A pilot study of the epilepsy risk awareness checklist (ERAC) in people with epilepsy and learning disabilities

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ABSTRACT

Purpose: People with epilepsy are at risk of injury, and protection from potential dangers must be balanced against the need for autonomy. We developed an epilepsy risk awareness checklist (ERAC) as a tool to assess potential risks of epilepsy and related injuries, aiming to improve management strategies. It was designed for use by specialist nurses (in learning disability and epilepsy), as there was no existing tool for this. This study refined and tested this checklist in patients with epilepsy and learning disability in a range of community settings.
Method: We used quantitative and qualitative measures to devise and revise the tool. Eleven qualified learning disability nurses completed the ERAC in three patients each (33 patients) using a purposive sampling method. They provided quantitative and qualitative feedback through questionnaires and interviews, and an expert panel reviewed and commented on the checklist.
Results: The checklist was revised through the evaluation process. All eleven nurses concluded that they would use the tool again.
Conclusion: The epilepsy risk awareness checklist (ERAC) provides a measure of risk, and this study suggests that it is a useful tool in the care of people with learning disability and epilepsy. A larger scale study is planned.

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1. Introduction

The epilepsy risk awareness checklist was developed through clinical practice in response to a clinical need. Support staff caring for an individual living in a residential home encountered problems with his atonic 'drop' seizures and multiple injuries due to falls in an unsuitable environment. The community learning disability nurse was unable to find a systematic tool for risk assessment, and this led to the development of the epilepsy risk awareness checklist (ERAC).

This pilot study reviewed the effectiveness of an epilepsy risk awareness checklist (ERAC). It provides a clinical tool for potential epilepsy related injuries and care management. It aims to identify risks in people with learning disability; and to improve supportive patient care, epilepsy management and quality of life. It was piloted for use in the community by specialist qualified nurses in their care of people with epilepsy and learning disability, as there was no pre-existing validated measure. The objective of this study was to identify problems and assess the practicality of administration, and refine the tool.

Epilepsy is one of the most common neurological disorders. The prevalence of individuals on treatment is approximately 1:200 and lifetime prevalence is between 2 and 5% of the general population.[1] Epilepsy is more common in those with learning disability.[2] In a primary care British practice with 2500 patients, it is estimated that 13–25 will have active epilepsy; and one to three will have severe epilepsy with major handicap.[3]

Seizure freedom brings a higher chance of independent living for patients with epilepsy,[4] but, despite treatment, about 30% continue to have seizures.[5] In people with learning disability, epilepsy co-exists in 14–45%, and is often severe.[6] Epilepsy affects quality of life, and the fear of having a seizure can isolate the patient and limit both work and leisure activities.[7,8] Maximising quality of life depends on appropriate and personalised safety advice,[9] as well as reducing seizures.

The National Institute for Clinical Excellence[10] recommended formal risk assessment for those with epilepsy and learning

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disabilities, as part of optimising care. This includes risks during daily activities (such as bathing, preparing food), in the context of the social situation.

Goodwin et al.[11] reviewed the epilepsy nurse's role; and Bradley and Lindsay[12] highlighted a main task of epilepsy specialist nurses as the follow-up care of patients with epilepsy. Despite the established need, epilepsy nurses have limited evidence-based data and standardised measures to support this role.[13] The ERAC tool aims to provide an evidence-based clinical aid to support their work practice in patients when there is a question of epilepsy risks. The ERAC incorporates aspects of personal safety, health care and quality of life related to epilepsy to address some of these issues. It was tested in a group of patients with epilepsy and learning disability, where the impact of epilepsy is often severe due to refractory seizures and co-morbidities.

2. Design and population

The ERAC consists of a 69-item form with accompanying guidance notes for nurses (see Appendix on the journal website). The checklist was adapted from Coulter's Quality Enhancement Survey Tool,[14] and other sources.[15–21]

A literature review used Psychinfo Data, Kings Fund, British Nursing Index, DH-Data, Embase and CINAHL databases (from 2000 to 2006), with the key words: epilepsy; risk and assessment. Coulter's model[14], based on an analysis of patient problems in epilepsy, was fundamental to the development of ERAC. In turn, Coulter's work was greatly influenced by the revised Quality Enhancement Survey Tool (QUEST).[22] The current QUEST is a comprehensive generalised tool, related to learning disabilities. It covers all aspects of service delivery; but is not tailored to epilepsy. The structure of ERAC (Form 2), and accessory guidance notes (Form 3), is adapted from the QUEST format.

ERAC is divided into three domains:

1. Personal Safety – this has four measures (A–D), each with 1 and 9 questions
2. Health Care – with six measures (A–F), each with between 1 and 9 questions
3. Quality of Life – with four measures (A–D) each with 1 and 8 questions

Each question (Form 2) has evidence for its inclusion in the accessory guidance notes (Form 3) for nurses. All questions are answered yes, no or not applicable.

2.1. Setting

The participants (specialist nurses) attended a training day and were shown how to use the ERAC tool and to complete the ERAC report (Form 4) based on the findings of the Checklist (Form 2).

Each nurse received the materials to carry out the checklist on three patients with epilepsy and learning disabilities, as summarised in Table 1.

Form 1 instruction sheet of the ERAC provides indications for the use the checklist: for example when seizures have increased or changed in pattern, when seizure related injuries occur and at times of patient transition or change in environment.

2.2. Data collection method

Underpinning our study is the proposal that evidence based practice should be drawn from research, expert opinion and clinical consensus.[23] We thus carried out a multi-centred mixed method study using two methodologies: quantitative data in the

Table 1
List of contents in the ERAC package.

Contents of the ERAC package
Form 1. Instructions Sheet
Form 2. ERAC Checklist
Form 3. ERAC Guidance Notes
Form 4. ERAC Final Report Template
Appendices
1. Nurse Procedure Sheet Form 5.
2. Patient Information Sheet Form 6.
3. Accessible Patient Information Sheet Form 7.
4. Carer Information Sheet Form 8.
5. Example of a completed Report Form 9.

epilepsy evaluation questionnaire (EEQ), and qualitative data from EEQ comments, plenary meetings and expert review.

An EEQ (Table 3) gathered quantitative and qualitative data. The qualitative data was enhanced by holding a series of plenary meetings with the nurses where they shared their experiences of using the ERAC; the feedback from the EEQ was used by the research lead to stimulate discussion. The plenary meetings were audio recorded and later transcribed and reviewed for key themes. Eight academic and medical professionals gave qualitative feedback (Table 2).

The nurses had 4–8 weeks to select three patients to visit and carry out the ERAC tool and the ERAC report (Form 4). Once all three patients had been seen, nurses completed the epilepsy evaluation questionnaire (EEQ).

2.3. Sample participants: ERAC

Eleven learning disability epilepsy nurses (or lead learning disability nurses with a specialist interest in epilepsy) employed by the National Health Service (NHS), from eleven London boroughs based with a learning disability service were recruited (see Acknowledgments). Five nurses worked with medical practitioners on a full time basis solely managing epilepsy patients, others worked in community settings dealing with patients with learning disability, many of whom had epilepsy. All nurses have experience of working with adults with learning disabilities. Their experience in these roles ranged from less than 5 years up to more than 16 years. Each nurse selected three patients (total of 33) using a purposive sampling method. The patients were selected where there were concerns regarding the management of risk; these were identified from the learning disability epilepsy clinic referrals. Each nurse administered the ERAC tool and completed a report.

2.4. Ethics

Ethical Approval was obtained from the Local Research Ethics Committee of Barnet, Enfield & Haringey Health Authority and COREC. Consent was also obtained from the patients and carers

Table 2
List of professionals providing the expert opinion for ERAC evaluation.

1. Professor John Duncan – Consultant Neurologist, National Hospital for Neurology and Neurosurgery, London
2. Professor Mike Kerr – Consultant Psychiatrist, Welsh Centre for Learning Disabilities, Cardiff
3. Professor Bob Gates – Head of Learning Disabilities, Thames Valley University, London
4. Dr Jackie Taylor – Consultant Paediatrician, Barnet and Chase Hospital, London
5. Dr Tim Von Oertzen – Consultant Neurologist, St George's Hospital, London
6. Dr Greg Rogers – General Practitioner with Special Interest in Epilepsy, Kent
7. Dr Henry Smithson – Senior Lecturer in Primary Care, Sheffield
8. Brian Chappell – National Manager, Neuroeducation, York