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

selected by the nurses for their involvement in the study. Patient data were anonymous.

3. Results

The comments from the taped plenary meetings and expert opinion are supplied as qualitative data.

3.1. Part 1 – quantitative analysis using the epilepsy evaluation questionnaire (EEQ)

This is provided as a written account following Figs. 1–3. Descriptive data were entered onto Microsoft Excel and analysed using SPSS for Windows, version 15. To analyse the data the results are based on descriptive quantitative (agree/disagree responses) from the EEQ shown below (Table 3).

Ten (91%) nurses found the checklist (Form 2) easy to follow, and one disagreed. Eleven (100%) reported that the three sections (personal safety, health care and quality of life) of the ERAC were divided clearly, and all agreed the structure and layout of the ERAC was logical. Ten (91%) nurses agreed the response section of the ERAC was easy to complete, and 1 (9%) disagreed.

The ERAC (Form 2) takes approximately 40 min to complete. The whole process including the community or home visit and the report write up (Form 4) takes approximately 3 h to complete for each patient. None of the nurses found the ERAC unduly time consuming to complete. Nine (82%) understood the general language and terminology in the ERAC whilst two (18%) nurses found some parts unclear. All eleven nurses understood the
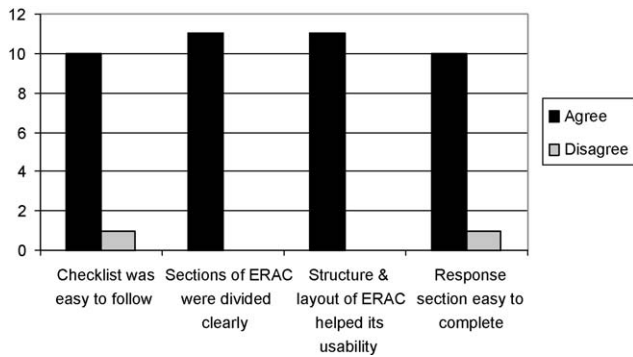

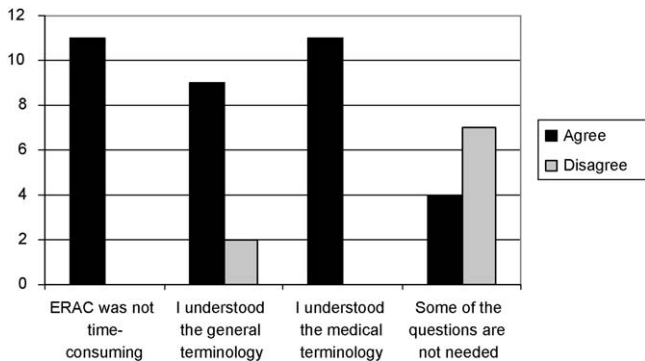**Fig. 1.** Response to EEQ questions 1–4.
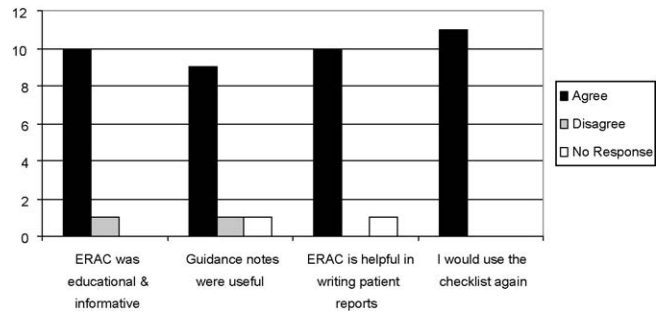

Fig. 2. Response to EEQ questions 5–8.

Fig. 3. Response to EEQ questions 9–12.

medical terminology used. Four (36%) nurses found some of the questions were unnecessary and seven (64%) did not.

Ten (91%) nurses reported they found the ERAC educational and informative and one disagreed. All eleven (100%) nurses understood the ERAC guidance notes. Nine (82%) nurses thought the guidance notes (Form 3) were useful, one (9%) disagreed and one (9%) made no response. Ten (91%) nurses agreed that the ERAC example report (Form 9) was helpful for completing the patient reports (one did not respond). All eleven (100%) nurses reported they would use the checklist again on other patients with epilepsy.

3.2. Part 2 – summary of qualitative analysis

Feedback, from the EEQ (Table 3), written comments and plenary sessions, was used to improve the ERAC; and instructions and language were clarified. Qualitative data was obtained from the EEQ comments section (Table 3), and from the taped plenary meetings with all of the eleven nurses. All eleven nurses completed the EEQ (100% response rate). The researchers collected detailed structured and unstructured responses to maximise feedback from the nurses. Nine nurses (82%) had no prior evidence based epilepsy risk assessment in their service and five (46%) used their own version of an epilepsy risk assessment. All 11 (100%) nurses concluded that they would continue to use the ERAC. This response indicates it is a meaningful clinical tool from a specialist nurse's perspective.

The tool is designed for use by specialist nurses working in collaboration with medical practitioners. In line with this, ten nurses (91%) stated the ERAC may not be applicable for carers to administer in residential homes. Ten (91%) nurses found the medical terminology easier for a health professional to understand and follow than it would be for carers. It was also noted in the plenary

Table 3
The ERAC evaluation questionnaire (EEQ).

1. I found the checklist easy to follow
   Agree   Disagree   Comments
2. I thought that the three sections of the ERAC were divided clearly
3. I thought the structure and the layout of the ERAC helped its usability
4. I thought that the response part on the ERAC was easy to complete
5. I thought the ERAC was not time consuming to complete
6. I understood the general language/terminology used
7. I understood the medical language/terminology used
8. I think that some of the questions are not needed
9. I found the ERAC very educational and informative in terms of my knowledge of epilepsy and risks associated with it
10. I understood the guidance notes
11. I thought that the guidance notes were not useful
12. The example ERAC report was helpful when writing the client/patient reports
13. I would use the checklist again on other clients/patients with epilepsy

meeting that carers in the community would not have access to the relevant patient data in the health care section of the ERAC (Form 2).

Results of the taped transcripts from the plenary meetings were informative. From this, nurses expressed the view that no formal training was necessary to administer the ERAC. They suggested it would be simple for nurses to complete if the form included brief instructions. This led to revising the instruction form included as part of the ERAC attachment notes (Form 1 – Instruction Sheet and Appendix 1- Nurse Procedure Sheet). The plenary meeting also clarified when the ERAC would be most appropriate to administer in clinical practice. The design of the ERAC checklist (Form 2) was also changed from portrait to landscape after consultations.

All nurses confirmed a need for such a checklist, that it would benefit their work, and reduce patients' risks of injuries or restriction of quality of life. One described it as 'a checklist tool nurses and healthcare workers can use to provide good support to epilepsy care in the community'.

3.3. Part 3 – results of the expert opinions review

We contacted eleven experts and enclosed a copy of the ERAC instrument and associated documents. A total of eight responses were received (Table 2). These were positive, including comments such as 'a very comprehensive document' and others ranging from 'good' to 'commendable' regarding the ERAC tool.

The main changes the experts recommended for amending the ERAC checklist (Form 2) and the guidance notes (Form 3) are summarised below:

- Include diagnosis according to ILAE classification
- Add co-morbidities (psychiatric/other organic diseases)
- Add co-medications
- Add details of seizure frequency
- Replace "neurological review" with "epilepsy review" in part 2 and 3
- Include sudden unexpected death in epilepsy
- Adjust the layout of the document
- Correct the grammar of some phrases
- Review and correct references where required
- Revise Nurse Procedure Sheet
- Provide Nurse Instruction Sheet

Two respondents were concerned about the time needed to complete the ERAC (3 h), which may inhibit its use. One respondent suggested there is a lot of information to complete and therefore the checklist could be split or completed on a number of occasions. A General Practitioner suggested that the ERAC should be linked to quality outcome measures[23] in the service contract, suggesting it may empower patients with refractory epilepsy to minimise risk.

4. Discussion

Sackett et al.[24] suggested that evidence based practice should be drawn from research, expert opinion and clinical consensus. This model was used in our pilot study, and it resulted in modifications to ERAC after consideration from users and an expert panel.

The ERAC (Form 2) should take approximately 40 min to complete. The whole process including the community or home visit and the report write up (Form 4) takes approximately 3 h to complete for each patient. This information is stated in the Nurse Procedure Sheet (Form 5). All eleven (100%) nurses mention the first ERAC took longer to complete than subsequent checklists. This is as expected, as using a new tool requires time to become accustomed to the resource.[25] Overall 11(100%) nurses found that the ERAC was not time consuming to complete and this was

endorsed by all 11(100%) nurses who wish to continue to use the tool in their clinical practice

The researchers acknowledge that 10 (82%) nurses thought the ERAC guidance notes (Form 3) were very helpful which was reassuring as the answers are based on reliable citations to support the checklist questions (Form 2). Therefore each question has evidence for its relevance/inclusion in the checklist outlined in the accessory guidance notes.

It is important to stress the ERAC tool is a checklist and not an assessment. In the nursing process, this checklist provides a clear and objective basis for an assessment. The latter involves the health status of a patient and there is analysis and synthesis of the collected data leading to a clinical judgement.[22,24] There were six (56%) nurses who declared the ERAC useful to identify and increase awareness of risks at the point of assessment. This is salient as the ERAC was devised as a checklist not an assessment giving nurses a prompt to follow up patient care.

A bias in this study was the small sample selection of nurses that evaluated the ERAC. It is customary in the learning disability field that community nurses tend to form long-term relationships with their patients in community residential/day settings, especially if the patients have refractory epilepsy which requires a lot of nursing intervention in the community supporting carers.[25] This may not be the case in adult nursing settings were there maybe a different type of contact/relationships with patients.[26] Therefore it is likely other nurses may have different responses or views about the ERAC. To examine this, a larger scale study with epilepsy specialist nurses who work with adults and children will examine the costs and benefits of use in a randomised sample of patients.

As this was a new tool our aim was to establish its ease of use by nurses, and therefore this pilot study did not seek to gather the views of families and patients. This is a significant gap that will be addressed in the follow up study.

5. Conclusion

This epilepsy risk awareness checklist (ERAC) was devised based on research and patient information sources[14–21] to quantify various risks in people with epilepsy, for immediate and longitudinal comparisons. It was designed to support standardisation and evidence based measures for epilepsy specialist nurses. The ERAC was assessed using the model of Sackett et al.,[24] with quantitative and qualitative feedback. This pilot study evaluated this epilepsy tool in patients with learning disability living in the community. There has been a favourable response to the tool, and constructive suggestions received from all sources. The tool was modified with the feedback received. Although the results from this pilot study are positive, there is a need to validate this through a large scale national study.

Goodwin et al.[11] and Capan et al.[27] highlight the role of epilepsy nurses, and this tool is designed to aid their role, and to support an important component of their assessment. Interventions that give patients and carers information, skills and encouragement to discuss concerns regarding epilepsy with clinicians improve communication and disease outcome.[28] It is hoped that the ERAC will help achieve this and add to the increasing number of evidence based interventions that enhance nursing practice. The intention is the ERAC will evolve into a robust epilepsy tool providing benefits to patient care and facilitating epilepsy-nursing assessments. This tool indicates areas of epilepsy risk, important in "striking a balance between empowering people to make choices, while supporting them to take informed everyday risks".[29]

Having established the usability of the ERAC in this pilot study for people with epilepsy and learning disability, a larger study is now planned in conjunction with the epilepsy specialist nurse

association in the United Kingdom. This will examine the reliability and validity in the use of the tool in the general epilepsy population, and in children as well as adults in community settings, and examine its cost-benefit ratio.

Acknowledgments

Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at doi:10.1016/j.seizure.2010.09.005.

References

1. Hauser WA, Kurland LT. The epidemiology of epilepsy in Rochester, Minnesota, 1935 through 1967. Epilepsia 1975;16:1–66.
2. Sillanpaa M, Gram L, Johannessen SI, Tomson T. Epilepsy and mental retardation. Petersfield: Wrightson Biomedical Publishing Ltd; 1999.
3. Sander JW, Hart YM, Johnson AL, Shorvon SD. National general practice study of epilepsy: newly diagnosed epileptic seizures in a general population. Lancet 1990;336:1267–71.
4. Shorvon SD. Handbook of epilepsy treatment, 2nd edition, Oxford: Blackwell Publishing Company; 2005.
5. Kwan P, Brodie MJ. Early identification of refractory epilepsy. New England Journal of Medicine 2000;342:314–9.
6. Kerr M. Epilepsy and learning disability. In: Sander JW, Walker MC, Smalls JE, editors. Epilepsy: from cell to community, a practical guide to epilepsy. 11th edition, London: International League Against Epilepsy (UK Chapter) and National Society for Epilepsy; 2007.
7. Manford M. Practical guide to epilepsy. Oxford: Butterworth Heinemann; 2003.
8. Smith PEM, Wallace SJ. Clinicians guide to epilepsy. London: Arnold; 2001.
9. Taylor MP. Managing epilepsy in primary care. Oxford: Blackwell Science; 1996.
10. Department of Health (DH). National Institute for Clinical Excellence (NICE). Newer drugs for epilepsy in adults. London: NICE (Technology appraisal 76); 2004.
11. Goodwin M, Higgins S, Lanfear JH, Lewis S, Winterbottom J. The role of the clinical nurse specialist in epilepsy. A national study. Seizure 2004;13:87–94.
12. Bradley P, Lindsay B. Specialist epilepsy nurses for treating epilepsy. The Cochrane database of systematic reviews. CDOO 2001;1907.
13. Rajpura A, Sethi S. Evidence-based standards of care for adults with epilepsy—a literature review. Seizure 2004;13:45–54.
14. Coulter DL. Comprehensive management of epilepsy in persons with mental retardation. Epilepsia 1997;38(Suppl. 4):S24–31.
15. Dreifuss FE. Epilepsy: standards of medical care. Medicine and Law 1997;16: 225–33.
16. Frost S, Crawford P, Mera S, Chappell B. Implementing good practice in epilepsy care. Seizure 2003;12:77–84.
17. Hoare P, Kerley S. Psychosocial adjustment of children with chronic epilepsy and their families. Developmental Medicine and Child Neurology 1991;33: 201–15.
18. Kerr M, Bowley C. Multidisciplinary and multi-agency contributions to care for those with learning disability who have epilepsy. Epilepsia 2001;42(Suppl. 1):155–6.
19. O'Brien D, Loughran S. Risk assessment. Learning Disability Practice 2004;7:12–7.
20. Santilli N. Psychosocial aspects of epilepsy. In: Wyllie E, editor. Education and counselling for patients and families in the treatment of epilepsy: principles and practices. Philadelphia: Lea and Febiger; 1993. p. 1163–7.
21. National Society for Epilepsy (NSE). Keeping safe inside and outside the home. UK: National Society for Epilepsy; 2004.
22. Massachusetts Department of Mental Retardation. Quest Quality Enhancement Survey Tool (QUEST for optimal care of epilepsy), 4th edition, Massachusetts: Department of Mental Retardation; 2004.
23. Department of Health (DH). Quality Outcome Indicators. HMS 2004.
24. Sackett DL, Rosenberg WM, Gray JA, Haynes RB, Richardson WS. Evidence based medicine: what it is and what it isn't. British Medical Journal 1996;312:71–2.
25. Creswell JW. Research design: qualitative & quantitative & mixed methods/ approaches. London: Sage; 2003.
26. Working group of the international association of the scientific study of intellectual disability (WGIASSID). Clinical guidelines for the management of epilepsy in adults with an intellectual disability. Seizure 2001;10:401–9.
27. Capan P, Beard M, Mashburn M. Nurse-managed clinics provide access and improved health care. Nurse Practitioner 1993;50:53–5.
28. Austin B, Wagner E, Hindmarsh M, Davis C. Elements of effective chronic care: a model for optimising outcomes for the chronically Ill. Epilepsy and Behaviour 2000;1:S15–20.
29. Department of Health (DH). Independence, choice and risk: a guide to best practice in supported decision making. HMS 2007 [product number 279664].