

# Health Related Quality of Life among Reproductive Age Women Having Polycystic Ovarian Syndrome

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## ABSTRACT

**INTRODUCTION:** Polycystic ovarian syndrome (PCOS) is a common endocrine disorder commonly seen in young reproductive age women and is manifested by polycystic appearing ovaries on ultrasonography along with oligomenorrhoea or amenorrhoea, hirsutism, obesity and emotional disturbances further leading to infertility and metabolic disturbances as well as chronic illness. These symptoms, however, are frequently linked to decline woman's self-esteem and self-image, and may have an impact on her health-related quality of life (HRQoL). **MATERIALS AND METHODS:** Descriptive, web based-cross sectional study was conducted among 686 reproductive age women of Facebook page named PCOS WARRIOR Nepali woman selected conveniently. Structured and standardized health related quality of life questionnaire (German PCOS Questionnaire -g) was used to collect data by posting google form on Facebook page. Obtained data were analysed in Statistical Package for Social Science (SPSS) version 20, descriptive statistics and inferential statistics. **RESULTS:** More than half (50.9%) of the respondents were found to have good quality of life. The most common health related concern was for Infertility (28.57%) and least was for Acne (71.43%). There was statistically significance between Health-related quality of life and Body Mass Index (BMI) ( $p < 0.001$ ), menstruation Pattern ( $p = 0.013$ ), duration of medication ( $p = 0.002$ ) and presence of co-morbidities ( $p = 0.010$ ) respectively. **CONCLUSIONS:** It is concluded that more than half of the respondents have good quality of life. Various programmes should be conducted regarding infertility and assisted reproductive technologies giving special attention to the women having PCOS. Management of PCOS should be directed to improve quality of life of PCOS patients.

**Keywords:** Health related quality of life; Polycystic ovarian syndrome; Reproductive age women.

## INTRODUCTION

PCOS (Polycystic Ovarian Syndrome) is a prevalent endocrine illness that affects 20-30% of all young reproductive-age women which can lead to infertility and other metabolic abnormalities [1,2,3]. It is associated with several painful and undesirable symptoms with minimal possibility of complete curability that can have a profound impact on psychological morbidity. Further, ranges of treatments that are offered to relieve them also are a vast contributor to an overall diminished woman's quality of life [4]. There is a need for the study regarding health related quality of women with PCOS to evaluate the effect of multiple signs and symptoms of PCOS on physical, psychological and social wellbeing that would be beneficial for

choosing right treatment and evaluating response to those treatments[5]. Since, no similar studies found done in Nepal, this study was aimed to assess health related quality of life in women with Polycystic Ovarian Syndrome (PCOS) of reproductive age group.

## MATERIALS AND METHODS

### Study design and setting

Descriptive web based cross-sectional research design was used to assess health related quality of life in women with Polycystic Ovarian Syndrome (PCOS) of reproductive age group through online survey on social media group named PCOS

WARRIOR Nepali woman at face book having 10,000 members. Data collection period was for one month from 13<sup>th</sup> February 2022 to 15<sup>th</sup> March 2022.

### Participants, sample size and sampling technique

Web based non-probability convenience sampling technique was used in this study. Number of responses obtained during data collection period of 1 month was considered as sample size for the study i.e. 686 responses were obtained during data collection period. Reminder was provided 3 times during the data collection period of 1 month. i.e.at 10<sup>th</sup> day, at 20<sup>th</sup> day at 28<sup>th</sup> day. All those who were diagnosed with PCOS clinically and were willing to participate in study were included in this study.

### Data collection procedure and study variables

Structured, self-administered German PCOS questionnaire -g standard tool after necessary modification was used to measure health related quality of life and socio-demographic information was prepared by researcher herself. Finally, 29 items were grouped into 7 domains: body hair (5 items), Alopecia (1 item), Acne (3 items), weight (5 items), emotions (8 items), infertility (2 items), and menstrual problems (5 items). Pretesting of the instrument was done among 25 PCOS diagnosed women in similar setting and was excluded from the final study.

Researcher's information, purpose and objectives of the study were clearly explained in the questionnaire form. Those who provided consent to participate in the study were asked to continue to fill the form. The form was prepared in such a way that whoever consent to participate in the study would have to click on a proceed button for a response that they had gone through the consent form and agreed to participate in the study. And respondents could withdraw from study any time during filling the form, until the submit button was not be clicked, the form would not recorded. Privacy, anonymity and confidentiality of records were strictly maintained throughout the study. The questionnaire was prepared in google forms and the link was shared in the Facebook and Messenger at PCOS WARRIORS Nepali women group. The researcher had introduced herself to the respondents and purpose of study was explained through post on Facebook and Messenger.

### Statistical analysis and data management

All the data were entered into Statistical Package for Social Science (SPSS IBM version 20.0). The collected data were analyzed and interpreted by using descriptive and inferential statistics to find out the association between level of health-related quality of life with selected variables according to the nature of data.

### Ethical considerations

This study was approved was by the Institutional Review Committee of Chitwan Medical college (CMC-IRC) (Ref No. 078/079-248).

## RESULTS

In this study, median age of respondents was 24 years and almost all of the respondents (93.6%) belonged to 15-29 years age group whereas minimum age of respondents was 16 and maximum age was 38 years. The mean BMI was  $24.25 \pm 4.25$  SD. One fourth of the respondents (26.5%) were overweight, 12.9 % were obese. Most of respondents (63.1%) were unmarried. Almost all respondents (93.1%) followed Hinduism. More than half of the respondents (52.6%) were Brahmin. Regarding place of residence, most of the respondents (90.7%) were residing in urban area. Regarding education level, majority (56.4%) had bachelor level education, nearly half (42.1%) of the respondents were students and 40.7% were employed full time. The mean age of menarche was  $13 \pm 1.45$  SD and most of them (61.5%) had menarche at more than 13 years of age where age of menarche ranged from 9 years to 19 years. Regarding menstrual cycle, majority (74.1%) had irregular menstrual cycle. Among 253 married women, one fourth (25.7%) of the women had previously conceived, while 33.2 % women were not able to conceive baby. Majority (45.9%) had duration of PCOS between 1 to 5 years. Nearly half of the respondents (48.7 %) had taken medicine in past, 53.0% of women had taken medicine for less than 1 year, while 32.4% women had not taken any medication yet for this morbidity. Most of the respondents (81.3%) didn't have any co-morbidities, while among 128 women having co-morbidities 56.2% women had hypothyroidism. Health related quality of life scores according to various domains were measured as: lesser the percentage, higher the concern and higher the percentage lesser the concern about health-related quality of life. Most

common health related quality of life concern reported was Infertility (28.57%) and least concern was about Acne (71.43%). Half (50.9%) of the respondents were found to have good quality of

life. There was statistically significance between Health-related quality of life and Body Mass Index (BMI) ( $p < 0.001$ ), menstruation pattern ( $p = 0.013$ ), duration of medication ( $p = 0.002$ ) and presence of co-morbidities ( $p = 0.010$ ) respectively.

**Table 1 |** Socio-demographic characteristics of women with polycystic ovarian syndrome (n=686)

Variables	Frequency	Percentage
<b>Age in completed years</b>		
Lower Reproductive age (15-29)	642	93.6
Upper Reproductive age (30-44)	44	6.4
<i>Median- 24, IOR = 03- 01 (26-22), Min- 16, Max- 38</i>		
<b>Body Mass Index(BMI) in Kg/m<sup>2</sup></b>		
Underweight (< 18.5 )	38	5.5
Healthy Weight (18.5- 24.9)	378	55.1
Overweight (25-29.9)	182	26.5
Obese ( $\geq 30$ )	88	12.9
<i>Mean- 24.25, SD-4.25, Min-15.18,Max- 37.97</i>		
<b>Marital status</b>		
Married	248	36.2
Unmarried	433	63.1
Divorced	5	0.7
<b>Religion</b>		
Hindu	641	93.1
Non Hindu	45	6.9
<b>Ethnicity</b>		
Brahmin	361	52.6
Chhetri	143	20.8
Others	182	26.6
<b>Place of residence</b>		
Urban	622	90.7
Rural	64	9.3
<b>Education level</b>		
Secondary	159	23.2
Bachelor level	387	56.4
Master level	140	20.4
<b>Occupational status</b>		
Employed full time	279	40.8
Employed part time	69	10.2
Housemaker	47	6.9
Students	291	42.1
<b>Age of menarche (in years)</b>		
<13	264	38.5
$\geq 13$	422	61.5
<i>Mean - 13, SD - 1.45, Min - 9, Max - 19</i>		
<b>Menstrual pattern</b>		
Regular	178	25.9
Irregular	508	74.1
<b>Pregnancy status of married women (n=253)</b>		
Previously conceived	65	25.7
Not able to conceive	84	33.2
Don't have any plan yet	104	41.1

**Table 2 |** Disease related Variables of Women with Polycystic Ovarian Syndrome (n=686)

Variables	Frequency	Percentage
<b>Duration of PCOS</b>		
Less than 1 year	254	37.0
1 to 5 years	315	45.9

Table 2   Continued		
More than 5 years	117	17.1
<b>Medication status for PCOS</b>		
Taking Medication regularly	130	19.0
Had taken medicine in past	334	48.7
Had not taken any medicine yet	222	32.3
<b>Duration of medication</b>		
Less than 1 year	364	53.0
1 to 5 years	99	14.4
More than 5 years	1	0.1
Had not taken any medicine yet	222	32.4
<b>Presence of co-morbidities</b>		
Yes	128	18.7
No	558	81.3
Types of co-morbidities, (n=128)		
Diabetes	14	10.9
Hypertension	8	6.3
Hypothyroidism	72	56.2
Dyslipidemia	27	21.2
Others*	7	5.4

Others\* = kidney stone, seizure, migraine & pituitary adenoma

Table 3   Health related Quality of Life Scores according to Various PCOS Domains (n=686)						
Domain	No. of items	Max Possible score	Obtained Score	Median	IQR	Median%
Body	5	35	5-35	23	29-16	65.71
Alopecia	1	7	1-7	3	5-2	42.86
Acne	3	21	2-21	15	19-10	71.43
Weight	5	35	5-35	17	30-9	48.57
Emotion	8	56	8-56	26	35-18	46.43
Infertilit	1	7	1-7	2	4-1	28.57
Menstru	5	35	5-25	17	21-12	48.57
<b>Total</b>	<b>28</b>	<b>196</b>	<b>28-196</b>	<b>104</b>	<b>128-104</b>	<b>53.06</b>

Table 4   Health related Quality of Life of Women with PCOS according to Median Score		
Quality of Life	Frequency	Percentage
Good ( $\geq 104$ )	349	50.9
Poor ( $<104$ )	337	49.1
Total	686	100.0

Table 5   Association between Health-related Quality of Life and related variables (n= 686)			
Variables	HRQOL		p-value
	Good	Poor	
<b>Age in years</b>			
Lower Reproductive age (15-29)	327(50.9)	315(49.1)	0.905
Upper Reproductive age (30-44)	22(50.0)	22(50.0)	
<b>Body Mass Index (BMI)</b>			
Non Obese*	258(62.0)	158(38.0)	<b>(&lt;0.001)</b>
Obese	91(33.7)	179(66.3)	
<b>Marital status</b>			

Married	130(51.4)	123(48.6)	0.839
Unmarried	219(50.6)	214(49.4)	
<b>Religion</b>			
Hinduism	328(51.2)	313(48.8)	0.559
Other than Hinduism**	21(46.7)	24(53.3)	
<b>Ethnicity</b>			
Brahmin	186(51.5)	175(48.5)	0.926
Chhetri	71(49.7)	72(50.3)	
Others***	92(50.5)	90(49.5)	
<b>Place of residence</b>			
Urban	319(51.3)	303(48.7)	0.501
Rural	30(46.9)	34(53.1)	
<b>Education level</b>			
Secondary	78(49.1)	81(50.9)	0.180
Bachelor	190(49.1)	197(50.9)	
Master	81(57.9)	59(42.1)	
<b>Occupational status</b>			
Employed Part time	35(50.7)	34(49.3)	0.243
Employed Full time	134(48.0)	145(52.0)	
Housemaker	20(42.6)	27(57.4)	
Students	160(55)	131(45)	
<b>Age of menarche</b>			
<13 years	127(48.1)	137(51.9)	
≥ 13 years	222(52.6)	200(47.4)	
<b>Menstruation pattern</b>			
Regular	108(58.7)	76(41.3)	
Irregular	241(48.0)	261(52.0)	
<b>Pregnancy status</b>			
Previously Conceived	39(60)	26(40)	0.139
Not able to conceive	36(42.9)	48(57.1)	
Don't have any plan yet	58(55.8)	46(44.2)	
Unmarried	216(49.9)	217(50.1)	
<b>Duration of PCOS</b>			
Less than 1 year	141(55.5)	113(44.5)	
1 to 5 years	151(47.9)	164(52.1)	
More than 5 years	57(48.7)	60(51.3)	
<b>Medication status for PCOS</b>			
Taking medication regularly	63(48.5)	67(51.5)	
Taken medicine in past	163(48.8)	171(51.2)	
Had not taken medicine yet	123(55.4)	99(44.6)	
<b>Duration of medication</b>			
Less than 1 year	191(52.5)	173(47.5)	0.002
More than 1 years	35(35.0)	65(65.0)	
Had not taken medicine yet	123(55.4)	99(44.6)	
<b>Presence of co-morbidities</b>			
Yes	52(40.6)	76(59.4)	0.010
No	297(53.2)	261(46.8)	

## DISCUSSION

This study was designed to find out the health-related quality of life among reproductive age group having PCOS. Almost all of the respondents (93.6%) belonged to 15-29 years age group indicating that PCOS is becoming more prevalent in younger population which is supported by other

studies in Nepal [6] and USA [7]. This study addresses weight problem as most common manifestation of PCOS showing 26.5% as overweight and 12.9% as obese as in other studies in Nepal and Bangladesh where the percentages were even more ranging from 33-41% for each

[8,9]. Most of respondents (63.1%) were unmarried, and 90.7% were residing in urban area. It was more prevalent among urban people which could be attributed to lack of awareness among rural people and lack of gynecologists and radiologists in rural areas to diagnose such patients.

Majority (74.1%) of the women were found to have irregular menstrual cycle as in other related studies [6,10]. Among 253 married women, one fourth (25.7%) of the women had previously conceived, while 33.3% women were not able to conceive baby. Infertility has been reported as major issue in the women of other developing to well developed countries showing 54.7% to 73.33% nulliparity among married women [7,9]. In this study, majority (45.9%) of the respondents were diagnosed with PCOS between 1-5 years whereas 17.1% has been diagnosed earlier (i.e. >5 years). Further the suffering with PCOS might have been even before that due to possibly late diagnosis as in other morbidities. Most of the respondents (48.7%) had taken medicine in past. More than half (53.0%) of the women had taken medicine for less than 1 year, while 32.4% of the women had not taken any medication yet. As there is no cure of PCOS, treatment modalities mainly includes symptomatic alleviation by regular medication [4] but many women had taken medicine in past and then discontinued, which also make them suffer from PCOS symptoms continuously. Most of the respondents (81.3%) didn't have any co-morbidities, while among 128 women having co-morbidities, majority (56.2%) women had hypothyroidism. This study result is supported by study done by Joshi et al. (2017) in Nepal, which showed 30% respondents had hypothyroidism, which is not an uncommon finding [8].

PCOS is a severe endocrine illness that affects young women's health-related quality of life (HRQOL) and mental well-being [10,11,12]. Likewise in this study nearly half (49.1%) of the respondents were found to have poor quality of life. Reduction in quality of life of women with PCOS may be due to presence of multiple signs and symptoms, complications like infertility and metabolic disturbances along with burden of treatment modalities.

Most common Health-related quality of life concern reported was Infertility (28.57%) and least concern was about Acne (71.43%) as in other similar studies

[13], while weight domain ranked fourth highest of concerns on PCOSQ even it was the most common domain reported in this study. The study conducted by McCook et al. (2005) in South east U.S cities showed that most common Health-related quality of life concern reported was weight and least concern was body hair, whereas infertility problems ranked third highest of concern on the PCOSQ [7]. As Nepal is a developing country, fertility status of women is first concern rather than adopting assisted reproductive technologies, while in developing countries assisted reproductive techniques are widely accepted and utilized, hence there is most concern about fertility status among Nepalese women over other domains.

Normal ovulation results in regular menstrual cycles, anovulation is pathognomic feature of PCOS which results in irregular menstrual cycle and irregular menstrual pattern may be associated with reduction in QoL of women with PCOS [6]. The array of undesirable symptoms not only can have a profound impact on psychological morbidity, but the ranges of treatments that are offered to relieve them also are a vast contributor to an overall diminished woman's quality of life [4]. Similarly in this study those women taking medication for more longer duration influences in overall quality of life, which may be due to burden of taking medication daily and its associated side effects. Presence of other co-morbidities along with PCOS makes women to feel physical and psychological burden and may be associated with decline in HRQoL as compared to women not having any co-morbidities. The study was conducted through online survey in facebook, so most of the respondents belongs young age group, women who are not active in social media cannot be included in this study, so the findings cannot be generalized to overall population.

## CONCLUSIONS

On the basis of the findings it is concluded that more than half of the respondents have good quality of life. The most common health related concern was infertility while least common health related concerns was about acne. Various factors like BMI, menstrual pattern, duration of medication and co-morbidities have found to influence health related quality of life of women with PCOS. It is important to educate and make unmarried PCOS

patients aware of its association with infertility and long-term medical problems. Various programmes should be conducted regarding infertility and assisted reproductive technologies giving special attention to the women having PCOS. Management of PCOS should be directed to improve quality of life of PCOS patients. Early and effective management of PCOS may result in the improvement of HRQoL in adolescents and the transition to adulthood. A similar study can be conducted in real situation like hospital by using interview schedule or self-administered

questionnaire to find out Health related quality of life among women having PCOS. The HRQoL of women with PCOS could be assessed in terms of various signs and symptoms that address wider aspect of patient wellbeing. Life style pattern and coping mechanism could also be taken in consideration while conducting study on HRQoL of women with PCOS. Psychological support should be considered as an additional care for women with PCOS. Qualitative studies should be incorporated in order to better understand the women's spiritual and emotional connections.

#### ADDITIONAL INFORMATION AND DECLARATIONS

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