

## Factors affecting stigma of epilepsy

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### Background

Epilepsy is a common and chronic brain disorder that affects about 50 million people worldwide. The majority of the affected population lives in the low-income regions of the world. Stigma and social marginalization are common to persons with epilepsy.

### Purpose

The aim of the present study was to evaluate the factors, including personality and psychological illnesses, likely to be influential in enhancing the social stigma of epilepsy.

### Methods

Data were collected from 102 epileptic adults recruited from the Epilepsy Clinic of Assiut University Hospital in Egypt, with 52 healthy adults included as controls. Clinical information about seizures was obtained from neurologists, and other information was collected from self-completed questionnaires, including those measuring stigma scales.

### Results

Overall, 65.7% of the people with epilepsy felt stigmatized by their condition and in 17.6% of these the stigma was severe. Multivariate analysis identified experiences of actual discrimination from society; more introverted personalities had a higher degree of depression and anxiety with a low self-esteem, and all dimensions of Quality of Life-36 questionnaire short form were negatively correlated with the social stigma of epilepsy.

### Conclusion

Factors suggested to have an impact on stigma of epilepsy include seizure-related aspects such as seizure type, frequency, duration of illness, type and number of medications, and EEG changes, and individual-related aspects such as age, sex, residence, occupational status, marital status, educational level, age at seizure onset, and the affection of the quality of life.

### Keywords:

epilepsy, personality, stigma

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### Introduction

Epilepsy is one of the most common chronic neurological disorders; it has no age, race, social class, or geographical boundary. At least 50 million people in the world have epilepsy and ~85% of them live in developing countries [1].

Although epilepsy is a largely treatable brain disorder and relatively cheap medication is available, between 60 and 98% of individuals with this disorder in developing countries receive no treatment [2].

People with epilepsy (PWE) present with health problems and also have to cope with a wide range of psychosocial difficulties that affect almost every aspect of their lives. Many of these difficulties are a consequence of public misconceptions, prejudice, and stigma [2].

Social stigma and discrimination were reported to be more devastating for persons with epilepsy than were the seizures themselves [3].

Widespread attitudinal and institutional barriers and prejudices exist against PWE in education, employment, marriage, and other socioeconomic activities [4].

Stigma is defined as a social process or related personal experience characterized by exclusion, rejection, blame, or devaluation, and which results from experience of an adverse social judgment about a person or a group [5].

At the individual level, stigma can manifest itself in the form of diminished self-confidence, withdrawal, self-imposed isolation, financial losses, and tendencies to internalize shame as well as negative perceptions of the self and of epilepsy [6].

At the level of larger social units, epilepsy-related stigma has the potential to influence social variables such as social integration, extent of interaction with social networks, and peer group activities [7].

Structural stigma can be perceived in the policies of private and state institutions, which systematically

discriminate against or restrict the opportunities available to stigmatized groups [8].

### Aim of work

The aim of the present study was to evaluate some of the factors likely to be influential in enhancing stigma of epilepsy and affecting all aspects of quality of life (QOL) of epileptic patients in Egypt, hoping to improve the management of epilepsy, and thus improving the well-being and functioning capacity of a large sector of the Egyptian society.

### Patients and methods

The present study was a cross-sectional descriptive study.

#### Patients

- (1) This study included 102 Egyptian epileptic patients (58 males, 44 females) with an age range of 19–62 years.
- (2) All the studied patients were recruited from the outpatient clinic of epilepsy of Assiut University Hospitals.
- (3) The diagnosis of epilepsy was established clinically on the basis of description of the seizure from the relatives of the patients and from eye-witnesses, and seizures were classified according to the ILAE Classification Scheme 2010.

#### Control group

- (1) A total of 52 healthy controls (29 men, 23 women) with an age range of 19–58 years, without any neurological complaints, were included in this study.

#### Procedures

All patients involved in this study were subjected to the following:

- (1) Data collection:
- (2) All participants were asked to fill out questionnaires on the day they visited their neuropsychiatrist at the outpatient clinic.
- (3) Demographic and clinical data were collected through interviews and from their medical files.
- (4) Seizure-related variables included age at seizure onset, epilepsy classification, duration of epilepsy, seizure frequency, and the number of antiepileptic drugs (AEDs) used.
- (5) Patients were subjected to full medical and neurological examination.
- (6) Full psychiatric evaluation was carried out for all patients.
- (7) Conventional EEG study was carried out for all patients.
- (8) Written informed consent was obtained from all participants.

- (9) Assessment of stigma of epilepsy was carried out through the Stigma Scale of Epilepsy. It was developed originally to measure patients' perception of the stigma of stroke and was subsequently adapted for epilepsy [9].
- (10) Each of the three items requires a simple yes/no response. Participants were asked to say whether, because of their epilepsy, they felt that other people were uncomfortable with them, treated them as inferior, and preferred to avoid them. Patients scored one for each item with which they agreed. Their overall score was the sum of their positive responses. Thus, the higher the score is, the patient is more likely to feel stigmatized.
- (11) Assessment of QOL was carried out using the Arabic version of Quality of Life-36 questionnaire short form (QOL-36-SF) [10,11]. The questionnaire comprised 36 items measuring eight dimensions of life quality. On the basis of these eight dimensions, two summary scales were constructed for physical and mental health, respectively: the Physical Component Summary, which is primarily a comprehensive measure and encompasses Physical Functioning, Role Physical (which refers to role limitations due to physical difficulties), Bodily Pain, and General Health; whereas the Mental Component Summary mainly encompasses Vitality, Social Functioning, Role Emotional, and Mental Health. However, the two summaries somewhat overlap; especially the Vitality, General Health, and Social Functioning scales have noteworthy correlations with both components.
- (12) Data were analyzed using SPSS (version 16.0; SPSS Inc., Chicago, Illinois, USA). The  $\chi^2$ -test was used for univariate analysis of categorical variables, which included sex, seizure frequency, type of epilepsy, medical treatment (monotherapy or polytherapy), level of education, marital status, and occupational status. Student's *t*-test and the Pearson correlation test were used to evaluate continuous variables: age, age at seizure onset, duration of illness, and scores on the QOL-36-SF questionnaire.

### Results

Tables 1 and 2 show the level of stigma among the epileptic patients who were involved in our study ( $N = 102$ ); it was found that there was a high percentage of patients feeling stigmatized (65.7%) and the stigma felt by about 17.6% of all patients was of severe degree.

Table 3 shows different demographic variables of all patients of the study, including age, sex, residence, marital status, employment status, and educational status, and their relation to the presence of stigma. No significant relation was found between all of these variables and the presence of stigma.

Table 4 shows different clinical variables of all patients of the present study and their relation to stigma. It shows a significant high percentage (42.2%) of patients feeling stigmatized with the early onset of illness (<20 years)

( $P = 0.007$ ). There was a significant negative correlation between age at onset of illness and the presence of stigma. Significant positive correlation was found between the frequency of seizures and the level of stigma ( $P = 0.004$ ). Patients under polytherapy were significantly feeling more stigmatized than were patients under monotherapy ( $P = 0.031$ ). Nonsignificant statistical values for the duration of illness ( $P = 0.706$ ) and seizure type were found ( $P = 0.939$ ).

As regards EEG changes of patients and their statistical significance, results showed significant correlation between

stigma and right frontal lobe activity ( $P = 0.031$ ), whereas correlations with other lobar activity were insignificant (Table 5).

Regarding stigma in relation to specific drugs, nonsignificant correlations were found between stigma and each of the most commonly used AEDs (Table 6).

In comparison with the control group, our patients revealed significant lower scores in all dimension of the QOL-36-SF questionnaire ( $P = 0.000$ ). As regards the correlation between the QOL-36-SF questionnaire and the presence of stigma, our results revealed that all the dimensions of the QOL-36-SF questionnaire were significant negatively correlated with the stigma ( $P = 0.000$ ).

**Table 1 The stigma scale of epilepsy**

| Stigma scale      | Frequency | %    |
|-------------------|-----------|------|
| None              | 35        | 34.3 |
| Mild              | 25        | 24.5 |
| Moderate          | 24        | 23.5 |
| Severe            | 18        | 17.6 |
| Total stigmatized | 67        | 65.7 |

## Discussion

Epilepsy is a common and chronic brain disorder that affects about 50 million people worldwide. The majority

**Table 2 The relation stigma and demographic characteristics of studied patients**

| Demographic variables         | Total (N=102) | Stigmatized (N=67) [n (%)] | Nonstigmatized (N=35) [n (%)] | P value | r value |
|-------------------------------|---------------|----------------------------|-------------------------------|---------|---------|
| Age groups (years)            |               |                            |                               |         |         |
| <30                           | 40            | 30 (29.4)                  | 10 (9.8)                      | 0.262   | -0.123  |
| 30-40                         | 28            | 16 (15.7)                  | 12 (11.8)                     |         |         |
| >40                           | 34            | 21 (20.6)                  | 13 (12.7)                     |         |         |
| Sex                           |               |                            |                               | 0.967   | 0.004   |
| Male                          | 58            | 38 (37.2)                  | 20 (19.6)                     |         |         |
| Female                        | 44            | 29 (28.4)                  | 15 (14.7)                     |         |         |
| Residence                     |               |                            |                               | 0.138   | 0.148   |
| Urban                         | 45            | 26 (25.5)                  | 19 (18.6)                     |         |         |
| Rural                         | 57            | 41 (40.2)                  | 16 (15.7)                     |         |         |
| Marital status                |               |                            |                               | 0.977   | -0.003  |
| Single                        | 41            | 27 (26.5)                  | 14 (13.7)                     |         |         |
| Married                       | 61            | 40 (39.2)                  | 21 (20.6)                     |         |         |
| Occupational status           |               |                            |                               | 0.848   | -0.019  |
| Unemployed                    | 51            | 32 (31.4)                  | 19 (18.6)                     |         |         |
| Employed                      | 17            | 15 (14.7)                  | 2 (2.0)                       |         |         |
| Housewife                     | 34            | 20 (19.6)                  | 14 (13.7)                     |         |         |
| Educational status            |               |                            |                               | 0.997   | 0.000   |
| Illiterate/can read and write | 67            | 44 (43.1)                  | 23 (22.5)                     |         |         |
| High level of education       | 35            | 23 (22.5)                  | 12 (11.8)                     |         |         |

**Table 3 Clinical data of studied patients and their relation to stigma**

| Clinical variables          | Total (N=102) | Stigmatized (N=67) [n (%)] | Nonstigmatized (N=35) [n (%)] | P value | r value |
|-----------------------------|---------------|----------------------------|-------------------------------|---------|---------|
| Age at onset (years)        |               |                            |                               | 0.007   | -0.196  |
| 10>                         | 14 (13.7)     | 9 (8.8)                    | 5 (4.9)                       |         |         |
| 10-20                       | 41 (40.2)     | 34 (33.3)                  | 7 (6.9)                       |         |         |
| >20                         | 47            | 24 (23.5)                  | 23 (22.5)                     |         |         |
| Duration of illness (years) |               |                            |                               | 0.706   | 0.038   |
| <10                         | 25            | 15 (14.7)                  | 10 (9.8)                      |         |         |
| 10-20                       | 48            | 33 (32.4)                  | 15 (14.7)                     |         |         |
| >20                         | 29            | 19 (18.6)                  | 10 (9.8)                      |         |         |
| Frequency of seizures       |               |                            |                               | 0.004   | 0.021   |
| Seizure-free for 1 year     | 17            | 11 (10.78)                 | 6 (5.9)                       |         |         |
| Yearly seizure              | 22            | 13 (21.7)                  | 9 (8.8)                       |         |         |
| Monthly seizures            | 51            | 36 (35.29)                 | 15 (14.7)                     |         |         |
| Weekly seizures             | 12            | 7 (6.8)                    | 5 (4.9)                       |         |         |
| Type of seizure             |               |                            |                               | 0.939   | 0.099   |
| Generalized epilepsies      | 53            | 35 (34.3)                  | 18 (17.6)                     |         |         |
| Focal epilepsies            | 49            | 33 (31.4)                  | 17 (16.7)                     |         |         |
| Treatment                   |               |                            |                               | 0.031   | 0.087   |
| Monotherapy                 | 67            | 42 (41.2)                  | 25 (24.5)                     |         |         |
| Polytherapy                 | 35            | 25 (24.5)                  | 10 (9.8)                      |         |         |

of affected persons live in the low-income regions of the world. Stigma and social marginalization are common to persons with epilepsy [12]. For many PWE, stigma is the continuing social reality of their condition. Stigma refers to the loss of status that arises from being in possession of an attribute (for example, a health condition) that has been culturally defined as ‘undesirably different’ and thus as ‘deeply discrediting’ [13].

Epilepsy affects patient’s overall QOL, with majority of patients tending to be socially stigmatized, and this, indeed, affects them both in psychological and financial terms, as in so many cases, employers reject epileptics without a clear reason.

According to the present study, 65.7% of epileptics were found to have feelings of being stigmatized. In addition,

**Table 4 EEG changes of the studied patients and their relation to stigma**

|                         | Stigma scale [n (%)] |                | Total [n (%)] | P value | r value |
|-------------------------|----------------------|----------------|---------------|---------|---------|
|                         | Stigmatized          | Nonstigmatized |               |         |         |
| Occipital lobe activity |                      |                |               |         |         |
| Right                   | 5 (4.95)             | 2 (2.0)        | 7 (6.9)       | 0.398   | -0.085  |
| Left                    | 3 (2.95)             | 0 (0)          | 3 (2.9)       |         |         |
| Temporal lobe activity  |                      |                |               |         |         |
| Right                   | 8 (7.8)              | 3 (2.9)        | 11 (10.8)     | 0.638   | 0.047   |
| Left                    | 20 (19.6)            | 14 (13.7)      | 34 (33.3)     |         |         |
| Frontal lobe activity   |                      |                |               |         |         |
| Right                   | 5 (4.9)              | 0 (0)          | 5 (4.9)       | 0.037   | 0.109   |
| Left                    | 12 (11.8)            | 13 (12.7)      | 25 (24.5)     |         |         |
| Lateralization          |                      |                |               |         |         |
| Right                   | 12 (11.8)            | 3 (2.9)        | 15 (14.7)     | 0.279   | -0.108  |
| Left                    | 25 (24.5)            | 15 (14.7)      | 40 (39.2)     |         |         |
| Generalized activity    | 20 (19.6)            | 8 (7.8)        | 28 (27.5)     |         |         |
| Normal EEG              | 10 (9.8)             | 9 (8.8)        | 19 (18.65)    |         |         |

**Table 5 Drug specific stigma**

| Drugs            | Stigma scale [n (%)] |                | Total [n (%)] | P value | r value |
|------------------|----------------------|----------------|---------------|---------|---------|
|                  | Stigmatized          | Nonstigmatized |               |         |         |
| Carbamazepine    | 53 (52.0)            | 28 (27.5)      | 53 (52.0)     | 0.916   | 0.011   |
| Others           | 14 (13.7)            | 7 (6.9)        | 14 (13.7)     |         |         |
| Sodium valproate | 17 (16.7)            | 7 (6.9)        | 24 (23.5)     | 0.548   | -0.060  |
| Others           | 50 (49.0)            | 28 (27.5)      | 78 (76.5)     |         |         |
| Clonazepam       | 16 (15.8)            | 12 (11.9)      | 28 (27.7)     | 0.288   | 0.107   |
| Others           | 50 (49.5)            | 23 (22.8)      | 73 (72.3)     |         |         |

**Table 6 Quality of Life-36 questionnaire short form of both patients and control group and its relation to stigma**

|   | Patient       | Control       | Relation between both groups |         | Relation to stigma |         |
|---|---------------|---------------|------------------------------|---------|--------------------|---------|
|   | Mean ± SD     | Mean ± SD     | r value                      | P value | P value            | r value |
| Physical functioning                      | 58.92 ± 13.74 | 99.13 ± 12.36 | 9.611                        | 0.000   | 0.000              | -0.398  |
| Role limitation due to physical problems  | 32.30 ± 13.75 | 71.68 ± 11.52 | 29.734                       | 0.000   | 0.000              | -0.372  |
| Role limitation due to emotional problems | 38.88 ± 14.97 | 72.36 ± 14.07 | 19.865                       | 0.000   | 0.000              | -0.571  |
| Energy/fatigue (vitality)                 | 42.06 ± 19.67 | 58.81 ± 11.75 | 24.895                       | 0.000   | 0.000              | -0.537  |
| Mental pain                               | 44.37 ± 18.25 | 61.42 ± 10.85 | 27.262                       | 0.000   | 0.000              | -0.585  |
| Social functioning                        | 44.14 ± 6.20  | 64.81 ± 7.60  | 24.813                       | 0.000   | 0.000              | -0.270  |
| Bodily pain                               | 38.36 ± 12.07 | 70.38 ± 11.30 | 59.610                       | 0.000   | 0.000              | -0.381  |
| General health                            | 46.61 ± 9.60  | 67.72 ± 10.09 | 41.996                       | 0.000   | 0.000              | -0.537  |
| Physical component summary                | 44.52 ± 11.21 | 73.37 ± 11.70 | 52.317                       | 0.000   | 0.000              | -0.486  |
| Mental component summary                  | 43.35 ± 12.18 | 63.98 ± 13.23 | 28.847                       | 0.000   | 0.000              | -0.516  |

17.6% of the patients were reported to feel severely stigmatized.

A large Korean study by Lee *et al.* [14] had reported that 31% of the participants reported feeling stigmatized because of epilepsy, 9% of them highly so. Similarly, a European study by Baker *et al.* [15] found that 51% of participants reported feeling stigmatized; of them, 18% were highly stigmatized.

On the other hand, Taylor *et al.* [16] reported that 54% of people reported feeling stigmatized (47.3% mild-moderate stigma, 6.1% high stigma). The difference can be attributed to cross-cultural differences.

Unlike our finding, the Korean study by Lee *et al.* [14] found a negative significant relationship between educational level and stigma of epilepsy ( $P = 0.060$ ). Epileptic patients, who were reported to have a lower educational level, were much more vulnerable to stigmatization than were those with higher educational level; this difference may be attributed to statistical factors as only a small percentage of patients with high level of education were included in our study (9.8%).

The study findings revealed that the age at onset of illness can be correlated to stigma of epilepsy. Overall, 33.3% of all patients, specifically patients with onset of illness between 10 and 20 years, felt significantly stigmatized ( $P = 0.008$ ). Negative correlation has been reported between age at onset of illness and the presence of stigma. In agreement with our findings, Baker *et al.* [15], in a study that covered a big section of Europe with more than 5000 patients, found out that age at onset of illness was a major determinant of stigmatization ( $P = 0.006$ ). It showed that increased levels of reported stigma were associated with a lower age at onset in France, Germany, and the UK.

Seizure frequency is vital to the general stability and satisfaction of the patient’s life. We found significant positive relationship between frequency of seizures and the level of stigma ( $P = 0.004$ ). The stigmatization reaches its maximum when seizure frequency is more than once per month, as 58% of the patients who had weekly seizures were feeling stigmatized. This finding was in agreement with those of a study by Baker *et al.* [15], where it was found that 63% of patients who had been seizure-free for the last year of their life felt

stigmatized to a much lesser degree than were the others. As the frequency of seizures increases, patients tend to feel more stigmatized. According to Baker's statistics, 67% of the patients felt that they were stigmatized to various extents when the frequency of seizures was one or more per month ( $P = 0.001$ ). The significant correlation between stigma and seizure frequency may be explained in the light of frequent seizures increasing the visibility of epilepsy and, hence, increasing the difficulties associated with interpersonal interactions and information control [17]; it may also be because of frequent injuries related to seizures.

In the present study, significant positive correlation was found between the number of AEDs and the level of stigma ( $P = 0.031$ ). Overall, 62% of the patients who were subjected to monotherapy were feeling stigmatized, whereas 71% of the patients who were subjected to polytherapy were feeling stigmatized. This may be related to the financial problems or associated poor control of seizures.

However, the Korean study by Lee *et al.* [14] had found that the correlation between the number of drug therapy and the level of stigma was insignificant ( $P = 0.075$ ), with 27.5% of patients who were subjected to polytherapy and 35.8% of patients who were subject to monotherapy feeling stigmatized. The difference may be attributed to the difference in economic status, to good seizure control on polydrug therapy, or to a difference in sample size.

As regards other clinical variables, such as the duration of illness and the type of seizure, there were no significant correlation to stigma; however, the duration of illness showed increased level of stigma in the early stages of illness, after which the level of stigma decreased.

This may be attributed to the adaptation that the patients develop toward their illness with longer duration, and to a bias in patient selection, as only patients with chronic illness and duration of illness greater than 7 years were included in the present study.

In the present study, the EEG changes of studied patients in correlation to stigma were significant as regards the right frontal lobe activity, with no significant correlation with the activity of all other lobes. This draws the attention toward the organic origin of stigma in the right frontal lobe.

Our study found that epilepsy adversely affects patient's QOL. In comparison with the control group, epileptic patients had worse QOLs. Epileptics were reported to have significantly less mean values of all dimensions in terms of physical functioning ( $P = 0.002$ ), role limitation due to physical problems, and role limitation due to emotional problems ( $P = 0.000$  for both). Patients were also reported to have less mean values for energy and more fatigue, more mental pain, less social functioning, and more bodily pain ( $P = 0.000$  for all these variables). Overall, patients scored less mean values for both mental and physical component summary ( $P = 0.000$  for both).

The effects of epilepsy on QOL were attributed to several factors described by studied patients such as the economic burden of their illness due to the expensive AEDs as most of them were unemployed; others said that it was due to the related repeated injuries and hospitalization and the side effects of the AEDs; for others it was due to the associated comorbidity with other psychiatric illnesses such as depression and anxiety, and still others attributed the effects on the QOL to the associated stigma, social rejection, and avoidance.

The present study also revealed significant negative correlation between QOL and stigma. All previously mentioned dimensions, which include physical functioning, role limitation due to physical problems and emotional problems, energy, fatigue, mental pain, social functioning, bodily pain, and mental and physical component summary, were significantly and negatively correlated to stigma, which means that with an increase in the degree of stigma, there is a decrease in all the QOL dimensions ( $P = 0.000$  for all). In agreement with our results, a study conducted by Lv *et al.* [18] in China also found that epileptic patients' mean scores in all subscales of QOL were less than their control group counterparts.

## Conclusion

Aspects that are suggested to impact stigma of epilepsy include the following:

- (1) Seizure-related aspects such as seizure type, frequency, duration of illness, type and number of medications, and EEG changes.
- (2) Individual-related aspects such as age at onset of epilepsy and the affection of the QOL.

From this study we can conclude that there are some factors that can affect the stigma of epilepsy:

### Inevitable factors

- (1) Early age at onset of illness.
- (2) Right frontal lobe activity on EEG.

### Correctable factors

- (1) High frequency of seizures.
- (2) Polytherapy.
- (3) Impairment of all aspects of QOL.

We recommend the following:

- (1) The stigma scale of epilepsy should be used routinely in the outpatient clinic to detect early evolving problems affecting the QOL of the epileptic patients, because functioning and well-being are the outcomes that are most important to patients.
- (2) Educational programs for the patients should be carried out to improve the compliance on treatment, which could result in having better seizure control and improving the felt stigma.

- (3) Programs spreading awareness about epilepsy and reducing negative public attitudes toward it should be enhanced.
- (4) Preparing widespread educational programs to remove the deeply rooted stigmatizing nature of epilepsy may help in improving the acceptance of the patient's state of health and improving their QOL.

#### Conflicts of interest

There are no conflicts of interest.

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