The short form endometriosis health profile (EHP-5): translation and validation study of the Iranian version

Azita Goshtasebi1, Maryam Nematollahzadeh1, Fatemeh Zahra Hariri1 and Ali Montazeri2*

Abstract

Background: Endometriosis Health Profile (EHP-5) is a valid instrument to measure health-related quality of life in endometriosis. This study was conducted to culturally adapt and validate the EHP-5 in Iran.

Methods: Using a standard “forward-backward” translation procedure, the English language version of the questionnaire was translated into Persian (Iranian language). Then a sample of 199 women aged 18-50 years completed the questionnaire. To test reliability the internal consistency was assessed by Cronbach’s alpha coefficient. Validity was evaluated using known groups comparison.

Results: The mean age of respondents was 31.4 (SD = 5.4) years. Reliability analysis showed satisfactory result (Cronbach’s alpha coefficient = 0.71). The questionnaire discriminated well between sub-groups of women differing in infertility and premenstrual syndrome (PMS) in the expected direction.

Conclusion: This preliminary validation study of the Iranian version of the EHP-5 proved that it is an acceptable, reliable and valid measure of quality of life in endometriosis patients.
Methods
Translation and culture adaptation
Forward-backward procedure was applied to translate the English version of the EHP-5 into Persian (the Iranian language). Two independent professional translators produced two forward translations. Both translators were instructed to aim for conceptual rather than literal translation. Translators with one of the authors compared their translations and produced a single provisional version. Then two other professional translators translated the provisional questionnaire back into the English. The two translators were not aware of the questionnaire. Finally, an expert committee consisting of translators, the researchers, two midwives, and one gynecologist and one epidemiologist reviewed all the translation and cultural adaptation processes were applied. They also evaluated the final English backward version with the original questionnaire. Consensus in terms of semantic, idiomatic, experiential, and conceptual equivalence was reached and a final version of the questionnaire (the Persian EHP-5) was provided. The final translated version of the questionnaire was given to 10 patients to complete and declare their understanding of the items to ensure face validity.

Questionnaire
The EHP-5 contains 11 questions (items): five items including pain, control and powerlessness, emotional well-being, lack of social support, self image from the core questionnaire and six items from the modular questionnaire that may not be applicable to every woman with endometriosis including work, intercourse, and worries about infertility, treatment, and relationship with children and medical professionals. Each item is rated on a four-point scale (never = 0, rarely = 1, sometimes = 2, often = 3, always = 4 and not relevant if not applicable). Scores on the EHP-5 core and modular questionnaire then are transformed on a scale of 0 (indicating best possible health status) to 100 (indicating worst possible health status). If the ‘not relevant’ box was ticked for items on modular questionnaire the score could not be computed for that dimension.

Sample and data collection
The final draft of the Iranian version of the EHP-5 was administrated to a sample of 199 women with a confirmed surgical diagnosis of endometriosis undergoing conservative surgery. All women were selected from two obstetrics and gynecology clinics in Tehran, Iran (Royan Institute and Avicenna Research Institute both affiliated to Iranian Academic Center for Education, Culture and Research).

The sample size calculation was based on an assumption that at least 10% of women in the reproductive age would suffer from endometriosis. Two trained female midwives collected the data by face-to-face interview 1 to 12 months after diagnostic laparoscopy. All patients completed a questionnaire containing brief background information (such as age, marital and reproductive status, and family history) and the EHP-5 questionnaire. The study was carried out during July 2009 to March 2011.

Statistical analysis
Internal consistency was assessed by calculating Cronbach’s alpha coefficient. Value of 0.7 or greater was considered satisfactory [10]. Validity was assessed using known groups comparison to test how well the questionnaire discriminates between subgroups of the study sample that differed in reproductive health status. It was expected that women with infertility and PMS would have higher scores than women without infertility and PMS in all measures. Mann-Whitney U test was performed for comparisons. Women with infertility and PMS were identified after a confirmed diagnosis by gynecologists.

Ethics
The study received ethical approval from the Iranian Institute for Health Sciences Research. The authors informed all women regarding the study objectives, and indicated that their participation is voluntary and they could withdraw at any time. Both oral and written instructions were given to patients to ensure that items were understood (i.e. there were no right or wrong answers to the questions and the participants should feel free and honestly state what they think), and the subjects were reassured about the confidentiality.

Results
The study sample
In all, 220 women were approached and 199 (90%) agreed to be interviewed. The main reason for those who did not participate in the study was dislike. The mean age of the respondents was 31.4 (SD = 5.4) years. Most were married (94.5%) and university educated (43.3%). The characteristics of the respondents are shown in Table 1.

Descriptive statistics and reliability
The descriptive statistics of the 5 items are shown in Table 2. The Cronbach’s alpha coefficient was 0.71 for the instrument indicating a satisfactory result.
Known groups comparison

Known groups comparison was used to test the validity. It was hypothesized that women with infertility and PMS would have poorer quality of life than women without infertility and PMS. The analysis showed that the women with infertility had higher scores in pain, control and powerlessness, emotional well-being and self image and individuals suffering PMS had lower scores in pain, control and powerlessness, emotional well-being and lack of social support measures as expected (Table 3). This indicated that the EHP-5 well discriminated between subgroups of the people who differed in reproductive health status.

Discussion

Although cross-cultural validation studies are very difficult to be carried out, their results might be considered worthwhile. Firstly, they provide standard health measures that make health status comparisons between different populations possible. Secondly, they provide validated instrument to monitor population health, estimate burden of disease and investigate outcomes in clinical practice and evaluate treatment effects. This was the first study on psychometric properties of the Iranian version of EHP-5 among an Iranian population. The results showed that the instrument was a reliable and valid measure that can be used in monitoring and measuring health-related quality of life of women with endometriosis.

Similarly the validity of the EHP-5 in different cultures was well documented. For instance, the finding from an English study showed that the instrument had good validity and could be applied among women with endometriosis [9]. Furthermore, a French version of the EHP-5 questionnaire has been developed and its acceptability and feasibility was desirable although validity was not reported [10].

Iranian version of the EHP-5 was extracted from its English version. The translation of the EHP-5 in Iran went through a rigorous method and was approved by the questionnaire’s developers. Thus we did not encounter any difficulties in data collection.

The EHP-5 was basically designed to be a self-administrated questionnaire but it can be completed through an interview in person or by telephone [11]. However, face-to-face administration of questionnaire allowed the interviewers to collect data without any missing data. Although method of completing the EHP-5 has not been mentioned in its manual, the designers administered it by mail (self-administrated) and the rate of returning the questionnaire was reported to be 37.1% [9].

Reliability was assessed by internal consistency and validity was examined by known groups comparison. Cronbach’s alpha coefficient showed a satisfactory result

| Table 1 Demographic characteristics of the studied women (n = 199) |
|----------------------|------|-----|
| Age (year)           | No   | %   |
| 18-25                | 26   | 13.1|
| 26-30                | 65   | 32.7|
| 31-35                | 65   | 32.7|
| ≥ 36                 | 43   | 21.6|
| Mean (SD)            | 31.4 (5.4) |
| Education            |      |     |
| Primary              | 15   | 8   |
| Junior high school   | 30   | 16  |
| High school          | 61   | 32.6|
| University           | 81   | 43.3|
| Marital status       |      |     |
| Single               | 9    | 4.5 |
| Married              | 188  | 94.5|
| Widowed              | 2    | 1   |
| Employment status    |      |     |
| Employed             | 51   | 25.6|
| Student              | 8    | 4   |
| Housewife            | 14   | 70.4|
| Fertility status     |      |     |
| Fertile              | 35   | 17.6|
| Infertile            | 164  | 82.4|
| PMS                  |      |     |
| Yes                  | 60   | 30.2|
| No                   | 139  | 69.8|

Table 2 Descriptive statistics for the EHP-5 core questionnaire

| Mean row scores (SD) | 95% CI       | Skewness | Response frequencies (%) |
|----------------------|--------------|----------|--------------------------|
| Pain                 | 0.085 (0.07) | 0.7-1    | 0.937                    | 52.8 | 17.1 | 24.1 | 4 | 2 |
| Control & powerlessness | 1.44 (0.09) | 1.26-1.62 | -0.95                   | 34.7 | 15.1 | 29.6 | 12.6 | 8 |
| Emotional well-being | 1.68 (1.3)   | 1.50-1.87 | 0.20                    | 25.1 | 18.1 | 30.7 | 15.1 | 11.1 |
| Lack of social support | 1.37 (1.35) | 1.18-1.57 | 0.511                   | 38.7 | 16.6 | 22.1 | 13.6 | 9 |
| Self image           | 1.48 (1.42)  | 1.27-1.68 | 0.375                   | 40.2 | 12.6 | 17.1 | 19.1 | 11.1 |
suggest this instrument provides the same picture of health-related quality of life as the longer version [9].

Although this study did not provide evidence for test-retest reliability, responsiveness to change or other tests; overall the findings showed that the Iranian version of EHP-5 is a reliable measure for measuring health quality of life in endometriosis patients. It will be especially useful in clinical settings where a short and economical endometriosis health status measure is needed. The future studies could focus on other psychometric properties of the EHP-5 questionnaire and also on different applications of the questionnaire as a recent study has suggested even it is a useful index in order to evaluate cost-effectiveness of healthcare interventions [19].

**Conclusion**

This study presents the first step in evaluating psychometric properties of a well-known instrument measuring health-related quality of life of Iranian patients with endometriosis. Since health-related quality of life was rarely assessed as primary end-point in studies of endometriosis in Iran, the Persian EHP-5 might possibly provide both clinicians and patients with numerous advantages as an important outcome measure in future studies. However, its sensitivity to change needs still to be studied.

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**Authors’ contributions**

All authors were involved in designing of the study, data collection and analysis, interpretation of results and manuscript preparation. AG, MN and FZH prepared the first draft of the paper. AM and AG provided the final manuscript. All authors read and approved the final manuscript.

**Competing interests**

The authors declare that they have no competing interests.

**References**

1. Melin A, Sparén P, Persson I, Bergqvist A: Endometriosis and the risk of cancer with special emphasis on ovarian cancer. Human Reproduction 2006, 98:1237-42.

2. Berek JS: Berek and Novak’s Gynecology. Philadelphia: Lippincott Williams and Wilkins; 2007, 1137-1184.

3. Gao X, Yeh YC, Outley I, Simon J, Botteman M, Spalding J: Health-related quality of life burden of women with endometriosis: a literature review. Current Medical Research and Opinion 2006, 22:1787-1797.

4. Aris A: Endometriosis-associated ovarian cancer: A ten-year cohort study of women living in the Estrie Region of Quebec, Canada. J Ovarian Res 2010, 3:2.

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**Table 3 known groups comparison for the EHP-5**

| Inertility | No (n = 35) | Yes (n = 164) |
|------------|------------|--------------|
| Pain       | 19.05 (2.01) | 32.14 (4.29) | 0.007 |
| Control & powerlessness | 34.14 (2.54) | 45.0 (5.2) | 0.07 |
| Emotional well-being | 38.87 (2.39) | 57.85 (6.21) | 0.002 |
| Lack of social support | 32.85 (5.95) | 34.75 (2.62) | 0.7 |
| Self image | 32.7 (7.74) | 57.14 (6.02) | < 0.0001 |
| PMS        | No (n = 139) | Yes (n = 60) |
| Pain       | 18.78 (2.16) | 27.5 (3.44) | 0.02 |
| Control & powerlessness | 31.47 (2.60) | 46.66 (4.38) | 0.002 |
| Emotional well-being | 37.76 (2.57) | 52.5 (4.55) | 0.003 |
| Lack of social support | 33.81 (2.88) | 35.83 (4.34) | 0.7 |
| Self image | 33.45 (2.97) | 45.41 (4.91) | 0.03 |

* The higher scores indicate worse conditions
** Derived from Mann-Whitney U test.
5. Lockhat FB, Emembolu JO, Konje JC. The evaluation of the effectiveness of an intrauterine administered progestogen (levonorgestrel) in the symptomatic treatment of endometriosis and in the staging of the disease. Human Reproduction 2004, 19:179-184.

6. Jones G, Jenkinson C, Kennedy S. Development of the Short Form Endometriosis Health Profile Questionnaire: The EHP-S. Quality of Life Research 2004, 13:695-704.

7. Jones G, Kennedy S, Barnard A, Wong J, Jenkinson C. Development of an endometriosis quality-of-life instrument: The Endometriosis Health Profile-30. Obstetrics & Gynecology 2001, 98:258-264.

8. Jones G, Jenkinson C, Taylor N, Mills A, Kennedy S. Measuring quality of life in women with endometriosis: tests of data quality, score reliability, response rate and scaling assumptions of the Endometriosis Health Profile Questionnaire. Human Reproduction 2006, 21:2686-2693.

9. Renouvel F, Fauconnier A, Pilkington H, Panel P. Linguistic adaptation of the endometriosis health profile 5: EHP-5. Journal de Gynécologie Obstétrique et Biologie de la Reproduction 2009, 38:404-410.

10. Nunnally JC, Bernstein IH. Psychometric theory New York: Mc Grow Hill, 1994.

11. Denny E. Women’s experience of endometriosis. Acta Obstet Gynecol Scand 2001, 80:628-637.

12. Gandek B, Ware JE. Methods for validating and norming translations of health status questionnaire: The IQoLA project approach. J Clin Epidemiol 1998, 51:953-959.

13. Levine S. The changing terrains in medical sociology: emergent concern with quality of life. J Health Soc Behav 1987, 28:1-6.

14. Wilson IB, Cleary PD. Linking clinical variables with health related quality of life. A conceptual model of patient outcomes. J Am Med Assoc 1995, 273:59-65.

15. Jones GL, Kennedy SH, Jenkinson C. Health-related quality of life measurement in women with common benign gynecologic conditions: a systematic review. Am J Obstet Gynecol 2002, 187:501-511.

16. Fitzpatrick R. Applications of health status measures. In Measuring Health and Medical Outcomes. Edited by: Jenkinson C. London: UCL Press; 1994:27-41.

17. Coste J, Guillemin F, Pouchet J, Ferrerian J. Methodological approaches to shortening composite measurement scales. J Clin Epidemiol 1997, 50:247-252.

18. Cox DR, Fitzpatrick R, Fletcher AE, Gore SM, Spiegelhalter DJ, Jones DR. Quality of life assessment: can we keep it simple? J R Statist Soc A 1992, 155:353-393.

19. Winkel CA. A cost-effective approach to the management of endometriosis. Curr Opin Obstet Gynecol 2000, 12:317-320.

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