

# Determining the Level of Knowledge and Awareness of the Term Sudden Unexpected Death in Epilepsy Among Healthcare Professionals

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## Abstract

**Objective:** Sudden and unexpected death is a serious condition seen in patients with epilepsy. This study aimed to determine the level of awareness and knowledge of the term “sudden unexpected death in epilepsy (SUDEP)” among healthcare professionals.

**Methods:** The study was conducted with 376 healthcare professionals working in a university hospital in Türkiye between May-July 2025. Data were collected through face-to-face interviews using a data collection form that the researchers developed based on a literature review.

**Results:** The majority of participants were physicians and nurses. The majority of healthcare professionals provided care/treatment support to epilepsy patients. Only 12.2% of participants were aware of the term SUDEP, while 8.5% stated that it meant “SUDEP patients.” Participants indicated that they heard this term most often at a symposium or conference and during their undergraduate or postgraduate training. A statistically significant difference was found between the preference for providing information to patients about SUDEP and the average age and occupational groups of individuals ( $p<0.001$ ;  $p=0.031$ ).

**Conclusion:** Although healthcare professionals have a high rate of providing care/treatment to epilepsy patients, their awareness and understanding of SUDEP are quite low. It is recommended that the curriculum be revised in undergraduate and postgraduate training to increase awareness and understanding of this term among healthcare professionals, that the literature be enriched with case studies, and that sessions or topics on epilepsy and its complications be included in congresses, symposia, and conferences.

**Keywords:** Epilepsy, sudden unexpected death in epilepsy, awareness, nursing

## INTRODUCTION

Patients with epilepsy are considered a population at high risk for premature mortality. Deaths associated with epilepsy may arise from a wide range of causes, both related and unrelated to epilepsy. The literature identifies seizure-related injuries, motor vehicle or bicycle accidents, adverse effects of antiepileptic drugs, aspiration pneumonia, drowning, and status epilepticus among the causes of epilepsy-related mortality.<sup>1</sup> Sudden unexpected death in epilepsy (SUDEP) is a significant cause of mortality among patients with the disorder. SUDEP is defined as a sudden, unexpected death in individuals with epilepsy that is not attributable to trauma, drowning, status epilepticus, or other known causes, but is often associated with evidence of a recent seizure.<sup>2,3</sup> Death may occur suddenly and unexpectedly, either witnessed or unwitnessed. The absence of anatomical or toxicological findings that could explain the cause of death on postmortem examination is also a key feature. Reports indicate that, in a large proportion of cases, patients are found prone in bed and deaths are most often unwitnessed. The prone position at death is considered indicative of a recent seizure followed by the development of respiratory failure.<sup>4</sup> The incidence of SUDEP has been reported as 0.81% in the general population and 1.16% among individuals diagnosed with epilepsy, ranking as the second leading cause of epilepsy-related mortality after stroke.<sup>5,6</sup> In Denmark, the incidence of SUDEP in patients aged 18-49 is 1.21 per 1000 people/year.<sup>7</sup>

Several studies have demonstrated that the level of awareness of SUDEP, which represents a critical risk factor for patients with epilepsy and their families, is lower than expected among healthcare professionals.<sup>8-10</sup> However, healthcare professionals' knowledge of the significance of SUDEP, its risk factors, and preventive strategies is essential for providing effective counseling to patients and their families and enabling the modification and management of potentially preventable risks.<sup>11</sup> The most important components of SUDEP counseling include an adequate level of knowledge, effective communication skills, and a multidisciplinary approach. Comprehensive epilepsy care should be delivered through collaboration among neurologists, epilepsy nurses, primary healthcare providers, and other relevant healthcare professionals.<sup>12</sup> From a broader perspective, professional expertise and nursing care play a central role in reducing the incidence of SUDEP and in ensuring safer living conditions for patients. A review of the literature indicates that most studies have focused on evaluating awareness of SUDEP among patients with epilepsy and their relatives,<sup>13-16</sup> whereas studies examining the awareness of healthcare professionals regarding this issue are limited.<sup>8-10</sup> In this context, this study was designed to assess knowledge and awareness of SUDEP among healthcare professionals.

## METHODS

### Study Desing

This study was conducted using a cross-sectional, descriptive design. Data were collected through face-to-face interviews with 376 healthcare professionals working at a university hospital in Türkiye between May and July 2025. Based on a literature review, the researchers developed a data collection form consisting of 13 questions (1, 4, 6, 9, 10-13). Inclusion criteria were: being 18 years of age or older and working as a physician, nurse, paramedic, etc., at the hospital where the study was planned. Exclusion criteria were having serious visual, reading, or writing problems, or refusing to consent to participate in the study. The first section covered sociodemographic characteristics and the second section addressed SUDEP-related information. On average, it took 10 minutes to complete the questionnaire. The sample size was calculated using G\*Power version 3.1 software, based on a 5% margin of error (95% confidence level), 95% statistical power, and a standardized effect size of 0.33. The power analysis indicated that a minimum of 120 participants was required. To further increase the study's statistical power, 376 healthcare professionals were included.

### Statistical Analysis

The collected data were analysed using SPSS version 20. The Kolmogorov-Smirnov test was used to assess the distribution of continuous variables. Descriptive statistics were presented as the

mean and standard deviation. The Mann-Whitney U test and chi-squared test were used to compare groups. A p-value of less than 0.05 was considered statistically significant.

Approval was obtained from the Balıkesir University Health Sciences Non-Interventional Research Ethics Committee (approval no: 2025/204, date: 16.05.2025), and institutional permission was obtained from Balıkesir University Health Practice and Research Hospital. Written informed consent was obtained from all participants. The study was conducted in accordance with the principles of the Declaration of Helsinki.

## RESULTS

The mean age of the participants was 38.21±12.6 years, and 52.9% were male. The majority of participants were physicians and nurses. Most participants were working in intensive care units (39.4%), followed by internal medicine departments (19.7%) and emergency departments (11.7%). The mean duration of professional experience was 8.77±8.5 years (Table 1).

When asked whether they had ever provided treatment or care for patients with epilepsy, 65.7% of participants reported that they had. Only 12.2% of participants stated that they were familiar with the term SUDEP, and 8.5% correctly defined it as "SUDEP patients." Participants reported that they most commonly encountered the term SUDEP at a symposium or conference (6.4%) and during undergraduate or postgraduate education (2.9%). When asked about their knowledge of SUDEP risk factors, 91.2% of participants reported no knowledge, whereas 5.8% identified nocturnal and frequent seizures as risk factors.

Regarding providing information about SUDEP to patients with epilepsy, 78.4% of participants stated that patients should be informed. The main reasons cited were that providing information would increase patients' or caregivers' attentiveness to the disease (43.6%), and that receiving such information is a legal right of patients (21.0%) (Table 2).

When examining the association between participants' sociodemographic characteristics (age, sex, professional group, and years of professional experience) and their awareness of SUDEP, no statistically significant differences were observed with respect to having known of the term SUDEP. However, a statistically significant difference in the preference for providing SUDEP-related information was found according to mean age ( $p<0.001$ ). In addition, a significant association was observed between professional group and the preference for providing information about SUDEP ( $\chi^2=8.905$ ;  $p=0.031$ ) (Table 3).

A statistically significant difference was found in healthcare professionals' attitudes toward providing information about SUDEP. Further analysis showed that physicians' attitudes towards providing information (41.2%) were significantly higher than those of midwives (10.5%) ( $p<0.05$ ). Upon examination (adjusted residual 2.6), physicians' tendency to provide information was above the expected value, whereas midwives' opposition to providing information (34%) was higher than the overall average (21.8%), showing a trend contrasting with that of physicians. Nurses and paramedics occupied an intermediate position between the two extreme attitudes (Table 3).

### MAIN POINTS

- Patients with epilepsy are at risk of sudden unexpected death in (SUDEP).
- Healthcare professionals need information on SUDEP in epilepsy.
- There is no consensus on how to educate patients about SUDEP.
- There is a need for guidelines regarding patient education on SUDEP.

**Table 1.** Sociodemographic characteristics of participants and their opinions regarding SUDEP

		Mean ± SD	min-max
Age (years)		38.21±12.6	22-65
Years of professional experience (years)		8.77±8.5	1-44
		n	%
Sex	Female	177	47.1
	Male	199	52.9
Health professional	Physician	142	37.8
	Nurse	112	29.8
	EMT/paramedic	75	19.9
	Midwife	47	12.5
Department	Intensive care units (neonatal, CVS, anesthesia, coronary)	148	39.4
	Internal medicine units (cardiology, pulmonology, PMR, neurology, infectious diseases)	101	26.9
	Emergency department	74	19.7
	Surgical units (ENT, urology, orthopedics, operating room, obstetrics, gynecology, plastic surgery)	44	11.7
	Other (medical biochemistry, radiology, pediatrics)	9	2.4
Providing care/treatment to a patient diagnosed with epilepsy	Yes	247	65.7
	No	129	34.3
Awareness of the term “SUDEP”	Yes	46	12.2
	No	330	87.8
Source of information about SUDEP	I have no information	337	89.6
	Symposium/conference	24	6.4
	Undergraduate/specialization training	11	2.9
	Academic article	2	0.5
	Social media	1	0.3
	Patient/treatment experience	1	0.3
What does the term “SUDEP” mean to you?	I have no information.	338	89.9
	Sudden unexpected death in epilepsy patients.	32	8.5
	Recurrent seizures.	5	1.3
	Defecation/mixing during seizures.	1	0.3
What do you think are the risk factors for “SUDEP”?	I don't know	343	91.2
	History of nocturnal seizures	11	2.9
	Frequent seizures (more than 13 seizures per year)	11	2.9
	Medication/treatment non-compliance	7	1.9
	Other*	4	1.2
Total		376	100

\*Use of more than three antiepileptic drugs, male gender, seizure onset age between 0-15 years, and epilepsy diagnosis more than 15 years ago. CVS: Cardiovascular surgery, PMR: Physical medicine and rehabilitation, ENT: Ear nose throat, EMT: Emergency medical technician, SUDEP: Sudden unexpected death in epilepsy, min: Minimum, max: Maximum, SD: Standard deviation

**Table 2.** Participants’ opinions on providing information about SUDEP

Question	Response	n	%
Should patients with epilepsy be informed about SUDEP? (n=376)	Yes, information should be provided.	294	78.4
	No, information should not be provided.	82	21.6
Epilepsy patients should be informed about SUDEP because; ..... (n=299)	Patients/caregivers would be more attentive to treatment and care.	164	43.6
	It is the patient’s legal right to be informed about the consequences of the disease.	79	21.0
	Patients/caregivers should be informed about risks at the time of diagnosis.	56	14.9
Epilepsy patients should not be informed about SUDEP because; ... (n=78)	It can cause unnecessary fear/anxiety in the patient.	35	44.9
	It can increase the frequency of seizures in the patient.	21	26.9
	It can cause non-compliance with medication and treatment in the patient/relative.	18	23.1
	It can prevent the patient from coping with their illness.	4	5.1

SUDEP: Sudden unexpected death in epilepsy

**Table 3.** Association between participants’ demographic and professional characteristics and SUDEP awareness and preference for informing patients (n=376)

Variable	Heard of SUDEP (mean ± SD)	Not heard of SUDEP (mean ± SD)	p-value	Provide information (mean ± SD)	Do not provide information (mean ± SD)	p-value
Age (year)*	39.57±12.32	38.02±12.7	0.38	36.86±12.10	43.06±13.53	<0.001
Professional experience (years)*	9.53±8	8.66±8.5	0.34	8.04±7.64	11.40±10.75	0.084
Sex**						
Female	22 (12.4)	155 (87.6)	0.96	136 (46.3)	41 (50.0)	0.548
Male	25 (12.6)	174 (87.4)		158 (53.7)	41 (50.0)	
Health professional**						
Nurse	20 (17.9)	92 (82.1)	0.14	86 (29.3)	26 (31.7)	0.031
Physician	16 (11.3)	126 (88.7)		121 (41.2) <sup>a</sup>	21 (25.6)	
EMT/paramedic	5 (6.7)	70 (93.3)		56 (19.0)	19 (23.2)	
Midwife	6 (12.8)	41 (87.2)		31 (10.5) <sup>b</sup>	16 (19.5)	

Note: Values in the same column with different superscripts (a, b) are significantly different according to Bonferroni-corrected column proportion comparisons (p<0.05). \*Mann-Whitney U test, \*\*Chi-square test, EMT: Emergency medical technician, SUDEP: Sudden unexpected death in epilepsy, SD: Standard deviation

**DISCUSSION**

This study found that, although most healthcare professionals care for patients with epilepsy, their awareness of and understanding of SUDEP is limited. Only a small proportion of participants were familiar with the term and could correctly identify its risk factors. These results are consistent with those of previous studies which have reported generally low levels of SUDEP awareness among healthcare professionals.<sup>8-10,17</sup>

In the present study, 78.4% of healthcare professionals stated that patients with epilepsy should be informed about SUDEP. International guidelines similarly recommend that SUDEP counseling should be provided at the time of diagnosis or during a consultation when the patient is deemed ready to receive such information.<sup>18-21</sup> In this study, physicians were most likely to provide information about SUDEP. In the United Kingdom, nurses are reported to be the professional group most frequently discussing SUDEP with patients.

This is because the United Kingdom has teams of nurses who specialise in epilepsy, and they play an important role in SUDEP counselling. In Norway and Türkiye, however, SUDEP counselling is considered the responsibility of physicians. It is thought that the high tendency of physicians to provide information on SUDEP in this study reflects this result.<sup>19</sup>

A study conducted in Germany revealed that 27% of patients had never heard of SUDEP; and one-third stated that they had not been informed by their physicians about any risk factors, morbidity, or mortality causes.<sup>16</sup> In one study involving 1123 neurologists from 27 countries, 41.5% were more hesitant to discuss SUDEP (surgical and clinical epilepsy-related education). Experts specializing in epilepsy, however, showed a higher level of awareness regarding the provision of information. This research shows that epilepsy is a specialized field requiring advanced knowledge and expertise. Providing care to epilepsy patients by specialists working in this field will closely affect both the disease and patient compliance.<sup>22</sup>

Whether or not to disclose information about SUDEP to patients remains a topic of ongoing debate.<sup>11</sup> In the present study, 21.6% of healthcare professionals opted not to provide information about SUDEP. Previous studies have also reported that healthcare professionals may be reluctant to discuss SUDEP due to concerns that such discussions could cause patient distress, anxiety, anger, fear or a decline in quality of life.<sup>23-25</sup> However, studies conducted with patients have shown that, while receiving information about SUDEP may initially cause discomfort, patients generally want to be informed about this risk.<sup>24,26</sup> Contrary to these views, it has been reported that early information does not increase depressive symptoms or anxiety. Furthermore, it has been added that epilepsy patients who are satisfied with receiving information do not experience negative effects on their overall health, quality of life, stigma, or seizure anxiety.<sup>27</sup>

This study found that healthcare professionals who preferred not to inform patients about SUDEP were older on average. Consistent with this finding, other studies have demonstrated that older physicians tend to avoid discussing SUDEP. Multivariate analyses have indicated that factors such as educational level, clinical experience and involvement in the treatment of patients with epilepsy also influence attitudes towards SUDEP counselling, in addition to age.<sup>23</sup> The literature suggests that reluctance to engage in SUDEP counselling is associated with clinical seniority and concerns about inducing anxiety in patients.<sup>11,23</sup> It has been suggested that insufficient experience and educational needs may contribute to hesitation in discussing epilepsy-related risks.<sup>12</sup> Conversely, younger healthcare professionals may be more inclined to provide information about SUDEP, as they are more likely to have received training through updated curricula and programmes, and to be familiar with recent guidelines and research findings.

It is thought that midwives' tendency to care for more female patients and to see fewer patients with epilepsy may have influenced their information-giving tendencies. Physicians, on the other hand, may be more willing to provide information regarding medical diagnoses as part of their professional duties. The negative tendency of midwives not to provide information and the positive tendency of physicians to provide information may both stem from this.

### Study Limitations

The research was conducted at a single center and within a limited time frame.

### CONCLUSION

The findings of this study demonstrate that although healthcare professionals are highly involved in the care and treatment of patients with epilepsy, their awareness and understanding of SUDEP remain limited. This gap indicates a critical unmet need for knowledge that may directly affect patient safety. To address this deficiency, it is recommended that SUDEP-related content be incorporated into undergraduate and postgraduate curricula, that interactive and problem-based learning approaches be implemented, and that continuing professional development programs supported by seminars and online training be expanded. In addition, increasing the number of SUDEP-focused awareness sessions at scientific meetings and establishing standardized national guidelines for clinical practice are strongly recommended. Collectively, these

strategies can enhance healthcare professionals' knowledge and awareness, thereby reducing preventable risks for patients with epilepsy and significantly improving the quality and safety of care.

### Ethics

**Ethics Committee Approval:** Approval was obtained from the Balikesir University Health Sciences Non-Interventional Research Ethics Committee (approval no: 2025/204, date: 16.05.2025), and institutional permission was obtained from Balikesir University Health Practice and Research Hospital.

**Informed Consent:** Written informed consent was obtained from all participants. The study was conducted in accordance with the principles of the Declaration of Helsinki.

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### Footnotes

### Authorship Contributions

Surgical and Medical Practices: B.C.K., T.Ç., B.F., Concept: B.C.K., T.Ç., B.F., Design: B.C.K., T.Ç., B.F., Data Collection or Processing: B.F., Analysis or Interpretation: B.C.K., T.Ç., Literature Search: B.C.K., T.Ç., Writing: B.C.K., T.Ç., B.F.

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