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Title	Silent threats: awareness and attitudes to communication of SUDEP among neurologists in India: a cross-sectional study
Type	Article
URL	https://clok.uclan.ac.uk/id/eprint/56439/
DOI	https://doi.org/10.1016/j.seizure.2025.07.008
Date	2025
Citation	Ravichandra, Nandan, Dale, Madeleine, Baheti, Neeraj, Das, Abhijit, Rathore, Chaturbhuj, Jalihal, Virupakshi and Shankar, Rohit (2025) Silent threats: awareness and attitudes to communication of SUDEP among neurologists in India: a cross-sectional study. Seizure: European Journal of Epilepsy, 131. pp. 212-218. ISSN 1059-1311
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Seizure: European Journal of Epilepsy 131 (2025) 212–218

Contents lists available at ScienceDirect

Seizure: European Journal of Epilepsy

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

Silent threats: awareness and attitudes to communication of SUDEP among neurologists in India: a cross-sectional study

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ARTICLE INFO

Keywords:
Epilepsy harm
Lower-middle income countries
Counselling
SUDEP

ABSTRACT

Background: International guidelines unequivocally endorse the importance and need to discuss Sudden Unexpected Death in Epilepsy (SUDEP) with people with epilepsy (PWE). India is a country accounting for a sixth of all global epilepsy burden. Despite this little is known of Indian neurologists' knowledge and attitudes to SUDEP.
Objective: To explore India Neurologists awareness and attitudes to SUDEP communication to PWE.
Methods: A cross-sectional online survey of Likert response questions using validated themes, was circulated among the neurology fraternity, India. Non-discriminatory exponential snowballing technique leading to convenience non-probability sampling was used. The inquiry involved SUDEP-related topics including the awareness, knowledge, need for and importance of counselling. A comparison with other epilepsy risk counselling was made. Descriptive statistics were used for analysis.
Results: Of 275 consenting participants, a majority were male (76 %), had over 5 years of practice (63 %), were private practitioners (61 %) and working in urban areas (99 %). Almost all participants (98 %) knew of SUDEP. A fifth (20 %) counselled most or all PWE of SUDEP compared to 90 % discussing risks from daily activities, 89 % driving risk and 38 % psychiatric concerns. There were significant differences to the likelihood of SUDEP counselling being undertaken based on formal epilepsy training ($p < 0.001$) familiarity with SUDEP guidelines ($p < 0.001$), and SUDEP risk factors knowledge ($p < 0.001$). Further training for SUDEP risk and communication was requested by 90 %.
Conclusion: While most Indian neurologists have SUDEP awareness there is a significant gap in communication of SUDEP risks to PWE. Virtual training and education could help bridge the knowledge gap.

1. Introduction

1.1. Epilepsy in India

Epilepsy is one of the most common neurological diseases, accounting for over 0.5 % of the global burden of disease [1]. Worldwide, there are approximately 50 million persons with epilepsy (PWE), with nearly eighty percent residing in developing countries [1]. In addition, the mortality rate of epilepsy is higher in low and middle-income countries (LMIC) compared to high income countries (HIC) [2,3]. India, a LMIC [4], contributes to nearly one-sixth of the global epilepsy burden, with approximately 12 million PWE residing there [5]. Its prevalence in India is reported to range from 3.0 to 11.9 per 1000 population, with an incidence of 0.2–0.6 per 1000 [5]. A study among

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https://doi.org/10.1016/j.seizure.2025.07.008
Received 24 May 2025; Received in revised form 13 July 2025; Accepted 14 July 2025

the general population of Kolkata, India, reported an average annual epilepsy mortality rate (AAMR) of 7.63 per 100,000 population per year over a five-year period [6]. Additionally, the all-cause standardized mortality ratio (SMR) for persons with epilepsy was 2.58, indicating that people with epilepsy had over twice the risk of death compared to the general population [6].

1.2. SUDEP

Sudden unexpected death in epilepsy (SUDEP) is described as "Sudden, unexpected, witnessed or unwitnessed, non-traumatic and non-drowning death in people with epilepsy, with or without evidence for a seizure and excluding documented status epilepticus, in which postmortem examination does not reveal a toxicologic or anatomic cause of death." [7]. SUDEP is the most common source of epilepsy-related death [8], contributing to 7–17 % of deaths among people with epilepsy (PWE) and up to 50 % in individuals with treatment resistant epilepsy [9]. Young PWE have a 24 times higher risk of death compared to those without [10]. SUDEP incidence increases from newly diagnosed to chronic epilepsy, with the highest rates observed in refractory epilepsy, at 2–10 per 1000 person years [10]. Several risk factors are associated with an increased risk of SUDEP, including, polytherapy, frequent changes in anti-seizure medication (ASM), generalized tonic-clonic seizures (GTCS), with seizure frequency being the leading risk factor [11]. Recently epilepsy guidelines advocate and promote SUDEP risk disclosure to PWE and their family [12,13].

1.3. SUDEP in LMIC

Mortality among PWE in LMIC is approximately 2.6 times higher than in the general population, with the primary cause of death being epilepsy related complications such as status epilepticus, SUDEP, and injuries [14]. A systematic review conducted by the International League Against Epilepsy (ILAE) suggested that risk factors for SUDEP, such as frequent seizures and poor access to ASMs are more common in LMIC compared to HIC [14]. Studies in Ethiopia and Pakistan have indicated poor adherence to ASMs, which is itself is a significant risk factor for SUDEP [15–17]. A study in rural Kenya found a six times greater risk of mortality associated with active convulsive epilepsy (ACE) with a possible link to ASM non-adherence and SUDEP [18].

1.4. Risk management and communication of SUDEP

Proposed modifiable and mitigatable risk factors for SUDEP include generalized tonic-clonic seizures, seizure frequency, polytherapy, nocturnal supervision, and the appropriate use of ASMs [10,19]. Generalized tonic-clonic seizures (GTCS) are one of the most significant modifiable risk factors, as individuals with three or more GTCS per year have a 15 times increased risk of SUDEP [13]. In a data-based study looking at longitudinal group-based trajectory modelling for ASM adherence, a declining pattern of adherence was shown to be associated with an eight times increased risk of SUDEP [17]. Nocturnal supervision has been shown to potentially reduce the risk of SUDEP [20,21].

Physicians caring for PWE should provide adequate counselling on SUDEP and its risk factors [22]. Studies have described a link between communication of SUDEP and its risk factors to PWE and a decrease in SUDEP [23,24]. Studies in the UK and Denmark estimate that a significant number of epilepsy-related deaths may have been preventable [12,25]. Communication tools, such as seizure safety checklists, have also shown to significantly decrease risk scores associated with SUDEP [26]. Although organizations such as the American Academy of Neurology (AAN) and the National Institute for Health and Care Excellence (NICE) recommend patient tailored disclosure of SUDEP risk, clinicians often limit discussions due to concerns about causing anxiety and generally restrict disclosure to high-risk PWE [12,13,27]. SUDEP counselling provided by physicians is inconsistent with clinical guidelines [28]. A survey conducted across 27 countries involving 1123 neurologists, found that 41.5 % of the participants rarely discuss SUDEP with their patients and caregivers [29]. However, on the flip side, PWE, their family members and caregivers, believe SUDEP disclosure is important, even if it may cause anxiety or fear, and this is preferred early after diagnosis [30,31]. There is however significantly limited research from LMICs such as India on SUDEP counselling.

India is a large LMIC with a population of approximately 1.4 billion divided across 28 states and 8 union territories [32]. As of 2023, 36.3 % of the population resides in urban areas, while 63.6 % resides in rural areas [33]. In 2023, India had a literacy rate of 77 % and an estimated 70 % of healthcare services provided by private establishments [32,34]. Approximately 12 million PWE reside in India, with over 2500 neurologists registered with the Indian Academy of Neurology as of 2024 [5,35]. There is a higher prevalence of epilepsy in rural areas compared to urban areas [5]. This is study looks to assess the awareness, attitudes, and knowledge of neurologists across India about SUDEP and other epilepsy-related risks.

2. Methods

2.1. Objective

Study the awareness, attitudes and knowledge of neurologists in India on SUDEP and epilepsy related risks.

2.2. Study design and survey tool

The Checklist for Reporting Results of Internet E-Surveys (CHERRIES) [36] and The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) checklist [37] were used to guide, design, and execute this cross-sectional study *(supplementary information 1)*. A modified questionnaire was designed using validated themes with supervision from epilepsy experts [28]. *(supplementary information 2)*. The survey was created on the Google Forms platform, The survey included a total of 35 questions covering a range of topics including respondent demographics, SUDEP and epilepsy risk knowledge, communication patterns of risk and perceived need for training (*supplementary information 3*). Specifically, respondents estimated how many patients they counsel on epilepsy-related risks, including SUDEP, psychiatric problems, driving restrictions, and the risk of activities of daily life including drowning and falling from heights.

2.3. Participants

Participants included Indian neurologists in academic positions (professor, additional professor, associate professor or assistant professor), private practitioners, neurology residents and post-doctoral fellows specializing in epilepsy. The survey was disseminated electronically through local and national professional networks, using a non-discriminatory exponential snowballing technique leading to a convenience non-probability sampling.

2.4. Ethics

Ethical approval was granted on 30/11/2024, from Dr. G.M. Taori Central India Institute of Medical Sciences. *(CIIMS/HEC/2024/20, supplementary information 4)*. Participants were informed that consent is implied through participation and submission of the survey. If respondents chose to participate, data would be pooled, anonymized and analyzed.

2.5. Data analysis

Demographic characteristics of respondents were summarized using descriptive characteristics. Chi-squared was used to analyse factors associated with routinely counselling patients on SUDEP. The factors analysed were based on apriori hypotheses. The R environment for statistical computing was used to organize and complete the analysis of the data.

3. Results

3.1. Characteristics of respondents (Table 1)

In total, 275 participants responded to the survey. The ages of participants ranged from 28 to 76 (median 39; IQR 34–47) for the 273 who gave their age. The majority of participants were male and reported seeing between 26 and 50 people with epilepsy per month.

3.2. Reported practices for counselling patients about SUDEP

Nearly all (270/275, 98 %) of respondents were aware of SUDEP and a third (90/275, 33 %) of respondents reported routinely discussing SUDEP with patients. Over half (156/275, 57 %) of respondents reported that at least one of their patients had died from SUDEP.

A fifth (20 %) of the respondents counselled most or all their patients of SUDEP. Nearly all respondents (90 %) discussed epilepsy risk from daily activities such as falling from heights or drowning. This was the same for driving related risk (89 %). Just over a third of respondents (38 %) discussed psychiatric concerns and epilepsy with most or all patients. Fig. 1 provides respondent replies to counselling for different risk situations.

Respondents reported that they were most likely to discuss SUDEP with patients who had refractory disease (235/275, 85 %). Other common reasons included non-compliance with treatment (171/275, 62 %), polytherapy with anti-epileptic drugs (164/275, 60 %), and nocturnal seizures (138/275, 50 %) (Table 2).

The most likely time for respondents to discuss the risk of SUDEP with patients was when the disease took a refractory course (203/275, 74 %), followed by if the relative asked (109/275, 40 %). Less than a fifth of respondents report discussing SUDEP when epilepsy is first diagnosed (48/275, 17 %) or within the first one to two years after diagnosis (49/275, 18 %).

3.3. Attitudes towards counselling patients about SUDEP

The most frequently reported expectation from discussing SUDEP was improved treatment compliance (219/275, 80 %). Over half (159/275, 58 %) of respondents expected it would prevent SUDEP and half (137/275, 50 %) expected it would improve nighttime supervision of patients. Two of five (110/275, 40 %) respondents reported that they would counsel patients on SUDEP because of a medical duty to disclose the risk.

The most common reasons for respondents to avoid discussing SUDEP with patients was raising unnecessary concerns in the patient, or their family or carers, and fear of the emotional reaction of the patient (Table 3).

Participants were asked whether all risks of a disease or therapy should be discussed with patients and just under two-third (170/275, 62 %) of respondents did believe all risks should be discussed. Minority of responders thought that risks should only be discussed if they are frequent (46/275, 17 %), cause great damage (27/275, 10 %), would result in consequences in action (16/275, 6 %), or are preventable (9/275, 3 %). Nearly two-third (176/275, 64 %) of respondents said clear guidelines on how frequently to discuss the risk of SUDEP with patients would be beneficial.

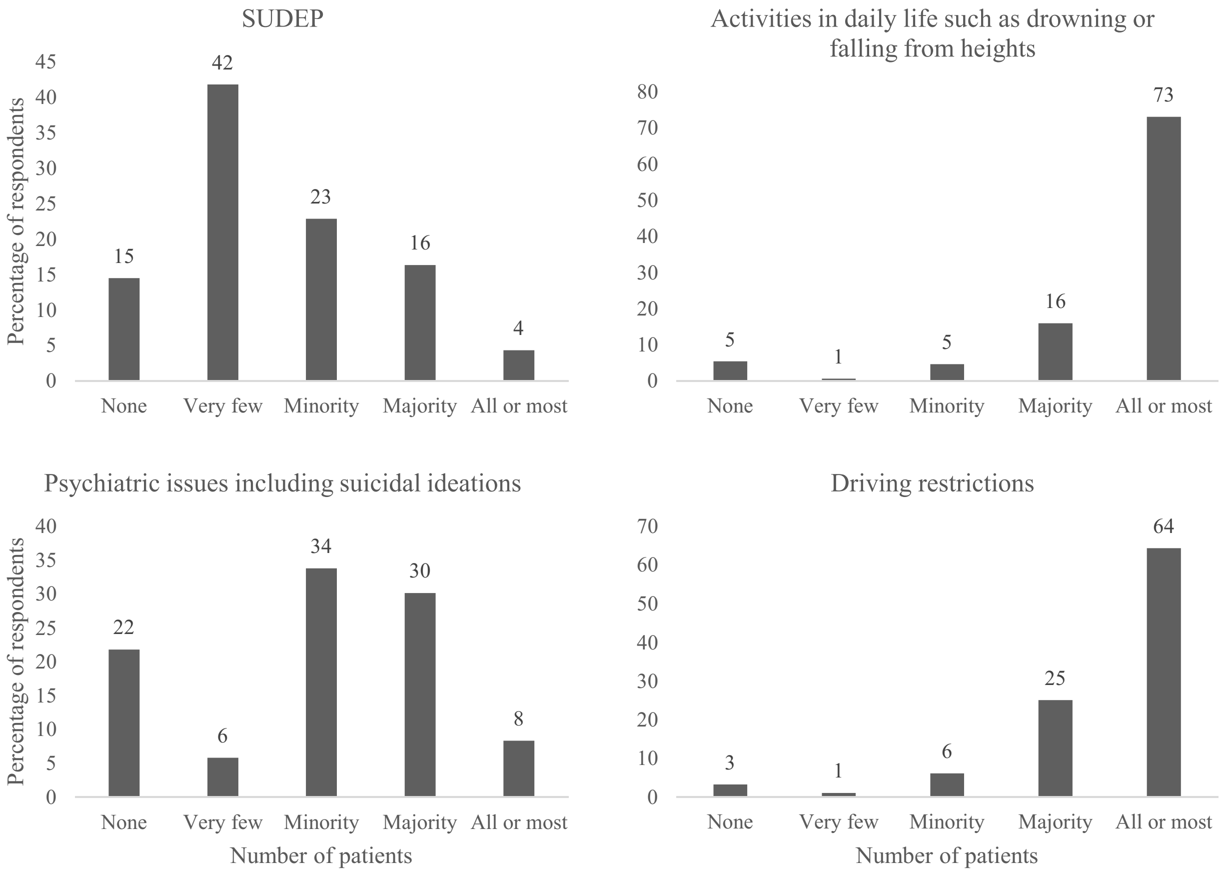

Fig. 1. The % of respondents report counselling about epilepsy-associated risks.

Table 1
Characteristics of respondents.

	n (%)
Gender	
Male	210 (76)
Female	65 (24)
Years in practice	
Training	37 (13)
<5 years	66 (24)
5–10 years	71 (26)
10–20 years	61 (22)
>20 years	40 (15)
Position at workplace	
Academic position (professor, assistant professor, associate professor)	56 (20)
Private practitioner	169 (61)
Post-doctoral fellow in epilepsy	10 (4)
Neurology resident	39 (14)
Other	1 (0.4)
Location of practice[*]	
Urban metropolitan city (population >40 million)	153 (56)
Urban non-metropolitan city (population 500,000 - 40 million)	100 (36)
Urban town (population <500,000)	27 (10)
Rural	3 (1)
Other	1 (0.4)
Practice setting[†]	
Private hospital	174 (63)
State medical college (government or private)	64 (23)
National academic institution	39 (14)
Office-based	39 (14)
Other	3 (1)
Number of patients with epilepsy seen per month	
<10	14 (5)
11–25	67 (24)
26–50	76 (28)
51–100	59 (21)
>100	59 (21)
Completed formal training in epilepsy	
Fellowship of ≥1 year	65 (24)
Observership of ≥3 months	28 (10)
Observership of <3 months	15 (5)
None	167 (61)

[*] *9 participants practiced in multiple locations.*

[†] *41 participants practiced in multiple settings.*

Table 2
Most commonly reported reasons to discuss risk of SUDEP with patients.

	n (%)
Refractory course of disease	235 (85)
Non-compliance of patient with treatment	171 (62)
Polytherapy with anti-epileptic drugs	164 (60)
Nocturnal seizures	138 (50)
Generalised tonic-clonic seizures	132 (48)
Patient requests information	94 (34)
Patient's capacity of understanding	87 (32)
Before epilepsy surgery	44 (16)
Before placebo-controlled trial	6 (2)

Table 3
Most commonly reported reasons to avoid counselling patients on SUDEP.

	n (%)
Raising unnecessary concerns in the family or carers	149 (54)
Raising unnecessary concerns in the patient	148 (54)
Fear of the emotional reaction of the patient	122 (44)
Patient is not at high risk for SUDEP	89 (32)
No known preventive measures against SUDEP	53 (19)
Lack of time	36 (13)
Do not want to discuss death	32 (12)
Poor benefit-risk ratio	27 (10)
Lack of consequences	3 (1)

Table 4
Factors associated with routine discussion of SUDEP.

	Routinely discuss (*n* = *90)*	Do not routinely discuss (*n* = *185)*	χ^2	*df*	*p*
Years in practice					
10 or more years	33	68			
<10 years	47	90			
Training	10	27	*0.7014*	*2*	*0.70*
Number of patients per month					
51–100	43	75	*1.016*	*1*	*0.31*
<50	47	110			
Formal training on epilepsy					
≥3 months of training	43	59	*10.74*	*1*	*0.001*
>3 months of training	47	135			
Number of patients died from SUDEP					
1 or more	38	58	*4.301*	*2*	*0.12*
None	26	52			
Uncertain	26	75			
Perceived confidence in ability to counsel a patient on SUDEP					
Very confident	46	31	*45.03*	*2*	*<0.001*
Somewhat confident	43	110			
Not confident	1	44			
Familiarity with SUDEP guidelines					
Very familiar	23	11	*45.40*	*2*	*<0.001*
Somewhat familiar	57	85			
Not familiar	10	89			
Perceived knowledge of SUDEP risk factors					
Very knowledgeable	21	15	*27.51*	*3*	*<0.001*
Moderately knowledgeable	59	102			
Slightly knowledgeable	10	51			
Not knowledgeable	0	17			

3.4. Factors associated with routine discussion of SUDEP (Table 4)

Participant personal and professional factors associated with routinely counselling patients on SUDEP was compared. Significantly greater likelihood of counselling was associated with having had formal training on epilepsy for over three months ($p < 0.001$), greater perceived confidence on counselling a patient ($p < 0.001$), greater familiarity with SUDEP guidelines ($p < 0.001$), and greater perceived knowledge of SUDEP risk factors ($p < 0.001$). Number of years in practice, number of patients reviewed per month, and having patients died from SUDEP was not associated with the likelihood of routinely counselling patients.

3.5. Confidence, knowledge, and training on SUDEP (Table 5)

Nearly all respondents reported having attended a webinar or a Continuing Medical Education (CME) activity in epilepsy within the previous two years (234/275, 85 %). Just over a quarter (72/275 26 %) reported that their training on SUDEP had been of poor quality. A minority (45/275, 16 %) of respondents felt not confident in their ability to counsel a patient about SUDEP. Just over a third (99/275, 36 %) reported they were not familiar with international guidelines on SUDEP. A minority (36/275, 13 %) felt very knowledgeable about the risk factors associated with SUDEP.

Most respondents (248/275, 90 %) expressed an interest in participating in SUDEP training programs. The majority of respondents want training to include SUDEP prevention strategies, risk factors for SUDEP,

Table 5
Clinician perceived confidence and knowledge of SUDEP counselling, guidelines and views on training.

	n (%)
Perceived confidence in ability to counsel a patient on SUDEP	
Very confident	77 (28)
Somewhat confident	153 (56)
Not confident	45 (16)
Perceived knowledge on risk factors associated with SUDEP	
Very knowledgeable	36 (13)
Moderately knowledgeable	161 (59)
Slightly knowledgeable	61 (22)
Not knowledgeable	17 (6)
Familiarity with SUDEP guidelines	
Very familiar	34 (12)
Somewhat familiar	142 (52)
Not familiar	99 (36)
Quality of previous training on SUDEP	
Excellent	5 (2)
Very good	25 (9)
Good	71 (26)
Fair	102 (37)
Poor	72 (26)
Desired frequency of SUDEP training	
Monthly	20 (7)
Semi-annually	101 (37)
Annually	118 (43)
On demand	34 (12)
Desired format of SUDEP training	
Online courses and seminars	204 (74)
Written provisions and guidelines	98 (36)
In-person workshops and seminars	74 (27)
Online tools or mobile applications	70 (25)
Expert panel discussions	69 (25)
Desired topics to be included in SUDEP training	
Prevention strategies	255 (93)
Risk factors	211 (77)
Counselling and communication strategies	209 (76)

and counselling and communication strategies.

Discussion

India bears a significant proportion, nearly one-sixth of the global epilepsy burden, with an estimated 12 million PWE [5]. It is essential for physicians involved in epilepsy care to be well versed in SUDEP to effectively communicate its risk factors and avenues for mitigation. Although almost all respondents (98 %) were aware of SUDEP, the challenge seems to lie in the translation between awareness and counselling, with only 33 % of respondents routinely discussing SUDEP with patients. This is a trend observed locally in India among other relevant stakeholder specialties for epilepsy such as pediatrics and psychiatry [38,39]. The results of poor communication to patients also align globally, as shown in a study involving 4000 doctors across 30 countries and more recently studies in the UK, Norway and Hungary [28,40,41].

The chief reasons for withholding discussion were concern about provoking anxiety in patients or families (54 % each), fear of an emotional reaction (44 %), and the perception that the patient had low SUDEP risk (32 %). These barriers mirror international findings [27,42,43]. This stands in contrast to not only to established clinical guidelines [12,13], but also to the preferences of patients. Several studies have detailed that PWE, family members and caregivers, express a strong preference for timely and transparent SUDEP disclosure [44–46]. Although SUDEP disclosure has been associated with potential short-term anxiety, it has no long-term effects on PWE, direct disclosure to PWE has shown to even reduce the risk of anxiety [47]. SUDEP disclosure has also shown to increase drug adherence without changes to quality of life or mood [48]. Timing of disclosure is essential for effective risk mitigation and promoting possible behavioral changes [49]. The majority of the respondents (85 %) stated they were most likely to discuss SUDEP with patients who had refractory epilepsy. This is consistent with research that shows many patients already have refractory epilepsy at the time of SUDEP counselling, yet most also have modifiable risk factors for SUDEP, presenting a missed opportunity for intervention earlier [50].

Despite a small percentage of respondents (13 %) citing the lack of time as a reason for not discussing SUDEP, it is significant given the disparity between the number of available neurologists in India and the high epilepsy burden in India. With the approximate 2500 neurologists supporting an estimated 12 million PWE in India, providing individualized epilepsy care including SUDEP counselling would pose a significant challenge [51]. In India, apart from the neurologists, a large majority of the people with epilepsy are also managed by the general practitioners, physicians and psychiatrists who even might have a lower awareness of SUDEP [38,39].

The implementation of structured tools could facilitate counselling, empowering both patients and clinicians. Seizure safety checklists [52–55] and communication frameworks, such as the SPIKE protocol [56], could alleviate the burden on clinicians by providing a streamlined and time efficient approach to SUDEP counselling. This approach would support patient needs, align with clinical guidelines and may contribute to risk mitigation. According to a study in the UK, the introduction of structured tools led to an increase in SUDEP counselling rates from 10 % to 80 % [57].

Studies of SUDEP are sparse and few from India [58,59]. A single site study of 558 people with epilepsy admitted to the epilepsy monitoring unit between 2000 −2004 found that at least 25 people had died from epilepsy 10 years or so on [58]. It recognised SUDEP to be an important cause of death.

In India, while there is no dearth of SUDEP awareness among neurologists' as shown by our study other issues such as availability of neurologists, time, training and their communication to patients continue to dominate concerns and are likely contributory factors for SUDEP [59]. SUDEP training programs, alongside structured guidelines, could improve physician knowledge, communication, and confidence, and could help standardize care among neurologists in India. Indeed, only 13 % of those in our study felt knowledgeable about SUDEP risk factors, while nine out of ten survey respondents expressed interest in SUDEP training programs and almost one-third stated clear guidelines on the recommended frequency of SUDEP discussion would be helpful. Formal training in epilepsy, perceived confidence in SUDEP counselling, greater familiarity with SUDEP guidelines, and greater perceived knowledge on SUDEP risk factors were all associated with an increased likelihood of routinely counselling patients on SUDEP.

Limitations

No questions were asked about the specific State (of 28) in which the respondents reside and practice. Knowing the geographical distribution of the respondents would allow for better understanding of the differences in epilepsy care within India. The study only managed to obtain a small percentage of neurologists practicing in rural regions (3/275, 1 %). More than two-thirds of the population, approximately 68.8 %, reside in rural areas. A wider distribution of respondents working in rural areas would allow for a better understanding of rural and urban disparities in practices. It also might be that this is a representative sample of rural neurologists. Neurologists are not present in large numbers in rural communities in India. There are only around 2500 neurologists who are predominantly based in centres of excellence, tertiary and specialist centres which would be urban locations.

Although the sample captured a broad range of the neurologists practicing in India, generalizations is limited due to the challenges in obtaining responses from a large number of neurologists in the country. Our study captures over 10 % of the total study sample. People with epilepsy in India have extremely diverse socio-economical and educational backgrounds that plays an important role while planning to discuss SUDEP and its risk factors. These factors are difficult to ascertain and quantify and form an important area for future studies.

Conclusion

This is the first study to look at SUDEP counseling attitudes among neurologists in India. Given India's substantial epilepsy burden, closing the awareness-to-counselling gap on SUDEP is an urgent priority. High awareness (98 %) contrasts with low routine counselling (33 %). Structured tools, dedicated training, and clear national guidelines could empower clinicians to deliver timely, patient-centered risk discussions—ultimately improving safety for the millions of PWE in India.

Ethics statement

We confirm that we have read the journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

Funding

None.

Author contributions

All authors satisfy the ICMJE guidance by substantially contributing to the design, analysis and interpretation of the work, drafting of the manuscript, final approval of the manuscript and all agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work is appropriately investigated and resolved.

Declaration of competing interest

There is no direct disclosure or conflict of interest for any author for this submitted body of work.

NB has received speaker's honorarium from Intas pharmaceuticals, Cipla limited, Lupin limited, Alkem laboratories and Torrent pharmaceuticals.

RS developed the non-commercial and free to use SUDEP and Seizure Safety Checklist and the EpSMon app to reduce the risk of SUDEP and enhance seizure safety. RS is the chief Investigator of the NIHR adopted national Ep-ID register. The Register is supported and monitored by the National Institute of Health Research UK. The funding for each molecule examined by the Register is via an Investigator Initiated Support grant from each of the molecule's parent company. The funding is to RS's NHS institution and goes towards the salary of the research co-ordinator and the institution's project oversight costs. The contributing companies till date include Eisai, UCB, Bial, Jazz pharma (previously GW pharma) and Angelini. This work sits outside the submitted work. In addition to the above RS has received institutional research, travel support and/or honorarium for talks and expert advisory boards from LivaNova, UCB, Eisai, Neuraxpharm, Veriton Pharma, Bial, Angelini, UnEEG and Jazz/GW pharma outside the submitted work. He holds or has held competitive grants from various national grant bodies including Innovate, Economic and Social Research Council (ESRC), Engineering and Physical Sciences Research Council (ESPRC), National Institute of Health Research (NIHR), NHS Small Business Research Initiative (SBRI) and other funding bodies including charities all outside this work. No other author has any declared conflict of interest related to this paper.

Acknowledgments

None.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.seizure.2025.07.008.

Data availability

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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