SEIZURE CLUSTERS SIGNIFICANTLY IMPACT QUALITY OF LIFE FOR PATIENTS AND THEIR CAREGIVERS, ACCORDING TO A LANDMARK SURVEY CONDUCTED BY HARRIS POLL

Findings from Survey Commissioned by the Epilepsy Foundation Presented at 69th Annual Meeting of the American Epilepsy Society

Philadelphia – December 7, 2015 – Results from a nationwide survey that measured the physical and emotional impact of seizure clusters, a seizure pattern experienced by some patients with epilepsy, were presented for the first time at the 69th Annual Meeting of the American Epilepsy Society (AES) in Philadelphia, December 4-8, 2015. The landmark Seizure Cluster Burden of Illness survey was conducted online in September 2014 by Harris Poll on behalf of The Epilepsy Foundation with unrestricted grant support from Upsher-Smith Laboratories, Inc. (Upsher-Smith). More than 850 patients, caregivers and physicians participated in the survey.

The survey revealed that seizure clusters have a negative impact on quality of life for patients and caregivers, including emotional, financial and social well-being burdens. Patients and caregivers also tended to perceive the impact of seizure clusters more negatively than clinicians did, a finding that demonstrates a significant disconnect between what many patients and caregivers experience and what clinicians believe. Finally, patients and clinicians characterized seizure cluster management quite differently, a finding that suggests clinical recommendations may not be implemented.

“This survey sheds new light on how seizure clusters detrimentally affect the well-being of patients as well as their caregivers,” said Patricia E. Penovich, MD, Minnesota Epilepsy Group. “Even more importantly, these results reveal a gap between the perceptions of clinicians who care for patients with seizure clusters and the reported experiences of patients and caregivers themselves. We hope that identifying this gap will be the first step towards increased education on managing seizure clusters and improved therapies to potentially reduce the burden of illness.”

“These survey results clearly highlight the perception disparities between clinicians and those living with seizure clusters,” said Joseph Sirven, MD, chairman, Department of Neurology, Mayo Clinic. “A majority of physicians (79 percent) reported that they recommend patients use a rescue medication when a seizure cluster occurs, while only a minority of patients (20 percent) reported typically doing so. This disconnect points to the need for identifying areas that require more attention during physician-patient interactions so that potential excessive costs of care due to the overutilization of ER services and underutilization of rescue treatments are avoided.”

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The Seizure Cluster Burden of Illness survey was developed and led by a steering committee comprised of renowned leaders in the field of epilepsy including: Janice Buelow, RN, PhD, FAAN, former vice president, programs and research, Epilepsy Foundation; Patricia Penovich, MD, Minnesota Epilepsy Group; Joseph Sirven, MD, chairman, Department of Neurology, Mayo Clinic; and James Wheless, MD, professor and chair, Department of Pediatric Neurology, University of Tennessee.

Key Findings

Burden of Seizure Clusters on Patients with Epilepsy and Caregivers

- The majority of patients (70 percent) felt that seizure clusters have a major/moderate negative impact on their quality of life; particularly affecting the ability to drive (69 percent), mood (69 percent), independence (67 percent), and social activities and hobbies (57 percent). Results for caregiver respondents were similar.
- Patients reported that seizure clusters made them feel exhausted (76 percent), confused or slow-thinking (70 percent), stressed (63 percent), depressed (62 percent), helpless (56 percent) and scared (51 percent).
- More than half of caregivers (58 percent) reported that seizure clusters have a major/moderate impact on their own quality of life and nearly half (48 percent) said their work has been negatively impacted by their patient’s seizure clusters.
- Caregivers reported feeling stressed (67 percent), helpless (64 percent), scared (59 percent) and overwhelmed (52 percent) when the patient experienced a seizure cluster.
- Almost three quarters of patients (74 percent) and more than half of caregivers (55 percent) felt that seizure clusters added a significant financial burden to the patient’s life.

Comparing Perceptions of the Impact of Seizure Clusters Among Clinicians, Patients and Caregivers

- Nearly half of patients (47 percent) and caregivers (48 percent) strongly agreed that seizure disorder prevents the patient from doing things other people can do compared with only 23 percent of clinicians (P < .05 for both). In addition, though only about half of patients (52 percent) and caregivers (54 percent) felt patients with seizure clusters can achieve a fulfilling life, nearly three quarters of clinicians (74 percent) felt a fulfilling life was possible (somewhat agree and strongly agree combined; P < .05 for both).
- Significantly more patients than clinicians strongly agreed that seizure clusters get in the way of daily living activities (32 percent vs. 14 percent; P < .05 ) as well as increased emotional (43 percent vs. 29 percent; P < .05) and financial (42 percent vs. 15 percent; P < .05) burden.

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Though significantly more clinicians somewhat or strongly agreed that patients are embarrassed to talk about their seizure disorder compared with patients or caregivers (58 percent vs. 38 percent and 37 percent; P < .05), the percentage of patients and caregivers reporting strong agreement (17 percent and 13 percent) was significantly higher than clinicians (7 percent; P < .05).

The Patient-Clinician Relationship in Seizure Cluster Management

About half of clinicians (51 percent) encouraged more than 75 percent of patients to use a seizure diary, but only 55 percent of patients and 62 percent of caregivers report the patient doing so. In addition, about half of clinicians (52 percent) reported that 51-100 percent of patients have a seizure emergency plan though only 30 percent of patients reported having one in place. Caregiver results showed that significantly more children have an emergency plan compared with adults (78 percent vs. 31 percent; P < .05).

When asked what typical recommendations are for when a seizure cluster occurs, clinicians most commonly recommended using a rescue medication (79 percent) followed by: call the doctor’s office (67 percent); visit the emergency room (61 percent); and stay calm (50 percent). In contrast, patient actions were to stay calm (34 percent), do nothing (27 percent), visit the emergency room (24 percent), call the doctor (20 percent) and take a rescue medication (20 percent).

About three in 10 patients and two in five caregivers used an emergency room for seizure clusters in the past year, with 24 percent of patients reporting that they would initially seek out emergency room care as their first option.

Abstracts of the poster presentations can be found online at www.aesnet.org. To schedule an interview with an author, please contact Andrea Preston at apreston@klcpr.com.

About the Seizure Cluster Burden of Illness Survey

The Seizure Cluster Burden of Illness survey was conducted online in the United States by Harris Poll on behalf of The Epilepsy Foundation with unrestricted grant support from Upsher-Smith Laboratories, Inc. from September 2-30, 2014, among 861 adults ages 18 and older, including: 259 patients, 263 caregivers of adult or pediatric patients, and 339 neurologists/epileptologists. Raw data were weighted as needed to achieve representativeness within the respective respondent populations. This online survey is not based on a probability sample and therefore no estimate of theoretical sampling error can be calculated. For complete survey methodology, including weighting variables and subgroup sample sizes, please contact Andrea Preston at Kovak-Likly Communications at 203-762-8833, apreston@klcpr.com.
About Epilepsy

Epilepsy is a medical condition that is characterized by recurrent seizures. More than two million people in the U.S. are estimated to be affected by epilepsy, with about 150,000 new cases of epilepsy diagnosed each year. Epilepsy can be associated with profound physical, psychological and social consequences that negatively impact people’s lives.

About Seizure Clusters

Seizure clusters, also referred to as acute repetitive seizures, seizure flurries, crescendo seizures, cluster seizures, or bouts of increased seizure activity, consist of multiple seizures which occur over a relatively brief period of time with a pattern distinguishable from the patient’s usual seizure pattern. Reports of seizure cluster prevalence vary depending on the population evaluated. Seizure clusters are associated with worse seizure control. In a study conducted in a tertiary epilepsy center in patients with a broad range of seizure control, the prevalence of seizure clusters was close to 30%. The number of epilepsy patients in the United States who experience seizure clusters is approximately 152,000.

About the Epilepsy Foundation

The Epilepsy Foundation, a national non-profit with 48 affiliated organizations throughout the United States, has led the fight against seizures since 1968. The Foundation is an unwavering ally for individuals and families impacted by epilepsy and seizures. The mission of the Epilepsy Foundation is to stop seizures and sudden unexpected death in epilepsy (SUDEP), find a cure and overcome the challenges created by epilepsy through efforts including education, advocacy and research to accelerate ideas into therapies. The Foundation works to ensure that people with seizures have the opportunity to live their lives to their fullest potential. For additional information, please visit www.epilepsy.com.

About Upsher-Smith

Upsher-Smith Laboratories, Inc., founded in 1919, is a growing, fully integrated pharmaceutical company dedicated to its mission of delivering high-value, high-quality therapies and solutions which measurably improve individuals’ lives. As a family-owned pharmaceutical company, we are able to adapt and thrive in a dynamic healthcare environment. Our world is constantly evolving, and we are continually adapting to the ever-changing needs of patients, physicians, pharmacists, and healthcare organizations. Where there is a need, we will work to deliver solutions that simplify access to treatment, deliver better health outcomes, and enhance life. Upsher-Smith has a particular focus on developing therapies for people living with central nervous system (CNS) conditions, such as seizure disorders. For more information, visit www.upsher-smith.com.

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References