The care of patients presenting to hospital after an epileptic seizure

Study Protocol

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Introduction

Epilepsy is defined as the tendency to have recurrent seizures and is one of the most common serious neurological conditions. It can exist alone or alongside a number of comorbidities. Epilepsy affects 0.8% of the population, and is more common in the elderly, the socially deprived, those with learning disability, and after stroke and brain injury [1-3]. Death with epilepsy is increasing by 3% per year and increases threefold with deprivation. 1.3 in every 1000 patients with epilepsy die suddenly and unexpectedly (SUDEP). A person with epilepsy has 2.15 times the risk of suicide, and 2.97 times the risk of unintentional injury. Most of this harm is avoidable[4].

Epilepsy is a long-term condition that requires multi-disciplinary team (MDT) input with clear leadership from an epilepsy specialist in its management and diagnosis. It is also vital that patient/carer involvement is considered at every stage to ensure that a care plan is arrived at in line with their needs and wishes. While specialist review is crucial to the management of epileptic seizure conditions, there exists huge variation in the length of time to specialist review and whether this specialist input occurs at all. For patients with a suspected first seizure, 32% of under-60s and 75% of over-80s are not referred to a neurologist following presentation to an acute setting. And for those with known epilepsy, 63% who are seen in A&E following a seizure event have no contact with an epilepsy specialist, with 18% of those having attended A&E in the preceding year. This variation in specialist review for both groups of patients leads to delay in appropriate diagnosis; unnecessary readmissions and presentations to A&E; and missed opportunities to reassess AED prescriptions and adherence (socio-economic contributing factors), all of which contribute to poorer outcomes[5].

Tests including EEG, ECG, CT scan etc. are recommended as adjunctive diagnostic tools to long term specialist assessment when diagnosing first seizure patients. However, these tests do not always feature in the diagnosis of epilepsy[6,7].

References

1) Morgan CLI, Ahmed Z, Kerr MPSocial deprivation and prevalence of epilepsy and associated health usageJournal of Neurology, Neurosurgery & Psychiatry 2000;69:13-17.
2) Beghi M, Cornaggia CM, Frigeni B, Beghi E. Learning disorders in epilepsy. Epilepsia. 2006;47 Suppl 2:14-8. doi: 10.1111/j.1528-1167.2006.00681.x. PMID: 17105453.
3) Zhao Y, Li X, Zhang K, Tong T, Cui R. The Progress of Epilepsy after Stroke. Curr Neuropharmacol. 2018;16(1):71-78. doi:10.2174/1570159X15666170613083253
4) Hayley C. Gorton, Roger T. Webb, Matthew J. Carr, et al. Risk of Unnatural Mortality in People With Epilepsy (2018) JAMA Neurol. 2018 Aug; 75(8): 929–938.
5) Dixon PA, Kirkham JJ, Marson AG, et al. National Audit of Seizure management in Hospitals (NASH): results of the national audit of adult epilepsy in the UK. BMJ Open 2015;5:e007325. doi:10.1136/bmjopen-2014007325
6) National Institute for Health and Clinical Excellence The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care. NICE clinical guideline 137. London: National Institute for Health and Clinical Excellence, 2012.
7) Diagnosis and management of epilepsy in adults: A national clinical guideline Scottish Intercollegiate Guidelines Network Royal College of Physicians of Edinburgh, 2003.

Guidelines and standards

- NICE Quality Standards: This quality standard reviews diagnosing, treating and managing epilepsy and seizures in adults (aged 18 and older). https://www.nice.org.uk/guidance/qs26/resources/epilepsy-in-adults-pdf-2098549136581

- Healthcare Improvement Scotland, SIGN 143: Diagnosing and managing of epilepsy in adults. (Revised 2018) https://www.sign.ac.uk/media/1079/sign143_2018.pdf

- Epilepsies: diagnosis and management. Clinical guidline 137 *https://www.nice.org.uk/guidance/qs26/resources/epilepsy-in-adults-pdf-2098549136581*

- NHS West London Mental Health NHS Trust: Policy: S42 Seizure and Epilepsy Policy (2018)

Aims and objectives

Overall aim:
To investigate variation and remediable factors in the processes of care of patients presenting to hospital following an epileptic seizure.

Objectives

- To identify patients seen in hospital with suspected seizure and to investigate their care, from presentation to resolution.
- To evaluate the quality of assessment, of physical, psychological and social contributors to their illness.
- To assess the availability of care and identify avoidable delay, obstacles to care, and harmful intervention.
- To assess how the ongoing care for patients with epilepsy is managed.
- To assess organisational aspects of care including education, local and national guidelines, and delivery of ongoing care.
- To produce recommendations for improvement.

Methods

Participating hospitals
Data will be collected from all hospitals in England, Wales, Northern Ireland, the Channel Islands and the Isle of Man that provide emergency care to patients post epileptic seizure.

Population/Inclusions
All patients aged 18 or over who presented to hospital following a seizure between 1st January 2020 - 31st December 2020 and had a pre-existing epilepsy disorder or were subsequently

diagnosed with epilepsy. Patients discharged from the emergency department and those admitted to hospital will be included.

Patients will be identified retrospectively using the following ICD10 codes in combination with the Emergency Care Data Set diagnoses codes for epilepsy.

G40.0	Localization-related (focal)(partial) idiopathic epilepsy and epileptic syndromes with seizures of localized onset
G40.1	Localization-related (focal)(partial) symptomatic epilepsy and epileptic syndromes with simple partial seizures
G40.2	Localization-related (focal)(partial) symptomatic epilepsy and epileptic syndromes with complex partial seizures
G40.3	Generalized idiopathic epilepsy and epileptic syndromes
G40.4	Other generalized epilepsy and epileptic syndromes
G40.5	Special epileptic syndromes
G40.6	Grand mal seizures, unspecified (with or without petit mal)
G40.7	Petit mal, unspecified, without grand mal seizures
G40.8	Other epilepsy
G40.9	Epilepsy, unspecified
G41.0	Grand mal status epilepticus
G41.1	Petit mal status epilepticus
G41.2	Complex partial status epilepticus
G41.8	Other status epilepticus
G41.9	Status epilepticus, unspecified
R56	Convulsions, not elsewhere classified

The selection of patients into the study cohort for questionnaire completion and peer review, will be biased towards those more likely to have had a more severe seizure or complications of the seizure/treatment. This will be done by dividing patients into 3 categories and where the number of cases allows, two patients from each category will be included per hospital:

1) Patient was discharged home from the emergency department
2) Patient admitted to hospital
3) The patient was admitted to critical care and/or died during the admission

Exclusions

Dissociative seizure disorders and acute symptomatic seizures in the elderly. First seizure patients that are not subsequently diagnosed with epilepsy.

Incidence and prevalence

In the UK, the prevalence of epilepsy is estimated to be 5–10 cases per 1000. 1.4% of emergency admissions are due to seizure, and an acute hospital will, on average, see 653 presentations, in adults, each year. Below are the number of admissions (and emergency admissions) reported in the UK in 2018

HES DATA:

Primary diagnosis: 3 character code and description		**Finished consultant episodes**	**Admissions**	**Emergency**
G40	Epilepsy	57,630	41,662	32,909

G41	Status epilepticus	6,830	4,046	3,785
R56	Convulsions, not elsewhere classified	59,506	44,521	40,639

PEDW DATA:

Primary diagnosis: 3 character code and description		Finished consultant episodes	Admissions	Emergency
G40	Epilepsy	2,390	1,769	1,609
G41	Status epilepticus	243	147	141
R56	Convulsions, not elsewhere classified	578	514	502

Case identification

Within each Trust/Health Board NCEPOD has a Local Reporter (usually employed in clinical audit) who is responsible for providing the details of cases for inclusion to NCEPOD. At the start of the study the Local Reporter will be contacted and sent details of the study criteria.
Patients who present to an emergency department following a seizure episode (both known epileptics and first seizure patients) will be identified retrospectively using the ICD codes or emergency dataset codes via completion of a spreadsheet with other selected data from central hospital records. This will include patient details (NHS number, hospital number, age), admission/discharge dates, patient destination after the emergency department, whether or nth the patient was admitted to a critical care ward and discharge location.

To exclude patients from the study who do not go onto be diagnosed with an epileptic condition, clinicians answering the questionnaires will be asked to identify whether or not any included first seizure patient was subsequently diagnosed with epilepsy. If the patient does not have a subsequent diagnosis of epilepsy they will be excluded before a questionnaire is completed.

Method of data collection

Clinician questionnaire
A questionnaire will be sent to the named consultant responsible for the patients care when they presented to ED or were admitted to hospital. Within this there will be instruction to pass the questionnaire on to most appropriate clinician should it not be the named person.
Data collected will include information on the treatments and investigations the patient received in hospital, specialist reviews, use of protocols and clinical pathways, discharge and follow up. In addition information of the ongoing management of the patient's epilepsy will be collected.

The questionnaires will be disseminated via the NCEPOD online questionnaire system which is accessed by NCEPOD local reporters. The local reports will then be able email the relevant clinician, granting them access to the online questionnaire. Reminder emails will be sent at six weeks and ten weeks where the data are outstanding. The Local Reporter will be asked to return copied extracts of the patient's case notes to NCEPOD alongside the completed questionnaires.

Organisational questionnaire
An organisational questionnaire will be sent to all hospitals that have an emergency department and treat patients post epileptic seizure
Data collected will include information around the organisation of services, networks of care and multidisciplinary team working, the use of guidelines and protocols and training.

The questionnaires will be disseminated via the online questionnaire system. Local reporters will be able to invite multiple clinicians to complete the questionnaire,

Case note review
Case note review will be collected for patients who presented to ED following a suspected epileptic seizure.

Case notes
Photocopies of the case notes of each included patient will be requested at the time of questionnaire dissemination. A list detailing the required case note extracts will be circulated to local reporters. Upon receipt at NCEPOD the case notes will be made anonymous for patient identifiable information.

Reviewer assessment form
A multidisciplinary group of reviewers (details below) will be recruited to assess the case notes and questionnaires and give their opinions on the quality of care via the reviewer assessment form.

Anonymous on-line parent carer survey
To be developed by NCEPOD. The survey will not be linked to any other aspects of data collection. This survey will gather data on patient/parent carer views of the services available to them. We will work closely with SUDEP action and epilepsy action, both which are represented on the study advisory group.

Below are the anticipated sample sizes of each type of data collected:

Data source	Target number
Organisational questionnaire	~200
Clinician questionnaires	~500
Case note review	~500
Patient survey	~100

Study method test
The data collection methods and data collection tools will be tested to ensure they are robust.

Analysis and Review of Data

Reviewers
A multidisciplinary group of reviewers will be recruited to assess the case notes and questionnaires and provide their opinion on the care the patients received. The reviewer group will comprise:

An advert will be sent to Local Reporters to disseminate throughout the relevant departments. It will also be placed on the NCEPOD website. Successful applicants will be asked to attend a

training day where they will work through anonymised case notes with the case reviewer form. A number of meeting dates will be arranged, and each reviewer will then be asked to attend a further 4 meetings. NCEPOD staff will ensure there is a mix of specialties at each meeting from across the UK. Each meeting will be chaired by an NCEPOD clinical coordinator who will lead discussion around the cases under review. Meetings will be held virtually if COVID restrictions prevent clinicians from attending. This method has been set up and approved by CAG. Towards the end of the study the reviewers will be invited to attend a meeting where the data will be presented to and discussed with them. The reviewers will also be sent two copies of the draft report for their comment as this is developed.

Confidentiality and data protection

All electronic data are held in password protected files and all paper documents in locked filing cabinets. As soon as possible after receipt of data NCEPOD will encrypt electronic identifiers and anonymise paper documents. Section 251 approval has been obtained to perform this study without the use of patient consent in England and Wales. Public Benefit Privacy Panel approval has been received for Scotland.

Study promotion

Prior to data collection, NCEPOD will contact all specialist epilepsy centres and organisations involved in promoting epilepsy care. The study will also be promoted to parent/carers and patients via patient groups, NCEPOD Local Reporters (sending the study poster on to the relevant departments), via study contacts recruited as part of the case identification strategy, and via the relevant Colleges and Associations

Dissemination

On completion of the study a report will be published and widely disseminated.

Data sharing

Post publication of the study there is the potential to share anonymised data sets with interested parties working in the same field. This will be undertaken following a strict process and will ensure the data does not become identifiable in their nature due to small numbers.

Time Scale (subject to delays with COVID-19)