



## Review

# Qualitative insights into the feelings, knowledge, and impact of SUDEP: A narrative synthesis

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## ABSTRACT

People with epilepsy (PWE) have a two- to threefold increased chance of premature death due to the condition. Interested in exploring the first-person perspective on this topic, we conducted a narrative synthesis to present the qualitative insight of PWE, their family, friends, and healthcare providers (HCPs) in relation to epilepsy-related death. A comprehensive electronic search of all peer-reviewed qualitative studies was conducted through databases using relevant keywords and Medical Subject Headings (MeSH) terms. Handsearching and exploration of pertinent gray literature was conducted thereafter. After a comprehensive literature search, the decisions of inclusion of literature were discussed and confirmed between the two authors. A total of 20 peer-reviewed papers were included. Within this, 17 were qualitative or mixed methods studies, and three were gray literature and guidelines/recommendations in discussing sudden unexpected death in epilepsy (SUDEP) with PWE and their families. The resultant main categories were the following: a) understanding of SUDEP and b) discussion of SUDEP. Findings show that there is an overall lack of understanding of unexpected epilepsy-related death for PWE and their relations. The literature focused on the education of PWE and their family in relation to SUDEP, and therefore, there is a lack of discussion on the general topic of epilepsy-related death. Findings show the conflicting perceptions, feelings, and thought processes that occur in learning about and deciding to discuss SUDEP as a HCP, PWE, or family/friend of a PWE. The literature suggests that it would be appropriate and necessary to discuss the topic of SUDEP with patients and their family members upon diagnosis.

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## 1. Introduction

People with epilepsy (PWE) have a two-to-threefold increased chance of premature death due to the condition [1]. Epilepsy-related deaths are most commonly caused by epilepsy-related accidents, suicide as a result of ill mental health, status epilepticus, and sudden unexpected death in epilepsy (SUDEP) [2,3]. Uncertainty and fear surrounding the possibility of epilepsy-related death cause PWE to desire to learn more about this aspect of living with epilepsy, particularly those with refractory epilepsy [4]. Sudden unexpected death in epilepsy is the most common cause of death for PWE [5], yet PWE are not always told about this risk [6]. Although research within epilepsy-related death causes and prevention has increased, the qualitative insight of PWE, their family, friends, and healthcare providers (HCPs) needs to be shown. Through sharing first person insight of epilepsy-related death, we aim to enable further understanding of what may aid adherence to management strategies, what is known about epilepsy-related death, and the psychosocial impact the knowledge of unexpected death has

upon the PWE and those around them who love and care for them. In presenting this literature, it is hoped that this could help prevent epilepsy-related death and further promote interventions that could decrease the occurrence of SUDEP.

Addressing this need, we aimed the following: a) to present the experiences of PWE (e.g., children, teenagers, adults) discussing their thoughts and beliefs of epilepsy-related death, what PWE have been told about epilepsy-related death by their HCP, and their thoughts and feelings about interventions to prevent unexpected death; b) friends/family of PWE's thoughts and feelings of epilepsy-related death and their thoughts and feelings on interventions to prevent epilepsy-related death; and c) HCPs' discussion of the topic with PWE and interventions and/or prevention methods HCPs believe work best.

## 2. Material and methods

We carried out a narrative synthesis to obtain a rigorous review of the qualitative research and gray literature within epilepsy-related death. This was through combining different types of evidence (e.g., qualitative research, mixed methods research, gray literature) and examining relationships within and between studies and reports [7].

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## 2.1. Search strategy

A comprehensive electronic literature search of all relevant peer-reviewed qualitative studies and gray literature was conducted (see Fig. 1). Databases included the following: PsychINFO, PubMed, Web of Science, MEDLINE, SPORTDiscus, CINAHL, ProQuest Social Sciences Index and Abstracts, Ovid British Nursing Index, Social Science Citation Index, AgeInfo, Autism Data, ChildLink, REHABDATA, and Scopus. Other sources, such as exploring organizational websites (e.g., Epilepsy Foundation), personal contacts, and social media were used to unearth other available sources, particularly unpublished literature. Handsearching of relevant journals and reports was also conducted to find additional literature.

The inclusion criteria were English language qualitative and mixed methods (e.g., need to have a clear qualitative component) research studies and gray literature. Literature that met the inclusion criteria examined the prevention and interventions of epilepsy-related death within the UK, explored epilepsy-related death in children, teenagers, and adults, or presented the viewpoint of health professionals and friends/family of PWE in relation to epilepsy-related death. Exclusion criteria were quantitative research investigating epilepsy-related death, mixed methods studies with a minor qualitative element or studies where the qualitative method was not easily recognizable, and qualitative research exploring death of PWE where epilepsy was not the cause. We did not limit our search by published year.

Following a search strategy that was inclusive as possible, SC found that the abundance of literature was within the context of SUDEP. To allow a more thorough search of the literature, ongoing adaptation of search terms, methods, and discussions with the coauthor (PR) in regard to opening up inclusion criteria was conducted. After a comprehensive literature search, the decisions of inclusion of literature were discussed with the PR (\*). These discussions examined the quality of the papers and applicability to the aims. This encouraged a more thorough examination of what was classed as inclusion and why. Reasons of inclusion were that all the criteria were met as well as the paper was not too limited in regard to the amount of qualitative findings presented, for example, only two open questions on a mixed methods

study. However, if there was still new and quality information provided from these results, the paper would be included. Upon the conclusion of the search and subsequent inclusion decisions for relevant literature, a total of 20 academic papers were included. Within this, 17 were qualitative or mixed methods studies; and 3 were classed as gray literature (e.g., commentaries, letters to the editor, and guidelines/recommendations in regard to discussing SUDEP with PWE and their families).

## 2.2. Describing and synthesizing literature

Following the narrative synthesis guidelines outlined [8,9], main author (\*) conducted the preliminary synthesis of the literature through extracting the descriptive characteristics of the studies and generated a table to summarize results (see Table 1). Next, a thematic analysis was conducted on the literature; and lastly, an assessment of the strength of the synthesis (refining and organizing themes to provide overall thematic synthesis). This was reviewed by second author (\*) and discussed with main author (\*) who then created the final synthesis.

## 3. Results

Our findings resulted in two main categories: a) understanding of SUDEP and b) discussion of SUDEP.

### 3.1. Understanding of SUDEP

The synthesis of the literature presents an overall lack of understanding of unexpected death in epilepsy for PWE and their relations [6,10–16]. Sudden unexpected death in epilepsy is an important topic that is in need of more discussion [17–19]. There is a lack of understanding of what SUDEP is and why it occurs, “Obviously, if you have too many [seizures] I assume ... that might be the case but I don't know... the ways” [10]. Others have stated that SUDEP was caused by “an ‘overloaded’ seizure or ‘bigger seizure than normal’, and several people said that it was something that happened in bed/during sleep but did not specify a cause” [10,p. 234]. Other research stated that SUDEP was caused by accidental death, for example suffocation, drowning, and being hit by a bus [11]. Some described it as very rare and another individual stated, “You just shut down and die, really, ehh from one big fit” [11]. Learning about SUDEP created shock and challenged their belief that one could not die from epilepsy [6]. Even harder to learn from, participants stated that they gained more understanding and became aware of the term SUDEP only after the death of the member of their family [6].

Additionally, there was a mixture of responses in relation to knowing what SUDEP meant and how it could occur. For instance, the acronym SUDEP was accurately described by some parents and adults with epilepsy [10,11,13]. However, this was not always the case. In adults with epilepsy, less than half of the participants knew what SUDEP was and the risks, etc. [14]. On the other hand, PWE expressed that medical professionals do not know enough about SUDEP, “They don't know exactly why it happens” [11]. This is a common thread throughout the literature. The lack of understanding was even expressed by a physician of a boy with epilepsy who had died:

“As Henry's pediatrician, it was not until a conversation with Henry's mother that I heard the term SUDEP for the first time. I had no experience with a child ever dying from epilepsy, nor was this something I ever discussed with parents.”

[12]

The lack of understanding about the risks of SUDEP and improving self-management to reduce these risks show that there is more to discuss in relation to teaching PWE, their family/friends, and HCPs about SUDEP.

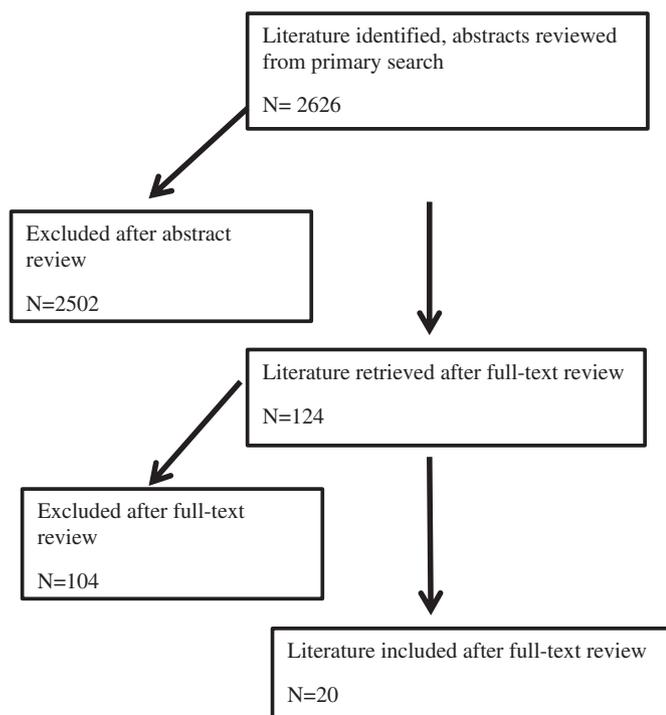


Fig. 1. Flow chart.

**Table 1**  
Summary of research findings.

Title/Authors (date)	Research question/aim	Participants	Study setting (e.g., place of study)	Method	Key findings
Recognizing and preventing epilepsy-related mortality: A call for action – Devinsky et al. (2015)	Summary of topic of SUDEP – leads to the need for prevention of epilepsy-related death	None—informational; author discusses some in first person – own epilepsy discussions	N/A	Review of literature; classifications	Misinformation; lack of education; methods to prevent epilepsy-related death; discussion of SUDEP
Many people with epilepsy want to know more: A qualitative study – Prinjha et al. (2005)	Exploration of why in 21st century people with epilepsy want more info	38 men and women	UK	Interviews; thematic analysis	SUDEP was shared to cause fear and more concrete answers/info to be shared with PWE.
SUDEP: To discuss or not? Recommendations from bereaved relatives – RamachandranNair et al. (2016)	To understand the experiences of relatives of SUDEP individuals and explore preferences regarding SUDEP counseling	27 bereaved relatives; at least 18 years old	Canada	Semi-structured interviews; directed content analysis	Experiences at the time of SUDEP; awareness of SUDEP; opinion of whether to discuss SUDEP; method and timing of SUDEP discussion; preferences for the content shared in the SUDEP discussion; perceptions of credible sources of info on SUDEP
'If you're going to die, you're going to die': Young adults' perceptions of sudden unexpected death in epilepsy – Harden et al. (2015)	Develop a better understanding of how young adults view SUDEP and SUDEP information giving in order to inform the debate of disclosure concerning SUDEP	27 young adults; 18–29 years; exclusion of high anxiety or depression	Scotland, UK	Semi-structured interviews; inductive thematic analysis	Control the occurrence of seizures through medication, lifestyle management; safeguarding techniques; SUDEP was rarely a worry, many knew little about it, lack of understanding of what it is; SUDEP info should be given to those with epilepsy, disagreement between timing of SUDEP information given (more categories within this); SUDEP information provided temporary concern, but also can lead to behavior change.
A qualitative study of the reactions of young adults with epilepsy to SUDEP disclosure, perceptions of views on the timing of disclosure, and behavioural change – Tonberg et al. (2015)	Examine young adults' responses to information about SUDEP	27 patients (15 females), aged 18–29; Hospital Anxiety and Depression score (HADS) score of <11; told about SUDEP 2 weeks prev., attend a specialist epilepsy clinic	Scotland, UK	Semi-structured interviews; inductive thematic analysis	Theme 1: Perceptions of SUDEP and risk – uncertainty in understanding of SUDEP; 2) getting information about SUDEP – views on SUDEP info giving, independent info seeking; 3) impact of being told about SUDEP – the emotional impact, behavioral impact
Increasing awareness of sudden death in pediatric epilepsy together – Lapham et al. (2017)	Provide experience of families who lost a child and his/her health provider	Henry's mother, pediatrician, and neurologist	US	Collaborative voice	Voice of those unheard; brings attention to the needs of families to be educated about SUDEP; HCP need to be educated about SUDEP; need for neurologists to discuss topic earlier
SUDEP: What do parents want to know? – RamachandranNair et al. (2013)	Exploring views of Parents of CWE—how and whether to approach SUDEP with families, timing and formulation of the information, optimal counseling strategies to deal with emotional upset	42 parents	Ontario, Canada	Focus groups and semi-structured interviews; directed content analysis	Feelings before and after meeting the neurologist, parental understanding of SUDEP, parental perceptions about routine counseling for SUDEP, parental preferences for providing routine information about SUDEP, perceptions about who should receive SUDEP counseling
SUDEP: What do adult patients want to know? – RamachandranNair & Jack (2016)	Understand the range of adult PWE's views on whether and how to discuss SUDEP with PWE and clarify timing and formulation of this information	23 participants (18–65 years); 19 – interviews, 4 – focus groups	Canada	Content analysis; semi-structured interviews and 1 focus group	Learning about SUDEP; opinion on informing patients and carers about SUDEP; benefits and disadvantages about knowing SUDEP; timing and setting of SUDEP discussion; method of discussion; what should be discussed; who should discuss SUDEP; changes after learning about SUDEP
Circumstances of death in	Study the circumstances of	34 participants (23 parents,	UK	Semi-structured interview	8 deaths not classified as

Table 1 (continued)

Title/Authors (date)	Research question/aim	Participants	Study setting (e.g., place of study)	Method	Key findings
sudden death in epilepsy: interviews of bereaved relatives – Nashef et al. (1998)	death in sudden death in epilepsy – case study using interviews, postmortem reports, etc.	5 siblings, 7 spouse/partner, 1 key worker)			SUDEP; 26 cases of SUDEP; relatives had been told or led to believe that epilepsy was not fatal; most stated in retrospect that they would have preferred to know of the possibility of premature death.
Sudden unexpected death in epilepsy (SUDEP) disclosure in pediatric epilepsy: An Italian survey on “to tell or not to tell” – Galli et al. (2017)	Examine whether HCP treating pediatric patients with epilepsy in Italy would disclose risk of SUDEP to parents	114 doctors (71 females, 43 males) for whole study, 42 answered the open questions	Italy	Mixed methods – open questions analyzed by content analysis	Timing of communication about SUDEP, handling emotions, explaining SUDEP – difficulty in handling communication of risk of SUDEP, avoidance of using words like death, prefer to address it only under the most severe circumstances, very little described their emotions of discussing it, issues in ways of addressing it—need to be educated on methods of communication
Practice guideline summary: Sudden unexpected death in epilepsy incidence rates and risk factors—Report of the Guideline Development – Harden et al. (2017)	Develop a practice guideline. 1) determine incidence rate of SUDEP in populations with epilepsy; 2) risk factors for SUDEP	Adults, children, epilepsy diagnosis	N/A	Systematic review; modified Grading recommendations assessment, development, and evaluation process; recommendations developed by consensus	Numbers of SUDEP; people with epilepsy and families prefer to be told of SUDEP; manage and reduce seizure frequency for Generalized tonic-clonic seizures (GTCS); GTCS are risk for SUDEP –presence of another in the room is linked to decrease chance of SUDEP; use nocturnal supervision or devices; PWE and families prefer to be told of risks – clinicians should inform PWE and families (particularly those with GTCS)
Report of the American Epilepsy Society and the Epilepsy Foundation Joint Task Force on Sudden Unexpected Death in Epilepsy—Special report – So et al. (2009)	Assess the state of knowledge about SUDEP – develop a position statement about discussing SUDEP; design methods by which the medical and lay communities become aware of the risk of SUDEP; recommend research directions with SUDEP; explore steps to perform large-scale studies of SUDEP to identify risk factors; identify possible preventative strategies for SUDEP	AES and EF Task Force	US	Report of the outcomes of the Task Force	Risk of epilepsy-related death should be discussed with all patients; SUDEP discussion once diagnosis is made – if they ask or not; individualization of material according to SUDEP risk; future research to ascertain the best method of providing the information; tremendous need for more research – this is discussed in more depth (type, etc.)
Should all patients be told about sudden unexpected death in epilepsy (SUDEP)? Pros and cons – Brodie & Holmes (2008)	Overview of SUDEP and recommendations for discussion	Case report included (woman who died suddenly); geared toward medical professionals	UK, US	Advice, case study report; guidelines	Ethical dilemma around disclosure – cause pain to patient?; epilepsy information pack should be supplied; family members should be involved in discussion; individualized approach on disclosure of risk to patients; disagreement between authors if disclosure about SUDEP should be to all patients
Sudden unexpected death in epilepsy: measures to reduce risk – Mclean et al. (2016)	Provides strategies that may help clinicians to improve person-centered communication when dealing with epilepsy, to reduce risk of SUDEP	None – but use a quote from a patient from SUDEP action	UK	Summary of literature/reflection/guidance to new technology to use and how it would be appropriate	Timing of discussions should be individualized – preferably at an early stage; patient empowerment to prevent SUDEP; SUDEP risk checklist; useful websites for SUDEP info; telehealth, mobile health, device technology; future developments

(continued on next page)

Table 1 (continued)

Title/Authors (date)	Research question/aim	Participants	Study setting (e.g., place of study)	Method	Key findings
Discussing sudden unexpected death in epilepsy (SUDEP) with patients: Practices of health-care providers – Miller et al. (2014)	Describe the practices of epileptologists, neurologists, and advanced practice nurses (APN) regarding discussing SUDEP with their patients, rationale for discussing SUDEP	43 participants – 19 epileptologists, 16 neurologists, 8 APNs	US	5 focus groups – 2 epileptologists, 2 neurologists, 1 APNs; conventional content analysis	Reasons for discussing SUDEP (practical accountability, moral accountability, proactivity, reactivity); reasons for not discussing SUDEP (not at first, moral accountability, out of options); ways in which SUDEP should be discussed (discussion – face to face, unscripted), written materials, standardization
'Breaking Good News': Neurologists' experience of discussing SUDEP with patients in Scotland - Nisbet et al. (2017)	Explore experiences of neurologists when discussing SUDEP with their patients	10 participants (6 consultant neurologists; 4 registered doctors)	Scotland, UK	Interviews; thematic analysis	SUDEP protocol/conversation—two conversations—one for new patients and one for chronic uncontrolled seizures; diffusion of the Fatal accident inquiry (FAI) into practice; ambivalence discussing SUDEP – important and beneficial to discuss, should patients be burdened with the worry; falsely anticipating distress – discussion will cause anxiety for patient and family, different ways of discussing topic; pressure hinders communication – not all liked the requirement to discuss it, could hinder patient/doctor communication
Experiences with pre-morbid SUDEP discussion among participants in the North American SUDEP Registry (NASR) – Louik et al. (2017)	Examine attitudes toward SUDEP discussion among family members of NASR	138 descendants—mix of parents/spouse, etc.	Canada and US	Semi-structured interviews via telephone; exploratory analysis	Discussing SUDEP with neurologist (some instigated conversation, some had neuro instigate, some appreciated, some did not); for those who could not remember conversation, some wished they had had it, some did not, and some were unsure; information that should have been discussed—info on SUDEP, incidence rate/risk factors of SUDEP, preventative measures, importance of Antiepileptic drug (AED) adherence
SUDEP – Whether to tell and when? – Black (2005)	Examine the potential consequences of providing information of SUDEP and analyze ethical issues involved	Summary of research	N/A	Review of research with advice	Raising the topic of SUDEP may cause anxiety and distress – causing the patient not to be able to make a good choice of treatment; choice between discussing the topic; patients need the necessary information in order to pursue treatments; presents opportunities for discussion and issues within that
Sudden unexpected death in epilepsy (SUDEP): don't ask, don't tell? – Morton et al. (2006)	What circumstances did they (neurologists) tell their patients about SUDEP	387 participants (288 neurologists, 63 specialist registrars, and other specialists and nurses); 299 responded to qualitative question	UK	Mixed methods – questionnaire with reactions of patients captured as qualitative data	Mixture of responses from patients – calm, alarmed, pragmatic; mixture of responses concerning telling patients – not always, combined with treatment, if another member of the family has died from SUDEP (those are all examples)
Explanations given by people with epilepsy for using emergency medical services: A qualitative study – Ridsdale et al. (2012)	Describes why PWE use Emergency medical services (EMS)	19 participants	UK	Nested study; semi-structured interviews; thematic analysis	Fear that they could die at any point—sudden and unexpected

### 3.2. Discussion of SUDEP

Literature exploring current methods of discussing epilepsy-related death focused on how, why, and when information about SUDEP should be discussed with PWE and their family [6,10–19]. There is, however, a lack of discussion on the topic of epilepsy-related death in general.

#### 3.2.1. How information is and should be provided

People with epilepsy and their family/friends feel the need to have the knowledge of the dangers of SUDEP [4,6,10,11,13,14,20,21]. Some felt that they had received sufficient information and felt reassured by HCPs that they should not worry about SUDEP [10]. Basic information was sufficient for some, but it was helpful if it was put into perspective of how it relates to their individual situation: “I liked being told how it related to me... just having someone to put it into perspective” [10]. Research shows that HCPs are sharing information to patients about SUDEP and the hazards of living with epilepsy [10,21–23], but there are still avenues to explore to allow more PWE and family/friends to learn and understand what SUDEP is and what can cause epilepsy-related death.

In terms of the most effective methods of providing information, multiple avenues have been discussed (e.g., pamphlets, HCP discussions, internet, etc.) [6,10,11,13,14,17,18,20,22–24]. Although some individuals were satisfied with information presented online, there was also a preference to being provided with SUDEP information by their clinician, “I’d rather ask them [clinicians] rather than get a second hand opinion online” [10, p. 235–236]. The trustworthiness of the information online was questioned, and this is one reason why some individuals desired to hear directly from their HCP rather than search for information online [10]. A consensus throughout the research was that any information provided should be in a face-to-face context [6,10,11,13,14]. Although not completely opposed to written information (e.g., information leaflet), it was not enough and was deemed a less effective method [10,11]. Both face-to-face discussions along with written information was key:

‘I think you should hear it face-to-face because a lot of the times when the doctors are talking to me I’m hardly even listening, that’s why my mom’s always with me. Because she’s getting it all in. But I think you should get it face-to-face and you should get a book or something, something explaining everything.’

[[14,pg. 197]]

Regarding who should provide the information, it was agreed that a person, e.g., epilepsy nurse specialist (ENS) would be appropriate:

‘The epilepsy nurses I would say...I feel they’ve got like a bit more time for you I would say, and they probably become...attached is not the right word but they, they know you more, I would say, than the doctors.’

[[10]]

Others stated that information about SUDEP should be provided to the patient or family members by the patient’s neurologist as he/she would be the most knowledgeable and was in charge of the individual’s long-term healthcare plan [6,13,14]. This information would need to be communicated with compassion and sensitivity and perhaps a social worker may also be available to provide information [6,13,14]. Family physicians and emergency department staff should not be the first to initiate this discussion [6,13,14]. As important of how the information concerning epilepsy-related death should be discussed, the timing of the discussion was important as well [10,11,16,20,22,23,25].

#### 3.2.2. Why SUDEP information is provided

One reason why information about SUDEP should be provided is to encourage good self-management (e.g., medication adherence, sleep, etc.) of epilepsy [4,6,10,11,13,14,17–19,22,25]. People with epilepsy and

their families share that they need to know about the risks of their condition:

“One of the questions, which I’m sure all epileptics would like to have answered, is more concrete answers on SUDEP, which is a very worrying question but it’s something that seems to be very hazy, but we have absolutely no idea what is the concrete cause of it. It’s just quite scary to think that one night we, any one of us, might just go to sleep and never wake up”

[[4,p.439]]

“You have a right to know. It’s not up to someone else to decide whether it’s a good or bad thing for you to have knowledge of something if it applies to you, absolutely. I really kind of resent the idea that a doctor in particular would not share that information because he had some personal feelings about ‘that’s not good for her [to know about SUDEP]”

[[5,p. 22–23]]

For HCPs, the reasons for discussing SUDEP are to allow the individuals to know the risks of uncontrolled epilepsy [22,23]:

“We talk about things like accidents that can occur, injuries that can occur, not driving, fatalities that can result from driving. I think SUDEP should be just part of that practical discussion.”

[(Epileptologist, [22,p. 30])]

“We inform every one of them that there are possibilities of complications that might include sudden death, with or without an accompanying seizure...so they have that information to base decisions on.”

[(Neurologist, [22,p. 39])]

“You talk about well, you’re already concerned and nervous about this when you react to—about SUDEP. You are already worried so let’s talk about what you can do. What can you do to try to prevent this? Give them some information to use.”

[(Advanced practice nurses (APN)) [22]]

“Well there are many patients with long-standing epilepsy who may have been diagnosed in the days when SUDEP wasn’t discussed but if a long-standing patient were to bring up concern about their risks of seizures or potential of harm then we would have a discussion about that as well.”

[(Consultant, Ss3) [23]]

Although literature discusses the importance of providing information to aid management of epilepsy, negative consequences were also discussed [6]. For example, parents with a child with epilepsy or a spouse of a person with epilepsy had an increase in anxiety and fear that he/she may die [6,13].

“In the case of SUDEP, to alarm somebody unnecessarily is concerning. If there’s a purpose—if you can benefit the patient then that’s a different matter. I think that to me the key is how will this benefit the patient versus unnecessarily alarming the patient and the family and alerting them to something that we really can’t do anything about.”

[(Epileptologist, [22,p. 40])]

“You have to consider will this just serve to make them more anxious, or can it actually help?”

[(Neurologist) [22]]

As discussed above, HCPs are the main providers of information on epilepsy-related death. Although guidelines discuss the importance of

discussions with patients and family members in regard to unexpected epilepsy-related death [17,18], there is still a mixture of responses in relation how and when SUDEP and epilepsy-related death should be discussed.

### 3.2.3. When to discuss SUDEP

The literature reported different opinions in the timing of providing information to PWE and their families/friends. This difference was shared by PWE, their family/friends, and HCPs. Some PWE and their families/friends believed that it should be discussed at the first diagnosis consultation and were angry, shocked, and anxious at not knowing that it could be a risk [6,10,11,13,14,22]: “You don’t wanna be in the dark about something that’s part of you...but I think that the time needs to be chosen carefully” [11,p.,101]. However, others also thought that it should be individualized (e.g., children not to know until a teenager) and the time be chosen carefully to limit the negative emotional impact, particularly in relation to individuals who were anxious, depressed, or had learning difficulties [6,10,13,14].

“I suppose that’s a judgement for the doctors and consultants and things to make if they think you can handle then you may as well have it all as soon as possible, but if you’re a more anxious person, or it’s more complicated ... maybe do it in chunks.”

[[10]]

“The one after [diagnosis]...cos getting epilepsy’s a bit of a shock to everybody never mind finding out that you could die from it.”

[[11,p.,101]]

“Maybe right away I think. Just you can never be too safe. So I think, it is scary, but like I said sometimes you just you have to be prepared for things and it’s good to know.”

[[14]]

One spouse stated, “So, on that first visit to the neurologist, you know when they are telling you that you can’t drive for six months? Maybe you ought to mention it at that point, you know, you just broke the news you can’t drive, you might as well tell us the rest of the bad news, which is you know, you could die in your sleep.”

[[6]]

For HCPs, there was also a mixed consensus in relation to the timing of the discussion of the risk of SUDEP. Some thought that it should be upon diagnosis, after some time, and individualized [15,17,18,21,22,25]:

“You shouldn’t counsel on SUDEP during the first encounter,” “It is important to schedule the meeting and to not be in a hurry,” “I never talk about SUDEP in a single meeting,” and “I never counsel on SUDEP at the moment of diagnosis, but later.”

[[16,p. 35]]

“I’ve moved toward trying in the first visit, or one of the first visits, because actually one of my concerns is that the educated patients are gonna go read about it somewhere else, and be upset that they hadn’t had the discussion.”

[(Epileptologist) [22,39,p.]]

“I think [as a] preventative it’s an important discussion to have and approaching it from a safety standpoint.”

[(APN) [22]]

The timing of when to discuss the topic of SUDEP also depends on the patient’s compliance to medication and good self-management [22].

“I only discuss it in those settings where I felt that people weren’t being compliant.”

[(Epileptologist) [22]]

“I’m not comfortable with every family to discuss [SUDEP]. I’d rather put it as a—I would say as a weapon when they are not agreeing with the medications.”

[(Epileptologist) [22]]

“Generally, I don’t talk...about it unless—the older patients are really noncompliant with medications. I tend to worry about them and start talking to them about all the possibilities.”

[(Neurologist) [22,39,p.]]

“I make sure that any of my kids who are teenagers are going away to college—that I have that discussion...they’re not under the parents’ vigilant eyes.”

[(APN) [22,40,p.]]

### 3.2.4. Discussion of SUDEP by HCPs

Specifically aimed at HCPs, literature and guidelines in relation to discussing SUDEP with PWE and their families show the importance of education to reduce the risk of unexpected epilepsy-related death [17–19,22,23,25]. However, within the literature, there was a mixture of responses in relation to HCPs discussing the topic with PWE and their families. For example, one neurologist described why he started to discuss the topic of SUDEP with patients:

“Before Henry’s death, I would wait for families to raise their fears, to the extent they occurred, by asking them non-specifically if they had any questions. If the concern for mortality was not raised, I would often defer the conversation for another visit, if at all. After Henry’s death, I still wait patiently for families to raise their own questions and fears, but if that question does not arise before the close of a clinic visit, I now directly ask what their greatest fear is, and it is invariably harm from seizures and death. When there is no response to my question, then I ask directly, ‘Do you fear your child will be harmed or die from their seizures?’ Capable and skilled physicians do not often discuss mortality. Yet, families wish to discuss these matters at the first visit, not later, and expect their doctor to do so. This is part of our duty and responsibility as physicians.”

[[12]]

As discussed, reasons of why HCPs discuss the topic vary. The worry of a negative emotional reaction causes some physicians to not discuss the topic unless questioned [22,23,26]. However, others use personal insight as to why they should discuss the topic:

“If I were him/her, I would want to know”; “Because I’ve lost a patient from SUDEP”; “I would be worried about the consequences for my own job of not speaking out”

[[23]]

Research conducted with HCPs concerning this topic share the moral and proactive reasons why a discussion of SUDEP should be conducted [22]:

“At some point in time, a conversation has to take place about what the end of life will be. Don’t want caregivers to spend the rest of their life with guilt if they come into the nursery one morning and find the child blue and cold.”

[(Neurologist)]

“You don't want to put up fear, but it is something that does have to be discussed...or we aren't doing our jobs.”

[(APN)]

“I've moved toward trying [to talk about epilepsy-related death] in the first visit, or one of the first visits, because actually one of my concerns is that the educated patients are gonna go read about it somewhere else, and be upset that they hadn't had the discussion.”

[(Epileptologist)]

“I would do it early on, rather than them finding it on the Internet, and then coming in talking to me.”

[(Neurologist)]

Although there were a mixture of responses in terms of timing and amount of information, some literature did discuss the positive impact on self-management through providing information about SUDEP. Upon reviewing literature on how, why, and when these discussions might take place, the impact on the PWE and his/her family will next be presented.

### 3.3. *Impact of learning about epilepsy-related death*

Most literature reported a positive impact on self-management after discussing the risks of SUDEP [6,10,13,14,17,18,22,23]. Upon learning about SUDEP risks, some research found more adherence to taking medication, positive adjustments to diet, decreased alcohol consumption, and adequate sleep was obtained [6,10,11,13,17,19].

“I got a wee bit more strict ... about when I take my tablets.”

[[10]]

However, this being said, the literature also shows that there can be a fatalistic viewpoint of the risks of having epilepsy [6,10,11,13,14]:

“It's [death] not something that I have to deal with every day ... it's just, it's not something that concerns me on a daily basis ... I don't take my medication because of SUDEP... yeah, I just do it to get on with my day.”

[[10]]

“If it's [death] gonna happen it's gonna happen there's not much I can do.”

[[11,p.,102]]

There was a mixture of findings in relation to managing PWE's health to reduce the risk of SUDEP. Learning of the risks of SUDEP presented the concern of negative emotional reactions that could cause more stress and worry than had the individual(s) not known [6,10,11,13,14,22]. There seems to be a consensus that one of the reasons behind discussing the topic of unexpected epilepsy-related death is to aid the individual to decrease their chance of possible complications. This being said, there was still an emotional impact upon learning and teaching about unexpected death in epilepsy.

#### 3.3.1. *Emotional impact*

Discussed in earlier sections, there was an emotional impact that has been shown in relation to discussing SUDEP, living with the possibility of SUDEP, as well as coping with the loss of a close family member, friend, or spouse/partner [6,13,14,17,19]. Although not always maintained over a long period of time, anger, worry, shock, stress, guilt, and fear were common emotional responses to learning about SUDEP [6,10,11,13,14,16,22,23,26].

“I was furious because the doctors all this time had known about it and had never said anything. [Husband's name] had gone his whole life thinking that [epilepsy] was just a condition and not

aware that having a seizure would bring him closer to a risk of possible SUDEP.”

[[6,22,p.]]

“I felt gutted, like ... cos ..., I found out that there was a, a new concept of dying ... and ... it was like: 'what?' ... ehh ... but then ... as the weeks went by you just sort of put it to the back of your mind and then you, you forget about it and then you move on I guess.”

[[10,p.,236]]

“I was totally shocked. Because I didn't know that that [SUDEP] was possible.”

[[14]]

Additionally, upon learning about the risks of death for their child, parents have expressed fear that leads to being highly stressed and vigilant when their child was sleeping as well as during most of his/her activities [13]. The emotional impact of learning about the risks of unexpected death in epilepsy has also shown to cause friends and family members to call emergency medical services:

“[I] just worried because I don't know anything about epilepsy and I don't...I mean I only know the bad things, I know it can be quite serious and things like that, and I know you can die from it so I decided...I was so worried I decided just to ring an ambulance... better safe than sorry.”

[[27]]

People with epilepsy also have expressed that for fear of sudden death, they would want the emergency services called:

“I don't want to die. [A]nything could happen, you see this epilepsy can happen to you, anywhere you know. So happy to call 999 for me.”

[[27]]

“Felt this thing was catching me, afraid I might die, and no one knows, that is why [the services were called].”

[[27]]

Although there is a strong negative emotional reaction, unexpected death has also been seen as an aspect of life [10,p.,236]:

“I'm kinda, a believer in fate type of thing, so if something's gonna happen, it's gonna happen anyway, but ... you can't really live your life in fear of what might happen.”

“Everything kind of has some kind of risk of death, doesn't it? To a degree ... so might as well just get on.”

Some PWE and family members did not become overly scared or worried upon learning about SUDEP and welcomed the discussion about this risk. However, a common response was, “I really don't want to know about that” [26].

## 4. Discussion

These findings present the multifaceted aspects of discussing and learning about SUDEP. As a recently heightened term, the bulk of the literature explored the fears, shock, anger, and worry about this aspect of living with epilepsy. Additionally, guidelines [17,18] presented the importance of discussing this term with one's patients to limit the anger and negative emotions that coincide. Our findings show the conflicting perceptions, feelings, and thought processes that occur in

deciding to discuss epilepsy-related death as a HCP as well as a PWE or family/friend of a PWE. However, although this conflict is present, the overall literature suggests that it would be appropriate and necessary to discuss the topic of SUDEP with patients and their family members even upon diagnosis.

This narrative synthesis has presented qualitative insights into how SUDEP is being discussed and the impact of such discussions. However, there were limitations in conducting this synthesis. In focusing on qualitative and gray literature, one of the main objectives was to present personal insight into the perceptions and feelings upon discussing and learning about epilepsy-related death. The literature did present such insight; however, the bulk of the literature found was exploring the topic of SUDEP rather than other aspects of epilepsy-related death (e.g., suicide as a result of depression) [3]. Additionally, the literature presented reviews or commentary on the topic of SUDEP. This did not meet the criteria for inclusion, thus limited the literature in our study. A further limitation was the lack of literature exploring the topic within non-Western regions. This limits applicability to those outside of westernized countries and thus fails to present the possible cultural impact and differences in the desire to learn about SUDEP, impact upon learning about SUDEP, as well as HCPs' thoughts of discussing SUDEP. Although the views of both genders and different ages of PWE were presented, there was not an abundance of literature to compare the differences between stages of life, age at diagnosis, and gender. Additionally, the limited amount of qualitative literature presenting the views of HCPs limited the in-depth and cross-disciplinary views regarding SUDEP.

## 5. Conclusion

The results of this narrative synthesis add more depth for further exploration on the methods, timing, and impact of discussing SUDEP. With guidelines published [17,18], it is hoped that further insight into the methods of delivering this information can be appropriately utilized to aid emotional reactions to SUDEP and in addition, improve self-management to reduce the risk of SUDEP.

## Conflict of interest

There are no conflict of interests.

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