

Original article**Readiness for emergencies and disasters, and health competencies among people with epilepsy**

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Abstract:

Objective: Epilepsy, one of the chronic diseases with a substantial share in the global burden of disease, can be brought under control with proper disease management. A part of disease management is preparedness for emergencies and disasters. Health competence is a protective mechanism in developing behavior and readiness for emergencies and disasters. This study aims to determine the relationship between preparedness against emergencies and disasters and health literacy competencies in people with epilepsy. **Methods:** The study was carried out with 270 epilepsy patients, 18 years of age and older, living in Turkey's Central Black Sea Region between April and May 2022. The questionnaire form included socio-demographic characteristics, health behaviors related to disease management (smoking use, regular exercise, regular use of drugs, etc.), and emergency and disaster preparedness behaviors. The disaster preparedness of the participants was evaluated through the "Disaster Preparedness Scale," and their health competence skills were evaluated through the "Health Literacy Scale-Short Form." **Results:** The median HLS-SF score was 30, and the median disaster preparedness score was 31. More than two-thirds of the participants knew the trigger of the seizures and had at least three days of medication with them when they left home. Only 6.7% of the participants stated that they had a medical alert wrist/card, and 37,4% stated that they know the emergency call number they need to call in case of any emergency. The median disaster preparedness scores varied by gender ($p<0,01$) and were 32 for women and 31 for men. The median disaster preparedness score was 31 for married, and it was found to be significantly higher than for singles ($p<0.05$). The disaster preparedness score was higher among those who lived in the city/district center ($p<0.01$). The median disaster preparedness score was 31 among those with regular physical activity, different chronic diseases, and who took their medications regularly, significantly higher than the other groups ($p<0.000$). There was a significant positive correlation between the individuals' age, sleep duration, epilepsy duration, HLS-SF, and disaster preparedness levels ($p<0.05$). **Conclusions:** People with epilepsy had some gaps in preparedness against emergencies and disasters and also health competence. During a disaster and emergency, medically vulnerable individuals with epilepsy must be able to meet their particular needs on their own. The way to develop emergency and disaster preparedness behaviors is to increase health competencies.

Keywords: Epilepsy; Emergencies; Disasters; Health, Competence

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Introduction:

Epilepsy includes a broad group of diseases/disorders with diverse etiologies, electroclinical presentations, and marked variability in clinical outcomes¹. The operational definition of epilepsy is

at least two unprovoked seizures (reflexes) occurring over 24 hours; the Presence of a single unprovoked seizure and a probability (at least 60%) of another seizure similar to overall risk of recurrence after two unprovoked seizures within ten years, or a diagnosis of an epilepsy syndrome². Epilepsy is one of the most

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common neurological diseases in society. Every year, 5 million people are newly diagnosed with epilepsy. There are still 50 million epilepsy patients in the world. The population rate with active epilepsy is between 4-10 per 1000 people.

Current Situation of Epilepsy in Turkey

No statistical data on epilepsy in Turkey was found in the whole country. However, the prevalence of active epilepsy is 6-7 per thousand in studies at the local level^{3,4}. Although many underlying disease mechanisms can lead to epilepsy, the cause of the disease is still unknown in approximately 50% of cases worldwide. It may develop due to structural, genetic, infectious, metabolic, immune, and unknown reasons. Contrary to commonly known, epilepsy seizures are not limited to convulsive attacks but may have many clinical manifestations associated with the cortical areas from which abnormal activity originates. Typically it is a form of spontaneous, short-term attacks involving unusual feelings, behaviors, or movements. Although the seizure intervals and types are incredibly variable, the patient usually lives normally between seizures⁵. The impact of disasters and emergencies on individuals with epilepsy is more challenging. Seizure and epilepsy-related complications are common for urgent medical evaluation, accounting for 5% of emergency calls and 1% emergency room visits⁶. Three basic steps can keep epilepsy patients safe during a natural disaster or other emergencies:⁷

- Self-management of epilepsy
- Prepare an emergency supply kit
- Making an emergency plan with family/friends

People with epilepsy have personal needs to consider when planning an emergency. As with any chronic condition, people with epilepsy can benefit from learning skills that help them better manage their illness and its impact on daily life. Self-management of epilepsy includes three areas⁸: 1- Treatment management: Taking medications as prescribed, not delaying medical appointments, and communicating effectively with healthcare providers; 2- Seizure management: Recognizing and avoiding seizure triggers, tracking when seizures occur, 3- Lifestyle management: Getting enough sleep and reducing stress.

Health literacy is defined as how individuals receive, process, and understand basic health information and services necessary to make appropriate health

decisions⁹. Patients with a tremendous disease burden often have the least ability to understand and use health information^[10]. Indeed, it is not surprising that in extensive epidemiological studies, people with epilepsy report lower levels of education, lower annual income, and worse health than the population without epilepsy. All this evidence strongly suggests that people with epilepsy are at risk for poor health literacy¹¹⁻¹³. On the other hand, preparedness for public health emergencies and disasters requires health literacy skills and competence¹⁴. However, no study has been found in the literature that relates the readiness of people with epilepsy to disasters and emergencies with their health competencies.

This study aims to determine the relationship between preparedness for emergencies and disasters and health literacy competencies in people with epilepsy.

Materials-methods:

The study was carried out with 270 epilepsy patients, 18 years of age and older, living in Turkey's Central Black Sea Region between April and May 2021.

The study data included socio-demographic characteristics of the participants (age, gender, education level, etc.), health behaviors related to disease management (smoking/alcohol use, regular exercise, regular use of drugs, etc.), and emergency and disaster preparedness behaviors. The disaster preparedness of the participants was evaluated through the "Disaster Preparedness Scale," and their health competence skills were evaluated through the "Health Literacy Scale-Short Form ." Questionnaire forms were sent to individuals by creating an online questionnaire.

Disaster Preparedness scale

A 14-item and 4-point Likert-type scale was developed to determine the disaster preparedness level of the general population (1): definitely not; (2): no, (3): yes, (4): absolutely yes. The lowest score obtained from the full scale was 15, and the highest score was 60 point¹⁵.

Short-Form Health Literacy Instrument (HLS-SF)

The "Short-Form Health Literacy Instrument" scale determines health literacy in adults between the ages of 18-65. The Cronbach alpha reliability coefficient of the scale was found to be 0.850. The formula (Index = (Average-1) x 50/3) is used to evaluate the scale. Average is calculated by dividing the scale's total score by the number of items on the scale. The index value calculated by the formula varies

between 0-50, with a higher score indicating better health literacy. Scale; It includes 4-point Likert-type response options ranging from 1 = very difficult to 4 = very easy and consists of 12 items¹⁶. Its Turkish validity and reliability were done in 2021, and the Cronbach alpha coefficient was determined at a high level of 0.856¹⁷.

Statistical analysis

The study data were evaluated using the Mann-Whitney-U test, Kruskal Wallis, and Spearman’s Correlation analysis via the SPSS 22.0 program. The p<0.05 value was considered statistically significant in the evaluations.

Ethical Clearance:

The study was carried out following the Helsinki Principles, and written and verbal consent was obtained from the participants with the Approval of the Non-Invasive Clinical Research Ethics Committee of Hitit University (2022-07).

Results: The study included 270 people with epilepsy who fully and accurately answered all survey questions. Among these participants, 50% were male, and 50% were female socio-demographic characteristics of the participants are presented in Table 1.

Table 1. Frequency distributions of socio-demographics

	Frequency (n)	Percentage (%)
Gender		
Male	135	50,0
Female	135	50,0
Educational status		
≤ Primary level	54	20,0
Secondary level	27	10,0
High school level	99	36,7
University level	90	33,3
Marital status		
Married	135	50,0
Single	135	50,0
Working status		
Working	117	43,3
Not working	153	56,7
Living place		
Rural area	19	7,0
Urban area	251	93,0
Smoking status		
Non user/quiter	207	76,7

	Frequency (n)	Percentage (%)
Current user	63	23,3
Do regular physical activity		
Yes	117	43,3
No	153	56,7
Additional chronic disease		
Had	90	33,3
Had not	180	66,7
Regular use of medications		
Yes	261	96,7
No	9	3,3

The median age was 38 years. The median night sleep time was 7,5 h/day, and the median epilepsy duration was 15 years. The median HLS-SF score was 30, and the median disaster preparedness score was 31 (Table 2).

Table 2. Descriptive statistics

	Mean	SD	Median	Minimum	Maximum
Age (y)	37,2	12,7	38	18	59
Night sleep time (h/d)	7,5	1,7	7,5	4	12
Epilepsy duration (y)	18,3	13,0	15	1	51
HLS-SF12	27,5	11,9	30	0	50
Disaster Preparedness	32,2	3,8	31	26	43

In Table 3, the preparedness of people with epilepsy for emergencies and disasters was questioned. When asked if they knew the triggers of their seizures, 66.7% of the participants answered yes. Despite this, only 6.7% of the participants stated that they had a medical alert wrist/card. The rate of those who answered yes to the question “Do you carry your medicine for at least three days when you leave your home in case of an emergency/disaster?” was 66.7%. When asked if you have identified a family member, neighbor, or friend to assist you in an emergency, 46.7% of the respondents answered yes. Those who answered yes to the question, “Do you have your doctor’s phone number in reserve in case of an emergency?” were 73.3%. Of the participants, 37,4% stated that they know the emergency call number they need to call in case of any emergency.

Table 3. Preparedness of participants for emergencies and disasters

	Frequency (n)	Percentage (%)
Do you know what triggers your seizures?		
Yes	180	66,7
No	90	33,3
Do you carry a medical alert bracelet/card stating that you have epilepsy?		
Yes	18	6,7
No	252	93,3
Do you carry your medicine for at least 3 days when you leave your home in case of an emergency/disaster?		
Yes	180	66,7
No	90	33,3
Have you identified a family member, neighbor or friend to assist you in an emergency?		
Yes	126	46,7
No	144	53,3
Do you keep your doctor's phone number in reserve in case of any emergency?		
Yes	198	73,3
No	72	26,7
Do you know the emergency number you should call in any emergency?		
Yes	101	37,4
No	169	62,6

The median disaster preparedness scores varied by gender ($p < 0,01$) and were 32 for women and 31 for men. The median disaster preparedness score was 31 for married, and it was found to be significantly higher than for singles ($p < 0.05$). The disaster preparedness score was higher among those who lived in the city/district center ($p < 0.01$). The median disaster preparedness score was 31 among those who had regular physical activity, had additional chronic diseases, and took their medications regularly, significantly higher than the other groups ($p < 0.000$). The level of preparedness for disaster did not differ significantly in terms of education, employment, and smoking status ($p > 0.05$) (Table 4).

Table 4. Comparisons socio-demographics by disaster preparedness

	Median (Min-Max) ^a	Test statistics	P
Gender			
Male	31 (26-43)	U:7047	0,001
Female	32 (29-41)		
Educational status			
≤ Primary level	31 (31-37)	$\chi^2:2,727$	0,436
Secondary level	28 (27-38)		
High school level	31 (26-43)		
University level	30,5 (29-41)		
Marital status			
Married	31 (26-36)	U:7816	0,041
Single	28 (27-49)		
Working status			
Working	31 (30-38)	U:7816,5	0,076
Not working	31 (26-43)		
Living place			
Rural area	30 (30-32)	U:1215	0,001
Urban area	31 (26-43)		
Smoking status			
Non user/quiter	31 (26-43)	U:5244	0,073
Current user	31 (30-38)		
Do regular physical activity			
Yes	31 (30-41)	U:6196	0,000
No	27 (26-43)		
Additional chronic disease			
Had	31 (26-43)	U:4941	0,000
Had not	29 (29-43)		
Regular use of medications			
Yes	31 (26-43)	U:81,00	0,000
No	27 (27-27)		

Note: U: Mann-Whitney- U; χ^2 , Kruskal-Wallis test statistics.

^aMin: minimum, Max: maximum.

There was a significant positive correlation between the individuals' age, sleep duration, epilepsy duration, HLS-SF, and disaster preparedness levels ($p < 0.05$). (Table 5).

Table 5. Examination of relationships according to disaster preparedness level

	r	p
Age	0,128	0,036
Night sleep time	0,442	0,000
Epilepsy duration	0,122	0,045
HLS-SF	0,474	0,000

Note: r, Spearman's correlation coefficient.

Discussion:

Although studies have shown that health competence is insufficient in medically vulnerable groups, especially in individuals with epilepsy^{18,19}, studies on health competence in individuals with epilepsy have been limited.^{20,21} On the other hand, health competence affects disaster preparedness in individuals with epilepsy has not been adequately studied. In this study, health competencies and disaster preparedness were low (Table 2). However, it is a pleasing result that the level of disaster preparedness increases with the increase in the health competencies of individuals with epilepsy (Table 5).

Epilepsy is characterized with disturbed neuronal movement behavior, muscle spasms, consciousness loss and convulsions and disease awareness is limited among patients^{22,23}. The present study determined that individuals with epilepsy had weak and inadequate behaviors in terms of preparedness for emergencies and disasters (Table 3). It is vital for people with epilepsy to keep themselves safe in the face of emergencies and disasters and guide those around them on how to help them. The practices that will keep people with epilepsy safe are as follows: knowing the triggers of seizures, using medications regularly, keeping medication with them for at least three days when leaving home, wearing a medical alert wrist/card, keeping the doctor's number in reserve, knowing the emergency call number, and informing the people nearby of their situation⁷.

Disaster effects depend on hazard type and intensity, exposure, levels of vulnerability, preparedness, and coping capacity. In addition to biological factors, resource and structural constraints are the main forces that will increase the impact of disasters on women. Therefore, risk management in disasters is affected by gender dynamics²⁴. Being a woman and being in a medically disadvantaged position can increase women's preparedness for emergencies and

disasters. As a matter of fact, in this study, women with epilepsy are more prepared for disaster than men. (Table 4).

Although there are difficulties in predicting disaster preparedness behaviors according to individuals' marital status in the literature, it is emphasized that the concept of family disaster behavior should be examined²⁵. In this study, married people are more prepared for disaster than single people (Table 4). Such a result suggests that marriage shapes disaster preparedness behaviors as a family member in individuals with epilepsy.

Although disaster preparedness and protective behaviors attract researchers, little research has been done on the differences between the preparedness of rural and urban households²⁶. On the other hand, the status of preparedness against emergencies and disasters according to the areas of people with epilepsy-medically vulnerable groups was taken for the first time in this study. Individuals with epilepsy living in urban areas were more prepared against disaster than those living in rural areas (Table 4). Socio-economic factors can explain such a difference.

Individuals with epilepsy should know how to manage their illness to lead a more active and fulfilling life. In this way, they gain self-management skills related to the disease by controlling their general health and seizures. Self-management strategies include exercising regularly, sleeping 7-8 hours a day, using prescribed medications regularly, and not failing to check with doctors for other health problems²⁷. In this study, individuals with epilepsy, those who do regular physical activity, had adequate night sleep, had comorbidities, and regularly used their medications were more prepared for disaster (Table 4,5).

As the participants' age and duration of epilepsy increased, their preparedness for disaster also increased (Table 5). Years spent with epilepsy can make individuals more sensitive and aware of the disease.

Conclusions:

During a disaster and emergency, medically vulnerable people with epilepsy must be able to meet their particular needs on their own.

Recommendation

The way to develop emergency and disaster

preparedness behaviors is to increase health competencies. Public health professionals should increase efforts to develop self-management strategies in individuals with epilepsy and prepare them for emergencies and disasters. Seminars, workshops, and social media are among the tools to support these efforts.

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Conflict of Interest: None

Ethical clearance: Non-Invasive Clinical Research

Ethics Committee of Hitit University (2022/07).

Authors's contribution:

Data gathering and idea owner of this study: Gulay Yilmazel

Study design: Gulay Yilmazel

Data gathering: Gulay Yilmazel

Writing and submitting manuscript: Gulay Yilmazel

Editing and approval of final draft: Gulay Yilmazel

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