



## The approach to patients with psychogenic nonepileptic seizures in epilepsy surgery centers regarding diagnosis, treatment, and education



Kette D Valente <sup>a,\*</sup>, Luciano De Paola <sup>b,c</sup>, Andre Palmiini <sup>d,e,f</sup>, Eduardo Faveret <sup>g</sup>, Gerardo Maria de Araujo-Filho <sup>h</sup>, Helio van der Linden <sup>i</sup>, Marino M. Bianchin <sup>j</sup>, Roger Walz <sup>k</sup>, Rudá Alessi <sup>l</sup>, Tonicarlo Velasco <sup>m</sup>, Wagner A. Teixeira <sup>n</sup>, W Curt LaFrance Jr <sup>o,p</sup>

<sup>a</sup> Department of Psychiatry, Clinics Hospital of the Faculty of Medicine, University of São Paulo (USP), São Paulo, SP, Brazil

<sup>b</sup> Department of Neurology, Clinics Hospital, Federal University of Paraná, Curitiba, PR, Brazil

<sup>c</sup> Comprehensive Epilepsy Center, Hospital N S das Graças, Curitiba, PR, Brazil

<sup>d</sup> Medicine and Health Sciences Post-Graduate Program, São Lucas Hospital, Catholic University (PUCRS) RS, Brazil

<sup>e</sup> Department of Neurology, São Lucas Hospital, Catholic University (PUCRS) RS, Brazil

<sup>f</sup> Epilepsy Surgery Program Service, São Lucas Hospital, Catholic University (PUCRS) RS, Brazil

<sup>g</sup> Brain Institute - Paulo Niemeyer, Rio de Janeiro, RJ, Brazil

<sup>h</sup> Department of Psychiatry and Medical Psychology, Faculty of Medicine of São José do Rio Preto, SP, Brazil

<sup>i</sup> Neurologic Institute, Goiania, GO, Brazil

<sup>j</sup> Basic Research and Advanced Investigations in Neurology, Clinic Hospital of Porto Alegre, Federal University of Rio Grande do Sul, RS, Brazil

<sup>k</sup> Applied Neuroscience Center and Epilepsy Center of Santa Catarina (CEPESC), Hospital Universitário, Universidade Federal de Santa Catarina, Florianópolis, SC, Brazil

<sup>l</sup> Department of Neurology, Medical School - ABC, Santo André, SP, Brazil

<sup>m</sup> Department of Neurology, Clinics Hospital, Faculty of Medicine, University of São Paulo, Ribeirão Preto, SP, Brazil

<sup>n</sup> Department of Neurology, Hospital de Base, Brasília, Brazil

<sup>o</sup> Department of Psychiatry, Rhode Island Hospital, Brown University, Providence, RI, USA

<sup>p</sup> Department of Neurology, Rhode Island Hospital, Brown University, Providence, RI, USA

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### ABSTRACT

Previous studies, using surveys, provided an understanding about how health-care providers address patients with PNES. To date, there is limited information on the management of patients with PNES by tertiary referral centers for epilepsy. In this study, we surveyed 11 Brazilian epilepsy center directors about diagnosis, treatment, education and research on PNES. Respondents reported that patients with PNES represented 10–20% of all adult patients recorded by video-EEG (VEEG). All respondents recognized VEEG as the method to confirm the diagnosis, and 81.8% used this approach for confirmation. Most centers had a standard protocol for diagnosis. None of the centers had a particular protocol to treat PNES, but 90.9% had a uniform treatment approach including therapy and educational measures. Psychotherapy was not easily obtained in nine centers (81.8%). Seven (63.3%) centers reported ongoing research projects with PNES. Five centers referred to an educational PNES program discussing diagnosis, but only one reported an educational program for treatment. This study showed a commitment to PNES diagnosis; however, some gaps remain regarding treatment and training, namely implementing a psychotherapy approach for patients and providing educational curricula for clinicians.

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### 1. Introduction

Psychogenic nonepileptic seizures (PNES) represent a universal human condition and are recognized as a worldwide phenomenon [1], sharing many similarities on patient demographics, semiology, and coexisting neurological and psychiatric disorders, despite cultural and economic differences across nations [2–4]. Approximately one-fifth of

patients referred with new-onset events and 20–25% of all patients referred to specialist epilepsy clinics have PNES [5–9]. Minimum requirements for PNES diagnosis and controlled protocols for treatment have been established [10,11] but are not implemented at all centers.

Previous studies, using surveys, provided an understanding about how health-care providers (HCP) from different countries, such as USA, Chile, UK, Australia, and Brazil address patients with PNES [12–15]. These surveys were directed to professionals who diagnose and treat patients with epilepsy and PNES. These studies showed differences in the diagnosis and treatment that were deemed to be related mainly to the health-care system and to professional medical attitudes.

\* Corresponding author at: Rua Dr. Ovídio Pires de Campos, 785 CEP, São Paulo, S.P., Brazil.

E-mail addresses: [kette.valente@hc.fm.usp.br](mailto:kette.valente@hc.fm.usp.br), [kettevalente@msn.com](mailto:kettevalente@msn.com) (K.D. Valente).

These findings highlighted that more regional health-care policies may be necessary because of these differences across countries and cultures and consequently in the HCPs' attitudes and the associated practice difficulties, including limited access to video-EEG (VEEG) and referral to effective psychotherapy for PNES.

To date, data are limited on how tertiary care centers for epilepsy manage diagnosis, treatment, education, and research on PNES. Tertiary care centers play a significant role in neurologists' education in diagnosis and treatment of epilepsy and PNES. Typically in Brazil, neurologists are the first to encounter, diagnose, and provide initial treatment for patients with PNES, and then sometimes refer the patients to psychiatric settings [15]. In this context, tertiary care centers play a major role in determining guidelines for patient management.

The Brazilian Health System has distinct particularities from other South American countries that notably influence health care. The Brazilian system is distinctly divided into private and public sectors. It is estimated that approximately 75% of a population of almost 200 million use the public sector in Brazil, representing one of the largest public health systems in the world [16].

The presence of a protocol with a uniform approach for diagnosis and treatment across tertiary centers could potentially provide better care and also could play a contributory role for educational purposes. In this study, we aimed to: (1) determine the presence of a uniform and standard approach to patients with PNES when considering diagnosis and treatment in different centers of a middle-income country, and (2) verify the existence of an educational program and of ongoing research about PNES in these centers.

## 2. Methods

### 2.1. Study design

The original questionnaire was used in an earlier survey developed by LaFrance et al. for assessing standard medical care (SMC) for PNES by North American HCPs [12]. As previously done with other HCPs, this questionnaire was administered in this study as a single group survey in a cross-sectional design, with the intent of quantifying the approaches to diagnosis, treatment, research, and education of PNES across Brazilian epilepsy centers.

### 2.2. Questionnaire design

A Brazilian physician (KV), with proficiency in both languages, translated the original PNES SMC questionnaire [12] from English to Portuguese. Next, a native-English-speaking teacher with proficiency in English and Portuguese back-translated the survey. The authors compared the back-translated version with the original translation and identified words that did not reflect the original meaning and that thus, needed a semantic adaptation. For the purpose of the current study, the authors modified this adapted questionnaire and submitted it to further analysis (WCL). The survey consisted of 30 questions assessing diagnostic and treatment practices, research, and education for PNES. The areas of interest covered by this questionnaire are shown in Table 1.

### 2.3. Data collection and preparation

Brazilian Epilepsy Center directors were contacted by e-mail by the lead author (KV) to provide an explanation about the objective of the questionnaire and its design. After consent, the survey was sent to Brazilian epilepsy centers' directors by email, who returned the completed questionnaires by email to the lead author.

The data were collected and entered directly in a Microsoft Excel database by the first author. All center directors completed the surveys entirely. Therefore, no questionnaire was excluded from the final analyses.

**Table 1**

Areas addressed in the questionnaire.

<b>1. Estimated Frequency of PNES</b>
1.1 Outpatient facility
1.2 Inpatient long-term VEEG
1.3. Estimated frequency of PNES and epilepsy
<b>2. Diagnosis of PNES</b>
2.1. Presence of a protocol for diagnosis
2.2. Main reasons for PNES referral for VEEG
2.3. Diagnostic methods used to confirm a suspected diagnosis of PNES
2.4. Is VEEG always used to confirm the diagnosis
2.5. Induction techniques
<b>3. Communication of Diagnosis of PNES</b>
3.1. Professional(s) in charge for communication (source of information)
3.2. To whom the diagnosis is given (patient; family; patient and family)
3.3. Terminology used when the diagnosis is given
<b>4. Treatment</b>
4.1. Presence of a protocol for treatment
4.2. Professional(s) in charge of treatment
4.3. Treatment proposed after diagnosis
4.4. Availability of psychiatric intervention, educative measures and psychotherapy
4.4 Pharmacologic treatment (AED withdrawn/Psychoactive drugs for comorbid diagnosis)
<b>5. Education</b>
5.1. Educational training for the diagnosis of PNES
5.2. Educational training for the treatment of PNES
<b>6. Knowledge about PNES among distinct professionals</b>
6.1. Psychiatrists
6.2. Psychotherapists
6.3. Neurologists
<b>7. Research about PNES</b>
7.1. Previous and current research about PNES
7.2. Previous and current research about psychiatric issues and epilepsy

### 2.4. Analysis plan

Categorical responses were tabulated as frequencies and percentages. Continuous variables were reported as means and ranges. For qualitative assessment, the open-ended questions were reviewed, and significant themes are noted in the Results. The study was approved by the local ethics committee of the University of São Paulo.

## 3. Results

### 3.1. Epilepsy center characteristics

The survey was sent by email to 13 tertiary epilepsy centers. Eleven centers responded to the survey. Five (45.4%) respondents were from the Southeast region of Brazil, four (36.4%) were from the South, and two (18.2%) were from the Central West region. All respondents were epileptologists (neurologists) responsible for their centers (Epilepsy Center Coordinators). One center did not answer the email, and one center was not accepting patients with PNES at the time of the survey administration.

All 11 responding centers identified themselves as tertiary epilepsy centers and 10 (90.9%) as epilepsy surgery centers. The reported number of adult patients with epilepsy attending the outpatient facility ranged from 60 to 680/month (mean 206.36; median 160; SD 176.76), and the long-term inpatient VEEGs ranged from 10 to 30/month.

The reported number of patients with PNES attending the outpatient facility ranged from 1 to 40/month. The number of patients with PNES documented by long-term inpatient VEEG was 1–5/month in nine centers, and 6–10/month in two centers. The centers reported an estimated frequency of co-existing PNES and epilepsy that ranged from 10%–50% (four centers reported 21 to 30%; three centers reported 41 to 50%; two centers related  $\leq$ 10%; one center, 11–20%; and one center, 31–40%).

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