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The Invisible Burden: A Qualitative Exploration of PCOS/PCOD's Psychosocial and Educational Consequences in Indian College Students

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ABSTRACT:

Background - Polycystic Ovary Syndrome (PCOS) and Polycystic Ovarian Disease (PCOD) are highly prevalent endocrine disorders among Indian women, with rising cases linked to genetic, lifestyle, and environmental factors. While biomedical aspects such as infertility and metabolic risks are well documented, the psychosocial and educational toll, particularly on college students, remains understudied. This qualitative study explores the invisible burden of PCOS/PCOD in young Indian women, examining how stigma, mental health struggles, and symptom management intersect with academic performance and daily life. By amplifying firsthand narratives, the research highlights unmet needs in healthcare and institutional support, aiming to bridge gaps between clinical diagnosis and holistic well-being**.**

Method- Qualitative research design was employed, using purposive sampling to select female undergraduate students who self-reported a diagnosis of PCOD (Polycystic Ovarian Disease) or PCOS (Polycystic Ovary Syndrome). Participants were interviewed, but no medical cross- validation (e.g., clinical records or hormonal tests) was conducted to verify their conditions. This narrative research study explores the lived experiences of 20 undergraduate girls in Lucknow, India, who are battling PCOS/PCOD. Through personal interviews, the study uncovers how societal silence, parental anxieties, and financial constraints shape their mental well-being and academic choices.

Results- Findings reveal that many girls face stigma, forced early marriage pressures, and self- esteem issues due to visible symptoms like facial hair and acne. Parents, fearing infertility- linked marital rejections, often discourage open discussions or higher education away from home. However, those with supportive families and coping mechanisms like yoga and meditation manage better.

Conclusion- The study highlights the urgent need for awareness, parental education, and institutional support to break the cycle of silence and empower these young women.

KEYWORDS: PCOS, PCOD, Mental Health, Educational barriers, Indian Society, Parental Influence, Stigma

INTRODUCTION AND LITERATURE REVIEW

Indian society maintains deeply entrenched menstrual stigma, perpetuating notions of impurity through religious prohibitions and cultural silence around menstruation (Jeffery & Jeffery, 2005). This stigma has severe consequences, with 71% of Indian girls reporting no menstrual education before menarche and 48% resorting to unsafe hygiene materials due to shame (NFHS-5, 2019-21).

For women with PCOS/PCOD - conditions affecting approximately 20% of Indian women of reproductive age (ICMR, 2023) - this stigma compounds their challenges. Symptoms like irregular cycles and hirsutism are frequently dismissed as personal failings, leading to delayed diagnosis (average 3+ years) and inadequate treatment (WHO, 2023). Institutional failures, including lack of menstrual accommodations in schools and gender-insensitive healthcare policies, further marginalize affected women (Miller-Kleinhenz et al., 2021).

The healthcare system reflects broader disparities in LMICs, where 1 in 3 women lacks access to essential services (WHO, 2021). In India, only 22% of women receive comprehensive reproductive health screenings (NFHS-5, 2019-21), with PCOS/PCOD particularly neglected despite their association with serious comorbidities like diabetes and cardiovascular disease (ICMR, 2022). Diagnostic

criteria for PCOS (oligo-anovulation, hyperandrogenism, and polycystic ovarian morphology; Pasquali et al., 2011) remain poorly implemented in primary care, especially in rural areas where 80% of endocrinologists are unavailable (ICMR, 2023).

This study examines the psychosocial and educational impacts of PCOS/PCOD among undergraduate women in Lucknow, India. Through narrative research with 20 participants, it reveals how these conditions intersect with academic pressures, familial expectations, and devastating blows to self-esteem in a culture that equates feminine value with fertility. Their stories expose an urgent need to address both medical and societal dimensions of PCOS/PCOD in India.

Research Questions:

1. How does societal and parental stigma around PCOS/PCOD affect the mental health of undergraduate girls?
2. How do financial constraints and lack of awareness impact their healthcare management?
3. How does this affect their mental health?
4. How did this influence their educational and career decisions?
5. Which coping mechanism are they using to overcome the worst effects of PCOS/PCOD?

METHODOLOGY

Sampling and Participant- This study employed an in-depth qualitative research design to investigate the psychosocial and educational impacts of PCOS/PCOD on young women in urban India. The research focused specifically on female undergraduate students aged 19-24 residing in Lucknow, Uttar Pradesh, a demographic particularly vulnerable to reproductive health stigma during critical life transitions.

Sampling Method and Sample Size - Using purposive sampling, 20 participants were recruited through various channels including the University Health Center, campus support groups, and PCOS-focused social media communities. This recruitment strategy ensured representation across diverse academic disciplines and socioeconomic backgrounds.

Participants were included based on three key criteria:

1) Self-reported diagnosis of PCOS/PCOD (acknowledging potential limitations in symptom recognition without clinical verification)
2) Current enrolment in undergraduate programs.
3) long-term residence in Lucknow to assess localized cultural impacts.

Data collection- Data collection involved 30–45-minute in depth interviews (Table 1) conducted in participants' preferred language (Hindi or English) at private campus locations or via secure video calls.

Table 1: Interview Guide

S. No.	Questions
1.	Please share your knowledge about PCOS and PCOD, including at what age you were diagnosed and what your experience has been so far?
2.	Do you consider it as financial burden?
3.	Can you describe how you are affected socially, physically and mentally in terms of quality of life?
4.	Do you feel this condition affects your educational or career decision-making and overall self-esteem? How you are managing this with you academics?
5.	What do you think is the best coping mechanism for this? Do you feel there is lack of awareness regarding PCOS and PCOD? Can you elaborate on how it impacts health-seeking behaviors?

The interview protocol explored five key domains:

1) Diagnostic journeys and healthcare access barriers.
2) Financial struggles and healthcare barriers.
3) Mental health and body image concerns.
4) Academic and social challenges.
5) Coping mechanisms and support systems.

DATA ANALYSIS

In this Narrative study using Purposive Sampling, Thematic analysis followed a detailed, iterative process to identify patterns and themes from interview data. After each interview, the researcher documented initial impressions to capture early insights.

Transcripts were read multiple times for immersion, allowing key themes to emerge systematically. Audio recordings were reviewed to verify transcripts and analyze nuances like tone and emotion, enriching the interpretation. Through repeated coding, grouping, and refinement, the final themes reflected participants' lived experiences while preserving narrative depth. This rigorous approach combining reflective documentation, repeated transcript review, thematic coding, and audio verification ensured a comprehensive and trustworthy analysis of the narrative data.

Table 2: Socio-Demographic Characteristic

Social-demographic Characteristic	**Women with PCOS/PCOD (n=20)**
Age range	19-24
Occupation	Student
Educational level	
1st Year Under graduate	3
2nd Year Under graduate	9
Final Year Under graduate	8
Place of Residence	
Urban	14
Rural	6
Living Arrangement	
With Family	12
Hostel/PG	8
Marital status	Unmarried
Duration of Disorder	
<3 Year	7
3 to 5	8
>5 Year	5

RESULTS

This study explored the experiences of twenty women with PCOS/PCOD, whose demographic details are presented in (Table 2). Through thematic analysis of the interviews, five key themes and fifteen subthemes emerged (Table 3), highlighting the multifaceted challenges faced by participants. The findings reveal that women with PCOS/PCOD frequently endure severe psychological distress, alongside other significant physical and emotional struggles. These insights underscore the need for holistic healthcare approaches to address both the medical and mental health aspects of the condition**.**

Table 3: Identification of themes and sub themes

S. No.	**Themes**	**Sub Themes**
1.	Stigma of infertility and marriage pressure	Low self esteem Fear of losing thing Menstrual Disorder and Infertility as source of Anxiety
2.	Financial struggles	Prescribed diets are unaffordable Economic limitation and medical underfunding make it worse
3.	Mental health crises	Bad physical health due to menstrual disorder Impact on Mental health Body image dissatisfaction Irregular emotion increases psychological distress
4.	Educational Sacrifices and restricted dreams	Effect of Educational and carrier decision making Restricted support from the family members
5.	Coping Mechanism	Family support Counselling of patient as well as family members Early awareness on Reproductive health Life style guidance

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The Stigma of Infertility and Marriage Pressures

The study participants revealed profound stigma surrounding their condition, particularly regarding marriage prospects. Multiple participants described family-enforced silence, with Respondent (21 years) sharing, "My mother warned me never to disclose my PCOS, even to future in-laws," while other respondent (20 years) reported parents rushing marriage arrangements, believing it would "solve" her PCOD. These narratives highlight how deep-rooted misconceptions equating PCOS/PCOD with infertility dominate family responses, often prioritizing marital concerns over proper healthcare or education. The resulting secrecy exacerbates psychological distress and limits access to support, underscoring an urgent need for community awareness programs to dispel myths and counselling services to help families navigate diagnosis without compromising daughters' wellbeing or academic futures.

Financial Struggles and Healthcare Barriers

The study revealed significant financial and attitudinal barriers preventing young women from receiving proper PCOS/PCOD treatment in Lucknow. Many respondents reported their families struggling to afford consistent medical care, with hormonal medications, specialist consultations, and prescribed diets often deemed unaffordable. One respondent (19 years) explained, "We can't afford the medicines every month. Sometimes I just take painkillers and hope the cramps go away," highlighting the dangerous coping mechanisms adopted due to financial constraints. Compounding this issue, several participants described family members dismissing their symptoms as normal menstrual discomfort rather than recognizing the chronic nature of their condition. While another respondent (22 years) shared, "My parents think it's just 'period problems' and say I'm overreacting." This combination of economic limitations and medical minimization creates a perilous situation where affected young women delay or forgo necessary treatment, leading to worsening physical symptoms like uncontrolled weight gain and severe menstrual irregularities, while simultaneously exacerbating mental health challenges including anxiety and depression. The findings underscore an urgent need for subsidized treatment programs and community education initiatives to improve both healthcare accessibility and family understanding of PCOS/PCOD as serious but manageable health conditions requiring consistent medical attention rather than temporary or dismissive solutions

The Mental Health Crisis: Anxiety, Depression, and Low Self-Esteem

The study highlights how visible PCOS/PCOD symptoms such as acne, hirsutism, and weight gain profoundly affect young women's self-esteem and academic engagement. One respondent (20 years) shared, "I skipped classes during acne flare-ups to avoid stares," while another respondent (21 years) admitted, "Constant worry about my appearance makes focusing on studies impossible." These body image struggles, combined with sleep disruptions from hormonal imbalances, led to frequent absenteeism, declining concentration, and social withdrawal. The findings underscore the need for integrated campus support, including counselling services to address self-esteem issues, academic accommodations for symptom flare-ups, and peer-led awareness programs to reduce stigma. By addressing both the medical and psychosocial dimensions of PCOS/PCOD, institutions can help mitigate its impact on education and mental health.

Educational Sacrifices: Restricted Dreams

The research uncovered how parental anxieties regarding health management and marriage prospects significantly constrain the educational and career trajectories of young women with PCOS/PCOD in Lucknow. Multiple participants reported their academic aspirations being curtailed due to family concerns, with Respondent (age 22) revealing, "My parents rejected my study abroad plans, fearing, 'What if your periods become more irregular there? Who will look after you?'" Similarly, other Respondent (age 19) shared, "My family insists I complete my degree quickly to focus on marriage, showing no interest in my career goals." These accounts demonstrate a troubling pattern where families, influenced by exaggerated health concerns and traditional marital priorities, actively discourage higher education opportunities. Many young women described being steered toward local colleges instead of preferred institutions, pressured to abandon career-oriented courses for "safer" options, or even compelled to discontinue education entirely to accommodate early marriage plans. These restrictive decisions, rooted in medical misinformation and entrenched gender norms, create a paradoxical situation where parental protectiveness ultimately limits daughters' personal growth and future independence. The findings underscore the urgent need for targeted interventions, including parental education programs about PCOS management and institutional support systems, to help young women pursue their academic and professional ambitions without compromising their health needs.

Coping Mechanisms

The study documented several encouraging cases where strong familial support and proactive coping mechanisms helped mitigate PCOS/PCOD's challenges. One respondent (age 20) reported, "My mother accompanies me to daily yoga sessions which significantly

improved my mood regulation and stress levels," demonstrating how family involvement in holistic interventions can yield positive outcomes. Similarly, other respondent (age 21) found solace in peer networks, sharing "Regular meditation and connecting with other PCOS patients through support groups reduced my feelings of isolation." These narratives reveal two effective coping frameworks: (1) family-facilitated lifestyle modifications (yoga, dietary changes) that address both physical symptoms and psychological wellbeing, and (2) community-based emotional support systems that combat the stigma and loneliness often associated with the condition. The data suggests that while biomedical treatment remains crucial, psychosocial support systems play an equally vital role in comprehensive PCOS/PCOD management. These success stories provide valuable models for developing targeted interventions that combine medical care with mental health support and community building, potentially improving treatment adherence and quality of life for young women navigating this complex condition.

DISCUSSION

The study revealed a self-perpetuating cycle of interrelated challenges surrounding PCOS/PCOD management among young women. At its foundation lies pervasive societal stigma that discourages open discussion of reproductive health issues, particularly those perceived to affect marriageability. This culture of silence directly contributes to delayed diagnoses and inadequate treatment, as symptoms are frequently normalized or ignored. Compounding this issue, financial constraints prevent consistent access to specialized healthcare, hormonal medications, and dietary interventions, leading to unmanaged symptoms that progressively worsen over time. The physical manifestations of the condition including weight fluctuations, dermatological issues, and menstrual irregularities intersect with emerging mental health concerns, creating a bidirectional relationship where anxiety and depression exacerbate physical symptoms, which in turn deepen psychological distress. This complex interplay significantly impacts academic engagement, manifesting as decreased concentration, higher absenteeism, and declining performance. Perhaps most consequentially, these accumulated challenges often prompt families to prioritize early marriage over educational or career aspirations, viewing matrimony as a solution to health concerns rather than addressing the root causes. This cyclical pattern demonstrates how medical, economic, social, and educational factors interact to create compounded disadvantages for young women with PCOS/PCOD. The findings underscore the critical need for integrated interventions that simultaneously address healthcare access, mental health support, educational accommodations, and community awareness to disrupt this destructive trajectory and empower affected individuals to achieve better health and life outcomes.

CONCLUSION

This study illuminates PCOS/PCOD as not merely a biomedical condition but a complex sociocultural crisis that systematically undermines young women's health, education, and life opportunities in India. The findings reveal how intersecting barriers including entrenched stigma, healthcare access disparities, familial pressures, and institutional neglect create a self-perpetuating cycle of disadvantage for affected individuals. Particularly concerning is the documented pattern where health concerns become justification for restricting educational and professional aspirations, reflecting deeper gender inequities in how young women's futures are valued. The data demonstrates that without intervention, PCOS/PCOD frequently functions as a catalyst for early school leaving, mental health deterioration, and constrained socioeconomic mobility. However, the research also identifies pathways for meaningful change.

Effective management requires moving beyond purely clinical approaches to develop:

1) Community-based awareness programs that demystify reproductive health issues.
2) Institutional support systems within educational settings.
3) Policy frameworks that address both medical and social dimensions of care. The demonstrated efficacy of peer support networks and holistic health practices points to the value of culturally-grounded, participatory interventions.

Ultimately, this study argues for reconceptualizing PCOS/PCOD as a public health priority demanding multidisciplinary response. By simultaneously improving medical access, challenging harmful stereotypes, and creating enabling environments in families and schools, society can transform this condition from a source of limitation to one of manageable health challenge. The participants' collective experiences serve as both warning and guide—revealing systemic failures while modelling the resilience needed to address them. Their narratives underscore the urgent imperative to develop solutions that honor the full humanity and potential of young women living with PCOS/PCOD, ensuring their health condition neither defines nor limits their life trajectories.

SUGGESTIONS AND RECOMMENDATIONS FOR FUTURE RESEARCH

To comprehensively address the multifaceted challenges of PCOS/PCOD in India, a dual approach combining rigorous research and

targeted interventions is imperative. Future studies should prioritize large-scale epidemiological research across diverse geographic and socioeconomic contexts to map regional variations in prevalence, symptom profiles, and healthcare barriers. Intervention-based research must evaluate the efficacy of school-based education programs, affordable treatment models, and digital support platforms, while longitudinal studies should track the long-term socioeconomic impacts on education, careers, and quality of life. Concurrently, systemic reforms should focus on institutional changes, including mandatory PCOS education in school curricula, university-based counselling services, and workplace accommodations. Healthcare systems require strengthening through subsidized diagnostic packages, standardized treatment protocols, and tiered medication pricing to improve accessibility. Community engagement through myth-busting campaigns, parent-daughter counselling clinics, and training for health workers can combat stigma and promote early detection. Policy advocacy must push for the inclusion of PCOS in national non- communicable disease programs, expanded insurance coverage, and corporate partnerships for workplace awareness. By integrating these research and intervention strategies, India can develop a comprehensive, evidence-based approach to mitigate the medical, social, and economic burdens of PCOS/PCOD, ensuring affected individuals receive holistic support across educational, healthcare, and professional domains.

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