Premature mortality and avoidable deaths in epilepsy

Epilepsy Society, March 2016

New research from a 25-year longitudinal study on epilepsy mortality has reinforced the strong link between epilepsy and premature death. Epilepsy Society will call on government to tackle avoidable premature death in people with epilepsy by identifying the weaknesses in aspects of health services that may contribute to avoidable premature death. We will call on the Government to commission a National Clinical Audit into all epilepsy-related deaths and to implement a target for the Department of Health to eradicate avoidable deaths.

Epilepsy mortality data

The National General Practice Study of Epilepsy (NGPSE), published in January 2016, was a 25-year cohort analysis of 558 people having recurring unprovoked seizures. 189 (34%) of the cohort died during the 25 year “follow-up” period and the research focused primarily on the “underlying and immediate causes of death and their relationship to epilepsy etiology.”

The study concluded that only 6 people in this group (3%) had died directly due to their epilepsy; however it strongly emphasised the relationship between epilepsy and other long-term conditions. While there has been a lack of analysis and understanding of this relationship in the past, recent research has highlighted the prevalence of a number of long-term conditions in people with epilepsy.

Around half of people with epilepsy have accompanying long-term conditions. Psychiatric conditions are particularly prevalent, as an estimated 41% of people with epilepsy have depression, anxiety or other psychiatric syndromes. Other common accompanying conditions include dementia, heart disease, stroke, peptic ulcers and arthritis. These conditions are up to eight times more common in people with epilepsy than in the general population.

The NGPSE found a consistent link between epilepsy, common accompanying conditions and premature death. The study concluded that in 23% of cases, the cause of death - for example brain tumour or stroke - was also the cause of the person’s epilepsy. This was the case for 58% of people dying within 2 years of their “index seizure”. The study also confirmed that the risk of premature death is two to three times higher in people with epilepsy than in the general population.

*The “index seizure” is the seizure which led to the patient seeking the attention of a GP.

National Sentinel Audit 2002

The 2002 National Sentinel audit researched 2412 deaths within a 12-month period where epilepsy was mentioned on the death certificate. The expert panel which compiled the report considered that 39% of epilepsy deaths were avoidable. They also concluded that there were deficiencies in care for 54% of adults where epilepsy was the probable cause of death.

The specific deficiencies were also examined. The findings underline the issue of inadequate access to specialist care, as this was found to be the main failing 35% of the time. The other major recurring themes were inadequate drug management (20%) and lack of appropriate investigations (13%).

Deficiencies in epilepsy care
The reasons for care deficiencies and the link to avoidable deaths found in the National Sentinel audit provide a picture that is consistent with current failings in neurology services. Epilepsy patients in secondary care are, in many cases, not receiving full and effective analysis from their doctors, causing poor care management and a lack of access to specialist care. The analysis of primary care in the audit (while less complete) found similar results regarding access, and suggested that poor communication and missed triggers for referral were at fault for deficiencies in care.

The audit also mentions “sparse evidence of structured management plans”. The Public Accounts Committee’s (PAC) recommendation that all people with neurological conditions be offered a personalised care plan by 2015 has not been met, as recent evidence suggests only 11% of people with neurological conditions (2014) and 14% of people with epilepsy (2013) have personalised care plans. This shows that a lack of individualised care continues to be a major issue.

The PAC evidence session on neurology services in 2015 found that people with epilepsy are being let down on a number of levels, primarily by the excessive time taken to diagnose; a lack of knowledge of neurology among GPs; and prohibitively long waiting times to see specialists. The committee heard that 32% of patients with neurological conditions are being re-admitted five or more times to emergency departments in the UK before seeing a neurologist.

Regional inequalities

Data collected by the Office of National Statistics (ONS) show clear disparities across England in epilepsy mortality rates and a significant variation between the best and worst areas. Someone living with epilepsy in West Yorkshire is 49% more likely to die as a result of their epilepsy than someone living in Cheshire.

Worst areas: death rates

1) West Yorkshire
2) Arden, Hertfordshire & Worcestershire
3) Thames Valley
4) Lancashire
5) Shropshire & Staffordshire

Best areas: death rates

1) Cheshire & Wirral
2) Durham, Darlington & Tees
3) Derbyshire & Nottinghamshire
4) Devon, Cornwall & the Isles of Scilly
5) Greater Manchester

What is good quality epilepsy care?

There are a number of improvements that can be made to health services to pave the way for good quality epilepsy care.

Hospital consultants, healthcare researchers and patients have consistently emphasised the need for more Epilepsy Specialist Nurses (ESNs) to improve quality and continuity of care for people with epilepsy. The work of ESNs allows more time for neurologists to see new patients and focus on the
core elements of their service. ESNs also reduce the burden on GPs who often do not have specialist knowledge of epilepsy. Research suggests that at least 60% of people with epilepsy will require ongoing access to an adult, paediatric or learning disability epilepsy specialist nurse. Despite this, Epilepsy Action’s Time for Change report in 2009 found that 60% of acute trusts and 64% of primary care trusts did not have an epilepsy specialist nurse. Anecdotal evidence suggests the overall number of ESNs across the UK to be around 250, far short of the 1100 identified as the necessary number.

The evidence available on epilepsy care in the UK shows a common trend of a lack of access and information for patients with epilepsy. Epilepsy specialist nurses help to mitigate these issues, but there are a number of other factors which contribute to high quality epilepsy care. For instance, the number of neurologists must increase if regional disparities are to be addressed and services are to improve. In London, where there is approximately one neurologist per 40,000 people, outcomes for people with epilepsy are generally better than the rest of England where there is around one per 90,000 people. In Camden, where outcomes for people with epilepsy are relatively strong, there is a six fold increase in access to neurologists compared to Doncaster, where outcomes are poor.

Additionally, two very recent studies, including the NGPSE, have emphasised the pressing need for new and validated screening instruments and guidelines to help with early detection and treatment. This relates especially to the common accompanying conditions that afflict such a high proportion of people with epilepsy. GPs must have the time and inclination to fully investigate the potential for other long-term conditions in their patients, a process which would help to ensure that crucial triggers for referral are recognised.

While the poor quality of available data on epilepsy makes best practice examples hard to identify, it would be unfair to suggest that there is a complete lack of understanding amongst commissioners and national decision-makers as to what good quality care should look like. The Public Accounts Committee’s February 2016 review on services for people with neurological conditions concluded that the quality of care is “not consistently good enough” and made six key recommendations for progress:

- NHS England to confirm how it will use new data initiatives to help CCGs and how it will hold them to account on performance
- The Department of Health to confirm how it is measuring performance against the objective that everyone with a long-term condition should be offered a personalised care plan
- NHS England to report on reducing variations in access to neurologists across England
- NHS England to retain the role of the National Clinical Director for Adult Neurology
- The Department of Health to report back on how it intends to link health and social care data, including a clear timetable for the implementation for care.data
- NHS England to confirm by April 2016 which specialised services are to be commissioned by CCGs and which by NHS England

Additionally, the NICE guidelines for epilepsy, published in 2012, present nine clear standards which, if implemented in practice, would undoubtedly lead to an improved service across the UK:

1) Adults presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within two weeks of presentation.

2) Adults having initial investigations for epilepsy undergo the tests within four weeks of them being requested.
3) Adults who meet the criteria for neuroimaging for epilepsy have magnetic resonance imaging.

4) Adults with epilepsy have an agreed and comprehensive written epilepsy care plan.

5) Adults with epilepsy are seen by an epilepsy specialist nurse whom they can contact between scheduled reviews.

6) Adults with a history of prolonged or repeated seizures have an agreed written emergency care plan.

7) Adults who meet the criteria for referral to a tertiary care specialist are seen within four weeks of referral.

8) Adults with epilepsy who have medical or lifestyle issues that need review are referred to specialist epilepsy services.

9) Young people with epilepsy have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.

NICE guidance also directs healthcare professionals to provide information on the risks of premature death to their patients with epilepsy. This is noted particularly in respect to SUDEP\textsuperscript{1}, which accounts for around half of all epilepsy deaths in the UK. The guidance advises that those caring for people with epilepsy, “take account of the small but definite risk of SUDEP when tailoring information and discussions.”\textsuperscript{xvi}

Healthcare professionals are also advised to contact affected families to “offer condolences, invite them to discuss the death, and offer referral to bereavement counselling and a SUDEP support group.”

SUDEP Action created the Epilepsy Deaths Register in 2013: a valuable resource which will help healthcare professionals better understand the causes of epilepsy-related deaths and aim to reduce future risk for those with the condition. Those who have been affected by an epilepsy-related death can contribute to the epilepsy deaths register at \url{https://epilepsydeathsregister.org/en} and can also contact the team at SUDEP Action for bereavement and counselling services (\url{www.sudep.org} or 01235 772850).

\textbf{Our policy aim}

Epilepsy Society will ask the Department of Health to commission a new National Clinical Audit on all epilepsy deaths in the UK. We are calling for this action to enable national health decision-makers to understand the magnitude of premature death for people with epilepsy and the factors that contribute to avoidable deaths. We will expect the Government to act on the findings of this report and aim to \textbf{eliminate all avoidable deaths for people with epilepsy}.

The only data currently available for avoidable deaths is from information gathered over 15 years ago (in the National Sentinel audit). In order to eliminate avoidable deaths, we must be able to measure these. A new national audit should be able to tell us:

\textsuperscript{1} SUDEP is “sudden unexpected death in epilepsy”.
a) Whether there has been any reduction in the number of avoidable epilepsy deaths
b) Whether the likely reasons for these deaths are still the same
c) Whether there are unacceptable regional variations in death rates.

The audit will provide a spur for action by clinical commissioning groups.

A new national audit on all epilepsy-related deaths should also provide a useful data set which would at least partly compensate for the dearth of statistics currently collected on epilepsy. A decision was made to retire two Quality and Outcomes (QOF) indicators for epilepsy after 2013/14, leaving only the incentive for practices to keep a list all patients with epilepsy.

The best data currently available for the condition has been collated and presented effectively by the Neurology Intelligence Network (NIN) via Public Health England’s “Public Health Profiles”. Unfortunately, DH is yet to confirm that this work will be funded beyond March 2016. Expert witnesses at the PAC evidence session in 2015 explained how a lack of detailed and consistent information is preventing commissioners from understanding the service needs of the population with epilepsy and other neurological conditions, and from recognising whether or not services are actually improving outcomes.

Another strength of NIN’s epilepsy profile is the ability for users to compare data between CCGs, and geographically by region, sub-region, strategic care network etc. The 2002 Sentinel audit did not provide any geographical analysis of quality of care relating to epilepsy deaths, but given the considerable disparities highlighted in recent data, our hope is that a new audit would take on an expanded remit to such an analysis in order for this information to remain up-to-date and publically available.

If a new national audit finds similar results to the 2002 study, this should lead to a renewed effort from the Department of Health to ensure quicker access to neurologists and ESNs, a greater focus on individualised care for patients with epilepsy, and an overall improvement in the quality of epilepsy services in the UK.

Data limitations

There are some limitations with the research drawn on for this report. For example, the data used in the National sentinel study is ultimately drawn from a small focus group. The national audit looked at all 2,412 deaths in a 12-month period between 1999 and 2000 for which epilepsy was mentioned on the death certificate. However, once the deaths were narrowed to cases where epilepsy was the probable cause of death, patients had been referred to secondary care, and where notes were available, the results were drawn from a total pool of 158 people.

The number of avoidable deaths was 62 of 158 (39%), and there were deficiencies in care for 85 of the same 158 people (54%).

Avoidable deaths were classified as “potentially” and “probably” avoidable. The expert panel concluded that the audit did not provide a definite and direct link between deficiencies in care and avoidable death, but it provided “important findings about shortcomings in care that may have contributed to a substantial number of potentially avoidable deaths.” The panel expanded further on the issue:
Although it is not possible to establish in each case whether a death was definitely avoidable, the panel assessed on the balance of probabilities whether deaths were likely to have been avoidable after reviewing the risk profile of each patient that died and overall seizure management.

The panel also concluded that for those whose care was found to be inadequate (85 people), death was unavoidable in 11 (14%), potentially avoidable in 44 (54%), probably avoidable in 8 (10%) and unclear in 18 (22%).

References


