



# Epilepsy and Quality of Life in the Shadow of Stigmatization

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## Abstract

**Aim:** Because of its chronic nature, epilepsy is a complex disease with psychosocial effects. This study aimed to investigate the stigma and quality of life of individuals with epilepsy.

**Methods:** This study was conducted between January 2022 and September 2022 in the epilepsy outpatient clinic of a university hospital located on the Anatolian side of Istanbul. In this descriptive and cross-sectional study, participants completed the Stigma Scale for Epilepsy (SSE), the Quality of Life in Epilepsy Inventory-10 (QOLIE-10), and a sociodemographic data form.

**Results:** The study included 130 patients (83 women and 47 men) with epilepsy. 56.2% of the participants had a medium stigmatization scores and 14.6% had a high stigmatization scores. It was determined that stigmatization was associated with age, education level, employment, and income. Total score of (SSE); participants aged 51 and over, primary school graduates, never worked, and receiving minimum wage were higher. The total SSE score did not differ according to gender, marital status, people with whom they lived together, date of diagnosis, duration of treatment, or date of the last seizure. Participants who had a seizure in the previous year without income had a lower quality-of-life score. It was determined that the QOLIE-10 scores did not differ in terms of gender, age, marital status, employment, education level, people they lived with, date of diagnosis, duration of treatment, and type of epilepsy.

**Conclusion:** The participants with high levels of stigma experienced a significant reduction in quality of life compared with the other groups. Therefore, the potential need for increased support and social rehabilitation for individuals affected by stigmatization should not be ignored.

**Keywords:** Epilepsy, stigma, quality of life, cross-sectional study

## Introduction

Throughout history, the interpretation of epilepsy in different cultures has varied. In some cultures, epilepsy was associated with evil spirits (djinn, demons, etc.) and paranormal powers, and non-scientifically valid methods (magic, witchcraft, etc.) were used in its treatment (1,2). Even though these negative attitudes are less prevalent today, individuals diagnosed with epilepsy still face stigma (3). Patients' social, educational, and professional lives have declined due to stigmatization, which has also negatively impacted their quality of life (4,5).

Numerous factors adversely affect the quality of life of individuals diagnosed with epilepsy. The physiological

effects and chronic nature of epilepsy, along with regular hospital visits, legal restrictions (like not obtaining a driver's license or exemption from military service), protective family attitudes, negative cultural attitudes towards the disease, and stigma, all contribute to a decrease in quality of life, according to reports (6-8).

The concepts of quality of life and stigma can vary over time due to societal dynamics (9). Hence, it is important to assess the levels of stigma and quality of life of individuals diagnosed with epilepsy. This study was conducted with the purpose of investigating the relationship between stigma and quality of life in individuals with epilepsy.

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**Received:** 04.01.2024 **Accepted:** 18.06.2024



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## Methods

### Complicance with Ethical Standards

For the conduct of this research, ethical approval was obtained from the Maltepe University Ethics Committee (approval no.: 2020/16-03, dated: 11.12.2020), and permission to conduct the study was also granted by the relevant institution (permission no.: 2022/02, dated: 25.01.2022). Written informed consent was obtained from all patients participating in the study. This study was conducted in accordance with the Helsinki Declaration. This article was derived from the master's thesis titled "Stigma and Quality of Life in Individuals with Epilepsy".

### Study Design

This cross-sectional study was conducted between February and September 2022. Participants were 18 years of age or older, had primary school graduates as their lowest level of education, did not have any perception or communication problems, and visited the epilepsy clinic for routine appointments (Figure 1). Data were collected through face-to-face interviews in a suitable and quiet room within the clinic where participants and the researcher were present. The data collection process for each participant took approximately 15 minutes.

### Data Collection Tools

The study employed the Stigma Scale for Epilepsy (SSE), developed by Baybaş et al. (11), to assess stigma levels in epileptic individuals in the Turkish population (10). The scale comprises 32 questions with a 4-point Likert-type answering system, with a minimum score of 25 and

a maximum score of 100, with a cut-off value set at 50. Epileptic individuals scoring between 51 and 75 were considered moderately stigmatized, whereas those scoring between 76 and 100 were considered highly stigmatized (11). The Quality of Life in Epilepsy Scale-10 (QOLIE-10), the validity and reliability of which was performed by Mollaoğlu et al. (12), was used to determine the quality of life of Turkish epilepsy patients. The QOLIE-10 gives a total score ranging from 0 to 100, with a lower score indicating better quality of life (12).

### Sample Size

The sample size was determined using G-Power 3.1.9.4 software, considering the correlation test ( $r=0.324$ ) in a reference study with a two-tailed hypothesis and a Type I error of 0.05. The calculated minimum sample size was determined to be at least 98, with a power of 0.95 (10). The study population consisted of patients who sought treatment at a university hospital's epilepsy outpatient clinic. This study had a sample size of 130 participants.

### Statistical Analysis

Statistical analysis was conducted using SPSS 25.0 (Statistical Package for the Social Sciences, IBM Corp., Armonk, New York). The Kolmogorov-Smirnov test was used to assess the normal distribution's suitability. Independent t-tests and ANOVA tests were used to identify significant differences between scale scores and participants' socio-demographic data. In cases of significant differences between groups, the LSD post hoc test was performed. The significance level was set at 0.05.

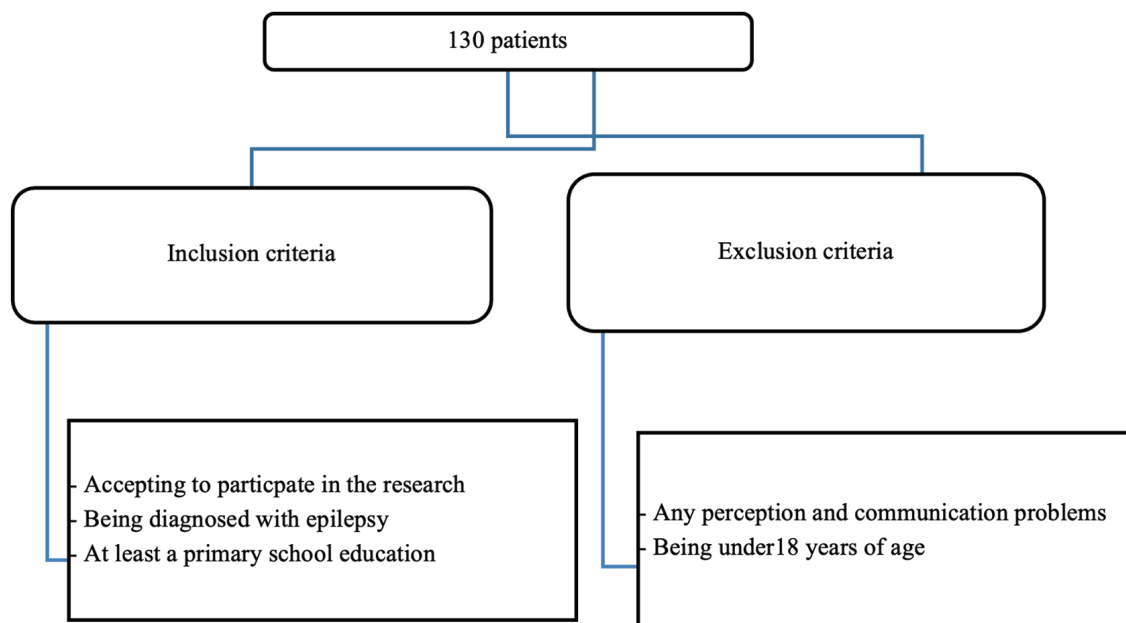


Figure 1. Study design

## Results

Of the participants, 43.8% were in the age range of 31-50, and 26.9% had elementary education. 53.8% of the participants had no monthly income, and 38.5% had had a diagnosis of epilepsy for at least 16 years. Furthermore, 50.8% of the participants had experienced seizures in the past year, and 63.1% had focal seizures.

When the participants' SSE and QOLIE-10 scores were compared in terms of sociodemographic variables, a statistically significant difference was found between the SSE total score and age, employment status, educational level, and income. Participants "aged 51 and above" ( $p=0.015$ ), those with an "elementary level" education ( $p<0.001$ ), those who responded "no" ( $p=0.048$ ) in terms of current employment status, and those with a "minimum wage" income ( $p=0.001$ ) were statistically significant when compared to other groups (Table 1).

A statistically significant difference was found between the QOLIE-10 Total Score and monthly income level, as well as the date of the last seizure. In comparison with the other groups, those without income ( $p=0.015$ ) and those who experienced seizures in the past year ( $p=0.001$ ) were found to have higher scores (Table 2).

A statistically significant difference was found between the QOLIE-10 total score and stigma levels. The QOLIE-10 total score was found to be significantly higher in those with higher stigma levels compared to other groups ( $p<0.001$ ). Regarding the relationship between quality of life and stigma levels in individuals diagnosed with epilepsy, it was determined that there is a positive correlation between the quality of life and stigma levels ( $r=0.454$ ,  $p<0.001$ ). However, since high QOLIE-10 scores indicate low quality of life, the relationship was indirectly found to be negative (13,14) (Table 3).

## Discussion

In our study, we found that the stigma levels were higher in participants who were 51 years of age or older, had primary education, had never worked, and received the minimum wage. Sabatello et al. (13) reported higher stigma levels in participants aged 60 years and older and those not working. However, unlike our study, the researchers reported that stigma scores did not vary according to educational level (13). Contrary to Sabatello et al. (13), another study found similar results in the relationship between education and stigma level (14). Similar to our study, previous studies have reported that patients who are not working or have a low income level experience more stigma (15,16). In our study, the higher stigma experienced by participants aged 51 may be attributed to the fact that younger individuals can access information about epilepsy more easily and faster through online channels. It is also believed that some participants

aged 51 years and older may have limited technological literacy, which may contribute to this trend.

In our study, participants who had no income and had a seizure within the last year were found to have a lower quality of life. In line with the current results, previous studies have consistently shown that patients with ongoing seizures and low income levels have a worse quality of life (17-20). Poor quality of life among participants with

**Table 1. Distribution of participants' mean SSE and QOLIE-10 total scores according to socio-demographic characteristics (n=130)**

Characteristics	n	QOLIE-10 $\bar{X} \pm SD$	SSE $\bar{X} \pm SD$
<b>Gender</b>			
Female	83	26.10±7.80	60.65±14.31
Male	47	24.94±8.99	60.53±16.61
t		0.770	0.043
p		0.442	0.966
<b>Age</b>			
1) Aged 18-30	50	26.62±7.92	57.96±14.57
2) Aged 31-50	57	24.95±8.11	59.68±14.69
3) Aged 51≤	23	25.43±9.33	68.65±15.25
F		0.557	4.343
		0.574	<b>0.015</b>
Post-hoc tests		-	<b>3-1, 2</b>
<b>Employment Status</b>			
Yes	93	25.51±8.56	58.96±14.83
No	37	26.11±7.47	64.76±15.23
t		-0.375	1.996
p		0.708	<b>0.048</b>
<b>Level of Income</b>			
1) No income	70	27.20±8.50	63.30±15.74
2) Minimum wage	26	26.04±8.32	63.96±14.99
3) Above minimum wage	34	22.26±6.68	52.50±10.64
F		4.354	7.286
p		0.015	<b>0.001</b>
Post-hoc tests		1>3	<b>1&gt;3 2&gt;3</b>
<b>Educational Level</b>			
1) Elementary	35	27.51±9.09	70.74±15.39
2) Secondary	14	22.00±7.82	60.71±10.91
3) High school	45	25.69±8.22	59.02±13.61
4) Undergraduate and higher	36	25.31±7.31	52.69±12.83
F		1.555	10.647
p		0.204	<b>&lt;0.001</b>
Post-hoc tests			1>2, 3, 4 3>4

t: Independent t-test, F: Anova test, post-hoc: LSD test  
QOLIE-10: Quality of Life in Epilepsy Inventory-10, SSE: Stigma Scale for Epilepsy, SD: Standard deviation

frequent seizures may be attributable to feelings of inadequacy and exposure to social discrimination. In our study, it is noteworthy that patients with lower income levels experienced more stigmatization and a lower quality of life. It has been reported that low income has a strong relationship with stigmatization and quality of life for epilepsy patients (19).

**Table 2. Distribution of participants' mean QOLIE-10 and SSE total scores according to disease-related characteristics (n=130)**

Characteristics	n	QOLIE-10 $\bar{X} \pm SD$	SSE $\bar{X} \pm SD$
<b>Duration of Epilepsy</b>			
1) 0-5 yrs	19	24.95±8.30	61.79±17.61
2) 6-10 yrs	31	24.48±7.54	57.03±12.88
3) 11-15 yrs	30	26.47±7.97	61.73±13.90
4) 16 yrs ≤	50	26.22±8.90	61.70±16.16
F		0.425	0.755
p		0.735	0.522
<b>Date of Last Seizure</b>			
1) No seizures for 1-3 yrs	35	24.66±8.42	57.54±12.93
2) No seizures for 4-6 yrs	8	19.88±8.89	57.75±12.95
3) No seizures for 6 yrs 6≤	21	21.48±6.97	56.81±12.39
4) Seizures in the past year	66	28.26±7.55	63.79±16.73
F		6.137	2.038
p		<b>0.001</b>	0.112
Post hoc tests		<b>4&gt;1, 2, 3</b>	-
<b>Seizure Type</b>			
Focal	82	26.13±8.71	62.18±15.34
Generalized	48	24.90±7.38	57.92±14.49
t		0.826	1.561
p		0.410	0.121
t: Independent t-test, F: Anova test, Post-hoc: LSD test QOLIE-10: Quality of Life in Epilepsy Inventory-10, SSE: Stigma Scale for Epilepsy, SD: Standard deviation, yrs: Years			

**Table 3. Distribution of QOLIE-10 total and subscale mean scores according to the stigma levels of participants (n=130)**

Characteristics	n	QOLIE-10 $\bar{X} \pm SD$
<b>Levels of Stigma</b>		
No Stigma	38	21.87±5.96
Moderate	73	25.93±8.21
High	19	32.32±8.14
F		12.023
p		<b>&lt;0.001</b>
Post-hoc tests		<b>1&gt;2, 3 2&gt;3</b>
F: Anova test, Post-hoc: LSD test QOLIE-10: Quality of Life in Epilepsy Inventory-10, SD: Standard deviation		

Participants with high levels of stigmatization were found to have a worse quality of life than those with low and moderate levels. Similarly, a study by Zhang et al. (21) found stigmatization to be negatively associated with quality of life, which is consistent with the findings of our study. In studies on quality of life and stigma associated with epilepsy, it is commonly observed that individuals diagnosed with epilepsy frequently experience stigmatization and tend to have a lower quality of life (16,22,23). This finding suggests that this finding arises from the difficulty that epilepsy patients experience in meeting their basic and social needs.

### Study Limitations

The sample used in this study was obtained from a specific hospital. This could limit the results' generalizability. In addition, experimental studies are required to clearly reveal causal relationships. Despite these limitations, the study is important in terms of revealing the effect of stigma on the quality of life of patients with epilepsy. Furthermore, this study demonstrated that psychosocial support for patients with epilepsy should consider stigma-related factors to enhance their quality of life.

### Conclusion

Our study showed that participants with high stigmatization levels had lower quality of life scores. Based on this information, it should be taken into consideration that the experience of stigmatization affects individuals' quality of life, and the potential need for more support and social rehabilitation for individuals affected by stigmatization should not be ignored.

### Ethics

**Ethics Committee Approval:** For the conduct of this research, ethical approval was obtained from the Maltepe University Ethics Committee (approval no.: 2020/16-03, dated: 11.12.2020), and permission to conduct the study was also granted by the relevant institution (permission no.: 2022/02, dated: 25.01.2022).

**Informed Consent:** Written informed consent was obtained from all patients participating in the study.

### Authorship Contributions

Surgical and Medical Practices: Z.A., Concept: Z.A., S.A., K.A.Y., Design: Z.A., S.A., K.A.Y., Data Collection or Processing: Z.A., S.A., Analysis or Interpretation: Z.A., S.A., Literature Search: Z.A., S.A., Writing: Z.A., S.A., K.A.Y.

**Conflict of Interest:** No conflicts of interest were declared by the authors.

**Financial Disclosure:** This study received no financial support.

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