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Comorbid epilepsy and psychogenic non-epileptic seizures: How well do patients and caregivers distinguish between the two

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ABSTRACT

Purpose: To determine whether patients with comorbid epilepsy and psychogenic nonepileptic seizure (PNES) and their caregivers can distinguish between these two events at least one year after initial diagnosis, and to investigate factors associated with correct identification.
Methods: Adult patients with at least a one year diagnosis of both epilepsy and PNES, confirmed through video-electroencephalography (VEEG), were selected. Patients and a caregiver of their choice were interviewed and shown videos containing the patients' epileptic and PNES events. Variables associated with correct identification of events by patients and their caregivers were evaluated.
Results: Twenty-four patients participated in the study. Mean time between VEEG diagnosis and enrollment in the study was 26.8 months (±12.4). Six of patients correctly distinguished between the events shown. Factors associated with correct identification were the absence of intellectual disability, unremitted PNES, and a degree of preserved awareness during the PNES event. Twelve caregivers correctly distinguished between the events shown. Factors associated with correct identification among caregivers were the presentation of only one epileptic seizure type in the patient, and the participation of the caregiver during VEEG monitoring and communication of PNES diagnosis to the patient.
Conclusion: A significant proportion of patients with epilepsy and PNES and their caregivers seem to be unable to discriminate between these events a year after diagnosis. These findings have implications for both clinical follow-up and research involving this population. Future research should further investigate methods that would allow patients and their caregivers to better distinguish between these two events.

1. Introduction

Psychogenic non-epileptic seizures (PNES) account for up to 30% of referrals for medically refractory epilepsy.[1,2] The burden of suffering and healthcare costs associated with PNES is considerable. Undiagnosed patients have high emergency services utilization, and receive unnecessary and expensive treatments. Accurate and early diagnosis and treatment are of utmost importance.[3,4] While there are efforts to identify clinical features such as semiological signs and psychosocial aspects that would aid in the diagnosis of PNES, clinical applicability of these methods is still under debate.[5,6] Current diagnostic gold standard is video-electroencephalography (VEEG) documentation of PNES, which is performed in specialized centers. [2,7]

Five to 60 percent of PNES patients have comorbid epilepsy.[8–10] Studies focusing on PNES outcome and treatment generally exclude cases with confirmed or suspected comorbid epilepsy,[11–13] since these conditions are not easily discernible.[14] One study included patients with comorbid epilepsy if patients reliably distinguished both events, not specifying how this distinction was made.[15] The distinction between both events is challenging, as there is a great inter and intraindividual variability in PNES presentations according to patients' and witnesses' description. Also, most events share similarities with epileptic seizures.[16] These difficulties may significantly hinder outcome evaluation.

The ability of patients to differentiate epileptic seizures and PNES has not been evaluated. Assuring that patients and caregivers

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are able to correctly distinguish both event types is crucial for clinical management and research. Failure to recognize the nature of an event may significantly impact patient care, leading to erroneous overmedication of PNES, as well as to insufficient and inadequate epilepsy treatment. Reliable PNES identification in patients with comorbid epilepsy is also of great importance for psychotherapic approach to PNES, which is currently an important treatment modality for the disorder.[7] Misinterpretation of event types may severely compromise therapy's efficacy.

The aim of this study is to determine if patients with comorbid PNES and epilepsy and their caregivers can distinguish between PNES and epileptic seizures, and to investigate factors associated with correct identification of both event types.

2. Methods

2.1. Patient sampling

We evaluated a consecutive series of patients with comorbid epilepsy and PNES diagnosed with VEEG monitoring at the *Hospital das Clinicas da Faculdade de Medicina da Universidade de São Paulo* (HC-FMUSP) from January 2009 to July 2012.

The diagnoses of epilepsy and PNES were established by a team of experienced epileptologists with VEEG monitoring after both event types were captured, and other events such as syncope or migraine were excluded. The diagnosis of PNES was further supported by induction of a typical event through the use of suggestion techniques by a team psychiatrist. Patients were asked to select a caregiver (spouse, family member or friend who had witnessed seizures) who verified that the video recordings represented the events that were causing significant distress to the patient. Recorded events were shown to the caregiver with the patients' consent. The comorbid diagnoses of epilepsy and PNES were then disclosed to the patient and caregiver, and video recordings of both event types were again presented to educate them in distinguishing both events. The complete clinical protocol is described elsewhere.[17]

After discharge, all these patients were referred for follow-up in the neuropsychiatry outpatient clinic in our institution, with the same psychiatry team with expertise in epilepsy and PNES that had participated in the VEEG monitoring. During clinical follow-up, patients underwent cognitive-behavioral therapy (CBT) sessions and educational meetings for the initial month after diagnosis, followed by long-term psychiatry outpatient appointments. In our service all patients are offered CBT and educational meeting, regardless of the presence of comorbid mental disorder or intellectual disability. Psychotherapy sessions and educational meetings are also offered to family members, with the purpose of helping caregivers understand and manage the patient's conditions.

2.2. Inclusion criteria and sample characteristics

All patients above 18 years who had undergone the aforementioned diagnostic procedures were included in the study. We chose to limit the sample to individuals with more than one year of diagnosis in order to examine patient's and caregiver's ability to distinguish the events on long term follow-up.

Patients with uncertain diagnosis after VEEG monitoring or suspected malingering were not included. Malingering was suspected if the patient had a clear and immediate benefit from having seizures, or acknowledged that the seizures were intentionally produced.

Cases fulfilling these criteria were invited to participate in the study, and were also asked to include a caregiver, though not necessarily the same person who had participated in the diagnostic process. This study was approved by the Institutional Ethics Committee.

2.3. Data acquisition

Clinical information at diagnosis and during follow-up were collected through chart review by the main investigator (PCG). Data included demographic information, mental disorder and epilepsy diagnosis, seizure features, and event frequency at the time of diagnosis.

Psychiatric disorders and intellectual disability were diagnosed after a series of psychiatric interviews by the psychiatry team members throughout the follow-up period, and were made according to DSM-IV-TR criteria.[18] Intellectual disability was diagnosed with DSM-IV-TR criteria for "Mental Retardation": intellectual deficit (reasoning, planning, abstract thinking, learning from experience) and adaptive function deficit (such as personal independence and social responsibility) with onset during the developmental period.[18] Psychiatric disorders and intellectual disabilities were classified as present or absent.

2.4. Study procedures

Patients and caregivers were evaluated individually by a psychiatrist (LCV) blinded to the nature of the patients' events. Patients answered six questions, presented in the same order:

"Do you remember your diagnoses?"
"Do you remember your different seizure types?"
"Can you tell the difference between one type of seizure and the other?"
"If so, how can you tell the difference between one type of seizure and the other?"
"When did your last epileptic seizure happen?"
"When did the last psychogenic non-epileptic seizure happen?"

The interview of caregivers followed the same structure, with an additional question: "Did you participate in the patient's VEEG, when the diagnoses were established?" The caregivers' relationship to the patients and their years of formal education were also noted. The aim of this interview was to verify the respondent's knowledge about the conditions, to assess both events frequencies, and to identify possible event related cues that could allow correct event identification.

Following the interview, respondents were presented with video excerpts obtained from the diagnostic VEEG monitoring procedure. Video excerpts were selected with the aid of an experienced epileptologist (CLJ) who had participated in the diagnostic process. Each respondent was presented with four video excerpts of approximately 20-s duration, which included two epileptic seizures and two PNES displayed in a random order. After each excerpt, the respondent was asked if the video represented an epileptic seizure or a PNES. If the respondent misidentified the event or was unable to classify the event, the answer was considered wrong. Only respondents who correctly identified all four events were considered as "correct identification."

After this procedure, respondents were again questioned about both events frequencies. If both the patient and the caregiver stated that a certain type of event (either PNES or epilepsy) had not occurred in the previous six months, the event would be considered controlled (controlled PNES or controlled epilepsy).

2.5. Statistical analysis

Groups were compared with univariate analysis, using Fisher's exact test and Chi-square (non-continuous variables) or independent samples *t*-test (continuous variables). Controlled analyses between variables were performed using the Mantel–Haenszel method.

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