

# Validity and reliability study of the turkish version epilepsy self-stigma scale (ESSS-T)

Esra Yildiz<sup>a,\*</sup>, Takayuki Iwayama<sup>b,c</sup>, Izumi Kuramochi<sup>b</sup>

<sup>a</sup> Faculty of Nursing, Atatürk University, Erzurum, Turkey

<sup>b</sup> Department of Psychiatry, Saitama Medical Center, Saitama Medical University, Saitama, Japan

<sup>c</sup> Department of Psychology, Showa Women's University, Tokyo, Japan

## ARTICLE INFO

### Keywords:

Epilepsy  
People with epilepsy (PWE)  
Self-stigma  
Reliability  
Validity

## ABSTRACT

**Aim:** We translated the Epilepsy Self-stigma Scale (ESSS) into Turkish and aimed to examine the Turkish version ESSS (ESSS-T) validity and reliability.

**Materials and method:** From April to August 2023, patients with epilepsy (PWE) were recruited from the neurology outpatient clinic of Atatürk University Hospital in the eastern Turkish city of Erzurum (inclusion criteria: age 18 years or older and adequate reading and speaking ability in Turkish). We conducted our survey using a self-administered questionnaire. The questionnaire consisted of the ESSS-T after appropriate translation by back-translation, and self-esteem (the Rosenberg's Self-Esteem Scale, RSES), depression (the Neurological Disorders Depression Inventory for Epilepsy, NDDI-E), and general stigma (the Stigma Scale for Epilepsy, ESE) for construct validity. Exploratory factor analysis (EFA) and confirmatory factor analysis (CFA) were used to test factorial validity. Also, Cronbach's alpha coefficient was calculated to verify reliability.

**Results:** Of the 126 patients, 106 agreed to give informed consent and responded to the questionnaire (84.1 % response rate). The results of EFA suggested the same three-factor structure as in the original version, but CFA showed some limitations in interpreting the three-factor structure and it may be safer to understand it as a unifactorial structure. The alpha coefficients were also validated by the ESSS-T. The alpha coefficients were  $\alpha = 0.74$  for the ESSS-T scale as a whole and  $\alpha = 0.69-0.74$  for each subscale, which were generally acceptable values.

**Conclusion:** The Turkish version of the ESSS proved valid and reliable. It is a measurement tool with a three-dimensional structure. It can be used to assess the self-stigmatization of patients with epilepsy in Turkey.

## 1. Introduction

Epilepsy is a neurological disease characterized by a predisposition to epileptic seizures, affecting individuals' life [1]. It is estimated to affect approximately 50 million people worldwide [2]. Epilepsy has negative effects not only physically but also psychologically and socially. People with epilepsy (PWE) often have depression, stigma, anxiety, low self-esteem due to the prejudice that exists in their background, resulting in many hidden and internalized negative effects [3]. Especially epilepsy causes stigmatization of both individuals and their families by society [4,5]. Self-stigmatization is the internalization of society's negative attitudes towards diseases by individuals and is generally seen in PWE [6]. Higher levels of self-stigma have been linked to lower self-esteem, and have also been associated with missed

opportunities for employment and independent living [7]. The consideration of self-stigma is particularly important in the treatment of PWE due to its potential influence on treatment outcomes, patient prognosis, and quality of life (QOL).

In Turkey, there is the stigma scale for epilepsy, developed by Baybaş et al. 2017 [4]. This scale was determined that the Turkish validity and reliability study of the stigma scale for PWE was conducted by Pazarıcı et al. 2017 [8]. However, these scales are designed to assess the general stigma of PWE, not only self-stigma (internalized stigma) and have as many as 32 items. There is no simple questionnaire to assess the severity of an individual's self-stigma in Turkey. One of the simplest and most specialized scales for measuring individual self-stigma is the Epilepsy Self-Stigma Scale (ESSS), created in Japan. ESSS is an 8-item questionnaire designed to assess the self-perceived stigma experienced by PWE.

\* Corresponding author at: Faculty of Nursing, Atatürk University, Erzurum, Turkey

E-mail addresses: [esrazengin82@gmail.com](mailto:esrazengin82@gmail.com) (E. Yildiz), [t-iwayama@swu.ac.jp](mailto:t-iwayama@swu.ac.jp) (T. Iwayama).

<https://doi.org/10.1016/j.yebeh.2023.109600>

Received 20 October 2023; Received in revised form 11 December 2023; Accepted 21 December 2023

Available online 30 December 2023

1525-5050/© 2023 Elsevier Inc. All rights reserved.

The reliability and validity of this scale has been confirmed in a previous study PWE [6]. One of the main characteristics of this scale is that it was developed based on the results of semi-structured interviews on PWE self-stigma, and it has high surface validity and reflects PWE narratives as much as possible in the scale items. The ESSS is rated on a four-point Likert-type scale (1: Strongly Disagree, 2: Slightly Agree, 3: Agree, 4: Strongly Agree), with scores ranging from 8 to 32, and higher scores indicating greater self-stigma caused by epilepsy. For the original Japanese version, three factors have been found: Internalization of stigma (internalized stigma), Societal incomprehension (perception of stigma), and Confidentiality (actions taken to avoid stigma). Cronbach's  $\alpha$  for the total scale and each factor demonstrated good internal consistency ( $\alpha = 0.76$  to  $0.87$ ) and high test-retest reliability ( $r = 0.72$  to  $0.90$ ). Furthermore, all scales and factors were well correlated ( $r = -0.30$  to  $0.55$ ) with Rosenberg's Self-Esteem Scale (RSES) and Beck Depression Scale (BDI-II), and the confidentiality factor was found to be uncorrelated with an objective self-stigma rating from the primary care physician, thus confirming the construct. Conceptual validity has also been adequately verified.

As described above, a simple and accurate scale to measure self-stigma in epilepsy patients is required to improve their quality of life and provide appropriate support. This research aimed to develop the Turkish version of the Epilepsy Self-Stigma Scale (ESSS-T), and to evaluate its reliability and validity. The development of a questionnaire such as the ESSS-T is expected to make it possible to assess the self-stigma experienced by PWE in Turkey, identify factors related to the intensity of self-stigma in PWE, and consider strategies for appropriate support and intervention.

## 2. Material and method

### 2.1. Participants and procedure

These study participants were PWE who applied to the neurology outpatient clinic of Ataturk University Hospital in Erzurum, a city in eastern Turkey. We asked patients whose neurologists were certain that they had epilepsy based on electroencephalography and clinical diagnosis to participate in the study and excluded patients who were without a confirmed diagnosis of epilepsy or who had possible psychogenic seizures.

The criteria for inclusion in the study were to be over 18 years old, to understand Turkish, to be open to communication, and to be willing to participate in the research. Exclusion criteria were intellectual disability or severe mental conditions, inability to complete the questionnaires due to language problems, and inability to consent to study participation voluntarily.

From April to July 2023, we asked 126 patients who met the inclusion criteria directly to participate in the study. We provided verbal and written information about the study; 106 patients (response rate: 84.1 %) signed their consent to participate and responded to the questionnaire.

### 2.2. Measurements

#### 2.2.1. Sociodemographic data

This survey consisted of items asking about the participants' age, duration of illness, gender, education level, marital status, working status, profession, and seizure frequency.

#### 2.2.2. The Turkish version of the epilepsy Self-Stigma scale (ESSS-T)

In accordance with the Principles of Good Practice Translation and Cultural Adaptation of Patient-Reported Outcomes Measures, we translated the Japanese version of the ESSS [9] into a Turkish version (ESSS-T). With these principles, the aim was to develop a culturally sensitive version of the scale equivalent to the original in the following aspects: item, semantic, and operational and measurement equivalence.

The integrated form was back-translated into Turkish and English by two independent translators and combined into one back-translation. We compared the back-translation with the original version. The Turkish suitability of the items was evaluated by the Davis technique by 8 academics whose second language is English, who are experts in the field of scale development in Turkey. Davis proposes that researchers should consider 80 percent agreement or higher among judges for new instruments. All of the items of the scale were evaluated as "appropriate". Finally, we conducted an expert group meeting to evaluate the content and face validity of the translated versions, the results of the pretesting, and the equivalence with the original, i.e., conceptual, semantic, and normative equivalence for each item. The ESSS-T was conducted on a four-Likert scale, as in the original Japanese version. The Japanese version of the Epilepsy Self-Stigma Scale is designed to help patients identify whether or not they are aware of their self-stigma, using a scale of "1. Strongly disagree" and "2-3 Slightly agree, Agree, or Strongly agree" [6]. The German version of the Epilepsy Self-Stigma Scale, which has already been translated, has the same scale items. There is some inequality between scale items, but we consciously chose the same items, as our goal is to enable future multicultural self-stigma comparisons of people with epilepsy [10].

#### 2.2.3. Rosenberg's Self-Esteem scale (RSES)

We assessed the construct validity of the ESSS-T by measuring self-esteem with the Rosenberg Self-Esteem Scale (RSES) Turkish version. The scale in the literature was developed by M. Rosenberg in 1965 [11]. The validity and reliability of the scale, which was adapted into Turkish by Çuhadaroglu (1986) [12].

In this study, only the subcategory of "Self-Esteem" consisting of 10 items was used. The scale is a four-point Likert-type question. The scale is a four-point Likert (Strongly Agree: 4 Agree: 3 Disagree: 2 Strongly Disagree: 1), with scores ranging from 10 to 40 points.

#### 2.2.4. Neurological Disorders depression Inventory for epilepsy (NDDI-E)

We measured depressive symptoms with the Neurological Disorders Depression Inventory for Epilepsy Turkish version (NDDI-E-T) in order to test construct validity in conjunction with the original Japanese version. The original NDDI-E Scale was developed by Gilliam et al. in 2006 in the USA, in the English language, to evaluate the depression of patients with epilepsy [13]. The NDDI-E T validity and reliability study was conducted by Cengiz and Tanik in Yozgat city. The scale consists of 6 items and is a four-point Likert-type scale scored from 1 (Always/often) to 4 (never-always) with scores ranging from 6 to 24 points. The cutoff point is over 15 in Turkey [14].

#### 2.2.5. The stigma scale for Epilepsy (ESE)

We conducted a convergent validity test of the ESSS-T by employing a stigma scale for Turkish epilepsy patients [4], even though it is not a scale specifically designed to measure self-stigma. The scale consists of 32 items and is administered on a 4-point Likert scale (1 point being "not at all disagree" and 4 points being "completely agree"). Items 31 and 32 are reverse coded.

When calculating the scale scores, the maximum total score that can be obtained from the scale is accepted as 100, and the scores obtained by the participants are evaluated on a 100-point system. The scale we applied to patients had 32 questions and patients could score between 32 and 128. Baybaş et al. turned this into a point system between 25 and 100. It was calculated so that someone who gave 1 point to all 32 questions would get 25, and someone who gave 4 points to all 32 questions would get 100. Scores ranged from 25 to 100, with 50 being the cutoff point, and scores of 50 or below were considered to be free of stigma. On the other hand, scores above 50 were evaluated as having stigma, and the severity of stigma could also be evaluated, with 51 to 75 points being considered as having moderate stigma and 76 to 100 points as having severe stigma [4].

**Table 1**  
The values of Demographic Variables and Descriptive Statistics for Each Scale.

	M ± SD
<b>Age</b>	37.78 ± 17.01
<b>Disease Duration</b>	11.60 ± 9.70
<b>ESSS-T</b>	19.27 ± 4.32
<b>SES</b>	49.61 ± 13.72
<b>NDDI-E</b>	20.72 ± 5.33
<b>RSES</b>	15.07 ± 3.40
<b>HA</b>	63.96 ± 23.36
<b>QOL</b>	6.20 ± 2.15
<b>Gender (N/%)</b>	
Female	53 (50)
Male	53 (50)
<b>Educational background (N/%)</b>	
Illiterate	11 (10.4)
Literate (not graduated)	3 (2.8)
Primary school	19 (17.9)
Middle school	21 (19.8)
High school	27 (25.5)
University	23 (21.7)
Postgraduate	2 (1.9)
<b>Marital Status</b>	
Married	60 (56.6)
Single	43 (40.6)
Widow/Divorced	3 (2.8)
<b>Working status</b>	
Not working	74 (69.8)
Working	32 (30.2)
<b>Seizures Time (N/%)</b>	
No seizures in the last six months	20 (18.9)
1–2 seizures in the last six months	21 (19.8)
3–5 seizures in the last 6 months	19 (17.9)
1–2 seizures per month	19 (17.9)
1 seizure or more per week	10 (9.4)
1 seizure or more per day	17 (16.0)

Ab\*abbreviations: ESSS-T, The Turkish version of the Epilepsy Self-Stigma Scale; SES, The Stigma Scale for Epilepsy; NDDI-E, Neurological Disorders Depression Inventory for Epilepsy; RSES, Rosenberg Self-Esteem Scale; HA, Subjective Health Awareness; SD, standard deviation.

**2.2.6. Subjective health awareness (HA)**

As a convenience measure for the same purpose as quality of life, participants were asked to respond on a 0–10 scale for subjective health awareness. Higher scores indicate higher subjective health awareness.

**2.2.7. Subjective quality of life (QOL)**

As a convenience measure to further test construct validity, participants were asked to respond on a 0–10 scale regarding subjective quality of life. Higher scores mean higher subjective Quality of Life.

**2.3. Data analysis**

First, means and standard deviations were calculated to evaluate the participants' demographic data, and item analysis was used to confirm the ceiling-floor effect. Next, the factor structure of the ESSS-T was examined by exploratory factor analysis (EFA). After confirming the validity of conducting factor analysis by the Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy and Bartlett's sphericity test, maximum likelihood methods and Promax rotation were employed for factor extraction as in the original Japanese version. The number of factors was determined based on Kaiser-Guttman's criterion and scree plot, factor loadings for each item. After checking the number of factors, a confirmatory factor analysis (CFA) was performed. Model fit was assessed by chi-square values, comparative fit index (CFI), and root mean square error of approximation (RMSEA)[15,16].

Second, to examine the reliability of the ESSS-T produced by this procedure, the Cronbach  $\alpha$  coefficient was calculated and internal consistency was evaluated. Then, correlation analyses were conducted among the scales to examine construct validity. All analyses were

**Table 2**  
Results of exploratory factor analysis of the ESSS-T.

Items ( $\alpha = 0.74$ )	1	2	3
<b>Internalization of stigma (<math>\alpha = 0.74</math>)</b>			
esss 3. "I feel myself different from others because of I have epilepsy."	<b>0.835</b>	0.006	0.090
esss 2. "I feel discriminated against by others because of epilepsy."	<b>0.731</b>	-0.114	-0.150
esss 4. "I feel sometimes embarrassed for epilepsy."	<b>0.505</b>	0.312	-0.013
esss 1. "When I hear news about traffic accidents related to epileptic seizures. I feel like I'm being told about myself."	<b>0.405</b>	0.040	0.070
<b>Social incomprehension (<math>\alpha = 0.69</math>)</b>			
esss 5. "Ordinary people do not understand my suffering from epilepsy and the worry of seizures."	0.058	<b>0.757</b>	0.041
esss 6. "Few people have the correct information about the disease of epilepsy."	0.073	<b>0.716</b>	-0.043
<b>Confidentiality (<math>\alpha = 0.74</math>)</b>			
esss 7. "I want to hide the fact that I go to hospital to receive therapy for epilepsy."	-0.044	-0.086	<b>0.940</b>
esss 8. "It is hard to tell others that I have epilepsy."	0.022	0.099	<b>0.628</b>
Inter factor correlation	1	2	3
1		0.066	0.501
2			0.123

conducted using SPSS 22 and LISREL 8.8 statistical software.

**2.4. Ethical principles**

Permission dated January 26th, 2023, and numbered B.30.2. ATA.0.01. /76 was obtained from the Atatürk University Medical Ethics Committee to conduct the research. Permission dated April 10th, 2023, and numbered E-45361945-000-2300118265 was obtained from Atatürk University Research Hospital Neurology Department. Verbal consent was obtained from the participants.

**3. Results**

**3.1. Descriptive statistics for demographic variables and each scale**

106 out of 126 patients who had been asked to participate completed the study questionnaire (response rate: 84.1 %). All questionnaires of these analyzed patients had been completely answered without missing values. As for demographic and clinical characteristics in Table 1, the patients covered an age, reflecting their educational background and employment status, and the proportion of female and male patients was equal. The mean disease duration of the respondents were 11.60 ± 9.70 years, and their ESSS-T score was 19.27 ± 4.32.

**3.2. Exploratory factor analysis of ESSS-T**

Before conducting the EFA, the ceiling and floor effects were checked in the item analysis (Appendix 1). A slight ceiling effect was observed in items 5 and 6 but was deemed not to interfere with the analysis, so an EFA was conducted for all 8 items. KMO's measure of sampling adequacy was 0.742, which is generally a good value [9], and Bartlett's sphericity test was significant, confirming the appropriateness of conducting a factor analysis. The Guttman criterion (eigenvalue > 1) and the scree plot confirmed the validity of the same three factors as in the original Japanese version, and the model fit of the three factors was also good ( $\chi^2(7) = 3.68, p = 0.82$ ). The eigenvalues of the three factors were 3.028, 1.576, and 1.002.

A three-factor structure was assumed, and factor analysis was conducted using the maximum likelihood method and ProMax rotation. Since the same factor structure as in the original version was obtained, it was adopted as the final factor structure (Table 2). Only item 4 "I feel

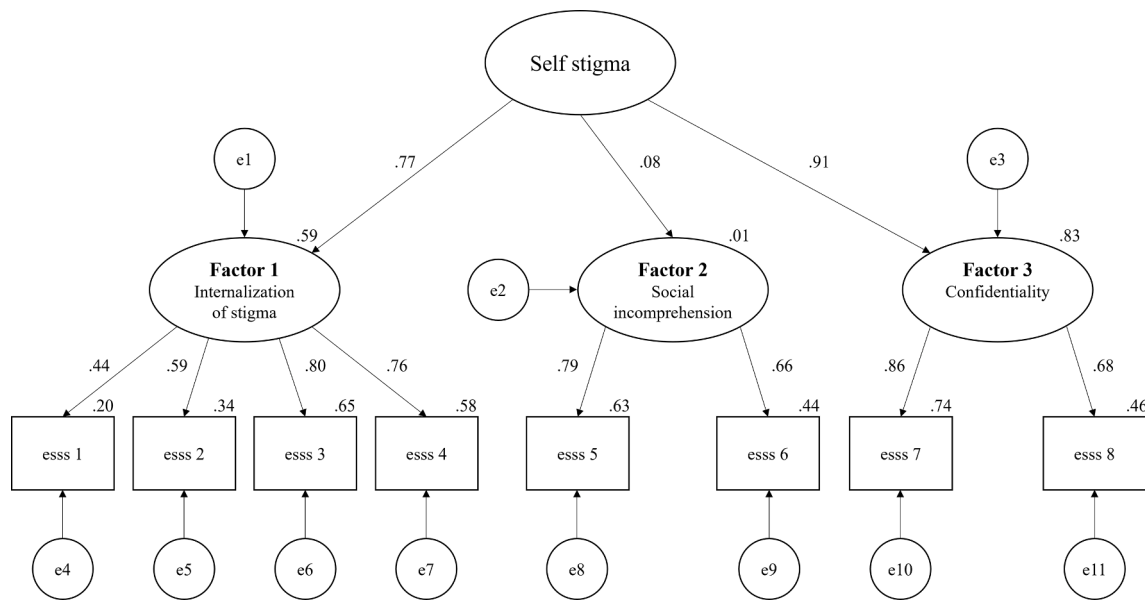


Fig. 1.

**Table 3**  
Correlation analysis of ESSS-T and each scale.

	SES	NDDI-E	RSES	HA	QOL
ESSS-T	0.45**	0.47**	-0.46**	-0.24*	-0.24*
Internalization of stigma	0.50**	0.44**	-0.51**	-0.30**	-0.28**
Social incomprehension	-0.10	0.04	-0.01	0.08	-0.01
Confidentiality	0.39**	0.43**	-0.30**	-0.18	-0.12

Note. HA: Subjective of Health Awareness, QOL: Subjective of Quality of Life.  
\*\*  $p < 0.01$ .  
\*  $p < 0.05$ .

sometimes embarrassed for epilepsy.” “Bazen epilepsiden utanıyorum” showed factor loadings across Factor 1 and Factor 2, but was included without deleting it. As in the original version, the factor names were Internalization of stigma (internalized stigma), Societal incomprehension (perception of stigma), and Confidentiality (actions taken to avoid stigma). Correlations between factors were found only for the first and third factors. Correlations between factors were observed only for Factor 1 and Factor 3, and Factor 2 did not correlate well with the other factors.

### 3.3. Confirmatory factor analysis of ESSS-T

In the confirmatory factor analysis (CFA) with a three-factor structure, we analyzed the validity of our structural equation model with the help of evaluation guidelines [16] and found a generally good fit (CFI = 0.97, RMSEA = 0.06).

Initially, we conducted CFA based on a three-factor model assuming covariance for each factor, but the model fit was poor, so we conducted analysis using a model assuming a “self-stigma” factor as a higher-order factor of the three factors, and the model fit was generally good as described above, so we used it as the final model (Fig. 1). The standardized coefficients from the higher-order “self-stigma” factor to each factor showed that only the standardized coefficient for the second factor, the “Social incomprehension” factor, was lower than the others.

### 3.4. Reliability and construct validity

To examine the reliability of the ESSS-T, for which a three-factor

structure was confirmed, the internal consistency of the items as a whole and by factor was evaluated based on Cronbach’s alpha coefficient. The results showed that the overall scale ( $\alpha = 0.74$ ), the first factor “Internalization of stigma” ( $\alpha = 0.74$ ), the second factor “Social incomprehension” ( $\alpha = 0.69$ ), and the third factor “Confidentiality” ( $\alpha = 0.74$ ). Although Factor 2 was slightly low, the internal consistency of the scale as a whole, Factor 1 “Internalization of stigma” and Factor 3 “Confidentiality” showed acceptable values. The construct validity and concurrent validity of the social incomprehension were not ideal.

Next, we conducted a correlation analysis between the ESSS-T and each scale to examine construct validity and concurrent validity (Table 3).

The analysis revealed a weak significant positive correlation between all ESSS-T items and SES, NDDI-E, ( $r = 0.46, p < 0.01$ ;  $r = 0.48, p < 0.01$ ), a weak significant negative correlation with RSES ( $r = -0.46, p < 0.01$ ) and a weak significant negative correlation with HA and quality of life ( $r = -0.24, p < 0.05$ ;  $r = -0.24, p < 0.05$ ).

In terms of subscales, Internalization of stigma was significantly positively correlated with SES, NDDI-E and RSES ( $r = 0.50, p < 0.01$ ;  $r = 0.44, p < 0.01$ ;  $r = -0.51, p < 0.01$ ). There is a statistically insignificant correlation between social incomprehension and NDDI and SES. Confidentiality was significantly positively weakly correlated with SES, NDDI-E ( $r = 0.39, p < 0.01$ ;  $r = 0.43, p < 0.01$ ).

## 4. Discussion

The purpose of this study was to develop a Turkish version of the Epilepsy Self-Stigma Scale (ESSS-T) to measure the degree of self-stigma in PWE and to examine the reliability and validity of the scale.

### 4.1. Reliability and validity of the ESSS-T

The ESSS-T, including its subscales, was found to have sufficient construct validity as well as the original version of the ESSS, including theoretically assumed correlations with existing stigma scales and other measures. On the other hand, there were some problems that differed from those of the original version.

First, the exploratory factor analysis (EFA) suggested the same three-factor structure as in the original version. However, in the validation factor analysis (CFA), the model fit did not show good values unless self-stigma was placed as a higher-order factor. Furthermore, when self-

**Table A1**  
Percentage and number distributions of ESSS-T answers.

Items			1 (Strongly Disagree)		2 (Slightly agree)		3 (Agree)		4 (Strongly Agree)	
	M	SD	N	%	N	%	N	%	N	%
1	2.14	0.97	31	29.2	41	38.7	22	20.8	12	11.3
2	1.78	0.97	54	50.9	30	28.3	13	12.3	9	8.5
3	2.22	0.91	24	22.6	45	42.5	27	25.5	10	9.4
4	2.17	0.93	29	27.4	39	36.8	29	27.4	9	8.5
5	3.18	0.83	0	0	12	11.3	40	37.7	54	50.9
6	3.40	0.69	5	4.7	13	12.3	46	43.4	42	39.6
7	2.01	0.97	38	35.8	40	37.7	17	16.0	11	10.4
8	2.38	0.97	24	22.6	31	29.2	38	35.8	13	12.3

stigma was placed as a higher-order factor, the standardized coefficient from self-stigma to the second factor, “social incomprehension,” showed a low value, indicating that it was partially difficult to interpret the model as a three-factor structure. The second factor “Social incomprehension” may reflect a different element than self-stigma in Turkey. Doğanavşargil et al., in their study of patients with epilepsy at a tertiary hospital in the city of Antalya, an urban area in the south of Turkey, found that the perceived stigma was similar to that in Europe [17]. This finding supports the findings of our research.

In the item analysis, there was a slight ceiling effect for both items 5 and 6, which make up the second factor. The reason for this result may be that the answer “strongly disagree” was never given among the answers given to item 5. Additionally, only five people answered strongly disagree on item 6. These answers, which are different from other questions, may have affected the reliability results. A stigma study of epilepsy patients in Turkey showed that 34 % of patients had experienced prejudice and another 16 % had experienced severe prejudice [5]. Therefore, the reason why the three-factor structure was not stable in this study may reflect many elements of the perceived social stigma of not being understood for epilepsy that PWE experience in Turkish society. When the German version of the ESSS (ESSS-G) [10] was developed, a three-factor structure was not suggested from the beginning, and a one-factor structure was used.

In addition, the internal consistency was lower than the original version by about 0.10, which was generally acceptable, but there were some issues, such as the second factor “Social incomprehension” being lower than 0.70 with  $\alpha = 0.69$ . This is an issue that was not seen when the ESSS-G [10] was developed. In particular, the low internal consistency of the second factor, “social incomprehension,” may indicate that although the tendency is the same as in Japan, the situations in which people feel social incomprehension, or distance from society, differ from person to person in Turkish society and cannot be adequately measured by the two items. Social incomprehension and confidentiality affect patients’ self-stigma. In Turkey, caring about what others think about you and its effects on social life cannot be denied. However, the common belief in Turkey is that if a person is sick, that illness has come from God and it must be accepted. For this reason, the fact that the research was conducted in this region where Islamic belief is widespread may have caused these results to be obtained.

A moderate statistically significant relationship was found between the SES scale used as a parallel form and the ESSS-T total score. This made us think that external stigma and self-stigma are related. Additionally, Internalization of stigma and Confidentiality subscales and ESSS-T total scores were related to NDDI-E and RSES scores. The findings are similar to the study conducted by Kuramochi and her colleagues [6]. Based on these results, it can be said that construct validity was fully confirmed in the ESSS-T. On the other hand, when focusing on the ESSS-T subscales, social incomprehension was not significantly correlated with the related scales, unlike previous studies. As discussed in the confirmatory factor analysis (CFA) section, the cultural background in Turkey is relevant, and aspects of self-stigma related to social alienation

may be more susceptible to cultural influences.

#### 4.2. Limitations

The first limitation of this study is the sample stratum. The study included patients from a university hospital in eastern Turkey, and the number of data included in the final analysis was limited to 106 patients. Therefore, it should be noted that the results of this study are not representative of Turkey as a whole. Studies on stigma reported to date have shown that there are differences depending on the cultural context of the stigma. In the region of Turkey where we conducted our study this time, different ethnic groups coexist, and the perception of epilepsy may differ depending on the birthplace and upbringing of each individual. Future studies will need to use the ESSS-T created in this study to collect data from a variety of regions and examine the differences in self-stigma trends of each region and the people living there from the data obtained in this study.

Finally, although our ESSS-T produced eight items with three higher-order factors and acceptable reliability (Cronbach’s  $\alpha = 0.69-0.74$ ), the construct validity and concurrent validity did not reach acceptable levels. Although the ESSS-T is a useful tool for measuring self-stigma in Turkish PWE, and for comparing self-stigma in other cultures, we believe that the three-dimensional structure should be carefully evaluated, and that one-dimensional values should be used for actual multi-cultural comparison studies.

#### 5. Conclusion

In this study, we attempted to develop a Turkish version of the ESSS (ESSS-T) that measures self-stigma in epilepsy patients. Validation of the ESSS-T after ensuring item equality with the original version showed that it was generally as reliable and valid as the original version, although internal consistency tended to be lower than in the original version.

The ESSS-T is useful for measuring self-stigma among Turks and would be useful for assessing perceptions of self-stigma in PWE and changes over time. Furthermore, the development of a Turkish version of the ESSS-G, in addition to the ESSS-G, will allow for cross-cultural comparisons of epilepsy-related self-stigma. We hope this scale will help clinicians and researchers in Turkey better understand the self-stigma experienced by PWE.

#### 6. Ethical publication statement

This study was conducted following the approval of the study protocol by the institutional review board of Ataturk University in Turkey (approval No. E-45361945-000-2300118265). Participation was voluntary, and information was collected anonymously after obtaining written consent from each respondent. Participants were assured that their data would be kept confidential throughout the data collection period. We confirm that we have read the Journal’s position on issues

involved in ethical publication and affirm that this report is consistent with those guidelines.

#### Author contributions

This study was designed by EY and IK. EY collected the data and EY and TI analyzed the data, together wrote the manuscript. EY, IK, and TI were involved in the research design and critically reviewed the manuscript for intellectual content. All authors contributed to the article and approved the submitted version.

#### Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

#### Acknowledgements

We would like to thank the institutions that gave permission for the research and the patients who agreed to participate in the research.

#### Appendix 1

See [Table A1](#).

#### References

- [1] Fisher RS, Acevedo C, Arzimanoglou A, Bogacz A, Cross JH, Elger CE, et al. ILAE official report: a practical clinical definition of epilepsy. *Epilepsia* 2014;55(4):475–82.
- [2] de Boer HM. Epilepsy stigma: moving from a global problem to global solutions. *Seizure* 2010;19(10):630–6.
- [3] Ak PD, Atakli D, Yuksel B, Guveli BT, Sari H. Stigmatization and social impacts of epilepsy in Turkey. *Epilepsy Behav* 2015;50:50–4.
- [4] Baybaş S, Yıldırım Z, Ertem DH, Dirican A, Dirican A. Development and validation of the stigma scale for epilepsy in Turkey. *Epilepsy Behav* 2017;67:84–90.
- [5] Yeni K, Tulek Z, Bebek N. Factors associated with perceived stigma among patients with epilepsy in Turkey. *Epilepsy Behav* 2016;60:142–8.
- [6] Kuramochi I, Iwayama T, Horikawa N, Shimotsu S, Watanabe S, Yamanouchi H, et al. Development and validation of the epilepsy self-stigma scale. *Epilepsia open* 2021;6(4):748–56.
- [7] Sirey JA, Bruce ML, Alexopoulos GS, Perlick DA, Friedman SJ, Meyers BS. Stigma as a barrier to recovery: Perceived stigma and patient-rated severity of illness as predictors of antidepressant drug adherence. *Psychiatr Serv* 2001;52(12):1615–20.
- [8] Kuloglu pazarci N, Parasiz yukselen N, Aydin S, Unlusoy acar Z, Necioglu orken D. Validation and reliability study of the Turkish version of the stigma scale of epilepsy. *Archives of Neuropsychiatry* 2017;54(4):295–300.
- [9] Field A. *Discovering statistics using IBM SPSS statistics*. London: SAGE Publications; 2013.
- [10] Kuramochi I, Iwayama T, Brandt C, Yoshimasu H, Bien CG, Hagemann A. Assessment of Self-Stigma in Epilepsy: Validation of the German version Epilepsy Self-Stigma Scale (ESSS-G). *Epilepsia open* 2023.
- [11] Rosenberg M. The measurement of self-esteem, society and the adolescent self-image. Princeton 1965::16–36.
- [12] Çuhadaroğlu F. Self-esteem in adolescents. Ankara, Turkey: Hacettepe University Faculty of Medicine, Psychiatry Department; 1986. Unpublished thesis.
- [13] Gilliam FG, Barry JJ, Hermann BP, Meador KJ, Vahle V, Kanner AM. Rapid detection of major depression in epilepsy: a multicentre study. *The Lancet Neurology* 2006;5(5):399–405.
- [14] Cengiz GF, Tanik N. Validity and reliability of the Turkish version of the Neurological Disorders Depression Inventory for Epilepsy (NDDI-E). *Epilepsy Behav* 2019;99:106471.
- [15] Hair JF, Babin BJ, Anderson RE, Black WC. *Multivariate Data Analysis*. 8th ed. England: Pearson Prentice; 2019.
- [16] Schermelleh-Engel K, Moosbrugger H, Müller H. Evaluating the fit of structural equation models: Tests of significance and descriptive goodness-of-fit measures. *Methods Psychol Res Online* 2003;8:23–74.
- [17] Doganavsargil-Baysal O, Cinemre B, Senol Y, Barcin E, Gokmen Z. Epilepsy and stigmatization in Turkey. *Epilepsy Behav* 2017;73:100–5.