



Health insurance and transportation barriers impact access to epilepsy care in the United States

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ARTICLE INFO

Keywords:

Health services research
Motor vehicle
Seizure
Driving
Neurological care

ABSTRACT

Purpose: Inconsistent access to healthcare for people with epilepsy results in reduced adherence to antiseizure medications, increased seizure frequency, and fewer appropriate referrals for epilepsy surgery. Identifying and addressing factors that impede access to care should consequently improve patient outcomes. We hypothesized that health insurance and transportation affect access to outpatient neurology care for adults living with epilepsy in the United States (US).

Methods: We conducted a retrospective cross-sectional study of US adults with active epilepsy surveyed via the National Health Interview Survey (NHIS) in 2015 and 2017. We established whether patients reported seeing a neurologist in the past year and used multiple logistic regression to determine whether health insurance status and transportation access were associated with this outcome.

Results: We identified 735 respondents from 2015 and 2017, representing an estimated 2.98 million US adults with active epilepsy. After adjusting for socioeconomic and seizure-related co-variables, we found that a lack of health insurance coverage was associated with no epilepsy care in the past year (adjusted odds ratio [aOR] 0.22; 95 % confidence interval [CI]: 0.09 – 0.54). Delayed care due to inadequate transportation (aOR 0.42; 95 % CI: 0.19 – 0.93) also resulted in reduced patient access to a neurologist.

Conclusion: Due to the inherent nature of their condition, people with epilepsy are less likely to have employer-sponsored health insurance or consistent driving privileges. Yet, these factors also impact patient access to neurological care. We must address transportation and insurance barriers through long-term investment and partnership between community, healthcare, and government stakeholders.

1. Introduction

Epilepsy, a chronic disease defined by an ongoing risk of recurrent, unpredictable seizures, affects over 3.4 million people in the United States (US) (Zack and Kobau, 2017). Most of these patients require long-term antiseizure medication treatment with the goal of achieving seizure freedom without adverse effects. Around one-third of people with epilepsy develop drug-resistant disease involving extensive medical and surgical intervention (Chen et al., 2018; Kwan et al., 2010; Kwan and Brodie, 2000). They are at high risk of experiencing recurrent

hospitalizations, reduced quality of life, and death (Blank et al., 2018; Choi et al., 2014; Jacoby et al., 1998; Ryvlin et al., 2013). Thus, it is essential that everyone with epilepsy receive consistent, quality neurological care.

In the US, inadequate health insurance coverage can prevent timely and necessary medical care. The American healthcare insurance and financing system is defined as a mixed system in which publicly financed government plans (Medicare and Medicaid) coexist with privately financed plans, which are often contributed to by employers in whole or part (group insurance) or purchased privately, e.g., through an

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<https://doi.org/10.1016/j.epilepsyres.2024.107424>

Received 29 April 2024; Received in revised form 25 June 2024; Accepted 5 August 2024

Available online 8 August 2024

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Affordable Care Act health insurance marketplace (LaFontaine, 2021). However, many people lack any health insurance coverage: 26.4 million, or 8.0% of the US population as of 2022 (Lee et al., 2022).

Several US studies report that differences in health insurance coverage negatively impact epilepsy management. For example, patients without health insurance had fewer neurologist visits compared to those with private coverage (Halpern et al., 2011). Adults with public insurance, e.g., Medicare and Medicaid, were also less likely to undergo epilepsy surgery for drug-resistant disease (Bernstein et al., 2021; Englot et al., 2012; Hamade et al., 2021; McClelland et al., 2010). Similarly, children with Medicaid experienced a longer time to referral for evaluation and epilepsy surgery than those with private insurance (Hauptman et al., 2013). Other factors associated with limited access to epilepsy care include minoritized race or ethnicity, low English proficiency, poverty, and geographical region of the country outside of the Northeast, largely due to structural inequities (Begley et al., 2009; Betjemann et al., 2013; Burneo et al., 2005; Kamitaki et al., 2022; McClelland et al., 2010; Szaflarski et al., 2020). As expanding access to treatment can improve health equity and mitigate racial disparities (Chen et al., 2016), understanding the influence of health insurance on routine epilepsy care is critical.

In an expansive report, the Institute of Medicine indicated that access to affordable and reliable transportation is closely linked with multiple determinants of health (Institute of Medicine Committee on the Public Health Dimensions of the, 2012). People with epilepsy may be restricted by state law from driving, which can affect many aspects of daily life, including employment, shopping for necessities, and attending medical appointments (Krumholz et al., 2016; Martin et al., 2005). A California study noted that further distance from an epilepsy center predicted a lower likelihood of receiving inpatient specialty epilepsy care (Schiltz et al., 2013). In another study, inability to drive to the pharmacy resulted in reduced medication adherence in people with epilepsy, but whether similar consequences are seen with other aspects of neurological care is less clear (Welty et al., 2010).

Our study aims to understand the relationship between health insurance coverage, transportation, and access to outpatient neurological care for people with epilepsy in the US. We hypothesized that patients without health insurance and those with inadequate transportation options for medical appointments had lower odds of having seen a neurologist in the prior year, compared to those who did not face those challenges.

2. Materials & methods

2.1. Study design, setting, participants

We conducted a retrospective cross-sectional study using the National Health Interview Survey (NHIS) a household survey that provides nationally representative information on members of the civilian noninstitutionalized US population. It is conducted via face-to-face personal interviews. In 2015 and 2017, NHIS included additional epilepsy and seizure-related questions. This study was designated as non-human subject research by the Rutgers University Institutional Review Board.

For this study, we examined access to neurological care for noninstitutionalized US civilian adults (age ≥ 18 years) with active epilepsy using the NHIS 2015 and 2017 Sample Adult, Person, and Family files. We defined people with active epilepsy as those who answered "Yes" to (1) "Have you ever been told by a doctor or other health professional that you have a seizure disorder or epilepsy?" and one of the following: (2) if they are either currently taking antiseizure medication, or (3) if

they have experienced at least one seizure in the past year. We chose to study only patients with active epilepsy, as people who are seizure-free off antiseizure medications would generally not require active care or treatment by a neurologist, e.g., resolved epilepsy (Fisher et al., 2014).

2.2. Measures

The dependent variable of interest was access to neurological care, defined as whether the person with epilepsy had seen a neurologist or epilepsy specialist in the past year (yes/no). Independent variables assessed included (1) health insurance coverage status (yes/no) and (2) whether the respondent had delayed care in the past year due to no transportation (yes/no), as a marker of inadequate transportation to medical appointments.

Covariates measured included sex (male/female), race/ethnicity (Hispanic/Latino, non-Hispanic White, non-Hispanic Black, non-Hispanic Asian, non-Hispanic other), poverty (<100% of the federal poverty level), and education level (less than high school, high school or GED, some college, or bachelor's degree or higher). We also included geographic region (Northeast, Midwest, South, or West) as an additional covariate (Szaflarski et al., 2020). Seizure characteristics included whether the person is taking antiseizure medications (yes/no) and seizure frequency in the past year (none, one, two or three, between four and ten, more than ten).

2.3. Data analysis

Descriptive statistics were calculated to characterize people with active epilepsy, including means and proportions with 95% confidence intervals (CI). Next, we used multiple logistic regression to determine whether health insurance and transportation were independently associated with the outcome of having seen a neurologist or epilepsy specialist in the past year (yes/no) among people with active epilepsy. We adjusted for covariates, including age, race/ethnicity, sex, poverty, education level, US geographic region, number of seizures in the past year, and current use of anti-seizure medication. Missing data were excluded listwise from analysis. SAS software version 9.4 (SAS Institute, Cary, NC) survey procedures were used for all statistical calculations to account for the complex survey design using stratification, clustering, and weighting.

3. Results

We identified 735 sample participants from the 2015 and 2017 NHIS, representing an estimated 2.98 million US adults with active epilepsy. Participants had a mean age of 45.2 years, and 49.6% were female. Overall, 64.8% of US adults with active epilepsy saw a neurologist or epilepsy specialist in the past year, while 35.2% did not. Most patients (88.7%) reported taking antiseizure medication(s), though people who had seen a neurologist were more likely to be on medication [Table 1]. Among the group with active epilepsy who had not seen a neurologist, 78.2% of them reported taking antiseizure medication. Seizure freedom was reported by 39.6% of those who had seen a neurologist and in 42.9% of those who were not seen [Table 1].

Of US adults with active epilepsy, 93.7% had health insurance coverage. However, uninsured patients were overrepresented among those who had not seen a neurologist in the prior year. Of those who did not receive neurological care, 9.6% did not have health insurance, compared with 4.5% of those who did receive care [Table 1]. Similarly, a higher proportion of patients without neurological care, 9.7%, had delayed care due to lack of transportation, while 5.7% of those who saw

Table 1

Demographics of US civilian non-institutionalized adults with active epilepsy, National Health Interview Survey, 2015 and 2017, n = 735.

Categories	Overall % (95 % CI)	Did not see neurologist in past year % (95 % CI)	Saw neurologist in past year % (95 % CI)
Total	100	35.2 (30.9 – 39.5)	64.8 (60.5 – 69.1)
Age, Mean (95 % CI)	45.2 (43.4 – 46.9)	47.2 (44.6 – 49.7)	44.1 (42.3 – 45.9)
Sex			
Female	49.6 (44.4 – 54.9)	55.8 (48.1 – 63.4)	46.3 (40.0 – 52.6)
Male	50.4 (45.1 – 55.6)	44.2 (36.6 – 51.9)	53.7 (47.4 – 60.0)
Race			
Hispanic	9.0 (6.2 – 11.8)	5.6 (2.5 – 8.7)	10.9 (6.9 – 14.8)
Non-Hispanic White	72.8 (68.3 – 77.3)	69.5 (61.9 – 77.2)	74.5 (69.0 – 80.1)
Non-Hispanic Black	14.8 (11.0 – 18.6)	20.0 (12.8 – 27.2)	11.9 (7.8 – 16.1)
Non-Hispanic Asian	1.2 (0.2 – 2.2)	1.9 (0.0 – 4.4)	0.9 (0.2 – 1.6)
Non-Hispanic All Other Race Groups	2.2 (1.0 – 3.4)	3.0 (0.5 – 5.4)	1.8 (0.6 – 3.0)
Poverty (<100 % of Federal Poverty Level)			
Yes	23.6 (19.5 – 27.7)	27.4 (20.9 – 33.8)	21.6 (16.6 – 26.7)
No	76.4 (72.3 – 80.5)	72.6 (66.2 – 79.1)	78.4 (73.3 – 83.4)
Missing	39		
Education Level			
< High School	20.4 (16.4 – 24.4)	26.6 (19.4 – 33.7)	17.1 (12.3 – 21.8)
High School / GED	32.5 (27.6 – 37.3)	35.3 (27.7 – 42.9)	30.9 (24.5 – 37.2)
Some College	26.7 (22.3 – 31.2)	23.9 (17.9 – 30.0)	28.2 (22.2 – 34.3)
Bachelors +	20.4 (16.5 – 24.3)	14.2 (8.9 – 19.5)	23.8 (18.5 – 29.1)
Missing	9		
US Region			
Northeast	16.3 (12.7 – 19.9)	9.9 (5.8 – 13.9)	19.7 (14.7 – 24.8)
Midwest	21.4 (17.7 – 25.2)	20.4 (14.7 – 26.1)	21.9 (17.1 – 26.8)
South	42.8 (37.6 – 48.0)	48.9 (41.1 – 56.6)	39.5 (33.2 – 45.8)
West	19.5 (14.9 – 24.2)	20.9 (14.4 – 27.3)	18.8 (13.2 – 24.5)
Health Insurance Coverage			
Yes	93.7 (91.2 – 96.2)	90.4 (85.9 – 94.9)	95.5 (92.8 – 98.3)
No	6.3 (3.8 – 8.8)	9.6 (5.1 – 14.1)	4.5 (1.7 – 7.2)
Missing	3		
Delayed care in past year due to no transportation			
Yes	7.1 (5.2 – 9.1)	9.7 (5.9 – 13.4)	5.7 (3.5 – 7.9)
No	92.9 (90.9 – 94.8)	90.3 (86.6 – 94.1)	94.3 (92.1 – 96.5)
Missing	8		
Number of seizures in the past year			
None	40.7 (35.7 – 45.8)	42.9 (35.0 – 50.8)	39.6 (33.3 – 45.8)
One	11.8 (8.9 – 14.8)	16.9 (11.0 – 22.8)	9.0 (6.0 – 12.2)
2–3	13.3 (10.1 – 16.5)	13.1 (8.6 – 17.6)	13.4 (9.2 – 17.6)
4–10	14.6 (11.0 – 18.3)	14.4 (8.5 – 20.2)	14.7 (10.2 – 19.3)
More than 10	19.5 (15.3 – 23.7)	12.7 (7.6 – 17.9)	23.2 (17.6 – 28.7)
Missing	6		
Currently taking anti-seizure medications			
Yes	88.7 (86.1 – 91.3)	78.2 (72.2 – 84.3)	94.3 (92.1 – 96.5)
No	11.3 (8.7 – 13.9)	21.8 (15.7 – 27.8)	5.7 (3.5 – 7.9)
Missing	2		

95 % CI: 95 % Confidence Interval

a neurologist had transportation difficulties [Table 1].

After adjusting for sociodemographic (age, race/ethnicity, sex, education level, geographic region, poverty) and seizure-related covariates (number of seizures in the past year, current use of antiseizure medications), people with active epilepsy without health insurance coverage had significantly lower odds (adjusted odds ratio [aOR] 0.22, 95 % CI: 0.09 – 0.54) of having seen a neurologist in the past year, as compared to those with health insurance [Table 2]. Having delayed care in the past year due to no transportation was also associated with significantly decreased odds of neurologist care (aOR 0.42, 95 % CI: 0.19 – 0.93) [Table 2].

4. Discussion

Unsurprisingly, a lack of health insurance coverage was associated with decreased access to neurological care for people with epilepsy. Health insurance coverage is not universal in the US, a country that has historically relied on private or employer-sponsored plans to finance healthcare (Blumenthal, 2006). People with epilepsy are more likely to be unemployed, disabled, and insured under Medicaid plans when compared to those without epilepsy (Thurman et al., 2016). They often struggle to maintain regular employment, especially when experiencing

seizures actively at work, and may encounter stigma and discrimination (Krumholz et al., 2016; Smeets et al., 2007). People with epilepsy who lose their jobs and, consequently, healthcare coverage are at higher risk for worsened outcomes (Elliott et al., 2009; Szaflarski et al., 2020). Of note, the proportion of people without health insurance coverage is significantly higher, 15.4 % versus 8.1 %, in states that have not adopted the Affordable Care Act Medicaid expansion for adults at or near the federal poverty level (Buchmueller et al., 2020; Rosenbaum and Wilensky, 2020). Such policy decisions unfortunately increase the risk of negative health consequences for people with epilepsy who live in poverty (Bensken et al., 2022).

People with epilepsy commonly report that transportation barriers negatively affect access to neurological care and overall quality of life. Laws vary, but many US states restrict driving privileges for people with epilepsy who are not seizure-free. Meanwhile, many regions of the US lack high quality, reliable public transportation or other viable alternatives to driving. The world is also a different place than it was in 2015 and 2017, however, with emerging technologies that allow us to connect in new and different ways. Telemedicine has emerged since the COVID-19 pandemic as a promising option for healthcare delivery when face-to-face visits are not possible. A recent study reported high levels of patient satisfaction with telehealth visits for epilepsy care (Casares et al., 2020).

Table 2

Multiple logistic regression examining factors associated with having seen a neurologist in the past year among US adults with active epilepsy, National Health Interview Survey, 2015 and 2017, n = 670 in the final adjusted model.

Categories	Odds Ratio (95 % CI)	Adjusted Odds Ratio (95 % CI) ^a
Health Insurance Coverage		
Yes	1.00	1.00
No	0.43 (0.19 – 0.98)	0.22 (0.09 – 0.54)
Delayed care in past year due to no transportation		
Yes	0.53 (0.29 – 0.98)	0.42 (0.19 – 0.93)
No	1.00	1.00

95 % CI: 95 % Confidence Interval

^a Adjusted for age, race/ethnicity, sex, poverty, education level, US region, number of seizures in the past year, and current use of anti-seizure medication

Health professionals felt positively about the use of telemedicine during the COVID-19 pandemic as well (Cross et al., 2021). Other means of supporting a healthy and vibrant car-free lifestyle, such as working from home or utilizing a food delivery service, are more normalized since the pandemic, albeit skewed towards those with higher incomes (Huang et al., 2024; Keeble et al., 2020).

Limitations of our study include the relatively small number of people with active epilepsy sampled in the NHIS. More details about each participant's epilepsy and ongoing therapies, which are not available in the NHIS, would be useful to clarify disease severity and impact on quality of life. Some patients may experience a less disabling seizure type, for example, focal aware seizures that do not affect driving privileges. Additionally, there was only a single question that addressed healthcare-related transportation barriers. Future research focusing specifically on transportation as a social determinant of health should inquire about familial support, access to public transportation, neighborhood walkability, and availability of other modes of travel.

5. Conclusion

Among a representative sample of noninstitutionalized US civilian adults with active epilepsy surveyed in 2015 and 2017, a lack of health insurance coverage and inadequate transportation to healthcare appointments were independently associated with lower odds of seeing a neurologist or epilepsy specialist, compared with people who did not experience these challenges. These associations persisted after adjusting for socioeconomic factors, seizure frequency, and use of antiseizure medications. Solutions to healthcare insurance-related barriers, especially for people with epilepsy without coverage, will likely require long-term investment and partnership between patients and their communities, healthcare organizations, and the government. Access to transportation and health insurance, critical social determinants of health, require ongoing monitoring to ensure equitable neurological care for people with epilepsy.

Funding

Dr. Kamitaki acknowledges funding from the American Epilepsy Society and the New Jersey Health Foundation. Dr. Kamitaki also received support from the Resource Center for Alzheimer's and Dementia Research in Asian and Pacific Americans under NIH/NIA Grant P30-AG083257. The contents of this manuscript are solely the responsibility of the authors and do not necessarily represent the official views of the NIH.

Dr. Choi acknowledges funding from the National Institute on Aging (R01AG074355).

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Investigation. **Brad K. Kamitaki:** Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Software, Resources, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation. **Michelle T. Bover Manderski:** Writing – review & editing, Writing – original draft, Supervision, Methodology, Investigation, Formal analysis, Conceptualization. **Hyunmi Choi:** Writing – review & editing, Supervision.

Declaration of Competing Interest

None of the authors has any conflict of interest to disclose.

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