

Can technology help reduce risk of harm in patients with epilepsy?

EPILEPSY MORTALITY AND CLINICAL GOVERNANCE

Sudden unexpected death in epilepsy (SUDEP) is possibly the most common cause of death as a result of complications from epilepsy, accounting for between 7.5% to 17% of all epilepsy-related deaths¹ and 50% of all deaths in refractory epilepsy.² The UK has 600 000 people with epilepsy (PWE), 30% being treatment resistant. Sudden death is 20-fold higher in PWE than the general population. Epilepsy is the fifth highest cause of life-years lost in men and eighth in women in the UK. The public health burden of SUDEP alone is estimated as second only to stroke among neurological conditions.³

Forty-two per cent of all deaths are considered avoidable.⁴ Consequently, the National Institute for Health and Care Excellence (NICE) epilepsy guidelines in 2004 and 2012⁵ recommend discussion of SUDEP with newly-diagnosed PWE. This is rarely delivered and until recently only 4% of PWE had a recorded SUDEP discussion.⁶

In their current publication of the NHS Outcomes Framework, the government prioritises the prevention of amenable mortality, making it a core focus for NHS services. Epilepsy mortality features in new NICE Standards as well as NICE Clinical Guidelines.⁵ However, the dilemma remains of when, where, how, and what to discuss about epilepsy risk, especially SUDEP. Further to the discussion there is a lack of a structured monitoring of risk especially in primary care. Meaningful management of SUDEP risk in particular, and epilepsy risk in general, is arbitrary, non-person centred and with no evidenced mechanism.

In clinical practice, especially in primary care, the lack of any tools to support risk management is of concern. Risk management has been highlighted as vitally important to reducing avoidable epilepsy-related deaths, both in research and reporting but also via Prevention of Future Death reports and Fatal Accident Inquiries held by those investigating sudden and unexpected deaths. A central theme of all these reports is a lack of awareness or underestimation of risk. In some places a myth that was widespread in the 1990s persists that seizures are benign.

SUDEP occurs today in the context of the removal of epilepsy indicators from Quality Outcome Framework (QOF) in primary care and pressures in hospitals to discharge

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patients early,⁷ impacting on the care for those with epilepsy. PWE want information on risk.⁸

There is a substantial body of work on SUDEP risk.^{9,10} While no definitive mechanism or factors have been categorically identified, research has shown that there are various factors that can influence risk of an adverse outcome. However, this has not been brought together in a systemic manner to help patients and clinicians have a person-centred discussion of individual risk.

The problem requires a solution that is evidenced based, simple to use in a clinical setting, easily adoptable across a range of settings and practices, and supportive of communicating to patients and/or their carers clear outcomes for change. It also needs to be modifiable to change and lend itself to a range of applications. Importantly, if achievable, it needs to be patient led.

SUDEP AND SEIZURE SAFETY CHECK LIST DEVELOPMENT

A detailed literature review⁹ was undertaken to determine SUDEP contributory risk factors. A total of 18 factors were identified, of which 11 were deemed modifiable and with the potential to influence the SUDEP risk. A SUDEP safety checklist^{9,10} to help communicate and quantify risk was postulated taking account of the epilepsy, psychological, social, and biological factors. The checklist supports the goal of patient safety by focusing on the modifiable factors to guide treatment. It is also a tool to open a person-centred discussion with PWE to outline how individual behaviours impact on risk (for example, lack of compliance or alcohol misuse) and to encourage therapeutic engagement.

The checklist was used as the data collecting tool for a retrospective SUDEP study, incidentally the largest epidemiological study for SUDEP in England.¹¹ It helped confirm risk factors for worsening of epilepsy control and SUDEP. In about 90% of the SUDEPs there was a noted increase in seizure frequency and/or intensity

3–6 months before death, but poor contact with primary or secondary care. The study highlighted presence of modifiable risk factors 3–6 months prior to demise, which going uncorrected had a potential cumulative effect on seizure control and risk.

FEEDBACK ON CHECKLIST IN ROUTINE PRACTICE

The checklist has been in use for 2 years as routine practice in epilepsy clinics in Cornwall, with feedback from over 200 PWE and/or their carers. Ninety-eight per cent responded positively, and 2% were neutral for the quality of consultation provided using the checklist. High scorers on the checklist said it made them think of issues to address and modify especially with lifestyle choices. Those with low scores and those who were previously aware of SUDEP said it was a relief to be discussed. In June 2014 to June 2015 approximately 80% of PWE accessing Cornwall epilepsy services have had their SUDEP risk assessed and recorded.

A 12-month telehealth pilot in a large GP primary care service initiated proactive checks using the checklist on 15 high risk PWE, all defined as having treatment-resistant seizures for >10 years but stable in the community. Every 3 months a telehealth practitioner called up the registered patients and conducted the checklist with them. All results were then communicated to the GP in a timely way. Telehealth services, in what was considered a stable 'at risk' population, led to 17% receiving several interventions in the previous year that would not have happened without the tool. Clinicians across primary and secondary care have reported that this is working well as an intervention to raise awareness and improves the management of high-risk patients; proving a useful system for clinicians and an improvement on previous clinical practice.

There is still ongoing debate about the need and value of informing PWE of SUDEP,¹² however our work challenges this view. A structured approach pays dividends in focusing individuals on items in their locus of

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control. There is developing local evidence of improving safety by indicators of accident and emergency admissions, clinicians, patients and carer feedback, and SUDEP reduction.

Changing cultural stereotypes takes a generation. Awareness of the public burden of SUDEP has improved in recent years, but has not been translated into communications with patients. While the checklist is being used in many places across the UK and internationally it is still not in the common professional, clinical psyche of the practising epilepsy clinician.

In this information-rich world people increasingly want to know more about their medical conditions, treatment, and their risks. This 5–10-minute risk assessment checklist serves to inform PWE about their risk factors and how some lifestyle changes, for example medication compliance and surveillance at night, can have a positive impact on mitigating their individual risk of SUDEP. It provides documentary evidence for the clinicians on the impact of the treatment plan over a period of time and demonstrates effective clinical governance while enhancing patient safety.¹³

While there is no proven intervention or national surveillance of epilepsy mortality, the safety checklist is a simple and practical tool that can be used to demonstrate effective clinical and corporate governance while enhancing patient safety. It can also help give some assurance to bereaved families that every effort was made to reduce risk and prevent a fatality.

Although the safety checklist was developed for SUDEP risk, factors such as non-adherence, depression, and substance misuse appear to closely overlap with the findings on risk from literature on all causes of epilepsy mortality.^{14–16}

EpSMon: A DIGITALISED MOBILE APP

It lends itself to a variety of templates such as paper A4 sheets, Microsoft Excel® spreadsheets to monitor risk longitudinally, telehealth services, and has been developed into a patient self-monitoring mobile app: EpSMon. EpSMon looks to incorporate key

evidence-based risk factors with a view to empowering service users to monitor their own risk and has been launched as a patient self-monitoring mobile app for adults in association with Plymouth University and SUDEP Action. The advantage of using patient-owned digital platforms backed onto secure servers is that it helps collect suitable datasets to enable well-powered studies into these risk factors. The checklist and EpSMon are part of the new Epilepsy Commissioning Tool kit (<http://www.epilepsytoolkit.org.uk/>). In addition to improving care it could also provide a cost-effective model to fill the safety void left from the recent removal of the QOF in epilepsy in primary care. This template of joint partnership of risk between patients and primary care could be a prototype for other chronic disorders that could adopt such evidenced-based e-approaches.

Registration for further information on EpSMon and a downloadable version of the SUDEP and seizure safety checklist are available online (www.sudep.org).

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