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Psychogenic non-epileptic seizures

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ABSTRACT – Psychogenic non-epileptic seizures (PNES) are diagnosed in at least 10-40% of the patients seen for long-term monitoring of epilepsy, and it is no surprise that patients with PNES are often treated for epilepsy. Given the substantial economic costs and mental health burden of misdiagnosis, it is imperative to establish early identification, correct diagnosis, and effective treatment of PNES in order to provide the greatest opportunity for remission of events, improved psychological functioning, and social-vocational outcome. This article outlines an informed, practical approach to diagnosing this common condition and provides a summary of factors, based on medical history and semiology, that may suggest PNES. We discuss also the issues of communicating the diagnosis to the patient and making treatment recommendations which should ideally be coordinated using a multi-disciplinary team approach, involving the disciplines of neurology, psychiatry, psychology, social work, and nursing.

Key words: non-epileptic seizures, epilepsy, psychiatric, diagnosis, treatment

Psychogenic non-epileptic seizures (PNES) are paroxysmal events that resemble epileptic seizures with regards to either behaviour or experience, but are without epileptiform activity on EEG. The aetiology of PNES is psychologically-based. Differentiating PNES from epilepsy and other medical/neurological conditions is essential to providing the correct treatment and avoiding morbidity and potentially life-threatening risks that can occur with misdiagnosis. Patients with PNES misdiagnosed as having epilepsy are apt to be subjected to unnecessary medical treatments (*e.g.* benzodiazepines, anti-epileptic drugs [AEDs]), procedures (*e.g.* intubation), and recurrent hospitalization (LaFrance and Benbadis, 2006). Moreover, these inappropriate treatments can lead to an over-reliance on AEDs, which are not an effective treatment for PNES. Delayed diagnosis of PNES may leave psychiatric comorbidity unaddressed. The economic burden of PNES is comparable to the costs of epilepsy. Both conditions can share similar extended symptomatic periods prior to definitive diagnosis, diagnostic/treatment pathways (*e.g.* emergency medical

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Table 1. Historical factors indicating possible PNES.

1. Treatment resistance to more than two antiepileptic drugs (AEDs).
2. AEDs do not impact seizures.
3. Events are consistently associated with specific environmental or emotional triggers.
4. Presence of witness(es) (*e.g.* family members, hospital/clinic lobby, classroom) at the time of an event.
5. History of chronic pain, fibromyalgia, chronic fatigue syndromes.
6. History of comorbid psychiatric illness, personality disorder or substance abuse.
7. History of remote or current abuse or trauma.
8. Presence of repeatedly normal EEGs in the presence of recurrent seizures.

Drawn from Benbadis and LaFrance (2010).

services, clinic visits, ICU, epilepsy monitoring unit, EEG, neuroimaging, AED resistance), and patterns of unemployment or underemployment.

Scope of the problem

In the epilepsy monitoring unit (EMU), PNES is diagnosed in 10-40% of the patients seen for long-term monitoring (Gates and Mercer, 1995). This may represent an underestimate of the scope of the problem, as many persons with PNES are never evaluated in an EMU or come to the attention of seizure specialists, or even neurologists, for that matter. It is not uncommon to encounter persons with PNES who have been treated for presumed epilepsy for years. Studies have shown that the average time between onset of PNES and diagnosis is 1-16 years (Reuber and Elger, 2008; LaFrance *et al*., 2014). Approximately 10% of these patients will have co-occurring epilepsy and PNES (Griffith and Szaflarksi, 2010). Given that the economic costs and mental health burden of misdiagnosis can be substantial (Martin *et al*., 1998), these issues argue for early identification, correct diagnosis, and effective treatment of PNES, to provide the greatest opportunity for remission of events, improved psychological functioning, and social-vocational outcome.

Establishing the diagnosis of PNES

The correct diagnosis of PNES begins with neurological and psychiatric history and examination. The DSM-5 conversion disorder criteria have now been modified to incorporate a criterion specifying the presence of signs that are not consistent with neurological disorders, making conversion disorder a "rule-in" diagnosis, rather than a diagnosis of exclusion (Stone *et al*., 2011). Moreover, the International League Against Epilepsy (ILAE) PNES Task Force published diagnostic levels of certainty for PNES, based on history, semiology, and workup (LaFrance *et al*., 2013a). A comprehensive chapter (Benbadis and LaFrance, 2010) reviews the importance of addressing historical aspects of the patient's presentation, as well as semiology of their events that should raise the suspicion of PNES and provide a basis for referring to vEEG. Historical factors that should raise suspicion for PNES are listed in *table 1*.

Semiological factors of events associated with PNES are listed in *table 2*. With the appropriate history and semiology, video-EEG can confirm the diagnosis of PNES.

Clinical signs and features can aid the practitioner in formulating a provisional diagnosis and treatment plan, even when vEEG may either not be available or feasible.

The National Association of Epilepsy Centers (NAEC) recommends referral to a specialised epilepsy centre if a patient's seizures are not fully controlled

Table 2. Semiological factors associated with PNES.

1. Gradual onset.
2. Rapid postictal re-orientation.
3. Undulating motor activity.
4. Side-to-side head shaking.
5. Closed eye-lids during event.
6. Event lasting >2 minutes.
7. Resisted eyelid opening.
8. Lack of cyanosis.
9. Partial responsiveness during ictus.

Drawn from Benbadis and LaFrance (2010) and Syed *et al*. (2011).

after one year (National Association of Epilepsy Centers, 2010). Furthermore, "if the diagnosis of epilepsy is in question or if psychogenic non-epileptic events are suspected, a referral to an epilepsy centre is appropriate early in the evaluation process for diagnostic purposes" (National Association of Epilepsy Centers, 2010).

Making the diagnosis

The gold standard for documenting PNES is being able to utilise vEEG to record all events under consideration, while excluding other physiological causes of the patient's events. Other common medical/neurological conditions that can masquerade as epilepsy include various syncopal disorders, migraine headaches, sleep disorders, and cerebrovascular accidents. Moreover, the evaluating epileptologist will be challenged with differentiating PNES from epileptic syndromes that present with subtle phenomenology and are difficult to visualise on vEEG (*i.e.* simple partial seizures and frontal lobe epilepsy). We refer the reader to Schachter and LaFrance (2010) for further discussion of this topic. Establishing the PNES diagnosis requires a clear understanding of the target events through careful examination of not only the patient's report, but also with regards to what other family members, friends, or caregivers have observed. Once the event(s) are described and catalogued, it is essential that the descriptions are communicated to the rest of the epilepsy team, nursing, and EEG technical staff, so that informed surveillance can begin. Equally important is establishing a notification method (*e.g.* nurse call button or EEG event trigger) for the patient to self-report symptoms. This allows for the recording of events that consist of internal experiences, may not have a motor component (*e.g.* sensory, visceral or cognitive symptoms), and are thus not readily amenable to direct observation.

A key evaluation that can be very important in making a diagnosis of PNES includes psychiatric diagnostic evaluation with psychosocial assessment. The role of the psychosocial assessment is to gain a better understanding of the patient's developmental history, family/social information, educational/occupational history, mental health/treatment, substance use/abuse/dependence, and abuse/trauma/neglect history. The psychosocial evaluation may be conducted by a hospital-based or outpatient mental health clinician, which may include psychiatrist, psychologist, neuropsychologist, clinical social worker, or other mental health (ideally one who has experience with somatic symptom disorders) or medical providers caring for the patient. This information can be very important in understanding vulnerabilities to PNES, potential external incentives, barriers to treatment, and resources available to the patient.

The psychiatric diagnostic evaluation is usually conducted by a psychiatrist or clinical psychologist by direct interview with the patient and which may be supplemented with adjunctive use of objective personality measures, such as the Minnesota Multiphasic Personality Inventory-2 (Cragar *et al.*, 2003) or Personality Assessment Inventory (Testa *et al.*, 2011). This evaluation can be instrumental in beginning to define the aetiology of the PNES and other psychiatric comorbidities (*e.g.* depression, substance abuse, and personality disorders), and to inform treatments best suited for the patient and his/her condition(s). Common comorbidities of PNES include other somatoform disorders (*i.e.* conversion disorder of another semiology), anxiety disorders (*i.e.* generalized anxiety or panic disorder), post-traumatic stress disorder, and dissociative disorders. The psychiatric diagnostic evaluation along with the psychosocial assessment will begin to inform the nature and extent of treatment that will be offered to the patient, if a PNES diagnosis is made.

In contrast to the unconscious symptoms of conversion disorders, such as PNES and psychogenic movement disorders, special note is made for the less commonly occurring (<5%) and sometimes more difficult to determine, intentionally produced symptoms, such as malingering (*i.e.* wilful fabrication of symptoms in the presence of external incentive or motive) and factitious disorder (*i.e.* wilful fabrication of symptoms to assume the sick role) conditions. The information required to make these particular diagnoses usually needs to be irrefutable (*e.g.* witnessed or with video evidence of an act). More often, the practitioner will amass a preponderance of information suggestive of a malingering or factitious disorder diagnosis.

There are several roles that a separate neuropsychological evaluation can play in assisting the evaluation of PNES. Cognitive complaints are common in patients with PNES, with memory problems being most frequently reported (Prigatano *et al.*, 2002). Patients with PNES report greater cognitive difficulties than are measured on objective examination (Prigatano and Kirlin, 2010). Though not pathognomonic of PNES, the neuropsychological evaluation may help to identify correlates for a psychogenic diagnosis in the context of a subjective report of cognitive impairment that is not substantiated by the objective test scores. This may be important in cases where the patient does not have his/her target events during monitoring and/or the vEEG results are inconclusive. Second, by providing an overall estimate of the patient's cognitive/intellectual status, the results of neuropsychological testing can help the practitioner interact with the patient at an appropriate level and make reasonable discharge plans with respect to follow-up interventions. For example,

the neuropsychologist can assist the epileptologist with presenting the diagnosis of PNES to the patient. Also, the information shared may be different for the small number of patients with borderline intellectual function versus another with a high average IQ and college education. Realizing that neuropsychological testing does not differentiate PNES from epilepsy at the individual level, the value of employing a multidisciplinary team approach to evaluate this disorder is highlighted when the corpus of data collected from the patient is pulled together from neurological and mental health to arrive at a final diagnosis. The benefits of a team approach will be further appreciated as the clinician proceeds to present the diagnosis to the patient and family or caregivers, and by sharing the diagnosis with treating clinicians outside the EMU.

Communicating the diagnosis

Once the diagnosis of PNES has been made, the next step is effective communication of the findings to the patient and their relatives and/or caregivers. Many patients diagnosed with PNES are left with the perception that the problem is "all in their head", or that they are "crazy" or "faking it". Use of the dated and inappropriate term "pseudoseizures" is discouraged, given that they are not "false" seizures, and the term creates a barrier between patients and providers. It is important to communicate the diagnosis in a thorough, understandable, positive, non-judgmental and compassionate manner. This should really be considered the first step in treatment. This communication may constitute a real opportunity to establish a treatment relationship. Studies have shown that a substantial proportion (24%-75%) of these patients either do not seek out or are unable to obtain follow-up mental health care after discharge from the EMU (Carton *et al*., 2003; Bisping *et al*., 2009; Mayor *et al*., 2012). This may be particularly true in locales where after-care mental health services are limited or even non-existent, and especially where providers familiar with treatment for somatic symptoms disorders are absent.

Communicating the diagnosis of PNES can be a difficult process for some providers for a variety of reasons, including past confrontational interactions with a patient and/or family who displayed resistance to receiving a psychiatric label, or reluctance to relinquish a neurological disorder diagnosis, and perceived or experienced stigma. Another barrier to effective communication can be clinician discomfort or unfamiliarity of handling psychiatric issues, and clinician bias toward this population. To that end, we recommend involving the team's mental health care provider when communicating the diagnosis, when possible. How well a patient receives a PNES diagnosis can be a strong determinant in their subsequent psychological recovery and utilisation of health care resources (Carton *et al*., 2003; Bisping *et al*., 2009).

A number of studies have evaluated patient experiences and outcome in relation to strategies and content of PNES diagnosis communication (Thompson *et al*., 2005; Bisping *et al*., 2009; Hall-Patch *et al*., 2010; Mayor *et al*., 2012). Clinical experience and results from these studies have supported an emerging consensus about how the diagnosis is communicated, which includes:

– having the neurologist deliver the diagnosis in the context of a team-oriented conference;
– communicating the diagnosis in a positive light or as "good news", that they do not have epilepsy or brain damage;
– emphasizing that the symptoms the patient is experiencing are "real" with real-life consequences and that they are not "faking it";
– avoiding the use of pejorative labels (*e.g*. "pseudoseizure", as noted above);
– explaining that AEDs are not necessary and are not used to treat PNES;
– explaining that psychological counselling for seizures is the most effective treatment;
– explaining that factors associated with PNES may be better understood during the course of mental health treatment;
– suggesting that the events will decrease following the correct diagnosis in some patients, but also upon acceptance of the diagnosis and sustained mental health treatment;
– and providing written material on PNES.

Many patients will desire an explanation of the diagnosis, (*i.e*. "what is it?"), its causes, and treatments. We have found that a discussion of how the body reacts to internal and/or external stressors suffices as an introduction with a clear instruction that therapy with a treating mental health care provider is important to help them better understand the factors contributing to their PNES.

Introducing the concept of PNES through "seed planting" by discussing the differential diagnosis of seizures at admission helps to prepare the patient diagnosed with PNES for the discharge conference and also allows the team to gauge how the patient may react to this information. This can also be important in preparing for the review of vEEG, neuroimaging, psychiatric diagnostics, and neuropsychological/personality testing at the discharge team meeting with the patient and family. The clinician must be careful and ask permission from the patient whether they wish to see any recordings of events, given the potential emotional nature of such a presentation. Patients who may be more resistant to the diagnosis may require a more

extensive review of the evaluations conducted to help support the clinician's case. For the 10% of patients with mixed epilepsy and PNES, they may require special consideration when communicating the diagnosis, as it is not uncommon for these patients to be unable to distinguish between the two seizure types. Therefore, careful characterisation of the events with respect to antecedents, semiology, and postictal behaviours is essential. To that end, it is often very helpful to review the vEEG of both the epileptic seizures and PNES with the family members, if possible. Providing concrete labels for each semiological event type (*e.g.* "whole body-shaking" or "arm tremor") helps to avoid confusion when treatment questions arise.

Treatment of patients with PNES

Treatment of PNES involves addressing the underlying psychological stressors and conflicts, comorbidities, and maladaptive emotional/cognitive functioning. This approach may involve pharmacological management of specific co-existing psychiatric symptoms (*e.g.* anxiety and depression) (LaFrance and Blumer, 2010), while psychological therapy is the mainstay of treatment to facilitate patient insight into the aetiology of the PNES and introduce strategies to manage the emotional symptoms, triggers, and cognitive distortions associated with this condition. Treatment begins, as noted above, with a potential beneficial therapeutic effect of a thorough EMU evaluation with positive communication of the diagnosis. Nevertheless, merely sharing the diagnosis does not have durable long-term effects for seizure freedom, and it is generally understood that psychological therapy is the most effective treatment for PNES (LaFrance *et al*., 2008). There are a number of specific treatments (*e.g.* cognitive behavioural, psychodynamic, family systems, and learning theory) that can be used for PNES (LaFrance *et al*., 2013b). There have been no definitive studies comparing one therapeutic approach over another, however, several recent randomised controlled trials (RCTs) for the treatment of PNES have established that conventional cognitive behavioural therapy (CBT) (Goldstein *et al*., 2010) showed improvement in PNES, and a CBT informed psychotherapy using a Workbook specifically designed for this condition (LaFrance and Wincze, 2015; Reiter *et al*., 2015) significantly reduced seizure frequency and improved comorbid anxiety and depression and psychosocial functioning, as opposed to no improvement in patients who received standard medical care (SMC) (LaFrance *et al*., 2009, 2014). The key focus of these trials is that the patients gain control over their symptoms. The durability of these time-limited therapies is to be seen.

For the neurologist/epileptologist seeing patients with PNES, referral for mental health treatment upon discharge from the EMU, while still receiving neurological follow-up, is a key component of multi-disciplinary care. The ability of the patient to follow through with an outpatient mental health referral will depend upon a number of factors, including health insurance coverage, finances, transportation, and availability of providers in their area. It is for this reason that at least one follow-up clinic appointment with the epilepsy programme should be scheduled, to provide support and assess functional outcome and compliance with discharge recommendations. Social work or support staff can be very helpful in identifying and scheduling outpatient mental health services. Discharging a patient with a solid treatment plan potentially increases the likelihood of improved outcomes and reduced subsequent health care utilisation. Along with mental health treatment, the neurologist can withdraw AEDs in a patient with lone PNES if they were specifically prescribed for the target events and are not being used for other purposes (*e.g.* migraine prevention or bipolar disorder). The reason for remaining on any AED for non-PNES conditions should be clearly communicated to and understood by the patient.

Outcome

The current state of knowledge on the prognosis of persons diagnosed with PNES remains generally sparse. There have been no large-scale prospective controlled studies on the long-term outcome of PNES. Most of the published studies describe small samples with relatively short follow-up periods, however, studies show that, on average, approximately 50% of patients continue to experience PNES at follow-up (Bodde *et al*., 2007). Duncan *et al*. (2014) found that 68% of PNES patients had not sought care for seizures over a period of six months, 5-10 years after diagnosis. Patients up to 10 years following diagnosis have high levels of disability and less than one in three have seizure freedom (Reuber *et al*., 2003). Factors that seem to predict better outcome include: relatively benign psychiatric history, more recent onset of PNES, no co-existent epilepsy, and an identifiable trauma that precedes the onset of PNES (Bodde *et al*., 2009). Prognosis may also depend upon the identified psychological aetiology of the PNES, personality characteristics of the patient, and his/her willingness to accept the diagnosis and receive treatment.

Conclusion

Patients with PNES are frequently seen in the practice of epilepsy/neurology/emergency medicine with

substantial economic costs to the health care system and workforce. Furthermore, delay to diagnosis and treatment may result in significant psychosocial and physical morbidity to the affected patient. The burden of PNES is at least comparable to that of epilepsy and probably greater given the increased psychiatric comorbidities (Hamilton *et al.,* 2010). This article outlines an informed, practical approach to diagnosing this common condition, communicating the diagnosis to the patient, and making treatment recommendations, all of which work best with a multi-disciplinary team approach to the problem. Increasing our understanding of PNES, as well as tailoring effective treatments for this condition, will require continued collaboration between the disciplines of neurology, psychiatry, psychology, social work, and nursing. □

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TEST YOURSELF

(1) What are the consequences of a delayed diagnosis of PNES?

(2) What is the cornerstone for confirming an accurate diagnosis of PNES?

(3) What factors should be addressed for treatment of PNES to be successful?

Note: Reading the manuscript provides an answer to all questions. Correct answers may be accessed on the website, www.epilepticdisorders.com, under the section "The EpiCentre".