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# **Knowledge and attitudes of critical care providers towards neurophysiological monitoring, seizure diagnosis and treatment: an explanatory sequential mixed methods study**

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## **ABBREVIATIONS:**

ANP: Advanced nurse practitioner

BIS: Bispectral index monitoring

CSA: compressed spectral array

ECMO: extracorporeal membrane oxygenation

EEG: electroencephalography

aEEG: amplitude integrated EEG

cEEG: continuous EEG

NICU: Neonatal Intensive Care Unit

PICU: Paediatric Intensive Care Unit

QUAL: qualitative

QUAN: quantitative

## **AUTHOR CONTRIBUTIONS**

EB: Collated and analysed data from the questionnaires used in phase one, performed the qualitative interviews, coded the data, performed initial thematic analysis, and reviewed the final draft of the paper.

JA: Helped conceive the idea for the study, reviewed the data, assisted with interpretation, and reviewed and revised the final draft of the paper from a neurophysiology perspective

NM: Helped conceive the idea for the study, reviewed the data, assisted with interpretation, and reviewed and revised the final draft of the paper from an intensive care perspective

AH: Conceived the study, wrote the questionnaire used in phase one, reviewed and interpreted data from phase one, wrote the interview schedule, trained EB in qualitative interview methods, performed coding and thematic analysis, interpreted the results and wrote the first draft of the paper.

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## **ABSTRACT**

**Aims:** To explore the attitudes of paediatric intensive care unit (PICU) health care professionals towards diagnosis and neurophysiological monitoring of seizures

**Methods:** Explanatory sequential mixed methods approach (QUAN→QUAL) comprising questionnaires and interviews, with equal weighting between stages, of health care professionals working in UK PICUs. Interview data was analysed using thematic analysis and triangulated with questionnaire data.

**Results:** 72 questionnaires were returned: 49/60 (71.0%) of respondents reported that seizures were extremely hard or somewhat hard to diagnose in a critically ill child, and 81.2% had seen misdiagnosis occur. Thematic analysis revealed two main themes: 1) feeling out of control when faced with “grey areas”, and 2) regaining control, which compromised three subthemes: aggressive intervention; accurate diagnosis; and eschewing diagnosis.

**Interpretation:** Health care professionals find accurate diagnosis of seizures difficult, particularly in sedated / paralysed children and those with chronic neurological disorders. They report they would like better educational opportunities on discriminating between epileptic and non-epileptic events to improve their confidence. Professionals want routine neurophysiological monitoring that can be applied and interpreted at the bedside throughout the day to regain a sense of control over their patient, direct treatment appropriately and, potentially, improve outcomes, but report appropriate training and peer review are essential if it is to be introduced into routine care.

## INTRODUCTION

Children admitted to Paediatric Intensive Care Units (PICUs) commonly have acute neurological conditions or deteriorations of long-standing neurological disorders, like epilepsy. Data on the frequency of seizures in PICUs are derived from studies with varying methodologies, prospective and retrospective designs, sometimes cohorts involving children and adults, different durations of electroencephalography monitoring, mixed aetiologies, and varying criteria on when to start continuous electroencephalography (cEEG). Estimates range from 6 to 62%,<sup>1-16</sup> of which 7.5-90% are non-convulsive.<sup>1-3; 6; 8; 10; 12; 14; 15</sup> Seizures are more common in young children, those with sepsis / meningoencephalitis, traumatic brain injury, a previous history of epilepsy, or where inpatient seizures are seen prior to the start of monitoring.<sup>1; 2; 6; 10; 12; 15; 16</sup> 52-70% of seizures occur within the first hour of monitoring,<sup>1; 15; 17</sup> 70-95% within 24 hours,<sup>1; 6; 8; 16; 17</sup> and a small number commence after that.<sup>6; 16; 17</sup> Children with pre-existing neurological conditions may also have movement disorders, and these may be misdiagnosed as seizures.<sup>5; 18</sup>

The gold standard neurophysiological technique to diagnose seizures is continuous EEG (cEEG) with video, but there are logistical and financial challenges in starting and interpreting cEEG in PICUs. Although cEEG is being introduced in some countries, it not likely to be part of routine care in the UK soon. In Neonatal Intensive Care Units (NICUs), amplitude integrated electroencephalography (aEEG) is used routinely in term babies with hypoxic ischaemic encephalopathy because it can be started any time of the day or night, and staff can interpret the recording at the cotside. However, aEEG is not used routinely in PICUs. Data reported from a single PICU has shown aEEG can assist with the diagnosis of seizures, although with a false positive rate of 52%, most likely because of abnormal EEG backgrounds, and despite significant training support.<sup>16</sup> This work aimed to study the attitudes of health care professionals working in PICU towards seizures diagnosis and neurophysiological monitoring.

## METHOD

We used an explanatory sequential mixed methods approach, interconnecting quantitative and qualitative features,<sup>19</sup> with two distinct phases (QUAN→QUAL).<sup>20</sup> Phase I involved collecting the views of a convenience sample of health care professionals working in PICUs on diagnosing seizures. A paper questionnaire was designed and comprised two sides of A4 paper and 8 full questions (supplementary material, available online). The electronic version was identical, without randomisation of questions, and participants could move back to review or change answers. The questionnaires were trialled prior to launch.

The addresses of PICUs were identified from the PICANet website ([www.picanet.org.uk](http://www.picanet.org.uk)), a network of all PICUs in the UK and two in Dublin (n=30) collecting data on the management of children requiring critical care. The paper questionnaire was sent to the clinical lead of each PICU with a stamped addressed envelope for its return and a cover letter giving the web address of the electronic questionnaire. We requested they disseminate the survey to other staff members. It was not mandatory to complete the questionnaire and no incentive was offered. No other advertising of the questionnaire was performed. Participant names were collected to identify multiple replies from individuals. All paper replies were entered into the online database. We collected answers between 1<sup>st</sup> January and 3<sup>rd</sup> June 2019. All questionnaires were analysed, including those that were incomplete. Frequencies and percentages of answers were calculated.

The final question asked if respondents were willing to attend a qualitative interview to explore their views in more depth. An intermediate stage connected Phase I and II, in which we used the answers from the questionnaire to design the topic guide for our qualitative interviews (supplementary material, available online). The topic guide was trialled during training of the interviewer. From the list of volunteers, we used a purposeful sampling approach to ensure we obtained a range of views. Specifically, we wanted to include roughly equal numbers of nurses, advanced nurse practitioners, and consultants, as well as

capturing views of men and women. A single consultant paediatric neurologist had completed the questionnaire because of their work on with PICU, and we invited them to take part in the interview to collect the fullest range of opinions possible. In total, no more than 3 participants were recruited from any single site and we selected a geographical spread of units across England

Phase II involved a qualitative semi-structured interview undertaken by a single member of the research team (EB), who was a female Psychology Graduate studying for an MSc in Clinical Neurology who had been trained in qualitative interview technique. The interviewer had no relationship with the participants prior to the study, and had not worked in PICU, so approached the topic with knowledge from the literature, but no pre-expectations of answers than may have led to bias. Interviews were arranged at a time and location of the participants' choice and were performed 1:1 without other people being present. Written informed consent was obtained, and the interviews were recorded digitally, transcribed verbatim, anonymised, and checked for accuracy. Thematic analysis was performed as per Braun and Clarke (2006).<sup>21</sup> This included familiarisation of data, initial coding using an inductive approach by two researchers (EB and ARH), review of initial codes, agreement on a coding structure for the whole dataset, and identification of a thematic structure to determine main and subthemes. Themes were developed using an iterative process to capture all range of views. We ceased recruiting for interviews when we reached thematic saturation.<sup>22; 23</sup> NVivo for Mac version 12 (QSR International PTY Ltd, 2018) was used to assist analysis. Equal weighting was given to both phases of the study. The results of the quantitative and qualitative phases were integrated to find explanations for any observed variations in practice. Ethical approval was obtained from the University of Sheffield (Reference Number 025398).

## **RESULTS**

### **Quantitative data on epileptic seizures on PICU**

72 questionnaires were returned and there were no duplicates. Responders reported they worked in 16 units (53.3% of units listed by PICAnet), although 18 responders did not report which units they worked in. Multiple responses from single units were received, with the largest being our own, from whom 18 (25.0%) responses were obtained, 14 (19.4%) from Addenbrookes Hospital, and between 1 and 3 responses from the other units. 16 (22.2%) responders were doctors, 54 (75.0%) other health care professionals, including nurses and advanced nurse practitioners, and 2 (2.8%) did not identify their role. 66/72 (91.7%) worked in PICU, 1 in PICU and NICU, 1 in Paediatric Neurology and PICU, 1 in Paediatric Cardiac Intensive Care Unit, 1 in PICU transport team, and 2 did not reply. The results of our questionnaire are summarised in table one. Some respondents did not answer all of the questions.

49/69 (71.0%) of all respondents reported that seizures were extremely hard or somewhat hard to diagnose in a critically ill child, 26/69 (37.7%) thought they differentiated between seizures and other abnormal movements somewhat or extremely poorly, and 81.2% had seen misdiagnosis. When asked about the challenges they faced in diagnosing seizures the most frequent factors listed were:

- Sedation or paralysis
- Not knowing the child's normal neurological baseline
- Limited equipment
- Limited education and training
- Lack of experience or confidence
- Difficult or subtle seizures
- Limited availability of expert opinion.

38/68 (55.9%) of responders reported their PICU did not perform cerebral function monitoring routinely, including responders from 12/16 (75.0%) units. 27 responders from 11



centres reported their unit did perform routine cerebral monitoring, including 6 PICUs where other responders indicated no routine monitoring occurred. Where responders had used cerebral monitoring, 54.1% of responders reported it was somewhat or extremely helpful. 57/64 (70.9%) responders thought better diagnosis of seizures would improve outcome in acquired / hypoxic brain injuries, 58/64 (90.6%) thought it would reduce duration of stay in PICU, and 59/62 (95.2%) would like to be able to diagnose seizures better.

### **Qualitative data on epileptic seizures on PICU**

Sixteen health care professionals were interviewed. None of the participants we approached to take part in the interviews declined to be involved, and no repeat interviews occurred. The demographics of the interviewees are shown in table 2. The length of interviews ranged from 11 to 55minutes, with a median length of 22minutes.

The overarching motif was “The need to be in control of my patient”, from which two themes were identified (Figure 1):

- *“Feeling out of control when faced with ‘grey areas’”*
- *“Regaining control”*, which comprised three subthemes: “aggressive intervention”, “accurate diagnosis”, and “eschewing diagnosis”.

Illustrative quotations for each theme are shown in table 3.

### **Feeling out of control when faced with ‘grey areas’**

PICU health care professionals monitor the body’s systems to identify deterioration and intervene to minimise harm. The fear of getting decisions wrong means health care professionals need to feel ‘in control’ of their patients’ care. As such, interviewees preferred decisions to be binary, with obvious correct and incorrect answers. Where the solution to problems was not clear, health care professionals felt out of control: *“Intensive care people can’t cope with grey areas, and that’s because that’s the way we get trained: you know, you find a problem, you treat a problem.” [Interview 2, ANP, Male]*

The diagnosis and management of seizures was one such challenge. Some seizures were thought to be easy to recognise, others were more difficult. Senior staff were more aware of diagnostic difficulties than less experienced staff. Children with chronic neurological diagnoses, such as cerebral palsy, presented a particular challenge if their baseline neurological status or typical seizures were unknown. Sedation and paralysis also made diagnosis difficult. This feeling of being out of control was compounded by health care professionals' belief that seizures cause harm to children, hypothesised to be through increased intracranial pressure or cerebral metabolic rate in a stressed brain. Some interviewees were less convinced that seizures cause harm, but no interviewee thought they didn't cause harm. These views related to acute symptomatic seizures, as seizures in a child with epilepsy were perceived to be less harmful.

### **Regaining control**

Interviewees adopted three approaches to regaining a sense of being in control, forming our three subthemes.

*Aggressive intervention:* This philosophy was summed up by interviewee 4, an advanced nurse practitioner, as “*treat first and then ask questions later.*” This attitude was encouraged by advanced paediatric life support courses, where participants were taught it was safer to treat all seizures lasting more than 5 minutes. The potential side effects of the drugs were rarely considered.

*Accurate diagnosis:* The majority of interviewees wanted to regain control through accurate diagnosis of seizures and non-epileptic events. Education was important because nurses and medical trainees reported that training on seizure semiology was limited. Where there was doubt about the nature of events, staff asked senior colleagues for their opinion. Certain features were thought to be particularly useful to discriminate epileptic seizures from non-

epileptic events, such as limb movements that did not stop during holding or autonomic features. The parents of a child with a chronic neurological disorder were frequently used to differentiate seizures from other movement disorders. Where parents were not available, “health passports” that contained information on the child’s usual neurological status, seizures and non-epileptic events were useful. Health care professionals acknowledged these strategies were imperfect, and the majority thought neurophysiological monitoring would improve diagnosis.

Electroencephalography (EEG) was available in daytime hours between Monday to Friday in most units. In some, EEG could only be requested by the neurology team, taking control away from PICU staff. Most units did not have continuous EEG, and health care professionals reported they wanted simplistic forms of continuous monitoring they could start and interpret to regain a feeling of control. Some PICU staff had used compressed spectral array (CSA) or bispectral index monitoring (BIS) in the past, but these were described as being “*not massively helpful*”. Amplitude integrated EEG was looked upon more favourably. Interviewees knew it was not as accurate as cEEG, but considered it a useful compromise. No health care professional felt expert in interpreting aEEG, and all wanted training and peer support when reviewing the results. Neurophysiological monitoring allowed staff to aim for accurate treatment, preventing over-diagnosis, allowing drugs to be stopped earlier, reducing drug side effects, and potentially shortening PICU stays. Although interviewees felt that aEEG would improve their confidence and sense of control, they also wanted long-term research evidence to prove these assumptions were correct.

*Eschewing diagnosis:* A small number of interviewees were against more neurophysiological monitoring: two were consultant intensivists and one was the paediatric neurologist. They acknowledged epileptic seizures were hard to diagnose accurately, particularly in paralysed or sedated children, but preferred to remain in control by ‘not knowing’ seizures were occurring, avoiding the dilemma of whether to treat them. The paediatric neurologist thought

the quality of data supporting aggressive treatment of acute symptomatic seizures in PICUs was not strong, and that short seizures in children with epilepsy were unlikely to be harmful. One Intensivist was equivocal on the value of treating electrical seizures and preferred to make a case-by-case decision. The final intensivist did not believe electrical seizures caused harm and saw little need to diagnose them. A further interviewee, a PICU nurse, felt the introduction of neurophysiological monitoring would lead to staff feeling out of control because the monitor was unfamiliar and they could not interpret it, increasing workload and anxiety.

## **DISCUSSION**

Seizures are common in children in PICU who are young, have sepsis, traumatic brain injury, and those with a history of epilepsy.<sup>1-3; 6; 10; 12; 15</sup> Electrographic seizures are common and may be the only form of seizures seen, which is not entirely attributable to sedation and paralysis.<sup>1-3; 6; 8; 10; 12; 14; 15</sup> The existing literature does not address well the rate of over-diagnosis of seizures.<sup>5; 18</sup> Our survey showed over 80% of respondents had seen misdiagnosis, and our interviews showed that diagnosis is particularly hard in children with chronic neurological disorders, where parents are not around to interpret their child's movements. A lack of training in seizure semiology and non-epileptic events compounds this issue, perhaps explaining why 71% of our questionnaire respondents reported epileptic seizures were either extremely hard or somewhat hard to diagnose, and the features noted in our free text boxes. These challenges lead PICU staff to feel "out of control" of their patient.

Neurophysiological monitoring was seen as a positive development to improve diagnosis, direct treatment accurately, prevent drug side effects, and reduce the length of PICU admissions; however, few UK PICUs use it routinely. The published literature, usually from the US, uses cEEG in PICUs, but this is unlikely to be introduced in the UK soon. One UK study using cEEG in a PICU found interpretation challenging, and resorted to aEEG mid

study instead.<sup>7</sup> Amplitude integrated EEG is a standard of care on NICU for term neonates with hypoxic ischaemic encephalopathy, and one driver for this may have been national therapeutic hypothermia studies. The lack of multicentre trials in UK PICUs using aEEG, the cost of purchasing monitors, training and governance needs, and doubts on whether aggressive treatments of seizures improve outcomes may explain why aEEG is not used more frequently in PICU care. In our study, aEEG was considered to be a pragmatic solution to improve seizure diagnosis, and the data on cEEG suggests 24-48 hours monitoring from admission would be satisfactory to detect most seizures.

The main driver for PICU staff wanting to improve diagnosis and 'regain control' was the belief that acute symptomatic seizures cause harm, independent of aetiology. 89.2% of our questionnaire respondents and the majority of our interviewees thought that diagnosing and treating acute symptomatic seizures would improve outcome; 90.6% of respondents thought improved diagnosis would reduce duration of PICU stay, and the interviewees indicated the latter was mediated through reduced over-diagnosis / side effects. These views are supported by the literature, where the presence of status epilepticus and seizure burden are associated with mortality or poor outcome in children and adults.<sup>2; 3; 7; 9; 10; 12; 14; 24-29</sup> For example, one study of over 200 children admitted to critical care unit found a strong link between increasing seizure burden and neurological decline at discharge from hospital,<sup>10</sup> although there is little data on whether this relationship is maintained with longer follow-up periods, or whether the identification and treatment of seizures improves outcome. Few studies have looked at whether aggressive seizure treatment improves outcome, but retrospective studies of status epilepticus suggest it may.<sup>25</sup>

There are limitations to our data. The data on how many members of staff work in PICU or were encouraged to complete our open questionnaire is not available, so we cannot report the response rate. It is unsurprising that around a quarter of responses were derived from our own unit, given we were organising the study and monitoring was of interest at the time,

but this may have skewed our findings; however, there were no obvious differences between these responses and the other PICU responders. The nature of questions in any questionnaire may also lead respondents to reply in a certain way, so it is unclear exactly how much answers truly reflect our responders' views. It is also debatable whether 72 questionnaire responses represents the full range of PICU staff opinion on the diagnosis of seizures, and bias may have led staff to complete the questionnaire in the first instance. A number of suggestions can be made based on our data. PICU staff report they want more directed training on seizure semiology and movement disorders, and they find "passports" describing the typical neurological state and the nature of any seizures or non-epileptic events in children with chronic neurological disorders to be invaluable. Parents of children with chronic neurological disorders could be encouraged to share videos of their child's usual neurological state, movements and seizures with PICU staff, who in turn could also use videos more frequently to review abnormal events with senior staff and neurologists. Neurophysiological monitoring, particularly amplitude integrated EEG, could be considered for "high risk" patients for at least 24-48 hours, although eligibility criteria need to be agreed and evidence based. Alongside this, research should examine whether aggressive or prophylactic anticonvulsant treatment of seizures improves patient care, outcomes, duration of stay, and health care costs.

In conclusion, health care professionals working in PICUs find the diagnosis and management of seizures difficult. This is partly because of a lack of education over seizure semiology and the differential diagnosis of non-epileptic events, but also related to not knowing the normal baseline of children with chronic neurological disorders, the effects of sedation and paralysis, and the inherent difficulties in diagnosing subtle or electrographic seizures. This leads to a feeling of being 'out of control' and that the child is coming to harm. Neurophysiological monitoring is seen positively by the majority of staff to allow for accurate diagnosis and management, helping staff to regain a sense of control. A minority would rather not know if a patient is having seizures because it is not clear that treating them

improves outcome. Even in those who view neurophysiological monitoring more positively, there is an acknowledgement that further research is needed into seizure treatment regimens in PICUs.

## **WHAT THIS STUDY ADDS**

- PICU staff feel out of control when faced with diagnosing seizures
- Neurophysiological monitoring is wanted to help diagnosis and treatment
- aEEG is the preferred, pragmatic tool by PICU staff



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**Table one:** Frequency of responses to questions in our questionnaire separated by primary type of unit in which respondents work

Question		Respondents		
		All respondents	Doctors	Nurses or ANPs*
<b>How easy do you think it is to diagnose seizures in critically ill patient on PICU</b>	Extremely hard	8/69 (11.6%)	0 (0%)	7/51 (13.7%)
	Somewhat hard	41/69 (59.4%)	6/15 (40.0%)	34/51 (66.7%)
	Neither easy nor hard	11/69 (15.9%)	7/15 (46.7%)	4/51 (7.8%)
	Somewhat easy	8/69 (11.6%)	2/15 (13.3%)	5/51 (9.8%)
	Extremely easy	1/69 (1.5%)	0 (0%)	1/51 (2.0%)
	Don't know	0/69 (0%)	0 (0%)	0 (0%)
<b>How well do you think staff on your PICU differentiate between abnormal movements and seizures in critically ill patients?</b>	Extremely poorly	3/69 (4.4%)	1/15 (6.7%)	2/51 (3.9%)
	Somewhat poorly	23/69 (33.3%)	3/15 (20.0%)	18/51 (35.3%)
	Neither well nor poorly	11/69 (16.0%)	4/15 (26.6%)	7/51 (13.7%)
	Somewhat well	21/69 (30.4%)	7/15 (46.7%)	13/51 (25.5%)
	Extremely well	6/69 (8.7%)	0/15 (0%)	6/51 (11.8%)
	Don't know	5/69 (7.2%)	0/15 (0%)	5/51 (9.8%)
<b>Have you ever seen misdiagnosis of abnormal movements as seizures in a child on PICU?</b>	Yes	56/69 (81.2%)	12/15 (80.0%)	41/51 (80.4%)
	No	7/69 (10.1%)	2/15 (13.3%)	5/51 (9.8%)
	Don't know	6/69 (8.7%)	1/15 (6.7%)	5/51 (9.8%)
<b>How frequently do you think misdiagnosis of seizures occurs?</b>	Extremely frequent	1/58 (1.7%)	0/12 (0%)	1/43 (2.3%)
	Somewhat frequent	11/58 (19.0%)	2/12 (16.7%)	9/43 (20.9%)
	Sometimes	34/58 (58.6%)	9/12 (75.0%)	22/43 (51.2%)
	Somewhat rare	6/58 (10.3%)	1/12 (8.3%)	5/43 (11.6%)
	Extremely rare	4/58 (6.9%)	0/12 (0%)	4/43 (9.3%)
	Don't know	2/58 (3.5%)	0/12 (0%)	2/43 (4.7%)
<b>Do you routinely perform some type of brain / cerebral function monitoring in children or young people who are at risk of seizures?</b>	Yes	27/68 (39.7%)	5/15 (33.3%)	21/51 (41.2%)
	No	38/68 (55.9%)	10/15 (66.7%)	27/51 (52.9%)
	Don't know	3/68 (4.4%)	0 (0%)	3/51 (5.9%)
<b>If your answer to Q5 was yes, how useful do you think this form of monitoring is for diagnosing seizures</b>	Extremely unhelpful	1/24 (4.2%)	0 (0%)	1/18 (5.6%)
	Somewhat unhelpful	6/24 (25.0%)	0 (0%)	6/18 (33.3%)
	Neither helpful nor unhelpful	3/24 (12.5%)	1/5 (20.0%)	2/18 (11.0%)
	Somewhat helpful	10/24 (41.6%)	2/5 (40.0%)	7/18 (38.9%)
	Extremely helpful	3/24 (12.5%)	2/5 (40.0%)	1/18 (5.6%)
	Don't know	1/24 (4.2%)	0/5 (0%)	1/18 (5.6%)

<b>If your answer to Q5 was yes, how confident do you feel interpreting the monitor?</b>	Extremely under-confident	4/24 (16.7%)	0 (0%)	4/18 (22.2%)	
	Somewhat under-confident	9/24 (37.5%)	1 (20.0%)	8/18 (44.4%)	
	Neither confident nor under-confident	3/24 (12.5%)	0 (0%)	2/18 (11.1%)	
	Somewhat confident	5/24 (20.8%)	2 (40.0%)	3/18 (16.7%)	
	Extremely confident	2/24 (8.3%)	1 (20.0%)	1/18 (5.6%)	
	Don't know	1/24 (4.2%)	1 (20.0%)	0/18 (0%)	
<b>Please indicate how much you agree or disagree with the following statements</b>	Strongly disagree	0/64 (0%)	0/14 (0%)	0/48 (0%)	
	Disagree	1/64 (1.6%)	1/14 (7.1%)	0/48 (0%)	
	Slightly disagree	0/64 (0%)	0/14 (0%)	0/48 (0%)	
	Slightly agree	12/64 (18.7%)	4/14 (28.6%)	8/48 (16.7%)	
	Agree	27/64 (42.2%)	3/14 (21.4%)	23/48 (47.9%)	
	Strongly agree	18/64 (28.1%)	4/14 (28.6%)	13/48 (27.1%)	
	I don't know	6/64 (9.4%)	2/14 (14.3%)	4/48 (8.3%)	
	<b>b) Improved diagnosis of seizures and non-epileptic events would lead to reduced duration of PICU stay</b>	Strongly disagree	0/64 (0%)	0/14 (0%)	0/48 (0%)
		Disagree	2/64 (3.1%)	1/14 (7.1%)	1/48 (2.1%)
		Slightly disagree	1/64 (1.6%)	1/14 (7.1%)	0/48 (0%)
		Slightly agree	20/64 (31.2%)	4/14 (28.6%)	16/48 (33.3%)
		Agree	24/64 (37.5%)	4/14 (28.6%)	18/48 (37.5%)
		Strongly agree	14/64 (21.9%)	4/14 (28.6%)	10/48 (20.8%)
I don't know		3/64 (4.7%)	0/14 (0%)	3/48 (6.3%)	
<b>c) I would like to be able to diagnose seizures from non-epileptic events better in my patients on PICU</b>	Strongly disagree	2/62 (3.2%)	0/13 (0%)	2/48 (4.2%)	
	Disagree	1/62 (1.6%)	0/13 (0%)	1/48 (2.1%)	
	Slightly disagree	0/62 (0%)	0/13 (0%)	0/48 (0%)	
	Slightly agree	7/62 (11.3%)	2/13 (15.4%)	5/48 (10.4%)	
	Agree	25/62 (40.3%)	5/13 (38.5%)	19/48 (39.5%)	
	Strongly agree	27/62 (43.6%)	6/13 (46.1%)	21/48 (43.8%)	
	I don't know	0/62 (0%)	0/13 (0%)	0/48 (0%)	
<b>How easy is it to get full, standard EEG on your PICU</b>	Very difficult	4/57 (7.0%)	0/13 (0%)	4/45 (8.9%)	
	Difficult	8/57 (14.0%)	1/13 (7.7%)	7/45 (15.6%)	
	Slightly difficult	12/57 (21.1%)	2/13 (15.4%)	9/45 (20.0%)	
	Slightly easy	16/57 (28.1%)	2/13 (15.4%)	14/45 (31.1%)	
	Easy	17/57 (29.8%)	5/13 (38.4%)	11/45 (24.4%)	
	Very easy	0/57 (0%)	3/13 (23.1%)	0/45 (0%)	

\*ANP = Advanced Nurse Practitioners

**Table two:** Demographics of participants in qualitative interviews

<b>Participant Number</b>	<b>Demographics</b>
<b>1</b>	Staff Nurse (Female) from a PICU in a trauma, neurosurgical, metabolic, and spinal centre with 17 critical care beds (unit 1)
<b>2</b>	Advanced Nurse Practitioner (Male) from a PICU in a trauma, neurosurgical, metabolic, and spinal centre with 17 critical care beds (unit 1)
<b>3</b>	Trainee Advanced Nurse Practitioner (Female) from a PICU providing 38 general, neurosurgical and cardiac care beds (unit 2)
<b>4</b>	Advanced Nurse Practitioner (Male) from a PICU providing 19 general and cardiac beds with ECMO (unit 3)
<b>5</b>	Consultant Paediatric Intensivist (Female) from a PICU providing 16 general and cardiac beds (unit 4)
<b>6</b>	Consultant Paediatric Intensivist (Female) from a PICU in a trauma, neurosurgical, metabolic, and spinal centre with 17 critical care beds (unit 1)
<b>7</b>	A Paediatric Trainee (Female) on rotation covering a number of tertiary and district general hospitals (unit 5)
<b>8</b>	A Staff Nurse (Female) from a PICU covering 13 general critical care bed (unit 6)
<b>9</b>	A Staff Nurse (Female) from a PICU covering 13 general critical care bed (unit 6)
<b>10</b>	Advanced Nurse Practitioner (Male) from a PICU providing 18 general, cardiac, trauma and burns critical care beds (unit 7)
<b>11</b>	Consultant Paediatric Intensivist (Male) from a PICU providing 18 general, cardiac, trauma and burns critical care beds (unit 7)
<b>12</b>	Advanced Nurse Practitioner (Female) in a Critical Care Transport Team (unit 8)
<b>13</b>	Consultant Paediatric Neurologist (Female) who contributed to care in Critical Care (unit 9)
<b>14</b>	Advanced Nurse Practitioner (Male) from a PICU providing 13 general and cardiac critical care beds with ECMO (unit 10)
<b>15</b>	Senior Sister (Female) from a PICU providing 13 general and cardiac critical care beds with ECMO (unit 10)
<b>16</b>	Consultant Paediatric Intensivist (Male) from a PICU providing 13 general and cardiac critical care beds with ECMO (unit 10).

**Table three:** Illustrative quotations from qualitative interview

Theme	Quotation	Interviewee
<b>1: Feeling out of control when faced with ‘grey areas’</b>		
Difficulties with diagnosing epileptic seizures	<i>The more trained I am in it, the more skill and knowledge I have in it, in adverted commas, the less confident I feel ... When you're a shop floor ITU nurse you're taught this is a seizure, get your docs, treat the seizure... Yeah, very basic, very barn door, very 'this is what it is, crack on with it'. And I hold my hands up and say that is exactly what I did when I was an ITU nurse... [junior staff] may be confident because of a lack of in-depth knowledge about what they're looking at.</i>	2, Advanced Nurse Practitioner, Male
	<i>In some of the children who are sedated and muscle relaxed and very unwell... it's difficult to say if they are having sub-clinical [seizures] because you're covering up every ability the child has to clinically have features of seizures. And then I think, the other thing, you know, we know from the research and the evidence is that sub-clinical seizures on-going can be just as damaging as full seizures. So, it's definitely important to recognise them.</i>	3, Advanced Nurse Practitioner, Female
Seizures causing harm	<i>They are causing damage while we are completely unaware that they are occurring and, I mean I don't know what proportion it is, but there must be a large proportion of our patients that this will happen in because of the sedation and potential paralysis</i>	1, PICU Nurse, Female
	<i>If they are already having signs of raised ICP and seizures – they are going to raise their ICP further – and definitely we need to control that...</i>	16, Consultant Paediatric Intensivist
	<i>So, I mean it's a massive metabolic demand on the brain that is already injured. So, it could well cause further damage... a lot of oxygen being taken away.</i>	4, Advanced Nurse Practitioner, Male
<b>Theme 2: Regaining control</b>		
Aggressive intervention	<i>Treat first and then ask questions later.</i>	4, Advanced Nurse Practitioner, Male
	<i>We say 'if somebody is seizing we must stop the seizure'... the philosophy of critical care is aggressive treatment.</i>	2, Advanced Nurse Practitioner, Male
Accurate diagnosis: education / training	<i>I think the only thing that would potentially be more helpful is maybe more training, study days, something that, you know, gives us a bit more background and learning. It's not something that we have an awful lot of exposure to, so that would be helpful.</i>	15, Senior PICU Sister, Female



<p><i>Accurate diagnosis: team support for diagnosis</i></p>	<p><i>Some of our staff members are very experienced nurses. They have been there a while, they've seen different types of seizures, they can sometimes go 'that's a seizure' and other days they will be like 'what are they doing?'. So it is, you know, very individual on the child, as well as the members of staff. I find that junior nurses, because of a lack of experience, might mistake abnormal movements as seizure activity purely because, like I said, they haven't got the experience, you know, about infantile spasms or any other sort of abnormal movement disorders. So, they rely on us to be like 'come here, come here, what is that? Is this a seizure? Do I need to do something?'... So, it is very team based.</i></p>	<p>9, PICU Staff Nurse, Female</p>
<p><i>Accurate diagnosis: family as team members</i></p>	<p><i>It's more difficult when you don't have a description from a parent.</i></p>	<p>8, PICU Staff Nurse, Female</p>
<p><i>Accurate diagnosis: health passports</i></p>	<p><i>So around [our region], I don't know if other places do it, they do an 'all about me' passport for learning disability children that gives... that goes with the child to school, to care, to rest bite, to home, to hospital. That has all their information, what they like, what they don't like, including how their seizures look.</i></p>	<p>8, PICU Staff Nurse, Female</p>
<p><i>Accurate diagnosis: features increasing confidence that events are epileptic seizures</i></p>	<p><i>So, while they are sedated or paralysed, it's just your other parameters, so your heart rate, your blood pressure, looking at their pupils on a regular basis, looking out for any movements that might break through the sedation not necessarily the paralysis.</i></p>	<p>1, PICU Nurse, Female</p>
	<p><i>Gently holding the limb to see if it's rhythmic movement can help</i></p>	<p>9, PICU Staff Nurse, Female</p>
<p><i>Accurate diagnosis: EEG</i></p>	<p><i>We may do an EEG, it would be down to neurology whether or not they want to go down that route.</i></p>	<p>10, Advanced Nurse Practitioner, Male</p>
	<p><i>It has to be done by the neurophysiologists. That's only in daytime hours in the week, so there is no out of hours cover. Sometimes they are busy and they can't come and do it, although they will try if its urgent - most of the time they will do it. So, no, weekends you can't get it, yeah, it's a bit of a hole in the service, I think.</i></p>	<p>4, Advanced Nurse Practitioner, Male</p>
<p><i>Accurate diagnosis: neurophysiological monitoring</i></p>	<p><i>I think the thing that I feel about monitoring is we need some monitoring that we can stick on the patient of ITU people 24/7 but it is not so complicated that we can't interpret it.</i></p>	<p>2, Advanced Nurse Practitioner, Male</p>
	<p><i>We also have CSA, but I've never had any proper training on it, and to my knowledge, and again I could just not know what's going on, it's not really in common use in paediatric intensive care ... I think it's a flashy bit of monitoring that the machine will do but I'm not sure we know how to interpret it. The other thing we have used a bit of is BIS, but that isn't telling you whether you are dealing with a fit. It's telling you how inverted commas, well sedated the patient is, so all it does is say I'm quite asleep, I'm not asleep, if you see what I mean. So, that isn't really a useful monitor.</i></p>	<p>2, Advanced Nurse Practitioner, Male</p>

	<i>If there was a [aEEG] monitor there that could give us a bit more of an indication as to whether, you know, this is a seizure or not, that would make, I would say, a huge difference because you would feel less like it's a stab in the dark.</i>	7, Paediatric Specialist Trainee, Female
	<i>There would be a number of advantages because first of all you can target treatment to only seizures because otherwise children do get a lot of rescue medication on the presumption that they are having seizures when they might not be having seizures. And, obviously, all medications do have consequences and particularly if they get medications such as benzodiazepines that could have secondary consequences in terms of respiratory depression, which may or may not be an issue in intensive care, hypertension, sedation, difficulty weaning off the ventilation.</i>	13, Consultant Paediatric Neurologist, Female
	<i>I think there's always reluctance when you're not familiar with the bedside monitor and being reluctant to making your clinical decisions, so there's a steep learning curve and once it's embedded in practice.</i>	11, Consultant Paediatric Intensivist, Male
<i>Accurate diagnosis: future research</i>	<i>I think [research] would be useful because that would help us in the understanding in the frequency of these seizures and the outcome of the children, because then you can actually run a long-term study as to the reliability of the amplitude integrated EEG for clinical seizure interpretation and what the long-term outcome is, and look at the treatments as well.</i>	13, Consultant Paediatric Neurologist, Female
<i>Eschewing diagnosis</i>	<i>I'm not certain that it would be particularly helpful to diagnose such seizures because, if they are not clinically evident. The patient is not coming to any harm by them, so I question the need to treat them. A test is useful if you are going to do something with the results and, if you're not going to do something with the results, then it's not going to change anything you do, so you have to question the reasons for doing the test.</i>	6, Consultant Paediatric Intensivist, Female
	<i>I don't think it's feasible to have electrophysiological monitoring for all patients at risk for sub-clinical seizures because the vast majority, and I say the vast majority, we have a fairly high proportion of patients who have neurodisability and neurological diagnosis on our unit all the time, and I can't see us doing electrophysiological monitoring on all those patients who are at risk for seizures.</i>	11, Consultant Paediatric Intensivist, Male
	<i>I just think you know it's potentially another piece of equipment round the bed space that might not necessarily be necessary.</i>	15, Senior PICU Sister, Female

**FIGURE ONE:** Summary of results of thematic analysis from qualitative interview study