

The Polycystic Ovary Syndrome Quality of Life (PCOSQOL) Scale: development and preliminary validation.

Abstract

Polycystic Ovary Syndrome (PCOS) is an endocrine disorder amongst women which can negatively impact quality of life (QoL). Research proposes a more sensitive PCOS QoL measure is needed. This study aims to develop and initially validate a QoL scale for women with PCOS in the UK. Women with PCOS (n=714) took part in the development and initial validation of the 35-item PCOSQOL ($\alpha=.95$). Subscales include: Impact of PCOS ($\alpha=.95$), Infertility ($\alpha=.95$), Hirsutism ($\alpha=.97$) and Mood ($\alpha=.89$). The PCOSQOL represents aspects of QoL important to women with PCOS and may be more sensitive for use in clinical and research settings.

Introduction

Polycystic ovary syndrome (PCOS), or Polycystic Ovarian Syndrome, is the most common endocrine disorder amongst women of reproductive age (Franks, 1995) affecting approximately 6.5% of women (Asucion et al., 2000; Azziz et al., 2004). It is the most prevalent cause of anovulatory infertility (Gorry et al., 2006). Other symptoms include hirsutism (the growth of excess hair), insulin resistance, obesity (Goudas and Dumesic, 1997), acne (Coffey et al., 2006) and hair loss (Elsenbruch et al., 2003). Women with PCOS are also more likely to experience depression and anxiety (Himelein and Thatcher, 2006) at increased levels compared women without PCOS (Deeks et al., 2011).

PCOS negatively impacts quality of life (QoL) (Brady et al., 2009; Coffey and Mason, 2003). Yet McCook et al. (2005) suggest that the psychological implications of PCOS are underestimated and have been largely ignored. Whilst PCOS has a negative impact on QoL, the manifestation of this impact varies across the globe. In Turkish women with PCOS, Acmaz et al. (2013) found that an irregular menstrual cycle and hirsutism had the largest impact on QoL. In Iran, menstrual irregularities and infertility were the most common QoL concern (Bazarganipour et al., 2013) followed by hirsutism, weight, emotion concerns and acne. For Brazilian women with PCOS, body weight and infertility had the largest negative impact on QoL (Benetti-Pinto et al., 2015). This research demonstrates the negative impact of PCOS on QoL, how this condition impacts QoL and how the condition manifests differently across the globe. A disease-specific scale, therefore, which measures QoL concerns as defined by women with PCOS in the UK is needed to reflect those domains of QoL which are important to this population.

At present, the PCOSQ, a 26-item questionnaire, developed in the USA (Cronin et al., 1998) is the most popular QoL measure used in research involving women with PCOS. McGee (2004) suggests that disease-specific measures should focus on the most important aspects of QoL for individuals with the condition. However, as the PCOSQ pertains mostly to physical symptoms, it overlooks many of the aspects of QoL raised by women with PCOS in the qualitative literature (Kitzinger and Willmott, 2002; Williams et al., 2014; 2015). Indeed, the 2012 Amsterdam ESHRE/ASRM workshop argued that QoL research in women with PCOS has been hampered by the existence of only one validated disease-specific questionnaire. More recently, Barry et al. (2017) suggested that a more sensitive measure of QoL for women with PCOS may be needed

for QoL research in this condition. This suggests that research in the area of PCOS could benefit from the availability of a more sensitive PCOS QoL scale.

Recent qualitative literature also supports the notion that the PCOSQ does not reflect QoL, as defined by the WHO (1994) and women with the condition (Snyder, 2006; Williams et al., 2014, 2015). The WHOQOL group (1994) proposes that there are six domains of QoL: physical health, psychological health, level of independence, social relationships, and environment and spirituality/religion/personal beliefs. The PCOSQ includes five subscales: emotions, body hair, infertility, weight and menstrual problems: as four of these subscales focus on physical aspects of the condition it suggests that the PCOSQ is concerned more with the physical impact of PCOS than psychological, social or environmental aspects (WHOQOL Group, 1994). Indeed, Malik-Aslam et al. (2010) suggests that QoL measures should represent those areas of importance to women with the condition. We contend that a QoL measure which represents those domains of QoL that women with the condition consider important, and which are reflective of the domains proposed by the WHO should be developed to address these concerns.

Whilst the PCOSQ has demonstrated some validity (Guyatt et al., 2004; Jones et al., 2004), due to a limited population used during development and validation, the utility of the scale is potentially limited. Specifically, the PCOSQ was developed using patients who represented only two phenotypes of PCOS, excluding two other phenotypes of PCOS recognised by the current recommended (NIH, 2012) diagnostic criteria in the UK (Rotterdam, 2004). Specifically, women who present with polycystic ovaries combined with either oligo or anovulation, or indeed, clinical or biochemical signs of hyperandrogenism (Rotterdam, 2004) were excluded in its

development and later validations (Guyatt et al., 2004; Jones et al., 2004). The perspectives of these women with different symptom profiles, therefore, would not have been considered when developing items for the scale. This further suggests that aspects of PCOS which impact QoL and are important to women with the condition may have been excluded from the development of the **scale. This is** a possible reason for the later critique of the PCOSQ as a measure of symptom-bother which may exclude important issues for women with PCOS that can impact on QoL (Malik-Aslam et al., 2010). A PCOS QoL scale developed to represent all phenotypes of PCOS in a UK population could help to overcome the concerns raised by the ESHRE/ASRM (2012) with regards to the limitations of only one PCOS QoL measure. This paper, therefore, details the development and initial validity testing of the PCOSQOL, a PCOS specific QoL measure which encompasses areas of QoL defined as important by women with the condition.

Methods

Participants and Procedure

According to scale development guidelines (DeVellis, 2012; Streiner and Norman, 2008) this scale development took place over four phases, each using distinct participant samples: phase I - item generation (n=18 participants), phase II - scale reduction and reliability (n=298), phase III - scale validity and re-test reliability (n=308) and phase IV - further validation (n=108).

Participants 18 years old and over, who lived in the UK, had English as a first language and experienced the symptoms of PCOS were recruited through UK PCOS groups on Facebook.

Participants were not excluded if they experienced co-morbid conditions. In phase II a total of 298 participants, aged 18 to 51 ($M_{age}=29.54$; $SD=6.26$) years, completed the prototype PCOSQOL scale. To assess the construct and discriminative validity, and reliability of the

reduced item PCOSQOL, in phase III a second large sample ($n=308$; $Mage= 29.88$; $SD=6.90$) of participants was recruited. Ninety of these participants completed the test re-test of the PCOSQOL. To further validate the PCOSQOL, in phase IV a third sample of participants was recruited, age ranged from 19 to 49 years ($Mage=30.52$; $SD=6.51$). Participant characteristics from phase II to IV of development can be found in Table I.

INSERT TABLE I HERE

Materials

All materials, including the information sheet, consent form, participant questionnaire and debrief were held and completed online using Limesurvey (www.limesurvey.org).

Hospital Anxiety and Depression Scale (HADS; Zigmond and Snaith, 1983) is a 14-item scale with seven items for each subscale (Depression/Anxiety) and each item is scored from zero to three. Items include ‘I get sudden feelings of panic’ and ‘I feel cheerful’. The subscales for HADS have demonstrated good internal consistency, with Cronbach’s alpha of 0.80 for the anxiety subscale and 0.76 for the depression subscale (Mykletun et al., 2001). Within this sample (Phase III), the subscales for HADS demonstrated similar internal consistency with Cronbach’s alphas of 0.72 for the anxiety subscale and 0.78 for the depression subscale.

WHOQOL-BREF (WHOQOL Group, 1998) has 22 items and uses a 5-point Likert scale. It contains four subscales, including: Physical Health, Psychological, Environment and Social

Relationships. Questions include issues regarding negative feelings, ability to perform daily activities, capacity to work and personal relationships. Cronbach's alphas for the scale has been found to be good for three domains; Physical ($\alpha=0.82$), Psychological ($\alpha=0.81$) and Environment ($\alpha=0.80$) but marginal ($\alpha=0.68$) for Social Relationships [49]. Cronbach's alphas for this sample (Phase IV) on the WHOQOL-BREF domains were similar: Physical ($\alpha=0.86$); Psychological ($\alpha=0.85$); Environment ($\alpha=0.78$); and Social Relationships ($\alpha=.70$).

PCOSQ (Cronin et al., 1998) is a disease-specific QoL measure for women with PCOS. It has 26 items and uses a 7-point Likert scale. Questions focus on issues concerning growth of visible hair, infertility problems and feelings of depression. The PCOSQ has five domains: Emotions (eight items), Body Hair (five items), Weight (five items), Infertility problems (four items) and Menstrual problems (four items). Cronbach's alpha were above 0.7 when the PCOSQ was validated (Jones et al., 2004).

Ethical Approval

Ethical approval was obtained from the Psychology Research Ethics Committee at the University of XXXX (06012-XX) and all participants gave written informed consent before participating. All data was anonymous however participants in phase III were asked to provide their email address if they were happy to complete the test-retest three weeks later in order to check consistency of the PCOSQOL over time.

Statistical Analysis

Data analyses were conducted using SPSS (v22). The factor structure was tested using exploratory factor analysis (EFA). Principal axis factoring was employed using a direct oblimin rotation. The internal consistency of the scale was assessed using Cronbach's alpha. Due to aspects of the data violating assumptions for parametric tests, Spearman's correlations were conducted between scale scores to assess construct validity. Independent t-tests, however, were performed to assess the discriminative validity of the PCOSQOL by comparing demographic data and condition characteristics.

Results

Phase I: Item Generation

Scale items were developed from qualitative research exploring QoL in women with PCOS (see XXXX) and a comprehensive review of the literature. Items were reviewed by an expert panel (n=5) of PCOS healthcare professionals and psychologists specialising in disease-specific scale development (DeVellis, 2012). This resulted in the prototype PCOS QoL (PCOSQOL) scale which consisted of 62-items using a 7-point Likert scale ranging from 'Does Not Apply' (7) to 'Usually' (1). As such, lower scores represent a decreased QoL. Example items included: 'Felt under pressure to have a child' and 'Felt depressed about how PCOS has impacted your life'.

Phase II: Scale Reduction and Reliability

Item Analysis and Reduction

Items in the prototype scale were analysed for frequency, means and correlations. Analysis of items' means (DeVellis, 2012) resulted in the removal of five items with item means below 2 (1.78 to 1.92). Two of these removed items related to weight, 'Felt under pressure to lose weight'

and 'Had negative thoughts about your weight'. One item related to the symptom of acne, 'Felt depressed because of the spots on your face' was also removed. All items significantly correlated with at least one other item; significant correlations ranged from 0.14 to 0.79. This resulted in 57 items being retained.

Exploratory Factor Analysis (EFA): An EFA was then run on the data collected (n=298). Kaiser-Meyer-Olkin measure (KMO= .906) indicated that sampling adequacy was met. Initially, using Eigenvalues above 1 as criteria for factor extraction, 12 factors were extracted. However, the scree plot was ambiguous and showed inflexions that would justify retaining either two or four factors. Four factors had eigenvalues over 2; therefore, the analysis was rerun specifying the extraction of four factors and coefficients below 0.45 were suppressed (Comrey and Lee, 1992). Of the remaining 57 items, 35 had factor loadings of at least 0.45 and each item loaded onto one factor only. As a result 35 items were retained. After inspection of items loading onto each factor, subscales were labelled: Impact of PCOS, Infertility, Hirsutism and Mood. None of the items relating to bodyweight loaded onto a factor. Results for the factor analysis can be seen in Table II.

Reliability: Cronbach's alpha for the PCOSQOL overall scale was excellent ($\alpha = .95$) as were the alphas for the four subscales: Impact of PCOS, Infertility, Hirsutism and Mood; $\alpha = .95$, $\alpha = .93$, $\alpha = .96$ and $\alpha = .85$, respectively (George and Mallery, 2003; Nunally, 1978).

Phase III: Scale Validity and Re-test Reliability

After initial item reduction (detailed above) the 35-item PCOSQOL was re-administered to a new sample of women with PCOS (n=308) in order to test cross-sectional validity of the revised scale.

Cross-sectional Validity and Correlations

HADS: Spearman's correlation was run to determine the relationship between the PCOSQOL, its subscales, and the HADS subscales. Results indicated that women with PCOS with greater levels of anxiety and depression had poorer QoL (Table III).

INSERT TABLE III HERE

EFA: DeVellis (2012) states that if data from different samples of individuals on different occasions produce essentially identical factor solutions using exploratory approaches, then the likelihood of those results being a 'quirk' is small. Accordingly, as part of initial validation, a second EFA was run on the revised 35-item PCOSQOL (n=308; KMO=.93). Principal axis factoring was employed using a direct oblimin rotation and missing values were excluded pairwise. The scree plot supported a four-factor structure. Coefficients below 0.45 were suppressed (Comrey and Lee, 1992). The factor analysis showed that all 35 items loaded onto the same factors as the EFA conducted during initial scale reduction and reliability testing.

Cronbach's alphas for this sample were found to be excellent for the overall scale ($\alpha = .95$) (George and Mallery, 2003) and the four subscales; Impact of PCOS, Infertility, Hirsutism and Mood ($\alpha = .95$, $\alpha = .95$, $\alpha = .97$ and $\alpha = .89$, respectively).

TEST RETEST RELIABILITY: Ninety of 308 (29%) participants completed a test re-test of the PCOSQOL after three weeks. Correlational analyses were used to examine the relationship between the 35-item PCOSQOL and the test re-test data. Results indicated a strong, positive relationship between the total scores of the reduced item PCOSQOL and the test-retest data (missing data excluded pairwise), which was statistically significant ($r(57)=.90$, $p<.001$ BCa CI [.817, .948]). Mean scores were 105.67 ($SD=37.32$) for the PCOSQOL and 112.44 ($SD=38.41$) for the retest. This difference suggests that QoL was improved for the participants at the re-test point. This was confirmed by a paired samples t-test which revealed a significant difference between initial scores of QoL and the re-test, $t(57)=-2.10$, $p<0.05$. At retest, Cronbach's alpha for the overall scale was excellent ($\alpha = .95$) (George and Mallery, 2003) as well as for the four subscales: Impact of PCOS ($\alpha = .96$), Infertility ($\alpha = .96$), Hirsutism ($\alpha =.97$) and Mood ($\alpha= .89$), indicating good internal consistency for each of the subscales.

DISCRIMINATIVE VALIDITY: Independent t-tests revealed a significant difference in scores of QoL on the PCOSQOL between those participants who experience symptoms of infertility ($t(213)=1.22$, $p<0.001$), excess hair ($t(213)=5.10$, $p<.001$), excess weight ($t(213)=3.66$, $p<.001$), alopecia ($t(213)=2.60$, $p<.05$), skin tags ($t(213)=3.45$, $p<.001$), mood swings ($t(213)=5.53$, $p<.001$), or had received a clinical diagnosis of depression ($t(205)=-2.14$, $p<.05$) compared to women who had not. There was also a significant lower QoL score for those women who were trying to conceive compared to those who were not ($t(193)=-6.48$, $p<.001$).

Phase IV: Further Validation

To further initial assessments of cross-sectional validity of the PCOSQOL, an additional sample of 108 women with PCOS were recruited.

WHOQOL-BREF: Spearman's correlation analyses were used to examine the relationship between the subscales of the WHOQOL-BREF (Physical Health, Psychological Health, Social Relationships and Environment) and the PCOSQOL (Impact of PCOS, Infertility, Hirsutism and Mood). Correlation analyses revealed positive significant relationships between the PCOSQOL subscales of Impact of PCOS and Mood and all the WHOQOL subscales. The PCOSQOL Hirsutism subscale had positive weak to moderate correlations with three of the WHOQOL subscales: Psychological, Social Relationships and Environment domains. The PCOSQOL subscale demonstrated a significant weak, positive relationship with the WHOQOL subscales, Psychological and Environmental QoL (Table III).

PCOSQ: Spearman's correlation analyses were used to examine the relationship between the PCOSQOL total score and the PCOSQ total score and the subscales of each scale (Table III). All subscales of the PCOSQ correlated with at least one subscale of the PCOSQOL except, the PCOSQ subscale of Menstrual Problems that did not correlate with the total score of the PCOSQOL or its subscales.

Discussion

This paper detailed the development and preliminary validation of a PCOS disease-specific QoL scale which would be a more sensitive measure of QoL as defined by women with the condition in the UK. Development resulted in a 35-item scale with four subscales: Impact of PCOS;

Infertility; Hirsutism; and Mood. Cronbach's alpha for the overall scale and for each sub-scale was excellent. Preliminary validation testing was positive, the scale demonstrated good test-retest reliability, demonstrating a robust factor structure and high internal consistency of factor structures.

Items for the PCOSQOL were developed from qualitative findings of previous qualitative research (Williams et al., 2014; 2015), expert opinion, and from a comprehensive literature review as recommended by Malik-Aslam et al. (2010). As a result, the PCOSQOL includes items which are reflective of the psychological, social and environment domains which are important for a QoL measure (WHOQOL Group, 1994). As such, the PCOSQOL may go some way to answering the call for a more sensitive PCOS QoL measure (Barry et al., 2017) that addresses those aspects of QoL important to women with PCOS (Malik-Aslam et al., 2010).

The PCOSQOL includes items reflective of concerns of women with PCOS including the impact of PCOS on feminine identity; the negative impact of PCOS on family and friends; and the feeling of being under pressure to have children. Interestingly, items pertaining to the spirituality/religion/personal belief domain (WHOQOL Group, 1994) were not endorsed by participants in the item reduction phase of the PCOSQOL, nor were any items pertaining to the symptom of the weight. These items therefore were not included in the final 35-item scale.

Arguably then, the PCOSQOL does not capture every aspect of QoL as defined by the WHOQOL Group (1994) but includes those items that are reflective of aspects of QoL that are deemed most important to women with PCOS in the UK (Fayers and Machin, 2007; Osborne et al. 2014). This begins to address the differences in QoL noted in global populations of women

with PCOS (Acmaaz et al., 2013; Bazarganipour et al., 2013; Benetti-Pinto Ferreira et al., 2015) however, further validation of the PCOSQOL in a UK sample is necessary to assess the utility of the measure.

Recruitment for this study via online Facebook support groups allowed for a large sample suitable for scale development. However, recruitment this way limited the control over the characteristics of the participant population (Coulson, 2015). For example, although women self-reported that they had received a clinical diagnosis of PCOS, it was not possible to verify this. It is also unclear what diagnostic criteria were applied to participants at the time of diagnosis, for example the Rotterdam criteria (2004) or the NIH 1991 criteria (Zawadski and Dunaif, 1992). To mediate this, participants reported the symptoms they experienced, these included polycystic ovaries, weight gain and hirsutism, amongst others, and suggests that the large sample of participants represented all phenotypes of PCOS as detailed in the Rotterdam criteria (2004). Nevertheless, further validation of the PCOSQOL within a clinical population is necessary to provide more evidence as to the utility of this disease-specific measure.

This paper details the development and preliminary validation of the PCOSQOL. Whilst further validation is necessary (Nunally, 1994; Streiner and Norman, 2008) research has proposed the need for a more sensitive QoL measure for women with PCOS (Barry et al., 2017) that addresses the psychological impact of the condition on QoL (Malik-Aslam et al., 2010). The PCOSQOL is a disease-specific QoL measure for women with PCOS that explores the impact of the condition on aspects of QoL deemed important by women with PCOS (Fayers and Machin, 2007; Osborne et al., 2014). This includes psychological, environmental and social domains (The WHOQOL

Group, 1994) in addition to items reflecting the impact of symptoms. The 35-item PCOSQOL provides a response to the issues raised by the 2012 Amsterdam ESHRE/ASRM group with regards to the limitation of having only one PCOS QoL measure. It demonstrates promising initial validity and reliability in a large non-clinical sample of women with PCOS in the UK.

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Declaration of Conflicting Interests

The Authors declare that there is no conflict of interest

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