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Research Paper

Lived Experiences of PCOS Among Women in Odisha: A Qualitative Inquiry

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ABSTRACT

Polycystic Ovary Syndrome (PCOS) is a widespread endocrine disorder, yet often underdiagnosed and poorly managed, particularly in culturally diverse, resource-limited settings. This qualitative study used a phenomenological approach to explore the lived experiences of 32 women (aged 18–32) in Odisha, primarily unmarried, urban, and educated. Through thematic analysis of semi-structured phone interviews, five key themes emerged: awareness of PCOS, physical and emotional changes, prevalent misconceptions, health behaviors, and digital health use. Findings revealed gaps in awareness, delayed diagnoses, and persistent myths around medication, fertility, and cultural norms. Women reported symptoms like acne, hirsutism, irregular periods, and psychological distress, worsened by social stigma. However, many adopted coping strategies such as lifestyle changes, yoga, and digital tools like period-tracking apps. While these apps supported symptom monitoring, misinformation online sometimes created confusion. The study calls for culturally relevant, integrated approaches combining medical, psychological, and digital support to enhance PCOS care and promote open dialogue around reproductive health.

Keywords: *PCOS, qualitative research, women's experiences, health behavior, digital health*

"A healthy outside starts from the inside." — Robert Urich

Polycystic Ovary Syndrome (PCOS) is one of the most prevalent and multifaceted endocrine disorders affecting women of reproductive age across the globe. Despite its growing incidence, PCOS remains underdiagnosed and inadequately managed due to its diverse causes and complex symptoms. The condition is typically marked by hyperandrogenism, irregular ovulation, and polycystic ovarian morphology as observed via ultrasound (Azziz et al., 2016; Rotterdam ESHRE/ASRM-Sponsored PCOS Consensus Workshop Group, 2004). Women with PCOS often face challenges such as irregular menstruation, excessive hair growth (hirsutism), acne, obesity, and increased susceptibility to insulin resistance, type 2 diabetes, and cardiovascular diseases. More than a reproductive or cosmetic issue, PCOS is a long-term condition that significantly affects metabolic and psychological well-being.

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Originally termed as Stein-Leventhal syndrome when first described in 1935, PCOS has since been recognized for its broader systemic impact (Stein & Leventhal, 1935). While the term PCOD is sometimes used interchangeably, it primarily refers to ovarian dysfunction, whereas PCOS encompasses wider reproductive, metabolic, and emotional dimensions (Moran et al., 2010). Engel's (1977) Biopsychosocial model offers a comprehensive lens to understand PCOS as the result of interlinked biological (e.g., genetic and hormonal factors), psychological (e.g., anxiety and depression), and social (e.g., stigma and fertility-related pressure) influences (Dokras et al., 2018).

The global prevalence of PCOS ranges from 5% to 20%, varying by diagnostic criteria (Bozdag et al., 2016). In India, estimates suggest 9% to 22% prevalence, with Odisha-specific data indicating rates between 11% and 18% (Nidhi et al., 2011; Deswal et al., 2020; Padhy & Pattnaik, 2020). However, diagnosis and treatment are often delayed due to low awareness, social taboos, and fragmented healthcare approaches. Women frequently receive treatment for isolated symptoms without addressing the root hormonal and metabolic issues. Mental health concerns, stigma related to infertility or physical appearance, and financial burdens further complicate disease management.

In recent years, a shift in perspective has identified PCOS more as a lifestyle and metabolic condition than purely a gynecological one. Factors such as processed food intake, sedentary routines, and urban living contribute to its rise. Digital tools, including mobile health applications and social media, have played a growing role in enhancing awareness and enabling women to take control of their health. Innovations in personalized medicine, reproductive technologies, and holistic interventions like yoga and mindfulness are contributing to improved care outcomes (Harris-Glocker & Davidson, 2021; Patel et al., 2021).

Given its diverse physical, emotional, and social implications, PCOS demands an integrative, patient-centered approach. Emphasizing culturally sensitive, multidisciplinary strategies is especially vital in under-resourced areas like Odisha, where access to specialized care remains limited. Addressing PCOS through combined medical, psychological, and lifestyle support is key to improving women's overall health and quality of life.

Objective of the Study

The objective of the study is to gain an in-depth understanding of the lives of women affected by PCOS in Odisha and to explore the correlates associated with the condition.

METHODOLOGY

Design of the Study

This study adopted a qualitative phenomenological approach to explore women's lived experiences with PCOS. Data were collected through telephone-based semi-structured interviews, focusing on participants' knowledge, beliefs, treatment practices, and lifestyle adaptations. The interview process was followed by a comprehensive literature review and validated by experts. Ethical protocols—including informed consent, confidentiality, and rapport-building—were strictly maintained to ensure openness and integrity in data collection (Barnard et al., 2007; Boomsma et al., 2006; Braun & Clarke, 2006; Colwell et al., 2010; Dokras et al., 2015; Guest et al., 2013).

Participants

Out of 32 participants the majority of participants were young women aged 18–22 years (56.25%), with most reporting PCOS onset between 14–19 years (84.37%). Most were unmarried (84.37%) and predominantly from urban areas (75%). Educationally, many had completed undergraduate (37.5%) or postgraduate studies (40.63%). Notably, a large proportion (93.75%) did not have children, indicating a young, educated, urban-dwelling sample.

Sl no	Categories		Frequency	Percentage
01	**Age**	18-22	18	56.25
		23-27	11	34.37
		28-32	03	9.38
02	**Age of Onset**	14-19 years	27	84.37
		20 years and above	05	15.63
03	**Marital Status**	Married	05	15.63
		Unmarried	27	84.37
04	**Area of Living**	Urban	24	75
		Rural	08	25
05	**Education**	Up to Matriculation	00	00
		Up to Higher Secondary	06	18.75
		Up to Under Graduation	12	37.5
		Up to Post Graduation	13	40.63
		More/Others	01	3.12
06	**Having Child**	Yes	02	6.25
		No	30	93.75

Recruitment of Samples

The researchers used a network-based recruitment strategy in Odisha, contacting potential female participants diagnosed with PCOS through personal and professional connections. An initial list of 52 women was created, and each was individually approached. Eligibility was confirmed via self-reported medical diagnosis and current treatment status. After excluding those who withdrew without reason, 32 women from various districts of Odisha participated in the interviews.

Procedure

Using a snowball sampling approach, potential participants were contacted to confirm their willingness to join the semi-structured telephone interviews. Individual interview times were scheduled based on participant convenience, and rapport was established to ensure comfort and trust. Participants were informed about the study's purpose, assured of confidentiality, and consent was obtained for recording. They were encouraged to seek clarification whenever needed. Each interview, conducted between late March and April 2025, lasted approximately 45 to 50 minutes. The recorded data were subsequently transcribed and analysed.

S.No.	Statement / Sample Interview Question
1	Can you describe how you first became aware of your PCOS symptoms?
2	How did you feel when you were first diagnosed with PCOS?
3	What lifestyle changes, if any, have you made to manage your PCOS?
4	How do you think your family or friends have influenced your health behaviors

S.No.	Statement / Sample Interview Question
	related to PCOS?
5	What physical or biological changes have you experienced because of PCOS?
6	In what ways has PCOS affected your mental or emotional well-being?
7	How has PCOS influenced your social interactions or relationships?
8	What kinds of misconceptions about PCOS have you encountered from family, friends, or society?
9	Have you tried any alternative or traditional treatments for PCOS? Please describe.
10	Do you use any mobile apps or online resources to manage your PCOS? How have they helped or confused you?

Data Analysis

In this study, the researchers applied Thematic Analysis following Braun & Clarke (2006)) to systematically derive meaning from qualitative data. Manual transcription of interview data marks the first step, followed by generating initial codes, searching for and reviewing themes, defining and naming them clearly, and finally producing a coherent report. This systematic approach helps identify, analyze, and interpret meaningful patterns and insights within qualitative data.

RESULTS AND DISCUSSIONS

Analysis of the interview transcripts led to the identification of five super ordinate main themes: awareness and understanding of PCOS, changes experienced due to PCOS, misconceptions about PCOS, health-promoting behaviors, and digitalization in PCOS management. Additionally, these lead to several themes and sub themes.

Sl. No.	Super Ordinate Theme	Themes	Sub-themes
1	Awareness and Understanding of PCOS	1.1 Initial Awareness and Diagnosis	
		1.2 Health-Promoting & Health-Deteriorating Behaviors	
2	Changes Experienced Due to PCOS	2.1 Biological Changes	
		2.2 Psychological Changes	
		2.3 Sociological Changes	
3	Misconceptions about PCOS	3.1 Misconceptions Relating to Medication, Fertility, Culture	3.1.1 Misunderstanding of Medication and Hormonal Treatment 3.1.2 Fertility-Related Myths 3.1.3 Cultural and Traditional Interpretations 3.1.4 Silence Around Menstruation and Reproductive Health 3.1.5 Pressure to Opt for

			Natural or Alternative Remedies
		3.2 Impact of Misconception	3.2.1 Distorted Self-image and Emotional Distress 3.2.2 Treatment Hesitancy and Delayed Diagnosis 3.2.3 Impact on Social and Romantic Relationships 3.2.4 Reduced Quality of Life and Isolation 3.2.5 Lack of Trust in Healthcare and Unmet Needs
4	Health Promotion Behaviors for PCOS	4.1 Medical & Alternative Treatments	
		4.2 Lifestyle Modifications	4.2.1. Dietary Changes 4.2.2. Exercise and Movement 4.2.3. Mental Health and Stress Reduction
5	Digitalization and PCOS Management	5.1 Use of Menstrual Tracking Apps	
		5.2 Misinformation and Digital Overload	

1. Awareness and Understanding of PCOS

This theme explores two key sub-themes: initial awareness and diagnosis of PCOS, and understanding of health-promoting and health-deteriorating behaviors.

1.1 Initial Awareness and Diagnosis of PCOS

Participants became aware of their PCOS symptoms through a combination of self-observation, social interaction, digital monitoring, and family involvement. Many initially dismissed their symptoms until recognizing similarities with peers: "*I didn't think much of my irregular periods until my friend told me she had PCOS. Her symptoms sounded just like mine, so I decided to get checked — and that's when I found out I had it too"* (P17).

Others credited mobile apps like FLO, Clover, and Maya for drawing attention to irregularities in their menstrual cycles:
"The app kept showing that my cycle was way off, so I figured something wasn't right, I went for a check-up, and the doctor confirmed it was PCOS" (P6).

Family members also played a significant role in encouraging medical attention: *"My mother noticed my skin breaking out badly and that my periods were all over the place. She insisted I see a doctor — and that's how I learned I had PCOS"* (P24).
These reflections highlight that awareness often stems from a mix of personal experiences, digital cues, peer discussions, and familial support.

1.2 Understanding of Health-Promoting and Health-Deteriorating Behaviors in PCOS

Participants demonstrated varying awareness about how lifestyle impacts PCOS. Some recognized the benefits of healthy habits:

"I realized that eating less junk food and exercising regularly really helped me feel better. My cycles became more predictable once I started focusing on healthier habits" (P12).

Others admitted a lack of early awareness:
"*I didn't know that skipping meals and constantly stressing about my studies was making my symptoms worse. I thought it was just part of my routine"* (P29).

Family guidance, especially from mothers and grandparents, influenced health behaviour: "*My mother kept telling me to drink more water and avoid sugary foods, but I never took it seriously until my doctor explained how it was affecting my PCOS*" (P5).

Participants from rural areas often followed traditional menstrual hygiene practices due to cultural and financial reasons:
"In our village, most women, including my family, believe using cotton cloth is better because pads are considered expensive. My grandmother always told me that cloth was sufficient and safer" (P20).
"*I wanted to start using pads, but my mother discouraged me, saying it's unnecessary spending when cloth can be reused*" (P8).
These insights highlight the need for improved awareness and support for informed lifestyle choices in managing PCOS.

2. Changes experienced due to PCOS

This theme provides valuable insights into the participants' experiences of the changes they underwent as a result of PCOS. Three key subthemes emerged from the data, highlighting the biological, psychological, and social changes associated with the condition.

2.1 – Biological changes experienced due to PCOS

Participants reported a range of biological symptoms that led to their PCOS diagnosis, with many identifying these physical changes as early warning signs. Excessive hair growth, or hirsutism, was commonly mentioned:
"I noticed thick hair growing on my chin and stomach. It didn't feel normal, and I kept wondering what was wrong with my body" (P14).

Persistent skin issues like acne and hyperpigmentation were also frequent concerns: *"No matter how many creams I tried, the acne stayed. Then I started getting these dark patches on my skin that wouldn't fade*" (P27).

Thyroid irregularities were often observed alongside PCOS symptoms: *"My thyroid levels were abnormal too, and the doctor said that's common with PCOS. It made me tired and sluggish all the time*" (P3).

Menstrual disruptions, including skipped periods and severe cramps, were another shared experience:
"Sometimes my period would skip for two or three months, and when it came, I couldn't get out of bed because of the pain" (P22).
Concerns about fertility were also voiced, with participants citing irregular ovulation: *"I wasn't ovulating regularly, and that's when they said I might face problems getting pregnant*" (P9).
Collectively, these accounts reflect the complex and distressing nature of PCOS-related biological symptoms.

2.2 – Psychological changes associated with PCOS

Participants detailed the psychological burden of living with PCOS, often expressing emotional distress linked to physical symptoms. Body image issues were common, especially due to visible changes like acne, hair growth, and weight gain: *"I couldn't recognize myself in the mirror. The acne, the hair—it just changed how I saw myself completely*" (P11).

Hormonal imbalances contributed to mood swings and emotional instability: *"Some days I would cry for no reason. Other times I would get angry at the smallest things. I knew it was the hormones, but I still couldn't control it*" (P26).

Anxiety about the future and uncertainty around fertility added to psychological strain: "*The uncertainty was the worst. I kept asking myself—will I ever be able to have kids? Will I always feel this tired? That anxiety just stayed with me*" (P4).

Feelings of helplessness were tied to a perceived loss of control over their bodies: *"It felt like my body was no longer mine. No matter what I did—exercise, diet—nothing seemed to work. That made me feels defeated*" (P19).

Delayed diagnosis and lack of awareness led some to internalize blame: *"For years, I didn't even know I had PCOS. I thought it was just me being lazy or weak. That kind of self-blame is hard to shake off"* (P30).

These narratives underscore the intertwined nature of PCOS's physical and psychological effects, highlighting the need for holistic support and early intervention.

2.3- Sociological Changes Associated with PCOS

Participants shared how PCOS affected their social lives, often leading to withdrawal, stigma, and misunderstandings. Visible symptoms triggered self-consciousness and avoidance of public gatherings:

"I stopped attending functions and gatherings. I felt like everyone was looking at my face or noticing my weight" (P15).

Menstrual irregularities and infertility were often taboo topics, causing discomfort within families:

"In my family, periods are not something we openly talk about. When mine were irregular, I was constantly asked why I wasn't 'normal' like others" (P28).

Societal pressure around marriage and motherhood heightened emotional stress: *"Relatives would ask me why I'm not married yet or when I'm planning to have kids. They don't understand what PCOS is or how it affects that"* (P6).

Participants also faced disbelief or lack of empathy from peers:

"My friends thought I was being dramatic about my symptoms. They didn't realize how serious it was because it's not something you hear about much" (P21).

However, some found relief through online communities:

"It was comforting to find online groups where women talk openly about PCOS. I felt less alone, and I learned so much from them" (P10).

These narratives reflect the significant social challenges of PCOS, shaped by cultural silence, judgment, and a general lack of awareness.

3. Misconceptions About PCOS

Participants' narratives revealed widespread misconceptions about PCOS, shaped by generational, social, and cultural beliefs. These misunderstandings affected how the condition was perceived, discussed, and managed, often leading to emotional, psychological, and relational challenges.

3.1. Misconceptions Relating to Medication, Fertility, Cultural Practices, Marriage, and Childbearing

This theme highlights the range of misconceptions that women with PCOS are subject to, often stemming from cultural narratives, lack of health education, and misinformation spread by family members or even poorly informed healthcare providers.

3.1.1. Misunderstanding of Medication and Hormonal Treatment

Many participants expressed fear and mistrust toward hormonal medications for PCOS, often influenced by family or social beliefs. Instead of seeing them as helpful, they viewed them as risky:

"*Everyone in my family warned me that these pills would harm my uterus. I was scared I'd never be able to conceive later"* (P23).

"*My cousin said hormonal treatments will cause early menopause, so I stopped taking them halfway*" (P7).

Such misconceptions often led to inconsistent treatment or complete withdrawal from medical care.

3.1.2. Fertility-Related Myths

A widespread myth equated PCOS with permanent infertility, leading to stigma and devaluation in familial and marital contexts:

"As soon as people heard I have PCOS, they assumed I can't get pregnant. It was like my worth dropped instantly" (P18).

"They keep saying – '*what's the use of marrying her if she can't have children?' – without even knowing the facts*" (P9).

This misconception deeply affected women's self-worth and future hopes, particularly where motherhood is highly emphasized.

3.1.3. Cultural and Traditional Interpretations

Cultural beliefs often overshadowed medical understanding of PCOS, with blame placed on lifestyle and modern habits:

"My grandmother said it's because I eat cold food during periods or wear tight clothes. They link everything to culture" (P25).

"They believe too much phone use or not waking up early caused my PCOS" (P13).

Such misconceptions hindered awareness and led to unwarranted shame over unrelated behaviors.

3.1.4. Silence Around Menstruation and Reproductive Health

Menstruation remained a taboo in many families, discouraging open discussion about reproductive health and reinforcing secrecy:

"My mom said not to tell anyone about my irregular periods. She said these things are better hidden if I want to get married" (P31).

"*Even the doctor was hesitant to explain things clearly, maybe because I was unmarried*" (P16).
This silence often delayed help-seeking and hindered women's understanding of their own health.

3.1.5. Pressure to Opt for Natural or Alternative Remedies

Participants were often discouraged from continuing allopathic treatment, being urged to follow unproven traditional remedies instead:
"*They said just do yoga and drink neem juice daily – no need for these 'chemicals'*" (P5). *"I felt guilty taking allopathy because they made it sound like I was doing something wrong"* (P17).

Such views delayed effective treatment and increased health risks. Misconceptions also included beliefs that PCOS would disappear after marriage, only affects overweight women, or was a result of modern behavior or not conforming to traditional gender roles. These myths led to confusion, self-blame, and social isolation for many women.

3.2. Impact of These Misconceptions on Self-image, Treatment Choice, Social Relationships, and Quality of Life

This theme captures the consequences of living with these misconceptions. The effects extended beyond medical issues, deeply influencing how women viewed themselves, how they sought treatment, and how they were treated within their personal and social networks.

3.2.1. Distorted Self-image and Emotional Distress

Many participants expressed that PCOS symptoms like weight gain, acne, and facial hair negatively impacted their self-esteem and femininity. The internalization of stigma led to feelings of unattractiveness and abnormality. One woman stated, *"I hated going out. I kept thinking everyone's staring at my face or my body*" (P7).
Another shared, *"I didn't feel like a woman anymore. The hair, the weight—it made me feel embarrassed*" (P26).
Constant comparisons with peers and prevailing cultural beauty standards further deepened their sense of shame and inadequacy (P19).

3.2.2. Treatment Hesitancy and Delayed Diagnosis

Traditional beliefs and family influence often caused delays in seeking medical help or led to discontinuation of treatments, worsening PCOS symptoms.
As one participant recalled, "*For years, I thought it was normal to skip periods. I didn't even think it was a medical issue until it got worse"* (P14).
Someone added, *"I would stop treatment whenever someone scared me about side effects. I kept switching doctors*" (P22).
Such hesitations reflected not only a lack of trust in healthcare but also uncertainty in personal health decision-making.

3.2.3. Impact on Social and Romantic Relationships

Stigma linked to PCOS significantly impacted women's social and intimate relationships. Many concealed their condition due to fear of judgment or rejection.
One participant shared, "*When I told my partner about PCOS, he said I should 'fix myself' first. That crushed me"* (P19).
Another noted, *"I avoided marriage discussions altogether. I didn't want to deal with being rejected for something I didn't choose*" (P7).

This pressure to remain silent often led to emotional isolation and hindered the development of close bonds.

3.2.4. Reduced Quality of Life and Isolation

Living with an unmanaged or misunderstood condition brought both physical discomfort and mental strain. Many participants spoke of feeling tired, anxious, and alone in their struggle.

"I was constantly anxious. It wasn't just the symptoms, but how people made me feel like I was broken." (P2)

"*I couldn't focus at work. I felt tired all the time and was scared to talk to anyone about it.*"(P7)

Women often had to navigate this journey without emotional support, intensifying feelings of helplessness and detachment.

3.2.5 Lack of Trust in Healthcare and Unmet Needs

Several participants felt dismissed by healthcare providers who prioritized physical symptoms over emotional well-being:

"*The doctor just told me to lose weight and didn't explain anything else. It felt like I wasn't being taken seriously*" (P26).

"*I left the clinic crying. No one talked about how I was feeling mentally. Just prescriptions and nothing more*" (P8).

This lack of holistic care discouraged follow-up visits and impacted treatment adherence. Participants also shared how fatigue, irregular cycles, and emotional burnout disrupted their academic or work life. Socially, many felt judged or disconnected, especially when unable to relate to traditional expectations of womanhood. Declines in sexual confidence and fear of intimacy were common, fueled by worries about partner acceptance. The absence of integrated support, especially counselling, left emotional needs unmet and care incomplete.

4. Health Promotion Behaviour for PCOS

This theme captures the proactive strategies employed by participants in managing PCOS through medical, traditional, and lifestyle-oriented approaches. Participants narrated a journey that included formal medical interventions, exploration of traditional healing systems, and deliberate changes in daily routines to promote holistic health.

4.1 Medical Consultation and Treatment Including Alternative and Traditional Practice

Participants commonly began their treatment journey with consultations from medical professionals, particularly gynaecologists and endocrinologists. Most were prescribed hormonal treatments, contraceptive pills, or insulin-regulating medications. These clinical encounters were often the starting point for diagnosis and initial management.

However, dissatisfaction with side effects or concern over prolonged medication use led many to explore alternative options. Several participants turned to Ayurveda, homeopathy, or naturopathy, seeking treatments perceived to be gentler and more holistic.

"*The tablets helped in the beginning, but once I stopped, the symptoms came back. That's when I looked for something natural—Ayurveda made me feel more in sync with my body".* (P5)

"*I took homeopathy for a few months, and though it worked slowly, I didn't have any side effects. It felt more sustainable.* (P13)

This blending of treatment systems—often called medical pluralism—illustrated how participants negotiated between biomedical authority and traditional knowledge in search of relief and balance.

4.2 Lifestyle Modifications

A significant sub-theme involved lifestyle adjustments, which participants viewed as foundational to managing PCOS effectively. These modifications were multi-dimensional, covering diet, physical activity, and mental well-being.

4.2.1. Dietary Changes

Participants expressed a strong awareness of the relationship between food and symptoms. Many reduced sugar intake, avoided processed foods, and adopted nutrient-rich, balanced diets. High-protein meals, complex carbohydrates, and anti-inflammatory foods were commonly mentioned.

"*I started avoiding white rice and sugar completely. I eat more greens now and include seeds and nuts in my meals"*. (P22)

Others mentioned food journaling and portion control as helpful practices.

4.2.2. Exercise and Movement

Regular physical activity was widely recognized as essential. While some engaged in structured workouts, others preferred moderate exercises like yoga or brisk walking. The emphasis was on consistency rather than intensity.

"*Even 20 minutes of yoga daily made a big difference. My periods became more regular, and I felt lighter mentally too*". (P15)

4.2.3. Mental Health and Stress Reduction

Participants frequently discussed the link between emotional well-being and PCOS symptoms. High stress levels were seen to exacerbate irregular cycles and fatigue. Strategies like mindfulness, meditation, journaling, and breathing exercises were commonly adopted.

"The more stressed I was, the worse my symptoms got. I began meditating in the mornings and that calmed me a lot". (P18)

These lifestyle adaptations were described not only as health practices but as empowering acts of self-care. Participants often reflected on the internal motivation and discipline required to sustain these changes, as well as the role of peer or familial support.

5. Digitalization and Management of PCOS

This theme explores how digital tools, particularly mobile applications and online information sources, have influenced the management of PCOS among participants. The theme highlights both the empowering potential of technology and the pitfalls associated with misinformation and digital overload.

5.1 Use of Menstrual Tracking Apps

With increased smartphone penetration and digital literacy, many participants reported using menstrual tracking apps to monitor their cycles and symptoms. These apps provided a sense of control and helped them visualize irregular patterns over time, which was especially useful in managing PCOS.

In the context of Odisha, commonly mentioned apps included Maya, Clue, Flo, and My Calendar, all of which were either recommended by peers or downloaded based on online

reviews. Some participants also used regional language support in these apps for better accessibility.

"I use the Maya app to track my periods. It sends me reminders and also tells me when to expect mood swings or cramps. It's been really helpful," shared one user from Bhubaneswar.

Others noted how these apps helped during medical consultations: *"When I showed my app data to the doctor, she could clearly see how irregular my periods were. It helped her decide on the next steps faster*," explained a participant from Cuttack.

These digital tools were often praised for improving self-awareness and encouraging consistent health tracking, especially among young women in urban and semi-urban settings.

5.2 Misinformation and Digital Overload

While digital platforms provided initial support, many participants faced confusion due to conflicting and unverified online information.

"I searched about PCOS diet and got so many different answers. Some said no dairy, others said have more milk. I was completely lost" (P14).

Some even experienced health issues after following online advice without medical consultation:

"I read online that taking apple cider vinegar would cure PCOS. I started it without checking with my doctor and ended up with severe acidity" (P30).

These experiences reflect cyberchondria—anxiety caused by excessive symptom searching online.

Participants stressed the need for reliable, doctor-verified resources in regional languages:

"I wish there was a government-backed app or website in Odia that we could trust. Most of what's available now is either too technical or not accurate" (P6).

This highlights the dual nature of digital health tools—empowering yet potentially misleading when unregulated.

DISCUSSION AND CONCLUSION

This qualitative study explores the lived experiences of women with PCOS in Odisha, revealing the interconnected challenges of biological symptoms, psychological distress, cultural stigma, and digital health use. Many participants lacked awareness of PCOS, often misinterpreting symptoms until recognizing patterns through social interactions or digital menstrual apps. While digital tools empowered symptom tracking, they also exposed users to conflicting, unverified information, reinforcing the need for accurate, culturally relevant online resources (Wang et al., 2019).

Participants adopted both helpful and harmful behavioral strategies—such as healthy lifestyle changes alongside meal skipping or unproven remedies—reflecting gaps in health education (Moran et al., 2011; Patel et al., 2018). Physical symptoms like hirsutism, acne, and menstrual irregularities were closely tied to anxiety, low self-esteem, and social withdrawal, compounded by societal pressures around fertility and womanhood (Dokras et al., 2018; Karjula et al., 2017; Nagarathnamma & Nirmala, 2020).

Widespread myths—such as the belief that PCOS causes permanent infertility or that hormonal medications are harmful—created further barriers to care (Bharathi et al., 2017).

These misconceptions, reinforced by cultural norms and family advice, often led to shame, secrecy, and reduced treatment adherence.

The findings highlight an urgent need for multi-level interventions integrating medical care, psychosocial support, community-based education, and verified digital tools tailored to local languages and contexts. Future efforts should involve local health workers and families to foster open dialogue and reduce stigma.

In conclusion, this study emphasizes the importance of holistic, culturally sensitive strategies to support women with PCOS in Odisha and recommends further research into the effectiveness of region-specific digital health solutions (Teede et al., 2018; Nayak & Devasenapathy, 2021).

Implications

- Healthcare must follow a holistic, patient-focused model combining medical care and psychological support.
- Public awareness programs should address myths, promote early detection, and improve understanding of PCOS.
- Community education should encourage open conversations on menstruation and reproductive health to reduce stigma.
- Region-specific, evidence-based digital tools in local languages are needed to aid PCOS self-care.
- Policies should support integrated treatment plans that include medical, emotional, and lifestyle-based care.

Limitations

- The study sample included mostly unmarried, urban, and educated women, which may limit the generalizability of findings to other groups (e.g., married women, rural populations).
- Data collection through telephone interviews may have limited non-verbal communication and affected rapport.
- Reliance on self-reported data introduces potential recall bias and subjective interpretation of experiences.
- The cross-sectional design does not allow for understanding changes over time or long-term impacts of PCOS.

Suggestions

- Include more diverse participant groups, considering variations in marital status, socio-economic background, and rural or urban residence.
- Conduct longitudinal studies to examine how women's experiences and coping strategies evolve over time.
- Design and implement interventions that integrate mental health support, family counseling, and culturally sensitive education.
- Develop and validate trustworthy digital platforms and apps, especially in regional languages, to improve accessibility and accuracy.
- Promote policy-level programs aimed at destigmatizing menstrual and reproductive health issues through community and school-based initiatives.

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Conflict of Interest

The author declares no conflict of interest.

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