



A European survey on current practices in epilepsy monitoring units and implications for patients' safety



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ABSTRACT

Objective: This study aimed to survey current practices in European epilepsy monitoring units (EMUs) with emphasis on safety issues.

Methods: A 37-item questionnaire investigating characteristics and organization of EMUs, including measures for prevention and management of seizure-related serious adverse events (SAEs), was distributed to all identified European EMUs plus one located in Israel (N = 150).

Results: Forty-eight (32%) EMUs, located in 18 countries, completed the questionnaire. Epilepsy monitoring unit beds are 1–2 in 43%, 3–4 in 34%, and 5–6 in 19% of EMUs; staff physicians are 1–2 in 32%, 3–4 in 34%, and 5–6 in 19% of EMUs. Personnel operating in EMUs include epileptologists (in 69% of EMUs), clinical neurophysiologists trained in epilepsy (in 46% of EMUs), child neurologists (in 35% of EMUs), neurology and clinical neurophysiology residents (in 46% and in 8% of EMUs, respectively), and neurologists not trained in epilepsy (in 27% of EMUs). In 20% of EMUs, patients' observation is only intermittent or during the daytime and primarily carried out by neurophysiology technicians and/or nurses (in 71% of EMUs) or by patients' relatives (in 40% of EMUs). Automatic detection systems for seizures are used in 15%, for body movements in 8%, for oxygen desaturation in 33%, and for ECG abnormalities in 17% of EMUs. Protocols for management of acute seizures are lacking in 27%, of status epilepticus in 21%, and of postictal psychoses in 87% of EMUs. Injury prevention consists of bed protections in 96% of EMUs, whereas antisuffocation pillows are employed in 21%, and environmental protections in monitoring rooms and in bathrooms are implemented in 38% and in 25% of EMUs, respectively. The most common SAEs were status epilepticus reported by 79%, injuries by 73%, and postictal psychoses by 67% of EMUs.

Conclusions: All EMUs have faced different types of SAEs. Wide variation in practice patterns and lack of protocols and of precautions to ensure patients' safety might promote the occurrence and severity of SAEs. Our findings highlight the need for standardized and shared protocols for an effective and safe management of patients in EMUs.

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1. Introduction

Long-term video-electroencephalography monitoring (LTM) in epilepsy monitoring units (EMUs) is an essential investigation for diagnosis of recurrent spells, classification of epileptic seizures, and presurgical evaluation of patients with intractable localization-related epilepsy [1,2]. Since the optimal yield is to obtain the maximal amount of information by recording seizures while minimizing the stay in the hospital, provocative procedures to elicit seizures, such as tapering of antiepileptic drugs, sleep deprivation, and hyperventilation, are commonly used. However, this practice may expose patients to potentially serious adverse events (SAEs) that have recently caught attention and raised concerns about patients' safety in EMUs [3–14]. The International League Against Epilepsy [1], the American Clinical Neurophysiological Society [15], and the National Association of Epilepsy Centers [16] have issued guidelines and recommendations regarding the clinical indications and the requirements for LTM in EMUs, which only marginally dealt with safety issues. Indeed, although EMUs have been operating for more than two decades and are increasing in number worldwide, there is no regulation at present on how to ensure patients' safety in EMUs [17].

The European Epilepsy Monitoring Unit Association (EEMA) was created to share the knowledge of the appropriate utilization of EMUs and to promote optimal quality of care in the best interest of the patients. In this framework, the task force on “Safety in EMU” of the EEMA has explored the current situation in Europe by submitting a survey to European EMUs with the aim to collect information on current practices, with a particular focus on safety issues. In this paper, we report the results of this survey.

2. Methods

The survey was designed by the “Safety in EMU” task force of EEMA (GR, SB, MPC, SC, HS, PK, WEB, and DV). Final approval of the survey was obtained after discussions among all members of the task force and the board of EEMA (AGN, BS, ET, GR, and PR). The survey used a 37-item questionnaire with multiple choice answers (see Supplementary material) and was sent via e-mail to the physicians of 150 EMUs identified in Europe and Israel according to a previously described procedure [18]. The survey was launched on October 15, 2012 and concluded on December 15, 2012. To avoid that more than one person from the

Table 1
General characteristics of EMU.

	Total N (%) of responders						
In your EMU you monitor: N (%) of responders	48 (100)	Adults 6 (13)	Children 6 (13)	Both 36 (74)			
How many physicians staff the EMU in your center?	47 (98)	1–2 15 (32)	3–4 16 (34)	5–6 9 (19)	>6 7 (15)		
What is their level of medical training?	48 (100)	Neurology residents 22 (46)	Neurophysiology residents 4 (8)	Neurologists not trained in epilepsy 13 (27)	Child neurologists 17 (35)	Neurologists trained in epilepsy 33 (69)	Neurophysiologists trained in epilepsy 22 (46)
How many EMU beds operate simultaneously?	47 (98)	1–2 20 (43)	3–4 16 (34)	5–6 9 (19)	>6 2 (4)		
Please indicate the average number of admissions in your EMU.	47 (98)	<50/year 8 (17)	50–150/year 17 (36)	150–250/year 13 (28)	>250/year 9 (19)		
Are intracranial recordings performed at your center?	48 (100)	Yes 37 (77)	No 11 (23)				
What are the types of invasive studies?	37 (77)	Foramen ovale electrodes 6 (16%)	Epidural electrodes 1 (3%)	Subdural electrodes 29 (78%)	Depth electrodes 27 (73%)		
Do you have any standardized form for preadmission screening that considers seizure frequency, seizure types, episodes of seizure clusters or status epilepticus, previous injuries, and psychiatric disturbances?	48 (100)	Yes 27 (56)	No 21 (44)				
Do you have any preliminary assessment of possible comorbidities (for instance, osteoporosis and cardiorespiratory compromise) that may render seizure provocation potentially harmful?	48 (100)	Yes 31 (65)	No 17 (35)				
Do you require a signed informed consent form prior to the video-EEG monitoring procedure?	48 (100)	Yes 40 (83)	No 8 (17)				
Do you have a standardized protocol to ensure patient safety after being discharged from the EMU?	48 (100)	Yes 42 (88)	No 6 (12)				
If yes to the previous question, which protocol do you use?	48 (100)	In-hospital stay for AED reintroduction 36 (75%)	Protocol for contacting on-call physicians (after discharge from the hospital) 20 (42%)	Others 3 (6%)			

The numbers in the columns indicate the number and the percentage (in italics within parentheses) of centers that responded.

Table 2
Intensity and level of observation.

	Total N (%) of responders				
Observation in EMU is:	48 (100)	Continuous	Intermittent	Daytime	
		38 (80)	5 (10)	5 (10)	
Patient observation in EMU is performed by:	48 (100)	Physicians	Neurophysiology technicians	Nurses	Relatives
		13 (27)	34 (71)	34 (71)	19 (40)
Is any diagnostic testing performed on the patient at seizure onset in the ictal and postictal phases?	46 (96)	Yes	No		
		42 (91)	4 (9)		
Do you use automatic systems for detection of ECG abnormalities and for alarming purposes?	48 (100)	Yes	No		
		8 (17)	40 (83)		
Do you use any system for oxygen desaturation detection and for alarming purposes?	48 (100)	Yes	No		
		16 (33)	32 (67)		
Do you use seizure detection systems based on detecting movement while the patient lies in bed?	48 (100)	Yes	No		
		4 (8)	44 (92)		
Do you use any online automated seizure detection system?	47 (98)	Yes	No		
		7 (15)	40 (85)		

The numbers in the columns indicate the number and the percentage (in italics within parentheses) of centers that responded.

same epilepsy center answered, the responses were not anonymous. The questionnaire was designed to identify general characteristics of EMUs; current practices during admission; and measures for prevention and management of clusters of seizures and status epilepticus and for prevention of injuries, psychiatric complications, and other seizure-related complications.

3. Results

Forty-eight (32%) out of 150 EMUs, from 18 European countries and Israel, responded. Results of each item of the questionnaire are reported in Tables 1–6.

3.1. General characteristics of EMUs (Table 1)

Thirty-six (74%) EMUs monitored both adults and children, 6 (13%) monitored only children, and 6 (13%) monitored only adults. Thirty-seven (77%) EMUs performed both invasive and noninvasive recordings, while the remaining performed only noninvasive recordings. The number of beds simultaneously operating in EMUs was 1–2

in 20 (43%), 3–4 in 16 (34%), and 5–6 in 9 (19%) EMUs; 2 (4%) EMUs were equipped with more than 6 beds. The number of staff physicians in EMUs ranged from 1 to more than 6, with 15 (32%) centers having 1–2 physicians, 16 (34%) centers having 3–4, 9 (19%) centers having 5–6, and 7 (15%) centers having more than 6. The level of training of the physicians working in EMUs was variable, including neurologists and clinical neurophysiologists trained in epilepsy (in 69% and in 46% of EMUs, respectively) as well as child neurologists (35% of EMUs), neurology and clinical neurophysiology residents (in 46% and in 8% of EMUs, respectively), and senior neurologists without epilepsy training (27% of EMUs). Signed informed consent prior to admission was requested in 40 (83%) EMUs, whereas a pre-admission screening investigating either epilepsy features (seizure types and frequency and previous status epilepticus), possible comorbidities, or both was performed in 27 (56%) and in 31 (65%) of EMUs, respectively. Forty-two (88%) EMUs had standardized procedures to ensure patients' safety after discharge from LTM, consisting of in-hospital stay for AED reintroduction in 36 (75%) EMUs and/or protocols for contacting on-call physicians after discharge from the hospital in 20 (42%) EMUs.

Table 3
Management of status epilepticus and clusters of seizures.

	Total N (%) of responders				
Do you have any written protocol for acute seizure management?	48 (100)	Yes	No		
		35 (73)	13 (27)		
Do you have any written protocol for management of status epilepticus?	48 (100)	Yes	No		
		38 (79)	10 (21)		
Do you introduce an IV line drip or a heparin lock when monitoring noninvasively?	47 (98)	In all patients	In most patients	Occasionally	Never
		6 (13)	15 (32)	16 (34)	10 (27)
Do you introduce an IV line drip or a heparin lock when monitoring invasively?	36 (97)	In all patients	In most patients	Occasionally	Never
		22 (61)	4 (6)	6 (17)	4 (11)
Is a physician promptly (on the floor) available in case of seizure clusters/status epilepticus/medical emergencies?	48 (100)	Yes	No		
		47 (98)	1 (2)		
Do you monitor vital signs (i.e., heart rate, blood pressure, oxygen saturation, and respiratory rate) during seizure clusters/status epilepticus?	48 (100)	Yes	No		
		44 (92)	4 (8)		
Do you have in place any protocol for emergency resuscitation?	48 (100)	Yes	No		
		42 (87)	6 (13)		

The numbers in the columns indicate the number and the percentage (in italics within parentheses) of centers that responded.

Table 4
Protective measures against seizure-related injuries.

	Total N (%) of responders			
	Yes	No		
Are there protections against injuries in beds in EMU rooms (e.g., guard rails)?	46 (96)	2 (4)		
Do you use antisuffocation pillows?	10 (21)	37 (79)		
Are there protections against injuries in EMU rooms?	18 (38)	30 (62)		
Are the bathrooms protected (soft toilets and recessed sinks)?	12 (25)	36 (75)		
Can patients ambulate during monitoring?	31 (65)	17 (35)		
If yes, are they obliged to wear protections?	1 (3)	15 (43)	In special cases 19 (54)	
Do you have precautions for patients with implanted electrodes?	26 (70)	22 (59)	Other 5 (14)	

The numbers in the columns indicate the number and the percentage (in italics within parentheses) of centers that responded.

3.2. Intensity and level of patients' observation (Table 2)

Patients' observation was continuous in 38 (80%) EMUs, performed only during the daytime in 5 (10%), and intermittent in the remaining 5 (10%). In 71% of EMUs, nurses and/or neurophysiology lab technicians performed observation. However, physicians and patients' relatives were involved in 27% and in 40% of centers, respectively. In 42 (91%) of the 46 centers which responded to this question, ictal and postictal evaluation of the patient to obtain diagnostic information on seizure semiology (such as degree of impairment of consciousness, occurrence of ictal/postictal aphasia, and timing of recovery of consciousness) was carried out. The use of seizure detection or alarm monitoring systems was limited. Indeed, automatic detection methods for ECG abnormalities were implemented in 8 (17%), for oxygen desaturation in 16 (33%), for seizure-related movements in 4 (8%), and for ictal EEG abnormalities in 7 (15%) EMUs.

3.3. Management of status epilepticus and clusters of seizures (Table 3)

Written protocols for the management of status epilepticus or seizure clusters were lacking in 21% and in 27% of EMUs, respectively, though a physician was readily available in case of epileptic or other medical emergencies in nearly all EMUs (98%). Monitoring of vital signs and protocols for general emergency situations were in place in 92% and in 87% of EMUs, respectively.

Table 5
Management of postictal psychosis.

	Total N (%) of responders			
	Yes	No	In specific cases	
Do you perform psychiatric evaluation in patients admitted in EMU?	17 (36)	5 (10)	26 (54)	
Do you have any protocol to promptly manage postictal psychosis?	6 (13)	42 (87)		

The numbers in the columns indicate the number and the percentage (in italics within parentheses) of centers that responded.

3.4. Protective measures against seizure-related injuries (Table 4)

Bed protections, such as guard rails, were available in 96% of EMUs. In contrast, antisuffocation pillows were used in 10 (21%) EMUs only, and there were protections in the monitoring rooms and bathrooms to prevent potential harm in case of seizures with falling or intense motor phenomena in only 18 (38%) and in 12 (25%) EMUs, respectively. In addition, although ambulation during monitoring was allowed in 65% of EMUs, wearing protections (such as helmets) was mandatory in only 3% of centers while being considered in patients with specific risks in 54%. Other precautions, such as restrained ambulation and reinforced observation, were used in 26 (70%) and in 22 (59%) of the EMUs, respectively, recording patients with implanted intracerebral electrodes.

3.5. Management of postictal psychosis (Table 5)

An evaluation of psychiatric comorbidities was performed systematically or in specific patients in 17 (36%) and in 26 (54%) EMUs, respectively. Only 6 (13%) EMUs used a specific protocol to manage postictal psychosis.

3.6. Seizure-related serious adverse events (SAEs) and causes of extended EMU stay (Table 6)

We did not investigate the incidence of any given SAE, but either one or several of the following seizure-related SAEs have been encountered in the EMUs during the last 15 years: bone fractures, other injuries, cardiorespiratory distress, SUDEP, postictal psychosis, status epilepticus, choking/aspiration, and ictal psychosis. As shown in Table 6, status epilepticus, injuries, and postictal psychosis have occurred in most of the EMUs. Bone fractures, ictal psychosis, cardiorespiratory distress, and choking were more rarely encountered. Only two EMUs reported a SUDEP case. Interestingly, the most common SAEs, i.e., status epilepticus, postictal psychosis, and injuries, were among the factors most commonly associated with a prolonged admission in EMUs.

4. Discussion

Occurrence and prevention of SAEs during LTM in EMUs are crucial issues that need to be considered for the organization and the standardization of long-term video-EEG monitoring [8,17]. Our survey aimed to

Table 6
Seizure-related SAEs and causes of extended EMU stay.

	Total N (%) of responders								
Which of these seizure-related events occurred in your EMU in the last 15 years?	48 (100)	Bone fractures 17 (35)	Injuries 35 (73)	Cardiorespiratory compromise 11 (23)	SUDEP 2 (4)	Postictal psychosis 32 (67)	Status epilepticus 38 (79)	Choking/aspiration 7 (16)	Ictal psychosis 15 (31)
Causes of extended EMU stays	48 (100)	Reintrod. of AEDs 26 (54)	Insuff. seizures 42 (88)	Injuries 10 (21)	Status epilepticus 18 (38)	Postictal psychosis 11 (23)	Other 6 (13)		

The numbers in the columns indicate the number and the percentage (in italics within parentheses) of centers that responded.

Reintrod. of AEDs: reintroduction of AEDs.

Insuff. seizures: insufficient number of recorded seizures.

collect information that could provide an overview of the current organization and practices in European EMUs. We believe that our data from 48 EMUs located in 18 European countries and Israel provide a representative sample of the 150 EMUs identified in these countries. Of course, the interpretation of the results must consider that only one-third of the EMUs answered, possibly indicating that our data were collected from EMUs particularly sensitive to and concerned by the issues explored by the survey.

Regarding the size of EMUs, our findings show considerable heterogeneity in terms of number of beds and staff. The analysis of the results did not discriminate between findings observed in EMUs with 1–2 beds and findings observed in EMUs with 5–6 beds. The relationship between size of the EMU and occurrence of SAEs should be further investigated, since it might influence the definition of safety criteria. The level of training of the medical staff also greatly varied from neurologists or neurophysiologists trained in epilepsy to child neurologists and neurologists without epilepsy training and neurology and neurophysiology residents. The level of expertise in epilepsy of the medical staff was found to be important for the appropriate management of at-risk situations such as status epilepticus or ictal/postictal psychosis [1,4,7,8]. Similarly, lack of protocols at the admission to evaluate patients' characteristics, risk factors, and comorbidities (e.g., history of status epilepticus and postictal psychosis) might hamper an optimal management of emergency situations [3]. Such protocols were missing in 44% of the surveyed EMUs.

In 20% of EMUs, patients' observation was intermittent or only performed during the daytime. This finding is in agreement with that of another survey performed by the American Epilepsy Society which reported that 26% of EMUs in the USA are unable to provide continuous monitoring [4]. Reduced level of patients' observation appears likely to increase the risk of seizure-related SAEs and of prolonged stay due to undetected seizures. For instance, almost all SUDEP cases reported in EMUs occurred at night in patients who were not or ill supervised [18]. Lack or delay of attendance to patients having seizures by nurses also tended to occur more frequently when supervision was limited [11].

Only a few EMUs have implemented automatic systems for detection of seizure, ECG abnormalities, oxygen desaturation, or seizure-related movements. Several methods for automated seizure detection based on online analysis of EEG, ECG, or body movements [19–22] have been developed in the last decades. The performance of several methods based on body movement detectors was recently assessed, showing a sensitivity of 88% to 94% to detect convulsive seizures with various rates of false alarms [23–26]. Such methods could, thus, prove useful in EMUs with suboptimal or intermittent patients' observation. However, at present, their effectiveness to avoid SAEs has yet to be proven, and supervised continuous monitoring of the patients still appears to be the highest quality standard that should be recommended.

Although status epilepticus was one of the most common SAEs, a written protocol for its management was lacking in 21% of EMUs. Similarly, 30% of US EMUs were reported to lack such protocol [4]. Despite a physician being readily available in almost all EMUs in case

of status epilepticus or seizure clusters, the lack of a standardized protocol combined with the limited training in epilepsy care of many of these physicians might expose the patients to the risk of inadequate treatment [4,7].

Protective measures in the EMU environment to prevent patients from having injuries were largely missing, with the exception of guard rails. Safety measures such as antisuffocation pillows, and physical protections in EMU rooms (such as floor mats, shielding of hard edges, and removal of obstacles) and bathrooms (such as soft toilet seats and recessed sinks) were available in a minority of EMUs. Most seizure-related traumatic events lead to minor injuries [9,27,28]; however, at times, they can lead to serious complications such as epidural hematoma, bone fractures, and shoulder dislocation [5,6,12]. In addition, drug tapering or withdrawal during LTM in EMUs may result not only in increase of seizure frequency but also in increment of seizure duration and intensity with a higher probability of secondary generalization, a circumstance that increases the risks of seizure-related injuries [3].

Psychiatric comorbidities in patients admitted to EMUs are associated with an increased risk of psychiatric complications [29], some of which might require admission in a psychiatry unit [6]. However, only 36% of EMUs systematically screened patients at admission for such comorbidities, and only 13% had developed a specific protocol to promptly manage psychiatric SAEs such as postictal psychoses.

Status epilepticus had occurred in 79%, seizure-related injuries in 73%, and postictal psychosis in 67% of EMUs during the last 15 years, while bone fractures, ictal psychosis, cardiorespiratory distress, choking, and aspiration were less frequently reported. Similarly, the most frequently reported adverse events in a US survey were falls in 68%, status epilepticus in 62%, and postictal psychosis in 54% of EMUs [7].

Risks of occurrence of SAEs in EMUs in epilepsy surgery candidates have to be contrasted with not performing EMU procedures, which will prevent these patients from proceeding to surgery, exposing them to the complications associated with drug-resistant focal epilepsies (such as antiepileptic drugs side effects, cognitive deterioration and SUDEP).

The assessment of the organization and activities in EMUs monitoring only children and the comparison with EMUs monitoring only adults or both adults and children were beyond the scope of this survey. The limited number of EMUs monitoring only children which participated in our survey (6 out of 48) and the heterogeneity of the data that they provided do not allow us to establish whether there were specific practices and concerns in this subgroup of EMUs, prompting further studies in a larger number of EMUs.

5. Conclusion

Our survey indicates that the organization of European EMUs varies considerably across centers and lacks essential pieces of safety measures in many. In particular, lack of standardized protocols to optimally manage status epilepticus, seizure clusters, and postictal psychosis represents a prevalent issue that could be improved by editing and disseminating appropriate practice parameters in the field. Inequalities

in the level of expertise of EMUs' medical staff might also be tackled by specific European training programs, such as those promoted by the International League Against Epilepsy and those currently developed by the **EU-funded pilot network of cooperation in epilepsy surgery, E-PILEPSY**. Reinforcing the level of patients' observation in EMUs not providing continuous supervision by dedicated staff is a more difficult issue often related to budget limitation. Dissemination of validated systems for automatic detection of generalized convulsive seizures might help to partly address this limitation. One should also balance the cost of permanent supervision with those deriving from the occurrence of SAEs and from seizures not recorded due to intermittent monitoring (i.e., prolonged admission to EMUs or to other intensive care or psychiatry wards). Further prospective studies are, thus, warranted to investigate the incidence and cost of SAEs in EMUs and their relation to EMU organization.

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Disclosure

None of the authors has any conflict of interest to disclose.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <http://dx.doi.org/10.1016/j.yebeh.2015.02.004>.

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