

Contents lists available at [ScienceDirect](https://www.sciencedirect.com)

Seizure: European Journal of Epilepsy

journal homepage: www.elsevier.com/locate/seizure

Sudden unexpected death in epilepsy: A pilot study on neurologists' knowledge and experience in the Eastern Mediterranean region

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ABSTRACT

Background- Sudden unexpected death in epilepsy (SUDEP) is an important concern in patients with epilepsy who are otherwise healthy. Current knowledge of SUDEP and attitudes of neurologists in the Eastern Mediterranean Region (EMR) towards discussing SUDEP with their patients remain unknown.

Objective- We aimed at assessing knowledge, attitudes and factors affecting SUDEP discussion practices of neurologists practicing in the EMR.

Methodology- An electronic and paper-based survey was sent to 350 neurologists practicing in the EMR. They were questioned about the frequency, timing, and factors affecting their willingness to initiate SUDEP discussion. We also included questions about perceived patient reactions towards SUDEP discussions and neurologists' preferred way to provide SUDEP information to their patients.

Results- We received 132 responses from the 350 surveys sent out (response rate 37.7%). Our results showed that only 1.5% of the neurologists discussed SUDEP with "most" of their patients and their caregivers while 55.3% "rarely" or "never" discussed it. Factors such as additional epilepsy training and more years of clinical experience did not significantly affect the frequency of SUDEP discussion ($p = 0.329$, $p = 0.728$). A significant negative association between the number of patients seen per year and the frequency of SUDEP discussion was seen ($P = 0.046$). Based on their selection of known risk factors, 81% of neurologists were considered as having insufficient knowledge of SUDEP. The top three perceived reactions by the neurologists on SUDEP discussion were distress (74.2%), anxiety (70.5%) and depression (65.9%). Most neurologists initiated SUDEP discussion by themselves and preferred brochures/pamphlets, websites and training sessions to provide SUDEP information.

Conclusion- Neurologists in the EMR rarely discuss SUDEP, and have limited knowledge about its risk factors. Upon discussing SUDEP, they overwhelmingly receive negative reactions but not always. Based on our findings, we believe an unintended knowledge gap exists on part of the neurologists. This, coupled with a lack of trained epilepsy nurses and patient education material in regional languages can also be attributed to poor SUDEP discussion practices in the EMR.

Introduction

Epilepsy is one of the most common neurological disorders in the world, affecting approximately 0.6–1% of the global population [1]. In the Eastern Mediterranean Region (EMR), which includes a range of twenty-two low to high-income countries, it is estimated that 4.7 million people have the disorder (2), indicating that epilepsy is a major public health concern in this part of the world as well. It is estimated that in low and middle-income countries (LMICs), the mortality rate in people with epilepsy is 2.6-fold higher than that of the general population (range 1.3–7.2). The estimated overall incidence of epilepsy is also higher in LMICs than in high-income countries (HICs) (incidence rate ratio: 1.8) [3].

Several causes of death during epilepsy are reported, either direct epilepsy-related or underlying etiology-related. However, sudden unexpected death in epilepsy (SUDEP) is one of the leading [4] and most

common [5] direct epilepsy-related causes of death. The Center for Disease Control and Prevention (CDC) defines SUDEP as the death of a person with epilepsy not caused by an injury, drowning, or an otherwise discernable reason [6]. SUDEP is more common among patients with refractory epilepsy and potential candidates for epilepsy surgery [7]. Known risk factors of SUDEP include poor seizure control through the use of antiepileptic drugs (AEDs), higher seizure frequency, longer disease duration, and early onset of epilepsy [8]. Generalized tonic-clonic seizures have been also found to be a leading risk factor, although other studies have had inconclusive findings when it comes to the exact causal factors of SUDEP [9,10]. SUDEP is undeniably a cause of concern for neurologists all over the world.

Guidelines for clinical practice from the United Kingdom (UK) [11] and Scotland [12] recommend that all patients should be counseled about SUDEP regardless of individual risk factors involved, whereas some studies suggest bringing up SUDEP discussion based on individual

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<https://doi.org/10.1016/j.seizure.2021.11.011>

Received 18 September 2021; Received in revised form 25 October 2021; Accepted 18 November 2021

Available online 24 November 2021

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risk factors to avoid unwarranted patient distress [13]. Studies in the Western region have looked at the frequency of SUDEP discussion between practitioners and patients, and other questions surrounding the disclosure of SUDEP when counseling patients [14–19]. Their findings generally indicate that the majority of practitioners do not counsel patients on SUDEP. This was correlated to the general reaction perceived by the physician when discussing SUDEP [15].

To date, there are no agreed-upon universal SUDEP discussion guidelines. Similarly, there is no regional or national accepted consensus or guidelines for SUDEP discussion among the neurology community in the EMR. At the time of our study, no previous studies had been done in the EMR to assess neurologists' knowledge about SUDEP. Therefore, we aimed at exploring SUDEP discussion practices among neurologists in the region, which might increase the awareness of SUDEP, related clinical risk factors, and possible perceived reactions that might influence SUDEP discussions.

Methodology

We prepared a modified survey using a questionnaire previously developed by Friedman et al. [18], adapted for participants from the EMR. The electronic and paper-based version of the survey was given to all members of the Emirati League Against Epilepsy (UAE Epilepsy Chapter), the Neuroscience Forum in the Gulf region, the Egyptian Pediatric Neurology Forum, and at the 6th UAE Epilepsy Congress held in 2018. Due to the varying nature of the groups given access to this survey, the total number of neurologists asked to participate in this study was estimated by adding all the neurologists in the different groups, and was approximated to 350 people. The electronic version of the survey was available on surverymonkey.com and reminders to complete the survey were sent at the 2 and 3-week mark via email. The informed consent form was solicited from each participant prior to filling out the survey questions. A copy of the survey is available in Appendix. Participants were only allowed to fill the questionnaire once. The study was granted ethics approval by the Institutional Review Board at the American Center for Psychiatry and Neurology, Abu Dhabi, UAE.

The survey was conducted over three months, between October 2018 and December 2018. It included participants' demographic information such as gender, age, current clinical position held, country of training and country of current practice. We looked into their type of practice (adult and/or child neurology, academic versus private), years of practice (0–5, 5–10, 10–15 or >15), the approximate number of patients with epilepsy seen per year (1–10, 11–20, 21–50, 51–100, or >100) and if they had additional training in epilepsy.

In the questionnaire, the participants were provided with the definition of definite and probable SUDEP according to Nashef 2012 [20]. Their clinical knowledge about SUDEP was assessed by asking them to identify known SUDEP risk factors. They were given seven clinical factors to select from, four correct answers with high confidence intervals and three incorrect answers with low confidence intervals based on the risk factors identified by the AAN/AES practice guideline [21]. Correct answers included “treatment with 3 or more antiepileptic drugs (AEDs)”, “lack of AED therapy”, “recent generalized tonic-clonic seizures” and “childhood-onset epilepsy”, while the incorrect answers included “nocturnal complex partial seizures”, “electrocardiogram showing QTC at the upper limit of normal” and “sleeping with two or more pillows”. The participant's scores were calculated based on the scoring method used by Friedman et al. [18]. The total score possible for this question was between –3 (selection of three incorrect answers) up to 4 (selection of four correct answers). Participants who were able to identify 2 or more correct risk factors (a score of 2 or above) were considered to have sufficient SUDEP knowledge.

Participants were asked to indicate the number of pediatric (<18 years) or adult (>18 years) patients, who in their experience, had encountered definite or probable SUDEP during the last 24 months. The frequency and timing of SUDEP discussion by the participants was

assessed by asking how often they discussed SUDEP with patients and/or their caregivers, and at what stage of treatment the discussion was initiated.

Participants who had indicated that they followed patients with epilepsy were asked to choose from a given list which clinical factors prompted them to discuss SUDEP with their patients and/or their caregivers. If participants indicated age to be a deciding factor whether to discuss SUDEP or not, they were asked to indicate which age group they chose to discuss it with (0–8, 9–16, 17–21, 22–54 or >55 years). They were also asked to indicate who discussed SUDEP with patients and/or their caregivers in their clinical practice (participants themselves, nurses, counselors, any other).

Participants who discussed SUDEP during their practice were then questioned about their perceived reactions from patients and caregivers. They were asked to choose the top three perceived reactions from a list of options. These included positive (relief, appreciation), neutral (indifference) and negative (distress, anxiety, depression) reactions. Participants were given a list of reasons to choose from for not discussing SUDEP and to indicate whether or not they believed that having knowledge about SUDEP would improve AED compliance in patients. Lastly, participants indicated which tools they would use for their patients and/or caregivers to support their SUDEP discussion.

Statistical analysis

Using the IBM Statistical Package for the Social Sciences software (SPSS version 20.0, IBM, USA), we used descriptive analysis of the frequencies and percentages to determine the demographics of the participants, discussion practices such as frequency and factors related to SUDEP discussion, timing and perceived patient reactions. Association between neurologists' experience-based factors such as additional epilepsy training, years of practice and number of patients seen per year, and SUDEP discussion frequency was examined through univariate analysis. A Chi-square test was performed for categorical data to observe an association between the same.

Results

Profile of the participants

Approximately 350 physicians were contacted, out of which 132 completed the survey (response rate 37.7%). The responses were comparable in terms of gender and current clinical practice (child versus adult neurologist). More than half (65.2%) of the participants were practicing in the government sector and a third (31.8%) had additional training in epilepsy. Nearly half of the participants (49%) had 10 or more years of clinical practice. The majority of responses were received from neurologists practicing in the following countries - United Arab Emirates (UAE) (26.5%), Kingdom of Saudi Arabia (KSA) (23.5%), and Egypt (14.4%). The rest of the responses were received from various other countries in the EMR like Jordan, Iraq, Syria, Kuwait, and Pakistan. A majority of participants (76.5%) treated 51 or more patients with epilepsy in any given year. There was no relationship found between the “skipped” data and any values, observed or missing. Detailed information of the participants is outlined in [Table 1](#).

Validating participant's knowledge about SUDEP

Based on the correct selection of 2 or more SUDEP risk factors in the questionnaire, 19% of the participants were considered as having sufficient knowledge about SUDEP. The remaining 81% had a score of less than 2 on the SUDEP knowledge scale, indicating insufficient knowledge as outlined in [Fig. 1](#). The most frequently correctly identified risk factor was “treatment with 3 or more AEDs” (84.8%) while “childhood-onset epilepsy” was the least correctly identified as a risk factor (28.8%). Details about the different possible answers and their frequency of

Table 1
Profile and clinical practice of the participants.

Characteristic		N (total = 132)	%	
Gender	Male	77	58.3	
	Female	55	41.7	
Age	25–34	20	15.2	
	35–44	47	35.6	
	45–54	40	30.3	
	55–64	19	14.4	
	65–74	6	4.5	
Current clinical practice	Child neurologist	76	57.6	
	Adult neurologist	56	42.4	
Additional training in Epilepsy		26	19.7	
Type of practice	Academic Practice	25	18.9	
	Private Practice	21	15.9	
	Government practice	86	65.2	
Number of years in practice	0 – 5	45	34.1	
	5 – 10	22	16.7	
	10 – 15	21	15.9	
	>15	44	33.3	
Country of training	Skipped (Unknown)	34	25.7	
	United Kingdom	26	19.6	
	Egypt	20	15.2	
	Sudan	11	8.3	
	USA	11	8.3	
	KSA	8	6.1	
	Canada	4	3.0	
	Iraq	4	3.0	
	Pakistan	4	3.0	
	France	2	1.4	
	Kuwait	2	1.4	
	Austria	1	0.8	
	Ireland	1	0.8	
	Jordan	1	0.8	
	South Africa	1	0.8	
	UAE	1	0.8	
	Yemen	1	0.8	
	Country of current clinical practice	United Arab Emirates	35	26.5
		Kingdom of Saudi Arabia	31	23.5
		Egypt	19	14.4
Unknown (from the EMR)		13	9.8	
Jordan		5	3.8	
Pakistan		5	3.8	
Iraq		4	3.0	
Syria		4	3.0	
Kuwait		3	2.3	
Qatar		3	2.3	
Sudan		2	1.5	
Tunisia		2	1.5	
Libya		2	1.5	
Lebanon		1	0.8	
Yemen		1	0.8	
Bahrain		1	0.8	
Morocco		1	0.8	
Number of patients with epilepsy seen per year		1–10	6	4.5
		11–20	11	8.3
		21–50	14	10.6
	51–100	35	26.5	
	>100	66	50.0	

selection are outlined in Table 2.

Experience with SUDEP and factors affecting frequency of SUDEP discussion

During the past 24 months of clinical practice, 18% of participants came across a patient with definite or probable SUDEP, of which they reported a total of 10 deaths among adults and 35 among children with epilepsy.

Among our participants, there was no significant association

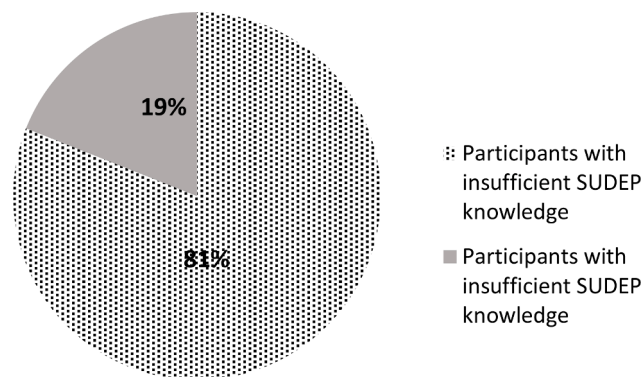


Fig. 1. Participants SUDEP knowledge.

Table 2
SUDEP Risk factors and frequency of participant’s selection.

		N (n/ 132)	%
Correct Answers	Treatment with 3 or more antiepileptic drugs (AEDs)	112	84.8
	Lack of AED therapy	100	75.8
	Recent generalized tonic-clonic seizures	70	53.0
	Childhood onset epilepsy	38	28.8
Incorrect Answers	Nocturnal complex partial seizures	69	52.3
	Electrocardiogram showing QTc at upper limit of normal	25	18.9
	Sleeping with two or more pillows	23	17.4

between having additional epilepsy training or years of practice ($p = 0.329$, $p = 0.728$) and frequency of SUDEP discussion. Additionally, there was no significant association between the number of SUDEPs encountered in clinical practice and frequency of SUDEP discussion with their patients ($P= 0.330$) as outlined in Table 3.

On the other hand, there was a significant negative association between the number of patients seen per year and the frequency of SUDEP discussion; those who saw >100 patients were less likely to discuss SUDEP with their patients ($P= 0.046$). Details are outlined in Table 3.

Participant’s attitudes towards SUDEP discussion

Only 8.3% of the participants discussed SUDEP with most or nearly all ($\geq 50\%$ of the time) of their patients and/or their caregivers, while 55.3% rarely or never discussed SUDEP (0–9% of the time). During the course of the treatment, SUDEP discussion was initiated by the participants with their patients and/or their caregivers mainly if the patient asked (64.4%) or when they considered the patient to be at high risk (55.3%). Otherwise, only 3.8% of the participants would initiate discussion at the time of diagnosis.

Intractable seizures (82.6%) and poor compliance with AEDs therapy (68.2%) were the most motivating clinical factors leading participants to discuss SUDEP among their patients and/or their caregivers. The majority of the participants (79.5%) reported that the age of the patient did not influence their decision about SUDEP discussion. However, our results showed that 59.3% and 29.7% of the participants would particularly discuss SUDEP among the pediatric age groups (0–8 and 8–16 years) respectively. SUDEP discussion was carried mostly (94.7%) by the participants themselves rather than a nurse or a counselor. The rest of the participant’s discussion attitudes are outlined in Table 4.

Perceived reactions to sudep discussion

The top three perceived reactions by the participants on SUDEP

Table 3
Relation of participant’s experience with the frequency of SUDEP discussion.

Variables		Frequency of SUDEP discussion										P value
		All the time		Most of the time		Sometimes		Rarely		Never		
		N	%	N	%	N	%	N	%	N	%	
Additional epilepsy training	Yes	0	0.0	4	15.4	9	34.6	10	38.5	3	11.5	0.329
	No	2	1.9	5	4.7	39	36.8	51	48.1	9	8.5	
Years of practice	0–5	0	0.0	4	8.9	18	40.0	20	44.4	3	6.7	0.728
	5–10	0	0.0	0	0.0	8	36.4	12	54.5	2	9.1	
	10–15	0	0.0	0	0.0	7	33.3	11	52.4	3	14.3	
	>15	2	4.5	5	11.4	15	34.1	18	40.9	4	9.1	
Had a patient with SUDEP	Yes	0	0.0	2	11.1	6	33.3	8	44.4	2	11.1	0.330
	No	2	1.8	7	6.1	42	36.8	53	46.5	10	8.8	
Number of patients seen per year	<100	0	0.0	7	10.6	29	43.9	26	39.4	4	6.1	0.046
	>100	2	3.0	2	3.0	19	28.8	35	53.0	8	12.1	

Table 4
Participant’s discussion attitudes about SUDEP.

Question		n (N = 132)	%
How often do you discuss SUDEP with patients with epilepsy and/or their caregivers?	Sometimes (10–49%)	48	36.4
	Rarely (1–9%)	61	46.2
	Never (0%)	12	9.1
	Most of the time (50–90%)	9	6.8
	All of the time (>90%)	2	1.5
When do you discuss SUDEP with patients with epilepsy and/or their caregivers? Please choose all that apply	If a patient asks	85	64.4
	When I consider a patient to be at high risk	73	55.3
	When initiating AED therapy	21	15.9
	Spontaneously during a follow-up appointment	11	8.3
	At the time of diagnosis	5	3.8
Which clinical factors lead you to discuss SUDEP with patients and/or their caregivers Please choose all that apply	Intractable seizures	109	82.6
	Poor compliance with AED therapy	90	68.2
	Patient lifestyle factors	52	39.4
	Surgical candidates	50	37.9
	Tonic-clonic seizures	48	36.4
	Symptomatic epilepsy	3	26.5
Does the age of the patient influence your decision to discuss SUDEP?	No	105	79.5
	Yes	27	20.5
At what patient age do you discuss SUDEP with patients with epilepsy and/or their caregivers? (Choose all that apply)	0–8 years	16	59.3
	9–16 years	8	29.7
	17–21 years	5	18.5
	22–54 years	5	18.5
	>55 years	5	18.5
Who in your practice discusses SUDEP with patients and/or their caregivers?	Yourself	122	94.7
	Nurse	11	8.3
	counselor	6	4.5

discussion were all negative - distress, anxiety, and depression (74.2%), (70.5%), (65.9%); respectively. Positive reactions were underrepresented - appreciation (32.6%) and relief (21.2%). Different reasons given by participants for choosing not to discuss SUDEP with their patients and/or their caregivers are outlined in Table 5.

Table 5
Perceived reactions to SUDEP and preferred tool for SUDEP awareness.

Question	N	%	
When you discuss SUDEP with people with epilepsy and/or their caregivers, they typically respond with (please choose 3 reactions)	Distress	98	74.2
	Anxiety	93	70.5
	Depression	87	65.9
	Appreciation	43	32.6
	Indifference	39	29.5
	Relief	36	27.3
When you do not discuss SUDEP with people with epilepsy and/or their caregivers, it is because:	Patient is at minimal or no risk	50	37.9
	SUDEP is so rare and the risks of discussion outweigh the potential benefits	38	28.8
	Information is available through other sources	36	27.3
	There is insufficient information about SUDEP	24	18.2
	The information could affect my patient’s quality of life or mood	21	15.9
	The patient lacks an adequate support network	10	7.6
	There is no proven way to prevent SUDEP	5	3.8
	I do not have sufficient time to discuss SUDEP during an office visit	4	3.0
	I do not know enough about SUDEP	4	3.0
	Will knowledge of SUDEP improve antiepileptic drug compliance in people with epilepsy?	Yes	102
No	30	22.7	
What tools would you employ in supporting your patients with epilepsy and/or their caregivers around the issue of SUDEP?	Brochures/pamphlets	82	62.1
	Support groups for families	65	49.2
	Websites	59	44.7
	Newsletters with the latest research in SUDEP	39	29.5
	Training sessions/webinars	33	25.0
	Guide for health care professionals about the medico-legal issues surrounding the discussion of SUDEP	33	25.0
	None	18	13.6

We performed a univariate analysis using different variables of participant's profile such as additional epilepsy training, current clinical practice, the number of patients seen per year, years of experience, how frequent SUDEP was discussed with patients and/or their caregivers, and their relation to perceived negative reactions to SUDEP discussion. Only frequency of SUDEP discussion yielded a significant association, indicating that the more often SUDEP was discussed, the less likely the participants were to receive depression ($p = 0.019$) or anxiety ($p = 0.046$) as a perceived reaction. Since we had only one significant result, multivariate logistic regression analysis was not carried out.

When participants were asked about the reason(s) they would choose not to discuss SUDEP with patients and/or their caregivers, 37.9% chose "patient is at minimal or no risk" and 28.8% chose "SUDEP is so rare and the risks of discussion outweigh the potential benefits" as their reasons. A small number of participants (3%) believed they did not know enough about SUDEP and hence did not discuss it. Further details are outlined in Table 5.

The majority of the participants (77.3%) believed that providing their patients' and/or their caregivers' knowledge about SUDEP would improve their compliance with AEDs. Participant choices of the different tools that can be employed to support knowledge about SUDEP are outlined in detail in Table 5.

Discussion

Our study looked into the different SUDEP discussion practices among adult and child neurologists across the EMR region. Since this study is the first of its kind to target neurologists practicing in the whole of EMR, we aimed to provide insight into current clinical practices and identify knowledge gaps that could help increase awareness about SUDEP in our region. We received responses from a wide range of countries in the EMR and our participants were from a broad range of types of practices, with an adequate distribution in age, years of clinical experience, training in epilepsy, and the number of patients with epilepsy treated per year.

Our results show that only 1.5% and 6.8% of the participants discussed SUDEP with "most" or "nearly all" of their patients and/or their caregivers, respectively, while 55.3% "rarely" or "never" discussed it. This indicates that neurologists in the EMR rarely discuss SUDEP with their patients and/or their caregivers. Our result is in line with figures from other western regions of the world such as the UK (4.7%) [15,16], Europe (2.7%) [19] USA and Canada (6.8%) [18,22] and Italy (8.8%) [17]. One study from the Middle East investigated SUDEP discussion practices of neurologists in Saudi Arabia. This study showed that only 1.7% of neurologists discussed SUDEP with all their patients and/or their caregivers [23].

On investigating the participant's knowledge about SUDEP based on identifying the correct risk factors, only 19% scored enough to be considered as having sufficient knowledge. Similar insufficient knowledge about SUDEP was reported in the USA and Canadian neurologist's survey, where they had a low rate of accurate identification of SUDEP risk factors [18]. Despite this, only 3% of our participants identified themselves as not having enough knowledge about SUDEP as their reason to avoid SUDEP discussions. Additionally, 55.3% of participants indicated that one of the reasons they would discuss SUDEP was if they considered the patient to be at high risk. However, they were not able to successfully identify known correct risk factors. This discrepancy in the results might reflect an unintended knowledge gap on part of the neurologists, where they are unaware that their understanding of SUDEP is not accurate or complete. Such a knowledge gap could be another reason why almost half of our participants chose not to discuss SUDEP with their patients since they considered them as either to be "at minimal or no risk" (37.9%) or that "SUDEP is so rare and the risks of discussion outweigh the potential benefits" (28.8%). This explains why the frequency of SUDEP discussion was low in our cohort.

We observed a significant association between the number of

patients seen and the frequency of SUDEP discussion; those participants who saw >100 patients with epilepsy were less likely to discuss SUDEP with their patients and caregivers. On the contrary, a study from the USA and Canada reported more frequent discussion practices among neurologists who saw a higher volume of patients with epilepsy. They speculated that this is due to having more experience about SUDEP allowing better discussion of such sensitive topics, and having more time and resources allocated during their clinical hours for this specific purpose [18]. We see that this is not the case here in the EMR with the increase in the number of patients with epilepsy seen per day in an outpatient clinic. We hypothesize that it might be difficult to secure enough time for SUDEP discussion during the clinic visit due to several possible factors such as limited resources [23,24], as well as misconceptions and social stigma related to patients with epilepsy [25,26]. This would leave practitioners with lesser opportunities to initiate discussions on contentious issues such as SUDEP, which may not be considered, on the part of patients and caregivers as requiring urgent and immediate attention. This might force neurologists to allocate most of the consultation time addressing more important issues such as accepting the diagnosis of epilepsy due to cultural beliefs, unavailability and cost of AEDs in absence of supportive care such as qualified epilepsy nurses and lack of information about SUDEP in the region's local languages [26,27].

On exploring the rate of SUDEP occurrence during the last 24 months of the participant's clinical practice (from 2016 until 2018), we found that SUDEP cases were encountered by 18% of the neurologists in our cohort. Our results were comparable with the Saudi Arabian study, where 21.7% of neurologists had patients with definite or probable SUDEP over 2 years [23]. Variable rates of SUDEP occurrence were reported from western studies [15–19, 22]. We also found that neither having additional epilepsy training nor more work experience among the participants was associated with increased frequency of SUDEP discussion. It appears as though neurologists in our region are not encouraged to discuss SUDEP with their patients despite witnessing SUDEP in their clinical practice. This is contrary to neurologists in the USA and Canada [18] whose discussion of SUDEP was significantly associated with the number of SUDEP occurrences in a given 24-month period of their clinical practice. Both participants in our study and neurologists in the USA and Canada [18] carried SUDEP discussion by themselves rather than a nurse or a counselor.

In addition to limited knowledge, perceived negative reactions from patients as well as participants' apprehension might be contributing factors to rare SUDEP discussions with patients and caregivers. This was evident when the majority of the participants (77.3%) believed that providing their patients' or caregivers' knowledge about SUDEP would improve their compliance with AEDs, but this was not reflected in their practice. Moreover, most neurologists in this cohort chose distress, depression, and anxiety as their patients' top three reactions to SUDEP discussions. This finding is in agreement with similar studies [19,28] where negative perceived reactions were almost always anticipated from patients even when the opposite outcome was true in places where SUDEP discussion is held more frequently [15,28,29].

On further analyzing the frequency of SUDEP discussion and the associated top three perceived reactions, we found that the more frequently the discussion about SUDEP the less likely to have depression or anxiety as a perceived reaction. Similarly, Nisbet and colleagues [27] reported that the practitioners in their cohort anticipate negative reactions (anxiety and distress, specifically) despite their experiences that patients do not generally react that way. Other studies [15,30,31] indicate that the anxiety-like symptoms experienced by patients, if and when they are experienced, are only short-lived. We agree with the previously suggested cautious approaches [28,32] to be implemented by practitioners at the time of SUDEP discussion. This ensures a calmer-than-anticipated response from patients and offers better adherence to AEDs.

The main way neurologists prefer to provide SUDEP information is

through the use of brochures/pamphlets, websites dedicated to SUDEP information, training sessions/webinars, and support groups for families. Studies [15,33,34] that surveyed parents and caregivers of patients have found that physician consultation accompanied by an information leaflet on SUDEP and associated risks are their preferred way of learning about SUDEP. Currently, there are no custom-made websites or any other types of resources available to people with epilepsy in the region. Having customized websites and applications in the local languages to disseminate epilepsy and SUDEP-related information might increase awareness.

To establish effective communication between patients and practitioners, studies [29,30,31] recommend endorsing an individualized approach to discussing SUDEP with patients and tailoring the discussion according to the need and circumstances of the individual. This can be implemented by initiating the conversation right after diagnosis in cases where the patient is known to take the news responsibly, in cases where the patient carries the known possible risk factors of developing SUDEP, and in cases where non-adherence to treatment is suspected. One study [35] reported that people with epilepsy generally attribute seizure occurrences to stress and lifestyle factors as opposed to non-adherence to medication. In the EMR, particular attention must be paid to combatting the social stigma related to epilepsy-related disorders in order to encourage neurologists to discuss SUDEP with their patients and caregivers. However, equal emphasis must be placed on general physicians and mental health professionals in the community to normalize discussions about epilepsy in general when consulting patients particularly in this part of the world. This might be achieved through implementing simple programs similar to other models applied by some developing

government and non-government organizations to provide educational and training programs in the form of workshops, booklets and educational websites in local languages designed for both practitioners and patients. Further studies in our region would be also helpful to investigate the possible role of misconceptions and social barriers such as stigma associated with epilepsy, and lack of awareness about SUDEP among patients with epilepsy and their caregivers to further explore their reactions on discussing this sensitive topic.

Funding

This research received no specific grant from any funding agency in the public, private, commercial, or not-for-profit sectors.

Availability of data and material

Our study used data already available from patient files in the internal Electronic Medical Record management system available in American Center of Psychiatry and Neurology, Abu Dhabi, UAE

Authors' contributions

This manuscript has been read, checked and approved by all authors, meeting all the requirements and we confirm that all work presented is original, authentic and factual. All persons listed as authors in the manuscript have made substantial contribution, so as to take public responsibility to it, in the production of this manuscript as detailed below:

Contributor	Concept	Study Design	Data Collection	Statistical Analysis	Literature overview	Discussion	Fund Generation
Dina Amin Saleh	Yes	Yes	Yes	Yes	Yes	Yes	No
Seada Kassie	No	Yes	Yes	Yes	Yes	Yes	No
Abeera Hassan	No	No	No	Yes	Yes	Yes	No
Taoufik Alsaadi	No	Yes	Yes	No	No	Yes	No

countries [24], that have shown success in overcoming the social and treatment gap by providing simple education and sharing information about epilepsy with the local population. This would relieve some stress for patients and their caregivers, which in turn may allow neurologists to share information regarding SUDEP more candidly.

Achieving a good response rate remains one of the limitations of survey-based studies. In our study, the high response rate (37.7%) along with the diversity in responses received in terms of participant profiles and their demographics adds to the strength of this study. This assures us that our sample, even if small in size, truly represents the neurologists practicing in the region. At the time of our survey, our study was the first to address SUDEP knowledge among neurologists in the EMR region. Our preliminary findings highlight that further investigation needs to be done in this area as both neurologist and patient attitudes towards SUDEP in the EMR remain largely unknown.

Conclusion

Our study, which explores SUDEP practices of neurologists in the EMR, has yielded similar results to studies conducted in other parts of the world. Participants rarely initiate SUDEP discussion by themselves, and currently have limited knowledge about its risk factors. When they do discuss SUDEP, they overwhelmingly receive negative reactions such as depression and anxiety. Based on our findings, we speculate that poor SUDEP discussion practices might be attributed to several factors, including but not limited to having limited knowledge about SUDEP, lack of resources such as trained epilepsy nurses, and lack of patient education material in local languages. To overcome these barriers, the authors propose that more research funding must be allocated by the

No person who had contributed substantially to the production of this manuscript had been excluded from authorship.

Ethics approval

Ethics approval was granted by the Institutional Review Board at the American Center for Psychiatry and Neurology, Abu Dhabi, UAE. The authors testify that the study was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards.

Consent to participate

Informed consent was solicited from each participant either in written form or electronically.

Consent for publication

This manuscript is based on original work and has not been published in whole or part, in any print or electronic media or is under consideration of publication in any print or electronic media other than as abstract of conference proceedings.

Declaration of Competing Interest

The authors declare that they have no direct or indirect potential conflict of interest.

Appendix

Physician SUDEP Questionnaire

Participant Information

Name:
Country of origin:
Country of training:
Address:
E-mail address:
Phone:
Nationality:
Country of practice:
Gender

- Male
- Female

What is your age? (years)

- 25–34
- 35–44
- 45–54
- 55–64
- 65–74
- 75 or older

Please choose your type of practice:

- Academic Practice
- Private Practice
- Government Practice

How many years have you been in practice? (Please choose only one of the following)

- 0–5
- 5–10
- 10–15
- >15

In a typical year, how many patients do you follow with epilepsy? (Please choose only one of the following):

- None
- 1–10
- 11–20
- 21–50
- 51–100
- >100

SUDEP experience

The following questions relate to your knowledge and experience with SUDEP

SUDEP is defined as

Definite: sudden, unexpected, witnessed or unwitnessed, non-traumatic, and non-drowning death in patients with epilepsy with or without evidence for a seizure in which autopsy does not reveal a structural or toxicological cause for death. This excludes death from status epilepticus.

Probable: sudden, unexpected death occurring under benign circumstances where no competing cause of death is known but no autopsy was performed.

Which clinical factors do you think put people with epilepsy at risk for SUDEP? (Please choose all that apply):

- Treatment with 3 or more antiepileptic drugs (AEDs)
- Lack of AED therapy
- Sleeping with two or more pillows
- Electrocardiogram showing QTc at upper limit of normal
- Recent generalized tonic-clonic seizures
- Nocturnal complex partial seizures
- Childhood onset epilepsy
- In the past 24 months, have any patients for whom you are the primary neurologist experienced definite or probable SUDEP? Only answer this question if you follow patients with epilepsy:
 - Yes
 - No (skip the question below)

If yes, how many in adult patients (>18 years of age)? _____
How many in children (<18 years of age)? _____

SUDEP Discussion Experience

The following questions pertain to your experience discussing SUDEP with patients and their caregivers:

How often do you discuss SUDEP with people with epilepsy and/or their caregivers? Only answer this question if you follow patients with epilepsy. Please choose only one of the following:

- All of the time (>90%)
- Most of the time (50–90%)
- Sometimes (10–49%)
- Rarely (1–9%)
- Never (0%) (Skip the question below)

When do you discuss SUDEP with people with epilepsy and/or their caregivers? Please choose all that apply:

- If a patient asks
- At the time of diagnosis
- When initiating AED therapy
- Spontaneously during a follow-up appointment
- When I consider a patient to be at high risk

Which clinical factors lead you to discuss SUDEP with patients and/or their caregivers? Please choose all that apply:

- Intractable seizures
- Tonic-clonic seizures
- Symptomatic epilepsy
- Surgical candidates
- Poor compliance with AED therapy
- Patient lifestyle factors (such as drinking alcohol/recreational drug use/living alone/smoking tobacco/poor fitness status)

Does the age of the patient influence your decision to discuss SUDEP? Please choose only one of the following:

- Yes
- No (skip the question below)

If yes, at what patient age do you discuss SUDEP with persons with epilepsy and/or their caregivers? Please choose all that apply:

- 0–8 years
- 9–16 years
- 17–21 years
- 22–54 years
- >55 years

Who in your practice discusses SUDEP with patients and/or their caregivers? Please choose all that apply:

- Yourself
- Nurse
- counselor
- Other:

When you discuss SUDEP with people with epilepsy and/or their caregivers, they typically respond with (please rank the top 3 responses in order of frequency): Please rank your top three responses:

- Relief
- Appreciation
- Indifference
- Distress
- Anxiety
- Depression

When you do not discuss SUDEP with people with epilepsy and/or their caregivers, it is because: Please choose all that apply:

- Patient is at minimal or no risk
- The information could affect my patient's quality of life or mood
- The patient lacks an adequate support network
- There is insufficient information about SUDEP
- I do not have sufficient time to discuss SUDEP during an office visit
- Information is available through other sources
- SUDEP is so rare and the risks of discussion outweigh the potential benefits
- There is no proven way to prevent SUDEP
- I do not know enough about SUDEP

Will knowledge of SUDEP improve antiepileptic drug compliance in people with epilepsy? Please choose only one of the following:

- Yes
- No

What tools would you employ in supporting your patients with epilepsy and/or their caregivers around the issue of SUDEP? Please choose all that apply:

- Brochures/pamphlets
- Websites
- Training sessions/webinars
- Newsletters with the latest research in sudep
- Support groups for families
- Guide for health care professionals about the medico-legal issues surrounding the discussion of sudep
- None

Thank you for taking the time to complete this survey.

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