Access to Care and Health Disparities Among People with Epilepsy

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Disclosure

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Learning Objectives

• Identify key literature on health care disparities
• Describe recent U.S. studies addressing health disparities in epilepsy
• Discuss implications
Brief Review of Literature

- Studies of health disparities—factors affecting occurrence and outcome:
  - Demographic: Age, Sex, and Ethnicity
  - Socioeconomic
  - Access to health care
How common are the “common” Neurologic disorders?

D. Hirtz, MD; D.J. Thurman, MD, MPH; K. Gwinn-Hardy, MD; M. Mohamed, MPH
A.R. Chaudhuri, PhD; and R. Zalutsky, PhD

NEUROLOGY 2007;68:326-337

Disparities in epilepsy: Report of a systematic review by the North American Commission of the International League Against Epilepsy

*Jorge G. Burneo, †Nathalie Jette, ‡William Theodore, §Charles Begley, ¶Karen Parko, **David J. Thurman, and †Samuel Wiebe for the Task Force on Disparities in Epilepsy Care, on behalf of the North American Commission of the International League Against Epilepsy
Review of Health Disparities in Epilepsy: Incidence by Demographic Attributes

Age — highest in infants & seniors

Sex — sl. ↑ males, but inconclusive

Race/ethnicity — inconclusive

Review of Health Disparities in Epilepsy: Prevalence by Social Attributes

Epilepsy is associated with:

• Lower income
• Higher unemployment
• Lower completion of post-secondary education

Review of Health Disparities in Epilepsy: Populations with Reduced Medical Care

• ↓AED adherence
  – Lower SES
  – No Insurance or Medicaid
  – Non-whites

• ↓Surgery
  – African Americans

• ↓Mental health services
  – Lower education, comorbidities

“Racial and ethnic minorities tend to receive a lower quality of healthcare than non-minorities, even when access-related factors, such as patients’ insurance status and income, are controlled.”

Institute of Medicine, 2003
Limits To The Safety Net: Teaching Hospital Faculty Report On Their Patients’ Access To Care

Access to certain specialty services and to routine inpatient care is often severely limited, even for insured patients.

by Joel S Weissman, Ernest Moy, Eric G. Campbell, Manjusha Gokhale, Recal Yucel, Nancyanne Causino, and David Blumenthal

Health Affairs 2003;27(6):156-165

VISITS TO SPECIALISTS UNDER MEDICARE: SOCIOECONOMIC ADVANTAGE AND ACCESS TO CARE

JAN BLUSTEIN, MD, PhD
LINDA J. WEISS, PhD

Journal of Health Care for the Poor and Underserved • Vol. 9, No. 2 • 1998
Unmet Need for Routine and Specialty Care: Data From the National Survey of Children With Special Health Care Needs

Michell L. Mayer, PhD, MPH, RN; Ashley Cockrell Skinner, BS; and Rebecca T. Slifkin, PhD

Pediatrics 2004; 113(2):109-115

Special Article

Report of the AAN Task Force on access to health care:

The effect of no personal health insurance on health care for people with neurologic disorders

Michael P. Earnest, MD; Jill M. Norris, PhD; Mark S Eberhardt, PhD; George H. Sands, MD; and the Task Force on Access to Health care of the American Academy of Neurology

NEUROLOGY 1996;46:1471-1480
Access-to-Care Studies: Specialty Care

- Identify limitations on access to specialty care in the United States
  - Even in populations with some insurance coverage
  - Even in populations with conditions recognized as requiring such care
Sociodemographic disparities in epilepsy care: Results from the Houston/New York City health care use and outcomes study.

Charles E. Begley, Rituparna Basu, Thomas Reynolds, David R. Lairson, Stephanie Dubinsky, Michael Newmark, Forbes Barnwell, Allen Hauser, Dale Hesdorffer, Nora Hernandez, Steven C. Karceski, and Tina Shih
The Houston/NYC Health Care Use and Outcomes Study

- Longitudinal survey of 560 epilepsy clinic attendees in 4 hospitals (NYC & Houston)
  - Represents spectrum of SES, not pop’n-based
- Non-whites compared to whites:
  - Non-specialist visits - odds ratio (OR) 5.3
  - Specialist visits - OR 0.3
  - ER visits - OR 3.1
  - Hospitalization - OR 5.4

The Houston/NYC Health Care Use and Outcomes Study (cont.)

- Differences related to clinic/hospital
  - Worse in sites serving predominantly lower income populations
- Site of care more important than individual characteristics

Recent CDC studies addressing health disparities in epilepsy
Adult active epilepsy prevalence is 1%.

Of these, only 53% have seen neurologist or epilepsy specialist in past year.
From the BRFSS—U.S., 2005

Behavioral Risk Factor Surveillance System

Survey on Epilepsy
BRFSS* Design

• 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 or 4 follow-up questions in 13 states

*Behavioral Risk Factor Surveillance System
BRFSS Epilepsy 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?
BRFSS Categories of Epilepsy

- 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.
BRFSS Results:
Epilepsy Prevalence, 2005

- Active Epilepsy (n=892) - 8.4 / 1000*
- Those w/ active epilepsy report:
  - Recent Seizure in 44%
  - No recent Seizure in 56%

Source: Behavioral Risk Factor Surveillance System, 13 States, 2005

MMWR 2008; 57(SS-6)
Socioeconomic Comparisons: Active Epilepsy vs. No Epilepsy

People w/ epilepsy are more likely:
• Not employed (unemployed or disabled)
  Odds ratio (O.R.) = 6.2 (5.4 - 7.1)
• Household income <$25,000
  O.R. = 3.0 (2.6 - 3.4)
• Education < HS
  O.R. = 1.5 (1.3 – 1.9)

BRFSS, 2005. See MMWR 2008; 57(SS-6)
Distribution of Employment Status within Epilepsy Severity Categories

BRFSS, 2005. See *MMWR* 2008; 57(SS-6)
Distribution of Annual Incomes within Epilepsy Severity Categories

BRFSS, 2005. See MMWR 2008; 57(SS-6)
Access to Medical Care by Level of Epilepsy Severity

Proportion who have not seen neurologist or epilepsy specialist in past year

BRFSS, 2005. See MMWR 2008; 57(SS-6)
Specialty Care Treatment Gap – U.S. People w/ Epilepsy, 2005

- Nearly half (44%) of PWE report recent seizures.
- One third (35%) of these are not receiving specialty care.

BRFSS, 2005. See MMWR 2008; 57(SS-6)
Access to Medical Care by Level of Epilepsy Severity

BRFSS, 2005. See MMWR 2008; 57(SS-6)
Recent Trends in Health Insurance Coverage

• Lack of private health insurance rose 27% from 1997-2009.
  (CDC, National Health Interview Survey)

• Estimated 46 million people uninsured

• Underinsurance rose 60% from 2003-2007
  (Schoen C et al. Health Affairs, June 10, 2008: w298–w309.)

• Estimated 25 million people under-insured.
Conclusions

• Major health disparities exist for PWE compared to the general population
• PWE, especially those w/o seizure remission, are more likely to have:
  • ↓income, ↑unemployment, & ↓education
  • ↓access to & utilization of health care svcs.
• ↓access to care greater for minority populations
Conclusions (cont.)

• There is a substantial “treatment gap” for PWE involving access to specialty care
  • Insurance coverage may not guarantee adequate access to specialty care
• Epilepsy is an example whose lessons apply to other chronic neurologic disorders.
Future Research Needs

- Distinguish access to epilepsy subspecialty care
- Health disparities and access to care among children with epilepsy
- Trends under the Affordable Care Act
“While research has documented disparities in receiving equitable and timely epilepsy care, the reasons for these inequities . . . and their magnitude . . . have to be better understood in order to improve access to care.”

— Institute of Medicine, 2012
“Medicine, as a social science, as the science of human beings, has the obligation to point out problems and to attempt their theoretical solution: the politician, the practical anthropologist, must find the means for their actual solution....”

— Rudolf Virchow (1821-1902)
Impact on Clinical Care and Practice

• Identify and address access-to-care barriers in patients
• Advocacy
References


