The Public Health Dimensions of the Epilepsies:

Epidemiologic Research and Surveillance of the Epilepsies

A Systems-level Perspective

David J. Thurman, MD, MPH
Centers for Disease Control and Prevention

dthurman@cdc.gov
770.488.6090
Definitions

- Epidemiologic research
  - study of the distribution and determinants of health-related states in populations

- Public health surveillance
  - The *ongoing* systematic collection and analysis of health data necessary for public health programs
  - Routine *practice* of public health

“Epidemiology is the basic science of public health.”
Purposes of Surveillance and Epidemiologic Studies

- Burden of illness
  - Incidence & Prevalence
  - Severity—disability, mortality, ↓ quality of life
  - Cost

- Risk factors / Etiology
  - Health Disparities

- Access to appropriate care

- Trends
  - Evaluation of public policy interventions
Health Data Resources for Epidemiology & Surveillance

- Established administrative datasets
  - Coded hospital discharge data, vital records, etc.
- Established population surveys
  - National health interview survey, BRFSS, others
- Retrospectively collected clinical data
  - Hospital records, etc.
- Prospectively collected clinical data
  - Data collected specifically for study
  - More detailed, complete, and accurate

Cost:
- +
- ++
- +++
- ++++
Limitations of Health Data Resources – Established Administrative Datasets

- Limited to information on original records (e.g., hospital/ED charts, death certificates)
- Limited diagnostic info in ICD epilepsy codes
  - Few categories
  - Can’t distinguish incident from prevalent cases
- Errors in coding
  - Common misclassification: epilepsy (ICD-9 345.x) vs. seizures (780.3)
- Difficult linkage across inpatient & outpatient data sets
  - Not possible with CDC/NCHS National Health Care Surveys
Limitations of Health Data Resources
—Established population surveys

- Self- or proxy-reported data
  - Diagnostic misclassifications
- Usually exclude institutionalized, military, and homeless populations
- Lower response rates may introduce bias
- Non-clinician interviewers
  - Little clinical detail
Limitations of Health Data Resources – Clinical Data

- Retrospectively collected clinical data
  (extracted from hospital/other clinical records)
  - Diagnostic & other clinical details vary
  - Requires skilled abstractors

- Prospectively collected clinical data
  (Data collected specifically for study)
  - Methods to find/screen potential cases difficult
  - Barriers to participation (incl. HIPAA, IRBs) may limit full case ascertainment or bias samples.
Practical Utility of Health Data — Population Studies of Epilepsy

- Established administrative datasets
  - At local level, can use to *screen* for *possible* prevalent cases
  - Can use national data for temporal trends in healthcare use

- Established general population surveys
  - Uns suited for epilepsy subtypes, etiology, or incidence
  - Useful for prevalence, quality of life & healthcare access

- Retrospectively collected clinical data
  - Useful for confirming *possible* (pre-screened) cases

- Prospectively collected clinical data
  - Clinically detailed, diagnostically accurate studies of incidence & risk factors; also cohort studies of outcomes
The CDC Epilepsy Program: Supported Surveillance Activities

- Epilepsy questions in Behavioral Risk Factor Surveillance System (BRFSS) and the National Health Interview Survey (NHIS)
  - Address prevalence, seizure frequency, access to specialty care, quality of life.

- National Health Care Surveys (CDC/NCHS)
  - Trends in health care utilization—inpatient, emergency, & outpatient.

Reference: http://www.cdc.gov/epilepsy/research_projects.htm
The CDC Epilepsy Program: Supported Epidemiologic Studies

- Population-based studies of epilepsy prevalence or incidence (e.g., New York City, SC, Houston TX, southern AZ, southwestern KS, District of Columbia)
  - Focus on health disparities, patterns of health care, and predictors of outcomes

- Studies of national epilepsy incidence using Medicare data sets
  - Focus on all seniors
  - Focus on nursing home

Reference: http://www.cdc.gov/epilepsy/research_projects.htm
Future Needs

- Further defining the public health burden of epilepsy through population-based epidemiologic studies
  - Updated cost estimates
  - Comorbidities
  - Disability and quality of life
  - Health disparities

- Early Predictors of Outcomes
  - Identifying new onset cases needing early referral for specialized care

- Epilepsy mortality surveillance
  - Including SUDEP and injury-related mortality
Suggested Reading

- The CDC Epilepsy Program research website: http://www.cdc.gov/epilepsy/research_projects.htm
End
Appendix
(Optional Slides for Q & A)
Prevalence of Epilepsy: Selected U.S. Studies, 1978-2005

- Copiah County, MS (1978)  
  - 7.1 / 1000\(^a\)

- Rochester, MN (1980)  
  - 7.1 / 1000\(^b\)

- N. Manhattan, New York, NY (2005)  
  - 5.0/1000\(^c\)

- Navajo Nation (2002)  
  - 10.2/1000\(^d\)

All rates age-adjusted to U.S. 2000 population

Prevalence of Epilepsy by Age—Composite of Selected U.S. Studies, 1978-2005

Summary Estimates of Epilepsy Prevalence in the United States

- 6.8 per 1,000
  - (data from previous slide)
- 7.1 per 1,000
  - (Hirtz et al., 2007)

Age-adjusted to U.S. 2000 population
Incidence of Epilepsy by Age—Composite of 12 Studies in Developed Countries, 1988-2005
### Estimates of Epilepsy Incidence—United States & other Developed Countries

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Median</th>
<th>Interquartile</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-4</td>
<td>93</td>
<td>70 - 108</td>
</tr>
<tr>
<td>5-19</td>
<td>37</td>
<td>26 - 44</td>
</tr>
<tr>
<td>20-64</td>
<td>29</td>
<td>24 - 36</td>
</tr>
<tr>
<td>65+</td>
<td>77</td>
<td>52 - 109</td>
</tr>
<tr>
<td><strong>Overall</strong></td>
<td><strong>41</strong></td>
<td><strong>32 - 52</strong></td>
</tr>
</tbody>
</table>

Estimated annual incidence of epilepsy per 100,000 population, age-adjusted to U.S. 2000 population. Based on age-specific estimates from 14 studies in developed countries published 1988-2008.
Lifetime Risk of Epilepsy by Age

Based on actuarial methods using median age-specific estimates from 12 studies in developed countries published 1988-2008.
Etiology of all unprovoked seizures

Access to Care Among People with Epilepsy

Recent Data from the Behavioral Risk Factor Surveillance System

BRFSS Epilepsy Survey

- BRFSS is state-based, random-digit-dialed telephone survey
- Surveys civilian, noninstitutionalized population aged ≥18 years
- Core questions used in 50 states
- Epilepsy questions added in some states in 2005
  - Screening question in 19 states
  - 3 to 4 follow-up questions in 13 states
BRFSS - State-added Questions

- Have you ever been told by a doctor that you have a seizure disorder or epilepsy?
- Are you currently taking any medicine to control your seizure disorder or epilepsy?
- How many seizures of any type have you had in the last three months?
- In the past year have you seen a neurologist or epilepsy specialist for your epilepsy or seizure disorder?
Categories of Epilepsy Severity

- Lifetime epilepsy
- Active epilepsy
  - ever told they had epilepsy AND
  - currently taking AED or had seizure(s) in last 3 months
- Active epilepsy strata:
  - with recent seizures
  - without recent seizures
Epilepsy Prevalence by Race
BRFSS 2005

- All Surveyed 8.4 / 1000
- African Americans 8.9 / 1000
- Hispanics 6.6 / 1000
- Whites 8.7 / 1000

*Weighted estimate from 13 states.*
A higher proportion of PWE in BRFSS survey report recent seizures than expected with optimum treatment (44% vs. <30%).
A Third of People with Epilepsy AND Recent Seizures Have Not Seen a Neurologist in Past Year

56% 44% 15% 29%

Source: Behavioral Risk Factor Surveillance System, 13 States, 2005 MMWR 2008; 57(SS-6)
Access to Medical Care by Level of Epilepsy Severity

- No Insurance: 0%
- Couldn't Afford MD: 5%
- (+) Sz: 15%
- (-) Sz: 10%

CDC