Risk Management: a personal perspective

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Leone Ridsdale offers a personal perspective on the introduction of electronic medical records and their use in preventive care. She outlines the possibility of using this approach to identify risks for avoidable deaths in epilepsy — and reduce them.
Many years ago, I qualified as a neurologist in Montreal. When I moved to the UK, I initially found my specialist qualifications were not recognised. I trained as a GP and did a weekly neurology clinic at my local district hospital. There, I saw patients newly referred from my colleagues in general practice and some follow-ups.

Most patients waited about six months for a new referral, and another six months for investigations and a follow-up appointment. The hospital provided only two half-day neurology clinics, so many patients referred for loss of consciousness/epilepsy and headache/migraine were seen by general physicians.

Investigations included a technetium scan and an EEG. I had trained in a university hospital with a computer scanner. Neither of the above tests gave me much confidence that we could exclude important pathology like a brain tumour.

When I entered primary care, it was just beginning to change, shifting from a demand-led, reactive service to one that was working in teams to provide preventive services and manage long-term conditions. Ideas were promulgated by the Royal College of General Practitioners and by visionary clinician-researchers, such as Julian Tudor Hart. This inspired GP made famous an idea he called the Inverse Care Law (Tudor Hart, 1971).

Tudor Hart proposed that the people with greater needs for healthcare may be less likely to access it. In poor countries or market-driven health services, this may be because those in need cannot pay for services. In the NHS, it may be because individuals do not know they would benefit from particular services, so they do not come forward to ask for them.

An early example I found in general practice was cervical cancer, which — in England and Wales in 1980 — caused over 2,000 deaths each year. If women came and asked their GP for a cervical screening test (then known as a ‘smear’ test), it would be provided. These women would then be recalled at given intervals for repeat tests. However, many women – particularly those with a lower level of education – did not know that they could (and should) be screened. As a result, these people were more likely to die from the disease.

In an attempt to combat this, GPs (including myself) began to offer screening to women, initially aged 36-60 (Ridsdale, 1987). The Department of Health, with Edwina Currie as a Health Minister, subsequently launched a national programme of cervical screening, and now, deaths from cervical cancer have decreased by over half (NHS, 2013).

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Being proactive
Risk management is now a common idea and practice. Even banks do it. GPs have grown increasingly expert at managing risk.

The introduction of computers and computer software has been important in enabling GPs to record detailed information about all their...
registered patients. In turn, this information allowed them to target the offer of specific services to appropriate groups — including those who do not come forward so readily. Targeting of services might be on the basis of gender in the case of cervical screening, age in the case of immunisation, or disease risk factors — for example, those with obesity and raised cholesterol — who are at risk of cardiovascular disease.

The additional work required to catalogue information about registered patients and deliver targeted preventive initiatives required the recruitment of increasing numbers of team members. These included managers, nurses and IT staff. Funding and remuneration for meeting targets was linked to practices producing data about the numbers and percentages of registered patients who had received primary and secondary preventive services. This was associated with better NHS outcomes, like decreasing deaths from heart disease and cancer (Dzeshka et al, 2015, Hamilton et al, 2013).

After our practice nurses led on cervical cancer screening, the local commissioners offered a group, including myself, some additional funding to audit epilepsy services. We decided it would be constructive to see if a nurse might invite everyone registered with epilepsy for advice on epilepsy self-management. The nurse had worked in the community as a health visitor and district nurse, and had some added training in epilepsy. We found that the response was good. The sessions allowed practices to create a structured record of the information that patients had been provided on topics like driving, alcohol intake and preventing accidents (Ridsdale et al, 1997). During the 1990s, many nurse-led, condition-specific clinics were set up, financially supported by the NHS. This helped to pay for the staff required. However, epilepsy advice and monitoring was not reimbursed.

Information translated into knowledge seems important to the effective self-management of long-term conditions. We therefore asked people with epilepsy who were registered with our local practices to complete epilepsy knowledge questionnaires. As a result, we learned more about their knowledge of epilepsy. Our patients had experienced their condition for over 20 years (on average), but their knowledge of epilepsy varied a lot.

Those who had been at school longer, who had more qualifications and who belonged to self-help groups had more epilepsy-specific knowledge (Ridsdale et al, 1999a). It seemed as though the inverse care law also applied in epilepsy. It was another example of Tudor Hart’s Inverse Care Law. If knowledge of a condition is important in self-management, it is likely that those who have less of it will experience more negative impact on the quality of their lives (Ridsdale, 2009).

It is difficult to show a change in knowledge when people have experienced a condition for many years. That said, knowing that people with epilepsy were satisfied with additional information provided by a nurse was encouraging (Ridsdale et al, 1999b).

We wondered if specialist nurses providing education on self-care might be most helpful after epilepsy was first diagnosed. We found that it was particularly the quarter of people who beforehand knew least about epilepsy that most improved their knowledge of the condition after step-up care with a specialist nurse (Ridsdale et al, 2000).

It seems likely to me that the growing number of nurses with an interest in epilepsy will improve
opportunities, particularly for people who know less about the condition to learn self-management skills within the context of their lives. This role is rather similar to the educational role played by a health visitor for young mothers, responsible for a family.

Epilepsy in QOF
I was delighted when the late Helen Lester asked me to contribute as chair to reviewing evidence for the inclusion of epilepsy-specific indicators in the Quality and Outcomes Framework (QOF). The addition of only a few points for epilepsy seemed appropriate at first, primarily to fund a register of patients with epilepsy and their monitoring.

I believe that a similar framework for services might be provided as it is for people with diabetes, in which a set tariff rewards the delivery of a bundle of services. As part of QOF, newly diagnosed patients with diabetes are referred for a structured education programme. In diabetes, nurse specialists also visit practices, and directly advise GPs and patients with more complex problems. I hope that we can learn from this, and ask that these sorts of structured services are funded for epilepsy. Increased capacity and better training will enable us to provide step-up services in the community.

By comparison to randomised trials, testing the effectiveness of drugs, testing what are sometimes called complex interventions – by which we usually mean specific, standardised innovations in services – is difficult. In addition, such randomised trials of say a nurse specialist service are not so amply funded as pharmaceutical research. Nevertheless, I learned from our earlier research in the community that the cost of not offering proactive care for people with epilepsy was high.

Not only is attending an emergency department for an epileptic seizure upsetting for the individual, their families and friends, it is also costly for the NHS. With colleagues, I was later able to describe why people with epilepsy come to emergency departments and exactly what the cost is (Noble et al, 2014, Ridsdale et al, 2012). When people with epilepsy experience seizures that are witnessed by family members or others, it is understandable that they worry about the risk of death. This is arguably made worse by the fact that their actual risks are often not explained to them. Where it has been explored, the evidence is that people with epilepsy do want to know their risks of sudden death (Tonberg et al, 2015). People with epilepsy who are more highly educated are more likely to know about this risk (Kroner et al, 2014), another example of inequalities affecting peoples’ knowledge of health and health risk (Tudor Hart, 1971).

I was encouraged by the success of risk identification programmes for cancer and cardiovascular disease. I was similarly encouraged by emerging evidence that people want to know about their epilepsy risks too, despite unequal access to this information. The addition of epilepsy to QOF and the availability of GP electronic records (which provide a database representative of the UK population) stimulated my colleagues and I to undertake an analysis. We analysed anonymised GP records of people with epilepsy between 1993 and 2007 (Ridsdale et al, 2011). Research subjects included anyone diagnosed with epilepsy and then prescribed
anti-epileptic medication. ‘Cases’ were defined as people with epilepsy who died from all causes. Cases were compared to ‘controls’, who were defined as people with epilepsy still alive at the end of the study period.

We found that deaths from all causes in people with epilepsy actually rose between 1993 and 2005 – at a time when mortality from all causes in the general population were in decline. We compared the group of patients with epilepsy who had died to patients who had not died during the study period. Patients who had alcohol problems were at almost three-fold increased risk of premature death. Risk in patients who had not collected their most recent anticonvulsant prescription for between 90 and 182 days was nearly doubled. Having ‘a history of injury’ during the previous year increased the risk by 40 per cent. Having been treated for depression increased the risk by about the same amount. Patients who had been seizure-free in the previous 12 months had a 22 per cent reduced risk of dying.

In a recent BMJ editorial, I outlined what might be done in general practice in the future (Ridsdale, 2015). This was endorsed in a letter to the editor from Philip Smith, on behalf of the Association of British Neurology. The model includes developing risk-assessment tools for epilepsy, just as has been done for cardio-vascular disease and cancer (Dzeshka et al, 2015, Hamilton et al, 2013). If GPs have a funded programme to perform risk assessment, there is much that might be offered to improve services and potentially reduce deaths. For example, medication adherence is something that can be monitored and discussed with patients at review.

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Smithson et al (2013) demonstrated that GPs can identify people who have not adhered to epilepsy medication and discuss this with them. A court in Scotland has argued that pharmacists and GPs should be involved in monitoring the uptake of anticonvulsant medications, and in explaining why this is important (Judiciary of Scotland, 2011). This could be rewarded by QOF.

Incremental change

Sometimes I ask myself: why is so little social or press space given to epilepsy? We are currently testing self-management workshops for people with epilepsy who attend hospital clinics with persistent seizures (Kralj-Hans et al, 2014). I have attended and taught some of them. We teach that up to one per cent of the population have epilepsy. At first I was surprised that most participants say that before coming they had either met no one or only one person with epilepsy. Then they add, laughing, that they have now met 10! Many people with epilepsy are barely aware of each other; it seems unsurprising that public and policymakers are barely aware of them. Why is this?

Scambler and Hopkins described how people with epilepsy report experiencing what they described as
‘felt’ and ‘enacted’ stigma (Scambler and Hopkins, 1986). [Felt stigma is an internalised sense of shame and the expectation of enacted stigma, while enacted stigma is a more concrete experience of unfair treatment.] To a certain extent this still holds. We notice stigma is particularly challenging for people from some ethic cultures (Sonecha et al, 2014). The perception of stigma reduces people’s willingness to talk, making them less socially visible and less supported in learning to manage and cope. It also means that society is less aware of them, and policymakers spend less on epilepsy research than its prevalence and impact warrants (Gross et al, 1999). Arguably, if ‘felt’ stigma results in social invisibility, one consequence is that society ‘enacts’ stigma by allocating less resources for services for people with epilepsy.

The government estimates it spends £175 million per annum on the identification of those at risk from cervical cancer in primary care, referral for monitoring to secondary care and, since the year-on-year expenditure to manage and cope. It also means that society is less aware of them, and policymakers spend less on epilepsy research than its prevalence and impact warrants (Gross et al, 1999). Arguably, if ‘felt’ stigma results in social invisibility, one consequence is that society ‘enacts’ stigma by allocating less resources for services for people with epilepsy.

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Further reading

Judiciary of Scotland (2011). ‘Fatal Accident Inquiry into the deaths of Erin Casey and Christina Fiorelli Ilia’. In: Judiciary (ed)
Kruuner BL et al (2014). ‘Characteristics of epilepsy patients and caregivers who either have or have not heard of SUDEP’. Epilepsia, (Vol 55, Issue 10) pp. 1,486–94.