

A general practice records audit of the process of care for people with epilepsy

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SUMMARY

Background. The appropriateness of epilepsy as a topic for general practice audit activity has been emphasized, but few audits have been undertaken to date and those that have are small scale. Historically, management of epilepsy has been a neglected area, and services for people with epilepsy remain generally poor.

Aim. The study was designed to examine the process of care for people with epilepsy through a region-wide audit of general practitioner records.

Method. General practitioners in 31 randomly selected general practices in one UK health region undertook a notes audit for all patients identified as having active epilepsy (patients who had had seizures in the last 2 years, or were currently seizure-free but on antiepileptic medication). A standard pro forma was used to collect information relating to diagnosis, drug treatment, and primary and secondary care contacts.

Results. Recording of information in the notes was generally good, but poor for some key items essential to the effective management of the condition; results suggest that a number of recommendations about provision of care for epilepsy are not being met: in particular, EEG and CT investigations often appear poorly directed; prescribed antiepileptic therapy is not always optimal; significant numbers of patients are being treated in hospital by non-neurologists; there is little evidence of any regular review being undertaken by general practitioners of their patients with epilepsy; and counselling about the non-clinical aspects of epilepsy often appears inadequate.

Conclusions. Despite recommendations in a number of recent reports, gaps and inconsistencies in epilepsy care persist, both at the primary and secondary level. The means by which such shortcomings can be reduced (e.g.

by specialist epilepsy nurses working across the primary-secondary care interface) should now be systematically examined. The study has highlighted a need for evidence-based guidelines which span the primary-secondary care interface and clarify the contribution of the various practitioners involved in the provision of care for people with epilepsy.

Keywords: epilepsy; notes audit; quality of care.

Introduction

EPILEPSY is an important clinical problem, with an estimated prevalence of between 0.5 and 1%.¹ There are currently over 300 000 people with epilepsy in the UK, and a general practitioner (GP) can expect to have 10 patients with active epilepsy and 15–25 with a history of seizures at any one time.² Although it is a common neurological problem, services for people with epilepsy are generally fragmented and poorly directed, perhaps reflecting the stigma historically associated with epilepsy and that the management of epilepsy has been a neglected topic.³ The 1986 *Report on Services for People with Epilepsy*⁴ has proposed that, following initial diagnosis and treatment by a neurologist, epilepsy is a condition best cared for by the GP in the majority of cases. There appears to be increasing interest in epilepsy both among specialists and GPs,⁵ and the recently published *Epilepsy Needs Document*² emphasizes the appropriateness of epilepsy as a topic for GP audit activity.

Since the government proposed in 1989 that 'every doctor should participate in regular systematic medical audit',⁶ audits in general practice have flourished, but the topics chosen have tended to reflect local practitioners' interests rather than any clinically defined or strategic need.⁷ Judged by the criteria specified by Kessner *et al.*,⁸ epilepsy appears to represent an appropriate condition for audit; but those audits which have been undertaken are few in number and almost all have been single-practice audits only.^{9–13} The results of these audits have led to recommendations for the future provision of care, including: the introduction of a system of regular review of patients taking anticonvulsants;⁹ development of a district-based epilepsy service;¹² and improvements in communication and coordination between hospital and GP.¹⁰ Reviewing the results of these various audits, Taylor⁵ concludes that the contribution of general practice to the care of people with epilepsy requires clearer definition. As part of a large community-based study of people with epilepsy, GPs in the Mersey Health Region undertook an audit of the medical records of their patients with epilepsy. This paper presents findings from that exercise.

Methods

The audit was part of the largest UK community study of epilepsy to date, which was undertaken in the Mersey Health Region. The patients whose records formed the basis of the study were identified through the morbidity and repeat prescription registers of 31 general practices, randomly selected after stratification by FHSA and practice size (single-handed, small group and large group practice). In the seven practices where the registers had been in place for less than 2 years, the GPs also collect-

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ed information about repeat prescriptions over a 3-month period, having been supplied with a list of antiepileptic medications (both generic and brand names). The completeness of case ascertainment using these methods was shown to be satisfactory during the pilot phase of the study, when patients identified through a supplementary trawl of 400 randomly selected medical records in each pilot practice constituted only 0.4% of the total number of patients identified.

The number of practices sampled at the main stage of the study was determined by the fact that it aimed to recruit 1000 individuals who met an agreed definition of *active* epilepsy (seizures in the past 2 years, or seizure-free but taking antiepileptic medication). Based on an estimated prevalence of 0.5–1%,¹ 36 practices were selected, out of which five opted not to participate. Out of a total practice population of 177 703, 1347 patients with active epilepsy were identified in the 31 participating practices, 151 (11%) of whom were children under the age of 16.

The audit of the medical records of these patients was done using a pro forma specifically designed for the study. The items included on the form were identified as relevant and appropriate for audit through discussion with GPs involved in the pilot phase. They focused on the process of care,¹⁴ and covered diagnosis and classification, antiepileptic therapy, and hospital and GP contacts (Box 1). General practitioners were asked to indicate whether or not a particular item of information was recorded in the notes, and (where it was), what information was given.

Results

Prevalence rate

The overall prevalence rate for individuals with active epilepsy was 0.8%, in line with other recent epidemiological studies;¹ the prevalence by individual practice ranged from 0.6% to 1.2%. Completed pro forma were returned for all but six of the 1347 patients identified.

- | | |
|----------------------------------|---|
| (a) Details of diagnosis/history | |
| (i) | date of first seizure |
| (ii) | classification of seizures |
| (iii) | aetiology of epilepsy |
| (iv) | nature of tests and investigations carried out |
| (v) | current seizure frequency |
| (vi) | presence of additional health problems |
| (b) Hospital care | |
| (i) | out-patient attendances in last year |
| (ii) | in-patient admissions in last year |
| (iii) | type of clinic attended |
| (iv) | reason for referrals |
| (c) Details of drug therapy | |
| (i) | duration of drug therapy |
| (ii) | present drug regime, including doses |
| (iii) | AED blood levels |
| (d) General practitioner care | |
| (i) | number of consultations for epilepsy in last year |
| (ii) | number of consultations with patient's own GP |
| (e) Other items | |
| (i) | health problems additional to epilepsy |
| (ii) | counselling about aspects of epilepsy |

Box 1. Audited items in the medical notes.

Information recorded about diagnosis and classification

There was good recording in the notes for date of the first seizure, but recording was poor for seizure frequency in the past year (Table 1). The aetiology of epilepsy or seizures was the least often recorded item of information; in the 42% of cases where it was, it was most commonly considered as cerebrovascular (18% of cases), genetic epilepsy syndrome (17%), head injury (14%), perinatal insult (10%) and structural brain malformation (9%). Seizure type could be classified from the notes in 67% of patients. Among these 901 individuals, 56% of cases were classified as tonic-clonic; 20% absences; 17% complex partial seizures; and 15% simple partial seizures (some patients were recorded as having more than one seizure type). Though it can be essential to making a correct diagnosis and seizure classification, an eye-witness account of seizures was recorded in the notes of only a little over half of all patients. Fifty-two per cent of patients were recorded in the notes as having health problems additional to epilepsy: 19% as having mental handicap; 18% neurological handicap; 16% a psychiatric disorder; and 36% some other chronic medical disorder.

An EEG was recorded as having been done in 75% of patients, with no record of one in the remaining 25%; a CT scan was recorded as having been done in 31% of patients. Where these two investigations were known to have been done, recording of the results was good (Table 1). Among patients whose seizures were classifiable from the notes, the recorded rate of CT scanning was highest for those with complex partial seizures (Table 2).

Information recorded about antiepileptic drug therapy

Information about antiepileptic drug (AED) therapy was generally well-recorded in the notes, with one exception (Table 3): reasons for withdrawal of previously prescribed AEDs were recorded in only 64% of cases. Among patients recorded as currently taking AEDs, 69% of patients were on monotherapy and 31% on polytherapy. The most commonly prescribed AEDs were phenytoin (38% of patients), carbamazepine (34%), sodium valproate (29%) and phenobarbitone (17%). The numbers of patients prescribed the newer AEDs were small, with only 3% each taking lamotrigine and vigabatrin.

Twenty-five per cent of patients currently on AEDs were

Table 1. Information about diagnosis and classification recorded in the notes.

Item of information	Percentage (n) of cases where recorded*
CT scan result recorded, where one known to have been done	90 (410 ^a)
EEG result recorded, where one known to have been done	89 (1008 ^b)
Date of the first seizure	81 (1341)
Seizure classification	67 (1341)
Eye-witness account of seizures	53 (1341)
Seizure frequency in the last year	45 (1341)
Aetiology of epilepsy/seizures	42 (1200 ^c)

*Figures in brackets are the base numbers on which percentages are calculated. ^aExcludes 841 patients recorded as never having had a CT and 90 for whom whether they had had one ever was unknown. ^bExcludes 257 patients recorded as never having had an EEG and 76 for whom whether they had had one ever was unknown. ^cExcludes 141 individuals recorded as having febrile or single spontaneous seizures only.

Table 2. CT scanning by seizure type.

Seizure type	Percentage (n) of patients where CT scan recorded*
Complex partial	56 (152)
Simple partial	45 (133)
Partial with secondary generalization	42 (99)
Other generalized seizures	39 (71)
Tonic-clonic	34 (505)
Myoclonus	31 (62)
Absence	31 (180)
All seizure types	37 (901)

*Analysis excludes 440 patients where seizure type could not be classified from the notes; base figures sum to more than 901 because some patients were recorded as having multiple seizure types.

Table 3. Information about AED therapy recorded in the notes.

Item of information	Percentage (n) of cases where recorded
Whether patient ever treated with AEDs	95 (1341)
Current AED therapy	95 (1231 ^a)
Precise drug dosage recorded for patients currently on AEDs	95 (1169 ^b)
Whether other AEDs taken previously	92 (1231 ^a)
Date first treated	86 (1231 ^a)
AED serum blood levels recorded as checked in last year	25 (1231 ^a)
Blood levels recorded, where checked in last year	82 (313 ^c)
Other AEDs recorded as used previously	42 (1231 ^a)
Reasons for withdrawal of previous AEDs	64 (524 ^d)

^aExcludes 110 patients who were never treated with AEDs.

^bExcludes 110 patients who were never treated and 62 patients for whom no information about current therapy was recorded.

^cExcludes 918 patients whose blood levels were not checked and 110 who were never treated with AEDs. ^dExcludes 605 patients where no other AEDs had previously been prescribed, 102 where this was unknown and 110 who were never treated with AEDs.

recorded as having had blood serum levels checked in the past year and the results were recorded in the notes for 82% (Table 3). The percentages of patients on phenytoin and sodium valproate whose blood levels had been checked were similar (29% and 31%, respectively), even though the pharmacokinetics of these two AEDs mean that monitoring is very useful in the former and often uninterpretable in the latter. Patients on AED polytherapy were somewhat more likely to have had their blood levels checked than those on monotherapy (33% compared with 26%; $\chi^2 = 6.48$, $df = 1$, $P = 0.01$). Among patients who had been treated with antiepileptics at any time, 24% were recorded as having been counselled about AED side-effects, 23% about alcohol consumption and AEDs, and 23% of the women patients about oral contraception interactions.

Information recorded about hospital and general practitioner contacts in last year

Just over a half of all patients (51%) had had no contact for epilepsy with either primary or secondary services in the past year. In all, 458 patients (34%) were recorded as attending a hospital out-patient clinic; 103 (8% of all patients and 22% of those

attending as out-patients) had been admitted as in-patients. Only 8% of patients had not seen the GP at all in the past year, but epilepsy had been the *main* reason for the consultation in only 37% of cases.

Hospital care. Seventy-six per cent of patients with frequent seizures (≥ 1 per month) had attended a hospital out-patient clinic, compared with 70% of those with less frequent seizures (<1 per month) and 28% of those who were seizure-free ($\chi^2 = 114.62$, $df = 2$, $P < 0.001$). Five per cent of those recorded as seizure-free, 26% of those recorded as having infrequent seizures and 42% of those with frequent seizures were admitted as in-patients for epilepsy care ($\chi^2 = 28.96$, $df = 2$, $P < 0.001$). Twenty per cent of those who had had hospital care as an in- or out-patient were seen at the Mersey Region Epilepsy Clinic, and a further 30% by a neurologist or paediatric neurologist. Twenty-nine per cent were seen by a general physician, 17% by a general paediatrician and 4% by a psychiatrist. Almost half (43%) of patients treated at the Mersey Region Epilepsy Clinic had frequent seizures; but so did a significant proportion (31%) of those treated by general physicians.

General practitioner care. Excluding those patients who had not consulted at all, 32% saw only one doctor in the practice, 27% saw two, and 34% saw three or more (for the remainder, this information was unrecorded). As for hospital care, the likelihood of consulting the GP was clearly related to current seizure activity: 73% of those with frequent seizures were recorded as having consulted at least once in the past year for epilepsy, compared with only 27% of patients who were seizure-free ($\chi^2 = 139.59$, $df = 2$, $P < 0.001$).

Discussion

This audit has examined both the quality of recording of key items of information about epilepsy in the GP records, and the nature of medical care currently provided to patients with epilepsy in one UK health region. The audit formed one part of a larger community study of epilepsy, which also involved collecting information from patients about their psychosocial functioning by means of postal questionnaires.¹⁵ Since the aim of the study was to survey an unselected population of people with epilepsy, the research team was dependent on GPs for the identification of the sample. A combination of methods was used for case ascertainment, and we are confident that this was almost complete. We were able to recruit a sufficiently large number of practices to attain our target figure of 1000 patients with active epilepsy.

One aim of the audit exercise was to assess the quality of information recorded in the medical notes, since previous studies of epilepsy suggest that record-keeping in general practice is often poor.^{12,16} In contrast, recording of information about epilepsy was generally good in the present study. The low recording of aetiology was unsurprising, given that it is unknown in up to 70% of cases; the recording of cerebrovascular disease as the commonest aetiological factor parallels the finding from another recent community-based sample of patients with newly diagnosed epilepsy.¹⁷ The finding that recording of an eye-witness account of seizures was poor is significant, given its potential contribution to the diagnostic process: since GPs are often the initial point of contact for people experiencing a first seizure, they may need to be made more aware of its value in the differential diagnosis of seizures.¹⁸ Similarly, poor recording of seizure classification and reasons for previous AED withdrawal are important because of their implications for current AED

treatment in the present study.

The Epilepsy Needs Document² recommends that people with epilepsy should be seen at regular intervals by the Primary Health Care Team, and at least annually. Our findings about the lack of information in the notes on current seizure status suggest that, even though the majority of patients had consulted their doctor at least once in the past year, thus providing an opportunity for review of their epilepsy and related care, GPs are not generally undertaking any regular review. This is in spite of the fact that around 15% each of patients were known to have learning disability, neurological handicap and psychiatric disorder in addition to epilepsy, and therefore may particularly warrant regular review. In addition, there was evidence that continuity of care was poor for those who were seen in the general practice setting, with around two-thirds of patients seeing a number of different practitioners. This is important, since although there is no documented benefit to patients with epilepsy of seeing the same doctor,¹⁹ it has nonetheless been shown^{20,21} that patients not receiving continuity of care are a vulnerable group, and that continuity, by increasing the clinician's level of accumulated knowledge, saves consultation time, influences use of laboratory tests and medication, and influences referral decisions, particularly for patients with chronic conditions.

Although undertaken in general practice, the audit provided some information about the nature of secondary as well as primary care for epilepsy, which we report here since we consider it has implications in relation to the interface between primary and secondary care. Only around a half of patients recorded as having hospital care for their epilepsy in the past year were seen by a neurologist; general physicians, who may have little or no post-graduate training in neurology, were the single largest providers of hospital care and saw one-third of all patients with frequent seizures. Perhaps as a result of patients being seen by non-neurologists, head injury appears to have been over-estimated as a cause for epilepsy, having probably been trivial and unrelated in some cases. The incidence of different seizure types, as classified from the notes, suggests that absences and simple partial seizures are being over-diagnosed and complex partial seizures under-diagnosed.¹ The question of whether non-specialist hospital consultants should continue to have so significant a role in treating people with epilepsy, particularly those in whom it is complex and difficult to manage, is one we think needs to be addressed further.

It has been proposed⁴ that every newly diagnosed case of epilepsy will require *at least one* standard EEG; and patients presenting with partial epilepsy should have neuroimaging unless there is a clear cause for epilepsy. In the present study population, a significant percentage of patients had never had an EEG or a CT scan. As noted elsewhere,²² the relatively low rate of scanning may partly reflect the fact that a proportion of patients would have been investigated and diagnosed in the pre-CT scan era. Nonetheless, our data suggest that scanning is not always well-directed: significant numbers of patients with partial seizures had not been scanned; conversely, many with primary generalized seizures had probably had unnecessary scanning.

It is now generally agreed that initial antiepileptic drug therapy should be with either sodium valproate or carbamazepine as monotherapy in the majority of cases,²³ and that routine serum level monitoring is generally unnecessary after stabilization of the medication regime and should be limited to particular categories of patients.²³ In the present population, just under three-quarters of patients were on monotherapy, a similar proportion to that found in a national study reported by Hart and Shorvon.²² Although sodium valproate and carbamazepine were commonly prescribed, the use of phenytoin as monotherapy remains wide-

spread; as in the national study,²² use of phenobarbitone is also not uncommon, although this finding may partly be a reflection of the many patients in the study who had been seizure-free for long periods of time and who may have been reluctant to alter a well-established therapeutic regime. Our analysis suggests that blood level checking tended to be routine and poorly directed: although of little value in patients on sodium valproate, blood levels had been measured in one-third of those for whom it was prescribed; conversely, only one-third of patients taking phenytoin, a drug where blood level monitoring is very useful, had had levels checked in the past year.

Findings from the study suggest that many patients with epilepsy are not being counselled by either the hospital or their GP about AED side-effects or possible interactions with other drugs, including oral contraceptives and alcohol. The question of how and by whom patients can be routinely counselled is one which needs to be addressed, and we would agree with the recent conclusions of other authors^{18,22} that a specialist epilepsy nurse working across the primary-secondary care interface might be best placed to do so.

The present study has highlighted a number of gaps and inconsistencies in the process of epilepsy care, both at the primary and at the secondary levels. The study has recently been replicated in two other regions of the UK, and these authors report similar findings about the lack of regular review and of counselling about specific aspects of epilepsy.^{24,25} Although carried out almost 2 decades later, the present findings do not contradict the conclusions drawn by the authors of an earlier study,²⁶ which documented an irregular pattern of care and a ritualistic approach to management. In a recent study of another chronic condition, diabetes, it was shown that glycaemic control was related to aspects of the organization and process of care.²⁷ We would argue that, as for diabetes, better-focused care for patients with epilepsy would contribute to better clinical and psychosocial outcomes, including improvements in seizure control, optimal medication regimes and reduced side-effects of medication.

Improving care for people with epilepsy depends in part on increasing GPs' knowledge about the condition and their confidence to manage it. It also involves clearer definition of how care should be apportioned between existing primary and secondary services and what the responsibilities of each should be; such a task could probably best be met by representatives of primary, secondary and tertiary services coming together to develop agreed local guidelines.²⁸ We believe that the study has also highlighted the need for national guidelines for epilepsy care which are rigorously developed and evidence-linked rather than, as is the case with existing ones,^{2,29} based on consensus and so open to potential bias.³⁰ Unless these issues are addressed, we would suggest that care for people with epilepsy will continue to be less than optimal.

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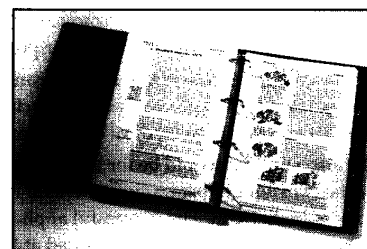
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