

# A Qualitative Study on the Lived Experiences of Women with Polycystic Ovary Syndrome Attending Gynecology OPD, Bangalore

Pitti Meghasandhya<sup>1,\*</sup>, S. Padmaja<sup>2</sup>

## Abstract

*Polycystic ovary syndrome (PCOS) is a prevalent hormonal disorder among women of reproductive age, affecting multiple aspects of their well-being, including physical, psychological, emotional, social, and spiritual dimensions. Despite its widespread occurrence, the lived experiences of women with PCOS remain inadequately understood. The present qualitative study aimed to explore and interpret these lived experiences to enhance professional awareness, improve understanding, and promote better support for affected women. A phenomenological research design using Interpretative Phenomenological Analysis (IPA) was employed. Purposive sampling was used to recruit participants until data saturation was achieved. A total of 21 women aged 18–30 years with a diagnosis of PCOS participated in semi-structured interviews guided by open-ended questions. Interviews were audio-recorded, transcribed verbatim, and coded. The data were analyzed to identify significant statements, which were organized into thematic clusters and overarching themes. The analysis revealed four major themes: physical; psychological and emotional; social; and spiritual experiences. Subthemes included weight concerns, hair and skin problems, menstrual irregularities, sleep disturbances, mood swings, anxiety about infertility, low self-esteem, social isolation, and feelings of divine punishment. The study highlights the profound impact of PCOS across various dimensions of women's lives and underscores the importance of holistic, empathetic, and individualized care. In conclusion, women with PCOS experience multifaceted challenges that affect their quality of life. These findings emphasize the need for greater professional recognition, targeted health education, and supportive interventions to enhance coping, understanding, and access to comprehensive care.*

**Keywords:** Polycystic ovary syndrome (PCOS), lived experiences, phenomenological study, interpretative phenomenological analysis (IPA), women's health

## INTRODUCTION

Polycystic ovary syndrome (PCOS) is a prevalent hormonal condition affecting women of reproductive age. It disrupts hormonal balance, often resulting in menstrual irregularities and the development of multiple abnormal cysts in enlarged ovaries. Worldwide, the prevalence of PCOS is estimated to be between 6 and 26%, whereas in India it ranges from 3.7 to 22.5%, depending on the population studied and the diagnostic criteria applied. The incidence of PCOS has been rising steadily each year, yet many women do not suspect PCOS even when experiencing symptoms. Additionally, there is nearly a 40% likelihood that a female child may develop PCOS if her mother has the condition. Qualitative research seeks to explore individual experiences and interpret concepts from

### \*Author for Correspondence

Pitti Meghasandhya  
E-mail: [meghasandhya.pitti@gmail.com](mailto:meghasandhya.pitti@gmail.com)

<sup>1</sup>Researcher, Department of Nursing, Rajiv Gandhi University of Health Sciences, Bangalore, Karnataka, India

<sup>2</sup>Guide, Department of Nursing, Rajiv Gandhi University of Health Sciences, Bangalore, Karnataka, India

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their personal perspectives, recognizing that these experiences often differ from person to person. With the rising incidence of PCOS, the researcher identified the need to gain in-depth insights into how the condition impacts women's lives [1–3].

## OBJECTIVES

- To explore and understand the lived experiences of women with polycystic ovary syndrome (PCOS).

## METHODOLOGY

- *Research approach:* Qualitative approach.
- *Research design:* Phenomenological research design.
- *Population:* Women with PCOS attending Gynecology OPD at a selected hospital, Bangalore.
- *Sampling technique:* A purposive sampling technique was used for this study.
- *Sample size:* In the present study, sample size comprised of 10 women with PCOS attending Gynecology OPD, Bangalore.
- The sample was altered based on the saturation of the data.
- *Setting:* The research setting was a tertiary care hospital at Gynecology OPDs of selected multi-specialty Bangalore.
- Permission was obtained from hospital authorities prior to the study.

## Sampling Criteria

### *Inclusion Criteria*

- Women who are diagnosed with PCOS.
- Women who are between 18 and 30 year age group.
- Women who are attending gynecology OPD.
- Women who are present during the data collection period.

### *Exclusion Criteria*

- Women who are not willing to participate in the study.
- Women who cannot speak or understand the languages English, Hindi, Telugu, Tamil, and Kannada.

## Description of the Tool

The instrument used in this study was based on the objectives.

- *Section A:* It consisted of structured items designated to collect the background information of participants related to age, religion, educational level, occupation, marital status, area of living, and duration of PCOS symptoms.
- *Section B:* An open-ended semi structured interview questionnaire was used to identify the experiences of women with PCOS.

## Data Collection Procedure

- Formal permission was obtained from medical superintendent.
- Ethical clearance was obtained before data collection.
- Written informed consent was obtained from the women and baseline data was collected using structured questionnaire.
- The subjects were selected according to inclusion criteria through purposive sampling technique.
- A semi-structured interview process was utilized using open-ended questionnaire to assess the experiences of women with polycystic ovary syndrome questions, which kept the interviewee focused, yet still allowed clarification of feelings and probing of issues raised.

## RESULTS

The data was analyzed and presented under the following headings:

- *Section-A:* Socio demographic variables of the participants.
- *Section-B:* Lived experiences of the women with PCOS.

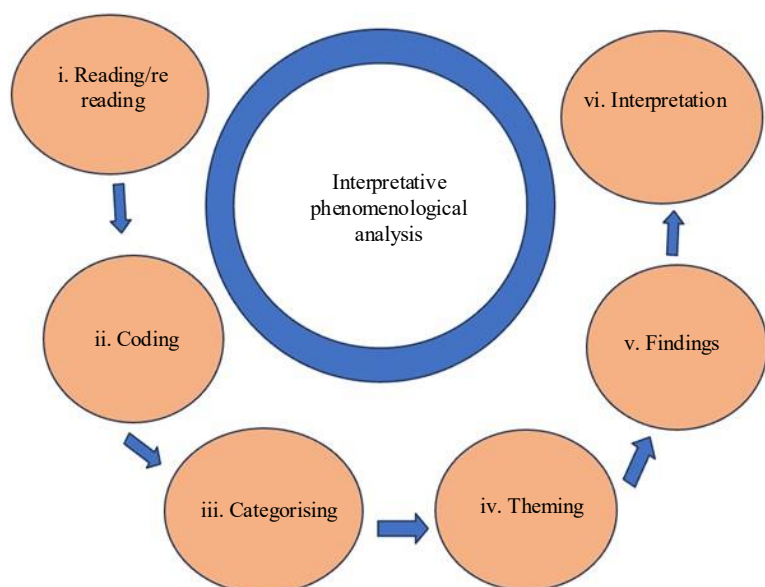
**Table 1.** Frequency and percentage distribution of sample characteristics (n=21).

S.N.	Variable	Category	Participants	
			Frequency	Percentage (%)
1	Age	18–20 years	2	9.5%
		21–25 years	7	33%
		26–30 years	12	57%
2	Religion	Hindu	17	80.9%
		Christian	3	14.2%
		Muslim	1	4.81%
3	Educational level	Higher Secondary Education	4	19%
		Under Graduation	14	66.6%
		Post Graduation & above	3	14.2%
4	Occupation	Private Employee	8	38.2%
		Government Employee	2	9.5%
		Self-Employed	3	14.3%
		Others	8	38.1%
5	Marital Status	Married	9	42.9%
		Unmarried	12	57.1%
6	Area of Living	Urban	14	66.6%
		Rural	7	33.3%
7	Duration of PCOS Symptoms	2 years	9	42.8%
		3–5 years	8	38.1%
		More than 5 years	4	19%

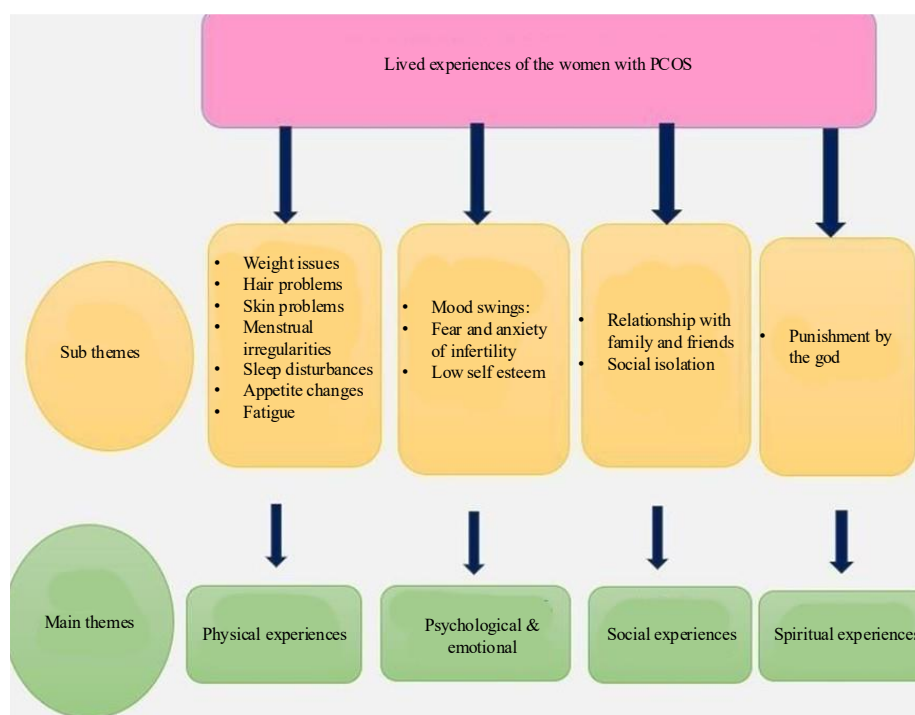
The frequency and percentage distribution of the socio-demographic variables of the study participants revealed the following (Table 1):

- *Age:* 9.5% of participants were in the age group of 18–20 years, 33% were between 21 and 25 years, and the majority (57%) were in the 26–30 years age group.
- *Religion:* A majority (80.9%) of participants were Hindus, 14.2% were Christians, and 4.8% were Muslims.
- *Education:* 19% of the participants had completed higher secondary education, 66.6% were undergraduates, and 14.2% had completed post-graduation or higher.
- *Occupation:* 38.1% were private employees, 9.5% were government employees, 14.3% were self-employed, and another 38.1% fell under the "other" category.
- *Marital Status:* 57.1% of the participants were unmarried, while 42.9% were married.
- *Area of Living:* A majority (66.6%) resided in urban areas, whereas 33.3% lived in rural areas.
- *Duration of PCOS Symptoms:* 42.8% of participants had experienced PCOS symptoms for the past 2 years, 38.1% for 3–5 years, and 19% for more than 5 years.

As per the Interpretative phenomenological analysis, each transcript was reviewed, and the data was reduced to codes (Figure 1). Differences in coding were resolved via discussions. Codes that were found to be conceptually similar in nature or related in meaning were grouped in to 12 subcategories, and based on these, main themes were developed. The themes were reviewed by the research experts and naming was derived and the report was produced as shown in Figure 2.



**Figure 1.** Interpretative phenomenological analysis.



**Figure 2.** Codes of verbatim and development of themes.

- *Physical experiences* (Sub themes: weight issues, hair problems, skin problems, menstrual irregularities, sleep disturbances, appetite changes and fatigue).
- *Psychological and emotional experiences* (sub themes: Mood swings, fear and anxiety of infertility, low self-esteem).
- *Social experiences* (sub themes: relationship with family and friends, and social isolation).
- *Spiritual experiences* (sub theme: punishment by the God).

The analysis of the lived experiences of women with polycystic ovary syndrome (PCOS) revealed a wide range of physical, psychological, emotional, and spiritual challenges. A significant number of participants reported weight issues such as rapid or excessive weight gain, which appeared as a common

concern across almost all cases. Many also described menstrual irregularities, including delayed periods, excessive or minimal bleeding, and associated pain or cramps. Other frequently mentioned physical symptoms included skin problems like pigmentation and acne, hair problems (e.g., facial hair or hair loss), sleep disturbances, fatigue, and changes in appetite [4–7].

**Table 2.** Distribution of primary codes, sub-themes, and main themes based on the lived experiences of women with PCOS.

S.N.	Sample	Primary codes (verbatim)	Sub themes (code category)	Main theme
1	PCOS1	Gained lot of weight	Weight Issues	Physical experiences
		Irregular menstruation	Menstrual irregularities	
		Get tired and exhausted	Fatigue	
		Mood swings	Mood swings	Psychological and Emotional Experiences
		Scared that I might not get pregnant	Fear and Anxiety of Infertility	
		Pressure from in laws	Relationship with family	
		I don't feel like something related to God		Spiritual experiences
2	PCOS2	Getting fat	Weight Issues	Physical experiences
		Irregular menstruation	Menstrual irregularities	
		Pain during menstruation, cramps		
		Mood wings	Mood swings	Psychological and Emotional Experiences
		Frustrated		
		Don't feel like something interlinked to God		Spiritual experiences
3	PCOS3	Unable to lose my weight	Weight Issues	Physical experiences
		Facial pigmentation	Skin problems	
		Many acnes		
		Irregular periods	Menstrual irregularities	
		Spotting		
		Lots bleeding		
		Not able to sleep	Sleep disturbances	
		Not feeling hungry	Appetite changes	
		Mood swings	Mood swings	Psychological and Emotional Experiences
		Geeting depressed		
		Frustrated		
		Angry		
		Fear of Infertility	Fear and Anxiety of Infertility	
Low self confidence	Low self Esteem			
4	PCOS4	Hair loss	Hair problems	Physical experiences
		Pigmentation on face	Skin problems	
		Menstrual problems	Menstrual irregularities	
		Problem for getting pregnant	Fear and Anxiety of Infertility	Psychological and Emotional Experiences
		Sad because of relatives talks	Relationship with family and friends	Spiritual experiences

		Very low feeling	Social isolation	
		Punishment of God	Punishment by God	
5	PCOS5	Rapid weight gain	Weight Issues	Physical experiences
		Facial hair	Hair problems	
		Facial pigmentation	Skin problems	
		More pimples		
		Irregular periods		Psychological and Emotional Experiences
		Heavy bleeding	Menstrual irregularities	
		Sadness	Mood swings	
		Feeling why God is giving me all	Punishment by God	Spiritual experiences
6	PCOS6	Extra facial hair growth	Skin problems	Physical experiences
		Irregular menstruation	Menstrual irregularities	
		Pain during menstruation, cramps		
		Sleeplessness	Sleep disturbances	
		Loss of appetite	Appetite changes	Psychological and Emotional Experiences
		Mood swings	Mood swings	
		Fear of infertile	Fear and Anxiety of Infertility	
		Relationship problems with family and friends getting disturbed some times	Relationship with family and friends	
7	PCOS7	I am 64 kg	Weight Issues	Physical experiences
		I have extra facial hair growth	Hair problems	
		More acne	Skin problems	
		Irregular periods		
		Minimal bleeding	Menstrual irregularities	
		Pain and cramps		
		I cannot sleep	Sleep disturbances	
		I cannot eat proper food	Appetite changes	
		Very tired	Fatigue	
Effectuated emotionally	Social isolation	Psychological and Emotional Experiences		
8	PCOS8	Weight gain	Weight Issues	Physical experiences
		Irregular periods	Menstrual irregularities	
		More bleeding		
		Weight gain	Weight Issues	Physical experiences
		Irregular periods	Menstrual irregularities	
		More bleeding		
		Frustration	Mood swings	Psychological and Emotional Experiences
		Irritation		
		God gave all this disease to me only	Punishment by god	Spiritual experiences
9	PCOS9	Weight gain lot of fat	Weight Issues	Physical experiences
		Irregular periods	Menstrual irregularities	

		Back pain		Psychological and Emotional Experiences
		Very emotional	Mood swings	
		Negative thoughts	Fear and Anxiety of Infertility	
10	PCOS10	Pain and cramps	Menstrual irregularities	Physical experiences
		Abnormal bleeding		
		Feeling of punishment	Punishment by God	Spiritual experiences
11	PCOS11	Weight gain, difficulty to lose weight	Weight Issues	Physical experiences
		Bleeding not getting stopped	Menstrual irregularities	
		Back pain		
		Feel angry	Appetite changes	
		Mood swings	Mood swings	Psychological and Emotional Experiences
		Like it is punishment	Punishment by God	Spiritual experiences
12	PCOS12	Irregular periods	Menstrual irregularities	Physical Experiences
		Heavy flow		
		Pain in abdomen		
		Very tired and fatigue	Fatigue	
		Terrible mood swings	Mood swings	Psychological and Emotional Experiences
		Depression	Mood swings	
		Overeating to for the things		
		I feel not to socialize	Social isolation	
I just feel my self				
13	PCOS13	Obesity is there	Weight Issues	Physical experiences
		Weight does not get reduced		
		Lot of facial hair	Hair problems	
		Lots of hair growth		
		Pigmentation	Skin problems	
		Skin discoloration		
Period irregular	Menstrual irregularities			
14	PCOS14	Rapid weight gain	Weight Issues	
		Irregular periods	Menstrual irregularities	
		Spotting		
		More hungry	Appetite changes	
15	PCOS15	More hair fall		Physical experiences
		Damaged hair	Hair problems	
		Lot of skin problems		
		Pimples are more	Skin problems	
		Pigmentation		
		Irregular period	Menstrual irregularities	Psychological and Emotional Experiences
		It will be late 50–60 days when I will get period		
		Mood swings	Mood swings	
Why God has given all this to me	Punishment by God	Spiritual experiences		
16	PCOS16			

		More facial hair growth	Hair problems	Physical experiences
		Irregular periods	Menstrual irregularities	
		Stomach pain, leg pain		
		Excessive sleeping	Sleep disturbances	
		I feel punishment	Punishment by God	
17	PCOS17	Very irregular	Menstrual irregularities	Physical experiences
		Less bleeding		
		Back pain cramps during periods		
		Mood swings	Mood swings	Psychological and Emotional Experiences
		God is punishing me	Punishment by God	Spiritual experiences
18	PCOS18	Irregular periods	Menstrual irregularities	Physical experiences
		More bleeding		
		Pain and cramps		
		Mood swings	Mood swings	Psychological and Emotional Experiences
		Low self esteem	Mood swings	
		I didn't get kids that makes me sad	Low self Esteem	
19	PCOS19	Much weight gain	Weight Issues	Physical experiences
		Pigmentation	Skin problems	
		Irregular periods	Menstrual irregularities	
		Excessive bleeding		
		I will get hungry after two hours like that	Appetite changes	
20	PCOS 20	Weight gain is problem	Weight Issues	
21	PCOS 21	Randomly gaining weight	Weight Issues	
		Facial hair growth	Hair Problems	
		Much pimple	Skin Problems	
		Irregular menstruation	Menstrual Irregularities	
		Severe body pain	Menstrual Irregularities	
		Not getting sleep	Sleep Disturbances	
		Feeling tired	Fatigue	
		Mood swings during periods	Mood Swings	

On the emotional and psychological front, participants expressed issues such as mood swings, frustration, low self-esteem, and fear of infertility, often exacerbated by family pressure or social stigma. Additionally, several women perceived their condition as a form of spiritual punishment, attributing their suffering to divine will. These themes are clearly outlined in Table 2, which categorizes the primary verbatim codes into relevant sub-themes and overarching main themes based on participant narratives [8, 9].

## DISCUSSION

- The findings of the present study revealed that most of the women with Polycystic ovary syndrome had faced various challenges in every aspect of their life.
- Majority of women with PCOS had expressed that they had experienced physical, psychological, emotional and social issues.

- In addition, few women reported that PCOS is a punishment given by the God.
- The present study can increase the understanding of the problems faced by women and their view of experiences of this syndrome.
- In future, this study's findings will be helpful to understand how women experience with this syndrome and will help in better planning of care and support needed by them.
- It also enhances the health care team to plan the care as they need [10].

## **CONCLUSION**

This phenomenological study was designed to explore the lived experiences of women with polycystic ovary syndrome. The aim of the study was to explore the lived experiences of women with polycystic ovary syndrome. Data was collected through semi structured interviews using open ended questionnaire from 21 participants. The interviews were voice-recorded and the verbatim was transcribed for each participant. Through Interpretative Phenomenological analysis, the essential descriptions of the experiences faced by women due to polycystic ovary syndrome were analyzed. The coding had been done based on the data collected from each participant, from which 12 subthemes were identified; finally, four main themes were developed such as physical experiences, psychological and emotional experiences, social experiences and spiritual experiences, all of which are part of the existential changes involved in the women with PCOS. The sub themes identified from the main themes include the physical experiences, psychological and emotional experiences, social experiences and spiritual experiences.

## **Nursing Implications**

The implications drawn from this study is a vital concern for the nursing practice, education, administration and research.

- The study was aimed to explore the experiences of women living with polycystic ovary syndrome and better understanding.
- The experiences of women with PCOS in different aspects in their view which is related to physical, psychological and emotional, social and spiritual experiences will help to understand the problems faced by the women.

## ***Nursing Practice***

- The primary step in the health care system is to elicit participants' experiences in their view, aspects and problems which they are facing due to PCOS, to understand them in a better way and to facilitate the health care system to help them fulfil their needs.
- Nursing students need updated knowledge to better understand the lived experiences of women with PCOS problems, faced by the women with PCOS, and also to provide comprehensive care to them.
- Assessing the experiences of women with PCOS will help the nurses to elicit the real felt needs of the participants and it could give a way for better physical, psychological and emotional, social and spiritual aspects of care.
- Nursing counsellors and psychologists can also use the responses given by the participants to understand the psychosocial problem of the participants, which can enable them to understand the clients and support them accordingly.

## ***Nursing Education***

- Nursing is an evidence-based quality care with adequate theoretical based knowledge. The nursing educators can include the identification and exploration of women's experiences with PCOS while teaching nursing students.
- When findings were interpreted from the perspective of suffering, actions, values, and existential concerns, they can be more clearly understood.
- Nursing educators should encourage nursing students to read, discuss and conduct research studies about the lived experiences to enable them to make data-based decisions rather than

intuitive nursing decisions.

- This kind of phenomenological study can provide additional knowledge, which will provide guidelines in developing nursing theory to guide nursing practice.

### ***Nursing Administration***

- The nursing administrator can be an important advocate for nurses. They can provide an in-service education in hospital set up to update the knowledge about the concerns of women living with PCOS and to understand them in a better way.
- The administrators of nursing service can encourage their staff members to involve in in-patient counselling and enable them to explore their feelings.

### ***Nursing Research***

- This qualitative research provides knowledge for evidence-based nursing practice for nurses and nursing students.
- The findings of this study can form the basis of future research.

Future researchers can use this study as guideline for conducting such researches in same or other areas of nursing.

### **Recommendations**

On the basis of the study, that has been conducted, certain suggestions are given for the future studies.

- The study can be done in a different setting.
- Similar study can be done for longer periods to note the lived experiences of women with Polycystic ovary syndrome.
- A study can be done focusing on only one aspect such as only physical experiences or psychological or emotional experiences.

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