

Measures of health-related quality of life in PCOS women: a systematic review

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Introduction: Polycystic ovary syndrome (PCOS) is associated with biochemical and hormonal disturbance and adverse cosmetic, reproductive, metabolic, and psychological consequences, resulting in reduced health-related quality of life (HRQoL). Various generic and specific questionnaires have been used for assessing different dimensions of HRQoL in PCOS women. The purpose of this systematic review was to identify those general and specific instruments and to determine the factors that affect HRQoL in PCOS women.

Materials and methods: The research strategy involved general and specific terms in relation to PCOS women and their QoL. A review was performed on studies that were published between 1945 to 2017 and that were indexed in MEDLINE, ISI Web of Science, and Scopus. A narrative synthesis of the data was provided.

Results: In total, 52 studies (9 qualitative and 43 quantitative) were included in the review. The analysis indicated that 3 specific and 5 general instruments were used to measure the QoL in PCOS women. Of these, the 36-Item Short Form Health Survey (SF-36) and the Polycystic Ovary Syndrome Health-Related Quality of Life Questionnaire (PCOSQ) were used most frequently. All studies assessed different aspects of QoL in PCOS women and found that PCOS had negative effects on QoL in this population.

Conclusion: The PCOSQ and the SF-36 were used most frequently for the assessment of QoL in PCOS women. Perhaps using either a specific questionnaire solely or a specific questionnaire in conjunction with a generic measure would be more appropriate when measuring QoL in PCOS women. However, both questionnaires showed that they are able to capture different aspects of QoL in PCOS women and to identify areas that can help to improve QoL in these women.

Keywords: polycystic ovary syndrome, health-related quality of life, questionnaires, systematic review

Introduction

Polycystic ovary syndrome (PCOS) is the most common hormonal disturbance that, depending on the population studied and diagnostic criteria, affects up to 15%–20% of women at reproductive age.^{1,2} The pathophysiology of this heterogeneous disease has not been clearly determined, but it is believed that it results from complex interactions between genetic, metabolic, and environmental factors.³ It is characterized by hyperandrogenism, ovulatory dysfunction, and polycystic ovarian morphology.⁴ PCOS is associated with adverse clinical complications including reproductive (menstrual irregularity and infertility),^{2,3} metabolic (insulin resistance, diabetes, and cardiovascular risk),⁵ and psychological disabilities (anxiety and depression).⁶ All have been mentioned as factors responsible for the reduction of life quality.⁷

Health-related quality of life (HRQoL) is a multidimensional concept used to describe physical, emotional, and social aspects of particular diseases or their treatment.⁸

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Chronic disorders such as PCOS may have major effects on the QoL that need to be precisely assessed.⁹

HRQoL can be assessed using both general and specific tools. General tools have generally no questions for specific conditions and diseases.¹⁰ Therefore, specific tools are generally preferable for each condition assessed, and PCOS is no exception. However, both tool types have been used for measuring QoL in the literature. The aims of this study were to identify 1) studies that have used standard instruments to measure HRQoL in women with PCOS; 2) general and specific instruments that have been used for assessing HRQoL in PCOS women; and 3) the effects of PCOS on different aspects of women's QoL.

Methods

Search engines

The electronic databases searched included MEDLINE (January 1950–March 2017), ISI Web of Knowledge (January 1945–26 July 2017), Scopus (May 2000–January 2017), and Google Scholar (March 1996–January 2017). More data were collected from the reference lists and databases related to scientific conference, and we contacted the authors of the publications to know they had any other studies which had remained unpublished.

Search strategy

In the current systematic review article, we managed to find general and specific instruments that assessed QoL, and we further delineated the factors relevant to QoL in women suffering from PCOS using key words: (questionnaire OR scale OR inventory) AND (“Quality of life” OR “Health-related quality of life” OR “Patient-Reported Outcome”) AND (“Polycystic ovary syndrome” OR “PCOS”).

Inclusion criteria

The following criteria were used to decide which relevant resources to be included:

1. Document type: article;
2. Article type: original, review, and theoretical;
3. Language: English;
4. Study design: qualitative, quantitative, and mixed methods;
5. Species: humans;
6. Subject: health and medicine;
7. Documents' subjects: QoL and its related factors in PCOS women; and
8. Questionnaire used for HRQoL: measured more than one dimension.

Data synthesis

Two authors were asked to go through the title and abstract of the studies obtained and to read the full texts finally to decide which studies had met the criteria to be included in the current systematic review. The variables of interest were the first author's name, year, country, study design, and study results. The two authors negotiated any disagreements to reach consensus.

In order to assess HRQoL measures, the Consensus-based Standards for the Selection of Health Status Measurement Instruments checklist was employed. Specifically, we assessed measures for the following criteria: internal consistency, reliability, content validity, construct validity, and factor analysis.¹¹

Results

Statistics

In all, 4,269 citations were identified. After removing duplicates (n=486), the remaining 3,783 citations were assessed, and an additional 3,161 irrelevant records were excluded. Of the remaining 622 papers, 570 articles were also removed because they were not eligible, and finally 52 full-text articles were included in the analysis (Figure 1). Of these, 9 studies were qualitative and had focused upon the impact of PCOS on patients' HRQoL.^{12–20} The remaining 43 studies were quantitative which are summarized in Table 1. The frequency of studies on QoL in PCOS women from various countries (n=52) was as follows: USA (n=13), UK (n=9), Iran (n=7), Australia (n=3), Germany (n=5), Sweden (n=2), Italy (n=2), Canada (n=2), the Netherlands (n=2), and Brazil (n=2). In addition, there was one article from each of the following countries: Belgium, Turkey, Austria, Taiwan, and Greece. Table 2 displays and summarizes different components of QoL in PCOS women.

Instruments used

Various general and specific questionnaires were used to assess QoL in PCOS women. Overall, three specific and 5 general measures were used to assess the QoL in PCOS women. Of these, one general instrument (36-Item Short Form Health Survey [SF-36]) and one specific instrument (Polycystic Ovary Syndrome Health-Related Quality of Life Questionnaire [PCOSQ]) were used most frequently (Table 3). The generic questionnaires were the following: the SF-36 (n=17), Symptom Checklist-90-Revised (SCL-90-R; n=5), World Health Organization Quality-of-Life-BREF (WHOQOL-BREF; n=4), Child Health Questionnaire-Child Form (CHQ-CF87; n=3), and General

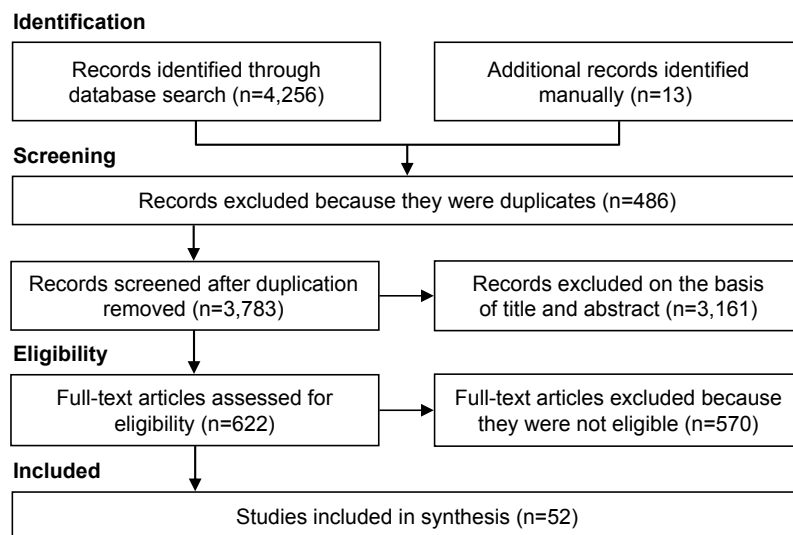


Figure 1 The flow diagram of the review.

Health Questionnaire-28 (n=1). The PCOS disease-specific instruments were the PCOSQ (n=20), the Modified PCOSQ (MPCOSQ; n=3), and the Polycystic Ovary Syndrome Questionnaire (PCOSQ-50; n=1). In the following sections, a short description for each of these is presented.

PCOSQ/MPCOSQ

The PCOSQ is an instrument that was specifically designed and validated to evaluate HRQoL in PCOS.^{21–23} In the first stage of the instrument development, 182 items were incorporated which belonged to 8 areas chosen as a result of running semi-structured interviews with 10 patients suffering from PCOS and an extensive literature review.²¹ In item reduction phase, 100 women with PCOS completed the instrument, and they identified the items of highest impact on their daily lives. By considering the factors influencing women and identifying the items that clinicians take as important, a factor analysis was performed, and the final questionnaire containing 26 items was provided. The PCOSQ contains the following domains: emotions (8 items), hirsutism (5 items), weight (5 items), infertility (4 items), and menstrual disorders (4 items). Each item can be answered by choosing from a Likert scale with 7 options from 1 (always) to 7 (never). Higher scores are indicative of better function. Studies that incorporated the PCOSQ revealed that women with PCOS had functioning impairments pertinent to some measured domains.^{24–29} However, the relative degree of impairment caused by each domain varied in societies depending on the religious, racial, cultural, and social factors.²⁴ Excess body weight has been widely reported as an important concern to

women with PCOS, especially in adolescents.^{27,30–32} In two more studies that were carried out in Australia and Germany, body weight domain was found to have the strongest association with lower QoL.^{33,34} The psychometric properties of PCOSQ are well documented in several studies indicating that it is a reliable and valid measure for assessing QoL in PCOS women.^{22,23,25,35} However, the PCOSQ was modified by Barnard et al, and 4 questions were added to it in order to evaluate issues associated with acne.³³ Thus, the MPCOSQ includes 30 questions from 6 HRQoL domains: emotional disturbance (8 items), weight concerns (5 items), infertility (4 items), acne (4 items), menstrual symptoms and predictability (4 items), and hirsutism (5 items). Each item was rated on a 7-point Likert scale where higher scores represent better function. The psychometric properties of the MPCOSQ were promising.³³ Using this instrument, Bazarganipour et al in a cross-sectional study of 300 women with PCOS found that infertility and menstrual domains were the most affected areas of HRQoL.³⁶

PCOSQ-50

The PCOSQ-50 was specifically developed by Nasiri-Amiri et al for measuring QoL in PCOS women.³⁷ They used a mixed-method, sequential, exploratory design to define the components of health-related QoL questionnaire and assessed the psychometric properties of instrument. A rudimentary questionnaire composed of 147 items was designed drawing on the findings of a qualitative study that was carried out with 23 Iranian women who suffered from PCOS. Exploratory factor analysis helped to reduce the number of items from

Table 1 Quantitative studies that measured HRQoL of women with PCOS (n=43)

Study; country	Design	Objective	Diagnosis criteria	Age (years, mean \pm SD)	HRQoL instruments used	Sample size	Main outcomes
Cronin et al; ²¹ USA	Cross-sectional	Designing tools for measuring the QoL in women with PCOS	NIH	18–45	PCOSQ	100 PCOS; 12 interviews	Developing PCOSQ, which includes 26 items
Wong et al; ⁶⁵ Canada	Cross-sectional	Examining the relative impact of the number and severity of patient problems on HRQoL	Not stated	30.5 \pm 6.7	PCOSQ	100	Including all potential items in calculating a domain score provided a more accurate portrait of HRQoL
Trent et al; ⁵² USA	Cross-sectional	Evaluating the HRQoL in adolescents with PCOS and its correlation with patients' perception	NIH	13–22	CHQ-CF87	146 control, 97 PCOS	Patients had worsened QoL. Patients with higher self-perceived severity scored were lower on the general health perception
Trent et al; ⁶⁶ USA	Cross-sectional	Evaluating the fertility concerns and sexual behavior in young PCOS women compared with healthy women	NIH	13–22	CHQ-CF87	146 control, 97 PCOS	PCOS women were 3.4 times more likely to be worried about fertility issues
Eisenbruch et al; ³⁰ Germany	Case-control	Evaluating the quality of life, mental status, and sexual satisfaction in PCOS women	NIH	Controls: 29.9 \pm 5.7; PCOS: 28.4 \pm 5.0	SF-36, SCL-90-R	50 control, 50 PCOS	PCOS caused a major reduction in the QoL and severely limits sexual satisfaction
Hashimoto et al; ⁶⁷ Brazil	Case-control	Evaluating the impact of weight status on symptom perception and QoL in PCOS women with different background	NIH	Brazilian: 25.5 \pm 3.9; Austrian: 23.8 \pm 4.7	PCOSQ	50 control, 50 PCOS	In Brazilian women, hirsutism and in Austria obesity had the greatest impact on QoL
Guyatt et al; ²² Canada	Cross-sectional	Measuring the psychometric properties of the PCOSQ	NIH	29.4 \pm 5.7	PCOSQ	393	Factor analysis provided moderate to strong support for the 5-domain structure of the PCOSQ
Schmid et al; ²⁴ Austria	Cross-sectional	Study of infertile PCOS patients QoL with different ethnic and cultural backgrounds	Not stated	18–39	PCOSQ	14 Muslim, 35 Austrian PCOS	HRQoL of women with an Islamic background was affected to a greater degree than that of Austrian women
Jones et al; ²³ UK	Cross-sectional	Measuring the psychometric properties of the PCOSQ	NIH	–	PCOSQ, SF-36	92	The PCOSQ is a reliable instrument for measuring the HRQoL
Van Wely et al; ⁶⁸ the Netherlands	Interventional	Evaluating the impact of laparoscopic electrocautery of the ovaries versus recombinant FSH on the PCOS patients' HRQoL	Rotterdam	Electrocautery: 28.5 \pm 3.7; FSH: 28.7 \pm 4.1	SF-36	Electrocautery: 83, FSH: 85	HRQoL was not affected in both groups. FSH treatment was slightly more burdensome for women's HRQoL than electrocautery
Clayton et al; ⁶⁹ UK	Interventional	Evaluating the effect of laser on the severity of facial hirsutism and on psychological complications in PCOS women	Not stated	PCOS: 33.0 \pm 8.0; control: 32 \pm 6.5	WHOQOL-BREF	37 control, 51 intervention	Laser treatment reduced the severity of facial hair as well as alleviating depression and anxiety in patients
McCook et al; ²⁷ USA	Cross-sectional	Evaluating the influence of the major clinical features of PCOS on patients' QoL	Not stated	20–41	PCOSQ	128	The most common HRQoL concern reported by women with PCOS was weight. BMI and fertility loss had the greater impact on QoL
Trent et al; ⁵³ USA	Cross-sectional	Assessing the BMI impact on the QoL of adolescents with PCOS	NIH	13–22	CHQ-CF87	146 control, 97 PCOS	BMI is a primary mediator in the relationship between PCOS and HRQoL reductions

Hahn et al; ⁴⁷ Germany	Case-control	Examining the extent of different PCOS manifestations on QoL, psychosocial well-being, and sexual satisfaction	NIH	PCOS: 29.0±5.4; control: 30.0±5.7	SF-36, SCL-90-R	120 control, 50 PCOS	PCOS patients showed significant reductions in QoL, psychosocial well-being, and sexual satisfaction
Eisenbruch et al; ⁴⁰ Germany	Cross-sectional	Evaluation of psychological stress in untreated PCOS patients and to assess the impact of emotional distress on QoL	NIH	31.3±1.3	SF-36, SCL-90-R	143	Majority of patients exhibited psychological disturbances. Emotional distress together with obesity leads to large decrements in QoL
Lipton et al; ⁷⁰ UK	Cross-sectional	Assessing the behavioral and psychological burden of facial hair in PCOS women	Not stated	33.0±7.4	WHOQOL-BREF	88	Facial hair carries a high psychological burden for women. 29% of patients reported depression and anxiety
Coffey et al; ²⁵ UK	Case-control	Comparing the QoL in women with PCOS with the general population and patients with other medical conditions	AES	PCOS: 27.5; control: 28.8	SF-36, PCOSQ	22 control, 96 PCOS	PCOS had a negative impact on HRQoL even when compared with other medical conditions (asthma, epilepsy, diabetes, arthritis, and coronary heart disease)
Hahn et al; ³⁹ Germany	Interventional	Evaluation the effects of metformin treatment on HRQoL, emotional well-being, and sexuality in PCOS women	NIH Rotterdam	29.3±6.3	SF-36, SCL-90-R	327	Treatment improved the psychosocial, emotional, and psychosexual situation of PCOS patients
Barnard et al; ³³ UK	Cross-sectional	Assessing the quality of life of women with PCOS, studying the factor analysis and adding acne factor	Rotterdam	31.0±6.5	MPCOSQ	935 control, 424 PCOS	The PCOSQ was modified to include acne. The PCOS groups had significantly worse QoL than controls
Drosdzol et al; ⁶⁰ the Netherlands	Case-control	To evaluate the effect of PCOS on QoL and marital sexual satisfaction	Rotterdam	19-40	SF-36	40 control, 50 PCOS	PCOS decreased QoL and sexual functioning among women. A negative effect of hirsutism severity on general well-being and sexual life was also observed
Ching et al; ²⁶ Australia	Case-control	Evaluation of QoL and psychological complications in PCOS women, compared the findings with general norms	NIH	PCOS: 15-65; control 18-44	SF-36, PCOSQ, GHQ-28	173 control, 203 PCOS	Impaired QoL and increased prevalence of psychological morbidity in PCOS compared with population norms were obtained
Tan et al; ⁴⁸ Germany	Cross-sectional	Assessing the impact of infertility on various aspects of psychological function in PCOS women	NIH	28.1±4.8	SF-36, SCL-90-R	115	PCOS obtained a major risk factor for psychosocial and emotional problems. Infertility was not a primary determinant of psychological problems
Rofey et al; ⁴¹ USA	Interventional	Evaluating cognitive-behavioral therapy on psychological problems of PCOS adolescents	AES	12-18	SF-36	25	Depressive symptoms and weight decreased significantly
Harris-Glocker et al; ⁷¹ USA	Interventional	Assessing the effect of treatment (metformin, lifestyle) on the QoL in obese PCOS adolescents	NIH	12-18	PCOSQ	36	QoL was improved in both groups (lifestyle and obsessive-compulsive disorder treatment)
Ladson et al; ⁷² USA	Interventional	Assessing the effect of treatment (metformin, lifestyle) on the QoL of adolescents with PCOS	NIH	13-18	PCOSQ	28	QoL was significantly improved in both treatment groups
Moran et al; ⁷³ Australia	Case-control	Evaluating the psychological features in young girl with PCOS compared with healthy women	Rotterdam	18-25	PCOSQ	22 control, 24 PCOS	Worsened QoL in PCOS women

(Continued)

Table 1 (Continued)

Study; country	Design	Objective	Diagnosis criteria	Age (years, mean \pm SD)	HRQoL instruments used	Sample size	Main outcomes
Thomson et al; ³⁴ Australia	Interventional	Assessing the effect of exercise and dietary restriction on depressive symptoms and HRQoL in obese women with PCOS	Rotterdam	29.3 \pm 0.7	PCOSQ	104	Dietary restriction, with/without exercise, had similar benefits for improving depression and HRQoL in obese women with PCOS
Ladson et al; ⁷⁴ USA	Interventional	Determining the effect of lifestyle changes (caloric restriction and exercise) on the QoL of PCOS women	NIH	29.0 \pm 4.5	PCOSQ	114	QoL was improved in emotion and weight areas within each treatment group
Bazarganipour et al; ⁷⁵ Iran	Cross-sectional	Assessing the prevalence of mood disorders and examine predictors for psychological well-being among Iranian PCOS women	Rotterdam	15–40	SF-36	300	32% of patients showed elevated anxiety and depression. QoL was very impaired in women with anxiety and depression
Bazarganipour et al; ⁷⁶ Iran	Cross-sectional	Evaluating the effect of different clinical symptoms of PCOS on patients HRQoL	Rotterdam	15–40	MPCOSQ	200	Worsened HRQoL in PCOS women was related to more menstrual problems and infertility than to obesity
Stener-Victorin et al; ⁷⁷ Sweden	Interventional	The effect of exercise and acupuncture on the QoL in PCOS women	Rotterdam	29.9 \pm 4.4	SF-36, PCOSQ	114	Anxiety and depression improved in women treated with acupuncture. HRQoL was improved in both groups
Bazarganipour et al; ⁷⁸ Iran	Cross-sectional	Determining the association between HRQoL and psychosexual variables in patients with PCOS	Rotterdam	15–40	MPCOSQ	300	The highest effect of PCOS symptoms on HRQoL was exerted by clinical variables, poor perception, negative body image, and sexual dysfunction
De Frène et al; ⁷⁹ Belgium	Cross-sectional	Investigating the relationship between PCOS symptoms with sexual and relational satisfaction in obese women and their partners	Rotterdam	18–43	PCOSQ	62	PCOS characteristics and its concerns were associated with the sexual and/or relational satisfaction of couples
McCook et al; ²⁸ USA	Cross-sectional	Investigating the relative contributions of PCOS manifestations to psychological symptoms	Rotterdam	18–48	PCOSQ	126	Patients were at a greater risk for depression, anxiety, and interpersonal sensitivity. Menstrual problems predicted every dimension of psychological distress
Benetti-Pinto et al; ⁵⁰ Brazil	Case-control	Assessing the sexual function and QoL in PCOS women	Rotterdam	PCOS: 26.9 \pm 4.9; control: 35.6 \pm 7.3	WHOQOL-BREF	102 control, 56 PCOS	PCOS women had a worse sexual function and worse QoL in the self-assessment of the health area. Obesity was correlated to the worsening in QoL
Guidi et al; ⁸⁰ Italy	Cross-sectional	Assessing the psychosocial effects of PCOS on adolescents	NIH	16–19	PCOSQ	394	Impaired well-being and QoL were found among young females with PCOS
Stefanaki et al; ⁸¹ Greece	Interventional	The effect of mindfulness – stress program on mental status and QoL in PCOS women	Rotterdam	15–40	PCOSQ	73	Stress, anxiety, and depression levels decreased and QoL improved
Nasiri-Amiri et al; ³⁷ Iran	Mixed methods	Designing HRQoL measurement tool in Iranian women with PCOS	Rotterdam	18–40	PCOSQ-50	200 PCOS, 23 interviews	The PCOSQ-50 was a valid and reliable instrument for the assessment of QoL of women with PCOS

Author(s)	Study Design	Location	Sample Size (PCOS/control)	Questionnaire	Findings
Shishehgar et al. ⁴² Iran	Case-control	AES	PCOS: 28.6±4.9; control: 29.0±5.8	SF-36	The physical aspects of HRQoL were adversely affected by obesity in both groups, but these impaired effects were greater in PCOS group
Huang-TzOu et al. ⁸² Taiwan	Interventional	Rotterdam	18-45	WHOQOL-BREF, PCOSQ	Metformin improved HRQoL of PCOS women especially in overweight patients
Dokras et al. ⁸³ USA	Interventional	Rotterdam	18-40	SF-36, PCOSQ	Weight loss result in significant improvements in several physical and mental domains related to QoL
Ozcan Dag et al. ⁸⁴ Turkey	Case-control	Rotterdam	PCOS: 22.6±4.5; control: 21.3±2.1	SF-36	PCOS patients had significantly higher rates of depressive and anxious compared with controls. QoL was significantly lower in patients
Panico et al. ⁴⁴ Italy	Case-control	Rotterdam	Controls: 16.4-31; PCOS: 17.2-29	SF-36, PCOSQ, SCL-90-R	Worsening of HRQoL in PCOS patients compared with controls

Abbreviations: AES, Androgen Excess Society; BMI, body mass index; CHO-CF87, Child Health Questionnaire-Child Form; FSH, follicle-stimulating hormone; GHQ-28, General Health Questionnaire-28; HRQoL, health-related quality of life; MPCOSQ, Modified PCOSQ; NIH, National Institutes of Health; PCOS, polycystic ovary syndrome; PCOSQ, Polycystic Ovary Syndrome Health-Related Quality of Life Questionnaire; PCOSQ-50, Polycystic Ovary Syndrome Questionnaire; QoL, quality of life; SCL-90-R, Symptom Checklist-90-Revised; SF-36, 36-Item Short Form Health Survey; WHOQOL-BREF, World Health Organization Quality-of-Life-BREF.

Table 2 Different components of quality of life in PCOS women

Dimensions	Studies
Psychological and emotional	McCook et al, ²⁷ Coffey et al, ²⁵ Elsenbruch et al, ⁴⁰ Jedel et al, ⁸⁵ Teede et al, ³ Månsson et al, ⁸⁶ McCook et al, ²⁸ Podfigurna-Stopa et al, ⁶² Weiss and Bulmer, ¹⁶ Bazarganipour et al, ⁷⁵ Nasiri Amiri et al, ⁸⁷ and Taghavi et al ¹⁹
Body image	Trent et al, ⁶⁶ Ekback et al, ¹⁴ Bazarganipour et al, ⁷⁵ and Taghavi et al ¹⁹
Social	Trent et al, ⁶⁶ Jones et al, ²³ Schmid et al, ²⁴ Ekback et al, ¹⁴ Moran et al, ⁷³ Bazarganipour et al, ⁷⁵ Taghavi et al, ¹⁹ and Weiss and Bulmer ¹⁶
Sexual	Elsenbruch et al, ³⁰ Trent et al, ⁶⁶ Tan et al, ⁴⁸ Månsson et al, ⁸⁶ Benetti-Pinto et al, ⁵⁰ and Taghavi et al ¹⁹
Physical	
Weight	Barnard et al, ³³ Hahn et al, ⁴³ Elsenbruch et al, ³⁰ Kaczmarek et al, ³² Trent et al, ⁵³ Benetti-Pinto et al, ⁵⁰ and Shishehgar et al ⁴²
Hirsutism and acne	Elsenbruch et al, ³⁰ Ekback et al, ¹⁴ and Khomami et al ²⁹
Menstrual problem	Bazarganipour et al, ³⁶ Bazarganipour et al, ⁷⁵ McCook et al, ²⁷ and McCook et al ²⁸
Infertility	Schmid et al, ²⁴ Elsenbruch et al, ³⁰ Hahn et al, ⁴³ Bazarganipour et al, ⁷⁵ Nasiri Amiri et al, ⁶¹ and Khomami et al ²⁹
Medical	Van Wely et al, ⁶⁸ Hahn et al, ³⁹ Trent et al, ⁵³ Hahn et al, ³⁹ Thomson et al, ³⁴ Harris-Glocker et al, ⁷¹ Dokras et al, ⁸³ Stefanaki et al, ⁸¹ and Rofey et al ⁴¹

Abbreviation: PCOS, polycystic ovary syndrome.

147 to 50. The ultimate draft of the questionnaire incorporated 50 items representing 6 areas, namely emotion, obesity and menstrual disorders, fertility, sexual function, hirsutism, and coping. Each item could be answered by selecting from options on a 5-point Likert scale with higher scores meaning better condition. The analysis of the psychometric properties of the questionnaire revealed promising results.

SF-36

The SF-36 is one of the most acknowledged and most frequently used instruments to measure QoL. The SF-36 is used in all types of patients and has been validated in many countries. This instrument has been proved to be reliable and widely validated and has been employed in the assessment of HRQoL in various medical conditions. It consists of 36 items tapping into 8 subscales, namely physical functioning, role physical, bodily pain, general health, vitality, social functioning, role emotional, and mental health.³⁸ The scores on each domain range from 0 to 100 where the higher scores indicate better conditions. Several studies used the SF-36 in order to assess HRQoL in PCOS patients.^{30,39-42} Findings have been rather consistent in revealing lower HRQoL in women suffering from PCOS. However, evidence suggests

Table 3 Most general and specific instruments for assessing HRQoL in women with PCOS

Instruments	No of items	Dimensions covered	Studies
General instruments			
SF-36	36	Physical functioning, vitality/energy, physical role limitation, bodily pain, mental health, emotional role limitation, general health perception, and social functioning	Elsenbruch et al, ³⁰ Jones et al, ²³ Van Wely et al, ⁶⁸ Hahn et al, ⁴⁷ Hahn et al, ³⁹ Elsenbruch et al, ⁴⁰ Coffey et al, ²⁵ Drosdzol et al, ⁶⁰ Ching et al, ²⁶ Tan et al, ⁴⁸ Rofey et al, ⁴¹ Bazarganipour et al, ⁷⁵ Stener-Victorin et al, ⁷⁷ Dokras et al, ⁸³ Shishehgar et al, ⁴² Ozcan Dag et al, ⁸⁴ and Panico et al ⁴⁴
SCL-90-R	90	Somatization, obsessive–compulsive, interpersonal sensitivity, paranoid ideation, psychoticism, anxiety depression, phobia, and aggression	Elsenbruch et al, ³⁰ Hahn et al, ⁴⁷ Hahn et al, ³⁹ Elsenbruch et al, ⁴⁰ and Tan et al ⁴⁸
CHQ-CF87	87	Change in health in the last year, role/social emotional, behavioral, physical, bodily pain, behavior, mental health, self-esteem, general health perceptions, family activities, family cohesion, and physical functioning	Trent et al, ⁵² Trent et al, ⁶⁶ and Trent et al ⁵³
WHOQOL-BREF	26	General health, physical health, psychological, health, Social relationship, and environmental	Clayton et al, ⁶⁹ Lipton et al, ⁷⁰ Benetti-Pinto et al, ⁵⁰ and Huang-TzOu et al ⁸²
GHQ-28	28	Somatic symptom, anxiety/insomnia, social dysfunction, and depression	Ching et al ²⁶
Specific instruments			
PCOSQ	26	Emotion, hirsutism, infertility, weight, and menstrual problem	Cronin et al, ²¹ Wong et al, ⁶⁵ Hashimoto et al, ⁶⁷ Guyatt et al, ²² Jones et al, ²³ Schmid et al, ²⁴ McCook et al, ²⁷ Coffey et al, ²⁵ Ching et al, ²⁶ Rofey et al, ⁴¹ Harris-Glocker et al, ⁷¹ Moran et al, ⁷³ Thomson et al, ³⁴ Ladson et al, ⁷² Stener-Victorin et al, ⁷⁷ De Frène et al, ⁷⁹ Stefanaki et al, ⁸¹ McCook et al, ²⁸ Dokras et al, ⁸³ and Panico et al ⁴⁴
MPCOSQ	30	Emotion, hirsutism, infertility, weight, menstrual problem, and acne	Barnard et al, ³³ Bazarganipour et al, ³⁶ and Bazarganipour et al ⁷⁸
PCOSQ-50	50	Psychosocial and emotional, fertility, sexual, obesity, and menstrual disorders, hirsutism, and coping	Nasiri-Amiri et al ³⁷

Abbreviations: CHQ-CF87, Child Health Questionnaire-Child Form; GHQ-28, General Health Questionnaire-28; HRQoL, health-related quality of life; MPCOSQ, Modified PCOSQ; PCOS, polycystic ovary syndrome; PCOSQ, Polycystic Ovary Syndrome Health-Related Quality of Life Questionnaire; PCOSQ-50, Polycystic Ovary Syndrome Questionnaire; SCL-90-R, Symptom Checklist-90-Revised; SF-36, 36-Item Short Form Health Survey; WHOQOL-BREF, World Health Organization Quality-of-Life-BREF.

that poor QoL in these women might be due to obesity. In some studies, it has been shown that body mass index (BMI) was a predictor of physical functioning as measured by the SF-36.^{43,44} Furthermore, by using a multivariable regression model, Panico et al in a recent study indicated that BMI is a predictor of physical functioning score.⁴⁴ Jones et al found that the role emotional was the poorest area of health, with mean scores of 50.4 on the SF-36 questionnaire, which had the greatest negative impact on HRQoL in women with PCOS.²³ In a study by Coffey et al, the psychological dimension was more affected than the physical dimension as measured by the SF-36.²⁵ Bazarganipour et al found that PCOS affected all domains in the SF-36, and psychological domains were most affected by PCOS.⁴⁵

SCL-90-R

The SCL-90 has also been widely used and extensively validated. It includes 90 items grouped into 10 main domains, namely somatization, obsessive–compulsive, interpersonal

sensitivity, depression, anxiety, aggression, phobia, paranoid ideation, psychoticism, and sleep disorders.⁴⁶ Three global areas are measured, including the Global Severity Index, Positive Symptom Distress Index, and Positive Symptom Total. For each item related to a single domain, a score ranging from 0 (not at all) to 4 (very much) can be selected. Higher scores represent less favorable conditions.⁴⁴ Some studies targeting adult women suffering from PCOS have employed the SCL-90 to measure life quality.^{30,40,44,47,48} By using this tool, Elsenbruch et al showed that emotional distress and obesity in PCOS women are associated with significant decrease in HRQoL.⁴⁰

WHOQOL-BREF

WHOQOL-BREF instrument is comprised of 26 items, which measure broad domains consisting of physical health, psychological health, social relationships, and environment. The WHOQOL-BREF is a shorter version of the original instrument and can be used for assessing the QoL in different

cultures and populations. In a study on 146 women having PCOS and 170 controls who were assessed by the WHOQOL-BREF questionnaire, it was discovered that the hirsutism scores were a major predictor of psychological distress and showed correlation with the emotion domain.⁴⁹ In Benetti-Pinto et al's study, the BMI was inversely correlated to the QoL in women suffering from PCOS, mainly with the physical, psychological, and environmental aspects of QoL.⁵⁰

CHQ-CF87

The CHQ-CF87 is a self-report questionnaire that was developed and validated at the Health Institute of the New England Medical Center in Boston.⁵¹ It has been used to measure HRQoL in general populations of youth. It consists of 12 summated scales and is designed to measure both the physical and psychosocial HRQoL of adolescents. The items on the CHQ-CF87 are scored from 0 to 100 except for the change in health in the last year, and the items on family cohesion subscales are scored from 1 to 5 as single-item measures. A higher score on each subscale indicates better QoL in a specific area or health improvement in the last year.

Trent et al in their study used the CHQ-CF87 and revealed that HRQoL scores of adolescents suffering from PCOS were significantly lower in 4 areas of physical functioning, general health perceptions, behavior, and family activities as measured by the questionnaire.⁵² These authors also carried out another study in this area and evaluated the influence of BMI on QoL disturbances in adolescent patients. PCOS adolescents had higher BMI than those of the controls and a significantly lower HRQoL. Similarly, PCOS girls scored lower on the general health perceptions, physical functioning, family activities, and the general behavior subscales of CHQ-CF87.⁵³

Discussion

The studies identified in this review have shown that PCOS is a major cause of psychological morbidity and has a negative impact on women's HRQoL. This feature has also been demonstrated in some qualitative studies.^{13,14,16,19} In all the studies reviewed, different aspects of the QoL in PCOS women were evaluated including physical, psychological, social, sexual as well as medical ones.

The impact of PCOS on the HRQoL may be more specifically seen in the perception of values and culture;²⁴ therefore, the major contributing factors of reductions of life quality in PCOS were discovered to be different in a variety of population. However, physical aspects of QoL may be best predicted by obesity and hirsutism.^{29,49} Excess body

weight has been widely reported as an important concern to women with PCOS, especially in adolescents.^{27,30-32} Obesity is believed to be a primary source for poor HRQoL and contributes substantially to negative psychological symptoms in women with PCOS.⁵⁴ The findings of an Italian study that was recently performed yielded a significant aggravation of HRQoL in PCOS patients with obesity compared with controls.⁴⁴

Hirsutism can be found in nearly 70% of women suffering from PCOS,² and patients take it as one of the most annoying aspects of PCOS.^{29,55} Women suffering from PCOS who experience hirsutism have often complained that they feel "unfeminine."^{12,30,56,57}

The comparison of psychological well-beings between women suffering from PCOS and control groups showed an increased risk for emotional distress in those with PCOS.⁶ Recent meta-analysis in PCOS women has yielded a raise in the prevalence of both depressive and anxiety symptoms in women suffering from PCOS in comparison with controls.⁵⁸ Loss of femininity, body image concerns, and coping with these conditions may all contribute to poorer mental health outcomes.⁵⁹

Moreover, changes in body dimensions and physical beauty as well as imbalance of sexual hormones could lead to reduction in QoL and sexual performance. Psychological distress from long-term health risks, infertility, and changes in appearance (obesity, acne, and hirsutism) can influence sexual function among PCOS women.^{50,60} These women often complain that they feel less attractive and being less sexually satisfied in comparison with non-PCOS women.³⁰

PCOS can also affect patients' QoL socially. Based on the results of qualitative studies, other factors that affected QoL were the reduction of interpersonal and social relationships.^{61,62} Accordingly, Ekbäck et al in their qualitative study showed that hirsutism causes severe psychological burden and negatively affected patients' HRQoL and social interactions.¹⁴ A few studies explored the impact of treatment on HRQoL. In 2009, Rofey et al showed that an enhanced cognitive behavioral therapy was practical and encouraging for adolescents suffering from PCOS.⁴¹

One of the major findings of the current research was the high frequency of application of specific and general instruments such as PCOSQ and SF-36. In our review, 24 studies had used specific tools for this purpose, and general questionnaires had been applied in other studies. PCOS affects women both psychologically and physically according to the SF-36. A recent meta-analysis showed that women with PCOS score lower in each dimension of the

SF-36, mostly in the “Role Emotional” subscale.⁷ General tools are designed to measure HRQoL in a wide range of diseases and therefore may not be sensitive enough to be used in specific conditions.⁶³ However, specific tools such as PCOSQ include some certain questions for these conditions. Obesity, hirsutism, irregular menses, and infertility are different aspects of PCOS exerting negative impacts on HRQoL that would not easily be detected by employing only a generic questionnaire. By using PCOSQ, it was demonstrated that clinical symptoms of PCOS, especially excess body weight^{22,23,25–27} and hirsutism,²⁹ could compromise women’s QoL. Ideally, employing both general and specific disease instruments in measuring HRQoL is recommended in order to make comparisons possible at a generic level and especially in the case of the disease under focus.⁶⁴

Conclusion

PCOS symptoms can result in remarkable worsening of life quality and may be highly stressful, adversely affecting psychological, social well-being and sexuality. This study revealed that the specific questionnaire PCOSQ and the SF-36 were mainly used for measuring life quality in women having PCOS. Perhaps using either a specific questionnaire solely or a specific questionnaire in conjunction with a generic measure would be more appropriate when measuring QoL in PCOS women. However, both questionnaires showed that they are able to capture different aspects of QoL in PCOS women and to identify areas that can help to improve QoL in these women.

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Disclosure

The authors report no conflicts of interest in this work.

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