A Disciplined Approach to Treatment of Psychogenic Nonepileptic Seizures

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Outcomes of Children and Adolescents 1 Year After Being Seen in a Multidisciplinary Psychogenic Non-Epileptic Seizures Clinic

Fredwall M, Terry D, Enciso L, Burch MM, Trott K, Albert DVF. Epilepsia 2021;62(10):2528-2538. doi:10.1111/epi.17031.

Objective: Psychogenic nonepileptic seizures (PNES) are paroxysmal events that may involve altered subjective experience and change in motor activity with a psychological cause. The aim of this work is to describe a population of pediatric patients with PNES and identify factors predictive of 12-month outcomes. Methods: We conducted a prospective observational study of children and adolescents referred to the multidisciplinary Nationwide Children’s Hospital PNES clinic between November 2017 and July 2019. Information was collected from patients during clinic visits and semistructured follow-up phone calls. Descriptive statistics and Fisher’s exact test were used for analysis. Results: Of the 139 consecutive patients referred to the PNES clinic, 104 were seen in clinic and 63 answered 12-month follow-up calls. Patients with comorbid epilepsy had increased rates of participation at 12-month follow-up (P = .04). Complete remission was achieved by 32% (20/63) of patients at 12 months. Combined PNES remission and improvement was 89% (56/63) at 12 months. Patients and families who were linked with counseling at 1 month were more likely to achieve remission at 12 months (P = .005). Less than half (44%, 28/63) of patients reached at 12 months had their events documented on video electroencephalogram (EEG) at diagnosis; however, those who did were not more likely to be accepting of the diagnosis at 12 months (P = 1.0), be linked with counseling at 12 months (P = .59), or be event-free at 12 months (P = .79). Significance: Remission occurred in one-third of patients by 12 months; however, improvement in events was seen in 89%. Connection to counseling by 1 month was associated with increased remission rates at 12 months. Capturing events on video-EEG was not associated with increased acceptance or event freedom at 12 months. Diagnosis should be followed by strong encouragement to connect with counseling quickly to achieve a goal of increasing 12-month PNES remission rates.

Commentary

One wonders what Jean Martin Charcot would have thought about a multidisciplinary psychogenic nonepileptic seizures (PNES) clinic. He likely would have approved the idea of multiple people involved in clinical problem solving, but there may have been some difficulty understanding the word “multidisciplinary.” Medical specialties were not so defined in the late 1800s, except for the distinction between a physician and a surgeon, the latter being more of a practical technician than an intellectual diagnostician. Of course, disciplines and specializations have exploded in the last 150 years, though whether this enhances a multidisciplinary approach or not is still up for debate. What is clear is that in Charcot’s day, thinking differently and incorporating multiple viewpoints was at least implicitly “de rigueur.” The very idea of PNES was the offshoot of pushing through the constraints of conventional wisdom. The novel insight was powerful enough to launch the whole new field of psychoanalysis, piloted by Sigmund Freud, and stemming from his witnessing the neurologist, Charcot, demonstrating PNES induction.

Psychogenic nonepileptic seizures continue to challenge conventional wisdom, and the current medical literature has grown in terms of studies for characterization of events as well as for treatment. For any clinician straddling fields of psychiatry and neurology, the progress has been gratifying if not always enlightening in terms of evidence-based algorithmic
approaches. Still, it is true that with each publication that emerges, new perspectives are appreciated, from the idea that treatment works\(^1,2\) to the utility of creative methods of service delivery.\(^3,4\) The study by Fredwall and colleagues\(^5\) is no exception, and lends new insight that extends well beyond the concrete results.

The initial appeal of the study is that it was done in pediatrics, a historically understudied population in both psychiatry and neurology. Additionally, the study offers a longitudinal perspective, which is uncommon in pediatric treatment studies in any discipline. The study itself is very concise and straightforward. Active patients who were identified as having PNES following an epilepsy monitoring unit stay were followed after referral to a specialized multidisciplinary PNES clinical program. Clinical visits routinely included both a neurologist and a psychologist at the same visit. Additional contact with nurses and social workers also occurred to arrange follow-up care or referrals. For the study, nurses contacted families at 1-, 3-, and 12-month time points and inquired about the persistence of events, functionality, and acceptance of the PNES diagnosis. Involvement in mental health services such as psychotherapy was also assessed, and although psychotherapy was not necessarily delivered by the program, assistance was provided by members of the multidisciplinary team not only to explain the diagnosis, but also to facilitate referrals and to engage support services.

The results were intriguing. Improvement was robust, with complete remission in 32%, and at least partial reduction in episode frequency in another 57% at 12 months, for a total of 89% with notable improvement.\(^5\) The results affirm that the intervention not only enabled successful engagement in treatment, but that the treatment benefit was widely present a year later. Such sustainability is difficult to obtain in chronic conditions. Illnesses such as asthma, hypertension, and substance dependence all have typical remission rates ranging from 30 to 60%.\(^6\) In fact, for diabetes, up to 50% of adult patients relapse within a year to the degree that significant medical care is required to regain stability.\(^6\)

But the outcome may not even be the most intriguing finding in this study. The positive outcome was unrelated to whether or not PNES was even identified on video electroencephalogram (VEEG). That is, patients with “proven” nonepileptic events were just as likely to have a positive outcome as those without clearly verified events. As a field, we place heavy weight upon capturing a characteristic nonepileptic event on VEEG. But from this study, we learned that such weight may not matter as much as we think, at least as reported by caregivers of these children and adolescents.

Patients and/or families were no more accepting of documented events than they were with “unproven” events. Furthermore, the outcomes did not depend upon having a “proven” diagnosis. This finding represents a fascinating conundrum. It implies that patients can engage in treatment despite not being confident of the diagnosis. Although in the study, acceptance of the PNES diagnosis improved through time, it did not predict reduction in the frequency of PNES events.

However, what did predict improvement, regardless of the establishment or acceptance of a PNES diagnosis, was rapid placement in psychotherapy within 30 days of the referral to the multidisciplinary program. Patients who were engaged in counseling within 30 days were more likely to have positive outcomes regardless of other factors, including acceptance of the diagnosis.

Perhaps that is the real value of a multidisciplinary program. A multidisciplinary team does not just mean multiple specialties; it means a consistent message and understanding of purpose. During the initial appointment in this program, patients and families heard a clear message from both a neurologist and a psychologist that the working diagnosis of PNES was being made and what that meant. More important than definitively establishing why or how it happens is instead, “what will be done next.” Ultimately, Fredwall and colleagues have shown that a crucial part of the treatment for pediatric PNES is for multiple clinicians to have the discipline to deliver a consistent message and to just start the treatment in the first place.

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