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RESEARCH ARTICLE

Frequent seizure and epilepsy-related emergency department visits in the United States: A retrospective cohort study

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Abstract

Objectives: Health disparities impact access to epilepsy care in the United States, but how these factors contribute to recurrent emergency department (ED) visits is unclear. We hypothesized that people who (1) were uninsured or had public health insurance, (2) belonged to minoritized racial/ethnic groups, or (3) resided in low-income zip codes were more likely to have frequent ED visits for seizure or epilepsy.

Methods: This was a retrospective cohort study of adult patients presenting to the ED in four U.S. states (Florida, Maryland, New York, and Wisconsin) with a primary diagnosis of seizure or epilepsy. We tracked ED visits for each patient longitudinally between 2016 and 2018. We performed a multivariable logistic regression analysis evaluating the association of the above factors with a high (>2) vs low (1–2) number of ED visits.

Results: We identified 200 962 patients who visited the ED for seizure/epilepsy, of whom 28 598 (14.7%) presented 2 times during the study period. Compared to private insurance, individuals with Medicare (adjusted odds ratio [aOR] 1.90, 95% confidence interval [CI]: 1.82–1.99), Medicaid (aOR 2.01, 95% CI: 1.93–2.09), or no insurance (aOR 1.55, 95% CI: 1.48–1.62) had increased odds of high ED visits. Black patients had a 60% higher odds of frequent ED visits compared with White patients (aOR 1.60, 95% CI: 1.55–1.65). However, these disparities were attenuated for Black patients with Medicare and Medicaid, vs private insurance. High ED use was not seen in other racial/ethnic groups. Finally, patients living in low-income zip codes (0–25th percentile of median household income; aOR 1.65, 95% CI: 1.58–1.73) were more likely to be in the high ED visit group, compared with the highest income quartile.

Significance: Racial/ethnic and socioeconomic inequities likely contribute to frequent ED visits for seizures, as evidenced by our findings from four U.S. states.

Effective, multi-level interventions are needed to reduce disparities for those most affected.

KEYWORDS
disparities, health care utilization, health services research, social determinants of health

1 | INTRODUCTION

Seizure-related emergency department (ED) visits account for ~1% of all ED presentations in the United States.[1,2] Although often necessary, these visits disrupt daily life for people with epilepsy, compounding challenges related to employment, personal responsibilities, and overall well-being.[3] Breakthrough seizures impose additional economic, social, and emotional burdens on patients and caregivers.[4,5] It is important to note that seizure freedom has been identified as the primary determinant of improved health-related quality of life in one study, reinforcing the need for effective and equitable epilepsy care.[6,7]

Prior research has identified several barriers—including lack of health insurance, public insurance coverage, poverty, and a higher burden of comorbidities—that contribute to inconsistent outpatient epilepsy care. For example, patients covered under public insurance plans are less likely to receive specialized epilepsy care,[8] whereas those without health insurance are less likely to see a neurologist altogether.[9,10] In addition, racial and ethnic minoritized groups and people living in low-income areas face additional systemic barriers when accessing specialized surgical and neurostimulation therapies.[8,11–14] Lack of access to a neurologist and increased poverty correlate with frequent all-cause ED visits among people with epilepsy insured under Medicaid.[15] In fact, the majority of people with epilepsy with a seizure-related hospitalization have at least one acute care visit within the year, with a median of two visits.[16] Thus, understanding ways that social determinants of health contribute to frequent seizure-related ED visits across a broad population of adults will be essential for designing targeted interventions to improve outcomes.

This study aims to examine the association between insurance coverage, socioeconomic status, race/ethnicity, and frequent ED visits for seizure/epilepsy in four U.S. states. We hypothesized that individuals who are uninsured, have public insurance, belong to minoritized racial/ethnic groups, or live in low-income areas are more likely to have frequent ED visits for seizures. By identifying these disparities, our findings may help to inform actionable, targeted policies that improve access to outpatient epilepsy care and reduce unnecessary ED utilization.

Key points

- Frequent seizure-related emergency department (ED) visits are associated with lack of insurance or public insurance, although public coverage may reduce racial gaps.
- Black patients have a 60% higher odds of frequent ED visits compared to White patients, highlighting persistent disparities.
- Residence in low-income zip codes is associated with higher ED utilization for seizures or epilepsy.
- Uninsured rates among people with epilepsy were significantly higher in Florida than in Maryland, New York, or Wisconsin.

2 | MATERIALS AND METHODS

2.1 | Study design and setting

This retrospective cohort study was reviewed and approved by the Rutgers University Institutional Review Board. We analyzed data from the Healthcare Cost and Utilization Project (HCUP) State Emergency Department Database (SEDD) and State Inpatient Database (SID) for Florida (FL), Maryland (MD), New York (NY), and Wisconsin (WI) over a 3-year period, from January 1, 2016, through December 31, 2018. These databases include information on all ED discharges that do not result in hospitalization (SEDD) and all inpatient discharges (SID), regardless of payer, from all non-federal short-term acute care hospitals in each state. Each unit of analysis in the SEDD/SID is an inpatient discharge record; however, individual patients can be tracked longitudinally within a state using the VisitLink identifier. For this study, we applied the RECORD statement for observational studies using routinely collected health data.[17]

2.2 | Participants

Eligibility criteria for this study included all adult patients (age ≥18 years), identified by their unique VisitLink number, with one or more seizure-related ED visits during the 3-year study period. We defined a seizure-related ED visit as either (1) a treat-and-release ED visit or (2) an ED visit leading to inpatient hospitalization. We defined a treat-and-release ED visit as any HCUP SEDD record with a primary (I10_Dx1) International Classification of Diseases, 10th Revision (ICD-10), diagnosis of seizure (R56.x) or epilepsy (G40.xxx). We considered an ED visit leading to inpatient hospitalization as any record in the HCUP SID with a primary (I10_Dx1) or admitting (I10_Dx_Admitting) ICD-10 diagnosis of seizure (R56.x) or epilepsy (G40.xxx) and ATYPE = 1, which identifies the admission as originating from the ED. These definitions followed published standards for epilepsy and seizure visit coding.[18]

2.3 | Variables/measurement

The primary outcome variable of interest is the number of seizure-related ED visits for each patient over the 3-year study period. Initial analysis determined that patients with more than two seizure-related ED visits during this time represented the top 15% of ED utilization. We thus classified patients into either "high" ED visit count (>2 seizure-related ED visits) or "low" ED visit count (1–2 seizure-related ED visits) groups.

Predictor variables of interest include patient race/ethnicity (White, Black, Hispanic or Latino, Asian or Pacific Islander, Native American, or other), primary expected payer (Medicare, Medicaid, private insurance, no insurance, or other), and median household income by national quartile classification for patient zip code (0–25th percentile, 26–50th percentile, 51–75th percentile, or 76–100th percentile). We also collected information on potential confounding variables, including age in years, sex (female or male), U.S. state of hospital (FL, MD, NY, or WI), National Center for Health Statistics (NCHS) urban–rural classification scheme,[19] refractory epilepsy ICD-10 diagnosis code (I10_Dx1 = refractory epilepsy, G40.x1x, for at least one admission), and Elixhauser comorbidity index, a measure of comorbid medical conditions.[20] For patients with multiple ED visits, we used demographic information from their first presentation. There was a low proportion of missing data, which we excluded from analysis using a complete-case approach.

2.4 | Statistical methods

We calculated descriptive statistics, including frequencies and percentages for categorical variables and means with standard deviations (SDs) for continuous variables. We compared the high (>2) vs low (1–2) ED visit groups using the chi-square test for categorical and the *t* test for continuous variables. We calculated unadjusted odds ratios (ORs) with 95% confidence intervals (CIs) to determine whether each variable of interest (race/ethnicity, primary expected payer, and median household income by zip code) was associated with the high vs low ED visit groups using binary logistic regression. We performed multivariable logistic regression to evaluate associations between high ED visits (>2), insurance type, race/ethnicity, and income quartile while adjusting for age, sex, U.S. state of hospital, refractory epilepsy diagnosis, Elixhauser comorbiditiy index, and urban–rural location. We obtained adjusted ORs (aORs) for predictors and co-variables using this model. Sensitivity analysis using Poisson regression yielded similar effect sizes. U.S. state of hospital was included as a fixed effect given the low number of states, as well as to account for state-level variations in health care policies and practices. To address potential effect modification, we tested two-way interactions between insurance type and race, as well as insurance type and income quartile, given prior evidence of socioeconomic-racial disparities in access to epilepsy care. We also explored a three-way interaction (insurance × income × race).

3 | RESULTS

Between January 1, 2016, and December 31, 2018, a total of 200 962 people presented at least once to the ED for seizure or epilepsy in FL, MD, NY, and WI. Of these, 28 598 (14.2%) presented more than 2 times over the study period, which comprised the high ED visit count group. A total of 11 453 patients (5.7%) presented five or more times. The low ED visit count group (1–2 ED visits) totaled 172 364 people (85.8%). Most patients presented in FL (45.3%), followed by NY (31.1%), MD (13.4%), and WI (10.3%) (Table 1). Detailed demographics, including frequencies of variables among all patients and high vs low ED visit count groups, are available in Table 1.

Compared to privately insured patients, those with Medicaid (aOR 2.08, 95% CI: 2.00–2.16), Medicare (aOR 1.91, 95% CI: 1.83–2.00), and no insurance (aOR 1.49, 95% CI: 1.42–1.56) had higher odds of frequent ED visits (Table 2). Black patients were also overrepresented in the high ED visit group, compared with White patients (aOR 1.63, 95% CI: 1.58–1.69) (Table 2). None of the other racially or ethnically minoritized groups were more likely than White patients to be in the high ED visit group. In fact, the Asian or Pacific Islander group was less likely than White patients to present frequently to the ED (Table 2). Native Americans represented a small proportion of the cohort (0.3%). Finally, those living in low-income zip codes were

TABLE 1 Demographics of patients presenting to the emergency department for seizure/epilepsy in four U.S. states (FL, MD, NY, and WI), 2016–2018.

Categories	Overall *N*	Low (1–2) ED visits for seizure/epilepsy *N* (%)	High (>2) ED visits for seizure/epilepsy *N* (%)
Total	200 962	172 364 (85.8)	28 598 (14.2)
Age in years, mean (SD)	46.3 (19.3)	47.1 (19.6)	41.5 (16.3)
Sex			
Female	95 429	82 248 (86.2)	13 181 (13.8)
Male	105 533	90 116 (85.4)	15 417 (14.6)
Race/ethnicity			
Hispanic or Latino	22 147	19 078 (86.1)	3069 (13.8)
White	117 120	102 959 (87.9)	14 161 (12.1)
Black	48 815	38 798 (79.5)	10 017 (20.5)
Asian or Pacific Islander	2300	2115 (92.0)	185 (8.0)
Native American	645	549 (85.1)	96 (14.9)
Other	8922	7942 (89.0)	980 (11.0)
Missing	1013	923 (91.1)	90 (8.9)
Hospital state			
FL	90 973	76 760 (84.4)	14 213 (15.6)
MD	26 909	23 151 (86.0)	3758 (14.0)
NY	62 413	54 404 (87.2)	8009 (12.8)
WI	20 667	18 049 (87.3)	2618 (12.7)
Primary expected payer			
Medicare	62 822	55 263 (88.0)	7559 (12.0)
Medicaid	53 714	42 991 (80.0)	10 723 (20.0)
Private insurance	48 526	43 843 (90.3)	4683 (9.7)
No insurance	28 551	23 895 (83.7)	4656 (16.3)
Other	7228	6261 (86.6)	967 (13.4)
Missing	121	111 (91.7)	10 (8.3)
Median household income by national quartile for zip code			
0–25th percentile	64 637	53 123 (82.2)	11 514 (17.8)
26–50th percentile	54 661	47 020 (86.0)	7641 (14.0)
51–75th percentile	43 244	37 955 (87.8)	5289 (12.2)
76–100th percentile	34 539	31 061 (89.9)	3478 (10.1)
Missing	3881 (1.9)	3205 (82.6)	676 (17.4)
Location by NCHS urban–rural code			
"Central" counties of metro areas of ≥1 million	70 459	59 747 (84.8)	10 712 (15.2)
"Fringe" counties of metro areas of ≥1 million	58 959	51 067 (86.6)	7892 (13.4)
Counties in metro areas of 250 000–999 999	37 944	32 377 (85.3)	5567 (14.7)
Counties in metro areas of 50 000–249 999	14 846	12 958 (87.3)	1888 (12.7)
Micropolitan counties	10 314	8937 (86.6)	1377 (13.4)
Not metropolitan or micropolitan counties	6557	5745 (87.6)	812 (12.4)
Missing	1883	1533 (81.4)	350 (18.6)
Mean Elixhauser comorbidity index (SD)	2.18 (3.59)	2.21 (3.62)	1.99 (3.39)
Refractory epilepsy diagnosis code	1657 (0.8)	1349 (81.4)	308 (18.6)

Abbreviations: ED, emergency department; FL, Florida; MD, Maryland; NCHS, National Center for Health Statistics; N, number; NY, New York; SD, standard deviation; U.S., United States; WI, Wisconsin.

more likely to belong to the high ED visit group. This occurred in a graded fashion, with the highest ED utilization occurring among the 0–25th percentile (aOR 1.49, 95% CI: 1.42–1.56), followed by the 26–50th percentile (aOR 1.28, 95% CI: 1.22–1.35) income group (Table 2).

TABLE 2 Logistic regression model examining factors associated with high vs low number of emergency department visits for seizure/epilepsy in four U.S. states (FL, MD, NY, WI), 2016–2018.

Categories	Unadjusted odds ratio (95% CI)	Adjusted odds ratio[a] (95% CI)
Race/ethnicity		
Hispanic or Latino	1.17 (1.12–1.22)	1.0 (0.96–1.05)
White	1.00	1.00
Black	1.88 (1.83–1.93)	1.63 (1.58–1.69)
Asian or Pacific Islander	0.64 (0.54–0.74)	0.66 (0.57–0.77)
Native American	1.27 (1.02–1.57)	1.21 (0.96–1.50)
Other	0.90 (0.84–0.96)	0.86 (0.80–.0.92)
Primary expected payer		
Medicare	1.28 (1.23–1.33)	1.91 (1.83–2.00)
Medicaid	2.34 (2.25–2.42)	2.08 (2.00–2.16)
Private insurance	1.00	1.00
No Insurance	1.82 (1.75–1.91)	1.49 (1.42–1.56)
Other	1.45 (1.34–1.56)	1.37 (1.27–1.48)
Median household income by national quartile for zip code		
0–25th percentile	1.94 (1.86–2.02)	1.49 (1.42–1.56)
26–50th percentile	1.45 (1.39–1.51)	1.28 (1.22–1.35)
51–75th percentile	1.24 (1.19–1.3)	1.15 (1.1–1.21)
76–100th percentile	1.00	1.00

Abbreviations: 95% CI, 95% confidence interval; FL, Florida; MD, Maryland; NCHS, National Center for Health Statistics; NY, New York; U.S., United States; WI, Wisconsin.

[a] Adjusted for age, sex, race/ethnicity, primary expected payer, median household income by zip code, U.S. state, location by NCHS urban–rural code, Elixhauser comorbidity score, and refractory epilepsy diagnosis code.

When examining effect modification between race, insurance type, and income, we found that racial disparities were most pronounced among Black patients with private insurance (Black vs White: aOR 1.83, 95% CI: 1.70–1.98). However, these disparities were lessened for Black patients with Medicare (aOR 0.84, 95% CI: 0.77–0.93; $p<.001$), as well as Black patients with Medicaid (aOR 0.88, 95% CI: 0.80–0.96; $p<.001$), compared with private insurance. Being uninsured and living in low-income zip codes compounded the risk for frequent ED visits (aOR 1.22, 95% CI: 1.04–1.43; $p=.02$). The three-way interaction between insurance type, race, and income was not statistically significant.

Patients hospitalized in FL were more likely than those in MD (aOR 0.85, 95% CI: 0.81–0.88), NY (aOR 0.78, 95% CI: 0.75–0.80), or WI (aOR 0.79, 95% CI: 0.79–0.83) to belong to the high ED visit group, after adjusting for other factors. We stratified patients in the high and low ED visit groups by state of hospitalization and expected primary payer, as displayed in Table 3. Patients without insurance in FL made up a much higher proportion of the high ED visit group and 25.5% of the high ED visit group in FL, compared with every other state (MD: 6.3%, NY: 7.4%, and WI: 7.8%) ($p<.01$). On the other hand, patients insured under Medicaid included 45.5% of the high ED visit group in MD, 49.1% in NY, and 40.2% in WI, but a significantly lower proportion, 28.4%, of the FL high ED visit group ($p<.01$). Medicare, private, and other insurance categories were relatively similar between states.

4 | DISCUSSION

Our analysis of community hospitalizations across four U.S. states from 2016 to 2018 highlights significant disparities in the frequency of breakthrough seizures that required emergency care. Patients with public insurance (Medicare or Medicaid), uninsured individuals, Black patients, and those living in lower-income areas were disproportionately represented in the high ED visit group (>2 visits). For example, Black patients comprised

TABLE 3 Insurance payer distribution (%) among high (1–2) and low (≤2) ED visit groups by state, 2016–2018.

	Florida		Maryland		New York		Wisconsin	
Payer	High visits	Low visits	High visits	Low visits	High visits	Low visits	High visits	Low visits
Medicare	26.0%	34.3%	26.6%	31.7%	26.0%	28.5%	30.0%	33.7%
Medicaid	28.4%	17.1%	45.5%	28.6%	49.1%	33.9%	40.2%	26.6%
Private	15.9%	23.5%	18.7%	27.8%	14.9%	25.9%	19.9%	29.1%
Uninsured	25.5%	20.4%	6.3%	8.0%	7.4%	9.1%	7.8%	7.8%
Other	4.2%	4.6%	2.9%	3.8%	2.6%	2.5%	2.1%	2.6%

35.0% of the high ED visit group, compared to 24.3% of the overall sample. Our findings validated prior research showing that systemic barriers, including lack of insurance, poverty, and racial inequities, contribute to disparities in access to epilepsy care. Nearly half of high ED visit patients were from FL, where between 20% and 25% of patients belonging to both high and low ED visit groups were uninsured.

Although the HCUP databases provide comprehensive statewide data, several limitations must be acknowledged. First, the administrative nature of the data may result in inaccuracies in demographic, diagnosis, or procedure coding.[21] For instance, we were unable to determine the underlying causes of breakthrough seizures (e.g., substance use vs drug-resistant epilepsy) or account for changes in patient characteristics, such as insurance payer or zip code, over time. We were also unable to control for clinical epilepsy characteristics, such as seizure type, severity, or medication regimen, which could confound the observed associations. In addition, misclassification of race/ethnicity in HCUP data, particularly for Hispanic/Latino, Asian or Pacific Islander, and Native American patients, may underestimate disparities among these groups.[22] Loss-to-follow-up or premature death may act as competing risks, potentially leading to an underestimation of repeat ED visit rates. Our data did not capture out of hospital deaths. We did not separately examine Medicare–Medicaid dual enrollees, who are known to have more chronic conditions and poorer health outcomes and may partly explain the association between Medicare and frequent ED visits.[23] Finally, our restriction to individuals with at least one ED visit introduces potential collider stratification bias. Shared factors, for example, epilepsy severity or poor access to care, that increase both initial and recurrent ED visits could distort associations between hypothesized predictors and the outcome. This further limits our ability to draw conclusions about the broader population of people with epilepsy who never presented to the hospital during the study period.

Prior work has demonstrated that racially minoritized patients, especially Black people, and those with insurance barriers experience difficulties in accessing epilepsy specialists and undergoing surgical evaluation when appropriate.[11–13,24,25] Poverty and lack of English proficiency further exacerbate challenges in receiving care by creating a vicious cycle in which restricted access to outpatient care leads to frequent ED visits and worsened health inequities.[14,26] Indeed, we found that poverty amplifies ED use most for people with epilepsy who are uninsured. Routine outpatient care is significantly more cost-effective than emergency visits. Therefore, U.S. policymakers should focus on expanding access to insurance, rather than reducing it. Furthermore, interaction analyses in our study showed that public insurance with Medicaid or Medicare resulted in reduced disparities in ED use for Black patients with epilepsy.

Prompt referral to epilepsy centers and improved outpatient neurology access are key measures that can reduce unnecessary ED visits for drug-resistant epilepsy.[27] Epilepsy centers offer advanced diagnostic testing, medical and surgical therapies, caregiver education, psychosocial support, and multidisciplinary care, all of which can significantly improve seizure control.[28,29] Systemic inequities, such as racial disparities, insurance barriers, and poverty continue to limit access to these critical services, on top of increasing ED utilization.[11–13,24,25] First, we need a clear understanding of regional referral patterns and better ways to direct patients to the level of neurological care they need, rather than what they can afford or what is available. Expanding access to tele-neurology could help bridge geographical gaps and improve care for people living distant from epilepsy centers, which can include outpatient or inpatient consultations, video-EEG (electroencephalography) monitoring, and neuroimaging.[30] Tele-mentoring and online webinars, if employed on a wider scale, can successfully educate primary care providers on important epilepsy topics, thereby improving overall patient care, communication, and patient triaging.[31]

Although not a part of the initial hypothesis, notable between-state differences emerged from our analysis. Nearly half of all patients in the high ED visit group were from FL. Moreover, a high proportion of the high ED visit group in FL were uninsured, whereas more were covered by Medicaid in other states (Table 3). This could be explained by the state's decision not to expand Medicaid under the Affordable Care Act, resulting in higher numbers of uninsured Floridians paying out-of-pocket for care or accruing medical debt.[32] In contrast, states that expanded Medicaid appreciated improved outpatient care, better health outcomes, and better diagnosis of chronic conditions.[33,34] Our findings underscore the impact of state-level policy decisions on health care utilization patterns and outcomes, particularly for low-income individuals with epilepsy.[35] State and national policy reform, improved health care coverage, and economic stability measures are essential to reduce disparities in epilepsy care and ED utilization.[36,37] Eliminating deeply rooted factors such as poverty, health care costs, and systemic racism requires comprehensive, multisectoral approaches far beyond the scope of health care providers alone. Even so, clinicians and researchers can play a crucial role by advocating for their patients, engaging policymakers, and providing resources and evidence-based strategies to address these systemic challenges.

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CONFLICT OF INTEREST STATEMENT

None of the authors has any conflict of interest to disclose. We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from Healthcare Cost and Utilization Project. Restrictions apply to the availability of these data, which were used under license for this study. Data are available from https://hcup-us.ahrq.gov with the permission of the Healthcare Cost and Utilization Project.

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