Predicting Sudden Unexpected Death in Epilepsy

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Related Article

Sudden Unexpected Death in Epilepsy: A Personalized Prediction Tool

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Why Is This Topic Important?

Sudden unexpected death in epilepsy (SUDEP) is a devastating and underrecognized cause of death in people with epilepsy. It can be a difficult subject to discuss. It can be even more difficult to predict. Previous studies have identified generally how often it occurs. These studies have also revealed some important factors that may put people with epilepsy at a higher risk of SUDEP. It is estimated that there are 1.2 cases of SUDEP per 1,000 people with epilepsy per year.¹ Researchers have also found that SUDEP occurs most often in those with ongoing, uncontrolled seizures.² These studies were done by evaluating various large populations of patients with epilepsy. Although this is useful information, it does not allow neurologists to accurately predict a patient's individual risk of SUDEP. A reliable and useful tool that neurologists could use for this purpose in their clinical offices has not yet been developed.

How Was This Study Done?

In this study, the authors developed and validated a model that uses individual patient characteristics to better predict a patient's personal risk of SUDEP.³ Their goal was to provide a clearer, more personalized assessment of SUDEP risk that would help both patients and neurologists.

The study used information from 1,273 patients with epilepsy, from 4 groups in England and Wales, Scotland, and the United States. The investigators then selected 22 variables. These included the variety and number of seizures patients were experiencing, which medications they were taking, and the age at which their seizures started occurring. The investigators used information that could be easily obtained during a routine clinic visit. Next, they used statistical analysis to validate the tool, and to decide the importance of each variable's influence on SUDEP risk. They then applied the tool to 10 patients with epilepsy to determine the patients' individual risk of SUDEP.

What Were the Main Findings?

The researchers first took steps to ensure that the prediction model was valid using statistics. They then evaluated certain factors that could be associated with an increased risk of SUDEP. They found that factors such as a higher number of uncontrolled seizures, alcohol and drug use, a family history of epilepsy, male sex, and younger age at the time of epilepsy onset were all associated with a higher risk of SUDEP. Taking antiseizure medications regularly was associated with a lower risk of SUDEP. One of the interesting findings of this

study was that people with focal seizures (that is, a seizure that causes involuntary movements or behaviors in only part of the body), rather than only generalized full-body convulsive seizures, were found to have an increased risk of SUDEP. This finding had not been seen before in other SUDEP studies. This helps show that this model has the potential to provide useful, individualized risk information for patients with epilepsy. This information can then help neurologists discuss SUDEP risk with their patients. In addition to providing a better idea of a patient's SUDEP risk, in the form of a percentage, ratio, or other number, the model provides insight into practical ways this information could be used. For example, it suggests that regular counseling regarding taking antiseizure medications as prescribed and avoiding drugs and alcohol should help patients with epilepsy reduce their risk of SUDEP.

What Are the Next Steps?

It is important to know how often SUDEP occurs and which risk factors are the most important predictors. Applying this knowledge to people with epilepsy on a case-by-case basis by using validated individualized SUDEP risk assessment tools could be a useful way to allow neurologists and people with epilepsy to have a more meaningful discussion about personal risk. It could also be useful to future research. Other areas of SUDEP research include practical solutions for prevention, as well as further study of which lifestyle changes and monitoring strategies are the most effective at reducing SUDEP risk. There are also many unanswered questions as to exactly how antiseizure medications relate to SUDEP risk. These topics require further study in the future.

About Epilepsy

What Is Epilepsy?

A person with epilepsy is prone to recurrent seizures. A seizure occurs when there is abnormal electrical activity in the brain. "Epilepsy" is typically diagnosed when a person has more than 1 seizure over the lifetime without a clear provoking cause. Seizures can come from a single focal point in the brain, which is described as a "focal" seizure. These seizures do not necessarily lead to a full body convulsion or loss of consciousness. Alternatively, seizures may occur more broadly across both the right and left halves of the brain and can lead to full body stiffening and shaking. This type of seizure is called a bilateral tonic-clonic, or "generalized," seizure. It is not uncommon for focal seizures to start in a small portion of the brain and spread to the entire brain over the course of seconds to minutes. People with epilepsy are often prescribed anti-seizure medications. These medications help reduce excessive and abnormal electrical activity in the brain. Some people with epilepsy can be treated with brain surgery or implanted devices designed to treat seizures if the medications are ineffective or cause side effects.

About SUDEP

What Is SUDEP?

Sudden unexpected death in epilepsy (SUDEP) is defined as sudden, unexpected, nontraumatic (that is, not caused by a specific injury) death in patients with epilepsy in which an autopsy does not reveal an otherwise obvious cause of death. SUDEP generally occurs in 1.2 per 1,000 people with epilepsy per year. People who experience uncontrolled generalized seizures are at a higher risk for SUDEP.⁴ There have been several other factors associated with SUDEP, but with less supporting evidence, such as sex, the number of antiseizure medications being taken, and age at which seizures began.²

The cause of SUDEP is unknown. Studies that have analyzed individual cases of SUDEP have found that a SUDEP-related seizure is typically followed by pauses in breathing and slowing of the heart rate, which then progresses to the

heartbeat stopping completely.⁵ The best way to minimize risk of SUDEP is to control seizures using tolerable anti-seizure medications and other therapies.

For More Information:

Brain & Life

brainandlife.org

Epilepsy Foundation

epilepsy.com

American Epilepsy Society

aesnet.org

National Association of Epilepsy Centers

naec-epilepsy.org

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