

Results of Eisai Inc. and Epilepsy Foundation National Survey Shed Light on Unmet Needs in Epilepsy Community

Findings of a survey among 250 patients and 250 caregivers suggest the need for improved education efforts within epilepsy community and beyond to address misperceptions about the disease

The Epilepsy Community Wants Improved Disease Information

Epilepsy patients and their caregivers expressed their desire for a better understanding of the disease, whether through educational resources or more meaningful discussions with their doctor.

- Nearly 9 out of 10 patients and caregivers say there are aspects of epilepsy even they don't completely understand. Topics they would like a better understanding of include:
 - Seizure triggers (62%)
 - Side effects of treatments (58%)
 - Types of treatments (49%)
- 55% stated information about lifestyle modifications for managing epilepsy needs improvement.
- 63% reported information about conditions or health problems associated with epilepsy needs improvement.

Epilepsy Education Is Needed to Increase Understanding and Help Reduce Stigma

There are many aspects of epilepsy that remain misunderstood, and misperceptions about the disease may be driving stigma.

- 89% of epilepsy patients and caregivers think there is a stigma associated with the condition; this may be caused by a lack of understanding about the disease.
- More than 2 in 5 (44%) epilepsy patients report experiencing discrimination due to their epilepsy.
- 40% of epilepsy patients report difficulty making or keeping friends, and 28% experience lack of family support.
- 58% of patients have kept their condition a secret for fear of being treated differently; if patients do decide to tell someone new in their life about their disease, they wait 2 months, on average, before speaking about it.

Support Services for People with Epilepsy Can Be Helpful, But Could Be Improved

Managing a complex disease like epilepsy goes far beyond medical treatment. The availability and accessibility of support services such as counseling programs, transportation services and employment assistance are crucial.

- More than half (51%) of epilepsy patients and caregivers do not have services for people with epilepsy in their area, or do not know if they are available.
- Those who have services in their area identify programs that need improvement:
 - Employment services (43%)
 - Educational services (42%)
 - Support groups (42%)
- While improvements are needed, 91% of patients and caregivers who have support services available and have used them found them to be helpful.

Epilepsy Can Have a Serious Impact on Daily Life

Survey results confirmed that epilepsy can affect the day-to-day lives of patients and caregivers

- 89% of epilepsy patients report experiencing difficulty with a daily life activity due to epilepsy, including:
 - Driving (59%)
 - Work (57%)
 - Socializing (52%)
- Similarly, 83% of epilepsy patients have avoided doing or attending something because of their epilepsy, including:
 - Driving (54%)
 - Work (34%)
 - Social gatherings (38%)
- The vast majority (89%) of epilepsy patients are worried about experiencing future seizures.
- And, 96% of caregivers report that their loved one's epilepsy has taken an emotional toll on them.

Key Takeaways

- Lack of understanding about epilepsy is widespread, and improved education efforts are needed to help combat stigma associated with the disease.
- Epilepsy patients need better information about their disease, whether from educational resources or more meaningful dialogue with their doctors.
- When it comes to support services for people with epilepsy, it's not just about availability of services—quality is important too, and patients and caregivers identified a number of services that need improvement.

About the Survey

- Eisai Inc. and the Epilepsy Foundation partnered to survey epilepsy patients and caregivers.
- The survey was conducted by Wakefield Research among 250 epilepsy patients and 250 caregivers ages 18+. It was fielded between March 28th and April 14th, 2014, using an email invitation and online survey.
- Among the respondents, 54% were female and 46% were male, with 43% under the age of 40 and 57% age 40 or older.