



Original Research Article

Lived experience of male spouses of poly cystic ovarian syndrome diagnosed females: An exploratory study

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ABSTRACT

Polycystic ovarian syndrome (PCOS) is a heterogeneous clinical entity leading to development of metabolic, endocrine, and reproductive disorder. Obesity lowers the chances of successful conception and even lowers the success rate of assisted reproduction technique cycles, and this is a major concern for young couples and females in their prime reproductive age.¹ But there are also studies also which shows reduces quality of life and sexual satisfaction and life satisfaction in females with PCOD. Hence, we should also consider the other partner in couples diagnosed with PCOD. Thus, when looking into the family dynamics of PCOD diagnosed females, psychological wellbeing of their husband should also be equally studied as their emotions are highly influenced by their wife's mental wellbeing. Even after biological treatment of PCOD, their psychological distress persists, and can may hinder their future quality of life. The objective of the study was to explore the experience of male spouse of clinically PCOS diagnosed females. The study was a phenomenological qualitative research design, with researcher-developed guiding questions to help direct interviews. The data was collected using purposive sampling from hospitals based on the inclusion criteria of the study. 6 participants were finally selected based on these criteria and saturation point was attained for the study by then. The findings of the study was 3 major themes were discovered, which were Awareness about PCOS, perception of husbands on PCOS and perception of women. 9 subthemes were also discovered under these themes. Implications of the study was more awareness should be given to both male and female population about the disorder and also encouraging men to talk more about their mental health.

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1. Introduction

Polycystic ovarian syndrome (PCOS) is a heterogeneous clinical entity leading to development of metabolic, endocrine, and reproductive disorder. This multifaceted clinical manifestation comprises of hyperandrogenism, menstrual dysfunction, infertility, and an increased prevalence of obesity and metabolic syndrome.¹

The underlying hormonal imbalance is created by a combination of increased insulin resistance, hyperandrogenemia and reversal of LH, FSH ratio.²

Women with PCOS have irregular periods, hirsutism, acne, fatigue and weight gain and are at a greater risk of moderate to severe psychological distress compared to women without PCOS.³

While considering couples, where the woman has PCOS, infertility, quality of life and sexual satisfaction are areas which affect their married life in one way or the other.

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Studies have shown that there is a 20% or higher chance of infertility being a contributory factor to divorces among couples around the globe.⁴ There are however other studies done which show that treatments taken for infertility such as IVF can help consolidate a relationship rather than leading to a break up.

There are numerous study which shows there is reduced life satisfaction and quality of life in female partners who have PCOD compared with non – PCOD patients.

A study conducted in China showed that women with PCOS suffer from depression, anxiety, and experience a lower quality of life, whereas their sexual function is not distinct from that of healthy women.

There are however very few studies done on the men in a relationship with a woman suffering from PCOS. There are a few self help blogs like “A Husband’s Advice on Coping with PCOS – and Moodiness” by Cliff Medling which addresses the importance of knowing ones wife’s medical condition and psychological wellbeing. Mark Sedeka, in his book “What He Can Expect When She’s Not Expecting: How to Support Your Wife, Save Your Marriage, and Conquer Infertility!”. He describes his emotional experience and distress he had to undergo along with his wife when undergoing infertility treatments.

Lived experience is defined by Given (2008) as representation and understanding of a research participants’ experiences, choices, options, and how these factors influence one’s perception of knowledge.

Despite extensive evidence of the importance of marriage and marital processes for mental health, little is known about the interpersonal processes around depression within marriage and the extent to which these processes are gendered. Recent research demonstrates that the psychological benefits of marriage depend on interpersonal processes within marriage.⁵

Studies have shown that a wife’s depressive symptoms influence her husband’s future depressive symptoms.⁵

As women with PCOS are at a higher risk of chronic anxiety, depression, mood swings, stress, in addition to menstrual irregularities, infertility, acne and hirsutism, they require not only medical management but psychological attention and help for their mental well being⁶. Thus, when looking into the family dynamics of PCOS diagnosed females, psychological wellbeing of their husband should also be equally studied as their emotions are highly influenced by their wife’s mental wellbeing.⁷

2. Aims and Objectives

2.1. Aim

To understand the lived experience of male spouse of PCOS diagnosed females

3. Materials and Methods

The study included 10 participants who fulfilled the inclusion and exclusion criteria but a saturation point was reached after 6 participants due to partial information obtained and a lack to follow up. The participants were informed about the study process and consent was obtained. They were subjected to an open ended semi structured interview with no time limit. The interview was recorded with an audio recorder with the permission of the participant for future usage. The interview was conducted in a language the participants were most comfortable with and was later converted to English. Themes were formulated and later analysed through Interpretive Phenomenological analysis.

3.1. Inclusion criteria for participants

1. Wife should be clinically diagnosed with PCOS.
2. Husband should be married for more than 6 months and should be living
3. Together.
4. Wife should have taken treatment for PCOS anytime during their
5. Reproductive life.
6. May or may not have children

3.2. Exclusion criteria for husbands

1. Wife should not have undergone hysterectomy
2. Wife should not have reached menopause
3. Husband should not be a health care practitioner

4. Results

6 husbands of wives diagnosed with PCOS who met the inclusion criteria were included in the study (due to saturation point).

4.1. Age

Age of the men included in the study ranged from 28 to 41 years.

Age of women included in the study ranged from 24-39 years

4.2. Educational status of men in the study

3 out of the 6 men (55%) included in the study had finished their under graduation, 2 had completed their post graduation (33%) and one had completed 12th std education

4.3. Educational status of women in the study

4 women included in the study had completed their under graduation, one of whom had completed her MBBS degree, 1 had completed post graduation (non medical field), 1 had passed 10th std. Occupation of the husbands 3 had their own businesses

- 1. Was a photographer
- 2. Was a professor
- 3. Was unemployed

4.4. Occupation of the women in the study

- 1. Were home makers
- 2. Was a doctor
- 3. Professor
- 4. I worked as engineers
- 5. Was a nurse

5 out of the 6 couples included in the study lived in an urban area and 1 lived in a rural area 3 couples had children, 1 was pregnant and 2 had no children. They all lived in a nuclear family and their married lives ranged from 3-13 years

4.5. The interview

The semi-structured interview was divided into 4 main sections to gather information from the husbands easily.

The questions included details about demographic details of the husband, knowledge about menstrual health of wife, fertility and PCOS and sexual health and emotions. Personal experience of the husband was elicited from the husband in line with these areas.

The semi-structured interview was divided into 4 main sections to gather information from the husbands easily.

10 interviews were collected and out of that 6 interviews were taken as saturation point reached and deletion of others had to be done due to missing data and lack of information. 40 codes were generated from the six interviews and subsequently nine subthemes were generated from it. Ultimately it got clubbed into three major themes which were Awareness about PCOS, Perception of husband on PCOS and Perception on women

4.6. Themes the men were questioned on included

- 1. Awareness and knowledge of pcos
- 2. Symptoms identified
- 3. Mode of treatment
- 4. Source of information
- 5. Coping with the condition
- 6. Effect of PCOS on marital status
- 7. Other stressors
- 8. Sensitivity to the wives needs
- 9. Importance of children in the marriage

4.7. Theme 1: awareness about PCOS

Only 4% of the women and 2.1% of the men said that they knew everything about PCOS. Overall, women with a diagnosis of PCOS reported that they had better knowledge than those who did not have PCOS.

4.8. Four sub themes were identified under this theme. They were,

- 1. Knowledge about PCOS
- 2. Symptoms identified
- 3. Source of information
- 4. Mode of treatment
- 5. 25 Codes were identified under this theme; hence it was very prominent

4.9. All 6 participants said they became aware about pcos after marriage

However the educated participants who had more complications and reported symptoms were more curious about their wife’s condition than the other participants.

4.10. Subtheme: Symptoms identified

There was a common set of symptoms the husband was able to identify yet were not specific as they were not sure what were the symptoms of PCOS. The common and recurrent symptom identified were irregular periods.

Table 1: Symptoms reported by husbands

Symptoms identified	Number of participants reported (of 6)
Body pain prior and during menses	4
acne	4
Irregular periods	5
Weigh gain	3
Facial hair	2
Mood swings	6
Conceiving difficulty	3

Again, when asked whether the above symptoms were that of PCOS they were not aware of the same and they all said that PCOS was a disorder which could be corrected with lifestyle modification and medications if lifestyle changes did not correct the same.

It can be seen throughout the interviews that the husbands were unable to identify specific symptoms and differentiate their wife’s mood during her menses and when she is not in her menses. Three husbands made sure they asked more questions to the researcher to get a better understanding on PCOS and was curious as to why such studies need to be conducted and studied (50%).

4.11. Subtheme: source of information

80 percent of the husbands were aware of PCOS through their wives after marriage, 2 of these couples, had a conversation about PCOS before marriage, these husbands became more aware of the symptoms post marriage. 10% of the men knew about PCOS through the internet and 10% from their wives or their wives gynecologist.

4.12. Subtheme: mode of treatment

Although the men included in the study were aware of certain symptoms the women were facing, when asked about the mode of treatment for PCOS, 75% percent of them said it could be cured with lifestyle changes. 10 % were aware of hormone medications available for treatment of irregular cycles. 15% didn't think it affected their lifestyle to an extent that required treatment. 66% of the couples did not link PCOS to infertility as they had children 2 couples included in the study had difficulty to conceive which was attributed to the wife's diagnosis of PCOS on further investigations.

4.13. Theme 2: perception of husband on PCOS

The subthemes that emerged under this theme were:

1. Coping with the condition
2. Effect of PCOS on marital relationship
3. Other stressors

4.14. Coping with the condition

When asked about coping with PCOS, 90 percent of the couples did not find PCOS a condition that they needed to cope with. 5% of the men said that apart from the mood swings they did not find PCOS affecting their lives. The 2 couples who had not conceived yet were hopeful about the treatment and the probability of conception with the right care

4.15. Effect of PCOS on marital relationship

5 husbands said that PCOS had no effect on their family lives 1 husband said that the delay in having a child, due to the treatments his wife had to undergo for PCOS, put a strain on the relationship for a few years None of the husbands addressed if PCOS affected the quality of their sexual life.

4 of the 6-participants(66%) reported that they had other stressors like work pressure, financial issues that bothered them. Since they didn't know much about PCOS they said it really hadn't bothered them on a day-to-day basis but they were more in check with their moods and behaviour when their wives were moody. Since the other two participants were going through difficulties in conceiving their major stress or worry was attributed to the condition (PCOS) itself.

4.16. Theme 3: Perception of women

The two subthemes that come under this theme are

1. Sensitivity to wife's need and
2. Importance of child in marriage

4.17. Subtheme: sensitivity to wife's need

One important thing that was observed under this subtheme was the lack of awareness that was given to the male population when they were young about menstruation and the female body. All 3 men mentioned that they did not know much about menstrual cycles and learnt more about it after getting married and having girl children.

3 Men said they had an idea about menstrual cycles through the internet and TV When asked if more men should be given awareness about PCOS, 4 out of 6 husbands said maybe (66%) and the rest said a definitive yes as they could have been more cautious during family planning and availed treatment early.

4.18. Subthemes: importance of children

Another difference that was observed in the husbands were their attitude towards PCOS also depended on whether they had children or not. Couple who are struggling /struggled to conceive were more curious and far more aware about PCOS than couples who did not have troubles conceiving.(45%) Another thing that was observed was the social and family pressure faced to conceive. Most husbands said it is more faced by the wife than them. (80%) Nevertheless, we could also see that though the husbands had lack of awareness they were all accepting in their own way about their family and their wife's condition.

5. Discussion

Polycystic ovarian syndrome (PCOS) is a heterogeneous clinical entity leading to development of metabolic, endocrine, and reproductive disorder. This multifaceted clinical manifestation comprises of hyperandrogenism, menstrual dysfunction, infertility, pregnancy complications and an increased prevalence of obesity and abdominal obesity.¹

The pathogenesis of PCOS is complicated and have not been fully understood. The underlying hormonal imbalance is created by a combination of increased androgens and/or insulin. Genetic and environmental contributors to hormonal disturbances with other factors including obesity, ovarian dysfunction and hypothalamic pituitary abnormalities are contribute to the aetiology of PCOS.²

Systemic dysfunctions and hormonal imbalances are hallmarks of the complicated disease known as polycystic ovarian syndrome (PCOS), which can cause a wide range of morbidities. The prevalence is higher than usual, particularly in tropical nations, and the primary reason for this is a lack of knowledge about the nature of the illness.⁸

In a study conducted by Rau et al in Cross-sectional Study on the Knowledge and Prevalence of PCOS at a Multi-ethnic University in 2020 reported that approximately, 66.3% of women and 83.0% of men ranked their knowledge of PCOS as a 3 ("Know some") or less,

with 42.6% of men and 21.7% of women indicating that they know nothing.

From studies conducted it was seen that the educated participants were more aware of their wives symptoms and were more curious about their wife's condition than the other participants.^{9,10}

5.1. These findings were corroborated by our study

Studies done by Alotaibi M et al, Eftekhari T et al and Galan, RN Nicole et al have shown that women who have PCOS have reduced quality of life and reduce quality of sexual life. But the husband was not open these two domains in the interview.^{11–13}

5.2. Similar findings were seen in our study

Alotaibi M, et al and Mason L et al have shown in their studies that men and women found the Internet to be the best resource for learning more about the PCOS.¹¹ In our study 30% of the couples knew about PCOS through their doctors and the rest through the internet.

In a study conducted by Linda et al in a qualitative study exploring boys perceptions of Menstruation, it was seen that boys had limited knowledge about menstrual cycles as they poorly understood the biological function of women and it was also seen that culture and customs in India also played an important role in the same. Our study showed similar findings.

While a lack of communication can share a role in contributing to negative effects of being a married doctoral student, good communication between spouses can be an effective coping strategy (Hyun, 2009; Murray & Kleist, 2011). There is a high degree of association between good communication and marital satisfaction (Perlow & Mullins, 1976), and good communication may be the biggest predictor of marital adjustment. This is because as communication improves, couples' roles within the relationship sync up with the role expectations they have for each other.^{14,15}

75% of the couples in our study stated that they were able to communicate effectively with each other while 25% of them said it was difficult to do the same due to their wives mood swings in addition to stress related to infertility, financial struggles, work stress.

In India, there hasn't been many studies done on how infertility affects marital and sexual functioning, health-related quality of life (QoL), and the acceptance of various treatment options. With an estimated median global incidence of 9%,¹⁶ a 47 reported prevalence of 15% in Indian couples, and an estimated 56% of these couples seeking medical attention, infertility accounts for a sizeable portion of the burden on healthcare resources and expenses. Out of these PCOS can also be a major reason contributing towards infertility problems in females.

Also, among divorcees in India, infertility is a major reason. But we can see that among the participants its more of acceptance of the condition and living forward can be seen.^{17–19}

2 couples in our study experienced infertility due to PCOS and was receiving treatment for the same.

5.3. Implications of the study

The findings of our study are useful across research and practice.

1. These findings indicate the importance of thinking systemically when developing interventions for women with PCOS.
2. A research gap was filled especially in the Indian research context on the lived Experiences of spouses on PCOS
3. The findings of the study can be incorporated in modules or health care programmes designed for husbands.
4. The research findings can draw attention to the need for health care services to be extended to partners who may themselves benefit from support. This can be through preparing special psychoeducational model where both psychological and physiological aspects of both the couples are discussed before and/or after marriage.
5. The research findings can be used in awareness programmes /campaign's focusing on the male spouse. Also to develop health education modules irrespective of gender should focus on health problem of both male and female from lower school levels so as to remove the stigma surrounding women's menstrual health.

5.4. Implications for future study

1. Practitioners need to have some awareness not only of the grief process but also of obstacles to move through this process of adjustment.
2. To support couples during difficult experiences with infertility and other stressful situations, future research should work toward a comprehensive understanding of men's response to such conditions and, their role as care takers and the impact of that role on their partners well-being.
3. This research can be used to highlight the importance of partners mental health along with their wife. Also, for the development of new types of holistic interventions which includes both. insights from these surviving couples can provide direction for intervention planning for relationships that are struggling under the unexpected burden of PCOS.
4. Research could be done with more participants discovering more depths into the lives of both couples related to PCOS rather than sticking to one.

6. Limitations of the Study

The limitations of the study are as follows.

1. interviews were conducted via the telephone and there was a difficulty in reaching out to them due the pandemic and the locations, they were in.
2. A large amount of codes were not possible to generate as saturation point was attained fast and due to the lack of awareness of the participants about PCOS The participants were defensive or less vocal when talking about certain aspects of their life.
3. The unwillingness of the husband to open about certain topics like quality of sexual life, more on the problems faced during their difficulty to have children have impacted the study and thus generating codes and reaching saturation point soon.
4. From the researcher's side certain precautionary factors were taken to reduce the effect of limitations in the study.

7. Conclusion

With high depth and detail in data collecting, qualitative methods foster a lot of knowledge about a small group of people (Patton, 2015).²⁰ The profundity of the emerging data from the current study, in the opinion of the researcher, accurately reflects the participants' lived experiences. We were able to elicit 3 major themes and 9 subthemes under it. From each theme we were able to capture the lived experience of husbands on their experience and knowledge about living with a female spouse who is diagnosed with PCOS. The objective of the study was carefully met and yet some areas were not met in depth due to the inhibition in husbands to open more on their quality of life and the effect of PCOS on the intimacy in their marital relationship. From the study we saw the lack of awareness in the male population or husband's about PCOS and menstrual health. The effect of the husbands mood by the fluctuations of mood in their spouse and the importance of acceptance and living together in spite of any setbacks in marital life. Gottman (1999) suggested that the quality of the marital friendship plays a significant factor on how couples address issues in their relationships, such as managing conflict through influence and compromise. From this study we can imply that more awareness should be spread within the community about PCOS and about the general health of the woman and the roles of women within the family. It has also shed light on the importance of the mental health of men in the relationship and the importance of addressing the same.

7.1. Major findings of the study are:

1. Lack of awareness among men about PCOS
2. Delayed treatment / follow up and identification of PCOS in females even

3. though they have taken treatment before marriage.
4. How the effect on perception of women and children by the husband in marital
5. Family and the role of PCOS in conceiving.

8. Summary

The aim of the study was to explore the lived experience of husbands of clinically diagnosed females with polycystic ovarian syndrome. For the study the researcher selected 10 participants by purposive sampling based on inclusion / exclusion criteria. The researcher stopped with 6 participants as saturation point of the study reached. The participants were interviewed in depth using semi-structured open ended interview. The interview was then carefully recorded using a recorder and then it was carefully transcribed and analysed using Interpretive Phenomenological Analysis. After analysing the interviews, 3 major themes were elicited from it along with 9 subthemes under it. The major three themes were 1. Awareness about PCOS, 2. Perception of Husband on PCOS 3. Perception on women. The subthemes identified were Knowledge about PCOS, Symptoms identified, Mode of treatment, Source of information, Coping with the condition, Effect on PCOS on marital relationship, other stressors, and Sensitivity to wife's need. The major findings that was very evident throughout the study is lack of knowledge about polycystic ovarian syndrome and lack of menstrual health awareness in husband. Lack of communication about PCOS and lack of communication of husband's personal emotional stress towards wife. The implications of the study were to create psychoeducational model to increase awareness about polycystic ovarian syndrome equally in both couples when visiting their gynaecologist, but also in lower levels of education to normalise speaking about menstrual health and mental health irrespective of gender identity.

9. Source of Funding

None.

10. Conflict of Interest

None.

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