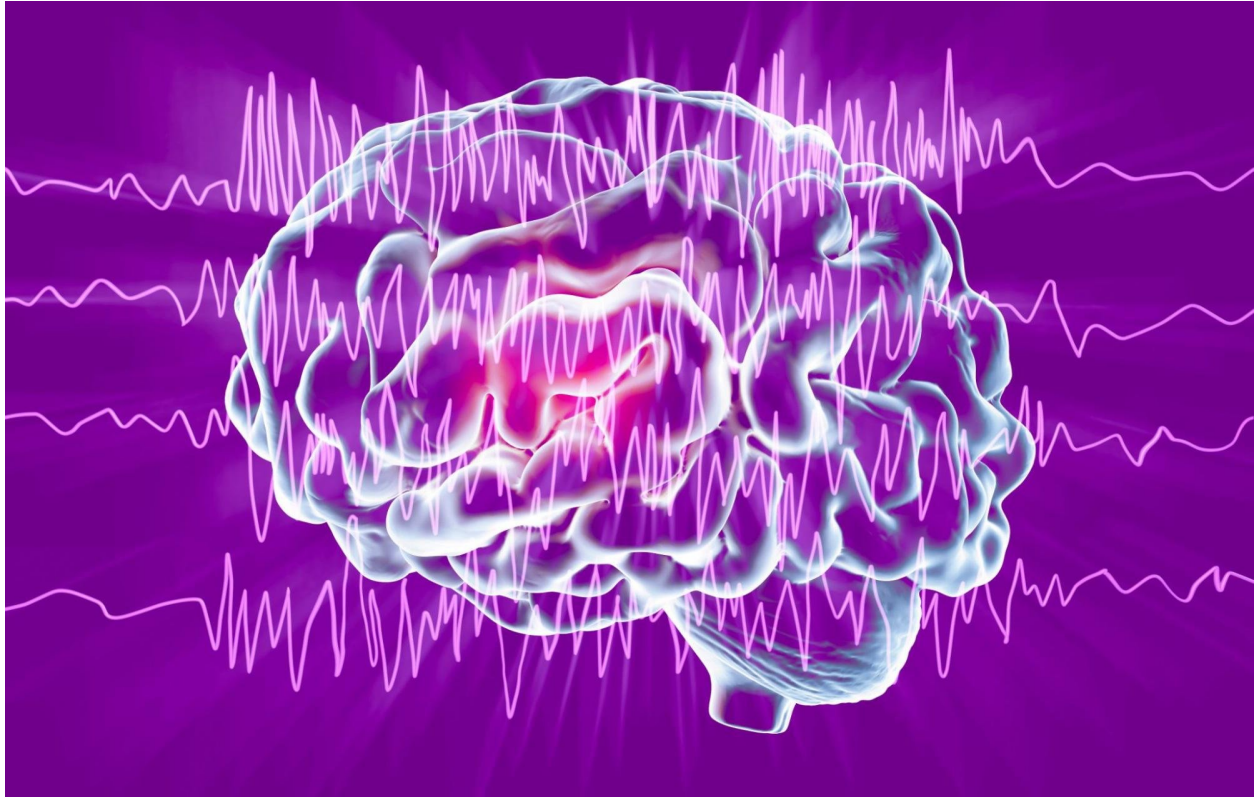


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A MULTI-MEDIA PLATFORM OF NAHJ

National Association of Hispanic Journalists



For many, trauma and scarring of the brain lead to epilepsy, now affecting a growing number of Latinos in the United States.

Photo illustration by Kateryna Kon via Shutterstock

A JOURNALIST DETAILS THE LOSS OF INDEPENDENCE HE'S LEARNED TO LIVE WITH - AND HIS EXPLORATION OF WHY EPILEPSY IS A GROWING PROBLEM AMONG LATINOS IN THE UNITED STATES.



I have epilepsy.

I had to come to grips with those three words in 2010 when I had three seizures in one day. With the seizures came the loss of my independence, punctuated by the pain of having my driver's license revoked.

After my seizures, an MRI scan found the culprit: scarring on my brain as a result of a bike crash in which I hit the ground so hard I cracked my helmet. The neurologist explained I had a traumatic brain injury (TBI), one of many causes of epilepsy. Seizures from this disorder happen when the brain is overloaded with abnormal electrical activity.

A neurologist prescribed medication and said I couldn't stop taking it or I'd put myself at risk of having more seizures. While medications can stabilize people with epilepsy and eventually allow them to regain their driver's licenses, there are still a variety of things that can increase the likelihood of more seizures. For some, lack of sleep is a trigger; mine is antibiotics. I worry about getting an infection and needing antibiotics, which could result in another seizure and further driving restrictions.

All this got me looking deeper into epilepsy. The exploration then triggered concern about the impact of this condition in the community around me: I live in California, in the city of San Rafael, north of San Francisco. The city has a large Latino population. I was stunned by statistics on the condition and Latinos that I found on the Epilepsy Foundation's [website](#).

MY NEW COMMUNITY

California, like many states, requires doctors to notify the Department of Motor Vehicles (DMV) when a person suffers a "Loss of Consciousness Disorder," as I did after a tonic-clonic – formerly known as a grand mal seizure. This notification results in a [ban on driving](#) until the DMV and a neurologist deem it safe to drive again, often after six months.

Many people are dependent on a car to get around, especially in areas without adequate public transportation. Where there is good public transportation, the hardship of getting from place to place is lessened. However, for those with epilepsy, the extra waiting and transit time poses a longer, more exhausting – sometimes debilitating – day as they take kids to and from school or childcare, get to and from work, shop for groceries and perform other daily activities.

This new complexity to my life compelled me to do extensive research, leading me to become acquainted with other people with epilepsy.



A physician examines EEG images. More than 3.4 million people in the U.S. live with epilepsy. Of that number, 710,000 are Latinos. Photo by sfam_photo via Shutterstock

Dulce Garcia is a 23-year-old full-time college student as well as a full time early childhood educator living in Newark, Delaware. She, too, wrestles with the loss of her independence because of epilepsy.

“The biggest struggle over these last seven years of living with epilepsy has definitely been not being fully independent because of not being able to drive,” she said. “My mom, my dad or my little sister are normally the ones that drive me to places whenever I need them to,” she said.

To get to school, work, appointments and other commitments, Garcia faces the daily challenge of coordinating her schedule with her family’s schedules. Too often she has to reschedule appointments for lack of a ride.

DISPARITIES FOR LATINOS

The Epilepsy Foundation says 3.4 million people in the U.S. live with this condition. Of that number, 710,000 are Latinos. The total number of new cases for all races continues to grow at 150,000 per year.

“Lack of access to treatment poses a grave threat. Uncontrolled seizures could lead to injury, stroke or brain damage ... Latinos also

face cultural and language barriers in seeking specialized medical care”

While researching health care services, I found large disparities in access for Latinos. A 2020 survey by the Kaiser Family Foundation found that, nationally, 16.3% of “Non-Hispanic” whites did not have a primary doctor or health care provider. The number for Latinos was more than double that figure, at 36.5%.

With regard to health insurance, at the state level, the largest number of Latinos without insurance was found in North Dakota at 55.8%, followed by North Carolina at 53.4% and Tennessee at 52.1%. The state with the highest number of uninsured whites was Alaska, at 29.4%.

Lack of access to treatment poses a grave threat to those with epilepsy because uncontrolled seizures could lead to stroke, brain damage and other serious injuries.

Latinos also face the challenge of cultural and language barriers, especially when trying to get specialized medical care, according to Jose Reyes, who leads a Spanish-language support group for the Epilepsy Foundation of Colorado and Wyoming.

“It's a very, very common occurrence when you're dealing with cultural diversity, with people who are minorities or represent a cultural group that many of the physicians may not know how to approach,” Reyes said.

He explained that it's important that Latinos get doctors who speak Spanish and interpreters who understand epilepsy so that the proper medical instructions are conveyed. But those services are few and far between.

A SOCIAL STIGMA

In addition to finding appropriate medical care, there is the stigma of epilepsy to contend with. Epilepsy has been variously regarded as a mental illness, an intellectual disability, demonic possession, or simple attention-grabbing behavior, among many other misconceptions.

Garcia experienced such a dismissal of her condition within her own family. “Coming from a Hispanic household, one of the biggest stigmas that I faced after being diagnosed with epilepsy was people, specifically certain family members, thinking I could control what I have with my brain,” she said. “They seemed to think that I was 'faking it,' that I was exaggerating and that there was no reason for me to be so scared because it was something that was going to go away. It wasn't until they saw me have a seizure when they understood that what I have is indeed a real illness and not something I could control,” she said.

Similarly, Reyes talked about growing up with his mother's epilepsy. His family didn't believe her condition was physical. Instead, it was common to believe the condition was caused by one's behavior.



For Latinos, social stigma and access to adequate health care are particular hurdles to treating epilepsy. Photo by Madrollly via Shutterstock

“There is a stigma with someone who has epilepsy,” he said. “It’s really hard to come to the understanding that it’s a brain abnormality. I thought I needed to be a good kid in order for my mom not to have that.”

It wasn’t until Reyes became an adult and could take his mother to a neurologist that she finally received a diagnosis. But his family still refused to believe his mother had a medical condition..

“The doctor put her on medication. The family then said to her, ‘You don’t need to take the medication because you’re not epileptic,’” he said.

Adriana Sartorio, a lecturer at Arizona State University’s New College of Interdisciplinary Arts and Sciences, has also experienced the stigma of epilepsy among Latinos. “We are really closed. When we don’t want to talk about it, we don’t talk about it. We just let it go,” she said. “We need to open up ... and not be ashamed of that condition that we have. It’s important for us to do that.”

DRUG PRICE BARRIERS

Besides social stigma, epilepsy can bring financial challenges that don’t stop with seeing doctors. Seizure medications cost money. Some cost a shocking amount.

I take a generic of the brand-name medicine Lamictal to control my seizures. I need to take three pills a day. The generic drug price at a national shopping warehouse chain is \$16 for 90 pills. The cost for the same 90 pills at two big-name drugstores starts at \$100. If I want the brand name of my seizure medicine, it would cost, on average, more than \$1,400 for 90 pills.

“Jose Reyes wants epilepsy support to be accessible to more people. His solution can be summed up in one word: Zoom”

A 2019 [World Health Organization report](#) stressed the importance of access to epilepsy medication. “Up to 70% of people living with epilepsy could become seizure-free with appropriate use of epilepsy medicines.”

According to a 2020 [National Institutes of Health report](#), the U.S. has no regulations to control drug prices. “Approximately 25% of Americans find it difficult to afford prescription drugs due to high out-of-pocket costs.”

HELP IS AVAILABLE

There are solutions for obtaining some high-cost medications. The website rxassist.org helps connect patients who cannot afford their medications with pharmaceutical patient assistance programs. The Epilepsy Foundation of Connecticut has an epilepsy prescription [assistance page](#) with a list of groups that can help people get their needed medications.

While lowering the cost of health insurance and medicines is vital, the biggest change needed in epilepsy care is education to overcome the stigma. Living with epilepsy is hard enough without having to expend extra energy to cope with the shame and marginalization associated with this condition. Equally important is for people who have epilepsy to be able to share their experiences with each other so that they and their families won't feel alone. This is where support groups come in.

The Epilepsy Foundation has many resources and information available in Spanish, including support groups like the one Jose Reyes leads. He wants epilepsy support to be accessible to more people, and his solution can be summed up in one word: Zoom.

“I think Zoom is the way to go,” he said. “If we did not have a virtual program, those people taking care of their children would not be able to attend the group.”

I, too, have learned that dealing with epilepsy on my own is not the way to cope. During the course of my own journey in learning how to live with my condition, it has helped me immeasurably to find people from all different backgrounds who know what I'm going through and to be able to discuss it together. And it has encouraged me to educate others.

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CONTACT INFO

Valeria Fernández - Managing Editor

valeria-palabra@nahj.org

General Inquiries

info_palabra@nahj.org

Sponsorship/Partnerships

sales_palabra@nahj.org

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