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Whether the Presence of Depressions Increases Stigmatization of People with Epilepsy?

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ABSTRACT

Introduction: Epilepsy is a disease that affects more than 50 million people worldwide. This most common chronic neurological disorder, which actually represents impairment of some brain structures, makes the patients suffering from epilepsy victims of environmental stigma, which, due to ignorance, is considered them to be mentally ill. **Aim**: The aim of the study was to examine the demographic data of epilepsy patients, disease duration, frequency of seizures and type of therapy (mono/polytherapy), determine the existence of depressive symptomatology in patients with epilepsy and to examine predictive gender significance, degree of education, employment status, type of epileptic seizure on the presence of stigma. **Patients and methods**: The sample consisted of 100 respondents, both sexes, treated in the Epilepsy Outpatient Clinic of the Clinic for Neurology of the Clinical Center of the University of Sarajevo, selected randomly. All respondents fulfilled the Mini Mental Status Test. Patients who met the required score (27 and more of a total of 30) performed a test to evaluate the possible presence of depressive affective disorder with Back's Depression Scale. They also responded to the questionnaire of the revised version of Epilepsy Stigma Scale. **Results:** The mean age of the respondents was 37.46±11.9 years. Men are on average older 40.84±11.9 years, than women 34.69±11.2 in the tested sample, and the difference shown is statistically significant, p=0.009. The difference in the frequency of respondents by status of employment is statistically significant, χc^2=50.4; p=0.0001. According to Beck's Depression Scale, a total of 15 respondents were without a stigma, a total of 51 respondents felt mild stigma, and 34 respondents felt high level of stigma, 18 of which (52.9%) with score ≤9, 2 (5.9%) score 10-15, 4 (11.8%) had a score of 16-19, 4 (11.8%) score of 20-29, while 6 (17.6%) had a score of ≥30. The degree of depression and the degree of stigma are in correlation, p=0.011. The time without epileptic seizures was approximately 6 (3-8) months for respondents without stigma, in respondents with mild stigma 4 (3-6) months and respondents with high stigma 6 (4-9) months. The mean time without epileptic seizures is statistically significantly different in relation to the degree of stigma, p=0.026 **Conclusion:** The results of this study showed that poor control of epileptic seizures and the presence of depression had a significant predictive value for the development of the stigma. Therefore, in addition to establishing good control over epileptic manifestations, it is extremely important to pay attention to psychological changes, to raise awareness in the community, to continuously carry out education, in order to have the best outcomes in treatment of a patient with epilepsy.
Keywords: Epilepsy, Depression, Therapy.

1. INTRODUCTION

Epilepsy can be defined as a paroxysmal disturbance of the central nervous system function that is recurrent, stereotyped and associated with synchronized neuronal excretion (1). The average prevalence of epilepsy for developed countries is 5.8/1000 and for developing countries up to 15.4/1000 (2). The incidence is higher for young children and the elderly. Greater frequency in underdeveloped countries is a consequence of poorer treatment of these patients due to health conditions as well as higher frequency of infections (3). What makes epilepsy as a disorder which is so difficult to control is the fact that for the affected person it is much more than the epileptic seizure itself. Apart from physical and cognitive impairment, psychiatric disorders are often present, which represent a significant burden both for the patients themselves, their

families and for the entire society (4). For years it has been considered that psychiatric disorders have been the result of difficult adaptation to this chronic and very stigmatized disease. However, today it is known that there is a bidirectional relationship between epilepsy and psychiatric disorders, depression above all (5). The emergence of depression in people with epilepsy contributes to the following psychosocial factors: unacceptable and poor adaptation of the person to epilepsy; stigma due to diagnosis of epilepsy; sudden and repeated loss of control in their own lives due to sudden occurrence of seizures; lack of social support, and the need to make meaningful lifestyle adjustments such as giving up driving or changing jobs (6). The stigma, according to Weiss and Ramakrishna, is defined as a social process or a personal experience that manifests itself as exclusion, rejection, guilt and devaluation (7). Based on this broadly accepted definition, stigma in epilepsy patients is divided into three types: Perceived stigma, Inclusion stigma and Familial stigma (8,9). It refers to the feeling of shame from epileptic seizures and the fear of facing stigma. Patients assume that their illness will be devalued and discriminated against. Because of this attitude, they adopt the strategy of social retreat and secrecy that has a negative effect on their quality of life and reinforces the perception of stigmatization.

2. AIM

The aim of the study was to examine the demographic data of epilepsy patients, disease duration, frequency of seizures and type of therapy (mono/polytherapy), to determine the existence of depressive symptomatology in patients with epilepsy and to examine predictive gender significance, degree of education, employment status, type of epileptic seizure on the presence of stigma.

3. PATIENTS AND METHODS

The sample consisted of 100 respondents, both sexes, treated in the Epilepsy Dispenser of Clinic for Neurology of the Clinical Center of the University of Sarajevo, randomly selected, during the time period 2015-2016. The main criteria for inclusion in the study were: respondents who signed Informed consent, respondents suffering from epilepsy of both sexes, at age 18-65 years, who by the level of education and general intellectual capacity could provide adequate responses in prepared forms for data collection, respondents who regularly visited Dispenser for Epilepsy of the Clinic for Neurology of the Clinical Center of the University of Sarajevo (minimum six months), respondents who provided complete data in prepared forms for data collection.

The main exclusion criteria were: respondents who could not independently provide data, respondents who refused to cooperate or provided incomplete data, respondents with previous depressive episodes, psychotic patients and previously treated patients due to mental disorder, respondents with primary diagnosis of some organ disorder or mental disorder that could affect cognitive impairment and expression of mental disorders.

All respondents fulfilled the Mini Mental Status Test. Patients who met the required number of points (27 and more from a total of 30) performed a test to evaluate the

possible presence of depressive-affective disorder with Beck's Depression Scale. They also responded to the questionnaire of the revised version of Epilepsy Stigma Scale.

Beck's Depression Assessment Scale (BDI) that was filled out by the patient.

The scale has 21 questions. There are four options for response, ranging from 0 to 4, and completion time is 5-10 minutes. The degree of expression of depressive symptoms can be quantified in the following manner: 0-9 state without depression, 10-15 mildly depressed state, 16-19 mild to moderate depression, 20-29 moderate to pronounced depression, 30-63 pronounced depression. This scale is used to assess the expression of depression symptoms in daily clinical work and in research (10).

Revised version of Epilepsy Stigma Scale (rESS)

The respondent was asked to complete a questionnaire containing 9 questions regarding demographic data and clinical characteristics of the epilepsy. Individuals were asked to respond by scale 0-3 (0=not at all, 1=yes/maybe, 2=yes/probable, 3=yes/definitive); whether due to epilepsy feel that others are uncomfortable with them, (2) treated as inferior, and (3) prefer to avoid them. This results in a total of 0-9, where 0 represents no stigma, the result of 1-6 is mild to moderate stigma, and grades 7-9 represent a high stigma (11). We used SPSS for Windows (version 19.0, SPSS Inc., Chicago, Illinois, USA) and Microsoft Excel (version 11, Microsoft Corporation, Redmond, WA, USA) for statistical analysis of the data obtained. Nominal and ordinal variables in the study were analyzed by Chi-square test. For the continuous variables in the study, we first analyzed the symmetry of their distribution using the Kolmogorov-Smirnov test. Where the distribution of continuous variables was statistically significant (p<0.05) deviating from the symmetric (Gaussian) distribution, we used medium and interquartile ranges for the mean value and dispersion measure and for comparing nonparametric tests (Mann-Whitney U test, Kruskal-Wallis test). Otherwise, where there was no statistically significant (p>0.05) deviation from the symmetric distribution, we used the arithmetic mean and standard deviation to represent the mean and the scattering mass, and to compute the independent t-test. Univariate regression analysis investigated the influence of independent factors (predictors) on the dependent variable-degree of stigma in respondents with epilepsy.

4. RESULTS

The study included 100 respondents with epilepsy. Of these, 45% men and 55% women. In this study women are more represented, but without statistically significant difference $c^2=1.0$; p=0.317.

The mean age of the sample (n=100) was 37.46±11.9 years, or the age was in the range from 29 to 46 years. The youngest respondent had 18, and the oldest 65 years. Men are on average older 40.84±11.9 years, than women 34.69±11.2 in the examined sample, and the difference shown is statistically significant, p=0.009. The difference in the frequency of respondents by status of employment is statistically significant, $c^2=50.4$; p=0.0001. Employed (57%) compared to unemployed respondents (43%) are more represented.

The difference in frequency of respondents according to

the therapeutic protocol is statistically significant, $c^2=36.1$; p=0.001. The most frequently respondents received poly-therapy (80%) compared to respondents on monotherapy (20%).

The difference in the frequency of respondents by type of seizure was statistically significant, $c^2=11.56$; p=0.001.

The most frequent were respondents with focal seizures (67%) compared to respondents with a generalized type of seizure (33%). The average duration of the disease is 12 years or between 7 and 20 years.

In the group of respondents with generalized seizures the average time without seizure is 6 months, ranging from 4-6 months. In a group with focal seizures, the average time without epileptic seizures is 6 months, ranging from 4-8 months.

		N	Percent
BDI	Without depression 0-9	69	69.0%
	Mild depression 10–15	5	5.0%
	Mild to moderate 16–19	10	10.0%
	Moderate to expressed depression 20–29	9	9.0%
	Expressed depression 30-63	7	7.0%
	Total	100	100.0%

Table 1. Beck's Depression Inventory (BDI)

According to Beck's Depression Inventory (Table 1), the categorization of the depression of the respondents was performed. Most frequent are respondents are without depression 69%, while other categories are represented by 10%, or less than 10%.

In the category without stigma, there were 15 respondents, dominated by those without depression, 12 (80.0%), while other categories are represented in less than 10%.

In the category of mild stigma, there were a total of 51 respondents, where also with 39 (76.5%) was respondents without depression, while other categories of depression were represented by less than 10%. 34 respondents experienced high level stigma, half of them 18 (52.9%) without depression, 6 (17.6%) respondents expressed depression, mild to moderate 4 (11.8%), and others the categories are represented in less than 10%.

Out of total 34 respondents felt high stigma, of which 18 (52.9%) had grade ⩽ 9, 2 (5.9%) score 10-15, 4 (11.8%) respondents score 16-19, 4 (11.8%) score 20-29, while 6 (17.6%) respondents was with score ⩾30.

Table 2 shows the relationship between demographic and clinical factors and the estimation of the stigma scale. The questionnaire filled out a total of 100 respondents, of which 45 (45%) men and 55 (55%) women.

Without stigma was 15 respondents, of which 7 (46.7%) males and 8 (53.3%) females. 51 respondents felt mild stigma, 23 (45.1%) men and 28 (54.9%) women. The high stigma was felt by 34 respondents, of whom 15 (44.1%) men and 19 (55.9%) women. Differences in the incidence of individual levels of stigma among the genders are not statistically significant, p=0.870.

Out of the total number of respondents by employed, there were 15 participants without stigma, out of which 9 (60.0%) were employed and 6 (40.0%) were unemployed. The mild stigma in this category was felt by 50 respondents, of whom 26 (52.0%) were employed and 24 (48.0%) unemployed. The high stigma was felt by 34 respondents, of which 22 (64.7%) were employed and 12 (35.3%) unemployed. The degree of stigma does not depend on the em-

rEES categories			
0 (without stigma)	1-6 (mild stigma)	7-9 (high stigma)	p-value
Sex			
Male 7 (46.7%)	23 (45.1%)	15 (44.1%)	0.870#
Female 8 (53.3%)	28 (54.9%)	19 (55.9%)	
Education level			
Grammar school 0 (0.0%)	3 (6.0%)	1 (2.9%)	
High school 10 (66.7%)	33 (66.0%)	21 (61.8%)	
College education 1 (6.7%)	8 (16.0%)	4 (11.8%)	0.809#
University qualifications 4 (26.7%)	6 (12.0%)	8 (23.5%)	
Employment			
Employed 9 (60.0%)	26 (52.0%)	22 (64.7%)	0.538#
Unemployed 6 (40.0%)	24 (48.0%)	12 (35.3%)	
BDI (0-63) Median (interquartile range) 5 (1-8)	3 (0-8)	8 (0-24.5)	
⩽9 –without depression 12 (80.0%)	39 (76.5%)	18 (52.9%)	
10-15 – mild depression 0 (0.0%)	3 (5.9%)	2 (5.9%)	
16-19 – mild to moderate depression 1 (6.7%)	5 (9.8%)	4 (11.8%)	0.011
20-29 – moderate to expressed depression 2 (13.3%)	3 (5.9%)	4 (11.8%)	
⩾30 – expressed depression 0 (0.0%)	1 (2.0%)	6 (17.6%)	
Type of seizures			
Focal 9 (60.0%)	34 (66.7%)	24 (70.6%)	0.476#
Generalized 6 (40.0%)	17 (33.3%)	10 (29.4%)	
The duration of disease/year Median (interquartile range) 15 (8-18)	12 (8-20)	11 (6.5-18.5)	0.768*
Period without EPI seizure/months Median (interquartile range) 6 (3-8)	4 (3-6)	6 (4-9)	0.026*
Age/years Median (interquartile range) 33 (21-38)	36 (28-46)	41 (29-49.5)	0.369*
Therapy			
Monotherapy 5 (33.3%)	7 (13.7%)	8 (23.5%)	0.430#
Polytherapy 10 (66.7%)	44 (86.3%)	26 (76.5%)	

Table 2. Relationship between the stigma measured by rESS scale, demographic and clinical characteristics of the respondents

ployment of the sample, p=0.538.

Of the total number of respondents according to vocational qualification, a total of 15 respondents were without stigma, of which 0 (0.0%) had basic qualifications, 10 (66.7%) secondary education, 1 (6.7%) higher professional qualifications and 4 (24.7%) high qualifications. The feeling of the stigma in this category was felt by 50 respondents, of which 3 (6.0%) had basic vocational qualifications, 33 (66.0%) secondary education, 8 (16.0%) more professional qualifications and (6.0%) high qualifications. 34 respondents felt high level of stigma, of which 1 (2.9%) had basic vocational qualifications, 21 (61.8%) secondary education, 4 (11.8%) higher education and 8 (23.5%) high education. The degree of stigma in this sample does not depend on the degree of education, p=0.830.

According to the Beck's Depression Inventory, a total of 15 respondents were without feeling of stigma, of which 12 (80.0%) had a score of ⩽9, 0 (0.0%) of 10-15, 1 (6.7%) respondents had a score of 16-19, 2 (13.3%) of 20-29, while none 0 (0.0%) of the respondents had a score of ⩾30. In this category, a total of 51 respondents felt mild stigma, of which 39 (76.5%) had a score of ⩽ 9, 3 (5.9%) scores of 10-15, 5 (9.8%) respondents rated 16-19, 3 (5.9%) scores 20-29, while 1 (2.0%) respondents rated ⩾30. 34 respondents felt high stigma, of which 18 (52.9%) had grade ⩽ 9, 2 (5.9%) scores 10-15, 4 (11.8%) respondents rated 16-19, 4 (11.8%) score 20-29, while 6 (17.6%) respondents rated ⩾30. The degree of depression and the degree of stigma depend on each other, p=0.011.

According to the seizure type category, a total of 15 respondents were without feeling of stigma, of whom 9 (60.0%) had focal seizures and 6 (40.0%) generalized epileptic seizures. In the same category, 51 respondents felt mild stigma, 34 (66.7%) had focal seizures and 17 (33.3%) generalized epileptic seizures. A total of 34 respondents felt high stigma, 24 (70.6%) had focal seizures and 10 (29.4%) generalized epileptic seizures. The stigma level does not depend on the type of epileptic seizure, p=0.476.

In the category of therapy, a total of 15 respondents did not feel stigma, of which 5 (33.3%) used monotherapy, and 10 (66.7%) used polytherapy. A mild stigma in this category was felt by 51 respondents, of whom 7 (13.7%) used monotherapy, and 44 (86.3%) used polytherapy. 34 respondents felt high stigma, of which 8 (23.5%) used monotherapy, and 26 (76.5%) used polytherapy. The stigma level does not depend on the type of therapy, p=0.430

The duration of the disease in the respondents without stigma was on average 15 (8-18) years, in respondents with mild stigma 12 (8-20) years and in respondents with high stigma 11 (6.5-18.5) years. The duration of the disease is uniform amongst the various degrees of stigma, p=0.768.

The time without epileptic seizures was approximately 6 (3-8) months for respondents with no feeling of stigma, in respondents with mild stigma 4 (3-6) months and respondents with high stigma 6 (4-9) months. The mean time without epileptic seizures is statistically significantly different in relation to the degree of stigma, p=0.026.

The age of respondents without feeling of stigma ranged on average 33 (21-38) years, in respondents with mild stigma 36 (28-46) years and in respondents with high stigma 41 (29-49.5) years. The difference in age among respondents with different degrees of stigma was not statistically significant, p=0.369. Univariate regression analysis investigated the effect of independent factors (gender, degree of education, employment status, type of therapy and type of epileptic seizure) on the dependent variable-degree of stigma in respondents with epilepsy.

These factors did not show a statistically significant effect (p>0.05) on stigma in our sample.

5. DISCUSSION

In the conducted study, women were slightly more represented with the average age of 37.46±11.9 years, while men were older (40.84±11.9 years). Out of the total number of respondents, 69% were without depression. Of the remaining 31% with pronounced signs, measured by Beck's Depression Inventory, 5% of the sample had a mildly depressed state (10-15), 10% mild to moderate (16-19), 9% moderate to pronounced depression 20-29), and 7% expressed depression (30-63).

Similar results were presented by Milovanovic and associates in their study, with a rate of 67% of those who did not have a depressive syndrome. However, differences are evident in the group suffering from depression. Measured with the same scale, in the sample of 203 patients with epilepsy, symptoms of depression were present in 33% of patients, namely: mildly depressed symptoms at 16% (10-15), mild to moderately pronounced at 7.4% (16 -19), moderate to severe 6% (20-29), and severe depression symptoms in 3.4% (30-63) patients with epilepsy. There is a greater difference in the rates between the group of respondents who had mild depression, 16% compared to those with an expressed depression of 3.4% (10,11).

Lacey and associates have shown an incidence of 44% of people with depression. However, in this Australian study, another tool for testing depression was used The Center for Epidemiologic Studies Depression Inventory- CES-D) with sensitivity of 0.985, specificity of 0.791 and predictive values comparable to the other widely used instrument, Beck's Depression Inventory used in this research (12).

In our study, moderate depression was most common in the category with high stigma respondents. And other studies have shown the influence of depression on stigma and vice versa. Brigo describes the association of stigma with deteriorating psychosocial load such as anxiety and depression in people with epilepsy (13).

The authors analyzed various factors related to stigmatization of patients with epilepsy. In general, the frequency of perceived stigma in this sample is 85%. Such a result is higher compared with the survey conducted at University Hospital Gondar, Northwestern Ethiopia, where a rate of 71.6% is presented. The reason may be multiple. First of all, different tools for stigmatization analysis were used, in the aforesaid study by Buffy et al., A modified Family Interview Schedule (FIS) tool was used, while is this study is used the revised version of Epilepsy Stigma Scale (rESS). Thus, we have had individual results of stigmatization of patients in society, not in relation to the whole family. Still, some of the reasons may be geographic area, sample size, degree of health care of these patients, but also work on

preventing stigmatization as one of the essential factors is acting to reduce it (14).

6. CONCLUSION

The results of this study showed that poor control of epileptic seizures and the presence of depression had a significant predictive value for the development of the stigma. Therefore, in addition to establishing good control over epileptic manifestations, it is extremely important to pay attention to psychological changes, to raise awareness in the community, to continuously carry out education, to have the best outcomes of treating a patient with epilepsy.

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