Development and validation of the stigma scale for epilepsy in Turkey

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ABSTRACT

Objective: Epilepsy is a chronic disease with an increased risk of stigma. The aim of this study was to investigate the efficacy of a scale developed by the authors to determine the level of stigma in Turkish patients with epilepsy and their relatives.

Methods: In this pilot study, two scales were developed, one consisting of 32 questions for the patients and one of 20 questions for the patients' relatives. Initially, a total of 30 patients with epilepsy and 30 relatives of the patients were included. The Cronbach's alpha coefficient was calculated in a reliability analysis of validity applying the scales to 302 patients and 201 relatives of the patients. The Pearson correlation coefficient was used for the reliability analysis of the test-retest. The *t*-test was used in paired series, and factor analysis was conducted. The correlation between the clinical and demographical data and the stigma scores was evaluated.

Results: The scales were applied to participants twice under the same conditions in one-week interval. In the test-retest analysis, the internal consistency of the scales was high and reliable. In the analysis of the patients, the Cronbach's alpha value of the scale was found to be 0.915. In the factor analysis, the questions were grouped into five factors including social isolation, discrimination, insufficiency, false beliefs, and stigma resistance. The factors with the highest contribution to the stigma level were social isolation and discrimination. In the stigma scores, a significant correlation was found between the age of the patient, frequency of seizures, education status, level of income, and the amount of antiepileptic drugs used. In the analysis of the patients' relatives, the Cronbach's alpha value of the scale was found to be 0.892. In the factor analysis, the questions were classified as discrimination, prejudgments, and false beliefs. The factor which most contributed to the stigma level was discrimination. A significant correlation was found in the stigma scores between sex, education status, marital status, and income distribution.

Conclusion: According to our study results, it is clearly seen that both patients and their relatives suffer from epilepsy-associated stigma. Patients with epilepsy and their relatives are faced with discrimination in society, resulting in social isolation. We, therefore, believe that both patients and their relatives should be informed in detail about discrimination to overcome this challenge.

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1. Introduction

Besides being a clinical disease, epilepsy is a social label for many patients. Several studies have shown that social prognosis is worse than clinical prognosis in patients with epilepsy. Furthermore, stigma is an important factor affecting the social prognosis of epilepsy [1,2]. The reason for the increased stigmatization of epilepsy is the psychosocial consequences resulting from the seizures, rather than the seizures. It has been suggested that the seizures themselves are less limiting in the lives of patients than the psychosocial problems [3].

The diagnosis of epilepsy also brings concerns related to seizures, the need for treatment adherence and compliance, and the phobia related with the reaction of others in society. When erroneous information related to epilepsy and the stigmatization phobia are considered, a diagnosis of epilepsy refers to the transition from being 'normal' to being 'epileptic' [3,4]. The stigma of epilepsy has been shown to correlate with lower sense of self, high anxiety level, and depression [3,5].

In the present study, we aimed to create a scale to determine the level of stigma in Turkey for both patients with epilepsy and their relatives. The approach to epilepsy varies depending on the society, and stigma is directly related to sociocultural structure. As there is no reliable, valid, and comprehensive scale which is suitable for the Turkish population, the authors created a scale according to the social factors of Turkey, rather than those designed for the use in other countries.

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2. Methods

2.1. Participants

The study protocol was approved by the Ethics Committee of Bakirkoy Prof. Dr. Mazhar Osman Mental Health and Neurological Disorders Training and Research Hospital. A written informed consent was obtained from each participant. The study was conducted in accordance with the principles of the Declaration of Helsinki.

The study was performed between February 2015 and October 2015 and included a total of 302 patients who were diagnosed with epilepsy according to the 1989 International League Against Epilepsy (ILAE) criteria and confirmed by electroencephalography, cranial magnetic resonance imaging, and type of convulsion and a total of 201 patient relatives in accordance with the criteria described below. All patients were being followed at the epilepsy outpatient clinic of our hospital.

The participants were selected from those with sufficient intelligence to have no difficulty in comprehension for proper communication. Also, patients included in the study were literate, had no other chronic medical problem or neurological disorder which could affect the stigma perception, except epilepsy, and had not experienced any generalized tonic-clonic seizures, absence, myoclonic seizures, or partial seizures within the last week.

First-degree relatives of the patients, who were over the age of 18 years, were literate and accompanied the patients during outpatient visits, were also included. Patients who were healthcare providers and their relatives were excluded from the study.

2.2. Procedures

2.2.1. Sociodemographic data form

A sociodemographic data form created by the authors was applied to the participants to evaluate their sociodemographic and clinical characteristics. The form included questions regarding age, sex, education status, marital status, working status, and socioeconomic status. There were also additional questions related to the disease onset, treatments that were used, frequency of seizures, type of seizures, and family history. Socioeconomic level was classified according to the minimum salary in January 2015 which was 1201.50 Turkish liras in gross and 949.07 Turkish liras in net. Data related to treatments that were used, frequency of seizures, and type of seizures, were collected using the detailed medical histories obtained from the patients, their relatives, and the hospital records.

2.2.2. Stigma scale in epilepsy

Initially, previous studies on epilepsy and stigma conducted by neurologists experienced in epilepsy were examined. Depending on clinical findings, two different self-reported measures were developed, one comprising 32 questions for the patients and one including 20 questions for the patients' relatives. These were 4-point Likert-type scales: 1. Absolutely disagree. 2. Disagree. 3. Agree. 4. Absolutely agree.

The patients were asked 32 questions, related to their false beliefs about epilepsy; whether they were exposed to ostracism or discrimination due to their disease; whether they considered themselves to be insufficient at work and in family life; whether they experienced social isolation due to the resistance to stigma.

The patients' relatives were asked 20 questions, developed for relatives, about their false beliefs related to epilepsy; whether they considered patients with epilepsy to be insufficient in social life, work, and family life; whether the patients were exposed to ostracism or discrimination in society.

A pilot study was conducted on 30 patients and 30 relatives to evaluate the validity and reliability of these scales. One week later, the scales were re-administered to the participants under the same conditions. Then, the scales were applied to 272 patients and 171 patient relatives to complete the study.

2.3. Statistical analysis

Statistical analysis was performed using SPSS version 22.0 software (SPSS Inc., Chicago, IL, USA). Descriptive data were expressed in mean, standard deviation, median, minimum, maximum, frequency, and percentage. The chi-square and Fischer's exact tests were used to compare the frequencies and percentages. Distribution of variables was measured with the Kolmogorov–Smirnov test. An independent sample t-test and one-way analysis of variance (ANOVA) were used to compare the mean values of normally distributed variables. In the presence of a significant difference in ANOVA, the post-hoc Tukey's Honestly Significant Difference (HSD) test was used for the paired comparison of subgroups. Nonparametric tests, such as the Mann–Whitney U test, Wilcoxon test, and Kruskal–Wallis ANOVA method were used, where applicable (depending on the number of subjects and for the homogeneity control).

The correlation (Pearson and Spearman) and regression analyses were performed to determine the correlation between variables and to show the correlations in mathematical relations. In the analysis of validity and reliability, the Cronbach's alpha coefficient was calculated to measure the success for establishing the intercompatibility and similarity of the questions. The Pearson correlation coefficient was used for the reliability analysis of the test-retest and the analysis was carried out according to Pearson correlation coefficient test methods in paired series. To reduce the large numbers of interrelated variables included in the scales, factor analysis was conducted to help understand and interpret the relationship between the concepts included in the data set by an evaluation of structural characteristics of basic factors.

Table 1
Demographic data of patients (n = 30) and patients' relatives (n = 30).

		Patients (n = 30)		Patients' Relatives (n = 30)	
		n	%	n	%
Sex	Female	19	63%	21	70%
	Male	11	37%	9	30%
Marital status	Single	17	57%	4	13%
	Married	13	43%	24	80%
	Divorced	0	0%	2	7%
Education status	Uneducated	3	10%	2	7%
	Primary	10	33%	18	60%
	Secondary	7	23%	2	7%
	High School	5	17%	6	20%
	University and higher	5	17%	2	7%
Occupation	Unemployed	13	43%	0	0%
	Housewife	5	17%	13	43%
	Irregular worker	1	3%	0	0%
	Regular work	10	33%	12	40%
	Student	1	3%	0	0%
	Retired	0	0%	5	17%
Income distribution	None	17	57%	5	17%
	Minimum wage	8	27%	14	47%
	Above minimum wage	5	17%	11	37%
Seizure medication	None	4	13%		
	1 drug	18	60%		
	2 drug	6	20%		
	≥3 drug	2	7%		
Presence of epilepsy in family	None	27	90%		
	1st degree relative	2	7%		
	≥2nd degree relative	1	3%		

	Min–Max	Mean ± standard deviation	Min–Max	Mean ± standard deviation
Age	16.0–73.0	31.0 ± 12.1	21.0–71.0	47.8 ± 12.9
Age of onset	1.0–23.0	14.7 ± 5.0		