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Title: Development of the Epilepsy Risk Awareness scale (ERA scale) for people with epilepsy

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Highlights

- People with epilepsy need the optimal balance of risk reduction and freedom from unnecessary restrictions
- Assessment of people with epilepsy regarding their safety in daily life is recommended
- The current Epilepsy Risk Awareness (ERA) scale refines the published Epilepsy Risk Awareness Checklist (ERAC)
- The ERA scale is a short quantified tool assessing the risk and safety profile in people with epilepsy

Abstract

Purpose: Quality of life in people with epilepsy depends on balancing protection from risks and avoiding unnecessary restrictions. The Epilepsy Risk Awareness Checklist (ERAC) was developed to summarise an individual's safety, health care and quality of life and to facilitate communication between professionals. Although effective, the existing Checklist required quantification and shortening to increase its utility, particularly as a longitudinal tool for measuring and communicating changes over time.

Methods: 5 clinical experts, 3 people with epilepsy and 5 carers assessed the importance of each item on the ERAC questionnaire in a two-round Delphi survey. The refined Epilepsy Risk Awareness scale (ERA scale) was piloted in 30 patients to obtain an overall and sub-scale score for personal safety, health care, and quality of life domains, and was compared with the validated Seizure Severity Scale and Epilepsy Self-Management Scale.

Results: ERAC was shortened from 69 to 48 items to take 15-20 minutes for completion. Pilot results showed good internal consistency for the overall ERA scale, for the Personal Safety and Health Care subscales, but less for the Quality of Life subscale. There was strong association between ERA scale and the Epilepsy Self-Management Scale, but little relationship with Seizure Severity Scale scores, which focus on individual seizures. User ratings were high.

Conclusions: The ERA scale has been shortened and quantified to provide an objective measure of the risks and safety profile in people with epilepsy. The scale will be further tested for intra-rater variability and utility.

Keywords: Epilepsy, Risk, Checklist, Seizure, Scale, Personal Safety, Health Care, Quality of Life

Introduction

Epilepsy is one of the most common neurological disorders, with a lifetime prevalence of 2 - 5% (1). It has major medical and psychosocial consequences (2), including a significant risk of injury and occasional fatality, most commonly through sudden unexpected death in epilepsy (SUDEP) (3-6). The fear of having a seizure can isolate the patient and limit both work and leisure activities (7-9).

Maximising quality of life depends on reducing seizure frequency, and appropriate personalised safety advice without undue restriction (4, 9-11). Scales are an important and established tool in neurological practice, for example the Glasgow Coma scale (12), the FAST score for stroke (13). In an attempt to reduce the risk of SUDEP, a self-monitoring platform, the Epilepsy Self-Mon (EpsMON) has recently been developed to educate and alert patients to their own seizure risk (14). New interventions to improve health care for people with epilepsy also require professional assessments of baseline need. Such evidence-based standardised measures of risk have been recommended for those with epilepsy, including assessment of daily activities (such as washing, preparing food), the social situation, and degree of independence (1). These measures have been lacking for healthcare professionals, particularly epilepsy nurses (15), despite their recognised importance (16-18).

To fill this need, the Epilepsy Risk Awareness Checklist (ERAC) was developed by the authors as an evidence based tool recording personal safety, health care and quality of life related to epilepsy. Face and content validity of the ERAC has been established in the pre-pilot work (19). The ERAC incorporated established epilepsy practices and was originally adapted from Coulter (20). The three sections within the previous ERAC and current ERA scale -Patient Safety, Health Care and Quality of life - ensure that all the facets affecting optimum care are covered (19). The Patient safety section assesses potentially modifiable physical safety in the environment and lifestyle factors. The Health care section assesses whether seizures are controlled, and, if not, whether appropriate medical care is accessed. The Quality of life (QoL) section looks at life and social activities to determine whether a patient has activities they find interesting and meaningful despite their epilepsy.

The aim of this study was to streamline and quantify the ERAC by examining whether any of the questions on the ERAC tool were redundant, and to establish a weighted numerical score for each item and a total risk score for adults with epilepsy. The purpose of the modified scale is to

allow more accurate risk measurement, and in turn, to improve the balance between risk reduction and restriction.

Methodology

The study incorporates a Public Patient Involvement component (four carers and one patient with epilepsy) who reviewed the study protocol, the participant information sheet, consent form and the Delphi and pilot questionnaires. Patient involvement (21) allowed review of the significance of risk management from a patient and carer perspective, to examine ease of use of the Checklist. The user consensus was that the ERAC checklist needed to be shorter and easier to complete.

A mixed methods (22) approach to tool development was used for the Delphi and pilot stages, drawing on established techniques of confirming items, validating that each item is a measure of risk and undertaking reliability and construct validity testing.

The study was carried out within the following two stages:

- Stage 1: Delphi Questionnaire

Clinical experts, adults with epilepsy and carers of people with epilepsy were recruited via clinical networks and epilepsy organisations to assess each item on the ERAC questionnaire. The objective was to reduce the number of items by one third to around 50 so that the questionnaire could be completed in about 15 minutes. The Delphi survey approach was used to reach consensus on health related issues (23). The survey was conducted in two rounds. The first round investigated the perceived usefulness of the items in the ERAC questionnaire. The Delphi technique was chosen as an established method in health research of reaching agreement amongst stakeholders on a wide range of issues. Three elements of the Delphi are critical to successful consensus - independence of decisions by stakeholders, decentralization and aggregation of findings (24). We sought this by sending out anonymised surveys to expert clinicians, patients and carers, which they completed in their own time autonomously and from which the data were aggregated statistically.

Panel members were asked to rate the usefulness and acceptability of each item to the concept of risk in epilepsy and its relevance to risk on a Likert scale (25) from 1 (unimportant) to 5 (essential). Participants could also rate an item as completely redundant (0) and suggest new items that they thought might be important. Additional space was provided for comments on each item, for example on patient acceptability, wording of the question, how relevant it is to the subject of epilepsy, and how it assesses risk (see Appendix).

Using the method of Paschoal (26), each item was scored by calculating the mean rating (redundant items were taken to be zero), and these scores used to rank the items based on their

perceived usefulness. Items in the lowest third of the scores were removed; new items suggested by more than 20% of the participants were added to the list. Items rated as borderline by the Delphi panel were discussed by the clinical members of the team and removed if regarded as unhelpful.

In Round 2 of the Delphi questionnaire, the same participants were asked to rank each of the remaining original items from the ERAC questionnaire along with any new suggested items using a Likert scale of 1 to 4. The ranked items were divided into quartile bands based on the sum of the Likert scores given by the participants. In the calculation of the ERAC totals, items in the highest quartile were assigned a weight of 4, those in the third quartile a weight of 3, those in the second quartile a weight of 2, with items in the lowest quartile having a weight of 1.

- Stage 2: Reliability and construct validity - Piloting

Following the Delphi phase, the refined ERAC questionnaire (ERA scale) was piloted with 30 patients, using sample size calculation methodology of Lancaster (27). The weights were used to score each item. A positive response, indicating good risk assessment, received the item weight and a negative response scored zero. These values were used to calculate an overall ERA scale score and a total for

each subscale (personal safety, health care, and quality of life), high scores indicating low risk. The pilot study questionnaire also contained the Seizure Severity Scale (28), the Epilepsy Self-Management Scale (29) and questions on age, gender, marital status, religion, current employment, education, and number of antiepileptic medicines currently prescribed. For socio-demographic variables, participants could indicate that they preferred not to answer. Participants were asked to rate the questionnaire (on a scale from 0 to 10) in terms of its usefulness and clarity (ease of completion).

ERA scale total scores were tested for internal consistency using Cronbach's alpha coefficient (α) (30). Unlike the kappa coefficient for observer agreement, there are no conventional benchmarks for Cronbach's alpha. On the issue of a satisfactory value it is difficult to specify a single level that applies in all situations (31). Bland and Altman's statement of 0.7-0.8 indicating satisfactory internal consistency is, however, widely accepted (32).

Construct validity for the ERA scale questionnaire was assessed by comparing total scores with those from the validated Seizure Severity Scale and Epilepsy Self-Management Scale using the Spearman rank correlation coefficient (r_s). In addition, the level of internal consistency was calculated for each subscale of the ERA scale. Internal consistency was considered to be satisfactory with a Cronbach's alpha coefficient of at least 0.7 (32). The Seizure Severity Scale and Epilepsy Self-Management Scale were selected as appropriate comparators for construct validity as the concept of risk is inherent in both. Seizure severity is related to the risk of an

individual seizure and its sequelae. Self-management relates to risk management through the person's ability to manage their epilepsy without unnecessary medical attention. The ERA scale aims to quantify epilepsy risk and is therefore a different construct that is theoretically related to these measures but not the same.

For the ERA scale items, "not applicable" and missing responses were scored as zero, a cautionary approach being taken so that a high score depended on positive data. The assumption made is that were the participant to become exposed to a particular risk through, for instance, a change in living circumstances, they would be vulnerable to that risk at least initially. A high score implies an active decision by the participant of the importance of the item. For Seizure Severity Scale data with missing information, the total score was estimated as the mean of the highest and lowest possible values, unless the range of possible totals was greater than 10. Totals that were too uncertain to be estimated were recorded as missing. With the Epilepsy Self-Management Scale, each of the five subscales (management of medication, information, safety, seizures, and lifestyle) was checked for missing values. If a subscale contained only one missing value, this was estimated by the median of the other subscale observations. Using this method, the total value for the Epilepsy Self-Management Scale total could be estimated in cases where all subscales contained no more than one missing value. Analyses were performed using SPSS Version 20 (33).

Ethics Approval

Ethics approval was through the NHS REC on 10/07/2015 (ID:15/NW/0607). The study was conducted in accordance with the guidelines of Good Clinical Practice, and data handling was in accord with the Data Protection Act 1998.

Results

- Delphi

The panels recruited for the Delphi exercise consisted of 3 patients, 5 carers and 5 professionals (2 Consultant Neurologists, 2 Epilepsy Specialist Nurses and 1 Epilepsy Nurse Consultant). Average age was 46 years. 11/13 disclosed their gender, 9 (82%) were female.

In Round 1 of the Delphi exercise, averaged usefulness scores across the 69 ERAC items ranged from 2.77 (for "Are injuries unlikely to occur while protective devices are in place?") to 4.85 (for "Is neurological (epilepsy) consultation or management obtained when seizures are not well controlled or when significant drug side effects are present?"). The number was reduced to 51 by retaining only the items with a score of greater than 3.6. Seven of the 8 items on the theme of social activities of the patient with family/ carers were removed at this stage. Each of the new items suggested by panel members were proposed by less than 20% (3) of those surveyed so none

were included.

Three items that received a mean score of less than 3.8 from the Delphi panel were thought to be either unnecessary or irrelevant by the team and were removed. These were: “Is the seizure type classified according to the International Classification of Epileptic Seizures?” (too technical for routine assessment) (panel mean 3.77); “Does the client/ patient attend paediatrician?” (irrelevant for adult patients) (panel mean 3.62); “Does individual and family/ carers use public transport?” (panel mean 3.62). The shortened version of the ERAC questionnaire consisted of 48 items, 14 from the Personal Safety section, 25 from the Health Care section, and 9 on Quality of Life. The goal of a reduction in the number of ERAC items to around 50 was therefore achieved.

For Round 2 of the Delphi exercise, the quartile bands were derived from the completed questionnaires of the 10 original respondents who participated at this stage (3 patients, 3 carers, 4 professionals). The total weighting scores were restricted to whole numbers so exact quartiles could not be derived. However, similarly sized bands were obtained. Of the 48 items, 11 received the lowest weight of 1, 12 received a weight of 2, 11 received a weight of 3, and the remaining 14 items

the highest weight of 4. The maximum possible ERA scale total score for these bands (124) was close to that for exact quartiles (120) indicating that the inequality of the band sizes would have little impact on the participant ERA scale totals.

- Pilot

For the 30 participants recruited in the pilot study, average age was 37 years and 20 (67%) were female. Some participants chose not to disclose certain socio-demographic details. Of those who did, 17/29 (59%), were single, 10/29 (34%) were married or in a partnership. Half (15/29) were in employment and 11/20 (55%) had either a university degree or a diploma. The median number of anti-epileptic drugs prescribed was two. For 15 (50%) of the participants a seizure usually lasted 1-10 minutes, and for 11 patients between 10 seconds to 1 minute (37%).

Data for the Seizure Severity Scale were complete and an ERA scale score could be calculated for each participant. For the Epilepsy Self-Management Scale, the total score could be obtained for 28/30 (93%) of the patients.

Internal consistency as determined by Cronbach's alpha was satisfactory for the ERA scale questionnaire as a whole – 48 items ($\alpha = 0.795$), the Personal Safety subscale – 14 items ($\alpha = 0.708$) and Health Care – 25 items ($\alpha = 0.705$). However, for the Quality of Life subscale – 9 items, internal consistency was low ($\alpha = 0.259$).

Construct validity was high for the ERA scale overall when compared to the Epilepsy Self-

Management Scale total scores ($r_s = 0.781$) (Fig.1) but was non-existent in a comparison of the ERA scale with the Seizure Severity Scale ($r_s = -0.100$) (Fig.2).

Feedback regarding the questionnaire was good. Participants gave it a mean score of 7.5 for usefulness and a mean score of 7.9 for clarity (ease of completing the questionnaire). There was no significant effect of gender or educational level on feedback responses. For example, rating for clarity had a mean score of 7.9, with a mean of 7.5 for those with tertiary education; 8.8 for those without, and 7.4 for those who did not specify.

The ERA scale is shown in full in the Appendix.

Discussion

The ERA scale is a quantified tool for determining individual safety and risk in people with epilepsy (Appendix). The scale had good overall internal consistency and acceptable consistency for personal safety and healthcare subscales. Internal consistency for quality of life was poor, possibly because the questions are too diverse; and further refinement of this section will be needed. User satisfaction was high. The survey takes approximately 15-20 minutes to complete, based on feedback from participants.

Association with other scales

The construct validity between the ERA scale and the Epilepsy Self-Management Scale was high. The ERA scale showed little correlation with the Seizure Severity Scale, despite it being a validated measure. The lack of correlation between the Seizure Severity Scale and the ERA scale suggests that the severity of a single seizure does not correlate with a person's epilepsy risk awareness or measures taken to reduce risk, such as an updated emergency plan. It suggests that multiple factors influence a person's response to their risk, and need to be factored in to provision of services, including education. Although there are other reasons to measure individual seizures, this lack of correlation highlights the importance of assessing overall risk for an individual. As well, the Seizure Severity Scale places a very high weighting on the time to complete recovery from a seizure (which is not necessarily related to safety or risk). The Seizure Severity Scale places weighting on automatisms, which may or may not correlate with risk. Automatisms include potentially risky behaviour (such as running onto the road or utilising nearby dangerous objects) and benign motor activity (such as orobuccal automatisms).

Limitations

A limitation of this study is that QoL did not reach a high level of internal consistency. Further

work may need to be done at the next pilot stage to address this, such as making the statements less generalised.

It is important to include measures of QoL as they influences potential risks, and vice versa. Risk can only be understood and moderated in the context of an individual's daily life. QoL is intrinsically multifaceted, and will always be difficult to measure.

As QoL is complex, questions in this section can only sample some components. Other studies suggest gastrointestinal disorders such as constipation (34), sleep quality (35) and physical activity (36) are important elements of QoL for people with epilepsy, and the validation process supports their inclusion.

A larger sample may have generated a wider range of statements from patients and carers with different types and severity of epilepsy. We did not include carers of people with epilepsy who had lost a relative with SUDEP or from other causes of mortality, and that may have had some specific impact on risk. Although we did not find a gender or educational bias, larger numbers should clarify this issue.

Future developments

The ERA scale is designed primarily for use by specialist nurses in epilepsy and intellectual disability, and allied health professionals such as occupational therapists. It will be a useful longitudinal tool in clinical trials for assessing interventions. It has potential use in occupational specialist practice in assessment of environmental adjustments.

The ERA scale provides rapid assessment of immediate risk, and longitudinal assessment of changes, essential for improving epilepsy management in patients, in particular, those with refractory epilepsy. It also facilitates communication between services. This is particularly important when a patient faces an acute change in their health (such as infection, operations, new co-morbidities), care provider or responsible healthcare professional. A strength of the ERA scale is that methodology ensured patient involvement in research and management at all stages, not only at the final stage of their treatment (37). Use of the Delphi method also ensured that the ERA scale is pragmatically acceptable as well as statistically valid.

Future development of the ERA scale is planned with a test re-test investigation involving 100-200 patients who will complete the ERA scale with their nurse or carer at baseline and at two months of follow-up. Scores will be analysed for repeatability using intra-class correlation coefficients. The final stage of the research will be to assess the utility of the ERA scale in measuring long-term outcomes of risk management interventions for people with epilepsy.

Conclusions

The ERA scale is a pragmatic and validated risk assessment scale for use in patients with epilepsy developed through an iterative process that included the Delphi technique. Whilst the scale needs a test re-test assessment, it has potential to estimate current risk. This will enable clinicians to stratify risk and prioritise those most in need of intervention. To our knowledge, the ERA scale is the only valid scale available for this purpose and it could be an invaluable tool in the reduction of risk with direct cost savings to healthcare providers, and indirect cost reductions to patients and carers. This would require further cost-effectiveness analysis. The ERA scale should be considered as part of the toolkit of the clinician in assessing the daily lives of people with epilepsy.

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Conflicts Of Interest

The authors declare no conflicts of interest.

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Figure 1: ERA scale vs. Epilepsy Self-Management Scale

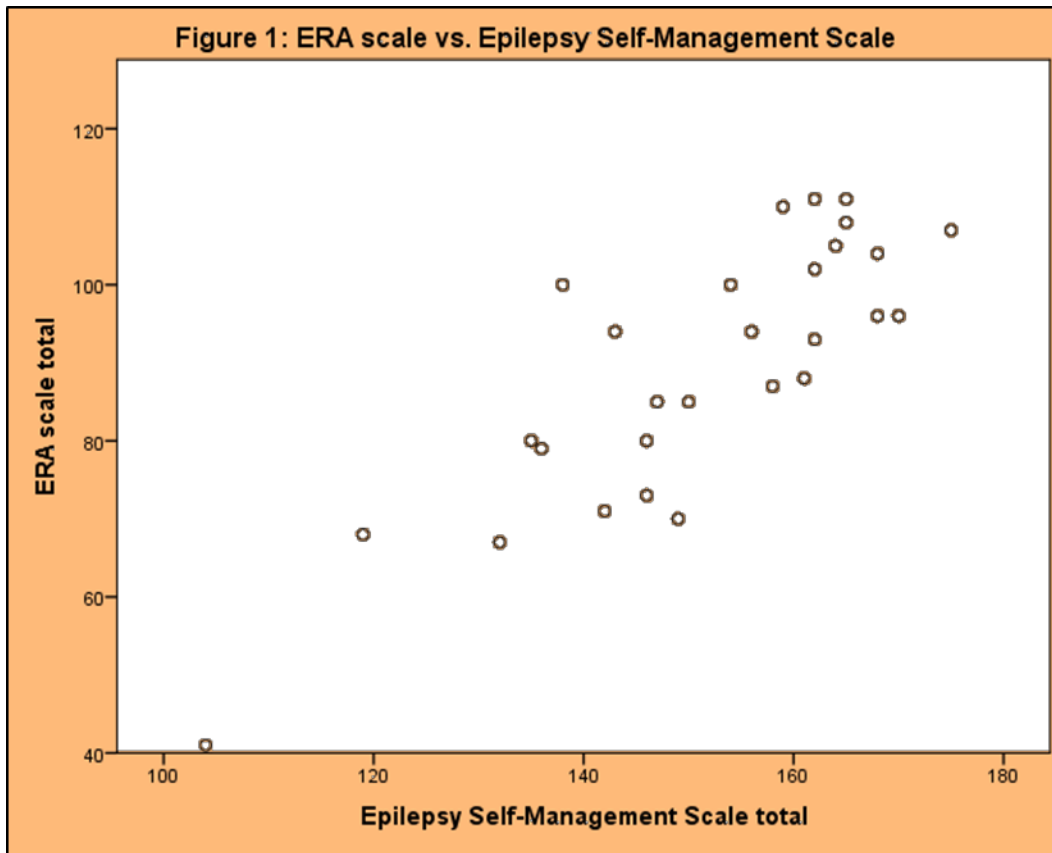


Figure 2: ERA scale vs. Seizure Severity Scale

