

Epilepsy monitoring and advice recorded: general practitioners' views, current practice and patients' preferences

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SUMMARY

Background. Epilepsy is a common condition that is managed at the interface between primary and secondary care.

Aim. A study aimed to describe general practitioners' criteria for aspects of optimal epilepsy care and their estimates of current levels of care achieved; to compare these estimates with clinical data extracted from their patients' medical records; and to compare general practitioners' estimates and recorded data with information provided by the patients themselves.

Method. Thirty seven general practitioners from six practices in the south Thames region were sent a questionnaire enquiring about current practice with regard to general practitioner and specialist monitoring of patients with epilepsy and provision of advice, and about their criteria for the optimum levels of aspects of epilepsy care. Of patients aged over 15 years in the study practices, 0.6% were found to have active epilepsy; 283 of these 326 patients were sent a questionnaire enquiring about their epilepsy, the service and advice provided, and whether they required more information. Responses to the general practitioners' questionnaire and to the patients' questionnaire were compared and also compared with information extracted from the patients' medical records.

Results. Ninety five per cent of the general practitioners responded. Of 255 patient questionnaires (90%) returned, 251 could be analysed. Of 247 patients, 168 (68%) reported having had no seizure in the previous six months. Forty of 241 patients (17%) had a regular arrangement to see their general practitioner regarding their epilepsy. Of 191 patients who expressed a preference, 116 (61%) reported preferring to receive their epilepsy care mainly from their general practitioner. General practitioners reported that ideally patients should be monitored in primary care every six months (the median recorded frequency was 14 months) and that there should be a record of advice given to all patients on driving, adverse effects of antiepileptic drugs, and self-help groups. Advice was recorded in

patients' records as having been given on driving (46% of records), adverse effects of antiepileptic drugs (9%), and self-help groups (3%); 82 of 237 patients (35%) reported not receiving enough advice.

Conclusion. Patients generally preferred to receive their epilepsy care in general practice. Monitoring and provision of advice were less than optimal from both the general practitioners' and the patients' point of view. New resources and skills will be necessary to bridge this perceived gap. Specially trained nurses may have a role in this monitoring and advice provision.

Keywords: epilepsy; management of disease; continuity of patient care; doctors' attitudes; patients' attitudes.

Introduction

EPILEPSY is a common condition that is managed at the interface between primary and secondary care. A general practice with 10 000 registered patients will include about 50 people who are receiving antiepileptic medication.¹ A catchment area with 300 000 registered patients will therefore include approximately 1500 people taking antiepileptic medication; it will also include one whole time equivalent neurologist.² There is an increased risk of sudden death among people with epilepsy and this has been reported to be so particularly among young men.³

Patients with epilepsy have reported that they received insufficient initial information and ongoing advice on how to manage their condition.⁴ They have reported that they felt they had to experiment with their antiepileptic drugs in isolation, and make decisions about activities such as driving and work based on insufficient information and advice. Their sense of isolation may have been greater because many patients with epilepsy perceived epilepsy as a stigmatized condition and, on this account, they were less likely to discuss it with other people.⁴

At present it is difficult for clinicians to develop a consensus on criteria and standards for care for patients with epilepsy as little is known about what services are currently provided or what might be regarded as ideal. A study was therefore undertaken that aimed to:

- Describe general practitioners' estimates of current practice and their criteria for the optimum level of care and advice recorded in the medical records of patients with epilepsy;
- Compare these estimates with information extracted from the medical records of patients with epilepsy registered with the general practitioners; and
- Compare general practitioners' estimates and recorded data with information provided by the same group of patients in response to a questionnaire.

Method

Seven general practices in the south Thames region were invited to participate; one refused on the grounds that it was already

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involved in a family health services authority audit. The practices chosen had no particular interest in epilepsy, but they had been computerized for several years. The project leader's (L R's) practice was used to pilot the procedures; data from this practice were not used subsequently. The pilot study took place in 1993 and the main study in late 1993 and 1994. The six study practices had 37 general practitioner principals and 70 100 registered patients, 57 400 of whom were aged over 15 years. Ethics committee approval was provided in the three districts in which the practices were located.

Data were derived from three sources: a questionnaire completed by general practitioners, clinical information extracted from the medical records of their patients with epilepsy, and a questionnaire completed by the patients.

General practitioners were sent a questionnaire enquiring about their estimates of current practice with regard to hospital specialists' and general practitioners' frequency of monitoring patients with epilepsy and recording of advice on specific topics (antiepileptic drugs and the social implications of epilepsy). The questionnaire also enquired about general practitioners' criteria for the optimum level of these aspects of care for patients with epilepsy. An epilepsy nurse specialist (D R) identified patients aged over 15 years with active epilepsy, using the diagnostic rubrics and drug record data held on computer, and cross-checked this information with the medical records. The definition used for active epilepsy was that patients were currently prescribed antiepileptic medication for seizures or were not taking antiepileptic medication but had reported a seizure in the past two years. The nurse extracted information about the service provided and advice recorded from the records, using a form which was slightly modified from one developed for an audit of epilepsy care.

Practice teams (including general practitioners, practice nurses, district nurses and carers) were asked to apply criteria to exclude patients for whom sending a questionnaire would have been inappropriate. The criteria for exclusion were: other severe illness, for example terminal cancer; severe psychological illness, for example active psychosis or severe depression; and low intelligence quotient (IQ), for example associated with learning disability or dementia.

Selected patients were sent a questionnaire enquiring about the service provided for their epilepsy care, their preference for receiving such care mainly from their general practitioner, mainly from a specialist or from both, the advice that they had received, and whether they still required more information. The patients' questionnaire also sought information on the frequency and severity of their epilepsy episodes and on the social implications of epilepsy.

Data were analysed using SPSS. Means of the ages of respondents and non-respondents were compared using the two sample *t*-test. For responses to the questionnaires: medians were compared using the Kruskal-Wallis test, proportions were compared using a standard chi square test, and the kappa statistic was used as a measure of strength of agreement.⁵ Not all patients or general practitioners responded to all the questions, so the relevant denominator is provided for each question.

Results

Response rates

Thirty five of the 37 general practitioners (95%) responded to the general practitioners' questionnaire.

Of the 57 400 patients aged over 15 years, 326 (0.6%) were found to have active epilepsy and data on epilepsy care were extracted from the records of these patients. After application of

the exclusion criteria, 283 of these patients were sent questionnaires and 255 (90%) returned them. The 43 patients who were excluded from the initial sample of 326 patients were significantly older than the 283 who were included (mean age 58 years versus 51 years, $P < 0.05$) but there was no significant difference in sex distribution between these two groups. No significant differences in age or sex were found between the 28 who failed to return questionnaires and the 255 who did. Of the 255 questionnaires returned, all but four were completed sufficiently to be usable. Data are presented for this group of 251 patients so that information derived from the medical records can be compared with that derived from questionnaires returned by the same group of patients.

Patients' histories and consultation patterns

The mean age of the 251 patients was 51 years (range 17 to 90 years), and 54% were men. Of 247 patients, 168 (68%) reported having had no seizure in the previous six months. Among the 79 patients (32%) who reported having had one or more seizures in the previous six months, 33 reported that these episodes included grand mal seizures, 28 reported that they had little or no control over their seizures, and 15 reported that their attacks had stopped them doing all or many of the things they wanted to do.

Data derived from the medical records of the 251 study patients indicated that the mean consultation frequency with a general practitioner for any reason was three (95% confidence interval (CI) 2.6 to 3.4) in the previous six months. Eighty of 247 patients (32%) had consulted their general practitioner in the previous six months regarding their epilepsy. Patients were asked if they had a regular arrangement to see their general practitioner about their epilepsy, and 40 of 241 patients (17%) responded 'yes', while 201 (83%) reported that they attended their general practitioner only when they had a problem regarding their epilepsy.

Epilepsy service provided: general practitioners' estimates

The 35 general practitioners who responded provided estimates of the time period that had elapsed since their average patient with epilepsy had last seen a specialist and last consulted a general practitioner regarding his or her epilepsy; this was compared with information in the medical records. The frequency distributions of the recorded intervals since patients had last seen doctors were skewed, so the medians and means were calculated; the mean may be a better indicator of doctor workload. General practitioners estimated that patients had seen a specialist more recently than was the case: median 24 months (interquartile range 16.5 to 39 months) versus median 39 months (interquartile range nine to 91 months) and mean 69 months (95% CI 57 to 81 months). They were, however, relatively accurate in their median estimates of when they themselves had seen patients: median 12 months (interquartile range 12 to 24 months) versus median 14 months (interquartile range five to 38 months) and mean 29 months (95% CI 23 to 35 months).

General practitioners were asked what the ideal interval between appointments for monitoring epilepsy and providing advice might be in primary care. The median response was six months (range three to 12 months), with 26 of 32 general practitioners (81%) suggesting an interval of six months or less as ideal.

Epilepsy service provided: patients' preferences

Patients were asked who they would prefer to provide most of their epilepsy care, and from whom they currently received such care. Responses from 242 patients are shown in Table 1. Of the 191 patients (79%) who expressed a preference, 116 (61%) preferred to receive their epilepsy care mainly from their general

Table 1. Patients' reported preferences and main source of care received for their epilepsy.

Care currently received from	Source of preferred care (no. of patients)				Total
	GP	Hospital specialist	GP and hospital specialist	No preference	
GP	89	9	8	28	134
Hospital specialist	3	12	9	2	26
GP and hospital specialist	11	3	23	9	46
Neither	13	5	6	12	36
Total	116	29	46	51	242

practitioner; 16 of these 116 patients reported that they were not receiving this. Of the 29 (15%) who would have preferred mainly hospital specialist care, 14 did not receive this, and of the 46 (24%) who would have preferred shared general practitioner/specialist care, 23 did not receive this. Overall 53 of 191 patients (28%) did not receive the care that they would have preferred.

Forty seven per cent of the 79 patients who had experienced one or more seizures in the previous six months and 21% of the 168 patients who had had no seizure in the previous six months reported that their main carer was a specialist or that they had received shared general practitioner/specialist care; the difference (26% (95% CI 13% to 38%)) was significant.

Advice on antiepileptic drugs and social implications of epilepsy

Forty one per cent of 241 patients reported that they had at some time experienced adverse effects which they attributed to their antiepileptic medication and 49% of 251 patients reported that they currently drove. General practitioners were asked to estimate the level of advice given by a general practitioner or a hospital specialist on these and other topics. These estimates were compared with information extracted from the medical records and with patients' responses. Results are shown in Table 2. There was a record of advice having been given by a general practitioner or specialist on driving, antiepileptic drug compliance, adverse effects of antiepileptic drugs, alcohol consumption and self-help groups in fewer than 50% of the patients' records. Patients were asked if they had received advice on driving, adverse effects of antiepileptic drugs and self-help groups; a larger percentage of patients reported that they had been given advice on each of these three topics than had actually been recorded. The agreement between the records and patient reports for advice given on driving was fair (κ 0.35), but it was low for advice given on adverse effects of drugs (κ 0.13), and self-help groups (κ 0.08).

All 35 general practitioners reported that in ideal circumstances they would aim to have a record of advice having been provided on each of the five topics to all patients.

Patients were asked whether they had received enough information overall about their epilepsy; 82 of 237 patients (35%) responded that doctors had not given them enough information. When patients were asked if they preferred to tell people about their condition, 135 of 238 (57%) responded 'no'. Seven per cent of 236 patients reported that they belonged to a self-help group, the British Epilepsy Association.

Discussion

The study practices were not chosen at random, and by being

Table 2. Estimates by 35 general practitioners compared with information in 251 medical records and reports by patients with epilepsy of GP and specialist advice given on antiepileptic drugs and social implications of epilepsy.

Advice on	% of patients receiving advice according to		
	Median GPs' estimate (IQR)	Medical records	Patient reports ^a
Driving	73 (48 to 90)	46	59 ^b
Antiepileptic drug compliance	50 (10 to 75)	25	–
Adverse effects of antiepileptic drugs	30 (10 to 70)	9	51 ^c
Alcohol consumption	25 (10 to 50)	11	–
Self-help groups	10 (5 to 20)	3	10 ^d

IQR = interquartile range. ^aPatients were asked if they had received advice on driving, adverse effects of antiepileptic drugs, and self-help groups. ^bOf 246 responses. ^cOf 247 responses. ^dOf 236 responses.

computerized were likely to be more innovative than some other practices.⁶ Extrapolating results from these practices alone should therefore be done with caution. Nazareth and colleagues have shown that for some conditions, case identification from computer records can be reasonably accurate.⁷ In the present study, however, some cases were missed using this method: three patients with epilepsy who had not been identified in the 1993–94 study were identified during a follow-up study in 1994–95. They were not included subsequently. Notwithstanding this, the prevalence of epilepsy among patients aged over 15 years in the six study practices was similar to that previously reported.⁸

Large gaps were found between estimates of advice given by doctors and advice actually recorded. Patients' responses indicated that they had received more advice than had actually been recorded in their medical records; this is consistent with evidence from studies of doctors' advice recorded in patients' medical records on the prevention⁹ and management¹⁰ of various conditions. Wilson and McDonald⁹ and Rethans and colleagues¹⁰ compared general practitioners' performance with the records of their management. They found that about a third of doctors' advice⁹ and actions¹⁰ were recorded in the patients' medical records, and that biological measurements, tests and therapy were more likely to be recorded than information categorized as history or advice given.

Both specialists and, particularly, general practitioners may aim to address patients' concerns in the long term, and to provide advice in an incremental way at sequential consultations. Freeman and Richards have shown that in seeking guidance for managing their epilepsy, patients consult different general practitioners in the practice.¹¹ A structured epilepsy record could prompt general practitioners to add to previous advice in a cumulative way. Without this, general practitioners may inadvertently repeat advice on some topics to some patients, while never raising other topics which are important for patients to know about.

In the National Health Service, general practitioners have large populations of patients to care for,¹² and the time spent with patients is inversely related to general practitioners' list sizes.¹³ If general practitioners provided the six-monthly monitoring that they indicated in the present study was ideal then the number of their consultations would increase, and if patients were provided with comprehensive advice, and this was recorded in a systematic way, then the length of consultations would increase.

In the present study, patients generally preferred to receive their epilepsy care in a general practice. Monitoring and advice

provision were less than optimal from both the general practitioners' and the patients' point of view. In the context of restricted medical manpower, it will be difficult for specialists or general practitioners to bridge this perceived gap between current service levels for patients with epilepsy and optimal monitoring and advice provision. The use of protocols and nurses with special training could help provide more systematic monitoring of and advice for patients with epilepsy, and could help the recording of such information in a structured way.¹⁴ A shift in skills mix can be achieved by providing long courses to train some nurses so that they can facilitate and advise groups of practices in a similar way to diabetes nurse specialists. The National Society for Epilepsy provides such courses, comprising a number of training weeks over several months. The society also offers short (one-day) courses for nurses so that they can begin to identify and monitor patients with epilepsy in general practice. The effects that the use of specially trained nurses may have on the monitoring of, advice provision to, and outcomes for patients with epilepsy will require evaluation.

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