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Comparison of the Relationship Between Stigmatization and Depression in Patients with Focal and Generalized Seizures

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ABSTRACT

Objective: Stigmatization in patients with epilepsy is seen in varying degrees at all times, all over the world. To determine whether the stigma value and depression scores perceived by patients with epilepsy were different in focal and generalized seizures and to reveal the factors that might be effective in stigmatization.

Methods: A total of 130 patients who were diagnosed as having epilepsy, 76 females and 54 males, were included in the study. Educational status, marital status, duration of illness, seizure control, and the number of drugs used were recorded. A questionnaire for depression and stigmatization was administered to all participants.

Results: The mean age of the women was 35.26 ± 12.82 (mean ± standard deviation) years and 33.67 ± 12.55 years for men. Of the patients, 44.6% had focal seizures, 44.6% had generalized seizures, and 10.8% had unknown seizures. Stigmatization was detected in 70% and depression was detected in 54.6% of the patients. There was no difference between the stigmatization and depression scores of focal and generalized seizures ($P = .338$; $P = .857$, respectively). There was no difference between the stigmatization and sex, age, and marital status ($P = .730$; $P = .657$; $P = .320$, respectively). In our subgroup analyses, the stigmatization rate decreased as the education level increased ($P = .000$). There was a significant correlation between depression and stigmatization severity. We find a weak relationship between insufficiency and duration of the disease ($r = 0.217$, $P < .01$).

Conclusion: The stigmatization rate was independent of seizure type, seizure frequency, sex, age, and marital status. Stigmatization severity was significantly correlated with the presence of depression. Although seizures are well controlled with treatment, patients with epilepsy should be followed closely in terms of psychological and social support.

Keywords: Depression, focal seizures, generalized seizures, stigmatization

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INTRODUCTION

According to this concept, which was first defined by the sociologist Goffman,[1] stigma means people who are thought to have different characteristics and behave differently from those who are accepted

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by society. Stigmatization is common in chronic diseases. Human immunodeficiency virus infection and epilepsy are diseases in which stigmatization is common.[2]

The stigmatization of patients with epilepsy has continued in varying forms from ancient times but has always existed. It is seen in every society, regardless of Eastern or Western countries.[3,4] The form and content of stigmatization in epilepsy vary according to society and culture. For example, in the African continent, epilepsy is believed to be a contagious disease and plays a role in stigmatization.[5,6] With stigmatization, patients' non-compliance with preventive treatments increases, and they seek non-drug treatment.[6]

Meta-analyses have shown that epilepsy is associated with an increased risk of depression. In subgroup studies, increased depression has been shown in adolescents and adults with epilepsy.[7] In addition to the disability caused by the disease, psychosocial factors brought about by the seizure are effective.[8] In general, when epilepsy is mentioned, society thinks of traumatic and generalized seizures and evaluates all patients in this group, which increases fear and stigma.[9]

Our study aimed to reveal whether the perceived stigmatization value of patients with epilepsy was different in focal and generalized seizures and to determine factors that affected stigmatization, such as seizure frequency and drugs used.

MATERIAL AND METHODS

The study was conducted on 130 epilepsy patients diagnosed between December 2021 and April 2022 at the neurology clinic. The study was performed in a descriptive and cross-sectional type to evaluate the stigmatization and depression scores of individuals with epilepsy. Literate individuals aged over 18 years who were followed up for 1 year due to epilepsy and those who accepted to participate in the study were included in the study. Patients with diagnoses of focal and generalized seizures, who had regular outpatient follow-ups and were literate, were included in the study. The forms were completed by the patients themselves during face-to-face interviews. The stigma of the patients was measured using the Epilepsy Stigma scale**.** Beck Depression Inventory was used to determine the accompanying neuropsychiatric status. Educational status, marital status, duration of illness, seizure control, and the number of drugs used were recorded. Patients were grouped according to the ILAE 2017 seizure classification.[10] Bad seizure control was defined as having at least 1 generalized convulsion per year. Good seizure control was defined as seizure-free in the past year. Drug-resistant epilepsy was defined as the continuation of seizures despite the use of 2 or more antiepileptic drugs (AEDs) appropriate for the seizure type for 2 years or more in sufficient doses (ILAE 2010-2017).[10,11]

Data Collection Tools

Epilepsy Stigma Scale: To determine the stigma level of the patients, a 32-item stigma scale with a 4-point Likert-type answer option was used, which was prepared for patients with epilepsy in the Turkish population (Cronbach's $\alpha = 0.915$). The scale consists of 5 factors: *social isolation*, *discrimination*, *inadequacy*, *false beliefs*, *and stigma resistance*. The cutoff value of the scale is 50. The lowest score is 25 and the highest score is 100. Patients with scores between 51 and 75 are considered moderately stigmatized, and patients with scores between 76 and 100 are considered highly stigmatized.[12]

Beck Depression Inventory: The inventory contains 21 self-assessment statements scored on a 4-point scale. A high total score indicates a high level or intensity of depression. A score of 0-10 points = no depression, 11-17 = mild, 18-23 = moderate, and 24 points and above = severe depression.[13,14]

Statistical analysis was performed using Statistical Package for the Social Sciences software version 25.0 (IBM SPSS Corp.; Armonk, NY, USA). Descriptive statistics of continuous variables were summarized in terms of mean and SD, and descriptive statistics of categorical data were summarized in terms of frequency and percentage. The Mann–Whitney *U*-test was used in the comparison of quantitative data because the assumption of normal distribution was not met. The chi-square test was used to compare categorical data, and the Kruskal–Wallis test was used in the comparison of more than 2 groups that did not show normal distribution. The results were evaluated at the 95% confidence interval and the significance level of $P < .05$. Correlations between parameters were evaluated using Pearson's correlation analysis. A correlation coefficient (*r*) between 0.00 and 0.24 was considered a weak correlation, 0.25-0.49 moderate, 0.50-0.74 strong, and 0.75-1.00 very strong.

This study was approved by the ethics committee of the Prof. Dr. Cemil Taşçıoğlu City Hospital (Date 06.12.2021; Number: 418). Written informed consent was obtained from the patients who agreed to take part in the study.

RESULTS

A total of 130 patients, 76 females and 54 males, whose mean age was 35.6 ± 12.82 and 33.67 ± 12.55 years, respectively, were included in the study. Sociodemographic data and seizure characteristics are shown in Table 1. Duration of epilepsy was median (Q1-Q3) 10 (6-17) years. There was no significant difference between the groups with focal and generalized seizures, except for the frequency of seizures ($P = .001$).

Table 1. Sociodemographic Data

Characteristics	Variable	Number (n)	Percentage (%)
Sex	Female	76	58.5%
	Male	54	41.5%
Age	Female	35.6 ± 12.82 (mean ± SD)	
	Male	33.67 ± 12.55 (mean ± SD)	
Education	Primary school	38	29.20%
	Middle school	10	7.70%
	High school	48	36.90%
	University	34	26.2%
Marital status	Single	61	46.90%
	Married	69	53.1%
Seizure type	Focal	58	44.6%
	Generalized	58	44.6%
	Unknown	14	10.80%
Seizure control	Good	96	73.80%
	Bad	34	26.20%
Comorbidity	No	114	87.70%
	Yes	16	12.3%
Therapy	Monotherapy	89	68.50%
	Polytherapy	41	31.5%

Table 2. Depression Severity and Stigmatization Subgroup Scores According to Seizure Types

	Seizure Type Focal (n = 58)	Seizure Type Generalized (n = 58)	*P*
Depression severity	12.72 ± 11.78	13.60 ± 12.68	.857
False beliefs	7.52 ± 2.85	7.05 ± 1.91	.509
Social beliefs	20.36 ± 6.88	20.03 ± 6.57	.744
Discrimination	18.81 ± 4.58	18.48 ± 5.24	.644
Insufficiency	8.19 ± 2.95	7.59 ± 3.05	.224
Stigma resistance	5.36 ± 1.43	5.33 ± 1.31	.898
Total stigma	60.55 ± 13.91	58.26 ± 14.28	.338

Stigmatization was detected in 70% of the patients. Stigmatization severity rates were found to be moderate in 56.2% and severe in 13.8%. Depression was present in 54.6% of the patients. Depression severity was mild in 23.1%, moderate in 17.7%, and severe in 13.8%. Depression severity and stigmatization subgroup scores are shown in Table 2. A significant correlation was found between depression scores and total stigmatization scores (correlation coefficient 0.425, $P < .001$). Correlation between depression score and stigmatization subgroups is shown in Table 3.

Table 3. Correlation Between Depression Score and Stigmatization Subgroups

	Depression Score	
Group (N = 130)	*r*	*P*
False beliefs	0.243**	.005
Social isolation	0.457**	.000
Discrimination	0.385**	.000
Insufficiency	0.359**	.000
Stigma resistance	–0.057	.522
Total stigma	0.439**	.000

*$P < .05$; **$P < .01$; Spearman correlation analysis.

There was no significant difference between the male and female sexes in terms of the total stigmatization score and depression severity ($P = .73$ and $P = .576$, respectively). When the stigmatization subgroups were evaluated according to the seizure type, no difference was found between the male and female. There was no difference between depression and stigmatization scores according to their marital status, being married or single ($P = .516$ and $P = .320$, respectively). There was no difference between the severity of depression and stigmatization scores in 2 groups, under 25 years and over 25 years according to age ($P = .285$ and $P = .657$, respectively) (Table 4).

In our subgroup analyses, the stigmatization rate decreased as the education level increased, but a significant difference was found between primary school and college education ($P = .000$) (Table 5) There was no difference in depression degrees according to education level ($P = .415$).

When the total stigmatization and its subgroups were evaluated according to the seizure type, no difference was found between focal and generalized seizures ($P = .459$) and the frequency of seizures ($P = .111$). There was no difference in the severity of depression according to the seizure type and frequency of seizures ($P = .105$ and $P = .326$, respectively). We found a weak relationship between insufficiency and duration of the disease ($r = .217$, $P < .01$).

When evaluated according to the presence of additional disease, there was no difference in the depression and total stigmatization scores ($P = .216$ and $P = .983$, respectively).

DISCUSSION

The stigmatization rate of 70% we found (56.2% moderate and 13.8% severe) was quite high. The stigmatization rate varies between 31.1% and 95.9% in the literature[12,15,16,17,18] These varying rates may be related to the variety of tests used and the different population

Table 4. Characteristics, Depression Severity, and Total Stigmatization Score

Characteristics	Variable	Depression Severity Score	*P*	Total Stigmatization Score	*P*
Sex	Female	12.96 ± 12,13	.576	59.01 ± 13.03	.73
	Male	14.06 ± 12.53		59.24 ± 16.16	
Age	<25	14.57 ± 12.01	.285	60.25 ± 15.36	.657
	>25	14.75 ± 12.43		58.45 ± 13.80	
Education	Primary school	14.64 ± 12.09	.415	67.54 ± 13.41	**.000**
	Middle school	19.20 ± 13.13		59.10 ± 11.03	
	High school	14.51 ± 12.16		57.27 ± 12.85	
	University	8.64 ± 11.20		51.97 ± 13.89	
Marital status	Single	13.66 ± 13.88	.516	58.7 ± 12.78	.320
	Married	12.91 ± 11.30		59.22 ± 15.67	
Seizure type	Focal	12.72 ± 11.78	.857	60.55 ± 13.91	.338
	Generalized	13.60 ± 12.68		58.26 ± 14.28	
	Unknown	15.50 ± 13.19		56.64 ± 16.78	
Seizure control	Good	12.53 ± 12.17	.326	58.62 ± 14.29	.111
	Bad	15.72 ± 12.25		60 ± 14.59	
Comorbidity	No	14.00 ± 12.43	.216	58.92 ± 13.88	.983
	Yes	8.07 ± 9.16		59.42 ± 17.43	
Therapy	Monotherapy	12.59 ± 13.15	.113	57.72 ± 14.53	.129
	Polytherapy	14.89 ± 10.13		61.30 ± 12.54	

Kruskal-Wallis. test $P < 0.01$

Table 5. Education and Stigmatization Subgroup

Stigmatization Subgroup	Education Level (*P*)
False beliefs	**.003**
Social isolation	**.003**
Discrimination	**.001**
Insufficiency	**.000**
Stigma resistance	.213
Total stigma	**.000**

Kruskal–Wallis tests.
$P < 0.01$

subgroups evaluated cross-sectionally. In the scale we used, the quality of the questions was mostly aimed at measuring the felt stigmatization, and this scale evaluated the sub-factors of stigmatization such as social isolation, discrimination, inadequacy, false beliefs, and stigma resistance from the patient's point of view.

In our study, when the focal and generalized seizures groups were compared, no significant difference was found between the stigmatization scores. There was a difference between our 2 groups in terms of seizure frequency. Although the frequency of seizures was high in patients with focal seizures in our patient group, the fact that there was no difference in terms of stigmatization scores might be because seizures were not noticed clinically. In patients with generalized seizures, absence and myoclonic seizures may have been overlooked.

Patients with well-controlled seizures were more common in our study group. Although there were reports that unpredictable seizures and uncontrolled seizures caused embarrassment, addiction, and social isolation.[19] It was seen that the diagnosis of epilepsy alone increased this rate of stigmatization level in our study. Here, the epilepsy diagnosis is considered as a factor independent of seizure frequency. Our rate was directly related to the diagnosis of epilepsy, independent of seizure frequency. There were studies in the literature that found a moderate correlation between seizure frequency and stigmatization.[12,20,21] However, we found no relationship between seizure frequency and stigmatization level in our study.

In the Turkish study, it was shown that the stigma score increased as the frequency of seizures and the number of drugs used increased, and the education level and income level decreased. In a study conducted in Iran in 2013, Ghanean et al[3] found that stigma scores were higher in uneducated and unemployed participants. In the study of Sweden, 2 different socioeconomic levels were compared. In the Iranian study, low health knowledge and non-individualized education in the population were reported as risk factors. Swedish subjects reported significantly lower levels of experienced stigma than Iranian patients. Improved seizure control, legal measures, and health education are the main factors contributing to the reduction of stigma regarding epilepsy and possibly others in society.[4] It was determined that as the education level of the patients increased, the level of stigma decreased. In our study, we found high stigmatization scores in primary school graduates.

A positive correlation was found between patient age and disease duration and stigmatization score.[12] In another study, the stigmatization rate was found to be higher as the duration of the disease increased and the frequency of seizures increased[20] We found a weak relationship between insufficiency and duration of the disease. In our study, when men and women were evaluated separately, we found no significant difference between total stigmatization scores and stigmatization subgroups. Similarly, no relationship was found between sex and seizure type and stigmatization levels in another study.[5] The patients in our study were aged over 18 years. We observed no differences between depression and stigmatization scores when we divided the participants according to age as over 25 years and under 25 years. Unlike our study, stigma scores were found to be higher at younger ages in the studies by Mbuba et al[5] and Taylor et al.[22] In a study from Turkey, stigmatization was found to be higher in young people.[20] When we evaluated the degrees of stigmatization and depression according to whether the participants were married or single, we found no significant difference. Contrary to our findings, Karakaş et al[21] included data from Turkey and found stigmatization to be high in single individuals. In their study, being under the age of 30 years, being single, having poor economic status, living with parents and siblings, seizure frequency, the experience of hurting someone due to epileptic seizures, and experience of having an accident were associated with higher stigma scores.[21]

In our study, the rate of depression in patients with epilepsy was 55.6%. The stigmatization rate was higher in those with high depression scores. If the stigmatization rate is high, social isolation increases[23] The prejudice of the society against individuals with epilepsy, the problems in finding a job and in the marriage process are effective on the mood of the patient. We found a significant correlation between these 2 parameters. We think that intermittent psychiatric evaluation and support are valuable in patients with epilepsy. Episodes of discrimination, coping strategies, and personality may be important in feeling the stigma of epilepsy. In our study, we did not perform any other psychometric analysis other than the depression scale. Further studies can be planned to elucidate the causal factors that cause the stigma of epilepsy.[24] Socially negative perception of epilepsy results in discrimination and rejection. Internal attributions of guilt lead to negative self-image and shame. Stigmatization affects daily life, leading to concealment and avoidance. Support is beneficial in patients with epilepsy. As the patient's knowledge of the disease increases, stigmatization and depression decrease.[25]

Content and method of support are related to the epilepsy knowledge and understanding of the patient and other individuals. Programs to inform communities about epilepsy are important.[26] As a result, stigmatization is associated with participants' knowledge of epilepsy. It is important to provide more comprehensive information about epilepsy to patients and their families, to establish longer communication with patients, and to ensure the participation of patient relatives in these sessions.

The limitation of our study was the inclusion of cross-sectional patients with epilepsy admitted to a tertiary hospital. It did not include population-based patients living in urban and rural areas homogeneously. The patients were evaluated only with stigmatization and depression scales; other social questionnaires and quality-of-life scales were not used.

In summary, we found that stigmatization increased with the presence of epilepsy. There was a significant correlation between depression and stigmatization severity. There was no difference between the stigmatization and depression scores of focal and generalized seizures. There was no difference between the stigmatization and sex, age, and marital status. There was a significant correlation between depression and stigmatization severity. We found a weak relationship between insufficiency and duration of the disease. The

longer the duration of the disease, the more difficult it becomes to cope with the problems and stigmatization increases. [12]

As a result, extensive information and continuing education programs are required for epilepsy in society. Treatment and early detection of depression and other psychological conditions are important to reduce stigmatization. A depressive state increases stigmatization scores, and high stigmatization scores increase depression. We think that breaking this cycle will be possible by raising awareness.

Ethics Committee Approval: Ethical committee approval was received from the Ethics Committee of Prof. Dr. Cemil Taşçıoğlu City Hospital (Approval no: 418, Date: 06.12.2021).

Informed Consent: Written informed consent was obtained from the patients who agreed to take part in the study.

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