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Translation and Validation of the Turkish Version of Multiple Sclerosis Treatment Adherence Questionnaire (MS-TAQ)

Multiple Skleroz Tedaviye Uyum Anketi (MS-TAQ)'nin Türkçe Versiyonu ve Geçerliği

Öznur USTA YEŞİLBALKAN[1], Öznur ERBAY[1], Ayşe Nur YÜCEYAR[2]

[1]Department of Internal Medicine Nursing, Ege University Faculty of Nursing, İzmir, Turkey
[2]Department of Neurology, Ege University Faculty of Medicine Hospital, İzmir, Turkey

ABSTRACT

Introduction: Poor adherence is widely observed in MS as in other chronic diseases; therefore, improving adherence should be a significant treatment objective. Therefore, it is important to determine the causes of nonadherence and to make improvement plans by establishing a special measurement tool for MS patients. The aim of this study is to investigate validity and Turkish equivalence of The Multiple Sclerosis Treatment Adherence Questionnaire (MS-TAQ) that developed by Paul Wicks and Michael Massagli in 2009.

Methods: The sample of the methodological study comprised 198 MS patients who stayed in University Faculty of Medicine, Department of Neurology, MS clinic between July 2016 and February 2017. In the research, "Data Collection Form" and "MS-TAQ" was used. To conduct this study, permission was obtained from the university ethics committee and the hospital administration. All participants in the study were informed of the study's purpose and their role.

Results: Translation procedure (forward and backward) and pre-test were performed for translation equivalence and linguistic adaptation. MS-TAQ's Cronbach alfa coefficient 0.83 were calculated. According to expert's suggestion modifications was made and content validity index was calculated with Davis technic between 1.0–1.4.

Conclusion: As a result, "MS-TAQ" has been found a sufficiently valid and reliable tool in Turkey.

Keywords: Multiple sclerosis, adherence, validity

ÖZ

Amaç: Diğer kronik hastalıkların yanında MS'de de zayıf uyum yaygındır ve uyumun iyileştirilmesi önemli bir tedavi hedefi olarak tanımlanmalıdır. Bu nedenle MS hastalarına özel bir uyum ölçme aracının oluşturularak uyumsuzluk nedenlerinin saptanması ve buna yönelik iyileştirme planlarının yapılması önemlidir. Bu araştırmanın amacı, Paul Wicks ve Michael Massagli tarafından 2009 yılında geliştirilen Multiple Skleroz Tedaviye Uyum Anketi (MS-TAQ)'in Türkçe eşdeğerliliğini sağlamak ve geçerliğini belirlemektir.

Yöntem: Bu metodolojik araştırmanın çalışma grubunu, Temmuz 2016 – Şubat 2017 tarihleri arasında bir Üniversite Hastanesi'nin Nöroloji birimindeki MS polikliniğine başvuran, araştırmayı kabul eden ve araştırma sınırlarına uyan 198 MS hastası oluşturmuştur. Araştırmada veri toplama araçları olarak; Birey Tanıtım Formu ve Multiple Skleroz Tedaviye Uyum Anketi kullanılmıştır. Araştırmanın yürütülebilmesi için etik kuruldan ve kurumdan yazılı izin, hastalardan da yazılı onamları alınmıştır.

Bulgular: Anketin dil eşdeğerliğinin sağlanması için Türkçe'ye çevirisi, geri çevirisi ve ön uygulaması yapılmıştır. MS-TAQ anketinin cronbach alfa katsayısı 0.83 olarak bulunmuştur. Anketin kapsam geçerliğini sınamak için uzmanlardan görüş alınarak gerekli değişiklikler yapılmış, Davis kapsam geçerlik indeksi 1.0 ile 1.4 arasında bulunmuştur.

Sonuç: "MS-TAQ" Türk toplumu için yeterli güvenirlik ve geçerliğe sahip bir ölçme aracı olarak bulunmuştur.

Anahtar Kelimeler: Multipl skleroz, uyum, geçerlik

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INTRODUCTION

Multiple sclerosis (MS), the most prevalent neurological disability, is an autoimmune-mediated disorder that affects the central nervous system in young adults (1). The MS patient number ranges between 1 and 2.5 million worldwide with approximately 400.000 in the USA. MS occurs twice as frequently in females and most commonly between ages 20 and 50 (2). It has a higher incidence in temperate zones, particularly in North Europe, Canada, and North America. Its prevalence and incidence are unknown in Turkey; however, it is thought to affect 30.000–35.000 people (3). No definite treatment exists for MS; and treatment includes lifelong disease and symptom management. Recurrences are controlled by Disease Modifying Therapy (DMT) including the first line treatments with Interferon beta-1a [Avonex®, Rebif®], interferon beta-1b [Betaferon®, Extavia®], and glatiramer acetate [Copaxone®]. Early treatment using DMT reduces recurrence frequency, disabilities' progression, and hospitalization frequency (4).

Correspondence Address/Yazışma Adresi: Öznur Usta Yeşilbalkan, Department of Internal Medicine Nursing, Ege University Faculty of Nursing, İzmir, Turkey • **E-mail:** oznurustayesilbalkan@hotmail.com
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Adherence means patients follow a regular dose regime (5). The World Health Organization (WHO) defines adherence to long-term treatments as using the medicines, following the diets, maintaining the lifestyle changes, and complying with healthcare personnel's recommendations (6). Medication adherence is required for patients to benefit fully from the treatment. Non-or poor medication adherence may lead to unsuccessful treatments and increased costs (6). Patients receiving DMT have nonadherence rates of 6–46%, patients most likely to quit therapy in the first 6 months (4, 5).

Although no standard exists, the three main assessment methods for medication adherence are patient self-reports, other people's reports, and clinical observations (7). Non-adherence to medication is imprecisely defined, ranging from less than 80% or 90% of the prescribed doses to missing even a single dose (8).

Poor adherence to MS medication has negative outcomes. Long interruptions in MS medication increase the recurrence risk. Improving adherence should be a significant treatment objective (5). Non or poor adherence is widely observed in MS as in other chronic diseases. Therefore, developing a questionnaire of specific to MS treatment has become essential to quantify adherence and barriers to achieving adherence. The aim of this study was to evaluate the reliability and validity of the Turkish version of the MS-TAQ in patients with MS.

METHODS

Design, Sample and Data Collection

This study is methodological and descriptive survey design. The study was conducted with patients from multiple sclerosis outpatient clinic in a university hospital between July 2016 and February 2017 in Izmir. The criteria for inclusion in the study were set as follows: diagnosed with MS, 18 years of age or over, received DMT for at least one month, had an EDSS score ≤6.5 assessed by a neurologist, able to speak, read and understand Turkish, want to join in this study. After Information on the study was given the patients, they were asked to fill MS-TAQ during waiting for examination in the outpatient clinic.

The data were collected by using the "Demographic Characteristics Form" (including items gender, educational level, marital status, having a children age, duration of the disease, disease type, DMT types) and the "Multiple Sclerosis Treatment Adherence Questionnaire (MS-TAQ)". This tool which was designed by Wicks et al. (2011), to assess the psychometric performance, Wicks and colleagues (2011) analyzed the dimensions (DMT-Barriers, DMT-Side Effects and DMT-Coping Strategies) using Cronbach's alpha (9). Barriers dimension is concerned with patients reporting that missing at least one dose of the previous 28 days. This dimension is about the importance of 13 barriers to adherence and rated based on 4-point scale from "not important at all" to "extremely important" in missing a dose. DMT-Side Effects dimension is about the side effects caused by treatment and 10 side effects rated on a 5-point scale from "never" to "all or nearly all of the time" were asked to report the frequency by patients. At the end, in the DMT-Coping Strategies dimension, all patients were asked on a dual yes/no format. There are questions about 7 coping mechanisms that patients use to reduce the side effects they experience within 28 days in this dimension. (9).

The Cronbach alpha coefficients of the DMT-Barriers and DMT-Side Effects dimensions were 0.82 and 0.86. For the dimension of DMT-Coping Strategies, Cronbach's alpha value was as low as 0.40. Wicks and colleagues think that the reason for this low value is a consequence of the dual response choices and the limited range of tool (9).

DATA ANALYSIS

The SPSS 21.0 (SPSS Inc.) program was used for data analysis. Descriptive statistics (means, standard deviations, frequencies, percentages) were used to show the define of the socio-demographic and disease-related characteristics. Statistical significance was set at $p<0.05$.

Because the MS-TAQ is not a scale but a questionnaire, it has been consulted with experts in "Measurement and Evaluation in Education" for validity and reliability analysis steps. According to the opinions of experts, only the language and content validation of the questionnaire was sufficient. However, we wanted to calculate the internal consistency coefficient of the questionnaire and we used the Cronbach alpha coefficient as a reliability analysis. Language validity and the content validity stages were used for validity analysis. Translation from English to Turkish and from Turkish to English to determine the language validity. For the content validity, expert opinions were consulted by Davis technique and the content validity index (CVI) was calculated. Also, we wanted to check Cronbach's alpha reliability coefficient to determine internal consistency.

Translation Procedures

The translation and re-translation process was carried out after the approval of those who prepared the Multiple Sclerosis Treatment Adherence Questionnaire (MS-TAQ) was received. The English Tool was translated into Turkish by a researcher, four doctors and five nurses. Later, the final Turkish version of the Tool was translated back into English by a native English speaker. The translated (MS-TAQ) was then compared with the original version and it was determined that they were quite similar in terms of meaning.

Content Validity

Expert opinion was received for content validity (10–12). An expert panel of 10, which was informed about the translated tool, the questionnaire and the content of the questionnaire, was presented with the form to measure the content validity including the item clarity. The expert panel consisted of 9 teaching staff members who had worked in multiple sclerosis services and were teaching at the nursing school, and one doctor. Each expert was asked to examine all items in the last version of the translated MS-TAQ, to compare it with the original and evaluate it using a four-item scale. The content validity index (CVI) was calculated using the commonly used Davis technique. The items on this technique are as follows: 4 = very suitable, 3 = suitable but some adaptations related to expression are required, 2 = only suitable if the prepositions are re-adapted, and 1 = not suitable. Then, for each item, the CVI was calculated according to the number of experts who are rating 3 or 4 (sorting by sorting scale according to relevant and unrelated options) and dividing by the total number of experts. A CVI score of 0.80 and above was considered as acceptable. For each item the evaluation was made as follows: If the CVI score is higher than 0.79, the item was accepted as appropriate. If it is between 0.70 and 0.79, it will have to be examined again. If it is lower than 0.70, it will be removed. (13, 14).

At the next stage, MS-TAQ was applied, for the first time, to a sample group of 20 people with MS disease. The purpose of this process was to evaluate the questionnaire in terms of clarity of terminology and instructions. This process was followed by interviews with patients in order to measure the intelligibility of each item in the questionnaire. Patients were asked to comment on each item so the questionnaire could be improved. All patients reported that the questionnaire was understandable, readable and culturally appropriate. It was observed that there were no problematic questionnaire items in the Turkish version of the MS-TAQ.

Internal Consistency

Cronbach's alpha coefficients were used to assess the internal consistency of the MS-TAQ. In order for a Likert-type measuring instrument to be valid, the Cronbach's alpha coefficient should be as close to 1.0 as possible, so that the reliability of the questionnaire can be shown through measurement consistency. For a well-developed measuring instrument to be acceptable, the lowest score can be 0.80 (15, 16). The reliability of the MS-TAQ was evaluated by means of the Internal Consistency. Internal consistency was determined by using Cronbach's alpha coefficient. Generally recognized values for Cronbach's alpha are described as substantial ($0.81<\alpha<1.00$), moderate ($0.61<\alpha<0.80$), fair ($0.41<\alpha<0.60$) and slight ($0.0<\alpha<0.40$) (16).

Ethical Considerations

Permission to use of the MS-TAQ and translate it to Turkish was granted by the developer, Paul Wicks. The permission for the study was received from the Ethics Committee of Ege University Nursing Faculty (decision number 2016-206/13-06-2016) and the institution in which the study was conducted. In addition, the participating patients were informed about the study and their written consent, which stated that they voluntarily participated in the study, was obtained. They were informed that their names and identities would be kept confidential and that the information they provided would not be disclosed.

RESULTS

Characteristics of Sample

In this study, 252 patients with MS were interviewed for participation. Fifty-four patients were excluded from the study due to their inability to meet inclusion criteria. Participants (n=43) used oral medicine, 2 of them had an EDSS score ≥6.5, 3 of them had no ability to read and write, 2 of them wasn't 18 years of age or older and 4 of them did not to want to join this study. Thus, this study was completed with 198 participants.

Table 1. Patient demographic characteristics and clinical features

Demographic characteristics	**n**	**%**
Gender		
Female	154	77.8
Male	44	22.2
Education level		
Primary	80	40.4
High	59	29.8
University	59	29.8
Marital status		
Married	143	72.2
Single	55	27.8
Having Children		
Yes	148	74.7
No	50	25.3
Disease characteristics	**n**	**%**
Disease duration		
<10 years	32	16.2
>10 years	166	83.8
Disease type		
RRMS	185	93.4
SPMS	13	6.6
DMT type		
Copaxone	70	35.4
Avonex	21	10.6
Rebif	51	25.8
Betaferon	56	28.3

DMT, disease modifying therapy; RRMS, relapsing remitting multiple sclerosis; SPMS, secondary progressive multiple sclerosis.

Participants had a mean age was 44±2.4 years, 77.8% were male, 40.4% had a primary educational level and 74.7% were married. Also, In Table 1 are shown disease-related characteristics of the patients.

Validity

Content validity index was calculated with Davis technic. In this study, CVI scores which evaluated by experts was found higher than 0.80 for the MS-TAQ (between 1.0 and 1.4).

Reliability

The Cronbach's alpha coefficient for the MS-TAQ in this research was founded as 0.83. Also, Cronbach alpha for 3 dimensions of the MS-TAQ Turkish version was found for DMT-Barriers: 0.82; for DMT-Side Effects: 0.76; and for DMT-Coping Strategies: 0.61.

DISCUSSION

The MS-TAQ is an instrument that measures a patient's adherence to treatment (9). The results of this study show that the MS-TAQ is a reliable and valid tool for measuring treatment adherence and can be used as a simple, well-accepted, easily-fillable tool in studies with Turkish multiple sclerosis patients.

The findings show that the psychometric properties of the Turkish version of MS-TAQ are promising. Expert opinions on the Turkish adaptation of the MS-TAQ indicates that there is no need to adapt or modify the content. In addition, a larger sample size is needed to provide semantic equilibrium.

The scale was translated by a native-English speaker who also spoke Turkish. In interpreting intercultural scales, the interpreter has to closely observe translation techniques and re-translation techniques (12, 17). The re-translation of the scale (translation of the latest Turkish version back into English) was done by a linguist after the translation from English into Turkish was completed. The re-translated text was compared with the MS-TAQ, and the necessary corrections were made to each item in the questionnaire. The translation process was meticulously carried out to ensure equivalence.

The most important factor in the evaluation of a measuring instrument is validity. Validity is reported as a measure of the accuracy of a feature that is intended to be measured. Validity can be evaluated in three ways: content validity, criterion-related validity and construct validity (18–20). In this study, the MS-TAQ was evaluated using the content validity.

It is important to note that the "consensus among experts" indicates that the questionnaire is holistic, that the materials reflect the parts to be measured and that the content validity is achieved (12, 17). The validity of the measuring instrument carried out by an expert committee in this study seems to be high enough.

Reliability is the ability of a measuring instrument to measure accurately (21). Internal consistency was used for the reliability of the MS-TAQ in this study. Cronbach's Alpha was used for the internal consistency of the MS-TAQ.

Cronbach's alpha values of MS-TAQ's ranged between 0.61 and 0.83. Current study's results are between the acceptable values the original study proposed by Wicks et al. found the Cronbach's alpha value to range between 0.40 and 0.86 (9). DMT-Coping Strategies' Cronbach alfa result was found low in this study too (α=0.61). The Turkish version's MS-TAQ Cronbach's alpha values are similar to those of the original version. In addition, MS-TAQ's validity was confirmed in a study by Pouryusef (2012) in Iran, and its reliability was approved with Cronbach's alpha of 0.87 (22).

Another study which use MS-TAQ for treatment adherence was found Cronbach's alpha of 0.85 (23).

In the comparison of the Cronbach's alpha value of our study with that of the original tool and other versions, the Cronbach alpha coefficient for the total questionnaire was similar and bit lower in our study (α=0.83).

CONCLUSION

According to the results obtained, the current Turkish version of the MS-TAQ scale has adequate reliability and validity for the use in samples of multiple sclerosis in Turkey. This study also provides intercultural evidence that the MS-TAQ can be used in another country with a different cultural background. With the existing Turkish version of the MS-TAQ, studies that examine and compare the DMT-treatment in multiple sclerosis patients in Turkey can be conducted. This study marks important progress because participation in treatment plays an important role in the effectiveness of nursing care and in improving the quality of life of patients.

Ethics Committee Approval: The permission for the study was received from the Ethics Committee of Ege University Nursing Faculty (decision number 2016-206/13-06-2016) and the institution in which the study was conducted.

Informed Consent: The participating patients were informed about the study and their written consent, which stated that they voluntarily participated in the study, was obtained.

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