The CDC Epilepsy Program’s activities in response to recommendations from 2012 IOM report on epilepsy

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Outline

- Data collection with regards to the burden of epilepsy
  - Focus on the recommendations 1-4
- Managing Epilepsy Well Network (MEW network)
  - Focus on the recommendation 3, 4, 8 and 9
- Important research gaps in epidemiological study
- Collaboration with Epilepsy Foundation and other organizations
  - Focus on other recommendations
The CDC, in collaboration with professional organizations, should fund demonstration projects to validate and implement standard definitions and criteria for epilepsy case ascertainment, health care and community services use and costs, and quality of life measurement.
Activities in response to recommendation 1

- A validation study for questions that were designed to identify lifetime and active epilepsy, medication use, and seizure occurrence on population-based surveys
  
  Brooks DR et al. Epilepsy Behav. 2012;23(1):57-63

- Validation of case ascertainment criteria to identify incident and prevalent cases of epilepsy using ICD-9 based algorithms
  
  Selassie AW et al. The South Carolina Epidemiological Studies of Epilepsy and Seizure Disorders. Medical University of South Carolina, Charleston, South Carolina, 2014.

- Developing and validating methods of natural language processing system using machine learning algorithms to detect “regular expression” of epilepsy or epilepsy-related issues from electronic medical records for epilepsy case identification and health care
  
  Barbour K et al. Epilepsia, 2019 (submitted); Grinspan ZM et al. Epilepsia, 2019 (in progress)
The CDC should continue and expand its leadership in epilepsy surveillance and data collection efforts, and 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.
Activities in response to recommendation 2

- **Epilepsy surveillance using nationally representative samples**
  - National Health Interview Survey (NHIS)---Included 5 validated epilepsy questions since 2010
    - Have you ever been told by a doctor or other health professional that you have a seizure disorder or epilepsy?
    - Are you currently taking any medicine to control your seizure disorder or epilepsy?
    - Think back to last year about the same time. About how many seizures of any type have you had in the past year?
    - In the past year have you seen a neurologist or epilepsy specialist for your epilepsy or seizure disorder?
    - During the past 30 days, to what extent has epilepsy or its treatment interfered with your normal activities like working, school, or socializing with family or friends?
Prevalence of active epilepsy in the U.S. and U.S. states

Data Used:

- 2015 NHIS data (adults, aged ≥18 yrs)
- 2011-2012 National Survey of Children's Health (NSCH) (0-17 years)
- 2015 Current Population Survey data

Results:

- In 2015, 1.2% of the U.S. population (3.4 million persons: 3 million adults and 470,000 children) reported active epilepsy or current epilepsy
- Numbers of persons with active epilepsy, after accounting for income and age differences by state, ranged from 5,900 in Wyoming to 427,700 in California

Activities in response to recommendation 2 (cont.)

- **Epilepsy mortality surveillance / study using statewide representative samples**
  - SUDEP surveillance in the Sudden Death in the Young Case Registry (SDY)
    - SUDEP in children from birth to <20 years of age
    - Starting from 2015, SUDEPs are collected in 10 states/jurisdictions. Now it expands to 14 states/jurisdictions
    - Complicated algorithm to diagnose SUDEP or possible SUDEP through child death review and advanced review teams with multidisciplinary experts including neurologists/epileptologist
    - 40-50 cases have been identified and SDY system is about 3 times more sensitive to detect SUDEP mortality rate than previous published systems or methods
  - Suicide among people with epilepsy
Activities in response to recommendation 2 (Cont.)

- **Epilepsy in other specific populations**
  (national, state or community population-based representative samples)
  - Epilepsy in Medicare and Medicaid recipients
    - CDC-supported state and national studies---published in 2012, 2015 and 2018
  - Rare epilepsy in children
    - In collaboration with Cornell University and four other medical centers in New York City, coverage of 3 million population, 2015-2018.
    - Data were collected from New York City Clinical Data Research Network
    - 1 million clinical notes of Electronic Health Records have been collected. Rare epilepsy prevalence and incidence data is planned to be published this year
  - Epilepsy among Veterans
The CDC should partner with other agencies and stakeholders to develop and evaluate prevention efforts for epilepsy and its consequences.

The IOM report especially addresses three major known risk factors such as neurocysticercosis (NCC), traumatic brain injury (TBI) and stroke for epilepsy prevention.
Activities in response to recommendation 3

- Developing a tool to detect NCC
  - The CDC has been supporting lab in our agency or commercial labs to develop an easy-to-use ELISA kit that can be used in the field with high sensitivity and specificity to human taeniasis coproantigen

- Studying on epilepsy-related TBI
  - CDC-supported South Carolina statewide, population-based studies--published in 2014

- Studying on epilepsy-stroke relationship
  - Statewide, population-based studies in other states---published in 2014 and 2015
The AES and the American Academy of Neurology (AAN) should lead a collaborative effort with other organizations including CDC to improve the early identification of epilepsy and its comorbid health conditions.
Activities in response to recommendation 4

- To promptly diagnose epilepsy and its comorbidities and improve access to epilepsy specialty care for people with epilepsy are major goals identified in National Healthy People 2020 objective for epilepsy.

- The CDC continually monitors the percentage of adults who accessed specialty care by using NHIS data:
  - Reports observed that only 52.8% of adults with active epilepsy in the US reported seeing a neurologic specialist in the preceding 12 months in 2010, and this number increased to 65.6% in 2010-2014 and 67% in 2015.

Cui et al. MMWR Morb Mortal Wky Rep. 2015 / 64(43);1209-1214
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Epilepsy Self-management and MEW network

- Epilepsy self-management programs
  - To advance the science of epilepsy self-management by conducting research in collaboration with network and community stakeholders, and broadly disseminating the findings
  - CDC leads “Managing Epilepsy Well Network” (MEW network) through the CDC's Prevention Research Centers to develop evidence for the efficacy/validation of epilepsy self-management programs
  - The MEW Network is a team of people who care about people with epilepsy and their caregivers.
Collaboration

Managing Epilepsy Well Network Community of Practice

8 Sites
- Case Western Reserve University
- Dartmouth College
- Morehouse School of Medicine
- New York University
- University of Arizona
- University of Illinois at Chicago
- University of Minnesota
- University of Washington

3 Partners
- Centers for Disease Control and Prevention (CDC)
- Epilepsy Foundation
- American Epilepsy Society

2 Associate Members
- Emory University
- University of Texas

The Power of Collaboration
Self-Management Programs Developed

- Programs Developed: 10
- In Development: 3
- Evidence-Based: 7

Programs:
- HOBSCOTCH
- PACES
- PEARLS
- Project UPLIFT
- MINDSET
- PAUSE
- YESS!

- SMART
- TIME
- WebEase
Public Health Science Impact 2014-2018

30 Articles published in peer-reviewed journals
25 Presentations at professional meetings
47 Abstracts & posters presented at professional meetings
Public Health Impact (cont.)

Public Health Practice Impact 2014-2018

1,000+ PATIENTS WITH EPILEPSY REACHED

137 FACILITATORS TRAINED

34 COLLABORATING ORGANIZATIONS

COMMUNITY
- Epilepsy Foundation of Central & South Texas
- Cleveland Epilepsy Association
- Epilepsy Foundation of Greater Chicago
- Epilepsy Foundation of Minnesota
- Pleasant Grove Baptist Church
- Angels of Epilepsy
- Epilepsy Foundation of Michigan
- United Way
- Big Miller Grove Baptist Church
- Epilepsy Foundation of Texas
- Epilepsy Foundation of Georgia

CLINICAL/ACADEMIC
- VAPSHCS Epilepsy Center of Excellence
- Georgia Clinical and Translational Science Alliance
- National and Scientific Research Center of South America
- American Academy of Neurology
- University of Texas School of Public Health
- Banner University Medical Center
- Kessler Foundation
- University of Illinois Hospital
- NYU Comprehensive Epilepsy Center
- Rancho Los Amigos National Rehabilitation Center

STATE/REGIONAL
- Cuyahoga County Addiction and Mental Health Services (ADAMHS) Board
- Texas Department of State Health Services
- New Hampshire Division of Public Health Services

Managing Epilepsy Well Network
PRC Prevention Research Centers
Epilepsy Foundation
American Epilepsy Society
For detailed info about MEW network

https://managingepilepsywell.org

https://www.cdc.gov/epilepsy/index.html
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Some important research gaps

- For 2012 IOM report recommendation 1
  - Validation of non-specific epilepsy-related terms is needed since many invalidated epilepsy synonyms are still used by the public (e.g., “drop attack”, “falling out spell”, and “staring spell”)
  - Standardization of definitions and criteria for epilepsy surveillance should reflect updated epilepsy definition and exclude those acute symptomatic seizures
  - Validation of ICD-code based algorithms for identification of epilepsy should be done in some commercial claim data which include large epilepsy samples

- For 2012 IOM report recommendation 2
  - More epilepsy-related questions should be added into NHIS
  - Studies using most recent, large, population-based, U.S. community representative samples to investigate epilepsy incidence are limited
Some important research gaps (cont.)

- 2012 IOM report recommendation 3
  - Continue to explore the possible risk factors for developing epilepsy, especially among incident cases, and to find disparity in different populations for possible intervention

- For 2012 IOM report recommendation 4
  - Develop and validate screening tests for the early identification of epilepsy in at-risk populations, especially those with developmental disabilities, mental health conditions
  - Develop and validate screening tests for epilepsy comorbidities.
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Public Health Programs with Epilepsy Foundation

- Promoting epilepsy as a public health issue and implementing public health programs
  - Improving health care provider’s education
  - Increasing public awareness/reduce stigma
  - Promoting evidence-based self-management programs

- Improving awareness of epilepsy-related death and SUDEP with National Association of Medical Examiner and Coroner, American Epilepsy Society, Epilepsy Foundation SUDEP Institute and North America SUDEP Registry

Middleton et al. National Association of Medical Examiners position paper:
Recommendations for the investigation and certification of deaths in people with epilepsy.

Epilepsia. 2018 Mar;59(3):530-543
Further Information

Reference our website at:
www.cdc.gov/epilepsy

Contact information:
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CDC Funded Cornell Project

--- Rare Epilepsy in New York City: Epidemiology and health outcomes

- Lack of diagnostic codes for the rare epilepsies make it nearly impossible to identify affected individuals

- Sophisticated natural language processing system using machine learning algorithms can be trained effectively to classify text documents, including physicians’ clinical notes

- 1 million clinical notes have been collected from five medical centers in New York City to establish a population-based cohort
  - Incidence, prevalence, comorbidities, and mortality
  - Easy-to-disseminate set of “regular expression” to identify rare epilepsies in large multi-institutional studies