






Hitit University Epilepsy Outpatient Clinic Experience

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Abstract

Objective: Although epilepsy can be controlled with treatment; misperceptions are a disease that negatively affects life due to the lack of knowledge about the disease, even in individuals with epilepsy.

Methods: Individuals between the ages of 18 and 65 years with epilepsy who applied to the epilepsy outpatient clinic were included in the study using a random sampling method. All participants were evaluated by the same neurologist and psychiatric specialist.

Results: The mean age of 34 individuals with epilepsy was 30.0±10.4 years, the duration of the disease was 132.9±101.2 months, and the age of onset of the disease was 18.7±12.1 years. Of the patients, 40% were males and 60% were females. Of the cases, 93.9% had generalized seizures and 6.1% had focal seizures. Of the participants, 47.1% were under treatment with monotherapy and the others with polytherapy. The rate of patients without drug side effects was 57.1%. The rate of regular use of the drug was 85.7%. The median Epilepsy Disease Concealment Scale scores of the participants were 33.5, the median Epilepsy Stigma Scale scores were 65.0, and the median Quality of Life Scale in Patients with Epilepsy scores were 60.7. The median scores of Hamilton anxiety and depression were calculated as 3.0 and 5.0, respectively.

Conclusion: Although the patient population was limited, many findings in our study were consistent with the literature. Our study will shed light on future epidemiological data of Turkey and Çorum.

Keywords: Epilepsy, Stigma, Quality of Life Scale in Patients with Epilepsy, Epilepsy Disease Concealment Scale

INTRODUCTION

Is epilepsy, which affects the whole life, requires frequent follow-up, can be controlled with antiepileptics, but causes frightening misperceptions, or is it a lifelong disease that makes people feel lonely and helpless? Seizures that develop in social environments, lack of information about the disease, even in individuals with epilepsy, and false beliefs cause individuals with epilepsy to be stigmatized and their quality of life to decrease.

Stigma is defined as being marked as bad, being shamed, or being despised, and signs or traits that are recognized by outsiders that may lead to exclusion. People are stigmatized because they have undesirable features that are different from those of society, and those who are stigmatized are not seen as full human beings by normal people.^{1,2} What is the current situation in one of the Central Anatolian provinces in epilepsy. In studies conducted in our country, it was determined that the social stigma will reveal the concealment of epilepsy.³

METHODS

In this study, patients with primary epilepsy were evaluated. Approval was obtained from the Hitit University Clinical Research Ethics Committee (decision no: 348, date: 23.12.2020). Participants were informed about the study, and a written consent form was obtained. The Declaration of Helsinki was complied with in this study. Patients under the age of 18 and over the age of 65, who had seizures due to secondary causes, had cognitive impairment, and had a history of psychiatric illness, were excluded from the study. Participants were included in the study using a random sampling method. Participants' age, gender, education levels, duration of disease, antiseizure medications, number of seizures in the last month, epilepsy, and seizure classification were questioned. The Epilepsy Disease Concealment Scale (EDCS), Epilepsy Stigma Scale (ESS), Quality of Life Scale in Patients with Epilepsy (EQoLS), Hamilton Anxiety Scale (HAM-A), and Hamilton Depression Scale (HAM-D) were administered by the same neurologist and psychiatrist.

Statistical Analysis

The evaluation of the data was done with the statistical package program (Statistical Package for the Social Sciences) 21.0. Descriptive tests were used for number, percentage, mean±standard deviation, median, range, and interquartile range values, and Spearman's correlation test was used to evaluate the relationship between data. The Mann-Whitney U test was used for group comparisons because the scale scores did not show a normal distribution. If the p values were below 0.05, it was considered statistically significant. r values were considered as no correlation between 0 and 0.25, weak correlation between 0.25 and 0.50, strong correlation between 0.50 and 0.75, and strong correlation between 0.75-1.00.

RESULTS

In the patient group we examined (n=34), the mean age was 30.0±10.4 years, the duration of the disease was 132.9±101.2 months, and the age of onset of the disease was 18.7±12.1 years. There were 40 (14) male and 60 (20) female participants in the study group. While the rate of patients with high school or higher education was 44.12% (n=15), the rate of patients with secondary education or below was 55.88% (n=19). It was learned that 37.2% (n=13) of the participants were unemployed, 20% (n=7) were housewives, and 17.1% (n=6) were working full-time. In terms of income level, 54.6% (n=19) of the patients were considered moderate, 21.2% (n=7) of them as bad, and the remaining group was considered good. 58.8% (20) of our patients were single, 41.2% (14) were married. It was found that 91.2% (31) of the individuals were followed up with generalized onset epilepsy and 8.8% (3) were diagnosed with focal onset epilepsy. The most common seizure type was generalized tonic-clonic seizure with 67.6% (n=23). The rate of patients without seizures for at least one year was 50% (n=17), 29.4% less than once a month (n=10), and the rate of patients who had seizures more than once a month was 20.6% (n=7). Unfortunately, none of the patients took precautions against accidents that may occur due to seizures, 17.6% (n=6) were victims of an accident during the seizure. Only one patient in the group developed disability due to a seizure. 47% (n=16) of the patients were under treatment with monotherapy and 53% (n=18) with polytherapy. Levetiracetam, valproic acid, lamotrigine, carbamazepine, and zonisamide were used in monotherapy. The rate of patients without drug side effects was 58.8% (n=20). The most common side effects were tremor 20% and forgetfulness 14.3%. Nervousness, weight gain, sedation sleep disturbances, and fatigue were the other reported side effects. When the drug dose was questioned; 97.05% of the participants (n=33) knew the drug dose they were using. The rate of regular drug use was 88.2% (n=30). Our rate of patients who were under regular doctor's control was 73.5% (n=25). Many patients who could not come to the controls came from outside the city. Apart from the physician's

recommendations, five of the patients wore amulets and one patient had lead pour. The remaining 28 patients did not receive non-drug treatment, but all of them said that they had a positive view of the issue. Three patients had hypertension. 91.2% (n=31) of the patients had no other concomitant chronic disease. Unfortunately, no significant difference was found between the scales between the high school and above group and the lower high school groups according to the education level of the patients. The median EDCS scores of the participants were 33.5 (interquartile range 30.0-39.0), the median ESS scores were 65.0 (interquartile range 53.0-72.0), and the median EQoLS scores were 60.7 (interquartile range 41.6-84.6). The median scores of HAM-D and HAM-A were calculated as 3.0 (interquartile range 1.0-8.0), 5.0 (interquartile range 2.0-8.5), respectively (Table 1).

Table 1. Median, range, interquartile range values of the evaluation scales used

| | Median (range) | Interquartile range |
|-------|-------------------|---------------------|
| EQoLS | 60.7 (10.9-95.2) | 41.6-84.6 |
| ECS | 33.5 (22.0-47.0) | 30.0-39.0 |
| ESS | 65.0 (43.0-108.0) | 53.0-72.0 |
| HAM-A | 5.0 (0.0-31.0) | 2.0-8.5 |
| HAM-D | 3.0 (0.0-27.0) | 1.0-8.0 |

EQoLS: Quality of Life Scale in Patients with Epilepsy, ECS: Epilepsy Disease Concealment Scale, ESS: Epilepsy Stigma Scale, HAM-A: Hamilton Anxiety Scale, HAM-D: Hamilton Depression Scale

DISCUSSION

Epilepsy is a complex disease that affects individuals, families, and society in psychological and social terms. A lack of social knowledge has a significant impact on many aspects, including education, business life, marriage, and acceptance of patients in society as individuals.

Studies show that there are different levels of stigma in individuals with epilepsy and that it harms the individual at least as much as the disease itself. When the literature was examined, while stigma was found at different rates in studies conducted with stigma scales in epilepsy, risk factors for stigma were listed as seizure frequency, number of drugs used, low education and income level, patient age, and duration of disease.⁴ In a study conducted in Turkey in 2022, the mean ESS was found to be 40.7±9.04, and the mean ESS was found to be 57.19±12.57.⁵

In a study among young people in Saudi Arabia, 31.2% of the participants thought that epilepsy was supernatural or black magic. In this study, 45.6% of the participants reported that they thought that epilepsy had an impact on their quality of life.⁶

In another study evaluating the stigma rates of 153 patients with first-diagnosis epilepsy, the rate that was 17.6% at the time of first diagnosis was found to be 30.7% in the first year.⁷ In another study conducted in 2020, the mean of the fear of negative evaluation scale in Turkey was found to be 31.19±4.86, and the mean EDCS was found to be 46.93±9.55. It was noted that individuals with epilepsy have a high level of fear of negative evaluation by the society and a strong tendency to hide their epilepsy. In this study, the tendency of individuals with epilepsy to hide their diseases increased with age

MAIN POINTS

- Epilepsy is a complex disease that affects individuals, families, and society in psychological and social terms.
- Stigma harms the individual as much as epilepsy.
- Increasing social awareness and providing positive coping strategies to increase social support in patients with epilepsy may be effective in reducing stigma.

and seizure frequency. Surprisingly, fears of negative evaluations decrease as the concealment of their diseases increases.⁸ In another study conducted in eastern Turkey, stigmatization rate was found in 62.4% of the participants, and some factors (being below the age of 30, being single, poor economic situation, living with parents and siblings, frequency of seizures, experience of harming someone due to epileptic seizure, and related accident experience) have been associated with a higher stigma score in patients with epilepsy. It has also been shown that there is a negative relationship between stigma score and social support score in patients with epilepsy.⁹ The quality of life and stigma affect each other in the opposite direction.

The quality of life in adults with epilepsy is predominantly affected by psychosocial factors. The quality of life in epilepsy is a broad multidimensional concept. Clinicians prioritize treatment, side effects, and prognosis in patients with epilepsy, but the psychosocial dimension of the disease should not be overlooked. Effective epilepsy management requires more than seizure control.^{10,11} Concomitant conditions in epilepsy, seizure frequency, severity, monotherapy or polytherapy, socioeconomic status, and stigmatization are important factors affecting the quality of life of patients. Cultural differences affect the quality of life outcomes between countries. Even within a country, different results can be obtained. Having general and accurate information about epilepsy is an important factor in coping with epilepsy.¹²

Depression and anxiety are two common comorbidities in patients with epilepsy.¹³ Comorbidities of psychiatric diseases complicate the follow-up and treatment process of epilepsy. Although we did not detect significant anxiety and depressive symptoms in our current group, we believe that the compatibility of the stigma and disease concealment scales with the literature is related to the sociocultural structure and the inability to fully recognize the disease. In a study in which the mean HAM-D scores applied to epilepsy patients were calculated as 2.63±2.66; an inverse correlation was found between HAM-D scores and quality of life.¹³ It is quite common for epilepsy to affect a person's quality of life, and additional psychiatric disorders will worsen the quality of life. Therefore, we believe that an early evaluation of patients with suspected psychiatric comorbidity by a psychiatrist would be beneficial in this regard.

A 2021 study showed that social phobia is positively associated with stigma in epilepsy. In individuals with epilepsy, psychiatric disorders are often under-recognized and their treatment can be ignored. Both conditions significantly impact the quality of life of patients.¹⁴ Showing sensitivity to this issue is also required in outpatient clinics following epilepsy patients.

Although the social integration of these patients is associated with the development ranking of the countries, quality of life, stigma, and concealment of the disease, stigma continues in developed countries. In a study conducted in Norway, it was found that 56% of the participants felt stigmatized and 35% experienced discrimination related to the disease.¹⁵

In a study examining the effect of monotherapy or polytherapy on quality of life in epilepsy treatment, patients receiving polytherapy had a significantly higher prevalence of psychiatric comorbidity than patients receiving monotherapy, and patients receiving

polytherapy scored significantly lower in the cognitive domain and overall quality of life in the epilepsy quality of life questionnaire.¹⁶ When we examine the literature, studies from many countries of the world in which different rates of stigma and epilepsy have been determined.^{17,18} As patients' knowledge about epilepsy and positive attitudes about the disease increase, stigma levels will decrease and the quality of life will increase.¹⁹

Study Limitations

Although the patient population was limited, many findings in our study were consistent with the literature. Our study will shed light on future epidemiological data of Turkey and Çorum.

CONCLUSION

The social stigma caused by epilepsy leads to the concealment of epilepsy and social isolation. It is important to determine the social perspective, epilepsy concealment, and the effects of stigma on the patient and quality of life. The data we obtained show that clinicians need to be about the existence of information pollution about the disease in epilepsy patients and in our society. Increasing social awareness and providing positive coping strategies to increase social support in patients with epilepsy may be effective in reducing stigma

Ethics

Ethics Committee Approval: Approval was obtained from the Hitit University Clinical Research Ethics Committee (decision no: 348, date: 23.12.2020).

Informed Consent: Participants were informed about the study, and a written consent form was obtained.

Peer-review: Externally and internally peer-reviewed.

Authorship Contributions

Surgical and Medical Practices: S.E., S.A., A.K., F.U.T., E.Ö., Concept: S.E., F.U.T., E.Ö., Design: S.E., F.U.T., E.Ö., Data Collection or Processing: S.E., S.A., A.K., Analysis or Interpretation: S.E., S.A., Literature Search: S.E., Writing: S.E.

Conflict of Interest: No conflict of interest was declared by the authors.

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