K
othing that people with epi-
lepsy have a greater risk of sud-
den death than those without a seizure disorder begs the question: Do physicians have that discussion with their patients? And in the case of physi-
cians tending to children, do they deliver the news to their patient’s families? If so, when?

There is an ongoing debate on whether all patients with seizure dis-
orders (or their caregivers, in the case of children) should be counseled on unexplained death in epilepsy, or SUDEP. Several recent studies have attempted to address the question and the results may be surprising.

“Many physicians have a ‘don’t ask, don’t tell policy,’” said Rajesh Ramachan-
dran Nair, MD, an associate professor of pediatrics in the Division of Neurology at McMaster University in Canada. “But it seems that parents want to know.”

SURVEY OF PARENTS
Dr. Ramachandran Nair and his colleagues say that many physicians fear that any discussion of an increased risk of sudden death might burden families already dealing with a diagnosis of epi-
lepsy. The Canadian neurologists brought 36 parents together in focus groups and another half-dozen mothers or fathers who lost children to SUDEP for a one-
one-on discussion about the importance of knowing about the increased risk, and who should deliver the news and when.

The investigators found that 37 percent of parents in the focus groups had not previously heard about SUDEP. Even among those who knew about the risk, most could not describe the meaning of SUDEP. Many also overestimated the risk. Still, said Dr. Ramachandran Nair, “it was unanimous, across both genders and regardless of seizure severity, that routine counseling about SUDEP should be provided by pediatric neurologists.”

But when should the news be deliv-
ered? “Parents thought that it would be important to understand SUDEP, but many said that it might not be appro-
priate at the time of the initial diag-
nosis,” said Dr. Ramachandran Nair. “They agreed that the follow-up meet-
ing would be a good time to hear about the increased risk for sudden death associated with refractory epilepsy.”

They also thought that a neurolo-
gist should discuss SUDEP during an appointment and not on the phone or through a pamphlet. “They said it would be good to have a credible website where they could go for more detailed infor-
mation after the neurologist explains SUDEP,” said Dr. Ramachandran Nair.

There was less agreement about whether children should be told about the increased risk of sudden death, he added. Fifty percent said that their children should know during their adolescent years, between 12 and 14.

Half of the parents said that they would want to discuss SUDEP with their chil-
dren and the others said that it should be handled by their child’s neurologist.

For Further Reading:
- Epstein RM, Alper BS, Quill TE. Communicating evidence for participatory decision making. JAMA 2004;291(19):2359-
2366.
**SUDEP**

*Continued from page 24*

“The parents said that they believed it was their decision to make, and not up to the neurologist,” explained Dr. Ramachandran Nair.

The parents thought that it should be stressed that the risk may be rare and that controlling epilepsy was important in protecting against this risk, he said.

The Canadian scientists are now running another focus group study with teenagers and adults with epilepsy.

**NEUROLOGISTS’ KNOWLEDGE ABOUT SUDEP**

Orrin Devinsky, MD, professor of neurology, neurosurgery, and psychiatry, and director of the Comprehensive Epilepsy Center at New York University Langone Medical Center, and his colleagues decided to find out just what neurologists in the United States and Canada think about discussing SUDEP with their patients or their families. They designed an electronic, web-based survey to assess knowledge and experience with SUDEP and whether they talked about SUDEP with patients or their parents.

The questionnaire was sent to 17,558 neurologists in the US and Canada. They received 1,200 replies and the neurologists filled out information on their years in practice, type of practice, training experience and average number of epilepsy patients followed annually, number of SUDEP cases in past two years, how often they discussed SUDEP with their patient’s families and their reasons for or against the discussion. They also asked questions about the reactions they received following a discussion of SUDEP.

They analyzed the data to figure out what factors influenced the frequency of the SUDEP discussion, reasons for discussing/not discussing SUDEP, timing of SUDEP discussions, and perceived patient reactions.

The study team reported that only 6.8 percent of respondents discussed SUDEP with nearly all (<90 percent of the time) epilepsy patients or their caregivers while 11.6 percent never discussed it. About 75 percent of neurologists had a discussion about SUDEP with less than half of their patients.

Factors that independently predicted whether SUDEP was discussed nearly all of the time were the number of epilepsy patients seen annually (p = 0.043) and if the neurologist had a SUDEP case in the past 24 months (p = 0.0008). Doctors said that the most common reported patient reaction to the SUDEP discussion was “anxiety.” Negative reactions were reported as most common by 59.5 percent of neurologists that responded to the survey, said Dr. Devinsky.

The frequency of the SUDEP discussion was independently associated with an increased likelihood of a negative perceived reaction while years in practice was associated with a decreased likelihood of negative reaction.

“The more experienced neurologists are less likely to encounter negative reactions, and this suggests that there may be ways to frame the discussion in a way that minimizes patient/caregiver distress,” added Dr. Devinsky. (In a podcast interview with Neurology Today, Dr. Devinsky discusses strategies for framing the discussion: http://bit.ly/rCBryX.)

**WHAT DO PATIENTS AND CAREGIVERS THINK?**

Dr. Devinsky and colleagues also created a survey that was filled out by 1,325 patients and 574 caregivers, virtually all of whom said that they wanted to know about SUDEP. Less than three percent of patients and one percent of caregivers said that they did not want to know about SUDEP. About 70 percent of patients and 80 percent of caregivers had at least heard of SUDEP. Less than 30 percent felt that they were educated about the risk, said Dr. Devinsky.

Only 10 percent of those respondents said that they had been told about SUDEP from a physician. They found that 68 percent of patients and 52 percent of caregivers learned about SUDEP from a website. So why aren’t physicians more open about SUDEP? “Many neurologists think that their patients are at low risk and that there is no way to prevent it, so why worry them,” said Dr. Devinsky.

There are studies that show that good control of seizures reduces the risk for SUDEP and that there are things that patients can do, including taking their medicines, making sure they get enough sleep, minimizing alcohol, and reducing stress. “But unless they know about SUDEP and what they can do to lower their risk, they can’t make this a priority,” he added.

**PEDIATRICIANS’ ROLE**

Part of the problem is that pediatricians who manage epilepsy in their practices are not well-educated about SUDEP, according to a third survey reported at the AES meeting. Doctors from the Hospital for Sick Children at the University of Toronto conducted a study of pediatricians through the Canadian Pediatric Surveillance Program (CPSP). A survey was sent to all 2,570 pediatricians in the program and 866 completed the ten questions, including information on the pediatrician’s experience providing care to children with epilepsy, knowledge of mortality risk among children with epilepsy, and knowledge of SUDEP.

Among these pediatricians, only 56 percent (380) had prior knowledge that children with epilepsy are at an increased risk of sudden unexplained death compared to children without epilepsy. Only 33 percent (225) of pediatricians caring for children with epilepsy were aware of the term SUDEP.

The findings from the survey also suggest that not all children with epilepsy who die suddenly are brought to autopsy. “These three studies very importantly assessed the knowledge gap about SUDEP among doctors, patients, and their families,” said Elson L. So, MD, a professor of neurology at the Mayo Clinic College of Medicine and vice president of the American Epilepsy Society. “Unless this gap is closed, we will not be able to reduce the risk of SUDEP, or eventually discover why and how SUDEP happens.”

**FOR FURTHER READING:**

- SUDEP Coalition, established by the American Epilepsy Society. The Epilepsy Foundation, Citizens United for Research in Epilepsy, and the National Institute for Neurological Diseases and Stroke: www.aesnet.org/sudep

**LISTEN UP, TUNE IN:** Orrin Devinsky, MD, professor of neurology, neurosurgery, and psychiatry, and director of the Comprehensive Epilepsy Center at New York University Langone Medical Center, and his colleagues decided to find out just what neurologists in the United States and Canada think about discussing SUDEP with their patients or their families.

**DR. RAJESH RAMACHANDRAN NAIR:** “Many physicians have a ‘don’t ask, don’t tell’ policy. But it seems that parents want to know (about SUDEP).”

**DR. ORRIN DEVINSKY** said there are studies that show that good control of seizures reduces the risk for SUDEP and that there are things that patients can do, including taking their medicines, making sure they get enough sleep, minimizing alcohol, and reducing stress. “But unless they know about SUDEP and what they can do to lower their risk, they can’t make this a priority,” he added.