



erc
epilepsy RESOURCE CONNECTION

www.arc-sedgwickcounty.org/ERC.html

hotline

Some Epilepsy Patients Not Always Aware of Seizures

In patients with focal epilepsy, simply asking how often they have seizures doesn't provide a true count of their seizure frequency, German research suggests.

Reminding patients to keep written records of their seizures may not help, either, because they may be unaware of some seizures, said the University of Bonn Medical Center researchers.

"In conclusion, patient seizure counts are not valid, and reports of complete seizure freedom may need objective evaluation (e.g., regarding a driver's license)," the study authors concluded.

The study, published in the November issue of the journal *Archives of Neurology*, included 91 adults with focal epilepsy -- also known as partial seizures -- which involves one specific area of the brain.

The patients were outfitted with electrodes and monitored by video for an average of 4.5 days. They were asked to keep a seizure diary and to push a warning button to summon a nurse when they detected the onset of a seizure.

About half (42) of the patients received daily reminders about documenting all their seizures.

During the study, the patients experienced a total of 582 partial seizures but did not report 323 of them. The researchers found that 85.8% of all seizures that occurred during sleep were unreported, compared with 32% of seizures that occurred while patients were awake.

"Patients activated the push-button alarm ahead of 51 seizures (8.8%) but failed to document 17 (33.3%) of these seizures," wrote the study authors, who also found that patient self-reporting varied by seizure type.

Patients failed to report 73.2% of complex partial seizures (which impair consciousness) and 26.2% of simple partial seizures (which don't affect consciousness). ✦ HEALTH DAY

New Seizure Drug on Horizon

The FDA has accepted UCB's New Drug Application (NDA) for the use of lacosamide as an adjunctive therapy in the treatment of partial onset seizures in adults with epilepsy. The application includes three lacosamide formulations -- tablets, syrup and an intravenous injection. The proposed trade name for lacosamide is Vimpat™.

"This filing is another step in support of UCB's epilepsy franchise and its long-term commitment to advancing treatment options for patients with epilepsy," said Iris Loew-Friedrich, MD, PhD, Global Head of Development, UCB.

The NDA for lacosamide in epilepsy is supported by data from three clinical trials with a total of approximately 1,300 adults with uncontrolled partial onset seizures, despite taking one to three antiepileptic drugs (AEDs). In these studies, significantly greater 50% responder rates and reductions in median seizure frequency were seen versus placebo. The most common adverse events of lacosamide (greater than or equal to 10%) reported in these trials included dizziness, headache, nausea and diplopia. ✦ MEDICAL NEWS TODAY



"Epilepsy Attitudes and Understanding" Survey

A new survey of people with epilepsy has revealed a surprising degree of underutilization of specialized treatment. While the nation's epilepsy specialists have adopted "no seizures, no side effects" as the major treatment goal, the survey found that only half of patients with continuing seizures ever expect to achieve it and that an even smaller number are receiving their medical care from epilepsy specialists. Only half of patients with frequent seizures are offered alternative treatment options.

The survey also suggests a lack of communication between patients and physicians on treatment goals, with patients unsure of what their doctors would consider to be a significant reduction in seizures. A sizeable minority of patients rely on information about the condition gained from sources other than the physician's office, while fears of seizures and their associated effects limit social interaction for many patients. Epilepsy's social impact continues its negative effects on day to day living, yet those issues are seldom addressed by caregivers.

The telephone survey, conducted in May 2007, focused on patient attitudes, perceptions of medical care and epilepsy's social impact. 402 patients, aged 18 or over, were interviewed. 177 of the respondents had more than one seizure per month; 225 had less than one seizure per month.



More than twice as many women as men took part (285 vs. 117). Suburban areas (93) were slightly less represented than city (168) or rural (128) areas. The study population was divided by age into three groups: 18-36 years (65); 40-59 years (235); and 60+ years (102).

The study, jointly sponsored by the American Epilepsy Society and the Epilepsy Foundation, was conducted by Penn,

Schoen & Berland Associates, Inc. with support from Pfizer Inc.

Results:

Only 5% of patients with refractory seizures receive care from an epileptologist or epilepsy clinic; 42% are cared for by non-neurologists. Among patients rating their seizures as poorly controlled, almost as many were cared for by a primary care provider as by a neurologist.

Only half of patients with the most frequent seizures are offered new treatment options [medication, vagus nerve stimulation (VNS), or surgery]. Neurologists are more likely than primary care physicians to discuss alternative treatments.

Patients with frequent seizures are slightly more likely than others to feel they have to request information on options from the doctor. A sizeable majority feel that discussing treatment options is a shared responsibility.

Patients are not sure what their physicians would consider to be a significant improvement in seizure frequency. While half of the patients identify a 90% reduction or no seizures at all as being a significant improvement, only 35% think their doctors would share that view. In addition, 26% did not know what their doctors would rank as a significant improvement.

Few physician visits specifically focus on general questions or concern about lifestyle and related issues. Most (69%) patients see their physicians two or four times a year, usually for a regular check up. Other reasons for physician visits include increased seizures and side effects from meds.

- Continued on back -

SURVEY (continued from front)

Physicians do not frequently address social issues with patients. Only about half will ask about epilepsy's impact on quality of life. Day to day activities and mood are more likely to be raised with younger patients and those who are having more than one seizure per month.

While the majority of patients say they are always accurate in reporting their seizures to the physician, some are not. 25% of women who underestimate say they don't want the doctor to know. Failure to track, forgetting, or just not being aware of having had a seizure are also reasons for underreporting.

Despite patients' expressed overall satisfaction with their care, they believe their level of control can be improved and over half say their treatment goal is never to have another seizure.

Patients with more frequent seizures are less satisfied with their level of control. Half of patients (49%) who have more than one seizure per month rank their seizure control at the lower or middle range of a ten point scale, and 17% are not at all satisfied with their control.

Younger patients (18-39) were disproportionately represented among patients having frequent seizures (39% weekly or bi-weekly) and were least likely to be satisfied with their level of control.

Many patients appear to have settled for less than optimal control, giving their physicians high marks for effort, while at the same time believing that more can be done.

Many patients are willing to try new ways of controlling seizures if given the opportunity. 68% of patients who have taken five or more medications in the past are interested in trying new ones. 33% would consider surgery or other treatment.

Among those who are not satisfied with their care, one quarter cite ineffective treatment; while others cite the need for other treatment options or other factors, such as insurance coverage. Of the patients in this category, 26% said that the treatment was not working; 16% wanted different medicines or other treatment options and 12% lacked sufficient insurance. Others cited, in declining order, poor care, transportation difficulties, perceived lack of epilepsy specialists (7%), and reluctance

to raise issues with the health care providers (4%).

The social impact of refractory epilepsy on daily life is substantial. More than half of all patients report hardship because of inability to drive; 45% have had to pass responsibilities on to other family members because of the condition. A similar number say they don't have the same freedom of action that other people do.

Social interaction is negatively affected. Approximately 40% feel people treat them differently because of epilepsy. Similar numbers worry about being a burden on family. More than a third are uncomfortable telling new acquaintances they have epilepsy (38%), are less social because of epilepsy (35%), and have had to give up sports because of epilepsy (33%). Among those with one or more seizures a month, 31% worry about holding a baby and 27% worry about swimming or bathing alone. ↵ EPILEPSY FOUNDATION

The Arc of Sedgwick County
2919 West Second Street
Wichita, Kansas 67203



erc, JobForce & Office This present

↑ WORK SUCCESS ↓

A Free Employment Workshop for Persons with Epilepsy

January 25, 2007

9:00 a.m. - Noon

@ Office This (4031 E. Harry)

Join the Employment Specialists from JobForce Employment Solutions® for this FREE hands-on workshop. *Participants will explore opportunities and strategies to overcome employment barriers to persons with epilepsy. **TO ATTEND, please REGISTER by calling (316) 943-1191 or on-line at www.epilepsybrainstorms.org**



Adult Epilepsy Support Group

Meets Second Tuesday of Month,
6:30 PM @ 2919 W. 2nd Street, Wichita

January 8th: "Advocating For Yourself"
February 12th: "Stress Management"

Survey Conclusions

The results underscore the need for enhanced patient knowledge of treatment objectives and improved patient-physician dialogue for better epilepsy care.

- There is significant underutilization of medical options by people with refractory epilepsy, specifically access to specialists and newer treatment options.
- There is a need to improve patient expectations about seizure control and better physician/patient communication about treatment goals and social issues.
- Social issues continue to have a major impact on daily lives; yet are not often discussed with physicians.
- Many patients are already committed to partnership and shared responsibility for care; they need additional education to become more active partners in their care and active advocates on their own behalf.
- Primary care physicians would benefit from education on availability of treatment options for their patients with refractory epilepsy, and when to refer for specialized care. ↵

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