Original Article

The adaptation of the Turkish version of the Assessment of Knowledge in Ankylosing Spondylitis Patients by a Self-Administered Questionnaire

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ABSTRACT

Objectives: The aim of this study was to adapt the Assessment of Knowledge in Ankylosing Spondylitis Patients by a Self-Administered Questionnaire for the Turkish ankylosing spondylitis (AS) patients.

Patients and methods: Between May 2016 and December 2016, a total of 100 AS patients (72 males, 28 females; mean age 43.4 years; range, 21 to 73 years) were included in the study. A forward (into Turkish) and backward translation of the questionnaire was performed. Reliability was evaluated using the Cronbach alpha (α) value, test-retest reliability, and intra-class correlations (ICCs). The correlations with demographic data including age, sex, time since diagnosis, and education status and with the disease-specific assessments including Bath Ankylosing Spondylitis Functional Index (BASFI), Bath Ankylosing Spondylitis Disease Activity Index (BASDAI), and the Ankylosing Spondylitis Quality of Life (ASQOL) questionnaire were investigated.

Results: The Turkish version of the questionnaire showed a good reliability (Cronbach-α: >0.70, ICC: >0.90). A significant correlation was found with the education status (p<0.001). However, no significant correlation was observed between the questionnaire and the other parameters (p>0.05).

Conclusion: Our study results show that the Turkish version of the questionnaire seems to be reliable for use in Turkish AS patients.

Keywords: Ankylosing spondylitis, awareness, knowledge, reliability.

Ankylosing spondylitis (AS) usually presents during young adulthood, and several studies have demonstrated an association with poor well-being, increased dependency, decreased work force, and consequent financial losses.[1-3] Higher levels of knowledge about the disease may have positive effects on disease management and reduce the negative impact of the disease on the economic status, such as frequent outpatient visits or absence from the work.[4,5] Thus, knowledge about disease can play a key role in the management of the AS patients. Although the level of knowledge in patients with rheumatoid arthritis and osteoarthritis has been previously evaluated,[6-8] only a few reports focused on patients with AS so far.[9] To address this, Lubrano et al.[10] developed the Assessment of Knowledge in Ankylosing Spondylitis Patients by a Self-Administered Questionnaire and validated in 62 AS patients who were living in England[10] While the questionnaire was used to determine the knowledge levels of the patients about their diseases in previous studies, the validity of the questionnaire has not been investigated extensively, yet.[11] Recently, the questionnaire has been validated into the Portuguese language.[12] However, to the best of our knowledge, no further efforts are available for a validation study in Turkish language.

In the present study, therefore, we aimed to conduct the validation and reliability studies of the Turkish version of the Assessment of Knowledge in Ankylosing Spondylitis Patients by a Self-Administered Questionnaire in AS patients.

PATIENTS AND METHODS

Since a number of patients between 5 and 10 are recommended to be employed for each question for version studies,[13] the sample size in the present study was determined as ranging between 98 and 112 (7-8 participants for each question). Therefore, the present study included a total of 100 consecutive AS patients (72 males, 28 females; mean age 43.4 years; range, 21 to 73 years) who were diagnosed according to the Modified New York and/or Assessment of SpondyloArthritis International Society (ASAS)-axial Spondyloarthropathy (SpA) criteria and who were followed in the rheumatology clinics in the Ege University Hospital or Dokuz Eylul University Hospital between May 2016 and December 2016. Patients were excluded from the study, if they were illiterate, had serious psychiatric or neurologic diseases preventing them from understanding and answering the questions, or refusing to participate in the study. A written informed consent was obtained from each patient. The study protocol was approved by the Ege University, Faculty of Medicine Ethics Committee (No. 17-2/17). The study was conducted in accordance with the principles of the Declaration of Helsinki.

The original instrument

The Assessment of Knowledge in Ankylosing Spondylitis Patients by A Self-Administered Questionnaire comprised 14 multiple-choice questions related to the pathogenesis, diagnosis, and the available treatments regarding to AS. The patients were asked to choose the correct answer/answers among suggested choices for each question. Only 25 of the recommended 72 choices were correct, and each correct choice was given one point (maximum of 25 points). This formed the correct answer score (CAS). In addition, one point was assigned for each question with all correct answers (maximum of 14 points), forming the correct item score (CIS). Then, two scores were summed for a total score.[10]

Translation

Prior to the study, the permission for conducting the Turkish version of the questionnaire was obtained from Lubrano et al.,[10] the developer of the Assessment of Knowledge in Ankylosing Spondylitis Patients by a Self-Administered Questionnaire.

A forward-backward translation method was used in the translation process. The questionnaire was translated into Turkish by two medical professionals (a physical medicine and rehabilitation specialist and a rheumatology specialist) who are proficient in English and an English teacher. This team determined the best suitable words in the Turkish language which reflect the meaning of English items. Then, the back-translations from Turkish to English were performed by two bilingual native English speakers who had no prior knowledge of the contents of the original version of the questionnaire. Finally, all versions were investigated regarding to the semantic context (Table 1). The final version of the Turkish questionnaire was compared to the original English version and both versions appeared to be identical. The Turkish version was delivered to 10 AS patients to determine whether they could understand all the items. None of the patients in this pilot group reported any problems related to understanding the items. Then, the questionnaire was administered to 100 AS patients twice for two weeks.

Assessment tools

Sociodemographic and disease-related information including age, education status, and the time since diagnosis were gathered using a structured form. The relationship of the questionnaire with the clinical assessments was also investigated using the following clinical assessment tools:

Bath Ankylosing Spondylitis Disease Activity Index (BASDAI): This index was performed to evaluate the level of fatigue, spinal pain, joint pain/swelling, areas of localized tenderness, and morning stiffness. The patients were asked to mark the degree of their symptoms on a 10-cm Visual Analog Scale (VAS). The total BASDAI score was obtained by converting the overall index (0-50) to a 0-10 scale.[14]

Bath Ankylosing Spondylitis Functional Index (BASFI): This index was used to assess the daily activities and the ability to cope with everyday life of the patients.[15] Each question was answered on 10-cm horizontal VAS. The mean of the 10 scales formed the BASFI score (0-10), with higher scores indicating more severe impairment.

Ankylosing Spondylitis Quality of Life (ASQOL) questionnaire: This questionnaire consists of 18 questions, each with a dichotomous "Yes/No" response format, scored "1" and "0," respectively. Total scores ranged from 0 to 18, with a higher score indicating poor quality of life (QoL).[16]

TABLE 1
Turkish Version of the Assessment of Knowledge in Ankylosing Spondylitis Patients by a Self-Administered Questionnaire

Turkish Version of the "The Assessment of Knowledge in Ankylosing Spondylitis Patients by a Self-Administered Questionnaire"

1. Aşağıdaki listeden doğru olan iki ifadeyi seçebilir misiniz:

    Ankilozan spondilit (AS)
    a. Enfeksiyöz bir hastalıktır
    b. Nedeni bilinmemektedir
    c. Ara sıra ailede birden fazla kişide görülebilmektedir
    d. En sık ileri yaşta görülür
    e. Sportif aktivite ya da yaralanmalar nedeniyle olabilir
    f. Bilmiyorum

2. Aşağıdaki listeden doğru olan iki ifadeyi seçebilir misiniz:

    AS
    a. Omurga eklemlerindeki yangısal (mikrobik olmayan iltihabi) bir durumdur
    b. Bazı hastalarda ilk şikayet sırt veya belde olmayabilir
    c. Soğuk havalarda daha kötü olur
    d. Tamamen iyileştirilebilir bir hastalıktır
    e. Bilmiyorum

3. Aşağıdaki listeden doğru olan iki ifadeyi seçebilir misiniz:

    AS
    a. Bazen gözü ve topuk kemiğini etkiler
    b. Kalp krizi veya inme (felç) riskini arttırır
    c. Sırt/bel bölgesinde ağrı ve sertliğe (tutukluğa) neden olur
    d. Kanser riskini arttırır
    e. Bilmiyorum

4. AS'nizin ne kadar aktif olduğunu değerlendirmede kullanılan iki kan testini seçebilir misiniz?

    a. Kolesterol düzeyleri
    b. Eritrosit sedimantasyon hızı
    c. Tam kan sayımı
    d. C-reaktif protein
    e. Bilmiyorum

5. AS gelişimine yatkınlığı belirlemede kullanılan kan testini seçebilir misiniz?

    a. Üre
    b. Human lökosit antijen (HLA)-B27
    c. HLA-DR4
    d. Plazma viskozitesi
    e. Bilmiyorum

6. AS'ye tibbi yaklaşım konusunda iki doğru cevabı seçebilir misiniz?

    a. Ağrı kesiciler ağrının geçmesine yardımcı olur
    b. Hastalığı kontrol etmede tek yaklaşım ilaç tedavisidir.
    c. Hiçbir ilaç hastalığı kontrol edemez
    d. Birçok anti-inflamatuar ilaç iyi kalitede gece uykusu sağlar ve egzersiz yapabilecek kadar yeterli ağrı kontrolü yapar.
    e. Bilmiyorum

7. Aşağıdaki listeden iki doğru ifadeyi seçebilir misiniz?

    a. Sadece egzersizler yapıldığında bile, her hasta normale dönecektir
    b. Semptomlar uzun bir süre boyunca gelip gidebilir
    c. En önemlisi iyi bir postürün korunmasıdır
    d. AS işinizi ya da fiziksel aktivitenizi engellemez
    e. Bilmiyorum

8. AS için istirahat hakkında iki doğru cevabı seçebilir misiniz?

    a. Beliniz ağrılı ve tutuk olduğunda en iyi yaklaşım günün büyük bir kısmını yatakta istirahat ederek geçirmektir.
    b. Hastalık çok aktif olduğunda, işe ara vermek veya hastanede kalmak gerekebilir.
    c. Bütün gece (gece boyunca) sırt üstü uzanmak
    d. Yatmadan önce ve sabah kalkmadan önce bir süre yüzükoyun uzanmak
    e. Bilmiyorum

9. AS'li hastalar için ideal yatak hakkında iki doğru cevabı seçebilir misiniz?

    a. Her yatak uygundur
    b. Yatak sert olmalıdır
    c. Yatağın altına bir kontraplak tabaka koymak idealdir
    d. Yumuşak bir yatak bel tutuk olduğunda daha yardımcıdır
    e. Bilmiyorum

10. AS için egzersiz tedavisi hakkında iki doğru cevabı seçebilir misiniz?

    a. Egzersiz, AS tedavisinin önemli bir parçasıdır
    b. Egzersiz AS'yi kalıcı olarak iyileştirir
    c. Egzersiz hasara uğramış eklemleri zayıflatır
    d. Düzenli günlük egzersiz aktif kalmak için akılcı bir yaklaşımdır
    e. Bilmiyorum

11. AS'li bir kişi için en uygun iki aktiviteyi seçebilir misiniz?

    a. Alışveriş gezileri
    b. Yüzme
    c. Kır koşusu
    d. Futbol
    e. Kas kuvvetlendirme egzersizi
    f. Bilmiyorum

12. Bütün eklemleriniz ağrılı ve tutuk olduğunda yani akut alevlenmede yapmanız gereken bir aktiviteyi seçebilir misiniz?

    a. Tüm egzersizlerden uzak durmak
    b. Günün çoğunda yatakta istirahat etmek
    c. Ağrısız olduğunuz sınırlar içinde eklem hareket açıklığı egzersizleri yapın
    d. Oldukça yoğun egzersiz yapmak
    e. Bilmiyorum

13. Bu listeden bir doğru cümleyi seçebilir misiniz?

    a. Omurga manipülasyonu hastalığa yardımcı olabilir
    b. Akupunktur hastalığı kalıcı olarak iyileştirebilir
    c. Havuz içi egzersiz harekete yardımcı olabilir
    d. Havuz içi egzersiz hastalığı kötüleştirebilir çünkü su ve nem eklemlere zarar verebilir
    e. Bilmiyorum

14. AS'yi aileyi nasıl etkileyebildiğini tanımlayan iki doğru cümleyi seçebilir misiniz?

    a. AS'li hastaların, AS olan çocuklara sahip olma şansları yüksektir
    b. AS'li ailelerin, AS'si olan çocuğa sahip olma şansları düşüktür
    c. HLA-B27 testi, hastaların çocuklarının hastalığı geliştirip geliştirmeyeceği konusuna yanıt verecektir.
    d. HLA-B27 testi, hastaların çocuklarının hastalığı geliştirip geliştirmeyeceği konusuna yanıt vermeyecektir.
    e. Bilmiyorum

TABLE 2
Demographic and disease-specific characteristics of patients

	Median	IQR 25/75	Min-Max
Age (year)	43	36/49.5	21-73
Time since diagnosis (year)	10	5/19.5	1-32
BASDAI	2	1/3	0-7.40
BASFI	2	0.95/4	0-8.0
ASQOL	4	1/8	0-18.0

IQR 25/75: Interquartile range 25/75; Min: Minimum; Max: Maximum; BASDAI: Bath Ankylosing Spondylitis Disease Activity Index; BASFI: Bath Ankylosing Spondylitis Functional Index; ASQOL: Ankylosing Spondylitis Quality of Life Questionnaire.

Statistical analysis

Statistical analysis was performed using the IBM SPSS for Windows version 25.0 software (IBM Corp., Armonk, NY, USA). The Kolmogorov-Smirnov test was used to identify the distribution of the data. As the data did not distributed normally, non-parametric tests were used. Descriptive data were expressed in mean ± standard deviation (SD), median (min-max) or number and frequency, where applicable. The reliability was analyzed through test-retest and internal consistency analyses. The test-retest reliability was investigated

TABLE 3
Cronbach-α values for CIS and CAS

	Corrected item-Total correlation	Cronbach's α if item deleted
Correct answer score (Cronbach's α for total: 0.80)		
1	0.48	0.79
2	0.47	0.79
3	0.51	0.79
4	0.53	0.78
5	0.54	0.78
6	0.35	0.80
7	0.59	0.77
8	0.55	0.78
9	0.28	0.81
10	0.43	0.79
11	0.44	0.79
12	0.27	0.80
13	0.34	0.80
14	0.21	0.81
Correct item score (Cronbach's α for total: 0.75)		
1	0.34	0.74
2	0.48	0.73
3	0.52	0.72
4	0.48	0.73
5	0.50	0.73
6	0.35	0.74
7	0.39	0.74
8	0.39	0.74
9	0.18	0.76
10	0.35	0.74
11	0.34	0.74
12	0.25	0.75
13	0.35	0.74
14	0.15	0.76

CIS: Correct item score; CAS: Correct answer score.

TABLE 4						
Correlation analysis results						
	CAS		CIS		Total	
Parameters	Spearman's rho	p	Spearman's rho	p	Spearman's rho	p
Age (year)	-0.176	0.080	-0.171	0.089	-0.141	0.160
Time since diagnosis (year)	0.001	0.994	0.014	0.891	0.046	0.651
BASDAI	0.037	0.717	0.051	0.613	-0.100	0.324
BASFI	-0.026	0.794	-0.005	0.959	-0.103	0.306
ASQOL	-0.110	0.276	-0.087	0.391	-0.130	0.197
Level of education	0.521	<0.001	0.513	<0.001	0.520	<0.001

CAS: Correct answer score; CIS: Correct item score; BASDAI: Bath Ankylosing Spondylitis Disease Activity Index; BASFI: Bath Ankylosing Spondylitis Functional Index; ASQOL: Ankylosing Spondylitis Quality of Life Questionnaire; p<0.05.

by using intraclass correlation coefficient (ICC), while the internal consistency was estimated from the Cronbach alpha (α) value. Both ICC and Cronbach-α values exceeding 0.70 were considered acceptable for reliability.[17]

As there is no other validated questionnaire related to the patient's knowledge level available in the Turkish language, construct validity was performed using correlation analysis. The correlations between the Assessment of Knowledge in Ankylosing Spondylitis Patients by A Self-Administered Questionnaire scores and demographic data including age, sex, time since diagnosis and education status, and with the disease-specific assessments such BASFI, BASDAI, and ASQOL scales were investigated using the Spearman's correlation. The Mann-Whitney U test was performed to compare groups according to sex, age, and time since diagnosis. A p value of <0.05 was considered statistically significant. The Kruskal-Wallis test was employed to compare the values according to education status. The Mann-Whitney U test was used as a *post-hoc* test after Kruskal-Wallis test with a *post-hoc* Bonferroni correction, and a p value of 0.017 was considered statistically significant.

TABLE 5										
Comparison of scores according to sex, age, time since diagnosis, and education status										
		CAS			CIS			Total		
	n	Median	IQR 25/75	p	Median	IQR 25/75	p	Median	IQR 25/75	p
Age (year)										
≤50	78	16	12/19	0.141*	7	4/9	0.145*	23.5	16/28	0.120*
>50	22	15.5	11/17		6.5	4/8		21.5	15/25	
Sex										
Male	72	16	12/19	0.758*	7	4.5/9	0.796*	23	16/28	0.761*
Female	28	16.5	11.5/18		7	4/9		24	15.5/27	
Time since diagnosis (year)										
≤5	27	17	14.5/19	0.356*	8	6/9	0.296*	24	20.5/28	0.337*
>5	73	16	12/18		7	4/9		22	16/27	
Level of education										
Elementary education	32	12.5	9/15	<0.001§	5	3.5/6.5	<0.001§	16.5	13/21	<0.001§
Secondary education	29	17	12/19	0.001†	7	4/9	0.005†	24	16/28	0.001†
Higher education	39	18	16/20	<0.001‡ 0.075ʃ	8	7/9.5	<0.001‡ 0.041ʃ	26	23/29	<0.001‡ 0.06ʃ

CAS: Correct Answer Score; CIS: Correct Item Score; IQR 25/75: Interquartile range 25/75; * Mann Whitney U test; § Kruskal-Wallis test (level of significance: 0.017 according to Bonferroni Correction for †, ‡ and ʃ); † Elementary education vs. secondary education; ‡ Elementary education vs. higher education, ʃ Secondary education vs. higher education.

RESULTS

The demographic and disease-related characteristics of the patients are shown in Table 2. The distribution of the education was as follows: 32 patients (32%) had elementary education, 29 patients (29%) had secondary education, and 39 patients (39%) had higher education.

The Cronbach-α values were found to be 0.80 and 0.75 for CAS and CIS, respectively. All items showed a positive correlation among each other. The Cronbach-α values for each question are presented in Table 3. As the Cronbach-α if item deleted values were approximately same as the total Cronbach-α value, all questions were found contributing to the questionnaire.

The ICC values for test-retest were 0.97 (95% CI: 0.96-0.98) for CAS, 0.95 (95% CI: 0.92-0.96) for CIS, and 0.96 (95% CI: 0.95-0.98) for the total score. The test-retest reliability was found to be in an excellent level.

Significant correlations were determined only between education status and CAS (rho: 0.521; $p < 0.001$) and education status and CIS (rho: 0.513; $p < 0.001$). Both relationships were at a moderate level and indicating that the level of knowledge tended to increase with increasing the education status.

The median CAS score was 16 (IQR 25/75: 12/19), the mean CIS score was 7 (IQR 25/75: 4/9), and the mean total score was 23 (IQR 25/75: 16/27.5). The comparison of the scores according to sex, age, time since diagnosis, and education status is presented in Table 5. There were statistically significant differences between the education status of the patients ($p < 0.05$).

DISCUSSION

The present study was designed with an intent to adapt the Assessment of Knowledge in Ankylosing Spondylitis Patients by a Self-Administered Questionnaire into the Turkish language. According to our results, the Turkish version of the questionnaire was showed a good reliability and reproducibility. The Turkish version of the questionnaire was found to be related to the education status. On the other hand, level of functionality, severity of the symptoms, and QoL were not correlated with the knowledge of the disease.

The internal reliability of a measure is indicated with the Cronbach-α value, and values over 0.70 are considered acceptable. The Cronbach-α value was detected as 0.80 in the present study. However, previous authors have reported different reliability values. A value of 0.85 (according to Kuder-Richardson Formula 20) was reported by Lubrano et al.[10] in the original study of the questionnaire. Recently, da Rocha Lopes et al.[12] reported the Cronbach-α value as 0.68 for the Portuguese version of the questionnaire. These authors also indicated that Questions 12 and 13 were removed. However, in the present study, no reduction was needed in the number of the questions and the original questionnaire was fully adapted into the Turkish language.

The reproducibility of a measure is important for obtaining similar results between various assessments and was evaluated by the test-retest reliability using ICC values. A very high ICC level (0.96) for the test-retest reliability was found in the present study, indicating the Turkish version of the questionnaire as reliable for repeated measures. However, the test-retest value obtained in our study was higher than the previously reported studies by Lubralo et al.[10] (0.77) and da Rocha Lopes et al.[12] (0.76). This difference may have resulted from the time interval between test-retest evaluations in these studies (four weeks), and the present study (two weeks). The shorter time interval between the evaluations might have resulted in a recall effect in the present study.

As in the present study, the possible relationships between the knowledge of disease and demographic data as age, sex, disease duration, and education status were investigated in previous studies. Lubrano et al.[10] reported no significant relationship between level of knowledge and age, sex, disease duration, and the education status. On the other hand, Claudepierre et al.[11] reported that female sex, higher education status, reading resources about AS, and awareness of AS support groups were associated with an increased knowledge of disease. Moreover, these authors found that three factors were independently related to knowledge of disease: reading resource about AS, general education status, and awareness of an AS support group. Recently, da Rocha Lopes et al.[12] compared the knowledge of disease of the AS patients according to sex (male vs. female), age (≤50 years vs. >50 years), education status (≤9 years vs. ≤12 years vs. >12 years), time since diagnosis (≤4 years vs. >5 years), and monthly salary (≤1,000 Euro vs. >1,000 Euro). These authors reported significant differences in age, education status, and salary regarding to knowledge of disease. Similar to the findings of Claudepierre et al.[11] and da Rocha Lopes et al.,[12] education status

was found to be related to knowledge of disease in our study. As expected, the level of knowledge increased as the education status of the patient increased. This relationship can be explained by the fact that individuals with high education status are more willing to seek information about their disease to ensure a more effective disease control.

In their study, da Rocha Lopes et al.[12] also suggested to investigate the correlation between disease knowledge and disease-specific measurements such as the Bath indices and the perception on the QoL to understand whether the severity the symptoms leading a better level of knowledge about disease. In this manner, the BASDAI which measures disease activity, the BASFI which evaluates the functional status, and the ASQOL questionnaire which evaluates QoL of the patients were evaluated in the present study. According to the results of our study, no significant correlation was observed between the level of knowledge and disease-specific assessments. It seems that the severity of symptoms, level of functionality, or QoL do not pave the way for acquiring more knowledge on the disease itself. However, the mean values of these tools were low in the present study. This finding indicates that the patients are not affected by the disease extensively. Nonetheless, a future study on more affected AS patients would provide a better understanding on the possible relationship between the knowledge of disease and disease-specific measures.

The limitations of the present study include the lack of the income evaluation and the lack of an evaluation according to previous treatment experiences of the patients, such as physiotherapy. Also, not using the Ankylosing Spondylitis Disease Activity Score, which has been shown to be more sensitive than the BASDAI, as a measure of disease activity can be regarded as another limitation. However, the routine practice includes BASDAI evaluation in the centers where the study was conducted, as some of the patients do not have routine blood tests.

The main strength of the present study is that the relationship between the questionnaire and BASFI, BASDAI, and ASQOL was examined for the first time and the sample size was larger than the studies of Lubrano et al.[10] and da Rocha Lopes et al.[12]

In conclusion, our study results show that the Turkish version of the Assessment of Knowledge in Ankylosing Spondylitis Patients by a Self-Administered Questionnaire is a valid and reliable tool to determine the level of knowledge in AS patients.

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