

PSYCHO-SOCIAL EXPERIENCES OF ADOLESCENT GIRLS WITH POLYCYSTIC OVARY SYNDROME: A QUALITATIVE STUDY

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ABSTRACT

Background: Polycystic Ovary Syndrome (PCOS) is prevalent among women of reproductive age, featuring psychological and physical challenges. Its global impact on adolescents is concerning, notably its link to depression. Our study delves into PCOS's psycho-social effects to uncover its lasting implications. **Aim:** To enquire about and comprehend the social and psychological experiences of adolescent girls, as well as their family support and socioeconomic aspects in Kashmir. **Methods and Materials:** This study used a qualitative research design, focusing on participants from a local hospital. We used non-probability purposive sampling and conducted semi-structured interviews for data collection. A qualitative thematic approach was used to derive themes from the data to provide a broader, more comprehensive analysis of the entire body of data. **Results:** The study uncovered high rates of anxiety, depression, obesity, hirsutism, and sleep disorders, especially anxiety disorders. This points to a lack of awareness among participants and their parents, which is a serious issue. The findings suggest that some awareness programs need to be developed, and if possible, a separate section in the hospital should be developed for these patients to provide them with full assistance promptly. **Conclusion:** Psychosocial problems are increasing among adolescent girls with PCOS in Kashmir due to a lack of awareness. The study suggests creating awareness programs and dedicated sections for timely assistance to address these issues. It is therefore necessary to develop an effective solution to lessen the long-term health issues linked to PCOS in adolescents.

Keywords: Adolescence, Kashmir, Polycystic ovary syndrome, Qualitative research.

INTRODUCTION

Polycystic ovary syndrome (PCOS) is a common reproductive endocrine disorder that affects 5-10% of reproductive-age women (Knochenhauer ES, 1998). The classic symptoms of polycystic ovary syndrome include irregular menstruation, biochemical or clinical hyperandrogenism, and ultrasound

evidence of polycystic ovaries (Wild RA, 2010). Any woman who displays at least two of the following three symptoms can be diagnosed with PCOS, according to the Rotterdam criteria, which is the one that is most frequently used. An ultrasound examination may identify ovarian cysts,

ovulation failure, biochemical hyperandrogenism, or hyperandrogenaemia (Dybciak P, 2022). PCOS increases the risk of infertility, preeclampsia, early pregnancy loss, and endometrial cancer in women. Furthermore, since PCOS is linked to insulin resistance, evidence suggests that women with PCOS are more likely to develop type 2 diabetes, dyslipidemia, hypertension, and heart disease (Bashir, 2020). The cysts are not harmful, but they do cause hormonal imbalances (Watson, 2019). Obesity, insufficient physical activity, and a family history of the condition are risk factors. Many observations may be temporary during this pubertal transition since various traits may be changing. Later, during adolescence, many findings may stabilize (Bashir, 2020). Early diagnosis and treatment can aid in symptom control and prevent long-term consequences. Changes in behavior and lifestyle are part of PCOS treatment (Gupta, 2018). Many groups have developed diagnostic standards for this illness. The National Institutes of Health (NIH) created the NIH criteria, the American Society of Reproductive Medicine created the Rotterdam criteria, and the Androgen Excess and Polycystic Ovary Syndrome Society created the AES criteria (AE-PCOS) (Naz MS, 2019). Women who have PCOS are more likely to experience psychological issues. Studies conducted in the past have revealed that PCOS patients have a greater prevalence of psychiatric diseases, notably mood disorders (Rasgon NL, 2003). The increased risk of depression among PCOS-affected women supports earlier studies. (Rassi A, 2010) revealed that 26.4% of PCOS patients had significant depression, and (Hollinrake E, 2007) found that 21% of PCOS patients and 3% of controls had depression. whereas, (Månsson M, 2008) and (Kerchner A, 2009) revealed that, correspondingly, 45% and 40% of PCOS patients had depression. This variance in depression prevalence between

studies can be attributed to a variety of screening and diagnosis techniques and instruments, the impact of culture on depression epidemiology, and ultimately, the usage of medications like oestrogen (Hussain A, 2015). (Sadeeqa S, 2018) Conducted extensive research on PCOS-related mental stress, indicating that the symptoms of PCOS most commonly affecting patients include increased androgen levels, menstrual disturbances, infertility, obesity, hirsutism, or alopecia, but behavioral scientists are now observing significant levels of mental stress in PCOS patients, particularly among young girls. This could be because young girls are more concerned with their physiology and physical health during adolescence. (Gupta, 2018) This syndrome is a growing concern among adolescents worldwide, with varying reports of its prevalence in different parts of the world. Reports on the prevalence of PCOS in adolescents are rare. (Joshi B, 2014) In an Indian study, the prevalence of this syndrome in 15-19-year-old adolescents was 22.6% based on the Rotterdam criteria and 9.8% based on the AE-PCOS criteria. Another study on adolescents aged 17 to 19 in Thailand found 5.29% had this syndrome (Kaewnin J, 2018). According to studies conducted in Iran, the prevalence rate ranges from 8.3% to 11.4% (Asgharnia M, 2011). Studies show that between 5% and 10% of the general population worldwide has PCOS (Azziz R, 2004). Depressive symptoms are common in PCOS patients, especially in young girls, and are present in about 40% of reproductive-age women (Kerchner A, 2009). It was found that 4% of people in the southwest of the United States have PCOS. The incidence was 9.13% among adolescent Indians (Nidhi R, 2011). According to the National Institute of Health, the prevalence of PCOS in adult reproductive-aged women worldwide has increased from 6.5% to 6.8% (Asunción M, 2000). Tabassum K conducted a study in a hospital in Bangalore

and discovered that 10% of women had PCOS. She also reported a 4.8% prevalence of PCOS in the 15-24, year age group (Hussain A, 2015). The prevalence of PCOS was reported to be 22.5% in a study conducted by (Joshi B, 2014) among adolescents and young girls in Mumbai, India. The prevalence of PCOS in adolescents was found to be 9.13% in a residential college in Andhra Pradesh, South India (Hussain A, 2015). In North India, (Gill H, 2012) found a prevalence of 3.7% in the age group of 18-25 years. Adolescent females with PCOS have more emotional stress and depression due to obesity, which is the condition's primary defining characteristic (Ibáñez L, 2009). The mechanisms underlying the relationship between PCOS and anxiety and depression disorders are unknown (Dybczak P, 2022). They can be the result of hormonal changes, PCOS symptoms, or a mix of the two. New therapy modalities may result from a better understanding of the risk of mood problems in women with PCOS. Therefore, in 2018, the Androgen Excess-Polycystic Ovary Syndrome Society published a call to action declaring mental health as a priority for PCOS research (Dokras, et al., 2018). Natural maturation characteristics overlap with PCOS signs and symptoms in adolescent girls (Naz MS, 2019). The condition is defined by three different sets of diagnostic criteria in adult women, although their applicability to adolescents is debatable (Merino PM, 2018). To the best of our knowledge, data on PCOS in Kashmir is limited to a few studies. In 2017, a study found that the age group 15-24 years had the highest prevalence of PCOS, i.e., 5.0% (Bashir, 2020). The researcher team believes that this study is necessary because the causes and consequences of PCOS have previously been discussed in many studies, but the impact of the problem on the psycho-social health of women, particularly adolescent girls, their experiences, and outcomes has yet to be

investigated, so this study was conducted to fill that gap.

METHODS AND MATERIALS

Universe and Sampling

The research was carried out at Srinagar's territory hospital, central to the Kashmir division. It's a sub-district facility in Hazratbal, Srinagar. The sample comprised ten participants from the Srinagar district, chosen via Non-Probability Purposive sampling.

Identification and contact with respondents

The researcher obtained permission from the hospital's higher authority to collect data and interact with participants during check-ups and treatments. With the hospital's open participant flow, interviews were conducted with the doctors' consent.

Research setting and participants

The researcher focused on adolescent girls' social and psychological experiences, family support, and socioeconomic aspects. A qualitative thematic approach (Braun, 2006) was used to derive themes for detailed analysis and comparative data assessment, aiming for rich descriptions.

Tool preparation and data collection

While preparing the tool, the Research team visited the hospital to understand the setting and participant availability. Developed semi-structured interview guides based on literature and expertise. Utilized prior experience from visits to other hospitals. Designed a background questionnaire. Conducted interviews with 10 adolescents, ages 12-19, in Kashmiri and Urdu. Sessions lasted 40-60 minutes with verbal consent. Recorded interviews and maintained a memo book for notes. Communication of the recording process was prior to the interviews. Data management and the Process of analysis
The conducted interviews (in Kashmiri and Urdu) were transcribed and translated by the first author, fluent in Kashmiri, Urdu, and English. Verbatim representation with

emotional indicators was prioritized, including interruptions, pauses, intonation, and simultaneous talk.

Analysis of data

We used thematic analysis to identify, organize, and draw patterns in the data (Braun, 2006). The analysis of the transcripts began as an iterative process carried out by the AUR. The authors closely read and reread the transcripts to become acquainted with the data, and preliminary notes of the important points were taken from the process. After the first few interviews, data coding began, and a codebook was created. The first author coded all of the interviews to generate as many patterns as possible. Themes were derived from the data, and emerging themes were identified and organized with descriptive categories and subthemes (JM, 2008). Using an inductive approach, the data were further analyzed for theme mapping and comparative analysis within document groups. Since the themes did not exactly correspond to the words, the analysis was not only dependent on an inductive framework (Banister P, 2011) or “emerge,” rather, they were deliberately created by the researchers and informed by the literature as well as their own experience and knowledge (Braun, 2006) (Williams, 2018).

Ethical Clearance

Ethical clearance was obtained from the Block Medical Officer, SDH Habbak of Hazratbal Srinagar. The research was conducted from September 2022 to November 2022.

RESULTS

Socio-economic Profile

Table 1 displayed that all participants were females aged 15 to 20, predominantly from the BPL category (below the poverty line). The BPL category refers to marginalized people for whom the Government of India has

imposed an income limit. Most participants, around 98%, fell into this category, with only 2% classified as APL (above the poverty line). The table shows the participants' family income, which starts at 2000 and does not exceed 10000. The participants' educational levels were found to be secondary and higher secondary. Secondary education in India serves as a bridge between elementary and secondary education, preparing young people aged 14 to 18 for entry into higher education. Higher secondary schools typically have classes from 11th to 12th grade, with students ranging in age from 16 to 18 years. Students can select their preferred stream and subjects at this level of education. They can major in the arts, business, or science (medical & non-medical).

TABLE 1 - SOCIO-ECONOMIC PROFILE

Participant	Age	Gender	Family	Income	APL/BPL	Educational status
1.	20	Female	Nuclear	7000	BPL	Higher Secondary
2.	20	Female	Nuclear	2000	BPL	Higher Secondary
3.	18	Female	Nuclear	7000	BPL	Secondary
4.	17	Female	Joint	8000	BPL	Secondary
5.	19	Female	Nuclear	8000	BPL	Higher Secondary
6.	18	Female	Nuclear	6000	BPL	Secondary
7.	17	Female	Joint	6000	BPL	Secondary
8.	19	Female	Joint	7000	APL	Higher Secondary
9.	15	Female	Joint	10000	APL	Secondary
10.	16	Female	Nuclear	6000	BPL	Secondary

Key themes from interviews

I) Obesity and depression-related factors

As demonstrated by various investigators, obesity, excessive body hair, infertility, and changes in physical appearance all contribute to psychosocial problems in PCOS patients (Sadeeqa S, 2018). Adolescents with PCOS experience extreme mental stress and depression when embarrassing symptoms such as hirsutism, obesity, and acne appear during adolescence (McCook JG, 2005). Obesity has been identified as the leading

cause of depression and emotional stress in PCOS adolescents (Moran LJ, 2009). Obesity is the most common feature in PCOS patients, increasing psychological strain and depression in adolescent girls (Ibáñez L, 2009). Obesity was identified as a major cause of depression and anxiety in this study's participants. And, as the researchers interacted with the participants, they shared their experiences dealing with issues such as (anger, mood swings, vulgar thoughts, High Blood Pressure, low interest in work or studies, etc.). The data revealed that obesity has a major effect on these participants' psychological health as well as their social life, as these participants avoid social gatherings and interacting with others due to their physical changes. As a result, it is possible to conclude that depression occurs as a result of the obesity factor, which affects both their psychological and social well-being.

One of the Participants added, "I started noticing changes in my body as my weight was increasing, and also my face was full of pimples and hair. That was the time I started worrying and consulted a doctor."

II) Social withdrawal

This high degree of sadness and anxiety in PCOS patients may be brought on by several variables, including a high BMI (body mass index) and social demoralization, which, if severe, can result in social disengagement (Veldhuis JD, 2001). In this study, social withdrawal has been found in these participants as they describe their personal experiences of isolating themselves due to the severity of the sickness by staying away from social settings, including schools, public places, and other gatherings. Even some of the participants admitted to having cut themselves off from their relatives. One of the only motives is embarrassment over bodily changes, such as weight gain, acne, facial hair, etc.

One of the Participants added, "Whenever I see my face in the mirror, I find myself ugly and fat, so I keep myself away from my siblings, and most of the time I sit alone in my room."

Similarly, another Participant "I started avoiding my friends and my family members as I was scared of going out because of my facial hair growth and lots of pimples."

III) Uncertainty about infertility

Furthermore, patients with PCOS who have a high BMI factor, depression in the family, infertility in the family, sleep issues (Dantzer, 2001), and elements of depression include tiredness, followed by a loss of interest in routine tasks and changes in appetite (Sadeeqa S, 2018). Several studies have linked specific PCOS symptoms, such as infertility, hirsutism, and acne to decreased mental well-being (Hussain A, 2015). 50% of PCOS patients will actively seek infertility treatment at some point in their lives (Azziz R M. C., 2005). The current study found that PCOS patients face a variety of challenges, with the majority of them dealing with infertility issues, such as being unable to have children. Individuals with a history of PCOS frequently require extensive treatment to become pregnant. Girls reach sexual maturity during puberty, as is well known. As a result, when people discover they have PCOS, it becomes a frustrating time in their lives as they begin to consider the consequences of their illness. The researcher discovered that the fear of being unable to bear a child in the future has a large impact on the minds of these participants, causing chaos in their psychological and social lives.

One of the Participants added, "The moment my doctor told me about my disease (PCOS), I got stressed as I had no awareness about the same before. By the time I reached my home, I started crying, thinking

that I won't be able to conceive in the future."

Another participant added, "My mother is worried because she thinks I will be having issues in my future, maybe I will never conceive."

IV) Cost of Medical Treatment

In this research study, it was revealed that the patient's cost of therapy can occasionally be high because it often takes months or even years for the disease to be cured. These participants revealed during the interview session that the cost of medicines sometimes causes them to consider discontinuing their treatment because the cost of medicines is so high. They feel very sad because they believe they are becoming a burden on their parents. According to a reasonable estimate, the annual financial cost of PCOS among people aged 14 to 44 is over \$4.37 billion. In the treatment of the associated menstrual dysfunction/AUB, 31% of the burden stems from the treatment of hirsutism, 14% from the treatment of hirsutism, and 12% is attributable to the provision of infertility treatments. Only around 2% of the estimated economic burden associated with healthcare was attributable to the costs of a single diagnostic examination for each patient (Azziz R M. C., 2005).

One of the participants added, "My father is a laborer, and our family income is modest. Since being diagnosed with PCOS, I have been on medication that costs me between 1500 and 2000 per month, and I sometimes feel sorry for my father because my medication has become a significant burden on his income."

V) Sleeping disorder

The researchers found that girls with PCOS struggle with sleep problems due to illness-related distress and despair. These issues lead to stress and sleep disorders, including lower sleep quality, increased snoring, and a

higher risk of obstructive sleep apnea. Women with PCOS have lower subjective sleep quality, snoring is more common, and they have a greater chance of having obstructive sleep apnea (Hachul H, 2019).

One of the Participants added, "My menstrual cycle was delayed, and I got worried why this was happening, so I consulted a doctor, and she suggested going for a USG, where I was diagnosed with PCOS. I started feeling sleepless as the fear was increasing with each passing day."

VI) Immediate Reaction

Because it is fundamental to human nature for every person to react to the same event differently, the researchers found that participants' reactions to learning about their illness varied. Many were unfamiliar with PCOS before and had initial thoughts like, "What is PCOS?"

One of the Participants added, "My mother was present when my doctor informed me of my PCOS condition, and the doctor helped us comprehend what PCOS is, as well as its causes and effects. Many unfavorable thoughts began to emerge in my brain, and by the time I knew about my disease, "I started crying hopelessly."

VII) Support systems

Participants mostly had strong family support, especially from parents who took care of their health and went with them to doctors. Some also found support in extended family and friends. Top of Form

One of the Participants added, "My family is very loving and caring by nature, and after learning that I had PCOS, my parents have become even more loving and concerned. My mother constantly reminds me that I must get regular check-ups on certain days."

VIII) Coping mechanism **Religious belief**

Some participants disclosed that they turned to religion and spirituality for comfort, going so far as to start seeing God-men (Peer Sahib) to treat their illnesses because religion holds such a high place in our culture. They felt a certain amount of relief since they believe that there is nothing these God-men cannot heal.

Resilience

After numerous visits, the researchers discovered a case history of a woman who had been 14 when she was first diagnosed with PCOS; today, she is 28 years old, but she has a long history of this particular illness. She is married right now, but she is having a lot of trouble becoming pregnant, and she is really upset. In this situation, we may conclude how crucial it is to raise the disease's awareness among every person in society, especially adolescent girls.

IX) Quality of life

Barriers to treatment

Treatment for PCOS is accessible but often costly due to its long duration. The study suggests that hospitals should have dedicated PCOS sections for easier access.

Stigma

PCOS causes concern due to its link to infertility, leading to worry and sadness. In some cases, doctors sometimes suggest early marriage for future childbearing.

DISCUSSION

Our study's main findings were high rates of depression, anxiety, obesity, hirsutism, and sleeping disorders. We discovered a high prevalence of anxiety disorders, in particular. One of the primary causes of social withdrawal is obesity and hirsutism. The study revealed how the cost of the medication makes the treatment burdensome for these patients. There is a stigma associated with infertility

of not being able to bear a child in the future, which causes great distress in the minds of these patients. Moreover, even though most patients have strong family support, the psychological burden prevents them from remaining positive. It was also concluded that many patients seek spiritual assistance to overcome this disease. This study discovered a high prevalence of anxiety disorders, in particular. (Månsson M, 2008) Also, an increased incidence of anxiety disorder was discovered in women with PCOS. Similarly, (Kerchner A, 2009) discovered that PCOS patients had high levels of anxiety disorders. Anxiety levels are understandable by continuous worries about fertility loss, the loss of one's sexuality, and concern over the possibility of never having children in future can be used to explain why there is such a high level of anxiety (Hussain A, 2015). As revealed in the current study, these participants are affected by thoughts of the consequences of their condition, which frustrates them at times and affects their psychological and social well-being. Adolescent girls with PCOS are prevalent in Kashmir. As it was not possible for the research team to include every case in the study, the team discovered that adolescent girls with PCOS are numerous, and further research could be done in future studies. Also, the study's limitation was that this study was conducted on a small number of participants, so it can't be generalized to the whole population. The research team found that more studies should be conducted to get more relevant data. And not every girl in this age group (12-19 years) has a proper understanding of PCOS, so it was concluded that special attention and care should be provided to women with PCOS, particularly adolescent girls, because they are young and do not have a proper understanding of the disease's consequences.

Possible measures

The study highlights the importance of early detection and counseling for PCOS in adolescent girls and their families. Awareness programs in schools and community health centers are crucial for addressing the lack of knowledge about PCOS.

CONCLUSION

The study discovered high rates of melancholy, anxiety, obesity, hirsutism, and sleeping difficulties among patients, with anxiety disorders being most common. Obesity and hirsutism contribute to social withdrawal, and drug costs increase the burden of therapy. Even individuals with great family support are deeply distressed by the stigma of infertility. Many sufferers seek spiritual assistance to cope. The study's shortcomings include a limited sample size and a lack of thorough understanding of PCOS among adolescent females, emphasising the importance of additional research and targeted education for this group.

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