



Racial and socioeconomic disparities in epilepsy in the District of Columbia

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Summary We investigated social and demographic factors as they relate to prevalence and incidence of epilepsy in Washington, DC, a culturally diverse area. Probability-based sampling was used to select 20,000 households to complete a mailed epilepsy screening survey on all household members. Screened individuals with a history of epilepsy were sent a detailed case survey about seizures and treatment. Prevalence and incidence of epilepsy were estimated using weighted data. Lifetime prevalence was 1.53% overall; 0.77% in Whites, 2.13% in Blacks, and 3.4% in those with less than a high school diploma. Prevalence of active epilepsy was 0.79% and followed similar subgroup comparisons as lifetime prevalence. Age-adjusted lifetime and active epilepsy from multivariate analyses demonstrated significantly higher rates for Blacks compared to Whites and for those not completing high school compared to those that attended graduate school. The incidence of epilepsy was 71 per 100,000 persons. Adults with active epilepsy were significantly less likely to live alone than those without epilepsy. Residents of DC for <4 years had the lowest prevalence and incidence of all subgroups indicating a possible healthy mover effect. This is the first study to provide estimates and profiles of the epilepsy population in DC which can help better target resources to improve the health and outcomes of people with epilepsy and their families.

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Introduction

General surveys measuring self-reported epilepsy occurrence among U.S. adult populations have yielded estimates of lifetime prevalence ranging from 1.2 to 2.9%, and estimates of active or point prevalence ranging from 0.8% to 1.6% (Konda et al., 2009; Kobau et al., 2008, 2006; Ottman et al., 2011). These variations may be due to differences in study population demographics and survey methodology. From population-based studies in developed countries, which include additional methods to confirm clinical diagnoses of epilepsy, estimates of epilepsy prevalence across all ages range from 0.4% to 0.9% and in children range from 0.4% to 0.5% (Hirtz et al., 2007). The median estimate of age-adjusted epilepsy incidence among such studies is 48 per 100,000 (Hirtz et al., 2007).

In most population-based surveys, lifetime prevalence has been estimated using a single screening question that asks about the history of a diagnosis of epilepsy or a seizure disorder. However, a study that involved additional self-reported information about seizures and treatment found that 18.5% of reports from a single screening question were false positive (Kelvin et al., 2007). When medical records were used as the gold standard for a diagnosis of epilepsy compared to a self-report, the false positive rate from a single screening question was 23.8% (Ottman et al., 2010) and 15.8% (Brooks et al., 2012).

With few exceptions, U.S. studies have found no significant differences in rates of epilepsy by race or ethnicity (Burneo et al., 2009; Ottman et al., 2011; Kelvin et al., 2007; Kobau et al., 2008, 2006; Haerer et al., 1986). However, there are previous reports of strong links between epilepsy and lower educational attainment and income (Elliott et al., 2008, 2009; Kobau et al., 2006, 2007; Konda et al., 2009; Ottman et al., 2011; Ferguson et al., 2008; Geerts et al., 2011; Sillanpaa, 2004). While education is highly correlated with income and expected to produce analogous results, it also involves cognitive aspects that can impact recognition of and self-care for epilepsy, as well as the ability to live independently.

The Washington DC Health Study (DCHS) was initiated to estimate the incidence and prevalence of epilepsy and seizure disorder among underrepresented groups to help guide policy makers and health care organizations in understanding potential disparities in access to care. The District of Columbia (DC) was chosen as the study site because of its rich cultural, racial and socioeconomic diversity. According to 2009 census data, DC includes a high proportion of non-Hispanic Blacks (52.7%) compared to the national estimate of 12.1%. Although the median household income for DC is higher than the country as a whole, the number of families living below poverty level is also higher than the national average (14.6% versus 10.5%). In addition, compared to national averages, DC has more adult residents that live alone (46.6% versus 27.4%) and are highly educated (28.0% versus 10.3%). We sought to investigate these factors and other demographic indicators as they relate to the prevalence and incidence of epilepsy.

Methods

Sampling methodology

Address-based sampling methodology was used to reach a representative sample of 20,000 households in DC. This method has gained recent popularity because of evolving problems associated with telephone-based samples, eroding rates of response to single methods of contact, and improvements in the databases of household addresses available to researchers. Specifically, the Computerized Delivery Sequence File of the US Postal Service, the most complete address database available in the US providing near perfect coverage, was used as the sampling frame to select a representative sample of household addresses. In order to increase the number of respondents in the analytical subgroups of interest, including Black and non-Black residents in the highest and lowest income strata, a stratified sampling design was used whereby DC households in certain Census Block Groups (CBG) were over-sampled according to the allocation summarized in Table 1.

Survey design and administration

There were three phases of data collection for the DCHS, involving three data collection instruments. In Phase I of the study, a one-page bi-lingual *screening survey* asked five basic demographic and three epilepsy screening questions for all household members. Demographic data included age, gender, race/ethnicity, education, and length of residency in DC. Answer choices for race/ethnicity included White, Black, Hispanic, Asian, and Other. The epilepsy screening questions were derived from the Behavioral Risk Factor Surveillance System's (BRFSS) epilepsy module (Kobau et al., 2008) and included "Ever diagnosed with epilepsy or a seizure disorder?", "Currently taking any medication to control seizures?", and "What year was the first seizure?." Limited space on the survey did not allow for a question about the date of the most recent seizure. AEDs can be taken for many non-seizure related conditions, and asking whether a subject was currently taking a medication to control seizures, rather than taking an AED, limited the possibility of positive responses that were not related to epilepsy.

In Phase II, a *case survey* was mailed to each household that had identified a prevalent case of epilepsy from the first screening question in the Phase I survey. The case survey included detailed questions about seizures and treatment, co-morbid conditions, quality of life, and social factors such as marital status, school, and employment. Parents were asked to complete the case surveys on behalf of children.

The Phase III survey was developed after preliminary analyses of the case survey suggested that the number of prevalent cases of epilepsy from the screening survey was overestimated due to self-reporting of febrile, provoked, and isolated unprovoked seizures. This *supplemental survey* was sent to all cases and included two pages of questions about the causes of the seizures.

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