SUDEP in the North American SUDEP Registry
The full spectrum of epilepsies

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Cite as: Neurology® 2019;93:e227-e236. doi:10.1212/WNL.0000000000007778

Study objective and summary result
The present study examined the clinical characteristics and postmortem features of patients whose deaths were reported as sudden unexpected death in epilepsy (SUDEP), and it found that SUDEP occurs in patients from across the spectrum of epilepsy conditions.

What is known and what this paper adds
Most investigations into the clinical and pathologic features of SUDEP cases have had small sample sizes and have focused on various patient subgroups. This investigation reports findings from a large and diverse sample of SUDEP cases.

Participants and setting
The investigators reviewed 237 cases of SUDEP (38% in women; median age at death, 26 years; range, 1–70 years) that were reported to the North American SUDEP Registry (NASR) between October 2011 and June 2017.

Design, size, and duration
The data for this analysis were collected by conducting telephone interviews with the decedents’ family members and by reviewing medical records and autopsy reports. Two epileptologists reviewed the available data to confirm and classify the SUDEP cases according to recently published criteria.

Primary outcome measures
The primary outcomes were the clinical and pathologic features of the SUDEP cases.

Main results and the role of chance
The selected SUDEP cases were confirmed as definite or probable. The cases represented the full spectrum of epilepsy conditions, ranging from benign epilepsy with centrotemporal spikes (n = 3) to intractable epileptic encephalopathies (n = 27). The reported lifetime generalized tonic-clonic seizure (GTCS) counts ranged from 0 to >500.

Bias, confounding, and other reasons for caution
Family interviews were conducted for only 69% of the cases, and the data from interviews might have been compromised by recall bias.

Generalizability to other populations
The NASR’s reliance on referrals might have biased the sample in favor of patients of high socioeconomic status, white patients, and younger patients. This may limit the generalizability of the results.

Study funding/potential competing interests
This study was funded by Finding a Cure for Epilepsy and Seizures, Lundbeck, and the American Epilepsy Society. Some authors report receiving consulting fees, committee appointments, lecture honoraria, and funding from healthcare companies; receiving funding from the US and Canadian governments and scholarly institutions, including NASR; serving on the NASR’s executive committee; and serving as editors and reviewers for journals. Go to Neurology.org/N for full disclosures.