

How Much is SUDEP Known by Patients by Epilepsy?

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Cite this article as: Uçan Tokuç FE, Genç F, Ağdak E, Biçer Gömceli Y. How Much is SUDEP Known by Patients by Epilepsy? *Arch Epilepsy*. 2023;29(4):111-114.



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Received: 12.05.2023 **Accepted:** 22.06.2023 **Publication Date:** 22.11.2023

DOI: 10.4274/ArchEpilepsy.2023.23083



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Abstract

Objective: Sudden unexpected death in epilepsy (SUDEP) is the most common cause of death in patients with epilepsy. The issue of informing every epilepsy patient and/or their relatives about SUDEP remains controversial. We evaluated the level of knowledge about SUDEP in patients with epilepsy.

Methods: Patients were asked whether they knew about seizure risks and wanted to be informed about seizure risks, whether they had heard of SUDEP before and if they did, from whom or where they had heard about it, and seizure triggers. In addition, the patient's relatives were asked about what to do or not to do during the seizure.

Results: We included 80 patients with epilepsy in the study, of which 45 were female (56.2%) and 35 were male (44.8%). Twenty-five (31.2%) patients stated that they had not received any information about epilepsy. Only nine (11.2%) patients stated that they heard about SUDEP, six of them learned from the internet, three from a doctor, two of them said it happened to their relatives, and 69 (86.2%) patients thought that epilepsy patients should definitely be informed about this issue.

Conclusion: Our findings indicate that the level of knowledge about SUDEP among epilepsy patients is quite low. Even though learning SUDEP caused uneasiness in patients, it was observed that patients wanted to learn this information. More efforts should be made to inform patients with epilepsy about epilepsy and its risks and SUDEP.

Keywords: Relatives, seizure risk, Sudden unexpected death in epilepsy, survey

INTRODUCTION

Epilepsy is one of the most common neurological diseases affecting approximately 0.6-1% of the world's population.¹ Epilepsy patients may die unexpectedly without structural or pathological etiology, and this condition is called sudden unexpected death in epilepsy (SUDEP). SUDEP is the most common cause of death in people with chronic epilepsy.² The incidence of SUDEP varies between 0.3 and 9.3 per 1000 people per year in population-based studies.³ Frequent seizures, especially a history of generalized tonic-clonic seizures (GTCS), nocturnal seizures, lack of nighttime supervision, male gender, use of multiple anti-seizure medication (ASM), long epilepsy duration, and being diagnosed with epilepsy at a young age are thought to increase the risk of SUDEP.⁴

Recent studies have shown that knowing about potential risks can prevent accidents, injuries, and therefore the occurrence of SUDEP, as well as increase drug compliance and awareness of triggering factors.⁵ Therefore, training and information given to patients and their relatives are of critical importance. However, the issue of informing every epilepsy patient and/or their relatives about SUDEP remains controversial. In addition, studies conducted under current conditions have pointed out that the rate of physicians discussing SUDEP with patients and their relatives varies between 12% and 30%, and the rate of physicians who never mention SUDEP varies between 7% and 10%, and cultural differences may play a role in attitudes toward counseling about SUDEP.⁶⁻⁸

We aimed to evaluate the level of knowledge about SUDEP and seizure triggers in patients with epilepsy who applied to a tertiary epilepsy center in Turkey, as well as the level of knowledge of patient relatives about behaviors that should or should not be performed during seizures.

METHODS

Between July 2022 and August 2022, patients with epilepsy and their relatives were asked questions about SUDEP and seizures through questionnaires prepared in the University of Health Sciences Turkey, Antalya Training and Research Hospital Epilepsy Outpatient Clinic. The Ethics Committee of University of Health Sciences Turkey, Antalya Training and Research Hospital approved this cross-sectional study (decision no: 14/53, date: 28.07.2022).

Patients and Their Relatives

Patients over the age of 18 years who do not have mental retardation and their relatives were included in the study. Patients without relatives during the outpatient clinic control were not included in the study. An informed consent form was obtained from all patients and their relatives.

Questionnaire

The demographic data of the prepared questionnaires were filled in from their files by the neurologist who followed up. Patients were asked whether they knew about seizure risks (possible answer yes/no), whether they wanted to be informed about seizure risks (possible answer: yes/no), whether they had heard of SUDEP before (possible answer: yes/no), and if they did, from whom or where they had heard (possible answer: doctor/internet/relative/other). Afterwards, the patients were told about SUDEP and asked how they felt learning SUDEP (possible answer: angry/shock/nervous/calm/confidence/courage). Then, the question "Do you think SUDEP should be explained all patients with epilepsy?" was asked. (Possible answer: yes/no). The patients were then asked about seizure triggers (such as adherence to ASM and sleep patterns).

In addition, the patient's relatives were asked about what to do or not to do during the seizure (such as trying to open the mouth during the seizure, trying to control the patient's limbs, trying to feed them).

Statistical Analysis

All statistical analyses were performed using the Statistical Package for the Social Sciences 25.0 software. Categorical variables are described as percentages, and continuous variables are described using mean±standard deviation. Means for continuous variables were compared using independent group t-tests when the data were normally distributed. Categorical variables were analyzed by chi-square and p values of 0.05 or below were considered statistically significant.

MAIN POINTS

- Sudden unexpected death in epilepsy (SUDEP) is the most common cause of death in patients with epilepsy.
- Knowing about potential risks can prevent accidents, injuries, and therefore the occurrence of SUDEP, and increase drug compliance and awareness of triggering factors.
- Our findings indicated that the level of knowledge about SUDEP among patients with epilepsy was very low (18.7%). In addition, even though learning SUDEP caused uneasiness in patients, it was observed that patients wanted to learn this information.

RESULTS

Of the 80 epilepsy patients included in the study, 45 were female (56.2%) and 35 were male (44.8%), with a mean age of 37.6±12.8 years and a mean frequency of seizures of 10.9±8.6 (most frequently every day, seizure-free for at least 3 years). Twenty-six patients (32.5%) had GTCSs ranging from 2 per month to 1 per year while using the available ASM. Twelve patients (15%) had nocturnal seizures. Demographic data of the patients are presented in Table 1.

Twenty-five (31.2%) patients stated that they had not received information about epilepsy and its risks before, whereas 69 (86.2%) patients reported that they wanted to know more. Only nine (11.2%) patients stated that they heard about SUDEP, six of them learned about it from the internet, three from a doctor, and two of them said it happened to their relatives. When asked how learning SUDEP felt after the SUDEP briefing, 36 (45%) patients stated that they felt anxious, 20 (25%) patients stated that they felt safe, five (6.25%) patients said that they felt shocked, and one (1.25%) patient said that they felt angry. When the patients were asked whether SUDEP should be discussed with all epilepsy patients, 11 (13.7%) patients answered no, while 69 (86.2%) patients thought that epilepsy patients should definitely be informed about this issue. The questions asked the patients about SUDEP are summarized in Table 2.

Considering the relationship between age, gender, educational status, frequent GTCS, presence of nocturnal seizures, and long epilepsy duration in patients with knowledge about SUDEP, no statistical significance was observed in our study ($p=0.181, 0.095, 0.076, 0.070, 0.110, 0.092$ respectively).

Table 1. Demographic data of the patients

Characteristics	n	Percent (%)
Gender		
Male	32	40
Female	48	60
Marital status		
Married	51	63.7
Single	29	36.2
Level of education		
Illiterate	2	2.5
Primary education	32	40
High school	28	35
University	18	22.5
Epilepsy type		
Focal	55	68.7
Generalized	20	25
Unknown	5	6.2
GTCS presence	26	32.5
Number of anti-seizure medications		
Monotherapy	55	68.7
2	15	18.7
3 and above	10	12.5

GTCS: Generalized tonic-clonic seizures

In addition, when the relationship between age, seizure frequency, and GTCS frequency was examined in patients who answered yes to the question of whether SUDEP should be explained to epilepsy patients, no statistically significant correlation was observed ($p=0.173$, $p=0.774$, $p=0.675$, respectively), whereas statistical significance was observed with long epilepsy duration ($p=0.035$).

Likewise, in the questionnaires, patients were asked about seizure triggers and the patient's relatives were asked about the dos and don'ts during seizures, and these answers are summarized in Table 3.

DISCUSSION

Our findings indicated that the level of knowledge about SUDEP among patients with epilepsy was very low (18.7%). When the literature is examined, it is observed that these rates vary between 14 % and 34% in accordance with our study.⁵ In a previous study conducted in North America, SUDEP awareness was associated with increased level of education, long epilepsy duration, and being followed by an epileptologist.⁹ In another follow-up study conducted in Germany, an inverse correlation was observed between SUDEP awareness and age.⁵ In our study, no correlation was observed between epilepsy awareness and age, gender, frequent GTCS, presence of nocturnal seizures, and long epilepsy duration, but it was noteworthy that all our patients who had knowledge about SUDEP were under 40 years of age.

One of the most important reasons for this low awareness of SUDEP detected in the literature and in our study is that most neurologists exclude informing patients and their relatives about

SUDEP in their daily medical practice. In a previous study in which multicenter and pediatric neurologists participated, it was questioned whether physicians gave information about SUDEP to their patients and/or their relatives, and it was observed that 2% of physicians informed all their patients and 8% frequently informed them.¹⁰ In a similar study conducted in Canada, 6.8% of the neurologists who participated in the study stated that they always provided information, while 11.6% of the physicians stated that they never provided information.⁸ It was stated that the reason for the tendency to not give information by physicians was the anxiety it would cause on patients, and indeed, the first reaction detected in these studies was fear and anxiety between 40 % and 60%.

During our study, when patients were asked if they wanted to have information about the risks of epilepsy, 86.2% of the patients said they wanted to be informed. All patients were told about SUDEP, and when asked whether SUDEP should be explained to all epilepsy patients, 89 patients (86.2%) stated that they should be explained. When asked how they felt, 45% of the patients stated that they felt anxious. The conclusion we can draw from this is that learning about the presence of SUDEP may indeed cause anxiety in some patients. However, despite this anxiety, a high majority of patients stated that SUDEP should be explained.^{7,8,10}

In our study, in support of other studies, although 45% of the patients who received detailed information about SUDEP stated that they felt anxious, despite the feeling of uneasiness, the majority of patients (86.2%) stated that all patients should be informed about this issue. In addition, in several previous studies, the effects on patients were investigated months after SUDEP was explained, and it has been shown that it did not have significant effects on the quality of life of patients or their relatives.^{11,12}

The practice guidelines of the American Academy of Neurology and the American Epilepsy Society also recommend that clinicians should warn adult patients with epilepsy to talk about SUDEP and exercise due care. However, to regress the anxiety that will occur in patients, it is recommended to inform the patients that SUDEP

Table 2. Questions asked to the patients about SUDEP

Questions	Answers	n (%)
Have you ever heard about epilepsy and its risks?	Yes	60 (75)
	No	20 (25)
Would you like to know more?	Yes	69 (86.2)
	No	11 (13.7)
Have you heard of SUDEP before?	Yes	15 (18.7)
	No	65 (81.2)
From whom?	Doctor	3 (20)
	Internet	6 (40)
	Other	6 (40)
When?	When the first diagnosis is made	4 (26.6)
	When seizures become frequent	4 (26.6)
	Other	7 (46.7)
How did you feel when you learned of the existence of SUDEP?	Angry	1 (1.2)
	Shock	5 (6.2)
	Anxious	36 (45)
	Calm	16 (20)
	Safe	20 (25)
Should all patients be told about SUDEP?	Courage	2 (2.5)
	Yes	67 (83.7)
	No	13 (16.2)

SUDEP: Sudden unexpected death in epilepsy

Table 3. Questions asked to the patients and the relatives

To the patients	Answers	n (%)
Epilepsy patients should sleep 7-7.5 hours if possible. Insomnia is a trigger for seizures	Yes	77 (96.3)
	No	3 (3.7)
A low level of anti-seizure medication for any reason is an important seizure trigger (adherence to the medications, medications change)	Yes	61 (76.2)
	No	19 (23.7)
Some antibiotics and medications can trigger seizures	Yes	50 (62.5)
	No	30 (37.5)
To the relatives	Answers	n (%)
It is correct to try to open one's mouth during a seizure to make it easier to breathe	Yes	25 (31.3)
	No	55 (68.7)
Is it right to block or try to stop the movement of the patient's limbs during a seizure?	Yes	14 (17.5)
	No	66 (82.5)
It is recommended to give water, food and even coffee to speed up the recovery of the patient after the seizure.	Yes	3 (3.8)
	No	77 (96.2)
Any convulsive seizure lasting longer than 5 minutes is indicative to call the emergency services.	Yes	72 (90)
	No	8 (10)

typically affects 1 in 1000 adult patients with epilepsy per year, and therefore 999 patients are not affected.¹³

In a recent multicenter study, it was observed that there was no increase in the depression and anxiety levels of the patients after SUDEP information, and it was argued that SUDEP training should be included in standard epilepsy training. In addition, in this study, it was observed that compliance with ASM increased with SUDEP training.¹⁴

As observed in our study, the majority of patients who have information about SUDEP access this information mostly from the internet. It is obvious that with the increase in internet use, the young population gains more information. Therefore, in our opinion, it will be more reliable for patients to access this information from the doctor instead of having information from the internet and will increase the patient's trust in the doctor. We believe that this will also increase the patient's compliance with ASM.

In addition, in our study, we received a significant amount of incorrect answers to the questions we asked the patients about seizure triggers and the questions we asked the relatives of the patients about the situations that should not be done during the seizure. Explaining SUDEP effectively to patients and their relatives can help them pay more attention to seizure triggers (such as lifestyle, sleep hygiene, regular use of ASM) and to draw attention to what the patient's relatives can do during the seizure.

Study Limitations

Our prospective study has several limitations. Although our study was conducted in an epilepsy center where high-level refractory epilepsy patients were followed, many patients with refractory seizures were excluded from the study because of mental retardation. Therefore, in our study population, there were relatively few patients with refractory epilepsy. In addition, all questions were asked to the patients in the presence of their relatives. The patients may not have expressed their feelings clearly because they are afraid of their relatives or in order not to disturb them. Furthermore, because the study was conducted in a tertiary hospital, patients with more frequent and severe seizures were more likely to be more common than the general population. Therefore, it is difficult to generalize the results to a larger epilepsy population.

CONCLUSION

In conclusion, our findings indicate that the level of knowledge about SUDEP among epilepsy patients is quite low. In addition, even though learning SUDEP caused uneasiness in patients, it was observed that patients wanted to learn this information. Therefore, more efforts should be made to inform patients with epilepsy about epilepsy and its risks and SUDEP.

Ethics

Ethics Committee Approval: The Ethics Committee of University of Health Sciences Turkey, Antalya Training and Research Hospital approved this cross-sectional study (decision no: 14/53, date: 28.07.2022).

Informed Consent: Written informed consent forms were obtained from all patients.

Peer-review: Externally peer-reviewed.

Authorship Contributions

Concept: F.E.U.T., F.G., Y.B.G., Design: Y.B.G., Data Collection or Processing: F.E.U.T., F.G., E.A., Analysis or Interpretation: F.E.U.T., Y.B.G., Literature Search: F.E.U.T., E.A., Writing: F.E.U.T.

Conflict of Interest: No conflict of interest was declared by the authors.

Financial Disclosure: The authors declared that this study received no financial support.

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