Certification of deaths attributable to epilepsy

Y Langan, L Nashef, J W A S Sander

Objective: To estimate the number of sudden unexpected epilepsy deaths occurring annually in England and Wales in those 16–50 years of age.

Methods: All 1997 death entries mentioning epilepsy as a cause of death in those 16–50 years were examined and classified as sudden unexpected death in epilepsy (SUDEP), other epilepsy related deaths, or non-epilepsy deaths.

Results: 612 death entries were obtained with postmortem examination having been performed in 498 cases. Forty four deaths were certified as being attributable to SUDEP and a further 292 deaths were considered to be probable SUDEP cases.

Conclusion: It is estimated that between 350 and 400 cases of SUDEP occurred in England and Wales in 1997 in those 16–50 years. SUDEP is the commonest category of epilepsy related death and accurate certification of such deaths is vital for the monitoring of trends in mortality.

RESULTS

Altogether 612 death entries were received relating to 397 men and 215 women with a median age of 35 years.

Only death certificates relating to those ages 16 to 50 years were requested. A total of 498 (81%) people had undergone postmortem examination. Forty four death entries stated that the cause of death was sudden unexpected death in epilepsy and a further 292 deaths were considered probable SUDEP. Sixty nine deaths were certified as being attributable to status epilepticus. There were a further 71 epilepsy related deaths with 136 deaths deemed unrelated to epilepsy.

Of the 50 death entries chosen at random 38 people had undergone postmortem examination. Thirty five postmortem reports were received from coroners and details are shown in table 1.

Of the 69 deaths certified attributable to status epilepticus 40 (58%) had undergone postmortem examination and necropsy reports were obtained in 23 of these cases. In 19 (83%) of these cases the coroner’s officers’ and postmortem reports indicated that there was no evidence of documented status epilepticus and that the case would be more appropriately classified as SUDEP. Taking into consideration the observation that sudden unexpected deaths, including SUDEP cases, often undergo necropsy in the UK, these figures suggest that nearly half of cases certified as status epilepticus are more appropriately classified as SUDEP. In three of the remaining four cases evidence supported a classification of status epilepticus and in one further case although there was no documented status epilepticus the person concerned had a congenital heart defect and death could not be reliably reclassified as SUDEP.

DISCUSSION

Thus, if we consider the rare false positive rate (1 of 35 or 2.9% among the random subgroup) among the 336 cases we classified as SUDEP, and the significant false negative rate among
other cases particularly the 69 status certified cases, we conclude that about 360 SUDEP cases occurred in England and Wales in 1997 in those 16–50 years. This confirms that SUDEP is the commonest category of epilepsy related death. We did not request death certificates on those who, in England and Wales in 1997, died less than 16 or greater than 50 years of age, there were 69 deaths in the age group 0–19 years certified as being attributable to epilepsy and 285 among those aged greater than 50 in England and Wales during 1997. It is possible that deaths attributable to epilepsy were not certified as such and therefore not included in this study.

For the most part, we interpreted death entries correctly, with the postmortem report only changing our classification in three of the 35 cases classified as SUDEP where such reports were received. The certification of cause of death as attributable to status epilepticus remains problematic, with false positive and less frequent false negative certificates. We would suggest that deaths only be certified as being attributable to status epilepticus if there is a documented history of uncontrolled fitting. A high proportion of deaths that are attributable to status epilepticus are SUDEP cases, especially where such deaths have been referred to the coroner. The mid-2000 population of England and Wales in the 16–50 age group was 25.64 million. The prevalence of epilepsy is 0.5%–1%6 and as there were about 360 sudden epilepsy deaths in this age group the incidence of SUDEP is therefore 1.356 to 1.712 comparable to the rates found in other studies. While this provides a population based estimate of the incidence of SUDEP it only applies to the age groups studied, which are generally considered of higher risk.

Correct certification of epilepsy deaths is vital both for accurate data on SUDEP and other epilepsy related deaths and to allow for the monitoring of trends in mortality.

**Table 1** Our classification of deaths in random subgroup of 38 cases before and after PM report

<table>
<thead>
<tr>
<th>Cases (n)</th>
<th>Death certified as Before</th>
<th>After</th>
</tr>
</thead>
<tbody>
<tr>
<td>18</td>
<td>1a epilepsy</td>
<td>probable SUDEP</td>
</tr>
<tr>
<td>2</td>
<td>1a SUDEP</td>
<td>probable SUDEP</td>
</tr>
<tr>
<td>2</td>
<td>1a epileptic seizure</td>
<td>probable SUDEP</td>
</tr>
<tr>
<td>1</td>
<td>1a epilepsy</td>
<td>probable SUDEP</td>
</tr>
<tr>
<td>1</td>
<td>1b head injury</td>
<td>probable SUDEP</td>
</tr>
<tr>
<td>1</td>
<td>1a asphyxia</td>
<td>probable SUDEP</td>
</tr>
<tr>
<td>1</td>
<td>1b epilepsy</td>
<td>probable SUDEP</td>
</tr>
<tr>
<td>1</td>
<td>1a respiratory failure</td>
<td>probable SUDEP</td>
</tr>
<tr>
<td>1</td>
<td>1a epilepsy</td>
<td>probable SUDEP</td>
</tr>
<tr>
<td>1</td>
<td>1b cerebral aneurysm (operated)</td>
<td>status epilepticus</td>
</tr>
<tr>
<td>1</td>
<td>1a bronchopneumonia</td>
<td>status epilepticus</td>
</tr>
<tr>
<td>2</td>
<td>1a status epilepticus</td>
<td>status epilepticus</td>
</tr>
<tr>
<td>1</td>
<td>1a status epilepticus</td>
<td>status epilepticus</td>
</tr>
<tr>
<td>2</td>
<td>1a aspiration</td>
<td>aspiration</td>
</tr>
<tr>
<td>2</td>
<td>1a drowning</td>
<td>drowning</td>
</tr>
<tr>
<td>1</td>
<td>1a ischaemic heart disease</td>
<td>non-epilepsy death</td>
</tr>
<tr>
<td>1</td>
<td>1 epilepsy</td>
<td></td>
</tr>
</tbody>
</table>

**REFERENCES**

Certification of deaths attributable to epilepsy

Y Langan, L Nashef and J W A S Sander

*J Neurol Neurosurg Psychiatry* 2002 73: 751-752
doi: 10.1136/jnnp.73.6.751

Updated information and services can be found at:
http://jnnp.bmj.com/content/73/6/751

These include:

**References**

This article cites 7 articles, 2 of which you can access for free at:
http://jnnp.bmj.com/content/73/6/751#BIBL

**Email alerting service**

Receive free email alerts when new articles cite this article. Sign up in the box at the top right corner of the online article.

**Topic Collections**

Articles on similar topics can be found in the following collections

- Epilepsy and seizures (846)

**Notes**

To request permissions go to:
http://group.bmj.com/group/rights-licensing/permissions

To order reprints go to:
http://journals.bmj.com/cgi/reprintform

To subscribe to BMJ go to:
http://group.bmj.com/subscribe/