

The Assessment of Reliability and Validity of Persian Version of the Endometriosis Health Profile (EHP-30)

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Abstract

Background: The Endometriosis Health Profile-30 (EHP-30) is a disease-specific questionnaire to measure the health-related quality of life in patients with endometriosis. The aim of this study was to evaluate the validity and reliability of the Persian version of Endometriosis Health Profile (EHP-30) in women with endometriosis referring to three Gynecology Clinics in Tehran, Iran.

Methods: One hundred women (20 to 50 years old) with surgically confirmed endometriosis recruited from three outpatient Gynecology Clinics affiliated to the Iran University of Medical Sciences. All 100 patients were asked to complete EHP-30 questionnaire while referring to the Clinics. The findings were analyzed using descriptive statistics, internal reliability consistency, construct validity (using short form-36, which had already been validated in Iran), factor analysis (with principle component analysis method), and item total correlation to assess the validity and reliability of the questionnaire.

Results: The internal consistency reliability of the questionnaire was high (Cronbach's α ranged between 0.80 and 0.93 for core, and 0.78 and 0.90 for modular parts). All items were loaded on their own factors except item 17 (feeling aggressive or violent) and item 18 (feeling unwell), which were loaded on pain and social support domains, respectively. Construct validity of EHP-30, established by using SF-36, indicates good correlations in several similar scales of these two questionnaires.

Conclusion: The findings of the study demonstrate that Persian version of EHP-30 is a valid and reliable measure to assess the quality of life in women with endometriosis.

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Keywords • Endometriosis • quality of life • validity • reliability • endometriosis health profile

Introduction

Endometriosis is a common gynecological condition that is associated with a variety of symptoms, most commonly chronic pelvic pain. Endometriosis affects near seven million women in the United States, and more than 70 million worldwide.¹ Other reported estimates of the prevalence of endometriosis range from 1% to 52%,^{2,3} and the most frequently reported rate was 10%.^{2,4}

The symptoms associated with endometriosis are major causes of morbidity and psychological complaints. Women with endometriosis have social dysfunction, feelings of frustration and isolation due to pelvic pain, infertility problems and a delay in diagnosis.⁵

In recent years, studies have begun to assess the effects of endometriosis on health-related quality of life (HRQL). Health related quality of life is a multi-dimensional concept including physical, psychological, and social aspects associated with a particular disease or its treatment.⁶

Health-related quality of life measurement has an important role as an outcome measure in investigations. Using generic instrument to evaluate the quality of life in women with endometriosis has a great limitation that may not be sensitive enough to assess specific changes of the disease.⁷ It has been shown that disease-specific instruments contains items developed from typical patients could be more responsive to changes of health status.⁸ Jones et al. recently reported a disease-specific questionnaire to measure the health status of women with endometriosis (Endometriosis Health profile-30).⁵ The evaluation of the original version of the 30-item Endometriosis Health profile-30 (EHP-30), performed in a gynecologic clinic at the John Radcliff Hospital, Oxford, England, showed a high internal consistency for all domains (Cronbach's alpha ranged from 0.83 to 0.93).⁵ In order to use a reliable and valid instrument in another country with a different language, it must be translated, and its reliability and validity be examined. The objective of this study was to examine the reliability and validity of Persian version of EHP-30 questionnaire employing patients with endometriosis in Tehran, Iran.

Materials and Methods

The EHP-30, a disease-specific questionnaire to measure the HRQL, was used in this study. This questionnaire was developed by Jones et al., in 2001.⁵ The EHP-30 consists of two parts. The first part is a core questionnaire with 30 items applicable to all women with endometriosis covering five areas including pain, emotional well-being, control and powerlessness, social support and self imaging scales. The second part is a modular section containing six domains, which comprised of 23 questions covering areas such as work, relationship with children, sexual activity, infertility, medical profession and treatment, which are not necessarily relevant to all women with endometriosis.

The score of each domain ranged from 0 (indicating the best health status) to 100 (indicating the worst health status). The score of each domain was calculated by dividing the total of the raw scores of each item in the domain by the maximum possible raw score of all items in the domain multiplied by 100.

The questionnaire was translated to Persian by a native Iranian health professional translator fluent in both English and Persian. Subsequently, the questionnaire was back translated to English. The two versions of the questionnaire were compared by investigators and any differences were discussed and resolved. Finally, the Persian version of the questionnaire was tested on few women with endometriosis and their understandings of the items were assessed. Afterwards, the final Persian version of the questionnaire was developed and tested in this study.

We used the questionnaire of Short-Form 36 (SF-36) health status survey in this study, which had previously been validated in Persian.⁹ The SF-36 contains eight subscales measuring aspects of physical and mental health. Each dimension is reported on a scale of 0 to 100 with higher score reflecting a better quality of life. Other variables measured in this study were demographic variables (age, marital status, education and occupation) and clinical variables including pelvic pain (unrelated to menstruation), feeling sick or nauseated, lack of energy and fatigue, painful urination, constipation or diarrhea, menstrual pain, irregular menstruation and also not having menstruation within previous four weeks.

This cross-sectional study was conducted between May and November 2009 recruiting all women with endometriosis referring to Out-patient Gynecology Clinics of three teaching hospitals affiliated to Iran University of Medical Sciences. The patients were selected using a convenience sequential method of sampling. The questionnaires were filled out in waiting room. One hundred women who had been given a surgical confirmation of endometriosis during the preceding five years were recruited in this study. All of them completed the EHP-30. The inclusion criteria were an age of 20 to 50 years and a confirmed endometriosis. The exclusion criteria included evidence of another major physical or mental illness that had a great effect on quality of life. The aims of the study were described for subjects, and those who agreed to participate in the study were included. Institutional Review Board of Medical School or Iran University of Medical Sciences approved the study.

Endometriosis Health profile-30 was evaluated using descriptive statistics, internal reliability consistency, construct validity, factor evidence and item total correlation (corrected for overlap). Internal consistency reliability was assessed by Cronbach's α . An Alpha coefficient of 0.70 or more was considered acceptable.¹⁰ The item total correlation (linear relationship between an item and its scale total) evaluated and a correlation coefficient of 0.40 or more was considered acceptable for having a good item total consistency.¹¹ To test the construct validity of the EHP-30, the SF-36 questionnaire was administered to subjects. Pearson's correlation coefficient was used to assess this type of validity. We hypothesized a significant correlation between the SF-36, and the EHP-30 and its subscales. Factor analysis (principal component analysis and varimax rotation) was performed to verify the scales produced from the first analysis in the development of the questionnaire. Items with a loading of 0.3 on a principle component analysis were used for factor analysis with varimax rotation. Data analysis was performed using Statistical Package for Social Sciences (SPSS version 13.0). A p value of ≤ 0.05 was considered statistically significant.

Results

The age of the participants was 39.5 ± 7.54 years ranging from 22 to 49 years. Eighty one percent of them were married, and 74% of them were housewives. About one third of the respondents had less than high school education.

Forty seven percent of women reported the lack of energy and fatigue. Non-menstrual pelvic pain (36%), menstrual pain (24%), constipation/diarrhea (18%), feeling sick/nauseated (14%), painful urination (9%) and irregular menstruation (7%) were the other symptoms respectively. Table 1 shows descriptive statistics of the core and modular part of EHP-30.

A factor analysis with a maximum five-factor solution developed (table 2). All items were loaded on their hypothesized factor except

items 17 (felt aggressive or violent) and 18 (feeling unwell) which were loaded on other factors (pain: 0.524, and social support: 0.568 domains, respectively).

Table 2: Factor analysis: factor load for core domain of EHP-30 questionnaire

Domain	Factor load	
Pain scale		
P1: Unable to go to social events	0.709	
P2: Unable to do jobs at home	0.802	
P3: Found it difficult to stand	0.738	
P4: Difficult to sit	0.357	
P5: Found it difficult to walk	0.811	
P6: Difficult to exercise	0.754	
P7: Lost appetite/unable to eat	0.707	
P8: Been unable to sleep	0.626	
P9: Had to lie down or go to bed	0.734	
P10: Unable to do things you want	0.710	
P11: Felt unable to cope with pain	0.582	
Emotional well-being scale		
E1: Felt depressed	0.890	
E2: Felt weepy/tearful	0.837	
E3: Felt miserable	0.683	
E4: Had mood swing	0.664	
E5: Felt bad or short-tempered	0.666	
E6: Felt aggressive or violent	0.360	0.568
Control and powerlessness scale		
C&P1: Generally felt unwell	0.318	0.524
C&P2: Symptoms not getting better	0.726	
C&P3: Not able to control symptoms	0.809	
C&P4: Felt unable to forget symptoms	0.802	
C&P5: Felt symptoms ruling your life	0.778	
C&P6: Felt symptoms taking away life	0.618	
Social support scale		
S1: Unable to tell people how you feel	0.661	
S2: Felt others do not understand	0.556	
S3: Felt others think you are complaining	0.627	
S4: Felt alone	0.475	
Self-image scale		
Self1: Can not wear clothes you choose	0.836	
Self2: Appearance has been affected	0.780	
Self3: Lacked confidence	0.551	

Table 1: Descriptive statistics of eleven dimensions of the endometriosis health profile-30 core and modular questionnaires

Domain	n	mean	SD	median	25 th percentile	75 th percentile
Pain	100	46.69	12.04	43.63	40	50.9
Control and powerlessness	100	41.76	14.33	40	33.33	43.33
Emotional well-being	100	46.73	10.75	43.33	40	52.50
Social support	100	43.80	13.85	40	35	45
Self image	100	36.20	12.25	33.33	26.66	40
Work	19	39.57	9.96	40	32	44
Relationship with children	68	34.85	13.9	40	20	40
Sexual activity	53	44.83	10.76	40	40	48
Medical profession	97	36.13	12.65	40	25	45
Treatment	92	45.36	14.93	46.66	40	60
Infertility	18	50.55	15.23	45	40	50

Cronbach's α ranged between 0.80-0.93 for core domains and 0.78-0.90 for modular domains. Table 3 and 4 shows corrected item to total correlation and scale internal reliability consistency (Cronbach's α) on the EHP-30 for core and modular domains, respectively. The EHP-30 item to total correlations exceeded the margin of 0.40 in all instances for core and modular parts.

Table 3: Corrected item to total correlation and scale internal reliability consistency on the EHP-30 (core questionnaire)

Scale item	Corrected item to total correlation
Pain scale (alpha=0.85, n=100)	
P1:Unable to go to social events	0.62
P2:Unable to do jobs at home	0.72
P3:Found it difficult to stand	0.72
P4: Difficult to sit	0.34
P5: Found it difficult to walk	0.67
P6:Difficult to exercise	0.58
P7:lost appetite/unable to eat	0.73
P8:Be unable to sleep	0.69
P9:Had to lie down or go to bed	0.71
P10: Unable to do things you want	0.68
P11:Felt unable to cope with pain	0.67
Control and powerlessness scale(alpha=0.93n=100)	
C&P1:Generally felt unwell	0.59
C&P2:Symptoms not getting better	0.75
C&P3:Not able to control symptoms	0.90
C&P4:Felt unable to forget symptoms	0.90
C&P5:Felt symptoms ruling your life	0.90
C&P6:Felt symptoms taking away life	0.76
Emotional well-being scale (alpha=0.86 n=100)	
E1:Felt depressed	0.73
E2:Felt weepy/tearful	0.75
E3:Felt miserable	0.67
E4:Had mood swing	0.63
E5:Felt bad or short-tempered	0.68
E6:Felt aggressive or violent	0.48
Social support scale (alpha=0.88 n=100)	
S1:Unable to tell people how you feel	0.80
S2:Felt others do not understand	0.78
S3:Felt others think you are complaining	0.73
S4:Felt alone	0.68
Self-image scale (alpha=0.80 n=100)	
Self1:Can not wear clothes you choose	0.66
Self2: Appearance has been affected	0.75
Self3:lacked confidence	0.54

Higher order factor analysis was undertaken on the five dimension of the EHP-30. The analysis produced a single component, which accounted for 65.67 % of the variance that indicated the dimensions can be summed up to create a single index (the EHP-30 summary index) score (table 5).

Table 4: Corrected item to total correlation and scale internal reliability consistency on the EHP-30 (modular questionnaire)

Scale item	Corrected item to total correlation
Work (alpha=0.78, n=19)	
W1: Time off work	0.69
W2: Unable to do duties at work	0.68
W3: Embarrassed at work	0.40
W4: Guilty taking time off work	0.58
W5: Worried not able to do job	0.56
Children (alpha=0.90, n=68)	
C1: Difficult to look after children	0.84
C2: Unable to play with children	0.84
Intercourse (alpha=0.83, n=53)	
Int1: Pain on intercourse	0.69
Int2: Worried about intercourse	0.73
Int3: Avoided intercourse	0.58
Int4: Guilty about not wanting intercourse	0.51
Int5: Frustrated cannot enjoy intercourse	0.65
Infertility (alpha=0.84, n=18)	
Infer1: Worried about not having children	0.74
Infer2: Inadequate about not having children	0.70
Infer3: Depressed about not having children	0.85
Infer4: Not conceiving putting strain on relations	0.65
Doctors(alpha=0.84, n=97)	
Dr1: Dr not doing anything for you	0.64
Dr2: Dr thinks its in your mind	0.66
Dr3: Dr lacks knowledge	0.75
Dr4: Feel like wasting doctors' time	0.65
Treatment (alpha=0.89, n=92)	
T1: Treatment not working	0.81
T2: Difficulty coping with side effects	0.77
T3: Annoyed at amount of treatment	0.78

Table 5: Principal component matrix from a higher order factor analysis of the five dimensions of the EHP-30.

EHP dimensions	Factor loadings
Pain	0.69
Control and powerlessness	0.88
Emotional well-being	0.81
Social support	0.89
Self-image	0.80

We administered SF-36 to assess construct validity of the EHP-30. The most powerful correlation was between emotional scale of EHP-30 and emotional well-being of SF-36 (-0.63). All correlations were significant at 0.01 levels (table 6).

Discussion

Endometriosis is a chronic gynecological disease caused by ectopic location of the endometrium outside the uterine cavity. Because of pathological changes, and gynecological and psychiatric problems, the decline of quality of life of women with endometriosis is observed.¹¹ Endometriosis Health profile-30 is a recently designed instrument to assess the quality of

Table 6: Correlations of endometriosis health profile-30 scales with short form-36 scales

Endometriosis health profile-30	short form-36	Pearson correlation (two-tailed test)	P values
Emotional	Emotional well being	-0.63	<0.01
Pain	Role limitations due to physical	-0.56	<0.01
Pain	Pain	-0.55	<0.01
Emotional	General health	-0.51	<0.01
Social support	Social function	-0.45	<0.01
Control & powerlessness	Role limitations due to physical	-0.56	<0.01

life in women with endometriosis. In this study the psychometric evaluation of Persian version of EHP-30, as a disease-specific instrument, was assessed. Internal consistency, descriptive statistics of data, factor analysis, item total correlation (corrected for overlap) and construct validity were the five criteria to assess psychometric properties of this questionnaire. The EHP-30 was evaluated and used in only a small number of countries around the world, including the United Kingdom, United States, Brazil, and more recently in Australia. It has been found to be a reliable, valid (in terms of both content and construct validity), acceptable and suitable tool to be used in endometriosis-related research in these countries.¹²⁻¹⁶

On the core questionnaire, emotional well-being and pain dimensions had the highest mean and; therefore, the most negative impact on ill health (46.73 and 46.69). As in United States and Australian reports the scales of self image had the lowest mean (36.2). In modular sections of our samples, infertility had the highest mean and the most negative impact upon ill health (mean scale score=50.55) that was similar to the United Kingdom and Australian results.^{12-14,16}

In factor analysis, all items loaded on their hypothesized factor except two, which were loaded on other factors. It seems that pain accompanying endometriosis makes patient feel generally unwell and lack of enough social supports yields to be more violent or aggressive. Therefore this version of the questionnaire has a strong factor structure.

The internal consistency reliability of the questionnaire was high with all scale exceeding the accepted α value of 0.70. Cronbach's α ranged between 0.80 to 0.93 for core domain, and between 0.78 and 0.90 for modular domain, which are comparable to the United Kingdom and American settings with Cronbach's α ranging from 0.83 to 0.93 and 0.84 to 0.91, respectively.^{13,14} Item total correlation of questionnaire concluded in acceptable correlation in core and modular parts of questionnaire. Higher order factor analysis suggests that single-factor solution, which was found in the United Kingdom and United States,^{13,14} is also

applicable in Iranian version. This means that dimensions can be summed up to create a single index score.

Construct validity of EHP-30 was measured using SF-6, a convenient and previously validated instrument for evaluating the quality of life in women with endometriosis in Iran.⁹ The findings indicate that there was good correlations in several scales of the two questionnaires (table 6).

This study suffers from a number of limitations. The first limitation was the inability to assess the discriminate validity of the questionnaire using clinical variables, because these variables were not measured prospectively under investigators' supervision. The second limitation was that the responsiveness was not assessed in the study. The third and main limitation was the relative small sample size of the study. Although our data was consistent with other psychometric evaluation of this instrument, we suggest the use of this questionnaire in future studies with samples of larger size in different clinics of the country.

Conclusion

The Persian version of EHP-30 demonstrated good reliability and validity. The questionnaire seems to be useful for evaluating the quality of life of women with endometriosis.

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Conflict of Interest: None declared

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