

Reliability and Validity of the Turkish Version of the Multiple Sclerosis Knowledge Questionnaire

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ABSTRACT

Introduction: Multiple Sclerosis Knowledge Questionnaire (MSKQ) is a self-administered inventory assessing patients' knowledge about Multiple Sclerosis. In this study, we aimed to test the reliability and validity of MSKQ in Turkish patients.

Methods: Patients with Multiple Sclerosis who attended an education seminar in our university hospital were enrolled in the study.

Results: Fifty-eight patients completed and returned the questionnaire twice, before and after the seminar. Mean number of items that were answered correctly in the first round was 12.8 (5.2), which increased to 18.7 (3.2) in the second round after the seminar. This increase was found to be significant ($p < 0.01$).

Conclusion: Questions regarding general characteristics of the disease were found to be answered correctly more often than those questions regarding diagnostic and treatment options. This finding indicates that patients may be more interested in the general characteristics of the

disease and in the factors that may have started the disease process. Higher number of incorrect answers regarding diagnostic and treatment strategies may be caused by a lack of interest on the part of the patient who may perceive these subjects to be too complex or who may choose to leave decision-making to healthcare professionals. Also, physicians may be unable to inform patients in these areas because of a lack of time or resources. New molecules developed for the treatment of Multiple Sclerosis makes it even more difficult for patients to follow and form their own opinions about the treatment process. These results show us that patient education is essential and our patients need more educational resources, especially regarding treatment options. The significant increase in the number of correct answers after the education seminar supports the need for broader patient education ($p < 0.01$). Turkish version of MSKQ is a reliable and valid measure for assessing patients' level of knowledge.

Keywords: Multiple sclerosis, surveys and questionnaires, diagnostic self-evaluation

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INTRODUCTION

Multiple sclerosis is an inflammatory demyelinating disease of the central nervous system. It is one of the leading causes of progressive disability in adults. Etiology of Multiple Sclerosis is still under investigation although it is known that various genetic and environmental factors contribute to its pathogenesis (1). Demyelination followed by axonal injury in the central nervous system causes gradual neurological dysfunction and disability in affected individuals. Prevalence of Multiple Sclerosis is 2-150/100,000 worldwide, showing great variation in different geographical regions (2). Multiple Sclerosis is usually diagnosed between 20 and 40 years of age and although some patients display more limited and temporary symptoms, it is usually associated with psychiatric disorders, decreased quality of life as well as physical disability (3).

OBJECTIVE

Patient education and participation in the treatment process has been shown to be beneficial in various chronic conditions (4). It is also necessary to educate patients about their disease to be able to better include them in the decision-making process and tailor treatments according to their individual situation. There are few studies investigating

Highlights

- Turkish version of the Multiple Sclerosis Knowledge Questionnaire is reliable.
- Turkish version of MSKQ is sensitive to educational activities.
- Patients need more educational materials related to their disease.

patients' levels of knowledge regarding Multiple Sclerosis etiology and treatment strategies. Giordano et al. (5) developed and validated the Multiple Sclerosis Knowledge Questionnaire (MSKQ), a 25-item self-administered questionnaire assessing patients' knowledge about the disease. In this study, we aimed to test the reliability and validity of MSKQ in Turkish patients with Multiple Sclerosis. In this way, it has been attempted to gain information on knowledge about Multiple Sclerosis for planning strategies to promote health in this population.

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METHODS

Turkish MSKQ

The original questionnaire was developed and validated for Italian patients by Giordano et al. (5). It is a 25-item, self-administered questionnaire, which takes about 20 minutes to complete. Scoring is done by summing the number of correct answers. The original study was published in English and we used the English version of the questionnaire for adaptation to Turkish.

The MSKQ was translated into Turkish by three Turkish physical medicine and rehabilitation doctors who are proficient in English. They met to determine the translation that best reflected the meaning of English items. English back-translations from Turkish were completed, separately, by two official linguists who had no prior knowledge of the contents of the original version of the MSKQ. Finally, they met to discuss and decide on the translations. The final version of the Turkish MSKQ was compared with the original English version and both versions appeared to be identical. Initially 5 Multiple Sclerosis patients were asked to answer this first version of the questionnaire and report any difficulties in understanding the items. Their feedback was used to give the questionnaire its final shape.

Subjects and Study Design

For the validation stage, patients that were diagnosed as having Multiple Sclerosis in our University Hospital and who attended the annual Multiple Sclerosis patient education seminar were enrolled into the study. Every year our University Hospital organizes a Multiple Sclerosis patient education seminar with the participation of physicians, nurses, and other health personnel from different departments such as neurology, physical medicine and rehabilitation, urology, and psychiatry. Participants were informed about the questionnaire and the validation study and those who accepted to participate in the study were asked to sign a written consent form. Patients were given a dossier with two copies of the questionnaire inside and were asked to answer the first questionnaire immediately, before the seminar began, which lasted for 4 hours. They were also asked to repeat the questionnaire after the end of the last lesson of the day. The researchers also recorded patients' demographic and disease characteristics including disease duration and Expanded Disability Status Scale (EDSS) (6).

The study was performed in accordance with the Declaration of Helsinki, approved by local ethics committee of our university hospital (Ethics committee decision number 16-4.1/19).

Statistical Analysis

Analyses were carried out using SPSS ver. 20.0 (IBM Corporation, New York, USA). Descriptive statistics were used to analyze patient and disease characteristics. Before statistical analyses, all answers were checked and evaluated by item, concerning missing responses and multiple responses. For the reliability of the questionnaire, internal consistency was evaluated by the coefficient alpha (α) or Cronbach's coefficient, and if the Cronbach's coefficient value was greater than 0.7, it was considered as an acceptable internal consistency (7, 8). To assess the distribution of correct and false answers and the levels of significance, Chi-square test was used. To compare the two questionnaires answered by the same patient before and after the seminar Wilcoxon signed-rank test was used. The existence of correlation between increase in the number correct answers to each question and patient characteristics was also analyzed. Significance was set at $p < 0.05$.

RESULTS

Fifty-eight patients completed and returned the questionnaire twice,

Table 1. Demographic and disease characteristics of the participants (n= 58)

Sex, women n (%)	46 (79.3)
Age, years, mean (SD)	42.3 (9.6)
Education n (%)	
Elementary	14 (24.1)
Middle school	2 (3.4)
High school	15 (25.9)
College/university or higher	27 (46.6)
Current employment status n (%)	
Blue-collar worker	5 (8.6)
White-collar worker	20 (34.5)
Self-employed	4 (6.9)
Retired	7 (12.1)
Homemaker	20 (34.5)
Other	2 (3.4)
Marital status n (%)	
Married	46 (79.3)
Single	9 (15.5)
Widowed	3 (5.2)
Can speak a foreign language n (%)	
English	22 (37.9)
French	2 (3.4)
German	3 (5.2)
Other	0
Multiple Sclerosis type n (%)	
Relapsing and remitting	44 (75.9)
Primary progressive	4 (6.9)
Secondary progressive	10 (17.2)
Source of information about disease n (%)	
Physician	56 (96.6)
Brochures	8 (13.8)
Internet	36 (62.1)
Media other than internet	7 (12.1)
Sources in foreign languages	7 (12.1)
Duration of symptoms, years, mean (SD)	8.4 (5.7)
Time since diagnosis, years, mean (SD)	6.3 (4.9)
EDSS score, mean (range)	2.3 (0-6)
SD, standard deviation; MS, multiple sclerosis; n, number; EDSS, expanded disability status scale.	

before and after the patient education seminar. Demographic and disease characteristics of the participants are presented in Table 1. Patients had a mean age of 42.3 ± 9.6 and 79.3% were women. Their EDSS scores ranged between 0 and 6. No subjects missed more than 1 item in the questionnaire. Cronbach's alpha was 0.88.

The number and proportion of correct answers to each question is presented in Table 2. Mean number of items that were answered correctly in the first round was 12.7, which increased to 18.6 in the second round after the seminar. This increase was found to be significant ($p < 0.01$).

There was a positive correlation between the number of correct answers and subjects' level of education ($p < 0.05$). No other significant correlation was detected.

Table 2. Number of correct responses before and after the educational seminar

Content	Correct response first time n (%)	Correct response second time n (%)	
1. Organs involved	48 (82.8)	55 (94.8)	
2. CNS composition	25 (43.1)	44 (75.9)	
3. Prevalence	18 (31)	46 (79.3)	
4. Lifespan	32 (55.2)	55 (94.8)	
5. Immune disease	39 (67.2)	55 (94.8)	
6. Contagiousness	55 (94.8)	57 (98.3)	
7. Etiology	12 (20.7)	55 (94.8)	
8. Genetics 1	31 (53.4)	44 (75.9)	
9. Genetics 2	14 (24.1)	39 (67.2)	
10. Myelin/axon*	33 (56.9)	27 (46.6)	
11. Onset age	36 (62.1)	53 (91.4)	
12. Gender	37 (63.8)	52 (89.7)	
13. Myelin	38 (65.5)	49 (84.5)	
14. Diagnosis 1	23 (39.7)	40 (69.0)	
15. MRI 1	48 (82.8)	55 (94.8)	
16. MRI 2*	22 (37.9)	21 (36.2)	
17. MRI 3	45 (77.6)	56 (96.6)	
18. CSF 1	26 (44.8)	46 (79.3)	
19. CSF 2	13 (22.4)	36 (62.1)	
20. Diagnosis 2	32 (55.2)	44 (75.9)	
21. Course 1	18 (31.0)	33 (56.9)	
22. Benign MS	16 (27.6)	41 (70.7)	
23. Pregnancy	23 (39.7)	50 (86.2)	
24. Therapy 1	44 (75.9)	52 (89.7)	
25. Therapy 2	12 (20.7)	30 (51.7)	
	First round	Second round	p
Number of correct answers, mean (SD) ^a	12.8 (5.2)	18.7 (3.2)	<0.01

^aWilcoxon signed ranks test; CNS, Central nervous system; CSF, cerebrospinal fluid; MRI, magnetic resonance imaging; MS, multiple sclerosis; SD, standard deviation.

DISCUSSION

Original researchers reported MSKQ to have a low reading difficulty and low burden on the patients (5). None of our subjects missed more than 1 item which supports its understandability and legibility in Turkish as well.

Giordano et al. also reported some items that were concerned with basic knowledge about Multiple Sclerosis to be answered correctly by the majority of the patients. Although some of those questions were also answered correctly by our subjects, the proportion of correct answers were not as high in our study when compared with the original study (5).

Questions regarding the anatomical distribution of disease involvement as well as general characteristics of the disease such as gender distribution and age of disease onset were found to be more correctly answered than those questions regarding diagnostic and treatment options. This finding indicates that patients may be more inclined to ask questions and read about the general characteristics of the disease and their interest lies in the factors that may have started the disease process. On the other hand, diagnostic and treatment strategies are not as well known by the patients, this may be caused by either lack of interest on the part of the patient who may perceive these subjects to be too complex or who may choose to leave decision-making to healthcare professionals. Also, healthcare workers may not inform patients in these areas, either because of a lack of time or resources, or they may find

giving detailed technical information to patients unnecessary. Every year new molecules are developed and tried for the treatment of Multiple Sclerosis. These developments are a welcome addition to our inventory of possible treatment options but at the same time create more confusion for the patients who are already having difficulties processing complex treatment choices and decisions.

We have shown that, similar to its Italian version, Turkish version of MSKQ is sensitive to an educational intervention and may be used to assess the effectiveness of educational interventions. We did not detect a relationship between gender and the number of correct answers, unlike the original study where it was reported that women scored higher on the questionnaire. The only significant correlation was found to be between the level of education and the MSKQ score, which was to be expected. We detected a positive correlation between education level and number of correct answers both before and after the seminar ($p<0.05$).

Ghojzadeh et al. (9) reported MSKQ scores to be negatively correlated to fear of progression and positively correlated to social support and physical health.

Most subjects in our study were active individuals with lower EDSS scores that were able to attend a day long educational seminar. Also, patients had different disease durations and educational levels. Still the significant increase in the number of correct answers after the educational seminar shows the questionnaires sensitivity to education through this heterogeneous group. Most patients in our patient group had received high school or higher education (72.5%). This is higher than the average value for Turkey. The increase in the number of positive answers was more pronounced in those patients with lower education levels and this correlation was found to be significant ($p<0.05$).

Multiple Sclerosis is a chronic disease that causes disability in young and middle-aged individuals and there is a reported increase in its incidence (10). Patients' increased knowledge about the disease is known to be correlated with lower anxiety, depression, tiredness, and pain levels (11, 12). Although our main goal was to assess the validity of MSKQ and also the effect our seminar had on patients' level of knowledge about their disease, the results also shows us that our patients still need more educational resources, especially regarding treatment options and prognosis to enable them to be an active part of the shared medical decision-making process.

The Turkish version of MSKQ is a reliable and valid measure for assessing patients' level of knowledge about their disease which indicates that it can be used in clinical and epidemiological research.

This study was presented as a poster at the 11th Neuroimmunology Symposium (Antalya) between 02-05 April 2020.

Ethics Committee Approval: Approval for this study was obtained from the Ege University Medical Faculty Hospital Local Ethics Committee (decision no. 16-4.1/19).

Informed Consent: Participants were informed about the questionnaire and the validation study. Written consent was obtained from the participants.

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Conflict of Interest: There is no conflict of interest in our study.

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