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SOCIAL WORK INTERVENTIONS IN MANAGING PCOD/PCOS AMONG WOMEN IN DELHI NCR (AGE GROUP 18-26)

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ABSTRACT

Polycystic Ovarian Disorder/Syndrome (PCOD/PCOS) is one of the most common endocrine disorders affecting women of reproductive age, with rising prevalence in India particularly among young urban women (Teede et al., 2018). Despite its far reaching physical, emotional, and psychological impact, it remains under diagnosed and poorly understood in many communities. This study delves into the lived experiences of women aged 18–26 in the Delhi NCR region, focusing on the social and mental health challenges posed by PCOD/PCOS and the role of social work in addressing these gaps.

Primarily qualitative in nature, the research draws on semi structured interviews with 60 participants selected via snowball sampling. Through thematic analysis, four key themes emerged: (1) lack of awareness and misinformation, (2) stigma and isolation, (3) limited access to affordable healthcare, and (4) the absence of psychosocial support structures, including trained social workers. To strengthen and visually support these findings, a limited set of quantitative data presented through bar and pie charts was included to corroborate patterns observed in participant narratives.

The study underscores the pressing need for integrated social work interventions in reproductive health, advocating for community based mental health support, social work training, and inclusive policy reforms. By highlighting a holistic model of care that prioritizes psychosocial well-being alongside medical treatment, this research contributes to the evolving discourse on reproductive justice in India. (Bhattacharya et al., 2021; Nair & Vaid. 2020).

Keywords: PCOD, PCOS, qualitative research, thematic analysis, social work, reproductive health, mental health, stigma, women's health, Delhi NCR

INTRODUCTION

Polycystic Ovarian Disorder/Syndrome (PCOD/PCOS) is a multifactorial endocrine disorder that affects approximately 1 in 10 women of reproductive age globally (Teede et al., 2018). Characterized by irregular menstruation, hyperandrogenism, and polycystic ovaries, the condition not only poses medical challenges but also carries profound psychological and social implications. While the clinical manifestations of PCOD/PCOS include weight gain, acne, and infertility, its psychosocial burden ranging from anxiety and depression to low self-esteem and social stigma often goes unnoticed and unaddressed (Rasgon et al., 2003).

In India, the prevalence of PCOD/PCOS among young women is on the rise, with estimates suggesting that nearly 22.5% of adolescent girls and women in urban areas may be affected (Nidhi et al., 2011). Sedentary lifestyles, poor nutrition, academic and career stress, and shifting societal pressures all play a role in this trend (Azziz et al., 2016). Women aged 18 to 26, in particular, often find themselves at the crossroads of crucial life transitions education, careers, relationships and that makes their experience of PCOD/PCOS even more challenging (Dokras et al., 2011). Furthermore, the taboo surrounding reproductive health in Indian society exacerbates feelings of isolation, making it difficult for affected individuals to seek timely support or intervention (Kumar & Srivastava, 2020).

Given the intersection of medical, psychological, and social challenges, PCOD/PCOS presents a critical area for social work engagement. Social workers, particularly those trained in health and mental health settings, are uniquely positioned to bridge the gap between biomedical care and psychosocial support. Through advocacy, community education, counseling, and policy level engagement, social workers can play a pivotal role in reducing stigma, enhancing awareness, and promoting holistic care for women with PCOD/PCOS (Bhattacharya et al., 2021).

This study focuses on understanding the lived experiences of women with PCOD/PCOS in the Delhi NCR, specifically within the age group of 18–26. The rationale for selecting this demographic lies in their increased risk of both clinical and psychological complications, as well as their limited access to specialized reproductive health resources. The primary objective of this research is to assess the effectiveness of current interventions

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and propose community based and policy driven social work strategies that can enhance the quality of life for women managing PCOD/PCOS in urban India.

LITERATURE REVIEW

Polycystic Ovarian Disorder/Syndrome (PCOD/PCOS) is a chronic endocrine disorder that significantly impacts reproductive, metabolic, and psychological health. It is primarily diagnosed through a combination of symptoms such as irregular menstrual cycles, hyperandrogenism (excess male hormones), and the presence of polycystic ovaries visible via ultrasound (Teede et al., 2018). In addition to infertility, women with PCOS often experience weight gain, hirsutism, acne, and insulin resistance (Azziz et al., 2016). The syndrome is also closely linked with long-term health risks such as type 2 diabetes, cardiovascular disease, and endometrial cancer (Balen et al., 2016).

The physical manifestations of PCOD/PCOS often intersect with deep-seated psychosocial challenges. Numerous studies have highlighted the mental health burden associated with the condition, with increased rates of anxiety, depression, body image dissatisfaction, and eating disorders among affected women (Dokras et al., 2011). These mental health concerns are further compounded by social stigma and cultural narratives that frame reproductive health issues as shameful or taboo, particularly in conservative societies like India (Kumar & Srivastava, 2020).

The stigma surrounding PCOD/PCOS is not just individual but systemic. Research shows that women's experiences with PCOS are shaped by societal expectations of femininity, fertility, and physical appearance (Harris-Glocker et al., 2010). In many cultural contexts, including South Asia, infertility is heavily stigmatized, leading to marital stress, social exclusion, and diminished self-worth (Patel et al., 2021).

In response to such limitations, feminist health scholars argue for a gender-sensitive understanding of PCOD/PCOS. Feminist theory emphasizes the structural and cultural contexts of women's health, encouraging a critique of how medical systems often marginalize women's embodied experiences (Lorber & Moore, 2002). In this framework, PCOS is not just a biological anomaly but a condition deeply entangled with gendered norms and healthcare inequalities. This lens is particularly useful for social workers and mental health practitioners who seek to address the psychological impact of the disorder.

The biopsychosocial model provides another useful framework, integrating biological, psychological, and social dimensions of health (Engel, 1977). Applied to PCOD/PCOS, this model underscores how physiological symptoms interact with stress, emotional resilience, social support, and access to care. Unlike narrow clinical models, the biopsychosocial perspective opens up space for interdisciplinary interventions, including social work engagement in treatment planning, counseling, and advocacy.

Social workers have historically played a vital role in promoting mental and reproductive health, particularly for marginalized populations. In the context of PCOD/PCOS, social workers are well-positioned to facilitate psychosocial interventions such as body image therapy, reproductive counseling, and community education programs (Bhattacharya et al., 2021). By advocating for patient-centered care and addressing the stigma surrounding menstruation and fertility, social workers can improve health-seeking behavior and support systems for women with PCOS.

Despite these potentials, there remains a notable gap in the literature on integrated, community-based approaches for PCOD/PCOS. Existing interventions tend to be medicalized, with limited attention to cultural competence, emotional well-being, and the social realities of affected individuals. Studies from countries like Australia and the UK have piloted comprehensive care models involving endocrinologists, dietitians, and mental health professionals, yet such interdisciplinary frameworks are rare in India (Dokras et al., 2011; Teede et al., 2018).

Moreover, few programs directly engage with younger populations (ages 18–26), who are often navigating educational or professional transitions alongside their diagnosis. This group faces unique challenges in disclosing their condition, accessing consistent treatment, and maintaining psychological well-being in the face of societal pressure and health misinformation (Nair & Mahajan, 2020).

The need for psychosocial approaches in reproductive health has never been more urgent. PCOD/PCOS is not merely a hormonal disorder it is a deeply lived experience that demands holistic care. Integrating mental health services, educational outreach, and social work perspectives into reproductive healthcare can not only improve quality of life for women with PCOS but also dismantle the stigma and silence that currently surround the condition.

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This review highlights a crucial need for qualitative, community centered research that elevates women's voices and centers their experiences. By addressing this gap, the current study aims to provide insights that are both clinically relevant and socially transformative.

RESEARCH METHODOLOGY

This study employs a mixed methodology to explore the lived experiences of women diagnosed with PCOD/PCOS. Using semi structured interviews, it captures the social, psychological, health, and socioeconomic challenges faced by women aged 18 to 26 in Delhi NCR. Given the stigma and misinformation around PCOD/PCOS, a qualitative approach is most appropriate for understanding its complex and personal impact. The research is primarily qualitative in nature, with thematic analysis used to identify patterns in participant narratives. To enhance the qualitative assessment, the quantitative data is corroborating the findings and the results.

A total of 60 participants were selected using the snowball sampling method, a non-probability technique ideal for reaching specific or hard-to-reach populations. Initial participants identified through community health organizations and women's support groups were asked to refer others from their networks who met the inclusion criteria. This strategy was particularly useful due to the social stigma and underreporting often associated with PCOD/PCOS, which can make random sampling ineffective (Noy, 2008).

Data collection was carried out through semi-structured interviews, this included open-ended questions on four key domains: (1) awareness and knowledge of PCOD/PCOS, (2) challenges faced, (3) experiences with healthcare and support services, and (4) perceptions of social work or community interventions. The questions were designed to elicit detailed responses while offering participants the freedom to explore aspects most relevant to their experience. Each interview lasted between 30 to 45 minutes and was conducted either in person or virtually, depending on participant preference and availability.

Ethical Considerations were rigorously followed throughout the research process. Prior to participation, each individual was provided with an informed consent form detailing the study's purpose, their voluntary involvement, and the right to withdraw at any time without consequence. Participants were assured that all information would remain confidential and that their identities would be anonymized in all reports and publications. The study received ethical clearance from the institutional review board of the affiliated academic institution, ensuring adherence to national and international guidelines for human subject research (Israel & Hay, 2006).

FINDINGS AND ANALYSIS

This chapter presents the findings from semi-structured interviews conducted with 60 women aged 18–26 years, residing in Delhi NCR and diagnosed with PCOD/PCOS. The qualitative data were analyzed using Braun and Clarke's (2006) six-phase thematic analysis approach, familiarization, coding, theme development, reviewing themes, defining/naming themes, and reporting which enabled the identification of recurring patterns such as stigma, emotional distress, lack of healthcare access, and the need for social work intervention. Four overarching themes emerged: awareness and knowledge, emotional and social challenges, access to healthcare and support, and the role of social workers. These themes are presented with illustrative quotes from participants to highlight the depth and diversity of their experiences.

Awareness and Knowledge

Participants displayed varying levels of awareness about PCOD/PCOS. Many first heard of it only after experiencing symptoms like irregular periods, weight changes, or fertility issues.

"I had never heard of PCOS until I started having severe hair fall and irregular periods." (Participant 12)

Educational background played a key role. Women with higher education were more likely to: Recognize symptoms early, Seek medical help, Understand lifestyle management. In contrast, those with limited education often delayed diagnosis or relied on myths.

"I thought my weight gain was normal. We didn't know it could be a condition." (Participant 40)

Socio-economic status also shaped awareness. Women from well-off families accessed specialists and support easily.

"I saw a specialist at 17. My doctor explained everything." (Participant 9)

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Those from lower-income backgrounds often lacked information and delayed treatment due to cost.

"I went to local clinics, but no one explained what PCOS was." (Participant 55)

Awareness of PCOD/PCOS is strongly influenced by education and socio-economic status. Those from educated and financially stable backgrounds are better informed and proactive, while marginalized women often face delayed care.

Emotional and Social Challenges

A dominant theme was the emotional distress experienced due to PCOD/PCOS. Body image issues were common, often linked to weight gain, facial hair, and acne symptoms that conflict with societal beauty standards.

"Since my diagnosis, I've felt frantic. I kept comparing myself to others and thought something was wrong with me." (Participant 18)

Many participants felt unsupported by family and healthcare providers, highlighting the need for integrated mental health support.

Stigma around reproductive health, particularly in conservative families, often left women feeling isolated and misunderstood.

- PCOS was associated with infertility, triggering social pressure around marriage.
- Common myths (e.g., PCOS only affects unhealthy or "rich" women) deepened the misunderstanding.

Participants also reported workplace discrimination and a lack of supportive policies. Symptoms like fatigue and pain impacted performance, yet were often dismissed.

"I took sick leave for pain, but my employer said I was making excuses." (Participant 11)

"I was afraid to disclose my condition, it might make me seem less capable." (Participant 38)

This theme highlights the multi-layered struggles women face, mental health issues, stigma, medical neglect, and workplace discrimination. There is a pressing need for comprehensive awareness, supportive workplace policies, and sensitive medical care that addresses both physical and psychological aspects of PCOD/PCOS.

Access to Healthcare and Support

Most participants reported delayed diagnosis, mismanagement, and financial barriers in seeking care for PCOD/PCOS.

"I went four years without a diagnosis every doctor said it was just stress." (Participant 22)

General physicians often lacked knowledge, dismissed symptoms, or prescribed birth control without explanation or follow-up.

"I was put on the pill without being told anything. When I stopped, it got worse." (Participant 37)

High costs of diagnostics, medications, and private consultations made care unaffordable for many. Public hospitals offered limited services with long wait times.

"I had to save for months just to see a specialist but I couldn't afford to continue." (Participant 50)

Healthcare access for women with PCOD/PCOS is hindered by delayed diagnoses, cost barriers, lack of mental health integration, and inadequate specialist care.

Role of Social Workers

Community-based initiatives have helped to raise awareness and support for women with PCOD/PCOS, particularly in urban settings. A Delhi-based NGO hosted workshops for over 500 young women, providing information on symptoms, treatment, and lifestyle improvements.

"I had no concept what PCOS was before attending the session. Now I have a doctor to help me."

Another NGO led support group offered peer counseling and mental health therapy to over 200 women, providing a secure environment for emotional expression and sharing experiences.

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"Talking to others helped me realize that I wasn't alone. It gave me the confidence to ask for help."

Despite these efforts, access to these services remains restricted. Most participants, particularly those from low-income families, did not connect with social workers or support groups. Public hospitals lacked reproductive health counselors, leaving many women without adequate instruction or emotional support. Participants emphasized the importance of school workshops, community counseling, and awareness initiatives for reducing stigma and providing early intervention. Expanding social work outreach, particularly in public healthcare and rural regions, is critical to providing comprehensive, holistic treatment to women with PCOD/PCOS.

RECOMMENDATIONS

Social Work Practice Recommendations

The findings of this study reveal significant gaps in the psychosocial support available to young women with PCOD/PCOS. A clear opportunity exists to integrate trained social workers into gynecological clinics and community health centers, particularly in urban areas like Delhi NCR. These professionals can offer emotional counseling, help navigate medical systems, and bridge the gap between patients and healthcare providers.

In addition to clinical roles, social workers should be involved in designing peer support networks and awareness campaigns within educational institutions. Many participants expressed a lack of early information and education about PCOD/PCOS, which could be addressed through school and college-based workshops. Such initiatives not only increase awareness but also help reduce the stigma and isolation often reported by those affected.

Social workers are also uniquely positioned to identify at-risk individuals in marginalized or low-income communities where healthcare access is already limited. Their role should expand beyond individual counseling to advocacy, education, and preventive health outreach.

Policy Suggestions

To address the psychological and reproductive health burdens associated with PCOD/PCOS, health departments should formally incorporate social work within gynaecological and endocrinological care. Training and financing for health social workers are critical. Public-private collaborations with non-governmental organisations (NGOs) can aid in culturally relevant awareness efforts, particularly in underprivileged areas. Policy changes should also include workplace and academic concessions, such as flexibility, mental health assistance, and staff training, in order to create inclusive workplaces for affected women.

Future Research Scope

While this study provides meaningful insights into the lived experiences of 60 women aged 18–26 in Delhi NCR, it also highlights the need for larger-scale studies across varied geographic and socio-economic contexts. Future research should include women from rural areas, different age brackets, and diverse cultural backgrounds to provide a more comprehensive understanding of the condition's impact.

There is also great potential for cross-cultural research comparing urban vs. rural challenges in India and contrasting those findings with international contexts. This would allow researchers and policymakers to identify global patterns and region-specific interventions.

Another emerging area is the use of digital health tools, such as mobile applications for reproductive health tracking and tele-counseling services. Research into the feasibility, accessibility, and effectiveness of such tools for PCOD/PCOS management can open doors to low-cost, scalable interventions, particularly for remote or underserved populations.

CONCLUSION

This qualitative study explored the awareness, challenges, and support needs of young women diagnosed with PCOD/PCOS in Delhi NCR. Thematic analysis of semi-structured interviews revealed several common threads: a lack of early awareness, emotional and psychological struggles, stigma, fragmented healthcare experiences, and an overwhelming absence of structured social work involvement.

These findings reaffirm the need for interdisciplinary healthcare models that recognize PCOD/PCOS as not just a medical condition but a complex social, psychological, and economic challenge. By embedding trained social workers within the reproductive healthcare system, designing community education programs, and reforming institutional policies, we can create more empathetic, informed, and equitable care environments.

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Ultimately, the study serves as a call to action for policy reform, institutional collaboration, and the elevation of social work practice in the field of reproductive health. As the burden of PCOD/PCOS continues to rise, such multidisciplinary and compassionate approaches will be essential in empowering affected women and transforming public health responses.

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