Health-related quality of life and psychological distress in polycystic ovary syndrome: a hidden facet in South Asian women

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Objective Polycystic ovary syndrome (PCOS) is associated with symptoms that affect psychological wellbeing and health-related quality of life (HRQoL). We wished to assess psychological distress and HRQoL among Sri Lankan women with PCOS.

Design Case–control study.

Setting Gampaha District, Sri Lanka.

Population A total of 146 newly diagnosed women with PCOS, according to the Rotterdam criteria, and 170 age-matched controls recruited from community screening of 3030 eligible women between 15 and 39 years of age.

Methods World Health Organization Quality of Life questionnaire (WHOQOL-BREF), validated for Sri Lankans with PCOS and a 30-item General Health Questionnaire (GHQ30) were used to assess HRQoL and psychological distress, respectively.

Main outcome measures Assessment of psychological distress, HRQoL and their correlates.

Results The mean GHQ score was significantly higher ($P < 0.001$) among women with PCOS (5.25 ± 6.25 SD) than among controls

(1.58 ± 1.46 SD), indicating greater psychological distress. Hirsutism in PCOS (defined as a Ferriman–Gallwey, FG, score ≥ 8) was significantly associated with psychological distress ($P = 0.002$). Multivariate analysis revealed the FG score as a significant predictor of psychological distress ($P < 0.05$). Mean scores for the physical, psychological and social relationships domains of the WHOQOL-BREF were significantly lower ($P = 0.01$) in women with PCOS than in controls, indicating poorer HRQoL. No significant predictors of HRQoL emerged from the multivariate analysis. Women with PCOS did not perceive excess body weight as a factor affecting their psychological wellbeing and HRQoL.

Conclusions PCOS occurring in South Asians adversely affects their psychological wellbeing and HRQoL. Their psychological distress is related to hirsutism rather than to obesity, which affects white Europeans with PCOS.

Keywords Health-related quality of life, polycystic ovary syndrome, psychological distress, Sri Lanka.

Introduction

Polycystic ovary syndrome (PCOS) causes a range of problems that can impact the health-related quality of life (HRQoL), emotional well-being and sexual satisfaction of women.[1–4] These effects have been reported in studies comparing women with PCOS with healthy controls, other gynaecological populations and with normative data,[5–8] which have demonstrated that PCOS has a greater impact on women's psychological well-being when compared with chronic problems such as asthma, epilepsy, diabetes, backache, arthritis and coronary heart disease.

The changes that occur in a woman's physical appearance as a result of PCOS, particularly hirsutism, acne and obesity, along with menstrual irregularity and infertility, have been found to be the main contributors to psychological morbidity.[2–5,9–12] Relying on the severity of clinical parameters of hyperandrogenism and oligo-ovulation alone overlooks the emotional problems and effects on HRQoL experienced by women with PCOS. Furthermore, objective measurements alone may not reflect the degree to which the affected woman perceives the severity of her symptoms. Self-perceived severity of symptoms are reported to correlate more directly with the HRQoL.[6,7,11,13] Hence, the

consequences and impact of PCOS on HRQoL and psychological well-being need to be studied in addition to its somatic effects to enable optimal care for those affected.

Research on HRQoL among women with PCOS has been conducted mainly in the UK, USA and Germany.[14] There is a paucity of data on the impact of PCOS on these aspects among other ethnic groups. Researchers have identified the need to explore the impact upon HRQoL in different cultures and ethnicities, as cultural traditions and culture-typical gender identity may influence the HRQoL of women with PCOS.[15–17] Problems related to HRQoL and psychological distress among South Asian women have not been reported in detail; therefore, we wished to study indigenous women with PCOS diagnosed by a community-based screening programme in Sri Lanka, in order to determine specific issues related to rural women from the region.

Methods

Recruitment of participants

Approval was obtained from relevant health authorities prior to the commencement of the study. Ethical approval was granted by the Ethics Review Committee of the Faculty of Medicine, University of Colombo, Sri Lanka. Informed written consent was obtained prior to interview, clinical examination and withdrawal of blood from subjects, following an explanation of the study objectives and their implications.

A community-based cross-sectional survey was carried out from August 2005 to February 2006 among 3030 women aged 15–39 years, residing permanently in the district of Gampaha, Sri Lanka. The random sample of 3030 women was selected by a cluster sampling technique. The primary sampling unit was a 'Grama Niladari Division' (GND: a village). As the size of a cluster was 30 eligible women, 101 clusters were located proportionately to the population size in the list of villages based on 2001 census data.[18] Within each cluster, 30 eligible women of 15–39 years of age were identified, in proportion to the distribution of women in the same district, from the age strata 15–19, 20–24, 25–29, 30–34 and 35–39 years.[18]

Data were collected by a team of five field investigators/female physicians and the principal investigator. The public health midwife of the selected GND functioned as the field guide to locate the households with eligible women. As she was a member of the team, this increased the confidence and the cooperation of the subjects. Every selected cluster was covered by the team on a weekday and on a Sunday to identify and interview eligible women. When more than one woman of the required age stratum was living in a given household, the investigator randomly selected one woman. When no woman from the desired age stratum was present in a household, the search continued in consecutive households until a woman in the desired age stratum was found. This procedure was carried out until each age stratum within a cluster had the requisite number of women. The outcome was recorded as a 'non-response' after a maximum of three failed attempts at interview.

A pre-tested interviewer-administered questionnaire (IAQ) was used for data collection, which included a checklist that evaluated two common categories of symptoms experienced by women with PCOS: oligo/amenorrhea, defined by menstrual cycle length, and clinical features of hyperandrogenism, as defined by methodological details published previously.[19] The IAQ was administered to all 3030 eligible women aged 15–39 years to screen for 'probable cases' of PCOS. A 'probable case' was defined as a woman with oligo/amenorrhea and/or clinical features of hyperandrogenism.

Age-matched controls were selected concurrently from the same community. A 'probable control' was defined as a woman with regular menses and no clinical features of hyperandrogenism, who was not a relative of a 'probable case'. 'Probable controls' were selected at a 1:1 ratio by drawing lots among eligible women from the same age stratum within a cluster.

All 'probable cases' and randomly selected 'probable controls' underwent clinical (hirsutism determined by FG score, acne and androgenic alopecia), biochemical (serum testosterone) and ovarian ultrasound assessment, following previously published methodological details.[19]

The overall response rate was 96.2% ($n = 2915$). A 'probable diagnosis' of PCOS was found among 220 women (7.5%) identified for the first time by this survey to have oligo/amenorrhea and/or clinical hyperandrogenism. Of the 220 'probable cases', 179 women underwent further evaluation. Concurrently, 238 age-matched eligible women were randomly approached from the same clusters where the cases were identified, as described above, to recruit 220 consenting 'probable controls'. Of these, 171 underwent further evaluation.

After clinical, biochemical and ultrasound evaluation, 164 newly diagnosed women with PCOS and 170 controls were found among the 2915 women screened, as described previously.[19]

A confirmed case of PCOS was diagnosed based on the case definition of the Rotterdam revised diagnostic criteria, i.e. having any two of the following: oligo/amenorrhea, clinical and/or biochemical hyperandrogenism, and polycystic ovaries.[20] All women with clinical, biochemical or ovarian ultrasound abnormalities were referred to a single endocrinologist (CNW) for confirmation of the diagnosis by exclusion of other possible causes.

However, only 146 women with PCOS and 170 controls, who had attended the local clinics for clinical and

biochemical assessment, completed the questionnaires that measured HRQoL and psychological distress.

Instruments and measures

The IAQ gathered information on demographic and socio-economic factors, reproductive health history, healthcare-seeking behaviour, and on perception of excess body hair, troublesome acne and being overweight.

The World Health Organization Quality of Life questionnaire (WHOQOL-BREF) and General Health Questionnaire (GHQ30) were used to get a self-assessment of the HRQoL and psychological distress, respectively, of the 146 newly diagnosed women with PCOS and 170 controls identified from the same community survey.

The WHOQOL-BREF also inquired about having any medical conditions at the time of data collection, viz. heart disease, hypertension, arthritis/rheumatism, diabetes, emphysema/chronic bronchitis, chronic nervous/emotional problems, cataract, stroke, Parkinson's disease, fractured/broken bone, chronic foot trouble, rectal growth/rectal bleeding, cancer and any other condition reported by the respondent. The medical conditions reported were confirmed by checking their diagnosis cards, clinic records or prescriptions.

The WHOQOL-BREF, an abbreviated 26-item version of WHOQOL-100, has four domains related to quality of life, i.e. physical health, psychological health, social relationships and environment, giving four scores relating to the four domains. Answers to all questions were rated on a Likert scale of 1–5. According to the guidelines recommended by the WHO study group on WHOQOL-BREF, the score for each domain was transformed into a 0–100 score, where high values represent a better quality of life. Each question assessed HRQoL in the preceding 2 weeks.[21]

Validation of the WHOQOL-BREF

The WHOQOL-BREF, which had previously been translated into Sinhala (vernacular), was validated first by applying the questionnaire on Lankan women with well-characterised PCOS, following WHO guidelines. The validation was carried out on a consecutive sample of 130 women with PCOS attending a specialist endocrine clinic at a tertiary referral centre in Colombo, and 130 community-based controls. Good convergent and discriminant validity was demonstrated by the WHOQOL-BREF for similar and different scales, respectively, in comparison with the 36-item Short Form Health Survey (SF-36). Internal consistency measured using Cronbach's alpha exceeded Nunnally's criteria of 0.7 for all except the social relationship domain in both groups, whereas the test re-test reliability measured using Pearson's correlation coefficients exceeded >0.7 ($P < 0.01$) in all domains. WHOQOL-BREF was found to be a valid and reliable tool to assess the HRQoL of women with PCOS.[22]

The Goldberg's GHQ30 is a self-administered questionnaire that has been previously validated and widely used in Sri Lanka.[23] It is recommended as a first-stage screening instrument for general population surveys to identify potential cases that could then be verified using a psychiatric interview. It is designed to identify two main classes of problems: i.e. the inability to carry out one's normal 'healthy' functions and the appearance of new phenomena of a distressing nature. It focusses on breaks in normal functioning rather than on lifelong traits. Each question of the GHQ30 assesses health in general in the preceding few weeks: i.e. present and recent complaints. An individual's response was given as a single score. High values represent greater distress.[24]

Analysis

Statistical analysis was performed using the computer program Statistical Package for Social Sciences (SPSS® 11.0, Chicago, IL, USA). The Kolmogorov–Smirnov test was used to test for normality of distribution for relevant demographic and clinical characteristics.

The GHQ30 score and scores for each of the four domains of WHOQOL-BREF were compared between cases and controls. A cut-off score of 6 was used to differentiate the presence (≥ 6) and absence of psychological distress (<6) among women with PCOS, based on a previous report from Sri Lanka.[23] The demographic, socio-economic and clinical characteristics were compared between women with PCOS experiencing psychological distress and those without psychological distress, and the significance of the difference was tested using the z-score test.

In the absence of a cut-off value for WHOQOL-BREF, to discriminate between good and poor HRQoL related to PCOS, the clinical characteristics and self-perceptions of those affecting appearance, i.e. acne, hirsutism and obesity, were scored and compared for each domain of the WHOQOL-BREF using a one-way analysis of variants (ANOVA). The differences between subcomponents of each characteristic were analysed using Tukey's test.

The best predictors of psychological distress (GHQ30 score) and poor HRQoL (WHOQOL-BREF score) were studied using multiple linear regression. The potential predictive variables used in the regression model based on previous research[2–5,9–12] were: endocrine status (PCOS versus control), age, body mass index (BMI), waist-to-hip ratio (WHR), FG score, and the presence of oligo/amenorrhea, acne and subfertility. These variables were measured as continuous variables or as binary variables when they were categorical. Separate models were developed for psychological distress (GHQ30 score) and HRQoL (WHOQOL-BREF scores), which were measured as continuous variables. The probability for regression models were fixed at the 0.1 level of significance for entry and for removal.

Results

Demographic, socio-economic and clinical characteristics among women with PCOS and controls

Demographic and socio-economic characteristics among women with PCOS and controls were comparable (Table 1). The occurrence of oligo/amenorrhea, hirsutism (FG score ≥ 8) and acne among those with PCOS were 95.1, 53.1 and 25.3%, respectively. As controls were selected from women with regular menses and no clinical features of hyperandrogenism, none of the controls had oligo/amenorrhea, hirsutism or acne. Among those with PCOS and hirsutism (FG score ≥ 8), only 56.4% thought that they had excess hair; similarly, among the PCOS group with acne, only 45.9% thought that they had an excess of pimples. Among the PCOS women with BMI ≥ 25.0 kg/m^2 (the Asian cut-off),[25] only 21.9% actually thought they were obese, whereas among those with BMI ≥ 30.0 kg/m^2 (non-Asian cut-off), 30.8% actually perceived their obesity (Table 2).

Generalised obesity, measured by a BMI ≥ 25.0 kg/m^2 (Asian cut-off),[25] occurred significantly more frequently among the PCOS group than among controls ($P = 0.001$). A significant difference was observed when generalised obesity was defined by a BMI ≥ 30.0 kg/m^2 (non-Asian cut-off) ($P = 0.003$) (Figure 1). Abdominal obesity also occurred in significantly more women with PCOS, with a greater WHR (>0.85) among 57.5% ($n = 84$) of them versus 41.2% ($n = 70$) of controls ($P = 0.01$).

The occurrence of medical illnesses among women with PCOS and controls were comparable (PCOS women versus controls): diabetes (2.1 versus 1.8%, $P = 0.58$), hypertension (3.4 versus 5.9%, $P = 0.29$) and heart disease (0.0 versus 1.8%, $P = 0.23$). In both groups no women had any other medical conditions. Infertility rates among the currently married women with PCOS and married controls were 13.5% ($n = 10$) and 11.6% ($n = 11$), respectively ($P = 0.71$).

Table 1. Demographic and socio-economic characteristics among women with PCOS and controls

Characteristic	Women with PCOS (n = 146)	Controls (n = 170)	*P* value
Age (years), mean (SD)	25.6 (7.1)	27.0 (7.1)	0.08
Currently married	50.7%	55.9%	0.35
Currently employed	21.2%	15.9%	0.22
Education (attended secondary school)	20.0%	17.6%	0.69
Household income less than 5000 SLR	19.2%	21.8%	0.62

Table 2. Actual occurrence and perceptions of hirsutism, acne and obesity among women with PCOS (n = 146)

Characteristic	Actual occurrence (%)	Perceived occurence (%)	Percentage who perceived out of actual occurrence
Hirsutism (FG ≥ 8)	78 (53.4)	44 (30.1)	56.4
Acne	37 (25.3)	17 (11.6)	45.9
Generalised obesity BMI ≥ 25 kg/m^2 (Asian definition)	64 (43.8)	14 (9.6)	21.9
Generalised obesity BMI ≥ 30.0 kg/m^2 (non-Asian definition)	26 (17.8)	8 (5.5)	30.8

Asian cut-off for generalized obesity BMI ≥ 25.0 kg/m2
Non-Asian cut-off for generalized obesity BMI ≥ 30.0 kg/m2
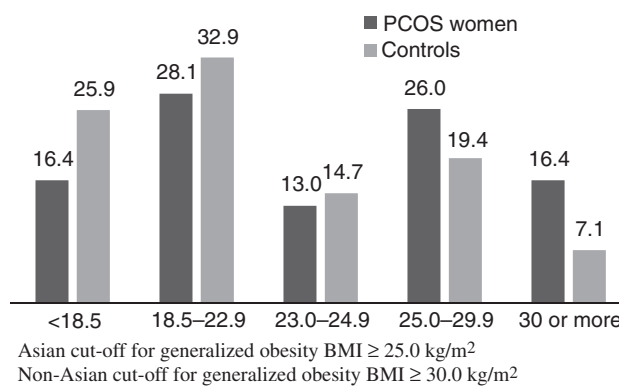
Figure 1. Percentages of women within each BMI subgroup, among women with PCOS and controls.

Of those with PCOS, only 55.5% ($n = 81$) had sought medical help previously for oligo/amenorrhea, hirsutism or acne. Reasons given for not seeking medical care were: 87% thought their symptoms and/or signs were not serious enough to seek treatment, 14.5% were reluctant to undergo physical examination, 6.5% thought that their symptoms and/or signs were normal consequences of marriage and/or pregnancy, 6.5% could not afford the cost of treatment and 4.8% were unaware of the available treatment options.

Psychological distress

The mean GHQ30 score was significantly higher ($P < 0.001$) among women with PCOS (mean 5.25; SD 6.25) than in controls (mean 1.58; SD 1.46), thus indicating greater distress among the affected group. Psychological distress (GHQ30 score ≥ 6) was observed in 32.9% ($n = 51$; 95% CI 25.1–40.7%) of women with PCOS, but was not reported among controls ($P < 0.001$). The risk of having psychological distress among women with PCOS

was three-fold greater than among controls (OR 2.8; 95% CI 2.38–3.28).

Factors associated with psychological distress

Table 3 denotes the distribution of clinical variables among women with PCOS both with and without psychological distress. Hirsutism (70.6 versus 44.2%) was the only factor significantly associated with psychological distress ($P = 0.002$). This was confirmed by the multiple linear regression analysis that revealed the FG score as a significant predictor of psychological distress among women with PCOS (standardised coefficient = 0.338; $P < 0.001$).

Quality of life

The mean scores for all four domains of WHOQOL-BREF were lower in women with PCOS than in controls, indicating a worse HRQoL among the affected women, with the lowest score being in the social relationships domain (Table 4). All, except the environment domain score, were found to be significantly lower in women with PCOS than in controls.

Factors associated with quality of life

Table 5 shows the mean scores for clinical variables and perceptions among women with PCOS, within each domain of the WHOQOL-BREF. The mean score for physical health and psychological health domains were lower among women with oligo/amenorrhea, acne, hirsutism, generalised and abdominal obesity, and infertility, and among those who thought they had excess acne, excess body hair and excess body weight. Mean scores differed significantly in the social relationships domain by the level

of generalised obesity (BMI ≥ 25.0 Asian cut-off; $P = 0.03$). However, multiple linear regression analysis did not reveal oligo/amenorrhea, acne, hirsutism, generalised obesity, central obesity or subfertility as being significant predictors of poor HRQoL among women with PCOS.

Discussion

To the best of our knowledge, this is the first report on HRQoL and psychological distress among community-based and untreated South Asian women with PCOS. The prevalence of PCOS in the same community setting was found to be 6.3% (95% CI 5.9–6.8%) among women aged 15–39 years.[19] This study demonstrates significant psychological distress in 32.9% of community-based women with PCOS when compared with normal controls from the same community setting who had no psychological affliction. However, a clinic-based study in India using GHQ28 reports that 54% of women with PCOS had a GHQ28 score > 8,[26] whereas Ching et al.[8] reported an even greater prevalence (62.4%) of psychological morbidity, but used a lower cut-off of GHQ28 score (>5). Elsenbruch et al.[11] reported a 15.4% prevalence of possible psychological disorder based on symptom checklist SCL-90-R global severity index (GSI) scores. These previous results are not directly comparable with the current study because of the differing study instruments and cut-offs being used to measure psychological distress. In addition, no controls were scored ≥ 6 for psychological distress, which might suggest that this cut-off is too high.

Additionally, our findings highlight that the main predictor of psychological distress in South Asian women with

Table 3. Clinical characteristics related to psychological distress among women with PCOS (n = 146)

Characteristic	With psychological distress, % (n = 51)	No psychological distress, % (n = 95)	P-value
Oligo/amenorrhea	96.1	94.7	0.72
Acne	25.5	22.1	0.64
Hirsutism (FG ≥ 8)	70.6	44.2	0.002
Generalised obesity BMI ≥ 25 kg/m² (Asian definition)*,**	45.1	43.2	0.82
Generalised obesity BMI ≥ 30.0 kg/m² (non-Asian definition)*,***	23.5	14.7	0.14
Abdominal obesity WHR > 0.85	54.9	58.9	0.64
Perception of excess acne	21.6	13.7	0.22
Perception of excess body hair	47.1	38.9	0.34
Perception of excess body weight	19.6	9.5	0.08
Infertility (n = 74)****	22.2	8.5	0.11

*Rows were amalgamated for the calculation of significance (χ^2).

**Asian definition BMI ≥ 25.0 kg/m² indicates generalised obesity.

***Non-Asian definition BMI ≥ 30.0 kg/m² indicates generalised obesity.

****Distrubution among the infertile group (n = 74): PCOS n = 27; controls n = 47.

Table 4. Distribution of WHOQOL-BREF and GHQ30 scores obtained by women with PCOS and controls

Characteristic	PCOS women (*n* = 146)					Controls (*n* = 170)					*P*
Domains of WHOQOL-BREF	Mean	SD	Range	Floor effect*	Ceiling effect**	Mean	SD	Range	Floor effect	Ceiling effect	
Physical health	64.8	16.2	21.4–96.4	0.0	0.0	69.4	15.4	21.4–100.0	0.0	2.4	0.01
Psychological health	64.9	17.2	4.2–100.0	0.0	1.4	68.8	14.4	20.8–100.0	0.0	1.2	0.01
Social relationships	60.5	21.4	12.5–100.0	0.0	4.1	66.8	20.7	8.3–100.0	0.0	1.2	0.01
Environment	60.8	17.4	3.1–96.9	0.0	0.0	63.3	15.0	21.9–100.0	0.0	0.6	0.19
GHQ 30	5.25	6.25	0–28	28.1	0.0	1.58	1.46	0–4	34.1	0.0	<0.001

For the WHOQOL-BREF: 100 is the best HRQoL score; 0 is the worst HRQoL score. For the GHQ30: 0 indicates the best psychological health; 30 indicates the worst psychological health.
*The floor effect is the percentage of women reporting the minimum score (GHQ30 = 0).
**The ceiling effect is the percentage of women reporting the maximum score (GHQ30 = 30).

PCOS is the FG score. There is conflicting evidence in the literature on the importance of the FG score and obesity in contributing to psychological distress. Hahn *et al.*[6] and McCook *et al.*[3] also reported similar findings in that the FG score correlated significantly with emotional subscales of their study instruments, whereas Ching *et al.*[8] reported that BMI correlated significantly with GHQ30 scores. Multiple linear regression analysis of our data suggests that BMI is not a significant predictor of psychological distress. It is noteworthy that only 19.6% of women with PCOS and psychological distress in our study sample thought that they had excess body weight. This brings into focus that hirsutism perhaps plays a more important role than obesity in the occurrence of psychological distress among the South Asian women affected. Moreover, the prevalence of hirsutism among women with PCOS reported by other investigators from the USA and Europe was higher than in this study.[27–29] Therefore, the current findings are likely to reflect the true impact of hyperandrogenic symptoms, rather than reflecting an ethnic difference in the severity of clinical symptoms between South Asian and non-Asian populations. Based on these findings, we recommend healthcare providers to be made aware that psychological distress of PCOS in South Asian women is mainly caused by their hirsutism, which requires appropriate management.

Health-related quality of life in terms of the physical health, psychological health and social relationships measures using WHOQOL-BREF were significantly lower among the community-based women with newly diagnosed PCOS than in controls from the same setting. In view of these domains, assessing a woman's ability to accept body appearance, her self-satisfaction, personal relationships, etc., probably gives better insight into PCOS-related HRQoL issues. Other tools, such as SF-36 and the Polycystic Ovary Syndrome Questionnaire (PCOSQ), have also reported HRQoL as being worse among women with PCOS when compared with healthy controls, as well as with those with other gynaecological conditions.[5–8] However, multivariate analysis did not reveal any significant predictors of HRQoL among our study population with PCOS.

In terms of the severity of physical changes of PCOS and the women's perception of these problems that can be determined by sociocultural issues, we studied the impact of irregular menstrual cycles, hirsutism, acne and obesity on HRQoL. The social relationships domain of women with PCOS was significantly affected by high BMI only when analysed using the Asian cut-off (BMI ≥ 25.0),[25] but failed to show a significant difference according to the non-Asian cut-off (BMI ≥ 30.0). The BMI did not emerge as a predictor from the multiple linear regression analysis. Furthermore, women with PCOS did not perceive excess body weight as a factor affecting their social relationships. In order to dispel any concerns about such differing thresholds for obesity based on ethnicity, we analysed our data based on recommended cut-off values for Asians and for Western populations, which depicted the prevalence of obesity among women with PCOS as 43.8 and 17.8%, respectively. However, only 30.8% of those with a BMI ≥ 30 kg/m^2 and 22% of those with a BMI ≥ 25 kg/m^2 (Asian cut-off)[25] thought of themselves as obese. This clearly indicates that the perception of obesity among South Asians with PCOS is far less than its actual occurrence, irrespective of the diagnostic threshold.

This phenomenon probably reflects different sociocultural views of obesity, which has important implications on management issues of South Asian subjects with PCOS. Schmid *et al.*,[17] reported that Muslim immigrant women rated menstrual irregularity, infertility and hirsutism as

Table 5. Clinical characteristics related to quality of life among women with PCOS*

Characteristic	Physical (n = 146)	P	Psychological (n = 146)	P	Social (n = 146)	P
	Mean (SD)		Mean (SD)		Mean (SD)	
Oligo/Amenorrhea						
Yes	64.4 (15.8)	0.47	64.7 (17.4)	0.51	59.9 (12.9)	0.16
No	68.8 (24.6)		69.0 (12.9)		71.4 (24.5)	
Acne						
Yes	63.1 (17.0)	0.07	63.9 (17.5)	0.26	58.9 (22.6)	0.13
No	69.0 (12.8)		67.7 (16.4)		64.9 (16.7)	
Hirsutism						
FG ≥ 8	63.6 (15.9)	0.50	63.8 (19.1)	0.39	60.5 (21.2)	0.97
FG < 8	65.4 (16.5)		66.2 (14.8)		60.4 (21.5)	
Obesity,*** (Asian definition)						
BMI ≥ 25.0	61.1 (21.5)	0.09	62.0 (23.5)	0.37	50.2[b] (23.4)	0.03*****
BMI 23–24.9	62.1 (16.0)		63.5 (17.3)		58.9[ab] (20.1)	
BMI < 23.0	67.9 (14.5)		67.1 (15.2)		64.7[a] (19.3)	
Obesity,**** (non-Asian definition)						
BMI ≥ 30.0	58.9 (16.2)	0.17	62.8 (16.6)	0.65	55.8 (20.2)	0.46
BMI 25–29.9	64.4 (15.6)		63.9 (17.9)		61.1 (23.3)	
BMI < 24.9	66.5 (16.3)		66.1 (17.2)		61.7 (20.9)	
Abdominal obesity						
WHR > 0.85	64.1 (16.1)	0.62	63.9 (17.3)	0.39	58.3 (20.9)	0.11
WHR ≤ 0.85	65.5 (16.6)		66.5 (17.2)		64.1 (21.9)	
Perception of excess acne						
Yes	63.6 (16.5)	0.11	64.4 (17.5)	0.42	59.6 (15.0)	0.33
No	69.5 (13.8)		67.5 (15.9)		64.4 (22.4)	
Perception of excess body hair						
Yes	64.3 (15.8)	0.88	63.5 (18.2)	0.41	60.1 (20.9)	0.86
No	64.7 (16.6)		65.9 (16.5)		60.7 (21.8)	
Perception of excess body weight						
Yes	63.5 (12.4)	0.76	63.6 (19.1)	0.72	58.1 (19.2)	0.58
No	64.7 (16.8)		65.1 (17.0)		60.8 (21.8)	
Infertility (n = 74)						
Yes	56.4 (11.5)	0.26	59.2 (14.9)	0.23	59.8 (21.3)	0.69
No	62.8 (16.9)		65.9 (16.6)		62.5 (22.6)	

For WHOQOL-BREF: 100 indicates the best HRQoL score; 0 indicates the worst HRQoL score.
*Means and P values for each domain were assessed separately for the selected characteristic.
**Rows were amalgamated for the calculation of significance (χ^2).
***Asian definition: BMI 23–24.9 kg/m^2 indicates overweight; BMI ≥ 25.0 kg/m^2 indicates generalised obesity.
****Non-Asian definition: BMI 25–29.9 kg/m^2 indicates overweight; BMI ≥ 30.0 kg/m^2 indicates generalised obesity.
*****Means with the same letter superscript are not significantly different using Tukey's test.

being bigger problems than being overweight or obese, whereas European women perceived these quite differently. Obesity with an android pattern of body fat having a negative impact on HRQoL may be explained by it being considered unattractive only in Western cultures and modes of dress, whereas Eastern cultures might even perceive obesity as a sign of prosperity.[17] We propose that this problem needs appropriate corrective action in the clinical setting of primary care in rural communities of South Asia, as weight reduction is an important step in the management of

PCOS. Our finding also suggests the potential for non-compliance with weight management protocols among affected South Asian women.

Infertility was not found to be a significant contributor towards psychological distress and poor HRQoL in women with PCOS. Only half of our study sample were married, and as single parents are uncommon in South Asian culture, this might explain the low percentage of infertile women (13.5%) among the PCOS group. Hence, our current findings cannot be extrapolated to the older

married South Asian women with PCOS, who are more likely to be affected by infertility.

The basic demographic and socio-economic characteristics, and occurrence of any medical conditions among the community-based women with PCOS and controls were not significantly different ($P > 0.05$). Therefore, the observed differences in HRQoL and psychological distress are likely to reflect PCOS-related factors rather than demographic, socio-economic factors or other medical conditions. These study cases were randomly selected from a community-based household survey, which ensured the inclusion of all eligible cases without selection bias. Being confined to newly diagnosed and untreated women with PCOS ensured the exclusion of the possible influence from prior knowledge of the disease status and/or by therapeutic and lifestyle changes encouraged by clinicians that might have contributed towards altered symptoms and signs affecting psychological well-being and HRQoL. Therefore, our findings are likely to reflect the actual impact of PCOS *per se*, rather than a composite presentation of the clinical problem and issues related to its management.

It is striking that despite their psychological distress and poor HRQoL, only 55.5% of women with PCOS had previously sought medical help for their physical symptoms of oligo/amenorrhea, hirsutism or acne. The main reasons stated by these women for not seeking medical care was that they considered the symptoms and signs as being not sufficiently serious to access care. This is a paradox, as Sri Lanka has a sustained commitment to maternal and child health, reflected by good health indices over the past three or four decades, along with gender equity and educational freedom,[30] which reflect equitable access to health care, particularly for women of reproductive age. Therefore, we believe that this 'culture of silence' is unlikely to be a result of a lack of available health services, but rather that the women's perceptions of symptoms and/or signs barred them from seeking appropriate care. We recommend that this 'culture of silence' among indigenous South Asian women with PCOS in rural communities, as observed by others previously,[31] requires attention. We also recommend that more studies using qualitative research methods should be conducted to explore factors that contribute to the poor HRQoL and psychological distress of women with PCOS in South Asia.

The main reason for the limited data available on these aspects of PCOS is attributed to the lack of a validated instrument.[14,15,32] A limitation to this study is that the disease-specific instrument available to measure the HRQoL of women with PCOS (PCOSQ) was not used.[33] This was because at the time that we conducted this community survey, although the reliability and validity of the PCOSQ had been established,[33,34] the PCOSQ had not yet been used nor validated for South Asian women.[14] We therefore did not use the PCOSQ in our study.

Meanwhile, the WHOQOL-BREF had been previously tested for cross-cultural use and was recommended for assessing the outcomes of gynaecological morbidity in developing countries, which was also applicable to Sri Lanka.[31] Nevertheless, WHOQOL-BREF is not a disease-specific instrument but a generic instrument. The generic instrument used for the assessment of the HRQoL in PCOS in the previous decade was mainly the SF-36.[14] However, the WHOQOL-BREF additionally seeks information on the well-being and functioning, such as acceptance of physical changes and satisfaction with sex life, that are more relevant to women with PCOS. For these reasons we selected the WHOQOL-BREF to complement the SF-36, and therefore first validated the WHOQOL-BREF against SF-36 to confirm its validity and reliability as an assessment tool for assessing the HRQoL of PCOS.[22] However, we acknowledge that this approach might not have been as sensitive for assessing changes in the HRQoL scores when compared with the PCOSQ. Therefore, the validation of the PCOSQ for Sri Lankan women with PCOS is required for future studies.

Conclusion

South Asian women with PCOS detected by community screening have significant psychological distress and poor HRQoL, in addition to their clinical and biochemical problems. These are related more to hirsutism than to obesity, which is distinct from Western findings, and suggests a potential for poorer compliance with weight management protocols among affected South Asian women. Thus a culturally appropriate, multidisciplinary approach through health education and counselling, with advocacy to provide holistic care, is recommended.

Disclosure of interest
We declare that there are no financial or other relationships that might lead to a conflict of interest.

Contribution to authorship
VLK carried out the literature review, contributed to the design of the study, supervised data collection, carried out statistical analysis and contributed to writing the manuscript. RAS contributed to designing the study, to the statistical analysis and to the writing of the manuscript. CNW contributed to designing the study, to writing the manuscript, to the clinical examination of all cases identified and supervised the laboratory investigations.

Details of ethics approval
Ethics clearance was obtained from the Ethics Review Committee, Faculty of Medicine, University of Colombo on 18 November 2004 (ERC-7, EC/04/083).

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