Identifying the strengths and weaknesses of epilepsy care in general practice – a case note review

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Aim: To suggest how to improve primary epilepsy care by assessing the strengths and weaknesses of epilepsy care in general practice by reviewing practice records in relation to qualities and outcomes framework (QOF) indicators and epilepsy guidelines. **Background:** Concerns have been raised about epilepsy care in the UK. The general practice QOF indicators offered the first opportunity to take on structured epilepsy care in the UK. The QOF includes targets for this condition and national guidelines list key priorities to improve care. This study explores how general practice systems are delivering this care. **Methods:** A case notes review in 27 practices in the north-east of England. Adults with epilepsy were identified from practice morbidity registers and a READ code search. Data from 1333 patients were collected on the frequency and location of epilepsy review, type of epilepsy and classification of seizures, epilepsy medication ordering, and individual and practice demographic data. The data were entered into SPSS for frequency analysis and grouped for further analysis: Primary Care Trust (PCT), age and medication ordering groups (satisfactory, moderate or poor). **Findings:** Of the patients, 24% did not have a record of type of epilepsy and about a third of patients had no seizure classification recorded. One-fifth of patients were not reviewed in the previous year but of those who were, the majority were seen in general practice. Seizure frequency was not recorded in the last 12 months in one-quarter of patients. Adherence and recording of seizure information were related to age of patient. Epilepsy registers were inaccurate. The findings suggest that epilepsy care can be improved by using review and monitoring systems to ensure a complete and accurate epilepsy register and appropriate annual clinical and medication review.

Key words: case notes review; epilepsy; primary care; qualities and outcomes framework

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Introduction

General practice was rewarded for managing conditions not previously included in chronic disease management programmes with the introduction of a Quality and Outcomes Framework (QOF) as part of the General Medical Services (GMS) contract (General Practitioners Committee,

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2003). While QOF was regarded as a potentially positive addition that rewarded general practitioners (GPs) for developing services of a high standard (Roland, 2005), it has been shown that QOF indicator performance does not correlate with adherence to guidelines (Cleland *et al*., 2006; Williams and de Lusignan, 2006). There is also concern that achieving QOF indicators may conflict with the core need to address the patients' agenda (Lipman, 2006). This should be regarded seriously because understanding the patients' perspective is central to a good doctor–patient

relationship (Stewart, 2005). However, QOF may be an opportunity to offer quality care, that is patient-centred treatment in an evidence-based manner (Lester *et al.*, 2006).

Epilepsy was one condition included in the QOF framework. Inclusion was welcomed because care for people with epilepsy had been criticised (Clinical Standards Advisory Group, 2000; Hanna *et al.*, 2002). The Chief Medical Officer (England) proposed an action plan to address the problem (www.dh.gov.uk). This resulted in the National Institute for Health and Clinical Excellence (NICE) guidelines for this heterogeneous, stigmatised and poorly managed condition (National Institute for Health and Clinical Excellence, 2004) published in the same year when the QOF indicators (www.bma.org.uk) were introduced. The guidelines set out recommendations to improve care and listed key priorities to achieve this (Box 1). This study assessed the strengths and

Box 1   NICE priorities for adults with epilepsy. CG 20 epilepsy in adults quick reference guide

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Key priorities for implementation

The following recommendations have been identified as key priorities for implementation:

Diagnosis
- All adults with a recent-onset suspected seizure should be seen urgently[a] by a specialist[b], This is to ensure precise and early diagnosis and initiation of therapy as appropriate to their needs.
- The seizure type(s) and epilepsy syndrome, aetiology and co-morbidity should be determined.

Management
- Health care professionals should adopt a consulting style that enables the adult with epilepsy, and their family and/or carers as appropriate, to participate as partners in all decisions about their health care, and take fully into account their race, culture and any specific needs.
- All adults with epilepsy should have a comprehensive care plan that is agreed between the individuals, their family and/or carers as appropriate, and primary and secondary care providers.
- The AED (anti-epileptic drug) treatment strategy should be individualised according to the seizure type, epilepsy syndrome, co-medication and co-morbidity, the individual's lifestyle, and the preferences of the individual, and their family and/or carers as appropriate.

Review and referral
- All individuals with epilepsy should have a regular structured review. In adults, this review should be carried out at least yearly by either a generalist or specialist, depending on how well the epilepsy is controlled and/or the presence of specific lifestyle issues.
- At the review, individuals should have access to: written and visual information; counselling services; information about voluntary organisations; epilepsy specialist nurses; timely and appropriate investigations; and referral to tertiary services, including surgery as appropriate.
- If seizures are not controlled and/or there is diagnostic uncertainty or treatment failure, individuals should be referred to tertiary services soon[c] for further assessment.

Special considerations for women of childbearing potential
- Women with epilepsy and their partners, as appropriate, must be given accurate information and counselling about contraception, conception, pregnancy, caring for children, breastfeeding and menopause.

[a] The Guideline Development Group considered that 'urgently' meant within two weeks.
[b] For adults, a specialist is defined throughout as a medical practitioner with training and expertise in the epilepsies.
[c] The Guideline Development Group considered that 'soon' meant being seen within four weeks.

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weaknesses of aspects of epilepsy care in general practice as recorded in practice clinical records in relation to these indicators and guidelines.

This study is the first stage of a two-stage community-based cross-sectional project exploring how people manage their epilepsy.

Method

The study was conducted in 27 practices located in three Primary Care Trusts (PCTs) in the north of England prior to the reconfiguration of organisations in 2006/07. None of the practices offered care from GPs with a special interest or from Epilepsy Nurse Specialists and so reflected usual GP care. A letter of invitation was sent to all 89 practices in Selby and York, West Hull and East Hull PCTs. A total of 27 practices (30%) agreed to take part in the study – 10 in Selby and York, 9 in East Hull and 8 in West Hull. The notes review focused on all adult patients with epilepsy registered at the 27 practices drawn from a combined practice population of 161 500 (see Table 1).

A data sheet was developed to collect information from the clinical and medication records of all patients with epilepsy aged 18 years and over. The data collected included the following:

a) Patient data – age, sex, co-morbidity, use of anti-epileptic drugs (AEDs) and QOF indicators for epilepsy – whether the patient was on the epilepsy register, recording of seizure frequency or freedom and whether the patient had a recent medication review;
b) Key priorities of the NICE Epilepsy guideline – epilepsy syndrome and seizure type recorded in the patient's notes as evidence of an accurate diagnosis, whether a structured review had been carried out in the 12 months prior to data collection and where it took place.

Data were collected at each practice by one or more of the research team. Each practice was asked to provide a copy of the epilepsy register developed using the designated QOF codes and to conduct an additional search using the general READ code for epilepsy (F25) to identify missed cases. The purpose of the search was to identify any additional patients who were not on the register but should be known to the practice, for example patients who were not taking medication but were still having regular seizures. The researchers provided a list of queries about diagnosis, classification, AED usage or review process and worked with the practice to verify the register and update the clinical records.

Where there was no clear record of epilepsy type or seizure classification – based on the International League Against Epilepsy (ILAE) – systems in the computer and paper notes, the researchers recorded any descriptions of the seizures and these were reviewed by an experienced clinician who gave a possible classification for these events.

The data were entered into SPSS V13 database for frequency analysis. The data were also split into the following groups for further analysis using the χ^2 test: PCT, age groups (18–30 years, 31–55 years and over 55 years) and medication ordering patterns. The sample of all patients taking AEDs was split into three groups in relation to the ordering of medication. A calculation was made of how many times a patient would be expected to order their medication in 12 months based on their dosing instructions. This was compared to how many times the patient actually ordered their medication in the previous 12

Table 1 Practice data by Primary Care Trust

	Selby/York	Eastern Hull	West Hull	Total
Total number of practices	33	28	28	89
No. of participating practices (%)	10 (30)	9 (32)	8 (29)	27 (30)
Practice population	68 100	38 100	55 300	161 500
Partners				
1	0	5	1	6
2–3	3	2	2	7
4+	7	2	5	14
No. of notes reviewed	480	367	486	1333

months and the patient was grouped accordingly: satisfactory adherence (80–100% of the expected order), partial adherence (50–79%) and poor adherence (<50% of the expected order).

Results

In total 1333 patient notes were reviewed. The patients were aged between 18 and 101. Of the patients, 50% were male and 13% were learning disabled. A total of 1076 patients (81%) were listed on their practice's epilepsy register. The remaining 257 patients (19%) were not on the epilepsy register but were identified from practice searches using READ codes for epilepsy. Of those patients not on the epilepsy register ($n = 257$), 14% were on epilepsy medication or had experienced seizures in the previous year.

Recording of epilepsy information

There was limited information about type of epilepsy or seizure classification to be found in either the general practice notes or hospital letters. The type of epilepsy could be defined as either generalised or partial in 76% of cases. The remaining patients had either a label of 'Epilepsy' or there was no mention of epilepsy at all (24%). Where there was a recording of generalised or partial epilepsy ($n = 1019$), 40% of patients only had it recorded in their paper notes.

About a third of patients had no seizure classification recorded anywhere, a third only had it recorded in the paper notes and only a third of cases had this information recorded on the computer.

Where a seizure classification was recorded ($n = 864$) in the computer or paper notes, it was judged that 11% of classifications were inaccurate (either due to contradictory terminology or because the description of the event did not match the classification). The notes review also identified 67 patients who were either recorded as not having epilepsy or who did not appear to have epilepsy from the description of their symptoms in the notes. Of these patients, 40 were on the epilepsy register.

In total there were 310 patients who could not be classified. Of this number, 218 (70%) could not be classified because there was no description of seizures to be found in either the computer or

paper notes with which to make a judgement on seizure type.

There were a total of 1036 patients who were on the epilepsy register after excluding those patients the notes review identified as not having epilepsy.

Date of diagnosis was not recorded in either the computer or the paper notes for 183 (21%) patients. Where it was recorded ($n = 853$), the recording was contradictory (ie, more than one date was recorded) in 8% of cases.

Epilepsy review

Approximately one-fifth of patients on the epilepsy register did not get an epilepsy review in the 12 months prior to data collection. Of those who did ($n = 838$) 66% were reviewed in general practice, 17% in secondary care and the remaining patients were seen in both primary and secondary care.

Seizure frequency was not recorded in the 12 months prior to data collection in one-quarter of patients on the epilepsy register. Where it was recorded, 399 patients (51%) had been seizure free in the previous 12 months.

Medication use

Nearly all patients on the epilepsy register (95%) were taking AEDs. Most patients were taking one AED (71%) with the remaining patients taking two or more AEDs.

The majority of patients (85%) had satisfactory adherence, 11% had partial adherence and 4% were classed as poor adherence.

There were more patients in the poor adherence group who were not on the epilepsy register (14%) compared with the partial adherence (2%) and satisfactory adherence (2%) groups.

There was no relationship between AED ordering and type of epilepsy, recording of epilepsy type, whether and where the patient was reviewed.

Seizure frequency was more likely to be recorded in patients classed as satisfactory adherence. There were a higher proportion of patients classed as partial or poor adherence on monotherapy for epilepsy compared with patients classed as satisfactory adherence (see Table 2).

Data grouped by age

Patients were classified by age: young adults (18–30 years), middle age (31–55 years) and older age group (56 years and over).

Table 2 Differences by medication use

	Satisfactory, n (%)	Partial, n (%)	Poor, n (%)	Test statistic (df), P value
Epilepsy type				$\chi^2 = 1.835$ (4), $P = 0.766$
Generalised epilepsy	378 (58)	48 (59)	19 (56)	
Partial epilepsy	205 (32)	22 (27)	10 (29)	
Generalised and partial	66 (10)	11 (14)	5 (15)	
Recording of epilepsy type				$\chi^2 = 0.085$ (2), $P = 0.958$
Recorded	649 (79)	81 (79)	34 (77)	
Not recorded	172 (21)	22 (21)	10 (23)	
Whether patient was reviewed in last 12 months				$\chi^2 = 2.494$ (2), $P = 0.287$
Reviewed	684 (83)	80 (78)	34 (79)	
Not reviewed	136 (17)	23 (22)	9 (21)	
Place of review				$\chi^2 = 7.916$ (4), $P = 0.095$
General practice only	450 (66)	58 (73)	29 (85)	
Hospital only	112 (16)	12 (15)	4 (12)	
Both	122 (18)	10 (13)	1 (3)	
Recording of seizure frequency				$\chi^2 = 15.208$ (2), $P = 0.001$
Recorded in last year	645 (79)	67 (65)	27 (61)	
Not recorded in last year	175 (21)	27 (35)	17 (39)	
Number of anti-epileptic drugs				$\chi^2 = 8.227$ (2), $P = 0.01$
Monotherapy	575 (70)	81 (79)	38 (86)	
Polytherapy	246 (30)	22 (21)	6 (14)	

There was no relationship between age and whether the patient had a review in the last year.

Young adults were more likely to have type of epilepsy and seizure classification recorded in their notes. Patients in the older age group were more likely to be seen for review solely in general practice. Patients in the older age group were less likely to have a recording of seizure frequency.

Young adults were more likely to be classed as poor adherence. Middle-aged adults were more likely to be classed as partial adherence (see Table 3).

Data grouped by PCT

Type of epilepsy was less likely to be recorded in Selby and York PCT. However, where seizure type was recorded, it was more likely to be found in the computer notes in Selby and York. East Hull patients were more likely to have had a seizure in the last 12 months.

There was no difference between PCT and whether the patient was reviewed in the last year and the recording of seizure frequency.

East Hull PCT were more likely to have patients who were not on the register but were taking AEDs (see Table 4).

Discussion

This study demonstrated how practices are currently managing epilepsy as part of the quality framework, but highlighted areas where care could be improved. General practice may be able to achieve a higher standard of care by using the systems developed for other long-term conditions. By ensuring epilepsy registers are accurate, a correct diagnosis is recorded, and using the annual review to inform, support patients and monitor medication, recommendations set out in national guidelines could be met.

An accurate and up-to-date epilepsy register is necessary for practices to manage the condition in line with guidelines. This study revealed incomplete lists with some people not on the register receiving treatment for epilepsy.

The prevalence data for epilepsy in the UK does not differentiate between patients on treatment and those people with seizures who have chosen not to take medicines. We found that practices construct epilepsy registers in different ways with variance in prevalence rates between participating practices and PCTs. This variation may arise because the QOF indicators only measure care of patients 'aged 16 years and over' (since 2006 over 18 years of age (www.bma.org.uk))

Table 3 Differences by age groups

	Young adults, n (%)	Middle age, n (%)	Older adults, n (%)	Test statistic (df), P value
Whether patient reviewed in last year				
Reviewed	130 (80)	421 (83)	286 (79)	$\chi^2 = 2.067$ (2), $P = 0.356$
Not reviewed	33 (20)	89 (17)	77 (21)	
Recording of type of epilepsy				
Recorded	147 (90)	404 (79)	269 (74)	$\chi^2 = 17.326$ (2), $P = 0.001$
Not recorded	17 (10)	106 (21)	96 (26)	
Recording of seizure classification				
Recorded	129 (79)	340 (67)	224 (61)	$\chi^2 = 15.228$ (2), $P = 0.001$
Not recorded	35 (21)	170 (33)	141 (39)	
Place of review				
General practice only	70 (53)	268 (64)	215 (75)	$\chi^2 = 21.960$ (4), $P = 0.001$
Hospital only	33 (25)	73 (17)	37 (13)	
Both	28 (21)	80 (19)	34 (12)	
Recording of seizure frequency				
Recorded	118 (72)	406 (80)	259 (71)	$\chi^2 = 9.553$ (2) $P = 0.008$
Not recorded	45 (28)	104 (20)	106 (29)	
Adherence				
Satisfactory	105 (80)	393 (83)	323 (90)	$\chi^2 = 24.635$ (4), $P = 0.001$
Partial	12 (9)	62 (13)	29 (8)	
Poor	15 (11)	21 (4)	8 (2)	

Table 4 Differences by Primary Care Trust

	Selby/York, n (%)	Eastern Hull, n (%)	West Hull, n (%)	Test statistic (df), P value
Whether patient reviewed in last year				
Reviewed	286 (82)	238 (83)	313 (78)	$\chi^2 = 2.606$ (2), $P = 0.272$
Not reviewed	65 (18)	48 (17)	86 (22)	
Recording of seizure frequency				
Recorded	273 (78)	217 (75)	293 (73)	$\chi^2 = 1.903$ (2), $P = 0.386$
Not recorded	78 (22)	71 (25)	106 (27)	
Was type of epilepsy recorded				
Recorded	262 (74)	241 (84)	317 (80)	$\chi^2 = 8.253$ (2), $P = 0.016$
Not recorded	90 (26)	47 (16)	82 (20)	
Where type of epilepsy was recorded				
Computer notes	213 (81)	121 (50)	148 (47)	$\chi^2 = 81.270$ (2), $P = 0.001$
Paper notes	49 (19)	120 (50)	169 (53)	
When patient last had a seizure				
Less than 12 months ago	91 (42)	120 (63)	84 (38)	$\chi^2 = 28.516$ (2), $P = 0.001$
More than 12 months ago	125 (58)	70 (37)	135 (62)	
Anti-epileptic drug (AED) use of patients not on epilepsy register				
Taking AEDs	6 (6)	21 (27)	6 (8)	$\chi^2 = 20.012$ (2), $P = 0.001$
Not taking AEDs	97 (94)	57 (73)	70 (92)	

receiving drug treatment for epilepsy. The practices in two of the PCTs captured most patients taking AED for epilepsy on the registers with only a 6% or 8% failure. However, there is a concern that in one PCT, the epilepsy registers missed people with epilepsy who were having seizures or were on AED medication. It is possible that people not taking treatment for their epilepsy would not be included on the practice register or recall system. Health planners should therefore treat prevalence figures derived from the QOF data with caution. However, measuring the prevalence of epilepsy has

always been problematic. The unadjusted national prevalence for the condition as reported by the 2005 Strategic Health Authorities varies by a factor of almost 2 from 0.4% to 0.7% (www.ic.nhs.uk). The discrepancies in the registers and reported prevalence may be due to the nature of the condition. The stigma of epilepsy, low expectations of care and unenthusiastic clinical engagement with epilepsy in general practice can inhibit attendance for regular review. There is a disincentive for patients to report seizures to their practitioner, particularly if they hold a driver's licence.

Making an accurate diagnosis is important because some types of epilepsy respond well to specific AED, and treatment should be tailored to the individual. However, in current practice, it seems optimistic to use the four-axis classification proposed 6 years ago (Engel, 2001). There was little evidence of accurate seizure classification although the findings in younger patients show that the diagnostic process may be improving. Practitioners should take the opportunity of the annual review to check the diagnosis in line with clinical guidelines.

We noted that a fifth of patients did not have a record of an annual review and a quarter of cases had no record of seizure frequency. However, as 66% of the epilepsy population attended general practice for their review, we have the opportunity to improve care by involving the patient in constructing a care plan, in reviewing the type of seizure and what sort and source of information is needed to improve seizure control. Local primary care commissioning groups may use the NICE guidelines to standardise the review process. The guidelines recommend providing information and support, and highlight the particular needs of special groups such as women of childbearing age and people with learning difficulties. It is not possible to measure these aspects of care in the present framework.

The QOF rationale for medication review is to monitor drug, dose, adverse effects, co-prescribing and adherence. The optimal use of AED treatment is when it is matched to the type of epilepsy and the individual. Medication records in general practices are almost completely computerised and hence easily accessible.

It was encouraging to find that 85% of patients ordered AED between 80% and 100% of the expected frequency. It would appear that the majority of patients have decided to order their medication as instructed. The clinical review offers the opportunity to check on the frequency of AED ordering. Poor adherence was associated with young age and monotherapy, but as adherence is a dynamic and variable behaviour (Haynes *et al.*, 2002; Sawyer and Aroni, 2003), practitioners may wish to enquire about the individual medication usage of all patients when attending for medication review.

While regular review can be helpful for both patient and practitioner, the QOF indicators can be recorded with little engagement between patient and practitioner. Practices should consider validating their epilepsy register and decide if they want to include people with epileptic seizures who have chosen not to take medication. Practitioners can then offer a personal invitation to patients for an individualised structured review. It seems counter-intuitive to expect a useful review that addresses the issues raised by this work to be conducted over the phone as was sometimes the case, and face-to-face reviews should be encouraged to address the complex issues of epilepsy diagnosis and treatment.

This study did not assess the process of epilepsy review in practice but the case notes suggested a variation in how review was carried out. Further work on the review process may be of interest.

Conclusions

There are now incentives for general practices to provide epilepsy care. Systems are now in place to allow regular monitoring and review. Practitioners can use these systems to improve care in three ways:

1) Practices should review the epilepsy register to ensure capture of patients of all ages with epilepsy irrespective of AED treatment, and hence identify those patients who require specialist review when a full diagnosis is either not recorded or contradictory. This will ensure a firm diagnosis with correct seizure classification that will lead to best treatment.
2) Patients should be invited for face-to-face consultations not only to address the clinical indicators listed in the quality framework but also to provide information and support, to review seizure control and to address specific issues of particular groups.

3) Practitioners should be aware of the need to discuss medication issues at the face-to-face review. This is particularly useful for younger patients and those on monotherapy who may have decided to take the treatment in a different way.

Acknowledgements

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