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Continuity of Care in the Management of Prolonged, Acute, Convulsive Seizures in Children: a review of guidelines and epilepsy specialist nurses' opinions

Summary:

- Clearer information is needed on prolonged, acute, convulsive seizures
- All children with a history of prolonged, convulsive seizures should have an individual health care plan
- There need to be clearer links between health and educational sectors
- There should be systematic training of all community caregivers, including teachers
- Comprehensive clinical guidelines are needed to ensure children are treated as quickly as possible wherever a prolonged convulsive occurs in the community

Epilepsy has a median incidence rate of 82.2 per 100,000 people, including children.¹ Approximately 20% of individuals with epilepsy are refractory to treatment² and at increased risk of breakthrough seizures. Some are prone to prolonged, acute, convulsive seizures and the risk of proceeding to status epilepticus if timely treatment with rescue medicine is not administered. Given that most breakthrough seizures occur outside hospitals, the National Institute for Health and Clinical Excellence (NICE) guidelines recommend a comprehensive care plan for people with epilepsy and training of non-healthcare professional caregivers in the administration of rescue medication. NICE also stresses that epilepsy specialist nurses should play an integral role in the treatment of epilepsy.³

Current management of children at risk of prolonged, acute, convulsive seizures in the community has not been well studied, but recent surveys of epilepsy services for children identified significant gaps in service provision in the UK.^{4,5} Epilepsy specialist nurses play an important role in the care plan for children with epilepsy, providing clinical management and a bridge between schools, parents and healthcare professionals. According to the

Epilepsy¹² national audit, and contrary to NICE guidelines advice, 47% of the epilepsy services audited do not have an epilepsy specialist nurse, and only 59% have an epilepsy clinic for young people and teenagers.⁴

Within this context, the Practices in Emergency and Rescue medication For Epilepsy managed with Community administered Therapy (PERFECT™) initiative was set up to explore how prolonged, acute, convulsive seizures are managed in the community in six European countries, including the UK. This paper discusses the first two phases of the PERFECT™ initiative, specific to the UK, with a particular focus on the findings relating to perceptions of epilepsy specialist nurses.

Methods

The first phase of the PERFECT™ initiative involved a desk-based review of clinical guidelines, policies and legal frameworks governing the administration of rescue medication to children in non-hospital settings.⁶ The second phase included a survey of health care professionals to gauge perceptions of care received by children outside of hospital. Twenty-nine health care professionals, including 10 epilepsy specialist nurses, were interviewed in the UK.

Results

Clinical Guidance

The policy analysis showed that, in the UK, management guidelines for prolonged, acute, convulsive seizures at the national level focus primarily on hospitals. Table 1 provides a list of current clinical guidelines and Table 2 outlines the key points of existing clinical and non-clinical guidance.

NICE issued guidelines specific to the management of prolonged, acute, convulsive seizures in community settings in the UK. In addition to the recommendations described above, they specify preferred treatments for prolonged, acute, convulsive seizures: buccal midazolam as first-line treatment in "children, young people, and adults with prolonged or repeated seizures in the community" and rectal diazepam "if preferred, or if buccal midazolam is not available".³

Table 1: Current clinical guidelines and their audiences

Audience	Guideline(s)
Hospital setting (i.e., Accident and Emergency, Intensive Care Unit departments)	APLS guidelines ⁵ SIGN 81 (2005) ⁶ NICE guidelines (updated 2012) ³
UK Ambulance Service	Joint Royal Colleges Ambulance Liaison Committee guidelines ¹⁷
Community setting (e.g., schools)	NICE guidelines (updated 2012) ³

APLS, Advanced Paediatric Life Support; SIGN, Scottish Intercollegiate Guidelines Network; NICE, National Institute for Health and Clinical Excellence.

Non-clinical guidance

The most relevant guidance to schools is offered by the Department of Health and Education, and refers to medication management in schools.^{7,9} This guidance describes how medicines should be administered to children with chronic disease in mainstream schools and what processes to follow. Most of this guidance, however, requires updating to be more specific to the management of children at risk of prolonged, acute, convulsive seizures. In our survey, we found that physicians and epilepsy specialist nurses were largely unaware of existing guidelines or legal frameworks relating to the treatment of children at risk of prolonged, acute, convulsive seizures in schools and other community settings. A paediatrician described the situation for school personnel as “a grey area” and one epilepsy specialist nurse surveyed stated, “Carers and teachers are in a vulnerable position when giving meds [medication] to other people’s children, so guidelines would be very helpful to clarify”.

The current chain of care

Health care professionals surveyed appeared to have limited knowledge of whether children who have been prescribed rescue medication for prolonged, acute, convulsive seizures actually receive this medication following discharge from hospital. They also found it difficult to estimate the number of patients managed in the community versus the hospital. Regarding seizure records, one neurologist described them as “very helpful” in making dose adjustments to patients’ medication; however, respondents stated that information about seizures occurring outside of the hospital may not be captured in detail. One epilepsy specialist nurse explained: “...some parents feel they do not need to write it down as they know how many seizures per month the child has, other children have so many seizures per day that the parents feel they could not possibly record the number”.

Epilepsy specialist nurses surveyed stated that their responsibilities included advising junior doctors on treatment choice, teaching families to administer rescue medicine and providing training to schools. Physicians have little time to coordinate care with schools, and rely on epilepsy specialist nurses to meet this need. Epilepsy specialist nurses surveyed believe that, because of their unique position as intermediaries between doctors and parents/caregivers, they are better placed to

Table 2: Overview of the main clinical and non-clinical guidelines

Clinical guidance
<ol style="list-style-type: none"> NICE 2012 guidelines recommend buccal midazolam as first-line treatment³ Joint Royal Colleges Ambulance Liaison Committee guidelines instruct paramedics on how to act after midazolam has been administered to a child by a parent or other caregiver; however, they are not permitted to carry, or administer to patients, any controlled substance such as buccal midazolam¹⁷
Non-clinical guidance
<ol style="list-style-type: none"> Parents, caregivers and teachers may administer rescue medication as long as: <ol style="list-style-type: none"> They have received specific training^{7,9} They follow previously agreed protocol^{7,9} It is not a legal requirement for school staff to administer medicines to children^{7,9} Schools should ensure that they have sufficient numbers of staff trained to administer emergency medicines, or make alternative arrangements with the local health service^{7,9} Schools must ensure that training is provided to all those who volunteer to administer medicines^{7,9} Schools must have an epilepsy policy as part of their obligation to meet the requirements of the Disability Discrimination Act^{7,9,14} <p>NICE, National Institute for Health and care Excellence.</p>

understand the needs of caregivers outside of the hospital, to advise physicians on treatment choice and to implement care plans. Key findings regarding the perceived roles of epilepsy specialist nurses, as reported by survey respondents, are summarised in Table 3.

Training in schools and other community settings

In the UK, training on the administration of rescue medication and resources for schools are made available by voluntary sector organisations such as Epilepsy Action and Young Epilepsy. The Joint Epilepsy Council provides training and an online repository of information for trainers that are used broadly across community settings. (<http://www.community-epilepsy-services.co.uk/training.html>)

Table 3: Overview of the key findings from the PERFECT™ initiative HCP surveys

Key findings
<ol style="list-style-type: none"> EPILEPSY SPECIALIST NURSES have some influence over which treatments physicians prescribe. This tends to be buccal midazolam because of convenience; in schools, teachers are generally unwilling to administer medication rectally. However, EPILEPSY SPECIALIST NURSES can advise on alternatives to buccal midazolam when required. The nurse’s role, therefore, is predominantly one of training (when the hospital/practice has an EPILEPSY SPECIALIST NURSE)
<ol style="list-style-type: none"> The perceived role of the EPILEPSY SPECIALIST NURSE is to: <ol style="list-style-type: none"> Inform and educate patients and caregivers, and answer questions about how to manage seizures in the home and the wider community. To reiterate and cover gaps in knowledge Inform and educate the wider community, including schools, and instill confidence to administer rescue medicine Teamwork approach alongside physician and caregiver

Physicians believe that they have a responsibility to educate and train, but because of time constraints, this is limited to training parents. The physicians assume that parents will then provide training to schools and other non-clinically trained caregivers in the community. Epilepsy specialist nurses often assume the responsibility of liaising with, and educating personnel in schools and the wider community. However, limited availability of epilepsy specialist nurses and lack of availability of a licensed rescue medication with a route of administration suitable for use in the community, were cited by physicians and epilepsy specialist nurses as barriers to on-site treatment of prolonged, acute, convulsive seizures in the community. Epilepsy specialist nurses also believe that lack of, or inadequate training of, teachers/main caregivers often results in unnecessary ambulance call-outs and/or inaction due to fear of liability and/or fear of doing harm.

Discussion

Findings from the PERFECT™ initiative highlight that health care professionals have low awareness of how children at risk of prolonged, acute, convulsive seizures are managed in the community, which can be compounded by a lack of accurate recording of seizures. Health care professionals have little engagement with schools and other community settings, and this role is traditionally taken on by epilepsy specialist nurses. The involvement of epilepsy specialist nurses in patient care has been shown to result in reduced hospital admissions, better management of physician time so that they are able to focus on more complex cases, reduced visits to GPs and improved patient self-management.^{4,10}

Despite NICE recommendations that all patients with epilepsy have access to an epilepsy specialist nurse, 47% of paediatric departments in the recent Epilepsy¹² audit did not.⁴ These findings were confirmed in our survey. Sufficient funding and provision of epilepsy specialist nurses is fundamental in ensuring a seamless transition from hospital to outpatient care for children with epilepsy¹⁰ and providing children and their parents with the support they need to help them more effectively manage their condition outside of hospital.

The NICE guidelines are unique in Europe in that they provide detailed guidance on the administration of rescue medication to children with a history of prolonged, acute, convulsive seizures outside of the hospital.^{3,11,12} They call for a comprehensive care plan for all children and young people with epilepsy, and training for non-clinically trained caregivers in the community on the administration of rescue medication.^{3,12} However, guidelines alone are insufficient to improve the management of children at risk of prolonged, acute, convulsive seizures. Their correct implementation requires the provision of clear information to parents, schools and other non-clinically trained caregivers on prolonged, acute, convulsive seizures and their management, and training on the administration of rescue medication. The lack of a licensed rescue treatment was highlighted as a barrier to on-site treatment of prolonged, acute, convulsive seizures in the community; however, since the PERFECT™ health care professional survey was conducted, a licensed treatment, Buccolam® (midazolam oromucosal solution) has become available in the UK for the treatment of prolonged, acute, convulsive seizures in infants, toddlers, children and adolescents (aged from 3 months to <18 years).¹³

Training on epilepsy management and timely administration of rescue medicine would instil confidence in school staff, and facilitate the implementation of a care plan for each child at risk of prolonged, acute, convulsive seizures enrolled in the school. The Epilepsy Action 2012 school survey found that 25.8% of teachers had not had epilepsy training in the last three years. Mainstream schools are required to appoint a Special Education Needs Coordinator (SENCO),¹⁴ as a teacher, the SENCO has the best insight into the needs of school personnel and

Table 4: Recommendations from the PERFECT™ initiative Steering Committee for improving treatment outcomes and addressing the treatment gaps in current management of PROLONGED, ACUTE, CONVULSIVE SEIZURES in the community

Recommendations

1. Raise awareness among physicians regarding the current inconsistent management of PROLONGED, ACUTE, CONVULSIVE SEIZURES in the community setting
 2. Develop realistic guidelines that integrate the role of EPILEPSY SPECIALIST NURSES and limit the burden placed on physicians
 3. Create new training materials that incorporate feedback from HCPs, patients and caregivers, and that use an interactive approach (e.g., DVDs, web-based training). An EPILEPSY SPECIALIST NURSE [surveyed] said "What we are missing is a decent DVD that shows midazolam administration for parents. We have had various commercial ones but not been totally satisfied with them. This is because professionals have not been quite as involved. Also, a coloured booklet/leaflet might be useful."
 4. Ensure consistent training in schools through standard formal guidelines and protocols
 5. Encourage discussion of how to fill gaps in PROLONGED, ACUTE, CONVULSIVE SEIZURES management by publicising the benefits of EPILEPSY SPECIALIST NURSES, such as:
 - a) Addressing patient/caregiver questions and providing practical support
 - b) Providing training to the community at large, including schools
 - c) Allowing physicians to focus on patient care in the clinical setting
- PROLONGED, ACUTE, CONVULSIVE SEIZURES, prolonged, acute, convulsive seizures; HCPs, healthcare practitioners.

can work with epilepsy specialist nurses to ensure that teachers and school nurses receive adequate in-house training and education on seizure management.

Leveraging insights gained through the PERFECT™ initiative, additional recommendations are detailed in Table 4. The next stage of our research involves a survey of children with prolonged, acute convulsive seizures and their caregivers in the UK and five other European countries in order to explore their perspectives on the quality of care received for prolonged, acute convulsive seizures in community settings. This survey will report in early 2014 and should help improve our understanding of existing gaps that should be addressed in the management of this group of children with epilepsy in community settings.

Summary

Prolonged, acute, convulsive seizures pose a serious risk to children with epilepsy, high-

lighting the need for a comprehensive management plan that addresses both the hospital and community settings such as schools to ensure that children at risk of prolonged, acute, convulsive seizures receive their rescue medication as quickly as possible, regardless of where their seizure occurs. When present, epilepsy specialist nurses function as a much-needed link between these settings and may improve the quality of care overall for patients. Surveys conducted as part of the PERFECT™ initiative confirm the essential role of the epilepsy specialist nurse and reveal the need for consistent guidelines, additional information and training materials to help facilitate the management of prolonged, acute, convulsive seizures in schools and other community settings.

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