Epilepsy prevalence and prescribing patterns in England and Wales

INTRODUCTION

Although epilepsy is the most common serious neurological disorder worldwide, only a few studies have examined the prevalence of epilepsy in the United Kingdom. Typically, they have examined relatively small populations and have not tried to examine time trends in prevalence. They have also used differing criteria to define epilepsy. In one of the most recent studies, Wallace found a period prevalence of 5.2 per 1,000 in 1995, after excluding the under five-year olds, from a sample of 2.05 million from the UK General Practice Research Database (GPRD). Few studies have examined the relationship between the prevalence of epilepsy and social deprivation.

Epilepsy has been neglected as a focus for health services policy, though there have been attempts to redress this recently. A European White Paper on epilepsy was presented to members of the European Parliament in March 2001. A report to the Department of Health in the UK has highlighted the need for research into the effectiveness and value of epilepsy services. The Department of Health has recently announced that it will develop a new National Service Framework (NSF) for long-term health conditions, with a particular focus on neurological conditions such as epilepsy.

Good treatment of epilepsy leads to a reduction in the frequency of seizures, which is in turn associated with improved psychosocial well being. Until recently, only a limited number of anti-epileptic drugs (AEDs) were available and all had troublesome side effects. There have been several new AEDs launched since 1990. Newer AEDs are mainly used as additional treatment in people whose epilepsy is not well controlled on older AEDs alone. Newer AEDs are promoted as effective as older drugs but with less side effects. However, comparative data on their cost-effectiveness are currently lacking. There are very few

This paper examines trends in the prevalence of treated epilepsy and in use of new anti-epileptic drugs (AEDs) in England and Wales between 1994 and 1998 using the General Practice Research Database. The age-standardised prevalence of epilepsy in 1998 was 7.4 per 1,000 in males and 7.2 per 1,000 in females, and increased by 7 per cent between 1994 and 1998. The percentage of patients prescribed newer AEDs increased from 6.8 per cent to 11.9 per cent in males and from 7.5 per cent to 13.7 per cent in females over the same period. In 1998, the use of newer AEDs was highest in those aged 5 to 15 years and lowest in the elderly. The prevalence of epilepsy was highest in deprived areas. The estimated number of patients with epilepsy in England and Wales in 1998 was 400,000 of which 50,000 (13 per cent) received new AEDs in 1998. The cost of prescribing AEDs in the community has risen from £26 to £86 million in less than 10 years, mainly due to an increase in the costs of prescribing newer AEDs.
comparisons between new drugs, though trials are now being undertaken. These newer drugs are significantly more expensive. For example, carbamazepine costs about £100 per patient per year, whereas the cost of using lamotrigine is £1,000 per year.

To address the lack of population-based information on recent trends in epidemiology and treatment of epilepsy we analysed data from the GPRD to:

- determine the age-specific prevalence of epilepsy in England and Wales between 1994 and 1998;
- explore the association between prevalence and deprivation; and
- examine trends in the treatment of epilepsy with newer AEDs during the same period.

We also used the Department of Health’s Prescribing Cost Analysis (PCA) data to examine time trends in prescribing volume and cost between 1991 and 1999.

**Methods**

**Data sources**

The GPRD is the world’s largest computerised database of longitudinal general practice patient records, with over 30 million patient-years of data. The comprehensiveness and accuracy of the database have been documented previously. Currently, information is collected prospectively on approximately 2.7 million patients, equivalent to approximately 4.7 per cent of the UK population. It contains anonymised information on practice demographic characteristics, individual medical diagnoses, as well as information on all significant consultations, prescriptions and events leading to withdrawal of a drug, investigations, hospital referrals, admissions and treatment outcomes. In this study we have used data from 1994 to 1998 to calculate the prevalence of epilepsy by age and sex across the whole age spectrum. We also examine the patterns of treatment with new versus old drugs with respect to age and time in England and Wales. Using 1998 mid-year population estimates we also provide estimates of the number of people in England and Wales with epilepsy in 20 age-sex strata.

PACT (prescribing analyses and cost) data are derived from prescriptions issued by general practitioners in England. These include all prescriptions dispensed in the community, i.e. by community pharmacists, dispensing doctors and prescriptions submitted by prescribing doctors for items personally administered in England. The Department of Health Prescription Cost Analysis system uses these data and includes prescriptions written in Wales, Scotland, Northern Ireland and the Isle of Man but dispensed in England. The data do not cover drugs dispensed in hospital or private prescriptions. The information collected includes the name and cost of the drug and the number of items dispensed (an item is defined as each preparation on the prescription). Drugs are categorised by the section of the British National Formulary (BNF) that they fall in. Hence, information is available for individual drugs (such as carbamazepine), for categories of drugs (such as benzodiazepines), or for therapeutic areas (such as antiepileptics). This information is available at individual practice level, health authority level, and national level. We have used data from the Department of Health Prescription Cost Analysis system to map trends in prescribing of individual drugs for epilepsy in England and associated costs from 1991 to 1999.

**Participants**

Data for the prevalence estimates in this study came from 211 general practices with a total list size of 1.4 million in England and Wales contributing data to the GPRD. This represents approximately half of all practices registered with the GPRD in 1994. We confined our analysis to those practices that contributed data throughout the period 1994 to 1998 that passed quality checks on its completeness. General practices participating in the GPRD follow agreed guidelines for the recording of clinical and prescribing data, and submit anonymised patient-based clinical records to the database at regular intervals. In this study the practices used either OXMIS or READ codes to code diagnoses. (OXMIS codes are based on ICD 8 and OPCS operation codes. READ codes are based on ICD 9 codes.)

**Selection of cases**

Patients of all age groups were included in the analysis if they were alive and permanently registered at the practice at 31 December during each year of the study, and had been registered for at least 6 months before that date. This was to ensure that sufficient time was allowed for the relevant information to be recorded on patients included in the analysis. The diagnosis of epilepsy was based on a clinical diagnosis of epilepsy recorded on the general practice computer using a code for epilepsy. In order to confine selection to active cases we only included cases that were prescribed drugs for epilepsy. For each year between 1994 and 1998, all patients who had ever had a diagnosis of epilepsy were identified based on READ and OXMIS codes and those patients who had been prescribed treatment with drugs in BNF section 4.8.1 (control of epilepsy) during the relevant year were selected.

Patients were then classified as having been prescribed a newer AED if they had at least one prescription for such a drug (see Box 1) during the relevant year. Similarly they were classified as having been prescribed an old AED if they had received at least one such prescription during the relevant year. Drug types are not mutually exclusive, i.e. patients can be prescribed both newer and older AEDs concurrently, so patients can appear in more than one drug category of Tables 1 and 2.

**Box one**

**Categories of anti-epileptic drugs (AEDs)**

<table>
<thead>
<tr>
<th>Established AEDs</th>
<th>New AEDs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carbamazepine</td>
<td>Gabapentin</td>
</tr>
<tr>
<td>Ethosuximide</td>
<td>Vigabatrin</td>
</tr>
<tr>
<td>Phenobarbitone</td>
<td>Lamotrigine</td>
</tr>
<tr>
<td>Methylphenobarbitone</td>
<td>Topiramate</td>
</tr>
<tr>
<td>Primidone</td>
<td>Tiagabine</td>
</tr>
<tr>
<td>Phenytoin</td>
<td></td>
</tr>
<tr>
<td>Sodium Valproate</td>
<td></td>
</tr>
<tr>
<td>Clonazepam</td>
<td></td>
</tr>
<tr>
<td>Clobazam</td>
<td></td>
</tr>
<tr>
<td>Acetazolamide</td>
<td></td>
</tr>
</tbody>
</table>

**Deprivation**

The GPRD does not contain information on the socio-economic status of individual patients and no information is available on where the practice patients live, so practice postcode was used to ascertain which census ward the patient’s practice was located in. Data were aggregated for all participating practices in each deprivation category. The deprivation categories were derived using the Townsend Material Deprivation Score.
In the analysis presented here the Townsend Scores for all the wards in England and Wales were arranged in ascending order along with the total population of each ward in 1991. The wards were divided into five groups each of which contained 20 per cent of the total population of England and Wales. A range of Townsend Scores describes each of these population quintiles (named Q1, Q2, Q3, Q4, and Q5, where Q1 is the least deprived and Q5 the most deprived). Each general practice was allocated to a quintile on the basis of the Townsend Score of the ward in which it is located.

**Statistical methods**

We calculated prevalence by age and sex. Directly age-standardised prevalence was calculated by applying the age-specific values, by 5-year age groups up to age 84 (except 10–15 and 16–19) and then 85 and over, to the European Standard Population.

We examined the percentage of patients with epilepsy prescribed new and old AEDs by age and sex. Again we calculated both crude and age-standardised rates. However, here we calculated the age-standardised prescribing rates by applying the prescribing percentages by 5-year age groups (as above) to a different standard population. The standard population used was the estimated number of cases of treated epilepsy in England and Wales between 1994 and 1998. This standard population was calculated by applying prevalence of treated epilepsy in the 211 practices, for males and females combined, to the estimated population of England and Wales in 1994 by the same age groups.

Age- and sex-specific prevalence and prescribing rates were applied to the population of England and Wales in 1998 to estimate the number of cases of treated epilepsy in the population and the number of patients prescribed new AEDs.

### Table 1

*Age-specific prevalence of treated epilepsy and prescribing rates of anti-epileptic drugs, males, 1994 and 1998*

<table>
<thead>
<tr>
<th>England and Wales</th>
<th>Age</th>
<th>0-4</th>
<th>5-15</th>
<th>16-24</th>
<th>25-34</th>
<th>35-44</th>
<th>45-54</th>
<th>55-64</th>
<th>65-74</th>
<th>75-84</th>
<th>85 and over</th>
<th>All ages</th>
<th>Age-standardised rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>1994</td>
<td>Prevalence rate per 1,000</td>
<td>2.1</td>
<td>4.2</td>
<td>6.3</td>
<td>7.2</td>
<td>7.2</td>
<td>7.7</td>
<td>9.0</td>
<td>10.9</td>
<td>13.5</td>
<td>16.2</td>
<td>7.2</td>
<td>7.0</td>
</tr>
<tr>
<td></td>
<td>Percentage prescribed newer anti-epileptic drugs</td>
<td>10.4</td>
<td>14.8</td>
<td>7.9</td>
<td>10.9</td>
<td>9.2</td>
<td>5.8</td>
<td>3.3</td>
<td>1.6</td>
<td>1.1</td>
<td>1.4</td>
<td>6.9</td>
<td>6.8</td>
</tr>
<tr>
<td></td>
<td>Percentage prescribed older anti-epileptic drugs</td>
<td>98.5</td>
<td>99.1</td>
<td>100.0</td>
<td>99.8</td>
<td>99.4</td>
<td>100.0</td>
<td>99.8</td>
<td>100.0</td>
<td>100.0</td>
<td>99.7</td>
<td>99.8</td>
<td></td>
</tr>
<tr>
<td>1998</td>
<td>Prevalence rate per 1,000</td>
<td>1.9</td>
<td>4.4</td>
<td>6.6</td>
<td>7.9</td>
<td>8.0</td>
<td>8.4</td>
<td>9.5</td>
<td>10.9</td>
<td>13.9</td>
<td>15.1</td>
<td>7.7</td>
<td>7.4</td>
</tr>
<tr>
<td></td>
<td>Percentage prescribed newer anti-epileptic drugs</td>
<td>22.2</td>
<td>25.1</td>
<td>18.7</td>
<td>14.6</td>
<td>15.7</td>
<td>10.3</td>
<td>6.1</td>
<td>5.4</td>
<td>1.7</td>
<td>3.3</td>
<td>12.1</td>
<td>11.9</td>
</tr>
<tr>
<td></td>
<td>Percentage prescribed older anti-epileptic drugs</td>
<td>96.8</td>
<td>91.8</td>
<td>96.8</td>
<td>99.0</td>
<td>98.6</td>
<td>98.9</td>
<td>98.8</td>
<td>99.0</td>
<td>99.4</td>
<td>98.1</td>
<td>98.1</td>
<td></td>
</tr>
</tbody>
</table>

Source: General Practice Research Database

### Table 2

*Age-specific prevalence of treated epilepsy and prescribing rates of anti-epileptic drugs, females, 1994 and 1998*

<table>
<thead>
<tr>
<th>England and Wales</th>
<th>Age</th>
<th>0-4</th>
<th>5-15</th>
<th>16-24</th>
<th>25-34</th>
<th>35-44</th>
<th>45-54</th>
<th>55-64</th>
<th>65-74</th>
<th>75-84</th>
<th>85 and over</th>
<th>All ages</th>
<th>Age-standardised rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>1994</td>
<td>Prevalence rate per 1,000</td>
<td>1.3</td>
<td>4.0</td>
<td>6.8</td>
<td>7.4</td>
<td>7.1</td>
<td>8.3</td>
<td>9.0</td>
<td>8.9</td>
<td>9.2</td>
<td>10.5</td>
<td>7.1</td>
<td>6.8</td>
</tr>
<tr>
<td></td>
<td>Percentage prescribed newer anti-epileptic drugs</td>
<td>31.6</td>
<td>12.5</td>
<td>10.7</td>
<td>11.1</td>
<td>11.0</td>
<td>5.5</td>
<td>3.6</td>
<td>2.6</td>
<td>0.3</td>
<td>0.0</td>
<td>7.3</td>
<td>7.5</td>
</tr>
<tr>
<td></td>
<td>Percentage prescribed older anti-epileptic drugs</td>
<td>94.7</td>
<td>98.2</td>
<td>99.4</td>
<td>99.3</td>
<td>98.8</td>
<td>100.0</td>
<td>99.8</td>
<td>99.8</td>
<td>100.0</td>
<td>99.4</td>
<td>99.4</td>
<td></td>
</tr>
<tr>
<td>1998</td>
<td>Prevalence rate per 1,000</td>
<td>1.8</td>
<td>4.1</td>
<td>6.9</td>
<td>7.9</td>
<td>7.8</td>
<td>8.7</td>
<td>9.0</td>
<td>10.2</td>
<td>9.9</td>
<td>11.0</td>
<td>7.6</td>
<td>7.2</td>
</tr>
<tr>
<td></td>
<td>Percentage prescribed newer anti-epileptic drugs</td>
<td>21.8</td>
<td>26.7</td>
<td>25.9</td>
<td>18.4</td>
<td>16.4</td>
<td>12.4</td>
<td>7.5</td>
<td>2.9</td>
<td>2.0</td>
<td>1.1</td>
<td>13.3</td>
<td>13.7</td>
</tr>
<tr>
<td></td>
<td>Percentage prescribed older anti-epileptic drugs</td>
<td>94.5</td>
<td>93.0</td>
<td>92.5</td>
<td>95.6</td>
<td>96.5</td>
<td>97.8</td>
<td>98.7</td>
<td>99.6</td>
<td>99.0</td>
<td>99.4</td>
<td>96.9</td>
<td>96.8</td>
</tr>
</tbody>
</table>

Source: General Practice Research Database
Costs of AEDs

We used PACT data to examine trends in the costs of prescribing AEDs in England between 1991 and 1999. The number of prescription items and the net ingredient cost for all the drugs studied was requested from the Department of Health Statistics Division whose Prescription Cost Analysis system conducts a full analysis of PACT data.

RESULTS

Prevalence of epilepsy

The prevalence of treated epilepsy in 1998 was 7.7 per 1,000 in men (Table 1) and 7.6 per 1,000 in women (Table 2). Age-standardised prevalences were 7.4 per 1,000 in men and 7.2 per 1,000 in women. Prevalence increased with age from less than 2 per 1,000 in under 5 year olds to over 10 per 1,000 in those aged 85 years and over. Age-specific prevalence was similar in men and women in all age groups up to 55 years. Above 55 years the prevalence was higher in men than in women and diverged most in those aged 75 years and over. There was a 7 per cent increase in the age-standardised prevalence of epilepsy in men and in women between 1994 and 1998 (Figure 1). The distribution of the burden of disease varies across different age groups. In 1998, for instance, 20 per cent of cases were under 24 years, 20 per cent over 65 years and 60 per cent aged between 25 and 64 years.

During the period 1994 to 1998, the recorded prevalence of treated epilepsy in the 211 practices shows a clear gradient across the deprivation categories for both males and females (Figures 2 and 3). The prevalence is 6.3 per 1,000 in the least deprived category in females rising to 7.9 per 1,000 in the most deprived; that is a 25 per cent difference in prevalence between the most and the least deprived groups. In males these rates are 6 and 8 per 1,000 respectively, again a 25 per cent difference.

Prescribing trends

GPRD: patterns of AED prescribing

Prescribing of newer AEDs for patients with epilepsy increased between 1994 and 1998. Between 1994 and 1998 the percentage of patients prescribed newer AEDs increased from 6.8 per cent to 11.9 per cent in men (Table 1), and from 7.5 per cent to 13.7 per cent in women.
There was no relationship between deprivation category and percentage prescribed newer AEDs, and little variation in prescribing patterns across NHS Regional Office areas as defined in April 1996 (data not shown).

**PCA: trends in prescribing volumes and costs**

The cost of prescribing AEDs in the community has risen three-fold in the last 10 years, from £26 to £86 million, a yearly increase five times the rate of inflation (Table 3, Figure 5). This is largely explained by a rapid increase in the prescribing of newer AEDs (Table 3, Figure 6). Over the period 1991 to 1999, the number of AED prescription items in England rose by 33 per cent and 42 per cent of this increase was accounted for by increased prescribing of new AEDs. The volume of

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(Table 2). The rate of prescribing of newer AEDs was age dependent. In 1998, 25.1 per cent of boys aged 5–15 years were prescribed newer AEDs compared with 1.7 per cent of men aged 75–84 years. The percentage of women prescribed newer anti-epileptic drugs in 1998 was highest in those aged 5–15 years at 26.7 per cent and lowest in those aged 85 years and over at 1.1 per cent (Figure 4).

By comparison, the use of older AEDs decreased slightly between 1994 and 1998. The percentage of males with epilepsy prescribed older AEDs decreased slightly from 99.8 per cent to 98.1 per cent. The percentage of females prescribed older anti-epileptic drugs also decreased from 99.4 per cent to 96.8 per cent during this period. Prescribing of older AEDs was highest among those over 65 years.

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**Table 3**

<table>
<thead>
<tr>
<th>England</th>
<th>Total community anti-epileptic drug (AED) prescription expenditures and new AED expenditures, 1991 to 1999</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year</td>
<td>All community AED expenditure*</td>
</tr>
<tr>
<td></td>
<td>Amount (£ million)</td>
</tr>
<tr>
<td>1991</td>
<td>26.4</td>
</tr>
<tr>
<td>1992</td>
<td>31.5</td>
</tr>
<tr>
<td>1993</td>
<td>36.9</td>
</tr>
<tr>
<td>1994</td>
<td>42.5</td>
</tr>
<tr>
<td>1995</td>
<td>49.1</td>
</tr>
<tr>
<td>1996</td>
<td>57.6</td>
</tr>
<tr>
<td>1997</td>
<td>65.8</td>
</tr>
<tr>
<td>1998</td>
<td>74.8</td>
</tr>
<tr>
<td>1999</td>
<td>86.5</td>
</tr>
</tbody>
</table>

Source: Data are from Department of Health, Statistics Division, Prescription Cost Analysis system

* The net ingredient cost (NIC) is the basic cost of a drug. This cost does not take account of discounts, dispensing costs, fees or prescription charges income.
† The Retail Price Index measures the change in average level of prices of goods and services purchased by most households in the UK. The figures for the 12 months to January are given here.
** The annual increase is the increase from the previous year.
older AEDs prescribed increased from 4.8 million prescription items in 1991 to 5.7 million in 1999, compared with more than a hundred-fold increase in prescribing of new AEDs from 5,400 to 721,000 over the same period (Figure 7). Expenditure on sodium valproate and carbamazepine has kept pace with inflation. However the greatest increase, accounting for approximately a third of the total costs in this class is lamotrigine. Gabapentin, which was launched later, shows a similar trend.

The four drugs that accounted for the highest percentage of these costs are listed in Table 4. This shows that gabapentin and lamotrigine accounted for 44 per cent of the total costs of prescribing of this group of drugs in the community in 1999, despite comprising only nine per cent of the total volume of prescription items.

**Epilepsy in England and Wales**

The estimated number of patients with treated epilepsy in England and Wales in 1998 was almost 400,000. Of these about 51,000 (13 per cent) were treated with new AEDs in 1998 (Figure 4). Most patients with treated epilepsy are aged 25 to 54 years.

**DISCUSSION**

Our study is among the largest population-based studies of trends in epidemiology and prescribing for epilepsy that have been carried out in England and Wales. The prevalence of epilepsy in our study is higher than that found by other researchers. Unlike many other studies, our study was large enough to provide robust estimates of the prevalence of epilepsy for men and women separately, and for different age groups. It has also allowed us to explore trends in prevalence and treatment over time.

There has been a change in the management of epilepsy in primary care in recent years as shown by community prescribing data. An increased percentage of patients were prescribed newer anti-epileptic drugs between 1994 and 1998, but this was restricted to younger age groups. We can speculate on possible explanations for these age-dependent prescribing patterns. The older patients in this study may include a cohort that have been maintained on older drugs for many years and are perhaps less likely to be started on newer treatments, especially if they are well controlled. Age-specific side effects, such as liver toxicity from sodium valproate in children, may mean newer AEDs are tried as first line agents. It will be important to monitor these trends as new drugs continue to be made available.
Comparison with previous studies

Because of the large number of cases included, our study provides reliable estimates of the prevalence and treatment of epilepsy, including estimates of prevalence and treatment by age group and sex. We found the prevalence of epilepsy (7.4 per 1,000 males and 7.2 per 1,000 females) to be higher than that reported in earlier epidemiological studies in England and Wales. This included a recent study using the GPRD that found a prevalence of 5.2 per 1,000 among those aged over 5 years. However, compared with this study, we used more sensitive criteria for selecting cases and more rigorous validity checks to exclude practices that were not coding data accurately. A recent community-based cross-sectional study of 39 practices covering a population of 225,439 based in Bradford, found a prevalence of 7.3 per 1,000 population. This finding was consistent with our own study, although this estimate included 209 (13 per cent) patients not on treatment. If only those cases that met internationally agreed definitions for active epilepsy were included (62 per cent) the prevalence was 4.5 per 1,000; and including all those on treatment (active or in remission), as we have done, the prevalence was 6.4 per 1,000.

The examination of time trends in the prevalence and treatment of epilepsy was an original feature of our study. This suggests that prevalence is increasing, particularly in older people. In view of the size of the study and the trend, this is likely to be a significant finding. We have not explored the reason for this, but it is probably attributable to increased survival of people with cerebrovascular disease, and would suggest that the burden of disease from epilepsy will increase in the future.

Although the relation between ill health and social deprivation has been well documented, few studies have examined the relationship between the prevalence of epilepsy and social deprivation. The association we found between epilepsy and socio-economic deprivation supports the findings of an earlier hospital-based study. We were not able to explore the reasons for this association. We are also aware that this is an ecological association, and individual patient characteristics are much more powerful predictors of demand than the characteristics of the areas in which patients live.

The rise in prescribing of the newer anti-epileptic drugs for patients with epilepsy found here is consistent with the findings of an earlier study reported by Roberts. They found the number of prescriptions for AEDs in Northern and Yorkshire region rose by 15 per cent between 1992 and 1995, and that a third of this rise was due to prescribing of the new AEDs vigabatrin, lamotrigine and gabapentin. Few previous studies have examined the effect of age on AED prescribing; our demonstration that community prescribing of newer AEDs is age related is new.

The most recent estimates of the total costs of epilepsy in the UK are £600 million per year, with 30 per cent of this attributable to AEDs. Our findings show the costs of prescribing these drugs in the community are currently rising at five times the rate of inflation. Newer drugs, despite making up only a small proportion of total prescriptions, are largely responsible for this rapid increase in costs.

Strengths and weaknesses of study

This study uses information from the GPRD, a large and well-validated general practice derived database. All the practices passed quality checks on the data they supplied to the database. The subset of general practices from the database we used in our study had a combined population of 1.4 million, with a similar age-sex composition to that of England and Wales in 1998. However, relatively few practices contributing information to the GPRD are located in inner city areas, particularly inner London. In selecting people who had been resident for more than 6 months, infants and the more mobile populations are also under-represented.

The main limitation of this study is that we did not validate the diagnosis, for example, by examining whether patients had their diagnosis confirmed by a specialist. The reason for not doing this is that this would have considerably increased costs and made it unfeasible. Another limitation is that the study only includes diagnosed cases of epilepsy and hence cases that had not come to the attention of a GP would not be included. Thus, there may be unmet need not identified by these estimates.

A commonly accepted clinical definition of epilepsy is at least two unprovoked seizures, but because of the limitations of the general practice coding systems we cannot be certain that all cases recorded here would conform to this definition. However, by including only those patients on treatment it is likely that we have excluded most cases of a single provoked seizure for which treatment with an AED would not normally be started in the UK. Finally, misdiagnosis is an important problem in the management of epilepsy, with as many as 20 per cent of cases inaccurately diagnosed.

There may also be some deficiencies in the prescribing data. For example, some patients with epilepsy may have their drug monitoring and prescribing carried out entirely in secondary care. Hence, the percentage of patients prescribed newer AEDs in this study may be an under-estimate. However, as most patients will have their ongoing treatment prescribed by their general practitioner, the effect of this is not likely to be great. There is also the difficulty with interpretation in that AEDs are not prescribed exclusively for epilepsy and therefore the PCA data, which are not patient linked, will include these drugs prescribed for other conditions, e.g. neuropathic pain, trigeminal neuralgia. However, gabapentin was not licensed for pain until after the period of the study and lamotrigine is only licensed for epilepsy.

Meaning of study

Our study suggests there were about 400,000 patients with epilepsy in England and Wales, of whom about 50,000 (13 per cent) received newer anti-epileptic drugs in 1998. Our study provides baseline figures for the expected prevalence of epilepsy in primary care and the percentage of patients currently prescribed new versus old AEDs. It should provide an important background to policy and planning for services such as the forthcoming NSF on long-term conditions. It will also help in clinical discussions on how appropriately special patient populations such as elderly patients or women of childbearing age are being treated.

Unanswered questions and future research

Our study gives estimates of the prevalence and treatment of epilepsy in England and Wales, including information on the ratio of new to old drugs. However, some questions remain unanswered. Ideally we would like to measure outcomes, e.g. reductions in morbidity, reduced seizure frequency, to account for benefit as well as costs of treatment. Karlsson suggested higher prices of newer AEDs (18 per cent of total sales in a district accounted for 70 per cent of the cost) is justified by evidence of improved seizure control. However, the benefits of newer therapies cannot be assumed to outweigh the substantially increased costs even when reduction in adverse events is taken into account. Future work should aim to establish the cost-effectiveness of new AEDs in different patient populations.
The recent addition of new AEDs has greatly widened the range of therapeutic options for patients, and has contributed to the increases in prescribing of AEDs overall. But given the lack of cost-effectiveness information on these novel drugs, the wider question of how funds should be allocated within a specialty to achieve equitable health gain remains open. Elderly patients, who are known to be less represented in drug trials, appear to have less access to these newer drugs.

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Key points
- The age-standardised prevalence of epilepsy in 1998 was 7.4 per 1,000 males and 7.2 per 1,000 females.
- There are about 400,000 people with epilepsy in England and Wales.
- The cost of prescribing drugs for the treatment of epilepsy in the community has risen from £26 million in 1991 to £86 million in 1999.
- Two drugs, gabapentin and lamotrigine, accounted for 44 per cent of the total drug costs for epilepsy in 1999 despite accounting for only nine per cent of drugs by volume of prescribing.

References