

Original Paper

Effect of Self-care Education Using Face-to-face Method and Pamphlets on Epilepsy Risk Awareness of Patients With Epilepsy and their Family Caregivers



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ABSTRACT

Introduction: For patients with epilepsy and their family caregivers, epilepsy risk awareness (ERA) can affect various aspects of health. They need effective education to improve their quality of life.

Objective: This study aims to compare the effect of self-care education on ERA in patients with epilepsy and their family caregivers using the face-to-face method and pamphlets.

Materials and Methods: In this quasi-experimental study, participants were patients with epilepsy referred to a neurological outpatient clinic in Tabriz, Iran and their family caregivers. They were randomly assigned to the intervention (60 patients and 60 caregivers) and control (60 patients and 60 caregivers) groups. The ERA scales for patients and family caregivers were completed before and one month after the education. The intervention group received ERA-based self-care education in a 60-minute session using the face-to-face method. The pamphlet group received the same education using pamphlets. Data were analyzed using descriptive statistics, paired t-test, independent t-test, Fisher's exact test, chi-square test, and ANCOVA.

Results: Most of the patients (70%) and caregivers (53.3%) in the intervention group were female, and their mean age was 28.07 and 40.75 years, respectively. In the pamphlet group, most of the patients (68.67%) and caregivers (63.3%) were female, with a mean age of 30.28 and 42.32 years, respectively. After education, mean ERA scores increased significantly in both intervention and pamphlet groups ($P=0.001$). Except for the two domains of physical and mental health, the mean scores of ERA domains were higher in the intervention group than in the pamphlet group ($P=0.01$). These results were confirmed by ANCOVA results ($P<0.01$).

Conclusion: Self-care education with the face-to-face method or pamphlets both can increase the ERA of patients with epilepsy and their family caregivers. Depending on the conditions and available facilities, nurses can use these methods to facilitate patient education and the learning process.

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Highlights

- Patients with epilepsy and their family caregivers in Tabriz, Iran had low level of ERA.
- Self-care education increased the ERA of patients with epilepsy and their family caregivers.
- Face-to-face self-care education improved the ERA of patient with epilepsy and their family caregivers better than the education with pamphlet use.

Plain Language Summary

Patients with epilepsy and their families need effective self-care education to improve their quality of life. This study aimed to compare the effect of self-care education on epilepsy risk awareness using face-to-face method and pamphlets. Participants were 120 patients with epilepsy and 120 family caregivers, divided into two groups. One group received self-care education based on ERA in a 60-minute session using the face-to-face method, and the other group received the education using pamphlets. One month later, the results showed that both methods increased the epilepsy risk awareness of patients and family caregivers, where the face-to-face method was more effective. Depending on the conditions and available facilities, nurses can use these methods to facilitate patient education and the learning process.

Introduction

Epilepsy is a chronic disorder that affects about 50 million people worldwide [1]. Epileptic seizures are unpredictable and often debilitating, affecting patients' quality of life throughout their lives [2, 3]. After a seizure, especially if it is frequent and uncontrolled, a variety of physical injuries can occur, ranging from minor injuries to sudden death [4, 5]. Effective epilepsy management, including raising awareness and improving patients' self-care skills, can protect them from possible injuries and prevent unnecessary restrictions to improve their quality of life [6, 7]. According to Orem's self-care theory, people can take care of themselves and the care should focus on strengthening self-care ability in patients or family members, especially family caregivers [8]. Patients with epilepsy should learn various skills to protect themselves. They need regular care and education [9, 10].

Although many studies have been conducted on different aspects of epilepsy care [11], there is scant research on the epilepsy risk awareness (ERA) of patients, and we found no studies in this field in Iran. However, some studies have examined the general knowledge of patients and families about epilepsy, and the results have shown that patients and families do not have enough knowledge of the different aspects of epilepsy care [12, 13] and that comprehensive and effective training is needed. Eze et al. reported that many school teachers have poor knowledge and practice related to

epilepsy and have negative attitudes towards patients with epilepsy. After an educational intervention, their knowledge, attitudes, and practice related to epilepsy were improved [14]. To meet the educational needs of patients, nurses play a main role in the care and education of patients and their families [15]. It is better to use the most effective educational strategies, such as the standard face-to-face method [16]. However, due to various factors such as the lack of resources, staff, and time [17-19], it can be challenging to assess risk factors and provide necessary training with the desired quality to the patients and family caregivers. Therefore, to overcome these challenges, it is necessary to use other effective, cost-effective and flexible educational strategies, such as the pamphlets. Accordingly, this study aims to investigate the effect of self-care training on the ERA of patients with epilepsy and their family caregivers in Tabriz, Iran using two methods, face-to-face training and pamphlets. In this regard, the objectives of this study include:

- 1) Comparing the ERA of patients with epilepsy before and after training in the intervention and pamphlet groups;
- 2) Comparing the ERA of the family caregivers of patients with epilepsy before and after training in the intervention and pamphlet groups.

Materials and Methods

In this quasi-experimental study, the study population consists of patients with epilepsy and their family caregivers referred to the neurological clinic of a hospital affiliated to [Tabriz University of Medical Sciences](#). To determine the sample size, a pilot study was conducted on 30 patients with epilepsy (mean ERA score=81.9±7.3) and their family caregivers (mean ERA score=83.7±9.2). Considering a 95% confidence level and a statistical power of 80%, the required sample size for each group was determined 54 for patients and 56 for caregivers. Considering a 10% sample dropout, 124 patients (62 in each group) and 124 caregivers (62 in each group) were selected for the study. Of these, three were excluded due to lack of consent and five were excluded for lack of interest ([Figure 1](#)). The samples were selected by a convenience sampling method. Opaque, numbered, and sealed envelopes were used for allocation concealment. Inclusion criteria were ability to communicate and answer the questions, age ≥15 years, no drug addiction based on medical records, and a confirmed diagnosis of epilepsy based on a history of seizures and EEG results according to a neurologist. Exclusion criteria for both groups were absence due to death or travel, withdrawal, unwillingness to continue participation, and not responding to ≥10% of the questions. The sampling was carried for 3 months from December 2021 to March 2022.

The primary outcome variable was ERA in patients with epilepsy and their family caregivers. The third edition of the ERA scale for patients and its modified version for family caregivers were used to collect data. The first part of the scales surveys demographic characteristics such as age (years), gender (female, male), marital status (single, married, divorced, widowed), occupation (employed, unemployed), ethnicity (Persian, Turkish, Kurdish), patient's history of seizures (year), educational level (elementary school, high school, high school diploma, academic), history of using anticonvulsants, and relationship with caregiver (spouse, father, mother, child, and other). The second part of the two ERA scales for patients and family caregivers had 40 items measuring ERA in four areas, including the characteristics of epilepsy (18 items), personal safety (10 items), physical wellbeing (6 items), and mental wellbeing (6 items). The items are rated on a four-point scale as yes (3 points), sometimes (2 points), no (1 point) and not applicable (0 points). The total score ranges from 0 to 120, with higher scores indicating more active participation, more safety, and lower risk level. The time required

to complete each questionnaire was 7-10 minutes [6]. In the present study, the ERA scale was first translated into Persian by a professional translator and then translated back to English by another professional translator. The translators and researchers evaluated all versions of the scale, and the final Persian version of the ERA scale for patients was developed and approved by consensus. After small modification of some items, an ERA scale for family caregivers was also developed. For determining the content and face validity of the scale, the Persian version was sent to 15 professors of the [Faculty of Nursing and Midwifery](#) and their suggestions were implemented. The reliability of the scale was assessed using the Cronbach's α coefficient in a pilot study with 30 patients with epilepsy ($\alpha=0.86$) and family caregivers ($\alpha=0.88$). For data collection, the researcher first visited the patients with epilepsy and family caregivers in the outpatient neurological clinic of a teaching hospital in the morning and evening shifts. After explaining the study objectives to them and obtaining their written informed consent, the questionnaire was completed through the interview with the participants (response rate=100%). Due to ethical considerations, all patients received routine medical and nursing care throughout the study.

After extensive review of literature, ERA-based self-care training content for patients with epilepsy and family caregivers was prepared in four sections ([Table 1](#)). To simplify and facilitate learning, the content was prepared with simple sentences, using large fonts, colored images, and three short videos. Its validity was confirmed by five professors and one neurologist. After the pre-test assessments, the intervention group received the ERA-based self-care training by face-to-face method. The training sessions were carried out in paired groups (patient and his/her family caregiver) in a designated room in the clinic 60 minutes. During the training, there was a question & answer session. The participants could ask their questions and receive feedback. The pamphlet group received the self-care education using pamphlets. Except for the videos, the content was the same as in the intervention group. A telephone number was provided to the participants in both groups to follow up and answer the questions. One week after the first visit, the researcher called the patients and their family caregivers and answered any questions they have. To prevent a possible exchange of information between the two groups, the training and the tests were carried out separately for them. The patients, family caregivers, and nurses were unaware of the allocation and the research details. One month after the first visit, both groups were

Table 1. Self-care content for patients with epilepsy and family care giver

Section	Topic	Content
1	Epilepsy disease characteristics	- Education goals - Information about epilepsy: Symptoms, risk factors, complications
2	Personal safety	- 1 st aid for a seizure
3	Physical wellbeing	- Self-care recommendations for the patient and family caregivers: Preventive measures, impact of epilepsy on life, proper medication use, having an identification bracelet, physical activity, sleep, stress, driving, marriage, computer use, social behavior, bathing, pregnancy, etc.
4	Mental wellbeing	- Three short videos

asked to fill out the ERA questionnaire again. For ethical considerations, participants in the pamphlet group also received the ERA-based self-care training by face-to-face method and the intervention group received the ERA-based self-care education pamphlets at the end of the post-test phase.

Collected data were analyzed in SPSS software, version 21 (SPSS Inc., Chicago, IL, USA) using descriptive statistics, paired t-test, independent t-test, Fisher’s exact test, chi-square test, and analysis of covariance (ANCOVA). The results of the Kolmogorov-Smirnov test indicated

the normality of the data distribution. $P < 0.05$ was considered as statistically significance.

Results

The mean age of the patients was 28.07 ± 10.87 years in the intervention group and 30.28 ± 10.64 years in the pamphlet group. Table 2 shows other demographic characteristics of the patients. The mean age of family caregivers was 40.75 ± 9.52 years in the intervention group and 42.32 ± 10.70 years in the pamphlet group. The independent t-test results indicated that the difference in age between groups was not statistically significant.

Table 2. Demographic characteristics of patients with epilepsy

Variables	Categories	No. (%)		P
		Intervention Group (n=60)	Control Group (n=60)	
Gender	Female	42(70)	37(61.67)	0.340**
	Male	18(30)	23(38.33)	
Marital status	Single	28(46.67)	28(46.67)	0.740*
	Married	31(51.67)	32(53.33)	
	Divorced and widowed	1(1.66)	0	
Occupation	Employed	10(16.7)	15(25)	0.369**
	Unemployed	27(45)	33(55)	
Language	Persian	2(3.33)	2(3.33)	0.321*
	Turkish	54(90)	57(95)	
	Kurdish	4(6.7)	1(1.67)	
Education status	Elementary school	4(6.67)	8(13.32)	0.781*
	High school	19(31.66)	10(16.66)	
	Diploma	21(35)	23(38.33)	
	Academic	16(26.66)	19(31.66)	

*Chi-square test, **Fisher’s exact test.

Table 3. Demographic characteristics of family caregivers of patients with epilepsy

Variables	Categories	No. (%)		P
		Face to Face Group (n=60)	Pamphlet Group (n=60)	
Gender	Female	32(53.3)	38(63.3)	0.270*
	Male	28(46.7)	22(36.7)	
Marital status	Single	2(3.3)	5(8.3)	0.763**
	Married	58(96.7)	54(90)	
	Divorced/Widowed	0 (0)	1(1.7)	
Occupation	Employed	33(55)	27(45)	0.36*
	Unemployed	27(45)	33(55)	
Ethnicity	Persian	0(0)	1(1.7)	0.1**
	Turkish	56(93.3)	58(96.7)	
	Kurdish	4(6.7)	1(1.7)	
Educational level	Elementary school	9(15)	9(15)	0.518**
	High school	13(21.7)	9(15)	
	Diploma	22(36.7)	21(35)	
	Academic	16(40)	21(35)	
Relationship with the patient	Spouse	24(40)	15(25)	0.207**
	Father	9(15)	10(16.7)	
	Mother	19(31.7)	24(40)	
	Child	3(5)	5(8.3)	
	Other	2(3.4)	6(10)	

*Fisher’s exact test, **Chi square test.

cant. [Table 3](#) shows other demographic characteristics of family caregivers.

The mean ERA scores for patients and family caregivers are presented in [Table 4](#) and [Table 5](#) , respectively. The ANCOVA was used to compare the post-test ERA scores between two groups, after controlling the pre-test scores. The results showed a significant increase in the domains of ERA in the intervention and pamphlet groups of patients and family caregivers after education. The mean post-test ERA scores in the intervention group of patients and caregivers were significantly higher than in the pamphlet group (Cohen’s d for patients=3.11, P=0.001; Cohen’s d for family caregivers=2.81, P=0.001) the rest of information is presented in [Table 6](#).

Discussion

The results of the present study showed that self-care education about ERA by face-to-face method resulted in a significant increase in all domains of ERA in patients with epilepsy and family caregivers. In patients with epilepsy, only two domains of ERA (characteristics of epilepsy and personal safety) were significantly different between the two intervention and pamphlet groups in the post-test phase. The difference in the domains of physical and mental health was not significant between the two groups after education. In the family caregivers, the results showed that, after education, the score of ERA were significant between the intervention and pamphlet groups in all domains exception for physi-

Table 4. Mean scores of epilepsy risk awareness for epileptic patients

Domains	Time	Mean±SD		P*
		Intervention (n=60)	Control (n=60)	
Epilepsy	Pre-test	39.85±5.43	40.38±4.97	0.576
	Post-test	46.76±3.31	44.48±4.37	0.002
	P**	0.001	0.001	
Personal safety	Pre-test	17.36±2.81	16.25±2.21	0.071
	Post-test	20.41±2.38	17.93±2.09	0.001
	P**	0.001	0.001	
Physical wellbeing	Pre-test	12.60±2.53	12.06±2.94	0.290
	Post-test	14.73±2.13	14.16±2.28	0.163
	P**	0.001	0.001	
Mental wellbeing	Pre-test	13.43±2.19	13.18±2.45	0.558
	Post-test	15.85±1.29	15.26±2.08	0.068
	P**	0.001	0.001	
Total	Pre-test	83.25±8.88	81.88±8.75	0.398
	Post-test	97.76±5.76	91.85±7.44	0.001
	P**	0.001	0.001	

SD: Standard deviation.

*Independent t-test, **Paired t-test.

cal wellbeing. In other words, the face-to-face method improved ERA of patients and their family caregivers in some cases better than the pamphlet use. Therefore, the self-care training programs based on the ERA for patients with epilepsy and their family caregivers are better in the face-to-face method. Effective education can improve self-care and quality of life of patients. A study used discussion sessions about health issues between nurses and patients or their families a patient education strategy [20]. The face-to-face education should be performed by an experienced nurse along with proper follow-up. In this way, patients can be protected against the possible risks of epilepsy and their lifestyle can be improved.

Based on the results of the present study, the ERA of patients with epilepsy and family caregivers were significantly improved in all domains in the pamphlet group. Therefore, in the absence of available resources, including lack of time, lack of human resources, or financial problems, nurses can use pamphlets to provide

self-care education for patients with epilepsy and their family caregivers to improve their ERA. It should be performed by an experienced nurse along with proper follow-up and responsiveness.

In ERA-based self-care education for patients with epilepsy and their family caregivers, the potential risks, educational needs, and the cases requiring intervention should be identified. After evaluating different strategies for patient education, Zirwas et al. found that due to various factors such as time and patient motivation, a single strategy is not always the most effective way to educate patients. They suggested that a combination of pedagogical strategies should be used for optimal learning [20]. Results of a systematic review study identified five themes that categorize facilitators and barriers to the successful implementation of epilepsy self-management programs, including relevance, personalization, intervention components, clinicians, and technology considerations. Their results indicated that involving patients with epilepsy and their caregivers in program

Table 5. Mean scores of epilepsy risk awareness for family caregivers

Domains	Mean±SD			P*
	Time	Face to Face Group	Pamphlet Group	
Epilepsy	Pre-test	41.56±4.60	41.23±4.95	0.703
	Post-test	47.68±2.98	45.30±4.19	0.001
	P**	0.001	0.001	
Personal safety	Pre-test	17.81±3.31	16.85±2.67	0.081
	Post-test	20.28±2.38	18.85±2.16	0.001
	P**	0.001	0.001	
Physical health	Pre-test	12.43±2.84	12.85±2.78	0.419
	Post-test	14.65±1.98	14.48±2.23	0.666
	P**	0.001	0.001	
Mental health	Pre-test	13.58±2.27	13.55±2.43	0.938
	Post-test	15.85±1.29	15.26±2.08	0.001
	P**	0.001	0.001	
Total	Pre-test	85.40±8.82	84.48±8.18	0.556
	Post-test	98.41±5.72	94.43±5.75	0.001
	P**	0.001	0.001	

SD: Standard deviation.

*Independent t-test, **Paired t-test.

development and then tailoring the educational content during the intervention can help ensure that the content is relevant to intervention participants. Their results also indicated that the clinician’s role in providing self-management training is important [21].

In the present study, most of patients with epilepsy and their family caregivers did not have enough knowledge of the side effects of antiepileptic drugs and the prevention of epilepsy risk factors before education. After the education, their information and awareness improved. Results of a study by Hu et al. showed that self-management training can reduce seizure frequency, improve quality of life, increase antiepileptic drug use, and reduce seizure-related accidental injuries in patients with epilepsy who are aware of seizure precursors or precipitating factors [22]. In the study by Yadegari et al., one month after the educational intervention in patients with epilepsy, the mean scores of medications self-management were significantly improved [23]. Hagemann et al. provided an educational program

for the parents of children with epilepsy in Germany and Austria. Their results showed that the educational program was effective and helped parents to manage their children’s epilepsy and reduce the anxiety associated with epilepsy [24]. Pascual et al. conducted a public education intervention with educational pamphlets and videos aimed at reducing the cost of epilepsy management. Four months after the educational intervention, the number of visits to the emergency department for patients with epilepsy decreased significantly. This finding supports patient and family education as a valuable strategy in reducing emergency room visits, which can reduce healthcare costs [25].

As one of the limitations of the present study, it should be taken into account that ERA is a subjective and multi-domain concept and is influenced in various ways by personal, social, and environmental factors. Although an appropriate instrument was used for measurement in this study, there was a possibility of response bias. In the present study, the education was provided in the

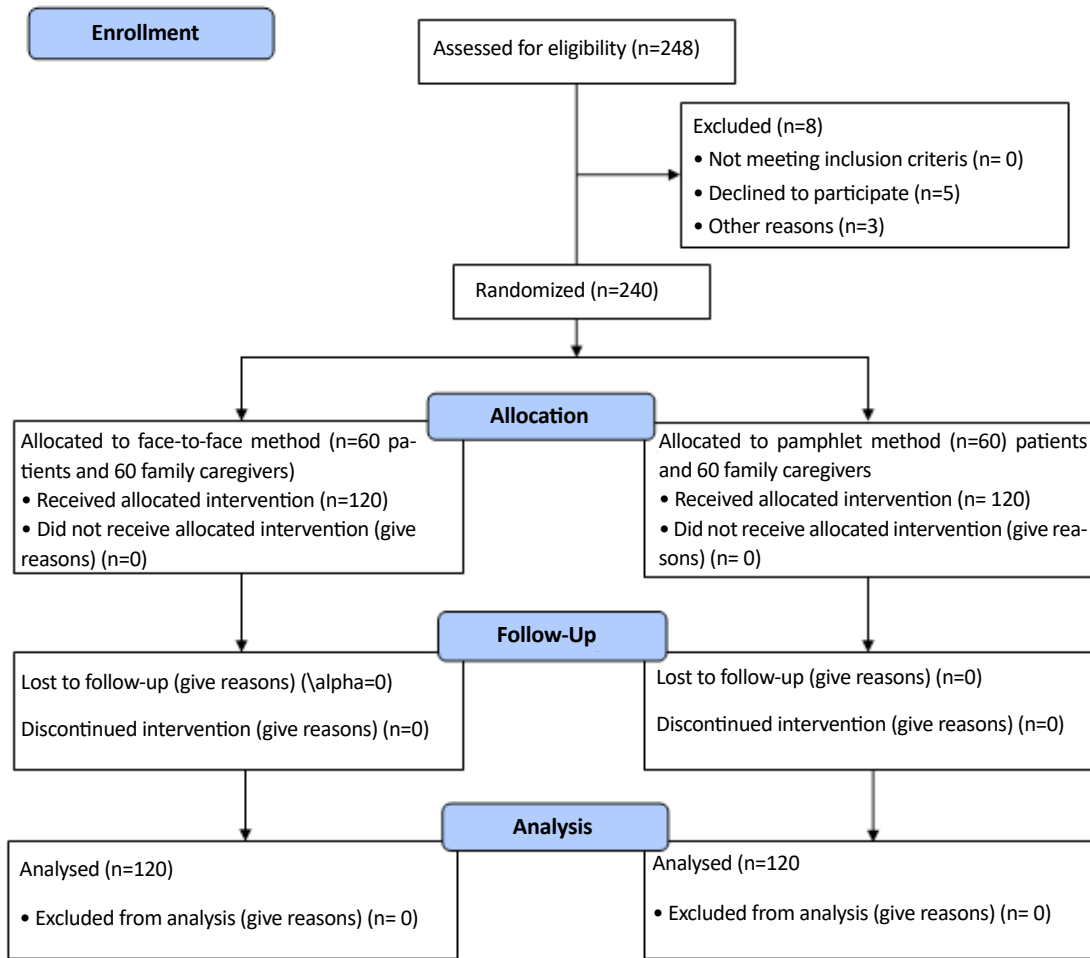


Figure 1. The CONSORT diagram of the recruitment process in the study

Table 6. ANCOVA results for patients and family caregivers

ERA Domains*	Group (Intervention and Pamphlet Group)	Cohen's d	95% CI (Lower-Upper)	P**
Epilepsy	Patients	3.50	2.87-4.13	0.004
	Family caregivers	1.51	1.06-1.95	0.001
Personal safety	Patients	3.11	2.52-3.69	0.001
	Family caregivers	2.24	1.73- 2.74	0.001
Physical health	Patients	0.89	0.10- 1.89	0.178
	Family caregivers	0.76	0.24-1.76	0.692
Mental health	Patients	0.91	0.09-1.92	0.089
	Family caregivers	1.52	1.07-1.96	0.001
Total	Patients	3.11	2.52-3.69	0.001
	Family caregivers	2.81	2.25-3.36	0.001

*Epilepsy Risk, ** ANCOVA test.

evening shift. The difference in the shift can affect the results. In addition, only patients and family caregivers with an appropriate cognitive level were included in this study. There are different types of epilepsy; the training on safety precautions should be tailored to the epilepsy type and treatment relevant. Therefore, the necessary considerations should be made when generalizing these results to all epilepsy types.

In conclusion, the ERA-based self-care education using both face-to-face method and pamphlets can significantly increase the ERA and its four domains (characteristics of epilepsy, personal safety, physical wellbeing, and mental wellbeing) in patients with epilepsy and their family caregivers, where the face-to-face method is more effective than the pamphlet use. Depending on the existing conditions and available resources, nurses can use the face-to-face method or education pamphlets to facilitate the learning process of patients with epilepsy and family caregivers and improve their quality of life.

Ethical Considerations

Compliance with ethical guidelines

This study was approved by the Ethics Committee of [Tabriz University of Medical Sciences](#) (Code: IR.TBZMED.REC.1400.840). Before the study, the patients and family caregivers were informed about the study objectives and their rights to leave the study at any time. Then, a written informed consent was obtained from them.

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Authors' contributions

Conceptualization, design, data collection, data analysis, data interpretation, and draft preparation: Hossein Feizollahzadeh and Golzar Tartibzadeh; Data analysis, data interpretation and final approval: All authors.

Conflict of interest

The authors declared no conflict of interest.

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