SEATTLE, December 8, 2014 – Sudden unexpected death in epilepsy (SUDEP) is the leading killer of people with chronic, uncontrolled epilepsy, but this phenomenon remains poorly understood. Three studies to be presented at the American Epilepsy Society’s (AES) 68th Annual Meeting aim to improve communication around SUDEP by re-evaluating how death certificates are coded, and by promoting the accessibility and distribution of SUDEP-related information for adult and pediatric patients.

People with epilepsy who die suddenly and unexpectedly often undergo post-mortem evaluation by medical examiners or coroners, but epilepsy is not always noted on the death certificate due to the lack of standardized terminology to describe SUDEP. Researchers from the University of Alabama (Poster 2.070) explored how medical examiners interpret SUDEP cases and how these practices might influence SUDEP surveillance.

The researchers surveyed members of the National Association of Medical Examiners, asking the respondents to indicate how they would certify immediate and underlying causes of death (Part 1), contributing factors (Part 2) and manner of death on death certificates for each of several clinical vignettes describing the sudden deaths of individuals with epilepsy or other seizure-related disorders. None of the vignettes described status epilepticus.

A total of 77 forensic pathologists completed the surveys, which were sent to the National Center for Health Statistics (NCHS) for coding according to the 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10) coding system.

“We hope this study brings awareness to some of the challenges that clinicians, medical examiners, and researchers face when dealing with terminology in SUDEP,” said Dr. Daniel Atherton, Department of Pathology, University of Alabama-Birmingham. “Our findings emphasize the need for continued communication and collaboration.”

Participants submitted a total of 847 responses on 11 different cases. The authors aggregated similar text coding, then assigned ICD-10 codes to 201 representative examples of completed death certificates. Approximately 3 to 62 percent of responses within each case were not assigned an ICD-10 seizure code. The most common code, G40.9 (i.e., “Epilepsy, unspecified”), was used six times.

Results of the survey suggest that a significant portion of death certificates relevant to SUDEP investigators would not be identified based on ICD-10 epilepsy codes. According to the authors, clear collaboration between neurologists and forensic pathologists is needed to develop a fine-tuned strategy and uniform approach to death certification in SUDEP.

A qualitative descriptive study (Poster 2.065) conducted by researchers at McMaster University assessed patient preferences about the amount of SUDEP-related information shared by medical professionals, to inform practice guidelines on SUDEP counseling. The researchers recruited 23 adults with epilepsy from an adult neurology clinic and a community epilepsy agency, engaging them in one-on-one telephone
interviews or a single focus group interview to elicit feedback on how the issue of SUDEP is broached by care providers.

Though more than 90% of the adults had been diagnosed with epilepsy for at least 1 year, more than half of them reported having no understanding of SUDEP before being invited to participate in the study. The patients expressed differing opinions on the desired topics of SUDEP discussions: risk of SUDEP was the most requested topic, followed by prevention, causes, personal relevance, and potential sources of more information. All participants preferred hearing about SUDEP from a physician, neurologist or expert in the field, while more than half suggested that the presence of a nurse or social worker would provide added support.

“To help healthcare professionals become more comfortable in discussing SUDEP with their patients, the first step in research is to ask people with epilepsy and their caregivers whether, when, what and how they want to hear about SUDEP,” said Dr. Rajesh RamachandranNair, Department of Pediatrics, McMaster University. “It is still unclear whether the opinion expressed by these selected participants represents the opinion of the entire population of people with epilepsy. However, for physicians who opt to discuss SUDEP with their patients and families, these findings will help them in that process.”

While most participants agreed that greater awareness of SUDEP might benefit patients and caregivers, about a quarter of the participants believed the information could contribute to emotional stress and worry. An overwhelming majority of the participants surveyed wanted to hear about SUDEP from their neurologist during an in-person meeting, preferably at the time of epilepsy diagnosis.

In a third study (Poster 2.142), researchers at the Children’s National Medical Center surveyed 22 board-certified child neurologists to assess their communication of SUDEP to pediatric patients and their families, focusing on their communication practices, knowledge of and comfort with the topic.

Nearly half of the respondents had finished their training within the previous five years, and half reported seeing between 21 and 50 patients with epilepsy in their clinic each month. Most respondents had experienced at least one patient death from SUDEP: 10 respondents reported zero cases of SUDEP, 5 reported one case, 4 reported two cases, 2 reported three cases, and one reported more than 5 cases. Only 4 participants reported discussing SUDEP with the majority of their patients, while 10 of the respondents reported discussing the topic with fewer than 10% of their patients.

Respondents who do not routinely discuss SUDEP with their patients cited several reasons for the lack of communication, including minimal or low patient risk (15), SUDEP being so rare that the risks of discussion outweigh the benefits (6), lack of sufficient personal knowledge of SUDEP (6), insufficient research-based knowledge about SUDEP (5), absence of a trusting relationship with the patient (5), no proven way to prevent SUDEP (4), lack of time during an office visit (4) and possible negative effect on quality of life or mood (2).

The findings reveal that within a single institution there can be a wide spectrum of experience and practice concerning SUDEP, and potential barriers of knowledge and practice can limit patient-provider discussions.

All three research studies will be provided in full at the American Epilepsy Society Annual Meeting in Seattle, December 5-9. Abstracts referenced above can be found on the American Epilepsy Society’s Annual Meeting Page.
Editor’s Note: Authors of these studies will be available at a press briefing on December 8, 2014 at 8:15 AM (PT)/ 11:15 AM (ET), in the onsite press room, Room 304, Level 3 of the Washington State Convention Center. The call-in number for off-site journalists is 1-605-475-4000, passcode 521653#.

About the American Epilepsy Society
The American Epilepsy Society (AES) is a non-profit medical and scientific society. Our individual members are professionals engaged in both research and clinical care for people with epilepsy from private practice, academia and government. For more than 75 years, AES has been unlocking the potential of the clinical and research community by creating a dynamic global forum where professionals can share, learn and grow. AES champions the use of sound science and clinical care through the exchange of knowledge, by providing education and by furthering the advancement of the profession.

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