The Diagnosis of Psychogenic Nonepileptic Seizures

By Selim R. Benbadis, MD [2]

About 25% of patients seen in epilepsy clinics and monitoring units who do not respond to antiepileptic drugs (AEDs) have received a misdiagnosis.1-3 The eventual diagnosis for most of these patients will be psychogenic nonepileptic seizure (PNES), a somatoform conversion disorder. It is treatable, but diagnosis, delivery of the diagnosis, and management present significant challenges. A major barrier to care has been the stigma associated with the label "psychogenic."

About 25% of patients seen in epilepsy clinics and monitoring units who do not respond to antiepileptic drugs (AEDs) have received a misdiagnosis.1-3 The eventual diagnosis for most of these patients will be psychogenic nonepileptic seizure (PNES), a somatoform conversion disorder. It is treatable, but diagnosis, delivery of the diagnosis, and management present significant challenges. A major barrier to care has been the stigma associated with the label "psychogenic." Both patients and clinicians—and remarkably, psychiatrists—are uncomfortable with a PNES diagnosis; a disconnect seems to exist between recognition of psychogenic ailments among neurologists, psychiatrists, and physicians in general and the ability to address such conditions.5 Consider that a search for the word "psychogenic" in the titles of articles from the archives of Neurology spanning 1994 to 2003 turned up 21 articles, all but 4 of which addressed the topic of psychogenic seizures. Meanwhile, a similar search of the New England Journal of Medicine found no articles in which the term "psychogenic" appeared in the title.5 More telling, a word search of titles in the "scientific sessions and all sessions" online database for the 2004 annual meeting of the American Psychiatric Association turned up 0 titles with the word "conversion" but 2 with the word "somatoform." In contrast, the word "depression" turned up in the titles of about 220 sessions and "anxiety" turned up in about 82. The word "eating" (eg, "eating disorder") also was popular, appearing in the titles of 70 sessions. Although these observations suggest that physicians avoid addressing psychogenic illnesses, psychogenic symptoms are commonly seen in medical practices. They include GI and respiratory symptoms, certain (often self-inflicted) dermatologic ills, chest pain, heartbeat irregularities, globus hystericus and dysphonia (seen in otolaryngology practices), visual disturbances, and pain syndromes. Data on overall prevalence are scare; however, it is estimated that at least 10% of all medical services are provided for patients with psychogenic symptoms.7 Furthermore, psychogenic illnesses and their lack of recognition and intervention place a significant burden on health care resources. A recent study by Barsky and colleagues8 found that health care utilization and its attendant costs for patients with somatization were twice those for nonsomatizing patients. When the data were extrapolated to the national level, it was determined that about $256 billion per year is spent on medical costs for somatic illnesses. Psychogenic illnesses also account for about 9% of inpatient admissions for neurologic ailments,9 and the percentage is probably higher for outpatient visits for neurologic consultations. Indeed, the estimated prevalence of PNES alone in the general population is 2 to 33 of every 100,000 persons.1 Common symptoms of neurologic somatoform disorders include paralysis, mutism, visual and sensory effects, movement disorders, problems related to gait and balance, and pain.9-11 Signs and maneuvers have been described to help the neurologist distinguish organic from nonorganic symptoms. For example, the Hoover test has been used to evaluate limb weakness, and signs of preserved optokinetic nystagmus are looked for in patients who present with alleged blindness. More commonly, the neurologist tries to elicit signs and symptoms during the clinical evaluation that do not make neuroanatomic sense, such as abasia-astasia in a patient who claims to have paralysis or a movement disorder. Unlike other psychogenic disorders, however, PNES can definitively be diagnosed. PNES is not simply a diagnosis of elimination. Video-electroencephalographic (EEG) monitoring will demonstrate no change in EEG pattern during the event. In addition, it will reveal a clinical ictal semiology inconsistent with other types of seizures that may occur in the absence of EEG changes. Nevertheless, although PNES has been extensively studied since the advent of video-EEG monitoring, 7 to 10 years typically elapse before PNES is finally diagnosed in an affected patient,12,13 presumably because suspicion is not high enough among neurologists to make the diagnosis. Meanwhile, patients with PNES are routinely and ineffectually treated with AEDs,14 contributing to further morbidity—and even mortality.
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unnecessary health care expenditures.16,17 WHAT’S IN A NAME? PNES is often presented in the neurology literature as a unique epileptiform disorder, but it is a somatoform conversion disorder that once diagnosed, should be treated like any other somatoform disorder, preferably in a psychiatric setting. It has been referred to as pseudoseizures, nonepileptic seizures, nonepileptic events, psychogenic seizures, and hysterical seizures. The first 3 terms, however, can describe psychogenic as well as organic events that mimic epilepsy and can include phenomena as syncope; paroxysmal movement disorders; cataplexy; complicated migraines; and in children, breath-holding spells and shuddering attacks. Therefore, to use these terms when PNES is meant may be misleading and confusing. "Psychogenic seizures" likewise is inaccurate because the term could be interpreted to mean epileptic seizures triggered by psychological factors. The term "hysterical" to describe psychogenic origin is archaic, and its use has been out of favor for a while. Nevertheless, the term "psychogenic" remains discomforting. Unfortunately, for many health care practitioners psychogenic means "faked." Thus, patients with this and other somatoform disorders are lumped together with patients who are malingerers (ie, persons deliberately feigning illness to avoid jail or to cash in on a liability claim) and patients with factitious disorders (ie, those who deliberately induce illnesses and play the role of an ill person as a symptom of psychopathology). Furthermore, patients and their families take offense at the diagnosis of PNES, assuming that they are being labeled "crazy" or are being accused of faking a medical condition. Anxiety about confronting the dismay or ire of patients causes neurologists to be timid or ambiguous in discussing the diagnosis and reluctant to refer the patient for psychiatric care. Such patients will continue to live under the impression that they have treatment-refractory epilepsy, will consider themselves disabled (unable to work or drive and limited in their social activities), and will continue to receive AEDs but experience seizures. SIGNS AND SYMPTOMS Unlike malingering and factitious disorders, somatoform disorders are not consciously produced. Although video-EEG findings distinguish PNES from epilepsy, for the patient, the seizures are real and disabling events. Clinical signs and symptoms suggestive of—but not definitively diagnostic for—PNES do exist. Careful observation and documentation are invaluable in making the diagnosis. They also aid the clinician in making the decision to refer a patient for video-EEG monitoring. The first clue to PNES is lack of response to AEDs and a high frequency of seizure events regardless of whether the patient is receiving medication. Motor phenomena during seizures also differ from motor phenomena witnessed in epilepsy, although patients and witnesses may not be able to describe them clearly, relegating such detection to a trained eye and video-monitoring data (see Table). Also, seizures tend to occur in the presence of an audience,18 and do not occur during sleep although the patient may report that they do.19,20 Like other somatoform disorders, PNES is associated with a history of sexual or physical abuse, or other profound trauma21,22 that can be deftly elicited during the history taking. Patients with PNES also typically report having concomitant maladies that are probably somatic. The maladies include fibromyalgia, chronic pain, irritable bowel syndrome, and chronic fatigue.18,23 Patients will generally report being under stress,22,24 and a history of maladaptive behavior or a psychiatric diagnosis also is not uncommon. Physicians should note the patient's demeanor and affect during the diagnostic workup. Alexithymia, overdramatization, and histrionic mannerisms should raise the level of suspicion. Patients also may display "give-way" weakness or "tight-roping" (abasia-astasia) during the clinical examination. On the other hand, clinical signs and symptoms suggestive of epilepsy—but not commonly seen in PNES—include significant post-ictal confusion, incontinence, and significant injury.25-29 Tongue-biting is particularly suggestive of tonic-clonic seizures.26 CONFIRMING THE DIAGNOSIS Routine EEGs alone are not helpful in diagnosing PNES because their sensitivity is low. The ictal EEG findings may be negative in simple partial seizures30,31 and in some partial complex seizures.28 The EEG also may be difficult or impossible to interpret if motor movements result in excessive artifact. Moreover, many patients in whom PNES is eventually diagnosed have "positive" EEG findings in their history. When such findings are reexamined, the EEG tends to display overinterpretation.32 If prior EEGs are available, it is worthwhile to acquire and reexamine them. Although EEGs may not be diagnostically definitive, a history of repeated normal EEGs, especially in patients who report frequent attacks that do not respond to AEDs, should raise the level of suspicion. Ambulatory EEG monitoring also may be helpful in documenting seizure-like activity in the absence of EEG changes, but it is highly recommended that the findings be backed up by video-EEG monitoring data to establish sufficient proof before discussing the diagnosis with the patient and his or her family. Video-EEG monitoring is the gold standard for diagnosis of PNES.4,12,19,20,25-28,33 As mentioned, video-EEG monitoring will provide evidence of whether the seizure is accompanied by EEG changes characteristic of epilepsy and will record clinical ictal semiology that may or may not conform to that seen in epilepsy or seizure types.
that occur in the absence of EEG changes. Characteristics identified on video that distinguish PNES from epileptic or other types of seizures (see Table) include very gradual onset or termination of the seizure, pseudosleep, and discontinuous or asynchronous activity. Motor phenomena that are relatively specific for PNES include side-to-side head movement, pelvic thrusting, back-arching (opisthotonic posturing), bilateral movements with preserved awareness, stuttering, and weeping.19,20,25,27,28,34-37 Provocative techniques (inductions), which only should be used in the setting of video-EEG monitoring, can be useful in the diagnostic process. The techniques are especially useful when the diagnosis remains uncertain or when seizures do not otherwise occur during monitoring. Although many epilepsy clinics use some type of induction for diagnosis of PNES, ethical concerns about some techniques, specifically placebo induction, have been raised.38-41 At issue is the deceptiveness a physician invariably perpetrates when administering placebo intravenously or performing a particular maneuver to convince the patient that the procedure will induce seizure.42-45 Although placebo induction in the form of intravenous saline injection has been the most common provocative technique used in the diagnosis of PNES, techniques that do not rely on placebo may be preferable because ethical conundrums can be avoided without compromising the integrity of the diagnosis.40,46 The best-documented provocative technique combines verbal suggestion with photic stimulation and hyperventilation (in patients in whom hyperventilation is contraindicated, substitute counting with arms raised).46,47 The sensitivity of this technique ranges from 60% to 90%.42-49 DELIVERING THE DIAGNOSIS How to inform the patient of the diagnosis and what to do once the diagnosis has been delivered remain challenges. Delivery of the diagnosis, however, probably is the most important part of initiating treatment for these patients and their families.13,50-52 Both the examining clinicians and the clinicians who interact with the patient and the patient's family need to be specific, and they should present their findings comprehensively. Appropriate, honest, and clear information about the findings must be communicated to the patient in a compassionate and confident manner. Unnecessary avoidance, euphemisms, and other "beating around the bush" or wishy-washy explanations are counterproductive. When the diagnosis is firmly established, it should be clearly stated; the clinician should explain that the episodes are "stress-related" or related to emotional issues. The patient should be referred for psychiatric intervention; however, for the most successful outcome, the neurologist needs to maintain involvement in patient care. Follow-up consultations should be provided to prevent the patient from feeling abandoned and to wean the patient from AEDs. Furthermore, the neurologist-in conjunction with the psychiatrist-needs to address the issues of perceived disability and activities of daily living. Patient education materials are essential. Patients who are informed about and learn to accept their condition will be more proactive about care and will have better outcomes.13 Such information is not abundant; however, thanks primarily to neurologic specialists who have an interest in PNES, it is available. Materials used at the Comprehensive Epilepsy Program at Tampa General Hospital can be viewed and downloaded at http://hsc.usf.edu/com/epilepsy/PNESbrochure.pdf. REFERENCES 1. Benbadis SR, Hauser WA. An estimate of the prevalence of psychogenic non-epileptic seizures. Seizure. 2000;9:280-281. 2. Scheepers B, Clough P, Pickles C. The misdiagnosis of epilepsy: findings of a population study. 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Practice. 4th ed. Philadelphia: Lippincott, Williams & Wilkins. 2005;623-630. SELIM R. BENBADIS, MD, is director of the Comprehensive Epilepsy Program and professor of neurology in the departments of neurology and neurosurgery at the University of South Florida and Tampa General Hospital, both in Tampa. --- TABLE Historical and ictal features that should raise the suspicion of PNES53,54 History: Ictal characteristics Chronic pain or "fibromyalgia": Very gradual onset Florid review of system: Asynchronous movements Psychosocial dysfunction: Pelvic thrusting Psychiatric diagnoses: Weeping Repeatedly normal EEGs: Stuttering Unusual triggers (pain, getting upset, stress): Opisthotonic posturing Occurrence in the medical setting (eg, waiting room): Side-to-side head movements, Closed eyelids, Duration > 5 minutes, Rapid post-ictal recovery PNES, psychogenic nonepileptic seizures; EEG, electroencephalogram.


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