Effects of Attitudes of Patients with Epilepsy Towards Their Disease on Mental Health and Quality of Life

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Objective: The study investigates the effects of attitudes displayed by patients with epilepsy toward their disease on their mental health and quality of life.

Materials and Methods: This descriptive cross-sectional study was conducted in the neurology outpatient clinic at Hafsa Sultan Hospital, Manisa Celal Bayar University between April 2015 and April 2016. The study sample comprised 182 patients. The study data were collected using the Personal Information Form for Patients with Epilepsy, Impact of Epilepsy Scale, Epilepsy Knowledge Scale, Epilepsy Attitude Scale, Short Form-36 (Quality of Life Scale), and Brief Symptom Inventory. In the analysis of the data, the t-test, ANOVA, Scheffé’s post-hoc test, and Pearson’s correlation coefficient were used.

Results: In the Epilepsy Attitude Scale, the participants obtained a mean score of 48.66±13.13, suggesting that they displayed negative attitudes toward epilepsy. In the subscales of the Short Form-36 (Quality of Life Scale), the participants’ scores were low. Of the participants with epilepsy, those with a significantly positive attitude toward epilepsy had a high quality of life perception. Psychological symptoms decreased in patients with epilepsy who have a positive attitude toward their disease.

Conclusion: The results of this study demonstrated that the participants’ “attitudes toward epilepsy” was significantly correlated to their “psychological symptoms and quality of life.” The fact that the negative attitudes of patients with epilepsy are related to their psychological symptoms and quality of life indicates the importance of recognizing and understanding patients’ attitudes toward their disease.

Keywords: Epilepsy, quality of life, attitude, psychological symptom

INTRODUCTION

Epilepsy, a chronic disease, has been a large part of studies conducted on quality of life. Epileptic seizures occurring recurrently and unpredictably are the most important factor that adversely affects the quality of life of patients with epilepsy. The frequency of seizures, fear of seizures, and patient self-evaluation of the disease have a significant impact on the general well-being of patients with epilepsy (1). Factors affecting the quality of life of patients with epilepsy can be classified into three categories:

1. Medical factors (seizures, anti-epileptic drugs and their side effects, and outpatient or inpatient treatment)
2. Social factors (stigma, intra-family dynamics, difficulties in finding a job, and legal restrictions)
3. Psychological factors (cognitive problems, mental retardation, and psychiatric diseases).

In other words, cognitive, emotional, and behavioral conditions, including being able to work, being able to fulfill social functions, intra-family consistency, self-worth, and adaptation to seizures, are among the extremely important factors affecting the quality of life of patients with epilepsy (2, 3). Unemployment, low marriage rates, and social isolation observed in patients with epilepsy have negatively affected their quality of life even more. Today, many individuals with epilepsy cannot find a job despite their qualifications and goals, and if they can, they have a lower status and receive a lower salary than people without epilepsy. In addition, the stigma occurring after a person is diagnosed with epilepsy reduces the patient’s motivation for both working and participating in social activities. Simultaneously, the fact that epileptic seizures can be witnessed by other people imposes additional restrictions on the person (e.g., not going to public places), which brings about additional problems in the patient’s life. In addition, the low marriage and reproduction rates among patients with epilepsy are among the important social issues affecting the quality of life of these patients because the low levels of social communication and self-worth, perceived stigma, and limited working opportunities lessen these patients’ opportunities to find a spouse (4).

Patients with epilepsy are deprived of participating in many activities, preventing them from feeling emotionally well and endangering their social relationships. A person’s quality of life can be affected by the unpredictable occurrence of seizures. At this stage, the focus should be on the stress factor, which is the source of the problem, and the methods...
of coping with seizures should be discussed with the patient. Patients are afraid that their brains can be damaged or they might die during seizures, that they can lose self-control when they have seizures in front of other people, and that they can lose their friends and jobs.

Women suffer from fear of being unsafe during the seizure more intensely, and they are concerned about giving birth to and raising a child. Patients with epilepsy often experience feelings of anger, denial, shame, and frustration. If these feelings are not overcome and become chronic, patients experience decreased self-esteem, social isolation, addiction, and social disruption. Patients feel angry and rejected and blame others for their problems (5, 6). Studies indicate that if patients are more knowledgeable about epilepsy, their compliance to epilepsy management increases and the negative effects of stigma and epilepsy decrease. These data demonstrate the importance of providing patients with information.

In addition, as the education levels of patients with epilepsy increase, so does their knowledge about epilepsy (4, 7). The results of several studies have demonstrated that epilepsy has important social and psychological effects (8).

This study is expected to contribute to the assessment of the mental health of patients diagnosed with epilepsy and their attitudes toward the disease, to reveal the changes and deficiencies caused by the disease in their quality of life, and to create a draft in the training plans to be made in this regard.

MATERIALS and METHODS

This descriptive cross-sectional study was conducted in the neurology outpatient clinic at Hafsa Sultan Hospital, Manisa Celal Bayar University between April 2015 and April 2016. This study investigates the effects of attitudes displayed by patients with epilepsy toward epilepsy on their mental health and quality of life.

Population and Sample of the Study

The study population comprised 320 patients with epilepsy who were followed up at the Neurology outpatient clinic at Hafsa Sultan Hospital, Manisa Celal Bayar University in 2015. The minimum sample size of the study was 175 patients, determined using Epi Info™ (Centers for Disease Control and Prevention, Atlanta, Georgia, USA) with 95% confidence interval, 5% error margin, and 1.0 pattern effect. The study sample consisted of 182 patients who were selected using the simple random method and agreed to participate in the study.

Ethical Issues

Before the study was conducted, approval from the Faculty of Medicine Health Sciences Ethics Committee, Manisa Celal Bayar University (date: April 13, 2015; number: 164), and permission from the Chief Physician of Hafsa Sultan Hospital, Manisa Celal Bayar University, where the study was conducted (date: April 13, 2015; number: 61804347-100/2560) were obtained. Moreover, written informed consent, indicating that they agreed to participate in the study was obtained from the participants. For the scales used in the study, permissions were obtained from their authors.

Data Collection Tools

The following six forms were used to collect the study data:

- Personal Information Form for Patients with Epilepsy
- Impact of Epilepsy Scale
- Epilepsy Knowledge Scale
- Epilepsy Attitude Scale
- Short Form-36 (Quality of Life Scale)
- Brief Symptom Inventory (BSI)

Personal Information Form for Patients with Epilepsy

The form includes items regarding the participants’ sociodemographic characteristics (sex, age, educational status, marital status, employment status, etc.) and disease-related characteristics (whether the patient has a chronic illness, how long the patient has had epilepsy, whether the patient had seizures, how often the patient had seizures, etc.).

Impact of Epilepsy Scale

The scale consisting of 10 questions was developed by Aydemir (2007) to measure the effect of epilepsy in a Turkish community (9). The Cronbach’s alpha value of the scale is 0.82. The Cronbach’s alpha value of the scale in this study is 0.85. The lowest score that can be obtained from the scale is 10, and the highest score is 40. The higher the score obtained from the scale, the greater the effect of epilepsy (9).

Epilepsy Knowledge Scale

The scale was developed by Aydemir (2007) for a Turkish population (9). The scale consists of 16 items regarding the following: causes of epilepsy, treatment methods, triggers of seizure, social restrictions due to epilepsy, and appropriate seizure interventions. The lowest and highest possible scores are 0 and 16, respectively. The higher scores mean that the person’s knowledge of epilepsy is high. The responses have three options: “true,” “false,” and “I don’t know.” The reliability value of the scale was 0.72 (9). The Cronbach’s alpha value of the scale in this study is 0.78.

Epilepsy Attitude Scale

The scale consisting of 14 items was developed by Aydemir (2007) to determine the attitudes of Turkish people toward epilepsy and individuals with epilepsy (8). The minimum and maximum possible scores of the scale are 14 and 70, respectively. The higher scores mean that the attitude displayed toward the person with epilepsy is positive. The reliability value of the scale was α=0.84 (9). The Cronbach’s alpha value of the scale in this study is 0.93.

Short Form-36 (Quality of Life Scale)

The scale was developed by Ware et al. in 1992 (10). A study on the validity and reliability of the Turkish version of the scale was conducted by Koçyiğit et al. (11). The scale consists of 36 items and 8 subscales and is a self-assessment scale.

The 8 subscales are as follows:

1. Physical functioning (10 items)
2. Social role functioning (2 items)
3. Role limitations due to physical health (4 items)
4. Role limitations due to emotional problems (3 items)
5. Mental health (5 items)
6. Energy/vitality (4 items)
7. Bodily pain (2 items)
8. Perceptions of general health (5 items)

The items of the scale are rated using a Likert-type scale. The items assessing health are scored between 0 and 100 for each subscale. While a score of 100 indicates good health, a score of 0 indicates bad health. The Cronbach’s alpha value of the scale in this study is 0.72.

BSI

Şahin and Durak conducted three studies to adapt the BSI into Turkish (2002) (12). The BSI includes 53 items rated on a five-point Likert-type scale ranging between 0 and 4 corresponding to “not at all” and “extremely,” respectively. The subscales included in the scale are as follows: “somatization,” “obsessive–compulsive disorder,” “interpersonal sensitivity,” “depression,” “anxiety,” “hostility,” “phobic anxiety,” “paranoid thoughts,” and “psychoticism.” A scoring key was prepared for each subscale based on the items in the subscales, additional items, and subscales of the severity index. The Cronbach’s alpha value of the scale in this study is 0.98.

Analysis of the Study Data

In the analysis of the study data, Statistical Package for the Social Sciences (version 21.0; IBM Corp., Armonk, NY, USA) was used. The demographic data of the participating patients with epilepsy were presented as frequency and percentage analysis. The skewness coefficient was used to test the normality of the scale scores. That the skewness coefficient used in the normal distribution of the scores obtained from a continuous variable was within the limits of ±1 can be interpreted as that the scores did not significantly deviate from the normal distribution (13). Because the normality test indicated that the scores for the scale and its subscales had a normal distribution, the independent samples t-test was used to compare the scores according to the demographic variables between two groups, and an analysis of variance (ANOVA) was conducted to compare the scores according to demographic variables between more than two groups. When a significant difference was observed in the ANOVA, Scheffé’s post-hoc test was used to determine from which group(s) the difference stemmed. Pearson’s correlation technique was used to analyze the relationship between the scores for the Impact of Epilepsy Scale, Epilepsy Knowledge Scale, Epilepsy Attitude Scale, the subscales of the Short Form-36 (Quality of Life Scale), and psychological symptoms. P values of <0.05 were used to denote statistical significance.

RESULTS

Of the 182 patients with epilepsy who participated in the study, 54.9% were women, 40.7% were ≤30 years old, 41.8% were high school graduates, 49.5% were married, 50.5% were single, 46.7% were employed at a paid job, and 45.1% lived in a metropolitan area (Table 1).

Furthermore, among the participants, 35.2% had comorbidities with epilepsy, 84.6% perceived their life as stressful, 68.7% presented for follow-up care regularly, and 83.5% received support to cope with the disease (Table 2).

According to the frequency of seizures, no significant difference
was observed between the scores in the Epilepsy Knowledge Scale (p>0.05) (Table 3); however, a significant difference was found between the scores in the Impact of Epilepsy Scale (F=8.19; p<0.05).

Scheffé’s post-hoc test performed to determine from which group the difference stemmed showed that the participants who had seizures every day had significantly higher positive scores than those who had seizures once a year (Table 3).

Furthermore, a significant difference was observed between the scores in the Epilepsy Attitude Scale according to the frequency of seizures (F=5.55; p<0.05).

Moreover, Scheffé’s post-hoc test revealed that the participants who had seizures once a year had significantly higher positive scores than those who had seizures once a week (Table 3).

In the Short Form-36 (Quality of Life Scale), significant differences were found between the scores in the physical functioning (t=3.92; p<0.05), social role functioning (t=3.11; p<0.05), role limitations due to physical health (t=3.56; p<0.05), role limitations due to emotional problems (t=2.47; p<0.05), mental health (t=2.54; p<0.05), energy/vitality (t=3.57; p<0.05), bodily pain (t=4.91; p<0.05), and perceptions of general health (t=5.64; p<0.05) subscales in terms of presenting for follow-up care regularly.

The participants who presented for follow-up care regularly had higher scores in the Short Form-36 (Quality of Life Scale) than those who did not present for follow-up care regularly.

Furthermore, in the BSI, significant differences were observed between the scores in the somatization, obsessive–compulsive disorder, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid thoughts, and psychoticism subscales than those who were employed. A negative significant relationship was observed between the scores in the Impact of Epilepsy Scale and psychological symptom scores (p<0.05). The participants whose perception of the impact of epilepsy was significantly negative had poorer quality of life and more psychological symptoms (Table 4). The scores in the Epilepsy Knowledge Scale were positively significantly related to the scores in the role limitations due to emotional health, bodily pain, and perceptions of general health subscales of the Short Form-36 (Quality of Life Scale) (p<0.05).

The relationship between the scores in the Epilepsy Knowledge Scale and psychological symptom scores was insignificant (p<0.05). In addition, of the participants, those whose Epilepsy Knowledge Scale scores were high had significantly high scores in the physical functioning, role limitations due to emotional health, bodily pain, and perceptions of general health subscales of the Short Form-36 (Quality of Life Scale). No significant relationship was found between the scores in the Epilepsy Knowledge Scale and psychological symptom scores (Table 4).

A positive and significant relationship was observed between the scores in the Epilepsy Attitude Scale and those in the energy/vitality, mental health, social functioning, and perceptions of general health subscales of the Short Form-36 (Quality of Life Scale) (p<0.05). The scores in the Epilepsy Attitude Scale were negatively and significantly related to psychological symptom scores (p<0.05). Moreover, of the participants, those who displayed high levels of positive attitudes toward epilepsy had high levels of positive perceptions of energy/vitality, mental health, social functioning, and perceptions of general health. In the participants whose attitudes

| Scale                             | Frequency of seizures | n   | Mean     | SD    | F      | p      | Significant difference |
|-----------------------------------|-----------------------|-----|----------|-------|--------|--------|------------------------|
| Impact of epilepsy                | A - Once a year       | 76  | 20.39    | 6.33  | 8.19   | 0.000  | D>A                    |
|                                  | B - Once a month      | 28  | 24.61    | 6.96  |        |        |                        |
|                                  | C - Once a week       | 30  | 24.50    | 8.48  |        |        |                        |
|                                  | D - Every day         | 11  | 29.82    | 5.02  |        |        |                        |
| Epilepsy knowledge               | A - Once a year       | 76  | 11.61    | 3.68  | 0.60   | 0.619  |                        |
|                                  | B - Once a month      | 28  | 12.25    | 3.86  |        |        |                        |
|                                  | C - Once a week       | 30  | 10.90    | 4.46  |        |        |                        |
|                                  | D - Every day         | 11  | 11.91    | 4.28  |        |        |                        |
| Epilepsy attitude                | A - Once a year       | 76  | 51.68    | 12.69 | 5.55   | 0.001  | A>C                    |
|                                  | B - Once a month      | 28  | 43.54    | 15.73 |        |        |                        |
|                                  | C - Once a week       | 30  | 41.30    | 11.82 |        |        |                        |
|                                  | D - Every day         | 11  | 46.00    | 14.72 |        |        |                        |

SD: Standard deviation

Table 3. Comparison of the scores from the Impact of Epilepsy Scale, Epilepsy Knowledge Scale, and Epilepsy Attitude Scale in terms of the frequency of seizures

The participants who were unemployed had higher scores from the somatization, obsessive–compulsive disorder, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid thoughts, and psychoticism subscales than those who were employed.
toward epilepsy were significantly positive, psychological symptoms decreased (Table 4). A negative and significant relationship was observed between the scores in the subscales of the Short Form-36 (Quality of Life Scale) and psychological symptom scores (p<0.05). Psychological symptoms decreased in the participants whose Short Form-36 (Quality of Life Scale) scores were significantly high (Table 4).

**DISCUSSION**

Because epilepsy affects patients’ social life and because negative attitudes toward epilepsy still exist, recently, more studies have been conducted on this issue.

In addition, patients who are more knowledgeable about epilepsy display a more positive attitude toward epilepsy (4). These results conform to the results of this study. In a study by Aydemir in 2011, of the patients with epilepsy, those whose knowledge level of epilepsy was low, those who were employed, and those who were male displayed a more negative attitude toward epilepsy (4). This difference probably stems from the fact that the participants were from different regions, that they experienced epilepsy-induced problems at work, and that they were exposed to stigma.

In this study, as the Impact of Epilepsy Scale scores increased, the psychological symptoms increased as well. Moreover, flirting with a patient with epilepsy and getting married were the most negative attitude toward epilepsy (4). This difference probably stems from the fact that the participants were from different regions, that they experienced epilepsy-induced problems at work, and that they were exposed to stigma.

Among the psychiatric symptoms of patients...
with epilepsy, the one suffered most is depression (14, 15). In addition, the prevalence of depression was higher than that of other chronic diseases in patients with epilepsy (16, 17). Studies have shown that patients with epilepsy suffer from psychological problems when they experience internalized stigma (18). In a study conducted on children and adolescents with epilepsy, perceived stigma was associated with a worse self-concept and more symptoms of depression (19). In another study, stigma feelings of patients with epilepsy were associated with increased anxiety and depression (15, 20). In Jacoby et al.’s study, 21% of 168 patients with epilepsy who still had seizures were depressed. These results conform to the results of this study (21). In this study, in the participants with high levels of psychological symptoms, the perception of quality of life decreased.

In this regard, healthcare professionals are responsible for raising patients’ awareness, which facilitates their acceptance of the disease and the development of favorable attitudes.

CONCLUSION

The results of this study suggest that the psychiatric conditions of patients with epilepsy should be diagnosed and treated early to improve their quality of life and to treat them more successfully. It is recommended that systematic and comprehensive studies should be conducted to investigate the origins and consequences of negative attitudes displayed by patients toward their disease, how prejudices have been developed, and when and how these prejudices have been turned into negative attitudes. In addition, we believe that increasing the level of knowledge, reducing false or inaccurate information and prejudices about epilepsy in society, and sharing the disease with others and accepting it rather than hiding it will have a direct impact on patients’ negative attitudes toward the disease. We believe that patients should be informed about their diseases more. Since negative attitudes toward the disease may have a direct effect on the quality of life and psychiatric symptoms of patients with epilepsy, we think that negative attitudes toward the disease and the relationship between these attitudes and conditions affecting the disease should be routinely evaluated in neurology clinics. With the awareness that patients need more education, counseling, and support, we believe that healthcare professionals who care for patients with epilepsy should question and guide these patients within a framework of the multidisciplinary approach.

In addition, these patients should be supported when they want to work, and they should be reintegrated into society.

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REFERENCES

1. Alcali A, Altindag A, Geyik S, Cansel N. Quality of Life, Depression, Anxiety and Multidimensional Perceived Social Support in Patients with Epilepsy. J Neuropsychiatry Arc 2009; 46(3): 91–7.
2. Aydemir CN. Quantitative and qualitative analysis of psychosocial factors and changes in attributes of epilepsy over time in chronic epilepsy patients. Istanbul University, Institute of Social Sciences, PhD Thesis. 2008.
3. Senol MG, Gön I, Togral E, Olgun N, Saracoglu M. Evaluation of Patients with Epilepsy Conform to Antiepileptic Medication. J Duzce Med Faculty 2009; 11(1): 21–31.
4. Aydemir N, Unsal P, Özkara Ç. Level of knowledge about and attitude toward, and sources of information about epilepsy. Epilepsy 2011; 17(3): 90–6. [CrossRef]
5. Görgülü Ü, Fesci H. Life with epilepsy: Epilepsy’s psychosocial effects. Göztepe Tip Dergisi 2011; 26(1): 27–32.
6. Suurmeijer TP, Reuvenkamp MF, Aldenkamp BP. Social functioning, psychological functioning, and quality of life in epilepsy. Epilepsia 2001; 42(9): 1160–8. [CrossRef]
7. May TW, Pfäfflin M. The efficacy of an educational treatment program for patients with epilepsy (MOSES): results of a controlled, randomized study. Modular Service Package Epilepsy. Epilepsia 2002; 43(5): 539–49. [CrossRef]
8. Erdoğan F, Soyuer F, Şenol V, Arman F. The effects of fatigue on the quality of life in patients with epilepsy. Epilepsi 2006; 12(1): 21–6.
9. Aydemir O, Koroglu E. Clinical scales used in psychiatry. 3rd edition. Ankara: Physicians publishing association; 2007. p.346–53.
10. Ware JE Jr, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. Med Care 1992; 30(6): 473–83. [CrossRef]
11. Koçyigit H, Aydemir O, Fisek G, Olmez N. Reliability and validity of Turkish version of Short Form-36 (SF-36). J Med Treatment 1999; 13: 102–6.
12. Sahin NH, Durak Batıgün A, Uğurtas S. The validity, reliability and factor structure of the Brief Symptom Inventory (BSI). [Article in Turkish]. Turk Psikiyatri Derg 2002; 13(2): 125–35.
13. Büyüköztürk Ş. Manual of data analysis for social sciences (14th Press.). Ankara: PEGEM Academy; 2011.
14. Zapata Barco AM, Restrepo-Martinez M, Restrepo D. Depression in People with Epilepsy. What is the Connection?. Rev Colomb Psiquiatr 2020; 49(1): 53–61. [CrossRef]
15. Liu X, Chen H, Zheng X. Effects of seizure frequency, depression and generalized anxiety on suicidal tendency in people with epilepsy. Epilepsia Res 2020; 160: 106265. [CrossRef]
16. Ngugi AK, Bottomley C, Kleinschmidt I, Sander JW, Newton CR. Estimation of the burden of active and life-time epilepsy: a meta-analytic approach. Epilepsia 2010; 51(5): 883–90. [CrossRef]
17. Elafros MA, Sakubitsa-Simasku C, Atadžhanov M, Haworth A, Chomba E, Birbeck GL. Stigma and psychiatric morbidity among mothers of children with epilepsy in Zambia. Int Health 2013; 5(4): 288–94. [CrossRef]
18. Yeni K, Tulek Z, Simsek OF, Bebek N. Relationships between knowledge, attitudes, stigma, anxiety and depression, and quality of life in epilepsy: A structural equation modeling. Epilepsy Behav 2018; 85: 212–7. [CrossRef]
19. Austin JK, MacLeod J, Dunn DW, Shen J, Perkins SM. Measuring stigma in children with epilepsy and their parents: instrument development and testing. Epilepsy Behav 2004; 5(4): 472–82. [CrossRef]
20. Adewuya AO, Ola BA. Prevalence of and risk factors for anxiety and depressive disorders in Nigerian adolescents with epilepsy. Epilepsy Behav 2005; 6(3): 342–7. [CrossRef]