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Special Communication

Epilepsy across the spectrum: Promoting health and understanding. ☆ A summary of the Institute of Medicine report

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ABSTRACT

Approximately 1 in 26 people will develop epilepsy at some point in their lives. Although epilepsy is one of the nation's most common neurological disorders, public understanding is limited. A complex spectrum of disorders, epilepsy affects an estimated 2.2 million people in the United States. Living with epilepsy is about more than just seizures; it is often defined in practical terms, such as challenges, uncertainties, and limitations in school, social situations, employment, driving, and independent living. People with epilepsy are also faced with health and community services that are fragmented, uncoordinated, and difficult to obtain. The Institute of Medicine's report (2012) [1], *Epilepsy across the spectrum: promoting health and understanding*, examines the public health dimensions of epilepsy with a focus on (a) public health surveillance and data collection and integration; (b) population and public health research; (c) health policy, health care, and human services; and (d) education for providers, people with epilepsy and their families, and the public. The report's recommendations range from the expansion of collaborative epilepsy surveillance efforts to the independent accreditation of epilepsy centers, to the coordination of public awareness efforts, and to the engagement of people with epilepsy and their families in education, dissemination, and advocacy activities. Given the current gaps in epilepsy knowledge, care, and education, there is an urgent need to take action—across multiple dimensions—to improve the lives of people with epilepsy and their families. The realistic, feasible, and action-oriented recommendations in this report can help enable short- and long-term improvements for people with epilepsy.

1. Introduction

Characterized by seizures that are unpredictable in frequency, epilepsy is a common neurological disorder that affects people of all ages, with onset most often occurring in childhood and older adulthood [2,3]. Epilepsy is a spectrum of disorders[1]—the epilepsies—with a range of severities, widely differing seizure types and causes, an array of coexisting conditions, and varying impacts on individuals and their families. Epilepsy is the fourth most common neurological disorder in the United States after migraine, stroke, and Alzheimer's disease [4]; it is estimated that 150,000 new cases are diagnosed in the United States annually [4] and that 1 in 26 individuals will develop epilepsy at some point in their lifetime [5].

While seizures are well controlled with medications and other treatment options for the majority of people with epilepsy [6], the impact of epilepsy goes well beyond the seizures. The challenges facing the estimated 2.2 million people with epilepsy in the United States [4] include having access to high-quality health care, becoming informed about and coordinating health care and community services, and dealing with stigma and common public misunderstandings. Living with epilepsy, particularly for people with refractory seizures, can involve challenges in school, uncertainties about social and employment situations, limitations on driving, and questions about independent living. Epilepsy can impose an immense burden on individuals, families, and society; the estimated annual direct medical cost of epilepsy in the United States is $9.6 billion [7], which does not consider community service costs or indirect costs from losses in quality of life and productivity (these indirect costs are estimated to constitute the majority of the cost burden of epilepsy [8]). Further, epilepsy is associated with substantially higher rates of mortality than experienced in the population as a whole [9], with sudden unexpected death in epilepsy (SUDEP) being the most common cause of epilepsy-related

☆ This summary is an excerpted version of the report's Summary chapter and Chapter 9, which is being reprinted with permission from the National Academies Press. Full-text versions of these chapters and the entire report are available as PDFs at www.iom.edu/epilepsy. The members of the report's authoring committee, the IOM Committee on the Public Health Dimensions of the Epilepsies, are listed in Box 7 at the end of this article.

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[1] This summary does not include definitions of terminology used throughout the report; discussion of various epilepsy disorders, syndromes, or comorbidities; or explanations of the derivation of statistics that are presented. In-depth discussion of these areas and the supporting evidence for the committee's recommendations and research, along with complete reference lists, appear in the report.

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deaths [10]. Estimates indicate that 10 years of life are lost for people whose epilepsy has a known cause and 2 years are lost for people with epilepsy from an unknown cause [11]. Additionally, incidence estimates for the number of people with epilepsy who die of SUDEP range from 1 per 10,000 person-years for those individuals who are newly diagnosed to 9 per 1000 person-years for those who are candidates for epilepsy surgery [12].

A significant challenge for people with epilepsy, as well as for the epilepsy field, has been the multitude of ways that epilepsy is perceived and, in many cases, misperceived. The centuries of misperceptions and misinformation about epilepsy have resulted in people with epilepsy being stigmatized [13]. As a consequence, people with epilepsy and their families may be faced with a lack of social support from extended family members; feelings of parental guilt; social isolation, embarrassment, and fear; and discrimination. Although efforts are being made to correct these misconceptions and to better inform people about the epilepsies, doing so remains a challenge.

Throughout its report [1], the committee emphasizes the ways in which epilepsy is a spectrum of disorders. Epilepsy comprises more than 25 syndromes and many types of seizures that vary in severity [14]. Additionally, people who have epilepsy span a spectrum that includes men and women of all ages and of all socioeconomic backgrounds and races/ethnicities, who live in all areas of the United States and across the globe. The impacts on physical health and quality of life encompass a spectrum as well, with individuals experiencing different health outcomes and having a range of activities of daily living that may be affected, including driving, academic achievement, social interactions, and employment. For some people, epilepsy is a childhood disorder that goes into remission (although the seizures may have lifelong consequences), while for others, it is a lifelong burden or a condition that develops later in life or in response to an injury or other health conditions. These many complexities of epilepsy make it a challenging health condition to convey to the general public and to promote understanding and alleviate stigma.

2. Scope of work

In 2010, the Institute of Medicine (IOM) was asked to examine the public health dimensions of the epilepsies with a focus on four areas:

- public health surveillance and data collection and integration;
- population and public health research;
- health policy, health care, and human services; and
- education for providers, people with epilepsy and their families, and the public.

The committee was asked not to examine biomedical research priorities because the Epilepsy Research Benchmarks, developed in 2000, are continually updated by the National Institute of Neurological Disorders and Stroke and collaborating agencies and organizations [15]. To accomplish its task, the IOM convened the Committee on the Public Health Dimensions of the Epilepsies, which comprised 17 members with expertise in epilepsy care, health services research, epidemiology, public health surveillance, mental health services, health care services and delivery, health literacy, public health, education, and communications. The IOM study had 24 sponsors: 12 federal agencies and 12 nonprofit organizations. Many of these sponsors are part of Vision 20–20, a coalition that focuses on epilepsy research, care, services, education, and advocacy efforts.

3. A vision for the future

Throughout its report, research priorities, and recommendations, the committee describes its vision for achieving a better understanding of the public health dimensions of the epilepsies and for promoting health and understanding. The committee's vision for the future involves

- epilepsy surveillance efforts that include the development of active and passive data collection systems that are coordinated, comprehensive, accurate, and timely, and that follow standardized methodologies to obtain valid measurement;
- enhanced prevention programs and well-designed epidemiologic studies that highlight areas ripe for further preventive efforts;
- access to patient-centered care for all individuals with epilepsy that incorporates a comprehensive and coordinated approach to both health and community services in order to meet the range of physiological, psychological, cognitive, and social needs;
- care and community resources that reflect current research findings and best practices in clinical care, education, and coordination in order to provide each person with the best care, in the right place, at the right time, every time;
- a health care workforce sufficiently prepared to provide every person experiencing seizures with effective diagnostic, treatment, and management services that are delivered through team-based approaches to care and that take into consideration health literacy, cultural, and psychosocial factors;
- access to relevant and usable knowledge for all individuals with epilepsy and their families that meets their individual needs and allows them to participate effectively in patient-centered care, to achieve optimal self-management of their epilepsy, and to attain the highest possible physical and emotional well-being; and
- an improved public understanding of what epilepsy is—and is not—that supports the full inclusion of people with epilepsy at all levels of society and that eliminates stigma.

Much of this vision resonates with broad goals of chronic disease management, and to achieve it, collaborative efforts with professionals and organizations involved with other conditions, especially those that are comorbidities of epilepsy, will help to maximize resources and progress.

Given the current gaps in epilepsy knowledge, care, and education, the committee believes that there is an urgent need to take action—across multiple dimensions—to improve care and services for people with epilepsy and their families. With this goal in mind, the committee examined the available evidence on surveillance, epidemiology, prevention, health care, community services, and education programs and campaigns and then developed recommendations and priorities for further research to improve these fields and the programs relevant to epilepsy. The report's evidence-based recommendations aim to present realistic, feasible, and action-oriented steps that a variety of stakeholders can take to enable short- and long-term improvements for people with epilepsy. The research priorities provide directions for further developing the evidence base.

4. Increasing the power of data and preventing epilepsy

Comprehensive, timely, and accurate epilepsy surveillance data are needed to provide a better understanding of the burden of the disorder, its risk factors and outcomes, and health services needs. Current data sources provide a patchwork of surveillance activity that substantially limits the ability to understand, plan, and guide the provision of policies related to health care for people with epilepsy. Improvements are necessary to enable informed and effective action in prevention; health care quality, access, and value; quality of life and community services; and education and awareness. At present, public health researchers, policy makers, and advocates are “flying blind” due to the lack of adequate epilepsy surveillance data [16]. The nation's data system for epilepsy can be strengthened by the collection of epilepsy-specific data and through collaborations with existing and emerging data-sharing efforts across health care providers and for other chronic diseases and disorders.

Ideally, a coordinated and comprehensive surveillance system for the epilepsies would collect data in several ways. To shed light on national trends and patient outcomes, surveillance would be longitudinal