

Epilepsy-linked memory loss worries more patients than doctors

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Patients with epilepsy worry more than their physicians do about the patients' potential memory loss accompanying their seizure disorder, according to a recent study.

In a survey, patients with epilepsy as a group ranked memory loss as their second-most important concern on a list of 20 potential medical or social concerns. Memory loss as a concern came in 12th in the frequency of responses among concerns recorded by physicians and nurse practitioners who completed the same survey.

Patients and practitioners agreed overall on three of the top five concerns: having a seizure unexpectedly, the legal right or ability to drive and [seizures](#) not being controlled. Practitioners ranked problems with medication side effects as their second-highest concern, and patients ranked being a burden to their family as their fifth-highest concern.

Both groups agreed that having a seizure unexpectedly was the No. 1 concern. Almost three-fourths of practitioners and just over half of patients ranked unexpected seizures as their biggest worry.

"In a lot of cases, there was a fair amount of overlap, but the thing that the patients had on their radar screen that practitioners didn't was the memory issue. Memory was a concern for a larger percentage of the patients than we had anticipated," said James McAuley, associate professor of pharmacy practice and neurology at Ohio State University and lead author of the study.

"Indirectly, we address memory concerns in the clinic by addressing seizures. But we don't typically sit down with a patient and say, 'Tell me about your memory.' This has heightened the awareness of our clinicians and should serve as a wake-up call to all practitioners treating people with epilepsy."

The National Institutes of Health describes epilepsy as a brain disorder affecting an estimated 2 million Americans in which clusters of [nerve cells](#) in the [brain signal](#) abnormally, causing strange sensations, emotions and behavior or sometimes convulsions, [muscle spasms](#) and loss of consciousness. In about 80 percent of patients, seizures can be controlled with medication or surgery.

The study is published in a recent issue of the journal *Epilepsy & Behavior*.

McAuley and colleagues collected survey responses from 257 patients seen in Ohio State's outpatient epilepsy clinic between March 2009 and February 2010, as well as from five clinicians – four physicians and a nurse practitioner – who treated those patients. McAuley practices in the clinic as a drug therapy adviser and did not participate in the survey.

The questionnaire listed 20 potential concerns of patients with epilepsy. These included the highest concerns generally agreed upon by all respondents, as well as a host of others: holding down a job or achieving desired education and employment goals, mood issues, medical costs, treatment by others and sexual health.

Respondents were asked to scan the entire list of 20 concerns and rank only their top five concerns in order from highest to lowest. The researchers documented both the frequency of responses as well as the ranks of the concerns based on their average overall scores.

The study revealed two gaps between how the two groups thought about the disorder: Patients as a group were far more concerned about memory loss than were practitioners, and practitioners demonstrated more concern about unexpected seizures than did patients.

"The mantra in our clinic is, 'No seizures, no side effects,' so uncontrolled seizures are seen as a medical concern by practitioners," McAuley said. "Patients tend to not want to have seizures because of the social stigma. An interesting point in this context is that we believe in the clinic that if we can improve seizures, we will improve memory."

In all, 71 percent of practitioners listed an unexpected seizure as their top concern, compared to 51 percent of patients. Forty-two percent of patients listed memory among their top five concerns, compared to only 21 percent of practitioners.

McAuley said that people with epilepsy know that cognition can be an issue for patients over time. There are generally four ways that memory can be affected by epilepsy: medication side effects, uncontrolled seizures, the effects of the disease itself on the brain, and associated mood disorders such as depression and anxiety.

He said that memory loss in epilepsy patients tends to be accompanied by awareness of the forgetfulness. For example, patients might know they went out to lunch a few days ago, but cannot remember what they ate.

Research has shown that drugs specifically designed to improve memory, such as those for patients with dementia, have not been effective in patients with epilepsy – this is probably because the medications act on a completely different part of the brain, McAuley noted.

Patients with [epilepsy](#) who require multiple drugs to control their seizures are at higher risk of suffering side effects as a result of the combined drugs, he added. About 15 drugs compose the arsenal of medications available to treat the disorder.

For these reasons, McAuley said, practitioners strive to prescribe medications at dose levels that can control seizures while also minimizing side effects – a sometimes daunting task. The most common side effect associated with these drugs is sleepiness, he said. This can occur with medicines designed to dampen excitation in the affected area of the brain.

"If you overshoot the dampening by applying more brake than gas, then there is a potential that the patient may be tired," he said.

Some antiepileptic medicines can also cause weight gain or weight loss.

The questionnaire's demographic data showed that 57 percent of respondents, or 147 patients, had had seizures within the last six months. Only two overall responses differed significantly based on these characteristics: Patients with controlled seizures were more likely to report the legal right or ability to drive as one of their top concerns as compared with patients with uncontrolled seizures, and patients with uncontrolled seizures were more likely to report a lack of seizure control as a concern than were patients whose seizures were controlled.

McAuley noted that he was surprised to find that the strong concern about memory crossed over both groups of patients.

"I would have anticipated that if patients are doing well, they are not worried about memory, driving, or loved ones having to take care of them because they are doing OK," he said. "That also tells us that even though they're doing OK, they know that because of the unexpected

nature of seizures that it could happen tomorrow, next week or two years from now. So I guess there is still underlying anxiety that seizures may return."

The researchers concluded that overall, practitioners are aware of their patients' concerns, memory notwithstanding. Patients' five most frequent concerns matched the seven most frequent concerns listed by practitioners.

The scientists plan to delve more deeply into this area of research by exploring what causes are behind memory problems that patients do report.

"We'll try to differentiate the cause of the memory problem and that will help guide us to either increase medication doses to get better control of seizures, decrease doses to eliminate side effects, or use an antidepressant to address mood," McAuley said. "It's quite a murky area and our goal is to learn more by dissecting the reasons for [memory loss](#)."

Provided by The Ohio State University

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