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

1. Introduction

People with epilepsy (PWE) have a two-to-three-fold 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 unexpected death causes PWE to desire to learn more about this aspect of living with epilepsy, particularly those with refractory epilepsy (4). SUDEP is the most common cause of death for PWE (5), yet PWE are not always told about this high risk (6). Although research within epilepsy-related death causes and prevention has increased, the qualitative insight of PWE, their family, friends, and healthcare providers (HCP) needs to be presented. This would enable further insight into what may aid adherence to management strategies, what is known about SUDEP, and the psychosocial impact the knowledge of SUDEP 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 and promote interventions of unexpected death of people with epilepsy. .

Addressing this need, we aimed to: a) present the experiences of PWE (e.g. children, teenagers, adults) discussing their thoughts and beliefs of SUDEP, what PWE have been told about SUDEP by their HCP, and their thoughts and feelings about interventions to prevent unexpected death; b) friends/family of PWE 's thoughts and feelings of SUDEP, and their thoughts and feelings on interventions to prevent SUDEP; 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 grey literature within epilepsy-related death. This was through combining different types of evidence (e.g., qualitative research, mixed-methods research, grey literature) and examining relationships within and between studies and reports (7).

2.1 Search strategy: A comprehensive electronic literature search of all relevant peer-reviewed qualitative studies and grey literature was conducted (see Figure 1). Databases included: 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 organisational websites (e.g., Epilepsy Foundation), personal contacts and social media were used to unearth other available sources, particularly unpublished literature. Hand searching 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 grey 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 recognisable, 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, main author (*) found the initial literature exploring the topic of SUDEP. To allow a more thorough search of the literature, ongoing adaptation of search terms, methods, and discussions with the co-author (*) in regards to opening up inclusion criteria was conducted. After a comprehensive literature search, the decisions of inclusion of literature were discussed with the (second author *). 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 regards to the amount of qualitative findings presented. For example, only two open questions on a mixed methods study. 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 grey literature (e.g. commentaries, letters to the editor and guidelines/recommendations in regards to discussing SUDEP or epilepsy-related death with PWE and their families).

2.2 Describing and synthesising 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 organising themes to provide overall thematic synthesis). This was reviewed by (second author*) and discussed with (main author*) who then created the final synthesis.

[Figure 1 here]

3. Results

Our findings resulted in two main categories: a) Understanding of SUDEP; and b) Discussion of SUDEP.

3.1 Understanding of epilepsy-related death

The synthesis of the literature presents an overall lack of understanding of SUDEP for PWE and their relations (6, 10-16). SUDEP 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, p.234). Others have stated 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 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, p.100). 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, p.100). 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, p.2)

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.

3.2 Discussion of SUDEP

Literature exploring current methods of discussing epilepsy-related death focused on the education of PWE and their family in relation to SUDEP (6, 10-16, 17-19). There was, however, a lack of discussion on the topic of epilepsy-related death in general.

3.2.1 How information is and should be provided

PWE and their family/friends feel the need to have the knowledge of the dangers in relation to SUDEP (4, 6, 10, 11, 13, 14, 20, 21). Some felt 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, p.235). 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, than the doctors.” (10, p.101)

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 Discussion of epilepsy-related death by HCPs

Literature and guidelines in relation to discussing SUDEP with PWE and their families show the importance of education to reduce the risk of 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, p.2)

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, p.334)

Research conducted with HCPs concerning this topic share the moral and proactive reasons why a discussion of epilepsy-related death, in particular about SUDEP should be conducted (22, p.40):

> "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 are a mixture of responses in terms of timing and amount of information, there positive impact upon self-management through providing information about SUDEP/ epilepsy-related death can also be shown. (edit?)

3.2.2.1 Why epilepsy-related death information is provided

One reason why epilepsy-related death information 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). PWE 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 epilepsy-related death 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.” (APN)
>
> (22, p.39)
>
> “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, p.74)

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, p.40)

As discussed above, HCPs are the main providers of information on epilepsy-related death. Although new guidelines discuss the importance of discussions with patients and family members in regards to SUDEP and epilepsy-related death (17, 18), there is still a mixture of responses in relation to when and how SUDEP and epilepsy-related death should be discussed.

3.2.2.2 When to discuss epilepsy-related death/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 it should be individualised (e.g. children not to know until a teenager) and the time 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, p.23)
>
> “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, p.197)

> 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, p.23)

For HCPs, there was also a mixed consensus in relation to the timing of the discussion of the risk of SUDEP. Some thought it should be upon diagnosis, after some time, and individualised (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, p. 39)

> “I think [as a] preventative it's an important discussion to have and approaching it from a safety standpoint.” (APN) (22, p.39)

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, p.39)

> “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, p.39)

> “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, p. 39)

> “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, p. 40)

Upon reviewing literature on why, how and when these discussions might take place, the impact upon the PWE and his/her family will next be presented.

3.3 Impact of learning about epilepsy-related death

There is mostly 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, p.236)

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, p.236)
>
> "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 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 SUDEP.

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, p. 22)

> "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, p.196)

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

> "[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, p.531)

PWE 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, p.531)
>
> "Felt this thing was catching me, afraid I might die, and no one knows, that is why [the services were called]." (27, p.532)

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 uponlearning about SUDEP and welcomed the discussion about this risk. . However, a common response was, ''I really don't want to know about that'' (26, p.201).

4. Discussion

These findings present the multifaceted aspects of discussing and learning aboutSUDEP. 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 and epilepsy-related death with patients and their family members 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 grey literature, one of the main objectives was to present personal insight into the perceptions and feelings upon discussing and learning about SUDEP. Further limitations are shown in 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 upon 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 was presented, there was not an abundance of literature to compare the differences between stages of life, age at diagnosis, and gender. Additionally, as the aims of this paper were to capture the personal views and lived experiences through qualitative research, the small amount of 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 utilised to aid emotional reactions to SUDEP and in addition, improve self-management to reduce the risk of SUDEP.

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