

Psychological Experiences in Women with Polycystic Ovary Syndrome: A Qualitative Study

Abstract

Background: Polycystic Ovary Syndrome (PCOS) is the most common endocrine disorder among women of reproductive years. In addition to multiple physical problems, this syndrome has many psychological complications. Thus, the present study attempted to explore the psychological experiences of women with PCOS in Iran's sociocultural context. **Materials and Methods:** The study was carried out in Isfahan, Iran, using a qualitative content analysis method. The participants were selected through purposive sampling from women with PCOS, their spouses, and healthcare providers in hospitals, clinics, workplaces, universities, and physicians' offices between September 2018 and November 2019. Data collection was performed through semi-structured interviews until data saturation. Data analysis was based on conventional content analysis. The interviews were transcribed and coded. Afterward, categories and concepts were extracted by grouping similar codes. **Results:** A total of 13 women with PCOS, four spouses, and 13 healthcare providers participated in this study. Data analysis yielded five main categories, including the patient's psychological reactions following infertility and its probability, psychological issues following menstrual disorders, patients' fear and concerns about the probability of developing chronic diseases, psychological problems following the disease, and psychological problems resulting from body appearance. **Conclusions:** The results of this study showed that women with PCOS were exposed to multiple psychological problems. Therefore, preventing and controlling the psychological consequences of PCOS and its complications requires healthcare providers' support and comprehensive and long-term planning to promote the mental health of these women.

Keywords: *Mental health, Polycystic ovary syndrome, Psychological, Qualitative research*

Introduction

Polycystic Ovary Syndrome (PCOS) is a common endocrine disorder that affects 5–20% of women in their reproductive years.^[1-3] This syndrome is characterized by various clinical manifestations, such as oligomenorrhea, obesity, acne, impaired fertility, and hirsutism.^[4-6] Patients with PCOS are prone to cardiovascular diseases due to suffering from impaired glucose tolerance, resistance to insulin, type 2 diabetes, hyperlipidemia, and increased blood pressure.^[7-10] Furthermore, the chronic nature of this syndrome and its various symptoms affect different aspects of an individual's life. The evidence suggests that this disease may cause psychological problems as well as physical problems, emotional disorders, and lower quality of life.^[11] Studies have shown that 56.9% of women suffering from this syndrome have

at least one mental disorder.^[12,13] Mental health is considered one of the main criteria for health in any society, and it is taken into serious consideration. In fact, providing mental health services can lead to greater efficiency in both individual and social fields.^[14] The psychological well-being of women with this syndrome is ignored at the expense of trying to reduce the complications of the condition and succeeding in fertilizing the women. However, psychological health is closely related to managing PCOS, and it is a vital component in adopting a healthy lifestyle.^[15] On the other hand, lifestyle interventions are the first line of PCOS management. The slight changes in lifestyle in these women have led to weight loss, improved symptoms, increased ovulation, and improved productivity.^[16] The results of previous studies show that maintaining a healthy lifestyle in women with PCOS

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depends on the level of self-efficacy and psychological status. Therefore, one of the barriers to lifestyle interventions includes psychosocial factors.^[17]

The factors for decreased mental health in these women are various in cultural and social environments.^[18] In addition, researchers believe that attention should also be paid to the psychological status of women with PCOS when developing comprehensive plans for them,^[19] and healthcare providers should consider the psychological conditions of each individual in providing consultation.^[20] Explaining the psychosocial experiences of women with PCOS reveals the most important factors for decreased mental health. Consequently, investigating psychological experiences leads to increased insight, understanding, and awareness regarding individuals' experiences.^[21] To date, limited data have described the experiences of women with PCOS, their spouses, and healthcare service providers about engagement and optimal effectiveness of mental health strategies in Iran's sociocultural context. Therefore, the present qualitative study aimed at exploring the psychological experiences of women with PCOS.

Materials and Methods

The present study is part of extensive qualitative research based on the naturalism paradigm conducted between September 2018 and November 2019 in Isfahan, Iran. The experiences of women, their spouses, and healthcare providers about psychological aspects of PCOS were elaborated through qualitative conventional content analysis. The participants included women with PCOS diagnosed by a gynecologist or endocrinologist according to Rotterdam criteria and recorded in their medical file who lived in Isfahan, Iran, met the inclusion criteria and were willing to participate in the study, as well as their spouses and providers of healthcare services to women with PCOS (gynecologists, endocrinologists, midwives, dermatologists, nutritionists, psychologists, psychiatrists, and reproductive health specialists), who could spare time to participate in the interview. The sampling was performed purposefully in hospitals, comprehensive health service centers, and physicians' offices. Inclusion criteria for women included informed consent to participate in the study, Iranian nationality, ability to speak and understand Farsi, no history of chronic diseases such as cardiovascular diseases, diabetes, kidney diseases, and no severe mental disorder (such as psychosis, schizophrenia) that required medication or hospitalization. The exclusion criterion included the unwillingness to continue collaboration and participation in the study.

The data were collected using semi-structured interviews. At first, guided questions were determined using a few pilot interviews. Interviews were conducted after introducing the objectives of the research. The questions during the interview included "How have you felt since you learned that you were affected by PCOS?" "Please speak about

your experiences with PCOS?" "What are your concerns after being affected by the disease?" Each participant was interviewed during one or two sessions with an average time of 45 minutes. Interviews were continued until no new data were extracted (data saturation) and were arranged to the convenience of the participants (hospital, clinic, workplace, university, physician's office). Before the interview, the researcher introduced himself and expressed the study's purpose.

The interviews were conducted one-on-one, in a private and peaceful environment, and were recorded by a digital voice recorder. In case the participants were unwilling to have their voices recorded, the researcher tried to win their trust by building a good and appropriate relationship. In case the participants were concerned about data confidentiality, the researchers explained the process of keeping the data confidential. Finally, the interviews were conducted without recording if the participants refused to have their voices recorded. The arrangements to conduct the subsequent interviews were made if needed.

Data analysis was performed using conventional content analysis. Immediately after each interview, the interviewer listened to the recorded voice and transcribed it verbatim. Afterward, the interview text was read line by line to tag the key sentences and statements (coding). Then, the codes were extracted in One Note software. Subsequently, similar codes were clustered, and more general and abstract subcategories were extracted. The main categories emerged from subcategories.

To establish data rigor, four criteria of credibility, dependability, transferability, and confirmability were assessed.^[21] Regarding credibility, different interviewing methods at different times and places, taking field notes, and selecting participants with maximum diversity (age, education, occupation, disease severity) were observed. The extracted codes were reviewed by the participants (after coding each interview, the participant received the results to check the codes and interpretations). Moreover, to ensure transferability, concepts and categories were provided to a few individuals similar to the participants (not among the participants) to comment on how similar they found the participants' experience to their own. To improve confirmability, the details of the study process were recorded, and the coding process was examined by other research team members and a few faculties familiar with qualitative studies.

Ethical considerations

The permission was obtained from the Ethics Committee, Department of Research, Isfahan University of Medical Sciences, Iran (IR.MUI.REC.1395.3.508). Ethical issues, including informed consent, the permission to record the interview, respecting the confidentiality of data, and

reminding the participants of the right to withdraw from the study at any stage, were considered.

Results

Thirty participants consisting of 13 women with PCOS [Table 1], four spouses, and 13 healthcare service providers, including one gynecologist, one endocrinologist, three midwives, one dermatologist, one nutritionist, three psychologists, one psychiatrist, and two reproductive health specialists, were included in the study. The majority of healthcare providers were in the age range of 40–50 with more than 10 years of work experience.

Data analysis yielded five main categories, including the patient’s psychological reactions following infertility and

its probability, psychological issues following menstrual disorders, patients’ fear and concerns about the probability of developing chronic diseases, psychological problems following the disease, and psychological problems resulting from body appearance. Each category contained several subcategories [Table 2].

Category 1: Patients’ psychological reactions following infertility and the probability of infertility

The participants’ experiences indicated their psychological reactions following infertility and the probability of infertility. The subcategories included “Feeling depressed following infertility” and “Fear of infertility following the diagnosis of the disease.”

Table 1: Description of the characteristics of women with PCOS1* participating in the study

Participants	Age	Educational status	Occupation	Marital status	Number of children	History of infertility	Duration of the disease (years)	Symptoms of the disease
1	23	Diploma	Housewife	Married	0	5 years	16	Oligomenorrhea, overweight, acne, hirsutism, hair loss
2	30	Master’s	Employee	Married	2	1 year and 7 months	10	Overweight, menstrual disorders
3	30	Bachelor’s	Employee	Married	1	6 years and 6 months	8	Overweight, acne, hirsutism, menstrual disorders
4	24	Bachelor’s	Employee	Single	-	-	6	Overweight, hirsutism
5	26	Bachelor’s	Tailor	Single	-	-	5	Acne, hirsutism, menstrual disorders
6	27	Bachelor’s	Student	Married	2	1 year and 9 months	8	Hirsutism, menstrual disorders
7	17	High School	Student	Single	-	-	2	Hair loss, menstrual disorders
8	34	First year of high School	Housewife	Married	1	Primary infertility 6 years	15	Hirsutism, menstrual disorders, overweight, acne,
9	34	Ph.D.	University faculty	Married	2	-	7	Hirsutism, menstrual disorders, overweight
10	26	Associate’s degree	Housewife	Married	0	3 years	4	Hirsutism, menstrual disorders, overweight, hair loss
11	42	Associate’s Degree	Employee	Married	3	-	22	Hirsutism, menstrual disorders, hair loss, overweight, acne
22	30	Diploma	Tailor	Married	2	-	6	Menstrual disorders, overweight
23	18	Diploma	Housewife	Married	-	-	1	Menstrual disorders, overweight, hirsutism

*Polycystic ovary syndrome

Table 2: Categories and subcategories based on interview analysis

Categories	Subcategories
1-Patient’s psychological reactions following infertility and its probability	1-1: Feeling depressed following infertility 1-2: Fear of infertility following the diagnosis of the disease
2- Psychological issues after menstrual disorders	2-1: Feeling concerned following irregularity of menstrual cycle 2-2: Menstrual disorder, a factor for stress
3- Patients’ fear and concerns about the probability of developing chronic diseases	3-1: Patient’s fear of being affected by diabetes due to their disease 3-2: Concerns about developing hypertension
4- Psychological problems following the disease	4-1: Feeling depressed due to symptoms and complications of the disease 4-2: Feeling helpless due to the chronic nature of the disease
5-Psychological problems resulting from body appearance	5-1: Psychological distress caused by hirsutism 5-2: Improper body image caused by the disease 5-3: Feeling uncomfortable with people’s behavior toward the body appearance

1-1: Feeling depressed following infertility

Since infertility is one of the complications of PCOS, women with this syndrome have faced numerous problems. According to participants' comments, feeling depressed was one of their problems. One of the women with PCOS said: "Pregnancy was difficult for me. I experienced so many menstrual cycles; it was natural as I tested negative for it; I was very depressed. I felt very sad. I felt like sitting somewhere alone and crying. Many women get pregnant; I think that I can't get pregnant for the problem I have. I was very depressed because of that" (A woman with PCOS, P2).

1-2: Fear of infertility following the diagnosis of the disease

Most participants expressed their fear of infertility following being diagnosed with PCOS. This fear is one of the critical issues preoccupying women, even expressed by some affected women when they were single. In this regard, trying to share her experiences of her singlehood, one of the married participants stated: "When I was single, I used to talk to my mom about the fear of becoming infertile. My mom laughed. She told me that I wasn't married yet, and it was surprising that I expressed such a concern. Moreover, there have been no cases of infertility in our extended family, to which I expressed the fear of having the same problem as some acquaintances. I fear being infertile. I used to repeatedly say, "I'm afraid of having some problems of ovarian laziness in the future" (A woman with PCOS, P4).

Category 2: Psychological issues following menstrual disorders

The findings showed that the mental health of these women was widely affected by menstrual disorders. This category contained subcategories: "Feeling concerned following irregularity of menstrual cycle" and "Menstrual disorder, a factor for stress."

2-1: Feeling concerned following irregularity of menstrual cycle

Another item that was expressed as the cause of mental issues in women with PCOS was the irregularity of the menstrual cycle: "Now, I wish for spontaneous menstruation. If I menstruate spontaneously in a cycle, I'll be on cloud nine, or as though I ranked first in a university entrance examination" (A woman with PCOS, P2).

2-2: Menstrual disorder, a factor for stress

Healthcare providers also mentioned that patients and their families were stressed out due to menstrual disorders. Furthermore, they pointed out that patients sought to treat the irregularities in their cycles due to the importance of menstrual cycle regularity. In this regard, one of the reproductive health specialists stated: "In general, this

syndrome causes menstrual disorder in patients including a wide range of problems. There may be a long distance between their periods; I've seen a case not menstruating for six months, which made her and her family so stressed that they were galvanized into treating the problem" (Reproductive health specialists, p19).

Category 3: Patients' fear and concern about the probability of developing chronic diseases

This category contained subcategories, namely "Patients' fear of being affected by diabetes due to their disease" and "Concerns about getting hypertension."

3-1: Patients' fear of developing diabetes due to their disease

Fear of diabetes was one of the issues pointed out by some participants who were aware of the increase in the risk of diabetes due to PCOS. In this regard, one of the participants mentioned: "I'm afraid of getting diabetes because I read on the Internet that such patients may get diabetes. I'm fat, with a family history of diabetes. I also have this syndrome. Well, these freak me out. As you know, diabetes is such a terrible disease" (A woman with PCOS, P2).

3-2: Concerns about getting hypertension

A number of participants expressed their concerns about hypertension. Evidently, being informed of the problems and disease complications in similar individuals without getting adequate and precise awareness of controlling the disease and its complications increased participants' concerns. One of the women with the disease said: "It's difficult to control this disease. For example, you may get high blood pressure in the future. There's a person in our extended family who was infected with high blood pressure at the age of 25; an obstetrician has told him that the condition had developed due to this syndrome and the stress she had felt. She's been suffering from the syndrome for ten years. The doctor has told him to be very cautious. Of course, I'm worried, lest I get high blood pressure" (A woman with PCOS, P2).

Category 4: Psychological problems following the disease

Participants' experiences showed that they underwent unpleasant feelings after being affected by PCOS and experiencing the symptoms and complications of the disease.

4-1: Feeling depressed due to symptoms and complications of the disease

Some participants pointed out that psychological problems, including depression, had some worse consequences compared to other problems caused by the disease, with depression overshadowing many other aspects of their lives. In this regard, one of the women with this disease said: "I've always been tired and curled up in some

corner at home. I neither liked to study nor to go out or have a relationship with anyone. This disease resembles a brakeless car that makes you collapse either with diabetes or depression. It's better to be paralyzed in two feet or become blind than become depressed because a depressed person has energy neither for work nor for studying nor meets anyone's needs" (A woman with PCOS, P11).

4-2: Feeling helpless due to the chronic nature of the disease

The experiences of some women affected by PCOS showed that they felt helpless and unable against this disease. The statements made by participants revealed that they considered this negative feeling to result from the permanent nature of their disease, which highlighted the role of consultative support for them. In this regard, one of the women affected by the disease said: "You can never feel it lets you alone. You feel it like a permanent pain in the neck. It always accompanies you like a twin brother and distresses you. It makes you feel desperate and helpless" (A woman with PCOS, P2).

Category 5: Psychological problems resulting from body appearance

"Psychological distress caused by hirsutism," "improper body image caused by the disease," and "feeling uncomfortable with people's behavior toward the body appearance" led to the emergence of the main category of "psychological problems resulting from body appearance."

5-1: Psychological distress caused by hirsutism

According to participants' statements, hirsutism was one of the issues that most participants experienced. Frequent growth of hair and finding a solution to remove them was one of the important issues in their minds, which distressed them. In this regard, one of the participants stated: "We can shave our legs and arms to chill out for a while. But the face is the most noticeable part of the body in people's eyes. It really gets on my nerve and doesn't give me a break at all. I say to myself: today, I'll remove the hair, and it'll not grow any longer, but it grows some days later, making me really nervous. Because I have tolerated the hair for years, I'm very disturbed" (A woman with PCOS, P1).

The distress the women with PCOS experienced and the mental problems resulting from it were considered important by service providers. In this regard, one of the experts stated: "One of my clients is a woman with a lot of hair on her chin, just like a man. This fellow uses razors to shave the hair, so she has become depressed. As she visits me in the office, I find out that she is upset" (A dermatologist, P24).

5-2: Improper body image caused by the disease

The analysis of participants' perceptions and experiences showed that some women affected by PCOS believed

that the disease made their bodies unnatural, which was frequently reflected in their statements. Some of these women felt that their appearance was masculine. They also stated that the improper body image made them upset and ashamed. A participant's experience was as follows: "When I want to go to a ceremony, wearing some clothes that don't fit me or comparing myself to others makes me feel very ill at ease. The alternative is to wear black clothes so my body and organs will not be noticeable" (A woman with PCOS, P1).

5-3: Feeling uncomfortable with people's behavior toward the body appearance

Participants' statements showed that they faced problems due to changes in their body appearance compared to other women, and they resented people's reactions to their appearance. They believed that others' ordinary reaction to their appearance caused them to hold a better feeling about the disease. In this regard, one woman suffering from the disease said: "Many people ask me what on earth the hair is for? Why are you losing hair? You should visit a doctor. You have a problem. There are also many people asking why I put on weight. There are many people reacting this way; I know many people act in such a way that makes you really upset, and you take it to heart" (A woman with PCOS, P1).

Some spouses likewise stated that women suffering from such a disease had voiced their sadness with people's behavior and their behavior upset them. In this regard, a woman's husband stated: "Sometimes, when we go somewhere, people ask her questions or taunt her, and she comes back home and asks me why people are so weird; As they see a little hair on your face, they start to show their wonder or ask if you've visited a doctor or similar questions" (A women's spouse, P28).

Discussion

According to the participants' experiences, women with PCOS show numerous psychological reactions following infertility and its probability, menstrual disorders, probability of developing chronic diseases, suffering from the disease, and body appearance.

The results of the present study showed that the fear of infertility followed by the diagnosis of the disease, feeling depressed, and psychological distress following infertility were some of the negative reactions on the part of women with PCOS. In a qualitative study on women in England, researchers pointed to infertility as one of the causes of psychological distress, which was consistent with the present study.^[22]

In the present study, most participants pointed to psychological problems caused by menstrual disorders, such as feeling worried and stressed following the irregularity of the menstrual cycle. The results of studies

show that menstrual disorders lead to a decrease in the quality of life of women with PCOS. Therefore, timely diagnosis and treatment of menstrual disorders are of utmost importance.^[23]

The results of this study showed that some women with PCOS feared and were concerned about developing chronic illnesses, such as diabetes and hypertension. Due to its chronic nature and various symptoms, PCOS affects the patients' different aspects of life.^[24] Therefore, these women should be encouraged to receive lifestyle interventions to reduce the long-term complications of this disease,^[25] which was consistent with the present study.

Some participants pointed out that psychological problems, including depression, had some worse consequences compared to other problems caused by the disease, with depression overshadowing many other aspects of their lives. In a qualitative study on women with PCOS, it was stated that six out of ten women participating in the study had depression symptoms. Their depression was so annoying that they reported the symptoms of hurting themselves or committing suicide,^[26] which was in line with the present study since women with PCOS experience numerous symptoms and complications, and the possibility of psychological problems increases in them.

The results of the study showed the unpleasant impact of hirsutism on the beauty of the face and feminine feeling. This unpleasant feeling seemed to have impacted the spirits of women suffering from hirsutism. In this regard, researchers stated that most women in the study considered themselves unattractive and ugly since hirsutism created a feeling of anguish in them, thus impacting the quality of their life negatively and imposing limitations on their personal and social life.^[22] Therefore, providing proper consultation with the patient to encourage her to control the disease and its symptoms by healthcare providers seems necessary.

On the other hand, the analysis of participants' perceptions and experiences revealed the belief that this syndrome created a negative body image in women. Those who provided relevant services believed that, due to unpleasant feelings about this issue, patients held a negative and poor body image, and they made an effort to achieve their ideal shape and a more desirable body image through possible solutions. A negative body image in women with PCOS leads to a decrease in their self-esteem.^[27] Therefore, psychological counseling in healthcare centers can help improve these women's psychological conditions. One of the limitations of this study was that women with PCOS undergoing treatment were selected to participate in the study, while many women with PCOS who have mental disorders may not seek treatment; therefore, further research should be carried out to design mental health guidelines for these patients. Another limitation of the study was that in some specialties, only one participant

with PCOS was interviewed to explain her psychological experiences; therefore, to enrich the data, selecting at least two participants in each specialty is suggested.

Conclusion

This study revealed the psychological experiences of women with PCOS. We can make serious attempts to decrease psychological problems through the revelation of their experiences. It seems that consultative support and comprehensive and long-term planning on the part of healthcare providers prove to be necessary to prevent and control the psychological consequences of the disease and its complications, including psychological problems caused by infertility and its probability, menstrual disorders, psychological distress by body appearance, and concerns about chronic diseases.

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Conflicts of interest

Nothing to declare.

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