

## ABSTRACT

Polycystic Ovary Syndrome (PCOS) is a common endocrine disorder of women in their reproductive age. It leads to psychological distress and diminished health-related quality of life (HRQoL) as its spectrum of symptoms interfere with feminine identity and culturally defined norms of womanhood. This study aims to translate and validate a disease-specific tool, the Modified Polycystic Ovary Syndrome Questionnaire (M-PCOSQ) and assess HRQoL, depressive symptomatology and coping strategies among a sample of women with PCOS in Sri Lanka. Furthermore, the study aims to explore the psycho-social experience of women diagnosed with PCOS. Finally, it aims to evaluate the effectiveness of peer-led support groups in improving HRQoL, depressive symptomatology and adaptive coping skills among women with PCOS.

The ethical approval was obtained from the Ethical Review Committee, Faculty of Medicine, General Sir John Kotelawala Defence University, Ratmalana. The forward and backward translations of the M-PCOSQ were synthesized during the translation process. A Modified Delphi process established consensual and content validity. Ninety-four PCOS women were recruited to assess the reliability and validity of the M-PCOSQ. During the second phase, 377 PCOS women participated in a cross-sectional survey and data was obtained using the M-PCOSQ, Centre of Epidemiological Studies Depression Scale and Brief COPE Inventory. To explore the psycho-social experience of living with PCOS, 16 affected women were interviewed in the third phase, the qualitative component. The final phase of the study adopted a pre-test-post test experimental design in which 42 women with PCOS were randomly allocated to the experimental (n=20) and control (n=22) groups. Participants in the intervention arm participated in the specific peer support program for 10 weeks, while the control arm received 10 general health reading material weekly for 10 weeks.

The results of the first phase indicated that the sub-scales of hair (0.96), infertility (0.8) and acne (0.91) had an excellent internal consistency and emotion subscale (0.67), a moderate level of internal consistency. Weight (0.46) and menstruation (0.329) domains indicated low internal consistency. All the sub-scales of the M-PCOSQ viz. emotions (0.98), hair (0.97), weight (0.99), infertility (0.99), menstrual problems (0.98) and acne (0.99) demonstrated high test-retest reliability. The MPCOSQ demonstrated a satisfactory level of convergent validity as the emotions sub-scale of the M-PCOSQ demonstrated a strong correlation with the psychological well-being of the SF-36 ( $r = 0.63, p < 0.01$ ). The findings of the second phase indicated that the common HRQoL concerns were infertility, menstrual problems and weight.

Severe depressive symptomatology was experienced by 60.7% (95% confidence interval 56.0-65.8) of the women in the sample. Maladaptive avoidant coping strategies like self-blame, denial, venting and behavioural disengagement were practised by the sample than more appropriate approach coping strategies. The interpretative phenomenological analysis found that participants experienced diminished mental health, poor body image, impairment in social interactions, stigmatization and marginalization due to the symptoms of PCOS. In the intervention phase, the comparison of the two groups at the baseline in terms of all the demographic and clinical variables, HRQoL, depressive symptomatology and coping skills showed that there is no significant difference between the groups. After the intervention, participants in the support group exhibited a statistically significant reduction in depressive symptomatology and avoidant coping ( $p < 0.01$ ). A statistically significant improvement was observed in approach coping and HRQoL as indicated by higher mean scores in the domains of hirsutism, menstrual problems, infertility, weight, emotions ( $p < 0.01$ ) and acne ( $p < 0.05$ ). In contrast, the control group did not show significant changes in these outcome variables. In conclusion, the peer support group is an effective intervention to uplifts psycho-social wellbeing of the affected women.

The findings offer new insight into the psycho-social aspects of PCOS in Sri Lanka. Drawing upon the outcomes of the peer support group, efforts to incorporate psycho-social interventions like peer support groups to enhance the psycho-social well-being of the affected women are warranted.

#### KEYWORDS

PCOS, Health-related quality of life, Coping Skills, Depression, Qualitative, Peer-led support groups