

Success Story: South Carolina Blazes a Trail for Epilepsy Surveillance



Epilepsy: A Public Health Problem



Epilepsy is a brain disorder that causes repeated seizures and affects up to 3.4 million people in the United States.¹ Uncontrolled seizures can interfere with life and lead to early death.²

Enhanced data collection on epilepsy began at the national level in 2010,³ but little or no data have been collected at the state level. This data gap has left state and local public health leaders without information on their population's needs for epilepsy services and programs.

Data Collection Critical to Public Health Efforts

With funding from the Centers for Disease Control and Prevention (CDC), the Medical University of South Carolina (MUSC) has collected data and conducted studies to help increase knowledge about epilepsy and how it affects people living in South Carolina. These efforts included setting up the South Carolina Epilepsy Surveillance System (SCESS), the country's first and only state-based epilepsy surveillance system.

The SCESS monitors incidence, prevalence, and unmet needs for people with epilepsy in South Carolina. Data come from inpatient, emergency, and hospital encounters, including information from outpatient surgical offices, physician offices, nursing homes, and specialized clinics and institutions. Health care providers are required to submit the data to the SC Office of Research and Statistics.

SCESS worked with several partners across the state to gain access to health-related data,⁴ including:

- SC Department of Health and Environmental Control
- SC Budget and Control Board Office of Research and Statistics
- Epilepsy Association of South Carolina
- Medical Association of South Carolina
- SC Hospital Association
- SC Chapter of the American Neurological Association

South Carolina Conducts Innovative Research

In addition to collecting data through the SCESS, MUSC conducted innovative research projects from 2001 to 2015 on the following topics:

- Epilepsy prevalence, incidence, and locations where people with epilepsy receive care.
- The prevalence and effect of comorbid conditions.
- The influence that income and social factors, health care access, attitudes, and beliefs have on health outcomes among people with epilepsy.

The first project was the South Carolina Epidemiological Studies of Epilepsy & Seizure Disorders, which established the SCESS in 2002.⁵ Other key activities included initial studies on prevalence and incidence and validation of the SCESS case definitions and data sources.⁵

From 2004 to 2007, the South Carolina Health Outcome Project on Epilepsy (SC HOPE) developed surveys and conducted phone interviews with 370 adults and young people aged 11 to 17 who had received treatment for epilepsy in the past 5 years. One goal was to learn more about their experiences living with epilepsy. The SC HOPE team used multiple strategies to reach people with epilepsy, including mail-outs and phone calls to patients identified from hospital discharge records, emergency department records, and some health plans.

MUSC found that targeted recruitment of patients in clinics worked better than community wide strategies, such as inserting information about the study in local water bills or publishing articles about the study in regional newspapers and local newsletters.⁶

The MUSC team continued to analyze data and publish findings between 2007 and 2011. Later, from 2011 to 2015, MUSC conducted a study called Risk Factors of Epilepsy Outcomes: Comorbidities in Population with Epilepsy.⁷ This project assessed the



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prevalence and effect of comorbid conditions and risk factors, such as frequent hospitalizations and long-term disability, and their association with negative outcomes and death. Researchers found that about 50% of people with epilepsy had at least one co-occurring condition, and both children and adults with epilepsy were at increased risk of early death. They also found that people with epilepsy in rural areas had more comorbidities than people with epilepsy in urban areas. The prevalence of comorbid conditions also varied by race, ethnicity, and income.⁷ For example:

- Whites had a higher prevalence of mood disorders, drug abuse, suicidal thoughts or attempts, lung disorders, and Parkinson's disease compared to other groups.
- Blacks had a higher prevalence of alcoholism, cerebral palsy, schizophrenia, Alzheimer's disease, heart disease, diabetes, HIV/AIDS, and stroke compared to other groups.
- Those living at lower income levels were more than 2.5 times more likely to have comorbid conditions than those at higher income levels.

Data Help Identify Problems and Lead to Action

The information collected in South Carolina helped expand knowledge about epilepsy in multiple ways. For example, it led to the publication of more than 30 peer-reviewed articles and 13 national and international conference presentations.⁷

Findings from these publications include the following:

- Children and adolescents with epilepsy, especially those living in rural areas, have a higher risk of death than those without epilepsy.⁸
- Young adults aged 19 to 25 years with epilepsy were more likely to have behavioral health comorbidities than those without epilepsy.⁹
- Common causes of death among children with epilepsy were developmental conditions, cardiovascular disorders, and injuries.¹⁰
- About 38% of people with active epilepsy said there was a time in the past 12 months when they needed to see a doctor but could not because of the cost.¹¹
- About 63% of adults in South Carolina with active epilepsy reported disability, compared to 18% of adults without epilepsy.¹²

- Stigma was associated with employment status, self-efficacy, social support, and seizure related variables.¹³

South Carolina Advocates for Epilepsy Helps Meet Community Needs

MUSC also assisted in the growth of the nonprofit South Carolina Advocates for Epilepsy (SAFE) in 2011.¹⁴ SAFE's mission is to:

- Advocate on behalf of patients, their families, and caregivers.
- Educate the public about epilepsy and seizure first aid.
- Inspire patients, caregivers, and community members to make a difference for people with epilepsy on a daily basis.

MUSC and SAFE worked together to identify the needs of people with epilepsy and caregivers across the state to determine whether services provided, such as transportation to health care providers and education support, were accessible and met clients' needs. Using surveys and focus groups, they identified the types of resources that people with epilepsy need and their likelihood of participating in SAFE activities or using materials provided by SAFE, such as online videos and in-person contact.

People with epilepsy reported that their top challenges¹⁴ were:

- Personal safety (27%).
- Lack of insurance or not enough money to pay for epilepsy treatment (16%).
- Difficulty with daily management of epilepsy (13%).



Lessons Learned in South Carolina

MUSC's groundbreaking work serves as a model for other states and programs for epilepsy surveillance activities.

- The SCESS has proven to be an effective tool to assess statewide epilepsy burden.
- Data from multiple sources have provided insight into comorbidity, access to care, and health disparities among children and adults with epilepsy.
- Policy makers and program planners can use local data to guide the development of programs and policies that improve outcomes for people with epilepsy.
- Local support for the SCESS produced new community partnerships, like SAFE.

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