

Why epilepsy may account for more lost years of life than other brain disorders

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Generalized 3 Hz spike and wave discharges in a child with childhood absence epilepsy. Credit: Wikipedia.

Recent studies conclude that people with epilepsy have a 27-fold greater risk of sudden death than people without the disorder. However, many of these deaths could be prevented through greater identification of epilepsy as a cause of death, and in educating the public more effectively about the disease's life-threatening dangers.

These are the opinions shared by some of the country's leading epilepsy researchers at NYU Langone Medical Center in New York, in an opinion article published online December 16 in the journal *Neurology*. The authors call for a broad public health campaign and improved cause-of-death reporting.

"The public does not know that uncontrolled or ineffectively managed epilepsy leads to more than 5,000 unexpected deaths each year," says article lead author Orrin Devinsky, MD, a professor of neurology, neurosurgery and psychiatry and director of the Comprehensive Epilepsy Center at NYU Langone. "The reason why is because most of these deaths are not accounted for as a result of epilepsy. Instead, they are classified as deaths resulting from other conditions that are directly or indirectly the result of epilepsy, such as heart disease, obesity, addiction and psychiatric disorders. This practice has to end."

Dr. Devinsky and his co-authors also conclude that many sudden unexpected deaths from epilepsy, or SUDEP, can be prevented by better educating patients, families, and the general public of its dangers—particularly epilepsy-induced seizures—and the benefits of individualized treatments.

"If people better understand the seriousness of epilepsy and are better educated about its risks and how to improve seizure control, we could save thousands of lives," says Dr. Devinsky.

Collection of Data is a Major Obstacle

Highlights from the article may surprise readers. For example, the authors conclude that the inability to accurately quantify epilepsy-related deaths is a major obstacle toward improving care, as is the difficulties in comparing data from different studies. To drive home this point, they examined two studies: an open cohort study of adult epileptics covered under the Ohio Medicaid system, and a closed cohort study of childhood-onset epilepsy in Finland. Devinsky says the results were striking: in the Ohio study, SUDEP was identified in 0.01 cases per 1,000 patient years of life; the Finnish study accounted for 2.6 cases per 1,000 patient years.

The authors point out that the most significant difference in these studies was in the comparison of different methods of determining cause of death. The Ohio study only relied on information from death certificates, while the Finnish study reviewed clinical records and detailed death investigations, including 70 percent of the studied cases undergoing autopsy, a more common practice in Finland than in the U.S.

The underestimation of epilepsy-related mortality is even greater among older adults, the authors say. For example, even though epilepsy disproportionately affects people age 65 and over, autopsies are rarely performed in this age group. When autopsies are performed, even if there is evidence that a seizure led to death, the death is more often categorized as "cardiovascular," stemming from a heart attack or arrhythmia.

The authors also conclude that thousands of deaths from drowning, car and bike accidents, pneumonia from aspiration, alcohol withdrawal, falls, burns, suicide, and sudden unexpected death can be attributed to epilepsy. Low socioeconomic status and minority groups, and those with comorbid psychiatric conditions, are also at especially high risk for epilepsy-related deaths, the article reveals.

Dr. Devinsky and his co-authors stress that many successful public

health campaigns have helped to arrest stroke-related deaths as well as deaths from sudden infant death syndrome (SIDS) and fires. Adopting similar strategies could help control seizures and save lives, he says.

"The public needs to be made aware of the potentially lethal consequences of seizures and that in many cases, simple measures can help to prevent them," says Dr. Devinsky. Efforts are underway by the Centers for Disease Control and Prevention and National Institutes of Health, but we need much more, he said. "We really need to underscore this in public service announcements and other outreach efforts, just like we have done for stroke, and legislators need to be brought on board," says Dr. Devinsky.

Dr. Devinsky also recommends devising a better taxonomy for cause-of-[death](#) reporting that more accurately reflects the impact of epilepsy-related deaths. To assess [public health](#) interventions to prevent [epilepsy](#)-related deaths, he says we need to accurately track these deaths and measure change over time.

Provided by New York University School of Medicine

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