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Patients' knowledge on epilepsy and SUDEP improves after a semi-structured health interview

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ABSTRACT

Background: Patients' education is the most relevant contributor to patient self-management of epilepsy. We aimed to assess the acquisition of knowledge after a semi-structured interview.
Methods: We performed a quasi-experimental prospective study with a cohort of patients with epilepsy admitted for prolonged video electroencephalogram (VEEG). We measured patients' baseline knowledge with a 10-item true–false test (test A). Then, a qualified nurse carried out a semi-structured interview. We measured acquired knowledge with another 10-item true–false exam (test B), prior to VEEG discharge and after a 3- to 5-month follow-up, and we compared the difference between the scores in test A and test B. Finally, we conducted a satisfaction and suitability survey on the interview at follow-up.
Results: Thirty-two patients participated, half were women. Their median age was 39.5, and the median length of schooling was 14 years. The median time since epilepsy onset was 13 years, 75% had suffered tonic–clonic seizures. The median score on test A was 7, while the median score on test B was 8.5 ($p < 0.001$) both at VEEG discharge and after follow-up. After the interview, 84.4% of participants reported that they were very satisfied with the information received; 87.5% stated that they had not previously heard about SUDEP (sudden unexpected dead in epilepsy); and 93.8% considered it important to receive detailed information about SUDEP.
Conclusions: Patient education through a semi-structured comprehensive interview improves knowledge of patients with epilepsy about their disease. The calm atmosphere and the qualified nursing working at VEEG units make them an appropriate setting for talking about epilepsy and its risks, including SUDEP.

1. Introduction

Epilepsy is a disease of the brain characterized by a permanent predisposition to present epileptic seizures, and by its neurobiological, cognitive, psychological, and social consequences [1]. The prevalence of active epilepsy ranges 0.5–1% [2,3], and it is associated with two- to three-fold mortality increase when compared to the general population [4,5]. This is partly due to seizures themselves, and partly due to the etiology and comorbidities.

Sudden unexpected death in epilepsy (SUDEP) is a nontraumatic, nondrowning death, in which no etiology is found [6]. It is the most common cause of death related to epilepsy [7], above status epilepticus or accidents, and its incidence is estimated to be 1 per 10,000 patients-years in newly diagnosed epilepsy, 1 per 1000 patients-years in chronic epilepsy, and 2–10 per 1000 patients-years in drug-resistant epilepsy [8,9]. Although the mechanism of death is not completely known, some risk factors have been identified, part of them are modifiable. The most important one is a history of uncontrolled tonic–clonic seizures, with patients with higher seizure frequency presenting a greater risk, regardless of seizure type [10]. Other proposed risk factors are nocturnal seizures, poor antiepileptic treatment, or drug-resistant epilepsy under polytherapy. On the other hand, protective effect has been related

Abbreviations: AED, antiepileptic drug; CEIC, Comité Ético de Investigación Clínica; HCSC, Hospital Clínico San Carlos; IQR, interquartile range; NDDI, Neurological Disorders Depression Inventory; QOLIE-10, 10-item version of the Quality of Life in Epilepsy questionnaire; STAI-T, State–Trait Anxiety Inventory; SUDEP, sudden unexpected dead in epilepsy; VEEG, video electroencephalogram.

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to appropriate nocturnal supervision and prompt assistance after seizures, successful epilepsy surgery, or supine position while sleeping [11,12].

While giving information about SUDEP and other seizure risks is clearly indicated by SUDEP guidelines right after epilepsy diagnosis, there is debate about who, where, and how to address these issues [9,13–15]. Given the sensitivity of the subject, it seems reasonable to assign this task to qualified health providers [16]. A semi-structured interview in a quiet environment with the possibility to solve all doubts in an open discussion time, carried out by the qualified nursing of VEEG (Video-electroencephalogram) units, trained and experienced in epilepsy, seems a good option. Moreover, patient education may improve therapeutic compliance [17] and lifestyle habits, which might reduce the frequency of seizures.

The objective of this study was to analyze the degree of learning of patients with epilepsy about their disease after a semi-structured interview carried by qualified nursing. We assessed the adequacy of the aforementioned interview and the VEEG admission as the time for carrying it out. We also measured the patients' willingness to learn more about SUDEP, and their level of satisfaction after the interview.

2. Methods

2.1. Patients

We performed a quasi-experimental prospective study on a cohort of patients aged ≥18 years diagnosed with epilepsy who were admitted for a scheduled prolonged 24-h VEEG in the Epilepsy Unit of Hospital Clínico San Carlos (HCSC), between 23 April and 23 July, 2018. Our medical institution is an academic tertiary hospital and serves a population of 370,501 inhabitants living in an urban area of Madrid (Spain). Epilepsy was diagnosed following the last practical definition of epilepsy of the International League Against Epilepsy (ILAE) [1]. In case of intellectual disability, we offered participation to the main caregiver of the patient. The study protocol was approved by the HCSC "Comité Ético de Investigación Clínica" (CEIC, protocol number: 18/176-E). Informed consent was obtained from all participants (patient or main caregiver in case of intellectual disability).

2.2. Study protocol

All participants recruited for the study went through the following phases:

1. Initial assessment at first day of VEEG admission, which included the following: i) a complete medical history; ii) a Likert-type questionnaire with two questions about previous contact of the patient or main caregiver with information about epilepsy and its risks and the desire for more information (Table 1); and iii) an assessment of the participants' baseline knowledge about epilepsy and its risks through a 10-item true–false test, named test A (Table 2).
2. Semi-structured interview: it was carried out by the qualified nurse of our Epilepsy Unit during the morning of the first day of admission, after assembly of the VEEG system. Video-electroencephalogram rooms are single, spacious, and quiet. We reserved 1 1/2 h for each interview. The educational program of the interview, which followed a structured script (Table 3), consisted of information not only about seizures and its risks (including SUDEP), but also about other issues such as the role of ancillary tests in epilepsy, the characteristics of AEDs (antiepileptic drugs) and keys for their self-management, the detection of stigma and ways to reduce its burden, or the driving license requirements in patients with epilepsy. To facilitate learning, we combined the structured script with free conversation time in which participants could raise their doubts and improve their knowledge. No visual or reading material was used.

Table 1
Likert-type questions for the evaluation of previous contact of the patient or main caregiver with information about epilepsy and its risks and the desire for more information.

Initial questions:	
Have you previously received information about epilepsy and its risks?	Would you like to receive more information about it?
a) Very little	a) Very little
b) Little	b) Little
c) Some but not much	c) Some but not much
d) Much	d) Much
e) Very much	e) Very much

Table 2
Test A: 10-item true–false test for the evaluation of baseline knowledge of the patient or main caregiver about epilepsy and its risks.

1. While attending a generalized tonic–clonic seizure, it is recommendable to manipulate the airway of the patient to ensure ventilation – *False*
2. Facing a generalized tonic–clonic seizure, it is not advisable to impede the movement of the limbs of the patient – *True*
3. The VEEG is a useful ancillary test for the study of epilepsy, and a normal result rules out the epilepsy diagnosis – *False*
4. The only seizure type that disables the driving license in Spain is generalized tonic–clonic seizures – *False*
5. Patients with epilepsy cannot travel by plane – *False*
6. The most frequent seizure trigger is low level of AEDs because of any origin (forgetting drug intake, changes in treatment regime…) – *True*
7. Patients with epilepsy should sleep a regular number of hours, if possible above 7–7.5 h per night [18] – *True*
8. Any tonic–clonic seizure that lasts more than 5 min is indicative of calling the emergency department – *True*
9. AEDs may cause mild or moderate adverse events, but never severe or life-threatening ones – *False*
10. During the postictal state, it is recommended to give water, food, or even coffee, in order to accelerate the recovery of the patient – *False*

AED, antiepileptic drug; VEEG, video electroencephalogram.

Table 3
Script of the semi-structured interview.

1. Epilepsy, concept, and main causes
2. Seizures, concept, and management:
   a. How to act when facing a seizure and during the postictal state
   b. How to use rescue medication and when to call the emergency department
3. Status epilepticus:
   a. Concept and severity
   b. Risk factors for status epilepticus
   c. What to do when it starts out of hospital
4. Risks associated with seizures, SUDEP:
   a. Strategies to prevent accidents and damage resulting therefrom
   b. SUDEP:
      i. Assessment of patient's previous contact with SUDEP information and degree of knowledge
      ii. SUDEP definition and concept; cardiorespiratory implications
      iii. SUDEP incidence; similarity with other exceptional accidents of daily living
      iv. Risks factors for SUDEP
      v. Modifiable risk factors and how to improve them
5. AEDs, myths, and truths:
   a. Therapy adherence, verification of patient's techniques for complying treatment
   b. Identification of possible mistakes made by the patient in following AEDs therapy
   c. How to act when forgetting medication intake
   d. Side effects of the AEDs
   e. Pregnancy, teratogenicity risk, and how to act when planning pregnancy
6. Utility of ancillary tests in epilepsy (EEG registries, cranial MRI…). Significance of normal and altered results
7. Integration and acceptance of epilepsy
   a. Identification of stigma and strategies to reduce its burden
   b. Detection of work or social discrimination
8. Vehicle driving legislation:
   a. When driving is allowed in Spain after the different types of seizures and epilepsies
   b. Professional driving

AED, antiepileptic drug; EEG, electroencephalography; MRI, magnetic resonance imaging; SUDEP, sudden unexpected dead in epilepsy.

3. Assessment prior to hospital discharge: evaluation of post-interview knowledge about epilepsy and its risks 24 h after the educational interview. This evaluation was performed through a 10-item true–false test, named test B (Table 4). Test A and test B were developed by our epilepsy team and designed to evaluate the same content. Equality in content was validated in a pilot sample of patients with epilepsy prior to the initiation of the former study. Such analysis is listed in the Results section.
4. Follow-up: between 3 and 5 months after the semi-structured interview, patients were checked on an outpatient basis. Consolidated knowledge was assessed with test B. In addition, we performed a satisfaction and suitability survey, which consisted of three Likert-type questions about the interview, and another three questions (two Likert-type and one yes–no question) about the proportion of patients that had heard about SUDEP before the interview and about the suitability of the information received (see Table 5).

The questionnaire about prior contact of the patient with information about epilepsy, the tests A and B, and the structured script of the educational program of the interview were elaborated by a group of seven epileptologists from the Epilepsy Program of Hospital Ruber Internacional of Madrid and the Epilepsy Unit of HCSC (AGV, MRJ, BPC, AAS, AGN, RT, and IGM).

2.3. Clinical and outcome assessment

For each participant, we recorded the following: i) demographic data (age, sex); ii) years of schooling since the beginning of compulsory primary education in Spain (six years old); iii) previous seizure history: years from onset, epilepsy type, seizure types and frequency, occurrence of nocturnal generalized tonic–clonic seizures, and number of AEDs used; iv) ownership of Spanish *Ministry of Health, Consumption, and Social Welfare* Disability Certificate and grade of disability (percentage, 100% means maximum disability); and v) kinship of main caregiver who participated in the study in case of intellectual disability.

We used the Neurological Disorders Depression Inventory (NDDI) for evaluation of mood [19], with a cutoff score > 13 for major depression diagnosis according to the Spanish validation of the NDDI [20]; the trait subscale of the State–Trait Anxiety Inventory (STAI-T) for anxiety [21], and the 10-item version of the Quality of Life in Epilepsy questionnaire (QOLIE-10) for quality of life [22]. Prior contact with information about epilepsy and its risks, suitability of the interview, and satisfaction of the patient were evaluated with Likert-type variables with five response options. Participant baseline knowledge about epilepsy and its risks was assessed through the score in test A (number of correct answers out of ten), and postinterview knowledge through the score in test B (number of correct answers out of ten), both at hospital discharge and at the 3- to 5-month follow-up.

The main outcome variable was the difference between the score obtained in test A and test B.

Table 4
Test B: 10-item true–false test for the evaluation of acquired and settled knowledge of the patient or main caregiver about epilepsy and its risks.

1. Holding the tongue, placing an object in the mouth, or practicing the mouth-to-mouth resuscitation are recommended during a seizure – *False*
2. Handling the limbs during a generalized tonic–clonic seizure is indicated to minimize convulsive movements – *False*
3. A normal result in a cranial MRI or an EEG registry rules out the diagnosis of epilepsy – *False*
4. Spanish legislation forbids driving vehicles for 6 months after a generalized tonic–clonic seizure – *False*
5. SUDEP is an exceptional cause of death in patients with epilepsy – *True*
6. Poor therapeutic compliance may lead to seizures or status epilepticus, and even death of the patient – *True*
7. Irregular sleep schedule and/or sleeping a deficient amount of hours may provoke seizures – *True*
8. A prolonged seizure that lasts more than 5 min is considered a status epilepticus, and needs emergent medical care – *True*
9. If a woman gets pregnant while being under AEDs, she must withdraw them immediately because of teratogenicity risk – *False*
10. During the postictal state, the patient may feel drowsy, confused, or disoriented; it is recommended to place the patient in the lateral safety position – *True*

EEG, electroencephalography; MRI, magnetic resonance imaging.

Table 5
Satisfaction and suitability survey on the semi-structured interview.

1. Do you find the information received during the interview useful?	2. Are you satisfied with the information received?
a) Very little	a) Very little
b) Little	b) Little
c) Some but not much	c) Some but not much
d) Much	d) Much
e) Very much	e) Very much
3. Would you have liked to receive the information before?	4. Do you think it is important to receive detailed information about SUDEP?
a) Never	a) Very little
b) Almost never	b) Little
c) Sometimes	c) Some but not much
d) Almost always	d) Much
e) Always	e) Very much
5. Have you ever heard about SUDEP before the interview?	6. Would you have preferred not to discuss about SUDEP?
a) Yes	a) Yes, I would have preferred not to discuss about SUDEP
b) No	b) Indifferent
	c) No, I think it as suitable and useful

2.4. Statistical analysis

First, we performed an exploratory univariate analysis. Qualitative variables were summarized by their frequency distribution. Continuous variables fulfilled the assumptions of nonparametric data after testing of normality and homogeneity of variance, so they were summarized as median and interquartile range (IQR). The main outcome measure was compared using the Wilcoxon signed-rank test for paired samples. The relation between the primary outcome variable and qualitative variables was analyzed using the Mann–Whitney *U* test, and the relation between the main outcome variable and quantitative variables was explored with the nonparametric Spearman's rho correlation coefficient. We did not perform multivariate regression analysis because there was no relation between the outcome variables and possible confounders on the bivariate analysis. Type I error cutoff for statistical significance was set at 0.05 ($p < 0.05$). The statistical analysis was performed using IBM SPSS Statistics 23.

3. Results

3.1. Assessment during hospital admission

During the 3-month inclusion period, we offered participation to 35 consecutive adult patients with epilepsy admitted for VEEG monitoring. Three patients declined participation. Two of them had major depression according to the NDDI score (16 and 18), and all three argued concern to worsen in mood and anxiety, as they felt that knowing the risks associated with seizures and epilepsy would lead them to become more worried and discouraged. The remaining 32 patients accepted participation, five of them through the relative main caregiver because of severe disability (median grade: 65%; IQR: 32–73). In these cases, the main caregiver was the patient's mother in three, the father in one, and an aunt in the last one.

Half of the patients were women (n = 16). The median age was 39.5 years (IQR: 27.5–52.5), and the median number of years of schooling was 14 (IQR: 12–17). The median time since disease onset was 13.0 years (IQR: 4.5–23.8). Epilepsy was focal in 62.5% (n = 20), generalized in 28.1% (n = 9), and unknown in 9.4% (n = 3). Twenty-four

patients (75%) had suffered tonic–clonic seizures in their lifetime, and 71% of them (n = 17) had presented them while sleeping. The median number of seizures of any type per year was 4 (IQR: 2–18), and the median number of tonic–clonic seizures per year was 0 (0–2); four patients were considered seizure-free. The median number of the AEDs used for epilepsy therapy was 2 (IQR: 1–3).

The median scores in mood, anxiety, and quality of life inventories were as follows: 12 in NDDI (IQR: 11–16), 26 in STAI-T (IQR: 16–40), and 37.5 in QOLIE-10 (IQR: 25.0–42.0). Fourteen patients (43.8%) obtained major depression diagnosis according to the NDDI score. When the participants were asked whether they had previously received information about epilepsy and its risks, 41% answered "very little" (n = 9) or "little" (n = 4), 28% answered "some but not much" (n = 9), and 28% answered "much" (n = 4) or "very much" (n = 5); when they were asked whether they would like to receive more information about it, 87.5% answered "very much" (n = 26) or "much" (n = 2), 6.3% "some but not much" (n = 2), 3.1% "little" (n = 1), and none answered "very little".

The median score in test A was 7 out of 10 (IQR: 6–8), and the median score in test B at hospital discharge was 8.5 (IQR: 7.3–9.0).

3.2. Follow-up assessment

After a median time of 3.6 months (IQR: 3.3–4.0), all participants were revisited on an outpatient basis. At this time, the median score in test B was 8.5 (IQR: 7.3–9.0). The complete results of the satisfaction and suitability survey are shown in Fig. 1. When patients were asked if they found the information received during the interview useful, 81.3% (n = 26) answered "very much", and when they were asked whether they were satisfied with the interview, 84.4% (n = 27)

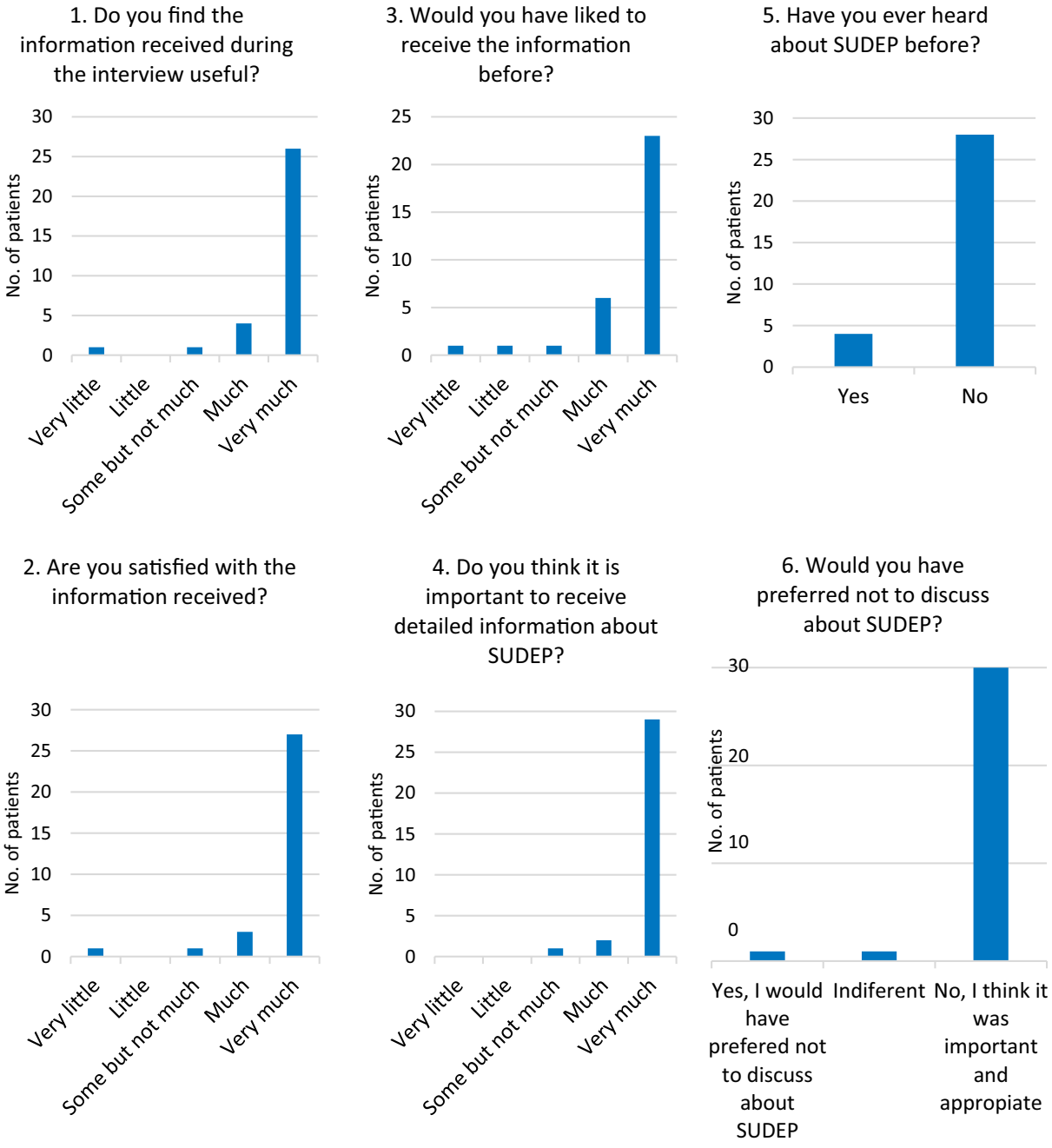

Fig. 1. Complete results of the suitability and satisfaction survey.

answered "very much". Most of them also stated that they would have "very much" liked to receive the information before (71.9%, n = 23). In addition, when they were asked if they thought it was important to receive detailed information about SUDEP, 90.6% (n = 29) answered "very much". It should be noted that 87.5% (n = 28) said they had not previously heard about SUDEP, and 93.8% (n = 30) reported that "it was important and appropriate" to receive specific information about SUDEP during the interview. There was only one patient who would have preferred not to discuss about SUDEP during the interview; he obtained a positive screening for major depression (NDDI score of 16).

3.3. Comparison of test A (baseline) and test B (hospital discharge and follow-up)

Equality in content of test A and test B was analyzed in a pilot sample of 20 patients with epilepsy, prior to initiation of the current study. The median score in test A and test B was both 6.0 (IQR for both tests: 5.0–7.8), so there were no differences between them ($p = 0.817$).

The participants in this study scored higher on test B (median score: 8.5 and IQR: 7.3–9, both at hospital discharge and at follow-up) than on test A (median score: 7.0 and IQR: 6.0–8.0; $p < 0.001$).

3.4. Relationship between the scores in tests A and B, and other variables

Years of schooling positively correlated with the score in test A (rho correlation coefficient: 0.372; $p = 0.047$), but did not correlate with the score in test B ($p = 0.74$). There were no significant correlations between the scores in test A or test B and other quantitative variables (age, years since epilepsy onset, number of AEDs for epilepsy treatment, seizure frequency, NDDI, STAI-T, or QOLIE-10). No association was found between the test scores and qualitative variables (sex, epilepsy type).

4. Discussion

Our results support that patient education may be suitable and beneficial in many diverse sociodemographic and clinical scenarios, as we found that knowledge acquisition and settlement did not depend on age, years of schooling, epilepsy type, mood, anxiety, or quality of life. Only the length of schooling was related with patients' baseline knowledge about epilepsy. These findings are consistent with the majority of studies that analyzed patients' knowledge of epilepsy [17,23,24], although Long et al. did not find a significant association between patients' knowledge of their disorder and the educational background [25]. In any case, our results support the effectiveness of health education in all patients irrespective of their educational level.

In recent times, educating patients with epilepsy about their disease and possible ways of improving self-caring is becoming increasingly important. Indeed, it is widely recognized as the most relevant contributor to patient empowering and better epilepsy self-management, with its potential benefits in treatment compliance, management of seizures, and mitigation of epilepsy effects in quality of life [17,26,27]. In our study, the vast majority of patients were highly interested in learning more about their disease prior to the interview. Furthermore, at the follow-up visit, they recognized the value of the information received. These results emphasize that epilepsy education is not only well accepted but also required by most of the patients [28].

One of the most relevant but least known risks in epilepsy is SUDEP, and patients with epilepsy also want to know about it [29–31]. This has been demonstrated in the recent literature, and was also found in our study, in which more than 90% stated that it was important to receive specific and detailed information about SUDEP. On the other hand, as aforementioned, most of them (around 90%) reported that they had not heard about SUDEP prior to the interview, and that they would have liked to hear about it before. This reality matches with other studies, such as that conducted by Surges et al. in which around 90% of epilepsy patients had never heard of SUDEP before [32], or that conducted by Friedman et al. in which less than 10% of neurologists discussed SUDEP with the majority of their patients [33].

Some known factors associated with low likelihood of SUDEP discussion are the concern of the health provider to generate stress or anxiety in the patient or caregiver, physicians' little interest or experience in epilepsy, or the absence of feasible strategies to reduce the risk of SUDEP in some particular cases [8,33,34]. Offering the patient an intimate and calm environment was our strategy to enhance their confidence and make the interview more assertive. We consider that scheduled VEEG admission fulfills this purpose, so we implemented the health interview in our routine clinical practice during prolonged VEEG in the Epilepsy Unit. After the interview, only one out of 32 patients referred that he would have preferred not to talk about SUDEP, a similar rate of regret as that found in other studies with adults or parents of children with epilepsy. This patient was diagnosed with depression during admission. Similarly, two of the three patients who refused to participate in the study had major depression diagnosis, and all three felt that knowing the risks associated with seizures and epilepsy would lead them to become more worried and discouraged. On the other hand, 43.8% of participants received major depression diagnosis according to the NDDI, and they were nevertheless satisfied with the interview. Taking into account the variability of the impact that information on epilepsy and its risks might have, mood disorders may make it advisable to delay educational programs or to carry them out more gradually over several successive visits. A qualitative study based on open interviews with patients with epilepsy or caregivers could assess the impact of SUDEP information on patients' lives in a greater depth.

Our study has some limitations. The single center design and the specific sociocultural aspects of every region may reduce generalizability. Additionally, Likert-type questions may increase the possibility of a response bias, such as the extreme responding bias or the social desirability bias. Nevertheless, the Likert-type variables were not the main outcome one, and their results were harmonious with those of previous studies. The instruments for measuring patient's knowledge (tests A and B) were not validated prior to our study, and therefore could have introduced a measurement bias. However, no specific tests had been previously used for this purpose, and the ones we created were validated to have the same content in a pilot sample; moreover, we used two different tests for avoiding learning bias.

In conclusion, this is as far as we know the first quasi-experimental study in showing the improvement of patients' knowledge about epilepsy and its risks, including SUDEP, after a semi-structured health interview. Our findings reinforce the value of healthcare education as a key part in epilepsy management. The quiet atmosphere of a VEEG Unit in a scheduled prolonged study and the qualified nursing working in it make VEEG admission an appropriate and successful time for patient comprehensive education.

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Declaration of competing interest

None.

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