

Original Article

Perceived Stigma and Associated Factors among Patients with Epilepsy in Eastern Turkey: A Cross Sectional Study

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Abstract

Objective: Stigma is an important risk in epilepsy patients. This study was carried out in order to determine the stigma status of epilepsy patients in Turkey. **Methods:** The study was conducted with 125 epilepsy patients between the ages of 18 and 70 years who were admitted to a neurology outpatient clinic in a city in eastern Turkey. An Epilepsy Stigma Scale and demographic information form were used to collect data. **Results:** The patients who participated in our study were found to be moderately stigmatized. Income status and seizure type affected patients' perceived stigma. **Conclusion:** Patients with epilepsy suffer from stigma. There is a need to develop strategies reduce the perceived stigma of patients.

Keywords: Epilepsy, Stigma, Patients, Turkey

Introduction

Epilepsy is a chronic disease of the brain that affects around 50 million people worldwide. Discrimination, false beliefs and social stigma have surrounded epilepsy for centuries. (<https://www.who.int/en/news-room/fact-sheets/detail/epilepsy>, 2019) Although seizures in approximately 70% of people with epilepsy are controlled with regular medical treatment, patients with epilepsy still have to fight against the "stigma" that is brought about by prejudice, social isolation and discrimination. The stigma is conceptually broad and culturally diverse. The concept of stigma from conceptual theories, the meaning and synonym of stigma in conceptual differences and perceptions, helps to understand the complexity of stigma in epilepsy. (Lim and Tan, 2014)

Conditions for overcoming the stigma of epilepsy should be established for patients with epilepsy (Hills, 2010). Quality of life may be improved as perceptual stigma decreases in patients with epilepsy (Scambler, 2011). In a study by Viteva found that with epilepsy patients, high stigmatization perception were found to be associated with low quality of life (Viteva, 2013) Stigma experienced by patients with epilepsy is also associated with learned helplessness, depression and anxiety, deterioration of physical health, increased somatic symptoms and other health problems, decreased self-esteem, and decreased life satisfaction (Jacoby and Austin, 2007).

The high levels of stigma in epilepsy are not caused by the medical effects of seizures but by the psychosocial consequences of seizures that occur in the community. Stigma is an important

factor affecting the social prognosis of epilepsy and is associated with many factors, such as inadequate health services, poor seizure control, and insufficient knowledge about epilepsy. Jacoby et al. reported that 62% of epilepsy patients experienced stigma due to seizures. (Jacoby, 2002; Jacoby et al., 2005)

Understanding the factors affecting stigma in patients with epilepsy will affect the patients' treatment process and socialization. Therefore, the present study was carried out to determine the stigma levels of epilepsy patients in Turkey.

Methods

This cross-sectional study was conducted in Erzurum, a province to the east of Turkey. Erzurum, where a continental climate prevails, is a city close to the Iranian border of Turkey.

Participants : The study consisted of epilepsy patients who were followed up for at least one year in the Neurology Outpatient Clinic of Atatürk University Research and Practice Hospital. All epilepsy patients who were admitted to the neurology outpatient clinic between December 2019 and February 2020, aged 18–70 years, who could respond to questions in the interview form, who had no communication problems, and who were willing to be interviewed were included in the study. A total of 125 epileptic patients who were eligible for sampling were interviewed.

Data Collection Tool

The Stigma Scale for Epilepsy: The stigma scale for epilepsy scale developed by Baybas et al. was used for collecting data (Baybas et al., 2017). The stigma scale for epilepsy is a 4-item Likert-type scale with 32 items. The scores of the scale are calculated over 100 points. Stigma scores were evaluated, ranging from a minimum of 25 points to a maximum of 100 points. The cut-off value was set at 50. Participants with a score of 25–50 were evaluated as not stigmatized, patients with a score of 51–75 were evaluated as moderately stigmatized, and patients with a score of 76–100 were evaluated as highly stigmatized. There are five sub-dimensions to the scale: Social Isolation, Discrimination, Insufficiency, False Beliefs, and Stigma Resistance. The Social Isolation sub-dimension of the scale includes items 7, 9, 10, 11, 15, 16, 19, 23, 24, 25, 27, and 29. The Discrimination sub-dimension includes items 5, 6, 12, 13, 14, 22, 28, and 30. The Insufficiency sub-dimension includes items 17, 18, 20, 21, and 26. The False Beliefs sub-

dimension includes items 1, 2, 3, and 4. The Stigma Resistance sub-dimension includes items 31 and 32 (Baybas et al., 2017). This study found that the total Cronbach's alpha coefficient of the scale is 0.830.

Soci-demographic Information Form: The form includes patients' age, gender, education level, place of residence, marital status, income, working status, health status, seizure type and numbers.

Application: The patients included in the study are those who were examined by a neurologist and diagnosed with epilepsy in the neurology outpatient clinic of our hospital. The form was applied to patients who were able to read and write as a paper and pencil test. While the data were collected, questions were read to the not literate patients in a polyclinic room using a face-to-face interview method, and the answers were recorded. Seizure types of patients were obtained from patients' records. Data collection was completed in about 10–15 minutes.

Statistical Analysis : The collected data were analyzed and evaluated with the SPSS package program. In the statistical analyses, the frequency and percentage values of the grouped variables, the arithmetic mean, and the standard deviation of the numerical variables were calculated. In addition, an Independent Sample t test, Kruskal Wallis test, ANOVA tests, and Pearson correlation tests were applied to determine the differences between the groups. A Bonferroni correction was used for further analysis. A Cronbach's alpha test was performed in the internal consistency assessment of the scale.

Ethical Aspects of the Study: Permission was obtained from the authors for the use of the scale. Ethic Committee decision taken from local committee. Patients were informed about the purpose and method of the study, and verbal consent was obtained from the patients for their inclusion. Participants were assured that participation was based on the principle of volunteerism and that the information would not be disclosed to others.

Results

The study was completed with a total of 125 participants. The socio-demographic characteristics of the participants are summarized in Table 1. The highest scores for the participants or each characteristic were male (55.2%), single (54.4%), with income equivalent to expenses (57.7%), high school graduates (38.4%), living in the city center (68.0%), and not working

(55.2%). The mean age of the participants was 27.99 ± 9.21 years.

According to the mean scores that patients received from the scale, moderate stigma was detected in the patients (54.80 ± 9.57 , Min: 29.69, Max: 89.584). According to the percentage calculations, 25.6% of the participants were not stigmatized (0–50 points), 72.8% were moderately stigmatized (50–75 points), and 1.6% were highly stigmatized. When we examined the relationship between total score on the Epilepsy Stigma Scale and the socio-demographic characteristics of the participants, it was determined that seizure type had an effect on the mean scores of epilepsy patients (F: 2.989, p: .022, Table 1).

When the sub-dimension scores of the scale were analyzed according to the socio-demographic data of the participants, it was found that the income status in the Social Isolation sub-dimension affected the mean scores of the sub-dimension. It was found that the perceived social isolation was higher in patients who had more income than expenditure. In the Discrimination sub-dimension, it was found that the marital status affected the mean scores of the scale sub-dimension. The Discrimination scores of married epileptic patients were higher. It was found that socio-demographic characteristics did not make any statistical difference in the Insufficiency sub-dimension. It was found that the income level had an effect on the mean sub-dimension scores in the False Beliefs sub-dimension. Patients with epilepsy whose income was more than their expenditure were more likely to have false beliefs. It was determined that socio-demographic characteristics did not make a statistically significant difference in the Stigma Resistance sub-dimension.

The seizure type of the patients was found to make a statistically significant difference in the Social Isolation (F: 2.871, p: .026) sub-dimension. When the mean total scores were compared in the Bonferroni advanced analysis, a statistically significant difference was found

between the mean score of the patients with generalized seizure type and the mean score of the patients with complex partial seizure type. In the Social Isolation sub-dimension, again, the statistical difference was due to the generalized seizure type and complex partial seizure type.

In the Pearson correlation analysis, no correlation was found between age and diagnosis time and the total scores of stigma and sub-scale scores.

Discussion

Epilepsy is one of the most common neurological disorders. It causes stigma of different degrees in all individuals. The stigma associated with epilepsy is a problem in many cultures for those who suffer from the disorder. In this study, we aimed to evaluate the stigma levels of epilepsy patients and the socio-demographic factors affecting those levels. In order to achieve this goal, we evaluated both the total scores on the Epilepsy Stigma Scale and the sub-dimension mean scores by comparing them with the socio-demographic data. On the scale that was used in our study, the majority of patients experienced moderate perceived stigma, scoring between 50 and 75 of a possible 100 points. In their study of an Asian society, Lee et al. found that Korean epilepsy patients perceived more stigma than did those in Western societies (Lee et al., 2005). In our study, the reason for patients perceiving moderate stigma may be due to the fact that Turkey is both an Asian and a European country.

Gender, working status, perception of health status, education status, and place of residence were not seen to have an effect on stigma. In their study in Turkey, Aydemir et al. reached the conclusion that gender had no effect on stigma.¹³ In their studies, Lee et al. and Robson et al. also determined that gender had no effect on perceived stigma by epileptic individuals (Aydemir, 2011; Lee et al., 2005; Robson et al., 2018). In our study, it was found that married patients perceived more discrimination. Taylor et al. reported that marital status saw moderate levels of stigma in the married and high levels of stigma in singles (Taylor et al., 2011).

Table 1. The Mean Epilepsy Stigma Scale Sub-dimension Scores According to Participants' Introductory Characteristics

Gender	N	%	Social Isolation	Discrimination	Insufficiency	False Beliefs	Stigma Resistance	Total
Female	62	44.8	18.03±4.73	17.18±3.46	7.89±2.22	6.34±1.67	3.80±1.28	55.05±10.47
Male	80	55.2	17.96±4.34	16.71±3.20	7.67±2.27	6.25±1.41	4.00±1.23	54.69±8.83
			t: .085, p: .932	t: .785, p: .435	t: .545, p: .586	t: .352, p: .725	t: .886, p: .377	t: .350, p: .727
Marital Status								
Married	57	45.6	18.56±4.52	17.66±3.04	7.95±2.23	6.30±1.56	3.94±1.32	56.18±9.21
Single	68	54.4	17.53±4.46	16.32±3.43	7.62±2.25	6.28±1.51	3.89±1.20	53.53±9.76
			t: 1.27, p: .203	t: 2.26, p: .025	t: .797, p: .427	t: .077, p: .939	t: .234, p: .815	t: 1.53, p: .127
Income								
Income Less than Expenditure	41	32.8	17.05±4.96	16.38±3.48	7.27±2.28	5.75±1.65	4.26±1.30	52.62±10.20
Income Equal to Expenditure	71	56.8	18.15±4.28	16.89±3.16	7.95±2.19	6.51±1.43	3.85±1.28	55.13±9.13
Income Higher than Expenditure	13	10.4	20.61±3.36	18.38±3.70	8.65±2.33	7.03±1.35	3.36±.66	59.85±8.33
			F: 3.216, p: .044	F: 1.788, p: .172	F: 2.221, p: .113	F: 4.950, p: .009	F: 2.973, p: .055	F: 3.005, p: .053
Working status								
Employed	56	44.8	18.12±4.71	17.02±3.54	7.89±2.38	6.25±1.59	3.86±1.18	55.03±10.53
Unemployed (not working)	69	55.2	17.95±4.31	16.69±3.11	7.70±2.11	6.40±1.50	4.03±1.37	54.52±8.32
			t: .211, p: .833	t: .546, p: .586	t: .467, p: .641	t: .549, p: .584	t: .748, p: .456	t: .300, p: .765
Health Status								
Bad	19	15.2	18.21±5.89	17.10±4.15	7.77±2.98	6.16±1.92	3.86±1.36	55.05±13.12

Moderate	49	39.2	17.71±4.39	16.70±3.14	7.63±2.15	6.44±1.75	4.16±1.16	54.48±9.06
Good	57	45.6	18.28±4.15	16.95±3.28	7.96±2.11	6.26±1.20	3.76±1.31	55.00±8.77
			F: .222, p: .801	F: .119, p: .888	F: .273, p: .762	F: .276, p: .759	F: 1.302, p: .276	F: .046, p: .955
Education Status								
Not Literate	13	10.4	18.44±5.78	17.90±2.80	8.23±2.66	5.76±1.79	4.26±1.03	56.97±11.75
Literate	10	8.0	16.56±6.24	16.25±5.00	7.26±3.21	6.79±1.52	4.06±1.36	52.65±14.91
Primary education	30	24.0	18.04±3.59	17.44±3.41	7.99±2.05	6.38±1.77	4.21±1.15	55.88±7.77
High School	48	38.4	18.88±4.03	16.65±3.04	8.00±2.06	6.52±1.30	3.82±1.36	55.76±7.77
University	24	19.2	16.79±4.87	16.34±3.35	7.16±2.25	5.92±1.54	3.58±1.23	51.26±10.67
			KW _x ² :5.775, p.217	KW _x ² :4.748,p:.314	KW _x ² :4.252,p.373	KW _x ² :4.468,p:.346	KW _x ² :4.497,p:4.497,p..343	KW _x ² :6.479,p:.166
Place of Residence								
City	85	68.0	17.78±4.45	16.85±3.17	7.60±2.21	6.24±1.56	3.88±1.31	54.16±9.01
District	27	21.6	17.85±4.39	16.17±3.63	7.89±2.12	6.48±1.38	3.93±1.29	54.05±9.72
Village	13	10.4	20.19±4.99	18.50±3.55	8.95±2.26	6.49±1.81	4.26±.88	60.57±11.52
			F:1.64, p:.196	F: 2.18, p: .117	F: 2.08, p: .129	F: .332, p: .718	F: .499, p: .608	F: 2.71, p: .071
Type of seizure								
Generalized	41	32.8	16.69±4.76	16.48±3.37	7.18±2.40	6.28±1.71	3.86±1.25	52.24±9.73
Simple partial	58	46.4	18.15±4.38	16.58±3.42	7.81±2.14	6.08±1.37	4.01±1.27	54.44±9.36
Complex partial	11	8.8	21.37±1.92	18.53±3.22	8.87±1.00	6.96±1.23	3.76±1.43	61.60±4.02
Absence	7	5.6	19.86±6.11	18.19±3.48	9.26±3.38	7.70±1.98	4.01±1.27	60.60±14.32
Myoclonic	8	6.4	18.16±2.55	17.67±2.08	8.20±1.61	6.05±1.30	3.76±1.43	56.15±4.62
			KW_x²:11.905, p.018	KW _x ² :4.487, p.344	KW _x ² :8.407, p.078	KW _x ² :58.758, p.067	KW _x ² :.737, p.947	KW_x²:12.608, p.013

Number of seizures									
Under control	14	11.2	15.56±4.15	15.29±	7.14±2.05	5.91±1.49	3.90±.86		49.3311.28
1 ≥ per year	27	21.6	18.34±3.96	16.60±3.55	7.89±2.30	5.98±1.30	4.36±1.30		54.86±8.43
1 ≥ per month	54	43.2	18.28±4.52	17.02±2.97	7.82±2.06	6.39±1.59	3.81±1.30		55.25±7.97
1 ≥ per week	30	24.0	18.51±4.96	17.60±3.51	7.99±2.68	6.66±1.66	3.77±1.29		56.51±11.69
			F: 1.624, p: .187	F: 1.639, p: .184	F: .481, p: .696	F: 1.278, p: .285	F: 1.376, p: .253		F: 1.925, p: .129
Number of drugs used									
1	79	63.2	18.03±3.97	16.85±3.19	7.91±1.98	6.26±1.42	3.94±1.23		54.75±8.30
2	33	26.4	17.75±4.27	17.09±3.00	7.41±2.32	6.41±1.39	3.69±1.37		54.16±9.05
3 and above	13	10.4	18.87±7.64	16.52±5.01	8.17±3.48	6.37±2.52	4.50±1.06		56.73±16.59
			F: .281, p: .755	F: .140, p: .869	F: .758, p: .471	F: .110, p: .896	F: 1.955, p: .146		F: .334, p: .717
Disease other than epilepsy									
Present	23	18.4	18.37±5.85	17.22±3.48	7.71±2.37	6.48±1.87	4.00±1.08		55.77±12.08
Absent	102	81.6	17.97±4.19	16.80±3.33	7.82±2.25	6.28±1.47	3.92±1.30		54.58±8.96
			t: .382, p: .703	t: .523, p: .605	t: .223, p: .824	t: .577, p: .565	t: .295, p: .769		t: .535, p: .593
Epilepsy in the family									
Present	22	17.6	16.47±3.99	17.00±3.21	7.35±2.12	5.78±1.69	3.97±1.46		52.59±8.60
Absent	103	82.4	18.38±4.57	16.85±3.39	7.90±2.29	6.43±1.50	3.92±1.23		55.27±9.74
			t: 1.815, p: .072	t: .205, p: .839	t: 1.040, p: .300	t: 1.784, p: .111	t: .161, p: .872		t: 1.197, p: .234

Table 2 Pearson Correlation with Age, Diagnosis Time, Scale Total Score and Sub-Scale Score

Correlations									
		Age	Diagnosis time	Total	Social Isolation	Discrimination	Insufficiency	False Belief	Stigma Resistance
Age	r	1	.192*	.071	.044	.086	.090	.041	.039
	p		.032	.435	.622	.339	.320	.649	.667
Diagnosis time	r	.192*	1	-.097	-.079	-.114	-.047	-.117	.092
	p	.032		.281	.379	.205	.606	.192	.305
*. Correlation is significant at the 0.05 level (2-tailed).									
**. Correlation is significant at the 0.01 level (2-tailed).									

Discussion cont. It was determined that patients with high income perceived more stigma due to social isolation and false beliefs. Baybas et al. determined that income status had an impact on perceived stigma (Baybas et al., 2017). In this study, no statistically significant difference was found in the total perceived stigma scores measured using the same scale. However, the scores were higher in social isolation and false beliefs in patients with high income. In their study, Yeni et al. reported that knowledge and attitudes toward epilepsy had an effect on the perceived stigma of epilepsy patients (Yeni et al., 2016). We have concluded that working status does not affect perceived stigma. In their study, Lee et al. concluded that the working status of epilepsy patients did not affect their perceived social stigma (Lee et al., 2005). Educational status also had no effect on the stigma perceived by individuals with epilepsy. Baybas et al. found that social stigma perceived by epilepsy patients with low educational levels was higher than that perceived. And they determined that, as the income level decreased, the stigma scores increased (Baybas et al., 2017). These results suggested that different in patients with epilepsy stigma perception of Turkey's east and west. Turkey in Asia and Europe is a country that borders both. Because our research was done at the Asia borders end of the Turkey. The place of residence, the number of seizures, the number of drugs used, the presence of diseases other than epilepsy, and the status of the individual with epilepsy in their family had no effect on the perceived stigma of individuals with epilepsy. The majority of the patients included in our study consisted of patients who had a seizure once a month (43.2%) or once a year (21.6%), and their seizures were under control. Therefore, the number of seizures may not have an effect on stigma. The number of drugs used had no effect on stigma. In their studies, Aydemir et al. and Lee et al. concluded that the number of drugs used in epilepsy did not affect the perceived stigma (Aydemir, 2011; Lee et al., 2005). It was determined that patients with complex partial seizures perceived social isolation and total stigma more than those who did not suffer from these seizures. In a study conducted by Baybas et al. in Istanbul, Turkey's largest city, it was reported that type of seizures had no impact on stigma (Baybas et al., 2017). The effect of the type of seizure on stigma in our study may have

been due to the fact that the site of the study was a less populated rural area.

Conclusion: In our study, we detected that patients with epilepsy perceived stigma. Income, marital status, and seizure type were found to affect perceived stigma. Other factors affecting the stigma perception of patients should be investigated. Efforts must be made to reduce the effects of these factors in order to reduce the stigma perception of patients.

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