Development and validation of the stigma scale for epilepsy in Turkey

Sevim Baybaş [a], Zerrin Yıldırım [a,b,*], Devrimsel Harika Ertem [c], Ayten Dirican [a], Ahmet Dirican [d]

[a] Bakirkoy Prof. Dr. Mazhar Osman Mental Health and Neurological Diseases Education and Research Hospital, Department of Neurology, Istanbul, Turkey
[b] Bagcilar Education and Research Hospital, Department of Neurology, Istanbul, Turkey
[c] Sisli Hamidiye Etfal Education and Research Hospital, Department of Algology, Istanbul, Turkey
[d] Istanbul University, Faculty of Medicine, Department of Biostatistics, Istanbul, 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.

* Corresponding author at: Bagcilar Education and Research Hospital, Department of Neurology Merkez Mh., Mimar Sinan Caddesi, 6. Sokak, 34100 Bağcılar, İstanbul.
E-mail address: yildirimzerrin@gmail.com (Z. Yıldırım).

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		

3. Results

3.1. Pilot study

For the validity and reliability analysis, a pilot study was initially conducted on 30 patients and 30 relatives of the patients who met the pre-defined criteria. Demographic data of the participants are summarized in Table 1.

The Cronbach's Alpha stigma value of epilepsy stigma scale for patients was found to be 0.915. The correlation coefficient was low for question 17, "When people look at me, they can immediately understand that I have epilepsy", for question 28, "When applying for a job, the chance of being accepted is higher for a person who doesn't have epilepsy.", and for question 31, "I can live a good life, despite having epilepsy". When these questions were excluded there was a minimal increase in the Cronbach's alpha value; however, we did not exclude these questions from the scale due to their clinical significance.

One week later, the scale was repeated under the same conditions. It was found that the scale was reliable according to the correlation coefficient of the two applications and the t-test in paired series. The high correlation between the scores and insignificance of the t-test results supports that the measurement method is reliable. Significance was only observed in question 13 ($p = 0.043$). One patient who answered "Absolutely disagree" in the first test answered "Disagree" in the second test, and three patients giving the answer "Disagree" changed their answer to "Agree" in the second test.

Furthermore, the Cronbach's alpha value of epilepsy stigma scale for the patients' relatives was found to be 0.903. When question 3, "Epilepsy is possession" with a low correlation coefficient was excluded, the Cronbach's alpha value of the scale increased; however, we did not exclude this question due to its clinical significance.

One week later, the scale was repeated under the same conditions. It was reliable according to the correlation coefficient of two applications and t-test in paired series. The high correlation between the scores and the non-significant t-test results support that the measurement method is reliable.

3.2. Study of validity and reliability of stigma scale in epilepsy

3.2.1. Patients

The study was conducted on 302 patients with epilepsy who met pre-defined criteria. Clinical and demographic characteristics and stigma scores of the patients are shown in Table 2.

The Cronbach's alpha value of epilepsy stigma score for patients was found to be 0.915. Question 32 showed a low corrected item-total correlation value. If this question was removed, the Cronbach's alpha value increased. However, this question was not excluded due to its clinical significance. In the item analysis, it was found that other questions had equal power in the scale.

In the factor analysis, the questions were grouped in five factors, according to the factor loading values: social isolation, discrimination, insufficiency, false beliefs, and stigma resistance (Table 3).

Table 2
Demographic data of patients (n = 302) and patients' relatives (n = 201).

		Patients (n = 302)		Patients' Relatives (n = 201)	
		n	%	n	%
Sex	Female	170	56%	137	68%
	Male	132	44%	64	32%
Marital status	Single	166	55%	27	13%
	Married	131	43%	168	84%
	Divorced	5	2%	6	3%
Education status	Uneducated	25	8%	24	12%
	Primary	82	27%	107	53%
	Secondary	68	23%	21	10%
	High School	77	25%	37	18%
	University and higher	50	17%	12	6%
Occupation	Unemployed	78	26%	5	2%
	Housewife	72	24%	109	54%
	Irregular worker	13	4%	0	0%
	Regular work	100	33%	50	25%
	Student	33	11%	4	2%
	Retired	6	2%	33	16%
Income distribution	None	139	46%	48	24%
	Minimum wage	93	31%	101	50%
	Above minimum wage	70	23%	52	26%
Medication	None	22	7%		
	1 drug	193	64%		
	2 drug	56	19%		
	≥3 drug	31	10%		
Frequency of seizures	Seizures under control	128	42%		
	≥1 in a year	68	23%		
	≥1 in a month	75	25%		
	≥1 in a week	31	10%		
Type of seizures	Generalized and secondary generalized	120	40%		
	Focal	172	57%		
	Other	10	3%		
Presence of epilepsy in family	None	262	87%		
	1st degree relative	20	7%		
	≥2nd degree relative	20	7%		

	Min–Max	Median	Mean ± standard deviation/n-%	Min–Max	Median	Mean ± standard deviation/n-%
Age	15.0–73.0	28.0	30.3 ± 9.9	18.0–71.0	44.0	44.5 ± 10.5
Age of onset	0.0–27.0	14.0	13.4 ± 5.4			
Duration of disease	2.0–61.0	15.0	16.9 ± 9.6			
Stigma score	25.8–88.3	42.2	45.5 ± 13.6	25.5–90.0	47.5	49.0 ± 15.6

Table 3
Factor analysis of stigma scale in patients and patients' relatives.

Patients	Patients' relatives
Social isolation	**Discrimination**
7[a] I think I have epilepsy as a punishment from God.	3[c] Epilepsy is possession.
9 As I have epilepsy, people don't take me seriously or ignore me.	7 I don't want to marry a person with epilepsy.
10 As I have epilepsy, people don't want to be in close relationship with me.	8 I don't want to be the friend of a person with epilepsy.
11 As I have epilepsy, I don't think that I would be successful in school and/or at work.	9 I don't want my relatives or children to be friendly with someone with epilepsy.
15 As I have epilepsy, I am ashamed.	10 If I had a child with epilepsy, I wouldn't want to send him to school.
16 Having epilepsy results in disappointment.	17 People with epilepsy don't contribute to society.
19 As I have epilepsy, I don't think that I could make a contribution to society.	18 People with epilepsy have this disease as a punishment from God.
23 I feel alienated due to the negative feelings about epilepsy in society	19 If I had a relative with epilepsy, I would be ashamed.
24 I keep away from events, as I don't want my family and friends to be ashamed.	**Prejudgments**
25 I am not accepted by others of the same age.	6 Epilepsy is an absolutely untreatable disease.
27 I don't think that I could be an adequate and good parent for my child.	11 People with epilepsy are exposed to discrimination.
29 I would prefer to have a disease other than epilepsy.	12 People with epilepsy could not be successful in life.
Discrimination	14 People with epilepsy should not be soldiers.
5[b] Onions, water and cologne are beneficial for stopping epileptic convulsions.	15 I don't want to give a job to a person with epilepsy.
6[b] Epilepsy is an absolutely untreatable disease.	16 People should not make any decisions alone about their own lives.
8 I think that other people discriminate because I have epilepsy.	20 People with epilepsy cannot be self-sufficient.
12 I am different from other people as I have epilepsy.	**False beliefs**
13 Having epilepsy make me feel inadequate.	1 Epilepsy is a contagious disease.
14 People who don't have epilepsy can't understand me.	2 Epilepsy is a mental disease.
22 Men with epilepsy can't become soldiers.	4 Epilepsy occurs due to fear.
28 When applying for a job, the chance of being accepted is higher for a person who doesn't have epilepsy.	5 Onions, water, cologne are beneficial for stopping convulsions.
30 I avoid being in relationships with other people because I think that I will be rejected as I have epilepsy.	13[d] People with epilepsy shouldn't give birth.
Insufficiency	
17 When people look at me, they can immediately understand that I have epilepsy.	
18 As I have epilepsy, I need others to make decisions for me.	
20 People with epilepsy can't get married.	
21 Women with epilepsy can't give birth.	
26 As I have epilepsy, I can't get along with my relatives.	
False beliefs	
1 Epilepsy is a contagious disease.	
2 Epilepsy is a mental disease.	
3 Epilepsy is possession.	
4 Epilepsy occurs due to fear.	
Stigma resistance	
31 I can live a good life, despite having epilepsy.	
32 I feel good when I am together with other people who have epilepsy.	

[a] This question has been included as a factor in social isolation, although it was developed for the evaluation of false beliefs.
[b] This question has been included as factor in discrimination, although it was developed for the evaluation of false beliefs.
[c] Question was included in the discrimination factors, although it was developed as a false belief assessment question.
[d] Question was included in the false beliefs factor, although it was developed as a discrimination assessment question.

A total of 51% of the total variance can be explained by five factors. The first factor was *Social Isolation* and the second factor was *Discrimination* (Table 4).

The total stigma score was calculated by the summation of the scores relating to the answer to each question, according to the Likert-type answering system. The stigma score of the individuals who marked all questions with 1 was calculated as 25; stigma score of the individuals who had marked all questions with 4 was calculated as 100 with a cut-off value of 50. A total of 68.9% of the patients (n = 208) had a score of 25 to 50; 28.1% of the patients (n = 85) had a score of 51 to 75, and 3% of the patients (n = 9) had a score of 76 to 100. The patients with a score of 25 to 50 were classified as *not stigmatized*, those with scores between 51 and 75 were classified as *moderately stigmatized*,

and those with scores between 76 and 100 as *highly stigmatized*. It was found that 31.1% (n = 94) of the patients were stigmatized.

On the other hand, no significant correlation was found between the stigma scores and sex (p = 0.802); marital status (p = 0.742); family history (p = 0.215), and type of seizures (n = 0.771). As the frequency of seizures increased, the stigma score significantly increased (p = 0.033). The stigma scores of the group whose seizures were under control were found to be significantly lower, compared to the stigma scores of the group who had one or more seizures per week (p = 0.043). In addition, as the education status decreased, stigma scores significantly increased (p = 0.000). The stigma scores patients who were uneducated, primary school-graduated, and secondary school-graduated were significantly higher, compared to the stigma scores of the patients that were high school-graduated and university-graduated. We also observed that, as the income level decreased, the stigma scores significantly increased (p = 0.000). Also, as the number of seizure medications used increased, the stigma scores significantly increased (p = 0.005). Furthermore, the stigma scores among the housewives and the retired participants were significantly higher compared to the irregular workers, regular workers, and the students (p = 0.000) (Table 5).

However, there was a significant positive correlation between the age and stigma scores (p = 0.016, r = 0.139). This correlation was thought to be associated with increased disease duration, as there was also positive correlation between duration of disease and stigma score (p = 0.002, r = 0.181). On the other hand, we found no significant

Table 4
Distribution of variance explained by the Stigmatization Scale Patient Form in patients with epilepsy (sub-factors).

n = 302	Specific variance of factor (%)	Cumulative variance (%)
Patient form of stigmatization in epilepsy		
Social isolation	32.278	32.278
Discrimination	5.723	38.002
Insufficiency	4.831	42.833
False beliefs	4.301	47.134
Stigma resistance	3.886	51.020

Table 5
Comparison of demographic data based on stigma scores (n = 302).

		Stigma score				p
		Min–Max		Median	Mean ± standard deviation	
Case						
Sex	Female	25.8 – 88.3		41.4	45.0 ± 12.9	0.802
	Male	26.6 – 81.3		43.0	45.2 ± 12.9	
Marital status	Single	25.8 – 88.3		42.2	45.6 ± 12.9	0.742
	Married	26.6 – 85.9		41.4	44.4 ± 13.0	
	Other	39.1 – 53.9		51.6	48.0 ± 6.8	
Education status	Uneducated	30.5 – 76.6		55.5	52.3 ± 14.0	**0.000**
	Primary	26.6 – 88.3		48.0	50.6 ± 14.5	
	Secondary	28.9 – 76.6		42.2	45.5 ± 11.6	
	High school	27.3 – 73.4		39.8	41.7 ± 10.3	
	University and higher	25.8 – 58.6		35.2	37.0 ± 8.0	
Income distribution	None	25.8 – 88.3		43.0	45.9 ± 13.1	**0.000**
	Minimum wage	26.6 – 85.9		45.3	47.2 ± 13.0	
	Above minimum wage	26.6 – 71.1		36.7	39.8 ± 9.8	
Frequency of seizures	Seizures under control	25.8 – 88.3		38.3	43.1 ± 12.9	**0.033**
	≥1 in a year	28.1 – 76.6		41.4	44.7 ± 12.4	
	≥1 in a month	26.6 – 85.2		44.5	46.8 ± 12.9	
	≥1 in a week	27.3 – 81.3		51.6	49.8 ± 12.4	
Seizure medication	None	28.1 – 53.9		40.2	39.7 ± 5.7	**0.005**
	1 drug	25.8 – 85.9		39.8	44.1 ± 13.1	
	2 drugs	27.3 – 79.7		46.1	47.5 ± 12.7	
	≥3 drug	25.8 – 88.3		50.0	50.6 ± 13.3	
Family history of epilepsy	Absent	25.8 – 88.3		42.2	44.6 ± 12.5	0.215
	1st degree relative	28.9 – 85.9		45.7	49.1 ± 16.1	
	≥2nd degree relative	28.9 – 70.3		42.2	47.6 ± 14.1	
Type of seizures	Generalized and secondary generalized	26.6 – 76.6		42.2	44.7 ± 12.4	
	Focal	25.8 – 88.3		42.2	45.2 ± 13.1	0.771
	Other	47.7 – 14.2		41.8	30.5 ± 81.3	
Occupation	Unemployed	25.8 – 81.3		46.1	47.8 ± 12.6	
	Housewife	26.6 – 79.7		43.8	46.1 ± 12.7	
	Irregular worker	28.9 – 53.9		39.1	39.7 ± 7.8	**0.000**
	Regular worker	26.6 – 85.9		39.8	43.8 ± 13.0	
	Student	28.9 – 88.3		36.7	42.6 ± 14.5	
	Retired	28.1 – 54.7		46.5	43.5 ± 10.4	

Kruskal–Wallis/Mann–Whitney *U* tests.
Bold italics is used for showing correlated items.

correlation between the onset of disease and stigma scores (p = 0.707, r = 0.022) (Table 6).

3.2.2. Patient's relatives

The study was conducted with 201 relatives of patients who fulfilled the pre-defined criteria. Demographic characteristics and stigma scores are shown in Table 2.

The Cronbach's alpha value of epilepsy stigma scale of patient relatives was found to be 0.892. Contribution of each question to the scale was equal.

Table 6
Comparison of age, age at disease onset, disease duration, and stigma scores among patients.

		Stigma score
Age	R	0.139
	P	**0.016***
Age at onset	R	0.022
	P	0.707
Disease duration	R	0.181
	P	**0.002***

Table 7
Distribution of variance explained by Epilepsy Stigma Scale Factor (sub-factors) of patients' relatives

N = 201 Patient relatives	Specific variance of factor (%)	Cumulative variance (%)
Epilepsy Stigma Scale Patient's Relative Form		
Discrimination	35.069	35.069
False beliefs	12.568	47.637
Prejudgments	9.286	56.924

In the factor analysis, the scale was divided into four factors: *Discrimination*, *Prejudgments*, and *False Beliefs* (third and fourth factors were combined) (Table 3). A total of 57% of variance can be explained by three factors. The first factor was *Discrimination* and the second factor was *False Beliefs* (Table 7).

The stigma scores were calculated to be a minimum of 25 and a maximum of 100 with a cut-off value of 50. Of the participants, 61.2% (n = 123) had a score of 25 to 50; 30.3% (n = 61) had a score of 51 to 75, and 8.5% (n = 17) had a score of 76 to 100. In addition, 38.8% of the total participants (n = 78) were considered stigmatized.

According to sex of the participants, the stigma scores of the males were significantly higher than the females (p = 0.016). According to the marital status, the stigma scores of the single and married group were significantly higher, compared to the divorced group (p = 0.035). According to the education status, it was found that as the education status decreased, the stigma scores significantly increased (p = 0.000). The stigma scores of unwaged individuals and those on minimum wages were significantly higher, compared to the individuals who had an income above the minimum wage (p = 0.000) (Table 8). On the other hand, we found no significant correlation between the age and stigma scores (p = 0.214).

4. Discussion

In the present study, we aimed to develop a scale which was applicable to measure the level of stigma in Turkish patients with epilepsy and their relatives. We also assessed the validity and reliability of the scale and compared the level of stigma based on the demographic and clinical data. Based on our study findings, the Cronbach's alpha values of the scales were the indicators of internal consistency.

Jacoby applied a stigma scale consisting of three questions to patients with epilepsy [6]. In the aforementioned study, no correlation

Table 8
Comparison of stigma scores and demographic characteristics of patients' relatives (n = 201).

		Stigma score				p
		Min–Max		Median	Mean ± standard deviation	
Patient's relative						
Sex	Male	25.0 – 72.5		46.3	45.2 ± 12.4	**0.016**
	Female	25.0 – 90.0		48.8	50.8 ± 16.6	
Marital status	Single	30.0 – 90.0		45.0	51.2 ± 18.8	**0.035**
	Married	25.0 – 88.8		48.8	49.2 ± 15.0	
	Divorced	30.0 – 38.8		31.9	33.3 ± 3.4	
Educational status	Uneducated	31.3 – 85.0		60.0	61.6 ± 15.5	**0.000**
	Primary	25.0 – 88.8		50.0	49.9 ± 16.4	
	Secondary	25.0 – 76.3		46.3	46.7 ± 12.0	
	High School	25.0 – 90.0		43.8	42.7 ± 11.1	
	University and higher	30.0 – 51.3		38.8	39.8 ± 8.0	
Income distribution	None	27.5 – 85.0		50.0	50.1 ± 13.6	**0.001**
	Minimum wage	25.0 – 90.0		50.0	52.0 ± 17.1	
	Above minimum wage	25.0 – 73.8		43.8	42.3 ± 11.9	

Kruskal–Wallis/Mann–Whitney *U* tests.
Bold italics is used for showing correlated items.

was found between the type of seizure, duration of epilepsy, sex, marital status, occupation, and level of stigma. Unlike the aforementioned study, we showed that as the duration of disease increased, stigma scores also increased. In addition, the percentage of patients who faced stigmatization was 14% in the study of Jacoby [6], whereas it was found to be 31.1% in the present study. This difference can be explained by the variability in socioeconomic levels of the U.K. and Turkish population.

Furthermore, in Turkey, Aydemir et al. [7] applied a stigma scale in 2011, developed by Jacoby [6], to 70 patients with epilepsy and 56 patients with migraine and compared stigma and depression levels in both disorders. The authors reported higher stigma scores of patients with epilepsy than patients with migraine. In the aforementioned study, 14.2% of the patients with epilepsy were stigmatized and this percentage was virtually the same as that of Jacoby [6]. The Jacoby scale was not selected for use in the present study, because it was developed according to the cultural standards of another society and as the questions were not inclusive. In two studies, Aydemir et al. [8,9] developed two scales for patients and the overall society to understand the knowledge and attitudes related to epilepsy and to evaluate the association with depression. They also interrogated altered emotions and the thoughts of the patients in relation to their epilepsy since the onset of disease. The authors reported that the patients with low levels of depression and who had more knowledge about their disorder had positive thoughts and feelings towards it. In the current study, we aimed to quantitatively measure the stigma levels of the patients; therefore, open-ended questions were not included. In our clinical observations, which were carried out to develop a scale, we considered that two-choice answers, such as 'Yes/No' would be insufficient to evaluate the feelings and thoughts of the patients and would be unsuitable for stigma grading.

In another study which was conducted in Turkey, Ak et al. [10] developed a 12-question survey with two-choice answers to evaluate the relationship between epilepsy and stigma. The patients were also asked whether they considered themselves different from others and were stigmatized, and whether they hide their disorder from their social network. Of the patients, a total of 43.3% (n = 140) reported that they were stigmatized. The authors also found a negative correlation between the education status and the feeling of stigmatization. No significant correlation was found between other sociodemographic variables and stigma. The authors concluded that the vast majority of the patients were more likely to hide their disorder from their social network. They assessed the presence of stigma by directly questioning the patients; therefore, it was impossible to provide sufficient information related to the level of stigma.

In a study from Iran, the Internalized Stigma of Mental Illnesses (ISMI) Scale, which was conducted to assess stigma in patients with mental illnesses, was adjusted for patients with epilepsy [11]. It was applied to 130 patients with epilepsy and a validation study was performed (the Cronbach's alpha > 0.70). The scale was assessed using five factors: *Alienation*, *Prejudgments*, *Discrimination*, *Social Isolation*, and *Stigma Resistance*. In the factor analysis of the stigma scale for patients, common headings such as *Social Isolation, Discrimination,* and *Stigma Resistance* were used, while discrete headings such as *Insufficiency* and *False Beliefs* were present in our study. In the present study, the cut-off value was found to be 2.5, according to the scoring system of 1 to 4, and 23.7% of the patients were classified as stigmatized. The highest scores resulted from *Discrimination*, followed by *Social Isolation* factors. In the present study, the cut-off value in the scoring system of 25 to 100 was found to be 50 and 31.1% of the patients were classified as stigmatized. Similar to the Iranian study, we found that the highest scores resulted from the *Social Isolation* and *Discrimination* factors. Also, in the aforementioned study, the stigma scores were found to be higher in patients with low education status and in unemployed participants, consistent with our findings. However, unlike the aforementioned study, the amount of antiepileptic drugs used by the patients

and the frequency of seizures were significantly correlated with the stigma scores. We speculate that attitudes towards epilepsy in Iran would be similar with Turkey, as Iran has similar religious, geographical, and cultural aspects. According to religious beliefs in these countries, it is necessary to approach someone, who has a serious illness, with respect and tolerance [12]. In the stigma scale that was used by us, 90% of the patients (n = 272) answered the question "I think I have epilepsy as a punishment from God." as Disagree/Absolutely disagree. Furthermore, in a study comparing epilepsy stigma in Iran and Sweden using the ISMI scale, it was found that, although the Iranian patient group had higher levels of education compared to the Swedish patient group, the stigma scores in the Swedish patient group were significantly lower [11,12]. The authors concluded that the reason for the lower stigma scores in Sweden could be due to the difference between the health systems of these countries and because the overall education status is higher in Sweden. Moreover, in Kenya, a scale was developed to assess stigma and was applied to 203 patients with epilepsy and 470 patients' relatives (Cronbach's alpha 0.85) [13]. Similar to our study, Likert-type scales were used, and a pilot study was initially conducted. In that study, no correlation was found between sex, type of seizure, and stigma level. Different from our study, stigma scores were found to be higher at younger ages. Furthermore, the authors found a mild correlation between the frequency of seizures and stigma. Similarly, in the current study, as the frequency of seizures increased, the stigma level also increased. Application of the same stigma scale to patients and patients' relatives and combined evaluation of the results made it impossible to compare the stigma that internalized by the patient and that imposed by the social network.

Fernandes et al. [14] composed a scale and applied it to 20 patients and 20 patient relatives for evaluation of stigma in epilepsy. They reported that the areas in which the patients had most difficulty were business life, prejudgments, and school life, respectively. As the scale that was applied in Brazil consisted of open-ended questions, it is difficult to define the grade of stigma level and make comparisons with results from other countries.

In addition, we were unable to make a comparison for the stigma level of the patient relatives as no other scales have been developed for patient relatives previously.

A stigma score of 51 and above for epilepsy in 31.1% of the patients (n = 94) and in 38.8% of the relatives (n = 78) reveals that stigmatization is common in Turkey. The absence of a universal validated scale for the measurement of stigma in epilepsy makes it complicated to draw a robust conclusion on whether the participants are stigmatized or not. However, according to our study results, both scales are suitable for sociocultural characteristics of the Turkish society.

There are some limitations to this study. Our study population consisted of those who were followed for at least one year in a tertiary epilepsy outpatient clinic. We also selected the patient relatives who were fully informed about the disease and engaged in treatment. Therefore, we believe that the stigmatization rate would be higher in all Turkish patient and relative groups with epilepsy.

5. Conclusion

In conclusion, our study revealed that both patients and their relatives suffer from epilepsy-associated stigma in Turkey. Social isolation and discrimination for these patients and discrimination alone for their relatives suggest that patients with epilepsy are faced with discrimination in society, resulting in social isolation. We, therefore, believe that both patients and their relatives should be informed more comprehensively on discrimination to overcome this challenge. As stigmatization can directly result in psychiatric comorbidities and lower quality of life for patients with epilepsy, we recommend evaluation of stigmatization in patients with epilepsy and their relatives on a regular basis.

6. Conflicts of Interest

The authors have no conflicts of interest to disclose and did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

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