



Consensus research priorities for paediatric status epilepticus: A Delphi study of health consumers, researchers and clinicians



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ABSTRACT

Purpose: Status epilepticus (SE) is a paediatric emergency with significant morbidity and mortality. Recommendations beyond first line care are not based on high quality evidence. Emergency physicians and neurologists are key stakeholders in managing this condition. A collaborative, widely consulted approach to identifying priorities can help direct limited research funds appropriately. The objectives of this study are to identify consensus research priorities in paediatric SE among experts and health consumers.

Methods: A three-stage Delphi process was conducted. Paediatric Neurologists and Emergency Physicians in Australia and New Zealand participated. Round one asked participants to generate three research questions important for further research in paediatric status epilepticus. Responses were refined into unique individual questions. Rounds two and three required participants to rate questions on a seven point ordinal scale. Health consumers were invited to participate by providing up to three problem areas that could be addressed by research.

Results: 54 experts and 76 health consumers participated in the process. Nine questions reached our definition of consensus "high priority", 21 questions achieved consensus "low priority" and seven questions did not achieve consensus. High priority areas included second line management including levetiracetam (efficacy, dose and timing), use of third line agents, induction of anaesthesia (timing and best agent), management of focal SE, and indicators of "subtle SE". Consumer priority areas included themes of treatment efficacy, aetiology, and community education.

Conclusion: We identified nine priority research questions in paediatric SE, congruent with the health consumer theme of treatment efficacy. Future research efforts should be directed towards these priority areas.

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1. Introduction

Status epilepticus (SE) is the most common childhood neurological emergency and is, with its underlying aetiology, associated with an estimated mortality of 3% and significant

morbidity [1,2] including development of focal neurological deficits, cognitive impairment, behavioural problems or epilepsy [3]. The incidence of paediatric SE is in the order of 20 per 100,000 population at risk [1,4]. Aetiology and outcomes of SE in children are different from adults [4]; therefore adult evidence is minimally applicable to paediatric settings. An operational definition of SE based on the indication to commence treatment has been proposed for seizures of five minutes or more [5], replacing the "traditional" definition requiring seizures of greater than 30 min

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duration or two or more sequential seizures without full recovery of consciousness between seizures. These concepts have been incorporated into recent clinical trials [6] and conceptually into recent consensus documents [7].

Benzodiazepines are widely used in the first line pharmacological management of SE, supported by good evidence of efficacy, but recommended subsequent management is based on expert opinion, tradition and consensus [8]. Despite the considerable burden of SE, addressing important clinical questions is challenging with single centre studies, and generally requires a collaborative approach with considerable resources and infrastructure [9]. A collaborative, consultative and systematic approach to identify and clarify the immediate research priorities in SE is indicated to ensure limited research funds are directed appropriately. Incorporating stakeholders' perspectives into the development of research priorities might lead to highly engaged researchers and increased likelihood of translating research into clinical practice.

The Delphi technique is a common approach for the solicitation and collation of opinions from experts in a particular field in the development of ideas and priorities. The Delphi technique has been widely used in health sciences research and is appropriate to correlate informed judgements on topics spanning the disciplines of neurology and emergency medicine. Briefly, the technique involves a set of sequential questionnaires, with information from previous responses summarised and fed back to participants [10]. The first round usually consists of open ended questions soliciting specific information about the content of subsequent structured questionnaires. Three to six rounds are usually employed to reach consensus on a topic [10]. The technique has been successfully used to identify research priorities in the field of paediatric neurology [11], paediatrics [12] and paediatric emergency medicine [13,14].

The perspective of emergency physicians is perhaps historically underrepresented in SE literature and guideline development, despite being responsible for the majority of acute care decisions in SE in many health systems. It is also imperative that health consumers (i.e. patients and families of patients) are represented to ensure that community expectations about research priorities are met.

The primary objective of this study was to use the Delphi technique to achieve consensus on research priorities in the management of paediatric SE among paediatric neurologists and emergency physicians who treat children. A secondary objective was to determine if research priorities identified by experts aligned with priorities identified by health consumers. The results of this study will help determine where to allocate scarce research resources to achieve better outcomes for patients.

2. Methods

This was an assessment of expert clinician and health consumer opinion via a Delphi survey to identify research priorities for paediatric SE. The survey was conducted with the support of the Australia and New Zealand Child Neurology Society (ANZCNS) and Paediatric Research in Emergency Departments International Collaborative (PREDICT) network.

2.1. Participants

Expert participants were paediatric neurologists and emergency physicians in Australia and New Zealand. An invitation to participate was distributed to paediatric neurologists through the ANZCNS by email, explaining the purpose of the study, the expected time commitment, the proposed number of rounds and timelines. Emergency physicians were invited to participate through site representatives of the PREDICT network. Site

representatives at PREDICT sites were asked to nominate interested clinicians, and provide email details, to approximate respondent numbers from neurologists to maintain balance and representation of both groups and inclusion of perspectives of non-researchers. Although controversy exists as to what constitutes the ideal number of subjects in a Delphi study [15–18], it has been recommended that one should have 30 experts from any one discipline, or at least 10 per category for different professional disciplines. It has been suggested that increasing a group size beyond 30 does not generally improve results [16]. A total sample of at least 30 respondents was sought, allowing for attrition.

Consumer participants included health consumers with a diagnosis of epilepsy and a prior SE event, as well as their families. Information regarding the study objectives was distributed through Epilepsy Queensland social media webpages, with an explanatory sheet, and a link to participation in the survey.

2.2. Study procedure and design

Surveys were constructed and distributed electronically via email, using SurveyMonkey [19]. In round one clinical participants were asked to identify research priorities in the field of paediatric SE that they believed was lacking by answering one single open question: “Thinking about your experience with paediatric convulsive status epilepticus, what are the most important research questions that need addressing”. The survey allowed for free text responses, and participants were encouraged to submit the research questions in the PICO format (referring to Population, Intervention, Comparison, Outcome). They were given three weeks in which to respond and could submit up to three questions. Non-responders were emailed a reminder at one and two weeks after initial contact. Consumers were asked to provide up to three problem areas associated with paediatric status epilepticus that could/should be addressed by research. Demographic details were collected from both experts and consumers.

Definitions of SE have been somewhat contentious and continue to evolve [7]. In the survey information we defined SE simply as an “abnormally long seizure” operationally defined as when emergency treatment should be started e.g. beyond 5 min for tonic-clonic SE. Questions concerning “children” referred to ages 1 month to 16 years, and “infants” as ages 1 month to 12 months.

Questions generated by round one were collated into themes, and developed into mutually exclusive research questions using NVivo 11 for Mac (NVivo qualitative data management Software; QSR International Pty Ltd. Version 10, 2014). Analysis of responses to round one used a grounded theory approach and a process of content analysis and open coding to categorize items into themes [17]. The compiled proposed questions were reviewed and refined by the investigator team and included in round two in a structured questionnaire. The investigator team included experienced paediatric emergency physicians, paediatric neurologists, clinician researchers and methodological expertise. Surveys were pilot tested for face validity on a group of ED physicians and paediatricians and amended as required. In round two participants were asked to rate the perceived priority of each research question using a seven point Likert-type, ordinal scale (Very low priority, low priority, fairly low priority, neutral, fairly high priority, high priority, very high priority). Participants were also encouraged to supply reasoning and further comments.

Round three consisted of the questions from round two that did not reach predetermined criteria for consensus “high” or “low” priority, together with a summary of feedback for each question including scores and text comments to allow responders to reflect on colleagues scores and thoughts. In round three participants were again asked to rate the perceived priority of each research question using the same seven point Likert-type/ordinal scale.

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