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.6

In recent years, studies have begun to assess the effects of endometriosis on health-related quality of life (HRQOL). 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 contain more 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 HRQOL, 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 worst health status) to 100 (indicating the best 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 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.

This cross-sectional study was conducted between May and November 2009 recruiting all women with endometriosis referring to Outpatient 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. 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. 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       |
| Control and powerlessness scale | 0.568     |
| C&P1: Generally felt unwell   | 0.318       |
| 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              |             |
| S1: Can not wear clothes you choose | 0.836 |
| S2: Appearance has been affected | 0.780 |
| S3: 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 | 25th percentile | 75th 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| 9.36 | 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                   | 82 | 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                  |                                     |
| 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    |                                     |
| 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   |                                     |
| E1: Felt depressed           | 0.73                                |
| E2: Felt weepy/tearful       | 0.75                                |
| E3: Felt miserable           | 0.67                                |
| E4: Had mood swing           | 0.65                                |
| E5: Felt bad or short-tempered | 0.68                              |
| E6: Felt aggressive or violent | 0.48                               |
| Social support scale         |                                     |
| 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             |                                     |
| Self1: Can not wear clothes you choose | 0.66                              |
| Self2: Appearance has been affected | 0.75                           |
| Self3: Lacked confidence     | 0.54                                |

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) |                                         |
| Inferr1: Worried about not having children | 0.74                      |
| Inferr2: Inadequate about not having children | 0.70          |
| Inferr3: Depressed about not having children | 0.85          |
| Inferr4: 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. Endometriosis Health profile-30 is a recently designed instrument to assess the quality of life of women with endometriosis.
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 $\alpha$ value of 0.70. Cronbach’s $\alpha$ 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 $\alpha$ 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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