# Epilepsy-associated stigma from the perspective of people with epilepsy and the community in Italy

Mario Tombini [a,*], Giovanni Assenza [a], Livia Quintiliani [b], Lorenzo Ricci [a], Jacopo Lanzone [a], Roberta De Mojà [b], Martina Ulivi [a], Vincenzo Di Lazzaro [a]

[a] Unit of Neurology, Neurophysiology, Neurobiology, Department of Medicine, University Campus Bio-Medico, via Álvaro del Portillo 21, 00128 Rome, Italy
[b] Psicologia Clinica, Università Campus Bio-Medico, via Álvaro del Portillo 21, 00128 Roma, Italy

## ARTICLE INFO

## ABSTRACT

*Objective:* The objective of this study was to assess the stigma related to epilepsy from the perspective of people with epilepsy (PWE) and from the Italian community (Rome and central Italy); moreover, the impact of the perceived stigma on the mood and quality of life of patients was also evaluated.
*Materials and methods:* We consecutively enrolled 100 PWE and 202 nonepileptic subjects (NES). Both PWE and NES completed an Italian version of the Stigma Scale of Epilepsy (SSE), a 24-items questionnaire that has been demonstrated to allow the quantification of the stigma perception by patients and people from the community. Moreover, the PWE fulfilled a 3-item Jacoby's Stigma Scale, the Quality of Life in Epilepsy-31 (QOLIE-31 [Q3])), and Beck Depression Inventory II (BDI-II) questionnaires for the evaluation of the quality of life and depressive symptoms. The results of the SSE were correlated with clinical and demographic details of PWE and NES, as well as the Q31 and BDI-II scores in PWE.
*Results:* The SSE scores were significantly higher in NES with respect to PWE (respectively 47.1 *vs* 39.5, p < .001). Forty-two percent of PWE reported feeling stigmatized, with 5% reporting feeling highly stigmatized. In PWE, the perceived stigma was not correlated with seizure frequency but was significantly associated with worse quality of life, more severe depressive symptoms, and higher number of AEDs. The multiple regression analysis showed that the quality-of-life overall score and Q31 subscale exploring "social function" are the most significant predictors of stigma.
*Conclusions:* By using an Italian translation of the SSE questionnaire, even if we cannot consider our sample representative of the whole Italian community our study evidenced higher rates of stigma related to epilepsy in NES than in PWE. The PWE still experience feelings of stigmatization strongly correlated with higher depressive symptoms and worse quality of life that has proven to be the most significant predictor of stigma. Finally, seizure frequency does not affect the perceived stigma, which is instead significantly influenced by antiepileptic therapy.

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## 1. Introduction

The age-adjusted prevalence of epilepsy in developed countries is 4–8 per 1000 [1,2], and almost half of the patients report feeling stigmatized [3]. The psychosocial impact of epilepsy has been well-recognized, and people with epilepsy (PWE) complain that the significant impact of this condition, in terms of family dysfunctioning [4], poor self-esteem [5, 6], reduced employment opportunities [7], and more generally impaired quality of life [3], with increased levels of anxiety, and depression [8–10]. Epilepsy has been defined a "stigmatizing condition par excellence" [3], and PWE report feelings of stigma and/or discrimination based solely on their label of epilepsy. For this reason, the European

Forum on Epilepsy Research (ERF2013), which took place in Dublin, Ireland, on May 26–29, 2013 to appraise epilepsy research priorities in Europe [11], identified the need to explore how the stigma and social burden associated with epilepsy could be reduced through targeted initiatives at national and regional levels as the first step to be taken. Half of the 6 million European citizens with epilepsy feel stigmatized and experience social exclusion, highlighting the need for funding trans-European awareness campaigns and monitoring their impact on stigma. Although public attitudes toward epilepsy have significantly improved over the last 40 years [12], recent surveys indicate that, at least in some circumstances, this improvement may have slipped back [13].

To our knowledge, there are no studies in Italy addressing specifically the prevalence of stigma related to epilepsy in PWE and nonepileptic subjects (NES). In 2000, Baker et al. [14] published results of a study collecting clinical data about patient-perceived stigma through a very simple and widely used 3-item questionnaire, the

Jacoby's Stigma Scale (JSS) [15] from 5211 patients with epilepsy residing in 15 European countries; based on these data, about 55% of the Italian patients reported feelings of stigma. Since then, there have been only a very few Italian studies focusing on the assessment of knowledge of attitudes toward and perception of epilepsy among the Italian population [16,17] and more specifically among primary and secondary Italian school teachers [18]. A study involving college students of the University of Messina in Sicily, high school students, and teachers from Sicily [19] revealed several misconceptions and negative attitudes toward epilepsy.

The goal of our study was to assess the stigma related to epilepsy from the perspective of both PWE and people from the Italian community (in particular, coming from Rome and central Italy). To this end, a validation of Italian translation of the Stigma Scale of Epilepsy (SSE) [20] was performed; this is a 24-item questionnaire, originally developed in Brazil, that has been demonstrated to allow the quantification of the perception of stigma by PWE and NES in different countries as India [21], Bolivia [22], Zambia [23], and in the Czech Republic [24]. Moreover, we evaluated the impact of the perceived stigma on the mood and quality of life of patients.

## 2. Material and methods

### 2.1. Translation of Stigma Scale of Epilepsy (SSE) in Italian language and validation

According to the rules for the translations of research tools [24] the SSE questionnaire was translated from English into Italian. At the beginning the Italian version of the SSE questionnaire was proposed to a group of students of the School of Medicine of Campus Bio-Medico University, who had not performed yet a specific training on epilepsy, in order to confirm the acceptability and comprehensibility of the questionnaire. Then, this questionnaire was proposed to a wide sample of NES belonging to the healthcare area (medicine and nurse students, physicians and nurses, technicians of neurophysiology) as well as other people of the community. The features of the NES who were enrolled for the study will be described in the next section ("Study population and experimental design") and are reported in Table 1.

### 2.2. Study population and experimental design

To the aim of the study, we enrolled consecutively 100 PWE (41 males, age 47.2 ± 18.7 years, education 12.2 ± 4.1 years; 52 seizure-free patients/48 with refractory epilepsy) and 202 NES (75 males, age 38.8 years ± 15.5, education 14.7 ± 3.1 years). The demographic and clinical features of NES and PWE are reported in Tables 1 and 2. The PWE and NES were coming from Rome and central Italy. The study protocol was approved by the local Ethics Committee, and written informed consent was obtained from all participants. All procedures were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Declaration of Helsinki and its later amendments.

Both PWE and NES were interviewed on an individual basis and completed the SSE. The SSE consists of a multiple-choice questionnaire containing 24 items grouped into 5 domains. It covers a range of topics about the perception of epilepsy in different contexts (attitudes and behavior in relation to PWE, perception and feelings regarding seizures, social aspects associated with having epilepsy). Each item was scored with a 4-point scale from 1 (not at all) to 4 (totally). The total score gives the level of stigma perceived by each person and ranges from 0 (no stigma) to 100 (maximum stigma). The SSE questionnaire has shown a good content validity and high internal consistency with a Cronbach's α coefficient of 0.88 for PWE and 0.81 for people from the community [20]. Moreover, the PWE fulfilled a 3-item stigma JSS [14, 15], the Quality of Life in Epilepsy-31 (QOLIE-31 [Q31]) [25], and the Beck Depression Inventory II (BDI-II) [26] questionnaires for the evaluation of the quality of life and depressive symptoms. In the JSS, PWE, because of their epilepsy, were asked to say whether, they felt that other people (I) were uncomfortable with them, (2) treated them as inferior, and (3) preferred to avoid them. Patients scored one for each item with which they agreed, and their overall score was the sum of their positive responses, so that the higher the score the greater their sense of stigma. The Q31 is a 31-item questionnaire abbreviated from the QOLIE-89 [27]

**Table 1**
Demographic features of nonepileptic subjects and patients with epilepsy and SSE.

|  | Nonepileptic subjects (NES) (n = 202 sb) | People with Epilepsy (PWE) (n = 100 sb) | p |
|---|---|---|---|
| Sex, m/f | 75/127 | 41/59 | n.s. |
| Age, y (mean ± sd) | 38.8 ± 15.5 | 47.2 ± 18.7 | <0.001 |
| Education, y (mean ± sd) | 14.7 ± 3.1 | 12.2 ± 4.1 | <0.001 |
| School level |  |  | p < 001 |
| • Illiterate | 0 | 0 |  |
| • Elementary school (6–10y) | 2 | 9 |  |
| • Middle school (11–14y) | 9 | 30 |  |
| • High school (15–19y) | 108 | 38 |  |
| • University degree (>19y) | 72 | 23 |  |
| • PhD/residency | 11 | 0 |  |
| Religion |  |  | 0.045 |
| • atheists,% | 22, (10.9%) | 24, (24%) |  |
| • Catholic,% | 177 (87.6%) | 73 (73%) |  |
| • Other religion,% | 3 (1.5%) | 3 (3%) |  |
| Work |  |  | 0.002 |
| • Students | 65 (32%) | 7 (7%) |  |
| • Nurses | 13 |  |  |
| • Residents | 7 |  |  |
| • Physicians | 23 |  |  |
| • Technicians | 2 |  |  |
| • Other jobs | 75 | 51 (51%) |  |
| • Retired | 3 (1.4%) | 24 (24%) |  |
| • Unemployed | 14 (6%) | 18 (18%) |  |
| SSE, (mean ± sd) | 47.1 ± 14.3 | 39.5 ± 16.9 | <0.001 |

SSE = Stigma Scale of Epilepsy.

**Table 2**
Clinical features of people with epilepsy (PWE).

| | |
|---|---|
| Number of patients | 100 |
| Duration of epilepsy, y | 12 ± 10.7 |
| Mean, sd | |
| Epilepsy type | |
| • Focal structural | 24 |
| • Focal unknown etiology | 63 |
| • Idiopathic generalized epilepsy | 13 |
| Epilepsy syndrome | |
| • TLE | 52 |
| • ExTLE | 35 |
| • IGE | |
| o JME | 6 |
| o JAE | 1 |
| o GM | 5 |
| o EMA | 1 |
| Antiepileptic drugs, N | |
| • 0 | 1 |
| • 1 | 74 |
| • 2 | 19 |
| • 3 | 5 |
| • 4 | 1 |
| Seizure-free/treatment-resistant | 52/48 |
| Seizure frequency (in 4 months) | 4 (1–120) |
| Median, range | |

TLE = temporal lobe epilepsy; ExTLE = extratemporal lobe epilepsy; IGE = idiopathic generalized epilepsy; JME = juvenile myoclonic epilepsy; JAE = juvenile absence epilepsy; GM = generalized epilepsy with tonic–clonic seizures; EMA = eyelid myoclonia with absences.

that focuses on specific areas of concern for people with epilepsy, and designed to serve as a brief assessment of epilepsy-specific and some overall quality-of-life issues. The BDI-II is a 21-item self-report measure of common depressive symptoms. Each item has four possible responses and higher total scores are indicative of a greater number and severity of depressive symptoms. Scores ranging from 0 to 13 indicate minimal symptoms, 14 to 19 indicate mild symptoms, 20 to 28 indicate moderate symptoms, and 29 to 63 indicate severe symptoms of depression.

The exclusion criteria for both groups were as follows: hearing problem, severe visual impairment, mental retardation, history of neurological disorders (except epilepsy for patients' sample), severe medical problems, and history of alcohol or drug abuse.

On the basis of the neuroimaging data (computed tomography [CT] scan and/or magnetic resonance imaging [MRI]), as well as the clinical and electroencephalography (EEG) features, 63 out of 100 patients had focal epilepsy of unknown etiology, 24 had structural focal epilepsy, and the remaining 13 had generalized idiopathic epilepsy (Table 2). The seizure frequency was collected through clinical diaries that were kept by the patients and their caregivers. During the 4 months before the study started (baseline period), 52 patients (52%) were seizure-free; the median seizure frequency in 4 months in the remaining 49 patients was 4 seizures (range: 1–120). The type, number, dosage, and administration schedule of drugs taken by the patients were recorded: 74 patients were on a single drug; 19 were taking 2 drugs; 5 patients 3 drugs; 1 patient was on 4 drugs, and only one patient was not yet in therapy with AEDs. The median number of AEDs used was 1 (range 0–4). The mean duration of antiepileptic treatment was 12 years, ranging from 1 year to 62 years (Table 2).

### 2.3. Statistical analysis

Descriptive statistic is presented as mean ± standard deviation or median ± range, depending on data distribution. Data distribution was assessed by means of Kolmogorov–Smirnov tests. Firstly, PWE and NES' measures were compared with $t$-test, Mann–Whitney $U$ test, or the Chi-Square test when appropriate.

Cronbach's α coefficient for reliability and internal consistency was used for validation and verification of the consistency of the instrument. This coefficient is used to verify the homogeneity or accuracy of instrument items. The accuracy should not be lower than 0.80 if the scale is widely used [20,24], thus indicating a very good internal consistency. Then, Spearman correlation was used to correlate SSE to the well-known JSS [15], to better validate the efficacy of SSE questionnaire in PWE. In addition, Mann–Whitney $U$ test was applied to compare different responses at the SSE questionnaire by NES and PWE.

Mann–Whitney $U$ test and $t$-test as appropriate were applied for analysis of comparative questions with variables of interest (SSE score, age, education, school level, religion, work, etc.) between the two groups (NES and PWE). In PWE parametric tests ($t$-test, univariate analysis of variance [ANOVA]) were used to detect any effect on the stigma perception by several factors (type of seizures, absence of seizures, side of epileptic focus, epilepsy type, epilepsy syndrome, etc.). Moreover, Pearson and Spearman correlation coefficients as appropriate were used to correlate SSE score with different factors in NES and PWE (age, education, duration of epilepsy, seizure frequency, number of AEDs, Q31 overall score and Q31 subscales, BDI-II score, etc.).

Finally, in PWE multiple stepwise-regression analyses were performed to detect the major critical factors linked to stigma perception (as evaluated through SSE score) as well as to quality of life and depressive symptoms (as evaluated respectively through Q31 and BDI-II scores). A p-value <.05 was considered significant for all statistical analyses. Bonferroni correction for handling the alpha inflation due to multiple comparisons was applied whenever appropriate. The IBM SPSS Statistics version 20.0 (SPSS, Chicago, IL) was used for statistical analyses.

## 3. Results

### 3.1. Nonepileptic subjects (NES) and people with epilepsy (PWE)

Comparing the PWE with the NES (Table 1), the first ones were significantly older (47.2 ± 18.7 vs 38.8 ± 15.5; p < .001) and less educated (12.2 ± 4.1 vs 14.7 ± 3.1; p < .001). Moreover, the two groups significantly differed for school level (p < .001), religion (p = .045), and work (p = .002). In particular, in the PWE group with respect to the NES, there were more atheists (24% vs 10.9%), unemployed (18% vs 6%), and retired people (24% vs 3%) and less students (7% vs 32%).

Finally, 45 out of 202 NES were belonging to the healthcare profession (nurses, residents, physicians, technicians); 99 out of 202 reported that they knew at least one person affected by epilepsy (in 41 cases, he was a friend, in 27 a family member, and in the other cases an acquaintance), and 53 received some theoretical training about epilepsy. Thus, considering the NES' features, we cannot consider our sample representative of the whole Italian community.

### 3.2. Stigma Scale of Epilepsy (SSE)

The internal consistency of the translated SSE was very good, with a Cronbach's α coefficient of 0.851 for control subjects and 0.880 for PWE.

A positive and significant correlation between SSE and JSS (Spearman's rho = 0.284; p = .004) was demonstrated. The score of JSS was 0 (that is 'no stigma') in 58 patients (58%), 1 in 30 (30%), 2 in 7 (7%) and 3 in 5 PWE (5%). The ANOVA showed a significant variance between groups (F: 2.860; df: 3; p = .041). The posthoc analysis evidenced a significant difference between the PWE who scored 0 (none perceived stigma) with respect to those who scored 1 or more (p = .027; Fig. 1).

Surprisingly at the SSE questionnaire, the NES had a total score significantly higher than PWE (47.1 ± 14.3 vs 39.5 ± 16.9, p < .001; Table 1).

In the NES' group no significant differences or correlations were found taking into account several features: sex, religion, type of profession (also belonging to healthcare profession), knowledge of PWE,
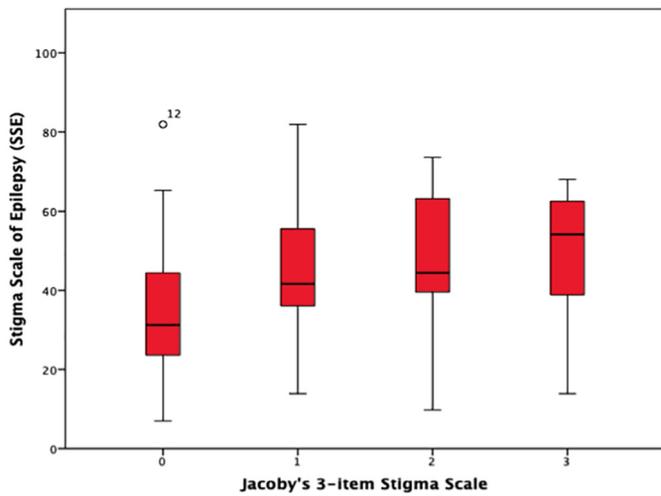
**Fig. 1.** The figure shows the relationship between the scores at Stigma Scale of Epilepsy (SSE) and at the well-known 3-item Jacoby's Stigma Scale; the posthoc analysis (ANOVA) evidenced a significant difference between the PWE who scored 0 at JSS (none perceived stigma) with respect to those who scored 1 or more (p = .027).

training about epilepsy. In PWE, the SSE total score did not show any correlation with age, education, duration of epilepsy, and seizure frequency, but only a positive significant correlation with a number of antiepileptic drugs (AEDs) was evidenced (rho = 0.276; p = .006). Moreover, in this group no effect on the perceived stigma of sex, religion, work (comparison between unemployed/retired and employed), absence of seizure (all types of seizures and secondarily generalized seizures), side of epileptic focus, epilepsy type, and epilepsy syndrome (temporal lobe epilepsy [TLE] vs other syndromes) has been identified.

### 3.3. Comparison of answers of NES and PWE at Stigma Scale of Epilepsy (SSE)

Table 3 depicts the frequency of SSE responses from NES and PWE. In general, the NES have given higher scores (compared to PWE) to the

different questions, in particular those regarding the query "Which difficulties do you think PWE have in their daily lives?" (in all areas: relationships, work, school, friendship, sexual, emotional, prejudice). Moreover, on the question "How do you think PWE feel?", they considered PWE more worried/fearful/ashamed/depressed than the patients. In addition, on the question "In your opinion, in which situation does prejudice against epilepsy occur?", they assigned higher scores than PWE for social relationships, marriage, and school. Finally, at the second question "What do you feel when you see an epileptic seizures?", we observed an opposite behavior: only for the item "fear" the NES scored less than PWE.

### 3.4. Correlations between SSE and Q31 and BDI-II scores

Taking into account the relationship between stigma and quality of life in PWE, we observed a strong and inverse correlation between the SSE total score and Q31 overall score (Pearson's r: −0.551, p < .001; Fig. 2). Moreover, the SSE score inversely correlated with all subscales of Q31: seizure worry (r = −0.340; p = .001), overall quality of life (r = −0.366; p < .001), emotional wellbeing (r = −0.306; p = .002), energy/fatigue (r = −0.299; p = .003), cognitive functioning (r = −0.474; p < .001), medication effects (r = −0.392; p < .001), and social functioning (r = −0.523; p < .001).

Considering the relationship between stigma and depressive symptoms, we observed a positive and strong correlation between SSE and BDI-II scores (rho = 0.428; p < .001). Finally, the BDI-II score showed a significant inverse correlation with the Q31 overall score (rho = −0.768; p < .001).

### 3.5. Effects of seizure frequency and antiepileptic therapy

Seizure frequency did not affect at all stigma perception and depressive symptoms as evaluated respectively through SSE and BDI-II scores. Instead, we evidenced a mild trend toward an inverse correlation between seizure frequency and the Q31 overall score (rho = −0.195; p = .05). Also comparing seizure-free patients and patients with treatment-resistant epilepsy, we did not observe significant differences for SSE and BDI-II scores,

**Table 3**
Answers of NES and PWE on the Stigma Scale of Epilepsy (SSE).

| | | Nonepileptic subjects (NES) n = 202(%) | | | | People with epilepsy (PWE) n = 100(%) | | | | p* |
|---|---|---|---|---|---|---|---|---|---|---|
| | | Not at all | A little | A lot | Totally | Not at all | A little | A lot | Totally | |
| Do you think that PWE feel able to control their epilepsy? | | 86(42.6%) | 78(38.6%) | 26(12.9%) | 12(5.9) | 34(34%) | 34(34%) | 25(25%) | 7(7%) | .036 |
| What do you feel when you see an epileptic seizures? | Shock | 83(41.1%) | 51(25.2%) | 55(27.2%) | 13(6.4%) | 38(38%) | 27(27%) | 20(20%) | 15(15%) | n.s. |
| | Fear | 80(39.6%) | 56(27.7%) | 50(24.8%) | 16(7.9%) | 28(28%) | 30(30%) | 25(25%) | 17(17%) | .020 |
| | Sadness | 64(31.7%) | 56(27.7%) | 58(28.7%) | 24(11.9%) | 24(24%) | 28(28%) | 27(27%) | 21(21%) | n.s. |
| | Pity | 69(34.2%) | 42(20.8%) | 57(28.2%) | 34(16.8%) | 29(29%) | 28(28%) | 25(25%) | 18(18%) | n.s. |
| Which difficulties do you think PWE have in their daily lives? | Relationships | 54(26.7%) | 87(43.1%) | 46(22.8%) | 15(7.4%) | 44(44%) | 30(31%) | 22(22%) | 4(4%) | .018 |
| | Work | 11(5.4%) | 50(24.8%) | 91(45%) | 50(24.8%) | 18(18%) | 26(26%) | 37(37%) | 19(19%) | .009 |
| | School | 17(8.4%) | 45(22.3%) | 93(46%) | 47(23%) | 22(22%) | 21(21%) | 37(37%) | 20(20%) | .027 |
| | Friendship | 17(8.4%) | 78(38.6%) | 74(36.6%) | 33(16.3%) | 35(35%) | 34(34%) | 21(21%) | 10(10%) | <.001 |
| | Sexual | 52(25.7%) | 81(40.1%) | 48(23.8%) | 21(10.4%) | 55(55%) | 26(26%) | 14(14%) | 5(5%) | <.001 |
| | Emotional | 29(14.4%) | 64(31.7%) | 79(39.1%) | 30(14.9%) | 31(31%) | 24(24%) | 33(33%) | 12(12%) | .021 |
| | Prejudice | 25(12.4%) | 63(31.2%) | 77(38.1%) | 37(18.3%) | 35(35%) | 30(30%) | 28(28%) | 7(7%) | <.001 |
| | Worried | 16(7.9%) | 51(25.2%) | 94(46.5%) | 41(20.3%) | 11(11%) | 34(34%) | 43(43%) | 12(12%) | .023 |
| | Dependent | 34(16.8%) | 73(36.1%) | 72(35.6%) | 23(11.4%) | 29(29%) | 30(30%) | 31(31%) | 10(10%) | n.s. |
| | Incapable | 89(44.1%) | 68(33.7%) | 33(16.3%) | 12(5.9%) | 48(48%) | 30(30%) | 20(20%) | 2(2%) | n.s. |
| How do you think PWE feel? | Fearful | 31(15.3%) | 64(31.7%) | 70(34.7%) | 37(18.3%) | 23(23%) | 36(36%) | 27(27%) | 14(14%) | .041 |
| | Ashamed | 51(25.2%) | 83(41.1%) | 51(25.2%) | 17(8.4%) | 46(46%) | 35(35%) | 14(14%) | 5(5%) | <.001 |
| | Depressed | 55(27.2%) | 82(40.6%) | 56(27.7%) | 9(4.5%) | 40(40%) | 36(36%) | 18(18%) | 6(6%) | .040 |
| | No different | 65(32.2%) | 90(44.6%) | 23(11.4%) | 24(11.9%) | 32(32%) | 28(28%) | 24(24%) | 16(16%) | n.s. |
| In your opinion, in which situation does prejudice against epilepsy occur? | Social relationships | 35(17.3%) | 66(32.7%) | 78(38.6%) | 23(11.4%) | 35(35%) | 34(34%) | 22(22%) | 9(9%) | <.001 |
| | Marriage | 93(46%) | 77(38.1%) | 29(14.4%) | 3(1.5%) | 65(65%) | 24(24%) | 8(8%) | 3(3%) | .004 |
| | Work | 28(13.9%) | 60(29.7%) | 82(40.6%) | 32(15.8%) | 27(27%) | 27(27%) | 25(25%) | 21(21%) | n.s. |
| | School | 28(13.9%) | 62(30.7%) | 77(38.1%) | 35(17.3%) | 34(34%) | 23(23%) | 26(26%) | 17(17%) | .009 |
| | Family | 121(59.9%) | 68(33.7%) | 11(5.4%) | 2(1%) | 64(64%) | 22(22%) | 10(10%) | 4(4%) | n.s. |

* p < .05 (Mann–Whitney).
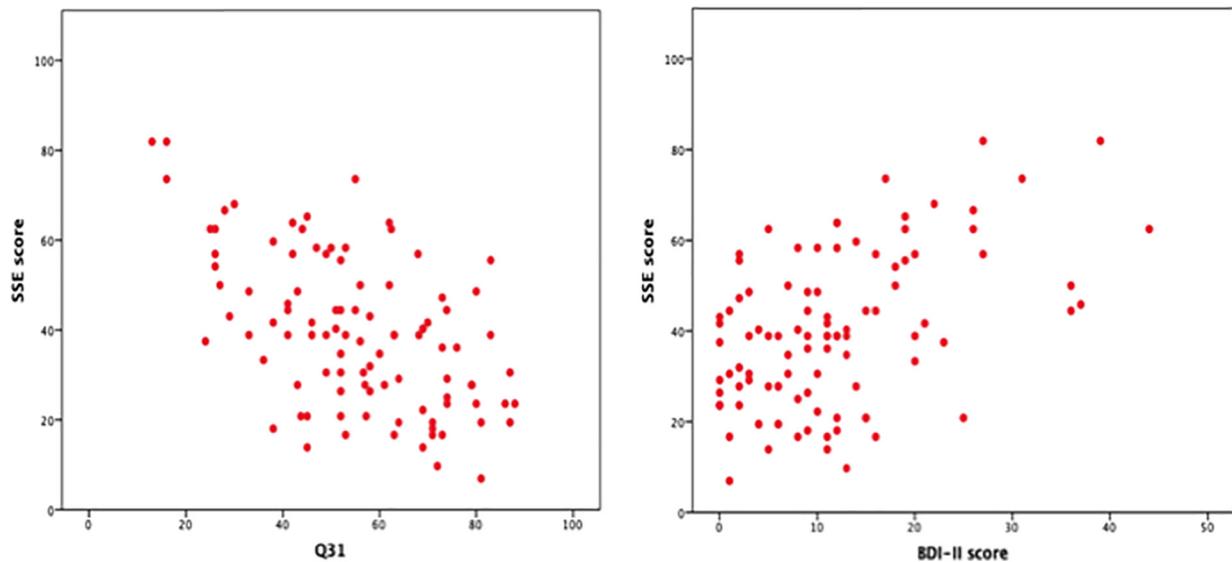
**Fig. 2.** Correlations between Stigma Scale of Epilepsy (SSE) total score and QOLIE-31 (Q31) overall score (Pearson's r: −0.551, p < .001) on the left, and between SSE total score and depressive symptoms as evaluated by Beck Depression Inventory-II (BDI-II) score (Spearman's rho = 0.428; p < .001) on the right.

but only a mild decrease of the Q31 overall value in the patients with treatment-resistant epilepsy with respect to seizure-free patients (51.3 ± 18.9 vs 58.3 ± 16.4; p = .05).

On the contrary, the number of AEDs was significantly and positively paired with SSE (rho: 0.276, p = .006) and BDI-II scores (rho: 0.251, p = .013) and inversely with the Q31 overall score (rho = −0.212; p = .036).

### 3.6. Multiple regression analysis

As some factors were related to the SSE score, multiple stepwise-regression analyses were performed to detect the major critical factors linked to stigma perception in PWE. The dependent variable was SSE total score. The independent or predictor variables were Q31 overall score as well as all the subscales of Q31, BDI-II score, and number of AEDs that resulted significantly correlated with SSE in the previous analysis. The regression analysis identified the Q31 overall score (Beta = −0.547; t = −6.403; p < .001) and the Q31 subscale targeting 'Social function' (Beta = −0.274; t = −2.184; p = .031) (Table 4) as the most significant factors connected with stigma perception. In order to better disentangle the relationships among these factors — stigma, quality of life, depressive symptoms — showing complex and frequently bidirectional connections, we have set as dependent variables also Q31 and BDI-II scores in subsequent model analysis. The results evidenced that the only predictors of quality of life were depressive symptoms (BDI-II score: Beta = −0.631; t = −8.479; p < .001) and stigma perception (SSE score: Beta = 0.240; t = −3.221; p = .002), while the most

significant factors related to BDI-II score were the overall score of quality of life (Q31: Beta = −0.748; t = −11.001; p < .001) and the number of AEDs (Beta = 0.207; t = 3.080; p = .003).

### 4. Discussion

Our study through the validation of the Italian version of the SSE questionnaire provided clear evidence that in Italy the stigma related to epilepsy is significantly higher in NES than in PWE. Considering that our NES' population was composed of young and well-educated subjects, even if not representative of the whole Italian community, present findings strongly suggest that the perception of this condition as a frightening label is still present and rooted in the Italian culture. Our results also indicated that in PWE the 'felt' stigma is strongly correlated with depressive symptoms and worse quality of life that has proven to be the most significant predictor of stigma.

The American sociologist Goffman [28] defined stigma as a phenomenon in which a person is discredited or rejected by society because of a particular attribute, in a way that spoils his/her normal identity. Starting from Goffman's work, Scambler and Hopkins [29,30] divided stigma into enacted and felt stigma. Enacted stigma refers to actual episodes or beliefs held by the public that would manifest as discrimination against PWE, solely on the grounds of their social unacceptability. Felt stigma describes self-stigmatization by PWE resulting from epilepsy-associated shame and fear of discrimination and is far more prevalent than enacted stigma [29]. While antiepileptic treatments and the awareness of the

**Table 4**
Multiple stepwise-regression analysis.

| Dependent variable | Predictors | Beta | t | p | 95%CI |
|---|---|---|---|---|---|
| SSE | **Q31 overall score** | −0.547 | −6.403 | <0.001 | −0.671; −0.353 |
| | **Social function (Q31)** | −0.274 | −2.184 | 0.031 | −1.854; −0.088 |
| | Model1 = Q31 (F = 40.993; p < .001; adjusted R$^2$ = 0.299) | | | | |
| | Model2 = Q31*social function (F = 23.687; p < .001; adjusted R$^2$ = 0.333) | | | | |
| Q31 | **BDI-II** | −0.631 | −8.479 | <0.001 | −1.445; −0.903 |
| | **SSE** | −0.240 | −3.221 | 0.002 | −4.11, −0.048 |
| | Model1 = BDI-II (F = 120.646; p < .001; adjusted R$^2$ = 0.552) | | | | |
| | Model2 = BDI-II *SSE (F = 71.323; p < .001; adjusted R$^2$ = 0.559) | | | | |
| BDI-II | **Q31 overall score** | −0.748 | −11.001 | <0.001 | −0.473; −0.328 |
| | **N° of AEDs** | 0.207 | 3.080 | 0.003 | 1.109; 5.132 |
| | Model1 = Q31 (F = 120.646; p < .001; adjusted R$^2$ = 0.552) | | | | |
| | Model2 = Q31 *N° of AEDs (F = 70.254; p < .001; adjusted R$^2$ = 0.558) | | | | |

SSE = Stigma Scale of Epilepsy; Q31 = Quolie-31; BDI-II = Beck Depression Inventory-II.

causes and effects of epilepsy have advanced, stigma around the condition has persisted over time [31,32], and PWE continue to face social and legal barriers even in Western countries [33].

The most widely used instrument for felt stigma is JSS [15] that measures PWE's perception of enacted stigma in their community, which theoretically contributes to felt stigma but may not fully encompass it. In order to overcome its limits (i.e., ceiling effect) and better describe epilepsy-associated knowledge, attitudes, practices, and felt stigma, Fernandes [20,34] developed and validated for use in Brazil the 24-item SSE that utilizes the same questions to measure both stigma in PWE and epilepsy-related stigmatization in the public. In addition, previous authors [24,35] evidenced that SSE had in contrast to JSS two latent traits — the first reflected difficulties faced by PWE and the second reflected emotions associated with epilepsy.

For the first time, we provided a characterization of the stigma related to epilepsy both in PWE and people from the Italian community by using the Italian translation of the SSE questionnaire. Even if the results of present study might not be generalized to the Italian population because the sample of NES interviewed did not include all features belonging to the general population, it is remarkable that the score of SSE is significantly higher than in PWE. Moreover, NES have given answers with higher scores (suggesting more stigma) with respect to PWE on the questions regarding both difficulties faced by patients with epilepsy and the reflected emotions associated with epilepsy, considering PWE more worried/fearful/ashamed/depressed than the same patients did. Our results are in line with the previous Italian studies focusing on the assessment of knowledge of attitudes toward and perception of epilepsy among the Italian population [16,17], students, and teachers [18,36], revealing several misconceptions and negative attitudes toward epilepsy. Recent research suggest that the legacy of these old myths about epilepsy lives on [37,38], and the negative connotations about epilepsy have been documented not just for general publics, but even for healthcare professionals [39], as in our study. Thus, as evidenced in other Western countries [33], our results reinforce the idea that also today in Italy the stigmatizing negative beliefs and attitudes toward epilepsy permeate the society.

In the Baker's study in 2000 [14], more than half of all respondents in the study (51%) felt stigmatized by their epilepsy, and almost one-fifth (18%) answered "yes" to all three items, indicating that they felt highly stigmatized by it. In our sample, the perception of stigma evaluated in PWE by the same scale (JSS) was a little lower: 42% felt stigmatized, and only 5% had a score of three. Moreover, in the Baker's study [14], a significant relationship between felt stigma and severity of epilepsy was evidenced, and these data were confirmed by other authors [40]. Instead, in our sample of PWE, the perceived stigma as evaluated by the SSE score is not affected at all by seizure frequency, but by other factors: quality of life, depressive symptoms, and antiepileptic drugs (mainly polytherapy).

Taking into account the relationship with quality of life, according to previous literature [3,40], the perceived stigma had a significant impact not only on the Q31 overall score but also on the all Q31 subscales exploring different aspects. Moreover, the multiple regression analysis revealed that lower Q31 overall score was the most significant factor associated with increased stigma. In previous studies [3,14], the extent to which stigma has a negative effect on the quality of life of PWE is strongly associated with seizure control. Anyway, Baker et al. [14] found that while seizure frequency significantly correlated with measures of stigma, this variable did not predict significant variance in stigma when entered into a regression model. Moreover, Viteva et al. [41] in Bulgarian patients with epilepsy found no correlation between seizure severity and stigma that was more severe in cases with concomitant personality and behavioral impairment and depression. We observed no correlation of the stigma with seizure frequency, which instead had a mild trend toward a negative effect on the Q31 measure. In our opinion, the lack of a significant effect of seizure frequency on stigmatization observed in our patients' sample highlights the need

for a psychosocial as well as a medical approach to management of epilepsy. Interestingly, the only feature explored by the Q31 subscales surviving in the regression analysis was the "social function", indicating a strong correlation between stigma and the social role that epilepsy could disrupt. In fact, several areas of social function like social and leisure activities and employment have been reported to be affected by stigma, both felt and enacted one [15]. Thus, for patients with epilepsy in remission or with a few seizures contending with the symptoms of their disease may well have become less important than coping with the impact of their treatment and the psychosocial consequences of their condition. Anyway, the relationship between stigma and quality of life is bidirectional; in fact, in the regression analysis in PWE, the depressive symptoms and SSE score are the most significant factors able to predict the quality of life.

Psychological and emotional factors were found to predict higher levels of reported stigma in regression analyses including feelings about life and perceived impact of epilepsy, lower self-efficacy, lower patient satisfaction, feeling more socially restricted, and poor global quality of life. Arnston et al. [42] have examined the relationship between perceived stigma and affective disorder and located significant correlations with perceived helplessness, depression, anxiety, and somatic symptoms. Significant correlations between stigma and subjects' affective state were also found in the present study. One limitation of the present data, however, is that the direction of these correlations (stigma/quality of life/depression) can only be hypothesized. Further longitudinal studies are needed of individuals with newly diagnosed epilepsy, in order to understand more clearly the process by which feelings of stigma and psychopathology are generated as well as the nature and direction of their interrelationships. In a longitudinal study completed by Reisinger and DiIorio [43], the stigma was found to be the third most important predictor of depression following employment status and social support.

Finally, the antiepileptic therapy has proven to be able to affect stigma as well as quality of life and depressive symptoms. This finding is keeping with previous reports [44,45] where greater number of epilepsy medications was correlated with increased stigma. However, in contrast Viteva [41] found no correlation between stigma and prescribed treatment. A possible explanation for our observation could relay in part to iatrogenic effects of treatments. In fact, when taking into account other illness-related variables in regression analyses, adverse events and side effects relating to the use of antiepileptic drugs were found to significantly predict stigma [46,47]. Anyway, it is possible that the antiepileptic therapy, and in particular polytherapy, could act also in a psychological way reinforcing in the patient the idea to feel sick or to be dependent on a drug.

A further limitation of our study is that PWE and NES were coming from a limited area (Rome and central Italy); moreover, the NES' features did not make our sample completely representative of the whole Italian community. Thus, further studies enrolling a bigger and more varied sample of PWE and NES are mandatory to get a more accurate picture of the perception of the stigma related to epilepsy in the Italian population.

## 5. Conclusions

In conclusion, our study by using the Italian translation of SSE questionnaire evidenced moderate rates of stigma related to epilepsy that resulted higher in NES with respect to PWE. In people with epilepsy, the perceived stigma was significantly correlated to worse quality of life, more severe depressive symptoms and higher number of AEDs. The multiple regression analysis showed the quality of life overall score and Q31 subscale exploring "social function" are the most significant predictor of stigma in PWE. We believe that our results strongly highlight the need of anthropological and educational interventions aimed at evaluating and overcoming these main factors contributing

to the stigmatization process and to ameliorate knowledge on the epilepsy.

## Declaration of Competing Interest

## Acknowledgments

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