

## Sociocultural Correlates of Health-Related Quality of Life of Women with Polycystic Ovarian Syndrome (PCOS) in Sri Lanka

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**Abstract** - Polycystic Ovary Syndrome (PCOS) is a common endocrine disorder of women. Chronic complex symptomatology and long-term comorbidity risk associated with PCOS may have negative effects on the quality of life of women. Current study assessed the sociocultural correlates of HRQOL of women suffering from PCOS.

A descriptive cross-sectional survey was conducted with hundred women diagnosed with PCOS at De Soysa Hospital for Women. World Health Organization Quality of life - Brief (WHOQOL-BREF) and a general information sheet were used to assess HRQOL and participants characteristics respectively.

Higher age at PCOS was associated with lower overall QOL ( $\beta=-0.357, p=0.010$ ) and overall health ( $\beta=-0.371, p=0.004$ ). Current unemployment was associated with lower overall QOL ( $\beta=-0.269, p=0.009$ ) and physical QOL ( $\beta=-0.206, p=0.039$ ). Having no children was associated with lower overall QOL ( $\beta=-0.313, p=0.005$ ). Not following diet and exercise advices was associated with lower overall health ( $\beta=-0.239, p=0.011$ ), physical QOL ( $\beta=-0.279, p=0.005$ ) and psychological QOL ( $\beta=-0.250, p=0.019$ ).

Education level (AL) was associated with higher overall QOL ( $\beta=-0.349, p=0.007$ ), physical QOL ( $\beta=0.258, p=0.041$ ) and environmental QOL ( $\beta=0.366, p=0.006$ ). Education level (OL) was associated with higher physical QOL ( $\beta=0.278, p=0.026$ ). Higher income level was associated with higher physical QOL ( $\beta=0.274, p=0.011$ ). Tamil ethnicity was associated with higher overall health ( $\beta=-0.248, p=0.045$ ). Religion as Christian or Roman Catholic was associated with higher physical QOL ( $\beta=0.225, p=0.026$ ).

Sociocultural factors were predictive of the level of HRQOL. Higher age at PCOS diagnosis, having no children, current unemployment and not following diet exercise advices were predictive of low HRQOL. Higher education and income levels, Tamil ethnicity and Christian or Roman Catholic religion were predictive of high HRQOL.

**Keywords** - health-related quality of life, polycystic ovary syndrome, sociocultural correlates

### I. INTRODUCTION

PCOS is recognized as the most prevalent endocrine disorder amongst women of childbearing age (Sanchez, 2014). The community prevalence of PCOS in Sri Lanka was reported as 6.3% in a random sample of 3030

women aged 15-39 of Gampaha District (Kumarapeli, Seneviratne, Wijeyaratne, Yapa, & Dodampahala, 2008) with a trend of increasing incidence rate (Arambewela et al., 2018). PCOS is being a chronic syndrome with a distressing symptomatology and long-term comorbidity risk, which can be diagnosed at an age range where important life events do occur, it is perhaps unsurprising such women to have poor psychological wellbeing with low quality of life (Sanchez, 2014). In particular, signs of compromised psychological wellbeing of South Asian women with PCOS, which is mostly an interplay of social cultural upbringing (Sharma and Mishra, 2018), were often expressed as health-related behavioural deviations such as poor or no medical assistance seeking with consequent late diagnosis, reduced treatment compliance and self-management (Kumarapeli et al., 2008; Kumarapeli, Seneviratne and Wijeyaratne, 2011; Nandi et al., 2016). Further, based on the understanding of PCOS as a multifaceted condition, that results from the interaction of various genetic (Fauser, 2017; Yilmaz et al., 2018) and environmental factors: diet, lifestyle, unhealthy behaviours, urbanization (Vidya Bharathi et al., 2017), possible influence of sociodemographic and cultural factors were in discussion in both South Asian (Chaudhari, Mazumdar and Mehta, 2018; Joseph et al., 2016; Prathap, Subhalakshmi and Varghese, 2018) and Western studies (Elsenbruch et al., 2006). Thus, expanding the knowledge of quality of life and specific contributing factors, through HRQOL measurements, which provide the perspectives of patients on diseases is of paramount importance.

Present study attempted to explore possible sociocultural correlates of HRQOL of PCOS.

### II. METHODOLOGY AND EXPERIMENTAL DESIGN

#### Design

A descriptive cross-sectional survey was conducted from November 2018 to January 2019 at De Soysa Hospital for Women, Colombo. The study was approved by the Ethics Review committee of University of West London. Local ethical clearance was granted by National Hospital of Sri Lanka and administrative clearance was obtained from De Soysa Hospital for Women.

#### Participants

Hundred women (N=100) diagnosed with PCOS and in the age range of 19-40 were selected. Participants were

consecutive attendees of endocrine, subfertility and gynaecologic clinics of the De Soysa Hospital for women. PCOS diagnosis was confirmed by a consultant gynaecologist, obstetrician, or reproductive endocrinologist based on the Rotterdam diagnostic criteria.

Female who were younger than 19 or older than 40, who were acutely ill and who could not declare consent, who were diagnosed with similar endocrine disorders; congenital adrenal hyperplasia, Cushing's syndrome, androgen-secreting tumors, females who had been previously diagnosed with a psychiatric disorder and females with language difficulties were excluded from the study.

**Materials**

General Information Sheet pertained to sociodemographic details; age, age at puberty, age at PCOS diagnosis, marital status, religion, ethnicity, whether having children, social level; occupation status, education level, monthly income and follow up status of diet and exercise advices. HRQOL was assessed through World Health Organization Quality of Life - Brief (WHOQOL-BREF), 26 item shortened version of WHOQOL -100. WHOQOL-BREF consists of two global items: overall perception of the QOL and health status and four specific domains: physical, psychological, social relationships and environment.

All data collection tools were available in three languages; English, Sinhala, Tamil. Forward and backward translation method was used. Consensual validation was achieved via five experts in the field for its suitability to be used in the target population. Translated instruments were pretested.

**Analysis**

The quantitative data derived were analysed using the Statistical Package for the Social Sciences software (SPSS) (version 24). For all analyses, a significance level of  $p < 0.05$  was assumed.

The sociodemographic profile has been expressed in terms of frequencies and percentages, while age profile as range, mean and standard deviations (SD). For scale variables, Shapiro-Wilk normality test has been carried out to decide on suitable analyses.

The possible impact of sociodemographic factors on HR-QOL was achieved through multiple regression analyses performed on two global scales and four QOL domains of WHOQOL-BREF. Potential predictive variables included in models were based on previous literature and enter method is used. Age, age at puberty and age at PCOS diagnosis were included as scale variables. For binary variables being married, having children, currently employed and following diet exercise advices were kept as reference categories. For nominal scales; ethnicity and religion, being Sinhala and Buddhist were the respective reference categories. For ordinal variables: education and income level, no school education to education up to grade 5 and income below Sri Lankan Rupees 10,000 respectively were kept as references. B coefficient and

adjusted  $R^2$  were evaluated in terms of strength, direction of variable and model fit accordingly.

**III. RESULTS**

*Sociodemographic profile of the study participants*

The age of selected women ranged from 19-40 with a mean age of 17(SD=5.3). Age at puberty and age at PCOS diagnosis had mean age of 13 (SD=1.62) and 23 (SD=5.32) respectively. Noteworthy, age at PCOS diagnosis ranged from adolescence (13) to mid-adulthood (38). The representation of gynaecologic, subfertility and endocrine clinics were 59%,37% and 4% respectively. Study group was comprised of 82% married and 18% unmarried women with an ethnically diversified sample of Sinhala (59%), Muslim (31%) and Tamil (10%) women. Majority of women were employed (66%). The most achieved educational levels were GCE ordinary Level (36%) and advanced level (24%) examinations. Majority (41%) reported a monthly income level between Sri Lankan Rupees (LKR) 10,000 - 30,000. The majority of both married (79%) and unmarried (78%) women were not following diet exercise advices, 80% of the total sample.

*Psychosocial and cultural correlates of HRQOL*

The regression model for overall QOL indicated there was a collective significant effect of the variables involved ( $F(17,82) = 2.455, p = 0.004$ ) and have accounted for 58.1% variance of overall QOL. Accordingly, having higher educational level (AL) had significantly increased overall QOL by 0.349 units ( $p = 0.007$ ), while higher age at PCOS diagnosis and being currently unemployed had decreased QOL by respective 0.357 and 0.269 units ( $p = 0.010$  and  $p = 0.009$  respectively) (table 1).

Regression model for overall perception of health was a significant fit for the data ( $F(17,82) = 3.732, p = 0.001$ ), which accounted for 66% variance of overall perception of health. Thereby, higher the age at PCOS diagnosis ( $\beta = 0.371, p = 0.004$ ), having no children ( $\beta = -0.313, p = 0.005$ ), not following diet exercise advices ( $\beta = -0.239, p = 0.011$ ) were predictive of lower perception of overall health, while being a Tamil woman predicted the opposite ( $\beta = -0.248, p = 0.045$ ) (table 1).

Table 1. Regression models for WHOQOL BREF - General QoL and General Health

Variables	General QoL		General Health	
	$R^2=0.581, F(17,82)=2.455$ $p=0.004$		$R^2=0.660, F(17,82)=3.732$ $p=0.001$	
	$\beta$	$p$	$\beta$	$p$
Age	-.079	.572	-.051	.689
Age at Puberty	.083	.389	-.069	.437
Age at PCOS diagnosis	-.357	.010	-.371	.004
Marital Status	.019	.892	.150	.238
Have no children	-.110	.354	-.313	.005
Not employed	-.269	.009	-.057	.535
Ethnicity - Tamil	.011	.933	.248	.045
<b>Religion</b>				
Hindu	.077	.565	-.203	.102
RC or C	-.142	.164	-.130	.168
Islam	-.120	.302	.175	.104
<b>Education Level</b>				
OL	.204	.108	.095	.417
AL	.349	.007	-.101	.391

environmental domain, it was only the education level (AL), which predicted a significant increase in QOL by 0.366 units ( $p=0.006$ ).

IV. DISCUSSION AND CONCLUSION

*The Impact of Sociodemographic Factors on QOL*

According to present results, age at puberty had no significant impact on QOL. Nevertheless, higher age at PCOS diagnosis and nonemployment, infertility and not

Table 2. Regression models for WHOQOL BREF domains

Variables	Physical		Psychological		Social Relationships		Environment	
	$R^2 = 0.604$		$R^2 = 0.231$		$R^2 = 0.371$		$R^2 = 0.494$	
	$F(17,82) = 2.773$		$F(14,85) = 1.819$		$F(17,82) = 0.768$		$F(15,84) = 1.808$	
	$P = 0.001$		$P = 0.049$		$P = 0.723$		$P = 0.047$	
	$\beta$	$p$	$\beta$	$p$	$\beta$	$p$	$\beta$	$p$
Age	.020	.885	NI		.023	.884	NI	
Age at Puberty	-.060	.527	-.154	.130	-.071	.518	-.030	.765
Age at PCOS diagnosis	.011	.932	-.143	.161	-.041	.790	-.128	.208
Marital Status	-.117	.383	NI		.107	.496	NI	
Have no children	-.208	.077	-.092	.380	-.167	.220	-.157	.138
Not employed	-.206	.039	.001	.989	.026	.821	-.180	.089
<b>Ethnicity - Tamil</b>	-.128	.324	NI		-.158	.296	-.187	.183
<b>Religion</b>								
Hindu	-.020	.880	-.095	.380	.054	.725	.029	.839
RC or C	.225	.026	.097	.363	.081	.484	.181	.092
Islam	.072	.524	-.031	.800	.024	.854	.130	.286
<b>Education Level</b>								
OL	.278	.026	.191	.140	-.029	.838	.170	.196
AL	.258	.041	.110	.396	.251	.087	.366	.006
Diploma, D, PG	.117	.357	.106	.415	.007	.962	.036	.781
<b>Monthly Income</b>								
10,000 -30,000	.057	.604	.005	.964	.094	.459	-.143	.226
30,000 -60,000	.172	.120	.215	.069	.202	.119	-.027	.815
60,000 -100,000	.274	.011	.219	.056	.112	.368	-.038	.734
Not following diet exercise advices	-.279	.005	-.250	.019	-.064	.574	-.120	.253

following diet exercise advices had predicted lower QOL, while higher education and income levels and ethnicity-Tamil, religion-Christianity were predictive of higher QOL.

With regard to QOL domains, regression models demonstrated collective significant predictive effect of variables involved at physical ( $F(17,82)=2.773$ ,  $p=0.001$ ), psychological ( $F(14,85)=1.819$ ,  $p=0.049$ ) and environmental ( $F(15,84)=1.808$ ,  $p=0.047$ ) domains, except for social relationships domain ( $F(17,82)=0.768$ ,  $p=0.723$ ).

Thereby, respectively, 60.4%, 23.1% and 49.4% of variances have been explained in terms of physical, psychological and environmental QOL.

Accordingly, higher education; GCE Ordinary level ( $\beta=0.278$ ,  $p=0.026$ ), Advanced level ( $\beta=0.258$ ,  $p=0.041$ ), higher income level ( $\beta=0.274$ ,  $p=0.011$ ) and religion as Christian or Roman Catholic ( $\beta=0.225$ ,  $p=0.026$ ) were predictive of increased physical QOL, whereas being unemployed ( $\beta=-0.206$ ,  $p=0.039$ ) and not following diet exercise advices ( $\beta=-0.279$ ,  $p=0.005$ ) reported the opposite. The only significant predictor at psychological domain, not following diet exercise advices showed a decreased QOL by 0.250 units ( $p=0.019$ ). For

A. Higher age at PCOS diagnosis

Time since diagnosis has been included in PCOS studies with late diagnosis trends, which is highly evident in South Asian countries (Nandi *et al.*, 2016) including Sri Lanka (Kumarapeli *et al.*, 2008; Kumarapeli, Seneviratne and Wijeyaratne, 2011). This situation is further proved by the

smaller percentage of young unmarried women in the present sample. There is a growing research interest on adolescent PCOS diagnostic markers in Asia, for instance, increased serum kisspeptin levels in Sri Lankan adolescents and have indicated the importance of detecting young women at risk (Umaya *et al.*, 2019).

Lack of awareness (Gupta *et al.*, 2017), cultural beliefs and practices, unattended lifestyle, dietary and visible bodily changes such as increased body weight, hirsutism (Kumarapeli, Seneviratne and Wijeyaratne, 2011) have really confounded her journey, which otherwise would have assisted in increasing prognosis, provided proper

early guidance. Furthermore, it may not be solely symptom-based evaluations, but studies, which reported reduced sexual satisfaction, partnership issues (Nasiri Amiri *et al.*, 2014), reduced career choices (Dowdy, 2012) have indicated how important social relationships can be complicated with age and would have at least managed or reduced to some extent if early diagnosis was present.

#### *B. Having no children*

The present sample being predominantly married, majority of women would have received their diagnosis when fertility issues are realized (Kumarapeli, Seneviratne and Wijeyaratne, 2011). South Asian PCOS studies, which were increasingly based on infertility clinics (Mandrelle *et al.*, 2012) were an indirect expression of late diagnosis. Infertility has reported as the most distressing symptom among married women of South Asian (Vora and Patil, 2015) and West Asian (Bazarganipour *et al.*, 2013) women. The recognition of the limitations associated with fertility treatments in achieving normal reproductive capacity, guilt and worry of not being able to detect the condition at an early stage, desire to conceive and related comparisons of own self to women of same age with children (Nasiri Amiri *et al.*, 2014) would have contributed for her decreased QOL perceptions. Even unmarried women reported to have fear of future infertility (Barrett *et al.*, 2018). Particularly, primary infertility can be extremely stressful due to cultural and social norms associated with motherhood (Sharma and Mishra, 2018). Even, secondary infertility is mattered in South Asian countries, certain ethnic groups such as Muslim Women with PCOS would have had more concerns of having more offspring based on religious beliefs (Taghavi *et al.*, 2015).

#### *C. Income, education levels and employment*

In consideration of the characteristics of the majority, irrespective of the responsibilities of the marriage life and being employed, the present sample had managed to be present at a routine clinic. Higher income, education level and current employment could have set their foundation respectively, by being economically able, knowledgeable and having some status in the society, thus, their chronic condition should be attended and treated.

However, expecting the situation to remain same in rural communities would be rather limited. Not being able to afford treatments (Kumarapeli, Seneviratne and Wijeyaratne, 2011), less knowledge on PCOS treatment opportunities available and being unemployed and confined to household work at large (Vidya Bharathi *et al.*, 2017) reflected the impact of income, education level and employment status of rural women in Asia. Thereby, evaluation of the socioeconomic status further implied the importance of understanding the context, which women live, and how it affects health-related behaviours. Thus, expecting rural women to appear at hospital-based clinics on their own decision as in urban areas would be limited (Kumarapeli *et al.*, 2008; Kumarapeli, Seneviratne

and Wijeyaratne, 2011) and even attended, they showed no knowledge of PCOS (Sharma and Mishra, 2018).

Increasing awareness is a necessity. However, the extend of awareness needed at urban and rural areas would be different depending on how women cope and understand this chronic disease (Vidya Bharathi *et al.*, 2017). Thereby, the awareness programmes for urban women could be hospital-based where women are more likely to be present at routine clinics and should concentrate more on maintaining the condition by required lifestyle changes including diet and exercise. Further, it became noteworthy that young PCOS women had higher education level and are currently employed. Considering their increased capacity to acquire knowledge, a proper awareness program could attract more young women in to treatments. Thus, the negative effects of seeking medical assistance only when infertility issues realized would be reduced, which found to be a common occurrence in Asian countries: India (Sharma and Mishra, 2018), Bangladesh (Nandi *et al.*, 2016) including Sri Lanka (Kumarapeli, Seneviratne and Wijeyaratne, 2011b). In a Sri Lankan community-based study, probable cases of PCOS were interviewed with the presence of public health midwife of that region (Kumarapeli *et al.*, 2008). This indicated, in order to be successful, rural awareness programs should largely be community-based with the presence of familiar field medical staff.

#### *D. Not following diet and exercise advices*

If health-related behaviours of Asian Women with PCOS are expressed in a continuum, it appears to range from little or no knowledge of PCOS, aware of symptoms but do not bother or neglect, to active participation in routine clinics. Due to information gaps throughout this continuum, medical assistance is sought mainly to resolve infertility and irregular periods respectively in part of married (Vora and Patil, 2015) and unmarried women (Nandi *et al.*, 2016). Thereby, essential lifelong maintenance needed by the syndrome is given scant attention, which is evident by 80% non-followers of diet exercise advices received from hospital dietician centre.

Present result also highlighted the risk of PCOS as growing lifestyle disorder in urban areas, which is already considered an epidemic in certain South Asian countries (Vidya Bharathi *et al.*, 2017). Cultural ignorance and lack of knowledge (Kumarapeli, Seneviratne and Wijeyaratne, 2011b) have got precisely coupled with the modern lifestyle of urban South Asian Women with PCOS to an extent, where her life stressors, behaviours including diet and exercise have confirmed the syndrome is continued to be worsened, the very reason for reduced psychological QOL in the present sample.

PCOS comes with the good news that it is manageable and highlighted the importance of initiating lifestyle modifications, the first-line of treatment at an early stage, which also proven to improve QOL of women (Pitchai, Sreeraj and Anil, 2016). The essential message of diet exercise programs should therefore go beyond advising

to reduce and maintain weight with proper dietary and exercise practices, but motivate lifestyle modifications to become a habit, which prove to be beneficial in reducing long term comorbidities, probable occurrence of endometrial cancer and success in fertility (Redman, Elkind-Hirsch and Ravussin, 2011). Perhaps, the present sample may have not reached to this message properly.

*E. Tamil ethnicity and Christian or Roman Catholic religion*  
The increased attention of screening and treatments options have made ethnic specific studies of PCOS to become largely symptom based (Wijeyaratne *et al.*, 2011). Diagnosis of PCOS may present similar physical characteristics, yet psychosocial-cultural factors at personal level may differ from woman to woman, making their identification with the disease is different (Karnilowicz, 2011). Thereby, the identification of central obesity and low BMI, the ethnic specific features of South Asian women should reach one step further in designing culturally appropriated psychosocial support for women at both personal and group levels to improve QOL.

#### *Strengths and limitations of the study*

In order to identify the true clinical-representation of PCOS, three clinics: endocrine, sub-fertility and gynaecology were included. Further, the sample being hospital-based, inclusion and exclusion criteria were well met other than to a community-based sample. Additionally, study was able to isolate the effect of PCOS by excluding other comorbid illnesses. Data collection tools were available in English, Sinhala and Tamil and confirmed no ethnic or religious constrains on participation. Thereby, represented the ethnic diversity of PCOS in an urban area in Sri Lanka. Further, the lack of control group enabled assessing probable intervening sociocultural factors of QOL in-depth.

However, majority being married women, generalizing current findings on to young unmarried women, adolescents and women at menopausal age would be limited. Secondly, the questionnaire used to assess QOL was generic and there was no disease specific questionnaire used. Thereby, the impact of PCOS symptoms on HRQOL was not assessed. Further, the sample being predominantly married women, fertility issues were a more likely concern vs other PCOS symptoms.

#### *Recommendations*

Late diagnosis of PCOS had a clear negative impact on QOL. Thereby, health education at community level for early diagnosis of PCOS is highly recommended. Furthermore, health counselling at clinic premises is a necessity in order to improve treatment compliance specially in lifestyle modifications required in diet and exercise.

#### *Future research*

Qualitative study to assess the impact of socio-cultural factors on HRQOL would allow in-depth assessment and grasping more QOL aspects of women with PCOS.

#### *Conclusion*

In conclusion, the HRQOL of Sri Lankan women with PCOS is affected by a host of sociocultural factors. This understanding indicated possible individual, clinical and societal level implications in achieving a holistic approach on HRQOL during PCOS journey.

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