

Seizures due to psychological distress are far more common than doctors or patients may be aware. Here's why they shouldn't be swept under the rug.

BY ELIZABETH STUMP

t was while driving home on a road she'd traversed since childhood in May 2005 that Gloria (not her real name) became confused and disoriented. The regular 90-minute drive took three hours because she became lost and had to pull over several times to get her bearings.

She immediately went to the hospital and underwent neurological testing. A CT scan showed clusters of abnormal blood vessels, known as a cavernous angioma, on the left side of her brain. The EEG showed epileptiform activity—that is, signals

indicating epileptic seizures. Gloria had her first seizure while in surgery to remove the angioma. Post-surgery she had several more, manifested by aphasia (loss of the ability to produce or understand language), right-sided tremor, and diaphoresis (sweating).

Gloria was diagnosed with epilepsy and started on the anti-epileptic drugs carbamazepine (Tegretol) and levetiracetam (Keppra), but the seizures continued. In December that year she moved to Leominster, MA, to be closer to her daughter. Gloria's driver's license had been revoked due to the seizures, which increased along with her depression. Even if she had been able to drive, she was afraid to leave the house by herself.

Nearly one year after her initial seizures, Gloria underwent continuous video-EEG monitoring, which demonstrated that the seizures were not epileptic but were psychological in origin.

"When I heard that, I had a variety of emotions: disgust,

fear, panic, relief," Gloria recalls. She was gradually taken off anti-epileptic drugs, began taking fluoxetine (Prozac), and started psychotherapy. The seizures disappeared. Although Gloria may have experienced true epileptic seizures during or immediately after surgery, during the following year she experienced what are known as psychogenic non-epileptic seizures, or PNES. (See "Two Types of Seizure, One Patient" box.)

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of epilepsy patients with uncontrolled seizures may actually have psychogenic non-epileptic seizures.

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HOW COMMON ARE THEY?

Epileptic seizures are caused by abnormal electrical discharges in the brain, but PNES are psychological or emotional in nature, says Selim Benbadis, M.D., professor of neurology and director of the Comprehensive Epilepsy Program at the University of South Florida in Tampa. The word "psychogenic" means "having a psychological rather than a physiological origin." Thus, when a patient has PNES, the physical symptoms—which are real—are caused by underlying psychological disturbances. Experts believe these disturbances are unconsciously converted into a neurological-like condition.

But exactly how psychological stressors are "converted" into physical symptoms such as seizures remains uncertain, says Orrin Devinsky, M.D., professor of neurology, neurosurgery, and psychiatry at New York University (NYU) Medical Center and Director of the NYU Epilepsy Center.

Common psychological stressors include sexual or physical abuse, the death of a loved one, or distressing emotions that a patient needs to dissociate from. For some patients, the seizures are a manifestation of post-traumatic stress disorder. Many PNES patients have prior histories of psychological traumas or abuse, notes Barbara Ann Dworetzky, M.D., assistant professor of neurology at Harvard Medical School and director of the EEG Laboratory at Brigham and Women's Hospital in Boston, MA. PNES are more common in young women, especially those who have had a history of abuse.

Like Gloria, most patients with PNES don't realize their seizures are psychogenic and are not consciously aware of the trigger. In part, this is because the experience and symptoms of PNES and epileptic seizures are so similar. Patients with PNES may fall and shake, as they do with the convulsions of tonic-clonic seizures; or they may stare and experience a temporary loss of attention that mimics absence seizures or complex partial seizures. Other symptoms include memory lapses, confusion, fainting spells, and body tremors.

Dr. Benbadis estimates that PNES has a prevalence of 2 to 33 per 100,000 in the general population, making it "nearly as common as multiple sclerosis or trigeminal neuralgia." In the epilepsy population, the numbers are even higher. About one-third of epilepsy patients have a refractory form of the disease, which means they have failed on at least two different medicines and may be candidates for another medicine, for surgery, or for vagus nerve stimulation. And about 15-30 percent of these patients referred for refractory seizures actually have PNES and not epileptic seizures, says Dr. Benbadis.

DIAGNOSIS OR DENIAL

Neurologists diagnose epilepsy by taking a patient's clinical history, conducting MRI scans, and ordering an EEG. Wires attached to the patient's scalp record the brain's electrical activity, which is then analyzed for certain EEG patterns that are typical of epilepsy.

The EEG is usually normal in psychogenic cases, unless there is a separate, existing epilepsy or other brain disorder present, says Dr. Devinsky. And that makes the PNES diagnosis more difficult. (See "Two Types of Seizure, One Patient" box.)



In fact, a routine EEG can also be normal in someone with refractory epilepsy. The brain's electrical activity quickly returns to normal in most people following a seizure, and a 20-minute EEG done hours or days afterwards can miss the unpredictable and brief brain wave changes that occurred during the seizure.

In Gloria's case, her first EEG was interpreted as showing epileptiform activity. Sometimes an EEG is misinterpreted as showing evidence for epilepsy when the waves are really a variation of normal, Dr. Dworetzky says. Gloria's brain surgery may have made her waves appear sharper, but they may not have been epileptic discharges. It is also not uncommon for a patient to have epileptic seizures during the period before, during, and after surgery, but then only PNES afterwards.

Because it is difficult to diagnose PNES and distinguish them from refractory epilepsy, neurologists rely on a special type of testing called video-EEG monitoring. Usually performed in a hospital where close supervision is ensured, patients are videotaped at the same time as their EEG is recorded, often over a period of days. By analyzing both the video and EEG images, neurologists can observe how a patient's behavior during seizures is related to the electrical activity in his or her brain. For patients with PNES, a video-EEG will document seizures on the video component and simultaneously show no evidence of epilepsy on the EEG.

"All patients with refractory seizures should be considered for this procedure, as PNES in this group are relatively common, and these patients will not respond to treatments for epilepsy," says Carl W. Bazil, M.D., Ph.D., professor of clinical neurology at Columbia University College of Physicians and Surgeons in New York City.

Dr. Benbadis says that in his experience, psychologists and therapists are often more open to treating PNES than psychiatrists. Some psychiatrists "simply do not believe the diagnosis, and most do not do therapy," Dr. Benbadis says.

Sometimes doctors are uncomfortable about the diagnosis and struggle with explaining it to patients. "Physicians are often uncomfortable giving the diagnosis or 'beat around the bush," says Dr. Benbadis. "It goes well if you take the time to establish a rapport with the patient, provide informational brochures on the topic, and realize that most patients are not 'faking."

According to Dr. Bazil, "Many patients also find the diagnosis difficult to accept, as they erroneously feel that they are being told the episodes are not 'real.' They are, in fact, very real, and one of our jobs as neurologists is to affirm that. It is also difficult in that the cause is not really known."

Sometimes, patients and families focus on a prior test result or a prior diagnosis of epilepsy, even though the treatments didn't work, Dr. Devinsky says. "It is much easier to 'reject' the diagnosis than to consider that the doctor may be correct."

TWO TYPES OF SEIZURE, ONE PATIENT

An estimated 10- to 20-percent of patients with PNES also have epilepsy. In some cases, PNES may develop in patients with a history of documented epilepsy who also have a psychological issue. When both epileptic and non-epileptic seizures co-exist, the conditions may alternate, and it's important to capture both seizure types on video-EEG to make an accurate diagnosis.

Since anti-epileptic drugs (AEDs) are not effective for PNES and may even make them worse, "the key is to document the epileptic seizure and treat it with the appropriate AED, while using the appropriate intervention for PNES," says W. Curt LaFrance, Jr., M.D., assistant professor of psychiatry and neurology (research) at Brown Medical School and director of neuropsychiatry and behavioral neurology at Rhode Island Hospital in Providence.

Dr. LaFrance cites a 2006 article in *Epilepsy Behavior* by Dietrich Blumer, M.D., which revealed that reducing the AED dosage—to the minimum required to achieve optimal freedom from seizures—was an effective therapeutic intervention for patients with coexisting epileptic and non-epileptic seizures.

However, according to Dr. Benbadis, the diagnosis of coexisting seizures can be "an easy 'cop-out' strategy for the physician who is uncomfortable with [giving a diagnosis of PNES]. Also, patients with epilepsy and their family frequently become hyper-vigilant and over-interpret other symptoms as 'seizures' when they are not."

There is also the unfortunate stigma that patients with epilepsy and with psychological disorders must contend with, Dr. Dworetzky observes.

Claire (not her real name), a 50-year-old woman from Colorado, was diagnosed with PNES last year after experiencing seizures since 1993. She first resisted the PNES diagnosis because she thought she was being told she was mentally unhinged. She did not feel she was "crazy."

"They told me these episodes were my body's way of dealing with stress," she says. "To me, the term 'psychogenic' meant 'fake' seizures, even though the doctor told me that I wasn't able to control them."

Although she rarely experiences the seizures today, Claire does not talk to anyone besides her physician about them because of the stigma. "I have a 12-year-old daughter, and I don't want her to be ostracized," she says.

Some patients, on the other hand, are relieved when told they don't have epilepsy and won't need brain surgery. Ultimately, most patients accept the diagnosis and the recommended treatment.

"It often takes time for patients to accept the possibility of the diagnosis, which is often the first step in getting better," Dr. Devinsky says.

TREATMENT

Because the underlying causes of PNES and epilepsy differ substantially, treatment differs as well. PNES are not controlled by anti-epileptic drugs (also called AEDs or anticonvulsants) or by other epilepsy therapies such as vagus nerve stimulation and surgery.

"Patients with psychogenic non-epileptic seizures frequently are misdiagnosed as having epilepsy, are placed on anticonvulsants, and may even get somewhat better, at least for a while," says Ronald P. Lesser, M.D., professor of neurology and neurosurgery at Johns Hopkins in Baltimore, MD. "In some of these patients, the anticonvulsant benefit may be due to a placebo effect. In addition, anticonvulsants are sometimes useful for psychiatric conditions, and so might help them for this reason." In some cases, AEDs make PNES worse.

If the prescribed AEDs are not alleviating their seizures, patients should request a second opinion to see a specialist in epilepsy and undergo video-EEG monitoring, Dr. Dworetzky says. "Psychogenic non-epileptic seizures that are diagnosed early are more successfully treated," she notes.

Unfortunately, it typically takes seven to 10 years for a patient to obtain an accurate diagnosis of PNES, according to Dr. Benbadis. During this time, these patients are wrongly treated for epilepsy with anti-seizure medications. They endure the medication side effects without deriving any benefit.

The good news is that there are effective treatments for PNES, which vary according to the nature of the patient and their specific situation. They include types of psychotherapy and counseling—such as cognitive-behavioral or group therapy—as well as stress-reduction techniques, hypnosis, and medications for patients with an underlying or co-existing psychiatric condition. Patients with PNES have a high incidence of depression and anxiety, which may respond to psychiatric drugs that improve mood such as serotonin reuptake inhibitors. In some patients, treating the depression will help decrease the number of PNES, but in most cases medication alone doesn't resolve the seizures and psychotherapy is necessary.

Ideally, a social worker, psychiatrist, neuropsychologist, neurologist, and nurse will work together as a team to gather information and then help address the factors that have led to these seizures, explains Dr. Dworetzky.

"Unfortunately, there is a shortage of psychotherapists experienced in the treatment of this kind of problem," Dr. Lesser says. "However, pastors, friends, and family members can all be of great help."

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SUCCESS

Some studies have indicated that about onethird of patients become seizure-free after treatment with psychotherapy, and the rest either have a reduction in seizures or show no change in seizure frequency. A 2003 study in *Annals of Neurology* suggested that some 70 percent of patients continue to have episodes.

However, says Dr. LaFrance, data on effective treatments for PNES are lacking, and randomized, controlled trials are desperately needed. He is currently conducting controlled studies of pharmacologic and psychotherapeutic interventions at Rhode Island Hospital and recently finished a study on cognitive behavioral therapy for PNES. According to Dr. LaFrance, the study not only shows significant reduction in PNES frequency but also improvements in depression, anxiety, and quality of life. Eleven of the 17 PNES patients who completed cognitive behavioral therapy had cessation of their seizures, he says.

"Patients with PNES have the same level of disability that patients with epilepsy do," Dr. LaFrance asserts. Frequently their quality of life deteriorates as their driving licenses are revoked and they lose their jobs. "Some patients in the PNES pilot treatment trials, however, not only had improvement in their seizures, but also have been able to return to work," Dr. LaFrance says.

Others remain symptomatic. Claire, for instance, rides a bike instead of driving and is on Social Security (SS) disability.

Today, Gloria feels very lucky for how far she's come since 2005. She'll be 63 in November this year, and is "delighted to be able to spend time with my daughter and her husband and watch my beautiful granddaughters grow up." Still, her cognitive function is impaired and she can no longer drive. Like many others with PNES, she was granted SS disability and receives long-term disability from her previous employer. She still struggles to understand why the seizures happened and is frightened that they could happen again.

For now, those like Gloria and Claire can take strength in the knowledge that PNES treatments do exist and are being studied—as well as in the hope that as PNES become more widely acknowledged, researchers will step up to the plate.

"The seizures are still very real to me," Claire says, but "I try not to let it control my life. I know that I am lucky in that I do not have a fatal disease. That's what I focus on."



For more information on seizures, see RESOURCE CENTRAL on page 36.