who were able to cope with the syndrome in a positive way had been able to accept PCOS/PCOD as a part of their lives. Acceptance of a disease has been linked to better health outcomes and life satisfaction.^[30] In PCOS patients, increased generalised self-efficacy and dispositional optimism were correlated to improved illness acceptance.^[31]

Limitations

The limitation of this study is the homogeneity in the sample. The perspectives of the women interviewed in this study may not represent those of a broader, more demographically diversified sample. The participants were mainly women who were educated and belonged to high-income families, which restricted the kind of experience and responses the researcher got in the study. The

researchers chose only sample belonging to the age group 19-25 years old as the researchers wanted to focus on the experiences of women concerning their diagnosis and acceptance of the disorder which generally is seen in the later adolescence or in women in their twenties. So the experiences, emotions and opinions of the sample may not be generalized to women who are in the later stages of their lives. Further research can be done including women from low-income families and rural areas to see the impact of PCOS on their lives. There was ample evidence from the data that both the initially received diagnosis of PCOS and its ongoing treatment and assistance resulted in discontented experiences which further brings us to the future implications.

Future implications

This study can be used in making various interventions for women with PCOS, treating not only the physical symptoms but also working upon how they cope with this lifestyle disease. Many of the participants felt that living with the syndrome's uncertainty was incredibly frustrating, and that knowing information would have considerably reduced the uncertainty. Healthcare practitioners can improve the lives of women diagnosed with PCOS/PCOD in numerous ways, including (a) diagnosis, (b) physical problem management, (c) psychosocial issue management, and (d) education.^[32] Before putting the best possible intervention into practice, all facets of the patient's mental and social situation should be taken into account.^[32]

Conclusion

The research sheds light on the experiences of women with PCOS/PCOD. The results show that healthcare professionals play a very important role in the diagnosis and treatment of the syndrome and how their behaviour can affect women's experiences. The research also talks about the dissatisfaction of women with respect to healthcare and the treatments regarding PCOS/PCOD. Psychological consultation can help these individuals deal with the unpleasant elements of PCOS. The above themes also shed light on a need for training of healthcare professionals sensitizing them about the symptoms and suffering of women with PCOS/PCOD.

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