Measures of health-related quality of life in PCOS women: a cross sectional study from Saudi Arabia

L.S.M. ALAHMARI¹, H.S. ALZAHRANI¹, N. ALZAHRANI², S.O. ALDHAFYAN³, R.H. AL-QAHTANI³, J.A. AL-ZAID³, M.S. ALSHAHRANI³, L.A. AL-GHAMDI³

Abstract. - OBJECTIVE: Polycystic ovary syndrome (PCOS) is the most common endocrine-gynecologic disorder affecting women of childbearing age. It has a wide range of clinical manifestations, including menstrual irregularity, infertility, hirsutism, acne, and obesity. Studies have confirmed that PCOS can significantly reduce a patient's health-related quality of life (HRQoL). The pathophysiology of PCOS is poorly understood, but it is believed to be caused by the interaction of several factors. Moreover, there is a lack of information about HRQoL among PCOS women in Saudi Arabia. This study aims to assess the HRQoL of PCOS patients by using the Arabic Version of the Polycystic Ovarian Syndrome Health-Related Quality of life Questionnaire (AR-PCOSQ) in Riyadh city.

SUBJECTS AND METHODS: A descriptive cross-sectional study was conducted on 281 women in Riyadh city using the translated questionnaire (AR-PCOSQ) to explore PCOS quality of life among Saudi females. The eligibility criteria were Saudi female who had been diagnosed with PCOS, living in Riyadh city, aged 18 and above, and willing to participate. The sample size was estimated using the 10-events-per variable rule for prediction models (REF). Informed consent was taken from all participants and a Google Form was used to create the survey and collect data.

RESULTS: The higher score represents poor QOL. However, the analysis revealed that higher scores of the weight-related QOL had the greatest impact on patients' quality of life in older age groups, including women aged 26 to 35 (beta = 0.143, 95% CI, 0.023 to 0.304, p-value = 0.046) and women aged > 35 (beta = 0.229, 95% CI, 0.039 to 0.428, p = 0.011). Other domains of QOL, such as emotions, body hair, infertility, and menstrual problems, were not significant-

ly predicted by any of the women's demographic characteristics.

CONCLUSIONS: The findings revealed that PCOS-related conditions such as weight problems, menstrual irregularity, and infertility were associated with a reduction in quality of life.

*Key Words:*Quality of life, Arabic, PCOS.

Abbreviations

Polycystic ovary syndrome (PCOS), health-related quality of life (HRQoL), Arabic Version of the Polycystic Ovarian Syndrome Health-Related Quality of life Questionnaire (AR-PCOSQ), quality of life (QOL), Princess Nourah Bint Abdulrahman University (PNU).

Introduction

Polycystic ovary syndrome (PCOS) is the most prevalent endocrine-gynecological disorder and affects women at their reproductive age1. It is widely spread in most parts of the world, with large variations between different regions. A retrospective study shows that the prevalence of PCOS is estimated between 4% and 20% worldwide2. Moreover, the prevalence of PCOS is 16% among Saudi females³. The name polycystic ovary syndrome describes a condition where numerous small cysts in the ovaries produce elevated level of androgens, which can cause irregular menstrual cycle and many symptoms of PCOS⁴. According to ESHRE/ ASRM criteria, PCOS is defined as the presence of two or more of the following three criteria: polycystic ovaries, oligo-/anovulation, and/or clinical or biochemical evidence of hyperandrogenism⁵. The

¹Department of Family and Community Medicine, College of Medicine, Princess Nourah bint Abdulrahman University, Riyadh, Saudi Arabia

²Department of Internal Medicine, College of Medicine, Princess Nourah bint Abdulrahman University, Riyadh, Saudi Arabia

³College of Medicine, Princess Nourah bint Abdulrahman University, Riyadh, Saudi Arabia

wide range of clinical manifestations, including menstrual irregularity, infertility, hirsutism, acne, and obesity, are all significant sources of psychosocial distress and lead to a reduction of life quality⁴. Numerous studies⁴⁻⁶ confirm the symptoms of PCOS can lead to a significant decrease in patients' health-related quality of life (HRQoL). According to a study conducted in Iran⁶, infertility is considered one of the most distressing symptoms of PCOS. In addition, a thorough review of the literature conducted by Bazarganipour et al⁷ show that hirsutism and menstruation are the main causes of HRQOL impairment in PCOS patients. The interaction between multiple factors is believed to be the cause of the hormonal disturbance seen in PCOS patients8. Additionally, genetic mutations are linked to PCOS, along with hypothalamic-pituitary dysfunction⁹. A genetic mutation of the aromatase enzyme deficiency may affect ovary functioning and elevate androgen level, leading to PCOS9. Despite this, research done to assess the quality of life of patients with PCOS is minimal, especially in Asian countries, even though it is the most common endocrine disorder in young females^{10,11}. Upon literature review, there has been minimal research assessing the HRQoL of PCOS patients in Saudi Arabia. HR-QOL is culturally dependent⁶; therefore, the unique characteristics of social and cultural life contexts suggest that information on the HRQoL of PCOS patients in Saudi Arabia may be different from that of Western countries. Since there is a scarcity of information about the HROoL among PCOS women in Saudi Arabia. This study aims to assess the HRQoL of PCOS patients by using the Arabic Version of the Polycystic Ovarian Syndrome Health-Related Quality of life Questionnaire (AR-PCO-SQ) in Riyadh city. We hypothesize that women with PCOS, would show worse HRQoL compared to women without PCOS.

Subjects and Methods

A descriptive cross-sectional study using the translated questionnaire (AR-PCOSQ) was conducted to explore PCOS quality of life among the Saudi female population, through an anonymous online questionnaire using a snowball convenience sampling technique from January 2023 to March 2023. The eligibility criteria to participate in this study were Saudi females who had been diagnosed with PCOS, living in Riyadh city, aged 18 and above, and willing to participate in the study. Since we planned to conduct a multivariate

linear regression model of the primary outcome variable (QOL score), the sample size was estimated using the 10-events-per-variable rule for prediction models¹². Given that the PCOSQ scale consists of 26 items, a sample of 260 women was required in the current study. The total sample size comprised 281 participants. Before starting the study, approval was obtained from the Institutional Review Board (IRB) at Princess Nourah bint Abdulrahman University (PNU), Riyadh, Saudi Arabia (IRB log number: 23-0077). Informed consent was taken from all participants after being explained briefly about the study's objectives and informed that they have the full right to withdraw from the study without any obligation. A Google Form was used to create the survey and collect data. The link was then shared and circulated randomly across different social media platforms (i.e., WhatsApp, Telegram, Instagram, and Twitter). The majority of participants were strongly encouraged to share the invitation link with their personal and professional contacts.

Data Collection

In the current study, we employed the PCO-SQOL scale, which consists of 26 items and 5 domains, including emotions (eight items), body hair (five items), weight (five items), infertility (four items), and menstrual problems (four items)¹³. The mean scores of each domain were computed based on the items allocated to each domain after validation. Each item was graded on a seven-item Likert scale, where higher scores indicated a poorer quality of life. Since the scores of each domain are based on the mean values of respective items, they ranged between 1 and 7.

Statistical Analysis

The normal distribution of the QOL score was assessed using a Shapiro-Wilk test, which revealed non-normally distributed data (p-value = 0.0001). Statistical analysis was performed using RStudio (R version 4.2.2): Integrated Development for R. RStudio, PBC, Boston, USA. Categorical variables were expressed as frequencies and percentages, whereas numerical variables were presented as median and interquartile range (IQR). To assess the predictors of poor quality of life among PCOS participants, we carried out a bootstrapped partial least squares structural equation modeling technique using the five subscales as endogenous variables and the demographic characteristics of the participants as predictor variables. The internal consistency reliability of the model was assessed using Cronbach's alpha coefficients and rhoC rhoA values. Furthermore, we used the average variance extracted (AVE) as a measure of the convergent validity in order to assess the degree to which each construct could have converged to express the indicators' variance. Beta coefficients and their respective 95% confidence intervals (95% CIs) were used to present the results of the structural model, and statistical significance was deemed at p-value < 0.05.

Results of the structural paths showed that higher scores of the weight-related QOL (poor QOL due to weight concerns) were predicted by older age categories, including 26 to 35 years women (beta = 0.143, 95% CI, 0.023 to 0.304, p = 0.046) and > 35 years women (beta = 0.229, 95% CI, 0.039 to 0.428, p = 0.011). Other domains of QOL, including emotions, body hair, infertility, and menstrual problems, were not significantly predicted by any of the demographic characteristics of women (Table I).

Results

Demographic Characteristics

The responses of 281 women with PCOS were analyzed in the current study. All the participants were Saudi women residing in Riyadh city. The majority of them were between 18 and 25 years old (70.1%), were singles (72.2%), and had a bachelor's degree (73.7%). Approximately two-thirds of the participants were students (61.6%) and had an average monthly income of < 5,000 SAR (68.7%).

Out of the 26 items of the PCOSOOL survey. 24 items showed adequate loadings to their original constructs (bootstrapped factor loadings > 0.5). Therefore, two items were excluded from the validated model, including one item from the body hair subscale (QOL 11) and one item from the menstrual problem subscale (QOL 24). Furthermore, we combined single, divorced, and widowed categories into one category (single) and unemployed and retired categories into another category (unemployed/retired) to avoid the zero-variance error in the bootstrapped model. The final model exhibited excellent reliability indicators since the Cronbach's alpha values ranged between 0.751 and 0.935, and the values of rhoC and rhoA exceeded 0.70. Additionally, the AVE values of subscales were generally above 0.50, ranging between 0.551 and 0.794. This indicates that the constructs explained at least 55.1% of the indicators' variance that formed the construct. Finally, there was no risk of multicollinearity since the values of the variance inflation factor (VIF) were generally below the threshold of 5 (Table II).

Validity and Reliability

Description of the PCOSQOL scale and subscales

The median (IQR) quality of life score for all the participants was 4.2 (2.8 to 5.2). Weight-related QOL had the highest median score (median = 4.8, IQR = 2.8 to 6.0), followed by menstrual problems-related QOL (median = 4.7, IQR= 3.3 to 5.3) and infertility-related QOL had the lowest score (median = 3.3, IQR = 2.0 to 4.8, Figure 1).

Discussion

PCOS HRQoL has been previously studied worldwide¹⁵⁻¹⁸. The purpose of this paper was to assess the PCOS HRQoL and to identify the predictors of poor HRQoL in a sample of Saudi females. It was found that women with PCOS have a lower HRQoL. This finding could be attributed to the fact that PCOS has metabolic, reproductive, and psychological features and consequences on health across the lifespan¹⁹. In this study, weight problems were the greatest concern reported by PCOS women. These results were in line with previous studies¹⁵⁻¹⁸. One possible explanation for this finding is that women with PCOS often report extreme difficulty in losing weight and maintaining weight loss, and interventions to lose weight are often failed and linked to high rates of weight gain¹⁷. Furthermore, two studies^{20,21} have reported that PCOS women have a worse body image and are dissatisfied with their weight, and consequently, have a poor quality of life. Noticeably, a weight reduction appears to improve HRQoL significantly²². Additionally, our study demonstrates that the weight-related OOL was significantly predicted by older age categories, including 26 to 35 years and > 35 years women. On the other hand, a systematic review by Jones et al²² revealed that weight-related QOL is significantly associated with the adolescent age group. It might be because there are few data on HRQoL in women with PCOS during their late reproductive years, with most prior studies focusing on women at younger ages23.

Although menstrual disorders demonstrate a high negative association in PCOS patients on a

Table I. Outcomes of the structural models.

		Emotions		Body hair		Weight		Infertility		Menstrual problems	
Parameter	Category	Beta (95% CI)	<i>p</i> -value	Beta (95% CI)	<i>p</i> -value	Beta (95% CI)	<i>p</i> -value	Beta (95% CI)	<i>p</i> -value	Beta (95% CI)	<i>p</i> -value
Age	18 to 25 26 to 35 > 35	Ref 0.072 (-0.198 to 0.237) 0.129 (-0.266 to 0.355)	0.258 0.199	Ref 0.026 (-0.149 to 0.212) -0.013 (-0.217 to 0.183)	0.387 0.551	Ref 0.143 (0.023 to 0.304) 0.229 (0.039 to 0.428)	0.046 0.011	Ref 0.122 (-0.051 to 0.285) 0.144 (-0.082 to 0.355)		Ref -0.077 (-0.229 to 0.110) -0.042 (-0.235 to 0.189)	
Marital status	Single* Married	Ref -0.092 (-0.273 to 0.141)	0.811	Ref -0.125 (-0.292 to 0.055)	0.925	Ref -0.125 (-0.301 to 0.049)	0.922	Ref -0.005 (-0.203 to 0.201)	0.521	Ref -0.019 (-0.207 to 0.145)	0.581
Highest	School Bachelor Post-graduate	Ref -0.100 (-0.223 to 0.103) -0.052 (-0.196 to 0.081)	0.882 0.768	Ref -0.151 (-0.279 to -0.026 -0.095 (-0.211 to 0.017)	/	Ref -0.025 (-0.150 to 0.106) -0.086 (-0.196 to 0.033)		Ref -0.039 (-0.166 to 0.093) 0.026 (-0.127 to 0.163)		Ref 0.015 (-0.134 to 0.184) -0.025 (-0.153 to 0.125)	0.426 0.633
Occupation educational level	Student Housewife Employed Unemployed / Retired	Ref 0.026 (-0.182 to 0.218) 0.106 (-0.098 to 0.283) 0.064 (-0.081 to 0.206)	0.399 0.136 0.192	Ref -0.004 (-0.158 to 0.144) 0.102 (-0.062 to 0.262) 0.117 (-0.030 to 0.246)	0.116	Ref -0.013 (-0.171 to 0.147) 0.081 (-0.110 to 0.256) 0.062 (-0.090 to 0.206)	0.195	Ref 0.019 (-0.195 to 0.200) 0.046 (-0.148 to 0.212) 0.031 (-0.122 to 0.169)	0.305	Ref 0.087 (-0.097 to 0.250) 0.117 (-0.098 to 0.282) 0.126 (-0.022 to 0.259)	0.126
Average monthly income	< 5,000 5,000 to 10,000 > 10,000	Ref -0.075 (-0.252 to 0.086) -0.054 (-0.202 to 0.116)	0.808 0.749	Ref -0.105 (-0.241 to 0.047) -0.088 (-0.221 to 0.049)		Ref -0.132 (-0.279 to 0.014) -0.160 (-0.302 to -0.011		Ref -0.016 (-0.168 to 0.140) -0.110 (-0.223 to 0.026)		Ref 0.019 (-0.129 to 0.179) -0.117 (-0.240 to 0.036)	

^{*}The category single indicates that the participant was single/divorced/widowed.

Table II. Convergent validity and construct reliability of the bootstrapped model of the used PCOSQ survey

Domains/items	BFL	VIF	alpha	rhoC	rhoA	AVE
Emotions			0.903	0.905	0.865	0.551
QOL_1	0.789	2.621				
QOL 2	0.655	2.578				
QOL 3	0.651	2.636				
QOL 4	0.706	1.940				
QOL_5	0.666	1.648				
QOL 6	0.817	3.734				
QOL ⁷ 7	0.748	2.499				
QOL ⁸	0.814	2.841				
Body hair			0.901	0.930	0.937	0.769
QOL 9	0.802	2.033				
QOL 10	0.860	2.434				
QOL 12	0.931	4.697				
QOL 13	0.907	3.979				
Weight			0.935	0.951	0.941	0.794
QOL 14	0.881	3.111				
QOL_15	0.860	2.814				
QOL 16	0.924	4.543				
QOL 17	0.885	3.313				
QOL 18	0.905	3.618				
Infertility			0.863	0.892	0.947	0.692
QOL 19	0.908	3.714				
QOL 20	0.941	4.853				
QOL_21	0.926	3.419				
QOL 22	0.570	1.235				
Menstrual problems		0.751	0.853	0.832	0.660	
QOL_23	0.746	1.407				
QOL 25	0.834	1.574				
QOL_26	0.802	1.575				

AVE: average variance extracted; Alpha: Cronbach's alpha; VIF: variance inflation factor; BFL: Bootstrapped factor loading.

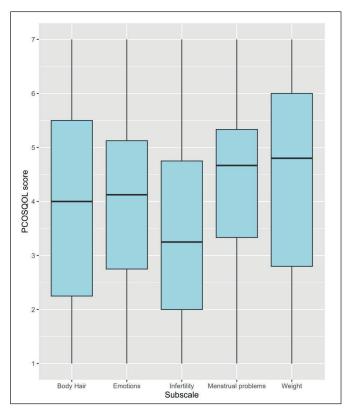


Figure 1. Description of the overall PCOSQOL scale and subscales.

clinical and biochemical basis²⁴, in some studies, it was not in the top three most affected domains⁷. The infertility outcome of this study shows the lowest score among the other domains. This finding explains that most of our participants are single, and infertility is not a big concern in this group. Another similar study²⁵ found an extremely low score for infertility in comparison to the other domains, although there is a significant negative impact on the quality of life of PCOS cases in relation to psychological distress, and this is because maternity has an effective role in the identity of women and the acceptance of society following marriage. Therefore, PCOS women can have sexual function issues where they sense less sexual satisfaction and desire due to long-term infertility and psychological stress¹⁵. Moreover, the Iranian study²⁶ displays the lowest score for infertility. Accordingly, infertility was detected as a concern of HRQOL because of the social pressure for childbearing.

Our study did not investigate a specific age group, but all females above 18 were included, which may affect the results since older females are more susceptible to health problems like metabolic syndrome. Also, symptoms might be affected by other factors, such as social stressors. Future studies should focus on specific age groups for a more accurate result.

Another limitation of the study is that the diagnoses of the disease were self-reported by the participants. This can be avoided by a validated diagnostic questionnaire to identify women with PCOS or by distributing the questionnaire from the primary healthcare and gynecological clinic to patients with a confirmed diagnosis of PCOS.

It should be noted that this study did not investigate any biochemical correlation related to PCOS cases and their HRQOL. Thus, it is suggested that future studies explore further correlations between HRQOL and PCOS cases.

The sample size was limited, and most participants were highly educated and might have had good health education regarding their self-care and health-seeking behaviors. Future researchers need to use large samples with various education and socioeconomic statuses.

Conclusions

In conclusion, this study provides evidence that HRQOL in patients with PCOS is impaired mostly by weight problems and menstrual irregularity,

while concerns about infertility had the lowest impact. Therefore, these problems must be considered by professional healthcare providers when dealing with PCOS patients, and more services need to be implemented to minimize the impact of PCOS on affected females.

Authors' Contributions

HAS has conceptualized the study and played a primary role in compiling, analyzing, and interpreting the data. RAS, BV, and CJJ did the manuscript preparation. SOA and RHA did the manuscript editing. JAA, LAA and MSA approved the final draft. RHA, JAA, MSA and LAA did the data cleaning and data analysis. LSMA and NA did the data collection. All the authors take complete responsibility for the content of the manuscript, and read and approve the final version of the manuscript.

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Ethics Approval

The ethical approval was obtained from the Institutional Review Board (IRB) at Princess Nourah bint Abdulrahman University (PNU), Riyadh, Saudi Arabia (IRB log number: 23-0077).

Informed Consent

Informed consent was obtained from the participants before initiating the study.

Data Availability Statement

The data can be made available by the corresponding author on request.

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