

UNHEARD, MISUNDERSTOOD & SUFFERING: THE EXPERIENCES OF SOUTH ASIAN WOMEN LIVING WITH PCOS IN THE UK

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01. INTRODUCTION

Previous literature suggests PCOS affects South Asian Women more adversely than Caucasian Women, [1] however there is very little research exploring and understanding the journeys, ideas and sociocultural contexts that affect South Asian women's experiences living with and how they manage PCOS.

02. OBJECTIVE

This ethnographic study aimed to explore the ideas, sociocultural contexts and journeys of South Asian women living with PCOS in the UK and understand the factors that could be contributing to their adverse outcomes.

03. METHODOLOGY

A qualitative ethnographic study was conducted of four purposively sampled participants:

DATA COLLECTION

Participant Recruitment

Via electronic outreach & participant referrals. Purposive sampling used.

STEP 1

Semi-structured Interviews

Conducted virtually on MS Teams, recorded & transcribed with consent.

STEP 2

DATA ANALYSIS

Axial Coding

Manual coding of key ideas using Taguette software & MS Excel.

STEP 3

Emergence of key themes

Ideas sorted into categories then into three key themes to work with.

STEP 4

Figure 1: Infographic depicting the methodology used to conduct the study

04. RESULTS & FINDINGS

The data analysis identified three key themes that were impacting South Asian women's experiences with PCOS:

THEME 1

Impact of Sociocultural Ideologies

- Limited understanding of women's health issues.
- Role of women as wife and mother.
- Social and cultural taboo, stigma and shame.
- Deep rooted cultural lifestyle practices & norms.

THEME 2

Lack of Medical Support

- Delayed & inaccurate diagnoses.
- Cultural prejudice & stereotyping by healthcare professionals.
- Lack of understanding or awareness of cultural contexts leading to inadequate care.

THEME 3

Positive Behaviours & Practices

- Impact of a strong support network.
- Organised sports and clubs.
- Social media & the internet as a positive tool.
- Initiatives that involve family.

Figure 2: Infographic illustrating research findings of ethnographic study exploring experiences of South Asian women living with PCOS in the UK

05. RECOMMENDATIONS

Based on research findings, the following measures could help improve the lives of South Asian women with PCOS:

Dedicated outpatient clinic for PCOS in secondary care or increasing GPs with special interest in Women's health.

Further ethnographic studies for South Asian women plus women from other backgrounds too.

Better treatments, emotional counselling and better training for HCPs to enable adequate culturally sensitive care.

Formation of a social media regulatory body to ensure the dissemination of accurate medical information online.

Public health initiatives and organised sports & educational programmes involving families and communities

Figure 3: Infographic depicting key recommendations based on research findings.

06. CONCLUSION

The findings of this study are incredibly important. They bridge the gap in existing research and shed light on the specific challenges and barriers South Asian women in the UK are facing which could ultimately be contributing to adverse outcomes for them. Further, the misconceptions regarding women's health and PCOS as revealed in this study evokes the question of how many women in the community could be experiencing distressing symptoms but not seeking help.

Currently, according to NICE guidelines, lifestyle changes and the contraceptive pill are amongst the first-line management options offered to patients with PCOS. However, the findings in this study reveal that South Asian women are facing sociocultural barriers adhering and complying to both. The inability of healthcare professionals in understanding these barriers and in helping them to overcome them is further failing patients.

Therefore, this study shows the crucial need for steps to be taken to improve provision of care for South Asian Women with PCOS and highlights that with the correct support and interventions there is great potential for their quality of life to be improved.

[1] Mehta J. Kamdar V. and Dumesic D. 2013. Phenotypic expression of polycystic ovary syndrome in South Asian women. Obstetrical & Gynecological Survey 68(3) pp.228-234