Epilepsy & Behavior 78 (2018) 265–268

Contents lists available at ScienceDirect

Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh

Epilepsy, stigma, and family

Glória Maria Almeida Souza Tedrus [a,*], Renato Buarque Pereira [a], Mariana Zoppi [b]

[a] School of Medicine, Pontifical Catholic University of Campinas, SP, Brazil
[b] Pontifical Catholic University of Campinas, SP, Brazil

ARTICLE INFO

Article history:
Received 24 March 2017
Revised 27 July 2017
Accepted 2 August 2017
Available online 8 November 2017

Keywords:
Epilepsy
Cohabiting relatives
Stigma

ABSTRACT

Epilepsy is surrounded by prejudice and stigma. Little is known about the perception of stigma by cohabiting relatives (CR) of people with epilepsy (PWE). The study investigated whether the Stigma Scale of Epilepsy (SSE) scores of 90 CR and 148 adult PWE were related to the PWE's clinical aspects and QOLIE-31 at a significance level of $p < 0.05$. The SSE scores of the CR were equivalent to those of PWE dyads (ICC $= 0.385$, $p = 0.001$). Cohabiting relatives of PWE with depressive disorder perceived more stigma (t-test: $p = 0.038$). Higher perceived stigma by PWE was significantly related to exclusively generalized seizures ($p = 0.005$), longer disease duration ($p = 0.002$), and higher perception of stigma by CR in the linear regression model. Both PWE and CR have high perception of stigma, which is related to clinical aspects. Higher perceptions of stigma by PWE and CR are associated with worse QoL in PWE.

1. Introduction

People with epilepsy (PWE) suffer from stigma, prejudice, and limitations, which may compromise social integration, self-esteem, social life, and quality of life (QoL) [1–6]. Stigma in epilepsy is more frequent in developing countries [4,6]. As a highly discrediting and negatively stereotyped attribute, stigma leads to loss of social status and discrimination [7].

A diagnosis of epilepsy may have negative consequences for PWE and their families, and indirectly, for the community. Some families are more prone to overprotecting the PWE in an attempt to hide the diagnosis from society [10,11]. People with epilepsy may have difficulties adapting to social norms, facing society, finding employment, and starting a family [2,8,9]. The stigma experienced by PWE may be exacerbated by the unpredictable nature of epilepsy, presence of neuropsychiatric comorbidities, cognitive involvement, or social difficulties that may stem from the family's low socioeconomic and education levels [10,11].

Studies have investigated the aspects of epilepsy associated with the perception of stigma by family members of children with epilepsy, but data on the perception of stigma by family members of adult PWE and its relationship with aspects of epilepsy are scarce.

This study intended to assess the perception of stigma by cohabiting relatives (CR) (e.g., mother, father, or spouse) and by PWE and to verify whether their perceptions of stigma are related to PWE's clinical aspects, presence of depressive disorder, and QoL aspects. The study also investigated whether the perception of stigma by PWE is related to that perceived by CR.

2. Methods

2.1. Patients and cohabiting relatives

During routine medical appointments at the outpatient clinic of neurology of PUC-Campinas, Campinas, Brazil, 148 consecutive PWE aged more than 18 years were invited to join the study. Those who agreed to participate answered a questionnaire on sociodemographic (age, gender, education level, marital status, and occupation) and clinical characteristics (age at onset, type and frequency of seizures, duration of epilepsy, number of antiepileptic drugs (AED) taken, and epileptic syndrome).

The presence of psychiatric comorbidity according to the DSM-IV and ICD-10 criteria was investigated by the university's psychiatry service. The patients were then classified into two groups: with and without depressive disorders.

Epilepsy was diagnosed according to the International Classification of Epilepsies and Epileptic Syndromes' (ILAE) [12] criteria. The study excluded patients who had difficulty understanding the questions in the instruments because of low education level or mental disability and patients with a history of cancer, stroke, progressive neurological diseases, and/or neurodegenerative diseases.

Forty-five of the 90 CR who agreed to participate in the study were spouses, 36 were mothers, and 9 were fathers. The companions provided sociodemographic data (gender, age, education level, and degree of kinship).

---

* Corresponding author.
E-mail address: gmtedrus@uol.com.br (G.M.A.S. Tedrus).

http://dx.doi.org/10.1016/j.yebeh.2017.08.007
1525-5050/

The participants were informed about the study protocol and asked to sign an informed consent form. The study was approved by the Human Research Ethics Committee of PUC-Campinas.

2.2. Procedure

The PWE answered the following questionnaires:

1. Stigma Scale of Epilepsy (SSE) [4]: This multiple-choice questionnaire quantifies the degree of stigma perceived by adults in different contexts (attitudes and behavior towards PWE, perception and feelings regarding seizures, social aspects associated with having epilepsy). The scale has 24 items distributed in five domains, and each item has four response options scored from 1 to 4 (1 = not at all, 2 = a little, 3 = a lot, 4 = totally). The results are transformed into 0 to 100 points. Perception of stigma increases with score.
2. Quality of Life in Epilepsy Inventory (QOLIE-31) [13]: This instrument is an epilepsy-specific QoL inventory with seven domains: seizure worry, overall quality of life, emotional wellbeing, energy-fatigue, cognitive functioning, medication effects, social functioning, and total score. The total score ranges from 1 to 100. Higher QOLIE-31 scores indicate better QoL. This inventory has been validated in Brazil [14].

Cohabiting relatives only answered the SSE. The SSE was administered separately to the PWE and CR. The questionnaires and scales were administered by a single a single examiner.

2.3. Data analysis

The study investigated whether the SSE scores of the PWE and CR were related to PWE's clinical aspects, sociodemographic characteristics, and QOLIE-31 score.

Equivalence testing was performed of the scores of 90 CR and PWE dyads using the intraclass correlation coefficient (ICC) and simple linear regression 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 (%). The independent *t*-test (for categorical data) verified whether the mean scores of each dimension differed significantly between the groups and Pearson's correlation coefficients (for continuous data) were calculated to determine whether the variables were linearly associated.

Based on the significant correlations, stepwise multivariate linear regressions were performed to determine the factors related with higher scores on the SSE — dependent variable (perception of stigma by PWE — total score) using variables with $p < 0.10$ in the respective prior correlation analyses (independent variables). The best models were selected on the basis of a trade-off between the highest explained variance (R^2) and highest cross-validity (adjusted R^2).

The data were treated by the software IBM SPSS Statistics, version 22. The significance level was set at 5%.

3. Results

This study assessed 238 subjects, namely, 148 consecutive PWE and 90 CR. The diagnoses included generalized idiopathic epilepsies in 12 (8.1%) cases, probable symptomatic focal epilepsies in 47 (31.8%) cases, and symptomatic focal epilepsies in 89 (60%) cases. Sixty-two patients had temporal lobe epilepsy with hippocampal sclerosis (TLE-HS).

Table 1 shows the sociodemographic data, age at first seizure, duration of epilepsy, SSE scores of PWE and CR, and total QOLIE-31 score.

Table 1
Sociodemographic and clinical aspects and QOLIE-31 of people with epilepsy and cohabiting relatives.

	PWE (n = 148)	CR (n = 90)
Gender — female	82 (55.4%)	46 (51.1%)
Age (y)	42.6 ± 14.4	54.4 ± 17.5
Education level (y)	6.1 ± 3.7	8.1 ± 3.2
Age at first seizure (y)	20 ± 15.1	–
Duration of epilepsy (y)	22.4 ± 14.2	–
Marital status: married/other	65 (43.9%)/83 (56.1%)	–
Occupation: employed/other	66 (44.6%)/82 (55.4%)	–
QOLIE-31 (total score)	60.6 ± 15.3	–

PWE: people with epilepsy, CR: cohabiting relatives.

3.1. Stigma, clinical and sociodemographic aspects, and QOLIE-31

The mean PWE and CR SSE scores were 45.7 (±15.7) and 44.5 (±14.2), respectively. There was positive correlation between the SSE scores of the 90 CR and PWE dyads (Spearman test: 0.385, $p = 0.007$).

People with epilepsy and CR SSE scores did not differ significantly by PWE's marital status and occupation.

People with epilepsy with exclusively generalized seizures had significantly higher SSE scores than PWE with focal seizures. Stigma Scale of Epilepsy scores did not differ by seizure frequency, presence of depressive disorder, number of AED taken, and epileptic syndrome (Table 2).

People with epilepsy with higher duration of epilepsy had significantly higher SSE scores. Stigma Scale of Epilepsy scores were not correlated with age, education level, and age at first seizure. The perceptions of stigma by PWE and CR dyads were significantly correlated (Pearson's correlation: 0.214, $p = 0.01$) (Table 3).

The SSE scores of the CR and PWE dyads were equivalent (ICC = 0.385, $p = 0.001$), but the magnitude between the scores was low. Simple linear regression analysis between the SSE scores of the CR and PWE found a significant relationship between the scores, but the magnitudes differed (EP (linear coefficient) = 5.88, $p < 0.001$; and EP (angular coefficient) = 0.126, $p = 0.001$), $R^2 = 0.1481$.

Cohabiting relatives of PWE with depressive disorder had significantly higher SSE scores. Stigma Scale of Epilepsy scores did not differ significantly by any other clinical aspect of epilepsy (Table 2).

Table 2
SSE scores of PWE and CR by clinical aspects.

	SSE	
	PWE (n = 148)	CR (n = 90)
Type of seizure		
Focal (n = 117)	37.8 ± 16.5	43.6 ± 13.4
Exclusively generalized (n = 31)	46.8 ± 14.9	48 ± 16.8
p-Value	0.004*	0.362
Seizure frequency		
Controlled (n = 103)	44 ± 16.7	42.9 ± 12.9
Uncontrolled (n = 45)	46.5 ± 14.9	48.1 ± 16.5
p-Value	0.400	0.196
Depressive disorder		
Yes (n = 35)	46 ± 16.2	46.3 ± 14.1
No (n = 113)	44.8 ± 14.4	37.6 ± 12.8
p-Value	0.687	0.038*
Number of AED taken		
Monotherapy (n = 84)	45.5 ± 14.4	44.7 ± 13.2
Polytherapy (n = 64)	46 ± 17.5	44.3 ± 15.6
p-Value	0.842	0.916
Epileptic syndrome		
TLE-HS (n = 62)	47.5 ± 16.7	45.4 ± 13.7
Other epilepsies (n = 86)	44.4 ± 15.3	43.7 ± 14.9
p-Value	0.247	0.633

SSE: Stigma Scale of Epilepsy, PWE: people with epilepsy CR: cohabiting relatives, *t*-test.
* Significant value: $p < 0.05$.