Epilepsy is different

Rhys H Thomas[1] • Phil EM Smith[2]

[1]Welsh Epilepsy Unit, University Hospital of Wales, Heath Park, Cardiff, UK
[2]Wales Epilepsy Research Network, Institute of Life Sciences, Swansea University, Swansea, UK
Correspondence to: Phil EM Smith. Email: smithpe@cardiff.ac.uk

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Epilepsy is different: a neurological disease that is common and treatable; a chronic disorder that is intermittent and not progressive; a common condition with no diagnostic test yet highly stigmatizing; and much more. We ask that epilepsy and epilepsy services be recognized as different from other chronic disorders, with inherent complexities that historically have perpetuated problems with patient care.

Epilepsy is the propensity for spontaneous seizures. There is no 'test' for epilepsy in the way that an HbA1c, FEV_1 or ECG may define and monitor other chronic disorders. Thus misdiagnosis rates, even in specialist centres, approach one-fifth – the error trending towards over- rather than under-diagnosing events as seizures.[1] The epilepsy 'tests' – MR brain scan and EEG – can each be normal despite an absolute confidence in an epilepsy diagnosis. With no test, the clinician must rely solely upon the patient's report in assessing seizure control, usually with no way to verify this. The physical examination, though important, is quite secondary to listening to the patient and witness describing the event. The witness account is essential, as a period of unconsciousness is indescribable. However, so much surrounding the seizure is difficult to articulate: déjà vu, an epigastric aura, an absence, a myoclonic jerk. How can anyone record an *accurate* history from someone with significant learning difficulties (30% of whom have epilepsy), or in a second language? Having the time to listen carefully to what is described and how it is said helps to differentiate an epileptic seizure from vasovagal syncope, cardiac arrhythmia, and psychogenic non-epileptic attacks.

As a syndrome of symptoms (the seizures) with many causes, the management approach is analogous to that for pain. After settling that the events are indeed seizures, with no serious or progressive cause, the aim is to mask the symptoms with tablets: only rarely is it possible to remove the root cause. A trial of treatment is perfectly reasonable in most chronic conditions; indeed, it might almost be negligent to withhold it. But a trial of anti-epilepsy treatment for 'blackouts' risks a lifetime of unnecessary medication. Furthermore, the medication itself reinforces and even imprints a label of epilepsy. With no clear diagnostic test, it is a common temptation to start medication with insufficient evidence of epilepsy. The problem then is to know at what timepoint a trial of anti-epileptic treatment has succeeded. When confidence is re-built and/or a driving licence returned, withdrawing anti-epilepsy medication in adults proves so much harder than starting it.

Unlike many chronic conditions in adults, epilepsy is almost as likely at any age, and perhaps becomes more common in older age. However, there is a UK-wide dearth of older-age epilepsy specialists. We need to encourage and nurture elderly care physicians towards specializing in epilepsy. Some epilepsies remit at puberty, but most are long-term and so anti-epileptic drug treatment must often be lifelong. Broadly speaking, all available anti-epileptic drugs work for all epilepsies, yet least one-fifth of people continue to have seizures despite best available treatment.[2] Young women with epilepsy must be managed with an eye to possible future effects on any unborn child. Valproate is physically[3] and cognitively[4] teratogenic and so women with idiopathic generalized epilepsy – for which valproate would otherwise be best[5] – often must cope with suboptimal seizure control on inferior treatment.

Epilepsy's intermittent nature permits its concealment, something impossible for most chronic conditions: stigma and driving ineligibility are the main motivators for non-disclosure. Epilepsy is poorly understood by the general public and generally perceived far more negatively than other chronic conditions. The lack of high-profile celebrity champions for such a common condition (though there must be many) reflects and reinforces epilepsy's perceived stigma. Its stigma may be felt more harshly by older people following exposure to (almost) Dickensian values in their youth; for example in the film, *Dr Kildare's Crisis* (1940), epilepsy's prognosis is 'gradual disintegration of the brain … and wretched living death'.[6] In the developing world, prevalent misconceptions about associations with the devil, witchcraft, contagion and family misfortune are the major reason for non-declaration of seizures and an astonishing (80–90% in many parts of the world) failure to access treatment.[7] People with epilepsy may have missed out on education and employment opportunities, and therefore may not graduate to a position to make a difference for others with epilepsy. This contrasts with educated and eloquent advocates with multiple sclerosis or motor neurone disease, where highly motivated and wealthy people in the public eye can raise their profile.

Solutions

Epilepsy is different, and recognizing this for service provision is essential. Most people attending a 'first seizure' service have not had a spontaneous epileptic seizure. Furthermore, many patients with psychogenic seizures are followed up in epilepsy clinics and may be major consumers of resources. Thus, basing required resources upon the prevalence of epilepsy alone will lead to a shortage of epileptologists. However, the skills needed to care for people with epilepsy are not the exclusive domain of tertiary referral centres, nor just neurologists. An epilepsy specialist (from a nursing, general practice, paediatric or adult medicine background) should see each person with suspected first seizure. A specialist may be best placed to deal with the inherent uncertainty integral to blackout diagnosis. No-one should have to wait longer than two weeks for this first consultation, not least because people with life-threatening cardiac conditions may present as first seizures. We must learn lessons from colleagues who have re-designed services to meet the needs of those with suspected malignancy. Using a form of critical path analysis (service mapping with results based accountability) we have reduced the number of steps where someone with a first seizure might wait, effectively halving the mean time to be seen by a specialist. Recognizing that people who attended the Emergency Department with their first suspected seizure may not receive best advice – regarding driving eligibility, when to start anti-epileptic medication, whom to admit or discharge – we have initiated an acute care liaison service. This nurse-run programme (created without additional funds) also allows a specialist to take a witness history immediately after the event and to ensure that all ECGs are reviewed to rule out conduction patterns associated with a high risk of recurrence of cardiac syncope.

Coordinating clinical care should be a priority, particularly because patients prioritize the improvement of public understanding of epilepsy and the tackling of treatable co-morbidities.[8] Clinical networks can bring together existing players and resources (both GP and secondary care) into a more coordinated way of working, while not incurring new costs. Alongside our open access patient telephone helpline, we are shortly to pilot a system where general practitioners can contact us for advice and encouragement, recognizing how much day-to-day care of people with epilepsy occurs in the community.

Although many chronic disorders are stigmatizing, hidden, misdiagnosed or mistreated, epilepsy is all of these; it is the toxic accumulation of all of these factors that explains why epilepsy is different. The way forward is through combining the forces of the specialists that currently see people with epilepsy or suspected epilepsy, agreeing on care pathways and (where possible) evidence-based management strategies, empowering patients to be more equal partners in their care, and raising the profile of a condition that remains terribly misunderstood, even in the developed world.

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