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Communicating diagnostic certainty of psychogenic nonepileptic seizures — a national study of provider documentation

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ABSTRACT

Management of psychogenic nonepileptic seizures (PNES) requires collaboration among and between health care professionals. Although criteria are established for diagnosis of PNES, miscommunication between neurologists, primary care providers, and mental health professionals may occur if the clinical impression is not clearly articulated. We extracted progress notes from the Department of Veterans Affairs (VA) electronic health record (EHR) nationally to study veterans who were evaluated for PNES. Of the 750 patients being worked up for PNES, the majority of patients did not meet criteria for PNES (64.6%). Of those who were thought to suffer from PNES, 147 (19.6%) met International League Against Epilepsy (ILAE) criteria for documented PNES, 14 (1.9%) for clinically established PNES, and 104 (13.9%) for probable or possible PNES. Neurologists tended to use ambiguous language, such as "thought to be" or "suggestive of" to describe their impressions of patients overall, even those with definitive PNES. Ambiguous language may lead to miscommunication across providers and inappropriate health care.

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1. Introduction

PNES is a commonly occurring conversion disorder that requires coordination of care between neurology, mental health, and primary care. Barriers to optimal care are due to challenges of diagnosis and treatment for this complex neuropsychiatric population. These gaps include the challenge of capturing representative paroxysmal episodes by video electroencephalogram (VEEG) in order to characterize seizure-like events using the diagnostic gold-standard, as well as the challenge of coordinating medical and mental health care across disciplines. Common techniques used to capture events, such as activation procedures (e.g., photic stimulation and hyperventilation) or presenting the triggering stimulus, are not always incorporated during epilepsy monitoring unit (EMU) admission. Similar to academic settings [1], as many as 45% of patients monitored with VEEG in the VA [2], a large U.S. national healthcare system, do not experience a seizure-like event in EMUs. Without an event, the VEEG is considered nondiagnostic, and patients are not given a clear diagnosis [2].

When mental health providers are consulted for management of PNES, they sometimes question the diagnosis. Even with VEEG diagnostic confirmation, many mental health providers do not believe the diagnosis is PNES [3]. Many patients with confirmed diagnoses are returned to the referring neurologist for reevaluation [4]. Uncertainty in the diagnosis of PNES may exacerbate the issue and be reflected in how providers communicate the diagnosis to patients [5,6], as well as with other providers. How providers communicate the diagnosis of PNES to other providers has not been studied, directly in the electronic health record (EHR), to date.

One potential reason for diagnostic uncertainty in PNES may be that the current clinical approach to definitively diagnosing PNES is dichotomous, that is, a patient either has PNES or not. In 2013, The International League Against Epilepsy (ILAE) Nonepileptic Seizures Task Force published a means of stratifying the level of certainty of the diagnosis to four levels: possible, probable, clinically established, and documented PNES (Table 1) [7]. The proposed criteria allow patients and providers with limited access to VEEG to make a diagnosis of PNES [7]. Published research has used the diagnostic levels [8,9], however, it is unclear how

Abbreviations: EHR, electronic health record; OEF/OIF, Operation Enduring Freedom/Operation Iraqi Freedom; PNES, psychogenic nonepileptic seizures; VEEG, video electroencephalograph.

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Table 1
Overview of proposed diagnostic levels of certainty for psychogenic nonepileptic seizures (PNES) by ILAE Task Force.

Diagnostic level	History	Witnessed event	EEG
Possible	+	By witness or self-report/description	No epileptiform activity in routine or sleep-deprived interictal EEG
Probable	+	By clinician who reviewed video recording or in person, showing semiology typical of PNES	No epileptiform activity in routine or sleep-deprived interictal EEG
Clinically established	+	By clinician experienced in diagnosis of seizure disorders (on video or in person), showing semiology typical of PNES, while not on EEG	No epileptiform activity in routine or ambulatory ictal EEG during a typical ictus/event in which the semiology would make ictal epileptiform EEG activity expectable during equivalent epileptic seizures
Documented	+	By clinician experienced in diagnosis of seizure disorders, showing semiology typical of PNES, while on video EEG	No epileptiform activity immediately before, during or after ictus captured on ictal video EEG with typical PNES semiology

Legend: PNES, psychogenic nonepileptic seizures; ILAE, International League Against Epilepsy; +, history consistent with conversion disorder/PNES; EEG, electroencephalogram.
From LaFrance WC, Jr., Baker GA, Duncan R, Goldstein LH, Reuber M. Minimum requirements for the diagnosis of psychogenic nonepileptic seizures: a staged approach: a report from the International League Against Epilepsy Nonepileptic Seizures Task Force. Epilepsia 2013; 54 (11): 2005–18.
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providers worldwide are utilizing the ILAE diagnostic guidelines in daily clinical practice.

Using an established national EHR examining 14 years of patient records, we examined the clinical criteria providers use to establish the diagnosis of PNES and how they communicated the diagnosis to other providers in the EHR. We hypothesized that when neurologists capture seizure-like events on VEEG, they will provide more clear language and express diagnostic certainty.

2. Methods

2.1. Design and data source

The study data were accessed using the VA Informatics and Computing Infrastructure (VINCI), which is a secure computing environment available to access national clinical data, including data from the VA EHR. Data from Operation Enduring Freedom/Operation Iraqi Freedom (OEF/OIF) veterans, which includes 749,036 veterans, were included in this analysis. Only veterans with a history of seizure disorders or epilepsy (ICD-9 code of 345 or 780.39) from 2001 to 2014 were included. Since there is no ICD-9 code to identify veterans with PNES in the VA national database and the ICD-9 code for conversion disorder (300.11) was and is not readily used by neurologists to label PNES, an EHR mining tool called Voogo was used to identify patients with PNES in neurologists' progress notes [10,11]. Voogo allows users to conduct keyword searches within text and retrieve texts of 20 words before and after each PNES keyword (*snippets* of texts). Keywords to search for PNES included the following: "nonepileptic seizure", "NES", "PNES", and "psychogenic". The above filtering criteria yielded 750 unique patients and 1645 neurology service progress notes.

Two reviewers (KE & JG), trained by a board-certified neurologist and neuropsychiatrist (HA) to perform chart reviews, reviewed each snippet. The reviewers determined the level of certainty expressed by providers in diagnosing PNES. Based on providers' documentation within the clinical notes, the reviewers manually classified each snippet into one of the following categories: "definite PNES" (incorporating both ILAE documented and clinically established categories), "probable PNES" (clinicians expressing they strongly suspected PNES but had not completed the work-up), "possible PNES" (PNES was on the differential diagnosis but not strongly suspected), and "not PNES" (PNES was ruled out). The first author (HA) reviewed all classifications and adjudicated when discrepancies occurred (261 snippets). For patients with multiple notes and snippets, the reviewers made a decision regarding the patient's final diagnosis based on the most recent note/document. The reviewers also extracted and identified the expressions, terms, and phrases used by neurologists in describing their level of certainty in diagnosing PNES. The reviewers then marked where in the progress note the neurologist documented a diagnosis of PNES. In addition, the reviewers screened the documents to explore the use of the ILAE criteria in clinicians' decision-making and what other clinical criteria they used to validate their diagnosis.

2.2. Statistical analysis

A Cohen's kappa statistic was calculated to test interrater agreement of the diagnosis of PNES, for each patient, between reviewers.

2.3. Standard protocol approvals, registrations, and patient consents

The study was approved by the VA Connecticut Healthcare System Institutional Review Board.

3. Results

The kappa statistic between the two reviewers demonstrated substantial agreement at 0.80 across evaluation of patients. Of the 750 unique patients who were being worked up for PNES, providers' notes contained language that allowed categorization of 147 (19.6%) patients meeting the ILAE criteria for documented PNES, 14 (1.9%) with clinically established PNES, and 104 (13.9%) probable or possible PNES. None of the clinicians explicitly cited or invoked the ILAE criteria or framed their clinical findings according to its recommendations. However, clinicians used terms and phrases similar to those recommended by the ILAE such as "probable" or "possible".

Of the 1653 notes reviewed, 520 snippets were classified as "definite PNES", 255 snippets were classified as "probable PNES", and 702 snippets were classified as "possible PNES". From the extraction review, 176 snippets were classified as "not PNES" because they were not related to PNES and they often described other psychogenic problems such as psychogenic impotence and psychogenic movement disorders (Table 2). We found that the term "documented PNES" was used in 15 snippets, "established PNES" was used in 4 snippets, "probable PNES" was used in 17 snippets, and "possible PNES" was used in 59 snippets. Although these are the terms describing levels of certainty recommended by the ILAE, we assume that clinicians are using them for their literal rather than technical meaning proposed by the ILAE, given that many of the notes were documented before 2013. Descriptive expressions and phrases were identified and classified (Table 3) into the

Table 2
Number of patients and snippets in each diagnostic category.

Classification	Number of snippets	Number of patients
Definite PNES	520	217
Probable PNES	255	110
Possible PNES	702	318
Not PNES	176	105
Total	1653	750