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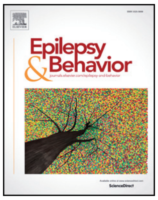

Brief Communication

Epilepsy or seizure disorder? The effect of cultural and socioeconomic factors on self-reported prevalence

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ABSTRACT

Self-reported epilepsy may be influenced by culture, knowledge, and beliefs. We screened 6420 residents of the District of Columbia (DC) for epilepsy to investigate whether socio-demographics were associated with whether they reported their diagnosis as epilepsy or as seizure disorder. Lifetime and active prevalence rates were 0.54% and 0.21%, respectively for 'epilepsy' and 1.30% and 0.70%, respectively for 'seizure disorder'. Seizure disorder was reported significantly more often than epilepsy among blacks, females, respondents ≥ 50 years, those with lower level education, respondents who lived alone and in low income neighborhoods, and those who resided in DC for at least five years. Clinicians should assure that patients and caregivers understand that epilepsy is synonymous with seizure disorder and other culturally appropriate terms, in order to optimize compliance with treatment, disease management instructions, and utilization of other resources targeted at persons with epilepsy. Furthermore, education and awareness campaigns aimed at improving access-to-care, reducing stigma, and increasing awareness of adverse events, such as SUDEP, should include a more diverse definition of epilepsy in their messages.

1. Introduction

For many individuals, the term 'epilepsy' is a complex and frightening diagnosis that is associated with social stigma. Some persons identify themselves as having a 'seizure disorder' rather than 'epilepsy,' although neurologists generally recognize these terms as equivalent in meaning. A diagnosis using either term can have far-reaching implications, particularly when it comes to self-identifying with the condition in some circumstances or populations, such as those in lower income brackets or with uncontrolled seizures [1,2]. Cultural dynamics may also play a role in self-reporting, either directly or indirectly, particularly in racially and economically diverse populations. For instance, Sirven et al. [3] found that 21% of Spanish-speaking adults in the US had no familiarity with the term epilepsy, and over 77% referred to seizures as convulsions or attacks.

The lifetime prevalence of self-reported epilepsy in community-dwelling adults in the US has ranged from 1.2% to 2.9% [4–7]. The differences across studies may be influenced by survey mode effects (e.g., mailed surveys versus random digit dial telephone surveys) as well as differences in culture and knowledge and beliefs about epilepsy that affect the sensitivity and specificity of self-reporting. For example, false negative cases due to recall bias, untruthful responses because of stigma, or a misinterpretation or misunderstanding of the question being asked will generally go uncounted and result in underestimation of the prevalence. Conversely, false positive cases, such as those that have experienced only provoked, febrile, or psychogenic nonepileptic seizures artificially increase the prevalence estimates. The latter can often be resolved through record-based validation studies; however, population-based studies do not always include this component. In reports of validation of self-reported epilepsy, population-based studies based on self-reports do indeed provide prevalence rates that are higher than clinical record-based studies with few exceptions [8–10].

In the Behavioral Risk Factor Surveillance Surveys (BRFSS) conducted in 19 States, a nonstatistically significant higher prevalence of epilepsy was found in Blacks compared with Whites [6]. Although also not statistically significant, a higher prevalence of self-reported epilepsy among Blacks compared with Whites was found in a biracial area of

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Mississippi when a more extensive set of survey questions was used [11] and in a multiracial community in New York City [12].

We conducted a population-based survey in the District of Columbia (DC), one of the most culturally, racially, and economically diverse populations in the nation, to estimate the prevalence and incidence of epilepsy in various demographic categories, as defined by either the clinical term epilepsy or the more generic term seizure disorder. Using the combined definition, we found that the epilepsy prevalence in non-Hispanic blacks was twice that found in non-Hispanic whites, after adjusting for age and education [13]. Here we report on the prevalence and incidence of epilepsy and seizure disorder, separately, within the adults that completed the screening survey, to demonstrate that subpopulations of affected persons are more likely to identify their condition as seizure disorder as opposed to epilepsy.

2. Material and methods

The full description of the study methods are described elsewhere [13]. Briefly, we used the Computerized Delivery Sequence File (CDSF) of the US Postal Service, the most complete address database available in the US providing near perfect coverage, as the sampling frame to select a representative sample of 20,000 household addresses in DC. 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, households in certain Census Block Groups were over-sampled according to the allocation summarized in Table 1. A single page bi-lingual epilepsy screening questionnaire was then mailed to the probability-based sample of 20,000 households in DC. The survey and the corresponding letter of invitation, which included a statement of informed consent, were approved by the institutional review board for protection of human subjects at RTI International. Nonrespondents to the first wave were mailed a second survey or called on the telephone by a trained interviewer. The survey instructions called for a complete enumeration of all household members, including their demographic characteristics. The instructions also stated that the person completing the survey should be listed on the form as the first member of the household, and hereafter we refer to this person as the primary respondent. For this report, we included only the information corresponding to the primary respondent, realizing that the proxy information on the other household members provided by the primary respondent would be influenced by their attitude and knowledge regarding the terms epilepsy and seizure disorder.

The first epilepsy screening question on the survey was derived from the Behavioral Risk Factor Surveillance System's (BRFSS) epilepsy module [6] and asked “Ever diagnosed with epilepsy or a seizure disorder?” with response options: No, Yes epilepsy, and Yes seizure disorder. Three response options were included to maximize the chance of identifying all possible cases of epilepsy in a single question in our culturally diverse population. Active epilepsy or seizure disorder was defined as a positive response to the second screening question “Currently taking any medicine to control seizures?”. All response data were weighted to reflect the sampling design and compensate for differential nonresponse and coverage. The population totals included in the weighting procedures were obtained from the 2009 Current Population Survey, which reported a total of 581,847 residents for the entire DC [14]. The 2009 census data coincided with the time of sample selection and are consistent with those used in the previous report. Findings presented for highest education level completed, which include graduate school, were restricted to the 6128 primary respondents at least 25 years of age. This is consistent with the age restriction used by the U.S. Census for reporting results on educational attainment.

In a second phase of the study, cases were mailed another survey which asked about employment, quality of life, comorbidities, seizure type, severity, frequency, and duration, treatment, and whether the case had ever had seizures as a result of a fever, head injury, drug or alcohol use, a stroke, or an acquired medical condition. This survey was used to categorize the etiology of the seizures and the confirmation of epilepsy by the study team neurologist (WDG) [13].

3. Results

There were 6447 primary respondents (6420 adults) that returned the screening survey for an overall adjusted response rate of 36.6%. The demographic composition of the adult primary respondents is presented in Table 2. There were more females (60.5%) than males (39.5%) and slightly more Blacks (45.2%) than Whites (44.4%). Half of the adult study population was at least 50 years of age and 39.7% had attended at least some graduate school. Primary respondents accounted for 107 (61.5%) of the 208 total cases of epilepsy or seizure disorder reported in 201 households. Weighted estimates and 95% confidence intervals for individual lifetime prevalence in the adult primary respondents were 0.54% (0.34–0.74) for epilepsy and 1.30% (0.98–1.62) for seizure disorder for an overall lifetime prevalence of 1.84% (1.47–2.21) for either condition. Adult primary respondents with active epilepsy were also significantly more likely to identify their condition as a seizure disorder than as epilepsy—0.70% (0.47–0.94) versus 0.21% (0.08–0.33). Of the 6420 primary respondents that were at least 18 years of age, the demographic characteristics by history of each self-reported condition are presented in Table 2. Lifetime prevalence of seizure disorder was reported more often than epilepsy in all primary respondent subgroups except those age 18–30 years. The comparative rates for seizure disorder ranged from almost equal compared with epilepsy to three times higher than that reported for epilepsy. The prevalence of seizure disorder was significantly higher than epilepsy among non-Hispanic Blacks, females, those 50 years of age or older, those with only a high school education, those living in low income neighborhoods, and those who resided in DC for at least five years.

Prevalence results for active seizure disorder and active epilepsy by demographic subgroups are presented in Table 3, and in all subgroups the rates were higher for self-reported seizure disorder than they were for self-reported epilepsy. The prevalence of active seizure disorder was significantly higher than the prevalence of active epilepsy among the same six subgroups identified for lifetime prevalence and included non-Hispanic Blacks, females, those 50 years of age or older, those with only a high school education, those living in low income neighborhoods, and those who resided in DC for at least five years. In four subgroups (young adults, Hispanic, race other than White or

Table 1
Distribution of all households in DC and in the sample by percent Blacks and median household income from Census.

Percent Blacks in CBG	Median household income for census block group									
	Less than $30,000		$30,000–$39,999		$40,000–$49,999		More than $49,999		Total	
	DC	Sample	DC	Sample	DC	Sample	DC	Sample	DC	Sample
>95%	15.2%	18.0%	6.9%	8.1%	1.2%	1.4%	1.2%	8.7%	24.5%	36.2%
70–94%	8.8%	5.2%	7.7%	4.5%	4.4%	2.6%	3.9%	2.3%	24.8%	14.6%
10–69%	4.5%	2.6%	6.3%	3.7%	3.8%	2.3%	8.8%	5.2%	23.4%	13.8%
<10%	0.5%	3.7%	1.6%	1.9%	3.8%	4.5%	21.4%	25.3%	27.3%	35.4%
Total	29.0%	29.5%	22.5%	18.2%	13.2%	10.8%	35.3%	41.5%	100.0%	100.0%