Managing patients at risk of epileptic seizures in the community

Around 61,000 people in the UK are living with epilepsy (Joint Epilepsy Council of the UK and Ireland, 2011). Although 70-80% have their seizures completely controlled – usually by antiepileptic drugs – many continue to experience sometimes life-threatening seizures.

As many as 21 people a week in the UK die of an epileptic seizure (Thurman et al, 2014), making epilepsy about nine times riskier than asthma in terms of premature mortality (SUDEP Action, 2018). People with epilepsy also tend to die younger than the general population; this makes stroke the only neurological condition with more years of potential life lost (Thurman et al, 2014).

Risk factors

There are four primary causes of death in epilepsy (Box 1) (Thurman et al, 2014). Evidence suggests suicide rates in people with epilepsy are significantly higher than in the general population. The causes of this may be multifactorial, but over 75% of people with epilepsy have comorbid mental health conditions, most notably depression and anxiety (Fazel et al, 2013). There is also a small increased suicide risk associated with all antiepileptic drugs (Medicines and Healthcare products Regulatory Agency, 2010). Accidents, particularly drowning, are not infrequent in people with epilepsy. Advice around bathing alone, and activities near open water, should be carefully discussed with patients – although swimming in life-guarded areas presents little danger. There are obvious risks associated with working at height and with machinery.

Prolonged or serial convulsive seizures are life-threatening. Effective first-aid treatments are available, but are not always prescribed, even though death is possible following a single, usually tonic-clonic, seizure. Thurman et al (2014) estimate there are 600 cases of sudden unexpected death in epilepsy (SUDEP) a year in the UK (about half of total lives lost). Counselling is needed for people with epilepsy, their family and carers, as it is thought 42% of deaths could be prevented (Hanna et al, 2002). Shankar et al (2013) found...
about 90% of deaths occurred in people with tonic-clonic seizures that had increased in frequency in the previous 3-6 months. Half had a record of alcohol misuse, and a quarter had been taking medication to treat depression or anxiety. Deterioration in seizure control must therefore prompt an urgent review by the patient’s epilepsy specialist, within four weeks of referral (Scottish Intercollegiate Guidelines Network, 2015; National Institute for Health and Care Excellence, 2012).

Clinical harm or error is usually due to faults in clinical processes. Epilepsy care involves a range of services and professionals, which need to be linked to provide optimum care. These include neurologists, epilepsy specialist nurses, emergency department practitioners and, most crucially, patients and their primary care team.

Ridsdale (2014) challenged primary care to reduce epilepsy deaths by 30%, suggesting referral to an epilepsy specialist nurse for management of ongoing (particularly deteriorating) seizures, better communication of accident risks and improved management of mental health issues. NICE (2012) and SIGN (2015) say all patients should have access to an epilepsy nurse, but Epilepsy Action says there are only 161 adult epilepsy specialist nurses in the UK, or one for every 3,800 patients (Bit.ly/EpilepsyServicesUK).

Managing high-risk patients
Community management of seizures at risk of developing into clinical status epilepticus is probably sub-optimal. Status epilepticus – defined as a continual seizure, particularly deteriorating) seizures, better communication of accident risks and improved management of mental health issues. NICE (2012) and SIGN (2015) say all patients should have access to an epilepsy nurse, but Epilepsy Action says there are only 161 adult epilepsy specialist nurses in the UK, or one for every 3,800 patients (Bit.ly/EpilepsyServicesUK).

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About 42% of deaths related to epilepsy are preventable

Improving patient safety
Epilepsy is a challenging condition to live with and manage. Health professionals, patients and carers often underestimate the risks, and there can still be a reluctance to discuss death during consultations. Much could be done, relatively easily, to improve safety.

In 2018, leading UK epilepsy charity, SUIDEP Action, organised a summit to address epilepsy deaths, bringing together politicians, bereaved families, carers and professionals to raise awareness of the risks and highlight strategies to mitigate them (SUIDEP Action, 2018). Patients’ use of self-monitoring technology, such as the EpsMon App (epsmon.com), and seizure-warning devices to alert carers (Bit.ly/EpilepsyAids), can also help keep patients safe. However, take-up of these remains patchy.

Conclusion
Many deaths from epilepsy are preventable. Wider engagement from health professionals, particularly in primary and community care and emergency departments, can make a huge difference in sign-posting patients towards early intervention and management of comorbidities (especially those associated with mental health) and empowering patients to monitor their condition and take early action if seizure control deteriorates.

References


Ridsdale L (2015) Avoiding premature death in epilepsy: general practice is the place to start, and much can be done. BMJ; 350: h718.


Shankar R et al (2017) Epilepsy awareness and rescue medication training: ignorance is bliss. Epilepsy and Behaviour; 70: (Pt A), 212-216.


