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The Truth about Psychogenic NonEpileptic Seizures

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Psychogenic nonepileptic seizures (PNES) are an uncomfortable topic, one which is difficult for both patients and healthcare professionals to discuss as well as treat, and yet it is estimated that PNES are diagnosed in 20 to 30% of patients seen at epilepsy centers for intractable seizures.¹ Moreover, in the general population the prevalence rate is 2-33 per 100, 000, making PNES nearly as prevalent as multiple sclerosis or trigeminal neuralgia.² Despite these startling statistics, PNES has largely remained a conversation held behind closed doors and in hushed tones throughout the medical community—until now.

“In addition to being common, psychogenic symptoms pose an uncomfortable and often frustrating challenge, both in diagnosis and management,” said Selim R. Benbadis, M.D., Director of Comprehensive Epilepsy Program, Professor, Departments of Neurology and Neurosurgery, University of South Florida and Tampa General Hospital. Benbadis is a leading pioneer in the study of PNES and has openly encouraged both the psychiatric and neurological community to broaden their clinical knowledge base when diagnosing and treating patients with PNES. In a recent editorial published in *Epilepsy & Behavior*, Benbadis wrote, “The American Psychiatric Association has abundant written patient education material available on diverse topics, but none on somatoform disorders. Psychogenic

symptoms are also not the subject of much clinical research. Thus, there seems to be a severe disconnect between the frequency of the problem and the amount of attention devoted to it.”³

Misdiagnosis

Benbadis also contends that the misdiagnosis of epilepsy in patients with PNES is common. In fact, approximately 25% of patients who have a previous diagnosis of epilepsy and are not responding to drug therapy are found to be misdiagnosed. “Unfortunately, once the diagnosis of epilepsy is made, it is easily perpetuated without being questioned, which explains the usual diagnostic delay and cost associated with PNES.” It is important to note that the diagnosis of PNES may be difficult initially for several reasons. First, physicians are taught almost exclusively to consider (and exclude) physical disorders as the cause of physical symptoms. Furthermore, physicians are more likely to treat for the more serious condition if they are in doubt of the diagnosis, which explains why many patients misdiagnosed with epilepsy are prescribed antiepileptic drugs. Second, the diagnosis of seizures depends largely on the observations of others who may not be trained to notice the subtle differences between an epileptic and nonepileptic seizure. Lastly, many physicians do not have access to EEG-video monitoring, which has to be performed by an epileptologist (a neurologist that specializes in epilepsy).

What exactly are PNES?

PNES are attacks that may look like epileptic seizures, but are not caused by abnormal brain electrical discharges. They are a manifestation of psychological distress. Frequently, patients with PNES may look like they are experiencing generalized convulsions similar to tonic clonic seizures with falling and shaking. Less frequently, PNES may mimic absence seizures or complex partial seizures with temporary loss of attention or staring. A physician may suspect PNES when the seizures have unusual features such as type of movements, duration, triggers and frequency.⁴

What Causes PNES?

A specific traumatic event, such as physical or sexual abuse, incest, divorce, death of a loved one, or other great loss or sudden change, can be identified in many patients with PNES. By definition, PNES are a physical manifestation of a psychological disturbance and are a type of Somatoform Disorder called a conversion disorder.¹ Somatoform Disorders are those conditions that are suggestive of a physical disorder, but upon examination cannot be accounted for by an underlying physical condition. Conversion Disorder is a somatoform disorder that is defined as physical symptoms caused by psychologic conflict, unconsciously converted to resemble those of a neurologic disorder. Conversion disorder tends to develop during adolescence or early adulthood but may occur at any age. It appears to be somewhat more common among women.⁵

How are PNES diagnosed?

According to Benbadis, while EEGs are helpful in the diagnosis of epilepsy, they are often normal in patients with proven epilepsy and should not be used alone as a diagnostic tool for epilepsy. The most reliable test to make the diagnosis of PNES is EEG-video monitoring. During a video-EEG, the patient is monitored (over a time-period spanning anywhere from several hours to several days) with both a video camera and an EEG until a seizure occurs. Through analysis of the video and EEG recordings, the diagnosis of PNES can be made with near certainty. Upon diagnosis, the patient will usually be referred to a psychiatrist for further care.

Treatment Issues

“Somatoform disorders are very difficult to treat because as soon as you extinguish one symptom another one pops up. These disorders consume a lot of time, money and tend to invoke a tremendous amount of frustration on the part of the healthcare professionals working with this population,” said Susan Kelley, Ph.D., Professor of Behavioral Health at the University of South Florida, Tampa, and psychotherapist in private practice. Kelley herself, has been able to circumvent this frustration as she has adopted a trauma-focused clinical approach, which not only serves her well as a clinician, but also helps her patients with PNES to overcome their

seizures. “For some patients with psychogenic nonepileptic seizures, the seizures are a manifestation of trauma, which is also known as Post Traumatic Stress Disorder. In order to treat patients with PTSD, the clinician has to take the seizure apart to see what the seizure represents in terms of emotions and memory as well as where this trauma is stored in the body.” She postulates that when a person experiences trauma such as physical abuse, sexual abuse, witness to violence, his/her body can absorb this trauma. Therefore, a seizure is the body’s way of expressing what the mind and mouth can not. What Kelley has found to be the most effective treatment for PNES is a therapeutic technique called Eye Movement Desensitization and Reprocessing (EMDR).

EMDR integrates elements of many psychotherapies including: psychodynamic, cognitive behavioral, interpersonal, experiential, and body-centered therapies. During EMDR the client attends to past and present experiences in brief sequential doses while simultaneously focusing on an external stimulus. Then the client is instructed to let new material become the focus of the next set of dual attention. This sequence of dual attention and personal association is repeated many times in the session.⁶

Dealing with the stigma associated with psychiatric disorders

Understandably, many patients’ first reactions upon hearing they have PNES, and not epilepsy, is one of disbelief, denial and confusion. That is because mental health issues come with highly stigmatized labels such as “crazy”, “insane” etc. These stigmas are embedded in our language and even more deeply in our unconscious belief system. However, people with PNES are not “crazy” or “insane”. Some of them are victims of trauma and their recovery from the trauma as well as the seizures depends largely on their ability to overcome the stigma and follow-up with a mental health professional. “PNES is a real condition that arises in response to real stressors. These seizures are not consciously produced and are not the patient’s fault,” said Benbadis. Kelley agreed and said, “We need to take the shame and stigma away associated with psychiatric illnesses and instead focus on the fact

that many people with PNES have a trauma history. It is so vital for people suffering with PNES to know that there is hope and that PNES is treatable through such techniques as EMDR.” While EMDR works for patients with PNES who have experienced trauma it does not work with patients who have not. Kelley emphasizes the need for “greater cooperation and collaboration among the neurology, psychiatry, and psychology disciplines, so that we can find more treatments that will bring relief to these patients.”

Latest Research

In his latest study, Benbadis and colleagues examined the relationship between chronic pain or fibromyalgia and psychogenic seizures. They designated two groups: **(1)** patients who had been diagnosed with fibromyalgia or chronic pain, and **(2)** patients who had a seizure during their visit, either in the waiting room or in the examining room. Benbadis et al. derived their data from the records of all patients evaluated over 5 years in a single epilepsy clinic for refractory seizures as well as through EEG/video monitoring. In the first group they identified 28 patients with a diagnosis of fibromyalgia and 8 with a diagnosis of chronic pain. After EEG/video monitoring 27 were diagnosed with PNES. In the second group they identified 13 patients who had a “seizure” during their clinic visit. After EEG/video monitoring, 10 were diagnosed with PNES. “These findings suggest that a history of fibromyalgia or chronic pain” and the occurrence of an episode during the visit both have a high predictive value (75% each) and a very high specificity (99%) for an eventual diagnosis of PNES,” said Benbadis. He speculates that the association between chronic pain and PNES may be “because chronic discomfort can cause psychological distress, which may result in PNES.” He also points out that another possibility is that “fibromyalgia and chronic pain are loosely made diagnoses that are largely psychogenic in themselves.”

Whether fibromyalgia and chronic pain are largely psychogenic in nature remains a highly controversial subject. Some researchers believe fibromyalgia is a disorder of central processing with neuroendocrine/neurotransmitter dysregulation. While others in the medical community strongly

believe fibromyalgia and chronic pain are psychogenic in their etiology since there is no clear underlying medical cause. Currently, the rift between these two schools of thought still remains.

If you would like more information regarding PNES you may go to:

<http://hsc.usf.edu/COM/epilepsy/PNESbrochure.pdf>

References

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