



Treatment Works, So Who's Afraid of PNES?

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Adherence With Psychotherapy and Treatment Outcomes for Psychogenic Nonepileptic Seizures

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Objective: We conducted a prospective cohort study of patients with psychogenic nonepileptic seizures (PNES) to examine the association between adherence to psychotherapy and outcomes, including significant ($\geq 50\%$) reduction in PNES frequency, PNES freedom, improvement in quality of life, and reduction in emergency department (ED) utilization. **Methods:** A total of 105 participants were referred to receive psychotherapy either at Brigham and Women's Hospital or with a local therapist. We called participants at 12 to 24 months of follow-up and obtained detailed follow-up data from 93 (89%) participants. Participants were considered adherent to psychotherapy if they attended at least 8 sessions within a 16-week period starting at the time of referral. **Results:** Adherence to psychotherapy was associated with reduction in seizure frequency (84% in adherent group vs 61% in nonadherent; $P = .021$), improvement in quality of life ($P = .044$), and reduction in ED utilization ($P = .040$), with medium effect sizes; there was no difference in PNES freedom. The association between adherence and $\geq 50\%$ reduction in PNES frequency persisted when controlling for potential confounders in a multivariate model. Psychotherapy nonadherence was associated with baseline characteristics of self-identified minority status (odds ratio: 7.47; $P = .019$) and history of childhood abuse (odds ratio: 3.30; $P = .023$). **Conclusions:** Our study is limited in that it cannot establish a causal relationship between adherence to psychotherapy and outcomes, and the results may not generalize beyond the single quaternary care center study site. Among participants with documented PNES, adherence to psychotherapy was associated with reduction in PNES frequency, improvement in quality of life, and decrease in ED visits.

Commentary

Despite the large literature based on psychogenic nonepileptic seizures (PNES), it is still difficult to ascertain “evidence-based treatment” and to gain a comfort level in managing this condition. Psychogenic nonepileptic seizures are ubiquitous in clinical epilepsy practice and may represent up to 30% of epilepsy monitoring unit admissions.¹ Prospective treatment studies that may guide clinical practice are emerging but still uncommon.² Some reports highlight the perceived lack of access to mental health care; others critique working relationships between neurologists and psychiatrists.³⁻⁵ The literature also shows that nomenclature has oscillated wildly over the years.⁶ Some authors prefer to use the word “events” instead of seizures, and the term psychogenic has gradually become more present in order to characterize apparent psychological etiologies from other epilepsy mimics. Although unfortunate, it is true that in medicine, deeming a condition, “psychogenic” is often a pathway for nonpsychiatrists to abdicate a treatment relationship.

Regrettably, relatively few papers in the epilepsy literature have focused upon how actually to improve the clinical state of patients with this condition. When evidence arrives from

prospective treatment of PNES, it is refreshing, and Tolchin et al have provided longitudinal data that are worthy for consumption. Over 100 patients with documented PNES were followed prospectively, essentially for the purpose of determining whether they attended psychotherapy appointments. Treatment aspects varied though consultation was facilitated between study clinicians and therapists regarding possible treatment approaches and the scope of PNES. Episode frequency and quality of life were measured at baseline and after a 1- to 2-year period. The results suggested that increased attendance at psychotherapy visits was associated with reduction in episodes, reduction in emergency department (ED) utilization, and improved quality of life. The improvement occurred regardless of specific philosophical bent, for example, dynamic or cognitive behavioral, and even though complete “seizure” freedom had not typically occurred. Although causality could not be attributed, the fact that treatment was associated with a sustained improved outcome after 1 to 2 years is a legitimate cause for optimism.

The results are particularly meaningful for anyone who tends to regard PNES with fear or discomfort. The reason for



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such fear is understandable. Psychogenic nonepileptic seizures events may seem unpredictable and frequently are the sources of high anxiety, especially if the events are prolonged. Emergency medical services are often involved, perhaps more than for epileptic seizures, which are typically much briefer and may resolve without need for emergent medical intervention.

Clinicians feel pressure from patients and families who are often desperate, maybe even frantic for answers. Yet the answers are not readily apparent, especially for clinicians who thrive upon answering questions precisely and algorithmically. Patients may regard the events themselves as the sole problem and are unable to consider underlying conditions that could be etiologic. They in turn regard any relapse as a treatment failure, placing more pressure upon clinicians to revise treatment approaches.

However, the findings of Tolchin et al did not support this fearful viewpoint. Most of the sample did not become “seizure”-free, but the treatment adherent group still improved significantly to the degree that they perceived a better quality of life and also did not visit the ED as much. Perhaps the treatment relationship itself was therapeutic. The investigators, experts in epilepsy and neuropsychiatry, also continued contact with the psychotherapists during the course of treatment.

The continued contact between the neurologically oriented clinicians and the psychotherapists highlights a particular conundrum that exists between epilepsy and PNES. If a patient with epilepsy has a seizure, a clinician asks about antecedent conditions, sleep, infections, missed medications, or even stress. If clear antecedents explain an altered seizure threshold, then there may be little justification to overhaul the treatment. Most epilepsy specialists would be comfortable in the short term saying the treatment is effective, and the seizure was explainable by the context. Yet this does not commonly happen with PNES. Most neurologists are uncomfortable treating PNES, even though they represent a sizeable percentage of epilepsy monitoring unit admissions, preferring instead that such patients exclusively become the realm of the psychiatrist.

Yet now we have information suggesting that basic collaboration and attending psychotherapy visits yield a robust improvement, possibly rivaling the effect sizes of anticonvulsants for electrical seizures. When we have treatment options, the fear of a condition decreases. The stigma of the condition also reduces. Patients with cancer in the 1970s or major depression in the 1980s would not admit that they had these

conditions for fear of being ostracized socially. But as treatment improved, people “survived” cancer and recovered from depression, and the diagnoses lost their power to induce fear. Fear and worry still exist for PNES, as evidenced by the fact that both neurologists and psychiatrists apparently resist taking responsibility to treat this condition. It exists because events themselves cause fear and clinicians are unsure how to help, yet as treatment outcomes improve, fear dissipates.

It seems that this could be a reality in PNES as well. If patients are engaged in a therapeutic treatment process, then they learn how to understand the antecedents and contexts for the events. They learn that all is not lost if an event recurs. They learn that they can live with the condition and even improve. They may have relapses, but begin to understand that they will recover. Interestingly, what happens if the word “epilepsy” is substituted for “PNES” in the first sentence of this paragraph? None of the meaning is lost at all; perhaps basic treatment approaches are similar between PNES and epilepsy, and both can be managed without undue fear among clinicians and caregivers alike.

By Jay A. Salpekar

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