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Keep safe: The when, why and how of epilepsy risk communication

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Manuscript Details

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Abstract

Purpose Risk communication between clinicians and people with epilepsy (PWE) and their families is under researched. There is limited guidance about when and how to have these discussions. This paper explores the current evidence on quality of risk related conversations in epilepsy and suggests a concept of an evidence-based guideline for person centred structured risk communication. Methods A literature search of four electronic database, Ovid Medline, Ovid Embase, PUBMED, and CINAHL, was conducted by two independent reviewers using relevant search terms following the principals of the PRISMA guidance. No limits were applied. Supplementary searches included using backwards and forwards citation searching. A predesigned inclusion and exclusion criteria was administered to the identified results. Results From 376 results identified, 17 studies met the final criteria of which ten were quantitative, five qualitative and two mixed methods. Perspectives of PWE and clinicians were represented. Extracted data was clustered into three domains: communication initiation (e.g. timing, individual tailoring); communication methods (preference for face to face with neurologists); and communication content (acknowledging the anxiety produced by risk communication, the benefits of being self-aware, normalising risk etc.). No papers focused on conversation structure (e.g. helpful phrases), or the best locations to hold conversations. Conclusion More research is needed to develop structured communication of risk. An attempt has been made to put current evidence into this format. Clearer guidance will enhance clinicians' confidence in communicating person centred epilepsy risk with PWE and their families thus improving outcomes.

Keywords	Epilepsy; Families; People with Epilepsy; Risk; Communication
Taxonomy	Risk Communication, Systematic Review

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Suggested reviewers	Matthew Walker, Lance Vincent Watkins, Michael kerr

Submission Files Included in this PDF

File Name [File Type]

Letter to Editor (1).pdf [Cover Letter]

Response to reviewers.pdf [Response to Reviewers]

Manuscript_Epilepsy Risk Communication Tracked Changes.docx [Revised Manuscript with Changes Marked]

Highlights_Communicating_In_Epilepsy.pdf [Highlights]

Abstract_Communicating_Risk_In_Epilepsy.pdf [Abstract]

Title Page_Communicating_Risk_In_Epilepsy.pdf [Title Page (with Author Details)]

Manuscript_Epilepsy Risk Communication.docx [Manuscript File]

Declaration of interest_Communication of Risk in Epilepsy.pdf [Conflict of Interest]

PRISMA-ScR Fillable Checklist_Communicating_In_Epilepsy.pdf [Supporting File]

To view all the submission files, including those not included in the PDF, click on the manuscript title on your EVISE Homepage, then click 'Download zip file'.

Research Data Related to this Submission

There are no linked research data sets for this submission. The following reason is given:
The document is a literature review and the reviewed papers are publicly available. Additional tables can be made available should that be helpful.

Dear Editor,

Thank-you for considering our paper and providing us an opportunity to submit a revision. We found the feedback of the reviewers instructive. We have worked through all of the comments from both reviewers, and made changes as detailed below and in the 'tracked changes' document. All comments have been addressed comprehensively. Our word count has increased marginally and we hope that this is acceptable. We are also pleased to inform you that the review underpinning this paper has been instrumental in developing and attaining a NIHR grant to further investigate the area of the role of communication in epilepsy risk transaction.

We hope that this now satisfies the requirements for publication, and welcome any further feedback as you feel might be appropriate.

Yours Sincerely,

Dr. Cordet Smart

Dr. Craig Newman

Miss. Georgia Page

Dr. Rohit Shankar

Please find attached a copy of the reviewers comments and our responses.

Response to Reviewers

Reviewer 1

The aim of this study was well written and clearly expressed. The introduction helps to explain the importance of this topic. The methodology seems appropriate and limitations were explained. The conclusions are appropriate based on the results and are not overstated or generalized.

One area that I would like to have seen discussed/explored further is the ability of the clinician to generalize the findings with respect to age, gender or cultural differences for example.

Response: We have re-visited the papers to ensure that we have accurately represented where age, gender and cultural differences have been captured. Currently this has not been explored, and so we comment on the limitations of this in the results section (results 1).

There was limited consideration of how gender, ethnicity or age might affect communication. Five papers commented that men were generally considered at higher risk but none discussed this in relation to how communication might be adapted. One paper considered age, gender, duration of epilepsy, level of education and employment as variables that might affect preference for discussions, finding none of these significant predictors.

We have also mentioned this as a limitation in the discussion section:

The evidence for guidance extracted here was limited. Studies have not considered directly how communication works, and most research focuses specifically on communication about SUDEP, rather than other epilepsy risks, such as: such as self-injury, problems with driving, overdose of medication, under-dosing of medication, drug interactions, ongoing seizures, status epilepticus, nor other risks associated with the clinical management of epilepsy. A greater amount of research around communication is required that covers these areas.

Methods and samples were heterogeneous. This heterogeneity captured the views of multiple stakeholders, including neurologists, non-specialist doctors, specialist nurses, PWE, their families, and bereaved families. However, the lack of homogenous studies meant that a meta-analysis or synthesis was not viable, thus reducing analytic power. There was unequal distribution (four studies examined PWE: six studies, clinicians; representing a total of 6,641:1638 participants). There was also no consideration of how PWE's nor clinician's individual differences, such as gender, ethnicity, learning disability, age or other demographics, beyond experience of epilepsy, may affect communication, which future research may address.

In addition, the authors mention how similar conversations occur in other areas of medicine such as oncology. I think this could have been further elaborated and I would like to learn how their findings compared.

Response: We have elaborated as follows.

Firstly, we have referred to some of the developments in other fields within the introduction, page 1.

This paper collates guidance from the literature around how clinicians might best hold conversations about epilepsy risks, without undermining clinician skills of undertaking these conversations. Difficult conversations especially around risk of death are complex and can be misconstrued. There is ongoing debate around risk discussion rationale (1, 2), however, recent research illustrates how better risk communication can change outcomes (3, 4). The focus of this paper is the communications themselves. Greater understanding of communication has significantly affected patient engagement with care, for example, discussing lifestyle risk assessments with GPs (5) and in facilitating delicate end of life conversations in oncology settings (6). A similar approach would be beneficial in the world of Epilepsy.

We have also elaborated in the discussion (p.33):

Lessons might be learnt from areas such as oncology where discussion of person-centred risk and mortality is common practice. Pino and colleagues (1) discuss the importance of learning from the observation of how experienced clinicians interact in order to enhance communication, for example including 'elaboration solicitations' in interactions in order to encourage PWE to discuss their end of life concerns, in a way that does not increase anxiety. Observation of experienced epilpetologists to better understand how they work, in order to offer guidance for other professionals would be similarly advantageous.

Overall, this study on an important topic was well written and thought out.

Reviewer 2

I found the title both challenging and questionable, in that the implication is that people from without the profession are instructing those within the profession how to practice medicine. This is always a dangerous position. No one would argue with the statement "…discussion of lifestyle behaviours, such as medicine adherence, alcohol and recreational substance intake…" is something that should be addressed with patients but I find it very difficult to consider that any medical practitioner would not do so and for a paper to preach this to clinicians is somewhat demeaning. To jump from that statement to the fact that such awareness would reduce the morbidity and mortality of SUDEP (Sudden Unexpected Death in Epilepsy) is a major leap that I have difficulty accepting, particularly when there is little evidence that awareness of the risk factors of SUDEP, other than drug adherence and lifestyle requirements that apply to all people with epilepsy, are modifiable.

Response:

We have framed the review with a locating paragraph:

This paper collates guidance from the literature around how clinicians might best hold conversations about epilepsy risks, without undermining clinician skills of undertaking these conversations. Difficult conversations especially around risk of death are complex and can be misconstrued. There is ongoing debate around risk discussion rationale (1, 2), however, recent research illustrates how

better risk communication can change outcomes (3, 4). The focus of this paper is the communications themselves. Greater understanding of communication has significantly affected patient engagement with care, for example, discussing lifestyle risk assessments with GPs (5) and in facilitating delicate end of life conversations in oncology settings (6). A similar approach would be beneficial in the world of Epilepsy.

.'

The authors refer to limitations of general practitioner's knowledge and attitudes but it is clear that GPs will change a consultant's treatment without requiring any referral back to that consultant. Discussions with patients will not alter that, nor has it done so over the last 30 years of investigating this issue. The authors imply that lack of knowledge is restricted to issues such as SUDEP but there is a far broader problem with the management of epilepsy by GPs and those without special interest therein.

Response: We have edited to ensure that it is clear that SUDEP is one risk factor. We have edited our discussions of GPs to reflect the link with difficult conversations (p. 2), as follows:

Lack of knowledge can be a concern for clinicians, too. General Practitioners (GPs) are often the person that PWE prefer for monitoring Epilepsy, but GPs can feel lacking in confidence to do so (22). Further, PWE perceive this 'lack of confidence' from GPs to avoid discussing the risk and social aspects of the condition, including work, driving and financial effects (22). Within the paediatric population, one study found that 75.4% of paediatric care providers were unaware that children with epilepsy were at a risk of SUDEP (23). Clinicians without a specialist interest in epilepsy particularly struggle with conversations about SUDEP and epilepsy risks and may benefit from further information (25).

The authors themselves acknowledge that there is "… No validated obvious tool or technique to help classify epilepsy risk definitely into 'high' or 'low'…" and they suggest that those with 'low risk' also die and therefore clinicians should not make "... false assurances…".

The authors also acknowledge that "… Epilepsy death in newly diagnosed PWE is very low (1:10,000)…". They also then identified a significant increase with refractory epilepsy, up to 1 in 300. The authors go on to paint a very paternalistic picture of medicine as a whole but epilepsy management in particular.

Response: We have added in the discussion section that the area is complex, and there is no intention to represent medicine as paternalistic, instead this is a reflection of the themes identified within the literature, and we would hope that further research is needed to map the picture more clearly. (P.37):-

Risk discussions with PWE are a complex issue and clinicians will need to make their own best judgement about engaging in them. A research focus on communication in epilepsy contexts may reveal better communication methods, facilitating future collaboration and engagement with people in managing their epilepsy.

The authors discuss SUDEP using such terms as a "… need to be able to make informed decisions…" without considering the pathophysiology of SUDEP or the fact that there is no remediable cause that would prevent SUDEP, other than proper patient care. The authors do not define what informed decisions should or could be made to basically prevent SUDEP, especially in newly diagnosed patients who have an 0.01% prevalence thereof. They state that the clinician "… should not have the right to remove this choice…" without stating what that choice is, how the chance to make that choice has been removed or anything else that relates to a remediable cause for SUDEP.

Response: We have clarified how the sited authors consider informed decisions and question the right of clinicians to remove it (p.4):

. It was observed that there is considerable debate, including, suggesting that a more compassionate and value based approach to care would recognise that PWE and their families need to be able to make informed decisions, which they cannot do without adequate information, and the clinician should not have the right to remove this choice (34). They clarify this, stating that PWE might develop better self-management strategies (e.g. not using soft pillows, sleep or medication manage), improving people's perception of control over their lives and possibly reducing risks directly (34).

The paper ignores the readily available information that any patient can access within the electronic media with various search engines, such as Google or Wikipedia, and the absolute need to honestly discuss things with patients based on their questions and their seeking of information.

Response: We have added a paragraph commenting on this (p.3/4, continuing from the prior):

It is also observed that access to online material can raise anxiety in an unmanaged way and people have less confidence in this material (34, 35). Both of these studies conclude that from a patient perspective, clinician supported conversations are important.

Even the inclusion/exclusion criteria appeared patronising and somewhat paternalistic and excluded any papers that dealt with epilepsy under the age of 18 years and only considered papers written in English. Further, the terminology used under Inclusions was very arbitrary.

Response: The search strategy was developed in conjunction with senior clinicians and information specialists. We have added this comment to the method section. We have clarified the rationale for focusing on those over 18 years and on papers written in English. (Pages 5). We stated:

'These criteria and the search strategy were developed in conjunction with senior clinicians and information specialists.'

It was difficult to appreciate the actual evaluation techniques used and I am prepared to acknowledge that that failing is, more likely than not, my own in adequacy rather than that of the authors or the method adopted. I could not avoid the impression that what was being used was pseudo science to drum home a point that was questionable.

Response: We have interpreted this as relating to the quality assessment of the papers, and as such have added a reference for this form of rigorous systematic approach (page 5).

Figure 2, "Participants in Studies" was impossible to understand and if I read it correctly, the suggestion is that one study had only 6 people with epilepsy in the study and yet that was deemed a suitable population. Another had 1 non-specialist clinician and one had a bereaved family. I am sure that this is an inappropriate interpretation of the Table. This is particularly so when one sees that studies have had between 50 and 200 participants and so Figure 2 is uninterpretable. There was a very detailed Table after that but I could not follow it clearly.

Response: Figure 2 title and axis labels have been edited (page 13).

It is interesting that the authors provided the statement, "… other studies have … insight into the experience of PWE in these discussions, suggesting that people feel anxious in the short-term but then reassured…". This particular sentence is not referenced, although the next sentence is, stating that people become more compliant with their medications after such discussion. This suggests that it is appropriate to discuss where people are non-compliant in the first place and that the authors totally reject input from people who actually deal at the coalface with epileptic patients, placing their own views ahead of those of clinicians in the field and yet they use such terms as paternalistic for most clinicians without acknowledging their own paternalistic approach telling people what to do and how to do it.

Response: Hopefully our position is now more clearly stated in the introductory paragraph. We certainly do not ourselves mean to be paternalistic, but would seek out a collaboration with patients and clinicians, question how and to question to what extent this might be achieved, however illusive it might be.

We have clarified the referencing, and tried to represent the literature more accurately. (p.29).

However, focusing on the experiences of PWE of risk discussions, found that people feel anxious in the short term but then reassured along with an association with subsequent increase in medication use (35). Other studies report that over 90% of PWE wanted to be informed of most if not all information through communication with their clinician (49 (Norway); 52 (Australia)). Of the 12 papers considering whether a conversation is valid, Ten supported the position that conversations should be held while two provided more balanced positions, acknowledging that the clinician is best placed to make the ultimate decision, but providing guidance should they feel it clinically appropriate.

They make the further point, "… over 90% of PWE wanted to be informed of most if not all information…". If that were to be true then these people would access the search engines already identified and would do their own research, as happens with so many patients in the current patient-concentric approach to the delivery of healthcare.

Response: This finding is based on that reported in the literature – we have added in the discussion section the question that we do not know how these findings reflect people's use of social media, and in the introduction. (P.29)

Other studies report that over 90% of PWE wanted to be informed of most if not all information through communication with their clinician (49 (Norway); 52 (Australia)).

On page 29 of the paper, the authors wrote, "… three postulated that the timing of discussion should be individually evaluated…". They do not comment on these nor discuss what this means but this is just routine patient care and is, more likely than not, the way things are done now. This does not mean that the risk of death is discussed at the first, the second or third consultation, unless it has a potential role in the management of the epilepsy. Where the causes of a condition, such as SUDEP, cannot be modified, other than to enhance adherence to treatment and lifestyle changes that have already been prescribed, it is inappropriate to add additional layers of burden to patients.

Response: Here we have reported directly what other authors have concluded in their findings. We have made every effort to ensure that all variations are included that we identified in the extant literature, and so present both approaches. We clarify that the literature did not always determine what factors should be considered at individual evaluation, and include this in the discussion section. We have also reminded the reader throughout that ultimately decisions are about individual clinical judgement, and at the beginning of the second part of the results sections have clarified that the details of how these judgements are made are not elaborated.

It is interesting that the authors state, "…one paper discussed the patient's right 'not to know'…" quoting Morton et al, 2006. Clearly this is not an isolated paper and not the only one that has taken this approach and hence the authors are showing their own individual bias and lack of transparency in providing this report. To equate discussing SUDEP with a patient to discussing problems of oncology with a patient is both inappropriate and misleading. The only similarity is that both are medical conditions.

Response: We have tried to clarify in the introduction, at the beginning of the second part of the results section, and within the discussion section that it was not our intention to review every paper that has assessed the debate as to whether to inform patients, but instead we had hoped to extract guidance for how to hold conversations that might help to improve clinical conversation. Within our sample, this was the only paper raising this issue, which is significant in that within this literature we would like to maintain the ethical position of informing balanced clinical judgement and decision making. We elaborate on this within the discussion.

We have also clarified the relationship that we are drawing with research in oncology communication within the discussion, and hope that this also clarifies for the reviewer that it is our contention that considerable learning can and should be gained from observing current best practice by experts, in order to facilitate the training of those less confident and knowledgeable (p.33):

Lessons might be learnt from areas such as oncology where discussion of person-centred risk and mortality is common practice. Pino and colleagues (1) discuss the importance of learning from the observation of how experienced clinicians interact in order to enhance communication, for example including 'elaboration solicitations' in interactions in order to encourage PWE to discuss their end of life concerns, in a way that does not increase anxiety. Observation of experienced epilpetologists to

better understand how they work, in order to offer guidance for other professionals would be similarly advantageous.

The other thing that comes through loudly within the Discussion section is that those studies chosen for review appear to have been biased in favour of that which the authors are trying to achieve and that of itself is somewhat misleading. Again the authors go onto highlight Morton's fairly sensible comment that patients and their families have a right "not to know" but at no stage does any of this suggest that clinicians would not discuss and advise on the necessity to follow medical advice, to take medications as prescribed, to avoid dangerous situations and to avoid excess alcohol and substance abuse. This has absolutely nothing to do with the discussion of SUDEP but rather appropriate patient care, which most clinicians follow anyway but these authors seem to suggest that clinicians do not understand their role within patient care. It is not without poignancy that two of the solutions start with the words, "… Part of moving toward a more psychological approach…", which encapsulates the true purpose and meaning behind this paper in which the first author comes from the school of psychology and appears to be pushing a personal viewpoint using questionable data to achieve the results to do so.

Response: Again, there is no intention here to challenge any of the positions offered by the reviewer, simply that we would like to provide support around how to deliver information, which clinicians can access as they see fit and struggle around communications. The first author is both a trained nurse and a psychologist, and the team are made up of medically trained professionals and clinical psychologists. The aim is not in any way to undermine clinicians, but to offer support in what can be for some, difficult conversations. We have edited the discussion section to reflect this, again, clarifying that our aim is to uncover and inspire interest into better understanding communication, rather than dictating how clinicians should make clinical judgements. We have added to the beginning of the discussion the following (page 32):

This paper was designed to extract guidance from the literature around how to communicate risk with PWE, offering additional information for clinicians to draw on in Epilepsy management. How this is appropriately applied will be determined by the clinical judgement of practitioners. However, the complexity of language and interaction deserves careful consideration to enable collaborative care with PWE.

The authors split hairs between words such as "disclosure" or "risk discussions" or "communications". They further suggest that the word, "disclosures" implies "… delivery of privileged information…". They have adopted such an attitude of negativity towards those doctors who actually treat patients as typified by the next sentence, "… This might carry with it an implicit sense of protectiveness, out of line with patient involved approach…".

Response: We did not mean in any way for this to be read as an attack against doctors using it, but as a reflective point. Rather than pursue this point, given the limited words, we have removed the paragraph.

The last paragraph, commencing with the word, "Finally" acknowledges the vast array of resources available to patients if they do want to seek information. The implication is that those patients will go to the doctor without asking any questions and thus it is the doctor's role to answer questions that have not been asked! Clearly those who have addressed information within search engines will

then address issues of concern with their treating doctor. One cannot avoid the impression from this paper that it is a patronising approach by those from without clinical medicine to tell doctors how they should practice medicine.

Response: This paragraph has been edited to clarify and now reads:

Finally, in terms of communication ethics, the broader social media context should be considered. Whether or not clinicians feel comfortable holding conversations, information is available from other sources such as the media and the internet. The quality of this information is variable, and frequently not designed to support the management of anxiety. PWE can experience this in uncontained ways (3; 35). They may or may not then raise these discussions with clinicians, and we propose that further research may be conducted to examine the effects of internet information and how this influences PWE. A cautious approach may be preferable, enabling PWE to receive accurate information from a supportive clinician who can refer to relevant support services if required.

The level of patronising attitude is provided in the sentence, "… Most guidelines and postulated consequences were based on neurologist opinions…", thereby suggesting that neurologist's opinions should be discounted or even possibly ignored.

Response: We apologise and have tried to reframe the paragraph as follows. It is our intention to understand how to develop best practice, and this may include through direct observation of and learning from experts in interaction – that is why we have emphasised that this is about opinion. Expert practice is often not accurately described as experienced people are successful but sometimes don't realise why they are more effective than others, and so attitude surveys might not be enough to extract this information. We have tried to make this clearer and hope that the writing does justice now to this (page 33):

Methods also varied. Views elicited from PWE were mainly from interviews (3) and one survey. Clinicians were included in four surveys, one interview and one focus group design, so overall with less opportunity for elaboration by clinicians. These surveys were also used to identify predictors of whether conversations were held. Three studies compared groups to test directly for causative relationships. These focused on the use of predesigned checklists (4) and showed evidence of significant improvement in awareness of risk and reduction of risk factors where communication about risk used this structured method. Thus, most guidelines and postulated consequences were based on neurologist perspectives, rather than those of PWE and families, such as that conversations appear to mediate AED adherence, despite there currently being limited evidence for this (47). There was less opportunity for clinicians to elaborate their responses given the survey methods, though this enabled larger participant numbers. Direct observation of skilled clinicians was also missing, hence people actually engage in risk discussions is not yet well understood.

The authors have provided an overview of their strengths and limitations but not one strength was identified under that rubric and the limitations did not go far enough.

Response: We have edited as follows (page 33-34):

Evidence base critique:-

The evidence for guidance extracted here was limited. Studies have not considered directly how communication works, and most research focuses specifically on communication about SUDEP, rather than other epilepsy risks, such as: such as self-injury, problems with driving, overdose of

medication, under-dosing of medication, drug interactions, ongoing seizures, status epilepticus, nor other risks associated with the clinical management of epilepsy. A greater amount of research around communication is required that covers these areas.

Methods and samples were heterogeneous. This heterogeneity captured the views of multiple stakeholders, including neurologists, non-specialist doctors, specialist nurses, PWE, their families, and bereaved families. However, the lack of homogenous studies meant that a meta-analysis or synthesis was not viable, thus reducing analytic power. There was unequal distribution (four studies examined PWE: six studies, clinicians; representing a total of 6,641:1638 participants). There was also no consideration of how PWE's nor clinician's individual differences, such as gender, ethnicity, learning disability, age or other demographics, beyond experience of epilepsy, may affect communication, which future research may address.

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Seven quantitate surveys were conducted, with Three studies including more than 50 participants and Two more than 200. This seems to offer reasonable confidence in generalisation of findings. These were conducted mostly in the UK (6) and one in Norway, potentially not capturing international variation. All studies, apart from the two group comparison studies, drew on retrospective reports from clinicians and PWE rather than examining how the communications actually took place. Group comparison studies can raise ethical issues, as trials cannot be run where communication is withheld. Alternatively, future research might focus more directly on clinical conversations, following the substantial rise in the use of Conversation Analysis to explore how communication works in practice (54). Analysing clinical conversations might enable the identification of best practice for clinicians in engaging people with risk discussions, and provide a helpful method for training clinicians (55). Experienced clinicians seem better able to discuss risk (42; 48), but it is not yet known how they do this, which could be identified and then trained more widely.

Strengths and Limitations of the review

This review was limited by the low number of published papers available that comment on how clinical communication about risk might be achieved (only 17, with no limiters, all published between 2001 and 2018). None of these papers directly addressed the question of how to have clinical conversations about risk. Six papers focused on the frequency of SUDEP conversations, four on evaluating clinical practices, three on SUDEP awareness, two on use of the safety checklist and one on mortality rates, and one more generally on discussion content. All guidance was extracted

from brief mentions of recommendations in the discussion section, not direct empirical data. We argue this is a gap that future research should address.

There were limited inductive studies that might identify new insights for practice. Of those qualitative inductive studies, there was diversity in how themes were extracted, some being driven by the questions asked, again limiting the inductive nature of the research.

Risk discussions with PWE are a complex issue and clinicians will need to make their own best judgement about engaging in them. A research focus on communication in epilepsy contexts may reveal better communication methods, facilitating future collaboration and engagement with people in managing their epilepsy.

The authors have been absolutely presumptive with the second paragraph of the Conclusions, which stated, "…this paper summarised the current guidance from the literature as a step towards addressing the gap of what to discuss…". This implies that there is a gap and I do not think the paper has actually confirmed such, nor what it is or how it has evolved and so it is testimony to the bias that has underlined the preparation of this paper.

Response: We agree that the phrasing is inadequate and have tried to improve it. What we have found is limited discussion around how to hold risk conversations with PWE:

There is frequent reference to the limited guidelines provided by NICE or the AAN, about how, when and whom to discuss SUDEP and epilepsy risk with. This paper revealed the limited research available around how conversations with PWE about risk might best be held. It is the first paper to summarise the available guidance, taking a step towards better understanding how conversations about risk with PWE might be held, which has not yet been directly addressed. The guidelines arising here should be used with discretion, as less than optimal empirical evidence is available. Situations should be considered individually, but in general, conversations about risk should be held early on. Future research should better integrate the perspectives of clinicians and PWE, to understand how anxiety on both parts can be overcome. Research should focus directly on clinical practice, to gain direct insight into how experts manage difficult conversations, in order to support and inform other clinicians. Focal areas could include: what it is helpful to and say when conversations are held about risk, how these conversations are received, and where they are best located in a treatment pathway. Research should explore how different service contexts are relevant to the delivery of risk discussions. This will enable clearer and more focused guidance, embedded directly in the experiences of PWE and clinicians, and within the realities of clinical practice.

This is further emphasised in the next sentence, which read, "… The guidelines arising from the paper should be used with discretion, as less than optimal empiric evidence is available…". The authors acknowledge the limitations yet give unequivocal advice to clinicians about how to practice

medicine and how to talk to their patients, something that seems quite presumptive and, as the authors have said themselves, this is based on "… less than optimal empirical evidence…".

Response: Edited as above.

While the paper addresses "risks", its true focus is only on SUDEP and ignores many of the other risks, such as self injury, problems with driving, risks associated with overdose of medication, risks associated with underdosing of medication, risks of drug interactions, risks of ongoing seizures, risks of status epilepticus and a host of other risks associated with the clinical management of epilepsy and patients who have it. The paper seems founded on biased thoughts and evaluations and is critical of something of which the authors appear to have little insight or acumen. It follows that the title of the paper is inappropriate and it is not 'risks' per se that are being dealt with but rather discussion of SUDEP. I am a strong believer in defending anybody's right to express their views, as long as they are well substantiated and I do believe the authors in this case have made a valiant attempt to examine the pre-held opinions and ideas while they have failed to address their inherent bias within the body of the text. I do not believe that this should preclude publication because I do believe that what the authors have done contributes to the debate and it is a debate that should be had and should continue. Having said that, to publish this paper without an editorial giving some of the points raised above would be lending credence to something for which credence is still awaiting proof. With that in mind, I would only accept this paper if it were accompanied by an editorial which brings balance back to something that I believe is quite unbalanced and has used questionable scientific approach to argue preconceived ideas.

Response: We thank the reviewer for their comments and have attempted to address these in a methodical manner, hoping that this satisfies a high level of rigour in our approach. We have developed our sections on the limitations of the available literature to include that there is inadequate coverage around how to best discuss the range of risks relevant to Epilepsy. (p.36/37)

The evidence for guidance extracted here was limited. Studies have not considered directly how communication works, and most research focuses specifically on communication about SUDEP, rather The evidence for guidance extracted here was limited. Studies have not considered directly how communication works, and most research focuses specifically on communication about SUDEP, rather than other epilepsy risks, such as: such as self-injury, problems with driving, overdose of medication, under-dosing of medication, drug interactions, ongoing seizures, status epilepticus, nor other risks associated with the clinical management of epilepsy. A greater amount of research around communication is required that covers these areas.

Keep Safe: The when, why and how of epilepsy risk communication

Introduction

This paper collates guidance from the literature around how clinicians might best hold conversations about epilepsy risks, without undermining clinician skills of undertaking these conversations. Difficult conversations especially around risk of death are complex and can be misconstrued. There is ongoing debate around risk discussion rationale (1, 2), however, recent research illustrates how better risk communication can change outcomes (3, 4). The focus of this paper is the communications directly. Greater understanding of communication has significantly affected patient engagement with care, for example, discussing lifestyle risk assessments with GPs (5) and in facilitating delicate end of life conversations in oncology settings (6). A similar approach would be beneficial in the world of Epilepsy.

The rationale for discussing epilepsy risk

People with epilepsy (PWE) and their families are concerned that they do not receive enough information about risks related to epilepsy, nor how to manage these (7). In 2002, 42% of epilepsy related deaths were identified to be potentially avoidable had PWE and/or their families been more aware of the risks of morbidity and mortality (8). Annual epilepsy deaths match those for asthma though the prevalence of asthma is ten times that of epilepsy (9). It appears that the incidence of epilepsy deaths is increasing, indicating the need for preventative interventions (10). Discussion of lifestyle behaviours, such as medicine adherence, alcohol and recreational substance intake and how to monitor seizures particularly at night and awareness of outcomes such as Sudden Unexpected Death in Epilepsy (SUDEP) might reduce morbidity and mortality from epilepsy (11, 12). It is a

clinical recommendation that epilepsy risks and SUDEP are discussed with PWE (13, 14, 15, 16)~~NICE, 2004, 2012; SIGN 2015; AAN, 2017)~~. Yet PWE and their families are continuing to report poverty of and inconsistent information about risk (17~~Kroner et al., 2014~~).

Another rationale for risk conversations is family sequelae following deaths. Families and PWE~~s'~~ believe that all those related to or working with a PWE ~~stakeholders involved in a PWE~~ should be informed (~~Stevenson & Stanton, 2014~~18). More than half of bereaved relatives of SUDEP highlighted lack of awareness that epilepsy could be fatal prior to their relative's death (19~~Bellon, Panelli & Rillotta, 2015~~). This can lead to feelings of guilt about not having done enough to help.

Barriers and challenges to risk communication

Despite clear justification and recommendation for discussing risks and risk factors, PWE and their families often remain poorly informed (20~~Harden, Tonberg, Chin, McLellan, Duncan, 2014~~). A study of a sample of Australian family and friends bereaved by epilepsy death, illustrated that the majority (53%) had believed that death from a seizure is not possible (19~~Bellon et al., 2015~~). Thirteen (of 101) participants believed seizure deaths could only be related to seizure accidents, not the seizure itself.

Even when PWE were informed about SUDEP, they can remain unsure of what this means (21~~Tonberg, Harden, McLellan, Chin, Duncan, 2015~~). Thus, some of the issues might relate to *how* information is communicated, not just *whether it is*.

L~~This l~~ack of knowledge can be a concern for clinicians, too.~~is also present for clinicians, who can be uncertain about epilepsy risks themselves.~~ ~~Risdale, Massey & Clark (2007) report that~~ General Practitioners (GPs) are often the person that PWE prefer for monitoring Epilepsy, but GPs can feel lacking in confidence to do so (22)~~Ridsdale, Massey & Clark (2007).~~ ~~Primary care practitioners including General Practitioners (GPs) report a lack of confidence in their ability to sufficiently manage epilepsy and make appropriate referrals to~~ ~~Risdale et al report that~~ Further, PWE perceive this 'lack of confidence' from ~~as leading~~ GPs to avoid discussing the risk and social aspects

of the condition, including work, driving and financial effects (22Ridsdale, Massey & Clark 2007). neurologists or other specialists (Ridsdale, Massey & Clark, 2007). Within the paediatric population, one study found that 75.4% of paediatric care providers were unaware that children with epilepsy were at a risk of SUDEP (23Berl, Goodkin, Kroner, Bumbut, Lapham, Gaillard, 2017). Clinicians without a specialist interest in epilepsy particularly struggle with conversations about SUDEP and epilepsy risks and may benefit from further information (25Miller, Young, Friedman, Buelow, Devinsky, 2014).

This difference between specialist and non-specialist information giving might relate to assumptions that discussion of SUDEP and epilepsy risk should be with only those at 'higher risk', and specialists are more likely to see this group. Though there are factors indicative of cumulative risk (25Shankar, Walker, McLean, Laugharne, Ferrand, Hanna et al., 2016) there is as yet no validated approach to obvious tool or technique to help classify epilepsy risk definitely into 'high' or 'low'. Also, people considered as 'low risk' die, and so care needs to be taken not to make false assurances (26Panneli, 2011). The preference for only discussing risk with tendency to hold risk conversations only with 'high risk' groups also occurs in specialist services. Another confounder is that epilepsy is a chronic condition which waxes and vanes with life event and age. Thus, risk rarely remains static and can fluctuate over time (4)Shankar, Henley, Boland, Laugharne, McLean, Newman et al., 2018).

The incidence of epilepsy death in newly diagnosed PWE is very low (1:10,000). However, if epilepsy is chronic, as in 30--40%, the risks can increase to significantly high levels such as those with pharmaco-resistant epilepsy that are failed by epilepsy surgery (1:300) (27Shankar, Donner, McLean, Nashef, Tomson, 2017). The lack of a continued dialogue or even a single discussion might reflect a paternalistic view of SUDEP and general risk communication (28Long, Cottenman-Hart, Shelby, 2018), that is, that PWE and their families need protecting from knowledge of SUDEP. As of now, SUDEP is only frequently discussed in relationship to increasing adherence to medication only

(29Radhakrishnan, Ramanujam, Srivastava, Dash, Tripathi, 2018), rather than routinely considered. However, SUDEP is only one issue risk, and evaluation of other factors that might be discussed does not seem widely available..

Ethics of risk communication

Clinicians may fear distressing PWE or making them uncomfortable in discussing risk (30Keddie, Angus-Leppan, Parker, Toescu, Nash, Adewunmi et al., 2015). This may relate to an ethical concern to "do no harm" (31,Ronen, 2017; 32) Hamid & Nass, 2010). This includes the possibility that clinicians might be giving information that is less relevant to that person where they are perceived as "low risk" (Hamid et al., 2010), to prevent creating unnecessary anxiety (31Ronen, 2017). Indeed, Beran (33an (2015) noted that the psychological sequelae of risk communications to PWE remain unknown. It was observed that there is considerable debate, including, suggesting that a more compassionate and value based approach to care would recognise that PWE and their families need to be able to make informed decisions, which they cannot do without adequate information, and the clinician should not have the right to remove this choice (34Donner & Buchhalter, 2014). Donner & Buchhalter (2014) They clarify this, stating is is further ied y thisthat PWE might develop better self-management strategies (e.g. not using soft pillows, sleep or medication manage), improving people's perception of control over their lives (and possibly reducing risks directly) (34Donner & Buchhalter 2014). It They is also observe thatobserved that access to online material can raise anxiety in an unmanaged way and people have less confidence in this material , as do (34, 35Donner & Buchhalter 2014, ()). Both of these studies authorconclude that from a patient perspective, clinician supported conversations are important.

Lack of guidelines to provide person centred communication of risk

The main barrier seems to be a lack of guidelines about how to communicate (36)Shankar, Newman, Hanna, Ashton, Jory, McLean et al., 2015). Guidelines might inform clinicians better on how discussions should take place or what should be covered (4Shankar et al., 2018). Currently,

varied aspects of good practice guidance seem spread across different papers possibly leading to key features being missed. These include recommendations that risk conversations should be tailored to individuals, focusing on modifiable risk factors (27~~Shankar et al., 2017~~); and the importance of considering repeating conversations at least yearly (3~~Young, Shankar, Henley, Rose, Cheatle, Sander, 2018~~, 36~~Shankar et al., 2018~~). Other guidance include the need to consider an individual's readiness to learn, preferred learning styles and expectations, and the range of information sources available (37~~So, Bainbridge, Buchhalter, Donalty, Donner, Finucane et al., 2009~~).

Objective/Aim:

The current review aimed to extract from the literature available evidence-based recommendations of how clinical conversations about risk and risk factors should occur with PWE, and identify what areas are still under researched.

Method

An open-ended search of four databases was conducted in November 2018; Ovid Medline, Ovid Embase, PUBMED, and CINAHL, using the search string: 'epilepsy death or epilepsy mortality or SUDEP AND patient or individual or disclosure or discuss or inform or communicat* or advice or risk. Where subject headings were available these were searched for 'Sudden Death' and 'Epilepsy' AND 'Information processing' and 'information dissemination'. Reference list checks were conducted. The PRISMA scoping review checklist was used as a guiding template (Supplementary information). The review protocol is detailed here.

Two researchers screened the papers independently for the pre- designed inclusion and exclusion criteria. A sample of these and all disagreements were discussed with a third researcher. Inclusion and exclusion criteria are detailed in table 1. These criteria and the search strategy were developed in conjunction with senior clinicians and information specialists.

Table 1:

Inclusion and exclusion criteria

Inclusion	Exclusion
Empirical studies	Reviews and opinion pieces
Peer reviewed studies	Papers focused only on identifying risk factors in Epilepsy
Written in English or having an English translation due to limited translation funds	Focuses on PWE under the age of 18 as communication with children may need different sensitivities
Any research method	No mention of SUDEP or epilepsy risks
Evaluations of frequency of conversations and communications	Doesn't explicitly discuss how to communicate risks
Papers including content of how clinicians discuss risk with PWE	Where there were no recommendations given for practice
Papers including recommendations about how to talk about risk in epilepsy	

Method of quality assessment

Following Booth, Sutton and Papaioannou (2016), PPpapers were subjected to quality assessment; using either Critical Appraisal Skills Programme (38CASP, 2018) or Appraisal tool for Cross-Sectional Studies (39, 40, 41)AXIS,2016; Downes, Brennan, Williams & Dean, 2016; Booth, Sutton and Papaioannou 2016),). The CASP Critical Appraisal tools were developed as a guide for evaluating research based on features such as clarity of aims and content and wastools were developed as a guide for evaluating research based on features such as clarity of aims and content and were used for qQualitative and qQuantitative studies. The AXIS was developed to explore medical cross-sectional studies based on features relevant to these study designs. The CASP and AXIS critical appraisal tools do not provide an overall score and ratings are subjective; therefore, ratings were given

independently by 2 researchers, and discussed in a moderation group with a third. Both tools are designed to give an indication of the credibility of the evidence and potential gaps.

Data extraction method

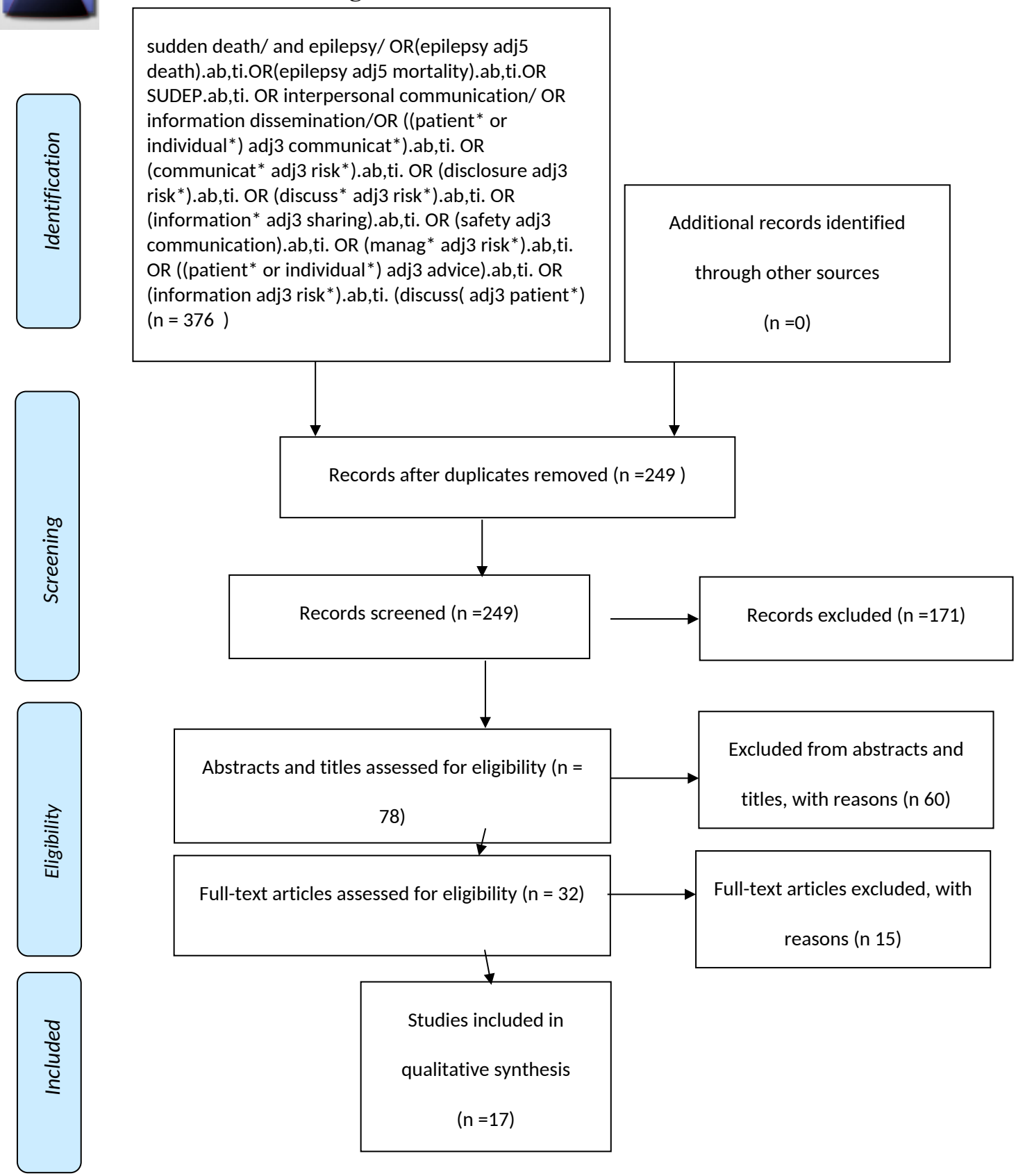
Data was extracted into a summary table (Results, Table 5). Key questions were applied to each paper, summarising: main points made about communication and risk; identified helpful and difficult factors; gaps identified by paper; guidance recommended. Key phrases offering communication guidance were extracted and grouped.

Results

Description of the papers

There were 376 results, 274 after removal of duplicates. 36 articles remained following title and abstract review and seventeen after application of inclusion/exclusion criteria. Fifteen of these 36 were agreed as suitable by 2 independent reviewers; a further five were disputed and arbitrated by a third reviewer, resulting in 3 further rejections, leaving 17 papers. See figure 1.

RISMA 2009 Flow Diagram



Of the 17 papers, two used mixed methods, 10 were quantitative and five were qualitative studies. Research quality was assessed using the CASP and AXIS tools, (tables 2-4). All studies received either a "good" or a "moderate" rating score. Ratings were derived by assessing potential problems in studies. Ratings were: 3 or less problems, good; 3-6 problems, moderate; 6< problems, poor.

Seven were rated as moderate quality. Problems were either due to difficulties matching controls in experimental designs, or not enough detail in the analysis to replicate qualitative analyses. These are common concerns in clinical research often related to the research context or journal restrictions. 10 articles were rated as good quality, all quantitative studies.

Table 2.

Quality ratings of mixed methods studies using CASP

Author and Date	Quality Score for the purposes of this review
Morton et al (2006) (42)	Quantitative data. Moderate quality. Analysis not detailed, limited word count. Qualitative data – Moderate Quality. Limited information aims unclear. More detail for method of analysis needed.
Vegni et al (2011) (43)	Quantitative data - Moderate quality. Low response rates, possible sample bias as only those with knowledge of SUDEP responded. Clear analysis. Ethics or conflict of interests not discussed. Qualitative - Moderate quality. Clear analysis, two coders used. Relationship of researchers to data not mentioned.

Table 3:

Quality rating of qualitative studies using CASP

Author and date	Quality Score for the purposes of this review

Miller et al (2014) (24)	Moderate quality- Methods could have more detail to explain thematic and content analysis making it difficult to assess rigour.
Ramachandran Nair et al (2016) (35)~~a)~~	Good quality – clearly organised. Clear method. Replicable method. Relationship between the researcher and data not addressed.
Nisbet et al (2017) (44)	Moderate quality- Clearly written. Method clear, including role of the researcher. Recruitment of participants might have been clearer.
Ramachandran Nair and Jack ~~et al~~ (2016~~b~~) (45)	Good quality- recruitment, methods and analysis clearly explained. Sample size justified. Replicable. Codes explained including how they were derived from the interview guide.
Ross et al (2015) (46)	Moderate quality- confounding variables possibly not considered e.g. not documenting SUDEP discussion. Follow up time short at only 6 months rather than a year as other research recommends. Acknowledged by researcher.

Table 4:

Quality ratings of qualitative papers using AXIS

Author and date	Quality Score
Louik et at (2017) (47)	Good quality. Article coherent. Methods clear. Replicable. All 138 enrolled took part in the study. Generalisable.
Friedman et al (2014) (48)	Good quality. Uses a p value of <0.02 in the logistic regression. 1200 surveys completed, though 9% response rate, remains substantive. Provides reasons for non-completions. Methods and analysis clear. Replicable. Sample appeared representative.
Henning et al (2018) (49)	Good quality. Has a high participation rate (2090), 56.6 being PWE, the remainder, carers or family members answering for the PWE or themselves. Participants likely to be representative of PWE. Statistical analysis clear and thorough. Replicable. Findings and discussions comprehensive.
Lewis et al (2008) (50)	Moderate quality. A representative sample of epilepsy nurses. High response rate, 103 surveys included in final analysis. Methodology and results difficult to replicate. This could be because of journal word limit.
Mohanraj et al (2006) (51)	Good quality. Used newly diagnosed PWE and those with chronic epilepsy over a 20-year period to assess mortality. Methods and analysis clear. Comparisons defined and statistical analysis clear.

Shankar et al (2018) (4)	Good quality. Methods clear. Analysis clear. Replicable. Generalizable to the population of PWE.
Shankar et al (2016) (25)	Good quality. Methods clear. Data collected over a 9-year period so likely to be representative of SUDEP deaths and reflects national records. Appropriate use of statistics.
Waddell et al (2013) (2)	Moderate quality. Measures used to assess SUDEP conversation may not be reliable, as they were dependent on accuracy of patient notes. Time constraints and different descriptions of SUDEP conversations e.g. using "serious harm" instead of SUDEP may have led to underestimation of SUDEP conversations. Results and method are very clear.
Xu et al (2015) (52)	Good quality. Sample seemed representative. Large number 105 taking part. High rate of participation. Appropriate use of statistics.
Young et al (2018) (3)	Good quality. Representative sample of PWE with LD. High response rate (77%). Appropriate population. Statistical analysis clear. Replicable.

Data range of all papers collected was between 2001 and 2018; and papers were published between 2006 and 2018. Ten were conducted in the UK, one in Australia, one in the US, two in Canada and the US, one in Canada, Australia and the UK, one in Norway and one in Italy. Four studies elicited the views of PWE and their families, and six studies focused on the views of clinicians, one study focused on bereaved families (see figure 2).

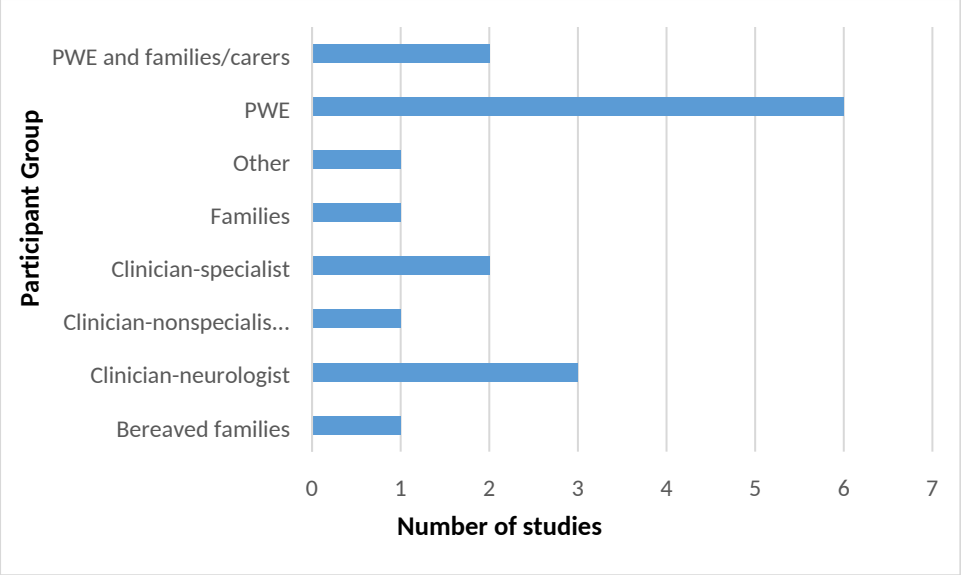


Figure 2. Participant groups in different studies~~Participants in studies~~.

There was limited consideration of how gender, ethnicity or age might affect communication. Five ~~5~~ papers commented that men were generally considered at higher risk but none discussed this in relation to how communication might be adapted. One paper considered age, gender, duration of epilepsy, level of education and employment as variables that might affect preference for discussions, finding none of these significant predictors.

There was diversity of methods (figure 3). Four studies compared risk communication between groups, such as using checklists (n=3), or reported discussions of risk (n=1). Two studies were case note reviews. Twelve studies included less than 50 participants, two studies included between 50 and 200 participants, and three studies included over 200 participants.

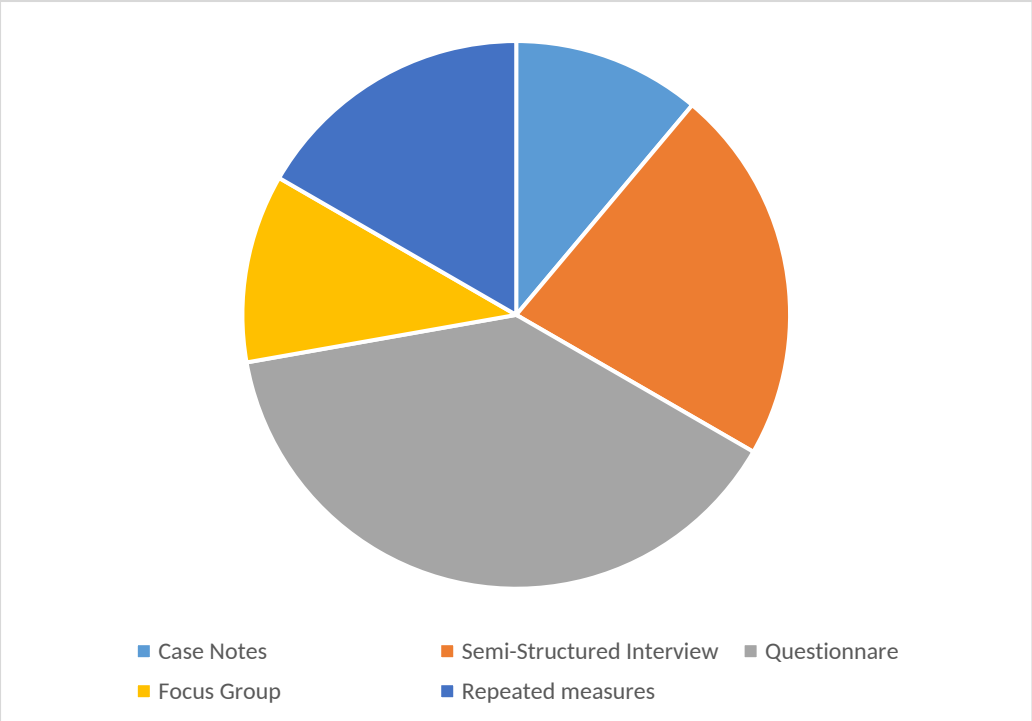


Figure 2. Methods used in the studies.

Recommendations about how to communicate risk

The papers are summarised in Table five~~5~~. Papers were identified based on whether they offered guidance on how to hold conversations about risk with PWE. However, 15 of the 17 papers focused on- SUDEP, suggesting a large gap in the literature. None of the papers focused directly on how to communicate about risk. We found limited elaboration around the individual differences that might affect whether, when or how to hold risk conversations; instead papers just reminded clinicians to

consider individual differences. ~~None of the papers directly addressed the question of how to communicate risk.~~ Extracted ~~R~~recommendations that might guide clinicians in how and whether to hold risk discussions with PWE ~~were extracted and~~ are summarised in table six~~6~~.

Table 5

Data extraction from all studies.

Title	Aims to:	Data Collected	Participants	Analysis	Key Findings	Recommendations/ implications
Mohanraj et al, 2006	Analyse mortality data for patients with newly diagnosed and chronic epilepsy who were referred to a single adult service over a 20-year period	Related measures. PWE were assessed for mortality risk on the basis of response to treatment.	Group 1: 890 newly diagnosed PWE; Group 2: 2689 PWE with chronic epilepsy and poor seizure control. Compared with age and sex matched controls.	Keplan-meier survival curves were plotted for the 2 groups and controls. Chi-squared test was used to compare observed and expected deaths.	There were 93 deaths in the newly diagnosed group compared to 64 in age and sex matched controls (p=0.0007). All excess mortality occurred in patients who did not achieve seizure freedom with treatment. In the chronic group there was more than double the expected number of deaths and incidence of SUDEP compared to newly diagnosed PWE, this being higher for those under 30 yrs. of age.	Routine discussion of mortality at the time of diagnosis not necessary, especially if this does not affect the management of the epilepsy. Epilepsy risks and mortality should be discussed with PWE who choose not to use AED's, and those who haven't achieved seizure freedom.
42Morton et al, 2006	Present the experiences of neurologists in discussing SUDEP with PWE.	Questionnaires to all practicing neurologists listed on the	387 questionnaires (of 738 sent). Represents 82% of consultant body. 63 were specialist	Chi squared test and qualitative analysis.	4.7% discussed SUDEP with all PWE. Years of experience, or level or registration (registrar/neurologist) had no effect. Those with a special interest in epilepsy were more likely to	The majority of neurologists are not following the NICE guidelines. Practice effect may make it easier to discuss SUDEP.

		British neurologist's database. Asked about the circumstances surrounding discussions about SUDEP and PWE's reactions.	registrars. Remainder were from specialist epilepsy clinics.		discuss SUDEP. Those discussing SUDEP routinely reported less negative reactions from PWE.	NICE give little guidance on how, when and whom to discuss SUDEP with. Epilepsy. Risks should be contextualised, e.g. likelihood of SUDEP compared to getting hit by a car. NICE guidelines deny the "right not to know".
~~Lewis et al, 200850~~	Examine what, when and how information about SUDEP is disseminated to patients by clinical nurse specialists in epilepsy (CNSEs)	Postal Questionnaires from ESNA members.	146 responses (from 250 sent). 43 excluded as respondents were not CNSE. Time in role ranged from 8 months to 21 years	Descriptive of responses.	6% discussed SUDEP with all patients. 48% stated risk discussions were prompted by discussions of risk factors (e.g. alcohol consumption. Length of service had no significant effect. Most discuss SUDEP over the telephone (42%). 62% reported an increase in medication adherence following SUDEP discussions, and subsequent avoidance of risk factors (62%).	CNSE do not discuss risk with all patients. SUDEP discussions need to be addressed carefully, balancing the negative effects of fear in patients, with the benefits of raising awareness. Timing of discussion should be individually determined.

Vegni et al, 2011	Explore whether Italian Physicians interested in epilepsy believe that they should discuss SUDEP with patients and or their families or not	Questionnaire.	Recruited through the Italian association against epilepsy (LICE). 195 responses. 49.5% were male. Mean age 45; average practice years 21.	Chi squared test & content analysis	28% of believed that SUDEP should be discussed with most patients. Most believed that PWE be emotional or have a negative reaction (73%). Physicians may decide to give risk information based on the patients themselves or for non-clinical reasons such as ethical issues.	More research is needed for in-depth understanding. Physicians may disclose risk more often if they have treated someone with SUDEP or following ethical discussions.
Waddell et al, 2013	Conduct an audit of current practices of discussing SUDEP with PWE at a specialist epilepsy clinic.	5 yr. case note analysis.	All patients who attended a specialist epilepsy clinic, and those who had experienced at least 2 unprovoked seizures were included, producing 345 case notes. Mean age 41 yrs. 50.7% were male.	Descriptive statistics and fishers 2 tailed test for comparisons between risk factor groups.	SUDEP is not discussed with all patients. Those with ongoing GTCS and drug resistant seizures were more likely to be informed. There was a trend towards discussing SUDEP with those non-compliant with medication.	An honest and frank debate is required between clinicians, patient advocacy groups and those involved in developing guidelines to allow one to reconcile the disparity between guidelines and clinical practice in regard to SUDEP.
Freidman et al, 2014	Examine SUDEP discussion practices among neurologists in the U.S and Canada.	Online questionnaire-based study.	117, 558 people invited by email. Self-selected if they: were a neurologist who devoted >5% of their time to clinical care and	A composite knowledge score was determined by subtracting the	82% had incomplete knowledge about SUDEP. 26.1% encountered at least one case of SUDEP in the past 24 months. 6.8% of neurologists discussed SUDEP with all patients.	SUDEP conversations can be framed to minimise distress. Neurologists with more experience and diverse caseloads report less perceived distress to SUDEP discussion. Guidance is needed regarding the best approach to SUDEP discussions for neurologists.

			had completed post-grad training. 200 completed surveys. 76% adult neurologists; 33% additional training in epilepsy or neurophysiology. 43% saw 100 PWE annually.	number of incorrect identified risk factors from correctly identified factors & multivariate logistic regression.	Epilepsy training, years in practice, having over 100 patients annually and having a case of SUDEP increased the likelihood of discussion. 62% discussed SUDEP when patients were 'high risk'. Risk level and additional training was associated with an increased risk of a perceived negative response to SUDEP discussion (p=0.038).	
Miller et al, 2014	Describe the practices of epileptologists, neurologists and advanced practice nurses (APNs) regarding discussing SUDEP with their patients, and their rationales for discussing SUDEP	Two focus groups: one with epileptologists and neurologists; one with APN's.	19 epileptologists, 16 neurologists and 8 APNs. All areas of central America were represented	Themes were inductively developed.	Themes: 1. Reasons for discussing SUDEP: Practical accountability; Moral accountability, proactivity and reactivity, and for nurses only – patient advocacy. 2. Reasons for not discussing SUDEP: to wait for a rapport to be established, being morally accountable, and being out of options. 3. Ways in which SUDE should be discussed: face to face discussion were common with	A standardised approach to discussing SUDEP is needed to facilitate clinicians, and overcome fears that discussions will cause harm, and have no benefit. Decisions not to disclose might not be patient centred. Clinicians should involve PWE in decision making. The next step is to provide a practical guide for discussing SUDEP. SUDEP education should be a component of epilepsy care.

					written materials; requirement for standardised protocols that can be adapted to individuals.	
Ross et al, 2015	Evaluate current clinical practice and determine whether there had been a change in frequency of SUDEP discussion following prior audit.	A retrospective case note review of a single service.	392 patients were reviewed, 240 case notes were available for review from PWE attending a specialist clinic. 27 new referrals. 213 return patients. 46% were males. Mean age 36yrs.	Descriptive statistics and comparisons between risk factor groups using fisher's two-tailed test.	SUDEP discussions were documented in 67% of new referrals, 30% of return patients. These included by neurologists with a specialist epilepsy interest (40%), 30% with epilepsy nurses, 17.4% with GPs. PWE with GTC's were more frequently informed of risks; PWE for longer than 15yrs, drug resistant seizures and LD were less frequently informed.	An inverse relationship between those at greatest risk and those most likely to be informed might reflect perceived difficulties in discussing SUDEP where it seems there are no therapeutic options left to cover. A tailored discussion in clinic with discussion of risk-reducing strategies will be a positive intervention.
Xu et al, 2015	Evaluate awareness and perspectives on SUDEP among adult PWE	Questionnaire.	40 males a 65 females took part in the study, mean age of 41 yrs.	Multivariate logistic regression explored the variables among patients associated with their awareness of SUDEP and	62% of PWE wished to know all information. 32% wanted a reasonable amount. 52% thought epilepsy was not associated with higher risk of death. 14% had heard about SUDEP before the study. 89% of participants wished to be informed about SUDEP, preferably by their neurologist.	The authors encourage health professionals and policy makers to incorporate SUDEP discussions in regular practice and as a quality measure of clinical practice.

				willingness to be informed of this.		
RamachandranNair and Jack, 2016	Understand the range of adult patients' views on discussing SUDEP with PWE; clarify the optimal timing and formulation of information.	Telephone semi structured interviews. 1 focus group.	23 PWE (7 males and 16 females) recruited through an adult neurology clinic and a community epilepsy agency. Aged 18-65, median, 33. 19 participated in interviews. 4 in focus group.	Directed content analysis	10 (43%) had heard about SUDEP previously; 2 learned through the internet, 4 through the community epilepsy agency, 3 from their neurologist, and one from their mother. All agreed SUDEP should be discussed at the diagnosis. 3 felt SUDEP disclosure should be individually decided. 19 considered there may be negative effects, such as anxiety. Neurologist rather than the emergency department, best person to inform. No participants correctly explained meaning of SUDEP, even when leaflet given. 50% of PWE felt anxious upon learning about SUDEP, short lasting. Some reported then increasing adherence to their medication.	Face to face discussion of SUDEP with the neurologist important. Written information beneficial. Content should include an estimate of individual risk, emphasis on actual prevalence and preventative strategies.

RamachandranNair, Jack and Strohm, 2016	Understand the experiences of relatives of individuals whose deaths were identified as SUDEP and to explore their preferences regarding SUDEP counselling.	In depth semi-structured interviews	Stratified purposeful sampling: people over 18 bereaved by SUDEP. 27 participants, 21 females and 6 males. 4 were siblings, 5 were spouses and 18 were parents.	Thematic analysis using categories from the questionnaire and emergent categories.	1. Experiences at the time of SUDEP: all experienced shock and guilt. 2. Awareness of SUDEP: families could accurately define SUDEP, most drawing parallel between SUDEP and SIDS. Only 9 participants knew about SUDEP before the cause of death. Many were angry not to have known earlier, feeling there could have been preventative steps. Awareness of SUDEP after death was valued, giving "peace of mind". 3. Whether to discuss SUDEP: SUDEP education was overwhelmingly valued, especially for those with specific risk factors. PWE stated it was their right to know about their condition. Possible negative effects included making people over protective of the PWE. 4. Information should be provided by the patient's neurologist shortly after or at the time of diagnosis. 5. Content of the SUDEP discussion: include an explanation of SUDEP; associated risk factors	Neurologists should inform patients SUDEP. Optimal timing decided case by case. Deliver information face to face at first or second visit. Give printed material. Content should include realistic risk appraisal. Emphasise preventative strategies.

					and preventative methods. Note the rarity of SUDEP.	
Shankar et al, 2016	Compare the 17 risk factors to cases of SUDEP deaths, and those living with epilepsy to determine how strongly these factors are associated with SUDEP risk	Comparison of risk factors as identified using the SUDEP and seizure safety checklist were compared between live samples and people who had died from Epilepsy related deaths.	43 SUDEP deaths of 93 Epilepsy deaths occurred between 2004 and 2012. The coroner's notes were used and compared with the medical notes from 220 live PWE.	Groups were compared and relative risk factors ranked.	9 (of 17) risk factors differed significantly between groups. 2 were not modifiable (duration of epilepsy and GTC's). 7 modifiable risk factors were identified and ranked.	The study supports the use of an evidences-based checklist to discuss potentially modifiable risk factors with patients

Louik et al, 2017	Examine attitudes towards SUDEP discussion among family members	Semi-structured telephone interviews about experiences of SUDEP discussions.	138 family members enrolled on the North American SUDEP Registry. 79% were conducted with at least one parent, 10% with widower and 10% with offspring and 40% with another next of kin or carers	Regression analysis to identify predictors of SUDEP awareness. Factors included: year of death, status epilepticus, GTCS and age.	18.1% recall having discussed SUDEP, initiated by the neurologist in 44% of these cases. 72% appreciated this discussion, 24% were unsure. For those who did not recall a SUDEP discussion 72.3% wish they had, 10% did not and 17% were unsure. Common themes they wanted discussed included: incidence of SUDEP, general SUDEP information, importance of AED adherence. No significance was found for factors increasing the likelihood of SUDEP discussion.	Frequency of SUDEP discussion may not be increasing, contrary to other research. Research should examine why people might not want to learn about SUDEP and whether SUDEP education can mitigate risk factors such as AED adherence. Healthcare should discuss SUDEP when caring for PWE rather than after the person has died.
Nisbet et al, 2017	To explore the experiences of neurologists in Scotland when discussing SUDEP with the patients.	Qualitative individual interviews	6 consultant neurologists and 4 registrar doctors participated in the research.	Thematic analysis.	Themes: 1) The SUDEP protocol: Clinicians engage in 2 types of SUDEP discussion – with PWE who are newly diagnosed, and uncontrolled. For those with uncontrolled seizures it was used to emphasise the risk and encourage AED adherence. SUDEP was not discussed if the PWE appeared to be distressed or anxious. 2) Diffusion of the FAI- The Fatal Accident	The FAI in Scotland has increased SUDEP discussion by highlighting possible medico-legal implications. Future studies should quantify behaviour changes post SUDEP discussion, as this might facilitate confidence to increase SUDEP conversations.

					Inquiry (specific to Scotland) heavily influenced how clinicians' emphasis on SUDEP discussions although there were some mixed feelings. 3) Breaking good news- there were mixed feeling surrounding discussing SUDEP. 4) Falsely anticipating distress- Clinicians believed they were likely to cause distress and anxiety by discussing SUDEP. Many being surprised when PWE react calmly. 5) Pressure hinders effective communication- Clinicians report that the requirement to discuss SUDEP sometimes inhibited their ability to do it well, due to time pressure.	
Henning et al, 2018	Assess how much information PWE and their family members wanted about epilepsy related risks and whether this need was met by health care professionals.	An online questionnaire available through a Norwegian epilepsy association.	1859 participants. 1183 were PWE. 676 were careers answering on behalf of PWE.	Chi squared test used to analyse group differences and multivariate logistic regression used to determine	90% wanted information about risks and premature death. Having generalised tonic clonic seizures was associated with wanting information about the death risk (p=0.001). Male gender, younger ages and aetiology of epilepsy were significant factors for having been told about SUDEP. 14% of patients felt they had been well informed.	There is a gap between what the patients want to know and what they are told by healthcare providers.

				factors that may predict a wish to be given more information, or people being given more information about increased risk.		
Shankar et al, 2018	Determine whether the introduction of a risk communication checklist in an epilepsy clinic leads to a reduction in individual SUDEP epilepsy mortality risk factors.	Repeated measures. Assessment of risk using a checklist was conducted twice as part of routine care in a specialist epilepsy clinic, one year apart.	130 consecutive individuals from the neurology clinic and 129 from the ID clinic. The second application 91 and 93 individuals, respectively.	Paired t-test to compare groups.	Overall reduction in mean risk score for the general population (p=0.049) but not for the ID population (who had received risk information on numerous occasions previously). There was a risk reduction in the top 25% in both patient groups (p=<0.001).	Safety advice had direct implications for reducing risk factors. The introduction of a safety Checklists supported. Policy might promote use of health promotional checklists in epilepsy to reduce morbidity and mortality.

Young et al, 2018	Assess whether PWE and their families or support workers were SUDEP aware and could recall discussions about SUDEP risk and the role of nocturnal surveillance.	Questionnaire.	121 responses from PWE with LD under active follow up in July 2017. 75% were living in a residential setting	Fisher's exact test was used to establish differences between those PWE living family or in a residential setting.	PWE with ID placed in a residential setting are more likely to not have person centred risk advice implemented compared to those in a family setting. Those in the family setting were more likely to recall the SUDEP discussion (65%) compared to those in the residential setting (39) ($p=0.006$).	PWE with ID should be offered nocturnal monitoring to help recognise previously unknown events. Structured communication tools might help to reduce risk. Risk discussions need to be repeated and tailored to match the PWE. A cost-effective intervention could be developing an electronic learning module for professions working with PWE with LD.

Table 6:

Guidance around how to communicate with PWE about epilepsy risk and risk factors

	Guidance	Paper
Timing and frequency of communications	1. Evaluate whether the clinician has the right experience to engage in discussions	50Lewis (2008) 42Morton et al (2006)
	2. Evaluate the risk of harm or distress in the PWE, for example it might not be appropriate to hold conversations at the time of diagnosis	24Miller et al 2014 51Mohanraj (2006) 46Ross et al (2015)
	3. Conversations should be held as early as possible	47, 45, 35Louik et al (2017); RamachandranNair and Jack (2016) RamachandranNair et al (2016)
	4. The timing of conversations should be individually evaluated	50, 3, 43Lewis et al (2008) Young et al (2018) Vegni et al (2011)
	5. Conversations should occur at least yearly, more frequently if there are risks, including where people are at low risk, or have an intellectual disability.	4, 3Shankar (2018) Young et al (2018)
	6. The clinician might also ask PWEthe patient whether they want to discuss risk.	42Morton (2006)
Method of communication	7. Full information should be provided to PWE and their families.	Henning et al (2018)49, 52 Xu et al (2015)
	8. People may prefer to be informed by a neurologist.	49Henning et al (2018), Xu et al (2015)52, 35 RamachandranNair et al (2016)
	9. There should be more than one method of communication about risk (online, printed, and verbal).	4RamachandranNair and Jack (20165)
	10. Having a policy that clinicians must discuss risk and ensure that people are better informed and overcome anxieties from the clinician	Nisbet et al, 201744
Content of communication	11. Conversations should be framed in a manner acceptable to a person with epilepsy	48Friedman et al 2014)
	12. More experienced clinicians should deliver discussions	48Friedman et al (2014), 42 Morton et al (2006)
	13. Acknowledge both the anxiety of the person with epilepsy and the benefits of increased awareness.	50, Lewis et al (2008) 2Waddell et al (2013)
	14. Normalise the risk of SUDEP / be realistic with actual prevalence and preventative strategies	42, Morton et al (2006) RamachandranNair et al 2016 35,

	RamachandranNair and Jack 201645
15. Checklists can help to guide risk discussions	Shankar et al, 2016;25, 27017 3Young et al (2018)

Timing and frequency of communication

Whether to hold discussions:-

Despite risk communication being considered important, it remains infrequent or ineffective (47Louik, Doumlele, Hussain, Crandall, Buchhalter, Hesdorffer et al., 2017 (US, Canada); 50Lewis, Higgins & Goodwin, 2008 (UK); Morton42, Richardson & Duncan, 2006 (UK)). The clinician's direct experience of epilepsy and SUDEP (Lewis et al.,50 2008 (UK); Morton et al., 2006 42(UK)) and whether they had a specialist interest in epilepsy (46Ross, Waddell, Heath, 2015, UK) are important determinants of whether risk is discussed. Communication was also affected by the clinician's experience of SUDEP (43Vegni, Leone, Canevini, Tinuper, Moja, 2011, Italy). Avoidance of harm to the PWE was the main rationale for not discussing risk (24Miller et al., 2014, US;). Vegni et al (201143, Italy). It was found in a study that many clinicians still do not believe that SUDEP or other mortality issues should be discussed with PWE (43, Vengi et al 2011, Italy). Some consider telling people who are newly diagnosed or who have good seizure control as "lower risk", thus believing they may cause distress for no reason (51Mohanraj, Norrie, Stephen, Kelly, Hitiris, Brodie, 2006, UK). However, RamachandranNair, Jack &Strohm (2016, UK other studiesfocusing on the experiences of PWE of risk discussions, foundhave allowed insight into the experience of PWE in these discussions, suggesting that people feel anxious in the short term but then reassured along with an association with subsequent increase in medication use (35RamachandranNair, Jack & Strohm 2016). They also report subsequent increase in medication use (RamachandranNair, Jack & Strohm, 2016, UK). This same study found that cause of death getting established as SUDEP provides closure to families. Other studies report that over 90% of PWE wanted to be informed of most if not all information through communication with their clinician (49Henning, Nakken & Lossius, 2018

(Norway); 52~~Xu, Ayyappan & Seneviratne, 2015,~~ (Australia)). Of the 12 papers considering whether a conversation is valid, Ten~~10~~ supported the position that conversations should be held while two ~~2~~provided more balanced positions, acknowledging that the clinician is best placed to make the ultimate decision, but providing guidance should they feel it clinically appropriate.

Timing:-

Seven of the 17 papers considered the timing of risk discussions. Louik et al (47~~2017~~, US and Canada) examined the experiences of bereaved families, and their concern that SUDEP should have been discussed with carers prior to death. Of 12 survey and interview studies of PWE, families and clinicians, three postulated that the timing of discussions should be individually evaluated (~~Lewis~~ 50~~et al., 2008~~ (UK); ~~Young~~ 3~~et al., 2018~~ (UK), 43~~Vegni et al., 2011~~ (Italy)), but how to do so was not detailed. ~~.~~ Two questioned the appropriateness of informing on risk at the time of initial diagnosis (51~~Mohanraj et al., 2006~~ (UK); 24~~and Miller et al., 2014~~ (US)). Three suggested conversations should occur at the first or second clinical meetings (47~~Louik et al., 2017~~ (Canada and US); 45~~RamachandranNair and Jack, 2016~~ (UK, Australia, Canada); 35 (~~and RamachandranNair et al., 2016,~~ UK). The remainder did not comment on timing.

Frequency of communication :-

Waddell, McCool, Turner, Norman, Coker, White et al.~~,~~ (2~~013~~, UK) found that SUDEP conversations were more likely to be held where people are non-compliant with medication. However, despite the emphasis on high risk people being more informed, a study by Ross et al.~~,~~ (46~~2015, UK~~) suggested that those who had had epilepsy for longer than 15 years, had drug resistant epilepsy and/or Learning Disability, were less likely to have been informed.

Ross et al. (46~~2015~~) also found an increase of case note documented discussions from 4% in 2009, to 31% of all referrals a year later, where 240 of 314 were available for the second audit.

Young et al (~~20083~~, UK) observed that it may be important to repeat discussions to ensure awareness and understanding, particularly for those with ID living in a care setting, or with less recent diagnosis.

Notably, the literature extracted was only that which focused on how to hold conversations~~,~~ ~~and did not~~ Although the evidence appears to be increasing in support of PWE being informed of risk, one paper discussed the PWE~~patient~~'s right not to know (42~~Morton et al., 2006~~, UK).

Method of communication

Method of communication :-

Six studies (52~~Xu et al., 2015~~ (Australia)); 35 ~~RamachandranNair et al., 2016~~ (UK); 45~~RamachandranNair and Jack, 2016~~ (UK, Australia, Canada); Ross et al., 2015 (UK); 47~~Louik et al., 2017~~ (US and Canada); 49~~Henning et al., 2018~~ (Norway)) focused on the views of PWE and their families directly. Over 90% of people wanted to be informed of most if not all information (49~~Henning et al., 2018~~ (Norway); 52 ~~Xu et al, 2015~~ (Australia)). All studies suggested that they would prefer to be informed face-to-face by an epilepsy specialist. Additional written (35; 45~~RamachandranNair et al., 2016; and RamachandranNair and Jack, 2016~~) or electronic material (3~~Young et al., 2018~~ (UK)) might also be helpful.

Protocols: -

Nisbet, Turbull, Mulhern & Razvi (442017, UK) evaluated the use of a protocol requiring clinicians to discuss SUDEP with PWE. Based on interviews of six neurologists and four senior medical trainees working in a neurology service, they found that pressure to discuss SUDEP created considerable anxiety in clinicians, who in turn believed this would create anxiety in PWE. PWE in fact responded calmly. Clinicians found the pressure of a forced conversation inhibited risk discussions.

Content of communication

Various points were made about the content of conversations.

Reducing distress:-

Friedman and colleagues (48), ~~Donner, Stephens, Wright, Devinsky (2014)~~ conducted a survey of US neurologists (n=1200), which suggested that conversation should be framed appropriately for the PWE who is the focus, which can then reduce levels of distress. Clinicians experienced in delivering these discussions, particularly those who had seen PWE for longer, seen more of them, and had more years since qualifying were more confident in reducing distress. However, a demand for further education for clinicians and PWE and care givers was also identified. Morton et al (42~~2006~~) also found experienced clinicians described feeling more at ease in discussing risks.

Balancing anxiety with risk reduction discussion:-

Following their study of 146 members of the Epilepsy Nurses Association, UK, Lewis et al (~~2008~~50) found that nurses felt that although it can be anxiety provoking, risk conversations increased adherence to medication, and 41% stated that it enhanced quality of life for people. Guidance was unclear from findings, but the authors argue that clinicians must balance too much information control with the potential benefits of awareness. They also found that nurses preferred face to face communications, however, 36% (n=37) of risk conversations were held in nurse led clinics; 27% (n=28) in a ward setting; and 36% (n=37) over the phone as these were opportunities where risk arose in conversation.

Normalising the risk discussion: -

Morton et al (42~~2006~~, UK) suggest that normalising the risk of SUDEP is also important, for example, by highlighting that it is less common than being hit by a car. RamachandranNair et al (35~~2016~~, UK) and RamachandranNair and Jack (45~~2016~~, UK, Australia, Canada) also support this

approach, stating that there should be a realistic appraisal of risk with the emphasis on the actual prevalence and preventative strategies.

Checklists: -

Discussions can also be supported by checklists (25; 4Shankar et al., 2016; 2018, UK), which can improve the safety for PWE (4Shankar et al., 2018; Young 3et al., 2018, UK).

Discussion.

This paper was designed to extract guidance from the literature around how to communicate risk with PWEpeople with epilepsy, offering additional information for clinicians to draw on in Epilepsy management. How this is appropriately applied will be determined by the clinical judgement of practitioners. However, the complexity of language eofand interaction deserves careful consideration to enable collaborative care with PWE patients. In the introduction, two barriers to communications about risk were identified.

1. *The lack of guidelines for how to hold clinical conversations about risk.*

This paper extracted from the literature the extent of current guidance on how to hold conversations about epilepsy risks and risk factors with PWE. Findings included: that initiating communications should be moderated on an individual basis, but should generally be held early on, and frequently; preferred methods of communication are face to face with a neurologist; and content of communications should be such that information is framed in an acceptable manner and that risk is communicated, but also normalised. This guidance might provide some direction for clinicians, and improve confidence in holding clinical conversations about risk.

2. Ethics of risk communication

All four studies that represented views of PWE and their families found they want increased communication, where those focusing on clinicians' views (six) were more reserved. The gap seems to be around concern from clinicians about creating more distress than is required. This review identified some methods of reducing anxiety, for example being realistic around effects of risk and normalising the risk of SUDEP; acknowledging anxiety and benefits of awareness; framing conversations appropriately for each individual, and having experienced clinicians available to support discussions. There is also disagreement where PWE recommend conversations are held as early as possible, and neurologists urging caution following recent diagnosis. Lessons might be learnt from areas such as oncology where discussion of person-centred risk and mortality is common practice. For example, Pino and colleagues (1) discuss the importance of learning from the observation of how experienced clinicians interact in order to enhance communication, for example including 'elaboration solicitations' in interactions in order to encourage PWE patients to discuss their end of life concerns, in a way that does not increase anxiety. We suggest that Oobservation of experienced epilpetologistsneurologists to better understand how they work, in order to offer guidance for other professionals would be similarly advantageous.

The caution reservation evident in practice recommendations may stem from the different participants involved in studies. Six studies focused on the clinician's views (48Friedman et al., 2014; Lewis 50et al., 2008; 24Miller et al., 2014; 42Morton et al., 2006; 44Nisbett et al., 2017 and 43Vegni et al., 2011), and four on PWE and their families (47Louik et al., 2017; 49Henning et al., 2018; 45; 35RamachandranNair and Jack, 2016; RamachandranNair et al., 2016; 52Xu et al., 2015). However, this reflected a higher number of PWE and their families (n= 6,641) than clinicians (n=1638), one study being of (n=1200) people in Norway (49Henning et al., 2018), and one not stating participant number just 5 focus groups (24Miller et al., 2014). The remaining 7 studies included researcher driven analyses of clinical notes (2); and comparative group studies (5), again testing researcher driven theories, rather than emergent from the views of PWE and their families. Capture of discussion between clinicians and PWE would be beneficial. Further, clinician's have

responsibility for care, making caution appropriate. There is emerging evidence of the benefits of communication (3) but the long term effects on risk management are not yet fully explored. ~~No study has yet examined longer term effects of good communication after the con~~Further, as expected, where there was caution from clinicians, the papers spent time discussing how to over come conversation difficulties, which seems to be a gap (e.g. 42, 43, 25, 4, 3, 50).

~~sultation.~~

Solutions: -

The future development of guidelines may ~~also~~ require nuancing with different stages of conversation. It may be appropriate to discuss the type of information that people wish to be informed of, prior to any discussion about risk. This is based on Morton et al's ~~(2006)~~ reminder that PWE and their families also have the 'the right not to know' (42~~Morton et al., 2006~~). This might be part of promoting a psychologically aware approach, considering the wider effects for people's lifestyle and relationships (53), moving beyond medication compliance as the main rationale for engaging with discussions. Services might engage both neurologists and clinical specialists, and PWE and their families in consultation groups to design how best to deliver information, so that the concerns of all stakeholders are represented.

~~Part of moving toward a more psychological approach might include reflection on language used to discuss risk communication. Seven papers used the term risk 'disclosure'. We opted to talk about risk discussions or communications. The term disclosure seems to imply the delivery of privileged information. This might carry with it an implicit sense of protectiveness, out of line with a patient involved approach.~~

Finally, in terms of communication ethics, the broader social media context should be considered. Whether or not clinicians feel comfortable holding conversations, information is available from other sources such as the media and the internet. The quality ~~and sources~~ of this information ~~are~~ is variable, and frequently not designed to support the management of anxiety. ~~Both~~

~~Young et al (2019), and RamachandranNair et al., (2016) commented that~~ PWE can experience this in uncontained ways (~~Young3 et al 2019~~; ~~35RamachandranNair et al.,2016~~). They may or may not then raise these discussions with clinicians, and we propose that further research may be conducted to examine the effects of internet information and how this influences PWE. A cautious approach may be preferable, enabling ~~. Therefore, regardless of assessed risk as 'low' or 'high' or other barriers, it may be better for~~ PWE to receive accurate information from a ~~a~~ supportive clinician who can refer to relevant support services if required.

Evidence base critique:-

The evidence for guidance extracted here was limited. Studies have not considered directly how communication works, and most research focuses specifically on communication about SUDEP, rather than other e~~E~~pilepsy risks, such as: such as self-injury, problems with driving, overdose of medication, under-dosing of medication, drug interactions, ongoing seizures, status epilepticus, nor other risks associated with the clinical management of epilepsy. A greater amount of research around communication is required that covers these areas.

Methods and samples were heterogeneous. ~~The information extracted here was based on heterogeneous methods and samples.~~ This heterogeneity ~~enabled~~ captured ~~of~~ the views of multiple~~different~~ stakeholders, including neurologists, non-specialist doctors, specialist nurses, PWE, their families, and bereaved families. However, the lack of homogenous studies meant that a meta-analysis or synthesis was not viable, thus reducing analytic power. ~~. Given the low number of homogenous studies, and to maintain the breadth of perspectives no meta-analysis or synthesis was possible.~~ There was unequal distribution (four studies examined PWE: six studies, clinicians; representing a total of 6,641:1638 participants). There was also no consideration of how PWE's nor clinician's individual differences~~PWE~~~~patients~~, such as gender, ethnicity, l~~L~~earning d~~D~~isability, age or other demographics, beyond experience of e~~E~~pilepsy, may affect communication, which future research may address.

Methods also varied. Views elicited from PWE were mainly from interviews (3) and one survey. Clinicians were included in four surveys, one interview and one focus group design, so overall with less opportunity for elaboration by clinicians. These surveys were also used to identify predictors of whether conversations were held. Three studies compared groups to test directly for causative relationships. These focused on the use of predesigned checklists (4~~Shankar et al., 2018~~) and showed evidence of significant improvement in awareness of risk and reduction of risk factors where communication about risk used this structured method. Thus, most guidelines and postulated consequences were based on neurologist ~~opinions~~perspectives, rather than those of PWE and families, such as that conversations appear to mediate AED adherence, despite there currently being limited evidence for this (47~~Louik et al., 2017~~). There was less opportunity for clinicians to elaborate their responses given the survey methods, though this enabled larger participant numbers. Direct observation of skilled clinicians was also missing, hence people actually engage in risk discussions is not yet well understood.

Seven quantitate surveys were conducted, with Three studies including more than 50 participants and Two more than 200. This seems to offer reasonable confidence in generalisation of findings. These were conducted mostly in the UK (6) and one in Norway, potentially not capturing international variation. All studies, apart from the two group comparison studies, drew on retrospective reports from clinicians and PWE rather than examining how the communications actually took place. Group comparison studies can raise ethical issues, as trials cannot be run where communication is withheld. Alternatively, future research might focus more directly on clinical conversations, following the substantial rise in the use of Conversation Analysis to explore how communication works in practice (54~~Smart and Auburn, 2019~~). Analysing clinical conversations might enable the identification of best practice for clinicians in engaging people with risk discussions, and provide a helpful method for training clinicians (55)~~Smart et al., 2019)~~. ~~We know that~~ ~~e~~Experienced clinicians seem better able to discuss risk (42~~Morton et al., 2006~~; 48~~Freidman et al.,~~

2014), but it is not yet known not yet how thow they do this, which could be extracted identified and then trained more widely.

Strengths and Limitations of the review

This review was limited by the low number of published papers available that comment on how clinical communication about risk might be achieved (only 17, with no limiters, all published between 2001 and 2018). None of these papers directly addressed the question of how to have clinical conversations about risk. Six papers focused on the frequency of SUDEP conversations, four on evaluating clinical practices, three on SUDEP awareness, two on use of the safety checklist and one on mortality rates, and one more generally on discussion content. All guidance was extracted from brief mentions of recommendations in the discussion section, not direct empirical data. We argue this is a gap that future research should address.

There were limited inductive studies that might identify new insights for practice. Of those qualitative inductive studies, there was diversity in how themes were extracted, some being driven by the questions asked, again limiting the inductive nature of the research.

Risk discussions with PWE are a complex issue and clinicians will need to make their own best judgement about engaging in them. A research focus on -communication in epilepsy contexts may reveal better communication methods, facilitating future collaboration and engagement with peopleatients in managing their eEpilepsy.

Conclusion.

There is frequent reference to the limited guidelines provided by NICE or the AAN, about how, when and whom to discuss SUDEP and epilepsy risk with. This paper revealed the limited research available around how conversations with PWE about risk might best be held. It is the first paper to summarise the available guidance, taking a step towards better understanding how conversations about risk with PWE might be held, which has not yet been directly addressed. ~~This paper summarised the current guidance from the literature as a step towards addressing the gap of what to discuss.~~ The guidelines arising here ~~from the paper~~ should be used with discretion, as less than optimal empirical evidence is available. Situations should be considered individually, but in general, ~~C~~conversations about risk should be held early on. Future research should better integrate the perspectives of clinicians and PWE, to understand how anxiety on both parts can be overcome. Research should focus directly on ~~the~~ clinical practice, ~~exploring~~to gain direct insight into how experts manage difficult conversations, in order to support and inform other clinicians. Focal areas could include: what it is helpful to and say when conversations are held about risk, how these conversations are received, and where they are best located in a treatment pathway. Research should explore how different service contexts are relevant to the delivery of risk discussions. This will enable clearer and more focused guidance, embedded directly in the experiences of PWE and clinicians, and within the realities of clinical practice.

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Keep Safe: The when, why and how of epilepsy risk communication

Highlights

- There is limited guidance and evidence for how clinicians should discuss risk with people with epilepsy, but derived from that available:
- *Timing and frequency:* Clinicians should ideally discuss risk with people with epilepsy at the first consultation
- *Method of communication:* People with epilepsy prefer to be informed by specialist clinicians, and through more than one mode of communication (online, verbal and printed).
- *How to communicate:* Clinicians should acknowledge in conversations both the anxiety that risk discussions can generate, and the benefits of increased awareness.
- Conversations should be modified to meet the unique life contexts and personal needs of individuals.

Keep Safe: The when, why and how of epilepsy risk communication

Abstract

Purpose

Risk communication between clinicians and people with epilepsy (PWE) and their families is under researched. There is limited guidance about when and how to have these discussions. This paper explores the current evidence on quality of risk related conversations in epilepsy and suggests a concept of an evidence-based guideline for person centred structured risk communication.

Methods

A literature search of four electronic database, Ovid Medline, Ovid Embase, PUBMED, and CINAHL, was conducted by two independent reviewers using relevant search terms following the principals of the PRISMA guidance. No limits were applied. Supplementary searches included using backwards and forwards citation searching. A predesigned inclusion and exclusion criteria was administered to the identified results.

Results

From 376 results identified, 17 studies met the final criteria of which ten were quantitative, five qualitative and two mixed methods. Perspectives of PWE and clinicians were represented.

Extracted data was clustered into three domains: communication initiation (e.g. timing, individual tailoring); communication methods (preference for face to face with neurologists); and communication content (acknowledging the anxiety produced by risk communication, the benefits of being self-aware, normalising risk etc.). No papers focused on conversation structure (e.g. helpful phrases), or the best locations to hold conversations.

Conclusion

More research is needed to develop structured communication of risk. An attempt has been made to put current evidence into this format. Clearer guidance will enhance clinicians' confidence in communicating person centred epilepsy risk with PWE and their families thus improving outcomes.

Keep Safe: The when, why and how of epilepsy risk communication

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Keep Safe: The when, why and how of epilepsy risk communication

Introduction

This paper collates guidance from the literature around how clinicians might best hold conversations about epilepsy risks, without undermining clinician skills of undertaking these conversations. Difficult conversations especially around risk of death are complex and can be misconstrued. There is ongoing debate around risk discussion rationale (1, 2), however, recent research illustrates how better risk communication can change outcomes (3, 4). The focus of this paper is the communications directly. Greater understanding of communication has significantly affected patient engagement with care, for example, discussing lifestyle risk assessments with GPs (5) and in facilitating delicate end of life conversations in oncology settings (6). A similar approach would be beneficial in the world of Epilepsy.

The rationale for discussing epilepsy risk

People with epilepsy (PWE) and their families are concerned that they do not receive enough information about risks related to epilepsy, nor how to manage these (7). In 2002, 42% of epilepsy related deaths were identified to be potentially avoidable had PWE and/or their families been more aware of the risks of morbidity and mortality (8). Annual epilepsy deaths match those for asthma though the prevalence of asthma is ten times that of epilepsy (9). It appears that the incidence of epilepsy deaths is increasing, indicating the need for preventative interventions (10). Discussion of lifestyle behaviours, such as medicine adherence, alcohol and recreational substance intake and how to monitor seizures particularly at night and awareness of outcomes such as Sudden Unexpected Death in Epilepsy (SUDEP) might reduce morbidity and mortality from epilepsy (11, 12). It is a clinical recommendation that epilepsy risks and SUDEP are discussed with PWE (13, 14, 15, 16). Yet PWE and their families are continuing to report poverty of and inconsistent information about risk (17).

Another rationale for risk conversations is family sequelae following deaths. Families and PWE believe that all those related to or working with a PWE should be informed (18). More than half of bereaved relatives of SUDEP highlighted lack of awareness that epilepsy could be fatal prior to their relative's death (19). This can lead to feelings of guilt about not having done enough to help.

Barriers and challenges to risk communication

Despite clear justification and recommendation for discussing risks and risk factors, PWE and their families often remain poorly informed (20). A study of a sample of Australian family and friends bereaved by epilepsy death, illustrated that the majority (53%) had believed that death from a seizure is not possible (19). Thirteen (of 101) participants believed seizure deaths could only be related to seizure accidents, not the seizure itself.

Even when PWE were informed about SUDEP, they can remain unsure of what this means (21). Thus, some of the issues might relate to *how* information is communicated, not just *whether it is*.

Lack of knowledge can be a concern for clinicians, too. General Practitioners (GPs) are often the person that PWE prefer for monitoring Epilepsy, but GPs can feel lacking in confidence to do so (22). Further, PWE perceive this 'lack of confidence' from GPs to avoid discussing the risk and social aspects of the condition, including work, driving and financial effects (22). Within the paediatric population, one study found that 75.4% of paediatric care providers were unaware that children with epilepsy were at a risk of SUDEP (23). Clinicians without a specialist interest in epilepsy particularly struggle with conversations about SUDEP and epilepsy risks and may benefit from further information (25).

This difference between specialist and non-specialist information giving might relate to assumptions that discussion of SUDEP and epilepsy risk should be with only those at 'higher risk', and specialists are more likely to see this group. Though there are factors indicative of cumulative risk (25) there is as yet no validated approach to classify epilepsy risk into 'high' or 'low'. Also, people considered as 'low risk' die, and so care needs to be taken not to make false assurances (26).

The preference for only discussing risk with 'high risk' groups also occurs in specialist services. Another confounder is that epilepsy is a chronic condition which waxes and vanes with life event and age. Thus, risk rarely remains static and can fluctuate over time (4).

The incidence of epilepsy death in newly diagnosed PWE is very low (1:10,000). However, if epilepsy is chronic, as in 30-40%, the risks can increase to significantly high levels such as those with pharmaco-resistant epilepsy that are failed by epilepsy surgery (1:300) (27). The lack of a continued dialogue or even a single discussion might reflect a paternalistic view of SUDEP and general risk communication (28), that is, that PWE and their families need protecting from knowledge of SUDEP. As of now, SUDEP is only frequently discussed in relationship to increasing adherence to medication only (29), rather than routinely considered. However, SUDEP is only one issue, and evaluation of other factors that might be discussed does not seem widely available.

Ethics of risk communication

Clinicians may fear distressing PWE or making them uncomfortable in discussing risk (30). This may relate to an ethical concern to "do no harm" (31, 32). This includes the possibility that clinicians might be giving information that is less relevant to that person where they are perceived as "low risk" (Hamid et al., 2010), to prevent creating unnecessary anxiety (31). Indeed, Beran (33) noted that the psychological sequelae of risk communications to PWE remain unknown. It was observed that there is considerable debate, including, suggesting that a more compassionate and value based approach to care would recognise that PWE and their families need to be able to make informed decisions, which they cannot do without adequate information, and the clinician should not have the right to remove this choice (34). They clarify this, stating that PWE might develop better self-management strategies (e.g. not using soft pillows, sleep or medication manage), improving people's perception of control over their lives and possibly reducing risks directly (34). It is also observed that access to online material can raise anxiety in an unmanaged way and people have less confidence in

this material (34, 35). Both of these studies conclude that from a patient perspective, clinician supported conversations are important.

Lack of guidelines to provide person centred communication of risk

The main barrier seems to be a lack of guidelines about how to communicate (36). Guidelines might inform clinicians better on how discussions should take place or what should be covered (4). Currently, varied aspects of good practice guidance seem spread across different papers possibly leading to key features being missed. These include recommendations that risk conversations should be tailored to individuals, focusing on modifiable risk factors (27); and the importance of considering repeating conversations at least yearly (3, 36). Other guidance include the need to consider an individual's readiness to learn, preferred learning styles and expectations, and the range of information sources available (37).

Objective/Aim:

The current review aimed to extract from the literature available evidence-based recommendations of how clinical conversations about risk and risk factors should occur with PWE, and identify what areas are still under researched.

Method

An open-ended search of four databases was conducted in November 2018; Ovid Medline, Ovid Embase, PUBMED, and CINAHL, using the search string: 'epilepsy death or epilepsy mortality or SUDEP AND patient or individual or disclosure or discuss or inform or communicat* or advice or risk. Where subject headings were available these were searched for 'Sudden Death' and 'Epilepsy' AND 'Information processing' and 'information dissemination'. Reference list checks were conducted. The PRISMA scoping review checklist was used as a guiding template (Supplementary information). The review protocol is detailed here.

Two researchers screened the papers independently for the pre- designed inclusion and exclusion criteria. A sample of these and all disagreements were discussed with a third researcher. Inclusion and exclusion criteria are detailed in table 1. These criteria and the search strategy were developed in conjunction with senior clinicians and information specialists.

Table 1:

Inclusion and exclusion criteria

Inclusion	Exclusion
Empirical studies	Reviews and opinion pieces
Peer reviewed studies	Papers focused only on identifying risk factors in Epilepsy
Written in English or having an English translation due to limited translation funds	Focuses on PWE under the age of 18 as communication with children may need different sensitivities
Any research method	No mention of SUDEP or epilepsy risks
Evaluations of frequency of conversations and communications	Doesn't explicitly discuss how to communicate risks
Papers including content of how clinicians discuss risk with PWE	Where there were no recommendations given for practice
Papers including recommendations about how to talk about risk in epilepsy	

Method of quality assessment

Papers were subjected to quality assessment; using either Critical Appraisal Skills Programme (38) or Appraisal tool for Cross-Sectional Studies (39, 40, 41). The CASP Critical Appraisal tools were developed as a guide for evaluating research based on features such as clarity of aims and content and were used for qualitative and quantitative studies. The AXIS was developed to explore medical cross-sectional studies based on features relevant to these study designs. The CASP and

AXIS critical appraisal tools do not provide an overall score and ratings are subjective; therefore, ratings were given independently by 2 researchers, and discussed in a moderation group with a third. Both tools are designed to give an indication of the credibility of the evidence and potential gaps.

Data extraction method

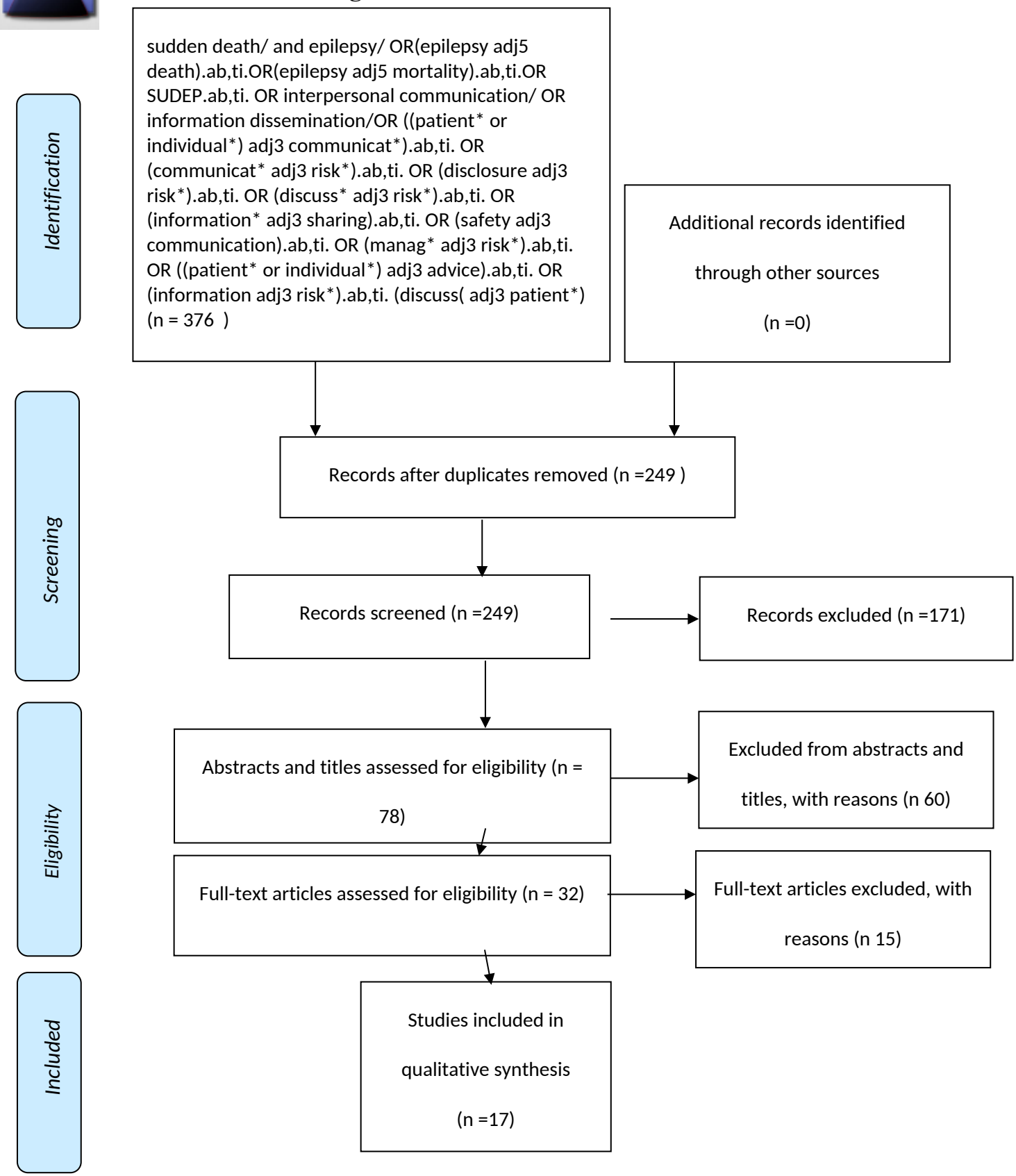
Data was extracted into a summary table (Results, Table 5). Key questions were applied to each paper, summarising: main points made about communication and risk; identified helpful and difficult factors; gaps identified by paper; guidance recommended. Key phrases offering communication guidance were extracted and grouped.

Results

Description of the papers

There were 376 results, 274 after removal of duplicates. 36 articles remained following title and abstract review and seventeen after application of inclusion/exclusion criteria. Fifteen of these 36 were agreed as suitable by 2 independent reviewers; a further five were disputed and arbitrated by a third reviewer, resulting in 3 further rejections, leaving 17 papers. See figure 1.

RISMA 2009 Flow Diagram



Of the 17 papers, two used mixed methods, 10 were quantitative and five were qualitative studies. Research quality was assessed using the CASP and AXIS tools, (tables 2-4). All studies received either a "good" or a "moderate" rating score. Ratings were derived by assessing potential problems in studies. Ratings were: 3 or less problems, good; 3-6 problems, moderate; 6< problems, poor.

Seven were rated as moderate quality. Problems were either due to difficulties matching controls in experimental designs, or not enough detail in the analysis to replicate qualitative analyses. These are common concerns in clinical research often related to the research context or journal restrictions. 10 articles were rated as good quality, all quantitative studies.

Table 2.

Quality ratings of mixed methods studies using CASP

Author and Date	Quality Score for the purposes of this review
Morton et al (2006) (42)	Quantitative data. Moderate quality. Analysis not detailed, limited word count. Qualitative data – Moderate Quality. Limited information aims unclear. More detail for method of analysis needed.
Vegni et al (2011) (43)	Quantitative data - Moderate quality. Low response rates, possible sample bias as only those with knowledge of SUDEP responded. Clear analysis. Ethics or conflict of interests not discussed. Qualitative - Moderate quality. Clear analysis, two coders used. Relationship of researchers to data not mentioned.

Table 3:

Quality rating of qualitative studies using CASP

Author and date	Quality Score for the purposes of this review

Miller et al (2014) (24)	Moderate quality- Methods could have more detail to explain thematic and content analysis making it difficult to assess rigour.
Ramachandran Nair et al (2016) (35)	Good quality – clearly organised. Clear method. Replicable method. Relationship between the researcher and data not addressed.
Nisbet et al (2017) (44)	Moderate quality- Clearly written. Method clear, including role of the researcher. Recruitment of participants might have been clearer.
Ramachandran Nair and Jack (2016) (45)	Good quality- recruitment, methods and analysis clearly explained. Sample size justified. Replicable. Codes explained including how they were derived from the interview guide.
Ross et al (2015) (46)	Moderate quality- confounding variables possibly not considered e.g. not documenting SUDEP discussion. Follow up time short at only 6 months rather than a year as other research recommends. Acknowledged by researcher.

Table 4:

Quality ratings of qualitative papers using AXIS

Author and date	Quality Score
Louik et at (2017) (47)	Good quality. Article coherent. Methods clear. Replicable. All 138 enrolled took part in the study. Generalisable.
Friedman et al (2014) (48)	Good quality. Uses a p value of <0.02 in the logistic regression. 1200 surveys completed, though 9% response rate, remains substantive. Provides reasons for non-completions. Methods and analysis clear. Replicable. Sample appeared representative.
Henning et al (2018) (49)	Good quality. Has a high participation rate (2090), 56.6 being PWE, the remainder, carers or family members answering for the PWE or themselves. Participants likely to be representative of PWE. Statistical analysis clear and thorough. Replicable. Findings and discussions comprehensive.
Lewis et al (2008) (50)	Moderate quality. A representative sample of epilepsy nurses. High response rate, 103 surveys included in final analysis. Methodology and results difficult to replicate. This could be because of journal word limit.
Mohanraj et al (2006) (51)	Good quality. Used newly diagnosed PWE and those with chronic epilepsy over a 20-year period to assess mortality. Methods and analysis clear. Comparisons defined and statistical analysis clear.

Shankar et al (2018) (4)	Good quality. Methods clear. Analysis clear. Replicable. Generalizable to the population of PWE.
Shankar et al (2016) (25)	Good quality. Methods clear. Data collected over a 9-year period so likely to be representative of SUDEP deaths and reflects national records. Appropriate use of statistics.
Waddell et al (2013) (2)	Moderate quality. Measures used to assess SUDEP conversation may not be reliable, as they were dependent on accuracy of patient notes. Time constraints and different descriptions of SUDEP conversations e.g. using "serious harm" instead of SUDEP may have led to underestimation of SUDEP conversations. Results and method are very clear.
Xu et al (2015) (52)	Good quality. Sample seemed representative. Large number 105 taking part. High rate of participation. Appropriate use of statistics.
Young et al (2018) (3)	Good quality. Representative sample of PWE with LD. High response rate (77%). Appropriate population. Statistical analysis clear. Replicable.

Data range of all papers collected was between 2001 and 2018; and papers were published between 2006 and 2018. Ten were conducted in the UK, one in Australia, one in the US, two in Canada and the US, one in Canada, Australia and the UK, one in Norway and one in Italy. Four studies elicited the views of PWE and their families, and six studies focused on the views of clinicians, one study focused on bereaved families (see figure 2).

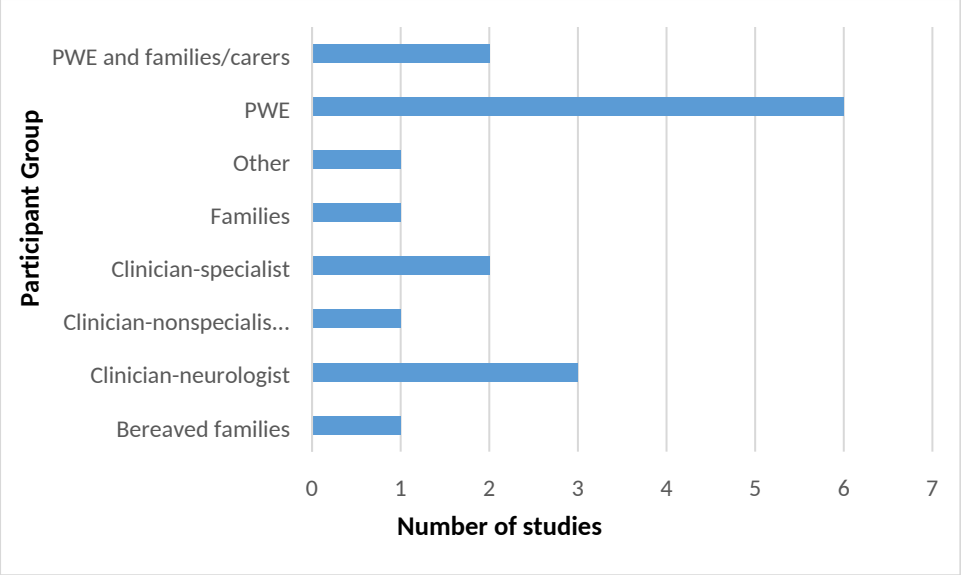


Figure 2. Participant groups in different studies.

There was limited consideration of how gender, ethnicity or age might affect communication. Five papers commented that men were generally considered at higher risk but none discussed this in relation to how communication might be adapted. One paper considered age, gender, duration of epilepsy, level of education and employment as variables that might affect preference for discussions, finding none of these significant predictors.

There was diversity of methods (figure 3). Four studies compared risk communication between groups, such as using checklists (n=3), or reported discussions of risk (n=1). Two studies were case note reviews. Twelve studies included less than 50 participants, two studies included between 50 and 200 participants, and three studies included over 200 participants.

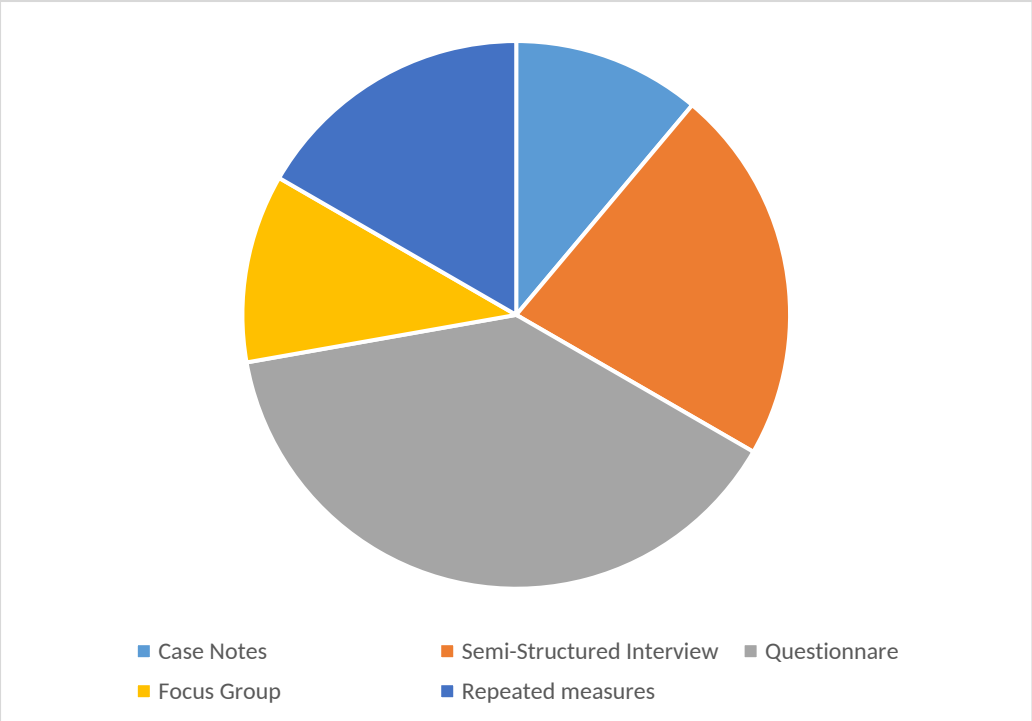


Figure 2. Methods used in the studies.

Recommendations about how to communicate risk

The papers are summarised in Table five. Papers were identified based on whether they offered guidance on how to hold conversations about risk with PWE. However, 15 of the 17 papers focused on SUDEP, suggesting a large gap in the literature. None of the papers focused directly on how to communicate about risk. We found limited elaboration around the individual differences that might affect whether, when or how to hold risk conversations; instead papers just reminded clinicians to

consider individual differences. Extracted recommendations that might guide clinicians in how and whether to hold risk discussions with PWE are summarised in table six.

Table 5

Data extraction from all studies.

Title	Aims to:	Data Collected	Participants	Analysis	Key Findings	Recommendations/ implications
Mohanraj et al, 2006	Analyse mortality data for patients with newly diagnosed and chronic epilepsy who were referred to a single adult service over a 20-year period	Related measures. PWE were assessed for mortality risk on the basis of response to treatment.	Group 1: 890 newly diagnosed PWE; Group 2: 2689 PWE with chronic epilepsy and poor seizure control. Compared with age and sex matched controls.	Keplan-meier survival curves were plotted for the 2 groups and controls. Chi-squared test was used to compare observed and expected deaths.	There were 93 deaths in the newly diagnosed group compared to 64 in age and sex matched controls (p=0.0007). All excess mortality occurred in patients who did not achieve seizure freedom with treatment. In the chronic group there was more than double the expected number of deaths and incidence of SUDEP compared to newly diagnosed PWE, this being higher for those under 30 yrs. of age.	Routine discussion of mortality at the time of diagnosis not necessary, especially if this does not affect the management of the epilepsy. Epilepsy risks and mortality should be discussed with PWE who choose not to use AED's, and those who haven't achieved seizure freedom.
42	Present the experiences of neurologists in discussing SUDEP with PWE.	Questionnaires to all practicing neurologists listed on the	387 questionnaires (of 738 sent). Represents 82% of consultant body. 63 were specialist	Chi squared test and qualitative analysis.	4.7% discussed SUDEP with all PWE. Years of experience, or level or registration (registrar/neurologist) had no effect. Those with a special interest in epilepsy were more likely to	The majority of neurologists are not following the NICE guidelines. Practice effect may make it easier to discuss SUDEP.

		British neurologist's database. Asked about the circumstances surrounding discussions about SUDEP and PWE's reactions.	registrars. Remainder were from specialist epilepsy clinics.		discuss SUDEP. Those discussing SUDEP routinely reported less negative reactions from PWE.	NICE give little guidance on how, when and whom to discuss SUDEP with. Epilepsy. Risks should be contextualised, e.g. likelihood of SUDEP compared to getting hit by a car. NICE guidelines deny the "right not to know".
50	Examine what, when and how information about SUDEP is disseminated to patients by clinical nurse specialists in epilepsy (CNSEs)	Postal Questionnaires from ESNA members.	146 responses (from 250 sent). 43 excluded as respondents were not CNSE. Time in role ranged from 8 months to 21 years	Descriptive of responses.	6% discussed SUDEP with all patients. 48% stated risk discussions were prompted by discussions of risk factors (e.g. alcohol consumption. Length of service had no significant effect. Most discuss SUDEP over the telephone (42%). 62% reported an increase in medication adherence following SUDEP discussions, and subsequent avoidance of risk factors (62%).	CNSE do not discuss risk with all patients. SUDEP discussions need to be addressed carefully, balancing the negative effects of fear in patients, with the benefits of raising awareness. Timing of discussion should be individually determined.

Vegni et al, 2011	Explore whether Italian Physicians interested in epilepsy believe that they should discuss SUDEP with patients and or their families or not	Questionnaire.	Recruited through the Italian association against epilepsy (LICE). 195 responses. 49.5% were male. Mean age 45; average practice years 21.	Chi squared test & content analysis	28% of believed that SUDEP should be discussed with most patients. Most believed that PWE be emotional or have a negative reaction (73%). Physicians may decide to give risk information based on the patients themselves or for non-clinical reasons such as ethical issues.	More research is needed for in-depth understanding. Physicians may disclose risk more often if they have treated someone with SUDEP or following ethical discussions.
Waddell et al, 2013	Conduct an audit of current practices of discussing SUDEP with PWE at a specialist epilepsy clinic.	5 yr. case note analysis.	All patients who attended a specialist epilepsy clinic, and those who had experienced at least 2 unprovoked seizures were included, producing 345 case notes. Mean age 41 yrs. 50.7% were male.	Descriptive statistics and fishers 2 tailed test for comparisons between risk factor groups.	SUDEP is not discussed with all patients. Those with ongoing GTCS and drug resistant seizures were more likely to be informed. There was a trend towards discussing SUDEP with those non-compliant with medication.	An honest and frank debate is required between clinicians, patient advocacy groups and those involved in developing guidelines to allow one to reconcile the disparity between guidelines and clinical practice in regard to SUDEP.
Freidman et al, 2014	Examine SUDEP discussion practices among neurologists in the U.S and Canada.	Online questionnaire-based study.	117, 558 people invited by email. Self-selected if they: were a neurologist who devoted >5% of their time to clinical care and	A composite knowledge score was determined by subtracting the	82% had incomplete knowledge about SUDEP. 26.1% encountered at least one case of SUDEP in the past 24 months. 6.8% of neurologists discussed SUDEP with all patients.	SUDEP conversations can be framed to minimise distress. Neurologists with more experience and diverse caseloads report less perceived distress to SUDEP discussion. Guidance is needed regarding the best approach to SUDEP discussions for neurologists.

			had completed post-grad training. 200 completed surveys. 76% adult neurologists; 33% additional training in epilepsy or neurophysiology. 43% saw 100 PWE annually.	number of incorrect identified risk factors from correctly identified factors & multivariate logistic regression.	Epilepsy training, years in practice, having over 100 patients annually and having a case of SUDEP increased the likelihood of discussion. 62% discussed SUDEP when patients were 'high risk'. Risk level and additional training was associated with an increased risk of a perceived negative response to SUDEP discussion (p=0.038).	
Miller et al, 2014	Describe the practices of epileptologists, neurologists and advanced practice nurses (APNs) regarding discussing SUDEP with their patients, and their rationales for discussing SUDEP	Two focus groups: one with epileptologists and neurologists; one with APN's.	19 epileptologists, 16 neurologists and 8 APNs. All areas of central America were represented	Themes were inductively developed.	Themes: 1. Reasons for discussing SUDEP: Practical accountability; Moral accountability, proactivity and reactivity, and for nurses only – patient advocacy. 2. Reasons for not discussing SUDEP: to wait for a rapport to be established, being morally accountable, and being out of options. 3. Ways in which SUDE should be discussed: face to face discussion were common with	A standardised approach to discussing SUDEP is needed to facilitate clinicians, and overcome fears that discussions will cause harm, and have no benefit. Decisions not to disclose might not be patient centred. Clinicians should involve PWE in decision making. The next step is to provide a practical guide for discussing SUDEP. SUDEP education should be a component of epilepsy care.

					written materials; requirement for standardised protocols that can be adapted to individuals.	
Ross et al, 2015	Evaluate current clinical practice and determine whether there had been a change in frequency of SUDEP discussion following prior audit.	A retrospective case note review of a single service.	392 patients were reviewed, 240 case notes were available for review from PWE attending a specialist clinic. 27 new referrals. 213 return patients. 46% were males. Mean age 36yrs.	Descriptive statistics and comparisons between risk factor groups using fisher's two-tailed test.	SUDEP discussions were documented in 67% of new referrals, 30% of return patients. These included by neurologists with a specialist epilepsy interest (40%), 30% with epilepsy nurses, 17.4% with GPs. PWE with GTC's were more frequently informed of risks; PWE for longer than 15yrs, drug resistant seizures and LD were less frequently informed.	An inverse relationship between those at greatest risk and those most likely to be informed might reflect perceived difficulties in discussing SUDEP where it seems there are no therapeutic options left to cover. A tailored discussion in clinic with discussion of risk-reducing strategies will be a positive intervention.
Xu et al, 2015	Evaluate awareness and perspectives on SUDEP among adult PWE	Questionnaire.	40 males a 65 females took part in the study, mean age of 41 yrs.	Multivariate logistic regression explored the variables among patients associated with their awareness of SUDEP and	62% of PWE wished to know all information. 32% wanted a reasonable amount. 52% thought epilepsy was not associated with higher risk of death. 14% had heard about SUDEP before the study. 89% of participants wished to be informed about SUDEP, preferably by their neurologist.	The authors encourage health professionals and policy makers to incorporate SUDEP discussions in regular practice and as a quality measure of clinical practice.

				willingness to be informed of this.		
RamachandranNair and Jack, 2016	Understand the range of adult patients' views on discussing SUDEP with PWE; clarify the optimal timing and formulation of information.	Telephone semi structured interviews. 1 focus group.	23 PWE (7 males and 16 females) recruited through an adult neurology clinic and a community epilepsy agency. Aged 18-65, median, 33. 19 participated in interviews. 4 in focus group.	Directed content analysis	10 (43%) had heard about SUDEP previously; 2 learned through the internet, 4 through the community epilepsy agency, 3 from their neurologist, and one from their mother. All agreed SUDEP should be discussed at the diagnosis. 3 felt SUDEP disclosure should be individually decided. 19 considered there may be negative effects, such as anxiety. Neurologist rather than the emergency department, best person to inform. No participants correctly explained meaning of SUDEP, even when leaflet given. 50% of PWE felt anxious upon learning about SUDEP, short lasting. Some reported then increasing adherence to their medication.	Face to face discussion of SUDEP with the neurologist important. Written information beneficial. Content should include an estimate of individual risk, emphasis on actual prevalence and preventative strategies.

RamachandranNair, Jack and Strohm, 2016	Understand the experiences of relatives of individuals whose deaths were identified as SUDEP and to explore their preferences regarding SUDEP counselling.	In depth semi-structured interviews	Stratified purposeful sampling: people over 18 bereaved by SUDEP. 27 participants, 21 females and 6 males. 4 were siblings, 5 were spouses and 18 were parents.	Thematic analysis using categories from the questionnaire and emergent categories.	1. Experiences at the time of SUDEP: all experienced shock and guilt. 2. Awareness of SUDEP: families could accurately define SUDEP, most drawing parallel between SUDEP and SIDS. Only 9 participants knew about SUDEP before the cause of death. Many were angry not to have known earlier, feeling there could have been preventative steps. Awareness of SUDEP after death was valued, giving "peace of mind". 3. Whether to discuss SUDEP: SUDEP education was overwhelmingly valued, especially for those with specific risk factors. PWE stated it was their right to know about their condition. Possible negative effects included making people over protective of the PWE. 4. Information should be provided by the patient's neurologist shortly after or at the time of diagnosis. 5. Content of the SUDEP discussion: include an explanation of SUDEP; associated risk factors	Neurologists should inform patients SUDEP. Optimal timing decided case by case. Deliver information face to face at first or second visit. Give printed material. Content should include realistic risk appraisal. Emphasise preventative strategies.

					and preventative methods. Note the rarity of SUDEP.	
Shankar et al, 2016	Compare the 17 risk factors to cases of SUDEP deaths, and those living with epilepsy to determine how strongly these factors are associated with SUDEP risk	Comparison of risk factors as identified using the SUDEP and seizure safety checklist were compared between live samples and people who had died from Epilepsy related deaths.	43 SUDEP deaths of 93 Epilepsy deaths occurred between 2004 and 2012. The coroner's notes were used and compared with the medical notes from 220 live PWE.	Groups were compared and relative risk factors ranked.	9 (of 17) risk factors differed significantly between groups. 2 were not modifiable (duration of epilepsy and GTC's). 7 modifiable risk factors were identified and ranked.	The study supports the use of an evidences-based checklist to discuss potentially modifiable risk factors with patients

Louik et al, 2017	Examine attitudes towards SUDEP discussion among family members	Semi-structured telephone interviews about experiences of SUDEP discussions.	138 family members enrolled on the North American SUDEP Registry. 79% were conducted with at least one parent, 10% with widower and 10% with offspring and 40% with another next of kin or carers	Regression analysis to identify predictors of SUDEP awareness. Factors included: year of death, status epilepticus, GTCS and age.	18.1% recall having discussed SUDEP, initiated by the neurologist in 44% of these cases. 72% appreciated this discussion, 24% were unsure. For those who did not recall a SUDEP discussion 72.3% wish they had, 10% did not and 17% were unsure. Common themes they wanted discussed included: incidence of SUDEP, general SUDEP information, importance of AED adherence. No significance was found for factors increasing the likelihood of SUDEP discussion.	Frequency of SUDEP discussion may not be increasing, contrary to other research. Research should examine why people might not want to learn about SUDEP and whether SUDEP education can mitigate risk factors such as AED adherence. Healthcare should discuss SUDEP when caring for PWE rather than after the person has died.
Nisbet et al, 2017	To explore the experiences of neurologists in Scotland when discussing SUDEP with the patients.	Qualitative individual interviews	6 consultant neurologists and 4 registrar doctors participated in the research.	Thematic analysis.	Themes: 1) The SUDEP protocol: Clinicians engage in 2 types of SUDEP discussion – with PWE who are newly diagnosed, and uncontrolled. For those with uncontrolled seizures it was used to emphasise the risk and encourage AED adherence. SUDEP was not discussed if the PWE appeared to be distressed or anxious. 2) Diffusion of the FAI- The Fatal Accident	The FAI in Scotland has increased SUDEP discussion by highlighting possible medico-legal implications. Future studies should quantify behaviour changes post SUDEP discussion, as this might facilitate confidence to increase SUDEP conversations.

					Inquiry (specific to Scotland) heavily influenced how clinicians' emphasis on SUDEP discussions although there were some mixed feelings. 3) Breaking good news- there were mixed feeling surrounding discussing SUDEP. 4) Falsely anticipating distress- Clinicians believed they were likely to cause distress and anxiety by discussing SUDEP. Many being surprised when PWE react calmly. 5) Pressure hinders effective communication- Clinicians report that the requirement to discuss SUDEP sometimes inhibited their ability to do it well, due to time pressure.	
Henning et al, 2018	Assess how much information PWE and their family members wanted about epilepsy related risks and whether this need was met by health care professionals.	An online questionnaire available through a Norwegian epilepsy association.	1859 participants. 1183 were PWE. 676 were careers answering on behalf of PWE.	Chi squared test used to analyse group differences and multivariate logistic regression used to determine	90% wanted information about risks and premature death. Having generalised tonic clonic seizures was associated with wanting information about the death risk (p=0.001). Male gender, younger ages and aetiology of epilepsy were significant factors for having been told about SUDEP. 14% of patients felt they had been well informed.	There is a gap between what the patients want to know and what they are told by healthcare providers.

				factors that may predict a wish to be given more information, or people being given more information about increased risk.		
Shankar et al, 2018	Determine whether the introduction of a risk communication checklist in an epilepsy clinic leads to a reduction in individual SUDEP epilepsy mortality risk factors.	Repeated measures. Assessment of risk using a checklist was conducted twice as part of routine care in a specialist epilepsy clinic, one year apart.	130 consecutive individuals from the neurology clinic and 129 from the ID clinic. The second application 91 and 93 individuals, respectively.	Paired t-test to compare groups.	Overall reduction in mean risk score for the general population (p=0.049) but not for the ID population (who had received risk information on numerous occasions previously). There was a risk reduction in the top 25% in both patient groups (p=<0.001).	Safety advice had direct implications for reducing risk factors. The introduction of a safety Checklists supported. Policy might promote use of health promotional checklists in epilepsy to reduce morbidity and mortality.

Young et al, 2018	Assess whether PWE and their families or support workers were SUDEP aware and could recall discussions about SUDEP risk and the role of nocturnal surveillance.	Questionnaire.	121 responses from PWE with LD under active follow up in July 2017. 75% were living in a residential setting	Fisher's exact test was used to establish differences between those PWE living family or in a residential setting.	PWE with ID placed in a residential setting are more likely to not have person centred risk advice implemented compared to those in a family setting. Those in the family setting were more likely to recall the SUDEP discussion (65%) compared to those in the residential setting (39) ($p=0.006$).	PWE with ID should be offered nocturnal monitoring to help recognise previously unknown events. Structured communication tools might help to reduce risk. Risk discussions need to be repeated and tailored to match the PWE. A cost-effective intervention could be developing an electronic learning module for professions working with PWE with LD.

Table 6:

Guidance around how to communicate with PWE about epilepsy risk and risk factors

	Guidance	Paper
Timing and frequency of communications	1. Evaluate whether the clinician has the right experience to engage in discussions	50 42
	2. Evaluate the risk of harm or distress in the PWE, for example it might not be appropriate to hold conversations at the time of diagnosis	24 51 46
	3. Conversations should be held as early as possible	47, 45, 35
	4. The timing of conversations should be individually evaluated	50, 3, 43
	5. Conversations should occur at least yearly, more frequently if there are risks, including where people are at low risk, or have an intellectual disability.	4, 3
	6. The clinician might also ask PWE whether they want to discuss risk.	42
Method of communication	7. Full information should be provided to PWE and their families.	49, 52
	8. People may prefer to be informed by a neurologist.	49, 52, 35
	9. There should be more than one method of communication about risk (online, printed, and verbal).	45
	10. Having a policy that clinicians must discuss risk and ensure that people are better informed and overcome anxieties from the clinician	44
Content of communication	11. Conversations should be framed in a manner acceptable to a person with epilepsy	48
	12. More experienced clinicians should deliver discussions	48, 42
	13. Acknowledge both the anxiety of the person with epilepsy and the benefits of increased awareness.	50, 2
	14. Normalise the risk of SUDEP / be realistic with actual prevalence and preventative strategies	42, 35, 45
	15. Checklists can help to guide risk discussions	25, 27 3

Timing and frequency of communication

Whether to hold discussions:-

Despite risk communication being considered important, it remains infrequent or ineffective (47 (US, Canada); 50 (UK); 42 (UK)). The clinician's direct experience of epilepsy and SUDEP (50 (UK); 42(UK)) and whether they had a specialist interest in epilepsy (46, UK) are important determinants of whether risk is discussed. Communication was also affected by the clinician's experience of SUDEP (43, Italy). Avoidance of harm to the PWE was the main rationale for not discussing risk (24, US; 43, Italy). It was found in a study that many clinicians still do not believe that SUDEP or other mortality issues should be discussed with PWE (43, Italy). Some consider telling people who are newly diagnosed or who have good seizure control as "lower risk", thus believing they may cause distress for no reason (51, UK). However, focusing on the experiences of PWE of risk discussions, found that people feel anxious in the short term but then reassured along with an association with subsequent increase in medication use (35). Other studies report that over 90% of PWE wanted to be informed of most if not all information through communication with their clinician (49 (Norway); 52 (Australia)). Of the 12 papers considering whether a conversation is valid, Ten supported the position that conversations should be held while two provided more balanced positions, acknowledging that the clinician is best placed to make the ultimate decision, but providing guidance should they feel it clinically appropriate.

Timing:-

Seven of the 17 papers considered the timing of risk discussions. Louik et al (47, US and Canada) examined the experiences of bereaved families, and their concern that SUDEP should have been discussed with carers prior to death. Of 12 survey and interview studies of PWE, families and clinicians, three postulated that the timing of discussions should be individually evaluated (50 (UK); 3 (UK), 43 (Italy)), but how to do so was not detailed. Two questioned the appropriateness of informing on risk at the time of initial diagnosis (51 (UK); 24 (US)). Three suggested conversations should occur at the first or second clinical meetings (47 (Canada and US); 45 (UK, Australia, Canada); 35 (UK). The remainder did not comment on timing.

Frequency of communication :-

Waddell, McCool, Turner, Norman, Coker, White et al. (2, UK) found that SUDEP conversations were more likely to be held where people are non-compliant with medication. However, despite the emphasis on high risk people being more informed, a study by Ross et al. (46) suggested that those who had had epilepsy for longer than 15 years, had drug resistant epilepsy and/or Learning Disability, were less likely to have been informed.

Ross et al. (46) also found an increase of case note documented discussions from 4% in 2009, to 31% of all referrals a year later, where 240 of 314 were available for the second audit. Young et al (3, UK) observed that it may be important to repeat discussions to ensure awareness and understanding, particularly for those with ID living in a care setting, or with less recent diagnosis.

Notably, the literature extracted was only that which focused on how to hold conversations. Although the evidence appears to be increasing in support of PWE being informed of risk, one paper discussed the PWE's right not to know (42, UK).

Method of communication

Method of communication :-

Six studies (52 (Australia)); 35 (UK); 45 (UK, Australia, Canada); Ross et al., 2015 (UK); 47 (US and Canada); 49 (Norway)) focused on the views of PWE and their families directly. Over 90% of people wanted to be informed of most if not all information (49 (Norway); 52 (Australia)). All studies suggested that they would prefer to be informed face-to-face by an epilepsy specialist. Additional written (35; 45) or electronic material (3 (UK)) might also be helpful.

Protocols: -

Nisbet, Turbull, Mulhern & Razvi (44, UK) evaluated the use of a protocol requiring clinicians to discuss SUDEP with PWE. Based on interviews of six neurologists and four senior medical trainees working in a neurology service, they found that pressure to discuss SUDEP created considerable anxiety in clinicians, who in turn believed this would create anxiety in PWE. PWE in fact responded calmly. Clinicians found the pressure of a forced conversation inhibited risk discussions.

Content of communication

Various points were made about the content of conversations.

Reducing distress:-

Friedman and colleagues (48) conducted a survey of US neurologists (n=1200), which suggested that conversation should be framed appropriately for the PWE who is the focus, which can then reduce levels of distress. Clinicians experienced in delivering these discussions, particularly those who had seen PWE for longer, seen more of them, and had more years since qualifying were more confident in reducing distress. However, a demand for further education for clinicians and PWE and care givers was also identified. Morton et al (42) also found experienced clinicians described feeling more at ease in discussing risks.

Balancing anxiety with risk reduction discussion:-

Following their study of 146 members of the Epilepsy Nurses Association, UK, Lewis et al (50) found that nurses felt that although it can be anxiety provoking, risk conversations increased adherence to medication, and 41% stated that it enhanced quality of life for people. Guidance was unclear from findings, but the authors argue that clinicians must balance too much information control with the potential benefits of awareness. They also found that nurses preferred face to face communications, however, 36% (n=37) of risk conversations were held in nurse led clinics; 27%

(n=28) in a ward setting; and 36% (n=37) over the phone as these were opportunities where risk arose in conversation.

Normalising the risk discussion: -

Morton et al (42, UK) suggest that normalising the risk of SUDEP is also important, for example, by highlighting that it is less common than being hit by a car. RamachandranNair et al (35, UK) and RamachandranNair and Jack (45, UK, Australia, Canada) also support this approach, stating that there should be a realistic appraisal of risk with the emphasis on the actual prevalence and preventative strategies.

Checklists: -

Discussions can also be supported by checklists (25; 4, UK), which can improve the safety for PWE (4; 3, UK).

Discussion.

This paper was designed to extract guidance from the literature around how to communicate risk with PWE, offering additional information for clinicians to draw on in Epilepsy management. How this is appropriately applied will be determined by the clinical judgement of practitioners. However, the complexity of language and interaction deserves careful consideration to enable collaborative care with PWE. In the introduction, two barriers to communications about risk were identified.

1. *The lack of guidelines for how to hold clinical conversations about risk.*

This paper extracted from the literature the extent of current guidance on how to hold conversations about epilepsy risks and risk factors with PWE. Findings included: that initiating communications should be moderated on an individual basis, but should generally be held early on, and frequently; preferred methods of communication are face to face with a neurologist; and content

of communications should be such that information is framed in an acceptable manner and that risk is communicated, but also normalised. This guidance might provide some direction for clinicians, and improve confidence in holding clinical conversations about risk.

2. Ethics of risk communication

All four studies that represented views of PWE and their families found they want increased communication, where those focusing on clinicians' views (six) were more reserved. The gap seems to be around concern from clinicians about creating more distress than is required. This review identified some methods of reducing anxiety, for example being realistic around effects of risk and normalising the risk of SUDEP; acknowledging anxiety and benefits of awareness; framing conversations appropriately for each individual, and having experienced clinicians available to support discussions. There is also disagreement where PWE recommend conversations are held as early as possible, and neurologists urging caution following recent diagnosis. Lessons might be learnt from areas such as oncology where discussion of person-centred risk and mortality is common practice. Pino and colleagues (1) discuss the importance of learning from the observation of how experienced clinicians interact in order to enhance communication, for example including 'elaboration solicitations' in interactions in order to encourage PWE to discuss their end of life concerns, in a way that does not increase anxiety. Observation of experienced epilpetologists to better understand how they work, in order to offer guidance for other professionals would be similarly advantageous.

The reservation evident in practice recommendations may stem from the different participants involved in studies. Six studies focused on the clinician's views (48; 50; 24; 42; 44 and 43), and four on PWE and their families (47; 49; 45; 35; 52). However, this reflected a higher number of PWE and their families (n= 6,641) than clinicians (n=1638), one study being of (n=1200) people in Norway (49), and one not stating participant number just 5 focus groups (24). The remaining 7 studies included researcher driven analyses of clinical notes (2); and comparative group studies (5), again testing researcher driven theories, rather than emergent from the views of PWE and their families.

Capture of discussion between clinicians and PWE would be beneficial. Further, clinician's have responsibility for care, making caution appropriate. There is emerging evidence of the benefits of communication (3) but the long term effects on risk management are not yet fully explored. Further, as expected, where there was caution from clinicians, the papers spent time discussing how to over come conversation difficulties, which seems to be a gap (e.g. 42, 43, 25, 4, 3, 50).

Solutions: -

The future development of guidelines may require nuancing with different stages of conversation. It may be appropriate to discuss the type of information that people wish to be informed of, prior to any discussion about risk. This is based on Morton et al's reminder that PWE and their families also have the 'the right not to know' (42). This might be part of promoting a psychologically aware approach, considering the wider effects for people's lifestyle and relationships (53), moving beyond medication compliance as the main rationale for engaging with discussions. Services might engage both neurologists and clinical specialists, and PWE and their families in consultation groups to design how best to deliver information, so that the concerns of all stakeholders are represented.

Finally, in terms of communication ethics, the broader social media context should be considered. Whether or not clinicians feel comfortable holding conversations, information is available from other sources such as the media and the internet. The quality of this information is variable, and frequently not designed to support the management of anxiety. PWE can experience this in uncontained ways (3; 35). They may or may not then raise these discussions with clinicians, and we propose that further research may be conducted to examine the effects of internet information and how this influences PWE. A cautious approach may be preferable, enabling PWE to receive accurate information from a supportive clinician who can refer to relevant support services if required.

Evidence base critique:-

The evidence for guidance extracted here was limited. Studies have not considered directly how communication works, and most research focuses specifically on communication about SUDEP, rather than other epilepsy risks, such as: such as self-injury, problems with driving, overdose of medication, under-dosing of medication, drug interactions, ongoing seizures, status epilepticus, nor other risks associated with the clinical management of epilepsy. A greater amount of research around communication is required that covers these areas.

Methods and samples were heterogeneous. This heterogeneity captured the views of multiple stakeholders, including neurologists, non-specialist doctors, specialist nurses, PWE, their families, and bereaved families. However, the lack of homogenous studies meant that a meta-analysis or synthesis was not viable, thus reducing analytic power. There was unequal distribution (four studies examined PWE: six studies, clinicians; representing a total of 6,641:1638 participants). There was also no consideration of how PWE's nor clinician's individual differences, such as gender, ethnicity, learning disability, age or other demographics, beyond experience of epilepsy, may affect communication, which future research may address.

Methods also varied. Views elicited from PWE were mainly from interviews (3) and one survey. Clinicians were included in four surveys, one interview and one focus group design, so overall with less opportunity for elaboration by clinicians. These surveys were also used to identify predictors of whether conversations were held. Three studies compared groups to test directly for causative relationships. These focused on the use of predesigned checklists (4) and showed evidence of significant improvement in awareness of risk and reduction of risk factors where communication about risk used this structured method. Thus, most guidelines and postulated consequences were based on neurologist perspectives, rather than those of PWE and families, such as that conversations appear to mediate AED adherence, despite there currently being limited evidence for this (47). There was less opportunity for clinicians to elaborate their responses given the survey methods, though this

enabled larger participant numbers. Direct observation of skilled clinicians was also missing, hence people actually engage in risk discussions is not yet well understood.

Seven quantitate surveys were conducted, with Three studies including more than 50 participants and Two more than 200. This seems to offer reasonable confidence in generalisation of findings. These were conducted mostly in the UK (6) and one in Norway, potentially not capturing international variation. All studies, apart from the two group comparison studies, drew on retrospective reports from clinicians and PWE rather than examining how the communications actually took place. Group comparison studies can raise ethical issues, as trials cannot be run where communication is withheld. Alternatively, future research might focus more directly on clinical conversations, following the substantial rise in the use of Conversation Analysis to explore how communication works in practice (54). Analysing clinical conversations might enable the identification of best practice for clinicians in engaging people with risk discussions, and provide a helpful method for training clinicians (55). Experienced clinicians seem better able to discuss risk (42; 48), but it is not yet known how they do this, which could be identified and then trained more widely.

Strengths and Limitations of the review

This review was limited by the low number of published papers available that comment on how clinical communication about risk might be achieved (only 17, with no limiters, all published between 2001 and 2018). None of these papers directly addressed the question of how to have clinical conversations about risk. Six papers focused on the frequency of SUDEP conversations, four on evaluating clinical practices, three on SUDEP awareness, two on use of the safety checklist and one on mortality rates, and one more generally on discussion content. All guidance was extracted from brief mentions of recommendations in the discussion section, not direct empirical data. We argue this is a gap that future research should address.

There were limited inductive studies that might identify new insights for practice. Of those qualitative inductive studies, there was diversity in how themes were extracted, some being driven by the questions asked, again limiting the inductive nature of the research.

Risk discussions with PWE are a complex issue and clinicians will need to make their own best judgement about engaging in them. A research focus on communication in epilepsy contexts may reveal better communication methods, facilitating future collaboration and engagement with people in managing their epilepsy.

Conclusion.

There is frequent reference to the limited guidelines provided by NICE or the AAN, about how, when and whom to discuss SUDEP and epilepsy risk with. This paper revealed the limited research available around how conversations with PWE about risk might best be held. It is the first paper to summarise the available guidance, taking a step towards better understanding how conversations about risk with PWE might be held, which has not yet been directly addressed. The guidelines arising here should be used with discretion, as less than optimal empirical evidence is available. Situations should be considered individually, but in general, conversations about risk should be held early on. Future research should better integrate the perspectives of clinicians and PWE, to understand how anxiety on both parts can be overcome. Research should focus directly on clinical practice, to gain direct insight into how experts manage difficult conversations, in order to support and inform other clinicians. Focal areas could include: what it is helpful to and say when conversations are held about risk, how these conversations are received, and where they are best located in a treatment pathway. Research should explore how different service contexts are relevant to the delivery of risk discussions. This will enable clearer and more focused guidance, embedded directly in the experiences of PWE and clinicians, and within the realities of clinical practice.

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56.

Declarations of interest:

For paper titled: Keep Safe: The when, why and how of epilepsy risk communication.

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Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	1
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	4- 7
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	7
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	6
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	7
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	7
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	7
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	7,8, 9
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	7, 8 9
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	6,7
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	11, 12, 13, 14, 15

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	9
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	10
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	16, 17
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	11, 12, 13, 14, 15
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	16 - 34
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	28-32
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	34-38
Limitations	20	Discuss the limitations of the scoping review process.	38
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	38-39
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	39

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

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