

Psychogenic non-epileptic seizures (PNES) in adults: what a psychologist needs to know

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Overview

Introduction to PNES: definitions and facts, how it is diagnosed, comorbid psychiatric conditions

Why psychologists are so important in the treatment of patients with PNES and what do we know about the utility of existing treatments that can be employed?

General recommendations for psychologists who are planning on treating a patient diagnosed with PNES

Resources for professionals working with this disorder and patients living with this disorder

Definitions

Seizures: Involuntary behavioral changes (movements of body parts, alteration of consciousness, loss of certain functions (i.e. speech, vision)-generalized, partial, etc.

Epilepsy: this diagnosis is given after a person has more than 1 seizure and the seizures are unprovoked (e.g. drug or alcohol induced). It is associated with abnormal electrical activity in the brain.

PNES: Behaviorally, these resemble an epileptic seizure but do not demonstrate epileptiform activity during recording of brain waves using EEG.

Definition of PNES

Episodic behavioral events that resemble epileptic seizures but are not associated with abnormal (epileptiform) electrical discharges of the brain.

PNESs are associated with underlying psychological stressors and there is often a history of psychological trauma.

PNES is not a single entity but rather a diagnosis given due to the symptoms of seizures but which is associated with multiple psychiatric comorbidities

The seizures are conceived of as **symptoms of an underlying psychological condition**

Definitions of PNES

As per DSM 5, PNESs are classified as a conversion disorder or functional neurological (abnormal central nervous system functioning of unknown etiology) symptoms disorder (FNESD).

A. 1 or more symptoms of altered voluntary motor or sensory fx

B. Clinical findings symptoms incompatible with medical/mental disorder

C. Symptom of deficit is not better explained by another med/mental disorder.

D. causes sig. distress or impairment in social, occupational or other important areas of life.

F44.5 with attacks or seizures

PNES risk factors

History of traumatic or adverse life experiences (including significant health events as well as physical, sexual, emotional abuse, major losses, etc.)

History of psychiatric disorders, including depression, anxiety, post-traumatic stress disorder and personality disorders

History of medically unexplained symptoms

PNES-historically

PNES are the most common paroxysmal events that are misdiagnosed as epilepsy.

PNES falls in an intersection between neurology and psychiatry/psychology which complicates smooth transitions to treatment

PNES has been recognized historically: wandering uterus (seizures might be resolved by becoming sexually active and having children) and demonic possessions

Charcot/Breuer/Freud: Hysteria, hypnosis, dissociation and conversion of psychic symptoms into physical symptoms (Anna O) and the importance of psychological trauma begins to be underscored.

The history of PNES



PNES-what is the correct name?

Current acceptable terms: Psychogenic non-epileptic seizures (PNES) or Non-epileptic attack disorder (NEAD)

Terms that have (or should) be abandoned:

- Pseudoseizures
- Hystero-epilepsy
- Hysteria

PNES- Facts

PNES occurs most frequently between the ages of 20-40 years. Much more common in women with a 3:1 ratio.

Average time that elapses between the first seizure and a definitive diagnosis 7.2 years.

Up to 20-30% of patients evaluated on an inpatient epilepsy monitoring unit will be diagnosed as having PNES.

Estimates of PNES prevalence ranges from 2-33 out of every 100,000 persons.

Approximately 5-10% are dually diagnosed with PNES and epilepsy

a b Reuber M, Fernandez G, Bauer J, Helmstaedter C, Elger C. Diagnostic delay in psychogenic nonepileptic seizures. *Neurology*. 2002;58(3):493-5.

b Benbadis, Hauser (2000). An estimate of the prevalence of psychogenic non-epileptic seizures. *Seizure* 9(4): 280-1

How is PNES diagnosed?

PNES can have a multitude of presentations: paralysis, violent thrashing, slurred speech or stuttering, blinking or odd eye movements, alteration of consciousness, etc.

The gold standard for diagnosis is Video-EEG during which all “typical” events are recorded, no associated epileptiform discharges are noted, before, during or after the event

History and semiology should be consistent with PNES.

What are the guidelines?

Referral Guidelines for seizure disorders have been established by the NAEC. Delayed or denied referral may be detrimental to the patient's health, safety and quality of life.

If seizures have not been brought under control after 3 months of care by a primary care provider (family physician, pediatrician), further neurologic intervention by a neurologist, or an epilepsy center is appropriate.

If seizures have not been brought under control after 12 months while being treated by a general neurologist, a referral to a specialized epilepsy center/epileptologist should be made.

https://www.aesnet.org/for_patients/find_a_doctor

How is PNES diagnosed?

Video-EEG

Camera and EEG



Ambulatory Video-EEG

Case contains



EEG leads placed on scalp



How is PNES diagnosed?

While still an inpatient, those patients with clinical features consistent with PNES should be evaluated by a mental health provider. This clinician determines whether there are typical risk factors, emotional triggers to seizures, significant psychiatric comorbidities, and past attempts at solutions.

If it is not possible to perform a psychological assessment during the hospital diagnostic phase, psychological assessment should be performed as soon as possible as an outpatient and therapy should also begin as soon as possible.

Comorbid psychiatric conditions in PNES

Unipolar or bipolar depression in 21% to 78% of patients with PNES.

Approximately 50% of patients with PNES also carry a diagnosis of anxiety disorder

Up to 25% have made a suicide attempt

≥75% of patients with PNES have a history of trauma and 22-100% carry a diagnosis of PTSD

D'Alessio, L., Giagante, B., Oddo, S., Silva, W.W., Solis, P., Consalvo, D. et al. Psychiatric disorders in patients with psychogenic non-epileptic seizures, with and without comorbid epilepsy. *Seizure*. Jul 2006; 15: 333–339

Comorbid conditions in PNES

Pain syndromes (22-89%)¹

Dissociative disorders (22-91%)¹

Personality disorders (10-86%): Borderline and obsessive compulsive¹

Often suffer from Medically Unexplained Symptoms (MUS)²

1 D'Alessio L, Giagante B, Oddo S, Silva WW, Solis P, Consalvo D, et al. Psychiatric disorders in patients with psychogenic non-epileptic seizures, with and without comorbid epilepsy. *Seizure*. 2006;15(5):333-9.

2 McKenzie PS, Oto M, Graham CD, Duncan R. Do patients whose psychogenic non-epileptic seizures resolve, 'replace' them with other medically unexplained symptoms? Medically unexplained symptoms arising after a diagnosis of psychogenic non-epileptic seizures. *Journal of Neurology, Neurosurgery & Psychiatry*. 2011:jnnp. 2010.231886.

Family characteristics in patients with PNES

Families tend to have more difficulty with communication, affect and general functioning. ¹

Families of origin of patients with PNES tend to have more health problems, a greater tendency to somatize, more critical and distressed than families of patients with epilepsy. ²

Tend to have substantial family psychiatric history.

¹ Krawetz P, Fleisher W, Pillay N, Staley D, Arnett J, Maher J. Family functioning in subjects with pseudoseizures and epilepsy. *The Journal of nervous and mental disease*. 2001;189(1):38-43.

² Wood BL, McDaniel S, Burchfiel K. Factors distinguishing families of patients with psychogenic seizures from families of patients with epilepsy. *Epilepsia*. 1998;39(4):432-7.

PNES-Emotional processing

Approximately, 30% fulfill criteria for alexithymia

Many patients can be classified into one of two subgroups:

- Under-modulators: emotional reactivity, low tolerance to excitement, difficulty controlling emotions. Poor quality of life and considerable psychiatric comorbidities (depression, anxiety, borderline PD).
- Over-modulators: emotional avoidance, excessively controlled behaviors, somatization tendencies, psychiatric comorbidities are less obvious. These patients can be resistant to the “psychogenic” diagnosis but with clear explanations and patience, they too can understand and benefit from treatment.

What treatments are available?

PSYCHOTHERAPY is the indicated mode of treatment once a diagnosis of PNES has been made.

There is empirical validation and reports of utility of the following treatment approaches:

Psychodynamic therapy

Mindfulness-based therapy

Cognitive Behavioral Therapy (CBT) *

- Prolonged exposure for therapy for dually diagnosed PNES/PTSD

Psychoeducational group interventions

Psychodynamic therapy for PNES

From this perspective, psychogenic symptoms are seen as produced by internal processes resulting from traumatic memories (often from childhood) that are maintained at an unconscious level through dissociative, conversion, and somatic defense mechanisms.

The goal of psychodynamic therapy is to bring unconscious material to the surface to promote change through insight.

Psychodynamic therapy for PNES

Oliveira et al: 37 patients were treated with weekly sessions of psychodynamic treatment for 12 months. 11/37 (29.7%) stopped having psychogenic seizures and 19 (51.4%) had a decline in seizure frequency.

Need follow up data on maintenance of improvements

Mayor et al: augmented psychodynamic interpersonal therapy (PIT) of 2-hour semi-structured initial interview and up to nineteen 50-minute weekly or biweekly sessions. Forty-seven of 66 patients completed follow-up questionnaires at a median of 42 months (12-61 months) after the end of treatment. Of those 47 patients, 12 (25.5%) were event-free, and 19 (40.4%) had experienced a >50% reduction in event frequency at the follow-up period compared to baseline.

Santos NdO, Benute GRG, Santiago A, Marchiori PE, Lucia MCSd. Psychogenic non-epileptic seizures and psychoanalytical treatment: results. *Revista da Associação Médica Brasileira*. 2014;60(6):577-84.

Mayor R, Howlett S, Grünewald R, Reuber M. Long-term outcome of brief augmented psychodynamic interpersonal therapy for psychogenic nonepileptic seizures: Seizure control and health care utilization. *Epilepsia*. 2010;51(7):1169-76.

Mindfulness-based treatments for PNES

Mindfulness involves being aware moment-to-moment of subjective conscious experiences.

Regular practice of meditative practices improve attention and emotional regulation as well as body awareness; all of these are key targets in a disorder such as PNES because patients very often present with alexithymia and difficulties with under or over-modulation of emotions and tend to avoid distressing thought content.

With this treatment modality, experiential avoidance is challenged while personal values are delineated which provides patients with healthier and consciously chosen behavioral pathways.

Mindfulness-based treatments for PNES

Baslet et al (2014) enrolled 6 adult females in a 12-session mindfulness protocol

Treatment components: 1) Psychoeducation and goal setting; 2) stress management training, 3) mindfulness training, and emotion recognition, 4) acceptance and behavioral regulation. By session 12: all had a reduction in event frequency and 3/6 stopped having episodes completely. Improvements in depression and anxiety.

Follow up of maintenance of improvements is needed.

Baslet G, Dworetzky B, Perez DL, Oser M. Treatment of Psychogenic Nonepileptic Seizures Updated Review and Findings From a Mindfulness-Based Intervention Case Series. Clinical EEG and neuroscience.

Cognitive Behavioral Treatments (CBT) for PNES

CBT operates on current maladaptive thoughts, behaviors and feelings to produce healthy changes. This approach proposes that core beliefs of oneself, others and the future can be modified through interventions. Dysfunctional thoughts and behaviors related to conversion symptoms can be challenged and changed.

CBT is the psychotherapeutic approach that has been reported to have the highest level of efficacy evidence at this time for PNES.

Cognitive Behavioral Treatments (CBT) for PNES

CBT

Most rigorously studied type of treatment (Class I).

Goldstein et al published a randomized, controlled pilot study in which a group received treatment as usual (TAU) and the other received CBT

Treatment components: 1) treatment engagement, 2) reinforcement of independence, 3) distraction, relaxation, and refocusing techniques when episode is imminent, 4) graded exposure to avoided situations, 5) cognitive restructuring, and 6) relapse-prevention.

CBT group experienced a significant reduction in monthly episode frequency (TAU group median: 6.75 monthly events; CBT + TAU: 2 monthly events ($p=0.002$). But at 6 months, the statistically sig difference was lost ($p=0.082$).

Need follow up data on maintenance of improvements

Goldstein L, Chalder T, Chigwedere C, Khondoker M, Moriarty J, Toone B, et al. Cognitive-behavioral therapy for psychogenic nonepileptic seizures A pilot RCT. *Neurology*. 2010;74(24):1986-94.

Cognitive Behavioral Treatments (CBT) for PNES

LaFrance et al conducted a multi-center pilot randomized study that produced class I data- 34 patients randomized into 1 of 4 treatment arms:

- 1) flexible dose sertraline hydrochloride only (n=9),
- 2) cognitive behavioral informed psychotherapy (CBT-ip) (n=9),
- 3) CBT-ip with sertraline (n=9)
- 4) treatment as usual (n=7)

CBT-ip group showed 51.4% reduction in event frequency ($p=.01$) and sig. improvement on 2ary measures (depression, anxiety, QOL and global functioning). CBT-ip + sertraline showed significant reduction (59.3%) in monthly events ($p=.008$) and sig. improvement on 2ary measures of global functioning ($p=.007$).

Need follow up data on maintenance of improvement

LaFrance et al. (2014) **Multicenter pilot treatment trial for psychogenic nonepileptic seizures: a randomized clinical trial.** JAMA Psych 71(9):997-1005.

Cognitive Behavioral Treatments (CBT) for PNES

Ssessions for CBT-ip with PNES: 1) Making the decision to begin taking control, 2) Getting support, 3) deciding about your drug therapy, 4) learning to observe your triggers, 5) channeling negative emotions into productive outlets, 6) relaxation training, 7) identifying your pre-seizure aura, 8) dealing with external life stresses, 9) dealing with internal issues and conflicts, 10) enhancing personal wellness, 11) other symptoms associated with seizures, 12) taking control: an ongoing process.

LaFrance C and Wincze JP (2015). Treating non-epileptic seizures-therapist guide. Oxford University Press.

CBT treatments for PNES/PTSD-Prolonged exposure (PE)

PE is a highly efficacious treatment for post-traumatic stress disorder (PTSD) developed by Edna Foa.

The core components of exposure therapy are to replace avoidance with exposure and confrontation:

Imaginal exposure, revisiting the traumatic memory, repeated recounting it aloud, and processing the experience of memory recollection, and

In vivo exposure, the repeated confrontation with situations and objects that have become associated to the trauma and cause distress but are not inherently dangerous.

CBT treatments for PNES/PTSD-Prolonged exposure (PE)

Prolonged exposure acts on:

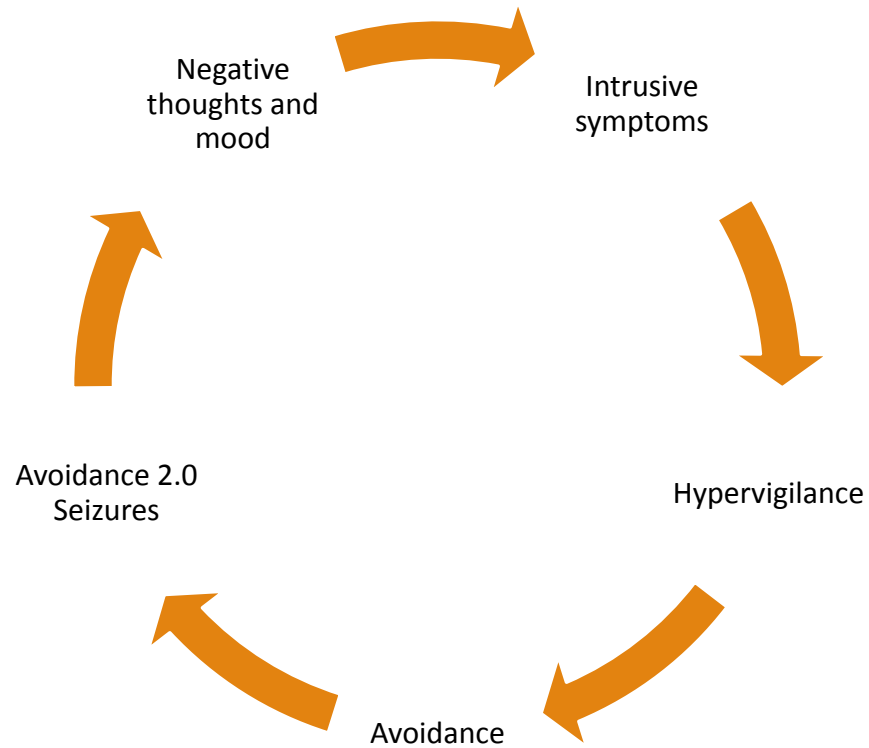
Avoidance symptoms (of the memory and other life aspects)

Intrusive symptoms because the patient learns to recollect the memory and associated thoughts voluntarily instead of being “intruded on.”

Hypervigilance because the patient learns that many “dangerous” situations are in fact safe and because intrusive symptoms come down.

Negative thoughts and mood because there is a sense of achievement and regained confidence.

PTSD and PNES



CBT treatments for PNES/PTSD-Prolonged exposure

Myers et al (2015) 7 adults dually diagnosed with PNES/PTSD enrolled in 12-15 weeks of PE. Results: significant reduction of depressive symptoms (W-value= 1; $p \leq 0.05$) and post traumatic symptoms (W-value = 0; $p \leq 0.05$). Seizure frequency reduced in all patients (W-value=0; $p \leq 0.05$). Follow up at 2-27 months revealed that all patients maintained improvements regarding seizure frequency except for one patient. Five of 7 were working or enrolled in school.

Myers, Vaidya, Lizardo (2015). The utility of Prolonged Exposure Therapy (PET) in the treatment of patients who are dually diagnosed with PNES and PTSD. **Poster session#:**
1.178 American Epilepsy Society

CBT treatments for PNES/PTSD-Prolonged exposure

PE with patients with PNES was administered according to the manual with some modifications that include specifics of PNES and to address overengagement.

Treatment components: 1) Session in which common reactions to trauma are discussed includes PNES as a potential common reaction. 2) During the trauma interview, detailed descriptions of seizures are also obtained. 3) Seizure logs are part of homework. 4) Breathing and grounding techniques can be used during the episodes themselves to recover control.

Psychoeducational groups for PNES

Zaroff et. al. (2004) psychoeducational group with 7 patients for 10 sessions. Topics: education about PNES, anxiety, depression, trauma, anger and assertiveness and healthy behaviors (diet, sleep, exercise). PTSD and dissociative symptoms and emotion-based coping strategies decreased. A trend toward a better QOL was noted. Event frequency did not change significantly, although this may have been because 3/6 were seizure-free at outset.

Zaroff CM, Myers L, Barr WB, Luciano D, Devinsky O. Group psychoeducation as treatment for psychological nonepileptic seizures. *Epilepsy Behav.* 2004;5(4):587-92.

Treatments for PNES-Psychoeducational group

Chen et al (2014) compared an intervention group (n=34) consisting of 3 monthly psychoeducational meetings and a routine seizure clinic follow-up control group (n=30). Interventions include lectures on: 1) PNES and safety and universality, 2) how physical symptoms can arise from underlying emotional causes and 3) empowering patients to take control using distress tolerance techniques, relaxation exercises, and scheduling time for naps. Patients were prospectively followed at 3 and 6 months. There was no significant change in event frequency/intensity but there was a significant improvement on a scale of work and social adjustment and a trend toward decreased emergency department visits or hospitalizations in the intervention group.

Chen DK, Maheshwari A, Franks R, Trolley GC, Robinson JS, Hrachovy RA. Brief group psychoeducation for psychogenic nonepileptic seizures: A neurologist-initiated program in an epilepsy center. *Epilepsia*. 2014;55(1):156-66.

Recommendations for psychologists

At the outset of treatment: Obtain a description of typical seizures and their frequency

- Aura?
- How do they start?
- What are their characteristics? Patient falls, makes vocalizations, thrashes, shakes, self harms (scratches, bangs), walks, bites, is hearing, speech or writing retained during episode, duration?
- Is there something that they find helps during the episode?
- How long to recover?

Recommendations for psychologists

Have an understanding with patient that you, the therapist, may touch them during the episode (come to an agreement as to what part of the body is safe to touch)

- Is there a part of the body that cannot be touched?
- Is it ok to squeeze arm or shoulder?
- If patient falls, make sure it is understood that therapist may need to hold body or head to avoid damage or maybe to place a pillow under head.

Recommendations for psychologists

Ensure patient is safe from injuries by making necessary modifications to office during these sessions

- Does session need to be conducted on a carpeted floor?
- Is there wooden or hard furniture that needs to be moved out of the way?
- Do you need to have a pillow?
- If patient scratches, should they use mittens?

Recommendations for psychologists

Begin therapy by teaching a breathing retraining exercise and make sure it is practiced and learned.

Speak to patient during the episode: grounding (reminding patient that this is an office, who you are, and that this is a session)

After a minute or two, depending on how episode is presenting, suggest that the episode is near its end and focus on breathing

Process what happened as soon as episode ends. It is not necessary to stop a session just because of an episode if the patient can continue. Assess if patient can continue with distressing topics (e.g. exposure) or if you should move on to processing.

Recommendations for psychologists

Do not leave patient alone or allow to leave office until they are recovered

- If you have an exam room, patient may remain there resting or may remain in a waiting room
- Ask office staff to monitor if you are in with another patient.

Make sure you have someone who can accompany patient home if needed (make sure you have emergency contact numbers from outset).

Unless the patient hurt her/himself during episode (e.g. fell), episode is notably different than typical episodes, or is not responsive, avoid calling 911.

Recommendations for psychologists

Most seizures are dissociative in nature, grounding techniques (ice or frozen orange, paddle board with little ball, hula hoop, transfer object from 1 hand to other) can be very helpful during discussion of intense topics

When conducting PE, it can be helpful to do imaginal exposure retelling the memory quickly, writing it, or using technology (apps to retell the taped memory)

Basic Resources

Help your patient find an epileptologist/epilepsy center in the USA:

https://www.aesnet.org/for_patients/find_a_doctor

FAQs about PNES:

<http://nonepilepticseizures.com/epilepsy-psychogenic-NES-information-answers.php>

PNES treatment referral sites:

<http://nonepilepticseizures.com/epilepsy-psychogenic-NES-information-referral-sites.php>

Professional Resources

Review Paper: Gaston Baslet, Ashok Seshadri, Adriana Bermeo-Ovalle, Kim Willment, Lorna Myers. **Psychogenic Non-Epileptic Seizures: An Updated Primer** (in press). Psychosomatics: the Journal of Consultation and Liaison Psychiatry.

Therapist Guide (CBT informed therapy): W Curt LaFrance and Wincze JP (2015) **Treating Nonepileptic Seizures: Therapist Guide (Treatments That Work) 1st Edition**. Oxford Press.

Gates and Rowan's Nonepileptic Seizures (Cambridge Medicine) 3rd Edition by Steven C. Schacter (Editor), W. Curt LaFrance Jr. (Editor). Cambridge Medicine.

Patient Resources

Books:

- **Psychogenic non-epileptic seizures: A guide** by Lorna Myers, Ph.D.
- **Lowering the Shield: Overcoming psychogenic non-epileptic seizures** by John Dougherty
- **The Color of Seizures: Living with PNES** by Kate Taylor and Jeffrey Underwood
- **In Our Own Words: Stories of those living with, learning from and overcoming the challenges of psychogenic non-epileptic seizures** by Mary Martiros, M.Ed and Lorna Myers, Ph.D.
- **View from the Floor: Psychogenic non-epileptic seizures: A patient's perspective** by Kate Berger

Patient Resources

Continuing Education Scholarships for adults diagnosed with PNES:

<http://www.epilepsyfree.com/support-for-epilepsy/continuing-education-and-summer-camp-scholarships/>

PNES awareness garments and charms (in exchange for donations to support Epilepsy Free):

<http://www.epilepsyfree.com/give-back/donation/>

Facebook: Psychological Non-epileptic seizures

https://www.facebook.com/Psychological-Non-Epileptic-Seizures-144184112260986/?ref=tn_tnmn

Thank you!

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