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Distinguishing language and race disparities in epilepsy surgery

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ABSTRACT

This study aimed to identify whether race/ethnicity and limited English proficiency impact the likelihood of pursuing surgical treatment for medically refractory epilepsy.

We conducted a retrospective cohort study of 213 patients with medically refractory epilepsy and mesial temporal sclerosis who were being considered for temporal lobectomy between January 1, 1993 and December 31, 2010 with follow-up through December 31, 2012. Demographic and clinical factors potentially associated with surgical utilization, including self-reported race/ethnicity and preferred language, were gathered from the medical record.

Patients of Asian/Pacific Islander or African American race were significantly less likely to pursue surgical treatment of epilepsy compared with non-Hispanic whites in a multivariate logistic regression model (adjusted for nonconcordant ictal EEG, age, and limited English proficiency) (OR 0.20, $p = 0.003$; OR 0.15, $p = 0.001$, respectively). Limited English proficiency was also significantly associated with lower odds of surgery (OR 0.38, $p = 0.034$).

Both race and limited English proficiency contribute to disparities in the surgical management of medically refractory epilepsy, especially among Asian/Pacific Islanders and African Americans. Culturally sensitive patient–physician communication and patient education materials might aid in surgical decision-making among minority groups.

1. Introduction

Epilepsy, defined as recurrent unprovoked seizures, is a common disease worldwide with a median incidence estimate of 46 per 100,000 per year [1]. Approximately 20–40% of patients with epilepsy have seizures that are medically refractory [2,3]. Despite constituting a minority of cases, patients with medically refractory epilepsy account for 80% of the total costs associated with epilepsy [4]. Temporal lobe epilepsy (TLE) is widely regarded as the most common cause of medically refractory epilepsy and is often amenable to surgery, with seizure-free rates ranging from 48 to 84% following anterior temporal lobectomy (ATL) for mesial temporal sclerosis (MTS) [5–7]. Studies have demonstrated an improvement in patient-perceived impacts and quality-of-life measures following resective surgery [8–12]. Importantly, seizure freedom one year postsurgery does not differ significantly for Hispanics and African Americans compared with non-Hispanic whites [13]. It is imperative that patients with epilepsy have access to surgery and be educated regarding their surgical options and outcomes.

The reasons for health care disparities in epilepsy and in other fields of medicine are complex. In 2003, the Institute of Medicine (IOM) published a landmark report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, that summarized years of research on health care disparities in the United States [14]. The IOM concluded that disparities among minority patients are pervasive and tend to persist, despite adjustments for age, gender, health insurance status, other socioeconomic factors, comorbidities, and location of care. Disparities in preventive services and treatment for certain chronic conditions, such as diabetes, have been more rigorously studied than has epilepsy. Moreover, physicians and health services researchers continue to face gaps in knowledge about specific racial or ethnic groups because data are often aggregated, or race/ethnicity is often commingled with language, making it difficult to measure progress toward health care disparity reduction initiatives [15].

In 2000, the National Institute of Neurological Disorders and Stroke set a benchmark to expand the use of surgery for epilepsy, especially earlier in the course of treatment [16]. However, the 2007 update of those benchmarks noted that surgery remains underutilized [17]. Several recent studies have suggested that disparities in the use of surgery for TLE exist among African American patients in particular, although some studies have been underpowered to detect differences across diverse racial/ethnic groups in a multivariable model [18–21].

Abbreviations: TLE, temporal lobe epilepsy; ATL, anterior temporal lobectomy; MTS, mesial temporal sclerosis; UCSF, University of California, San Francisco; EMU, epilepsy monitoring unit; EEG, electroencephalogram; NIS, Nationwide Inpatient Sample.

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Whether adult patients with limited English proficiency underutilize epilepsy surgery has not been evaluated, although race/ethnicity and language have been investigated together in other fields of medicine [22].

We aimed to determine whether race/ethnicity impacts use of anterior temporal lobectomy among patients with MTS who self-identify as non-Hispanic white, African American, Asian/Pacific Islander, or Hispanic in a single epilepsy center. Additionally, we wanted to evaluate whether limited English proficiency, serving as a proxy for acculturation, contributes to our understanding of which patients underutilize epilepsy surgery by assessing whether it confounds or modifies the relationship between race/ethnicity and surgical utilization. Attempting to detect, understand, and eventually close gaps in care that contribute to health and health care disparities could have a profound effect on the treatment of patients with epilepsy.

2. Methods

We conducted a single unmatched retrospective cohort study to examine if indicators of race/ethnicity are associated with differential use of ATL as a treatment for medically refractory epilepsy in the setting of MTS. The University of California, San Francisco (UCSF) Medical Center functions as a tertiary referral center (level 4 epilepsy center), serving a diverse demographic of patients throughout Northern and Central California. The UCSF Committee on Human Research approved the study, which utilized a waiver of informed consent and an intention to rely agreement with the University of California, Berkeley. We searched an administrative claim database to identify all patients admitted to the UCSF epilepsy monitoring unit (EMU) between January 1, 1993 and December 31, 2010, with follow-up through December 31, 2012. The demographic and clinical variables abstracted from the medical records were predetermined, and the abstractors were aware of the study hypotheses. Initial MRI data were gathered by trained research assistants and verified by JPB and CSS.

All EMU admissions were screened for a radiographic diagnosis of unilateral MTS, defined as the presence of hippocampal atrophy with increased signal intensity on either 1.5-T or 3.0-T MRI [23]. A minority of cases displayed hippocampal atrophy in the absence of increased signal intensity, which was felt to represent early MTS appropriate for surgical planning. We included patients with other lesions on their MRI as long as these were not typical epileptogenic lesions and provided that the ictal onset was not inconclusive or was felt to be originating from these lesions based on scalp electroencephalography (EEG). The EEG data were gathered from EEG reports and discharge summaries (JPB and CSS). All EEGs were digitally recorded according to the standard international 10-20 system with sphenoidal electrodes occasionally used to help with ictal onset lateralization and localization.

We excluded all patients without an MRI unless it was clearly stated in the chart that an outside MRI was reviewed and reported as consistent with MTS. Patients with bilateral MTS were excluded, as were pediatric patients (<18 years of age) and patients who did not experience a seizure during their EMU stay or were having only focal seizures without impairment of consciousness. We excluded all patients whose epilepsy was not medically refractory, defined as persistent debilitating seizures despite two trials of antiepileptic medications [3,5,24]. It was assumed that all patients who underwent EEG monitoring at UCSF would also have their surgery at UCSF, except for Kaiser Permanente patients who were excluded since they returned to Kaiser for consideration of surgery.

The University of California, San Francisco accepts Medicare, Medicaid (Medi-Cal), and most types of private insurance to cover the costs of diagnostic work-up and surgical treatment for patients with TLE; all EMU admissions were prescreened to ensure sufficient insurance coverage. Thus, our patient base was restricted to those with insurance, which reduced confounding from health insurance in our sample. Baseline demographic data extracted from the chart included sex, laterality of MTS, year and age at time of EMU admission, as well as race/ethnicity (African American, Asian/Pacific Islander, Hispanic, or non-Hispanic white) and preferred language, which were self-reported when the patients established care. Because the length of the study extended over a time period (1993–2010) during which census reporting of race categories changed, thus influencing hospital reporting (Office of Management and Budget categories), and because of small sample size, we chose to use Asian/Pacific Islander as a single category for the purposes of analysis [25,26]. Patients who were missing key data for race/ethnicity, language, etc. or who were reported as "other" race/ethnicity in the medical record were excluded from the analysis. We categorized patients as having limited English proficiency if they indicated in their medical chart that they preferred to use a language other than English. As a proxy for socioeconomic status, we matched patients by their home zip code to median household income by race according to Zip Code Tabulation Areas from the US Census 2000, which has been utilized in prior similar studies [19,20,27–29]. Video-EEG reports were reviewed (JPB and CSS), and ictal EEG findings were classified as "concordant" if seizures arose from the hemisphere ipsilateral to the MTS. Ictal findings were grouped as "nonconcordant" if the seizures occurred from the hemisphere contralateral to the MTS (discordant), if the ictal onset could not be lateralized (inconclusive), or if bilateral independent seizures were noted (bilateral). We grouped these all as "nonconcordant" because these patients all received similar counseling in our institution.

Statistical analysis was completed using STATA (12.1, College Station, TX). The baseline demographic, radiographic, and EEG characteristics of the patients were first summarized by descriptive statistics. Bivariate analysis between categorical variables and ATL as well as categorical variables and race/ethnicity was performed using the Pearson chi-square test. We fitted separate logistic regression models for each characteristic against the outcome of ATL and reported the unadjusted odds ratios (ORs) and 95% confidence intervals (CIs). Then a multivariate logistic regression model was constructed using the aforementioned characteristics to examine associations with ATL. The primary covariate of interest was race/ethnicity categorized as African American, Asian/Pacific Islander, and Hispanic. Based on a review of the literature, demographic and clinical covariates were tested in the model [18–20]. For example, year of admission (categorized as 1993–1998, 1999–2004, or 2005-2010) was included to assess for potential period effects due to changing practice parameters [18,20]. Additional covariates tested in the model were limited English proficiency, age as a continuous quadratic term centered at the median age of 35, sex, area median household income by race (categorized into tertiles: 0–45,000, >45–65,000, >65,000 dollars per year), laterality of MTS (left versus right), and an ictal EEG recording that was nonconcordant with the laterality of MTS. In models that contained median household income derived from zip codes, adjustment for correlated units was also made by running a generalized estimating equation clustered at the zip code level using a sandwich estimator to generate robust standard errors in order to obtain proper inference [30]. Covariates that neither confounded the association between race/ethnicity and surgery (defined as failure to alter the magnitude of the OR on race/ethnicity by >10%) nor reached a statistical significance of $p \leq 0.05$ on Wald test were excluded from the model [31]. Interaction terms between the primary covariate of interest (race/ethnicity) and potential effect modifiers (age, sex, year of admission, laterality of MTS, and nonconcordant ictal EEG) and between limited English proficiency and either Asian/Pacific Islander race or Hispanic ethnicity were also tested individually in the model with their main effect terms. Interaction terms that did not reach statistical significance were excluded from the model, and a likelihood ratio test of a full model with interaction terms compared with a restricted model without interaction terms was also performed using a p-value cutoff of 0.20 for interaction [31]. All