

## CRITICAL REVIEW AND INVITED COMMENTARY

# Research implications of the Institute of Medicine Report, *Epilepsy Across the Spectrum: Promoting Health and Understanding*

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### SUMMARY

In March 2012 the Institute of Medicine (IOM) released the report, *Epilepsy Across The Spectrum: Promoting Health and Understanding*. This report examined the public health dimensions of the epilepsies with a focus on the following 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 report provided recommendations and research priorities for future work in the field of epilepsy that relate to increasing the power of data on epilepsy; prevention of epilepsy; improving health care for people with epilepsy; improving health professional education about epilepsy; improving quality of life for people with epilepsy; improving education about epilepsy for people with epilepsy and families; and raising public awareness about epilepsy. For this article, the authors selected one research priority from each of the major chapter themes in the IOM report: expanding and improving the quality of epidemiologic surveillance in epilepsy;

developing improved interventions for people with epilepsy and depression; expanding early identification/screening for learning impairments in children with epilepsy; evaluating and promoting effective innovative teaching strategies; accelerating research on the identification of risk factors and interventions that increase employment and improve quality of life for people with epilepsy and their families; assessing the information needs of people with epilepsy and their families associated with epilepsy-related risks, specifically sudden unexpected death in epilepsy; and developing and conducting surveys to capture trends in knowledge, awareness, attitudes, and beliefs about epilepsy over time and in specific population subgroups. For each research priority selected, examples of research are provided that will advance the field of epilepsy and improve the lives of people with epilepsy. The IOM report has many other research priorities for researchers to consider developing to advance the field of epilepsy and better the lives of people with epilepsy.

**KEY WORDS:** Institute of Medicine report, Epilepsy, Research priorities.

The 2012 Institute of Medicine (IOM) report, *Epilepsy Across the Spectrum: Promoting Health and Understanding* ([http://books.nap.edu/openbook.php?record\\_id=13379](http://books.nap.edu/openbook.php?record_id=13379)), provides 13 recommendations for future work in the field of epilepsy in the United States, with a focus on 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 report also includes 46 research priorities related to the following: increasing the power of data on epilepsy; prevention of epilepsy; improving health care for people with epilepsy; improving health professional education about epilepsy; improving quality of life for people with epilepsy; improving education about epilepsy for people with epilepsy and families; and raising public awareness about epilepsy.

However, for this article, the authors were asked to focus on one research priority in each of the major chapters

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discussed in the IOM report in order to highlight the potential impact of research on improving lives for people with epilepsy and their families. Discussion of the selected research priorities are organized in the same way; each research priority is presented, current research in the area is summarized to lay a foundation for describing the research implications of the specific research area selected, and then a discussion of the implications of pursuing the research described concludes each section.

Selecting seven research priorities from the myriad of important research questions proposed in the report was challenging. However, by highlighting one research priority from each chapter, we hope to raise awareness of the many research recommendations and priorities identified in the IOM report so that epilepsy researchers worldwide will consider addressing these questions to advance the field of epilepsy and improve the lives of people with epilepsy.

## INCREASING THE POWER OF DATA ON EPILEPSY

### Research priority

Expand and improve the quality of epidemiologic surveillance in epilepsy.

### Background

#### *Public health surveillance*

Public health surveillance is defined as “the ongoing systematic collection, analysis, and interpretation of health data necessary for designing, implementing, and evaluating public health prevention programs” (German et al., 2001).

#### *Better surveillance is needed to determine the number of people with epilepsy*

Recent surveillance provides varying estimates of the prevalence and incidence of epilepsy, but little is known about subpopulations (e.g., race/ethnicity) (Hirtz et al., 2007; Kelvin et al., 2007; Kobau et al., 2008). Prevalence estimates suggest that 1.3–2.8 million people have epilepsy (Hirtz et al., 2007). Information suggests that the incidence of epilepsy may be declining in children and increasing among older adults (Hauser et al., 1993; Kotsopoulos et al., 2002; Sillanpää et al., 2011). However, it is not known whether these trends will continue or what drives them.

#### *Surveillance is important to evaluate access to appropriate health care services*

Recent studies suggest that disparities exist in access to epilepsy care for populations with low socioeconomic status, racial and ethnic minority populations, and uninsured populations (Begley et al., 2009; Elliott et al., 2009; Farhidvash et al., 2009; Bautista & Jain, 2011; Bisgaier & Rhodes, 2011; Halpern et al., 2011). Better surveillance is needed to determine the impact of these differences on health, the magnitude

of gaps in care for the general population, the importance of different factors that explain disparities, and the cross-sectional variations and trends in disparities.

#### *Surveillance is important to determine the economic burden of epilepsy*

The lack of standardized study methods and data sources has led to diverging estimates of the economic burden of epilepsy and difficulties in comparing the costs of services across settings of care and treatment approaches. Recent estimates of the average cost of medical care due to epilepsy range from \$4,523 per person per year (in 2009 dollars) (Yoon et al., 2009) to \$7,190 (in 2005 dollars) (Ivanova et al., 2010). These estimates are much higher than reported in previous studies from the 1990s (Begley et al., 2000; Halpern et al., 2000).

The cost-effectiveness of specific therapies is a critical topic for surveillance research. A recent review of 12 studies completed between 2003 and 2007 found that newer seizure medications used in monotherapy had similar effectiveness for seizure remission, but were significantly more expensive than older medications (Beghi et al., 2008). Similar findings were reported in a recent meta-analysis by the Agency for Healthcare Research and Quality (AHRQ, 2011).

### Research implications

An organized effort is needed to improve the quality of epilepsy surveillance by developing standardized and valid data elements for identifying cases, more detailed survey questions, and validated algorithms for combining data elements into measures. The standards, definitions, data elements, and criteria should be disseminated, and researchers should be encouraged to adopt them. A variety of data sources are needed including population surveys, registries and condition-specific reporting systems, and records from visits to health care providers (e.g., administrative and clinical records). Using these surveillance systems, it would be possible to address the following types of questions: trends in incidence, prevalence, and risk factors over time and in subgroups; the relationship between disparities in health care and health; and the balance of cost and effectiveness of different seizure medications and other specific services (e.g., electroencephalographic monitoring and magnetic resonance imaging protocols) for different types of epilepsy.

### Ways in which pursuing the research will advance the field of epilepsy and improve the lives of people with epilepsy

More accurate information on the incidence and prevalence of epilepsy should lead to better and more targeted research on causes, preventive interventions, treatment, and rehabilitation. Access-to-care studies should lead to programs and policies to reduce the barriers that people with epilepsy face in obtaining needed services. Cost studies should identify the potential savings that can be achieved

from interventions that prevent the condition, alleviate its affects, or streamline the delivery of care.

## EPILEPSY AND PREVENTION

### Research priority

Develop improved interventions for people with epilepsy and a history of depression.

### Background

Depression is the most common epilepsy comorbidity, affecting 14% in the general population with epilepsy (Télliez-Zenteno et al., 2007) and up to 54% in people with refractory epilepsy admitted to the epilepsy monitoring unit (Boylan et al., 2004). More than seizure frequency or driving restrictions, depression adversely affects quality of life in epilepsy (Gilliam et al., 1999). Depression is associated with internalized or felt stigma at epilepsy onset (Leaffer et al., 2011), and results in a greater burden of adverse events at epilepsy onset, even in people who are not taking seizure medications (Perucca et al., 2011). Among people with epilepsy, depression is associated with a substantial increased risk for suicide (Christensen et al., 2007).

In addition to the poor psychosocial outcomes associated with depression in people with epilepsy, depression is also associated with an increased risk for developing epilepsy (Forsgren & Nystrom, 1990; Hesdorffer et al., 2000, 2005, 2012b; Adelow et al., 2012) and with poor seizure outcomes. A history of depression is associated with worse seizure outcomes in people with newly treated epilepsy (Hitiris et al., 2007) and with poor outcomes after anterior temporal lobectomy (Kanner et al., 2009), even after the putative seizure focus has been removed.

In childhood-onset epilepsy, a first-degree family history of epilepsy is associated with depression in the child with epilepsy (Hesdorffer et al., 2012a), suggesting an underlying predisposition to both that may have a genetic basis.

### Research implications

Research is needed to determine whether treatments for depression ameliorate the adverse psychosocial outcomes of epilepsy, including poor quality of life, internalized stigma, increased burden of adverse events, and the increased risk for suicide. Through the Centers for Disease Control and Prevention's (CDC's) Managing Epilepsy Well (MEW) Network (DiIorio et al., 2010), a pilot randomized study showed that a mindfulness approach coupled with cognitive-behavioral therapy resulted in an improvement in mood, knowledge, and skills in people with epilepsy and depression (Thompson et al., 2010). This is a good beginning, but the issue is not limited to current or recent depression—it extends to a lifetime history of depression, which is associated with many of the adverse outcomes mentioned above.

Pilot prevention trials of therapies for recent depression in people with epilepsy and cognitive interventions for lifetime history of depression are also needed to determine whether these therapies or interventions improve quality of life, reduce internalized stigma, and reduce the burden of adverse events. In addition, pilot trials are needed to reduce suicidal ideation with plan and intent as well as suicide attempt (both strongly associated with suicide) in people with epilepsy and depression.

Studies are needed to understand the pathophysiology and genetics of the association between depression and epilepsy. As mentioned above, a lifetime history of depression is associated with an increased risk for developing epilepsy and for poor seizure outcome. Pilot trials are needed to determine whether antidepressants reduce seizure frequency. Evaluation of whether serotonergic abnormalities occur in unselected samples of people with epilepsy and a lifetime history of depression is also important. There is also a necessity for research into the possible genetic etiology of the comorbidity of depression and epilepsy.

### Ways in which pursuing the research will advance the field of epilepsy and improve the lives of people with epilepsy

Results of these studies could inform best practices to improve the psychosocial and seizure outcomes of people with epilepsy and increase knowledge about the epilepsy–depression comorbidity. These types of studies are those envisioned by the committee to prevent the adverse consequences and improve the lives of people with epilepsy.

## IMPROVING HEALTH CARE FOR PEOPLE WITH EPILEPSY

### Research priority

Expand early identification/screening for learning impairments in children with epilepsy.

### Background

In children with epilepsy, cognitive difficulties compromise educational progress and achievement during adult life (Sillanpää, 1983; Davies et al., 2003; Berg et al., 2008), with 40–60% having impairment in at least one academic area (Vinayan et al., 2005; Fastenau et al., 2008). Cognitive difficulties are present even in children functioning at or near an average IQ (Ostrom et al., 2003, 2005). Approximately 45% of children with epilepsy and an IQ of at least 80 require special education services, and 16% of these children repeat a year of education (Aldenkamp et al., 1990; Berg et al., 2011).

There is increased academic risk in both reading skills (including single word, phonological awareness, comprehension, and speed or fluency deficits) and math skills (Seidenberg et al., 1986; Bailet & Turk, 2000); often several educational areas are affected. In addition, children

with epilepsy often show deficits in memory and attention (Metz-Lutz et al., 1999; Sanchez-Carpintero & Neville, 2003). There is also some evidence for epilepsy-specific patterns of neuropsychological impairment (Chaix et al., 2006). Despite these difficulties, many children with epilepsy are not identified in the school setting. Therefore, the relationship between epilepsy and educational underachievement exists, although the academic needs of children with epilepsy have not been adequately addressed.

### Research implications

As a *first research goal*, it is important to characterize learning impairments in children with epilepsy and to establish whether there are relationships between epilepsy characteristics and learning impairments that may help teachers identify these children early. In addition, research is needed to identify the neurobiologic mechanisms underpinning cognitive impairments. Other research goals include determining whether children with epilepsy are more likely than their classmates without epilepsy to have learning impairments, assessing the nature of those impairments, testing educational strategies, and establishing whether improvements are associated with alterations in underpinning neural networks.

Studies should design, implement, and evaluate interventions. Ample research demonstrates that dyslexia can be ameliorated with intensive phonics-based training and growing evidence that remediation targeting an understanding of numerosity and number sense can address deficits associated with dyscalculia (Torgesen et al., 2001; Butterworth et al., 2011). Moreover, appropriate management of reading and math difficulties in children without epilepsy improves school performance. Whether such interventions work to improve the reading and math difficulties observed in children with epilepsy remain unanswered empirical questions. It is also unknown whether nonspecific approaches (e.g., environmental enrichment) have a broad impact on cognitive functioning in individuals with neurologic disorders including epilepsy. Finally, it is important to determine whether specific interventions for children with epilepsy affect learning and the neural networks underpinning cognition.

### Ways in which pursuing the research will advance the field of epilepsy and improve the lives of people with epilepsy

Drivers for reduced quality of life (i.e., the degree of satisfaction with life) include seizures, associated behavioral impairments, and cognitive deficits. To maximize quality of life, all domains must be appropriately managed. To date, there has been an emphasis on the management of seizures. Unfortunately cognitive deficits and learning disabilities are infrequently recognized, which leads to a failure to appropriately intervene and support these children. Children with epilepsy are an underserved population in which appropriate educational and medical interventions could improve quality of life, social, and economic outcomes.

To help young people with epilepsy and learning disabilities attain their potential as productive members of families, schools, and communities, their psychosocial and cognitive status should be evaluated early in life and treated with appropriate interventions. The approach offers hope for the cognitively challenged children with epilepsy.

## IMPROVING HEALTH PROFESSIONAL EDUCATION ABOUT EPILEPSY

### Research priority

Evaluate and promote effective innovative teaching strategies. In particular multidisciplinary simulation programs need to be evaluated to determine their suitability as a primary educational tool for development of competencies for acute seizure management by various health professionals.

### Background

In assessing the training, continuing education, and preparedness of the myriad of health professionals that individuals with epilepsy are likely to encounter, the IOM committee identified several gaps in epilepsy knowledge and awareness in its report. It became clear that additional education is needed across the health care professions, regarding various epilepsy diagnosis, treatment, and systems-based practice (IOM, 2012).

Because exposure to neurologic disorders is not required for many health care professional degrees including MDs, the result is a disjointed and random epilepsy educational experience with a lack of a standardized approach to either acute or chronic seizure management (Devinsky et al., 1993). This section focuses on the use of medical simulation, which has potential for expanding epilepsy education and training.

In medical simulation exercises, participants are placed in complex clinical situations, are required to respond to a simulated medical or health scenario, and receive feedback on their performance. The most important aspect about a simulation is that it must be high fidelity in order to duplicate real world experience and provide valid simulation of a realistic clinical situation. In the education of health professionals, simulation and the multidisciplinary approach to simulation-based training have been introduced in multiple areas such as trauma teams or neonatology where the use of simulation has consistently been associated with positive outcomes in terms of clinical knowledge, skill, and behaviors as demonstrated by a number of observational studies and a meta-analysis (Galletta et al., 2006; Lippert et al., 2009; Papangelou & Ziai, 2010; McGaghie et al., 2011).

Medical simulation has rarely been used in epilepsy education to date but has significant potential to help ameliorate professional educational gaps, to improve and standardize the level of medical knowledge about managing individuals with seizures, and to better organize the health care team

around that patient. This is particularly true for acute care settings, where most individuals with epilepsy are likely to enter the health care system.

### Research implications

Given the number of specialists that an individual with epilepsy will encounter in the acute care setting, team training using full-scale simulation of a seizure emergency in either the emergency room or epilepsy monitoring unit could be beneficial. This type of simulation offers many advantages that could lead to improvements in safety of care and potentially contribute to better quality of life outcomes. In particular, a randomized controlled trial needs to be done to compare which teaching method would produce better clinical outcomes for patients with acute seizures: traditional individual classroom education for health care professionals performed in the relative isolation of each health care professional's discipline (e.g., neurology clerkship vs. continuing education for nurses) versus multidisciplinary simulation curriculums. Simulation should encompass responses to different ethnic/cultural groups. Research on the impact of simulation-based team training to improve epilepsy care is also needed for health care workers in rural settings where tertiary care may be far away.

### Ways in which pursuing the research will advance the field of epilepsy and improve the lives of people with epilepsy

Because seizures and its management in acute care settings, such as epilepsy monitoring units, can result in significant morbidity and mortality (Noe & Drazkowski, 2009), potential benefits of research in team-based simulation techniques for epilepsy care could improve patient safety, particularly in the emergency management of seizure situations such as status epilepticus or acute seizure clusters. Moreover, multidisciplinary simulation could address an important gap in systems-based competencies such as communication, professionalism, and improvement in the basic responses to seizure emergencies in the acute care setting.

## IMPROVING QUALITY OF LIFE FOR PEOPLE WITH EPILEPSY

### Research priority

Accelerate research on the identification of risk factors and interventions that increase employment and improve quality of life for people with epilepsy and their families.

### Background

Reductions in social and emotional health and in employment opportunities often negatively affect quality of life (QOL) for people with epilepsy. A high rate of unemploy-

ment among people with epilepsy has been found in population-based studies. Unemployment is more than two times greater than in the general population when people experience one or more generalized tonic-clonic seizures or complex partial seizures a year (Hauser & Hesdorffer, 1990; Thorbecke & Fraser, 1997). Therefore, employment disparities particularly affect adults with epilepsy whose seizures are not controlled (Jacoby, 1995). Additional contributions to unemployment include psychosocial factors such as social skill deficits, isolation, and fears about employer attitudes and stigma (Jacoby et al., 2005a). Relatively little is known about the most effective vocational interventions and practices for people with epilepsy, because research in this area has been primarily cross-sectional in small clinical samples. Although early research demonstrated that comprehensive and specialized programs in epilepsy vocational rehabilitation were more effective for increasing employment in people with epilepsy than general disability vocational rehabilitation programs (e.g., Fraser et al., 1983; Carroll, 1992; Thorbecke & Fraser, 1997), efforts to replicate these small programs have been limited (Fraser et al., 1984; Thorbecke & Fraser, 1997; Smeets et al., 2007).

The employability of people with epilepsy also involves epilepsy education of employers. Such education has been shown to have positive effects on promoting knowledge and attitude change in educational and health settings (e.g., Rose et al., 1955; Martiniuk et al., 2010; Roberts & Farhana, 2010), although relatively few educational efforts have focused on improving employment.

### Research implications

Community-based research is needed to identify the risk factors for unemployment in people with epilepsy in order to propose targets for intervention that apply broadly to people with epilepsy, rather than focusing on the select group of people with epilepsy who are seen at tertiary care centers. Risk factors should include personal barriers to employment, such as seizure frequency and cognitive or psychological difficulties. Once these risk factors are identified, interventions can be developed to achieve better employment and improved QOL. One possibility is implementation research studies that apply strategies to carry out employment programs that are based on successful strategies for increasing employment for people with epilepsy that were found in previous studies.

There is also a clear need to implement community-based studies to evaluate the efficacy of approaches to promote employer knowledge and improve attitudes about epilepsy and to identify the most effective and strategic methods for reaching and educating employers about employment of people with epilepsy. These methods will need to be tested to determine whether employers are more likely to hire and retain people with epilepsy.

With respect to both vocational rehabilitation practices and employer education, it is critical not only that research

be expanded, but that mechanisms for meaningful evaluations of efficacy and outcomes be explicitly incorporated in the planning and execution of these investigations.

### **Ways in which pursuing the research will advance the field of epilepsy and improve the lives of people with epilepsy**

Information gained from these studies can lead to the community-based programs and resources that are effective in increasing employment of people with epilepsy. These studies are an essential part of meeting the IOM committee's vision for all people with epilepsy to have access to opportunities and attain the best possible emotional contentment.

## **IMPROVING EDUCATION ABOUT EPILEPSY FOR PEOPLE WITH EPILEPSY AND THEIR FAMILIES**

### **Research priority**

Assess the information needs of people with epilepsy and their families associated with epilepsy-related risks, specifically sudden unexpected death in epilepsy (SUDEP).

### **Background**

SUDEP is the most common epilepsy-related cause of death. Risk factors include generalized tonic-clonic seizures (Hesdorffer et al., 2012c), nocturnal seizures (Lamberts et al., 2012), and nonefficacious doses of seizure medications (Ryvlin et al., 2011). There is a general consensus that information about SUDEP should be provided after diagnosis and within the context of a larger discussion of epilepsy-related risks (So et al., 2009; Devinsky, 2011; Hirsch et al., 2011).

Although research demonstrates that people with epilepsy and their families desire to receive SUDEP information (Prinjha et al., 2005; Gayatri et al., 2010), few individuals or families are routinely receiving it. In recent surveys only 28% of Italian physicians (Vegni et al., 2011), 30% of United Kingdom neurologists (Morton et al., 2006), and 50% of United Kingdom epilepsy nurses (Lewis & Goodwin, 2008) discussed SUDEP with all or a majority of patients. Similarly, a United Kingdom survey of pediatric neurologists and parents found that 91% of parents of children with epilepsy wanted information about SUDEP, but only 20% of neurologists consistently provided it to all patients (Gayatri et al., 2010). This latter study also investigated the impact of SUDEP information on parents. Approximately one fourth reported an adverse emotional reaction to receiving the information. In addition, 61% of parents reported that they would provide more information to others about their child's epilepsy, 54% would monitor their child's medications more, and 46% would increase supervision of their child. Finally, parents preferred that information on SUDEP be provided in discussions with

their child's pediatric neurologist accompanied by provision of a leaflet (Gayatri et al., 2010).

### **Research implications**

It is unclear why people are not consistently receiving information about SUDEP. Research is needed to determine the extent of SUDEP education provided to patients by different types of health care providers. Studies of providers are also needed to identify possible barriers to the provision of SUDEP information, including their educational needs about SUDEP, their comfort in providing information, and strategies for addressing any barriers identified (Hirsch et al., 2011).

Studies of preferences related to SUDEP education in people with epilepsy, families, and caregivers are needed to guide future educational approaches and to contrast their preferences with those of providers. Research is also needed to identify desired content, including the type and amount of information that is necessary to provide a context for understanding the risk and is appropriate to age, culture, and health literacy of people with epilepsy and their families. In addition, studies are needed to identify best strategies to deliver SUDEP information including provider, timing, and format (e.g., oral, written).

Studies are needed to identify the effects of SUDEP education on patient outcomes including changes in SUDEP risk factors (e.g., better medication compliance, use of monitors during sleep), emotional functioning, and quality of life. Moreover, studies are needed to identify strategies for minimizing negative emotional impact of SUDEP education on patients and families.

### **Ways in which pursuing the research will advance the field of epilepsy and improve the lives of people with epilepsy**

Information gained from these studies should lead to the identification of best practices, most effective strategies, and preferred formats for SUDEP education for patients with epilepsy and their families in order to develop guidelines. These studies are essential to meeting the committee's vision for all people with epilepsy and their families: to have access to relevant and usable knowledge to meet their individual needs and to allow them to participate effectively in patient-centered care, to be competent in the self-management of their epilepsy, and to attain the highest possible physical and emotional well-being.

## **RAISING PUBLIC AWARENESS ABOUT EPILEPSY**

### **Research priority**

Develop and conduct surveys (e.g., General Social Survey, HealthStyles Survey) that capture trends in knowledge, awareness, attitudes, and beliefs about epilepsy over time and in specific audience segments.

## Background

A critical goal of public education and awareness about epilepsy is to increase the knowledge, attitudes, beliefs, and behaviors of the general public that reduce stigma and improve: (1) positive acceptance of people with epilepsy in all areas of society; and (2) self-efficacy among members of the general public to provide first aid to someone experiencing a seizure.

Some studies suggest a relationship between stigma and poorer seizure control, psychopathology, and reduced quality of life (Hermann et al., 1990; Jacoby, 1994, 2002; Jacoby et al., 2005b; Whatley et al., 2010). Society reinforces the general public's fears about epilepsy due to a lack of knowledge and awareness, belief in misperceptions surrounding epilepsy and seizures, and negative attitudes and behavior that marginalize people with epilepsy (Jacoby, 2002; Morrell, 2002; MacLeod & Austin, 2003; Paschal et al., 2005; de Boer et al., 2008; Fernandes et al., 2011; Taylor et al., 2011).

## Research implications

In the decades leading up to 1980, survey data suggested that attitudes toward people with epilepsy improved in the United States. The authors of a historic study, which summarized findings from seven Gallup surveys conducted between 1949 and 1979, attributed improved attitudes to educational efforts, along with medical, employment, and policy advances (Caveness & Gallup, 1980). Since the late 1980s, some studies have shown a troublesome lack of knowledge among the general public. In a 1987 Gallup survey, nearly half of respondents could not identify a cause of epilepsy, only 19% said it was a brain disorder, and one in six believed it was a mental illness (LaMartina, 1989). In the 2002 HealthStyles survey, slightly more than one third knew how to give first aid to someone having a seizure (Kobau & Price, 2003).

A population-based survey specific to epilepsy has not been conducted in the United States in many years, but this type of survey data is critical to address gaps in knowledge about contemporary attitudes and beliefs of the general public to inform public education efforts. The CDC's Attitudes and Beliefs about Living with Epilepsy (ABLE) instrument has been tested and validated to measure characteristics of the public on four dimensions: "negative stereotypes, risk and safety concerns, work and role expectations, and personal fear and social avoidance" (DiIorio et al., 2004; Kobau et al., 2006). ABLE items could be used in population-based surveys such as the Social Service Survey and HealthStyles Survey.<sup>1</sup> Ongoing data collection would provide an important mechanism to inform strategic message

development and dissemination and to allow epilepsy organizations to develop systematic, coordinated efforts to improve public education and awareness.

Studies that compare attitudes toward epilepsy and at least one other condition over time could provide information about whether changes are related to a general shift in attitudes toward chronic conditions or changes that are specific to epilepsy.

Regular population-based data collection would also support evaluation, by tracking the effects of interventions and strategies to inform ongoing public education campaigns, funding proposals, and advocacy efforts.

## Ways in which pursuing the research will advance the field of epilepsy and improve the lives of people with epilepsy

Data from population-level surveys will allow researchers and planners to develop evidence-based approaches and campaigns to reduce stigma, by addressing the public's lack of knowledge, misinformation, and negative beliefs about and behaviors toward people with epilepsy. With the support of Vision 20/20, the epilepsy community is in a unique position to use reliable data to coordinate more effective campaigns with systematic, sustained approaches; to leverage scarce resources; and to reach and educate key audiences within the general public. As a result, people with epilepsy will experience greater acceptance and support from the general public, thereby enabling the full participation of people with epilepsy in society.

## CONCLUSIONS

For each chapter, we focused upon one of the many research priorities that the authors thought would most advance epilepsy research and improve the lives of people with epilepsy and their families. Areas covered included surveillance, depression, early identification and treatment of learning impairments in children, teaching strategies for health professionals, employment, sudden unexpected death in epilepsy, and public education and awareness. Although some of our research suggestions focused on people with epilepsy, it is clear that the lives of people with epilepsy are affected by the health care community, family, employers, and the general public. Therefore, each of these communities was also the focus of the research proposed in this article.

Research proposed to improve epilepsy surveillance stressed the importance of developing standardized and valid data elements for epilepsy that could then be applied to track incidence and prevalence of epilepsy as well as to examine disparities and cost-effectiveness of epilepsy therapies and services. Results of research to develop interventions that have the potential to ameliorate psychiatric and cognitive comorbidities will improve the lives of people with epilepsy. There has been relatively little research

<sup>1</sup>The HealthStyles Survey is a nationally representative mail survey conducted by Porter Novelli through a partnership with the CDC that includes questions on consumer topics such as media habits, product use, lifestyle habits, and health topics.

focusing on educating employers about epilepsy to increase the employability of people with epilepsy; such work may help people with epilepsy to be hired and retain jobs. Health professionals serving people with epilepsy were the core of possible research using simulation programs to create effective team-based approaches to epilepsy treatment. Research was proposed to identify the educational needs of people with epilepsy, families, and caregivers when they receive information on SUDEP, as well as to categorize the barriers experienced by providers when they consider discussing SUDEP so that optimal delivery of this crucial information is conveyed effectively. Surveys of the general public were suggested to develop evidence-based programs to reduce stigma; programs that can be used as the backbone of effective public campaigns.

The IOM report includes a concluding chapter that describes the recommendations and research priorities for all of the preceding substantive chapters. Some recommendations and priorities provide a direction for future research that will advance our knowledge about epilepsy and offer potential treatments to reduce the burden of epilepsy and thereby improve the quality of life of people with epilepsy. Other recommendations and research priorities will further research to improve care, expand knowledge about epilepsy, and improve access to epilepsy education for people with epilepsy and for the general public. Together research in the areas described in the IOM report has the potential to provide opportunities for people with epilepsy that will allow them to attain optimal physical and emotional well-being.

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## DISCLOSURE

Dr. Joan Austin serves on the editorial boards of *Chronic Illness* and *Applied Nursing Research*. She is a consultant to the Intramural Program of the National Institute of Nursing Research, National Institutes of Health. Vicki Beck has nothing to disclose. Dr. Charles E. Begley serves on the editorial board of *Epilepsia* and editorial board of *Epilepsy Research*. He participates on an advisory board for UCB and the Epilepsy Foundation. He is funded by grants from the Center for Houston's Future, Cancer Prevention Research Institute of Texas, U.S. Centers for Disease Control and Prevention, and the Hogg Foundation for Mental Health. Malachy L. Bishop is a member of the American Epilepsy Society, the Educational Committee International Bureau for Epilepsy, the International League Against Epilepsy, and International Epilepsy Congress 2012–13; member of the Epilepsy Foundation of America, advisory board, and the International Bureau for Epilepsy, Research Task Force. Sandra Cushner Weinstein is a volunteer for the Patient/family workgroup of Vision 20/20, manages the Newly Diagnosed Seizure Clinic at Children's National; and director of Brainy Camps. She is funded by CDC grant 1U01DP003255-01, 2011–2015. Dale C. Hesdorffer serves on the editorial board of *Epilepsy & Behavior* and *Epilepsy Research*, and as contributing editor to *Epilepsy Currents*. She

consults for the Mount Sinai Medical Center Injury Prevention Center. Dr. Hesdorffer received a travel award from GlaxoSmithKline in 2010. In 2012, she participated in advisory boards for UCB and Upsher-Smith. She is funded by grants from CDC, DP002209, PI, 2009–2014; AUCD, RT01, Co-I (PI of Columbia subcontract), 2008–2012; NINDS, NS31146, Co-I (PI of Columbia subcontract), 2007–2014; NINDS, NS043209, Co-I (PI of Columbia subcontract), 2003–2013; CDC, MM1002, Co-I, 2006–2010; NICHD, HD042823, Co-I, 2002–2013; NINDS, 5U01NS04911, Co-I (PI of Columbia subcontract), 2011–2012; NINDS, NS078419, Co-I, 2012–2015; and the Epilepsy Foundation of America 2010–2012. Gregory L. Holmes serves on the editorial board of *Epilepsy & Behavior*, *Brain & Development*, and *Paediatric Drugs*. He is on the safety monitoring board of the National Heart, Lung and Blood Institute and Eisai Pharmaceuticals. He has participated in advisory boards for the National Institutes of Health, Food & Drug Institute, Upsher-Smith Laboratories, and GlaxoSmithKline. He is funded by grants from NINDS (NS075249, NS044295, NS073083), and the Emmory R. Shapses Research Fund [GLH]. Patricia O. Shafer is Consultant, Epilepsy Therapy Project; Board of Directors, Epilepsy Foundation; Professional Advisory Board, Epilepsy Foundation of Massachusetts, Rhode Island, New Hampshire, and Maine; Member and Committee Chair, American Epilepsy Society; Affiliate member, Managing Epilepsy Well Network. Co-Chair, Patient/Family Workgroup of Vision 20/20; Joseph I. Sirven NIH funding for Research; Time compensation from Epilepsy Therapy Project; Research funding from: Eisai, Vertex, MAP, NeuroPace, LGH Upsher-Smith. IOM authoring committee for the Committee on the Public Health Dimensions of the Epilepsies: Mary Jane England, M.D.; Joan K. Austin, Ph.D., R.N., F.A.A.N.; Vicki Beck, M.S., Charles E. Begley, Ph.D.; Malachy L. Bishop, Ph.D., C.R.C.; Lionel Carmant, M.D.; Carolyn Cocotas, R.T., M.P.A., C.H.C., C.H.P.C.; Sandra Cushner-Weinstein, P.T., L.I.C.S.W., L.I.C.S.W.-C.; Ramon Diaz-Arrastia, M.D., Ph.D.; David Grant, Ph.D.; Christianne N. Heck, M.D., M.M.M.; Dale C. Hesdorffer, Ph.D., M.P.H.; Gregory L. Holmes, M.D.; Paul e. Jarris, M.D., M.B.A.; Diplex V. Jeste, M.D.; Patricia O. Shafer, R.N., M.R.; Joseph I. Sirven, M.D. We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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