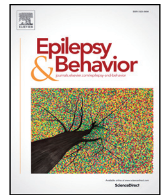
Epilepsy & Behavior 70 (2017) 212–216

Contents lists available at ScienceDirect

Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh



Brief Communication

Epilepsy awareness and emergency rescue training: Ignorance is bliss!

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ARTICLE INFO

Article history:
Received 23 January 2017
Revised 5 March 2017
Accepted 5 March 2017
Available online xxxx

Keywords:
Emergency rescue training
Midazolam
Status epilepticus

ABSTRACT

Status epilepticus (SE) has a high mortality rate and is associated with complications such as neurological deficit and cognitive decline. Buccal midazolam is the recommended emergency rescue medication in the UK to reduce the duration of a seizure and SE. It should be administered by an appropriately trained person. There are agreed guidelines on training standards for its administration in the UK produced by the Joint Epilepsy Council of the United Kingdom and Ireland. Training should provide an overview of epilepsy to facilitate safe, person-centered care and appropriate administration of rescue medication to people with epilepsy (PWE). Unfortunately the current guidelines do not assure satisfactory practice. An investigation was conducted to quantify the nature and degree of the problem in Cornwall, UK (population 550,000). To address the identified inconsistencies, a web-based test was developed using a focus group of experts and stakeholders. Over 800 carers for PWE took the test at different intervals of its development. A consistent 20% failure rate was noted. Over 90% of participants felt it kept PWE safer. The test was incorporated into routine clinical practice and has contributed to reduction of primary epilepsy deaths. The e-test is a cost-effective solution to help harmonize practices across different settings and can be easily adopted by other countries.

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1. Background

It is estimated that 42% of the 1200 deaths/year due to seizures in the UK are potentially avoidable [1]. Convulsive status epilepticus (SE) is a medical emergency with high morbidity, especially if early treatment is not initiated [2]. Ten percent of all UK Emergency Department (ED) admissions are due to seizures, usually over-represented by cases of SE [3]. The majority of epilepsy cases seen in ED are admitted into medical care [4].

When a seizure lasts for 5 min or more the patient is at high risk of continuing into SE and this may result in death or brain damage [2]. Receiving appropriate treatment on time depends not only on the presence of another person but also on that person being appropriately trained to recognize the situation, and to administer, if required, rescue medication.

Rescue medication be administered by a trained person and is widely used due to its effectiveness and social acceptability. In the UK, epilepsy education and training courses are expected to be conducted by epilepsy professionals in line with the agreed training guidelines of Joint Epilepsy Council (JEC) backed up by evidence from National Institute of Clinical Excellence (NICE) [5,6].

The JEC of the UK and Ireland (JEC) was an umbrella charity constituted in the early 2000s to provide the representative voice working for the benefit of people affected by epilepsy in the UK. It involved all leading clinical organizations and charities. Its mission was to represent the united voice of epilepsy in the UK and Ireland and to present evidence-based views on the need for improved epilepsy services and influence decision makers in the health, social, and education arenas. The JEC produced the 1st nationally recognized incidence and prevalence of epilepsy in the UK and Ireland in 2005. It followed this up by providing the 1st guidance on minimum standards needed in training and administration of midazolam in community [7]. The JEC was disbanded in 2016 due to lack of funding, leaving a vacuum in sustaining and delivering current good practice.

The stage of management focused on by these guidelines is the premonitory or pre-hospital stage for patients who have established epilepsy and have increasingly frequent or severe seizures and which precedes the status epilepticus (SE). This stage can usually be managed well in community with appropriate understanding of the individual's epilepsy and a good care plan to use rescue emergency medication. Emergency treatment will usually prevent the evolution to true SE. Buccal midazolam is an emergency rescue medication prescribed routinely in the UK to reduce the duration of a seizure and prevent SE [2,8]. Buccal

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http://dx.doi.org/10.1016/j.yebeh.2017.03.010
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midazolam has shown superiority over rectal diazepam in trials with children, and is now considered in the UK to be the drug of choice in children and adults [9]. The earlier treatment is administered the better in order to prevent the progression to SE. Training should provide an overview of epilepsy to facilitate safe person-centered care and appropriate administration of rescue medication to people with epilepsy (PWE) when experiencing a prolonged seizure.

In spite of the steps the JEC took to streamline training delivery, epilepsy care and training standards vary considerably across the UK [10]. The consequence of this may be catastrophic for the individual patient given the high risks associated with a prolonged seizure. There are also associated significant cost implications in paramedic services and ED admissions [11].

There are seven main concerns with present guidance:

1. The current structure of the UK guidelines has gaps in its framework which can allow people connected to epilepsy but lacking relevant skills and competencies to set themselves up as trainers as there may be a lucrative financial market in delivering such training. This in turn could lead to improper education of carers.
2. Buccal midazolam is prescribed by epilepsy specialists either directly or via recommendation to the GP. In such a situation, the prescriber has no direct mechanism of assuring themselves of the safe use of the medication if the trainer is working independent of the prescriber and the prescriber has no feedback system to enable confidence in the trainer to support their prescribing.
3. Even among qualified trainers such as specialist epilepsy nurses, there is no consistent curriculum for topics to be covered [12], specified length of training and feedback systems for both the trainee, and trainer. There is a lack of a clear structure to support the competencies of trainers such as peer groups and good practice portfolios. There is no universally approved template to construct individual guidelines. Practice varies significantly across UK.
4. The trainees come from diverse backgrounds including paramedics, family members, and paid carers. There is no consistent mechanism to assess how effective the training has been.
5. There is more than one midazolam preparation available with different administration advice, which may confuse carers, particularly when generic substitution is common.
6. There is no obvious framework or assurance for the complex situation requiring close cooperative working of multiple groups/agencies such as specialists, nurses, trainers, GP, family, paid carers, etc. to ensure the safety of an individual who is unconscious and is dependent on local resources.
7. The disbanding of the JEC is a loss of an independent platform interested in improving and delivering good care and also terminated the organizational backing on the current standards of care.

Cornwall is a county in the UK with 600,000 people. A specialist service exists for people with intellectual disability (ID) and epilepsy. An audit in 2013 for the 353 people open to the service showed 162 PWE on midazolam for generalized seizures. All carers and stakeholders for the PWE had been trained comprehensively by the 2 epilepsy nurse specialists in the service using the JEC guidance and peer reviewed material. A brief survey in clinics of the carers and families of the PWE on Midazolam showed revealed that 30% of carers of PWE on rescue preparation of buccal midazolam were not able to give satisfactory confidence to the prescriber of their abilities to manage an emergency involving rescue preparation despite rescue medication training in the previous year.

On further inquiry there were two main areas of concern: -

1. Despite training, carers' understanding of basic concepts of epilepsy remained poor.
2. There were a wide variety of trainers with different backgrounds, some delivering courses that were inconsistent with current good practice.

2. Methods

It was felt that a summative test using the 'driving licence test' model where different trainers provide input, but the final test is standardized, was the best method to reduce the identified risk. It was hoped that the availability of a structured assessment would indirectly achieve some standardization of the trainers, too.

In the interest of patient safety, it was felt that there needed to be an evidence-based, peer-reviewed, standardized assessment with relevant stakeholder consensus to instill confidence in all parties involved. A standardized, peer-reviewed, video-based 30-min e-test was developed to enable epilepsy trainers across the South West of the UK to assess their course attendees' understanding of delivering good care and rescue medication. The e-test had a robust, inbuilt audit process for quality assurance.

The test was created in partnership with the South West Epilepsy Nurses group, local neurologists, psychiatrists, and GPs. A question bank was created requesting all stakeholder organizations to contribute. A set of demonstration videos was created to align the questions. Service user opinion was sought from PWE, family members and

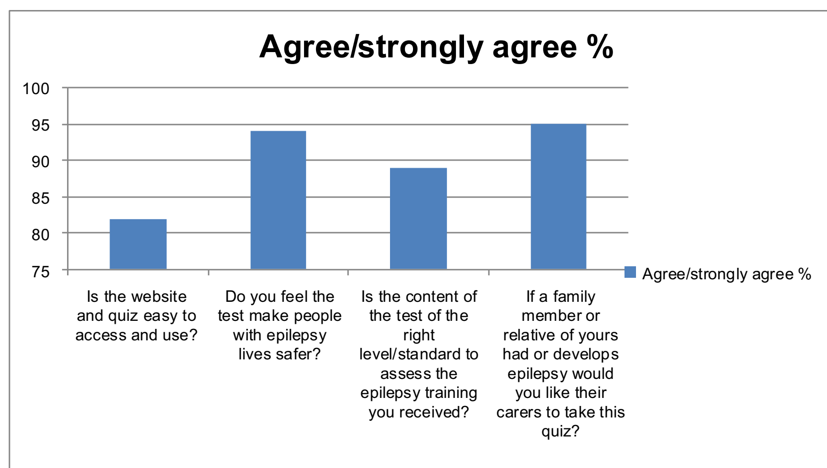

Fig. 1. Feedback from 427 of 723 carers.

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