ORIGINAL ARTICLE





Assessment of Health-Related Quality of Life Using PCOSQ Tool, Its Determinants and Coping Mechanisms Used by Women with Polycystic Ovarian Syndrome Attending Multidisciplinary Clinic in Mumbai, India

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Abstract

Background Polycystic ovary syndrome (PCOS) is one of the most common endocrine disorder having most impact on women of reproductive age group, affecting their quality of life (HRQOL) and psychological well-being.

Objective This paper aims to determine QOL among women affected with PCOS attending a multidisciplinary clinic using PCOSQ tool and its association with socio-economic status, phenotypes, anxiety, depression and metabolic comorbidities and evaluate the coping strategies adapted by these women.

Design Retrospective study.

Setting Integrated multidisciplinary PCOS clinic.

Patient(s) Two hundred and nine women diagnosed with PCOS as per Rotterdam criteria.

Results Infertility was an important condition for reduced HRQOL and psychological morbidity across all socio-economic status and phenotypes. The poor psychological status and obesity were identified as determinants of HRQOL among women affected with PCOS. Those who suffered from anxiety, depression and showed lower HRQOL used emotional maladaptive coping strategies.

Conclusion Results reveal that HRQOL of PCOS women is worsened in the presence of comorbidities. Maladaptive and disengagement coping strategies used by women may worsen their psychological status. Holistic assessment of comorbidities and its management can help improve HROL of affected women. Personalised counselling based on the assessment of coping strategies used by women could empower women to cope better with PCOS.

Keywords Polycystic ovary syndrome · Quality of life · Coping strategies · Anxiety · Depression

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Introduction

Polycystic ovary syndrome (PCOS) is one of the most common endocrine disorder affecting women from adolescence to menopause impacting reproductive health and general wellbeing [1]. Studies on PCOS in India report varied prevalence ranging from 3.7 to 22.5% [2]. Most common symptoms of PCOS are menstrual irregularities, infertility, hirsutism, acne vulgaris, acanthosis nigricans and androgenetic alopecia [1]. Many women diagnosed with PCOS also present with features of metabolic syndrome (MS) [3].

There are various reports linking specific features of PCOS with decreased psychological well-being. This is often due to negative body image not conforming to the societal norms of physical and cosmetic appearance and hence lowering the self-esteem of these women [4]. Irrespective of severity of symptoms, studies have shown that this may result in anxiety and depression and have a negative impact on health-related quality of life (HRQOL) in women with PCOS including adolescents [5–12]. Hence, guidelines [13, 14] recommend screening for psychological well-being in all women with PCOS.

Not much is known about how women in India cope with PCOS and how it affects their psychological well-being and HRQOL. Studies on HRQOL and PCOS have used generalised tools such as SF 36 [5, 6, 9] and WHOQOL BREF [10, 12]. However, Polycystic Ovarian Syndrome Questionnaire (PCOSQ) is a very specific tool [15] that has been developed based on signs and symptoms affecting women with PCOS. Very few studies in Indian context have used PCOSQ [16, 17] and studied their association with phenotypes and associated morbidities.

Coping strategies (CS) form an important link between a stressful situation and the resulting psychological response of the person towards it [18]. An illness and its subsequent sequelae can bring about stressful reactions in people [19]. The process of successful or unsuccessful coping can affect their health behaviour, choices and outcomes including psychological well-being and HRQOL. [19, 20]. Successful use of adaptive CS helps in reducing psychological problems in women with PCOS [18, 21].

This paper aims to determine HRQOL among women affected with PCOS attending a multidisciplinary clinic using PCOSQ tool and its association with socio-economic status (SES), phenotypes, anxiety, depression and MS and evaluate the CS adapted by these women.

Methods

This is a retrospective analysis of case record forms, of 209 women between 15 and 40 years of age, who presented to an integrated multidisciplinary PCOS clinic at

Indian Council of Medical Research—National Institute for Research in Reproductive and Child Health (ICMR-NIRRCH) Mumbai, India, from May 2016 to February 2020. They were diagnosed with PCOS as per Rotterdam Criteria [14] and after ruling out other differential diagnosis conditions [22]. PCOSQ, DSM-5 [23] and the Coping Strategy Inventory (CSI) [24] are used routinely at the clinic to offer holistic management for PCOS and are administered by the counsellors at the clinic. Permission for publication of the retrospective data was obtained from the institute's ethics committee, and all data were anonymized for analysis.

BG Prasad 2019 classification [25] was used to determine the SES of the participants. Diagnosis of MS was done according to the NCEP ATP III definition [26].

PCOSQ was used to measure HRQOL which is a 26-item Questionnaire subdivided into five domains, namely emotional, body hair, weight, infertility and menstruation answered on a 7-point Likert scale,. The mean scores for each domain reflect the respondent's feelings in the preceding 2 weeks with higher values indicating better HRQOL. PCOSQ scoring provides separate domain scores for each of the five domains, as the numeric mean as well as a global score, as the mean of the five domain scores. Copyright permission to use the PCOSQ was obtained. (Order No.501312418). Total HRQOL Scores above Mean + SD were considered as better QOL.

The DSM-5 self-rated level 1 cross-cutting symptom measure-Adult was used to assess the psychological status of women with PCOS. It has 23 questions assessing participant's feelings about certain situation across 13 psychiatric domains, measured on a 5-point Likert scale with mean score ranging from 0 to 4. The presence of anxiety and depression was considered if the mean score was 2 and above in the respective domains.

The CSI was used to assess the CS used by women with PCOS. It is a 72-item questionnaire assessing eight primary CS and further broadly assessed as adaptive/ engagement CS and maladaptive/ disengagement CS, mentioned in detail in Table 3. Mean score is calculated for each subscale and ranges from 1 to 5, where higher mean value indicates better response in the particular CS.

Scoring and analysis of each questionnaire was done as per their respective manuals. SPSS for Windows, Version 23, Chicago, SPSS Inc., was used to analyse the data. Descriptive statistics was used for all categorical data. Comparing PCOSQ and CSI scores between different groups was done using the independent t tests.

The magnitude of the association between HRQOL and selected independent variables was measured by odds ratio (OR) and their 95% confidence intervals (CI) obtained with simple logistic regression (LR) models. All variables that were significant at a P value of < 0.05 were entered in



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univariate analysis. The step-up model was used for multivariate analysis.

Results

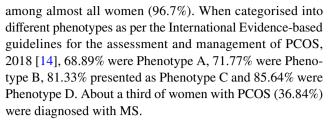
Socio-demographic Profile and Clinical Profile

The mean age of the participants was 26.27 ± 4.9 years. Socio-demographic and clinical characteristics of the women with PCOS are given in Table 1. Majority were married, housewives belonging to higher or middle socioeconomic strata.

Nearly half (48.8%) presented with oligo menorrhoea as chief complaint, and a third of women (31.1%) presented with amenorrhoea. A large majority (88.53%) from the 157 married females presented with infertility. More than half (62.2%) had hirsutism score more than 8 and BMI above 25 (58.9%). Hormonal analysis revealed that 69.4% women had hyperandrogenism and 10.52% had hyperinsulinemia. Polycystic ovarian morphology on ultrasound was observed

Table 1 Socio-demographic and clinical presentations of the participants

Socio-demographic profile	Frequency	Percentage
Marital status $(N = 209)$		
Married	157	75.1
Unmarried	50	23.9
Divorcee	02	01
Education $(N = 209)$		
Illiterate or up to primary	06	2.9
Secondary	76	36.4
Higher Secondary	95	45.5
Post graduate and beyond	32	15.3
Occupation $(N=209)$		
Student	29	13.9
House wife	105	50.2
Service (skilled + unskilled)	41	19.7
Professional	34	16.3
Socio-economic class $(N = 209)$		
Class 1	107	51.2
Class 2	80	38.3
Class 3	17	8.1
Class 4	05	2.4
Clinical presentations of signs and symptoms of PCOS (N = 209) (multiple responses)		
Menstrual complaints	167	79.9
Hirsutism	130	62.2
Acne	98	46.8
Infertility* (out of 157 married)	139	88.53
Obesity	123	58.9



PCOSQ revealed that maximum score was present in the hair domain (5.70 ± 1.79) followed by weight (4.76 ± 2.01) , menstrual (4.53 ± 1.38) and emotional (4.44 ± 1.42) domains. The least score was obtained in the infertility (3.85 ± 1.86) domain indicating that it affected HRQOL the most.

Symptoms of anxiety and/or depression were present in 68.9% of the respondents, out of which 61.7% had anxiety, 39.2% had depression, while 32.05% had both. No significant difference was noted in the prevalence of anxiety and depression based on the different phenotypes.

Association of HRQOL scores with Socio-economic profile, PCOS Phenotypes, Comorbidities and Anxiety, Depression

Mean values of PCOSQ scores were found to be higher in Class 3 and 4 of socio-economic classes, across all domains. Infertility scores were the lowest in all the socio-economic groups (Table 2). No significant difference was observed in the mean scores of PCOSQ across the different phenotypes.

The mean scores of the group with anxiety and depression symptoms in all the domains and the total HRQOL was found to be low and statistically significant compared to the group without anxiety and depression symptoms, indicating a lower HRQOL in the group with anxiety and depression symptoms. (Table 2).

The mean scores of the group with MS in all domains (except Hair) and the total HRQOL was found to be low compared to the group without MS. This difference was found to be statistically significant across the emotional and weight domains and the total HRQOL (Table 2).

Coping Strategies and its Association with Anxiety, Depression and HRQOL

Mean score 3 and above was observed in 28.7% women for engagement CS alone and in 7.2% women for disengagement CS. However, majority (63.6%) of them scored above mean in both engagement and disengagement CS (Table 3).

Comparison of mean scores of different CS was done between groups with and without anxiety and depression symptoms. The mean scores of the group with anxiety and depression was higher and statistically significant across all domains of maladaptive CS indicating that it was most used by those with psychological morbidity (Table 3).



Table 2 Association of HRQOL scores with socio-economic status, PCOS phenotypes, comorbidities and anxiety, depression

HRQOL Domain	Mean ± SD (range 1–7)							
	Total women $(N=209)$	Class 1 (N	V = 107)	Class 2 $(N=80)$	Class 3 (<i>N</i> = 17)	Class	4(N=05)	
HRQOL and socio- economic status		,						
Emotional domain	4.44 ± 1.42	4.4 ± 1.4	-5	4.42 ± 1.39	4.5 ± 1.49	5.3 ±	5.3 ± 0.78	
Hair domain	5.70 ± 1.79	5.54 ± 1.8	34	5.99 ± 1.62	5.23 ± 2.27 6.2		0.89	
Weight domain	4.76 ± 2.01	4.55 ± 2.0	13	5.01 ± 1.95	4.91 ± 2.17	4.88 ± 2.02		
Infertility domain	3.85 ± 1.86	3.93 ± 1.9)4	3.69 ± 1.76	3.98 ± 1.92	4.4 ± 1.95		
Menstrual domain	4.53 ± 1.38	4.48 ± 1.4	2	4.70 ± 1.29	4.05 ± 1.52	4.85 ± 1.39		
Total HRQOL	4.67 ± 1.20	4.59 ± 1.27		4.77 ± 1.09	4.57 ± 1.31	5.19 ± 0.98		
HRQOL domain		Phenotype A $(N=144)$	Phenoty $(N=150)$		Phenotype C (N=170)	Phenotype I) (N=179	
HRQOL and Pheno- types								
Emotional domain	4.44 ± 1.42	4.13 ± 1.44	4.17 ± 1	.43	4.15 ± 1.46	4.39 ± 1.48		
Hair domain	5.70 ± 1.79	5.63 ± 1.79	5.67 ± 1	.76	5.6 ± 1.78	5.77 ± 1.7		
Weight domain	4.76 ± 2.01	4.56 ± 2.01	4.57 ± 2	2.05	4.55 ± 2.02	4.65 ± 1.98		
Infertility domain	3.85 ± 1.86	3.52 ± 1.78	3.53 ± 1	1.76	3.61 ± 1.82	3.78 ± 1.89		
Menstrual domain	4.53 ± 1.38	4.5 ± 1.38	4.52 ± 1	.37	4.47 ± 1.40	4.59 ± 1.39		
Total HRQOL	4.67 ± 1.20	4.45 ± 1.15	4.48 ± 1	.15	4.46 ± 1.18	4.63 ± 1.16		
HRQOL domain	Total women	n (N=209)	209) MS present (<i>N</i> =77)		MS absent ($N=$	132)	P value	
HRQOL and metabolic (comorbidities)	c syndrome							
Emotion domain	4.44 ± 1.42	4.15 ± 1.4		ļ	4.63 ± 1.39		0.018	
Hair domain	5.70 ± 1.79		5.85 ± 1.8	31	5.63 ± 1.80		0.515	
Weight domain	4.76 ± 2.01	4.08		32	5.16 ± 2.02		0.000	
Infertility domain	3.85 ± 1.86		3.58 ± 1.8	± 1.82 4 ± 1 .			0.126	
Menstrual domain	4.53 ± 1.38	4.38 ±		33	4.66 ± 1.42		0.161	
Total HRQOL	4.67 ± 1.20		4.40 ± 1.14		4.83 ± 1.21		0.013	
HRQOL domain	Total women (N=	= 209)	Anxiety and/o sent $(N=144)$	r depression pre	re- Anxiety and/or depression absent (N=65)		P value	
HRQOL and anxiety, a	depres-							
Emotion domain	4.44 ± 1.42		4.12 ± 1.42		5.14 ± 1.13		0.000	
Hair domain	5.70 ± 1.79		5.52 ± 1.92		6.10 ± 1.42		0.031	
Weight domain	4.76 ± 2.01		4.46 ± 2.04		5.43 ± 1.79		0.001	
Infertility domain	3.85 ± 1.86		3.68 ± 1.82		4.24 ± 1.92		0.046	
Menstrual domain	4.53 ± 1.38		4.36 ± 1.40		4.93 ± 1.27		0.005	
Total HRQOL	4.67 ± 1.20	4.42 ± 1			5.21 ± 0.99		0.000	

The total HRQOL score was divided into two groups considering the mean + SD score of 5.87. Those who scored above this value were presumed to have a better HRQOL than those who scored below. Comparison of mean scores of CS was done between the two groups. The mean scores across disengagement or maladaptive CS were higher and statistically significant among the lower HRQOL score group (Table 4).

Determinants of HRQOL

LR was performed to ascertain the effects of several independent variables such as marital status, infertility, obesity, MS, psychological morbidity, SES and CS on better HRQOL. Table 5 shows that non-obese PCOS women have better HRQOL (U.O.R = 7.25, AOR = 8.02) compared to obese women. Similarly, those without



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Table 3 Mean coping scores and comparison of coping scores in groups with and without anxiety and depression symptoms

Coping Strategies	Mean \pm SD range (1–5)			
	Total women (N=209)	With anxiety and/or depression ($N=144$)	Without anxiety and/or depression (N=65)	
1. Engagement	3.026 ± 0.632	3 ± 0.573	3.06 ± 0.748	0.417
1.1 Problem Focused Engagement	3.09 ± 0.704	3.06 ± 0.639	3.17 ± 0.829	0.241
1.1.1 Problem Solving	3.14 ± 0.74	3.11 ± 0.686	3.20 ± 0.871	0.321
1.1.2 Cognitive Restructuring	3.04 ± 0.735	3.01 ± 0.671	3.13 ± 0.859	0.213
1.2 Emotion Focused Engagement	2.95 ± 0.659	2.95 ± 0.615	2.96 ± 0.751	0.779
1.2.1 Express Emotions	2.80 ± 0.72	2.83 ± 0.678	2.74 ± 0.816	0.489
1.2.2 Social Support	3.10 ± 0.751	3.07 ± 0.704	3.18 ± 0.846	0.246
2. Disengagement	2.712 ± 0.639	2.804 ± 0.633	2.511 ± 0.611	0.006
2.1 Problem Focused Disengagement	2.88 ± 0.64	2.938 ± 0.625	2.76 ± 0.659	0.128
2.1.1 Problem Avoidance	2.70 ± 0.669	2.73 ± 0.647	2.64 ± 0.717	0.461
2.1.2 Wishful Thinking	3.04 ± 0.735	3.11 ± 0.717	2.87 ± 0.752	0.54
2.2 Emotion Focused Disengagement	2.55 ± 0.745	2.676 ± 0.74	2.27 ± 0.676	0.001
2.2.1 Self-criticism	2.54 ± 0.853	2.67 ± 0.86	2.25 ± 0.769	0.002
2.2.2 Social Withdrawal	2.55 ± 0.75	2.68 ± 0.738	2.28 ± 0.721	0.001

Table 4 Comparison of coping scores in groups with HRQOL above and below 75th percentile

Coping strategies	Mean HRQO (N=68) Mean HRQO	P value	
	Score <5.87 (N=141)		
	Mean ± SD	Mean ± SD	
1. Engagement	2.94 ± 0.805	3.04 ± 0.585	0.316
1.1 Problem focused engagement	3.02 ± 0.914	3.10 ± 0.863	0.445
1.1.1 Problem solving	3.05 ± 0.95	3.15 ± 0.67	0.345
1.1.2 Cognitive restructuring	3.00 ± 0.92	3.05 ± 0.67	0.611
1.2 Emotion focused engagement	2.86 ± 0.793	2.98 ± 0.631	0.246
1.2.1 Express emotions	2.65 ± 0.807	2.86 ± 0.71	0.066
1.2.2 Social support	3.07 ± 0.89	3.10 ± 0.72	0.77
2. Disengagement	2.52 ± 0.722	2.78 ± 0.62	0.006
2.1 Problem focused Disengagement	2.72 ± 0.748	2.93 ± 0.617	0.03
2.1.1 Problem avoidance	2.58 ± 0.779	2.74 ± 0.645	0.123
2.1.2 Wishful thinking	2.85 ± 0.828	3.11 ± 0.717	0.02
2.2 Emotion focused Disengagement	2.32 ± 0.777	2.63 ± 0.739	0.005
2.2.1 Self-criticism	2.28 ± 0.839	2.64 ± 0.862	0.005
2.2.2 Social withdrawal	2.36 ± 0.836	2.63 ± 0.728	0.018

psychological morbidity have three times better HRQOL. PCOS women without MS were found to have better HRQOL (U.O.R = 2.53) as compared to those who had; however, the adjusted odds were not significant. Post hoc

assessment of model fit (Hosmer and Lemeshow test, P = 0.48) showed good fit of the mathematical model.

Discussion

Clinicians often are more objective in treating PCOS such that they focus on clinical and laboratory parameters to treat physical health parameters. This paper aims to highlight the importance of addressing HRQOL and CS that are less addressed in clinical practice.

HRQOL is a very subjective concept and is determined by a number of measurable and non-measurable aspects of how a woman, her family and society perceives the symptoms and associated comorbidities. Many tools have been used to measure HRQOL. Qualitative interviews with women with PCOS have demonstrated that generic questionnaires can underestimate the full impact of PCOS on their HRQOL, as they do not explore issues specific to PCOS. [27] However, PCOSQ is specifically developed tool to assess HRQOL in PCOS women.

Indian studies using SF 36 and WHO BRIEF [12, 28] to evaluate HRQOL in women with PCOS have also reported lower HRQOL scores across different domains like social and interpersonal relationships, physical, environmental, financial, psychological, etc., as compared to healthy controls. Having used PCOSQ, we have reported reduced HRQOL in women with PCOS in domains like emotion, hair, menstruation, weight and infertility which are more specific to PCOS. Our findings reveal infertility affected HRQOL the most. A strong association is reported between infertility and emotional well-being of women with PCOS



Table 5 Determinants of HRQOL (logistic regression)

Variables	Unadjusted O.R (95% CI)	Adjusted O.R (95% CI)
Marital status		
Married	1	1
Unmarried	1.09(0.56-2.14)	0.29(0.08-1.09)
Infertility		
Yes	1	1
No	1.24(0.68–2.28)	2.41(0.76-7.66)
Obesity		
Yes	1	1
No	7.25*** (3.79–13.87)	8.02*** (3.79-16.98)
Metabolic syndrome		
Yes	1	1
No	2.53** (1.31-4.86)	1.06(0.47-2.39)
Psychological morbidity		
Yes	1	1
No	3.21*** (1.73-5.96)	2.93**(1.39-6.18)
Socio Economic Status (B J Prasad Scale)		
Class 3 and 4	1	1
Class 1 and 2	1.21(0.48–3.04)	1.03(0.35-3.06)
Engagement coping strategy		
No	1	1
Yes	0.8(0.52-1.24)	1.24(0.6–2.57)
Disengagement coping strategy		
No	1	1
Yes	0.54** (0.34-0.85)	0.53(0.24-1.19)
Homer–Lemeshow test goodness of fit	Chisquare	7.56
	P value	0.477

in another study done in North India [17] using PCOSQ. It is obvious as infertility is a socially stigmatising problem less addressed through the public health system in India. This finding is also supported by other studies using SF 36 and WHO BRIEF [10, 12, 28]. The WHO BRIEF study also found that patients with hirsutism had lower HRQOL scores [10]. Study done in Hyderabad [16] using PCOSQ reported menstruation affected HRQOL the most, different from our finding, probably due to majority of the study population being unmarried girls, and pregnancy not being a priority. This reveals that health priorities differ in different age groups and affect different dimensions or domains of HRQOL.

Our finding, that higher the SES, better the HRQOL, resonates with the findings published from Poland [29]. This is one very strong pointer of how PCOS is a social and economic issue irrespective of the phenotypes women present with as also seen in a study from Iran [30].

Poor HRQOL, psychological status such as anxiety, depression, and use of improper CS are interdependent factors that need a holistic assessment and care using a multidisciplinary approach. The meta-analysis [4] published in 2012 on prevalence of anxiety in PCOS women

suggested that hirsutism, obesity and infertility are triggers for psychological distress, unfortunately it did not include any studies from India that have also reported prevalence of psychological disorders [12, 27, 31] among women with PCOS much higher as compared to controls [12, 27, 32]. Our analysis reported that about two-third (68.9%) women had anxiety and depression, which are the most commonly reported psychological disorders associated with PCOS [8]. However, the prevalence was higher than that reported in another study from Mumbai, India, that used HADS tool and reported 38.6% prevalence for anxiety disorders and 25.7% for depressive disorders [12]. The prevalence of anxiety and depression in our subjects may be higher as a large proportion (88%) of our participants were suffering from infertility unlike the study in Mumbai, where infertility was reported by less than a quarter of total sample. Another Indian study from Kashmir [32] reported prevalence of generalised anxiety disorder to be 15.5% and 23% had depression on using a DSM-IV tool.

The presence of anxiety and depression was correlated with specific PCOSQ domains which has not been reported earlier, to our knowledge. Results revealed that women with anxiety and depression scored significantly poor on



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all the PCOSQ domains and total HRQOL score, as compared to those who did not. Further analysis revealed that among all independent variables, obesity and psychological status affected HRQOL significantly. As expected, infertility greatly affected psychological status. Thus, addressing infertility is an important strategy to facilitate PCOS women improve their HRQOL.

Research studies have found individuals using problemoriented CS are better suited to handle stressful situations and that has positive effect on the HRQOL [33]. Negative impact of stress can reduce individual's resilience, and leave long-term adverse health impacts, thus emphasising that CS adopted by individuals is critical [34, 35].

Our findings suggest that mostly a combination of both engagement and disengagement CS was used. However, those who had lower HRQOL and anxiety and depression used disengagement CS, which was statistically significant similar to a study done in Turkey [36]. Some of the earlier studies report disengagement CS to be positively correlated with psychological morbidity [21, 37] and inversely correlated with the HRQOL [21, 38].

Women generally tend to use emotion focused CS [34, 39]. Improper CS severely affects the HRQOL of women affected with PCOS [37]. High level of stress and a feeling that the situation is not under their control makes it difficult to use problem focused CS [40]. Given that our study population constituted of a large number of women with infertility, which is a very stressful condition, emotion focused disengagement CS approach was seen extensively used in our study.

This study has the limitation due to the absence of a control group. Intervention studies using multidisciplinary approach are needed to assess impact of various therapeutic drugs, biofeedback strategies, cognitive therapies and involvement of marital partners, families and social support groups to provide an enabling environment that could help avert these morbidities among women affected with PCOS.

Conclusion

Data reveal that HRQOL of PCOS women is worsened in the presence of comorbidities. Maladaptive and disengagement coping strategies used by women may worsen their psychological status. Holistic assessment of comorbidities and its management can help improve HROL of affected women. Personalised counselling based on the assessment of coping strategies used by women could empower women to cope better with PCOS.

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Declarations

Ethics Approval All necessary ethical approvals were obtained from NIRRCH Ethical Committee for Clinical Studies and use of retrospective data. The study was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments.

Conflict of interest The authors have no conflicts of interest to declare that are relevant to the content of this manuscript.

Consent to Participate Informed written consent for participation in study was obtained from all individual participants included in the study.

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