

Validation and Reliability Study of the Turkish Version of the Stigma Scale of Epilepsy

Epilepsi Damgalanma Ölçeği'nin Türkçe Formu'nun Geçerlilik ve Güvenilirlik Çalışması

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ABSTRACT

Introduction: We aimed to validate the Turkish version of the Stigma Scale of Epilepsy (SSE) (from Brazil) and present the results.

Method: The SSE was completed by 33 patients with epilepsy (PWE), 25 of the patients' family members, and 23 people from the community. Subjects were interviewed on an individual basis; a physician read the questions and the subjects wrote the answers on a sheet. The form was the same for all subjects. In addition, the Beck Depression Inventory (BDI) and the Hamilton Anxiety Inventory (HAI), Short Form-36 (SF-36) were completed by the subjects.

Results: We interviewed 81 subjects. The internal consistency of the SSE showed Cronbach's α coefficients of 0.785 for the PWE, 0.733 for the family members and 0.798 for the people in community. The mean scores on the SSE were 57 for patients, 66 for family members and 65 for the community where a score of 0 would suggest no stigma and 100 would indicate maximum stigma. The SSE scores of patients, family

members and the community who believed that patients with epilepsy are stigmatized or rejected were higher than the SSE scores of who did not believe it. Although there were strong correlation between high SSE scores and poor functionality and BDI; there were not any correlation between with SSE and HAI, age of epilepsy onset, time of epilepsy, education, and social class.

Conclusion: The SSE has satisfactory content validity and high internal consistency. It allows for the quantification of the real perception of the epilepsy associated stigma. Prejudice and discrimination are often worse than the seizures themselves in terms of the impact on the daily lives of people with epilepsy and their families. Understanding this aspect of epilepsy is important for reducing the burden of epilepsy, and the SSE can be used for cross cultural, media, and social campaigns aimed at minimizing the negative influences of stigma.

Keywords: Stigma, epilepsy, prejudice

ÖZ

Amaç: Brezilya'da geliştirilen Epilepsi Damgalanma Ölçeği'nin Türkçe formunun geçerliliğinin araştırılarak sonuçlarının sunulması amaçlandı.

Yöntem: Epilepsi Damgalanma Ölçeği'nin Türkçe Formu 33 epilepsili hasta, 25 hasta yakını ve 23 sağlıklı gönüllüde tamamlandı. Tüm gruplardaki katılımcılara ayrı bir odada yalnız olarak açıklama yapıldıktan sonra ölçekteki sorular okundu ve kendilerinin en uygun buldukları seçeneği işaretlemesi istendi. Ayrıca hasta grubuna Beck Depresyon Ölçeği (BDÖ), Hamilton Anksiyete Ölçeği (HAÖ), Short Form-36 (SF-36) Ölçeği uygulandı.

Bulgular: Seksenbir denek çalışmaya alındı. Damgalanma ölçeğinin iç tutarlılığını gösteren α Cronbach' katsayısı hasta grubunda 0.785, hasta yakını grubunda 0.733 ve sağlıklı kontrol grubunda 0.798 bulundu. Ortalama damgalanma ölçek skoru (0=damgalanma yok ve 100=maksimum damgalanmayı gösterir) hasta grubunda 57, hasta yakını grubunda 66 ve sağlıklı kontrol grubunda 65 idi. Her üç grupta da dam-

galanma ölçeği skorları epilepsili hastaların dışlandığını düşünenlerde düşünmeyenlere kıyasla yüksek saptandı. BDÖ ve kötü fonksiyonellik ile damgalanma ölçeği arasında güçlü bir korelasyon saptanırken HAÖ, epilepsi başlama yaşı, epilepsi süresi, eğitim düzeyi ve sosyal sınıf arasında bir korelasyon saptanmadı.

Sonuç: Epilepsi damgalanma ölçeğinin tatminkar bir seviyede geçerliliği ve yüksek iç tutarlılığı vardır. Önyargı ve ayrımcılık epilepsili hastaları ve ailelerini nöbetlerden daha fazla olumsuz olarak etkileyebilmektedir. Bu sorunun farkına varılması, neden olabilecek psikososyal sorunların giderilmesi epilepsili hastaların yaşam kalitelerinin artırılması açısından gereklidir; bu amaçla epilepside damgalanmanın olumsuz etkilerini en aza indirmek amacıyla epilepside damgalanma ölçeği kültürler arası araştırmalarda, sosyal ve medya kampanyalarında kullanılabilir.

Anahtar kelimeler: Damgalanma, epilepsi, önyargı

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INTRODUCTION

Epilepsy is a chronic and common neurological condition without racial, national, social, or geographical boundaries. It has been estimated that epilepsy affects at least 50 million people worldwide. According to the results of a limited number of studies including all age groups, the prevalence in Turkey is reported to be 6 to 12.2 per 1000 (1,2,3).

Stigma is a complex concept to investigate in PWE because it involves personal attitudes and beliefs, as well as influences from the social environment. Tools to measure perceived stigma among PWE have mostly been developed in Western countries and middle income countries. This facet of epilepsy, however, is rarely studied in developing countries, where the burden of epilepsy stigma is probably very high (4,5). In Turkey there are a limited number of studies that evaluate stigma in epilepsy, the psychosocial impact of epilepsy, and personality in epilepsy (6,7,8,9,10,11,12). Aydemir et al. (10) compared PWE and patients with migraine, and found that the participants with a high number of intractable seizures had quality of life, psychological well being, and self-esteem values lower than those of the control participants. Additionally, almost half of the PWE concealed their epilepsy. Doğan Ak et al. (11) found a negative correlation between education level and stigma of epilepsy, and that PWE are more likely to be socially dysfunctional than the general population. Değirmenci et al. (6) indicated that people believe that epilepsy is a result of good or bad spirits. People perceive epilepsy as a super-natural event, and frequently go to hodja, wear an amulet, and participate in religious ceremonies. Oto et al. (7) showed that epilepsy has a great impact on the everyday life of the patients as well as on their quality of life in different ways.

Epilepsy affects not only individual patients but also their family and community. The burden of epilepsy may be due to psychological and social as well as physical consequences of epilepsy from the unpredictability of seizures; social exclusion as a result of negative attitudes of the others toward patients with epilepsy (PWE). Epilepsy is a stigmatizing condition, because PWE may not be adapted to the social norms due to unexpected seizures, and society may be afraid of interacting with a person who has epileptic seizures. When epilepsy is diagnosed, patients' perceptions change and they start to fear being different and become concerned about the future. Patients often describe social stigma and the fear of being discriminated. Epilepsy Stigma erodes individuals' social status and social network, all of which contribute to poor outcomes such as isolation, unemployment, lower prospects of marriage and not seeking treatment (4,13,14,15). Perceived stigmatization is a significant part of the hidden psychosocial burden of epilepsy since it has been related to low self-esteem, depression, anxiety, negative feelings, and impaired social skills (5). Although this is well known, this facet of epilepsy is rarely studied.

Stigma is a term frequently used nowadays, but it is still difficult to conceptualize and measure it (13). In the literature, we found four stigma scales on epilepsy; Jacoby, Austin, Caroline, and the 24-item stigma scale of epilepsy (SSE), which was developed in Brazil. From a theoretical perspective, stigma is divided into enacted and felt stigma. Enacted stigma describes beliefs held by the public that manifest as discrimination. Most attempts to measure enacted stigma assess epilepsy associated knowledge, attitudes, and practices (KAP) among the public. Felt stigma describes self-stigmatization by PWE resulting from epilepsy associated shame and fear of discrimination. Stigma is a universal construct. Customized instruments may more completely capture the local burden of stigma, but are challenging to develop and prohibit cross-cultural comparisons. The most frequently employed instrument for felt stigma is Jacoby's Stigma Scale. This scale measures perception of enacted stigma in the communities of PWE, which theoretically contributes to felt stigma, but may not fully encompass it. Additionally it has been used to assess felt stigma associated with other conditions (15).

A cross-cultural instrument that could quantify both KAP and felt stigma would facilitate cross-cultural studies of stigma determinants and would be valuable for stigma reduction interventions. The SSE may fulfill this need. The SSE has been used in India, Bolivia, and Zimbabwe. Additionally this scale seems to be the best for evaluating patients' real perceptions and can be used very easily.

We aimed to validate the Turkish Form of the Stigma Scale of Epilepsy (SSE) to draw attention to this common psychosocial problem associated with epilepsy.

METHODS

The subjects were divided in three groups: Patients With Epilepsy (PWE), Patients' Relatives (PR), and People in the Community (PC).

The epilepsy group consisted of thirty-three participants who had received detailed neurological and neuropsychological evaluations. Patients who had low IQs or who were uncooperative were not included in the study. Patients with additional serious impairments and those with other neurological and psychiatric disorders were also excluded.

The present study was approved by the Şişli Hamidiye Etfal Training and Research Hospital of Ethics Committee [11.06.2013, No: 412]. Additionally, all the participants gave informed consent for their participation in the study.

Clinical/Demographic Questionnaire

In order to collect information about the participants' clinical and demographic characteristics, a questionnaire was developed. Demographic data included age, gender, marital status, level of education, employment status, and monthly income. Educational level was divided into three categories: (1) primary and secondary school (5-8 years), (2) high school (11 years), and (3) university. When analyzing employment status, subjects were divided into four categories: (1) employed, (2) unemployed, (3) currently studying, and (4) retired. The questionnaire contained questions about seizure frequencies, the amount of medication used, the duration of the illness, the duration of the diagnosis, and the existence of other chronic conditions.

Health Related Quality of Life (HRQOL)

We used the Medical Outcomes study short form-36 (SF-36), which consists of eight subscales to evaluate the different domains of HRQOL: (1) physical functioning (PF); (2) role limitations because of physical health problems (RP); (3) bodily pain (BP); (4) social functioning (SF); (5) general mental health (psychological distress and psychological well being) (MH); (6) role limitations because of emotional problems (RE); (7) vitality (energy/fatigue) (VT); and (8) general health perception (GH). Total scores range from 0 to 100, with higher scores representing a better quality of life. This scale was only completed by patients to compare two important aspects of the daily lives of people with epilepsy: stigma and quality of life. Although it is a generic measure, the SF-36 has been used in previous quality of life research in epilepsy. The validity and reliability of the SF-36 for the Turkish population have been tested by Demirsoy (16).

Depression

The Beck Depression Inventory (BDI), a 21-item scale, was administered to assess the depression levels of the participants. Total scores range from 0 to 63, with higher scores indicating greater severity of depressive symptoms. In the present study, 17 were accepted as a cut off point for severe depression. The validity and reliability of the BDI for the Turkish population have been tested by Hisli (17).

Anxiety

The Hamilton Anxiety Inventory (HAI), a 14-item scale, was administered

to assess the anxiety levels of the participants. Total scores range from 0 to 56; 0-5 scores represent no anxiety, 6-14 scores represent minor anxiety, and 16 was accepted as a cut off point for major anxiety.

Stigma

The scale was in English and went through a process of translation and back-translation into Turkish by professional translators to ensure consistency and accuracy. Based on the results of this version of the translated questionnaire, we reviewed the questions and answers to produce the most understandable questionnaire. First, a short training session was held with the interviewers and the questionnaire was completed by five patients and then according to their opinions, we added an explanation to the end of the questionnaire.

The stigma scale of epilepsy (SSE) contains five questions with twenty-four items, each with a four-point scale. Individuals were asked to indicate the most appropriate answer for each item, marking the number corresponding to the category (1: not at all, 2: a little, 3: a lot, 4: totally). All items cover the most important areas of daily life activities, including education, relationships with partners/other close family members, social life/social activities, work, health, relationships with friends, feelings about self, and plans and ambitions for the future. An additional question asked "Do you think that PWE are stigmatized by society?". First the question was read and then the subject wrote down their answer. The form was the same for all subjects.

For validation purposes, it was necessary to compare to other questions related to stigma; like the original scale validation process, we used questions to compare perceptions of epilepsy with that diabetes and AIDS. These questions were:

- What score would you rate for the prejudice that the general population has toward epilepsy (Sizce toplumun epilepsi hastalarına karşı önyargısı ne ölçüdedir) (0=no prejudice, 10=maximum prejudice)?
- What score would you rate for the prejudice that the general population has toward AIDS (Sizce toplumun AIDS hastalarına karşı önyargısı ne ölçüdedir) (0=no prejudice, 10=maximum prejudice)?
- What score would you rate for the prejudice that the general population has toward diabetes (Sizce toplum şeker hastalarına karşı önyargısı ne ölçüdedir) (0=no prejudice, 10=maximum prejudice)?

A further question was asked to give an idea of the distribution of the stigma scores and the perception of stigma in society:

- Do you believe that people with epilepsy are stigmatized or rejected by society? (Epilepsi hastalarının toplum tarafından damgalandığını veya dışlandığını düşünüyor musunuz?) (Yes or No).

Participants completed the information form first, and then the PWE group received the SF-36, BDI, HAI, and the stigma scale of epilepsy. The PC and PR groups did not receive the clinical/demographic questionnaire, BDI, HAI, and SF-36,

Statistical Analysis

Statistical Package for the Social Sciences version 16.0 software (SPSS Inc.; Chicago, IL, USA) Descriptive statistics were calculated for continuous variables and frequency for categorical variables. Cronbach's α coefficient for reliability and internal consistency was used for validation and verification of the consistency of the instrument. This coefficient is used to verify the homogeneity or accuracy of instrument items. The accuracy should not be lower than 0.80 if the scale is widely used, although values above 0.60 indicate consistency. Pearson correlation and Mann-Whitney U tests were applied for analysis of comparative questions with variables of inter-

est. Spearman correlation was used to correlate the scores of stigma in epilepsy with the SF-36 score. The significance level used was 5% (p -value < 0.05). The item scores from the questionnaire were summed and the score was linearly transformed onto a 0-100 scale, with 0 indicating no stigma and 100 indicating the highest level of epilepsy stigma.

RESULTS

We interviewed 81 subjects (33 patients, 25 of their relatives, and 23 people in the community). The main characteristics of the subjects are shown in Table 1.

Table 1. Characteristics of the subjects

Characteristics	Patients n=33	Relatives n=25	Community n=23
Mean age	30.5±9.8	32.4±11.1	29.8±9.0
Gender			
Men	14 (42%)	10 (40%)	9 (39.1%)
Women	19 (59.4%)	15 (60%)	14 (60.9%)
School Level			
Illiterate/incomplete elementary school			
Complete elementary school	19 (5.6%)	16 (64%)	12 (52.2%)
Complete high school	11 (33.3%)	7 (28%)	8 (34.8%)
University degree	3 (9.1%)	2 (8%)	3 (13%)
Epilepsy characteristics			
Age at seizure onset (SD) (year)	19.16±10.355		
Duration of the illness (SD) (year)	10.84±7.445		
Medical treatment			
Yes	32 (100%)		
No	0		
Seizure type			
Partial seizure	4 (12.12%)		
Partial seizure evolving bilateral convulsion	15 (45.46%)		
Generalized seizure	14 (42.43%)		
Marital status (%)			
Single	39.4		
Married	57.6		
Divorced/widow	3.0		
Occupational status (%)			
Employed	48.5		
Unemployed	15.20		
Housewife	19.17		
Student	14.16		
Retired	3.0		
Seizure frequency (%) (per month)			
None	51.1		
<10	42.9		
>10	6.0		
SD: standard deviation			

Table 2. Stigma scale of epilepsy questions and the results from 33 patients with epilepsy, 25 relatives of patient and 23 people from the community

	Patient with epilepsy n=33 (%)				Patient's relatives n=25 (%)				People in community n=23 (%)			
	Not at all	A little	A lot	Totally Not	Not at all	A little	A lot	Totally Not	Not at all	A little	A lot	Totally Not
Do you think that people with epilepsy feel able to control their own epilepsy?												
	7 (21)	11 (33)	11 (33)	4 (12)	4 (16)	8 (32)	11 (44)	2 (8)	8 (35)	9 (39)	4 (17)	2 (9)
How would you feel when you see an epileptic seizure?												
Scared	12 (36)	4 (12)	9 (27)	8 (24)	1 (4)	12 (48)	10 (40)	2 (8)	3 (13)	7 (30)	8 (35)	5 (22)
Fear	5 (15)	6 (18)	10 (30)	12 (36)	0 (0)	2 (12)	10 (40)	12 (48)	2 (9)	5 (22)	10 (43)	6 (26)
Sadness	0 (0)	2 (6)	16 (48)	15 (45)	0 (0)	1 (4)	12 (48)	12 (48)	1 (4)	7 (30)	11 (48)	4 (17)
Pity	9 (27)	4 (12)	7 (21)	13 (39)	0 (0)	7 (28)	4 (16)	11 (44)	2 (9)	5 (22)	11 (48)	5 (22)
Which difficulties do you think people with epilepsy have in their daily lives?												
Relationships	10 (30)	10 (30)	7 (21)	6 (18)	0 (0)	6 (24)	13 (52)	6 (24)	1 (4)	6 (26)	13 (57)	3 (13)
Work	5 (15)	11 (33)	5 (15)	12 (36)	0 (0)	7 (28)	12 (48)	6 (24)	0 (0)	2 (9)	14 (61)	7 (30)
School	4 (12)	5 (15)	16 (48)	8 (24)	0 (0)	7 (28)	12 (48)	5 (20)	0 (0)	2 (9)	13 (57)	8 (35)
Friendships	12 (36)	10 (30)	10 (30)	1 (3)	0 (0)	12 (48)	11 (44)	2 (8)	2 (9)	6 (26)	12 (52)	3 (13)
Sexual	12 (36)	13 (39)	7 (21)	1 (3)	0 (0)	8 (32)	14 (56)	2 (8)	2 (9)	8 (35)	11 (48)	2 (9)
Emotional	4 (12)	3 (9)	14 (42)	12 (36)	0 (0)	1 (4)	19 (76)	3 (12)	0 (0)	4 (17)	11 (48)	8 (35)
Prejudice	6 (18)	5 (15)	10 (30)	12 (36)	0 (0)	3 (12)	13 (52)	8 (32)	0 (0)	5 (22)	8 (35)	10 (43)
How do you think that people with epilepsy feel?												
Worried	3 (9)	5 (15)	19 (58)	6 (18)	0 (0)	8 (32)	12 (48)	5 (20)	1 (4)	3 (13)	16 (70)	3 (13)
Dependent	8 (24)	10 (30)	8 (24)	7 (21)	0 (0)	6 (24)	17 (68)	2 (8)	0 (0)	7 (30)	15 (65)	1 (4)
Incapable	21 (64)	8 (24)	2 (6)	2 (6)	0 (0)	13 (52)	12 (48)	0 (0)	2 (9)	15 (65)	6 (26)	0 (0)
Fearful	15 (45)	9 (27)	6 (18)	3 (9)	0 (0)	14 (56)	9 (36)	1 (4)	2 (9)	9 (39)	12 (52)	0 (0)
Depressed	8 (24)	7 (21)	14 (42)	4 (12)	0 (0)	6 (24)	14 (56)	5 (20)	0 (0)	6 (26)	16 (70)	1 (4)
Ashamed	16 (48)	5 (15)	10 (30)	2 (6)	0 (0)	13 (52)	8 (32)	1 (4)	2 (9)	12 (52)	9 (39)	0 (0)
The same as those without epilepsy	8 (24)	12 (36)	8 (24)	5 (15)	0 (0)	11 (44)	7 (28)	0 (0)	5 (22)	14 (61)	3 (13)	1 (4)
In your opinion, the prejudice in epilepsy will be related to?												
Relationships	11 (33)	7 (21)	10 (30)	5 (15)	0 (0)	6 (24)	15 (60)	4 (16)	1 (4)	9 (39)	8 (35)	4 (17)
Marriage	14 (42)	10 (30)	6 (18)	3 (9)	0 (0)	8 (32)	11 (44)	4 (16)	1 (4)	9 (39)	10 (43)	3 (13)
Work	13 (39)	5 (15)	10 (30)	5 (15)	0 (0)	5 (20)	10 (40)	8 (32)	0 (0)	3 (13)	12 (52)	8 (35)
School	14 (42)	5 (15)	11 (33)	3 (9)	0 (0)	4 (16)	13 (52)	7 (28)	0 (0)	6 (26)	9 (39)	8 (35)
Family	12 (36)	8 (24)	8 (24)	5 (15)	0 (0)	15 (60)	3 (12)	0 (0)	11 (48)	5 (22)	4 (17)	3 (13)

For comparative questions in the PWE group, the median prejudice score was 6 for epilepsy, 7.1 for AIDS and 3.7 for diabetes. Nonparametric analysis revealed a difference among the three groups (Friedman[2]=57, $p<0.001$). For the PR group, the median prejudice score was 5.2 for epilepsy, 7 for AIDS, and 3.4 for diabetes. Nonparametric analysis revealed a difference among the three groups (Friedman[2]=29, $p<0.001$). For the community group, the median prejudice score was 5.2 for epilepsy, 7.2 for AIDS and 3.4 for diabetes. Nonparametric analysis revealed a difference among the three groups (Friedman[2]=34, $p<0.001$). In all situations, Wilcoxon paired analyses corrected for multiple comparisons revealed significant differences among the three groups (AIDS>epilepsy>diabetes). For the question "Do you think people with epilepsy are stigmatized or rejected by society?" 76% of the PC group, 64% of the PR group and 73% of patients believed that people with epilepsy are stigmatized or rejected by society. The subjects' answers using the scale from 1 to 4 (from not at all to totally) were then used to calculate a SSE general score (Table 2). The means and standard deviations (SD) of the total stigma scores were: 57, SD=10.09 for patients; 66, SD=7.48 for patients' relatives; and 65, SD=8.83 for community.

All of the questionnaire items were answered. The mean time for completion of the scale was twenty minutes. After completing the scale, on direct questioning the subjects stated that they did not have problems understanding the questions.

Reliability and validity evaluation: the internal consistency of the SSE for the score showed a general Cronbach's α coefficient was 0.785 for the patients with epilepsy, 0.733 for patients' relatives and 0.798 for people in the community.

Table 3 shows Pearson correlation coefficients for SSE scores and the results of the questions "What score would you rate for the prejudice that the general population has toward people with Epilepsy, AIDS, and Diabetes (0=no prejudice, 10=maximum prejudice)?"

Regarding the comparative question "Do you believe that people with epilepsy are stigmatized or rejected by society? (yes or no)," the median of SSE scores of patients that believe that people with epilepsy are stigmatized or rejected was 56, which is high-

Table 3. Pearson's correlation with comparative questions and SSE score

Comparative questions																	
Epilepsy						AIDS						Diabetes					
Patients		Relatives		Community		Patients		Relatives		Community		Patients		Relatives		Community	
R	p	R	p	R	p	R	p	R	p	R	p	R	p	R	p	R	p
0.600	0.095	0.606	0.108	0.394	0.063	0.285	0.192	0.123	0.316	0.132	0.286	0.316	0.180	0.130	0.311	0.143	0.264

R: pearson's correlation coefficient. The scores rated for the prejudice that the general population has toward epilepsy, AIDS, and diabetes (0=no prejudice, 10=maximum prejudice) when correlated for SSE score showed in overall a significant correlation only with epilepsy but not with AIDS or diabetes

Table 4. SSE score correlated with the eight domains of the quality of life questionnaire (SF-36)

Domains of the quality of life questionnaire (SF-36) correlated to SSE score	r	p
Physical functioning (PF)	-0.389	0.022
Role limitations because of physical health problems (RP)	0.254	0.154
Bodily pain (BP)	0.225	0.208
Social functioning (SF)	-0.599	0.001
General mental health (MH)	0.254	0.154
Role limitations because of emotional problems (RE)	-0.442	0.010
Vitality (energy/fatigue) (VT)	-0.442	0.010
General health perception (GH)	-0.400	0.021

R: spearman's correlation coefficient; SSE: showed a negative linear correlation with the domains of quality of life

Table 5. SSE score correlation with the BDI, HSI, marital status, education level, epilepsy duration, and economic and education levels

	r	p
BDI	0.621	0.000
HAI	0.294	0.094
Marital Status	0.354	0.044
Education Level	0.187	0.145
Economic Level	0.294	0.094
duration of illness	0.111	0.471
Age of epilepsy onset	0.154	0.294

BDI: beck depression index; HAI: Hamilton anxiety index; R: spearman's correlation coefficient; SSE: showed a correlation with the BDI and marital status

er than the median of SSE scores (36) of patients who did not believe it (Mann-Whitney U test, $p=0.004$). Similarly, the median of SSE scores of the PR group who believed that people with epilepsy are stigmatized or rejected was 67, which is higher than the median of SSE scores (49) of people who did not believe it (Mann-Whitney U test, $p=0.01$). The median of SSE scores of the PC group who believed that people with epilepsy are stigmatized or rejected was 66, which is higher than the median of SSE scores (46) of people who did not believe it (Mann-Whitney U test, $p=0.01$).

The quality of life and stigma scores were also correlated. Except limitations because of emotional problems, bodily pain, and general mental health, significant differences were observed in all the other subscales of

the SF-36. Table 4 shows Spearman correlation coefficients for the relationships between SSE scores and the SF-36 instrument.

Results showed that there were strong correlations between positive SSE scores and BDI ($p=0.001$) scores, and marital status (the married patients' SSE scores were higher than those of unmarried patients); there were not any correlations between SSE scores and HAI scores ($p:0.94$), age of epilepsy onset ($p:0.295$), time of epilepsy ($p:0.097$) or education level ($p:0.145$) Table 5. The only demographic factor significantly associated with stigmatization in our study was marital status.

DISCUSSION

The SSE is one of the first instruments to allow for quantification of stigma in epilepsy. The questions of the SSE have satisfactory content validity and high internal consistency. It complies with the main requirements of a validation process, offering reliable measurements of stigma in epilepsy (13).

Numerical scales are easy to analyze, allowing assessment of high numbers of subjects in an objective manner (13). In our study all subjects completed the measure in a short time and very easily after the first correction.

Like the original article, the results of the comparative questions suggest that there exists a difference in the stigma perception of chronic diseases such as epilepsy, AIDS, and diabetes. AIDS had the highest level of stigma and diabetes had the lowest. Epilepsy was in the intermediate position but close to AIDS. We agree with the creators of the SSE that the stigma measured by the SSE appeared to be specific for epilepsy in the analysis of correlation with these questions.

Furthermore, the results of a comparative instrument, the SF-36, completed by patients with epilepsy also showed significant negative correlations to SF-36, and showing that the higher the stigma score, the lower is the quality of life.

Stigma associated with epilepsy has considered to be one of the most important factors having a negative influence on the lives of PWE and their families, as children with epilepsy may be banned from school, adults may be barred from marriage, and employment is often denied, even when seizures would not render the work unsuitable or unsafe. (6). Unsatisfactory knowledge and false perceptions about the disease make epilepsy a stigmatizing condition within the community. In this situation, epilepsy is considered as a social problem as well as a clinical disease. Furthermore, negative attitudes on the part of family and friends, in addition to difficulties in interpersonal relationships, are factors that perpetuate stigma in society. The are asmost affected by epilepsy observed in this study relate to difficulties at work, at school, and in social interactions, activity restriction and negative feelings by patients (18).

Furthermore, people with epilepsy may experience social disqualification and discrimination as a consequence of stigma, which lead to a lower qual-

ity of life. They are less often married, less educated, and more underemployed and unemployed than the general population: The unemployment rates for Turkey in the general population in 2013 and 2014 were 9.7 and 10.1%, respectively (19,20). In our study, the unemployment rate (44.8%) was prominently higher than the national values. Moreover, a significant percentage of patients reported difficulty in finding a job and experienced being terminated from their job because of their epilepsy (11). In Doğan Ak et al. (11) study, the marriage rate in the subgroup composed of 15-49-year-old female patients (45.32%) was significantly below the national marriage rate for Turkey with the same age group (65.2%) (21). In our study, the marriage rate (57.6%) was below the national marriage rate for Turkey but higher than the rate reported by Doğan Ak et al. (11) In our study, the married patients' SSE scores were higher than those of the unmarried patients. This result may be because only one patient was divorced and the majority of patients were married.

In summary, higher unemployment and lower marriage rates, and impaired personal independence indicate that PWE still struggle, especially with social problems. Prejudice and discrimination are often worse than the seizures themselves in terms of impact on the daily lives of people with epilepsy and their family. Understanding this aspect of epilepsy is important for reducing the burden of epilepsy. We believe that the Turkish version of the SSE is ready to be used and opens new prospects in the study of stigmata epilepsy as it allows objective quantification. In the same time it also can be used to assess intervention campaigns and cross-cultural evaluations. The SSE can be used to provide quantitative data regarding the magnitude of the stigma perception of epilepsy in our society. Additionally, epilepsy is a condition that influences perceptions of health and people's quality of life. It is important to highlight that poor functionality is very stigmatizing and there are strong correlations between poor functionality and BDI scores. For this reason, physical, economical, and psychological support must be supplied by patients' families, society, and politicians.

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