The relationship between the perceptions of stigma expressed by the relatives of patients with epilepsy and sociodemographic factors: The case of eastern Turkey

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ABSTRACT

Purpose: Stigma is a significant risk that exists in the immediate vicinity of patients with epilepsy. The present study was performed to determine the stigma perceptions of the relatives of patients with epilepsy in Turkey.
Method: The study was conducted with the relatives (aged 18–70 years) of 137 patients with epilepsy who were referred to a neurology outpatient clinic in a city east of Turkey. The Epilepsy Stigma Scale Patient's Relative Form and a Personal Information Form were used to collect data.
Result: The relatives of the patients were found to be moderately stigmatized. There was a statistically significant difference between the stigma mean scores of the relatives of the patients whose income was more than their expenditures and other income groups. It was also determined that those whose income was more than their expenditures had higher scores in the discrimination and prejudgment subdimensions; those residing in villages had higher scores in the prejudgment subdimension; those with a low education level had higher scores in the false belief subdimension; and the siblings of patients with epilepsy had higher scores in the prejudgment subdimension.
Conclusion: The results of our study indicate that the relatives of patients with epilepsy suffer from stigma. The differences in terms of the discrimination, prejudgment, and false belief subdimensions between different income statuses, education statuses, places of residence, and degrees of relationship refer to the problems that need to be overcome.

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1. Introduction

Besides being a neurological disease, epilepsy also affects both the patient and their relatives socially. Relatives of patients with epilepsy both care for them and contribute to their presence in social settings. The stigma perceived by relatives who give social support to patients with epilepsy affects the quality of life of those patients [1]. Also, the stigma perceived by relatives affects their own quality of life as well [2]. Especially in intractable epilepsy, the stigma perceived by the relatives of patients increases their burnout levels [3]. The support of families is essential for patients with epilepsy to cope with their condition [4].

The discrimination, prejudgment, and false beliefs created by epileptic seizures also affect family members and their totality [5,6]. Besides, patients' relatives can manage the stigma that the patient perceives. Therefore, relatives have to cope with the stigma perceived by both the patient and themselves [7].

In this study, the levels of stigma perceived by the relatives of patients with epilepsy in a city in eastern Turkey were examined. Turkey is a country with different cultural characteristics. Eastern Turkey is a region with unique sociocultural characteristics. This region exhibits rural characteristics and has a traditional social structure. Since stigma is directly related to the sociocultural structure, results from this region are important.

Studies on the stigma perceived by the families of patients with epilepsy [4,8–10] have revealed both the family support and burnout and depression levels of families. In Turkey, the scale developed by Baybas et al. [11] can be used to evaluate the stigma of patients with epilepsy.

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To the best of the authors' knowledge, no studies have been conducted in eastern Turkey on the stigma perceived by the relatives of patients with epilepsy. Therefore, the present study was conducted to evaluate the stigma perceived by the relatives of patients with epilepsy in eastern Turkey and to evaluate its relationship with sociodemographic factors.

2. Material and methods

This cross-sectional study was conducted in Erzurum, a city east of Turkey. It is close to Turkey's border with Iran.

2.1. Participants

The study included relatives of patients with epilepsy who were followed up at the Neurology Outpatient Clinic of Atatürk University Research and Application Hospital for at least one year. The inclusion criteria were as follows: having no communication problems, being able to answer questions in interview form, volunteering to participate in the study, being in the 18–70 year age range, and being a relative of a patient with epilepsy who was referred to the Neurology Outpatient Clinic between June and December 2018. A total of 137 relatives that met the inclusion criteria were interviewed.

2.2. Data collection tool

The Epilepsy Stigma Scale Patient's Relative Form developed by Baybas et al. [11] was used as a means of data collection. It is a 4-point Likert-type scale with 20 items. The scale consists of 100 points in total. Stigma scores were evaluated in the range of 25–100 points. The cutoff value was set at 50. Participants with a score of 25–50 were evaluated as no stigmatized, those with a score of 51–75 as moderately stigmatized, and those with a score of 76–100 as highly stigmatized. The scale has three subdimensions: discrimination, prejudgment, and false beliefs. The false beliefs and prejudgment subdimensions include items 6, 11, 12, 14, 15, 16, and 20. The false beliefs subdimension includes items 1, 2, 4, 5, and 13. The total Cronbach's alpha coefficient of the scale is 0.782.

2.2.1. Application
This study included relatives who accompanied the patients who were examined by the neurologists in the Neurology Outpatient Clinic of our hospital and who were diagnosed with epilepsy. The literate participants were asked to fill in the interview forms. On the other hand, face-to-face interviews were conducted with illiterate participants in a room in the polyclinic. Data collection took about 10–15 min.

2.2.2. Statistical analysis
The collected data were analyzed and evaluated using the Statistical Package for the Social Sciences (SPSS) package program. For the statistical analyses, frequency and percentage values were calculated for grouped variables, and arithmetic mean and standard deviation were calculated for numeric variables. In addition, an independent samples t-test, Kruskal–Wallis test, and ANalysis Of VAriance (ANOVA) were performed to determine the difference between groups, and Bonferroni and Least Significant Difference Test (LSD) tests were performed for further analysis. Cronbach's Alpha test was used to evaluate the internal consistency of the scale.

2.2.3. Ethical aspects of the study
Permission was obtained from the authors to use the scale. The participants were informed about the purpose and method of the study, and their oral consent was obtained. They were also told that participation in the study was voluntary and assured that the data obtained from them would not be disclosed to any other people.

Table 1
Distribution of participants by sociodemographic characteristics.

	N	
Sex		
Female	72	52.6
Male	65	47.4
Marital status		
Married	97	70.8
Single	40	29.2
Income status		
Income less than expenditures	46	33.6
Income equal to expenditures	79	57.7
Income more than expenditures	12	8.8
Working condition		
Employed	47	34.3
Unemployed	90	65.7
Education status		
Illiterate	10	7.3
Literate	21	15.3
Primary education	34	24.8
High school	47	34.3
University	25	18.2
Place of residence		
City	99	72.3
District	28	20.4
Village	10	7.3
Degree of relationship		
Parent	45	32.8
Spouse	23	16.8
Sibling	30	21.9
Friend	28	20.4
2nd-degree relative (aunt, uncle, cousin, grandfather, or niece)	11	8.0
Total	137	100

3. Results

The study was completed with a total of 137 participants. The sociodemographic characteristics of the participants are summarized in Table 1. The majority of participants were female (52.6%), married (70.8%), had an income level equal to expenditures (57.7%), were housewives (40.9%), were high school graduates (34.3%), resided in city centers (72.3%), and were the parents of the patients (32.8%). The mean age of the participants was 34.40 ± 12.14. According to the scale, the lowest stigma score was 25 and the highest was 100. Baybas et al. [11] determined the cutoff value of the scale as 50. Participants with a score of 25–50 were evaluated as not stigmatized, those with a score of 51–75 were evaluated as moderately stigmatized, and those with a score of 76–100 were evaluated as highly stigmatized. According to the mean scores, the relatives of the patients had a moderate stigma (54.07 ± 10.97, Min: 27.50, Max: 77.50). According to the percentage calculation, 72.2% of the participants were moderately stigmatized (50–75 points) and 0.7% were highly stigmatized. When we examined the total scores from the Epilepsy Stigma Scale Patient's Relative Form and the sociodemographic characteristics of the patients, we found no statistically significant difference in terms of sex, marital status, employment status, education status, place of residence, and degree of relationship. However, we found that income status affected the average scores of the relatives of patients with epilepsy (F: 6.08, $p < 0.01$ ($p = 0.002$); see Table 2).

The Bonferroni correction revealed that there was a statistically significant difference between the mean scores of the relatives of patients with income less than their expenditures and those with income equal to or more than their expenditures. On the other hand, there was no statistically significant difference between the mean scores of the relatives of patients with income equal to their expenditures or those with income more than their expenditures.

When the averages of the subdimension scores were analyzed according to the sociodemographic characteristics of the participants, we

Table 2
Average scores of subdimensions by sociodemographic characteristics.

	Discrimination	Prejudgment	False beliefs	Total
Sex				
Female	20.83 ± 5.59	19.89 ± 4.93	13.83 ± 3.02	54.56 ± 10.98
Male	20.92 ± 5.79	19.32 ± 4.58	13.28 ± 3.39	53.53 ± 11.09
	t: 0.092, p = 927	t: 697, p = 487	t: 1.00, p = .319	t: 0.586, p = .586
Marital status				
Married	20.63 ± 5.77	19.42 ± 4.86	13.49 ± 3.18	53.54 ± 11.27
Single	21.46 ± 5.42	20.12 ± 4.50	13.78 ± 3.29	55.37 ± 10.21
	t: 0.784, p = .434	t: 0.787, p = .433	t: 0.478, p = .633	t: 888, p = 376
Income status				
Income less than expenditures	18.96 ± 5.78	17.90 ± 4.24	12.66 ± 3.52	49.53 ± 11.64
Income equal to expenditures	21.78 ± 5.69	20.12 ± 4.82	14.09 ± 3.03	56.01 ± 10.37
Income more than expenditures	22.18 ± 2.82	22.91 ± 3.96	13.64 ± 2.35	58.75 ± 5.74
	F: 4.127, p = .018	F: 6.84, p = .001	F: 3.002, p = .053	F: 6.08, p = .002
Working condition				
Employed	19.97 ± 5.42	19.76 ± 4.60	13.45 ± 3.48	53.19 ± 11.39
Unemployed	21.34 ± 5.77	19.55 ± 4.86	13.65 ± 3.06	54.54 ± 10.77
	t: 1.350, p = .179	t: 0.239, p = .812	t: 0.313, p = .754	t: 683, p = 496
Education status				
Illiterate	19.87 ± 6.88	18.62 ± 5.21	11.75 ± 3.39	50.25 ± 12.70
Literate	20.47 ± 6.11	17.26 ± 3.96	12.79 ± 2.84	50.53 ± 11.38
Primary education	19.70 ± 5.54	19.70 ± 6.07	13.27 ± 3.34	52.68 ± 12.84
High school	21.72 ± 5.13	20.26 ± 4.32	14.65 ± 3.11	56.64 ± 9.32
University	21.60 ± 6.00	20.70 ± 3.32	13.35 ± 2.96	55.65 ± 9.18
	F: 0.829, p = .509	F: 1.995, p = .099	F: 2.684, p = .034	F: 1.805, p = .132
Place of residence				
City	20.41 ± 5.68	19.19 ± 4.67	13.53 ± 3.28	53.18 ± 11.06
District	22.27 ± 5.97	19.77 ± 4.35	13.34 ± 3.10	55.40 ± 10.67
Village	21.50 ± 4.28	23:50 ± 5:36	14.25 ± 2.89	59.25 ± 9.93
	F: 1.243, p = .292	F: 3.896, p = .023	F: 0.289, p = .750	F: 1.66, p = .194
Degree of relationship				
Parent	20.36 ± 6.64	18.22 ± 5.74	12.83 ± 3.22	51.41 ± 13.40
Spouse	20.27 ± 4.63	20.43 ± 4.34	14.83 ± 3.90	55.54 ± 10.45
Sibling	21.70 ± 5.05	21.41 ± 4.59	13.75 ± 3.07	56.87 ± 10.36
Friend	20.49 ± 5.64	18.79 ± 3.28	13.70 ± 2.81	52.99 ± 8.70
2nd-degree relative	22.95 ± 5.13	20.90 ± 2.74	13.18 ± 2.26	57.04 ± 4.04
	F: 0.715, p = .583	F: 2.753, p = .031	F: 1.596, p = .179	F: 1.54, p = .192
Total	20.87 ± 5.67	19.62 ± 4.7	13.57 ± 3.20	54.07 ± 10.97

found that sex, marital status, employment status, education status, place of residence, and degree of relationship did not have statistically significant effects on the discrimination subdimension. However, there was a statistically significant difference between income statuses in terms of the discrimination and prejudgment subdimensions (F: 4.127, p = .018; F: 6.84, p = .001). The Bonferroni correction revealed that there was a statistical difference between the participants with income less than their expenditures and those with income equal to their expenditures in terms of the discrimination subdimension. Moreover, a statistical difference was found between the participants with income less than their expenditures and those with income equal to or more than their expenditures in terms of the prejudgment subdimension. There was also a statistical difference between the participants residing in city centers, districts, or villages in terms of the prejudgment subdimension. The Bonferroni correction revealed that the statistical difference was between participants residing in villages and those residing in city centers.

Furthermore, it was found that the education statuses of the participants led to statistical differences in the false belief subdimension. The LSD test revealed that this difference was caused by the illiterate participants and those who were literate but did not have any degree of education.

There was also a statistical difference between different degrees of relationship in terms of the prejudgment subdimension. The LSD test revealed that the mean scores of those who were siblings of patients with epilepsy had higher scores. Moreover, the LSD test also showed a statistically significant difference between parents and spouses in terms of

the false belief subdimension. A Pearson's correlation analysis did not reveal a statistically significant difference between the age and stigma scores.

4. Discussion

The stigma associated with epilepsy is a problem that disturbs the relatives of patients in many cultures. In this study, we aimed to evaluate the stigma levels of the relatives of patients with epilepsy. To this end, we evaluated the total scores of the scale and the mean scores from the subdimensions, along with sociodemographic data. The Epilepsy Stigma Scale Patient's Relative Form that we used in our study had a cutoff point of 50. So, the relatives of the patients who participated in the present study perceived a moderate level of stigma. We obtained similar results to those of Baybas et al. [11]. The findings indicated that relatives of patients in Turkey suffer from stigma. In a study conducted in Kenya, Mbuba et al. [12] found that relatives of patients perceived stigma. In a US study, Hansen et al. [3] reported that family members of patients with intractable epilepsy perceived stigma. Most of the relatives of the patients who participated in our study were stigmatized. The stigma scores of the relatives of the patients in this study were higher than those reported by Baybas et al. [11]. This may be because this part of Turkey has a lower population, a rural lifestyle, and a traditional social structure. On the other hand, we obtained similar results to the stigma scores reported for the relatives of patients with intractable epilepsy by Hansen et al. [3]. This result may be due to the difficulty of hiding the stigma associated with epilepsy [3,5]. In this direction, we

naturally obtained these results in rural areas. In the present study, it was found that sociodemographic factors (age, education status, employment status, sex, marital status, etc.) other than income status did not affect perceived stigma. It was determined that the relatives of patients with higher income levels perceived more stigma. This result is quite surprising. It was found that social welfare, income status, and perceived stigma are correlated in patients with epilepsy [9]. However, we found that this situation differs for the relatives of patients with epilepsy. Because people with a high-income level are often recognized more in a community, the emergence of a chronic and uncontrollable disease in their immediate vicinity may embarrass them more than other income groups. As a result, they may have perceived more stigma.

When we examined the mean scores of the subdimensions of the scale, we saw that income status also affected the subdimensions of discrimination and prejudgment. Similarly, we found that a low education level affected the false belief subdimension. These results are not surprising. Education level affects the level of knowledge about the disease. The participants who resided in villages had higher scores on the prejudgment subdimension. This may be due to the difficulty that people living in less-populated places have in hiding the disease. The participants who were siblings of the patients with epilepsy had higher prejudgment subscores. Harden et al. found that siblings felt loneliness, sadness, and anxiety when their siblings had epileptic seizures. Besides, they also found that siblings felt that it was difficult to inform others about the epilepsy because they were anxious about others' reactions and feared that they themselves and their sibling would be stigmatized [10]. A sibling of a patient with epilepsy is usually negatively affected [10,13]. However, the fact that siblings perceived more stigma than parents may be because their ages are closer to the patients and they spend more time together outside.

It seems that while patients with epilepsy consider it unfair that their siblings and peers do not have epilepsy [8], their siblings perceive as much stigma as they do.

5. Conclusion

In our study, we found that the relatives of patients with epilepsy perceived stigma. We also found that the degree of relationship, income status, education status, and place of residence have an influence on perceived stigma. The income status of the relatives of patients with epilepsy is effective in the discrimination and prejudgment subdimensions. Siblings suffer from prejudgment, and the education status of relatives of epilepsy is effective in the false belief subdimension. Positive attitudes should be developed to reduce discrimination, false beliefs, and prejudices against relatives of patients with epilepsy. We believe that there is a need for efforts to reduce the effects of these factors that may have an impact on the stigma perceived by patients' relatives.

Conflict of interest

There is no conflict of interest.

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