

## Highlights from *Epilepsy Across the Spectrum: Promoting Health and Understanding*

### **A Focus on Mortality and Sudden Unexpected Death in Epilepsy**

The Institute of Medicine (IOM) examined the public health dimensions of the epilepsies with a focus on four areas: (1) public health surveillance and data collection and integration; (2) population and public health research; (3) health policy, health care, and human services; and (4) education for providers, people with epilepsy and their families, and the public. In the resulting report, *Epilepsy Across the Spectrum: Promoting Health and Understanding*, the committee describes its vision for achieving a better understanding of the public health dimensions of the epilepsies and for promoting health and understanding. This vision involves a variety of efforts related to mortality and sudden unexpected death in epilepsy (SUDEP), including the improvement of surveillance and prevention as well as increased education.

#### **Statistics for Epilepsy-Related Mortality and SUDEP<sup>1</sup>**

- The risk of death increases for people with epilepsy, with an estimated 10 years of life lost for people whose epilepsy has a known cause and 2 years lost for people with epilepsy from an unknown cause.
- Compared to the general population, people with epilepsy have more than twice the risk of death due to accidents and injuries.
- While one study failed to find a significantly increased risk of death due to suicide, other studies have found a risk of suicide in epilepsy that is 3.5 to 5.8 times that of the general population.
- SUDEP is the most common of the epilepsy-related causes of death. People with epilepsy have a more than 20 times higher rate of sudden death than does the general population.
- Estimates of the number of people with epilepsy who die of SUDEP vary from 1 of every 10,000 newly diagnosed to 9 of every 1,000 candidates for epilepsy surgery.
- People with cognitive impairment and refractory epilepsy are particularly vulnerable populations in which the cumulative risk of SUDEP can exceed 10 percent.
- The strongest evidence from a meta-analysis of randomized placebo-controlled clinical trials suggests that it is the occurrence of seizures that drives an increased risk for SUDEP, not polytherapy as suggested in previous studies.

#### **Enhancing Surveillance**

- Current estimates of SUDEP incidence based on death certificates are inadequate.
- To accurately count the number and distribution of SUDEP cases, determine its cause, and—ultimately—seek opportunities for prevention, more accurate forensic data are needed.
- The creation of a registry on epilepsy-related deaths would provide a valuable new information resource.

#### **Preventing Epilepsy-Related Deaths**

- Many challenges remain to identify effective strategies for decreasing the risk of epilepsy-related deaths. Future population health studies on comorbidities, including mental health conditions, and important outcomes (e.g., SUDEP, injuries) may provide opportunities for successful interventions to promote optimal quality of life and avoid preventable deaths.
- While it is possible that SUDEP is associated with more severe epilepsy and that treating the seizures will not alter SUDEP risk, prevention trials should be undertaken in high-risk individuals (e.g., people with continued seizures, people with known causes of seizures) to determine whether SUDEP risk declines.

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<sup>1</sup> References can be found in the full text of the report, which is available at [www.iom.edu/epilepsy](http://www.iom.edu/epilepsy).

- Risk factors for SUDEP have been described, but interventions to reduce the occurrence of this devastating outcome have not been tested in those at highest risk. Interventions to promote seizure control may decrease rates of preventable deaths.

### **Improving Education and Raising Awareness**

- **Health Professionals:** It is important that health professionals learn how to be comfortable discussing risks associated with the epilepsies and their treatments including SUDEP, suicide, and status epilepticus.
- **People with Epilepsy and Their Families:** Across the span from initial diagnosis through ongoing treatments and services, people with epilepsy and their families need to be aware of the disorder's potential risks, including SUDEP, and the range of treatments and services available. Information must be conveyed in ways that are easily understandable and relevant to specific age groups and cultures. A consensus appears to be growing that information about SUDEP should be provided around the time of diagnosis and within the context of a discussion related to epilepsy's risks.
- **General Public:** Core public knowledge about epilepsy needs to include that epilepsy can be a serious, life-threatening disorder with great impact on health and quality of life including increased risk of injury and death.

### **Recommendations and Research Priorities**

The report's recommendations are directed to the broad categories in its task, as described above, including a call for (1) standardizing the practices of coroners and medical examiners with the goal of working toward a national epilepsy-related death registry, (2) preventing epilepsy related causes of death, and (3) improving the education and awareness of health professionals, people with epilepsy and their families, and the general public. The report's research priorities also include several specifically related to mortality and SUDEP.

#### **Research Priorities for Mortality and SUDEP**

##### *Surveillance and Prevention*

- Case-control studies of risk factors for injuries, suicide, status epilepticus, and SUDEP
- Studies or analyses that inform new approaches to randomized controlled trials in epilepsy, in order to minimize the time spent on placebo or on a study drug that is ineffective and thus minimize the risk for SUDEP
- Studies that develop and evaluate educational programs to improve the knowledge of coroners and medical examiners about SUDEP and other epilepsy-related deaths

##### *Health Professional Education*

- Identification of knowledge gaps across health professions that relate to areas such as seizure recognition and classification; new treatment options; SUDEP; and appropriate treatment modalities for specific subpopulations, including infants and children, women, individuals with more severe epilepsy syndromes, people with complex comorbidities, and older adults
- Development and assessment of educational interventions and resources focused on communication skills and strategies for discussing sensitive topics (e.g., SUDEP, suicide, risks associated with medication nonadherence, treatment preferences)

##### *Education of People with Epilepsy and Their Families*

- Assessment of information needs associated with epilepsy-related risks such as injuries, suicide, status epilepticus, and SUDEP