

10th Annual Congress on **Polycystic Ovarian Syndrome and Fertility**

Oral Presentation

July 16-17, 2026 | London, UK (Hybrid Event)

Health literacy and health-seeking behavior for Polycystic Ovary Syndrome (PCOS) among women in Nepal: A qualitative study**Shristy Shrestha*** and **Assoc. Prof. Roy William Batterham**

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Introduction: PCOS is a common condition affecting 10-13% of reproductive-age women. Some symptoms include hormonal imbalance, irregular periods, ovarian cysts, facial hair growth, acne, and weight gain. Up to 70% of affected women worldwide do not know they have this condition. In Nepal, over one-third of women with PCOS are unaware of their symptoms; most wait over two years, seeing three or more different doctors, to confirm their PCOS diagnosis. Women often misunderstand or normalize their symptoms and delay seeking appropriate healthcare.

Objective: The purpose of the study was to explore how women understand, perceive, and identify PCOS symptoms to take action for management, and to identify barriers and facilitators in access and utilization of healthcare services for PCOS among women.

Methods: Semi-structured interviews were conducted with 24 women (12 with PCOS and 12 at-risk women) in Kathmandu and Lalitpur districts of Nepal. A mix of purposive sampling and snowball sampling was used. Women were clustered into two groups to ensure the sample included different levels of awareness. Reflexive thematic analysis was undertaken in MAXQDA. Ethical approval was taken before start of the study.

Findings: The findings have been organized under four themes to provide progressive pathway from confusion to awareness to understanding to action.

Theme 1: Recognition and interpretation of PCOS symptoms: Women often normalize or dismiss symptoms, such as irregular periods, weight gain, body hair, and acne, under the influence of intergenerational family thinking, state of denial, and limited understanding of PCOS. However, a shift in thinking was seen in women, from normalization of symptoms to awareness that PCOS can be managed with lifestyle modification and stress management. This growing awareness was hastened after women received a diagnosis. The at-risk women frequently struggled with determining if symptoms were meaningful or not, learning gradually

through self-study, discussion with friends, or family. After diagnosis, the women were more able to relate their symptom observation, lived experiences, and self-research to their diagnosis.

Theme 2: Health information seeking and knowledge navigation: Both groups of women relied on the internet and social media platforms like Google, Facebook, TikTok, and YouTube for PCOS-related information. After noticing symptoms or feeling uncomfortable discussing their concerns openly, and being dissatisfied with medical consultations, most women sought information online. Misconception and confusion about PCOS were common due to conflicting sources, contradictory advice, and technical language. Those who have been diagnosed found social support groups beneficial and learned from others' successes and failures in managing PCOS. Over time, most women developed improved skills in finding information, understanding it, and applying strategies to their lives to manage PCOS, but this often depended on the support of their social networks.

Theme 3: Barriers and facilitators to healthcare-seeking: Many women reported delaying healthcare visits because they had normalized irregular periods, feared being judged for having PCOS, had limited financial capacity, or had work or academic commitments. Poor communication and dismissiveness of concerns from doctors discouraged women from going for follow-ups and hindered care. In contrast, self-research on PCOS, having support from family and peers encouraged help-seeking prompting action. Empathetic, informative consultations fostered trust and sustained engagement, encouraging women to seek healthcare.

Theme 4: Impact of PCOS on well-being and Cues to action for PCOS management: Having symptoms such as acne, weight gain, and facial hair undermined women's body image and self-esteem. Both groups of women reported experiencing anxiety, stress, and depressive feelings that were intensified by fear around fertility. Family concern for persistent irregular periods for women acted as catalyst for immediate

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care-seeking. Women with PCOS reported more proactive management of PCOS symptoms, while at-risk women were reactive in managing their symptoms. High emphasis was given to diet modification (inclusion of nuts and seeds) and exercise.

Discussion: The findings suggest that health literacy in the context of PCOS is not merely an individual ability to access and understand information and recognize symptoms but a socially constructed factor that significantly shapes women's health-seeking behavior. Health-seeking behavior was influenced by emotional validation and contextualized information. Increased awareness alone may not translate into timely health-seeking behavior without addressing systemic issues. Women relied on social media, peers, and online platforms for information; however, inconsistent and unreliable information created confusion. Social networks often determined if women sought professional information and advice, whereas the empathy and practicality of the contacts with the health professions affected decisions about self-care behaviors. Women's decision-making was influenced by previous encounters with the healthcare system, the normalization of symptoms within families, and societal pressures related to beauty, femininity, and reproductive expectations. The findings highlighted gaps

in functional and interactive health literacy, showing that understanding PCOS alone does not ensure effective health-seeking behavior or an accurate understanding of PCOS management strategies. There is a need for context-specific PCOS awareness, improved reproductive health literacy, and supportive healthcare services for women in Nepal.

Conclusion: The delay in diagnosis and health-seeking behavior was a combination of ignorance, socio-economic factors, structural and communication gaps within the health system in both groups of women. Improving PCOS outcomes in Nepal requires raising public awareness of PCOS, strengthening healthcare provider-patient communication, and addressing the socio-cultural normalization of symptoms.

Biography

Shristy Shrestha is a public health researcher and a Master of Public Health in Global Health graduate at the Faculty of Public Health, Thammasat University, Thailand. She has experience working in public health surveillance, reproductive health, and (qualitative and quantitative) health research in Nepal. Her current research was inspired by her own diagnosis of PCOS and curiosity about how others understand PCOS and what they do about it. She has also co-authored a peer-reviewed publication on genital health and hygiene among adolescent girls in Nepal. Shrestha is passionate about evidence-based public health interventions and advancing awareness of women's reproductive health issues in Nepal.