

# A Seizure by Any Other Name: Challenges and Long-Term Implications of Psychogenic Nonepileptic Seizures

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Psychogenic nonepileptic seizures are a spectrum of somatoform disorders that present with clinical signs of seizure-like events without organic etiology. Specifically, psychogenic nonepileptic seizures represent a subtype of conversion disorder in which patients experience involuntary physical events without abnormal or epileptiform activity on EEG monitoring (1). The American Epilepsy Society estimates that 20%–30% of intractable seizures seen at specialist epilepsy clinics are attributable to psychogenic nonepileptic seizures (2). A patient with psychogenic nonepileptic seizures in the United States can expect an average monthly medical cost of \$1,359 (3), adjusted to \$24,313.56/year, per the 2017 consumer price index (4). Given an average duration of 7.2 years before the proper diagnosis is made and an estimated prevalence of 2–33 cases per 100,000, these costs represent a substantial burden on the health care system (5). In this article, we highlight the barriers to care in management of psychogenic nonepileptic seizures and the associated diagnostic challenges. We further posit strategies for addressing these barriers to meet the treatment needs of patients more effectively.

## COMORBIDITY AND PREDISPOSING FACTORS

While there is no clearly discernible cause of this disorder, it is widely thought to be a manifestation of increased psychological burden, since comorbidities such as anxiety (25%), de-

pression (38%–54%), and chronic pain (57%) have been reported (6). However, the most strongly correlated factors appear to be trauma-related. Past history of nonsexual (86.6%) and sexual (30%) trauma has been well documented (7). Many of these psychosocial issues are unknown or unrecognized when a patient presents for initial evaluation, emerging only after a strong therapeutic alliance has been formed between the patient and the provider (8). Importantly, there appears to be no temporal relationship between the trauma and the onset of seizure-like events, with lapses ranging from days to years (9), and thus providers must be mindful of this when obtaining a patient's history.

## STIGMA AND PROVIDER MISUNDERSTANDING

Patients with psychiatric conditions frequently experience feelings of stigmatization at higher rates than those without psychiatric conditions (10). In a subgroup analysis, the odds ratio of perceived stigma among patients with psychogenic nonepileptic seizures compared with those with epilepsy was found to be 4.27, suggesting a fourfold greater odds in an individual's lifetime (11). Contributing factors to perceived stigma include perceptions of weakness and difficulty in clinical management (12). A survey of 143 neurologists in an academic setting indicated that patients whose symptoms were “less explained by organic disease,” including but not limited to psychogenic nonepileptic sei-

zures, were perceived as “very difficult” or “extremely difficult” to treat (13).

However, assumptions of malingering appear to be the most heavily cited source of perceived stigma. In one investigation at a university medical center, as much as 48% of ancillary staff members who cared for patients with psychogenic nonepileptic seizures regularly described these seizures as “fake” and attributable to patients' voluntary control (14). Similarly, as much as 20% of primary care physicians mistake psychogenic nonepileptic seizures for a conscious attempt to deceive for either primary gain (e.g., Munchausen's syndrome) or secondary gain (e.g., malingering) (15). This belief reflects a core misunderstanding among some providers: that patients with psychogenic nonepileptic seizures exert a greater level of control over their events than their epileptic counterparts. In fact, the opposite may be true, as epileptic seizures are commonly accompanied by aura or prodromal signs enabling the patient to recognize the impending event and react accordingly (16). Nonepileptic episodes typically do not involve such warning signs.

In light of this misunderstanding within the health care system, patients frequently report a lack of provider empathy (17). Empathy levels shown by health care providers have been found to affect both the quality of care and treatment outcomes in numerous pathologies (18). In our review of the literature, we found no studies that directly assessed the impact of provider empathy on patients with psychogenic nonepileptic

seizures. However, it stands to reason that provider education, both formal and informal, may improve empathy and overall patient outcomes.

## DIAGNOSTIC CHALLENGES AND THE RULE OF 10S

Epilepsy and psychogenic nonepileptic seizures are not mutually exclusive disease processes (19). LaFrance and Benbadis (20) were the first to report that 10% of epilepsy patients experience comorbid psychogenic nonepileptic seizures, while, similarly, 10% of patients with psychogenic nonepileptic seizures have comorbid epilepsy. Epileptologists colloquially refer to these results as the “rule of 10s.” However, more recent investigations suggest that the true prevalence of comorbidity may be as high as 35%–50% (20). This overlap makes clinical distinction more challenging. Several differences in presentation between epileptic and nonepileptic seizures have been noted across the literature (21, 22). These findings are summarized in Table 1. Given the variability in the presentation of both conditions, the International League Against Epilepsy recommends the use of clinical characteristics as guides to diagnosis, rather than absolute qualifiers (23). Nevertheless, in one survey of physicians in an academic hospital, 62% of respondents felt that they could differentiate psychogenic nonepileptic seizures from epileptic seizures purely on clinical presentation (24). Such limited diagnostic strategy may further delay correct diagnosis and access to care.

Numerous investigators have found utility in physical examination techniques, such as the Hand Drop Test and Hoover’s sign, to differentiate disorders of hypoactivity (namely, catatonia versus pseudoparalysis) (25). Psychogenic nonepileptic seizures and epilepsy are both disorders of hyperactivity; however, in our review of the literature, we found no clinical examination that reliably differentiated them.

Anecdotally, withdrawal to noxious stimuli, such as ammonia capsules (“smelling salts”), has been suggested to be a useful technique in some hospital settings, but in our review of the literature

**TABLE 1. Clinical Distinction Between Epileptic and Psychogenic Nonepileptic Events**

Demographic Characteristics and Clinical Indications	Epileptic Seizures	Psychogenic Nonepileptic Seizures
Age at onset (years)	Bimodal: most common among children and adolescents	All ages, but most common among individuals aged 20–35
Gender	1:1	3:1 in favor of females
Motor activity	Bilateral, stereotyped, synchronous movements	Asynchronous, commonly involves lateral (“side-to-side”) movements and pelvic thrusting
Urinary incontinence	Common	Uncommon
Duration	2–3 minutes	Often prolonged more than 3 minutes
Fatigability	Rare	Common
Sequelae	Tongue biting, head trauma, nonbracing trauma	Braced trauma
Amnesia	Common	Variable, nondefinitive
Prolonged ictal atonia	Very rare	May be present
Postictal symptoms	Headache common, usually drowsy, confused	Headache rare, often awake and reoriented quickly
Eyes	Usually open	Often closed, with forced eye closure suggesting psychogenic nonepileptic seizures
Vocalization	Uncommon	May be present
Autonomic signs	Cyanosis, tachycardia common with major convulsions	Uncommon

we found only one case series to support efficacy of this evaluation (26). Moreover, clinicians should be cautioned against attempting this technique with a patient with unknown pulmonary history, as it may trigger exacerbation of underlying respiratory conditions (e.g., asthma, emphysema). Of the induction techniques, verbal suggestion appears to be the most consistent. In one investigation of patients with confirmed psychogenic nonepileptic seizures, clinician suggestion of a “seizure” evoked an episode in 54% of patients (27). This technique is highly reliant on provider skill. Furthermore, inductive methods have drawn significant criticism for misleading or deceiving patients, as they may strain the patient-provider relationship (28).

Correct diagnosis remains dependent on secondary testing. In 96% of tonic-clonic seizures and 60% of complex partial seizures, serum prolactin levels increase more than three times the upper limit of the normal range within 20 minutes of onset (29). Still, lack of prolactin elevation is not diagnostic of psychogenic nonepileptic seizures, since levels may remain within normal limits following frontal lobe seizures and simple partial seizures (30). Randomized trials of patients assigned to video EEG monitoring consistently show both positive predictive value and negative predictive value greater than 90% for psychogenic nonepileptic seizures (31). Accordingly, 24-hour video EEG remains the gold standard for diagnosis of psychogenic nonepileptic

seizures, as endorsed by both the International League Against Epilepsy and the American Psychiatric Association. The presence of physical seizure-like activity without the presence of epileptiform or ictal discharge on video EEG is a positive result. However, given that video EEG is available only at specialized (tertiary) centers, it remains an expensive option with somewhat limited availability.

## **APPROPRIATE TREATMENT MODALITIES: A PATIENT-CENTERED APPROACH**

Proper treatment of psychogenic nonepileptic seizures necessitates a strong patient-provider relationship. Early psychoeducation, within 4 weeks of diagnosis, has been shown to improve performance on the Work and Social Adjustment Scale and to reduce seizure-related emergency department visits (32). Conversely, delays in psychiatric intervention are associated with poorer working memory and executive function (33). The key to establishing appropriate care is presenting the diagnosis to the patient and his or her family in a nonjudgmental, empathetic manner, while treating the patient with cognitive-behavioral therapy. With this approach, patients are approximately three times more likely to experience remission of their symptoms within 3 months of starting treatment (34). However, the inverse is also true: some patients will experience exacerbation of symptoms after their diagnosis is revealed, and premature discontinuation of neurologic follow-up may lead to resistance to accepting the diagnosis and worsening of symptoms (35).

Decisions regarding antiepileptic drugs are equally challenging. The majority of patients with psychogenic nonepileptic seizures are prescribed long-term (1 year or longer) antiepileptic drug therapy prior to receiving the correct diagnosis, exposing them to unnecessary adverse effects. Furthermore, prolonged nonepileptic events (>5 minutes) are often mistaken for status epilepticus. These patients are at risk for intubation and medically induced coma (36).

In evaluating the efficacy of antiepileptic drug therapy, a lack of response is the most common “red flag” for identi-

## **KEY POINTS/CLINICAL PEARLS**

- Clinically, nonepileptic events can best be differentiated from epileptic seizures by asynchronous movements, lack of tongue biting, and minimal postictal changes.
- While no examination finding allows for definitive diagnosis, verbal suggestion is the most reliable, although it may hinder patient trust.
- Video EEG monitoring is the gold standard for diagnosis, and patients likely benefit from early referral.
- Early psychiatric intervention, in the context of multidisciplinary care, leads to improved long-term outcomes in patients with psychogenic nonepileptic seizures, who already face significant provider misunderstanding and stigma.

fying psychogenic nonepileptic seizures and determining the need for referral to a tertiary epilepsy center for video EEG monitoring (37). Additionally, there is an associated placebo effect between psychogenic nonepileptic seizures and antiepileptic drugs. One study reported that 46.8% of patients with sole psychogenic nonepileptic seizures treated with antiepileptic drugs achieved complete or partial remission (38). Patients may therefore benefit from early referral to a tertiary center in lieu of empiric antiepileptic drug therapy, despite greater initial costs. This is especially true considering that the likelihood of developing epileptic seizures more than 1 year after a diagnosis of psychogenic nonepileptic seizures is remarkably low, and a diagnosis of psychogenic nonepileptic seizures does not seem to inhibit patients from seeking future neurologic care (39).

## **IMPLICATIONS FOR THE NEXT GENERATION OF PROVIDERS**

The aim of this article is to underscore the systemic challenges in diagnosing psychogenic nonepileptic seizures, as well as the necessity for earlier diagnosis and intervention. Patients with undiagnosed psychogenic nonepileptic seizures (or impaired insight into their condition) continue to present with seizure activity to primary care providers, urgent care facilities, and emergency departments. This not only contributes to the negative misconceptions held by some health care providers but also leads to a host of problems for the patient, from high financial burden to medical sequelae, such as antiepileptic drug

side effects, intubation, and even the induction of a medically induced coma for prolonged episodes.

Earlier diagnosis and treatment of psychogenic nonepileptic seizures is critical to provide better patient outcomes and to avoid adverse effects associated with overtreatment. While patient history and clinical presentation are essential components of diagnosis, health care professionals must use all the diagnostic tools available. More frequent utilization of 24-hour video EEG will aid in decreasing the time between patient presentation and recognition of the disorder. Further education on the nature of psychogenic nonepileptic seizures is necessary for health care providers, leading to better understanding and decreased stigmatization.

It is imperative that neurologic, psychiatric, and primary care providers are in frequent communication with each other to ensure that patients receive consistent information in a compassionate manner. The therapeutic alliance between patients and clinicians is a cardinal element in providing the necessary care to patients and in helping to negate the stigma associated with their condition. While the task of such coordination may seem daunting, it is the duty of health care providers to accept this charge and be the leaders in engendering a change that will improve the quality of life for thousands of patients each year.

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## REFERENCES

1. American Psychiatric Association: Diagnostic and Statistical Manual of Mental Disorders, 5th ed. Washington, DC, American Psychiatric Association Publishing, 2013
2. Asadi-Pooya A, Sperling M: Epidemiology of psychogenic nonepileptic seizures. *Epilepsy Behav* 2015; 46:60–65
3. Martin R, Gilliam F, Kilgore M, et al: Improved health care resource utilization following video-EEG-confirmed diagnosis of nonepileptic psychogenic seizures. *Seizure* 1998; 7(5):385–390
4. Consumer Price Index for All Urban Consumers: <https://data.bls.gov/cgi-bin/cpicalc.pl> (Accessed July 29, 2017)
5. Acton EK, Tatum WO: Inpatient psychiatric consultation for newly-diagnosed patients with psychogenic non-epileptic seizures. *Epilepsy Behav* 2013; 27(1):36–39
6. D'Alessio L, Giagante B, Oddo S, et al: Psychiatric disorders in patients with psychogenic non-epileptic seizures, with and without comorbid epilepsy. *Seizure* 2006; 15(5):333–339
7. Reuber M, Howlett S, Khan A, et al: Non-epileptic seizures and other functional neurological symptoms: predisposing, precipitating, and perpetuating factors. *Psychosomatics* 2007; 48(3):230–238
8. LaFrance W: Psychogenic nonepileptic “seizures” or “attacks”? It's not just semantics: seizures. *Neurology* 2010; 75(1):87–88
9. de Timary P, Fouchet P, Sylin M, et al: Non-epileptic seizures: delayed diagnosis in patients presenting with electroencephalographic (EEG) or clinical signs of epileptic seizures. *Seizure* 2002; 11(3):193–197
10. Lau Y, Picco L, Pang S, et al: Stigma resistance and its association with internalised stigma and psychosocial outcomes among psychiatric outpatients. *Psychiatry Res* 2017; 257:72–78
11. Rawlings G, Brown I, Reuber M: Deconstructing stigma in psychogenic nonepileptic seizures: an exploratory study. *Epilepsy Behav* 2017; 74:167–172
12. Benabadis SR: The problem of psychogenic symptoms: is the psychiatric community in denial? *Epilepsy Behav* 2005; 6(1):9–14
13. Carson A: Patients whom neurologists find difficult to help. *J Neurol Neurosurg Psychiatry* 2004; 75(12):1776–1778
14. Bass C, Halligan P: Factitious disorders and malingering in relation to functional neurologic disorders. *Handb Clin Neurol* 2016; 139:509–520
15. Sahaya K, Dholakia S, Lardizabal D, et al: Opinion survey of health care providers towards psychogenic non epileptic seizures. *Clin Neurol Neurosurg* 2012; 114(10):1304–1307
16. Altalib H, Elzamzamy K, Pugh M, et al: Communicating diagnostic certainty of psychogenic nonepileptic seizures: a national study of provider documentation. *Epilepsy Behav* 2016; 64:4–8
17. Kang J, Mintzer S: Driving and epilepsy: a review of important issues. *Curr Neurol Neurosci Rep* 2016; 16(9):80
18. Green B, Norman P, Reuber M: Attachment style, relationship quality, and psychological distress in patients with psychogenic nonepileptic seizures versus epilepsy. *Epilepsy Behav* 2017; 66:120–126
19. Santamaria-García H, Baez S, García A, et al: Empathy for others' suffering and its mediators in mental health professionals. *Sci Rep* 2017; 7(1):6391
20. LaFrance W, Benbadis S: How many patients with psychogenic nonepileptic seizures also have epilepsy? *Neurology* 2002; 58(6):990–991
21. Bowman ES, Markand ON: Psychodynamics and psychiatric diagnoses of pseudoseizure subjects. *Am J Psychiatry* 1996; 153:57–63
22. Barry JJ, Sanborn K: Etiology, diagnosis, and treatment of nonepileptic seizures. *Curr Neurol Neurosci Rep* 2001; 1:381–389
23. LaFrance W, Baker G, Duncan R, et al: Minimum requirements for the diagnosis of psychogenic nonepileptic seizures: a staged approach. *Epilepsia* 2013; 54(11):2005–2018
24. Gordon P, Valiengo L, Proença I, et al: Comorbid epilepsy and psychogenic nonepileptic seizures: how well do patients and caregivers distinguish between the two. *Seizure* 2014; 23(7):537–541
25. Koehler P, Okun M: Important observations prior to the description of the Hoover sign. *Neurology* 2004; 63(9):1693–1697
26. Levine W, Ramirez C: Identifying pseudo-seizures with anhydrous ammonia. *Am J Psychiatry* 1980; 137(8):995
27. Goyal G, Kalita J, Misra U: Utility of different seizure induction protocols in psychogenic nonepileptic seizures. *Epilepsy Res* 2014; 108(6):1120–1127
28. Burack J, Back A, Pearlman R: Provoking nonepileptic seizures: the ethics of deceptive diagnostic testing. *Hastings Cent Rep* 1997; 27(4):24
29. Mishra V, Gahlaut DS, Kumar S, et al: Value of serum prolactin in differentiating epilepsy from pseudoseizure. *J Assoc Phys India* 1990; 38:846–847
30. Aminoff MJ, Simon RP, Wiedemann E: The hormonal responses to generalized tonic-clonic seizures. *Brain* 1984; 107(pt 2):569–578
31. Gedzelman E, LaRoche S: Long-term video EEG monitoring for diagnosis of psychogenic nonepileptic seizures. *Neuropsychiatr Dis Treat* 2014:1979
32. Chen D, Maheshwari A, Franks R, et al: Brief group psychoeducation for psychogenic nonepileptic seizures: a neurologist-initiated program in an epilepsy center. *Epilepsia* 2013; 55(1):156–166
33. van der Kruijs S, Bodde N, Vaessen M, et al: Functional connectivity of dissociation in patients with psychogenic non-epileptic seizures. *J Neurol Neurosurg Psychiatry* 2011; 83(3):239–247
34. Goldstein L, Chalder T, Chigwedere C, et al: Cognitive-behavioral therapy for psychogenic nonepileptic seizures: a pilot RCT. *Neurology* 2010; 74(24):1986–1994
35. Carton S, Thompson P, Duncan J: Non-epileptic seizures: patients' understanding and reaction to the diagnosis and impact on outcome. *Seizure* 2003; 12(5):287–294
36. Reuber M, Baker G, Gill R, et al: Failure to recognize psychogenic nonepileptic seizures may cause death. *Neurology* 2004; 62(5):834–835
37. Alessi R, Valente K: Psychogenic nonepileptic seizures: should we use response to AEDS as a red flag for the diagnosis? *Seizure* 2014; 23(10):906–908
38. Oto M: The safety of antiepileptic drug withdrawal in patients with non-epileptic seizures. *J Neurol Neurosurg Psychiatry* 2005; 76(12):1682–1685
39. Hill C, Schwartz H, Dahodwala N, et al: Postdiagnosis neurological care for patients with psychogenic nonepileptic spells (PNES). *Epilepsy Behav* 2017; 74:64–68