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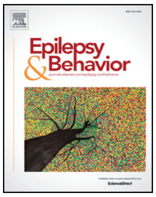

Development and psychometric evaluation of the Perceived Social Stigma Questionnaire (PSSQ-for adults with epilepsy): A mixed method study

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ABSTRACT

Background: Stigma is a subjective and multidimensional concept that is dependent on the understanding of individuals and social culture potentially influencing treatment and health in various aspects. The study of patient beliefs about epilepsy can help design preventive interventions. This study was conducted to develop and psychometrically evaluate the Perceived Social Stigma Questionnaire (PSSQ-for adults with epilepsy).
Methods: This mixed method study of sequential exploratory quantitative–qualitative design was conducted within the framework of instrument development variant. The qualitative section consisted of item development and scale development.
In the quantitative section (item analysis), the instrument was validated by investigating face, content, and construct validity and its reliability by internal consistency and stability.
Conclusion: The PSSQ-for adults with epilepsy is a culturally appropriate measure with strong psychometric properties. The tool developed in this study can measure the perceived social stigma of epilepsy.
However, more information on the scale is needed before it is adequately improved to test interventions, including concurrent validity and sensitivity to change.

1. Introduction

Epilepsy is a chronic cerebrovascular disorder that may affect people of all ages [1]. The disease is one of the most common neurological diseases worldwide such that epilepsy affects approximately 50 million people. The proportion of diagnosis of active epilepsy (i.e., the continuation of seizures or the need for treatment) to the general population at a given time interval has been estimated to be 4–10 per 1000 individuals. However, some studies in low- and middle-income countries reported much higher rates, i.e., 7–14 per 1000 population. According to the World Health Organization, the number of new cases of the disease per year is 4.2 million worldwide. This rate in high-income countries is 30–50 per 100,000 general population. In low- and middle-income countries, this rate can be even doubled [2]. The pooled prevalence of epilepsy in Iran was estimated to be around 5% (95% confidence interval (CI): 2 to 8) [3]. In addition to being faced with physical and psychological problems associated with epilepsy, patients with this disease also deal with numerous social problems, such as discrimination, occupational restrictions, marriage-related problems, and limited social relationships that are the main reasons for the common negative perceptions in society and the stigma of this disease [4,5].

Today, although knowledge, attitudes, and beliefs regarding epilepsy have improved in most countries, living in the community is still challenging for people with epilepsy because of the socially inappropriate, dominant beliefs in the community [6]. Interestingly, surveys in developing countries have shown common beliefs such as *Epilepsy is a contagious disease or a kind of mental retardation* in different cultures [7,8]. The low level of knowledge about the causes and symptoms of epilepsy in the community and how to manage it, on the one hand, and the lack of effort to destigmatize it, on the other hand, are known to be important reasons for the perseverance of the stigma of the disease [9].

Goffman considers stigma to be a distorted identity in which certain attributes are attached to a particular person or group of people; therefore, their credibility is devalued, and an unwanted distinction is imposed on them so that they will not be considered adequately qualified to be accepted in the community [10]. Social stigma is associated with various psychosocial and physical consequences such as feelings

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Abbreviations: KMO, Kaiser–Meyer–Olkin sampling index; BT, Bartlett's test of sphericity; CVR, content validity ratio; CVI, content validity index; PSSQ-for adults with epilepsy, Perceived Social Stigma Questionnaire for adults with epilepsy.

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of helplessness, depression, and anxiety and increased physical symptoms due to disease [11], reduced self-care behaviors [6], reduced self-esteem, embarrassment [12], and declined life satisfaction and quality of life [13].

In Asian countries, people with epilepsy are less likely to marry, have academic education, or be employed, and therefore, their quality of life is declined [14].

In this regard, studies have shown that one of the important barriers to promotion of a health-related lifestyle, compliance with therapeutic regimens [15], and provision of the opportunities to use therapeutic interventions is the stigma of the disease [16]. Masoudi et al. have argued that stigmatization is a procedure in which people detect the unhealthy persons by assigning stereotypes to them inappropriately. The literature on stigma in Iranian context has mainly emphasized patient compliance and the convenience of care. Besides that, scientific information about stigma has focused mainly on helping people and preventing discrimination [17].

In most cases, social stigma perceived by patients is associated with mood disorders, anxiety, and low self-esteem in them, leading to perception of epileptic seizures as a factor for further disability and lower levels of quality of life and psychological wellbeing. Considering the potential adverse impact of perceived social stigma of epilepsy on the various dimensions of patient health, it is necessary to integrate this type of stigma into a holistic healthcare system, especially for adults [18].

Therefore, different dimensions of this concept need to be explored by community health policy makers, healthcare providers, and researchers in order to develop and implement destigmatization programs [6]. Although it is important to examine the experiences and beliefs of family and community members about epilepsy, gathering information on patients' experiences and understanding their beliefs about the stigma of the disease by means of valid tools can lead to identifying their psychological and social challenges and developing efficient interventions for them.

In order to study the stigma in adults with epilepsy in terms of its different individual, environmental, and social levels, it is necessary to conduct research in different contexts and cultures according to specific requirements and conditions, and to develop appropriate tools to determine the extent, severity, and determinants of stigma, as well as its potential outcomes, such as emotional health and self-management, and clinical outcomes, as well as changes in it in response to interventions over time; therefore, evidence-based research cannot be tactfully conducted without valid and appropriate tools for measuring stigma in adults with epilepsy.

Given the fact that adults with epilepsy are stigmatized in various ways, at work and in family and social networks over time, special attention needs to be paid to designing healthcare plans for these patients so that the effectiveness of these plans to reduce this multifaceted problem can be carefully examined. Therefore, the necessity of developing a measure for these interventions is intensified as health planners need them to improve care.

Questionnaires are a group of tools to measure knowledge, attitude, cognition, feeling, intention, and behavior. The questionnaires enable researchers to collect information in a standard manner, and if they gather this information from a representative sample of a certain population, then the results can be generalized to larger populations [19].

There are very few tools available to measure social stigma in adults with epilepsy [20–22]. The development of such research instruments has not yet been accomplished through a mixed method, which is the most comprehensive approach to examining research topics and an exploratory design [23].

In Iran, no study has yet been conducted on the development of research instruments to measure social stigma of epilepsy in adults. In addition, stigma is a subjective and multidimensional concept that is dependent on the understanding of individuals and social culture [24]. Age at onset of the disease is an important variable [25]. It is, therefore, necessary to develop an appropriate tool for the underlying, cultural, and age-related conditions of people with epilepsy [20].

This study was conducted to develop and psychometrically evaluate the Perceived Social Stigma Questionnaire (PSSQ-for adults with epilepsy). The results of this study will create a new perspective in research and can be used to plan for effective interventions.

2. Methods

2.1. Design

This mixed method study of sequential exploratory quantitative–qualitative design was conducted within the framework of instrument development variant.

Participant recruitment and data collection were conducted from 2018 to 2019.

2.2. Participants and sampling

Related literature, adult patients with epilepsy, and faculty members were the samples of this study in two qualitative and quantitative phases. The faculty members were used as experts to investigate content validity.

Sampling was purposive in the qualitative phase and convenience in the quantitative phase.

Inclusion criteria for patients with epilepsy were diagnosis of epilepsy by a neurologist, having suffered from the disease for at least one year, seizure-related epilepsy, age range of 74–19 years, lack of suffering from other chronic diseases and psychiatric disorders (based on diagnosis of a specialist), volunteering to participate in the study, being able to understand Persian language, and to express understanding and experiences regarding the studied concept. The samples in this study were patients who had been treated. Patients' data were obtained from medical records available at the neurologist's office.

Exclusion criterion was withdrawing from the study at any time during the study.

2.3. Procedure

In this study, the development and psychometric evaluation of the questionnaire were performed based on the proposed steps of Schwab. Schwab divided the development and psychometric evaluation of a research instrument into three basic steps, namely, item development, scale development, and evaluation scale [26].

In the present study, the first and second stages of the study comprised the qualitative phase, and the third stage was the quantitative phase.

2.3.1. Qualitative phase

2.3.1.1. Item development. In this study, inductive and deductive approaches were used to codify the items:

Deductive approach (theoretical step or review of literature)

By reviewing the literature, the researcher accessed a variety of potential items that evaluated the construct in question precisely [27]. In the present study, research instruments on epilepsy were searched for in library and electronic resources. The inclusion criterion for publications was accessibility of full texts (articles and theses) in Persian or English. Contents related to the subject under study in the articles indexed in databases such as *Science Direct*, *Google OVID*, and *Google Scholar* were searched for without any time limit using the keywords Questionnaire, Instrument, Tool social stigma epilepsy, adult, and social stigma.

Inductive approach (field survey)

In this study, the studied region is Tonekabon, north of Iran. The location to meet participants was determined at their convenience.

The data were collected using individual, face-to-face interviews with 20 patients with epilepsy.

The interviews lasted 20–60 (mean: 45) min and were recorded word-by-word after participants provided consent to do so. These interviews were conducted at potential participant's referral to the neurologist and in the clinic if he/she provided content for being interviewed. Interview questions were raised using the interview guide. Some questions are as follows:

- *What perceptions/assumptions of your illness do you think the people of the community have?*
  What emotions do the reactions of people in the community and family to epileptic attacks induce in you?
- *Can you talk to me about your experiences of people's encounters when you're having a seizure or in other situations?*
- *What social problems do you face due to epilepsy through your daily life?*
- *Can you talk to me about the psychological and emotional problems due to epilepsy?*

Besides that, if necessary, during the interview, probing questions, such as *what do you mean?* Or *if you can, please explain more?* were also asked.

Before the beginning of each interview, the written consent form including information about the purpose and protocol (including participants' selection) of the study, the researcher, and the advantages and disadvantages of the study, was submitted to the participants, and they were asked to read and then fill it out, or provide verbal consent, to participate in the study.

Besides that, prior to the recording of the interviews, informed consent to record the interview was obtained from the participants.

Before the start of each interview, a demographic questionnaire was completed by all the participants, and then, the interview was started after establishing relationship with the participant and gaining his/her confidence, during which the participant was asked to talk about his/her experiences regarding the social stigma of epilepsy.

At the end of each interview, the participant was allowed to talk about the issues that had not been raised by the interviewer, and then, the interviewer talked of potential additional interviews with him/her.

In this study, the data collection process continued until data saturation was achieved. Data saturation was achieved when no new data could be drawn from participants' statements, all codes and categories were completed, further information that needs new code or development of existing code was not drawn, and deep and rich data regarding the studied subject were obtained.

2.3.1.2. Trustworthiness. Data trustworthiness is checked by four criteria: credibility, dependability, confirmability, and transferability [28]. In this study, maximum variation sampling with respect to age, gender, marital status, occupation, education level, duration of illness, number of seizures per month, etc. was followed to achieve credibility.

To perform member checking, the transcripts of the interviews and the drawn codes were provided to a number of participants so that they could comment on their correctness.

To achieve conformability, every attempt was made to provide a comprehensive description of the research procedure, including data collection and analysis, and the formation of themes in order to allow the readers of the article to judge the quality of the study.

In order to facilitate transferability, every possible effort was made to clearly judge the applicability of the findings in similar situations by explicitly describing the context, the way of selecting participants, their characteristics, as well as the process of data collection and analysis.

Besides that, rich and accurate findings, supported by appropriate quotes, were provided to further improve transferability.

2.3.1.3. Development scale. Here, three steps were taken to develop the research instrument:

1. At this stage, the items were combined to prepare the questionnaire.
2. The researchers considered the number of items to be sufficient. Cox believes that item drafting and layout are two key issues in developing a questionnaire. Categorizing and systematically evolving items can make it easier for respondents to respond to them [29]. In this study, the researchers also discussed the ordering and potential integration of the items.
3. The format response was also determined to be Likert, consisting of *absolutely sure*, *almost sure*, *A little sure*, and *not sure*, scored as 4, 3, 2, and 1, respectively.

2.3.2. Quantitative phase

2.3.2.1. Evaluation scale. This step involves performing psychometric evaluation of the validity (face, content, and construct) and reliability of the designed questionnaire, the presentation of the participants' characteristics, and the procedure of collecting and analyzing quantitative data:

Face validity

Face validity was evaluated both qualitatively and quantitatively. Qualitatively, face validity refers to the relevance of the tool's appearance to what it is assumed to measure. Impact score is used to quantitatively calculate face validity:

$$\text{Importance}\ (\%) \times \text{Frequency} = \text{Impact score}.$$

The items with impact score equal to or greater than 1.5 were retained, and other items were deleted [30].

In this study, in order to qualitatively evaluate face validity, 10 patients with epilepsy were asked to comment on the level of difficulty, the degree of appropriateness, and the ambiguity and complexity of the items; and the quantitative face validity was investigated by calculating the impact score by studying the same individuals' comments regarding the significance of each item for the questionnaire.

Content validity

In this study, qualitative and quantitative methods were used to investigate content validity. In the qualitative method, grammar, proper wording, the appropriate placement of the words, and scoring were examined by the experts.

To evaluate the content validity quantitatively, the indicators content validity ratio (CVR) and content validity index (CVI) were calculated:

- CVR
  Developed a model for content validity, in which the questionnaire is presented to a panel of experts to comment on the necessity of the items for the questionnaire [31]. In this study, the questionnaire was sent through email to 10 faculty members who had experience with qualitative research and research instrument development, and they were asked to comment on the items using a 3-point scale (*Not essential*; *Useful but not essential*; and *Essential*). The results were then compared with the criteria of the Lawshe's table.
- CVI
  The CVI is the rate of experts' agreement with the relevance of the item;, that is, the number of experts who score the item as 3 and 4 is divided by the total number of experts, representing the rate of consensus on its relevance [32]. In this study, the questionnaire was sent by e-mail to 10 experts who were invited to investigate the face and content validity of the tool. To this end, they were asked to rate the items using a 4-point Likert scale (from *Irrelevant* to *Absolutely relevant*).

Construct validity

In this study, construct validity was determined by exploratory factor analysis. In the exploratory factor analysis, the researcher does not have any particular expectations about the number or nature of underlying constructs or factors. Principal component analysis with oblique rotation is the most common method to draw factors. Before drawing of factors, to ensure that the tool items are suitable for principal component analysis, the tests of sampling sufficiency Kaiser–Meyer–Olkin (KMO) and the Bartlett's test of sphericity (BT) were conducted. The BT is conducted to answer the question of whether the obtained correlation matrix has a significant difference to zero and based on it, factor analysis is justifiable, and the items of the questionnaire are sufficiently correlated to be merged [33].

Reliability

In this study, internal consistency and test–retest were used to examine the reliability of the research instrument.

Internal consistency

The most common method to evaluate internal consistency is to calculate the Cronbach's alpha coefficient, which serves as an indicator of the average correlation between all the components of the instrument. Piedmont, in this regard, recommends to calculate average interitem correlation [34].

Test–retest

Test–retest is used to assess the consistency of a measure by administering the same tool to the same people in two different situations. In this study, 15 patients with epilepsy were asked to fill out the final version of the questionnaire two times with a 2-week interval to calculate interclass correlation (ICC) for all dimensions and the whole questionnaire. The ICC is a measure of reliability and a type of alpha coefficient, which simultaneously represents a measure of the agreement among individuals and a measure of reliability in terms of average rank [35].

2.4. Questionnaire scoring

In most cases, the item format determines the overall protocol of scoring. If the items are rated on a Likert scale, a cumulative score on the instrument is determined by summing up its items [36]. In the present study, for each statement, participants were required to represent the level of their confidence on a four-point Likert-type scale, where one equals not sure, and four equals absolutely sure. The total score was calculated by summing up the responses to each item. The minimum and maximum attainable scores on the questionnaire are 49 and 196, respectively, with high scores representing increase in social stigma perception by patients with epilepsy. The total score of the questionnaire comes from the sum of 5 subscales scores. The score of each subscale is the score that participants assume.

2.5. Data analysis

In the qualitative phase, after the interviews, the data were analyzed using a conventional content analysis method. In this study, the first stage began by selecting the unit of analysis. The second stage included open encoding and the generation of categories, and the third stage included the presentation of categories.

In this study, to conduct data analysis, the audio files of the interviews were first transcribed, and then, the researcher made an attempt to gain a general sense of them by carefully studying the transcripts that formed the units of analysis. Then, the transcripts were organized by open coding. The drawn codes were managed manually. The repeated study of drawn codes helped identify their similarities and differences and then classify them. Eventually, with the progression of the analysis process, the relationship between the categories was figured out, and then, the latent elements in the transcripts were drawn.

In the quantitative phase, after completing the questionnaires, the data were analyzed using the Statistical Package for the Social Sciences (SPSS) version 18. Absolute and relative frequency of qualitative and quantitative variables were calculated. Spearman correlation coefficient was used to investigate the relationship between factors. Cronbach's alpha values varied from zero (no consistency) to 1 (complete consistency).

The threshold value of alpha was considered to be 0.7 [37], and the average interitem correlation of 0.10–0.50 was regarded as acceptable [38]. The significance level (P) in this study was considered to be <0.001. To calculate the CVR, the Lawshe table (2014) with minimal acceptable value of 0.62 was used [39]. The minimum acceptable value for KMO was considered to be 0.6 [40]. In this study, the factors with eigenvalue over 1 were retained. To perform exploratory factor analysis, 450 samples were enrolled, and the minimum acceptable factorial load was considered to be 0.4 [41].

2.6. Ethical considerations

In this study, ethical considerations were fully taken into account, and the approval of the study protocol was obtained from the Ethics Committee of Babol University of Medical Sciences (Code of Ethics IR.MUBABOL.HRI.REC.1398.031). In addition, the letter of reference was obtained from the respective authorities, and the informed consent, oral or written, to participate in the study was provided by all participants after the objectives and procedure of the study were explained to them. The recording of the interviews in the qualitative phase, the roles of the researcher and the participants, and observance of the privacy of the individuals were fulfilled by taking necessary ethical measures. Further, determining the time of the interviews at participants' convenience, allowing them to withdraw from the study whenever they wished, and keeping all of their information (including the names of participants, questionnaires, interview files, and transcripts) confidential in both qualitative and quantitative phases of the study were tactfully observed.

3. Results

3.1. Participant characteristics

Our participants consist of 53.4% males, and 65.5% were single. The mean age of our participants was 47.9 ± 9.5 years (Table 1).

3.2. Item development

A total of 32 publications related to the present study were retrieved, and 36 items were developed after reviewing them. From the qualitative analysis, 40 items were obtained (Table 2).

Table 1
Demographic characteristics of participants in the study (N = 450).

Characteristics		N	%
Mean age (year)	47.9 ± 9.5		
Gender	Female	210	46.6
	Male	240	53.4
Marital status	Married	124	27.6
	Widow/widower	3	0.6
	Divorced	28	6.3
	Single	295	65.5
Education level	Illiterate	8	1.7
	Under high school diploma	45	10.0
	Diploma	311	69.1
	Academic	86	19.2
Occupation	Worker	51	11.3
	Farmer	59	13.1
	Unemployed	100	22.3
	Housewife	209	46.5
	Clerk	16	3.5
	Retired	15	3.3
Seizure type	Partial seizure	169	37.6
	Partial seizure with a secondary generalization	211	46.9
	Generalized seizure	70	15.5
Medical treatment	Yes	450	100
	No	0	0
Mean age at seizure onset	18.14 ± 1.9		
Mean age at epilepsy diagnosis	22.29 ± 2.5		

Table 2
Examples of the PSSQ-for adults with epilepsy codification process.

Participants' ideas and experiences	Item	Construct
Often, I see my family refusing to talk about my illness in front of others, and they're embarrassed when I have seizure and somebody from relatives is our home.	My family is embarrassed by my illness.	Family consequences
Whenever I feel it's necessary to comment, or even when I'm certain that my suggestions are right and can help others, I feel they don't pay attention to me and deal with my words or comment trivially.	Others do not take me seriously.	Internal emotions
People have no knowledge of this disease. Neighbors would say to me fainty. This label was attached to me. Some people said I have a jinn. Nobody knew about my real illness.	I feel the label fainty is always with me.	
I was a construction worker. Few times at work, I had seizure and for this I was kicked out by my employer. I often get a negative answer for my illness wherever I refer to for employment. I decided to stay at home. Actually, I've become a burden on my family.	Because of lack of facing others' reactions, I refuse to work outside the home.	Dangerous escape
Few times I have decided to get married, but as soon as they're informed of my illness, my proposal of marriage is rejected. When I asked why? They told me you have a contagious disease or we cannot have children because of your illness.	Every decision in my life (marriage, childbirth, education, travel, etc.) depends on my illness.	Individual consequences
Once I had seizure in the street. When I became a little alert, I saw two people saying he is grimacing or spuriously doing it consciously to scare people.	The inadequate knowledge of people about my illness has caused some people to think that I'm getting smiley.	Destructive assumptions
People have a series of false beliefs in their minds. Some people are afraid of epileptic seizures, they think these patients have risk for them, or their disease is contagious, people avoid us because they don't have enough information.	People think my disease is contagious.	

3.3. Scale development

Here, the researchers reviewed the items. Four items were deleted because of being duplicate, and five items were merged. Finally, 67 items were retained.

3.3.1. Evaluation scale

3.3.1.1. Face and content validity. Regarding face validity, 8 items were deleted because of the impact score of less than 1.5. After the qualitative study of content validity, no items were deleted, but 13 items were reviewed and all proposed changes were made to the face of the items. After calculating the CVR, three items were deleted and after calculating the CVI, two other items were excluded. Finally, 54 items were retained in the questionnaire.

3.3.1.2. Exploratory factor analysis. Finally, a 54-item questionnaire was prepared for the exploratory content analysis. Before the exploratory analysis was done, the KMO and BT were performed. The KMO was obtained 0.838, and the BT was drawn to be significant ($P = 0.001$, $\chi^2 = 3.2843$). Principal component analysis showed that five factors had eigenvalue of over one (Fig. 1). Five factors including *family consequences*, *internal emotions*, *dangerous escape*, *individual consequences*, *and destructive assumptions* with eigenvalue of over 1 were drawn from principal component analysis with oblique rotation, explaining 23.28%, 39.18%, 53.86%, 61.72%, and 77.73% of the cumulative variance, respectively. The five factors accounted for 89.2% of the observed variance. At this stage, 5 items were deleted because of factorial load of less than 0.4. Finally, a 49-item instrument with a factorial load of 401–879 was achieved (Table 3).

3.3.1.3. Reliability. In this study, to determine the internal consistency between the items in a sample of 450 adult patients with epilepsy, Cronbach's alpha coefficient was calculated at 0.901.

No items were deleted in this stage. In order to determine the consistency of the questionnaire with respect to replication, the ICC coefficient was calculated for all dimensions. This coefficient was calculated at 0.911 for the whole instrument (Table 4).

In the present study, Spearman correlation coefficient was used to describe the linear relationship between factors. Results showed that there was a strong and positive correlation between the main factors ($r = 0.603.0.923$, $N = 450$, $P < 0.0001$) (Table 5).

4. Discussion

In the present study, through qualitative research, it was assured that the codified items were tailored to the context. In this study, the PSSQ-for adults with epilepsy was evaluated according to recommended standards [42], which is consistent with the main validation criteria.

In this study, in order to study face and content validity, in addition to qualitative methods, a quantitative method with more objective results was also used. In the development process of this instrument, the participants were selected from target population to whom it would be administered. This is one of the most important issues in a research instrument validation, and it is therefore recommended to use this instrument to measure perceived social stigma of epilepsy in adults.

The results of the factor analysis show that the PSSQ-for adults with epilepsy is a multidimensional instrument and measures adult patients' understanding of the social stigma of epilepsy.

In this study, *dangerous escape* was drawn as one of the dimensions of the instrument. This dimension refers to strategies that a patient with epilepsy adopts to deal with epileptic seizures.

These strategies can threaten the health and quality of life of these individuals and, therefore, should be addressed by healthcare providers and community health policy makers.

Using the PSSQ-for adults with epilepsy will lead to an analysis of the condition in this dimension and assist in needs assessment for preventive or therapeutic interventions.

Measuring perceived social stigma by using a valid and reliable tool can lead to preventive and timely interventions. Standard research instruments are therefore essential to examine and document the effectiveness of evidence-based programs. In addition, the questionnaire designed in this study is specific to adults with epilepsy.

There is evidence that suggests that the age at the onset of the disease and the feelings of social stigma influence the patient's perception of the stigma, so that any intervention program should be developed based on a number of indicators. Age is one of these indicators; and tools that are specific to adults are essential to measure the efficacy of the programs [43]. Collard et al. identified two types of stigma in people with epilepsy, stigma felt and stigma enacted. The stigma felt represents feelings of embarrassment due to epilepsy and fear of being confronted with stigma of epilepsy, resulting from the patient's exposure to family or community reactions, while the stigma enacted refers the actual

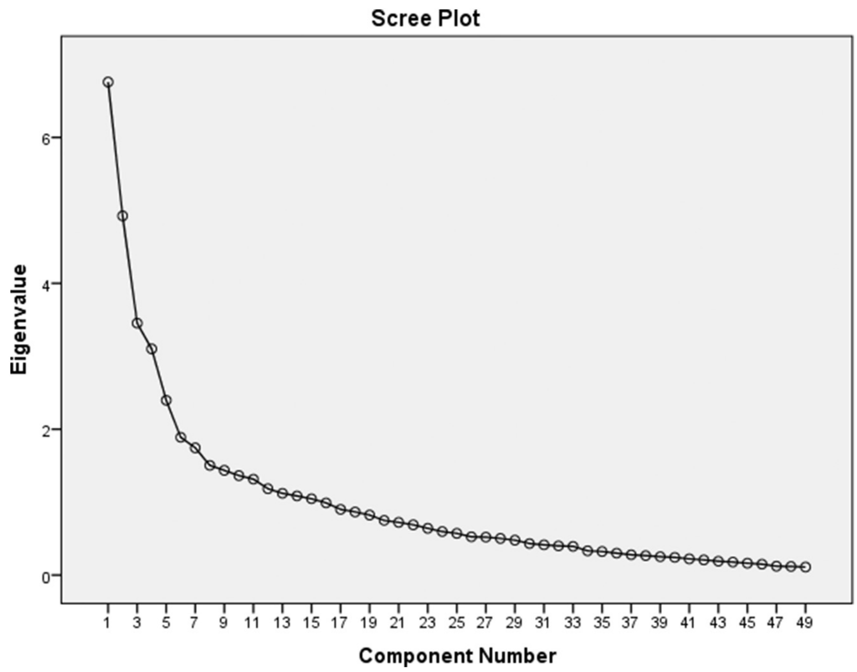

Fig. 1. The gravel curve for the PSSQ-for adults with epilepsy.

periods of discrimination due to the disease [44]. Various tools that are currently available to measure stigma have not yet been used to measure the stigma and its resulting problems from the perspectives of community members, or do not have the standard principles of content validity [22].

In a study in Iran, for the measurement of stigma in 130 patients with epilepsy, Mental Illnesses (ISMI) Scale was used. The ISMI is nonspecific for people with epilepsy, and its reliability (Cronbach's alpha coefficient) was obtained >0.70 [45].

However, the questionnaire developed in our study can be used to measure the perceived social stigma of epilepsy due to its specificity.

A tool was also developed and validated by Baybaş et al. in Turkey to measure epilepsy. To this end, 32 patients were asked to answer questions about false beliefs regarding epilepsy, ostracism, or discrimination caused by illness, insufficiency at work, and in family life, and social isolation due to resistance to stigma. The mean age of the participants in that study was 31.1 ± 12.1 years. The results of the factor analysis showed that the tool has five factors (social isolation, discrimination, insufficiency, false beliefs, and stigma resistance). Social isolation and discrimination had the highest contribution to stigma, with Cronbach's alpha coefficient of 0.915 for patients with epilepsy. This tool was developed based on a review of existing materials rather than the understanding and experience of patients with epilepsy. Baybaş et al. did not use exploratory design that is appropriate to develop research instruments [46]. In addition, the abstractness and the subjectivity of the social stigma construct and cultural differences can be one of the reasons for designing the PSSQ-for adults with epilepsy in our study.

The overall consistency of the whole questionnaire designed in our study is greater than those of similar instruments [21,47,48]. The reliability of its dimensions is also acceptable [37].

But we do not consider the greater Cronbach's alpha to be the strength of the questionnaire, because reliability is a function of increased number in items, and the PSSQ-for adults with epilepsy has more items than some of the currently used research instruments. The results of test–retest and obtained ICC showed that this instrument has acceptable consistency [49].

5. Conclusion

The PSSQ-for adults with epilepsy is a culturally appropriate measure with strong psychometric properties. The tool designed in this study measures the perceived social stigma of epilepsy.

However, more information on the scale is needed before it is adequately improved to test interventions, including concurrent validity and sensitivity to change.

The strengths of this study include the following:

- The results of our study led to an explanation of the dimensions of social stigma, especially in adults with epilepsy.
- The questionnaire developed in this study is a scientific, culturally oriented, and psychometrically evaluated instrument for monitoring the social stigma of epilepsy
- The results of this research can help conduct additional research and generate and increase the scope of knowledge about epilepsy.

6. Limitations

- In this study, inversely scored items were not used. However, their use can be helpful because they are thought to reduce the response pattern bias.
- Our questionnaire is a paper-and-pencil, self-report tool. Therefore, responses may be influenced by the respondent's interpretation of the items, which may not be the one that is intended by the developer of the questionnaire.
- The sampling in the quantitative phase was convenience. This may have led to enrolling samples who are not representative of the general population.
- Since epilepsy is a culturally sensitive issue, participants may have given dishonest answers to some questions despite the lack of identifying information.
- The scale has certain weaknesses (e.g., length, lack of comparison with other stigma scales to determine concurrent validity, and lack of study of sensitivity to change).
- The scale needs further development before it can be claimed that it can be reliably used in interventions.

Table 3
Table of factors of the PSSQ-for adults with epilepsy after varimax rotation.

Domains (cumulative % = 89.2%)	Item	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
Family consequences (77.73)	*My family feel guilty because of my illness.*	0.701				
	I'm always afraid of being together with my family.	0.608				
	Because of my illness, my family has lost opportunities such as childbirth, marriage and receiving training in caring for me.	0.606				
	I feel that my family have become tired of me and the existing conditions.	0.590				
	Encouraging people's negative beliefs about my disease caused my wife/love to leave me.	0.579				
	All my family's decisions (parties, travel, leisure, etc.) depend on my illness.	0.529				
	My family is embarrassed by my illness.	0.510				
Internal emotions (% of variance = 61.72)	*Others do not take me seriously.*		0.879			
	I feel a permanent defect is with me.		0.615			
	I feel that because of the symptoms and characteristics of my illness, anyone dares to violate my personal rights.		0.611			
	People look at me with sorrow.		0.599			
	I feel seizure attacks cause a sense of disgust in others.		0.527			
	I feel when I have seizure, others are afraid of me.		0.445			
	Others' beliefs and opinions have made me see myself as different from others.		0.417			
	I feel others are avoiding me because of my illness.		0.404			
Dangerous escape (% of variance = 53.86)	*To evade others' negative reactions, I stay at home.*			0.775		
	I feel this disease is a compensation for some of my behaviors throughout my life.			0.679		
	I feel the tag is always with me.			0.665		
	I refuse to work outside the home due to not being faced with others' reactions.			0.601		
	To prevent someone from finding out my illness, I refuse to carry the paper stating "I am an epilepsy patient".			0.599		
	I feel being discriminated because of my illness.			0.555		
	To keep my confidence, I keep my illness secret.			0.542		
	My wife/sexual partner's fear of my seizure during sexual intercourse has led me into avoiding sexual behavior.			0.469		
Individual consequences (% of variance = 39.18)	*The criticisms that I've heard from others because of my illness have made me feel humiliated.*				0.772	
	I don't enjoy my life at all.				0.702	
	Others' dealings with me are as if I'm an immature person.				0.700	
	Thinking that people will be anxious when I get rid of a seizure.				0.669	
	I feel embarrassed by being in public.				0.628	
	Others' treatment of me has made me feel hopeless about life.				0.623	
	I'm sad due to others' feeling sympathetic to me in social ceremonies.				0.622	
	I regard myself as defeated and weak.				0.614	
	I need to explain to others the conditions and symptoms of my illness.				0.611	
	I feel inefficient and frustrated.				0.607	
	The negative reactions of others have made me aggressive.				0.567	
	Every decision in my life (marriage, childbirth, studying, traveling, etc.) depends on my illness.				0.556	
	I'm worried due to being always in the focus of others' attention.				0.545	
	My social interactions have diminished as a result of my illness.				0.531	
	I'm very sensitive to others' behaviors.				0.509	
	I'm not accepted by my peers.				0.507	
	I think I do not have a valuable life.				0.501	
	I have lost the opportunity of academic and professional progress.				0.452	
	I encounter others' violence/misconduct when I have seizure.				0.403	
	I avoid being in public.				0.401	
Destructive assumptions (% of variance = 23.28)	*Others consider my epileptic attacks to be compensation for my sins.*					0.703
	People think that evil forces have intruded in me.					0.647
	I think people are not aware of my illness, and this makes me angrier.					0.641
	The inadequate knowledge of people about my illness has caused some people to think that I'm getting smiley.					0.630
	People think my disease is contagious.					0.429
	People find me crazy when they see me having seizure.					0.407

- Because of cultural differences, the validity and reliability of this questionnaire should also be evaluated with the people from other regions. It is also necessary to validate the tool using the confirmatory factor analysis.

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Table 4
Reliability of the PSSQ-for adults with epilepsy (N = 450).

Factor	Mean (standard deviation)	Range	Interclass correlation coefficient	Cronbach's alpha coefficient
Family consequences	23.08 (3.47)	7 to 28	0.803	0.764
Internal emotions	32.40 (8.44)	11 to 44	0.723	0.783
Dangerous escape	16.46 (2.55)	5 to 20	0.817	0.804
Individual consequences	51.30 (9.26)	20 to 80	0.799	0.698
Destructive assumptions	18.41 (1.42)	6 to 24	0.896	0.792
Total	154.51 (20.11)	49–196	0.911	0.901

Table 5
Spearman correlation coefficient between the PSSQ-for adults with epilepsy.

Factor	Family consequences	Internal emotions	Dangerous escape	Destructive assumptions	Individual consequences
Family consequences		0.691	0.704	0.786	0.675
Internal emotions	0.680		0.923	0.870	0.798
Dangerous escape	0.603	0.808		0.788	0.811
Individual consequences	0.699	0.801	0.777	0.806	
Destructive assumptions	0.766	0.782	0.808		0.789
Total	0.766	0.805	0.888	0.873	0.809

Authors' contributions

FGh contributed substantially to the conception of the study and the interpretation of the data, and drafted the manuscript. ASH, RM, and RER contributed substantially to the conception of the study and the interpretation of the data, and critically revised the manuscript. FGh contributed substantially to the conception of the study and the analysis of the data, and critically revised the manuscript. All authors approved the final version of the manuscript.

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Ethical publication statement

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.

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