Report of empirical study

The Polycystic Ovary Syndrome Quality of Life scale (PCOSQOL): Development and preliminary validation

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Abstract

Polycystic ovary syndrome is an endocrine disorder amongst women, which can negatively impact quality of life. Research proposes that a more sensitive PCOS quality of life measure is needed. This study aims to develop and initially validate a quality of life scale for women with the condition in the United Kingdom. Women with PCOS (n = 714) took part in the development and initial validation of the 35-item polycystic ovary syndrome quality of life scale (PCOSQOL)(α = .95). Subscales include Impact of PCOS (α = .95), Infertility (α = .95), Hirsutism (α = .97) and Mood (α = .89). The PCOSQOL scale represents aspects of quality of life important to women with PCOS and may be more sensitive for use in the 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 per cent of women (Asuncion 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 to 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. While PCOS has a negative impact on QoL, the manifestation of this impact varies across the globe. In Turkish women with PCOS, Açmaz 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 concerns (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 United Kingdom 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 United States (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

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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 World Health Organisation (WHO) (WHOQOL Group, 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 (The WHOQOL Group, 1994). Indeed, Malik-Aslam et al. (2010) suggest 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.

While 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 (National Institutes of Health (NIH), 2012) diagnostic criteria in the United Kingdom (The Rotterdam ESHRE/ASRM-Sponsored PCOS Consensus Workshop Group, 2004). Specifically, women who present with polycystic ovaries combined with either oligo or anovulation, or indeed, clinical or biochemical signs of hyperandrogenism (The Rotterdam ESHRE/ASRM-Sponsored PCOS Consensus Workshop Group, 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 (The Amsterdam ESHRE/ASRM-Sponsored 3rd PCOS Consensus Workshop Group, 2012) with regard to the limitations of only one PCOSQOL measure. This article, 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 the 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 above, who lived in the United Kingdom, 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 18–51 (M age = 29.54; standard deviation (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; M age = 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, whose age ranged from 19 to 49 years (M age = 30.52; SD = 6.51). The participant characteristics from phase II to IV of development can be found in Table 1.

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. 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

Table I. Characteristics, n (%), of participants who completed the scale at all stages.

	Phase II (n = 298)	Phase III (n = 308)	Phase IV (n = 108)
Marital status:			
Married	152 (51.0%)	133 (43.18%)	46 (42.59%)
Civil partnership	4 (1.34%)	2 (0.65%)	0
Divorced	4 (1.34%)	9 (2.92%)	1 (0.93%)
Single	32 (10.74%)	47 (15.26%)	16 (14.81%)
Living with partner	68 (22.82%)	67 (21.75%)	30 (27.78%)
Long-term relationship	45 (15.1%)	41 (13.31%)	11 (10.19%)
Engaged	3 (1.0%)	25 (8.12%)	9 (8.33%)
Separated	3 (1.0%)	4 (1.3%)	2 (1.85%)
Other	1 (0.34%)	3 (0.97%)	0
Children:			
Had children	107 (35.91%)	86 (27.92%)	48 (44.44%)
Were pregnant	12 (4.03%)	17 (5.52%)	4 (3.7%)
Trying to conceive	144 (48.32%)	125 (40.58%)	38 (35.19%)
Received a clinical diagnosis of:			
PCOS	286 (95.97%)	295 (95.78%)	107 (99.07%)
Depression	146 (48.99%)	134 (43.51%)	39 (36.11%)
Anxiety	91 (30.54%)	104 (33.77%)	30 (27.78%)
Symptoms reported:			
Infertility	196 (65.77%)	177 (57.47%)	58 (53.70%)
Irregular periods	251 (84.23%)	260 (84.42%)	85 (78.70%)
Excess weight	259 (86.91%)	268 (87.01%)	88 (72.22%)
Skin discolouration	81 (27.18%)	87 (28.25%)	20 (18.51%)
Excess hair	228 (76.51%)	228 (74.03%)	88 (81.48%)
Acne	139 (46.64%)	139 (45.13%)	47 (43.52%)
Alopecia	87 (29.19%)	75 (24.35%)	33 (30.56%)
Skin tags	139 (46.64%)	139 (45.13%)	42 (38.89%)
Mood swings	231 (77.52%)	236 (76.62%)	86 (79.63%)

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-BREF (The WHOQOL Group, 1998) has 22 items and uses a 5-point Likert-type 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 have 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. 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-type 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 Derby (06012-SW) and all participants gave written informed consent before participating. All data were anonymous, however, participants in phase III were asked to provide their email address if they were happy to complete the test–retest 3 weeks later in order to check the consistency of the PCOSQOL over time.

Statistical analysis

Data analyses were conducted using SPSS v22 (IBM Corp., 2013). 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-type scale ranging from 'Does Not Apply' (p. 7) to 'Usually' (p. 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.

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. The results for the factor analysis can be seen in Table 2.

Reliability. Cronbach's alpha for the PCOSQOL overall scale was excellent (α=.95) as were the alphas for the four subscales: Impact of PCOS, Infertility, Hirsutism and Mood; α=.95, α=.93, α=.96 and α=.85, respectively (George and Mallery, 2003; Nunnally, 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. The results indicated that women with PCOS with greater levels of anxiety and depression had poorer QoL (Table 3).

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 a 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 (α=.95) (George and Mallery, 2003) and the four subscales; Impact of PCOS, Infertility, Hirsutism and Mood (α=.95, α=.95, α=.97 and α=.89, respectively).

Test–re-test reliability. A total of 90 of 308 (29%) participants completed a test re-test of the PCOSQOL after 3 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 (rs (57)=.90, p<.001 BCa confidence interval (CI) [.817, .948]). Mean scores were 105.67 (SD=37.32) for the PCOSQOL and 112.44 (SD=38.41) for the re-test. 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 re-test, Cronbach's alpha for the overall scale was excellent (α=.95) (George and Mallery, 2003) as well as

Table 2. Factor analysis and Cronbach's alphas for PCOS-QOL and its subscales.

Overall scale α = .95	Factor loadings			
Impact of PCOS (α = .95), eigenvalue = 17.21, % of variance = 30.20	I	2	3	4
Felt like you weren't a real woman because of your PCOS	.818			
Felt abnormal because of your PCOS	.800			
Felt that it is unfair that you have PCOS	.727			
Felt angry that you have PCOS	.716			
Felt like you don't know what to do to control your PCOS	.705			
Been envious of women without PCOS	.678			
Felt embarrassed about the way you look	.666			
Felt like you don't know what to do to help yourself	.662			
Felt embarrassed about having PCOS	.653			
Felt like less of a woman because of having PCOS	.638			
Felt like your PCOS is in control of your life	.638			
Struggled to cope with your PCOS and your other condition(s)	.634			
Felt like you hated yourself	.613			
Felt depressed about how PCOS has impacted your life	.539			
Wanted to do something but haven't because of your PCOS	.503			
Wanted to take part in a social activity but haven't because of your PCOS	.499			
Infertility (α = .95), eigenvalue = 4.99, % of variance = 8.76				
Felt depressed over your struggle to have children		.940		
Felt depressed over difficulties conceiving a child		.917		
Felt depressed because of your infertility		.893		
Felt like a failure because of your trouble conceiving		.866		
Felt anxious about conceiving a child		.842		
Felt under pressure to have a child		.734		
Been scared that you may not have children		.723		
Hirsutism (α = .97), eigenvalue = 4.11, % of variance = 7.22				
Felt embarrassed by your facial hair			.937	
Felt depressed because of your facial hair			.926	
Been worried about other people seeing your facial hair			.919	
Spent a lot of time and energy removing excess hair			.883	
Felt moody because of your excess hair			.876	
Felt depressed because of your hirsutism			.797	
Mood (α.89), eigenvalue = 2.24, % of variance = 3.92				
Felt guilty for being overly aggressive towards a friend of family member				.715
Over reacted to a day-to-day occurrence because of your PCOS				.711
Had a short temper with your close friends and/or family				.664
Felt overwhelmed by your PCOS and depression				.595
Felt depressed				.482
Felt like crying for no reason				.459

for the four subscales: Impact of PCOS (α=.96), Infertility (α=.96), Hirsutism (α=.97) and Mood (α=.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).

Table 3. Spearman's correlations exploring the relationship between the PCOSQOL, its subscales and HADS, The PCOSQ and the WHOQOL-BREF.

The PCOS-QOL							
		Impact of PCOS	Infertility	Hirsutism	Mood	Total score
HADS	Depression	−.615**	−.187**	−.357**	−.563**	−.532**
	Anxiety	−.521**	−.240**	−.285**	−.588**	−.493**
The PCOSQ	Emotions	.833**	.443**	.397**	.619**	.760**
	Body Hair	.376**	−.124	.716**	.121	.366**
	Weight	.568**	.460**	.306**	.389**	.585**
	Infertility Problems	.679**	.818**	.148	.492**	.732**
	Menstrual Problems	.237	.157	.100	.248	.251
	Total score	.787**	.557**	.519**	.554**	.817**
The WHOQOL BREF	Physical health	.422**	.031	.144	.451**	.282**
	Psychological	.646**	.255*	.272**	.599**	.518**
	Social Relationships	.342**	.028	.303**	.305**	.251*
	Environment	.514**	.225*	.209*	.301**	.449**

PCOSQOL: polycystic ovary syndrome quality of life; HADS: Hospital Anxiety and Depression Scale; PCOSQ: Polycystic Ovary Syndrome Questionnaire, WHOQOL-BREF: World Health Organization Quality of Life
*p < .05.
**p < .01.

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 3).

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 3). 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 article 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 United Kingdom. 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 re-test 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 (The 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 (The 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 United Kingdom (Fayers and Machin, 2007; Osborne et al., 2014). This begins to address the differences in QoL noted in global populations of women with PCOS (Açmaz et al., 2013; Bazarganipour et al., 2013; Benetti-Pinto 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 (The Rotterdam ESHRE/ASRM-Sponsored PCOS Consensus Workshop Group, 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, among others, and suggests that the large sample of participants represented all phenotypes of PCOS as detailed in the Rotterdam Criteria (The Rotterdam ESHRE/ASRM-Sponsored PCOS Consensus Workshop Group, 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 which would afford hypothesis testing by Confirmatory Factory Analysis (confirmatory factor analysis (CFA)).

This article details the development and preliminary validation of the PCOSQOL. While further validation is necessary (Nunnally, 1978; 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 regard 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

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