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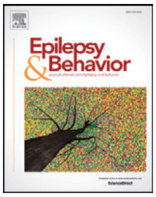

First evidence of the clinical impact of a general practitioner with a special interest in epilepsy

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ABSTRACT

Purpose: The purpose of the study was to review the clinical outcomes of people with epilepsy (PWE) attending a primary care-based specialist epilepsy service.

Method: The case notes of 355 people attending the service and subsequent follow-up from 2005 to 2013 were reviewed.

Results: There had been 37 deaths (all nonattributable to epilepsy), and 38 people had left the area, leaving 280 people who completed the audit. Positive outcomes could be attributed in 94% still attending the service at the end of follow-up. Seventy-five percent of people on treatment, referred with poor seizure control, achieved seizure remission with antiepilepsy drug (AED) changes initiated by the service.

Conclusion: This study suggests that the majority of people who attended the service had a positive outcome and provides the first evidence for the clinical effectiveness of a general practitioner (GP) with special interest in epilepsy (GPwSIe) and provides support for the recommendations in earlier government reports to promote the use of such a service. Clinical Commissioning Groups (CCGs) and Government should consider investment in this intermediate tier of care as a means to both improving the quality of care and potentially reducing costs.

1. Introduction

The National Health Service (NHS) Plan [1], published in 2000, was a blueprint on how the various components of the NHS should develop and highlighted the need to create new career pathways for general practitioners (GPs), in particular the recommendation for the creation of an intermediate role for practitioners, stating that 'there will be a bigger role for GPs in shaping local services, as more become specialist GPs'. The rationale being that a GP with a special interest (GPwSI) could provide an intermediate tier of expertise and advice to their primary care colleagues, potentially creating an alternative and more accessible service for referral and specialist investigation, consequently reducing waiting times. The primary rationale for such a framework being that GPs working in specialist areas could bring their unique and in-depth knowledge of primary care to the respective clinical area and are able to work across physical, psychological, and social paradigms, while providing effective multidisciplinary working and service delivery for people with chronic relapsing conditions (Appendix A). It was postulated that a GPwSI could augment and add value to patient care while not replacing the need for secondary and tertiary care services. The Chief Medical Officers Report described the possible mechanisms and time frame for the introduction of GPwSI, and outlined of the possible roles of a GPwSI [2].

The GP lead of the International League Against Epilepsy (ILAE) British Chapter in 2002 proposed a model to compliment the one outlined by the Chief Medical Officer. Overall, it was estimated that the average GP will only see one or two new cases of epilepsy per year and will care for about twelve people with epilepsy (PWE). It was proposed that, in an ideal situation, each GP practice should have a lead GP for epilepsy. The local GP with special interest in epilepsy (GPwSIe), ideally would attend an 'in-house' clinic every 4–8 weeks in every practice, with the local lead GP sitting in on this clinic to provide background information on the PWE; they, in turn, would also then receive training in epilepsy, and ideally consequently becoming a resource for epilepsy expertise and advice for the other GPs in the surgery [3].

According to the ILAE British Chapter records, there are currently 30 GPwSIe across United Kingdom, several of whom have been in place for the past 10 years. Despite this, to date, there has been no published data on the impact that this intermediate tier of expertise has had on overall clinical management of PWE.

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The aim of this clinical audit was to evaluate the clinical outcomes of people who attended and were subsequently followed up by a primary care epilepsy service managed by a GPwSIe.

2. Methods

After several audits demonstrating the variable standards of care for PWE, the Western Cheshire Primary Care Trust (PCT) agreed to fund the training (46 clinical sessions undertaken and a Master of Science (MSc) module in care of PWE) and the creation of a primary care clinic managed by GPwSIe [4,5].

This clinic commenced in July 2005, with referral guidelines, accepting referrals from local GPs, practice nurses, and consultants (neurologists and pediatricians), by direct letter or the Choose and Book system (NHS computerized appointment service) with appointments booked directly with the clinic. The clinic maintains a two-week wait for emergency cases. Clinical telephone support was available on a weekly basis from a consultant neurologist, in addition, routine consultant review of all clinical letters generated by the service in response to all new referrals to the service. Educational events on epilepsy have been provided by the first author (IM) on the locally organized educational rolling half days. A yearly review of the service is undertaken by the Clinical Commissioning Group (CCG).

The notes of the 355 people, newly referred to the service, who attended and were followed up between July 2005 and December 2013 were reviewed, in all the 37 practices in West Cheshire CCG. The service did not accept direct referrals from the first author's (IM) own practice.

Data were remotely collected in 31 practices using the EMIS (Egton Medical Information System) operating system, and at 6 surgeries who expressed confidentiality issues or did not have the EMIS system. In scenarios where data could not be accessed remotely, clinical clarification was obtained by direct consultation with the patient's primary GP. Clinical outcomes concerning newly diagnosed or established epilepsy and other diagnoses were evaluated. The review took place from June 2014 to allow for at least a six-month period to have elapsed since the last review.

3. Results

In total, 702 people were referred to the service over the nine years at the time of the audit, of whom 147 (21%) remain under active care with the service.

The remaining 555 people referred to the service were no longer under active care. Of these, 200 people had either failed to attend the initial clinic appointment offered in the service or subsequently failed to attend a follow-up appointment and were discharged [6].

Of the other remaining 355, there were 37 (10%) deaths during the period of observation, all of which were nonattributable to epilepsy, with the majority of whom, 30 (81%) had improved outcomes relative to their baseline at the time of referral to the service (Table 1).

Thirty-eight people (11%) left the area, on whom no information could be obtained on their current status. Of these, 26 (68%) had known improved seizure outcomes up to the time of migration (Table 2).

The remaining 280 (79%) people completed the audit with current outcomes established, which are summarized in Table 3 (new diagnoses) and Table 4 (established epilepsy diagnosis). Of these, 263 (94%) people were felt to have derived benefit from interaction with the service.

There were, in total, 18 onward referrals from the service to cardiology (9), neurology (4) and neuropsychology (4).

Table 1
Deaths with primary reason for referral and clinical outcomes (unknown or negative outcomes in italics).

People who died: primary reason for referral to the service		N = 37
New event(s)	Seizures diagnosed, AED started — no seizures	5
	Syncope — no events	3
	Excessive alcohol, therefore, no AED suggested	2
	Single seizure — no further seizures (not known)	2(*1*)
	Seizures diagnosed, side effects AED – stopped – not known	*1*
	Seizures diagnosed, chose to observe — not known	*1*
	Uncertain diagnosis — not known	*1*
Poor control	AED changed — no seizures	5
	AED changed — improved	7
	No wish to change to AED	1
	AED changed — not known	*2*
	AED changed — no improvement (AED noncompliance)	*1*
Diagnostic query	One old diagnosis in remission, one NEAD (nonepileptic attack disorder)	2
AED review	No change — no seizures	1
Proposed AED withdrawal	No change to AED — no seizures	2

4. Discussion

The primary aim of this audit was to evaluate the effectiveness of a primary care specialist epilepsy service by determining the clinical outcomes of people newly referred to the service by other primary care practitioners or from consultant led services.

The principal findings were that 94% of people referred to the service were judged to have a positive clinical outcome as a result of interaction. There were positive outcomes for people who had subsequently died of other causes (81%) and who had left the area (68%) where data were available. Most significantly, of the 85 PWE referred to the service with poor seizure control at the time of referral, many of whom had previously been under the care of general neurology, 64 (75%) went into seizure remission as a result of antiepilepsy drug (AED) change initiated by the service; two were rediagnosed with nonepileptic attack disorder (NEAD), and one had their diagnosis questioned and AEDs discontinued when referred to cardiology, with subsequent pacemaker insertion.

This study is the first large, comprehensive clinical audit of a primary-based epilepsy service. Limitations of this study primarily relate

Table 2
People who left the area with primary reason for referral and clinical outcomes (unknown or negative outcomes in italics).

People who left the area: primary reason for referral to the service		N = 38
New event(s)	Seizures diagnosed, AED started — no seizures	3
	Syncope — no events	3
	Syncope — referred cardiology – scanned – glioma-resected — not known	1
	Seizures diagnosed, AED started — not known	*2*
	NEAD diagnosed — not known	*1*
	Seizures diagnosed, second opinion – loss of consciousness cause uncertain – nothing more in notes	*1*
Poor control	AED changed — no seizures	4
	AED changed — improved	4
	No change to AED as infrequent seizures	1
	AED changed — not known	*3*
	AED changed — no better (noncompliant)	*1 (1)*
	New events in well controlled epilepsy – not seizures – not known	*1*
Diagnostic query	*Uncertain diagnosis — not known*	*1*
In remission	No change to AED — no seizures	5
Withdrawal	No change to AED suggested (further seizure)	2(1)
Preconceptual	(One woman on valproate declined switch)	2
Side effects	Advice on memory	1

Table 3
People with new events who completed the review with primary reason for referral and clinical outcomes (unknown or negative outcomes in italics).

New event(s): primary reason for referral to the service		N = 107
Syncope	No subsequent events	39
	Pacemaker inserted following cardiology referral	4
	Referred with frequent episodes — not seizures — diagnosis subsequently reiterated by Neurology as syncope	1
	Referred cardiology who agreed — further events confirming the diagnosis	*1*
	Neurology diagnosed seizures — AED started — no events	*1*
	Difficult diagnosis — neurology subsequently diagnosed epilepsy no events	*1*
	Further events – admitted – tumor diagnosed	*1*
Focal onset epilepsy	New AED initiated — seizure remission	19
	Tumor diagnosed on MRI — debulked	1
	Alcohol-related seizures — no further seizures	1
	AEDs suggested — declined — no seizures	*2*
Generalized onset epilepsy	AEDs started — seizure remission	1
	EEG abnormal — pediatricians query diagnosis	*1*
Another diagnosis not epilepsy — no further events		25
Non epileptic attack disorder — no further events		4
New events in previously well-controlled epilepsy — not seizures — no seizures		4
Provoked seizures — no seizures		1
Myoclonus — referred neurology — subsequently improved		1
Single seizure — no subsequent seizures		**N = 17**

Table 4
People with an established epilepsy diagnosis who completed the review with primary reason for referral and clinical outcomes (unknown or negative outcomes in italics).

Referral with purported poor seizure control	N = 85
AEDs changed — seizure remission achieved	64
Assessed and in remission — no change	7
Diagnosed with NEAD — no further events	2
Poor control no wish to change	2
AED changed — improved but not controlled	2
Behavioral issues not epilepsy — no events	1
Diagnosis questioned – suggested cardiology – AEDs discontinued by service	1
AEDs changed — no improvement	*2*
AED changed — worse — reverted to original AED — no seizures	*1*
AED changed — side effects so reverted — toxic, no events	*1*
Switch suggested still on original AED, not controlled	*1*
AED suggested but declined — ongoing seizures	*1*
Referred for preconception advice	**N = 5**
Switch from valproate (2 lamotrigine, 1 levetiracetam) — no seizures	3
No change — no seizures	1
No change — (carbamazepine + clobazam) — further seizures — referred neurology	1
Pregnancy care	**N = 4**
No change — normal deliveries	3
Withdrawal suggested — came under neurology in 2nd pregnancy — successful withdrawal	1
Referred for AED withdrawal	**N = 17**
No change to continue AED — no seizures	13
Successful withdrawal	2
No change suggested — withdrew AED — further seizures	1
No change suggested — withdrew AED — no seizures	*1*
In seizure remission at the time of referral	**N = 25**
No change to AED — no seizures	21
Withdrawal suggested and completed — no seizures	1
Original diagnosis questioned — no change — AED stopped by person — no seizures	*2*
Prescription changed because of side effects — AED stopped by person — no seizures	*1*
Referred because of AED side effects	**N = 4**
Gum hypertrophy on phenytoin	2
Successful AED switch	1
Memory issues on valproate addressed	1
Miscellaneous advice	**N = 16**
Biochemistry issues — hyponatraemia, abnormal liver function tests, bone health	8
Myoclonus — side effect clozapine and one nonepileptiform	2
Advice on medication — hormone replacement therapy, antidepressant therapy	2
Referral for a new helmet	1
Valproate and phenytoin for controlled idiopathic epilepsy — phenytoin stopped — no seizures	1
Suggested referral to psychology for NEAD — improved	1
Phenytoin levels	1

to inconsistencies or inaccuracies in GP records, sometimes with no documented record of an annual review or seizure frequency. Moreover, another issue of concern is that of people who had stopped AEDs of their own accord following review in the service, that this was not subsequently reviewed or commented on by their GP. This brings into question the value of mandated GP annual reviews of PWE when the Quality and Outcomes Framework (QOF) was still in place [7].

In a previous study of epilepsy care in secondary care setting, with links to primary care, 676 people who had never attended an epilepsy clinic and who would not have been referred were invited for reassessment. Of these, only 108 (16%) accepted the offer of follow-up, of whom 55 (51%) had persistent refractory epilepsy, of which 17 (31%) subsequently achieved at least a 1-year remission as a result of treatment change initiated in the clinic. The authors highlighted the need for people with suspected epilepsy to be initially assessed and reviewed by a neurologist and ideally one with a subspeciality interest in epilepsy. In addition, they recommended that all PWE in primary care with uncontrolled epilepsy should be under shared care [8].

There is a paucity of research in the management of epilepsy in primary care, much of which is more than 10 or even 20 years old [9]. Consequently, such data may no longer accurately reflect ordinary GP competencies in managing PWE, particularly in light of the significant treatment options that have emerged in the intervening years [10]. Previous data from the Clinical Standards Advisory Group (CSAG) report suggested that PWE favor a shared care model between primary and secondary/tertiary care. People with epilepsy criticized poor communication in hospital outpatients and long waiting times. The study showed that many patients would be happy to be managed in primary care, especially those with mild or controlled epilepsy. Patients found their GP easy to talk to, and the latter listened to their problems. There was an emphasis on specialist services to support primary care effectively and improve communication between the two. The report emphasized that GPs have a pivotal role in the management of epilepsy, and that role should be strengthened as a matter of fundamental importance. Overall PWE's satisfaction with general practice was high. Unfortunately, most patients thought GPs had a poor level of knowledge of epilepsy, and this was a barrier to them attending surgery, a situation that has certainly deteriorated since the CSAG study was completed. Better access for GPs to hospital expertise was emphasized [11]. Other studies have also demonstrated a low level of confidence and perceived level of expertise in the management of PWE by GPs [12], although this varies by country and accessibility to neurology services [13].

There has not been a previous assessment of the impact of primary care epilepsy service, although some work has been done on the effectiveness of community speciality clinics. Waiting times were shorter with fewer follow-up appointments and an increased likelihood in being discharged. Outreach patients were more satisfied with the range of clinic processes asked about. National Health Service costs were more expensive for outreach patients; at six months, the benefits on health status were relatively small [14]. One study compared a GPwSI led headache clinic and a general neurology outpatient service. People were significantly more satisfied with the GPwSI service, particularly in relieving symptoms. The service was significantly cheaper to provide. Overall outcomes for headache management were broadly comparable [15].

The Royal College of General Practitioners (RCGP) position paper on the governance on GPs with an extended role (GPwER), in whatever speciality, raises the fear that such a role may erode the traditional role of a GP while replacing them with “mini-secondary care specialist” [16]. We would argue, in contrast, that in the case of epilepsy, the traditional model of shared care between primary and secondary/tertiary care no longer accurately reflects everyday management of PWE. Consequently, the role of a GPwSIe, a term that we favor than the nondescript term GPwER recently proposed by the RCGP, rather than supplanting the traditional role of a GP, in fact by providing an intermediate level of care between primary and secondary/tertiary services, offers a more viable model of shared care.

In much the same way that the term consultant neurologist with a special interest in epilepsy is more appropriate than the uninformative consultant neurologist with an extended role, we would argue that GPwSIe is the more appropriate terminology, which emphasizes the area of subspecialization while underlying the importance of the principal role of general practice. We would also advocate that the CSAG study (20 years old) [11] should be repeated to ascertain GPs' current levels of confidence in managing PWE.

The primary aim of this study was to evaluate the effectiveness and indeed viability of a primary care specialist epilepsy care service. While the results of this study are encouraging and support the viability, these results need to be independently replicated before any general conclusions can be made. Nevertheless, we would argue for an urgent need for an intermediate level of care for PWE between primary and secondary/tertiary care, as the previously shared care model no longer really exists. Moreover, we believe that for GPs interested in epilepsy, the position of a GPwSIe provides GPs to take a genuine active role in the management and care of PWE.

Consequently, it is possible to envisage in time a service where a full time GPwSIe reviews, yearly or as frequently as required, all PWE, including those under secondary care and pediatrics. People with well-controlled epilepsy on AEDs could gradually be handed back to a GPwSIe for follow-up. This will comprehensively include all those people with poor control not currently under shared care. In addition, this would facilitate a natural transition of children into an adult service, particularly where such services do not exist and indeed would reduce the pressure on the secondary care. This service could also provide a forum where up to date preconceptual advice could be given to women with epilepsy.

For governance reasons, if necessary, we would propose that all people referred to the service with a new diagnosis of epilepsy should be referred to the local neurology or epilepsy service for confirmation of such diagnosis but with subsequent follow-up managed by the GPwSIe, with an agreed appropriate epilepsy action plan between the two services. Once a service is well established, with referral pathways in place, the GPwSIe could review and triage any new epilepsy referrals to neurology in order to prevent inappropriate referrals. In addition, other, often overlooked, issues such as and mental health and bone health could be addressed. This, in turn, could reduce the demand on already overburdened secondary and tertiary care neurology care services with the added benefit that many PWE could be followed up in the community.

5. Conclusion

In conclusion, to our knowledge, this is the first study to evaluate the outcomes of PWE (or suspected epilepsy) who attended and were followed up by a specialist epilepsy clinic in primary care. The findings suggest that a trained GPwSIe can provide an efficient and clinically sound service, the majority of people who attended the service had a positive outcome. It adds weight to the effectiveness of a GPwSIe and provides support for the recommendations in earlier government reports to promote the use of such a service. Clinical Commissioning Groups should consider investment in this intermediate tier of care to both improve the quality of care and potentially reduce cost.

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Ethical approval

Audit does not need ethical approval.

Declaration of competing interest

There were no conflicts of interest.

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Thanks to all the practices who allowed me access to their clinical systems, to those in 2004 who trained me and to those who had the faith and foresight to set up the service.

Appendix A

Core Activities:

Clinical: Providing a locally determined clinical service, with defined pathways for people. Education and liaison: In partnership with other established educating bodies to develop skills and knowledge of primary care. To provide information in best practice, and develop templates for review and to facilitate audit.

Leadership: In developing services, developing shared care, and support for GPs and the PHCT.

Competencies:

Clinical: In diagnosis, psychological issues, natural history, pharmacological treatments and side effects, comorbidity such as special needs, and appropriate referral. Leadership: Good negotiating and communicating skills.

Education and liaison: Establish a register with recall and audit mechanisms. Liaison with voluntary sector, providing information for support organizations and carers.

The Service: The GPwSI should not work in isolation away from specialist services.

Local Guidelines: Type of person to be referred, referral pathways, response time and communication pathways to be established.

Facilities:

Recommended: Direct access to specialist support and investigations, clinical supervision, educational material, and to shared care services.

Desirable: Direct access to genetic and prenatal counseling, neuropsychological, and neuropsychiatric services.

Clinical Governance: Accountability to the PCT board, mechanisms for defining audit, communication standards, significant event monitoring, and complaint handling.

Evidence of training: To maintain a professional development portfolio. To have obtained MRCGP. To have obtained relevant experience, and to have worked under direct supervision with a specialist clinician (20–50 sessions). Attending relevant bench marked courses.

Accreditation: RCGP suggests PCT, Clinical Governance Lead, GP Tutor and specialist clinician, decide this at a local level.

Maintenance of competences: Undertakes 15 h a year of CPD in relevant areas and annual appraisal. This should be appropriately funded and supported time wise.

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