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The Experiences and Challenges Faced by Women with Polycystic Ovary Syndrome (PCOS) in Lahore, Pakistan

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ABSTRACT

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Polycystic ovarian syndrome (PCOS) is one of the major health problems for women of reproductive age. In Pakistan, the prevalence of this syndrome is increasing with every passing year. Besides its rapid increase, the majority of Pakistani women do not have knowledge of this disease. The current study is intended to examine the experiences and challenges faced by women with PCOS. For this purpose, a sample of twelve women suffering from PCOS was interviewed through the purposive sampling technique. Eight out of twelve women were married, and four were unmarried. The researchers chose thematic analysis to analyze the data. The analysis revealed several major themes, including participants' experiences with the diagnosis and awareness of PCOS, initial family reactions particularly from mothers and husbands—the impact of PCOS on mental and physical well-being, and common myths and misconceptions surrounding the condition. These findings indicate that there is an urgent need for raising awareness about PCOS among the public, particularly among young women. This study is significant as it sheds light on the personal and societal challenges associated with PCOS, highlighting the critical need for awareness and supportive interventions to improve the quality of life and wellbeing of affected women in Pakistan.

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1.0 Introduction

Polycystic ovarian syndrome (PCOS) is one of the global public health problems for women of reproductive age (Pasquali, 2018). This disease has now widespread prevalence across the globe (Tahir et al., 2020). The World Health Organization (WHO) indicates that 116 million women are affected by PCOS (Joham et al., 2022). Moreover, it is estimated that 4–18% of women of reproductive age are suffering with PCOS (Tahir et al., 2020) every year, and the majority of them do not know about its early symptoms (Haq et al., 2017). This endocrine disorder develops in puberty. It slowly continues in adulthood and has a long-lasting impact beyond menopause (Diamanti-Kandarakis, 2010). Thus, the majority of the women can cure themselves of PCOS at an early age if they have appropriate knowledge of its symptoms and risk factors contributing to its prevalence.

This is the fact that women across the world are suffering with PCOS, but each region has its own kind of PCOS risk profile. It is noted that South Asian, Filipino, and Chinese women have diverse risk factors for this disease. South Asian women are at a higher risk of PCOS in comparison to Chinese and Filipino women (Wijeyaratne et al., 2011). This is happening because the root cause of PCOS is not yet fully understood. However, the majority of the medical experts are of the view that women suffer with PCOS due to the combination of genetic and environmental factors (Himelein & Thatcher, 2006).

Doctors and medical experts use three different sets of diagnostic criteria to diagnose PCOS among middle-aged women and young girls (Merino, Codner, & Cassorla, 2011). The first criterion is designed by the National Institute of Health (NIH). The second criterion is called the Rotterdam criteria. This criterion is designed by the American Society of Reproductive Medicine. The last criterion is made by the Androgen Excess and Polycystic Ovary Syndrome Society (AE-PCOS), and it is called AES criteria. In order to diagnose women with PCOS, they must fulfill two of three criteria (Aziz et al., 2006; Hussin & Kadir, 2020). At present, most of the medical experts prefer Rotterdam criteria for the diagnosis of PCOS.

The women who are suffering with PCOS may have different kinds of early warning signs and symptoms. Weight gain, acne, and the increase of uninvited hair on the body are considered early warning signs of PCOS. The primary symptom of this endocrine disorder is facing problems in the menstrual cycle. Women suffer during menstruation and may have excessive bleeding. Consequently, they feel tired and weak (Zaikova, 2021). The secondary symptoms of this disease include repeated headaches, voice changes, and insomnia. They also suffer with hirsutism, loss of scalp hair, and infertility (Sharma & Mishra, 2018). Therefore, PCOS presents a range of physical health challenges, impacting the quality of life for many women (Sidra et al., 2019).

Alongside physical health challenges, the patients of PCOS have to cope with mental health challenges as well. Research highlights a strong correlation between PCOS and an increased risk of mood disorders, especially depression and anxiety (Azziz et al., 2016). According to Tahir et al. (2020), 14-67% of women who have PCOS are reported to have depression. Similar findings are reported by Cooney et al. (2017), who found that depression rates among women with PCOS are significantly higher than in the general female population. The hormonal imbalances inherent

in PCOS, particularly around androgens, are suspected to contribute to emotional regulation difficulties, which may exacerbate depressive symptoms (Elsenbruch et al., 2010). These studies indicate that there is a need to address both the physical and mental health dimensions of PCOS for providing comprehensive care and improving the quality of life of the effected women.

2.0 Literature Review

Pakistan is one of those countries where the prevalence of PCOs is relatively higher than other countries (Shakeel, Ashraf, & Wajid, 2020). Studies indicate that Pakistani women have a 52% prevalence of PCOs (Butt et al., 2024; Akram & Roohi, 2015). This is quite high as compared to China (Yang et al., 2022), India (Ganie et al., 2022), Sri Lanka (Ranathunga et al., 2022), and the United Kingdom (Michelmore, 1999). This clearly indicates that Pakistani women do not have adequate knowledge and awareness of this disease (Rizvi et al., 2023; Zulfiqar et al., 2022). Thus, there is a need to take drastic steps to educate and make women aware of the symptoms and contributing factors of PCOS(Ilyas, 2024).

Women suffer with PCOS due to multiple risk factors (Himelein & Thatcher, 2006; (Blay, Aguiar, & Passos, 2016). Pakistani society has witnessed socio-cultural change due to technological advancement and globalization (Mughal, 2023). Modernization has had a substantial impact on the daily lives of Pakistani people. Their lifestyle has changed a lot during the last three decades (Jamal, 2020). More importantly, the young generation wants to live their lives as per modern-day needs. They prefer fast foods and soft drinks over traditional and continental foods (Irfan et al., 2024). Such unhealthy foods increase the risk of PCOS among young girls (Hajivandi et al., 2020).

Despite the fact that Pakistan has made socio-cultural and economic advancements, it has limited impact on improving health outcomes for women (UNICEF, 2017). The majority of Pakistani women have no access to basic health facilities (Butt, 2004). About 48% of them also lack the right to have a say in their health facilities (Omer, Zakar, Fischer, 2021). Pakistani women face societal pressure to remain silent about health issues, fearing judgment or backlash that could lead to shame or social isolation (Micheal, 2020). This silence is perpetuated by limited family support, inadequate sex education, and religious and cultural beliefs that frame such discussions as improper (Tomlinson, 2017). Consequently, young girls and women lack information about early warning signs and symptoms of PCOS. They are also hesitant to seek assistance for the diagnosis of this disease and fear that they will be judged negatively (Agyekum, 2021). Another challenge Pakistani face is the availability of female gynae doctors and other paramedics, including ultrasound specialist. The major cities of Pakistan do have good number of female medical persons, however there is difference of ratio in male and female doctors in small towns and villages as female medical staff ratio is low, compared to men. This makes identification of women specific health issues more difficult, thus resulting into prevalence of many medical issues including PCOS (Anwar, Green, & Norris, 2012).

2.1 Statement of the Problem

As discussed above, PCOS has significant implications for the physical, emotional, and social well-being of women. Despite its high prevalence, little is known about the role of family

dynamics, particularly the reactions of mothers and husbands, when women disclose their diagnosis. This study aims to address this research gap by increasing knowledge and awareness among the women about this disease. This study seeks to examine women's and their families' early responses to the diagnosis. This study also aims to explore the health-related challenges faced by polycystic women. Understanding these aspects will provide critical insights into improving support systems and healthcare strategies for women affected by PCOS.

3.0 Methodology

A qualitative research approach was chosen to capture the intricate meanings and intentions underlying human interactions in the context of PCOS. This approach facilitates a nuanced exploration of participants' beliefs and feelings, allowing for a comprehensive understanding beyond numerical metrics. The research design selected for this study is a case study, defined as an empirical investigation of a contemporary phenomenon in its real-life context. Specifically, the researcher focuses on understanding the early reactions of women upon receiving a PCOS diagnosis, as well as exploring the challenges and experiences faced by these individuals (Poses, & Isen,1998). The target population for this study is the district of Lahore, Pakistan. Purposive sampling, a non-probability technique, was employed to select participants who could provide comprehensive and detailed descriptions of their experiences with PCOS.

A local government hospital was approached and lady gynecologist was taken on board whom, after taking the consent of female's patients she was treating with PCOS issues, provided list and contacts to researcher. The researcher received twenty-five contacts that included unmarried and married girls with Symptoms of PCOS. A total of twelve case studies were conducted to gather rich and detailed information and a detailed interview guide was made for this purpose. The decision on the sample size was not predetermined but based on data saturation, the point at which no new topics or insights emerged from the interviews. This iterative approach ensured that the interviews continued until saturation was achieved, guaranteeing comprehensive data collection and a thorough exploration of the challenges and experiences faced by women with PCOS. The data were collected in March and April 2023 and participants were contacted through phone and email. Thematic analysis was employed, involving verbatim scription and simultaneous literature review to derive codes and themes from frequently mentioned statements. The study's ethical and methodological rigor is underscored by its commitment to participant consent, thorough data collection, and systematic analysis.

4.0 Findings and Results

4.1 Socio economic demographic profile of the respondents

Out of 12 respondents, four were unmarried girls with average age of 21 years. The rest of the respondents were married women with average age of 31 years. The average monthly income of the respondents was between 75 thousand to 100 thousand Pak rupees. The majority had been living in rental houses. The educational status of the unmarried girls was intermediate while out of eight married women, three reported to have a bachelor's degree, two informed of passing intermediate and rest had done matriculation. The married women had average two children.

Diagnose and awareness about the disease

The greater number of respondents of the study informed of having no or very less information on symptoms of PCOS. The respondents revealed that they had heard of PCOS, but were not able to diagnose and recognize the diseases. The respondents were of the view that most of the members in families do not know about the prevalence of PCOS which result into delays in treatment. Such delays effect the health of both married and unmarried woman.

One of the unmarried girls in her early twenties said,

"I had been going to problem of irregular periods. This resulted into loss of blood too. One day at school in my class suddenly I started shivering and my hands feet went numb. I was taken to the hospital. When I reached the hospital, I had my periods and was in extreme pain. After the checkup and medical reports doctor told me that I have a PCOS.

According to one married respondent,

"I had polycystic ovary syndrome for a very long time but I did not know. I thought It was normal periods problem but after marriage when I was unable to conceive. I consulted my gynecologist she told me that you have PCOS ".

Another married woman added,

"I had my menstrual cycle started very late. My face would have heavy hair and I would feel embarrassed in front of my friends. I would go through extreme abdomen pain during my periods. I was able to conceive after five years of my marriage and that was possible only when I took treatment of PCOS. Today I feel how badly I neglected this issue because of shame factor and lack of awareness.

4.2 Reaction of families

Majority of the women reported that their families were not aware of the prevalence of this disease among women. They were hesitant to accept it as a disease. They were ill informed about the factors contributing in the prevalence of this disease. They had many misconceptions related to PCOS that led to certain confusions about the treatment of this disease. One of the unmarried respondents said,

"My mother after knowing of certain complication related to irregularities in periods took me to a gynecologist. After having diagnosis of PCOS, my mother broke into tears and thought of this disease is serious and has no treatment. The gynecologist eventually made her realize the treatable nature of disease.

Another married woman shared,

"It was after birth of my first baby I had certain symptoms. The internet was full of misinformation related to such symptoms. My husband really thought I won't be able having another baby because of such symptoms. This led to so many conflicts between me and my husband. My deteriorated condition was a result of not being able to diagnose and treat PCO timely because of harsh reaction and lack of support from husband"

4.3 Effects of PCO on women health

The respondents of the study were of the view that the prevalence of PCOS and delays in treatment left considerable effects on the overall health of young girls and women. Many studies have indicated that women face serious consequences in absence of treatment of PCOS, so far, their physical, mental and emotional wellbeing is concerned. The similar findings were revealed in the current study. One of the unmarried girl respondents reported,

'I had to deal with weight gain and acne throughout. Initially my family did not make any effort to investigate reason of abdomen pain and irregular periods. After graduating from university, my marriage proposals were rejected because of being obese. I went through lots of mental traumas. It is just two years ago I started a treatment and I can see a visible change in myself"

A Married women similarly said,

"I would miss my periods after the birth of second child quite often. I had no idea what is happening. My husband would attribute everything to hormonal changes post-delivery, even with consulting a doctor. I would have bad mood swings and facial pigmentations would make me look like a sixty years old lady. Today I regret neglecting myself and not consulting a doctor in time.

4.4 Social and cultural barriers

There are certain social and cultural barriers that significantly impact the diagnosis and treatment of PCO in a country like Pakistan. Though the information and understanding on PCO vary from region to region, it has been stigma talking on menstrual cycles and women reproductive rights, both in urban and rural households of Pakistan. Such stigmatizations lead to a greater reluctance in seeking medical care.

A young unmarried girl shared,

"I would miss my periods very often and as a result I was gaining weight. I would feel extremely ashamed of sharing this even to my mother. Once a close friend guided me and eventually shared with my mother. My mother decided to hide this from my father and we seek medical help without informing my father. The delay in treatment damaged my overall health".

A married woman shared her perspective,

"I was unable to conceive a child after six years of my marriage. I had PCO which were diagnosed very late. My mother in law was very furious on knowing my issues and blamed my mother on hiding this issue before marriage. I had been consulting a physician instead of gynecologist as my mother in law did not want anyone to know of this issue and was reluctant to see gynecologist. It was my husband who later took stand and after six months of treatment, I got pregnant"

4.5 Hurdles on available treatments

Pakistan health system has been facing serious challenges since its inception. The access to health centers and people's trust on the available medical services has been a grave issue in the country. The current study also indicated that sensitive issues in women health, in particular related to women reproductive health and menstrual health are difficult to handle because of certain myths. Besides, once there is a diagnosis, the biggest challenge is to reach to right doctor as country is full of quacks and non-certified doctors. The role of spiritual healers (peer) and people blind trust on considering water given by that spiritual healer as a solid treatment is a matter of grave concern in the country.

A married respondent added,

"My diagnosis with PCO was very late. Initially when i shared my symptoms with my husband; he took me to a spiritual healer who gave me an amulet to wear. My husband disbelief on the medical practitioner and element of shame and embarrassment of my issues increased the intensity of PCO disease in me".

A young unmarried girl revealed,

"What bothered my mother was her fear what people would say if I am caught at a gynecology clinic. My mother was of view that people would make false stories on my character. This led her to get me consulted from a traditional birth attendant (Dai) of my area. I was treated by her for many months before coming here in hospital as my abdomen pain was getting worsen with passage of time"

5.0 Discussion and Conclusion

The purpose of this study was to highlight the experiences of women who had PCOS. Findings indicate that majority of respondents had little or no knowledge about the symptoms of PCOS. While they had heard of PCOS, they were unable to diagnose or recognize the condition. In addition, most of their family members were unaware of its prevalence, leading to delayed treatment, which adversely affects the health of both married and unmarried women. According to the findings, majority of women indicated that their families were unaware of the prevalence of this disease among women and were reluctant to acknowledge it as a medical condition. They did not have proper knowledge about the contributing factors behind its prevalence and held numerous misconceptions regarding PCOS, which caused confusion about its treatment. Therefore, it is critical to raise awareness among the general public, especially women, about the early signs and symptoms of this disease to ensure timely detection and treatment.

In a society like Pakistan, socio-cultural values pose significant challenges to the diagnosis and treatment of the diseases related to the reproductive health of the women. PCOS is one of those diseases. The majority of the women did not want to share and discuss their menstrual health with anyone, even with their close family members. This is because their menstrual problems might lead to stigmatization and a perception that they were not fertile women. Family members might not be aware of complexity of this disease. Their negative attitude undermining the severity of the disease could badly affect patients physical as well as mental health. Their derogatory comments and negative reactions could discourage them from seeking medical attention or openly

sharing their symptoms with their families. They may be afraid of being judged, criticized, or disappointed again. This might cause delays in identification and treatment, worsening the woman's physical and emotional suffering. This stigmatization exacerbated reluctance to seek medical care, further hindering timely diagnosis and intervention. Thus, there is need to initiate a special health intervention program for the early diagnosis and treatment. This can be done by providing these services through national programme for family planning and primary health care. This study indicate that women faced health-related challenges, both mental or physical, in order to cope with PCOS. Their mental health got worsened due to hormonal abnormalities. They were more worried about body image concerns and concerned about the impact of PCOS on fertility. Some of the symptoms of PCOS, weight gain, loss of scalp hair, irregular periods, and unwanted hair, had a negative impact on women's health that may deteriorate their mental health. Findings indicate that participants had unhealthy lifestyles. They had bad eating habits and did not do physical activities, and did not have proper sleep. But after the diagnosis, majority of participants changed their lifestyle to healthy food and eating habits, adding physical activity in their routine and also started taking proper sleep for the relaxation of their mind.

5.1 Conclusion

This study concluded that the participants did not have proper knowledge and awareness of the prevalence of PCOS. They did know about this disease, or their knowledge was very limited. Due to the lack of awareness about this disease, they were confused and worried about long-term consequences. They were also uncertain about recovering from this disease. This fear and uncertainty were making them more depressed. In this study, it was found that weight gain, loss of scalp hair, unwanted body hair, and irregular periods were the most common symptoms of PCOS. These physiological changes impacted their mental health as well. They had low self-esteem and were worried about their future. This study found that participants received mix reactions of their family members and relatives when they disclosed that they had PCOS. Their close family members were supportive but extended family member were not. Their views were negative about PCOS and they did not understand the severity, complexity and longevity of this disease. Their mothers supported them they also faced social pressure and criticism from others. They were asked to keep the disease private and did not tell anyone about missed periods or visits to gynecologists, especially among unmarried women.

Multiple risk factors, unhealthy dietary habits, lack of physical activity, and insufficient sleep, were reported as major causes of getting affected with PCOS in our study sample. However, they changed their lifestyle after being diagnosed with PCOS. They opted healthy dietary habits and did more physical activities in their daily routine. They also started prioritizing their sleep. Regarding myths and misconceptions about PCOS, the researchers found that people took infertility as a impact of this disease on women lives. Such myths raised the participant's anxiety and fear about their condition. In conclusion, this study highlighted the significance of raising PCOS awareness and education. Addressing myths, limiting stigma, and providing mental health support are all critical components of comprehensive PCOS care. Furthermore, promoting healthy lifestyle changes can dramatically enhance PCOS patient's well-being and quality of life.

Radma Tariq: Problem Identification and Theoretical Framework

Sonia Omer: Data Analysis, Supervision and Drafting **Qaisar Khalid Mahmood**: Methodology and Revision

Conflict of Interests/Disclosures

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