



Sudden Death in Epilepsy: Knowledge among Pediatric Providers

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A survey of 146 pediatric care providers (PCPs) revealed that 75.3% were unaware that children with epilepsy were at risk of death, specifically from sudden unexpected (or unexplained) death in epilepsy (SUDEP). PCPs assume that the treating neurologist discusses these risks. Increasing PCPs' knowledge of SUDEP will help address the care gap related to informing families about SUDEP. (*J Pediatr* 2017;188:291-3).

Epilepsy affects 1 in 26 people of all ages and is the most common and significant neurologic disorder across the lifespan.¹ With a prevalence of active pediatric epilepsy of 0.6%, more than 460 000 US children are currently living with the disorder.² Children with epilepsy are at high risk for cognitive impairment, psychosocial difficulties, and other health comorbidities (eg, sleep disorders, migraine, osteoporosis) as a consequence of the seizures themselves, epilepsy treatments, or the underlying cause of the epilepsy.¹ Furthermore, epilepsy is associated with significantly higher rates of mortality.³ Although adults with epilepsy have up to a 3-fold increase in risk of mortality, children with epilepsy have up to an 8.5-fold increase because of the low rate of death among children in general.³

Sudden unexpected (or unexplained) death in epilepsy (SUDEP) is the most common epilepsy-specific cause of death,⁴ and sudden death is over 20 times more common in young people with epilepsy compared with the general population.⁵ A survey of caregivers of people with epilepsy indicated that a majority worry that their child with epilepsy will die, and want to discuss SUDEP with their health care provider.⁶ Although most neurologists are aware of the risk of mortality in epilepsy, only a minority of neurologists discusses SUDEP with all of their patients.⁷ The reasons provided by neurologists for not discussing the risks of SUDEP vary, but approximately one-half stated that it is because the patients are at low risk. Other cited reasons included the absence of proven intervention, concerns that the information would negatively affect the patient's mood or quality of life, not yet having established trust with the family, not having time during an office visit, and not having sufficient knowledge about SUDEP. Thus, there is a gap in care regarding informing families about SUDEP.

Given that families of children with epilepsy want to discuss the risk of death, and that care of these children is shared between the primary care provider (PCP) and the neurologist, we investigated pediatric PCPs' awareness of SUDEP. We hypothesized that only a minority of the sample would be aware of SUDEP, and that even fewer would discuss the topic with families.

Methods

Surveys were sent to a professional network of PCPs from 2 pediatric medical institutions, the University of Virginia Medical Center and Children's National Health System (CNHS). Both institutions partner with PCPs that span a geographic region that includes Maryland, the District of Columbia, Virginia, and West Virginia. Surveys were distributed both online and in paper form. For online surveys, an invitation to complete a Web-based survey using QuestionPro was sent to PCPs via e-mail from 3 sources: (1) a personal e-mail (from H.P.G.) to general pediatricians and family medicine faculty at University of Virginia Medical Center; (2) an e-mail blast to the professional contact list of pediatricians who refer to CNHS; and (3) an online newsletter sent from the Virginia Chapter of the American Academy of Pediatrics (VA-AAP). Online announcements included a brief description of the purpose of the survey and a link to participate ([Appendix](#); available at www.jpeds.com). Paper versions of the same survey were hand distributed to the attendees at a conference hosted by CNHS designed for PCPs to receive continuing education.

The survey was comprised of 17 questions that took less than 10 minutes to complete. Four questions determined the type of medical practitioner and the type of practice. The remaining questions were related to the respondent's knowledge of SUDEP and how that related to care of their patients with epilepsy. The design of the survey included providing a definition of SUDEP and online resources for SUDEP education for physicians and patients. Descriptive statistics, including central tendency measures, ranges, and frequencies, were conducted.

The study was approved by both Children's National Health System's and the University of Virginia's Institutional Review Boards. Respondents gave informed consent of their willingness to take part in this study at the introduction of the survey.

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| CNHS | Children's National Health System |
| PCP | Primary care provider |
| SUDEP | Sudden unexpected (or unexplained) death in epilepsy |

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Supported by the BAND Foundation. The authors declare no conflicts of interest.

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<http://dx.doi.org/10.1016/j.jpeds.2017.05.036>

Results

A total of 163 respondents started the survey, but 14 responses were incomplete and left 149 for consideration; 92 responses were from the 289 surveys distributed in-person at the CNHS annual conference, giving a response rate of 32%. An additional 58 responses were completed online including 42 of the 44 (95%) personal e-mails (from H.P.G), which included a link to the online survey, and 15 from the e-mail blast to the CNHS network of 1400 pediatricians and Virginia Chapter of the American Academy of Pediatrics newsletter, which has a distribution of 1180 members. The precise response rate to the e-mail blast is difficult to ascertain because only 84 people in total viewed the survey (including those who received a personal e-mail). We removed 3 respondents (2 medical/nursing students and a social worker) who were not PCPs, which left a final sample of 146 respondents.

The majority (110; 75.3%) of the respondents were pediatricians; other PCPs in the sample included 25 (17.2%) nurse practitioners in pediatric practices, 6 (4.1%) general/family practitioners, and 1 (0.7%) emergency medicine physician. The respondents had been in practice for an average of 18.2 ± 10.7 years, with a range of 0-45 years of experience since completing residency. The sample comprised mostly private PCPs practicing in a suburban setting, with 126 (86.9%) having at least 1 patient with epilepsy in their caseload (Table I).

Before the survey, 109 respondents (74.7%) were not aware that children with epilepsy were at risk of death. Even more respondents (125; 85.6%) were not familiar with the term SUDEP, and 128 (87.7%) were exposed to the definition for the first time because of the survey.

Rates of familiarity with SUDEP differed by practice type (Cramer $V = 0.271$; $P = .031$), such that higher percentages of PCPs in academic or medical centers knew about SUDEP compared with PCPs in private practice or school/clinic settings (Table II). Reported rates of exposure to formal education on the topic did not differ among the different practice types. The rate of familiarity with SUDEP also differed by practice setting (Cramer $V = 0.209$; $P = .042$), with a higher percentage of those

Table II. Knowledge of SUDEP by practice type and setting

| Practice type/settings | Familiarity with SUDEP, n (%) |
|------------------------|-------------------------------|
| Practice type | |
| Private practice | 9 (9.1) |
| Medical center | 4 (19.0) |
| Academic setting | 8 (34.8) |
| Clinic/school | 0 (0) |
| Practice setting | |
| Rural | 2 (50) |
| Suburban | 9 (9.9) |
| Urban | 9 (18) |

who knew about SUDEP in rural and urban settings compared with suburban settings. The sample size from the rural setting was small ($n = 4$), and interpretation of this finding is tentative; however, 2 of the respondents were familiar with the term SUDEP. Five PCPs, all in a private practice urban or suburban setting, had a patient die from definite or probable SUDEP as defined in the survey. Despite this experience of losing a patient to sudden death, only 1 of these 5 PCPs reported familiarity with the term SUDEP before this survey.

Only 5 PCPs (3.4%) reported ever discussing SUDEP with patients or caregivers, whereas two-thirds (100; 68.5%) had discussed other seizure risk factors/lifestyle modifications. Of the minority that had discussed SUDEP, 1 PCP had cared for a patient who died from definite or probable SUDEP. The 2 primary reasons that PCPs gave for not discussing SUDEP were insufficient knowledge of the topic (115; 78.8%) and the expectation that the patient's neurologist would discuss SUDEP and other risk factors with the patient (115; 78.8%). Other reasons reported by 9 respondents (6.2%) for not discussing SUDEP included not having sufficient time, not knowing how to phrase the words, not knowing if SUDEP can be prevented, not having a close enough rapport with the patient, and considering the patient to be at minimal risk. The vast majority (130; 89%) believed that learning more about SUDEP is relevant to their practice and preferred a variety of formats for receiving information (eg, lecture, Web-based, journal articles).

Table I. Demographic data of respondents (n = 147)

| Variables | Value, n (%) |
|----------------------------------|--------------|
| Practice type | |
| Private practice | 99 (67.8) |
| Medical center | 21 (14.4) |
| Academic | 23 (15.8) |
| Clinic/school | 2 (1.4) |
| Missing | 1 (0.7) |
| Practice setting | |
| Rural | 4 (2.7) |
| Suburban | 91 (62.3) |
| Urban | 50 (34.2) |
| Missing | 1 (0.7) |
| Number of patients with epilepsy | |
| None | 19 (13.0) |
| 1-10 | 94 (64.4) |
| 11-10 | 23 (15.8) |
| >20 | 9 (6.2) |
| Missing | 1 (0.7) |

Discussion

In a community of experienced PCPs from a variety of practice types and settings who treat children with epilepsy, PCPs commonly do not discuss SUDEP with patients because it is largely an unknown risk, and because they expect the treating neurologist to address the topic. However, our survey findings suggest that PCPs would discuss SUDEP if they were better informed, given that these providers frequently discuss other important areas of risk associated with epilepsy. Moreover, recent research highlights that it is incorrect to assume that neurologists are discussing SUDEP.⁷

Although the risk of sudden death in children is a sensitive topic to broach, families nonetheless want to discuss SUDEP with their doctors.⁶ The reasons for not having this discussion

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