

Validation of the Portuguese Version of EHP-30 (The Endometriosis Health Profile-30)

Validação da Versão Portuguesa do Questionário EHP-30 (The Endometriosis Health Profile-30)



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ABSTRACT

Introduction: Endometriosis Health Profile Questionnaire-30 is currently the most used questionnaire for quality of life measurement in women with endometriosis. The aim of this study is to evaluate the psychometric properties and to validate the Portuguese Endometriosis Health Profile Questionnaire-30 version.

Material and Methods: A sequential sample of 152 patients with endometriosis, followed in a Portugal reference center, were asked to complete a questionnaire on social and demographic features, the Portuguese version of the Endometriosis Health Profile Questionnaire-30 and of the Short Form Health Survey 36 Item – version 2. Appropriate statistical analysis was performed using descriptive statistics, factor analysis, internal consistency, item-total correlation and convergent validity.

Results: Factorial analysis confirmed the validity of the five-dimension structure of the Endometriosis Health Profile Questionnaire-30 core questionnaire, which explained 83.2% of the total variance. All item-total correlations presented acceptable results and high internal consistency, with Cronbach's alpha ranging between 0.876 and 0.981 for the core questionnaire and between 0.863 and 0.951 for the modular questionnaire. Significant negative associations between similar scales of Endometriosis Health Profile Questionnaire-30 and Short Form Health Survey 36 Item – version 2 were demonstrated. Data completeness achieved was high for all dimensions. The emotional well-being scale in the core questionnaire and the infertility scale in the modular section had the highest median scores, and therefore the most negative impact on the quality of life of participating women.

Discussion: The test-retest reliability and responsiveness of the questionnaire should be evaluated in future studies.

Conclusion: The present study demonstrates that the Portuguese version of the Endometriosis Health Profile Questionnaire-30 is a valid, reliable and acceptable tool for evaluating the health-related quality of life of Portuguese women with endometriosis.

Keywords: Endometriosis; Quality of Life; Questionnaires; Portugal.

RESUMO

Introdução: O *Endometriosis Health Profile Questionnaire-30* é atualmente o questionário mais utilizado para avaliação da qualidade de vida em mulheres com endometriose. O objetivo do presente estudo é avaliar as propriedades psicométricas e validar a versão portuguesa do *Endometriosis Health Profile Questionnaire-30*.

Material e Métodos: Amostra sequencial de conveniência, constituída por 152 doentes com endometriose, de um centro de referência no país, que autopreencheram um questionário sociodemográfico, a versão portuguesa do *Endometriosis Health Profile Questionnaire-30* e do *Short Form Health Survey 36 Item* – versão 2. Procedeu-se a análise estatística apropriada, com estatística descritiva, análise fatorial, avaliação da consistência interna, correlação item-total e validade convergente (usando o *Short Form Health Survey 36 Item* – versão 2).

Resultados: A análise fatorial confirmou a validade da estrutura em cinco dimensões do questionário central, explicando uma variância total de 83,2%. A correlação item-total apresentou resultados aceitáveis em todos os itens e a consistência interna foi elevada, com α Cronbach variando de 0,876 a 0,981 nas dimensões do questionário central, e de 0,863 a 0,951 no modular. Demonstrou-se associação negativa significativa entre as dimensões similares do *Endometriosis Health Profile Questionnaire-30* e do *Short Form Health Survey 36 Item* – versão 2. A taxa de preenchimento do questionário foi elevada para todas as dimensões. A perda do bem-estar emocional (no questionário central) e a infertilidade (no modular) apresentaram as pontuações médias mais elevadas e, conseqüentemente, impacto mais negativo sobre a qualidade de vida.

Discussão: São necessários estudos para avaliar a fiabilidade teste-reteste e a sensibilidade à mudança desta versão portuguesa do *Endometriosis Health Profile Questionnaire-30*.

Conclusão: Este estudo demonstra que a versão portuguesa do *Endometriosis Health Profile Questionnaire-30* é um instrumento adaptado, validado e bem aceite para a avaliação da qualidade de vida das mulheres portuguesas com endometriose.

Palavras-chave: Endometriose; Qualidade de Vida; Questionários; Portugal.

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INTRODUCTION

Endometriosis is a chronic, frequently progressive and relapsing disease, characterised by the presence of extra-uterine glandular tissue and endometrial stroma. Although difficult to estimate, it is thought that approximately 10% of reproductive-age women are affected, corresponding to 176 million women with endometriosis worldwide.¹ Endometriosis may present with dysmenorrhea, chronic pelvic pain, dyspareunia, dysuria, dyschezia, infertility and abnormal uterine bleeding and may induce important physical, emotional and social morbidity affecting quality of life.²⁻⁵

Health-related quality of life is a multidimensional and dynamic concept, involving physical, psychological and social issues related to a disease or its treatment.^{3,6} As endometriosis globally affects women's life, the assessment of treatment's efficacy based on pain improvement and fertility rates alone is clearly insufficient.^{7,8} In addition, the lack of correlation between symptom intensity and the severity and extension of lesions is largely recognized⁹ and the patient's subjective assessment of her own quality of life is crucial for an optimal approach to endometriosis.

Several studies have recently shown a decreased quality of life in patients with endometriosis.^{10,11} However, only generic instruments (namely the Nottingham Health Profile, Short Form-36 and Short Form-12) lacking sensitivity for the detection of changes and response to therapy in specific and complex diseases such as endometriosis have been used.^{4,12-15} An endometriosis-specific instrument sensitive to changes in patient's health and quality of life is therefore required.²

The *Endometriosis Health Profile Questionnaire-30* (EHP-30) is currently the most used and validated instrument for the assessment of quality of life in patients with endometriosis^{16,17} and is recommended by the American Society for Reproductive Medicine (ASRM), as well as by the European Society of Human Reproduction and Embryology.¹⁸ In fact, it was already shown that the EHP-30 is sensitive to changes in health status over time in patients with endometriosis.^{19,20}

EHP-30 was developed in 2001 in the UK, involving exploratory interviews in patients with surgically confirmed endometriosis.² This is a self-reported questionnaire with a 30-item, five-dimension (pain, control and powerlessness, emotional well-being, social support and self-image) core part and an optional 23-item modular questionnaire divided into 6 dimensions (that may not apply to every woman as regards work, relationship with child/children, sexual relationship, feelings about medical profession, feelings about treatment and feelings about infertility).^{2,21} Each scale is translated into a scoring system ranging from 0-100 and the lower the score, the better the patient's quality of life. The EHP-30 is already validated for North America context and includes Australian, Dutch, Italian, Chinese, Iranian and Brazilian Portuguese versions.^{8,16,17,21-24} The translation process to a culture-adapted Portuguese version of the EHP-30 has been recently carried out.^{25,26} However, this instrument has so far not been validated, which would allow

for the assessment of quality of life in Portuguese patients, as well as for the comparison with different international studies using the same instrument.

Our study aimed to assess the psychometric properties and the validation of the Portuguese version of the EHP-30 used in Portuguese women diagnosed with endometriosis in a reference hospital.

MATERIAL AND METHODS

Questionnaire adaptation

Translation (semantic and content equivalence obtained from two independent translations and two retroversions; consensus and reviewed version obtained from physicians) and content validation (from a panel of 20 patients with endometriosis) were previously obtained.^{25,26} This translated and culture-adapted version was used in the present study, upon authorization from the authors.

Psychometric studies and validation

The study was approved by the Ethics Committee of the *Centro Hospitalar Lisboa Norte (CHLN) - Hospital Universitário de Santa Maria*.

All patients included in the study participated voluntarily and were informed about its aims, its anonymity and confidentiality, as well as about the possibility of suspending or interrupting the participation at any point without any kind of penalty or loss for that reason, namely regarding her right to medical assistance. All participants signed an informed consent before questionnaire completion.

Sample and questionnaires

Our study involved a convenience sequential sample of 152 reproductive-age women above 18 years of age diagnosed with endometriosis, followed at the Gynaecology Department from the *Clínica Universitária de Obstetrícia e Ginecologia do CHLN/ Hospital Universitário de Santa Maria*. This is a reference outpatient department for patients with endometriosis and therefore attends to patients from across the country (although with a predominance for the region of Lisbon and Tagus Valley).

The size of the sample was determined according to the recommendations by *Hair et al.*:²⁷ at least 100 participants and five times more observations than the number of items to be analysed. The presence of another physical or mental disease with any relevant impact on quality of life was considered as an exclusion criteria.

The following questionnaires were applied to all the patients: socio-demographic questionnaire (patient's age, nationality, ethnicity, schooling, occupation and marital status), Portuguese version of the EHP-30 and Portuguese version of the *Short Form Health Survey 36 Item - version 2* (SF-36v2). This 36-item questionnaire has been validated for the Portuguese population and includes eight dimensions (physical functioning, role physical, bodily pain, general health, vitality, social functioning, role emotional and mental health), allowing for assessment of aspects

regarding physical and mental health. Each dimension was scored on a 0 to 100 scale and the higher the score, the better the quality of life.²⁸

Questionnaires were self-reported by patients undergoing treatment for endometriosis (watchful waiting, medical or surgical), waiting for their medical appointment in the Outpatient Department, between the 8th April 2013 and the 31st March 2014.

Data were also obtained through a clinical form completed by the physician in charge of the patient, including the symptoms described during the four weeks prior to the medical appointment and the stage of endometriosis (according to the ASRM classification).²⁹

Statistical analysis

Six criteria were used for the assessment of psychometric properties of the questionnaire, namely exploratory factorial analysis, internal consistency evaluation, item-total correlation, convergent validity, data completeness and score distribution. The Statistical Package for Social Sciences (SPSS®, version 22.0) was used for the analysis. A descriptive analysis was previously performed, using frequency distribution, central tendency and dispersion measurements for the variables in the study. The results regarding quantitative variables are presented as mean \pm standard deviation. In order to determine the factor structure of the questionnaire, the exploratory factor and principal component analysis (with Varimax rotation) of the core part of the EHP-30 was obtained. In order to assess the internal consistency for each scale of the core and modular parts the Cronbach's alpha coefficient was used and values \geq 0.7 were considered as acceptable.²⁷ Values of item-total correlation above 0.4 were considered as acceptable.²⁷ In order to determine the convergent validity, in line with the study describing the design of the original version as well as the versions in other languages, a significant correlation between the dimensions of the EHP-30 and the SF-36v2 was hypothesized.^{2,5,23} The convergent validity was determined by Pearson's coefficient. Statistical significance was established for values of $p < 0.05$.

RESULTS

A 34.7 ± 6.1 years (range: 19-49) average age was found in the 152 patients with endometriosis in our study, mostly Portuguese (96.1%), Caucasian (88.2%) and married or living as a couple (69.6%). As regards schooling, 40.8% ($n = 62$) completed high-school education, while 38.2% ($n = 58$) had a college degree; 78.9% ($n = 120$) of the participants were professionally active (Table 1).

As regards clinical data, 66.4% ($n = 101$) of our patients presented with stage IV endometriosis according to the ASRM classification and most patients described dysmenorrhoea (63.6%), dyspareunia (54.8%), chronic pelvic pain (50.0%), asthenia (59.2%) and gastrointestinal symptoms (54.6%) over the four weeks prior to questionnaire completion (Table 1).

Exploratory factor analysis

The factor analysis of the core questionnaire was performed defining a maximum of five factors, in order to determine whether the current structure reflected the structure in the original version of the EHP-30. The original study describing the design of the EHP-30 assumed there was no correlation between the factors and therefore used a Varimax rotation,² which was therefore also used in our study. Those items with a minimum 0.4 factor saturation in the principal component analysis were maintained for the factor analysis (i.e. all the items were maintained) (Table 2).

The five-factor analysis (all with values above 1) explained for 83.2% of variance and the percentage of variance explained by each factor was 36.8% for pain, 18.6% for control and powerlessness, 12.2% for emotional well-being, 8.2% for social support and 7.4% for self-image. All the items were more clearly saturated in the correct dimension, except six (Table 2): the item '*Em geral, sentiuse mal*' ('Generally felt unwell') was associated to the 'pain' dimension; the items '*Sintomas não estão a melhorar*', '*Incapacidade de controlar sintomas*', '*Sintomas a controlar a vida*' and '*Sintomas a tirar a vida*' ('Felt frustrated because your symptoms are not getting better', 'Felt frustrated because you are not able to control your symptoms', 'Felt as though your symptoms are ruling your life' and 'Felt your symptoms are taking away your life') were associated to the dimension 'pain' beyond the dimension hypothesized ('control and powerlessness'); finally, the item '*Incapacidade de dizer como se sente*' ('Felt unable to tell people how you feel') was associated to the hypothesized dimension ('social support'), beyond the dimension 'emotional well-being'.

Upon establishing the five first-order dimensions, these were submitted to a new factor analysis, in order to determine whether a single second-order component emerged. The results showed that it is possible to generate a single component explaining for 78.0% of variance. This means that the dimensions may be added in order to obtain a single score. A high principal component factor saturation for the five dimensions was found (pain: 0.877; control and powerlessness: 0.906; emotional well-being: 0.903; social support: 0.897; self-image: 0.831).

Item-total correlation and internal consistency assessment

An item-total correlation above 0.4 was found in all the items in the short-form core (variation: 0.656 – 0.951; Table 3) and modular questionnaires (variation: 0.573 – 0.937; Table 4) of the EHP-30, showing a good item-total consistency.

A Cronbach's alpha above 0.7 was found for all the dimensions in internal consistency assessment, varying between 0.876 and 0.981 in the dimensions in the core questionnaire (Table 3) and between 0.863 and 0.951 in the dimensions in the modular questionnaire (Table 4).

Convergent validity

When applying the Pearson's correlation between

Table 1 - Socio-demographic and clinical characteristics of our group of patients (n = 152)

Socio-demographic characteristics	
Age*	34.7 ± 6.1 (19 - 49)
Nationality, n (%)	
Portuguese	146 (96.1%)
Other ^a	6 (3.9%)
Ethnicity, n (%)	
Caucasian	134 (88.2%)
Black	12 (7.9%)
Other	6 (3.9%)
Schooling, n (%)	
1 st Cycle	0 (0.0%)
2 nd Cycle	2 (1.3%)
3 rd Cycle	20 (13.2%)
Secondary level	62 (40.8%)
Undergraduate	10 (6.6%)
College degree	48 (31.6%)
Masters / PhD	10 (6.6%)
Profession, n (%)	
Active	120 (78.9%)
Student	6 (3.9%)
Non-working ^b	26 (17.1%)
Marital status, n (%)	
Single	33 (21.7%)
Married / Living as a couple	106 (69.6%)
Divorced / Separated	12 (7.9 %)
Widow	1 (0.7%)
Clinical characteristics	
Endometriosis classification, n (%) ^c	
Stage I	1 (0.7%)
Stage II	13 (8.6%)
Stage III	37 (24.3%)
Stage IV	101 (66.4%)
Symptoms, n (%) ^d	
Dysmenorrhea (n = 88)	56 (63.6%)
Dysuria	23 (15.1%)
Dyschezia	57 (37.5%)
Dyspareunia (n = 115)	63 (54.8%)
Chronic pelvic pain	76 (50.0%)
Asthenia	90 (59.2%)
Gastrointestinal symptoms	83 (54.6 %)
Abnormal uterine bleeding	37 (24.3%)
Time since the first symptoms*	9.6 ± 7.4 (1 - 31)

*mean ± standard deviation (range); age, time since the first symptoms: years; ^a: from other nationality although living in Portugal for more than 5 years; ^b: includes unemployed and housewives; ^c: Classification according to the American Society of Reproductive Medicine; stage I – minimum, stage II – mild, stage III – moderate, stage IV – severe³¹; ^d: different n for dysmenorrhea and dyspareunia, as it is not applicable to all the situations.

the dimensions in the EHP-30 and SF-36v2, a significant correlation for all assessed dimensions was found, which was maximum between the dimension 'pain' from the EHP-30 and the dimension 'bodily pain' from the SF-36v2 ($r = -0.739$); (Table 5).

Data completeness, descriptive statistics and sensitivity of the different dimensions

The average time for completion of the EHP-30 was 13.84 ± 6.1 minutes (minimum three minutes; maximum 30 minutes).

High data completeness (96.7% in the dimension 'pain' and 100% in 'social support' and self-image') by the 152 patients in our group of participants was found. As regards the modular questionnaire, the *n* likely to respond to each dimension depends on personal circumstances, as not all the dimensions apply to all patients (for instance, 'relationship with child/children' does not apply to patients with no children). Therefore, according to the *n* likely to respond, data completeness varied between 93.1% in the dimension 'relationship with child/children' and 98.6% in the 'feelings about infertility' dimension.

The descriptive statistics and values of asymmetry and kurtosis for the dimensions included in the EHP-30 are shown in Table 6. Except for 'feelings about medical profession', all the dimensions showed negative flatness values (platykurtic distribution) and close-to-zero asymmetry values. We may therefore assume that, except for 'feelings about medical profession', the dimensions do not show relevant sensitivity or normality issues. As regards the core questionnaire, the 'emotional well-being' dimension showed the highest average score (41.2) and therefore the most negative impact on the quality of life. In addition, the 'self-image' dimension showed the lowest average score (34.1). In the modular questionnaire, 'feelings about infertility' showed the highest average score (55.9) and the most important negative impact on quality of life and 'feelings about medical profession' showed the lowest values (12.8) (Table 6).

DISCUSSION

Our study involved the psychometric assessment of the Portuguese version of the EHP-30, that was previously only translated,^{25,26} according to the recommendations of the International Society for Pharmacoeconomics and Outcomes Research.³⁰ This allows for the validation of the EHP-30 as well as its clinical application to the assessment of quality of life in Portuguese women with endometriosis.

Our group of patients had an average age (34.7) in line with the average age of Portuguese women within the 18-49 age group – 34.65.³¹ As regards schooling, 40.8% had completed high school and 38.2% had a college degree, corresponding to a high-schooling sample regarding Portugal average. In fact, according to *Censos 2011* (Portuguese 2011 Census data), around 15% of the Portuguese population aged 23 or above had completed a college degree, from which 60% were women.³²

Table 2 - Factor analysis of the core questionnaire of the EHP-30 (principal component analysis with Varimax rotation)

	Communalities	Factor saturation				
		Pain	Control and powerlessness	Emotional well-being	Social support	Self-image
1. Incapacidade de ir a acontecimentos sociais	0.844	0.808				
2. Incapacidade de fazer tarefas domésticas	0.861	0.843				
3. Dificuldades em estar em pé	0.874	0.868				
4. Dificuldades em sentar-se	0.794	0.831				
5. Dificuldades em andar	0.892	0.859				
6. Dificuldades em fazer exercício ou atividades de lazer	0.883	0.854				
7. Perda de apetite e/ou incapaz de comer	0.781	0.766				
8. Incapacidade de dormir bem	0.842	0.816				
9. Necessidade de ir para a cama/ deitar-se	0.830	0.815				
10. Incapacidade de fazer as coisas que queria	0.923	0.860				
11. Incapacidade de lidar com as dores	0.859	0.759				
12. Em geral, sentiu-se mal	0.841	0.801				
13. Sintomas não estão a melhorar	0.857	0.624	0.508			
14. Incapacidade de controlar sintomas	0.874	0.649	0.496			
15. Incapacidade de esquecer os sintomas	0.754		0.726			
16. Sintomas a controlar a vida	0.879	0.623	0.520			
17. Sintomas a tirar a vida	0.872	0.550	0.479			0.458
18. Sentir-se deprimida	0.834			0.729		
19. Sentir-se com vontade de chorar	0.854			0.701		
20. Sentir-se extremamente infeliz	0.770			0.661		0.404
21. Alterações de humor	0.877			0.839		
22. Sentir-se mal-humorada ou irritável	0.870			0.811		
23. Sentir-se violenta ou agressiva	0.658			0.635		
24. Incapacidade de dizer como se sente	0.747			0.515	0.425	
25. Sentir que os outros não compreendem	0.875			0.448	0.674	
26. Sentir que os outros pensam que se está a lamuriar	0.889				0.693	
27. Sentir-se sozinha	0.738				0.548	0.499
28. Não poder vestir as roupas que queria	0.778					0.785
29. Sentir aparência afetada	0.821					0.772
30. Falta de confiança	0.775					0.671
Cronbach's alpha		0.878	0.908	0.902	0.901	0.839
Own values		11.05	5.57	3.65	2.45	2.22
Total variance explained by each factor (accumulated)		36.8%	18.6% (55.4%)	12.2% (67.6%)	8.2% (75.8%)	7.4% (83.2%)

Table 3 - Internal consistency of the core questionnaire of the EHP-30 (Cronbach's alpha)

Dimensions	Item-total correlation
Pain ($\alpha = 0.981$; $n = 147$)	
1. Incapacidade de ir a acontecimentos sociais	0.901
2. Incapacidade de fazer tarefas domésticas	0.913
3. Dificuldades em estar em pé	0.919
4. Dificuldades em sentar-se	0.853
5. Dificuldades em andar	0.923
6. Dificuldades em fazer exercício ou atividades de lazer	0.918
7. Perda de apetite e/ou incapaz de comer	0.848
8. Incapacidade de dormir bem	0.898
9. Necessidade de ir para a cama/ deitar-se	0.889
10. Incapacidade de fazer as coisas que queria	0.951
11. Incapacidade de lidar com as dores	0.892
Control and powerlessness ($\alpha = 0.947$; $n = 150$)	
12. Em geral, sentiu-se mal	0.802
13. Sintomas não estão a melhorar	0.895
14. Incapacidade de controlar sintomas	0.912
15. Incapacidade de esquecer os sintomas	0.656
16. Sintomas a controlar a vida	0.913
17. Sintomas a tirar a vida	0.851
Emotional well-being ($\alpha = 0.943$; $n = 151$)	
18. Sentir-se deprimida	0.874
19. Sentir-se com vontade de chorar	0.883
20. Sentir-se extremamente infeliz	0.803
21. Alterações de humor	0.874
22. Sentir-se mal-humorada ou irritável	0.872
23. Sentir-se violenta ou agressiva	0.667
Social support ($\alpha = 0.912$; $n = 152$)	
24. Incapacidade de dizer como se sente	0.764
25. Sentir que os outros não compreendem	0.857
26. Sentir que os outros pensam que se está a lamuriar	0.854
27. Sentir-se sozinha	0.735
Self image ($\alpha = 0.876$; $n = 152$)	
28. Não poder vestir as roupas que queria	0.758
29. Sentir aparência afetada	0.810
30. Falta de confiança	0.717

However, this schooling level is below those described for other populations, like for instance, from Brazil. Bellelis *et al.*, on a retrospective study about epidemiological and clinical aspects of pelvic endometriosis, involving 892 patients, described that 51.9% of these had completed a college degree.³³

According to the ASMR classification, all stages of endometriosis are represented in our group of patients. However, most women presented with stage-IV endometriosis, explained by the fact that the questionnaire

was applied to patients attending a reference Gynaecology Outpatient Department for patients with endometriosis, mainly with advanced disease. The lack of correlation between symptom intensity (and therefore worse quality of life) and disease severity¹ shown in our study by the ASMR's surgical classification is well recognized. Therefore, there is no evidence that the asymmetric distribution of surgical stages in our group of patients may have influenced the assessment of the quality of life.

As regards the exploratory factor analysis aimed

to determine the dimensions produced by the analysis made within the original questionnaire's development, five dimensions were included in the core questionnaire's structure. However, six items were saturated in other than the hypothesized factor, i.e. beyond the original dimension. In fact, the items in 'control and powerlessness', 'generally feeling unwell', 'felt frustrated because your symptoms are not getting better', 'felt frustrated because you are not able to control your symptoms', 'felt as though your symptoms are ruling your life' and 'felt your symptoms are taking away your life' items were also associated from the 'pain' dimension. Not surprisingly, this was also found in the secondary factor analysis carried out in 2006 for the original version³⁴ as pain is a cardinal symptom in endometriosis and may have a negative influence on how the disease is perceived.¹ In addition, the 'Felt unable to tell people how you feel' item was associated to 'emotional well-being', beyond the 'social support' dimension. This association was also described in the North American version²¹ and is easily

explained as the ability to communicate depends on the emotional well-being.

It should be mentioned that the new factor analysis confirmed the emergence of a single second-order component that explains for 78% of the variance, in line with the original version, as well as in the North American and Iranian versions.^{2,21,24} This means that the dimensions may be added in order to obtain a single score.

A high internal consistency was found for all the dimensions of both the core and the modular questionnaires, with a Cronbach's alpha above 0.7. In fact, eight of the 11 dimensions (72.7%) in the EHP-30 presented values above 0.9, showing that these dimensions would be adequate for patient's individual analysis. Cronbach's alpha values in our study were similar and even higher to those described in the original study, except for 'relationship with child/children' (0.916 vs. 0.97), 'sexual relationship' (0.941 vs. 0.96) and 'feelings about infertility' (0.880 vs. 0.92) dimensions.² In addition, these were higher to those found in the Brazilian-

Table 4 - Evaluation of internal consistency of the modular questionnaire of the EHP-30 (Cronbach's alpha)

Dimensions	Item-total correlation
Work ($\alpha = 0.951$; n = 117 in 120)	
1. Ausência do trabalho	0.843
2. Incapacidade para cumprir deveres no trabalho	0.924
3. Embaraçada com sintomas no trabalho	0.784
4. Sentimento de culpa por ausência do trabalho	0.891
5. Preocupação por não ser capaz de fazer o trabalho	0.896
Relationship with child/children ($\alpha = 0.916$; n = 54 in 58)	
1. Dificuldade em cuidar dos filhos	0.846
2. Incapacidade de brincar com os filhos	0.846
Sexual relationship ($\alpha = 0.941$; n = 112 in 115)	
1. Dores na relação sexual	0.757
2. Preocupação com a relação sexual	0.910
3. Evitar relação sexual	0.860
4. Sentir-se culpada por não querer ter relação sexual	0.871
5. Angustia por não conseguir ter prazer na relação sexual	0.813
Feelings about medical profession ($\alpha = 0.948$; n = 121 in 123)	
1. Médico não está a fazer nada por si	0.937
2. Médico acha que é tudo da sua cabeça	0.897
3. Angustia com a falta de conhecimentos do médico	0.872
4. Sentir que faz perder tempo ao médico	0.812
Feelings about treatment ($\alpha = 0.863$; n = 100 in 103)	
1. Angustia porque o tratamento não está a funcionar	0.731
2. Dificuldade em lidar com os efeitos secundários	0.723
3. Aborrecida com a quantidade de tratamentos	0.771
Feelings about infertility ($\alpha = 0.880$; n = 70 in 71)	
1. Preocupada com a possibilidade de não ter (mais) filhos	0.791
2. Sentir-se diferente por não poder/ não conseguir ter (mais) filhos	0.824
3. Sentir-se deprimida com a possibilidade de não ter (mais) filhos	0.793
4. Sentir que a possibilidade de infertilidade provoca tensão na relação com o parceiro	0.573

Portuguese version for all the dimensions.⁸

As regards the comparison of the EHP-30 version in our study to the Brazilian Portuguese version, there are mainly differences regarding the language used. In fact, a translation that would ensure the semantic equivalence with the original instrument was sought in both versions and sought to at the same time ensure that the meaning and clinical relevance would be maintained both in the Portuguese or the Brazilian culture. Therefore, given the linguistic differences, the planning of questions was frequently different. For instance, the question '*Felt your symptoms are taking away your life?*'² from the original version corresponded in the Brazilian Portuguese version to '*Sentiu como se seus sintomas estivessem prejudicando a sua vida?*'⁸ while in the Portuguese version analysed in our study corresponded to '*Sentiu que os seus sintomas lhe estão a tirar vida?*' As regards the assessed psychometric properties, the different versions presented coefficients that show an excellent internal consistency and convergent validity, although different tests were used (SF-36v2 in our study vs. WHOQOL-Bref and the Beck's Depression

Inventory in the Brazilian Portuguese version).⁸

In line with what was described in several validated versions of the EHP-30,^{16,17,21,24} the item-total correlation exceeded the minimum acceptable 0.4 coefficient in all the items in the core and modular questionnaires, corresponding to a good item-total consistency.

As regards the assessment of the convergent validity, a significant negative association between similar dimensions from the EHP-30 and the SF-36v2 questionnaires (the Portuguese version was previously validated as an instrument for the assessment of quality of life) was found. In fact, Pearson's coefficient in our study was the same or even higher in all the dimensions, when compared to the original study.² For instance, maximum correlation (0.73) was found on both studies between 'pain' in the EHP-30 and 'bodily pain' in the SF-36v2. A maximum correlation between these dimensions was also found in the Chinese version of the EHP-30 and was significant in the seven hypothesized correlations.¹⁶ In addition, a maximum correlation was found between 'emotional well-being' in the EHP-30 and 'role emotional' in the SF-36 questionnaire.²⁴

Table 5 - Correlation between the dimensions of core and modular questionnaires of the EHP-30 and the dimensions of the SF-36v2

EHP-30	SF-36v2	Pearson's correlation ^a	p
Pain	Bodily pain	-0.739	< 0.001
Pain	Physical functioning	-0.556	< 0.001
Control and powerlessness	Social functioning	-0.655	< 0.001
Control and powerlessness	Role physical	-0.559	< 0.001
Emotional well-being	Role emotional	-0.600	< 0.001
Emotional well-being	Mental health	-0.738	< 0.001
Emotional well-being	General health	-0.567	< 0.001
Social support	Social functioning	-0.628	< 0.001
Work	Physical functioning	-0.627	< 0.001

EHP-30: Endometriosis Health Profile-30; SF-36v2: MOS Short Form Health Survey – 36 Item - version 2; ^a: Negative correlations as the EHP-30 and SF-36v2 scores follow different directions.

Table 6 - Descriptive statistics for the 5 dimensions of the core questionnaire and the 6 dimensions of the modular questionnaire of the EHP-30

Dimension	n	Mean ± SD	Minimum	Maximum	Asymmetry	Kurtosis
Core questionnaire						
Pain	147	37.11 ± 30.32	0	93.18	0.092	-1.503
Control and powerlessness	150	40.94 ± 30.43	0	95.83	0.021	-1.373
Emotional well-being	151	41.20 ± 27.43	0	95.83	-0.015	-1.134
Social support	152	40.21 ± 29.17	0	100.00	0.004	-1.200
Self-image	152	34.10 ± 27.57	0	100.00	0.303	-1.087
Questionário Modular						
Work	117	28.89 ± 30.09	0	100.00	0.558	-1.122
Relationships with child/children	54	27.78 ± 29.00	0	87.50	0.529	-1.148
Sexual relationships	112	46.12 ± 31.07	0	100.00	-0.109	-1.171
Feelings about medical profession	121	12.76 ± 24.44	0	100.00	2.079	3.325
Feelings about treatment	100	30.92 ± 28.46	0	100.00	0.418	-1.038
Feeling about infertility	70	55.89 ± 28.92	0	100.00	-0.394	-0.617

mean ± SD: mean ± standard deviation.

Data completeness was high both in core and in modular questionnaire, explaining for its basic acceptability and comprehension. In fact, even the 'sexual relationship' dimension, which could involve more constraints, showed a 97.4% data completeness. The Brazilian Portuguese version of the EHP-30 already had shown to be an easily and quickly applied instrument, readily acceptance by patients.⁸

In line with what was described in the core questionnaire from the Iranian version of the EHP-30, the highest median score was found in the 'emotional well-being' dimension and therefore with the most negative impact on quality of life.²⁴ In addition, like the North American and Australian versions, the 'self-image' dimension showed the lowest median score.^{21,22} In the modular questionnaire, in line with the original, Australian, Dutch, Iranian and Chinese versions, the 'feelings about infertility' dimension showed the highest median score and therefore the most negative impact on quality of life.^{2,16,17,22,24} According to our results and in line with literature, the decrease in emotional well-being and concerns regarding a possible infertility are the issues that have more impact on the quality of life in endometriosis. The impact of endometriosis on quality of life has been largely shown and other aspects have been discussed.^{1,5,10,11,35,36} Nnoaham *et al.* described in their study involving 1,418 women from 10 different countries that endometriosis impairs quality of life and labour productivity regardless of the patient's origin or ethnicity.¹⁰ These results were confirmed by Fourquet *et al.* showing that endometriosis-related symptoms have an impact on absenteeism and reduce labour productivity, as well as reducing patient's physical and mental well-being.³⁵ A more recent multi-centric study involving 931 women from 10 countries, described a significant effect of endometriosis on patient's physical, mental and social well-being, namely at work (51% of the patients) and in relationships (50%).³⁶ It should be mentioned that the EHP-30 questionnaire allows for the assessment of different dimensions of quality of life, namely in 'pain', 'control and powerlessness', 'emotional well-being', 'social support' and 'work' dimensions.

As regards the limitations to our study, the fact that the test-retest reliability and sensitivity to the change of questionnaire were not assessed should be mentioned. Despite acceptable intra-class correlation coefficients having been described for different versions,^{2,8,19,20} including the original, the sensitivity to the change of the Portuguese

version of the questionnaire should be analysed in further studies as this is the only way the capability of the Portuguese version of the EHP-30 in measuring the effect of a certain therapy on the quality of life of Portuguese women with endometriosis could be determined.

CONCLUSIONS

Our study showed that the Portuguese version of the EHP-30 is an adequate, validated and well accepted instrument for assessing the quality of life in Portuguese women with endometriosis. This version will allow for the objective assessment of the quality of life in Portuguese women with endometriosis, as well as for the comparison with other studies in which this instrument is used.

Further studies are needed to assess test-retest reliability and sensitivity to the change of this Portuguese version of the EHP-30. If its adequacy is confirmed, this instrument may subsequently be used in assessment studies of therapeutic efficacy.

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HUMAN AND ANIMAL PROTECTION

The authors declare that the followed procedures were according to the regulations established by the responsible body of the Ethics and Clinical Research Committee and according to the Helsinki Declaration of the World Medical Association.

DATA CONFIDENTIALITY

The authors declare that they have followed the protocols of their work centre on the publication of patient data.

CONFLICTS OF INTEREST

The authors declare that there were no conflicts of interest in writing this manuscript.

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REFERENCES

- Giudice LC. Clinical practice. Endometriosis. *N Engl J Med.* 2010;362:2389-98.
- Jones G, Kennedy S, Barnard A, Wong J, Jenkinson C. Development of an endometriosis quality-of-life instrument: The Endometriosis Health Profile-30. *Obstet Gynecol.* 2001;98:258-64.
- Colwell HH, Mathias SD, Pasta DJ, Henning JM, Steege JF. A health-related quality-of-life instrument for symptomatic patients with endometriosis: a validation study. *Am J Obstet Gynecol.* 1998;179:47-55.
- Dubernard G, Rouzier R, David-Montefiore E, Bazot M, Darai E. Use of the SF-36 questionnaire to predict quality-of-life improvement after laparoscopic colorectal resection for endometriosis. *Hum Reprod.* 2008;23:846-51.
- Bodner CH, Garratt AM, Ratcliffe J, Macdonald LM, Penney GC. Measuring health-related quality of life outcomes in women with endometriosis--results of the Gynaecology Audit Project in Scotland. *Health Bull.* 1997;55:109-17.
- Guyatt GH, Feeny DH, Patrick DL. Measuring health-related quality of life. *Ann Intern Med.* 1993;118:622-9.
- Loverro G, Carriero C, Rossi AC, Putignano G, Nicolardi V, Selvaggi L. A randomized study comparing triptorelin or expectant management following conservative laparoscopic surgery for symptomatic stage III-IV endometriosis. *Eur J Obstet Gynecol Reprod Biol.* 2008;136:194-8.
- Mengarda CV, Passos EP, Picon P, Costa AF, Picon PD. Validation of

- Brazilian Portuguese version of quality of life questionnaire for women with endometriosis (Endometriosis Health Profile Questionnaire-EHP-30). *Rev Bras Ginecol Obstet.* 2008;30:384-92.
9. Fauconnier A, Chapron C. Endometriosis and pelvic pain: epidemiological evidence of the relationship and implications. *Hum Reprod Update.* 2005;11:595-606.
 10. Nnoaham KE, Hummelshoj L, Webster P, d'Hooghe T, de Cicco Nardone F, de Cicco Nardone C, et al. Impact of endometriosis on quality of life and work productivity: a multicenter study across ten countries. *Fertil Steril.* 2011;96:366-73.
 11. Simoens S, Dunselman G, Dirksen C, Hummelshoj L, Bokor A, Brandes I, et al. The burden of endometriosis: costs and quality of life of women with endometriosis and treated in referral centres. *Hum Reprod.* 2012;27:1292-9.
 12. 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;187:501-11.
 13. Garry R, Clayton R, Hawe J. The effect of endometriosis and its radical laparoscopic excision on quality of life indicators. *BJOG.* 2000;107:44-54.
 14. Miller JD. Quantification of endometriosis-associated pain and quality of life during the stimulatory phase of gonadotropin-releasing hormone agonist therapy: a double-blind, randomized, placebo-controlled trial. *Am J Obstet Gynecol.* 2000;182:1483-8.
 15. Neelakantan D, Omojole F, Clark TJ, Gupta JK, Khan KS. Quality of life instruments in studies of chronic pelvic pain: a systematic review. *J Obstet Gynaecol.* 2004;24:851-8.
 16. Jia SZ, Leng JH, Sun PR, Lang JH. Translation and psychometric evaluation of the simplified Chinese-version Endometriosis Health Profile-30. *Hum Reprod.* 2013;28:691-7.
 17. van de Burgt TJ, Hendriks JC, Kluivers KB. Quality of life in endometriosis: evaluation of the Dutch-version Endometriosis Health Profile-30 (EHP-30). *Fertil Steril.* 2011;95:1863-5.
 18. Vincent K, Kennedy S, Stratton P. Pain scoring in endometriosis: entry criteria and outcome measures for clinical trials. Report from the Art and Science of Endometriosis meeting. *Fertil Steril.* 2010;93:62-7.
 19. Jones G, Jenkinson C, Kennedy S. Evaluating the responsiveness of the Endometriosis Health Profile Questionnaire: the EHP-30. *Qual Life Res.* 2004;13:705-13.
 20. van de Burgt TJ, Kluivers KB, Hendriks JC. Responsiveness of the Dutch Endometriosis Health Profile-30 (EHP-30) questionnaire. *Eur J Obstet Gynecol Reprod Biol.* 2013;168:92-4.
 21. Jenkinson C, Kennedy S, Jones G. Evaluation of the American version of the 30-item Endometriosis Health Profile (EHP-30). *Qual Life Res.* 2008;17:1147-52.
 22. Khong SY, Lam A, Luscombe G. Is the 30-item Endometriosis Health Profile (EHP-30) suitable as a self-report health status instrument for clinical trials? *Fertil Steril.* 2010;94:1928-32.
 23. Maiorana A, Scafidi Fonti GM, Audino P, Rosini R, Alio L, Oliveri AM, et al. The role of EHP-30 as specific instrument to assess the quality of life of Italian women with endometriosis. *Minerva Ginecol.* 2012;64:231-8.
 24. Nojomi M, Bijari B, Akhbari R, Kashanian M. The assessment of reliability and validity of Persian version of the endometriosis health profile (EHP-30). *Iran J Med Sci.* 2011;36:84-9.
 25. D'Albergaria Martins C. Adaptação do Endometriosis Health Profile Questionnaire (EHP-30) para a cultura portuguesa. Dissertação de Mestrado (Fisioterapia em Saúde da Mulher). Alcoitão: Escola Superior de Saúde de Alcoitão; 2011.
 26. Repositório de Instrumentos de Medição e Avaliação em Saúde (RIMAS); Centro de Estudos e Investigação em Saúde da Universidade de Coimbra (CEISUC). EHP-30. [Consultado 2013 Mar 01]. Disponível em: http://www.uc.pt/org/ceisuc/RIMAS/Lista/Instrumentos/EHP_30.
 27. Hair JF Jr, Anderson RE, Tatham RL, Black WC. Multivariate data analysis. 5th ed. New Jersey: Prentice Hall; 1998.
 28. Ferreira PL, Santana P. Percepção de estado de saúde e de qualidade de vida da população activa: contributo para a definição de normas portuguesas. *Rev Port Saúde Pública.* 2003;21:15-30.
 29. American Society for Reproductive Medicine. Revised American Society for Reproductive Medicine classification of endometriosis: 1996. *Fertil Steril.* 1997;67:817-21.
 30. Wild D, Grove A, Martin M, Eremenco S, McElroy S, Verjee-Lorenz A, et al. Principles of Good Practice for the Translation and Cultural Adaptation Process for Patient-Reported Outcomes (PRO) Measures: report of the ISPOR Task Force for Translation and Cultural Adaptation. *Value Health.* 2005;8:94-104.
 31. Instituto Nacional de Estatística. Inquérito à Fecundidade 2013. Lisboa; 2014. [Consultado 2014 Jul 5]. Disponível em http://www.ine.pt/xportal/xmain?xpid=INE&xpgid=ine_publicacoes&PUBLICACOESpub_boui=218611955&PUBLICACOESmodo=2.
 32. Instituto Nacional de Estatística. Censos 2011 Resultados Definitivos - Portugal. Lisboa; 2012. [Consultado 2014 Jul 5]. Disponível em: [censos.ine.pt/xportal/xmain?xpid=INE&xpgid=ine_censos_publicacao_det&contexto=pu&PUBLICACOESpub_boui=73212469&PUBLICACOESmodo=2&selTab=tab1&pcensos=61969554](http://www.inecensos.pt/xportal/xmain?xpid=INE&xpgid=ine_censos_publicacao_det&contexto=pu&PUBLICACOESpub_boui=73212469&PUBLICACOESmodo=2&selTab=tab1&pcensos=61969554).
 33. Belleis P, Dias JA Jr, Podgaec S, Gonzales M, Baracat EC, Abrão MS. Epidemiological and clinical aspects of pelvic endometriosis – a case series. *Rev Assoc Med Bras.* 2010;56:467-71.
 34. 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. *Hum Reprod.* 2006;21:2686-93.
 35. Fourquet J, Báez L, Figueroa M, Iriarte RI, Flores I. Quantification of the impact of endometriosis symptoms on health-related quality of life and work productivity. *Fertil Steril.* 2011;96:107-12.
 36. De Graaff AA, D'Hooghe TM, Dunselman GA, Dirksen CD, Hummelshoj L, WERF EndoCost Consortium, et al. The significant effect of endometriosis on physical, mental and social wellbeing: results from an international cross-sectional survey. *Hum Reprod.* 2013;28:2677-85.

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