

# Infertility and Social Issue Have the Most Significant Impact on Health-related Quality of Life among Polycystic Ovarian Syndrome Women in South India

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ABSTRACT

**Background:** Infertility can have a significant impact on the identity of women. Individual women, who are infertile, experience tragic emotions, as well as those who are sad for great losses, like the death of a loved one. In this case, the woman is experiencing the loss of the ability to procreate. **Aim:** In the present study, our major concern was to implement the health-related quality of life (HRQOL) Questionnaire on South Indian polycystic ovarian syndrome (PCOS) women to assess the impact of various clinical features of polycystic ovary syndrome on the HRQOL of South Indian women diagnosed. **Settings and Design:** A total of 126 females in the first phase and 356 females in the second phase between the age group of 18–40 years characterised under the Rotterdam criteria were selected for the study. **Materials and Methods:** The study was carried out in three different phases which included a one-to-one interview, group discussion and questionnaire session. In our study, we found that all the females who attend the study showed positivity for all the domains developed in the previous study and suggested that further domain can be developed. **Statistical Analysis Used:** Suitable statistical methods were used with Graph pad PRISM (version 6). **Results:** Hence, in our study, we developed a further new sixth domain called as ‘social impact domain’. Among South Indian PCOS women, we found that infertility and social issue have the most significant impact on HRQOL. **Conclusion:** The revised questionnaire by including the sixth domain called ‘Social issue’ is likely to be useful in measuring the quality of health of female having PCOS in regard to South Indian population.

**KEYWORDS:** Female health, health-related quality of life, polycystic ovarian syndrome, Rotterdam criteria, South Indian

## INTRODUCTION

Polycystic ovarian syndrome (PCOS) is an endocrine dysfunction, which is characterised by the imbalance of several hormones and reflects the clinical appearance dominated by the symptoms of hyper androgenism.<sup>[1]</sup> In addition, it is a complex genetic state, a common syndrome of the clinical and/or biochemical surplus of androgens, the dysfunction of ovulation and polycystic ovary.<sup>[2]</sup> Stein and Leventhal first described the characteristics of the PCOS.<sup>[3]</sup> Universally it affects

6%–10% of women, according to NIH classification in 1990, and more people according to the broader standards of Rotterdam criteria.<sup>[4,5]</sup> Infertility is one of the most disturbing features of this condition.<sup>[6-8]</sup> The exact cause of PCOS is still unknown, but is probably

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caused by the interface of genetic and environmental factors.<sup>[7,8]</sup> Women with PCOS can show many metabolic and cardiovascular abnormalities, depression, anxiety, disturbances of sexual functions.<sup>[9-11]</sup> Hirsutism and acne are important PCOS symptoms, can be the result of excess androgens or increased sensitivity to androgen receptors, despite normal levels of androgens.<sup>[12]</sup> These symptoms can affect psychological and social aspects of patients. Presented among adolescents, this could lead to tension and sadness due to the perception of the body image.<sup>[13,14]</sup>

PCOS has a serious impact on quality-related life and increases the threats of depression and anxiety.<sup>[15,16]</sup> The new consensus reports that PCOS's health aspects of women take into account the psychological problems of all women in PCOS and emphasise the requirements for the growth of the appropriate intervention.<sup>[7]</sup> The PCOS Quality of Life questionnaire was first developed by Cronin *et al.* and contains 26 elements that calculate five domains that are emotional, hirsutism, weight difficulty, infertility and menstrual difficulties.<sup>[17]</sup> Health-related quality of life (HRQOL) is a multidimensional idea used to explain the physical, emotional and social performance of patients with a specific disease or specific dysfunction.<sup>[18]</sup> PCOS and the quality of life (QoL) consists analysing these syndromes in a critical way.<sup>[19]</sup> Studies show that the impact of physical health and emotional effects of the PCOS are neglected.<sup>[20]</sup>

PCOS may set off infertility by causing distress, sadness, anxiety, sexual troubles, marital and social maladjustment, loss of control and lower self-respect.<sup>[21]</sup> In the current study of HRQOL for PCOS patients in South Indian cohort our foremost concern was whether the questionnaire developed to test out the HRQOL Questionnaire (PCOSQ) for Women with PCOS can be implemented for PCOS patients in South Indian cohort and if so then which domain is more important and which one is the least. The further aim was to see if any domain that can be added to already existing domains.<sup>[17]</sup>

## MATERIALS AND METHODS

Women between the age group of 18 and 40 years characterised as PCOS under the Rotterdam criteria were selected for the study. Patients underwent various preliminary tests for confirmation of PCOS. The presence of polycystic ovarian morphology was confirmed using a transvaginal ultrasound scan. The evaluation of hirsutism was done based on Ferriman–Gallwey score and a woman was considered hirsute with a score >8. The study was approved by the Institutional Human Ethical Committee with EC No (IECH/2013/Dec 18-008) and all potentially eligible PCOS patients

consulting the doctors at the institution were included in the study after informed written consent was obtained. The study design was well informed to all the participants in advance including one to one nature of the interviews. The study adheres to the principles of the Helsinki Declaration (2013).

The study was carried out for 6 months from April 2022 in the following three phases.

### Phase 1

In this phase, we searched the search engines using these words such as 'quality health questioners', PCOS and infertility based on which the study questionnaire was developed based on five domains in PCOS patients.

### Phase 2

In this phase, we made the planning to check whether we can implement this health-related questionnaire for PCOS patients in South Indian cohort and also to know whether any further domains can be formed. During this stage, 126 women with PCOS participated to validate the questionnaire and the evaluation was conducted in the presence of a senior gynaecologist. During the discussion with all 126 participants, they showed positive responses to all the questions and they also talked about social issues due to this problem of PCOS which has a major impact on their health.

### Phase 3

Based on the discussion, we decided to use the questions based on the five domains for our study and also to include another domain called 'social impact'. During this phase, 365 women with PCOS participated and answered the questionnaire. For each question, the PCOS women rated its importance on a 5-point scale (1 count for not significant then up to 5 it is extremely significant).

## RESULTS

The demographic results show that among all age groups, 57.45% of PCOS patients come under the age group of 21–25, followed by 21.28% of PCOS patients are in the age group of 26–30, 10.64% in 31–35 age group and also in 10–15 age group. Marital status among PCOS patients shows that 87.24% are married and 12.77% are unmarried. The highest education level 70.21% had qualification up to school level, 21.28% up to college level, 4.26% had diploma and finally, 2.13% of PCOS patients are still in school and college. Among all the PCOS patients 76.60% of patients had a duration of PCOS in the range of 01–40 months, 14.89% in the range of 41–80 months and the least were 8.51% in the range of 8.51%. Demographic results also showed that most of PCOS patients are housewife (80.85%),

followed by 12.77% of students and only 6.38% are working. After evaluating the questionnaires, we found that between all the domains, PCOS women have given more importance to infertility, emotion and social impact domains [Figure 1]. In the emotion domain, we found that more than 90% of women felt the following impact on their health (depressed, worried, scared about the future, get depressed easily, tense, anxiety tearful) [Figure 2]. In the body hair domain, our study found that most women did not feel that this had a major effect on their health [Figure 3]. In the weight domain we found that <25% of women felt that the items have a major impact on their health [Figure 4] and in the case of infertility domain, we found that all the items have a major impact on their health such as frustration as others do not understand their condition (92.00%), felt lack of control over the situation (86.60%), worry that they do not have menstruation (86.80%), felt afraid of not being able to have children (84.50%) and fear of not having children (93%) [Figure 5]. In the last domain of social impact, our study found that the following items have major impact on their health such as no eye contact from relatives and friends (95.10%), pressure by husband’s family for baby (92.00%), misunderstanding between couples (91.30%), girl’s parents being under

pressure (87.40%), negative comments from neighbours (85.00%), domestic violence, isolation during any social events (83.40%) and fear of getting divorced (83.00%) [Figure 6].

### DISCUSSION

Our study found that all women who answered questionnaires have shown positive concern for the Cronin *et al.* questionnaires and during group discussion we observed that social issue may also be considered as another domain to the existing domain. Among the entire domain, PCOS patients in our study have given more importance to infertility, menstrual problem, emotion domain and at the same time they have also given more importance to the social issue domain. The study also reveals that PCOS patients in South Indian cohort have given least score for body weight and hair domain which is a sign of least importance. South Indian population selected for the study was observed to be under severe stress due to infertility. Most of the women selected in the study belong to the middle socioeconomic class. Working women were under family stress and work pressure. Parents of unmarried girls are worried about

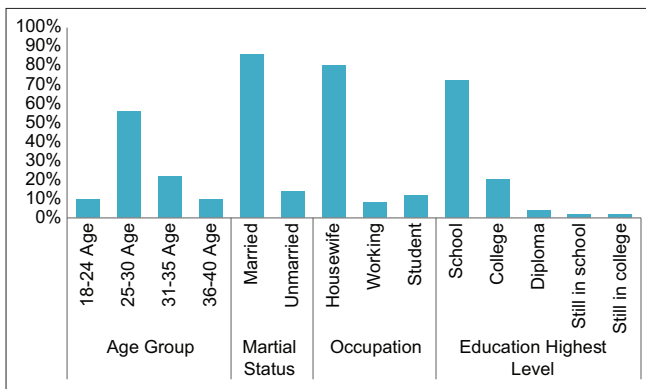


Figure 1: Demographic details of patients

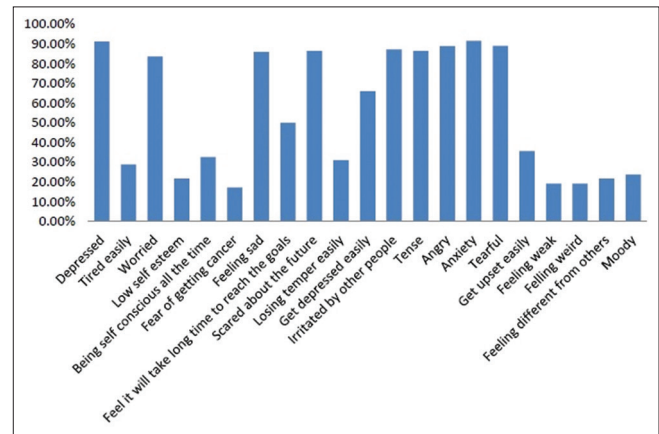


Figure 2: Graph showing the impact of various items of emotion domain on PCOS women’s health. PCOS = Polycystic ovarian syndrome

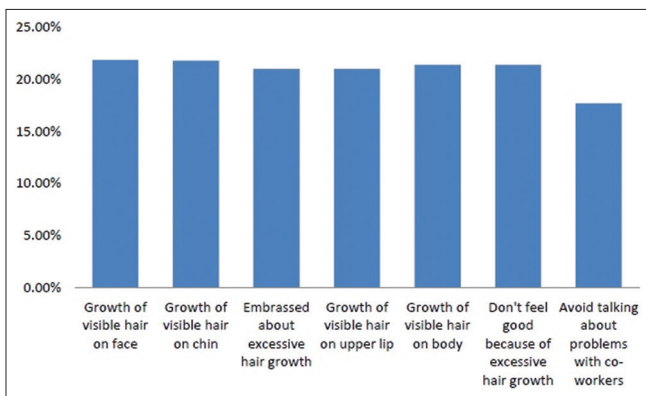


Figure 3: Graph showing the impact of various items of body hair domain on PCOS women’s health. PCOS = Polycystic ovarian syndrome

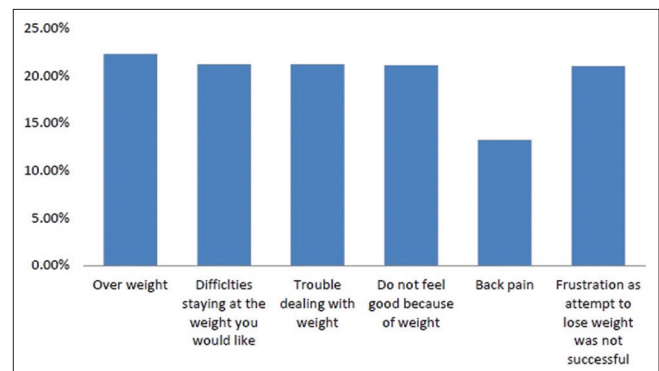
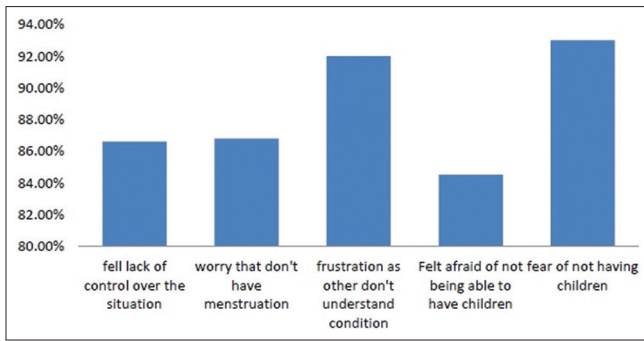


Figure 4: Graph showing the impact of various items of weight domain on PCOS women’s health. PCOS = Polycystic ovarian syndrome

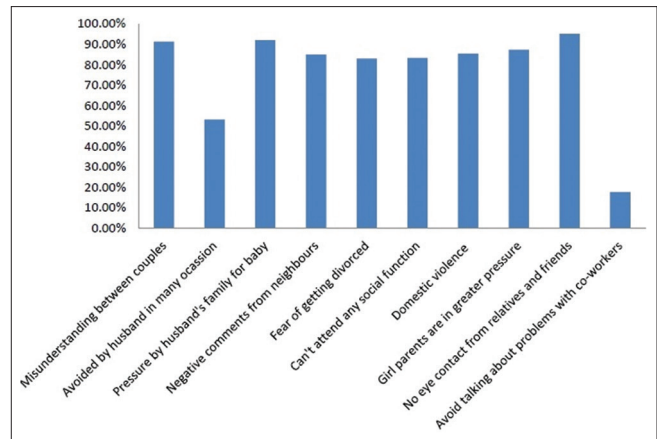


**Figure 5:** Graph showing the impact of various items of menstrual problem domain on PCOS women's health. PCOS = Polycystic ovarian syndrome

the future of their daughters. Women at the marriageable age are stressed out about marriage, relocation and new job stress and continuation of the treatment.

In a study by Khomami *et al.* to assess the impact of various clinical features of PCOS on the HRQOL of Iranian women found that hirsutism had the strongest impact on the HRQOL trial and this study concluded that health-care officials need to appraise in depth the effect of each clinical trait of PCOS separately and design management strategy, keeping in mind the mental and physical manifestations.<sup>[22]</sup> In another study done in 2013 by Açmaz *et al.* to determine which symptoms increased such problems as depression, anxiety, low self-esteem and social worry by classifying PCOS according to symptoms found that depression scores of infertile group were higher, whereas anxiety scores of the obese group were bigger than other groups. It was the obesity group that received the smallest score in self-esteem and trust in people and the highest score in sensitivity to criticism. The most affected group was oligomenorrhoea-hirsutism group in terms of physical functioning, physical role function, pain, social functioning, emotional role function and emotional well-being and concluded by suggesting that not only gynaecologist but also a multidisciplinary team may examine these patients.<sup>[23]</sup>

One of the studies on the quality health of PCOS women from the South Asia carried out by Kumarapeli *et al.* found that PCOS occurring in South Asians adversely affects their psychological well-being and HRQoL and their psychological distress is related to hirsutism rather than to obesity.<sup>[24]</sup> But we have shown in this study that psychological distress is more because of menstrual problem issue, infertility and also due to social issue rather than obesity. Infertility is often associated with divorce, low social status, lowered self-esteem, altered self-perception and job dissatisfaction.<sup>[25,26]</sup> Our study also found that the majority of the women have psychological issues due to infertility which again



**Figure 6:** Graph showing the impact of various items of social issue domain on PCOS Women's health. PCOS = Polycystic ovarian syndrome

turn into social issue as these women are not able to conceive. Among the social issue domain, we found that the entire questionnaire has importance as these questions have a direct impact on the quality of health of PCOS patients in the South Indian cohort. Women with PCOS have been found to have higher levels of depression and overall psychological morbidity and decreased QoL in overall health and sex.<sup>[27]</sup>

A majority of experts acknowledge that the psychosocial burden in women with PCOS cannot be ignored and should be treated as a secondary symptom.<sup>[21]</sup> The rural patients selected for the survey were observed to have a better health status than those from the urban areas. In this present work, it was observed that importance is given to infertility rather than symptoms and health of the concerned patient, this observation was contrary to the European population where most of the PCOS patients are aware of their physical appearance than infertility associated with PCOS.<sup>[9]</sup> McCook *et al.* reported that the psychological implications of PCOS are easily underestimated and have been largely ignored. Nursing care has a pivotal role in recognising these concerns and implementing therapy to improve QoL in women with PCOS.<sup>[20]</sup> To review the psychological health of women with PCOS a larger sample size will refine a better understanding of depression of QoL in PCOS women.<sup>[28]</sup> A study which compared the QoL and sexual function of women with PCOS concluded that the relationship of PCOS results with a decrease in the QoL and disorders in the sexual domain of women was well established.<sup>[29]</sup> Another study aimed to assess the HRQoL, depression and anxiety in Iranian women with contrasting PCOS phenotypes revealed similar psychological profiles in all phenotypes tested.<sup>[30]</sup>

## CONCLUSION

Women play an important part in the normal functioning



of society. The South Indian cohort participating in this study revealed that the stress mainly is because of infertility problems and also due to social issue.

As South Indian society is concerned about social interface, social issue is the main problem in PCOS women here. Hence new domain (Social issues) was included in the questionnaire measuring HRQL in PCOS patients. The impact of these issues on a woman's QoL may be reflective and can result in psychological misery which brings her feminine identity at risk. The condition might further result in altered self-perception, a disturbed family life and tribulations at work too. Future studies are required to confirm the validity of the revised questionnaire including the sixth domain of 'Social issue'.

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Nil.

### Conflicts of interest

There are no conflicts of interest.

### Data availability

Data are available on request from the corresponding author.

## REFERENCES

- Teede H, Deeks A, Moran L. Polycystic ovary syndrome: A complex condition with psychological, reproductive and metabolic manifestations that impacts on health across the lifespan. *BMC Med* 2010;8:41.
- Goodarzi MO, Dumesic DA, Chazenbalk G, Azziz R. Polycystic ovary syndrome: Etiology, pathogenesis and diagnosis. *Nat Rev Endocrinol* 2011;7:219-31.
- Azziz R, Adashi EY. Stein and leventhal: 80 years on. *Am J Obstet Gynecol* 2016;214:247.e1-11.
- Michelmore KF, Balen AH, Dunger DB, Vessey MP. Polycystic ovaries and associated clinical and biochemical features in young women. *Clin Endocrinol (Oxf)* 1999;51:779-86.
- Broekmans FJ, Knauff EA, Valkenburg O, Laven JS, Eijkemans MJ, Fauser BC. PCOS according to the Rotterdam consensus criteria: Change in prevalence among WHO-II anovulation and association with metabolic factors. *BJOG* 2006;113:1210-7.
- Mascarenhas MN, Flaxman SR, Boerma T, Vanderpoel S, Stevens GA. National, regional, and global trends in infertility prevalence since 1990: A systematic analysis of 277 health surveys. *PLoS Med* 2012;9:e1001356.
- Fauser BC, Tarlatzis BC, Rebar RW, Legro RS, Balen AH, Lobo R. Consensus on women's health aspects of polycystic ovary syndrome (PCOS). *Hum Reprod* 2012;27:14-24.
- Boyle J, Teede HJ. Polycystic ovary syndrome – An update. *Aust Fam Physician* 2012;41:752-6.
- Jones GL, Hall JM, Lashen HL, Balen AH, Ledger WL. Health-related quality of life among adolescents with polycystic ovary syndrome. *J Obstet Gynecol Neonatal Nurs* 2011;40:577-88.
- Bazarganipour F, Ziaei S, Montazeri A, Foroozianfar F, Kazemnejad A, Faghihzadeh S. Psychological investigation in patients with polycystic ovary syndrome. *Health Qual Life Outcomes* 2013;11:141.
- Trent ME, Rich M, Austin SB, Gordon CM. Quality of life in adolescent girls with polycystic ovary syndrome. *Arch Pediatr Adolesc Med* 2002;156:556-60.
- McKenna TJ. The use of anti-androgens in the treatment of hirsutism. *Clin Endocrinol (Oxf)* 1991;35:1-3.
- Hahn S, Janssen OE, Tan S, Pleger K, Mann K, Schedlowski M, *et al.* Clinical and psychological correlates of quality-of-life in polycystic ovary syndrome. *Eur J Endocrinol* 2005;153:853-60.
- Elsenbruch S, Hahn S, Kowalsky D, Offner AH, Schedlowski M, Mann K, *et al.* Quality of life, psychosocial well-being, and sexual satisfaction in women with polycystic ovary syndrome. *J Clin Endocrinol Metab* 2003;88:5801-7.
- Adali E, Yildizhan R, Kurdoglu M, Kolusari A, Edirne T, Sahin HG, *et al.* The relationship between clinico-biochemical characteristics and psychiatric distress in young women with polycystic ovary syndrome. *J Int Med Res* 2008;36:1188-96.
- Pastore LM, Patrie JT, Morris WL, Dalal P, Bray MJ. Depression symptoms and body dissatisfaction association among polycystic ovary syndrome women. *J Psychosom Res* 2011;71:270-6.
- Cronin L, Guyatt G, Griffith L, Wong E, Azziz R, Futterweit W, *et al.* Development of a health-related quality-of-life questionnaire (PCOSQ) for women with polycystic ovary syndrome (PCOS). *J Clin Endocrinol Metab* 1998;83:1976-87.
- Colwell HH, Mathias SD, Pasta DJ, Henning JM, Steege JF. A health-related quality-of-life instrument for symptomatic patients with endometriosis: A validation study. *Am J Obstet Gynecol* 1998;179:47-55.
- Brady C, Mousa SS, Mousa SA. Polycystic ovary syndrome and its impact on women's quality of life: More than just an endocrine disorder. *Drug Healthc Patient Saf* 2009;1:9-15.
- McCook JG, Reame NE, Thatcher SS. Health-related quality of life issues in women with polycystic ovary syndrome. *J Obstet Gynecol Neonatal Nurs* 2005;34:12-20.
- Eggers S, Kirchengast S. The polycystic ovary syndrome – A medical condition but also an important psychosocial problem. *Coll Antropol* 2001;25:673-85.
- Khomami MB, Tehrani FR, Hashemi S, Farahmand M, Azizi F. Of PCOS symptoms, hirsutism has the most significant impact on the quality of life of Iranian women. *PLoS One* 2015;10:e0123608.
- Açmaz G, Albayrak E, Acmaz B, Başer M, Soyak M, Zararsız G, *et al.* Level of anxiety, depression, self-esteem, social anxiety, and quality of life among the women with polycystic ovary syndrome. *ScientificWorldJournal* 2013;2013:851815.
- Kumarapeli V, Seneviratne Rde A, Wijeyaratne C. Health-related quality of life and psychological distress in polycystic ovary syndrome: A hidden facet in South Asian women. *BJOG* 2011;118:319-28.
- Paulson JD, Haarmann BS, Salerno RL, Asmar P. An investigation of the relationship between emotional maladjustment and infertility. *Fertil Steril* 1988;49:258-62.
- Downey J, Yingling S, McKinney M, Husami N, Jewelewicz R, Maidman J. Mood disorders, psychiatric symptoms, and distress

- in women presenting for infertility evaluation. *Fertil Steril* 1989;52:425-32.
27. Anokye R, Acheampong E, Mprah WK, Ope JO, Barivure TN. Psychosocial effects of infertility among couples attending St. Michael's Hospital, Jachie-Pramso in the Ashanti region of Ghana. *BMC Res Notes* 2017;10:690.
  28. Barnard L, Ferriday D, Guenther N, Strauss B, Balen AH, Dye L. Quality of life and psychological well being in polycystic ovary syndrome. *Hum Reprod* 2007;22:2279-86.
  29. Castelo-Branco C, Naumova I. Quality of life and sexual function in women with polycystic ovary syndrome: A comprehensive review. *Gynecol Endocrinol* 2020;36:96-103.
  30. Fatemeh B, Shahideh JS, Negin M. Health related quality of life and psychological parameters in different polycystic ovary syndrome phenotypes: A comparative cross-sectional study. *J Ovarian Res* 2021;14:57.