

Investigation of factors associated with stigma and social support in patients with epilepsy in Turkey: A cross-sectional study

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ABSTRACT

Aim: The purpose of this study was to identify the stigma and multidimensional perceived social support levels of patients with epilepsy, as well as the factors affecting them.

Method: The sample of the study consisted of 115 patients with epilepsy followed up in a university hospital in eastern Turkey. The data of the study were collected using the descriptive information form, the Jacoby Stigma Scale, and the Multidimensional Scale of Perceived Social Support. Data analysis was performed using t-test, one-way analysis of variance (ANOVA), and Pearson correlation coefficient.

Results: The rate of exposure to stigma of the patients in the study was 62.4%. Those under 30 years of age, single, with low economic status, and living with their parents and siblings had higher stigma scale mean scores than the other groups ($p = 0.001$, $p < 0.001$, $p = 0.001$, $p = 0.019$, respectively). Multidimensional Scale of Perceived Social Support total scores were higher in women and married people ($p = 0.020$, $p = 0.01$, respectively). A statistically significant negative moderate correlation was found between the patients' Stigma scale mean values and Multidimensional Perceived Social Support Scale mean values ($r = -0.568$, $p < 0.01$).

Conclusion: According to the study's findings, stigma is prevalent among patients with epilepsy. Increasing social awareness in order to augment social support in patients with epilepsy and providing the patient with positive coping strategies may be effective in reducing stigma in patients with epilepsy.

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1. Introduction

After headache, epilepsy is the most common chronic neurological disease. According to the World Health Organization, about 50 million people worldwide are diagnosed with epilepsy, and about 2 million new cases are recorded each year [1]. The prevalence of epilepsy has been recorded as 6 per thousand in developed countries and 18.5 per thousand in developing countries. In Turkey, on the other hand, the prevalence of epilepsy is reported as 6.1–10.2 per thousand [2,3]. Epilepsy has been known since the earliest times of history and is considered dangerous and frightening by society [4]. Many studies have found that the social prognosis of

epilepsy is worse than the clinical prognosis, and thus treating epilepsy solely as a neurological disease will not suffice [2,5].

Stigma is a significant factor affecting the social prognosis of epilepsy. According to Goffman, stigma has been defined as “undesirable differences” [6]. Almost half of patients with epilepsy by age in developed countries reported feeling stigmatized [7]. Various studies among adults have stated that the prevalence and severity of the perceived stigma of epilepsy varies geographically, as high as 71.6% in Northwest Ethiopia [8] and as low as 17.6% in Korea [9]. A study conducted in European countries found that the prevalence of epilepsy-related stigma in high-income countries was 51%, with 18% of respondents reporting high levels of stigma [10]. Several studies in low- and middle-income countries, however, have found that the perceived stigma of epilepsy ranges from 31% to 69% [8,11–13].

Various forums and events are planned to combat the stigma against patients with epilepsy, particularly in Europe [14].

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Although the public's attitude toward epilepsy has improved significantly over the past 40 years, recent research demonstrates that this improvement has slipped back [15,16]. Despite the increase in knowledge about epilepsy, stigma and negative attitudes toward this disease continue. Patients with epilepsy are often perceived as insane, aggressive, contagious, or even under the influence of sinful or evil spirits, and are excluded from society [17]. In a study conducted in Nigeria, it was determined that participants believed epilepsy was caused by supernatural forces and had negative attitudes toward patients with epilepsy [18]. Other research suggests that stigma is a universal construct [19]. Stigma may cause problems in many areas such as marriage, education, employment, social life and quality of life in patients with epilepsy [7]. Moreover, it is reported that stigma related to the disease can have even stronger effects on economic status, psychological well-being, social interactions, and general health, even than the disease itself. Being devalued by others causes people with epilepsy to carry a psychological burden [20].

Social support is essential in helping patients with epilepsy struggle with epilepsy and stigma. Patients often feel lonely and ostracized from society. The relationship between social support and health has been the subject of much research in health psychology and behavioral science in recent days [21]. From this point of view, the aim of this study was to examine the relationship between stigma and social support in patients with epilepsy.

Study questions:

- What is the perceived social support and stigma level of patients with epilepsy included in the sample?
- Is there a relationship between stigma and social support in patients with epilepsy? If yes, in which direction is this relationship?
- Does the level of stigma decrease in patients with epilepsy who have high social support?
- What is the social support and stigma level of patients with epilepsy according to some variables?

2. Materials and methods

This descriptive and cross-sectional study was conducted in patients with epilepsy followed up in a university hospital in eastern Turkey between March 2020 and July 2021.

2.1. Population and sampling

The population of the study consisted of 147 adult patients followed up in a university hospital in eastern Turkey. The entire universe was included in the sample without using any sampling method for the study. The inclusion criteria were as follows: having no communication problems, being able to answer questions in interview form, volunteering to participate in the study, and being in the 18–70 year age range. Patients with epilepsy who did not fill out the questionnaires completely (17 patients with epilepsy) and did not volunteer to participate (15 patients with epilepsy) were excluded from the study. A total of 115 patients with epilepsy that met the inclusion criteria were interviewed. Data collection took approximately 10–15 min.

2.2. Data collection tools

The data of the study were collected with the data collection form prepared by the researchers. In the first part of the form, descriptive characteristics of the participants such as age, gender, and marital status were questioned and epileptic seizure characteristics of the patients were questioned in the second part, the three-item Jacoby Stigma Scale was included in the third part of

the form, and the Multidimensional Scale of Perceived Social Support in the fourth part.

2.2.1. Stigma Scale

The stigma scale, developed by Jacoby and consisting of three questions, is asked [22]

- 1) whether other people are comfortable with/around them.
- 2) whether people treat them like they are inferior.
- 3) whether they prefer to stay away from them because of their epilepsy.

If the participants agree with the statement, they are asked to say “yes” and if they do not agree, they are asked to say “no” for each question. The total score of the participants is the sum of the questions to which they answered “yes,” so a higher score indicates more stigma. The scale's internal consistency coefficient was 0.86 in our study.

2.2.2. Multidimensional Scale of Perceived Social Support (MSPSS)

This scale was developed by Zimet et al. [23]. Its Turkish validity and reliability was studied by Eker et al. [24]. This short 12-item scale was developed to assess the adequacy of support from three sources which are “family”, “friend”, and “significant other person or special person”. The MSPSS scale, which consists of three sub-dimensions (3.4.8.11 family, 6.7.9.12 friends, and 1.2.5.10 a special person), each containing 4 items, is a Likert-type scale scored from 1 to 7. The scale does not have a cutoff point; however, a high score indicates high social support. The internal consistency coefficient of the scale varies between 0.80 and 0.95 [15]. In our study, the internal consistency coefficient of the scale was found to be 0.91.

2.3. Data analysis

SPSS 21.0 (Statistical Package for Social Sciences) statistical software was used to evaluate the data obtained as a result of the study. The data had a normal distribution, according to the Kolmogorov–Smirnov normality test, and the variances were homogeneous, according to Levene's test result ($p > 0.05$). In this context, parametric statistical methods were chosen. *T* test and one-way analysis of variance (ANOVA), Tukey test and Pearson correlation coefficient were used in the analysis of the data. A value of $p < 0.05$ was considered statistically significant.

2.4. Ethical issues

This study was approved by the Ataturk University ethics committee (Ethics Committee Approval Number: 2020-1/10). Attention was paid to the principle of voluntary participation in the study; patients with epilepsy constituting the sample group were informed about the aim of the study, and their written consents were obtained.

3. Results

The mean age of the patients included in the study was 37.79 ± 11.30 years, and 30.8% were under 30 years of age. 61.5% were male, 59.8% had a high school or higher education. 44.4% of the patients, most of whom were married (71.8%), lived with their spouses and children. 61.5% described their economic status as middle-class.

In Table 1, patients' Stigma Scale and Multidimensional Scale of Perceived Social Support sub-dimensions and mean total scores are presented. The participants' mean Stigma Scale score was 1.51 ± 1.33 . As presented in Fig. 1, 62.4% of the participants in

Table 1
Sociodemographic and epileptic seizure characteristics of patients.

	n	%
Age		
Below 30 years	36	30.8
31–40 years	33	28.2
41–50 years	31	26.5
51 years and above	17	14.5
Gender		
Female	45	38.5
Male	72	61.5
Educational status		
Primary Education	47	40.2
High School and Above	70	59.8
Marital status		
Single	33	28.2
Married	84	71.8
Economic status		
Poor	26	22.2
Middle-class	72	61.5
Good	19	16.2
The persons lived together		
Alone	12	10.3
Parents and siblings	28	23.9
Spouse	25	21.4
Spouse/children	52	44.4
Seizure frequency in the last year		
Did not have seizures	28	23.9
Had less than one seizure per month	59	50.4
Had more than one seizure per month	30	25.6
Harming someone because of a seizure		
Yes	43	36.8
No	74	63.2
Accident exposure due to seizure		
Yes	77	65.8
No	40	34.2
	Mean ± SD	min–max
Stigma Scale	1.51 ± 1.33	0.00–3.00
Multidimensional Social Support Scale		
Support from someone special	14.88 ± 6.12	4.00–28.00
Friend	16.37 ± 5.46	8.00–28.00
Family	17.94 ± 4.57	10.00–28.00
Total score	49.20 ± 13.83	24.00–76.00

n; frequency, %; percent, sd; standard deviation, min; minimum score, max; maximum score.

our study enunciated that they felt stigmatized due to epilepsy, and 37.6% of them reported that it was too much. While the total score of Multidimensional Scale of Perceived Social Support was 49.20 ± 13.83 , the mean of special person support from sub-dimensions was 14.88 ± 6.12 , friend support was 16.37 ± 5.46 , and family support was 17.94 ± 4.57 .

Table 2 shows the mean scores of the Stigma Scale, Multidimensional Scale of Perceived Social Support, and its sub-dimensions according to the sociodemographic characteristics of the patients. Stigma scale mean scores of those under 30 years of age, single, with poor economic status, and living with their parents and siblings were higher than those of the other groups ($p = 0.001$, $p < 0.001$, $p = 0.001$, $p = 0.019$, respectively). Multidimensional Scale of Perceived Social Support total scores were higher in women and married people ($p = 0.020$, $p = 0.01$, respectively). Looking at the sub-dimensions of the Multidimensional Scale of Perceived Social Support, women had higher mean scores for family and friend support ($p = 0.029$, $p = 0.08$, respectively). The mean score of friend support of primary school students was higher ($p = 0.046$), and the mean score of support for a special person and friend sub-dimension of singles was lower ($p = 0.007$, $p = 0.023$). The group who defined their economic status as poor had a lower mean score of special person support than those who defined it as middle-class or good ($p = 0.042$).

In Table 3, the mean scores of Stigma, Multidimensional Scale of Perceived Social Support, and its sub-dimensions are given with regard to some epileptic seizure characteristics of the patients. 23.9% of the patients within the scope of the study had never had a seizure over the last year. The stigma scale mean scores of this group were lower than those of the other groups ($p < 0.01$). Moreover, the group that had never had a seizure in the previous year had statistically higher mean scores on the multidimensional scale of perceived social support and sub-dimensions ($p < 0.01$). 36.8% of the participants had harmed someone due to an epileptic seizure. While the group who harmed someone due to an epileptic seizure had higher mean Stigma Scale scores than those who did not, their perceived social support scores were lower ($p < 0.01$). 65.8% of the patients were exposed to an accident during the seizure. While the mean score of the Stigma Scale was higher, the Perceived Social Support Scale scores were lower in the group who were exposed to the accident during the seizure compared to those who did not ($p < 0.01$).

Table 4 contains responses of participants to the stigma scale questions. Because of their epilepsy, 55.6 percent of the patients reported that others did not feel comfortable around them. 45.3% stated that people treat them as inferior because of their epilepsy, and 50.4% notified that people preferred to stay away from them due to their epilepsy. The relationship between the patients' Stigma Scale scores and the Multidimensional Scale of Perceived Social Support sub-dimension and total scores is as seen in Table 5. A statistically significant negative moderate correlation was discovered between the mean values of the patients' Stigma scale and the mean values of the Multidimensional Scale of Perceived Social Support ($r = -0.568$, $p < 0.01$). The stigma scores of the patients decreased as the special person support, family support, and friend support scores increased ($r = -0.527$, $r = -0.548$, $r = -0.415$, $p < 0.001$, respectively).

4. Discussion

The prevalence of stigma in patients was found to be high in this study. A statistically significant negative moderate correction was found between the patients' Stigma scores and the Multidimensional Scale of Perceived Social Support scores in this study. In addition, as the patients' personal support, family support, and

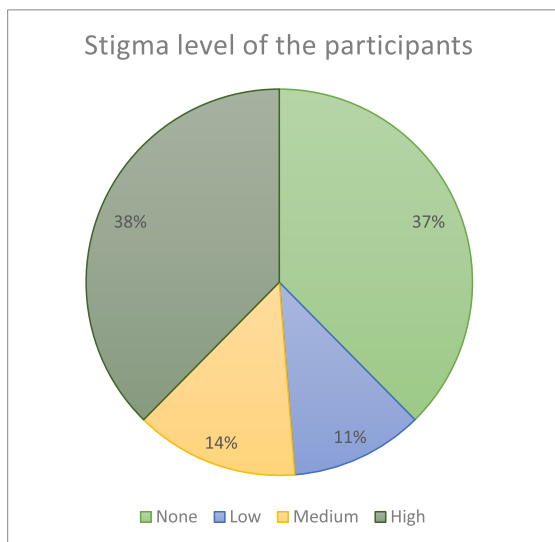


Fig. 1. Stigma level of the participants.

Table 2
Comparison of the mean scores of the total and sub-dimensions of the Stigma Multidimensional Scale of Perceived Social Support according to the sociodemographic characteristics of patients.

Variable	Stigma Mean ± SD	Special person Mean ± SD	Friend Mean ± SD	Family Mean ± SD	Total Mean ± SD
Age					
Below 30 years	2.05 ± 1.26	14.11 ± 4.95	17.36 ± 5.96	19.08 ± 5.44	50.55 ± 12.74
31–40 years	1.06 ± 1.41	14.18 ± 5.13	15.15 ± 4.20	16.64 ± 3.06	45.97 ± 11.29
41–50 years	1.29 ± 1.29	14.77 ± 8.47	16.00 ± 6.20	17.67 ± 5.15	48.45 ± 18.16
51 years and above	1.65 ± 0.99	18.06 ± 4.26	17.29 ± 4.93	18.58 ± 3.30	50.55 ± 12.74
Test	F = 3.886	F = 1.904	F = 1.83	F = 1.157	F = 1.428
p	p = 0.011*	p = 0.133	p = 0.145	p = 0.330	p = 0.238
Gender					
Female	1.44 ± 1.44	15.98 ± 7.6	17.86 ± 6.38	19.35 ± 5.54	53.20 ± 15.87
Male	1.55 ± 1.26	14.19 ± 4.92	15.43 ± 4.60	17.07 ± 3.61	46.69 ± 11.82
Test	t = -0.425	t = 1.541	t = -2.225	t = -2.461	t = -2.369
p	p = 0.672	p = 0.126	p = 0.029*	p = 0.008*	p = 0.020*
Educational status					
Primary Education	1.38 ± 1.31	15.38 ± 7.03	17.60 ± 5.76	18.19 ± 5.35	51.17 ± 15.09
High School and Above	1.60 ± 1.34	14.54 ± 5.46	15.54 ± 5.13	17.79 ± 3.99	47.87 ± 12.85
Test	t = -0.864	t = 0.726	t = 2.019	t = 0.470	t = 1.269
p	p = 0.389	p = 0.470	p = 0.046*	p = 0.640	p = 0.207
Marital status					
Single	2.24 ± 1.30	12.45 ± 5.61	14.54 ± 5.75	17.15 ± 4.62	44.15 ± 15.07
Married	1.22 ± 1.24	15.83 ± 6.08	17.08 ± 5.20	18.26 ± 4.53	51.17 ± 12.86
Test	t = 3.950	t = -2.760	t = -2.303	t = -1.185	t = -2.531
p	p = 0.001*	p = 0.007*	p = 0.023*	p = 0.238	p = 0.013*
Economic status					
Poor	2.39 ± 0.94 ^a	12.23 ± 5.069 ^a	14.92 ± 4.27	17.15 ± 5.59	44.31 ± 9.08
Middle-class	1.26 ± 1.33 ^b	15.71 ± 6.022 ^b	16.69 ± 5.58	18.51 ± 3.91	50.92 ± 13.84
Good	1.26 ± 1.33 ^b	15.37 ± 7.072 ^b	17.10 ± 6.35	16.89 ± 5.24	49.37 ± 17.76
Test	F = 8.053	F = 3.272	F = 1.216	F = 1.463	F = 2.230
p	p = 0.001*	p = 0.042*	p = 0.300	p = 0.236	p = 0.112
Person lived together					
Alone	1.25 ± 1.54 ^a	13.41 ± 7.44	14.08 ± 5.38	3.92 ± 1.13	16.70 ± 4.82
Parents and siblings	2.11 ± 1.37 ^b	14.21 ± 5.57	16.29 ± 5.88	4.47 ± 0.85	14.93 ± 2.82
Spouse	1.00 ± 1.00 ^a	14.44 ± 3.50	16.52 ± 5.45	4.47 ± 0.89	10.65 ± 2.13
Spouse/children	1.50 ± 1.31 ^a	15.79 ± 7.04	16.87 ± 5.27	4.71 ± 0.65	13.83 ± 1.92
Test	F = 3.468	F = 0.758	F = 0.849	F = 1.634	F = 1.066
p	p = 0.019*	p = 0.520	p = 0.470	p = 0.185	p = 0.360

F: one-way ANOVA, t: Independent sample t-test. *p < 0.05.

Table 3
Comparison of mean Stigma, Multidimensional Scale of Perceived Social Support and its sub-dimensions scores in terms of patients' some epileptic seizure characteristics.

	Stigma	Special person	Friend	Family	Total
Seizure frequency in the last year					
Did not have seizures	0.11 ± 0.31	20.82 ± 5.88	21.75 ± 2.89	20.89 ± 3.21	63.46 ± 8.48
Had less than one seizure per month	1.93 ± 1.26	13.80 ± 4.89	15.31 ± 5.14	16.44 ± 4.40	45.54 ± 12.04
Had more than one seizure per month	2.00 ± 1.14	11.46 ± 4.64	13.43 ± 4.42	18.17 ± 4.71	43.06 ± 12.05
Test	F = 31.350	F = 27.216	F = 27.851	F = 10.563	F = 29.813
p	p = 0.001*	p = 0.001*	p = 0.001*	p = 0.001*	p = 0.001*
Harming someone because of a seizure					
Yes	2.67 ± 0.60	12.21 ± 4.42	13.60 ± 4.01	16.79 ± 3.76	42.60 ± 9.92
No	0.837 ± 1.16	16.43 ± 6.46	17.97 ± 5.57	18.62 ± 4.87	53.03 ± 14.38
Test	t = 9.641	t = -3.797	t = -4.504	t = -4.204	t = -4.504
p	p = 0.001*	p = 0.001*	p = 0.001*	p = 0.036*	p = 0.001*
Having accident due to seizure					
Yes	1.90 ± 1.23	13.57 ± 6.22	14.49 ± 4.68	16.66 ± 3.81	44.73 ± 12.35
No	0.75 ± 1.19	17.40 ± 5.14	19.98 ± 5.08	20.43 ± 4.92	57.80 ± 12.48
Test	t = 4.893	t = -3.344	t = -5.837	t = -4.576	t = -5.410
p	p = 0.001*	p = 0.001*	p = 0.001*	p = 0.001*	p = 0.001*

F: one-way ANOVA, t: Independent sample t-test. *p < 0.05.

friend support scores increase, their stigma scores decrease. Stigma prevention is as important as seizure control in patients with epilepsy.

Epilepsy-related stigma is a common condition in both developed and less developed countries. In different studies, the rate of exposure to stigma in patients with epilepsy is reported as 31.0% in Korea, 42.0% in Italy, 52.0% in England, 68.7% in Africa,

and 43.3% in Turkey [7,12,25–27]. The rate of exposure to stigma in patients in our study was 62.4%.

In all societies, stigma has a negative impact on the social lives of patients with epilepsy [5]. In our study, more than half of the patients stated that people preferred to stay away from them because of their epilepsy. It is known that married people are more advantageous considering life satisfaction and positive health out-

Table 4
Patients' responses to the Stigma Scale.

	n	%
I feel that some people are not comfortable with me because of my epilepsy.		
Yes	65	55.6
No	52	44.4
Because of my epilepsy, I feel like some people treat me as if I am inferior.		
Yes	53	45.3
No	64	54.7
I feel like some people choose to stay away from me because of my epilepsy.		
Yes	59	50.4
No	58	49.6

n; frequency, %; percent.

Table 5
The relationship between the patients' Stigma Scale scores and the Multidimensional Scale of Perceived Social Support sub-dimension and total scores.

		Multidimensional Scale of Perceived Social Support			
		Special person	Friend	Family	CAA (Total)
Stigma	r	-0.527	-0.548	-0.415	-0.568
	p	0.001*	0.001*	0.001*	0.001*
	n	117	117	117	117

r; Pearson correlation coefficient, *p < 0.001.

comes than people who have never been married throughout their lives [28,29]. The perceived social support scores of married patients in this study were higher than those of single patients. Furthermore, in this study, patients with epilepsy under the age of 30 and single patients had higher stigma scores than married patients. In accordance with our findings, Taylor et al. reported that young and single patients with epilepsy had higher stigma scores [26]. In the literature, it is reported that the marriage rate in patients with epilepsy is lower than that of the healthy population [27]. This can be attributed to the stigma associated with epilepsy. Furthermore, those living with their parents and siblings were stigmatized more in our study. This could be because single people in Turkish society are more likely to live with their mothers, fathers, and siblings. In our study, the perceived stigma level was higher in patients with low income. Similar to our findings, Dilorio et al. reported that low-income patients who could not work due to their diseases had higher stigma scores [30].

Seizures are one of the most significant factors that influence in the stigma experience of patients with epilepsy. According to studies, having frequent seizures leads to a higher level of stigma [10,25,31]. It shows that injuries are common during generalized tonic-clonic seizures and that injury during seizure causes patients with epilepsy to feel more stigma. Patients in the study had higher rates of injury during seizures and injuring someone during seizures than in similar studies in the literature [8,25]. Besides that, those who were exposed to an accident during a seizure had higher stigma levels, whereas those who had never had a seizure in the previous year had lower stigma scores and higher social support scores than those who had seizures, according to the literature. From this point of view, good seizure control will provide significant benefits in reducing stigma in patients with epilepsy.

Stigma is a common problem among patients with epilepsy. According to the literature, social support perceived by patients is important in preventing stigma in patients with epilepsy [32]. In our study, a statistically significant negative moderate correlation was found between the patients' Stigma scores and the scores of the Multidimensional Scale of Perceived Social Support. Also,

stigma scores decreased as the patients' special person support, family support, and friend support scores increased.

As a result, the prevalence of stigma among patients in the study was quite high. Patients' quality of life, social and occupational functionality can all suffer as a result of stigma epilepsy. Prevention of stigma is as important as seizure control in patients with epilepsy. Increasing perceived social support can reduce stigma and its negative consequences in patients with epilepsy who become lonely and isolate themselves from social life due to stigma. According to this viewpoint, increasing social awareness in order to increase social support in patients with epilepsy and providing positive coping strategies to the patient may be effective in reducing stigma in patients with epilepsy.

Increasing social awareness about epilepsy, ensuring that the disease is recognized by the society, providing the patient with positive coping strategies, and improving social support can be effective in reducing the psychological burden of patients.

5. Limitations

The limitations of the current study are determined by several issues. First, the responses of the participants are limited to those provided in the statements. Second, the study data were collected during the COVID-19 pandemic. Finally, the data were obtained in a cross-sectional setting, and only from the patients with epilepsy at a university in Turkey. Therefore, the results may not be representative of all Turkish patients with epilepsy.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.yebeh.2022.108572>.

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