

Talking about SUDEP is first step to understanding it

Q: Can you die from epilepsy?

A: Anyone who has witnessed a generalized tonic clonic seizure (also known as grand mal seizure) can imagine that such a seizure can be lethal – not only through trauma or drowning, but also just through the impact of the seizure itself. The person with epilepsy, unconscious for the event, often realizes this only when listening to family and friends who witnessed the event. We tend not to think and talk about it too much, but it is self-evident that a seizure in the wrong place and time can be very dangerous.

Many topics in medicine come and go like a pendulum, meaning different aspects of a medical problem get more or less attention at different times in history. Scientists in the mid 19th century realized an increased risk of death related to epileptic seizures and speculated about the potential causes and possible prevention. Numerous, and



often unnecessary, restrictions were then imposed on patients with seizures. This changed in the second part of the 20th century when the “benign” aspects of epilepsy, like the chance of full seizure control in over half of all patients or the low risk of seizure recurrence after a first event became apparent. “Out of the Shadows” has been an ongoing movement for several decades to encourage patients and society to deal with epilepsy and seizures in a more open way and raise awareness that seizures do not preclude patients from an active and fulfilling life. With the optimism that came along with modern medical and surgical treatment options, the pendulum went to the other side and physicians even questioned if there is a shortened life expectancy associated with epilepsy.

Unfortunately, there is a real risk of dying from epilepsy. A study of Minnesota residents over a period of 40 years showed that the risk of death in patients with epilepsy was three times higher than that of the general population. The risk for sudden unexpected death is even greater and can be 25 times higher for patients with epilepsy in their 20s to 40s compared to the general population. Around 10% of patients with epilepsy die either from seizure related traumatic causes or directly from a seizure itself.

The risk of traumatic death from seizures can often be prevented with adequate counseling (avoidance of high altitudes, heavy and dangerous machinery, unobserved swimming or bathing and adequate driving restrictions) and optimal treatment. A large study in 2008 demonstrated that mortality in epilepsy is significantly higher for patients who are not compliant with their medications, outweighing any possible suicide risk related to taking antiepileptic medications.

Q: But what can we do about this “sudden unexplained death from epilepsy,” also known as SUDEP?

A: Family and physicians are often hit even harder when losing a family mem-

ber or a patient unexpectedly. It leaves us with the question: could we have done something to prevent this? We know that SUDEP is associated with generalized tonic clonic seizures and so far has not been reported in patients who only have partial seizures and have never had a generalized convulsion. Currently, the only reliable way to prevent SUDEP is complete seizure control, at least of all generalized convulsions.

When patients present with a first generalized convulsive seizure, many physicians prefer not to discuss the risk of SUDEP, which seems understandable given that there is a good chance to control these events with medications and the low risk of even having a second seizure. On the other hand, I would definitely discuss the risk of increased mortality and SUDEP with patients who have uncontrolled tonic clonic convulsions and are noncompliant to their medications.

At some point, I think all patients, even if they are compliant with their medication, should have an understanding of the severity and risks associated with their disorder. This is so that they can make informed decisions in regards to why they choose to take medications, why they bear with medication side effects, or why they may consider the risks of brain surgery to stop seizures. As mentioned above, patients often do not realize the severity of a convulsive seizure. Similar to the family who may be hesitant to describe the seizure symptoms to the patient, I don’t want to scare them; however, I think it is important to choose the right moment and discuss what happens during the event, how seizures can be dangerous, and what can be done about it.

For around a third of patients, epilepsy is not a benign condition. Acknowledging the problem has led most patients and their primary neurologist to take epilepsy more seriously and to seek the collaboration of an epilepsy specialist—a recommendation for those with seizures that still persist after a year of treatment. Families affected by the death of someone with SUDEP are fighting for more awareness and research funding and are very clear about their wish that their doctor should discuss the risk of death with their patients early on.

In the last few years, SUDEP has become a recurrent topic at national neurological and epilepsy meetings. There are still many steps to go. First, we will have to better understand the mechanisms of SUDEP. Is it caused by a sudden failure of the heart or lungs or does the brain shut down after a seizure and is unable to recover? Do we need a cardiac pacemaker, something that will keep the patient breathing, or a medication that prevents the post-seizure shutdown? Who is at higher risk, and how can we prevent SUDEP without unnecessarily restricting quality of life and independence? Hopefully, we can repeat the success seen in neonates in the prevention of sudden infant death syndrome (SIDS). The risk of SIDS has been reduced by more than half by a campaign emphasizing proper positioning and bedding. But before we are able to change things, we have to be willing to talk about it, in society and with our patients.

“There is a real risk of dying from epilepsy. But before we are able to change things, we have to be willing to talk about SUDEP.”

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