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Stigma, emotional aspects, and psychological symptoms in individuals with epilepsy

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ABSTRACT

The relationship between stigma and psychological aspects in adults with epilepsy is poorly studied.
The Stigma Scale of Epilepsy (SSE) was related to the Factorial Neuroticism Scale (FNS), Symptoms Assessment Scale-40 (SAS-40), and clinical aspects of 71 individuals with epilepsy, at a significance level of $p < 0.05$.
Clinical and sociodemographic aspects are associated with the presence of psychological symptoms and emotional maladjustment. The occurrence of psychological symptoms in the SAS-40 was associated with uncontrolled seizures, longer illness duration, and perception of greater stigma. There was a relationship between perceived stigma, age, and epilepsy duration. In the linear regression for determining the factors that potentially affected perception of stigma, the symptom dimensions 'somatization' in the SAS-40 ($p < 0.001$) and the 'psychosocial maladjustment' in the FNS ($p = 0.012$) were included, and the clinical aspects were excluded.
Psychological symptoms were associated with uncontrolled seizures and perceived stigma. Perception of stigma was associated with somatization and psychosocial maladjustment.

1. Introduction

Epilepsy is the most common medical condition associated with stigma [1,2]. Stigma influences the lives of individuals with epilepsy, leads to negative psychosocial consequences, and often causes more suffering than the disease itself [1,2]. The relationship between the perceived stigma, sociodemographic aspects, variables related to the disease, and quality of life (QoL) in individuals with epilepsy is described [3–6].

However, the factors that influence the onset and maintenance of stigma are still unclear [3,7]. The lack of social support networks and social restrictions are important factors that have been associated with the development of stigma in epilepsy [8].

There are studies that describe an association between stigma and depressive and anxiety symptoms [9,10]; however, there are controversies in the literature, and there are still gaps in knowledge concerning the relationship between the perceived stigma, emotional aspects, and psychological symptoms in epilepsy.

The hypothesis of the present study is that the occurrence of psychological symptoms may be a stronger determining factor of perceived prejudice and stigma than the clinical aspects of epilepsy. Thus, the objective of the present study was to evaluate the relationship between clinical aspects and psychological symptoms and perceived stigma in adults with epilepsy.

2. Method

The study consisted of 71 consecutive individuals with epilepsy, aged 18–59 years, who were being followed up at the neurology outpatient clinic of the Hospital of the Pontifical Catholic University of Campinas (PUC-Campinas, São Paulo, Brazil). Epilepsy was diagnosed according to the criteria of the International Classification of Epilepsies and Epileptic Syndromes of the International League Against Epilepsy (ILAE) [11].

Patients who had difficulty understanding the questions in the instruments due to their low education level or mental disability were excluded.

Individuals invited to participate in the study signed the free and informed consent form. The research was approved by the Human Research Ethics Committee of PUC-Campinas (No. 45923215.0.0000.5481).

2.1. Procedures

Participants were invited to complete the following instruments:

- Interview for collection of sociodemographic data (age, gender, education level) and clinical data (age at onset, type and seizure frequency, epilepsy duration, number of antiepileptic drugs administered, and epileptic syndrome).

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- Stigma Scale of Epilepsy (SSE) [12]: a questionnaire with 24 items that quantify the level of perceived stigma in epilepsy in different contexts. Responses were scored on a 4-point scale (1: not at all–4: totally), and the scores were converted to a scale of 0 to 100; higher scores indicated higher rates of stigma. Individuals also answered questions about their perception of discrimination at work, relationships with individuals of the opposite sex, friends, and relatives. These aspects are part of the scale, but they were not used in the general score. Individuals answered 'yes' or 'no' to each of these questions.
- Factorial Neuroticism Scale (FNS) [13]: the scale assesses emotional maladjustment and human personality traits. It is composed of 82 items on a seven-point Likert-type scale (1: strongly disagree–7: strongly agree). The scale assesses emotional stability based on four dimensions: vulnerability, psychosocial maladjustment, anxiety, and depression. Total score values ranging from 80 to 120 indicate absence of symptoms.
- Symptoms Assessment Scale-40 (SAS-40) [14]: a multidimensional scale that assesses the presence of psychological symptoms (within the last week) in patients with physical illnesses, and it was adapted from the Symptom Checklist-90-Revised. It is a three-point Likert scale (0: not at all–2: a lot) composed of 40 items, and it assesses symptom intensity based on four dimensions: psychoticism, obsessive–compulsive, somatization, and anxiety. Score of ≥0.63 indicates the presence of symptoms.

2.2. Data analysis

The continuous variables were analyzed by descriptive statistics (mean, standard deviation, frequency, and percent (%)). The categorical variables were tabulated by absolute frequency (n) and percent (%). Chi-square test or Fisher's exact test was used to evaluate associations among the categorical variables. The independent *t*-test (for categorical data) verified whether the mean scores of each dimension differed significantly between the groups, and Spearman correlation coefficient (for continuous data) was used to analyze the relationship between the numerical variables and the absence of normal distribution of variables.

Based on the significant correlations, multivariate linear regressions (stepwise criteria) were performed to determine the factors related to the higher scores on the SSE, FNS, and SAS-40. The best models were selected based on a trade-off between the highest explained variance (R2) and highest cross-validity (adjusted R2).

The SAS-40 was calculated as the binary variable ≥0.63 or not. Logistic regression was used to determine the relationship between predictor variables and binary or continuous outcome variables (dependent variables) using variables at $p < 0.10$ in the respective prior correlation analyses (independent variables).

Data were analyzed using the software IBM statistical package for the social sciences (SPSS) Statistics, version 22. The significance level adopted for the statistical tests was $p < 0.05$.

3. Results

Forty-two individuals were diagnosed with temporal lobe epilepsy and hippocampus sclerosis (TLE-HS), who were not submitted to surgery (surgery-naïve patients), with right laterality in 20 cases and left laterality in 22 cases; probably symptomatic focal epilepsy (PSFE) was diagnosed in 29 (40.8%) cases. Sociodemographic and clinical aspects are shown in Table 1.

There was a significantly lower score in the FNS 'depression' factor in married individuals when compared with single ones, divorced individuals, or widowers (Mann–Whitney test, 65.6 ± 28.3 vs 79.6 ± 15.5, $p = 0.047$).

There were significantly lower scores in the dimension 'somatization' in the SAS-40 for men than for women (0.51 ± 0.43 vs 0.70 ± 0.40, $p = 0.034$) and in individuals with uncontrolled seizures when compared with women with controlled seizures (0.50 ± 0.42 vs 0.74 ± 0.42, $p = 0.047$).

Table 1
Sociodemographic and clinical aspects and SSE, SAS-40, and FNS scores, according to type of epilepsy.

	PSFE (n = 29)	TLE-HS (n = 42)	*p*
Age (year)	39.2 (±9.6)	45.1 (±10.4)[c]	0.018[a,*]
Education (year)	8.0 (±3.4)	6.5 (±3.2)	0.06[a]
Gender: male/female	13/16	20/22	0.817[b]
Marital status: married/other	14/15	25/17	0.349[b]
Occupation: employed/unemployed	13/8	15/17	0.666[b]
Age of first seizure (year)	21.2 (±11.9)	18.8 (±8)	0.04[a,*]
Epilepsy duration	18.5 (±11.5)	28.9 (±14)	0.001[a,*]
Seizure frequency: controlled/uncontrolled	16/13	23/19	0.97[b]
AED: Single/>1	19/10	20/21	0.165[b]
SAS-40			
Psychoticism	0.27 (±0.23)	0.48 (±0.91)	0.166[a]
Obsessive–compulsive	0.57 (±0.35)	0.68 (±0.43)	0.242[a]
Somatization	0.63 (±0.32)	0.59 (±0.49)	0.549[a]
Anxiety	0.33 (±0.33)	0.45 (±0.42)	0.159[a]
Total score	0.63 (±0.4)	0.71 (±0.45)	0.514[a]
FNS			
Vulnerability	67.6 (±26.6)	70.9 (±28.7)	0.414[a]
Psychosocial maladjustment	46.5 (±27.8)	57.9 (±27)	0.09[a]
Anxiety	56.7 (±31.7)	68.9 (±30)	0.109[a]
Depression	70 (±22)	73.3 (±27)	0.570[a]
Total score	106.3 (±13.3)	109.4 (±15.3)	0.082[a]
SSE	40.7 (±11.3)	43.4 (±16.1)	0.423[a]
Do you think people with epilepsy are rejected by society?	19 (70.4%)	30 (71.4%)	0.92[b]
Would you hire a person with epilepsy to work for you at home?	23 (88.5%)	28 (66.7%)	0.044[b,*]
Would you marry a person with epilepsy?	21 (77.8%)	28 (66.7%)	0.032[b,*]

PSFE: probably symptomatic focal epilepsy; TLE-HS: temporal lobe epilepsy and hippocampus sclerosis; AED: number of antiepileptic drugs; SSE: Stigma Scale of Epilepsy; SAS-40: Symptoms Assessment Scale-40; FNS: Factorial Neuroticism Scale.
[a] *t*-test.
[b] Chi-square test.
[c] Fisher's exact test.
[*] $p < 0.05$.

A correlation was observed among higher formal schooling, lower scores on the 'anxiety' factor (Spearman correlation, −0.287, $p = 0.015$), 'psychoticism' factor (−0.400; $p = 0.031$) in the SAS-40, and the dimension 'depression' (−0.295; $p = 0.012$) in the FNS.

No significant difference was observed in the SAS-40 and FNS scores according to the epileptic syndrome (Table 1).

In the SAS-40 total score, the presence of psychological symptoms was significantly related to uncontrolled seizures (n = 39 vs n = 32, *t*-test, 0.72 ± 0.42 vs 0.61 ± 0.44, $p = 0.034$).

Individuals with uncontrolled seizures (n = 32) presented significantly more psychological symptoms in the SAS-40 total score when compared with those with controlled seizures (n = 39) (28 vs 4; Fisher's exact test; $p = 0.034$). For the other clinical aspects, there was no significant difference in the occurrence of psychological symptoms in the SAS-40 total score.

A greater occurrence of symptoms of psychoticism and somatization was observed in individuals who had had epilepsy for a longer period (Table 2). Longer epilepsy duration correlates with the greater occurrence of 'obsessive–compulsive' (Spearman correlation, 0.253, $p = 0.033$) and 'anxiety' symptoms (0.239; $p = 0.045$) in the SAS-40 and 'depression' (0.235; $p = 0.048$) in the FNS.

No significant differences were observed in the SAS-40 and FNS scores according to other sociodemographic and clinical aspects.

3.1. Stigma: clinical and emotional aspects and psychological symptoms

No significant difference was observed in the SSE total score according to epileptic syndrome (Table 1).

Table 2
Relationship between psychological symptoms in the SAS-40, SSE scores, and epilepsy duration.

	SSE	p	Disease duration	p
Psychoticism				
No (n = 61)	41.4 (±14.3)	0.230	23.4 (±14)	0.039*
Yes (n = 10)	47.5 (±14.1)		32.5 (±11.2)	
Obsessive–compulsive				
No (n = 43)	37.5 (±14)	<0.001*	22.2 (±13.6)	0.071
Yes (n = 28)	49.5 (±11.6)		28.4 (±13.9)	
Somatization				
No (n = 43)	35.6 (±12)	0.000*	21.2 (±13.5)	0.008*
Yes (n = 28)	52.5 (±11.3)		30.0 (±13.2)	
Anxiety				
No (n = 53)	39.5 (±14.2)	<0.000*	24.2 (±14.1)	0.599
Yes (n = 18)	50.4 (±11.6)		36.2 (±13.7)	
Total score				
No (n = 39)	39.1 (±15.2)	0.033*	23.0 (±12.6)	0.266
Yes (n = 32)	46.2 (±12.2)		26.8 (±15.4)	

SAS-40: Symptoms Assessment Scale-40; SSE: Stigma Scale of Epilepsy; *t*-test.
* $p < 0.05$.

Perceived stigma and the sense of rejection and prejudice in society when seeking employment, marriage, and education were accentuated in individuals with epilepsy. A significant number of individuals with TLE-HS responded that they would not marry (23 vs 28; Chi-square test $p = 0.044$) or offer employment (21 vs 28; $p = 0.032$) to individuals with epilepsy when compared with those with PSFE (Table 1).

Perceived stigma in older individuals (Spearman correlation, 0.236, $p = 0.047$) and in those with a longer illness duration (0.335; $p = 0.004$) was greater. No significant difference was observed between the SSE scores according to other sociodemographic and clinical aspects of epilepsy.

The presence of psychological symptoms is significantly related to higher scores on the stigma scale (Table 2).

The occurrence of psychological symptoms such as anxiety, somatization, and obsessive–compulsive was greater in individuals who perceived greater stigma (Table 2). There was a significant correlation between the FNS factors and SAS-40 dimensions with the stigma scale scores, suggesting that psychological and emotional aspects are related to perceived stigma in epilepsy (Table 3).

3.2. Multivariate analysis

The logistic regression model for determining the factors that were associated with the presence of psychological symptoms in the SAS-40 (total score) included the variables: age at first seizure, seizure frequency, epileptic syndrome, and SSE — total score (Table 4). Higher seizure frequency and higher scores in the SSE were significantly associated with the presence of psychological symptoms in the SAS-40 (Table 4).

Table 3
Correlation between the SSE and SAS-40 and FNS scores, according to type of epilepsy.

	PSFE (n = 29)		TLE-HS (n = 42)	
	Correlation	p	Correlation	p
SAS-40				
Psychoticism	0.220	0.251	0.372	0.015*
Obsessive–compulsive	0.316	0.094	0.454	0.002*
Somatization	0.444	0.015*	0.538	<0.001*
Anxiety	0.387	0.037*	0.486	0.001*
Total score	0.263	0.167	0.297	0.055
FNS				
Vulnerability	0.165	0.391	0.352	0.021*
Psychosocial maladjustment	0.089	0.643	0.501	<0.001*
Anxiety	0.256	0.178	0.477	0.001*
Depression	0.423	0.022*	0.323	0.036*
Total score	0.275	0.147	0.440	0.003*

PSFE: probably symptomatic focal epilepsy; TLE-HS: temporal lobe epilepsy and hippocampus sclerosis; SSE: Stigma Scale of Epilepsy; SAS-40: Symptoms Assessment Scale-40; FNS: Factorial Neuroticism Scale. Spearman correlation.
* $p < 0.05$.

Table 4
Adjusted odds ratio for factors associated with the presence of psychological symptoms (SAS-40) (score ≥0.63) in 71 adult individuals with epilepsy.

Variable	Odds ratio	95% confidence interval (CI)		p-Value
Seizure frequency (<1/year/≥1/year)	1.081	1.066	8.149	0.037*
SSE total score	0.038	1.001	1.077	0.041*
Age of first seizures (years)				0.551
Epileptic syndrome (TLE-HS/other epilepsies)				0.124
Constant	−2.415			0.008*

SSE: Stigma Scale of Epilepsy; SAS-40: Symptoms Assessment Scale-40; TLE-HS: temporal lobe epilepsy and hippocampus sclerosis.
* $p < 0.05$.

In the multivariate linear regression analysis for determining the factors that potentially affected perceived stigma (SSE — total score), the clinical aspects of epilepsy (age at first seizure, seizure frequency, and epileptic syndrome), the SAS-40 (dimensions and total score), and the FNS (factors and total score) were included. The linear regression indicated that greater perceived stigma was significantly associated with the dimension 'somatization' in the SAS-40 ($p < 0.001$) and the 'psychosocial maladjustment' factor in the FNS ($p = 0.012$). Clinical aspects were excluded because they were not significant (Table 5).

Linear regression analysis was used to determine which factors were associated with the presence of emotional maladjustment in the FNS (total score), including clinical aspects of epilepsy (age at first seizure, seizure frequency, and epileptic syndrome). Linear regression indicated that greater stigma was the unique significantly related factor ($p = 0.024$). The adjusted R2 values and standardized regression weights are shown in Table 5.

4. Discussion

In this study, the authors examined the association of stigma with psychological symptoms in 71 adult individuals with epilepsy (TLE-HS and PSFE) and found that the perception of stigma was associated with somatization and less psychosocial adjustment.

No significant difference was observed in the occurrence of psychological symptoms and emotional aspects when individuals with TLE-HS were compared with those with PSFE. The prevalence of psychiatric comorbidities is high in adults with epilepsy when compared with individuals in the general population [15,16]. Depressive and anxiety symptoms, psychotic and affective disorders, as well as specific personality traits, behavioral, and mood disorders are the most frequently described conditions in epilepsy [15]. However, there is still a controversy about the prevalence of these comorbidities in different types of syndromes. Some studies have reported a higher occurrence in TLE-HS [15,17], but others have found no association [18,19].

Table 5
Multivariate linear regression analysis of higher SSE scores and with the greatest emotional maladjustment in the FNS.

Independent variables	SSE			FNS		
	Beta (EP)	Adjusted R^2	p	Beta (EP)	Adjusted R^2	p
Somatization (SAS-40)	16.031	3.374	<0.001*			
Psychosocial maladjustment (FNS)	0.135	0.052	0.012*			
SSE				0.351	0.268	0.024*

SSE: Stigma Scale of Epilepsy; SAS-40: Symptoms Assessment Scale-40; FNS: Factorial Neuroticism Scale.
* $p < 0.05$.

In the present study, psychological aspects were associated with sociodemographic aspects and some clinical aspects of epilepsy, such as uncontrolled seizures, as also previously described by several other authors [15,16,18–21].

4.1. Stigma, clinical and emotional aspects, and psychological symptoms

Our findings confirm the occurrence of stigma in epilepsy, which corroborates several studies in the literature [1–4,6–10,13,22]. Discrimination and stigmatization of patient with epilepsy (PWE) is common and related to social, cultural, and/or geographical aspects, with higher occurrence in developing countries and in those where there is lack of social security and legal protection [7,23,24]. Perceived stigma was not significantly different among the types of epilepsy, which suggests that the social consequences suffered by individuals with epilepsy are associated with the diagnosis of epilepsy, regardless of the clinical aspects, as described in some studies [21,24,25]. It was observed that individuals with TLE-HS reported greater perceived stigma in marriage and employment, which is similar to the findings of other studies in the literature [1,8].

The older individuals or those with longer disease duration perceive greater stigma, similar to the literature [7,10,22,25,26]. Other studies do not confirm this finding [3,24,26,27] and associate the stigma with the recent onset of epilepsy [28,29].

This study singles out the significance of perception and stigma and the occurrence of depressive and anxiety symptoms in adults with epilepsy. Published data are consistent with our findings [3,10,11,24,27–29], and other authors describe the relationship between severity of depressive symptoms and stigma [3,21,26,28]. In contrast, other studies have drawn attention to the association of depression with increased stressor events, lower levels of adjustment to seizures, greater financial burden, and gender (women) rather than with stigma [30]. Stigma, lack of social and family support, social limitations, and employment-related difficulties have been reported as precursors of depression in adults with epilepsy [9,10,21].

In the present study, a correlation was observed between greater perceived stigma and other psychological symptoms such as psychoticism, obsessive–compulsive, somatization, vulnerability, and psychosocial maladjustment. Similarly, Doganavsargil-Baysal et al. reported that greater stigmatization is associated with higher scores on all subscales in the positive symptom total of the Symptom Checklist-90 [24].

In conclusion, this study indicates that in individuals with epilepsy, stigma was more frequently associated with psychological symptoms of somatization and less psychosocial adjustment and poorly related to clinical aspects of epilepsy. This relationship between stigma and epilepsy and negative psychological aspects characterizes the perception of 'double stigma', which has been described in other diseases associated with mental health disorders.

5. Limitations of the study

One of the limitations of the study is that our epilepsy clinic is located in a university hospital, but it is not a tertiary epilepsy center. Second, this was a cross-sectional study with a relatively small sample from a single institution. Although cross-sectional studies are an important step in identifying associations, there are limited to correlational inferences; without suitable additional information, they do not allow conclusions to be drawn with regard to causation.

Declaration of conflicting interests

The authors declare no potential conflict of interest regarding the research, authorship, and publication of this manuscript.

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