Original Article

Psychological Experiences of Adolescent Girls with Polycystic Ovary Syndrome: A Qualitative Study

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Abstract

Background: Polycystic Ovary Syndrome (PCOS) is one of the most common endocrine disorders in the women of reproductive age. In addition to multiple physical problems, this syndrome has many psychological manifestations. Thus, the present research was conducted aimed at investigating the psychological experiences of the adolescent girls with PCOS. **Materials and Methods:** This research was conducted using the qualitative content analysis method. A total of 18 adolescent girls with PCOS and 15 healthcare providers were selected by the purposive sampling method. The data were collected through in-depth interviews, focus group discussions, and field notes, which were analyzed using the conventional content analysis method. **Results:** After analyzing, three main categories and seven subcategories were extracted. First, the psychological experiences related to the disease symptoms had three subcategories: "psychological experiences related to hirsutism, alopecia, and acne," "psychological experiences related to obesity," and "psychological experiences related to menstrual disorders." Second, the psychological experiences related to disease complications had two subcategories: "psychological experiences related to infertility" and "psychological experiences related to disease progression." Third, the psychological experiences related to treatment of the disease had two subcategories: "psychological experiences related to prolongation of the treatment and uncertain fate of the disease" and "psychological experiences related to the complications of the medical treatment." **Conclusions:** Results of the study showed that adolescent girls with PCOS were exposed to multiple concerns endangering their psychological health. Therefore, it is recommended to provide adequate and appropriate information about the disease and its consequences, as well as psychosocial supports and regular assessment of psychological state by the team of healthcare providers in the adolescent girls with PCOS.

Keywords: *Adolescence, mental health, polycystic ovary syndrome, qualitative research*

Introduction

Polycystic Ovary Syndrome (PCOS) as a heterogeneous disorder affects at least 7% of adult women.[1] Based on the diagnostic criteria, the prevalence of PCOS is between 1.8% and 15% among the adolescent girls.[2] This syndrome is one of the most common endocrine disorders in the women of reproductive age. It is characterized by morphological manifestations in ultrasonographic findings, obesity, clinical hyperandrogenism (hirsutism, acne, and alopecia), biochemical hyperandrogenism, menstrual disorders, and infertility.[3] This multi-factorial syndrome starts from puberty and has long-term metabolic and cardiovascular complications. It should be noted that diagnostic criteria for PCOS could be applied in adolescents, but natural features of puberty such as menstrual irregularities and acne would make it diagnosis difficult.[4-7] Several recent studies have shown that PCOS is associated with psychological problems, such as anxiety, depression, as well as social maladjustment.[8,9] Although it seems that only infertility and menstrual irregularities influence the psychological health and life quality of the patients with PCOS, it has been reported that appearance of the changes such as obesity, hirsutism, acne, and alopecia may change feminine identity and increase the levels of psychological burden.[10]

Adolescents with PCOS experience several problems influencing their psychological health that probably lead to psychological distress and impaired

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emotional well-being.[11,12] Previous studies have shown that the psychological symptoms of PCOS include feeling ill, melancholy, sadness, and depression.[8,13] Depression in women with PCOS has a wide range of prevalence rates, reported between 14% and 64%.[9] Depression influences different dimensions of life and reduces life quality in adolescent girls with PCOS who are in the active phase of their lives. It can also lead to social isolation, disruption of interpersonal relationships, incompatibility with social norms, social stigma, and suicide ideation.[14,15]

A number of studies have been conducted on the quality of life and psychological health in women and adolescent girls with PCOS throughout the world.[6,9,16,17] Although it has been found that psychological distress influences different dimensions of life in adolescent girls with PCOS, only few studies have been conducted in this area. On the other hand, the psychological experiences of the adolescent girls with PCOS have been less investigated in the context of Iran. Qualitative research as an approach is used to investigate and explain people's experiences and give meaning to them. This approach leads to increased insight, understanding, and awareness regarding humans' experiences.[18] Therefore, the present qualitative research was carried out aimed at investigating the psychological experiences of adolescent girls with PCOS.

Materials and Methods

This qualitative research is part of an extensive qualitative research conducted between November 2016 and September 2017 in which the content analysis method was used. Participants were 18 adolescent girls with PCOS (aged between 15 and 21 years old[19]) and 15 health care providers (two midwives, six gynecologists, two endocrinologists, and five nutritionists) residing in Shiraz, Fars Province, Iran. Participants were recruited directly or, in some cases, telephone numbers of the subjects were obtained and they were subsequently telephoned. The sampling started using the purposive sampling method. Purposive sampling is widely used in qualitative research for the selection of information-rich cases related to the phenomenon of interest.[18] In the present study, information-rich participants (adolescent girls with PCOS and healthcare providers) were accessed through gynecology clinics and gynecologists' offices. The sampling continued considering the maximum variety in age, educational level, occupation, marital status, body mass index (BMI), and duration of the disease (for adolescent girls). Also, healthcare providers with different working experiences were included in the study. According to the inclusion criteria, adolescent girls with PCOS diagnosed by a gynecologist through diagnostic criteria,[20] aged between 15 and 21 years old (considering that at least 2 years must be passed from the menarche for diagnosis of PCOS[20]), who were willing to participate in the research, presented an informed consent from themselves and their parents (if they were under 18 years old), and those who were overweight or obese, and had no history of major psychiatric disorders diagnosed under medical treatment (by asking from the individuals), and also no history of chronic diseases such as cardiovascular diseases, diabetes, kidney diseases, etc. with prescribed specific diets were included in the study. The exclusion criterion was the unwillingness to continue collaboration and participation in the study.

The data were collected via individual, in-depth and semi-structured interviews, focus group discussions (FGDs), and field notes. The second author conducted interviews and FGDs. She had 14 years of working experience in midwifery and the experience in conducting qualitative research and interviews. The individual interviews with the adolescent girls were initiated with questions like "What feelings and concerns do you have to encounter because of your disease? Please explain them." Open and interpretive answers of the participants guided the course of interviews. In the present study, nonverbal behaviors of the interviewees (facial expressions and movements) were recorded[21] by the second author and were used in data analysis phase of the research to enhance deep description and interpretation. Interviews continued until the data saturation occurred, meaning that when new data was a repetition of previous data and new conceptual data was not obtained. In this study, 21 individual interviews (with 10 adolescent girls and 11 healthcare providers including gynecologists, midwives, endocrinologists, and nutritionists) were performed in the desired places of the participants (such as parks) that lasted for 30–85 min. As a research technique, FGD is used to collect the data through group interaction;[18] two FGDs (one for eight adolescent girls with PCOS and one for four health care providers including 2 gynecologists, 1 midwife, and 1 nutritionist) were conducted. Both of the group discussions were conducted in an agreed place such as gynecology clinics. In the FGD with the presence of health care providers, the interview was initiated with the questions like "In your opinion, what psychological experiences do the adolescent girls with PCOS have about their disease? Please explain to them." At the group discussion sessions, the researcher acted as the facilitator and guided the discussions, and another person was present to take notes.

Data analysis was conducted using conventional qualitative content analysis.[18] All the individual interviews and FGDs were digitally recorded. The interviews and FGDs were transcribed verbatim by the second author and then, the text was reviewed repeatedly to achieve a comprehensive understanding of the interviews. Afterward, the statements and sentences were coded, and codes with similar meanings were categorized in one group and subcategories were created through an inductive approach. The categories with similar concepts were grouped in one category by comparing the subcategories in order to create a main category. Four criteria proposed by Lincoln and Guba were used to ensure

the rigor of the results. These criteria were credibility, dependability, transferability, and confirmability.[18] The in-depth interviews were carried out and a combination of data collection methods was used such as FGDs, field notes, and selection of the participants with maximum variety in their demographic characteristics to increase the credibility. Coded interviews were shared with the four participating girls at different sessions and their opinions were sought to increase the confirmability so that, member checking could be obtained. The opinions of two experts were also obtained to confirm the consistency between the coded data and the participants' statements in order to increase the dependability. The results of the study were given to five participating girls to judge on the similarity of the results with their own experiences in order to increase the transferability.

Ethical considerations

The present research was approved by the Ethics Committee of Isfahan University of Medical Sciences, Isfahan Province, Iran (Ethics Code: IR.MUI.Rec. 1395.8.885). The objectives of the study were explained for the participants prior to each individual interview and FGD. Informed consent, the confidentiality of the information, anonymity, and the right to leave the study at any time were all preserved. In the cases where the adolescent girl was less than 18 years old, informed consent was obtained from their parents.

Results

Tables 1 and 2 present the demographic characteristics of the participants. After data analysis, a total of 98 refined codes were extracted classified into 7 subcategories and 3 main categories of "psychological experiences related to disease symptoms," "psychological experiences related to disease complications," and "psychological experiences related to treatment of the disease" [Table 3].

Psychological experiences related to disease symptoms

This category includes three subcategories of "psychological experiences related to the hirsutism, alopecia, and acne," "psychological experiences related to obesity," and "psychological experiences related to menstrual disorders."

Psychological experiences related to hirsutism, alopecia, and acne

Most of the participating girls (90%) considered hirsutism, alopecia, and acne as the main causes of losing their physical attractiveness. They stated that these symptoms were the main causes of their fear, sadness, and reduced self-confidence. "*Hirsutism makes me so sad because it influences on my appearance. I look for an appropriate time to initiate the laser therapy. But, at this time, I try not to look at the mirror!"* (Adolescent girl N. 3).

Psychological experiences related to obesity

The participating girls expressed dissatisfaction with their weight and obesity as one of their main concerns. They assumed that their current appearance has made them very ugly and ridiculous. Feeling of dullness in performing daily activities, inability to participate in sport activities, inappropriate appearance, looking older than their actual age, limitation in selecting the suitable clothes, and lack of feminine delicacy were their main reasons for these feelings. They experienced some negative feelings and felt ashamed, worthless, and loathsome. *"When I want to buy a piece of clothing, the salesperson brings me several clothes, but none of them fits me. I feel really ashamed and this makes me sad."* (Adolescent girl N. 4).

Table 1: Demographic characteristics of adolescent girls with polycystic ovary syndrome

Participant	Age (years)	Duration of the disease (month)	Education status	Occupation	Marital status	BMI (kg/m^2)
1	20	9	Bachelor's degree	Student in college	Married	29.70
2	19	3	Bachelor's degree	Student in college	Single	28.70
3	15	7	Middle school degree	Student	Single	32.90
4	16	2	Middle school degree	Student	Single	28.51
5	17	5	Middle school degree	Student	Single	33.11
6	20	9	Diploma	Housewife	Married	27.60
7	15	1	Middle school degree	Student	Single	33.10
8	19	5	Bachelor's degree	Student in college	Married	30.43
9	18	4	Middle school degree	Student	Single	30.80
10	21	2	Bachelor's degree	Student in college	Married	29.31
11	19	10	Bachelor's degree	Student in college	Single	28.32
12	16	5	Middle school degree	Student	Single	28.50
13	19	1	Diploma	Diploma	Single	31.30
14	15	6	Middle school degree	Student	Single	26.31
15	17	8	Middle school degree	Student	Single	27.60
16	16	3	Middle school degree	Student	Single	30.92
17	19	12	Diploma	Housewife	Single	27.53
18	21	18	Diploma	Housewife	Married	30.14

Psychological experiences related to menstrual disorders

Participating girls emphasized the importance of normal and regular menstruation. They narrated the menstrual irregularities as the main reason for consulting with a physician. Almost all of the participating girls (99%) regarded prolonged menstrual irregularities as a stressful factor, which not only has disrupted their daily life activities but also has made them anxious and angry. *"Irregular period is so embarrassing; on the one hand, I am always anxious about its delay, and on the other hand, it ruins all my plans."* (Adolescent girl N.1).

"These girls complain about menstrual irregularities. They are very worried about this problem." (Gynecologist N. 2).

Table 2: Demographic characteristics of healthcare providers

Participant	Age (years)	Education status	Work experience (years)
1	49	Nutritionist	20
2	48	Nutritionist	17
3	50	Nutritionist	19
4	38	Nutritionist	6
5	45	Nutritionist	11
6	43	Gynecologist	17
7	38	Gynecologist	9
8	46	Gynecologist	12
9	40	Gynecologist	5
10	54	Gynecologist	20
11	44	Gynecologist	10
12	35	BS in midwifery	10
13	47	MSc in midwifery	10
14	58	Endocrinologist	20
15	51	Endocrinologist	16

Psychological experiences related to disease complications

This main category includes two subcategories of "psychological experiences related to infertility" and "psychological experiences related to disease progression."

Psychological experiences related to infertility

Most of the participating girls stated that they have not received sufficient information from the healthcare providers, and consequently, lack of awareness about this disease and its complications has doubled their concerns about infertility. They narrated their fears and concerns about infertility in the future, as well as deprivation from the pleasure of motherhood. They claimed that infertility stigma and public viewpoint toward their infertility have made them lie about their disease. *"I'm scared of having a problem with childbearing after my marriage. Infertility makes me mad, even thinking about it scares me!"* (Adolescent girl N. 15).

"Ever since I have found out about my disease, I have no longer talked about it, because I hate being labeled." (Adolescent girl N. 10).

Psychological experiences related to disease progression

Participating girls were deeply concerned about developing prolonged complications such as diabetes and

Table 3: Codes, subcategories, and main categories extracted from the analysis of interviews

Code	Subcategory	Main category
Feeling anxious and depressed due to acnes Losing selfconfidence after hair loss Feeling ashamed about physical appearance	Psychological experiences related to hirsutism, alopecia, and acne	Psychological experiences related to disease symptoms
Feeling ashamed in buying clothes Loss of selfconfidence and isolation Feeling inferior to others Feeling worthless in the society	Psychological experiences related to obesity	
Concern, anxiety and depression after menstrual irregularities Feeling disappointed about menstrual irregularities	Psychological experiences related to menstrual disorders	
Fear of permanent complications, such as infertility Fearing infertility stigma Feeling depressed and loss of selfconfidence about infertility	Psychological experiences related to infertility	Psychological experiences related to disease complications
Fear of side effects, such as diabetes and high blood pressure Fear of cancers, such as breast and endometrial cancers	Psychological experiences related to disease progression	
Tiredness about the long course of treatment Concern about return of the disease Disappointment about affectability of the treatment	Psychological experiences related to prolongation of the treatment and uncertain fate of the disease	Psychological experiences related to treatment of the disease
Concern about obesity after hormonal treatment Concern about severity of the disease after hormonal treatment Concern about infertility after taking oral contraceptive pills	Psychological experiences related to the complications of the medical treatment	

cardiovascular diseases, as well as formation of ovarian masses and cancers such as ovarian and breast cancers. *"I am too concerned about the future that makes me mad. I get goosebumps when I think about the situation where my ovarian cysts change into ovarian masses!"* (Adolescent girl N. 14).

"I am concerned about having problems at my old age, for example, uterine and breast cancers." (Adolescent girl N. 11).

Psychological experiences related to treatment of the disease

This main category includes two subcategories of "psychological experiences related to prolongation of the treatment and uncertain fate of the disease" and "psychological experiences related to the complications of the medical treatment."

Psychological experiences related to prolongation of the treatment and uncertain fate of the disease

Prolongation of the treatment process, development of symptoms, and recurrence of the disease after discontinuation of the treatment were among other concerns that had negative effects on psychological status of the participating girls. They narrated these can cause unpleasant feelings such as depression. *"In this disease, you are always depressed and in a bad mood. Sometimes I sit for one hour and keep staring, just thinking about what will happen? When there is no treatment, I will be sick until the end of my life. What should I do?"* (Adolescent girl N. 8).

Psychological experiences related to the complications of the medical treatment

Most participating girls were concerned about the adverse complications of hormonal drugs (such as oral contraceptive pills) on their fertility. They assumed that they would be prone to infertility in the future. *"...I say to myself what these drugs (oral contraceptive pills) are doing to me? Because I heard these drugs make people infertile. I don't like drugs at all, I feel worried whenever I take them!!!"* (Adolescent girl N. 6).

"Most of these girls think that if they take hormonal drugs for a long time, they will become infertile in the future. They are very worried about this!" (Midwife N. 2).

Discussion

The present research was conducted to investigate the psychological experiences of adolescent girls with PCOS. The results indicated that the adverse effects of this syndrome on their appearances such as hirsutism, alopecia, and acne were the main concerns of the adolescent girls with PCOS. These changes in appearance lead to disappointment and loss of self-confidence. These findings are consistent with those reported in the study by Weiss and Bulmer on 18–22 year old girls with PCOS. They introduced hirsutism as the main concern of adolescent girls with PCOS. They reported that the patients felt inferior to other women due to their appearance, and consequently, felt disappointed and ashamed.[22] Nasiri Amiri *et al*. indicated that PCOS was a disappointing experience for the women that was accompanied by many challenges such as changes in their gender roles, negative psychological assumptions (due to hirsutism and acne), and reduced life quality.[23] In the present study, obesity was pointed out as the symptom causing disappointment, loss of self-confidence, and emotional stress among the adolescent girls. Camargo *et al*. showed that most of the girls with PCOS described their appearance as abnormal and strange.[12] Another research indicated that obese women with PCOS were more prone to depression in comparison with those in the control group.[24] Seemingly, symptoms like obesity can influence the adolescents' beauty and create great psychological burdens. Hence, the adolescent girls with PCOS should be aware of the nature of their disease and how to control and treat it. It can reduce the negative effects of the disease on their psychological status. The findings of the present study revealed that menstrual disorders were among the main concerns in adolescent girls with PCOS. They regarded prolonged menstrual irregularities as a stressful factor, which has made them anxious and angry. Hadjiconstantinou *et al*. also reported a relationship between irregular cycles and impaired psychological performance in women suffering from PCOS.[25]

Participants in the present study stated the worries about infertility as the complication of PCOS and also a result of medical treatment (hormonal drugs). Results of qualitative research indicated that issues related to the fertility influenced emotional health, self-concept (body image, self-esteem, and self-awareness), and sexual behavior in the adolescent girls with PCOS.[26] Also, Gibson *et al*. showed that most of the women with PCOS were worried about the side effects of the medical treatment on their health.[27] It seems that raising awareness and developing the right attitude in adolescent girls with PCOS about complications of their disease and its medical treatment (hormonal drugs) can increase appropriate cognitive evaluations in stressful situations and reduce their stress. Our findings showed the fear of developing other complications including cardiovascular diseases, diabetes, and some cancers as another concern among the adolescent girls with PCOS. Also, Cooney *et al*. concluded that untreated PCOS could pave the way for its progression and the relapse of its complications, which could lead to significant negative effects on the life quality and psychological health in the women with PCOS.[28]

Findings of the present study showed that prolonged treatment process, concerns about the uncertain fate of the disease, and complications of the medical treatment were among other factors negatively influencing the psychological state in the participating girls. Benetti-Pinto

et al. in their study on participants with PCOS found that PCOS was prolonged, troublous, and untreatable and has reduced their health level.[29] Likewise, Nasiri Amiri *et al*. pointed out that the women with PCOS who were dissatisfied with the prolonged treatment process were disappointed, displeased, and exhausted. They believed that this disease has raised various challenges for the women with PCOS.[30] In this regard, it is essential to regularly assess the adolescent girls with PCOS aimed at screening their psychological disorders and referring them to the counseling centers. Also, the healthcare providers should pay much attention to the psychological aspects of this disease, irrespective of the severity of its symptoms or response to the treatment in order to provide the patients with more comprehensive care. They can contribute to the improvement of coping strategies through education and psychosocial support in adolescent girls with PCOS. All the participants of the present study were adolescent girls with PCOS who were overweight and obese. Therefore, the current results may be different in adolescent girls without overweight and obesity that highlights the need for further research.

Conclusion

Findings of this research indicated that the adolescent girls with PCOS were exposed to multiple concerns (related to symptoms, complications, and treatment of the disease) endangering their psychological health. Therefore, in case of the adolescent girls with PCOS, the team of healthcare providers is recommended to provide adequate and appropriate information about the PCOS and its consequences, as well as psychological supports, regularly screen the patients for psychological disorders, and refer them to the consulting centers.

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Conflicts of interest

Nothing to declare.

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