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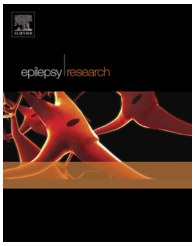

The prevalence of epilepsy along the Arizona—Mexico border

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Summary

Purpose: This study describes the epidemiology of epilepsy on the Arizona—Mexico border.
Methods: Households in Southern Arizona were identified using two strategies. County-wide random digit dialing telephone surveys were supplemented with door-to-door recruitment in three Arizona border communities. Utilizing a two-step screening process, individuals with a seizure disorder or epilepsy were identified. A consensus diagnosis was arrived at after reviewing results from the detailed interview, medical records and clinical examination.
Results: A total of 15,738 household individuals were surveyed. Two hundred and three individuals were identified as having had epilepsy at some point in their life; 25% of them were previously not diagnosed. The sex and age-adjusted prevalence estimate was 14.3 per 1000 (95% CI: 12.5—16.1) for lifetime epilepsy, and 11.8 per 1000 (CI: 10.2—13.5) for active epilepsy (seizures in the past 5 years or currently taking antiseizure medications). Non-Hispanic Whites were two times more likely to have active epilepsy than Hispanics. The majority of individuals with lifetime history of epilepsy had idiopathic or cryptogenic epilepsy; most were localization-related epilepsy although the exact location could not be determined for the majority. Although most individuals with epilepsy report receiving care from a neurology specialist, they were more likely to have visited a non-specialist in the past 3 months.

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Significance: The lower prevalence of epilepsy among Hispanics compared to non-Hispanics supports previous survey findings in the Southwest US and may be due to language, acculturation factors, stigma, or a reflection of the ''healthy immigrant effect''. The surprisingly high proportion of previously un-diagnosed individuals shows a need for further investigation as well as a need to increase community awareness.

Introduction

The racial and ethnic composition of a geographic region has important consequences for the health status of its population because measures of disease and disability can differ significantly by race and ethnicity. While these differences have been explored for prevalent diseases such as cancer, heart disease, and stroke through publicly-funded programs, epilepsy, one of the more common neurological disorders, has not been extensively investigated. Epilepsy prevalence estimates vary as a function of population characteristics (race, ethnicity, age), study definition and methodology (Hauser and Kurland, 1975; Locke et al., 1989). The wide variation in estimates suggests that results in one population may not be representative or generalizable to other regions. To better understand the needs of individuals with epilepsy residing in Southern Arizona, our goal for the current study, funded by the Centers for Disease Control and Prevention (CDC) between 2006 and 2009, was to determine the prevalence of epilepsy and the health care utilization of individuals with epilepsy along the Arizona—Mexico border, an area where Hispanics account for 50% or more of the population (cf. Arizona with 30%) using previously validated instruments for comparability.

Lifetime epilepsy prevalence is defined as the proportion of patients with a history of epilepsy, regardless of treatment or seizure activity (International League Against Epilepsy, 1993). Within the US, reported lifetime prevalence estimates ranged between 5.9/1000 and 22.0/1000. From the mostly Caucasian patients in the Rochester Epidemiology Project, age-adjusted lifetime prevalence was reported to be 8.2/1000 (Hauser et al., 1996). Self-reported data from the Behavioral Risk Factor Surveillance Survey (BRFSS) in 13 states suggest a range of lifetime prevalence estimates for adults between 11.5/1000 and 22.0/1000 (Kobau et al., 2008). From the 2003 California Health Interview Survey, 12/1000 adults reported ever being told that they had epilepsy or a seizure disorder (Kobau et al., 2007). The crude lifetime prevalence for Copiah County in Mississippi was 10.43/1000 (Haerer et al., 1986). In contrast, Kelvin et al. (2007) found the age-adjusted lifetime prevalence of self-reported epilepsy in a New York City community to be 5.9/1000.

In a major managed care organization in New Mexico, a search of 5 years of epilepsy-related diagnostic codes yielded an age-adjusted epilepsy period prevalence estimate of 9/1000 (Holden et al., 2005). Using data from international epidemiologic studies on epilepsy, Hirtz et al. (2007) reported a median period prevalence of 7.1/1000 in studies conducted from 1970 to 1989. Parko and Thurman (2009) estimated the age- and sex-adjusted four-year period prevalence on the Navajo Nation to be 20/1000 using records review.

The demographic profile of Arizona is different from many of the other states; minorities are a much larger part of the population. Hispanics make up approximately 30% of the population and Native Americans 4.5% (Arizona, 2009). In contrast, the U.S population during that same period had approximately 15.1% Hispanics and 1.5% Native Americans. Epilepsy prevalence also varies widely in the Hispanic population in the U.S. Hispanics in New York City were found to have higher age-adjusted lifetime epilepsy prevalence than non-Hispanics (Kelvin et al., 2007), while the unadjusted lifetime prevalence was lower both in California (Kobau et al., 2007), and in Arizona using the Arizona BRFSS data (Chong et al., 2012). It is clear that understanding epilepsy needs within the community requires a local assessment as reported in the current study. This information will highlight gaps in our knowledge about individuals with epilepsy in this geographic region, including potential disparities and barriers to epilepsy care, as well as allow comparisons with other studies using similar instruments.

Methods

Households in the three rural Arizona—Mexico border counties of Cochise, Santa Cruz, and Yuma were targeted for recruitment using both telephone (random digit dialing) and door-to-door approaches. Telephone numbers were generated using known stems drawn from the first three numbers for the three counties as well as through commercially available lists of residential numbers guaranteed to have 80% active residential numbers. The door-to-door approach was to oversample 500 households randomly in the largest border community for each county (Douglas, Nogales, and San Luis). These communities have lower residential telephone coverage and proportionately more Hispanic residents than other county areas (from Census 2000 Summary File 3 data). Our goal was to interview 12,000 households for the telephone component to obtain a reliable estimate between 5 and 10/1000 with 95% confidence. Eligibility requirements included: consent to participate from one of the heads of household (male or female), household located in Cochise, Santa Cruz, or Yuma Counties (for telephone surveys), and household residents living or expect to live in the county for 6 or more months of the year. In most cases, one household member acted as the informant for all other household members. Up to seven contacts were attempted before the number was discarded. All study procedures were approved by the University of Arizona's Institutional Review Board.

Screening for seizures

Two questionnaires were used to increase the probability that all individuals with seizures would be detected. Questions from the epilepsy module used in the BRFSS (Kobau