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## **NATIONAL SENTINEL CLINICAL AUDIT OF EPILEPSY-RELATED DEATH**

Short-form report

The full report can be found on - [www.sudep.org](http://www.sudep.org)

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### **Background**

People with epilepsy have a risk of premature death that is 2-3 times higher than in the general population (1). 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 (Section 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 risk (2).

## **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." (3)

Clearly since most epilepsy deaths are related to seizures good seizure control is the key to minimising the risk of death. Although most people in the UK (up to 70%) have the potential to be seizure-free, five government reports since 1953 have highlighted serious deficiencies in service provision for epilepsy (4). 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 (5,6).

The National Sentinel Clinical Audit of Epilepsy-Related Death - reported 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. Three key areas were reviewed:

- investigations into the deaths (pathology)
- care prior to death (general practice and hospital-based [secondary] care)
- contact with the bereaved family

The audit was developed using a standard approach (Section B), by 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 (Section C). During that time, 2412 deaths were reported where epilepsy was mentioned somewhere on the death certificate. In 812 of these deaths, epilepsy was considered to be the main cause and in 238 deaths epilepsy was considered to be the possible cause of death.

## **B. How was the audit developed and performed?**

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 7-10), literature searches and the views of expert panels in these three areas. Audit tools were developed.

Areas for pathology audit were: background, post-mortem investigation, further investigations and certification - information collected from post-mortem reports and coroner's officer and police reports.

Areas for primary and secondary care audit were: access to care and clinical assessment, investigations, drug treatment, non-drug therapies, continuing care, information and support,

and communication between professionals and services - information collected from case notes.

The information collected was entered into a centralised computer system. Experts assessed the data including performing checks to eliminate inconsistencies and duplication.

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

### **C. Number of deaths audited**

#### **Investigation of death**

- 439 post-mortem records

- 156 doctor-certified deaths (no post-mortem)

Care prior to death\*

- 286 primary care case notes

- 45 from patients only receiving GP care

- 241 from patients also receiving secondary care

- 180 secondary care case notes

- 158 adults, 50 with learning disability

- 22 children, 15 with learning disability

- 227 cases fully audited (i.e. all medical and pathology records examined)

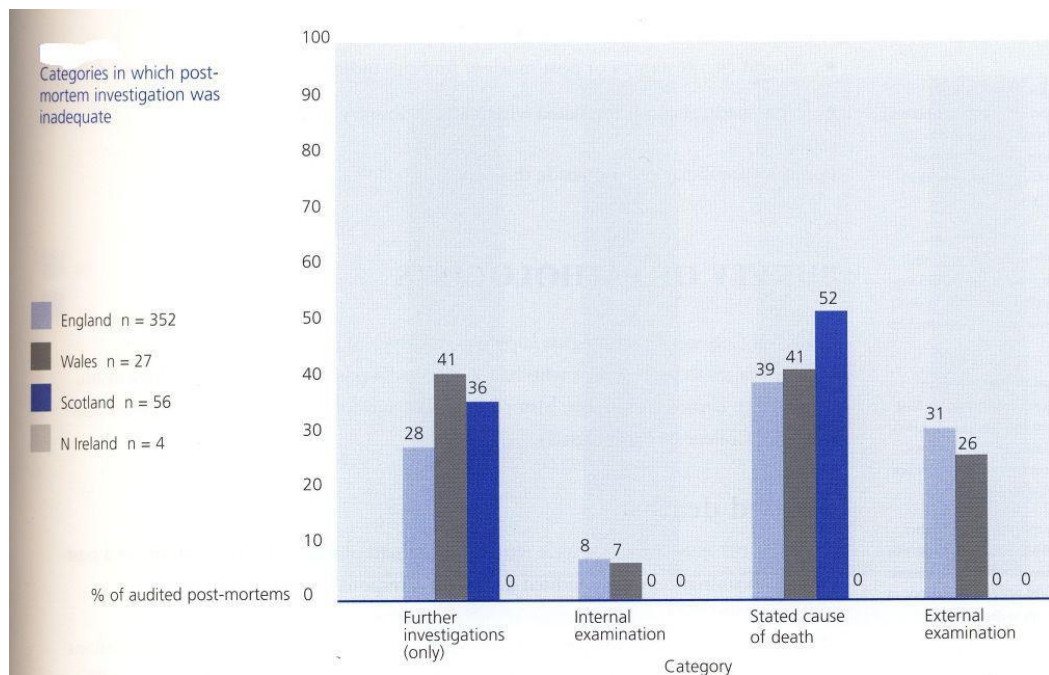
\*In cases where epilepsy was judged to be the main cause of death.

#### **Investigation into the Deaths**

Although most deaths were confirmed as being in keeping with epilepsy as the cause, many (87%) of the deaths involving a post-mortem were considered to have been inadequately investigated (Figure 1). The main problems were with "further investigations" (Section D) and certification. Not all pathologists request further investigations, and furthermore, these procedures tend to be non-standardised. These investigations are important to eliminate other potential causes of death.

#### D. '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



**Figure 1**

Certification of death (with or without post-mortem) was inconsistent and, in some cases, inappropriate. Of deaths certified without post-mortem as due to epilepsy, 38% were sudden and/or unwitnessed and should have been subject to post-mortem. Certification was inadequate in 41% of deaths involving a post-mortem, and there were various reasons for this, including the following.

- Phrasing of the cause of death. This was very variable (Section E). Although the term 'SUDEP' has been in use since 1997, it was cited on the death certificate in just 10% 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 if this had not contributed to the death.
- In general, problems with certification highlighted the difficulty of establishing the true number of epilepsy-related deaths from certification data.

## **E. Some terms used on the death certificate to describe the cause of death**

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

Two-thirds of pathologists were not aware of a system in place to inform relatives about post-mortem results.

In a minority of deaths the post-mortem examination was considered inadequate (27% of external examinations and 7% of internal examinations). Information from pathologists indicated variable and non-standardised access to information regarding the medical history and circumstances of death.

If deaths are not appropriately or adequately investigated it is difficult to establish the true number of epilepsy-related deaths.

## **Specific Findings on Aspects of Care**

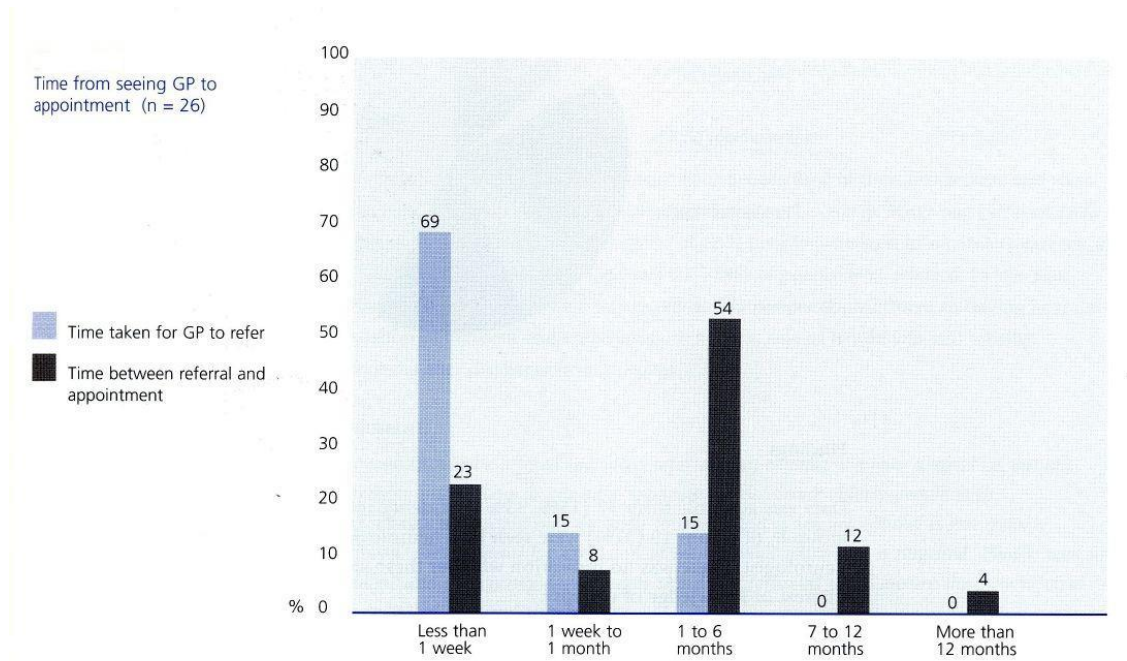
Clinical review of 180 deaths audited by secondary care suggests that 60% of epilepsy-related deaths were SUDEP and a further 7% were possible SUDEP. These numbers are estimates because of concerns about information available to the audit on the circumstances of death, the events leading up to death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

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.

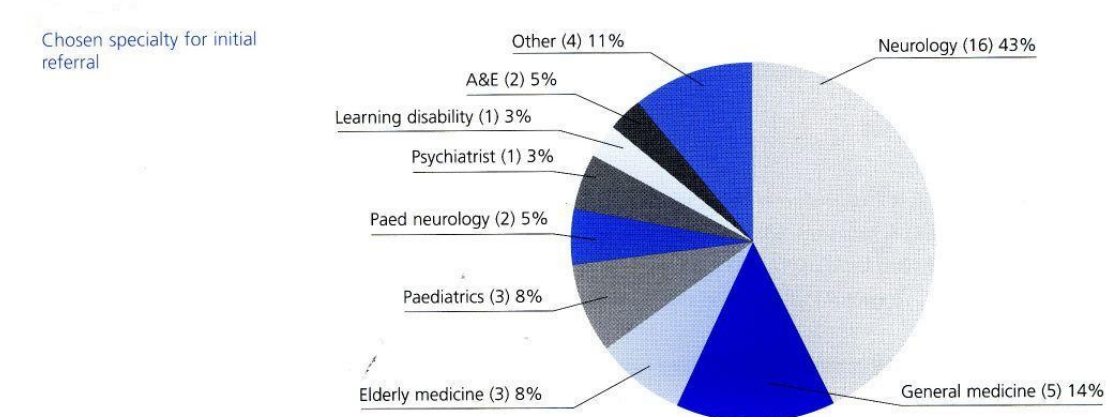
## **Access to Specialist Care**

After a first seizure, individuals are normally referred to secondary care by their GP. In this setting, they undergo confirmation of diagnosis, initial investigations and initiation of care. Individuals whose seizures are not well controlled should receive ongoing specialist care. Of the 286 people whose GP case notes were audited, 84% had been referred. Around 70% of individuals diagnosed within 5 years of death had been referred within 1 week; however, it took some GPs up to 6 months to refer. Waiting times for a specialist appointment were disappointingly long, with 15% of individuals having to wait more than 6 months (Figure 2). Clearly, this was an area of concern.

Just under half of individuals diagnosed in the 5 years before death were initially referred to an adult or paediatric neurologist (Figure 3).



**Figure 2**



**Figure 3**

The secondary care case notes indicated that 66% of all adults seen in out-patients had seen a neurologist and 35% of all children had seen a paediatric neurologist.

Only 3% of all people who died were recorded as seizure-free at their last hospital appointment (Figure 4).

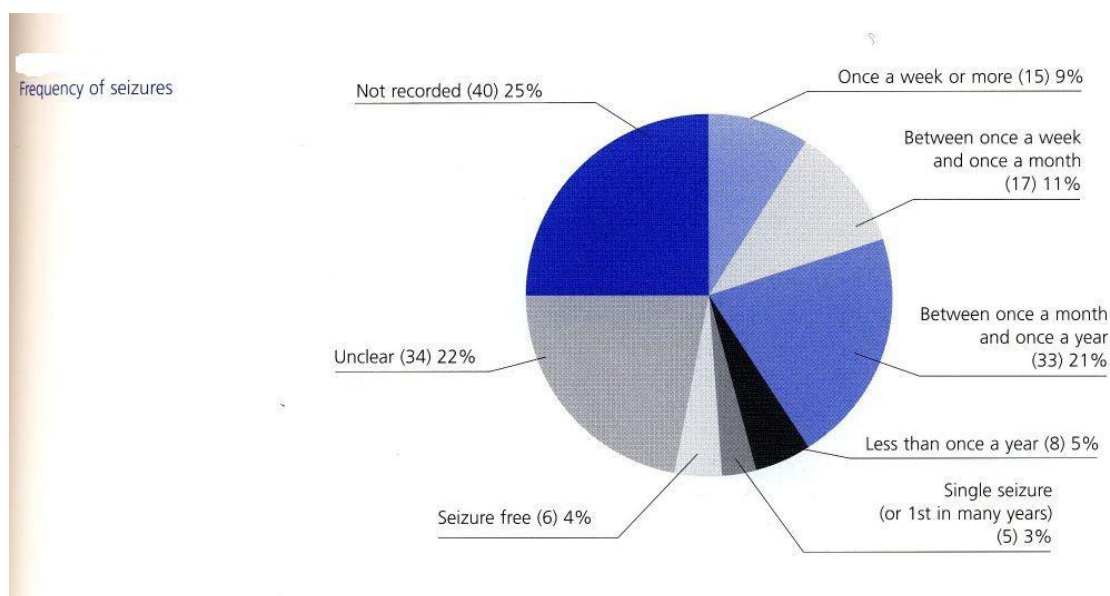
No children were known to be seizure-free in the year before they died. Although all children were seen in secondary care in the year prior to death, it was considered that 36% of children



had inadequate access to appropriate care. The main deficiency was lack of access to appropriate specialist care for children who had learning and/or physical disabilities and frequent seizures.

It was found that at least 37% of adults who were not recorded as being seizure-free had not been seen in the year before they died. Around 15% of adults missed at least one appointment but there was no standard way in which these missed appointments were managed:

- 57% were sent at least one further appointment
- 30% were not sent any further appointments
- 13% of cases were unclear



**Figure 4**

There were particular concerns about access to appropriate specialist care for adults with special needs (e.g. learning disability). Three adults with learning difficulties had been completely lost to follow-up in the transfer from paediatric to adult care.

Also of concern was the lack of re-referral by the GP for individuals fulfilling the criteria for re-assessment. For example, among the 241 individuals receiving combined GP/specialist care, the GP notes suggested that 68 people fulfilled the criteria for re-referral (including 11% with a change in seizure frequency). Of these 68, only 6 (9%) were re-referred. Although four individuals receiving all of their care through the GP had a change in seizure frequency, none was referred.

## **Clinical Assessments**

Clinical assessments were poorly documented throughout primary and secondary care. Many details were lacking in relation to:

- classification of seizure type and syndrome
- seizure triggers
- seizure frequency
- drug treatment issues
- non-drug therapies.

In 47% of adults and 36% of children whose secondary care case notes were audited, seizure frequency had either not been recorded or was unclear. For 25% of adults and 27% of children, seizure frequency had not been recorded at their last hospital visit.

## **Investigations**

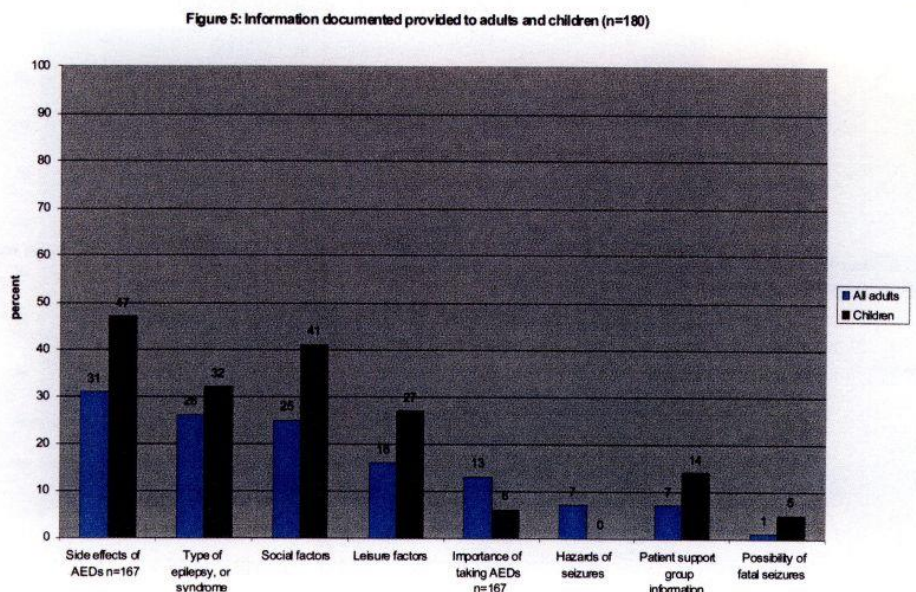
The use of appropriate hospital investigations was poor. Secondary care notes did not report a scan for 57 adult patients (36%) - at least 19 of these should have had one; and there was no documented report of an EEG for 51 (32%) adult patients - at least 22 of these should probably have had one. No brain scan or EEG was documented for seven (32%) children, although they should probably have undergone these investigations.

## **Information Provision**

Information provision was another area that was considered to be poor throughout primary and secondary care. There was little written evidence 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). 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 were not able to take advantage of the advice and support that these organisations could have provided.





**Figure 5**

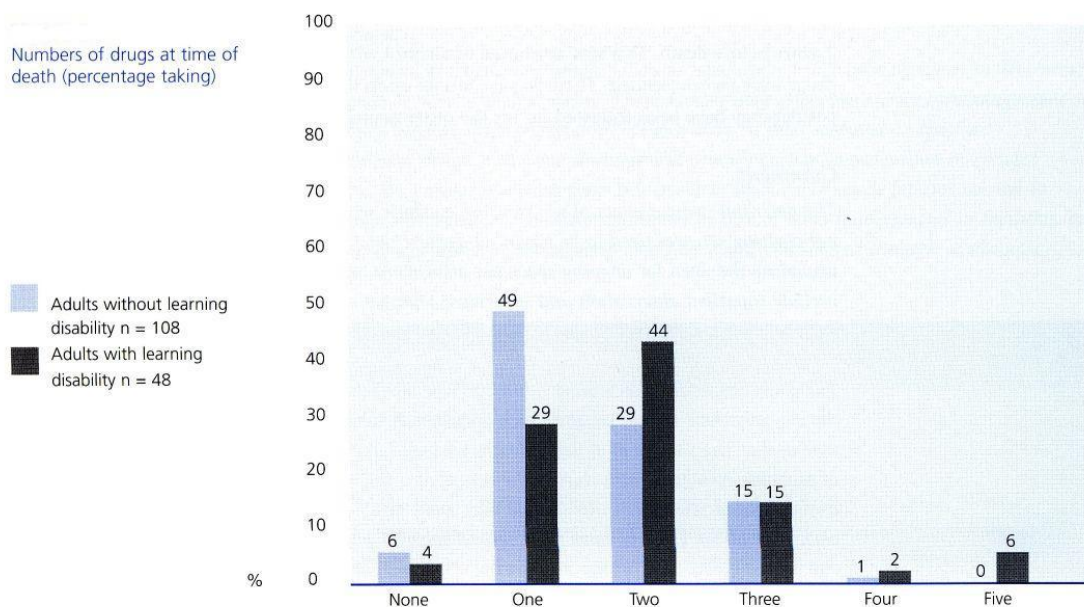
## Drug Management

From a review of the audit data, an expert panel considered that drug management was deficient in 20% of all adults and 45% of children. Most individuals were receiving one or two anti-epilepsy drugs (AEDs), though 6% of adults (Figure 6) and 18% of children were not receiving any anti-epilepsy medication when they died. Problem areas relating to drug management are shown in Section F.

### F. Problem areas of drug management

- No medication prescribed despite ongoing seizures
- Inappropriate choice of AED
- Inappropriate combinations of AEDs
- Doses too low or inappropriate
- Unsupervised/inappropriate management of AED changes
- Little consideration of alternative or additional AEDs in cases of ongoing seizures
- Major drug errors

Although 14% of adults had a problem adhering to their drug regimen, there was little to suggest that this important issue was discussed with patients.



**Figure 6**

### Patient Review

The primary care review process was unstructured and lacking in detail. In the year before they died, only 33% of those who received all of their care through the GP had been reviewed. Of patients who were also receiving secondary care, 78% had been reviewed by either the GP or specialist in the year prior to death and 31% had been seen by the GP at their last review. Most GP reviews were just to provide medication or to check blood drug levels. Interestingly, 29% of individuals 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.

### Communication

Communication between healthcare professionals was poor throughout primary and secondary care - not just between the two, but also within each. In some cases, there appeared to have been a total breakdown in communication between primary and secondary care. Communication with the person with epilepsy and their carer/family also appeared to be inadequate and there was little documented evidence to suggest that individualised, written management plans were being used. Where there was a management plan, this generally consisted only of a date for the next review or plans to take a blood sample for drug monitoring. The fact that epilepsy may cause deaths appeared rarely to have been discussed with the patients and families, even amongst most of the patients in this audit whose epilepsy required ongoing secondary care and who had many apparent risk factors.

From the records audited, there was little documented evidence of contact with relatives after a death. About 10% of families of people who died were contacted after the death by the specialist. (Only 5% of families of adults were contacted compared with 45% of families of children who died.) Only 7% of all families were contacted by the GP after the death.

## Overall Quality of Care before Death

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 been inadequate in 85 adults (54%) and 17 children (77%). For both adults and children, there tended to be deficiencies in more than one aspect of care. The panel considered that the main inadequacies in epilepsy management (Figures 7 and 8), excluding lack of information and support, were:

- access to specialist advice for investigation and treatment
- drug management
- appropriate investigations

Overall, 39% of adult deaths and 59% of deaths in children were considered to have been potentially or probably avoidable.

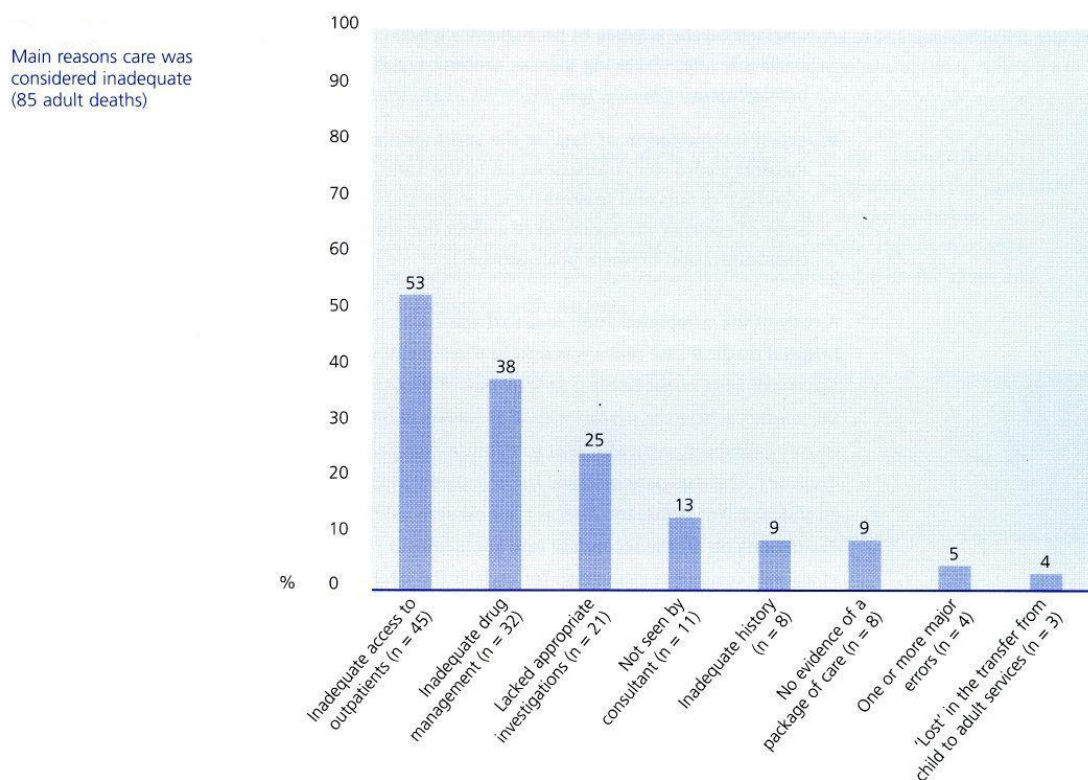
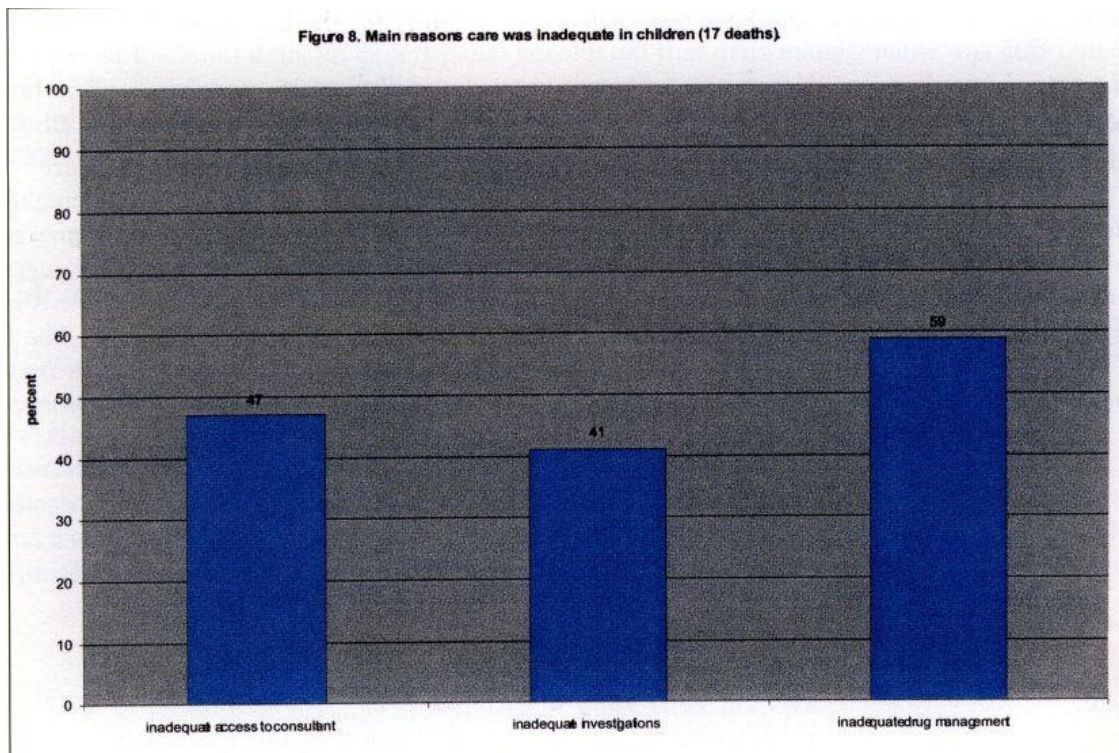


Figure 7





**Figure 8**

## Conclusions

It was difficult to establish the true number of epilepsy-related deaths from certification data. This must cast doubt on the reliability of national statistics as a source for monitoring public health, setting targets for healthcare policies, or research aimed at reducing epilepsy-related deaths.

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 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 difficulties.

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, documentation, 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.

In conclusion, poor epilepsy management results in a substantial number of potentially avoidable deaths.

### **Further Action**

The Chief Medical Officer for England has recommended that within 3 months of completion of this audit an action plan should be in place in England to cut the level of preventable epilepsy-related deaths. The plan will need to address the problems identified in this audit, particularly: inadequate access to appropriate epilepsy care; lack of education of healthcare professionals about the principles of epilepsy management and the risks of epilepsy-related deaths; poor communication with patients and their families and other carers; and deficiencies in post-mortem investigations.

The conclusions 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 May 2004
- technology appraisal of drugs in epilepsy in children and adults, which is due to be completed in December 2003.

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**Note:**

**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,**

<http://dspace.dial.pipex.com/epilepsybereaved/>