EPILEPSY *across the* SPECTRUM

PROMOTING HEALTH AND UNDERSTANDING

Committee on the Public Health Dimensions of the Epilepsies

Board on Health Sciences Policy

Mary Jane England, Catharyn T. Liverman,
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INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

THE NATIONAL ACADEMIES PRESS
Washington, D.C.
www.nap.edu

THE NATIONAL ACADEMIES PRESS • 500 Fifth Street, NW • Washington, DC 20001

NOTICE: The project that is the subject of this report was approved by the Governing Board of the National Research Council, whose members are drawn from the councils of the National Academy of Sciences, the National Academy of Engineering, and the Institute of Medicine.

This study was supported by Contract No. N01-OD-4-2139, T.O. #242, between the National Academy of Sciences and the National Institutes of Health (Eunice Kennedy Shriver National Institute of Child Health and Human Development, National Institute of Mental Health, National Institute of Neurological Disorders and Stroke, and National Institute on Aging); Contract No. HHSP23337026T, T.O. #47, between the National Academy of Sciences and the Department of Health and Human Services (Administration on Developmental Disabilities, Center for Devices and Radiological Health and Center for Drug Evaluation and Research at the Food and Drug Administration, National Center for Chronic Disease Prevention and Health Promotion and National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention, Office of the Assistant Secretary for Health, Office of the Assistant Secretary for Planning and Evaluation, and Office on Women's Health); and with support from Vision 20-20 sponsors (American Epilepsy Society, Citizens United for Research in Epilepsy, Dravet.org, Epilepsy Foundation, Epilepsy Therapy Project, Finding A Cure for Epilepsy and Seizures, Hemispherectomy Foundation, International League Against Epilepsy, National Association of Epilepsy Centers, Preventing Teen Tragedy, Rasmussen's Encephalitis Children's Project, and Tuberous Sclerosis Alliance). Any opinions, findings, conclusions, or recommendations expressed in this publication are those of the author(s) and do not necessarily reflect the view of the organizations or agencies that provided support for this project.

Library of Congress Cataloging-in-Publication Data

Institute of Medicine (U.S.). Committee on the Public Health Dimensions of the Epilepsies.
Epilepsy across the spectrum : promoting health and understanding / Committee on the Public Health Dimensions of the Epilepsies, Board on Health Sciences Policy, Institute of Medicine of the National Academies ; Mary Jane England ... [et al.], editors.
p. ; cm.
Includes bibliographical references.
ISBN 978-0-309-25506-6 (hardcover) — ISBN 978-0-309-25507-3 (pdf)
ISBN 978-0-309-25953-8 (paperback)
I. England, Mary Jane, 1938- II. Title.
[DNLM: 1. Epilepsy—United States. 2. Health Education—methods—United States. 3. Health Policy—United States. 4. Quality of Health Care—United States. WL 385]

362.196853—dc23

2012016603

Additional copies of this report are available from the National Academies Press, 500 Fifth Street, NW, Keck 360, Washington, DC 20001; (800) 624-6242 or (202) 334-3313; http://www.nap.edu.

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Printed in the United States of America

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Suggested citation: IOM (Institute of Medicine). 2012. *Epilepsy across the spectrum: Promoting health and understanding*. Washington, DC: The National Academies Press.

"Knowing is not enough; we must apply.
Willing is not enough; we must do."
—Goethe

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This report has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the National Research Council's Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published report as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the deliberative process. We wish to thank the following individuals for their review of this report:

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Although the reviewers listed above have provided many constructive comments and suggestions, they were not asked to endorse the conclusions or recommendations, nor did they see the final draft of the report before its release. The review of this report was overseen by **Enriqueta C. Bond,** President Emeritus at Burroughs Wellcome Fund, and **Dan G. Blazer,** Gibbons Professor of Psychiatry, Duke University Medical Center. Appointed by the Institute of Medicine, they were responsible for making certain that an independent examination of this report was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this report rests entirely with the authoring committee and the institution.

Preface

Millions of lives in the United States are affected by epilepsy, yet this fourth most common neurological disorder is not as well understood as less prevalent conditions, such as Parkinson's disease and multiple sclerosis. Epilepsy is a complex medical disorder—not all seizures are the result of epilepsy, and epilepsy-related seizures can vary widely in severity and in the parts of the brain affected. Further, epilepsy is more than the seizures: many people with epilepsy have other coexisting health conditions that can significantly affect their health and well-being. Health care and community services relevant to epilepsy care are often fragmented and uncoordinated and are not always easily accessible. Children and older adults represent the fastest-growing populations with newly diagnosed epilepsy.

Quality of life for people with epilepsy can be impacted to varying degrees; it may result in limits on the person's ability to drive and on his or her employment and can have effects on social interactions and family dynamics. These challenges result in significant indirect costs for individuals, their families, and society that include lost productivity connected to unemployment, underemployment, and premature mortality. Throughout the centuries, misperceptions about epilepsy have developed and been perpetuated in popular culture, resulting in stigma and social isolation, which can affect health and further diminish quality of life. This history of discrimination and stigma has been difficult to reverse.

Despite these challenges, there are many ongoing efforts to improve the lives of people with epilepsy and their families; these efforts must continue and be strengthened so that, ultimately, all people with epilepsy have ac-

cess to the full range of coordinated health and community services they need. Access to current medications and other medical treatments, medical devices, and surgery allow many people with epilepsy to be seizure-free or to have fewer seizures. New treatment options are needed for those whose epilepsy does not respond to available treatments or who have unacceptable treatment side effects. Educating people with epilepsy, their families, health professionals, and the general public about epilepsy requires different types of information and varying levels of detail, depending on the audience. Educational resources and tools designed to promote optimal self-management need to be evaluated and disseminated widely in order to facilitate the active participation of people with epilepsy and their families in patient-centered epilepsy treatment and management. Further, more needs to be known about the extent of epilepsy and its impact, as well opportunities for prevention and early identification, so that programs can be focused most effectively and, in these times of limited resources, be more sustainable. Data from enhanced surveillance and research can guide planning and policy efforts to improve the lives of people with epilepsy.

This report emphasizes five key messages:

- Epilepsy is a common and a complex neurological disorder that affects health and quality of life. In the provision of coordinated health and human services, a whole-patient perspective is needed.
- Effective treatments are available for many types of epilepsy, but timely referrals and access to those treatments fall short. Better data from surveillance and research could improve epilepsy care and prevention.
- Many health professionals need to be better informed about epilepsy.
- Education efforts for people with epilepsy and their families need to be thorough and sensitive to health literacy and cultural considerations.
- The stigma associated with epilepsy has to be eliminated.

The committee's work was greatly enhanced by the testimony and presentations provided by people with epilepsy, their family members and friends, epilepsy researchers, and health professionals. Their compelling insights into the challenges that epilepsy imposes spurred the committee toward developing practical, action-oriented recommendations to improve the lives of people with epilepsy. The committee thanks everyone who provided testimony for sharing their personal experiences and perspectives, and it also thanks the experts who shared their research and knowledge during the public workshops.

It was my great privilege to chair this Institute of Medicine committee

and to work with such dedicated committee members and staff who delved into the committee's statement of task with energy, intellectual commitment, creative talent, and carefully considered discussion. They devoted countless hours to this work. We hope that this report will be both a foundation and a stepping stone to further the diligent efforts by the epilepsy community, government agencies, nonprofit organizations, researchers, and individuals with epilepsy and their families. People with epilepsy will need all of our efforts to provide appropriate and compassionate care and services in order to live fully and with optimal quality of life.

Mary Jane England, *Chair*
Committee on the Public Health
Dimensions of the Epilepsies

Acknowledgments

This report was informed by the contributions of many individuals who provided expertise, personal insights and perspectives, and data. The Institute of Medicine (IOM) Committee on the Public Health Dimensions of the Epilepsies would like to express its sincere gratitude to everyone who made this report possible.

First, the committee would like to thank the sponsors of this study. Funds were provided through several divisions of the U.S. Department of Health and Human Services (HHS): Administration on Developmental Disabilities, Center for Devices and Radiological Health (Food and Drug Administration [FDA]), Center for Drug Evaluation and Research (FDA), Eunice Kennedy Shriver National Institute of Child Health and Human Development (National Institutes of Health [NIH]), National Center for Chronic Disease Prevention and Health Promotion (Centers for Disease Control and Prevention [CDC]), National Center on Birth Defects and Developmental Disabilities (CDC), National Institute of Mental Health (NIH), National Institute of Neurological Disorders and Stroke (NIH), National Institute on Aging (NIH), Office of the Assistant Secretary for Health (HHS), Office of the Assistant Secretary for Planning and Evaluation (HHS), and Office on Women's Health (HHS); and by members of the Vision 20-20 collaborative: American Epilepsy Society, Citizens United for Research in Epilepsy, Dravet.org, Epilepsy Foundation, Epilepsy Therapy Project, Finding A Cure for Epilepsy and Seizures, Hemispherectomy Foundation, International League Against Epilepsy, National Association of Epilepsy Centers (NAEC), Preventing Teen Tragedy, Rasmussen's Encephalitis Children's Project, and Tuberous Sclerosis Alliance. These 24 federal agen-

cies and nonprofit organizations came together with a vision for advancing the field of epilepsy and improving the lives of individuals with epilepsy by focusing this study on the public health dimensions of the disorder. The efforts of many individuals, including Frances Jensen, Howard Koh, and Story Landis, were instrumental in getting the study under way.

Over the course of the study, the committee conducted two public workshops during which more than 80 researchers, experts, health professionals, and individuals with epilepsy and their families and friends provided presentations and testimony (Appendix A). The committee also heard from numerous individuals throughout the study who shared their personal stories via e-mail. The committee is especially grateful to the individuals who provided compelling and candid information about their own personal experiences with epilepsy, including their concerns, burdens, joys, and challenges. Excerpts from testimony the committee received is interspersed throughout the chapters of this report.

The committee is also appreciative of the background information and data that individuals, sponsors, and other epilepsy-related organizations generously provided to inform the committee's work, including a wealth of information about research, programs, campaigns, website statistics, and the history of the epilepsy movement.

The committee would like to recognize a number of individuals who graciously devoted time and energy to gathering and summarizing the data on people with epilepsy and their health services use that appear in Appendixes B and C of this report. Contributors included David R. Nerenz, Gregory L. Barkley, Marianna Spanaki-Varelas, Aida Li, and their colleagues at Henry Ford Health System; Matthew A. R. Eccher, Joshua N. Liberman, Amanda C. Bengier, Frank G. Gilliam, and their colleagues in the Geisinger Health System; Mary Jo Pugh, Megan Amuan, and their colleagues at the Veterans Health Administration; Anbesaw W. Selassie, Chris Finney, Sandra Kelly, and their colleagues from the South Carolina Epilepsy Surveillance System; and Robert J. Gumnit, David M. Labiner, Nathan B. Fountain, Susan T. Herman, Ellen Riker, and the epilepsy centers that participated in the 2011 NAEC Center Designation Survey and the 2011 Supplemental Survey for the IOM, both conducted by the NAEC.

The committee is also grateful to the more than 50 health professional boards and associations that took the time to answer the committee's questions and provide information on certification and licensure requirements, curricular content, and continuing education opportunities and requirements for the wide range of health professionals that work daily to provide people with epilepsy and their families with high-quality, patient-centered health care, community, and educational services. While these boards and associations are too numerous to list here, many of them are listed Appendix D, and the information they provided was vital to the committee's

understanding of the complexity and variation in health professional education about the epilepsies.

Special appreciation goes to the dedicated IOM study staff members who supported and contributed to the committee's work during the last 18 months. Cathy Liverman and Andrea Schultz co-directed the study; Lara Strawbridge provided invaluable research support; and Judy Estep skillfully managed all logistical and administrative aspects of the study. The committee is also grateful to Vicki Weisfeld of NEW Associates, LLC, for their assistance in editing the report and for their keen attention to detail; to Florence Poillon for copyediting the final version of the report; and to LeAnn Locher for her artistic talents in creating the cover and design elements throughout the report.

Finally, the committee would like to express its thanks to the IOM and National Academies staff members who worked behind the scenes to ensure a seamless study process and successful production and dissemination of this report: Clyde Behney, Daniel Bethea, Laura DeStefano, Jim Jensen, Rachel Marcus, Abbey Meltzer, Andy Pope, Donna Randall, Lauren Rugani, Christine Stencel, Lora Taylor, Vilija Teel, Lauren Tobias, Gary Walker, and Sarah Ziegenhorn.

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Acronyms

AAN	American Academy of Neurology
AANN	American Association of Neuroscience Nurses
ABLE	Attitudes and Beliefs about Living with Epilepsy
ABNN	American Board of Neuroscience Nursing
ABPN	American Board of Psychiatry and Neurology
ACA	Patient Protection and Affordable Care Act
ACR	American College of Radiology
ACS	American College of Surgeons
ADA	Americans with Disabilities Act
ADD	attention deficit disorder
ADDM	Autism and Developmental Disabilities Monitoring
ADHD	attention deficit hyperactivity disorder
AES	American Epilepsy Society
AHRQ	Agency for Healthcare Research and Quality
AIDS	acquired immune deficiency syndrome
APCD	all-payer claims database
ASMP	Arthritis Self-Management Program
BRFSS	Behavioral Risk Factor Surveillance System
CART	Cardiovascular Assessment, Reporting and Tracking
CDC	Centers for Disease Control and Prevention
CDE	Common Data Element
CDIS	Clinical Decision Intelligence System
CDSMP	Chronic Disease Self-Management Program

CE	continuing education
CEO	chief executive officer
CFF	Cystic Fibrosis Foundation
CHIS	California Health Interview Survey
CI	confidence interval
CME	continuing medical education
CMS	Centers for Medicare and Medicaid Services
CNS	central nervous system
COPE	Coping Openly and Personally with Epilepsy
CPR	cardiopulmonary resuscitation
CPT	Current Procedural Terminology
CT	computerized tomography
CURE	Citizens United for Research in Epilepsy
DALY	disability-adjusted life-year
DHEC	Department of Health and Environmental Control
DOD	Department of Defense
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition
DSME	diabetes self-management education
DUI	driving under the influence
ECOE	Epilepsy Center of Excellence
ED	emergency department
EEG	electroencephalogram, electroencephalograph, electroencephalography
EFNS	European Federation of Neurological Societies
EHR	electronic health record
EMR	electronic medical record
EMS	emergency medical services
EMT	emergency medical technician
EMU	epilepsy monitoring unit
END	electroneurodiagnostic
ETP	Epilepsy Therapy Project
EURAP	International Registry of Antiepileptic Drugs and Pregnancy
EUROCAT	European Surveillance of Congenital Anomalies
FDA	Food and Drug Administration
FY	fiscal year
GHS	Geisinger Health System

HAP	Health Alliance Plan
HEDIS	Healthcare Effectiveness Data and Information Set
HFH	Henry Ford Hospital
HFMG	Henry Ford Medical Group
HFWBH	Henry Ford West Bloomfield Hospital
HHS	U.S. Department of Health and Human Services
HIPAA	Health Insurance Portability and Accountability Act
HIV	human immunodeficiency virus
HMO	health maintenance organization
HMORN	HMO Research Network
HON	Health On the Net
HONcode	HON Code of Conduct
HRSA	Health Resources and Services Administration
IAN	Interactive Autism Network
ICD-9	International Classification of Diseases, Ninth Revision
ICD-10	International Classification of Diseases, Tenth Revision
ICD-CM	International Classification of Diseases, Clinical Modification
IDEA	Individuals with Disabilities Education Act
IEP	individualized education program
ILAE	International League Against Epilepsy
IOM	Institute of Medicine
IRB	institutional review board
LGS	Lennox-Gastaut syndrome
LPN	licensed practical nurse
LVN	licensed vocational nurse
MEG	magnetoencephalography
MEPS	Medical Expenditure Panel Survey
MEW	Managing Epilepsy Well
MNS	mental health, neurological, and substance-use
MOSES	Modular Service Package Epilepsy
MRI	magnetic resonance imaging
MUSC	Medical University of South Carolina
NAACCR	North American Association of Central Cancer Registries
NAEC	National Association of Epilepsy Centers
NAMI	National Alliance on Mental Illness
NASN	National Association of School Nurses
NCCDPHP	National Center for Chronic Disease Prevention and Health Promotion

NCQA	National Committee for Quality Assurance
NCI	National Cancer Institute
NETT	Neurological Emergencies Treatment Trials
NHIS	National Health Interview Survey
NIH	National Institutes of Health
NIMH	National Institute of Mental Health
NINDS	National Institute of Neurological Disorders and Stroke
NIS	Nationwide Inpatient Sample
NOS	not otherwise specified
NPCR	National Program of Cancer Registries
NPSNC	National Population Health Study of Neurological Conditions
NQF	National Quality Forum
OEF	Operation Enduring Freedom
OIF	Operation Iraqi Freedom
OPD	outpatient department
ORS	Office of Research and Statistics
PAHO	Pan American Health Organization
PCAST	President's Council of Advisors on Science and Technology
PCPI	Physician Consortium for Performance Improvement
PEARLS	Program to Encourage Active, Rewarding Lives for Seniors
PET	positron emission tomography
PTSD	posttraumatic stress disorder
QOLIE	quality of life in epilepsy
QUIET	QUality Indicators in Epilepsy Treatment
RAMPART	Rapid Anticonvulsant Medications Prior to Arrival Trial
RHIO	regional health information organization
SCESS	South Carolina Epilepsy Surveillance System
SD	standard deviation
SE	status epilepticus
SEE	Seizures and Epilepsy Education
SEER	Surveillance, Epidemiology, and End Results
SES	socioeconomic status
SHP	State Health Plan
SIRE	Stockholm Incidence Registry of Epilepsy
SPECT	single positron emission tomography
SSN	Social Security number
SUDEP	sudden unexpected death in epilepsy

TAPS	Training Applicants for Placement Success
TBI	traumatic brain injury
UB	uniform billing
UCSD	University of California, San Diego
UID	unique identifier
UPLIFT	Using Practice and Learning to Increase Favorable Thoughts
USC	University of Southern California
VA	Department of Veterans Affairs
VDW	Virtual Data Warehouse (HMORN)
vEEG	video-EEG
VHA	Veterans Health Administration
VIREPA	Virtual Epilepsy Academy (ILAE)
VNS	vagus nerve stimulation
WebEase	Web Epilepsy Access, Support, and Education
YRBSS	Youth Risk Behavior Surveillance System

Summary

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. 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; it is estimated that 150,000 new cases are diagnosed in the United States annually and that 1 in 26 individuals will develop epilepsy at some point in their lifetime.

While seizures are well controlled with medications and other treatment options for the majority of people with epilepsy, the impact of epilepsy goes well beyond the seizures. The challenges facing the estimated 2.2 million people with epilepsy in the United States 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,

[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 and their references. Discussion of these areas and citations for the information presented in the summary appear in subsequent chapters of the report.

families, and society; the estimated annual direct medical cost of epilepsy in the United States is $9.6 billion, 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). Further, epilepsy is associated with substantially higher rates of mortality than experienced in the population as a whole, with sudden unexpected death in epilepsy (SUDEP) being the most common cause of epilepsy-related deaths. 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. Additionally, estimates of the number of people with epilepsy who die of SUDEP range from 1 of every 10,000 newly diagnosed to 9 of every 1,000 candidates for epilepsy surgery.

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. 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 this report, the committee emphasizes the ways in which epilepsy is a spectrum disorder. Epilepsy comprises more than 25 syndromes and many types of seizures that vary in severity. 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 condition. These many complexities of epilepsy make it a challenging health condition to convey to the general public to promote understanding and alleviate stigma. This report aims to provide evidence and impetus for actions that will improve the lives of people with epilepsy and their families.

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, continue to be updated by the National Institute of Neurological Disorders and Stroke and collaborating agencies and organizations. 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.

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. Critical to realizing this vision will be additional research to further develop the evidence base as outlined in the research priorities in Chapter 9.

INCREASING THE POWER OF EPILEPSY DATA

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. 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 with other chronic diseases and disorders.

RECOMMENDATION 1 ***Validate and Implement Standard Definitions and Criteria for Epilepsy Case Ascertainment, Health Care and Community Services Use and Costs, and Quality-of-Life Measurement***
The Centers for Disease Control and Prevention (CDC), in collaboration with professional organizations (e.g., the American Epilepsy Society [AES] and International League Against Epilepsy [ILAE]) and other federal entities, including the Centers for Medicare and Medicaid

Services, Department of Defense, Department of Veterans Affairs, and National Institutes of Health (NIH), should fund demonstration projects to validate and implement standard definitions for epilepsy case ascertainment, health care and community services use and costs, and measures of quality of life for use in different data collection systems and for different specific objectives. Once validated, these definitions and criteria should be adopted by funding agencies and used in surveillance and research, which is the basis for planning and policy making.

RECOMMENDATION 2 ***Continue and Expand Collaborative Surveillance and Data Collection Efforts***

The CDC should continue and expand its leadership in epilepsy surveillance and work with state and local public health researchers, academic researchers, and other relevant stakeholders (including other agencies within the Department of Health and Human Services). Surveillance efforts should be funded that use large, representative samples to determine the overall incidence and prevalence of epilepsy—and mortality—over time as well as in specific populations (e.g., different types of epilepsy, ages, genders, races/ethnicities, socioeconomic statuses). Data collection efforts should include the following:

- Population health surveys should expand their questions about epilepsy, its comorbidities, and health care services use and include these questions more frequently and consistently.
- Existing registries for comorbid conditions, such as the Surveillance, Epidemiology, and End Results program and state-based cancer registries, state-based Alzheimer's registries, and the Interactive Autism Network, should collect data on epilepsy.
- Efforts should be expanded to standardize the practices of coroners and medical examiners in evaluating and recording cause of death in people with epilepsy with the goal of working toward a national epilepsy-related death registry.
- Pilot projects should explore the linkage and use of emerging data collection and sharing partnerships using electronic health records and other electronic repositories (e.g., all-payer claims databases, regional health information organizations, the Health Maintenance Organization Research Network, NIH's Health Care Systems Research Collaboratory, the Health Care Cost Institute) for epilepsy surveillance and research.
- Epilepsy-specific data should be included in the NIH National Children's Study and future longitudinal studies.

PREVENTING EPILEPSY

An important first step in designing programs to prevent epilepsy and its consequences is the identification of risk factors, comorbidities, and outcomes for epilepsy. At present, many research questions and gaps remain where more complete information could provide a sound basis for prevention, including in public health, clinical care, education programs, and community efforts. Neurocysticercosis[2] is a growing concern in the United States and represents a known risk factor for epilepsy—one in which fundamental improvements in education and sanitary measures could decrease a specific infection that causes epilepsy. Continued intervention efforts are needed to prevent the occurrence of traumatic brain injury (TBI), through mechanisms such as the use of seatbelts, to prevent TBI associated with motor vehicle accidents, as well as helmets, including improved helmet design, to reduce the occurrence and severity of TBI in sports and military combat. In addition, progress in the prevention of epilepsy's other risk factors—such as stroke, through targeted efforts to reduce risk factors, and brain infections such as meningitis, through sustained vaccination programs—will likely result in fewer new cases of epilepsy. Further options for primary prevention may come to light if epidemiologic studies identify other risk factors for epilepsies whose etiologies are currently unknown. Secondary prevention of seizures may be possible through the use of antidepressants. Prevention efforts are needed that target felt stigma and specific risk factors for death due to accidents and suicide among people with the epilepsies. Additionally, risk factors for SUDEP have been described, but interventions to reduce the occurrence of this devastating outcome have not been evaluated in those at highest risk.

RECOMMENDATION 3 ***Develop and Evaluate Prevention Efforts for Epilepsy and Its Consequences***

The CDC should partner with the World Health Organization, ILAE, NIH, the Action Alliance for Suicide Prevention, and other stakeholders to develop and evaluate culturally appropriate and health literate prevention efforts that focus on

- preventing neurocysticercosis in high-risk populations;
- continuing prevention efforts for established risk factors of epilepsy (e.g., TBI, stroke, brain infections such as meningitis);
- preventing continued seizures in people with epilepsy and depression;
- reducing felt stigma; and

[2]Neurocysticercosis is a parasitic brain infection that can cause epilepsy (Chapter 3).

- preventing epilepsy-related causes of death, including accidents and injuries, SUDEP, and suicide.

IMPROVING HEALTH CARE

Improving the lives of people with epilepsy and their families, to a large extent, begins with access to high-quality, patient-centered health care that facilitates accurate diagnosis and effective treatments and management. While significant progress has been made in developing seizure medications with fewer adverse effects, as well as in refining devices and surgical techniques for specific types of epilepsy, much remains to be done to reduce the sometimes lengthy delays in diagnosis and referral to more advanced levels of care and to improve care for those with refractory epilepsy. Currently, troubling disparities are suggested in the research, based on racial, ethnic, and socioeconomic factors. High-quality health care for the epilepsies cannot be provided on a population basis until the problems of accessibility, efficiency, and equity are resolved. An important element in high-quality care is access to specialized epilepsy centers, especially for people with refractory epilepsy. Epilepsy centers are vital in providing specialized epilepsy care and have the potential to build on their current efforts by forming a network for health professional education, clinical research, and data collection and analysis. Developing and maintaining a national quality measurement and improvement strategy is another critical component of ensuring high-quality epilepsy care. This strategy would help hold providers accountable for adherence to practice guidelines through the standardization and implementation of quality metrics.

Building the health care workforce's knowledge base and skill sets in diagnosing, treating, supporting, and generally working with people with epilepsy is also necessary to ensure that people with epilepsy and their families have access to high-quality care. Health professionals need current knowledge about many aspects of the epilepsies: seizure recognition and diagnosis; prevention strategies and treatment options; associated risks, comorbidities, and safety concerns; necessary social services; psychosocial and quality-of-life factors; and the need to counter stigma. The specific types and depth of knowledge required vary across professions, depending on the roles, responsibilities, and scope of practice of the professionals and the specific settings in which they work.

RECOMMENDATION 4 ***Improve the Early Identification of Epilepsy and Its Comorbid Health Conditions***

The AES and the American Academy of Neurology (AAN) should lead a collaborative effort with the wide range of relevant professional organizations (including primary care professional organizations) and

federal agencies (including the CDC and Health Resources and Services Administration), and others that promote and disseminate screening programs to

- develop and validate screening tests for the early identification of epilepsy in at-risk populations (e.g., people with developmental disabilities; people with mental health conditions; people who have had a TBI, brain tumor, or stroke);
- establish and disseminate a standard screening protocol for people with epilepsy that implements screening on a regular basis for comorbidities with currently approved screening tests (e.g., for bone disease, depression, generalized anxiety disorder); and
- establish and disseminate a screening tool for the early identification of patients with persistent seizures that would lead to earlier referral to an epileptologist for further diagnosis and treatment.

RECOMMENDATION 5 ***Develop and Implement a National Quality Measurement and Improvement Strategy for Epilepsy Care***
The AES, in conjunction with other professional organizations involved in epilepsy care, education, and advocacy (including primary care professional organizations) should initiate the development of a national quality measurement and improvement strategy for epilepsy care. An independent organization with expertise in quality measurement and care should assist in the development of the national strategy, particularly the development of performance metrics. The national quality improvement strategy should

- develop and implement a plan to disseminate existing clinical guidelines and educate health professionals and people with epilepsy and their families about them;
- define performance metrics for epilepsy with specific attention to access to care for underserved populations, access to specialized care, co-management of care among all health care providers, and coordination of care with other health care providers and community services organizations;
- continue the development and implementation of a set of performance metrics that includes patient-generated measures; and
- develop demonstration projects to validate performance metrics and test the feasibility of tracking outcomes of care.

RECOMMENDATION 6 ***Establish Accreditation of Epilepsy Centers and an Epilepsy Care Network***
The National Association of Epilepsy Centers and the AES should col-

laborate with relevant organizations to establish accreditation criteria and processes with independent external review mechanisms for the accreditation of epilepsy centers. Accredited epilepsy centers should work together to form an Epilepsy Care Network that includes data sharing, clinical trial and other research networking, professional education, and other collaborative activities.

- Independently accredited epilepsy centers should
    - emphasize patient-centered care that focuses on co-management approaches with primary care providers, mental health care providers, and other specialists;
    - ensure that community service providers are an integral part of the centers and actively collaborate with them to link people with epilepsy to services for all facets of the individual's health and well-being;
    - use standardized performance metrics for quality epilepsy care;
    - publicly report on a standard set of quality, outcome, and health services data;
    - provide onsite education and training for epilepsy specialists (e.g., technicians, nurses, researchers, physicians) as well as educational opportunities, particularly continuing education, for other health and human services professionals in the community; and
    - serve as sites for pilot projects on innovative approaches to improving co-management and coordination of care, as well as health care quality, access, and value for people with epilepsy.
- The Epilepsy Care Network of Accredited Epilepsy Centers should
    - conduct collaborative clinical and health services research;
    - collect, analyze, and disseminate quality, outcome, and health services data from all of the accredited centers; and
    - collaborate and partner with state health departments and other health care providers to ensure coverage across rural and underserved areas through telemedicine, outreach clinics, and other mechanisms.

RECOMMENDATION 7 ***Improve Health Professional Education About the Epilepsies***

The AES and AAN should collaborate with relevant professional organizations that are involved in the education of the wide range of health

professionals who care for people with epilepsy to ensure that they are sufficiently knowledgeable and skilled to provide high-quality, patient-centered, interdisciplinary care. In their efforts to improve health professional education, these organizations should do the following:

- Define essential epilepsy knowledge and skills for the range of health professionals who care for people with epilepsy and their families.
- Conduct surveys of the relevant health professionals to identify knowledge gaps and information needs.
- Evaluate the efficacy and reach of existing educational materials and learning opportunities (e.g., websites, continuing education courses).
- Develop engaging and interactive educational tools, such as online modules, that meet specific learning needs and could be easily integrated into existing curricula and education programs.
- Ensure that educational materials and programs for health professionals reflect current research, clinical guidelines, and best practices. These educational materials and programs also should convey positive messages that reduce stigma and reinforce the need for (and skills associated with) clear health communication, which takes into account the culture and health literacy of the target audience.
- Explore and promote opportunities to expand the use of innovative interdisciplinary educational approaches, such as high-fidelity simulation.
- Disseminate educational materials and tools widely to health professional educators and other relevant professional associations and organizations.

IMPROVING COMMUNITY RESOURCES AND QUALITY OF LIFE

The burden of seizures and epilepsy, particularly severe forms of epilepsy, can be overwhelming for many people with epilepsy and their families. The social and emotional toll of care can place financial and emotional strains on marriages and families and can alter roles, relationships, and lifestyles. Many speakers at the committee's workshops emphasized that epilepsy—regardless of its level of severity—creates life challenges because of the unpredictability of seizures. This report examines the range of community services—daycare and school, employment, transportation, housing, sports and recreation, and others directed at family support—relevant to improving quality of life for people with epilepsy. The committee urges improvements to community services and programs to ensure that they are

- patient centered to meet the needs of the person with epilepsy;
- locally focused, taking into account the full range of resources in the area;
- easily accessible;
- thoroughly evaluated;
- closely linked to health care providers, particularly epileptologists and epilepsy centers; and
- innovative and collaborative in working with organizations and agencies focused on other neurological and chronic conditions or on similar service needs.

RECOMMENDATION 8 ***Improve the Delivery and Coordination of Community Services***

The CDC, state health departments, and the Epilepsy Foundation, in collaboration with state and local Epilepsy Foundation affiliates and other relevant epilepsy organizations, should partner with community service providers and epilepsy centers to enhance and widely disseminate educational and community services for people with epilepsy that encompass the range of health and human services needed for epilepsy, its comorbid conditions, and optimal quality of life. These services include support groups; vocational, educational, transportation, transitional care, and independent living assistance; and support resources, including respite care for family members and caregivers. Specific attention should be given to identifying needs and improving community services for underserved populations. These efforts should

- support and expand efforts by the Epilepsy Foundation's state and local affiliates and other organizations to link people with epilepsy and their families to local and regional resources, emphasizing active collaboration among affiliates in the same region or with similar interests;
- develop innovative partnerships and incentives to collaborate with organizations and public-private partnerships focused on other neurological and chronic diseases or disorders;
- conduct and evaluate pilot studies of interventions to improve the academic achievement of students with epilepsy;
- maintain effective private, state, and national programs that assist people with epilepsy regarding transportation, employment, and housing;
- develop and disseminate evidence-based best practices in employment programs for people with epilepsy;
- identify and disseminate best practices for the coordination of health care and community services, including programs using patient and parent navigators;

- provide a 24/7 nonmedical help line offering information on epilepsy and links to community resources (this effort should involve collaboration with similar efforts for related health conditions); and
- develop, disseminate, and evaluate educational and training opportunities (including interactive web-based tools) for community service providers focused on epilepsy awareness and seizure first aid training.

RAISING AWARENESS AND IMPROVING EDUCATION

Patient and Family Education

Research consistently demonstrates that many people with epilepsy do not have a solid understanding of basic information about their condition—how it is diagnosed, seizure precipitants or triggers, types of seizures, the purpose and potential side effects of seizure medications, safety concerns, and the risks and potential consequences of seizures. Additionally, the diagnosis of epilepsy, although given to an individual, affects the entire family and its constellation of friendships and other relationships. At onset all are confronted with the immediate need to learn about the disorder, and their information needs continue throughout the course of treatment and management.

Education for people with epilepsy and their families plays an important role in adapting to life with epilepsy, developing self-confidence, and becoming competent in self-management, which entails being aware of one's own needs and being able to access resources to meet those needs. Obtaining requisite knowledge and skills related to epilepsy and its management can also promote optimal well-being and quality of life for people with epilepsy and their families, help prevent misconceptions about the condition, and reduce concerns about stigma.

RECOMMENDATION 9 ***Improve and Expand Educational Opportunities for People with Epilepsy and Their Families***

To ensure that all people with epilepsy and their families have access to accurate, clearly communicated educational materials and information, the Epilepsy Foundation, the Epilepsy Therapy Project, the CDC, and other organizations involved in Vision 20-20 should collaborate to do the following:

- Conduct a formal evaluation of currently available epilepsy websites and their educational resources to ensure that they meet requirements of clear health communication and are linguistically

and culturally appropriate for targeted audiences. This requires thorough testing of content with target audiences, including underserved groups, and revision as necessary.

- Develop a central, easily navigated website ("clearing house") that provides direct links to websites containing current, accurate epilepsy-related information for individuals and their families. This centralized resource should be comprehensive; it should include concise, easy-to-understand descriptions of the information available on the linked websites and up-to-date contact information for epilepsy organizations; and it should be widely disseminated to health care providers and people with epilepsy and their families.
- Ensure that educational resources are up to date, are effective, and reflect the latest scientific understanding of the epilepsies and their associated comorbidities and consequences.
- Engage a wide and diverse spectrum of people with epilepsy and their families in the development of online educational resources to ensure that the content meets the specific needs of target audiences at the outset.
- Support the development, evaluation, replication, and expanded use of self-management and educational programs, including those developed through the Managing Epilepsy Well Network.
- Engage state and local Epilepsy Foundation affiliates, epilepsy centers, and health care systems and providers to expand the dissemination of available educational resources and self-management tools to people with epilepsy and their families.
- Explore the development of a formal, standardized certificate program for epilepsy health educators.

Public Awareness and Knowledge

While some surveys have suggested that attitudes regarding epilepsy have become less negative over time, it is not certain how contemporary attitudes compare and whether overall improvements in attitudes have affected behavior. Compelling testimony from families dealing with epilepsy and research on employment suggest that problems of stigma remain widespread. Efforts to increase public awareness and knowledge are motivated by the expectation that information that reduces misconceptions and misinformation will improve attitudes and, ultimately, behavior toward people with epilepsy and thereby reduce stigma. Stigma, whether felt or overtly experienced, has many negative consequences for both health and quality of life, and overcoming it is an important goal for the field.

For the public in general, the news and entertainment media are sig-

nificant sources of health information. Unfortunately, inaccurate depictions of people with epilepsy and of severe seizures, used for dramatic effect, reinforce negative perceptions. Clear messages conveyed through multiple forms of media, including social media and the Internet, along with diverse educational activities targeted to specific audiences, are necessary for successful stigma reduction and public awareness efforts. Any such efforts, local or national, should take into account the health literacy and cultural characteristics of target audiences, with different strategies developed for reaching each audience.

RECOMMENDATION 10 ***Inform Media to Improve Awareness and Eliminate Stigma***

The CDC and other Vision 20-20 and relevant organizations should support and bolster programs that provide information to journalists and to writers and producers in the entertainment industry to improve public knowledge about epilepsy and combat stigma. Efforts to collaborate and engage with the media should include the following:

- Promote more frequent, accurate, and positive story lines about and depictions of characters with epilepsy.
- Continue to encourage high-profile individuals with epilepsy (or high-profile individuals who have family members with epilepsy) to openly discuss their experiences and act as spokespeople.
- Establish partnerships with stakeholders that represent related conditions associated with stigma (e.g., mental health). Efforts could include the development of fellowships or integration of epilepsy information into existing education programs for journalists.
- Continue to work with national and local news media on breaking news about epilepsy research and human interest stories.
- Disseminate regular updates on research and medical advances to journalists and policy makers through a variety of mechanisms, including e-mail updates, listserv messages, social media, and face-to-face meetings.

RECOMMENDATION 11 ***Coordinate Public Awareness Efforts***

The Epilepsy Foundation and the CDC should lead a collaborative effort with relevant stakeholder groups, including other members of Vision 20-20, to continue to educate the public through awareness efforts, promotional events, and educational materials and should collaborate to do the following:

- Establish an advisory council of people with epilepsy and their families, media and marketing experts, private industry partners,

and health care experts to meet regularly and to inform future efforts.
- Develop shared messaging that emphasizes the common and complex nature of the epilepsies and the availability of successful seizure therapies and treatments.
- Explore the feasibility and development of an ongoing, coordinated, large-scale, multimedia, multiplatform, sustainable public awareness campaign that would start by targeting key audience segments to improve information and beliefs about the epilepsies and reduce stigma.
- Ensure that all awareness campaigns include

  - consideration of health literacy, cultural appropriateness, and demographics of target audiences (e.g., age, gender);
  - rigorous formative research and testing of materials throughout the campaign; and
  - appropriate evaluation and follow-up tools and efforts.

STRENGTHENING STAKEHOLDER COLLABORATION

Epilepsy advocacy and research organizations and government agencies are working together to create a strong, united voice for change. Efforts are being made by a number of organizations to advance research and to improve health care and human services for people with epilepsy and their families. One of the impressive collaborative efforts is the uniting of more than 20 nonprofit organizations and 3 federal agencies in the Vision 20-20 coalition, which focuses on moving the epilepsy field forward through coordinated efforts and the development of public-private partnerships. Vision 20-20 could be the driving force for developing strategies and plans for implementation of this report's research priorities and recommendations, including monitoring and evaluating progress over the short and long term. This coalition has the breadth and depth of expertise to take the public health agenda provided in this report and move it forward into action steps to improve the lives of people with epilepsy.

RECOMMENDATION 12 ***Continue and Expand Vision 20-20 Working Groups and Collaborative Partnerships***

The member organizations of Vision 20-20 should continue their collaborative endeavors and further these efforts by expanding ongoing working groups that aim to advance the field, support people with epilepsy and their families, and educate the public. They should explore partnerships with other organizations as well as with stakeholders who represent related conditions (e.g., mental health, TBI, stroke,

autism spectrum disorders). The working groups should communicate regularly, identify common goals, develop strategic plans, and, when possible, carry out joint activities. The working groups should focus on, but not limit their efforts to, the following areas:

- health policy, health reform, and advocacy;
- surveillance and epidemiologic and health services research;
- health care and community resources and services;
- education of health professionals;
- education of people with epilepsy and their families; and
- public education and awareness.

ENGAGING PEOPLE WITH EPILEPSY AND THEIR FAMILIES

Among the most persuasive advocates and educators are people with epilepsy and their family members who are willing to speak out in order to provide a more complete picture of the disorder and its impact. While many people may be willing to play such a role, training and support will help them do so more effectively. This may be the case regardless of whether they are advocating for improvements in care in general terms, working with support groups serving other families, or advocating for a higher level of service for themselves, a special school accommodation for their child, or a new medication regimen for their parent. People with epilepsy and their families also advance knowledge about epilepsy and its treatment when they participate in clinical research studies, surveys, and other investigations into ways to improve care and increase understanding of the meaning of epilepsy in individuals' lives.

RECOMMENDATION 13 ***Engage in Education, Dissemination, and Advocacy for Improved Epilepsy Care and Services***

People with epilepsy and their families should, to the extent possible, work to educate themselves and others about the epilepsies, participate in research, and be active advocates for improvements in care and services for themselves, their family members, and other people with epilepsy. Given their interests and to the extent possible, people with epilepsy and their families should

- become informed about epilepsy and actively participate in and advocate for quality health care and community services with policy makers at the local, state, and national levels;
- discuss best options for care with health care providers, including exploring referrals to epileptologists or epilepsy centers and learning about available community resources and services as needed;

- consider participation in available research and surveillance opportunities;
- engage with teachers, school officials, daycare workers, coaches, and other professionals to educate them about epilepsy and ensure that necessary services and accommodations are provided;
- talk openly, when possible, with family, friends, and colleagues about epilepsy and the impact it has on daily living and quality of life;
- actively participate in support networks to share experiences with other people with epilepsy and their families; and
- work with nonprofit organizations to raise awareness and educate others about epilepsy and participate in advocacy efforts.

PROMOTING HEALTH AND UNDERSTANDING

Much can be done to improve the lives of people with epilepsy. This report highlights numerous gaps in knowledge about and management of epilepsy and also presents opportunities to move the field forward. Improvements in surveillance methods and electronic health records hold promise for more precise information about the epilepsies, which could enable better identification of high-risk groups and better matching of treatments to individuals. There are a number of opportunities for the public health community to improve efforts to prevent epilepsy and its consequences. The growing emphasis on quality of care, as well as access and cost containment, in the U.S. health system offers an opportunity to improve the lives of this large patient group. Preparing health professionals to provide better epilepsy care, although a challenge, will help improve quality and reduce costs. Consistent delivery of accurate, clearly communicated health information can better prepare people with epilepsy and their families to cope with the disorder and its consequences. Efforts aimed at raising awareness about the epilepsies among the general public will reduce stigma and enable the participation of people with epilepsy in society to the fullest extent of their capabilities. Through collaboration and commitment over time, the bold goals outlined in the committee's recommendations can be accomplished.

1

Introduction

Our quality of life is turned upside down with each new challenge as the disorder progresses.

–Lisa Soeby

In the beginning of William's journey in life people would say seizures aren't a big deal, people live with them every day. It was tough to not get angry because it is just like cancer or other diseases that attack people's bodies. William's brain was being attacked and for many they couldn't see that or know what the early mortality rates in epilepsy patients are. I hope we could educate the public better, because the right education teaches more tolerance and sensitivity.

–Tiernae Buttars

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. Epilepsy is a spectrum of disorders—the epilepsies—with a range of severities, widely differing seizure types and causes, and varying impacts on individuals and their families. Beyond actually living with epilepsy, its seizures, and coexisting health conditions, the challenges facing the millions of people living with epilepsy include having access to high-quality health care; learning about and coordinating health care and educational, vocational, independent living, and other community services; and dealing with stigma and common public misunderstandings. Epilepsy imposes an immense burden on individuals, families, and society. Estimates[1] are that

[1]The committee used the prevalence and incidence ranges from Hirtz and colleagues (2007) and applied them to a U.S. population number of 313,000,000. (The U.S. Census population

- 2.2 million people in the United States and more than 65 million people worldwide have epilepsy;
- 150,000 new cases of epilepsy are diagnosed in the United States annually;
- 1 in 26 people in the United States will develop epilepsy at some point in their lifetime;
- children and older adults are the fastest-growing segments of the population with new cases of epilepsy;
- 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;
- the number of people with epilepsy who die of sudden unexpected death in epilepsy (SUDEP) varies from 1 of every 10,000 newly diagnosed to 9 of every 1,000 candidates for epilepsy surgery; and
- the annual direct medical care cost of epilepsy in the United States is $9.6 billion.[2] This 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).[3]

Throughout the report, the committee emphasizes the ways in which epilepsy is a spectrum disorder. Epilepsy comprises more than 25 syndromes and many types of seizures that vary in severity. 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 condition. These many complexities of the epilepsies make it a challenging health condition to convey to the general public to promote understanding

estimate for January 30, 2012, was 312,933,845; www.census.gov/main/www/popclock.html.) In the paper by Hirtz and colleagues (2007) the median for incidence, based on the four studies of all age groups, was 48 per 100,000; median prevalence rate for all age groups was 7.1 per 1,000.

[2]Data are in 2004 dollars. As discussed later in this chapter and in Chapter 4, estimates of the cost burden of epilepsy vary widely and more data are needed on the use of health care services and on indirect costs.

[3]Begley et al., 2000; Gaitatzis et al., 2004; Hauser et al., 1980; Hesdorffer et al., 2011; Hirtz et al., 2007; Thurman, 2011; Thurman et al., 2011; Tomson et al., 2008; Yoon et al., 2009.

and alleviate stigma. This report aims to provide evidence and impetus for actions that will improve the lives of people with epilepsy and their families.

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's statement of task (Box 1-1) details the request for realistic priorities and recommendations in these four areas. The committee was asked not to examine biomedical research priorities because the Epilepsy Research Benchmarks, developed in 2000, continue to be updated by the National Institute of Neurological Disorders and Stroke (NINDS) and collaborating agencies and organizations (NINDS, 2007a,b, 2010).

To accomplish its task the IOM convened the Committee on the Public Health Dimensions of the Epilepsies, comprised of 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 (Box 1-1). Vision 20-20, a coalition that includes many of the nonprofit organizations and federal agencies that sponsored the study, focuses on epilepsy research, care, services, education, and advocacy efforts.

The committee held five meetings and two public workshops during the course of its work (Appendix A). Throughout the study, many people with epilepsy and their family members and colleagues, as well as study sponsors and other organizations and individuals, provided compelling testimony to the committee about their concerns, burdens, joys, and challenges. The quotes throughout the report highlight some of the issues raised in testimony presented at the workshops and in e-mails to the committee.[4] In addition to the meetings and workshops, a comprehensive review of the scientific literature and other available evidence formed a critically important part of the committee's efforts. The committee's work also benefited from information provided by sponsoring organizations, health systems,

[4]Public testimony and other materials submitted to the committee are available by request through the National Academies' Public Access Records Office.

Box 1-1 INSTITUTE OF MEDICINE STUDY ON THE PUBLIC HEALTH DIMENSIONS OF THE EPILEPSIES: TASK AND SPONSORS

Statement of Task

An ad hoc committee will conduct a study and prepare a report to recommend priorities in public health, health care and human services, and health literacy and public awareness for the epilepsies and to propose strategies to address these priorities. The committee will focus its work on the following four topic areas:

- Public Health Surveillance, Collection, and Data Integration: Examine how existing or new surveillance systems could support a more accurate assessment of the public health burden of the epilepsies for patients and their families.
- Population and Public Health Research: Identify what research questions or areas of focus should be priorities for future epidemiological and population health studies on the epilepsies that may inform the development of interventions or preventive strategies.
- Health Policy, Health Care, and Human Services: Identify what constitutes adequate care and access to health and human services for people with epilepsy; what can be done to improve the consistency and quality of care for persons with epilepsy; what gaps and needs for improvement exist. Discussion is needed on maximizing community inclusion and personal outcomes for persons with epilepsies (e.g., changes in public health and health services policies and practices or community- and family-based support programs).
- Patient, Provider, and Public Education: Define what needs exist to improve the education and training of health and other professionals who treat or support persons with epilepsy. Additionally, explore how public education and awareness campaigns could best be used to increase patient and public literacy, reduce stigma, and improve community support and participation for people with epilepsy.

professional organizations, and others on specific topics (e.g., health education programs, health services use). Underpinning all its work was the committee's desire to set forth practical, action-oriented goals to improve the health and well-being of people with epilepsy and their families.

This report provides the committee's findings, research priorities, and recommendations and documents the evidence base. The report was written for a broad audience, including people with epilepsy; family members; health care and human services providers; local, state, and national policy makers; researchers; and foundations and nonprofit organizations.

Organization of the Report

The report covers the breadth of the statement of task. The current inadequacy of surveillance data on the epilepsies, methodologic consider-

Recommendations should be made for potential and realistic solutions and should, to the extent possible, prioritize the needs to be addressed taking into account the relative urgency of the identified needs, feasibility of implementing solutions, and considerations of time and cost. The recommendations should have a domestic focus, yet can identify major international issues. The committee should not focus on biomedical research priorities, such as those included in the 2007 Epilepsy Research Benchmarks so as to not duplicate this existing effort within the epilepsy research community to identify and monitor biomedical research needs.

Sponsors

Department of Health and Human Services sponsors: Administration on Developmental Disabilities, Center for Devices and Radiological Health (Food and Drug Administration [FDA]), Center for Drug Evaluation and Research (FDA), Eunice Kennedy Shriver National Institute of Child Health and Human Development (National Institutes of Health [NIH]), National Center for Chronic Disease Prevention and Health Promotion (Centers for Disease Control and Prevention [CDC]), National Center on Birth Defects and Developmental Disabilities (CDC), National Institute of Mental Health (NIH), National Institute of Neurological Disorders and Stroke (NIH), National Institute on Aging (NIH), Office of the Assistant Secretary for Health, Office of the Assistant Secretary for Planning and Evaluation, and Office on Women's Health

Vision 20-20 nonprofit organization sponsors: American Epilepsy Society, Citizens United for Research in Epilepsy, Dravet.org, Epilepsy Foundation, Epilepsy Therapy Project, Finding A Cure for Epilepsy and Seizures, Hemispherectomy Foundation, International League Against Epilepsy, National Association of Epilepsy Centers, Preventing Teen Tragedy, Rasmussen's Encephalitis Children's Project, and Tuberous Sclerosis Alliance

ations, and potential data sources that could be used to build the knowledge base so as to better focus future efforts in health policy, research, and public health are discussed in Chapter 2. Chapter 3 looks at the epidemiologic research with a focus on risk factors, comorbidities, and outcomes of the epilepsies and the corresponding prevention strategies and research needs. Chapter 4 examines health care for people with epilepsy and highlights the actions needed to improve the quality, access, and value of care. Improving quality of care will necessitate enhancing the education and training of the range of health professionals involved; this topic is covered in Chapter 5. Because epilepsy can produce challenges that limit quality of life, the committee focuses on community resources and supporting human services and makes recommendations for improving quality of life in Chapter 6. For people with epilepsy and their family members, being informed about epilepsy is critically important, and opportunities for improving these educational efforts are explored in Chapter 7. Information needs

are then broadened in Chapter 8 to look at ways of raising awareness and overcoming the stigma and misperceptions often associated with epilepsy by communicating clearly with the public. Based on the evidence, findings, and conclusions discussed in the preceding chapters, the report concludes with the committee's research priorities and recommendations in Chapter 9. In reading the report it is important to note that the concluding chapter draws together the evidence presented throughout the report and its common themes (see later discussion in this chapter) and puts forth the committee's call for action from a wide range of government, nonprofit, community, and health professional organizations to improve the lives of people with epilepsy and their families.

To begin the report, this chapter provides an overview of epilepsy—a challenging task, given the complexity of the disorder and its varied impacts. The chapter begins with details on the extent and costs of epilepsy followed by an overview that discusses definitions and terminology and reviews types of seizures and epilepsy syndromes. A short synopsis of health care, quality of life, and education needs is followed by an overview of current biomedical research efforts and public health responses to epilepsy. The chapter ends by identifying several of the report's cross-cutting themes.

EPILEPSY IS A FREQUENTLY OCCURRING AND COSTLY NEUROLOGICAL DISORDER

Incidence and Prevalence in the United States

Epilepsy is the fourth most common neurological disorder in the United States after migraine, stroke, and Alzheimer's disease (Hirtz et al., 2007). For many neurological disorders (such as Parkinson's disease and Alzheimer's disease), the number of new cases (incidence) is highest in older adults, while others (such as autism spectrum disorders and cerebral palsy) may be congenital or appear in early childhood (Table 1-1). For the epilepsies, the incidence is bimodal—highest in both young children and older adults (Figure 1-1a), although epilepsy may occur at any point in the life span, with the total number of people in the population who have epilepsy (prevalence) increasing with age (Figure 1-1b).

An estimated 1 in 100 people in the United States has had a single unprovoked seizure or has been diagnosed with epilepsy (NINDS, 2011c). It remains challenging to determine the total number of people with epilepsy in the United States and, in particular, the extent of the disorder in various subpopulations (e.g., by age, gender, race/ethnicity, socioeconomic status, geography). The 2.2 million prevalence estimate is most accurately viewed as approximating a midpoint in a wide potential range of 1.3 million to 2.8 million people with epilepsy (Hirtz et al., 2007; see also footnote 1). This

TABLE 1-1
Prevalence and Incidence of Common Neurological Diseases and Disorders

Disease/Disorder	Estimated U.S. Prevalence (total number of cases)	Estimated Annual U.S. Incidence (number of new cases per year)	Age(s) of Peak Incidence
Migraine	35,461,000	—	—
Stroke	2,956,000	541,000	Older adults
Alzheimer's disease	2,459,000	468,000	Older adults
Epilepsy[a]	2,200,000	150,000	Children and older adults
Autism spectrum disorders	500,000 individuals younger than 21 years	—	Children
Parkinson's disease	349,000	59,000	70 years and older
Multiple sclerosis	266,000	12,000	30 years
Cerebral palsy	207,000	—	First year of life

NOTES: The disorders listed in the table were selected by the authors of the Hirtz and colleagues (2007) study because they are neurological disorders across the life span that cause substantial morbidity and mortality.

[a]The epilepsy estimates are based on the calculations described in footnote 1; Hirtz and colleagues (2007) estimated 2,098,000 for epilepsy prevalence and 142,000 for incidence. Current estimates were not calculated for the other conditions since several are based on subpopulations (e.g., adults age 65 and older), and up-to-date general subpopulation denominators were not available.

SOURCE: Adapted from Hirtz et al., 2007. Reprinted with permission from Wolters Kluwer Health.

rather high degree of uncertainty exists because the population-based assessments of epilepsy prevalence are outdated and do not reflect the current size and diversity of the U.S. population (Chapters 2 and 3).

Cost of the Epilepsies in the United States

Epilepsy is a costly disorder in terms of its impact on individuals and their families, as well as on society. For example, seizures and seizure medications may affect cognitive ability—a concern for people at all ages, including young children whose brains and cognitive functions are still developing. For young and middle-aged adults, epilepsy can impact the ability to live and function independently, drive to and from school and work, maintain employment, have children, and participate in social life. For older adults, epilepsy may contribute to the health burden of other neurological disorders, such as stroke or dementia, and may hinder safety and independent living. These limitations can pose considerable economic, social, and emotional burdens on individuals with epilepsy and their families.

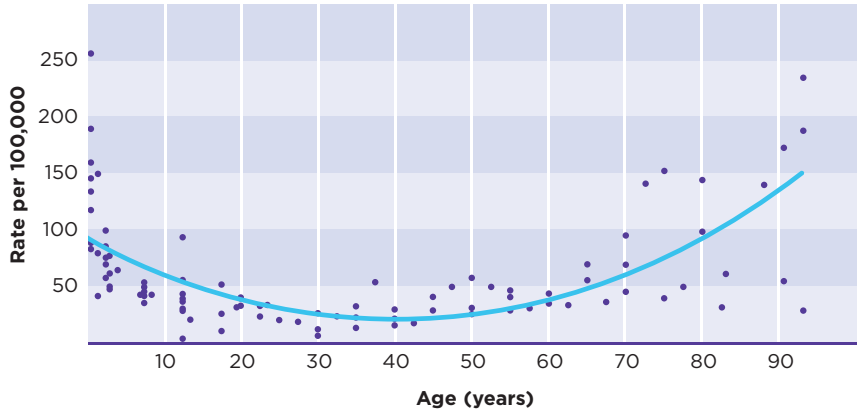

FIGURE 1-1a
Incidence of epilepsy by age—composite of 12 studies in developed countries, 1988–2005.

SOURCE: Thurman, 2011.

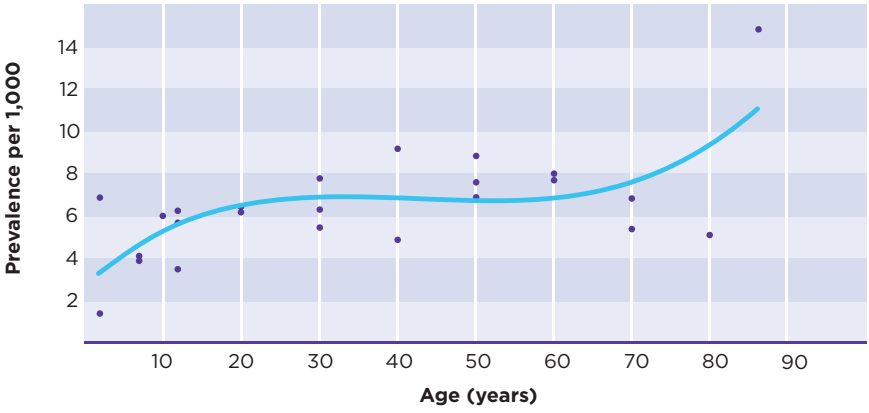

FIGURE 1-1b
Prevalence of epilepsy by age—composite of selected U.S. studies, 1978-2005.

SOURCE: Thurman, 2011.

For society, the cost burden of epilepsy is a sum of direct health care costs (e.g., hospitalizations, health care visits), direct nonmedical costs (e.g., informal care, community services), and indirect costs due to lost productivity from unemployment, underemployment, and premature mortality. Indirect costs—the social costs resulting from effects on employment, productivity, and independent living—are considerably higher than direct medical costs for many types of epilepsy. Estimates of the annual economic burden of epilepsy in the United States range from $9.6 billion to $12.5 billion[5] (Begley et al., 2000; Yoon et al., 2009). A significant percentage of the direct health costs of epilepsy is associated with the more severe forms of epilepsy and the unresponsiveness of some types of epilepsy to medications or other treatments (Begley et al., 2000).

Global Burden of Epilepsy

Epilepsy is estimated to affect more than 65 million people worldwide, with more than 80 percent of people with epilepsy living in developing countries (Ngugi et al., 2010; Thurman et al., 2011). This disproportionate burden is reflected in prevalence estimates that are at least twice as high in developing countries compared to developed countries (Ngugi et al., 2010). These markedly higher rates may be explained in part by larger numbers of cases caused by specific infectious diseases endemic in some developing nations (Ngugi et al., 2010). Further, as shown in Table 1-2, in terms of impact on disability and premature mortality, epilepsy ranks fifth among mental health, neurological, and substance-use disorders in low- and middle-income countries (Collins et al., 2011).

Although data are scant and developed using varying methodologies (Leonardi and Ustun, 2002), a number of consistently identified barriers to healthy living confront people with epilepsy globally, including inadequate infrastructure (e.g., health care services and workforce, rehabilitation programs, social supports), poor access to medications and other treatments, limited public knowledge and awareness, and stigma (Dua et al., 2006).

Generally, the availability of diagnostic services and community services for people with epilepsy varies, with lower-income countries having fewer services (Dua et al., 2006). The "treatment gap," or the difference between the number of people who need treatment for epilepsy and the number who receive it, is significant. While the treatment gap is less than 10 percent in many high-income countries, it rises to more than 50 percent in middle-income countries and more than 75 percent in low-income countries (Meyer et al., 2010). Furthermore, variations are seen within countries, with rural

[5]The lower estimate is in 2004 dollars and is an estimate of direct costs (Yoon et al., 2009). The higher estimate is in 1995 dollars, 85 percent of which is attributable to indirect costs (Begley et al., 2000).

TABLE 1-2
Global Burden of Mental Health, Neurological, and Substance-Use (MNS) Disorders[a]

	Worldwide		High-Income Countries[b]		Low- and Middle-Income Countries	
Rank No.	Cause	DALYs[c] (millions)	Cause	DALYs (millions)	Cause	DALYs (millions)
1	Unipolar depressive disorders	65.5	Unipolar depressive disorders	10.0	Unipolar depressive disorders	55.5
2	Alcohol-use disorders	23.7	Alzheimer's and other dementias	4.4	Alcohol-use disorders	19.5
3	Schizophrenia	16.8	Alcohol-use disorders	4.2	Schizophrenia	15.2
4	Bipolar affective disorder	14.4	Drug-use disorders	1.9	Bipolar affective disorder	12.9
5	Alzheimer's and other dementias	11.2	Schizophrenia	1.6	Epilepsy	7.3
6	Drug-use disorders	8.4	Bipolar affective disorder	1.5	Alzheimer's and other dementias	6.8
7	Epilepsy	7.9	Migraine	1.4	Drug-use disorders	6.5
8	Migraine	7.8	Panic disorder	0.8	Migraine	6.3
9	Panic disorder	7.0	Insomnia (primary)	0.8	Panic disorder	6.2
10	Obsessive-compulsive disorder	5.1	Parkinson's disease	0.7	Obsessive-compulsive disorder	4.5
11	Insomnia (primary)	3.6	Obsessive-compulsive disorder	0.6	Posttraumatic stress disorder	3.0
12	Posttraumatic stress disorder	3.5	Epilepsy	0.5	Insomnia (primary)	2.9
13	Parkinson's disease	1.7	Posttraumatic stress disorder	0.5	Multiple sclerosis	1.2
14	Multiple sclerosis	1.5	Multiple sclerosis	0.3	Parkinson's disease	1.0

[a]Examples of MNS disorders under the purview of the Grand Challenges in Global Mental Health initiative.

[b]World Bank criteria for income (2009 gross national income per capita): low income is US$995 equivalent or less; middle income is $996-$12,195; high income is $12,196 or more.

[c]A disability-adjusted life-year (DALY) is a unit for measuring the amount of health lost because of a disease or injury. It is calculated as the present value of the future years of disability-free life that are lost as a result of the premature deaths or disability occurring in a particular year.

SOURCE: Collins et al., 2011. Reprinted with permission from Macmillian Publishers, Ltd. *Nature:* http://www.nature.com/nature/index.html.

areas having a wider treatment gap than urban ones, which likely reflects some combination of inadequate access to services; stigma, negative beliefs, and discriminatory attitudes about epilepsy; and low health literacy (Ngugi et al., 2010). However, as described further below, stigma is universal: "[E]verywhere in the world it is a hidden disease" (de Boer, 2010, p. 631).

DEFINING THE EPILEPSIES

> *While most people only see the seizures themselves, there is far more to epilepsy. Being proactive in treatment means not only taking daily medication, but also participating in activities, talking to doctors or therapists as necessary, actively participating in school, and thriving at work.*
>
> –Elizabeth Musick

The occurrence of two or more unprovoked seizures separated by at least 24 hours is the broad operational definition of epilepsy (ILAE, 1993), which the committee uses for the purposes of this report. Seizures[6] are, in essence, symptoms of epilepsy, and epilepsy is the disorder. However, the details are much more complex.[7] Seizures differ from person to person with respect to their cause and severity, the areas of the brain involved, the location(s) and functions of the body affected, the effectiveness of medications and other treatments, and many other factors. These large and significant differences are why epilepsy, as noted, is understood as a spectrum of disorders—the epilepsies. More than 25 epilepsy syndromes and other epilepsy disorders have been delineated (Berg et al., 2010). While epilepsy is a chronic disorder, some people with epilepsy, particularly children, go into remission (Berg et al., 2001; Callaghan et al., 2007; Choi et al., 2011; Sillanpää and Schmidt, 2006).

Individuals with epilepsy are at risk not only for seizures, but also for a myriad of comorbid health conditions (i.e., conditions that occur in persons with epilepsy more than would be expected by chance; Chapter 3). Often the comorbidities that accompany epilepsy outweigh the burden of the seizures themselves. Common comorbidities that occur in epilepsy include cognitive dysfunction, such as memory, attention, or concentration problems; mental health conditions, such as depression or anxiety; and somatic comorbidities, such as sleep disorders, migraines, or cardiovascular disease. Other health problems can occur as a result of ongoing seizures, the cause of the epilepsy, or problems associated with the treatment, such

[6]An epilepsy seizure has been defined as a "transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain" (Fisher et al., 2005, p. 470).

[7]This report does not provide an in-depth clinical description of the epilepsies; resources such as Ropper and Samuels (2009) and Bazil and Pedley (2009) can be consulted for additional information.

as fractures and other injuries, osteoporosis, reproductive problems, and even death. Several disorders are causally related to developing epilepsy. These include traumatic brain injury, brain tumor, stroke, central nervous system infection, autism spectrum disorders, Alzheimer's disease, and genetic disorders (such as Rett syndrome and tuberous sclerosis complex, among others). Further, epilepsy is associated with substantially higher rates of mortality than experienced in the population as a whole (Chapter 3). Goals for epilepsy efforts focus on preventing seizures in people at risk, controlling seizures in those with epilepsy, eliminating side effects of treatments, and helping people with epilepsy and their families achieve a high quality of life.

Not all seizures or seizure-like events are epilepsy (Figure 1-2). One of the challenges for neurologists and other health care providers is to determine whether their patient is having seizures because of electrical activity in the brain and, if so, the seizures' type and cause. For some seizures, such as febrile seizures, the cause and treatment may be relatively straightforward (AAP Subcommittee on Febrile Seizures, 2011), although even a single seizure can have health and quality of life implications. Many medical problems including migraines, cardiac problems, or sleep disorders can give rise to events that appear similar to seizures. These seizure-like events, including those with a psychological basis, are not caused by electrical disturbances in the brain, and identifying the cause and determining appropriate treatments may be challenging (Binder and Salinsky, 2007; Devinsky et al., 2011).

TERMINOLOGY, STIGMA, MISPERCEPTIONS, AND CULTURAL BELIEFS

A major 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 unpredictable nature of seizures, the feelings of helplessness of those who witness them, and the centuries of misperceptions and misinformation about epilepsy have resulted in people with epilepsy being stigmatized and isolated. Baker and colleagues (2008), for example, found that 36 percent of students with epilepsy said that they had kept their epilepsy a secret, because they did not want to be treated differently (23 percent of their parents also did not disclose the diagnosis because they did not want their son or daughter to face the potential stigma). This type of internalized stigma (i.e., "felt" stigma) can reduce quality of life even when seizures are well controlled by medications or other treatments. In a history of epilepsy, Eadie and Bladin (2001) wrote, "It can be safely said that epilepsy has been one of the least understood and most maligned of medical conditions" (p. 230).

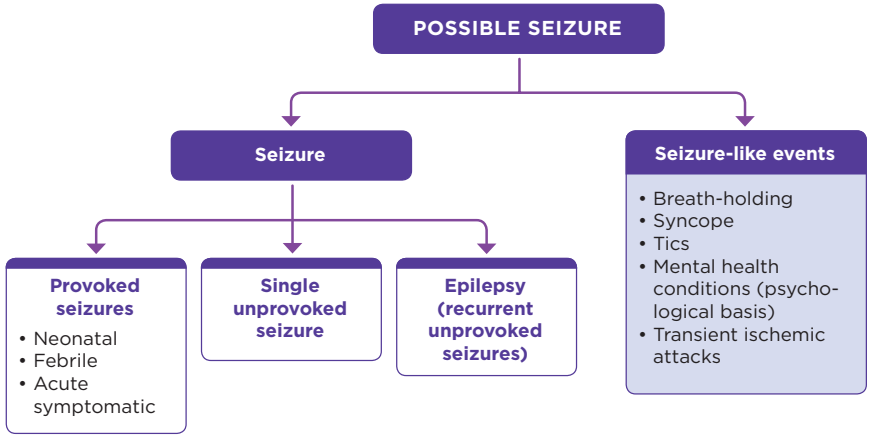

FIGURE 1-2
Seizures and seizure-like events.

NOTES:

- Neonatal seizures are seizures that occur in infants ≤ 4 weeks old (ILAE, 1993). While epilepsy can begin in the neonatal period, neonatal seizures are frequently reactive to an acute injury and often do not persist beyond a few days or weeks (Glass et al., 2011; Mizrahi and Clancy, 2000).
- Febrile seizures are seizures "occurring in childhood after age 1 month, associated with a febrile illness not caused by an infection of the CNS [central nervous system], without previous neonatal seizures or a previous unprovoked seizure, and not meeting criteria for other acute symptomatic seizures" (ILAE, 1993, p. 593).
- Acute symptomatic seizures are seizures "occurring in close temporal association with an acute systemic, metabolic, or toxic insult or in association with an acute CNS insult (infection, stroke, cranial trauma, intracerebral hemorrhage, or acute alcohol intoxication or withdrawal)" (ILAE, 1993, p. 594).
- Single unprovoked seizures include a single cluster occurring within a 24-hour period or a single episode of status epilepticus (ILAE, 1993).
- Seizure-like events with a psychological basis are "events resembling epileptic seizures that are not caused by paroxysmal neuronal discharges or other physiologic problems, and are thought to be of psychological origin" (Salinsky et al., 2011, p. 945).

Epilepsy was recognized as early as circa 1050 B.C.E. in Babylon, and Hippocratic writings talk about epilepsy as a disorder of the brain as early as circa 400 B.C.E. (Eadie and Bladin, 2001; Epilepsy.com, 2011c; Reynolds and Kinnier Wilson, 2008; Temkin, 1971). Throughout the centuries, associations of seizures with mental health conditions, witchcraft, and demonic or divine possession have resulted in terminology with negative and sensationalized connotations and led to cultural and societal beliefs, perceptions, and stereotypes about epilepsy that can be difficult to modify. For example, although depictions in the movies of characters with epilepsy are becoming more realistic, examples of characters with seizures being portrayed as violent or dangerous still persist, as do inaccurate and misleading depictions in print media (Baxendale, 2003; Krauss et al., 2000).

Some cultural beliefs include misperceptions that the person with epilepsy is being punished for sins, has a lack of spiritual faith, is taking illegal drugs, or is possessed by spirits (Sirven et al., 2005; Szaflarski et al., 2006). 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 (particularly connected with having a seizure in public), and discrimination. Although efforts are being made to correct these misconceptions and to better inform people about the epilepsies, doing so remains a challenge (Chapter 8). Awareness and sensitivity to individual and cultural beliefs about epilepsy and about medicine and health care (including traditional healing techniques in some cultures) are key considerations for efficient and effective interactions between health professionals and individuals with epilepsy.

Epilepsy-related terminology is complex. Historically, terms to describe the disorder have included "the sacred disease" and "falling sickness," and, until recently, seizures have been termed "fits" and "spells." The committee considered the terminology to be used throughout this report carefully. As noted above, epilepsy is a spectrum of disorders—ranging from severe, life-threatening, and disabling disorders to ones that are much more benign and sometimes transient. Therefore, the term "epilepsies" is more descriptive of the spectrum. The plural use of the term, however, can be cumbersome as in "people with the epilepsies." In this report, for the sake of clarity, the committee generally uses the singular "epilepsy," except when it is important to remind readers of the considerable spectrum of disability that the epilepsies represent. The report does not use the term "seizure disorders" because, as discussed above, there are a number of conditions that result in seizures that are not epilepsy.

The epilepsy field has moved away from the use of the term "epileptics" and toward the phrase "people with epilepsy," just as other general terms such as "the disabled," "the elderly," and "the homeless" have been replaced with the phrases "people with disabilities," "older adults," and "homeless individuals." Because the term "epileptic" has a pejorative connotation, the committee believes it should be discontinued. To paraphrase a 16-year-old with epilepsy, "Epilepsy is what I have, not who I am" (Clark, 2011). Throughout the report the committee suggests using more precise—and less negative terms—such as "seizure medications" (to replace "anti-epileptic drugs"), epilepsy seizures (to replace "epileptic seizures"), and "seizure-like events with a psychological basis" (rather than psychogenic, non-epileptic seizures).

OVERVIEW OF EPILEPSY

Types of Seizures and Syndromes

Although much remains to be learned about the neuroscience of the epilepsies and the causes of specific types of epilepsy, generally seizures are caused by excessive and hypersynchronized neuron discharges in the brain (McNamara, 1994; Pitkanen and Lukasiuk, 2011). These discharges can involve widespread areas of the brain simultaneously or be focused in one specific area. The effects of seizures on a person's health and well-being depend on the location and extent of the nerve cells involved; as a result, seizures can range from mild (such as a momentary loss of awareness) to severe (such as body convulsions).

Defining and categorizing the multiple types of epilepsy can be difficult. In 1964, the International League Against Epilepsy (ILAE) developed a classification system for epilepsy seizures and syndromes that continues to be updated (Arnautova and Nesmeianova, 1964; Berg et al., 2010). Because of the complex and disparate nature of where and to what extent the brain is affected by seizures, the epilepsies can be categorized according to multiple dimensions:

- Seizure type—Seizures are classified into two major categories: (1) focal seizures that originate in a network of neurons limited to one hemisphere of the brain and (2) generalized seizures that originate in a network of neurons that is distributed to both brain hemispheres (Berg et al., 2010). Seizures also can be categorized as of unknown type. Box 1-2 provides an overview of seizure types.
- Syndromes—Berg and colleagues (2010) recently defined a syndrome as "a complex of clinical features, signs, and symptoms that together define a distinctive, recognizable clinical disorder" (p. 681). Often, a syndrome is characterized by the typical age of onset, specific characteristics of the electroencephalogram (EEG), and seizure types. Table 1-3 provides an overview of a few of the many epilepsy syndromes.

As described by Engel (2001), in addition to seizure type and syndrome, other dimensions used to characterize the epilepsies can include the specific etiology (cause), the extent of impairment, and general descriptions of the seizure(s).

Most seizures last from fractions of a second to less than a minute and end on their own without intervention. However, sometimes a seizure does not stop spontaneously. Status epilepticus is usually defined as a prolonged seizure or series of seizures without full recovery of consciousness

Box 1-2 SEIZURE TYPES

Focal seizures originate within a network of neurons limited to one hemisphere of the brain, and the signs and resulting symptoms depend on precisely where the disruptions in brain activity occur. Focal seizures may have motor, sensory, autonomic, or other symptoms (e.g., hallucinations, déjà vu). Focal seizures are often categorized as

- those without impairment of consciousness or awareness or
- those with impairment of consciousness or awareness.

Generalized seizures originate within a network of neurons that is distributed to both hemispheres of the brain and vary considerably in their clinical features, from subtle alterations in consciousness to body convulsions. Generalized seizures are categorized as the following:

- **Tonic-clonic[a] seizures**—A generalized tonic-clonic (previously called grand mal) seizure is a severe type of seizure that starts with a sudden loss of consciousness and generalized stiffening of the body (tonic phase) followed by contraction of the muscles (clonic phase).
- **Absence seizures**—Often common in childhood, absence (previously called petit mal) seizures are generally brief lapses in awareness. Some clonic motor activity may occur.
- **Myoclonic seizures**—Characterized by sudden and brief muscular contractions, myoclonic seizures may involve any group of muscles and can resemble tremors.
- **Clonic seizures**—These seizures consist of alternating successions of contractions and partial relaxations of a muscle.
- **Tonic seizures**—These brief seizures involve a sudden onset of increased muscle tone.
- **Atonic seizures**—Characterized by a sudden loss of muscle tone, atonic seizures begin suddenly and cause the individual, if standing, to fall quickly to the floor.

[a]The term *tonic* describes the prolonged muscular contraction. The term *clonic* describes the rapid alternating succession of contractions and partial relaxations of a muscle.

SOURCES: Bazil and Pedley, 2009; Berg et al., 2010; Ropper and Samuels, 2009.

in between (Bazil and Pedley, 2009). In clinical care this generally involves seizures lasting longer than 5 minutes. Status epilepticus can occur in individuals who do not have a prior history of seizures. Status epilepticus is a neurological emergency and can be fatal.

In the past two decades, awareness has been raised about high rates of SUDEP; people with epilepsy have a more than 20 times higher rate of sudden death than does the general population (Ficker et al., 1998). Little

TABLE 1-3
Examples of Epilepsy Syndromes with Differing Severities

Syndrome	Description	Disease Course
Benign rolandic epilepsy[a] (benign childhood epilepsy with centrotemporal spikes)	Infrequent seizures in children typically occurring at night, generally affecting the facial muscles, may be accompanied by tonic-clonic seizures	Average age of onset is 6 to 8 years, seizures go into remission without treatment, usually stopping by age 15 years
Childhood and juvenile absence epilepsy	Commonly involves brief (about 10 seconds) staring episodes or times of seeming to be absent	Childhood absence epilepsy has an onset between ages 4 and 10 years, and the majority of absence seizures stop by mid-adolescence. Juvenile absence epilepsy may evolve into juvenile myoclonic epilepsy, which may require lifelong treatment with medications
Juvenile myoclonic epilepsy	Involves absence seizures, myoclonic seizures, and generalized tonic-clonic seizures; often characterized by myoclonic jerks that occur when waking up	Onset usually between ages 5 and 16 years, seizures may improve after the fourth decade of life. Seizures are generally well controlled with medications
Temporal lobe epilepsy	Seizures include focal seizures with or without out impairment of consciousness, including auras	May start in childhood, but most common in adolescence or early adulthood. Varying responses to medications; however, seizures that arise from one temporal lobe respond well to surgery
Dravet syndrome	Begins with frequent febrile seizures with later myoclonic seizures; often children have poor development of language and motor skills	Genetic disorder with onset typically during the first year of life; degree of cognitive impairment may stabilize or improve slightly with age depending on the frequency of the seizures
Lennox-Gastaut syndrome	Involves multiple types of seizures including tonic and atonic seizures; children often have impaired intellectual functioning and developmental delays	Accounts for approximately 2 to 5 percent of childhood epilepsies; difficult to control with medications

[a]Also termed "rolandic epilepsy."

SOURCES: Epilepsy.com, 2011a,b,d,e,f,g; NINDS, 2011b.

is known about the causes of SUDEP, although rates are higher in people with seizures that are refractory[8] (Tomson et al., 2005; Chapter 3).

Health Care

Epilepsy is typically diagnosed by self-report of seizures (or report by family members) and the patient's medical history, since it is unusual for the health care provider to actually observe a seizure during an office visit. Whereas some seizures, such as generalized tonic-clonic seizures, are relatively easy to diagnose, other types, such as absence or focal seizures, may be more challenging. As noted above, a number of medical problems can mimic epilepsy seizures. Tests such as the EEG and magnetic resonance imaging often provide support for the diagnosis (Chapter 4). Continuous video-EEG monitoring over several days is an option that provides an opportunity to record a seizure and is typically used to confirm the diagnosis, determine seizure type, and inform decisions about whether surgery is a viable treatment option.

The major medically based approaches to seizure treatment are medications, medical devices, and surgery. Additionally, other treatments, including behavioral and dietary approaches, may be used. Epilepsy treatment is often highly effective in reducing or eliminating seizures. However, most treatments are used to suppress seizures and do not cure the disorder. In a study of newly diagnosed people with epilepsy, using both older and more recently introduced seizure medications, up to 63 percent of individuals became seizure free during treatment (Kwan and Brodie, 2000); seizures in approximately half of patients were controlled with the first seizure medication tried. When a second drug was necessary, an additional 13 percent became seizure-free. However, among those whose seizures persisted after treatment with two epilepsy medications, only an additional 4 percent controlled their seizures through subsequent medication trials. For many people with epilepsy, concerns about medications include the effectiveness of the medications in seizure control, side effects, dosing schedules, and high costs (Fisher et al., 2000b). In a community-based survey, only 68 percent of people with epilepsy were very satisfied with their current seizure medication (Fisher et al., 2000b). While relatively few individuals with epilepsy are candidates for surgery in which brain tissue involved in the origin of the seizure is removed, this is a therapy that reduces or eliminates seizures for some individuals. Medical devices are also an effective treatment option for some people with epilepsy (Chapter 4). An important consideration regarding health care for people with epilepsy is the need to

[8]Refractory epilepsy is defined as the failure to control seizures after two seizure medications (whether as monotherapies or in combination) have been appropriately chosen and used (Chapter 4) (Kwan et al., 2010).

use a whole-patient approach—not only trying to eliminate or alleviate the seizures but also treating comorbid health conditions—which will necessitate coordinated care among a number of health professionals.

Although there is wide variation in experiences, individuals with new-onset seizures are often first seen in an emergency room or by a primary care provider (Chapter 4). Depending on the availability of neurologists, the primary care provider's expertise, the type or severity of initial seizure(s), and initial findings on examination, patients may be referred to a general neurologist for further evaluation, diagnosis, and treatment. Epilepsy specialists (epileptologists[9]) provide specialty care and are generally a part of an epilepsy center, which has the expertise and facilities to provide thorough patient assessments and, if indicated, surgical and device consultations and treatment, as well as connections to other health professionals (detailed below), as needed. Clinical practice guidelines and recommendations from professional organizations suggest that when the diagnosis is in question, or seizure control is not achieved after (1) a trial of two or three appropriate seizure medications or (2) 1 year of care with a general neurologist, patients should be referred to an epileptologist or epilepsy center (Cross et al., 2006; Labiner et al., 2010). Whether and when patients actually receive such a referral vary greatly (as do other aspects of health services for epilepsy; see Appendix B). Chapter 4 emphasizes the need to ensure a more timely referral process. Some patients are not referred to an epilepsy center for surgical consultation until 15 or more years after initial diagnosis and years of living with uncontrolled seizures (Haneef et al., 2010). Currently, 166 health care facilities—located in 42 states, the District of Columbia, and Puerto Rico—identify themselves as epilepsy centers (NAEC, 2012) (see also Appendix C).

Over the continuum of care from diagnosis to treatment and management, people with epilepsy may encounter a variety of health professionals, including an array of physicians (e.g., neurologists, epileptologists, psychiatrists, neurosurgeons, primary care physicians), nurses, psychologists and counselors, pharmacists, emergency medical technicians and first responders, electroneurodiagnostic technologists, physical and occupational therapists, community health workers, and direct care workers, who play a variety of roles in their health care (Appendix D provides an overview of these roles and the relevant professional boards and organizations). To ensure that people with epilepsy and their families have access to high-quality, patient-centered, coordinated care, the health care workforce's knowledge base and skills in diagnosing, treating, supporting, referring, and gener-

[9]Neurologists with concentrated training in epilepsy are designated as epileptologists. A new subspecialty board certification in epileptology is being created by the American Board of Psychiatry and Neurology. A board-certification examination for epileptologists will be offered for the first time in 2013 (Chapter 5).

ally working with people with epilepsy need to be enhanced. As discussed in Chapter 5, health professionals need current knowledge about many aspects of the epilepsies: seizure recognition and diagnosis; prevention strategies and treatment options; associated comorbidities, risks, and safety concerns; necessary social services; psychosocial and quality-of-life factors; and countering stigma. The specific types and depth of knowledge required vary across professions, depending on the roles, responsibilities, and scope of practice of the professionals and the specific settings in which they work.

Quality of Life and Community Services

Living with epilepsy is about seizures but also much more. Beyond the seizures, comorbid health conditions and epilepsy-related limitations can have an impact on many aspects of health and quality of life. Living with epilepsy, particularly refractory epilepsy, can involve challenges in school, uncertainties about social and employment situations, limitations on driving, and questions about independent living.

In a U.S. community-based survey that received responses primarily from adults with epilepsy, respondents noted that the major problems they experienced due to having epilepsy included limitations on daily activities, stigma, family concerns, and fear of the seizures (Fisher et al., 2000a). Survey respondents had median household incomes less than the general population, and unemployment among people with epilepsy who were able to work was five times higher than the national rate at the time. Side effects of seizure medications were a problem for many; the most common concerns noted were cognitive problems and impacts on energy level, school performance, motor skills coordination, having children, and sexual function (Fisher et al., 2000b). Similarly, in focus groups of people with epilepsy in South Carolina, many participants said they had to change life plans due to having epilepsy (Sample et al., 2006). These and similar surveys reinforce well-documented challenges for many people with epilepsy that extend beyond medical care. The need to treat the whole person and family often requires a network of professionals and agencies across a variety of health care and community settings (Chapters 4 and 6).

Educating People with Epilepsy and Their Families

Much is being done and more is needed to educate people with epilepsy and their families about the disorder, the range of treatment options, and the array of community services that might be helpful to achieve optimal self-management[10] (Chapter 7). Access to information about topics such as

[10]Self-management for epilepsy includes the information and resources that people with epilepsy and their families need to develop skills and behaviors that enable them to actively

diagnosis, prognosis, treatment, strategies for injury prevention and healthy living, employment rights and protections, and self-management skills can increase the individual's (and family's) sense of empowerment, promote adaptation to the disorder, and enhance overall quality of life (Couldridge et al., 2001).

Because of the complexity of epilepsy and the varied cultural perceptions connected to the disorder, both health literacy and attention to cultural considerations are particularly relevant. Health literacy is understood as "the degree to which individuals have the capacity to obtain, communicate, process, and understand basic health information and services needed to make appropriate health decisions" (Ratzan and Parker, 2000, p. vi). Nearly 9 out of every 10 adults in the United States have limited health literacy (many have limited general literacy as well), and although limited health literacy is widespread and not specific to any sociodemographic group, it disproportionately affects certain population subgroups, including people in lower socioeconomic groups, racial/ethnic minorities, people with disabilities, and older adults (Grabois et al., 1999; Kutner et al., 2006; ODPHP, 2010). Kutner and colleagues (2006) found that only 12 percent of English-speaking U.S. adults have "proficient" health literacy skills. Ensuring that health information is conveyed in ways that are understandable and take into account cultural considerations is key to making sure that all people with epilepsy have the tools to understand and deal with their disorder and attain optimal quality of life. Health literacy is not solely attributable to the characteristics of the individual but also reflects the efforts of the health care and educational systems, and much can be done to provide information that is easily and well understood.

Biomedical Research on Epilepsy

This report comes at a time when the number of new discoveries about the brain and its associated disorders is increasing rapidly, and innovative tools and approaches continue to be developed and refined that can allow researchers to examine the mechanisms of a range of neurological disorders. As a result, improved treatments and, ultimately, preventive measures and cures may become possible. Although it is not within the purview of this report to examine the biomedical research agenda, it is important to acknowledge that recent biomedical research advances in epilepsy include improving the understanding of the mechanisms of

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participate in patient-centered care; it is "the sum total of steps taken and processes used by a person to control seizures and manage the effects of having a seizure disorder" (DiIorio, 1997, p. 214). The committee adopted the concept of "optimal self-management," recognizing that it represents a wide range of possibilities toward autonomy and independence and that what is optimal for one person may be beyond the capacity of another (Chapter 7).

epileptogenesis; identifying clinical and genetic correlations of epilepsy; exploring and refining prevention and treatment options; and improving technologies for imaging.

The NINDS, in collaboration with many professional and voluntary epilepsy organizations and stakeholders, held two Curing Epilepsy Conferences that developed and updated the Epilepsy Research Benchmarks (NINDS, 2007b, 2010). The first, held in 2000, developed benchmarks for a research agenda to cure epilepsy. A follow-up conference in 2007 demonstrated many biomedical advances toward this goal, identified critical areas needing further attention, and focused new attention on the comorbidities that complicate epilepsy. The benchmarks continue to be updated to reflect progress in epilepsy-related research (NINDS, 2010). Key areas of focus in the benchmarks, and in National Institutes of Health (NIH) research initiatives in general, are in translating basic research into practical applications and comparative effectiveness studies to identify effective interventions (NIH, 2011a,b).

The level of epilepsy research funding at the NIH in fiscal year 2011 was estimated to be $134 million (Meador et al., 2011).[11] An analysis by Meador and colleagues (2011) found that epilepsy—the third most prevalent of the six neurological diseases examined—gets less funding than the other disorders when adjusted for prevalence (comparisons ranged from 1.7 times as much funding for stroke to 61.1 times as much for amyotrophic lateral sclerosis). To date, treatment of epilepsy has been focused on suppressing seizures rather than curing the disorder. With further research it is hoped that symptomatic treatment will be replaced with curative treatment and with prevention strategies.

Mobilizing the Public Health Response to Epilepsy

A number of organizations are working on research, programs, and policies to improve health and human services for people with epilepsy and their families, as well as being active in promoting prevention, education, and awareness of epilepsy. Many of the recent public health efforts focused on epilepsy, particularly in the United States, draw from the initiatives and priorities put forth by the 1978 U.S. Commission for the Control of Epilepsy and Its Consequences (U.S. Commission for the Control of Epilepsy and Its Consequences, 1978) and the Living Well with Epilepsy conferences held in 1997 and 2003 (AES et al., 2004; CDC et al., 1997). Sponsored by the Centers for Disease Control and Prevention, the Epilepsy Foundation, the American Epilepsy Society, the National Association of Chronic Disease Directors, and the National Association of Epilepsy Centers, the Living

[11] Actual spending in fiscal year 2011 was $152 million (NIH, 2012).

Well conferences spearheaded the development of a public health agenda for the epilepsies and resulted in a set of recommendations and goals that a range of research, public policy, community service, and advocacy efforts have since pursued.

The following collaborative public health initiatives highlight coordinated efforts that are under way. Other examples are provided throughout the report of the many organizations and individuals working to prevent, treat, and cure epilepsy and its comorbidities:

- The Vision 20-20 coalition was formed in 2004 and originally brought together five nonprofit organizations and one federal agency focused on epilepsy research. Initially the organizations shared progress on their own initiatives and funding resources and explored areas for collaboration. As of January 2012, 22 organizations and 3 federal agencies are part of the coalition and work through joint meetings and subgroups to develop and promote a "common message" that can be used to support efforts in epilepsy prevention, health care, research, and public awareness (Personal communication, Margaret Jacobs, American Epilepsy Society, January 5, 2012).
- The U.S. Department of Health and Human Services has organized an Interagency Collaborative to Advance Research in Epilepsy with membership from 20 federal agencies, as well as from research and advocacy groups (NINDS, 2011a). Vision 20-20 representatives are also invited to participate in the interagency working group.
- Globally, the ILAE, the International Bureau of Epilepsy, and the World Health Organization have led efforts, including the *Global Campaign Against Epilepsy: Out of the Shadows*, to increase public awareness and education about epilepsy and eliminate the barriers and stigma often associated with it (WHO, 2011). The campaign supports public and professional education and awareness, identifies service gaps and supports demonstration projects for national and regional areas, and promotes involvement of government and public health departments to target the needs of people with epilepsy (ILAE, 2011b; WHO, 2011).
- The Pan American Health Organization (PAHO) recently endorsed a *Strategy and Plan of Action on Epilepsy* (PAHO, 2011). This resolution encourages the more than 35 member nations of PAHO to develop national programs for epilepsy. Similar efforts by European Union nations in 2011 resulted in a Written Declaration on Epilepsy that urges research, policy assessment, and equitable services relevant to epilepsy (ILAE, 2011a).

CROSS-CUTTING THEMES

Throughout this report several cross-cutting themes are highlighted by the committee:

- **Epilepsy is a common and a complex neurological disorder.** Epilepsy is not a single disorder but rather a spectrum of disorders—the epilepsies. Further, epilepsy is more than seizures and may be accompanied by a range of associated comorbid health conditions that can have significant health and quality-of-life implications. Some people with epilepsy have lives that are essentially unchanged, while others' health and well-being are severely affected, and for some people, epilepsy is fatal. Communicating this range of outcomes and meeting the spectrum of needs are major challenges faced by the epilepsy field.
- **Epilepsy often affects quality of life.** For many individuals with epilepsy and their family members, living with epilepsy means challenges in school and work, social functioning and relationship dynamics, limits on driving, and daily worries about the possibility of seizures.
- **A whole-patient perspective is needed.** Because the effects of epilepsy go beyond health concerns and seizures, a whole-patient, patient-centered perspective is needed that provides people with epilepsy, their families, and caregivers with a coordinated, individual-specific approach to health care, mental health care, educational opportunities, and community services and promotes optimal self-management and quality of life.
- **Effective treatments are available for many types of epilepsies, but timely referrals and access to those treatments fall short.** For many people with epilepsy, seizures can be effectively reduced or eliminated by medications, surgery, devices, and dietary or other therapies. However, in the United States, referrals to epileptologists and epilepsy centers for surgical consultations can take 15 years or more.
- **Data are lacking that could improve epilepsy care.** Accurate, timely data on the extent and consequences of epilepsy and comorbid conditions and on health care and community services use and outcomes are sorely needed to make improvements in epilepsy prevention; diagnosis; health care access, quality, and value; and community services.
- **Many health professionals need to be better informed about epilepsy.** Improvements in epilepsy care can be made only if the quality and quantity of education about epilepsy for health care

professionals are improved dramatically through undergraduate and graduate levels and lifelong learning programs.

- **Education efforts for people with epilepsy and their families need to be thorough and sensitive to health literacy and cultural considerations.** Across the continuum 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.
- **The stigma associated with epilepsy needs to be eliminated.** The long history of epilepsy is full of examples of discrimination and secrecy due to misinformation and lack of understanding by the general public. Since stigma can have a detrimental effect on people with epilepsy, continued and sustained efforts are needed to raise public awareness and convey what epilepsy is and what it is not, as well as the basic messages embodied in these themes.

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2

Surveillance, Measurement, and Data Collection

Existing surveillance data on epilepsy do not provide current or complete information on how this disorder affects the U.S. population. This information is critical to guide prevention and intervention efforts, service delivery programs, quality improvement efforts, and health policy. Currently epilepsy-related data are not standardized across studies, which limits the accuracy of case ascertainment and coding and hinders monitoring of health services and quality of life. In addition, epilepsy is not routinely included in major population surveys, registries, and other databases. Actions needed to provide more timely information on a number of key attributes of the epilepsies—such as incidence, prevalence, comorbidities, services utilization, and costs—include the standardization of definitions and criteria for epilepsy surveillance and research as well as the continuation and expansion of epilepsy-related data collection from a variety of sources. The increasing use of electronic health records, which can be linked across providers and payers, may facilitate the gathering of surveillance data.

Data collection is the first step toward better classification and understanding of the problems individuals with epilepsy and their families face. These data are critical to position us to make informed decisions on deploying limited resources . . . [to] improve the life of individuals and their families. . . . We are dealing with a poorly addressed public health problem, and we urge you to help us better define its many dimensions and magnitude in order to begin to offer desperately needed solutions.

–Michelle Marciniak

Public health surveillance systems provide public health agencies, health care providers, policy makers, and the general public with critically important information on the health of people in the United States. Data collected through these efforts provide better understanding of a health condition's burden (e.g., frequency, severity, impact on functioning and quality of life, health care use, cost) and risk factors for its onset, comorbidities, and outcomes. This information facilitates priority setting, program development, and evaluation decisions (IOM, 2011a; Trevathan, 2011). Surveillance for public health is defined as "the ongoing, systematic collection, analysis, interpretation, and dissemination of data regarding a health-related event for use in public health action to reduce morbidity and mortality and to improve health" (German et al., 2001); surveillance may include the collection of data from a variety of sources, including registries and disease-specific reporting systems, surveys, and administrative and clinical data sets (CDC, 2011f).[1] This chapter describes the need for more comprehensive, timely, and accurate epilepsy surveillance by

- discussing gaps in current data,
- assessing the measurement and methodological challenges of collecting data, and
- reviewing available data sources.

It also discusses how epilepsy surveillance might be improved by enhancing data collection and standardizing methods of measurement and case ascertainment.

Epilepsy surveillance data inform all of the other chapters of this report. However, current epilepsy surveillance resources and mechanisms are inadequate, and improvements are necessary to increase understanding of the epidemiologic aspects of epilepsy and to identify effective action in prevention, health care, and community services, as well as education and awareness. At present, public health researchers, policy makers, and advocates are "flying blind" due to the lack of adequate epilepsy surveillance data and infrastructure (Trevathan, 2011). While the focus of this chapter is on epilepsy surveillance and data collection in the United States, the assessment is informed by epilepsy surveillance efforts internationally as well as by surveillance systems for other health conditions in the United States.

The committee's vision for effective epilepsy surveillance involves the development of active and passive data collection systems that follow stan-

[1]As noted in the Data Collection section, data collected through these sources can also be used for epidemiologic research, including longitudinal cohort studies such as the Rochester Epidemiology Project (discussed below).

dardized methodologies to obtain valid measurement. Such systems need to be coordinated, comprehensive, accurate, and timely. In times of economic constraint, collaborative efforts may facilitate this surveillance, which will provide critical information to stakeholders at the local, state, regional, and national levels. Surveillance data can be used to achieve a range of goals, including

- guiding programs and policies aimed at prevention, treatment, and rehabilitation;
- detecting barriers in health care access and quality, such as delayed diagnosis, treatment gaps, and disparities;
- determining optimal service delivery models that are cost-effective; and
- providing a basis for further epidemiologic and health services research.

GAPS IN INFORMATION ABOUT EPILEPSY

We need factual data. This would include the incidence and severity of refractory [epilepsy], disparities in access to care, comorbidities . . . and [epilepsy's] impact financially and on quality of life for patients and providers.
–Gary Mathern

At the heart of public health surveillance are data. The information presented in Chapter 1 and throughout this report about the significant burden of the epilepsies on health and quality of life is based on data collected through a variety of surveillance data sources, such as administrative and clinical records, population-based surveys, and registries (discussed later in the chapter). To meet the informational needs of the broad epilepsy community, data collected through epilepsy surveillance systems should be able to provide timely and accurate estimates of

- incidence and prevalence[2] (Chapter 3);
- etiology (i.e., causes), risk factors, and comorbidities (Chapter 3);
- health status and quality-of-life outcomes (Chapters 3 and 6);
- health disparities (Chapter 4);
- quality of care (Chapter 4); and
- access to and utilization of health care and community services and costs (Chapters 4 and 6).

[2]Incidence is the number of new cases of a disease or disorder in a set period of time; prevalence is the number of existing cases of a disease or disorder at a given point in time.

For example, accurate and detailed surveillance data on the etiologies of, and risk factors for, epilepsy are needed in order to identify opportunities for public health efforts to prevent epilepsy from developing in the first place or to prevent a range of possible consequences. Furthermore, because the burden of the comorbidities often outweighs that of the epilepsy itself, surveillance of its comorbidities is also crucial to appropriate targeting of public health interventions. Currently, gaps in data collection prevent accurate and timely information to monitor and evaluate these basic public health dimensions of the epilepsies, one of the most common neurological disorders in the United States.

The data generated by the Rochester Epidemiology Project[3] have formed the foundation of much of the current understanding about the epilepsies in the United States. This project's contributions have been substantial, but many of the epidemiologic estimates it has generated are outdated and may not reflect the diversity of the current U.S. population. Up-to-date and representative data are needed on epilepsy trends and disparities in specific populations in order to generate actionable information that enables the public health community to target its resources for prevention and intervention in areas that will produce maximum benefit.

Obtaining a complete picture of epilepsy in the United States would require collecting many data elements (Box 2-1). Although all these elements are important—and in an ideal world would be available at the national, state, and local levels—some are more difficult to obtain than others and compromises will need to be made, given limited resources and technology. However, developing the capacity to gather many, if not all, of these data elements—using validated instruments and different data sources on representative populations and subgroups over time—will enable an informed public health response to promote health and well-being for people with epilepsy.

IMPROVING MEASUREMENT AND METHODOLOGY

Improving epilepsy surveillance will involve overcoming several challenges in measurement and methodology. Many of the data currently

[3]The Rochester Epidemiology Project (http://www.rochesterproject.org/) is a collaborative effort by health care providers in Olmsted County, Minnesota, and the surrounding area. This project links medical records across practices that may see Olmsted County residents, making the linked records available to researchers. These records include inpatient, outpatient, and emergency room visits. Records linkage-based research is ongoing in Rochester for a variety of disorders. Data on epilepsy from 1935 to 1994 have been analyzed to provide estimates of epilepsy incidence, prevalence, and cost, as well as information on etiologies, risk factors, and outcomes (e.g., Annegers et al., 1996; Begley et al., 2001; Ficker et al., 1998; Hauser et al., 1991, 1993). Additional projects undertaken include studies on status epilepticus and the genetics of the epilepsies (e.g., Hesdorffer et al., 1998; Ottman et al., 1996).

Box 2-1 EPILEPSY DATA ELEMENTS

- Age (including birth date when possible)
- Sex
- Geographic location
- Race/ethnicity
- Personal and family demographics
  - Relationship status
  - Household composition
  - Educational attainment
  - Employment status
    - –Occupation
  - Income
    - –Personal
    - –Household
- Current health status
  - General health status
  - Epilepsy-specific status
  - Current medical treatment status
    - –Surgical status
  - Disability status
  - Mortality, including sudden unexpected death in epilepsy and other epilepsy-related deaths
- Epilepsy-related
  - Age at onset
  - Seizure type and frequency
  - Epilepsy syndrome
  - Etiology
    - –Stability of underlying condition
  - Severity
- Comorbidities
  - Somatic disorders
  - Neurological disorders
  - Mental health conditions
  - Cognitive disorders
  - Infectious diseases
  - Infestations
  - Physical disabilities
  - Injuries
  - Nutritional problems
- Health insurance status
- Health care
  - Source of care
  - Type and frequency of use
  - Quality of care
  - Patient's perceptions of care quality
  - Direct costs
- Use of informal and community services
  - Type of caregiver
  - Type of community service
- Quality of life
  - Overall quality of life
  - Seizure worry
  - Emotional well-being
  - Energy-fatigue
  - Cognitive functioning
    - –Attention or concentration
    - –Memory
  - Medication effects
  - Social functioning
  - Role limitations
    - –Emotional
    - –Physical
  - Stigma
    - –Enacted
    - –Felt
  - Indirect costs

SOURCE: Adapted from Thurman et al., 2011.

collected cannot be validated, are not comparable, cannot be used to understand trends over time, are not representative of the U.S. population, and cannot be analyzed for important population subgroups. Many of these challenges are shared by clinical researchers as well, who are currently collaborating on the Common Data Elements project (described

below). The following are among the major measurement and methodological considerations that are barriers to epilepsy surveillance and research:

- a lack of standardization in case ascertainment[4] and diagnostic accuracy, such as the use of varying definitions and coding algorithms;[5]
- variations in measurement of health service use, quality, access, and costs;
- heterogeneous approaches to assessing the impact of epilepsy on health status and quality of life; and
- challenges in identifying and recruiting health care providers and people with epilepsy to participate in surveillance and research projects.

Case Ascertainment and Diagnostic Accuracy

Unlike other disorders that have definable stages, . . . we have not defined epilepsy for epidemiologic [research] in a reproducible manner.

–Frances Jensen

Determining timely and accurate incidence and prevalence estimates of epilepsy requires identifying individuals within a population who have epilepsy and determining when they developed the disorder. Although this sounds simple, it is unfortunately quite difficult. Case ascertainment and diagnostic accuracy depend on a number of factors, including standardization and validation[6] of definitions and coding of the data, as well as the strengths and limitations of the source of the data (discussed later in this chapter).

Surveillance of the epilepsies strives toward complete ascertainment of people with epilepsy. For epidemiologic studies, this is particularly important to reduce the chance of artificially increasing or decreasing the proportion of the study population with epilepsy. Under- or overestimating the number of people with epilepsy in a population can occur for many reasons. For example, if data from health care facilities are used to identify who has epilepsy, some cases will be missed because some people with epilepsy never seek medical care for their seizures (Beran et al., 1985) or cannot access

[4]Case ascertainment is the identification and inclusion of people who meet the criteria being studied.

[5]An algorithm is the combination of codes and other criteria used to identify a case.

[6]Validation involves testing and verifying the accuracy of a specific research method, such as the ability of a set of criteria to identify > 90 percent of the individuals in a population who have epilepsy.

health care because of socioeconomic or health system barriers (Szaflarski et al., 2006).

Variations in the Definition of Epilepsy

The use of varying definitions of epilepsy leads to some studies including cases that others would not, which increases the potential for under- or over-reporting epilepsy incidence and prevalence and prevents researchers from being able to compare data across sites and studies. Efforts are ongoing within the epilepsy research field to develop and use standardized definitions and algorithms for identifying epilepsy, epilepsy remission, refractory epilepsy, and active epilepsy, despite using different data sources. As described in Chapter 1, the occurrence of two or more unprovoked seizures separated by at least 24 hours is the broad operational definition of epilepsy, which was proposed by the International League Against Epilepsy (ILAE, 1993) and remains the most widely accepted. However, alternative definitions of general epilepsy and epilepsy subgroups continue to be discussed, and accurate and consistent case ascertainment depends on translating these definitions into standard data collection measures; for example, the length of time covered by the term "active" epilepsy may need to be shorter in surveys than in studies of medical records, in order to account for memory recall of survey respondents. The strengths and weaknesses of current methods of case ascertainment in a number of data sources used for epilepsy surveillance are considered later in this chapter.

Diagnostic Challenges

On the clinical level, epilepsy can be difficult to diagnose (Chapters 1 and 4) because the health care provider rarely sees the seizure occur and accurately identifying the nature of the seizure or seizure-like event involves determining whether it was due to electrical disruptions in the brain (i.e., a seizure) or other reasons and whether it was provoked (e.g., by a fever). For example, seizures suffered during alcohol withdrawal or seizure-like events with a psychological basis may incorrectly be assumed to be epilepsy and may lead to over-reporting of epilepsy cases. On the other hand, under-reporting of epilepsy may occur if the health professional does not recognize the symptoms as a seizure. Further, if seizure activity begins following a brain insult such as stroke, the focus may be on the primary diagnosis of cerebrovascular disease, and the seizures may not be diagnosed as epilepsy. Educating primary care providers and other health professionals regarding seizures and epilepsy can lead to more accurate diagnoses (Chapter 5), as can tools such as decision prompts in electronic health records (EHRs) to guide health professionals toward accurate diagnoses.

Diagnostic and Treatment Coding

Health care diagnoses and treatment decisions are coded in the patient's medical record, generally with International Classification of Disease Clinical Modification (ICD-CM) codes, for billing and follow-up purposes. Researchers use these disease- or disorder-specific diagnostic and treatment codes to identify records for individuals with specific health conditions. Using codes for case ascertainment is more cost-effective than conducting reviews of each record by hand or interviewing each individual in the study population (Jetté et al., 2010). Furthermore, the current nationwide drive to implement EHRs (discussed later in the chapter) offers unprecedented opportunities to capture, share, and analyze coded data for surveillance purposes.

Nonetheless, epilepsy is challenging to diagnose and match to the appropriate code, and variations in coding practices can lead to over- or under-reporting of epilepsy. Both the ninth revision of the coding structure (ICD-9-CM), which is currently used in the United States, and the ICD-10-CM classification, which will be implemented in 2013 (HHS, 2009), have a number of codes for different types of seizures, signs, and symptoms and a limited number of codes for epilepsy (ICD-9-CM: 345.xx; ICD-10-CM: G40.x).

Currently there are several limitations to the use of codes for surveillance purposes. First, the ICD-9-CM and ICD-10-CM versions lack specificity in the epilepsy codes with respect to etiology, which limits researchers' ability to elucidate risk factors for epilepsy and report outcomes by cause. Second, coding practices differ; for example, an epileptologist often provides more detailed and accurate information for coding as to type of epilepsy or seizure than an emergency department physician or general neurologist (Jetté et al., 2010). Third, few studies have been conducted to validate the algorithms used to identify epilepsy in different health care settings and across age groups; standardization is lacking in the codes used and in the period of "look back" to determine the incidence of epilepsy (see discussion of the data-gathering effort below). "Seizure, convulsion, epilepsy" were systematically reviewed as part of the Food and Drug Administration's (FDA's) Mini-Sentinel pilot project (discussed later in the chapter) to establish validated algorithms that can be applied in surveillance using administrative and claims data, and Kee and colleagues (2012) found that currently the validity of algorithms for identifying epilepsy in comparison to non-epilepsy seizures varies and further research is needed.

Validation studies have found that the presence of multiple occurrences of epilepsy codes—along with record of a prescribed seizure medication—improves accuracy in identifying someone with epilepsy (Holden et al., 2005a,b). Importantly, the algorithms used by Holden and colleagues required that multiple data types be linked (e.g., claims data, data from a

visit to a health professional, pharmacy data, membership data). Some studies have the time and resources to review the medical records in order to validate a subsample of the population (e.g., Parko and Thurman, 2009; Pugh et al., 2008); this enables understanding of the degree to which false positives and false negatives exist. Some studies combine information from the medical record with information from patient interviews and subject this information to review by experts to reach a consensus diagnosis (e.g., Benn et al., 2008; Berg et al., 1999; Olafsson et al., 2005). In these circumstances, cases are most often excluded due to syncope (i.e., fainting) or to seizure-like events with a psychological basis (Scheepers et al., 1998; Smith et al., 1999). For surveillance work, algorithms need to follow agreed-upon definitions and sets of codes so that searches of coded data sources will consistently retrieve cases with epilepsy.

Even given accurate coding, challenges remain for many studies because not all records are coded or complete with all required data, such as type of physician seen and race/ethnicity of the patient. Over time, as patients move from one health care provider or system to another, duplicate case counts can occur and attempts to measure incidence are compromised by the movement of patients within and between health care systems. Recently, researchers have begun using natural language processing to search the free text of the EHR in order to validate the ICD codes for specific conditions, such as pneumonia, pancreatic cancer, and psoriatic arthritis (Dublin et al., 2011; Friedlin et al., 2010; Love et al., 2011), and for other purposes, such as identifying patients who were due for recommended screening tests (Denny et al., 2012) or postoperative complications (Murff et al., 2011). One of the next steps in the validation of epilepsy codes is the use of natural language processing to determine their accuracy.

Self-Reporting Through Surveys

Researchers often use population-based surveys to collect health data. To identify individuals with epilepsy, an initial set of screening questions is generally asked, and these questions vary from survey to survey. These population surveys, such as the Behavioral Risk Factor Surveillance System (BRFSS) (discussed below), rely on self-reports of physician-diagnosed epilepsy and tend to generate considerably higher prevalence estimates than those from medical records or community-based studies. Following up on an initial identification of persons with epilepsy based on self-report, more in-depth questions and validation or review, such as medical examinations or review of medical records, help to reconcile these estimates. For example, a prevalence study in New York City produced initial rates of epilepsy similar to the BRFSS; additional information to aid case ascertainment and expert review of responses by a panel of epileptologists lowered prevalence

levels to those of other studies (Kelvin et al., 2007). Generating accurate incidence estimates from self-report population-based studies is not possible due to the difficulty of validating cases and faulty recall concerning the timing of epilepsy onset. In addition, some types of information may not be captured reliably through the self-reports of people with epilepsy and their families; for example, some studies have found that seizure frequency counts are underestimates because the majority of respondents are unaware of some seizures (Akman et al., 2009; Blum et al., 1996; Hoppe et al., 2007).

A focus is needed on identifying the screening questions that accurately determine the epilepsy status of individuals and contribute to information on overall prevalence. Recently, Brooks and colleagues (2012) validated the use of the five epilepsy-related screening questions developed by the Centers for Disease Control and Prevention (CDC) Epilepsy Group, which have been used by the BRFSS and other population-based surveys, in a sample of patients who receive care at a tertiary care center in Boston. Their findings suggest that prevalence estimates of lifetime and active epilepsy based on self-reports, while slightly higher than estimates based on medical review, are reasonably accurate and valuable for population-based studies. Further work is needed to determine whether their findings are generalizable to other populations. Because individuals may say they have a seizure disorder and not realize they have epilepsy and because communities may differ in the words used for seizures and epilepsy, as well as the extent and nature of the stigma associated with epilepsy, questions should not only follow standardized concepts and methods, but also be culturally adapted, designed using the principles of clear communication, and validated in the specific population being studied. Like other conditions with a similar prevalence, obtaining sufficient data for studying specific segments of the population (e.g., racial/ethnic minorities, age groups) is difficult because large sample sizes are needed. Further, surveys generally do not collect data on certain subpopulations such as homeless individuals or institutionalized individuals, and many do not include children.

Monitoring Health Care Quality, Access, and Direct Costs

In the last few decades, greater attention has been focused on the need to conduct surveillance of the quality, access, and value aspects of health care in order to maximize health outcomes and control costs (Chapter 4). Quality of care can be measured in several ways:

- by characteristics of health care structure (e.g., type of health care provider seen during visits by patients with epilepsy, type of health care facility where care was sought such as an epilepsy center),

- by elements of the process during a visit by the patient to a health professional (e.g., procedure or test ordered, such as video-electroencephalograph [EEG]), or
- by data on the individual's outcomes or resulting health status (e.g., seizure frequency, disability status) (Brook et al., 1996).

Collecting data on the process of care may provide the most sensitive estimates of high-quality care. Performance metrics derived from evidence-based practices can be used to assess and incentivize high-quality care. Importantly, to effect change, these metrics should be oriented to the health care provider's direct role and responsibilities (Giuffrida et al., 1999). As discussed in Chapter 4, there has been significant progress recently in developing performance metrics specific to epilepsy, such as counseling about treatment side effects or referring a patient with refractory epilepsy for surgical evaluation (Fountain et al., 2011; Pugh et al., 2011). Much work remains to implement the metrics and establish a measurement framework and consistent mechanisms for monitoring the quality of different aspects of epilepsy care. EHRs are a possible source for the collection of relevant data for measuring quality. One goal of the implementation of EHRs is to improve the quality, safety, and efficiency of care by collecting structured data that will allow efficient information exchange (CMS, 2010b; HHS, 2010a).[7]

Assessing whether people with epilepsy have adequate access to care can be measured by examining potential (e.g., having a usual source of care), realized (e.g., visits to a physician), and outcome (e.g., health status) metrics (Andersen and Aday, 1978). The presence of significant differences in access metrics helps identify health care disparities between disadvantaged individuals or population groups that differ from the general population in demographic or socioeconomic status but have comparable needs. Factors to consider in measuring access to care include health system factors (e.g., availability of health care resources and providers, accessibility and acceptability of those resources to potential patients) and personal factors (e.g., gender, age, race/ethnicity, geographic location, education, income, type of insurance coverage).

Estimates of the frequency of service use and the related costs contribute to assessments of the value of health care (Chapter 4). Capacity is needed to accurately identify and track the frequency of service use by an individual and the costs directly related to those services (e.g., physician visits, diagnostic procedures, hospital stays, prescriptions). In measuring service use, data need to be collected about the type of provider seen and

[7]Other goals include reducing health disparities, engaging patients and families in their health care, improving care coordination, and improving public health (CMS, 2010b).

the health care setting. Critically, in order to capture complete data on an individual's health care services and costs, databases need to be linked across relevant providers and health care settings. In epilepsy, this often requires obtaining data from multiple sources, since few data sources are comprehensive enough to include all relevant service types and settings.

The measurement of nonmedical direct costs, such as informal care by family members, and community service costs, such as education, training, and rehabilitation, is necessary to assess the full economic impact of the disorder. Because of the difficulty in obtaining nonmedical care cost data, some studies have not included these costs in their estimates (Begley et al., 2000), and variations in how studies have measured costs and made projections make it difficult to compare estimates across studies. In addition, epilepsy is known to be associated with mental health conditions and learning disabilities, and the costs associated with these comorbidities are not reflected in current estimates. To accurately assess the direct cost burden of the epilepsies on people with epilepsy and their families, additional work is needed to develop common methodologies that capture nonmedical direct costs in a more comprehensive, valid, and representative way.

Assessing Quality of Life and Indirect Costs

Increased emphasis on patients' perspectives about their health and health care has led to the development of tools to measure quality of life. Quality of life is a multidimensional construct that includes components of emotional well-being, cognitive functioning, and social functioning (Chapter 6). Although a gold standard for assessing overall quality of life is not available currently, a number of validated generic and epilepsy-specific instruments can be used (Solans et al., 2008).

Generic instruments, such as the Medical Outcomes Study 36-Item Short Form health survey, focus on aspects of life that are widely applicable to all people (Brazier et al., 1992; Coons et al., 2000). Data collected with these types of surveys enable comparisons between people with epilepsy, those with other diseases and disorders, and the general public that identify the burden of disease attributable to epilepsy and how it compares to other conditions. However, generic instruments may not be able to identify more subtle aspects of epilepsy's impact on quality of life (Sabaz et al., 2000). Validated epilepsy-specific instruments include the Liverpool Batteries (Baker, 1998), QOLIE-10 (Quality of Life in Epilepsy) (Cramer et al., 1996), QOLIE-31 for adults and QOLIE-AD-48 for adolescents (Cramer et al., 1998, 1999), QOLIE-89 (Devinsky et al., 1995), QOLCE (Quality of Life for Childhood Epilepsy) (Sabaz et al., 2000), the Seizure Severity Questionnaire (Cramer et al., 2002), and the Impact of Childhood Neurologic Disability Scale (Camfield et al., 2003).

Epilepsy-specific instruments assess the most important problems associated with the aspects of life directly affected by seizures and the side effects of medications taken to control them. For example, a patient-completed symptom checklist might be used to measure the impact of side effects from seizure medications. Quality-of-life instruments may also assess health state preferences (e.g., through scoring of various levels of functioning and well-being) to ensure that the perspective of the individual with epilepsy is captured (e.g., Stavem, 1998). Recent work has focused on development and validation of the Neuro-QOL instruments, which can be used for a number of neurological disorders (Nowinski et al., 2010), as well as qualitative interviews to understand the impact of epilepsy on various aspects of life (Kerr et al., 2011).

Each of these types of instruments has its own characteristics and requires careful consideration before being used to monitor quality of life in surveillance systems. Generally, surveys and questionnaires are the primary sources of this information since the data needed to assess quality of life must come from perceptions of people with epilepsy or from family members if the individual with epilepsy is a child or is intellectually impaired. With the variety of validated instruments that are available, standardizing the approach and frequent use of a common instrument will help generate comparable data on the impact of epilepsy on individuals.

The measurement of indirect costs associated with productivity losses reflects the full impact of epilepsy in economic terms. A few estimates of these costs have been calculated by estimating the lost productivity of people with epilepsy due to premature morbidity and mortality. Other dimensions of indirect costs, such as those associated with pain and suffering or those due to lost productivity of family members who care for an individual with epilepsy, have not been addressed. Studies that have examined the indirect costs of epilepsy find that they generally exceed direct costs by a significant margin (Begley et al., 2000; Strzelczyk et al., 2008). To accurately assess the full burden of epilepsy on people who have the disorder and their families and on the economy of the United States, additional work is needed to develop common methodologies that predict indirect costs in a comprehensive, valid, and representative way.

Participation in Surveillance and Research

Lack of participation by people with epilepsy and their health care providers in surveillance and research efforts can be a challenge to researchers. The low scientific and health literacy of the general U.S. population may lead to potential participants being unaware of the reasons why they should participate (IOM, 2011b; Macleish, 2011). Reporting information and responding to surveys can be time-consuming, and accurate, complete

reporting may be difficult for people with cognitive and memory impairments. Further, people with epilepsy may not want to openly discuss their condition out of fear of repercussions due to stigma (Jacoby, 2002).

To maximize participation in surveillance and research and to help ensure that research has valid results,

- the burden on participants should be minimized;
- participants should be informed of the value of their participation and the ways their data will be used;
- any relevant HIPAA[8] or privacy considerations should be communicated to participants, who should also be informed that their data will be de-identified; and
- research instruments should follow the principles of clear communication and be culturally appropriate.

Further, recruitment strategies should be evaluated to ensure that requests for participation are sufficiently disseminated to target audiences. Additional research questions include identifying specific subpopulations where response rates are low, determining the impact of this on the bias of the research, and assessing the degree to which improved recruitment of those populations eliminates this bias.

Next Steps

To overcome the paucity of surveillance data and use the data to improve the lives of people with epilepsy, expanded data collection efforts must use consistent methodologies. Currently the National Institute of Neurological Disorders and Stroke (NINDS) is leading a collaborative effort to encourage standardized data collection in clinical research across neurological conditions, including epilepsy (Loring et al., 2011). The Common Data Elements (CDE) project aims to establish common methodologies and terminologies to enable comparable datasets across studies. Public health researchers in epilepsy should look to the CDE project for guidance as the new standards are put into place and should apply its approach to surveillance of the epilepsies.

Demonstration projects that validate the use of specific definitions of epilepsy and criteria for case ascertainment, health care services use, quality of life, and cost measurement are needed to help standardize the current diversity of measures used in surveillance. To ensure validity for all people with epilepsy, these projects should be conducted in a range of

[8]HIPAA, the Health Insurance Portability and Accountability Act of 1996, established national privacy standards defining protected health information.

health care settings and among diverse population groups. During times of financial constraint, collaborations among federal agencies and advocacy and professional organizations could minimize the burden of conducting these projects.

OPPORTUNITIES FOR ENHANCING SOURCES FOR DATA COLLECTION

Data elements for epilepsy surveillance (see Box 2-1 above) can come from many different sources. Each data source has strengths and limitations in providing insights into the disorder. The principal data sources for public health surveillance of the epilepsies include

- population surveys,
- registries and condition-specific reporting systems, and
- records from visits to health care providers (e.g., administrative and clinical records).

These data sources can be mined for broad, population-based surveillance purposes and can be used to inform a variety of population-based studies. Optimally, they could be linked within or across systems to generate a broad collection of data on large populations for use in improving prevention and treatment efforts. Specific research studies are included below to illustrate the types of analyses that could be conducted using these types of data if surveillance systems collected the data in a representative U.S. population.

Population Surveys

CDC-Funded Population Health Surveys

General population health surveys are rich sources of data on a wide range of health-related topics. Population health surveys capture many aspects of health conditions and individual characteristics that are well suited for understanding the public health burden of the epilepsies. In the United States, the federal agency responsible for public health surveillance is the CDC. The CDC conducts two large general population surveys, the National Health Interview Survey (NHIS) and the BRFSS surveys (Box 2-2) and also provides support for some other state and local health surveys.

These population health surveys are an important part of epilepsy surveillance and provide representative data to estimate epilepsy prevalence as well as comparative data to understand the burden of the epilepsies. Further, they provide an evidence base to track trends over time in preva-

Box 2-2 EXAMPLES OF POPULATION HEALTH SURVEYS

The Centers for Disease Control and Prevention's National Health Interview Survey (NHIS) and the Behavioral Risk Factor Surveillance System (BRFSS) surveys operate in all 50 states, the District of Columbia, Puerto Rico, the U.S. Virgin Islands, and Guam. These large surveys use representative samples of the general population and typically interview civilian participants in person or by telephone. Survey responses are aggregated into data files and statistically weighted to represent the entire reference population (e.g., nation, state, county). Survey content changes from survey to survey and from year to year but generally includes detailed respondent demographics (e.g., age, sex, race/ethnicity), socioeconomic status (e.g., income, educational attainment), health conditions, and health behaviors. BRFSS surveys also include optional modules that states can administer. Some states conduct their own health surveys that include epilepsy content, such as the California Health Interview Survey (CHIS).

Analyses from these surveys provide information about the comorbidities of a disease or disorder and a population's access to and utilization of health care services. Epidemiologic studies of epilepsy based on data collected from the NHIS, BRFSS surveys, and CHIS provide epilepsy prevalence estimates and have established a number of important and consistent relationships by comparing people with epilepsy to those in the general population without epilepsy (Elliott et al., 2008, 2009; Kobau et al., 2007, 2008; Strine et al., 2005). Analyses of some population health surveys have further differentiated people with a history of epilepsy into those with active epilepsy (one or more seizures in the past 3 months or taking medication for seizure control) and those with inactive epilepsy (no seizures in the past 3 months and not taking seizure medications) (Kobau et al., 2007, 2008). Studies based on these data have documented differences between people with and without epilepsy on numerous socioeconomic and health behavior dimensions, such as educational attainment, employment, income, quality of life, physical activity, and overweight or obesity, among others.

lence and treatment practices and in the relationship between epilepsy and a broad range of social and health-related outcomes. The sample size of these surveys tends to be large enough to compare people with and without epilepsy. As samples of the general population, results represent the entire population, including people who may not otherwise interact with the health care system, such as those without health insurance coverage.

These surveys, however, have several important limitations. First, participation is voluntary and declining, and some populations are not covered. Response rates to general population surveys, particularly those conducted by telephone, have declined significantly over the past several decades and may lead to nonresponse bias (Galea and Tracy, 2007). The increased use of cellular telephones has created challenges to adequately cover the general population with traditional landline random-digit dialing sampling methods. These surveys also generally omit other important segments of the population, such as people who are homeless or those living in institutions. This is of particular importance to epilepsy surveillance due to the grow-

ing population of older adults, who (along with children) have the highest incidence of epilepsy and who may live in nursing homes and assisted-living facilities.

Additionally, population survey data on children with epilepsy are insufficient. The CDC conducts the Youth Risk Behavior Surveillance System (YRBSS), but these surveys cover only high school students and are limited in scope as they focus on the six categories of high-risk behaviors that are leading causes of morbidity, mortality, and social problems in U.S. youth (Brener et al., 2004). As currently framed, the YRBSS is not a potential source of epilepsy data. The NHIS asks parents whether their child has had any seizures in the last 12 months (Boyle et al., 2011; CDC, 2011d) but does not ask whether these are epilepsy seizures, which limits its usefulness for epilepsy surveillance. The National Survey of Children's Health did not include epilepsy in its 2003 version (Gurney et al., 2006), but the 2007 version asked whether the parent was ever told that the child had epilepsy. Thus far, studies based on these data have looked at epilepsy only as a comorbidity of another condition, such as attention deficit hyperactivity disorder (Larson et al., 2011), or as part of the comparison group for another condition, such as autism spectrum disorders (Schieve et al., 2011).

A second limitation of population surveys is that they cannot be used for data on specific populations with epilepsy, and epilepsy-related content thus far has not been regularly included. Although population health surveys have large samples, due to the relatively low prevalence rate of epilepsy, they produce samples that are too small to identify any rate differences across specific population groups, such as differences by race/ethnicity or by severity of epilepsy. The problem of sample size is exacerbated by the infrequent inclusion of epilepsy content in these surveys. BRFSS surveys have included content about epilepsy only in a few years and in a handful of states. In 2005, 19 participating states asked at least one question about epilepsy, and some asked additional questions about recent seizures and seizure frequency, use of seizure medications, and visits to a neurologist or epilepsy specialist in the previous year (Kobau et al., 2008).

Third, these surveys rely on self-reported data and are vulnerable to error (Kobau et al., 2008). For example, as discussed above, self-reported epilepsy may overestimate the presence of epilepsy within the population due to reports of seizures that are not epilepsy seizures (Ferguson et al., 2005; Kelvin et al., 2007), and, as discussed above, they may underestimate seizure count (Akman et al., 2009; Blum et al., 1996; Hoppe et al., 2007). Additionally, epilepsy-specific content has been limited to epilepsy diagnosis, frequency of seizures in the past year, use of medication, and visits to a neurologist in the past year; these surveys are unable to ascertain epilepsy syndrome or seizure type, severity, and etiology.

Epilepsy ruins many lives, and it is essential that we identify and address the enormous treatment gaps that still exist today.

–Claude Wasterlain

Although incorporating questions about epilepsy into the BRFSS surveys has limitations, as described above, having a broader set of epilepsy-related questions asked in all participating states would generate more and improved surveillance data. One opportunity is for additional survey questions to explore the extent of treatment gaps in epilepsy. Although most research on treatment gaps in epilepsy is in developing countries (e.g., Meyer et al., 2010), BRFSS surveys and the California Health Interview Survey (CHIS) both show that a significant percentage of individuals who have had a seizure in the last 3 months report that they are not currently taking seizure medications (26 percent in CHIS in 2003 and 16 percent in 13 states from BRFSS in 2005) (Kobau et al., 2007, 2008). Additional survey questions on receiving medical care from epileptologists or at an epilepsy specialty center have been developed by CDC but not yet included in surveys. While there is speculation that people with epilepsy who receive specialty care have better outcomes than those who do not, there is currently no population-based evidence to test this hypothesis. Results from such studies could inform knowledge about the treatment gap for limited seizure medication usage in addition to the well-documented treatment gap in surgical treatment for refractory epilepsy (Engel, 2008; Haneef et al., 2010).

Additional questions on the BRFSS surveys would also increase their usefulness for epilepsy surveillance. Specifically, questions about memory and cognition problems would be useful, as would having the existing optional "anxiety and depression" module administered alongside the epilepsy questions to assess the frequency of mental health and cognitive comorbidities. This would permit an assessment of how depression may affect treatment outcomes, quality of life, and other health-related outcomes for people with epilepsy. Further, research is needed that focuses on epilepsy based on the results from the National Survey of Children's Health.

The Medical Expenditure Panel Survey

While individuals can readily and accurately report many aspects of their health and health care during an interview, the complete cost of their medical treatment is not one of them. To measure and assess medical costs among the general population, the Agency for Healthcare Research and Quality (AHRQ) conducts the Medical Expenditure Panel Survey (MEPS), which is used to evaluate current and predict future health care costs and services use (Box 2-3).

MEPS can be used to specifically examine epilepsy-related data. Over

Box 2-3 THE MEDICAL EXPENDITURE PANEL SURVEY

The Medical Expenditure Panel Survey (MEPS) is a series of household surveys of the U.S. civilian noninstitutionalized population using a sample of the previous year's National Health Interview Survey, with supplemental information from a survey of medical providers and insurance providers (AHRQ, 2011a; Cohen, 2002). MEPS's design is overlapping: each year a new panel begins whose cohort is followed for a period of 2 calendar years. It compiles data on patient demographics (including employment status), self-reported health status, use of health services, costs and payments by payer source, and health insurance status. Using a computer-assisted method, there are 5 personal interviews over 30 months, and the Agency for Healthcare Research and Quality (AHRQ) calculates costs for 2 years. De-identified data are provided by AHRQ for public use, including sufficient information about the survey's methods and measurements to enable analyses of the results that are nationally representative.

multiple years, the collected data contain enough information about people with epilepsy to calculate estimates of the use of health services, costs, and informal care received. MEPS can also be used to monitor access to care and cost of employer-based health insurance as well as health status and well-being (Cohen, 2003). For example, Halpern and colleagues (2011) used MEPS data from 2002 to 2007 to analyze how insurance status affected health care utilization and out-of-pocket costs for people with epilepsy, and Yoon and colleagues (2009) used MEPS data from 1996 to 2004 to estimate the burden of direct health care costs for epilepsy in the United States. Importantly, the longitudinal nature of MEPS, although limited to 2 years, allows a rich source of data that describes service use and cost over time, while avoiding the need for lengthy recall periods by participants. Further, similar to the BRFSS surveys and NHIS, MEPS can be used for comparisons between people with and without epilepsy.

MEPS has similar limitations as the BRFSS and NHIS, such as nonresponse and too small a sample to allow for analysis of population subgroups of people with epilepsy; also, as MEPS participants are sampled from the NHIS, they do not include people who are institutionalized or who are homeless. Nor does MEPS capture data on indirect costs of epilepsy. However, MEPS has ways to at least partially compensate for some of its shortcomings. While data collected from households are self-reported and are thus subject to error, parallel surveys of the medical providers who care for participants help to improve the accuracy of these self-reports (Cohen, 2003). In addition, unpaid care services provided by family members are obtained (Yoon et al., 2009), so direct costs of nonmedical care are included to some extent.

Future revisions of MEPS could consider increasing the follow-up time to enable analysis of individuals' patterns of care, health outcomes, and productivity. Given the chronic and recurring nature of epilepsy, this could help to identify trends in the progression of this condition over time. However, proposals to increase the time window should ensure that response rates and validity of data are not adversely affected (Cohen, 2003).

The Children's Health Study

The Children's Health Study is a new longitudinal study being planned and conducted by the National Institutes of Health (NIH), in partnership with the CDC and the Environmental Protection Agency. It aims to cover a representative, population-based sample of 100,000 children from birth until they are 21 years old and study the impact of the environment (e.g., water, diet, community influences) and genetics on their health, as well as their growth and development (NIH, 2011b,f). Data will be collected through in-person, telephone, and/or web-based interviews and questionnaires; additional data will include environmental and other samples, physical measurements, and neurological and other assessments (NIH, 2011e). The study plans to monitor the development of EHRs to determine the feasibility of including medical records in its data collection, but currently the primary mechanism will be surveys (NIH, 2011c). Epilepsy is one of the study's outcomes of interest (NIH, 2011d), and several research projects have begun to develop and validate its questionnaires and other data collection mechanisms (NIH, 2011b). Given the scope in terms of the size and length of this study, it offers a valuable opportunity for prospective data collection in a representative group of U.S. children as part of broader surveillance efforts across age groups.

Registries and Condition-Specific Reporting Systems

In recent years, registries[9] have become a common source of data that facilitate health condition-specific research. While registries vary from system to system, they share a common goal of collecting condition-specific, comprehensive incidence and related diagnostic data in a defined population. These condition-specific reporting systems may also be used to track health outcomes over time. Well-developed registries can be a valuable resource for conditions such as epilepsy that may yield relatively small samples in population surveys and other surveillance data sources.

[9]Registries are databases that contain information about people who have something in common, such as women with epilepsy who are pregnant and taking seizure medications.

Epilepsy Pregnancy Registries

> *I have been successful at responding to epilepsy treatment but I was not prepared for how my epilepsy would impact my son's life the way it has. We need to know and address the full effects of antiepileptic drugs prescribed to patients with epilepsy. These drugs impact the mother, as well as her unborn children. This must be included when we talk about the true impact of epilepsy.*
>
> –Brandy Parker

Since ethical considerations limit prospective clinical trials for studying pregnancy outcomes, pregnancy registries have become an important source of information about the impact of individual seizure medications on developing fetuses. Several types of pregnancy registries for women with epilepsy have been established, including national databases, independent academic registries, and registries sponsored by pharmaceutical companies (Box 2-4). At present, the only U.S. epilepsy-specific registry is for pregnant women with epilepsy (the North American AED[10] Pregnancy Registry). Prior to the establishment of these registries, the only information available to patients and their physicians to guide decisions on epilepsy management during pregnancy came from studies based on case reports and anecdotal experience. These studies enabled the identification of potential risks to fetal development from exposure to seizure medications, including major congenital malformations, such as heart defects, spina bifida, and cleft lip and palate, and also minor malformations such as small digits, although to a lesser extent (Anderson, 1976; Arpino et al., 2000; Holmes et al., 2001; Kaneko et al., 1999; Koch et al., 1992; Lindhout et al., 1992; Olafsson et al., 1998; Omtzigt et al., 1992; Rosa, 1991; Samrén et al., 1997, 1999). However, these studies did not have sufficient statistical power to identify whether specific seizure medications differed in their teratogenic[11] potential. The rapid increase of new seizure medications has brought urgency to the need for better understanding of the risks that these drugs pose to the developing fetus (Tomson et al., 2007).

Most of the epilepsy pregnancy registries are prospective, aiming to enroll large numbers of seizure medication-exposed pregnancies. In addition to pregnancy registries providing opportunities to study the effects of seizure medications on developing fetuses, they can also provide information on the impact of seizures during pregnancy and labor. Further, pregnancy registries can identify whether infants who are born with major congenital malformations had these malformations prenatally diagnosed or identified through prenatal screening, and they can also provide data on the number

[10]AED stands for antiepileptic drug. As described in Chapter 1, the term seizure medication is used in place of AED in this report.

[11]Teratogenic means relating to or causing malformations.

Box 2-4 EXAMPLES OF EXISTING PREGNANCY REGISTRIES

National Databases

Two notable national databases exist for tracking pregnancy outcomes: the Swedish Medical Birth Register and the Finnish Prescription Drug and National Medical Birth Registry. The Swedish Medical Birth Register is population based and collects data from prenatal maternal health records as well as maternity department records. All pregnant Swedish women attending maternity health clinics are screened for chronic disease and medication history. This information is entered into a national database. It is believed that 98 percent of all pregnant women in Sweden attend these clinics. The Finnish Prescription Drug and National Medical Birth Registry identifies all women who are prescribed seizure medications during pregnancy and cross-references these data with the Finnish National Medical Birth Registry in an effort to identify all pregnant women who take seizure medications during pregnancy.

Independent Academic Registries

The North American AED Pregnancy Registry is a prospective voluntary registry where enrollment may be recommended by a physician, and pregnant women in the United States and Canada self-enroll. The primary goal is to determine the frequency of major malformations in infants who are exposed to as many as 34 different seizure medications during pregnancy. Since its inception in 1997 and as of September 2010, this registry has enrolled more than 7,700 self-reporting subjects from the United States and Canada.

The UK Epilepsy and Pregnancy Register, established in 1996, was one of the first pregnancy registries to follow patients prospectively through their pregnancies. To capture outcomes of seizure medication-exposed pregnancies in the United Kingdom (and, since 2007, in Ireland), pregnant women with epilepsy are self-referred or are recruited for participation by their general practitioners, midwives, or other

of pregnancies that were terminated due to prenatal diagnoses or screening results. A large registry such as EUROCAT (European Concerted Action on Congenital Anomalies and Twins) can use pooled data to identify rare malformations and their association with infrequent exposures.

Pregnancy registries have several limitations. A principal weakness is that they are observational studies, not randomized controlled trials. Women are not randomly assigned to receive different seizure medications, and the selection of a particular seizure medication and its dose depends on individual environmental and genetic variables that in themselves may influence the risk of a malformation. Further, if a registry does not actively recruit participants but relies on passive, voluntary participation, it has the potential to introduce bias. For example, in the North American AED Pregnancy Registry, the majority of participants are insured, white, and have a minimum of some college education, making the captured data not representative of the U.S. population (Tomson et al., 2007). Since some

health professionals. Entry into this study requires that the pregnancy outcome not be known at the time of enrollment. The health care provider is contacted after the birth for data collection.

The largest of epilepsy pregnancy registries, the International Registry of Antiepileptic Drugs and Pregnancy (EURAP), has become an international collaboration representing 40 countries in Europe, Australia, Asia, and South America and is focused on the prospective observational study of pregnancies with seizure medications. EURAP also has a retrospective arm for those pregnancies that do not meet criteria for the prospective study. As of the end of 2011, EURAP had enrolled more than 16,900 pregnancies.

EUROCAT (European Concerted Action on Congenital Anomalies and Twins), a significantly more comprehensive but general (not epilepsy-specific) pregnancy outcome registry, gathers data from dozens of population-based registries to conduct surveillance of congenital malformations, including the impact of seizure medications taken during pregnancy. EUROCAT encompasses 43 registries from 23 countries, covering 29 percent of the birth population of Europe, amounting to 1.7 million births annually. It is a multisource registry collecting data on births as well as terminations of pregnancies following a prenatal diagnosis of congenital malformation.

Pharmaceutical Company Registries

The GlaxoSmithKline International Pregnancy Registry and the UCB, Inc., AED Pregnancy Registry have been used to monitor outcomes from lamotrigine- and levetiracetam-exposed pregnancies, respectively.

SOURCES: EURAP, 2012; EUROCAT, 2012; GlaxoSmithKline, 2012; Irish Epilepsy and Pregnancy Register, 2012; Morrow et al., 2006; North American AED Pregnancy Registry, 2012; Socialstyrelsen, 2012; Tomson et al., 2007, 2010; UCB, Inc., 2012; UK Epilepsy and Pregnancy Register, 2012.

participants have diagnoses other than epilepsy (e.g., migraine), conclusions may be confounded by the underlying maternal health condition, resulting in the impact of epilepsy and seizures during pregnancy and labor not being clearly isolated. Although control subjects are a problem in most registries, the North American AED Pregnancy Registry responds to this problem by recruiting friends and family members of enrolled women as unexposed controls (Tomson et al., 2007, 2010). Limitations of pharmaceutical company-driven seizure medication registries include small samples, lack of control groups, and the potential for bias and conflict of interest (real or perceived) in data interpretation. An important limitation is that existing registries vary in design, which makes systematic comparison of results between registries difficult. Recently, discussions have begun in an attempt to improve the standardization of data collected by several registries in order to enable pooled data comparisons (Tomson et al., 2010).

In moving forward, the North American AED Pregnancy Registry

would benefit from increasing the diversity of its participants through active recruitment and through standardization of its data elements with other major registries to allow analysis among a larger and more diverse sample. Accomplishing these goals might involve dissemination efforts to raise awareness and encourage the participation of women from demographic groups that are currently underrepresented as well as collaborative, international efforts to establish common methodologies. These are not small tasks, but pregnancy registries are currently the major source of data on the safety of seizure medications for the developing fetus. An alternative mechanism for this type of data collection may be the creation of EHR linkages of data on the mother's seizure medication use with data on the child's birth outcome, but the capacity to do this has not yet been developed.

The EpiNet Registry

A voluntary, international registry is being developed in New Zealand to collect data on people with epilepsy with the goal of using the database to help recruit participants and run large randomized clinical trials as well as prospective observational studies (Bergin and the EpiNet Study Group, 2011a; Bergin et al., 2007). The EpiNet registry, a secure web-based database, is accessible to approved investigators (i.e., neurologists with expertise and interest in epilepsy) who can input information on seizure type, epilepsy syndrome, etiology, and treatment. Bergin and colleagues (2010) conducted a pilot project in New Zealand and demonstrated that people with epilepsy can be recruited through the Internet for clinical trials. Currently a number of other countries, including Australia, Belgium, Canada, Italy, Pakistan, South Korea, and the United States, are participating in an international pilot project to evaluate the feasibility of the project's website and database (Bergin and the EpiNet Study Group, 2011b). If privacy protections are put into place and the project is able to enroll sufficient numbers of participants whose data are reported in uniform ways, this registry could be a valuable source of longitudinal data on people with epilepsy around the world.

Registries for Other Conditions

Cancer registries Registries have played an important role in national-level cancer surveillance in the United States for nearly four decades. The Surveillance, Epidemiology, and End Results (SEER) program, which is operated by the NIH's National Cancer Institute (NCI), began collecting cancer-related data in 1973 as a result of the National Cancer Act of 1971 (NCI, 2012). In 1992, the CDC's National Program of Cancer Registries (NPCR) was created through the Cancer Registries Amendment Act of 1992 to develop a national system of state-based registries (CDC, 2010b) (Box 2-5).

Box 2-5 NATIONAL CANCER REGISTRIES

The Centers for Disease Control and Prevention's National Program of Cancer Registries (NPCR) supports state-based cancer registries in 45 states, the District of Columbia, and 3 U.S. territories. Combined, these registries cover approximately 96 percent of the U.S. population and collect data such as cancer occurrence, type, extent, and location (CDC, 1999). Data are reported to each state's registry by health care facilities. Over the last decade, NPCR has worked with states to establish registries where they did not exist previously and to improve the completeness of the data collected (CDC, 2011e).

The National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program is a national database that links data from population-based cancer registries. SEER collects an array of information, including data on patient demographics, diagnosis, treatment, and outcomes. SEER includes data from 8 state registries and 12 city or regional registries within states (e.g., Los Angeles, Seattle, Puget Sound) and covers approximately 28 percent of the U.S. population (Cockburn, 2011; NCI, 2011; Warren et al., 2002). A database has also been formed that links both SEER and Medicare claims data (NCI, 2009).

In 2001, CDC's NPCR and NCI's SEER agreed to collaborate in order to form an integrated network and report national-level cancer statistics on incidence, type of cancer, stage of cancer at diagnosis, geographic location, demographics, and mortality (CDC, 2011e; Jemal et al., 2010; Wingo et al., 2003). The comparison and coordinated analysis of their data were possible, in part, because the data compiled through both programs use standards developed by the North American Association of Central Cancer Registries (NAACCR) for case ascertainment and measurement. NAACCR is a professional organization that develops and encourages the use of consensus data standards for the cancer registries' data collection and categorization, including standard definitions and codes. NAACCR annually certifies registries in the United States and Canada to ensure standardization and availability of high-quality data; all state-based cancer registries were certified in either 2010 or 2011 (NAACCR, 2010a,b, 2011, n.d.).

Data from these registries have been used for a variety of valuable research and reporting purposes, including analysis of cancer risk and treatment disparities by social factors and cancer-related outcomes over time and by group. In addition to annual cancer statistics reports produced by the CDC and the American Cancer Society (CDC, 2011e,g; Jemal et al., 2010), these registries have been used to examine cancer comorbidities, screening and prevention opportunities, treatments, outcomes, quality of care, and costs (Cockburn, 2011; Klabunde et al., 2002; Warren et al., 2002). The data have also been used to evaluate prevention programs, such as sun-exposure awareness programs and the effectiveness of screening programs in reducing rates of late-stage cancer diagnosis (Cockburn, 2011).

Despite the wealth of research that has been conducted as a result of the availability of these registries, limitations do exist. For example, SEER data are limited to patient demographics, diagnosis, initial treatment, and mortality outcome; the SEER-Medicare database is needed for studies on comorbidities, long-term treatment, or health status over time (Warren et al., 2002). Other than broad categories of initial treatment, the SEER-Medicare database is not able to capture data on services that are not covered by Medicare (e.g., long-term care), and the Medicare claims data that SEER links to do not include individuals who receive care through health maintenance organizations (HMOs). The SEER-Medicare database also does not provide adequate data on cancers that occur primarily in younger populations (e.g., leukemia, testicular cancer) (Warren et al., 2002). At the state level, challenges for registries include data inaccuracies or misclassifications (e.g., race/ethnicity), duplicate reporting and multiple diagnoses in the same patient, and reporting delays (Izquierdo and Schoenbach, 2000).

Alzheimer's disease South Carolina developed a comprehensive registry in 1988 to collect data on diagnosed cases of Alzheimer's disease and related disorders. This registry links multiple data sources—including records from hospitals, emergency departments, long-term care settings, and memory clinics—with mental health and vital records as well as Medicaid data. These data are used to track and estimate prevalence, including by specific population groups, and to plan resource allocation (University of South Carolina Arnold School of Public Health, 2010, 2011). Other states, including West Virginia (West Virginia University, 2011) and New York (New York State Department of Health, 2004), have also developed registries for Alzheimer's disease and other dementia disorders. Each of these registries has limitations. The South Carolina registry is voluntary, and there may be underreporting due to failure to capture a diagnosis of dementia in the coded data (e.g., because other health conditions were the focus of the health care visit) (Sanderson et al., 2003). The New York registry captures only data from inpatient hospital stays and nursing homes, and the quality and completeness of the coded data are unknown (New York State Department of Health, 2004, 2006). The West Virginia registry recently completed a pilot test (West Virginia University, 2011); analyses of its value and limitations should be conducted after it is implemented across the state.

Autism spectrum disorders A number of state-based registries devoted to autism spectrum disorders surveillance have been developed in recent years, including in Delaware, New Hampshire, and New Jersey. These states have passed legislation that requires reporting of autism spectrum

disorders by health professionals in order to better understand the incidence and geographic distribution of cases and to assist with planning for resource allocation (Delaware Health and Social Services, 2011; New Hampshire Department of Health and Human Services, 2011; New Jersey Department of Health and Senior Services, 2007). Evaluations of the completeness and quality of the data collected by these mandatory registries will be needed as they are developed. On a national level, the Kennedy Krieger Institute has developed the Interactive Autism Network (IAN), a voluntary online registry that includes more than 41,000 participants and collects data on family history, environment, and treatment, which may allow for exploration of potential causes and of diagnosis and treatment options (Kennedy Krieger Institute, 2011). Lee and colleagues (2010) reported that using IAN's parent-reported data was a reliable method of case ascertainment; however, the web-based registration may introduce bias in the representativeness of the population covered. In April 2011, the Mental Health Research Network announced the development of a new autism spectrum disorders registry that will include 20,000 children and adolescents from 5 health care organizations in Boston, Northern and Southern California, Oregon, Washington, and Georgia (Kaiser Permanente, 2011).

Summary The experiences of registries specific to other conditions offer some insights for surveillance of epilepsy. Standardization of data collection, including definitions and coding, is essential. To successfully achieve this goal, collaborations such as NAACCR are critical. Further, linkages across data sources, such as between registries and Medicare claims data, offer opportunities to understand cost and patterns of health service utilization, and centralized databases facilitate data compilation and processing. Successfully establishing and operating a number of these registries has depended on legislative support at the national and state levels, which provides funding and requires reporting. However, there are also limitations to these registries; for example, they may not be comprehensive, and the quality of their data may be hindered by inaccurate or incomplete coding.

The existing infrastructure of registries focused on conditions such as cancer, Alzheimer's, and autism spectrum disorders offers an opportunity to capture data on people who have one of these conditions and also have epilepsy. This could both expand available epilepsy data and offer a better understanding of the relationship between epilepsy and its comorbidities. In addition, further exploration is needed to determine the value and limitations of alternative ways to collect valid self-reported data, such as through online databases (e.g., IAN, PatientsLikeMe.com) (Wicks et al., 2012) and possibly through self-management tools (e.g., My Epilepsy Diary) (Le et al., 2011).

Data from Visits to Health Care Providers

Administrative Data

Administrative datasets are collected from medical records of health care providers and claims files of insurance companies that were generated in the course of managing, paying for, or monitoring the provision of health care services. Health encounters create claims for payment, and public and private health care providers and insurance plans collect these claims data and include them in their own administrative databases. Additionally, birth and death records serve administrative purposes by creating legal records. Common administrative data sources include national and state hospital discharge data; Medicare, Medicaid, and private insurance claims data; and vital statistics (i.e., birth and death records).

Hospital discharge data Since the 1980s the federal government has required submission of uniform data on all acute hospital inpatient discharges paid through Medicare and Medicaid (Kanaan, 2000). In 2010, a total of 48 states had systems for reporting hospital discharge data, many of which included statewide all-payer, all-patient data on inpatient hospital stays (Love et al., 2010). Recently, trends toward increasing use of outpatient care has led 32 states to collect data from ambulatory treatment centers and 30 states to include data from emergency department visits. Hospital discharge data are population based and can be used for analyses that examine patient demographics, use of codes for diagnosis and treatment, hospital service use, and total costs (Love et al., 2010). The data typically contain diagnosis, treatment, and cause-of-injury codes for each admission or visit; unique personal identifiers can be used to link admissions and visits to specific individuals for determining admission type, length of stay, acute care charges, primary and secondary procedures, sources of payment, and discharge disposition (Iezzoni, 2003).

Hospital discharge data are relatively easy to obtain from the state agencies that maintain the database. The Nationwide Inpatient Sample (NIS), maintained by AHRQ, contains a 20-percent randomly stratified sample of all discharges from U.S. community, nonfederal hospitals (AHRQ, 2011b). As the United States' largest all-payer hospital care database, the NIS collects data from about 1,000 hospitals, resulting in data on approximately 8 million hospital stays each year. Hospital discharge data can be used in combination with other data sources for a range of analyses, such as estimates of age- and race-specific hospital admission rates for people with epilepsy and of disparities in surgery (CDC, 1995; McClelland et al., 2010; Szaflarski et al., 2006).

Hospital discharge data have important limitations. Hospitalization datasets do not include actual payments to the health care facility, nor do

they collect data on the majority of pharmacy services or ambulatory care services provided outside of hospitals (Love et al., 2010), and these categories, when combined, represent a significant portion of expenditures for epilepsy care (Begley et al., 2000). Validating the data obtained from hospital discharge databases is rarely possible, and coding errors and diagnostic misclassification that result in over- or underdiagnosis are known to occur for epilepsy and other conditions (Andaluz and Zuccarello, 2009; Baaj et al., 2008; Huang et al., 2011). Even when accurately coded, the diagnoses available in such datasets provide limited clinical information and are not sufficient to determine the type of epilepsy or its severity (Kaiboriboon et al., 2011). Finally, costs of hospitalization can only be approximated by applying hospital cost-to-charge ratios to hospital charges obtained from discharge data or by applying Medicare payment rates to hospital stays (Drummond et al., 2005).

Claims data In the process of providing public (e.g., Medicare, Medicaid, Children's Health Insurance Plan) and private (e.g., Blue Cross Blue Shield, United Health, CIGNA) health insurance coverage and paying providers, fiscal intermediaries collect large quantities of data. Many of the data elements that are included in hospital discharge data also are included in claims data for every covered visit or service, including demographic information, dates of service, service type, diagnosis and treatment codes, charges, and payments.

Claims data are particularly useful because they may include information on a comprehensive set of services, including hospital, physician, and medication use, which can be linked to de-identified individuals to track cases, service use patterns, and costs over time. Because these datasets are often large and cover many people and services (Iezzoni, 2003), they can be used for studies of people with epilepsy and even, in some instances, for studies comparing incident versus prevalent cases or subgroup analyses of different demographic groups or types of epilepsy. Claims data have been used recently to study the use and cost of care for people with epilepsy, medication adherence, and the impact of adherence on health care use and costs (Davis et al., 2008; Faught et al., 2009; Griffiths et al., 1999; Ivanova et al., 2010). HMO claims data have been used to study incidence and variation in the use and cost of care by seizure type and frequency (Begley et al., 2001). Medicare data are useful for studying specific populations, such as older adults with epilepsy, and studies have been conducted using this dataset to look at costs, disparities in care, and use of seizure medications (Bond and Raehl, 2006; Christian-Herman et al., 2004; Hope et al., 2009; Pugh et al., 2010). These and other claims-based studies have been useful in identifying the major medical services that contribute to the cost of epilepsy care and analyzing how the medical cost burden is distributed

Box 2-6 EXAMPLE OF A COLLABORATIVE CLAIMS DATABASE

The Health Care Cost Institute is a recently formed partnership among Aetna, Humana, Kaiser Permanente, and UnitedHealthcare to provide data for surveillance and research on health care costs and service use. Launched in September 2011, these health systems formed a database that covers claims from 5,000 hospitals and more than 1 million health care providers from 2000 to the present; it includes 5 billion claims and $1 trillion in costs. This database will be updated on a regular basis, and the institute will conduct research on its data to identify trends in costs as well as making the data available to independent researchers.

SOURCE: Health Care Cost Institute, 2011.

across individuals. Emerging efforts such as the Health Care Cost Institute stem from the cooperation of different health systems to share claims data for improved surveillance of cost and service use trends (Box 2-6).

As valuable as these data are for surveillance and research purposes, they have important limitations. Claims data provide no information on populations lacking health insurance coverage or those who avoid care because co-pays and deductibles are too expensive. Without all-payer claims data (Box 2-7), analyses of where patients receive health care if they change their type of insurance coverage are not possible (Love et al., 2010). As with hospital data, accurate case identification is difficult for several reasons: ICD-9-CM codes are not consistently applied or sufficiently detailed, and treatment codes are complex and may be prescribed for other conditions besides epilepsy. In addition, the various methods used to identify cases and services are infrequently validated and the representativeness of the population samples for which data have been obtained has not been confirmed. Shatin and colleagues (1998) found variations in service use patterns between children with epilepsy who have Medicaid and those who have employer-based insurance and emphasized the need to look at data

Box 2-7 ALL-PAYER CLAIMS DATABASES

All-payer claims databases (APCDs) are state-based resources that aim to collect comprehensive claims data. Some states have mandated reporting while others are voluntary. One goal of the APCDs is to help standardize the reportable data elements to enable comparisons across payers. These databases provide data on a range of measures, including costs, quality of care, service use, access, and barriers to care (Love et al., 2010). Nearly two-thirds of states currently have APCDs or are evaluating their feasibility (APCD Council, 2011).

from multiple sites to ensure the representativeness of the study population. Studies to validate the identification of people with epilepsy and the services they receive are needed, as is a closer look at the representativeness of epilepsy populations for which claims data are available.

Vital statistics The U.S. Standard Certificate of Live Birth has a section for any "abnormal conditions in the newborn," which includes a line item for "seizure or serious neurologic dysfunction" (CDC, 2003b). However, this line refers to neonatal seizures, which are not generally considered to be epilepsy (ILAE, 1993). Birth certificates are not a source for data collection on the epilepsies other than as the means to capture data on major congenital malformations, which could be linked to the mother's use of seizure medications, as described in the pregnancy registries section above.

> *As a father, I had to tell the coroner what my son's cause of death was. His response made it very clear that he was not familiar with SUDEP [sudden unexpected death in epilepsy], didn't know what the term meant. When I explained what it was, he said, "Oh, we've had three or four similar cases in Boulder County in the past year." The clear implication is that SUDEP is vastly under-reported.*
>
> –Steve Wulchin

Accurate death certificates that capture data on mortality in people with epilepsy are necessary to monitor trends in the overall mortality, identify risk factors, and estimate the incidence of cases where epilepsy may have contributed to, or caused, death, including instances of SUDEP. Epilepsy must be entered somewhere on the death certificate in order to accomplish these goals (Antoniuk et al., 2001). However, Bell and colleagues (2004) examined UK death certificates and found that epilepsy was recorded for only 7 percent of the people who had epilepsy, with more frequent recording among people who had frequent seizures. Currently in the United States, death certificates include cause of death (Part I) and "significant conditions contributing to death" (Part II in the United States), but not a full medical history (CDC, 2003a). The CDC provides national mortality data to researchers, and these data can be requested by underlying cause of death, which are categorized by ICD-9 or ICD-10 codes, depending on the time frame of the study (CDC, 2011b). In the United Kingdom, Goldacre and colleagues (2010) found that the underlying cause of mortality was listed as epilepsy in less than half of cases with epilepsy on the death certificate; thus, mortality rates for epilepsy that are based on one cause of death only, and not also on "significant conditions contributing to death" (Part II), are likely to be underestimates.

Current estimates of SUDEP incidence based on death certificates are inadequate for several reasons. First, there is no specific code for SUDEP in ICD-9 or ICD-10, which may contribute to underdiagnosis and a lack of

awareness of the problem (Hitiris et al., 2007; Lathers et al., 2011b). Second, in some cases, the cause of death may be inappropriately recorded; for example, a review of death certificates with cause of death listed as status epilepticus found that nearly half of the cases were actually SUDEP (Langan et al., 2002).[12] Hanna and colleagues (2002) reported that 41 percent of autopsy reports, which are used to inform death certificates, inadequately documented epilepsy-related causes of death.

Third, there is a lack of awareness about SUDEP among coroners, medical examiners, and others who fill out death certificates (Devinsky, 2011; Lathers et al., 2011a). SUDEP may be under-reported due to the misconception that seizures do not have fatal consequences (Nashef and Sander, 1996; Schraeder et al., 2006). Coroners (who are not necessarily medically trained) are often unaware of SUDEP as a major cause of death in epilepsy (Leestma, 1997). Recognition of SUDEP as a valid diagnosis is more likely among trained pathologists compared to those without training in pathology or medicine (84 versus 63 versus 58 percent); seeing some epilepsy cases per year and having higher autopsy rates are also linked to greater recognition (Schraeder et al., 2006). However, Schraeder and colleagues (2006) found that SUDEP was used as a final diagnosis in few of the cases where it was appropriate, even among those who recognized SUDEP as a valid diagnosis. Instead, the cause of death was often attributed to status epilepticus, fatal seizure, respiratory failure, or cardiac arrhythmia. Educational efforts should focus on providing information on SUDEP to coroners and medical examiners (Schraeder et al., 2006) to improve the reliability of death certificate data. To inform these efforts, additional research is needed on how SUDEP is used as a diagnosis in the United States.

Surveillance of SUDEP is difficult because cases are ascertained using a variety of definitions, source populations, and data sources, including death certificates and autopsy records (Tomson et al., 2005, 2008). Complete ascertainment of the incidence of SUDEP can be achieved only through autopsies in order to exclude other definite causes of death (Antoniuk et al., 2001; Lathers et al., 2011a; Schraeder et al., 2006). Further, although detailed and accurate autopsies may improve understanding of SUDEP, currently there is no mandatory autopsy requirement (Schraeder et al., 2006). In addition, there is no national standard in the United States for documenting conditions at the time of death (e.g., where, body position) or for deciding whether to perform an autopsy (Schraeder et al., 2006).

[12]Status epilepticus is usually defined as an extended seizure or a series of seizures where consciousness is not regained in between, and it occurs in people with and without a diagnosis of epilepsy (Bazil and Pedley, 2009). In contrast, SUDEP is defined as a "sudden, unexpected, witnessed or unwitnessed, nontraumatic and nondrowning death, occurring in benign circumstances, in an individual with epilepsy, with or without evidence for a seizure and excluding documented status epilepticus" (Nashef et al., 2012).

To accurately count the number and distribution of SUDEP cases, to determine its cause, and—ultimately—to seek opportunities for prevention, more accurate forensic data are needed. Achieving these objectives will require standard criteria to define SUDEP and standard protocols for autopsies (So et al., 2009). Verbal autopsy—in the form of information from family and friends of the deceased about the circumstances of death—may add to understanding of SUDEP (Aspray, 2005). In 2008, the NINDS hosted a workshop on SUDEP and participants identified the need for standardized autopsy protocols (Hirsch et al., 2011), and in 2010, the NINDS solicited applications for collaborative research on SUDEP, including on approaches to "standardized procedures for collecting postmortem tissue and clinical data" (NINDS, 2010). If standardized reporting to a registry or other mechanism were required, coroners and medical examiners would be held accountable for knowing about and using SUDEP as a diagnosis.

Summary Though not created for surveillance and research purposes, administrative data—including data from hospital discharges, reimbursement claims, and vital statistics—may include sufficient details to provide information on the incidence and prevalence of epilepsy, the amount and cost of services that patients receive, the characteristics of people who receive services, and mortality patterns. Administrative data offer important advantages because they include large numbers of people, employ service and diagnostic coding that can be used to identify people with epilepsy, permit the tracking of people over time, and follow standardized federal and/or state regulations to ensure comparable content is collected among the health care systems. Administrative data provide information on patterns of care in real-world practice that may be more generalizable than those observed in clinical trials, where study subjects may not be typical of patients in actual practice settings. Since administrative data are collected for purposes other than research, they are relatively inexpensive to obtain and can be manipulated to examine various surveillance questions.

However, these datasets also have several limitations for surveillance and research purposes. For example, the use of service and diagnostic coding to identify cases is problematic. As discussed earlier, the accuracy of the coding often has not been verified and may not provide sufficient detail to determine the type and severity of epilepsy, the types of services received, the outcomes of care, or whether death was attributable to epilepsy. The validity of administrative data depends on the quality and consistency of record keeping among the many providers submitting the data. There may be difficulty in linking and comparing data across sites, populations (e.g., insured and uninsured), provider types, and systems of care.

Moving forward, the increasing use of EHRs (discussed below) and electronic systems for the capture of discharge and claims data will enable

more timely and efficient retrieval of data from each health care facility or insurance provider. Additional opportunities involve emerging collaborations, such as the Health Care Cost Institute and all-payer claims databases, as well as efforts to improve knowledge about and protocols for evaluating SUDEP and other epilepsy-related deaths. However, as noted throughout this chapter, standardized methods for recording information in these databases will be critical if these data are to be used for broad surveillance of epilepsy.

Clinical Data

Retrospective use of clinical data In addition to the data that providers collect for billing and administrative purposes, researchers can also retrospectively review clinical data that are collected and recorded as part of the patient-provider interaction, through such methods as chart reviews, in an attempt to systematically glean information related to a condition or its treatment. Such data permit the identification of probable cases of epilepsy, and studies have used clinical records to investigate a variety of epilepsy-related topics, including incidence, prevalence, cause of death, health outcomes, and cost-effectiveness (Annegers et al., 1999; Knoester et al., 2005; Mohanraj et al., 2006; Ojemann et al., 1987; Parko and Thurman, 2009).

Limitations of surveillance and research using clinical data include many that are similar to those discussed for administrative data, including a general absence of validation of various case ascertainment algorithms and service use and outcome measures. When using retrospective data, coding inaccuracies and missing data can make it hard to identify people with epilepsy and determine their characteristics. Additionally, the coding may not include seizure type and syndrome, particularly for records from visits to health care providers who do not specialize in epilepsy. Since patients may seek care from more than one provider, identification of incident epilepsy can be difficult if databases from different providers are not linked and multiple records for an individual reconciled.

Prospective use of clinical data Data from clinical settings can also be collected prospectively to investigate aspects of a particular condition or treatment plan. Prospective studies afford the opportunity to screen for possible cases of epilepsy and then validate the diagnosis using standardized or semi-structured interviews, which provide far greater detail about seizures than the typical medical record. Patients may be screened from hospitals, neurologists' offices, primary care settings, long-term care facilities, and other care settings for studies of epilepsy incidence. These studies provide the opportunity to interview people with epilepsy and follow them for a discrete time period to monitor a range of outcomes, including health

status, quality of life, quality of care, and mortality. Although prospective studies are more expensive and take more time than retrospective ones, they have advantages in their ability to generate rich and comparable data on an array of questions about epilepsy, including incidence, comorbidities, pregnancy outcomes, refractory epilepsy, health outcomes, cause of death, and stigma (Benn et al., 2008, 2009; Berg et al., 2006; Danielsson et al., 2005; Leaffer et al., 2011; Meador et al., 2009; Perucca et al., 2011; Viinikainen et al., 2006). Prospective studies in epilepsy centers, such as Friedman and colleagues' (2010) study of seizure-related injuries, may be especially useful for the collection of data on more severe or chronic epilepsy.

Prospective ascertainment of epilepsy data also faces challenges. Identification of subjects can be costly, involving active screening of several sources of care to make a preliminary identification of a sufficient number of potential cases, letters sent to potential cases inviting study participation, telephone calls to screen potential cases, lengthy interviews, and other data collection to confirm an epilepsy diagnosis. End points for follow-up must be carefully selected to maximize the information that can be obtained from medical records. Furthermore, losses to follow-up can limit the representativeness of the study population.

Electronic health records As repositories for both administrative and clinical data, the adoption and expanded use of linkable EHRs will enhance the utility of these data for public health surveillance of the epilepsies. A report of the President's Council of Advisors on Science and Technology (PCAST, 2010) examined how health information technology, and specifically EHRs, could improve the quality of health care and reduce costs. The PCAST report concluded that information technology has the potential to facilitate surveillance of public health trends if a standardized infrastructure and language for health information are implemented. However, the council reported that, despite great promise, significant progress is needed to achieve integrated electronic health information and exchange. For example, only about one-third of office-based physicians have systems that meet the defined criteria for basic EHR capability, although this number is increasing (e.g., the number rose from 11 percent in 2006 to 34 percent in 2011, with about half of physicians using some form of EHR as of November 2011) (HHS, 2010b; Hsiao et al., 2011). Barriers to the use of EHRs for surveillance identified in the PCAST report include the following:

- EHRs are typically owned by vendors who have proprietary interests, which may lead to barriers in implementing standard data formats (in addition to the technical challenges) and participating in health information exchange.

- Health care organizations may view EHRs as internal resources and may be reluctant to enable external uses of the data, such as making them available in de-identified or aggregated formats for public health agencies and researchers.
- Concerns about privacy and data security may cause individuals to be uncomfortable with giving consent for their EHRs to be used in research (PCAST, 2010).

However, the council report also highlighted the successes of organizations such as Kaiser Permanente and the Veterans Health Administration (VHA) in implementing EHRs to improve care and emphasized the potential value of EHRs in providing large quantities of data in a timely manner for surveillance and research (PCAST, 2010).

The Health Information Technology for Economic and Clinical Health Act of 2009 was created to help overcome these and other barriers by authorizing $27 billion in funds for the Centers for Medicare and Medicaid Services to use as incentive payments to health care providers to promote the adoption and use of EHR technologies (Blumenthal, 2011). The incentive payments require "meaningful use" of EHRs, which means that health care providers must demonstrate that they are using certified EHRs that enable them to monitor data and use them for quality improvement (CMS, 2011). As part of the meaningful use process, one of the priority outcomes is ensuring that adequate privacy protections are in place for personal health information (CMS, 2010a). The value of this effort to implement compatible EHRs nationwide may be to enable much more accurate estimates of disease and disorder rates in the population, patterns of care and their outcomes, and treatment costs.

As noted by Tyler and colleagues (2011), EHRs are a cost-effective way to study a specific health condition, and they can enable improved monitoring of care for people with chronic health conditions (Baldwin, 2011). Charlton and colleagues (2011) reported that EHRs have some advantages over registries, including the potential for better follow-up and—since they do not rely on voluntary enrollment—greater representativeness. Additionally, VanWormer (2010) looked at the Heart of New Ulm Project, a possible model for EHR-based surveillance, and found that EHR-based estimates of coronary heart disease risk factors are in line with manually derived estimates. In that project, risk factors for coronary heart disease are derived from EHR data and reviewed annually over 10 years (VanWormer, 2010). Another model for EHR-based surveillance is the Department of Veterans Affairs' (VA's) Cardiovascular Assessment, Reporting and Tracking (CART) System for tracking cardiovascular disease in real time (Box 2-8). Significantly, several ongoing and emerging collaborative efforts are focused on sharing EHR data to enhance surveillance and research opportunities (Box 2-9).

Box 2-8 THE DEPARTMENT OF VETERANS AFFAIRS' CARDIOVASCULAR ASSESSMENT, REPORTING AND TRACKING SYSTEM

The Department of Veterans Affairs (VA) recognized the limitations of retrospective studies using administrative and clinical records—they had electronic health records (EHRs) and a registry for veterans with implantable defibrillators, but data were often in free text, and analysis required significant labor resources and time. In response, the VA established the CART (Cardiovascular Assessment, Reporting and Tracking) System, where data collection is integrated into the care process through the EHR, which allows for treatment and real-time surveillance of cardiovascular disease. The reports are standardized and completed at the time of care. To make this possible, collaborations between the relevant players (e.g., VA Offices on IT [Information Technology], Patient Care Services) were crucial. CART enables quality of care and patient safety reviews along with disease surveillance (Varosy, 2011).

Box 2-9 EXAMPLES OF ELECTRONIC HEALTH RECORD DATA-SHARING EFFORTS

The Health Maintenance Organization Research Network (HMORN) is a collaboration of 19 HMOs—all of which have electronic health records (EHRs)—that links hundreds of researchers and includes multicenter research projects. The HMORN holds an annual meeting and also convenes smaller committees and forums to discuss research and potential studies and methodologies, including data coordination, best practices, and operational strategies (HMORN, 2012a,b). One central feature of the HMORN is its Virtual Data Warehouse (VDW), where data remain at the original site but the VDW facilitates comparison of data between sites (HMORN, 2010).

Building on the successes of the HMORN, and through Common Fund support from the National Institutes of Health, a Health Care Systems Research Collaboratory is being formed to facilitate collaborative research across U.S. health care systems (NIH, 2012; Van Den Eeden, 2011). Participating organizations represent integrated health care systems with EHRs and linked biospecimen repositories. The goal of the collaboratory is to use the organizations' data and operational infrastructure to facilitate longitudinal studies across multiple sites, including large-scale epidemiologic studies and prospective observational studies, as well as randomized clinical trials (NIH, 2011a). Planning for this work is still under way, but this program may offer valuable opportunities for future epilepsy surveillance.

Regional health information organizations (RHIOs) aim to support health information exchange, one of the eligibility requirements for Centers for Medicare and Medicaid Services incentive payments for EHR meaningful use. RHIOs are organizations that coordinate the exchange of data in a region (e.g., city, state). The number of RHIOs has increased over the past few years, but health care provider participation rates vary as do the RHIOs' ability to facilitate robust health information exchange. Infrastructure is still being developed to allow interoperability (Adler-Milstein et al., 2011).

All of these efforts point to opportunities for epilepsy surveillance through the use of EHRs. Considerable improvements must be made to standardize EHRs for valid health information exchange across providers, but the federal government's investment in this process is helping to move these efforts forward. To determine the usefulness of EHRs for epilepsy surveillance, pilot projects that validate methods for case ascertainment, including look-back periods for incident cases, and service use will be necessary. Furthermore, strategies should be explored to determine the appropriate balance of coded versus free-text data collected in EHRs—searchable by code or natural language processing—to maximize both efficiency and the data available for surveillance and research. As noted elsewhere in this chapter, collaborations will be important to minimize costs and ensure interoperability.

Surveillance That Includes Linked Data Sources

The concept of records linkage was first formulated by Dunn (1946) to describe the combination of multiple sources of health information into a single file for each individual in a population from birth to death. As described below, in some populations it has been possible to link clinical records and administrative data across hospitals, practitioners, and payers, permitting ascertainment of epilepsy and reasonable follow-up for end points, such as number and type of contacts with the health care system or death. Linkage is not always perfect, particularly when a patient has more than one medical record number at the same facility or when date of birth, gender, or ZIP Code are missing (Bradley et al., 2010). These problems may lead to a high false-negative rate in the records linkage system. Also, records linkage systems may suffer from a high false-positive rate if records linked together do not belong to the same patient (Bohensky et al., 2010). Although there are a number of challenges to establishing EHRs systematically, they can help to link multiple kinds of data for individuals within and across health care systems moving forward.

The major example of records linkage in epilepsy is the Rochester Epidemiology Project, where records for Minnesota residents of Rochester, Olmsted County, and the region around Olmstead County have been centralized. The system includes medical records from private physician offices, hospitals, and nursing homes, as well as death records. Numerous studies have been conducted on epilepsy using the Rochester data (e.g., Annegers et al., 1995, 1996; Begley et al., 2001; Ficker et al., 1998; Hauser et al., 1991, 1993; Hesdorffer et al., 1996a,b, 2011). An advantage of Rochester's records linkage system was that it enabled studies of epilepsy incidence and other attributes over a number of decades to allow analysis of trends. Another advantage of records linkage is that the cost of ascertaining and

following cases is much less than that of prospective studies that must examine multiple unlinked data sources (Bradley et al., 2010). One challenge in this type of study is identifying a population that reflects the diversity of the U.S. population.

Results of a Data-Gathering Effort

To better understand the opportunities and barriers to broad surveillance of the epilepsies, the Institute of Medicine committee requested that several health care systems (Henry Ford Health System, Geisinger Health System, and the VHA) and one state's records linkage system (South Carolina Epilepsy Surveillance System [SCESS]) explore a list of surveillance questions for their populations and analyze the strengths and limitations of their systems to generate information about epilepsy (Appendix B). Researchers in each system generously responded to the committee's request and provided candid evaluations of their system's ability to capture data on epilepsy. Unfortunately, variability in the methods of these systems meant that the data were not comparable, but looking at each system individually is informative about the current state of surveillance capabilities in the United States and highlights some important lessons for future surveillance. While these systems have limitations, they offer a preview of the wealth of opportunities that records linkages and EHRs could offer for epilepsy surveillance in the future.

Michigan's Henry Ford Health System is a large health system that includes 6 hospitals, more than 30 ambulatory care centers, and more than 2,000 physicians. Its managed care plan has approximately a half-million members. Henry Ford also has a Comprehensive Epilepsy Program that provides specialty care for people with epilepsy from the metropolitan Detroit area and the surrounding regions. Using administrative data and its EHR, Henry Ford researchers were able to estimate incidence and prevalence of epilepsy and comorbidities in their population using ICD-9-CM codes; service use, patterns of care, and care settings were identified as well. Strengths of the Henry Ford Health System to inform surveillance of epilepsy include that it has a comprehensive record of all paid claims for individuals in its Health Alliance Plan. Analysis of this cohort can identify incident cases, cases with comorbidities, and the comprehensive set of services used by an individual. However, Henry Ford's population is not representative of the U.S. population, further validation is needed to ensure accurate estimation of incidence and prevalence, and validation of the algorithms used to identify comorbidities and use of health care services is necessary.

Pennsylvania's Geisinger Health System includes 37 community practice sites and more than 1,800 clinical staff serving approximately 2.6

million people (Geisinger Health System, 2011). Geisinger also has an epilepsy center that provides specialty epilepsy care (Geisinger Health System, 2012). For the last decade, Geisinger has used a central electronic repository that integrates data from all clinical visits, laboratory reports, and claims. These data were used to estimate incidence and prevalence of epilepsy, comorbidities, and health service use using ICD-9-CM codes. Strengths of the Geisinger Health System to inform surveillance of epilepsy include that its EHR is comprehensive and contains a multiple-year period of look-back data to establish incidence, and it provides data on a largely rural population. However, the Geisinger population is not representative of the U.S. population, its algorithms for case ascertainment and service use have not been validated, and its incidence and prevalence estimates are likely overestimates due to the inclusion of ICD-9-CM code 780.09.[13]

The VHA runs the nation's largest integrated health care system, with more than 53,000 health professionals at 152 medical centers and almost 1,400 clinics, community centers, and other settings providing care to more than 8.3 million veterans (VA, 2011). The VHA's EHR encompasses care provided by VA hospitals, outpatient clinics, nursing homes, and other facilities, as well as services rendered by non-VA providers if VA funds are used for payment. These care data are sent to a central repository and linked with a patient identifier. Previous VA studies successfully linked epilepsy data from multiple VA databases, including an investigation of the impact of epilepsy on health status (Pugh et al., 2005) and an analysis of trends in seizure medication prescriptions among older adults with newly diagnosed epilepsy (Pugh et al., 2008). In the current data-gathering effort, diagnosis codes, dates and location of care visits, and data on prescribed medications were analyzed to provide estimates of incidence, prevalence, comorbidities, and service use for two populations: veterans 65 years old and older and veterans from Afghanistan and Iraq. Strengths of this system for surveillance of the epilepsies are the comprehensive, linked nature of the data repository and that many of the algorithms have been validated for comorbidities and service use, as well as for incidence and prevalence estimates in the older veterans cohort. However, a look-back period of more than a year would help rule out the possibility of overestimation of incidence. A limitation is that incidence and prevalence in the Afghanistan and Iraq cohort may be overestimated due to the high prevalence of posttraumatic stress disorder in this population, which is strongly associated with seizure-like events with a psychological basis that may be misdiagnosed as epilepsy. Also, there may be care received outside the VA that is not included in these estimates; the extent to which this would affect the results is unknown.

[13]This code is for "alteration of consciousness" (ICD9data.com, 2011).

The SCESS, funded by the CDC, was formed in 2002. Collaboration has been critical to its successful acquisition of data from a variety of sources. The SCESS collects and links claims data on privately insured individuals, those insured through the State Employee Insurance Program, and Medicaid and Medicare beneficiaries; incorporates hospital admissions data, including emergency room visits; and has access to medical chart data in some hospitals and doctors' offices. The data are collected and housed by the South Carolina Budget and Control Board's Office of Research and Statistics, which assigns a unique identification number to each individual to allow linkage across data sources. A review of the clinical records was conducted in the initial funding cycle to validate the information obtained from the data sources. In the current data-gathering effort, incidence and prevalence were estimated, as well as comorbidities and services use. Strengths of the SCESS include its use of unique identifiers that enable accurate linkages, its ability to analyze cost and effects of services through its collection of costs by type of service and procedure, and that it is a passive surveillance system, which minimizes cost. However, while the SCESS is representative of the state's civilian population, it does not include people in the military or veterans, and the accuracy of codes for specific types of epilepsy is undetermined.

These multisource surveillance systems permit reasonably complete case ascertainment in their populations and identification of fairly comprehensive service use, and they allow longitudinal follow-up of individuals and trend analysis. Problems with records linkage arise if individuals are counted twice or not at all due to incorrect matching of records in case ascertainment; further, the diagnostic and treatment codes used may not be accurate. The verification of the codes through cross-checking with other data sources makes the multisource approach very powerful for surveillance and research. The expanded use and adoption of linkable EHRs will enhance the opportunity for linked data sources in the future, and validation studies can confirm the methodologies and results. Linked surveillance systems have the potential to be invaluable resources for policy making, allocation of service resources, and prevention efforts.

The FDA's Sentinel Initiative

In 2008 the FDA announced its Sentinel Initiative, which includes the creation of an electronic system that will conduct national surveillance to monitor the safety of FDA-regulated medical products (e.g., drugs, biologics, medical devices). A year later, the Mini-Sentinel, a 5-year pilot project, was started to develop and evaluate methods to capture these data across a variety of electronic sources (e.g., claims data, EHRs, registries) (Behrman et al., 2011). Challenges and barriers encountered during the pilot project

will inform the implementation of the full-scale Sentinel System. One key aspect of the Mini-Sentinel is the importance of collaboration between the FDA and other institutions, which provide access to health data and also contribute expertise in the development of the system (FDA, 2012); after 2 years, the Mini-Sentinel project includes participation from more than 30 academic and private institutions (Platt et al., 2012). Another critical feature of the Mini-Sentinel is its use of a "distributed data system," where each collaborating institution has control of its own data, which may ease some privacy and proprietary concerns. As the Mini-Sentinel project, and the broader Sentinel Initiative, continue to evolve, relevant experiences and lessons learned should inform epilepsy surveillance efforts. Additionally, opportunities to collect epilepsy-related data (e.g., seizure medications, adverse events) should be explored when the full system is established.

The Autism and Developmental Disabilities Monitoring Network

An example of records linkage for surveillance of autism spectrum disorders, a comorbidity of epilepsy, is the Autism and Developmental Disabilities Monitoring (ADDM) Network. The ADDM Network evolved from previous CDC developmental disabilities surveillance efforts when the Children's Health Act of 2000 was enacted, which provided the CDC with the authority to fund autism spectrum disorders surveillance across the country (CDC, 2011c; Yeargin-Allsopp, 2011). The ADDM Network uses standard methodologies to examine prevalence trends over time, prevalence across geographic regions, and characteristics of children with autism spectrum disorders (CDC, 2011a; Yeargin-Allsopp, 2011). To study the peak prevalence of autism spectrum disorders, the ADDM Network focuses on children who are 8 years of age. Cases are identified through a retrospective review of records from a variety of health and education sources, such as pediatric hospitals and clinics, diagnostic centers and other clinical settings, and schools. The review collects testing, developmental, and behavioral data, and identified cases are validated through clinician review (Yeargin-Allsopp, 2011). A number of studies have been published using data from the ADDM Network (CDC, 2010a). However, the ADDM Network does not include data on children who are home-schooled or who attend private or charter schools, and, like many other surveillance efforts, there are concerns about quality and completeness of the collected data (Yeargin-Allsopp, 2011).

Although a similar effort in surveillance of epilepsy would likely focus on a wider age range and collect different records (e.g., EEG results), the ADDM Network offers an example of the value of legislation in enabling a standardized surveillance mechanism. In particular, the use of educational records as a source of data to identify children with autism spectrum dis-

orders highlights a possible additional resource for epilepsy surveillance to capture data on children with both epilepsy and cognitive dysfunction (e.g., learning disorders) (Chapters 3 and 6). Critical to this effort has been the memorandum of understanding between the participating state's Departments of Education and Human Resources to access the records. The ADDM Network then screens potential cases by looking in the educational records for a diagnosis, for Department of Education eligibility criteria, or for behavioral triggers that have been noted in the child's clinical record (Yeargin-Allsopp, 2011). Thus, for epilepsy-related data to be collected from educational records, collaborations with the Department of Education would be critical, and clear criteria for screening these records to identify children with epilepsy and cognitive comorbidities would be necessary. Research is needed to develop appropriate criteria and screening methods and to assess the value of these records to further understanding about epilepsy when it is accompanied by cognitive comorbidities.

International Surveillance with Records Linkage

Several other countries, notably Denmark, Sweden, and Canada, have or are in the process of linking medical records across providers and administrative data from providers and payers for studies of epilepsy (Box 2-10). Significantly, these three countries have health care systems that are largely or entirely nationalized, which minimizes the variability among data sources and maximizes the representativeness of the results. Despite their different health care systems, these countries can offer lessons for epilepsy surveillance in the United States, including the importance of unique identifiers and of the collaboration needed for linking information. Further, they illustrate the common challenges faced in epilepsy surveillance, including the accuracy of codes for analyzing specific epilepsy types, syndromes, and etiologies.

Next Steps

EHRs, health information exchanges, and linked datasets have considerable promise for improved and cost-effective surveillance as they evolve in the years ahead. As described earlier in this chapter, the currently limited experience in obtaining comparable surveillance information from several electronic data systems demonstrates some of the challenges these systems present for epilepsy surveillance. In particular, efforts must be made to ensure that case ascertainment is complete and accurate, the length of look-back periods for determining incidence is adequate, patient mobility in and out of systems is accounted for, population representativeness is ensured, and comprehensive health care use and cost information are available and

Box 2-10 EXAMPLES OF INTERNATIONAL SURVEILLANCE OF THE EPILEPSIES

Denmark has a number of longitudinal registries, including the National Patient Registry and the National Hospital Register, which contain more than three decades of health information, including diagnoses, treatments, and surgeries, from all patient contacts with the health care system. The Civil Registration System gives a unique identifying number to each individual, and the registries link their data using this number, enabling records linkage that avoids the false negatives and positives experienced in the United States. Based on these epilepsy-related data, studies have been conducted on a range of topics, including estimates of the effect of breastfeeding on risk for epilepsy, costs and impacts of epilepsy, risk for comorbid schizophrenia and psychosis, and risk for health outcomes including myocardial infarction, stroke, and death (Bredkjaer et al., 1998; Jennum et al., 2011; Olesen et al., 2011; Qin et al., 2005; Sun et al., 2011).

The Stockholm Incidence Registry of Epilepsy (SIRE), established in 2001, aims to identify cases with new-onset, unprovoked seizures among residents in a defined geographical area in Northern Stockholm, Sweden. This prospective registry uses multiple sources for case identification, including neurologists (both private and public), pediatricians, geriatricians, and nurses in nursing homes. Recently, SIRE data have been linked with other national registries, including the Swedish Hospital Discharge Register and the Population and Housing Census (Adelöw et al., 2011). Additional methods that help to ensure complete case ascertainment include review of all electroencephalographs (EEGs) at the central EEG lab, review of medical records for all new neuro-oncology referrals and all neurology and pediatric patients who receive their first epilepsy diagnostic code, and review of records from pediatric emergency rooms. Thus, the registry uses administrative data supplemented by more time-consuming review of records. Once all available information is obtained for a case, identified by the assigned identification number, a panel classifies the case. Studies conducted using the SIRE data have reported incident cases of unprovoked seizures and epilepsy as well as relevant risk factors (Adelöw et al., 2009, 2011).

Canada has recently undertaken a National Population Health Study of Neurological Conditions (NPSNC) to improve understanding of the epidemiology and impact of 14 neurological conditions, including epilepsy. Its aims include using linked administrative, electronic health record, and survey data to study incidence and prevalence; comorbidities; the impact of epilepsy on affected people, families, and society; health care services; and risk factors for the development of poor outcomes and other conditions. This work is made possible by the collaboration of many different federal agencies, Neurological Health Charities Canada (a collaborative effort of more than two dozen health organizations), researchers, and other stakeholders, including provincial health ministry managers. Work undertaken before the development of the NPSNC validated epilepsy coding in Canada when patients are seen in the emergency room or are hospitalized (Jetté, 2011). However, the validity of primary care data was not been previously examined and is being assessed as part of the NPSNC.

accurate. There is much to learn from the development and experiences of surveillance systems established for other purposes and conditions and in other countries, and pilot studies conducted in the near future could attempt to overcome these limitations. As part of these efforts, all privacy

concerns that may arise must receive an adequate response, and partnerships will be needed in order to improve sustainability.

CONCLUSION

A variety of data sources are currently used for epilepsy surveillance in the United States. These data sources can provide only partial estimates of many basic surveillance indicators, including epilepsy incidence, prevalence, etiologies, risk factors, comorbidities, health status, quality of life, access to care, quality of care, and cost of care. Demographic information is often inadequate, and sample sizes are generally too small to examine disparities in population subgroups. This patchwork of surveillance activity nevertheless has been mined to conduct important research on epilepsy; however, in terms of both completeness and timeliness, current data fall short of providing the information that would be most useful for understanding, planning, and guiding health care provision and policy for people with epilepsy.

Throughout this chapter, the committee has provided the basis for the research priorities and recommendations regarding improvements needed in the collection of epilepsy-related data that are detailed in Chapter 9. Improved surveillance of epilepsy will require linked electronic databases that cover large, representative populations. A crucial prerequisite for accurate and meaningful surveillance will be the validation of algorithms and methods for different age groups and settings. Standardized definitions and methods will allow surveillance data to be compared and actionable. Several opportunities may offer improved surveillance of the epilepsies, and existing examples such as those described throughout this chapter can provide useful lessons. The nationwide move to EHRs offers an unprecedented chance to capture data on epilepsy. Also, collection of epilepsy-specific data in population health surveys, registries for related conditions, and longitudinal studies will increase the amount of information about epilepsy, and the creation of a registry on epilepsy-related deaths would provide a valuable new information resource.

None of these efforts alone will accomplish comprehensive surveillance of the epilepsies, close current knowledge gaps, or adequately inform policy makers, public health agencies, health care providers, and the general public. Instead, coordinated action on multiple fronts is needed to ensure the collection of epilepsy-related data from a range of data sources. Collaboration with emerging data-sharing efforts across health care providers and with projects collecting data on related diseases and disorders will maximize resources, enable improved data collection, and, potentially,

increase momentum in advocacy efforts to fund and develop national-level surveillance, such as the National Neurological Diseases Surveillance System.[14] Currently there is unparalleled change occurring within public health surveillance in terms of capability and innovation, and the epilepsy field should capitalize on the opportunity to transform knowledge about epilepsy and its burden in the United States.

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3

Epidemiology and Prevention

Epidemiologic research assesses epilepsy's risk factors, burden, comorbidities, and outcomes to identify opportunities for prevention efforts. Although data are incomplete, it is clear that epilepsy is one of the most common brain disorders and is likely to increase in prevalence with the aging population. Most cases of epilepsy result from unknown causes, but some cases with known causes—such as neurocysticercosis and other brain infections, traumatic brain injury, and stroke—could be avoided. Epilepsy is linked to numerous physical, neurological, mental health, and cognitive comorbidities, including heart disease, autism spectrum disorders, Alzheimer's disease, depression, anxiety, and learning and memory problems. People with epilepsy are also more likely than others to have injuries, primarily seizure-related (e.g., fractures, burns, concussion), and to commit suicide. In addition to experiencing prejudice and discrimination, many people with epilepsy internalize feelings of stigma. Overall death rates, including from sudden unexpected death, are higher among people with epilepsy than in the general population. Actions needed to prevent epilepsy and its consequences include interventions to reduce the occurrence of epilepsy's known risk factors, to eliminate seizures in people with epilepsy and mental health comorbidities, and to decrease felt stigma and epilepsy-related causes of death.

Epidemiologic research in epilepsy aims to assess the risk factors for developing the disorder; to evaluate its burden, comorbidities, and outcomes; and to identify opportunities for preventing epilepsy and its consequences. Chapter 2 explores the various methodological and

measurement issues associated with epilepsy surveillance and describes sources for data collection. This chapter focuses on the gaps in epilepsy research in terms of what is known and not known related to incidence, prevalence, risk factors, comorbidities, and outcomes. These gaps suggest opportunities for prioritizing future epidemiologic studies in order to guide preventive and early intervention strategies. Improved epilepsy data collection and measurement, as described in Chapter 2, are necessary for better epidemiologic research, along with well-designed and targeted studies to illuminate significant trends and inform health care providers, policy makers, and the public.

To improve knowledge regarding preventing epilepsy and its outcomes, the committee's vision is for well-designed epidemiologic studies that highlight areas ripe for preventive efforts. Some, but by no means all, key focus areas are discussed here, including prevention of epilepsy, its comorbidities, and its consequences, including death. Before discussing these research areas, the continuum of public health prevention is described as background.

PUBLIC HEALTH AND PREVENTION

In the context of public health, there are traditionally three levels of prevention: primary, secondary, and tertiary. Each aims to intervene at a different point along the continuum of a disease or disorder and involves different types of actions to ameliorate the condition or its impact.

"Primary prevention" is the prevention of a disease or disorder before it begins, with the goal of decreasing its incidence in a population. For example, public health agencies, policy makers, and others work to eliminate environmental hazards (e.g., through sanitary measures such as ensuring clean drinking water), to improve disease resistance (e.g., through immunization), and to decrease high-risk behavior (e.g., tobacco use) and promote healthy behavior (e.g., seatbelt use). In looking forward, future advances in biomedical research hold the promise of greater understanding of epileptogenesis or possibly a cure; meanwhile, it may be possible to prevent some known causes of epilepsy, such as neurocysticercosis through education and sanitary measures, other brain infections through vaccines, traumatic brain injury (TBI) through seatbelt and helmet use, and stroke through reduction of known risk factors.

"Secondary prevention" is the early identification and mitigation of a disease or disorder once it is present in the body but before it is symptomatic. For example, public health agencies collaborate with health professionals to screen a population (e.g., blood glucose or blood pressure screenings) and follow up to manage early symptoms and forestall the development of full-blown disease. Secondary prevention of epilepsy may be possible in the future, if biomarkers of epileptogenesis are identified and early intervention measures are developed.

"Tertiary prevention" is the prevention of the progression of a disease or disorder and its outcomes after it has become symptomatic, in order to decrease the degree of resulting disability or impacts on health (i.e., to improve quality of life). For example, health professionals, together with public health agencies, work to minimize or eliminate exposures that make a disease or disorder worse (e.g., air pollution for people with asthma) and to screen for early detection of adverse outcomes (e.g., vision changes for people with diabetes). For chronic diseases and disorders, tertiary prevention is sometimes called disease management, although it should not be confused with medical treatment, and it may involve rehabilitation therapy, as after stroke. Some tertiary prevention efforts target the consequences of epilepsy (e.g., early identification of those who do not respond to seizure medications in order to identify options to prevent seizure recurrence), whereas others focus on its comorbidities (e.g., screening and interventions to identify and manage depression in people with epilepsy, described in Chapter 4). Future population health studies on comorbidities, including mental health conditions, and important outcomes (e.g., sudden unexpected death in epilepsy [SUDEP], injuries) may provide opportunities for successful interventions to promote optimal quality of life and avoid preventable deaths.

INCIDENCE AND PREVALENCE

Incidence

Studies of the incidence of epilepsy describe the rate of new-onset epilepsy and the characteristics of newly diagnosed epilepsy. The annual incidence of epilepsy in the United States is estimated at approximately 48/100,000 people (Hirtz et al., 2007). This estimate represents the median of a range of incidence estimates across all age groups. The hallmark longitudinal study of the epilepsies in the United States is the Rochester Epidemiology Project (described in Chapter 2), in which the incidence of epilepsy was examined in more than 2 million residents of Rochester, Minnesota, across 5 decades from 1935 to 1984. The Rochester study found an age-adjusted incidence of 44/100,000 (Hauser et al., 1993). Based on the Rochester project, Hesdorffer and colleagues (2011a) estimated that 1 in 26 people (3.8 percent of people born today) will develop epilepsy over the course of their lifetime. However, this estimate is based on a nonrepresentative population from one community in the United States. Furthermore, diagnostic data from this study are out of date, given the advances in imaging and other medical technologies (e.g., none of the Rochester participants had available MRI [magnetic resonance imaging] data).

More recent studies have arrived at varying estimates of epilepsy incidence:

- A population study in northern Manhattan reported an incidence of 41/100,000 (Benn et al., 2008).
- Holden and colleagues (2005) looked at managed care organizations and found an incidence of 47/100,000 for those who were continuously enrolled for 3 years and 71/100,000 for those enrolled for 5 years.
- In a health maintenance organization population, incidence for enrollees under age 65 was 35.5/100,000 (Annegers et al., 1999), although this age group would be expected to have a lower incidence than adults 65 years old or older, who have a high incidence of epilepsy (Thurman, 2011).

Existing trend 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 if changes in the distribution of risk factors for epilepsy (discussed later) are driving them.

Research Gaps

Epidemiologic research is needed in large, representative U.S. populations to monitor trends in epilepsy incidence and related mortality and to track outcomes. Studies need to be conducted among the general population and in subpopulations at higher risk: children, for whom prognosis is a major concern; older adults, who have greater mortality associated with epilepsy; women, to track outcomes, including reproductive outcomes; as well as veterans and diverse racial/ethnic and socioeconomic groups, in order to assess any disparities in incidence, prognosis, and mortality and to determine opportunities for intervention. Within these subpopulations, sufficient numbers are needed to compare incidence by etiology, seizure type, syndrome, and the presence of comorbid conditions. With respect to treatment, these surveillance data could be used to monitor the outcomes of epilepsy care and provide feedback to health care providers (Box et al., 2010; Trevathan, 2011). As examples, specific populations for whom further research is needed—older adults, veterans, children, and people with epilepsy and associated comorbidities—are described below.

Older adults The incidence of epilepsy is highest in children and older adults (Faught et al., 2012; Hauser et al., 1993; Kotsopoulos et al., 2002; Stephen and Brodie, 2000). By 2030, about 20 percent of the U.S. popula-

tion will be age 65 or older, an increase from approximately 13 percent in 2010 (Census Bureau, 2011; IOM, 2008). Due to the aging of the population and increases in life expectancy, the number of older adults who develop or have epilepsy will increase. Some of the increase will be from known causes, such as stroke, dementia, and TBI, which is often due to falls. Better medical management of stroke has increased survival rates and, thus, the number of survivors at risk for epilepsy; the number of people with aging-related dementia also is increasing; and the incidence of fall-induced TBI is rising in older adults (Annegers et al., 1995; Broderick et al., 1989; Fuster and Bansilal, 2010; Kannus et al., 2007; Ramanathan et al., 2012; Tartaglia et al., 2011; Watson and Mitchell, 2011). Older adults with epilepsy may experience greater disability because of deteriorations in health due to advanced age, comorbid conditions, and greater likelihood of side effects from seizure medications due to altered pharmacokinetics and interactions with other medications (Faught, 1999). The resultant impairments can decrease quality of life and increase the need for health services and long-term care (Guralnik et al., 1996). In anticipation of a growing number of older adults with epilepsy, additional research is needed that focuses on concerns specific to this population, including preventing adverse medication interactions and disability and maintaining independent living.

> *Epilepsy takes freedom from those who suffer from it. We cannot allow our citizens who have fought for freedom to lose their own freedom.*
>
> –Kevin Malone

Veterans Returning service members from Operation Enduring Freedom (OEF) and Operation Iraqi Freedom (OIF) are a specific population in which research on epilepsy incidence is needed, because TBI, the most common injury of OEF-OIF (U.S. Army Traumatic Brain Injury Task Force, 2007), is associated with up to a 53-percent risk for posttraumatic epilepsy, depending on the severity of the injury (Salazar et al., 1985). The number of service members who survive after sustaining a serious injury is higher now than for any previous war (Goldberg, 2010; Lowenstein, 2009). Between 2001 and 2007, an estimated 1.6 million U.S. military personnel were deployed to Afghanistan and Iraq (Tanielian et al., 2008). Among a study population of approximately 868,000 service members, approximately 1,300 were hospitalized with a severe TBI, 1,550 with a moderate TBI, and 133 with a mild TBI (Wojcik et al., 2010). However, most people who sustain a mild TBI are not hospitalized, and many do not go to the emergency department (U.S. Army Traumatic Brain Injury Task Force, 2007), and mild TBIs comprise approximately three-quarters of all TBI cases in OEF-OIF service members (Armed Forces Health Surveillance Center, 2012). A report of the Armed Forces Epidemiological Board (2006) found that the Department of Defense (DOD) did not have a system-wide

approach for identifying, treating, and monitoring TBIs, especially mild cases. Since that report, the DOD has established and is working to implement guidelines for the identification and treatment of mild TBI (U.S. Army Traumatic Brain Injury Task Force, 2007). Similarly, the Department of Veterans Affairs has also dedicated efforts to recognizing and managing mild TBI in OEF-OIF veterans (GAO, 2008). The emphasis on improved surveillance and care of mild TBI in today's conflicts contrasts with earlier eras, when attention focused on more severe, penetrating TBI (Evans, 1962; Salazar et al., 1985).

Studies of returning veterans require validated diagnosis of the severity of TBI and follow-up to monitor a range of potential outcomes, including the onset of epilepsy. Questions about the validity of the diagnosis of mild TBI have arisen in connection with a study of 2,525 service members answering a questionnaire after 1 year of deployment in Iraq, where symptoms of mild TBI were reported by 15.2 percent (Hoge et al., 2008). An accompanying *New England Journal of Medicine* editorial highlighted the difficulty of separating symptoms of mild TBI from posttraumatic stress disorder (PTSD) and other psychological reactions due to the emotional trauma of wartime (Bryant, 2008). Because TBI among returning veterans may be associated with an increased risk for developing epilepsy, work to distinguish mild TBI from PTSD is crucial. PTSD itself is associated with the occurrence of seizure-like events that are not epilepsy (D'Alessio et al., 2006). Recently, Salinsky and colleagues (2011) found that there is a significant delay in the diagnosis of seizure-like events with a psychological basis in veterans treated with seizure medications, suggesting a presumptive diagnosis of epilepsy. Among veterans with seizure-like events with a psychological basis, the delay in diagnosis was nearly five times as long as for civilians, and the cumulative treatment with seizure medications was four times higher. Progress in distinguishing between mild TBI and PTSD as well as between epilepsy and seizure-like events with a psychological basis is needed to determine the incidence and prevalence of TBI-related epilepsy among veterans and to provide optimal care.

Children The most catastrophic forms of epilepsy occur in children, particularly young children. Previous incidence studies have not assembled a sufficiently large incidence cohort of children with epilepsy to study the prognosis of most individual syndromes. However, it has been possible to study risk factors for poor seizure prognosis in childhood onset epilepsy overall, the risk for status epilepticus (SE), and the risk for early refractory epilepsy[1] in different etiologic categories (Arts et al., 2004; Berg et al.,

[1]As noted in Chapter 1, refractory epilepsy is defined as the failure to control seizures after two seizure medications (whether as monotherapies or in combination) have been appropriately chosen and used (Kwan et al., 2010) (see also Chapter 4).

2001a,b; Camfield et al., 2002; Sillanpää and Shinnar, 2002, 2010). However, studies have focused on common syndromes, and studies that have elucidated risk factors for poor prognosis within specific syndromes have been rare (Wirrell et al., 1996). Future studies of unselected incident cohorts of children with epilepsy are needed to assemble large enough cohorts with rare syndromes to study factors affecting prognosis.

Epilepsy accompanied by comorbidities There is some evidence (see the discussion below on comorbidities) that the prognosis for epilepsy is worse in the presence of comorbidities that predate the diagnosis of epilepsy. Because comorbidities may influence epilepsy prognosis and are known to affect quality of life, studies of the incidence of epilepsy in people with comorbidities at or before the onset of epilepsy will permit greater understanding of the consequences of the disorder when it is accompanied by comorbidities. For example, case-control studies of people with newly diagnosed epilepsy could be conducted retrospectively to identify preexisting comorbidities, or prospective cohort studies of individuals with depression or migraine could look at the incidence of epilepsy in these groups. These studies may provide a greater understanding of how the timing of epilepsy onset in relation to its comorbidities affects prognosis.

Prevalence

Studies of the prevalence of epilepsy provide information on its burden in the population. Prevalence data encompass the number of newly diagnosed cases of epilepsy as well as cases of epilepsy that persist over time, which includes people with continued seizures and people who are in remission but who take seizure medications. Except for rapidly fatal conditions, prevalence is greater than incidence, because it accounts for the accumulation of cases over time. Prevalence thus reflects the incidence, chronicity, and related mortality of epilepsy.

Similar to incidence, there is a range of estimates of prevalence of epilepsy in the United States:

- Hirtz and colleagues (2007) estimate annual prevalence at 7.1/1,000 people.
- The Rochester Epidemiology Project found that prevalence increased from 2.7/1,000 in 1940 to 6.8/1,000 in 1980 (Hauser et al., 1991).
- Kelvin and colleagues (2007) found a 5/1,000 prevalence in New York City.
- The Centers for Disease Control and Prevention's (CDC's) Behavioral Risk Factor Surveillance System (BRFSS), which depends on

self-reporting, estimated 8.4/1,000 cases of active epilepsy[2] (Kobau et al., 2008). If lifetime prevalence (i.e., ever having epilepsy) is considered, the BRFSS estimate increases to 16.5/1,000 (1.7 percent of respondents) (Kobau et al., 2008).

Research Gaps

More studies have been done on the prevalence of epilepsy than on its incidence because prevalence studies are easier and faster to conduct. Prevalence data are used to inform planning for resources and services to meet the health care and social needs of people with epilepsy. To obtain a complete picture of epilepsy, prevalence studies should be conducted using the same data sources as those in which long-term studies of epilepsy incidence are conducted. Socioeconomic status (SES) and race/ethnicity are discussed below as examples of two areas in which further research on incidence and prevalence is needed.

Socioeconomic status Low SES is associated with a higher incidence of epilepsy (Heaney et al., 2002). Hesdorffer and colleagues (2005) studied adults in Iceland and found that people with epilepsy are more likely to have low SES in comparison to age- and gender-matched controls without epilepsy. This association exists in a society with universal health care where everyone has health insurance, and it also persists in adults with epilepsy of unknown etiology, even after adjustment for cumulative alcohol consumption, which could be a confounding factor. Furthermore, low SES is also associated with an increased prevalence of epilepsy (Morgan et al., 2000; Shamansky and Glaser, 1979). Reasons for this are not well understood because these studies did not distinguish between epilepsy of unknown etiology and epilepsy of known etiology, which is problematic because some known etiologies of epilepsy (e.g., TBI, stroke) may themselves be associated with low SES (Chang et al., 2002; Cubbin et al., 2000). While associations between SES and the etiology of epilepsy is one possible explanation for the association between SES and prevalence, existing treatment gaps may play a role as well, since people of lower SES are less likely to obtain seizure medications or to be under the care of a neurologist than people of higher SES (Begley et al., 2009), making them more likely to experience persistent seizures (Chapter 4).

Race/ethnicity A study in the Harlem neighborhood of New York City found epilepsy prevalence to be higher in Hispanics than in non-Hispanics

[2]Defined as "a history of epilepsy and currently taking medication or reporting one or more seizures during the past 3 months" (Kobau et al., 2008, p. 1).

and a higher prevalence of active epilepsy[3] in whites than in blacks, although the prevalence of lifetime epilepsy[4] was higher in blacks compared to whites (Kelvin et al., 2007). In this community, there were racial/ethnic disparities in care; blacks were more likely to receive care in the emergency department compared to whites and Hispanics. Similarly, Hope and colleagues (2009) found that blacks and Hispanics were more likely than whites to be diagnosed in an emergency department, and blacks were more likely to receive a suboptimal seizure medication. Differences in care for prevalent epilepsy were also observed in residents of Alabama and surrounding states, where blacks were 60 percent less likely than non-Hispanic whites to undergo epilepsy surgery after receiving electroencephalograph (EEG) monitoring as part of a surgical evaluation, an association that persisted after controlling for factors such as SES and medical insurance coverage (Burneo et al., 2005). The degree to which differences in epilepsy incidence and prevalence in different racial/ethnic groups reflect differences in socioeconomic status is unknown. Also unknown is the degree to which treatment gaps contribute to the higher epilepsy prevalence in some subgroups.

Next Steps for Incidence and Prevalence Studies

As described in Chapter 2, none of the recent estimates of incidence and prevalence are based on active and ongoing surveillance of epilepsy in the U.S. population over time. Updated and longitudinal data are needed from large, representative populations throughout the country to generate population-wide estimates of incidence and prevalence and allow subgroup analysis by severity and type of epilepsy, age, gender, race/ethnicity, geography, and SES. This information is necessary to have a complete understanding of the burden of epilepsy in the United States compared to other diseases and conditions, to show trends over time, and to learn whether specific populations carry a disproportionate amount of the epilepsy burden so that actions can be taken to provide needed health care and support services.

Future studies of time trends in the incidence and prevalence of epilepsy conducted in large, representative cohorts will also be able to assess trends in remission, relapse, and refractory epilepsy. Although previous and ongoing prospective studies have examined these outcomes, the studies are mostly short term, outdated, and too small to enable subgroup analysis. A major contribution of the types of surveillance and population-based studies suggested in this report would be the ability not only to report incidence and prevalence but also to examine the course of epilepsy overall and in

[3]In this study, active epilepsy was defined as having ongoing seizures or taking a seizure medication within the previous 5 years.

[4]In this study, lifetime epilepsy was defined as having a history of two or more unprovoked seizures.

subpopulations. Such data may allow assessment of how risk factors influence the prevalence of epilepsy over time. Specific subgroups of interest include older adults, veterans, children, people with epilepsy accompanied by comorbidities, and diverse racial/ethnic and socioeconomic populations. These data are needed to know where and how to better focus epilepsy prevention and treatment efforts.

RISK FACTORS

Epilepsy Due to a Known Cause

Cases of epilepsy that have a known etiology have a worse overall prognosis, more commonly involve persistent seizures, and have a higher mortality rate than cases in which the cause is unknown (Forsgren et al., 2005b; Hauser et al., 1998). Less than half of all newly diagnosed cases of epilepsy have a known structural or metabolic cause (Adelöw et al., 2009; Forsgren et al., 2005a; Hauser et al., 1993). Among people with newly diagnosed epilepsy, the predominant known causes are stroke, neurodegenerative diseases such as dementia and multiple sclerosis, primary brain tumors or the spread of cancer from another site to the brain, and TBI (Annegers and Coan, 2000; Hauser et al., 1993; Herman, 2002; Hesdorffer et al., 1996a; Kelley and Rodriguez, 2009). Other known causes are rarer but confer a strong risk for developing epilepsy: brain infections, such as meningitis, encephalitis, and neurocysticercosis; pre- and perinatal injury; intellectual disability; cerebral palsy; and autism spectrum disorders (Annegers et al., 1988; Bergamasco et al., 1984; Carpio et al., 1998; Nelson and Ellenberg, 1987; Rocca et al., 1987; Tuchman and Rapin, 2002; Van der Berg and Yerushalmy, 1969). A recent study by Crump and colleagues (2011) found that preterm birth is associated with an increased risk of epilepsy in adulthood.

Identifying causes of epilepsy is the first step in primary prevention. Prevention of posttraumatic epilepsy has been attempted through indirect means and planned interventions. Efforts to prevent epilepsy from developing after TBI have involved randomized clinical trials of drug therapies; regrettably, these have not been successful (Temkin et al., 1990, 1999, 2007). Prevention of epilepsy after TBI is a complex problem, because the types, location, and extent of brain injury vary widely, and the process of epileptogenesis after TBI is not well understood. The heterogeneity of TBI has hindered the development of effective interventions to prevent poor functional outcomes in general. A systematic review of the literature found that only a third of randomized clinical trials of interventions to prevent negative health outcomes after TBI have been successful, underscoring the complexity of this injury (Hernández et al., 2005). Currently, the prevention of TBI itself allows the best opportunity to prevent posttraumatic epilepsy.

Significant public health efforts have successfully increased the use of helmets and seatbelts to prevent TBI (Coronado et al., 2011). These measures to reduce the occurrence of TBI have likely led to a decrease in new cases of epilepsy associated with TBI, although this is undocumented. However, motor vehicle accidents are still among the leading causes of TBI (Bruns and Hauser, 2003; Coronado et al., 2011; Labi et al., 2003; Tagliaferri et al., 2006). Furthermore, in some populations, the incidence of TBI appears to be rising. For example, the number of visits to the emergency department because of TBI due to sports and recreational activities, in particular bicycling and football, increased from approximately 150,000 to 250,000 between 2001 and 2009 (Gilchrist et al., 2011). Therefore, TBI remains a significant public health problem, where people who participate in sports, especially children and adolescents, and members of the military and older adults (discussed earlier in the chapter) are at particularly high risk (Armed Forces Health Surveillance Center, 2012; Gilchrist et al., 2011; Ramanathan et al., 2012).

The prevention of other risk factors for epilepsy could decrease the incidence of epilepsy as well. Prevention efforts for stroke often target its established risk factors, which include hypertension, cigarette smoking, and insufficient physical activity (Sacco et al., 1999). Results from the 2005 BRFSS found disparities in stroke prevalence among categories such as race/ethnicity, age, and educational level (Neyer et al., 2007), indicating a need for targeted prevention programs. Prevention of brain infections such as meningitis through the use of childhood vaccines has proven to be effective (Robbins et al., 1996; Tsai et al., 2008) and should be continued.

Among the known infectious etiologies of epilepsy, primary prevention associated with neurocysticercosis[5] may be most likely to succeed. Neurocysticercosis is caused by infection of the nervous system by a type of tapeworm, *Taenia solium*, and is a major cause of epilepsy in many developing countries throughout the world, including Latin America. Like other parasites that are transmitted through the digestive tract, tapeworms are spread to others through the consumption of food contaminated with the feces of an infected carrier, primarily due to poor sanitation, improper food handling practices, and inadequate hand washing. Neurocysticercosis is increasingly diagnosed in areas of the United States, especially the Southwest and other areas with large populations who travel to or immigrate from countries where the parasite is endemic (Del Brutto, 2012; Ong et al., 2002; White, 2000). For people who develop epilepsy from neurocysticercosis,

[5]Cysticercosis is a parasitic infection with *Taenia solium*, an adult tapeworm, resulting from ingestion of the eggs of the tapeworm through consuming undercooked food (e.g., vegetables, pork) or water contaminated with the feces of a carrier of *T. solium* larvae. Cysticercosis that involves the central nervous system is termed neurocysticercosis and is the most common parasitic brain infection (DeGiorgio et al., 2004).

treatment of the infection has not been shown to reduce seizures (Carpio and Hauser, 2002; Carpio et al., 1998, 2008).

A study in a farming community in California found the sero-prevalence of *T. solium* was associated with decreased frequency of hand washing (DeGiorgio et al., 2005), suggesting a feasible intervention for primary prevention. The annual economic burden of neurocysticercosis infection due to hospitalizations was estimated to be $7.9 million per year in Los Angeles County from 1991 to 2008 (Croker et al., 2010).

Although the risk for developing epilepsy following infection with the *T. solium* parasite is unknown, neurocysticercosis has been associated with premature death (Sorvillo et al., 2007). In an effort to identify new diseases or epidemics and mount a rapid response, the CDC has assembled a network of 11 U.S. emergency departments. One focus of this network is neurocysticercosis (Talan et al., 1998). In a study of patients who visited the network's emergency departments with seizures, 2.1 percent had seizures attributable to neurocysticercosis, and among the Hispanic patients, approximately 9 percent had seizures attributable to it (Ong et al., 2002). Hispanic ethnicity, uninsured status, being born outside the United States, and visiting an endemic country are all risk factors for neurocysticercosis.

In the few mortality studies conducted, few deaths are attributed to cysticercosis on death certificates (Santo, 2007; Sorvillo et al., 2007). The disease was identified as causing an estimated 221 deaths in the United States from 1990 to 2002; however, given the limited data on cysticercosis in the United States, this may be an underestimate due to a failure to diagnose or recognize the disease (Sorvillo et al., 2007).

In a Bolivian study of people with active epilepsy,[6] 26 percent were identified as having neurocysticercosis, based upon epidemiologic criteria and clinical manifestation. Additionally, neurocysticercosis was present in 83 percent of those with epilepsy of a known cause who died during the study (half of the total deaths in the study) (Nicoletti et al., 2009). Thus, neurocysticercosis represents a meaningful proportion of epilepsy cases in developing countries and increasingly in the United States, particularly among Hispanics.[7] In the BRFSS, the prevalence of active epilepsy[8] among U.S. Hispanics was 6.6/1,000 and the prevalence of inactive epilepsy was 9.0/1,000 (Kobau et al., 2008). Using the 2010 U.S. Census data (Ennis et al., 2011), this translates into 333,300 U.S. Hispanics with active epi-

[6]Defined in this study as people who have ongoing seizures (within the last 5 years) or are currently taking seizure medications.

[7]Hispanics made up 16 percent of the U.S. population in the 2010 U.S. Census, which was an increase from 13 percent in the 2000 Census (Ennis et al., 2011).

[8]Active epilepsy in this study was defined as "a history of epilepsy and currently taking medication or reporting one or more seizures during the past 3 months" (Kobau et al., 2008, p. 1).

lepsy and 454,500 with inactive epilepsy, among whom approximately 10 percent may have epilepsy caused by neurocysticercosis (Ong et al., 2002).

Next Steps for Prevention: TBI, Stroke, and Brain Infections, Including Neurocysticercosis

Continued efforts are needed to prevent the occurrence of TBI, including from motor vehicle accidents and in sports and the military. Research assessing risk factors for sports-related TBI and effectiveness of helmet design in preventing TBI should be part of these efforts in addition to the promotion of helmet use. Additional work is needed in the prevention of stroke, including interventions to decrease risk factors in disproportionately affected populations, and the continued use of vaccines is needed to prevent brain infections such as meningitis.

With growing numbers of people being diagnosed, neurocysticercosis is an important public health problem in the United States (Del Brutto, 2012; Ong et al., 2002; Serpa et al., 2011; Sorvillo et al., 2011; Wallin and Kurtzke, 2004; White, 2000). Recently, cysticercosis was highlighted as a "neglected infection of poverty in the United States" (Hotez, 2008). There are opportunities for prevention of this disease; in fact, in 1992, the International Task Force for Disease Eradication determined that cysticercosis is one of ten potentially eradicable diseases (CDC, 1992). Public education and sanitary measures should be used to decrease the occurrence of infection with the *T. solium* parasite (Sotelo, 2011). If these primary prevention measures are successfully implemented, it may be possible to track their effects on the development of epilepsy in different populations and geographic areas. Interventions to decrease the prevalence of neurocysticercosis in high-risk populations who travel to or immigrate from endemic countries could significantly reduce the percentage of those populations who will develop epilepsy.

Epilepsy Due to Unknown Causes

In this chapter epilepsy due to unknown, genetic,[9] or presumed genetic causes is called "epilepsy of unknown etiology" for simplicity. The majority of new-onset cases of epilepsy are of unknown etiology (Adelöw et al., 2009; Forsgren et al., 2005a; Hauser et al., 1993). The assumption is that etiologies exist but have not yet been detected. While the risk for continued seizures is relatively lower in epilepsy of unknown etiology than in epilepsy due to structural or metabolic causes and early mortality is lower (Forsgren

[9]For example, identified genes, such as SCN1A, are rare but confer a strong risk for developing epilepsy (Ferraro et al., 2006).

et al., 2005b; Hauser et al., 1998), there are risk factors for continued seizures and for increased mortality long after the diagnosis of epilepsy, suggesting that such cases are not benign. Moreover, increasing numbers of genetic mutations are being discovered that result in catastrophic epilepsies such as Dravet syndrome and other severe epilepsy syndromes with onset in infancy (Carranza Rojo et al., 2011), or in congential syndromes such as tuberous sclerosis complex that may result in epilepsy (Holmes et al., 2007).

Although several risk factors for developing epilepsy of unknown etiology have been elucidated recently, including mental health conditions and migraine (Hesdorffer et al., 2004, 2006; Ludvigsson et al., 2006; Ottman and Lipton, 1994), evidence that would support causality is lacking. It is possible that genes may be discovered to explain the occurrence of some of these epilepsies or that other factors common to both epilepsy and the risk factors may be found that contribute to the occurrence of these disorders.

Research Gaps

The potential array of risk factors for epilepsy of unknown etiology is incompletely understood and elucidated. This is a significant gap in knowledge pertaining to more than half of all new cases of epilepsy. Further epidemiologic studies can help to close this gap by examining other potential risk factors for developing epilepsy in the absence of established causes and can examine factors such as stress that may contribute to the association between low SES and risk for developing epilepsy. As knowledge accumulates, it may be possible to consider ways to prevent some of these cases, but this is a hope for the future.

COMORBIDITIES

Comorbidity is defined as the "co-occurrence of two supposedly separate conditions at above chance levels" (Rutter, 1994, p. 100). Common comorbidities among people with prevalent epilepsy include somatic,[10] neurological, and mental health conditions (e.g., Beghi et al., 2002; Boylan et al., 2004; Gaitatzis et al., 2004a; Jacoby et al., 1996; O'Donoghue et al., 1999; Ottman et al., 2011; Téllez-Zenteno et al., 2007b). Only a subset of these comorbidities has been examined in incidence and prevalence studies. Having additional information from studies in new-onset epilepsy is important, because studies of comorbidities in prevalent epilepsy do not permit identification of the sequence in which the conditions occur, which can be vital in understanding the reasons why comorbidities co-occur with epilepsy. In addition, little is known about the best strategies for prevent-

[10]Related to the body.

ing these comorbidities in people with epilepsy or minimizing their adverse effects. The additional cost and burden on the health care system of epilepsy's comorbidities are likely to be significant, but at this point no cost or utilization studies have been done. Further, changing trends in the incidence and prevalence of comorbidities may affect the prevalence of epilepsy, as described previously with respect to stroke, dementia, and TBI.

Many of the risk factors for epilepsy are also comorbidities, because they are chronic or episodic conditions that continue to affect the individual's health after the onset of epilepsy. Table 3-1 lists common comorbid conditions associated with epilepsy. Recently, Berg (2011) proposed a conceptualization of epilepsy as linked to a spectrum of disorders and highlighted potential shared mechanisms that may cause both epilepsy and some of its comorbidities as well as affect health and quality-of-life outcomes. However, the mechanisms that underlie these associations and the impact of comorbidities on the prognosis of epilepsy itself are not well understood currently, including whether specific populations (e.g., older adults, people of low SES) are more likely to have a higher comorbidity burden (Thurman et al., 2011). Improved data on epilepsy's comorbidities and their impact on the course of epilepsy and quality of life are needed. This chapter discusses comorbidities in terms of opportunities in epidemiologic research and prevention efforts, Chapter 4 analyzes the impact of comorbidities on health care, and Chapter 6 explores the consequences of comorbidities for quality of life.

Somatic Disorders

A number of somatic disorders have been associated with epilepsy in cross-sectional studies. In a population-based, cross-sectional study, the most common somatic comorbid conditions among adults with prevalent epilepsy were fractures, asthma, diabetes, ischemic heart disease, and heart failure (Gaitatzis et al., 2004a). Another large, cross-sectional study of prevalent epilepsy reported an increased prevalence of fibromyalgia and asthma among people with epilepsy compared to those without epilepsy (Ottman et al., 2011). In addition to the comorbidities already mentioned, another population-based study identified anemia and nonischemic heart disease as comorbidities (Nuyen et al., 2006). Conversely, one case-control study of people with congenital heart disease identified epilepsy as an associated disorder (Billett et al., 2008).

Fractures are likely consequences of epilepsy or its treatment, discussed later in the chapter. Neoplasia likely precedes the onset of epilepsy, since primary brain tumors and cancer metastases from another site to the brain are known epilepsy risk factors. Some somatic conditions, such as ischemic heart disease, diabetes, and heart failure, may be related to epilepsy through

TABLE 3-1
Comorbid Conditions Associated with Epilepsy

Category	Condition	Sources
Somatic disorders	• Fractures • Asthma and other pulmonary conditions • Diabetes • Heart disease and heart failure • Osteoarthritis, osteopenia, and osteoporosis • Fibromyalgia • High blood pressure • Anemia	Babu et al., 2009; Coppola et al., 2009; Gaitatzis et al., 2004a; Hesdorffer et al., 1996b; Nuyen et al., 2006; Ottman et al., 2011
Neurological disorders	• Stroke • Alzheimer's disease • Brain neoplasm • Autism spectrum disorders • Cerebral palsy • Migraine • Chronic pain and neuropathic pain	Berg et al., 2011; Bolton et al., 2011; Gaitatzis et al., 2004a; Hauser et al., 1993; Ottman et al., 2011; Wallace, 2001
Mental health conditions	• Mood disorders (e.g., depression) • Anxiety disorders • Alcohol-related disorders • Attention deficit hyperactivity disorders • Schizophrenia and psychotic disorders • Personality disorders • Suicidality • Seizure-like events with a psychological basis	Berg et al., 2011; D'Alessio et al., 2006; Davies et al., 2003; Gaitatzis et al., 2004a,c; Hesdorffer et al., 2000, 2004, 2006, 2007; Qin et al., 2005; Rodenburg et al., 2005
Cognitive disorders	• Cognitive impairment • Intellectual disability • Learning disability • Memory dysfunction	Elger et al., 2004; Hermann and Seidenberg, 2007; Sillanpää, 2004
Infectious disease	• Neurocysticercosis • Meningitis • Encephalitis	Annegers et al., 1988; Carpio et al., 1998; Rocca et al., 1987
Infestations	• Possibly onchocerciasis and toxocariasis	Kabore et al., 1996; Nicoletti et al., 2002, 2007, 2008; Pion et al., 2009
Physical disabilities	• Hearing and vision loss	Murphy et al., 1995
Injuries	• Accidents and injuries	Tomson et al., 2004
Nutritional problems	• Malnutrition • Gastrointestinal bleeding • Obesity	Crepin et al., 2007; Daniels et al., 2009; Gaitatzis et al., 2004a

SOURCE: Adapted from Thurman et al., 2011. Reprinted with permission from John Wiley and Sons.

their association with stroke. Little is understood about the relationship between the remaining somatic comorbidities and epilepsy (Gaitatzis et al., 2004a).

Research Gaps

Gaps in knowledge include

- the identification of risk factors for somatic comorbidities related to epilepsy, which could provide insights into whether these comorbidities are currently unrecognized risk factors for developing epilepsy of unknown etiology; and
- the extent to which increased identification of somatic comorbidities in prevalent epilepsy is due to more frequent medical visits by people with epilepsy, compared to those without.

Neurological Comorbidities

Many of the neurological comorbidities identified in people with epilepsy are themselves causal factors for developing epilepsy, such as Alzheimer's disease and stroke in adults, brain neoplasms in children and adults, and autism spectrum disorders and cerebral palsy in children (Gaitatzis et al., 2004a; Hauser et al., 1993; Hesdorffer et al., 1996a; Tuchman and Rapin, 2002; Wallace, 2001). Several pain disorders are associated with prevalent epilepsy, including migraine, chronic pain, and neuropathic pain (Ottman et al., 2011); however, none of these are known causal factors.

Among children, there is a bidirectional relationship between autism spectrum disorders and epilepsy, particularly for children with a low IQ (Amiet et al., 2008; Berg et al., 2011; Tuchman and Rapin, 2002) (see also the discussion of cognitive dysfunction).

- A study in a cohort of children with epilepsy found that 5 percent of the children also had autism spectrum disorders (Berg et al., 2011), compared to the estimate of 0.9 percent in the general population of children aged 8 years (CDC, 2009). Both West syndrome[11] and intellectual impairment were associated with the autism spectrum. Among children with epilepsy and without cognitive impairment, autism spectrum disorders occurred in 2.2 percent and being male was the only associated risk factor (Berg et al., 2011).

[11]West syndrome (i.e., infantile spasms) is an epilepsy disorder in children usually accompanied by severe and multiple comorbidities.

- In a prospective study, the risk for autism spectrum disorders in children with epilepsy diagnosed within the first year of life was 14 percent. Among those with autism spectrum disorders and seizures, 69 percent had symptomatic seizures, generally due to brain injury, and 46 percent had West syndrome (Saemundsen et al., 2008).

These studies suggest that at least part of the increased risk for epilepsy in autism spectrum disorders may reflect increasing brain damage, some of which may have a genetic basis.

Two of the neurological disorders mentioned above, migraine and stroke, bear specific mention because they offer an opportunity to understand ways to prevent epilepsy or ameliorate its outcomes. There is a bidirectional relationship between migraine and epilepsy, where having a history of one condition is associated with an increased risk for the other (Ludvigsson et al., 2006; Ottman and Lipton, 1994). Velioğlu and colleagues (2005) found that people with both epilepsy and migraine had poorer seizure control than people with epilepsy but without migraine. The latter finding is important, because it suggests that the drugs used to treat epilepsy, some of which are also used in migraine, may not work to the same degree in people with both conditions. There may be a common risk factor for both disorders or a common underlying genetic susceptibility that may, in the future, suggest novel therapies in epilepsy accompanied by migraine.

Among older adults, the occurrence of either stroke or epilepsy is associated with an increased risk for the other condition (Cleary et al., 2004; Hauser et al., 1993; Kotila and Waltimo, 1992; Shinton et al., 1987). This bidirectional relationship may be explained by hypertension or, in epilepsy of unknown cause, by untreated left ventricular hypertrophy, a marker of severe hypertension, both of which are associated with an increased risk for developing seizures, even in the absence of stroke (Hesdorffer et al., 1996b; Ng et al., 1993). In this context, it is interesting to note that diuretics, a first-line treatment for hypertension, are protective for the development of epilepsy of unknown cause (Hesdorffer et al., 2001), a finding supported by animal studies (Hochman et al., 1995; Maa et al., 2011). Epidemiologic studies have stimulated the development of novel diuretics as treatments for seizures and the use of carbonic anhydrase inhibitors (which can act as diuretics), previously used in childhood epilepsy, in adult epilepsy (Edwards et al., 2010; Haglund and Hochman, 2005; Kozinska et al., 2009; Lim et al., 2001).

Mental Health Comorbidities

Mental health comorbidities have been recognized in people with epilepsy since the time of the ancient Greeks (Temkin, 1971), yet even today a

significant percentage of people with epilepsy may have mental health conditions that remain undiagnosed and untreated. The term "mental health conditions" is used here to reflect a range of conditions (e.g., depression, anxiety, attention deficit hyperactivity disorder [ADHD], psychosis) described in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV).

In the 1970s, studies of mental health conditions in people with prevalent epilepsy became a topic of interest for researchers exploring the adverse effects of seizure medications (Trimble and Reynolds, 1976). Many studies subsequently examined the frequency of these disorders and conditions in people with prevalent epilepsy (e.g., Beghi et al., 2002; Boylan et al., 2004; Jacoby et al., 1996; O'Donoghue et al., 1999; Téllez-Zenteno et al., 2007b). These studies, which included population-based studies and studies in referral centers, found that many mental health comorbidities were attributable to the challenges of living with epilepsy, an unpredictable and stigmatizing disorder. As a group, the cross-sectional studies did not assess the sequence of the conditions, and some lacked a comparison group. Despite these methodological weaknesses, some people with epilepsy clearly experience adverse psychosocial outcomes associated with mental health conditions that affect their quality of life (Gilliam et al., 2003).

Longitudinal epidemiologic studies have established a more complex relationship between mental health conditions and epilepsy than revealed by cross-sectional studies. For example, behavioral problems and ADHD have been found to have a bidirectional relationship with epilepsy, with either condition increasing the risk for the other (Austin et al., 2001; Dunn et al., 1997; Hesdorffer et al., 2004; Holtmann et al., 2003; Jones et al., 2007; Williams et al., 1998). In two case-control studies of children with their first recognized, unprovoked seizure, behavioral disturbances before the onset of the first seizure were more frequent among children who developed epilepsy than among controls (siblings without epilepsy or children with no additional seizures) (Austin et al., 2001; Dunn et al., 1997). A population-based, case-control study conducted among Icelandic children found that those with an unprovoked seizure were 2.5 times more likely than age- and gender-matched controls to have a prior history of ADHD (95 percent CI = 1.1-5.5) that met DSM-IV criteria (Hesdorffer et al., 2004). The association was restricted to ADHD-predominantly inattentive type (Hesdorffer et al., 2004). When the occurrence of new-onset seizures is examined in people with ADHD (Holtmann et al., 2003; Williams et al., 2001), the percentage developing unprovoked seizures is 4 to 40 times greater than expected (Hauser et al., 1993; Hesdorffer et al., 2004). Recent research suggests that the co-occurrence of ADHD and epilepsy is due to frontal lobe dysfunction (Hermann et al., 2008a).

The incidence of psychosis increased following the diagnosis of epilepsy in two population-based registry studies in Denmark. In the earlier study,

the incidence of nonorganic, nonaffective psychoses was significantly increased for people with epilepsy, even after those diagnosed with learning disabilities or substance abuse were excluded (both of which increase the risk for developing epilepsy) (Bredkjaer et al., 1998). In the second study, epilepsy was associated with a 2.5-fold increased risk for schizophrenia, even for people without a family history of psychosis—an important exclusion, because positive family history might be expected to explain the increased risk (Qin et al., 2005). The risk was dependent on age at onset of epilepsy, with a significantly increased likelihood of schizophrenia observed with increasing age of epilepsy onset, suggesting that the peak age of schizophrenia incidence among people with epilepsy is greater than the peak incidence of 22 years reported for the general population (Thorup et al., 2007). The risk of developing schizophrenia is also increased in individuals with a history of febrile seizures, particularly when febrile seizures are followed by the development of epilepsy (Vestergaard et al., 2005). Recently, Chang and colleagues (2011) found that the association between schizophrenia and epilepsy is bidirectional.

Next Steps for Prevention: Depression

A history of depression is associated with an increased risk for developing epilepsy (Forsgren and Nystrom, 1990; Hesdorffer et al., 2000, 2006). Depression is also associated with a worse prognosis of seizures (Hitiris et al., 2007a), and a lifetime psychiatric history is associated with poor seizure control after surgery (Kanner et al., 2009). This latter finding implies that a worse seizure outcome could exist even after surgical removal of the lesion presumed to cause the seizures. Given current knowledge, it is possible that interventions can be developed for the comorbidity of depression and epilepsy.

Rather than the burden associated with having epilepsy increasing the risk for depression, the above findings suggest that depression may lower the seizure threshold, leading to an increased risk for epilepsy and an increased risk for continued seizures. This possibility is further supported by data from phase II and III clinical trials of psychotropic drugs conducted in the United States between 1985 and 2004, which found that the incidence of seizures was 52 percent lower in people who received antidepressants than in people receiving placebo (Alper et al., 2007). This result suggests that serotonergic mechanisms (i.e., those related to the neurotransmitter serotonin) underpin the occurrence of seizures in people with depression. Serotonergic mechanisms also may be associated with continued seizures in people with a history of depression and epilepsy; this possibility is supported by animal studies (Mazarati et al., 2008). Thus, it may be possible to decrease the occurrence of seizures in people with epilepsy and depres-

sion through the use of antidepressants that affect serotonin activity. This approach has been taken in interventions for people with stroke, in which placebo-controlled randomized clinical trials of antidepressants within 6 months of a stroke showed significant decreases in mortality (67.9 percent of people receiving antidepressants were alive at 9-year follow-up compared with 35.7 percent of those receiving the placebo treatment), whether they had depression or not (Jorge et al., 2003).

Research Gaps

As described in Chapter 4, standard screening protocols are needed to identify people with epilepsy who have mental health comorbidities. Studies are needed in populations of people with epilepsy and diagnosed mental health comorbidities to determine whether treatment of these comorbidities improves overall health outcomes for people with epilepsy. Further, additional research is needed to identify effective public health interventions for epilepsy and mental health comorbidities. Few studies have examined interventions for mental health conditions in people with epilepsy. In one of the only studies of children or youth, Martinovic and colleagues (2006) observed that a cognitive-behavioral intervention reduced depressive symptoms in adolescents with epilepsy and improved quality of life, but the results were not statistically significant, perhaps due to small sample size. Future studies of behavioral and other types of interventions for people with epilepsy and comorbid mental health conditions require adequate sample sizes to demonstrate effectiveness.

The Managing Epilepsy Well (MEW) Network[12] is an important effort in the development of behavioral interventions for people with epilepsy and comorbid mental health conditions (see also Chapters 4 and 7). The CDC Prevention Research Centers and Epilepsy Program formed the MEW Network in 2007 to encourage research focused on the self-management of epilepsy, with the ultimate goal of improving quality of life. The MEW Network conducts research on interventions aimed at the broad area of self-management support, defined by the Institute of Medicine as "the systematic provision of education and supportive interventions [by health professionals] to increase patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support" (IOM, 2003, p. 52). Self-management for epilepsy includes the information and resources that people

[12]Currently four academic universities participate in the MEW Network, in collaboration with community partners (e.g., state and local Epilepsy Foundation affiliates), state and federal agencies (e.g., the CDC), and others. For more information, see www.sph.emory.edu/ManagingEpilepsyWell/.

with epilepsy and their families need to develop skills and behaviors that enable them to actively participate in patient-centered care. Studies conducted by the MEW Network seek to identify and better understand what epilepsy self-management needs are and evaluate programs that are designed to improve self-management skills in a variety of contexts. Since mental health comorbidities are common in epilepsy, the MEW Network is testing interventions such as Project UPLIFT (Chapter 4), which is designed to help people with epilepsy and co-occurring depression through a combination of cognitive-behavioral therapy and mindfulness techniques (Thompson et al., 2010; Walker et al., 2010). Broadening the scope of comorbidities covered by MEW Network interventions—for example to look at anxiety disorders—would be beneficial.

Cognitive Dysfunction

Cognitive dysfunction is a major concern for people with epilepsy, particularly at both ends of the age spectrum. Many people with epilepsy experience declines in cognitive function, which will become increasingly important as the population with epilepsy ages. In addition, the impact of having intellectual disability on the risk for developing epilepsy is profound in children and young adults as well.

In a study of children with intellectual disabilities (98 percent had an IQ less than 70), approximately 15 percent developed epilepsy[13] by 22 years of age (Goulden et al., 1991), reflecting a 43-fold increased risk in comparison to children without intellectual disability (Hauser et al., 1993). When adjustment is made for age, SES, and gender, among children with intellectual disabilities a 9-fold increased risk to have one or more seizures was found when compared to matched comparisons (Richardson et al., 1980). Furthermore, the presence of disabilities associated with intellectual disability strongly increases the risk for developing epilepsy. The risk is 38 percent for those with intellectual disability and cerebral palsy, compared with 5.2 percent risk in the absence of associated disabilities (Goulden et al., 1991). In addition to the 43-fold increased risk for epilepsy in children with intellectual disability, there is a 123-fold increased risk in children with cerebral palsy (Carlsson et al., 2003). Results are similar for autism spectrum disorders with or without intellectual disability and cerebral palsy. By 10 years of age, the cumulative probability of developing epilepsy is 8 percent for children with autism spectrum disorders only, compared to 27 percent for children with autism spectrum disorders and severe intellectual disability and 67 percent for children with autism spectrum disorders, severe intellectual disability, and cerebral palsy (Tuchman and Rapin, 2002).

[13]In this study, defined as two or more nonfebrile seizures.

Common epilepsy-associated cognitive impairments affect several domains, especially memory and psychomotor speed. Executive dysfunction, such as deficits in working memory and planning abilities, has been noted in many children and adolescents with epilepsy (MacAllister et al., 2011). As noted by Bhise and colleagues (2010), these problems have been attributed to an interplay of genetic susceptibility, uncontrolled seizures, subclinical epileptiform discharges,[14] postictal states,[15] psychosocial factors, underlying abnormalities of the brain, and use of seizure medications. A variety of factors—many of which are not intrinsically associated with having seizures or treatment—impact the neurobehavioral status of people with epilepsy (Hermann and Seidenberg, 2007). For example, even people with newly diagnosed epilepsy who have not yet begun treatment—and who do not have other neurological disorders—have significantly worse results than healthy volunteers in several cognitive domains (Taylor et al., 2010). Similarly, Hermann and colleagues (2006a) found that children with new-onset epilepsy demonstrate cognitive impairment and academic underachievement in comparison to children without epilepsy.

The presence of neurobehavioral comorbidities, particularly ADHD or academic problems, at the time of epilepsy onset is an important marker of impaired cognitive development before and after epilepsy onset (Hermann et al., 2008c). Clinically significant declines in intellectual or cognitive abilities are seen in a subgroup of about 10 to 25 percent of children after the onset of epilepsy. This subgroup includes children who have frequent seizures, those who take multiple seizure medications, and those whose epilepsy began at an early age, although the role of psychosocial factors may be important as well (Vingerhoets, 2006). An increased risk for SE appears to be associated with severe cognitive impairments, rather than SE being the cause of cognitive decline (Helmstaedter, 2007). Furthermore, even if seizures are controlled, cognitive impairments may remain, some of which may be due to the side effects of seizure medications (Loring and Meador, 2001).

Long-term epilepsy in adults is commonly associated with significant impairments in cognition, and in some people these become worse by middle age (Hermann et al., 2008b). In people with chronic temporal lobe epilepsy, adverse cognitive outcomes are seen in approximately 20 percent, including deficits in memory, psychomotor or motor abilities, naming, and some executive functions (Hermann et al., 2006b). The cognitive decline often seen in refractory epilepsy can be stopped or reversed to some degree by successful epilepsy surgery (Téllez-Zenteno et al., 2007a); however,

[14]Subclinical epileptiform discharges refer to EEG abnormalities without clinical correlates.

[15]Postictal states follow a seizure and are characterized by a range of responses, including confusion, drowsiness, and unresponsiveness.

many people who undergo epilepsy surgery have low memory functioning on presurgery tests, and further decline below presurgery levels may not be possible in some people (Baxendale et al., 2012).

Research Gaps

Currently, there is insufficient knowledge about cognitive impairment in epilepsy, including its timing, its prognosis, and to what extent refractory epilepsy causes cognitive decline over time (Hermann and Seidenberg, 2007). Much of the published work is cross-sectional; such studies have several methodological problems that preclude them from clearly elucidating the cognitive course of people with epilepsy. These shortcomings include the studies' inability to evaluate cognitive status over time and to account for cohort effects. Further, research on epilepsy and cognitive disorders has, for the most part, been descriptive rather than explanatory (Hermann and Seidenberg, 2007). The few prospective studies that have sought to identify the etiology of cognitive impairment in people with epilepsy also have methodological shortcomings, such as evaluating cognitive status only through assessments of IQ, use of cohorts that have a mixture of seizure types, lack of appropriate control groups, absence of baseline data, polypharmacy, varying test-retest intervals, and relatively short follow-up periods (Bhise et al., 2010).

Analysis of cognitive decline in children with epilepsy is particularly difficult given the extremely small number of studies that have used comprehensive neuropsychological test batteries (Vingerhoets, 2006). The course of cognition in middle-aged and older adults with chronic epilepsy has been even less studied (Hermann et al., 2008b). Limitations in the few long-term studies of outcomes after epilepsy surgery include failure to include an adequate control group; not reporting on outcomes beyond seizure-related measures, such as cognitive outcomes over a period longer than 5 years; and a focus on temporal lobe epilepsy (Téllez-Zenteno et al., 2007a).

For these reasons, a large-scale, well-designed epidemiologic study on cognitive impairment in epilepsy is a research priority. This might be achieved though the addition of questions on cognitive impairment in surveys such as the CDC's BRFSS. In addition, people with epilepsy who are already experiencing cognitive decline need to be identified and referred to specialists in order to try to halt additional impairment (Chapter 4). School performance can be used to identify children at high risk for attention and behavior problems early on, allowing appropriate management to begin (Bhise et al., 2010).

Future longitudinal prospective investigations are needed to accurately describe seizure type and frequency and compare cognitive effects in groups

of people with different epilepsy syndromes (Vingerhoets, 2006). Studying middle-aged people with epilepsy, who may face later neurocognitive declines typical of aging, is another important area for future research (Hermann et al., 2006b). Neuropsychological evaluation can provide essential information for maximal sparing of functional tissues if epilepsy surgery is undertaken and for monitoring surgery outcomes (Helmstaedter, 2004). Longer-term, prospective, controlled studies of the effects of epilepsy surgery on cognitive functioning also are warranted (Téllez-Zenteno et al., 2007a).

OUTCOMES

In addition to the seizures themselves, a number of negative health outcomes are possible for people with epilepsy, including poorer overall health status, impaired intellectual and physical functioning, a greater risk for accidents and injuries, and side effects from seizure medications and other treatments (Camfield and Camfield, 2007; Kobau et al., 2008; Tomson et al., 2004). According to data collected by the BRFSS surveys and the California Health Interview Survey, adults with epilepsy are more likely than adults without epilepsy to report poor quality of life (Kobau et al., 2007, 2008). They are more likely to be unemployed or unable to work; to have low annual household incomes; to be obese and physically inactive; and to currently smoke. Further, people with poorly controlled epilepsy report worse quality of life than people with well-controlled epilepsy; and they report more mentally and physically unhealthy days per month compared to people without epilepsy (Baker et al., 1997; Kobau et al., 2007) (Chapter 6).

The focus in this chapter is on potentially preventable outcomes in epilepsy, including accidental injury and epilepsy-related mortality, specifically accidents and injuries, suicide, and SUDEP. First, the course of epilepsy is discussed briefly to provide some context.

Remission, Relapse, and Refractory Epilepsy

As discussed in Chapter 1, with the appropriate diagnosis and treatment, many people with epilepsy can be free of seizures. Using data from the Rochester Epidemiology Project, Annegers and colleagues (1979) found that at 20 years after diagnosis with epilepsy, 70 percent of people with epilepsy were in remission with at least 5 consecutive seizure-free years. Similarly, 63 percent of people with epilepsy achieved remission in a study by Kwan and Brodie (2000), who noted that people who did not respond to their first seizure medication and those who had numerous seizures before beginning a medication regimen were more likely to have refractory

epilepsy. Among adults, the cumulative probability of early remission[16] is 56.3 percent, and the cumulative probability of a 2-year remission by the time an individual has had epilepsy for a decade is 79.5 percent (Del Felice et al., 2010).

In a prospective study of newly diagnosed children with epilepsy, 74 percent achieved 2 seizure-free years (Berg et al., 2001c). This early remission was less likely if the epilepsy had a structural or metabolic etiology[17] or in cases where there was an increased baseline seizure frequency, family history of epilepsy, and slowing of brain function as measured by an EEG. When children with epilepsy of genetic cause[18] were excluded and remission in those with epilepsy of unknown etiology[19] was compared to those with epilepsy of structural or metabolic causes, remission was markedly higher for epilepsy of unknown etiology, and the only predictor of lack of seizure remission was perinatal complications (Wirrell et al., 2011). A study examining long-term outcomes of childhood epilepsy found that children were more likely to achieve at least 5 years of remission if they had epilepsy of unknown etiology, no previous febrile seizures, a 3-month remission in the first 6 months, and a fast response to seizure medications (Geerts et al., 2010). Refractory epilepsy[20] occurred in 9 percent of children who were followed for almost 15 years (Geerts et al., 2010).

Periods of remission and relapse cycle back and forth in adults and children who have continued seizures despite treatment. Cycling of remission and relapse is seen in adults with refractory epilepsy, with 13 to 24 percent entering at least a 12-month remission; of those who achieved this remission, 60 to 71 percent subsequently relapsed (Callaghan et al., 2011; Choi et al., 2011). In adjusted analysis, the only factor associated with lack of remission was the number of drugs that had failed to help (Callaghan et al., 2011). For those who did achieve remission, only focal epilepsy[21] predicted seizure relapse. Repeated remissions and relapses also are common among children whose seizures do not respond to two drugs, with structural or metabolic causes of epilepsy being the only predictors of lack of remission (Berg et al., 2009). Risk factors for lack of remission in children with a

[16]In this study, early remission is defined as beginning immediately after the initiation of treatment and lasting at least 2 years.

[17]The most recent terminology, structural or metabolic etiology, is used here in place of the previous terminology, remote symptomatic etiology.

[18]The most recent terminology, genetic etiology, is used here in place of the previous terminology, idiopathic etiology.

[19]The most recent terminology, unknown etiology, is used here in place of the previous terminology, cryptogenic etiology.

[20]In this study, refractory epilepsy is defined as continued seizures for at least 3 months in a single year despite adequate treatment for at least 2 years.

[21]In focal epilepsy, seizures originate in a network of neurons limited to one hemisphere of the brain (Chapter 1).

period of continued seizures despite treatment include seizure etiology and family history of epilepsy, which are not amenable to intervention.

Among people with continued seizures for whom medications do not work and who then receive surgery, 66 percent experienced at least 2 seizure-free years, and 25 percent subsequently relapsed (Spencer et al., 2005). Predictors of remission in the group with medial temporal lobe surgery included absence of generalized tonic-clonic seizures and presence of hippocampal atrophy. In a meta-analysis, predictors of remission included febrile seizures, mesial temporal sclerosis, tumors, abnormal MRI, concordance between MRI and EEG, and extensive surgery (Tonini et al., 2004). These results suggest that surgery is most likely to be effective for mesial temporal sclerosis, compared to other types of epilepsy.

Research Gaps

Accurate estimates of the number of people with refractory epilepsy and its severity are not available, nor are estimates of the number of people who could be in remission if they received the appropriate treatment at the appropriate time. Improved data on the number of people who could be seizure-free would suggest opportunities to mitigate the current burden of disease and improve health outcomes and quality of life associated with epilepsy.

Nonfatal Accidents and Injuries

Accidents and injuries are common among people with epilepsy.[22] Severity of epilepsy affects the risk for injury, with injury rates being higher in people with poorly controlled epilepsy, particularly those with generalized tonic-clonic seizures (Asadi-Pooya et al., 2012; Tomson et al., 2004). This risk factor has been confirmed in a large multicenter European cohort study, where the risk of injury in children (ages 5 and older) and adults with epilepsy of less than 10 years' duration (without any progressive neurological condition) were compared to age- and gender-matched controls (Beghi and Cornaggia, 2002). After 2 years of follow-up, the cumulative risk for accidents among people with epilepsy was 17 percent at 12 months and 27 percent at 24 months, compared to 12 and 17 percent in the control group—a significant difference. For study participants, the probability of accidents not related to seizures was 14 percent by 12 months and 22 percent by 24 months. Wounds, abrasions, and concussions were each more common among people with epilepsy than in the control group.

[22] Accidents are used in this report to refer to unexpected and unintended events that lead to physical injury or death (also see Epilepsy-Related Death section).

Complications after the injury also were more common, with people with epilepsy spending more days in the hospital than the control group (Beghi and Cornaggia, 1997).

Across studies, seizure type, severity, and frequency were found to be predictors of accidents and injuries in people with epilepsy as was having more than three treatment-related adverse effects (Tomson et al., 2004). Seizure severity is associated with an increased risk for any injury and for specific injury types—burns or scalding, head injury, dental injury, and fractures. Having at least one seizure per month is associated with an increased risk for injuries, including burns or scalding and seizures while bathing or swimming; and a number of adverse events are associated with fractures and seizures while bathing or swimming (Tomson et al., 2004).

Scant data exist on injury in children with epilepsy. Among children with newly diagnosed epilepsy, 12.6 percent experienced an injury before diagnosis, most of which were presumed to be seizure related (Appleton, 2002). In a comparison of children with epilepsy who had no cognitive impairment and their peer controls, there was no difference in injury rates, and only the presence of ADHD was associated with a higher injury rate—in children both with and without epilepsy (Kirsch and Wirrell, 2001). Since children with cognitive impairment experience more seizures than those without (Aicardi, 1990; Berg et al., 2007), the absence of an increased risk for injury in this population of children with epilepsy but without cognitive impairment may reflect less severe and less frequent seizures.

Next Steps for Prevention: Accidents and Injuries

In combination, these studies suggest that prevention of accidents and injuries among people with epilepsy will be related to improving seizure control and avoiding, if possible, adverse effects of seizure medications, such as dizziness, which may themselves lead to injury. Once seizure-related accidents are eliminated from consideration, the excess accident and injury risk for people with epilepsy decreases (Beghi and Cornaggia, 2002). This finding underscores the importance of controlling risk factors for seizures. To date there have been no accident and injury prevention trials in people with epilepsy, although they are clearly needed. Such trials should focus on those at high risk for injury and build on injury prevention efforts in the general population.

The risk for fractures in epilepsy is a special case because of the possible relationship between seizure medications and impaired bone health, including changes in bone turnover and osteoporosis (Pack, 2008). This is particularly important among children with disorders that cause vitamin D deficiency (Vestergaard, 2008). A large population-based study docu-

mented increased hip-fracture risk associated with ever taking a seizure medication, particularly liver enzyme–inducing medications (Tsiropoulos et al., 2008). Other epidemiologic studies also have found an increased fracture incidence associated with the use of seizure medications and an association between seizure medications and falls, themselves a common cause of fractures (Bohannon et al., 1999; Cummings et al., 1995; Ensrud et al., 2002).

However, the association between fractures and seizure medications remains uncertain, and fractures in people with epilepsy also may be caused by the seizures themselves (Vestergaard et al., 1999). Still, given the potential role of seizure medications in the development of osteoporosis, routine screening for bone disease in epilepsy is advisable. Currently, only 41 percent of pediatric neurologists and 28 percent of adult neurologists evaluate patients with epilepsy for bone mineral disease (Valmadrid et al., 2001). Of those who screen, only 40 percent of pediatric neurologists and 37 percent of adult neurologists reported that they prescribe calcium or vitamin D supplements to patients with detected bone disease and approximately half referred patients to specialists (Valmadrid et al., 2001). Thus, a gap in practice for the prevention of fractures in people with epilepsy is screening for bone disease and treating it when it is found.

Mortality

Overall mortality is 1.6- to 3.0-fold greater in people with epilepsy than in the general population (Forsgren et al., 2005b). Among children, the increased risk of death associated with epilepsy is greater than among adults, because the usual mortality rate among U.S. children in the general population is low, whereas the expected mortality among adults increases with advancing age. Between 1950 and 1994, epilepsy-related mortality decreased among people under age 20; in adults age 70 years and older, the mortality rate first declined and then increased (O'Callaghan et al., 2000). In epilepsy of unknown cause, mortality is increased 1.1- to 1.8-fold (Forsgren et al., 2005b), with only one study showing a statistically significant mortality increase 25 to 29 years after diagnosis (Hauser et al., 1980). In epilepsy of known etiology, by contrast, mortality is increased 2.2- to 6.5-fold (Forsgren et al., 2005b). Gaitatzis and colleagues (2004b) estimated that 2 years of life are lost in people with epilepsy of unknown etiology, and 10 years in people with epilepsy of known etiology.

As noted above, among children and adults with epilepsy with known etiologies of structural or metabolic disorders, studies consistently demonstrate a statistically significant increased mortality. Mortality is highest when epilepsy is accompanied by neurodeficits, such as cerebral palsy, with mortality increasing 3- to 12-fold above that of the general population

(Forsgren et al., 1996). Most deaths in people with a known underlying cause of their epilepsy occur due to the underlying cause, such as brain tumor or stroke (which are themselves associated with an increased risk for death) (Benn et al., 2009). Many challenges remain to identify effective strategies for decreasing the risk of epilepsy-related deaths.

Status Epilepticus

SE is a common neurological emergency associated with high mortality (DeLorenzo et al., 1996; Hesdorffer et al., 1998; Logroscino et al., 1997, 2001). Most cases of SE (54 percent) are not associated with epilepsy; however, when SE is associated with epilepsy, it is usually either the first or the second time that an unprovoked seizure has been diagnosed; thus, an epilepsy diagnosis does not often exist prior to the occurrence of SE (Hesdorffer et al., 1998). Less than 20 percent of unprovoked cases of SE occur in people with an established diagnosis of epilepsy (Hesdorffer et al., 1998).

Mortality is high in the first 30 days after SE, with almost 90 percent of deaths occurring in people with acute symptomatic SE and no deaths in those with SE of unknown etiology (Logroscino et al., 1997). A 10-year follow-up study of people who initially survived more than 30 days after SE found that, of those who died, 43.5 percent of deaths occurred in acute symptomatic SE and 56.5 percent in unprovoked SE; overall, the study population had a mortality rate three times that of the general population (Logroscino et al., 2002). In people surviving who had unprovoked SE, long-term mortality over a 10-year period occurred in 43 percent of people whose seizures had a structural or metabolic cause, in 75 percent whose seizures were progressive, and in 29 percent whose seizures were of unknown cause (Logroscino et al., 2002). Risk factors for long-term mortality in SE include SE lasting 24 hours or longer, acute symptomatic etiology, and myoclonic SE (Logroscino et al., 2002).

An important question is whether SE itself is associated with death or whether death is due to an underlying etiology. This has been examined in unprovoked seizures of unknown cause, comparing mortality of people with SE to those with a brief seizure (Logroscino et al., 2008). Compared to people with brief seizure, those with SE had a 2.4-fold increased risk of death over 10 years, and increased risk was found in the group over age 65 and among those who later developed epilepsy, where there was a 5- and 6-fold increased risk for death, respectively. This suggests a specific vulnerability of older adults who experience SE of unknown etiology. Currently, the only prevention measure available for SE is early identification or recognition and treatment of a seizure lasting more than 5 minutes.

Epilepsy-Related Deaths

Causes of epilepsy-related deaths include accidents and injuries, SUDEP, and suicide. These deaths may be preventable and are the focus of the rest of this section.

Fatal accidents and injuries In population-based studies, accidents and injuries accounted for between 6 and 20 percent of all deaths of people with epilepsy (Cockerell et al., 1994; Hauser et al., 1980; Rafnsson et al., 2001; Shackleton et al., 1999). Among institutionalized people with severe epilepsy, 3 to 16 percent of deaths were due to accidents and injuries (Iivanainen and Lehtinen, 1979; Klenerman et al., 1993; Krohn, 1963), and in a hospital-based cohort, 7 percent of deaths were due to accidents and injuries (Nilsson et al., 1997). Compared to the general population, people with epilepsy have more than twice the risk of death due to accidents and injuries (Hauser et al., 1980; Rafnsson et al., 2001) and nearly six times the risk in a hospital-based cohort (Nilsson et al., 1997). Prevention measures to reduce the occurrence of deaths due to accidents and injuries in epilepsy should rely on the same interventions proposed for prevention of nonfatal accidents and injuries.

> *All of us have recollections of our first exposure to epilepsy. The stigma, the fear of the tonic-clonic episodes, the restrictions, but not death. People don't die from epilepsy. But Carei did—her death certificate reads "cause of death: SUDEP" . . . This can't be, no one told me she could die, no one ever mentioned SUDEP. . . . Research in this field has been limited, but the small amount of available literature consistently identifies risk factors. There is a significant underappreciation of mortality in epilepsy.*
>
> –Linda Coughlin Brooks

Sudden unexpected death in epilepsy As noted in Chapter 2, deaths categorized as SUDEP encompass nontraumatic, non-drowning-related deaths in people with epilepsy that may or may not be associated with a recent seizure, but are not due to SE (Nashef et al., 2012). In definite SUDEP, an autopsy reveals no evidence of an anatomical or toxicological cause of death (Nashef et al., 2012).

SUDEP is the most common of the epilepsy-related causes of death (Tomson et al., 2004). The risk of sudden death in people with epilepsy is more than 20 times greater than in the general population (Ficker et al., 1998), making efforts to prevent SUDEP of paramount importance. Current estimates suggest that the incidence of SUDEP is 0.1 to 2.3 per 1,000 person-years[23] in community samples; 1.1 to 5.9 for people treated in

[23] "Person-years" is calculated by multiplying each person being followed by the time that he or she is observed and then adding across all of the study subjects being followed. A person followed for 1 year contributes 1 person-year.

epilepsy centers, many of whom have refractory epilepsy; and 6.3 to 9.3 among those who are candidates for epilepsy surgery or who have seizures after surgery (Tomson et al., 2008). People with cognitive impairment and refractory epilepsy are particularly vulnerable populations in which the cumulative risk of SUDEP can exceed 10 percent (Sillanpää and Shinnar, 2010).

Risk factors for SUDEP have been identified in case-control studies (Hesdorffer et al., 2011b; Hitiris et al., 2007b; Langan et al., 2005; Nilsson et al., 1999; Walczak et al., 2001). A recent 40-year follow-up of childhood-onset epilepsy found recurrent seizures to be the strongest SUDEP risk factor (Sillanpää and Shinnar, 2010). Seizure-related risk factors include onset of epilepsy at an early age, ongoing frequent seizures, frequent generalized tonic-clonic seizures, and long duration of epilepsy. Neurological status, such as IQ less than 70, and the presence of a major neurological insult (e.g., stroke) also have been identified as risk factors; these are factors associated with recurrent seizures, as well. Studies have suggested that an increased risk for SUDEP is associated with frequent changes in dosing of seizure medication, use at subtherapeutic levels, polytherapy, use of lamotrigine, and nocturnal seizures (Aurlien et al., 2012; Berg et al., 2001a; George and Davis, 1998; Hesdorffer et al., 2011b; Lamberts et al., 2012; Langan et al., 2005; Nilsson et al., 1999; Walczak et al., 2001). Some authors have suggested that sleep-related disorders, such as obstructive sleep apnea, may contribute to SUDEP (Nobili et al., 2011; Surges et al., 2009). Among surgical patients in whom the seizure focus in the brain was removed, there were no cases of SUDEP, compared to 3 percent among people whose seizures continued (Sperling et al., 1999).

Although some studies have identified seizure medication polytherapy as a risk for SUDEP (Hesdorffer et al., 2011b), 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 (Ryvlin et al., 2011), not polytherapy as suggested in previous studies (Hesdorffer et al., 2011b; Nilsson et al., 1999; Walczak et al., 2001). In this analysis, the risk for SUDEP in the group treated with polytherapy at efficacious doses was seven times less than that of the group receiving add-on placebo. This provides strong evidence that polytherapy at efficacious doses actually protects against SUDEP (Ryvlin et al., 2011). Additionally, since the risk for SUDEP is higher in people with recurring seizures, these findings suggest that trial designs are needed in epilepsy that minimize the time spent on adjunctive placebo or ineffective adjunctive seizure medications. A reanalysis of the combined case-control studies supports this argument (Hesdorffer et al., 2012); after simultaneous adjustment for the number of seizure medications and the number of generalized tonic-clonic

seizures, the latter had a strong effect on SUDEP risk, whereas the number of medications did not affect SUDEP risk.

The role of continued seizures in SUDEP is further implicated by reports of witnessed SUDEP. In one study, 15 of 135 instances of SUDEP were witnessed (Langan et al., 2000), 12 of which occurred in conjunction with a generalized tonic-clonic seizure. One person shouted, "I'm going to have a seizure" and collapsed without a generalized seizure; one recovered consciousness after a seizure and collapsed; and one likely died during the postictal period. Case reports of patients who were monitored in epilepsy monitoring units when they died or nearly died from SUDEP show that all experienced a secondary generalized tonic-clonic seizure; most of these were accompanied by a flat or diffusely suppressed EEG and changes in the electrocardiogram, including asystole and premature heart beats (Bateman et al., 2010; Bird et al., 1997; Lee, 1998; McLean and Wimalaratna, 2007; So et al., 2000).

Next steps for prevention: SUDEP These and other data are very important for considering potential prevention strategies for these sudden deaths. One study has found a decreased risk for SUDEP associated with supervision at night (Langan et al., 2005), suggesting that sleeping in the same room as another adult or installing monitoring devices may offer the opportunity to help someone having a seizure during sleep. If SUDEP is related to continued seizures as suggested above, then it would be important to aggressively treat people with continued seizures and to optimize compliance with seizure medications (Chapter 7), as is done in randomized clinical trials. While it is also 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.

Suicide Deaths due to suicide accounted for 1.3 percent of deaths in a hospital-based cohort of people with epilepsy (Nilsson et al., 1997) and 1.6 to 9.1 percent in a population-based cohort (Hauser et al., 1980; Rafnsson et al., 2001). While one study failed to find a significantly increased risk of death due to suicide (Hauser et al., 1980), other studies have found a risk of suicide in epilepsy that is 3.5 to 5.8 times that of the general population (Nilsson et al., 1997; Rafnsson et al., 2001).

An increased risk for developing epilepsy is associated with both suicide attempt and major depression (Hesdorffer et al., 2006); these also are strong risk factors for later completed suicide (Harris and Barraclough, 1997). In people with epilepsy, the prevalence of suicidal ideation is 12.2 percent, with increased prevalence associated with current or past history

of major depression and generalized anxiety disorder (Jones et al., 2003). A Food and Drug Administration report implicated seizure medications in suicidality generally and in people with epilepsy in particular (FDA, 2008). Controversy exists concerning whether adverse event reporting to identify suicidality is complete and whether it may reflect reporting bias because adverse events tend to be reported more frequently by people on the active drug in comparison to those using the placebo (Hesdorffer and Kanner, 2009). Additionally, only two seizure medications had a statistically significant increased risk for suicidality, and small protective effects were observed for two others. Further observational studies have failed to clarify these associations (Hesdorffer et al., 2010).

Next steps for prevention: Suicide Suicide prevention strategies have been systematically reviewed, and those with greatest efficacy include education of physicians, restriction of the means to commit suicide, and gatekeeper education[24] (Mann et al., 2005).

- Clinicians need to know how to inform patients with epilepsy and their families about the risk for suicidal ideation when they take seizure medications, how to screen these patients for increased suicide risk, and also how to implement the screening and make referrals for mental health treatment when appropriate.
- Restricting access to highly lethal means of suicide—through firearms control, detoxification of natural gas, restrictions on pesticides, control of drugs used for intentional overdose, mandatory use of catalytic converters in cars, and barriers at jumping sites—are all ways to reduce suicide risk at the population level that can have an impact on suicide in epilepsy.
- Education of gatekeepers is needed to increase their awareness of what constitutes increased risk for suicidality and their knowledge of how to encourage at-risk individuals to seek help.

As yet, no systematic interventions have been reported that focus on preventing suicide in people with epilepsy who are at high risk. Early detection of suicidal ideation is needed for all people with epilepsy, including children (Caplan et al., 2005). Targeted interventions are needed for those who have a past or current history of suicidality, depression, anxiety, bipolar disorder, or schizophrenia. Broad-based interventions are also needed for people with

[24]In the field of suicide prevention, gatekeepers are professionals who spend time with people who may be vulnerable to suicidal ideation. Gatekeepers include a range of people, such as health professionals, teachers, coaches, law enforcement officers, and members of the clergy.

epilepsy generally because epilepsy itself is associated with an increased risk for suicide (Christensen et al., 2007).

Stigma

As described in Chapter 1, over time people with epilepsy have been subject to stigma based on misinformation and misconceptions about epilepsy. Historically, the legal system was used to limit the rights of people with epilepsy (Alström, 1950; Jacoby, 2002). Recent research comparing attitudes of lay people regarding acquired immune deficiency syndrome (AIDS), epilepsy, and diabetes demonstrated that prejudice scores for epilepsy were just below those for AIDS and noticeably higher than those for diabetes (Fernandes et al., 2007). In the United States, two important studies, one of adults and another of adolescents, reported on institutional and interpersonal stigma (Austin et al., 2002; DiIorio et al., 2004). They found that lower levels of knowledge about epilepsy were associated with these types of stigma, they identified negative stereotypes, and they described personal and social avoidance. Interventions to reduce stigma in the general public require public education and awareness campaigns (Chapter 8). Negative attitudes are reflected in the internal experience of "difference" and fear of prejudice experienced by people with epilepsy, called "felt" or internalized stigma (Jacoby, 1994; Jacoby and Austin, 2007). This section focuses on the internalized experience of stigma.

Stigma is related to continued seizures and therefore is less likely to be experienced by people whose seizures are in remission than by those with ongoing seizures (Jacoby, 2002). Among people with prevalent epilepsy, who by definition have ongoing seizures or are taking seizure medications, the perception of stigma has been associated with increased depression and poor health status, as well as poor quality of life (Baker, 2002; Jacoby and Baker, 2008; Kumari et al., 2009; Reisinger and DiIorio, 2009). Furthermore, results from a study conducted by DiIorio and colleagues (2003) suggest that felt stigma negatively affects self-management skills. Felt stigma is present in one-fifth of people with newly diagnosed epilepsy, with more newly diagnosed people reporting felt stigma if they also had a lifetime history of major depression; this association remained a year later (Leaffer et al., 2011). The relationship among felt stigma, negative outlook on life, and increased levels of worry has been described in populations with prevalent epilepsy (Baker et al., 2000).

Next Steps for Prevention: Stigma

Interventions to reduce depression or negative outlook on life in people with prevalent epilepsy may also reduce felt stigma. Additionally, interven-

tions to decrease a negative outlook and foster self-esteem may prevent the development of felt stigma for people with newly diagnosed epilepsy who have a past history of depression.

CONCLUSION

There are a number of opportunities for the public health community to improve efforts to prevent epilepsy and its consequences. Throughout this chapter, the committee has provided the basis for its research priorities and recommendations regarding improvements needed to achieve this goal in Chapter 9. Further research is needed to improve knowledge about epilepsy's incidence, prevalence, risk factors, comorbidities, and outcomes, which will inform future prevention efforts. For example, research is needed to determine if treatment of mental health comorbidities and behavioral interventions improve health outcomes for people with epilepsy, including reduction in seizure frequency.

Actions are needed to prevent risk factors for epilepsy. Neurocysticercosis, which is a growing concern in the United States, represents a known risk factor for epilepsy where education and sanitary measures could decrease infections and resulting cases of epilepsy. Continued intervention efforts are needed to prevent the occurrence of TBI, through mechanisms such as the use of seatbelts, to prevent TBI associated with motor vehicle accidents, as well as helmets, including improved helmet design, to reduce the occurrence and severity of TBI in sports and military combat. In addition, progress in the prevention of other risk factors—such as stroke, through targeted efforts to reduce risk factors, and brain infections such as meningitis, through sustained vaccination programs—will likely result in fewer new cases of epilepsy. Further opportunities for primary prevention may come to light if epidemiologic studies identify other risk factors for epilepsies whose etiologies are currently unknown. Secondary prevention of seizures may be possible through the use of antidepressants.

While risk factors for accidents, injuries, and suicide are generally known, there is less information on risk factors specific to people with the epilepsies. This information is needed in order to design tertiary prevention efforts. Additionally, 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. Further, the implementation of screening for bone disease, mental health comorbidities, suicidality, and felt stigma will identify populations for whom tertiary prevention measures are needed.

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4

Health Care: Quality, Access, and Value

While significant progress has been made in developing seizure medications with fewer adverse effects, as well as in refining medical devices and surgical techniques for select types of epilepsy, much remains to be done to reduce the sometimes lengthy delays in diagnosis and referral to more advanced levels of care, to improve access to care for underserved and rural patients, to improve co-management of patients between primary care and specialty providers, and to improve care for those with refractory epilepsy. Efforts are ongoing to improve the quality of epilepsy care through the development and implementation of physician performance measures and other performance metrics. Involvement of epilepsy centers is critical to providing specialized care. Clarifying the role of primary care providers in epilepsy care is also crucial as is delineating clinical pathways and decision points for referrals. A patient-centered approach to health care is needed with an emphasis on the coordination of epilepsy-specific services with care for comorbidities and with links to community services. Actions needed to ensure that health care for people with epilepsy is evidence based, population based, and patient centered include accrediting epilepsy centers and establishing a network of centers, developing and implementing a quality care framework and performance measures, and enhancing the screening and referral options and protocols for early identification of epilepsy in high-risk populations, of comorbidities, and of refractory epilepsy.

My daughter (now 16) started having seizures when she was 9. Her first seizure was big and we thought she was dying . . . maybe she was having

a brain hemorrhage . . . we couldn't figure it out. It was terrifying. . . . We were very blessed to meet a good neurologist from the start. He was rare—a small town doctor with the big town connections. . . . He encouraged us to get a second opinion and was extremely accessible to us. He had personal experience with epilepsy in his family, a real plus. In my volunteering with the Epilepsy Foundation of Virginia, I have encountered many people whose neurologists did not refer them to an epileptologist or a neurologist with a special interest in epilepsy.

–Laurie Kelly

Like other rural-frontier populations, Wyoming's citizens continually face problems in accessing quality health care and health education. Health care accessibility is particularly problematic in Wyoming, where distance, geography, inclement weather, and isolated communities all present challenges for the state's residents in gaining education and access to health care.

–Richard Leslie

Improving the lives of people with epilepsy and their families involves sustained and coordinated efforts, ranging from increasing the understanding of the biomedical mechanisms of the disorder to enhancing clinical treatment and community services. Because epilepsy is a common neurological disorder that can have many physical, psychological, cognitive, and social manifestations, quality care may require the knowledge and skills of a wide range of health and community service professionals and necessitate that people with epilepsy, family members, and caregivers are knowledgeable about the disorder, can recognize potential danger signs, and are skilled in self-management as appropriate.

The committee's vision for improving health care for people with epilepsy is that all individuals with epilepsy should have access to patient-centered care that incorporates a comprehensive and coordinated approach to addressing the physiological, psychological, cognitive, and social dimensions relevant for each person and his or her family. This care is best delivered by a coordinated team of professionals that can assess and treat all facets of the patient's condition and comorbidities and can integrate appropriate community services.

As highlighted in the Institute of Medicine (IOM) report *Crossing the Quality Chasm*, "Health care should be:

- *Safe*—avoiding injuries to patients from the care that is intended to help them
- *Effective*—providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit (avoiding underuse and overuse, respectively)
- *Patient-centered*—providing care that is respectful of and respon-

sive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions
- *Timely*—reducing waits and sometimes harmful delays for both those who receive and those who give care
- *Efficient*—avoiding waste, including waste of equipment, supplies, ideas, and energy, and
- *Equitable*—providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status" (IOM, 2001, pp. 5-6).

This chapter begins with an overview of epilepsy care (patterns of care, diagnosis, and treatment), followed by a discussion of the key components of improving care—quality, access, and value; it concludes with the committee's model of patient-centered, collaborative, and high-quality epilepsy care. A comprehensive and coordinated approach to health and human services is explored in this and subsequent chapters.

OVERVIEW OF EPILEPSY CARE

Patterns of Care

As noted in Chapter 1, when someone first has a seizure the initial medical visit is generally to the emergency department or primary care provider.[1] Some health systems have first seizure clinics that explore potential diagnoses (Hamiwka et al., 2007), or patients may be referred to a general neurologist or an epileptologist, particularly if seizures recur frequently; however, little is known about referral patterns other than that there is tremendous variability. The likelihood of a referral may vary according to the seriousness of the patient's condition, including the presence of comorbidities; the patient's age; demographic and social factors; the preferences of the patient, family, and health professionals involved; and availability of specialized health professionals. A community-based survey of people with epilepsy explored views and experiences of epilepsy care and found that primary care providers were the first health professionals consulted by 58 percent of respondents (Fisher et al., 2000b). During the course of their disorder, almost all (94 percent) had consulted a neurologist at some point, with 62 percent having a neurologist as their primary physician for epilepsy care at the time of the survey. Respondents were more likely to have consulted a neurologist if they had been diagnosed within the previous

[1] Throughout the report, the term "primary care provider" is used to encompass many health professionals, including family physicians, general internists, general pediatricians, obstetrician-gynecologists, geriatricians, physician assistants, and nurse practitioners.

year, had a seizure in the previous month, were diagnosed before age 12, or had multiple seizure types.

To obtain more information on patterns of epilepsy care, four different health care and surveillance systems (Geisinger Health System, Henry Ford Health System, South Carolina Epilepsy Surveillance System, and the Veterans Health Administration) agreed to assist the committee by querying their databases on health care utilization patterns of people with epilepsy. The data provided by these systems (Appendix B) highlight the variability in patterns of care, but they also reveal three common initial points of care where people are first evaluated: (1) in the hospital emergency department, (2) with a referral to a neurologist, or (3) during a regular visit with a primary care provider. Across the four systems, from 32 to 71 percent of patients' first encounters were with neurologists. Evidence from several of these systems suggests that people with new-onset epilepsy use more health services than people with prevalent epilepsy. However, the types of services received during the initial year after diagnosis, such as the number of physician visits or diagnostic procedures performed, varied widely across systems. Evidence from some of the health systems seems to confirm that care of individuals with ongoing epilepsy (prevalent epilepsy) tends to stabilize over time, but again, the patterns varied among systems and also among subgroups within each system. For example, over the course of a year, 14 to 48 percent of epilepsy patients were treated in emergency departments, 8 to 55 percent were hospitalized, 21 to 75 percent had a neurologist visit, and 68 to 100 percent received seizure medications. The range in percentages of patients receiving seizure medications was more consistent across sites, ranging from 70 to 80 percent. More needs to be learned about these patterns of care and the extent to which variations in care affect patient outcomes.

Information about patterns of care from non-neurologist health professionals could not be obtained. Although nurses, social workers, psychologists, psychiatrists, and vocational specialists are all described as important members of an interdisciplinary epilepsy care team (Labiner et al., 2010), whether and when patients or families are seen by these professionals varies between health systems. A clearer understanding of how multidisciplinary teams are best implemented and of the individual roles of health professionals in the care trajectory is needed to identify best practices and improve quality of care.

Diagnosis of the Epilepsies

Accurately diagnosing epilepsy is challenging because clinicians rarely have the opportunity to observe seizures and there are many types of seizures and epilepsy syndromes with differing presentations. A clinician

typically diagnoses epilepsy based on the patient's self-report or a family member's report of seizures and the patient's medical history. This is complicated by the fact that a number of medical conditions that are not epilepsy can look like seizures (Chapter 1). Diagnostic tests can provide relevant information, usually starting with the electroencephalogram (EEG) (Table 4-1). However, because the typical duration of an EEG is only 20 to 45 minutes, it is unlikely to coincide with an actual seizure. Further, the initial EEG may not show evidence of seizures in approximately half of people with epilepsy (Marsan and Zivin, 1970; Salinsky et al., 1987). Continuous video-EEG monitoring, which can last from hours to days and is usually conducted in a hospital setting, is often the only way to definitively diagnose the type of seizure and affected areas of the brain.

TABLE 4-1
Diagnostic Studies Used in Evaluating and Treating People with Epilepsy

Diagnostic Tests	Description	Indication
Electroencephalograph (EEG)	Measures electrical activity in the brain	Useful for any individual with suspected seizures
Continuous video-EEG monitoring	Combines long-term EEG recording with video recording of an individual's behavior	Useful in determining seizure type; essential for patients undergoing a surgical evaluation for epilepsy
Magnetic resonance imaging (MRI)	Uses magnetic fields to detect structural abnormalities in the brain	Useful for imaging the brain for lesions such as tumors and scar tissue
Computerized tomography (CT)	Uses radiation to detect structural abnormalities in the brain	Useful for detecting structural abnormalities such as tumors as well as hemorrhages
Magnetoencephalography (MEG)	Uses magnetic signals to detect abnormalities in the brain's electrical activity	Useful primarily for patients undergoing surgical evaluation
Positron emission tomography (PET) or single positron emission tomography (SPECT)	Uses radioactive tracers to assess glucose metabolism or blood flow in the brain	Useful in determining the area of the brain where seizures arise since these areas typically have decreased glucose metabolism and blood flow in between seizures
Genetic or metabolic testing	Uses blood, urine, and spinal fluid tests to determine if there is a genetic cause of the epilepsy	Useful for diagnosing epilepsy-related genetic or metabolic disorders. Although many tests are available, there is not yet a standard screen

SOURCES: Chandra et al., 2006; Engel, 1984; Erbayat Altay et al., 2005; Knake et al., 2006; McNally et al., 2005; Provenzale, 2010; Stockler-Ipsiroglu and Plecko, 2009; Thadani et al., 2000; Wheless et al., 2004.

Advances in technology permit family members and other caregivers to record seizures as they occur. Kotani and colleagues (2007) described a case study where the mother of a teenager with epilepsy was able to capture his seizure on a cell phone camera, which a doctor had not been able to diagnose due to seizure infrequency. Similarly, the improved visualization of seizures through digital cameras with video capabilities and video monitoring in home settings may be particularly beneficial for individuals with infrequent seizures or with more than one type of seizure and for those who do not have easy access to epileptologists and epilepsy monitoring units. Also, the recording of seizures using web-based tracking systems, diaries, or journals can help people with epilepsy and their families maintain records of seizure activity and evaluate patterns with their health care provider (Le et al., 2011). The observation of seizure patterns can help identify a target for medication and lifestyle interventions to improve seizure management.

Treatment of the Epilepsies

For many people with epilepsy, current treatment options are effective in reducing or eliminating seizures. However, medication side effects are a concern, and approximately one-third of people with epilepsy do not respond to medications (Kwan and Brodie, 2000). This report provides only a brief overview of the treatments for epilepsy and its comorbidities, which need to be tailored to the unique diagnostic and treatment considerations of specific individuals and also of specific populations, some of which are highlighted in Table 4-2.

Seizure Medications

The primary method of treatment for the epilepsies is medication aimed at controlling seizure recurrence, typically by decreasing brain excitation or increasing brain inhibition. In a population-based survey, Kobau and colleagues (2008) found that among adults reporting they have active epilepsy, 93 percent were currently taking a medication, and 55 percent had no seizures in the previous 3 months (Table 4-3).

The first medication to be used in the treatment of epilepsy in the 1800s was potassium bromide; more than 35 seizure medications have been introduced since then (Figure 4-1) (Loscher and Schmidt, 2011). Initially medications were developed that blocked sodium channels in neurons, resulting in reduced brain excitation or increasing inhibition of neurons through activation of inhibitory receptors (Brodie, 2010; Rogawski and Loscher, 2004). In the past 20 years, a better understanding of the pathophysiology of the epilepsies and epileptogenesis (the process by which epi-

TABLE 4-2
Diagnostic and Treatment Considerations for Specific Populations

Population	Diagnostic and Treatment Considerations
Children	• Diagnostic challenges of age-related clinical and electroencephalograph features of seizures • Different side effects and dosing schedules for medications • Identifying seizure medication formulations determined to be appropriate for children • Potential lifelong cognitive and disabling effects of seizures suffered during childhood • Helping children begin to take responsibility for self-management • Education of school personnel in recognition and treatment of seizures
Youth	• Impact of hormonal changes on seizures, side effects of medications, drug interactions, and comorbidities • Increased responsibilities for self-management • Impact of seizures, treatment, and comorbidities on educational and vocational planning and on driving and transportation
Older adults	• Potential for drug interactions with medications for other health conditions • Possible cognitive side effects of some medications • Increased potential for injury • Self management may be in jeopardy, depending on cognitive functioning caregiver assistance may be needed
Women	• Susceptibility to changes in seizures during menstrual cycle or at other times of hormonal fluctuations (e.g., menopause) • Potential impact of seizures and/or medications on reproductive functioning, pregnancy, breastfeeding • Risk for malformations and impaired cognitive development of offspring of women taking seizure medications or suffering seizures during pregnancy
Individuals with intellectual disabilities	• Communication difficulties may hamper diagnosis and ability to delineate the seizure type • Assessing drug toxicity or treatment side effects in patients with severe intellectual disabilities may be challenging • High risk of injury from seizures and side effects of medications • High rate of psychiatric comorbidities
Underserved populations	• Reduced treatment options relative to access to health services • Medication adherence • Other access and health literacy issues, including language barriers and the need, in some cases, for medical interpreters • High rates of comorbidities
People with traumatic brain injury	• Seizures associated with brain injury may be missed or misdiagnosed as mental health conditions or other physical problems • Seizure medications must be selected carefully to avoid exacerbating other problems of traumatic brain injury
Oncology patients	• Interactions of seizure medications with chemotherapeutic drugs that may decrease concentrations of chemotherapeutic agents in the body

TABLE 4-3
Adults with a History of Epilepsy, Behavioral Risk Factor Surveillance System, 2005

	Total with History of Epilepsy (n = 1,626)	Active Epilepsy[a] (n = 919)
Currently taking medication to control seizure disorder or epilepsy		
Yes	48.8 (44.1-53.6)	93.1 (90.3-95.1)
No	51.2 (46.4-55.9)	6.9 (4.9-9.7)
Number of seizures in previous 3 months		
None	71.0 (66.5-75.2)	55.1 (48.6-61.5)
One	8.1 (5.8-11.1)	15.3 (11.1-20.7)
More than one	15.0 (11.9-18.9)	28.6 (23.0-34.9)
No longer have	5.9 (4.0-8.6)	1.0 (0.3-2.8)[b]

[a]Defined as having been told by a doctor they had a seizure disorder or epilepsy and also responded that they were currently taking medication for epilepsy, had 1 or more seizures in the previous 3 months, or both.

[b]Respondents who reported taking medication for epilepsy.

SOURCE: Kobau et al., 2008.

lepsy develops), as well as the development of animal models that mimic clinically relevant forms of the disorder, have resulted in medications with other specific mechanisms of action that achieve the same effect but with fewer side effects. These mechanisms include targeting calcium and potassium channels and the synaptic release and uptake of neurotransmitters (Brodie, 2010; Loscher and Schmidt, 2011; Rogawski and Loscher, 2004). Seizure medications can be categorized into those used to stop seizures and those used to prevent them. Drugs used to stop seizures are typically given intravenously, rectally, intranasally, or buccally. For example, status epilepticus is treated with intravenous lorazepam, diazepam, phenobarbital, or phenytoin (Abend et al., 2010). Rectal diazepam is often used in children as an outpatient rescue medication to stop seizures (Poukas et al., 2011). The vast majority of seizure medications are used in chronic therapy and taken daily. Chronic seizure medications are either broad-spectrum drugs that are effective in treating a variety of different seizure types or narrow-spectrum drugs that are primarily effective for specific seizure types (e.g., absence, myoclonic, tonic-clonic).

Despite the large number of available drugs for epilepsy, patients remain concerned about the effectiveness of medications in controlling seizures, side effects (e.g., headache, fatigue, cognitive impairment), being able to establish an appropriate dosing schedule, and the high cost of some medications (Fisher et al., 2000b). In a community-based survey, approximately one-third of people with epilepsy reported that they were not

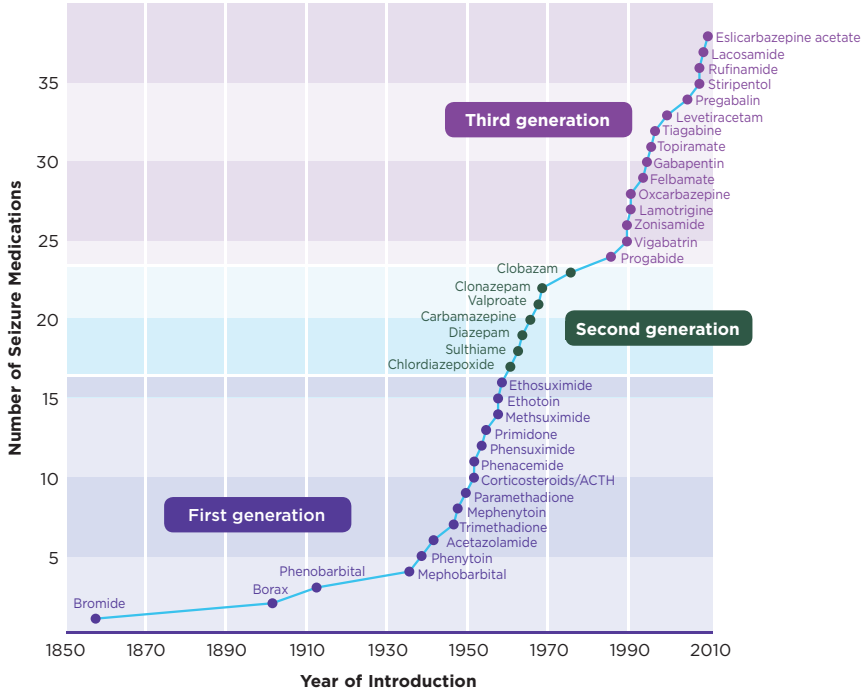

FIGURE 4-1
Seizure medications.

NOTE: Some medications are not available in the United States.

SOURCE: Loscher and Schmidt, 2011. Reprinted with permission from John Wiley and Sons.

fully satisfied with their current seizure medication(s) and noted a range of problems including issues with cognition, energy level, and sexual function (Fisher et al., 2000b).

For people whose seizures do not respond to medications, surgery or medical devices are potential treatment options. However, not all types of epilepsy are amenable to surgery. Today, surgically remediable epilepsy syndromes are easier to recognize than they were previously, largely because of improvements in magnetic resonance imaging (MRI) and other imaging technologies, which allow noninvasive identification of areas in the brain with abnormal neural function. Unfortunately, the length of time from seizure onset to surgery remains quite long, averaging 17 to 23 years (Choi et al., 2009; Cohen-Gadol et al., 2006; Haneef et al., 2010) (see later discussion of access).

A randomized controlled study found that 58 percent of people with mesial temporal lobe epilepsy who received epilepsy surgery were free

of disabling seizures by the end of the first year, compared to 8 percent among those who continued with medical therapy for 1 year (Wiebe et al., 2001). Long-term outcomes also are promising. De Tisi and colleagues (2011) found that 52 percent of adults who had undergone epilepsy surgery remained seizure-free (excluding simple partial seizures) 5 years after surgery and 47 percent were seizure-free after 10 years. Promising new, less invasive types of surgery for epilepsy are being evaluated (Chang and Huang, 2011).

An evidence review that was conducted to develop practice parameters for epilepsy surgery found that surgery's benefits outweighed the benefits of continued medical therapy in people with mesial temporal lobe epilepsy, while not posing greater risk, and recommended consideration of referral to an epilepsy surgery center for individuals with refractory seizures (Engel et al., 2003). The biological, psychological, and social consequences of uncontrolled seizures have been well documented, but the timing of when these problems develop varies, complicating decisions regarding the timing of surgery. For many people, cognitive and behavioral problems are found early in the course of their epilepsy, and questions may arise as to whether surgery could prevent these problems from becoming disabling. Variability among epilepsy types and syndromes also complicates the question about when or if to consider surgery. This complexity is particularly true for children, some of whom stop having seizures when they get older (Berg et al., 2006; Langfitt and Wiebe, 2008). Further study is needed to assess the most beneficial timing of surgery, as well as its long-term results, impact on quality of life, and effectiveness compared to other forms of treatment.

Devices implanted to electrically stimulate the vagus nerve have been found to reduce or eliminate seizures in some individuals (DeGiorgio et al., 2000, 2001, 2005; Elliott et al., 2011; Handforth et al., 1998; Uthman et al., 2004). Studies of vagus nerve stimulation in adults showed a mean seizure reduction of 49 to 64 percent 2 years after implantation, with the number of seizures at least halved for 43 to 75 percent of patients (Rossignol et al., 2009). This technique also was shown to be cost-effective within 1.5 years of implantation (Helmers et al., 2011). Results among children with epilepsy have been variable (Englot et al., 2011; Rossignol et al., 2009); however, vagus nerve stimulation appears particularly effective for those with Lennox-Gastaut syndrome (Englot et al., 2011; Frost et al., 2001; Rossignol et al., 2009). Other forms of brain stimulation being tested include deep brain stimulation and focal responsive brain stimulation (Morrell, 2011). At present, these invasive therapeutic approaches are reserved for patients who are not good candidates for surgery.

Additional Treatments

Several additional types of treatments have been found to be helpful for controlling seizures, teaching people how to manage their epilepsy, and improving quality of life. Some of these therapies, such as behavioral therapy, are used as complements to medical treatment, while some—such as dietary therapy—may be used as a form of medical therapy. Further efforts are needed to study the effectiveness of some of these therapies.

Dietary therapy is a treatment modality often tried for children with epilepsy. The observation that individuals with epilepsy have fewer seizures during fasting led to diets that reduce carbohydrate ingestion and induce ketosis (Wheless, 2008). Several small studies have shown reductions in seizures for people with epilepsy who adhere to the ketogenic diet, medium-chain triglyceride diet, modified Atkins diet, or low-glycemic-index diet (Kossoff et al., 2009; Payne et al., 2011); however, more research is needed in larger populations. Further, dietary therapy is rigorous, requiring daily adherence to a strict schedule, which can be a challenge for both the individual with epilepsy and his or her family (Kossoff et al., 2009). Many physicians are reluctant to recommend dietary therapy because of the difficulty of adherence and the need for close monitoring by a dietician and clinician.

Certain types of behavioral therapy can be considered a form of self-management[2] (the strategies people use to manage their epilepsy and its effects on their daily life). A behavioral therapy is usually intended to change unhealthy behavior and promote positive or healthy behavior. Many of these strategies overlap with educational efforts for patients and families (Chapter 7). For example, trigger management involves teaching people how to recognize or identify possible seizure triggers by observing environmental, personal, or lifestyle factors (such as lack of sleep, flashing lights, fever, or excessive alcohol consumption) that appear to increase their susceptibility to seizures. For many people, seizure control can improve if they avoid these triggers. Teaching about trigger management and lifestyle modifications is a frequent component of epilepsy care provided by nurses and social workers (Legion, 1991; Shafer, 1994).

Other behavioral approaches include seizure control using relaxation, yoga, biofeedback, and counseling; self-control approaches or acceptance and commitment therapy using individual and group sessions; and mind-body techniques (Andrews and Schonfeld, 1992; Lundgren et al., 2006, 2008a,b; Snead et al., 2004; Wagner et al., 2010). Relaxation treatment studies, while limited in number, generally show positive results in reducing seizures and improving quality of life (Dahl et al., 1987; Puskarich et al.,

[2]As noted in Chapter 1, the committee adopted the concept of "optimal self-management," recognizing that it represents a wide range of possibilities and that what is optimal for one person may be beyond the capacity of another.

1992; Rousseau et al., 1985). All such approaches need rigorous review. Other behavioral treatments frequently taught to people with epilepsy and their families focus on knowledge about safety and adapting behavior to prevent injuries (Shafer, 1998). These techniques are generally incorporated into educational programs or cognitive-behavioral techniques for epilepsy self-management.

IMPROVING QUALITY OF HEALTH CARE

I wish we had more information about our daughter's seizures. We worry that the staring spells are interfering with her ability to learn, but since we cannot see them on the EEG we don't know for sure how to treat them. It is very worrisome to make decisions without more information. We hope that increased research in the field of epilepsy might provide more information into seizure activity and treatment for people like our little daughter.

–Jon VanWagoner

You would think finally armed with a correct diagnosis, things would get easier. We were educated advocates with resources and FedExed Mark's MRI and reports to the top international pediatric neurosurgeons and centers worldwide. The diversity of recommendations returned was overwhelming.

–Ilene Miller

Quality has been defined by the IOM as "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge" (IOM, 1990, p. 21). Priority areas identified by the committee for improving quality of health services for the epilepsies include the following:

- Improve the early identification of epilepsy and comorbid conditions.
- Improve treatments.
- Improve communications between the care team and patients.
- Develop a national quality framework for epilepsy care, which involves improving and implementing practice guidelines and developing, implementing, and assessing performance metrics to enhance the quality of epilepsy care.
- Evaluate and accredit epilepsy centers.

This section discusses each of these priority areas and makes suggestions for next steps.

Early Identification of Epilepsy and Comorbid Health Conditions

As discussed in Chapter 3, prevention efforts are needed for epilepsy and comorbid health conditions. A key step toward prevention involves screening efforts, which promote the early identification and diagnosis of epilepsy in populations that may be at risk (e.g., older adults who have had a stroke, children with autism spectrum disorders) and the early identification and diagnosis of comorbid conditions in people diagnosed with epilepsy. The public health value of screening tests is that they provide the early identification of a disease or a disorder that can lead to early intervention, which can potentially eliminate or reduce the health consequences for the individual and reduce the burdens and costs on the health care system.

The state of screening tests and guidelines relevant to epilepsy and its comorbid conditions varies widely. Screening tests for epilepsy (prior to seizure occurrence) that could be used at a health screening or annual physical are not yet available. Research is needed to develop and validate tests and guidelines for early identification that are specific to this disorder. Currently, clinicians may inquire about seizures or seizure symptoms by asking questions about unexplained and episodic changes in awareness, movement, sensation, or behavior. The occurrence of frequent injuries, academic decline, mood changes, or developmental delay may trigger more detailed inquiry into the possibility of seizures or comorbid conditions. In addition, a screening test or protocol is needed that could identify individuals with persistent seizures who need to be referred to an epileptologist for further evaluation and treatment. As discussed later in this chapter and throughout the report, referrals of patients with refractory epilepsy to epilepsy centers often take more than 15 years and the goal is to move toward earlier referral patterns.

Early detection tests for some comorbid conditions relevant to epilepsy, such as bone disease, are fully validated, readily available, and commonly conducted as a part of annual physicals and health screenings for specific populations (e.g., women over the age of 65) (U.S. Preventive Services Task Force, 2011); however, these tests are not consistently administered in people with epilepsy (Chapter 3). While rapid or easily administered screening tests for cognitive impairment that could be conducted in health screenings or at annual physicals are not yet available, validated screening tests are available for depression, anxiety, and attention deficit hyperactivity disorder (Richardson et al., 2010). More complex tests, such as neuropsychological evaluations, are fully validated and available, but they are more time-consuming and not suitable for an initial screen (Chapter 6).

Once well-tested screening tests and guidelines are approved and established, mechanisms should be developed to institute the dissemination and widespread adoption of epilepsy screening as a part of standard health checkups (e.g., following similar timing as the pediatric immunization

schedule or as part of the protocols for follow-up of people who have an increased risk of developing epilepsy, such as those who have had a stroke, brain cancer, or traumatic brain injury) and in routine health screening programs (e.g., Medicaid's Early and Periodic Screening, Diagnosis, and Treatment program). Additionally, the screening of people with epilepsy for at-risk conditions, including mental health conditions and impaired bone health as a side effect of some seizure medications, needs to be part of the standard protocol for epilepsy care.

Improving Treatment of the Epilepsies

Improving Seizure Medications

Side effects One of the major challenges with some seizure medications has been their adverse side effects. Older seizure medications have been associated with clinically significant problems with cognitive function (e.g., memory, attention, speed of mental processing), mood and behavioral disorders, and in some cases, birth defects when exposure occurs during pregnancy (Brunbech and Sabers, 2002; Meador, 2002; Vining et al., 1987). Although the newer seizure medications are similar in efficacy to first-generation medications, they appear to have better tolerability and fewer side effects (AHRQ, 2011; Brodie et al., 1995; Elger and Schmidt, 2008; Meador et al., 1999, 2001). Improving efficacy and further reducing adverse effects are ongoing goals for seizure medication development.

More information is needed about the efficacy and tolerability of the newer medications for patients with specific epilepsy types and syndromes, such as juvenile myoclonic epilepsy, Lennox-Gastaut syndrome, and absence epilepsy. Furthermore, relatively little information is available on the risks and benefits of the newly introduced seizure medications in vulnerable populations, such as children, pregnant women, and older adults.

Generic medications Because of the lower costs of generic versions of brand-name seizure medications, people with epilepsy may be switched to generic formulations once they are released to the market. In the epilepsy community, discussions continue regarding the safety of changing from brand-name to generic medications or from one generic manufacturer to another, because current studies have mixed conclusions (Andermann et al., 2007; Kesselheim et al., 2010; Sander et al., 2010; Yamada and Welty, 2011). The concern is that differences in bioequivalence between different manufacturers may increase the risk of seizures or adverse events (Andermann et al., 2007). Studies are needed to understand the extent of any variability in efficacy between brand-name seizure medications and their generic formulations, including variations in side effects. Patients need

to be informed about potential changes in their seizure medications (including switching to generics or between generics), and efforts are needed to ensure that medication choices are not driven solely by cost considerations.

Medication adherence Adhering to a medication regimen is a significant challenge for many people with epilepsy. A retrospective review of claims data for adults with epilepsy found that 39 percent did not follow their prescribed regimen at some point during the 27-month follow-up period (Davis et al., 2008). Lack of adherence was associated with an increased likelihood of hospitalization or admission to the emergency department and with increased inpatient and emergency care costs of $1,799 and $260, respectively, per patient per year. Similar results were found in a multiyear study of Medicaid costs in three states, which found that poor adherence can have significant adverse health effects and result in increased mortality and increased hospital and emergency department costs (Faught et al., 2008, 2009).

Understanding the patient perspective on taking medications is critical in developing strategies to promote adherence and, ultimately, to improve seizure control. Among the most commonly reported fears expressed by people with epilepsy (such as experiencing a seizure or losing control during a seizure) is concern about having side effects from taking seizure medications (Fisher et al., 2000a,b; Kucukarslan et al., 2008). An online survey of adults with epilepsy and health care providers supports these conclusions and anecdotal reports suggest that common reasons for not sticking with a prescribed regimen include forgetting to take the medication and not having it available (Hovinga et al., 2008). Methods of managing medications are critical self-management skills that include tracking pill taking, using pill dispensing boxes, using reminders and alarms, modifying lifestyles to make medication taking easier, and participating in counseling to identify and work to overcome other barriers to medication management.

Ensuring appropriate use of seizure medications For epilepsy patients, excessive drug load can lead to suboptimal outcomes, including greater incidence or severity of side effects or even increased frequency of seizures (Perucca and Kwan, 2005; Schmidt et al., 2002). An excessive drug load can occur when one or more seizure medications is not the right choice for the individual's specific disorder, when higher-than-necessary dosages are prescribed or used, or when medication interactions are not considered. Tailoring epilepsy therapy to meet the needs of the individual patient is one element of the art of epilepsy management (Perucca and Kwan, 2005). As noted by Perucca and Kwan (2005), "Even though the importance of complete seizure control cannot be overemphasized, no patient should be made to suffer more from the adverse effects of treatment than from

the manifestations of the seizure disorder" (p, 897). For some patients with epilepsy, the medication burden can be reduced without increasing seizures (Bourgeois, 2002; Chuang et al., 2007; Pellock and Hunt, 1996). To reduce the inappropriate use of seizure medications, clinicians should assess whether some drugs can be safely reduced, substituted, or eliminated—and at what pace—and should examine potential pharmacokinetic interactions with medications treating comorbidities (Bourgeois, 2002). Decision-support tools for use in seizure medication management are being developed (Legros et al., 2012), and further such efforts are needed.

Comparative effectiveness Approximately half of all treatments delivered today for a wide range of health conditions have not been examined for evidence of effectiveness (IOM, 2009b). Comparative effectiveness research involves comparison of the benefits and harms of various methods of preventing, diagnosing, treating, or monitoring a clinical condition or comparison of various mechanisms of delivery of care (HHS, 2009). Given the many approaches (e.g., medications, devices, surgery, diets, behavioral interventions) used to treat epilepsy, comparative effectiveness studies would be valuable in providing rigorous assessment of these options for different types of epilepsy. Standardized measures and outcomes need to be applied in comparative effectiveness studies in order to determine which medical and nonmedical measures may be most beneficial in different population groups or settings. Determining the most effective therapies would provide the information that people with epilepsy, clinicians, payers, and policy makers need to make informed decisions about improving epilepsy care at both the individual and population levels.

One of the challenges of conducting comparative effectiveness research in epilepsy is specifying the methods and measures that should be used to collect data on the range of outcomes of interest. Seizure frequency is a widely used measure of the clinical efficacy of epilepsy medications, both in clinical practice and in research protocols (Marson et al., 1996). However, the relationship between seizure frequency and the degree of disability resulting from the seizures is poor, and instruments that are sensitive to the behavioral, affective, and cognitive comorbidities and other problems that frequently complicate the management of epilepsy need wider implementation. Such measures include the 31-item Quality of Life in Epilepsy Inventory, Beck Depression Inventory II, Beck Anxiety Inventory, Children's Depression Inventory, Hospital Anxiety and Depression Scale, Multidimensional Health Locus of Control scale, and the International Classification of Functioning, Disability, and Health (Cramer et al., 1998; Ronen et al., 2011; Sperling et al., 2008; Tracy et al., 2007) (Chapter 2). These measures focus not only on freedom from seizures but also on improved quality of life and decreased disability.

Determining priorities for comparative effectiveness studies is the first important step (Dubois and Graff, 2011). The Patient-Centered Outcomes Research Institute established under the Patient Protection and Affordable Care Act of 2010 (ACA) (P.L. 111-148) is an independent nonprofit organization charged with identifying national priorities for research on patient-centered outcomes (PCORI, 2012). Because there are numerous treatment and management approaches for epilepsy, the research, clinical, and patient communities need to identify priorities for comparative effectiveness research for epilepsy treatment.

Improving Treatment for the Refractory Epilepsies

Epilepsy treatment should be directed to preventing seizures whenever possible and achieving control early in the course of the disorder (Sperling, 2004). While the majority of individuals with epilepsy respond well to seizure medications, approximately one-third continue to have seizures, despite trying multiple medications (Kwan and Brodie, 2000). The operational definition of refractory epilepsy is the failure to control seizures after two seizure medications (whether as monotherapies or in combination) that have been appropriately chosen and used (Kwan et al., 2010). A recent study shows that failure to respond to the first seizure medication predicts an increased risk for refractory epilepsy and adverse health outcomes (Perucca et al., 2011).

Refractory epilepsy often has significant adverse effects on physical, psychological, cognitive, social, and vocational well-being. Individuals with refractory epilepsy are at higher risk for a shortened life span, excessive bodily injury, neuropsychological and mental health impairment, and social disability (Sperling, 2004). Mortality rates are substantially higher in people with refractory seizures (Sillanpää and Shinnar, 2010; Sperling et al., 1999), and injury rates are substantial (Buck et al., 1997; Nei and Bagla, 2007) (Chapter 3). People with refractory epilepsy often have poor quality-of-life scores and high rates of depression and anxiety (Jacoby et al., 2011; Taylor et al., 2011). They face driving restrictions (Drazkowski, 2007) and are frequently unemployed or underemployed (Marinas et al., 2011; Smeets et al., 2007; Sperling, 2004) (Chapter 6). In light of the heightened risk for death and injury, all individuals with refractory epilepsy should have seizure action plans in case of prolonged or frequently recurring seizures. Action plans may include rescue medications that could be used to stop seizures as well as instructions regarding when transport to the emergency room is necessary. School-aged children need detailed seizure action plans for school and camp.

Individuals with persistent seizures need prompt referrals to epilepsy centers to determine whether the diagnosis is correct, medications are ap-

propriate, or devices or surgery are potential treatment options (Smolowitz et al., 2007). In-depth evaluations by an epilepsy specialist and continuous video-EEG monitoring can lead to more definitive diagnoses and are essential when surgery is considered for people with refractory epilepsy (Cascino, 2002). Upon referral to epilepsy centers, up to 40 percent of patients with a diagnosis of refractory epilepsy are found to have been misdiagnosed (Chemmanam et al., 2009); seizure-like events with a psychological basis are a common erroneous diagnosis. Because surgery or devices are not options for everyone with refractory epilepsy, more effort is needed to develop medications or other treatments to reduce the burden of uncontrolled seizures.

Improving the Diagnosis and Treatment of Comorbid Conditions

While stopping seizures is a major goal in the treatment of epilepsy, it is not the only treatment goal. As detailed in Chapter 3, epilepsy is associated with a range of comorbid conditions that may also result in diminished well-being and reduced quality of life. More attention is needed to the full range of side effects including effects on oral health (Karolyhazy et al., 2003). Improving the diagnosis and treatment of these conditions will include greater emphasis on coordination and co-management of care.[3] Diagnosis of comorbidities may be delayed in part because office visits with the health care provider are usually short, and many topics and concerns need to be discussed, including seizure frequency and severity, medication and other adverse effects, mood, sleep patterns, fitness, bone health, and endocrine status (Chapter 7). However, allocating time to discuss comorbid conditions is important whether or not seizures are controlled. A division of responsibilities within the care team to diagnose, treat, and manage these conditions can be an effective allocation of skills, time, effort, and cost.

Further, some unique aspects of the relationships between epilepsy and its comorbidities can complicate diagnosis and treatment. For example, a history of depression or depressive symptoms has been reported in up to two-thirds of patients with refractory epilepsy (Lambert and Robertson, 1999), but the side effects of some seizure medications include symptoms of depression (Andersohn et al., 2010; Bell and Sander, 2009; Mula and Sander, 2007). Once the comorbidities are recognized, the clinician needs

[3]This report uses the term "co-management" to describe efforts in which health care providers from different disciplines work together and with the patient to make decisions and provide patient-centered care for multiple health conditions. The term "coordinated care" is used as a broader term to discuss efforts across health care and community settings in order to provide health and human services (e.g., health care, housing, education, employment) that meet the needs of the individual with epilepsy. Both co-management and coordinated care are necessary to provide high-quality, patient-centered care.

to determine whether they are related to the occurrence of seizures, seizure medication side effects, or other causes. Diagnostic tools such as the Neurological Disorders Depression Inventory for Epilepsy can be used as practical screening instruments (Barry et al., 2008; Friedman et al., 2009). Selecting the appropriate medications to treat comorbidities also may be difficult. For example, several psychotropic medications may lower seizure threshold, whereas others have been found to have antiseizure properties (Alper et al., 2007). In general, more research is needed on the safety, efficacy, and interactions of medications for epilepsy and comorbid conditions.

Working to alleviate or eliminate comorbid conditions often necessitates collaboration across a range of health care and community service providers. Barriers to collaboration include multiple sources of payment, inadequate communication and co-management across providers, and difficulties with scheduling logistics for referrals. Pilot programs developed through the Managing Epilepsy Well Network (described in Chapter 3) are using online tools, support networks, and collaboration between multiple health care providers to provide care and assistance. Treatment programs for comorbidities such as those discussed in Box 4-1 warrant further investigation to see who benefits most, how they may complement traditional medical approaches and epilepsy care, and whether these programs can help bridge the gaps in mental health care for people with epilepsy.

Improving Communication Between Health Care Providers and Patients

Building a trusting and collaborative relationship that enables quality care requires clear communication between health care providers and the individual with epilepsy, family members, and caregivers. Health professionals need to convey information in ways that take into account health literacy and cultural sensitivities. In particular, they need to clearly communicate the risks of epilepsy and be aware of the resources and services that are available, including state and local Epilepsy Foundation affiliates and organizations working to help individuals with specific epilepsy syndromes or types of epilepsy. In Chapter 9 the committee calls for the development of a 24-hour telephone or Internet helpline that would be an information resource for people with epilepsy and their families. This does not need to be a stand-alone effort but could be part of a collaborative effort that builds on an ongoing help line for a related health condition.

Studies have shown that health literacy affects health care utilization, outcomes, and costs (ODPHP, 2010; Parker et al., 2008). Low health literacy is widespread in the U.S. population and is estimated to cost the U.S. economy between $106 billion and $238 billion annually, or between 7 and 17 percent of personal health expenditures (Vernon et al., 2007). Individuals with low health literacy may not understand their treatment options,

Box 4-1 EXAMPLES OF TREATMENT PROGRAMS FOR COMORBIDITIES

The following two multifaceted programs were developed and evaluated as part of the Center for Disease Control and Prevention's (CDC's) Managing Epilepsy Well (MEW) Network.

PEARLS (Program to Encourage Active, Rewarding Lives for Seniors) was originally developed to reduce minor depression in medically ill, low-income, older adults through a home-based self-management program (Ciechanowski et al., 2004). Major components of the program, which showed reduced symptoms of depression and improved health status in a randomized controlled trial, included problem solving, encouragement of social and physical activity, and communication between the psychiatrist and the patient's primary care physician about possible treatment with antidepressants (Ciechanowski et al., 2004). This program was revised for people with epilepsy through collaboration with the MEW Network (Dilorio et al., 2010). In a randomized trial, people with epilepsy were assigned either to receive eight 50-minute problem-solving sessions in the home from a trained therapist and monthly follow-up telephone calls, or to receive usual care. In the intervention group, therapists regularly reviewed progress of the sessions with a team psychiatrist who consulted with the neurologist regarding treatment related to depression. Sessions were modified to encourage people with epilepsy to be active both socially and physically, and unemployed individuals were given contact information for vocational rehabilitation. On average people with epilepsy in the intervention group had 6.2 problem-solving sessions and 2.5 follow-up telephone calls. Results are promising. The intervention group had significantly less depression severity and suicide ideation and greater emotional well-being, compared to the control group (Ciechanowski et al., 2010).

Project UPLIFT (Using Practice and Learning to Increase Favorable Thoughts), which also has the goal of reducing depression, uses a mindfulness approach and cognitive-behavioral therapy. Project UPLIFT was designed to be delivered in eight weekly sessions to small groups by telephone or the Internet (Walker et al., 2010). An initial pilot study demonstrated that people with epilepsy who received the intervention (randomly assigned to phone or Internet) had a greater decline in symptoms of depression and greater increase in knowledge and skills than the control group at 8 weeks (Thompson et al., 2010). Project UPLIFT was effective in using both the Internet and telephone methods; however, participants reported that they would have liked to have been able to participate using both methods (Walker et al., 2010).

may not understand how to take prescribed medications correctly and why that is important, and may not be able to navigate the health system effectively, which can be a particular challenge for people with epilepsy given the multiple services and providers sometimes involved in epilepsy and care for associated comorbidities.

Bautista and colleagues (2009) found that people with epilepsy who had low health literacy (measured by the frequency with which they had someone help them read hospital materials or their confidence in filling out medical forms by themselves) were more likely than others to have poorer

quality-of-life scores. Health professionals need to focus on how they convey information to their patients as well as how they respond to and encourage questions and interactions. Efforts to develop epilepsy-specific tools and materials to assist health professionals in meeting health literacy needs are ongoing, as are efforts to improve the epilepsy-related knowledge of patients and their families (Chapter 7).

Discussions about the risks of epilepsy, possible treatment side effects, and the importance of self-management are critical components of effective communications between clinicians, patients, and families. Elevated rates of death and increased risks of injury in people with epilepsy underscore the seriousness of epilepsy as a public health problem (Chapter 3). Suicidal ideation, suicide attempt, suicide, death as a consequence of a seizure or of status epilepticus, and sudden unexpected death in epilepsy (SUDEP) are potential catastrophic consequences of living with epilepsy but are not commonly discussed with individuals with epilepsy and their families. One of the major areas to be addressed is the discussion of SUDEP (Devinsky, 2011) (see also Chapter 7). A consensus conference on SUDEP (Hirsch et al., 2011), as well as public testimony received by the committee, indicate that people with epilepsy and their families want to know about SUDEP and other epilepsy-related risks, as well as learn about any strategies they can pursue to minimize them. Recommendations of a joint task force of the American Epilepsy Society (AES) and the Epilepsy Foundation urge that SUDEP be discussed in the context of comprehensive epilepsy education (So et al., 2009).

Developing a National Strategy for Performance Measurement and Quality Improvement in Epilepsy Care: Improving Practice Guidelines and Implementing Performance Metrics

Evidence-based guidelines provide the basis for ensuring the consistent delivery of high-quality health care. The implementation of evidence-based guidelines can be incentivized through the use of performance metrics[4] to track what is being done in clinical practice and to hold health professionals and health care facilities accountable for the quality of care delivered. As defined by Sackett and colleagues and adapted by the IOM in *Crossing the Quality Chasm*, "Evidence-based practice is the integration of the best research evidence with clinical expertise and patient values" (IOM, 2001, p. 34; Sackett et al., 1996). In 2003, the Living Well with Epilepsy II Con-

[4]The term "performance metrics" is being used broadly in this report to encompass the wide range of measures of health care quality that include measures and indicators of clinical care, health care processes, and patient outcomes and satisfaction. The goal for the development and implementation of performance metrics is improvement in the quality of health care.

Box 4-2 EXAMPLES OF PRACTICE GUIDELINES

American Academy of Neurology Practice Guidelines[a]

- Antiepileptic Drug Selection for People with HIV/AIDS (Birbeck et al., 2012)
- Update: Management Issues for Women with Epilepsy—Focus on Pregnancy: Obstetrical Complications and Change in Seizure Frequency (Harden et al., 2009a)
- Update: Management Issues for Women with Epilepsy—Focus on Pregnancy: Teratogenesis and Perinatal Outcomes (Harden et al., 2009b)
- Update: Management Issues for Women with Epilepsy—Focus on Pregnancy: Vitamin K, Folic Acid, Blood Levels, and Breast-Feeding (Harden et al., 2009c)
- Evaluating an Apparent Unprovoked First Seizure in Adults (Krumholz et al., 2007)
- Reassessment: Neuroimaging in the Emergency Patient Presenting with Seizure (Harden et al., 2007)
- Diagnostic Assessment of the Child with Status Epilepticus (Riviello et al., 2006)
- Use of Serum Prolactin in Diagnosing Epileptic Seizures (Chen et al., 2005)
- Efficacy and Tolerability of the New Antiepileptic Drugs I: Treatment of New Onset Epilepsy (French et al., 2004a)
- Efficacy and Tolerability of the New Antiepileptic Drugs II: Treatment of Refractory Epilepsy (French et al., 2004b)

International League Against Epilepsy

- Evidence-Based Analysis of Antiepileptic Drug Efficacy and Effectiveness as Initial Monotherapy for Epileptic Seizures and Syndromes (Glauser et al., 2006)
- Guidelines for Imaging Infants and Children with Recent-Onset Epilepsy (Gaillard et al., 2009)

ference highlighted the need to define and establish criteria for quality care of epilepsy (Austin et al., 2006).

Practice Guidelines

The push for evidence-based medicine has resulted in a number of practice guidelines for the evaluation and treatment of epilepsy in the United States and internationally (Box 4-2). Many of the U.S. guidelines are available through the National Guideline Clearinghouse of the Agency for Healthcare Research and Quality (AHRQ, 2012). In these documents, the nature and level of the evidence are detailed for specific clinical services or procedures and the balance of risk versus benefit is discussed. To date, epilepsy-specific practice guidelines have been developed primarily by pro-

American Academy of Pediatrics

- Neurodiagnostic Evaluation of the Child with a Simple Febrile Seizure (AAP Subcommittee on Febrile Seizures, 2011)
- Utility of Lumbar Puncture for First Simple Febrile Seizure Among Children 6 to 18 Months of Age (Kimia et al., 2009)

American Association of Neuroscience Nurses

- Care of the Patient with Seizures. Second edition (AANN, 2009)

American College of Radiology (ACR)

- ACR Appropriateness Criteria® Seizures: Child (Prince et al., 2009)

United Kingdom, National Institute for Health and Clinical Excellence

- CG20 Epilepsy in Adults and Children: Full Guideline (NICE, 2004)

European Federation of Neurological Societies (EFNS)

- EFNS Guideline on the Management of Status Epilepticus (Meierkord et al., 2006)

Scottish Intercollegiate Guidelines Network

- Diagnosis and Management of Epilepsy in Adults. A National Clinical Guideline (Scottish Intercollegiate Guidelines Network, 2003)

[a]Some of the AAN Practice Guidelines were developed in conjunction with the American Epilepsy Society, ILAE, or the Child Neurology Society.

fessional associations and organizations. Assessments should be conducted of the need for additional guidelines in epilepsy care and areas should be identified in which robust evidence does not yet exist, so that systematic, transparent, and reproducible methods can be used to develop the needed evidence base.

While the guidelines are based on evidence-based medicine, little is known about how often the guidelines are implemented and followed, the extent to which improvements in patient care result, and why failures in implementation or improved outcomes may occur (Davis et al., 2004; Stephen and Brodie, 2004). For example, Bale and colleagues (2009) assessed whether pediatricians were aware of a practice parameter, or clinical practice guideline, on nonfebrile seizures and, if so, the extent to which they incorporated the parameter into practice. Although most of the respond-

ing pediatricians were caring for children with seizures, 60 percent were not aware of the practice guideline. In responding to a clinical scenario, many said they would order laboratory tests that were not in the guideline. Similarly, a questionnaire sent to UK neurologists asked whether they discussed SUDEP with all epilepsy patients and their families, which has been recommended by the UK National Institute for Health and Clinical Excellence (Morton et al., 2006). Of the validated respondents, only 5 percent discussed SUDEP with all patients, 26 percent with a majority, 61 percent with a few, and 7.5 percent with none.

In addition to educating clinicians and patients about the existence and content of evidence-based guidelines, tools are needed to ensure that the guidelines are implemented at the point of care. Performance metrics (described below) are increasingly being used to incentivize the use of best practices in health care. Additionally, many hospitals and other health care facilities have developed clinical pathways that help health professionals formulate plans for the process of care; for example, epilepsy-specific pathways may focus on care for people with new-onset seizures, for women during pregnancy, or for patients considering surgery. Given the ongoing transition to electronic health records (EHRs) and the potential that EHRs hold for providing immediate information to health professionals and their patients, the epilepsy community must work to incorporate relevant guidelines into EHR development, create decision prompts, keep treatment information current, and ensure integration of relevant clinical information across providers. EHRs also may simplify and lower the cost of conducting audits that can provide feedback to clinicians, patients, and health systems on the alignment of care with evidence-based guidelines and performance metrics.

Performance Measurement and Improvement

The IOM has published several reports defining the quality of health care and outlining the aims for which the health system should strive—safety, effectiveness, patient-centeredness, timeliness, efficiency, and equity (e.g., IOM, 2001, 2006a,b, 2011). To achieve quality in health care and develop the accountability and transparency needed to incentivize change and to allow comparisons within and among health care providers, the focus over the past 20 years has been on developing, implementing, and analyzing performance metrics.

The evolution of performance measurement and improvement Large and small employers, federal agencies, and state governments have worked with health care providers and relevant organizations to develop systems for measuring performance and improving quality and also for understanding

the value of purchased health care services. One example is the Healthcare Effectiveness Data and Information Set (HEDIS), designed by a broad coalition of stakeholders (Committee on Performance Measurement) in collaboration with the nonprofit National Committee for Quality Assurance (NCQA), which measures the performance of the managed care industry (NCQA, 2012). Early and ongoing supporters of the implementation and use of performance metrics include a number of managed care organizations around the country that use the information to assess performance across their organization and compare it to other managed care organizations. Similar performance measurement and improvement efforts for hospitals, physicians, and other providers have been developed or endorsed by the Joint Commission, the National Quality Forum (NQF), the Physician Consortium for Performance Improvement (PCPI), and other organizations, and many of these efforts work through broad coalitions of stakeholders.

Early developers of performance metrics recognized the importance of establishing a set of criteria or a strategy that specified how performance measurement areas would be selected and how specific metrics would be built, tested, used, and eventually, retired. For example, in *HEDIS 2000: What's in It and Why It Matters,* the NCQA (1999) outlined the categories (domains) selected for performance measurement (effectiveness of care, access and availability, satisfaction with the experience of care, health plan stability, use of services, cost of care, informed health care choices, and health plan descriptive information) and detailed a set of desirable attributes of performance metrics, which were organized into three broad areas: relevance, scientific soundness, and feasibility. The set of metrics that emerged covered a range of topics but focused on clinical areas in which good evidence existed to support quality improvements. The development of the HEDIS metrics included an emphasis on patient participation. The NQF has a similar set of criteria for measurement adoption (NQF, 2011).

Early efforts in the development of performance metrics aimed to build sets of metrics that would drive toward standardization and the ability to compare providers and provider organizations. These standardization activities emerged in part to add value to the certification and accreditation of hospitals, health maintenance organizations, and other types of health care facilities, recognizing that performance measurement was a prerequisite to improving care. Since that time, the concept of pay-for-performance has continued to evolve, and public and private payers are attempting to financially reward high-quality providers and organizations based on standardized metrics.

Measuring performance and improving quality in epilepsy care The epilepsy community has taken important first steps in the development of performance metrics for high-quality epilepsy care. The American Academy

of Neurology (AAN), in conjunction with the PCPI, sponsored a literature review and assessment, conducted by an expert panel, that identified eight performance metrics that could be used in quality improvement, pay-for-performance, or maintenance of certification programs (Fountain et al., 2011). The eight metrics submitted to the NQF for consideration were evidence based and represented gaps in care of people with epilepsy (Fountain et al., 2011):

- Documentation in the medical record of "Seizure type and current seizure frequency
- Documentation of etiology of epilepsy or epilepsy syndrome
- EEG results reviewed, requested, or test ordered
- MRI/CT [computerized tomography] scans reviewed, requested, or scan ordered
- Querying and counseling about side effects of [seizure medication]
- Surgical therapy referral consideration for [refractory] epilepsy
- Counseling about epilepsy-specific safety issues
- Counseling for women of childbearing potential with epilepsy."

While the metrics were not endorsed by the NQF, the Centers for Medicare and Medicaid Services (CMS) has adopted three of the metrics (documentation of seizure type and frequency, documentation of etiology of epilepsy, and counseling for women of childbearing potential) to be used by providers participating in the Physician Quality Reporting System (CMS, 2011a). Provider documentation of the CMS quality metrics is currently voluntary but will become mandatory beginning in 2015 in order to qualify for full Medicare reimbursement (CMS, 2011a,b). The epilepsy-specific metrics will apply to any health professional who submits a bill for care of a person with seizures or epilepsy to Medicare. This represents a significant step forward in evaluating the quality of care in epilepsy. However, additional evidence-based performance metrics are needed to focus on the full range of gaps in care, such as referral of people with refractory epilepsy for surgical consultation or evaluation of adverse effects of treatments. The epilepsy community, in conjunction with the CMS, NQF, private insurers, and other organizations involved in performance measurement and quality improvement, should continue to develop, implement, evaluate, and report on evidence-based metrics for care of people with epilepsy.

Further, there are ongoing efforts to develop a set of performance metrics focused on epilepsy care within primary care and general neurology clinics. The QUIET (QUality Indicators in Epilepsy Treatment) study used a multipronged approach of literature and guideline review, patient focus groups, and an expert panel to examine quality of care for adults with epilepsy (Bokhour et al., 2009; Pugh et al., 2007, 2011). The process led to a set of performance metrics ("quality indicators") consisting of both

evidence- and patient-based metrics (Bokhour et al., 2009; Pugh et al., 2007). The evidence-based metrics were tested in a tertiary medical center (Pugh et al., 2011). The QUIET study then compared chart abstractions for epilepsy-focused medical encounters from primary care and neurology clinics separately, as well as from patients who received care in both neurology and primary care settings. Approximately 44 percent of the 1,985 possible care processes were performed in concordance with the defined metrics (Pugh et al., 2011). People who received care from both groups or "shared care" had the highest rate of concordance with the metrics. Incorporating the patient perspective is an important part of quality-improvement efforts and is integral to ensuring patient-centered care.

Next steps for improving quality in epilepsy care The committee believes that the efforts described above form a solid basis for moving forward to assess and improve the quality of epilepsy care. A national strategy for performance measurement and quality improvement in epilepsy care is needed that would specify the broad areas (domains) that are meaningful for assessing epilepsy care (e.g., access to care for epilepsy and comorbid health conditions, including mental health services, effectiveness of care, quality of life improvements, communications between patient and health care provider, and cost of care) and that would detail the criteria for and attributes of performance metrics that the epilepsy field believes are important to emphasize (e.g., evidence based, patient centered). Development of this strategy should involve people with epilepsy and their families, relevant professional and advocacy organizations, researchers, health and human services professionals, and experts in performance metrics and health care quality improvement.

A national strategy for performance measurement and quality improvement in epilepsy care could

- provide a roadmap for next steps in developing performance metrics to allow for an organized effort to prioritize, develop, evaluate, and approve new metrics;
- establish definitive standards for the attributes that performance metrics must meet in order to be included in a measurement set;
- ensure transparency;
- emphasize a patient-centered focus for quality in epilepsy care; and
- provide an agenda for next steps in effectiveness reviews and the development of additional practice guidelines for epilepsy care.

Evaluating and Accrediting Epilepsy Centers

In 1978, the U.S. Commission for the Control of Epilepsy and Its Consequences noted in a report that there were many gaps in epilepsy care,

including insufficient patient and family education and psychosocial treatment (U.S. Commission for the Control of Epilepsy and Its Consequences, 1978). Epilepsy centers of excellence were then funded in response to a National Institutes of Health (NIH) initiative, and these served as regional treatment and referral networks. The centers spearheaded research into the psychosocial needs of people with epilepsy and developed educational programs to respond to individual, family, and community needs. Subsequent changes in funding mechanisms led to curtailment of NIH funding for epilepsy centers and the eventual establishment of health care facility-based epilepsy centers. The committee looked at the current criteria for the four levels of epilepsy centers and explored how centers for other health conditions are evaluated in order to make recommendations for strengthening the nation's epilepsy centers.

Current Epilepsy Centers

National Association of Epilepsy Centers Currently, 166 self-designated epilepsy centers are members of the National Association of Epilepsy Centers (NAEC, 2012a). NAEC guidelines for level 3 and level 4 epilepsy centers are voluntary, and each center self-designates based on the level of care it provides (NAEC, 2012b). Level 1 care is designated as that provided by emergency care or primary care providers, while level 2 care is provided by general neurologists (Labiner et al., 2010). Level 3 and level 4 care are provided by epilepsy centers, with both of these levels providing EEG services with long-term monitoring, epilepsy surgery (level 4 centers also provide non-lesional epilepsy surgery), neuroimaging, neuropsychological and psychological services, rehabilitation services, and other specialized services (including pharmacology consultations and interdisciplinary clinical services). Level 4 centers also provide functional cortical mapping, specialized neuroimaging, electrocorticography, and other more specialized services (Labiner et al., 2010).

In a survey conducted for this report (Appendix C) and completed by approximately one-quarter of the NAEC centers, each center served an average of 1,300 patients per year and provided an average of 3,400 outpatient visits with an epileptologist per year. Referral patterns varied significantly across the NAEC centers; approximately 40 percent of patients were referred by primary care providers, 36 percent by neurologists, 16 percent by other specialists, and 4 percent by the Epilepsy Foundation.

Tuberous Sclerosis Alliance specialty clinics The Tuberous Sclerosis Alliance has established criteria for specialty clinics that provide comprehensive treatment for tuberous sclerosis complex—both clinic standards and gold standards are specified and centers are encouraged to meet gold standard

requirements (Tuberous Sclerosis Alliance, 2011). Health care facilities attest that they meet the standards for a specialty clinic and are required to submit an annual report to the Tuberous Sclerosis Alliance to maintain that designation.

Department of Veterans Affairs (VA) Epilepsy Centers of Excellence The increasing prevalence of epilepsy in older veterans from age-related conditions and in younger veterans with recent war-related injuries led to a recent resurgence of interest in epilepsy at the VA,[5] and in 2008, 16 Epilepsy Centers of Excellence were created within the Veterans Health Administration (VA, 2011a,b). Epilepsy Centers of Excellence must be affiliated with a medical school for education and training, and they collaborate with VA Polytrauma Centers to provide care to veterans with traumatic brain injury who are at risk for epilepsy (VA, 2011a). The VA Epilepsy Centers of Excellence provide both inpatient and outpatient care for veterans with seizures, including advanced diagnostics and evaluation services and other clinical care by epilepsy specialists, with co-management between specialists and primary care providers within and external to the VA when appropriate (Parko, 2011; VA, 2011a). The centers collaborate nationally to conduct epilepsy research and provide epilepsy education, and they are developing information systems, national databases, and telehealth programs to improve patient care and research. Clinical pathways have been developed to ensure consistent approaches to care and facilitate access to specialists for people at risk for seizures or comorbid health conditions. The centers have not been operational long enough for publication of evaluation data.

Models of Center Evaluation and Accreditation

In considering next steps for epilepsy centers, the committee looked at processes used to designate and evaluate centers focused on other diseases. Relevant models having some preliminary outcome data and models of quality improvement initiatives include stroke centers, trauma centers, VA cancer centers, and cystic fibrosis centers.

Over the past decade, a coalition of professional organizations established accreditation criteria and a certification process for Primary Stroke Centers (Alberts et al., 2000; Reeves et al., 2010). These centers collect and compare data on 10 quality measures, are evaluated through site visits by the Joint Commission, and are assessed every 2 years for recertification (Rymer, 2011). Plans are under way for a second type of certified stroke

[5] An epilepsy monitoring unit was established at a VA hospital in the early 1960s and in 1972 the VA designated several hospitals as epilepsy centers (Parko, 2011).

center, a Comprehensive Stroke Center that would provide more complex care, including surgical care and care for patients with specific types of stroke (Alberts et al., 2005; Joint Commission, 2011a). Few studies to date have compared outcome data for the accredited primary stroke centers; however, studies by Lichtman and colleagues (2011a,b) found that Joint Commission–certified Primary Stroke Centers had lower 30-day mortality risk for two different types of stroke compared to noncertified hospitals, although readmission rates were similar.

The designation of trauma centers follows a different process than that of stroke centers. The American College of Surgeons (ACS) verifies that a hospital has the specific resources needed to provide one of three levels of trauma care (ACS, 2011). A designated team of trauma experts conducts site visits, and verification certificates must be renewed every 3 years. A study of this process, comparing the experience of trauma patients in a community hospital before and after level 2 designation, found that, after designation, patients experienced shorter hospital stays, lower inpatient mortality, and reduced costs (Piontek et al., 2003).

Positive changes in quality of care were documented for veterans with chronic disease following VA restructuring in the mid-1990s that involved integrated networks of care, enhanced use of information technology, quality measurement and performance initiatives, and improved access to care (Jha et al., 2003; Kizer et al., 2000). Cancer centers in the VA are organized into regional comprehensive centers as well as secondary centers (Keating et al., 2011). VA cancer center care for older men (over age 65) with one of four types of cancer (colorectal, lung, prostate, or hematologic) has been found to be equal to or better than that for older men receiving fee-for-service care (through Medicare) in the private sector.

The Quality Improvement Initiative of the Cystic Fibrosis Foundation (CFF) Centers provides a model of how centers are working together to collect and learn from data on a specific disease. The CFF accredits 110 care centers in the United States (CFF, 2012a). The Quality Improvement Initiative involves the collection of data on seven key health measures from each of the accredited centers, including data on lung function, nutritional status, percentage of persons screened for cystic fibrosis-related diabetes, and percentage of people with cystic fibrosis who have had the recommended four clinic visits, one sputum or throat culture, and two lung function tests per year (CFF, 2012b; Kraynack and McBride, 2009; Quon and Goss, 2011). Additionally the CFF supports the Cystic Fibrosis Patient Registry that provides an overview and collated data on more than 25,000 people with cystic fibrosis and issues an annual report on progress in improving care (CFF, 2012a).

External Accreditation of Epilepsy Centers and Development of an Epilepsy Care Network

The committee considered information on the benefits and limitations of external accreditation of epilepsy centers and believes that this process would be valuable to ensure excellence, consistency, clarity, and transparency in the provision of epilepsy care. The challenges of accreditation include cost and time burdens on the centers, but the committee believes that the advantages of accreditation and the rigor and external validation it could bring to the field far outweigh these disadvantages. Currently, each center self-designates as providing one of the four levels of care, but no external evaluation process is used to assess whether the voluntary guidelines are being met.

The Joint Commission has developed a process for Disease-Specific Care Certification that includes epilepsy and requires that programs comply "with consensus-based national standards, effective use of evidence-based clinical practice guidelines to manage and optimize care, and an organized approach to performance measurement and improvement activities" (Joint Commission, 2011b, p. 1). However, epilepsy-specific criteria have not been developed, and only a few programs have pursued this certification.

The committee believes that increasing the level of rigor for epilepsy centers through the use of external evaluation, as well as establishing a research and data-sharing network, would enhance the quality of epilepsy care and lead to advances in the field. Health outcomes data are needed for epilepsy care, and data required for accreditation would help to provide that information. The following qualities of an accredited epilepsy center are deemed critical:

- External evaluation—Processes need to be developed for external review by the Joint Commission or a similar independent external body that will assess an applicant against national standards, criteria, and quality metrics.
- Research and data sharing network—A set of common data elements to measure services, quality, and outcomes could be developed and reported by accredited epilepsy centers for accountability, quality, reporting, and research purposes.
- Interdisciplinary care—Comprehensive and coordinated biopsychosocial approaches to acute and chronic care of epilepsy that involve a wide range of health professions should be implemented with a patient-centered focus.
- Quality improvement—A rigorous quality improvement program should be required that measures the processes and outcomes of a certified center to ensure care is safe, effective, patient centered, timely, efficient, and equitable.

- Co-management of care—Criteria and best practices for the co-management of health care must be established between epilepsy specialists, primary care providers, and specialists treating comorbid conditions, including mental health treatment providers.
- Community outreach—Active efforts should be focused on connecting with local primary care providers to enhance their knowledge about epilepsy and their care of people with the disorder as well as ensuring that community health programs providing health services for underserved populations are connected to epilepsy specialists.
- Educational and community referral resource—Accredited epilepsy centers should be sites where patients and their families receive education and self-management training, screening for common comorbid conditions, and referrals for support within appropriate community agencies, including schools, day care centers, vocational rehabilitation services, and those providing housing and other independent living resources, financial assistance, and respite care.
- Professional education—Accredited centers should train epilepsy technicians, nurses, and physicians as well as provide a training locus for emergency personnel, general neurologists, primary care providers, and other interested health professionals.

The committee is not specifying a particular system of certification or accreditation for epilepsy centers but emphasizes the need for an accreditation process that uses external evaluation. The approach could involve a tiered system of primary and comprehensive epilepsy centers, such as the system being put in place for Joint Commission–certified stroke centers or the ACS-designated trauma centers, or it could involve some other organizational structure.

Accredited epilepsy centers are envisioned as having strong links to each other and to community resources through an Epilepsy Care Network of Accredited Epilepsy Centers. This network could promote research advances through collaborative clinical and health services research. More needs to be known about the use of health services by people with epilepsy in order to identify and close gaps (Reid et al., 2012). Each center should be well integrated into the health system and locality that it is a part of as well as into the network of centers. Strong ties and partnerships with state health departments and other health care providers, particularly those focused on other neurological disorders, could expand the reach of coverage to people with epilepsy who are in rural and underserved areas through use of telemedicine, outreach clinics, and other relevant mechanisms. People with epilepsy and their families, as well as

researchers and health care providers, could also benefit from the compilation and analysis of quality, outcomes, and health services data provided by all centers in the network.

IMPROVING ACCESS TO HEALTH CARE

> *Common challenges for patients in getting to their epilepsy appointments are transportation need, not being able to afford to go to their doctor, and getting a referral from their primary care or neurology provider.*
>
> –Sandra Helmers

Access to health care was defined in a 1993 IOM report as the "the timely use of personal health services to achieve the best possible health outcomes" (p. 4). This study went on to point out that "access problems are created when barriers cause underuse of services, which in turn leads to poor outcomes" (IOM, 1993, p. 35).

For individuals with epilepsy, as with all people, having adequate access to care involves being able to obtain and keep public or private health insurance coverage and navigate through the complex U.S. health system in a timely and effective way to obtain services they need. Challenges arise due to many factors, including the limited number of specialty care providers, variability in the skills and knowledge of epilepsy by primary care providers, and limited options for epilepsy care offered by hospitals and communities. Connections need to be strengthened and referrals available—when appropriate—among the different care options that include primary care providers, neurologists, epileptologists, and specialists in the various comorbidities of epilepsy. Further, referrals may be needed to obtain the services of other professionals, such as social workers, occupational specialists, or nutritionists. Limitations in access may result from the location of services in multiple health care and community facilities with limited transportation options, as well as from limits in health insurance plans for the coverage of certain services.

Recent studies provide evidence that disparities exist in access to specialized epilepsy care in populations with low socioeconomic status (SES) and in racial/ethnic minority populations. In a study of patients at four neurology clinics in Houston and New York City, low-SES patients had more frequent emergency room visits and higher hospitalization rates than people in higher-income groups (Begley et al., 2009). In a California population survey, low-income people with epilepsy (incomes below poverty level) were 50 percent less likely to report taking seizure medications (Elliott et al., 2009). African Americans were found to have poorer adherence to seizure medications (Bautista et al., 2011). People using emergency rooms for treatment of seizures were more likely to be uninsured (Farhidvash et al., 2009). Use of neurologists was relatively

similar, regardless of SES, in a study of people with epilepsy in Houston and New York City (Begley et al., 2011), although other studies have found a lower rate of neurologist visits for uninsured individuals (Halpern et al., 2011) and greater difficulties for children enrolled in Medicaid to obtain neurologist appointments (Bisgaier and Rhodes, 2011). Studies examining disparities for racial/ethnic minority populations found that African American individuals were more likely than whites to use emergency departments for epilepsy care (Kelvin et al., 2007) and less likely to have epilepsy surgery (Berg et al., 2003; Burneo et al., 2005; McClelland et al., 2010). African American and Hispanic individuals had lower rates of epilepsy-related visits to specialists than white individuals (Begley et al., 2009). However, for those who did have surgery, race and SES did not appear to affect outcomes (Burneo et al., 2006).

These subgroup differences reflect broader challenges faced by people with epilepsy and people with other neurological conditions in trying to access specialized care. Child neurologists reported wait times for new patients averaging 53 days, while returning patients had to wait 44 days (Polsky et al., 2005). Physicians serving patients covered by public insurance (Medicaid and the Child Health Insurance Program) reported difficulty finding a neurologist to whom to refer patients (GAO, 2011).

Disparities in access to epilepsy care as reflected in treatment gaps are major concerns internationally, as well as in the United States, as noted in Chapter 1. While research has documented disparities in receiving equitable and timely epilepsy care, the reasons for these inequities, their importance for health outcomes, and their magnitude in relation to overall gaps in care have to be better understood in order to improve access to care. The committee developed a framework for considering the many factors that affect access to care (Figure 4-2) to assist in identifying priority areas for additional research and for improvement. These priorities are

- strengthen epilepsy care by primary care providers and clarify clinical pathways for referrals and for care by specialists,
- promote a collaborative and patient-centered approach to the care of epilepsy and comorbid conditions,
- ensure a robust, well-educated health professional workforce for epilepsy care,
- reach rural and underserved populations,
- provide smooth transitions of care, and
- make health insurance coverage affordable and readily available.

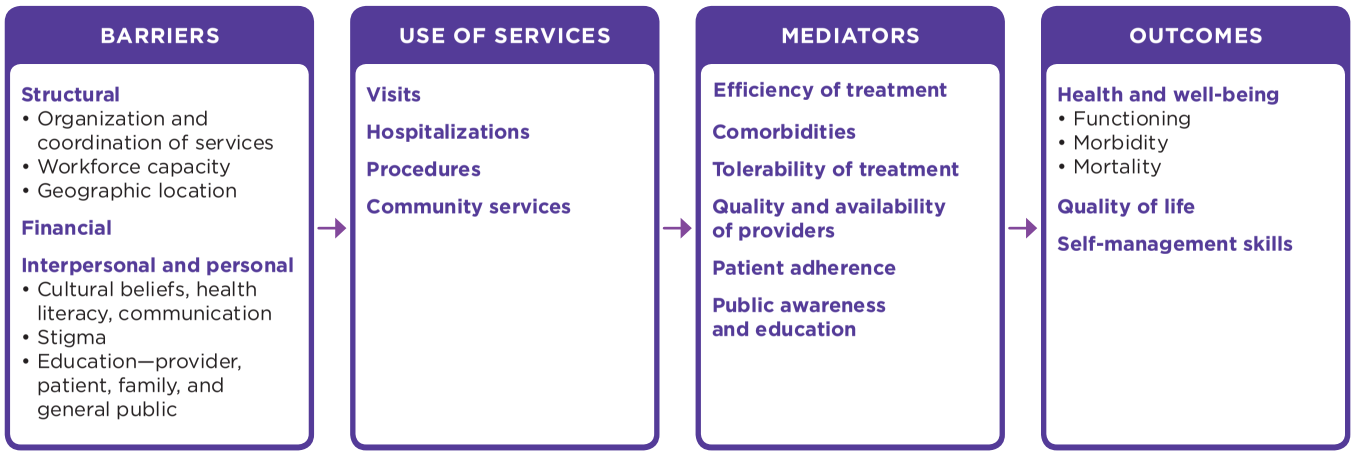

FIGURE 4-2
Model of access to health care services for people with epilepsy.

SOURCE: Adapted from IOM, 1993.

Strengthen Epilepsy Care by Primary Care Providers and Clarify Clinical Pathways for Referrals and Care by Specialists

One of the biggest challenges to improving access to care of people with epilepsy is ensuring timely, adequate care by the appropriate health care and human services providers. Often primary care providers are the first to see the patient after an initial seizure (Browne and Holmes, 2001; Mantoan and Kullmann, 2011; Reuter and Brownstein, 2002). In a community-based survey of people with epilepsy, 40 percent of respondents reported that they first saw a family or general practitioner, 32 percent a neurologist, 13 percent a pediatrician, 5 percent an internist, and 5 percent an emergency room physician (Fisher et al., 2000b). Further, primary care providers may often provide the long-term management of epilepsy care for people whose seizures are well controlled. In a survey by Fisher and colleagues (2000b), the respondents who noted that they were currently seeing a primary care provider for their epilepsy care were generally those who had not had a seizure in the past year and had received their diagnosis of epilepsy 5 years ago or more. A survey involving primary care physicians found that the majority referred at least half of their patients having seizures to a neurologist, while a smaller percentage was comfortable treating most patients with seizures themselves (Moore et al., 2000). Because there is a significant role for primary care providers in the care of epilepsy patients (often over the lifetime of their patients), it is critical that they are knowledgeable about epilepsy care (Chapter 5), are communicating with their patients about care options and the risks associated with epilepsy (Chapter 7), and have clear direction on the timing and options for referrals to epilepsy centers and epileptologists.

As noted earlier in this chapter, concerns have been raised about the length of time that some patients with refractory epilepsy wait for referrals to an epilepsy monitoring unit for further evaluation and a surgical consultation. Clinical practice guidelines and recommendations from professional organizations suggest that when the diagnosis is in question, or seizure control is not achieved after (1) a trial of two or three appropriate seizure medications or (2) 1 year of care with a general neurologist, patients should be referred to an epileptologist or epilepsy center (Cross et al., 2006; Labiner et al., 2010). However, one center studied in the 5 years after release of an AAN practice parameter that specified referral to an epilepsy surgery center after appropriate trials of seizure medications had failed to stop seizures from recurring and found that in that center, approximately 18 years elapsed between therapeutic intervention and surgical evaluation (Engel et al., 2003; Haneef et al., 2010). Similarly, a retrospective review of adult admissions to an epilepsy monitoring unit and surgical referrals found wide variations in time from onset of seizures to referral, with a median elapsed time of 15 years (Smolowitz et al., 2007).

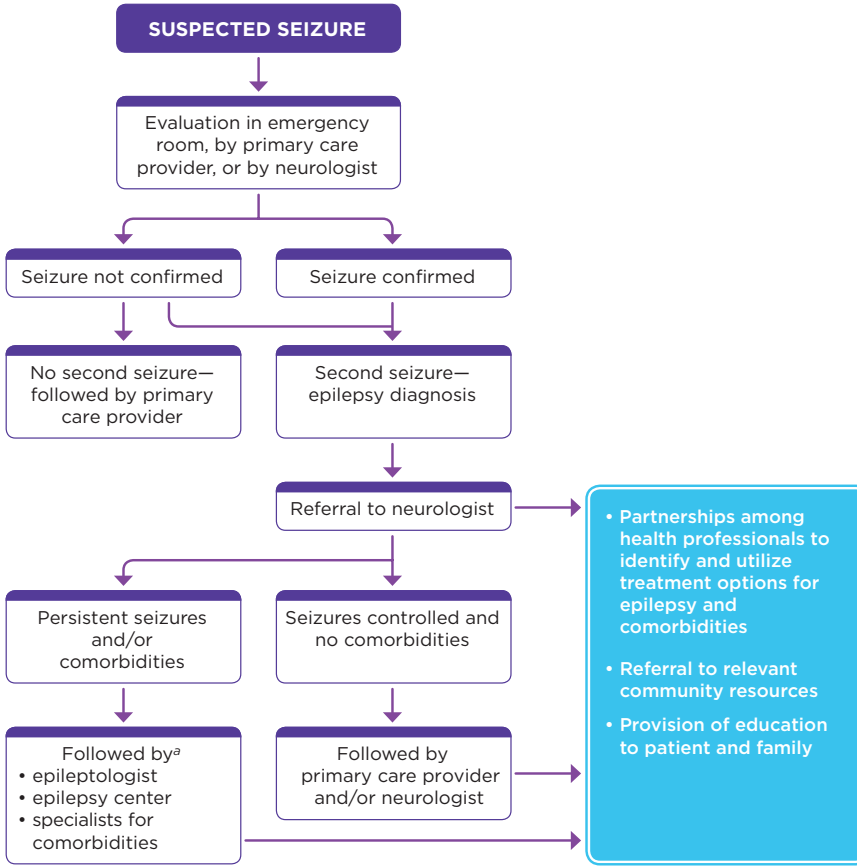

FIGURE 4-3
Treatment pathway for individuals with epilepsy.

[a]When seizures become controlled, the patient can receive ongoing care from a primary care provider or neurologist, with care provided for comorbid health conditions as needed by specialists or primary care providers.

Figure 4-3 illustrates the committee's view of the potential decision points for referrals to various providers and emphasizes that strong connections are needed with community resources throughout. In brief, the figure follows practice guidelines stipulating that epilepsy care for patients who are diagnosed and have seizures that are easily controlled with medical therapy may continue treatment with a general neurologist or primary care provider (Labiner et al., 2010). When the diagnosis is in question or when seizure control is not achieved, then the patient should be referred to an epilepsy specialist or center (Cross et al., 2006; Labiner et al., 2010).

Clearly delineated professional roles and responsibilities could increase the efficiency of care. A survey of epileptologists and neurologists found perceptions of overlapping roles and responsibilities and that territorial issues and financial considerations can, in some cases, influence referral decisions (Hayes et al., 2007). The survey also noted recommendations that an interdisciplinary guideline for clinical practice of epilepsy care—a continuum-of-care map—be developed. Enhancing the possibility of successful implementation of a clear and concise clinical pathway for epilepsy care would require the efforts of professional associations and organizations across the relevant primary care professions in addition to neurology, mental health, and epilepsy-specific professional associations.

Because epilepsy is a spectrum of disorders that ranges broadly in severity, the care needs of individuals vary from the time of initial diagnosis to long-term management and from one individual to another. Clear clinical pathways should be laid out for people with epilepsy so that they are aware of their options, informed about available specialist care, and understand when to talk with the health care team about moving to another level of care. Another purpose in establishing clinical pathways is to move toward consistent protocols and accountability within and across institutions. Quality metrics that emphasize timely referrals and co-management will make important progress toward this goal.

Promote a Patient-Centered and Collaborative Approach to the Care of Epilepsy and Comorbid Health Conditions

The committee emphasizes the need for a patient-centered, collaborative, and comprehensive approach to epilepsy care. Historically, the medical model of health care has centered on physicians and hospitals and the policies and systems needed to support their proper functioning. Outcomes of care were (and still are in many cases) measured in numbers of outpatient visits, procedures performed, and hospitalizations, with limited reporting of patient outcomes. The focus of care was on the disease or disorder. By contrast, while patient-centered care still requires strong health systems and the active engagement of physicians, nurses, and an array of other health professionals, in this model the patient and family are the focus, not the disease. In patient-centered care, shared models of decision making are made possible through effective communication between patients and providers and through respect for each individual's strengths, expertise, and experiences. Other dimensions of patient-centered care include respect for the patient's experiences, values, preferences, and needs; involvement in decision making; and coordination of care (Gerteis et al., 1993). From a patient-centered perspective, the ideal goal for quality care is "providing the care that the patient needs in the manner the patient desires at the

time the patient desires" (Davis et al., 2005). The epilepsy community has measures to evaluate quality of life, self-efficacy, self-management, and other patient-related outcomes and processes that, if deployed in clinical settings, could improve care. These tools need to be validated (if they have not previously been validated) and more widely used. New tools to assist in patient-centered decision making and choices of care are also needed.

A patient-centered, collaborative approach also would provide comprehensive management for epilepsy comorbidities. In a set of focus groups conducted by the AES (Personal communication, C. A. Tubby, AES, 2011), epileptologists and other professionals in epilepsy care stated that managing comorbidities is a major challenge in their professional practice and one in which they wished they had more training. The current organization of health care and reimbursement systems can create barriers to collaborative management across various types of specialists or between primary and specialty care. While managed care plans may offer a more systematic way of caring for people with chronic and multiple conditions than traditional fee-for-services approaches, individuals with refractory epilepsy or comorbid conditions who require specialized evaluation and treatment may find it difficult to gain access to appropriate care. Organized health care delivery models (e.g., integrated delivery systems, medical or health homes, accountable care organizations) promoted under health reform—the ACA (P.L. 111-148)—may provide and incentivize coordinated, high-quality, and more efficient care to people with complicated chronic conditions (McCarthy, 2011; Takach, 2011). Partnerships with organizations, such as the Association of Maternal and Child Health Programs and the Association of University Centers on Disabilities, that work across disease-specific lines and focus on the whole patient's needs will be important to further improving the quality of care for people with epilepsy.

An ongoing initiative to improve access to quality epilepsy care is focused on children and youth with epilepsy in medically underserved and rural areas (HRSA, 2011). Project Awareness and Access to Care for Children and Youth with Epilepsy (Project Access) was started in 2003 by the federal Health Resources and Services Administration's (HRSA's) Maternal and Child Health Bureau and the Epilepsy Foundation. The project is now in its third phase and is anticipated to continue through 2013. As part of the HRSA initiative, statewide demonstration projects in 17 states have established partnerships among health care providers and community service providers, including schools and nonprofit organizations (HRSA, 2012a). One of the grant requirements has been participation by an interdisciplinary and interagency team in a Learning Collaborative, based on the Institute for Healthcare Improvement's Breakthrough Series for quality improvement (IHI, 2003). Best practices from the learning collaborative and the state grants are posted on the Project Access website (Box 4-3) (Epilepsy Founda-

Box 4-3 EXAMPLES OF LESSONS LEARNED AND TOOLS DEVELOPED FROM THE LEARNING COLLABORATIVES

University of Southern California's Learning Collaborative

Strategies for improving care identified during the course of the Learning Collaborative include the following:

- Provide quarterly training to primary care providers.
- Enter into a service agreement with ambulatory clinics and large community pediatric practice groups to outline referral criteria and communications methods.
- Hire a pediatric nurse practitioner to oversee follow-up appointments and assist neurologists.
- Hire a part-time health educator to work with families.
- Work with a social worker to support families in accessing community services.
- Extend visit intervals based on patient needs, not on a standard return policy.
- Schedule return appointment prior to the patient or family's departure from the clinic.
- Track referrals from primary care to specialty care and provide follow-up to families.

The following tools were developed from the work of many states participating in Project Access and the Epilepsy Learning Collaborative to assist patients, families, and health care providers:

- **Parent Notebook:** Binder with information (some of which would be completed by the parents, such as medical history template, seizure log, provider list, and notes on visits with health care providers). Other information, such as the resource lists, could be provided by the health care or community services staff.
- **Home Medication Sheet:** Designed to help parents keep a history of their child's medications and to reconcile medications with their child's health care provider during an appointment.
- **Seizure Description Tool:** Designed to help parents and caregivers describe the child's seizures; uses simple graphics.
- **Seizure Action Plan:** Designed to help parents define a consistent plan with their doctor to use when their child has a seizure. This tool could be used by teachers or other family members.
- **Resource Guide for Parents:** Includes information on community resources, treatment options, federal laws that protect the rights of children with epilepsy in school, first aid for seizures, and finding support, among other resources.

SOURCE: University of Southern California et al., 2008.

tion, 2011). Because each grant team can choose its project's priorities and the variables to be assessed, the program has few common metrics to assess progress in improving access to care broadly, which hampers comparisons of results across projects.

Nevertheless, progress on improving the percentage of children with seizure action plans has been noted and a number of tools have been developed and lessons learned about collaborative approaches to epilepsy care (National Initiative for Children's Healthcare Quality, 2011). Project Access provides the epilepsy community with a starting point for improving access to and coordination of care for individuals with epilepsy. The committee urges wider dissemination of the best practices identified by Project Access grantees and increased opportunities for discussion of their broader implementation.

Collaborative efforts to care for people with epilepsy should benefit from ongoing efforts to improve clinical information systems, particularly EHRs, as noted previously. Another avenue to improve collaborative and patient-centered epilepsy care that deserves more exploration is the use of patient navigators; these individuals—who often are current patients, former patients, or family members and also often are volunteers—have been through the rigors of navigating the health care system and are willing to use their knowledge and additional training to help others. Further, patient navigators can help bridge cultural and language differences that may exist between the health care team and the patient. The patient navigator concept began in the 1990s to provide assistance to people with low incomes who had abnormal findings in cancer screenings as they followed up on medical appointments to have a biopsy (Freeman et al., 1995). Expansion of the patient navigator approach has enabled positive results not only in screening, diagnosis, and treatment adherence, but also in improving quality-of-life outcomes (Robinson-White et al., 2010). While informal navigator programs and family networks currently exist, including support groups, a more systematic approach is desirable and could be explored by epilepsy centers. Medical interpreters also provide another resource to patients that can provide the translation services needed to facilitate discussions and allow more in-depth patient education.

Ensure a Robust, Well-Educated Health Professional Workforce for Epilepsy Care

Waiting times for appointments with epilepsy specialists present another challenge for access to specialized epilepsy care. Limitations in the number and geographic distribution of epileptologists and pediatric neurologists are a major cause of these delays. An International League Against Epilepsy report noted that the geographic "distribution of neurologists is very uneven" in the United States, with the highest concentrations in the Northeast and Midwest, especially in metropolitan areas (Theodore et al., 2006, p. 1708). In a survey of NAEC epilepsy centers, responding centers indicated that the time for a new patient to see an epilepsy specialist aver-

aged 32 days, with a median of 21 days (Appendix C). Waiting time for an inpatient evaluation to the center's epilepsy monitoring unit averaged 25 days, with a median of 21 days.

The AES reports that it has approximately 1,875 physician members, but the number of epileptologists in this group is uncertain (Personal communication, Kathy Hucks, AES, October 17, 2011). A new subspecialty certification for epilepsy by the American Board of Psychiatry and Neurology (discussed in Chapter 5) may allow a more precise determination of the number of U.S. epileptologists and may encourage more neurologists to specialize in epilepsy care. Pediatric neurologists—who care for a range of neurological disorders, including epilepsy—are in particularly short supply. A 2005 survey of child neurologists found there were 904 full-time child neurologists in the United States, or 1.27 per 100,000 children (Polsky et al., 2005).

In addition to increasing the number of physicians trained in epilepsy, increasing the number of nurses, social workers, and other care providers with epilepsy expertise will also improve access to care. Currently, nurses specializing in epilepsy are found primarily at epilepsy centers. This limits the availability of nursing care and epilepsy education for people who do not have access to the centers or who do not require specialized epilepsy care. The use of epilepsy specialist nurses or epilepsy health educators more consistently in epilepsy centers and in community settings could alleviate some pressure on the physician supply and provide a greater depth of resources for people with epilepsy and families. UK studies suggest that nurses can provide the important—although time-consuming—roles of coordinating care for comorbid health conditions and educating patients and families, and the United Kingdom has worked to strengthen its provision of epilepsy care through the work of epilepsy specialist nurses (Box 4-4). In the United States, there is no certification for epilepsy specialist nurses, although many nurses work in epilepsy centers and epilepsy monitoring units. Further efforts to define these roles and explore epilepsy health educator certification (Chapter 7) are needed.

Reach Rural and Underserved Populations

Ensuring that high-quality epilepsy care is available throughout the United States, including rural and underserved areas, is an access goal for epilepsy care in the decades ahead. As is evident in Figure 4-4, epilepsy centers are not available in every state and can be located far from individuals with epilepsy. In addition to geographic challenges, there are also challenges in reaching epilepsy patients who do not have adequate health care coverage.

Improving access to high-quality epilepsy care for underserved popula-

Box 4-4 EPILEPSY SPECIALIST NURSES

The United Kingdom has implemented a systematic approach to the use of epilepsy specialist nurses to remediate documented problems with poor patient education services and gaps in counseling and coordination of care (Kwan et al., 2000). A survey of epilepsy nurse specialists found that they were in diverse practice settings, with many working in nurse-run clinics and the majority in multidisciplinary hospitals or community practices (Goodwin et al., 2004). Common to the practice of most epilepsy specialist nurses was that care was guided primarily by individual patient needs and that they worked to enhance co-management practices between hospitals and primary care providers.

A literature review found that attempts to quantify outcomes of epilepsy nurse specialist care are complicated by the diversity of patients and families encountered, geographical diversity of practice settings, and different scopes of practice (Bradley and Lindsay, 2001). No statistically significant changes in health outcomes were found. However, some studies noted improvements in quality of life, knowledge about epilepsy, communication with health care providers, and satisfaction with care. The impact of epilepsy specialist nursing care on patients' ability to manage their epilepsy—a major outcome of self-management education and care—was not evaluated by any of the studies examined and requires more review. Opportunities to further explore the potential roles and responsibilities of epilepsy specialist nurses are needed.

tions will involve building stronger links between epilepsy specialists and primary care providers in community health centers and in other local health programs. Accomplishing these efforts can include working with the many local programs that provide health care for underserved populations, including the efforts of Federally Qualified Health Centers and Title V Maternal and Child Health programs at the state and local levels.[6] For example, the University of Virginia has developed satellite clinics in rural areas of the state in which a nurse coordinator works with patients to help them access a range of health care and community services. The project is supported in part through Care Connection for Children, an effort that is part of the Title V Children with Special Health Care Needs programs in Virginia (Carter, 2011). In addition, several epileptologists visit satellite clinics in the community each month, and referrals are made to clinics at the University of Virginia, including the epilepsy monitoring unit, for care that cannot be performed in satellite locations.

The increased use of video technologies is opening additional care op-

[6]The goal of the Federally Qualified Health Center Program is to "enhance the provision of primary care services in underserved urban and rural communities" (CMS, 2012a). The Title V Maternal and Child Health Services Block Grant Program administered by HRSA provides resources (primarily to state health departments) to support services for underserved women and children (HRSA, 2012b).

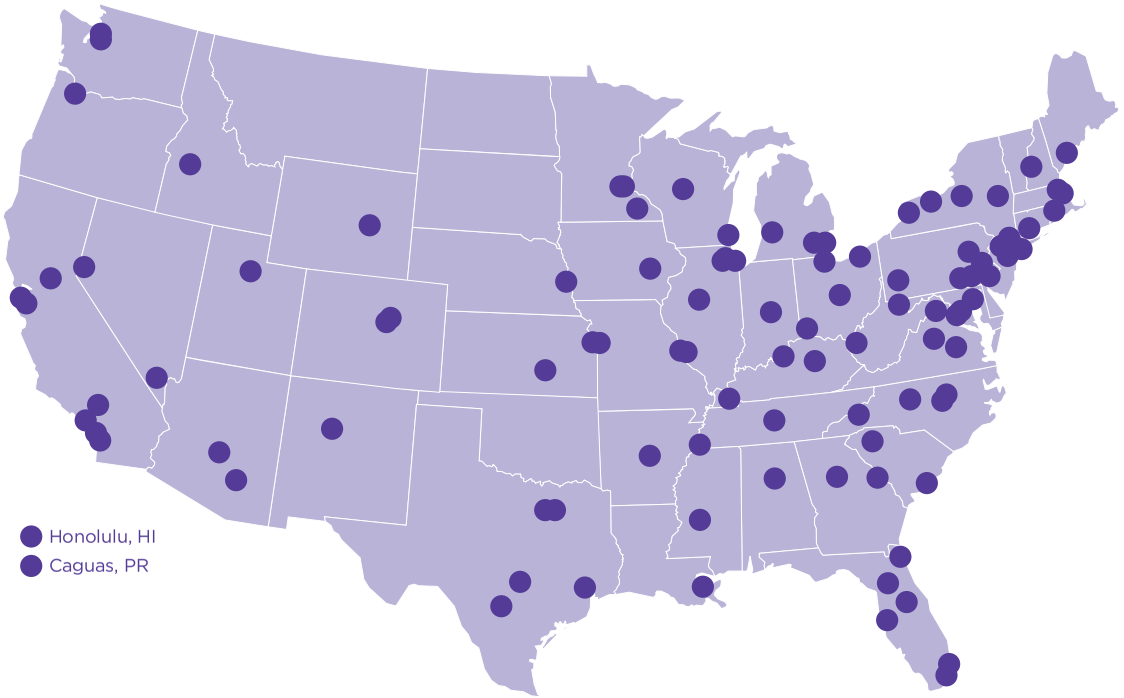

FIGURE 4-4
National Association of Epilepsy Centers: Locations of the centers.

NOTE: Some large cities have multiple epilepsy centers.

SOURCE: NAEC, 2011.

tions in rural areas. Telemedicine programs are viable and valuable alternatives to in-person physician visits in rural and geographically isolated areas, as well as for patients for whom travel is difficult (Larner, 2011; Rasmusson and Hartshorn, 2005). Initiatives in teleneurology focus on neurological consultations and interactions among the patient, the community health care provider, and epileptologists or other specialists via video links. Such links also provide opportunities for patient education. A study in Alberta, Canada, found that epilepsy patients' costs for travel and lost time at work were significantly reduced by using a telemedicine clinic and that 83 percent of telemedicine patients preferred that their next visit also be through telemedicine (Ahmed et al., 2008). Similar outcomes in seizure control and medication adherence were achieved by telemedicine and conventional clinics in a study in southeast Texas (Rasmusson and Hartshorn, 2005). Further, as noted above, some patient and family information needs could be addressed through a 24-hour telephone or Internet epilepsy help line that would serve to provide nonmedical information and direct people to the appropriate resources. A survey of Canadian epileptologists found that obstacles to clinicians' use of telemedicine included lack of infrastructure support and reimbursement concerns as well as limited clinical examinations (Ahmed et al., 2010).

Internationally, a variety of approaches are being tried to reduce distance barriers. These include nurse-led clinics in Cameroon (Kengne et al., 2008), mobile clinics and training of district medical officers in India, training of village doctors in rural areas of China, and improving the epilepsy expertise of community health workers in Kenya (Scott et al., 2001).

Ongoing technology innovations in recording and transmitting home videos of seizures will continue to provide ways to reduce geographic barriers. More studies are needed to determine cost-effective approaches for the utilization of specialists (epileptologists and neurologists) and primary care providers, including nurse practitioners and physician assistants, in the management of epilepsy, including in rural communities, cultures, and societies. Efforts in conjunction with the Indian Health Service could be explored to learn more about ensuring quality epilepsy care in rural areas. Social workers and case managers can help coordinate these efforts, yet more work is needed to establish effective designs for care management that take into consideration local cultural beliefs and values.

A number of questions remain for the relatively small but growing field of disparities research in epilepsy care. Of critical importance is whether differences in care patterns lead to differences in health, quality of life, and mortality. More information also is needed on the relative importance of various factors associated with disparities, such as individual patient characteristics and behaviors or variations in provider practices and practice settings.

Provide Smooth Transitions in Health Care

Transitions in epilepsy care most often occur as youth move into adult health care and as some older adults with epilepsy move into long-term care. Models and evidence-based evaluation tools (described below) have been developed to promote effective older adult transitions from independent living into nursing homes or other community care options, with more dissemination needed of best practices. Additional efforts are necessary to ensure smooth transitions for young adults.

While epilepsy has not been a primary focus of research on transitional care for older adults, patient-centered transitional services following hospital stays for older adults, including individuals with congestive heart failure, have been shown to reduce readmissions (Naylor et al., 1999; Rich et al., 1995) and hold promise for older adults with epilepsy. A model developed by Coleman and colleagues (2006) found that four domains are critical for successful transitions in care for older adults: a patient record that is owned by the patient to facilitate transfer of information between providers, timely follow-up with primary and specialty care providers, support for medication self-management, and information on "red flags" that indicate the potential for a worsening condition along with instructions on how to respond. In a randomized controlled trial of older patients, Coleman and colleagues (2006) consistently found that older patients who received transition coaching following these four domains had lower rates of rehospitalization and lower hospital costs, compared to patients who did not. Advanced practice nurses served as the transition coaches and encouraged effective strategies that included communicating needs, recognizing when a condition was worsening, and knowing how to contact the appropriate physicians.

Transitional models for youth with epilepsy moving from pediatric to adult health care need to be developed. During a time when young adults' concerns expand to include careers, college, driving, and independence, fragmented transitional care can produce conflicting recommendations, misdiagnoses, and medication errors (Appleton et al., 1997; Smith et al., 2002). Young adults with comorbid health conditions may face many challenges in the transition from pediatric to adult providers (Camfield et al., 2011). Further, many parents of young adults with epilepsy experience anxiety as they relinquish decision making to their children. Although the transitional process should begin in adolescence and give youth increasing levels of responsibilities for independent decision making and self-management, few guidelines or programs are available to assist health professionals or parents. One tool that has been explored is the use of a transfer checklist to help in planning and preparation (Viner, 1999). The timing and readiness for transferring care can be assessed with questionnaires and interviews (Tuffrey and Pearce, 2003).

As discussed below, changes in health policy will facilitate continuity of insurance coverage and the development of new service delivery models that could enable more comprehensive, coordinated, and patient-centered epilepsy care and facilitate transitions across care settings. Efforts are needed to assess the impact of these policy reforms for people with epilepsy broadly and to include successful care transitions for young adults and older adults through evidence-based performance metrics.

Improve Health Insurance Coverage

Advances in medications and therapies offer the promise of improved health and reduced burden of epilepsy. However, as discussed earlier in this chapter, evidence suggests that current health care for people with epilepsy is less optimal for those who have public insurance or no coverage than it is for those with private insurance. Further, the fragmented nature of systems for health care, including mental health care and dental care, often presents people with epilepsy with challenges in navigating the system and paying for care. Rising health care costs threaten the sustainability of public and private health insurance programs, as well as the affordability of health insurance purchased by individuals. Among the efforts to slow the growth in health spending have been numerous payment reforms that have implications for epilepsy care.

Current information is limited on health insurance coverage of people with epilepsy. A recent study of patients who presented at a hospital emergency department in Arizona found similar proportions of non-epilepsy and epilepsy patients who had private insurance and who were uninsured (Ouellette et al., 2011). However, patients with epilepsy were more likely to have public insurance.

The ACA (P.L. 111-148) offers opportunities to address some of the shortfalls of health insurance coverage faced by people with epilepsy. New coverage initiatives under the ACA intend to expand insurance coverage, eliminate lapses in coverage, and improve the organization and delivery of health services. The federal emphasis on health information technology, particularly EHRs, is intended to increase system efficiency and improve quality of care. For epilepsy care, the coverage expansions will eliminate exclusion of preexisting conditions (and have already done so for children and youth under age 19). Temporary federal high-risk insurance pools are available for individuals with preexisting conditions. Individuals who need high-cost care may not be subject to lifetime or annual caps, may not lose their coverage because of their health condition, and will have coverage for essential medical services such as rehabilitative care. Premium assistance to individuals with low or moderate incomes should make it possible for people with epilepsy to access affordable health insurance even if they are

not able to work and are not yet eligible for Medicaid or Medicare. Assistance may also be available to cover high out-of-pocket costs. Medicare patients will be able to receive medically necessary outpatient therapy without limits, and the Medicare prescription drug "doughnut hole" is being eliminated. In addition, coverage of preventive services has expanded with no copays and will potentially benefit from Medicare provider reforms to improve care coordination between primary and specialty care providers in outpatient and inpatient settings. These changes could be particularly relevant to people with refractory epilepsy. The net effects of these changes on the continuity, efficiency, and equity of epilepsy care should be monitored, so that policies can be adjusted to ensure greater value in health care.

IMPROVING VALUE OF HEALTH CARE

Value in health care has been defined as "the *physical health and sense of well-being achieved relative to the cost*. This means getting the right care at the right time to the right patient for the right price" (IOM, 2009a, p. 95). By this definition, value centers around the patient and depends on results—in terms of both physical and mental functioning and quality of life. Value in health care is a goal that is widely sought but challenging to measure and to achieve, because many stakeholders—patients, health care providers, payers, facilities, and suppliers—all contribute to value with differing views on where improvements are needed. Given the scarcity of resources for health care and the opportunity cost of using resources in one way versus another, value also encompasses the concept of efficiency or achieving the best results with the least expenditure.

The total cost burden of epilepsy encompasses the direct costs of health and social services (e.g., costs related to physician visits, hospital use, seizure medications, counseling, rehabilitation, training) and the indirect costs related to lost productivity, reduced functioning, and early mortality. As noted elsewhere in this report, the majority of the costs of epilepsy are attributable to indirect costs (Begley et al., 2000). The total direct cost of care and the indirect costs of impairment due to epilepsy are beginning to be documented; however, to date there is insufficient information to accurately estimate a comprehensive set of direct costs or to evaluate the cost-effectiveness of specific health care services for epilepsy. This section highlights the data available on the cost of health care for epilepsy and discusses improving the value of epilepsy care by examining the cost and effectiveness of seizure medications.

Cost of Health Care for Epilepsy

The lack of standardized study methods and data sources has led to widely diverging estimates of the overall economic burden of epilepsy

and difficulties in comparing the costs of services across settings of care and treatment approaches. A study published in 2009, based on 9 years of Medical Expenditure Panel Survey (MEPS) data[7] from 1996 to 2004, found that the average cost of medical care due to epilepsy was $4,523 per person per year, which was the cost of excess medical expenditures (in 2004 dollars) for people with epilepsy compared to costs for those without the condition (Yoon et al., 2009). This result was higher than reported in some previous research (Begley et al., 2000; Halpern et al., 2000), in part because it took into account total medical expenditure differences, not just those directly attributed to epilepsy. The excess cost estimates were similar for children and adults.

Another U.S. study, conducted using claims data for enrollees in private insurance plans rather than the all-payer data used in MEPS, estimated that the annual excess expenditures for each enrollee with focal onset seizures (identified by the International Classification of Diseases, Ninth Edition coding) were $7,190 (in 2005 dollars) (Ivanova et al., 2010). Total annual direct medical costs per enrollee with focal onset seizures were $11,276, compared to $4,087 for enrollees without epilepsy. Enrollees with focal onset seizures were found to have significantly higher rates of mental health conditions, migraine and other neurological disorders, and other comorbidities compared to other enrollees, which contributed to the difference in total costs. Costs of seizure medications and health services directly attributed to epilepsy or seizures were $3,290 per person and accounted for less than half of the cost differential between enrollees with focal onset seizures and those without epilepsy (Ivanova et al., 2010).

The direct costs associated with managing epilepsy are generally highest following the initial onset of seizures and diagnosis, due to the costs of diagnostic evaluation and initial treatment (Table 4-4) (Begley et al., 2000). Studies have found that direct costs are highest for people with refractory seizures and people with new-onset seizures (Argumosa and Herranz, 2004; Begley et al., 2000; Guerrini et al., 2001). Decreases in service use and the associated costs are seen over time for those whose seizures are controlled with treatment.

In terms of total costs to the health care system, the authors of the MEPS study cited above estimated that the excess health care costs experienced by patients with epilepsy amounted to $9.6 billion a year (in 2004 dollars) (Yoon et al., 2009). An AHRQ Statistical Brief identified approximately 277,000 hospital stays in 2005 in which patients had a principal diagnosis of epilepsy or seizures, generating nearly $1.8 billion in hospital costs alone (Holmquist et al., 2006).

Additional estimates of the overall medical care costs for epilepsy are needed using comprehensive and representative data on health care service

[7]See Chapter 2 for a description of the MEPS study and methodology.

TABLE 4-4
Direct Costs of Epilepsy, 1995 Dollars

	Lifetime cost[a] (in thousand $)	% of total cost	Annual cost[b] (in thousand $)	% of total cost
Direct Costs				
Physician and hospital services	669,391	38.2	658,988	39.1
Diagnostic procedures	237,174	13.7	185,859	13.1
Laboratory tests	140,462	8.0	126,603	7.6
Emergency transportation and other services and procedures	70,368	5.0	86,180	5.1
Drug treatment	512,710	29.2	522,586	31.0
Surgery	123,774	7.1	106,388	6.3
Total	1,753,879	100.0	1,686,605	100.0

[a]Average cost of epilepsy care from onset to death of new cases (incident) identified in 1995.

[b]Average cost of epilepsy care for 1 year of all cases (prevalent) in 1995.

SOURCE: Adapted from Begley et al., 2000. Reprinted with permission from John Wiley and Sons.

use, including care of comorbidities, as well as social services, to reconcile the different estimates that currently exist (Chapter 2). In addition, estimates are needed of the cost to families of the "informal care" they provide. Too little is currently known about these important markers of the burden of epilepsy on the health care system.

Cost-Effectiveness of Specific Services

One of the areas in health care value that has received considerable attention regarding epilepsy care is the cost and cost-effectiveness of seizure medications. A recent review of 12 studies completed between 2003 and 2007, including 5 cost-minimization analyses and 7 cost-effectiveness studies, found that when used alone (monotherapy), newer seizure medications had similar effectiveness in terms of seizure remission, but were significantly more expensive than older medications (Beghi et al., 2008). At the same time, newer medications may offer the advantages of reduced side effects, particularly when compared with the long-term side effects associated with earlier seizure medications and their potential to cause birth defects (Knoester et al., 2005; Sheehy et al., 2005). The newer drugs also may produce fewer adverse drug interactions. A recent meta-analysis by AHRQ examined the evidence on the effectiveness and safety of newer seizure medications (available since 1993) versus older medications and innova-

tor versus generic seizure medications in patients with epilepsy (AHRQ, 2011). The evaluation of newer versus older antiepileptic medications was predominantly limited to newer seizure medications in comparison with carbamazepine, valproic acid, and phenytoin. The wide variety of seizure types makes it difficult to compare seizure medications. Further studies are needed to examine the balance of cost, efficacy, and adverse side effects of different seizure medications for specific types of epilepsy, patient populations, and various combinations of polytherapy. Studies are also needed on the cost of specific services such as routine EEG monitoring and certain MRI protocols, to assess their value in different populations.

CONCLUSION: DEVELOPING AN EPILEPSY CARE MODEL

As noted throughout this report, epilepsy is a complex disorder that requires the active involvement of the individual with epilepsy, family and friends, and other caregivers; the time and expertise of many health care providers; and the knowledge and skills of varied community services providers. To emphasize the need for a patient-centered and collaborative approach to providing high-quality and efficient care, the committee conceptualized the following model for epilepsy care.

The committee started with the biopsychosocial approach that acknowledges the multidimensional interactions of early life (e.g., genetics, environmental factors), physiologic factors (e.g., seizures, cognitive changes, treatments, adverse events, other neurological problems), and psychosocial factors (e.g., social support, psychological state, life stressors, adaptation) that can have an impact on an individual's symptoms, behavior, and health outcomes (e.g., seizure control, quality of life, self-management) (Borrell-Carrio et al., 2004; Engel, 1977). This approach emphasizes the dynamic and synergistic relationships that occur in a disorder such as epilepsy and can help guide the approach to care.

Building on the biopsychosocial approach, the committee then explored the Chronic Care Model developed by Wagner and colleagues (Wagner, 1998; Wagner et al., 2001, 2005). This model's approach to the care of chronic health conditions recognizes that the partnership between a competent clinical team and a patient skilled in self-management is foundational, but to be most effective, the partnership also needs to include family members and community service providers. Three themes emphasized in the development of the Chronic Care Model resonate for epilepsy care:

- Care should be evidence-based with treatments and care approaches based on the best clinical evidence.
- Care should be population-based, with all who need care receiving equitable, timely, and high-quality health care and community services for their epilepsy and other medical conditions.

- Care should be patient-centered, with meaningful interactions among providers and patients and support for self-management skills, to improve health and quality of life (Austin et al., 2000).

The model of epilepsy care developed by the committee (Figure 4-5) illustrates the emphasis placed on an integrated and collaborative approach to health care and community services. The model necessitates that community and health care systems are organized to provide access to and delivery of education and services that support self-management by the person with epilepsy and his or her family. Harmonization among services is essential to achieve high-quality outcomes. Implementing this model of epilepsy care is feasible and should be pursued through various organizational, financial, and payment strategies. Demonstration projects are needed of collaborative approaches to care, such as those currently sought by the CMS Center for Medicare and Medicaid Innovation (CMS, 2012b). The model should be the basis for accreditation, certification, guideline development, performance evaluation activities, and initiatives in epilepsy care.

The patient–clinician encounter takes place in the context of a larger health care system, which, in turn, operates within the context of the broader community. Because the majority of health decisions are made by the individual with epilepsy within the context of his or her family and community, patients must have the education, skills, and tools to manage their epilepsy appropriately day-to-day (Chapter 7). This model recognizes that self-management is a critical element in achieving quality health outcomes. By being patient-focused, self-management approaches promote support by the patient's network of health care providers and community resources. The patient and family are responsible for setting goals and implementing recommendations from their health care team and community services providers in a way that allows them to receive the care and support that are needed at the right time and in the way they can use it best. In addition, community resources and policies are vital to quality of life (Chapter 6).

The main focus of this model is on the individual with epilepsy and his or her family—not the health care system—with efforts made to identify patient needs, recommend services, remove barriers to treatment, and facilitate care, including co-management of comorbid health problems when appropriate. Collaboration among care team members is critical to ensure that patients' needs are being met.

To achieve a coordinated and collaborative approach to epilepsy care will involve focused efforts across a range of research and implementation priorities. Throughout this chapter, the committee has provided the basis for the research priorities and recommendations regarding improvements needed in health care for people with epilepsy that are detailed in Chapter 9. Research on new screening and decision-support tools is needed as

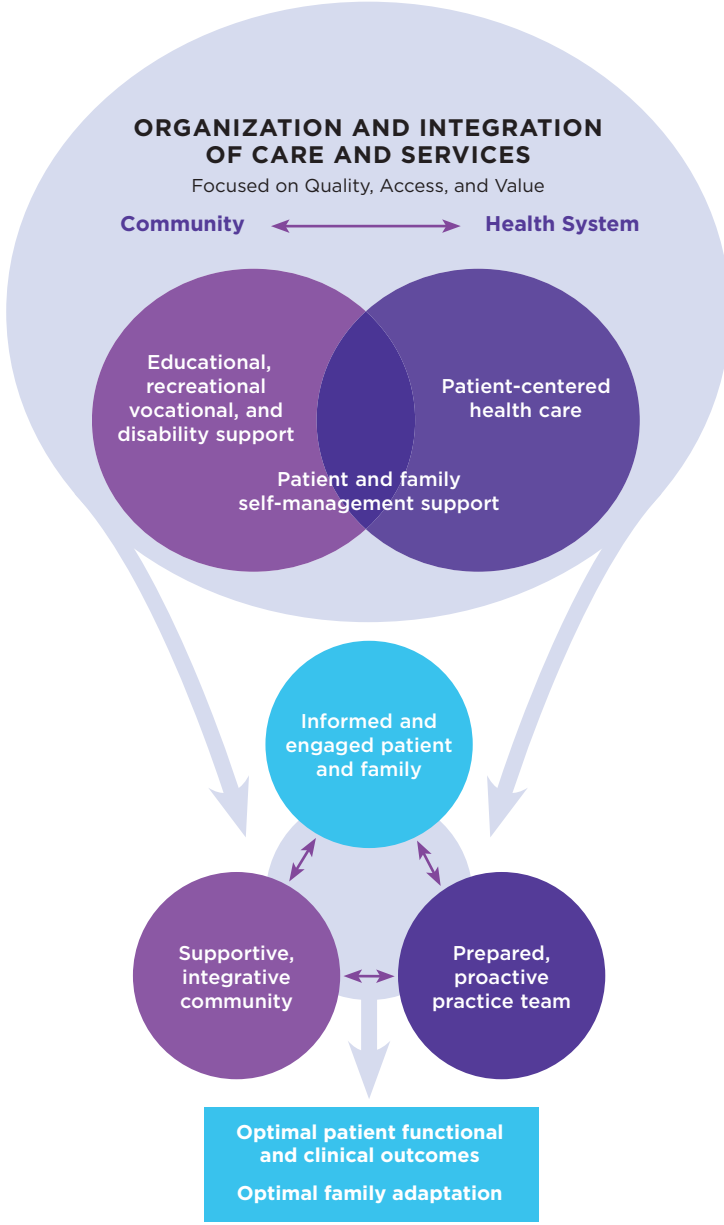

FIGURE 4-5
Epilepsy care model.

SOURCE: Adapted from Wagner, 1998. Reprinted with permission from the American College of Physicians.

are comparative effectiveness studies of epilepsy treatment options and prioritization of those studies. The health services evidence base for epilepsy care needs to be bolstered, including a focus on the workforce and ensuring value in epilepsy care. Actions needed to improve health care for people with epilepsy include accrediting epilepsy centers and establishing a network of centers, developing and implementing a quality care framework and performance measures, and enhancing the screening and referral options and protocols for early identification of epilepsy in high-risk populations, of comorbidities, and of refractory epilepsy.

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5

Health Professional Education

In seeking treatment for epilepsy and its comorbidities, patients and families interact with primary care, emergency, and specialist physicians, as well as a range of other health professionals. Beyond the technical aspects of care, high-quality care for people with epilepsy requires health professionals who are willing and able to co-manage patients across specialties (e.g., primary care, neurology, psychiatry, obstetrics/gynecology) and to coordinate care across disciplines (e.g., medicine, nursing, psychology, nutrition, rehabilitation, pharmacy). Teams should comprise professionals assembled and prepared to meet the diverse needs of individual patients. Research has identified gaps in health professionals' knowledge about treating epilepsy and its comorbidities and in their level of confidence in doing so. At the same time, few educational interventions have been developed to improve health professionals' knowledge about the epilepsies, and researchers have found that physicians outside of the epilepsy field may be reluctant to take advantage of epilepsy education programs that are available. Negative perceptions of people with epilepsy among health professionals contribute to stigma and can affect quality of care. Epilepsy centers and epilepsy advocacy organizations can—and often do—play a major role in supporting professional education programs. Actions needed to improve the education of health professionals include defining essential knowledge and skills, indentifying specific knowledge gaps and information needs, evaluating the efficacy and reach of current educational opportunities, exploring and developing innovative educational tools and technologies, and disseminating educational materials and tools more broadly.

Building the health care workforce's knowledge base and skill sets in diagnosing, treating, supporting, and generally working with people with epilepsy is necessary to ensure that patients and families have access to high-quality care. People with epilepsy typically encounter a variety of health professionals, including an array of physicians (e.g., neurologists, epileptologists, psychiatrists, neurosurgeons, primary care physicians), nurses, psychologists and counselors, pharmacists, emergency medical technicians (EMTs) and first responders, electroneurodiagnostic (END) technologists, and direct care workers, who play differing roles in their health care (Appendix D provides examples of these roles and the relevant professional boards and organizations). Health professionals need current knowledge about many aspects of the epilepsies: seizure recognition and diagnosis; prevention and treatment options; associated comorbidities, risks, and safety concerns; necessary social services; psychosocial and quality-of-life factors; and stigma. The specific types and depth of knowledge required vary across professions, depending on the roles, responsibilities, and scope of practice of the professionals and the specific settings in which they work.

In considering how to improve the education of health professionals, the committee conducted a search for literature and available resources. However, at the outset, it must be underscored that few articles are available on the epilepsy-related educational needs of the wide range of health professionals or on effective teaching methods for meeting those needs. Much of the available information is outdated or international and not necessarily applicable to professionals in the United States. For some aspects of education, the strongest information pertains to physicians, although the committee fully recognizes the important role of the nonphysician workforce (e.g., nurses, pharmacists, psychologists and counselors, END technologists, direct care workers) in caring for people with epilepsy. However, very little has been done to assess their specific knowledge gaps and information needs or to develop targeted, effective educational interventions for them. The committee was not asked to conduct an in-depth review and analysis of the various educational opportunities, licensing and certification requirements, or specific curricula and content taught in the diverse range of educational programs for all of the health care disciplines individually. Therefore, this chapter focuses on how education and training could be improved broadly, across all professions involved in caring for people with epilepsy, rather than focusing on specific professions or educational opportunities, except to describe a few illustrative programs and knowledge gaps.

The committee's vision for the education of health professionals about epilepsy would culminate in a workforce that has been taught and trained in multidisciplinary settings to provide high-quality, coordinated, and patient-

centered care (as described in Chapter 4). It further sees the ideal practice environment as being a team-oriented, learning environment that allows professionals to practice to the fullest extent of their training and skills, consistent with their roles, responsibilities, and scope of practice. Health professionals also need to have opportunities to deepen their understanding and strengthen their array of skills over entire careers, in accord with evolving guidelines, best practices, and research advances. Ideally, the health care workforce would be sufficiently prepared to provide every person experiencing seizures with accurate diagnostic services and patient-centered care that meets the patient's (and family's) needs, delivered in a manner that takes into consideration health literacy, cultural, and psychosocial factors.

DEMONSTRATED KNOWLEDGE GAPS

> *Physicians in every branch of medicine and mental health workers in every branch of mental health need to recognize the symptoms of epilepsy, and they need to know where to refer and what good treatment looks like.*
>
> –Susan Farber

Through its work the committee identified three areas with documented knowledge gaps in epilepsy care: providing primary care, treating comorbidities, and responding to the specific needs of women. The testimony provided to the committee during its deliberations by people with epilepsy and their families suggests additional gaps in knowledge, including areas related to accurate diagnoses, new treatment options, the risks of sudden unexpected death in epilepsy (SUDEP), and how to sufficiently and sensitively convey those risks. Additionally, Hirsch and colleagues (2011) noted the dearth of research and data related to health professionals' knowledge about SUDEP and their comfort in discussing SUDEP with patients and their families. Gaps in knowledge across various areas likely exist among neurologists without specialized education in epilepsy and, more broadly, among physicians and other health professionals outside of the neurology field (e.g., emergency medicine, psychiatry). Specific knowledge gaps may also exist with respect to treating a number of subpopulations:

- infants, very young children, and all children with the rarer, more severe epilepsy syndromes;
- people at any age who have complex comorbidities or who have seizure-like events with a psychological basis that may or may not be associated with an epilepsy diagnosis;
- the growing number of older adults whose clinical picture is complicated by chronic physical and mental conditions associated with aging and who may already have a complicated drug regimen;

- people who have low health literacy and who may have difficulty following clinicians' instructions; and
- people who can be identified as at higher risk of premature death from suicide, injury, or SUDEP.

However, detailed exploration of knowledge gaps in these areas and how to remedy them awaits future assessment and documentation.

Primary Care

Each [pediatrician] asked about car seats, home safety, and second-hand smoke, but none noticed [the] seizures or developmental delays until we asked.

–Carrie Baum

I experienced a couple of complex partial seizures for the first time, then a dozen or so complex partial seizures in a single day. Our family doctor was unavailable so I saw one of his associates. He was baffled and prescribed Tylenol, Gatorade, and rest.

–Jim Ashlock

A number of medical disciplines make up the nation's primary care physician workforce, including family physicians, general internists, general pediatricians, obstetrician-gynecologists, and geriatricians. Other primary care providers include physician assistants and nurse practitioners. Many patients with new-onset seizures are first evaluated in primary care settings (Chapter 4). In the United States, high-quality primary care is essential for people with epilepsy, inasmuch as only 17 percent of those with new-onset epilepsy see a neurologist, and primary care physicians provide most of the day-to-day care and treatment for about 40 percent of epilepsy patients (Fountain et al., 2011; Montouris, 2000). Additionally, Begley and colleagues (2009) found that people with epilepsy who were racial/ethnic minorities, had low incomes, or were uninsured or insured through public programs (e.g., Medicaid, Medicare) were less likely to receive specialty care and more likely to receive care through generalists (Chapter 4). This finding further emphasizes the importance of high-quality epilepsy care in primary care settings and the importance of these providers having sufficient knowledge about diagnosing, treating, and referring patients with epilepsy to specialty care when needed.

Primary care providers' knowledge, skill, and comfort regarding diagnosing and treating the epilepsies have been questioned (by themselves and others) and sometimes criticized (Chappell and Smithson, 1999; Elliott and Shneker, 2008; Gomes, 2000; Hayes et al., 2007; Minshall and Smith, 2012; Montouris, 2000; Moore et al., 2000; Sweetnam, 2011; Thapar et al., 1998; Theodore et al., 2006). It is believed that primary care physi-

cians gain the majority of their knowledge pertaining to epilepsy during medical school through a combination of didactic coursework and clinical experiences, such as neurology clerkships. One study concluded that medical students and residents had low confidence and difficulty when caring for patients with neurological conditions generally, which resulted, in part, from limited exposure to neuroscience subject matter and neurological patients throughout their education. The authors expressed concern about these findings, noting that the number of patients with neurological conditions being cared for in primary care settings is increasing (Zinchuk et al., 2010). Education about epilepsy and other neurological conditions in medical school curricula is disjointed, and not all medical schools require students to participate in a neurology clerkship (discussed below) (Devinsky et al., 1993; Galetta et al., 2006). Moore and colleagues (2000) hypothesized that the development of new seizure medications and a lack of knowledge in prescribing them likely contribute to clinicians' lack of confidence in caring for people with epilepsy.

An international literature review revealed the need for "earlier targeted education to improve [primary care physicians'] attitudes toward and beliefs about epilepsy and confidence in managing epilepsy" (Elliott and Shneker, 2008). Yet it appears that few educational interventions have been specifically developed to improve education and training about the epilepsies. Such programs need to be sensitively designed, taking into account the considerable caseloads, wide range of clinical conditions, increasing responsibilities, and lower reimbursements that primary care providers face.

The American Academy of Neurology's (AAN's) Family Practice Curriculum in Neurology is the result of collaborations between neurology and family practice faculty that aims to provide family care physicians with knowledge about common neurological conditions. The curriculum was designed for medical students, residents, and practicing physicians and includes information and case studies on seizures and epilepsy (AAN, 2011). However, the curriculum is provided as an informational resource and may or may not be widely used in developing or updating educational programs. Nor has the impact of this resource on physician education and knowledge been assessed insofar as the committee could determine.

Surveys of UK general practitioners have concluded that the epilepsy-related topics about which they are most interested in learning are medication therapies and side effects, diagnosis and referral, how to give advice about lifestyle, and non-medication therapies (Chappell and Smithson, 1999; Stuart and Muir, 2008). Practitioners preferred courses that were up to a day in length and that were offered during the week. Additionally, they wanted the information on epilepsy to be combined with information on other neurological conditions. Younger practitioners preferred online

courses and case studies as teaching mechanisms (Chappell and Smithson, 1999; Stuart and Muir, 2008).

A handful of educational programs have been developed and used in different countries to improve the knowledge of primary care providers and general practitioners about epilepsy (Adamolekun et al., 1999; Fernandes et al., 2007; Isler et al., 2008; Minshall and Smith, 2012; Stuart and Muir, 2008):

- Stuart and Muir (2008) developed a half-day course specifically tailored to the needs and preferences of UK general practitioners and nurses. The course used case studies and multidisciplinary lectures to deliver information on medication therapy and side effects, the specific needs of women with epilepsy, and ways to respond to prolonged seizures or status epilepticus. Although participants expressed satisfaction with the course, the developers conducted no assessment of improved knowledge or changes in practice.
- In another UK study, the authors concluded that to be most effective in promoting practice changes among general practitioners, practice guidelines should be paired with targeted educational interventions (Minshall and Smith, 2012; Minshall et al., 2011).
- A Brazilian study found success in three types of educational programs: an 8-hour information course for physicians stressing diagnosis, treatment, and related basic content; a 3-hour "social reintegration" course on the biopsychosocial aspects of epilepsy, designed to equip practitioners and community leaders to provide social support; and a 20-hour "train-the-trainer" course to prepare physicians to pass information on to other health care personnel. These authors highlighted the need for ongoing education to improve quality and management of care (Fernandes et al., 2007).
- Isler and colleagues (2008) used a modular education program that included videos and was delivered via CD-ROM. The program significantly improved seizure recognition and classification skills among pediatric residents, nurses, and electroencephalography (EEG) technologists working in general pediatric clinics in Turkey.
- A program developed in Zimbabwe taught rural primary care nurses and community health educators about epilepsy with a focus on diagnosing and managing people with generalized tonic-clonic seizures. The program included a 1-day seminar with lectures, case studies, and video presentations, and authors documented a significant increase in the knowledge of the nurses, increased patient recruitment to the health center (74 percent), and improved medication adherence (Adamolekun et al., 1999).

As noted in Chapter 4, high-quality primary care services for people with epilepsy can lead to improved seizure control and reductions in emergency hospitalizations (Shohet et al., 2007). Targeted educational interventions can be used to increase knowledge and change practices among primary care providers, which in turn would improve quality of care. Although educational programs and courses need to be tailored to meet the needs, preferences, and time constraints of primary care providers (Chappell and Smithson, 1999), all primary care providers, including nurse practitioners and physician assistants who are playing an increasingly important role in primary care (Bielaszka-DuVernay, 2011; IOM, 2011), need current knowledge about the epilepsies.

Special consideration also should be given to epilepsy education for primary care providers who focus on children, older adults, and women's health because these groups have specific, and often complex, epilepsy-related needs, as described throughout this report. Part of this training should enable primary care providers to recognize when referrals to specialist physicians or specialized assistance are necessary (Montouris, 2000).

Care for Comorbidities

The epilepsies are associated with a range of physical and mental health comorbidities and cognitive impairments that can have an impact on many aspects of quality of life from family and social relationships and interactions to academic performance and independent living. Research has connected epilepsy with a variety of physical conditions (somatic comorbidities), such as diabetes and cardiovascular disease (Chapter 3). Often these comorbidities, especially mental health conditions and cognitive impairment, go undiagnosed and untreated or undertreated, despite patients' symptoms (Barry, 2003; Devinsky, 2003; Marchetti et al., 2004; Ott et al., 2003; Wiegartz et al., 1999). Mental health services are a critical component of comprehensive and effective epilepsy care for many people. A range of health professionals—including psychiatrists, neurologists, primary care physicians, psychologists and counselors, psychiatric nurses, and clinical social workers—can provide the necessary services. However, knowledge about these comorbidities—even among epileptologists and neurologists—appears to be lacking, and knowledge about epilepsy among mental health professionals is also inadequate.

Few studies have examined health professionals' knowledge about comorbidities of epilepsy and their specific educational needs. However, common concerns voiced among neurologists and epileptologists caring for both children and adults with epilepsy are that they are not confident in assessing and diagnosing common comorbid mental health conditions and that few mental health specialists are available and both willing and well

prepared to treat individuals with epilepsy (Hayes et al., 2007; Smith et al., 2007; Sweetnam, 2011). Participants in focus groups conducted at the 2010 American Epilepsy Society (AES) annual meeting identified management of psychological and social comorbidities as a "critical professional practice gap" and noted that "they weren't trained to treat comorbidities and are uncomfortable doing so" (Sweetnam, 2011, p. 5). At the same time, participants were reluctant to refer patients to psychiatrists and psychologists because of their perceived lack of knowledge about epilepsy.

A study conducted in Brazil, where many psychiatrists reported caring for people with epilepsy,[1] found a significant lack of knowledge about epilepsy and its comorbid conditions (Marchetti et al., 2004). Of particular concern was the fact that less than half of psychiatrists knew that depression is the most common comorbid mental health condition associated with epilepsy, which leads to questions about whether depression is being recognized and appropriately treated. While this study may not be directly transferable to U.S. health professionals, it does demonstrate that regular interaction with epilepsy patients is not enough to establish awareness about the complexities of their condition, and specific educational interventions are necessary.

In an effort to improve knowledge of mental health and cognitive comorbidities associated with epilepsy, Smith and colleagues (2007) demonstrated the efficacy of a 50-minute lecture in improving the knowledge of pediatricians and pediatric neurologists on epilepsy topics, such as the cognitive and mental health comorbidities; effects of epilepsy, seizure medications, and stress on behavior and learning; and suicidality. Despite the effectiveness of this small intervention, pediatricians and pediatric neurologists "made it clear that they did not have time" (p. 405) to pursue such educational opportunities, regardless of delivery mechanism (e.g., lecture, video, papers, manuals). This response reiterates the overall deficit in awareness and knowledge about the importance of mental health and cognitive comorbidities and their impact on patients' quality of life. Clinicians' lack of awareness and understanding creates a substantial barrier to obtaining needed mental health services, which, in turn, can increase morbidity and mortality (Barry, 2003).

The committee did not find studies that evaluated the epilepsy-specific knowledge of nonphysician mental health professionals, such as psychologists, counselors, or psychiatric nurses. Apparently, despite the demonstrated educational needs and concerns of health professionals, few efforts have been made to develop corresponding educational programs or resources. Developing creative ways to encourage and incentivize health

[1]Of those psychiatrists surveyed, 95 percent had worked with people with epilepsy and mental disorders previously and 48 percent frequently work with epilepsy patients with comorbid mental health conditions (Marchetti et al., 2004).

professionals to participate in educational opportunities that focus on comorbidities appears essential.

Caring for Women with Epilepsy

Women with epilepsy have specific needs and concerns that health care providers must understand in order to provide high-quality care. For example, hormonal fluctuations can affect seizure frequency, and some seizure medications have adverse effects on reproductive functioning, pregnancy, and breastfeeding. A number of evidence-based practice guidelines and parameters exist that define optimal care for people with epilepsy, and there are a number of guidelines and parameters that are specific to women with epilepsy (see Box 4-2 in Chapter 4). These guidelines are designed to inform health professionals caring for women with epilepsy about evidence-based best practices in the field; they include specific information on a number of topics such as which medications are safe to prescribe during pregnancy, risks associated with seizure frequency during pregnancy, and the use of folic acid supplements during pregnancy (Harden et al., 2009a,b,c). The guidelines present an important opportunity to educate physicians about caring for women with epilepsy. However, little information is available on how often existing guidelines are followed or what role they play in educating health professionals.

A survey was conducted in 1998 by the Epilepsy Foundation to assess the knowledge and awareness of health professionals involved in the care of women with epilepsy following the release of practice guidelines for providing care for women with epilepsy by the AAN and the American College of Obstetricians and Gynecologists. The majority of respondents across all disciplines were not aware of the effects of estrogen and progesterone on seizures or the interactions of seizure medications with oral contraceptives (Morrell et al., 2000). More recent surveys continue to find that physicians, including neurologists and neurology residents and pharmacists, lack critical knowledge about the unique needs of women with epilepsy, particularly the effects of epilepsy and seizure medications on pregnancy, breastfeeding, and sexual dysfunction (Long et al., 2005; McAuley et al., 2009; Roberts et al., 2011).

Roberts and colleagues (2011) concluded that, despite the availability of guidelines from the AAN and AES, knowledge about the use of seizure medications during pregnancy was low—less than half of neurologists were able to identify which medications were linked to adverse events during pregnancy. Additionally, less than a third knew that women with epilepsy do not have a significantly increased risk for pregnancy complications or that epilepsy does not increase the risk of perinatal mortality. The authors concluded that more needs to be done to implement existing guidelines, including educational outreach (Roberts et al., 2011).

These studies and others highlight the persistent knowledge gaps associated with the specific needs of women with epilepsy, and they identify an important opportunity for targeted educational efforts.

ATITTUDES AND BELIEFS OF HEALTH PROFESSIONALS

Because physicians can by their personal attitudes enhance or diminish stigma of epilepsy in the community and within the family, they are also central to quality of life issues.

–Paula Apodaca

Effective epilepsy care requires a productive and positive relationship and effective communication among health care providers and patients and their families. Negative attitudes and beliefs about people with epilepsy that may exist among some health professionals can perpetuate stigma and negatively affect quality of care. Generally, the literature on the attitudes and beliefs of health professionals who care for people with epilepsy is outdated; it comes primarily from Australia, the United Kingdom, and Brazil; and it focuses solely on medical students and physicians. In these studies, health professionals recognize the social stigma associated with the epilepsies (Beran et al., 1981; Davies and Scambler, 1988; Gomes, 2000; Hawley et al., 2007; Hayes et al., 2007), but they may not recognize how their own attitudes and beliefs affect the quality of care they provide and contribute to broader societal stigma and felt stigma for their patients.

International studies of medical students, general practitioners and other physicians have identified negative perceptions of people with epilepsy (who may be characterized as having behavioral and emotional problems, mood swings, or aggressive behavior, for example) and linked these perceptions with stigma (Beran and Read, 1983; Beran et al., 1981; Caixeta et al., 2007; Davies and Scambler, 1988; Frith et al., 1994; Marchetti et al., 2004). Davies and Scambler (1988) emphasized that health care providers can unknowingly promote stigma by avoiding discussion and treatment of patients' psychosocial challenges and mental health and cognitive comorbidities. Two decades later, Hayes and colleagues (2007) highlighted attitudes of U.S. health professionals as a serious barrier in achieving positive health outcomes for people with epilepsy, especially attitudes associated with caring for patients with multiple needs, working with families that have expectations that may be misaligned or unrealistic, treating patients who do not follow medication regimens as prescribed, responding to cultural variation, and managing patients with negative attitudes, including skepticism and denial. The resulting perception among some health professionals is that people with epilepsy can be difficult to work with (Hayes

et al., 2007). These studies demonstrate the need for targeted efforts to improve the attitudes of health professionals about working with people with epilepsy and their confidence and skills in working with these patients and families.

According to a UK study, attitudes of general practitioners can affect patient-rated quality of care. In this research, patients rated quality of care higher when general practitioners indicated they believed epilepsy is "a primary care responsibility" (Thapar and Roland, 2005, p. 3). A previous study noted that educational initiatives could play a role in building health care providers' confidence in caring for people with epilepsy and in improving quality of care (Thapar et al., 1998). The results from the few international studies that have examined the impact of educational interventions on improving attitudes of health professionals are mixed (Fernandes et al., 2007; Mason et al., 1990; Noronha et al., 2007). However, it is promising that the more recent studies have observed positive changes in attitude as a result of educational interventions (Fernandes et al., 2007; Noronha et al., 2007).

As mentioned above, some health professionals in the epilepsy field may also be concerned about the nature of the care provided to people with epilepsy by other health professionals, which can negatively affect the interface among primary care, mental health, and neurology professionals (Hayes et al., 2007; Sweetnam, 2011). Hayes and colleagues (2007) indicated that negative attitudes can interfere with professional relationships, which in turn affect referral patterns, effective interdisciplinary collaboration, and patient co-management. The extent of distrust and lack of referrals among health care providers is unknown but could potentially have a significant impact on the quality of epilepsy care. Efforts are needed to foster improved interdisciplinary collaboration and co-management of patients with epilepsy, and those efforts must start during the educational process (see also Chapter 4).

Although it is unknown whether the negative attitudes of health professionals observed in other countries are prevalent in the United States or have persisted over time, some evidence suggests that attitudinal challenges do exist here (e.g., Hayes et al., 2007). As Gomes (2000) pointed out, "Care is influenced not only by knowledge, but by doctors' attitudes." Additional research is needed, in order to understand current attitudes and beliefs of U.S. health professionals about epilepsy and the corresponding impact on stigma and quality of care. Educational programs can attempt to foster more positive attitudes and beliefs through building confidence in providing care; providing opportunities to practice strategies for handling challenging situations; and, in general, promoting a patient-centered approach to improve quality of care through professional collaboration and co-management (Chapter 4).

INNOVATIVE TEACHING STRATEGIES

Interactive Online Education

The widespread availability and use of interactive, web-based teaching has had a great impact throughout the educational continuum and can be used in didactic education, clinical training, and continuing education (CE) programs. It offers opportunities to improve and expand the reach of epilepsy educational information and programs, not only for health professionals, but also for individuals with epilepsy and their families (Chapter 7) as well as the public (Chapter 8). Demand for online education[2] will likely increase as health professionals become accustomed to using the growing array of new technologies and devices for obtaining educational content.

Studies of online education for health professionals have shown that it is efficient and just as effective as traditional teaching approaches such as lectures (Chumley-Jones et al., 2002; Cook et al., 2008). Online education can be interactive, provides instant feedback, can be flexible in time and location, promotes active learning, and can adapt to the pace and other specific needs of users (Cook et al., 2008; Ochoa and Wludyka, 2008).

Health professionals' preferences as to the delivery mechanism for educational material on the epilepsies vary. Some professionals and students prefer online education, while others prefer in-person courses or facilitated case discussions (Bye et al., 2009; Chappell and Smithson, 1999; Farrar et al., 2008). A few studies of epilepsy-specific online educational programs demonstrate efficacy and significant improvements in the knowledge of users. Most of these programs were developed and evaluated outside the United States (Bye et al., 2009; Farrar et al., 2008; Isler et al., 2008; Ochoa and Wludyka, 2008; Wehrs et al., 2007). One U.S. study used an interactive, multimedia, online approach with real case studies to supplement didactic lectures for third-year medical students (Ochoa and Wludyka, 2008). The program focused on seizure identification and classification, diagnosis, and management and included photos and videos of people having seizures and links to more detailed information. Because clinicians witness seizures only rarely, the authors emphasized the importance of using video to teach seizure recognition and classification and concluded that their online program, in combination with the standard curriculum, was more effective in short-term learning than the standard curriculum alone (Ochoa and Wludyka, 2008).

Available evidence supports the further development, implementation, and evaluation of interactive, online modules to enhance and augment education about the epilepsies. Targeted online modules could be developed

[2]Online education is used in this section to describe learning opportunities that are computer based and may be accessed through the Internet.

for different professions or for specific topic areas (e.g., health care for women with epilepsy). The committee supports the use of video to teach seizure recognition and classification whenever possible and emphasizes the importance of the interactive nature of online educational modules, rather than static slide sets or lectures on video. Dissemination and incorporation of these types of modules into curricula and CE will require collaboration among a variety of professional organizations and academic health centers.

In addition to online educational programs, many other online informational resources are available to educate health professionals about epilepsy. For example, peer-reviewed journals (e.g., *Epilepsia, Epilepsy and Behavior*, *Epilepsy Currents*) and clinical guidelines specific to epilepsy are available for physicians and nurses through professional organizations such as the AAN and American Association of Neuroscience Nurses (AANN). Additionally, the International League Against Epilepsy (ILAE) is currently developing an e-textbook that will cover a wide range of topics and is expected to be launched in 2012 (Personal communication, C. T. Tan, ILAE, November 21, 2011). Epilepsy organizations, such as the AES, the Epilepsy Foundation, and the Epilepsy Therapy Project (ETP), maintain websites that offer resources targeted to health professionals. As the nation's foremost provider of epilepsy-related CE and educational resources for health professionals, the AES has a range of resources available on its website[3] for its members and health professionals; many of these resources are described in more detail below. Additionally, the ETP's health professional website[4] features videos and webcasts, case studies, and a variety of educational resources on comorbid conditions, the needs of people with specific epilepsy conditions, diagnosis and treatment, refractory seizures, and "challenging cases." Also, there are informational websites maintained by federal agencies (e.g., National Institutes of Health [NIH],[5] Centers for Disease Control and Prevention [CDC][6]) and private organizations (e.g., Medscape[7]) that may also be valuable for informing and educating health professionals about seizures and the epilepsies.

While extensive online resources such as those mentioned above are available, clinicians must seek them out. To date, the effectiveness of these types of resources in educating health professionals and how frequently they are used by those within and outside of the epilepsy field have not been systematically assessed. Existing online educational resources should be evaluated, kept up to date, and tested for reproducibility across different

[3]See www.aesnet.org.
[4]See www.professionals.epilepsy.com.
[5]See http://www.ninds.nih.gov/disorders/epilepsy/epilepsy.htm.
[6]See http://www.cdc.gov/epilepsy.
[7]See http://www.medscape.com/resource/seizures.

health professions. Additional online resources, including those available for CE credit, are described below.

Simulation

One teaching strategy being deployed in many health professional education and training programs is the use of simulation, often involving high-fidelity mannequins.[8] Simulation allows students to practice skills in a safe environment where they can make and learn from mistakes without endangering patients. Simulation can provide students with opportunities to practice decision making and prioritization; communication, collaboration, and conflict resolution; and delegation and role clarification (Deering et al., 2011; IOM, 2010b). It also increases exposure to conditions or events that may not happen often enough in a clinical setting to ensure that all students gain experience with them (Weaver, 2011).

The nursing profession, in particular, has embraced simulation as an opportunity to improve education and expand hands-on learning experiences to augment clinical education (IOM, 2010b; Weaver, 2011). To further promote the use of simulation in nursing education, the National League for Nursing has developed the Simulation Innovation Resource Center,[9] an online community that provides nursing faculty with resources for designing, implementing, and evaluating education using simulation (IOM, 2011).

Recent literature reviews of the use of simulation in the education of health professionals demonstrate the efficacy and value of this approach to teaching (Cook et al., 2011; McGaghie et al., 2011; Weaver, 2011). Simulation can be used to teach virtually every aspect of clinical encounters and has been used for decades in surgery, emergency resuscitation, and medical examinations, and in a "nearly endless variety of scenarios" (Deering et al., 2011, p. 95). One review of more than 600 studies of the use of simulation in the education of physicians, nurses, EMTs, and other allied health professionals concluded that simulation is "consistently associated with large effects for outcomes of knowledge, skills, and behaviors and moderate effects for patient-related outcomes" (Cook et al., 2011, p. 978).

In its review of the literature, the committee identified few examples of simulation that have been used to teach information on the epilepsies. Konikow (1987) evaluated a program for neuroscience nurses that used computer simulation exercises to deliver case studies on a range of neuroscience topics, including epilepsy and febrile seizures. The authors highlighted

[8] "High-fidelity" refers to interactive mannequins that are full scale and to other learning experiences (e.g., virtual reality) that "are extremely realistic and provide a high level of interactivity and realism for the learner" (NLN, 2011).

[9] See http://sirc.nln.org.

the value of this simulation in teaching diagnostic reasoning skills. Currently, an evaluation of a team-based simulation program that focuses on improving patient safety in epilepsy monitoring units (EMUs) is being conducted by Dworetzky and colleagues (Personal communication, B. Dworetzky, Harvard Medical School, January 3, 2012). The study is testing the use of a procedural checklist for responding to simulated, unexpected events in order to develop critical-thinking, decision-making, and communication skills in teams of residents and nurses; to build the confidence of teams in managing seizures and responding to complications; and to educate them about standard safety procedures and emergency responses in EMUs. This set of knowledge and skills is vital to the safety of patients in EMUs, whose seizure medications are purposefully discontinued to trigger seizures in order to facilitate the diagnosis of seizure type and locus. As a result of the interruption in medication schedules, these patients are at increased risk for unexpected—and serious—events (e.g., falls, injuries, status epilepticus, cardiac arrest, SUDEP) that necessitate immediate and appropriate response from the health care team.

High-fidelity simulation offers a unique opportunity to improve epilepsy education for health professionals, promote interdisciplinary education and collaboration, and ultimately improve quality of care. Simulation's standardized scenarios can be repeated as necessary and may be particularly useful in teaching seizure recognition and identification, seizure first aid, response to status epilepticus, and connections between epilepsy and its comorbidities. Simulations of seizures and status epilepticus could be especially beneficial for teams of health professionals working in emergency rooms, intensive care units, and EMUs. In many ways, EMUs are a natural fit for the use of simulation for educating health professionals. EMU patients are at higher risk for serious, unexpected events; care is often team-based and requires the participation of a range of health professionals (e.g., epileptologists, nurses, END technologists); and many patient encounters are videotaped as part of standard practice and can easily be reviewed. Simulation of EMU events for health professionals new to this type of setting provides them with an opportunity to practice and learn from scenarios that may be common in EMUs without endangering patients.

MODELS FOR PROFESSIONAL EDUCATION

> *There is no formal curriculum in medical school and . . . there is currently a great diversity of training, which is dependent on the interests of the faculty, the patient mix at the clinical training facility, and the individual resident interests.*
>
> –John Pellock

A baseline knowledge about the epilepsies is essential for all health professionals, given the large population of people with epilepsy and the challenges of their comorbidities, which may bring them in contact with professionals in multiple disciplines, from cardiology, to mental health, to nutrition, to gerontology and nursing. Very few studies have examined knowledge gaps broadly (studies of specific knowledge gaps are described above). While the epilepsy knowledge base of U.S. physicians—and other health professionals—has not been widely assessed, international studies have demonstrated an overall lack of epilepsy knowledge among physicians and medical students (Beran and Read, 1983; Beran et al., 1981; Caixeta et al., 2007; Elliott and Shneker, 2008; Gomes, 2000; Tiamkao et al., 2007). However, some efforts are being made across the health professional education continuum in the United States to ensure the adequacy and availability of epilepsy-specific education; this section highlights a few of these models and approaches, most of which have focused on the physician workforce.

In an effort to guide medical education in neurology, the AAN has developed core curricula and competencies for neurology clerkship, residency, and fellowship programs, which feature seizures, status epilepticus, and epilepsy as areas to be taught. However, as previously noted, these curricula and competencies are offered as resources, and the extent of their actual implementation is unknown (AAN, 2011). Providing additional guidance for physician education, Morse and Holmes (2011) recently outlined the requisite knowledge and skills for pediatric neurologists treating children with epilepsy.

To fully understand the extent to which epilepsy is represented in medical education and in curricula for other health professions, comprehensive curricula assessments would be required that encompass a range of programs from prelicensure training through CE. Almost two decades after an AES committee found that "education of medical students about epilepsy is often fragmentary and incomplete" (Devinsky et al., 1993, p. S2), epilepsy content in medical school curricula—and other health professions' training programs—is believed to remain low. Updated studies of curriculum content could provide insight into any advances that have been made and identify important remaining gaps.

For medical students, neurology clerkships are an important opportunity to learn about the epilepsies through clinical experiences and hands-on teaching approaches. However, not all medical students are required to complete a neurology clerkship (Galetta et al., 2006), and the time and content devoted to epilepsy are unknown and can be assumed to be variable, as clerkships must cover information on the full range of neurological conditions from headache and chronic pain to autism spectrum disorders and Alzheimer's and Parkinson's diseases. One example of a clerkship that has taken a unique approach to teaching students about epilepsy is a

combined neurology-psychiatry clerkship program at the University of California, San Francisco, School of Medicine. During this clerkship, students develop a patient history, differential diagnosis, and clinical strategy for hypothetical cases presented through an interactive online module, including cases that focus on topics relevant to epilepsy. These exercises bring in both neurological and mental health factors for the students to consider (Hales, 2011), and the advantages include interdisciplinary collaboration and the use of highly informative, rigorously developed case studies that emphasize patient-centered care. The efficacy of these types of modular approaches should be evaluated, and opportunities for expanding the use of them in other clerkship programs and in advanced training of other health professionals—such as advanced practice registered nurses, physician assistants, and emergency medical services (EMS) personnel—could be explored.

Another example of a strategy for educating health professional students about the epilepsies involves the use of "standardized patients," trained volunteer patients or actors who typically are given a script or specific instructions for a scenario to role-play with a medical student. Standard patients are a staple of medical education and can be especially useful in teaching about disabling conditions (Long-Bellil et al., 2011). The University of South Carolina's School of Medicine has updated the standard patient scenarios used during its family medicine rotation to include epilepsy as an example and teaches students about high-risk comorbidities for patients with intellectual developmental disabilities (Long-Bellil et al., 2011). Standardized-patient scenarios and simulation specific to epilepsy also could be used to educate advanced practice registered nurses, physician assistants, and other health professionals who are involved in the diagnosis, treatment, and management of epilepsy and its comorbidities. Additional epilepsy-specific medical educational models have been developed and evaluated outside the United States (e.g., Bye et al., 2007; Mason et al., 1990; Noronha et al., 2007). In these studies, content was delivered through lectures and seminars that ranged from intensive 1-day courses to a series of shorter lectures, and they effectively increased students' knowledge about the epilepsies. These studies highlighted the importance of ongoing and continuous education about the epilepsies, the use of video and expert commentary in educational efforts, and the need for monitoring and evaluation of educational opportunities to determine efficacy and best teaching practices.

Residency and fellowship programs for the range of physician specialties, and clinical rotations and preceptor programs for advanced practice registered nurses and physician assistants, offer additional opportunities for improving epilepsy education. However, program requirements and curricula vary considerably from one discipline, specialty, or program to another, and diverse competing interests typically preclude extensive

focus on epilepsy. The curricula and content for these advanced training programs need to be assessed in order to evaluate the epilepsy-specific content and to identify specific opportunities and strategies for improving these programs.

In literature about the experiences of individual neurology residents, observations have indicated that these programs tend to focus on less prevalent neurological conditions in acute care settings rather than on more common neurological diseases and disorders, including epilepsy, that are predominant in outpatient care (Ances, 2011; D'Esposito, 1995; Moore and Chalk, 2005). Additionally, an informal survey of psychiatry residency program directors demonstrated large variation in the "attention paid to neurology rotations and objectives" (Hales, 2011).[10] Box 5-1 provides an example of one psychiatry residency program that may provide insight into some best practices for educating psychiatry residents about epilepsy and its associated comorbidities.

An important step toward improving education for physicians interested in specializing in the care of people with epilepsy is a new subspecialty board certification in epilepsy, being created by the American Board of Psychiatry and Neurology (ABPN). A subspecialty board-certification examination for epilepsy will be offered for the first time in 2013 and, for the first few years only (through 2017), will be open to all practicing neurologists. Subsequently, eligibility will be limited to graduates of accredited 1-year fellowships in epilepsy (ABPN, 2012). The core curriculum for the accredited fellowships is being developed by the AAN and includes five subjects: the basic science of epileptology, clinical epileptology, pharmacologic therapy of epilepsy, surgical therapy of epilepsy, and other therapies for epilepsy (AAN, n.d.). Approximately 80 1- to 2-year epilepsy fellowships currently are available in the United States (Theodore et al., 2006). The creation of this subspecialty will promote standardization of fellowships and the content that is taught and also will provide a better understanding of the number of practicing epileptologists in the United States. To assist its members who are interested in taking the certification exam, the AES plans to develop self-assessment and "performance in practice" modules (Personal communication, C. A. Tubby, AES, September 28, 2011).

Although there is not an epilepsy-specific certification for nurses in the United States, the American Board of Neuroscience Nursing (ABNN) offers a certification exam for registered nurses who are interested in specializing in neuroscience nursing. In addition to this certification, educational resources are available through the AANN, including a core curriculum

[10]Deborah Hales, Director of the Education Division for the American Psychiatric Association, conducted this informal survey to inform the presentation she gave at the committee's June workshop.

Box 5-1 UNIVERSITY OF MASSACHUSETTS PSYCHIATRY RESIDENCY PROGRAM

The first 2 years of the 4-year program provide didactic instruction through a weekly clinical neuroscience course, which includes 3 or 4 hours on epilepsy (including classification of seizures, seizure terminology, phenomenology, and recognition of seizure types through video) and 1 hour on electroencephalograph (EEG) interpretation. The neuropsychiatry section of the core curriculum includes a 90-minute session on behavioral concerns relevant to epilepsy that reviews common neuropsychiatric comorbid conditions. A psychopharmacology seminar includes side effects of seizure medications, among other topics. First-year residents also participate in a 3-month rotation in neurology. One of those months is devoted to neuropsychiatry and includes pre- and post-surgical evaluation of people with epilepsy, neuropsychiatric pathology, drug treatment challenges for people with epilepsy, and weekly EEG reading tutorials. The third and fourth years of the residency provide a 90-minute session on epilepsy surgery and a 2-year biological psychiatry seminar, which includes four sessions per year on clinical neuropsychiatric conditions. An elective neuropsychiatry journal club devotes 1 month per year to epilepsy-related papers. Additional opportunities to learn about epilepsy and its comorbidities include an elective longitudinal neuropsychiatric clinic; weekly case discussion among all residents, fellows, and faculty; and case conferences and readings.

SOURCE: Hales, 2011.

for neuroscience nurses that has a chapter on epilepsy and clinical practice guidelines for nurses caring for patients with seizures (AANN, 2009; Bader and Littlejohns, 2010). Like neurology clerkships, residency programs, and the board certification exam for physicians, this exam and core curriculum cover a wide range of neurological conditions and disorders, including epilepsy. Certification offered through the ABNN is not required to practice as an epilepsy nurse, which in the United States is usually a self-designated titled for nurses working in epilepsy centers. It is believed that epilepsy nurses practicing in the United States receive most of their epilepsy-specific education through on-the-job training. Efforts should be made to assess nurses' knowledge gaps about the epilepsies, to evaluate existing educational programs and opportunities, and to develop educational interventions that meet the specific learning needs of epilepsy nurses and the wide range of nurses (e.g., advanced practice registered nurses, psychiatric nurses) who work with people with epilepsy and their families.

Epileptologists, neurologists, and other health professionals involved in the care of people with epilepsy have benefited from the J. Kiffin Penry Epilepsy Education Programs, developed almost three decades ago. Box 5-2 describes the intensive courses offered through the Penry program, which provide opportunities beyond what may be possible through standard health professions education and training programs.

Box 5-2 THE J. KIFFIN PENRY EPILEPSY EDUCATION PROGRAMS

Since the launch of the first pilot program in 1986, the J. Kiffin Penry Epilepsy Education Programs have provided learning opportunities for more than 4,000 physicians and other health professionals. Approximately 20 percent of all practicing U.S. neurologists have participated in at least one of its five educational programs:

1. The Residents Program in Epilepsy is a 3-day course designed for second-year residents in neurology or pediatric neurology. Its goals are to "host at least one resident from each neurology residency program in the country" and to "increase residents' knowledge and interest in epilepsy and encourage them to pursue epilepsy fellowships."
2. The Pediatric Epilepsy Program is a 3-day course available to child neurology residents, and it covers a diverse spectrum of topics relevant to diagnosing, treating, and managing children and adolescents with epilepsy, with an emphasis on seizures and syndromes with pediatric onset.
3. The MiniFellowship Program is targeted to epilepsy fellows and in 4 days covers a comprehensive range of topics that includes diagnosis, treatment, and management of the epilepsies; advances in the field;, quality of life; psychosocial concerns; and needs of specific subpopulations.
4. The Advances in Epilepsy Program provides practicing neurologists and other health professionals with a streamlined weekend course that covers the fundamentals of diagnosis, treatment, and management of the epilepsies. Continuing medical education (CME) credit is available for this course.
5. The Advances in Epilepsy IDD/LTC Program was designed specifically for physicians who care for individuals with epilepsy who are also intellectually developmentally delayed. This weekend course qualifies for CME credit and focuses on specific diagnosis, treatment, and management considerations for this population, including quality of life and behavioral challenges.

The sessions are conducted in an intensive learning environment, are limited to a small number of participants, and include lectures, peer group discussions, and case studies. Experts across the epilepsy field and faculty from the Comprehensive Epilepsy Center at Wake Forest University teach the sessions. Participation not only provides access to an online alumni center that includes educational and networking resources but also fosters lasting relationships among professionals. During a focus group discussion conducted at the 2010 AES Annual meeting, participants identified the Penry program as a "seminal event that changed [their] professional practice" (Sweetnam, 2011).

SOURCE: J. Kiffin Penry Epilepsy MiniFellow Network, 2011.

CONTINUING EDUCATION

CE is critical to a well-educated health care workforce and essential for keeping health professionals' knowledge and competencies up to date and abreast of advances in research, diagnosis, treatments, technology, and approaches to caring for patients with epilepsy. CE also offers an op-

Box 5-3 SELECTED EXAMPLES OF ORGANIZATIONS THAT OFFER EPILEPSY-RELATED CONTINUING EDUCATION OPPORTUNITIES

- American Academy of Neurology
- American Academy of Neuropsychology
- American Association of Neurological Surgeons
- American Association of Neuroscience Nurses
- American Clinical Neurophysiology Society
- American Epilepsy Society
- American Psychiatric Association
- American Society of Electroneurodiagnostic Technologists
- Association of Child Neurology Nurses
- Child Neurology Society
- Congress of Neurological Surgeons
- Epilepsy Foundation
- Foundation for Education and Research in Neurological Emergencies
- International League Against Epilepsy
- International Neuropsychological Society
- National Academy of Neuropsychology
- National Association of School Nurses
- Society of Neurological Surgeons

portunity to broaden the understanding of health professionals regarding comorbidities, psychosocial concerns, quality of life, and needs of specific populations. Box 5-3 provides examples of professional organizations that offer, or have offered, epilepsy-relevant CE.

The requirements and approaches to CE vary significantly across professions and often are guided by requirements developed by professional boards, associations, and state licensing authorities. In 2010, the Institute of Medicine (IOM) released the report *Redesigning Continuing Education in the Health Professions* that described some of the shortcomings of current CE approaches, noting that "there are major flaws in the way CE is conducted, financed, regulated, and evaluated" (p. 2) and that "the science underpinning CE for health professionals is fragmented and underdeveloped" (p. 2). The report called for additional emphasis on interdisciplinary CE opportunities—which would be particularly valuable for professionals caring for people with epilepsy—and a new, comprehensive vision for professional development (IOM, 2010a).

This section of the chapter provides examples of currently available CE opportunities related to epilepsy that range from annual meetings and lectures to online education and targeted courses. The committee encourages developers of epilepsy-related CE to explore interdisciplinary educational opportunities, use innovative approaches that move beyond lectures at annual meetings, develop teaching approaches that are interactive and

relevant to clinical settings and situations, focus on improving outcomes rather than merely fulfilling credit-hour requirements, and reach health care providers beyond the epilepsy fields (e.g., primary care providers, nurses, psychologists, counselors).

Annual Meetings and Lectures

The annual meetings of professional organizations, such as the AES, ILAE, AAN, AANN, and those listed in Box 5-3, offer numerous lectures and workshops for CE credit that are relevant to epilepsy. The committee did not review these educational opportunities in detail, but notes that they typically are designed to meet the educational needs and preferences of the specific association's membership. The AES's annual meeting draws more than 4,000 attendees, who have available to them a range of educational programs (AES, 2011a). The society maintains online archives of all of its symposium programs. However, CE credits for physicians, nurses, and pharmacists are available only for those who attend the meeting in person (Personal communication, C. A. Tubby, AES, September 28, 2011). Participants have highlighted the need for additional educational opportunities at these meetings, explicitly for nurses and surgeons (Sweetnam, 2011).

The ILAE also hosts regional and international meetings (called congresses) for health professionals around the world. The sessions at these meetings range from lectures and poster presentations to interactive workshops and debates. The 2011 International Epilepsy Congress, held in Rome, drew almost 4,000 delegates from 114 countries. Increasingly, congress sessions and teaching courses are uploaded to a website for the benefit of people unable to attend in person. Additionally, the organization is creating short video summaries of selected presentations and using social media to disseminate congress messages and facilitate distance learning. European continuing medical education credits are available for these meetings and workshops, which can be converted to CE credits recognized by the American Medical Association (Personal communication; E. Bertram, F. Quinn, and C. T. Tan; ILAE; November 17, 21, and 26, 2011).

According to the IOM (2010a) report on CE, experience suggests that health professionals who attend these meetings for CE credit are likely to focus on fulfilling requirements to maintain their licenses and certification in areas they are familiar with, rather than pursuing topics that would advance their practice. Evidence that these programs effectively improve knowledge and change attendees' practice patterns is generally lacking (IOM, 2010a). Nevertheless, they offer important opportunities for developing and sustaining professional relationships in the field of epilepsy—a field with relatively small numbers of health professionals (Sweetnam, 2011).

Online Continuing Education Courses

Online education can be an effective and innovative approach to expanding the reach of educational opportunities for health professionals and is increasingly used to fulfill CE requirements. This section describes three examples of epilepsy-specific CE programs offered exclusively online: one is targeted to END technologists (also referred to as EEG technologists), one is targeted to neuropsychologists, and the third to health professionals outside the United States. Those descriptions are followed by brief summaries of programs available both online and in-person for school nurses and for EMS and law enforcement personnel. Online epilepsy education programs should be evaluated for their suitability as models for a range of health professionals, such as other types of nurses, counselors, and direct care workers, and more broadly for others who interact with people with epilepsy, including teachers, day care workers, coaches, and social workers (Chapter 6).

As described above and throughout the report, psychologists, psychiatrists, and other mental health professionals are essential for delivering comprehensive epilepsy care, including diagnosis, treatment, and management of mental health and cognitive comorbidities. In an effort to educate neuropsychologists about the epilepsies, the National Academy of Neuropsychology developed an online program first offered in March 2011 that focuses on the neuropsychological aspects of epilepsy and epilepsy surgery. The program is 8 weeks in duration and provides 16 CE credits for participants. Since its inception, 75 participants have taken the course including practicing neuropsychologists, clinical psychologists, and psychology students (e.g., graduate students, interns, postdoctoral residents). The course is divided into four learning modules that cover the range and classification of epilepsy disorders and syndromes, approaches to diagnosis and treatment, the cognitive and behavioral effects of epilepsy and seizure medications, and the role of the neuropsychologist in providing care for people with epilepsy. The course uses a textbook, a DVD on seizure classification developed by the Epilepsy Foundation, online discussion forums, and quizzes to convey and test knowledge (NAN, 2010, 2011; Personal communication, Gregory Lee, Medical College of Georgia, December 6, 2011).

END technologists play an important role in the diagnosis and care of people with epilepsy, especially in EMUs. The American Society of Electroneurodiagnostic Technologists offers structured online CE courses, including one on EEG and epilepsy that features information on seizure classification, identification of EEG patterns associated with epilepsy, clinical identification of different seizure types and other seizure-like events, case studies, and samples of EEG patterns. Other online courses offer information on seizure first aid and EEG pattern recognition (ASET, 2011). These courses build on content taught through END programs, which include

competencies in long-term monitoring for epilepsy, knowledge of treatment options for epilepsy, and recognition of common seizure patterns on EEGs (ASET, n.d.).

Highlighting the global need for improved education for health care providers about the epilepsies is the Out of the Shadows Campaign, launched in 1997 and developed through a collaboration of the ILAE, the International Bureau for Epilepsy, and the World Health Organization (WHO, 2011). In order to extend educational opportunities for health professionals globally, the ILAE in 2004 developed a distance-learning program called VIREPA (the Virtual Epilepsy Academy).[11] A variety of courses are offered each year, including pharmacology and pharmacotherapy, use of the EEG in the diagnosis and management of epilepsy, and neuroimaging. A course on the genetics of epilepsy will be offered in 2012. Courses designed for mental health professionals working in African countries also are being developed (Personal communication, P. Shisler, ILAE, November 16 and 18, 2011).

VIREPA courses are generally targeted to practicing neurologists, last a few months in length, are limited to 30 participants, and are taught and moderated by actively practicing experts from around the world (ILAE, 2011). Each course is designed around learning scenarios that feature virtual discussion forums and require participants to complete specific tasks. Approximately 100 health professionals from 40 to 45 countries participate in VIREPA programs each year, but only a small number (3 of 96 in 2011) are from the United States. CE credits are not provided for participants. In addition to its workshops and VIREPA, the ILAE offers additional educational opportunities and resources[12] (Personal communication; E. Bertram, F. Quinn, and C. T. Tan; ILAE; November 17, 21, and 26, 2011).

A small number of targeted CE programs have been developed to improve the knowledge of specific nonphysician health professionals who do not typically fall within the epilepsy field. Two are described below.

School nurses play an important role in the lives of children with epilepsy across the country, but few have received formal education about epilepsy and its management. The Epilepsy Foundation, in collaboration with the National Association of School Nurses (NASN) and with support from the CDC, developed a program to educate school nurses about caring for students with epilepsy. The learning objectives for the program include seizure recognition, treatment options and side effects, first aid, seizure ac-

[11]See http://ilae-epilepsy.org/Visitors/Centre/VIREPA.cfm.

[12]For example, the Asian Epilepsy Academy offers a two-part EEG certification exam and the Asian Epilepsy Academy and Latin American Commission offer fellowship opportunities. Additionally, the North American Commission has developed visiting professorships programs in North America, Latin America, and the Caribbean (Personal communication, C. T. Tan, ILAE, November 21, 2011).

tion planning, and teaching school personnel about epilepsy (NASN, 2011). The program is offered in two formats, both of which provide 3.2 CE credits: in-person meetings offered through state and local Epilepsy Foundation affiliates and online modules through the NASN website (NASN, 2011). Between October 2009 and September 2010, more than 6,700 school nurses participated in the in-person meetings and almost 1,500 participated in online training, making the program among the NASN's most frequently used sources of CE (Personal communication, K. Price, Epilepsy Foundation, June 9, 2011).

EMS personnel and other first responders (e.g., firefighters, law enforcement personnel) are frequently involved in the emergency care and transportation of people with epilepsy. Box 5-4 describes two targeted programs designed to supplement epilepsy-relevant information in existing EMS curricula. The first program was developed by the Epilepsy Foundation under a cooperative agreement with the CDC, and the second was included as part of a clinical trial network funded by the NIH. One of the Epilepsy Foundation's goals with its educational efforts for EMS and law enforcement personnel is to prevent emergency personnel from using excessive force when confronted with a person having a seizure or someone who is disoriented following a seizure. The Epilepsy Foundation's legal defense fund has represented individuals who have been injured, in some cases fatally, as a result of interactions with first responders (Epilepsy Foundation, 2011a,b). Because of their vital interactions with epilepsy patients during emergency situations, some of which may be life-threatening, first responders and EMS personnel require accurate, up-to-date knowledge and skills and must be trained to recognize, stabilize, and treat seizures and seizure-related emergencies, such as status epilepticus. Programs such as the one offered through the Epilepsy Foundation are necessary to ensure high-quality, safe emergency services for people with epilepsy.

ROLE OF EPILEPSY ORGANIZATIONS AND CENTERS

Epilepsy Organizations

The AES, ILAE, Epilepsy Foundation, and ETP each play a vital role in educating health professionals, as described previously. This section of the chapter describes some additional educational efforts that have been attempted by the AES, which has the mission to "promote research and education for professionals dedicated to the prevention, treatment, and cure of epilepsy" (AES, 2012a; Personal communication, C. A. Tubby, AES, September 28, 2011).

In addition to educational sessions at its annual meeting, the AES offers numerous educational opportunities throughout the year, including an

Box 5-4 PROGRAMS FOR EDUCATING FIRST RESPONDER AND EMERGENCY MEDICAL SERVICES PERSONNEL ABOUT SEIZURES AND THE EPILEPSIES

As a person who has lived with epilepsy since the age of 3, I am very concerned that many people know what a tonic-clonic seizure is and looks like, as well as the first aid needed, but they have no idea how to recognize or react to someone who has a complex-partial seizure. Police departments and other public workers need to be educated about this type of seizure and other seizures that are not . . . tonic-clonic.

–Colleen Cady

The Epilepsy Foundation's program for law enforcement officers focuses on seizure types, seizure recognition, and on-scene care, while the program for emergency medical services (EMS) personnel promotes seizure recognition, prehospital care, and transportation issues. Between December 2009 and September 2010, nearly 4,000 EMS personnel were trained through 16 state and local Epilepsy Foundation affiliates using the EMS personnel training curriculum. The Epilepsy Foundation contracted with Centrelearn to provide an online learning portal and develop online training modules for both the law enforcement and the EMS training curricula. Through this mechanism, an additional 1,200 EMS personnel completed the training online between March and June 2011, and nearly 200 officers completed the law enforcement training online in the first 5 months of 2011 (Epilepsy Foundation, 2011c). Continuing education credits are available through both the classroom-based and online training programs. Additional national partnerships with EMS and law enforcement entities will allow further outreach as well as seizure and epilepsy awareness and education in the coming years (Epilepsy Foundation, 2010).

Seizure-related educational opportunities for first responders also have been available through research projects. For example, the National Institutes of Health developed the NETT (Neurological Emergencies Treatment Trials) Network "to conduct large simple trials to reduce the burden of very acute injuries and illnesses affecting the brain, spinal cord, and peripheral nervous system" (Barsan, 2011), including a randomized control trial (RAMPART [Rapid Anticonvulsant Medications Prior to Arrival Trial]) for status epilepticus in the prehospital care setting. It has involved more than 4,000 advanced emergency medical technicians (EMTs) and EMT paramedic personnel from more than 75 hospitals and dozens of EMS agencies (NETT, n.d.). A training curriculum was developed by the NETT Clinical Coordinating Center that included emphasis on seizure treatment and protocol training, thus providing epilepsy and seizure-related information to large numbers of participating professionals (Barsan, 2011; Cearnal, 2006).

online Epilepsy Education Program, available at no charge but that does not provide CE credit (AES, 2012b). The program contains five sections: neurogenetics of epilepsy, basic mechanisms of epilepsy, clinical epilepsy, neuropharmacology, and neurosurgical aspects of epilepsy (AES, 2011b) and could be useful to medical students, residents, and practicing health professionals alike. However, the program consists of static slide sets that can be downloaded and reviewed by the user and is not interactive. Four

of the five sections offer a self-test on the information covered. The AES continues to develop new slide sets and two new ones will focus on improving nurses' knowledge about epilepsy. The first set will target nurses who are new to epilepsy and will be available in early 2012. The second set will focus on nurses who are already working in the epilepsy field; a launch date for this program has not yet been determined (Personal communication, C. A. Tubby, AES, November 17, 2011). Although the Epilepsy Education Program is consistently among the top educational resources visited on the AES website, it has not been evaluated (Personal communication, C. A. Tubby, AES, September 28, 2011). Further, the committee encourages the AES to investigate more interactive educational options.

The AES previously offered a program called Teleconsults in Epilepsy that, over 8 years, presented 16 webinars targeted to nurses and other nonphysician health professionals, but the program was discontinued in 2009 due to lack of funding (Personal communication, C. A. Tubby, AES, November 17, 2011). The webinars were led by experts from various disciplines; they covered a wide range of topics, such as seizure recognition and diagnosis, comorbidities, learning disabilities, quality of life, vocational opportunities, SUDEP, and treatment side effects; and they offered CE credits for those who participated in the live webinars. Although the last webinar was hosted in 2009, the manuscripts and audio files are archived and available on the AES website.[13] It appears that this program was among the few designed specifically for nurses and other nonphysicians, and the AES may be able to fill some of the remaining gap through the nurse-focused content being developed for the Epilepsy Education Program, above.

In recent years, the AES has attempted to develop more interactive educational opportunities. The society partnered with Aurora Health Systems and TheraSim to develop an interactive epilepsy patient simulation module called "Waiting for Your Diagnosis." The module was designed for general neurologists and featured two clinical case studies that involved a simulated patient interview, diagnostic testing orders, and simulated treatment and follow-up. The program was available for CE credit for physicians through June 2011 (Personal communication, J. Melin, AES, November 16, 2011). However, the AES faced a number of challenges in developing and implementing this program, including loss of funding, lack of interest among general neurologists despite an e-mail marketing effort, and challenges in developing an algorithm to provide the underpinnings of the case studies. In reviewing the program, after only a few dozen neurologists used the module, the AES ultimately decided not to continue marketing it (Personal communication, J. Melin, AES, November 16, 2011).

[13]See http://www.aesnet.org/go/professional-development/educational-opportunities/teleconsults/archived-programs.

The AES has recently formed a potentially fruitful collaboration with the National Association of Epilepsy Centers (NAEC) to develop an online, interactive program (described below) to improve patient safety in EMUs. Despite some setbacks, online and interactive approaches to education are promising and deserve further exploration. Significant and creative efforts will be required to promote and incentivize the use of these modules by health professionals inside and outside the epilepsy field.

Epilepsy organizations have developed an array of educational opportunities to teach health care providers about the epilepsies. They need to continue to lead efforts to promote improved education and to expand efforts to reach the full range of health professionals. These organizations need to forge partnerships with each other and with other professional organizations (e.g., the AAN, ABPN, and those listed in Box 5-3 and Appendix D), in order to develop, implement, and evaluate innovative approaches. Partnerships are essential for expanding the reach of the resources that are available and are especially important when funding is scarce. Partnerships with organizations that represent other neurological diseases and disorders (e.g., autism spectrum disorders, stroke, Alzheimer's disease) also could be especially beneficial in expanding the reach of educational efforts.

Epilepsy Centers

Although the NAEC's 2010 guidelines for specialized epilepsy centers primarily focus on the essential elements of care delivery, some guidance on professional education within the centers also is included. The guidelines note that CE offered through the centers "can take the form of journal clubs, case management conferences, didactic lectures, development of care plans or clinical pathways, and quality assessment and improvement activities" (Labiner et al., 2010, pp. 2325-2326). Despite promulgating professional education as a goal for epilepsy centers, the NAEC has not collected data from epilepsy centers about the actual educational opportunities they offer (Personal communication, E. Riker, NAEC, September 20, 2011). A survey of opportunities, format, and frequency could be beneficial in establishing best practices for engaging clinicians in continuous, interdisciplinary learning within epilepsy centers.

The specific educational area highlighted in the NAEC guidelines is the need for educating nurses about patient safety. The guidelines indicate that "there should be a formal educational program at centers to assure nursing competency with regard to patient safety. This should include epilepsy-specific training for nursing staff that will be responsible for the patients undergoing video-EEG monitoring and other diagnostic testing" (Labiner et al., 2010, p. 2325). The number of centers that have formal programs of this nature is unknown. However, the NAEC and AES currently are

partnering to develop an online program called "Enhancing Patient Safety in Epilepsy Monitoring Units," which could be implemented across all epilepsy centers and will benefit physicians, nurses, and END technologists. The program will include modules and case studies that will cover areas such as a culture of safety, injury and adverse events, assessing safety, patient and family education, and transitions to outpatient care and will include systematic and individual aspects of patient safety. The objectives of this program are to "provide standardized information, teach appropriate skills, and make usable resources on patient safety and preferred practices readily available to professionals caring for people in monitoring units" and to promote interdisciplinary approaches to patient safety (Personal communication, C. A. Tubby, AES, September 28, 2011). The development of this online program and the collaboration between the NAEC and AES signify important steps toward improving the education of clinicians who care for patients in epilepsy centers.

Significant opportunities exist for epilepsy centers not only to play a role in educating health professionals within the centers, but also to develop partnerships and educational opportunities for other health professionals in the communities and regions where they are located. The NAEC guidelines say that "comprehensive epilepsy center personnel [should] also participate in education of the larger health care community" (Labiner et al., 2010). While this may happen in some locations, the extent of any such efforts has not been documented.

Epilepsy centers provide an important venue for educating a wide range of health professionals about the epilepsies. The education of health professionals could be made a priority among the criteria for epilepsy center accreditation (Chapter 4). Continued collaboration between the NAEC and AES could facilitate definition of best educational practices and improve educational programs and resources for many disciplines. Opportunities to use innovative teaching approaches and technologies, including high-fidelity simulation, also could be explored.

EDUCATING HEALTH PROFESSIONALS TO EDUCATE PEOPLE WITH EPILEPSY AND THEIR FAMILIES

Health professionals need good skills in communication and patient education (see also Chapters 4 and 7). They play an essential role in educating patients and families about the epilepsies and in directing them to accurate and reliable resources and tools to improve knowledge, skills, and self-management. In contrast, poor clinician-patient communication is a major barrier to patients' ability to successfully navigate the health care system, act on basic health instructions, and self-manage chronic or other health conditions. Studies indicate that patients recall as little as half of what their

physicians tell them during an outpatient appointment (Schillinger et al., 2003). Physicians need to confirm that patients understand their condition (e.g., specific seizure type, epilepsy syndrome, seizure triggers), how to carry out treatment and medication instructions, and risks associated with their condition and nonadherence or discontinuation of their treatment regimen. However, in one diabetes study, physicians assessed patients' recall and comprehension of new concepts in only one in five patient encounters, even though such practices have been shown to improve clinical outcomes (Schillinger et al., 2003). Therefore, it is critically important that health professionals provide patients and their families with written information about their specific seizure type, epilepsy syndrome, and treatment plan to augment discussions that happen in the clinical setting.

In order to educate patients and families effectively, health care providers must be knowledgeable and skilled in communicating and conveying information that meets the individual needs and preferences of patients. A UK survey highlighted the desire of patients with epilepsy to have physicians who are both knowledgeable and effective communicators (Poole et al., 2000). In addition, patient-rated quality of care also increases when health care providers use patient-centered communication and shared decision making (Thapar and Roland, 2005).

Based on the discussion presented in Chapter 7, it is important that health professionals learn how to

- recognize the critical junctures for patient and family education—at diagnosis, during the first year, when there is a change, in treatment options (e.g., introduction, switch, discontinuation), or when a new concern develops (Box 7-5);
- understand the specific information needs and preferences of patients and their families and take into consideration factors related to health literacy and culture, including cultural differences that may exist between them and their patients (Chapter 7);
- listen actively and put the patients and their needs first when providing education and counseling;
- be competent in patient and family education and communication, including targeting education to the specific needs of the patient;
- be comfortable discussing risks associated with the epilepsies and their treatments including SUDEP, suicide, and status epilepticus (Chapter 3, 4, and 7);
- be aware of informational resources for patients and families that are available online and through local epilepsy organizations; and
- promote the use of self-management tools and programs.

CONCLUSION

The preceding review of current information about efforts for educating health professionals about epilepsy reveals several important points:

- Because of epilepsy's prevalence and its diverse comorbid conditions, most clinicians need at least a basic knowledge of epilepsy diagnosis, treatment, comorbidities, and mortality risks.
- Primary care providers and others providing epilepsy services need a deeper understanding of the epilepsies and more skills and ongoing educational opportunities (a priority list of educational areas for health professionals is included in Box 5-5).
- Ideally, epilepsy education programs would be evidence-based, with content designed to meet providers' needs and fill identified knowledge gaps; programs would be delivered in ways most likely to improve practice; and effective incentive systems would encourage participation by a wide range of health professionals.
- Epilepsy education programs should reflect current research findings, promote best practices, incorporate clinical guidelines, and undergo evaluation to ensure that educational objectives are being met.
- Providers need to know how to educate other members of the care team and patients and families.
- Educational innovations—interactive online courses, increasingly sophisticated simulations, and other means—need to be developed, tested, and evaluated, so that limited resources for educational programs are used most effectively.
- Innovative and effective strategies should be used to train health professionals throughout the educational continuum and into their careers, through robust CE programs.
- Epilepsy centers and organizations have an important leadership role in designing high-quality educational programs, but they need to work collaboratively with each other and with other professional associations and credentialing bodies within and outside the epilepsy field, in order to ensure the programs' quality, relevance, value, and sustainability.
- Epilepsy centers and organizations should be at the forefront of disseminating high-quality educational tools and resources to health professionals, making them available online, and promoting their use.
- Research is needed on the scope and penetration of current epilepsy education and training in order to identify specific gaps and make improvements.

Box 5-5 PRIORITY EPILEPSY EDUCATIONAL AREAS FOR HEALTH PROFESSIONALS

In order to ensure the highest quality of care for people with epilepsy and their families, the committee believes that health professionals should have—at a level appropriate to their roles, responsibilities, and scope of practice—knowledge and skills regarding the following:

- various seizure types and syndromes associated with the epilepsies, broadly, and mechanisms for recognizing and diagnosing them;
- appropriate responses to seizures, seizure first aid, and response and treatment for status epilepticus;
- etiologies of and risk factors for seizures and the epilepsies, with a focus on prevention;
- available treatments—including medications, diet, devices, and surgery—and the efficacy and effectiveness of those treatments—including awareness of which treatments work best for which patients, their possible side effects or harmful interactions, and the risks associated with discontinuation or nonadherence;
- available clinical guidelines, best practices, and quality indicators for ensuring the best possible care for people with epilepsy;
- risks associated with seizures and the epilepsies, such as accidental injury, early mortality (e.g., sudden unexpected death in epilepsy, suicide);
- the full range of comorbid conditions—including somatic disorders, neurological disorders, mental health conditions, cognitive disorders, infectious diseases, infestations, disabilities, injuries, and nutritional problems—and the impact they have on a patient's health and quality of life;
- factors related to quality of life and burden of the disorder on patients and families;
- available health care and community resources and services, such as epilepsy treatment centers, sources of information for patient and family education, family support groups, and tools for self-management;
- approaches to personalizing care based on the patient's social situation, cultural background, health literacy level, and other personal and family factors;
- effective strategies for patient and family education and patient self-management;
- the role of other health professionals in providing care for individuals with epilepsy and best practices in referring patients to other clinicians;
- stigma that people with epilepsy face and strategies for reducing stigma; and
- applicable laws and regulations, such as driving restrictions for individuals with active seizures.

Throughout this chapter, the committee has provided the basis for its research priorities and recommendations regarding improvements needed in epilepsy education for health professionals that are detailed in Chapter 9. In order to improve epilepsy education for health professionals, additional research and time needs to be devoted to

- define the essential knowledge and skills for the various professions;
- identify knowledge gaps and information needs;
- evaluate existing educational materials and learning opportunities to ensure they reflect current research, clinical guidelines, and best practices;
- explore and develop innovative educational tools and technologies that are interactive and engaging; and
- disseminate educational information and tools more broadly.

Partnerships among epilepsy organizations and relevant professional boards and associations, such as the AES, ILAE, Epilepsy Foundation, and those listed in Appendix D, will be critical to realizing these goals.

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6

Quality of Life and Community Resources

Having epilepsy is about much more than having seizures. People with epilepsy and their families typically face an array of challenges to daily living that vary with the severity and nature of the epilepsy disorder and that may change as the individual gets older. The negative effects on quality of life can be severe and involve family and social relationships, academic achievement, and opportunities for employment, housing, and the ability to function independently. Family and community support is critical across a range of services. Improvements in community services and programs are needed to ensure that they are individually centered to meet the needs of the person with epilepsy; locally focused, taking into account the full range of resources in the area; easily accessible; thoroughly evaluated; closely linked to health care providers, particularly epileptologists and epilepsy centers; and innovative and collaborative. Actions necessary to achieve these goals include identifying and disseminating best practices in the provision of epilepsy services and innovative collaborations with organizations and agencies focused on other neurological and chronic conditions or on similar service needs.

We saw four pediatric neurologists in that first year. The fourth doctor told us to stop worrying about stopping the seizures because he could not figure out her EEG [electroencephalogram]. He told us to concentrate on her quality of life. She was 4, not talking, no longer walking, and could not even smile. We were losing everything. What quality of life did she have and where was the bottom of this spiral? We did not want to find out, but we did. We now live at the bottom of the spiral looking up.

–Janna Moore and Tom Weizoerick

It is a terrifying helplessness that one feels as a parent knowing that your child's brain is misfiring so badly that if left to continue untreated it will result in a vastly reduced life expectancy and severely reduced intellectual function.

–Jeffrey Catania

Epilepsy is much more than seizures. For people with epilepsy, the disorder is often defined in more everyday terms, such as challenges in school, uncertainties about social and employment situations, limitations on driving a car, and questions about independent living. Family members also may struggle with how to best help their loved one and maintain their family life. Because of the range of seizure types and severities and the high rate of comorbid health conditions, the types of issues that have an impact on quality of life for people with epilepsy and their families and the degree to which they are affected vary widely. As a result, the range of community services potentially needed may be extensive (Table 6-1).

This chapter aims to provide a brief introduction to the diversity of ways in which the lives of people with epilepsy are affected by the disorder and the range of community efforts that can provide support and assistance. The chapter begins with an overview of quality of life and the facets of quality of life that are particularly relevant for differing age groups. The major areas of focus for community services are then discussed—families, day care and school, sports and recreation, employment, transportation, housing, and first aid training—with each section providing the committee's thoughts on next steps and opportunities to be explored. The chapter concludes with a discussion of navigating the broad array of community services and cross-cutting opportunities to improve services for people with epilepsy and their families.

OVERVIEW OF THE IMPACTS OF EPILEPSY ON QUALITY OF LIFE

Quality of life is a person's subjective sense of well-being that stems from satisfaction with one's roles, activities, goals, and opportunities, relative to that individual's values and expectations, within the context of culture, community, and society. According to the World Health Organization (1996), "Quality of life is defined as individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (p. 5).

The term "health-related quality of life" is generally used when referring to quality of life in the context of a person's health status (CDC, 2011a; Wilson and Cleary, 1995). Health-related quality of life is multidimensional, and for people with chronic conditions such as epilepsy, it is often related to functioning in three areas: physical, psychological, and social (Elliott and Mares, 2012; Koot, 2001; Solans et al., 2008). For the

TABLE 6-1
Spectrum of Potential Epilepsy-Related Needs and Community Services

Types of Needs	Community Services
Information needs about the disorder, treatments, and health services (Chapter 7)	• Nonprofit organization websites with general information about epilepsy (e.g., epilepsyfoundation.org; epilepsy.com) • Nonprofit organization websites with information specific to an epilepsy syndrome (e.g., dravet.org; tsalliance.org) • Federal and state websites and information resources • Health care providers, including community health workers • Case managers and social workers
Information needs about local community services	• State and local Epilepsy Foundation affiliates[a] • Nonprofit organizations • Social workers, case managers
Help in coping with the disorder and the associated comorbidities and challenges	• Support groups • Self-management programs • Counseling
School-related needs	• Cognitive testing and educational assistance • Individualized education programs (IEPs) • Teachers and school counselors who are informed about epilepsy
Employment-related needs	• Vocational programs, vocational rehabilitation programs • Disability-related organizations and government agencies
Transportation-related needs	• Social service organizations • Local transportation agencies • Government agencies
Housing-related needs	• Social service organizations • Nonprofit organizations, including faith-based organizations • Government agencies
Recreation and leisure	• Camps • Sports and recreational programs
Assistance for family members and caregivers	• Respite care programs • Support groups for family members

NOTE: As indicated throughout the report, family members, friends, caregivers, and others are key providers of social and psychosocial support.

[a]The Epilepsy Foundation is a nonprofit organization with a national office and more than 50 affiliates nationwide that offer varying services.

SOURCE: Adapted from IOM, 2008.

purposes of this report, the committee uses the term quality of life to incorporate health-related quality of life. Many of the physiological aspects of improving quality of life (e.g., improved treatment options, optimal care, improved access to care) are discussed in Chapter 4.

The burden of seizures and epilepsy, particularly severe forms of epilepsy or disabling comorbidities, can be overwhelming for many individuals and their families. The social and emotional toll of care (sometimes round-the-clock care) can place financial and emotional strains on marriages and families, altering roles, relationships, and lifestyles. Family members may need to take extensive leave or unexpected days off work that can disrupt careers and drain family finances. Many speakers at the committee's workshops emphasized that epilepsy—regardless of its level of severity—creates life challenges because of the unpredictability of seizures (Box 6-1).

Studies that have examined the economic impact of epilepsy find that the indirect costs to society (productivity-related costs) generally exceed direct costs (treatment-related costs). A number of validated generic and epilepsy-specific instruments are used to assess quality of life (Chapter 2). In a systematic review of 22 cost-of-illness studies conducted around the world, among those that used reasonably comprehensive accounting for indirect cost, the indirect costs of epilepsy ranged from 12 to 85 percent of total costs (Strzelczyk et al., 2008). A study of the cost burden of epilepsy in the United States estimated a total annual cost of $12.5 billion per year, $10.8 billion in indirect costs (86.5 percent) and $1.7 billion in direct costs (13.5 percent) (Begley et al., 2000). Overall, lifetime productivity is estimated to decline 34 percent for men and 25 percent for women. Estimates of indirect costs are significantly higher for people with refractory epilepsy (Begley et al., 2000).

Children and Adolescents

In general, research comparing quality of life across different chronic conditions indicates that children and adolescents with epilepsy have a relatively high physical quality of life, but fare much worse in the psychological and social quality-of-life domains. For example, in a study comparing children with epilepsy with children with asthma, those with epilepsy had better quality of life in the physical domain but significantly lower quality of life in the psychological and social domains (Austin et al., 1994).

Many studies have focused on the psychosocial challenges faced in childhood. Recent comparison studies demonstrate that children and adolescents with epilepsy have relatively more social problems than children and youth who do not. Social problems in children and adolescents include feelings of being different, social isolation, and being subject to teasing and bullying (Elliott et al., 2005). Children with epilepsy who were 3 to 6 years

Box 6-1 COSTS OF EPILEPSY

At the March workshop, Lori Towles, the mother of Max, who is 17 years old, detailed the impact of epilepsy on Max and their family. Max had brain surgery in 2010 to remove the lesion that was causing his seizures and in December 2011 celebrated 18 months of being seizure free.

$3,000	The amount I've paid to an advocate to secure services for Max at his current high school because of the ignorance of the school district regarding epilepsy and students with medical disabilities
19	Anti-seizure pills Max has taken per day
10	Medical and service providers that make up Max's support team
9	Anti-seizure medications he's tried
6:30	Pill-time—morning and night—it's set as an alarm on everyone's cell phone in the house
5	Number of caring and gifted teachers that have come to the house to teach math, English, and science in the last 3 years
4	Number of neurologists he sees regularly
3	Number of times Max has received the Anointing of the Sick
2	Number of additional diagnoses: ADD at age 7 and anxiety at age 10 due to the seizures
1	Years of home schooling while we tried to find a working combination of medications to control the seizures
0	Number of times he has said, "Why me"
0	Number of friends he has now

Countless

- Hours waiting in line at the pharmacy, driving to doctors' appointments, and documenting his seizure activity
- Days missed from school due to seizures
- Insulting and rude remarks made by classmates (ignorant and informed) because of his twitching, mumbling, seizing, and falling asleep in class
- Meetings, e-mails, and phone calls to his teachers and school support personnel to explain what to expect with his medical condition
- Days missed from my work to take him to doctors appointments, have meetings at school, and just be there for him
- Minutes where my daughter and I watch Max slip away into another place while his brain seizes
- Prayers from family and friends, coworkers, and neighbors

NOTE: ADD = attention deficit disorder.

old showed fewer age-appropriate social skills (Rantanen et al., 2009). Children with epilepsy ages 8 to 16 were found to have significantly lower social skills (cooperation, assertion, responsibility, and self-control) compared to healthy children; however, they did not differ significantly in social skills from children with chronic renal disease (Hamiwka et al., 2011). In a somewhat older group, youth ages 11 to 18 with epilepsy had poorer social competence, with girls having significantly less social competence than boys (Jakovljevic and Martinovic, 2006).

Having a chronic condition might help explain some of the poorer social skills described among children with epilepsy (Hamiwka et al., 2011). Beyond that possibility, Caplan and colleagues (2005) identified a number of other variables associated with social problems in children with epilepsy, including lower IQ, externalizing behavior problems, racial/ethnic minority status, and impaired social communication skills. In this study, seizure variables (e.g., age of onset, frequency, duration) were not related to social functioning. In addition, a prospective study of children and adolescents who had epilepsy surgery showed no changes in social functioning one year later, regardless of surgery outcome (Smith et al., 2004); however, improvement in social functioning was found after 2 years (Elliott et al., 2008). In childhood epilepsy, school performance and academic achievement are commonly affected, as described later in this chapter.

Compared to children with other chronic health conditions, siblings, and control groups, children with epilepsy are at increased risk for mental health conditions such as depression and attention problems (Rodenburg et al., 2005). In the 1999 nationwide British Child and Adolescent Mental Health Survey, rates of mental health comorbidities were higher in children with epilepsy (37 percent) than in children with diabetes (11 percent) or in control children (9 percent). In children with epilepsy and another type of comorbidity, such as cognitive or neurological deficits, the rate of mental health comorbidities was even higher (56 percent) (Davies et al., 2003). Children with epilepsy and intellectual disability have high rates of mental health conditions; in one study, more than 90 percent of children with epilepsy and intellectual disability could be classified as having a psychiatric diagnosis also (Steffenburg et al., 1996). A meta-analysis of 46 studies found that internalizing problems such as anxiety, depression, and social withdrawal were more common in children with epilepsy than externalizing problems such as aggression or delinquency (Rodenburg et al., 2005).

Prior to the past decade, it was generally assumed that mental health conditions and other comorbidities occurred in response to having a chronic condition, such as epilepsy. Studies of children with new-onset seizures, however, have demonstrated that mental health conditions, cognitive problems, and behavioral problems can occur very early in the disorder and in some cases precede the onset of seizures (Austin et al., 2001, 2011;

Jones et al., 2007; Oostrom et al., 2003). In addition, epidemiologic studies have shown that attention deficit hyperactivity disorder (ADHD) and other mental health conditions are risk factors for developing seizures in children (Hesdorffer et al., 2004; McAfee et al., 2007) (Chapter 3).

A number of other risk factors for mental health comorbidities have been identified. Seizure severity and frequency are associated with an increase in mental health comorbidities in some but not most studies (Austin and Caplan, 2007). Family-related psychosocial variables, such as greater family stress, fewer family resources, negative child and parent attitudes about epilepsy, poorer coping skills, and poorer family adjustment also were associated with higher rates of mental health comorbidities in children (Austin and Caplan, 2007). The authors concluded that research has not identified the causal direction of children's mental health comorbidities and that disruptions in the family environment and mental health conditions in the child are most likely reciprocal.

Although for some individuals, epilepsy is an experience of childhood with seizures stopping during adolescence or early adulthood, for many other people seizures continue into adulthood and others live with the long-term effects that seizures have had on their cognitive or social development (Geerts et al., 2011; Kokkonen et al., 1997; Shackleton et al., 2003). For example, a 35-year prospective, population-based study in Finland found that compared to adults without epilepsy, adults who had epilepsy during childhood had poorer social outcomes in adulthood; they had less formal education, were less likely to be married or have children, and were more likely to be unemployed (Jalava et al., 1997; Sillanpää et al., 1998). Adverse lifespan outcomes have been found to be associated with histories of neurobehavioral comorbidities including early learning or cognitive and psychiatric problems (Kokkonen et al., 1997; Shackleton et al., 2003). In working to reduce the health and quality-of-life impacts of epilepsy, it is critical to address the needs of all individuals affected by the disorder.

Adults

Surveys of adults have identified risk factors for reduced quality of life for people with epilepsy, including having a greater number of seizures, longer duration of seizures, and earlier age of seizure onset (Baker et al., 1997; Jacoby and Baker, 2008; Kerr et al., 2011; Wheless, 2006). Other factors affecting quality of life include side effects of seizure medications, lack of adherence to medications, depression or anxiety, lack of social support, stigma, and concerns about employment (Aydemir et al., 2011; Baker et al., 2005; Hovinga et al., 2008; Taylor et al., 2011b). Higher rates of comorbid mental health conditions for adults with epilepsy compared to those without are described in Chapter 3, and large surveys indicate that adults

with epilepsy are relatively likely to report more mentally and physically unhealthy days per month than adults without epilepsy, with the highest rates found in those with seizures in the past 3 months (Kobau et al., 2007, 2008; Wiebe et al., 1999) (Figure 6-1).

Results from a large U.S. survey also indicated poorer social outcomes for adults with a history of epilepsy, compared to those without, including being less likely to be married and more likely to have lower levels of education, employment, and income (see Table 6-2 and discussion later in this chapter on employment and epilepsy) (Kobau et al., 2008).

Older Adults

The quality of life for older adults with epilepsy is understudied (Devinsky, 2005). A recent study by Laccheo and colleagues (2008) demonstrated that older adults with epilepsy have a significantly lower quality of life across all domains when compared with the general population.

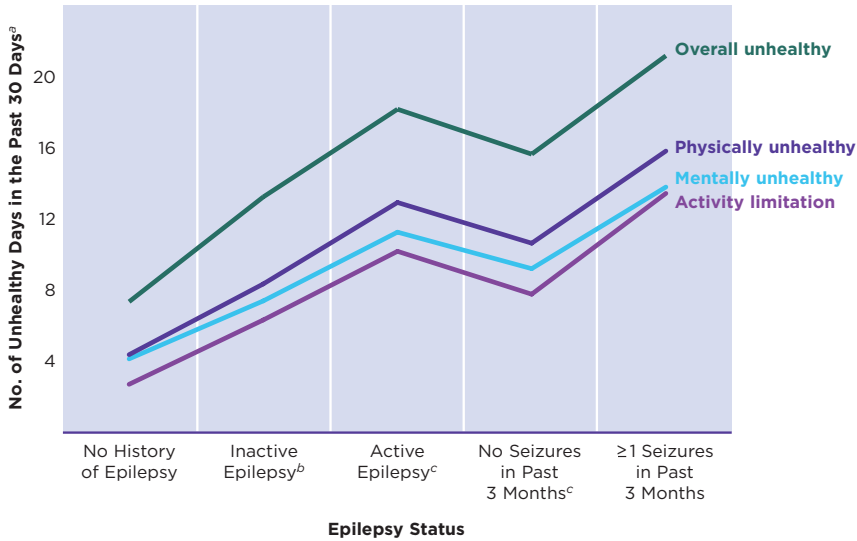

FIGURE 6-1
Health-related quality of life in adults with epilepsy.

[a]Self-reported measure of health-related quality of life (Behavioral Risk Factor Surveillance System data).

[b]Respondents with self-reported, doctor-diagnosed seizure disorder or epilepsy who had not had a seizure in the past 3 months and were not taking medication to control epilepsy.

[c]Respondents with self-reported, doctor-diagnosed seizure disorder or epilepsy who were currently taking medication to control it, had one or more seizures in the past 3 months, or both.

SOURCE: CDC, 2011b; based on data from Kobau et al., 2008.

TABLE 6-2
Comparison of Adults With and Without a History of Epilepsy

	With History of Epilepsy (*n* = 2,207) %	Without History of Epilepsy (*n* = 118,638) %
Marital status		
• Married or unmarried couple	55.5	64.1
• Formerly married	22.9	18.0
• Never married	21.5	17.9
Income		
• < $25,000	40.9	26.3
• $25,000 to $49,999	30.0	29.7
• ≥ $50,000	29.2	43.9
Employment status		
• Employed	45.8	61.6
• Unemployed	6.8	5.0
• Unable to work	23.7	4.8
• Other (homemaker, student, or retired)	23.7	28.6
Could not visit doctor because of cost		
• Yes	23.7	13.4
• No	76.3	86.6
Self-rated health		
• Good, very good, or excellent	63.0	84.2
• Fair or poor	37.0	15.8
Life satisfaction		
• Very satisfied or satisfied	83.4	94.6
• Dissatisfied or very dissatisfied	16.6	5.4

SOURCE: Kobau et al., 2008.

Because a relatively higher percentage of epilepsy in older adults is a result of stroke, brain tumor, or dementia (Chapter 3), each with the potential to decrease quality of life, it might be anticipated that compared to other people with epilepsy, the quality of life would be lower in older populations. However, this study did not find a difference in quality-of-life scores between older adults with epilepsy and other age groups with epilepsy (Laccheo et al., 2008). The authors noted that instruments evaluating all facets of quality of life for older people with epilepsy need to be developed (Laccheo et al., 2008).

The impact of epilepsy on quality of life may reflect some differences by age and time since diagnosis. A study of three adult groups (young, middle-aged, and older) with epilepsy found that young and middle-aged adults had higher physical functioning and poorer psychological functioning than

older adults (Pugh et al., 2005). The authors propose that having epilepsy made it more difficult for middle-aged adults to accomplish the many tasks of middle age, such as providing financial and emotional support to the family, mentoring the younger generation, and providing support to aging parents. In other studies, quality of life was not found to differ between older and younger people with epilepsy, however, older adults diagnosed later in life reported more anxiety and symptoms of depression than those diagnosed earlier (Baker et al., 2001) and more concern about medication side effects (Martin et al., 2005).

FAMILIES

My family and I took a trip to Florida once, and in the midst of my enjoyment and bliss, [my brother], who had been seizure-free for a couple months, had a relapse. [It] sent my parents into shock, my sister into tears, and me into a hurricane of resentment, fear, anger, and hatred. Why did he have to have these things at the most inopportune times? . . . I was afraid [my brother] would die, but I disliked that every family conversation focused on his disease. And I didn't want to disturb the already fragile nest which was my family by inserting my own issues regarding the situation.

–Joseph Abrahams

[W]hen I was 12 years old, my mother, who had suffered a stroke at the age of 29, had begun to have seizures. ln the coming weeks she was diagnosed with epilepsy and our lives were never the same. . . . As an adolescent, I struggled with being my mother's primary caretaker. . . . I vacillated between fear and anger, grief and bitterness, self-sacrifice and resentment. These emotions are often conveyed by parents of children with epilepsy, but l'm here to tell you that those feelings are no less intense for the children of those who suffer. lmagine being the one immediately responsible for a patient's care—and now imagine shouldering that burden as 12- or 13-year-old.

–Carmita Vaughan

Epilepsy in one family member can negatively affect the quality of life of the entire family (Baker et al., 2008; Ellis et al., 2000; Lv et al., 2009; Taylor et al., 2011a). Epilepsy can be more disruptive to the family than many other chronic conditions because of its hidden, episodic, and unpredictable nature; potential for injury and death; frequency of comorbidities; and associated stigma. Episodic chronic health conditions are considered among the most stressful for families, because even during periods of no symptoms, the family remains on alert in anticipation of problems (Rolland, 1994). Concerns about the safety and possible death of the person with epilepsy can further increase the stress and anxiety experienced by families. Comorbidities, such as depression and cognitive deficits, present additional demands on the family's attention. Finally, the stigma associated

with epilepsy and the possible fears that people with epilepsy and their families associate with seizures in public can curtail social and leisure activities, increasing social isolation and further reducing quality of life (Ellis et al., 2000; Fisher, 2000).

The literature contains few studies focusing on the quality of life of the family, rather than the person with epilepsy, and most family studies assess effects on the parents of children with epilepsy (Ellis et al., 2000). Studies comparing families of children with epilepsy to families of children with other chronic conditions or healthy children consistently demonstrate that families of children with epilepsy experience more dysfunction and parental anxiety, depression, and worry (Lv et al., 2009; Rodenburg et al., 2005).

Although families of adults and older adults with epilepsy have been studied much less, findings indicate that the quality of life of these families is similarly affected (Ellis et al., 2000). Research is needed to identify the impact on the quality of life and psychosocial adjustment of family members and the services that might be particularly helpful to them in learning to cope. Limitations of the literature include small sample sizes, studying only one person from each family, focusing on mothers, an underrepresentation of men and racial/ethnic minorities, and a lack of focus on families with very young children (Duffy, 2011).

The committee's vision is for all family members of people with epilepsy to have access to resources, support, and services that would allow them to make an optimal adjustment to having a family member with epilepsy and to attain the highest possible physical, emotional, and social well-being.

The next section reviews what is known about the impact of epilepsy on the quality of life of the family, followed by how these negative effects can be reduced by improving programs and services. Three broad areas are discussed: emotional health, family social and leisure activities, and employment and role expectations.

Impact on the Emotional Health of Family Members

Epilepsy can have a negative effect on the emotional and psychological health of family members. Parents of children with epilepsy—the most studied group—had high rates of worry, stress, anxiety, and depression symptoms; this is especially true for parents of children with refractory epilepsy (Duffy, 2011; Lv et al., 2009; O'Dell et al., 2007b; Taylor et al., 2011a; Thompson and Upton, 1992; Wood et al., 2008). A common parental worry focused on the future of the child with epilepsy (Baker et al., 2008; Ramaglia et al., 2007). Some family members appear to be more at risk for a negative emotional impact. The emotional impact on parents of younger children, unmarried parents, and parents of children and adolescents who have both epilepsy and comorbidities have been shown to produce a rela-

tively poorer quality of life (Taylor et al., 2011a). In one of the few studies comparing mothers and fathers, mothers were found to bear more of the responsibility for caregiving and also to experience more anxiety and strain, as well as more worry about the stigma associated with epilepsy (Ramaglia et al., 2007). A study of caregivers determined that women caregivers over age 60 who were the only person responsible for giving medication experienced the greatest impact on their quality of life (Westphal-Guitti et al., 2007). Other factors described as contributing to increased depression were lack of emotional and practical support (Thompson and Upton, 1992), loss of sleep (Modi et al., 2009; Wood et al., 2008), and financial burden (O'Dell et al., 2007b).

All members of the family appear to be at risk for psychosocial problems (Ellis et al., 2000). Although understudied, children who watched their parents have a seizure were often confused and frightened that their parent might die. These children also experienced fear of abandonment when parents were hospitalized (Lannon, 1992). This finding is consistent with a survey reporting that parents with epilepsy worried about their children becoming upset from witnessing them have a seizure (Fisher, 2000). In a recent study, siblings expressed sadness, fear, anxiety, and worry about their brothers and sisters with epilepsy. Some siblings also reported they were worried because their parents were so exhausted, and they often felt lonely because the parents were so busy caring for their sibling with epilepsy (Hames and Appleton, 2009).

Impact on Family Social and Leisure Activities

Family social and leisure activities are often restricted because of epilepsy (Ellis et al., 2000; Taylor et al., 2011a). Parents of children with epilepsy were found to spend less time outside the home on recreational activities than controls (Modi, 2009), to rate their quality of life lower in the areas of impact on their time and on family activity (Taylor et al., 2011a), and to lack time to pursue personal interests (Lv et al., 2009). Families of adults with refractory seizures reported restricted social lives (Thompson and Upton, 1992).

Challenges that affect quality of life for families and may lead to restrictions on social and outside family activities include the need to provide caregiving, the lack of support from outside the family unit, inadequate support from extended family members, and a lack of awareness about the resources available (Ellis et al., 2000; Saburi, 2011; Thompson and Upton, 1992). Ellis and colleagues (2000) suggested that the lack of family activities might indirectly contribute to the increase in emotional difficulties experienced by family members, because participation in leisure activities can help buffer against stress and family demands.

Impact on Employment and Role Expectations

A third area in which the quality of life of family members is affected relates to employment and the disruption in meeting role expectations. Parents reported that epilepsy had a negative effect on employment, with many parents missing work due to caregiving responsibilities (Lv et al., 2009). In a survey of families from 16 countries, Baker and colleagues (2008) found that many parents needed to take time off from work because of epilepsy, and some parents gave up their jobs to care for their child. In a 12-month study of the impact of epilepsy on parents, Ramaglia and colleagues (2007) found that 33 percent of mothers and 7 percent of fathers left their jobs temporarily. One year later, all fathers were back at work; however, 16 percent of mothers were still not working. In a study of caregivers of adolescents and adults, caregivers reported that the negative impact of epilepsy (e.g., emotional challenges) was a burden that affected and interfered with their ability to work and participate in other activities. In this study, women were more likely to be caregivers and more likely to experience these burdens (Westphal-Guitti et al., 2007).

In some families, disruption of roles reduced the quality of life of family members. Lannon (1992) found that children of parents with epilepsy sometimes experienced a reversal of roles, when they felt the need or were asked to take on adult responsibilities. Siblings of children with epilepsy also reported that their activities were disrupted because of caregiving responsibilities (Hames and Appleton, 2009).

Improving Programs and Services for the Family

Many of the authors whose research is discussed above identified resources and services that could help reduce the negative impact of epilepsy on the quality of life of family members. However, family members may be unaware of available community services. Health care providers should routinely provide information about community resources and support services to all families, and state and local Epilepsy Foundation affiliates and other epilepsy-specific organizations should be an integral part of discussions with individuals with new-onset epilepsy and their families to help direct them to needed community services. Access to a 24-hour, nonmedical help line could be a valuable source of information if broadly marketed, as could in-depth websites (Chapter 7). Strategies for building social support networks could be encouraged (Rodenburg et al., 2007); for example, joining with families in similar situations for leisure and social activities. Sharing experiences through online social networks with people facing similar issues also can provide needed support (Wicks et al., 2012).

Because the negative emotional effects from epilepsy can affect family functioning and quality of life, health and community service professionals

should provide families, especially parents, with information on strategies to help reduce family stress and successfully cope with epilepsy (Rodenburg et al., 2007). For example, Hames and Appleton (2009) identified a need for materials that are specifically developed for siblings. Family members also could benefit from support groups and counseling. In the survey by Baker and colleagues (2008), 36 percent of families had consulted an epilepsy counselor.

Seeking respite care is an important strategy, particularly for families of individuals with uncontrolled seizures or serious comorbidities. These families also could benefit from the availability of respite and day care services (Thompson and Upton, 1992). These services, if available, could reduce the caregiving burden and provide opportunities for families to have time to participate in social activities or pursue personal interests. An extended family network could serve a similar function, but for unknown reasons, it appears that many families do not receive support from extended family members (Saburi, 2011). Research is needed to identify barriers to receiving support and assistance and strategies for overcoming those barriers. Public awareness campaigns may be able to disseminate information about how people with epilepsy and their families need the support of extended family members and friends. Future research that focuses on multiple members in each family would provide important information about which family members are most in need of resources and support.

DAY CARE AND SCHOOL

[Our son] has tuberous sclerosis complex and epilepsy and he has had seizures since birth. . . . At age 2, Evan was placed into early intervention services in our county, and he was evaluated for special education, which included being placed on an individualized education program (IEP) when he was 3. . . . The IEP process empowers parents to be effective advocates for their children. . . . Through the IEP process [we] realized early on that many of the teaching staff were unfamiliar with epilepsy and apprehensive about caring for individuals with seizures. Included in his IEP was the request for seizure training for all staff members who would have [our son] in their care and that this training would occur prior to him entering kindergarten. We were under the impression this would involve a small meeting with . . . his teacher and possibly the school nurse. We walked to the library with the school principal, who was carrying a case of water, and we weren't quite sure what we had gotten ourselves into! We learned that "staff caring for [our son]" included his teachers, the school health aide, PE and art teachers, office staff, librarians, and the list goes on. We meet with 25 to 30 staff members yearly to describe [our son's] typical seizures and how they may affect his ability to perform in the school setting. The staff has a separate training performed by the county nurse and are required to review a seizure training video created by the

national Epilepsy Foundation. . . . We expect that by the time Evan exits elementary school, over 100 teachers and staff will have received extensive seizure training, and many teachers will have had annual refreshers. But this is just [one] school, and training like this needs to be expanded to all schools nationwide.

–Lisa and Robert Moss

Although most children with epilepsy do not have cognitive disabilities, as a group, children with epilepsy are at a greater risk of developing learning problems and of academic underachievement (Fastenau et al., 2008). One reason for this increase is that intellectual disability is a risk factor for developing epilepsy (Chapter 3). However, even children with epilepsy who do not have intellectual disability are at increased risk for learning and academic problems (Fastenau et al., 2008), as well as for psychosocial problems later in adolescence and adulthood (Sbarra et al., 2002). The age of onset of epilepsy is associated with effects on intelligence (Bjørnaes et al., 2001; Bulteau et al., 2000; Cormack et al., 2007; Hermann et al., 2002), learning (Fastenau et al., 2008; Sillanpää, 2004), social outcome (Lindsay et al., 1979; Sillanpää, 1983), and medical refractoriness (Berg et al., 1996; Camfield and Camfield, 2007; Casetta et al., 1999). Children who achieve seizure control relatively early in the course of epilepsy and have few cognitive impairments can attain average or above-average educational achievement. As described below, these learning, academic, and cognitive problems can result in the need for an array of support services in day care and school.

Early Childhood and Day Care

In the United States, more than 11 million children under 5 years of age are in some form of day care (professional or home) each week (NACCRRA, 2011). The paid early childhood care and education workforce in the United States is estimated at 2.2 million individuals, with approximately one-fourth caring for infants (IOM and NRC, 2011). Although little is known about the extent to which day care providers are aware of epilepsy and the range of types of epilepsy that could affect young children, there are concerns that some child care providers may refuse to accept a child with epilepsy based on their misconceptions about the disorder and about the amount of attention a child with epilepsy may need (Epilepsy Foundation, 2010).

Child care workers' training and qualifications vary widely, with each state having its own requirements (BLS, 2009). Requirements range from less than a high school diploma to a college degree in child development or early childhood education. Requirements are generally higher for workers at child care centers compared to those for family child care providers (BLS,

2009). An increasing number of child care employers require an associate's degree in early childhood education as a minimum requirement; however, only 12 states require training in early childhood education before leading a classroom in a child care center (BLS, 2009; NACCRRA, n.d.). As noted later in the chapter, first aid training is a requirement for many day care providers, and well-established first-aid courses (e.g., Red Cross training) provide education on how to recognize and respond to seizures. Further efforts to identify the educational needs and the knowledge and attitudes of day care staff regarding epilepsy are necessary. Such research would inform the development of guidelines and educational programs.

Additionally, parents of children with epilepsy can play an important role as advocates for training of their child's day care providers (Epilepsy Foundation, 2010). As parents take on the role of advocate they can be supported by state and local Epilepsy Foundation affiliates and other nonprofit organizations through parent support groups; these organizations can provide written materials on epilepsy that parents can supply to their day care providers and other supporting efforts.

School

School and Academic Achievement

A major developmental task for all children is to achieve success in school. On average, school-aged children and youth spend about half of their waking hours at school. Although many children and youth with epilepsy do well in school and do not have cognitive disabilities, as a group they are relatively more likely to have learning and achievement problems, to have cognitive deficits, and to need special services. Parents report that communication and interactions with school personnel when seeking help for their children are major sources of family stress (Buelow et al., 2006).

Learning disabilities[1] often are part of the school challenge for children with epilepsy. In a study of children and adolescents with epilepsy, 48 percent had a learning disability in at least one academic area using an IQ achievement discrepancy definition, and 41 to 62 percent had a learning disability using a low-achievement definition (Fastenau et al., 2008). In a recent study of special school services for children with epilepsy who had an IQ of at least 80, 45 percent used special education services, and 16 percent had been held back a year (Berg et al., 2011). In comparison studies, children with epilepsy demonstrate more cognitive deficits and academic

[1]Learning disabilities are defined as disorders in the basic psychological and neurological processes involved in understanding or using language, spoken or written, that may manifest themselves in an imperfect ability to listen, think, speak, read, write, spell, or use mathematical calculations.

problems than their healthy siblings (Berg et al., 2011; Dunn et al., 2010), healthy controls (Oostrom et al., 2003), and children with another chronic condition such as asthma (Austin et al., 1998, 1999). Poor achievement has generally been found in all academic areas (Austin et al., 1998; Fastenau et al., 2009; Sturniolo and Galletti, 1994).

Academic problems have been found to precede seizure onset in 15 to 24 percent of children with epilepsy (Berg et al., 2005, 2011). One of the risk factors for academic underachievement is poor cognitive functioning (Dunn et al., 2010; Fastenau et al., 2004; Schouten et al., 2002). Other risk factors include younger age of seizure onset (Dunn et al., 2010; Schoenfeld et al., 1999; Seidenberg et al., 1986), more frequent seizures or more severe seizure conditions (Austin et al., 1998, 1999; Berg et al., 2005; McNelis et al., 2007), presence of comorbidities such as ADHD (Fastenau et al., 2008), and psychosocial adjustment problems (Sturniolo and Galletti, 1994).

A supportive family environment and certain caregiver characteristics can be protective factors for children with epilepsy and can buffer the effect of poor cognitive functioning on academic achievement. For example, one study found that children with cognitive problems who lived in more supportive and organized family environments had better academic achievement than those who lived in less supportive, more disorganized homes (Fastenau et al., 2004). In a recent prospective study investigating the effect of cognitive functioning on academic achievement in children with epilepsy, Dunn and colleagues (2010) found that a higher education level of the caregiver was associated with better academic achievement and that greater caregiver anxiety was associated with lower academic achievement. These findings suggest that community support resources to help parents reduce their anxiety and create more supportive environments might also help their children in school.

The high prevalence of cognitive deficits consistently found in children with epilepsy, along with the negative impact of those deficits on academic achievement, make it imperative that children with epilepsy be screened early for cognitive problems and that early interventions be developed and applied (Fastenau et al., 2009). In addition, because children with epilepsy often have the inattentive form of ADHD (Dunn et al., 2003), which is associated with poorer academic achievement (Fastenau et al., 2008; Hermann et al., 2008), they also should be screened routinely for ADHD. Such assessments may occur as part of diagnostic testing at the time of epilepsy onset (depending on the age of the child when first diagnosed), but must be repeated regularly. Screening for cognitive problems and ADHD is important for adolescents as they transition to post–high school education and enter the workforce, so that they can identify and access programs and services to help meet their needs or seek accommodations at college

or in their work. Neuropsychological testing is a critical tool for identifying major learning impairments in children with epilepsy as well as diffuse mild cognitive impairments often missed in standardized school testing. Results and recommendations from these tests are used in developing IEPs and other educational plans and are also important in helping adolescents and young adults identify independent living needs and skills and assist in planning their future.

Unfortunately, currently there is no quick psychometric screen for assessing cognitive functioning for epilepsy, and research is needed that would enable the development of a tool to help identify children at risk for academic achievement problems. Further, the committee found few studies that tested programs that would help children with epilepsy improve their learning skills. A promising Direct Instruction[2] program was piloted with children who had poor seizure control and learning difficulties in a classroom at the Hospital for Sick Children in Toronto (Humphries et al., 2005). Prior to entering a program up to 16 weeks in duration, children completed placement tests to identify their academic needs. All staff members were trained in Direct Instruction, there were no more than eight children in a classroom, and the educational program was delivered using standardized methods. Instruction was provided in a range of areas, including reading, reasoning and writing, math concepts, language, and spelling. Following the completion of the program, significant improvement was found in all academic areas except word identification in reading. The authors concluded that Direct Instruction can help children with epilepsy close gaps in learning skills that will provide a good foundation for learning. More research is needed to develop screening tools for assessing cognitive functioning in children with epilepsy, to evaluate programs to improve learning problems they experience, and to implement effective programs more widely.

School Personnel

The attitudes of teachers and other education providers (including day care providers) toward epilepsy can significantly influence students' school performance and social skill development (Bishop and Slevin, 2004). Teachers play an important role in the health care of children with epilepsy, in that they are frequently in the best position to observe a child for possible seizures or adverse medication effects during the day. However, students

[2]Direct Instruction is a highly structured approach to teaching designed to facilitate learning among students with various learning problems. The method focuses on making material as clear as possible and building toward more complex ideas and skills. See, for example, http://www.promisingpractices.net/program.asp?programid=146.

with epilepsy can be at increased risk for social and academic problems if their teachers have misperceptions or a lack of information about epilepsy, or if they perpetuate the stigma often associated with the disorder (Chapter 8) (Bishop and Slevin, 2004; Dantas et al., 2001).

In several studies, teachers report little confidence in instructing students with epilepsy and acknowledge that they have limited information about the disorder, how best to work with students with epilepsy, or how to respond to seizures if they occur in the classroom (Bannon et al., 1992; Bishop and Boag, 2006; Bishop and Slevin, 2004; Wodrich et al., 2011). Further, teachers appear unlikely to actively seek information about epilepsy (Bishop and Boag, 2006). Changes may be under way in some schools as a result of a recent evaluation that found teachers who were currently teaching a child with epilepsy appeared to have more school-relevant epilepsy facts than teachers generally, and they expressed greater confidence in their ability to meet these students' instructional, safety, and psychosocial needs (Wodrich et al., 2011).

Effective programs for educating and increasing student, teacher, school nurse, counselor, and parent awareness are critical. The Epilepsy Foundation has developed programs and resources to educate teachers and to help them increase epilepsy awareness in their classrooms. For example, the website-based program, Epilepsy Classroom, developed by UCB, Inc., in collaboration with the Epilepsy Foundation, provides lesson plans, classroom resources, and parent resources on a range of topics relevant to children with epilepsy in the school setting (Epilepsy Classroom, 2012). Several studies have shown that even brief, focused interventions in educational settings can produce improvements in epilepsy-related knowledge and attitudes among students (Fernandes et al., 2011; Martiniuk et al., 2007; Roberts and Farhana, 2010). However, teacher-focused research is limited; teacher-focused interventions need to be developed and tested; and increased education about epilepsy is needed in teacher preparation programs (Bishop and Boag, 2006) and in continuing education for school nurses, counselors, and other school personnel. Efforts are needed to design, implement, and evaluate interventions for school settings that build on techniques and methods that have been evaluated and found to be effective.

Legal Mandates

Access to special education services or other educational supports may be mandated or otherwise available for children with epilepsy as a result of the Individuals with Disabilities Education Act (IDEA) (reauthorized most recently in 2004, P.L. 108-446) and the 1973 Rehabilitation Act (P.L. 93-112) and its amendments (U.S. Department of Justice, 2005). IDEA and its

amendments mandate free and appropriate public education for all students with disabilities through age 21 or high school graduation; require that school districts identify, evaluate, and reevaluate children who need special education and related services; stipulate that education should be provided for students in the least restrictive environment and alongside of students without disabilities whenever possible; and mandate nondiscrimination in testing and evaluation services for children with disabilities. The legislation specifies the rights and processes for the development of an IEP for each student enrolled in special education and individualized transition planning to prepare special education students for post-school environments (Box 6-2).

Students with disabilities who do not qualify for an IEP but have a disability and require reasonable accommodation while attending school may have an educational plan under Section 504 of the Rehabilitation Act of 1973. Section 504 regulations require a school district to provide qualified students with a disability a "free appropriate public education" regardless of the nature or severity of the disability. Further, nondiscrimination is mandated; students with disabilities must not be excluded from nonacademic activities, such as athletics, transportation, health services, recreational activities, and special interest groups or clubs. Students qualifying for protection under Section 504 include those who have been identified as having a physical or mental impairment that substantially limits one or more major life activities (U.S. Department of Education, 2011a).

Box 6-2 EDUCATIONAL PLANS FOR STUDENTS WITH DISABILITIES

Individualized education program (IEP) An IEP is a multipart written statement for the child with a disability that includes information on annual academic and functional goals, plans on how progress will be measured on those goals, details on the special education and related services to be provided to the child, and information on any appropriate individual accommodations necessary to measure the academic achievement and functional performance of the child on state- and district-wide assessments (U.S. Department of Education, 2011b). By the time the student reaches 16 years of age, the IEP must include a discussion of postsecondary goals and transition services needed (U.S. Department of Education, 2011c).

Section 504 educational plan Students with disabilities who do not have an IEP can have a Section 504 educational plan that outlines the educational services and accommodations necessary to ensure equal access to education (U.S. Department of Education, 2011a). Accommodations may include, for example, schedule modification, a structured learning environment, modified test instructions and test delivery, and assistive technology and medical and transportation services. Section 504 plans also allow for any necessary and related services as occupational therapy, physical therapy, and speech and language services.

The 2008 amendments to the Americans with Disabilities Act (ADA) expanded the definition of major life activities to include learning, reading, concentrating, and thinking, as well as expanding the definition to include neurological and brain functions (U.S. Access Board, 2008). The amendments also clarified that the act covers impairments, such as epilepsy, that are episodic in nature or in remission and that substantially limit a major life activity when not in remission (U.S. Access Board, 2008). Epilepsy advocates and numerous other disability advocacy groups were active in supporting and informing these changes.

Improving School and Day Care Programs

A large part of improving school and day care services for children with epilepsy revolves around enhancing teachers' awareness about epilepsy and developing an educational plan focused on meeting students' individual needs. Although not all children and youth with epilepsy require specialized services, these services must be available for those that do, so that all students have opportunities to reach their full potential. The committee believes that teachers, counselors, day care providers, and school personnel working with children with epilepsy have the responsibility to become informed about the disorder so that they can work effectively with parents and students to develop tailored educational plans. Additionally, the committee recognizes that parents may have to be active advocates for their children in the development and implementation of educational plans. Parents and school staff can encourage students with epilepsy to reach out to peers and teachers for help with accommodations as needed and help students become strong and informed self-advocates.

SPORTS AND RECREATION

Physical activity and recreation are important components of physical and emotional well-being and quality of life for all people, and people with epilepsy are encouraged to be as physically active as possible (Epilepsy Foundation, n.d.; Howard et al., 2004). Obesity and being overweight are a concern for people with epilepsy because studies have found that children with newly diagnosed, untreated epilepsy have higher body mass index levels than children in a comparison cohort and that women with epilepsy have a higher body fat ratio than healthy controls (Daniels et al., 2009; Howard et al., 2004). A population-based study using the Canadian Community Health Surveys between 2001 and 2005 found that individuals with epilepsy were 1.4 times more likely to be physically inactive than the general population (Hinnell et al., 2010). In addition, some seizure medications have been associated with weight gain (Ben-Menachem, 2007; Biton, 2003;

Verrotti et al., 2011). Although exercise-induced seizures are rare, factors that may exacerbate seizures include hyperventilation, fatigue, altering levels of metabolism of seizure medications with exercise, psychological stress, and increased heart rate during intense activity (Dubow and Kelly, 2003; Fountain and May, 2003; Howard et al., 2004; Sahoo and Fountain, 2004).

However, research in sports and exercise suggests that regular physical activity—in addition to its well-known positive psychosocial and physiologic benefits—can reduce the frequency and severity of seizures among children and adults, including women (Arida et al., 2009, 2010; Conant et al., 2008; Eriksen et al., 1994; Nakken et al., 1990, 1997). A survey of Norwegians with epilepsy, for example, found that exercise was associated with better seizure control (Nakken, 1999). Physical activity also can improve attention, mood, and physical health and may have a role in minimizing depression in people with epilepsy (Arida et al., 2012). Although some seizure medications can affect bone density, which peaks in adolescence and has consequences in adulthood related to risks for fractures and osteoporosis (Pack, 2011; Pack and Morrell, 2004; Samaniego and Sheth, 2007), participation in regular weight-bearing activities in conjunction with adequate calcium consumption and vitamin D can mediate the process of bone loss (HHS, 2004).

A few studies have examined the extent to which people with epilepsy engage in sports and recreational activities or experience limitations in their activities. The 2003 California Health Interview Survey found that adults who have had epilepsy reported twice as many activity limitation days as those without (Kobau et al., 2007). In a study comparing siblings with and without epilepsy, no significant differences were seen for physical activity in children under 12 years, but youth ages 13 to 17 years participated less frequently in group sports and total sports activities, although participation in individual sports was similar (Wong and Wirrell, 2006).

Researchers found that Canadians ages 12 to 39 spent similar amounts of time in leisure physical activity regardless of whether they had epilepsy or not; they noted that people with epilepsy reported more walking and were less likely to be involved in ice hockey, weight training, or home exercise (Gordon et al., 2010). A study in South Korea evaluated active and inactive individuals with epilepsy to identify barriers to exercise (Han et al., 2011). Anxiety, taking multiple seizure medications, and previously experiencing a seizure during exercise were significantly associated with inactivity. In addition, fear of participation, overprotection, and discouragement from family, friends, or physicians were significant barriers. Other barriers in the study included fatigue following activities, the lack of an exercise partner, limited time, and uncertainty of how to begin and continue an exercise program.

Recommendations on participation in sports by people with epilepsy have changed over the years. The 1968 American Medical Association

Committee on Medical Aspects of Sports opposed participation in collision and contact sports by individuals with epilepsy, but by 1978 the committee had reversed that recommendation, and its 1983 statement urged full participation in physical education programs and interscholastic athletics, aided by common sense and proper supervision (Dubow and Kelly, 2003). Further research is required to understand the effects of intense exercise and the effect of exercise and sports on metabolism of seizure medications. In addition, research is needed to understand the effect of epilepsy and seizures on aerobic endurance and balance.

Selection of sports and leisure time activities for children and adults with epilepsy involves consideration of personal preferences, the nature of the sport, the risk of injury, and individual factors regarding seizure type, frequency, and severity (Drazkowski and Sirven, 2011; Dubow and Kelly, 2003; Fountain and May, 2003). Since rates and degree of injuries during participation in contact sports are similar between people with and without epilepsy, participation in contact sports is an option (Miele et al., 2006). Recommendations for athletes with epilepsy in competitive sports, contact sports, and high-risk sports include the need to receive an initial neurological evaluation to establish a baseline and another after any injuries, to adhere to prescribed medication regimens, to inform the team manager or coach about epilepsy, and to use adequate protective equipment (Dimberg and Burns, 2005). Table 6-3 provides a general categorization of sports and activities by risk.

One way to encourage exercise, skill development, and independence for children with epilepsy is through residential camps that either are specifically focused on this disorder or more broadly serve children with various serious or chronic health conditions. These types of camps offer opportunities for children to learn about self-management and interact with other children and youth who share similar experiences. Studies of health condition-specific camps found improvements in participants' attitudes about their health condition and quality of life and reduced anxiety (Bekesi et al., 2011; Briery and Rabian, 1999). Similarly, in a 3-year study that examined adaptive coping behavior in campers at an epilepsy-specific summer camp, significant improvements were observed for return campers in communication, responsibility, and social interactions (Cushner-Weinstein et al., 2007). Many nonprofit organizations, including state and local Epilepsy Foundation affiliates, offer information on and opportunities for summer camps and other recreational activities (Epilepsy Foundation, 2011; Epilepsy.com, 2011).

Expanding participation in sports and other recreational activities will involve continued efforts to increase awareness that people with epilepsy can and should be physically active. Further, coaches, workout instructors, counselors, camp directors, and others in the physical activity and recre-

TABLE 6-3
Sporting and Recreational Activities Classified According to a Possible Risk for the Individual with Epilepsy

Low Risk	Moderate Risk	High Risk
Baseball	Basketball	Boxing
Bowling	Biking	Downhill skiing
Cross-country skiing	Boating or sailing	Gymnastics (equipment with height)
Golf	Football	Hang gliding
Ping-Pong	Gymnastics (floor)	Hockey
Track	Horseback riding	Motor sports
Walking	Karate	Rock climbing
Weight training (machines)	Skateboarding	Scuba diving
Yoga	Soccer	Swimming (long distance)
	Swimming	
	Waterskiing	

SOURCE: Adapted from Drazkowski and Sirven, 2011. Reprinted with permission from Lippincott Williams and Wilkins, http://www.lww.com.

ation fields need up-to-date information about epilepsy. Methods for most effectively providing this information need to be explored. Nonprofit organizations and the public health community can disseminate information tailored to meet this need. Individuals, parents, and caregivers should be sure that those with whom they work and who coach children and youth with epilepsy are fully aware of any specific limitations. As discussed later in the chapter, seizure first aid training is critically important.

EMPLOYMENT

By the time I was in high school, everybody knew I had epilepsy, and it was not really a big deal. . . . But then one day I decided I wanted a job. . . . Now, this was 1972, [and] the application looked more like a new patient intake form. It actually listed a huge long list of medical disorders, and one of them was epilepsy. I was telling everybody I had epilepsy, so I marked it. And so I took my little application up, handed it in at the window, and the person there right in front of me picks up a red pen and makes circles where I checked I had epilepsy. They did not call me for an interview. So the next day I went to another store. I saw they had a "help wanted" sign. And I filled out the application, and they did not ask for specifics, but there was a health-related question. And right there, 18 years before Congress, I enacted my own Americans with Disabilities Act. I had two qualifications. One, could I do the job and, two, if I did have a seizure, would somebody else get hurt? If I got hurt, well, couldn't do anything about that. Since then I have never put epilepsy on the application.

–Mary Macleish

Employment is a critically important aspect of quality of life and psychosocial health, providing avenues for social participation, economic security (Bishop and Chiu, 2011), and for many people in the United States with epilepsy, access to health insurance. For some people with epilepsy, transportation to and from work poses major challenges to gaining and maintaining employment.

Although most people who have epilepsy are able to fully participate in the labor market, they consistently have higher levels of unemployment compared to the general population (Bishop, 2002; Fisher, 2000; Kobau et al., 2008; Smeets et al., 2007). Further, they are more likely to be employed in unskilled and manual jobs or underemployed (employed in a job where they have more skill, education, or training than what is required, which results in their earning capacity not being met) (Bishop and Chiu, 2011; Smeets et al., 2007). Although the lack of standard definitions makes the measurement of employment, unemployment, and underemployment a complex and inexact science (Chaplin, 2005), research using population-based samples has consistently suggested that the unemployment rate of people with epilepsy is at least twice that of the general population (Fisher, 2000) and even higher among people who seek care in tertiary care centers, which is often those individuals with more severe types of seizures (Hauser and Hesdorffer, 1990; Thorbecke and Fraser, 2008).

Available evidence underscores consistent and persistent employment problems for people with epilepsy. Responses to a community-based survey of adults with epilepsy indicated that 25 percent of eligible workers reported being unemployed at a time when the average unemployment rate in the United States was slightly more than 5 percent (Fisher et al., 2000). Data from the 2005 Behavioral Risk Factor Surveillance System (BRFSS) surveys, which included population data from 19 states, suggested that the unemployment rate was 9.8 percent for people with active epilepsy,[3] 8.3 percent among those with inactive epilepsy, and 5.4 percent for those with no epilepsy history (Kobau et al., 2008). Nine-state data from the 2006 BRFSS indicated that people with a lifetime prevalence of epilepsy[3] were more than three times as likely to be unemployed or unable to work as people who did not have epilepsy (34 percent versus 9 percent), and people with active epilepsy were more than four times as likely to be unemployed or unable to work in a similar comparison (42 percent versus 9 percent) (Konda et al., 2009). Although estimates of the extent of employment disparities vary based on methodology and sample characteristics, relatively lower levels of employment have been consistently found for people with

[3]In both studies analyzing the BRFSS results, active epilepsy was defined as having 1 or more seizures in the past 3 months or taking medication for seizure control, and lifetime prevalence of epilepsy was defined as responding affirmatively to ever being told by a physician that they had a seizure disorder or epilepsy (Kobau et al., 2008; Konda et al., 2009).

epilepsy for more than three decades (Bishop, 2002). Employment disparities have continued despite improvements in clinical treatment and laws protecting the employment rights of people with disabilities (Jacoby et al., 2005).

The apparently difficult employment situation for people with epilepsy is not reducible to a single factor, such as the experience of seizures, but rather represents a complex interaction of variables (Thorbecke and Fraser, 2008). A variety of seizure-related factors (e.g., seizure frequency, type, perceived impact, felt stigma) have been shown to predict employment status, as have the age of epilepsy onset, comorbid mental health and cognitive conditions, the adverse effects of seizure medications, and various psychological factors, such as depression and anxiety (Bishop, 2004; Chaplin et al., 1998; Jacoby et al., 1996, 2005; Rätsepp et al., 2000; Yagi, 1998). Psychosocial factors relevant to unemployment rates among people with epilepsy include social isolation, social skill deficits, low self-esteem, lack of family support, and fears about negative attitudes on the part of employers (e.g., Smeets et al., 2007; Thorbecke and Fraser, 2008). External factors, such as enacted stigma and discrimination, also contribute to employment problems for people with epilepsy, and the effects of these may be more significant in times of high unemployment, when competition for jobs is heightened (Jacoby et al., 2005).

In the employment application process, deciding on the appropriateness and necessity of openness about the epilepsy diagnosis "may be influenced by legal, medical, social, and personal concerns" (Bishop and Chiu, 2011, p. 100). People with epilepsy may need to be open in acknowledging that they have epilepsy if they need work-related accommodations. If accommodations are not required and the applicant can perform the required duties of the position, then openness about the diagnosis may not be necessary (Bishop et al., 2007). In general, however, opinions vary about the advisability of disclosure. In a survey of state and local Epilepsy Foundation affiliates, none of the organizations reported that they counsel people to be open about their condition either on applications or in initial interviews, and more than half of respondents indicated that if an open discussion about the condition is necessary, they would advise that it be done after being hired (Bishop and Allen, 2001). By contrast, in a survey of employers by Jacoby and colleagues (2005), a majority of employers indicated that prospective employees with active epilepsy (defined as "currently having seizures, even if only occasionally," p. 1981) should discuss their disorder openly, preferably early in the recruitment process, even if seizures are well controlled. As the researchers noted, "There is a clear mismatch between the position of employers, who may see non-disclosure as a breach of trust, and [people with epilepsy], many of whom opt not to disclose out of fear of enacted stigma" (Jacoby et al., 2005, p. 1984).

Employer attitudes can be a significant barrier to employment (Bishop, 2002; Bishop and Chiu, 2011; Epilepsy Foundation, 2001; Jacoby et al., 2005). Researchers have found that employers' attitudes regarding employment of people with epilepsy include concerns about the comfort and safety of workers, worries about increased accident rates and subsequent increases in insurance rates, and questions about the need to revise work flows with possible increases in expenses for work-related accommodations (e.g., Bishop et al., 2007; Hicks and Hicks, 1991; Jacoby et al., 2005; John and McLellan, 1988). However, there is no empirical support for these concerns (Jacoby et al., 2005).

In the past several decades, survey research has found improving attitudes toward people with epilepsy (Chapter 8). However, contrasting data have been reported by researchers who used indirect survey methods that are less susceptible to socially desirable responses (Antonak and Livneh, 1995; Baumann et al., 1995; Bishop and Slevin, 2004) and by evidence that the level of unemployment for people with epilepsy and employers' attitudes have remained fairly constant over a 30-year period (Bishop, 2002; Jacoby et al., 2005). Based on their 2005 survey of a representative random sample of UK employers, Jacoby and colleagues found that 26 percent of employers reported having employed individuals with epilepsy knowingly; 16 percent believed their company had no jobs suitable for individuals with epilepsy; 21 percent thought employing people with epilepsy would be "a major issue"; and epilepsy created high concern for around half (in part because of concerns about work-related accidents), although they said they were willing to make accommodations for people with epilepsy. Further, a U.S. study among employers and human resources personnel suggested that hiring an individual with epilepsy was less likely than hiring people with any number of other disabilities, including cancer in remission, depression, a history of heart problems, AIDS, mild intellectual disabilities, and spinal cord injury (Bishop et al., 2007).

Attitudes of employers toward hiring people with disabilities generally differ depending on the ways in which attitudes are defined and measured, as well as the size of the employer and the employer's experience with previous hires. Positive attitudes tend to be found in studies that assessed general, as opposed to specific, attitudes and situations involving workers with disabilities. Further, although employers may have positive attitudes toward workers with disabilities, those attitudes do not always translate into active efforts to employ people with disabilities (Hernandez et al., 2000). In surveys of employers, those from large companies were more likely to have positive attitudes about workers with disabilities; to hire more workers with disabilities, including workers with epilepsy (Jacoby et al., 2005); and to have made worksite accommodations (Bruyère et al., 2003; Lee, 1996).

Larger companies were also more likely to be familiar with employment-related legislation such as the ADA (Bruyère et al., 2006).

Potential avenues for improving employment opportunities for people with epilepsy include employer education programs and awareness campaigns, vocational rehabilitation programs and career services, and enforcement of antidiscrimination and equal opportunity legislation.

Employer Education Programs

Several public education efforts have been specifically directed at employers. For example, the Epilepsy Foundation has developed and sponsored employer education and awareness campaigns and developed and disseminated other materials to promote the hiring of people with epilepsy. During Epilepsy Awareness Month, efforts have been made to educate employers about the nature of epilepsy, its successful treatment, workplace accommodations, and vocational rehabilitation for people with epilepsy. Although epilepsy education campaigns and interventions have been shown to have positive effects in promoting knowledge and attitude change in educational, health, and more general settings (e.g., Martiniuk et al., 2010; Roberts and Farhana, 2010) (Chapters 5 and 8), the number of such efforts with an employment focus has been small, and evaluations of their efficacy in the research literature are scarce.

In a study examining the impact of an epilepsy education campaign in one U.S. city that focused on the mass media, community organizations, and mailings to selected employers, Sands and Zalkind (1972) did not find differences between pre- and post-campaign attitudes. However, understanding of the techniques that increase the effectiveness of public education campaigns has evolved considerably since 1972. Further efforts are needed to design, implement, and evaluate the efficacy of focused campaigns aimed at promoting employer knowledge and attitudes.

Workplace Programs

To improve employment opportunities, research has consistently pointed to the need for effective employment training programs for people with epilepsy (Smeets et al., 2007). A two-pronged approach has been supported for epilepsy vocational rehabilitation, one focused on specialized vocational rehabilitation services and the other focused on targeted epilepsy training for staff of broader vocational rehabilitation programs (Fraser, 2011).

Specialized employment programs and resources specifically for individuals with epilepsy have proved successful. These include the now discontinued TAPS (Training Applicants for Placement Success) and Job-

Tech programs (Bishop and Allen, 2001; Thorbecke and Fraser, 2008). Ongoing employment services provided by the Epilepsy Foundation include an online career support center, the Jeannie Carpenter Legal Defense Network (whose work includes employment discrimination), and employment-related services offered by state and local Epilepsy Foundation affiliates across the country (Fraser, 2011). The Epilepsy Foundation's website includes an employment section that is designed to assist people with employment searches; in addition, the website provides guides on job preparation and job search sites, gives suggestions on ways to discuss information about epilepsy in the workplace, and offers other resources, including a discussion forum on epilepsy and employment (Epilepsy Foundation, 2012). The Epilepsy Foundation and its affiliates also organize employer education training and employer and employee awareness and training conferences that bring employers together with supporting and enforcement agencies, such as the Equal Employment Opportunity Commission, to provide information on the rights of workers with epilepsy (Epilepsy Foundation Northwest, 2012).

General (not epilepsy-specific) employment services are available through state-federal vocational rehabilitation programs and One Stop Career Centers in each state (U.S. Department of Labor, 2012). Little research has evaluated the effectiveness of epilepsy and vocational rehabilitation programs (Smeets et al., 2007). However, programs that are focused on vocational rehabilitation for people with epilepsy appear to be more effective than general vocational rehabilitation programs (Fraser et al., 1984; Thorbecke and Fraser, 2008). For example, Fraser and colleagues (1984) reported that whereas general state vocational rehabilitation agencies achieved 9 to 21 percent placement rates among people with epilepsy, specialized vocational rehabilitation programs achieved placement for almost half of individuals, a finding reiterated in more recent research (Mount et al., 2005). These results may reflect both the focused delivery and the epilepsy knowledge of the professionals providing services. For example, the extent to which state-federal vocational rehabilitation programs hire master's level and certified rehabilitation counselors varies by state.

Available research suggests that the most successful employment programs for people with epilepsy focus on specific skills, such as training individuals to request work accommodations, promoting self-confidence and self-efficacy in handling work-related problems, and providing training aimed at job retention (Smeets et al., 2007). Further, programs that bring employers and individuals with epilepsy into direct contact, such as through negotiated short-term work experience placements, "are likely to have more impact than educational initiatives undertaken in the abstract" (Jacoby et al., 2005, p. 1986).

The committee believes that overcoming employment barriers faced by

people with epilepsy will require the efforts of advocacy groups working with federal, state, and local vocational programs and counselors. Epilepsy-specific training provided to vocational rehabilitation counselors and other state vocational rehabilitation program personnel will improve awareness of epilepsy and allow for discussions of specific employment problems. Additionally, there is a significant need for increased longitudinal and evidence-based evaluations of the efficacy of both specialized and general vocational rehabilitation programs, in order to more specifically identify effective factors and interventions for job attainment and retention.

Employment Legislation

Employers' awareness and knowledge about epilepsy is enhanced indirectly through the enactment and enforcement of employment and civil rights legislation. Several major laws aimed at protecting equal opportunities for people with disabilities, including the Rehabilitation Act of 1973, the Workforce Investment Act of 1998, the Ticket to Work and Work Incentive Improvement Act of 1999, and the ADA of 1990 and ADA Amendments Act of 2008 have significant potential for promoting employment opportunities for people with epilepsy (Box 6-3).

After the enactment of the ADA, several U.S. Supreme Court decisions narrowed its scope of coverage in such a way that many individuals with epilepsy were no longer protected against employment discrimination (Bishop and Chiu, 2011). However, people with epilepsy and advocates for epilepsy were among those who worked to inform policy makers of the need to expand the definition of a disability to include impairments of neurological function and episodic conditions that, when active, limit major life activities. The ADA Amendments Act incorporated these changes.

The impact of the ADA on employers' attitudes and on rates of employment for people with disabilities generally has been mixed (Hernandez et al., 2000; Houtenville and Burkhauser, 2004). While there is evidence that employers are increasingly aware of and have more positive attitudes about general disability issues and ADA rights that they have identified as less costly to implement, they may have concerns about other ADA mandates that are perceived to be complex and costly, including accommodating workers with disabilities. At the same time, they are also concerned about the potential threat of legal actions (Hernandez et al., 2000). Roessler and Sumner (1997) found positive employer attitudes toward employees with chronic health conditions, including epilepsy. However, epilepsy was noted as one of the conditions with which employers were least familiar (Jacoby et al., 2005).

Although the ADA amendments expanded access to discrimination protection for people with epilepsy, the law's impact is not yet evident.

Box 6-3 KEY EMPLOYMENT LEGISLATION

1973 Rehabilitation Act This act and its subsequent amendments have made significant revisions to the operation of the state-federal vocational rehabilitation programs, established funding for independent living services, and increased funding for rehabilitation and disability research through the establishment of the National Institute on Disability and Rehabilitation Research. In addition, Title V of the act served to advance the civil rights of people with disabilities, including through mandating nondiscrimination on the basis of disability in federal hiring and employment. Section 504 prohibited disability-based exclusion of otherwise qualified persons with disabilities from participation in any federal program or activity or from any program or activity that receives federal funding.

1990 Americans with Disabilities Act (ADA) The ADA ensures "equality of opportunity, full participation, independent living, and economic self-sufficiency" for individuals with disabilities. Civil rights are addressed across several domains including employment discrimination (Title 1), discrimination in public services (Title 2), and discrimination in public accommodations (Title 3). Title 1 specifically protects people with disabilities from employment discrimination in hiring, advancement, or discharge of employees, employee compensation, job training, and other terms, conditions, and privileges of employment. Titles 2 and 3 prohibit discrimination based on disability by public entities (e.g., public transportation) at all local and state levels, and they require public accommodations when needed.

2008 ADA Amendments Act As noted above, the ADA amendments clarified that the act covers impairments, such as epilepsy, that are episodic in nature or in remission and that substantially limit a major life activity when active.

Continued review and monitoring are necessary, as is ongoing research on employers' attitudes and on the employment experiences of people with epilepsy.

Improving Employment Opportunities and Awareness About Employment Rights

People with epilepsy need to be informed and aware of their employment protections and how to invoke them. The American Epilepsy Society (AES), the Epilepsy Foundation, and Epilepsy.com of the Epilepsy Therapy Project have developed and actively promote programs and educational materials that detail the provisions of the ADA and its amendments, as well as provide information and resources relevant to employment, such as job accommodations. The extent to which these resources are accessed by employers and whether they have increased employers' willingness to hire people with epilepsy needs to be explored.

In addition, best practices in employment programs need to be identi-

fied and widely disseminated. The committee regards this as an important area in which organizations involved with a number of chronic diseases or other neurological disorders could come together to identify and disseminate programs that work in vocational rehabilitation and to work with employers to promote the hiring of qualified people with epilepsy and other disorders.

DRIVING AND TRANSPORTATION

> *As a practical consequence of my disorder, I have had to give up driving and to stop working. . . . I have had to reshape my lifestyle in order to maintain my usefulness and the esteem of those whose opinion of me matters most, as well as my own self-respect. . . . I have traded many duties around the house with my wife and sons so that they now do anything that requires driving, while I have taken over many more house-husband routines. To the extent that epilepsy challenged us to be a better team, we have become a stronger family. It has taken a lot of work, and that work has taken change, and change has taken courage and commitment, and all of that from all of us has taken love.*
>
> –Michael Bornemann

In the United States, the ability to drive or to be able to access reliable, affordable transportation is closely connected to employment and educational opportunities, social engagements and activities, access to health care services, and overall independence and quality of life. Seizures may limit transportation options. Challenges and fears associated with driving and transportation are frequently cited in surveys and interviews of adults with epilepsy, regardless of age or gender (Fisher et al., 2000; Gilliam et al., 1997; Martin et al., 2005; Paschal et al., 2005; Personal communication, C. A. Tubby, AES, June 28, 2011; Sare et al., 2007). In a quality-of-life study, Gilliam and colleagues (1997) found that driving, independence, and employment are the chief concerns among people with epilepsy.

Driving and Epilepsy

Driving requires a complex array of neurological functions and skills that involve vision, cognition, attention, and judgment, as well as coordination, reaction time, and motor control. Any or all of these could be impaired by epilepsy and seizures, comorbidities associated with epilepsy, or side effects of seizure medications. People with epilepsy who drive vehicles may present safety concerns for themselves, their passengers, and the public (Drazkowski, 2007a,b; Drazkowski and Sirven, 2011).

Data on the number of people with epilepsy who drive and on the

number of accidents that result from seizures are inconsistent. Surveys and interviews have indicated that approximately 20 to 30 percent of people whose epilepsy is not well controlled nevertheless drive (Bautista and Wludyka, 2006; Berg et al., 2000; Tatum et al., 2012; Webster et al., 2011). Although the number of accidents that occur as a direct result of seizures is unknown, 5 to 27 percent of people with epilepsy report that they have had a seizure that has led to an auto accident (Berg et al., 2000; Drazkowski et al., 2010; Fisher et al., 2000). Studies that analyze data on automobile accidents and deaths have mixed results as to whether risks are greater for people with epilepsy compared to the general public or to people with other health conditions (Drazkowski, 2007a; Kwon et al., 2011; Lings, 2001; Sheth et al., 2004).

Legal Considerations

Unlike other health conditions that could impair one's ability to drive safely (e.g., cardiovascular disease, diabetes), epilepsy is explicitly addressed in driving laws in every U.S. state (Krauss et al., 2001). Although the laws and regulations vary, most states require a defined seizure-free interval, ranging from 3 to 12 months, before a person with epilepsy may legally drive. Some states have no seizure-free interval requirement at all, and others allow exceptions—for example, in cases where seizures are strictly nocturnal, there is an aura before a seizure, or when a recent seizure was the direct result of medication change (Krauss et al., 2001).

The "seizure-free interval" is a proxy for predicting which individuals are likely to remain seizure free—generally speaking, the longer the interval, the less likely is another seizure—although a definitive seizure-free interval for safe driving has not been established (Drazkowski and Sirven, 2011). Krauss and colleagues (1999) found a 93-percent lower risk of being involved in an auto accident for a person with epilepsy who had been seizure free for a year or more compared to individuals who were seizure free for a shorter period of time, whereas Drazkowski and colleagues (2003) found no significant increase in auto accidents or deaths associated with seizures when Arizona reduced its seizure-free requirement from 12 to 3 months. Sheth and colleagues (2004) also found no greater fatality rate in states with a 3-month seizure-free interval requirement, compared to states with 6- and 12-month requirements. In 1994, the American Academy of Neurology (AAN), AES, and Epilepsy Foundation developed a consensus statement that recommends a 3-month interval (AAN et al., 1994). The consensus statement also includes a list of modifiers that could alter the duration interval requirement (e.g., lack of compliance with medication regimen, a seizure that was a result of sleep deprivation or a reversible acute illness).

The role of physicians in determining driving eligibility also varies by state. For example, some states allow physicians the discretion to determine the appropriate seizure-free interval on an individual basis (Krauss et al., 2001). Similarly, reporting regulations differ by state; most states allow voluntary reporting but do not mandate it (Drazkowski et al., 2010). Six states—California, Delaware, Nevada, New Jersey, Oregon, and Pennsylvania—take a strict, and controversial, approach by requiring physicians to report people with epilepsy and active seizures who are driving (or would like to drive) to the state driving authorities (Drazkowski, 2007a; Drazkowski and Sirven, 2011). In the consensus statement noted above, the three organizations agreed that physicians should not be required to report people with epilepsy to state driving authorities (AAN et al., 1994).

Mandatory reporting requirements for physicians may affect a patient's honesty about seizure frequency and, in turn, a clinician's ability to provide quality care and improve management of the disorder. One survey indicated that 19 percent of patients did not accurately reveal their seizure frequency to their physician so that they could continue to drive (Elliott and Long, 2008). Moreover, a Canadian study demonstrated that a physician reporting requirement did not decrease the risk of auto accidents for drivers with epilepsy (McLachlan et al., 2007). Nor do people with epilepsy necessarily self-report their seizures to driving authorities or reply honestly to questions about their condition on driver's license applications (Drazkowski and Sirven, 2011; Salinsky et al., 1992; Taylor et al., 1995; Tomson et al., 2004). However, the majority of drivers with epilepsy do express concerns about their safety and the safety of others and indicate they would not drive until their physician or the state driving authorities indicate it is safe to do so (Tatum et al., 2012).

There is no simple determination for when and under what circumstances a person with epilepsy can safely drive. As Krumholz notes, "no single standard satisfies all situations because of varied cultural, social, and environmental factors and risk tolerance that influence such a decision" (2003, p. 817). As new studies become available and science advances, driving laws should be reevaluated and updated. For example, one innovative study recently explored the relationship between brain activity that occurs between seizures and can be measured on EEGs, and its relationship with reaction time when driving (Krestel et al., 2011). The authors suggested that reaction-time EEGs could play a future role in evaluating individuals' ability to drive. Additional population-based studies using innovative approaches are needed, and policy changes should be considered to ensure that driving laws are equitable, both guarding the safety of the public and preventing undue burden and diminished quality of life for people with epilepsy.

Educating People with Epilepsy and Clinicians

Due to the risks associated with having a seizure while driving, educating individuals with epilepsy about those risks and the applicable state driving laws and regulations is essential, and clinicians have an obligation to do so. The need for improved education about driving laws has been demonstrated in surveys, which indicate that many people with epilepsy (48 to 86 percent) are not aware of their state's seizure-free interval requirements (Long et al., 2000; Tatum et al., 2012). Additionally, Long and colleagues (2000) found that almost a quarter of people with epilepsy thought that it was okay to drive "if they either 'double-up on medication,' are not driving alone, or are able to 'pull over' at the onset of a seizure" (p. 729). The proportion of individuals with epilepsy who have received counseling about driving and associated risks varies significantly—from one-tenth to three-quarters (Shareef et al., 2009; Tatum et al., 2012). Only 7 percent of patients who sought care in an emergency room following a loss of consciousness or a seizure received counseling about driving if a neurologist was not consulted; when a neurologist was involved the counseling rate was still only 34 percent (Shareef et al., 2009).

Physician knowledge of state driving laws varies by specialty; more than a third of family physicians and internists incorrectly identified whether their state required mandatory reporting, compared with approximately 19 percent of neurologists (Vogtle et al., 2007). These differences are worth noting, since many people with epilepsy seek care and management of their disorder through primary care providers (Fountain et al., 2011). Regardless of specialty, all physicians, nurses, physician assistants, and others who provide patient education for people with epilepsy need to be knowledgeable about driving laws and risks and be prepared to effectively counsel patients on these topics.

When educating and counseling patients, clinicians should recognize the links between driving, independence, and quality of life and should be prepared for an honest discussion and a potentially emotional or negative response if the patient is counseled not to drive (Drazkowski, 2007a,b). Box 6-4 provides topics for clinicians to consider in educating patients with epilepsy about driving.

Studies clearly indicate a lack of awareness in clinicians and patients about driving laws and regulations; there is a need for increased counseling and patient education. Gaps in clinician knowledge could be closed through a variety of mechanisms, including the implementation of a performance measure recommended by AAN stating that all epilepsy patients should be counseled at least once a year about "context-specific safety issues, appropriate to the patient's age, seizure type(s) and frequency(ies), occupation and leisure activities, etc. (e.g., injury prevention, burns, appropriate driving restrictions, or bathing)" (Fountain et al., 2011, p. 96). If the per-

Box 6-4 DISCUSSION POINTS FOR EDUCATING PATIENTS ABOUT DRIVING

- Know and explain the applicable legal requirements in your jurisdiction
- Allow enough time to counsel patients and answer questions
- Be compassionate and understanding of the patient's concerns and circumstances
- Use clear communication and be frank about the risks and consequences of driving
- Explain the risks of driving, including risks associated with seizures, and how comorbidities and side effects of seizure medications may affect driving ability
- Remind the patient of the potential consequences of driving illegally (e.g., possible prosecution or litigation following an accident and denial of insurance claims)
- Be aware of ancillary risk factors that may increase the likelihood of a person with epilepsy driving despite legal limitations and advice not to, such as having a valid driver's license, being employed, or not having experienced a seizure-related accident
- Be aware of and discuss local transportation services (e.g., public transportation, ride sharing or carpools, transportation for people with disabilities) as alternatives to driving
- Document the discussion and advice in the patient's health record
- When possible, provide written information on driving and advice to the patient
- Revisit the topic of driving with the patient in subsequent visits

SOURCES: Drazkowski, 2007a,b; Elliott and Long, 2008; Webster et al., 2011.

formance measure is adopted, implemented, and specific enough to include mention of driving restrictions, the potential impact could be significant if it were followed consistently: clinicians would be more likely to learn the state laws and restrictions in order to counsel their patients, the rates and regularity of patient counseling would increase significantly, patient awareness about safety issues could increase, and the topic would be revisited on an annual basis and messages about safety would be reinforced.

Transportation and Quality of Life

I thought I was well adjusted, but as I got older, living with epilepsy became more difficult. Not being able to drive because of my epilepsy has always been difficult. It seems like such a little thing, but it has been a major factor in making decisions on where we live, where I work, who will employ me, what activities my son can participate in, who goes to the grocery store, etc. I qualify for a reduced fare card for the bus, but it

limits where I go, the days I can go, and the times I can leave and arrive at a destination.

–Sabrina Cooke

Fortunately, I've had a great support system, but over the years, it's been difficult to get around since I can't drive.

–John Gambo
(lives in a rural area where public transportation is not an option)

When people with epilepsy are not able to drive, they must rely on public transportation or family, friends, and caregivers to get where they need to go. Many U.S. cities have a public transit infrastructure, but these options are not always reliable or timely. Lack of local transportation options other than driving was cited by almost half of people with epilepsy in one study (Elliott and Long, 2008). For individuals who live in less urban areas or rural regions, access to transportation may be an even greater challenge.

Connections have been made between social support and access to transportation. For example, a survey of African American women with epilepsy indicated that those individuals with a strong social network were more likely to have access to needed transportation (Paschal et al., 2005). Approximately three-quarters of people with epilepsy believe that their family and friends would be supportive of changes to their driving patterns (when and where they drive). However, 40 percent said that they did not have family or friends available to help provide transportation (Elliott and Long, 2008).

For many people with epilepsy, the ability to drive legally is an integral part of gaining and maintaining employment, and a valid driver's license is needed for some jobs. Additionally, getting to and from work is a challenge for many people and usually requires some form of transportation. Employment is a principal reason that people with uncontrolled epilepsy continue to drive (Bautista and Wludyka, 2006).

Driving and transportation also play a role in access to health care services, including keeping appointments with health care providers and picking up prescriptions. People with epilepsy and clinicians alike cite transportation as a significant barrier to accessing needed care (Hawley et al., 2007; Paschal et al., 2005; Personal communication, C. A. Tubby, AES, June 28, 2011). A recent study explored the connection between transportation and medication adherence—a key factor in managing epilepsy and seizure frequency (Welty et al., 2010). Approximately half of respondents who were not able to drive reported challenges with transportation as a barrier to getting medication on time. In fact, more than a fourth indicated that they believed they had had a seizure as a result of not being able to obtain their prescription in a timely manner.

HOUSING

Housing issues for people with epilepsy are primarily focused on meeting the needs of individuals who are physically or intellectually disabled (e.g., from injuries, from seizures suffered during brain development, or due to comorbid conditions). Another potential area of concern is housing options for older adults with epilepsy. A review of housing-related studies relevant to epilepsy found limited data on the extent and nature of housing needs (van Blarikom et al., 2006). A study of living arrangements for people with intellectual disability in Europe found that higher numbers of people with epilepsy lived in staffed residences versus unstaffed ones (Martínez-Leal et al., 2011). Van Blarikom and colleagues (2009) noted the higher staff-to-resident ratios needed by people with more severe forms of epilepsy, some of whom also had intellectual disabilities.

The Fair Housing Act as amended in 1988 prohibits housing discrimination on the basis of disability (U.S. Department of Justice, 2005). The disabilities that people have may range widely in severity and complexity, yet the law's overall goal is for individuals to have equitable housing options that meet their needs and maximize independent living and functioning. The experience of the intellectual disability community in housing is long standing, and recent efforts have focused on implementing a range of community-based housing settings, including supportive and independent group homes (Lakin and Stancliffe, 2007; Mansell and Beadle-Brown, 2009; Wong and Stanhope, 2009).

Many nonprofit organizations help link families and individuals with appropriate housing options. For example, the Jewish Foundation for Group Homes has 22 group homes in the Washington, DC, area that provide housing for people with disabling conditions, including epilepsy (Rubin, 2011). The organization also provides a range of support services and a 1-year transitional program for individuals moving out of the school system or other programs. This transitional program focuses on self-sufficiency, community inclusion, and pre-vocational planning (Rubin, 2011).

Continuing these and other efforts to help people with epilepsy with their housing needs can improve quality of life. This is another area where the committee believes collaborative efforts of epilepsy organizations with disability organizations and other disease-specific organizations could be advantageous. Innovative housing models, including those that focus on older adults with disabilities, need to be explored and championed by nonprofit organizations, public–private collaborations, and government agencies.

SEIZURE FIRST AID TRAINING

Attention to first-aid training that includes seizure recognition and response is particularly important for personnel in school and day care settings, nursing home and long-term care staff, employers, and community service staff members. Although many public school teachers receive some first-aid training, the limited, and somewhat dated, research available suggests that emergency training generally, and seizure training for school staff, more specifically, may be lacking (Gagliardi et al., 1994; O'Dell et al., 2007a; Sapien and Allen, 2001). Staff of day care facilities often have training in cardiopulmonary resuscitation (CPR) and first aid, with seizure response specifically identified as a training need for some child care staff in the recent guidelines for early care and education programs published by the American Academy of Pediatrics, American Public Health Association, and National Resource Center for Health and Safety in Child Care and Early Education (AAP et al., 2011). The American Heart Association and American Red Cross Guidelines for First Aid (Markenson et al., 2010) and the National Guidelines for First Aid Training in Occupational Settings (NGFATOS, 2002) include seizure first aid.

Areas that require increased attention include more current and nationally based explorations of the extent to which teachers, day care workers, nursing home and long-term care staff, coaches, social workers, and other community service workers receive initial and refresher instruction in seizure first aid and feel confident in providing seizure care. Further explorations of the extent to which CPR and first aid training programs provide sufficient content and information on seizure recognition and appropriate response are also necessary.

IMPROVING COMMUNITY-BASED PROGRAMS

As introduced in Chapter 4, the committee supports an approach to service design and delivery that focuses on the specific health care and community service needs of the individual. Making this approach work involves changes in the organization of health care, strong links between health care and community services, and the efforts of many engaged and committed individuals and organizations. It requires familiarity with the range of available services, knowing how to access those services, and having the time and resources to make those connections or help people with epilepsy do so. Further, this approach emphasizes the importance of the family and the need to support family members and other caregivers.

Community-based programs may be epilepsy-specific or they may address needs of people with a range of health conditions. For example, many epilepsy-specific programs at the community level are affiliated with the Epilepsy Foundation. Initiatives of other epilepsy-focused organizations

are also an important part of community efforts, generally providing information and referral, individual and family support, advocacy, and education. Epilepsy-specific employment assistance, camps, and school support programs may also be offered, and many community-based organizations have strong partnerships with a range of state agencies and other nonprofit organizations.

Other community agencies offer various types of assistance (including housing, employment, transportation, counseling, and other services) to people who have a wide range of health conditions or disabilities. These agencies have the potential to help people with epilepsy; again, however, their expertise and available resources vary. The types of services are usually targeted to people who are most severely affected by epilepsy or to specific groups of individuals, such as children, older adults, people with intellectual developmental disabilities, or those with head injuries.

The needs of people with epilepsy and their families span a number of state and federal departments and agencies, and local organizations can often help identify how to obtain this assistance. A central website (www.disability.gov) serves as a guide to federal and state government resources in a variety of areas of concern to people with disabilities.

Next Steps for Community Services

Moving forward with improving and sustaining community services is vital to the well-being of people with epilepsy, particularly those with cognitive and physical disabilities. Several areas discussed below indicate where focused efforts would help improve quality of life and access to services. As discussed throughout this chapter, individual, family, and community resources can help reduce the negative effects of epilepsy and associated comorbidities on the quality of life of individuals with epilepsy and their families (Figure 6-2).

Bridging the Gaps—Making the Connections

Recognizing the complexity of the services needed by some people with epilepsy and their families, the committee urges increased attention to developing innovative approaches for navigating the myriad of resources. Both professionals and lay volunteers can bridge the gaps between people with epilepsy and community services, as well as provide links and referrals to other services. Rehabilitation counselors frequently work with adults who have epilepsy in vocational rehabilitation programs or they may be employed by hospitals and schools to help people with psychosocial adjustment and coping, as well as educational and vocational planning and services. Social workers and case managers are employed in a

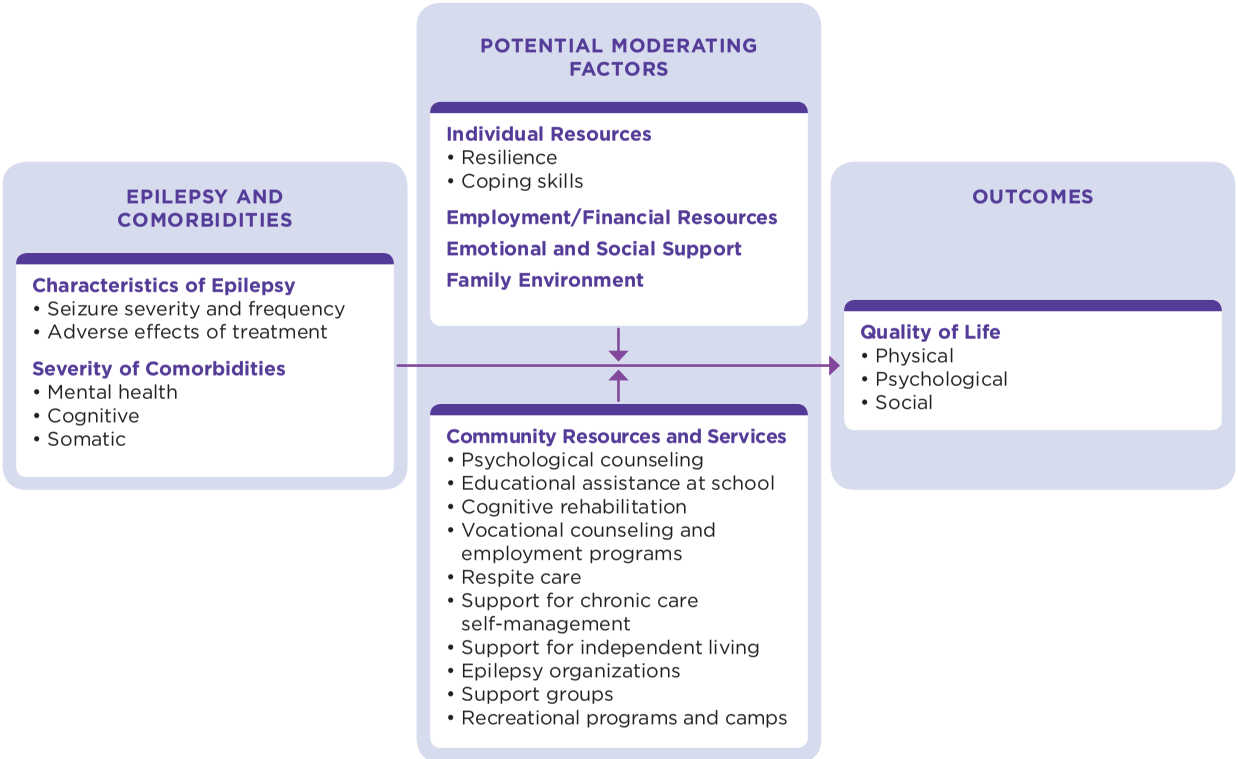

FIGURE 6-2
Factors integral to quality of life for people with epilepsy.

number of settings—often in health care, educational, and social services settings—to give support and counseling, coordinate referrals, provide case management, and establish links with community services. Ensuring that these professionals are knowledgeable about epilepsy and aware of epilepsy-specific resources is critically important. Continuing education and training sessions offer opportunities to provide information about epilepsy, as does working with relevant counseling and social work professional organizations.

Drawing on the wealth of experiences gained in navigating the array of services is another way to help individuals or families facing a recent diagnosis of epilepsy. Patient or parent navigators are often volunteers who provide their insights and expertise and work with the newly diagnosed patient and their family over the course of weeks or months to help them become connected to needed services (Chapter 4). Community health workers or lay health educators, including promotores de salud, often develop a specialty in a particular condition, including epilepsy; speak the language of the patient and family population; and build strong ties with the health and social services sectors.

Clarifying Eligibility

While services provided by Epilepsy Foundation affiliates and other epilepsy-specific organizations are open to any person with epilepsy or seizures, eligibility for other programs may be related to level of disability (e.g., Social Security Disability Insurance, Medicare, special education), income (e.g., Medicaid and other financial assistance programs), age (e.g., Child Services, Children's Health Insurance Program, educational assistance, older adult services), need (e.g., vocational programs, respite care, independent living, group homes), or comorbidity (e.g., mental health services, head injury services). Not all of these programs have clearly defined and detailed eligibility requirements. People with epilepsy often "fall between the cracks," especially if they do not have a developmental disability or mental health condition that fits specific, often narrowly defined, criteria. Because epilepsy can be a hidden disorder, with unpredictable periods of disability that may or may not affect functioning every day, it may not fit the eligibility definitions or criteria for some programs. Efforts are needed to identify those programs whose eligibility requirements should be broadened or revised and to work with program officials and epilepsy policy and advocacy organizations to make the appropriate changes, taking into account the spectrum of severity of epilepsy and its comorbidities.

Building Sustainability Through Partnering

Community nonprofit programs are often transient and depend on charitable donations and volunteers to run critical programs. Although agencies that receive federal or state funding have been considered more stable than nonprofit organizations that rely solely upon charitable donations, this is changing rapidly. The ability of community services agencies of all types to sustain their activities over time and meet the needs of their constituencies must be strengthened through innovative partnerships. Epilepsy organizations are well poised to build relationships and forge advocacy partnerships with organizations whose missions are to help people with other chronic diseases, especially other neurological disorders and health conditions that are frequently comorbid with epilepsy. Finding ways to work together to strengthen existing programs and identifying innovative approaches to coordinate use of resources will be critical in responding to constrained government and charitable dollars.

Finding Innovative Approaches to Expand Access

The availability and sustainability of community resources varies across geographic regions and between urban and rural areas. For example, the lack of public transportation and inability to drive can leave rural and suburban individuals with epilepsy unable to reach appointments and access community resources. As discussed in Chapter 4, telemedicine and local clinics may help ease some of the transportation challenges. Access concerns, particularly regarding public transportation, need to be brought to the attention of state and local transportation programs and other relevant programs so that people with epilepsy have access to transportation resources.

Establishing Links with Health Care Providers

While previous chapters have stressed the role of health professionals in the care and lives of people with epilepsy, there is a critical gap in the lack of awareness of professionals about community resources. Even when health professionals know about community services, they may not have the time, expertise, or resources to connect patients and families with the appropriate agencies. As noted in Chapter 4, epilepsy centers need to develop alliances and partnerships with community agencies to establish referral mechanisms to enable patients and families to obtain the help they need. All providers would be aided by greater use of—and funding for—community health workers or professionals who can make vital connections with community resources, as described above.

Evaluating and Disseminating Community Service Programs

Applying more resources to evaluating community programs and services will allow best practices to be identified and disseminated. Evaluations typically focus on process measures (e.g., number of brochures distributed), rather than the health, quality-of-life, and economic outcomes of community services. Comparing services and programs for effectiveness may be difficult for a number of reasons, including differences in outcome measures, audience, and size. In-depth evaluations that examine impact on quality of life can be challenging and costly to conduct. Finding ways to help community service organizations and agencies evaluate programs in an effective and informative manner is a priority and can provide the accountability that is needed.

Further, once effective programs are identified, resources may be insufficient to fund and implement wide-scale outreach and dissemination of the program models. For example, as described above, research has shown significant differences in the effectiveness of various epilepsy-specific vocational program models, yet efforts to disseminate and replicate the more robust programs are often lacking.

Enhancing Support to Families and Caregivers

Efforts to improve community programs and services for families and caregivers are needed in three critical areas identified by the committee:

1. *Knowledge*—Families and caregivers who face the challenges of caring for someone with epilepsy, especially severe types of epilepsy, need to be informed about the disorder, its comorbidities, the treatment options, the paths to obtaining high-quality health care, and available community resources (Chapter 7).
2. *Supportive services*—Parent, sibling, and caregiver support groups help family members share their experiences and draw on the experiences of others. In addition to in-person support groups and discussions, online social networks and web connection tools can be a source of assistance. Respite care is an essential supporting service for families with significant caregiving responsibilities.
3. *Advocacy*—Promoting the rights and needs of people with epilepsy and raising awareness about this disorder are vital to progress in preventing, treating, and curing epilepsy. People with epilepsy, their family members, and their caregivers can often be the first and most insightful source of information regarding epilepsy and can inform teachers, employers, colleagues, friends, and extended family as well as work to promote improved community services. For

example, parents can be advocates for their child to access school services and ensure that teachers are informed and competent in meeting the child's needs. Advocacy can also take place through informing policy makers and decision makers about epilepsy and the needs facing people with it. Advocacy can be difficult, given that epilepsy is a complex, highly variable, and often misunderstood disorder. Efforts to improve the skills of people with epilepsy, their family members, and caregivers who are interested in honing their ability to be effective advocates can be integrated into self-management programs, support group training, and other educational campaigns and programs.

CONCLUSION

People with epilepsy and their families face an array of challenges to daily living that vary with the severity and nature of the epilepsy disorder and may change as the individual grows older. The negative effects on quality of life can be severe and involve family and social relationships, academic achievement, and opportunities for employment, housing, and the ability to function independently. Family and community support are critical across a range of services. As a result, the committee urges improvements in community services and programs to ensure that they are

- individually centered to meet the needs of the person with epilepsy;
- locally focused, taking into account the full range of resources in the area;
- easily accessible;
- thoroughly evaluated;
- closely linked to health care providers, particularly epileptologists and epilepsy centers; and
- innovative and collaborative in working with organizations and agencies focused on other neurological and chronic conditions or on similar service needs.

Chapter 9 provides the committee's research priorities and recommendations for improving community services. Many epilepsy-specific and non-epilepsy organizations are involved in community services, from transportation to employment to education to recreation. Collaborations are needed that tap into the energy and dedicated efforts of individual organizations and that work to coordinate and evaluate ongoing programs and identify best practices for community services for people with epilepsy. Once best practices are identified, they need to be widely disseminated. Instilling the use of performance indicators will provide benchmarks to assess prog-

ress in community services. Of particular concern are ensuring that children with epilepsy have opportunities for early identification of academic and social problems and are provided with creative approaches to promoting academic achievement and strong social relationships. Improved collaborations with mental health services are highlighted because current U.S. health system approaches can raise disconnects between clinical and mental health services. Innovative and financially attentive approaches to community services—such as a 24-hour nonmedical help line for people with epilepsy and their families or ensuring the availability of local transportation—can build on and contribute to efforts by organizations and programs for other chronic health conditions. A strength of the epilepsy community is the depth and number of epilepsy organizations and involved individuals; building on and coordinating their work is critical to further improvements in quality of life for people with epilepsy.

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7

Educating People with Epilepsy and Their Families

Accurate information for individuals with epilepsy and their families, education about the consequences of epilepsy, and skills development in self-management are essential components for helping individuals become better partners in patient-centered care. People with epilepsy and their families are often not educated about epilepsy's risks, including injury and mortality. Parents of children with epilepsy need information about the disorder and available support resources. Children and youth with epilepsy, as they get older, need increasing information about the disorder and its implications for their future. Adults' information priorities relate to employment, driving, and management of stress; and women need information about hormonal influences on the disorder and the potential effects of seizure medications on pregnancy. Older adults also may have specific information needs, given the likelihood they are taking medications for other chronic health conditions and have an increased risk of falls. People often rely on health care providers for this information, and a wealth of information is offered in written form and online. However, research suggests that both printed and online epilepsy information is written at too high a literacy level. Actions needed to improve education for people with epilepsy and their families include evaluating available educational resources, such as Internet resources and tools; expanding the reach and dissemination of available resources; engaging people with epilepsy and their families in developing and testing educational resources; evaluating, replicating, and expanding the use of self-management programs; and exploring new opportunities for improving education, such as a centralized web resource to connect people with epilepsy to reliable websites and a certification program for epilepsy health educators.

> *Our introduction to epilepsy came when we were abruptly woken to the sound of Savannah shaking and gagging. Doctors called her seizures attacks and spells, but never seizures. . . . [A]s a family living with these [epilepsy] statistics, what do we need? In the early years, we needed the facts—like the fact that approximately 33 percent of people with epilepsy don't respond to treatment. We lost a great deal of trust in doctors because of their choice to censor.*
>
> –Tracy Dixon-Salazar

The diagnosis of epilepsy, although given to an individual, affects the entire family and its constellation of friendships and other relationships. At onset all are confronted with the immediate need to learn about the disorder and its management. Receiving helpful information and education[1] in the diagnostic phase of a chronic health condition can facilitate coping, because early perceptions may affect long-term adjustment to the condition (Johnson, 2003). Living with epilepsy, its unpredictable seizures, and its comorbid conditions presents many challenges over time. Again, continued educational efforts can play a key role in helping people learn to live with and understand epilepsy and its effects over the life span. Thus, individuals and families need education and skills building throughout the course of the disorder, particularly during times of change, such as an increased frequency of seizures, changes in treatment (e.g., switching medications, starting a new treatment option, discontinuing a medication or other treatment option), and major life transitions (e.g., from youth to adulthood, from adulthood to older adulthood).

This chapter describes goals and priorities for educating people with epilepsy and their families, their knowledge acquisition needs across the life span, and methods through which individuals and families currently learn about epilepsy. It reviews different models, programs, and approaches to providing epilepsy education that have been developed and contrasts them with educational efforts in other chronic disease fields, in order to identify strategies for improvement.

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[1]For this report, the committee conceptualized awareness, information, education, and skills building as representing a rough continuum of knowledge development regarding epilepsy. *Awareness* is often the first step in knowledge development (discussed further in Chapter 8) and can be targeted to reducing stigma. For some diseases and conditions, awareness suffices for people in the general public. *Information* is what the public, to be well informed, needs to know about epilepsy (or other common medical conditions). Information tends to be general but suffices for most people not involved in the care or supervision of individuals with epilepsy. *Education* is the goal of efforts to provide more in-depth knowledge that increases understanding, decision-making capacity, and preparedness for action among people with epilepsy, families, and caregivers. *Skills-building* efforts are aimed at helping people acquire the specific capacities to carry out certain tasks. In the context of epilepsy, skills-building is often aimed at improving self-management and care provided by family members or other caregivers and begins with education.

GOALS AND PRIORITIES FOR EDUCATION

In conceptualizing goals for patient and family education,[2] the committee considered recommendations for health care from the Institute of Medicine in *Crossing the Quality Chasm: A New Health System for the 21st Century*. The report recommends that health care in the 21st century be patient centered, which involves health care providers' partnering with patients and families so that the care provided "is respectful of and responsive to individual patient preferences, needs, and values and [ensures] that patient values guide all clinical decisions" (IOM, 2001, p. 6). As described in Chapter 4, patient-centered care is the committee's foundation for an epilepsy care model. The medical literature supports the importance of a patient-centered approach and indicates that people prefer patient-centered care. It even suggests which aspects of patient-centered care are most important to them. For example, a study of UK patients found that three important components of a patient-centered approach were "communication, partnership, and health promotion" (Little et al., 2001, p. 468). For patient-centered care and physician-patient partnerships to work, consistent, relevant health education efforts for patients and families are required.

Cochrane (1995) emphasizes that epilepsy education helps people with epilepsy become self-confident, competent in self-management, aware of their needs, and able to access resources to meet their needs—in other words, it helps them become better partners in patient-centered care. Moreover, having accurate, in-depth information about epilepsy helps people better understand the disorder, prevents misconceptions, and reduces concerns about stigma. Finally, epilepsy education helps promote optimal well-being and quality of life. The committee's vision is for all individuals with epilepsy and their families to have access to relevant and usable knowledge to meet their individual needs and allow them to participate effectively in patient-centered care, to be competent in the management of their epilepsy, and to attain the best possible physical and emotional well-being.

UNDERSTANDING INFORMATION NEEDS

In patient-centered care, the specific health and quality-of-life needs of people with epilepsy and their family members must be paramount in guiding the care provided by health professionals; similarly, the information,

[2]As noted in Chapter 1, terminology is a challenge for people with epilepsy and for the field in general. The committee was purposeful in the terms used throughout this report. The committee recognizes that people with epilepsy and their families should not always be identified as patients, and throughout the report individuals are usually referred to as patients only when there is a direct intersection with health care providers or the health care system. However, for the sake of brevity, the committee uses the phrase "patient and family education" or "patient and caregiver education" in this chapter.

knowledge, and skills-building needs of patients and families must guide educational efforts.

Lack of Knowledge and Familiarity with Epilepsy

At the time of epilepsy onset and diagnosis, most patients and families probably know as much about epilepsy as the general public does, and their knowledge does not always improve in the period following diagnosis (Elliott and Shneker, 2008). Literature reviews and U.S. surveys show that knowledge about epilepsy among the general public is low (Chapter 8):

- An analysis of the 2002 Porter Novelli HealthStyles Survey results concluded that only about one-fourth of respondents believed they were knowledgeable about epilepsy, and only about one-third thought they knew what to do in the event of a seizure (Kobau and Price, 2003).
- A large telephone survey of U.S. Spanish-speaking adults found a similar lack of information about epilepsy and many misperceptions about the causes of seizures, beliefs that people with epilepsy were dangerous, and the use of unconventional treatments such as vitamins, herbal remedies, and spiritual healing (Sirven et al., 2005).
- According to Paschal and colleagues (2005), lack of knowledge and misperceptions about epilepsy in the African American community increase the stigma burden on African Americans with epilepsy. Moreover, people with epilepsy reported they had to spend a substantial amount of time teaching family members about their disorder.

Research consistently demonstrates that people with epilepsy themselves do not have a solid understanding of basic information about the condition, including knowledge about their diagnosis, seizure precipitants or triggers, specific seizure type(s), the purpose and potential side effects of seizure medications, safety concerns, and the risks and potential consequences of seizures (Bishop and Allen, 2007). In one of the few U.S. studies that examined knowledge about epilepsy among people with the disorder, less than 60 percent of the questions were answered correctly (Long et al., 2000). Thirty percent of respondents believed that epilepsy is contagious or a type of mental disorder. Some of this misinformation had the potential to affect personal safety; for example, 41 percent of people with epilepsy believed that something should be put in the mouth of the person having a seizure, 25 percent thought that women should discontinue medication when they are pregnant, and 25 percent believed it is safe to drive if they

double their medication dose before driving, do not drive alone, or pull over when they feel a seizure coming on (Long et al., 2000).

When children lack knowledge about epilepsy, they are more likely to be worried and to have more negative attitudes about having epilepsy (Austin et al., 2006b). Moreover, when parents of children with epilepsy lack adequate knowledge or hold inaccurate beliefs about epilepsy, they may develop negative attitudes and reduced expectations for their children (Frank-Briggs and Alikor, 2011).

Knowledge Needs of All People with Epilepsy and Their Families

The literature indicates that all individuals with epilepsy and their families need to receive some level of education about the disorder, especially as it relates to each person's specific diagnosis and treatment plan. It is especially important that individuals with epilepsy and their families be given, preferably in writing, specific information about their syndrome, seizure type, and treatment plan. A review of literature on health information for adults with epilepsy by Couldridge and colleagues (2001) identified specific information needs related to diagnosis and treatment options, medications and their side effects, seizures and seizure control, safety and injury prevention, and common social and psychological problems. Individuals with epilepsy and their families also need to be informed about the full range of comorbid conditions associated with the disorder, including mental health, cognitive, neurological, and somatic disorders (Chapter 3).

People with epilepsy and their family members may have many fears when the diagnosis is made. The onset of epilepsy during childhood can be particularly frightening (Oostrom et al., 2001), and seeing seizures may make parents believe their child's condition is life-threatening (Besag et al., 2005). Children and adults with epilepsy likewise fear that mental health conditions, injury, or death may ensue (Austin, 2000). To manage these fears and prevent unnecessary anxiety, people with epilepsy and their families need complete and accurate information about the comorbidities and mortality risks associated with epilepsy, including sudden unexpected death in epilepsy (SUDEP), suicide, the risks of seizure-related injuries, and the risks of prolonged seizures such as status epilepticus (Ficker et al., 1998; Kwon et al., 2011; So et al., 2009). Patients and families need to be made aware of the risk for suicidal ideation associated with seizure medication, including symptoms of depression and mood changes that should be reported to health care providers (FDA, 2008).

> *My son, Tyler Joseph Stevenson, passed away on January 23, 2011, from a seizure in his sleep at the young age of 20. The more research we do and the interactions with families who have lost loved ones to SUDEP all share that they were never advised that their loved one could die from epilepsy*

or a seizure. I knew in my previous research that people with epilepsy do not normally live as long as others but did not think that Tyler would die so young.

–Mark J. Stevenson

My son, Dallas, at the age of 5, passed away on January 12, 2011, of SUDEP. I and many other parents had never even heard of SUDEP until we lost our child. Physicians don't want to scare parents, so they don't discuss SUDEP, but the medical community has a responsibility to properly inform patients and parents of SUDEP risk factors. The risk factors may not always be controlled, but it is only fair to tell parents the risks that are involved.

–Mylissa Daniels

The majority of families first hear about [SUDEP] upon the loss of their loved one. Realization of a lack of prior knowledge can have a devastating emotional impact, not only for individuals bereaved by a death in their family but also for individuals who first learn of SUDEP after having lived with epilepsy for some time. Education and communication is paramount to prevent this.

–Tamzin Jeffs

During its public workshops, the committee heard testimony from several families who had lost loved ones due to SUDEP; all of the families reported that health professionals had not discussed SUDEP with them, and they advocated for SUDEP education and information for people with epilepsy and their families (see excerpts of testimony above). Additional work is necessary to determine if health professionals need more education and knowledge about SUDEP generally and if they need more education on how to discuss this and other sensitive topics related to risks and mortality with their patients. Hirsch and colleagues (2011) recommended the development of evidence-based guidelines to inform health professionals of "why, when, and how SUDEP should be discussed with people affected by epilepsy" (p. 1937) based on discussion at a 2008 SUDEP workshop hosted by the National Institute of Neurological Disorders and Stroke. Additionally, the efficacy and reach of existing SUDEP educational materials designed for health professionals and individuals with epilepsy and their families needs to be reviewed and additional materials may have to be developed.

Interviews with UK adults with epilepsy indicated a desire for more information about a broad range of disease-related topics, including mortality risks (Prinjha et al., 2005). A survey of UK neurologists indicated that only 30 percent discussed SUDEP with all or a majority of their patients, and one of the most common reasons for such a discussion was that the patients requested it (Morton et al., 2006). Similarly, a UK survey of pediatric neurologists and parents found that 91 percent of the parents desired information about SUDEP, but only 20 percent of the neurologists

consistently provided it to all patients (Gayatri et al., 2010). In this study, 61 percent of parents did not want their children to be told about SUDEP, while 21 percent did. Of those wanting their children to be told, almost half of the parents wanted to be the ones to tell them, and about one-third wanted the health professional to do so (Gayatri et al., 2010).

People with epilepsy and their families also need information about living a healthy lifestyle, not only because of the impact of epilepsy, but also because of the associated physical comorbidities (e.g., diabetes, heart disease, high blood pressure). A survey of adults showed that in addition to information about epilepsy and their treatment, they wanted information on self-management, available social and community resources, support groups, and counseling (Paschal et al., 2007). Box 7-1 provides an overview of these broad information needs. Having access to information about healthy lifestyles and community resources is essential for ensuring that people with epilepsy are able to achieve the best possible quality of life (see also Chapter 6).

In a survey conducted by Paschal and colleagues (2007), concerns about stigma were prominent, with 89 percent of respondents perceiving that the public lacks awareness of and knowledge about epilepsy, 65 percent experiencing stress because of this lack of awareness, and 42 percent reporting stigma in the general public. Feelings of secrecy, shame, and worry about stigma also were identified in a qualitative study of children and adolescents (Lewis and Parsons, 2008). As described in Chapter 6, stigma has been associated with diminished quality of life. Additional work is needed to examine the role that educational materials and programs, support groups, and counseling resources may play in helping individuals and their families successfully cope with stigma and related concerns, such as the fear of having a seizure in public.

Knowledge Needs of Children, Adolescents, and Youth Transitioning to Adulthood

Studies consistently indicate that children and adolescents with epilepsy need increasing knowledge about their condition over time, tailored to their growing ability to comprehend the information and its implications. Empirical evidence suggests that children's information needs are not being met. For example, a prospective study indicated that these needs remained high even 2 years after seizure onset, with 64 percent of children continuing to have questions about epilepsy's causes, 64 percent still wanting to talk to another child who has seizures, and 62 percent wanting more information about keeping safe during a seizure (Shore et al., 2009).

Children and adolescents want to understand and resolve their fears related to epilepsy, to understand how it might affect their future, and to

Box 7-1 EXAMPLES OF BROAD KNOWLEDGE AREAS FOR PEOPLE WITH EPILEPSY AND THEIR FAMILIES

Basic Educational Needs of All People with Epilepsy

- Epilepsy—seizure type, syndrome, causes
- Treatment and management—options, medications, devices, surgery, dietary modifications, side effects, treatment discontinuation, seizure triggers, risk for suicidal ideation associated with medications, other management strategies
- Safety risks—risk assessment, seizure first aid, injury prevention, equipment to prevent injury
- Mortality risks—sudden unexpected death in epilepsy, status epilepticus, seizure-related injury, suicide
- Healthy lifestyle—general health, sleep, fatigue, physical exercise
- Possible comorbidities
    - Mental health (e.g., anxiety, depression, attention problems, behavior problems, psychosis, seizure-like events with a psychological basis)
    - Cognitive (e.g., memory, information processing problems, learning problems)
    - Neurological (e.g., stroke, autism spectrum disorders, migraine)
    - Somatic (e.g., heart disease, bone health)
- Social concerns—engaging new friends, seizures in social settings, telling others, family burden, stigma
- Emotional response—coping, dealing with fears, stress management
- Available informational and community resources—websites, state and local Epilepsy Foundation affiliates, community agencies, health care providers

Specific Educational Needs for Population Subgroups

Children, adolescents, and youth transitioning to adulthood

- School—managing seizures at school, common learning problems, safety, participation in extracurricular activities

learn how to manage it in their daily lives, especially at school (McNelis et al., 1998). A UK study demonstrated that providing information about mortality, including SUDEP, is especially relevant for youth, because of the higher death rates in individuals under age 30 who have long-term epilepsy (Mohanraj et al., 2006). While reluctant to initiate a conversation about sensitive topics such as alcohol use and sexual activity, older adolescents participated in these discussions when health professionals began them (Lewis et al., 2010). However, the researchers found that young people believed health professionals were more interested in providing medical information than in helping with more practical aspects of daily living (Lewis et al., 2010).

Youth transitioning into adulthood need information and knowledge that will help them assume appropriate responsibility for managing their epilepsy and living a healthy lifestyle. However, few studies could be found

- Mental health—attention deficit hyperactivity disorder, autism spectrum disorders, social withdrawal
- Dealing with fears—future, death, mental health conditions, stigma
- Lifestyle management—establishing healthy habits
- Opportunity to discuss sensitive information, such as puberty, sexuality, drugs, and alcohol
- Career planning
- Transition to adulthood, such independence and driving

Adults

- Career and vocational concerns
- Discussions with employers
- Driving regulations and transportation concerns
- Sexual and gender-specific topics, such as reproductive health and family planning, hormonal changes and seizure frequency, effects of seizure medications on pregnancy
- Drug-alcohol interactions
- Impact on relationships
- Independent living

Older adults

- Medication side effects, adverse interactions, and adherence
- Drug-alcohol interactions
- Independent living
- Safety and injury risks

that focused on the needs of this "in-transition" group. Jurasek and colleagues (2010) believe these youth need to be knowledgeable about the following:

- Epilepsy management—Knowledge about their specific epilepsy condition (e.g., specific syndrome, seizure type and triggers) and treatment plans helps them make informed decisions about care.
- Topics that emerge during adolescence—Knowledge about topics such as sexuality, alcohol and drug use, and driving, in the context of living with epilepsy, helps to support informed decision making.
- Living independently—Skills that facilitate independent living are related to (1) education, career, and employment decisions; (2) living a healthy lifestyle, including managing stress and getting sufficient sleep; (3) self-management skills, such as knowing which

health care provider to contact, getting to appointments, knowing how to fill prescriptions, and medication adherence strategies; and (4) obtaining and paying for medications.

Knowledge Needs of Adults

In a large national survey, adults with epilepsy indicated that they have many fears related to seizures or dying during a seizure and that they face specific social challenges, including potential embarrassment about having a seizure in public (Fisher, 2000). Areas in which adults desired more information were related to employment (e.g., discussion of epilepsy with employers), the link between seizures and stress, dealing with cognitive problems, managing their emotions, and sleep and fatigue (Fraser et al., 2011). In another study, adults also needed more information about driving regulations (Couldridge et al., 2001) (see also Chapter 6).

Gender-Specific Needs

The predominant knowledge needs of women and men with epilepsy are summarized in Box 7-2.

Women The specific knowledge needed by women with epilepsy, which may vary by age, has generally received insufficient attention. Because sex hormones can affect seizure frequency, girls and women need information related to hormonal fluctuations and seizure frequency.[3] Further, women of reproductive age need to understand how their epilepsy and its treatment could affect pregnancy. In a UK survey, adult women with epilepsy between the ages of 19 and 44 identified their most important information needs as relating to risks of epilepsy and medication affecting the fetus (87 percent), the effect of pregnancy on seizure control (49 percent), and the risk of their children developing epilepsy (42 percent) (Crawford and Hudson, 2003). For example, recent findings that show an increased risk for congenital malformations and impaired cognition in children of women treated during pregnancy with valproate, a commonly used seizure medication, suggest that all women of child-bearing age need to be kept apprised of the latest research in this area (Harden et al., 2009). Women with epilepsy also have been found to have higher-than-expected rates of sexual dysfunction (Pennell and Thompson, 2009). Among women over age 44, the most

[3]Studies have found higher-than-expected onset of seizures during the year of menarche; in girls with preexisting seizures, 29 percent experienced more frequent seizures during perimenarche (Klein et al., 2003). Because of hormonal fluctuation, some women have a cyclic pattern of seizure frequency associated with their menses that often is unrecognized (Pennell and Thompson, 2009).

Box 7-2 EXAMPLES OF SPECIFIC KNOWLEDGE NEEDS FOR WOMEN AND MEN

- Pregnancy, effects of medications on the fetus, and breastfeeding (women)
- Bone health
- Hormonal states (e.g., sexual dysfunction; fertility rates; for women: menarche, monthly hormonal patterns, menopause, hormone replacement therapy)
- Sexual dysfunction
- Reproductive endocrine disorders (women)
- Driving and transportation
- Employment
- Cognitive problems—memory
- Social concerns

important information needs concerned epilepsy medication and osteoporosis (63 percent), seizure medications and aging (57 percent), and seizure changes during menopause (44 percent) (Crawford and Hudson, 2003).

Men One of the least studied subgroups of people with epilepsy is men. Studies show that men with epilepsy are less likely to be married, they have lower-than-expected fertility rates, and about one-fourth have problems with sexual dysfunction (Pennell and Thompson, 2009). In one of the few studies examining the perceptions and experiences of adult men with epilepsy, 18 percent rated themselves at the highest level of knowledge about the condition, but 25 percent said they have a low level of knowledge (Sare et al., 2007). In that study, the men's most common concerns related to limitations on driving and employment. More than half of the men reported that their epilepsy affected them either "a lot" or "some" in other areas, such as memory problems, confidence, ambition and plans for the future, sense of self-esteem, overall health, social life, and quality of life. Finally, more than half indicated that they worried about the possibility that their children might inherit their epilepsy.

Knowledge Needs of Older Adults

The education needs of older adults with epilepsy, their family members, and other caregivers are poorly understood and underexplored (Martin et al., 2003). The committee found few studies that considered them. Likely areas for education were identified by extrapolating factors that are unique to older adults with epilepsy. For example, because older adults are especially vulnerable to the adverse effects of medication (Leppik, 2006), they need education about the side effects of seizure medications, particularly given the likely complications of aging-related factors, such as

memory impairment, complex multidrug regimens, and difficulty affording medications (Rowan, 2000).

An important concern among older adults is avoiding fall-related injuries, which may result in skeletal fractures. Risks for fractures are significantly higher in people with epilepsy than in the general population (Donald and Bulpitt, 1999; Gaitatzis et al., 2004; Tinetti and Williams, 1997) (Chapter 3). In addition to seizures, contributing risk factors for falls include female gender, polytherapy, side effects of seizure medications (including dizziness or ataxia), and coexisting neurological conditions and deficits (Fife et al., 2006; Mattson and Gidal, 2004). The high prevalence of osteoporosis among older adults increases the risk of injury when falls occur (Cohen et al., 1997; Pack and Morrell, 2001). In a recent community-based survey of older adults living with epilepsy, Martin and colleagues (2005) identified that driving and transportation and medication side effects were the most frequently cited concerns, followed by personal safety, medication costs, employment, social embarrassment, and memory loss. Information about independent living resources and housing modifications to enhance and increase personal safety at home was also indicated.

Additionally, consideration should be given to the educational needs of older adults who are newly diagnosed versus those of older adults who were diagnosed at an earlier age and who have lived with epilepsy for many years. Although few studies have been conducted to assess the knowledge needs of older adults, as mentioned above, individuals who have lived with epilepsy for a long time and who are transitioning from adulthood to older adulthood may need information on how aging could affect their epilepsy and treatment regimens (e.g., necessary dosage adjustments). Older individuals with new-onset epilepsy may need basic information about epilepsy, such as seizure type, treatment side effects, and safety. For example, if their seizures developed as a result of another condition, such as a stroke or Alzheimer's disease, they also may require information about the interplay of their condition and epilepsy.

Education Needs of Parents and Other Caregivers

Research demonstrates that families of children with epilepsy function less well, experience more problems in parent-child relationships, and show more maternal stress and depression than families of children with other chronic conditions (Rodenburg et al., 2005). Studies show that parents of children with epilepsy experience high rates of stress, anxiety, and depression, particularly when the child has a comorbid condition such as a behavior disorder or intellectual disability (Buelow et al., 2006; Chiou and Hsieh, 2008; Ferro and Speechley, 2009; Lv et al., 2009; Mu, 2005; Wood et al., 2008). Children's depression and learning disabilities can significantly

increase the stress of parenting (Cushner-Weinstein et al., 2008). Parents need information and strategies that can help them come to terms with having a child with epilepsy so that they, in turn, can help their children cope more effectively (Austin and Tooze, 2003). Families especially require reliable information about accessing services to meet their children's needs (Mu, 2008; Nolan et al., 2008; Wagner et al., 2009; Wu et al., 2008), communicating with health professionals, interacting with school personnel, and finding support in the community (Buelow et al., 2006; Wagner et al., 2009). In focus groups, parents report needing information about how to coordinate health care among the numerous medical consultants and specialists with whom they interact (McNelis et al., 2007). Box 7-3 provides an overview of the educational needs of parents and other caregivers.

Few studies describe the educational needs of parents with infants or very young children with epilepsy or children with more severe forms of childhood-onset epilepsies, such as Lennox-Gastaut syndrome, infantile spasms (West syndrome), and severe myoclonic epilepsy of infancy (Dravet syndrome). Studies by Nolan and colleagues (2006, 2008) examined how families of children with Dravet syndrome coped across different stages of the disorder. These parents experienced such high levels of stress from the frequent seizures and behavioral problems that the integrity of the parental relationship and other social relationships was threatened. With regard to managing the syndrome, parents reported that they needed help with identifying social and community resources, such as respite care, and that they also needed specific information on developing a protocol for emergency management of seizures (Nolan et al., 2006). They reported that online support groups were helpful to connect them with other families whose children had Dravet syndrome and other severe syndromes (Nolan et al., 2008).

Educational needs of caregivers vary depending on their relationship to the person with epilepsy, their role in providing care, and their emotional needs. Kendall and colleagues (2004) conducted a study of families and

Box 7-3 EXAMPLES OF SPECIFIC EDUCATIONAL NEEDS OF PARENTS AND OTHER CAREGIVERS

- First aid for seizures
- Parenting concerns—overprotection, discipline, accessing needed services
- Emotional response
- Typical child cognitive and psychosocial development
- Sources of age-appropriate information for children
- Resources—respite care, support groups, equipment, assistance in navigating health care, school, and community services
- Advocacy skills

caregivers of older teens and adults with epilepsy and identified several themes related to educational needs. Barriers to receiving information included respondents' lack of confidence in their ability to seek the needed information and health care providers' not recognizing that caregivers have unique information needs. Some caregivers reported that they felt that health care providers did not care about their information needs (Kendall et al., 2004).

Needs of People with Seizure-Like Events

In many cases, seizure-like events include symptoms very similar to the seizures associated with epilepsy, but occur without the electrophysiological changes associated with epilepsy seizures (Carton et al., 2003). These events can be attributed to psychological causes and may occur in people who have a confirmed epilepsy diagnosis as well as those who do not. There is scant evidence of what constitutes appropriate management of seizure-like events that have been identified as not being epilepsy (Martlew et al., 2007), and little is known about the knowledge needs of people with seizure-like events. A study investigating response to diagnosis in patients with these types of events who had been misdiagnosed previously with epilepsy found that the most common reactions to the new diagnosis were confusion (38 percent), relief (21 percent), and anger (18 percent) (Carton et al., 2003). Factors associated with poor outcomes were persistent seizure-like events and responding to the diagnosis with either confusion or anger (Carton et al., 2003). Carton and colleagues recommend that people with seizure-like events that have a psychological basis receive understandable information about the new diagnosis, that their retention of information is checked later, and that they be referred to psychological resources. Box 7-4 includes examples of education needs for individuals with these types of events.

Closing Knowledge Gaps

In general, the committee found substantial evidence that people with epilepsy, their families, and caregivers want more information than they

Box 7-4 EXAMPLES OF SPECIFIC EDUCATIONAL NEEDS OF PEOPLE WITH SEIZURE-LIKE EVENTS

- Information about seizure-like events that are not epilepsy
- Information about treatment
- Emotional support—coping with a new diagnosis
- Resources—psychological counseling

currently receive and that they want to be educated in a manner that best meets their specific situations (see discussion below). Although all people with epilepsy and their families need certain basic information, beyond that, educational needs vary because of the wide diversity in the epilepsies (e.g., seizure type, severity, comorbidities), ages of onset, cognitive abilities, health literacy levels, and cultural and demographic considerations.

The quality and scope of the research literature exploring these knowledge gaps varies, and the committee identified persistent gaps in research to support patient and family education. Across the board, the current research base on the design and implementation of educational programs for people with epilepsy, regardless of demographic group, is insufficient. A number of groups have specific vulnerabilities that educational programs could take into account. For example, recent studies have tied racial and ethnic minority populations' beliefs that epilepsy medications are harmful or only minimally helpful to lower medication adherence (Nakhutina et al., 2011), which may help explain African Americans' lower epilepsy medication adherence in comparison with Caucasians (Bautista et al., 2011). Although more research is needed to clarify these topics, the gaps already identified need to be eliminated.

These gaps might be remediated, at least in part, through targeted patient and family education efforts. Moreover, people with persistent seizures, severe forms of epilepsy, or more severe comorbidities and their caregivers undoubtedly will have relatively greater needs for education. Much of the research conducted on education needs was based on international samples, and findings from these studies might not directly translate to the U.S. population, because of health system, cultural, and other differences.

WHERE, WHEN, AND HOW PEOPLE WITH EPILEPSY AND THEIR FAMILIES RECEIVE INFORMATION

Traditionally, people with epilepsy and their families received information and education about the disorder one-on-one from health care providers. Although many people still prefer to receive health education in this manner (Fraser et al., 2011; Kendall et al., 2004), it is not always practical for today's clinicians to provide extensive education. Consultation times with neurologists and other health care providers are brief, and patients commonly report that provider visits are rushed (Escoffery et al., 2008; Gilliam et al., 2009; Prinjha et al., 2005). In a recent study by Gilliam and colleagues (2009), epilepsy patients' clinical interviews with neurologists averaged slightly less than 12 minutes; Figure 7-1 depicts the proportion of time spent discussing a range of topics. Four percent of a 12-minute visit—

the amount of time spent on quality of life and daily living—amounts to less than half a minute.

Some settings, such as large health care systems and epilepsy centers, may employ nurses who specialize in epilepsy to help provide patient education (see also Chapter 4). However, such personnel are not generally available to people who receive care from primary care providers, general pediatricians, or neurologists in private practice.

The educational content of clinical encounters may be further limited by patient discomfort in asking questions or by other factors that impede effective communication (DiIorio et al., 2003; Swarztrauber, 2004). For these and a number of other reasons, individuals with epilepsy and their families increasingly seek information from sources outside the health care setting. In fact, many providers recommend that patients and families seek information from outside sources to complement their own educational efforts. It is important that health professionals who educate patients and their families in a clinical setting understand the specific information needs and preferences of patients and their families and take into consideration factors related to health literacy and culture, including cultural differences that may exist between them and their patients (Chapter 5).

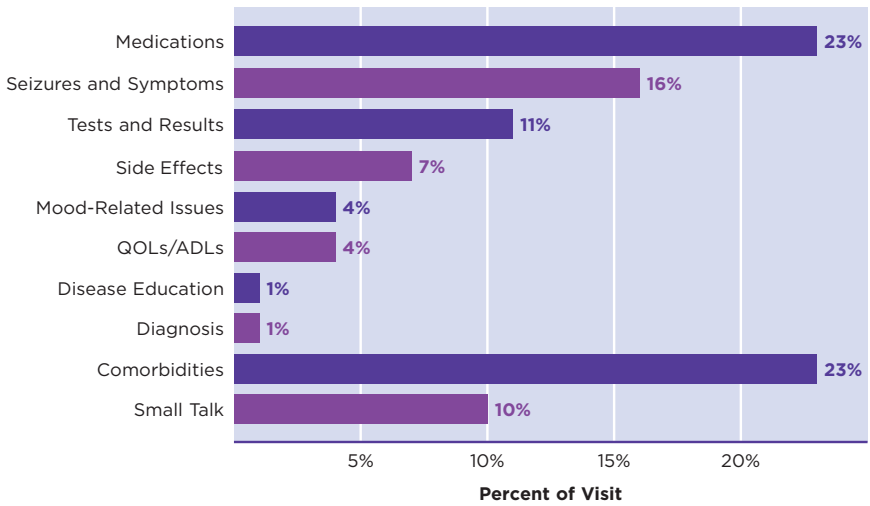

FIGURE 7-1
Topics discussed and percent visit spent on each.

NOTE: QOLs = quality of life; ADLs = activities of daily life.

SOURCE: Gilliam et al., 2009. Reprinted with permission from Elsevier.

Timing, Format, and Delivery of Epilepsy Education

Timing

Few studies have investigated how epilepsy information should be provided, and most such studies were conducted in the United Kingdom. Interviews and surveys provide some information related to appropriate timing, format, and delivery of epilepsy patient and caregiver education. The greatest agreement across studies relates to timing. Although information could be given when a person seeks care for the first seizure, as described below, there is general consensus that education about epilepsy is more effective when provided around the time of diagnosis, inclucing when waiting for diagnosis, at diagnosis, and after the reality of the diagnosis has set in.

Because receiving an epilepsy diagnosis is often upsetting, health professionals must be sensitive to whether the patient and family are sufficiently recovered to be receptive to an educational intervention (Kendall et al., 2004). Even in less stressful situations, patient-provider and family-provider communications can miss the mark, and many efforts have been made to improve them.[4] When discussing epilepsy, clear communication is essential. For example, a recent study found a persistent pattern of seizure medication nonadherence in 58 percent of children with new-onset epilepsy during the first 6 months of therapy; the authors emphasized the importance of providing clear information and education that dispels misconceptions about drug treatment at the time the medication is prescribed (Modi et al., 2011). As discussed below, people with epilepsy also need education to build skills in self-management, which include medication management skills.

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, either around the time of diagnosis or in the presence of SUDEP risk factors (e.g., when seizures persist, when treatment is refused, when generalized tonic-clonic seizures occur) (Devinsky, 2011; Hitiris et al., 2007; Lewis et al., 2008; Mohanraj et al., 2006; Shorvon and Tomson, 2011; So et al., 2009). In the case of young children or people with intellectual disabilities, of course, such information would be provided to family and caregivers.

Research suggests that some information is most useful before it is actually needed; for example, women need information about the effect of epilepsy on pregnancy and the possible effects of seizure medications on the fetus before becoming pregnant (Crawford and Hudson, 2003).

The timing of epilepsy education for young people depends on the youth's ability to understand it and interest in receiving it. Because youth

[4]As one example, the National Patient Safety Foundation's Ask Me 3 campaign (http://www.npsf.org/for-healthcare-professionals/programs/ask-me-3).

are often diagnosed with epilepsy when they are quite young, it is usually parents who need and receive education around the time of diagnosis. Age 13 to 19, when youth are transitioning to adult care, is considered a critical period for them to be educated about epilepsy and to learn skills that help them become responsible for appropriate self-management (Lewis et al., 2010). Finally, there is agreement that education related to living with epilepsy is most helpful if offered repeatedly at regular intervals over time and as needed during changes or transitions, as shown in Box 7-5.

Format and Delivery

Little evidence is available on the best format for education, with the exception that educational materials and information need to be customized to meet individual needs and circumstances, regardless of whether they are presented orally or in writing (Couldridge et al., 2001). In their literature review. Couldridge and colleagues (2001) found that some studies support information being provided in written form, rather than orally, because remembering oral information can be a challenge for people with epilepsy who may also have memory impairment. However, as described below, written materials can also present challenges for the large number of U.S. residents with low literacy and poor health literacy.

People vary as to their preferred format for receiving information. For example, in a study of family caregivers of adults with epilepsy in

Box 7-5 EXAMPLES OF CRITICAL JUNCTURES FOR PATIENT AND FAMILY EDUCATION

- **At diagnosis**
- **During first year**
- **When there is a change or new concerns develop**
  - Developmental status (beginning school, transitioning from pediatric to adult care, transitioning from adulthood to older adulthood, living independently)
  - Seizures (breakthrough seizures, type, frequency)
  - Treatment-related concerns (surgery, change in or discontinuation of medication or other treatment, dietary therapy, alternative therapy, side effects, nonadherence)
  - When treatment fails (reevaluation of options)
  - Health status changes (pregnancy, injuries, other health complications)
  - Life stressors (moving, change in occupation, change in marital status, death or grief)
  - Travel (new environments, time changes)
  - Comorbidities (mental health, cognitive, neurological, somatic)
  - Employment and vocational status

the United Kingdom, Kendall and colleagues (2004) found the majority believed they obtained the most benefit when they received information orally during personal contact with a physician, preferably a neurologist (66 percent). As noted in Chapter 4, telemedicine offers an innovative delivery mechanism for patient care, and its effectiveness in providing patient education warrants further exploration. Telemedicine opportunities may be especially valuable for connecting health professionals and health educators to patients and caregivers who live in rural and geographically isolated areas or to patients for whom travel is difficult.

In their literature review on delivery of information to young people, Lewis and colleagues (2010) found that this population wanted to receive information in an age-appropriate format and that, while the presence of parents can be supportive, their absence can also have a positive impact in that youth may feel more comfortable discussing sensitive topics, such as alcohol use and pregnancy. These young people also wanted to see the same health care provider at each visit, in order to become more comfortable talking with them. Finally, they preferred to receive information in a quiet room rather than during clinic visits, which can be too distracting to attend to the information or to learn skills related to self-management (Lewis et al., 2010). As noted in Chapter 8, electronic media formats (e.g., the Internet, social networking) are very popular among youth and young adults, and they may present an opportunity for educating young people with epilepsy about the disorder and self-management.

Health Literacy Considerations for Educational Resources

Written materials, which are often used to augment a clinical encounter, can be an effective, inexpensive, and easy-to-implement strategy to improve patient and family understanding of a condition or its treatment (Arhan et al., 2009). However, they fall short of their potential when, as is often the case in the United States, materials for adults are written at a ninth-grade reading level or higher, even though the average U.S. adult reads at the eighth-grade level and materials for children and adolescents are written above a fifth-grade level (that is, a level more appropriate for some adults) (Foster and Rhoney, 2002; Safeer and Keenan, 2005). Almost 20 years ago, testing showed that 68 to 73 percent of U.S. parents could read at less than a ninth-grade level, and 28 to 55 percent read at less than a seventh-grade level (Davis et al., 1994). Materials that pediatricians typically give these parents—for example, consent forms, take-home instructions, and medication guidelines—are frequently poorly understood. At that time, the authors noted the trend within the American Academy of Pediatrics and the public health community to create more low-literacy materials. Recent reviews of both print and online epilepsy educational materials indicate the problem

persists, and the reviewers found scant content appropriate for low-literacy individuals and their families (Elliott and Shneker, 2009; Elliott et al., 2007; Foster and Rhoney, 2002; Rajasundaram et al., 2006). One analysis found that materials from general Internet sources and university websites required the highest level of reading ability, while other Internet material from state epilepsy organizations required the lowest (seventh grade, approximately) (Foster and Rhoney, 2002). The authors suggested that the common measures of readability used in their analysis[5] may underestimate the difficulty in understanding health and medical written materials, because such information often contains unfamiliar terms or concepts.[6]

In an effort to provide guidance for developing materials that are user friendly and understandable to broad audiences for all health conditions, the Centers for Medicare and Medicaid Services produced a *Toolkit for Making Written Material Clear and Effective* (CMS, 2011a). Use of the toolkit is intended to provide practical assistance, not strict guidelines. Rather than specifying a target grade level or readability standard, the toolkit urges users to "orient toward the subset of your readers for whom the potential barriers are the greatest, that is, the readers who are less attentive, less interested, less knowledgeable, and less skilled at reading. If you can make your material work well for these readers, it will work well for the rest of your readers, too" (CMS, 2011a). It provides information on assessing the readability of a text and guidance on establishing a robust user feedback program. Similarly, the Centers for Disease Control and Prevention (CDC) has developed an array of materials to help public health entities and other health professionals create clear communications about health topics (CDC, 2011), notably *Simply Put: A Guide for Creating Easy-to-Understand Materials*, which also includes information on how to test the readability of a text. Commercial health literacy testing products also are available, such as those marketed by Health Literacy Innovations or the tests and strategies described in Pfizer, Inc.'s Clear Health Communication Program (Health Literacy Innovations, 2012; Pfizer, 2012).

The National Action Plan to Improve Health Literacy recommends that developers of health educational content of any type (e.g., web, audio, video, print)

- adopt user-centered design (e.g., involve members of the target audience in product design and testing),
- target and tailor communications for specific groups of individuals, and

[5]The Flesch Reading Ease Score and the Flesch-Kincaid Grade Level Score.

[6]Centers for Medicare and Medicaid Services' *Toolkit for Making Written Material Clear and Effective* (described later) includes a useful section on the limitations of using some of the common readability assessment tools in evaluating health education materials (CMS, 2011b).

- assess how well the health care organization is responding to the health literacy characteristics of its patients. (Tools to accomplish this have been developed for hospitals, health centers, and pharmacies.) (ODPHP, 2010)

In addition to having access to clearly written materials, individuals—especially those with low literacy skills—are also likely to benefit from the use of pictures in health communications (Houts et al., 2006). For example, research shows that picture-based communications improve understanding of how to take medications and decrease medication errors (ODPHP, 2010). Key factors to keep in mind when using pictures are to minimize distracting details, use simple language to link to and support the message of the picture, include people from the intended audience and health professionals in designing the pictures (rather than relying solely on artists), and evaluate the effectiveness of the materials, comparing those with pictures to those without (Houts et al., 2006).

The number of people in the United States who have poor health literacy is high; it is estimated that only 12 percent of adults have proficient health literacy skills (IOM, 2004; Kutner et al., 2006). Physicians may recognize the need to identify patients who cannot read and therefore may be unable to follow a complex regimen of seizure medications or other instructions. However, the extent of a patient's health literacy is difficult to assess, and physicians have to be aware of and recognize the effects that low health literacy can have on patients' ability to understand health information related to their diagnosis and treatment (e.g., specific syndrome, seizure type and triggers). Physicians also need to recognize the resulting impact that low health literacy may have on health outcomes.

Sources of Information for People with Epilepsy and Their Families

Most parents navigate [the care] process with very little information. There are costs for that, too, especially for the failure to provide resources and information to patients, families, and care providers.

–Joan Skluzacek

In addition to receiving education from health care providers, people with epilepsy and their families access a variety of other sources for information. Individuals and family members who are knowledgeable about epilepsy serve as important resources for others. Information sources identified in a Canadian study of families of children with epilepsy included health care providers, the Internet, television, radio, newspapers, books, family and friends, families whose members have epilepsy, and epilepsy organizations (Lu et al., 2005). In this study, the average family accessed 3.5 sources recommended to them by their health care provider as well as 4 additional

sources. In another study, Prinjha and colleagues (2005) found that patients received information from health care providers, epilepsy organizations, first aid training, leaflets, books, magazines, newspapers, videos, and the Internet. A UK survey of men with epilepsy that asked about preferences for receiving information found that the Internet was the third most preferred choice, after general practitioners and consultant neurologists (Sare et al., 2007). In this study, 84 percent were more likely to find information on their own, rather than ask health professionals. Sample and colleagues (2006) noted that word-of-mouth was frequently cited in addition to physicians, nurses, and the Internet as sources of information about medications and services.

Role of the Internet in Educating People with Epilepsy and Their Families

As Internet use becomes more widespread, it is an increasingly promising vehicle for delivering health education to people with epilepsy and their families, as well as general information about epilepsy to the public (Chapter 8). The Internet enables provision of information to many people with limited access to other information sources. Helpful information about epilepsy can be found on websites for health care systems and hospitals, on general health information sites such as WebMD, on government websites such as those maintained by the CDC and the National Institutes of Health, and on a host of epilepsy-specific websites run by epilepsy organizations and people with epilepsy and their families (see Box 7-6).[7] A recent survey of individuals participating in an online epilepsy community indicated that participants believed that their online interactions with others provided a number of benefits, including gaining knowledge about epilepsy (e.g., increased understanding of seizures) (Wicks et al., 2012).

Gaps in Internet use are closing, but disparities still exist among people with lower incomes and racial/ethnic minorities. Surveys of Internet use indicate that, nationwide, 96 percent of adults with annual incomes of $75,000 or more use the Internet, compared with 63 percent of those with incomes less than $30,000 a year; additionally, 78 percent of English-speaking Hispanic adults and 79 percent of white, non-Hispanic adults use the Internet, compared with 67 percent of black non-Hispanic adults (Census Bureau, 2012). Population groups disproportionately affected by epilepsy (e.g., older adults, those who are less well educated) are less frequent Internet users: U.S. adults with the lowest Internet use are those 65 and older and those with less than a high school

[7]Box 7-6 contains a list of examples of existing epilepsy-related websites as of March 2012. Due to the dynamic nature of the Internet, websites and website content will change over time.

BOX 7-6 EXAMPLES OF WEB RESOURCES AVAILABLE FOR INFORMATION ABOUT THE EPILEPSIES

- American Epilepsy Society: www.aesnet.org
- Centers for Disease Control and Prevention: www.cdc.gov/epilepsy
- Citizens United for Research in Epilepsy: www.cureepilepsy.org
- Dravet.Org (formerly International Dravet Syndrome Epilepsy Action League): www.dravet.org
- Epilepsy Foundation: www.epilepsyfoundation.org
- Epilepsy Therapy Project: www.epilepsy.com
- Finding A Cure for Epilepsy and Seizures: www.nyufaces.org
- Health Resources and Services Administration's Maternal and Child Health Bureau: www.mchb.hrsa.gov/programs/epilepsy
- The Hemispherectomy Foundation: www.hemifoundation.intuitwebsites.com
- Hope for Hypothalamic Hamartomas: www.hopeforhh.org
- International Bureau for Epilepsy: www.ibe-epilepsy.org
- International League Against Epilepsy: www.ilae-epilepsy.org
- Lennox-Gastaut Syndrome Foundation: www.lgsfoundation.org
- National Association of Epilepsy Centers: www.naec-epilepsy.org
- National Institute of Neurological Disorders and Stroke: www.ninds.nih.gov/disorders/epilepsy/epilepsy.htm
- National Library of Medicine Medline Plus: www.nlm.nih.gov/medlineplus/epilepsy.html
- Preventing Teen Tragedy: www.preventingteentragedy.net
- Rasmussen's Encephalitis Children's Project: www.rechildrens.org
- TalkAboutIt.org: www.talkaboutit.org
- Tuberous Sclerosis Alliance: www.tsalliance.org
- WebMD: www.webmd.com/epilepsy

education. Only 42 percent of adults in these two groups use the Internet (Census Bureau, 2012). Two recent epilepsy-specific studies suggest that Internet access among people with epilepsy varies and is on the lower end of general population ranges. For example, only 51 percent of veterans with epilepsy had Internet access (Pramuka et al., 2010), as did 62 percent of adults recruited from an epilepsy clinic (Escoffery et al., 2008).

Among the many websites devoted to epilepsy information in the United States, Escoffery and colleagues (2008) identified two sites as being the most comprehensive: that of the Epilepsy Foundation (www.epilepsyfoundation.org) and Epilepsy.com (www.epilepsy.com), the public website of the Epilepsy Therapy Project (ETP). Both sites have up-to-date information on epilepsy (e.g., seizures, treatments, medication side effects, pregnancy, school and education, safety precautions, resources), information on living with epilepsy for individuals and families across the life span, strategies for communicating with health professionals, answers to frequently asked questions, and opportunities for e-community programs. The Epilepsy Foundation has developed parts of its website to reach culturally

diverse population subgroups, including African Americans and Hispanics, and many of its pages are available in Spanish. Other websites, such as the International League Against Epilepsy (ILAE) site (www.ilae-epilepsy.org/), provide patient and family educational material in languages such as Spanish, Russian, Farsi, and Chinese. The Epilepsy Foundation's website also includes links to its affiliate organizations as sources for state and local information and support for people with epilepsy and their families. In developing its content, Epilepsy.com provides information at varying levels of detail and complexity.

The Internet has an especially important role for families coping with the more severe epilepsy syndromes. For example, Dravet.org (formerly the International Dravet Syndrome Epilepsy Action [IDEA] League) provides advocacy and support for families with a child who has Dravet syndrome (Black and Baker, 2011). Because this syndrome is so rare, families often feel isolated and have problems obtaining specific information about it. The Dravet.org website includes a social networking function for families, which includes forums in four languages. In addition, the website provides comprehensive clinical information and links to resources (Black and Baker, 2011). As noted in Box 7-6, there are also websites specific to hypothalamic hamartoma, Lennox-Gastaut syndrome (LGS), and tuberous sclerosis complex that provide content on the complicated health needs and consequences of these disorders and support for families. More broadly, Wicks and colleagues (2012) demonstrated that online communities, such as PatientsLikeMe.com, can help connect people with epilepsy; 30 percent of participants did not know anyone else with epilepsy previously, but 63 percent of those participants identified at least one other person through the online community with whom they could openly discuss and share information. Although there are many websites devoted to epilepsy information in the United States, a central, reliable resource that provides a place to which professionals can easily refer patients and their families does not exist. A centralized resource could provide a venue for people with epilepsy and their families to learn about and navigate the wealth of available websites, which may be useful for them to learn more about epilepsy generally and about specific syndromes and seizure types.

To determine the types of information that people are looking for when it comes to the epilepsies, one study (Escoffery et al., 2008) concluded that information was sought in the following areas: general information (43 percent), medication (30 percent), epilepsy type (23 percent), different treatment options (20 percent), updated information (15 percent), social support (12 percent), and other (16 percent). Topics included in the "other" category related to lifestyle, daily living, sleep, diet, stress, pregnancy, and menopause. During the course of its work, the committee reached out to its sponsors and other epilepsy organizations, many of which maintain

websites (examples listed in Box 7-6) with the goal of informing people with epilepsy, their families, and the public about the epilepsies, to gain a better understanding of how their websites are being used. The following organizations generously shared web statistics for the committee's consideration: the American Epilepsy Society, CDC, Citizens United for Research in Epilepsy, ETP, Finding A Cure for Epilepsy and Seizures, ILAE, LGS Foundation, National Institute of Neurological Disorders and Stroke, and Tuberous Sclerosis Alliance. Because of variations in methodologies used to capture statistics and the variation in site content and audiences of the websites, direct comparisons could not be made regarding the number of users and visits or pages viewed. However, in reviewing the available information the committee was able to determine the following:

- There is wide variation among the types of data that can be collected from websites, such as time spent on a page, bounce rate, number of pages per visit, and referral websites.
- Average visits per month to the various websites ranged from approximately 1,000 to more than 360,000, with the most-visited site being geared toward general information for a broad audience.
- Search engines are the largest source of traffic for many of the sites, in a number of cases representing approximately two-thirds of referrals.
- Websites that are able to track how many visitors they receive through social media and visitors using mobile devices noted an increase in traffic from these sources over time.
- Keyword searches and the most-viewed pages vary from one site to another depending on the site content and its audience, for example:

    - General terms and page topics, such as epilepsy, seizure types, and treatment (e.g., medication, surgery, ketogenic diet) and frequently asked questions, were common across many of the websites.
    - Topics related to quality of life, family and caregiving, and schools were popular for users of websites that target families of people with specific epilepsy syndromes.
    - When available, patient-oriented tools and resources, such as seizure first aid, seizure diaries, seizure action plans, and medication information, were popular with users.

Although individuals and families may be trying to find and use health information online, the sites are not often geared to people with low health literacy. Content assessments of the basic consumer education por-

tions of the Epilepsy Foundation website and the Epilepsy.com website in 2007 and 2009, respectively, found that only between 3 and 6 percent of pages were written at a sixth-grade level or lower (31 to 46 percent of the Spanish-language pages on the Epilepsy Foundation website were at that level) (Elliott and Shneker, 2009; Elliott et al., 2007). On the Epilepsy.com website, only 15 percent of pages were at the eighth-grade level or below. In the long run, with additional focus on health literacy, comprehensive content testing with users, and optimization of content based on user feedback, online epilepsy educational resources could be important tools for all individuals and their families, including those with low health literacy. Online resources allow users to proceed at their own pace, and the technology enables written, visual, audio, and video learning experiences (Lewis, 2005). Someday, it may be possible to tailor web-based health information to the learning style and, potentially, language and literacy level of a specific user.

Design guidelines specific to websites are evolving as use of the Internet for health care communications expands to ensure readability for populations with limited literacy (Eichner and Dullabh, 2007). Nevertheless, guidelines that do exist emphasize many of the same themes relevant to health communication in general:

- Keep it simple in design, content, and navigation.
- Highlight important information.
- Develop content that is culturally relevant.
- Take advantage of the Internet's capacity to provide choices and additional information in various forms (e.g., audio transcription).
- Include a simplified search function (e.g., one that can recognize misspelled words).
- Use the most widely accessible formats (e.g., HTML) and be sure the website can be used on both old and new hardware.
- Engage in iterative testing. (Eichner and Dullabh, 2007; IOM, 2009)

There are downsides to health information obtained online, including varying quality of the information, complexity that may lead to misunderstanding, and its sheer volume (Lewis, 2005). To assess quality of Internet content for education about epilepsy in Canada, Burneo (2006) evaluated websites to determine compliance with the Health On the Net (HON) Foundation Code of Conduct.[8] None of the sites evaluated followed all

[8]The HON Foundation, based in Switzerland, has developed the HON Code of Conduct (HONcode). HONcode defines principles for "quality, objective and transparent medical information tailored to the needs of the audience" (Health On the Net Foundation, 2011). Websites can be certified through the Health on the Net Foundation (http://www.hon.ch/HONcode/Conduct.html).

eight principles of the HON Code of Conduct, with average compliance at 3.3. The author of this study highlighted the potential value of the Internet in educating patients and families, which has the potential to help health care providers maximize their time with patients. Another Canadian study of families of children with epilepsy found that Internet sites were the most often used sources of information outside the clinic, and those recommended by a health care provider were judged by families to be the most accurate (Lu et al., 2005). In a review of the literature on how Internet users find, evaluate, and use websites for health information, Morahan-Martin (2004) found that many users are concerned about the quality of the information they retrieve, but their skills in evaluating the material are limited. The author recommended that health professionals specifically recommend sites and be proactive in helping patients and families become better at conducting searches and evaluating and using the information found. However, the committee questions the feasibility of this recommendation given the very short clinical encounters and lack of reimbursement for patient education.

The committee found limited research that would guide health professionals in making recommendations about specific Internet sites to patients and families. The committee has identified this as an opportunity for epilepsy organizations to fill an important gap in patient and family education. These organizations could collaborate on a common website (clearing house) linking to the spectrum of websites that include reliable, high-quality information. The common website could describe the content and types of information found on various websites, along with contact information for the organizations providing it. Information about the common website could be widely disseminated to the full range of professionals who work with people with epilepsy.

Based on its review of Internet sources of patient and family education, the committee concludes the following:

- There is a wealth of reliable and accurate information available online for individuals and their family about the epilepsies.
- Greater attention to health literacy and concepts of clear communications is needed when developing web content.
- Greater attention to the needs of target audiences is necessary to ensure they are able to find the information they want and need.
- Innovative strategies to convey information that is engaging, user friendly, and action oriented and that provides links to other epilepsy resources need to be explored and implemented.
- Epilepsy organizations can take advantage of communications opportunities offered by online communities, social networking, and the increasing use of mobile devices when possible.

Opportunities to Improve Information Delivery

The committee has identified the need for more research to guide the delivery of patient and family education in epilepsy. Individuals and families vary greatly in how they want to receive information, with some wanting it orally, some wanting written instructions, and some being comfortable using the Internet, which suggests that educational content will reach the greatest numbers of people if it is made available in multiple formats. Oral (face-to-face) education could be delivered to small groups, requiring less time from health care providers (Couldridge et al., 2001).

Delivery mechanisms need to take into consideration the age, health literacy level, and cultural background of the target audience. The lack of studies on racial/ethnic minorities' preferences related to the delivery of epilepsy education suggests that research within these populations is especially needed to ensure that efforts are sensitive to potential cultural differences. Research is needed on the level of Internet access among different subpopulations of people with epilepsy (older adults, racial/ethnic minorities), as well as their preferences with regard to sources, format, and delivery of epilepsy education. Studies are needed on relationships between Internet use for education and various clinical or psychosocial outcomes. Epilepsy-specific websites need to be evaluated for their inclusion of information that reflects health literacy and cultural considerations. Knowing which websites are best suited to different population groups would aid health professionals in making recommendations to patients and families. The committee also noted that research on the use of social networking websites for information sharing and obtaining social support for people with epilepsy is needed.

In short, although today there are many more channels for delivering health education about epilepsy, what is not yet known is which channels are the most useful for which purposes. For example, social networking websites may be most effective in providing social support or helping families with practical problems encountered in daily living; epilepsy-specific websites may be most effective in helping individuals with epilepsy and their family understand drug regimens and side effects, because they can be visited repeatedly, or in identifying local resources; and a one-on-one visit with a clinician, in which follow-up questions can be asked, may be the most effective educational approach in initial conversations about diagnosis and in providing the motivation and reassurance to engage in self-management.

MODELS OF EPILEPSY EDUCATION AND SELF-MANAGEMENT

Self-Management: A Critical Goal of Epilepsy Education

Health professionals have been informally educating patients and families about epilepsy for many years using a variety of strategies and supporting materials; however, only in recent decades have formal education models and programs been developed that focus on self-management strategies to improve health outcomes, quality of life, and well-being. "Self-management" is a commonly used term that generally refers to the active involvement of individuals with chronic conditions in their health care (Clark et al., 2010; Lorig and Holman, 2003). Although by definition ("self-") these terms refer to the individual with epilepsy, management is often carried out by family members ("family management"), such as the parent of a child with epilepsy or an adult caring for a parent or other older relative (Grey et al., 2006). Sometimes, a caregiver is not related to the individual at all. Many people with epilepsy may find full participation in self-management beyond their capabilities for any number of reasons—such as age, developmental status, extent of impairment and comorbidities, overwhelming personal situations, or low health literacy—which makes it difficult to understand, take necessary steps, or follow clinical recommendations. As a result, the committee adopted the concept of "optimal self-management," recognizing that participating in health care represents a wide range of possibilities and that what is optimal for one person may be beyond the capacity of another.

The broad definition of self-management for chronic health conditions used by Lorig and Holman (2003) includes reference to both tasks and skills that can be introduced through education. The tasks focus on three areas: managing the medical aspects of the condition, adapting or creating new behavior and new roles that incorporate the condition into one's life, and dealing with the emotional effects of having a chronic condition; and the five skills involve learning to solve problems, make decisions, use resources, develop partnerships with health care providers, and take action. It is important to note that learning self-management skills begins with education and that a critical goal for patient and family education is to help people acquire and master self-management skills. This section focuses on the educational factors and efforts that are necessary to facilitate and promote optimal self-management for people with epilepsy and their families. Over the last two decades, a number of self-management programs have been designed that include educational programs, behavioral and counseling programs, and mind-body techniques (DiIorio, 2011). A number of the efforts focused on education are described below. Chapter 4 includes discussion of PEARLS (Program to Encourage Active, Rewarding Lives for Seniors) and Project UPLIFT (Using Practice and Learning to Increase

Favorable Thoughts), self-management programs that incorporate behavioral, counseling, and mindfulness techniques and are designed to reduce depression among people with epilepsy.

Self-management for epilepsy includes the information and resources that people with epilepsy and their families need to develop skills and behaviors that enable them to actively participate in patient-centered care; it is "the sum total of steps a person takes to control seizures and to control the effects of having a seizure disorder" (DiIorio, 1997, p. 214). The identification of the core elements of self-management for individuals with epilepsy is an evolving process that has been informed by the Living Well Conferences and the work of the Managing Epilepsy Well (MEW) Network,[9] an organization whose mission is to advance self-management in the epilepsy field (AES et al., 2004; Austin et al., 2006a; CDC et al., 1997; DiIorio et al., 2010). Core elements of self-management models often focus on the connections between knowledge, attitudes, skills, and behaviors and individuals' ability to manage seizures, medications, safety considerations, communication, and healthy lifestyle choices (Buelow, 2001; DiIorio, 1997, 2011; Shope, 1980). Some models have been expanded to include skills and knowledge in the following areas: information management, general health status, self-advocacy, development of productive patient-provider partnerships, individuals' ability to manage their lives within the context of having a chronic health condition, and competence and autonomy derived from self-determination theory[10] (Buelow and Johnson, 2000; Clark et al., 2010; DiIorio et al., 2004; Shafer, 1998, 2009; Shafer and DiIorio, 2004, 2006). Many of these elements support the need for a patient-centered approach to education, provide individuals and their families with knowledge and skills that promote competency in optimal self-management, and apply to managing both epilepsy and its comorbidities.

Knowledge and skills necessary for optimal self-management can be divided into two broad categories—epilepsy-specific management and chronic care management. Epilepsy-specific self-management domains relate to managing seizures, medications and treatments, safety concerns, seizure triggers, and comorbidities. The epilepsy-specific knowledge needs of individuals and their family vary, depending the characteristics of seizures and the severity of comorbidities. Other information is useful for all people with epilepsy and their families. For example, they must understand the

[9]The MEW Network is a collaborative research network created through funding from the CDC's Prevention Research Centers and Epilepsy Program. http://www.sph.emory.edu/ManagingEpilepsyWell/http://www.sph.emory.edu/ManagingEpilepsyWell/about/at_a_glance.php.

[10]The self-determination theory is based on the premise that internal and external motivators exist and have varying roles in and influence on individual and social development (Deci and Ryan, 1985).

importance of medication adherence, because nonadherence is a common trigger for the development of status epilepticus (Neligan and Shorvon, 2010) and is associated with higher rates of emergency room visits, hospital admissions, auto accidents, fractures, and mortality in adults (Faught et al., 2008). Similarly, teaching all individuals and their caregivers to keep a record of seizures in a seizure diary or an online tool,[11] such as "My Log" used in WebEase (Web Epilepsy Access, Support, and Education) (DiIorio et al., 2009a), can help identify seizure triggers.

Chronic care self-management education domains relate to knowledge and skills that are necessary for maintaining a healthy lifestyle, having an active partnership with the health care team, and living independently—broad domains that are important to all individuals living with a chronic condition regardless of the specific condition. Table 7-1 provides an overview of the knowledge and skills for epilepsy-specific management and chronic care self-management.

Development and Evaluation of Epilepsy Education Programs

The committee explored the literature on the development and evaluation of epilepsy education programs aimed at improving at least one aspect of knowledge, self-management, coping, or quality of life in either patients or their families and found that the research base lags behind that for other chronic conditions, such as arthritis (Nunez et al., 2009). There are signs of progress, however, with a number of innovative education programs that are now under development and being evaluated. This section describes what is known about the efficacy of several epilepsy-specific educational and self-management programs for children, families, and adults. These descriptions are followed by discussion of a program specific to seizure-like events with a psychological basis and a review of educational programs for people with low health literacy.

Programs for Children and Their Families

In its review of the literature, the committee determined that educational programs for children and their families were generally intended to increase knowledge about epilepsy; improve skills in self-management, communication about epilepsy to others, and developmental tasks (e.g., increasing independence); and optimize quality of life and psychological well-being (e.g., improving attitudes, coping, adjustment, self-esteem, behavior). Programs differed in length (from intensive 2-day programs to

[11]A variety of seizure diaries and tracking tools are available online and through epilepsy organizations.

TABLE 7-1
Areas of Self-Management Education for Epilepsy

Epilepsy-Specific Management	Examples of Knowledge and Skills
• Seizures	• Knowledge—Specific seizure type, first aid response, recognition and treatment for seizure emergencies (seizure action plans) • Skills—Recognizing, recording, and tracking episodic events; identifying seizure triggers; keeping a seizure diary
• Medications, Treatments	• Knowledge—Medication name, dosage, possible medication interactions and side effects, consequences of missed or late doses, drug-alcohol interactions • Skills—Tracking medication intake, tracking medication dose and changes, managing refills, responding to allergic reactions or adverse effects
• Safety	• Knowledge—Risks for injury related to seizures and treatment, strategies for reducing injury, risks for mortality, including sudden unexpected death in epilepsy • Skills—Assessing risks in environment, modifying environment and lifestyle to reduce risks yet maintain quality of life
• Comorbid conditions	• Knowledge—Common comorbidities, symptoms, treatments, and management • Skills—Recognizing symptoms, knowing when to seek support and treatment, monitoring treatment
Chronic Care Management	**Examples of Knowledge and Skills**
• Maintaining a healthy lifestyle ◦ Physical activity ◦ Adequate sleep ◦ Pleasurable activities ◦ Physical health ◦ Emotional health	• Knowledge—How seizures and everyday life interact, importance of a healthy lifestyle and behaviors, symptoms of an unhealthy lifestyle • Skills—Assessing the impact of seizures on daily life and making modifications; developing strategies for maintaining a healthy lifestyle, for seeking emotional support, and for coping with stressful situations
• Active partnership with health care team	• Knowledge—Need for active partnership with health care providers, effective communication strategies • Skills—Communicating, problem solving, decision making, self-advocating, goal setting, developing action plans
• Independent living	• Knowledge—Environmental support, resources, and services needed • Skills—Assessing and evaluating resources, developing action plans, handling emergencies

weekly sessions over 1-2 months), intervention strategy (e.g., lecture, group sessions, role-playing, use of games, videoconferencing, film, workbooks), and target group (children and family separately or together). Although many education programs focused solely on epilepsy, others were geared toward families of children with epilepsy and cognitive comorbidities; Buelow

(2007), for example, taught parents of children with long-term epilepsy and learning difficulties skills related to problem solving, partnership development, and advocacy.

Epilepsy education programming for children and families has not been as thoroughly evaluated in the United States as in some other countries. Of four educational programs tested using randomized controlled trials (often referred to as the gold standard of research methodology) (Glueckauf et al., 2002; Lewis et al., 1990, 1991; Rau et al., 2006; Tieffenberg et al., 2000), only one was carried out in the United States (Glueckauf et al., 2002). A challenge for many U.S. evaluation studies has been recruitment of sufficient numbers of study participants (Mittan, 2009; Wagner and Smith, 2006).

Nevertheless, programs tested in randomized clinical trials and those with sound methodologies have achieved improvements in a number of outcome variables for both children and parents. In a review of epilepsy education programs for youth, Lewis and colleagues (2010) found these programs produced positive trends toward improvements in health-related knowledge and quality of life. The evaluation of a large, comprehensive educational program for children is highlighted in Box 7-7.

Other promising research may contribute to the field by overcoming recognized limitations in program and study design, such as the lack of a theoretical foundation for a program and limited study participation. For

Box 7-7 AN EDUCATIONAL MODEL TO PROMOTE SELF-MANAGEMENT IN CHILDREN

Tieffenberg and colleagues (2000) developed a program to enhance child autonomy and self-management and tested it in children, ages 6 to 15, with epilepsy. The program involved five weekly meetings of separate parent and child groups. Data were collected before the start of the program and at 6 and 12 months afterward, and clinical and school records were monitored. Children were taught to assume a leading role in managing their condition, and parents were taught to help their children take on this role. Trained teachers used a variety of activities, including games, drawing, storytelling, videos, and role playing to develop the children's skills in observation (e.g., seizure triggers), communication, and decision making (e.g., working through decision trees). Outcomes measured health locus of control; parent and child knowledge, beliefs, attitudes, and behavior; family dynamics; patient–physician relationships; school attendance; and clinical variables (i.e., seizure frequency, physician visits, hospitalizations). Results showed significant improvement at both 6 and 12 months in the experimental group, compared to controls, on most parent outcomes, including knowledge, fear of child's death, and disruptions in family life. Children also showed significant improvement in internal locus of control and child–physician relationship. Additional improvements were found for clinical and school variables, including reduction in seizure frequency, absenteeism, and emergency room visits.

example, despite a small sample size, Wagner and colleagues (2010) used empirically supported cognitive-behavioral treatment as the foundation for their COPE (Coping Openly and Personally with Epilepsy) program, which has the objective of improving skills related to self-management, self-efficacy, and coping. Other programs use communications technology to make education programs more available to families unable to travel long distances to participate. For example, Glueckauf and colleagues (2002) used videoconferencing to offer counseling to rural teenagers and their parents, and Austin and colleagues (2002) used telephone conferencing to deliver tailored educational materials for the Be Seizure Smart intervention.

Germany's FLIP&FLAP program (Jantzen et al., 2009) has many attributes that might be considered in future U.S. programs for educating children and families. The curriculum was carefully developed based on needs identified in qualitative interviews and further evaluated in a pilot study. Researchers created a wide range of teaching materials, including a notebook, a film, rag dolls called FLIP&FLAP, a game about epilepsy, and a comic book, in order to accommodate different learning styles. Teaching methods also varied and included imagination techniques, role playing, and teaching problem-solving skills using an experience-based learning approach. The intervention was an intensive 2-day program delivered to parents and children separately; data were collected immediately before the program and 6 months later. Compared to a control group, children in the intervention group showed greater knowledge about epilepsy and improvement in parent-reported self-management and communication skills. Parents showed improvement in knowledge and fewer epilepsy-related worries.

Programs for Adults

Relatively few evaluations of epilepsy-specific educational programs for self-management were found for adults. Of the studies identified in literature reviews (Bradley and Lindsay, 2009; May and Pfäfflin, 2002; Mittan, 2009), only two were conducted in the United States. However, the committee found significant recent progress in the development and evaluation of self-management educational programs through the MEW Network (DiIorio et al., 2010). WebEase, one of the programs developed through the MEW Network, is described below.

One of the earliest adult programs, the Seizures and Epilepsy Education

(SEE) program,[12] delivers health education and psychosocial therapy in a 2-day program. The program uses facts to resolve common fears of individuals with epilepsy and their families, provides information on medication management, and teaches strategies for living successfully with epilepsy. A small randomized clinical trial by Helgeson and colleagues (1990) tested the SEE program and demonstrated a significant decrease in participants' fears and misinformation or misunderstandings, as well as a significant improvement in self-management and medication adherence, compared to the control group.

Another comprehensive self-management program, the Modular Service Package Epilepsy (MOSES) program (Ried et al., 2001) has nine educational modules: living with epilepsy, epidemiology, basic knowledge, diagnostics, therapy, self-control, prognosis, psychosocial aspects, and resources. The modules are designed to improve knowledge about epilepsy, its treatment, and its psychosocial effects; self-management; and independence (Ried et al., 2001). May and Pfäfflin (2002) examined the efficacy of the MOSES program when formatted as a 2-day course for adults with epilepsy. Participants reported significantly greater knowledge, improved coping with epilepsy, and improved seizure outcomes at the 6-month follow-up.

The committee found assessments of two self-management programs for adults with epilepsy who also had intellectual disabilities. Clark and colleagues (2001) evaluated a video-assisted program that involved three 1-hour group sessions, a 10-minute video that was viewed twice, participation in a discussion of epilepsy medication and safety, and learning about using seizure diaries. Pre- and post-assessments documented a 43-percent increase in knowledge about epilepsy, with increases particularly in understanding the purpose of an electroencephalograph (EEG) and the need to keep a seizure diary. A second program, the PEPE Program, was developed in Germany and replicated in the United Kingdom (Kushinga, 2007). This multimedia program, which used film clips, quizzes, and photographs, was led by two trained interviewers and was presented over eight 2-hour sessions. A pilot study showed high participant satisfaction with the program characters and the social interaction during the program, and an increase in participants' knowledge about seizures and medication.

Educational programs developed for improving self-management via the Internet also are being tested. One of the first of these was WebEase, designed by DiIorio and colleagues (2009b), and it is one of the programs included in the CDC-sponsored MEW Network. The theoretical founda-

[12]Developed by R. J. Mittan and formerly known as the Sepulveda Epilepsy Education program. The SEE program has recently been revised for children with epilepsy and their families; a pilot study showed promising results (Shore et al., 2008).

tions for WebEase include social cognitive theory (Bandura, 1976), the transtheoretical model of behavioral change (Prochaska and DiClemente, 1982), and motivational interviewing (Miller and Rollnick, 2002). WebEase program modules encourage participants to learn about targeted concerns, explore readiness for change, and set goals. Participants have access to online tools that are used to track thoughts, concerns, actions, and progress. Modules focus on medication-taking practices, sleep, and stress management. The program was evaluated in a randomized controlled trial in adults with epilepsy and demonstrated improvements in medication adherence, perceived stress, knowledge, and self-management compared to a control group (DiIorio et al., 2011). This study also collected information from participants about their experience in using the online program that could be helpful in further program development (DiIorio et al., 2009a). Despite the advantages offered through online programs, some individuals prefer programs that consist of individual meetings or in-person group meetings that are led by a health professional or a peer (Fraser et al., 2011), and it is important that personal preferences and individual needs are taken into consideration in program design and dissemination.

Educational Programs for Seizure-Like Events

Although literature reviews show few assessments of educational interventions for seizure-like events that are determined to not be epilepsy (Martlew et al., 2007), there is some empirical support for the notion that educational interventions might be helpful in this population (Gaynor et al., 2009). One educational program that shows promise was developed by Hall-Patch and colleagues (2010) in the United Kingdom, based on the self-regulation model (Leventhal et al., 1992). In a study of the program's effects, patients newly diagnosed with seizure-like events with a psychological basis were given an informational leaflet with 14 points covering patients' representations of their health condition. There was also a guide for physicians with explanations for each of the points and advice for providing information to patients. Follow-up interviews indicated that 94 percent of patients found the leaflet easy to understand, and only 11 percent had questions that it did not answer. Although 86 percent of patients reported negative emotions during the consultation, 94 percent had their questions answered, and 90 percent felt their feelings had been heard. Moreover, only 14 percent were confused about the diagnosis, and only 4 percent were angered by it, a much lower rate than described in an earlier study (18 percent) among people who did not receive an educational intervention (Carton et al., 2003). Approximately 3 months later, 63 percent of the study participants had a greater than 50-percent reduction in seizure-like events, and 14 percent were event-free (Hall-Patch et al., 2010). In addition

to educational interventions, cognitive-behavioral therapy shows promise as an effective approach for reducing the frequency of seizure-like events and improving psychosocial outcomes for individuals who have seizure-like events with a psychological basis (Goldstein et al., 2010; LaFrance et al., 2009).

Health Literacy Considerations for Educational Programs

Clear communication about health-related topics not only helps those who have low health literacy, but can benefit everyone. As a result, the concept of "universal precautions" has been borrowed from the infectious disease field to convey the importance of making "clear communication . . . the basis for every health information exchange" (ODPHP, 2010, p. 11). This concept is an important consideration for the development and evaluation of epilepsy education programs.

Berkman and colleagues (2011) conducted a recent review of studies of programs for low-literacy populations, including those with diverse chronic diseases and conditions, not specifically epilepsy, but their findings regarding the impact of these programs are suggestive for this population. Findings from 42 studies of general interventions (i.e., non-epilepsy specific) to mitigate the effects of low health literacy were assessed in the review (Berkman et al., 2011). Although the overall strength of evidence supporting specific design features was low (in part because of the diversity of interventions), the following features seemed to improve the comprehension of low-literacy populations:

- presenting essential information by itself,
- presenting essential information first,
- presenting quality information so that higher numbers mean higher quality (e.g., a basketball score, not a golf score),
- using the same denominators to present baseline risk and treatment benefits,
- adding icons to numerical presentations of treatment benefit, and
- adding video to verbal narratives.

Berkman and colleagues concluded that intensive self-management and adherence interventions appeared to increase self-management and reduce disease severity, as well as reduce emergency department visits and hospitalizations.

Next Steps for Epilepsy Education Programs

Despite the paucity of epilepsy education program evaluations, the committee was encouraged that all of the programs that were tested documented significant improvements in at least one outcome. However, none of the programs appeared to have been tested in more than one study. Replication and assessment of existing programs, especially those tested in only a small number of individuals, are needed. Moreover, new programs should be developed and tested in populations that have been understudied, including older adults, parents and caregivers of infants and young children, and individuals with uncontrolled seizures, serious comorbidities, and cognitive limitations. Finally, educational programs that include all of the recommended content for epilepsy-specific knowledge and skills that are necessary for optimal self-management (described in Table 7-1) also are still needed.

The committee noted the need for greater attention to cultural diversity in the programs. Educational programs developed for diverse population groups in other clinical areas have achieved positive results and might provide a model for epilepsy. For example, one diabetes education program designed to respond to cultural barriers to diabetes self-management successfully managed cultural barriers, increased participants' self-efficacy,[13] and promoted engagement in healthier lifestyles (McCloskey and Flenniken, 2010).

The committee found that many programs currently being developed have the potential to make major contributions to the field of epilepsy self-management. Many are being guided by evidence-based principles of program design. For example, the WebEase self-management program, which is based on proven techniques of motivational interviewing and stages-of-change research (DiIorio et al., 2009b), has the potential to provide an effective comprehensive epilepsy self-management program via the Internet. Additional core modules could be developed for epilepsy-specific areas, such as comorbidities, safety, and risks including mortality, again using evidence-based methods.

Finally, the positive outcomes from the available educational programs, coupled with the promise of innovative programs being developed, led the committee to conclude that this is a propitious time for the CDC to continue its investment in educational and self-management programs for individuals with epilepsy. Existing MEW Network programs should be implemented using strategies that will ensure their sustainability and expanded use. The MEW Network could also work to develop additional

[13]In the context of epilepsy, self-efficacy theory stresses the importance of an individual's belief that he or she can successfully manage the challenges of the condition, and it is an important underpinning for self-management programs that affects many aspects of how people think, feel, and act.

educational programs for people with epilepsy across the life span and across the epilepsy spectrum.

LESSONS FROM MODELS FOR OTHER HEALTH CONDITIONS

In selecting models from other health conditions that might suggest strategies to inform the development of educational programs for people with epilepsy and their families, the committee considered (1) the nature of the epilepsies, with their wide spectrum of characteristics and associated comorbidities; (2) the broad range of individual and family needs for information; and (3) the areas of knowledge and skill development identified in epilepsy self-management models. Therefore, the committee explored both condition-specific models and models for the management of chronic health conditions in general and selected one of each for further exploration below.

Diabetes Self-Management Education

Diabetes educators are a model for the provision of condition-specific health education by a health professional and are certified by the National Certification Board for Diabetes Educators. Diabetes educators come from a variety of health care disciplines (e.g., medicine, nursing, psychology, nutrition, social work) and provide patient education, commonly referred to as diabetes self-management education (DSME) (NCBDE, 2012).

Diabetes education programs are based on evidence-based standards and take into account the individual needs, goals, circumstances, and experiences of the patient. DSME is designed to increase knowledge, improve problem-solving skills, and develop skills for self-management. Patients learn informed decision making and how to establish effective partnerships with their health care team, which in turn can lead to improved clinical outcomes (e.g., lower blood glucose levels), health status, and quality of life (NCBDE, 2012). An Australian national consensus study on outcomes and indicators for diabetes education identified primary goals and optimal outcomes in three areas: living with diabetes, physical health, and cost-effectiveness (Colagiuri and Eigenmann, 2009). Because of the difficulty in linking diabetes education with clinical and cost outcomes, the desired outcomes identified by this group were knowledge, self-management, self-determination, and psychological adjustment. Outcomes such as these are clearly relevant to epilepsy education.

An international literature review of studies evaluating outcomes of DSME was carried out to explore theoretical foundations, outcomes, and the use of community partnerships (Jack, 2003). Of the eight studies selected for review, only two used a theory to underpin the education. Half

of the programs measured both short-term and intermediate outcomes. Results demonstrated that both short-term (e.g., fasting glucose, glycosylated hemoglobin, body mass index) and intermediate (e.g., exercise, diet, diabetes knowledge) outcomes can be improved with DSME. Many programs developed collaborative relationships among diabetes care providers, researchers, and community programs, including faith-based organizations, support groups, and health clubs and recreational facilities. These community partnerships were important to the success of all of the programs studied, by improving recruitment and continued participation (Jack, 2003).

Lessons from this review of DSME programs that are applicable for epilepsy education include (1) identification of the components (knowledge, self-management, self-determination, and psychological adjustment) that are relevant to optimal living with a chronic condition; (2) the importance of effective community partnerships in the delivery of educational programs; and (3) recognition of the importance of outcomes of educational programs over time. Additionally, the development of a cadre of well-trained, certified diabetes educators could serve as a model for an educator program specific to the epilepsies.

Chronic Disease Self-Management Program

The Chronic Disease Self-Management Program (CDSMP) is intended for adults with a range of chronic conditions. A major assumption underlying this generic approach to self-management is that many concerns, tasks, and skills are common to managing all chronic conditions (Lorig et al., 1999). In developing the CDSMP, two needs assessments were carried out. The first was a review of the literature on programs for chronic health conditions to identify components taught across conditions. The authors identified 12 of these components, including symptom monitoring and response, strategies for handling emergencies, maintaining a healthy lifestyle, and managing emotional responses to the health condition. The second needs assessment involved 11 focus groups of adults older than age 40. It asked participants to describe, for example, the impact (e.g., physical, social, psychological) of their condition on their lives, strategies they used to cope with their chronic health condition, and their thoughts about the future. Information from these two needs assessments shaped both the content and the delivery of the CDSMP program (Lorig et al., 1999).

The theoretical foundation for delivery of the program is self-efficacy theory, which suggests that people do better in managing a situation when they believe they can do so successfully (Bandura, 1997). There is empirical support for using self-efficacy concepts in self-management programs (Marks et al., 2005), and strategies consistent with this theory are used in CDSMP, such as modeling behaviors, action planning and feedback, and

participation in problem solving. The content is delivered in small groups of 10 to 15 adults with diverse chronic conditions and their family members. The group is facilitated by a volunteer lay leader, often someone who also has a chronic condition. The leader is trained and uses a teaching manual. The course is generally offered in weekly 2.5-hour sessions for 7 weeks (Lorig et al., 1999).

A test of CDSMP's effectiveness, compared to a condition-specific self-management program (the Arthritis Self-Management Program [ASMP]), was conducted in adults with arthritis (Lorig et al., 2005). ASMP was also developed based on needs assessments of patients and their rheumatologists. The two programs were compared in a randomized controlled trial and followed for a year. Both programs showed improvements. However, short-term results indicated that individuals in the arthritis-specific self-management program had significantly greater improvement in distress, limitation of activity, and fatigue, compared to individuals in the generic program. Furthermore, there was a trend toward greater improvement in other outcomes, such as global health and pain. By the 1-year follow-up the gap in improvements between the groups had narrowed, and participants in both programs had significant improvements; however, overall improvement and self-reported ratings of global health and fatigue were still better for people who received the arthritis-specific program (Lorig et al., 2005).

These findings have relevance for epilepsy. Individuals with epilepsy might benefit from attending CDSMP programs, because some of the content (e.g., developing strategies for handling emergencies, living a healthy lifestyle) is directly relevant to epilepsy. Attending these programs might also reduce feelings of social isolation. The finding that people in the condition-specific program demonstrated both earlier and greater improvement than people in the generic program suggests epilepsy-specific self-management programs cannot be replaced with generic chronic health conditions education programs.

A VISION FOR OPTIMAL EPILEPSY EDUCATION

People who are informed, supported, and actively engaged in productive interactions with "prepared, proactive, practice teams" (Wagner et al., 2005, p. S-9) should be at the center of a health care system that is designed to provide access to high-quality epilepsy care (Chapter 4). To be consistent with this broad framework for the delivery of health care, appropriate educational programs and resources ought to be readily available to ensure that people with epilepsy (and their families and caregivers, as needed) are knowledgeable about their condition and have the requisite skills to engage in productive interactions with their health care

team. The committee conceptualized a combination of epilepsy-specific self-management—which would include epilepsy-specific knowledge and skills related to seizures, medication and treatments, safety, and comorbid conditions—with chronic care management, which would include knowledge and skills related to maintaining a healthy lifestyle and behaviors, actively partnering with a health care team, and living independently (see Table 7-1).

Educational Needs Across the Spectrum

The committee recognizes that because of the diverse nature of the epilepsies, some people with epilepsy will need more educational assistance than others. Figure 7-2 depicts how different severity levels of seizures and comorbidities could be linked to different levels of education and resources. Epilepsy-specific education may meet the needs of people with mild forms of epilepsy or those who are mildly compromised—people who may be seizure-free and have no associated comorbidities or those with occasional seizures or mild comorbidities. However, individuals who are seriously compromised—those with uncontrolled seizures and severe comorbidities—will have much greater resource and educational needs. These individuals and their families will need comprehensive education that would include both epilepsy-specific and chronic care self-management program elements.

Some moderately compromised adults also might benefit from both epilepsy-specific education and chronic care programs, such as the CDSMP. A possible benefit of this combined approach, which could be tested through research, is that some somatic comorbidities associated with epilepsy, such as cardiovascular disease, diabetes, and osteoporosis (Chapter 3), could be improved through participation in a generic chronic care program. The finding that online delivery of the CDSMP effectively improved health status (Lorig et al., 2006) suggests that online programs, both epilepsy-specific and generic for chronic conditions, could provide benefits for people with epilepsy who otherwise would not have access to them.

Optimal Educational Outcomes for People with Epilepsy and Their Families

The committee's vision for optimal patient and family education and outcomes is depicted in Figure 7-3. The education side of the model includes three major domains—knowledge, self-management, and self-determination—and the corresponding indicator areas necessary for optimal patient and family education. The indicator areas define a combination of knowledge, perceptions, tasks, and skills that can be used to measure the efficacy of education programs.

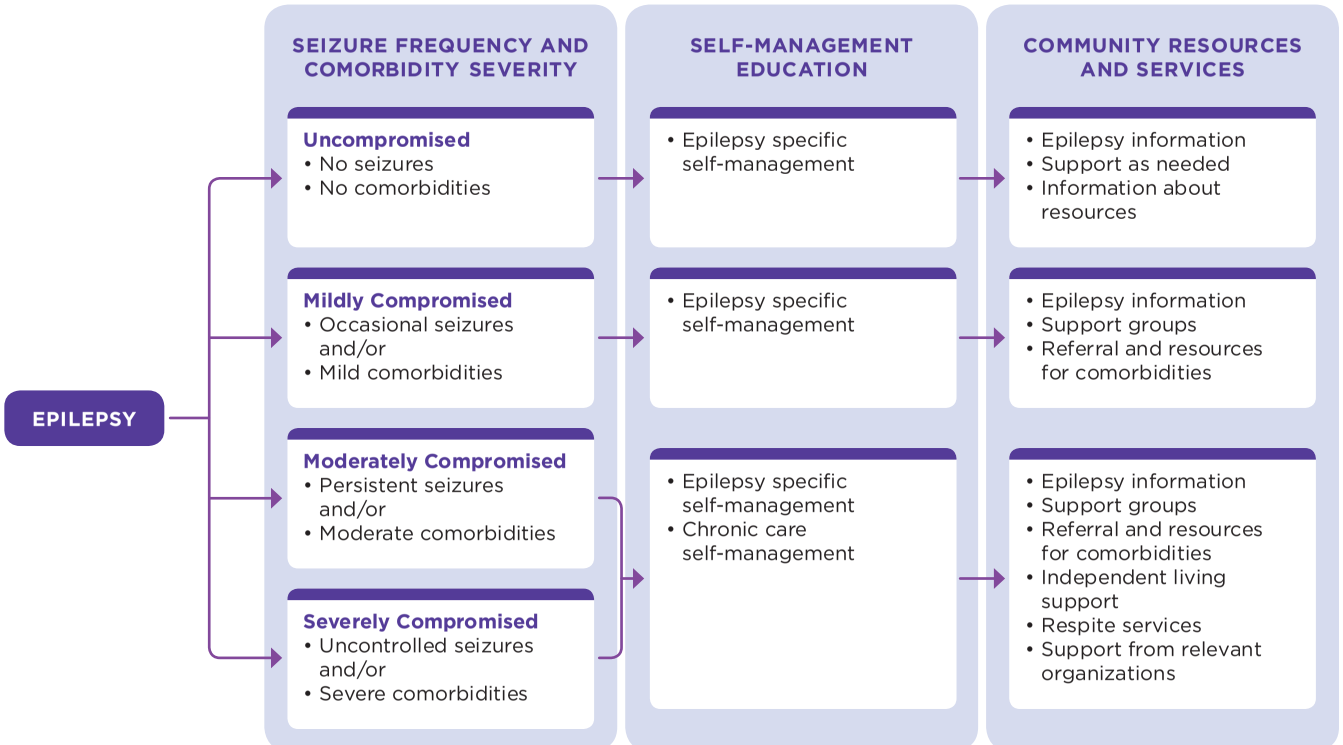

FIGURE 7-2
Linking seizure frequency and comorbidity severity to self-management education and community resources and services.

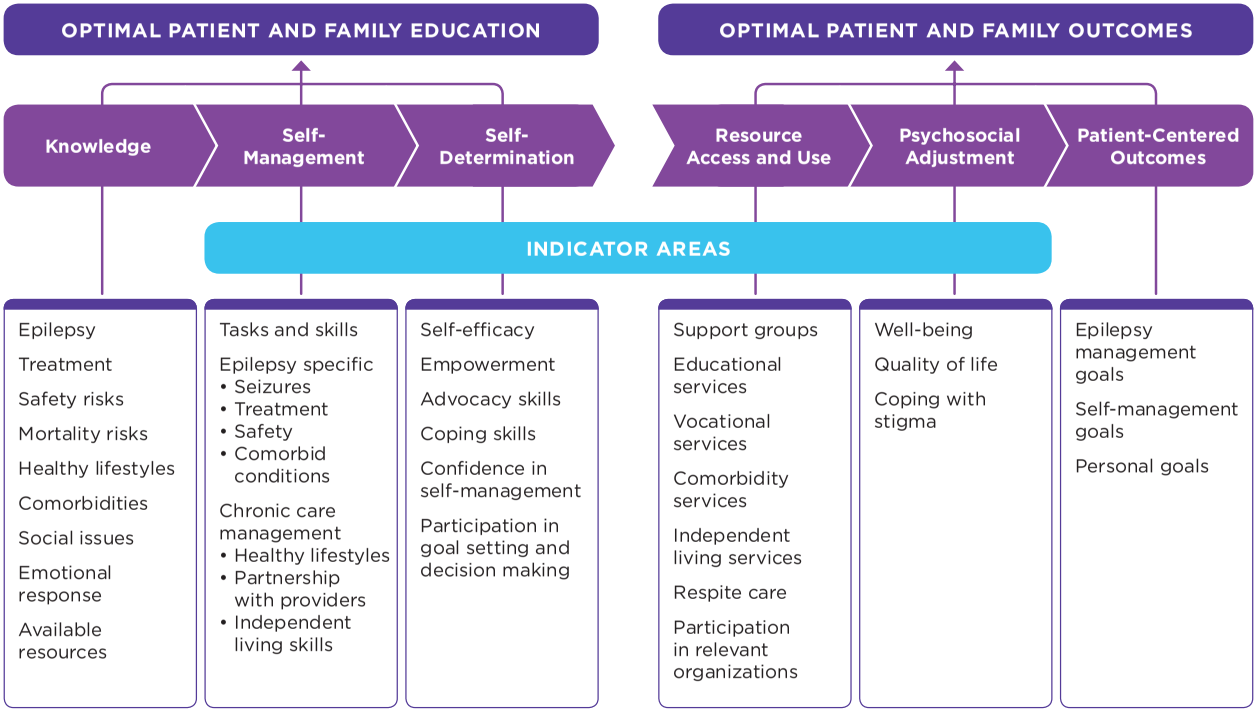

FIGURE 7-3
Education for people with epilepsy and their families to promote optimal outcomes.

SOURCE: Adapted from Colagiuri and Eigenmann, 2009. Reprinted with permission from John Wiley and Sons.

Because there is not a direct cause and effect between the quality of patient education and health outcomes and because health outcomes can be affected by a complex array of factors, the committee concentrated on outcomes more directly related to education. Therefore, the outcomes side of the model focuses on those that can result from optimal education: access to and use of community resources, psychosocial adjustment, and patient-centered outcomes. Corresponding indicator areas define a range of desirable services and patient outcomes. For example, educational programs focusing on self-management and self-determination would prepare people to take advantage of community resources, such as support groups and educational services; similarly, educational programs focusing on increasing knowledge about treatment would help individuals set and monitor epilepsy management goals. Thus, the outcome indicators are important measures of the success of educational efforts.

Designing educational programs to achieve optimal outcomes requires consideration of the characteristics of program participants, such as health literacy, cultural diversity, age and developmental stage, cognitive ability, severity of disease, and gender.

CONCLUSION

Over the course of its work, the committee identified and reviewed the literature base documenting the general information needs of people with epilepsy and their families. However, the needs of many specific subgroups are understudied, including men, older adults, racial/ethnic minority populations, people with seizure-like events, caregivers of infants and young children, youth transitioning into adulthood, and individuals with the severest forms of epilepsy. In addition to these gaps in research, this chapter highlights several important points about education for people with epilepsy and their families:

- Education for people with epilepsy and their families is critical around the time of diagnosis; through the first year; whenever there is a change in the person's condition, developmental status, or health status; and if new concerns or comorbidities develop. Few studies identify the most effective formats and delivery mechanisms for patient and family education, and evidence on educational preferences is lacking, especially across diverse populations.
- Relatively few epilepsy-specific self-management programs have been developed and tested, and none have been replicated. All of the programs have demonstrated some positive outcomes, and newer programs show much promise in improving options for the delivery of patient and family education. Studies comparing the

effectiveness of generic chronic care versus epilepsy-specific education programs individually and in combination are needed.
- The use of the Internet presents many potential opportunities to expand the reach and sophistication of epilepsy education programs, enabling them to respond to the needs of individual learners of different literacy levels, language proficiencies, cultural backgrounds, and learning styles. Increased availability of online educational information and the use of social networking websites provide new opportunities for sharing information about the epilepsies and providing interpersonal support.
- Individuals and their families need guidance to ensure that they are connected to the most accurate and reliable information resources and tools available, especially those available online.
- High-quality, validated epilepsy education programs can provide individuals, families, and caregivers with accurate information and education to build the skills needed to achieve optimal self-management. In order to be effective and to maximize reach, programs eventually will need to stratify and balance many dimensions—the severity of the disorders, the existence of comorbidities, the racial/ethnic and cultural background of users, language, the level of general literacy and health literacy, age and gender, and preferred learning styles.

Throughout this chapter, the committee has provided the basis for its research priorities and recommendations regarding improvements needed in education for people with epilepsy and their families, which are detailed in Chapter 9. In order to improve this education and build the necessary knowledge and skills of people with epilepsy and their families, additional research and time needs to be devoted to

- evaluating available educational resources and tools, including those available on the Internet;
- expanding the reach and dissemination of available resources;
- engaging people with epilepsy and their families in developing and testing educational resources;
- evaluating, replicating, and expanding the use of self-management programs; and
- exploring new opportunities for improving education, such as a centralized web resource to connect people with epilepsy to reliable websites and a certification program for epilepsy health educators.

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8

Public Education and Awareness

A principal goal for epilepsy education and awareness programs for the public at large is to combat stigma, in the hope that this will lead to improved quality of life for people with epilepsy. Misinformation and misperceptions regarding epilepsy have a long history and are still prevalent throughout society. Although some surveys suggest that attitudes toward people with epilepsy have improved over time, it is not certain how contemporary attitudes compare and whether the overall improvements have affected behavior. People acquire information about epilepsy from many sources, including family and friends, entertainment and news media, the Internet, and social media. However, the accuracy of these sources is variable. Public campaigns have been conducted by the Epilepsy Foundation since the 1970s, including efforts to reduce stigma, but their long-term impact on attitudes is unknown. Advocacy campaigns for other health conditions provide a variety of lessons and best practices for the epilepsy community; some efforts have effectively used carefully selected spokespeople and have achieved important policy changes. Actions needed to improve public awareness and knowledge include informing journalists as well as writers and producers in the entertainment industry; engaging people with epilepsy and their families in public awareness efforts; coordinating public awareness efforts and developing shared messaging; and ensuring that all campaigns include rigorous formative research, considerations for health literacy and audience demographics, and mechanisms for evaluation and sustainability.

Most of my life, I have been scared to talk about my epilepsy. Why? Because I was scared what others would think. Society does isolate, even discriminates against people with epilepsy.

–Louis Stanislaw

Through my relatively brief span of living with epilepsy, I have encountered a large number of individuals who feel very ostracized and excluded from the general public. This emotion can lead to some tragic outcomes. I did get to know one man, approximately my age, who actually took his own life as a result of this apprehension. . . . He repeatedly had mentioned the fear his two teenage daughters had to be seen with him, lest a seizure should occur. Another individual whom I had met was a young lady who was also facing the struggles with epilepsy. I do recall her saying that she "simply wanted someone to go out to eat with or even just to see a movie."

–Mark Brooks

Why does it matter whether the public at large knows much about the epilepsies? Earlier chapters of this report have explored what health professionals need to know to care for their patients with epilepsy and how knowledge is vital to people with epilepsy and their families for them to attain their maximum health and quality of life. But why should the public be a target for epilepsy information?

People have harbored misunderstandings and passed on misinformation and misperceptions about epilepsy and seizures for centuries. This misinformation has stimulated prejudice and discrimination against people with epilepsy, has caused them to be stigmatized and ostracized, and has compromised their ability to work and have an active social life (Bandstra et al., 2008; Eadie and Bladin, 2001; Jacoby et al., 2004, 2005a,b). Stigma is so prevalent that people with epilepsy may experience "felt" stigma, being ashamed of their condition and afraid to be open about it because of the negative reactions they anticipate may ensue. Stigma adds to the burden of the condition and significantly affects health and quality of life. To the extent that public awareness and information efforts can lay these misunderstandings to rest, correct misinformation, and provide accurate information and an understanding of the "human face" of people with epilepsy, they also may engender more positive attitudes—and, ultimately, behavior—toward people with this common condition.

The stigma of epilepsy has evolved over the centuries, with "enacted" stigma (e.g., overt prejudice and discrimination) becoming less common in developed countries (Jacoby et al., 2005b; Reis and Meinardi, 2002). However, beliefs that epilepsy is caused by evil spirits, witchcraft, or weakness persist in some cultures and regions of the world (de Boer, 2010). Surveys indicate that some people in the United States consider epilepsy a mental health condition or believe that it may be contagious (Austin et al., 2002; DiIorio et al., 2004; LaMartina, 1989; Sirven et al., 2005). Some cultures

represented in the United States may attribute health conditions such as epilepsy and its seizures to supernatural or divine causes, and people in these communities who have epilepsy may face increased stigma and unique challenges in obtaining medical care (Fadiman, 1997).

This chapter focuses on the U.S. public's knowledge, attitudes, and beliefs concerning epilepsy: how the public receives information, campaigns to improve knowledge and reduce stigma, and goals for public awareness and education initiatives. The chapter also highlights the influential role of the news and entertainment media. As Coelho (2006) noted in an editorial in *Epilepsy and Behavior*, "The cloud grows darker each time the media . . . portrays epilepsy in a way that highlights myths, misconceptions and misunderstanding" (p. 3).

The committee's vision for appropriate public awareness and knowledge of epilepsy focuses on 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.

PUBLIC KNOWLEDGE, ATTITUDES, AND BELIEFS ABOUT EPILEPSY[1]

People with epilepsy who are stigmatized can endure devastating consequences, including lower self-esteem, social anxiety, discrimination, isolation, reduced access to care and resources, and negative health outcomes. Some studies suggest a relationship between stigma and reduced seizure control, psychopathology, and reduced quality of life (Hermann et al., 1990; Jacoby, 1994, 2002; Jacoby et al., 2005b; Whatley et al., 2010), and many of the psychosocial challenges experienced by people with epilepsy are also associated with stigma (Austin et al., 2002; Bandstra et al., 2008; Jacoby and Austin, 2007; Jacoby et al., 2004, 2005b).

People with epilepsy may hide their symptoms from others and even delay seeking care, as found in interviews with African American women with epilepsy (Paschal et al., 2005) and in a survey of Midwestern neurologists (Hawley et al., 2007). Many people with epilepsy fear that openly discussing their diagnosis will result in the loss of relationships, driving privileges, jobs, and more. Society reinforces these fears because of a lack of public knowledge and awareness, belief in misperceptions surrounding epilepsy and seizures, and negative attitudes and behavior that marginalize

[1]The committee recognizes that a significant amount of work has been conducted on public knowledge, attitudes, and beliefs internationally (e.g., Chomba et al., 2007; Kim et al., 2003; Le et al., 2006; Njamnshi et al., 2009; Tekle-Haimanot et al., 1991; Yoo et al., 2009). For the purposes of this chapter, the discussion focuses primarily on work conducted in the United States and other developed nations having relatively comparable educational levels, health care availability, and media enterprises.

people with epilepsy (de Boer et al., 2008; Fernandes et al., 2011; Jacoby, 2002; MacLeod and Austin, 2003; Morrell, 2002; Paschal et al., 2005; Taylor et al., 2011).

Survey research suggested that attitudes toward people with epilepsy in the United States improved in the decades leading up to 1980. The authors of a historic study, which summarized findings from seven Gallup surveys conducted over a 30-year period from 1949 to 1979, attributed the improved attitudes to educational efforts, improved control of seizures, employment of people with epilepsy in major industries, and policy and legal changes that protect against discrimination and improve opportunities for people with epilepsy (Caveness and Gallup, 1980). However, in a 1987 survey of U.S. adults conducted by Gallup, nearly half (49 percent) of respondents could not identify a cause of epilepsy, only 19 percent said it was a brain disorder, and one in six believed it was a mental health condition (LaMartina, 1989). Results from nine questions included on the 2002 HealthStyles Survey[2] indicated that one-fourth of respondents believed they were knowledgeable about epilepsy, and about 30 percent said they knew someone with epilepsy, but this was not associated with improved knowledge about the condition. Only slightly more than one-third knew what to do if someone had a seizure, and most people reported that their information about epilepsy came from family, friends, or television (Kobau and Price, 2003).

Studies conducted in other countries, including Italy, New Zealand, and Denmark, have identified a need for improved knowledge and attitudes about epilepsy (e.g., Canger and Cornaggia, 1985; Hills and MacKenzie, 2002; Jensen and Dam, 1992), while also documenting some progress. The United Kingdom's Omnibus Survey has found that respondents are generally well informed, with about 90 percent expressing positive attitudes on several stigma questions. However, one-fourth of respondents tended to agree or strongly agree with a statement that people with epilepsy have "personality problems," and more than half agreed that they are treated differently by society (Jacoby et al., 2004). The authors nevertheless concluded that the trend appears to be moving in a positive direction, with the public more likely to "value rather than reject human differences" (p. 1412). They noted that the transition away from epilepsy being considered within a moral domain (focusing on misperceptions of "badness") and toward epilepsy being identified within the medical model (emphasizing a brain disorder amenable to treatment) may have contributed to this change,

[2]The HealthStyles Survey is a nationally representative mail survey conducted by Porter Novelli through a partnership with the Centers for Disease Control and Prevention that includes questions on consumer topics such as media habits, product use, lifestyle habits, and health topics.

and they called for research to design strategic communications campaigns that target negative attitudes.

Similar findings were noted in analyses of opinion polls conducted in 1994 and 2000 in Hungary, with a notable trend toward acceptance of people with epilepsy in the second survey, which followed the Out of the Shadows global campaign on epilepsy (Mirnics et al., 2001). Positive attitudes about epilepsy and people with the disorder were highlighted in a survey conducted in New Zealand, and the authors attributed these findings, in part, to public education efforts and the work of the Epilepsy Association of New Zealand (Hills and MacKenzie, 2002).

Although these surveys suggest possible improvements in attitudes toward people with epilepsy and generally point to the success of public education efforts, there remains a troubling lack of basic knowledge about the condition. Further, misperceptions about epilepsy remain remarkably common and fuel negative attitudes and, ultimately, stigma (Bandstra et al., 2008; de Boer, 2010; Kilinç and Campbell, 2009; Paschal et al., 2007). A large-scale, population-based survey specific to epilepsy has not been conducted in the United States in many years, so gaps in knowledge about contemporary attitudes and beliefs may exist. As noted in Chapter 6, questions have been raised about the ability of surveys to accurately measure attitudes due to participants' tendencies to provide socially desirable responses, especially when they are aware that their responses are being used to measure their attitudes (Antonak and Livneh, 1995; Baumann et al., 1995; Bishop and Slevin, 2004; Caixeta et al., 2007). However, a number of tools for measuring stigma have been developed and validated in the last decade (described below) and offer potential for studying current attitudes, beliefs, and stigma.

Measuring Stigma

Tools have been developed and tested and numerous studies have been conducted to measure stigma among target audiences. The Centers for Disease Control and Prevention's (CDC's) ABLE (Attitudes and Beliefs about Living with Epilepsy) instrument is a 46-item scale that measures attitudes of the public on four dimensions related to epilepsy: "negative stereotypes, risk and safety concerns, work and role expectations, and personal fear and social avoidance" (DiIorio et al., 2004, p. 970). Kobau and colleagues (2006) used the ABLE instrument to describe differences in negative stereotypes and risk and safety concerns in subgroups of the U.S. population. This instrument recognizes that attitudes are complex and multidimensional and can range from a general lack of knowledge and uncertainty to concern, worry, and fear about epilepsy, seizures, and people with epilepsy. These attitudes, in turn, have an impact on behavior and stigma. A short-form

Box 8-1 EXAMPLES OF SURVEY ITEMS FROM THE ATTITUDES AND BELIEFS ABOUT LIVING WITH EPILEPSY INSTRUMENT

1. I would be nervous around a person with epilepsy because they might have a seizure.
2. I believe people with epilepsy are unreliable.
3. I would consider a divorce if my spouse were diagnosed with epilepsy.
4. I believe people with epilepsy are not as smart as those without epilepsy.
5. I believe people with epilepsy should not marry.
6. I believe people with epilepsy are possessed by a supernatural spirit.
7. I would be uncomfortable being around a person with epilepsy.
8. I would not want to work with someone who has epilepsy.
9. I would not want my child to date someone with epilepsy.
10. I would be afraid to be alone with someone who has epilepsy.
11. I would avoid a person with epilepsy who has frequent seizures.
12. I would be embarrassed if someone in my family had epilepsy.

SOURCE: Dilorio et al., 2004; Personal communication, R. Kobau, CDC, March 16, 2011.

version of the ABLE instrument, which includes 12 questions (see Box 8-1) drawn from the original 46-item scale, was developed to further examine negative stereotypes and general discomfort and avoidance. If feasible, the CDC plans to support data collection using items from the ABLE instrument to capture current attitudes toward epilepsy and assess the current level of epilepsy stigma (Personal communication, R. Kobau, CDC, March 16, 2011).

Brazilian researchers developed the Stigma Scale of Epilepsy, which is used to assess perceptions about epilepsy held by people with epilepsy and people in the community who do not have epilepsy (Fernandes et al., 2007, 2009). In a 2006-2007 study based on this scale, involving students at a summer camp, the word "epileptics" and the phrase "people with epilepsy" were used in questionnaires about perceived rejection, perceived difficulties in obtaining employment, perceived difficulties at school, and the respondent's prejudice toward such people. The findings, which showed that the term "epileptics" generated higher scores on stigma measures, underscore the important influence that language and terminology have on stigma perceptions (Fernandes et al., 2009).

Another mechanism that has been used to measure stigma involves interviews with people with epilepsy and their caregivers (Kilinç and Campbell, 2009; Wagner et al., 2009). In these situations, people with epilepsy are viewed as experts on their condition and discuss their own lack of knowledge, the lack of knowledge about epilepsy and stigma among

the general public and school personnel, and their recommendations for responses to medical, educational, and social challenges.

These tools and other validated mechanisms need to be used to measure and track improvements in the public's knowledge and acceptance of people with epilepsy in society. A more precise understanding of how the public learns about epilepsy (and health generally) will help to inform interventions intended to produce the desired attitudinal and behavioral changes.

HOW THE PUBLIC RECEIVES INFORMATION ABOUT EPILEPSY

Healthy People 2020 ascribes an important role to the communications media in shaping the public's views on health and disease. "Health communication and health information technology (IT) are central to health care, public health, and the way our society views health" (HHS, 2011). Health information—of varying accuracy—is widely available and frequently consulted through a range of sources in today's crowded media marketplace; this information plays a significant role in influencing knowledge, attitudes, and beliefs about epilepsy. Sources of epilepsy information include print, broadcast, and cable or satellite media; Internet websites such as YouTube and Facebook; and a diverse group of health and non-health organizations that conduct campaigns and host websites, such as the Epilepsy Foundation, the CDC, and TalkAboutIt.org. Additional sources of information include health care providers, family members, friends, and colleagues in professional and community settings.

In a discussion of the 2002 HealthStyles Survey findings, the authors noted that fictional depictions of seizures, such as those on television, typically portray severe tonic-clonic seizures (Kobau and Price, 2003). These vivid depictions may frighten the viewing public and foster the development of negative social attitudes. More than half of all survey respondents reported that they have seen a seizure on television, with adults under 35 more likely than other age groups to have seen one. Thus, television writers and producers are a critical audience for epilepsy education efforts. Despite the influence of writers and producers on public attitudes and beliefs about epilepsy, they may not be well informed about epilepsy or the potential impact of their story lines on viewers.

The media preferences and habits of youth and adolescents are key to planning interventions that foster more positive attitudes and beliefs in this age group. Since 1999, the Kaiser Family Foundation has tracked media use by youth ages 8 to 18 (Rideout et al., 2010). The 2009 survey found clear evidence that older youth spend more time with media of all types than in the past, totaling nearly 12 hours a day (Rideout et al., 2010). Since 2004, the largest increases in media use by older youths are for television and video games. Use of print media (books and newspapers) has declined

slightly, while hours viewing movies in a movie theatre have remained constant. Ownership of mobile media (e.g., smartphones, MP3 players, laptops) has increased significantly since 2004 (Rideout et al., 2010). These mobile devices are creating a shift in how youths in the United States access entertainment and information; youth are still watching television shows, but they are increasingly using computers, phones, and other mobile devices (e.g., iPads or tablet computers) to stream them (Stelter, 2012).

The sheer variety of media used—and, even for a single medium such as television, the variety of channels available—splinters this audience and makes it difficult to design a campaign that would have substantial reach. A recent Nielsen report indicates that the Internet is becoming a larger part of everyday life and a means for streaming entertainment, including television shows, for many people (Nielsen Wire, 2012). Moreover, the rise in popularity of social media (e.g., Facebook, Twitter) requires completely different content and tactics than the radio and television "public service announcement" campaigns of past decades. Of those who use the Internet, 65 percent of U.S. adults and 83 percent of those ages 18 to 29 now use social networking websites (Pew Internet and American Life Project, 2011).

The Internet as a Source of Information About Epilepsy

The Internet is the leading source for health information, primarily for consumers who are actively seeking more information regarding a diagnosis for themselves or someone they know (Sarasohn-Kahn, 2008). It is estimated that more than 100,000 websites are directly health related (McNeil et al., 2012). Information retrieved on the Internet also may influence people who access it for entertainment and social networking purposes and are passively exposed to health-related content.

Depictions of epilepsy and seizures on the video-sharing website YouTube offer both challenges and opportunities for reducing stigma. In August 2011, YouTube attracted nearly 128 million of the Internet's estimated 215 million users in the United States (Nielsen Wire, 2011b). The website hosts epilepsy-related videos that show physiology lectures, diaries, and a variety of seizure types, with "real-life" videos of seizures having vastly more hits than the informational videos (Lo et al., 2010). In a content analysis of viewer comments about the 10 most-watched epilepsy videos in 2007 (from 8 amateur and 2 professional producers), researchers found information-providing comments far more common than information-seeking comments, with a high rate of inaccuracy. While many viewers expressed empathy, many others found the seizures comedic. One video showed a fake seizure in a mall, with people walking by or stopping to stare, but not attempting to help or seek aid. The study's authors called for more effective public education through more accurate YouTube videos

to counter the stigma and misperceptions about epilepsy reflected in user comments. The authors proposed that YouTube might be an appropriate venue for public education because the website's largely youthful audience may be amenable to change. However, new videos must be entertaining as well as educational to attract this audience.

TalkAboutIt.org is an example of a website that features entertaining and informative videos designed to educate viewers about epilepsy. The website was developed by the parent of a person with epilepsy to encourage dialogue among individuals, family members, and the general public. Content for the site was created with support and input from members of the epilepsy community, and it involves celebrity spokespeople. The premise is that greater knowledge will lead to more positive attitudes, beliefs, and behavior toward people with epilepsy. The interactive site allows visitors to "travel along a subway" where they hear from celebrities, learn about epilepsy and how it affects families, encounter common misperceptions that are subsequently dispelled, and are given credible resources for more information. The interactive technology and graphics, along with the celebrities and engaging website design, create an appealing and entertaining learning environment. Future educational efforts would benefit from an evaluation of this website's reach and effectiveness in correcting misinformation and changing attitudes.

As mentioned previously, social media are significant vehicles for information sharing that reach large audiences. There is growing interest in how social media can be used to disseminate messages related to health promotion, medical advances, and health education. McNeil and colleagues (2012) conducted a review of seizure-related messages (tweets) posted on the social networking website Twitter during a week-long sample period. The study was conducted to understand how the public uses the term "seizure" and how seizures are characterized and to determine the potential for information dissemination. The review analyzed more than 5,000 messages and determined that 41 percent of the tweets that referred to seizures were derogatory or had negative connotations, and only 12 percent were informative[3] in nature. The authors concluded that, while social media and social networking websites provide an opportunity to share accurate information, a significant portion of the current usage disseminates negative messages about seizures and perpetuates negative attitudes, stereotypes, and stigma (McNeil et al., 2012). The study's authors reiterate the existence of negative attitudes and stigma and the need for additional public education.

[3]The accuracy of the information included in the messages that were classified as informative was not assessed. Authors indicated that additional work is needed to assess whether these informative messages may be propagating misinformation (McNeil et al., 2011).

Television and Film as Sources of Information

In addition to the Internet, television and film remain popular media where viewers frequently receive information about health-related topics, including epilepsy, primarily in the form of news and entertainment shows, documentaries, and movies. In the 2001 HealthStyles Survey, more than half of respondents who were regular television viewers reported that they learned something about a health topic from a television story line, with black and Hispanic viewers reporting more resulting actions (e.g., discussion with others, seeking more information, doing something to prevent a problem, telling someone to do something, calling a health care provider) than white viewers (CDC, 2011). Discussion with others about the health topic included in the story line was the most common action taken by all groups of viewers, suggesting that televised information can penetrate beyond the viewing audience.

Educating the Public Through Television Story Lines

A variety of health topics have been featured in story lines—including obesity, breast cancer, organ donation, syphilis, and human immunodeficiency virus (HIV)—with the goal of producing positive impacts on audiences. Increases in awareness, knowledge, discussions with other people, information seeking, and healthy behaviors and practices have been measured as a result of exposure to these story lines.

- At the same time as public health campaigns on obesity and healthy eating, an obesity story line was featured on the television drama *ER* that included an overweight African-American teenage male character with hypertension. Surveys conducted after this story line aired found a significant increase among some viewers in self-reported healthy behaviors (e.g., walking or other physical activity, having blood pressure checked, eating more fruits and vegetables). The greatest changes were among men, who had lower levels of nutrition knowledge pre-test than women (Valente et al., 2007).
- A breast cancer story line included on a Spanish-language telenovela (soap opera) resulted in increased knowledge among viewers, with a significant increase in the number of male viewers who said that they would suggest that a woman they knew should have a mammogram (Wilkin et al., 2007).
- Members of the organ donation community consulted with television writers on story lines that would correct misinformation about organ donation. Six story lines on four television dramas (*Numb3rs*, *Grey's Anatomy*, *CSI: NY*, and *House*) resulted in a positive change in knowledge and attitudes among viewers. The intention

to become an organ donor increased significantly among viewers exposed to the story line on *Numb3rs*, which featured a dinner discussion that resulted in several characters' encouraging the one non-donor to designate himself as an organ donor on his driver's license (Huang et al., 2006).

- A syphilis story line on *ER* involved homosexual men and was broadcast during a period of time when syphilis outbreaks had occurred in this population in several U.S. metropolitan areas. A survey revealed that viewers of the story line reported significantly greater intentions than non-viewers to be tested for syphilis and to advise someone else to be tested (Whittier et al., 2005).
- An increase in information seeking was demonstrated by Kennedy and colleagues (2004) when a daytime drama (*The Bold and the Beautiful*) featured a story line about a character diagnosed with HIV. A public service announcement featuring the character aired at the end of two episodes and included the toll-free phone number for the National Sexually Transmitted Diseases and Acquired Immune Deficiency Syndrome (AIDS) Hotline. Two large spikes in calls occurred, the first after the episode in which the main character learned he was HIV positive, and the second after he told his girlfriend. This viewer response created more calls to the hotline that year than any television broadcast that included AIDS-relevant information (five out of six included the hotline number), as illustrated in Figure 8-1.

Although the examples of story lines described above are not specific to epilepsy, a variety of lessons can be learned and may be useful in promoting the development and use of epilepsy-related story lines:

- Principles from social-cognitive theory, or social modeling, suggest that audiences learn from individuals with whom they identify and that they are likely to emulate behavior that has positive outcomes and avoid behavior with negative outcomes (Bandura, 1986). The entertainment-education approach, which involves educating writers about health and social issues to inform storylines, was used in television in the 1970s with early work in Mexico to convey literacy messages through Spanish-language telenovelas (Bandura, 1986; Singhal et al., 2004).
- Careful evaluation and viewer surveys are required to measure the success of story lines and to identify best practices for future efforts.
- Clear, concise, accurate, and compelling information is necessary to inform writers and producers. For example, the following was used

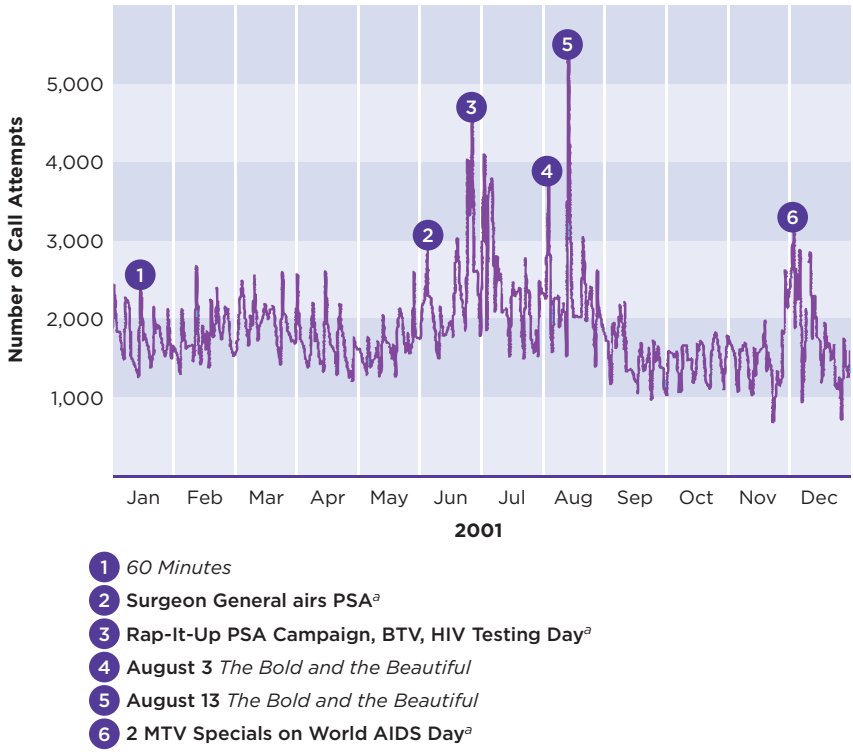

FIGURE 8-1
Calls to the Centers for Disease Control and Prevention's National Sexually Transmitted Diseases and AIDS Hotline, January–December 2001. *The Bold and the Beautiful* story lines aired on August 3 and August 13.

NOTE: AIDS = acquired immune deficiency syndrome; BTV = Black Entertainment Television; HIV = human immunodeficiency virus; MTV = Music Television; PSA = public service announcement.

[a]Hotline number aired.

SOURCE: Kennedy et al., 2004. Reprinted with permission from John Wiley and Sons.

in conjunction with pitching an organ donation story line to writers: "Over 93,721 people are waiting for the gift of life" (Huang et al., 2006).

- A variety of resources, such as websites, social media, and 800 numbers, offered in connection with the story lines provide viewers with multiple access points to valuable information, as well as a way to track audience response.
- Public-private partnerships facilitate and expand advocacy and outreach efforts and can play an important role in activities, such as expert consultations on story lines and development of informational resources.

Currently, nearly 200 million viewers tune in to a variety of prime-time (8 to 11 p.m. in most U.S. time zones) television programs each week, including 56 percent who watch reality shows and nearly 24 percent who watch dramas (Nielsen Wire, 2011a). While reality television programs have grown in popularity over the past decade, especially among young adults and teens who may view them as factual, little systematic study has been conducted of audience effects and the health messages they might (sometimes incidentally) convey (Christenson and Ivancin, 2006). Primarily, researchers have conducted content analysis of reality television shows and found a lack of prevention messages (Manganello and McKenzie, 2009) or mixed messages at best (Blair et al., 2005; Christenson and Ivancin, 2006). Although some reality programs have included positive health-related messages (e.g., *The Biggest Loser* includes tips on diet and exercise), many portray risky behavior (e.g., alcohol and drug use). Despite the popularity of these programs, more information and data will be needed to determine whether there are any opportunities to leverage this form of entertainment to deliver accurate health information to viewers. Further, not all forms of entertainment are well suited to serve as vehicles to educate the public.

Depictions of Epilepsy in Television and Film

Several studies have been conducted to analyze epilepsy depictions in television and film, and they conclude that inaccurate first-aid treatment and exaggerated occurrences of more severe types of seizures are common. A study of four popular television medical dramas (*House*; *Grey's Anatomy*; *Private Practice*; and *ER*) during the 2004-2009 seasons identified 65 depictions of seizures (Moeller et al., 2011). The vast majority of these (53) were tonic-clonic seizures, but, most notably, nearly half of the depictions showed medical staff treating the seizure inappropriately. Because medical dramas are far more likely than other television dramas to retain medical consultants and writers, these depictions are arguably the closest-to-accurate seizure depictions on television. This suggests a critical need for education and awareness about seizure first aid among television writers who have the power to educate the general public through their storytelling.

Popular motion pictures also may influence the public's attitudes and beliefs about epilepsy. A 2010 survey of U.S. adults found that two-thirds of respondents had gone to a movie in the previous 6 months and one-fourth within the past 90 days (Experian Marketing Services, 2010). These figures do not include the millions of viewers who watch movies on DVD and television. Kerson and colleagues (1999) analyzed 20 films with epilepsy depictions, noting that seizures were often used by the filmmakers as part of

character development. The researchers found fairly accurate depictions of seizures, but severe and uncontrolled seizures were far more common than less severe ones and offered mostly sensationalized and frightening images for viewers. Similarly, Baxendale (2003) reported that seizure depictions in film continue to be frightening, showing men with seizures to be "mad, bad, and dangerous," while women with seizures were depicted as "exotic and vulnerable." These portrayals may negatively influence the public's attitudes, beliefs, and responses to seizures, as well.

Based on experience in the mental health community, Wahl (2011) proposed strategies to improve the accuracy of epilepsy depictions, including education of entertainment media writers, in part by having people with epilepsy share their personal stories. The Los Angeles affiliate of the Epilepsy Foundation recognizes the need for outreach to the entertainment industry:

> [W]e cannot fulfill our mission until we proactively impact and influence the entertainment industry to ensure that correct epilepsy information, accurate seizure first aid, and sensitive portrayals of epilepsy are portrayed on the big and small screen. This is both a local and national imperative if we are to increase awareness about epilepsy, secure the safety of individuals with epilepsy, and ensure their acceptance and access to all life experiences. (Pietsch-Escueta, 2009)

To ensure that the public receives accurate information, the epilepsy community will need to target the writers and producers of popular media content, including web, mobile, film, and television formats. Informational guidelines for accurate depictions and periodic meetings with writers are needed. Further, partnerships need to be developed between media content producers and the epilepsy community, with perhaps the most effective strategy being to connect content producers with people who have the disorder themselves or those who have a child or close family member affected.

Models for Improving Coverage and Depictions of the Epilepsies in the Media

A number of models and strategies for improving the accuracy and coverage of health topics in the news and entertainment media have been developed by government agencies, academic universities, nonprofit organizations, and foundations. These initiatives, which include a variety of educational opportunities and awards, typically target journalists and entertainment media writers and producers, in order to inform and engage the writers whose stories and interviews will inform and educate the public.

Programs for Journalists

In 1994, recommendations from a national workshop on suicide contagion and reporting on suicides were published in CDC's *Morbidity and Mortality Weekly Report*, in response to concerns that news media coverage of youth suicide had the potential to fuel suicide clusters (O'Carroll and Potter, 1994). The recommendations included general topics that public officials and health and media professionals should consider when reporting about a suicide and focused on factual and concise media coverage with specifics on ways to avoid sensationalizing the event or promoting suicide contagion among youthful audiences. Furthermore, the recommendations described how communities could confront the problem of youth suicide and potential contagion more effectively when a news story appeared (O'Carroll and Potter, 1994). This workshop provided public health guidance for journalists and emphasized the potential negative impact of media coverage on vulnerable populations.

Programs that have demonstrated success in training journalists about public health topics and in generating more accurate and in-depth coverage have evolved over the past few decades. One example is a program hosted through the Carter Center, the Rosalynn Carter Fellowships for Mental Health Journalism.[4] This fellowship program offers stipends for journalists from the United States and other countries to support their efforts (including training and mentorship) to report on topics related to mental health.

Other programs designed to educate journalists about health-related topics include the following:

- The California Endowment's Health Journalism Fellowships at the University of Southern California offer journalists an opportunity to learn from nationally renowned health experts, policy analysts, community health leaders, top journalists, and each other. Participants are encouraged to explore health challenges and social justice issues as they develop stories for their media outlets.[5]
- The Association of Health Care Journalists offers a number of Health Journalism Fellowships that are supported through partnerships with the CDC and other organizations. These fellowships provide opportunities for reporters, writers, editors, and producers to study a variety of public health topics.[6]
- The National Press Foundation, based in Washington, DC, conducts a variety of educational and awards programs around health

[4]See http://www.cartercenter.org/health/mental_health/fellowships/index.html.
[5]See http://www.reportingonhealth.org.
[6]See http://www.healthjournalism.org.

and other topics, with an emphasis on public policy and how it affects U.S. readers and viewers.[7]

- The Kaiser Media Fellowships in Health provide in-depth briefings and week-long site visits for invited health and health policy journalists, helping them to understand complex health policy dilemmas. The Kaiser Media Internships in Health Reporting program is designed for young U.S. journalists who want to specialize in health reporting.[8]

Programs for Writers in the Entertainment Media

For many years, key health organizations have worked closely with writers and producers of television shows to cultivate a "Hollywood presence." By building relationships and making their health experts available to scriptwriters, they have identified and promoted constructive public health messages, with many of these messages subsequently used by writers in daytime and prime-time dramas on subjects such as HIV/AIDS and other health topics (KFF, 2008; Rideout, 2008). For example, it should be noted that pro-health messages are always subject to what the writers and producers need for their story lines. If they need a more compelling drama, they are likely to use a more dramatic portrayal of a topic. In the absence of expert input and consultation, it is even more likely that writers will take liberties with the health content to amplify the drama, which may help to explain why seizures of the most dramatic type are what television dramas typically portray.

Hollywood, Health and Society[9] is an initiative conducting outreach to entertainment writers on public health topics in the United States (Beck, 2003). The project is funded by the CDC, other federal health agencies, and private foundations, and it is based at the Norman Lear Center at the University of Southern California's Annenberg School for Communication and Journalism. National health experts consult on specific story lines, provide briefings on a variety of public health topics, and participate in educational panels. Hollywood, Health and Society staff also help connect scriptwriters with people who have specific health conditions, so writers can "put a human face" on the experiences they are writing about, understand the emotional burden and challenges people confront, and ultimately develop a more realistic and compelling story line with characters to whom the audience will relate.

To reinforce exemplary depictions, several awards programs recognize accurate portrayals of health topics in entertainment programming and

[7]See http://nationalpress.org.
[8]See http://www.kff.org/mediafellows.
[9]See http://hollywoodhealthandsociety.org.

showcase winning story lines. The Sentinel for Health Awards, sponsored by Hollywood, Health and Society, and the Voice Awards, funded by the Substance Abuse and Mental Health Services Administration, are two examples. The Voice Awards program specifically recognizes entertainment programming that promotes dignified, respectful, and accurate portrayals that raise "awareness and understanding of behavioral health (mental health and/or addiction issues) and [promote] the social inclusion of individuals with behavioral health problems" (SAMHSA, 2011).

While none of the models described in this section have focused specifically on epilepsy, they suggest potential partners for collaboration to help media writers and producers understand the epilepsies and influence information and portrayals read and viewed by the public. Members of the epilepsy community need to build on these existing efforts in order to further improve public education about epilepsy.

PUBLIC AWARENESS CAMPAIGNS

The Evolution of Epilepsy Campaigns

The Epilepsy Foundation is a national, nonprofit organization whose mission, in part, focuses on educating the public "to improve how people with epilepsy are perceived, accepted and valued in society" (Epilepsy Foundation, 2011). Throughout a longstanding partnership with the CDC, the Epilepsy Foundation has committed substantial resources to improving public awareness, public understanding, and public acceptance of people with epilepsy—"the three cardinal virtues" on which the foundation's public education programs are based (Scherer, 2004). Noteworthy results have been achieved during and immediately following multiple Epilepsy Foundation campaigns, including the efforts described below. Results include increased phone calls for information on epilepsy, visits to the foundation's website, and attendance at educational events. However, the cost-effectiveness and long-term impact of these campaigns have not been evaluated to date.

Since the 1970s, Epilepsy Foundation campaigns have focused on improving seizure recognition and awareness and eliminating stigma, although their specific messages have evolved over time (Finucane, 2011). They have employed a variety of media channels at the national level, assisted by state and local Epilepsy Foundation affiliates' efforts to disseminate campaign messages locally.

In the 1970s, the Epilepsy Foundation engaged celebrities in education efforts, and epilepsy advocacy groups and campaigns consolidated.[10]

[10]Prior to this consolidation, which led to the establishment of the present day Epilepsy Foundation, there were four independent nonprofit organizations—the Epilepsy Foundation, the Epilepsy Association of America (also known as the United Epilepsy Association), the

During this period, important policy changes (e.g., disability policies; Chapter 6) were being enacted and the first federally funded epilepsy treatment centers were established. In the next decade or so, from the 1980s to early 1990s, November was declared Epilepsy Awareness Month, and a common campaign theme for epilepsy recognition and awareness was "get the facts," with an emphasis on messages that dispelled misperceptions (e.g., "it's not what you think") and described the sometimes hidden signs of seizures ("is it daydreaming, spacing out, or a seizure?") (Finucane, 2011). For the rest of the 1990s, normalizing messages that conveyed epilepsy as a chronic health condition were dropped in favor of messages that focused on epilepsy as a serious condition that required emergency response to a seizure and appropriate seizure first aid. Campaign messages were both general and tailored to specific audience segments, including women (to change behavior and treatment), older adults ("is it old age or epilepsy?"), and those who interact with people with epilepsy (Finucane, 2011). In the 2000s, campaign activities and educational programs have targeted teens and minority groups (Scherer, 2004) as well as specific professionals, such as school nurses and emergency medical services and law enforcement personnel (Chapter 5).

Epilepsy Campaigns to Reduce Stigma

Examples from epilepsy campaigns offer evidence that strategic education and awareness efforts can reduce stigma with a positive short-term impact on knowledge and attitudes, but there is little evidence to support positive changes in attitudes and beliefs over a longer time frame.

The Entitled to Respect Campaign

In 2001 and 2002, the Epilepsy Foundation partnered with the CDC to promote knowledge about the epilepsies and to increase social acceptance of adolescents with epilepsy (Austin et al., 2006; Epilepsy Foundation, 2001b; Scherer, 2004). The message of the Entitled to Respect Campaign was "that young people with epilepsy, like everyone else, are entitled to respect" (Scherer, 2004, p. 275), and the primary campaign medium was radio. Before the campaign launched in November 2001, a national survey on attitudes and beliefs about epilepsy was distributed to high school students in the areas of 20 local Epilepsy Foundation affiliates, with more than 19,000 surveys returned. These baseline data indicated that about half of youth were not sure whether seizures were contagious, and two-thirds

American Epilepsy Federation, and the National Epilepsy League; each had separate missions and operating functions (Epilepsy Foundation, 1974).

would not know what to do in the presence of someone having a seizure (Austin et al., 2006; Epilepsy Foundation, 2001a,b). The subsequent campaign ran for a full year. In a review of stigma studies, Bandstra and colleagues (2008) questioned why the unfavorable perceptions from the 2001 survey were not explored to determine their origins. No post-test evaluation of the 2001-2002 campaign was conducted; therefore, although the need for the campaign was demonstrated by the national survey, its results are unknown.

In 2003, the campaign was adapted to target African American youth, through a partnership with 66 radio stations with strong reach into African American communities in 22 of the nation's largest urban markets (Epilepsy Foundation, 2001b, 2002; Scherer, 2004). Popular singers and actors served as spokespersons for the campaign's public service announcements, which received 9,900 plays and created 120 million media impressions (80 percent of which were among African American listeners). In addition, 12,000 brochures were distributed by participating stations, and 33 stations provided links to the Entitled to Respect Campaign website. Additional public service announcements were distributed to 1,800 youth-oriented radio stations, for a total of 5,800 broadcasts (Scherer, 2004).

Seizures and You: Take Charge of the Facts

In response to recommendations from the Living Well with Epilepsy II Conference, the Epilepsy Foundation, with CDC support, developed a focused classroom campaign and curriculum called Seizures and You: Take Charge of the Facts that was designed to raise awareness about epilepsy and improve knowledge of seizure first aid (Austin et al., 2006). During the 2006-2007 school year, a training module on basic seizure recognition and first aid, titled "Take Charge," was distributed by state and local Epilepsy Foundation affiliates to science and health teachers nationwide (Epilepsy Foundation, 2009). In June and July, Harris Interactive conducted the 2007 Study on Teen Attitudes and Awareness of Epilepsy Survey of more than 2,000 teens whose demographics were similar to those in the 2001 attitude and awareness study. Results indicated a substantial drop in students who indicated they were "not at all/not too familiar with epilepsy," from 70 percent in 2001 to less than 25 percent in 2007 (Epilepsy Foundation, 2009; Harris Interactive, 2007). Respondents who knew someone with epilepsy were more than twice as likely to say they were "extremely" or "very" comfortable around someone with epilepsy, compared to those who did not (47 versus 20 percent). This suggests that people with epilepsy who are willing to discuss their disorder openly can have a positive and powerful influence on friends and family members. Surprisingly, given the availability of the Take Charge curriculum, only

11 percent of students reported that they received epilepsy information in the classroom, pointing to a potential weakness of the campaign and an area for further development.

Project Access Communication Action Plan

Project Access (also discussed in Chapter 4) is a national initiative, funded by the Health Resources and Services Administration, that launched in September 2004 "to improve awareness and access to comprehensive, coordinated health care and related services for children and youth with epilepsy in medically underserved areas" (Epilepsy Foundation, 2010, p. 5). The public awareness component for the project's eight state demonstration grants funded from 2004 to 2007 had as a main goal to create community action "to improve awareness and understanding of epilepsy, reduce stigma, improve access, and achieve early detection, diagnosis and referral" (Epilepsy Foundation, 2010, p. 6). Target audiences included children and youth with epilepsy and their family members, as well as the general public.

With technical assistance from the Epilepsy Foundation, Ogilvy Public Relations Worldwide, and local community partners, each of the states planned and implemented social marketing outreach, including engagement with diverse communities, media utilization, and evaluation. Some of the tools and products developed by individual states included public service announcements and advertisements that ran on radio and television, in newspapers, and on public transit. Additional print materials were produced for health care providers, families with children who had epilepsy, and other target groups. One grantee estimated that the epilepsy awareness message on public transit reached 36 million riders during the 3 months it ran and 2,916 people attended 69 educational programs (Epilepsy Foundation, 2010).

Lessons Learned

All of these campaign efforts included anti-stigma messages; however, there was little or no measurement of attitudes and beliefs that characterize stigma to determine how they might have changed as a result of the campaigns. Most of the data documented process accomplishments, including audience reach and response in terms of dissemination of messages and materials, attendance at events, callers to 800 numbers, and website visits. The National Teen Survey conducted in association with the Entitled to Respect Campaign was a partial exception in that it provided credible pre-campaign data, but again, data on any changes in teens' awareness and

attitudes were not collected. Prospective data collection over time, using reliable measures for epilepsy stigma, is necessary to help campaign planners assess and compare the impact of different campaign interventions. With data collection throughout the duration of the campaign, especially collection of pre- and post-campaign data on attitudes and behavior, planners will be in a stronger position to know how to allocate future resources most effectively.

Project Access identified important lessons learned from the eight demonstration projects. The lessons emphasize the importance of partnerships and collaboration to the overall success of the project, as well as buy-in from leadership to support the project when challenges arise and alternative approaches are needed (Epilepsy Foundation, 2010). Benefits of partnership and collaboration included

- diversity of input in planning and implementation to better meet community needs,
- improved performance accountability,
- improved learning from a variety of past experiences,
- building support for long-term success and sustainability,
- improved service provider performance, and
- project buy-in from community leaders.

Examples of Non-Epilepsy Health Campaigns to Reduce Stigma

The experiences of health campaigns that have focused on stigma associated with other conditions and those that have targeted specific audiences offer lessons to inform epilepsy campaigns. The following section provides a brief overview of lessons learned from campaigns that focused on HIV/AIDS, mental health, and youth.

HIV/AIDS Campaigns

Interventions to reduce stigma around HIV/AIDS have successfully used a variety of strategies, including information dissemination and personal contact with individuals with HIV/AIDS, with the combination of several interventions yielding the strongest effects (Brown et al., 2003). However, efforts to reduce HIV/AIDS stigma have had mixed results (Herek et al., 2002), because the disease is entangled with public attitudes concerning intravenous drug users, homosexuality, and sexual behavior (IOM, 2001). Little research is available to guide the individual who is newly diagnosed with HIV on the best approaches to confront stigma, including whether to talk to other people about the diagnosis or to conceal it (Rintamaki and Weaver, 2008).

In the United States, most efforts to reduce HIV/AIDS stigma have been targeted primarily to individuals, rather than population-level audiences.[11] In other countries, especially African countries where the majority of the population knows someone with HIV or AIDS, stigma interventions are aimed at the community level (Brown et al., 2001). However, evaluations to measure impact have not been well documented. In most cases, an evaluation was not conducted or was not rigorous enough to demonstrate any effects of intervention. Limitations cited by researchers include the lack of studies with formative research that focus on stigma (Sengupta et al., 2011) and the lack of evaluations that include follow-up over time.

Mental Health Campaigns

In the United States, the mental health community has attempted to ameliorate stigma through both national campaigns and grassroots strategies. In 1999, a Surgeon General's report on mental health declared stigma a public health concern (HHS, 1999), and the President's New Freedom Commission on Mental Health (2003) called for a national campaign to reduce stigma and encourage people to seek care for mental health concerns.

Results from the 2006 General Social Survey indicate that the public's acceptance of mental health conditions as a neurobiological disorder had increased since the 1996 General Social Survey, when data on this topic were first collected, along with an increased belief in the benefits of treatment and hospitalization (Pescosolido et al., 2010). However, the public's acceptance of people with mental health conditions and the attitudes associated with stigma have not improved, motivating the authors to call for strategies that emphasize the competence of people with mental health conditions and the need for their inclusion in all areas of society.

In 2007, similar findings from 35 states[12] indicated that more than 85 percent of respondents agreed that treatment could help people with mental health conditions, but far fewer (slightly more than 57 percent) believed that people are generally caring and sympathetic toward those with mental health conditions (Manderscheid et al., 2010). Only one-fourth of people who had a mental health condition responded positively to the second statement. The authors called for public education to help people understand how they can support individuals with these conditions and for local programs and media to decrease negative stereotypes that prevent people from seeking treatment.

The Substance Abuse and Mental Health Services Administration has a three-pronged approach to stigma reduction in mental health: (1) public

[11] A notable exception is the CDC's "Greater Than" campaign: http://www.greaterthan.org.

[12] The survey results are from questions related to mental health that were part of the 2007 CDC's Behavioral Risk Factor Surveillance System survey.

education campaigns to counter misperceptions, (2) reward and protest strategies to respond to stigmatizing media coverage and business practices, and (3) the contact approach—to encourage interpersonal interactions between people with mental health conditions and the general public (Corrigan et al., 2001; Marshall, 2011). The campaign, titled What a Difference a Friend Makes, is based on a peer support recovery model, with public service announcements, a dedicated website, and social media components to reinforce campaign messages among 18- to 25-year-olds. Most noteworthy is the extensive evaluation undertaken to measure campaign impact. An Ad Council survey tracked the number of young adults who supported friends with mental health conditions, as well as any decreases in stigma around mental health. Additional evaluations were conducted using the HealthStyles Survey and a survey from the CDC's Behavioral Risk Factor Surveillance System, as well as a study conducted by the National Institute of Mental Health. Evaluation results indicate that respondents exposed to campaign messages were more likely to say they would support a friend with a mental health condition and more likely to discuss these conditions with friends and family (Marshall, 2011). Suggestions for successful campaign design deriving from this experience include that it should

- be of at least 3 years' duration,
- have clearly defined targets and results,
- involve extensive pre-testing of materials,
- include frequent distribution of new materials to drive media coverage, and
- employ multifaceted approaches, including a variety of web and mobile materials and strategies.

The National Alliance on Mental Illness (NAMI) is a nonprofit organization that advocates for improved services and develops support and educational programs to educate the general public, people with mental health conditions, and family members about mental health conditions.[13] To take on the problem of stigma, NAMI has adopted five strategies: praise, protest, personal contact, partnerships, and advocacy (Carolla, 2011). The protest strategy is operationalized through NAMI's Stigma Busters Program, which identifies negative portrayals of mental health conditions in the media and brings the portrayal to the media outlet's attention for remedial action and public education. In Our Own Voice and NAMI Walks are two programs that respond to stigma through personal presentations by, and community involvement of, people with mental health conditions (NAMI,

[13]See http://www.nami.org.

2011, 2012). Development of important partnerships and increased community awareness are considered significant outcomes that result from these types of programs.

Youth-Focused Campaigns

Two health campaigns that target youth are particularly informative for epilepsy, because youth are a priority target for epilepsy education and awareness. The American Legacy Foundation's well-funded Truth Campaign and the CDC's VERB campaign both have a long-term goal of preventing disease through reduced tobacco use and increased physical activity, respectively.

Since 2000, the American Legacy Foundation's Truth Campaign has focused on the prevention and cessation of youth tobacco use to prevent short- and long-term health consequences. To reach youth who are at greatest risk, the campaign has to overcome substantial challenges, such as the longstanding use of tobacco as a form of teenage rebellion and young people's disinterest in health risks that lay far in the future. Early evaluations of the Truth Campaign demonstrated impressive declines in youth smoking rates, with 22 percent of the decline between 1999 and 2002 attributed to the campaign (Farrelly et al., 2005). In more recent years, the campaign's awareness ratings have extended beyond the target age group of 12- to 17-year-olds to reach 18- to 24-year-olds. A majority of this older group is aware of the campaign, and about half of the reported antismoking attitudes and beliefs in this group are associated with the campaign (Richardson et al., 2010). However, these beliefs were only marginally associated with older teens' intention not to smoke or to quit smoking. A cornerstone of the foundation's work in tobacco prevention and control that has proven to be successful is youth activism, which engages youth in a range of activities including a fellowship program, leadership institute, online community, technical assistance, training, briefings on Capitol Hill, and an alumni network (American Legacy Foundation, 2012).

About the same time the Truth Campaign started, the CDC launched the VERB campaign to promote youth physical activity and reduce obesity and its associated chronic health conditions. The VERB campaign illustrates the power of paid advertising and social marketing approaches to create awareness of campaign messages and to positively influence youth behavior within a short period of time. The VERB campaign operated from 2002 to 2006 and was congressionally funded (Berkowitz et al., 2008; Cavill and Maibach, 2008; CDC, 2007; Wong et al., 2008). The campaign organizers invested in and planned evaluation mechanisms from the start. After a year of paid advertising, Huhman and colleagues (2005) reported that 74 percent of surveyed children were aware of the VERB campaign, and this

awareness was associated with higher levels of physical activity (up to 34 percent) in several groups of children, compared to children unaware of the campaign. Higher levels of physical activity were found for 9- to 10-year-olds, girls, youth whose parents had less than high school education, youth in urban areas, and youth with low levels of physical activity at baseline (Huhman et al., 2005). Campaign organizers were encouraged by these results because awareness is the first step in changing attitudes and behavior. The authors also noted the importance of the message that physical activity is a fun social activity with friends, which may have had the strongest influence on the younger audience of 9- to 10-year-olds and girls, who generally have lower levels of physical activity. Importantly, advertisements were realistic, portraying activities that were appropriate for the environments in which the target groups of children lived.

Lessons Learned

The campaigns discussed in this section offer several lessons for the epilepsy community:

- Engaging target audiences in the development of campaigns can increase efficacy.
- Multiple interventions increase the success of stigma reduction efforts.
- A variety of strategies and ongoing activities is required to reach campaign goals.
- Peer support can be a powerful and effective strategy to reduce stigma.
- Youth who are engaged as activists can have a significant influence on peer behavior.
- Paid advertising can be an effective way for a social marketing campaign to engage high-risk target audiences and community members from the beginning. However, this approach may be costly.
- Both short- and long-term evaluations are necessary to understand successes and shortcomings and to plan for future campaigns.

Health Literacy and Cultural Considerations

An improved understanding of epilepsy is needed by the general public and specifically among groups with limited health literacy and those with unique cultural backgrounds and beliefs. Since nearly half of adults in the United States have limited health literacy in terms of their ability to understand and act upon health information (IOM, 2004), all public education

campaigns need to follow the principles of clear communication to ensure that key messages are comprehensible to their audiences.

A 2004 report based on qualitative research conducted to inform a grassroots communications campaign in 15 U.S. cities (StrategyOne, 2004) offers some formative data on African Americans' knowledge and views about epilepsy. More than half of the respondents in focus groups and interviews reported that they had too little information about epilepsy, and about half said they would not know what to do if someone had a seizure. Among those who said they knew what to do, 59 percent said they would put something in the person's mouth, an action that is not appropriate. One in three agreed with statements that people with epilepsy could be dangerous (to themselves or others) and that they should be accompanied by someone most of the time.

Similar studies in Hispanic populations found a lack of information about epilepsy and perceptions that are sometimes influenced by religious beliefs and the fear of death (Lopez, 2004; Sirven et al., 2005). Factors that negatively impact quality of life, such as stigma and restricted living, are often perceived as "sacrifices" that must be endured to earn a place in heaven (Lopez, 2004). Language barriers, reliance on word-of-mouth for health information, and distrust of sources outside the community contribute to poor access to accurate information.[14] In this type of environment, misperceptions are common (e.g., a seizure can be contagious, a person will die if they have a tonic-clonic seizure, a person who has a focal seizure with impairment of consciousness or responsiveness is on drugs or has a mental health condition). Four focus groups with adults were conducted in four U.S. cities by the Epilepsy Foundation (Media Network, Inc., 2003) to learn about the experiences of Hispanic people with epilepsy. A key concern was the lack of knowledge about epilepsy in Hispanic communities. Participants described members of their community as having many misperceptions about epilepsy and its treatment. These serious misperceptions contribute to reluctance to discuss epilepsy openly with others.

In the formative process of a communication and awareness campaign, target audiences must be identified and engaged, including groups with low health literacy, populations with diverse cultural beliefs and backgrounds, and groups whose age, injury status, or health condition puts them at increased risk for epilepsy. Message development and dissemination need to be tailored to take into account the unique needs, health literacy levels, cultural beliefs, and media preferences of these populations.

[14]As in noted in Chapters 4 and 6, parent navigators, medical interpreters, community health workers/promotores de salud, social workers, and others may play a valuable role in bridging language, cultural, and access gaps between health professionals, health services, and people with epilepsy and their families.

Advocacy and Policy Considerations

Everyone knows why people wear pink ribbons, why do we not have this for epilepsy?

–Melinda Heine

Public policy and advocacy for people with epilepsy embrace a wide range of national, state, and local situations and priorities. The Epilepsy Foundation's areas of advocacy emphasis include civil rights, disability and Social Security benefits, family and community support, and public awareness. Advocacy efforts and campaigns target policy makers and influential individuals in order to improve their knowledge and awareness about epilepsy and to enlist their support for people with epilepsy, their family members, and organizations that conduct research, offer treatment, and provide services.

The breast cancer movement offers an example of continuing and successful advocacy and policy achievements, with increased public knowledge and awareness, reduced stigma, and impressive gains in research funding. Braun (2003) described the movement as having four key steps:

- The first step, priming the market, occurred when two First Ladies—Betty Ford and Nancy Reagan—spoke publicly about their breast cancer in 1974 and 1987 (Altman, 1987; Lane et al., 1989; Rosenthal, 2011).[15] Countless other women began sharing their stories about breast cancer through popular media[16] and continue to do so today, through websites, chat rooms, and social media (Bender et al., 2011; Sharf, 2001). Equally important, breast cancer statistics were translated into easily understood messages for the general public.
- The second step, engaging consumers, materialized as guidelines were developed for breast self-exams, mammograms, and clinical breast exams. At the same time, more media coverage and the launch of the Susan G. Komen for the Cure organization[17] in 1982 helped to educate and involve the public and reach audience segments through targeted media.
- The third step, political action, occurred during the 1980s and

[15]The impact of Betty Ford's mastectomy on public awareness was intensified when, 2 weeks later, the vice president-designate's wife, Happy Rockefeller, also underwent a mastectomy (Medicine: Breast cancer: Fear and facts, 1974).

[16]A prominent example was television journalist Betty Rollin's memoir, *First, You Cry*, published in 1976, which received (partly because of her media connection) tremendous publicity and further opened the public discussion about the emotional side of breast cancer and mastectomy (Lerner, 2001).

[17]See http://ww5.komen.org/Default.aspx.

1990s, when breast cancer advocates joined forces with the research community, which developed federal standards for mammography and gained quadrupled research funding in the 1990s.
- The fourth step, going mainstream, established a strong base of ongoing support. This was achieved through extensive, creative partnerships with members of the business, government, sports, and scientific communities.

Since policy makers are members of the viewing public, they can be influenced by popular television programs as well. For example, after experts from the National Cancer Institute briefed writers and producers from the TV show *ER* about the patient navigator program for underserved individuals with cancer, the scriptwriters developed a story line that appeared in a program episode in early 2005. As a result, viewers heard about the patient navigator service and its benefits and about misinformation that was preventing some individuals from seeking early care for cancer. An important unintended effect of the *ER* story line was that congressional staff members and members of Congress viewed clips of the episode and discussed it, just prior to passing H.R. 1812, the Patient Navigator Outreach and Chronic Disease Prevention Act of 2005 (Marcus et al., 2010).

Grassroots media advocacy has resulted in enforcement and changes in a variety of health policies at state and local levels, as well. The following examples demonstrate the power of individuals and communities to mobilize and engage media for policy purposes:

- The Community Trials Project in Berkeley, California, used media advocacy to raise community awareness of alcohol abuse and driving under the influence (DUI) enforcement efforts. The project was shown to be more effective than a public information campaign and demonstrated that community members, including volunteers, could be trained to generate local news coverage about DUI enforcement in electronic and print media (Holder and Treno, 1997). With increased awareness of enforcement, drivers may have been more likely to avoid driving under the influence of alcohol.
- In 2005, Autism Speaks,[18] a national organization founded by the former chairman of NBC Universal and his wife after their grandson was diagnosed with an autism spectrum disorder, began advocating for health insurance to cover treatment and services for children with autism spectrum disorders (Ursitti, 2008). At the time, few states required this coverage, and most insurance companies did not offer it. Through outreach efforts to media,

[18]See http://www.autismspeaks.org.

stories about treatment needs and challenges were presented on the *Today Show*, NPR, and CNN, and articles appeared in the *New York Times*, *Los Angeles Times*, *Boston Globe*, and *Washington Post*. In addition to media outreach, the organization created a website that included state-by-state updates, access to resources, news updates, and legislative information. During this same time, under the auspices of Autism Speaks, families shared their stories in state legislative and committee sessions and, in some cases, with state news media. By 2008, seven states had passed laws requiring insurance coverage for children with autism spectrum disorders. As of February 2012, 29 states have such laws, 14 others are pursuing reform (Autism Speaks, 2012).

- Epilepsy California was a collaboration among three local Epilepsy Foundation affiliates that led advocacy efforts focused on the California legislature to pass Senate Bill 161 in 2011. The bill allows teachers and other nonmedical school personnel to be trained to give emergency Diastat medication to students with epilepsy who have a seizure at school (Epilepsy California, 2011). Communications strategies included e-mails to stakeholders requesting they contact legislators, letters to the governor from neurologists, op-eds in daily newspapers, working with reporters to obtain news stories, and radio interviews (Personal communication, Jill Cabanillas, Epilepsy Alliance, October 27, 2011).

In summary, these organizations and efforts offer examples that may help inform epilepsy public awareness and education efforts. Specifically, they illustrate the important roles that volunteers and families can play in garnering media attention and promoting change at the national,[19] state, and local levels—to achieve greater public awareness and education to reduce stigma, increase funding, support the development of new guidelines, encourage policy reform and enforcement, and even accomplish insurance reform. In the current economic environment, mobilizing families, volunteers, and organizational partners is critical to effectively communicate the challenges of epilepsy and other educational messages. By sharing their stories, as people with epilepsy and their families did during the Institute of Medicine committee's workshops and the advocacy effort for Senate Bill 161 in California, they become vital members of the public education effort.

[19]One recent example of a national-level effort to promote change and improve awareness was the introduction of H.R. 298, in the U.S. House of Representatives on June 3, 2011, which was developed in order to recognize the "need for specified agencies to coordinate and capitalize on existing programs for epilepsy awareness" (Govtrack.us, 2011).

HIGH-PROFILE INDIVIDUALS MAKING A DIFFERENCE

In addition to families and individuals who share their personal stories, carefully selected public personalities and celebrities who openly discuss a health condition can increase understanding of the condition and foster greater acceptance throughout society. People often become involved in a celebrity's narrative and may be inspired to care about a disease or disorder that is beyond the concerns of their own life and family (Beck, 2005). Brown and Fraser (2004) noted that it takes more than information to capture the public's attention, the celebrity's ability to engender emotional impact can lead to behavior change. Many celebrity stories have brought global attention to health concerns, reduced stigma, and influenced improvements in public education, public health, prevention, research funding, and policy.

In addition to the attention to breast cancer stimulated by the public stance taken by Betty Ford and Happy Rockefeller in 1974 and Nancy Reagan 13 years later (Altman, 1987; Lane et al., 1989; Rosenthal, 2011), two other announcements that similarly and immediately launched public dialogue and increased prevention and screening were Magic Johnson's revelation of his HIV-positive status and Katie Couric's campaign to promote colorectal screening after her husband died from colon cancer (Brown and Basil, 1995; Casey et al., 2003; Cram et al., 2003). Magic Johnson's greatest impact was on youth, who already closely identified with him as a popular professional basketball player. The important mediating influence was emotional, which had not characterized prior HIV informational messages that were prevalent, but often ignored. Katie Couric's story and resultant educational campaign helped to open public dialogue about the importance of colonoscopy, a procedure people often dread and generally consider inappropriate for public discussion. Both examples conveyed awareness that "anyone can be affected," and the resulting campaigns increased knowledge about these diseases and arguably reduced the stigma associated with testing.

Michael J. Fox, who began an open discussion of his Parkinson's disease in 1998 (Michael J. Fox Foundation for Parkinson's Research, 2012), raised awareness of this neurological disorder with the same candor as the other celebrities cited above, but with some differences over time that are worth noting. The public has witnessed him living, acting, and aging with a disease that began when he was relatively young (he was diagnosed with early-onset disease at age 30 and publicly acknowledged it at age 37 [Michael J. Fox Foundation for Parkinson's Research, 2012]). His situation contrasts sharply with the experience of most people who develop Parkinson's disease later in life; the average age of onset is 60 years old (NINDS, 2004). He pursues an active and inspiring public life and career, despite his disability and dyskinesia, which causes the tremors and tics associated

with Parkinson's. In 2000, Fox established the Michael J. Fox Foundation for Parkinson's Research.[20] The foundation's success started with the dedication and efforts of its founder, but the annual reports and website also emphasize the critical role of volunteers, families, partnerships, and collaborations in maintaining its operations and the success of its fundraising and research. Fox also has appeared before Congress to advocate for more government funding for Parkinson's research.

Public figures and celebrities offer unique opportunities for building awareness, education, and advocacy and for increasing acceptance of people with the disorder. Policy makers and other leaders are often receptive to celebrities and high-profile individuals when they testify, participate in public forums, and "put a face on" a medical condition.

IMPROVING CAMPAIGNS TO ELIMINATE STIGMA

Public education and awareness campaigns are most often designed to communicate key campaign messages through mass media channels, such as television, radio, print, and other media (e.g., the Internet, DVDs, mobile devices), as well as through media targeted to specific groups. Over decades of evaluation, the literature supports the notion that mass media campaigns can influence large numbers of people to modify or avoid behavior that leads to disease, addiction, or injuries. Jacoby and Austin (2007) argued that disability and associated stigma are a social construct, so they are amenable to change. Lo and colleagues (2010) noted that epilepsy stigma is the result of misperceptions that flourish in the absence of authoritative, accepted information, which well-launched and well-presented campaigns can provide.

The National Cancer Institute's "pink book" details how to develop health communication campaigns and discusses their potential for changing social norms—that is, the beliefs and attitudes that contribute to stigma:

> Society as a whole influences individual behavior by affecting norms and values, attitudes and opinions, laws and policies, and by creating physical, economic, cultural, and information environments. Health communication programs aimed at the societal level can change individual attitudes or behavior and thus change social norms. (NCI, n.d.)

People with epilepsy believe that education and awareness campaigns would help to reduce stigma in the general public (Paschal et al., 2007). Experts suggest that stigma needs to be tackled head on for longer-lasting effects (Birbeck, 2006). In a review of stigma studies, Bandstra and col-

[20]See http://www.michaeljfox.org.

leagues (2008) noted that "few interventions have specifically addressed the stigma associated with epilepsy" among the general public.

When the Carter Center hosted an international meeting on mental health stigma in 2009, participants identified three components of successful anti-stigma campaigns for the public: (1) a focus on positive rather than negative messages (what you can do rather than what you should not do), (2) a plan for long-term sustainability, and (3) an evaluation that is planned and conducted from the beginning of the campaign, allowing evaluators to track data over time (Carter Center, 2009).

The literature supports similar components, noting that the success of public health campaigns relies on several factors, including targeted, well-executed campaigns that are strategically designed to achieve behavior change (Noar, 2006) and the availability of resources, community programs, and policies to reinforce behavior change (Wakefield et al., 2010). If the desired changes are going to be sustained over time, campaigns must be ongoing. Shorter campaigns may temporarily increase knowledge (Evans-Lacko et al., 2010) but are less likely to achieve the more difficult changes in attitudes, beliefs, and behavior.

In short, efforts to reduce the stigma associated with epilepsy will require a commitment to long-term campaigns that stimulate broad-based community support and participation, supportive policies, and the resources for sustainability, in order to ensure that interventions and evaluations can be maintained at a level where they can both make a difference and document it.

CONCLUSION

In the summary report of the 2003 Living Well With Epilepsy II Conference, the work group on quality of life called for research to "assess the impact of public education campaigns and specific messages on social stigma and apply the results to future campaigns" (AES et al., 2004, p. 25). In a 2009 report, the Epilepsy Foundation proposed that a desirable goal for a social marketing campaign to reduce epilepsy stigma would be for the majority of people in a community to agree that epilepsy does not have a stigma (Epilepsy Foundation, 2009), with the implication that community members' attitudes and behavior would support this belief. Numerous other studies and reports that discuss the well-being of people with epilepsy recommend public education in order to remedy society's lack of knowledge, misinformation, and stigmatizing attitudes and behavior.

The committee agrees with these previous recommendations and proposes some goals for consideration in future public awareness and education campaigns, recognizing that formative research and data will dictate specific goals for the general public and for target audiences:

- Promote core public knowledge about epilepsy:
    - Epilepsy is a common brain disorder that affects men, women, and children of all ages, races/ethnicities, and socioeconomic backgrounds.
    - Epilepsy is a spectrum disorder that varies in severity, causes, treatments, and outcomes and is not contagious.
    - Epilepsy can be a serious, life-threatening disorder with great impact on health and quality of life, including increased risk of injury and death.
    - Nearly two out of three people with epilepsy control their seizures with medication.
    - Epilepsy specialists and centers have the expertise to treat and manage complex cases with both time-tested and new therapies and procedures, including surgery.
    - Anyone can learn basic first aid to help someone when a seizure occurs.
    - Most people with epilepsy are fully functioning members of society, with responsibility for jobs, families, and all aspects of life.
    - The stigma associated with epilepsy can cause serious harm to the physical, mental, and social well-being of a person with epilepsy.

- Increase positive attitudes and behavior, so that
    - people feel comfortable around someone who has epilepsy;
    - parents believe it is all right for their child to be around someone with epilepsy;
    - teachers, employers, and colleagues understand that a person with epilepsy can be just as reliable and smart as someone without epilepsy;
    - society supports the right of a person with epilepsy to marry and have children;
    - no one would be embarrassed to have a family member with epilepsy; and
    - everyone knows how to help someone having a seizure.

Throughout this chapter, the committee has provided the basis for its research priorities and recommendations regarding improvements needed in educating the public about epilepsy, which are detailed in Chapter 9. In order to improve public awareness and knowledge, additional efforts need to be devoted to informing journalists as well as writers and producers in the entertainment industry, engaging people with epilepsy and their

families in public awareness efforts, coordinating public awareness efforts and developing shared messaging, and ensuring that all campaigns include rigorous formative research, considerations for health literacy and audience demographics, and mechanisms for evaluation.

With the broad base of support and collaboration demonstrated by members of Vision 20-20, the epilepsy community is positioned to embrace a coordinated communication planning effort to improve public awareness and education and reduce stigma. Recognizing the challenges and barriers associated with the current economic climate, the planning and implementation of a large-scale, nationwide public awareness campaign will, more than ever, require creative partnerships and collaborations. Developing new partnerships—both within and outside the epilepsy field, identifying common goals, and exploring key strategies and messaging will take time, but first steps could begin now. The planning process should be informed by new data from national surveys, an understanding of the diverse media through which the public receives health information, and lessons from past health campaigns.

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9

Next Steps and Recommendations

People with epilepsy face a number of challenges, from living with seizures and comorbidities to dealing with side effects of treatments and the increased chance of early death. They encounter a health system that does not consistently provide care that is accessible and of high quality and value, and their care is poorly coordinated among health care providers and across health care and community services. To provide high-quality care, the health professionals who care for people with epilepsy need to know more about epilepsy, its diagnosis, and its treatment and management, as well as its comorbidities and the risk of premature death. Given the range of effects that epilepsy has on quality of life, people with epilepsy and their families often need a variety of community services, but work remains to ensure that these services are consistently available and evidence based. Furthermore, people with epilepsy and their families have significant information needs about epilepsy and its management, which must be appropriately communicated and tailored to their specific situations (e.g., age, gender, cultural background, literacy level). Finally, many people with epilepsy continue to confront stigma, which results from society's limited awareness and understanding of epilepsy. Underpinning all of these challenges are significant gaps in information about the number of people who have epilepsy, the health care and other services they use, and opportunities for prevention of epilepsy and its range of consequences.

Given the current gaps in epilepsy knowledge, care, and education, the committee believes 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 following 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.

INCREASING THE POWER OF DATA AND PREVENTING EPILEPSY

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 and nationally representative, enabling subgroup analysis by epilepsy type, population characteristics, and environmental factors. The nation's data collection efforts should be sufficiently robust to support active research projects on specific topics, but large amounts of data also can be collected passively, including through the increasing use of electronic health records, where well-designed databases can be mined for new insights. Given the ambition of this goal and the current economic environment, the committee has identified several priority areas that need attention, in order to improve the collection and utilization of epilepsy data over time:

- Surveillance data must be up to date, representative of the U.S. population, and collected using standardized methods to ensure validity and comparability across studies.
- Multiple data sources have to be linked to capture all of the necessary data on people with epilepsy and to avoid duplicate counting. New data sources, including those that may develop under health care reform, need to be reviewed for their potential to contribute to an understanding of epilepsy.
- Once more robust data are available, analyses should be performed to determine overall incidence, prevalence, health disparities, services use and costs, quality of and access to care, risk factors, comorbidities, health status, and quality-of-life outcomes, as well as data for specific subgroups.

A variety of efforts is needed to accomplish comprehensive surveillance of the epilepsies, close current knowledge gaps, and adequately inform policy makers, public health agencies, health care providers, and the general public. Coordinated action on multiple fronts will ensure the collection of epilepsy-related data from a range of data sources.

The strengthened usefulness and diversity of data, as described above, would facilitate the identification of risk factors for epilepsy, comorbidities, and adverse events. Risk factor identification is an important first step in designing programs to prevent epilepsy and its most serious consequences. At present, many research questions and gaps remain where more complete information could provide a sound basis for prevention, including in public health, clinical care, education programs, and community efforts.

Box 9-1 RESEARCH PRIORITIES FOR IMPROVING SURVEILLANCE AND PREVENTION

To improve surveillance and prevention of epilepsy and its consequences, the following areas should be considered priorities for future research:

- Studies to identify effective interventions for epilepsy accompanied by mental health comorbidities
- Studies that test whether treatment of comorbid mental health conditions ameliorates adverse outcomes
- Case-control studies of risk factors for injuries, suicide, status epilepticus, and sudden unexpected death in epilepsy (SUDEP)
- Population-based studies using existing data resources that have included epilepsy, such as the National Survey of Children's Health
- Studies to examine the capacity of data systems to link seizure medication use and birth outcomes
- Continued research on the risk factors for epilepsy of unknown, genetic, or presumed genetic cause[a]
- Studies on the directionality of the relationship between epilepsy and its comorbidities, risk factors for developing an epilepsy comorbidity, and prognosis of epilepsy in people with comorbidities present before the onset of epilepsy
- A longitudinal study that examines epilepsy's outcomes (for example, a study of cognition in people with different syndromes, seizure types, and seizure frequencies that includes a sufficient number of older adults to enable studies of risk factors for cognitive deterioration)
- Long-term prospective studies that examine the effects of epilepsy surgery on cognitive function and that include appropriate control groups
- 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
- Evaluation of behavioral interventions on health outcomes and quality of life for people with epilepsy
- Development of screening methods and criteria to identify children with epilepsy and cognitive comorbidities through the use of educational records

[a]Previously known as idiopathic or cryptogenic.

RECOMMENDATION 1 ***Validate and Implement Standard Definitions and Criteria for Epilepsy Case Ascertainment, Health Care and Community Services Use and Costs, and Quality-of-Life Measurement***
The Centers for Disease Control and Prevention (CDC), in collaboration with professional organizations (e.g., the American Epilepsy Society [AES] and International League Against Epilepsy [ILAE]) and other federal entities, including the Centers for Medicare and Medicaid Services, Department of Defense, Department of Veterans Affairs, and National Institutes of Health (NIH), should fund demonstration projects to validate and implement standard definitions for epilepsy case ascertainment, health care and community services use and costs, and measures of quality of life for use in different data collection systems and for different specific objectives. Once validated, these definitions and criteria should be adopted by funding agencies and used in surveillance and research, which is the basis for planning and policy making.

RECOMMENDATION 2 ***Continue and Expand Collaborative Surveillance and Data Collection Efforts***
The CDC should continue and expand its leadership in epilepsy surveillance and work with state and local public health researchers, academic researchers, and other relevant stakeholders (including other agencies within the Department of Health and Human Services). Surveillance efforts should be funded that use large, representative samples to determine the overall incidence and prevalence of epilepsy—and mortality—over time as well as in specific populations (e.g., different types of epilepsy, ages, genders, races/ethnicities, socioeconomic statuses). Data collection efforts should include the following:

- Population health surveys should expand their questions about epilepsy, its comorbidities, and health care services use and include these questions more frequently and consistently.
- Existing registries for comorbid conditions, such as the Surveillance, Epidemiology, and End Results program and state-based cancer registries, state-based Alzheimer's registries, and the Interactive Autism Network, should collect data on epilepsy.
- Efforts should be expanded to standardize the practices of coroners and medical examiners in evaluating and recording cause of death in people with epilepsy with the goal of working toward a national epilepsy-related death registry.
- Pilot projects should explore the linkage and use of emerging data collection and sharing partnerships using electronic health records and other electronic repositories (e.g., all-payer claims databases, regional health information organizations, the Health Maintenance Organization Research Network, NIH's Health

Care Systems Research Collaboratory, the Health Care Cost Institute) for epilepsy surveillance and research.
- Epilepsy-specific data should be included in the NIH National Children's Study and future longitudinal studies.

RECOMMENDATION 3 ***Develop and Evaluate Prevention Efforts for Epilepsy and Its Consequences***
The CDC should partner with the World Health Organization, ILAE, NIH, the Action Alliance for Suicide Prevention, and other stakeholders to develop and evaluate culturally appropriate and health literate prevention efforts that focus on

- preventing neurocysticercosis in high-risk populations;
- continuing prevention efforts for established risk factors of epilepsy (e.g., traumatic brain injury [TBI], stroke, brain infections such as meningitis);
- preventing continued seizures in people with epilepsy and depression;
- reducing felt stigma; and
- preventing epilepsy-related causes of death, including accidents and injuries, sudden unexpected death in epilepsy (SUDEP), and suicide.

IMPROVING HEALTH CARE

The many challenges that people with epilepsy and their families face are so diverse, even from a medical point of view, that although treatment must continue to be held to high standards, it nevertheless should be tailored to individual patient needs and characteristics, and no single health professional discipline can provide all of the elements required for high-quality epilepsy care. Historically, persuading health professionals to work across professional boundaries has been difficult. One of the challenges for government and institutional policy makers will be to devise organizational structures and incentive systems that make it easy—even attractive—for people from multiple professions to work together.

Throughout this report, the committee has emphasized a number of important elements of epilepsy care including

- *patient centeredness*, recognizing that the "patient" may include the family, that people with epilepsy are more than their medical condition, and that quality-of-life factors are also important;
- *co-management* for patients with comorbid conditions whose care may cross specialty boundaries;

- *coordination*, involving a team of professionals across disciplines and sectors (e.g., housing, education, employment);
- *community orientation*, with the engagement of as many community resources as needed; and
- *education focused*, in order to improve the self-management skills of people with epilepsy and their family members, clinicians' knowledge and skills, and the awareness and understanding of others who interact with people with epilepsy (e.g., teachers, social workers, emergency personnel).

Even in an ideal system of care, the epilepsies will remain complex to diagnose and treat. While significant progress has been made in developing seizure medications with fewer adverse effects, as well as in refining medical devices and surgical techniques for select types of epilepsy, much remains to be done to reduce the sometimes lengthy delays in diagnosis and referral to more advanced levels of care, to improve care for those with refractory epilepsy, and to provide a better response to comorbidities, including mental health conditions. While this committee was asked not to explore biomedical research, over time there will be advances in this field that need to move into routine care in a timely and equitable fashion. No matter how specific epilepsy treatments have improved, currently care is not uniformly accessible due to geographic, economic, and other considerations; nor is it necessarily equitable, with troubling disparities suggested in the research that are based on racial/ethnic and socioeconomic factors. High-quality health care for epilepsy cannot be provided on a population basis until the problems of accessibility and equity are resolved.

An important element in high-quality care is access to specialized epilepsy centers, especially for people with refractory epilepsy. Epilepsy centers are vital in providing specialized epilepsy care and have the potential to build on their current efforts by forming a network for health professional education, clinical research, and data collection and analysis. To ensure the ongoing quality of their work, as well as appropriate recognition for it, the centers should develop a robust external accreditation process. A national quality measurement and improvement strategy for epilepsy should be developed and implemented. Standardization and implementation of quality metrics will hold health care providers accountable for adherence to practice guidelines and will allow people with epilepsy and their families to have more information in selecting care providers.

Expanding access either to specialized epilepsy care or to high-quality care in community settings is hampered by the shortage of clinicians with adequate knowledge and skill related to epilepsy and its comorbidities. Research suggests that primary care and specialist physicians alike have significant gaps in knowledge about epilepsy. Further, many types of health

Box 9-2 RESEARCH PRIORITIES FOR IMPROVING HEALTH CARE

To improve health care for people with epilepsy, the following areas should be considered priorities for future research:

- Development of methods for early identification of and new treatment approaches for refractory epilepsy
- Development of screening tools (useful in clinic settings) for the early identification of people with epilepsy who have potential cognitive impairments
- Development of decision-support tools for electronic health records for use by primary care and emergency room providers regarding care of persons with epilepsy, the use of screening tests, and referral steps for further evaluation and care
- Comparisons of the efficacy of brand and generic formulations of seizure medications
- Comparative effectiveness studies of epilepsy therapies and of treatments used to manage epilepsy (including reducing medication side effects) and comorbidities, with initial attention to setting priorities for this research
- Health services research on the provision and effectiveness of epilepsy care by primary care providers, neurologists, and epileptologists, including referrals to epilepsy centers and to specialists for care of comorbidities
- Assessment of differences in the utilization of epilepsy health care services, particularly for underserved populations
- Studies of the capacity of the workforce that cares for people with epilepsy
- Studies that examine value measures for epilepsy care as well as potential reductions in health care costs through changes in access to specialized care and improved coordination with providers caring for comorbid health conditions
- Analysis of cost savings by reducing emergency department use and hospitalizations
- Assessment of incentive strategies for the participation of clinical staff in collaborative service models and co-management of complex cases, including strategies to promote timely referral to surgery, mental health services, and higher levels of care

professionals, in addition to physicians, are involved in epilepsy care. These include nurses, nutritionists, pharmacists, psychologists, and clinical social workers. These professionals also must be current in their understanding of epilepsy and its treatment, as well as the array of educational and community resources that may be available to and needed by individual patients.

RECOMMENDATION 4 ***Improve the Early Identification of Epilepsy and Its Comorbid Health Conditions***

The AES and the American Academy of Neurology (AAN) should lead a collaborative effort with the wide range of relevant professional organizations (including primary care professional organizations) and federal agencies (including the CDC and Health Resources and Services

Administration), and others that promote and disseminate screening programs to

- develop and validate screening tests for the early identification of epilepsy in at-risk populations (e.g., people with developmental disabilities; people with mental health conditions; people who have had a TBI, brain tumor, or stroke);
- establish and disseminate a standard screening protocol for people with epilepsy that implements screening on a regular basis for comorbidities with currently approved screening tests (e.g., for bone disease, depression, generalized anxiety disorder); and
- establish and disseminate a screening tool for the early identification of patients with persistent seizures that would lead to earlier referral to an epileptologist for further diagnosis and treatment.

RECOMMENDATION 5 ***Develop and Implement a National Quality Measurement and Improvement Strategy for Epilepsy Care***

The AES, in conjunction with other professional organizations involved in epilepsy care, education, and advocacy (including primary care professional organizations) should initiate the development of a national quality measurement and improvement strategy for epilepsy care. An independent organization with expertise in quality measurement and care should assist in the development of the national strategy, particularly the development of performance metrics. The national quality improvement strategy should

- develop and implement a plan to disseminate existing clinical guidelines and educate health professionals and people with epilepsy and their families about them;
- define performance metrics for epilepsy with specific attention to access to care for underserved populations, access to specialized care, co-management of care among all health care providers, and coordination of care with other health care providers and community services organizations;
- continue the development and implementation of a set of performance metrics that includes patient-generated measures; and
- develop demonstration projects to validate performance metrics and test the feasibility of tracking outcomes of care.

RECOMMENDATION 6 ***Establish Accreditation of Epilepsy Centers and an Epilepsy Care Network***

The National Association of Epilepsy Centers and the AES should collaborate with relevant organizations to establish accreditation criteria

Box 9-3 RESEARCH PRIORITIES FOR IMPROVING HEALTH PROFESSIONAL EDUCATION

To improve health professional education about epilepsy, the following areas should be considered priorities for future research:

- Identification of knowledge gaps across health professions that relate to areas such as seizure recognition and classification; new treatment options; sudden unexpected death in epilepsy (SUDEP); and appropriate treatment modalities for specific subpopulations, including infants and children, women, individuals with severe epilepsy syndromes, people with complex comorbidities, and older adults
- Development and testing of educational interventions and incentives that will expand the reach of education and training opportunities about epilepsy and its associated comorbidities for health professionals outside of the epilepsy field (e.g., primary care, psychiatry, psychology, nursing)
- Assessment of current attitudes and beliefs of U.S. health professionals about epilepsy and the impact of these beliefs and attitudes on stigma and on access to and quality of care
- Evaluation of curricula and content of advanced training programs for physicians, nurses, and physician assistants for epilepsy-specific content and identification of specific opportunities and strategies for improving these types of programs
- Evaluation of innovative teaching strategies, such as online epilepsy education and simulation programs, to determine their suitability as models for a range of health professionals and others who interact with people with epilepsy, including teachers, daycare workers, coaches, and social workers
- Assessment of the format and frequency of educational and training opportunities existing within epilepsy centers in order to establish best practices for engaging clinicians in continuous, interdisciplinary learning
- 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)

and processes with independent external review mechanisms for the accreditation of epilepsy centers. Accredited epilepsy centers should work together to form an Epilepsy Care Network that includes data sharing, clinical trial and other research networking, professional education, and other collaborative activities.

- Independently accredited epilepsy centers should
  - emphasize patient-centered care that focuses on co-management approaches with primary care providers, mental health care providers, and other specialists;

  - ensure that community service providers are an integral part of the centers and actively collaborate with them to link people with epilepsy to services for all facets of the individual's health and well-being;
  - use standardized performance metrics for quality epilepsy care;
  - publicly report on a standard set of quality, outcome, and health services data;
  - provide onsite education and training for epilepsy specialists (e.g., technicians, nurses, researchers, physicians) as well as educational opportunities, particularly continuing education, for other health and human services professionals in the community; and
  - serve as sites for pilot projects on innovative approaches to improving co-management and coordination of care, as well as health care quality, access, and value for people with epilepsy.

- The Epilepsy Care Network of Accredited Epilepsy Centers should

  - conduct collaborative clinical and health services research;
  - collect, analyze, and disseminate quality, outcome, and health services data from all of the accredited centers; and
  - collaborate and partner with state health departments and other health care providers to ensure coverage across rural and underserved areas through telemedicine, outreach clinics, and other mechanisms.

RECOMMENDATION 7 ***Improve Health Professional Education About the Epilepsies***

The AES and AAN should collaborate with relevant professional organizations that are involved in the education of the wide range of health professionals who care for people with epilepsy to ensure that they are sufficiently knowledgeable and skilled to provide high-quality, patient-centered, interdisciplinary care. In their efforts to improve health professional education, these organizations should do the following:

- Define essential epilepsy knowledge and skills for the range of health professionals who care for people with epilepsy and their families.
- Conduct surveys of the relevant health professionals to identify knowledge gaps and information needs.
- Evaluate the efficacy and reach of existing educational materials and learning opportunities (e.g., websites, continuing education courses).

- Develop engaging and interactive educational tools, such as online modules, that meet specific learning needs and could be easily integrated into existing curricula and education programs.
- Ensure that educational materials and programs for health professionals reflect current research, clinical guidelines, and best practices. These educational materials and programs also should convey positive messages that reduce stigma and reinforce the need for (and skills associated with) clear health communication, which takes into account the culture and health literacy of the target audience.
- Explore and promote opportunities to expand the use of innovative interdisciplinary educational approaches, such as high-fidelity simulation.
- Disseminate educational materials and tools widely to health professional educators and other relevant professional associations and organizations.

IMPROVING COMMUNITY RESOURCES AND QUALITY OF LIFE

Epilepsy is much more than seizures. For people with epilepsy, the disorder is often defined in more everyday terms, such as challenges in school, uncertainties about social and employment situations, limitations on driving a car, and questions about independent living. Family members also may struggle with how to best help their loved one and maintain their family life. Because of the range of seizure types and severities and the high rate of comorbid health conditions, the ways in which quality of life is affected by epilepsy vary widely. This report has examined the range of community services—daycare and school, employment, transportation, housing, sports and recreation, and others directed at family support—relevant to improving quality of life for people with epilepsy. The committee urges improvements to community services and programs to ensure that they are

- patient-centered to meet the needs of the person with epilepsy;
- locally focused, taking into account the full range of resources in the area;
- easily accessible;
- thoroughly evaluated;
- closely linked to health care providers, particularly epileptologists and epilepsy centers; and
- innovative and collaborative in working with organizations and agencies focused on other neurological and chronic conditions or on similar service needs.

Box 9-4 RESEARCH PRIORITIES FOR IMPROVING QUALITY OF LIFE AND COMMUNITY RESOURCES

To improve quality of life and community resources for people with epilepsy, the following areas should be considered priorities for future research:

- Development of interventions to identify academic problems and improve academic achievement in students with epilepsy
- Identification of factors that increase the resiliency of the individual and family and of behaviors that improve quality of life
- Evaluations of community programs that go beyond process measures and assess outcomes for people with epilepsy and their families
- Evaluations of the effectiveness of vocational rehabilitation programs
- Identification of creative and innovative models of funding community service providers and collaborations
- Development of performance indicators for vocational and other community services and independent living programs

RECOMMENDATION 8 ***Improve the Delivery and Coordination of Community Services***

The CDC, state health departments, and the Epilepsy Foundation, in collaboration with state and local Epilepsy Foundation affiliates and other relevant epilepsy organizations, should partner with community service providers and epilepsy centers to enhance and widely disseminate educational and community services for people with epilepsy that encompass the range of health and human services needed for epilepsy, its comorbid conditions, and optimal quality of life. These services include support groups; vocational, educational, transportation, transitional care, and independent living assistance; and support resources, including respite care for family members and caregivers. Specific attention should be given to identifying needs and improving community services for underserved populations. These efforts should

- support and expand efforts by the Epilepsy Foundation's state and local affiliates and other organizations to link people with epilepsy and their families to local and regional resources, emphasizing active collaboration among affiliates in the same region or with similar interests;
- develop innovative partnerships and incentives to collaborate with organizations and public-private partnerships focused on other neurological and chronic diseases or disorders;
- conduct and evaluate pilot studies of interventions to improve the academic achievement of students with epilepsy;

- maintain effective private, state, and national programs that assist people with epilepsy regarding transportation, employment, and housing;
- develop and disseminate evidence-based best practices in employment programs for people with epilepsy;
- identify and disseminate best practices for the coordination of health care and community services, including programs using patient and parent navigators;
- provide a 24/7 nonmedical help line offering information on epilepsy and links to community resources (this effort should involve collaboration with similar efforts for related health conditions); and
- develop, disseminate, and evaluate educational and training opportunities (including interactive web-based tools) for community service providers focused on epilepsy awareness and seizure first aid training.

RAISING AWARENESS AND IMPROVING EDUCATION

Patient and Family Education

Education for people with epilepsy and their families plays an important role in adapting to life with epilepsy, developing self-confidence, and becoming competent in self-management, which entails being aware of one's own needs and being able to access resources to meet those needs. Obtaining the requisite knowledge and skills related to epilepsy and its management can also promote optimal well-being and quality of life for people with epilepsy and their families, help prevent misconceptions about the disorder, and reduce concerns about stigma.

People with epilepsy and their families should

- receive and have access to up-to-date, accurate information about epilepsy, treatment options, and associated comorbidities and risks, including SUDEP, as well as information about available vocational and community resources and health care services upon diagnosis and throughout their care;
- have access to information that meets their specific needs and that is clearly written and communicated, appropriate for various health literacy levels, and linguistically and culturally appropriate;
- build knowledge and self-management skills, including how to solve problems, make decisions, use resources, develop partnerships with health care providers, and participate actively in patient-centered care; and

Box 9-5 RESEARCH PRIORITIES FOR IMPROVING PATIENT AND FAMILY EDUCATION

To improve the education of people with epilepsy and their families, the following areas should be considered priorities for future research:

- Assessment of the information needs of specific subpopulations, including women, men, older adults, children and adolescents, youths transitioning to adulthood, racial/ethnic minorities, people with low socioeconomic status, individuals with more severe forms of epilepsy or comorbidities and their families, individuals with cognitive limitations, and individuals with seizure-like events with a psychological basis
- Assessment of information needs associated with epilepsy-related risks such as injuries, suicide, status epilepticus, and sudden unexpected death in epilepsy
- Identification of best practices, effective strategies and preferred formats, and innovative mechanisms for educating patients and families, especially individuals in underserved populations
- Development of a knowledge base to support comprehensive educational programs that feature content for epilepsy-specific self-management as well as relevant aspects of the chronic care management models
- Testing of methods for developing educational programs and resources that appropriately reflect health literacy, cultural diversity, developmental stage, cognitive ability, and gender
- Examination of the role that educational materials and programs, support groups, and counseling resources may play in helping individuals and their families successfully cope with stigma and related concerns, such as the fear of having a seizure in public

- have access to appropriate educational resources and opportunities regardless of their socioeconomic status, demographic group, culture, or geographic location.

RECOMMENDATION 9 ***Improve and Expand Educational Opportunities for People with Epilepsy and Their Families***

To ensure that all people with epilepsy and their families have access to accurate, clearly communicated educational materials and information, the Epilepsy Foundation, the Epilepsy Therapy Project, the CDC, and other organizations involved in Vision 20-20 should collaborate to do the following:

- Conduct a formal evaluation of currently available epilepsy websites and their educational resources to ensure that they meet requirements of clear health communication and are linguistically and culturally appropriate for targeted audiences. This requires thorough testing of content with target audiences, including underserved groups, and revision as necessary.

- Develop a central, easily navigated website ("clearing house") that provides direct links to websites containing current, accurate epilepsy-related information for individuals and their families. This centralized resource should be comprehensive; it should include concise, easy-to-understand descriptions of the information available on the linked websites and up-to-date contact information for epilepsy organizations; and it should be widely disseminated to health care providers and people with epilepsy and their families.
- Ensure that educational resources are up to date, are effective, and reflect the latest scientific understanding of the epilepsies and their associated comorbidities and consequences.
- Engage a wide and diverse spectrum of people with epilepsy and their families in the development of online educational resources to ensure that the content meets the specific needs of target audiences at the outset.
- Support the development, evaluation, replication, and expanded use of self-management and educational programs, including those developed through the Managing Epilepsy Well Network.
- Engage state and local Epilepsy Foundation affiliates, epilepsy centers, and health care systems and providers to expand the dissemination of available educational resources and self-management tools to people with epilepsy and their families.
- Explore the development of a formal, standardized certificate program for epilepsy health educators.

Public Awareness and Knowledge

While surveys have suggested that attitudes regarding epilepsy have become less negative over time, it is not certain how contemporary attitudes compare and whether overall improvements in attitudes have affected behavior. Compelling testimony from families dealing with epilepsy and research on employment suggest that problems of stigma remain widespread. Efforts to increase public awareness and knowledge are motivated by the expectation that information that reduces misconceptions and misinformation will improve attitudes and, ultimately, behavior toward people with epilepsy and thereby reduce stigma. Stigma, whether felt or overtly experienced, has many negative consequences for both health and quality of life, and overcoming it is an important goal for the field.

For the public in general, the news and entertainment media are primary sources of health information. Unfortunately, inaccurate depictions of people with epilepsy and of severe seizures, used for dramatic effect, reinforce negative perceptions. An ongoing effort is needed to create key part-

Box 9-6 RESEARCH PRIORITIES FOR IMPROVING PUBLIC AWARENESS AND KNOWLEDGE

To improve public awareness and knowledge, the following areas should be considered priorities for future research:

- Surveys (e.g., General Social Survey, HealthStyles Survey) that capture trends in knowledge and awareness and attitudes and beliefs about epilepsy over time and in specific subpopulations
- Evaluations of websites seeking to promote accurate knowledge about epilepsy (e.g., Talk About It) to determine effective strategies for educating the public through online resources
- Evaluation of public awareness campaigns that include documentation and analysis of pre- and post-campaign data to assess changes in public understanding of and beliefs about epilepsy and to establish best practices in developing public awareness efforts

nerships within the entertainment media to encourage less sensationalistic portrayals and more opportunities for the passive acquisition of accurate knowledge about epilepsy, recognizing that the entertainment media have limits as educational vehicles. Meanwhile, the news and information (versus entertainment) media can be approached with story ideas about various aspects of epilepsy and its care—new treatments, compelling personal stories, epilepsy in specific population groups (e.g., military veterans), and so on.

Using multiple forms of media, including social media and the Internet, clear messages, and diverse activities targeted to specific audiences would increase the chances of success for stigma reduction and public awareness efforts. Any such efforts should take into account the health literacy and cultural characteristics of target audiences, with different strategies developed for reaching each audience, one of which should be policy makers. Some campaigns for chronic conditions have effectively used high-profile spokespeople. Campaigns can be local or national; the infrastructure of state and local epilepsy organizations could be a valuable resource for extending a national campaign's reach to communities. Successful, multifaceted campaigns are expensive, need to be sustained over a period of years, must include an effective formative evaluation strategy to enable revision of messages and tactics as needed, and yet must be flexible enough to respond to unanticipated opportunities.

RECOMMENDATION 10 ***Inform Media to Improve Awareness and Eliminate Stigma***

The CDC and other Vision 20-20 and relevant organizations should support and bolster programs that provide information to journalists and to writers and producers in the entertainment industry to improve

public knowledge about epilepsy and combat stigma. Efforts to collaborate and engage with the media should include the following:

- Promote more frequent, accurate, and positive story lines about and depictions of characters with epilepsy.
- Continue to encourage high-profile individuals with epilepsy (or high-profile individuals who have family members with epilepsy) to openly discuss their experiences and act as spokespeople.
- Establish partnerships with stakeholders that represent related conditions associated with stigma (e.g., mental health). Efforts could include the development of fellowships or integration of epilepsy information into existing education programs for journalists.
- Continue to work with national and local news media on breaking news about epilepsy research and human interest stories.
- Disseminate regular updates on research and medical advances to journalists and policy makers through a variety of mechanisms, including e-mail updates, listserv messages, social media, and face-to-face meetings.

RECOMMENDATION 11 ***Coordinate Public Awareness Efforts***
The Epilepsy Foundation and the CDC should lead a collaborative effort with relevant stakeholder groups, including other members of Vision 20-20, to continue to educate the public through awareness efforts, promotional events, and educational materials and should collaborate to do the following:

- Establish an advisory council of people with epilepsy and their families, media and marketing experts, private industry partners, and health care experts to meet regularly and to inform future efforts.
- Develop shared messaging that emphasizes the common and complex nature of the epilepsies and the availability of successful seizure therapies and treatments.
- Explore the feasibility and development of an ongoing, coordinated, large-scale, multimedia, multiplatform, sustainable public awareness campaign that would start by targeting key audience segments to improve information and beliefs about the epilepsies and reduce stigma.
- Ensure that all awareness campaigns include

    - consideration of health literacy, cultural appropriateness, and demographics of target audiences (e.g., age, gender);

- rigorous formative research and testing of materials throughout the campaign; and
- appropriate evaluation and follow-up tools and efforts.

STRENGTHENING STAKEHOLDER COLLABORATION

Epilepsy advocacy organizations are working to pull together diverse stakeholders in order to create a stronger, united voice for change. The Vision 20-20 group is an informal coalition of nonprofit organizations and federal agencies. It provides an opportunity to move the field forward through coordinated efforts among task force members and the development of public-private partnerships. Vision 20-20 could be the driving force for developing strategies and plans for the implementation of this report's research priorities and recommendations, including monitoring and evaluating progress over the short and long term. This coalition has the breadth and depth of expertise to take the public health agenda provided in this report and move it forward into action steps to improve the lives of people with epilepsy.

Vision 20-20 could create a framework and mechanism for continued cross-organizational collaboration by establishing a set of working groups in key areas. Such groups could monitor advances in the epilepsy field, share and disseminate information, engage a diverse spectrum of people with epilepsy and their families, and create a united voice for advancing research, care, and education. For example, a working group on health policy, health reform, and advocacy could monitor legislative and policy activities at the local, state, and national levels; activate people with epilepsy and their families to play a role in informing policy makers; and advocate for legislation and policy changes that could improve health and quality of life for people with epilepsy. A working group on surveillance and population health and health services research could develop a comprehensive strategy to encourage people with epilepsy to participate in a broad range of research efforts from population-based surveillance to research focused on self-management and education. Among other efforts, it also could request and advocate for the regular inclusion of questions targeted to epilepsy, its comorbidities, and epilepsy-related health care services in national and state health surveys.

RECOMMENDATION 12 ***Continue and Expand Vision 20-20 Working Groups and Collaborative Partnerships***

The member organizations of Vision 20-20 should continue their collaborative endeavors and further these efforts by expanding ongoing working groups that aim to advance the field, support people with epilepsy and their families, and educate the public. They should ex-

plore partnerships with other organizations as well as with stakeholders who represent related conditions (e.g., mental health, TBI, stroke, autism spectrum disorders). The working groups should communicate regularly, identify common goals, develop strategic plans, and, when possible, carry out joint activities. The working groups should focus on, but not limit their efforts to, the following areas:

- health policy, health reform, and advocacy;
- surveillance and epidemiologic and health services research;
- health care and community resources and services;
- education of health professionals;
- education of people with epilepsy and their families; and
- public education and awareness.

ENGAGING PEOPLE WITH EPILEPSY AND THEIR FAMILIES

Among the most persuasive epilepsy advocates and educators are people with epilepsy and their family members who are willing to speak out in order to provide a truer picture of the disorder and its impact. While many people may be willing to play such a role, training and support will help them do so more effectively. This may be the case regardless of whether they are advocating for improvements in care in general terms, working with support groups serving other families, or advocating for a higher level of service for themselves, a special school accommodation for their child, or a new medication regimen for their parent. People with epilepsy and their families also advance knowledge about epilepsy and its treatment when they participate in clinical research studies, surveys, and other investigations into ways to improve care and increase understanding of the meaning of epilepsy in individuals' lives.

RECOMMENDATION 13 ***Engage in Education, Dissemination, and Advocacy for Improved Epilepsy Care and Services***

People with epilepsy and their families should, to the extent possible, work to educate themselves and others about the epilepsies, participate in research, and be active advocates for improvements in care and services for themselves, their family members, and other people with epilepsy. Given their interests and to the extent possible, people with epilepsy and their families should

- become informed about epilepsy and actively participate in and advocate for quality health care and community services with policy makers at the local, state, and national levels;

- discuss best options for care with health care providers, including exploring referrals to epileptologists or epilepsy centers and learning about available community resources and services as needed;
- consider participation in available research and surveillance opportunities;
- engage with teachers, school officials, daycare workers, coaches, and other professionals to educate them about epilepsy and ensure that necessary services and accommodations are provided;
- talk openly, when possible, with family, friends, and colleagues about epilepsy and the impact it has on daily living and quality of life;
- actively participate in support networks to share experiences with other people with epilepsy and their families; and
- work with nonprofit organizations to raise awareness and educate others about epilepsy and participate in advocacy efforts.

CONCLUSION

This review of the public health dimensions of the epilepsies highlights numerous gaps in knowledge about and management of epilepsy and also presents opportunities to move the field forward. Improvements in surveillance methods and electronic health records hold promise for more precise information about the epilepsies, which could enable better identification of high-risk groups and better matching of treatments to individuals. There are a number of opportunities for the public health community to improve efforts to prevent epilepsy and its consequences. The growing emphasis on quality of care, as well as access and cost containment, in the U.S. health care system offers an opportunity to improve care for this large patient group. Preparing health professionals to provide better epilepsy care, although a challenge, will help improve quality and reduce costs. Consistent delivery of accurate, clearly communicated health information can better prepare people with epilepsy and their families to cope with the disorder and its consequences. Efforts aimed at raising awareness about epilepsy among the general public will reduce stigma and enable the full participation of people with epilepsy in society. Through collaboration and commitment over time, the bold goals outlined throughout this report can be accomplished.

A

Workshop Agendas

WORKSHOP ON PUBLIC HEALTH SURVEILLANCE,[1] POPULATION HEALTH RESEARCH, AND DATA COLLECTION FOR THE EPILEPSIES

March 21, 2011

The Beverly Hilton
9876 Wilshire Boulevard
Beverly Hills, California

8:30 a.m. **Welcome and Opening Remarks**
Mary Jane England, Chair
IOM Committee on the Public Health Dimensions of the Epilepsies

8:45 **Public Testimony—Registered Speakers**
Moderator: Mary Jane England
(3 minutes per speaker)
Claude Wasterlain, University of California, Los Angeles, School of Medicine, Department of Veterans Affairs Greater Los Angeles Health Care System
Jeffrey Catania, Children's Institute, Inc.

[1]Surveillance is defined broadly as continuous and methodical data collection and analysis for public health programs, including registries and disease-specific reporting systems, surveys, and administrative and clinical data sets.

Louis Stanislaw, LJPS Creations—The Epilepsy Project LLC
Michelle Marciniak, CURE
Tracy Dixon-Salazar, University of California, San Diego, Howard Hughes Medical Institute
Carrie Baum, Greater Los Angeles Epilepsy Foundation
Jim Abrahams, Charlie Foundation to Help Cure Pediatric Epilepsy
Lisa Soeby, Hope for Hypothalamic Hamartomas
Lori Towles
Frances Jensen, American Epilepsy Society
Gary Mathern, International League Against Epilepsy
Joan Skluzacek, IDEA League

9:30 **Panel 1: The Impact of Epilepsy on Patients, Families, the Health Care System, and Society**
Facilitator: Charles Begley

9:30-9:40	Panel Introductions
9:40-9:50	Direct Costs—Diagnosis and Treatment *David R. Lairson*, University of Texas Health Science Center at Houston
9:50-10:00	Indirect Costs—Academic Achievement, Employment, and Productivity *John Langfitt*, University of Rochester Medical Center
10:00-10:10	Quality of Life *Gus Baker*, University of Liverpool and the Walton Centre for Neurology and Neurosurgery (via phone)
10:10-10:20	Impact Across Populations—Health Disparities and Considerations for Subpopulations *Samuel Wiebe*, Hotchkiss Brain Institute at the University of Calgary Medicine
10:20-11:00	Discussion with the Committee

Questions:

- *What is known about the impact of epilepsy on patients, families, the health care system, and society?*
- *How is the impact of epilepsy measured for direct and indirect costs and quality of life? What are the limitations of these measurements?*

- *What are the direct costs associated with epilepsy and how do those costs change over time and with severity of disease?*
- *What are the indirect costs associated with epilepsy? How does epilepsy affect academic achievement, employment, and productivity?*
- *What impact does epilepsy have on quality of life for patients and family members?*
- *How does the impact of epilepsy vary across subpopulations (e.g., children, women, older adults, racial and ethnic minorities)?*
- *How does stigma affect quality of life and how does stigma vary across cultures?*
- *Where are the gaps in knowledge from a population perspective? From an individual and family perspective?*
- *What data need to be collected to accurately capture the burden of the epilepsies, particularly with regard to differences in specific populations as well as differences in etiology, severity, and outcomes?*
- *What is the future for collecting data and information on the impact of the epilepsies? How will advances in technology and electronic health records (EHRs) affect data collection efforts?*

11:00 **Break**

11:15 **Panel 2: Epilepsy Surveillance—Gaps and Opportunities**
Facilitator: David Grant

11:15-11:20 Panel Introductions
11:20-11:30 Current State of Epilepsy Surveillance
Edwin Trevathan, St. Louis University School of Public Health
11:30-11:40 Building on Existing Public Health Surveillance Systems
Wayne H. Giles, National Center for Chronic Disease Prevention and Health Promotion
11:40-11:50 Lessons from the Development of a Canadian National System of Surveillance
Nathalie Jetté, University of Calgary Medicine
11:50-12:00 Challenges and Opportunities for Surveillance—The Patient and Family Perspective
Mary Macleish, Epilepsy Foundation of Arizona

12:00-12:30 Discussion with the Committee

Questions:

- *What are the current mechanisms for surveillance of epilepsy?*
- *How can epilepsy surveillance be better integrated with existing public health surveillance and survey systems?*
- *How can surveys and registries be used to better assess the impact of the epilepsies?*
- *What are the challenges associated with collecting data on specific subpopulations (e.g., children, women, older adults, racial and ethnic minorities)?*
- *What are the gaps and opportunities?*
- *What can be learned from international epilepsy surveillance models?*
- *What is the future for epilepsy surveillance? How will advances in technology and EHRs affect epilepsy surveillance?*

12:30 p.m. **Lunch**

1:15 **Panel 3: Improving Epilepsy Surveillance—Lessons from Other Surveillance Systems**
Facilitator: Dale Hesdorffer

1:15-1:20 Panel Introductions

1:20-1:30 SEER—Lessons from Cancer Surveillance
Myles Cockburn, University of Southern California Keck School of Medicine

1:30-1:40 Lessons from Autism Surveillance
Marshalyn Yeargin-Allsopp, National Center on Birth Defects and Developmental Disabilities (via phone)

1:40-1:50 Veterans Surveillance Systems
Paul D. Varosy, Department of Veterans Affairs, Eastern Colorado Health Care System

1:50-2:00 Future Opportunities for Use of Existing Data Collection Systems—The Health Maintenance Organization Research Network
Stephen K. Van Den Eeden, Kaiser Permanente Northern California

2:00-2:30 Discussion with the Committee

Questions:

- *What are the successes and challenges associated with other disease surveillance systems?*
- *What are the challenges and opportunities offered by surveys and registries?*
- *What lessons have been learned from these systems that could be applied to epilepsy?*
- *How can strategies used for surveillance in the military and the veterans health systems be applied to civilian surveillance systems?*

2:30 **Break**

2:45 **Panel 4: Improving Epilepsy Surveillance—Overcoming the Complexities of Data Collection**

Facilitator: Joseph Sirven

2:45-2:50 Panel Introductions

2:50-3:00 Defining and Classifying the Epilepsies
Jerome Engel, University of California, Los Angeles, Seizure Disorder Center

3:00-3:10 Comorbidities—Pediatric, Adolescent, and Young Adult Populations
Anne Berg, Northern Illinois University

3:10-3:20 Comorbidities—Adult and Geriatric Populations
Frank Gilliam, Geisinger Health System

3:20-3:30 Emerging Models of Data Collection and Surveillance
Arien Malec, Nationwide Health Information Network

3:30-4:00 Discussion with the Committee

Questions:

- *How do definitions vary in the epilepsies and how do these variations affect data collection?*
- *What are the limitations and barriers associated with current classification systems and how can they be overcome?*
- *How do variations in definitions affect data collection and classification?*
- *What data need to be gathered to determine how epilepsy interacts with other conditions?*
- *How has and how will technology change the way that surveillance is conducted (e.g., EHRs, online data collection, move to cell phones)?*

4:00 **Panel 5: Risk Factors and Prevention**
Facilitator: Christi Heck

4:00-4:05 Panel Introductions
4:05-4:15 Measuring and Assessing Risk
W. Allen Hauser, Columbia University Mailman School of Public Health
4:15-4:25 Risk Factors in Pediatric Populations
Shlomo Shinnar, Montefiore Medical Center and the Albert Einstein College of Medicine
4:25-4:35 Strategies for Primary Prevention
Susan Herman, Beth Israel Deaconess Medical Center
4:35-5:00 Discussion with the Committee

Questions:

- *What is known about the risk factors for developing epilepsy and how can these risk factors be measured?*
- *How do risk factors vary across specific subpopulations?*
- *How can risk factors be identified for comorbid conditions?*
- *How can risk factors be used to inform efforts in prevention?*
- *What epidemiologic research or public health studies are needed to inform the development of strategies to prevent epilepsy?*

5:00 **Concluding Remarks**
Moderator: Mary Jane England

5:15 **Adjourn**

WORKSHOP ON THE PUBLIC HEALTH DIMENSIONS OF THE EPILEPSIES: HEALTH CARE QUALITY AND ACCESS AND EDUCATION OF PATIENTS, FAMILIES, AND PROVIDERS

June 28-29, 2011

Keck Center
500 Fifth Street, NW
Room 100
Washington, DC

June 28: OPEN SESSION

8:15 a.m. **Welcome and Opening Remarks**
Mary Jane England, Committee Chair

8:30 **Public Testimony**
Moderator: *Mary Jane England*

- *Brandy Parker*
- *Ilene Miller*, Hope for Hypothalamic Hamartomas
- *Carmita Vaughan*, CURE
- *Steve Wulchin*
- *Cheryl Ann Tubby*, American Epilepsy Society
- *Mark Brooks*, Abilities Network-Epilepsy Support Group
- *Mylissa Daniels*
- *Kevin Malone*, Epilepsy Therapy Project
- *Melinda Heine*

9:00 **Panel 1: Systems and Pathways of Health Care for the Epilepsies: Existing Models and Opportunities for Improvement**
Facilitators: Patricia Osborne Shafer and Paul Jarris

9:00-9:05 Panel Introductions
9:05-9:15 The Patient Perspective
Warren Lammert, Epilepsy Therapy Project
9:15-9:25 Epilepsy Centers
Robert J. Gumnit, National Association of Epilepsy Centers
9:25-9:35 Department of Veterans Affairs (VA) Epilepsy Centers of Excellence
Karen Parko, San Francisco VA Medical Center

9:35-9:45 UK System: Lessons Learned
Helen Cross, Great Ormond Street Hospital for Children (via phone)
9:45-9:55 Clinical Pathways: Health System Perspective
David Nerenz, Henry Ford Health System
9:55-10:25 Committee Questions and Discussion
10:25-10:30 Concluding Remarks and Panel Summary

Questions:

- *What experiences do people with epilepsy and their families have when entering and moving through the health system? What challenges do they confront, and how are they overcome?*
- *What are the current pathways and models of care for people with epilepsy in your health system? What are the current models of care for specific populations with epilepsy, including children, women, older adults, and racial and ethnic minorities?*
- *How do people with epilepsy move through your health system? What is known about the time to treatment and referral for people with epilepsy in your health system?*
- *How is care coordinated for people with epilepsy? What is the role of epilepsy specialists in your health system?*
- *How do you measure quality of care in your health systems? What strategies do you use to ensure access to care in your system?*
- *What is known about health outcomes for people with epilepsy treated in your health system?*
- *What international models of care for people with epilepsy have lessons learned that could be applied to the United States?*
- *What are your priority recommendations for improving systems of care to better meet the needs of people with epilepsy?*

10:30 **Break**

10:45 **Panel 2: Health Care for the Epilepsies: Quality of Care**
Facilitators: Ramon Diaz-Arrastia and Carolyn Cocotas

10:45-10:50 Panel Introductions
10:50-11:00 Treatment Guidelines and Comparative Effectiveness Research
Jacqueline French, New York University
11:00-11:10 Medication Issues: Brand Versus Generic Seizure Medications
Michel Berg, University of Rochester
11:10-11:20 Lessons Learned from the Implementation of Performance Measures and Centers of Excellence for the Care of Stroke Patients
Marilyn Rymer, Saint Luke's Brain and Stroke Institute (via phone)
11:20-11:30 New Models in Health Care Services Delivery and Reimbursement
Benjamin Druss, Emory University
11:30-12:10 Committee Questions and Discussion
12:10-12:15 Concluding Remarks and Panel Summary

Questions:

- *What further efforts are needed on epilepsy treatment guidelines and parameters for care? How are treatment guidelines evaluated? What comparative effectiveness research exists for best practices?*
- *How are performance measures endorsed and instituted?*
- *What is known about the efficacy of brand versus generic seizure medications? How does this impact access to medications?*
- *How do reimbursement issues impact access to care?*
- *How could health care reform affect the access to and quality of care for people with epilepsy?*
- *What innovative approaches are needed to improve health care?*
- *What is the future for models of care in light of the 2010 Patient Protection and Affordable Care Act?*
- *In your perspective, what makes up appropriate care for people with epilepsy in regards to services and personnel?*
- *What are your priority recommendations for improving quality of care and access to care for people with epilepsy?*

12:15 p.m. **Lunch**

1:00 **Panel 3: Health Care for the Epilepsies: Access and Barriers**

Facilitators: Sandra Cushner-Weinstein and Lionel Carmant

1:00-1:05	Panel Introductions
1:05-1:15	Overcoming Disparities in Access to Care for Underserved Populations *Jorge Burneo*, University of Western Ontario
1:15-1:25	Barriers to Access *Charles Onufer*, University of Illinois at Chicago (retired)
1:25-1:35	Lessons Learned from the Epilepsy Learning Collaborative *Deanna McPherson*, Health Resources and Services Administration
1:35-1:45	Care Coordination: Improving Transitions and Coordination Between Health Care Providers and Intersections with Community Services *Diane Carter*, University of Virginia, Care Coordination for Children
1:45-1:55	Innovative Approaches to Improving Access to Care *Jeanette Hartshorn*, Telemedicine Epilepsy Management Program of Texas
1:55-2:25	Committee Questions and Discussion
2:25-2:30	Concluding Remarks and Panel Summary

Questions:

- *What are the barriers to access and care across populations? For specific populations? What disparities in care exist currently?*
- *What lessons have been learned about improving access and eliminating disparities? What are possible solutions to overcome these barriers?*
- *What is known about whether the current workforce is adequate to provide quality health care for people with epilepsy?*
- *How might changes in technology (e.g., telemedicine) impact access to care?*
- *What successful models exist for integrating the care of risk factors, comorbidities, and sequelae in people with epilepsy?*

- *What needs to be done to improve care coordination encompassing health care, mental health care, education, employment, and other services? What are your priority recommendations for improving access to care and reducing health disparities for people with epilepsy?*

2:30 **Break**

2:45 **Panel 4: Education of Health Care Professionals**
Facilitator: Gregory Holmes

2:45-2:50	Panel Introductions
2:50-3:00	Educating Neurologists and Epileptologists *David Labiner*, University of Arizona
3:00-3:10	Educating Primary Care Providers *Paul Levisohn*, University of Colorado
3:10-3:20	Nursing Education *Janice Buelow*, University of Indiana
3:20-3:30	Psychiatry *Deborah Hales*, American Psychiatric Association
3:30-3:40	Geriatrics *Ilo Leppik*, University of Minnesota
3:40-4:10	Committee Questions and Discussion
4:10-4:15	Concluding Remarks and Panel Summary

Questions:

- *What are the current approaches being used to educate and test knowledge and competence of health professionals about the epilepsies?*
- *Are there core competencies and/or curricula currently available that focus on the epilepsies?*
- *How much time is devoted to teaching information relevant to the epilepsies? At what level of detail is the information taught?*
- *What role does continuing education play in educating health professionals about the epilepsies?*
- *How could technology be used to expand and improve education opportunities and provide decision support for health professionals who work with people with epilepsy?*
- *What are the best strategies for educating health professionals about clear communication and*

effective interactions with patients who have epilepsy?
- *What are the barriers and challenges to improving education of health professionals about the epilepsies? How can these barriers be overcome?*
- *What are your priority recommendations for improving the education of health professionals about the epilepsies?*

4:15 **Panel 5: Education of Patients and Families**
Facilitators: Joan Austin

4:15-4:20	Panel Introductions
4:20-4:30	Successful Patient and Family Education *Kate Lorig*, Stanford University (via phone)
4:30-4:40	Educating Patients in Health Care Settings *Mimi Callanan*, Stanford University
4:40-4:50	Education for Self-Management *Colleen DiIorio*, Emory University (via phone)
4:50-5:00	Ensuring Health Literacy and Cultural Appropriateness *Cheryl Bettigole*, Philadelphia Department of Public Health
5:00-5:10	The Role of Technology in Educating Patients and Families *Michael Wolf*, Northwestern University
5:10-5:40	Committee Questions and Discussion
5:40-5:45	Concluding Remarks and Panel Summary

Questions:
- *What are the health care (psychosocial as well as medical) education needs of patients? Of families? Where are the gaps in knowledge? How can interventions be aimed at these gaps?*
- *What are the critical junctures for educating patients and families about the epilepsies?*
- *How can successful education efforts improve self-management?*
- *What are the roles of health care providers, foundations and organizations, and community programs in ensuring that patients and families are well educated and informed about the epilepsies?*
- *What are the key components and best practices required for developing successful patient and family education programs?*

- *What are the challenges and barriers for developing successful patient and family education interventions and programs?*
- *How can new technology, online resources, and social media tools effectively be used to improve patient and family education?*
- *What are the best strategies for ensuring that education interventions are targeted appropriately in terms of health literacy and cultural sensitivity?*
- *What are your priority recommendations for improving the education of patient and families about the epilepsies?*

5:45 **Adjourn**

June 29: OPEN SESSION

8:15 a.m. **Welcoming Remarks**
Mary Jane England, Committee Chair

8:30 **Public Testimony**
Moderator: *Mary Jane England*
- *John Pellock*, American Epilepsy Society
- *Robert Moss*, SeizureTracker.com
- *Richard Leslie*, Wyoming Epilepsy Association
- *Mary Jo Pugh*, Veterans Health Administration
- *John Gambo*
- *Michael Bornemann*
- *Sabrina Cooke*

9:00 **Panel 6: Improving Quality of Life: Community Programs and Resources**
Facilitator: Dilip Jeste

9:00-9:05 Panel Introductions
9:05-9:15 Mental Health Services and Resources Across the Lifespan
Naomi Chaytor, University of Washington (via phone)
9:15-9:25 School-Based Services and Resources
Bruce Hermann, University of Wisconsin
9:25-9:35 Vocational and Employment Services and Resources
Robert T. Fraser, University of Washington (via phone)

9:35-9:45	Independent Living Resources and Services *Rebecca Rubin*, Jewish Foundation for Group Homes
9:45-9:55	Other Community Resources *Patricia Gibson*, Wake Forest University
9:55-10:25	Committee Questions and Discussion
10:25-10:30	Concluding Remarks and Panel Summary

Questions:

- *What mental health services and resources (including psychosocial and mood issues) are available for people with epilepsy and their caregivers? What services exist for people with psychogenic seizures?*
- *What school-based services and resources (e.g., individualized education programs) exist for children and young adults with epilepsy to address cognitive and developmental issues, including learning and behavioral problems? How are program employees educated about epilepsy?*
- *What vocational and employment services and resources exist for people with epilepsy? What exists for young adults transitioning from school to the workforce? How are cognitive problems related to employment handled? How are employers educated about epilepsy?*
- *What resources and services exist to support independent living for people with epilepsy? How are cognitive and geriatric issues handled?*
- *What general community resources and services currently exist for people with epilepsy? What opportunities exist to support the participation of people with epilepsy in society? What programs exist specifically for children and young adults? For seniors? For other specific populations?*
- *How successful are these programs? What is known about the impact of these programs on the quality of life of people with epilepsy and their families?*
- *What are the gaps and opportunities for improvement?*
- *What are your priority recommendations for improving community programs to better meet the needs of people with epilepsy?*

10:30 **Break**

10:45 **Panel 7: Beyond Stigma: Public Education and Awareness Campaigns**
Facilitator: Vicki Beck

10:45-10:50 Panel Introductions
10:50-11:00 Epilepsy Education and Awareness Campaigns: Successes, Challenges and Next Steps to Reduce Stigma
Sandy Finucane, Epilepsy Foundation
11:00-11:10 Global Mental Health Programs: Progress, Lessons Learned, and Recommendations to Reduce Stigma
Bernice A. Pescosolido, Indiana University
11:10-11:20 Social Marketing Campaigns: Impact on Mental Health Stigma
Chris Marshall, Substance Abuse and Mental Health Administration
11:20-11:30 Advocacy Efforts to Reduce Mental Health Stigma
Robert Carolla, National Alliance on Mental Illness
11:30-11:40 Leveraging Media to Reduce Stigma: Broadcast, Print, Internet, and User-Generated Sites
Otto Wahl, University of Hartford
11:40-12:10 Committee Questions and Discussion
12:10-12:15 Concluding Remarks and Panel Summary

Questions:

- *Please describe public education and awareness campaigns with which your organization has been involved. What were the outcomes of the campaign and how was success measured?*
- *How can public education and awareness campaigns be used to increase knowledge and understanding about the epilepsies, change attitudes and perceptions, and reduce stigma?*
- *What are the key components and best practices that are required to develop a successful public education and awareness campaign?*
- *How can online tools and social media effectively be used for public education and awareness campaigns?*
- *What are the challenges and barriers for developing a successful public education and awareness campaign for the epilepsies?*
- *What is the role of the media in educating the public and how can this role be leveraged to better educate the public about the epilepsies?*

- *What are your priority recommendations for improving the education of the public about the epilepsies?*

12:15 p.m. **Closing Remarks**
Mary Jane England, Committee Chair

12:30 **Adjourn**

B

IOM Data-Gathering Effort

The Institute of Medicine (IOM) committee requested that several health systems (Henry Ford Health System, Geisinger Health System, and Veterans Health Administration) and one state records linkage system (South Carolina) gather data in response to a list of surveillance questions for their populations and analyze the strengths and limitations of their systems in generating information about epilepsy. Researchers in each system generously responded to the committee's request and provided candid evaluations of their systems' ability to capture data on epilepsy. The following questions were posed to each system:

1. Overall Description: What are the major features of your data system and the major ways your organization makes use of the data?

    - Major sources of data (billing, medical charts, surveys, vital records, etc.)
    - Methods for identifying and classifying people with epilepsy
    - Capacity to follow individuals over time
    - Used for management, clinical, policy decision making, research, etc.
    - Algorithms and characterizations used
    - Strengths and limitations of your type of data system to report data on epilepsy

2. Incidence and Prevalence:

    - What are the overall incidence of epilepsy in your population per 100,000 person-years and prevalence per 1,000 persons?
    - What are the incidence and prevalence by gender, race/ethnicity, age ranges (< 19, 19-64, > 64), and/or insurance status (public, private, none)? (Use Office of Management and Budget [OMB] classification for race/ethnicity, collapsing American Indian/Alaska Native, Native Hawaiian-Pacific Islander, and "two or more" into an "other" category to produce the following groups: Hispanic, non-Hispanic black/African American, non-Hispanic white, non-Hispanic Asian, and non-Hispanic other.)
    - What time period is covered by these incidence, prevalence, and demographic data?
    - Methods—short description of methods or algorithms used to make the estimates
    - Strengths and limitations of your type of data system to identify incidence and prevalence and at what level of granularity

3. Comorbidities:

    - For those patients with prevalent epilepsy, what percentage also has comorbid conditions?
    - For those patients with incident epilepsy, what percentage also has preexisting comorbid conditions?
    - Methods—short description of methods or algorithms used to make the estimates
    - Strengths and limitations of your type of data system to link with comorbidities

4. Health Care Services:

    - For those with psychiatric comorbid conditions (e.g., depression, anxiety, bipolar disorder, schizophrenia/psychosis), how many are receiving treatment for those conditions?
    - What is the percentage of patients in your epilepsy population receiving epilepsy care by type of provider (primary care, neurologist, epileptologist)? Provide this separately for incident and prevalent epilepsy.
    - What is the percentage of patients in your epilepsy population with seizure medication use (mono- versus polytherapy)? With antidepressant use? With both seizure medication and antidepres-

sant drug use? Provide this for prevalent and incident epilepsy separately.
- What are annual rates of use (percentage with use, average number of services among users) and costs (average) of hospital care, emergency room care, physician services, and seizure medications for individuals with epilepsy? Provide this separately for prevalent and incident epilepsy. Provide comparable figures for the full non-epilepsy patient population as well.
- How many patients annually receive neurosurgical interventions, including epilepsy surgery and neurostimulator implants? Provide this separately for incident and prevalent epilepsy.
- How many patients annually receive electroencephalograph (EEG), magnetic resonance imaging (MRI), or video-EEG monitoring related to their epilepsy? Provide this separately for incident and prevalent epilepsy.
- Methods—short description of methods or algorithms used to make the estimates
- Strengths and limitations of your type of data system to assess services

5. Ideas for improving epilepsy surveillance through the use of health systems data (optional)

The systems were also provided with the relevant International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) codes and algorithms to identify epilepsy cases, health care service use, and comorbidities:

- *Incident epilepsy:* A single medical encounter with an ICD-9 code of 345.xx in the absence of a prior 345.xx code in the medical record *or* two or more medical encounters on separate days each with an ICD-9 code of 780.39 in the absence of a prior 780.39 code or 345.xx code in the medical record *or* a single medical encounter with an ICD-9 code of 780.39 and a seizure medication prescribed for outpatient use for 3 or more months without a prior 780.39 code or 345.xx code.
- *Prevalent epilepsy:* A single medical encounter with an ICD-9 code of 345.xx *or* two or more medical encounters on separate days each with an ICD-9 code of 780.39 *or* a single medical encounter with an ICD-9 code of 780.39 and a seizure medication prescribed for outpatient use for 3 or more months. These codes can be in the primary field or a secondary field.

- Incident and prevalent cases in estimating health care service use: The health care use of prevalent and incident cases should be included, even if the incident case contributes only a day to the prevalent year.
- Diagnostic fields for comorbidities: Use both the primary and the secondary diagnosis field.
    - Mental Disorders—290-319 inclusive
    - Other Major Neurological Disorders
      –Cerebral palsy—343.x
      –Cerebrovascular accident
        - 434.xx Occlusion of cerebral arteries
        - 435.x Transient cerebral ischemia

      –Dementia
        - 290.xx Dementias
        - 294.1x Dementia in conditions classified elsewhere

      –Parkinson's disease—332.x
      –Multiple sclerosis—340
    - Traumatic Brain Injury (TBI)
      –310 Specific nonpsychotic mental disorders due to brain damage
      –850-854 (concussion and other)
    - Autism—299.x
    - Other Chronic Disease
      –410-414 (ischemic heart disease)
      –401-405 (hypertensive heart disease)
    - Asthma—493.xx

The following summaries of each system's data-gathering effort help to identify the opportunities and barriers to surveillance of the epilepsies using linked electronic health records (EHRs). Although the data are not comparable due to the variety of methodologies used across the systems, each summary is informative about current U.S. surveillance capabilities and opportunities for improving surveillance of the epilepsies.

HENRY FORD HEALTH SYSTEM

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Organizational Context

The Henry Ford Health System is a large, vertically integrated system with 6 hospitals, a 1,000-member multispecialty group practice, more than 2,000 other affiliated private practice physicians, more than 30 ambulatory care centers, a 500,000-member managed care plan, free-standing emergency rooms, and many other components or "business units."

The Henry Ford Comprehensive Epilepsy Program at Henry Ford Hospital (HFH) and Henry Ford West Bloomfield Hospital (HFWBH) serves as a tertiary referral center for epilepsy care for southeast Michigan (metropolitan Detroit) and, to some extent, for a wider area that includes the rest of the State of Michigan and northern Ohio. Some patients with epilepsy are seen as one-time consults, some are seen for ongoing care through referrals from non–Henry Ford physicians, and some are seen as part of a broader medical care relationship that includes primary care and other types of specialty care within the Henry Ford Medical Group (HFMG). Patients with epilepsy who are members of Health Alliance Plan (HAP—the system-affiliated health plan) may elect to receive care from HFMG physicians but may also elect to receive care from other physician networks.

In analyzing patterns of care for patients with epilepsy then, it is a challenge to distinguish visits that represent the first contact with an HFMG physician for long-standing epilepsy from visits that represent the true onset of the condition. It is also a challenge to estimate overall service use (e.g., hospitalizations, emergency department [ED] visits), since not all services are necessarily provided within the HFH-HFWBH-HFMG network. For these reasons, some analyses reported here were conducted within a defined population of individuals who were HAP members assigned to the HFMG for care; others were conducted in a larger population of patients receiving epilepsy care at the HFH, HFWBH, or HFMG who were not necessarily HAP members. Because HAP has a record of all paid claims, including claims from other hospitals or physician networks, it is possible to get a complete picture of services provided to HAP members; it is not possible to guarantee a complete picture of services provided to patients with other types of insurance.

Methods

HAP-HFMG Patients

Using existing administrative data, we identified all individuals who were HAP members assigned to the HFMG for care for the years 2006-2010. (This is a well-defined population used as a denominator population for a variety of research and quality improvement projects.) Using the HFHS Corporate Data Store (an administrative database with data on all inpatient and outpatient care in the HFH and HFMG used for a combination of financial analysis, quality improvement, and research purposes), we identified all individuals with one or more encounters with a primary or secondary diagnostic code of epilepsy or seizure.[1] For all of these individuals, we conducted a "look-back" search in records of prior years (potentially as far back as 1995 for patients whose records went back that far) to identify whether there had been previous inpatient or outpatient encounters for epilepsy. If no, cases were then labeled as "incident cases" for the year in which the first coded encounter occurred. If yes, cases were labeled as "prevalent cases" in any year in which an epilepsy-related encounter occurred. Incident cases in any one year typically became prevalent cases in later years, but patients with encounters in only one year were counted as incident cases in that year and were not counted as prevalent cases.

Patients with All Insurance Types

Using the Corporate Data Store, we identified all patients who had had one or more inpatient or outpatient encounters for epilepsy or seizure disorder (using the same ICD-9 diagnostic codes) at the HFH or with HFMG physicians in 2009 or 2010. We then conducted look-back analyses for these patients to identify the first coded encounter at the HFH or HFMG for epilepsy, the site of care for that first encounter (e.g., clinic, hospital, ED), and the specialty department of the first encounter.

Sample for Full Medical Record Review

Because of concerns about limitations of the administrative data, we created a random sample of cases that had been identified in the HAP-HFMG cohort of both incident and prevalent cases. We conducted a focused review of the complete electronic medical record (EMR) for these

[1]ICD-9 codes to identify epilepsy: 345.0, 345.00, 345.01, 345.1, 345.10, 345.11, 345.2, 345.3, 345.4, 345.40, 345.41, 345.5, 345.50, 345.51, 345.6, 345.60, 345.61, 345.7, 345.70, 345.71, 345.8, 345.80, 345.81, 345.9, 345.90, 345.91, 780.39.

patients to confirm diagnosis of epilepsy, use of anti-epileptic medications, and use of antidepressant medications.

Incidence or Prevalence

Incidence estimates were calculated for each of the 5 years 2006-2010, using the number of incident cases (definition above) as the numerator and the number of HAP-HFMG-assigned individuals in each year as the denominator. Similarly, prevalence estimates were calculated each year and then again for the entire 5-year period by identifying the unique patients included in any one year as the numerator and the unique individuals who were in the denominator populations in any year as the 5-year denominator.

Patient Demographics

Patient age, gender, and race or ethnicity were available as standard data elements in the Corporate Data Store. Patient age was recorded in the year in which he or she was identified as either an incident or a prevalent case (HAP-HFMG cohort) or the year in which he or she was first seen in the 2009-2010 cohort.

Use of Medications

Pharmacy claims data in the Corporate Data Store for the HAP-HFMG cohort were used to identify filled prescriptions for either anti-epileptic medications[2] or antidepressant medications. The claims data include prescriptions filled at Henry Ford pharmacies as well as "outside" pharmacies, but do not include prescriptions paid either by patients themselves or by other insurance.

[2]Acetazolamide, carbamazepine, carbamazepine XR, Carbatrol, Celontin, Depacon, Depakene, Depakote, Depakote ER, Depakote Sprinkle, Diamox Sequels, Dilantin, Dilantin-125, divalproex sodium, divalproex sodium ER, Epitol, Equetro, ethosuximide, Fanatrex, felbamate, Felbatol, fosphenytoin sodium, gabapentin, Gabitril, Gralise, Keppra, Keppra XR, Lamictal, Lamictal (Blue), Lamictal (Green), Lamictal (Orange), Lamictal ODT, Lamictal ODT (Blue), Lamictal ODT (Green), Lamictal ODT (Orange), Lamictal XR, Lamictal XR (Blue), Lamictal XR (Green), Lamictal XR (Orange), lamotrigine, levetiracetam, Lyrica, Mebaral, Mysoline, Nembutal Sodium, Neurontin, oxcarbazepine, Peganone, pentobarbital sodium, phenobarbital, Phenytek, phenytoin, phenytoin sodium, potassium bromide, primidone, Sabril, Stavzor, Tegretol, Tegretol XR, Topamax, Topiragen, topiramate, Trileptal, valproate sodium, valproic acid, Vimpat, Zarontin, Zonegran, zonisamide.

Service Utilization

The Corporate Data Store was used to identify outpatient visits, ED visits, hospitalizations, or other forms of service use for epilepsy. ICD-9 diagnostic codes were used to identify epilepsy-related encounters. Current Procedural Terminology (CPT) and ICD-9 procedure codes were used to identify epilepsy surgeries and services in the inpatient Epilepsy Monitoring Unit (EMU). The EMU includes video-EEG monitoring for all cases, and an MRI is standard practice, either just before or just after the EMU admission.

Other Patterns of Care Issues

Provider, department, and site codes available for every encounter in the Corporate Data Store were used to calculate time intervals between initial presentation for epilepsy and consult with a neurologist and "flow patterns" between the ED, other sites of care (e.g., primary care), and neurology.

Results

Analysis of Administrative Database on an Enrolled Population

Incidence or prevalence The incidence of epilepsy in the population was estimated at 266 per 100,000 in 2006 and 163 per 100,000 in 2010. There was a gradual, steady decline in estimated incidence of new cases over the 5-year study period. This incidence is considerably higher than the 48 per 100,000 reported by Hirtz and colleagues (2007). We believe that the higher incidence estimate here may reflect the fact that health plan members are free to choose a provider network and that plan members with epilepsy, or with newly diagnosed epilepsy, would be inclined to select the HFMG network upon either joining the health plan or receiving the diagnosis. They would appear to be incident cases in our administrative data set, but some would not in fact be incident cases and others would be, but would be "self-selecting" into both numerator and denominator populations used to calculate incidence.

The prevalence of epilepsy was relatively stable over the 5-year period, with each individual year yielding an estimate of approximately 4 cases per 1,000 in the denominator population. We also identified all of the individuals who had been in the denominator population in any of the 5 years studied and calculated a prevalence estimate in that larger group. The numerator in this estimate included any individual who had had an encounter coded as epilepsy or seizure disorder at any time during the 5-year period. This prevalence estimate was approximately 8 per 1,000 (1,884 out

of 231,347). We believe that the difference between the prevalence estimate based on single-year data and the estimate based on 5-year data reflects the fact that many patients with stable, well-controlled epilepsy are seen at intervals greater than one year, so they appear in the numerator once or twice in the data set in a 5-year period, but do not appear in each individual year, even though they are consistently in the denominator population.

Demographics About two-thirds of both incident and prevalent cases were adults between the ages of 19 and 64. The remaining cases were evenly split between children (< 19) and older adults (65+). There were approximately equal numbers of males and females among both incident and prevalent cases. The race or ethnicity distribution of the incident and prevalent cases reflected the distribution of both health plan membership and the Detroit area, with relatively large black and non-Hispanic white groups (each approximately 40-50 percent of the total) and much smaller Hispanic, Asian, or other groups.

Comorbidity Patients with epilepsy in our population also had other medical and psychiatric conditions for which they receive care. In the 1,603 incident cases for example, 1,213, or 76 percent, had at least one other coded diagnosis at an HFMG medical encounter. In the 3,258 cases who had either incident or prevalent epilepsy, 1,174, or 36 percent, had another psychiatric condition coded for at least one visit, along with epilepsy.

Sources of care Virtually all patients had at least one physician encounter of some kind in any one study year. The average number of physician office visits for incident cases in the year in which they were diagnosed was approximately 12; the average number of physician office visits for prevalent cases in any year in which they had at least one visit at all was in the range of 9-10. Most encounters for which epilepsy was coded were with neurologists. Fewer than 20 percent of cases have a recorded ED visit (although ED visits at hospitals outside the Henry Ford system would not be recorded); 25-30 percent of cases have visits with primary care physicians, and approximately 75 percent have at least one visit with a neurologist.

Use of medications The pharmacy claims data for both incident and prevalent cases did not show any filled prescriptions at all for 20 percent of the patients. Although this could conceivably reflect a true absence of prescriptions filled, it seemed to us more likely that to be a reflection of patients' having drugs paid for through an insured spouse or perhaps having a benefits plan with a high deductible for prescription drugs so that some prescriptions were not shown as having been paid for by HAP.

Keeping this issue in mind, we found that 25-30 percent of the incident

cases in any one of the 5 years had a filled prescription for anti-epileptic medications in that year and 55-65 percent of the prevalent cases had a prescription for anti-epileptic medications in any one of the 5 years. Approximately 20 percent of both incident and prevalent cases had a prescription for antidepressant drugs in any one of the 5 years. Approximately 5-10 percent of the incident cases and 15 percent of the prevalent cases had both types of medications in any one year. Because all of these proportions seemed unreasonably low, we generated a random sample of 100 cases from the lists of both incident and prevalent cases in order to more carefully analyze the use of prescription drugs by doing a complete review of the patients' EMRs.

Medical Record Review

Of the 100 cases selected for full medical record review, 72 were confirmed as having epilepsy, either through text in physician notes or text from EEG or EMU reports; 6 of the remaining 28 had possible epilepsy, but the diagnosis either was not confirmed by EEG testing (e.g., patient was seen in the ED several times and did not return for EEG evaluation) or was in some other way ambiguous. Of the 22 remaining patients, the primary reasons for reactive seizures other than epilepsy were encephalopathy, brain tumor, alcohol withdrawal, or hydrocephalus. In one case, a neurocardiogenic syncope was the diagnosis eventually given to what had originally been labeled as a seizure.

All but one of the 72 cases with confirmed epilepsy were receiving seizure medications. That one patient had been seizure-free since 1989 and seizure-free after having been weaned off anti-epileptic medications for 2 years prior to the 5-year study period. Use of antidepressant medications was much less common in these patients; only 7 of the 72 confirmed cases were prescribed antidepressant medications during the 5-year study period.

Administrative Data on Hospitalizations and ED Visits

The proportion of patients hospitalized in any one year was higher among incident cases than among prevalent cases, perhaps reflecting admissions to the EMU as part of the process of establishing epilepsy as a diagnosis for seizures. The mean number of hospitalizations for a patient in any one year was in the range of 1.7-2.2 for both incident and prevalent cases, among those with any hospitalizations at all. The maximum number of hospitalizations observed in any one year was 13 for incident cases and 22 for prevalent cases. The proportion of incident cases with at least one hospitalization in each year ranged from 43 percent in 2006 to 55 percent in 2010. The proportion of prevalent cases with at least one hospitalization

in each year was stable in the range of 26-29 percent across the 5 years studied.

ED care was relatively stable in its occurrence, both across study years and in incident and prevalent cases. Among incident cases, the proportion with at least one ED visit ranged from 30 to 38 percent in specific study years. Among prevalent cases, the range was 29 to 33 percent. There were on average of two to three ED visits per year among those patients who had any ED visits at all, among both incident and prevalent cases. (We note that not all ED visits were for epilepsy or epilepsy-related problems.)

Surgical treatment was relatively rare. There were only seven surgeries among 1,603 incident cases in the 5-year study period and 24 among the 1,884 prevalent cases. This rate is, however, higher than that reported nationally. Our higher rate probably reflects the presence of a well-respected epilepsy surgery program in the medical group and the potential for health plan members who might be candidates for surgery to elect the HFMG network and thereby enter both numerator and denominator of the surgery rate.

Patterns of Care for Patients with All Insurance Types

There were 9,588 patients in 2009-2010 who met criteria for epilepsy based on ICD-9 diagnostic code criteria and were seen by HFMG physicians at one of 35 clinic sites. An additional 2,588 patients in the same time period were classified as "possible epilepsy" based on the presence of just one epilepsy code (suggesting its use as a "rule-out" diagnosis) or an ICD-9 code such as "seizure or seizure disorder" that could signify either epilepsy or some other form of seizure.

The distributions of age, gender, and race or ethnicity were essentially the same in this larger sample of patients as in the cohort of HAP-HFMG patients described above. Most of the patients were in the 19-64 age range, most were either non-Hispanic black or white, and there were approximately equal numbers of males and females. The proportion of patients insured by Medicare was larger than the proportion of patients over age 65, suggesting that many patients with epilepsy had obtained Medicare coverage on the basis of disability.

A preliminary examination of patterns of visits to different types of providers suggested the presence of four distinct groups of patients under care for epilepsy at Henry Ford. These include the following:

1. patients in the system with a primary care relationship who develop epilepsy;
2. patients who come to the neurology department from outside the system for outpatient consult or referral;

3. patients whose first point of contact for epilepsy is the ED at a Henry Ford facility; and
4. patients whose first point of contact is a hospital admission.

Of the 9,588 patients, the first known point of contact was neurology for 4,269 of them (44 percent). The ED was the most common first point of known contact other than neurology. Among the patients who had a first contact in the ED, 52 percent did not have a subsequent visit to neurology, 16 percent went from the ED to neurology without an intervening visit elsewhere, and the remaining 32 percent had a visit to some other department and then had a visit in neurology after that.

Of the patients who had a first point of contact for epilepsy other than neurology, 2,838 saw a neurologist in our system at some point; 2,438 did not see a neurologist in our system. Among the total of 9,588 patients with epilepsy then, 7,107 (74 percent) saw a neurologist at Henry Ford at some time.

For the patients who had a first point of contact other than neurology, the average time from first contact to a neurology visit was 15.3 months. The average time was longer for adults than for either children or adults over 65 and was somewhat longer for black patients than for white patients.

The role of Henry Ford as a regional referral center suggests that at least some visits to Neurology for patients with epilepsy are for consults, second opinions, or purposes other than continuing care. Among the patients whose first recorded contact was in neurology:

- most (3,303) had subsequent epilepsy care provided in both primary care and neurology;
- only a very small number (27) had all subsequent epilepsy visits in primary care; and
- many of the remaining 939 neurology-only patients were one-time consults.

In the larger sample of patients, 4,901 (51 percent) had a recorded session in the inpatient EMU. As a general policy, the vast majority of the EMU admissions are for incident cases, but it was not possible for us to clearly identify incident versus prevalent cases in the larger sample of patients, many of whom had a first point of contact at Henry Ford for a specialty consult but had some previous epilepsy care elsewhere. There were 68 surgeries for epilepsy in this group.

Discussion

Our findings about patterns of care for patients with epilepsy in a single, large, vertically integrated health care system indicate both opportunities and challenges for working with existing data sources. On the one hand, the administrative data could be used relatively easily and quickly to identify patients with epilepsy or seizure disorders, identify sites and types of care provided, and estimate basic features of patient "flow" (e.g., sequence and timing of visits) through various sources of care. Available demographic data on age, gender, and race or ethnicity allowed analysis of potential disparities in patterns of care on the basis of those demographic factors.

On the other hand, however, the detailed medical record review and the unusually high annual incidence estimates from administrative data suggest caution in using the administrative data without additional checking (e.g., full medical record review on a sample of cases). Approximately 28 percent of the cases identified as "epilepsy" in the administrative data base (using a set of ICD-9 codes for both epilepsy proper and seizure disorders) did not actually have confirmed epilepsy based on information in the full medical record. Virtually all of the patients did have seizures, or at least one seizure, but there was a cause other than epilepsy for 28 percent of cases. The set of codes we used, then (see footnote 1), seems to work well for identifying patients with seizures and appears to be sensitive for identifying patients with epilepsy, but is not highly specific for identifying patients with epilepsy.

Among the patients with confirmed epilepsy, we were generally pleased with the proportion receiving anti-epileptic medications (essentially 100 percent) and the proportion who were receiving care in a collaborative or team fashion between a neurologist and a primary care physician. The fact that administrative data gave much lower estimates for anti-epileptic medication use than the medical record review is interesting—in addition to the possibility of drugs being paid for through a spouse's insurance or other means, we also note that many patients take advantage of "$4 generic" programs at some retail pharmacy outlets and would not then have pharmacy claims recorded in our databases.

Although some neurologists in the neurology department of the HFMG specialize in epilepsy, this is not an official designation, and we were not able to formally distinguish between "epileptologists" and "other neurologists" in our analysis of practice patterns. Informally, however, it appeared that the majority of care in neurology was provided by three or four staff members most highly specialized in epilepsy care. For most patients, ongoing care was a collaborative or team effort between neurology, primary care, and perhaps other specialists in the group; the relatively high number of patients seen only in neurology suggests (1) a number of one-time consult visits; (2) some patients for whom a neurologist is the sole or primary care

provider; and (3) a specialty-only care role for Henry Ford, with other types of care provided elsewhere.

Understanding patterns of care, then, is possible in a system such as Henry Ford that has health plan, hospital, primary care, and specialty care components that do not completely overlap, but is perhaps more challenging than in more completely self-contained systems with well-defined denominator populations, such as Kaiser.

GEISINGER HEALTH SYSTEM'S DATA ON HEALTH CARE SERVICES FOR PATIENTS WITH EPILEPSY

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Introduction

As we collect, collate, and summarize our own contribution to the IOM's Committee on the Public Health Dimensions of the Epilepsies, the issue of exactly how to capture epilepsy—how to define and classify, how to find and count—is very much an active discussion (Berg et al., 2010; Thurman et al., 2011). The perennial American conversation regarding how to fund our health system is no less active. Obtaining systematic epidemiologic data, especially from large, complex health systems, must of necessity be an iterative, continually renewing process. We are grateful to the IOM and the committee for the opportunity to make a contribution to this important project, and we hope information of utility is learned from our work.

Methods

Data were retrieved from Geisinger Health System's (GHS's) electronic repository of health record information. Data are entered into this system, the Clinical Decision Intelligence System (CDIS), on an ongoing basis from the EMR system, EpicCare (Epic Systems Corporation, Verona, Wisconsin). Data are also entered from pathology laboratory computer systems, insurance claims and billing systems, and other computerized systems as well. Comprehensive data are compiled, including all inpatient and outpatient ICD-9-CM diagnostic codes utilized for documentation of and billing for care delivered, all CPT codes for procedures performed, all inpatient and outpatient medication prescriptions, and all laboratory values. Data collec-

tion began in 2001. CDIS is used in the GHS for purposes of policy decision making—in particular for designing "product line"-level initiatives to improve the quality of care system-wide for patients with specific health conditions—as well as for epidemiologic research such as our own. According to Geisinger's internal website description of the system (http://infoweb.geisinger.edu/cdis, accessed January 2, 2012),

> [t]he CDIS is a single, enterprise-wide data aggregation ("Enterprise Wide Data Warehouse" or "EDW") architected to support and interoperate with an analytic system designed to identify and measure trends, interrelate different forms of information (e.g. patient clinical, eligibility and preference data) to inform care and support data-driven clinical and operational decision making throughout Geisinger Health System. The EDW will consist of all relevant Geisinger data, cleansed, normalized and stored in a common database at the most granular level to allow for an effectively unlimited number of reporting, analysis and application roles.

Our own previous study experience (Weinstein et al., 2011) has shown that catchment of all medical diagnoses, diagnostic studies, and treatments is far more consistent for patients with a primary care practitioner (PCP) within the GHS than for those receiving only subspecialty care from the GHS and that data are most accurate for the years 2004 and thereafter; therefore we restricted our analysis to patients fitting these parameters.

For estimation of prevalence of epilepsy, records were reviewed for the prevalent year July 1, 2010, to June 30, 2011. A diagnosis of epilepsy was defined as appearance within that year of two codes: either (1) two separate outpatient care visits including an epilepsy-related ICD-9-CM code (any diagnosis from the Epilepsy family of codes 345.xx, or 780.09 Alteration of Awareness Not Otherwise Specified [NOS], or 780.39 Convulsive Disorder NOS), or (2) any one encounter with such a diagnosis and one outpatient medication order for any agent in the anticonvulsant class of medications.

For estimation of the incidence of epilepsy, records were reviewed for the entire study period January 1, 2004, to June 30, 2011. A new diagnosis of epilepsy was considered established if the above definition of prevalent epilepsy was newly met in a record not previously containing such codes, with the additional requirement that the subjects' record contain documentation of GHS PCP care establishment at least 2 years prior to the new appearance of the epilepsy-related codes.

Our database and approach have, as all do, inherent strengths and limitations; for the broader applicability of our results, there are also strengths and limitations of the context of our work in a unified, integrated health system located in a rural environment.

Strengths:

- a large population under management;
- a comprehensive EMR, through which all care is delivered;
- > 10 years' epidemiologic research experience with the database, with ongoing reengineering to improve the quality of the database over this time;
- fairly low turnover of population in the region of coverage; and
- rural derivation of data, in contradistinction to many previously published epidemiologic data.

Limitations:

- coding is only as accurate as clinicians' use thereof in delivery of care and coders' and billers' entries for financial purposes;
- ICD-9-CM codes are of imperfect validity for epilepsy;
- analysis is limited to codes entered in the EMR—free text of clinical care notes not accessible within CDIS;
- low numbers of nonwhite subjects in the population; and
- CDIS's importation of cost and charge data has not yet been optimized; we were unable to abstract reliable information regarding costs and charges.

Incidence and Prevalence

Prevalence

Of 421,174 patient records with an associated GHS PCP in the study year (7/1/2010-6/30/2011), 4,293 met prevalent case definitions, resulting in a one-year period prevalence of 10.2 cases per 1,000 patients. This is nearly within the range of estimates reported previously (3.70-9.99 per 1,000) (Annegers, 2004). Roughly 74 percent of cases met both definitions we prespecified, and 20 percent met only the first definition of two separate entries of an epilepsy-class ICD-9 code, leaving 6 percent captured by the second definition of one diagnosis code and an anticonvulsant order. Within the 20 percent of prevalent cases that were captured by the two definitions, only a small minority (exact number unavailable) were captured on the basis of the least-specific ICD-9 code 780.09 (Alteration of Consciousness, Other).

Incidence

Records for 439,204 patients had at least 2 consecutive years of GHS PCP assignment over the study period (1/1/2004-6/30/2011). Thus, requiring 2 years' preceding data, incidence is assayed beginning January 1, 2006,

and ending June 30, 2011. With a cumulative 2,335,208 patient-years of data, 485 cases met prevalent case definition after 2 years with GHS PCP and no epilepsy-related codes entered, resulting in an incidence rate of 20.8 per 100,000 patient-years. This appears to be a moderate underestimate on multiple grounds:

1. The case duration provided by dividing our prevalence estimate of 0.0102 cases by incidence of 0.000208 cases per year = 49 years. As early-childhood-onset epilepsy is likely to be associated with a shortened life expectancy (Sillanpää and Shinnar, 2010), and later-adulthood-onset epilepsy (Hauser et al., 1993) occurs with fewer years of life remaining, case duration of epilepsy averaged across an entire population of patients with epilepsy seems likely to be considerably lower than 49 years.
2. Previously published meta-analyses estimate incidences of 43 to 82 per 100,000 (Kotsopoulos et al., 2002; Ngugi et al., 2011).

It is likely that our restrictive definition, designed in the interests of specificity (avoiding accepting prevalent cases as newly incident), achieved our aim at the expense of sensitivity.

Incidence and Prevalence Rates by Demographic Groups

Prevalence and incidence rates were roughly balanced by gender (prevalence 48.3 percent male, 51.7 percent female; incidence 46.8 percent male, 53.2 percent female). By age groups (19 years and under, 19-64, over 64), prevalence rates were 21.2 percent, 58.5 percent, and 20.1 percent, respectively, and incidence rates 34.6 percent, 47.6 percent, and 17.7 percent, respectively. Ethnic background was dichotomized simply by "white" versus all other because of the low number of minorities in rural Pennsylvania; prevalence was 95.8 percent white, 4.2 percent nonwhite, and incidence 95.4 percent white, 4.5 percent nonwhite. Numbers were subdivided into a $2 \times 3 \times 2$ table, that is, by gender, age group, and ethnicity, respectively; all 12 resulting 95 percent confidence intervals (95 percent CIs) on the point estimate within each cell were completely mutually overlapping.

Medical Comorbidities

Rates of comorbidity with medical diagnoses of interest provided by the IOM were also sought, for both prevalent and incident cases; comparison rates were derived from records for all other patients under GHS PCP care during the same period. All diagnoses were assayed on the basis of ICD-9 code entry by any practitioner at any point during the study pe-

riod; for incident cases, no distinction was made for this data abstraction between diagnoses coded prior to versus after the coding of case-defining epilepsy ICD-9 diagnoses. ICD-9 codes of interest were obtained from IOM study staff. One mental health diagnosis code (any code from the Axis I disorders of American Psychiatric Association's Diagnostic and Statistical Manual, Fourth Edition; i.e., 290-319 inclusive) was coded in 86.2 percent of prevalent epilepsy cases and 69.3 percent of incident cases, compared to 32.5 percent of the primary care population; more than one such diagnosis was coded in 47.3 percent of prevalent, 58.7 percent of incident, and 24.0 percent of comparators. Cerebral palsy (343.x) was coded in 2.7 percent of prevalent, 5.5 percent of incident, and 0.1 percent of comparators. Cerebrovascular disease (434.xx or 435.x) was coded in 4.7 percent of prevalent, 3.2 percent of incident, and 0.7 percent of comparators. Dementia (290.xx or 294.1x) was coded in 1.9 percent of prevalent, 2.0 percent of incident, and 0.4 percent of comparators. Parkinson's disease (332.x) was coded in 1.2 percent of prevalent, 1.1 percent of incident, and 0.3 percent of comparators. Multiple sclerosis (340) was coded in 0.8 percent of prevalent, 0.8 percent of incident, and 0.2 percent of comparators. TBI (310, or 850-854 inclusive) was coded in 1.9 percent of prevalent, 3.1 percent of incident, and 0.4 percent of comparators. Autism spectrum disorders (299.x) were coded in 1.2 percent of prevalent, 1.7 percent of incident, and 0.1 percent of comparators. Ischemic heart disease (410-414 inclusive) was coded in 5.1 percent of prevalent, 8.0 percent of incident, and 4.1 percent of comparators; hypertensive heart disease (401-405 inclusive) was coded in 24.3 percent of prevalent, 27.8 percent of incident, and 18.4 percent of comparators. Asthma (493.xx) was coded in 13.0 percent of prevalent, 13.0 percent of incident, and 6.9 percent of comparators. Obesity (278.xx) was coded in 8.2 percent of prevalent, 9.1 percent of incident, and 4.9 percent of comparators; morbid obesity (278.01), in 2.7 percent of prevalent, 3.1 percent of incident, and 1.6 percent of comparators. Cancer (140.xx-210.xx) was coded in 6.2 percent of prevalent, 9.8 percent of incident, and 4.7 percent of comparators. Obstructive sleep apnea (327.23) was coded in 0.4 percent of prevalent, 1.8 percent of incident, and 0.7 percent of comparators. Rheumatoid arthritis (714.0) was coded in 0.8 percent of prevalent, 0.9 percent of incident, and 0.6 percent of comparators.

Health Care Services

The database was queried for medication orders in the psychoactive and anticonvulsant classes, for types (ED, outpatient, inpatient) and numbers of patient care encounters—including whether with a neurological practitioner—and for numbers of cases in which specific epilepsy evaluation

and management procedures (EEG, MRI, EMU evaluation, and neurosurgical treatments) were used.

Of the 419 incident cases with at least one psychiatric comorbidity, 165 (39 percent) were receiving an agent from the psychiatric class of pharmacologic agents, exclusive of their seizure medications; of the 2,973 prevalent cases, 1,698 (57 percent) were on such treatment. This compares with 69,279 of 135,466 (51 percent) treatment rate among the primary care comparators.

Of incident cases of epilepsy, 469 (97 percent) had a visit with a PCP; however, only 161 (33 percent) had a documented outpatient visit with a neurology physician or advanced practitioner. Among prevalent cases, 4,206 (98 percent) had at least one PCP visit, and 2,665 (62 percent) had a neurology outpatient visit. These numbers merit a brief comment—the database does not permit effective audit of whether a practitioner in a specific specialty has seen a patient during an ED evaluation or inpatient admission; we suspect that some of these patients did in fact see neurology in such a manner but were not seen in clinic subsequently during the audit period. That noted, the rates of outpatient neurology visitation, which we would prefer close to 100 percent, did not completely surprise us: we have had a subspecialty-oriented comprehensive epilepsy program for just over 2 years as of this writing and have noticed a pattern of practice whereby many patients with epilepsy in the system are in fact receiving their care from a PCP only. We suspect we are impacting on this pattern of practice only incrementally.

Utilization of hospital resources (ED, inpatient, and outpatient visits) was reasonably stable and consistent across time: 15.8 percent of prevalent patients utilized the ED over the study year (with 2.1 services utilized), compared with 5.2 percent of non-epileptic primary care patients (1.5 services); 15.3 percent utilized inpatient services (3.0 services), compared with 3.7 percent of primary care comparators (2.6 services); fully 78.5 percent of prevalent patients had outpatient visits anywhere in the system (7.8 services), compared with only 56.6 percent of primary care comparators (4.6 services). For incident cases, the extended time period over which these cases were studied allows us to assess changes in rates of use after establishment of diagnosis. In the first 12 months after meeting case definition, 14.4 percent had ED visits (1.7 services), 19.3 percent had inpatient admissions (2.4 services), and 100 percent received outpatient care of some type (7.8 services); over the subsequent (second, third, and fourth) years after diagnosis, rates fell from the first year but were thereafter stable from year to year, with ED visits at 10.1-11.1 percent across those 3 years (1.5-1.9 services), admissions 7.8-11.9 percent (1.6-2.5 services), and outpatient visits 85.3-88.3 percent (4.4-6.1 services). Clearly, the outpatient service utilization of 100 percent the first year is an artifact of the case definition, but this does

not mute the interest that utilization in years following the first appears to fall stably to rates similar to those among prevalent cases in general and to remain substantially elevated above primary care comparators.

With regards to medication use, among incident cases, 269 (55 percent) had orders for only one seizure medication, and another 59 (12 percent) had orders for more than one (reflecting either polytherapy or a switch from one agent to another), leaving 158 (32 percent) for whom no order for seizure medication was documented; 120 (25 percent) had orders for at least one seizure medication and at least one antidepressant. Among prevalent cases, the rates for monotherapy were 2,493 (58 percent) and polytherapy 938 (22 percent), leaving 862 (20 percent) for whom we do not have documented seizure medication orders; we believe that there are large inherent incompletions in the data on medication ordering.

Our documented rates of specific EEG and MRI utilization were surprising to us: 390 (41 percent) of incident and 3,794 (37 percent) of prevalent cases had an EEG documented, 184 (19 percent) of incident and 2,815 (27 percent) of prevalent cases had an MRI, and 115 (12 percent) of incident versus 1,720 (17 percent) of prevalent cases had a video-EEG monitoring unit evaluation. We believe these apparently low rates of EEG and MRI use to be a function of three primary limitations in our database: (1) because our system focuses on cost-effective care, we frequently utilize outside MRIs and EEGs for provision of care, reviewing them ourselves if we deem them at all questionable and repeating them only if necessary; (2) many of our own patients had diagnostic EEGs and MRIs within the system performed well before the period of the study, and we presume this applies to the prevalent population as a whole; and (3) procedure rates especially appear suboptimally accurate (see discussion of neurosurgery below).

Neurosurgical interventions were predictably uncommon in the incident group, with a total of 3 (1 vagus nerve stimulation [VNS] implantation, and 2 craniotomies)—we are presuming that these few patients caught as "incident" were most likely in fact longstanding prevalent cases. Among prevalent cases, data indicate 40 VNS procedures (0.4 percent of the group) and 33 craniotomies (0.3 percent). We are quite certain these electronically captured rates are low—we know that our program recently passed its hundredth craniotomy for epilepsy since the two epileptologists among the authors (M.E., F.G.) joined, yet only 33 of them were captured by the electronic query.

Conclusion

Our data clearly contain a degree of inaccurate classification of cases utilizing our case definitions. This is unsurprising, given our "quick-and-dirty" criteria, derived rapidly to provide data to the IOM as expeditiously

as possible, and the structure of the database itself, as discussed. The advantage of CDIS's structure is that data can be abstracted by research institute personnel rapidly, without any patient identifying information at all, and therefore full institutional review board (IRB) review and approval can be waived; this is the approach under which our data were abstracted. Rates of procedure utilization are especially suspect, as above. Rates of comorbidity diagnosis are likely also prone to undersensitivity for some and oversensitivity for other diagnoses. This cannot be a surprise, however, and the fact that the prevalence estimate of 10.2 per 1,000 is essentially right at the top end of the previously published range augurs fairly well for accuracy of diagnoses at least. The power of the chart-derived CDIS system is that analyses can be run fairly quickly, which should mean that they can periodically be re-run to assess changes in numbers previously obtained—changes in population and the impact of system-wide treatment initiatives could be thus evaluated. We hope that in the future, this will allow us within our own system to polish an institution-wide care approach with minimized tolerance for continued seizures.

VETERANS HEALTH ADMINISTRATION

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Overall Description

The Department of Veterans Affairs' (VA's) Veterans Health Administration (VHA) operates the largest integrated health care system in the United States. The availability of these data derives from the long history of computerized clinical information systems in the VHA. Episodes of care provided by VA hospitals, outpatient clinics, nursing homes, and so forth, or paid for using VA funds are input to the EHR by facility staff using the Computerized Patient Record System. These data are then transmitted to a central repository in Austin, Texas, where clinical data elements are maintained in SAS data sets (SAS Institute, Cary, North Carolina). The data sets that are most commonly used include the VHA annual medical SAS data sets for VA inpatient and outpatient care, VA pharmacy data, VHA extended care, VA inpatient short stay (< 24 hours) observation care, health care provided for veterans outside the VA with VA funding (fee-basis),

[3]We acknowledge funding of this work from VA Health Services Research and Development Service, IIR 06-062 and DHI 09-237 (Dr. Pugh, principal investigator) and the VA Epilepsy Centers of Excellence. The views expressed here are those of the authors and do not necessarily represent the views of the Department of Veterans Affairs.

and clinical data extracts from the Decision Support System files. These databases are used for administrative purposes and are commonly used to conduct epidemiologic, in addition to health policy and health services, research. While decades of inpatient data are available, outpatient and pharmacy data are available from fiscal year (FY) 1999 onward, allowing us to follow individuals over time as long as they receive care within the VHA.

Our surveillance of epilepsy within the VA contains inpatient, outpatient, and pharmacy data that are linked using an encrypted patient identifier. These databases include diagnosis codes, dates of care, clinic or hospital ward in which care was received, facility in which care was received, specific medications received, the dose of each medication, and the number of days that medication was received. While an active surveillance program through the VA Epilepsy Centers of Excellence (ECOEs) is in development, for the purposes of this report we provide estimates of epilepsy in two distinct cohorts of VA patients for whom we had research data: elderly veterans (≥ 65 years of age) in FY 2006 (October 1, 2005-September 30, 2006) and veterans from Afghanistan and Iraq (Operation Enduring Freedom-Operation Iraqi Freedom [OEF-OIF]) in FY 2009 who received VA care in the index year (FY 2006 or FY 2009) and the year prior.

Incidence and Prevalence

Methods

Using inpatient and outpatient data files, we identified prevalent cases of epilepsy as those with a diagnosis indicative of epilepsy (ICD-9-CM codes 345 or 780.39) in the index year, who also had at least 30 days of seizure medications prescribed during that year. Using a look-back period (the previous year), we identified individuals who had neither a diagnosis nor a seizure medication prescribed the previous year as having incident epilepsy. We then conducted cross-tabulations of epilepsy status by race or ethnicity and gender and calculated the prevalence per 1,000 and incidence per 100,000 among different race or ethic groups and for men and women based on the overall population for each category in each cohort.

It is important to note that the algorithms used in this assessment were validated and found to have a positive predictive value between .94 and .98 in the elderly VA population; the positive predictive value for the OEF-OIF population has not been determined.

Strengths and Limitations

The major strength of this approach is ease of use in a large integrated medical system. However, several limitations exist. First, our reported inci-

dence may be inflated because we had only a year of prior data to determine previous diagnosis and treatment. We are unsure of the extent to which incident cases may be overestimated based on a 1-year compared to a 2- or more year clean period; however, overestimation is certain. Second, it is possible that individuals who receive medications and health care outside the VA are misclassified if their diagnosis of seizure or prescription for a seizure medication occurs in a non-VA setting. However, many individuals with epilepsy receive free VA health care and medications; therefore we believe this bias is not significant. Third, there is also a risk of identifying individuals as having epilepsy when they had a provoked seizure and received a seizure medication for another indication, such as bipolar disorder, depression, or chronic pain. We validated this algorithm for use in the geriatric veteran population using chart abstraction and found a positive predictive value of .94-.98 (Pugh et al., 2008), but no such validation has yet been conducted for the OEF-OIF veteran population. Thus, these estimates are preliminary assessments of incidence and prevalence.

A final limitation with regard to examining prevalence and incidence by race or ethnicity is that although the data are quite accurate when available, race data were missing for approximately 22 percent of older veterans and 19 percent of OEF-OIF veterans.

The first estimates are based on the geriatric VA patient population in FY 2006 who received care in FY 2005 and FY 2006 (N = 2,023,477). Overall, if all groups that meet epilepsy criteria are included, 1.8 percent of older veterans meet criteria for epilepsy (N = 37,023), which equates to 18.3 per 1,000. This is similar to our estimate using data from FY 1999 (Berlowitz and Pugh, 2007). If we exclude those with ambiguous onset (N = 23,102), the prevalence is 11 cases per 1,000. Our prior study incorporating Medicare data suggests that inclusion of individuals with ambiguous epilepsy onset is more accurate since many individuals (about 60 percent with new diagnosis) are initially diagnosed in the Medicare setting (Hope et al., 2009).

For incident epilepsy, we included only the group for which we could definitively identify onset of diagnosis and treatment in the VA. The finding for incident epilepsy (N = 1,412) was 70 per 100,000 person-years.

The second estimates are preliminary and unvalidated reports from FY 2009 based on the OEF-OIF VA patient population who received VA care in FY 2008-2009 (N = 191,797). It is important to note that inclusion in this cohort was based on deployment to a war zone. As such the age range was 20-73 years in FY 2011 (median = 31; interquartile range = 16), and this population has a high prevalence of blast injury and TBI, which place them at elevated risk of epilepsy. Including all groups that meet epilepsy criteria (N = 1,545) the prevalence is 8.1 per 1,000 individuals. Incidence of epilepsy (N = 255) was 133 per 100,000 person-years. Because our algorithm

has not been validated in the younger veteran population, we also examined incidence and prevalence of epilepsy excluding gabapentin from the list of seizure medications, since it is also commonly used for pain. Using that less inclusive algorithm, we found 503 individuals with epilepsy; prevalence is 3 per 1,000 and incidence (N = 90) 47 per 100,000 person-years.

Incidence and Prevalence by Race or Ethnicity and Gender Within Cohorts of Geriatric and OEF-OIF Veterans

The prevalence and incidence of epilepsy by gender and race or ethnicity are provided for the following groups: black or African American, Hispanic, other (Asian, American Indian or Alaskan Native, Native Hawaiian or other Pacific Islander), white, and unknown. Of interest with regard to race or ethnicity, in the geriatric cohort, we saw significantly higher prevalence and incidence in veterans from black or African American and Hispanic heritage, while we see significantly higher incidence and prevalence of epilepsy in whites among the OEF-OIF cohort.

Among the geriatric cohort, we saw prevalences (per 1,000) and incidences (per 100,000) of 33.1 and 155 (black or African American), 23 and 105 (Hispanic), 17 and 78 (other), 19 and 71 (white), and 12 and 42 (unknown). For the OEF-OIF cohort, we saw prevalences (per 1,000) and incidences (per 100,000) of 7 and 71 (black or African American), 7 and 121 (Hispanic), 8 and 64 (other), 10 and 159 (white), and 5 and 127 (unknown).

With regard to gender, there were no statistically significant differences between males and females in the geriatric cohort (prevalence 19 per 1,000 males or females, incidence 81 per 100,000 males and 71 per 100,000 females). The prevalence and incidence of epilepsy were significantly higher in males in the OEF-OIF cohort. The prevalence of epilepsy for males was 8 per 1,000 and for females 6 per 1,000. The incidence of epilepsy was 140 per 100,000 for males and 86 per 100,000 for females.

We also calculated the incidence and prevalence for OEF-OIF veterans excluding gabapentin as a seizure medication and found the exact same patterns but with different magnitude. Prevalence was 2 per 1,000 for blacks or African Americans and Hispanics, 3 per 1,000 for those of white and unknown race, men, and women. Incidence was 23 (black or African American), 42 (Hispanic), 32 (other), 61 (white), and 34 (unknown) per 100,000 person-years.

Further research will be required to determine the most appropriate algorithm for this new population of veterans. For the purposes of this report, comorbidities, treatment, and health care utilization are based on the definition of epilepsy using all seizure medications since the pattern of findings is essentially the same using both definitions.

Comorbidities

Methods

Comorbidities were identified using inpatient and outpatient administrative data. We used validated ICD-9-CM code algorithms from the Selim and Elixhauser comorbidity indices to identify mental and physical health conditions. ICD-9-CM codes from the Australasian Rehabilitation Outcomes Centre and the Department of Defense were used to identify TBI-related diagnoses.

Strengths and Limitations

The strength of this approach in linking epilepsy with comorbidities is that the integration of inpatient, outpatient, and pharmacy data in this system allows ready identification of chronic comorbid conditions in large numbers of individuals relatively quickly. However, we can only identify conditions that are diagnosed during the process of VA care. It is less likely that active mental health conditions and TBI-related diagnoses are underdiagnosed in the OEF-OIF VA patient population since mental health conditions and TBIs are the subject of service-connected disabilities. The high levels of posttraumatic stress disorder (PTSD) in particular, while logical given the combat exposure of the population, suggest we should more closely explore the possibility of seizure-like events with a psychological basis in this population. The greater weakness for the geriatric population is that TBI-related diagnoses are only acute and do not provide a history of TBI, which may be substantial in those with prior combat (e.g., World War II, Korea).

Among the individuals in these cohorts, there was a high prevalence of physical comorbidities, especially in the geriatric population. As expected, cerebrovascular disease and dementia were high in geriatric cohorts (cerebrovascular disease: 33 percent prevalent, 46 percent incident; ischemic stroke: 8 percent prevalent, 15 percent incident; transient cerebral ischemia: 5 percent prevalent, 10 percent incident; dementia: 18 percent prevalent, 25 percent incident), but relatively low in OEF-OIF cohorts (cerebrovascular disease: 4 percent prevalent, 2 percent incident; ischemic stroke, transient cerebral ischemia, dementia: less than 1 percent for both prevalent and incident). Approximately 7 percent of older veterans with prevalent epilepsy and 9 percent with incident epilepsy had other major neurological conditions such as multiple sclerosis or Parkinson's disease. OEF-OIF veterans had lower rates (2 percent prevalent and incident) than the elderly. Cardiac-related diseases were also common. Cardiovascular disease (e.g., myocardial infarction, congestive heart failure, angina) was diagnosed in 24 percent of those older veterans with prevalent epilepsy and 25 percent

of those with incident epilepsy; 73 percent of prevalent and 81 percent of incident cases also had hypertension. Cardiovascular disease was far less likely (0.8 percent prevalent and 0.4 percent incident) for OEF-OIF veterans with epilepsy; hypertension affected 16 percent of those with prevalent and 15 percent of those with incident epilepsy. Similarly, chronic obstructive lung disease affected older veterans with epilepsy (prevalent 24 percent and incident 25 percent) more frequently than OEF-OIF veterans with epilepsy (prevalent 6 percent and incident 7 percent).

The opposite patterns were observed for the OEF-OIF veterans when examining mental health comorbidities. OEF-OIF veterans had high rates of having a diagnosed comorbid mental health condition (81 percent prevalent, 87 percent incident) compared to the geriatric population (44 percent prevalent, 51 percent incident). Further exploration suggests this was due to very high rates of PTSD (60 percent prevalent, 68 percent incident), depression (33 percent prevalent, 35 percent incident), anxiety (19 percent prevalent, 24 percent incident), substance abuse or dependence (17 percent prevalent, 22 percent incident), bipolar disorder (9 percent prevalent and incident), and other mental health conditions including psychosis (51 percent prevalent, 47 percent incident). These high rates were similar regardless of the cohort definition algorithm and are consistent with the fact that this cohort is based on deployment to a war zone. The prevalence of psychiatric conditions was lower in the geriatric cohort, but the psychiatric disease burden was still significant. The most common single condition was depression (18 percent prevalent, 19 percent incident) followed by anxiety (8 percent prevalent, 9 percent incident), substance abuse or dependence (5 percent prevalent, 6 percent incident), PTSD (4 percent prevalent and incident), bipolar (3 percent prevalent, 2 percent incident), and other mental health including psychosis (29 percent prevalent, 38 percent incident). Finally, head injuries were more commonly found in OEF-OIF veterans due to an ongoing TBI screening program associated with postdeployment. Moderate to severe TBI was found in 4 percent of prevalent and 5 percent of incident cases; concussion diagnoses were found in 28 percent of prevalent and 32 percent of incident cases. Among the geriatric cohort, moderate to severe TBI was less than 0.5 percent in both prevalent and incident cases, and concussions were diagnosed in 2 percent of prevalent and 3 percent of incident cases.

Health Care Services

Methods

We identified the seizure medications, antidepressants, and antipsychotic medications received by each individual using VA pharmacy data

based on the VA product name. We identified the type of outpatient care (neurology [315, 335, 345], primary care [301, 322, 323, 348], emergency care [130, 131], EEG [106], prolonged video-EEG monitoring [128]) using VA clinic codes indicated, and inpatient care was identified based on data present in the inpatient data file. Neurology hospitalizations were identified using bedsection (10) found in the inpatient treatment file. We then counted the number of days for all hospitalizations completed during the index year. Because much of the prolonged video-EEG monitoring occurs at academic affiliates, these estimates are considered extremely conservative. These methods have been previously validated for use in documenting sources of inpatient and outpatient care broadly in VA settings though not specifically for epilepsy.

Strengths and Limitations

Our method allows us to accurately describe care received in the VA since previous studies have found that care provided is routinely documented. However, several limitations exist. First, the only data available were those approved for use in our ongoing research: inpatient, outpatient, and pharmacy data. We did not have access to cost data or data for outside care that was paid for by the VA (fee-basis files). Thus, we were not able to provide information on neurosurgical interventions and the costs of care or to ensure that our assessments of other utilization—especially prolonged video-EEG monitoring—were complete. Second, it is possible that individuals received care outside the VA as described above. We are unsure of the extent to which this non-VA care may affect our estimates. Finally, individuals who received hospital care for epilepsy would be evaluated by a neurologist as an inpatient; therefore our assessment of neurology care may be underestimated.

Treatment of Comorbid Conditions

In the geriatric cohort, we found that among those with any mental health diagnosis 57 percent of prevalent cases and 58 percent of incident cases received a prescription of a psychotropic medication. Antidepressants were prescribed to 51 percent of both prevalent and incident cases in FY 2006; 17 percent of prevalent and 19 percent of incident cases received an antipsychotic. When restricting the analysis to those diagnosed with depression, 78 percent of prevalent and 82 percent of incident cases received an antidepressant in FY 2006. When examining only those with a psychosis, 55 percent of prevalent and 70 percent of incident cases received an antipsychotic.

We found that OEF-OIF veterans with any mental health diagnosis

were commonly treated with a psychotropic medication (79 percent prevalent, 84 percent incident). Antidepressants were commonly used in both prevalent (75 percent) and incident cases (82 percent), as were antipsychotics (33 percent prevalent, 35 percent incident) in FY 2009. When examining only those with depression we found that 87 percent of prevalent cases and 91 percent of incident cases received an antidepressant in FY 2009. Restricting analyses to those with any psychosis, we found that 56 percent of prevalent cases and 57 percent of incident cases received an antipsychotic.

Treatment in Specialty Care

Our examination of the type of care received by veterans in the geriatric epilepsy cohort indicated that for prevalent cases, 23 percent had at least one visit with a neurologist in FY 2005 and 21 percent received neurology care in FY 2006. For those with incident epilepsy, 44 percent received care at least once in a VA neurology outpatient clinic. Frequent primary care visits (five or more in a year) were similar for prevalent (29 percent) and incident (30 percent) cases.

For the OEF-OIF cohort, 56 percent of those with prevalent epilepsy received outpatient neurology care in FY 2008 and 60 percent received outpatient neurology care in FY 2009. For those with incident epilepsy, 71 percent received care at least once in a neurology outpatient clinic. Frequent primary care visits were more common in incident (34 percent) than in prevalent (21 percent) patients.

Treatment in Primary Care

In the geriatric cohort, of those with prevalent epilepsy, 74 percent received primary care only, 20 percent received primary and neurology care, 1 percent received only neurology care, and 4 percent received neither primary nor neurology care. For incident cases, we found that 54 percent received only primary care, 43 percent received neurology and primary care, 1 percent received only neurology care, and 2 percent received neither primary nor neurology care. These rates are significantly different for older veterans without epilepsy (92 percent primary care only, 3.5 percent primary and neurology care, and < 1 percent with just neurology care; $p < .001$). The mean number of primary care visits in FY 2006 was 4.0 (standard deviation [SD] = 4.7) for prevalent cases, 5.1 (SD = 5.1) for incident cases, and 3.1 (SD = 3.3) for those without epilepsy. Differences among all groups were statistically significant ($p < .001$).

In the OEF-OIF cohort, among those with prevalent epilepsy 34 percent received only primary care, 54 percent received neurology and primary care, 6 percent received only neurology care, and 6 percent received neither

primary nor neurology care. Among incident cases, 29 percent received only primary care, 65 percent received primary and neurology care, and 5 percent received only neurology care (< 1 percent received neither primary nor neurology care). This was significantly different from OEF-OIF veterans without epilepsy (72 percent only primary care, 6 percent neurology and primary care, < 1 percent only neurology care, 22 percent neither neurology nor primary care ($p < .001$). The mean number of primary care visits in FY 2009 was 3.5 (SD = 4.3) for prevalent cases, 3.9 (SD = 2.9) for incident cases, and 1.9 (SD = 2.1) for those without epilepsy. Differences among all groups were statistically significant ($p < .001$).

Medications

For those with prevalent epilepsy, 84 percent of geriatric and 89 percent OEF-OIF cohort patients received at least one seizure medication, with most receiving monotherapy (geriatric: 77 percent; OEF-OIF: 63 percent). Among incident cases, 80 percent of geriatric patients and 84 percent of OEF-OIF patients received seizure medication monotherapy during their first year of treatment.

For those with prevalent epilepsy, 30 percent of geriatric and 57 percent of OEF-OIF patients received concomitant seizure medication and antidepressant treatment. For incident cases, 34 percent of geriatric patients and 73 percent of incident patients received concomitant seizure medication and antidepressant treatment.

Hospital and Emergency Care

Prevalent cases in the geriatric cohort had relatively stable utilization of care, with approximately 15 percent of the cohort having at least one hospitalization (mean hospital days 6.4, SD = 118 in FY 2005; mean 6.3, SD = 41 in FY 2006) and 27 percent having at least one emergency visit in FY 2005 and FY 2006 (16 percent > 1 visit FY 2006). Incident cases demonstrated significant utilization that was likely associated with epilepsy. In FY 2005 17 percent had at least one hospitalization (mean hospital days 7, SD = 34) in the year of epilepsy diagnosis, and 30 percent had at least one hospital stay (mean hospital days 18.0, SD = 75). Similarly, the year before meeting epilepsy criteria, 32 percent received emergency care, while the year of meeting epilepsy criteria, 48 percent had at least one emergency visit (19 percent > 1 visit FY 2006).

Similar findings were obtained from the OEF-OIF cohort where 21 percent of patients with prevalent epilepsy were hospitalized at least once in FY 2008 and FY 2009 (mean hospital days 6.0, SD = 26, FY 2008; mean 6.0, SD = 27, FY 2009). Emergency care was also common for patients

with prevalent epilepsy, with 39 percent receiving emergency care in both FY 2008 and FY 2009 (22 percent > 1 visit FY 2009). For incident epilepsy patients, only 9 percent had at least one hospitalization in FY 2008 (mean hospital days 3.3, SD = 23), with an increase to 30 percent (mean hospital days 6.8, SD = 23) in the year of meeting epilepsy criteria. Similarly, in FY 2008 29 percent of incident patients had at least one emergency visit, and 49 percent had at least one emergency visit in FY 2009 (29 percent > 1 ER visit FY 2009).

Neurosurgical Interventions

We were unable to assess this due to unavailability of data given the time constraints of this evaluation, since most neurosurgical interventions are conducted at academic affiliates and data are not readily available.

EEG, MRI, Video-EEG Monitoring

Assessments for EEG and video-EEG related to epilepsy were available for this assessment. MRI data were not specific to epilepsy. In the geriatric cohort, VA EEG testing was completed for 3 percent of prevalent cases and 16 percent of incident cases. Prolonged video-EEG was conducted for less than 0.5 percent of older veterans regardless of epilepsy status. For the OEF-OIF cohort, 22 percent of prevalent cases and 55 percent of incident cases received EEG testing. Less than 0.5 percent of prevalent cases and 2 percent of incident cases received prolonged video-EEG testing within the VA. However, these numbers are likely to be an underestimate since so much prolonged video-EEG testing is conducted through academic affiliates.

Ideas for Improving Epilepsy Surveillance Within the VA

The funding of VA ECOEs provides an opportunity to proactively conduct surveillance of epilepsy within the VA using available data and technology. We are currently validating the epilepsy detection algorithm for use in the OEF-OIF patient population. In addition, the ECOEs have invested in a biostatistician who will assist in providing surveillance in real time using the clinical enterprise data. That real-time identification, combined with chart abstraction when specific issues arise, will help us refine algorithms to provide the best approach to epilepsy surveillance. A second recommended improvement is to begin a national epilepsy registry for the VA. There are ongoing efforts to begin a registry of individuals who receive care from an ECOE clinician. However, to date, our data suggest that this would include only a portion of VA patients with epilepsy since only a small portion of the

patient population is seen in an ECOE clinic or hospital. Thus, such a registry would have to be based more broadly on all VA patients who receive epilepsy care rather than only the most severe patients who receive care in ECOE clinics. A national registry of all VA patients with epilepsy will allow ECOEs and other neurology providers to better monitor the quality of care for the VA epilepsy patient population.

SOUTH CAROLINA

Anbesaw W. Selassie, Dr.P.H.[4,5]

Overview

The South Carolina Epilepsy Surveillance System (SCESS) was established in response to funding announcement from the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), Centers for Disease Control and Prevention (CDC), which sought a comprehensive system to monitor incidence, prevalence, and unmet needs of persons with epilepsy. Funding was granted to the Department of Biostatistics and Epidemiology at the Medical University of South Carolina. The SCESS was established in August 2002 in partnership with public and private organizations that have a stake in epilepsy surveillance. The partners include the SC Department of Health and Environmental Control, the SC Budget and Control Board Office of Research and Statistics (ORS), and the Epilepsy Association of South Carolina. Other stakeholders that supported the surveillance effort are the Medical Association of South Carolina, the SC Hospital Association, and the SC Chapter of the American Neurological Association. The broad collaboration and interprofessional support still remain critical to the flow of data and access to medical records.

The SCESS relies on multifaceted data sources to collect, analyze, and monitor the occurrence of epilepsy in the statewide population (Figure B-1). The primary goal of the surveillance activities is to determine the service needs of people with epilepsy, identify risk characteristics that impact in their quality of life, and monitor incidence and prevalence. As a chronic health condition that requires periodic access to clinical care, the main task in the development of the SCESS was to identify the venues of care for people with epilepsy. These include inpatient, emergency,

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[5]This report is prepared with the support and collaboration of Mr. Chris Finney, M.S., Office of Research and Statistics, South Carolina Budget and Control Board. Special thanks go to Ms. Sandra Kelly for facilitating permission to the various data sources and securing approval from the South Carolina Data Oversight Council.

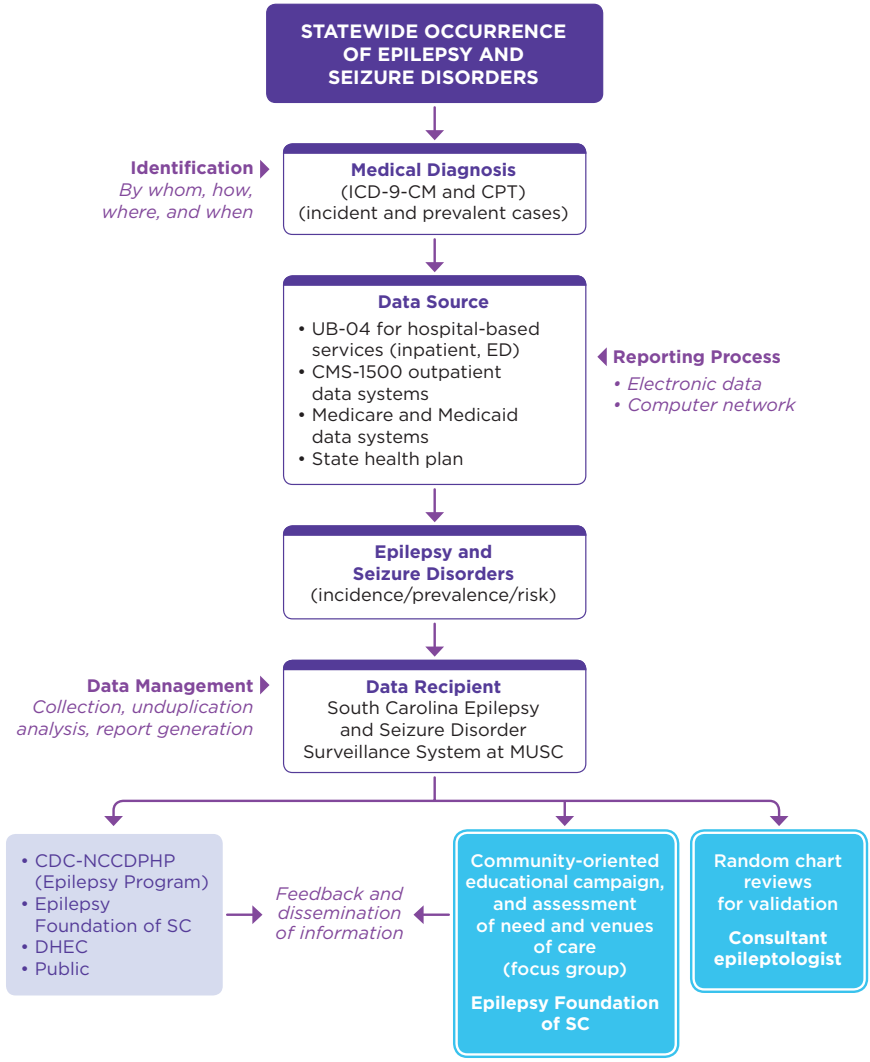

FIGURE B-1
Systems involved in epilepsy and seizure disorder surveillance in South Carolina.

NOTE: CDC-NCCDPHP = Centers for Disease Control and Prevention's National Center for Chronic Disease Prevention and Health Promotion; CMS = Centers for Medicare and Medicaid Services; CPT = Current Procedural Terminology; DHEC = Department of Health and Environmental Control; ED = emergency department; ICD-9-CM = International Classification of Diseases, Ninth Revision, Clinical Modification; MUSC = Medical University of South Carolina; SC = South Carolina.

and hospital-based outpatient departments (OPDs) including outpatient surgery, physician office visits, nursing homes, and specialized clinics and institutions. In this regard, the unique strength of the State of South Carolina is the availability of a central data repository for all of these services. The ORS is the designated repository for all health and human services in the state and is legally charged to receive uniform billing (UB) and noninstitutional claims (Centers for Medicare and Medicaid Services [CMS]-1500) extracted data from all nonfederal health care establishments. The full list of the data systems housed in the ORS along with the integrated data system that enables the tracking of individuals is described elsewhere (South Carolina Budget and Control Board Office of Research and Demographics, 2012). The main sources of data that provide and validate clinical, demographic, socioeconomic, and short-term outcome information are as follows.

UB-04 (Hospital Discharge, Emergency Department, and Hospital-Based Outpatient Data Systems)

The UB-04 is an electronic claim form for institutional health care services. The ORS receives copies of patient billing extracted quarterly from all nonfederal hospitals, EDs, and hospital-based OPDs and outpatient clinics. In South Carolina, this reporting system is population-based for all patient encounters in a hospital setting for the civilian population. The database includes up to 15 ICD-9-CM codes, primary and secondary external causes of injury codes, unique personal identifiers (full name, Social Security number [SSN]) date of birth, address and county-level information, length of hospital stay, acute care charges, primary and secondary procedure codes, and discharge disposition. The data set is required to be 99 percent complete and 99 percent accurate with exception granted to the fifth digit of the diagnosis codes, which may be inaccurate due to limited access to diagnostic resources. Because the data sets are legally mandated, compliance with the submission guideline for UB reporting is 100 percent. Furthermore, the ORS has developed a report card as a feedback mechanism to provide accuracy rates to each hospital on an annual basis. The inclusion of personal identifiers (SSN and name) and addresses for each encounter greatly increases the potential benefits of these data sources for data linkage, medical record review, and follow-up of patients. The variables included in the UB-04 data set are described elsewhere (South Carolina Budget and Control Board Office of Research and Demographics, 2012). Data captured through the UB-04 are collated into the venues of clinical services as the inpatient department, ED, outpatient surgery, or clinic. The hospital inpatient department captures 20-22 percent of

people with epilepsy, while the ED and OPD jointly capture 45 percent of people with epilepsy each year. Hospital inpatient data mostly capture severe and refractory forms of epilepsy. ED surveillance is invaluable to capture people with epilepsy who do not have health insurance and use the ED as their medical home. One in ten people with epilepsy have no health insurance because they earn the bare minimum that makes them ineligible for Medicaid. The S.C. surveillance data suggest that two-thirds of people with epilepsy could be captured through hospital-based surveillance that includes inpatient, ED, and outpatient encounters.

Centers for Medicare and Medicaid Services-1500 (Noninstitutional Claims)

This billing system captures insurance claims for medical services provided by health professionals in noninstitutional facilities that are exempt from submission of electronic claims. These include clinical services rendered in physician offices, nursing homes, and long-term care facilities. Th ORS receives copies of patient billing extracted data on all items included in the CMS-1500 form, which are collated into the various venues of patient care as physician office visits, nursing home care, et cetera. The data set has a comparable level of completeness and accuracy to the UB-04 for most of the data items since it is intended to validate the accuracy of reimbursable billing. This data system captures young adult males with private insurance and older patients with Medicare. Nearly 15 percent of people with epilepsy are captured through this billing data set.

The Statewide Medicaid Data Set

The ORS has been receiving Medicaid data since the 1990s. According to Title XIX of the Social Security Act, a state's Medicaid program must offer medical assistance for certain basic services to most categorically needy populations. The ORS works under contract with the state Medicaid agency supplying statistical analysis for utilization and quality assurance issues. Health care providers are required to submit all claims within a year if they are to be reimbursed. The ORS receives all transactions files for Medicaid including payment and eligibility files from all providers. Because about half of adults with epilepsy are classified as needy without employment, Medicaid captures about half of the people with epilepsy. The Medicaid state plan represents 500,000 eligible state residents.

State Health Plan Data Set

The ORS obtains this data set under a signed, open-ended contract with the State Employee Insurance Program, an agency also under the Budget and Control Board. The State Health Plan (SHP) has 463,000 subscribers and their families, accounting for 10 percent of the state population. The program tracks deductibles and copays associated with the health care system for enrollees and dependents. Information contained in the SHP data set includes physician office visits, hospitalizations, outpatient services, rehabilitation, procedures, and so forth. There are limitations to the SHP data set. It is not subject to Title 44 of the South Carolina Code of Laws and therefore is not subject to the same completeness and accuracy requirements as the health services utilization data sets. It also does not include information on race. However the SHP data set captures 10 percent of people with epilepsy that are not captured by any other data system.

Medicare Standard Analytic Files

These data provide a population-based analysis for persons older than 65 years of age and persons qualified for Social Security disability. The outpatient physician office visit data along with the pharmacy data will provide a mechanism for identifying patients with epilepsy. The detailed data elements for these files are compiled into a Medicare Data Dictionary. The ORS applies for the Beneficiary Encrypted Standard Analytical Files for all claims from the CMS. Approval to access the data set is more cumbersome than the direct access that the surveillance system has to other sources. Because it overlaps with the UB-04 system, 20 percent of people with epilepsy under Medicare are captured through the UB system. Given the increasing incidence of epilepsy among the elderly, access to Medicare Standard Analytic Files is important to complement epilepsy surveillance. Based on the 2010 demographic distribution of the state, this data system could provide detailed information on 12 percent of the South Carolina population (536,000: 486,000 older adults and 50,000 individuals with disability).

Medical Chart Review

Review of clinical records is one of the most important components of the surveillance system to validate and complement information. Records of randomly selected epilepsy (345.x) and seizure unspecified (780.39) patients are reviewed to estimate the sensitivity and predictive value positive of the case ascertainment criteria and acquire more detailed information on severity, frequency, type of seizure diagnosed, and seizure medication use. During the initial funding cycle, we reviewed 3,881 (5.5 percent) of the 70,955

records with 345.x and 780.39. A comprehensive report on the findings of chart reviews is available (Selassie et al., 2005). Since there is no specific code for seizure-like events and in order to validate the accuracy of 780.39, chart reviews are invaluable to determine the extent to which misdiagnosis confounds estimation of the incidence and prevalence of epilepsy. Sampling of records takes into account the size and status of the hospitals. There is oversampling of records from underresourced and rural hospitals where the accuracy of diagnosis is likely to be affected.

Methods of Identifying and Classifying People with Epilepsy

The SCESS receives electronic data from the ORS on all patient encounters with a primary or secondary diagnosis of epilepsy (345.x) and 780.39 (seizure unspecified) collated in UB, SHP, and Medicaid files on a biannual basis. The latter two files include noninstitutional claims on patient encounters rendered in physician offices, nursing homes, and long-term care facilities. A case of epilepsy is identified in each data file from any one of the 15 diagnosis fields. Each observation in these data files has a unique identifier (UID)—an encrypted individual tracking number developed by the ORS using various combinations of personal identifiers that include SSNs, dates of birth, and other demographic attributes. The UID is unique enough to allow linkage across multiple providers and services since 1995. The reported error rate of the UID for matching observations across files is < 0.05 percent (South Carolina Budget and Control Board Office of Research and Demographics, 2012).

Case identification begins by sorting the type of epilepsy diagnosis recorded in the data files. A flag variable is assigned for each observation based on the ICD-9-CM diagnosis grouped in the following order using "arrays" and "do loops" in a SAS program data step:

1. Generalized nonconvulsive epilepsy (345.0)
2. Generalized convulsive epilepsy (345.1)
3. Petit mal status (345.2)
4. Grand mal status (345.3)
5. Focal epilepsy with complex partial seizures (345.4)
6. Focal epilepsy with simple partial seizures (345.5)
7. Infantile spasms (345.6)
8. Epilepsia partialis continua (345.7)
9. Other recurrent forms of epilepsy (345.8)
10. Epilepsy unspecified (345.9)
11. Seizure NOS (780.39)

Types of seizure listed in items 1 through 10 are considered highly probable cases of epilepsy, while the eleventh classification (seizure NOS) is considered as a likely case of epilepsy based on satisfying the decision algorithm depicted in Figure B-2. After cases have been identified, they are sorted by the UID and seizure type in an SAS data step (Proc sort data = xx; by UID ascending type). This step is followed by counting the number of times a given UID is listed in the database for encounters at least 2 days apart in each calendar year. Observations with more than one count (encounter) are allowed to have up to five seizure diagnoses and dates of encounter retained by extending the logical record length of the files using the SAS command "Proc transpose." Duplicate records with identical entries or encounters noted in < 48 hours are deleted, keeping the updated and more complete information. The sorting of the type of seizure diagnosis in ascending order reduces the likelihood of deleting the more suggestive diagnosis of epilepsy than the least suggestive (345.9 versus 780.39). Data analysis shows that specific epilepsy diagnoses are frequently assigned by neurologists or after EEG evaluations. This procedure guides the process of deleting the less accurate provisional diagnosis.

Capacity to Follow Individuals Over Time

The SCESS has capacity to track and follow individuals over the course of accessing the health care system in South Carolina. This capacity is facilitated in partnerships with the ORS—the state entity with the legal authority to link the UID to secured files with names, telephone numbers, mailing addresses, and other information that aids in tracking. There are two levels of tracking. The first involves tracking of individuals across the various data systems housed in the ORS. A partial list includes the ED, hospitalizations, outpatient surgeries, Medicare, Medicaid, state employee health, vital records, mental health, alcohol and drug services, disabilities and special needs, vocational rehabilitation services, social services, home health, and disease registries. This tracking activity provides substantial amounts of information on vital events and utilization rates of services across health and social services in the state. Examples include how many people with epilepsy receive behavioral and mental health services or how many died in a given year. The second level of tracking occurs when researchers want to identify and acquire specific data on individual patients for IRB-approved study. In such circumstances, the ORS mails a letter of invitation, after approval from the data oversight council, to people with epilepsy on behalf of the study inquiring their willingness to participate in the proposed study. If they grant their consent to participate in the study, the ORS releases their personal information to the research team, including access to their medical records. In summary, the key factors that enable tracking and follow-up

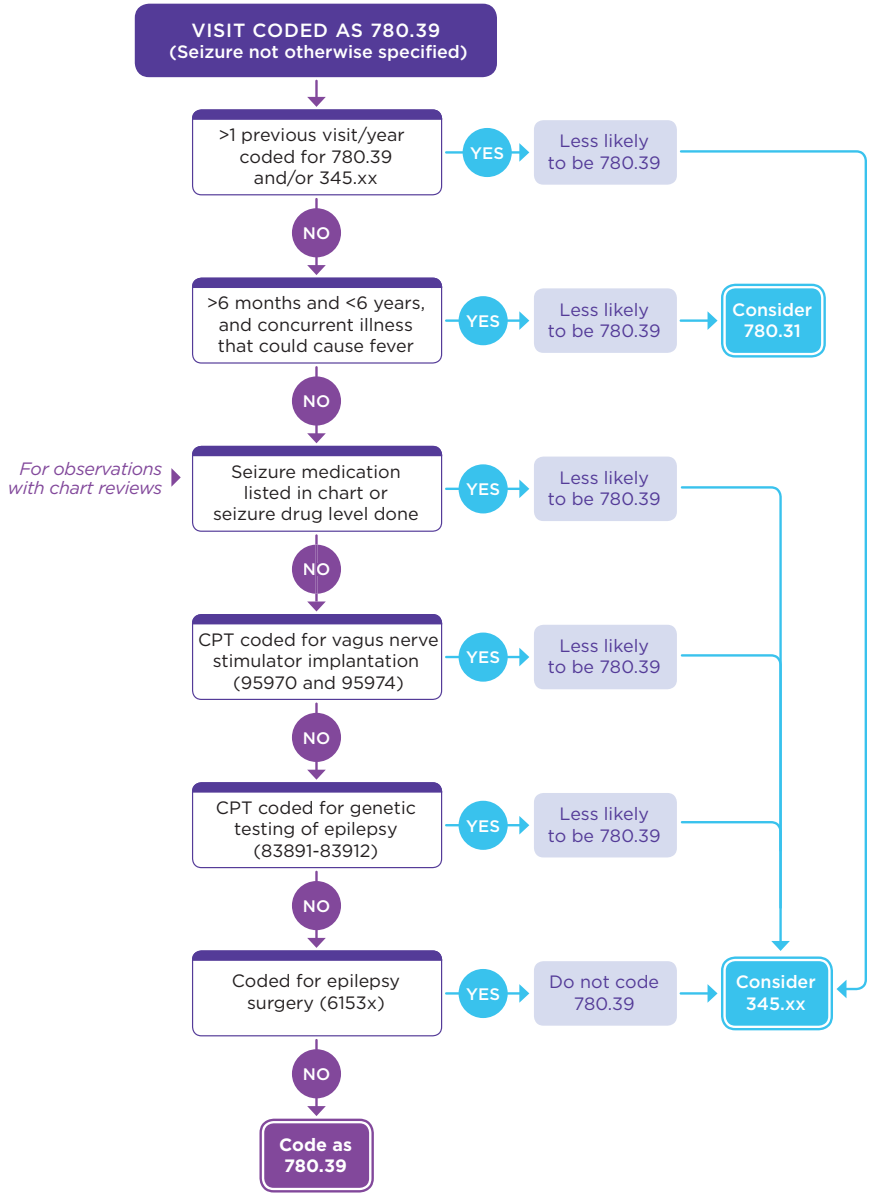

FIGURE B-2
Decision algorithm for individuals coded with a seizure not otherwise specified (780.39).

NOTE: CPT = Current Procedural Terminology.

are the availability of a central data repository for multiple data systems in an agency that has legal authority to identify people with epilepsy and the availability of the UID linked to personal information files to contact patients as needed.

Usefulness

The SCESS has demonstrable usefulness for case management and service delivery, policy development, and research. Examples include identifying low-income, severe cases of TBI-related epilepsy for service delivery in the Department of Disabilities and Special Needs. In this collaborative work, data gleaned from the SCESS inform resource planning based on periodic prevalence estimates and prioritizing for services. In the areas of policy development, the SCESS provided the information needed to build the case for a joint resolution (Act No. 168) to develop a comprehensive service delivery system for people with epilepsy. This act is currently pending the signature of the governor. In areas of clinical services, planning is under way to incorporate epilepsy care in underserved communities via telemedicine platforms. The overwhelming evidence of need for this approach emanated from the surveillance information. Data show that 40.7 percent of people with epilepsy in the state reside in rural counties that require at least a day's trip to see a neurologist. In areas of research, the SCESS continues to be critical for development of pilot projects and cooperative grants by providing the preliminary data needed for research applications. Other uses include public information and education in an annual event known as "Epilepsy Boot Camp" and dissemination of brochures to health workers and physician offices on depression among people with epilepsy.

Strengths and Limitations

The SCESS has several strengths. First, it is a passive surveillance system that relies on existing data sources collected for administrative purposes. This makes the system cost-efficient with little or no need for data solicitation. Second, the events of epilepsy are captured from a well-defined population base, making the numerator representative of the denominator. This ensures that estimates derived are generalizable and valid. Third, data acquisition is timely, providing estimates on short- and long-term trends. Currently, 15 years of person-specific data are available on epilepsy and seizure disorders, making the system among the best sources of epilepsy data for epidemiological analysis. Fourth, the data system includes UIDs that allow linkage across multiple data platforms for service delivery, clinical research, and outcome studies. Capacity to link electronic surveillance data with medical charts has been particularly useful to evaluate positive

predictive value, sensitivity, and coding accuracy. Fifth, the data sets include information on procedures (up to 50 CPT codes) and acute care charges. CPT codes provide substantiating information on VNS implant, epilepsy surgery, genetic testing for epilepsy, and EEG monitoring to validate the diagnosis codes of epilepsy among persons coded with 789.03. Lastly, the availability of the full range of acute care charges broken down by type of service and procedure is important for cost-related comparative effectiveness studies.

Despite the aforementioned strengths, there are important limitations worth noting. First, while the data system is representative and complete for the civilian population, it does not capture cases diagnosed in federal medical facilities, specifically persons from the two VA and the five military hospitals. Given the high incidence of TBI-related epilepsy among Gulf War veterans, this is likely to contribute to underestimation of prevalence. South Carolina has an estimated 300,000 veterans whose risk for epilepsy is presumed to be higher than that of the general population. However, this limitation is a universal flaw of all public health data systems in the United States. Second, data come from administrative records designed primarily for billing third-party providers. This makes the coding of a diagnosis responsive to the policies of providers and the preference for diagnosis codes that maximize reimbursement. Further, there is preference for diagnosis codes that are less likely to be denied, lead to reduced reimbursement, or put more financial burden on the patient. A plausible explanation for the preference of 789.03 over 345.x in the face of multiple visits is in part to avoid labeling patients with a diagnosis of epilepsy. Our data evaluation shows that 82.6 percent of cases coded as 789.03 are true epilepsies. Third, with wide variability in skill sets and diagnostic resources among hospitals, the accuracy of the fourth and fifth digit of the diagnosis codes from underresourced hospitals might be unreliable. Fourth, the CPT codes are nonspecific for assessing if all EEGs, video-EEGs, and MRIs are related to the diagnosis of epilepsy without medical record evaluation. Likewise, cost estimates for epilepsy are "contaminated" by costs incurred by other conditions unrelated to epilepsy, requiring the development of a better methodology for cost analysis.

Incidence and Prevalence Estimates for 2006-2010

Brief Description of Methods for Estimating Prevalence and Incidence

Cases of epilepsy are discriminated as incidence or prevalence based on their first encounter. Case ascertainment criteria are described earlier. A flag variable is constructed by counting the number of times a case with a

UID is encountered. Cases with more than one encounters are labeled as "R" for repeat and "N" for new encounters. Because this report provides information on encounters since 2006, a few incident cases seen in the latter part of 2005 might have been labeled as new in 2006, making the estimated incidence in 2006 slightly higher—0.14 percent compared to 0.10 percent for the average of 2007-2010. The advantages and disadvantages of the system are described earlier.

Nontabular Description of Incidence and Prevalence

Incidence and prevalence were calculated taking the 2008 (the median year) population of the state as the standard. Population estimates were acquired by county and demographic characteristics from the CDC National Center for Health Statistics website (CDC, 2010). County-specific information on income and poverty level was extracted from the U.S. Census Bureau Small Area Income and Poverty Estimate (Census Bureau, 2011). Results show that the cumulative incidence of epilepsy from 2006 through 2010 is 0.5 percent, which yields an annual incidence of 0.095 percent, or 95 per 100,000 population per year. This estimate is much higher than the 39 per 100,000 per year reported from Rochester, Minnesota, for the period 1955-1984 (Annegers et al., 1995)—the only population-based study published based on complete case ascertainment criteria. This discrepancy is attributable to temporal variation and differences in population composition (Sander, 2003). By taking the mean age (32.2 years) of people with epilepsy in the state as the average duration of follow-up, person-year denominator was constructed to generate incidence density that can readily be converted to risk as proposed by Morgenstern and colleagues (1980). Accordingly, a probability of 0.0051 (5.1 in 1,000 S.C. residents) is estimated for new onset of epilepsy over the 5-year period of observation.

Annual incidence by age group showed 0.19 percent, 0.08 percent, and 0.05 percent for 0-18, 19-64, and ≥ 65, respectively. Gender differences were minimal, with females at 0.11 percent and males 0.10 percent per annum. Incidence was twice as high in blacks (0.16 percent) as in whites (0.08 percent). Incidence was 0.09 percent in Hispanics and 0.07 percent in other races. The most profound difference in incidence was noted among the insurance categories. Medicaid-insured individuals had 26-fold increased risk of new onset of epilepsy compared to those with private insurance (0.398 percent per year for Medicaid and 0.015 percent per year for private). Incidence was 0.053 percent for Medicare and 0.020 for the uninsured. Comparison of ratios in reference to private insurance indicates that the incidence of new onset was 26.0, 3.5, and 1.3 times greater in Medicaid, Medicare, and uninsured, respectively.

Annualized prevalence was in the same direction as the incidence. It was higher in the age group 0-18 (0.541 percent) followed by 19-64 (0.375 percent). The prevalence among older adults, age ≥ 65, was 0.242 percent. Analysis by gender showed higher prevalence in females (0.468 percent) than in males (0.328 percent). The magnitude of the difference in prevalence among the race or ethnic groups was comparable to incidence, with ratios nearly twice as high in blacks (0.626 percent) as in whites (0.317 percent). The prevalence among Hispanics was 0.222 percent and in races grouped as "other" was 0.273 percent. Prevalence estimates also show the disproportionate burden of epilepsy borne by persons with Medicaid insurance (1.059 percent). This is nearly seven times higher than the prevalence of people with epilepsy with private insurance (0.153 percent). The second highest prevalence was among persons with Medicare insurance. It is important to note the discrepant prevalence estimates observed in older adults (0.242 percent) and the high prevalence in persons with Medicare insurance (0.474 percent). This discrepancy is explained by Medicare eligibility criteria. Although all older adults are eligible for Medicare, not all Medicare eligibles are older adults. Medicare is also an entitlement program for persons with disability who qualified for Social Security Disability Income. In the epilepsy data set analyzed for this report, 25 percent of people with epilepsy younger than age 65 have qualified for Medicare. In fact the mean age of Medicare insured was 55.9 (±17.6) and the median age was 55. Thus, Medicare insurance carries a large proportion of prevalent cases of epilepsy with disability as reflected by the higher prevalence than that observed among older adults.

Comorbidities

Brief Description of Methods for Estimating Comorbidities

Co-occurrences of illnesses other than the primary disease of interest (epilepsy) are identified from the secondary diagnosis fields (9 in Medicaid and the SHP; 14 in the UB) in the data sets. Thirty-one comorbid conditions known to be associated with epilepsy beyond those that could be explained as chance and/or of interest to this report were identified using "arrays" and "do loops" in SAS V9.1.3. The SAS program was written in such a way that it identifies one disease at a time while ignoring the other comorbid diseases until the "do loop" exhausts all the diagnosis fields referenced in the array listing. This procedure allowed counting of more than one comorbid condition per patient. For example, 170 patients had 5 or more of the 31 conditions at the same time.

Description of Comorbidities Among Prevalent Cases

Of the prevalent cases, 39.3 percent have one or more comorbid conditions (i.e., 18.3 percent with two or more, 21.0 percent with one condition). Mental health comorbidities accounted for 14.9 percent, while cardiovascular diseases including established hypertension accounted for 21.6 percent. Diabetes mellitus and asthma with chronic bronchitis accounted for 7.9 percent and 8.1 percent, respectively. Based on corroborating Vcode (V15.82) and CPT code (99406-07), most of the chronic bronchitis cases appear to be associated with smoking. Substance abuse disorders (drugs and alcohol) were noted in 2,607 (4 percent) of the prevalent cases. Cognitive and learning difficulties were noted in 1,981 (3 percent) of the prevalent cases and appear to be associated with duration of illness based on the number of encounters with these patients. Stroke was noted in 2.5 percent of the prevalent cases, but it is uncertain whether it is temporally antecedent to the epilepsy or a subsequent event. Forty-three percent of stroke was noted among older adults with epilepsy. Another high-frequency comorbidity among prevalent cases is anemia, noted in 2,179 (3.25 percent) patients. While 59.5 percent of the prevalent cases are females, the proportion of females with anemia was 68.5 percent, suggesting the preponderance of females with epilepsy that have comorbid anemia. Other low-frequency but important comorbid illnesses include nutritional deficiency (N = 879; 1.3 percent), brain trauma (N = 272; 0.41 percent), multiple sclerosis (N = 265; 0.40 percent), and HIV/AIDS (human immunodeficiency virus/acquired immune deficiency syndrome) (N = 232; 0.35 percent).

Description of Comorbidities Among Incident Cases

Of incident cases, 16.2 percent have comorbid conditions. In contrast to the number of persons with comorbid illnesses among prevalent cases, comorbidity among incident cases is 60 percent less. The distribution of comorbid illnesses mirrors that of the prevalent cases with the difference being the counts of comorbidities. When proportions are derived from the number of cases with at least one comorbid illness (i.e., positive cases for comorbidity), significant differences exist between incident and prevalent cases. Chronic physical illnesses such as cardiovascular disease, diabetes, and asthma were significantly higher among prevalent cases, while the proportion of emotional and behavioral problems such as depression, mood, and anxiety disorders was significantly higher among incident cases: 48.3 percent of incident cases had emotional and behavioral problems in contrast to 37.5 percent of prevalent cases; conversely, 56.4 percent of the prevalent cases with at least one comorbidity had cardiovascular disease, compared to 39.2 percent of incident cases. These differences in the distribution of comorbidities between incident and prevalent cases yield

important information to estimate the residual risk of comorbid illnesses attributable to epilepsy.

Health Care Services

Brief Description of Methods Used to Estimate Health Care Services

The UB, SHP, and Medicaid files were linked with mental health and substance abuse service files that provide information on service utilization in clinics run by various agencies. Additional information pertaining to receipt of services was acquired with the CPT codes of 96150-96155, which indicate treatment for psychological, behavioral, emotional, and cognitive health problems. Information on access to specialty care was identified from rendering the specialty label included in all of the data sets utilized. Professional specialties were grouped in the following manner. Evaluations made by neurologists and neuropathologists were listed as a "neurologist care"; neurological (epilepsy) surgeons as "neurosurgery"; evaluations made by neuropsychiatrists and psychiatrists as "psychiatric care." Evaluations made by family physician, internist, pediatrician, emergency medicine, and general practitioner were listed as "primary care." All other consults and evaluations made by various specialties, including radiologist, nurse practitioner, psychologist, neuropsychologist, et cetera, were grouped as "all other care." Receipt of care for psychiatric problems was determined by the specialist rendering the service or by referral disposition to mental health clinics, which when flagged indicated that the service was received. Venues of care were grouped as inpatient, hospital outpatient, or ED; physician offices; and ambulatory care services. Annual rate of use by venues of care was estimated by counting the total encounters made in each of the venues and expressed as a proportion. The algorithm used to identify epilepsy cases and recency of onset (incidence) is described earlier. Information on seizure medication use and most common prescription was identified from 2,226 randomly selected chart reviews in the state. The abstraction expenses were covered by funding from the CDC, NCCDPHP Epilepsy Program Office. Estimates for selected services are provided by the CPT codes. Direct cost of medical care was derived from charged amount per specialty and venues of care. According to the ORS, the charge-to-revenue ratio in South Carolina is $1.0:$0.92. Cost summary is analyzed using SAS "Proc tabulate" with "sum*$charge" and "mean*$charge" options. Information on provider specialty was missing in 24.3 percent of the cases. In these circumstances, missingness was determined to be completely at random and ignorable when comparisons of demographic, hospital, and payer characteristics of observations with missing and nonmissing values were not significantly different.

Receipt of Care for Psychiatric Problems

There is some discrepancy between the number of people with established diagnosis of psychosis, depression, mood and anxiety disorders, and receipt of care for these problems. While 9,489 (10.6 percent) of the total 89,938 people with epilepsy had the mentioned diagnoses, 7,570 (8.4 percent) received treatment. This suggests that of those with these psychiatric diagnoses, 79.8 percent received treatment for mental health problems, which included therapies offered by primary care physicians, clinical psychologists, and psychological counselors. The number of people with epilepsy who received treatment from psychiatrists was only 856 (0.93 percent of those with mental health problems).

Receipt of Epilepsy Care

Of the total 67,040 prevalent cases of epilepsy identified from 2006 to 2010, 22.8 percent were diagnosed and treated by neurologists (includes the 18 epileptologists in the state); 59.6 percent were evaluated and treated by PCPs; and 16.3 percent were evaluated and treated by other providers. Of the total 22,898 incident cases of epilepsy, 32.1 percent had evaluation and treatment rendered by a neurologist; 55.8 percent by PCPs; and 11.9 percent by other providers.

Seizure Medication Types and Combinations

Information on treatment relied on 2005 chart reviews since the surveillance data are not linkable to pharmacy files. Further, while revenue codes based on National Drug Codes are available, there are too many codes for the same generic product depending on dosage, routes of administration, and brand names, making such linkage unwieldy. Data from chart reviews of randomly selected 2,226 people with epilepsy showed that 70.5 percent were only on monotherapy; 24.2 percent were on two medications; and 5.3 percent were on three or more seizure medications. The most commonly prescribed seizure medications were phenytoin (55 percent), valproic acid (19 percent), carbamazepine 18 percent, phenobarbital (13 percent), and gabapentin (6 percent). Fifteen other seizure medications have usage rate of 5 percent or less. Odds of taking more than one seizure medication was influenced by severity (adjusted odds ratio = 1.72; 95 percent CI 1.29-2.30). Unfortunately, this information was completed earlier and could not be separated by incidence and prevalence. Similarly, it was not possible to obtain data on antidepressant use alone or in combination with seizure medications.

Annual Rates of Use and Direct Cost of Care

Usage rates were estimated by rates of encounters. Over the 5 years, there were 1,226,479 encounters with 89,938 unduplicated patients. The average encounters per patient per annum were 2.73. The most frequently utilized venue of care was the hospital-based ED at 26.6 percent. Most of the ED encounters were made by Medicaid and uninsured people with epilepsy, suggesting the disproportionate reliance of these patients on the ED as their medical home. Medicaid accounted for 55.4 percent of the total 1,226,479 encounters contributing to the heavy utilization of the ED. Medicaid patients have limited quota in private practices because of the very low reimbursement rate of Medicaid. Inpatient hospital care has the second-highest utilization rate per annum at 22.9 percent, with a preponderance of children and older patients for admission regardless of insurance status. Hospital-based outpatient services were the third most common venues of care, accounting for 17.8 percent of the encounters. Case mix was 33.8 percent Medicaid, 25.4 percent Medicare, and 25 percent private insurance. There were an average of 38,757 private physician office visits per annum accounting for 15.8 percent of the total encounters. The case mix was predominantly Medicare and Medicaid. EEG, psychological testing, imaging, and laboratory evaluation accounted for 16.9 percent of the visits.

The average charged amount per annum was $6,884 for inpatient care, $586 for ED care, $469 for hospital-based outpatient care, and $186 for private office visits. Hospital-based bills, EDs, and OPDs include procedure charges that are less frequently rendered in private offices. This analysis was not able to partition total charges per service into subcharges.

Receipt of Neurosurgical Interventions

There were 5,173 surgical interventions over the 5 years of observation, with annual interventions averaging 1,034. For this analysis, interventions were not partitioned by procedure types. The average cost of neurosurgical intervention ranged from $1,809 for Medicaid to $5,602 for commercial insurers, with an overall average of $4,501.00 per intervention. The total charge included the whole range of neurosurgical interventions from inserting and replacing a neurostimulator pulse generator in outpatient surgery to lobectomy. The great majority (90 percent) of the interventions were implants.

Detailed information on annual rates of use and costs of hospital care, ED care, and physician services in a given year; average number of services per setting; cost of seizure medications; and comparison to non-epilepsy population were not available. Furthermore, it is not possible to partition services by prevalence and incidence status until supplementary data elements are acquired from the sources.

Suggestions and Recommendations

For population-based analysis and public health activities, systematic and ongoing surveillance of epilepsy is best conducted by using existing multifaceted data sources. It will be ideal if there is a centralized agency or organizations, such as the ORS, that has the legal authority to serve as a data repository in defined jurisdictions. It will be important that there be unique identifiers to link files across multiple data platforms to unduplicate observations and discriminate incident and prevalent cases. Access to medical charts for periodic evaluations of positive predictive value, sensitivity, and accuracy of the case ascertainment criteria is of paramount importance. Because of the chronic nature of epilepsy and the stigma associated with it, epilepsy diagnosis is frequently masked with seizure unspecified, delirium, and even syncope codes. Sufficient knowledge of these cases is acquired when corroborating evidences is available from CPT codes, medication use, prior visits, and review of records. There is sufficient evidence gleaned from periodic surveillance to indicate the disproportionate burden of epilepsy in minorities and economically disadvantaged groups, rampant payer-related substandard care, and the occurrence of comorbidities among people with epilepsy that exceed the general population threshold. The increasing trends of epilepsy in the elderly and socioeconomically disadvantaged population groups suggest the plausibility of an ecological link between the disease and socioeconomic determinants. The chronic nature of epilepsy, with its major impact on quality of life, economic impact on the national health care cost, and potential to prevent secondary conditions associated with it, are strong public health rationales supporting the need to maintain four to six sentinel sites across the nation for ongoing surveillance of epilepsy.

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Data on Specialized Epilepsy Centers: Report to the Institute of Medicine's Committee on the Public Health Dimensions of the Epilepsies

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The National Association of Epilepsy Centers (NAEC) is pleased to provide the Institute of Medicine's (IOM's) Committee on the Public Health Dimensions of the Epilepsies with data related to services provided by specialized epilepsy centers.

BACKGROUND INFORMATION ON SPECIALIZED EPILEPSY CENTERS

The goal of epilepsy treatment provided in a specialized epilepsy center is to eliminate seizures and side effects (CDC et al., 1997). NAEC defines a specialized epilepsy center as a program that specializes in providing comprehensive diagnostic and treatment services to individuals with uncontrolled seizures (i.e., refractory epilepsy). Of the 2.7 million Americans estimated to have some form of epilepsy, approximately 30 percent do not have adequate seizure control and suffer from refractory epilepsy (Kobau et al., 2008).

Typically, epilepsy care starts with an evaluation at an emergency room or a primary care physician's office. This is considered the first level of epilepsy care. It then most often proceeds to the second level of epilepsy care,

which is a consultation with a general neurologist or possibly a specialized epilepsy center if considered necessary and locally available. Many, and perhaps most, patients with seizures can be initially evaluated and managed at the first or second level of epilepsy care by a primary care physician or a general neurologist in their local community. If seizure control is obtained, no further specialized epilepsy evaluation may be necessary. If seizures persist and cannot be brought under control by the primary care provider within 3 months, further neurological intervention is appropriate; the neurologist should assume full management of the patient's care at this point (Scheuer and Pedley, 1990). Once seizures are under control, care can be transferred back to the primary care provider.

NAEC recommends that referral to a level 3 or 4 specialized epilepsy center should occur when a patient's seizures are not fully controlled with the resources available to the general neurologist after 1 year. This recommendation was included in a technical assistance document supported by a grant from the Centers for Disease Control and Prevention for state Medicaid programs in contracting with managed care plans for epilepsy services (GWUMC, 2002).

Level 3 and 4 epilepsy centers provide an interdisciplinary and comprehensive approach to the diagnosis and treatment of patients with epilepsy. The team typically includes neurologists and neurosurgeons, neuropsychologists, nurse specialists, electroencephalography (EEG) technologists, and other personnel with special training and experience in the treatment of epilepsy. The primary goal of the team is to achieve complete control or at least a reduction in the frequency of seizures and/or medical side effects in patients with refractory epilepsy. This is accomplished through a comprehensive epilepsy evaluation, which provides epilepsy specialists with the necessary information to formulate a treatment plan, whether medical, surgical, or through use of an implanted stimulator.

A comprehensive epilepsy evaluation may require an inpatient admission to the epilepsy center's epilepsy monitoring unit (EMU). The evaluation is done to confirm a diagnosis of epilepsy seizures, to classify the type of seizures, and/or to determine if the patient would be a candidate for epilepsy surgery. It can include EEG monitoring with video (vEEG), cognitive testing, specialized brain imaging, and other procedures to determine the diagnosis and to prepare the most effective medical or surgical treatment plan. During hospitalization, withdrawal of seizure medications is often necessary to precipitate seizures in order to characterize them. In some cases, this may precipitate generalized tonic-clonic or severe seizure types that the patient is otherwise unlikely to experience, or it could precipitate status epilepticus. Balancing the need to provoke seizures but not induce status epilepticus requires expertise and intensive care. Seizures are recorded with vEEG and analyzed by an epileptologist and other members

of the center team who collectively determine the patient's course of treatment. To develop the patient's treatment plan the interdisciplinary team also considers medical and mental health comorbidities, injury and safety assessments, patient and family educational needs, rehabilitation needs, and social, occupational, and educational dysfunction.

Level 3 epilepsy centers provide the basic range of medical, neuropsychological, and psychosocial diagnostic and treatment services needed to treat patients with refractory epilepsy. In addition, many level 3 centers offer noninvasive evaluation for epilepsy surgery, straightforward resective epilepsy surgery, and implantation of devices such as the vagus nerve stimulator. Knowledge of and experience with epilepsy surgery have become sufficiently widespread that lesionectomy and anterior temporal lobectomy in the presence of clear-cut mesiotemporal sclerosis can be performed at level 3 epilepsy centers. The center's epileptologists are fully knowledgeable regarding all surgical options available and establish appropriate referral arrangements for more complex surgeries to level 4 centers.

Level 4 epilepsy centers serve as regional and/or national referral facilities for patients with refractory epilepsy and offer a complete evaluation for epilepsy surgery. These centers provide more complex forms of intensive neurodiagnostic monitoring, as well as more extensive medical, neuropsychological, and psychosocial treatment, including intracranial electrode placement, functional cortical mapping, evoked potential recording, electrocorticography, and resection of epileptogenic tissue in the absence of structural lesions; they also provide a broad range of surgical procedures for epilepsy. Many level 4 centers are actively involved in clinical trials and are well aware of trials conducted in other level 4 centers to make patient referrals.

SURVEY DATA

Data for this analysis were collected from two surveys sent to NAEC membership in 2011. The first source is NAEC's center designation survey, which is sent to all NAEC member centers annually. Each year, NAEC asks its members to provide information on their personnel, facilities, and services. The survey is based on NAEC's *Guidelines for Essential Services, Personnel, and Facilities in Specialized Epilepsy Centers* (Labiner et al., 2010). In 2011, 133 centers completed this survey. The NAEC annual designation survey has an extremely high response rate and provides information from approximately 90 percent of the specialized epilepsy centers in the United States.

Following discussions with members of the IOM committee and staff, NAEC sent a supplemental survey to its members in August 2011. This survey (see below) sought additional information on numbers of patients

seen annually, referral patterns, waiting times, and follow-up care. Forty-seven centers participated in this survey. The supplemental survey was blinded as to which centers responded so that the identity and level of the centers are not known. Nevertheless, the data are likely to be generalizable in a broad sense.

2011 National Association of Epilepsy Centers Designation Survey—Data from 133 Centers

Personnel

Based on the information gathered in its designation survey, NAEC recognized 115 level 4 and 18 level 3 epilepsy centers. On average, level 3 centers reported having one to three epileptologists and a neurosurgeon. Level 4 centers, on average, had three to six full-time epileptologists and two neurosurgeons. Level 4 centers tended to have a full-time advanced practice nurse and neuropsychologist, while most level 3 centers had part-time personnel in these positions.

Number of Inpatient vEEG and Surgery Cases

As part of the annual designation survey, centers reported the number of hospital inpatient cases of vEEG. This can be used as a proxy for the annual number of inpatient admissions for a comprehensive epilepsy evaluation. The level 3 centers reported 115 cases (median) of vEEG and level 4 centers reported 330 cases (median) of vEEG. Level 3 and 4 centers reported a total of 3,022 surgeries.

2011 Supplemental Survey for the Institute of Medicine—Data from 47 Centers

Forty-seven centers completed the supplemental survey. Total numbers are given below:

- On average, each center saw 1,300 unique patients with a diagnosis of epilepsy.
- On average, each center had 3,400 total outpatient visits where the patient was seen by an epileptologist.
- Waiting time for a new patient to see an epilepsy specialist averaged 32 days, with a median of 21 days.
- Waiting time for an inpatient evaluation to the center's EMU averaged 25 days, with a median of 21 days.

- Of those patients admitted to the EMU for a pre-surgical evaluation, 29 percent went on to have epilepsy surgery.
- Referral patterns varied significantly across the centers surveyed. Across all centers, the average percentage of patients referred from each source was as follows:

    - Primary care providers: 40.30 percent (range of 5 to 95 percent)
    - Neurologists: 35.6 percent (range of 5 to 80 percent)
    - Non-neurologist specialists: 16.2 percent (range of 0 to 65 percent)
    - Epilepsy Foundation or other organizations: 4 percent (range of 0 to 25 percent)

- On average, two-thirds of patients (66.4 percent) are seen for long-term, ongoing epilepsy care at an epilepsy center, rather than being returned to the referring provider.

DISCUSSION

Overall, these data suggest that only a minority of the 1 million Americans with refractory epilepsy are seen at an epilepsy center in any 1 year. If there are approximately 170 epilepsy centers nationally, then approximately 221,000 unique patients, or 22 percent of Americans with refractory epilepsy, are seen at these centers annually. Despite recommendations to the contrary, less than a quarter of patients with uncontrolled seizures see an epilepsy specialist.

The data also show that an even smaller number of patients with refractory epilepsy are admitted to an EMU for a comprehensive evaluation. Using a median number of 330 vEEG cases at the level 4 centers as a proxy for the number of inpatient admissions to the centers, we can extrapolate somewhere between 50,000 and 60,000 admissions to EMUs in the United States. This suggests that an even smaller number of patients are being fully evaluated and effectively treated.

Level 3 and 4 centers reported 3,022 surgeries annually. It is likely that epilepsy surgery takes place at a few centers that are not members of NAEC or did not report data. However, even a conservative estimate would be that 4,000 surgeries per year are performed in the United States. This suggests that surgery is underutilized because epidemiological data suggest that 100,000 to 200,000 people in the United States are candidates for epilepsy surgery.

The data on referral sources for epilepsy centers are difficult to interpret. The surveys showed that patients are referred to epilepsy centers almost evenly by primary care physicians and neurologists. However, the

high numbers of primary care referrals may be due to the fact that many insurers require referrals to be formally generated by primary care providers even when it is a neurologist who makes the recommendation for referral.

The data overall suggest a shortage of epilepsy specialists. Waiting times to see a specialist at a center or to be admitted to the hospital for an epilepsy evaluation are 3 to 4 weeks. The data also show that many patients receive their ongoing epilepsy care at the center. This means that epilepsy clinics rapidly fill up with returning patients and leave few appointments available for new patient evaluations. This is reflected in the average 3-week waiting time to see an epileptologist.

NATIONAL ASSOCIATION OF EPILEPSY CENTERS SURVEY FOR THE INSTITUTE OF MEDICINE—AUGUST 2011

As many of you know, the Institute of Medicine (IOM) is currently undertaking a review of the public health dimensions of the epilepsies. The IOM has asked NAEC to help collect data related to the care of patients in epilepsy centers.

The brief survey should not take you more than a few minutes to complete, but if possible, please pull data from your center to complete the survey. We recognize that some answers may be estimates of the typical experience at your center.

Thanks in advance for completing the survey. We want to provide IOM with the best possible information about the state of epilepsy care in the United States and know that this data will help that effort.

1. How many patients with the diagnosis of epilepsy are seen in your center's outpatient clinic or office by an epileptologists annually (unique number of patients, not patient visits)?
2. What is the total number of outpatient visits with an epileptologist for a diagnosis of epilepsy (including patients who are seen more than once per year) that occur annually at your center?
3. What are your major referral sources? Please provide a percentage for each, adding up to 100 percent.

    - Primary care providers
    - General neurologists
    - Other non-epilepsy/neurologist specialists
    - Epilepsy Foundation or other organization

4. What is the average waiting time in days for a new patient to get an appointment to see an epilepsy specialist at your center?

5. What is the average waiting time in days for a patient to be admitted to your epilepsy monitoring unit for a routine admission?
6. What percentage of patients referred to your center for an epilepsy surgery evaluation go to have epilepsy surgery?
7. What percentage of your patients are seen for long-term, ongoing epilepsy care rather than returned to the referring provider?
8. What is the percentage of patients transferred back to the referring physician for further ongoing epilepsy care?

    - Primary care physician
    - General neurologist

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Health Professionals Who Care for People with Epilepsy: Possible Roles and Relevant Boards and Organizations

Profession	Possible Roles in Caring for People with Epilepsy	Relevant Certifying Boards and Professional Organizations
Medical Physicians		
Child and adolescent psychiatrists	Similar care as adult psychiatrists (described below), but focused on children and adolescents and their specific needs	• American Academy of Child and Adolescent Psychiatry • American Board of Psychiatry and Neurology • American Psychiatric Association
Critical care specialists or intensivists	Critical care services, such as life-support or organ-support systems in acute care settings, which may be relevant for people with epilepsy in life-threatening situations or those who have serious comorbidities or seizure etiologies, such as brain tumors or stroke	• American Board of Anesthesiology • American Board of Emergency Medicine • American Board of Internal Medicine • American Society of Anesthesiologists • Society of Critical Care Medicine • See also boards and associations listed for emergency physicians

Profession	Possible Roles in Caring for People with Epilepsy	Relevant Certifying Boards and Professional Organizations
Emergency physicians	• Diagnosis, assessment, and treatment of new-onset seizures if a patient visits the emergency department • Diagnosis, assessment, and treatment for epilepsy-related emergencies, including status epilepticus and seizure-related injuries • Non-epilepsy-related emergency situations for people with epilepsy • Referrals to follow-up and other health services • Initial patient and family education and counseling	• American Academy of Emergency Medicine • American Board of Emergency Medicine • American College of Emergency Physicians • Emergency Medicine Residents Association • Society for Academic Emergency Medicine
Epileptologists	• Diagnosis, assessment, treatment, and management of epilepsy, often difficult or refractory cases • Patient and family education and counseling • Referrals to health and human services • Care primarily for people with epilepsy and are often affiliated with an epilepsy center	• American Academy of Neurology • American Board of Clinical Neurophysiology • American Board of Psychiatry and Neurology • American Clinical Neurophysiology Society • American Epilepsy Society • American Neurological Association
Family physicians	• Often first point of contact with the health care system • Diagnosis, assessment, treatment, and management of epilepsy • Referrals to specialists and other health and human services • Coordination of care, monitoring of general health status • Patient and family education and counseling	• American Academy of Family Physicians • American Board of Family Medicine
General pediatricians	Similar care as family physicians (described above) and internists, but focused on children and adolescents and their specific needs	• American Academy of Pediatrics • American Board of Pediatrics
General surgeons	• General surgical procedures and care, usually not epilepsy related in nature • Vagus nerve stimulation implants and maintenance	• American Board of Surgery • American College of Surgeons • American Society of General Surgeons

Profession	Possible Roles in Caring for People with Epilepsy	Relevant Certifying Boards and Professional Organizations
Geriatricians	Similar care as family physicians (described above) and internists, but focused on older adults and their specific needs	• American Board of Family Medicine • American Board of Internal Medicine • American Geriatrics Society
Hospitalists	• Attending physicians for hospital inpatients • Diagnosis, assessment, treatment, and management of epilepsy in the inpatient setting • Referral to specialists and other health and human services • Coordination with patients' usual care providers	• American Board of Family Medicine • American Board of Internal Medicine • American Board of Pediatrics • Society of Hospital Medicine
Internists	See description of family physician above	• American Board of Internal Medicine • American College of Physicians • Society of General Internal Medicine
Neurologists	• Diagnosis, assessment, treatment, and management of epilepsy • Patient and family education and counseling • Referrals to other health and human services • Also provision of care for patients with a wide array of neurological conditions beyond epilepsy	• American Academy of Neurology • American Board of Psychiatry and Neurology • American Epilepsy Society • American Neurological Association
Neurosurgeons	• Epilepsy-related surgeries, pre- and post-surgery care, determination of surgery candidacy • Referral to specialists and other health and human services	• American Association of Neurological Surgeons • American Board of Neurological Surgery • American Epilepsy Society • Congress of Neurological Surgeons • Society of Neurological Surgeons

Profession	Possible Roles in Caring for People with Epilepsy	Relevant Certifying Boards and Professional Organizations
Obstetrician-gynecologists	• Possible role as primary care provider for women • Preventive care, diagnosis, assessment, treatment, and management of conditions of the female reproductive system, including care that takes into account the specific needs and concerns of women with epilepsy related to reproductive health, pregnancy, and the use of seizure medications • Referrals to specialists and other health and human services • Patient and family education and counseling	• American Board of Obstetrics and Gynecology • American Congress of Obstetrics and Gynecologists
Osteopathic physicians	• Similar care as family physicians (described above) and internists when practicing as primary care physicians • 60 percent fill primary care roles, but the other 40 percent specialize and subspecialize in areas such as neurology, psychiatry, and pediatrics	• American College of Osteopathic Family Physicians • American College of Osteopathic Internists • American Osteopathic Association • American Osteopathic Board of Family Physicians • American Osteopathic Board of Internal Medicine • American Osteopathic Board of Neurology and Psychiatry • American Osteopathic Board of Pediatrics
Pediatric neurologists	Similar care as adult neurologists (described above), but focused on children and adolescents and their specific needs	• American Academy of Neurology • American Board of Psychiatry and Neurology • American Epilepsy Society • American Neurological Association • Child Neurology Society
Physical and rehabilitation medicine	• Diagnosis, assessment, treatment, and management of physical disabilities and limitations, which could be the result of a seizure, a seizure-related injury, or a comorbidity • Referral to specialists and other health and human services	• American Academy of Physical Medicine and Rehabilitation • American Board of Physical Medicine and Rehabilitation • American Congress of Rehabilitation Medicine • American Pain Society • Association of Academic Physiatrists

Profession	Possible Roles in Caring for People with Epilepsy	Relevant Certifying Boards and Professional Organizations
Psychiatrists	• Diagnosis, assessment, treatment, and management of comorbid mental health conditions in patients with epilepsy • Treatment and management of patients with seizure-like events with a psychological basis	• American Board of Psychiatry and Neurology • American Psychiatric Association
Radiologists or neuroradiologists	• Neuroimaging services that aid in diagnosis, treatment, and determination of candidacy for epilepsy-related surgery	• American Board of Radiology • American College of Radiology • Radiological Society of America
Nurses		
Licensed practical or vocational nurses (LPNs, LVNs)	• Basic nursing care, including monitoring vital signs, performing ordered treatments (e.g., dressing changes), and dispensing medications in many states (IOM, 2011) • Possible employment in long-term care and home health and in physicians' offices; LPNs and LVNs may encounter people with epilepsy and their families in those settings	• National Association for Practical Nurse Education and Service • National Council of State Boards of Nursing • National Federation Licensed Practical Nurses Association • Many states have associations for LPNs or LVNs as well
Neuroscience nurses	Similar care as registered nurses (described below), as well as diagnosis and treatment of patients with disorders and conditions related to the nervous system, such as epilepsy	• American Association of Neuroscience Nurses • American Board of Neuroscience Nursing • American Epilepsy Society • Association of Child Neurology Nurses • See also organizations included below for registered nurses

Profession	Possible Roles in Caring for People with Epilepsy	Relevant Certifying Boards and Professional Organizations
Nurse practitioners	• An advanced practice registered nurse who often provides primary care services • Scopes of practice vary by state (IOM, 2011) • Provision of a wide spectrum of health care services, including physical examinations, health assessments, and diagnosis and treatment of acute and chronic conditions, such as epilepsy • Patient and family education, counseling, and instruction in self-management • Referrals to specialists and other health and human services	• American Academy of Nurse Practitioners • American College of Nurse Practitioners • American Epilepsy Society • American Nurses Association • American Nurses Credentialing Center • National League for Nursing • Many states have associations for nurse practitioners as well
Nursing aides or certified nursing assistants	• Similar care as direct care workers (described below), including providing assistance with daily living activities, such as bathing, dressing, eating, and moving patients • Possible employment in home health care and long-term care facilities; they may encounter people with epilepsy and their families in those settings	• National Council of State Boards of Nursing • National Network of Career Nursing Assistants • Many states have associations for nursing assistants
Registered nurses	• Provision of holistic, patient-centered care, including health assessment and monitoring, administration of prescribed treatments and medications, and care coordination • Patient and family education, counseling, and instruction in self-management • Employment in virtually all health care and residential settings, including emergency departments, inpatient units, outpatient departments, clinics, schools, public health departments, group homes, nursing homes and long-term care facilities, and workplaces; registered nurses may encounter people with epilepsy and their families in those settings	• American Association of Colleges of Nursing • American Epilepsy Society • American Nurses Association • Commission on Collegiate Nursing Education • National Council of State Boards of Nursing • National League for Nursing • Many states have associations for nursing as well

Profession	Possible Roles in Caring for People with Epilepsy	Relevant Certifying Boards and Professional Organizations
School nurses	• Assessment of student health • Education of students and their families • Referrals to available services and resources, especially those in the community • Administration of medication, including seizure medications and emergency medications, such as diazepam	• American Epilepsy Society • National Association of School Nurses • National Board for Certification of School Nurses • See also organizations included above for registered nurses
Examples of Other Health Professionals		
Clinical health psychologists	• Provision of support for rehabilitation of illness, injury, and disability by applying and understanding how biological, psychological, and social factors affect health and illnesses and disorders, such as epilepsy • Possible provision of care in comprehensive epilepsy centers, hospitals and clinics, community mental health settings, or private practice	• American Board of Clinical Health Psychology • American Board of Professional Psychology • American Psychological Association, Division of Health Psychology • Counsel of Specialties in Professional Psychology
Clinical psychologists	• Assessment and treatment of a wide range of mental health conditions, including mental, emotional, and behavioral disorders, which may include comorbid conditions of epilepsy • Possible provision of care in comprehensive epilepsy centers, hospitals and clinics, community mental health settings, or private practice	• American Academy of Clinical Psychology • American Board of Clinical Psychology • American Board of Professional Psychology • American Psychological Association, Society of Clinical Psychology • Counsel of Specialties in Professional Psychology
Counseling psychologists	• Provision of counseling services to individuals and groups for a range of emotional, behavioral, and mental health conditions, which may include comorbid conditions of epilepsy • Possible provision of care in comprehensive epilepsy centers, hospitals and clinics, community mental health settings, or private practice	• American Board of Counseling Psychology • American Psychological Association, Society of Counseling Psychology • Counsel of Specialties in Professional Psychology

Profession	Possible Roles in Caring for People with Epilepsy	Relevant Certifying Boards and Professional Organizations
Counselors	• This profession includes a wide range of specialties that are relevant to the health and well-being of people with epilepsy and their families, including mental health counselors, rehabilitation or vocational counselors, school counselors, genetic counselors, gerontological counselors, marriage and family counselors, and substance abuse or addiction counselors • Employment in a variety of hospital or community-based mental health settings or private practice • Mental health counselors promote optimum mental health related or unrelated to a diagnosed psychological disorder or condition, including addiction or substance abuse; family, parenting, or marital problems; or other concerns associated with mental and emotional health, which may include comorbid conditions of epilepsy • Rehabilitation counselors work with people with disabilities to help achieve personal, social, psychological, and vocational goals and assist with psychosocial adjustment and coping, benefits planning, and educational and vocational planning and services	• American Board of Genetic Counseling, Inc. • American Counseling Association • American Mental Health Counselors Association • American Rehabilitation Counseling Association • American School Counselor Association • Commission on Rehabilitation Counselor Certification • National Board for Certified Counselors and Affiliates, Inc. • National Rehabilitation Association • National Society of Genetic Counselors • Many states also have state associations for a variety of counseling specialties
Direct care workers[a]	• Provision of assistance with daily living activities, including bathing, dressing, eating, and moving patients • Possible assistance with household activities, including cleaning, laundry, and meal preparation • Possible assistance with medication management • Possible employment in group homes, private homes, long-term care, and nursing home settings; direct care workers may encounter people with epilepsy and their families in those settings	• National Alliance for Direct Support Professionals • National Association of Health Care Assistants • Many states have direct care worker associations and associations for nursing aides

Profession	Possible Roles in Caring for People with Epilepsy	Relevant Certifying Boards and Professional Organizations
Electroneuro-diagnostic technologists (sometimes known as electro-encephalography [EEG] technologists)	• Recording, monitoring, and analysis of nervous system function using a variety of electroneurodiagnostic procedures, such as an EEG, intraoperative neuromonitoring, and long-term monitoring, which may be part of epilepsy diagnosis and assessment • Preparation of relevant information for physician interpretation • Employment in a variety of settings, including hospitals, intensive care units, clinics, research facilities, operating rooms, and epilepsy monitoring units	• American Association of Electrodiagnostic Technologists • American Board of Registration of Electroencephalographic and Evoked Potential Technologists • American Clinical Neurophysiology Society • American Society of Electroneurodiagnostic Technologists, Inc. • Committee on Accreditation for Education in Electroneurodiagnostic Technology
Emergency medical services (EMS) personnel	• Profession includes a range of personnel with varying backgrounds and education and training, such as medical first responders, emergency medical technicians (EMTs)—basic, intermediate, and paramedic • Provision of medically supervised transportation in out-of-hospital settings, which may include transportation for people with new onset seizures, status epilepticus, or seizure-related injuries • Part of emergency medical organizations that respond to emergency calls	• International Association of EMTs and Paramedics • National Association of Emergency Medical Technicians • National Association of EMS Educators • National Highway Traffic Safety Administration • National Registry of Emergency Medical Technicians • Many states also have state associations for emergency response personnel

Profession	Possible Roles in Caring for People with Epilepsy	Relevant Certifying Boards and Professional Organizations
Neuropsychologists	• Assessment of cognitive impairments; diagnosis of neuropsychological conditions; and administration and interpretation of neuropsychological tests, brain mapping, and Wada testing, which may be part of diagnosis and assessment for people with epilepsy • Assistance in rehabilitation and the development and provision of cognitive, behavioral, and psychosocial interventions, which may be connected to comorbidities of epilepsy • Possible provision of care in comprehensive epilepsy centers, hospitals and clinics, community mental health settings, or private practice	• American Board of Clinical Neuropsychology • American Psychological Association, Division of Clinical Neuropyschology • Association of Postdoctoral Programs in Clinical Neuropsychology • Counsel of Specialties in Professional Psychology • National Academy of Neuropsychology
Pharmacists	• Dispensing of seizure medications and other medications • Identification and prevention of medication errors • Provision of advice to patients about possible side effects, adverse reactions, and drug interactions, as well as specific information and considerations for subpopulations such as older adults, children, and women	• American Association of Colleges of Pharmacy • American Epilepsy Society • American Pharmacists Association • American Society of Health System Pharmacists • National Association of Boards of Pharmacy • National Community Pharmacists Association

Profession	Possible Roles in Caring for People with Epilepsy	Relevant Certifying Boards and Professional Organizations
Physician assistants	• Profession works under the supervision of physicians to provide a range of medical services including physical examinations, diagnosis, assessment, treatment, and management of a variety of acute and chronic conditions, such as epilepsy • Physician assistants often serve in a primary care capacity, but also may specialize and work with medical specialists, such as surgeons, neurologists, and obstetrician-gynecologists who work with people with epilepsy • Scopes of practice and specific practice roles and responsibilities vary by state and clinical setting • Patient and family education and counseling • Referrals to specialists and other health and human services	• Accreditation Review Commission on Education for the Physician Assistant • American Academy of Physician Assistants • Association of Family Practice Physician Assistants • National Commission on Certification of Physician Assistants • Physician Assistant Education Association • Many states have associations for physician assistants
Rehabilitation psychologists	• Application of psychological knowledge and skills to the care of individuals with disabilities and chronic conditions, such as epilepsy • Possible provision of care in comprehensive epilepsy centers, hospitals and clinics, community mental health settings, or private practice	• American Board of Professional Psychology • American Board of Rehabilitation Psychology • American Psychological Association, Division of Rehabilitation Psychology • Counsel of Specialties in Professional Psychology

Profession	Possible Roles in Caring for People with Epilepsy	Relevant Certifying Boards and Professional Organizations
Social workers	• Provision of support, education, coordination of referrals, and case management, as well as counseling and therapeutic interventions • Specialties that are relevant to the health and well-being of people with epilepsy and their families may include areas such as clinical, medical, and public health social workers • Specific areas of practice, also relevant to the health and well-being of people with epilepsy and their families, include child and adolescent health, family dynamics, health broadly, aging, behavioral health, bereavement and end of life, diversity and equity, social justice, schools, and violence • Employment in a variety of settings, including schools, private practice, and hospital, community, and public health settings	• American Association for Psychoanalysis in Clinical Social Work • Association of Social Work Boards • Clinical Social Work Association • Council on Social Work Education • National Association of Social Workers • Society for Social Work Leadership in Health Care • Many states also have state associations for a variety of social work specialties

[a]The title "direct care worker" often includes aides, orderlies, attendants, home health aides, and personal and home care aides, among others (IOM, 2008).

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Committee Biographies

Mary Jane England, M.D. (*Chair*), is visiting professor of health policy and management at the Boston University School of Public Health, where she also serves on an advisory committee for health policy and management. In 1964, Dr. England received her medical degree from Boston University and launched an international career as a child psychiatrist. As an authority on employer and employee benefits, she has brought multiple informed perspectives to bear on health care reform. She was the first commissioner of the Massachusetts Department of Social Services (1979-1983), associate dean and director of the Littauer Master in Public Administration Program at the John F. Kennedy School of Government at Harvard University (1983-1987), president of the American Medical Women's Association (1986-1987), president of the American Psychiatric Association (1995-1996), and a corporate vice president of Prudential (1987-1990) and chief executive officer (CEO) of the Washington Business Group on Health (1990-2001). A nationally known expert on health care and mental health parity, in 2004-2005 Dr. England chaired the Institute of Medicine (IOM) committee that produced the *Crossing the Quality Chasm* report on adaptation to mental health and substance use. In 2008 she chaired an IOM committee on parental depression and its effect on children and other family members. Recently completing a term on the Commission on Effective Leadership (2006-2009) in the American Council on Education and currently participating in the ACT project in Colorado (2009-present), Dr. England continues to serve on Mrs. Rosalynn Carter's Task Force on Mental Health at the Carter Center and on the National Academies-IOM Board on Children and Families. As president of Regis College (2001-2011), she oversaw a number of transfor-

mations, including taking the historic undergraduate women's college into coeducation; building its graduate programs, notably in nursing, health administration, and other health professions; and developing curricula to serve the needs of diverse populations of 21st century students through interdisciplinary pathways.

Joan Kessner Austin, Ph.D., R.N., FAAN, is a distinguished professor emerita at the Indiana University School of Nursing in Indianapolis. She is a consultant for the Intramural Program of the National Institute of Nursing Research at the National Institutes of Health (NIH). She has held leadership positions and has been a member of numerous professional associations, including the American Epilepsy Society (AES) (where she was president in 2005), the Epilepsy Foundation (where she served four terms on the Professional Advisory Board), and the IOM (since 2000). Her research focuses on improving the quality of life of children with epilepsy and their families and also on researching how new-onset seizures as well as chronic epilepsy impact children's behavior, mental health, and academic performance. Dr. Austin is the recipient of many awards for her research, including the Distinguished Contribution to Nursing Science Award from the American Nurses Foundation, the AES-Milken Family Medical Foundation International Research Award for contributions to clinical research, the International Bureau for Epilepsy-International League Against Epilepsy (ILAE) Award of Social Accomplishment, and the Jacob Javits Award for Research in Neurosciences from the National Institute of Neurological Disorders and Stroke. She is author of numerous articles and a reviewer and member of the editorial board of *Chronic Illness* as well as other journals.

Vicki Beck, M.S., is a communication consultant with nonprofit organizations, academic institutions, and private companies and foundations that address public health and medical research, treatment, and education issues. She is director emerita and founder of Hollywood, Health and Society at the University of Southern California (USC) Annenberg School for Communication's Norman Lear Center, where she created a model for promoting and evaluating the impact of public health topics in entertainment programs. Ms. Beck's research has focused on the effects of television health content and health campaign messages on audiences. She is the author of a number of articles and book chapters on audience research topics. Prior to USC, Beck was a senior health communications specialist at the Centers for Disease Control and Prevention (CDC), where she advised on national health campaigns, served as the founder and director of the CDC's entertainment education program, and conducted audience research. As a communications expert for 25 years, she has participated in numerous

committees for national health campaigns and has presented program and research results at national and international meetings of public health, medical, and scientific professional organizations.

Charles E. Begley, Ph.D., is professor of management and policy sciences and co-director of the Center for Health Services Research at the University of Texas Health Science Center, Houston School of Public Health. He is also adjunct professor in the Department of Economics at Rice University. He is the author of numerous articles and book chapters on the cost and burden of epilepsy as well as health disparities and access to care issues. He has been the chair or a member of several ILAE committees on issues such as health policy and the economic burden of epilepsy. He is on the editorial board of *Epilepsia* and is a member of the AES and the ILAE.

Malachy L. Bishop, Ph.D., CRC, is professor of rehabilitation counseling with the Department of Special Education and Rehabilitation Counseling at the University of Kentucky, Lexington. He serves on the Epilepsy Foundation's Professional Advisory Board, the International Bureau for Epilepsy's Research Task Force, and the clinical advisory committee of the National Multiple Sclerosis Society Kentucky-Southeast Indiana Chapter. Dr. Bishop's clinical background includes rehabilitation psychology, neuropsychology, assessment of injured workers, and rehabilitation counseling. He conducts research in the psychosocial aspects of chronic neurological conditions, including epilepsy, multiple sclerosis, and brain injury; quality of life and adaptation to disability; and employment issues for people with epilepsy. Dr. Bishop is on the editorial board of the *Journal of Rehabilitation* and the *Rehabilitation Counseling Bulletin*, and he has authored many journal articles, book chapters, and monographs in health care and rehabilitation.

Lionel Carmant, M.D., is full professor in the department of pediatrics at the Université de Montréal, Canada. Dr. Carmant is a clinician scientist who is in charge of the Epilepsy Program at Hôpital Sainte Justine and of the Epilepsy Research Group at the institution's research center. He also coordinates the international effort supporting the Port-au-Prince Epilepsy Clinic in Haiti. As part of that effort, he initiated the Hispaniola Project, which combines resources with the Dominican Republic to treat Haitians who require epilepsy surgery. More recently, he was involved in setting up the first Commission of African Affairs for the ILAE. He has written a number of scientific articles, and his current research focuses on the mechanisms that are involved in seizure-induced brain damage as well as ways to prevent them.

Carolyn Cocotas, R.T., M.P.A., CHC, CHPC, is senior vice president of Quality and Corporate Compliance at F·E·G·S Health and Human Services System in New York City, one of the largest voluntary, nonprofit health, education, and human services organizations in the country. F·E·G·S provides treatment, housing, job training and placement, and case management to persons with severe mental health conditions and/or developmental or other disabilities. F·E·G·S provides counseling, support, education, and prevention programs for those facing family problems, domestic violence, life-limiting illness, aging, and other issues, as well as in-school, out-of-school, and after-school programs to help at-risk young people complete their education and transition to productive adulthood. Previously, Ms. Cocotas was director of Community Health Innovation at Affinity Health Plan, where she directed innovation work in care delivery to the Medicaid population in New York City. Over the span of her career, Ms. Cocotas has held a number of progressively responsible positions throughout the health care industry, including at the U.S. Department of Health and Human Services, the U.S. Government Accountability Office, U.S. House of Representatives, National Committee for Quality Assurance, and Kaiser Permanente. She is a member of the IOM Roundtable on Health Literacy.

Sandra Cushner-Weinstein, P.T., LICSW, LCSW-C, is director of Services and Camps in the Center of Neuroscience and Behavioral Medicine at the Children's National Medical Center in Washington, DC, where she develops programs and runs camps for children with epilepsy and other chronic neurological and health disorders. She also works directly with children diagnosed with chronic health conditions and neurological disorders and their families as a psychotherapist, develops programs, promotes education, and conducts research. In addition, Ms. Cushner-Weinstein is assistant professor of neurology and pediatrics at George Washington University. In the past, she was director of the Epilepsy Foundation for the National Capitol Area and team leader for the DC Epilepsy Learning Collaborative. She also developed the Newly Diagnosed Seizure Clinic and produced an educational DVD in English and Spanish *Coping with Epilepsy: From Seizures to Success*. She has held several committee and board appointments, including the Professionals in Epilepsy Care and the Educational Committees at the AES. Her research focuses on the impact of condition severity on quality of life and parenting stress as well as predictors of adaptive coping and resiliency. She has published numerous abstracts and papers and serves as a reviewer for several professional journals and web-based resources.

Ramon Diaz-Arrastia, M.D., Ph.D., is professor of neurology at the Uniformed Services University of the Health Sciences, and Director of Clinical Research at the Center for Neuroscience and Regenerative Medicine. Dr.

Diaz-Arrastia's research interests are focused in the area of understanding the molecular-, cellular-, and tissue-level mechanisms of secondary neuronal injury and neuroregeneration. Dr. Diaz-Arrastia received his M.D. and Ph.D. degrees at Baylor College of Medicine in 1988, where he was elected to Alpha Omega Alpha. After a 1-year medicine internship at Beth Israel Hospital and the Harvard Medical School, he completed his neurology residency at Columbia-Presbyterian Medical Center. From 1993 to 2011, Dr. Diaz-Arrastia was on the faculty of the Department of Neurology at the University of Texas Southwestern, where he was promoted to professor in 2006. Dr. Diaz-Arrastia has published more than 100 peer-reviewed primary research papers, as well as more than 20 invited reviews and book chapters. He has also served on several national committees related to traumatic brain injury research and practice. He has served on expert panels convened by the IOM, the National Institute of Neurological Disorders and Stroke, and the National Institute of Aging. He has also served on Scientific Review Committees for the NIH, the Department of Defense, the Veterans Administration, Alzheimer's Association, and the Victoria (Australia) Neurotrauma Fund, among others. He is also a peer reviewer for the leading journals in neurology, neuroscience, neurotrauma, and neurorehabilitation. In 2008 he received a Distinguished Alumnus Award from Baylor College of Medicine.

David Grant, Ph.D., is the director of the California Health Interview Survey (CHIS) at the University of California, Los Angeles, Center for Health Policy Research. CHIS is the nation's largest state health survey and a state-of-the-science public health project that has become a national model for building evidence-based health policy and for widespread dissemination of data and findings. Dr. Grant joined the CHIS team in 2001 and became the project's director in 2006. As the CHIS director, he is responsible for all aspects of the project, including the planning, data collection, and dissemination phases of CHIS, under the direction of principal investigator Dr. E. Richard Brown. In his capacity as director, he works with a broad range of agencies, including federal, state, and local health agencies; philanthropic and community-based organizations; advocacy groups; and academic researchers to meet their diverse needs for population health data. Dr. Grant has collaborated with the CDC to include epilepsy content in several CHIS cycles, analyze and publish epilepsy findings from CHIS, and conduct focus groups and cognitive interviews to aid in the development of new questions on epilepsy for use in population-based surveillance efforts.

Christianne N. Heck, M.D., M.M.M., is the director of the USC Adult Comprehensive Epilepsy Program, and she has served as chief operating officer of USC Neurologists, Inc., a private academic practice, in Los An-

geles. Her board certification in neurology includes subspecialty training in epilepsy. She is a board member and professional adviser to the Epilepsy Foundation of Greater Los Angeles and is on the Board of Directors of the National Association of Epilepsy Centers. She completed a master's degree in medical management at the USC Marshall School of Business in 2005 and the Donald M. Palatucci Advocacy and Leadership Forum sponsored by the American Academy of Neurology in 2006. She is a member of the California Neurology Society Board of Directors, where she actively participates in opinions and discussions regarding patient care and access to care within the State of California. She volunteers regularly for Hollywood, Health and Society of the USC Annenberg School of Communications Norman Lear Center, whose goals are the promotion and evaluation of public health topics in film and television. Her research focuses on innovative approaches to treating epilepsy, including vagus nerve stimulation, responsive neurostimulation, and gamma knife radiosurgery; her expertise also includes services to minority populations as well as furthering understanding of status epilepticus, neuronal injury, memory dysfunction, and the psychosocial impact of epilepsy.

Dale C. Hesdorffer, Ph.D., M.P.H., is associate professor of clinical epidemiology at the Mailman School of Public Health, in the Gertrude H. Sergievsky Center, Columbia University, New York. She is a member of the AES. She is also on the board of Vision 20-20 and the Professional Advisory Board for the Epilepsy Foundation. Her research is focused on studies on the comorbidity of epilepsy, status epilepticus, and incidence and prevalence of epilepsy, as well as on traumatic brain injury. Dr. Hesdorffer co-chairs the Commission on Epidemiology for the ILAE and serves on the Psychiatry Task Force of the AES. Dr. Hesdorffer served on the IOM Committee on Gulf War and Health: Brain Injury in Veterans and Long-Term Health Outcomes. She has written many journal articles and serves on the editorial board for *Epilepsy Research* and *Epilepsy and Behavior*. She is also a contributing editor for *Epilepsy Currents*.

Gregory L. Holmes, M.D., is chair of the department of neurology and professor of neurology and pediatrics at Dartmouth Medical School in Hanover, New Hampshire. He has been a member of many professional society boards, including the AES (where he was president from 2005 to 2006), the American EEG (Electroencephalography) Society, the Eastern Association of Electroencephalographers, and the Child Neurology Society. He also served on the Food and Drug Administration's Peripheral and Central Nervous System Drugs Advisory Committee and has been on a number of NIH study sections. His research focuses on pediatric epilepsy, including the long-term consequences of seizures on brain development, the patho-

physiological basis of epilepsy, and status epilepticus. Dr. Holmes has been the recipient of many awards, including the United Cerebral Palsy Association Sidney Farber Research Award, the AES Research Award, the ILAE Ambassador for Epilepsy Award, the Child Neurology Society Bernard Sachs Award, and the American Clinical Neurophysiology Society Pierre Gloor Research Award. He is the author of numerous articles and books and has been on the editorial board of several journals, including *Epilepsy Research*, *Pediatric Drugs*, *Epilepsy and Behavior*, *Brain and Development*, the *Journal of Epilepsy*, and the *Annals of Neurology*.

Paul E. Jarris, M.D., M.B.A., is executive director of the Association of State and Territorial Health Officials. He served as medical director of Vermont's largest nonprofit health maintenance organization, Community Health Plan, from 1992 to 1996. He was president and CEO of Vermont Permanente Medical Group from 1998 to 2000, as well as CEO of Primary Care Health Partners, Vermont's largest statewide primary care medical group, from 1999 to 2000. From 2000 to 2003, he served as president of Jarris and Associates, an independent consulting firm providing services to major regional health plans and provider groups. He was appointed commissioner of the Vermont Department of Health by Governor Jim Douglas in March 2003. Throughout his career, Dr. Jarris has maintained an active clinical family practice, including work in federally qualified health centers, and he served as physician to an inner city school and a shelter for homeless adolescent youth. He graduated from the University of Vermont and received his M.D. from the University of Pennsylvania School of Medicine. He interned at Duke-Watts Family Medicine Residency Program in Durham, North Carolina, and completed his residency at the Swedish Family Practice Residency Program in Seattle, Washington. He received an M.B.A. from and completed a faculty development fellowship at the University of Washington. Dr. Jarris is board certified by the American Board of Family Medicine and the American Board of Medical Management and is clinical assistant professor of family medicine at Georgetown University Medical Center.

Dilip V. Jeste, M.D., is a distinguished professor of psychiatry and neurosciences at the University of California, San Diego (UCSD). He is director of the UCSD Geriatric Psychiatry Division as well as of the National Institute of Mental Health (NIMH)-funded Advanced Center on Innovation in Services and Intervention Research, focusing on psychosis in older populations. He is an IOM member and is the principal investigator on several research and training grants. He is the President-Elect of the American Psychiatric Association. He completed his psychiatry residency at Cornell and neurology residency at George Washington University. He was chief

of Units on Movement Disorders and Dementias at NIMH before joining UCSD in 1986. He is a past president of the American Association of Geriatric Psychiatry and founding president of the International College of Geriatric Psychoneuropharmacology. He is the editor-in-chief of the *American Journal of Geriatric Psychiatry*. He has published 10 books and more than 500 journal articles. He is in the Institute of Scientific Information's list of the world's most cited authors among publishing researchers of the last two decades. He has received multiple awards for research, education, and service to the field. He was a member of the National Advisory Mental Health Council as well as of the NIH Council of Councils. His current areas of interest include informed consent and successful cognitive aging.

Patricia Osborne Shafer, R.N., M.N., is an epilepsy clinical nurse specialist at the Comprehensive Epilepsy Center, Beth Israel Deaconess Medical Center in Boston, Massachusetts, and a resource specialist with the Epilepsy Therapy Project. She is a past member and chair of the Epilepsy Foundation's Professional Advisory Board, a past member of the board of directors of the Epilepsy Foundation, and a current member of the Epilepsy Foundation's Professional Advisory Board of Massachusetts, Rhode Island, New Hampshire, and Maine. She has served on the AES board of directors and numerous committees and work groups. Ms. Shafer has also participated in the creation of the North American Declaration on Epilepsy, a public health agenda for epilepsy, and guidelines for first seizures and women with epilepsy. She is an affiliate member of the CDC-funded Managing Epilepsy Well Network and a member of the American Association of Neuroscience Nurses; and she has served on numerous research review panels and advisory committees for regulatory reform, disability concerns, and public health concerns in epilepsy. Her clinical and research interests include self-management and health education in epilepsy, psychosocial concerns, women's issues, and treatment options and consequences of refractory epilepsy. She received a bachelor of science in nursing from the University of Vermont and a master's in nursing at the University of Washington. Ms. Shafer brings a personal perspective to the committee, having lived with epilepsy for many years.

Joseph I. Sirven, M.D., is a professor of neurology and chair of the department of neurology at the College of Medicine of the Mayo Clinic in Arizona. Previously, he served as director of education for Mayo Clinic Arizona with oversight of all educational activities at the Mayo Clinic Arizona campus, including programs for medical students, residents, fellows, Ph.D. candidates, nurses, allied health professionals, and continuing medical education. He is currently education chair for the Epilepsy Section of the American Academy of Neurology, chair of the Annual Course Committee

for the AES, and chair-elect of the Professional Advisory Board of the Epilepsy Foundation. He is also editor-in-chief of Epilepsy.com. Dr. Sirven has published extensively on epilepsy and its treatment. His interests in epilepsy include status epilepticus, surgical therapy, epilepsy in older adults, and psychosocial issues, particularly those involving Hispanic populations and transportation. His articles have appeared in *Neurology*, *Epilepsia*, *Lancet*, *Archives of Neurology*, *Annals of Neurology*, *Epilepsy and Behavior*, and *Mayo Clinic Proceedings*. He is editor of four textbooks: *Clinical Neurology of the Older Adult*; the American Epilepsy Society's *Introduction to Epilepsy; Clinical Epilepsy*; and *An Atlas of Video EEG Monitoring*. He is currently co-director of the Epilepsy Program at Mayo Clinic Arizona.