Self-management, Spousal Support, and Related Factors Among Individuals Diagnosed with Epilepsy

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Abstract

Objective: This study aimed to determine the self-management of epilepsy, spousal support, and related factors in individuals diagnosed with epilepsy. Manage the disease process in individuals diagnosed with epilepsy is crucial in terms of daily functionality and quality of life.

Methods: This descriptive cross-sectional study included 135 individuals diagnosed with epilepsy. Data were collected using a patient information form that included sociodemographic and clinical characteristics and the Epilepsy Self-Management Scale and Spousal Support.

Results: In this study, the mean score of the epilepsy self-management scale was 133.64 (18.40). Education, gender, income level, presence of children, and frequency of seizures were determined as factors affecting epilepsy self-management. No relationship was found between spousal support and epilepsy self-management.

Conclusion: This study makes a significant contribution to the literature in determining factors affecting self-efficacy. Our results revealed the personal characteristics of the patients, especially sociodemographic factors that affect epilepsy self-management.

Keywords: Epilepsy, self-management, spousal support, family health, nursing

INTRODUCTION

Epilepsy is a neurological disease that occurs as a result of the sudden, abnormal, and hypersynchronous discharge of neuron groups located in the cortical and subcortical regions of the central nervous system. Epilepsy usually progresses with recurrent changes in consciousness. In other words, epilepsy is a chronic disease that aims to achieve a high quality of life by keeping seizures under control, which requires significant behavioral and psychosocial adjustments.[1] There are 50 million people diagnosed with epilepsy in the world, and 125,000 of them die each year, with more than 80% of these deaths occurring in low- and middle-income countries.[2] Due to the unpredictable nature of the disease, epilepsy can present many challenges for those affected.[3] In order to adapt to the disease, lifestyle changes and good self-management are required.[4] Self-management refers to the individual's ability to control the negative consequences of the disease, adapt to treatment, and make and manage lifestyle changes to keep her/his health at the highest level, together with the family, society and health worker.[4]

Self-management for epilepsy includes regular use of antiepileptic drugs, minimizing conditions that lead to seizures, taking safety precautions to avoid injury during seizures, regular and adequate rest and nutrition and coping with stress.[4] It is essential to increase patients' and families' coping abilities, develop their self-efficacy, preserve and enhance their skills, meet their information needs, increase self-control over the disease, and improve their quality of life.[5] Nurses can help patients improve epilepsy self-management by teaching them.[5-8] Self-management activities have been reported to reduce seizure frequency, increase seizure control, and improve overall quality of life. Self-management may be linked to higher quality of life and lower depression.[3]

The primary caregivers of married individuals diagnosed with epilepsy are often spouses.[9] Evidence indicates that spousal support may be important for health and life satisfaction.[10] Social relationships, especially close relationships (such as romantic relationships characterized by emotional attachment and support), have been found to significantly affect mental and physical well-being in both healthy people and those with the disease.[11] Married individuals diagnosed with epilepsy have a better quality of life.[12] A dysfunctional family is associated with social anxiety in patients with epilepsy.[13] It has been determined that individuals receiving spousal and physician support are more inclined to accept the disease.[14]

The aim of this study was to determine the level of self-management, status of spousal support received, and sociodemographic factors influencing self-management in patients diagnosed with epilepsy.

METHODS

This descriptive cross-sectional study was conducted after obtaining ethical approval from the İzmir Democracy University Non-interventional Clinical Research Ethics Committee (decision no: 2022/01-07, date: 05.01.2022). This study was conducted in accordance with the ethical standards of the Declaration of Helsinki. Institutional permission for the study was obtained from the administration of Kocaeli University Research and Practice Hospital where the study was conducted. Additionally, the principle of volunteerism was adopted in the study, and all participants provided written consent.

The study population included individuals who were over the age of 18, had a spouse/partner, voluntarily agreed to participate in the study, and were diagnosed with epilepsy and seeking care at the Neurology outpatient clinic. The G*Power 3.1.5 program was used to determine the sample size of the study, and the sample size was found to be 135 people, taking into account the values of $\alpha=0.05$, $\beta=0.95$, effect size=0.30 in the study.

In this study, the questionnaire form prepared by the researcher, the epilepsy self-management scale (ESMS) and Spouse Support Scale (SSS) were administered to the participants. The questionnaire includes questions about the socio-demographic characteristics of the participants and the disease. The ESMS was developed by Dilorio et al.[15,16] The Turkish validity and reliability of the scale were examined by Yeni et al.[4] in 2019. The scale, which consists of five subscales evaluating drug treatment, knowledge, safety, seizure, and lifestyle management in patients with epilepsy, is a 5-point Likert scale with 38 items. The scores to be obtained from the scale vary between 38 and 190, and high scores indicate good self-management. According to the internal consistency analysis on the validity and reliability of the scale, the Cronbach's alpha coefficient for the entire scale was determined as 0.740.[4]

Statistical Analysis

The SSS developed by Yıldırım[17] was used to measure the social support of married individuals from their spouses. The results of the analysis show that the scale consists of four dimensions: emotional, financial, and information support, appreciation, and social interest support.[17] The SSS comprises 27 items and is a 3-point Likert type. The total score varied between 27 and 81, with higher scores indicating greater perceived spousal support. While the Cronbach's alpha value was 0.95 in the original form of the SSS, in this study the Cronbach's alpha and McDonald's

omega values were found to be 0.96.[17] The data were evaluated using the Statistical Package for Social Sciences package program, and the significance level was accepted as $p<0.05$. Shapiro-Wilk and Kolmogorov-Smirnov tests were used for data conformity with normal distribution, and percentages and means were used for data evaluation. Pearson's correlation analysis was used to investigate the relationship between self-management and spousal support. Student's t-test was used to determine the relationship between sociodemographic factors and the epilepsy self-management and spousal support scale. The Bonferroni test was used for further analysis.

RESULTS

Approximately six out of ten participants were women, while approximately four out of ten were at undergraduate or higher education levels. Individuals whose income was equal to their expenses were 54.1%. Two-thirds of the patients had children. The mean age of the patients was 38.21 (13.26) years, and the mean time to diagnosis was 10.63 (8.41) months (Table 1).

Table 2 presents the patients' ESMS, its subdimensions, and mean SSS score. The mean ESMS score of patients was 133.64 (18.40). When we examined the subdimension mean scores of the scale, it is 40.75 (5.79) for drug management, 20.65 (6.75) for information management, 28.79 (3.63) for security management, 22.94±4.68 for seizure management, and 20.49 (5.08) for lifestyle management. The SSS score was 52.88 (14.21).

Table 3 presents the mean scores of the patients from the ESMS according to their sociodemographic characteristics. Compared with women, men's medication score was statistically significantly higher (p=0.035). Significant differences were observed in the total score of the ESMS and its subscales, specifically in the information and seizure domains, based on the educational level of the participants in our study. To identify the group that made the difference, a corrected Bonferroni test was applied.

Table 1. Sociodemographic characteristics of patients (n=135)

Characteristics	n	%
Gender		
Female	82	60.7
Male	53	39.3
Education level		
Primary school or lower education level	37	27.4
Secondary school	45	33.3
High school or higher	53	39.3
Income level		
Income less than expenses	62	45.9
Income equals expenses	73	54.1
The child		
Yes	90	66.7
No	45	33.3
	Mean	**Standart deviation**
Age	38.21	13.26
Mean time to diagnosis (as months)	10.63	8.41

High school graduates had lower epilepsy self-management scale scores than both primary and lower education graduates and individuals with undergraduate and graduate education (p=0.002). High school graduates had lower knowledge management scores than individuals with undergraduate and higher education and individuals with primary education and below (p<0.005). Individuals with undergraduate or higher education scores had higher seizure management scores than high school graduates (p=0.026). Those with a bachelor's degree or higher had higher lifestyle management scores than high school graduates (p=0.001). On the other hand, eta squared (η^2) was examined to determine the effect size of education. The obtained eta squared value was interpreted in accordance with Cohen's (1988) "d" index, which is an effect size measure. Cohen (1988) defined specific cutoff points for interpreting the d index as follows: effect sizes are categorized as "small" at d=0.02, "medium" at d=0.06, and "large" when d=0.14.[18] In this case, considering the eta square value (η^2=0.091) obtained for the education variable, it is seen that the gender variable has a moderate effect on epilepsy self-management. Those whose income was equal to their expenditure received a higher level of knowledge management score than those whose income was less than their expenditure (p=0.0259). Knowledge management and lifestyle management for those who did not have children are at a better level.

There was a statistically significant negative correlation between the number of seizures per year and the ESMS score. Disease self-management scores decreased as the number of seizure increases. Similarly, a negative and statistically significant relationship was found between age and ESMS score. As age increased, the ESMS score of the disease decreased (Table 4).

DISCUSSION

This study was conducted to determine epilepsy self-management, spousal support, and sociodemographic factors affecting patients diagnosed with epilepsy. It is widely accepted that self-management is increasingly important for quality of life, self-efficacy, and self-esteem in patients diagnosed with epilepsy.[19] Self-management interventions in epilepsy help patients manage their daily lives by

Table 2. Mean scores of participants in the epilepsy self-management scale and Spousal Support Scale (n=135)

Scales	Mean±SD	Min-max	Score range
Epilepsy self-management	133.64±18.40	81-181	38-190
Medication	40.75±5.79	23-50	10-50
Information	20.65±6.75	8-37	8-40
Safety	28.79±3.63	18-37	8-40
Seizures	22.94±4.68	6-30	6-30
Lifestyle	20.49±5.08	6-30	6-30
Spouse Support Scale	52.88±14.21	27-79	27-81

SD: Standard deviation, Min-max: Minimum-maximum

Table 3. Comparison of epilepsy self-management scale and Spouse Support Scale levels according to sociodemographic characteristics of the participants (n=135)

Characteristics	Epilepsy self-management scale Mean±SD	Medication Mean±SD	Information Mean±SD	Safety Mean±SD	Seizure Mean±SD	Lifestyle Mean±SD	Spouse Support Scale Mean±SD
Gender							
Female	134.28±19.46	39.91±6.19	21.13±7.28	29.06±3.69	23.15±4.95	21.01±4.91	52.85±14.62
Male	132.66±16.78	42.05±4.87	19.90±5.82	28.37±3.52	22.62±4.25	19.69±5.28	52.94±13.71
	p=0.619	**p=0.035**	p=0.304	p=0.287	p=0.518	p=0.143	p=0.972
Education level							
Primary school or lower education (37)	136.70±17.01	40.72±6.03	22.05±6.43	29.45±4.88	23.78±3.31	20.67±4.25	53.94±15.34
Secondary school (45)	125.86±12.81	40.91±4.14	16.46±4.59	28.73±2.85	21.42±3.36	18.33±4.70	54.68±6.71
High school or higher level (53)	138.11±21.32	40.64±6.83	23.22±6.90	28.37±3.17	23.66±6.02	22.20±5.31	50.62±17.63
	p=0.002	p=0.974	**p=0.000**	p=0.380	**p=0.026**	**p=0.001**	p=0.323
	1>2, 3>2		1>2, 3>2		3>2	3>2	
Perceived economic level							
Income less than expenses (62)	131.90±15.87	40.79±5.63	19.25±6.24	29.25±2.96	22.75±4.34	19.83±4.77	53.06±12.48
Income equals expenses (73)	135.12±20.30	40.72±5.95	21.83±6.98	28.39±4.09	23.10±4.97	21.05±5.29	52.73±15.62
	p=0.313	p=0.949	**p=0.025**	p=0.160	p=0.662	p=0.163	p=0.895
The child							
Yes	131.93±17.98	40.74±5.77	19.72±6.55	28.92±3.50	22.80±4.53	19.74±5.12	51.68±12.44
No	137.06±18.97	40.77±5.88	22.51±6.84	28.53±3.50	23.24±5.0	22.0±4.70	55.28±17.13
	p=0.127	p=0.975	**p=0.023**	p=0.560	p=0.605	**p=0.015**	p=0.166

SD: Standard deviation

Table 4. Correlations between the epilepsy self-management scale scores

		Spouse Support Scale	Mean time to diagnosis	Number of seizures in a year	Age
Epilepsy self-management	r	-0.57	-0.129	-0.175	-0.186
	p	0.512	0.137	**0.042***	**0.031***

*p<0.001

developing behaviors to manage epilepsy seizures and improve medication and treatment.[20] In this study, the average ESMS score was 133.64 (18.40). Although studies in the literature report scores that are much better than our findings, there are also findings that have lower scores than our findings. Quon et al.[21] found an ESMS score of 71.1 (8.23). An increase in epilepsy self-management skills is associated with an increase in quality of life.[21] In addition, disease management can help improve symptom management, potentially enhancing well-being and reducing seizure frequency in patients.[22]

In this study, the ESMS medication management subscale score was higher in men than in women. Similarly, Adadıoğlu and Oğuz[23] found higher epilepsy self-management scores in men than in women. In another study, it was determined that epilepsy seizure management was better in women than in men.[24] Mohsen and Ahmed[25] found that women with epilepsy had a higher quality of life than men in their study. The ESMS score of patients with epilepsy did not vary by gender.[26,27] Self-management education and support interventions are effective in improving self-efficacy, self-esteem, and quality of life in individuals diagnosed with epilepsy.[19] It is recommended that nurses working in neurology departments prioritize providing these trainings to at-risk groups.

High school graduates have lower ESMS and knowledge management scores than those who have graduated from primary school or below, as well as those with bachelor's degrees or higher. Adadıoğlu and Oğuz[23] found that individuals with higher education levels had better self-management skill scores than those with lower education levels. Individuals with low education levels are associated with an increased risk of depression.[28] In this study, individuals with a bachelor's degree or higher education received higher scores in seizure management and lifestyle management than high school graduates. Low education levels are associated with quality of life.[29] Yildirim and Yildiz[26] determined that the ESMS score did not vary according to educational level of the patients. Epileptic patients with higher education levels also have higher levels of knowledge about their disease.[30] Nurses are healthcare professionals who constantly work together with patients to provide education and care tailored to their needs. Therefore, nurses play a significant role in helping patients understand their condition, adhere to treatment, and adapt their daily lives to the symptoms of the disease.

Those whose income equals their expenses received a higher level of knowledge management score than those with lower income than expenses. Adadıoğlu and Oğuz[23] found that patients with high and middle incomes had better epilepsy self-management skills than those with low levels. Income status has an impact on the ability to manage epilepsy, as with many other diseases. Income status is believed to facilitate access to healthcare services and use of other treatment options, and this outcome may be related to income. In the study, knowledge management and lifestyle management of those who did not have children were at a better level. Having children and spending time with them can reduce patients' time allocated to themselves. It is thought that this outcome may be related to that. Additionally, it is believed that those who have children should receive educational support.

In this study, no statistically significant relationship was found between SSS and ESMS scores. The high score 52.88 (14.21) obtained on the spousal support scale in this study is believed to have affected this result. Adadıoğlu and Oğuz[23] determined in their study that epilepsy self-management was better in patients with high family support scores.[26] A good level of SSS is desirable; however, providing support to spouses at certain intervals is also thought to have a positive effect. Practitioner nurse-physician teams can more effectively implement epilepsy education and screen for psychological disorders.[31] In cases of family issues, it is important to identify at-risk individuals who require support, such as couple therapy or family therapy, and to refer them to an expert. For this purpose, nurses use their observational and communication skills within the clinical setting to provide assistance to patients.

In this study, we found that as the number of seizures increased, the ESMS scores of the patients decreased. This result may be related to the association between seizures and fatigue in patients.[32] In the literature, there have been different findings regarding this result. Adadıoğlu and Oğuz[23] found that the self-management score of epilepsy increased as the number of seizures increased. In a Ugandan study, self-management was associated with improved quality of life and reduced incidence of depression, stigma, and seizures among individuals with epilepsy and a history of adverse health events.[33] Yildirim and Yildiz[26] did not find a relationship between seizure frequency and epilepsy self-management in their studies.

In this study, a statistically significant negative correlation was found between patient age and ESMS score. Yildirim and Yildiz[26] found no correlation between age and the epilepsy self-management score in epilepsy patients. In a study evaluating quality of life in patients with epilepsy, a negative correlation was found between age and quality of life.[34] It has been reported that anxiety levels increase in individuals living with the disease for 16 years or more.[35] It is believed that individuals with aging may experience fatigue, burnout, and a decrease in their ability to manage the disease. This result shows that although patients gain experience as they age, their self-management may decrease. For this reason, follow-up of patients is considered important.

Study Limitations

This study has several limitations. First, because the study design is cross-sectional, it is not possible to evaluate causal or temporal relationships. The study sample was obtained from a single tertiary university hospital. Therefore, it should be taken into account that patients receiving primary care may produce different results.

CONCLUSION

In this study, the ESMS score was found to be at a moderate level in individuals diagnosed with epilepsy, and the medication management scores were found to be better in men. In those with higher education levels, seizure management and lifestyle management were found to be better, while knowledge management was found to be better in those with higher economic status and no children. The study found that spousal support did not have a statistically significant effect on epilepsy self-management. The ESMS score decreased as the age and seizure frequency increased.

Implications

Epilepsy is an important disease that affects the quality of life of patients and requires long-term treatment and follow-up. Self-management significantly affects daily functioning in individuals diagnosed with epilepsy. Spousal support is a protective and supportive factor for patients. Our results revealed the personal characteristics of the patients, especially sociodemographic factors that affect epilepsy self-management. Due to the nature of the disease, the emotional burden of patients can also affect their spouses. From the time of diagnosis, supporting the family and counseling have a positive effect on disease self-management. Family therapists, nurses, and psychologists can support the patient and caregiver by taking an active role in providing spousal support. Health professionals should support the mental aspect of the disease as well as their self-care skills. It is recommended to conduct experimental studies that support spouses. In addition, the conditions of the patient and the family should be evaluated through home visits, and improvements in the patient's self-management skills should be achieved.

Ethics

Ethics Committee Approval: This descriptive cross-sectional study was conducted after obtaining ethical approval from the İzmir Democracy University Non-interventional Clinical Research Ethics Committee (decision no: 2022/01-07, date: 05.01.2022).

Informed Consent: All patients read and approved the enlightened information sheet.

Authorship Contributions

Surgical and Medical Practices: S.D., Y.C.Ö., Concept: S.D., Y.C.Ö., Design: S.D., Data Collection or Processing: S.D., Y.C.Ö., Analysis or Interpretation: S.D., Y.C.Ö., Literature Search: S.D., Y.C.Ö., Writing: S.D., Y.C.Ö.

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