

Expanding Surveillance to Better Understand the Burden of Epilepsy

Public Health Problem

Epilepsy is one of the most common neurological disorders in the world, affecting about 50 million people, including an estimated 2.7 million in the United States. While epilepsy affects people of all ages, the very young and older adults are particularly vulnerable because risk factors for the condition are more common in these age groups. About 10% of Americans will experience a seizure, which is a defining characteristic of epilepsy, sometime during their lives, and about 3% will have been diagnosed with epilepsy, marked by recurrent, unprovoked seizures, by age 80.

Recurrent seizures often result in limitations in activities, co-occurring depression or anxiety, stigma, and impaired quality of life. The second National Conference on Public Health and Epilepsy, titled *Living Well with Epilepsy II*, identified the need for methods and systems to monitor trends related to critical issues, such as disease burden, mortality risks, and incidence and prevalence in diverse populations. Congress has recognized the importance of epilepsy as a public health problem and the need for "...expanding current surveillance activities through existing monitoring systems . . ." (Title VIII – Children and Epilepsy, Section 801 [2000]).

Taking Action

CDC supports epidemiological studies to define the incidence and prevalence of epilepsy among different racial and ethnic populations in the United States. Texas, Georgia, Tennessee, and South Carolina were among the first states to use the Behavioral Risk Factor Surveillance System (BRFSS) to assess state-level epilepsy prevalence using five standardized questions developed by CDC's Epilepsy Program. In 2003 and 2005, CDC partnered with UCLA to use the California Health Interview Survey (CHIS) for epilepsy surveillance.

Beginning in 2004, CDC's Epilepsy Program and the national Epilepsy Foundation (EF), working through its local affiliates, collaborated with state public health departments to incorporate at least one of the five CDC standardized epilepsy questions into their 2005 BRFSS state-added questions. Nineteen state public health departments used BRFSS that year to collect data on self-reported epilepsy prevalence and associated behavioral risk factors, chronic disease co-morbidity, and health-related quality of life.

Data analysis has been completed and findings will be reported as a Surveillance Summary for *Morbidity and Mortality Weekly Reports*. Additional studies using data from the CHIS will be completed in FY2008. These studies will examine the prevalence of self-reported epilepsy, with sub classification of active and inactive cases; associated sociodemographic and behavioral characteristics; and psychological distress, mental health utilization, and health-related quality of life of people by epilepsy status.

Implications and Impact

These findings have helped to identify the burden of epilepsy in a number of states. This is the first time that this kind of data has been available, allowing the public health community to have a better understanding of relevant issues affecting people with epilepsy. Additional descriptive and analytic studies of epilepsy occurrence in diverse U.S. communities and populations are needed to better characterize epilepsy incidence rates, risk factors and etiologies, types, severity, associated conditions and disability, and other consequences of public health concern.