

Validity and Reliability Study of the Turkish Version of the Subjective Handicap of Epilepsy

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Abstract

Objective: This study aimed to investigate the validity and reliability of the Turkish version of “The Subjective Handicap of Epilepsy (SHE)” questionnaire.

Methods: Upon the permission from the authors of the questionnaire, the English questionnaire was separately translated into Turkish by two neurologists who had a native language of Turkish and who had a valid certificate for English. A single translation was created by combining these two translations by another neurologist specialized in epilepsy. Afterwards, the Turkish translation was translated back to English by two other neurologists, blind to the original questionnaire. Internal consistency of the test was measured by using the Cohen’s kappa coefficients. The questionnaire was interpreted in 20 patients and was repeated after 15 days. After the intraclass consistency coefficient between the two evaluations was determined to be positive, it was applied to a total of 252 patients during the study period.

Results: A total of 252 patients (146 women- 57.9%, 106 men- 42.1%) with a mean age of 33.4+11.5 years were included in the study. The mean age of epilepsy onset was 19.0+10.9 years, and the mean disease duration was 14.4+11.2 years. The internal consistency of the scale was found to be highly consistent with Cohen’s kappa value of 0.864. The intraclass correlation coefficient value for the test-retest reliability was found to be excellent, with a value of 0.945 for the whole questionnaire ($p<0.001$).

Conclusion: We observed that the Turkish version of the SHE is a valid and reliable assessment for determining disability in epilepsy patients.

Keywords: Epilepsy, disability, validity, reliability, handicap

INTRODUCTION

Epilepsy is a chronic disease of the central nervous system that occurs in the form of attacks and affects people all over the world. Epilepsy is a condition characterized by sudden, recurrent epileptic seizures resulting from abnormal and excessive electrical discharge in cortical neurons. The probability of a person experiencing a single epileptic seizure in their lifetime is 10%. The incidence of epilepsy is 50.4 to 81.7 per 100,000 people per year.¹

There are approximately 50 million people with epilepsy worldwide, and approximately 30-40% have seizures that are resistant to treatment with anti-seizure medications.^{2,3} The International League Against Epilepsy (ILAE) defines resistant epilepsy as a condition in which seizure control cannot be achieved despite the use of two or more appropriately selected, appropriately used and tolerated anti-seizure medications (monotherapy or combination).⁴

Epilepsy, especially in its resistant subtypes, not only disrupts the patient’s daily living activities but also creates disability by seriously restricting the person’s participation in social and community life.⁵ In epilepsy, comorbid conditions, seizure frequency and severity, treatment modality, medication and side effects, socio-economic status and stigmatization are considered to be the most important factors affecting the quality of life of patients.⁶ Quality of life in patients is affected by psychosocial factors rather than seizures. Quality of life assessment is frequently preferred to evaluate the effect of epilepsy on the individual. Although quality of life scales are accepted as an indirect measurement of disability, they do not adequately assess the effects of epilepsy on social and community participation.

The World Health Organization defines the concept of disability as “a disadvantaged situation that limits or prevents the fulfillment of one or more roles that are considered normal, depending on age, gender, social and cultural factors, as a result of an impairment or disability”.

In our country, the legislation regarding the definition of disability and how health board reports should be submitted is regulated by the ‘Regulation on disability assessment for adults’ published by the Council of Ministers in the official newspaper dated 20 February 2019 and numbered 30692.⁷ In this regulation, the concept of disability refers to ‘an individual who is affected by attitudes and environmental conditions that limit his/her full and effective participation in society on equal terms with other individuals due to various levels of loss of physical, mental, spiritual and sensory abilities’.

Today, disability assessments are carried out in accordance with the legislation determined by the Ministry of Health (Figure 1). As a

matter of fact, many physicians and researchers are interested in the diagnosis and treatment of epilepsy consider the current disability rating for epilepsy patients as inadequate. When determining disability in patients with epilepsy, not only the frequency of attacks but also other problems that may accompany epilepsy should be considered and these patients should be evaluated in more detail. In 1998, O’Donoghue et al.⁸ developed “The Subjective Handicap of Epilepsy (SHE)” scale in English, which is a more comprehensive measurement model based on the disability concept of the World Health Organization. This study aimed to assess the validity and reliability of the Turkish version of the “SHE” questionnaire.

METHODS

Study Design and Participants

Patients diagnosed with epilepsy who had applied to the Department of Neurology Epilepsy Center for two years were included in the study. The inclusion criteria were (i) definitive diagnosis of epilepsy; (ii) age between 18 and 65 years; and (iii) agreement to participate in the study. Patients with other diseases that could cause disability were not included in the study.

In terms of treatment response, patients were evaluated as treatment responsive if they had been seizure-free within the last 2 years and as treatment unresponsive if not.

The following permission from the authors who created the SHE scales for this study, a Turkish adaptation was made (Appendix 1). This scale, developed by O’Donoghue et al.⁸ specifically for health problems related to epilepsy, consists of 32 items under six subheadings. These items are: (i) “Work and activity” (eight items), (ii) “Social and personal” (four items), (iii) “Physical” (four items), (iv) “Self-perception” (five items), (v) “Life satisfaction” (four items) and (vi) “Change” (seven items) subscales. The questionnaire takes approximately 10 minutes. Each item is scored between 1-5 points using the Likert measurement method. After item scores are collected, the subscale score is linearly converted to a scale of 0-100. Low scores indicate poor disability, and high scores indicate reduced disability (Appendix 2). The SHE questionnaire has high internal consistency and reliability. The test-retest reliability of the scale was found to be high, and intraclass correlation coefficients (ICC) were found to be between 0.83 and 0.89.

In our study, the translation-back-translation method was applied to adapt the scale to Turkish. The English questionnaire was translated into Turkish separately by two neurologists who are native Turkish speakers and have English certificates. The two translations were combined into a single translation by a neurologist who specializes in epilepsy. It was then translated back into English by two other neurologists, regardless of the original Turkish translation. The test, translated into Turkish, was applied to a total of 20 patients and repeated 15 days later. The questionnaire, whose question and questionnaire consistency were found to be positive in the analysis of preliminary results, was applied to a total of 252 patients who met the inclusion criteria of the study during the two-year study period.

Statistical Analysis

Microsoft Excel 2016 and Statistical Package for the Social Sciences (SPSS-version 21.0) were used for statistical evaluation. Nominal

EPİLEPSİ (Uygun ve yeterli tedavi altında)

1-Nöbeti olmayan ancak nöbet geçirme riski olanlar	5
2-Günlük aktiviteleri engellemeyen ancak gerçekleştirilmesini güçleştiren nöbetler	15
3-Bazı günlük aktiviteleri engelleyen nöbetler	
a) Seyrek	20
b) Sık	40
4-Günlük aktivitelerin korunma tedbirleri veya başkasının yardımıyla gerçekleştirilmesine izin veren sıklık ve sayıda nöbetler	70
5-Günlük aktiviteleri tamamen engelleyen şiddet ve sıklıkta kontrol edilemeyen nöbetler	90

Figure 1. February 2019, official newspaper, regulation on disability assessment for adults, from the Ministry of Family, Labor, and Social Services and the Ministry of Health, Epilepsy

MAIN POINTS

- The degree of disability in patients with epilepsy is affected not only by the clinical features associated with the disease, the frequency and severity of seizures, but also by psychosocial factors.
- Detailed evaluation of disability in patients with epilepsy is required.
- Turkish version of the Subjective Handicap of Epilepsy is a valid and reliable assessment for determining disability in epilepsy patients.

Table 1. Sociodemographic and clinical characteristics of the patients

Demographic and clinical characteristics	Minimum	Maximum	Mean	Standard deviation
Age (years)	18	65	33,4	11.5
Education (years)	0	15	10.6	4.0
Age at epilepsy onset (years)	1	58	19,0	10.9
Duration of epilepsy (years)	1	60	14,4	11.2

data are expressed as numbers and percentages, and numerical data are expressed as mean + standard deviation. Reliability analysis was performed by calculating internal consistency and test-retest reliability. Internal consistency was determined by calculating Cohen's kappa value. Test-retest reliability was performed by calculating the ICC for each question in the SHE test.⁹ ICC data were classified as poor (<0.50), fair (between 0.50 and 0.75), good (between 0.75 and 0.90), and excellent (above 0.90).¹⁰ A p value of 0.05 or less was accepted as statistical significance.

Ethical Approval

The study was approved by the İstanbul University Cerrahpaşa-Cerrahpaşa Faculty of Medicine Clinical Research Ethics Committee (date: 22.05.2019, no.: 77991). Informed consent was obtained from all patients participating in the study.

RESULTS

Of the patients with epilepsy, 146 (57.9%) were female and 106 (42.1%) were male. The mean age of the whole group was calculated as 33.4±11.5 years. The mean educational level of the patients was 10.6±4.0 years. The mean age at epilepsy onset was 19.0±10.9 years and the mean duration of the disease was 14.4±11.2 years (Table 1). Regarding marital status, 50.4% of the patients were single and 44.8% were married. When the treatment response was analysed, it was observed that 64.8% of the patients had not yet achieved a response, while 35.2% had partial and/or complete response to treatment. A total of 129 (50.8%) patients were followed with monotherapy, and 117 patients (46.6%) had polytherapy; only 6 patients (2.6%) were followed without any anti-seizure medication.

Cohen's kappa value for internal consistency was 0.864 for the entire questionnaire. When considered separately for all questions, it ranged between 0.838 and 0.885 [test statistics (F)=7.252; p<0.001].

According to the ICC data analyzed for test-retest reliability, Question 1, "Has epilepsy caused problems at work in the last 6 months?", Question 2, "Have you ever been unable to go to work due to epilepsy in the last 6 months?", Question 6, "Does epilepsy prevent you from doing the type of work you really want to do?", Question 8, "Does epilepsy cause problems in your relationships with your relatives (e.g., your children, relatives)?" Question 9: "Does epilepsy cause problems in your relationships with your friends?", Question 20: "Has epilepsy prevented you from going out for sightseeing or travelling?" was found to be excellent in terms of score agreement (ICC value >0.90). In all other questions, the agreement was evaluated as good (0.75< ICC value <0.90). No question was observed to indicate poor agreement. In the entire questionnaire evaluation, the ICC was 0.945, and the agreement was found to be excellent (p<0.001; Table 2).

Table 2. Intraclass correlation coefficient for each question in the scale

Questions	ICC	ICC (min-max)	F values	p values
1	0.917	0.893-0.935	12.021	<0.001
2	0.911	0.886-0.930	11.198	<0.001
3	0.891	0.861-0.915	9.204	<0.001
4	0.887	0.855-0.912	8.836	<0.001
5	0.873	0.837-0.901	7.853	<0.001
6	0.911	0.887-0.931	11.292	<0.001
7	0.892	0.861-0.916	9.245	<0.001
8	0.912	0.887-0.931	11.351	<0.001
9	0.903	0.876-0.924	10.335	<0.001
10	0.894	0.865-0.918	9.462	<0.001
11	0.898	0.869-0.920	9.763	<0.001
12	0.827	0.779-0.865	5.796	<0.001
13	0.843	0.798-0.877	6.358	<0.001
14	0.862	0.823-0.892	7.232	<0.001
15	0.845	0.802-0.879	6.459	<0.001
16	0.800	0.743-0.844	4.993	<0.001
17	0.867	0.830-0.896	7.532	<0.001
18	0.874	0.839-0.902	7.963	<0.001
19	0.879	0.845-0.906	8.279	<0.001
20	0.908	0.882-0.928	10.845	<0.001
21	0.880	0.847-0.907	8.354	<0.001
22	0.872	0.836-0.900	7.798	<0.001
23	0.885	0.853-0.910	8.698	<0.001
24	0.894	0.865-0.918	9.476	<0.001
25	0.861	0.822-0.891	7.184	<0.001
26	0.772	0.708-0.822	4.393	<0.001
27	0.821	0.770-0.860	5.581	<0.001
28	0.803	0.748-0.846	5.078	<0.001
29	0.847	0.804-0.881	6.535	<0.001
30	0.855	0.815-0.887	6.915	<0.001
31	0.852	0.811-0.885	6.769	<0.001
32	0.864	0.826-0.894	7.372	<0.001
Total	0.945	0.928-0.957	17.926	<0.001

ICC: Intraclass correlation coefficient, min-max: Minimum-maximum

DISCUSSION

With this study, it has been shown that the internal consistency of the Turkish version of the Subjective Handicap of Epilepsy questionnaire, which is called "The Subjective Handicap of Epilepsy, SHE" in English, is significantly compatible with Cohen's

kappa value of 0.862. The reliability coefficient measured by test-retest was found to be excellent with an ICC value of 0.944. Based on these findings, it was concluded that the Turkish version of the SHE questionnaire is a valid and reliable test for the evaluation of disability in patients with epilepsy.

With the current legislation determined in our country, disability due to epilepsy is evaluated only on the basis of seizure frequency and is inadequate. Moreover, accurate assessment of seizure frequency is not always possible due to difficulties in recognizing seizures by the patient’s relatives.¹¹ On the other hand, epilepsy is a disease that affects almost every aspect of patients’ lives. Patients with epilepsy experience problems in society not only because of seizures but also because of the negative effects caused by the existence of the epilepsy diagnosis. The fear caused by sudden and unexpected seizures, side effects of the drugs used, cognitive impact due to epilepsy, psychosocial impact, and stigma are the main causes of epilepsy-related disability. In addition, epilepsy becomes a serious social disorder due to difficulties in finding or maintaining a job and problems in obtaining a driver’s license.¹² Studies have found that approximately half of epilepsy patients feel stigmatized. Epilepsy is a stigmatized disease worldwide. Although there have been sensitization efforts to reduce stigma among people with epilepsy, there has been limited progress.¹³ Even if epilepsy is treated and seizures are controlled, people experience serious problems in society due to stigma.¹⁴ The negative impact of stigma on the quality of life of epilepsy patients is greater than the impact of the disease itself.¹⁵ In a survey conducted with epilepsy patients, it was determined that the diagnosis of epilepsy most frequently evokes a feeling of fear. This fear has been reported as fear of death, fear of having a seizure and accident while driving, fear of having children witness a seizure, fear of being embarrassed in public, and fear of losing one’s job.¹⁶ In the same survey, the degree to which epilepsy limits life choices and experiences and the stigma epilepsy imposes were the worst things cited by at least a quarter of respondents, while physical problems associated with epilepsy were among the least mentioned problems.

In addition, in our country’s legislation, it is accepted that there is no disability if the disease progresses seizure-free with treatment, and the psychosocial situation due to epilepsy is not evaluated.

More detailed evaluations are needed to better understand the deficiencies of patients with epilepsy, especially in work and social situations. There are limited studies in the literature on quality of life and disability in epilepsy patients. It was thought that it would be appropriate to conduct a Turkish validity and reliability study of the SHE because it evaluates all aspects of epilepsy and has a simple scoring system. O’Donoghue et al.⁸ developed the SHE questionnaire, and in their study using this scale, they reported that even patients with a low number of seizures had high disability.¹⁷ In another study, the effect of extratemporal epilepsy surgery on quality of life was evaluated using the SHE questionnaire before and one year after surgery, and it was suggested that it was a reliable test that well revealed the disability associated with epilepsy and its surgery.¹⁸ In a study conducted by Hopker et al.¹⁹ in 2017 with 30 treatment-resistant temporal lobe epilepsy patients, SHE was used as one of the tests used to evaluate the patients’ quality of life. Researchers found significant correlations between stigmatization, work and social activity, problems in personal and social areas, and SHE scores, and showed that the SHE questionnaire can be used reliably. In the validation study of the questionnaire

conducted in another language, the questionnaire was found to be psychometrically sufficient for both the post-epileptic surgery and drug treatment follow-up groups.²⁰

CONCLUSION

It is clear that the effects of epilepsy on the degree of disability and quality of life should be evaluated not only by the clinical features associated with the disease, the frequency and severity of seizures, but also by psychological and social factors. The SHE questionnaire evaluates additional parameters such as psychosocial factors in the assessment of disability/disability degrees of patients with epilepsy and provides much more detailed information than the evaluation made according to the Ministry of Health Legislation. In this respect, it is important that this survey, whose validity, and reliability we have demonstrated, be widely used in our country. As a matter of fact, conducting numerous prospective studies with a higher number of patients and revealing the “real” disability in patients with epilepsy may enable adjustments to be made in the current legislation.

Ethics

Ethics Committee Approval: The study was approved by the İstanbul University Cerrahpaşa-Cerrahpaşa Faculty of Medicine Clinical Research Ethics Committee (date: 22.05.2019, no: 77991).

Informed Consent: Informed consent was obtained from all patients who participated in the study.

Authorship Contributions

Concept: F.K.M., S.N.Y., Design: G.B.Ş., F.K.M., S.N.Y., Data Collection or Processing: E.K.K., G.K., İ.N.C., E.A.C., Ç.Ö., Analysis or Interpretation: G.B.Ş., Literature Search: E.K.K., G.B.Ş., Writing: E.K.K., G.B.Ş.

Conflict of Interest: Two authors of this article, Seher Naz Yeni, Güray Koç, are member of the Editorial Board of the Archives of Epilepsy. However, they did not take part in any stage of the editorial decision of the manuscript. The editors who evaluated this manuscript are from different institutions. The other authors declared no conflict of interest.

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