

Original citation:

Hunter, Lindsey, Sidebotham, Peter, Appleton, Richard and Dunkley, Colin. (2015) A review of the quality of care following prolonged seizures in 1–18 year olds with epilepsies. *Seizure - European Journal of Epilepsy*, Volume 24 . pp. 88-92. ISSN 1059-1311

Permanent WRAP url:

<http://wrap.warwick.ac.uk/66331>

Copyright and reuse:

The Warwick Research Archive Portal (WRAP) makes this work by researchers of the University of Warwick available open access under the following conditions. Copyright © and all moral rights to the version of the paper presented here belong to the individual author(s) and/or other copyright owners. To the extent reasonable and practicable the material made available in WRAP has been checked for eligibility before being made available.

Copies of full items can be used for personal research or study, educational, or not-for-profit purposes without prior permission or charge. Provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way.

Publisher's statement:

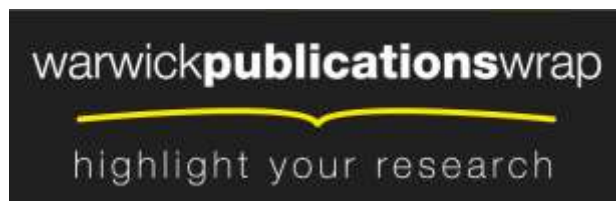
“NOTICE: this is the author's version of a work that was accepted for publication in *European Journal of Epilepsy*. Changes resulting from the publishing process, such as peer review, editing, corrections, structural formatting, and other quality control mechanisms may not be reflected in this document. Changes may have been made to this work since it was submitted for publication. A definitive version was subsequently published in *European Journal of Epilepsy*, Volume 2 (2015)]

DOI: <http://dx.doi.org/10.1016/j.seizure.2014.09.001>

A note on versions:

The version presented here may differ from the published version or, version of record, if you wish to cite this item you are advised to consult the publisher's version. Please see the 'permanent WRAP url' above for details on accessing the published version and note that access may require a subscription.

For more information, please contact the WRAP Team at: publications@warwick.ac.uk



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

Hunter, L¹., Sidebotham, P²., Appleton, R³., Dunkley, C⁴.

¹*Corresponding author:* Lindsey Hunter, RCPCH, 5-11 Theobald Road, London, WC1X 8SH,

02070926171, Lindsey.hunter@rcpch.ac.uk

²Dr Peter Sidebotham, Warwick University, Coventry, UK

³Richard Appleton, Alder Hey Children's Hospital, Liverpool, UK

⁴Colin Dunkley, Kings Mill Hospital, Sutton-in-Ashfield, UK

Word Count: 2666

Keywords

Paediatric Practice

Neurology

Intensive Care

Epilepsy

Seizures

Abstract

Objective: 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.

Design: Notifications collected from consultant paediatricians over 10 months. For all eligible cases a clinical questionnaire was sent to the notifying clinician. A sample of these cases was 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.

Setting: England, Wales, Scotland and Northern Ireland.

Patients: Children between 1 and 18 years with a prior diagnosis of epilepsy who received high-dependency or intensive care following a prolonged seizure.

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.

Background

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 co-morbidities, seizure control may be impossible and with a high risk of frequent, severe and prolonged seizures. Data from England in 2011-12 showed that there were 10,840 hospital admissions of children aged 0-14 with a primary diagnosis of epilepsy, and 1,402 with a status epilepticus³. The 2012 report of the Paediatric Intensive Care Audit Network (PICANet) for the UK and Ireland, listed 1,101 admissions to intensive care units with status epilepticus over three years (2009-11⁴).

Children with prolonged seizures, including convulsive status epilepticus, are at a higher risk of morbidity and mortality. 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 care⁸.

Methods

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.

Case notification: An active electronic reporting system was used to collect notifications of children who met the inclusion criteria (Figure 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.

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.

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 (Figure 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. 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.

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 research⁹. 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. A secondary review of the data was carried out by the research team in the light of these themes, to identify consistencies and discrepancies in the data and to triangulate the qualitative and quantitative data.

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; the time constraints of the study meant that no cases from Northern Ireland were recruited.

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 intensive care and 19 to high-dependency care. Case characteristics are presented in Table 1.

Of those cases selected for detailed case review, four were inpatients at the time of incident, and 32 were in the community (28 at their home of normal residence, three at school, and one in other residential care).

Pre-hospital care

Of the 32 cases that presented in the community, there was evidence of an emergency care plan in the records of 15 children, but evidence that this had been followed in only five cases. Rescue medication was administered prior to the arrival of an ambulance in eight cases (buccal midazolam in seven and rectal diazepam in one). For 13 cases no treatment was administered and for 11 cases there was no documented evidence of any treatment administration. In one case, on a previous admission, the parents had administered an inappropriate dose of buccal midazolam, following a change to a different preparation; there were no other instances of inappropriate management prior to the arrival of ambulance services.

The management provided by ambulance or paramedic staff was not always clear due to missing or illegible ambulance logs in the clinical notes. Ambulance crews administered buccal midazolam in one case, rectal diazepam in eight and intravenous diazepam in four.

Emergency department care

On arrival at the emergency department 18 children (56%) were still seizing; seven were post-ictal, one fully alert and two recorded as being unconscious. Of the 18 still seizing, nine had been given rescue medication by the parents prior to the arrival of an ambulance, and a further five had been given benzodiazepines by the ambulance crew. Four children arrived at the emergency department still seizing and having not received any emergency rescue medication. The mother of one of these four had brought her child to the emergency department herself, without having called an ambulance.

Of the 18 children with continued seizures, one child stopped spontaneously and the remaining 17 received one or more anticonvulsants (Table 2). Eleven children required more than one anticonvulsant to terminate the seizure.

Reviewing the case records, the case assessors evaluated the quality of emergency department care had been excellent and met current best practice, or fell short in only minor areas, in 22 cases (69%). In eight children (25%), the quality of care was considered to have fallen short of current best practice in one or more significant areas. Factors which the case assessors considered to indicate poor quality care included delays in obtaining specialist advice or support from senior clinicians or anaesthetists, delays in administering appropriate medication, deviation from the NICE, SIGN or APLS guidelines, and poor communication within or between the treating teams. In several cases, poor documentation in the case records made it difficult to assess the quality of some aspects of care.

Intensive/high-dependency care

On admission to intensive or high-dependency care, 11 (31%) children were post-ictal and were admitted for observation and monitoring; 12 (33%) were intubated with their seizures controlled; and seven (19%) were still seizing. The condition of six (17%) children was not specified.

The case assessors considered that the quality of intensive/high-dependency care had been excellent and met current best practice, or fell short in only minor areas, in 26 cases (72%). In two children (6%), the quality of care was considered to have fallen short of current best practice in one or more significant areas. In one, the child continued to seize for a further 72 hours following admission; the assessors commented on the lack of a clear management plan and no documented consultant review during that time. The remaining child was given additional anticonvulsants even after seizure-cessation.

Outcomes

Twenty three children (64%) fully recovered to their pre-admission state; three (8%) recovered but with residual new impairment; eight children (22%) died; and information was not recorded for two children (6%). There was limited information in the case notes for two of the eight children who died. The remaining six had all required ventilatory support; the presenting seizure had terminated in four.

Of the eight children whose quality of care in the emergency department was considered to have fallen short of current best practice, six fully recovered, one died, and for one the outcome was not

known. Both children whose quality of care in the intensive/high-dependency unit was considered to have fallen short of current best practice fully recovered.

Discussion

Overall the study findings demonstrate that many of the children who received intensive or high-dependency care following a prolonged seizure had refractory epilepsies, multiple comorbidities, frequent seizures and previous hospital admissions. However, prolonged seizures, including convulsive status epilepticus were also seen in children with infrequent seizures. Any child with epilepsy who has experienced a prolonged seizure should have a written emergency care plan for the management of prolonged seizures, and appropriately prescribed rescue medication for community use⁵. This particularly applies to those children with associated neurological/developmental impairments. Emergency care plans were identified in less than half of cases and were only followed in a small proportion of cases. This was associated with failure or delay in the administration of rescue (emergency) medication. Of the 32 children who presented in the community, 19 (59%) had evidence that they had been given rescue medication prior to arrival at hospital. This confirms previous reports that appropriate and timely treatment is not being administered in many cases of prolonged seizure¹⁰.

Clear and comprehensive care plans are required for parents, schools and others who care for children with epilepsies. This should include information on how to respond to prolonged seizures, training in resuscitation and the use of rescue medication. Such care plans could be included in an 'epilepsy passport'. The use of a 'passport' to keep all relevant information concerning the patient's care has been found to be effective in treating diabetes and recommended nationally^{11, 12}. The use of such passports in childhood epilepsies could complement existing systems to ensure key information is accessed across healthcare sectors and by all those who care for these children. This will help ensure that the child will be prescribed, dispensed and given the same formulation of not only their emergency medication, but also their maintenance anti-epileptic drugs, and that those looking after the child know when and how to respond in an emergency.

The study found evidence of good initial assessment by ambulance staff. However, there were delays in the administration of emergency medication in some cases. Diazepam (rectal or intravenous) was

the most commonly administered medication, with buccal midazolam administered in only one case. Buccal midazolam is widely accepted as the rescue medication of choice for children with prolonged seizures^{13, 14}. The use of an outdated drug (diazepam) or inadequate doses was assessed to have contributed to delays in terminating seizures in some children in this study. The Joint Royal Colleges Ambulance Liaison Committee (JRCALC) recently updated their guidelines to incorporate the use of buccal midazolam¹⁵. Local guidelines should be updated to ensure all ambulance crews are trained and equipped to be able to administer buccal midazolam for prolonged seizures. This could help to ameliorate the risk of continuing seizures and potentially the need for intensive or high-dependency care.

The findings show that the care provided by emergency departments and intensive or high-dependency care was generally of a high standard. In most cases there was evidence that the clinical team instituted appropriate treatment, reviewed the child's overall care, made appropriate adjustments to their management, communicated with parents, and arranged follow up. However, a few cases did identify difficulties with staff recognising a seizure and following appropriate prolonged seizure guidelines.

These data seem to indicate an improvement compared to previous findings^{10, 16} and may reflect a change in practice following recently-published guidelines^{5, 7}. It is important that all emergency departments ensure that staff follow and apply this guidance and audit their practice. In some cases deviation from the guidelines may be appropriate, depending on the specific clinical situation; this would represent an appropriate responsive approach. Reasons for any deviation from national guidelines should be clearly documented to inform future emergency management of the child, and for auditing the implementation and impact of these guidelines. An admission to intensive or high-dependency care provides an opportunity to review the child's overall care and to make appropriate adjustments to their management and follow-up. Such reviews should involve the family as well as the relevant healthcare professionals. They enable the clinical team to reflect on the care provided and learn lessons for improvement of care.

Limitations

The limitations of notification and obtaining case notes for this study mean that it cannot be regarded as fully representing the care of all children with epilepsies who receive intensive or high-dependency care for prolonged seizures. Nevertheless, comparison with published PICANet data suggest that the study was notified of most cases^{4, 10}. It is likely that there was under-ascertainment of 16 and 17 year olds, many of whom would be managed on adult intensive care units. As with any case-note review, there are dangers of subjectivity in the assessment of the quality of care. The use of paired paediatrician-nurse assessors and a structured, criterion-based component minimised this risk.

Conclusions

The findings from this national themed review provide important insights into the quality of care for children with epilepsies who present with prolonged seizures. Overall, there was evidence of high standards of care in emergency departments and intensive or high-dependency care units, suggesting overall improvements in the quality of care compared to previous studies. Nevertheless, specific issues were identified that need to be addressed to improve the management of this vulnerable group of children. There is a clear need for improved communication with parents and carers, with clear, up to date emergency care plans. Ambulance staff should be equipped and empowered to respond promptly and appropriately to prolonged seizures, using the same rescue medication as that used by families and hospitals. National guidelines for the management of prolonged seizures should be followed, and clear communication and documentation is essential where clinical assessment indicates deviation from such guidelines. Children with refractory epilepsy and complex co-morbidities require regular specialist and carefully coordinated care, with regular reviews and support for them and their families.

Funding: This project formed part of the Child Health Reviews-UK programme commissioned by the Health Quality Improvement Partnership on behalf of NHS England, NHS Wales, the Health and Social care division of the Scottish government, The Northern Ireland Department of Health, Social Services and Public Safety (DHSSPS) the States of Jersey, Guernsey, and the Isle of Man.

Competing Interests: None declared

Contributorship statement: All authors contributed to the concept and design of the study. LH & PS carried out data analysis and all authors contributed to the interpretation of data and drafting of the article.

What is already known on this topic:

- Prolonged seizures are a risk for all children with epilepsies and can result in mortality and morbidity.
- NICE/APLS recommendations give guidance on how to treat prolonged seizures and these form the basis for care plans and emergency department protocols.

What this study adds:

- The importance of clear communication with parents and carers, including detailed emergency care plans.
- Buccal midazolam should be the rescue medication of choice for ambulance crews and appropriate training should be provided.
- Admission to intensive care or high-dependency care provides an opportunity for the review of a child's clinical care.

References

1. Forsgren L, Beghi E, Oun A, Sillanpaa M. The epidemiology of epilepsy in Europe - a systematic review. *Eur J Neuro*. 2005;**12**(4):245-53.
2. Tidman L, Saravanan K, Gibbs J. Epilepsy in mainstream and special educational primary school settings. *Seizure*. 2003;**12**(1):47-51.
3. Health and Social Care Information Centre. Hospital Episode Statistics, Admitted Patient Care - England, 2011-12. 1.11.12 ed. Leeds: Health and Social Care Information Centre; 2012.
4. Draper E, Hobson H, Lamming C, et al. Annual Report of the Paediatric Intensive Care Audit Network January 2009— December 2011. Summary Report. Leeds: Universities of Leeds and Leicester; 2012.
5. National Institute for Health and Clinical Excellence. The diagnosis and management of the epilepsies in adults and children in primary and secondary care. London: National Institute for Health and Clinical Excellence, 2012.
6. Scottish Intercollegiat Guidelines Network. Diagnosis and Management of Epilepsies in Children and Young People: A National Clinical Guideline. Edinburgh: Scottish Intercollegiat Guidelines Network; 2005.
7. Samuels M, Wieteska S. Advanced paediatric life support : the practical approach. 5th ed. ed. Chichester: Wiley-Blackwell; 2011.
8. RCPCH. Coordinating Epilepsy Care: a UK-wide review of healthcare in cases of mortality and prolonged seizures in children and young people with epilepsies. London: Royal College of Paediatrics and Child Health; 2013.
9. Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In: Bryman A, Burgess R, eds. *Analysing qualitative data*. London and New York: Routledge; 1994:172-94.
10. Chin RF, Verhulst L, Neville BG, Peters MJ, Scott RC. Inappropriate emergency management of status epilepticus in children contributes to need for intensive care. *J Neurology, Neurosurgery, and Psychiatry* 2004;**75**(11):1584-8.
11. Dijkstra R, Braspenning J, Grol R. Empowering patients: how to implement a diabetes passport in hospital care. *Patient Educ Couns* 2002;**47**(2):173-7.

12. National Patient Safety Agency. The adult patient's passport to safer use of insulin (NPSA/2011/PSA003). 2011. <http://www.nrls.npsa.nhs.uk/resources/?EntryId45=130397> (accessed 20.11.13).
13. McIntyre J, Robertson S, Norris E, et al. Safety and efficacy of buccal midazolam versus rectal diazepam for emergency treatment of seizures in children: a randomised controlled trial. *Lancet* 2005;**366**(9481):205-10.
14. Appleton R, Macleod S, Martland T. Drug management for acute tonic-clonic convulsions including convulsive status epilepticus in children. *The Cochrane Database Syst Rev*. 2008;(3):CD001905.
15. University of Warwick, Joint Royal Colleges Ambulance Service Liaison Committee. UK Ambulance Services Clinical Practice Guidelines 2013. Coventry: University of Warwick, 2013.
16. Hussain N, Appleton R, Thorburn K. Aetiology, course and outcome of children admitted to paediatric intensive care with convulsive status epilepticus: a retrospective 5-year review. *Seizure*. 2007;**16**(4):305-12.

Licence for Publication: The Corresponding Author has the right to grant on behalf of all authors and does grant on behalf of all authors, an exclusive licence (or non-exclusive for government employees) on a worldwide basis to the BMJ Group and co-owners or contracting owning societies (where published by the BMJ Group on their behalf), and its Licensees to permit this article (if accepted) to be published in Archives of Disease in Childhood and any other BMJ Group products and to exploit all subsidiary rights, as set out in our licence.

Table 1: Case characteristics

| Characteristic | | Clinical questionnaire N=135* | Case assessment N=36* |
|----------------------------------------------------------------------|----------------------------------|----------------------------------|--------------------------|
| Type of care | Intensive care | 66 (48.9%) | 17 (47.2%) |
| | High-dependency care | 69 (51.5%) | 19 (52.8%) |
| Gender | Male | 72 (53.3%) | 20 (55.6%) |
| | Female | 63 (46.7%) | 16 (44.4%) |
| Age | 1-4 | 59 (43.7%) | 15 (41.7%) |
| | 5-9 | 36 (26.7%) | 6 (16.7%) |
| | 10-13 | 31 (23.0%) | 8 (22.2%) |
| | 14-17 | 9 (6.7%) | 7 (19.4%) |
| Ethnicity | White | 96 (71.1%) | 26 (72.2%) |
| | Non-white | 39 (28.9%) | 10 (27.8%) |
| Identified epilepsy syndrome | | 27 (20.0%) | 11 (30.6%) |
| Identified comorbidities | | 108 (80.0%) | 28 (77.8%) |
| Identified underlying cause for the epilepsy | | 83 (61.5%) | 25 (69.4%) |
| Seizure frequency (in the six months prior to the reported incident) | Daily | 22/115 (19.1%) | 9/31 (29.0%) |
| | At least weekly | 29/115 (25.2%) | 4/31 (12.9%) |
| | At least monthly | 23/115 (20.0%) | 3/31 (9.7%) |
| | Less than one per month | 26/115 (22.6%) | 10/31 (32.3%) |
| | No reported seizures | 15/115 (13.0%) | 5/31 (16.1%) |
| Hospital admissions for prolonged seizures in prior twelve months | Any hospital admission | 66/94 (70.2%) | 16/32 (50.0%) |
| | More than six admissions | 24/94 (25.3%) | 2/32 (6.3%) |
| Anti-epileptic drug therapy at time of incident | Not on any anti-epileptic drugs | 7/130 (5.4%) | 2/33 (6.1%) |
| | Monotherapy | 42/130 (32.3%) | 17/33 (51.5%) |
| | Two or more anti-epileptic drugs | 73/130 (56.2%) | 14/33 (42.4%) |

* For some variables, data were missing in the clinical questionnaire/case assessment. Where this is the case, the denominator minus the missing cases is given.

Table 2: Anticonvulsant management in Emergency Departments

| Treatment given | Number |
|------------------------------------------------------------------------|--------|
| Buccal midazolam | 2 |
| Rectal diazepam | 3 |
| Rectal paraldehyde | 6 |
| Intravenous phenytoin | 7 |
| Intravenous lorazepam | 7 |
| Intravenous thiopentone | 3 |
| Other (Intravenous diazepam, phenobarbitone, midazolam, levetiracetam) | 5 |