

Differences in elective epilepsy monitoring unit admission rates by race/ethnicity and primary payer in New Jersey

Brad K. Kamitaki^{a,*}, Pengfei Zhang^a, Aditi Master^b, Shoshana Adler^b, Saloni Jain^b, Charlotte Thomas-Hawkins^c, Haiqun Lin^c, Joel C. Cantor^d, Hyunmi Choi^e

^a Rutgers-Robert Wood Johnson Medical School, Department of Neurology, 125 Paterson Street, Suite 6200, New Brunswick, NJ 08901, USA

^b Rutgers-Robert Wood Johnson Medical School, 675 Hoes Lane West, Piscataway, NJ 08854, USA

^c Rutgers University School of Nursing, Division of Nursing Science, 180 University Ave, Newark, NJ 07102, USA

^d Rutgers University, Center for State Health Policy, 112 Paterson Street, 5th Floor, New Brunswick, NJ 08901, USA

^e Columbia University, Department of Neurology, 710 West 168th Street, 7th Floor, New York, NY 10032, USA

ARTICLE INFO

Article history:

Received 2 June 2022

Revised 21 August 2022

Accepted 13 September 2022

Available online 24 September 2022

Keywords:

Health services research

EMU

Healthcare access

Insurance

Disparities

EEG

ABSTRACT

Elective admission to the epilepsy monitoring unit (EMU) is an essential service provided by epilepsy centers, particularly for those with drug-resistant epilepsy. Given previously characterized racial and socioeconomic healthcare disparities in the management of epilepsy, we sought to understand access and utilization of this service in New Jersey (NJ). We examined epilepsy hospitalizations in NJ between 2014 and 2016 using state inpatient and emergency department (ED) databases. We stratified admissions by race/ethnicity and primary payer and used these to estimate and compare (1) admission rates per capita in NJ, as well as (2) admission rates per number of ED visits for each group. Patients without insurance underwent elective EMU admission at the lowest rates across all racial/ethnic groups and payer types studied. Black patients with Medicaid and private insurance were admitted at disproportionately low rates relative to their number of ED visits. Hispanic/Latino and Asian/Pacific Islanders with private insurance, Hispanic/Latinos with Medicaid, and Asian/Pacific Islanders with Medicare were also admitted at low rates per capita within each respective payer category. Future studies should focus on addressing causal factors driving healthcare disparities in epilepsy, particularly for patients without adequate health insurance coverage and those who have been historically underserved by the healthcare system.

© 2022 Elsevier Inc. All rights reserved.

1. Introduction

Epilepsy, a disorder characterized by recurrent seizures, is one of the most common chronic neurological conditions and affects approximately 3.4 million people in the United States (US) [1]. Approximately one-third of all people with epilepsy will develop drug-resistance, that is, continue to have seizures despite multiple trials of antiseizure medication [2–4]. Evidence-based guidelines recommend referral to a comprehensive epilepsy center once a patient is diagnosed with drug-resistant epilepsy [5]. Inpatient admission to the epilepsy monitoring unit (EMU) is one of the most important services offered at epilepsy centers. In the EMU, recording a patient's seizures with continuous video-EEG (VEEG) monitoring serves as the gold standard for defining the seizure/epilepsy type or underlying epilepsy syndrome, as well as mimickers such as psychogenic nonepileptic seizures [6–9]. Epilepsy mon-

itoring unit admission is also required as part of the presurgical epilepsy work-up, including seizure localization with intracranial EEG electrodes. Thus, ensuring access to the EMU is critical, especially for those with drug-resistant epilepsy.

Access to epilepsy services in the US, including admission to the EMU, is complicated by differential, inequitable access to healthcare. The US healthcare insurance and financing system does not currently provide universal coverage to its population and is defined as a mixed system in which publicly financed government plans (Medicare, which provides coverage for those age 65 and older, those under 65 with permanent disability, or with end-stage renal disease; and Medicaid, jointly funded by the federal government and individual states, which provides care to those below the poverty level or who cannot afford to pay for healthcare) coexist with privately financed plans (often contributed to by employers in whole or part [group insurance] or purchased privately through the health insurance marketplace) [10]. Those without health insurance pay for their entire cost of care “out-of-pocket,” with often financially devastating consequences. Indeed,

* Corresponding author.

E-mail address: brad.kamitaki@rutgers.edu (B.K. Kamitaki).

up to 62.1% of all bankruptcies in 2007 were due to medical debts. Moreover, three-quarters of medical debtors had health insurance coverage; thus, even those with coverage can sustain high out-of-pocket costs [11]. Further, structural racism—that is, laws and policies that allocate resources in ways that perpetuate inequitable access for people of color—continues to afflict the American healthcare landscape [12,13]. Examples of ways that structural racism impacts coverage, financing, and overall quality of healthcare are worth reviewing [14].

As in many other health conditions, prior studies have demonstrated racial and socioeconomic disparities in the management of drug-resistant epilepsy in the US. Minority race/ethnicity, limited English proficiency, and health coverage by a public insurance program or lacking health insurance altogether were associated with decreased access to epilepsy surgery [15–18]. Non-surgical epilepsy services are also important to examine from a health equity standpoint, as not all patients with drug-resistant epilepsy are surgical candidates. Unsurprisingly, patients with public insurance plans or without insurance were also less likely to see an epilepsy provider or receive inpatient VEEG monitoring and were more likely to experience greater antiseizure medication costs [19–21]. Because US hospitals typically require a guarantee of payment prior to undertaking higher cost elective services, including MRI testing, EEG monitoring, elective EMU admission, and epilepsy surgery, those without health insurance often have little ability to seek higher level epilepsy care if needed. Many people with epilepsy are also unable to drive due to serious risks of vehicle accidents, which can prevent timely access to medical care [22–24]. Closer proximity to an epilepsy center was associated with improved access to specialty epilepsy care in a prior study [20]. Therefore, a better understanding of whether epilepsy services are provided disproportionately on a local- or state-wide basis, with attention to communities historically underserved by the healthcare system, will allow us to address obstacles to delivery of care.

To this end, we investigated EMU admission rates for seizures/epilepsy in New Jersey (NJ), a diverse state well-suited for examining healthcare disparities. We calculated EMU admission rates per capita, as well as per number of emergency department (ED) visits for seizure/epilepsy for each group to determine whether this service is distributed equitably by race/ethnicity and expected primary payer. We hypothesized that patients of minority race/ethnicity and those without health insurance coverage would have lower rates of utilization of the EMU as compared with White patients and those with health insurance coverage.

2. Materials and methods

2.1. Data collection

This study was approved by the Rutgers University Institutional Review Board. We examined data from the Healthcare Cost and Utilization Project (HCUP) State Inpatient Database (SID) and State Emergency Department Database (SEDD) for New Jersey. These databases contain information on all inpatient and emergency department discharges, respectively, regardless of payer from all non-federal short-term acute care hospitals in NJ. In the NJ HCUP-SID/SEDD, the unit of analysis is an inpatient discharge record. Thus, individual patients who have been admitted multiple times during a one-year period will occupy multiple rows in the dataset, one for each admission. However, individual patients cannot be tracked in the NJ HCUP-SID/SEDD.

We performed a retrospective cross-sectional study of elective EMU admissions from the NJ HCUP-SID between January 1, 2014 through December 31, 2016. Of note, the coding system changed

from the International Classification of Disease (ICD)-9 to ICD-10 coding system on October 1, 2015. We identified inpatient discharges coded as: (1) age \geq 18 years and (2) with a VEEG monitoring procedural code (CPTn = 95951; PRn = 89.19 for ICD-9; I10_PRn = 4A10X4Z for ICD-10), and (3) with a seizure or epilepsy admitting diagnosis code (DX_Admitting = 345.xx or 780.3x for ICD-9; I10_DX_Admitting = R56.x or G40.xxx for ICD-10), and (4) elective admission status. We excluded admissions with an intracranial surgical procedure code (PRn = 01.xx for ICD-9; I10_PRn = 00Hxxx for ICD-10) to study only admissions with conventional scalp VEEG monitoring. We previously validated this method to identify elective EMU admissions in a prior study [25].

We also examined all ED visits for seizure/epilepsy from the NJ HCUP-SEDD and SID. We defined these as emergency department visits with a primary diagnosis (DX1 or DX_Visit_Reason1 for ICD-9; I10_DX1 or I10_DX_Visit_Reason1 for ICD-10) of seizure/epilepsy from the NJ HCUP-SEDD, as well as emergency department visits admitted to the hospital with an admitting diagnosis (DX_Admitting for ICD-9; I10_DX_Admitting for ICD-10) of seizure/epilepsy from the NJ HCUP-SID.

2.2. Data analysis

Statistical analyses were performed using SAS OnDemand for Academics. First, we calculated descriptive statistics for patients undergoing elective EMU admission for seizure/epilepsy, including patient age, sex, length of stay, race/ethnicity, income quartile by zip code, and primary insurance payer, including frequencies for categorical variables and means with standard deviations for continuous variables. We categorized race/ethnicity as follows: (1) White, (2) Black, (3) Hispanic or Latino, (4) Asian or Pacific Islander, (5) American Indian or Alaska Native, or (6) Other, which in NJ includes multiracial individuals or those of “Other Race.” These racial/ethnic group categories were created and defined using the HCUP SID/SEDD data elements for New Jersey [26,27]. We also categorized admissions based on the expected primary payer as (1) Medicare, (2) Medicaid, (3) Private Insurance, (4) No Insurance (including self-pay and no charge), and (5) Other Insurance. We combined admissions with primary payer designations of “Self-pay” and “No charge” and considered those as admissions for patients without health insurance based on prior methodology [28]. We calculated similar descriptive statistics for patients undergoing ED visits for seizure/epilepsy and additionally determined disposition status as: (1) discharged home, (2) Inpatient Admission, (3) Transferred to Facility (including Skilled Nursing Facility, Intermediate Care Facility, or Another Type of Facility), (4) Home Health Care, (5) Against Medical Advice, or (6) Died.

Next, we determined EMU admission rates per capita in NJ stratified by: (1) race/ethnicity alone, (2) primary payer alone, and (3) both race/ethnicity and primary payer. We determined the number of person-years at risk for each group using data from the NJ Census and the Kaiser Family Foundation and then calculated elective EMU admission rates per 1000 person years stratified on two levels: race/ethnicity and primary payer [29,30]. Given insufficient numbers of patient admissions and census data on the primary payer for American Indian, Alaska Native, and multiracial individuals in NJ, we were unable to examine EMU admission rates for these groups. As an additional metric, we determined elective EMU admission rates per 100 ED visits for seizure/epilepsy, again stratified by: (1) race/ethnicity alone, (2) primary payer alone, and (3), race/ethnicity and primary payer. We tested for differences in admission rates using a Poisson distribution and corrected for multiple comparisons with the Tukey–Kramer method. We considered a corrected *p*-value of <0.05 as statistically significant.

3. Results

There were 2372 elective inpatient EMU admissions in NJ between 2014 and 2016. Admitted patients had a mean age of 42.2 years (standard deviation [SD]: 16.5), and 57.5% were women. The mean length of stay was 3.8 days (SD: 3.0) [Table 1]. There were 53,194 ED visits for seizure/epilepsy in the same period. Patients had a mean age of 43.1 years (SD: 16.9), and 45.1% were women. Of these ED visits, 80.7% resulted in discharge home, 12.0% were admitted to the hospital, 1.9% transferred to facility, 0.2% discharged to home health care, 5.2% left against medical advice, and 0.1% died [Table 2].

Per capita elective EMU admission rates in NJ differed between groups when assessing the main effects of race/ethnicity and primary payer separately. After stratifying by race/ethnicity alone, we found that Black patients were admitted at the highest rate per capita (0.147 admissions/1000 person years [py], 95% CI: 0.135–0.161), followed by White (0.117 admissions/1000 py, 95% CI: 0.111–0.124), then Hispanic/Latino (0.072 admissions/1000 py, 95% CI: 0.064–0.079), with Asian/Pacific Islanders admitted at the lowest rate (0.023 admissions/1000 py, 95% CI: 0.017–0.030). Differences between each group were statistically significant ($p < 0.001$). After stratifying by primary payer alone, patients with Medicare were admitted at the highest rate per capita (0.168 admissions/1000 py, 95% CI: 0.155–0.181), followed by Medicaid (0.139 admissions/1000 py, 95% CI: 0.127–0.151), private insurance (0.082 admissions/1000 py, 95% CI: 0.077–0.088), and uninsured patients at the lowest rates (0.017 admissions/1000 py, 95% CI: 0.013–0.024). These rates were also significantly different from each other.

Next, we obtained per capita EMU admission rates stratified on two levels, by race/ethnicity and primary payer [Table 3, Fig. 1]. Among those with private insurance, EMU admission rates were highest for White and Black patients, followed by Hispanic/Latinos, and then lowest for Asian/Pacific Islanders (0.082 fewer admissions/1000 py for Asian/Pacific Islander versus White patients,

Table 1
Demographics of patients undergoing elective epilepsy monitoring unit admission in New Jersey, 2014–2016.

Categories		N (%)
Total, N		2372
Age, Mean (SD)		42.2 (16.5) years
Length of stay, Mean (SD)		3.8 (3.0) days
Gender	Men	1007 (42.5)
	Women	1365 (57.5)
Expected primary payer	Private Insurance	1004 (42.3)
	Medicaid	561 (23.7)
	Medicare	701 (29.6)
	No Insurance	45 (1.9)
	Other	61 (2.6)
Race	White	1311 (55.3)
	Black	474 (20.0)
	Hispanic/Latino	379 (16.0)
	Asian/Pacific Islander	55 (2.3)
	American Indian/Alaska Native/Other Race	96 (4.0)
	Missing	57 (2.4)
Zip Code Income by Quartile	First Quartile–\$1–42,999	400 (16.9)
	Second Quartile – \$43,000–53,999	218 (9.2)
	Third Quartile – \$54,000–70,999	461 (19.4)
	Fourth Quartile – \$71,000+	1282 (54.1)
	Missing	11 (0.5)

SD: standard deviation; EMU: epilepsy monitoring unit.

Table 2
Demographics of patients who visited the emergency department for seizure/epilepsy in New Jersey, 2014–2016.

Categories		N (%)
Total, N		53,194
Age, Mean (SD)		43.1 (16.9) years
Gender	Men	29,215 (54.9)
	Women	23,978 (45.1)
Expected primary payer	Private Insurance	13,645 (25.7)
	Medicaid	14,882 (28.0)
	Medicare	17,117 (32.2)
	No Insurance	6503 (12.2)
	Other	1047 (2.0)
Race	White	25,582 (48.1)
	Black	17,130 (32.2)
	Hispanic/Latino	6994 (13.1)
	Asian/Pacific Islander	798 (1.5)
	American Indian/Alaska Native/Other Race	2155 (4.1)
	Missing	535 (1.0)
Zip Code Income by Quartile	First Quartile–\$1–42,999	13,145 (24.7)
	Second Quartile – \$43,000–53,999	7348 (13.8)
	Third Quartile – \$54,000–70,999	11,696 (22.0)
	Fourth Quartile – \$71,000+	20,452 (38.4)
	Missing	553 (1.0)
Disposition Status	Discharged Home	42,923 (80.7)
	Inpatient Admission	6383 (12.0)
	Transferred to Facility	987 (1.9)
	Home Health Care	110 (0.2)
	Against Medical Advice	2758 (5.2)
	Died	33 (0.1)

SD: standard deviation.

$p < 0.001$). For those with Medicaid, admission rates were higher among White and Black compared with Hispanic/Latino patients (0.113 fewer admissions/1000 py for Hispanic/Latino versus White patients, $p < 0.001$). There was no significant difference seen, however, between Asian/Pacific Islanders and any other racial/ethnic group with Medicaid. Black patients with Medicare had the highest per capita elective EMU admission rate of all groups and nearly double the rates of White and Hispanic/Latino patients with Medicare. Asian/Pacific Islander patients with Medicare had lower admission rates compared with all other racial/ethnic groups with Medicare (0.125 fewer admissions/1000 py for Asian/Pacific Islander versus White patients, $p = 0.004$). Lastly, patients without insurance demonstrated the lowest admission rates across all racial/ethnic groups studied, between 3 and 9 times lower than those with private insurance.

The number of elective EMU admissions in NJ per 100 ED visits for seizure/epilepsy varied between racial/ethnic groups differently than the per capita rates. Using the ED visit metric, White (5.16 admissions/100 ED visits, 95% CI: 4.88–5.45), Hispanic/Latino (4.72 admissions/100 ED visits, 95% CI: 4.72–5.81), and Asian/Pacific Islander (6.64 admissions/100 ED visits, 95% CI: 5.05–8.74) patients were admitted at comparable rates, while Black patients were admitted at significantly lower rates compared with all other groups (2.75 admissions/100 ED visits, 95% CI: 2.51–3.01, $p < 0.001$). After stratifying by primary payer alone, patients with private insurance (5.74 admissions/100 ED visits, 95% CI: 5.38–6.12) and Medicare (5.08 admissions/100 ED visits, 95% CI: 4.71–5.48) were admitted at similar rates. Patients with Medicaid were admitted at the next lowest rate (3.69 admissions/100 ED visits, 95% CI: 3.39–4.02, $p < 0.001$ versus patients with private insurance/Medicare). Patients without insurance were admitted to the EMU at much lower rates than any other payer group (0.67 admissions/100 ED visits, 95% CI: 0.49–0.92, $p < 0.001$).

Table 3
Elective epilepsy monitoring unit admission rates in New Jersey stratified by race/ethnicity and primary payer, 2014–2016.

Primary Payer	Race/Ethnicity	Number of elective EMU admissions per 1000 person years (95% CI)	Number of elective EMU admissions per 100 ED visits for seizure/epilepsy (95% CI)
Private Insurance	White	0.099 (0.091–0.107)	6.40 (5.91–6.93)
	Black	0.106 (0.091–0.123)	3.55 (3.04–4.14)
	Hispanic/Latino	0.066 (0.056–0.078)	7.46 (6.30–8.83)
	Asian/Pacific Islander	0.017 (0.012–0.025)	7.07 (4.85–10.31)
Medicaid	White	0.195 (0.172–0.221)	4.72 (4.17–5.35)
	Black	0.164 (0.139–0.193)	2.16 (1.83–2.55)
	Hispanic/Latino	0.082 (0.068–0.098)	5.14 (4.29–6.16)
	Asian/Pacific Islander	0.085 (0.054–0.135)	11.76 (7.41–18.67)
Medicare	White	0.147 (0.134–0.162)	5.22 (4.75–5.74)
	Black	0.353 (0.302–0.413)	4.20 (3.60–4.92)
	Hispanic/Latino	0.190 (0.152–0.237)	7.17 (5.75–8.94)
	Asian/Pacific Islander	0.022 (0.010–0.055)	3.82 (1.59–9.17)
No Insurance	White	0.012 (0.006–0.024)	0.38 (0.19–0.76)
	Black	0.018 (0.008–0.041)	0.28 (0.13–0.63)
	Hispanic/Latino	0.022 (0.015–0.033)	1.55 (1.05–2.29)
	Asian/Pacific Islander	0.005 (0.001–0.033)	0.98 (0.14–6.96)

CI: confidence interval.

Subsequently, we calculated EMU admission rates per 100 ED visits stratified on two levels, by race/ethnicity and primary payer [Table 3; Fig. 2]. Among those with private insurance, EMU admission rates for White, Hispanic/Latino, and Asian/Pacific Islanders were all significantly higher compared with Black patients (2.85 fewer admissions/100 ED visits for Black versus White patients, $p < 0.001$). For those with Medicaid, Black patients were also admitted at the lowest rate compared with all other racial/ethnic groups (2.56 fewer admissions/100 ED visits for Black versus White patients, $p < 0.001$). Among those with Medicare, Black patients were admitted at lower rates versus Hispanic/Latino patients (2.97 fewer admissions/100 ED visits for Black versus Hispanic/Latino patients, $p = 0.01$), without other significant differences seen between other groups. Finally, patients without health insurance again demonstrated much lower EMU admission rates compared to those with any insurance. This was especially pronounced for White and Black patients without insurance. White and Black patients with private insurance were admitted at rates 16.8 and 9.3 times higher, respectively, than those who lacked health insurance coverage.

4. Discussion

In this retrospective cross-sectional study of NJ hospitalizations, we examined elective EMU admission rates, a surrogate measure of specialty epilepsy care, between groups stratified by race/ethnicity and primary expected payer. With respect to our hypothesis that minority individuals have less access to the EMU than White people, these differences depended on the metric and primary payer. While Black patients were admitted at high rates for all payer categories when measured on a per capita basis, Black patients with private insurance and Medicaid demonstrated the lowest EMU admission rates relative to number of ED visits for each group. Hispanic/Latinos and Asian/Pacific Islanders were also admitted at relatively lower rates per capita to the EMU compared with White patients, depending on insurance type. Hispanic/Latino and Asian/Pacific Islanders with private insurance, Hispanic/Latinos with Medicaid, and Asian/Pacific Islanders with Medicare were admitted at low rates per capita within each respective payer category. However, significant differences were not seen in admission rates for these minority groups when compared against the number of ED visits for any payer type. Finally, patients without insurance were uniformly admitted at the lowest rates across all racial/

ethnic groups and payer categories, both per capita and per number of ED visits.

Prior studies have revealed significant Black-White disparities for several epilepsy outcome measures. Black patients undergo epilepsy surgery at lower rates and generally have poorer access to specialty epilepsy care when compared with White patients [16,20,31]. A prior study by Schiltz et al. examining California hospitalizations noted that Black people with frequent seizures had significantly lower odds of undergoing VEEG monitoring compared with White people [20]. On the other hand, we found the highest rates of elective EMU admission among Black people in NJ on a per capita basis. It is important to consider whether explanations other than disparities in access to care could drive this finding. For example, a higher prevalence of epilepsy or greater severity of disease in Black versus White people in NJ could explain higher admission rates without necessarily reflecting equal access to epilepsy care. The mismatch we noted between emergency versus specialty epilepsy care, with significantly greater utilization of the ED by Black people in NJ with Medicaid and private insurance, may corroborate this hypothesis. Studies on this are mixed; data collected from the National Health Interview Survey more than thirty years ago showed a significantly higher age-adjusted prevalence of epilepsy among Black versus White people [32]. Similar results were seen in more recent community surveys of Washington, DC and New York City [33,34]. An updated National Health Interview Survey from 2010 and 2013, however, found comparable rates of epilepsy in Black and White people [35]. If not clearly defined, differences in epilepsy prevalence and disease severity could confound any relationship between race/ethnicity and access to epilepsy care. Ongoing monitoring of epilepsy disparities should therefore utilize multiple, varied data sources to account for these factors.

Hispanic, Latino, Asian, and Pacific Islander patients also experience poorer access to epilepsy care. Schiltz et al. found that Hispanic/Latino patients with frequent seizures were less likely than White patients to receive VEEG monitoring. However, their data source did not include further classification of Asian or Pacific Islander populations [20]. Some patients belonging to these groups face additional hurdles to care due to language barriers. Betjemann et al. found that African Americans, Asian/Pacific Islanders, and those with limited English proficiency were less likely to undergo epilepsy surgery for drug-resistant seizures due to mesial temporal sclerosis, despite federal law guaranteeing language assistance services for people who do not speak English [18,36]. Future studies

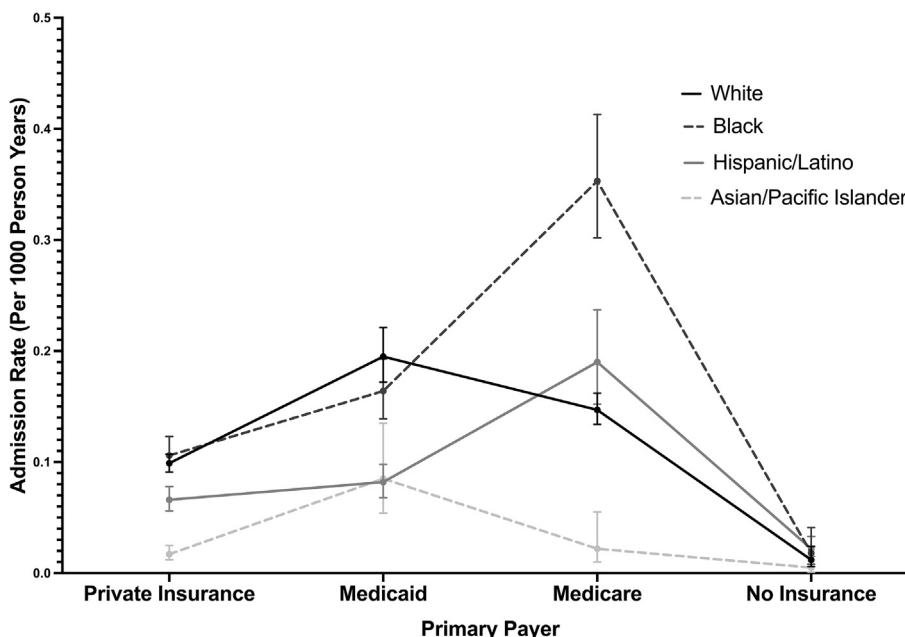


Fig. 1. Elective epilepsy monitoring unit admission rates per capita in New Jersey stratified by race/ethnicity and primary payer, 2014–2016.

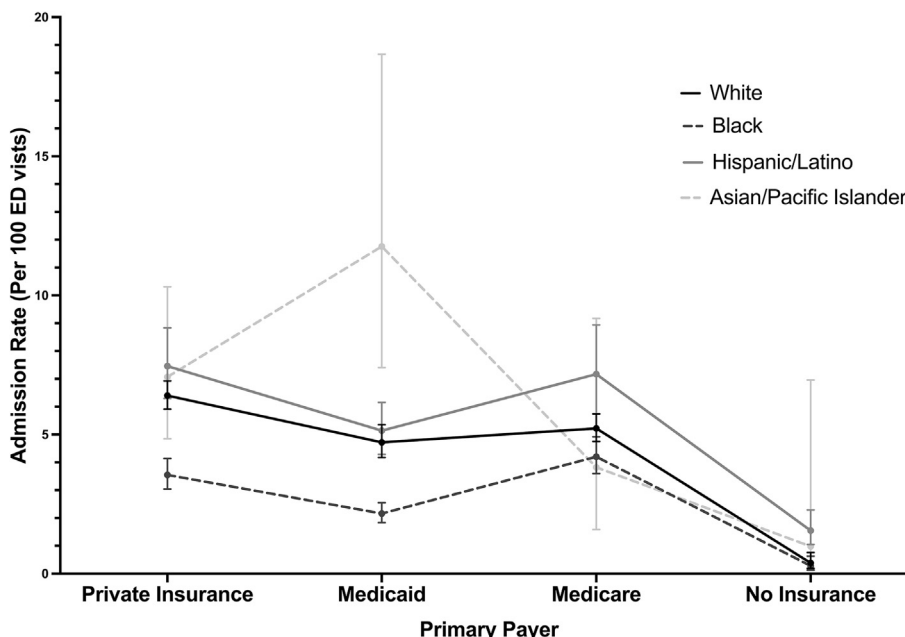


Fig. 2. Elective epilepsy monitoring unit admission rates per 100 ED visits in New Jersey stratified by race/ethnicity and primary payer, 2014–2016.

should consider a patient’s language, as well as patient-provider language mismatch, as additional factors that impact epilepsy care. Attitudes and beliefs about epilepsy among Asians also play an additional role when seeking treatment for epilepsy. Chung et al. surveyed Chinese and Vietnamese adults in the US and found that a significant number of participants held negative or discriminatory views toward people with epilepsy [37]. Other factors influencing the ability of patients of color to access epilepsy care, such as proximity and ability to travel to an epilepsy center, should also be considered [20,23]. While transportation barriers certainly do exist for people with epilepsy in NJ, however, most residents are located within a 1–1.5-h drive from an epilepsy center, located in

both urban and suburban regions [38]. It would be interesting to contrast access to epilepsy care between NJ and states with populations located at much further distances from an epilepsy center. Implicit racial bias, where an individual’s attitudes and beliefs unconsciously influence clinical judgment, could also impact the care of people with color with epilepsy, though would be difficult to measure its effects [39–41]. Lastly, there is a significant dearth of health services research on access to and utilization of care among Asian Americans with epilepsy, making it difficult to draw specific conclusions from our findings. More studies describing and addressing disparities in access to epilepsy care among people of color are clearly needed.

While our finding that NJ residents without health insurance experienced reduced access to epilepsy care is not unexpected, this nonetheless deserves attention. As adults with epilepsy are less likely to be employed, more likely to be disabled, and more likely to be insured under public payer plans, it is critical to understand utilization of care for these populations [22]. As previously discussed, health insurance coverage in the US is not universal, and elective EMU admissions typically require guarantee of payment prior to proceeding. Given the high costs of inpatient hospitalization in the US, this service is effectively out of reach of nearly all people without health insurance. Our results suggest that charity care programs are insufficient for ensuring that uninsured people receive inpatient EMU admission, a service that influences treatment plans to help prevent seizure-related morbidity/mortality [8,9]. New Jersey provides substantial funding for charity care, so the gaps we observed may be even greater in states with less generous programs. Our findings echo prior studies showing that patients with epilepsy without healthcare coverage have demonstrably worse outcomes, including limited access to an epilepsy provider and less treatment with antiseizure medications [19,42]. In addition to those without insurance, patients with public insurance plans may receive differential epilepsy treatment compared to those with private insurance. For example, Englot et al. found that privately insured individuals were more likely to receive epilepsy surgery for drug-resistant epilepsy than those with Medicaid or Medicare [15]. However, these findings may differ by the type of healthcare service rendered. Halpern and colleagues found that people with Medicaid had similar rates of outpatient neurologist visits as those with private insurance [21].

Although our examination of all hospitalizations statewide was a strength of our study, other aspects of the HCUP databases present notable limitations. Again, if differences exist in the prevalence or severity of epilepsy between racial/ethnic groups in NJ, equal rates of elective VEEG monitoring may not necessarily reflect equal access to care. We lack data on the prevalence of epilepsy or the need for specialty epilepsy care in NJ. We thus had to use the blunter measures of admission rate per capita and per number of ED visits, instead of per individual with overall or drug-resistant epilepsy. Population-based measures of inpatient utilization by payer should especially be considered with caution, as hospitals routinely seek to enroll uninsured patients in coverage for which they may be eligible upon admission. Furthermore, information regarding the severity of epilepsy, including the frequency of seizures or the number of antiseizure medications used, are not available in the HCUP databases. We were also unable to track or confirm patient access to outpatient neurology or epilepsy care. Additionally, NJ is situated between two large cities, New York, NY and Philadelphia, PA, which both have multiple comprehensive epilepsy centers for which inpatient admissions would not be recorded in the NJ HCUP databases. New Jersey residents with epilepsy with the ability and means to seek care at these centers are not represented in our study, which may lead to biased population-based admission rates. The number of NJ residents who seek care at centers outside of the state is currently unknown but likely includes those with greater affluence and ability to travel. Finally, we were unable to study American Indian or Alaska Native populations, primarily due to limited admission numbers of patients from these groups. This is a major limitation, especially given that detailed information on access to care for indigenous people is lacking in the epilepsy literature.

In conclusion, there appear to be substantial inequities in access to specialty epilepsy care in NJ. People who lack health insurance face serious challenges in receiving these services, consistent with low rates of elective EMU admission that we observed in our study. Our findings also suggest that there is inequitable access to care for patients from racial/ethnic minority groups, depending on the pri-

mary payer. While it is important for neurologists to continue to advocate for access to care for all people with epilepsy, less clear is how we can intervene on an individual basis to address these disparities. Lasting solutions for people with epilepsy who are uninsured or underinsured, especially those from minority racial/ethnic groups historically underserved by the healthcare system, will ultimately require addressing systemic barriers to care by increasing coverage for the uninsured, ensuring the adequacy of provider networks, and increasing reimbursement rates for charity care and publicly insured patients.

Funding

This work was supported by research grants to Dr. Kamitaki from the American Epilepsy Society and the New Jersey Health Foundation.

Declaration of Competing Interest

Dr. Zhang has received honorariums from Lundbeck Biopharmaceuticals, Board Vitals, and Fieve Clinical Research. He collaborates with Headache Science Incorporated without receiving financial support. He has ownership interest in Cymbeline LLC.

The other authors do not have competing interests to declare.

References

- [1] Zack MM, Kobau R. National and State Estimates of the Numbers of Adults and Children with Active Epilepsy – United States, 2015. *MMWR Morb Mortal Wkly Rep* 2017;66(31):821–5.
- [2] Kalilani L, Sun X, Pelgrims B, Noack-Rink M, Villanueva V. The epidemiology of drug-resistant epilepsy: A systematic review and meta-analysis. *Epilepsia* 2018;59(12):2179–93.
- [3] Sultana B, Panzini M-A, Veilleux Carpentier A, Comtois J, Rioux B, Gore G, et al. Incidence and prevalence of drug-resistant epilepsy: A systematic review and meta-analysis. *Neurology* 2021;96(17):805–17.
- [4] Chen Z, Brodie MJ, Liew D, Kwan P. Treatment outcomes in patients with newly diagnosed epilepsy treated with established and new antiepileptic drugs: A 30-year longitudinal cohort study. *JAMA Neurol* 2018;75:279–86.
- [5] Patel AD, Baca C, Franklin G, Herman ST, Hughes I, Meunier L, et al. Quality improvement in neurology: Epilepsy Quality Measurement Set 2017 update. *Neurology* 2018;91(18):829–36.
- [6] Reuber M, Fernandez G, Bauer J, Helmstaedter C, Elger CE. Diagnostic delay in psychogenic nonepileptic seizures. *Neurology* 2002;58(3):493–5.
- [7] Labiner DM, Bagic AI, Herman ST, Fountain NB, Walczak TS, Gumnit RJ. Essential services, personnel, and facilities in specialized epilepsy centers—revised 2010 guidelines. *Epilepsia* 2010;51:2322–33.
- [8] Ghougassian DF, D'Souza W, Cook MJ, O'Brien TJ. Evaluating the utility of inpatient video-EEG monitoring. *Epilepsia* 2004;45(8):928–32.
- [9] Kumar-Pelayo M, Oller-Cramsie M, Mihu N, Harden C. Utility of video-EEG monitoring in a tertiary care epilepsy center. *Epilepsy Behav* 2013;28(3):501–3.
- [10] LaFontaine PS, Daryl S. United States Healthcare System. In: ISPOR—The Professional Society for Health Economics and Outcomes Research; 2021.
- [11] Himmelstein DU, Thorne D, Warren E, Woolhandler S. Medical bankruptcy in the United States, 2007: results of a national study. *Am J Med* 2009;122(8):741–6.
- [12] Malina D, Bailey ZD, Feldman JM, Bassett MT. How structural racism works - Racist policies as a root cause of U.S. Racial Health Inequities. *N Engl J Med* 2021;384(8):768–73.
- [13] Braveman PA, Arkin E, Proctor D, Kauh T, Holm N. Systemic and structural racism: definitions, examples, health damages, and approaches to dismantling. *Health Aff (Millwood)* 2022;41(2):171–8.
- [14] Yearby R, Clark B, Figueroa JF. Structural racism in historical and modern US Health Care Policy. *Health Aff (Millwood)* 2022;41(2):187–94.
- [15] Englot DJ, Ouyang D, Garcia PA, Barbaro NM, Chang EF. Epilepsy surgery trends in the United States, 1990–2008. *Neurology* 2012;78(16):1200–6.
- [16] McClelland S, Guo H, Okuyemi KS. Racial disparities in the surgical management of intractable temporal lobe epilepsy in the United States: A population-based analysis. *Arch Neurol* 2010;67(5):577–83.
- [17] Burneo JG, Black L, Knowlton RC, Faught E, Morawetz R, Kuzniecky RI. Racial disparities in the use of surgical treatment for intractable temporal lobe epilepsy. *Neurology* 2005;64(1):50–4.
- [18] Betjemann JP, Thompson AC, Santos-Sánchez C, Garcia PA, Ivey SL. Distinguishing language and race disparities in epilepsy surgery. *Epilepsy Behav* 2013;28(3):444–9.

- [19] Szaflarski M, Wolfe JD, Tobias JGS, Mohamed I, Szaflarski JP. Poverty, insurance, and region as predictors of epilepsy treatment among US adults. *Epilepsy Behav* 2020;107:107050.
- [20] Schiltz NK, Koroukian SM, Singer ME, Love TE, Kaiboriboon K. Disparities in access to specialized epilepsy care. *Epilepsy Res* 2013;107(1-2):172–80.
- [21] Halpern MT, Renaud JM, Vickrey BG. Impact of insurance status on access to care and out-of-pocket costs for U.S. individuals with epilepsy. *Epilepsy Behav* 2011;22(3):483–9.
- [22] Thurman DJ, Kobau R, Luo Y-H, Helters SL, Zack MM. Health-care access among adults with epilepsy: The U.S. National Health Interview Survey, 2010 and 2013. *Epilepsy Behav* 2016;55:184–8.
- [23] Welty TE, Willis SL, Welty EA. Effect of limited transportation on medication adherence in patients with epilepsy. *J Am Pharm Assoc* (2003) 2010;50:698–703.
- [24] Sundelin HEK, Chang Z, Larsson H, Lichtenstein P, Almqvist C, Tomson T, et al. Epilepsy, antiepileptic drugs, and serious transport accidents: A nationwide cohort study. *Neurology* 2018;90(13):e1111–8.
- [25] Kamitaki BK, Rishty S, Mani R, Wong S, Bateman LM, Thomas-Hawkins C, et al. Using ICD-10 codes to identify elective epilepsy monitoring unit admissions from administrative billing data: A validation study. *Epilepsy Behav* 2020;111:107194.
- [26] Agency for Healthcare Research and Quality. Central Distributor SID: description of data elements. Race (all states). Available at: <https://www.hcup-us.ahrq.gov/db/vars/siddistnote.jsp?var=race>. Accessed August 21, 2022.
- [27] Agency for Healthcare Research and Quality. Central Distributor SEDD: description of data elements. Race (all states). Available at: <https://www.hcup-us.ahrq.gov/db/vars/seddnote.jsp?var=race>. Accessed August 21, 2022.
- [28] An Examination of Expected Payer Coding in HCUP Databases. Available at: <http://www.hcup-us.ahrq.gov/reports/methods/methods.jsp>. Accessed.
- [29] United States Census Bureau. Available at: <https://data.census.gov/cedsci/>. Accessed June 1, 2022.
- [30] KFF's State Health Facts. Data source: 2008–2019 American Community Survey, 1-Year Estimates. Available at: <https://www.kff.org/statedata/>. Accessed June 1, 2022.
- [31] Begley CE, Basu R, Reynolds T, Lairson DR, Dubinsky S, Newmark M, et al. Sociodemographic disparities in epilepsy care: Results from the Houston/New York City health care use and outcomes study. *Epilepsia* 2009;50:1040–50.
- [32] Prevalence of self-reported epilepsy—United States, 1986–1990. *MMWR Morb Mortal Wkly Rep* 1994;43: 810–11, 817–18.
- [33] Kroner BL, Fahimi M, Kenyon A, Thurman DJ, Gaillard WD. Racial and socioeconomic disparities in epilepsy in the District of Columbia. *Epilepsy Res* 2013;103(2-3):279–87.
- [34] Kelvin EA, Hesdorffer DC, Bagiella E, Andrews H, Pedley TA, Shih TT, et al. Prevalence of self-reported epilepsy in a multiracial and multiethnic community in New York City. *Epilepsy Res* 2007;77(2-3):141–50.
- [35] QuickStats: Age-adjusted percentages of adults aged ≥18 years who have epilepsy, by Epilepsy Status and Race/Ethnicity - National Health Interview Survey, United States, 2010 and 2013 Combined. *MMWR Morb Mortal Wkly Rep* 2016;65:611.
- [36] Youdelman MK. The medical tongue: U.S. laws and policies on language access. *Health Aff (Millwood)* 2008;27(2):424–33.
- [37] Chung K, Ivey SL, Guo W, Chung K, Nguyen C, Nguyen C, et al. Knowledge, attitudes, and practice toward epilepsy (KAPE): a survey of Chinese and Vietnamese adults in the United States. *Epilepsy Behav* 2010;17(2):221–7.
- [38] National Association of Epilepsy Centers. Find an epilepsy center. Available at: <https://www.naec-epilepsy.org/about-epilepsy-centers/find-an-epilepsy-center/?state=New+Jersey>. Accessed August 21, 2022.
- [39] Williams DR, Wyatt R. Racial Bias in Health Care and Health: Challenges and Opportunities. *JAMA* 2015;314:555–6.
- [40] Sabin JA. Tackling implicit bias in health care. *N Engl J Med* 2022;387(2):105–7.
- [41] Marulanda-Londoño ET, Bell MW, Hope OA, Leacock RO, O'Carroll CB, Posas J, et al. Reducing neurodisparity: Recommendations of the 2017 AAN Diversity Leadership Program. *Neurology* 2019;92(6):274–80.
- [42] Elliott JO, Lu B, Shneker BF, Moore JL, McAuley JW. The impact of 'social determinants of health' on epilepsy prevalence and reported medication use. *Epilepsy Res* 2009;84(2-3):135–45.