



Nisbet, T., Turnbull, S., Mulhern, S., and Razvi, S. (2017) 'Breaking Good News': Neurologists' experiences of discussing SUDEP with patients in Scotland. *Epilepsy and Behavior*, 70(Pt. A), pp. 72-79.  
(doi:[10.1016/j.yebeh.2017.02.024](https://doi.org/10.1016/j.yebeh.2017.02.024))

This is the author's final accepted version.

There may be differences between this version and the published version. You are advised to consult the publisher's version if you wish to cite from it.

<http://eprints.gla.ac.uk/140099/>

Deposited on: 21 April 2017

**‘Breaking Good News’: Neurologists’ experiences of discussing SUDEP with patients in Scotland.**

Authors:

(Given name first, family name second)

Dr Tom Nisbet<sup>a</sup>

<sup>a</sup>Psychological Services, NHS Ayrshire and Arran, Ayrshire Central Hospital, Scotland, KA12 8SS. [Tom.Nisbet@aapct.scot.nhs.uk](mailto:Tom.Nisbet@aapct.scot.nhs.uk)

Dr Sue Turnbull<sup>b</sup>

<sup>b</sup>Mental Health and Wellbeing, University of Glasgow, Gartnavel Royal Hospital, 1055 Great Western Road, Glasgow, Scotland G12 0XH. [Sue.Turnbull@glasgow.ac.uk](mailto:Sue.Turnbull@glasgow.ac.uk)

Dr Sharon Mulhern<sup>c</sup>

<sup>c</sup>University Hospital Crosshouse, Kilmarnock Road, KA2 0BE, Scotland.  
[Sharon.Mulhern@aapct.scot.nhs.uk](mailto:Sharon.Mulhern@aapct.scot.nhs.uk)

Dr Saif Razvi<sup>d</sup>

<sup>d</sup>Department of Neurology, Queen Elizabeth University Hospital, 1345 Govan Road, Glasgow G51 4TF, Scotland.  
[Saif.Razvi@ggc.scot.nhs.uk](mailto:Saif.Razvi@ggc.scot.nhs.uk)

Corresponding author:

Dr Tom Nisbet, Clinical Psychologist  
Psychological Services  
Department of Clinical Health, Older Adults & Neuropsychology  
Ayrshire Central Hospital  
1st Floor, Horseshoe Building  
Kilwinning Road  
Irvine, Scotland  
KA12 8SS

[Tom.Nisbet@aapct.scot.nhs.uk](mailto:Tom.Nisbet@aapct.scot.nhs.uk)

Final Publication DOI (Epilepsy and Behavior): <http://doi.org/10.1016/j.yebeh.2017.02.024>

## **Abstract**

Since the findings of a Fatal Accident Inquiry (FAI) in 2010, clinicians working in Scotland have been advised to discuss the risk of Sudden Unexpected Death in Epilepsy (SUDEP) with patients immediately or soon after a diagnosis of epilepsy is made. A thematic analysis was used to describe the experiences discussing SUDEP of 10 clinicians (six Consultant Neurologists and four Neurology Registrars) working in Scotland. Contrary to previous research, clinicians appear to be routinely discussing SUDEP in a standardised fashion with newly diagnosed patients and the FAI appears to have instigated this change in practice. Clinicians are ambivalent about the practice and whether this is a Breaking Bad News (BBN) experience. Clinicians appear to anticipate that patients will be anxious or distressed discussing SUDEP, despite their experiences that patients do not react this way. There are further concerns that the pressure to discuss SUDEP, as a result of the FAI, hinders effective communication of the SUDEP message. Implications for guideline development are discussed.

## *Highlights*

- A qualitative examination of Neurologists' experiences discussing SUDEP with patients
- Clinicians state they are regularly discussing SUDEP with patients who have newly been diagnosed with epilepsy
- Clinicians feel ambivalent about discussing SUDEP despite indicating the experience is not distressing for themselves, or apparently for their patients
- Clinicians raise concerns about being under pressure to discuss SUDEP, and the implications this has for the quality of their communication

*Keywords: SUDEP, epilepsy, qualitative, thematic analysis, neurology practice, breaking bad news*

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Abbreviations: Sudden Unexpected Death in Epilepsy (SUDEP)  
Breaking Bad News (BBN)  
Fatal Accident Inquiry (FAI)

## **1. Introduction**

Epilepsy is a chronic long term neurological condition affecting approximately 1 percent of the population and is associated with significant morbidity and mortality. However, it has been suggested that in the 20th century the risk of death due to epilepsy became minimised then denied by the medical community [1]. It was not until 1996 that the term ‘Sudden Unexpected Death in Epilepsy’ (SUDEP) was proposed [2]. SUDEP is defined as “sudden, unexpected, witnessed or unwitnessed, non-traumatic and non-drowning death in a patient with epilepsy, with or without evidence for a seizure, and excluding status epilepticus, where the autopsy examination does not reveal a toxicological or anatomical cause of death.” [3, p66]. SUDEP is more common in younger individuals, with an incidence rate of approximately 1 in 1000 individuals with epilepsy [9]. The mechanism of SUDEP is not fully understood but may involve impaired autonomic, cardiac and respiratory function [4]. Individuals with epilepsy may potentially reduce the risk of SUDEP by lowering seizure frequency and by compliance with anti-seizure medications [5, 6].

Harden, et al [13] reported young adults with epilepsy were keen to have a SUDEP discussion with their clinician preferably during the session they were diagnosed with epilepsy, or soon thereafter. Parents of children with epilepsy also wish to be informed about SUDEP during their first discussion of epilepsy [14, 15]. Despite the literature and guidelines, it has been reported that clinicians are not regularly having SUDEP discussions with their patients. For example, Morton, et al [16] analysed 387 questionnaires when surveying the practice habits of UK based Neurologists. Approximately 70% discussed SUDEP with ‘very few’ or ‘none’ of their patients. Similarly, of 1200 American and Canadian Neurologists surveyed in 2012, less than 7% reported routinely discussing SUDEP with all patients [18] and a perceived negative reaction to discussions of SUDEP was common.

Miller, Young, Friedman, Buelow, and Devinsky [19] used a qualitative approach to understand the practice of American clinicians when discussing SUDEP. A theme of ‘moral accountability’ was present when clinicians expressed a reluctance to discuss SUDEP with their patients if they felt it was ‘morally wrong to give information about a complication that is poorly understood and difficult to prevent’ [19, p40]. Clinicians wanted to wait until rapport was built with their patients before discussing SUDEP and there was a reluctance to discuss SUDEP if all treatment options had been tried.

Clinicians may fear a negative response from patients during breaking bad news (BBN) experiences, and clinicians can feel responsible for the bad news [20, 21]. BBN is especially difficult when there are limited options for treatment [22] or if there is a feeling of inadequacy treating an uncontrollable disease [23].

### *1.1 National Guidelines and Context*

National Institute of Clinical Excellence (NICE) guidelines in the United Kingdom specify that following a first seizure, patients should see a specialist in the management of epilepsy [10]. Discussion regarding SUDEP with patients should contain ‘tailored information’ that ‘takes account of the small but definite risk of SUDEP’ [10, Section 1.3.13, p16] However, access to this information should depend on the certainty of the diagnosis [10]. The American Epilepsy Society and the Institute of Medicine recommend that the increased risk of death associated with epilepsy be disclosed to patients [11, 12].

In Scotland, where this research was conducted, Neurologists are also likely to be aware of a Sheriff-led Fatal Accident Inquiry (FAI) into two patient deaths in 2010 [26]. This established that two Scottish Health Boards were at fault for not informing these patients, and their parents, of the risk of SUDEP and that the ‘vast majority’ of patients should be informed about SUDEP upon being diagnosed with epilepsy or it should be recorded as to why this did not occur. An indication of the impact of this on the clinical practice of Neurologists can be seen by comparing a study conducted on medical records from 2004 to 2009 which identified that only 4% of 345 patients with epilepsy had a documented discussion of SUDEP in their records [17] with one conducted in 2013/14 which found that newly diagnosed young adults with epilepsy in Scotland had been uniformly informed about SUDEP following diagnosis [13, 24]. Scottish Intercollegiate Guidelines Network (SIGN) guidelines published in 2015 advise that: ‘Counselling about the risks of sudden unexpected death in epilepsy should be considered for patients with epilepsy at an appropriate time for the patient and by an appropriate healthcare professional’ [27, p55].

## *1.2 Aim*

To explore the experiences of Neurologists when discussing SUDEP with their patients and develop themes to account for these.

The objectives of the research were to understand how the participants discussed SUDEP; how the participants felt when discussing SUDEP (including their thoughts on the impact of the discussion on patients); how they classified good and bad experiences when discussing SUDEP; methods of support utilised or envisioned; feelings about the legal/legislative context to discuss SUDEP and reflections on the practice; as well as assessing if similar themes identified in previous research were present [19].

## **2. Material and Methods**

### *2.1 Participants*

Consultant Neurologists and Registrar Doctors were considered for inclusion in the research (typically, Registrar Doctors who specialise in Neurology will have at least 4 years of clinical training in neurology before becoming a consultant).

### *2.2 Recruitment and Interview Procedures*

Ethical approval was obtained from the school of Medical, Veterinary and Life Sciences at the University of Glasgow. Clinicians were asked to participate following the researcher attending a departmental educational meeting of the West of Scotland Neurology Service (a group of Consultant Neurologists and Registrar Doctors). A set of questions was developed by examining the previous literature and consulting with the Consultant Neurologist Field Supervisor (Appendix A). Supplemental questions were asked based on the content of the interviews.

### *2.3 Qualitative Design and Research Procedures*

A thematic analysis was conducted as previous research had used a similar approach to investigate the experiences of American clinicians’ practice of discussing SUDEP [19] and it was felt a comparison of practice would be useful. The researcher used an inductive approach to analysis [29] and themes were primarily identified using a semantic approach;

taking themes from the explicit statements of participants. The research procedure was conducted in line with Braun and Clarke’s [29] proposed six phases of thematic analysis. Data was anonymised and stored in line with the University of Glasgow’s policy on confidential data. After the 8<sup>th</sup> interview no novel themes were found indicating that data saturation had occurred.

### 2.4 Reflexivity

Blumer [32] describes the assumptions and prior knowledge of a researcher as ‘sensitizing concepts’. Therefore, the researcher’s background as a Trainee Clinical Psychologist is relevant. Issues of support and the psychological impact of breaking bad news were areas of interest to the researcher. The researcher’s own thoughts and interpretations were monitored by keeping a reflective log throughout the research process.

## 3. Results

Six Consultant Neurologists and four Registrar Doctors participated in the research. The participant details are shown in table 1.

Participant Number	Role	Number of years practising in current role	Length of interview (mins)
Ss 1	Registrar Doctor	5	34.22
Ss 2	Registrar Doctor	4	36.36
Ss 3	Consultant Neurologist	16	32.33
Ss 4	Consultant Neurologist	15	33.11
Ss 5	Registrar Doctor	2	44.07
Ss 6	Registrar Doctor	4	39.54
Ss 7	Consultant Neurologist	10	44.07
Ss 8	Consultant Neurologist	3	35.25
Ss 9	Consultant Neurologist	7	25.20
Ss 10	Consultant Neurologist	2.5	27.24 (Phone interview)

Table 1: Participant characteristics and interview length

Five main themes accounted for the experiences of clinicians when discussing SUDEP: The SUDEP Protocol; Diffusion of the FAI; Breaking Good News – ambivalence discussing SUDEP; Incorrectly Anticipating Distress; and Pressure hinders effective communication.

### 3.1 The SUDEP Protocol

Clinicians regularly inform patients about SUDEP with only slight variations in practice noted. Clinicians appear to engage in two types of SUDEP conversation; those for patients with newly diagnosed epilepsy (shown diagrammatically in Appendix B) and those for chronic, uncontrolled epilepsy patients.

For chronic uncontrolled epilepsy patients, the SUDEP conversation was invariably used as a means of emphasising the risks associated with poor epilepsy control and in an attempt to encourage medication adherence:

*'so, as I said, the two patient groups - patients who have chronic epilepsy you are seeing back and they have poor control and you talk about it.'* (Registrar, Ss2)

Sometimes this conversation would occur with people with long standing epilepsy because they had never been made aware of SUDEP:

*'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)

Unlike chronic epilepsy patients, clinicians appear to regularly discuss SUDEP with newly diagnosed patients:

*'in the last couple of years or the last few months when I was doing first seizure clinics perhaps - almost every new patient, yeah.'* (Registrar, Ss6)

There was one very common exception to this rule - the topic of SUDEP is often not mentioned if the patient appears distressed or anxious about the epilepsy diagnosis. Clinicians noted that they will make notes to discuss SUDEP at the next appointment or they rely on Epilepsy Nurses to discuss SUDEP:

*'and if they are very anxious during the first consultation I usually do not tell them regarding the diagnosis – regarding the SUDEP risk.'* (Consultant, Ss8)

*'I heavily rely on my follow-up appointment with nurses where they discuss it far better than me I think, I believe.'* (Registrar, Ss5)

Clinicians usually raise the issue of SUDEP first. It was rarer for a patient to initiate a conversation about SUDEP following diagnosis:

*'I've certainly seen some patients who have asked about it. Um, you know I have had, you do get informed patients.'* (Registrar, Ss1)

*'Um, well at new diagnosis, that's uncommon.'* (Consultant, Ss3)

Clinicians often raise the topic of SUDEP towards the end of the diagnosis appointment:

*'...towards the end, generally. It's usually the last thing we talk about.'* (Consultant, Ss4)

There is often a 'script' employed which contains the same information and similar phrasing:

*'It's probably a personal script I'm not sure I don't know if everybody does that, yes.'* (Registrar, Ss6)

The information tended to include risk factors for SUDEP and it was common to emphasise that the risk of SUDEP is low and modifiable.

*'you can explore that a bit further and say yes there is so much risk but it varies and the risk is higher in people who have persistent seizures and it's important that you take your medications and control it and so on.'* (Consultant, Ss7)

Many clinicians noted that they will not actually use the term SUDEP, preferring to state there was a risk of harm:

*'What I have been doing is discussing that epilepsy can potentially cause serious harm but not quite use the 'death' word straight away.'* (Consultant, Ss7)

SUDEP conversations, or the lack of them, were commonly documented to the GP.

*'we will either refer you to the nurse specialist who'll cover some of it and if not it will be covered in the next medical clinic. But I'll try and document that as much as possible that it's not done.'* (Registrar, Ss6)

### 3.2 Diffusion of the FAI into practice

Clinicians were aware of the FAI and some explicitly noted their thoughts and feelings regarding the ruling having read the inquiry:

*'I don't want to point any direction against the sort of judge or the individual people or giving evidence but I don't think that was an amazingly useful event that ruling.'* (Registrar, Ss1)

*'it was only after the Sheriff's ruling a few years ago that it kind of became mandatory to bring up SUDEP with patients at the point of diagnosis or soon thereafter.'* (Consultant, Ss3)

Although others expressed a more vague understanding of the FAI, everyone was aware of its implications:

*'I think there have been rulings, but I wouldn't be able to know the specifics of it, to say that we should all be informing and making [SUDEP] a priority to discuss.'* (Consultant, Ss9)

The suggestion is that the practice of discussing SUDEP has been heavily influenced by the FAI ruling. This was in contrast to the impact of guidelines on SUDEP discussions - Clinicians were aware that guidelines relating to SUDEP practice existed but universally these had not been read.

The FAI appears to have influenced practice by three mechanisms: initial neurology training, teaching days, and discussions with colleagues. Both Registrars and recent Consultants noted that their practice of discussing SUDEP was influenced by their training in neurology:

*'[my practice] is from my training days itself- I've not read any guidelines but from the training days itself.'* (Consultant, Ss8)

*'I think there were a few training sessions that I had attended last time when we were in \_\_\_\_\_teaching training day.'* (Registrar, Ss5)

However, the greater influence on practice appeared to be exerted from colleagues, training and team discussions:

*'I've gone to outside meetings and ... those kind of things. And we've had epilepsy training days and we have a monthly training day in epilepsy perhaps comes once a year or things like that.'* (Consultant, Ss6)

*'Meetings mostly yes - so reasonably formal departmental meetings.'* (Consultant, Ss9)

*'[I learn it] from peers and epilepsy meetings.'* (Consultant, Ss3)

### 3.3 Breaking Good News – ambivalence discussing SUDEP

Individual clinicians expressed both their support and dissatisfaction with the practice of discussing SUDEP with newly diagnosed patients. This ambivalence extended to the benefits to patients, the feelings regarding the FAI, and whether it is a Breaking Bad News experience or not. In general clinicians stated that SUDEP was an important topic to discuss and patients should be well informed about their condition:

*'I think the practice should be that it is important that the patient has all the information of their condition.'* (Consultant, Ss7)

Many clinicians viewed SUDEP as a positive topic to discuss as it could increase medication adherence and meant that risk issues could be addressed:

*'I think particularly if someone is swithering about compliance for medication – then I think a discussion of SUDEP can make them more adherent to the recommendations.'* (Consultant, Ss10)

*'I want to frame it and structure it in a way that they think that compliance, lifestyle modification - if I do these two things well from my end then, actually, I am working towards less risk of coming to harm with these seizures. I want to bring a positive approach towards it.'* (Registrar, Ss5)

An alternative feeling was also commonly expressed:

*'I think there is an argument for should you discuss it should you not and clearly the court has made a decision and that's...but I think there is still an argument as to whether patients should be burdened by this worry'* (Consultant, Ss4).

*'I think that the guideline that you tell everyone um leaves slightly at the discretion of the clinician. And it's a bit like any other guideline it's a one size does not always fit all. So I think it might be clinically appropriate to leave that to a subsequent*

*consultation to discuss. Particularly if someone is upset having received a diagnosis of epilepsy.’ (Consultant, Ss10)*

Clinicians were unaware of the impact of discussing SUDEP with patients on their behaviour however they hoped that it might influence them positively:

*‘they probably contribute to good compliance and you know, possibly, they lead to more regular lifestyles and avoidance of binge drinking and other drugs and, I don't, I have no evidence to prove it but that's the hope.’ (Consultant, Ss3)*

*‘would hope it would make a difference to them is for them to take control of their condition and try and you know as I say get regular sleep, get the regular meals, avoid alcohol in excess, avoid drugs and take their medication that's what I'm hoping for.’ (Registrar, Ss2)*

Clinicians were divided as to whether they considered discussing SUDEP a BBN experience:

*‘no I don't think it's breaking bad news because it's not happened to them it's just, you're just telling them about a potential risk and you've already gone through a lot of potential risks about epilepsy by that stage as well.’ (Registrar, Ss2)*

*‘sort of, yeah, it's an educational thing. Sort of breaking bad news.’ (Registrar, Ss1)*

*‘I'd say it's breaking good news you know there is this risk but it's usually very, very low.’ (Consultant, Ss9)*

Clinicians noted that they had not needed or considered personal support for any conversation about SUDEP with patients. Support could come in the form of discussions with colleagues or supervisors however it seemed rare for clinicians to do this.

### *3.4 Falsely Anticipating Distress*

Clinicians stated that they were likely to cause anxiety by discussing SUDEP. There were suggestions that clinicians were unduly worried about what the reaction might be from their patients:

*‘but I think it's, if it was said to me I think it would be something that would sit you know if I had epilepsy and somebody told me 'you could go to sleep and have a seizure and not wake up' or 'you could have seizure and die from that' I suppose that would worry me, a lot.’ (Consultant, Ss4)*

*‘and then very softly say the word death - because it's frightening ... [later on] I think that is more fear in the medics approaching this topic rather than in patients discussing this.’ (Registrar, Ss5)*

Interestingly, there was only one account of a patient reacting badly to the SUDEP discussion. No other clinician had encountered a bad reaction from any patient when

discussing SUDEP. In contrast, the general picture is that patients react calmly perhaps only occasionally expressing surprise:

*'um so maybe slight surprise - not people getting upset though I don't think in my experience.'* (Registrar, Ss2)

*'I've not seen any patient giving any anxious reactions so far.'* (Consultant, Ss8)

There was some surprise expressed at the fact that patients react so calmly to SUDEP information and some suggestions as to why this is the case. Clinicians felt that the epilepsy diagnosis, or the impact of the condition on their lifestyle, was more distressing than information about SUDEP:

*'I think the majority, again, 4 in 5 will respond, pretty surprisingly, without anything. They will just take that as factual information.'* (Registrar, Ss6)

*'often the implications of the seizure on their driving activity and other things is of greater concern to them than what is a relatively small risk [of SUDEP].'* (Consultant, Ss10)

Clinicians suggested that the cautious approach clinicians take may result in the settled manner patients receive the news. The suggestion was that their way of discussing SUDEP reduced patients' anxieties:

*'Uh, I tell in a very smooth manner so that it does not hurt or does not make them very anxious.'* (Consultant, Ss8)

*'I think to be honest I have never seen it too positive or too negative. There is one standard conversation. And I don't know if maybe I am getting it too easy (laughing) or, if it's just me.'* (Registrar, Ss5)

In general clinicians do not find discussing SUDEP with patients an anxiety provoking experience:

*'Um...I feel happy talking about it, I feel comfortable talking about it.'* (Registrar, Ss2)

There were suggestions that the initial change of practice brought about as a result of the FAI had been anxiety provoking, however, patients' reactions alleviated this anxiety:

*'Initially I used to be hesitant but nowadays because it's become routine and after observing the reaction from the patient because it's not an anxiety reaction it is a – they feel it is something like expected.'* (Consultant, Ss8)

### *3.5 Pressure hinders effective communication*

Despite reporting that SUDEP is not a distressing experience for them, clinicians did not report universal satisfaction with the requirement to discuss it. It appears that pressure affects

clinicians' ability to communicate SUDEP information in a number of ways. In a practical sense, many clinicians note that the main difficulty they had with SUDEP conversations was the limited time they had to discuss the information in addition to diagnosing epilepsy:

*'so there's lots of things we have to talk about, or we feel pressure to talk about. We have to talk about lots of different bits that's just one of the other things we have to talk about.'* (Registrar, Ss2)

*'there is a lot to cover in a 30 minute consultation. You take the history from the patient, sometimes from a witness of a possible event when they've lost consciousness. You're asking them about their past medical history, you're clinically examining them, you are going over investigations they may have had, if they've had imaging, you then sort of discuss the diagnosis you talk about drugs – you don't have, it's something that is kind of shoehorned in – you don't have, it's one of a list of things you need to do.'* (Consultant, Ss10)

As a result of the limited time, clinicians wondered if this led to patients being 'overloaded' with information. Clinicians wondered if this affected patients' ability to understand their discussions about SUDEP. This may also be the reason that patients accept the diagnosis so calmly:

*'so by the time you come to it the patient already has a lot to absorb. And that's why I think they're already in their minds you know, trying to grasp as much information as they can, so they don't immediately show a response that I have seen.'* (Registrar, Ss5)

*'I think the new patients are sort of slightly numbed by the time you start to talk about it or are slightly overwhelmed already so they are less likely to engage and ask lots of questions about it I think, in my experience.'* (Registrar, Ss2)

There was also a suggestion that the pressure clinicians are under in the initial session to correctly diagnose epilepsy may mean that SUDEP is not given the appropriate emphasis:

*'So you've got a very limited time to try and sort of, we say getting the diagnosis right and conveying that to the patient is the primary aim.'* (Consultant, Ss7)

In a broader sense clinicians noted their feelings regarding the pressure to discuss SUDEP as a result of the FAI. Clinicians acknowledged the pressure they felt and questioned if the legal system should recommend medical advice to patients:

*'and from my perspective too I also need to play safe from the medical legal point of view.'* (Consultant, Ss8)

*'but whether one feels [discussing SUDEP] is appropriate or not, the fact is if you choose not to do it you're laying yourself open to risk - medical legal risk.'* (Consultant, Ss3)

*'I think it's probably a bit unfortunate that the way we practice medicine, and this as an example, is not - the decision does not come from the doctors.'* (Consultant, Ss4)

## 4. Discussion

We report five main themes that accounted for Neurologists' experiences when discussing SUDEP. Neurologists appear to employ a standardized way of discussing SUDEP ('the SUDEP protocol'); the recommendations of the FAI have diffused into their practice through meetings and training; Neurologists feel that discussing SUDEP has both negative and positive aspects to it; they report that patients are not distressed by SUDEP information, although they appear to be concerned that it will be distressing for them; and there is concern that the pressure to discuss SUDEP information soon after diagnosis may hinder communication. Our study corroborates other recent research, which suggests that Neurologists in Scotland regularly discuss SUDEP with newly diagnosed epilepsy patients [13, 24]. Additionally, our study suggests that SUDEP is not routinely discussed with historically diagnosed epilepsy patients. This may reflect that the FAI and guidelines refer to newly diagnosed patients only and have not explicitly stated that SUDEP be discussed with chronic epilepsy patients [27].

### *4.1 Guidelines versus Legal Recommendations*

The FAI has had an impact on Neurologists' practice in Scotland. Even Neurologists unaware of the specific details of the FAI have had their practice impacted. The FAI has created a pressure to discuss SUDEP that is exerted through meetings and discussions amongst Neurologists. In contrast, Neurologists are less aware of the content of medical guidelines. This is in keeping with prior systematic reviews on the impact of guidelines on clinical practice. [33] Guidelines may be more successful when introduced alongside rigorous evaluations of their impact [34]. Our study would suggest that compared to medical guidelines, a FAI may have a greater ability to influence medical practice, perhaps because of perceived medico-legal implications on clinicians.

The FAI has led to an individualised 'protocol' for Neurologists discussing SUDEP. Neurologists noted that many of the epilepsy diagnosis sessions take a similar format and SUDEP has been added to the list of 'necessary' topics to discuss. Moreover, there appears to be a standardised way of discussing SUDEP towards the end of diagnosis sessions and a similar approach noted in terms of discussing a 'risk of harm', rather than death, and noting measures that patients can take to reduce risk. The 'SUDEP protocol' for chronic epilepsy patients is not as detailed as the protocol for initial diagnosis.

### *4.2 Impact of Anxiety*

The FAI has also met with some resistance from clinicians. Miller et al. [19] reported that clinicians suggested it was 'morally wrong' to give information about SUDEP because it was poorly understood and difficult to prevent. In our study, similar to other research findings [18], Neurologists suggested that SUDEP information potentially could make a patient anxious or distressed – and this was an unnecessary reaction given the low risk of SUDEP occurring. A number of additional statements can be made about this finding: firstly, although clinicians in the current study were mindful of not creating an anxious response in *patients*, it was clear that they were not anxious about having the discussion themselves. This is in concordance with other research which suggests that despite the difficulties involved,

doctors in general feel comfortable with BBN experiences [20]. Secondly, despite anticipating an anxious response from patients, there were almost no accounts of this occurring. This finding is corroborated by Harden et al. [13] and Tonberg et al. [24] as patients in these studies reported that SUDEP information created only short-lived anxiety. There may be a suggestion that the cautious approach employed by clinicians, and their anticipation of anxiety, may create the circumstances and atmosphere which results in the calm response from patients. The clinicians in the current study raised another possibility that the pressure to convey SUDEP information in the diagnosis session has resulted in impaired communication. There was concern that the information about SUDEP will not be conveyed sympathetically or that patients will not be able to explore or understand the information in sufficient detail, given the emotional impact of having just received a diagnosis of epilepsy.

#### *4.3 How could SUDEP conversations make a difference?*

Neurologists felt that the conversations about SUDEP might possibly influence adherence to medication. Medication adherence is a multi-factorial process with numerous studies investigating the impact of providing information, self-monitoring, psychological therapy and many more interventions [39]. Evidence would suggest that a conversation with a clinician would, at best, have only a modest influence on rates of medication adherence [40, 41]. Qualitative research has highlighted that patients report their clinicians SUDEP conversations do not affect adherence decision [13, 24] however it may be useful to quantifiably measure the behaviour change that results from SUDEP conversations.

#### *4.4 Limitations*

The participants in the study were volunteers and likely to be interested in the practices relevant to SUDEP. This may have resulted in a more extreme view being expressed either in favour of or against current practice. Participants expressed concern about medico-legal risk if they did not discuss SUDEP with newly diagnosed patients. It would be understandable if Neurologists not practicing in the legally recommended way may have avoided participation in the study.

Neurologists expressed support was available to them but was rarely used. Exploring how clinicians utilise support from colleagues may be best met with an alternative methodology. Notably, it was felt that clinicians often appeared hesitant and in some cases avoidant when asked about how they utilise or require support. An Interpretive Phenomenological Analysis may be more suited to explore this hesitancy and to analyse how the participant is making sense of this phenomenon [43].

#### *4.5 Conclusions*

Neurologists are concerned about the impact of SUDEP information on patients and are interested in evaluating if SUDEP discussions make a difference to patients' behaviour.

Our study suggests limited impact of guidelines on medical practice and that legal recommendations have a higher impact on Neurologists' practice in Scotland. This research may provide a useful comparative model for countries, health boards or organisations that are considering guideline recommendations for how and when SUDEP is discussed with patients.

Our study suggests additional pressure and concerns can arise as a result of a ‘blanket’ approach to medical practice and that Neurologists value a sense of clinical autonomy [19]. The perceived removal of clinical autonomy increased Neurologists’ concerns about the quality, emotional impact, and benefits of the SUDEP conversation.

## Acknowledgements

## References

- [1] Hanna J, Panelli R. Challenges in overcoming ethical, legal, and communication barriers in SUDEP. In Lathers CM, Schraeder PL, Bungo MW, Leestma JE, editors. Sudden Death in Epilepsy: Forensic and Clinical Issues, FL: Taylor and Francis; 2011, p. 915-37.
- [2] Nashef L. Sudden unexpected death in epilepsy: terminology and definitions: International Workshop on Epilepsy and Sudden Death. *Epilepsia* 1997;38: S6–S8.
- [3] Scorza FA, Cysneiros RM, Albuquerque MD, Scattolini M, Arida RM. Sudden unexpected death in epilepsy: an important concern. *Clinics* 2011;66: 65–9.
- [4] Duncan S, Brodie MJ. Sudden unexpected death in epilepsy. *Epilepsy Behav* 2011;21; 344-51.
- [5] Hughes JR. A review of sudden unexpected death in epilepsy: Prediction of patients at risk. *Epilepsy Behav* 2009;14: 280-7.
- [6] Scorza FA, Arida RM, Terra VC, Cavellheiro EA. What can be done to reduce the risk of SUDEP? *Epilepsy Behav* 2010;18: 137–8.
- [7] Nobili L, Proserpio P, Rubboli G, Montano N, Didato G, Tassinari CA. Sudden unexpected death in epilepsy (SUDEP) and sleep. *Sleep Med Rev* 2011;15; 237-46.
- [8] Hesdorffer DC, Tomson T, Benn E, Sander JW, Nilsson L, Langan, Y et al. Combined analysis of risk factors for SUDEP. *Epilepsia* 2011; 52:1150-9.
- [9] Gayatri NA, Morrall MC, Jain V. Parental and physician beliefs regarding the provision and content of written sudden unexpected death in epilepsy (SUDEP) information. *Epilepsia* 2010;51:777–82.
- [10] NICE, National Institute for Health and Clinical Excellence. The diagnosis and management of epilepsy in children, young people and adults. London: National Institute for Health and Care Excellence, <http://www.nice.org.uk/guidance/cg137>; 2012 [accessed 19.07.16]
- [11] Hirsch LJ, Donner EJ, So EL, Jacobs M, Nashef L, Noebels, J.L et al. Abbreviated report of the NIH/NINDS workshop on sudden unexpected death in epilepsy, *Neurol* 2011;76:1932-8.
- [12] Institute of Medicine (U.S.) Epilepsy across the spectrum: promoting health and understanding. Washington, DC: National Academies Press; 2012.
- [13] Harden J, Tonberg A, Chin RF, McLellan A, Duncan S. 'If you're gonna die, you're gonna die': Young adults' perceptions of sudden Unexpected death in epilepsy. *Chronic Illn* 2015;11:230-41.
- [14] Nair RR, Jack SM, Meaney BF, Ronen GM. SUDEP: What do Parents Want to Know? *Epilepsy Behav* 2013;29:560-4.
- [15] Nair RR, Jack SM, Strohm S. Sudep: To discuss or not? Recommendations and experiences from bereaved relatives. *Epilepsy Behav* 2016;56:20-25.
- [16] Morton B, Richardson A, Duncan S. Sudden unexpected death in epilepsy (SUDEP): don't ask don't tell? *J Neurol Neurosurg Psychiatry* 2006;77:199–202.
- [17] Waddell B, McColl K, Turner C. Are we discussing SUDEP?—a retrospective case note analysis. *Seizure* 2013;2:74–6.
- [18] Friedman D, Donner EJ, Stephens D, Wright C, Devinsky O. Sudden Unexpected Death in Epilepsy: Knowledge and Experience among US and Canadian Neurologists. American Epilepsy Society Annual Meeting Abstract #2,324. [https://www.aesnet.org/meetings\\_events/annual\\_meeting\\_abstracts/view/16121](https://www.aesnet.org/meetings_events/annual_meeting_abstracts/view/16121); 2012 [accessed 19.07.16]
- [19] Miller WR, Young N, Friedman D, Buelow JM, Devinsky O. Discussing sudden unexpected death in epilepsy (SUDEP) with patients: Practices of health-care providers. *Epilepsy Behav* 2014;32:38-41.

- [20] Schildmann J, Cushing A, Doyal L, Vollmann J. Breaking bad news: experiences, views and difficulties of pre-registration house officers. *Palliat Med* 2005;19: 93-8.
- [21] Tesser A, Rosen S, Tesser M. On the reluctance to communicate undesirable messages (the MUM effect) a field study. *Psychol Rep* 1971;29:651-4.
- [22] Ptacek JT, Eberhardt TL. Breaking Bad News. A Review of Literature. *J Am Med Assoc* 1996;276:496-502.
- [23] DoH (Department of Health). Breaking Bad News – Regional Guidelines. Belfast: DOHSSPS 2003.
- [24] Tonberg A, Harden J, McLellan A, Chin RF, Duncan S. A qualitative study of the reactions of young adults with epilepsy to SUDEP disclosure, perceptions of risks, views on the timing of disclosure, and behavioural change. *Epilepsy Behav* 2015;42:98-106.
- [25] SIGN. Scottish Intercollegiate Guidelines Network. Diagnosis and management of epilepsy in Adults. Edinburgh (UK); [updated 2005], <http://www.sign.ac.uk/guidelines/fulltext/70/index.html>; 2005 [accessed 23.07.15]
- [26] Fatal Accident Inquiry Into the deaths of Erin Casey and Christina Fiorre Ilia. Sherrifdom of Tayside Central and Fife at Dundee, <http://www.scotcourts.gov.uk/search-judgments/judgment?id=778986a6-8980-69d2-b500-ff0000d74aa7> 2010 [accessed 19.07.16]
- [27] SIGN. Scottish Intercollegiate Guidelines Network. Diagnosis and management of epilepsy in adults. Edinburgh (UK) [updated May 2015], <http://www.sign.ac.uk/pdf/SIGN143.pdf> 2015 [accessed 19.07.16]
- [28] Guest G, Bunce A, Johnson L. "How many interviews are enough? An experiment with data saturation and variability". *Field Methods* 2006;18:59-82.
- [29] Braun V, Clarke V. Using Thematic Analysis in Psychology. *Qualitat Res Psychol* 2006;3:77-101.
- [30] Charmaz K. Constructing Grounded Theory. London: Sage Publications Ltd; 2006.
- [31] Clarke V, Braun V. Teaching thematic analysis: Overcoming challenges and developing strategies for effective learning. *The Psychol* 2013;26:120-3.
- [32] Blumer H. What is wrong with social theory? *Am Sociol Rev* 1954;18:3-10.
- [33] Ament SMC, De GrootJJA, Maessen JMC, Dirksen CD, Van der WeijdenT, Kleijnen J. Sustainability of professionals' adherence to clinical practice guidelines in medical care: a systematic review. *Br Med J Open* 2015;5:1-13.
- [34] Grimshaw JM, Russel IT. Effect of clinical guidelines on medical practice: a systematic review of rigorous evaluations. *The Lancet* 1993;342:1317-22.
- [35] Ley P. Memory for medical information. *Br J Soc Clin Psychol* 1979;18,:245-55.
- [36] Wessel I, Van der Kooy P, Merckelbach H. Differential recall of central and peripheral details of emotional slides is not a stable phenomenon. *Memory* 2000;8:95-109.
- [37] Kessels RPC. Patients' memory for medical information. *J R Soc Med* 2003;96:219-22.
- [38] Shapiro DE, Boggs SR, Melamed BG, Graham-Pole J. The effect of varied physician affect on recall, anxiety, and perceptions in women at risk for breast cancer: an analogue study. *Health Psychol* 1992;11:61-6.
- [39] Haynes RB, Ackloo E, Sahota N, McDonald HP, Yao X. Interventions for enhancing medication adherence. *Cochrane Database Syst Rev* 2008;16:2.
- [40] Adams RJ. Improving health outcomes with better patient understanding and education. *Risk Manag Healthc Policy* 2010;3:61–72.
- [41] Sheridan SL, Viera AJ, Krantz MJ, Ice CL, Steinman LE, Peters KE et al. The effect of giving global coronary risk information to adults: a systematic review. Cardiovascular Health Intervention Research and Translation Network Work Group on Global Coronary Heart Disease Risk. *Arch Intern Med* 2010;170:230-9.

- [42] Horne R, Weinman J. Patients' beliefs about prescribed medicines and their role in adherence to treatment in chronic physical illness - processes and applications. *J Psychosom Res* 1999;47:555–67.
- [43] Smith JA. Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Res Psychol* 2004;1:39-54.
- [44] Scottish Government. Fatal Accident Inquiry Recommendations. <http://www.gov.scot/Topics/archive/law-order/fatalaccidentinquiries/Recommend> [accessed 16.09.16].

## Appendix A: Interview Schedule

These questions were designed to facilitate the conversation and often evolved to focus more on specific areas depending on the issues and themes encountered in initial interviews.

Most questions were expanded with follow up prompts. Examples of prompts are given in bullet points below.

### Demographics:

Can you describe your role to me?

How long have you been practicing in your current role?

In a typical week or month, how many people would you discuss SUDEP with?

### Knowledge

What can you tell me about SUDEP?

What factors influence the risk?

- Prompts: What controllable risks exist? What uncontrollable risks exist?

Are there any guidelines that inform you about SUDEP and what to discuss with patients?

- Prompts: What do SIGN/NICE guidelines say in the subject?

Are there any local NHS policies that affect your practice with regards to SUDEP discussions?

- Prompts: Can you tell me about these?

Typically, what do patients know about SUDEP before you speak to them?

- Prompt: What sources of information have you used?

### Practice/Intention

“I am now interested in finding about your typical practice or how you would normally wish to discuss SUDEP with a patient”

When would you typically first discuss SUDEP with a patient?

What influences the timing of when you discuss SUDEP?

- Prompt: are there times or situations when you won't discuss SUDEP?

How is the topic of SUDEP usually first raised?

How do you feel when you know you are about to discuss SUDEP with a patient for the first time?

What key messages do you hope that patients take away with them?

- Prompt: Is there anything you do to help get these messages across to patients?

## Experience

“I am interested in hearing about some specific experiences you have had discussing SUDEP with patients.”

Can you tell me about the last time you discussed SUDEP with a patient or carer?

- Prompts: Who initiated this discussion?
- What did you tell the patient/carer about SUDEP?
- What did the patient/carer ask about? What information did they already have? Where had they got this information from?
- How did the patient/carer seem to react/cope with the discussion?
- How did you feel about this discussion?
- What did you do to cope with this discussion?
- Looking back, is there anything you think you could have done/said differently?
- Would you say this was typical as to how SUDEP is discussed?

Can you tell me about a SUDEP discussion that particularly stands out as a difficult discussion?

- Prompts: What was it that was difficult about this discussion?
- Who initiated this discussion?
- What did you tell the patient/carer about SUDEP?
- What did the patient/carer ask about? What information did they already have? Where had they got this information from?
- How did the patient/carer seem to react/cope with the discussion?
- How did you feel about this discussion?
- What did you do to cope with this discussion?
- Looking back, is there anything you think you could have done/said differently?
- Would you say this was typical as to how SUDEP is discussed?

Can you tell me about a SUDEP discussion that particularly stands out as a good or positive discussion?

- Prompts: What was it that was positive about this discussion?
- Who initiated this discussion?
- What did you tell the patient/carer about SUDEP?
- What did the patient/carer ask about? What information did they already have? Where had they got this information from?
- How did the patient/carer seem to react/cope with the discussion?
- How did you feel about this discussion?
- What did you do to cope with this discussion?
- Looking back, is there anything you think you could have done/said differently?
- Would you say this was typical as to how SUDEP is discussed?

## Reflection/thoughts on the future

“I would like to hear some of your reflections on your experiences and any thoughts about what could support your practice.”

Looking back on your experiences, what could make SUDEP discussions easier for you or the patient?

- In particular, are there any resources or training courses that could help?

Has your way of discussing SUDEP changed over time?

How do your discussions about SUDEP compare with other times you have had to discuss other ‘bad news’ with a patient?

If you had a difficult experience discussing SUDEP what would you do?

Prompts: Is there anyone you would go to for support?

Is there anything else you would do following a difficult experience?

How do your SUDEP discussions make a difference to patients’ behaviour?

What advice would you give to a junior colleague regarding how to have SUDEP conversations and what to say?

## Appendix B: The SUDEP protocol diagram

