Sudden unexpected death in epilepsy (SUDEP): don’t ask, don’t tell?

B Morton, A Richardson, S Duncan

Background: The National Institute for Clinical Excellence in the UK has issued guidelines stating all individuals with epilepsy be given information about sudden unexpected death in epilepsy (SUDEP). Methods: We conducted a survey of current practice among UK neurologists, using a questionnaire sent to all practising neurologists in the UK listed on the Association of British Neurologists database, asking under what circumstances they told patients about SUDEP. Results: Of the validated respondents, 5% discussed SUDEP with all patients, 26% with a majority, 61% with a few, and 7.5% with none. The commonest reasons for SUDEP to be discussed were the patient asking about it and the neurologist counselling people with known risk factors for SUDEP. Conclusions: The variation we found, although not necessarily in tune with the guidelines, reflects the variation in patients’ need for knowledge about their condition.

RESULTS
Quantitative data
In total, 738 questionnaires were posted, of which 387 were returned. Of these, 288 were completed by consultant neurologists. As there are approximately 350 consultants in the UK, this represents 82% of the consultant body and 74% of all respondents. In addition, 63 specialist registrars (SpRs) responded, approximately 19% of trainees. The remainder comprised associate specialists, consultants in other specialties who run epilepsy clinics, and specialist nurses. Those who had attained consultant status (that is, were in possession of Central Consultants and Specialists Committee membership or equivalent) were included in the consultant neurologist group for analysis. Of the respondents, 120 (31%) stated a special interest in epilepsy.

Only 18 (4.7%) of respondents discussed SUDEP with all of their patients (table 1). The \( \chi^2 \) analyses of the data are shown in table 2. Half the respondents discussed SUDEP in only one clinical scenario others were prompted by a number of different patient circumstances (table 3).

*Number who did not reply to question.

Year of qualification (date of MB, ChB or equivalent), had no effect on whether the neurologist discussed SUDEP or not, and there was no difference in responses between registrars and consultants (table 1). Knowing about SUDEP was not thought by 47% of respondents to have any effect on patients’ quality of life. A third of respondents thought information about SUDEP caused anxiety. Most respondents (80%)

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Analysis of response from medical personnel</th>
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<tbody>
<tr>
<td></td>
<td>n</td>
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<tr>
<td>Discuss SUDEP with all patients</td>
<td>18</td>
</tr>
<tr>
<td>Discuss with majority of patients</td>
<td>99</td>
</tr>
<tr>
<td>Discuss with very few of my patients</td>
<td>237</td>
</tr>
<tr>
<td>Discuss with none of my patients</td>
<td>29</td>
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<tr>
<td>Total no. of respondents</td>
<td>383</td>
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<tr>
<td>Missing data*</td>
<td>4</td>
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</tbody>
</table>

*Four responses not analysed.

Abbreviations: NICE, National Institute for Clinical Excellence; SIGN, Scottish Intercollegiate Guidelines Network; SpR, specialist registrar; SUDEP, sudden unexpected death in epilepsy.

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thought patients did not understand the relative risks of SUDEP compared with smoking 20 cigarettes per day or the risk of developing lung or breast cancer. Interestingly, a majority reported they did not think informing patients about SUDEP improved drug compliance or to avoidance of risk factors for SUDEP.

Respondents who stated a special interest in epilepsy were significantly more likely to tell patients about SUDEP. Doctors who discussed SUDEP with all or the majority of their patients were significantly less likely to report negative reactions from patients than those who did not (table 1).

Qualitative responses
Respondents were asked to record their experiences/opinions and suggestions about practice in this area (tables 4 and 5).

Table 3 Reasons for discussing SUDEP

<table>
<thead>
<tr>
<th>(Only) if patient asks</th>
<th>Spontaneously at time of diagnosis</th>
<th>When initiating AED therapy</th>
<th>Spontaneously at subsequent appointment</th>
<th>Only in patients with recognised risk factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. of respondents who discussed SUDEP in one or more clinical scenario</td>
<td></td>
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<tr>
<td></td>
<td>60</td>
<td>15.7</td>
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<td>42</td>
<td>10.9</td>
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<td>17</td>
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<td>0.3</td>
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<tr>
<td>Total</td>
<td>178</td>
<td>46.4</td>
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</table>

Table 4 Responses to the question “If you do discuss SUDEP with your patients when do you do so?”

| Variable, sometimes spontaneously and always if asked |
| When asked and when I think it is appropriate, although it is always a subjective assessment |
| If refused treatment |
| If not compliant with treatment |
| To help patients decide they should go on treatment |
| If there are problems with adherence to treatment that are putting the patient at increased risk |
| If patient is considering the option of no treatment |
| Risk act for non-compliance |
| Those patients with frequent attacks who decline drug therapy |
| If the patient asks generally what the risks of epilepsy are |
| Since I qualified in 1969, none of my patients have died of SUDEP. I see children and adolescents with special educational needs. None of them or their parents has ever asked about SUDEP |
| I discuss that epilepsy is dangerous and death can result. I do not state that if they have it they are at risk of death immediately and at any time |
| If another member of the family/friend has been a victim of SUDEP |
| Difficult to say, but when it feels appropriate—that is, patient led |

There were 299 respondents who wrote comments in the “how do patients react?” question box, of which 275 could be assigned to the “positively”, “with equanimity”, and “negatively” groups. The remainder were comments that could not be assigned, for example “difficult to tell”.

DISCUSSION
As 82% of consultant neurologists in the UK replied to our survey, we have obtained a representative picture of how neurologists practise in this area. Other specialties in the UK such as psychiatry and medicine for the elderly also care for people with epilepsy, and practice may be different in those fields.
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be told they could die because of epilepsy, then it would be
information on SUDEP should be imparted. If patients are to
would appear that many neurologists were led by their
clinical scenario were prompted most often by the patient
SUDEP (16%). Those who discussed SUDEP in more than one
SUDEP because of a wish not to cause distress or as a way of
served to inhibit these doctors from frequent discussion of
This may reflect familiarity with NICE or the Scottish
statistically more likely to discuss SUDEP with patients.
In my limited experience I can distinctly recall one young woman with
epilepsy well controlled on monotherapy who was extremely
distressed and resentful that SUDEP was discussed during her first
consultation
I recently saw a young man with multiple sclerosis and a
neurologist who was discussing SUDEP. He was surprised to
learn that the patient was not aware of SUDEP.

Our study suggests that the majority of neurologists in the
UK are not following the NICE guidelines. It does not
necessarily mean that patients are ignorant of SUDEP. There
are many sources of information now available, most notably
patient groups and the internet, but it implies that many
neurologists do not feel this information is something all
patients need to know.

Neurologists with a special interest in epilepsy were
statistically more likely to discuss SUDEP with patients. This
may reflect familiarity with NICE or the Scottish
Intercollegiate Guidelines Network (SIGN), the influence of
patient advocacy groups, or a patient population that is more
likely to ask about SUDEP. These neurologists were also
significantly less likely to report negative reactions. This
might be explained by a practice effect, with those
neurologists who frequently discuss SUDEP being more at
ease with the topic, or patients who have already heard about
the phenomenon being prepared for the information.
Neurologists who only discussed SUDEP in a minority of
cases were significantly more likely to report negative
reactions. Emotive terms such as “terrified”, “acute distress”,
and “catastrophic” were used. Such reactions may have
served to inhibit these doctors from frequent discussion of
SUDEP because of a wish not to cause distress or as a way of
protecting their own emotional state.

Practitioners were equally divided between those who only
discussed SUDEP in one of the clinical scenarios put to them
and those who did so in more than one clinical situation. The
commonest single scenario was if the patient asked about
SUDEP (16%). Those who discussed SUDEP in more than one
clinical scenario were prompted most often by the patient
asking or a patient having risk factors for SUDEP (16%). It
would appear that many neurologists were led by their
patients’ request for information.

NICE gives no guidance on how, when, and by whom
information on SUDEP should be imparted. If patients are to
be told they could die because of epilepsy, then it would be
useful to put that risk in context. There is a striking lack in
NICE/SIGN and the literature of league tables of relative risks
to enable patients to see what their chances of succumbing to
SUDEP are compared with a fatal road traffic accident,
myocardial infarct, or common cancers. One recent paper has
produced estimated years of lost life expectancy in a table
format. A man aged 20 years with idiopathic epilepsy has,
according to the authors, a 9 month reduction in life
expectancy. Some would question what use this information
would be to a patient. Another study concluded that as the
main risk factors for SUDEP, such as male sex, need for
polyparmacy, and having a localisation epilepsy are impos-
sible to modify, information on SUDEP should be targeted at
this group.

Medical opinion leaders and patient advocates maintain
people must be given as much information as possible, and
that guidelines will cover all medical contingencies. This
stance denies the patient the right not to know, and
undermines the physician’s ability to treat patients as
individuals. One in depth examination of the information
needs of patients with Parkinson’s disease identified three
equally sized patient groups: “seekers”, who needed infor-
mation and found ignorance unbearable; “weavers”, who
incorporated information into their lives at their pace, often
ignoring much of it; and “avoiders”, who found more than the
minimum of information a threat to their overall sense of
wellbeing. A broadly similar pattern is seen in cancer
patients, with patients differing markedly in the quantity
and type of information they want, and a small but
significant number stating they do not want to be told they have
an incurable or terminal illness.

The variation in neurologists’ practice in respect of SUDEP,
although out of tune with the current vogue for medicine by
guidelines, reflects what every doctor knows: that patients
differ vastly in their need for information. To our knowledge,
there have been no studies of the impact of telling patients
about SUDEP. In the whole SUDEP debate, the voice of the
individual patient has been absent. Perhaps when such
studies are undertaken, we will discover that Ruth Pinder’s
conclusions about Parkinson’s disease patients hold true for
other neurological conditions:

“knowledge of what the clinical facts mean is not always
the priceless resource other writers suggest. Sometimes it is
too threatening.”

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REFERENCES

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2 Langan Y. Sudden unexpected death in epilepsy (SUDEP): risk factors and
Focal splenial hyperintensity in epilepsy

A 13 year old boy presented with complex partial epilepsy of 10 years duration with a seizure frequency of 1–2 per month and one recent episode of secondary generalisation. Clinical and video EEG localisation was towards the right parieto-temporo-occipital region. Brain MRI scan done 5 years previously was reported as normal. He was on treatment with carbamazepine with no clinical evidence for drug toxicity. MR imaging showed a focal hyperintensity of the splenium of corpus callosum on T2 weighted sequences with evidence of cytotoxic oedema on diffusion weighted imaging (fig 2C, D). Various mechanisms have been proposed for this rare, transient MR finding in epilepsy, including drug toxicity, vasogenic oedema, and vitamin deficiency. However, cytotoxic oedema due to excitotoxicity appears to be the more likely cause as demonstrated by diffusion imaging.

References


Figure 1  (A) T1 weighted axial SE; (B) T2 weighted axial FLAIR; (C) Coronal T2 fast SE; (D) Coronal FLAIR. Note the well defined focal hyperintensity in the splenium of corpus callosum on T2 weighted images, which is hardly visible on T1.

Figure 2  Sagittal FSE (A) and high resolution axial (B) T2 weighted images demonstrate the hyperintense signal through the centre of the splenium. On the axial diffusion weighted image the lesion appears hyperintense (C) and the corresponding ADC map shows hypointensity (D) (arrow) suggesting cytotoxic oedema as the cause of T2 hyperintensity.
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