

Section Editors

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Are epilepsy surgery guidelines being followed?

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Most patients with epilepsy have good control of seizures using medications. However, up to 1/3 of epilepsy patients still have seizures despite trying several medications. Evidence has shown that surgery can be an effective way of treating temporal lobe epilepsy (TLE) that does not respond to medications. In 2003, this led the American Academy of Neurology (AAN) to recommend that patients with TLE whose seizures did not respond to drug treatment should consider surgery. They released a clinical practice guideline (CPG) to alert doctors to this information. The goal of the study by Haneef et al.¹ was to find out if the AAN's recommendations led to quicker referrals to epilepsy centers.

WHAT DID THE RESEARCHERS DO? The researchers collected data about epilepsy patients sent to their center (University of California, Los Angeles) between January 1995 and September 1998, and compared them to information about patients sent 10 years later (between January 2005 and September 2008). They were interested in seeing whether the guidelines resulted in earlier referrals of patients for epilepsy surgery. To focus on possible surgery candidates, they did not include patients who were referred for other reasons such as those who just recently started having seizures or those who had epilepsy surgery before. The time it took for doctors to refer epilepsy patients for surgery evaluation was defined as the length of unsuccessful drug therapy.

WHAT WERE THE RESULTS? For their report, the researchers studied 83 patients with TLE from the 1995–1998 group and 102 patients from the 2005–2008 group. There was no major difference in average time to referral or most other patient characteristics. This seemed to show that the published guidelines did not affect referral patterns for epilepsy surgery.

Even though there were no large changes, there were some differences in the timing of referrals. More patients in the 2005–2008 group were referred either earlier or later in the course of their treatment compared to the 1995–1998 group. Some earlier referrals may have happened because of the new guidelines. Balancing this, some older patients with more years of uncontrolled epilepsy may have been referred because of more recent recognition that epilepsy surgery may be successful in that age group. When these groups were averaged, these differences were hidden.

HOW DOES THIS IMPACT YOU? This study showed that although surgery is helpful to patients whose seizures are resistant to drugs, the period of unsuccessfully trying medications is still very long: about 18 to 23 years. There may be many reasons for this.

Epilepsy surgery has improved in the past 10 years, but it is not as well-advertised as drugs. This might partially explain why some doctors still send patients later for surgery evaluation, or only after trying every drug. Most epilepsy surgery is safe, but patients or doctors may still be very cautious about brain surgery. In many cases, continued seizures and their bad effects are more dangerous than surgery. Some epilepsy gets worse over time. When patients have surgery earlier it helps avoid some of the bad long-term effects of seizures. Some patients and doctors still think of epilepsy surgery as a last resort instead of an effective treatment option.

If you have tried 2 or more medications and still have seizures, you should talk to your doctor about visiting an epilepsy center. Doctors have different standards before they send patients to these centers, but it cannot hurt to ask. Even if you are not sure surgery is right for you, if medications do not work you should consider going to an epilepsy center to talk about other treatments.

WHAT IS NEXT? Now that CPGs for doctors have been established, the next challenge is creating ways to successfully apply CPGs to treatment decisions. Simply writing guidelines does not quickly change doctors' practices. For this new information to be useful, it must be put into action.

Researchers in other fields have studied the best way to put CPGs into practice. Some methods work better than others. We need more research to understand what might work best to get doctors to follow epilepsy guidelines. There might not be a one-size-fits-all approach. We have to realize that each patient is different and the CPGs may not apply to everyone. There may also be local, cultural, or other barriers to putting CPGs into practice. Therefore, the strategies will have to be adaptable, while still keeping basic principles. What is clear is that both good information about medical treatments and good communication of these findings to doctors are needed for the best patient care.

1. Haneef Z, Stern J, Dewar S, Engel J Jr. Referral pattern for epilepsy surgery after evidence-based recommendations: a retrospective study. *Neurology* 2010;75:699–704.

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About epilepsy

WHAT IS A SEIZURE? Nerve cells in the brain send electrical and chemical signals (called neurotransmitters) to each other at all times. When an abnormal electrical signal is sent, it sometimes causes other brain cells to send abnormal signals as well. If enough of these signals are sent, it results in a seizure.

WHAT IS EPILEPSY? Epilepsy is not 1 illness. There are many kinds of epilepsy. Epilepsy means having 2 or more seizures in a lifetime. Just as there are many kinds of epilepsy, there are many kinds of seizures.

One way to think of this is that the brain works like an orchestra. There are different sections in an orchestra, each with its own instruments. Although each instrument plays its own part, it is only when they all play together that complex music is made. While playing, each member of the orchestra has to listen to the other members. When the orchestra works as a team, the best music is made. However, what if one person began playing a different tune? At first, no one would notice. As more members of the orchestra began playing the different tune, it would become noticeable. At some point, the different tune might become louder than the original music.

This is similar to how a seizure gets started, and keeps going.

HOW IS EPILEPSY DIAGNOSED? The doctor will need to know as much as possible about what

happened immediately before, during, and after the seizure. How often seizures occur, whether there are any warning signs, and whether the patient remembers anything about the seizure are all important pieces of information. Someone who has witnessed the seizures can provide valuable information that the patient may not know.

EEG is a simple and painless study that records the brain's electrical activity picked up by tiny wires taped to the head. Specific brain wave patterns may be noted during or between seizures in patients with epilepsy and may help with diagnosis.

Imaging studies to look at the brain may be helpful in locating tumors, scars, or other abnormalities that may be causing seizures. MRI and CT scans create pictures of the inside of the brain.

The above section (How Is Epilepsy Diagnosed?) was adapted from Szabo CA. Risk of fetal death and malformation related to seizure medications [Patient Page]. *Neurology* 2006;67:E6–E7.

FOR MORE INFORMATION

aan.com For patients and caregivers

<http://patients.aan.com/>

Citizens United for Research in Epilepsy (CURE)

<http://www.CUREepilepsy.org>

Epilepsy Foundation

<http://www.epilepsyfoundation.org>

Epilepsy Institute

<http://www.epilepsyinstitute.org>

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