Teens With Epilepsy Face More Social Hurdles

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SAN DIEGO — Studies have suggested that the social environment can be a rocky place for children with epilepsy, Joan K. Austin, D.N.S., said at the annual meetings of the American Epilepsy Society and the Canadian League Against Epilepsy.

According to a survey that she and her associates conducted of 19,441 teens in the general population, 75% of the respondents thought that teens with epilepsy were more likely to be bullied or picked on, compared with their peers (Epilepsy Behav. 2002;3:368-75). More than half of the respondents (52%) had never heard of epilepsy; 46% were not sure if it was contagious; and 40% were not sure if people with epilepsy were dangerous. Only 31% reported that they would date someone with epilepsy, and 19% thought it was a form of mental illness.

"This survey shows lack of familiarity with epilepsy," said Dr. Austin, a distinguished professor of nursing at Indiana University, Indianapolis. "It also reflects some of the dimensions of risk and safety concerns ... about the contagiousness or the dangerousness. It also has hints of social avoidance."

In a Canadian survey of 41 healthy children and 108 teens with chronic conditions, most respondents held several misconceptions about epilepsy, compared with other chronic conditions, including the notion that epilepsy causes a mental handicap, leads to self-injury and death, and that epilepsy causes injury to others during a seizure (J. Child. Neurol. 2006;21:214-22). "Other perceptions about epilepsy were that persons with epilepsy were less honest, less popular, less fun, and less adept at sports, compared with normal teens," said Dr. Austin, also a past president of the American Epilepsy Society.

A survey of 512 teachers in all regions of the United States revealed that while their attitudes toward epilepsy were generally positive, less than 5% had ever had frequent contact with a child with epilepsy and 70% reported inadequate knowledge about the condition (Epilepsy Behav. 2006;8:397-405).

Another study led by one of Dr. Austin's colleagues showed that when teachers knew a child had epilepsy, they underestimated the child's academic achievement on objective achievement tests (Epilepsia 2005;46[suppl 8]:A1.185). "These results suggest that teachers' ratings of children's achievement might be negatively influenced by the label of epilepsy," she said.

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Ms. Austin went on to note that children's perceptions of the stigma are associated with mental health problems. Parents' perception of stigma is associated with depressed mood and behavior problems at home and at school. In addition, child stigma perceptions have been associated with poor self-concept and depressive symptoms, while adolescent stigma perceptions have been associated with anxiety and also depression.

One way to address the roots of internalized stigma in the clinical setting is to focus on the child's fears and worries about having epilepsy.

Based on research Ms. Austin and her associates have conducted in children with epilepsy "we found them to have imagined causes of seizures, unfounded worries about getting hurt, worries about not knowing when another seizure would occur and how to make plans, concerns that they would continue to get sicker and sicker, worries about death, and worries about becoming mentally ill."

Many of their anxieties "were based on inaccurate or incomplete information," she said. "These could be addressed in a clinical setting." Another helpful strategy is to address the child's need for information and support. Ms. Austin said children like to know about the causes of seizures, techniques for handling future seizures, how to prevent injury, and how to handle restrictions on their activity.

The presentation was part of a program supported by an educational grant from Abbott Laboratories, Cyberonics Inc., and GlaxoSmithKline. ■

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