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ORIGINAL ARTICLE - VALIDATION STUDIES

Cross-cultural adaptation and validation of the Portuguese version of "The assessment of knowledge in ankylosing spondylitis patients by a self-administered questionnaire"

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Abstract Knowledge is an important factor in patients with ankylosing spondylitis regarding the adoption of appropriate behaviours and education. The aim of this study was to culturally adapt and validate "The assessment of knowledge in ankylosing spondylitis patients by the self-administered questionnaire" for the Portuguese population with ankylosing spondylitis. The Portuguese version of "The assessment of knowledge in ankylosing spondylitis patients by a self-administered questionnaire" was administered to a sample of 180 subjects, from which 63 individuals responded. The adaptation process involved translation, back-translation and submission to a committee of experts in the area, culminating with a Portuguese version of the instrument. Next, the scale reliability and validity were assessed. There was a statistically significant decrease from test to retest, although the intra-class correlation coefficient between test and retest was 0.76 (95 % CI 0.61–0.86), which was considered good. From 180 individuals, 63 (35.0 %) subjects were available for the present study. The proportion of individuals that correctly answered each item ranged from 19 to 92 %, corresponding to items 8 and 13, respectively. The mean number of correct answers was 8.5 [mean (SD) = 2.4] in 12 questions. The proposed Portuguese version of the ankylosing spondylitis knowledge scale showed good reliability, reproducibility and construct validity.

Keywords Cross-cultural validation · Ankylosing spondylitis knowledge · Ankylosing spondylitis education

Introduction

Ankylosing spondylitis (AS) is a systemic disease characterised by chronic inflammation, leading to a loss of mobility and functionality of the entire axial skeleton [1–3]. Intervention for AS has generally a pharmacological and nonpharmacological nature, with nonpharmacological measures including physical exercise and patient education [4–6].

Education is of utmost importance when it comes to patients with chronic condition, in particular with rheumatic diseases, as in the case of patients with AS. According to the recommendations of the European League Against Rheumatism (EULAR) (2010), education is considered the cornerstone of nonpharmacological treatment [7]. Education programmes shall be used as a complement to treatment, to teach patients how to deal with pain, to control symptoms and to deal with the worsening and chronic nature of their condition. These programmes must be patient oriented, focused on improving their skills and self-efficiency as to the disease, thereby promoting the psychological and behavioural well-being and inducing in the long run a better understanding of their disease [4, 8].

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A better knowledge of the disease provides a greater involvement in decision-making, with patients taking an active role in managing their situation [9]. In addition, it affects the reduction of the associated costs, both direct, such as medication, outpatient visits, hospitalisations, surgery, and indirect, such as the absence from work, anxiety and decreased quality of life [4, 10, 11]. Developing the skills of patients with AS and their relatives is fundamental for a good understanding inside the family, so that the appropriate behaviours can be adopted by the family as a whole [12].

Currently, in Portugal, few data are available on the knowledge of patients with AS regarding their disease, as there is no instrument in the Portuguese language which allows doing that assessment. In the UK, Lubrano et al. [13] developed a questionnaire to evaluate the knowledge of patients with AS, with this questionnaire being afterwards translated and validated by Claudepierre et al. [14] for the French population with this disease.

The relevance of creating a Portuguese version of this questionnaire is based on the need to assess the type of knowledge each patient has about themselves and about their condition, so as to minimise the negative impact AS has on their quality of life and also on the country's socio-economical context.

The aim of the present study was to culturally adapt and validate "The assessment of knowledge in ankylosing spondylitis patients by a self-administered questionnaire" for the Portuguese population with AS.

Methods

Sample and recruitment

The present study was observational, cross-sectional and included a population of 180 individuals, members of the National Association of Ankylosing Spondylitis (ANEA), from the Northern Portugal branch, diagnosed with AS. As inclusion criteria, we have defined the diagnosis of AS, according to the Modified New York criteria [14]. The study excluded individuals with other clinical conditions common to AS, such as rheumatoid arthritis and systemic lupus.

Original instrument

The questionnaire "The assessment of knowledge in ankylosing spondylitis patients by a self-administered questionnaire" is used to assess AS patients' level of knowledge, using 14 multiple-choice questions. It has 72 possible responses, but only 25 of them are correct. This questionnaire examines different areas: (1) general knowledge, aetiology, symptoms, blood tests; (2) immunogenetic tests (B27 antigen) and inheritance; (3) general management, including pharmacological and nonpharmacological (posture, exercise regimen) intervention; (4) joint protection, pacing and priorities [13, 14]. The score is obtained by assigning one point for each correct answer, with a possible maximum score of 25 points, and by assigning one point to each question (14 questions) with all correct answers (maximum of 14 points), and then these two scores are summed to give a final score [14].

Cross-cultural adaptation

This process included two stages. In the first stage, two bilingual translators working independently translated and adapted the questionnaire to the Portuguese culture, to detect possible understanding and translation problems resulting from the use of technical and uncommon vocabulary [15, 16]. The two resulting translations were compared and merged into one single version. Then, two different bilingual translators working independently from one another performed the translation into English (back-translation) of the document. Following this step, the expert committee constituted by two rheumatology specialists proofread the translated questionnaire, comparing the original and final versions to merge them into a single document, analysing and discussing the differences found between the two versions until reaching an agreement. The final version of the questionnaire was first piloted in a group of 10 individuals with AS, to understand whether the vocabulary used was appropriate and whether the questionnaire was easily understood. On the second stage, the questionnaire was assessed as to its psychometric properties, reliability and validity [17].

The present study was approved by the Ethical Committee of Escola Superior de Tecnologia da Saúde do Porto (ESTSP). The access to data of ANEA's members, in particular their addresses, was granted by the president of ANEA's North branch.

One hundred eighty envelopes were sent by post, each one containing a characterisation questionnaire, the knowledge questionnaire which constitutes the object of the present study and an informed consent statement. Individuals who returned the questionnaire were sent the same questionnaire 4 weeks after the first, to assess its reproducibility [13].

Statistical analysis

In the present study, and given the binary structure of the data, the latent trait model (LTM) was used to identify dimensions in knowledge about AS in the patient population. LTM is simply a binary data factor analysis that considers one or more factors [18].

Interpretation of the model is usually done considering the standardised factor loadings. A standardised factor loading is classified as weak if the corresponding absolute value is less than 0.30, moderate if it is between 0.30 and 0.70, and strong if it is higher than 0.70.

The standardised Cronbach's alpha was estimated to evaluate the internal consistency of the group of items.

The final score was the sum of all items in the questionnaire with absolute standardised factor loadings higher than 0.3. The questionnaire has two types of questions: the first type only has one correct answer: if the participant selects the right answer we have one point; if did not select the right answer we have 0 points; the second type has two correct answers: if the participant selects both we have one point; if not, we have 0 points.

The test–retest reliability was assessed using a two-way mixed intra-class correlation coefficient (ICC) for single measures.

To assess the construct validity, we compared the scores by gender, age, education level, years since diagnosis and salary.

Two independent sample Student *t* test and one-factor analysis of variance (ANOVA) were used to compare the score between two or three independent groups, respectively.

Results

From the 180 individuals, 63 (35.0 %) subjects were included in the present study. The mean age was 49 (±14) years, and 41.3 % of them had more than 12 years of education; 31 (49.2 %) were women, and 38 (60.3 %) reported having been diagnosed with AS at less than 5 years (Table 1).

The proportion of individuals that correctly answered each item ranged from 19 to 92 %, corresponding to items 8 and 13, respectively.

As no prior information on the number of latent variables to be held was available, a one-factor LTM was fit to the 14 items. Twelve items showed a moderate-to-strong positive association with the latent variable, while 2 (12 and 13) presented a weak association (Table 2). The item fit and the inspection of 2 by 2 marginal residuals showed a good fit of this model. The standardised alpha was 0.6837, showing good/moderate reliability after eliminating items 12 and 13.

There was a statistical significant decrease from test to retest, although the ICC between test and retest was 0.76 (95 % CI 0.61–0.86), which was considered good (Table 3).

The mean number of correct answers was 8.5 [mean (SD) = 2.4] in 12 questions. Table 4 shows that AS knowledge was significantly higher in younger individuals, with high education and higher salaries. There was no significant association with gender or years since diagnosis.

Table 1 Sample characteristics: socio-demographic information and history of AS

	N (%)
Gender	
Female	31 (49.2)
Male	32 (50.8)
Age (years) [mean (SD)]	49 (13.9)
Education level (years)	
≤9	25 (39.7)
≤12	12 (19.0)
>12	26 (41.3)
Diagnosis (years)	
≤4	38 (60.3)
>5	25 (39.7)
Salary (monthly)	
≤1000 euros	34 (54.8)
>1000 euros	28 (45.2)

The final version of the questionnaire was first piloted in a group of 10 individuals with AS, to understand whether the vocabulary used was appropriate. After this step, we had to reformulate the question number four and number five for a better understanding of individuals with this disease.

Discussion

The present study results from the need of describing the knowledge level of the Portuguese population with AS regarding their condition.

The cultural and linguistic adaptation of the questionnaire "The assessment of knowledge in ankylosing spondylitis patients by a self-administered questionnaire" to the Portuguese patients with AS resulted from a process of translation and assessment of psychometric properties.

The factor analysis demonstrated that the scale information could be summarised into a single domain. However, items 12 and 13 did not correlate to this global domain, which means that the questionnaire original structure was not fully replicated. After eliminating these two questions, good/moderate reliability was demonstrated, with a 0.68 Cronbach's alpha correlation index, a value lower than the value in the study of Lubrano et al. [13] (0.85).

The test–retest value obtained was good (0.76), as in the study of Lubrano et al. [13] (0.77), demonstrating good reliability.

The patients with AS included in the present study demonstrated a high level of knowledge regarding their condition. Knowledge levels were higher in younger individuals, having higher levels of general education and higher

Table 2 Proportion of correct answers, standardised for the one-factor latent trait model and reliability for the questionnaire

Item	*N* (%)	Standardised factor loading	Standardised alpha reliability deleting each item in turn
1	27 (43.5)	**0.716**	0.6579
2	28 (45.2)	**0.573**	0.6789
3	55 (88.7)	**0.717**	0.6614
4	23 (37.1)	**0.562**	0.6832
5	53 (85.5)	**0.660**	0.6725
6	32 (51.6)	**0.504**	0.6865
7	42 (67.7)	**0.707**	0.6672
8	12 (19.4)	**0.785**	0.6669
9	24 (38.7)	**0.588**	0.6794
10	57 (91.9)	**0.999**	0.6247
11	55 (88.7)	**0.953**	0.6316
12	49 (79.0)	0.164[a]	–
13	57 (91.9)	−0.270[a]	–
14	14 (22.6)	**0.930**	0.6554
Standardised alpha			0.6837

[a] Item eliminated

Table 3 Test–retest reliability of the questionnaire

N = 52	Mean (SD)
Time 1	8.7 (2.23)
Time 2	7.3 (2.13)
P	<0.001
ICC (95 % CI)	0.76 (0.61–0.85)

Table 4 Score of the questionnaire by gender, age, education level, years since diagnosis and salary

	Mean (SD)	Test statistic	*P*
Total	8.5 (2.4)		
Gender			
Female	8.8 (2.0)	0.8058[a]	0.424
Male	8.3 (2.7)		
Age (years)			
≤50	9.5 (2.1)	3.4168[a]	0.001
>50	7.7 (2.1)		
Education level (years)			
≤9	7.2 (2.4)	7.7119[b]	0.001
≤12	8.6 (1.7)		
>12	9.7 (2.0)		
Diagnosis (years)			
≤4	8.6 (2.4)	0.419[a]	0.677
>5	8.4 (2.4)		
Salary (monthly)			
≤1000 euros	7.6 (2.4)	−3.2966[a]	0.002
>1000 euros	9.5 (2.0)		

[a] Two independent sample *t* test

[b] ANOVA

salaries, as in the study of Lubrano et al. [13] and Claudepierre et al. [14], which confirms the scale validity. These associations can be explained by the fact that individuals with higher education levels are more demanding in their search for information regarding their disease, as a way to control it more effectively. The same happens with younger individuals or with higher economic power, who have access to a different type of information [4]. In most individuals with chronic diseases, the education level is a good predictor of a favourable outcome, considering that low education levels, associated with lower socio-economical condition, are normally associated with poor health [19].

As in the study of Hennell et al. [20], in the present study no correlation was found between the level of disease knowledge and gender. This can result from the lack of interest demonstrated by male patients in getting more information regarding their condition, as in the study of Cooksey et al. [9], which proves that, between gender, women are more interested than men in gathering information on AS. No correlation was verified between knowledge and the number of years since diagnosis, which corroborates the results in the study of Jennings et al. [21] as to knowledge regarding rheumatoid arthritis. These authors have justified this by the fact that old individuals' time since diagnosis is longer and, as they get older, they show no interest in increasing their knowledge as to their disease.

The results obtained demonstrate that in the present study symptoms, immunological testing and treatment are the areas where knowledge is higher, which can be explained by the fact that the clinical onset of the disease occurs early, motivating a quick search of diagnosis and treatment. The characteristics of these patients and their surrounding environment, in particular their attitude and knowledge as regards the disease, and the type of treatment they are submitted to, can be responsible for increasing/reducing symptoms [9].

Most individuals affected by AS discover the characteristics of their disease as symptoms appear and limitations become more visible. Even the management of pain, fatigue and negative emotions commonly associated with changes in some family and professional roles make that basic information is not enough for these patients, with the search of more complete knowledge and education as regards the disease becoming crucial [8].

The present study has some limitations, such as the fact that participants are members of an association of AS, which in some way results from their interest in being more informed. Another limitation is related to the sample size, which is very reduced when compared to the study of Lubrano et al. [13], and this limitation did not allow to confirm whether the questionnaires work in all subgroups (gender, years since diagnosis).

In the future, it would be appropriate to study the correlation between knowledge and other variables, such as the *Bath* indexes and the perception on the quality of life, to facilitate the understanding and knowledge influence on this disease. According to the results of the present study, we suggest a reflection to be made on the application of strategies such as education, as this must be regarded as the cornerstone in adopting behaviours and making decisions with a positive impact on the quality of life of individuals with AS.

Main findings

The proposed Portuguese version of the ankylosing spondylitis knowledge scale showed one dimension with good internal consistency. The test–retest showed that the ankylosing spondylitis knowledge scale had good reproducibility.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Informed consent Informed consent was obtained from all individual participants included in the study in accordance with the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards.

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