Estimating Epilepsy Prevalence: Design, Implementation and Preliminary Results from a Population-based Survey of Washington, DC Residents

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1. Background

- It is estimated that almost 2% of the U.S. population has a history of epilepsy; however, few studies provide data on the prevalence of epilepsy in low-income and racial minority populations
- Washington, DC selected to implement a population-based study of epilepsy
  - Racially and socially diverse, with a high proportion of non-Whites
  - Economically diverse, with a high proportion below poverty level
  - Housing units for non-Whites clustered and can be targeted by zip code and census track
  - Fewer under-coverage issues (e.g., P.O. boxes)
  - Potential for comparison of estimates with the CDC's Behavioral Risk Factor Surveillance System (BRFSS)

2. Study Goal

- Estimate the prevalence and incidence of epilepsy among DC residents and subgroups of the population.

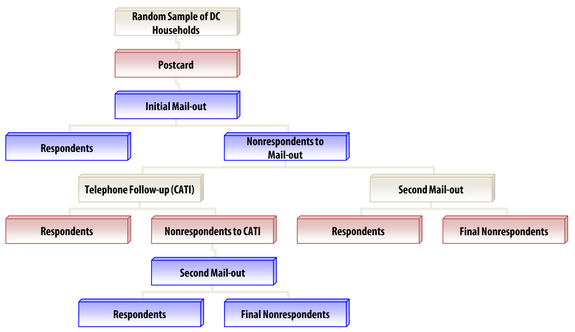
3. Sample Design

- Used probability-based sampling to select 20,000 DC addresses
- Stratified by areas with high concentration of Blacks and Low income Whites
- For complete coverage, included drops (single delivery point for multiple addresses), PO boxes, and throwbacks (street address but mail delivery made to a PO box); excluded seasonals, vacants and rurals
- Phase 1: Screen all members of the household for epilepsy or a seizure disorder
- Phase 2: Identify and collect additional information from individuals with epilepsy or a seizure disorder

4. Data Collection Protocol

- Households were mailed a screening questionnaire to collect demographic information and identify individuals with epilepsy
- Individuals with epilepsy were then mailed an "extended" questionnaire
- Option to complete screening and extended questionnaires by phone or Web
- Data collection took place from June 2008–October 2008

Figure 1. Data Collection Protocol



5. Approaches to Maximizing Response Rate

- Advance postcard announcing household selection and future mailing
- Study logo on postcard, survey, and mailing envelope
- Simple, single-page screener, Spanish translation on reverse
- Surveys mailed in 9x12 envelope to reduce appearance of junk mail
- List of supporters printed on postcard and letters
- Option to complete survey by mail, telephone, or Web
- Enclosed $1 with initial screener mailing
- Increased incentive offered in second mailing for completion of screener

6. Data Collection Results

- 6,447 households representing 12,894 individuals (10,753 adults and 2,141 children) responded to the screening questionnaire
- 208 cases with a history of epilepsy (174 adults and 34 children) were identified in 201 households
- Data were weighted using the March supplement of the Current Population survey (CPS) 2009 to reflect the entire DC population of 581,847 (10,374 cases with a history of epilepsy, 571,473 non-cases)

7. Demographics of Epilepsy Cases

Table 1. Prevalence and Incidence of Epilepsy by Groups

		Ever Epilepsy (percent)	Current Epilepsy (percent)	New Annual Epilepsy (per 100,000)
All cases		1.8	0.9	64.1
Gender	Male	1.9	1.0	73.5
	Female	1.7	0.8	77.0
Age	0–17	1.8	0.7	139.8
	>17	1.8	0.9	59.9
Race	Black	2.4	1.2	109.2
	Hispanic	1.3	0.7	25.6
	White	1.0	0.4	34.2
	Other	1.1	0.5	79.5
Size of Household	1 person	2.2	1.3	106.9
	2 people	1.6	0.9	54.4
	> 2 people	1.7	0.6	89.9
Education in >24 yr old	< High School	4.2	2.8	75.8
	HS Grad	2.6	1.4	89.1
	Some College	2.5	1.1	176.1
	College Grad	1.5	0.7	24.1
	Grad School	0.8	0.4	21.0
Years in DC	0–3	0.9	0.3	111.4
	>3	2.0	1.1	65.9

8. Results

Figure 2. Ever Epilepsy, Current Epilepsy, and New Epilepsy, by Age Group

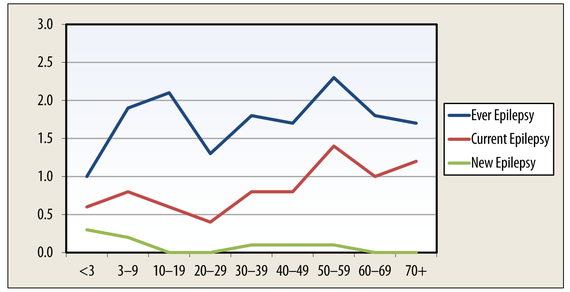


Figure 3. Epilepsy Prevalence in Blacks and Whites, by Age

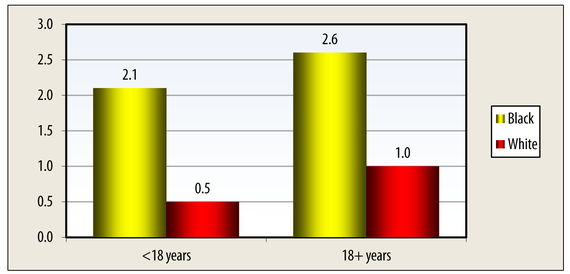


Figure 4. Epilepsy Prevalence in Adult Blacks and Whites, by Education

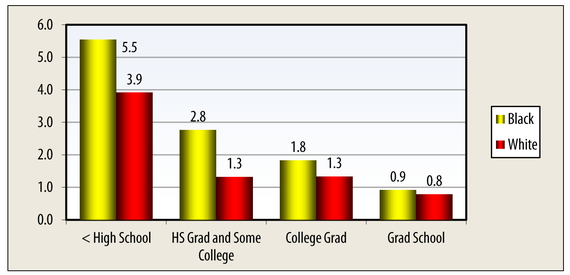
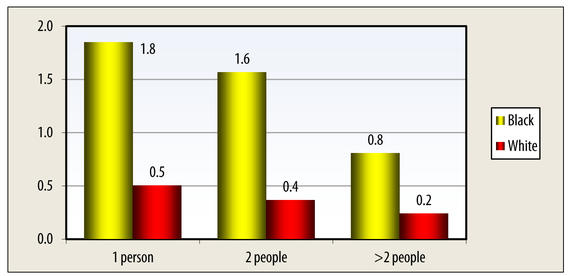
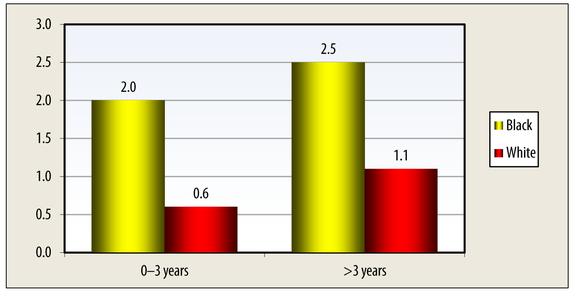


Figure 5. Active Epilepsy in Adult Blacks and Whites, by Household Size



8. Results *(continued)*

Figure 6. Epilepsy Prevalence in Adult Blacks and Whites, by Years Lived in DC



9. Discussion

Results

- The incidence of epilepsy in DC is bi-modal with the highest rate in children < 3 years of age. We did not see a high rate of new cases in the elderly
- Race and education were independent and significant predictors in a multivariate analysis of both active and prevalent epilepsy
- Prevalence is highest in those adults that did not graduate from high school
- Blacks and Whites with active Epilepsy are significantly more likely to live in single-person households than in multi-person households
- Adult Blacks and Whites with a history of epilepsy are more likely to have lived in DC for more than 3 years, suggesting that people with epilepsy are less likely to relocate
- While the data were weighted to reflect the current population in DC, the overall response rate of 35% may have influenced the final results, particularly if those with epilepsy were more likely to respond. We are currently validating our results through the DC Behavioral Risk Factor Surveillance Study being conducted for 2009

Methods

- Incentives encouraged response
- Mail was most effective mode: 78% of responses received by mail, followed by 13% by phone and 8% by Web—offering multiple modes improved response
- Despite efforts to eliminate vacancies and bad addresses, 10–11% of the screening questionnaires were returned as undeliverable (5.6% of these as vacant)
- Use "Current Resident" rather than the name associated with the address to prevent mail forwarding and/or envelopes returned marked "deceased" or "no longer at this address"

Contact Information

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