
Sudden unexplained death in children with epilepsy

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Mortality rates in children with epilepsy exceed those of the general population. While many deaths may be explained by the underlying cause of seizures or co-morbid conditions, a proportion of deaths in children with epilepsy remain unexplained. The phenomenon of sudden unexpected death in epilepsy (SUDEP) refers to the death of a person with epilepsy that is sudden, unexpected and unexplained. Autopsy does not reveal a cause of death. SUDEP deaths may be witnessed or unwitnessed and may occur with or without evidence of a recent seizure.

The incidence of SUDEP in adults is estimated to be 1 death per 1,000 people with epilepsy per year, with rates approaching 1 per 100 person years in individuals with medically refractory seizures. The incidence of SUDEP in children has not been explored adequately; the limited literature suggests lower rates than in adults, ranging from 0.2 to 0.4 per 1,000 person years. These incidence rates are generally believed to be an underestimate, as it is widely acknowledged that poor awareness of SUDEP among health care practitioners and people with epilepsy results in low case ascertainment.

The CPSP conducted a one-time survey to determine whether a gap in knowledge of SUDEP exists among Canadian paediatricians and inform strategies for a prospective study of SUDEP among Canadian children. The survey was circulated to all CPSP participants and the response rate was 34% (866/2,570). Of the respondents, 78% (674/866) reported that they had cared for children with epilepsy in the preceding 24 months. Among these paediatricians, only 56% (380/674) knew that children with epilepsy are at an increased risk of sudden unexplained death compared to children without epilepsy. Only 33% (225/674) of paediatricians caring for children with epilepsy were aware of the term SUDEP.

Fourteen paediatricians reported knowledge of a case of SUDEP. Of the 11 cases for which details of the death investigation process were reported, five children (45%) did not undergo autopsy, suggesting inadequate investigation of deaths in children with epilepsy. The survey methodology does not permit accurate incidence calculations.

This survey identifies poor awareness of SUDEP among Canadian paediatricians and highlights the need for educational initiatives to support future studies involving SUDEP case collection. Accurate incidence data will require prospective surveillance of SUDEP in children. More information about SUDEP may be found at www.sudepaware.org.

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