Epidemiologic Research and Surveillance of the Epilepsies:
A Systems-level Perspective

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I. Definitions
A. Epidemiologic research: the study of the distribution and determinants of health-related states in populations
B. Public health surveillance: the ongoing systematic collection and analysis of health data necessary for public health programs
N.B. Surveillance is not considered research, but is a routine practice of public health. The collection of mortality data for state and national vital records is an example of public health surveillance.
N.B. “Epidemiology [including surveillance] is the basic science of public health.”

II. Purposes of surveillance and epidemiologic studies
A. Burden of Illness
   1. Incidence & Prevalence
   2. Severity—disability, mortality, ↓ quality of life
   3. Cost
B. Risk factors / Etiology
C. Health disparities
   1. Access to appropriate care
D. Trends
   1. Evaluation of public policy interventions

III. Health data resources for epidemiology and surveillance
A. Established administrative datasets
   1. “Complete” data sets (e.g., hospital discharge data, emergency medical care data, vital records)
   2. Sampled data sets (e.g., CDC/NCHS National Health Care Surveys such as the National Hospital Discharge Survey, National Hospital Ambulatory Medical Care Survey, others)
N.B. Often collected for billing or reimbursement purposes, these computerized datasets contain coded data concerning diagnoses, procedures, and therapies.
B. Established population interview surveys (e.g., Behavioral Risk Factor Surveillance System, National Health Interview Survey, others)
C. Retrospectively collected clinical information (e.g., hospital or ED charts)
D. Prospectively collected clinical data (data collected specifically for study)

N.B. In general, prospectively collected clinical information is the reference (“gold”) standard for epidemiologic studies. Since data are collected for the specific purpose of a study, clinical information can be more detailed, complete, and accurate.

IV. Limitations of Established Administrative Datasets

A. Limited to information on original records
   (e.g., hospital or ED medical charts, death certificates)

B. Limited diagnostic information in ICD epilepsy codes
   1. Few categories that do not correspond well with the International League Against Epilepsy (ILAE) classification of seizure types and syndromes
   2. Cannot distinguish incident from prevalent cases
   3. Errors in coding

   N.B. A common misclassification (and serious problem) is the confusion of epilepsy (ICD-9 code 745.x) and seizures (code 780.3)

   4. Difficult linkage across inpatient & outpatient data sets

   N.B. While such linkage is possible with some state-level data and with Medicare data, it is not possible with the CDC/NCHS National Health Care Surveys. This is a major limitation. Administrative data can be used to assess epilepsy incidence or prevalence only by linking inpatient and outpatient (including ED, clinic, and physician office) medical encounter data over an extended period (usually at least one year).

V. Limitations of Established Population Interview Surveys

A. Self- or proxy-reported data

B. Diagnostic misclassifications, especially the potential for confusing symptomatic seizures and epilepsy

C. Usually exclude institutionalized, military, and homeless populations

D. Lower response rates may introduce bias

E. Non-clinician interviewers can record only limited clinical detail

VI. Limitations of Clinical Data

A. Retrospectively collected clinical data
   (extracted from original hospital or other medical records)
   1. Diagnostic & other clinical details vary
   2. Requires skilled abstractors
   3. Somewhat expensive
B. Prospectively collected clinical data
(collected specifically for study)
1. Usually require two phases: (1) screening for possible/probable cases, and (2) diagnostic confirmation of definite cases.
2. Methods to screen potential cases can be difficult; clinicians are required for diagnostic confirmation.
3. Barriers to participation (e.g., IRB and HIPAA requirements, subject unavailability or unwillingness) may limit full case ascertainment or result in an unrepresentative (biased) sample
4. Expensive.

VII. Practical Utility of Health Data for Population Studies of Epilepsy
A. Established administrative datasets
1. At local level, can use to screen for possible prevalent cases
2. Can use national data for temporal trends in healthcare use
B. Established general population surveys
1. Uns suited for epilepsy subtypes, etiology, or incidence
2. Useful for prevalence, quality of life & healthcare access
C. Retrospectively collected clinical data
1. Useful for confirming possible (pre-screened) cases
D. Prospectively collected clinical data
1. Useful for clinically detailed, diagnostically accurate studies of incidence & risk factors; also cohort studies of outcomes.

VIII. The CDC Epilepsy Program: Supported Surveillance Activities
A. Epilepsy questions in Behavioral Risk Factor Surveillance System (BRFSS) and the National Health Interview Survey (NHIS)
B. Address prevalence, seizure frequency, access to specialty care, quality of life.
C. National Health Care Surveys (CDC/NCHS)
D. Reference: http://www.cdc.gov/epilepsy/research_projects.htm
IX. The CDC Epilepsy Program: Recently Supported Epidemiologic Studies

A. Population-based studies of epilepsy prevalence or incidence in specific localities
   1. New York City
   2. South Carolina
   3. Houston, Texas
   4. Southern Arizona
   5. Navajo Nation
   6. Southwestern Kansas
   7. District of Columbia
   N.B. Focus on health disparities, patterns of health care, and early predictors of outcomes in cohorts of incident cases.

B. Studies of national epilepsy incidence using Medicare data sets
   1. Focus on all seniors
   2. Focus on nursing home residents

C. Reference: http://www.cdc.gov/epilepsy/research_projects.htm

X. Future Needs

A. Further defining the public health burden of epilepsy through population-based epidemiologic studies
   1. Updated cost estimates
   2. Comorbidities
   3. Disability and quality of life
   4. Health disparities
   5. Early Predictors of Outcomes
      a) Identifying new onset cases needing early referral for specialized care

B. Continuation of population interview surveys
   1. Biennial inclusion of epilepsy questions in the National Health interview Survey commenced in 2010. This may include future question on access to subspecialty (i.e. epileptologist or epilepsy center) care.

C. Epilepsy mortality surveillance
   1. Addressing sudden unexpected death in epilepsy (SUDEP) and injury-related mortality.
   N.B. The Epilepsy Benchmarks of the National Institute of Neurological Disorders and Stroke has identified SUDEP as a research priority. This priority includes a need to better understand the epidemiology of SUDEP, especially its incidence and risk factors in the U.S. population. In October 2010, the CDC, in collaboration with NINDS, convened an international group of experts to consider methods to implement epilepsy mortality surveillance in the United States that would complement the
research needs identified by NINDS. The proceedings of this meeting are being prepared for publication. In the meantime, CDC has submitted a Funding Opportunity Announcement for a pilot study to establish epilepsy mortality surveillance through a medical examiner’s office in one state. See http://www07.grants.gov/search/search.do?&mode=VIEW&oppId=59087.

XI. Suggested Reading

The CDC Epilepsy Program research website: http://www.cdc.gov/epilepsy/research_projects.htm. This site contains information about specific CDC-supported research projects as well as references for publications arising from this research.

Hirtz D, Thurman DJ, Gwinn-Hardy K et al. How common are the "common" neurologic disorders? Neurology 2007; 68(5):326-37. This NINDS/CDC evidence-based review of epidemiologic studies of incidence and prevalence addresses epilepsy and other relatively common neurologic conditions.

Appendix

Selected Findings Pertaining to the Public Health Burden of Epilepsy in the United States

The Prevalence of Epilepsy: Selected U.S. Studies, 1978-2005
(Rates age-adjusted to U.S. 2000 population)

- Copiah County, Mississippi (1978) 7.1 per 1000 \(^a\)
- Rochester, Minnesota (1980) 7.1 per 1000 \(^b\)
- Northern Manhattan, New York, NY (2005) 5.0 per 1000 \(^c\)
- Navajo Nation (2002) 10.2 per 1000 \(^d\)

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Summary Estimates of Epilepsy Prevalence in the United States
(Rates age-adjusted to U.S. 2000 population)

- From previous data 6.8 per 1,000
- From Hirtz et al., 2007 7.1 per 1,000

Age-specific estimates of epilepsy incidence from 12 studies in the United States and other developed countries, 1988-2005

Summary estimates of epilepsy Incidence—United States and other developed countries

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Median Annual Rate/100,000</th>
<th>Interquartile Range</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>Overall</td>
<td>41</td>
<td>32 - 52</td>
</tr>
</tbody>
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Lifetime Risk of Epilepsy by Age


Design of the BRFSS Epilepsy Survey

- BRFSS is a state-based, random-digit-dialed telephone survey of the civilian, non-institutionalized population aged ≥18 years
- BRFSS contains core questions used in 50 states
- Up to 5 epilepsy questions were added in some states in 2005
  - Screening question in 19 states
  - Follow-up questions in 13 states
- State-added questions included:
  - Have you ever been told by a doctor that you have a seizure disorder or epilepsy? [screening]
  - Are you currently taking any medicine to control your seizure disorder or epilepsy? [follow-up]
  - How many seizures of any type have you had in the last three months? [follow-up]
  - In the past year have you seen a neurologist or epilepsy specialist for your epilepsy or seizure disorder? [follow-up]

Classification of epilepsy severity

- Lifetime epilepsy ever told they had 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
Findings of Access to Care:

- A higher proportion of people with active epilepsy report recent seizures (44%) than would be expected with optimum treatment (<30%).
- Of people with epilepsy with recent seizures, 34% have not seen a neurologist or epilepsy specialist in the past year.
- Of people with epilepsy with recent seizures, 41% reported difficulty accessing medical care because of lack of health insurance or other inability to afford care.