



A review of the quality of care following prolonged seizures in 1–18 year olds with epilepsies



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ARTICLE INFO

Article history:

Received 6 January 2014

Received in revised form 31 July 2014

Accepted 4 September 2014

Keywords:

Paediatric practice

Neurology

Intensive care

Epilepsy

Seizure

ABSTRACT

Purpose: To review the quality of care of children and young people with epilepsies who, following a prolonged seizure, received high-dependency or intensive care. To identify and learn from clinical, organisational, management or personal issues that contributed to these admissions, in order to inform practice and improve clinical services for children across the UK.

Method: Notifications were collected from consultant paediatricians in England, Wales, Scotland and Northern Ireland over a 10-month period. For all eligible cases a clinical questionnaire was sent to the notifying clinician. A sample of these cases were selected for a detailed case note review. Case notes were reviewed by paediatrician–nurse pairs using a purpose-built assessment tool derived from national guidelines.

Results: Data were collected from 135 clinical questionnaires, and 36 sets of case notes were reviewed. Findings were compared to national standards of care and emerging themes identified. There was evidence of good epilepsy management in many cases. In some cases there was evidence of a lack of clear emergency care plans, of delays in administration of emergency medication, and of deviation from established national guidelines.

Conclusion: The findings of this review suggest there have been improvements in the care of children and young people with epilepsies presenting with prolonged seizures compared to previous studies. Nevertheless, further improvements are needed, particularly in communication with families and prompt administration of emergency medication.

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1. Introduction

Childhood epilepsies are heterogeneous and are comprised of different epilepsies and epilepsy syndromes. Many are associated with additional co-morbid neurological, educational or psychosocial problems, and these children place significant demands on the health service and on other non-health services to provide optimal care and to ensure that they can fulfil their potential.

Although the precise prevalence of the epilepsies in children is unknown, a 2005 systematic review found a median reported

prevalence of active epilepsies (i.e. seizures within the previous five years) in European 0–19 year olds of 4.3 per 1000.^{1,2} This equates to an estimated 65,000 children and young people with active epilepsies in the UK. With appropriate treatment, many of these children will achieve seizure-freedom and be able to participate in their home and school environments. For others though, particularly those with associated developmental comorbidities, seizure control may be impossible and with a high risk of frequent, severe and prolonged seizures. Data from England in 2011–2012 showed that there were 10,840 hospital admissions of children aged 0–14 with a primary diagnosis of epilepsy, and 1402 with a status epilepticus.³ The 2012 report of the Paediatric Intensive Care Audit Network (PICANet) for the UK and Ireland, listed 1101 admissions to intensive care units with status epilepticus over three years (2009–2011⁴).

Children with prolonged seizures, including convulsive status epilepticus, are at a higher risk of morbidity and mortality.

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Consequently, early seizure termination is essential and this is emphasised in the National Institute of Clinical Excellence (NICE),⁵ Scottish Intercollegiate Guideline Network (SIGN)⁶ and Advanced Paediatric Life Support (APLS)⁷ epilepsy guidelines.

This study, as a component of a national Clinical Outcomes Review Programmes, aimed to review the management and outcomes of all children admitted to intensive or high-dependency care and to identify and learn from clinical, organisational, management or personal factors that might have contributed to their admission and outcome and which could lead to improved clinical care.⁸

2. Methods

2.1. Population

Children aged between one and 18 years with an established diagnosis of epilepsy who received intensive or high-dependency care following a prolonged seizure.

2.2. Case notification

An active electronic reporting system was used to collect notifications of children who met the inclusion criteria (Fig. 1). Case notifications were collected over a 10-month period from 1st June 2012 to 31st March 2013. Monthly emails were sent to all RCPCH-registered consultant paediatricians in the UK requesting they respond, whether or not they had seen a case. To maximise case ascertainment the study was advertised widely so others could notify cases, and a data-sharing agreement was set up with PICANet.

2.3. Clinical questionnaire

For each case, the reporting consultant was asked to complete a secure on-line clinical questionnaire. The questionnaire included a minimum number of patient and hospital identifiers which enabled data on a single case submitted by two or more clinicians to be merged, and questionnaire data to be linked to the case notes review. The clinical dataset was used to guide case selection for detailed case review and to provide demographic and clinical information on the entire group of reported cases.

2.4. Case note review

A sample of cases was selected for more detailed case review using a stratified sampling technique. Cases were recruited sequentially and each month the cases selected were reviewed according to the purposive sampling criteria (Fig. 2); groups that were underrepresented (particularly young people aged 13–17, and those from the UK devolved nations) were preferentially selected.

A specifically designed case assessment tool was produced to evaluate the entire care pathway including pre-hospital care, emergency department care, and intensive/high-dependency care

- Boys and girls
- Three age groups: under five years, five to 12 years, and 13 to 17 years
- Epilepsy as sole diagnosis, and epilepsy with concurrent learning difficulties or other disabilities ('epilepsy plus')
- White Caucasian and ethnic minorities
- Intensive care and high-dependency care (tertiary and secondary care)
- All UK devolved nations

Fig. 2. Purposive sampling criteria.

(Appendix 1). The tool incorporated a criterion-based assessment based on clinical standards and a structured implicit review for each phase of care. The implicit review included a six-point scale whereby case assessors graded overall care at each phase of the care pathway. Assessors used their clinical reasoning to determine whether, in their opinion, care fell short of current best practice in one or more significant areas, resulting in the potential for, or actual, adverse impact on the patient, through care which fell short of current best practice in only minor areas, without potential for, or actual harm to the patient, to excellent care which met current best practice. Case assessments were carried out by pairs of paediatricians and nurses in hospitals and at the RCPCH. When completing the assessment tool if pairs of assessors could not agree on a response they were asked to try and reach a consensus. If a consensus could not be reached the assessors were able to record their responses separately in the assessment tool and both responses considered in the analysis.

2.5. Analysis

Quantitative data from the case assessment tools were transferred to an SPSS database and linked to the clinical questionnaire data, using a unique project identifier. Qualitative analysis was carried out using a framework approach based on that developed by Ritchie and Spencer for applied policy research.⁹ Both quantitative and qualitative data were reviewed by the research team and an expert advisory group to identify emerging themes. This allowed for modification and clarification of the core themes and further review of the source data. In light of these themes a secondary review of the data was carried out by the research team, to identify consistencies and discrepancies in the data. Quantitative analysis and qualitative themes were triangulated and are reported together in the results and discussion.

2.6. Ethics

As part of the national Clinical Outcomes Review Programme, National Information Governance Board 251 and Scotland Caldicott Guardian approvals were granted to collect patient identifiable data without consent. The Northern Ireland Privacy Advisory Committee advised that consent was required from the child's parent or carer; time constraints of the study meant that no cases from Northern Ireland were recruited.

3. Results

During the 10-month data collection period 288 case notifications were received. The monthly response rate for notifications was 33–43% and the questionnaire completion rate was 47%. A total of 135 questionnaires were completed; 66 for intensive care and 69 for high-dependency care admissions. The majority of cases were reported from England, with five cases from Wales and four from Scotland. A sample of 36 cases was selected from these 135 for detailed case review; 17 had been admitted to

A child with epilepsy who has died, of any cause
OR
 A child who has received intensive care or high-dependency care following a prolonged seizure (seizure lasting longer than five minutes)
AND
 The child was aged between their 1st and 18th birthdays at the time of incident
AND
 Prior to the incident the child had a diagnosis of epilepsy based on two or more epileptic seizures more than 24 hours apart that were not acute symptomatic seizures or febrile seizures.

Fig. 1. Inclusion criteria.

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