

SUDEP counselling: How and when?

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Abstract

Sudden unexpected death in epilepsy (SUDEP) is not a recent phenomenon. Although not understood, it has long been recognised as one possible outcome of a difficult illness. However, as modern management has offered improved seizure control, epilepsy has acquired the perception of a more benign condition. In this setting, deaths which occur can be both unexpected and shocking. Bereaved families have responded by calling for research and education. However, with no known cause for SUDEP health workers have been uncertain how to discuss the issue. Fortunately, epidemiological research is providing insight into risk factors, thereby opening the door for doctor-patient discussion on personal risk evaluation and SUDEP. Global practice varies but health care policies are starting to promote the routine inclusion of SUDEP information in patient counselling. Early understanding of risk may improve patient choices regarding adherence to treatment and the need to strive for optimum seizure control.

INTRODUCTION

Guidance on how and when to provide SUDEP counselling, first needs to address why. SUDEP is not a recent phenomenon.¹ However, historically, when treatments rarely provided good seizure control, deaths were frequently accepted as a sad outcome of a difficult medical condition. Those who died suddenly were often assumed to have suffocated during a seizure. As modern treatments became more effective in limiting seizures, epilepsy became less conspicuous, and increasingly perceived as a benign condition. Epilepsy information focussed on positive aspects of modern care, and death slipped from the discussion of risk.¹ In this setting, the sudden unexpected death of a young person who is apparently healthy, apart from epilepsy, is rarely expected or accepted by family and friends. It is a shocking event aggravated by the fact of not knowing such deaths are possible. Despite comprehensive investigation of the deaths, including autopsies, a clear explanation of the cause remains elusive² adding to the bewilderment of those who are bereaved and leaving them with many unanswered questions.^{3,4}

GLOBAL DEBATE

Not surprisingly, many who experience sudden and unexpected bereavement due to epilepsy respond to the experience by calling for research and action to prevent or reduce SUDEP, and in 1993 the first consumer agency dedicated to reducing epilepsy-

related deaths (Epilepsy Bereaved) was established in the UK. The organisation quickly initiated an international scientific meeting⁵, followed by a significant national audit of epilepsy-related death in the UK.⁶ Internationally, several similar organisations have sprung into existence and, in addition, the web sites of most epilepsy agencies now include SUDEP information. Awareness of SUDEP has increased amongst clinicians, researchers, and health administrators, resulting in diverse research, education, and policy initiatives targeting SUDEP.

Two crucial, interrelated questions have emerged about SUDEP. Firstly, what is the cause and, secondly, what should we tell people with epilepsy? Research has not yet been able to reveal the cause, or causes, of SUDEP and consequently, there is reluctance amongst some health workers to discuss SUDEP with patients. If we do not know the cause, they ask, how can it help people to hear about this risk? Others argue that despite the fact that SUDEP has no known cause, or guaranteed method of prevention, patients have a right to know that it occurs. This is in line with the contemporary style of Western medicine with its patient-centred approach, and the expectation that patients will be well informed and able to participate in decisions. Risks are routinely disclosed and the community has come to expect this.^{7,8} Families bereaved by SUDEP have felt betrayed in this setting, where they perceive that they have not been fully informed.

Evaluation and communication of risk

The gradual identification of possible risk factors for SUDEP through epidemiological research has facilitated improved risk communication in epilepsy, as doctor-patient discussions can now take on the character of a personalised risk assessment.⁹ Risk factors can be considered in light of a patient's individual diagnosis and circumstances. Where there are negligible risks associated with certain seizure types this allows the doctor to provide some reassurance to lower risk patients. On the other hand, seizure frequency is a significant risk factor, and this leads well into a discussion with all patients about the importance of striving for the best seizure control possible. As with SIDS, a fatal occurrence in children, for which the cause is also not yet known, it is hoped that community education about risk factors might prevent some deaths.¹⁰ Nevertheless, deaths still unfortunately occur in apparently low risk patients; so while trying to inform, and minimise the fear factor, it is also important not to create false assurances. Concerns about raising anxiety in patients can be balanced by consideration of the benefits which can accrue from an open discussion. Many patients and parents already harbour unexpressed fears for themselves or their children. Epilepsy counsellors argue that careful discussion with a realistic appraisal of an individual's situation often helps to reduce anxiety.¹¹

Also important to consider is the ready availability of internet information, much of which is not correct or tailored to the individual circumstances of the reader. The community use of internet sites to obtain health information is escalating¹², and whilst some web sites do provide useful general material, personal discussion with their own doctor is the best way for people to appraise their unique risk. Frank discussion will also facilitate the building of trust in the therapeutic relationship. A recent UK study in a paediatric setting found that 91% of parents studied expected their doctor to provide SUDEP information, and that it did not have significant immediate or longer term negative impacts on the families. Interestingly one third of the participants had already heard about SUDEP.¹³ Although current practice regarding the discussion of SUDEP amongst doctors is evolving, it may not be changing as rapidly as patient expectations. A UK study published in 2006 comprising neurologists and medical practitioners working with epilepsy found that whilst 30.3% of respondents reported

discussing SUDEP with the majority or all of their patients, 68.7% discussed the issue with very few or none of their patients. Those with a special interest in epilepsy were significantly more likely to discuss SUDEP.¹⁴ Similar figures were noted in an Italian study published this year.¹⁵

A discussion of SUDEP can sit well in the routine overall consideration of risk, which is an important aspect of the diagnostic phase.² Treatment decisions involve a comparison of risks and benefits, and although death may not be a common outcome, the catastrophic nature of the event warrants consideration when the diagnosis is explained.¹⁶ Complacency about medication adherence is a common problem in epilepsy.¹⁷ Also, life circumstances can change and a person may decide to reduce or cease treatment without the benefit of timely medical advice; for example, when an unexpected pregnancy occurs.¹⁸ If a full disclosure of risk has not been provided early, people with epilepsy may not have sufficient understanding to make safe choices over the passage of time. Nonadherence to prescribed medication regimens in epilepsy has been found to be associated with a more than threefold increased risk of mortality.¹⁷ It is understood that patients vary in personality and coping styles, and therefore in their attitude to information and how they use it to navigate health issues. In settings where risk is introduced to epilepsy patients it would be advantageous to provide additional support workers, to allow for extended discussion where it is desired.

Looking to the future

SUDEP continues to be an important topic of discussion and research internationally with scientific studies yielding some promising results.¹⁹ From the clinical perspective, SUDEP is exerting a positive influence on the approach to epilepsy management. The epidemiology of risk factors underlines the need to strive for the best possible seizure control in all epilepsy patients², and this is an important message for epilepsy care worldwide. Guidelines for epilepsy services published in the UK now recommend a discussion of SUDEP as part of general epilepsy information and something to be considered when decisions are made regarding antiepileptic drug treatment.^{20,21} Legal inquiries into epilepsy-related deaths have endorsed the provision of SUDEP information to patients.^{22,23} In rare cases, the treating doctor may feel that it is necessary to initially limit the amount of information provided, for example in

the case of co-existing mental illness. In such cases it is expected that the doctor will record the reasons.

In the US an epilepsy taskforce is looking at the priorities for a public health agenda on epilepsy and the blueprint includes a special focus on SUDEP.²⁴ In Australia, Epilepsy Australia continues to promote discussion of SUDEP and other epilepsy-related risks.^{25,26} In partnership with bereaved families, people who have epilepsy, Epilepsy Bereaved UK, and colleagues worldwide, Epilepsy Australia strives for quality epilepsy care and a reduction in all epilepsy-related deaths. A taskforce has recently been created with epilepsy-related deaths as its focus.²⁷

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