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Disparities in access to specialized epilepsy care

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Summary
Objective: To examine the impact of individual and community characteristics on access to specialized epilepsy care.
Methods: This retrospective cross-sectional study analyzed data from the California State Inpatient Sample, the State Ambulatory Surgery Database, and the State Emergency Department Database, that were linked with the 2009 Area Resource File and the location of the National Association of Epilepsy Center's epilepsy centers. The receipt of video-EEG monitoring was measured and used to indicate access to specialized epilepsy care in subjects with persistent seizures, identified as those who had frequent seizure-related hospital admissions and/or ER visits. A hierarchical logistic regression model was employed to assess barriers to high quality care at both individual and contextual levels.
Results: Among 115,632 persons with persistent seizures, individuals who routinely received care in an area where epilepsy centers were located were more likely to have access to specialized epilepsy care (OR: 1.81, 95% CI: 1.20, 2.72). Interestingly, the availability of epilepsy centers did not influence access to specialized epilepsy care in people who had private insurance. In contrast, uninsured individuals and those with public insurance programs including Medicaid and Medicare had significant gaps in access to specialized epilepsy care. Other individual characteristics such as age, race/ethnicity, and the presence of comorbid conditions were also associated with disparities in access to specialized care in PWE.

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Conclusion: Both individual and community characteristics play substantial roles in access to high quality epilepsy care. Policy interventions that incorporate strategies to address disparities at both levels are necessary to improve access to specialized care for PWE.

Introduction

Disparities in access to specialized care pose significant challenges to the treatment and quality of care improvement in persons with epilepsy (PWE) (Institute of Medicine, 2012a). Previous studies provide evidence that gaps in access to comprehensive high-quality epilepsy care exist in people with low socioeconomic status, and in racial minority populations (Kelvin et al., 2007; Begley et al., 2009; Burneo et al., 2009). In addition, insurance status has also been found to be important factor that can influence access to specialized care in PWE (McClelland et al., 2007, 2010; Begley et al., 2009; Halpern et al., 2011; Baca et al., 2013). So far, very little attention has been paid to the role of contextual factors in the variation of access to epilepsy care. Several studies in other disease entities have shown that characteristics of the area of residence such as socioeconomic status of the neighborhood, degree of urbanization, availability of resources and services including provider availability and managed care penetration also play an important role in access to specialty care (Gresenz et al., 2000; Diez Roux et al., 2001; Litaker et al., 2005). A recent study found that geographic location of residence influenced the timing of referral for epilepsy surgery evaluation (Hauptman et al., 2013). As the availability of specialized epilepsy care is mostly limited to urban large medical centers (Schiltz et al., 2013), comprehensive analysis of the influence of contextual and individual attributes is a vital step for planning effective policies to reduce disparities in access to care for PWE.

The objective of this study was to examine the nature of multilevel relationships in accessing specialized epilepsy care in PWE. We used the receipt of video-EEG (VEEG) monitoring as an indicator for access to specialized epilepsy care and examined barriers to VEEG monitoring at both individual and contextual levels. VEEG monitoring is an important diagnostic test that is commonly used to confirm a diagnosis of a seizure disorder and to classify seizure type, especially in persons with persistent seizures (Cascino, 2002). Moreover, determination of candidacy for epilepsy surgery requires VEEG monitoring. It, therefore, is likely that most, if not all, of individuals with persistent seizures would have undergone VEEG monitoring, had they had access to specialized epilepsy care.

Materials and methods

The study protocol was approved by Institutional Review Board at Case Western Reserve University.

Data sources

We performed a retrospective cross-sectional study using 2005—2009 data from the California State Inpatient Sample (SID), the California State Ambulatory Surgery Database (SASD), and the California State Emergency Department Database (SEDD). These datasets are part of the Healthcare Cost and Utilization Project (HCUP) sponsored by the Agency for Healthcare Research and Quality (AHRQ) (Agency for Healthcare Research and Quality, 2011). The HCUP SID, SASD, and SEDD provide complete information on all hospital discharges, ambulatory surgeries, and emergency room (ER) visits. Each record contains patient demographic information, hospital and county identifier, diagnoses, procedures, discharge status, length of stay, as well as total charges and payment source.

Since an individual record in the HCUP State databases represents one discharge abstract rather than an individual patient, we used the HCUP revisit variables to link multiple records belonging to the same individual across facilities and hospital settings (Agency for Healthcare Research and Quality, 2012), thus making it possible to analyze the data at the individual level, rather than at the encounter level. The revisit variables are states and year specific, and can only be created for states that provide unique encrypted patient identifier (Agency for Healthcare Research and Quality, 2012). In 2005, the revisit variables for all HCUP state data including SID, SASD, and SEDD were available in 4 states including California, Florida, Nebraska, and Utah (Agency for Healthcare Research and Quality, 2013). California data were readily available to us, and therefore were used for the analysis of this study.

In addition, we used the Area Resource File (ARF), which provided a comprehensive collection of contextual data, including socioeconomic and environmental characteristics for each county within the US (US Department of Health and Human Services, 2011). ARF 2009 data elements were linked to the California SID, SASD, and SEDD based on the location of hospital and/or ambulatory centers by a common 5-digit Federal Information Processing Standards (FIPS) code that was unique to each US county.

We also obtained the address of all Level 3 and Level 4 epilepsy centers (ECs) in the State of California from the National Association of Epilepsy Center (NAEC) website (http://www.naec-epilepsy.org/find.htm) and linked the location of ECs to other socioeconomic and environmental variables in the ARF by matching the county of each individual center to a corresponding FIPS code.

Study population

Individuals with at least 1 occurrence of the International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) code for epilepsy (ICD-9-CM: 345.xx), or 2 or more occurrences, at least 30 days apart, of ICD-9-CM codes for convulsion (ICD-9-CM: 780.39) were included. These criteria have been shown to have high degree of accuracy for identifying epilepsy cases from facility-based administrative records (Jette et al., 2010; Faught et al., 2012). We further