Psychology Research and Behavior Management

Dovepress

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ORIGINAL RESEARCH

Polycystic Ovary Syndrome in adolescents: a qualitative study

This article was published in the following Dove Press journal:
Psychology Research and Behavior Management

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Background: Adolescents with Polycystic Ovary Syndrome (PCOS) use different coping strategies to confront the challenges of this disorder. Various studies extracted coping strategies amongst adult women with PCOS, but regarding the mental difference between adults and adolescents, specific study was conducted to gain a deep understanding of how adolescents cope to the many health issues they experience.

Methods: Fifteen adolescents aged 13–19 years with PCOS participated in comprehensive individual interviews with goal-oriented, semi-structured questions. Sampling was purposive and continued until data saturation was reached. Data were analyzed using the thematic analysis technique. The validity of the data was verified through measures including credibility, transferability, dependability, confirmability and authenticity.

Results: The analysis of the data helped extract the main theme of the research as "dealing with PCOS". The main theme consisted of three themes and 12 sub-theme: (1) Escaping the problem (sub-themes: Adopting a forgetting mindset, and concealment and minimization of the disorder); (2) Depressive mood (sub-themes: Poor self-perception and low self-esteem, isolation, sleep disturbances, passive aggressive behavior, emotional turmoil, feelings of humiliation, and adolescents' perceptions); and (3) Coping with the disease (sub-themes: Recovery of health, positive thinking, hope for recovery).

Conclusion: In this study, the adolescents with PCOS showed a coping response to their disorder in the form of problem-solving, developing a depressive mood or adjusting to the disorder. Recognizing the mental health needs of these adolescents and improving their quality of life require the identification of ways through which they deal with PCOS.

Keywords: polycystic ovary syndrome, adolescents, qualitative research

Introduction

Polycystic Ovary Syndrome (PCOS) is a multifactorial disorder caused by interactions between genetic, environmental and intrauterine factors.[1] Various studies have reported the prevalence of this syndrome in adolescence as 9% to 15%.[2–4] Based on the available evidence, metabolic, inflammatory, oxidative, emotional and psychological stress is an important part of PCOS.[5] While the incidence of any disease or disorder can lead to anxiety and worry,[6] studies have shown that women with PCOS experience emotional distress, depression and anxiety more frequently than others, and when confronted with the disorder, some become more anxious and stressful.[7–10] PCOS therefore affects the daily life of many people.[11] It disturbs the joys of adolescence, because the stigma associated with hyperandrogenism is more intensely felt in this age group and is likely to damage the psychosocial development of adolescent girls.[12]

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http://doi.org/10.2147/PRBM.S207727

Patients with this disorder have to go through different stages of coping wherein they will likely have to respond to internal stress (physiological and psychological stressors) and external stress (environmental and social factors related to the syndrome) using coping responses.[13] The acceptance of any disorder is a complicated process that depends on factors such as the manifestation of the disorder, the availability and quality of treatment, individual demands (eg, mental demands, emotional demands, stress, coping strategies, etc.), support of the family members and other relatives and socioeconomic status.[14] Adolescence is a time of physical, cognitive and emotional changes as well as a period of great change in various aspects of life.[15] Adolescents usually deal with their problems through a variety of methods, including problem-solving methods that focus on changing the status quo, problem-solving, approaching others (seeking spiritual and social support from friends), using strategies to ignore their problems and running away from them, and self-blaming and non-coping behaviors.[16] Managing chronic conditions such as chronic pain, diabetes and cancer in adolescents leads to a variety of coping responses and some are associated with successful adaptation.[17]

The aim of qualitative research is to understand the experiences and circumstances of individuals and explain concepts from their perspective, and experiences often vary from one person to the other.[18] The review of literature suggests the diversity of the coping strategies used by adult women with PCOS,[19,20] while studies on adolescents with this syndrome are rather limited. Given the crucial role of coping strategies in adolescents with this chronic disease, the present study was conducted to gain a comprehensive understanding of the strategies used by adolescents with PCOS to cope with the challenges of this disorder.

Methods

Fifteen adolescents with PCOS able to share their rich experiences of coping with the disorder participated in this qualitative study. All the interviews were in Persian. The entire research team members and participants were fluent in Persian. The research team was composed of a qualitative methodologist as the principal researcher, a gynecologist and a PhD student of reproductive health. Purposive sampling continued until data saturation was achieved. The inclusion criteria for the study consisted of being an adolescent with PCOS as diagnosed by a gynecologist (based on the National Institute of Child Health and Human Development (NICHD) or the National Institutes of Health (NIH) criteria), having hyperandrogenism, oligo-ovulation/anovulation, age between 13 and 19 years, and willingness of the patient and their parents for participation in the study and sharing experiences. In this study parent or legal guardian provided written informed consent for any participant under the age of 18 years.

Before beginning data collection, the research project was approved by the ethics committee of Shahid Beheshti University of Medical Sciences in Tehran, Iran. The ethical principles observed for the research included obtaining informed consent, preserving the confidentiality of the data and giving the participants the right to leave the study whenever they desired.

Individual in-depth interviews were held with semi-structured questions ("What are your experiences with this disorder at this stage of life?" and "How has this disorder affected your mental state?"). The minimum and maximum duration of the interviews was 30 and 55 mins. The interviews were held in a relaxed and private environment in the health centers of Shahid Beheshti University of Medical Sciences in Tehran, Iran. All the interviews were recorded with prior permission from the participants. Thematic analysis was used in this study. Thematic analysis is a flexible and foundational method for qualitative analysis.[21] In the beginning, to immerse in the data, the research team transcribed the recorded audio interviews and the members read transcripts thoroughly. In order to generate the initial codes, the research team members extracted the semantic units. Then, the codes were collated into potential themes. The themes were reviewed for generating a thematic map. Finally, the themes were defined and given names and the final report was prepared.

Trustworthiness

Credibility, transferability, dependability, confirmability and authenticity measures were used to verify the data. The methods used in this study to verify the accuracy of the data included the selection of contributors with a variety of experiences, persistent observation, member checking, use of a coding framework, prolonged engagement with data, team consensus on themes, thick descriptions of context, purposive maximum variation sampling (selection of adolescents with different characteristic such as age, family economic status, education, etc.) and discussing some of the findings with a number of the participants.

Results

Thematic analysis categorized coping strategy into one main-theme as "Dealing with PCOS" and 3 themes and 12 sub-themes. Themes and sub-themes are as follow:

Escaping the problem (sub-themes: Adopting a forgetting mindset, and concealment and minimization of the disorder).

Depressive mood (sub-themes: Poor self-perception and low self-esteem, isolation, sleep disturbances, passive aggressive behavior, emotional turmoil, feelings of humiliation, adolescents' perceptions)

Coping with the disease (sub-themes: Recovery of health, positive thinking, hope for recovery), as shown in Figure 1.

The characteristics of selected participants are mentioned in Table 1.

Escaping the problem

The "escaping the problem" theme was formed in this study by combining two sub-themes, namely "forgetting" and "concealment and minimization of the disorder". The adolescents tried to escape their challenges by not disclosing their disorder to others so as to reduce the burden of psychological issues, and they used the method of forgetting to rid themselves of intrusive thoughts. The experiences of some of the participants in the study showed that they used the method of "forgetting" to escape their problems and tried to understand which thoughts resulted in their stress and then chose different ways to distract themselves from these thoughts. In the words of the participants:

"Sometimes, when I think of the disorder, I push the thoughts away. I've become inattentive" (Participant 1, 19 years old).

> Because I was immersed in my university entrance exam, my mind was preoccupied. This issue (PCOS) has not been important to me at all. I'm always busy studying. I do not have the time to think about it. (Participant 8, 18 years old).

> I've become indifferent now. It's no more important to me how it has gotten on my nerves. I don't think about it anymore because I can't do anything about it. I went to the doctor, I took medicines, but it didn't get better. (Participant 6, 19 years old).

The experiences of some of the participants also showed that they somehow tried to escape the problem by "concealing and minimizing the syndrome". In the words of the participants:

"I'm not upset because they say it is very common and could happen to anyone, and it's not a rare disorder. Anyone I see, I tell them I have PCOS and I'm taking medicines. It's normal" (Participant 1, 19 years old).

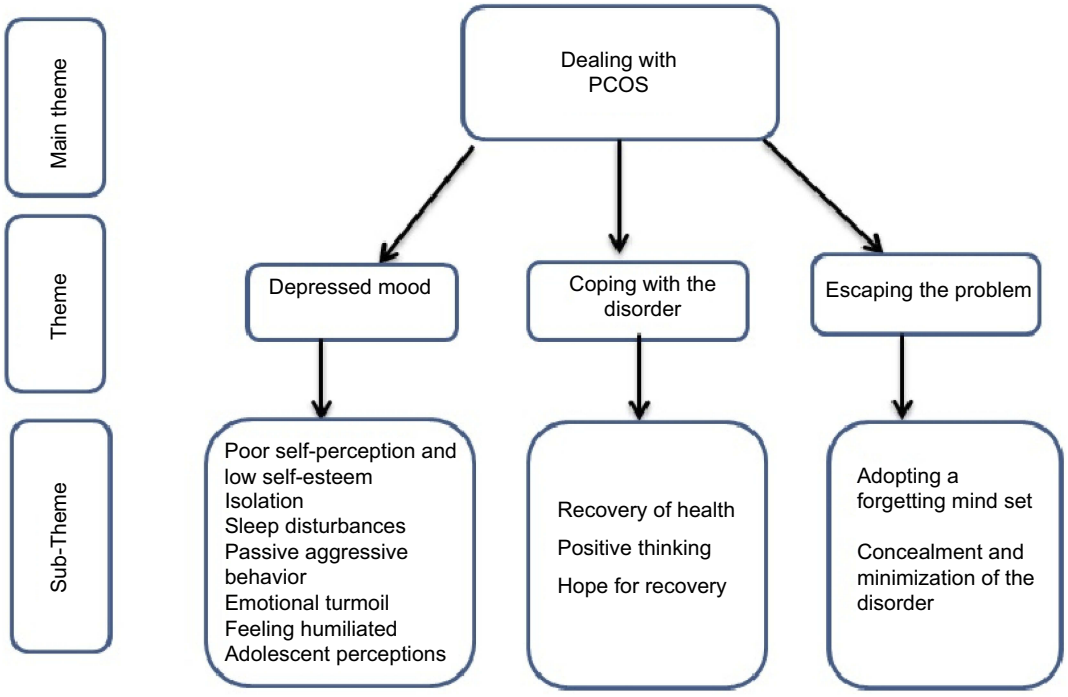

Figure 1 Theme and sub-themes.

Table 1 Characteristics of study samples (n=15)

Variable		Number
Age group	13–15 15–17 17–19	2 3 10
Marital status	Single Married	13 2
Years living with PCOS	<1 year >1 year	8 7
Main symptom	Obese or overweight Acne Hair loss Hirsutism Irregular menstruation	8 11 11 13 12

"I try not to take my pills in front of people because they ask why I'm taking pills. I don't tell anyone about my disorder" (Participant 9, 18 years old).

Depressive mood

The "depressive mood" theme was developed with seven sub-themes, including "poor self-perception and self-esteem", "isolation", "sleep disturbances", "passive aggressive behavior", "emotional turmoil", "feeling humiliated" and "adolescents' perceptions". Some of the adolescents experienced "laziness" and "sadness" after their diagnosis with PCOS and also concerns about failing to recover, constant worries about the disorder and psychological distress, which eventually ended in their "losing the joys of adolescence" and they began to lose focus. These experiences led to unpleasant feelings, and struggles with the disorder for many years caused "emotional disturbances" for some of the adolescents. According to participants' experiences, some of them tried to cope with their problems through "aggressiveness" and "making excuses." Often, they became isolated because of "limiting their relationships with their friends and close relatives" and "preferring to be alone than to be with others". The experiences of the participants also showed that, because of "internal feelings of distress when in gatherings where people were inquisitive" and "being in turmoil due to feeling different from peers", some of them felt humiliated and had a low self-esteem and sometimes also experienced symptoms of physical change caused by their psychological changes. The experiences of most participants showed that the visibility of their symptoms to their peers and others made them feel vulnerable, and as a result, they preferred not to be in touch with anyone in order to avoid showing their vulnerability. In the words of the participants:

"When I'm in front of the mirror, I feel bad, cause I have a lot of hair and acne" (Participant 15, 19 years old).

"I do not have much confidence when with others, cause I think they are better than me. It's the same for my family, my friends … " (Participant 3, 16 years old).

Loneliness and "isolation" were one of the common strategies of the adolescents in this study to cope with their disorder. In the words of the participants:

> I don't have much patience for myself; I don't have patience for others; I prefer to be left alone at home. What I mean is that I prefer everyone to go out visiting and enjoying themselves but leaving me home alone. (Participant 13, 19 years old).

"I try not to be in touch with my friends … I've only told my best friend about my polycystic ovary syndrome" (Participant 15, 19 years old).

Stressful conditions were associated with "sleep disturbances" in some of the participants. In the words of the participants:

"I'm always sleepy. I feel so sleepy. I'm constantly falling asleep. It's awful. It has been two or three years that I've become like this. I mean, since the morning, when I wake up, I feel sleepy" (Participant 6, 19 years old).

"I think so much about it that I can't sleep. I go out [of my bedroom] to drink water. I can't sleep at all until 5 or 7 am" (Participant 12, 13 years old).

Some of the adolescents who participated in the study expressed their agitation and negative feelings about the onset of their syndrome and were unknowingly showing passive aggressive behavior. In the words of the participants:

"I'm always fighting with everyone. I've become stubborn. When I get worried about something, I go to my room and shut the door. I start to cry and then lock the door" (Participant 3, 16 years old).

"I'm so distressed that I keep fighting with my family. I say, 'It's all your fault, you've caused this problem for me!" (Participant 12, 13 years old).

Concerns about the syndrome and its presentations and reasons caused tension in most of the participants and they were faced with "emotional disturbances". In the words of these participants:

"I'm worried about seeking further treatment because they told me that no special treatment exists yet" (Participant 2, 15 years old).

"I really don't have the patience, unlike in the past. For example, I had so many interests to pursue that I really enjoyed going out, but not anymore" (Participant 10, 19 years old).

"I don't think so much about it. It makes me very upset. My entire life has become consumed with this problem. I've lost my appetite. I'm so upset" (Participant 12, 13 years old).

"My inner feelings are such that, like, when you want to do something for yourself, say, make an effort for the sake of your life, continuing it causes problems because of this disorder" (Participant 2, 15 years old).

"Right now, I feel that, the way my friends hang out and are happy in each other's company, I'm not like that" (Participant 6, 19 years old).

"Most of the time, my mind was preoccupied and I couldn't concentrate on a particular problem" (Participant 2, 15 years old).

"My particular concern is that if this continues, what's going to happen … Will this illness be with me all my life and will I have to always cope with it and take medications?" (Participant 4, 19 years old).

"I think so much about it. When I look at myself in the mirror, I say, 'What kind of life is this?" (Participant 2, 15 years old).

"My nerves are so weakened … " (Participant 12, 13 years old).

> I didn't use to go and visit others … not that I said I didn't like to go and see people. For example, when I sat down, someone would ask me if I was on a diet and I would get angry and want to answer back, but I had to keep the boundries of respect, so I wouldn't say anything. And then, I wouldn't go to visit people at all because of this. (Participant 13, 19 years old).

Some of the adolecents who participated in the study preceived themselves as below optimal because of the symptoms of their syndrome and imagined that they were not worthy and felt "humiliated". In the words of the participants:

> Compared to my friends, I see myself very different. For example, they wear fashionable items that I have always liked to own, but I could never be like that, because of the excessive hair that I have to hide, my obesity and hair loss. (Participant 2, 15 years old).

The manifestation of mental stress as a result of the syndrome and mental turmoil in some of the participants led to "adolescents' perceptions". In the words of the participants:

"I'm usually tired. My activities have diminished, unlike the vitality I had before" (Participant 14, 17 years old).

"I don't like to move too much. I like to just always sit somewhere" (Participant 10, 19 years old).

Coping with the disorder

"Coping with the disorder" consisted of three sub-themes, namely "the recovery of health", "positive thinking" and "hope for recovery". Most of the adolecents who participated in this study tried to reduce the mental stress of having PCOS through academic accomplishments and took measures to promote their physical health.Although the adolescents felt responsible for their own health, they neglected it nonetheless, because they prioritized their studies and future career prospects.

Some of the adolescents attempted to create a positive image of their disorder and created a positive vibe for seeking treatment by adopting a "hope for recovery" approach. Some of them coped with the syndrome through a "positive internal dialogue". Some of the participants in this study were taking "health recovery" measures to cope with their syndrome. In the words of the participants:

"Right now, studying is my priority, and when I've completed my studies, I want to go to the doctor again" (Participant 1, 19 years old).

"I am far too busy with the university entrance examination and my studies to have any time for this disease at all" (Participant 8, 18 year-old).

"I used to regard my disorder as trivial. I didn't think it was necessary for me to take my pills. Later, I began taking it very seriously" (Participant 9, 18 years old).

Some of the participants were able to rid themselves of disturbing thoughts through "positive thinking" and coped with their disorder. In the words of these participants:

"I came to accept myself, 'Okay, you have this condition, you have this pimple!' I accepted it as it was and then wouldn't think about it" (Participant 4, 19 years old).

"It's a mild illness –not a very dangerous disorder" (Participant 4, 19 years old).

Some of the participants took steps to cope with the disorder through a "hope for recovery". In the words of this group of the participants:

"My medications are one too many, but I take them with the hope of getting better. Just like this. I take my

medications to get better soon" (Participant 6, 19 years old).

"When I take my medicines, since they regulate my period, I feel good" (Participant 8, 18 years old).

Discussion

The findings of this study include concepts such as escaping the problem, depressed mood and coping with the disorder. In conjunction with each other, these concepts led to the formulation of dealing with PCOS.

As the sociocultural context of any society can affect individuals' strategies for coping with critical situations, the sociocultural and religious contexts of the Iranian society can also affect the type of strategies adolescents adopt to cope with PCOS. Like in many Middle Eastern countries, cultural and educational issues also have a major role in adolescents' mental health in Iran.[22]

Evidence suggests that dealing with a chronic disease, such as adolescent diabetes, requires a coping strategy that can help improve the health outcomes and quality of life of the patient.[23]

Other chronic diseases such as adolescent cancer or serious infections that may cause future infertility have also become a serious concern for both adolescent patients and their parents as per their responses.[24,25] The diagnosis of any fertility disorder in adolescents can disrupt the normal psychosocial development of the individual.[26] In general, the manifestation of symptoms such as obesity, acne, hirsutism and the disruption of the menstrual cycle lead to stress in these patients and they cope with this stress in different ways.

In the experiences of the participants, some of the adolescents with PCOS were trying to escape their problems by forgetting and often with the concealment and minimization of their disorder. The results of a study on women with PCOS showed that those who suffered more psychological problems used maladaptive coping strategies, such as avoidance strategies, and used less problem-focused coping strategies.[27] Avoidance coping is known as an effective short-term strategy, but in the long term, it prevents psychological adjustment and increases depression.[28,29]

The results of other studies on social coping strategies have shown that adolescents use different coping techniques, such as avoidance coping, problem-solving and seeking social support.[30]

It seems that most participants in the present study were turning to these strategies to escape being labeled as "sick" and to be able to cope with the disorder in some way by denying its existence to themselves and others. It is a proven fact, however, that avoidance coping could cause a downward spiral in the long-term.

The experiences of the participants of this study showed that adaptation to illness could emerge as a depressive mood in some adolescents. The diagnosis of PCOS has psychological ramifications.[31] Depression and moodiness in adolescents and the appearance of a depressive mood have been argued to be associated with symptoms such as disturbed sleep, lethargy, restlessness, changes in appetite and weight, decreased motivation and concentration, decreased self-esteem and isolation.[32] In one qualitative study, the experiences of 12 people with PCOS aged 17 to 51 years revealed great mental anxiety in coping with this disorder.[19] The onset of PCOS is associated with the instability of emotions, confusion and moodiness and leads to feelings of irritability, fear and despair in social relationships and a general sense of unhappiness.[33,34]

The establishment of social relationships is vital during adolescence.[35] Adolescents with this disorder choose isolation to counteract the reactions of those around them. The acceptance of adolescents with PCOS by the community and those close to them helps improve their behavior, while increased criticism, especially in this vulnerable age group, reduces self-esteem and increases anxiety and depression and ultimately leads to abandoned social relationships.[36] In contrast, a negative body image destroys the individual's social competence and causes the abandoning of intimate relationships.[37,38] Changes in one's physical appearance, concerns over changes in one's mental body image and the development of anxiety about the ramifications of the disorder seem to play a role in the manifestation of a depressive mood as a kind of coping response to the disease.

The experiences of the participants in this study also showed that those who responded with positive thoughts and had hope for their future well-being and recovery chose an adaptive coping response to the disorder. The various factors affecting the acceptance of the disorder also contribute to the PCOS patient's coping with the disorder.[39] The results of a study on women with PCOS showed that coping strategies were more excitement-oriented.[40] Another qualitative study on women with PCOS also showed that coping strategies include deliberation (religious beliefs, paradoxical thoughts), practical steps (positive steps such as seeking information and treatment as well as negative steps such as detachment and

concealment) and seeking support (family support and peer support) in these patients.[41] Evidence suggests that the types of coping strategies chosen by women with PCOS affect their quality of life.[20] Some studies have even suggested that hope is a very powerful force that can play a key role in coping with adolescent illnesses.[42] Hope is occasionally a solution to tension that increases the individual's ability to adapt.[43] Some of the participants of this study were able to cope with their mental turmoil through their hope to recover. Meanwhile, some attempted to take steps towards coping with their disorder through positive thoughts. Positive thoughts comprise a branch of cognitive therapy that can be defined as the usage of hopefulness, happiness and positive mental abilities.[44]

A study by Benson et al (2010) conducted on 449 women with PCOS showed that some participants had a passive coping strategy in dealing with this syndrome (retreating and accepting one's fate regarding the disorder), which is an unharmonious strategy that leads to the emergence of anxiety and depression and in turn decreases the quality of life. In contrast, some participants who adopted active coping strategies (problem-solving and information-seeking) had lower levels of depression.[45] The participating adolescents of this study had a positive attitude and took health-recovery measures to cope with the disorder.

Active coping involves problem-solving and social support-seeking while passive coping involves social isolation.[17] The results of one study on children and adolescents with a chronic illness showed that coping with such a disease may lead to effective coping with daily stressors of life.[46]

Some of the participants used problem-solving through positive thoughts and measures to deal with the stressful conditions of life. They used a rational strategy to accept their disorder and their tensions thus decreased. In general, chronic PCOS requires self-efficacy and lifestyle modifications.[47] As for the psychological burden of PCOS, choosing a proper coping strategy plays a decisive role in the quality of life of adolescents with the disorder, as irrational strategies could cause harm and threaten different dimensions of life. The use of clinical counseling, mental health services, beauty counseling services and support services for patients and their families can contribute significantly to the improvement of the quality of life of adolescents with chronic PCOS.[48]

Implementing psychological counseling programs (by psychologists and other allied health professionals) and teaching adolescents adaptive coping strategies are recommended to prevent future mental health problems. Attention to mental health and related care measures is imperative for medical teams.

The study limitations include the non-generalizability of the results to all adolescents with this syndrome, although this limitation applies to all qualitative studies in nature. Furthermore, forgetting certain experiences or the unwillingness to actually express these experiences and feelings on the part of the adolescents could be considered another limitation of the study.

Conclusion

When confronted with the stressful symptoms of PCOS, the participants adolescents of this study showed coping responses such as escaping the problem, depressive mood or coping with the syndrome. Identifying the ways through which these adolescents cope with their syndrome is vital for recognizing the mental health needs of PCOS patients and improving their quality of life.

Acknowledgments

This article is a part of a PhD thesis of Shahid Beheshti University of Medical Sciences, Tehran, Iran. The researchers are grateful to the adolescents who participated in the study and their parents and vice-chancellor of research from the Shahid Beheshti University of Medical Sciences.

Disclosure

The authors have no conflicts of interest in this work.

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