



Short communication

Specialist epilepsy service input following an epilepsy related unscheduled care episode

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ABSTRACT

Background: Emergency and unplanned epilepsy-related attendances are associated with an increased risk of subsequent death within 6 months. Although further work is required to provide a definitive explanation to account for these findings, in the interim it would seem reasonable that services are designed to ensure timely access and provide support at a time of greatest risk.

We aim to determine the frequency of patients with epilepsy (PWE) accessing specialist neurology services following an epilepsy-related admission/unscheduled care episode.

Methods: Patients were included in the cohort if they had at least 1 prescription for an anti-seizure medication and at least one epilepsy-related admission, emergency department attendance, or outpatient neurology clinic attendance between January 2011 and November 2021.

We evaluated the rate of any outpatient neurology clinic attendance in the subsequent 6 months following an epilepsy related unscheduled care episode.

Results: Of the 6,449 PWE included in the cohort, 4,465 were included for analysis. At the end of the follow up period less than 40% were accessing specialist services within 6 months of an episode of admission/unscheduled care episode. Around a third (31.1%) of deaths occurred within 6 months of an epilepsy-related admission, and in the majority of cases patients were not seen by an epilepsy specialist in the period between discharge and death.

The frequency of mental health comorbidity in PWE accessing unscheduled care remains very high with almost 80% having a diagnosis of either depression or anxiety.

Conclusion: A significant proportion of PWE are not accessing specialist services in a timely manner following an episode of unscheduled care. Such provision may potentially provide an opportunity to reduce epilepsy related mortality by altering antiseizure medication doses and considering reversible factors associated with poor outcomes in PWE, such as poor medication adherence.

1. Introduction

Patients with epilepsy (PWE) are at a higher risk of premature death than the general population, and the rate of epilepsy-related death is a significant public health challenge [1].

A previous study of epilepsy-related deaths identified that of the 1921 deaths between 2009 - 2016, 62% were preceded by the patient being hospitalised for seizures but only 27% were seen in an outpatient neurology clinic during the time between their discharge and death [2]. Although we cannot state with any degree of certainty, it is not unreasonable to speculate that this may represent a missed opportunity to address reversible factors which are associated with increased mortality in PWE, such as poor medication adherence and poor mental health [3]. Previous studies examining care within the UK and Europe have highlighted significant variability in specialised input following an epilepsy related emergency department (ED) attendance or unscheduled

admission, with a significant proportion of people not receiving input from an epilepsy specialist in a timely manner or in some cases never at all [4–6].

It remains unclear whether lessons have been learned following the publication of these studies. Given this, our aim was to assess the rate at which epilepsy-related admissions were subsequently followed up by epilepsy specialist services.

2. Methods

2.1. Cohort identification

Patients were included in the cohort if they had at least 1 prescription for an anti-seizure medication and at least one epilepsy-related admission, emergency department attendance, or outpatient neurology clinic attendance between January 2011 and November 2021. All

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patients in this study were registered with a GP within the NHS Greater Glasgow and Clyde health board area. Patients under 16 years old were excluded. Patients were followed up from the date of their first ASM prescription and censored if they died, moved out of the NHS GGC health board area or at the end of the follow-up period on 31/11/2021, whichever was earliest. Data were accessed using the Glasgow Safe Haven [7], and included demographics, deaths, hospitalisations, ED attendance and outpatient clinic attendance [8].

2.2. Definitions

Hospitalisations were classified as being epilepsy related if there was an ICD-10 code (G40.x) for epilepsy listed in any position. Individual admission records were combined to form single continuous stays where the admission and discharge dates overlapped. We calculated the total number of admissions per year for the full follow-up period. Patients were considered to have been followed-up if they had at least one contact with neurology outpatient services within 6 months of the discharge date, including face-to-face, telephone or video link appointments with or written advice from clinicians, specialist nurses and other allied health professionals. Anti-seizure medications were defined as those listed in sub-section 04.08.01 of the British National Formulary (BNF). We identified history of treatment for mental health comorbidities based on prescribing records and hospital admissions, using the criteria and clinical coding defined in previous publications [9].

3. Results

In total 6449 patients were identified for this cohort, 4465 of whom were still being followed up at the end of the study period, equating to 46,120.9 patient years of follow up. Fig. 1 shows the number of epilepsy-related admissions for cohort patients between 2012 and 2021 and the proportion of admissions which were followed up within 6 months annually. The total number of admissions increased from 2012 to 2016 and then decreased year on year for the remainder of the follow-up period. The number of patients followed up within 6 months steadily increased until 2016 and remained around 40% for the remainder of the

follow-up period excluding 2021.

3.1. Recent service provision

Between 2019 and 2021, 1514 (33.9%) patients had at least 1 ED attendance and/or hospital admission (Table 1). Of these patients, 787 (52.0%) had 1 admission, 325 (21.5%) had 2 and 402 (26.6%) had 3 or more during this period. This equates to 3527 epilepsy related admissions or ED attendances over the period of interest.

Of the patients with a recorded epilepsy related attendance/admission, 450/1514 (29.7%) attended a neurology clinic appointment within 6 months of discharge. A higher percentage of ED admissions were followed up compared to inpatient admissions (39.9% vs. 27.3%). The DNA rate within neurology out-patients was low, with 87% of patients with scheduled appointments attending.

3.2. Deaths

In total, 2602 cohort patients died between 2012 and 2021. Of these patients, 634 (31.1%) died within 6 months of a prior epilepsy-related hospital admission. Most of these patients (596, 94.1%) did not attend an outpatient neurology clinic in the time between discharge and death. Of the 2602 deaths, 362 (14%) had epilepsy listed as the primary or contributing cause. Within this group, 97/362 (26.8%) had an epilepsy related attendance/ admission within 6 months of death, with only 29/

Table 1

Summary of admissions and ED attendance followed up at outpatient neurology clinics, 2019 – 2021.

	Inpatient	ED	all
Total admissions	2575	1259	3527
Total admissions where patient was followed up within 6 months	651 (25.3%)	490 (38.9%)	1016 (28.8%)
Total patients with 1+ epilepsy related admission	1290	654	1514
Patients followed up at least once within 6 months	352 (27.3%)	261 (39.9%)	450 (29.7%)

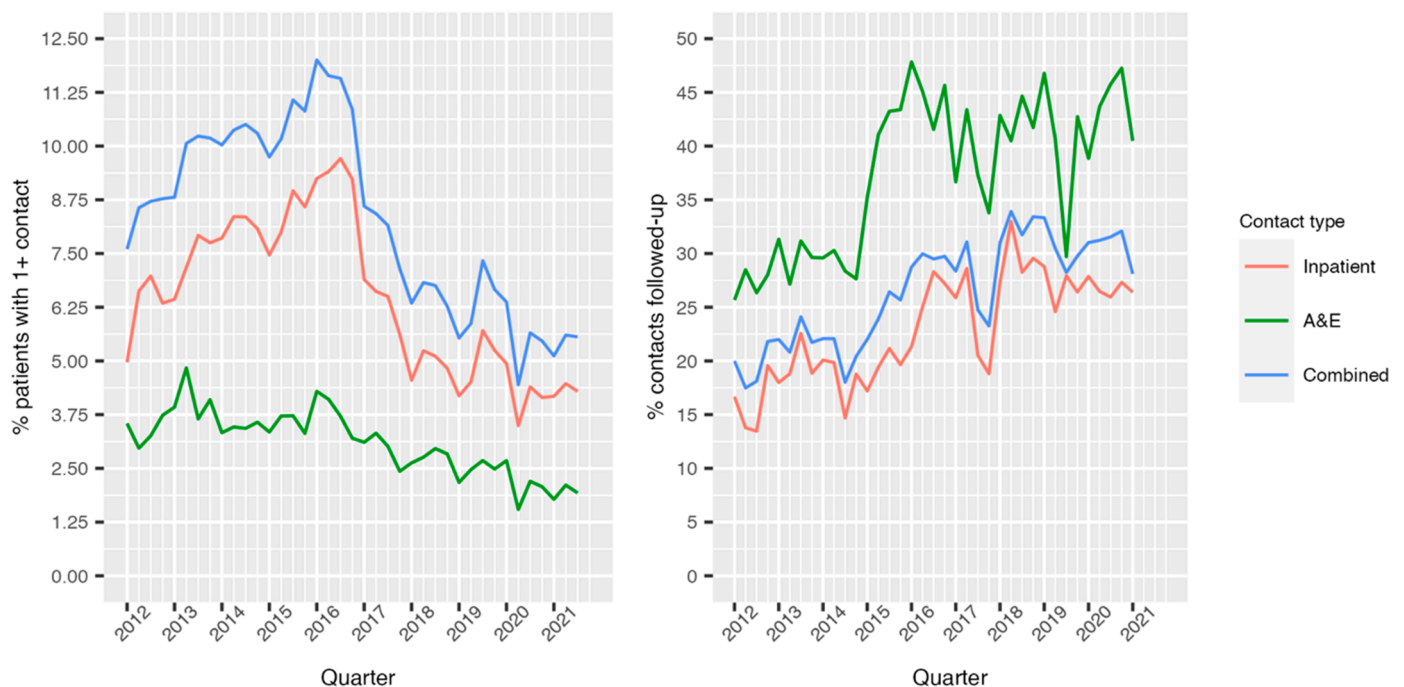


Fig. 1. Summary of the proportion of patients with 1 or more epilepsy-related admission per year over the follow-up period, and the percentage of admissions where patients attended an outpatient neurology clinic within the following 6 months.

362 (8%) of those patients interacting with neurology services during this time.

3.3. Mental health comorbidity

The frequency of mental health comorbidity is high within those utilising unscheduled care between 2019 and 2021, with 1176/ 1514 (77.4%) having been previously treated for either anxiety or depression. In 218/1514 (14.4%) alcohol or other substance abuse was documented during the full follow-up period.

4. Conclusion

The aim of this study was to assess the rate at which epilepsy-related hospitalisations were followed up in outpatient clinics alongside the rate of post-admission mortality. We found that over the last 10 years, approximately 40% of epilepsy-related admissions per year were followed up at outpatient clinics within 6 months. Although the rate of follow-up improved, particularly between 2012 and 2016, at the end of the study period the majority of PWE were not supported during the period of greatest risk. In addition, over 30% of all fatalities experienced an epilepsy-related admission within 6 months, with less than 10% seen by a specialist in the intervening time. Assessment soon after admission would allow clinicians to escalate ASM treatment, consider ASM adherence and assess mental health comorbidity or substance abuse issues all of which are potential risk factors for increased mortality in PWE [3,10]. This is of particular concern given the recognition that almost 80% of those attending for a period of unscheduled care have depression and or anxiety.

These findings are consistent with the findings of the UK National Audit of Seizure management (NASH) in adults published in 2013 [4], the National Confidential Enquiry into Patient Outcome and Death [6] and the European Audit of Seizure Management in Hospitals [11] and emphasise that services are not currently designed to meet the need of those at greatest risk of death from epilepsy. The observed mortality rate was slightly higher than in other large cohort studies, potentially due to the high levels of social deprivation and increased comorbidity in the NHS GGC population compared to other studies [3,12]. There was a significant decrease in the mortality rate for this cohort from 2018 onwards, which does correspond to both a decrease in the rate of unplanned attendance and a comparatively higher rate of follow-up, but regression modelling shows no significant link between the two based on the available data.

One strength of this study is the quality of the data used. Within Scotland, most care for epilepsy is provided through the NHS, and CHI-linkage means that all available data on a patient's contact with NHS services can be identified to give high levels of data completeness over a long period of follow-up [13]. There are still limitations to the data, however. Detailed dosing instructions for ASMs would allow accurate assessment of ASM adherence and access to primary care data would identify additional follow-up taking place through general practices rather than outpatient clinics. A manual review of electronic records could potentially have identified if advice was sought or if ASM doses had been changed prior to discharge and classification of epilepsy, but this data was not available for this study.

The challenge for those involved in the planning health care is to provide a service that meets the needs of those at highest risk, with assessment being undertaken in a timely manner, despite significant on-

going pressure for out-patient specialist services. Influenced by these findings, we have developed an Integrated Epilepsy Dashboard for use within NHS Greater Glasgow and Clyde which identifies a number of key adverse events (including unscheduled care episodes) and makes clinicians aware in a timely manner. This will potentially allow HCP to support PWE at a time of greatest risk, and if viewed in combination with other key variable, such as objective measures of medication adherence, may go some way to reducing avoidable death in PWE.

We should regard this data as a wake-up call. Despite improvements over the last ten years, the proportion of patients being followed up by a specialist neurologist after an epilepsy-related hospital admission remains a cause for concern. Improved communication between patients, emergency departments, primary care and those providing specialist epilepsy services care providers could facilitate additional clinical intervention in a timely manner, a process that could be facilitated by investment in IT infra-structure.

Declaration of Competing Interest

None.

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