Evaluating racial/ethnic variations in outpatient epilepsy care

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ABSTRACT

This study evaluated the quality of epilepsy care in an ambulatory population of a major medical center and determined if there were any racial/ethnic variations. The well-established 'Quality Indicators in Epilepsy Treatment (QUIET)' study dataset was used. Medical record, phone interview, and mail-out survey data of 311 patients with epilepsy were linked and analyzed. Evaluation of care from provider and patient perspectives was performed. Overall, the patients with epilepsy received 40.9% of QI recommended care. The black patients were more likely to receive 50% or more QI recommended care compared with non-Hispanic whites (odds ratio [OR] = 2.16, 95% confidence interval [CI] 1.09–4.27). Black patients scored significantly worse than non-Hispanic whites for two patient-reported measures — perceived racial/ethnic disparities (OR = 3.14, 95% CI 1.15–8.53) and difficulties getting follow-up appointments (OR = 3.37, 95% CI 1.55–7.32). The results indicate the need to evaluate both provider- and patient-centered measures in quality-of-care studies in disparities research.

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1. Introduction

While widespread concerns have been raised regarding the overall quality of health care, there is a particular need to apply evidence-based practices to more vulnerable patient populations [1–3]. The IOM key report *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* highlights the inadequacies that exist in the quality of care in terms of socio-demographic disparities and suggests that "many sources, including health care systems, health care providers, patients, and utilization managers, are contributors" [4,5]. One of the recent reports of the Agency for Healthcare Research and Quality (AHRQ) on National Healthcare Disparities indicates that racial/ethnic and socio-economic disparities "still pervade the American health care system" and that "although varying in magnitude by condition and population, disparities are observed in almost all aspects of health care" [6]. More recently, the U.S. Department of Health and Human Services (HHS) has launched *HHS Action Plan to Reduce Racial and Ethnic Health Disparities* where it "acknowledges the existence of health and health-care disparities between the country's ethnic minority populations and White Americans and outlines goals and actions to evaluate, reduce, and eliminate those" [7,8].

Continuing efforts have been directed towards evaluating and reducing health disparities on different levels of health care in many clinical areas. There is a growing body of research targeted at documenting, understanding, and improving the quality of care and outcomes for racial/ethnic minority and socio-economically vulnerable population groups. Disparities research in the area of epilepsy has been growing recently as well, and although the research evidence is still limited, it has suggested that the quality of many aspects of epilepsy care is lower for vulnerable population groups [9,10].

Epilepsy is a chronic neurological condition that has a significant impact on the overall well-being and the quality of life of patients and their families. It is one of the most common neurological disorders, affecting about 50 million people worldwide [11]. In the U.S., about two to three million people have epilepsy, and about 140,000 new cases are identified every year [12–14]. The medical care of epilepsy is a substantial part of epilepsy management and constitutes an important determinant of a patient's physical, mental, cognitive, and psychosocial well-being. Any disparities observed in epilepsy care have the potential to impair the well-being and quality of life of patients, adding to the significant vulnerability already caused by the disease.

A recent systematic literature review conducted by the North American Commission of the International League against Epilepsy provided a summary of epilepsy disparities research between 1965 and 2008 in the U.S., Canada, and the English-speaking countries of the Caribbean region. The Commission reported that there was evidence

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indicating socio-demographic disparities in epilepsy care [10]. The authors also found that research assessing disparities in epilepsy care was limited and emphasized the need for more attention to this area. One of the research gaps identified by the Commission was the lack of prior disparities studies aimed at evaluating the quality of routine outpatient epilepsy care—an important component in the care of patients with epilepsy.

Our study aimed to examine disparities in the processes of epilepsy care by focusing on the delivery of therapeutic care in an outpatient setting. We not only evaluated the technical processes of care but also assessed several targeted measures of inter-personal care in order to understand the broader picture of the quality of care provided to patients with epilepsy. The main research objectives were to determine if there were any differences in the processes of care among racial/ethnic groups and what factors led to those differences. We used a comprehensive, hospital-based dataset of patients' socio-demographic, clinical, and access to care characteristics, as well as a series of measures of epilepsy care processes [15]. The richness of the dataset allowed us to perform an in-depth evaluation of the quality of care and its variations while controlling for multiple potential confounding variables.

2. Methods

2.1. Data source

This project was based on the dataset of the Quality Indicators in Epilepsy Treatment (QUIET) research study; methods for patient recruitment and data collection for the QUIET study have been described previously [15,16]. The study included 311 subjects. Data from the patients' hospital administrative and medical records were linked with phone interview and mail-out survey data in a cross-sectional design. The data were based upon patient information between 2004 and 2008 on the processes of care received, as well as socio-demographic, clinical, and access/utilization of care characteristics. The quality indicators were based upon clinical data obtained from patients' medical charts. We used a rigorous approach for medical record review which complied with published methodological standards [15,17]. The inter-rater agreement previously reported was 86%. By linking these datasets, we were able to measure and compare the processes of routine epilepsy care – both technical and inter-personal care – among patients of different socio-demographic characteristics. This paper specifically focuses on the findings related to racial/ethnic differences in care. The study was approved by the institutional review board of Boston Medical Center (BMC).

2.2. Study setting and population

The study participants were patients receiving outpatient care at Boston Medical Center (BMC) — a multispecialty urban teaching hospital. It serves a socio-demographically diverse population and provides primary, secondary, and tertiary care services. The hospital has a specialized epilepsy center within the neurology department providing a wide range of diagnostic, therapeutic, and surgical services to patients with epilepsy.

The study population included adults (≥18 years old) with epilepsy or a seizure disorder receiving epilepsy care at the primary care and/or neurology departments of the hospital. Patients were identified for the primary study as having ICD-9 codes for epilepsy or seizure disorder (345.xx or 780.39) in hospital administrative and/or medical records, or a diagnosis of epilepsy or seizure disorder written in the medical record problem list. Patients were required to speak English and have at least two eligible visits (two or more visits to the primary care or neurology clinics or one visit to the primary care or neurology clinic and at least one non-emergency inpatient visit) to the hospital during the two-year period prior to study enrollment.

2.3. Variables

2.3.1. Patient socio-demographic characteristics

Patient socio-demographic characteristics included age, gender, race/ethnicity, income, education, employment, and marital status. Race/ethnicity data were based on self-identification of the study participants during the phone interview and were further categorized into the following groups: white, black, Hispanic, and 'other'. The 'other' group included all others, with a larger net proportion of Asians. There were more patients in two of the categories, whites (n = 147) and blacks (n = 133), compared with the patients in the categories for Hispanic (n = 15) and 'other' (n = 16). Identification of income level was based on assigning a neighborhood median household income to each patient using information on their residence ZIP code and linking it to 2000 Census data. Income was analyzed as a categorical variable. Educational level, employment, and marital status data were based on participants' reports during the phone interviews, and age and gender data were based on medical chart reviews. We analyzed age as a continuous variable in the regression models, and the remaining variables included in the analyses were categorical.

2.3.2. Patient clinical characteristics

Patient clinical characteristics included variables such as epilepsy duration, seizure control, side effects to antiepileptic drugs (AEDs), and comorbidities. Epilepsy duration was a dichotomous variable, with patients categorized into new or chronic epilepsy cases. Patients with epilepsy who were newly diagnosed within the two years prior to study enrollment were considered new cases and represented 21% of the sample (n = 65). The fraction of newly-diagnosed patients was larger than commonly reported rates of new cases in a population with epilepsy, largely because we used a two-year time period to identify new cases. The incidence of new-onset epilepsy in our population was also higher because our sample was recruited from a hospital with a specialized epilepsy center serving as a referral point for new patients with epilepsy. In this study, seizure control data were retrieved from patients' medical charts and described seizure occurrence documented during the initial visits of the two-year index period before patient enrollment. The AED side effects variable was a dichotomous measure based on medical records data and occurrence of any or no side effects to AEDs in two years. The data on comorbidities were retrieved from patients' medical charts as well and were based on two indices, medical and mental, previously validated in populations with ambulatory chronic disease [18].

2.3.3. Access and utilization of care characteristics

We considered insurance status as a proxy measure to evaluate access to care. Insurance status data were retrieved from patients' hospital medical records and were grouped into the following categories: Medicare, Medicaid/Boston Medical Center Health Plan (BMCHP), private insurance, and free care. Epilepsy-related visits reflected the number of visits over the two-year study period during which epilepsy was discussed. All epilepsy-related visits to primary care and neurology departments during the study period were captured from patients' medical records. Data indicating whether or not a patient saw an epilepsy care provider outside of BMC were also available. We did not have further information about the dates, number, and types of those visits, and, therefore, these data were not integrated with the epilepsy-related visits variable but used as a covariate in the analyses. The percent neurology variable described the proportion of neurologist visits among all the epilepsy-related visits over two years.

2.3.4. Dependent variables: processes of care

Several processes of care measures were used as dependent variables in this study. To evaluate the technical processes of care, an established measure based on the QUIET study quality indicators