

Trends in mortality and hospital admissions associated with epilepsy in England and Wales during the 1990s

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INTRODUCTION

Epilepsy is a chronic neurological condition characterised by recurrent (two or more) seizures unprovoked by any immediate identifiable cause.¹ In the UK, epilepsy is the most common chronic neurological condition with a prevalence rate 10-fold higher than that of Multiple Sclerosis and 100 times that of motor neurone disease.² Data from the General Practice Research Database (GPRD) revealed an age standardised prevalence rate of treated epilepsy of 7.4 per thousand in males and 7.2 per thousand in females in 1998, with an increase of 7 per cent between 1994 and 1998.³

Epileptic seizures can occur at anytime, have varying presentations, can be the result of various aetiologies and may start or stop for no clearly defined reason. Epilepsy can have widespread effects on individual sufferers and their families. Social, psychological and emotional problems, which can occur in both adults and children with epilepsy, can be considerable. Side effects of medication, being 'different', the unpredictability of seizures, limitations because of associated neurological problems, inability to cope in the job market with subsequent financial problems and the limitations on driving can all lead to social isolation and loss of self esteem. Children consistently fail to achieve their potential and unemployment in vocationally active people with epilepsy is at least twice that of the general population.⁴ Psychiatric morbidity has also been shown to occur more commonly in epileptic patients than would be expected by chance and there is an increased risk of suicide.⁵

Previous research studies, surveys, and official reports have highlighted the many problems and deficiencies present in the management of people with epilepsy. Some of these problems were again highlighted in the Chief Medical Officer's Annual Report for the year 2001.⁶ The Department of Health plans to include standards on the management of

This article examines trends in mortality and hospital admissions associated with epilepsy in England and Wales during the 1990s. Mortality data were analysed for the period 1993 to 2000. Data on hospital admissions where the main diagnosis was epilepsy were obtained from the Hospital Episode Statistics information service of the Department of Health and analysed for the period 1991/92 to 2000/01. There were about 800 deaths per year where epilepsy was the underlying cause and about 37,000 admissions where epilepsy was the main diagnosis. Both mortality and hospital admission rates for epilepsy remained relatively stable during the periods examined.

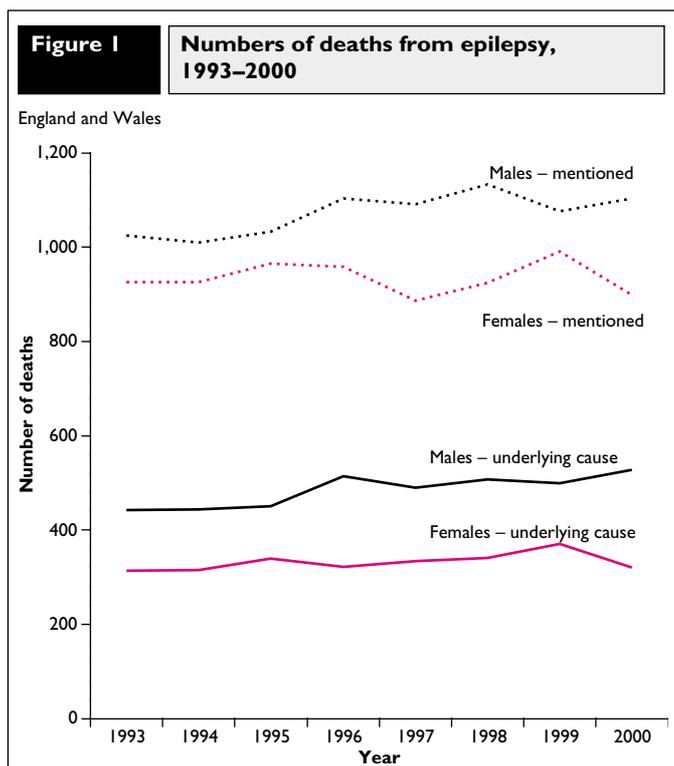
epilepsy in a forthcoming National Service Framework on Long Term Limiting Illnesses, expected to be published in 2004.⁷

Despite the many adverse consequences of a diagnosis of epilepsy, there is a lack of routinely available population-level data on the outcomes of epilepsy. A limited number of primary-care-derived indicators on the management of epilepsy are included in the quality framework in the new general practitioner contract that will be implemented in April 2004. In the interim, hospital admission data and mortality statistics can provide some information on the outcomes of epilepsy at a population level. Hospital admissions and mortality data, though difficult to interpret, may be regarded as surrogate markers for epilepsy care in general. This article examines recent trends in hospital admissions and deaths from epilepsy in England and Wales using routinely available national data. The article provides baseline information on these two measures before the implementation of the new general practitioner contract and the forthcoming National Service Framework on Long Term Limiting Illnesses.

METHODS

Death registration

This article examines deaths occurring in England and Wales between 1993 and 2000 in which epilepsy was implicated. Mortality data were obtained from the Office for National Statistics (ONS) mortality database. Routine mortality statistics are usually based on the underlying cause of death (defined by the World Health Organisation as the disease which initiated the train of events directly leading to death or the circumstances of the accident or violence which produced the fatal injury.^{8,9}) However, in 1993, the redevelopment of the ONS mortality database allowed all the diseases and conditions mentioned on the death certificate to be coded and stored in addition to the underlying cause. The International Classification Diseases Ninth Revision (ICD-9) coding was used for death certification for the entire period 1993 to 2000. It was replaced by ICD-10 coding in 2001 (Box 1). As the move to coding cause of death using ICD-10 has an impact on the number of deaths in which epilepsy is selected as the underlying cause,¹⁰ we have chosen to restrict our analysis to the period 1993–2000.



Box one

ICD-9 and ICD-10 codes for epilepsy

Coding system	Relevant code(s)	Use for Mortality data	Used for HES data
ICD-9	345 Epilepsy	1979–2000	Until 1994/95
ICD-10	G40 Epilepsy G41 Status Epilepticus	2001 onwards	1995/96 onwards

Age- and sex-specific rates were calculated using mid-year population estimates for England and Wales, revised on the basis of the 2001 Census (published in March 2003), as denominators for the relevant year and death rates were directly standardised using the European Standard Population.

Hospital admission rates

Hospital Episode Statistics (HES) record episodes of in-patient treatment delivered by NHS hospitals in England. A ‘finished consultant episode’ is defined as a period of treatment under the care of a particular consultant. A single admission may generate more than one episode if, for example, a patient receives medical care from two different consultants during a single admission. The first episode during an admission can be used as a proxy measure of the number of admissions. Overnight stays in Accident and Emergency units would only be included if the hospital considered them to have been admitted. For this, they would have used a bed and seen a consultant. Admissions are categorised as emergency and elective (i.e. when admission is planned), with a small number of other types, including admissions of babies.

HES data were obtained from the HES information service of the Department of Health. All finished consultant episodes in which epilepsy or status epilepticus was given as the primary diagnosis were selected for analysis. It was assumed that the primary diagnosis for the first finished consultant episode was the main reason for the admission.

Between 1989 and 1994, ICD-9 codes were used for HES data. In 1995, ICD-10 coding was introduced. It is unlikely that this change of coding had much impact on the number of admissions coded to epilepsy. The HES data used in this paper have been grossed for both coverage and unknown/invalid clinical data.

As for the mortality data, rates were calculated using the mid-year population estimates revised on the basis of the 2001 Census. Age-standardised admission rates were calculated using the European Standard Population. As HES data is for financial, rather than calendar, years, we chose to take the mid-year estimate which covered the majority of the financial year being examined.

RESULTS

Mortality

The number of deaths mentioning epilepsy was consistently higher in males throughout the period 1993 to 2000. This was true for deaths where epilepsy was selected as the underlying cause of death as well as those where epilepsy was mentioned anywhere on the death certificate (Figure 1).

Epilepsy was mentioned in approximately 2,000 death registrations each year, and identified as the underlying cause in around 800 deaths each year. The mean annual number of deaths attributed to epilepsy, as the underlying cause during this 8-year period, was 484 (males) and 332 (females).

Age-specific mortality rates for deaths where epilepsy was mentioned anywhere on the death certificate were highest in those aged 65 and over in both sexes (Table 1).

Age-specific rates for epilepsy as the underlying cause of death were highest in those aged 65 and over in females but in males the 35–64 age group and 65 and over group had equally high rates (Table 2). Looking at the patterns in 5-year age bands (Figure 2), there was a sharp increase in mentions of epilepsy after the age of 65, with a corresponding increase in the rates for deaths with epilepsy as the underlying cause, although this increase was not as steep. Males had higher rates than females at every age group. There appears to be a peak in the rates for under 65s in the 35–39 age group for males, but this pattern was not seen for females.

Age-standardised death rates for epilepsy have varied little between 1993 and 2000 (Figure 3).

We also examined the other conditions mentioned on the death certificate along with epilepsy. Looking at the number of deaths where epilepsy was mentioned (Table 3), we can see that epilepsy itself was selected

as the underlying cause of death in just over 40 per cent of cases. This means that in nearly 60 per cent of cases where epilepsy was mentioned on the death certificate it was not selected as the underlying cause of death. However, epilepsy was the most common condition selected as the underlying cause of death. The next most common conditions selected as the underlying cause of death were cerebrovascular diseases (14 per cent of cases), pneumonia (9 per cent of cases) and ischaemic heart disease (8 per cent of cases). Neoplasms, other diseases of the nervous system and other circulatory diseases were also mentioned in between 5.1 and 3.7 per cent of cases each. Some of these cases may be where damage to the brain caused by a stroke or cancer has caused the epileptic fit, and others cases where the person has had epilepsy for a long time and died from another condition, with epilepsy reported in Part II of the death certificate (the part of the certificate which is used to record conditions contributing to the death but not related to the disease or condition which caused death). It is not easily possible to distinguish between these two from the routinely available information.

When epilepsy was selected as the underlying cause of death, the other most commonly mentioned conditions were respiratory diseases; symptoms, signs and ill-defined conditions; and external causes of mortality, each being mentioned in about 15 per cent of deaths where epilepsy was selected as the underlying cause (Table 4). ICD coding rules allow some external causes of death (e.g. drowning) to be due to epilepsy in both ICD-9 (used in this article) and ICD-10.

Table 1 Age-standardised death rates for epilepsy (mentions) per 100,000 population, by age group and sex, 1993–2000

England and Wales

	1993	1994	1995	1996	1997	1998	1999	2000
Males								
0–14	1.12	0.88	0.86	1.30	1.01	0.98	0.85	0.91
15–34	2.19	2.41	2.15	2.40	2.60	2.66	2.18	2.33
35–64	3.61	3.72	3.67	4.42	4.22	4.32	4.19	4.57
65 and over	14.33	13.36	14.62	13.21	13.07	13.71	13.12	12.31
All ages	3.85	3.79	3.83	4.13	4.03	4.15	3.87	3.99
Females								
0–14	0.98	0.91	0.86	0.50	0.76	1.16	0.98	0.74
15–34	1.50	1.45	1.66	1.42	1.41	1.31	1.34	1.18
35–64	1.99	2.34	2.30	2.25	2.24	2.28	2.82	2.40
65 and over	10.07	9.56	9.98	10.56	8.95	9.59	9.39	8.88
All ages	2.52	2.57	2.65	2.55	2.42	2.57	2.72	2.41

Table 2 Age-standardised death rates for epilepsy (underlying cause) per 100,000 population, by age and sex, 1993–2000

England and Wales

	1993	1994	1995	1996	1997	1998	1999	2000
Males								
0–14	0.54	0.42	0.41	0.66	0.37	0.36	0.38	0.36
15–34	1.79	1.99	1.65	1.80	2.00	2.10	1.66	1.82
35–64	2.26	2.15	2.24	2.75	2.59	2.52	2.62	3.00
65 and over	2.09	2.24	2.96	2.64	2.28	2.67	2.94	2.30
All ages	1.73	1.73	1.75	2.01	1.90	1.94	1.89	2.01
Females								
0–14	0.54	0.34	0.32	0.21	0.47	0.35	0.41	0.33
15–34	1.19	1.15	1.37	1.10	1.13	1.04	0.99	0.95
35–64	1.15	1.35	1.28	1.28	1.32	1.21	1.68	1.36
65 and over	1.71	1.61	1.74	2.01	1.85	2.38	1.96	1.71
All ages	1.09	1.10	1.14	1.08	1.14	1.10	1.24	1.06

Figure 2 Age-specific mortality rates for epilepsy, 1993-2000 combined

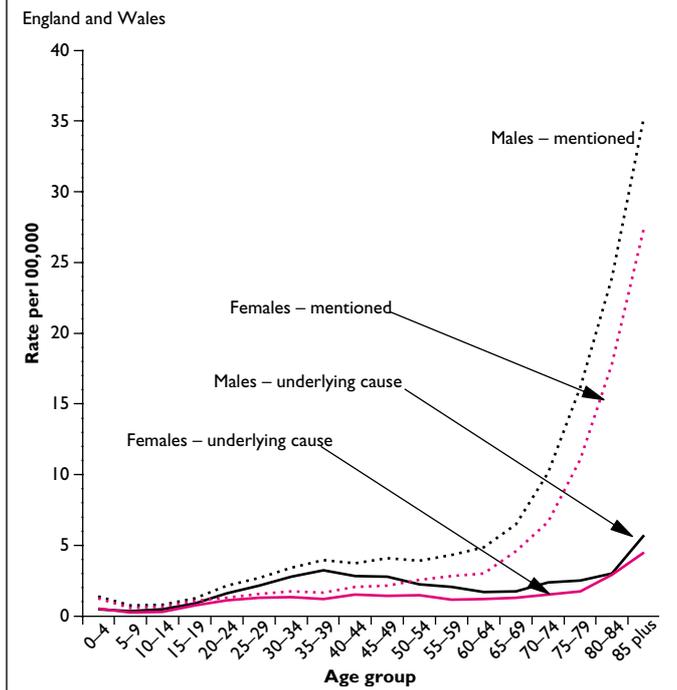


Figure 3 Age-standardised death rates for epilepsy in 1993-2000

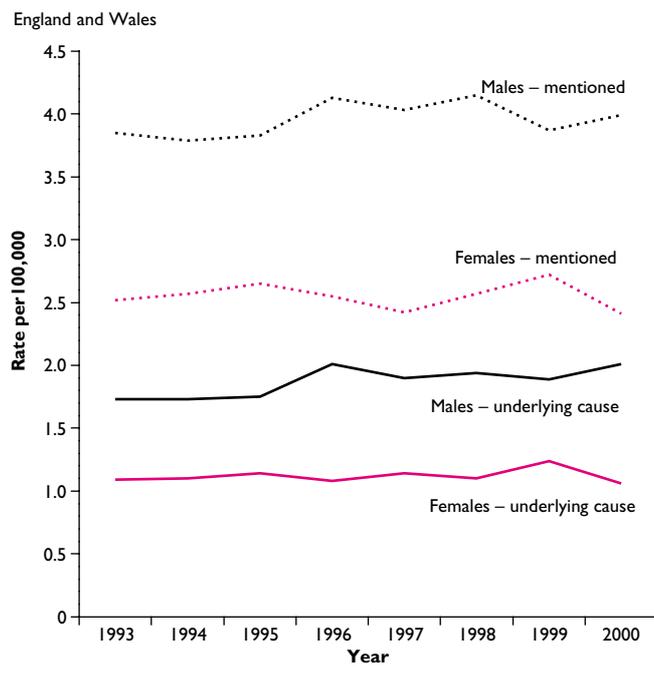


Table 3 Most common diagnoses coded as underlying cause of death from death registrations in which epilepsy was mentioned on the death certificate, 1993-2000 combined

England and Wales

Description	ICD-9 code	Number	Percentage
All deaths		15,990	100.0
Epilepsy	345	6,494	40.6
Cerebrovascular disease	430-438	2,267	14.2
Pneumonia	480-486	1,472	9.2
Ischaemic heart disease (IHD)	410-414	1,192	7.5
Neoplasms	140-239	818	5.1
Diseases of the nervous system and sense organs (excluding epilepsy)	320-344, 346-359	813	5.1
Circulatory diseases (excluding IHD/cerebrovascular disease)	390-409, 415-429, 439-459	585	3.7
Mental and behavioural disorders	290-319	471	2.9
Chronic lower respiratory diseases	490-494, 496	420	2.6
External causes of mortality	E800-E999	268	1.7
Congenital malformations, deformations and chromosomal abnormalities	740-759	261	1.6
Endocrine, nutritional and metabolic diseases and immunity disorders	240-279	211	1.3
Other		718	4.5

Table 4 Most common diagnoses mentioned on the death certificate when epilepsy was coded as the underlying cause of death, 1993-2000 combined

England and Wales

Description	ICD-9 code	Number	Percentage
All deaths		6,497	100.0
Respiratory diseases	460-519	1,068	16.4
Symptoms, signs and ill-defined conditions	780-799	978	15.1
External causes of mortality	E800-E999	907	14.0
Diseases of the nervous system and sense organs (excluding epilepsy)	320-344, 346-389	539	8.3
Circulatory diseases (excluding IHD/cerebrovascular disease)	390-409, 415-429, 440-459	486	7.5
Mental and behavioural disorders	290-319	458	7.0
Cerebrovascular disease	430-438	357	5.5
Ischaemic heart disease (IHD)	410-414	238	3.7
Digestive system diseases	520-579	161	2.5
Congenital malformations, deformations and chromosomal abnormalities	740-759	140	2.2

Table 5 Age-standardised hospital admission rates for epilepsy per 100,000 for epilepsy by age and sex, 1991/92–2000/01

England										
	1991/92	1992/93	1993/94	1994/95	1995/96	1996/97	1997/98	1998/99	1999/00	2000/01
Males										
0–14	94.1	100.9	94.6	91.6	106.9	100.4	112.1	109.9	109.8	115.6
15–34	74.4	72.6	74.3	75.7	72.4	72.2	76.2	73.0	70.8	70.3
35–64	70.6	70.1	72.3	73.3	74.2	72.8	75.6	77.2	76.3	73.9
65 and over	122.8	116.1	120.7	125.5	119.4	141.7	142.9	119.3	111.4	109.7
All ages	82.6	82.6	83.1	83.8	85.9	86.3	91.2	87.8	86.0	86.0
Females										
0–14	85.2	84.0	79.7	84.2	94.8	90.0	90.0	95.5	94.4	100.3
15–34	70.7	72.2	72.8	71.6	69.2	63.9	68.8	65.5	61.7	63.1
35–64	49.0	50.0	51.1	53.0	53.5	52.9	53.2	54.7	52.8	52.6
65 and over	75.6	79.9	78.1	78.3	74.4	79.9	82.2	76.0	73.5	76.6
All ages	66.0	67.0	66.4	67.9	69.3	67.1	68.9	69.0	66.7	68.7

Figure 4 Number of hospital admissions for epilepsy by type and sex, 1991/92–2000/01

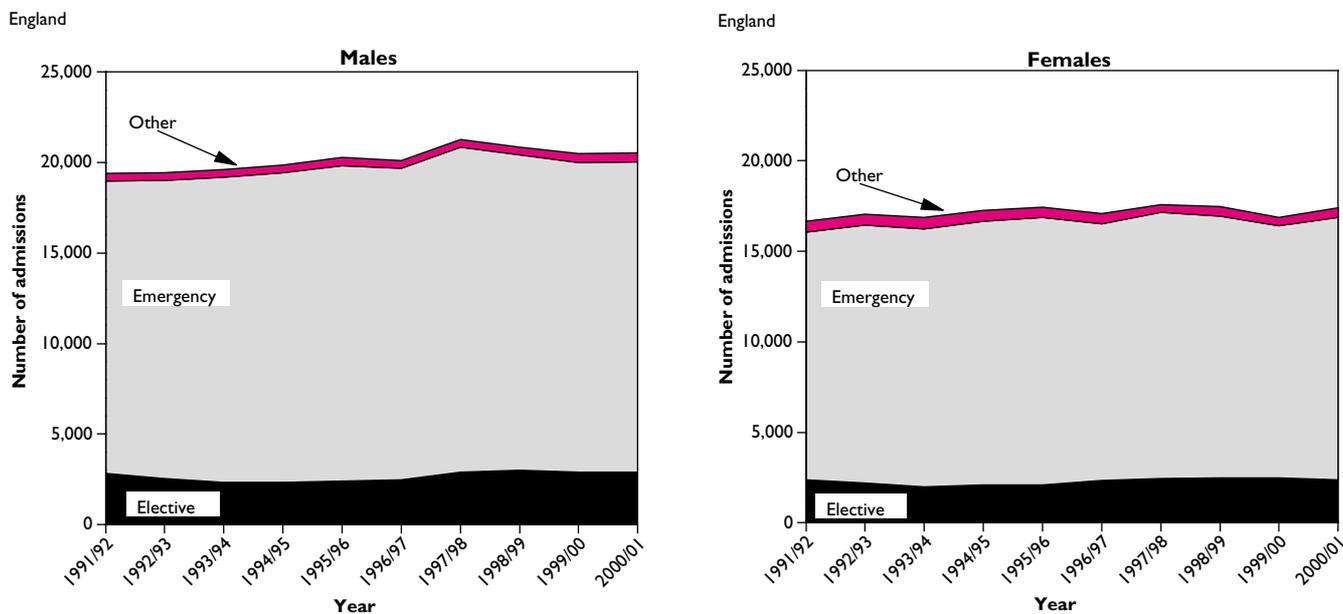
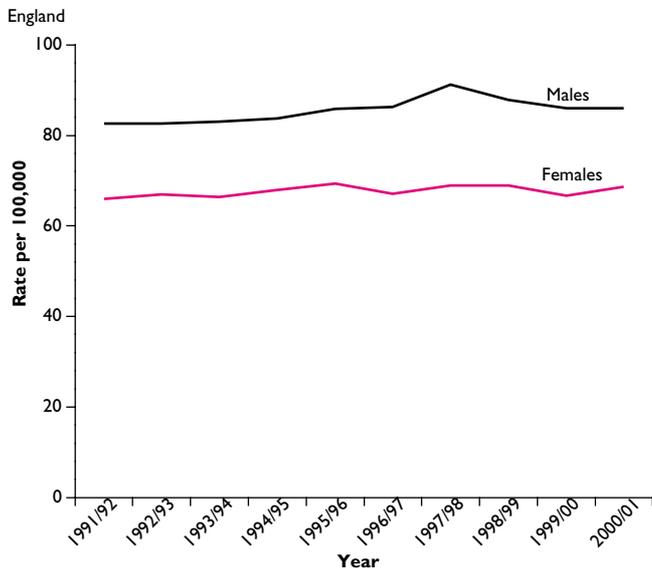


Figure 5 Age-standardised hospital admission rates for epilepsy, 1991/92–2000/01

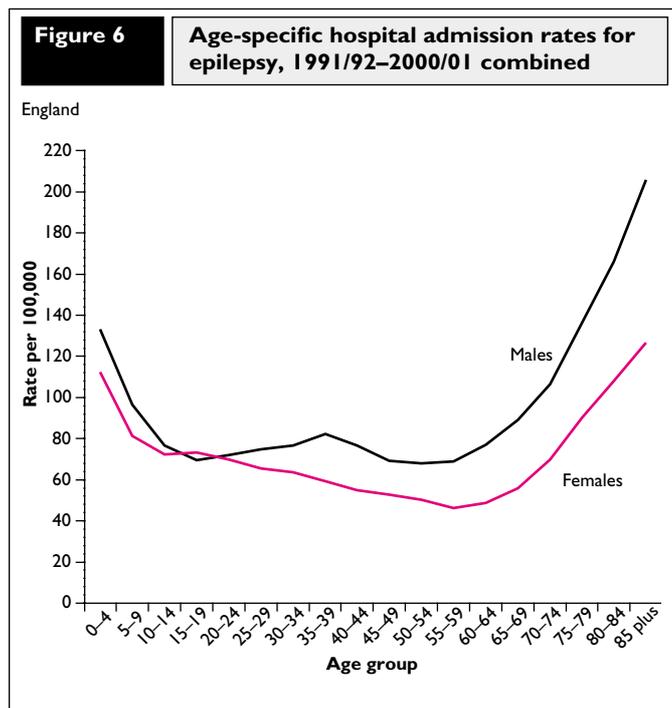


Hospital admissions

The average number of hospital admissions for epilepsy each year was around 37,000. The number of admissions was consistently higher for males than females during the period 1991/92 to 2000/01 (Figure 4). In fact, male numbers of emergency admissions were similar to the total number of female admissions in most years. The ratio of emergency to elective admissions was the same as or greater among males than females in each of the years examined except the last. On average there were 6.5 emergency admissions for each elective admission among males and 6.3 among females.

The rate of admission for males was consistently higher than for females during the entire period 1991/92 to 2000/01 (Figure 5).

Examining age-specific rates, males aged 65 and over and 0–14 had consistently higher rates than males in other age groups, and females in any age group. Rates for males aged 65 and over were highest in each year except 2000/01 when those aged 0–14 had higher rates. In contrast, females aged 0–14 had consistently higher admission rates than females aged 65 and over throughout the period (Table 5). Looking at the patterns



in 5-year age bands (Figure 6), both sexes had high rates in the under 20s. These declined steadily to the 55–59 age group among women, and then increased strongly with age. Among men, however, the decline in the earlier years stopped at age 20, with rates then increasing to a peak among those aged 35–39 (matching the pattern for mortality). The rates then followed the same pattern as those for females.

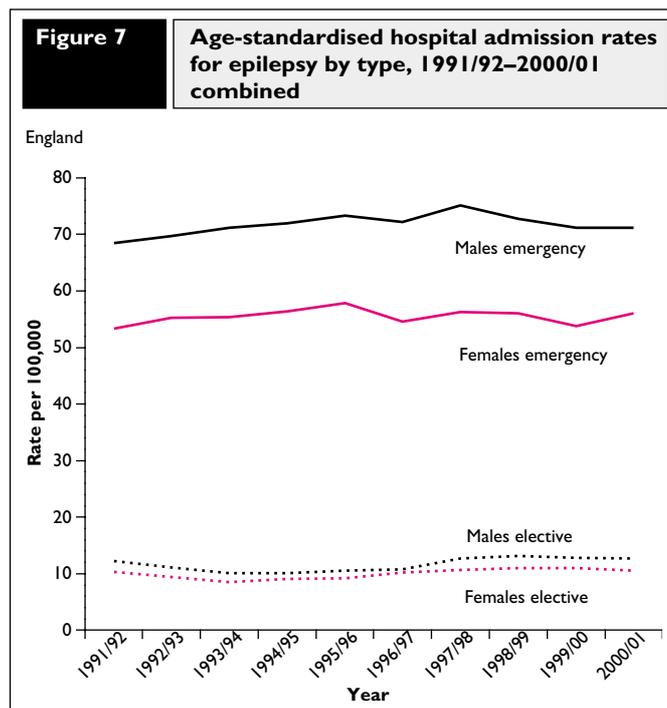
Figure 7 shows that for both emergency and elective admissions, rates changed little over the time period, with male rates being around 1.3 times higher than female rates for emergency admissions and 1.2 times higher for elective admissions.

DISCUSSION

Our study showed that death rates and hospital admission rates for epilepsy changed little during the periods examined (1993–2000 and 1991/92–2000/01 respectively). This was despite a large increase during the same period in the costs to the NHS of drugs prescribed for the treatment of epilepsy.³ Hence, increased spending on drugs for epilepsy (and in particular, spending on the newer high-cost drugs) appears to have had little discernible impact on the two population outcome measures for epilepsy examined in this article.

Most hospital admissions for epilepsy were emergency rather than elective. This is as would be expected for a condition where seizures are often sudden and unexpected. In addition to this a recent study of death certificates where epilepsy was mentioned, found that sudden death in epilepsy is the most common category of epilepsy-related death and concluded that accurate certification is therefore vital for the monitoring of trends.¹¹

Since 1953, five major reports have made recommendations to improve services for people with epilepsy but services remain fragmented.⁶ Between September 1999 and August 2000 a nationwide audit of epilepsy-related deaths was conducted in the UK. This National Sentinel Clinical Audit of Epilepsy-Related Death¹² aimed to establish whether deficiencies in the standard of clinical management, or in the overall health care package, could have contributed to the death. It revealed considerable problems with death certification for epilepsy. Only 42 per



cent of these deaths were subject to post mortem examination. Although most deaths were confirmed as being in keeping with epilepsy as the cause, many (87 per cent) of those deaths scrutinised that involved a post mortem were considered to have been inadequately investigated, largely because further investigations such as toxicology, histology or neuropathology had not been carried out.

The report concluded that it was difficult to establish the true number and nature of epilepsy-related deaths from national data and that action should be taken to improve the quality of death certification in relation to these deaths. Recent reviews of death certification and the role of the coroner, for example the Fundamental Review of Coroners¹³ and the Shipman Inquiry,¹⁴ have proposed changes to the process of death certification in England and Wales. One proposal is that post mortems be supplemented with more systematic collection of information about the patient’s medical history. Such investigations may improve the quality of information on deaths related to epilepsy.

The National Sentinel Clinical Audit of Epilepsy-Related Deaths also found deficiencies in access to and quality of care, communication between clinical staff and between healthcare professionals and patients and their families. A recent study¹⁵ also found that a significant proportion of patients with epilepsy under-reported seizures to their GP, especially among those patients holding a driving licence. The study concluded that GPs’ ability to treat patients is hampered by their role in regulating access to driving licences and particular occupations. Some of these problems with health services for epilepsy will be addressed in the new general practitioner contract and in the forthcoming National Service Framework on Long Term Limiting Illnesses. In response to the national audit, the Department of Health has published an action plan to improve services for people with epilepsy.⁷

Both the outcome measures examined here have limitations. Some of the limitations of mortality data on epilepsy have been discussed above. In particular, epilepsy is often not mentioned on death certificates (either in Part I or in Part II) even when it may have contributed to the death. Hence, the burden of epilepsy-related mortality is likely to be greater than indicated from official mortality statistics.

Hospital episode statistics also have limitations. Hospital admissions often reflect the views of local clinicians and factors such as the availability of acute hospital beds. Furthermore, emergency admission rates tend to be highest in areas of socio-economic deprivation.¹⁶ Hence, admission rates can vary widely in different parts of the country. The incidence of epilepsy itself also varies with deprivation, with one study showing incidence in deprived areas at over twice that in less deprived areas.¹⁷ The accuracy and completeness of the coding of hospital admissions data can also vary and this also introduces some errors in hospital admission rates.

CONCLUSIONS

This article has drawn together data on epilepsy from two national sources and has shown that mortality and hospital admissions related to epilepsy appear to have changed little during the 1990s, with rates higher in males than females. Rates varied by age, with mortality rates highest in those aged 65 and over. Hospital admission rates were highest in those aged 65 and over for males and those aged 0–14 for females. Among males aged 20–59, both mortality and hospital admission rates had a peak in the 35–39 age group. This peak was not present among females.

In the absence of better outcome measures, mortality rates and admission rates could continue to be monitored to provide a measure of the impact of epilepsy on the health of the population and on the National Health Service. In the longer term, more clinically-focused indicators may become available from electronic health records and complement the information available from currently available data.

Key findings

- Mortality and hospital admissions relating to epilepsy remained stable over the 1990s, at around 800 deaths and 37,000 admissions each year.
- Males had higher mortality rates and higher hospital admission rates than females.
- Mortality rates were highest in those aged 65 and over for both sexes.
- Hospital admissions were highest in those aged 65 and over for males until 2000/01 when rates were higher for 0–14s.
- Among males aged 20 to 59, both mortality and hospital admission rates had a peak in the 35–39 age group. This peak was not present among females.
- Hospital admission rates for females were highest for those aged 0–14 throughout the period 1991/92 to 2000/01.
- Hospital admissions for epilepsy tend to be emergency admissions rather than planned, with on average 6.5 emergency admissions to every planned admission for males and 6.3 for females.

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