

Patients' perspectives on services for epilepsy: a survey of patient satisfaction, preferences and information provision in 2394 people with epilepsy

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The objectives of this study were to provide a comprehensive survey of satisfaction with care, care preferences and information provision for patients with epilepsy, and to formulate recommendations for the development of epilepsy services based on the findings.

A questionnaire was distributed to 4620 patients who were currently receiving antiepileptic drugs for epilepsy, regardless of aetiology, duration or severity. Two different samples of patients with epilepsy were questioned: the first an unselected sample drawn from primary care, and the second consisting of consecutive patients drawn from hospital clinics.

There were 2394 responses to the questionnaire. Satisfaction with primary and hospital care was high, both overall and for specific aspects. However, two major shortcomings were identified. First, few respondents felt that their care was shared between hospital and GP. Secondly, provision of information about epilepsy was perceived to be poor, particularly by the elderly.

Younger patients and patients with severe epilepsy had a higher satisfaction with and preference for hospital care, whereas older age groups were more satisfied with and preferred primary care. Patients' main reasons for preferring primary care were that it was more personal and the GP was more familiar with them, and secondary care was preferred because the hospital doctor knew more about epilepsy.

In conclusion, we have conducted the largest representative UK survey of patients' perceptions and views of the care available for epilepsy. Although patient satisfaction was high, information provision is poor and the shared care model is not operating effectively. We recommend that an emphasis be placed on methods for improving the interface between primary and secondary care. The setting up of hospital epilepsy centres, as recommended by the recently published Clinical Standards Advisory Group report on epilepsy¹, would provide a focus for these efforts and for information provision.

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Key words: epilepsy; health care quality, access, and evaluation; health services research; patient satisfaction; questionnaire; health services needs and demand; primary care; secondary care; UK.

What is already known on this topic

- Care for patients with epilepsy is distributed across all NHS levels but little is known about patients' preferences for their main source of care or the extent to which shared care is realized.

What this study adds

- Overall, most patients with epilepsy were satisfied with their experience at both the primary and secondary care levels.
- Most people with epilepsy would prefer their care to be community based, especially older patients and patients with mild epilepsy.

- Shared care for epilepsy is failing but has the potential to improve levels of care and patient satisfaction.
- The provision of information about epilepsy is perceived to be poor at all levels of care.
- It is recommended that epilepsy centres be set up to provide a focus for hospital service provision with strong links to general practice and with emphasis on methods of shared care.

INTRODUCTION

Epilepsy is one of the most common serious neurological conditions. In the West, the annual incidence is approximately 50 people per 100 000, and rises steeply in older age; about 25% of people will continue with the condition for life^{2,3}. It results in considerable morbidity and demands on health services^{4,5} and is associated with an approximately threefold excess mortality rate⁶. In women with epilepsy, fertility rates are lower and there is an increased incidence of serious congenital conditions in their offspring⁷. Many adults with epilepsy have problems with employment, driving and social relationships and other aspects of social life, and many children with epilepsy suffer social and educational restriction with enduring sequelae⁸.

In the last decade there have been at least 20 surveys of the patients' perspective of epilepsy services in the UK, including Hart and Shorvon 1995⁹ (1628 cases), Jacoby *et al.*, 1996¹⁰ (696 cases), Ridsdale *et al.*, 1996¹¹ (251 cases), and Bradley, 1998¹² (251 cases). In addition, since the foundation of the NHS, there have been five government-sponsored reports on epilepsy services¹³⁻¹⁷. This literature suggests that care for epilepsy tends to be fragmented, with insufficient coordination between primary and specialist care, and insufficient information provision for patients.

Consideration of the most recent Government report, The Winterton Report¹⁶, was largely overshadowed by the massive reorganization of the NHS in the current decade and few of its recommendations were implemented. Although the reforms are ongoing, it is an apposite time to re-evaluate epilepsy care services, particularly as the focus in health service planning has shifted to embrace the user's perspective, and also because of the major medical advances in the diagnosis and treatment of epilepsy. We have carried out the largest representative UK survey to date of user satisfaction, perceived levels of information provision and

preferences for epilepsy services. The aims of this paper were:

- (a) To identify patient preferences and whether they were met.
- (b) To assess patient satisfaction with primary and hospital care for epilepsy, overall and for specific aspects.
- (c) To assess the level of provision of information about epilepsy for patients.
- (d) To survey the views of service users on how their care might be improved.

As patient satisfaction with care is known to be influenced by age and disease severity, older and healthier patients tending to report higher levels of satisfaction^{18,19}, we sought to identify any differences that may exist in different age and epilepsy severity groups.

MATERIALS AND METHODS

The questionnaire

The questionnaire included sections for sociodemographic details; seizure frequency and severity; the number of visits to primary care and hospital doctors for epilepsy in the last 12 months; satisfaction; information provision; the preferred and actual main source of medical care for epilepsy; and suggestions for improvement of care. For children and patients with learning difficulties, the parents or carers were asked to help complete the questionnaire.

Seizure severity was assessed using a patient-completed version of the National Hospital Seizure Severity Scale (NHS3)²⁰. Respondents were asked to indicate their level of overall satisfaction with primary and hospital care and their satisfaction with specific submeasures for each type of care (for both primary and hospital care; doctor communication, whether the doctor took their views into account; for primary care only: the ease of routine and emergency access). Fixed responses were offered, with the most favourable ones appearing first. For hospital care, respondents were asked about the level of continuity of care with three fixed responses available. To assess information provision, respondents were asked whether they recalled receiving information on 14 subjects[†] (with fixed responses: 'Yes', 'No', 'Don't know' or 'Not applicable' for each item). Respondents were asked whether their main source of care was at the primary or hospital

[†] Cause of epilepsy; type of epilepsy; chances of becoming seizure free; potential hazards of epilepsy; potentially hazardous activities; job restrictions; AED adverse effects; free prescriptions; alcohol use; need for adequate sleep; photosensitivity; voluntary groups; social services/allowances; driving.

level or shared between the two, and which they preferred and why, with three fixed responses provided. Finally, patients were asked to suggest ways in which the care for epilepsy at the primary and hospital levels could be improved (free text).

Ethical approval

Ethical approval was obtained from the North Thames Multi-centre Research Ethics Committee and from each Local Research Ethics Committee.

Patient recruitment

Patients were drawn from primary care, *the population-based* (PB) sample, and hospital practice, *the specialist care* (SC) sample. The PB sample was recruited via 80 geographically distributed GP practices with disease and age/sex registers. It is therefore an unselected, population-based sample, and representative of all patients with epilepsy. GPs were asked to send questionnaires to all patients currently receiving antiepileptic drugs (AEDs) for epilepsy, excluding febrile convulsions. The SC sample was recruited via hospital doctors identified from databases held by The Association of British Neurologists, The British Paediatric Neurologists Association and from the 1998 Medical Directory²¹. Sixty-two hospital doctors, 41 neurologists and 21 paediatricians and paediatric neurologists, were selected to provide national coverage. Each was asked to hand out questionnaires to up to 25 consecutive patients attending out patient clinics and taking AEDs for epilepsy, again excluding febrile convulsions.

Data processing and analysis

A secure coding system was used to protect patient identity. Questionnaires were distributed from December 1998 and those returned by 30th April 1999 were included in the analysis. Patients with an NHS3 score above 15 were classified as having severe epilepsy and patients with a score of 15 or less were classified as having mild epilepsy, unless they had 10 or more seizures in the last 12 months, in which case they were classified as severe. For the analysis of satisfaction with primary and hospital care, only patients who had visited their GP or a hospital clinic, respectively, within 12 months were included. For each question, the responses were quantified by calculating the proportion of responses that indicated satisfaction (e.g. 'Very satisfied', 'Fairly satisfied').

Information provision for specific topics was quan-

tified by calculating the proportion of patients that recalled receiving information on the topic. In order to obtain an overview of information provision, all the topics were pooled and the proportion of positive responses were calculated to obtain an *overall level of information provision*. We did not compare information provision between patients with mild and severe epilepsy, as the needs for information in these groups are likely to be different. For the analysis of whether patients' preferences for primary or hospital care were met, only patients who stated both their preference and their actual main source of care were included.

The above variables were analysed separately for the PB and SC samples. Patients were grouped by age and seizure severity and chi-squared tests were used to compare the findings in these different categories.

RESULTS

Questionnaire response rates

In the PB sample, 3455 questionnaires were sent and 1652 (48%) returned completed. In the SC sample, 1165 questionnaires were sent and 742 (64%) returned completed. The overall response rate was 52%.

Objective details and severity of epilepsy

PB sample

There were 47.2% males, 48.5% females (and 4.4% gender not stated). The median age was 43 years. The breakdown of epilepsy severity was: mild 64.3%, severe 32.5% and unclassified 3.2%.

SC sample

There were 45.1% males, 52.6% females (and 2.3% gender not stated). The median age was 28 years. The breakdown of epilepsy severity was: mild 25.6%, severe 71.0% and unclassified 3.4%.

Satisfaction

PB sample

Table 1 shows that 91.7% of respondents were satisfied with their overall primary care, in comparison to 86.4% satisfied with their overall hospital care. Satisfaction with both overall primary care and overall hospital care was lower in patients with severe epilepsy compared to those with mild epilepsy (for primary care, $\chi^2 = 12.91$, df. = 1, $P = 0.0003$; for hospital

Table 1: Overall satisfaction with primary and hospital care in people with epilepsy. The number of patients that responded to each question, *n*, and the proportion of the responses that indicated satisfaction, Sat(%), are shown.

| Age (years) | Seizure severity | | | | Patients* | |
|---|------------------|--------|----------|--------|---------------|--------|
| | Mild | | Severe | | All patients* | |
| | <i>n</i> | Sat(%) | <i>n</i> | Sat(%) | <i>n</i> | Sat(%) |
| Overall satisfaction with primary care (PB) | | | | | | |
| <17 | 12 | 91.7% | 35 | 71.4% | 53 | 79.2% |
| 17–65 | 195 | 96.9% | 292 | 90.8% | 501 | 92.8% |
| >65 | 36 | 97.2% | 22 | 86.4% | 63 | 93.7% |
| All† | 257 | 96.5% | 364 | 88.5% | 647 | 91.7% |
| Overall satisfaction with hospital care (PB) | | | | | | |
| <17 | 36 | 94.4% | 53 | 98.1% | 97 | 96.9% |
| 17–65 | 101 | 88.1% | 214 | 79.4% | 325 | 82.5% |
| >65 | 18 | 88.9% | 16 | 93.7% | 37 | 91.9% |
| All† | 160 | 90.0% | 289 | 83.7% | 470 | 86.4% |
| Overall satisfaction with primary care (SC) | | | | | | |
| <17 | 17 | 88.2% | 72 | 83.3% | 95 | 85.3% |
| 17–65 | 60 | 91.7% | 228 | 90.4% | 296 | 90.9% |
| >65 | 3 | 100.0% | 5 | 80.0% | 8 | 87.5% |
| All† | 84 | 91.7% | 319 | 89.0% | 418 | 89.7% |
| Overall satisfaction with hospital care (SC) | | | | | | |
| <17 | 42 | 92.9% | 149 | 96.0% | 199 | 95.5% |
| 17–65 | 105 | 97.1% | 289 | 92.4% | 405 | 93.3% |
| >65 | 8 | 87.5% | 10 | 100.0% | 18 | 94.4% |
| All† | 163 | 95.7% | 465 | 94.0% | 648 | 94.3% |

* Including patients with epilepsy of unknown severity.

† Including patients of unknown age.

care, $\chi^2 = 3.35$, *df.* = 1, *P* = 0.0673). Overall satisfaction with primary care was lower in patients under 17 years (79.2% satisfied) in comparison to older patients (92.9% satisfied) (χ^2 with Yates' correction = 10.19, *df.* = 1, *P* = 0.0014). In contrast, overall satisfaction with hospital care was higher in patients under 17 years (96.9% satisfied) compared to older patients (83.4% satisfied) ($\chi^2 = 11.74$, *df.* = 1, *P* = 0.0006). Most patients (299 out of 401, 74.6%) reported a satisfactory level of continuity of hospital outpatient care (i.e. seeing the same doctor on different visits).

There were no significant gender differences in overall satisfaction levels for either primary or hospital care, overall or within the age/epilepsy severity categories (data not shown).

SC sample

Table 1 shows that 89.7% of respondents were satisfied with their overall primary care, and 94.3% were satisfied with their overall hospital care. For overall satisfaction with primary care and with hospital care there was no significant difference between patients with mild and severe epilepsy (primary care, $\chi^2 = 0.50$, *df.* = 1, *P* = 0.481; hospital care, $\chi^2 = 0.68$, *df.* = 1, *P* = 0.411). Overall satisfaction with primary care and hospital care did not significantly differ with age (primary care: under

17 years 85.3% satisfied; over 17 years 90.8% satisfied; $\chi^2 = 2.35$, *df.* = 1, *P* = 0.126) (hospital care: under 17 years 95.5% satisfied; over 17 years 93.4% satisfied; $\chi^2 = 1.05$, *df.* = 1, *P* = 0.306).

For the hospital care submeasures of satisfaction, the findings were similar to those in the PB sample. For continuity of care in outpatients clinics, 83.1% (516 out of 621) reported a satisfactory level. As in the PB sample, there were no significant differences in the primary care submeasures, overall or within any of the age/epilepsy severity categories. There were no significant differences in overall satisfaction levels for primary or hospital care between males and females, overall or within the age/epilepsy severity categories (data not shown).

Responsibility for care and care preferences

The PB sample

Table 2 shows that most adults (830 out of 1228, 67.6%) preferred primary care and, in most, this preference was met (770, 92.8%). This preference was significantly more marked in patients over 65 years (≤ 65 years: 640 preferred GP, 129 preferred hospital; > 65 years: 190 preferred GP, 14 hospital; $\chi^2 = 12.64$, *df.* = 1, *P* = 0.0004). In patients under 17 years, however, more preferred hospital as opposed to pri-

mary care (adults: 830 preferred primary care, 143 preferred hospital care; children: 26 preferred primary care, 42 preferred hospital care; $\chi^2 = 96.36$, $df. = 1$, $P < 0.0001$). In all age groups, a higher proportion of the patients with severe epilepsy, as opposed to those with mild, preferred hospital care (under 17 years: $\chi^2 = 4.58$, $df. = 1$, $P = 0.0324$; 17–65 years: $\chi^2 = 25.41$, $df. = 1$, $P < 0.0001$; over 65 years: χ^2 with Yates' correction = 0.67, $df. = 1$, $P = 0.4131$).

The SC sample

There were, 642 valid responses to the questions about the main source of care and patient preference (see Table 2). Three-hundred and seventy-seven (58.7%) patients preferred to receive their main care from hospital, and of these, 344 (91.2%) did so. Of 63 (9.8%) patients who would have preferred to receive their main care from their GP, 31 (49.2%) did so. In all age groups, a higher proportion of patients with severe epilepsy as opposed to mild, preferred hospital care (under 17 years: χ^2 with Yates' correction = 0.06, $P = 0.8065$; over 17 years: $\chi^2 = 4.56$, $P = 0.0328$). The reasons given for care preference in the PB and SC samples are shown in Table 3.

Table 2: Patients' preferences for the main source of care for their epilepsy compared to their perceived actual main source of care. 'Matched' refers to the proportion of patients whose stated care preference coincided with their actual care. Patients were included in the table if they had returned valid responses to both questions (i.e. their actual main source of care and their preferred main source of care). Patients who responded 'Other' or 'Not sure' to the question on the actual source of care or who responded 'Other' or 'Don't mind' to the question on care preference were excluded.

| Age (years) | | % of patients | | | Total |
|------------------|------------|---------------|---------------|-------------|-------|
| | | Primary care | Hospital care | Shared care | |
| PB sample | | | | | |
| <17 | preference | 24.3% | 39.3% | 36.4% | 107 |
| | matched | 50.0% | 95.2% | 46.2% | 66.4% |
| 17–65 | preference | 64.4% | 13.0% | 22.6% | 994 |
| | matched | 92.6% | 72.1% | 44.9% | 79.2% |
| >65 | preference | 81.2% | 6.0% | 12.8% | 234 |
| | matched | 93.2% | 50.0% | 46.7% | 84.6% |
| All* | preference | 64.9% | 13.6% | 21.5% | 1398 |
| | matched | 91.2% | 75.3% | 45.0% | 79.1% |
| SC sample | | | | | |
| <17 | preference | 4.8% | 74.1% | 21.2% | 189 |
| | matched | 33.3% | 96.4% | 37.5% | 81.0% |
| 17–65 | preference | 12.2% | 51.4% | 36.5% | 403 |
| | matched | 51.0% | 88.9% | 54.4% | 71.7% |
| >65 | preference | 14.3% | 61.9% | 23.8% | 21 |
| | matched | 66.7% | 69.2% | 80.0% | 71.4% |
| All* | preference | 9.8% | 58.7% | 31.5% | 642 |
| | matched | 49.2% | 91.2% | 52.5% | 74.9% |

* Including those of unknown age.

Provision of information: general questions

The PB sample

The overall level of information provision was 51.7% (see Table 4). In the over 65 years group, it was 44.9%, significantly less than the provision (54.0%) in the 17–65 years age group (Mann–Whitney *U* test, $U = 121167.5$, $P < 0.0001$). There was little difference in the overall level of information provision between males and females (52.7% vs. 51.8%). For two topics (driving restrictions and free prescriptions) the proportion of informed respondents was 80% or above. For the remaining twelve topics, the proportion of informed respondents was between 22.1% and 67.3%.

The SC sample

The overall level of information provision was 59.4%. There was no significant difference between the overall level of information provision in the under and over 65 years age groups (59.5% vs. 59.1%). There was little difference between males and females (59.4% vs. 58.9%).

For five topics (driving restrictions, adverse effects of AEDs, free prescriptions, alcohol use and photosensitivity) the proportion of informed respondents was 70% or above. For the remaining nine topics, the proportion of informed respondents was between 34.7% and 65.5%.

Patients' suggestions for improvement of care

The findings are shown in Table 5.

DISCUSSION

The current study is the largest available representative survey of the users' perspective on services for epilepsy in the UK. Users were defined as those with epilepsy who were receiving anti-epileptic drugs (AED). The patient sample was drawn from all health regions and all levels of NHS care. It is likely, however, that people with learning difficulties were under-represented as they tend to receive less medical supervision at all NHS levels but are over-represented in people with epilepsy²².

Table 3: Reasons for patients' preferences for whether they would prefer to receive their main care for their epilepsy from the GP or HD.

| Reason | Sample | | | |
|---|-----------------|---------------|-----------------|---------------|
| | PB | | SC | |
| | Care preference | | Care preference | |
| | Primary care | Hospital care | Primary care | Hospital care |
| The care is more personal | 51.0% | 19.1% | 45.3% | 20.1% |
| Doctor knows more about epilepsy | 11.5% | 76.6% | 21.9% | 84.7% |
| Doctor knows more about me and my history | 80.4% | 57.4% | 75.0% | 50.9% |
| Doctor is more understanding | 20.2% | 16.5% | 21.9% | 19.6% |
| It is easier for me to get there | 39.3% | 5.3% | 43.8% | 1.9% |
| You get more time to discuss things fully | 11.8% | 25.0% | 15.6% | 31.9% |
| You usually see the same Doctor each time | 32.3% | 22.3% | 35.9% | 29.0% |
| Doctor is easier to contact | 18.9% | 4.8% | 18.8% | 6.7% |
| There are facilities for special tests | 1.1% | 30.9% | 1.6% | 26.3% |
| Other | 1.8% | 1.1% | 1.6% | 2.1% |
| Total number of respondents | 898 | 188 | 64 | 373 |

Table 4: Overall level of information provision in patients with epilepsy (excluding reproduction and child care topics). Overall level of information provision is defined in the Materials and Methods section. 'Valid responses' is the total number of responses returned for a particular question about information provision.

| Age (years) | Epilepsy severity | | | | | | | | |
|------------------|--------------------|---------------------------|--|--------------------|---------------------------|--|--------------------|---------------------------|--|
| | Mild | | | Severe | | | All | | |
| | Respondents (n) | Valid responses (n) | Overall level of information provision (%) | Respondents (n) | Valid responses (n) | Overall level of information provision (%) | Respondents (n) | Valid responses (n) | Overall level of information provision (%) |
| PB sample | | | | | | | | | |
| <17 | 55 | 610 | 52.8% | 66 | 761 | 54.6% | 130 | 1480 | 53.5% |
| 17–65 | 725 | 9370 | 52.7% | 401 | 5137 | 56.3% | 1157 | 14868 | 54.0% |
| >65 | 211 | 2066 | 45.6% | 40 | 470 | 40.7% | 260 | 2608 | 44.9% |
| All* | 1043 | 12597 | 50.6% | 527 | 6601 | 54.0% | 1622 | 19780 | 51.7% |
| SC sample | | | | | | | | | |
| <17 | 50 | 591 | 53.3% | 159 | 1852 | 55.1% | 219 | 2558 | 55.1% |
| 17–65 | 120 | 1583 | 59.6% | 333 | 4370 | 62.5% | 466 | 6105 | 61.5% |
| >65 | 11 | 113 | 59.0% | 11 | 139 | 59.2% | 22 | 252 | 59.1% |
| All* | 190 | 2409 | 58.4% | 525 | 6600 | 59.8% | 739 | 9289 | 59.4% |

* Including those of unknown age.

Satisfaction and care preference

In both the PB (population-based) and SC (specialist care-based) samples, 86–94% of patients were satisfied with their overall primary and hospital care. There is no 'gold standard' to compare these figures to but, on face value, they appear high. Similarly high levels are usually found in studies addressing overall satisfaction with other aspects of health care, however, we also found marked differences in the relative levels of overall satisfaction between different seizure severity and age groups, as well as between the specific satisfaction submeasures. Overall satisfaction was lower in patients with severe epilepsy, particularly for primary care in the PB sample where twice as many patients with severe epilepsy were dissatisfied compared to those with mild epilepsy. This might be because the greater need for medical care in patients with severe

epilepsy is less likely to be met, leading to a disparity between expectations and experience. In addition, severe disease might predispose patients to be more critical of their care, specifically, because it is perceived to be ineffective and, more generally, because of the frustration and discontent arising from severe epilepsy.

Patients under 17 years in the PB sample were less satisfied with primary care, compared to their satisfaction with hospital care and also to satisfaction levels in the older age groups. To an extent, this may reflect a bias characteristic of young people, as other studies have found¹⁹. However, this cannot fully account for the finding because in the SC sample there was far less contrast in satisfaction between younger and older patients and, for hospital care in the PB group, younger patients were more satisfied than older ones. In addition, 39% of under 17s in the PB sam-

ple preferred to receive their main care from a hospital (and in 95% with this preference it was met), a much higher proportion than in the older age groups. Our findings therefore suggest that, from the patients' perspective, hospital-based care is more satisfactory for children and adolescents. This coincides with the consensus medical view that epilepsy care for children and adolescents should be hospital centred. In contrast to younger patients, adults in the PB sample were clearly more satisfied with primary care for their epilepsy and 68% preferred it to be their main source of care. This preference was particularly marked in the over 65 years age group. Most adults (93%) who preferred primary care stated that it was their main source of care. The main reasons for a preference for primary care were that the doctor was more familiar with the patient and their medical history, and that the care was more personal.

Table 5: Patients' free text suggestions for their overall care for epilepsy. Number of suggestions = 563. 'Other' included better GP access (including home visits, improved continuity of care, access to epilepsy surgery, availability of alternative therapy, better liaison between the GP and hospital, higher funding, longer term prescriptions and GP epilepsy clinics).

| Suggestion | Frequency (%) | |
|--|---------------|----------|
| | Adults | Children |
| Better information provision | 19% | 17% |
| Access to specialist | 15% | 18% |
| Improved medication/cure | 13% | 8% |
| Access to investigations e.g. scans, EEG | 9% | 8% |
| Better Doctor communication skills | 7% | 7% |
| Improved public education | 4% | 4% |
| Improved doctor's knowledge | 4% | 0% |
| Specialist nurse | 4% | 7% |
| Counselling | 3% | 0% |
| Annual review | 3% | 0% |
| Help groups | 3% | 4% |
| Better awareness by school | — | 6% |
| Help in community/help for families | 0% | 6% |

The effective operation of the NHS depends upon shared care between primary and hospital services perhaps particularly in conditions such as epilepsy, which is often chronic and has extensive medical and psychosocial ramifications. Our finding that only around one-fifth of patients feel that their care is shared is therefore disquieting. One reason for this may be, as found repeatedly in previous studies, that patients perceive their GPs, and many GPs perceive themselves, as having a limited knowledge of epilepsy²³. The importance placed on this factor by patients is clear from our finding that the leading reason for preferring hospital care was that the doctor 'knew more about epilepsy'. Possibly, the increasingly technological nature of investigation in epilepsy and the introduction of several new anti-epileptic drugs has increased the perceived impenetrability of this area of medicine to GPs.

Provision of information

We found that there is a deficit in information provision for people with epilepsy. The interpretation of the levels of information provision should be tempered by the consideration that some of the topics that we asked about will not have been relevant to some patients. Nevertheless, some, such as hazardous activities and the chances of becoming seizure free, are of relevance to most or all patients. There seems to have been little improvement in information provision, even though the problem has been highlighted in a number of older studies^{8,24}. In many cases the information may have been conveyed at some point, but the salient finding is that patients did not recall having received it.

Information provision by doctors is likely to occur mainly at the time of diagnosis. Patients should be free to seek expert medical information at any stage of their illness, but restricted consultation time is inevitably largely consumed with the management of the immediate medical issues. This limits the ability of the patient to seek information, or of the doctor to explore the need for and convey specific information. It is unrealistic to propose that a discussion of all of the relevant issues could be reiterated with any frequency. In addition, it is well recognized that patients may not recall much of what doctors tell them²⁵ and, although written information may be helpful, it is not a substitute for direct communication. A solution to the information deficit might be to make more use of other medical professionals, such as specialist epilepsy nurses, who could foster an environment of ongoing education and address specific issues as they arise.

Patients suggestions

Analysis of the free text suggestions for improving primary care for epilepsy indicated that people with epilepsy want knowledgeable doctors with good communication skills and better information provision. These findings are consistent with our other findings and, in particular, suggest that patients are aware of the poor level of information provision.

CONCLUSION

Patients with epilepsy reported a high level of satisfaction with most aspects of their care at both the primary and hospital levels. However, this study found two important deficits. First, the ideal of shared care is failing and, secondly, there was a marked perceived

deficit of information provision. We believe that the correction of these deficits would significantly reduce the morbidity associated with epilepsy. Although these problems have been identified in previous studies and have appeared in government reports, there is no indication of any improvement in this large-scale and geographically inclusive study. From our findings, it seems clear that many people with epilepsy want their medical care to be community based but with effective input from hospital specialists. Many would like more regular supervision rather than being seen only when a problem arises and are aware of the deficiency in information provision.

The CSAG committee made the following recommendations. It was suggested that hospital care for epilepsy should be reorganized into epilepsy centres that focus on improving the primary–secondary care interface and experiment with novel methods of doing so. The centres would provide a readily identified contact place for patients with epilepsy at the secondary care level, and information provision would be a priority. It also recommended the provision of specialist epilepsy nurses who would have a key role in information provision and maintaining the primary–hospital care interface.

ACKNOWLEDGEMENTS

This study was funded by CSAG (Clinical Standards Advisory Group). The authors are very grateful to all the general practitioners and hospital doctors who handed out the questionnaires, and to all the people with epilepsy who completed them. We are also grateful to Dr Sam Lhatoo, Mr Shailen Nandy and Ms Sarah Candlish.

CONFLICT OF INTEREST/FUNDING

This project was funded by the Clinical Standards Advisory Group (CSAG).

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