The view of the clinician and the scientist on the family experience of sudden epilepsy deaths

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Abstract

A sudden epilepsy associated death is a tragedy for the bereaved, a failure for the clinician and a challenge for a research scientist. Sudden death in epilepsy cannot be truly anticipated or prepared for by the bereaved, or the clinical team. Communications and provision of pastoral care following SUDEP is an important part of an epilepsy service where interaction with the family and specialist services for the bereaved can be rewarding. Sudden death and SUDEP are valid targets for research attention but families may be less aware of opportunities to assist in life science research or conversely feel coerced at a vulnerable time. We have a responsibility to ensure that the SUDEP risk is minimised and that we maximise the learning potential from each death. Out of such tragedies some good must come, but this will take combined efforts from doctors, families, the voluntary sector acting in league with scientific and academic funders. In this review we set out to consider the dual viewpoints of the clinician and the scientist and how they consider the family experience of sudden deaths to provide advice for all parties.

Keywords

SUDEP, Epilepsy Death, Communication, Scientist, Family
1 Introduction

While death might be inevitable, the circumstances, the timing, and the age of the deceased, can mean some deaths will force a heavier emotional burden than others. Grief reactions can vary hugely in their timing and evolution. In general, expected deaths permit emotional support and palliative care to be afforded ante mortem. All sudden deaths are a shock and can leave a psychological legacy for the bereaved; but SUDEP (that is primarily recognised in people of school and working age adults) carries a great potential for traumatic grief.

The epilepsies are a diverse range of disorders characterised by a single feature – their propensity towards spontaneous seizures. It is well-recognised that people with epilepsy are more likely to have a number of physical and mental health comorbidities, but many people are living and working with epilepsy as their only ‘diagnosis’. The first seizure is commonly terrifying and witnesses, particularly if they are family members, will have natural anxiety. This may be modified by the passage of time as epilepsy becomes a long-term condition responsive to medication.

For patients, their reminder that they have epilepsy may occur twice daily when they take their medication or - if this becomes automatic – the yearly health check. For them and their families, the existence of epilepsy will become regarded as part of their ‘normal’, rather than a source of risk. SUDEP risk can be stratified on crude clinical factors – but all people with epilepsy may be considered to carry some degree of SUDEP risk. A sense of missed opportunity in the wake of a death will be amplified when the relative did not know that epilepsy could kill.

2 Clinical Discussion of Sudden Epilepsy Death

To be a clinician is to be in a privileged position. The derivation, from the ancient Greek κλινικός (klinikós, “pertaining to a bed”) positions the doctor alongside the patient. The patient is an expert in their symptoms and their experience whereas their doctor has experience based on amalgamated patient stories in combination book-learning and clinical training. Every
consultation will pose challenges with experiential imbalance, especially within a first clinical encounter.

A patient may bring with them their own expectations, their knowledge of epilepsy, and their concerns about the consequences for work and driving. The Doctor has the advantage of being on ‘home turf’ having notes and records available, a degree of control over the style of the consultation, and will then try and create a rapport. When trying to put the patient and relatives at ease, the clinician has to integrate the details of the story from A&E record, the phoned witnesses, the videos, investigations (ECG, bloods, imaging, EEG) in order to formulate a diagnosis.

The doctor is the gatekeeper to therapy, specifying the choices and tailoring the plan for the individual. Despite this, the ultimate power is retained by the intended recipient, the patient who will decide if and how they will adhere to the advice. Only then can the medication options be addressed and discussed so that a prescription and advice can be dispensed. The time is constrained yet the clinician will have to provide stratified safety advice, put the condition in context, and consider any implications on pregnancy, occupation, driving, and hobbies, alongside the risk of harm and complications from epilepsy. The list of undertakings mandated in clinical guidelines such as NICE (5) or SIGN (6) is imposing and extensive - it will be possible that some items on these lists may be overlooked. Where the discussion may be uncomfortable, even where directions from guidelines are clear, discussions about the risk of harm may be overlooked or avoided. (7, 8)

There is a small but measurable risk of SUDEP that comes with every seizure diagnosis, and the advice from bereaved families is clear – they wish that this risk had been explicitly laid out at the soonest possible opportunity.(9, 10) Even when an individual is adequately counselled there are no guarantees that proffered information is retained, acted upon, or shared with relatives for perfectly reasonable reasons of ‘not wanting to worry them’, or failing to acknowledge how important this information is for their relatives. As a result, many families
brereaved from SUDEP are unaware that their relative was at risk. Families’ understanding of SUDEP is a modifiable factor that can predict their traumatic grief following a death.

3 Clinician

3.1 Clinician’s Response to Sudden Epilepsy Death

Epilepsy-related death can rarely be truly anticipated or prepared for whether death occurs soon after diagnosis, or following frequent, severe seizures and ‘near misses’. In this way SUDEP differs from progressive neurological conditions where some relief can be taken that a time of suffering may be over. Although death in epilepsy may not be uncommon in a large neurology practice and physicians will have prior experience of losing patients this way, a clinician never becomes accustomed to it. A dialogue between doctor and the bereaved family may not alleviate shock and grief but can be strongly therapeutic for both sides. Whereas there can never only be a single appropriate response it would be reasonable to expect the physician to be open and ready to respond.

Unless the event occurs under the direct care of the clinical team there are rarely fail-safe mechanisms to alert caring physicians of an untimely death of one of their patients. This is especially so where the neurology specialist may be one of a large team, or in the case of transition. Where an individual has moved between epilepsy centres such as from a regional service or between paediatric and adult services, the response from each of the services concerned will be equally welcome and neither should assume that the responsibility or opportunity lies elsewhere.

3.2 Initial Contacts in Sudden Epilepsy Death

Once informed, the responsible clinician should make efforts to learn of the circumstances of death. It may not always be simple to establish what occurred, such deaths are often unobserved. (11) The cause of death may be uncertain initially, such as in care of the older
adult where SUDEP is a less recognised event. When there are doubts around the cause of
death, the certification process for investigating the death is unlikely to have concluded. The
link between the deaths registration services and caring teams is often not clearly integrated
and universal nomenclature around countries and states is lacking. (12) A contact to provide
information to the local forensic services such as when post-mortem or autopsy is being
considered should be with the intention of assisting and does not imply a treatment deficiency.

An initial message from the clinician can simply let the bereaved know that are available if they
wish. It is hard to predict who will take up such an invite but nearly all welcome the
opportunity. (13) There may be a number of people that would take up the offer be they family
members, residential carers or close friends but it should be open enough to be interpreted as
they feel suitable. Grieving is a private affair but can be shared. Invites should not be exclusive
to a particular circumstance or mechanism of death. Many morbidities accompany epilepsy (14)
and where self-harm has been implicated it may be particularly comforting to lessen the impact
and learn if there were opportunities for intervention. Establishing contact via a simple
personal message may be sufficient whether this is delivered over the phone or written. (15) A
short, open, sympathetic message may be enough to open a dialogue. In the United Kingdom,
the charity SUDEP Action (16) who provide support and advice can facilitate contact, prompted
from the physician or by family interaction with the Epilepsy Deaths Register. (17)

3.3 Barriers to Contact

Legal responsibilities may be expected in some jurisdictions, but this is unlikely to be a
contraindication to contacting the bereaved. An appreciation of uncertainties and
acknowledgement of these difficulties may guide the bereaved, and can be helpful when the
family is searching for answers. Unless there is a strong indication that an approach would be
unwelcome, it is safe to assume that any offered contact will be comforting and clinicians
should not be dissuaded from meeting. In established epilepsy units such pastoral care should
be regarded as part of comprehensive responsibilities. A wish to avoid being intrusive, may
shape the treating physician’s enthusiasm for contact, but this is usually unjustified and
unrealised, especially if the physician team has had an input into the patient’s care for some duration.

There may be sensitivities among certain spiritual groups where the clinician’s search for a cause of death may be tempered by religious beliefs and the need for a speedy resolution. No time is too early or too late, with people who have been bereaved may reach out to support groups, many years after the event has occurred, during which time there could have been a valuable intervention. (18, 19)

3.4 Epilepsy Clinical Team Response

All members of the team should be informed of a death, and be aware of the need to be sensitive when corresponding by phone. Sending appointment reminder letters to someone who has passed away is not unheard of, but must be avoided. All too often, this can be an unfortunate mechanism of learning of a death in epilepsy. When a unit is aware of a death in epilepsy a priority should be that no routine letters or missed follow up correspondence letters are sent. The impact of a patient death upon a treating team should not be underestimated. An awareness of the effects and a readiness to discuss distressing information can improve care and prevent a team becoming disheartened. The invitation to contact is not an exclusive privilege of physicians and could be extended from the epilepsy specialist nurse if circumstances felt more appropriate.

Having an open conversation without any set agenda other than providing comfort may not come naturally. Physicians, who are more used to communicating results and opinions may have created their own methods of dealing with a sudden epilepsy-associated death, as it is unlikely that this has been taught to them. The value of time in such a circumstance cannot be underestimated and the consultation should not be rushed. The burden of involvement in such a conversation may be little compared to the benefit. Interaction with the family can be
therapeutic and rewarding for the treating team, sometimes unexpectedly so. The avoidance of an attribution or apportion of blame is usually unfounded.

### 3.5 Local Direction in Response to Sudden Epilepsy Death

It is in the interest of patients, their families, and their carers that lessons are learned from deaths in people with epilepsy. The death may give cause to identify or reinforce mechanisms to prevent harm or give comfort to others. It is invaluable to gather information on the circumstances to learn where the service gaps occur to lead and shape services: is there a target group to which the service could be reaching out or monitoring? Was there a block to the initial service that could be renegotiated?

Many units have mandated morbidity meetings, and patients that were known to a local unit should be included as an integral part of quality care to improve knowledge. An example of this in the United Kingdom, is the Learning Disabilities Mortality Review (LeDeR) programme, led by the University of Bristol. This was developed in conjunction with patients with intellectual disability and their families. Reviews are carried out to improve the standard and quality of care for people with an intellectual disability. There is currently a bias towards inpatient deaths although community deaths can also be reported, and this can be by a family member or a member of the clinical team.

### 4 Scientist

#### 4.1 Contacting the family following a death

It is over 100 years since SUDEP was recognised as a distinct cause of epilepsy associated death and yet the mechanisms to intervene are not well developed. We need to boost the clinical and basic science focus on epilepsy, and make it easier for scientists to work on SUDEP. How best to facilitate this need, with balancing that of supporting the bereaved family? When studying biological markers of SUDEP a post-mortem tissue sample may be needed.
other areas of best practice – where it is preferred that the bereaved make contact with the researcher at a time and in a manner of their choosing, here time is of the essence and windows of opportunity close. Unlike ‘brain bank’ studies where, for example, people with dementia can be consented for organ donation before death – mortality rates in epilepsy would require many thousands of individuals to consent for a relatively modest number of tissue samples. Scientists, and by extension, their ethical review boards, may debate the consequences of discussing such research in otherwise healthy adults for fear of causing excessive health anxieties that should be allayed.

4.2 Motivation
Some research within the life sciences develop a passion for a clinical area based on the patient group or the fundamental scientific challenge, some have a personal reason for prioritising one area over another.(22) Separate to this is the issue of impact: solving the greatest challenges has the potential for the greatest good – for example on reducing suicide rates in people with epilepsy, rather than how to self-manage mild depression. With this focus SUDEP becomes an attractive research theme and one that superficially appears to have no drawbacks; it is hard to predict a negative consequence of reducing SUDEP rates. SUDEP research scientists should prioritise questions that are a) fundable, b) achievable, c) have the greatest impact.

4.3 Families’ contributions to SUDEP Research
Bereaved relatives can be indefatigable advocates and driven grass-root-campaigners for fundraising and research. Great care must be taken when enrolling bereaved families in to research. It is clear that within and between bereaved families there are many individuals for whom any contribution to SUDEP research is too emotionally impactful, even many years after death. Experience has shown that many families who participate actively in research programmes are in need of additional bereavement support during their research participation; furthermore even expert researchers may not be able to identify which families are vulnerable at the point of recruitment in to research. Due to the time-limited nature of research projects, researchers in fixed-term posts may become a visible ‘point of contact’ but then move on and can no longer fulfil this role; also very few biomedical researchers will have sufficient training to
be able to provide adequate counselling. It is for these reasons that we would advise early involvement of an appropriate bereavement focused charity (in the UK this would be SUDEP Action). Integrating this support with a research programme – ideally before the families are contacted for involvement in the project – provides capacity for parallel counselling and a legacy of support that would outlast the research project.

What could bereaved families do to engage with and help SUDEP researchers? The first action would be to join an organisation in your country with bereavement expertise that may provide specialist support and direct to ongoing studies. In the UK this would include SUDEP Action and the Epilepsy Deaths Register. This patient organisation may help identify a number of ways in which the families could help – such as -

i. Raise the profile of epilepsy in general and SUDEP specifically amongst informal network and with people of influence

ii. Contact a researcher and offer to write an impact statement – If this research was funded, what would it mean to you and your family?

iii. Let epilepsy charities know what your research priorities are or join advisory committees so that the correct projects are identified (23, 24)

iv. Take opportunities to meet with and speak to epilepsy researchers at engagement events

5 Summary

SUDEP is a devastating potential complication of epilepsy and should be highlighted to all patients following a first seizure or diagnosis of epilepsy. The effects of SUDEP on families cannot be underestimated, but also its effects among the treating team should be acknowledged. After taking stock, reflecting on events, and supporting each other, the team can begin to lay down further processes to ensure that the SUDEP risk is minimised and that protocols for passing on information and education are reinforced and supported. Out of such tragedies some good must come, but this will take combined efforts from doctors, families, the
voluntary sector acting in league with scientific and academic funders. As we learn more about SUDEP we can begin to put in place proper and lasting prevention.
References:


16. SUDEP Action https://sudep.org/

17. Thomas RH, Osland K. Learnings from deaths – the Epilepsy Deaths Register Epilepsy & Behav 2019 (same issue)


