



## Topical Review

## Understanding Death in Children With Epilepsy



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## ABSTRACT

Death in children with epilepsy is profoundly disturbing, with lasting effects on the family, community, and health care providers. The overall risk of death for children with epilepsy is about ten times that of the general population. However, the risk of premature death for children without associated neurological comorbidities is similar to that of the general population, and most deaths are related to the cause of the epilepsy or associated neurological disability, not seizures. The most common cause of seizure-related death in children with epilepsy is sudden unexpected death in epilepsy (SUDEP). SUDEP is relatively uncommon in childhood, but the risk increases if epilepsy persists into adulthood. Although the direct cause of SUDEP remains unknown, most often death follows a generalized convulsive seizure and the risk of SUDEP is strongly related to drug-resistant epilepsy and frequent generalized tonic-clonic seizures. The most effective SUDEP prevention strategy is to reduce the frequency of seizures, although a number of seizure detection devices are under development and in the future may prove to be useful for seizure detection for those at particularly high risk. There are distinct benefits for health care professionals to discuss mortality with the family soon after the diagnosis of epilepsy. An individual approach is appropriate. When a child with epilepsy dies, particularly if the death was unexpected, family grief may be profound. Physicians and other health care professionals have a critical role in supporting families that lose a child to epilepsy. This review will provide health care providers with information needed to discuss the risk of death in children with epilepsy and support families following a loss.

**Keywords:** epilepsy, mortality, sudden death in epilepsy, children

Pediatr Neurol 2017; 70: 7–15

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Death is the most devastating outcome of epilepsy in a child. When a child dies, it affects the community and family and often leaves both the family and health care providers with difficult and challenging questions. Most

deaths in children with epilepsy are not seizure related; they are rather secondary to the underlying condition or comorbid neurological disability. Despite the recommendations of multiple professional bodies that people with epilepsy be informed of the risks of their disorder,<sup>1–4</sup> including premature death, many health care providers are uncomfortable with the discussion. With increasing attention to seizure-related deaths and sudden unexpected death in epilepsy (SUDEP), health care providers should be knowledgeable regarding mortality in children with epilepsy. The objective of this review is to provide health care

## Article History:

Received October 4, 2016; Accepted in final form January 11, 2017

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providers with the necessary facts to discuss the risk of death in children with epilepsy and support families following a loss.

### How common is death in pediatric epilepsy?

Mortality in children with epilepsy has been well described by several prospective and retrospective, population-based and regional cohorts.<sup>5–13</sup> A combined analysis of four large cohorts of children with new-onset epilepsy<sup>5,7,9,10</sup> has consolidated information about risk factors and causes of death for children with epilepsy who have been followed into early adult life.<sup>6</sup> The analysis included 2239 subjects with more than 30,000 person-years of follow-up and found an overall mortality rate of 228 per 100,000 person-years, five to ten times greater than the age-matched death rate in the general population. Throughout this article, we refer to this study as the “combined cohort study.”

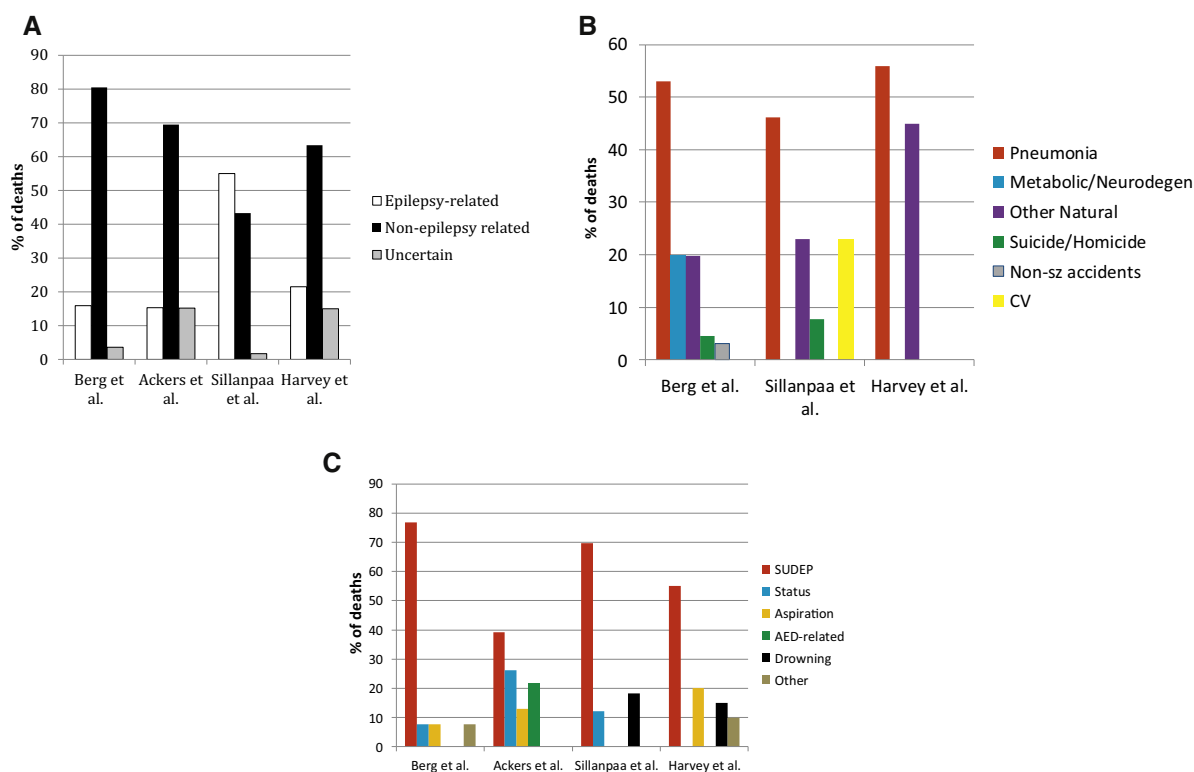
### What are the causes of death?

Mortality in children with epilepsy may be unrelated or related to the seizure disorder (Figure). Non-epilepsy-related causes of death include *natural* and *non-natural* causes, the latter including accidents, suicide, and homicide. Specific *natural* causes can be associated with epilepsy such as brain tumors or neurometabolic diseases, but more commonly are related to severe, underlying neurological disability associated with diffuse brain pathology. Death

during childhood occurs predominantly in those with “complicated” epilepsy, defined as epilepsy associated with an abnormal neurological examination, intellectual disability, or a known structural cause,<sup>6</sup> and is due to natural causes resulting from the underlying neurological disability.

Epilepsy-related causes of death include status epilepticus, aspiration due to a seizure, an accident during a seizure, a complication of therapy such as valproate-induced hepatotoxicity or anti-epileptic drug (AED)-induced Stevens-Johnson syndrome, and SUDEP. SUDEP is defined as the sudden and unexpected, nontraumatic and nondrowning death of a person with epilepsy, witnessed or unwitnessed, occurring in benign circumstances, with or without evidence of a seizure and excluding documented status epilepticus. To meet the criteria for definite SUDEP, a postmortem examination must be performed and it should fail to identify the cause of death.<sup>14</sup>

In the combined cohort study, 70% of seizure-related deaths were due to nonepilepsy *natural* causes, and of these, pneumonia accounted for 35 of 48 (73%) deaths.<sup>6</sup> Sepsis and ventriculoperitoneal shunt malfunction each accounted for an additional 6% of natural deaths. *Non-natural* causes accounted for five of 69 (7%) deaths (two suicides, one homicide, and two non-seizure-related accidents). The very-long-term, Finnish study followed children with epilepsy into midadulthood and found that cardiovascular disease was also an important cause of natural death, accounting for approximately 13% of deaths.<sup>8</sup>



**FIGURE.** Causes of death in children with epilepsy. (A) All deaths, (B) non-epilepsy-related deaths, and (C) epilepsy-related deaths. (The color version of this figure is available in the online edition.)

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