



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



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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 min 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.

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1. 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 health-care 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

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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.

2. 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:

2.1. 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 min. 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 in Supplementary material).

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 1–4. 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.

2.2. 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

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