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Current practices in long-term video-EEG monitoring services: A survey among partners of the E-PILEPSY pilot network of reference for refractory epilepsy and epilepsy surgery☆

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ABSTRACT

Purpose: The European Union-funded E-PILEPSY network aims to improve awareness of, and accessibility to, epilepsy surgery across Europe. In this study we assessed current clinical practices in epilepsy monitoring units (EMUs) in the participating centers.
Method: A 60-item web-based survey was distributed to 25 centers (27 EMUs) of the E-PILEPSY network across 22 European countries. The questionnaire was designed to evaluate the characteristics of EMUs, including organizational aspects, admission, and observation of patients, procedures performed, safety issues, cost, and reimbursement.
Results: Complete responses were received from all (100%) EMUs surveyed. Continuous observation of patients was performed in 22 (81%) EMUs during regular working hours, and in 17 EMUs (63%) outside of regular working hours. Fifteen (56%) EMUs requested a signed informed consent before admission. All EMUs performed tapering/withdrawal of antiepileptic drugs, 14 (52%) prior to admission to an EMU. Specific protocols on antiepileptic drugs (AED) tapering were available in four (15%) EMUs. Standardized Operating Procedures (SOP) for the treatment of seizure clusters and status epilepticus were available in 16 (59%). Safety measures implemented by EMUs were: alarm seizure buttons in 21 (78%), restricted patient's ambulation in 19 (70%), guard rails in 16 (59%), and specially designated bathrooms in 7 (26%). Average costs for one inpatient day in EMU ranged between 100 and 2200 Euros.
Conclusion: This study shows a considerable diversity in the organization and practice patterns across European epilepsy monitoring units. The collected data may contribute to the development and implementation of evidence-based recommended practices in LTM services across Europe.

1. Introduction

Several studies over the past two decades have confirmed the essential role of long-term video-EEG monitoring in the evaluation of patients with epilepsy [1–5]. Clinical applications of LTM are divided into three main categories: (1) differential diagnosis between non-epileptic and epileptic seizures (2) classification and characterization of seizure types and epilepsy syndromes, and (3) presurgical evaluation of patients with medically refractory epilepsy [6].

It is often necessary to use methods that provoke seizures in order to achieve the principle goal of a LTM investigation. These methods may include tapering and/or withdrawal of antiepileptic drugs (AEDs), hyperventilation, sleep deprivation, and photic stimulation, alone or in combination. Although LTM is generally considered to be a safe procedure the seizure induction methods can pose a potential threat to patients' safety, and may result in serious adverse events. These can include seizure clusters and status epilepticus (SE), postictal psychosis, falls and physical injuries, complications associated with invasive electrodes and infrequently death [7–12].

Highly qualified personnel and adequate infrastructure/equipment may play a fundamental role in achieving safe and effective care of patients [6]. Furthermore, implementation of evidence-based practice and adherence to standardized protocols is the key to optimizing clinical decision making that may eventually lead to better patient outcome and care experience [8]. The American Clinical Neurophysiology Society (ACNS), the National Association of Epilepsy Centers (NAEC), and the International League Against Epilepsy (ILAE) released the guidelines and recommendations for LTM; however, these guidelines relate mainly to services provided, qualification of personnel, and technical and methodological considerations of video-EEG recording, while safety requirements for LTM are only sparsely addressed [6,13,14]. Furthermore, the most recent version of the "guideline for essential services, personnel, and facilities in specialized epilepsy centers" from NAEC is dated January 2010, while "Guideline Twelve: guidelines for long-term monitoring for epilepsy" provided by ACNS was last updated in 2008.

Recent studies conducted in the United States by the American Epilepsy Society (AES) and in Europe by the European Epilepsy Monitoring Units Association (EEMA) demonstrated variety in practice patterns among different centers and emphasized the lack of appropriate safety culture in EMUs [8,15].

In 2014, an EU-funded pilot network of reference centers E-PILEPSY [http://www.e-pilepsy.eu] was established with the primary aim to increase the number of European patients being cured from refractory epilepsy, through the enhancement of epilepsy surgery in Europe. Under this view, the main task of the E-PILEPSY is to reduce existing major inequalities in all aspects related to epilepsy surgery and to harmonize and optimize presurgical diagnostic procedures across European countries.

In order to provide insights into the current variability in practices across European monitoring units, we conducted the survey among the reference centers of the network.

2. Methods

2.1. Sample and procedure

The survey was approved by the E-PILEPSY network board. It was conducted electronically: the 25 participating centers across 22 European countries were provided access to a web-page where the survey could be filled in electronically. A unique survey link has been created for each participant to ensure a single answer from a single respondent. Data were collected between August 2014 and January 2015. The investigator was available for questions and sent reminders.

2.2. Survey instrument

The questionnaire consisted of 60 items; all questions contained multiple choice components and covered the areas as follows: EMU characteristics (8 questions), personnel, qualifications, and responsibilities [5], admission to EMU [3], technical equipment [3], procedures undertaken in EMU [11], tapering/withdrawal of AEDs [15], safety issues and prevention of adverse events [11], and reimbursement [4] (see supplementary material).

3. Results

Complete responses were received from all 25 reference centers surveyed. Of these 25 centers, 23 included one EMU. Two reference centers each had two separate EMUs, one dedicated to pediatric patients and one to adult patients. Therefore, there were 27 EMUs included in the present study. The results for the survey are summarized in Tables 1–6.

3.1. General characteristics

Of the 27 (100%) EMUs, 17 (63%) evaluated both pediatric and adult patients, 6 (22%) only adults and 4 (15%) only pediatric patients. Twenty-seven (100%) EMUs admitted patients for presurgical evaluation of epilepsy, 26 (96%) for differential diagnosis, and 25 (93%) for classification of seizure types and epilepsy syndromes. Admission for seizure quantification and treatment modification were reported by 16 (59%) and 10 (37%) EMUs, respectively.

EMUs had between 1 and 11 beds, with the following distribution: 1–2 beds in 10 (37%) EMUs, 3–5 beds in 15 (56%), and 10–11 beds in 2 (7%). The large majority, i.e., 21 (78%) EMUs, conducted both invasive and non-invasive video-EEG investigations, while the remaining 6 (22%) only performed non-invasive investigations. The minimum number of hospital days for invasive recordings ranged between 2 and 7 days and the maximum number between 5 and 21 days. EMU characteristics are presented in Table 1.

3.2. Personnel, qualifications, and responsibilities

Professional qualifications of the staff involved in EMUs were variable, including senior and resident neurologists for pediatric and adult patients, neurophysiologists, biomedical engineers, EEG technicians, and nurses. Data are shown in Table 2.

Continuous observation of patients was performed in 22 (81%) EMUs during regular working hours and in 17 EMUs (63%) outside of regular working hours. Observation was mainly conducted by EEG technicians and nurses. During regular working hours neurologists were involved in continuous observation in 3 EMUs and in intermittent observation in 9 EMUs. Eight (30%) EMUs asked patient's relatives to observe patients' behavior. In 1 (pediatric EMU) out of 22 EMUs continuous observation of pediatric patients was conducted by their parents, while EMU staff was only involved in intermittent observation of the patients. Table 3 summarizes the details on the modality of patient's observation in EMU.

3.3. Admission to the EMU

Respondents were asked whether they use a questionnaire/standardized form on patients' admission to an EMU. The majority of EMUs, i.e., 19 (70%) performed an interview on admission through standardized questionnaires including issues on epilepsy characteristics, history of previous injuries or SE, and comorbidities. Two EMUs reported that similar information was obtained from the patient's history collected by an epileptologist (neurologist or neuropediatrician).

Fifteen (56%) of the 27 EMUs requested signed informed consent from patients or their caregivers before admission. In the twelve (44%) remaining EMUs physicians provided either information leaflet alone (one EMU), or verbal instructions alone (6 EMU), or verbal instructions were supported by information leaflets (4 EMUs); one EMU obtained informed consent only for the use of patients' video-recordings for educational purposes. Results are presented in Table 4.

Table 1
Epilepsy Monitoring Unit (EMU) characteristics.

Mean duration of activity of the EMUs	19 years (range 1–45 years)	
The total number of patients admitted per year[a]	5290	
The total number of admissions per year	5877	
	No. (%) of EMUs;(n = 27)	
	Yes	No
Age distribution of patients		
Adult patients (aged 18 years and above)	23 (85)	4 (15)
Only adult patients	6 (22)	21 (78)
Pediatric patients (aged 0–18 years)	21 (78)	6 (22)
Neonates (aged 0–28 days)	5 (19)	22 (81)
Infants (aged 28 days to 1 year)	14 (52)	13 (48)
Children and adolescents (aged 1–18 years)	21 (78)	6 (22)
Only pediatric patients	4 (15)	23 (85)
Both	17 (63)	10 (37)
Average duration of non-invasive monitoring		
24 h or less	1 (4)	26 (96)
≥1–3 days	4 (15)	23 (85)
≥3–7 days	17 (63)	10 (37)
≥1 week	5 (19)	22 (81)
Average duration of invasive monitoring		
Invasive monitoring not performed	6 (22)	21(78)
24 h or less	0 (0)	27 (100)
≥1–3 days	0 (0)	27 (100)
≥3–7 days	9 (33)	18 (67)
1–2 weeks	10 (37)	17 (63)
≥2 week	2 (7)	25 (93)
Access to intensive therapy units		
Intermediate care unit alone	7 (26)	20 (74)
Intensive care unit alone	2 (7)	25 (93)
Both	16 (59)	11 (41)
None	2 (7)	25 (93)

EMU: epilepsy monitoring unit.
[a] Data is provided for the period of 2013–2014, including all-cause EMU admissions, n = 27.

Table 2
Epilepsy monitoring unit personnel.

EMU staff	No. (%) ofEMUs (*n* = 27)	No. (%) of EMUs (*n* = 27)	Min–Max number of personnel
Fully trained neurologist(s)[a]	**Yes**	**No**	0–7
	22 (81)	5 (19)	
Neurologist(s) in training[b]	21 (78)	6 (22)	0–4
Fully trained pediatric neurologist(s)[a]	17 (63)	10 (37)	0–3
Pediatric neurologist(s) in training[b]	10 (37)	17 (63)	0–5
Neurophysiologist(s)	12 (44)	15 (56)	0–6
Biomedical engineer(s)	10 (37)	17 (63)	0–3
EEG technician(s)	24 (89)	3 (11)	0–21
Nurse(s)	21 (78)	6 (22)	0–22
additionally trained as technicians	1 (4)	26 (96)	n/a
PhD student(s)	1 (4)	26 (96)	n/a
Medical students trained for monitoring purposes	4 (15)	23 (85)	0–25
Non-medical students trained in epileptology	2 (7)	25 (93)	0–1
Non-medical students trained for monitoring purposes	1 (4)	26 (96)	n/a
Medical students not trained	2 (7)	25 (93)	0–3
Psychiatrist on call	21 (78)	6 (22)	n/a
Neurosurgeon on call	22 (81)	5 (19)	n/a
Anesthesiologist on call	21 (78)	6 (22)	n/a
Non-physicians involved in preliminary screening of VEEG data			
Biomedical engineers	1 (4)	26 (96)	n/a
EEG technicians	12 (44)	15 (56)	n/a
Nurses	4 (15)	23 (85)	n/a
Students	1 (4)	26 (96)	n/a

EMU: epilepsy monitoring unit, n/a: not applicable, VEEG: video-EEG monitoring.
[a] Consultant/attending physician/senior physician, etc.
[b] Registrar, resident, etc.

Table 3
Modality of patients' observation in epilepsy monitoring unit.

	Regular working hours		Outside regular working hours	
	Continuous[a]	Intermittent[b]	Continuous[a]	Intermittent[b]
	No. (%) of EMUs (*n* = 27)	No. (%) of EMUs (*n* = 27)	No. (%) of EMUs (*n* = 27)	No. (%) of EMUs (*n* = 27)
	22 (81)	**5 (19)**	**17 (63)**	**10 (37)**
EMU personnel involved in patients' observation[c]				
Neurologists				
Fully trained neurologist(s)	3 (11)	5 (19)	1 (4)	2 (7)
Neurologist(s) in training	2 (7)	3 (11)	1 (4)	3 (11)
Fully trained pediatric neurologist(s)	2 (7)	2 (7)	1 (4)	0 (0)
Pediatric neurologist(s) in training	1 (4)	3 (11)	1 (4)	1 (4)
Neurophysiologist(s)	1 (4)	5 (19)	0 (0)	1 (4)
Biomedical engineer(s)	0 (0)	2 (7)	0 (0)	0 (0)
EEG technician(s)	15 (56)	5 (19)	4 (15)	2 (7)
Nurse(s)	13 (48)	4 (15)	10 (37)	5 (19)
Medical students trained for monitoring purposes	0 (0)	0 (0)	3 (11)	0 (0)
Non-medical students trained for monitoring purposes	0 (0)	0 (0)	1 (4)	0 (0)
Patients' relatives	7 (26)	1 (4)	6 (22)	2 (7)

EMU: epilepsy monitoring unit.
The patients' observation in EMU were performed by EMU personnel. However, in some EMUs patients' relatives were also involved. In order to discriminate between personnel and non-personnel the corresponding subheadings are highlighted in bold type.
[a] Indicates EMUs where patients are observed continuously by EMU personnel and/or patients' relatives.
[b] Indicates EMUs where continuous observation of patients is not performed.
[c] Includes direct observation of the video/EEG/patient.

3.4. Technical equipment

Respondents were asked which EEG system they use for long-term video-EEG recordings.

Four different EEG systems were employed, by 11 (41%), 11 (41%), 6 (22%), and 2 (7%) EMUs, respectively. Furthermore, two centers (7%) reported that they use in-house developed software.

The proportion of EMUs using various different types of electrodes for invasive EEG recordings was the following: of 21 EMUs performing invasive video-EEG monitoring 19 (90%) EMUs used depth electrodes; strip and grid electrodes were employed by 16 (76%) and 14 (67%) EMUs, respectively; combination of depth and grid electrodes were shown in 14 (67%); less commonly used electrode types were sphenoidal and foramen ovale electrodes, reported by 5 (24%) and 3 (14%) EMUs, respectively. Of these 21 EMUs, only 2 applied all types of invasive electrodes and another 2 were using depths electrodes exclusively.

Automatic seizure and spike detection software was implemented in 5 (19%) out of 27 EMUs.

3.5. Procedures

Seventeen (63%) EMUs performed ictal single photon emission computed tomography (SPECT) as part of the presurgical work-up. The remaining centers reported lack of access to this resource. Of 17 centers performing SPECT 15 (88%) used manual injection of tracer, performed by a physician or an EEG-technician. The remaining two (12%) EMUs used a remotely operated injector pump.

Table 4
Admission to epilepsy monitoring unit.

	No. (%) of EMUs ($n=27$)	No. (%) of EMUs ($n=27$)
	Yes	No
Questionnaire/standardized form used on admission	19 (70)	8 (30)
Neurological examination	25 (93)	2 (7)
Psychiatric examination	16 (59)	11(41)
By non-psychiatrist	13 (48)	14 (52)
By psychiatrist	4 (15)	23 (85)
By both	1 (4)	26 (96)
12-lead ECG	13 (48)	14 (52)
None	2 (7)	25 (93)
A written informed consent[a]	15 (56)	12 (44)
Written consent alone	9 (33)	18 (67)
An information leaflet/form[b]	9 (33)	18 (67)
Leaflet alone	1 (4)	26 (96)
Verbal information and instruction	15 (56)	12 (44)
Verbal information and instructions alone	6 (22)	21 (78)
None	1 (4)	26 (96)

EMU: epilepsy monitoring unit. ECG: electrocardiography.
[a] With signature of a patient and an informing physician.
[b] Without signature of a patient and an informing physician.

3.6. Safety issues and prevention of seizure-related adverse events

All EMUs reported that they use different seizure provocative methods in order to increase the diagnostic yield of video-EEG monitoring. More than half (56%) of EMUs reduced or completely discontinued one or more antiepileptic drugs (AEDs) in 75–100% of patients. Most common factors influencing the strategy of AEDs tapering/withdrawal were seizure frequency, history of SE and seizure clusters, seizures' type and severity, and presurgical evaluation. Fourteen (52%) of 27 EMUs performed tapering/withdrawal of AEDs before admission. Three of these EMUs prescribed tapering/withdrawal of AEDs at home, 6 in hospital setting and in 5, individually based decisions were made. Specific protocols of AEDs tapering/withdrawal were only available in 4 (15%) EMUs. Seventeen EMUs (63%) reported that they performed therapeutic drug monitoring within EMU settings: one (4%) performed it daily, 6 (22%) more than once during hospital stay, 5 (19%) only once, 2 (7%) rarely, 3 (11%) on an individual bases and 10 (37%) never. Data are summarized in Table 5.

Oxygen saturation was monitored in 12 (44%) EMUs, and peri-ictal respiratory rate in 7 (26%). In contrast, monitoring of heart rate was performed in almost all EMUs ($n = 26$, 96%). Standardized Operating Procedures for the treatment of seizure clusters and SE were available in 16 (59%) EMUs, while emergency resuscitation equipment was in place in only 11 (41%). Prevention of venous thrombosis was performed by 7 (26%) EMUs. Three of them prescribed compression stockings, while subcutaneous low molecular weight heparin was administered by all seven.

In order to prevent seizure-related adverse events, the following safety measures were implemented: seizure alarm buttons were available in 21 (78%) EMUs, 19 (70%) had restricted patients' ambulation and 9 (33%) allowed only accompanied

Table 5
Seizure provocative methods used in EMU.

	No. (%) of EMUs ($n=27$) Yes	No. (%) of EMUs ($n=27$) No
Tapering/withdrawal of AEDs	27(100)	0(0)
Up to 25% of cases	3 (11)	24 (89)
More than 25–50% of cases	5 (19)	22 (81)
More than 50–75% of cases	4 (15)	23 (85)
More than 75% to <100%	15 (56)	12 (44)
In all patients	0 (0)	27 (100)
Tapering/withdrawal of AEDs prior to admission to an EMU	14 (52)	13 (48)
Up to 25% of cases	8 (30)	19 (70)
More than 25–50% of cases	2 (7)	25 (93)
More than 50–75% of cases	3 (11)	24 (89)
More than 75% to <100%	1(4)	26 (96)
In all patients	0 (0)	27 (100)
Setting		
At home in all patients	3 (11)	24 (89)
In hospital in all patients	6 (22)	21 (78)
Decision based on individual case	5 (19)	22 (81)
Hyperventilation	25 (93)	2 (7)
Photic stimulation	21 (78)	6 (22)
Sleep deprivation	24 (89)	3 (11)
Physical exercise	4 (15)	23 (85)
Seizure triggering factors	3 (11)	24 (89)
For differential diagnosis of non-epileptic seizures		
Verbal suggestion	19 (70)	8 (30)
Administration of placebo[a]	8 (30)	19 (70)
Other methods[b]	7 (26)	20 (74)

EMU: epilepsy monitoring unit.
[a] Aministration of intravenous saline test, etc.
[b] Other methods include: administration of cold water to the skin of neck area superficially (1 EMU); any provocative method reported by the patient (1 EMU); hyperventilation and sleep deprivation (4 EMUs); placebo, not administered intravenously.

Table 6
Cost and reimbursement methods for long-term video-EEG monitoring service.

	No. (%) of EMUs; ($n=27$)
Average cost for inpatient day	
100–500 Euros	7 (26)
500–1000	6 (22)
1000–2200	8 (30)
No data available	6 (22)
Coverage/Reimbursement	
By National Health System/National Health Service	
Covered	12 (44)
Fully	
Partly	5 (19)
Not covered	6 (22)
Other[a]	1 (4)
Reimbursed	
Fully	0 (0)
Partly	4 (15)
Not reimbursed	20 (74)
By private insurance company/companies	
Reimbursed	
Fully	3 (11)
Partly	7 (26)
Not reimbursed	14 (52)
None	2 (7)
No data available	1 (4)
Procedures covered/reimbursed	
By National Health System/National Health Service	
Non-invasive VEEG	21 (78)
Invasive VEEG	17 (63)
Ictal SPECT	14 (52)
Cortical stimulation	13 (48)
By private insurance companies	
Non-invasive VEEG	11 (41)
Invasive VEEG	11 (41)
Ictal SPECT	9 (33)
Cortical stimulation	5 (19)

EMU: epilepsy monitoring unit, VEEG: video-EEG monitoring.
[a] National health system only refers to those patients that are considered difficult to treat, insurance only pays 30% of the bill (1 EMU); covered by insurance companies as a part of the total hospital budget, no direct payment/reimbursement (2 EMUs).

standing-up and walking during invasive recordings. Guardrails were used in 16 (59%) EMUs. Specially designated bathrooms were only available in 7 (26%), out-swing design for doors in 6 (22%), padded toilet seats in 3 (11%), and shower seats in 6 (22%). Higher nurse-to-patient ratio in EMUs compared to hospital ward was reported by greater than half, i.e., 15 (56%) EMUs.

Participants were asked whether they systematically assessed adverse events occurring in the EMU. Six (22%) EMUs reported that they collected data retrospectively, 4 (15%) did this prospectively, and in another 4 (15%), data were collected according to both methods. In remaining 13 (48%) EMUs adverse events were not systematically assessed and recorded. The data on various types of adverse events occurring in EMUs were provided only by 8 respondents, other EMUs did not give answer to this question. The following adverse events were observed: injuries, post-ictal psychosis, mood disorders, generalized convulsion, bleeding, and infection due to invasive recordings.

3.7. Cost and reimbursement

Twenty-one (78%) EMUs provided information on costs associated with LTM service and the principles of repayment within their healthcare reimbursement system. Six EMUs (representing 4 countries) were unable to report exact costs associated with the procedure. However, two of these EMUs (representing a single country) reported that the costs for hospital stays are covered by insurance companies as part of the total hospital budget, and there is no direct payment and/or reimbursement. Another two EMUs (representing a single country) reported that the healthcare system is completely public in their country.

The average cost for inpatient day ranged between 100 and 500 Euros in 26%, 500 and 1000 Euros in 22%, 1000 and 2200 Euros in 30%. The majority of EMUs (63%) reported that the costs associated with LTM, including additional procedures required for invasive recordings were covered by national health system. Reimbursement by private insurances companies were reported by 41% of respondents. Details are presented in Table 6.

4. Discussion

The findings from our survey revealed great heterogeneity in current practice among European EMUs. Some practices discussed below may pose a substantial risk to patients' safety and therefore demand reconsideration.

The level of observation throughout 24-h monitoring period varied considerably between EMUs. Of 27 EMUs, including 6 performing only non-invasive monitoring and 21 both, invasive and non-invasive monitoring, 10 (37%) were unable to provide continuous 24-h observation. Off those 21 EMUs which were performing invasive monitoring in 5 (24%) patients' observation was only intermittent. Furthermore, 67% of these EMUs used subdural grids and 90% depths electrodes. Our findings differ from those reported in two previous surveys conducted by AES and EEMA, with 26% of EMUs in the United States and 20% in Europe not having continuous observation. This can be explained in part by different representation of centers/countries in these studies, as well as possible differences in the definitions used for "continuous observation".

The reduced level of observation, especially during invasive presurgical evaluation may impose a substantial risk of severe adverse events to the patients. In a survey conducted by American Epilepsy Society (AES), 22 of 58 respondents (37.9%) reported that patients pulled out or dislodged intracranial electrodes [9]. Recent studies also reported significant morbidity, such as subdural hemorrhage and brain edema associated with intracranial EEG monitoring and found the highest risk of complications when subdural grid electrodes were used [10,11]. Wong et al., reported that 2 (2.8%) of the 72 patients undergoing invasive monitoring with grid electrodes died [16]. One of these patients was found unresponsive, with no clinical seizures witnessed. However, EEG revealed a seizure 2 h prior to death [16]. These studies highlight the importance of adequate supervision provided by dedicated staff especially in patients with implanted intracranial electrodes.

Significant diversity was also shown in terms of qualification and number of personnel involved in patients monitoring. While observation was mainly conducted by EEG technicians and nurses, some centers also employed students outside of regular working hours for monitoring purposes. Furthermore, qualification of personnel involved in observation throughout the day considerably varied across each EMU. This issue has been addressed in a study by Kandler et al., where authors recommended 24 h surveillance by healthcare professionals with similar staffing throughout the monitoring period. Moreover, optimum nurse-to-patient ratio not less than 1:4 was suggested as appropriate [17]. Within our survey the higher nurse-to-patient ratio compared to hospital ward was observed in more than half EMUs.

Seizures in EMU can lead to cardio-respiratory arrest and death [12]. Bateman et al. showed that oxygen desaturation below 90% was observed in about one-third of seizures, and below 80% in about 10% [18]. Although these studies clearly show the importance of monitoring vital signs in EMU, our survey revealed that continuous observation of oxygen saturation and respiratory rate was performed in less than 40% of monitoring units and only in case of life-threatening conditions, such as seizure clusters and SE. Furthermore, availability of life supporting (resuscitative) equipment and access to intensive care units was missing in 41% of EMUs.

A recent study among the participating centers of the E-PILEPSY consortium by Mouthaan et al. showed that ictal SPECT is used by majority of centers both in adult and pediatric patients. Main indications reported for performing SPECT were negative MRI and/or discordant results on presurgical evaluation [19]. However, some centers do not employ SPECT. Our study showed the main reason for not performing SPECT was unavailability of radionuclide tracer in five EMUs, and lack of a SPECT gamma camera in three. Furthermore, two centers did not consider SPECT a helpful diagnostic tool for delineating the seizure onset zone.

Although more than half of EMUs perform tapering/withdrawal of AEDs in 75–100% of patients, specific protocols were available only in four. Our results are consistent with previous studies [7,20,21] in which centers do not use standardized protocols and taper/withdraw medication on experience based decisions.

Despite the high level of risk associated with medication withdrawal in a non-hospital setting, our survey shows that three of the EMUs instruct patients to withdraw medication at home in all patients in order to have a higher diagnostic yield in a shorter duration in the EMU.

Although SE is considered one of the most frequent adverse events in EMU, SOPs required for the management of this condition was available in only 14 (52%) EMUs.

Patients with psychiatric comorbidities have a 16-fold increased risk of developing adverse events [7]. Psychiatric complications in patients with pre-existing comorbidities may require admission to psychiatric department or the management of the condition within EMU setting.

Only two (7%) EMUs had developed a specific protocol for the management of post-ictal psychosis and suicidality, while SOPs for the management of panic attacks were only available in one (4%) EMU.

Although LTM is considered a time consuming and relatively expensive investigation, there are few, if any, studies evaluating its

cost-effectiveness. Results of our survey showed a huge difference in costs related to LTM in EMUs across Europe. This may be, in part, attributed to heterogeneity of healthcare system and differences in resource utilization and costs across different countries. The reasons behind this disparity need further exploration.

Taking into account the considerable resources needed for inpatient video-EEG monitoring, the benefits of innovative approaches such as home video-telemetry in a selected group of patients can be significant. Studies show that the home-telemetry can be both safe and feasible [22,23]. Furthermore, chances of successfully recorded seizure attacks may be increased while patients are evaluated in their home environment, avoiding a huge stress factor associated with hospital stay [24]. However, home-telemetry has several limitations and the implementation of this technique remains a challenge. Further research is needed to fully explore the pros and cons of this innovative approach.

5. Conclusion

Our survey demonstrated considerable diversity in current organization and practice across European epilepsy monitoring units. We aimed to gain a deeper insight into variability of practice among EMUs and identify the areas where harmonization and improvement is needed. Moreover, the survey covers some issues that have not been previously addressed in other studies and thus complements the previous research in this domain which was more focused on safety issues. Further, our research will be supported by systematic reviews being undertaken within the E-PILEPSY consortium.

Several important aspects that will later help to define guidelines and can be potentially addressed by E-PILEPSY were identified. Continuous monitoring by highly qualified staff throughout a 24-h period is crucial to perform EMU activities safely and effectively. When conducting invasive monitoring with intracranial electrodes, this issue gains even more importance. However, this is not always achieved due to financial restrictions that some centers experience. This further raises the issue of cost-effective utilization of LTM. Obtaining signed informed consent on admission, along with providing all relevant information including possibility of SUDEP and SE has to be addressed. To manage life threatening adverse events in a timely and effective manner, availability of a well trained staff, continuous monitoring of vital signs, and a proximity to intensive care unit are deemed necessary. Furthermore, standardized protocols for management of SE, seizure clusters, and postictal psychosis that could significantly improve patients' outcome should be in place.

Adequate EMU infrastructure in terms of preventing seizure related adverse events is pivotal. Future research is necessary to identify factors that can both enable and hinder improvement of safety.

We believe that the collected data will provide valuable insight into the aforementioned issues. In conjunction with the systematic literature reviews conducted by the consortium and the opinion of expert panels, our study will contribute to the development and implementation of evidence-based practice in EMUs across Europe.

Conflict of interest statement

All authors have read and approved the manuscript and take responsibility for its content.

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Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at http://dx.doi.org/10.1016/j.seizure.2016.03.009.

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