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Short communication

Managing epilepsy in austerity – Evaluating the utility and value of the epilepsy specialist nurse in an open access model of service delivery. Aneurin Bevan Epilepsy Specialist Team (A.B.E.S.T.)

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ABSTRACT

Purpose: Healthcare organisations in the UK primarily measure clinical activity from data collected on numbers of attendances at outpatient clinics, inpatient admissions and procedures performed etc. Telephone contacts with patients are not typically measured as clinical activity. This service evaluation examines the utility and value of the Epilepsy Specialist Nurse (ESN) within an innovative 'Open Access Model', giving a breakdown of clinical workload and outcomes.

Methods: A retrospective service evaluation analysing all patient encounters made by the ESN and their outcomes, over a 3-month period from the 01/02/2017 to 30/04/2017.

Results: During the 3-month data collection period there were 620 patient encounters with 251 different patients. Nurse-led clinic appointments and telephone calls were the two most common types of encounter. Eighteen percent of ESN time was spent on the phone directly addressing patient concerns (368 encounters). Of these calls, 72% led to prevention of a clinic appointment (268 appointments avoided) while only 22% needed a subsequent clinic appointment. The most common outcome of telephone encounters was 'medication management' (25%).

Conclusions: The evaluation demonstrates that timely intervention by telephone reduces the need for outpatient appointments and leads to treatment changes being implemented quickly to address individual need.

1. Introduction

Epilepsy is a common, unpredictable disorder associated with an array of psychosocial complications [1,2]. Its episodic and varying nature means that conventional models of service delivery do not always suit it well.

Across Wales, epilepsy prevalence is 1% (approximately 32,000 people with epilepsy (PWE), with localised variation linked to levels of deprivation [3]. Optimal use of anti-epileptic drugs (AEDs) could control seizures fully in up to 70% of patients. Unfortunately, only around 52% of patients achieve sustained seizure freedom, with 30% of patients becoming refractory to all treatment. This shortfall in the success of treatment with AEDs may be due to refractory disease, poor tolerability, patient adherence to medication, lifestyle factors (e.g. alcohol, drugs, poor sleep, and stress) or misdiagnosis [4]. These data extrapolate to an estimated 5200 people in Wales with preventable seizures.

The Aneurin Bevan University Health Board (ABUHB) has a catchment population of 640,000, including approximately 6000 PWE.

2. Background

In 2013, ABEST consisted of one Consultant Neurologist and one whole time equivalent, band 7, ESN. We used a traditional out-patient follow-up appointment booking model; [5] leading to long waiting lists, patient dissatisfaction and clinical risks. A pioneering new model was introduced, the 'Open Access Model' (OAM), aiming to provide patients and families with a point of contact via the ESN to discuss problems as they arise [6]. This enabled the ESN to triage patients in a timely manner, implement treatment changes over the phone, and reduce the need for outpatient appointments. An initial evaluation of this model, in 2014, demonstrated reduced waiting time for appointments, from 6 months to 13.4 days. Unfortunately, this evaluation did not look in detail at the nature of the individual tasks undertaken by the ESN.

NHS Wales does not operate a tariff system (i.e. there is no

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purchase-provider split) and so teams cannot generate additional income (and therefore staff and resources) by increasing their NHS activity (though they can through research and teaching).

3. The role of the epilepsy specialist nurse

In times of austerity the role of the ESN has come under scrutiny; reducing and downgrading roles has been considered by Health Boards as a quick way to reduce staffing costs [7]. ESNs have been considered an expensive commodity, with increasing pressure to demonstrate the value and cost-effectiveness of their role in patient care. Epilepsy Action commissioned a team of researchers from Liverpool's John Moore's University who summarised that the ESN was a central point of care for PWE, reducing the Consultant Neurologist's workload [8]. Their specialist nursing skills enable them to undertake work which otherwise puts further demands on Consultant Neurologists time. The ESN performs similar duties to the Consultant, with almost 94% being involved in monitoring and adjusting medication to optimize seizure control. Those who have worked with ESNs will appreciate that they are typically better at many holistic aspects of epilepsy management than doctors, including rescue medication training and providing and signposting emotional support.

4. Study aim

To evaluate the utility and workload of the ESN role in an OAM four years after its inception.

5. Method

A retrospective service evaluation analysing all patient encounters made by the ESN and their outcomes, over a 3-month period from the 01/02/2017 to 30/04/2017.

We utilised our electronic health record system where all ESN patient encounters are documented; specifying the type of contact, time spent and allowing free text to describe the nature and outcomes of each contact (Fig. 1).

Traditional scheduled follow-up outpatient appointments are no longer routinely provided for PWE unless there is a clear clinical need; e.g. the patient is considered vulnerable, unable to engage via the telephone, or there are communication barriers. Therefore, after diagnosis most patients are discharged onto a 'see on system' coding, eradicating the need for further referral to ABEST when difficulties arise as the patient, GP or any advocate can contact ABEST for advice or an appointment at any time. The telephone model is well-described [9]. The ESN is responsible for the triage of patient calls through initial telephone assessment. Patients are then either managed remotely (with a call back and subsequent written record to patient and GP) or given a timely appointment with the ESN or their Consultant Neurologist. Most appointments are booked within 2 months and some are seen within 1 week (Consultants and nurses have dedicated 'open access' clinics that are booked only by team members, Consultants also have emergency clinics that can be utilised when on-call). Difficult problems are discussed in the weekly team meeting, in order to determine the advice given or whether advice already given is agreed amongst team members. The ESN does not presently hold an independent prescribing qualification, however the team is housed in a shared office, enabling rapid case discussion and initiation of prescription changes within 24 h. Prescriptions are either sent out by the team by post, collected from the hospital, or advised via formal electronic communication to GPs the same day.

Although telephone advice-lines are an effective mode of providing timely and effective intervention for patients [10], calls are not currently recorded as clinical activity in ABUHB and therefore this work has been 'unseen'. By analysing our records, we were able to demonstrate telephone interventions as clinical activity with clear outcomes. Our evaluation confirmed that telephone contact made up 73% of non face-to-face contacts, and constituted a third of the ESN's overall clinical activity.

6. Results

During the 3-month data collection period there were 620 patient encounters with 251 different patients. Nurse-led clinic appointments and telephone calls were the two most common encounters. The division of the principal outcomes of each encounter are represented in Fig. 2.

Eighteen percent of ESN time was spent on the phone directly addressing patient concerns (368 encounters), the vast majority of these encounters obviating the need for contact with a Consultant Neurologist. Of these calls, 72% led to prevention of a clinic appointment (268 appointments avoided) while only 22% needing a subsequent clinic appointment. The most common outcome of telephone encounters was 'medication management' (25%).

During the 3-month evaluation, 89.2 h were spent in face-to-face clinical contacts, compared to 100.1 h on indirect clinical contacts (of which 71 h were telephone calls). The contracted working hours per week for the ESN are 37.5 h, and the average hours worked during the study were 39.3 h per week, creating a difference of 17.9 h of unpaid/uncontracted overtime during the study period.

7. Discussion

This evaluation was labour intensive as some database entries were brief and data had to be cross referenced with corresponding clinical letters to identify themes and outcomes (Fig. 1). We have since improved our database recording to make future analyses more efficient.

Failure to take anti-epileptic medication significantly increases risks of seizures, injury and sudden unexpected death in epilepsy (SUDEP) [11,12]. This OAM enables the ESN to quickly discuss changes in seizure presentation/frequency and explore reasons for this. Medication adherence is routinely discussed at every encounter by the ESN and rescue plans are implemented for patients who have stopped AEDs against advice. It is difficult to calculate the impact of this timely intervention on prevention of admission due to seizures, and SUDEP, but this evaluation has demonstrated that 25% of all calls relate to patient concern with medication.

In times of austerity, where prudent healthcare must be delivered, this evaluation highlights the valuable role the ESN plays. These interventions by the ESN prevented 268 clinic appointments over 3 months. At a cost of £130 per clinic appointment, this extrapolates to a potential saving of £34,840 in three months, or £139,360 annually.

The ESN, applying the OAM, also enabled 73% of patients contacting the service to be managed successfully in the community, a primary objective for ABUHB, Welsh Government, and the wider NHS (https://improvement.nhs.uk/resources/moving-healthcare-closer-home/).

The OAM has made efficient use of the limited resources available to ABEST, with huge reductions in out-patient appointment requirements (and therefore follow-up waiting times) and rapid response to urgent clinical problems. Over the study period the ESN worked 21 extra minutes per day and whilst it is acknowledged that many of us work above our contracted hours, this is not a sustainable long-term solution for managing demand and does not allow cover during annual/sick leave. The collection of this data facilitated the recruitment of a second ESN, which is driving further service development. For example, we are now collating patient reported outcome measures and quality of life assessments as well as initiating additional clinics in community settings closer to patients' homes.

Telephone contacts are not visible in conventional health-service clinical activity monitoring and consequently we are now setting up clinical coding to reflect this role. These contacts will now be

Reasons for Encounter	Outcomes
Medication/rescue medication/adherence/drug changes/repeat prescriptions	Medication advice/rescue medication plan/ prescription provided
Drug tolerance issues	Medication adjustment
Increase/breakthrough seizures/new symptoms/non-epileptic attack	Discuss at MDT/request videos/open access/joint clinic/earlier appointment/admission/contact GP
Post diagnosis	Counselling/home visit
Lifestyle issues – stress/education/psycho-social issues/mental health/learning disabilities/employment/financial concerns/sleep/alcohol/drugs	Lifestyle advice, advised to keep diary
Results – bloods/EEG/MRI/CT/EEG/videos	Results provided
Safety and risk management	Advice/provision of literature & links
Contraception/pre-conception counselling/pregnancy	Nurse-led/antenatal epilepsy clinic
Supportive letters	Provide supporting letter
Education/training	Education/training provided
DVLA (driving) related	Driving advice
Inpatient/discharge planning	Ward-visit
Clinic appointment request	Prevention of clinic appointment
Other – onward referrals/complaints/contact information/duplicate call/not given/unable to attend clinic	

Fig. 1. Reasons and outcomes for encounters.

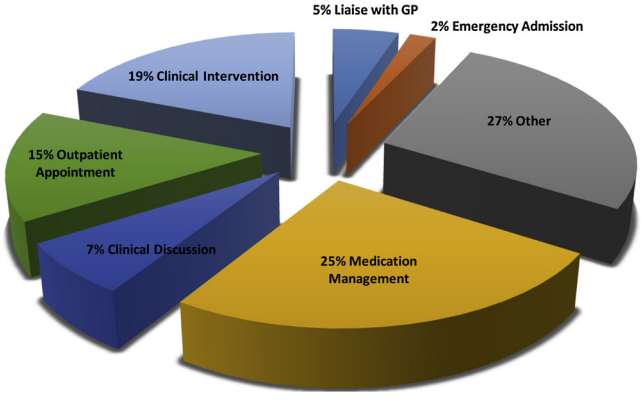

Fig. 2. Principal Outcomes from Telephone Calls.

recognised as telemedicine.

Declarations of interest

None.

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