



*National Institute for
Clinical Excellence*

**National Clinical Audit of
epilepsy-related death**

Contents

1 Background	3
2 Audit methods	4
3 Findings	6
4 Discussion	12
5 Further action	13
References	14
Details of full report	15

The National Institute for Clinical Excellence commissioned Epilepsy Bereaved to produce a national audit report on epilepsy-related death in England and Wales in 1999. The audit was subsequently extended to cover Scotland and Northern Ireland. The report has been subjected to validation and consultation with stakeholders.

This summary report presents key aspects of the audit methods, findings and conclusions. Participating organisations in the audit included the International League against Epilepsy (British Branch), the Royal College of General Practitioners, the Royal College of Nursing, the Royal College of Paediatrics and Child Health, the Royal College of Pathologists and the Royal College of Psychiatrists (Learning Disability Faculty). The full report is available from the Epilepsy Bereaved website, www.sudep.org.



1 Background

Epilepsy, meaning a tendency to have recurrent seizures, is the most common serious neurological condition. At any one time between 1 in 140 and 1 in 200 people in the UK (at least 300,000 people) are being treated for epilepsy^{1,2}. Each year, in a community of 250,000 people between 125 and 200 will develop epilepsy³.

People with epilepsy have a risk of premature death that is 2–3 times higher than in the general population⁴. Most premature deaths among people with epilepsy are directly related to the epilepsy itself. Every year in the UK about 1000 people die because of epilepsy, and most of these deaths are associated with seizures. Sudden unexpected death in epilepsy or SUDEP (Box A) is the principal cause of seizure-related death in people with chronic epilepsy and has been estimated to account for about 500 deaths each year. Young adults are most at risk of SUDEP, and most deaths occur at home. Although it is not entirely clear what causes SUDEP, the most important risk factor is the occurrence of seizures – the more frequent the seizures, the higher the risk⁵.

A. What is SUDEP?

“SUDEP is the sudden, unexpected, witnessed or unwitnessed, nontraumatic and nondrowning death in patients with epilepsy, with or without evidence for a seizure, and excluding documented status epilepticus, in which post-mortem examination does not reveal a toxicological or anatomic cause for death.”⁶

Most people with epilepsy (up to 70%) have the potential to be seizure-free. The latest Chief Medical Officer’s report points out that despite five government reports over a 50-year period drawing attention to the neglect of epilepsy, there has been little action⁷. Another problem is the inconsistency with which the causes of death in people with epilepsy are reported – this may be due to a lack of awareness of epilepsy-related death among clinicians, coroners and pathologists^{8,9}.

National Clinical Audit of Epilepsy-related Death

© National Institute for Clinical Excellence May 2002. All rights reserved. This material may be freely reproduced for educational and not for profit purposes within the NHS. No reproduction by or for commercial organisations is permitted without the express written permission of the Institute.

First published in May 2002

ISBN: 1-84257-173-7

For further copies please call the order line on 0870 1555 455 and quote reference: N0101

National Institute for Clinical Excellence, 11 Strand, London WC2N 5HR www.nice.org.uk

Designed by Westhill Communications Printed by Abba Litho

2 Audit methods

2.1 Introduction

The National Sentinel Clinical Audit of Epilepsy-related Death – reported in summary here – was the result of a call for a confidential enquiry into epilepsy-related deaths. The aim was to establish whether deficiencies in the standard of clinical management, or in the overall healthcare package, could have contributed to the deaths.

Two key areas were reviewed:

- investigations into the deaths (pathology)
- general practice (primary) and hospital-based (secondary) care.

The audit was developed using a structured approach (Box B) involving multiprofessional and lay groups. The audit team reviewed the official records of individuals who died from an epilepsy-related death in the UK between September 1999 and August 2000. During that time, 2412 deaths were reported where epilepsy was mentioned somewhere on the death certificate.

2.2 Audit of investigation of death

Of the 2412 deaths with epilepsy mentioned on the death certificate, 1023 were subject to post-mortem and 1389 were not.

For the audit of investigation of death, records were examined for 439 (43%) of the 1023 deaths for which there were post-mortem records and for 156 of the 1389 (11%) deaths for which there were no post-mortem records (see Box C).

In the pathology audit the areas examined were: background, post-mortem examination, further investigations and cause of death. This information was collected from post-mortem reports and coroner's officer and police reports.

B. How was the audit developed?

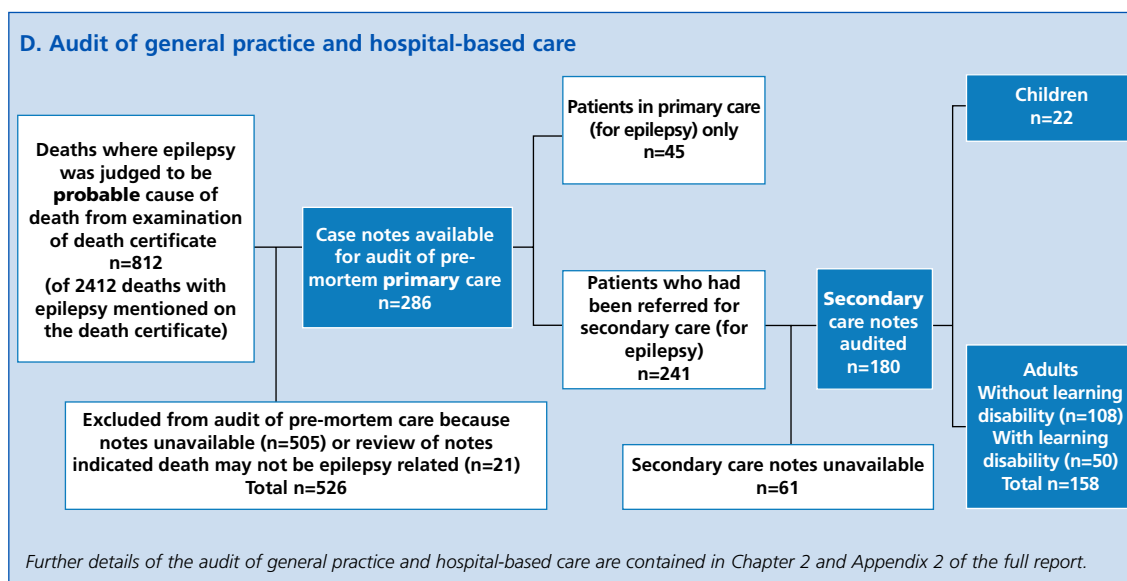
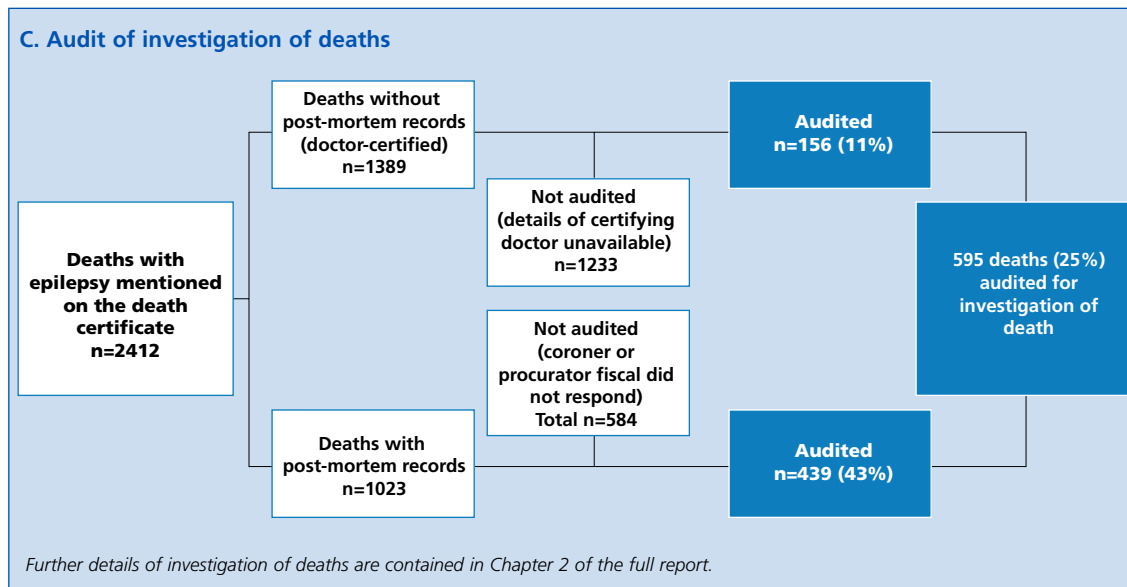
A steering group provided overall guidance; an executive committee planned and monitored audit activity; an audit officer and five nurses (fieldworkers) identified cases and collected data.

Criteria for standards of care in pathology and primary and secondary care were identified using published guidelines (including references 10–13), literature searches and the views of expert panels in these three areas. Audit tools were developed, and data were collected and analysed.

Panels of experts for review of the audit findings were drawn from pathology, primary care and secondary care to reflect the views of clinicians with a particular interest in epilepsy care (panel membership is listed in appendix 1 of the full report).

The audit report was distributed to policymakers and stakeholders to provide strategic guidance for the prevention, investigation and management of epilepsy deaths.

Full details of the methods used for the audit are presented in the full report which is available from the Epilepsy Bereaved website (www.sudep.org). Copies of the audit tools and criteria are available from Epilepsy Bereaved.



2.3 Audit of general practice and hospital-based care

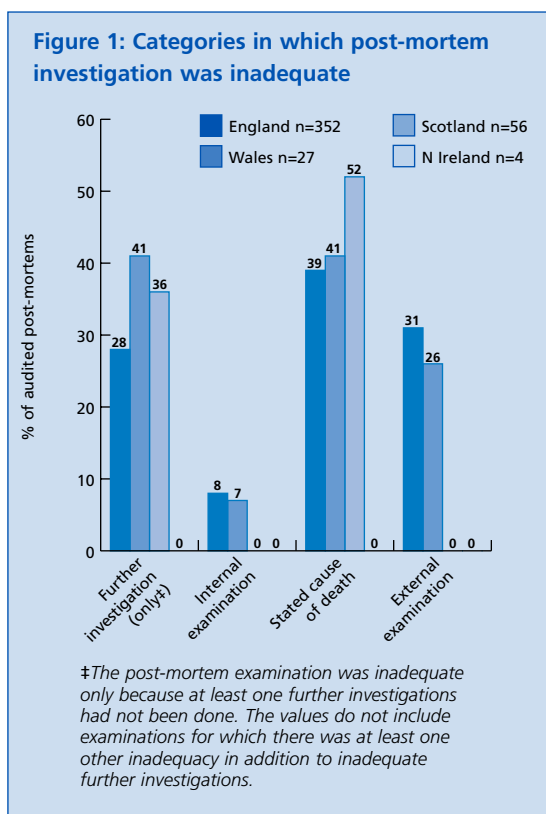
For the audit of care before death, a total of 286 primary care case notes and 180 secondary care case notes were examined. (For more details of the cases audited, see Box D.)

In the audit of general practice and secondary care the areas examined were: access to care and clinical assessment, investigations, drug treatment, non-drug therapies, continuing care, information and support, and communication between professionals and services.

3 Findings

3.1 Investigation into the deaths

Many (87%, 383/439) of the deaths involving a post-mortem were considered to have been inadequately investigated. Figure 1 shows the categories in which post-mortem investigation was inadequate. Because deaths were not appropriately or adequately investigated it was difficult to establish the true number of epilepsy-related deaths.



3.1.1 Stated cause of death

Whether or not a post-mortem was carried out, the cause of death stated was inconsistent and, in some cases, inappropriate. Of the 156 deaths certified without post-mortem, 39 were certified as due to epilepsy. Of these 38% (15/39) were

sudden and/or unwitnessed and should have been subject to post-mortem. The cause of death was inadequately stated in 41% (178/439) of deaths involving a post-mortem. The main findings in reporting the cause of death were as follows.

- Phrasing of the cause of death. This was very variable (Box E). 'SUDEP', which is a term that has been in use since 1997, was cited in 9% (54/595) of audited cases.
- A cause was often cited (e.g. asphyxia, aspiration of stomach contents, status epilepticus) despite a lack of pathological evidence.
- In some cases, every medical condition the person had was listed on the death certificate, even where this had not contributed to the death.

E. Some of the terms used to describe the cause of death

- *Epilepsy*
- *Epileptic seizure*
- *Status epilepticus*
- *Sudden adult death syndrome (SADS)*
- *SUDEP*
- *Unascertained*

3.1.2 Further investigations

Further investigations (Box F) were not carried out or were not standardised. 86% (377/439) of post-mortems did not include all further investigations listed in Box F; 30% (130/439) of post-mortems were inadequate only because one further investigation had not been done. These investigations are important to eliminate other potential causes of death.

F. 'Further investigations' carried out during post-mortem

- *Toxicology – blood analysis for alcohol and drugs*
- *Histology – microscopic examination of small pieces of major organs*
- *Neuropathology – specialist examination of brain and nervous system*

3.1.3 External and internal examinations

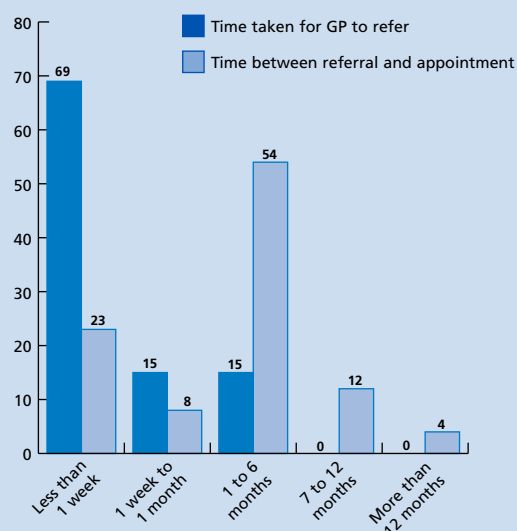
In a minority of deaths the external or internal examination part of the post-mortem was considered inadequate (27% [117/439] of external examinations and 7% [29/439] of internal examinations).

3.2 Audit of general practice and hospital-based care

3.2.1 Referral for specialist care

- After a first seizure, individuals are normally referred to secondary care by their GP. Of the 286 people whose GP case notes were audited, 84% (241/286) had been referred.
- The referral process was analysed for people whose epilepsy was diagnosed recently (that is, within 5 years before death; n=47). Information on waiting times was available for 26 of these individuals. Of these, 69% (18/26) had been referred within 1 week; but for 15% (4/26) it had taken between 1 and 6 months to be referred by their GP. Waiting times for a specialist appointment were long, with 15% (4/26) of individuals having to wait more than 6 months (Figure 2).

Figure 2: Time from seeing GP to appointment

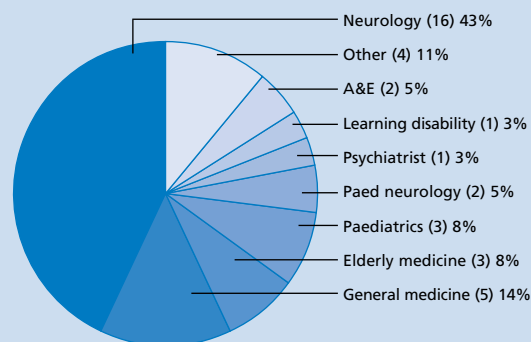


Data are for 26 patients whose epilepsy was diagnosed in the 5 years before death and for whom information on waiting times was available.

3.2.2 Referral specialty

- Referral should be to a specialist with an interest in epilepsy¹². Just under half (18/37) of individuals diagnosed in the 5 years before death were initially referred to an adult or paediatric neurologist (Figure 3).

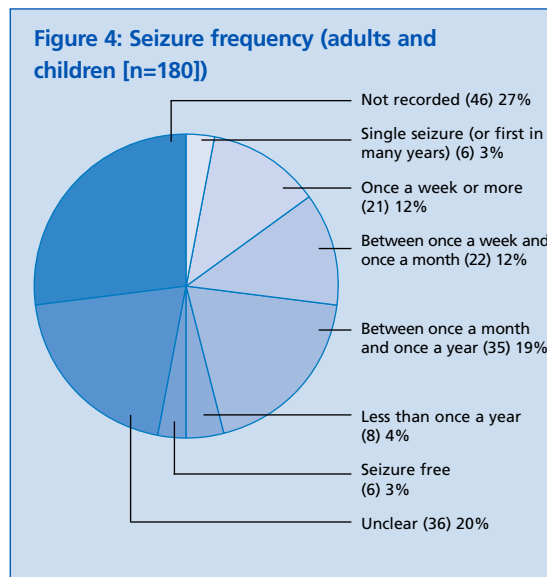
Figure 3: Chosen specialty for initial referral



- There was documented evidence that 80% (127/158) of the adults and 77% (17/22) of children whose secondary care notes were audited had seen a consultant at some time during their secondary care. The case notes indicated that 66% (91/138) of all adults seen in outpatients had seen a neurologist at any of their last three appointments; 35% (7/20) of all children seen in outpatients had seen a paediatric neurologist at any of their last three appointments.

3.2.3 Seizure status

- Of the people whose deaths were included in the audit of secondary care 3% (6/180) were recorded as seizure-free at their last hospital appointment (Figure 4).



- None of the 22 children whose secondary care notes were audited were known to be seizure-free in the year before they died.
- In 47% (74/158) of adults and 36% (8/22) of children whose secondary care case notes were audited, seizure frequency had either not been recorded or was unclear.
- Primary care notes indicated 11% (26/241) of individuals referred to secondary care had evidence of an increase in seizure activity in the 3 months before death.

3.2.4 Re-referral

- The audit of all of the primary care case notes showed a lack of re-referral by the GP for individuals fulfilling the criteria for re-assessment. Among the 241 individuals receiving combined GP/specialist care, the GP notes suggested that 28% (68/241) fulfilled the criteria for re-referral. Of these 68, 9% (6) were re-referred. Although four individuals receiving all of their care through the GP had a change in seizure frequency, none was referred.

3.2.5 Hospital visits

- 37% (54/147) of adults who were not recorded as being seizure-free had not been seen in the year before they died.
- Around 15% (23/158) of adults had missed at least one of their last three appointments but there was no standard way in which these missed appointments were managed. Of the 23 adults who had missed at least one appointment, 57% (13/23) had been sent at least one further appointment and 30% (7/23) were not sent any further appointments; it was unclear what action had been taken in 13% (3/23) cases.
- All children were seen in secondary care in the year before death.

3.2.6 Transfer from paediatric to adult care

- Three of 50 (6%) adults with learning disability had been lost to follow-up in the transfer from paediatric to adult care.

3.2.7 Clinical assessments

- Documentation of clinical assessments was variable throughout primary and secondary care. Many details were lacking in relation to:
 - classification of seizure type and syndrome
 - seizure triggers
 - drug treatment issues
 - non-drug therapies.

3.2.8 Hospital investigations

- Secondary care notes did not report a scan for 57 adult patients (57/158, 36%) – at least 19 of these should have had one according to existing guidance^{11,12}.
- There was no documented report of an EEG for 51 (32%) adult patients – at least 22 of these should have had one because they were aged under 25 at the age of diagnosis¹².
- No brain scan or EEG was documented for seven (32%) of the 22 children whose secondary care notes were audited, although all of these children should probably have undergone these investigations.

3.2.9 Drug management

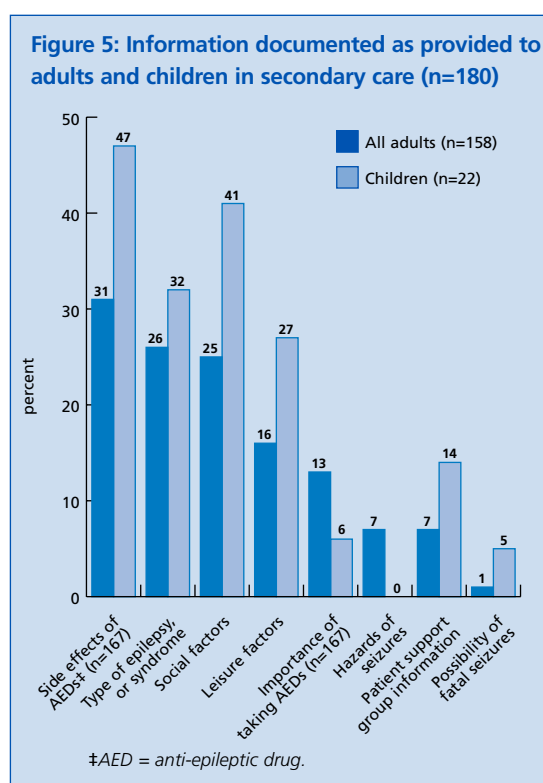
- From a review of the audit data (secondary care), an expert panel considered that drug management was inadequate in 20% (32/158) of all adults and 45% (10/22) of children.
- Most adults (76% [119/156; data unavailable for 2 adults]) were receiving one or two anti-epilepsy drugs (AEDs). However, 6% (9/156) of adults and 18% (4/22) of children were not receiving any anti-epilepsy medication when they died.

3.2.10 Patient review through primary care

- From the audit of all the primary care case notes there was evidence that the review process in primary care was unstructured and lacking in detail.
- Of patients who were also receiving secondary care, there was evidence that 78% (187/241) had been reviewed by either the GP or specialist in the year prior to death and 31% (75/241) had been seen by the GP at their last review.
- In the year before they died, there was documented evidence that 33% (15/45) of those who received all of their care through the GP had been reviewed.
- Most GP reviews were just to provide medication or to check blood drug levels.
- 29% (82/286) of individuals whose primary care notes were audited had been seen by their GP for non-epilepsy-related problems in the month before they died, which would have been a good opportunity for the GP to talk about their epilepsy.

3.2.11 Information provision

- There was little written evidence in secondary care to suggest that epilepsy and its management, and in particular the hazards of epilepsy (including the risk of death), had been discussed with the individual or their carers/family (Figure 5).



- Primary care notes indicated that 31% (89/286) of patients had some recorded information provision on epilepsy from any health professional in primary or secondary care. Most of the people in this audit had epilepsy that required ongoing care and had many apparent risk factors. However, only 1% (3/286) had documented that information had been given on the risk that seizures could be fatal.
- The help of specialist epilepsy nurses and counsellors was rarely recorded and may not have been used.

- Rarely was there any indication that the individual or their carer/family had been told about voluntary organisations and patient advocacy support groups. Consequently, they might not have been able to take advantage of the advice and support that these organisations could have provided.
- Although 14% (22/158) of adults had a problem adhering to their drug regimen, there was little to suggest that this important issue was discussed with patients. Further, of these, only 9% (2/22) had documented information about the hazards of seizures and none about the risk of death.

3.2.12 Contact with relatives after death

- From the records audited, there was little documented evidence of contact with relatives after a death. About 10% (18/180; secondary care audit) of families of people who died were contacted after the death by the specialist. (Only 5% [8/158] of families of adults were contacted compared with 45% [10/22] of families of children who died). Only 7% (19/286, primary care audit) of all families were contacted by the GP after the death. Contact with relatives is particularly important in relation to epilepsy deaths because many deaths are sudden and unexpected and families experience bewilderment, isolation and prolonged distress¹⁴.

3.2.13 Estimate of SUDEP

- A clinical review of 180 deaths audited by secondary care suggests that of deaths where epilepsy was judged to be the probable cause, 60% were SUDEP and a further 7% were possible SUDEP. These numbers are estimates because of concerns about information available to the audit on the circumstances of death, the events leading up to death and the adequacy of post-mortem investigations.

3.3 Expert panel review of overall quality of care

3.3.1 Secondary care

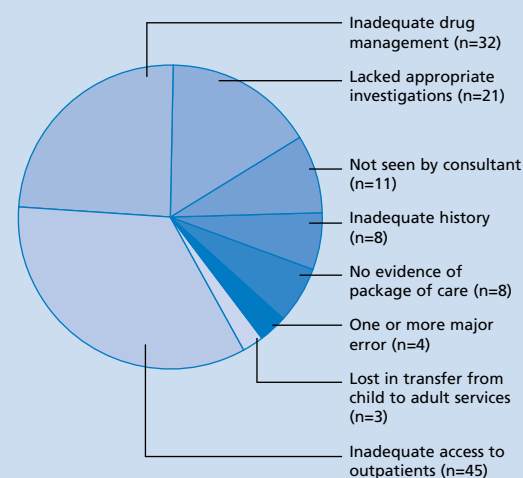
An expert panel reviewed the specific findings from the audit of secondary care and judged the overall quality of care received by individuals.

The panel considered that care had deficiencies for 54% (85/158) of adults. There tended to be deficiencies in more than one aspect of care. The panel considered that the main deficiencies in the epilepsy management of these 158 adults, excluding lack of information and support, were:

- inadequate access to specialist care (35%, 56/158)
 - access to outpatients (28%, 45/158)
 - not seen by consultant (7%, 11/158)
- inadequate drug management (20%, 32/158)
- lack of appropriate investigations (13%, 21/158).

Figure 6 shows the types of deficiencies identified among the adults who died whose care was judged to be deficient for some reason.

Figure 6: Distribution of inadequacies of care in adults (85 of 158 deaths)



Note: the distribution is shown for the 85 adults whose care was judged to have had at least one inadequacy; for some adults, care had more than one inadequacy.

Overall, 39% (62/158) of adult deaths were considered by the expert panel to have been potentially or probably avoidable.

The panel considered that care had deficiencies in 77% (17/22) of children. There tended to be deficiencies in more than one aspect of care. The panel considered that the main deficiencies in epilepsy management in these 22 children, excluding lack of information and support, were:

- inadequate drug management (45%, 10/22)
- inadequate access to specialist care (36%, 8/22)
- inadequate investigations (32%, 7/22).

Figure 7 shows the types of deficiencies identified among children who died whose care was judged to be deficient for some reason.

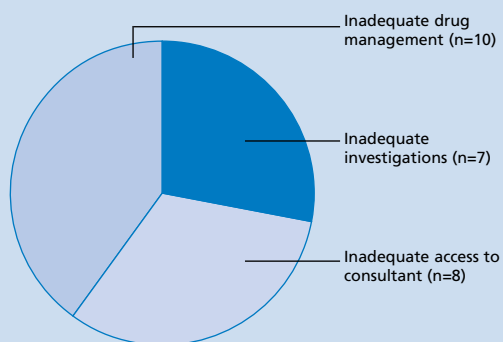
3.3.2 Primary care

Detailed information in primary care records was sparse and for this reason judgements of overall quality of care were not made in relation to individual patients who died. The primary care panel considered the main inadequacies in primary care management were:

- access to skilled specialists
- sparse evidence of structured management plans
- triggers for referral were sometimes missed.

For example, 31% (8 of 26) were seen within 4 weeks by a specialist; 8% (6/72) of patients with indications for re-referral were referred to secondary care.

Figure 7: Distribution of inadequacies of care in children (17 of 22 deaths)



Note: the distribution is shown for the 17 children whose care was judged to have had at least one inadequacy; for some children, care had more than one inadequacy.

Overall, 59% (13/22) of deaths in children were considered by the expert panel to have been potentially or probably avoidable.

4 Discussion

4.1 Audit of investigation of deaths

It was difficult to establish the true number of epilepsy-related deaths from national data. National statistics are an important source for monitoring public health, setting targets for healthcare policies, and research aimed at reducing epilepsy-related deaths. The results of this audit indicate that because of the high percentage of inadequately investigated epilepsy-related deaths, action should be considered to improve the quality of death certification in relation to these deaths.

4.2 Audit of care before death

In general, record keeping was very poor throughout primary and secondary care. Although an audit based on case notes cannot assess non-recorded activity and so the findings may not be entirely comprehensive, the information obtained raises matters of urgent concern.

Epilepsy-related death, particularly SUDEP, is still underestimated by healthcare professionals and this may reflect the mistaken belief that epilepsy is a benign condition. The risk of death associated with epilepsy appeared rarely to have been discussed with patients or their families. There was little documented evidence of contact with bereaved relatives after the death. These issues need to be highlighted with all relevant professionals through better education.

There was concern about many aspects of epilepsy management, and frequently management did not meet published national criteria. There are particular problems in managing epilepsy in people who have associated problems such as learning disabilities.

From the available documentation, the audit found evidence of deficiencies in access to and quality of care, communication between clinical staff and between healthcare professionals and patients and their carers, and post-mortem investigation of epilepsy-related deaths.

These system failures need to be addressed when planning professional education, clinical and audit guidance and systems for service delivery.

By its very nature, an audit of epilepsy-related deaths should not be assumed to be representative of the care provided to patients in general. Nevertheless, audit can compare clinical care to published best practice guidelines in a systematic way. This clinical audit does not establish that the epilepsy-related deaths were directly caused by inadequate care – but it provides very important findings about shortcomings in care that may have contributed to potentially avoidable deaths.

5 Further action

The Chief Medical Officer for England has recommended in his Annual Report 2001⁷ that within 3 months of the publication of this audit the Department of Health should issue an action plan. In the meantime, local NHS clinicians and organisations should establish or review policies and practices regarding the management of epilepsy and the management of epilepsy-related deaths.

The findings from this audit of epilepsy-related deaths will be taken into account in the following NICE guidance to the NHS in England and Wales:

- guideline on the diagnosis and management of epilepsy in children and adults, which is expected to be published in June 2004
- technology appraisal of drugs in epilepsy in children and adults, which is due to be completed in December 2003.

References

- ¹ Muir TM, Bradley A, Wood SF, Murray GD, Brodie MJ (1996) An audit of treated epilepsy in Glasgow. West of Scotland Epilepsy Research Group. *Seizure* 5(1): 41–46.
- ² Wallace H, Shorvon S, Tallis R (1998) Age-specific incidence and prevalence rates of treated epilepsy in an unselected population of 2,052,922 and age-specific fertility rates of women with epilepsy. *Lancet* 352: 1970–1973.
- ³ Frost S, Crawford P, Mera S and Chappell B (2002) *National Statement of Good Practice for the Treatment and Care of People who have Epilepsy*. Joint Epilepsy Council. Available via www.jointepilepsycouncil.org.uk.
- ⁴ Cockerell OC, Johnson AL, Sander JWAS, Hart YM, Goodridge DM, Shorvon SD (1994) Mortality of epilepsy: results from a prospective population-based study. *Lancet* 344: 918–921.
- ⁵ Nilsson L, Farahmand BY, Persson PG, *et al* (1999) Risk factors for sudden unexpected death in epilepsy: a case-control study. *Lancet* 353: 888–893.
- ⁶ Nashef L (1997) Sudden unexpected death in epilepsy: terminology and definitions. *Epilepsia* 38 (Suppl. 11): S6–8.
- ⁷ CMO (2001) Epilepsy – death in the shadows. In: *Annual Report 2001*, Chief Medical Officer, Department of Health, London.
- ⁸ Coyle HP, Baker-Brian N, Brown SW (1994) Coroners' autopsy reporting of sudden unexplained death in epilepsy (SUDEP) in the UK. *Seizure* 3(4): 247–254.
- ⁹ Nashef L, Sander JWAS (1996) Sudden unexpected deaths in epilepsy – where are we now? *Seizure* 5(3): 235–238.
- ¹⁰ Royal College of Pathologists (1993) *Guidelines for Postmortem Reports*. Royal College of Pathologists, London.
- ¹¹ Wallace H, Shorvon SD, Hopkins A, O'Donoghue M (1997) *Guidelines for Adults with Poorly Controlled Epilepsy*. Royal College of Physicians, London.
- ¹² SIGN (1997) *Diagnosis and Management of Epilepsy in Adults*. Scottish Intercollegiate Guidelines Network, Royal College of Physicians, Edinburgh.
- ¹³ Taylor MP (2000) *Managing Epilepsy: a Clinical Handbook*. Oxford: Blackwell Science Ltd.
- ¹⁴ Nashef L, Garner S, Sander JWAS, Fish DR, Shorvon SD (1998) Circumstances of death in sudden death in epilepsy: interviews of bereaved relatives. *Journal of Neurology, Neurosurgery and Psychiatry* 64(3): 349–352.

Details of full report

The full report of the National Sentinel Clinical Audit of Epilepsy-related Death, and a patient information leaflet, are available from the Epilepsy Bereaved website, www.sudep.org. If you would like to contact the Epilepsy Bereaved helpline, please telephone 01235 772 850 or 01235 772 852.

The authors of the full report were:

Ms N Jane Hanna

Director of Epilepsy Bereaved; Joint Epilepsy Council representative

Dr Marjorie Black

Consultant forensic pathologist; Royal College of Pathologists representative

Professor Josemir W Sander

Consultant neurologist; International League against Epilepsy representative

Dr W Henry Smithson

General practitioner; Royal College of General Practitioners representative

Dr Richard Appleton

Consultant paediatric neurologist; Royal College of Paediatrics and Child Health representative

Professor Stephen Brown

Consultant neuropsychiatrist; Royal College of Psychiatrists representative (Learning Disability Faculty)

Professor David R Fish

Consultant clinical neurophysiologist and neurologist; International League against Epilepsy representative

Note: Epilepsy Bereaved commissioned the College of Health to conduct research into the experiences of bereaved relatives who contacted the charity during the period of the audit. A report on this research will also be published on the Epilepsy Bereaved website during 2002.



*National Institute for
Clinical Excellence*

**National Institute for
Clinical Excellence**

11 Strand, London WC2N 5HR
Tel: 020 7766 9191
Fax: 020 7766 9123

Email: nice@nice.nhs.uk
Web: www.nice.org.uk