The Impact of Epilepsy Education on Knowledge, Self-Management, and Stigma in Individuals With Epilepsy

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ABSTRACT

BACKGROUND: Epilepsy should be approached in a multidimensional manner, considering its biological, psychological, and social aspects. The aim of this study is to examine the impact of epilepsy education on people with epilepsy regarding knowledge level, self-management, and stigma. **METHODS:** An online survey, including an epilepsy information form, epilepsy self-management scale, and stigma scale was sent to registered patients in our epilepsy clinic. After the survey, patients were invited to a 1.5-hour epilepsy education program, conducted by 2 instructors on different days, followed by a question-and-answer session. Participants were retested posttraining. **RESULTS:** Of 265 patients who filled out the pretraining survey, 69 (26%) attended the education program. Those who participated were generally more knowledgeable at the baseline. University graduates and those using the internet as a source of information were more inclined to attend, whereas unmarried individuals attended less. The participant age was 39.1 years (9.2 years), with 61% female, 65% having a university degree, and 61% actively working. Seizure types included focal (45%), generalized (22%), and both (33%), with 70% experiencing less than 1 seizure per month. Posteducation, participants answered more knowledge questions correctly ($P < .001$, before: 37.0 [6.0], after: 40.7 [6.1]). Awareness about swimming risks increased in the self-management scale, along with the tendency to carry informative cards, join support groups, and educate relatives. There was no change in the stigma scale. **CONCLUSION:** Epilepsy education has a positive impact on raising awareness about the disease and promoting self-management in people with epilepsy. The fight against stigma needs to involve broader segments of society.

Keywords: education program, epilepsy, knowledge, nursing, seizure, self-management, stigma

Introduction

Epilepsy is associated with various neurobiological, cognitive, psychosocial, and social consequences. People with epilepsy (PwE) often encounter psychosocial challenges, including decreased self-esteem, social isolation, academic decline, unemployment, and reduced quality of life, in addition to anxiety and depression.[1] One significant challenge faced by PwE is societal stigmatization. Stigma, discrimination, and prejudiced attitudes from society toward PwE can be more harmful than the disease itself.[2,3] Lack of knowledge about the disease fosters misconceptions leading to condition concealment, treatment nonadherence, and social isolation. Despite advances in treatment and awareness efforts, factors such as inadequate medical services, treatment failure, lack of knowledge, and low socioeconomic status trigger stigma.[3–6] Therefore, educational programs that provide accurate information are essential for improving self-management and coping with epilepsy-related stigma. In this study, we aimed to examine the preferred sources of information for adult epilepsy patients and evaluate the impact of a structured education intervention on their knowledge level, self-management, and perception of stigma.

Methods

This study was designed as a quasi-experimental, pretest and posttest intervention study to evaluate the

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impact of an online epilepsy education program on knowledge, self-management, and stigma perception in epilepsy patients. An online survey containing an epilepsy information form, epilepsy self-management scale, and stigma scale was sent to 5463 patients in the epilepsy outpatient clinic of our university hospital. Following the survey, patients were invited to an online live epilepsy education program. A message group, created for those who filled out the pretraining forms and wanted to be involved in the training, was used to announce the dates and times of the training sessions. Two clinical neurophysiologists conducted 1.5-hour training sessions on 2 different days, covering multiple aspects of epilepsy-included diagnosis, pathophysiology, etiological factors, epidemiology, and treatment, via an internet platform to reach patients living in different provinces to increase participation. The social section addressed psychosocial topics, potential consequences of stigma, and daily life challenges faced by PwE. After the education, approximately 1.5 hours were allocated for participants to ask their own questions. The same surveys were readministered in the following 5 days to assess any changes from the baseline. A consent form was sent to the patients along with the survey.

The *Epilepsy Information Form*, derived from a previous study[7] and created to measure healthcare professionals' knowledge and awareness of epilepsy, was modified for the patients. The form has 10 multiple-choice and true-or-false questions with additional screening questions about the sociodemographic and clinical characteristics of patients and their preferred sources of information about epilepsy. There were a total of 81 phrases across 10 questions, and each question had more than 1 correct phrase. There were a total of 46 correct phrases across the 10 questions. The correct answers given by the patients for each question, the score they received for each question, and their total score were calculated.

We used the *Epilepsy Self-Management Scale*,[8,9] as the Turkish form is validated.[7] The scale has 38 items, evaluating 5 subsections: medication (10 items), information (8 items), safety (8 items), seizure (6 items), and lifestyle (6 items) management. Responses are rated on a Likert scale ranging from 1 to 5. The minimum score is 38, indicating less frequent use of self-management behaviors. The maximum score of 190 suggests more frequent use of self-management behaviors. The scale does not have a specific cut-off value.

The *Stigma Scale* has 3 questions asking participants about other people's comfort level, treating them as if they were less valuable, and preferring to keep their distance because of their epilepsy. The Turkish form of the stigma scale was obtained from a previous study.[2] Participants respond with "yes" or "no" to each question, and the total score is calculated based on the sum of "yes" responses, indicating higher perceived stigma.[10]

Data analysis was performed using SPSS v.27.0. Descriptive methods were used to define the demographical data. Shapiro-Wilk test was used to test for normality. Mann-Whitney *U* and chi-squared tests were used to study differences between people that have attended and not attended the education program. Wilcoxon signed-rank test was used to compare the test scores before and after the education. The significance level was defined as $P \leq .05$.

Results

Of 265 patients who completed the pretraining survey, 69 (26%) attended the education program. The mean age of education-participants was 39.1 years (9.2 years), 61% were female, 65% had a university degree, and 61% were employed. Of all patients, 45% had focal seizures, 22% had generalized seizures, and 33% experienced both focal and generalized seizures. Seizure frequency was less than 1 per month in 70% of patients and more in the remaining. Patients received monotherapy in 50.7% of cases, and 94.2% claimed they used their antiseizure medications regularly. Doctors, internet, other patients, television, and social media were reported as preferred information sources (100%, 65.2%, 27.5%, 20.3%, and 17.4%, respectively). The mean age of patients who did not attended to the education program was 37.4 years (11.7 years), 49% were female, 41% had a university degree, and 46% were employed. Similar to the patients who attended the program, the most frequently preferred sources of information were their doctors and internet. Demographic and clinical data are summarized in Tables 1 and 2. No significant differences were observed between patients who participated in the training and those who did not with respect to age and gender. Those who participated were generally already more knowledgeable at the baseline compared with those who did not participate ($P = .021$). Individuals who had previously attended a class, seminar, or course related to epilepsy were more likely to participate in the training ($P = .006$). University graduates and individuals using the internet as a source of information showed a stronger tendency to attend the education, whereas single individuals were less inclined.

When comparing the baseline scale results of patients who participated in the program with those who did not, differences between the groups were observed in certain questions of the epilepsy information form and the epilepsy self-management form. However, no differences were found in the stigma scale. After the education program, participants gave more correct answers to information question compared with their baseline (before: 37.0 (6.0) vs after: 40.7

TABLE 1. Demographic Data of the Patients Based on Participation in the Education Program

Demographic Data	Attended (n = 69)	Not Attended (n = 196)	*P*
Age, mean (SD), y	39.1 (9.2)	37.4 (11.7)	.162
Sex (F/M)	1.6	0.9	.890
Residency, n (%)			.230
Village	2 (3)	12 (6)	
Small city	0 (0)	8 (4)	
City	15 (22)	44 (22)	
Metropolis	52 (75)	132 (67)	
Employment status, n (%)			.150
Worker	42 (61)	91 (46)	
Housewife	11 (16)	26 (13)	
Student	3 (4)	15 (8)	
Retired	5 (7)	20 (10)	
Not working	8 (12)	44 (22)	
Income status, n (%)			.431
Good	14 (20)	27 (14)	
Moderate	45 (65)	140 (71)	
Bad	10 (15)	29 (15)	
Marital status, n (%)			**.01**
Married	40 (58)	100 (51)	
Single	21 (30)	89 (45)	
Widow	8 (12)	7 (4)	
Educational status, n (%)			**.01**
Literate	1 (1)	3 (2)	
Primary school	3 (4)	24 (12)	
Secondary school	4 (6)	23 (12)	
High school	16 (23)	66 (34)	
University	45 (65)	80 (41)	
Preferred information sources of patients (%)			**.001**
Doctor	100	95	
Internet	65	43	
Other patient	27	17	
TV program	20	11	
Social media	17	11	
Medical book	14	13	
Health employee	12	8	
Brochure	10	8	
Friend	3	5	
Patient school	0	0.5	

(6.1); $P < .001$). Awareness regarding the risks of swimming, which is in the safety management category on the self-management scale, increased. Participants' motivation for carrying informative cards about their illness, joining support groups, and educating their relatives, which are in the information management category on the self-management scale, increased. There was no significant change in the stigma scale.

Discussion

This study shows that this educational intervention has a positive short-term impact on increasing knowledge,

TABLE 2. Clinical Features of the Patients Based on Participation in the Education Program

Clinical Features	Attended (n = 69)	Not Attended (n = 196)	*P*
Age of epilepsy onset, mean (SD), y	20.6 (13.5)	18.8 (12.5)	.448
Seizure types, n (%)			.371
Focal	31 (45)	107 (55)	
Generalized	15	33	
Focal + generalized	23	56	
Seizure frequency, n (%)			.647
<1/mo	48 (70)	142 (72)	
≥1/mo	21	54	
Epilepsy treatment, n (%)			.803
Monotherapy	35 (51)	96 (49)	
Polytherapy	34	100	
Regular medication use, n (%)			
Yes	65 (94)	184 (94)	.922
No	4	12	

raising awareness and promoting self-management in PwE. Participants who attended the educational sessions demonstrated a significant increase in their knowledge about epilepsy and reported improved self-management practices. However, combatting stigma necessitates more intricate and sustained interventions beyond one-time education sessions.

An important observation in this study is the preexisting higher knowledge level among participants who chose to attend the educational program. This implies that those who are already more motivated about their health are more inclined to look for more information and resources about their disease. University graduates and individuals who actively use the internet as an information source particularly tended to participate, indicating the impact of personal and sociodemographic factors on the participation in educational activities. This points to a critical need for targeted outreach strategies to connect with a larger, more diverse population, particularly those who might be less motivated or have less access to information.

Patient education aims to improve knowledge and enhance self-management skills also contribute to overcoming the challenges of disease management and societal acceptance. Various patient education initiatives, including structured classes, workshops, online resources, and community-based support groups, provide comprehensive information about epilepsy, its management, seizure types, triggers, medication adherence, lifestyle adjustments, and emergency protocols. Improved knowledge leads to better understanding of the disease and informed decision-making about lifestyle modifications. Studies consistently show the positive impact of patient education on increasing knowledge about epilepsy.[11] They also emphasize the need for continuous education.[11] In our study, participants with higher baseline knowledge improved further posteducation. However, patients with better preeducation knowledge, university graduates, and those using the internet as a source of information were more motivated to attend the education. This highlights the significant influence of personal factors, such as preexisting enthusiasm for learning and using the internet for information about the disease, on tendency to attend such education programs. Therefore, different strategies need to be developed to reach out to a broader group, targeting every patient, even the underprivileged ones or those with no motivation.

Particularly important in chronic diseases, self-management refers to an individual's ability to manage symptoms, treatment, and the physical and psychosocial consequences of the disease, allowing them to make lifestyle changes.[7] To strengthen self-management, individuals need to be accurately informed about the disease and possible outcomes of adhering or denying treatment or necessary lifestyle changes through educational programs. These programs generally focus on medication adherence, recognizing seizure triggers, lifestyle changes such as stress management and sleep hygiene, and understanding when to seek medical help. Education empowers individuals, enabling them to feel in control of their illness and improving their quality of life. Consequently, this can lead to reduced medical costs, more successful treatment, and a higher quality of life.[12] Previous studies have shown that individuals who receive information about epilepsy were more likely to take their medications regularly, resulting in a reduction of seizure frequency.[13–15] Similarly, a study implementing an epilepsy self-management protocol found that structured education programs could improve patient self-management behaviors, with significant increases in self-management scale scores posteducation. Notably, the total self-management score, as well as seizure management and information management subscale scores, showed statistically significant improvements.[16] In our study, an increase in awareness and tendency in certain areas was observed in patients after education. In the self-management scale, it was observed that the participants provided better responses to 3 questions related to information and 1 question related to security compared with the baseline.

Many studies indicate that improving the knowledge levels of patients becomes crucial, as patient education will foster positive attitudes and reduce perceived stigma.[4,17–20] Patient education initiatives play a vital role in dispelling myths, fostering understanding, and reducing stigma associated with epilepsy. Several studies have reported that knowledge levels are associated with attitudes, and educational interventions can reduce prejudices toward the disease and the patients.[21–23] One study observed a decrease in stigma in adult PwEs with their implemented education program, although they did not find any differences in medication use, medication adherence, or psychiatric issues.[24] Most studies have focused on identifying stigmafew effectively demonstrate a reduction in stigma and negative attitudes toward PwE.[25,26] Nevertheless, the lack of significant change in stigma perception suggests that reducing stigma requires a multifaceted approach, involving not just patients but also their families, communities, and healthcare professionals. Educational programs should be complemented by community-wide awareness campaigns and continuing support. Our study also indicated that a one-time education session did not cause a significant change in stigmatization. This suggests that short-term interventions may not be sufficient to achieve long-lasting attitude changes.

The implications for neuroscience nurses include a critical role in educating and supporting PwE. As frontline healthcare providers, they offer structured patient education, address misconceptions, and promote self-management. This study highlights the need for continuous educational interventions rather than 1-time sessions for meaningful stigma reduction. Education should be tailored to reach both motivated patients and those with limited healthcare access or knowledge. Neuroscience nurses can develop targeted outreach strategies, such as incorporating epilepsy education into routine clinical visits, using digital platforms for remote education, and collaborating with community organizations to reach underserved populations. Structured interviews and communication tools can help nurses better understand the needs of PwE and provide more effective guidance on disease management, thereby improving the quality of patient care.[27] Moreover, interdisciplinary collaboration with neurologists, psychologists, and social workers can increase the effectiveness of educational interventions.

Our study had several limitations. First, our sample consists of highly educated patients from urban backgrounds, which may influence the results and limit the generalizability to larger populations, including those with lower educational levels or different socioeconomic backgrounds. The urban setting of the study may also contribute to this bias, as access to technology and healthcare resources can differ significantly between urban and rural areas. Second, the significant dropout rate during the study protocol could give rise to bias, as those who completed the study may have been more motivated or had better access to technology than those who did not. To mitigate this, future studies should consider strategies to reduce dropout rates, such as providing technical support for online participation or offering alternative methods for data collection. In addition, organizing a 1-time educational intervention may have caused not enough change in the stigma perception, self-management behaviors, and scales. For these reasons, evaluation of these scales through repeated or ongoing educational programs could be more guiding. However, there are not many studies in the literature aimed at reducing stigma and negative attitudes toward adult epilepsy patients and their relatives. Despite these limitations, our study provides valuable insights into the role of education in improving knowledge and self-management among epilepsy patients and highlights the need for ongoing efforts to reduce stigma and enhance patient education in epilepsy clinics. Despite their effectiveness, patient education programs face challenges such as accessibility, cultural barriers, and varying educational needs among individuals. Future trends may include increasing accessibility of education, tailoring programs to different populations, and taking advantage of technology for broader access and effectiveness.

Another important aspect worth emphasizing is the value of ongoing education. Even while knowledge and other parts of self-management improved in measurable ways after a single educational session, ongoing education programs are probably needed to maintain these gains and deal with more complicated problems like stigma. Future research should examine the impact of repeated educational interventions and the integration of different formats, such as online modules, in-person workshops, and peer support groups, to optimize and maximize reach and effectiveness.

Conclusion

Epilepsy education has a positive impact on raising awareness about the disease and promoting self-management in PwE. The fight against stigma needs to involve broader segments of society. Different patient populations and demographics may not be reachable via conventional methods; therefore, education strategies transcending beyond cultural, economic, and structural barriers should be developed.

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