



LIVED EXPERIENCES OF CLINICALLY DIAGNOSED YOUNG ADULT WOMEN WITH POLYCYSTIC OVARY SYNDROME

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Abstract:

Polycystic Ovary Syndrome (PCOS) is a complex hormonal disorder that affects many young adult women, often altering not just physical health but also emotional and social well-being. While clinical literature typically emphasizes its physiological symptoms, the lived experiences of those diagnosed with PCOS offer deeper insight into how this condition reshapes everyday life. This qualitative study explored the experiences of eight young adult women clinically diagnosed with PCOS, aiming to uncover how they coped with and adapted to its emotional, physical, and social dimensions. Through in-depth interviews and thematic analysis, four key themes emerged. First, participants described the emotional toll of PCOS, expressing how changes in their physical appearance—such as weight gain and acne—damaged their self-esteem, triggered social anxiety, and led to academic disengagement. Despite these difficulties, some gradually embraced self-acceptance by reframing their worth beyond societal beauty standards and drawing strength from supportive environments. Second, experiences with medication reflected a complex mix of hope and frustration. While some noted improvements like regulated menstruation, others discontinued treatment due to side effects, emotional instability, and the financial burden of sustaining long-term medication. Third, fertility and family

planning surfaced as deeply personal concerns. For some, PCOS raised fears about infertility and disrupted visions of motherhood, while others redefined or detached from traditional reproductive expectations, affirming choices not to bear children. Finally, coping mechanisms and lifestyle strategies, including exercise, dietary changes, and self-motivation, emerged as essential tools for regaining a sense of control. Participants also highlighted the value of self-education and family medical awareness, especially when genetic predisposition was evident. These elements reinforced informed decision-making and early consultation. Ultimately, living with PCOS is not just a medical condition—it is a layered experience shaped by emotional resilience, shifting identities, daily struggles, and proactive adaptation. These narratives call for more empathetic, holistic healthcare that acknowledges the full scope of what it means to live with PCOS.

Keywords: polycystic ovary syndrome, young adult women, emotional impact, fertility concerns, medication experience, coping mechanisms

1. Introduction

Polycystic Ovary Syndrome (PCOS) is a multifaceted hormonal disorder affecting 8–13% of reproductive-aged women globally, with approximately 4.5 million Filipinas currently living with the condition (Karen *et al.*, 2022; Belen & Lao, 2022; UKRI, 2023). Clinically, PCOS is characterized by irregular or absent ovulation, elevated androgen levels, and polycystic ovarian morphology. Yet beyond its physical manifestations, PCOS deeply influences women's psychological well-being, body image, and social functioning.

For young adult women aged 18–25, a PCOS diagnosis coincides with a crucial period of identity formation, social role exploration, and increasing academic or personal responsibility (Simpson, 2018; Cunha, 2021). During this life stage, managing a chronic condition like PCOS can disrupt self-perception, confidence, and quality of life. Symptoms such as acne, hirsutism, and weight gain often challenge societal beauty norms, while emotional and hormonal fluctuations can further complicate day-to-day functioning. At the same time, some women report that receiving a diagnosis brings clarity, validation, and motivation to adopt healthier lifestyle choices (Copp *et al.*, 2019). This study explores the lived experiences of clinically diagnosed young adult women with PCOS enrolled in a private university in Metro Manila. It seeks to understand how they make sense of their diagnosis, navigate physical and emotional symptoms, and cope within the social and academic environment. Rooted in both personal and observed experiences, the inquiry highlights voices that are often overlooked in clinical and educational discourse.

By documenting these lived experiences, the study aims to contribute to more empathetic healthcare approaches, strengthen support systems for students with PCOS, and promote greater awareness of the condition's personal and social dimensions.

2. Literature Review

Polycystic Ovary Syndrome (PCOS) is a widespread hormonal disorder affecting an estimated 8–13% of reproductive-aged women globally, with approximately 4.5 million Filipinas currently living with the condition (Karen *et al.*, 2022; United Kingdom Research and Innovation, 2023). Clinically, PCOS is characterized by elevated androgen levels, anovulation, and polycystic ovarian morphology, often accompanied by dermatological and metabolic symptoms such as acne, weight gain, alopecia, and insulin resistance (National Library of Medicine, 2020; Ajmal *et al.*, 2019). These symptoms can lead to more serious complications, including infertility, type 2 diabetes, and cardiovascular disease (Barber & Franks, 2021; Diamanti-Kandarakis *et al.*, 2012). While pharmacologic treatments such as oral contraceptives and insulin-sensitizing agents offer symptom control (Patel, 2018), lifestyle interventions remain a central strategy, with evidence supporting diet and exercise modifications to improve hormonal and metabolic profiles (Moran *et al.*, 2017; Shahid *et al.*, 2022; Calcaterra *et al.*, 2024).

For young women, especially those aged 18 to 25, the diagnosis of PCOS coincides with a period of significant psychosocial development. Young adulthood is characterized by the pursuit of independence, identity formation, and preparation for future life roles, including forming relationships and establishing career or family goals (Simpson, 2018; Cunha, 2021). At this developmental stage, PCOS can disrupt physical self-perception and emotional well-being. Symptoms such as acne, hirsutism, and weight gain conflict with societal ideals of feminine beauty and often lead to diminished self-esteem and increased emotional distress (Ray, 2018; Allen *et al.*, 2021). Research suggests that women with PCOS are more likely to experience depression and anxiety than women without the condition, with prevalence rates for depression ranging between 27% to 50% (Hersh, 2019). These psychological effects are further compounded by concerns about fertility, a central component of many young women's life aspirations (Yin *et al.*, 2020; Zahra Basirat *et al.*, 2019).

The academic and social consequences of PCOS are similarly significant. Women pursuing higher education often experience fatigue, menstrual irregularities, and mental health issues that affect their academic participation and performance. Studies by Coffin *et al.* (2023) and Munro *et al.* (2021) show that these symptoms may lead to classroom absenteeism, reduced concentration, and impaired social functioning. Beyond academics, societal and familial expectations regarding reproductive capacity further contribute to the emotional burden, as seen in findings by Hariprasath *et al.* (2024), which documented social pressure and misunderstanding in family dynamics. These factors can lead to isolation, anxiety, and a sense of diminished personal agency among women with PCOS. Access to healthcare and effective treatment are essential but not always readily available or adequate. Saei Ghare Naz *et al.* (2019) highlighted barriers to care among adolescents with PCOS, such as emotional distress, lack of knowledge, and inadequate support systems. Even when medical help is accessible, experiences with treatment are varied.

Some women report improved symptom management with oral contraceptives (Galan, 2022; News-Medical, 2022), while others face side effects such as irregular bleeding, weight changes, or mood disturbances (Barbieri & Ehrmann, 2023; LeDuc, 2019). These varying responses to treatment highlight the need for individualized care tailored to each woman's needs and experiences.

Support systems play a crucial role in helping young women navigate the complexities of living with PCOS. Emotional support from peers, family, and structured communities can buffer the psychological toll of the condition. Studies have shown that support groups—particularly those tailored to age and shared experiences—foster emotional resilience, increase health literacy, and improve treatment outcomes (Avery *et al.*, 2020; Ranasinghe *et al.*, 2023; Ismayilova *et al.*, 2022). Online communities also provide valuable platforms for emotional validation, shared problem-solving, and advocacy for better care. Social support has been consistently identified as a protective factor that enhances self-management and reduces the impact of stigma and isolation.

Self-awareness and education are also central to managing PCOS effectively. However, multiple studies have reported low awareness levels among young women. Jabeen *et al.* (2022) found that a lack of information was a primary barrier to early diagnosis and intervention, while Alshdaifat *et al.* (2021) and Zaitoun *et al.* (2023) emphasized the gap between general familiarity with the term PCOS and deeper knowledge of its causes, complications, and treatment options. This lack of awareness often results in delayed healthcare-seeking behaviors and inadequate self-management. Conversely, targeted educational interventions—such as workshops, school-based programs, and digital health campaigns—have shown promise in improving PCOS-related knowledge and promoting early intervention (Smith *et al.*, 2020; Al-Labadi *et al.*, 2023).

Lifestyle modification remains a cornerstone of PCOS management. Several studies have emphasized the benefits of low-glycemic diets, pulse-based nutrition, and regular physical activity in controlling symptoms and enhancing well-being (Che *et al.*, 2021; Calcaterra *et al.*, 2024; Aster DM Healthcare, 2023). These interventions help regulate insulin levels, improve ovulation, and manage weight gain—common concerns among women with PCOS. Walking, aerobic exercise, and strength training have also been shown to enhance metabolic health, mood, and body composition (Butt *et al.*, 2023; Pasquali & Gambineri, 2004). However, adherence remains a challenge, particularly when lifestyle changes are not supported by counseling or community reinforcement.

Ultimately, PCOS affects multiple dimensions of a young woman's life—physiological, psychological, academic, and social. The condition challenges self-perception, disrupts routine, and often introduces feelings of uncertainty about the future. By understanding the lived experiences of young adult women with PCOS, it becomes possible to design more responsive healthcare interventions, reduce stigma, and offer meaningful psychosocial support. Promoting awareness, early diagnosis, and

integrated care systems will be vital to improving the overall quality of life for individuals managing this chronic condition.

3. Materials and Methods

This study employed a descriptive phenomenological design to explore the lived experiences of clinically diagnosed young adult women with Polycystic Ovary Syndrome (PCOS) enrolled in a private university in Metro Manila. The approach followed Colaizzi's (1978) method, which involved bracketing prior assumptions, intuitively engaging with participant narratives, analyzing significant statements, and synthesizing thematic meanings into an exhaustive description. Interviews were conducted using structured, open-ended questions, allowing participants to share personal experiences in depth. A psychologist was present during interviews to provide emotional support, given the sensitive nature of the topic.

Participants were selected through purposive and snowball sampling. Inclusion criteria required respondents to be clinically diagnosed with PCOS, aged 18 to 25, diagnosed for at least six months, currently enrolled in the university, and willing to participate. Recruitment took place through social media platforms, and interviews continued until data saturation was achieved. Each interview lasted approximately one to two hours, was conducted face-to-face, recorded with consent, and stored securely. Researchers conducted self-reflexivity to manage bias, and ethical clearance was obtained from the university's College of Nursing. Confidentiality was maintained by anonymizing data, and all recordings were scheduled for deletion within one year.

To ensure rigor, the study incorporated Denzin's triangulation techniques. Data triangulation was achieved by collecting responses from various participants across Metro Manila, while investigator triangulation was implemented by rotating researcher roles during data collection and analysis. Member checking was conducted after each interview batch and upon study completion, allowing participants to validate the findings. To enhance confirmability, all data were documented and reviewed by researchers uninvolved in the interviews, and care was taken to reduce groupthink through independent interpretation. The final analysis resulted in educational materials, such as handouts and leaflets, aimed at raising awareness and supporting women with PCOS.

4. Results and Discussion

Following in-depth interviews with eight clinically diagnosed young adult women with Polycystic Ovary Syndrome (PCOS), the researchers identified eight major themes and sixteen sub-themes reflecting the participants' lived experiences. These themes revealed the emotional, physical, and social challenges the respondents faced, including struggles with body image, hormonal imbalances, diagnostic uncertainty, and the impact of PCOS

on academic and social life. Despite these difficulties, strong support systems—particularly from family and peers—played a vital role in their coping and resilience. Participants emphasized the importance of self-education, awareness, and lifestyle adjustments in managing their condition. Collectively, their experiences highlighted a journey of vulnerability, strength, and empowerment in navigating life with PCOS.

4.1 Main Theme 1: Experiencing Emotional and Social Disruption

Living with PCOS extends beyond physical symptoms; it infiltrates the emotional core of an individual, affecting how young women perceive themselves, how they connect with others, and how they function in daily environments. This theme captures the internal struggles with identity, self-worth, and interpersonal dynamics that unfold as they deal with the visible and invisible symptoms of the condition.

4.1.1 Navigating Self-Esteem and Body Image

Participants reported that symptoms such as weight gain, acne, and abnormal hair growth led to significant emotional distress, often resulting in a distorted body image and reluctance to engage in social activities. Their physical appearance, shaped by hormonal imbalances, became a source of shame and insecurity, especially under the scrutiny of societal beauty standards. *“Sometimes I don’t want to look in the mirror because I see how my body has changed after I was diagnosed with PCOS,”* one participant shared, revealing the profound impact of PCOS on how they viewed themselves and their confidence in public.

4.1.2 Managing Anxiety and Academic Withdrawal

The psychological toll of PCOS manifested in decreased academic motivation, social avoidance, and feelings of isolation. Chronic fatigue, mood instability, and anxiety were recurring experiences that led some participants to skip classes or withdraw from group activities. One explained, *“There were times when the anxiety hit. I wasn’t motivated to go to school. Even though I slept all day, I still felt exhausted,”* illustrating how the emotional weight of the condition impaired their ability to function and perform in academic and social environments.

4.2 Main Theme 2: Coping Through Lifestyle and Health Practices

This theme emphasizes how participants actively took charge of their health through intentional lifestyle changes and adaptive coping behaviors. In the absence of one-size-fits-all medical solutions, young women diagnosed with PCOS developed personalized strategies to manage their symptoms and improve their quality of life. These coping mechanisms were both physical and emotional in nature, combining discipline with self-compassion.

4.2.1 Adopting Physical Activity and Healthy Habits

Exercise routines and dietary modifications emerged as the most accessible and controllable ways participants could respond to PCOS symptoms. Walking, cardio workouts, cutting back on sugar, and switching to healthier food alternatives helped regulate their weight and improve menstrual regularity. These behaviors were not only physically beneficial but also emotionally uplifting, contributing to a sense of control and empowerment. *“Maintaining a balanced diet and regular exercise have been the most effective for me. They helped in regulating my periods, managing my weight, and improving my energy levels,”* one participant shared, demonstrating how lifestyle became a form of proactive health management.

4.2.2 Balancing Self-Motivation and Emotional Self-Care

While some embraced routine, others leaned into emotional healing by loosening dietary restrictions and prioritizing comfort. This approach reflected an understanding that mental health is just as crucial as physical wellness in the PCOS journey. By allowing themselves moments of self-indulgence, participants acknowledged the need to protect their emotional well-being and avoid self-blame. As one said, *“I tried forcing myself to diet, but it didn’t have an effect, so now I do what makes me happy and eat what I want,”* showing that lifestyle management is not just about discipline, but also about compassion and emotional balance.

4.3 Main Theme 3: Confronting Fertility and Future Uncertainty

The possibility of infertility loomed large in the minds of many participants, especially as societal expectations around motherhood remained prominent. This theme explores the dualities of fear and hope, acceptance and redefinition, and how PCOS can shape, challenge, or align with an individual’s reproductive desires and life goals.

4.3.1 Fearing Infertility and Clinging to Hope

For most respondents, even the suggestion of future infertility triggered anxiety and sadness, regardless of whether they were currently planning to have children. The unpredictability of PCOS-related reproductive issues made it difficult to plan ahead, leaving many to wonder if they would ever become mothers. *“The constant thought of not being able to build a family in the future weighs heavily on me,”* one participant admitted. Yet, amidst the fear, hope remained present as others clung to their doctors’ reassurances and held on to faith that medication and early intervention could preserve their chances.

4.3.2 Redefining Motherhood and Accepting Alternatives

Not every participant saw motherhood as a central life goal. Some had already come to terms with the possibility of infertility, citing family history, religious beliefs, or personal convictions. These individuals found peace in redefining what fulfillment meant to them. *“That’s why I’m already in the acceptance stage now, thinking that maybe it’s really not possible...”*

but don't lose hope because God still has a plan for me," shared one respondent, reflecting how acceptance can exist alongside spiritual trust and emotional resolution. Others noted that PCOS confirmed long-standing suspicions about their fertility, allowing them to emotionally prepare for a child-free future.

4.4 Main Theme 4: Seeking Understanding and Support

Knowledge and social connection serve as protective factors in the PCOS experience. This theme examines how young women either find strength through learning about their condition or suffer due to the widespread lack of awareness. Access to information and emotional support emerged as central to building resilience, fostering advocacy, and reducing the burden of isolation.

4.4.1 Relying on Support Systems for Strength

Family, friends, and peers provided essential encouragement, helping participants stay on track with treatment, affirm their feelings, and cope during emotionally difficult moments. These support systems were often the first to recognize symptoms and the ones to offer practical help and moral reinforcement. *"My friends help lift me up when I feel anxious or overwhelmed, giving me the comfort to express emotions I can't share elsewhere,"* one participant noted, demonstrating the value of social bonds in managing a condition that can often feel overwhelming and lonely.

4.4.2 Learning Through Self-Education and Health Awareness

Many participants took the initiative to research PCOS through blogs, YouTube, TikTok, and academic sources. This thirst for information was driven by a desire to understand their symptoms, find alternatives to conventional medication, and advocate for themselves more effectively in clinical settings. Education reduced fear and helped participants feel more in control. As one shared, *"Even before I found out I had PCOS, I was already doing research and looking for alternative ways to manage it without medication,"* highlighting how knowledge acquisition became an act of empowerment and self-preservation.

5. Conclusion

The lived experiences of young adult women with Polycystic Ovary Syndrome (PCOS) reveal a complex interplay of physical symptoms, emotional challenges, lifestyle adaptations, and socio-relational dynamics. Through their narratives, it becomes clear that PCOS is not merely a medical diagnosis—it is a multidimensional condition that impacts identity, well-being, and life trajectories in deeply personal ways.

The emotional and social disruptions brought by PCOS affect self-esteem, body image, and academic engagement, with many participants expressing feelings of anxiety, isolation, and diminished confidence. Despite these difficulties, many also demonstrated

emotional growth and resilience, particularly through the support of family, friends, and peer communities. These support systems provided vital encouragement and validation, buffering the psychological burden of the condition.

Participants actively engaged in lifestyle management, embracing exercise, dietary changes, and various coping mechanisms to gain a sense of control. Some paired self-discipline with self-compassion, showing that effective management also involves honoring one's emotional needs. Fertility concerns further shaped participants' outlooks, with responses ranging from fear and uncertainty to acceptance and redefinition of future plans. Meanwhile, their efforts to seek knowledge underscored the importance of health literacy and advocacy in reducing stigma and promoting informed decision-making.

Lastly, the role of family history and genetic predisposition served as a reminder that PCOS is not an isolated experience, but often one rooted in broader familial patterns. Participants who were aware of such histories used this knowledge to guide their health choices and seek early intervention.

Overall, this study highlights the need for a more holistic and compassionate approach to supporting women with PCOS—one that integrates medical care with psychosocial support, inclusive education, and culturally responsive counseling. Understanding their lived experiences opens a pathway toward designing more responsive interventions that honor both the physical realities and emotional truths of those living with this condition.

Conflict of Interest Statement

The authors of this study declare that there is no conflict of interest regarding the publication of this research. No financial, personal, or professional relationships have influenced the research process, data collection, analysis, or interpretation of the findings. This work has been conducted with integrity and transparency, adhering to ethical guidelines to ensure unbiased and independent results.

About the Author(s)

The authors are nursing students guided by their faculty adviser who worked together to complete this research as part of their academic journey

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LIVED EXPERIENCES OF CLINICALLY DIAGNOSED YOUNG ADULT
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