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Markers of Quality Care for Newly Diagnosed People with Epilepsy on Medicaid

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Abstract

Background: For newly diagnosed people with epilepsy (PWE), proper treatment is important to improve outcomes, yet limited data exists on markers of quality care.

Objective: Examine markers of quality care for newly diagnosed PWE.

Methods: Using Medicaid claims data (2010 – 2014) for 15 states we identified adults 18-64 years of age diagnosed with incident epilepsy in 2012 or 2013. We built 5 sequential logistic regression models to evaluate: (1) seeing a neurologist; (2) diagnostic evaluation; (3) anti-epileptic medication adherence; (4) serum drug levels checked; and (5) being in the top quartile of number of negative health events (NHEs). We adjusted for demographics, comorbidities, county-level factors, and the outcomes from all prior models.

Results: Of 25,663 PWE, 37.3% saw a neurologist, with decreased odds for those of older age, those residing in counties with low-density of neurologists, and certain race/ethnicities; about 57% of PWE received at least one diagnostic test; and nearly 62% of PWE were adherent to their medication. The most common comorbidities were hypertension (37.1%) and psychoses (26.9%). PWE with comorbidities had higher odds of seeing a neurologist and to have NHEs. Substance use disorders were negatively associated with medication adherence and positively associated with high NHEs.

Conclusions: There are notable differences in demographics among people with incident epilepsy who do or do not see a neurologist. Differences in NHEs persist, even after controlling for neurologist care and diagnostic evaluation. Continued attention to these disparities and comorbidities is needed in the evaluation of newly diagnosed PWE.

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Introduction

Epilepsy affects over 3 million individuals in the United States. People with epilepsy (PWE) have difficulties with their daily activities, especially when seizures are not well controlled.[1-3] The economic marginalization and social isolation associated with driving restrictions and unemployment greatly affect their quality of life. In addition to these social burdens, PWE face numerous barriers to timely and adequate health care.[1,4-8]

Presently in the United States, no clear guidelines exist on when a patient with seizures should be referred for specialty care. But, there is evidence that patients with poorly controlled seizures benefit substantially from seeing a neurologist, epileptologist, or from receiving care at an epilepsy center.[9-13] Similarly, our knowledge on patterns of diagnostic evaluation of seizures, being on antiepileptic drugs (AED), AED medication adherence, and follow-up care remains very limited.[14] Not surprisingly, studies have evaluated the occurrence of negative health events (NHEs) including emergency department visits and hospitalizations, which may be associated with poor epilepsy control.[6,7,15,16] Yet, failure at each of these markers can be highly consequential, affecting another downstream quality of care marker and/or outcome. For example, PWE who are seen by a neurologist may be more likely to undergo diagnostic evaluation of their seizure, to be on AEDs, to be medication adherent, and to receive follow-up care. Thus, we posit that these markers of care are strongly interrelated, and that there may be a cascade effect, such that a failure at one marker may predict failure at another marker, cumulatively leading to a greater likelihood of NHEs.

While the Medicaid program, which covers up to 1/3 of PWE, provides broad coverage for their health services, PWE continue to face barriers accessing timely and adequate care, and are among the most vulnerable segments of PWE.[17]

We sought to understand markers of quality care for people with incident epilepsy on Medicaid. We hypothesized that fewer than 50% of PWE on Medicaid see a neurologist within 1 year of their epilepsy index date, and that those who did not see a neurologist would be significantly less likely to have diagnostic evaluation of epilepsy, to be adherent to AEDs, or to undergo follow-up testing. Finally, we hypothesized that failure at these markers have cumulative effects relative to NHEs.

Methods

This is a retrospective observational study using Medicaid data from 15 states for persons identified with epilepsy or seizures during the 5-year period 2010-2014. The states for which we obtained Medicaid data were selected based on their availability in 2014, the most recent year for which Medicaid Analytic eXtract (MAX) data were available when we began this study: California, Georgia, Idaho, Iowa, Michigan, Minnesota, Missouri, Mississippi, New Jersey, Pennsylvania, South Dakota, Tennessee, Utah, Vermont, West Virginia, and Wyoming, providing a rich representation of racial/ethnic and urban/rural populations. Louisiana and Idaho were available but excluded due to incomplete data.

This study was approved by the Institutional Review Board of Case Western Reserve University (Protocol #2018-0780), and the Privacy Board of the Centers for Medicare and Medicaid Services (CMS; Data Users Agreement #52636).

Data Sources

The MAX data includes enrollment and claims data for individuals enrolled in Medicaid. This includes: demographics, monthly indicators for Medicaid enrollment, inpatient and outpatient claims with their respective diagnostic, procedure, and place and date of service codes. The pharmacy data contains the national drug code as well as the supply, date of fill/refill, and charges for each filled prescription.

The files also include a ‘Recipient Indicator’ (RI) defined as a “code indicating if and how the eligible [individual] received a Medicaid service during the calendar year and whether those services were received under a fee-for-service or pre-paid plan”.[18] We conducted sensitivity analyses to test and potentially remove categories with likely incomplete data (i.e., categories yielding low counts/rates of outcomes of interest). Our sensitivity analysis did not yield any meaningful differences in the outcomes, so we did not exclude any individuals based on their RI categories.

County-level data were obtained from the Area Health Resources File (AHRF) from the Health Resources and Services Administration (HRSA).

Study Population

The study population was identified using published criteria for identifying incident cases of epilepsy in administrative data.[19] Individuals were required to have: (1) at least 1 visit with an epilepsy diagnosis or 2 visits on different dates for non-febrile convulsions; (2) another epilepsy or non-febrile convulsion visit at least 30-days later, and (3) 2 pharmacy dispensing claims at least 30 days apart for any of the published list of anti-epileptic drugs.[19,20] This cohort was further restricted to individuals whose index date was in 2012 or 2013, allowing for a look-back period of at least 2-years to ensure that all claims were free of seizure or epilepsy diagnosis codes to establish status as an incident case, as well as 1 year post-index date to examine health outcomes.[19] We required that individuals have 2 full years of Medicaid enrollment prior to index date and 1 full year after index date, for a total of 36 months. This was further limited to individuals 18-64 years old at index date, to ensure that for no individual their time overlapped with Medicare coverage.

Variables of Interest

The variables selected as markers of care included: (1) seeing a neurologist (identified using the Provider Taxonomy code for neurologist); (2) receiving diagnostic evaluation (defined as electroencephalogram [EEG], video-electroencephalogram [vEEG], magnetic resonance imaging [MRI], computed tomography scan [CT], single-photon emission computed tomography [SPECT], and positron emission tomography scan [PET]); (3) AED medication adherence via the proportion of days covered (PDC); (4) having serum drug levels checked; and (5) being in the top quartile of negative health events (NHEs) which include all hospitalizations and emergency department visits. Outcomes other than visit to a neurologist, PDC, and NHEs were defined using CPT, HCPCS, and ICD-9 codes (Supplementary Table 1). All of these outcomes were evaluated in the 1-year post-index date.

The PDC is the proportion of days in a time period, in this study the 1-year post index date, where an individual had access to AEDs via a prescription fill. We calculated the PDC for each AED an individual was on and then averaged this to obtain their overall PDC to then dichotomize using a standard cutoff of 0.8, with those below considered to not be adherent.[21-23] While the PDC was used in our main analyses, we conducted sensitivity analysis using another measure of medication adherence, the medication possession ratio (MPR) (Supplementary Table 2).[20,22,24-26]

Independent variables included: sex, age at index date, race and ethnicity, rurality (at the county-level via the Rural Urban Continuum Code), and evidence, from procedure codes, of residing in a nursing home.[27-30] In an effort to capture the comorbidity burden we identified Elixhauser comorbidities, via ICD-9 codes on all non-pharmacy claims, with a prevalence of over 10% (excluding electrolyte disorders) for inclusion in the models.[31,32] These comorbidities were deficiency anemias, chronic pulmonary disease, depression, diabetes mellitus, drug abuse, hypertension, obesity, paralysis, and psychoses. We further identified other neurological conditions that are known to be associated with epilepsy including cerebrovascular disease, intellectual and developmental disabilities, cerebral palsy, and traumatic brain injury.[33-35] In an effort to capture disease severity and treatment regimen we determined whether individuals were on a third unique AED, as a marker for drug-resistant epilepsy – defined as the failure of two AEDs.[36] All of these covariates were identified using 36-months of data for each individual.

Finally, using the AHRF we identified a small set of county-level measures which we hypothesized would be associated with our markers of quality care. These included: median household income, percent of individuals over 25 years of age with a college degree, density of primary care providers, density of neurologists, and number of Medicaid-eligible individuals. These final three measures were standardized to the county-level population and presented as per 100,000 individuals. Median household income was scaled to thousands of dollars for the logistic regression models to examine the effect of a $1,000 difference.

The full list of study variables and associated diagnosis or procedure codes are tabulated in the supplementary material (Supplementary Table 1).

Statistical Analyses

We built 5 sequential logistic regression models, with each containing the same basic independent variables, but also added the dependent variables or markers of quality care from prior model(s) as independent variables in the new model. The five model outcomes were (in this order): (1) seeing a neurologist; (2) diagnostic evaluation; (3) AED medication adherence; (4) having serum drug levels checked; and (5) being in the top quartile of negative health events (NHEs). Thus, the model for receiving diagnostic tests also included an indicator for a visit to a neurologist; the model for medication adherence included both visit to a neurologist and receipt of diagnostic test as independent variables, and so on. All 5 outcomes of interest were assessed in the 12 months after epilepsy index date.

We performed data processing in SAS Version 9 and analyses and visualization in R version 3.6.1.

Data Availability

Access to these data is restricted to the study team under a Data Users Agreement from CMS.

Results

In total 283,685 PWE were identified, 25,663 met the final inclusion criteria (Figure 1). Of those, 57.5% were female, 57.6% were White, and 83.3% lived in non-rural counties (Table 1). There was a high prevalence of comorbidities including 60.8% having other neurological conditions, 34.4% with hypertension, 22.2% with chronic pulmonary disease, and 17.9% with depression (Table 1). 26.5% were put on a third AED, suggesting drug-resistant epilepsy, which is consistent with previous estimates of approximately 30% of PWE having drug resistant epilepsy.[36,37]

In examining multiple unmet markers of quality of care, only 4.2% (n = 1,088) met all five markers of quality care. Additionally, 65% (n = 16,676) did not meet 2 (32.6%) or 3 (32.4%) of these 5 markers of quality care. The most common two unmet markers were not seeing a neurologist and not having serum drug levels checked (38.5% of all individuals), followed by not seeing a neurologist and not receiving a diagnostic evaluation (33.6% of all individuals).

Model 1: Neurologist

Of 25,663 PWE included, 37.3% (n = 9,584) received care from a neurologist within 1 year of index epilepsy date (Table 1). When controlled for potential confounders, Native Hawaiians and Other Pacific Islanders, those living rural areas, those diagnosed with psychoses, and those living in areas with low neurologist density all independently had significantly decreased odds of seeing a neurologist (Figure 2, Supplementary Table 2). There was also a notable age gradient, whereby being older was associated with decreased odds of seeing a neurologist. Conversely, Black individuals, and those with other neurological conditions, hypertension, chronic lung disease, depression, and deficiency anemia had significantly increased odds of seeing a neurologist (Figure 2, Supplementary Table 3.

Model 2: Diagnostic Tests

Nearly 15,000 PWE in our cohort received some type of diagnostic test within 1 year of index epilepsy date (14,785 (57.6%), Table 1). Seeing a neurologist was associated with greater odds of receiving vEEG or imaging tests (adjusted odds ratio (AOR): 3.75; 95% CI: 3.52, 4.00). Further, American Indians and Alaskan Natives, Hispanic/Hispanic and 1+ race, and those with comorbidities (except paralysis) had significantly increased odds of undergoing diagnostic evaluation (Figure 2, Supplementary Table 3).

Model 3: AED Medication Adherence

Of all newly diagnosed PWE in this study, 15,880 (61.9%) adhered to their AED medications, with proportion of days covered (PDC) ≥ 0.8. Those seeing a neurologist had increased odds of being adherent, but those receiving a diagnostic evaluation and those who were on a 3rd AED had decreased odds of being adherent. Although males had lower odds than females to be seen by a neurologist or to undergo diagnostic testing, males had higher odds of adhering to their medications. Age increased the odds of being adherent. Substance use disorders (SUD), hypertension, chronic lung disease, deficiency anemia, and depression were independently associated with decreased odds of being adherent to AEDs (Figure 3, Supplementary Table 3). Additionally, there were notable racial disparities in medication adherence, with Black and Hispanic/Hispanic and 1+ Race having decreased odds of being adherent.

In sensitivity analysis using the MPR, instead of the PDC, 65.1% were identified as adherent, while the results from the multivariable models remained the same (Supplementary Table 2).

Model 4: Serum drug levels

Just over 10,000 individuals had serum drug levels checked (10,263, 40.0%) within 1 year of epilepsy index date. While seeing a neurologist did not affect the odds of having serum drug levels checked, receiving diagnostic evaluation, being adherent, and being male all independently increased the odds. Further, being put on a third AED increased the odds of having the serum levels tested (AOR: 2.05 (95% CI: 1.93, 2.17)). Overall, comorbidities were associated with having serum levels checked to a lesser extent compared to previous models, with the exception of psychoses, which increased odds, and depression which decreased odds (Figure 3, Supplementary Table 3).

Model 5: Negative Health Events

The median number of NHEs (all-cause hospitalizations and emergency department visits in the year after index date) was 2 (IQR: 0 – 5). Therefore, those in the top quartile of NHEs were those with 5 or more hospitalizations and emergency department visits. Seeing a neurologist and adherence decreased the odds of being in the top quartile of NHEs, however diagnostic evaluation and having serum AED levels checked were positively associated with being in the top quartile of NHEs. All comorbidities were also associated with increased odds of being in the top quartile of NHEs (Figure 4, Supplementary Table 2). Among the most common primary reason for visit for NHEs (identified via the first diagnosis slot) were epilepsy or seizures, or epilepsy/seizure related diagnoses (migraine, altered mental status, syncope and collapse, head injury), as well as other symptoms such as chest and abdominal pain.

Discussion

This analysis of newly diagnosed people with epilepsy (PWE) on Medicaid identified several distinct patterns of neurology specialist visits and care. Our original hypothesis that fewer than 50% of newly diagnosed PWE on Medicaid saw a neurologist was confirmed in that of 25,663 PWE in our study population, only 37.3% received care from a neurologist within 1 year of their index epilepsy date. In contrast to previous work, which did not report benefits to seeing a neurologist, we observed that seeing a neurologist was associated with increased odds of diagnostic evaluation and medication adherence.[13] On the other hand, seeing a neurologist was not associated with having serum drug levels checked, and was associated with decreased odds of being in the top quartile for NHEs only at borderline significance levels. This suggests other factors such as unintentional injuries resulting in emergency department use or social determinants of health (e.g., lack of transportation resulting in the use of emergency health care services for routine needs) may also influence NHEs, but this study was unable to assess those factors. The association between receiving diagnostic evaluation and being in the top quartile of NHEs is likely driven by both the fact that these tests directly contribute to more health care interactions and that the patients who undergo these tests are likely to be more clinically complex and/or have poor seizure control.

Our study reveals that who is seen by a neurologist for newly diagnosed PWE on Medicaid clearly varies. This is consistent with a previous study, although that work found fewer disparities and of less magnitude in the Medicare population.[38] It is evident that females, and younger adults, as well as those in non-rural areas have increased odds of seeing a neurologist, even when controlling for all other factors. The residential factors associated with seeing a neurologist were confirmatory in that there exist clear gaps in accessing care due to where someone lives and rural individuals and those in areas with a low-density of neurologists may require outreach and/or expanded access. Simply, our research suggests that outcomes for newly diagnosed PWE are improved if they see a neurologist, further supporting efforts to expand access.

Evaluating the models together, we see clear disparities in medication adherence; a variable that also decreases the odds of being in the top quartile of NHEs (models 3 and 5, Figures 3 and 4). This reinforces that these disparities for specific race and ethnicities warrant greater attention. This includes examining factors such as health literacy, trust, access to pharmacies and affordability of medications, and other factors that can inform the development of targeted culturally appropriate interventions to decrease these disparities. While this study was unable to assess the causes of these racial and ethnic disparities, it is important to recognize and specifically name the role of racism and policies that have fostered structural racism and persistent barriers to access adequate care, in creating disparities in outcomes.[39]

The positive association between comorbidities and receiving diagnostic testing suggests that PWE who have a high comorbidity burden are more likely to undergo extensive testing. Even when controlling for having undergone testing, these comorbidities remained positively associated with NHEs. The research surrounding the role of depression in the self-management of epilepsy is reinforced in these findings as evidenced by its negative association with adherence and strong positive association with being in the top quartile of

NHEs, even when controlling for medication adherence and other comorbidities.[40-44] This would suggest a renewed attention to screening and management for depression and other psychiatric conditions for newly diagnosed PWE. Also elucidated in these findings is the impact of less commonly examined and discussed comorbidities, including substance use disorders (SUD), which were associated with receiving diagnostic evaluation, worse/ suboptimal adherence, and with more hospitalizations and emergency department visits. The implications are that individuals with SUDs represent a high-risk population who need a broad-based diagnostic evaluation that considers not just immediate evaluation for cause of seizures, but also assessment and support in managing addiction or other substance use problems.

This study fills research gaps by indicating that less than one-half of adults with newly diagnosed epilepsy on Medicaid were seen by a neurologist within one year of epilepsy index date, and notably Native Hawaiians and Other Pacific Islanders, rural-dwelling adults, those diagnosed with psychoses, and those living in areas with low neurologist density all independently had significantly decreased odds of seeing a neurologist. Overall, two-thirds of people with newly diagnosed epilepsy have 2 or 3 markers of quality care that were unmet. Further, comorbidities were associated with both receiving diagnostic evaluation as well as outcomes, with continued, but less pronounced racial and ethnic disparities. Strengths of this study include use of data from 15 states, the large sample size which facilitated the study of racial/ethnic subgroups of PWE, as well as the completeness of claims allowing for capture of all health-care interactions during the study period.

This work, however, is not without its limitations, including inherent limitations with claims data in understanding the clinical complexity that contribute to the decisions for diagnostic testing and outcomes. First, in this study we balanced our limited years of data with work demonstrating still adequate incidence estimates for 2-years' data, although this differs from the traditional 3-year look-back period.[19] Second, the use of the PDC is limited in that it determines adherence based on medication fills but is unable to assess if a patient is actively taking medication. Third, while these data were the most recently available at the time the study was initiated, there may have been changes in population mix, practice, or medication management that influence these findings when placed in the current context. Importantly, we note the expected wide fluctuations in Medicaid enrollment due to the Affordable Care Act and Medicaid expansion. Our use of administrative data precludes the ability to conduct an in-depth analysis of factors contributing to the observed patterns of care. For example, access to a neurologist does not necessarily imply a direct referral pathway from any particular general practitioner. A more nuanced analysis using a mixed-methods approach is warranted to elucidate the mechanisms that explain these patterns. Furthermore, we note that our approach to build sequential logistic regression models is based on a hypothetical care pathway and a cascade effect, such that a failure at one marker may predict failure at another marker, cumulatively leading to greater odds of NHEs. Additional studies are needed to map, in real life, the timing and sequence of our study markers relative to the diagnosis of incident epilepsy. While our sequential logistic models do not account for temporality, they assume a cascade effect, temporality, and a strong interdependence between our markers of quality care and study outcomes. Future work should continue to evaluate these important aspects of referral and care for PWE.

Conclusion

This study identifies key gaps in markers of quality care for newly diagnosed people with epilepsy. Only 37.3% of newly diagnosed PWE see a neurologist within 1-year of index date, and neurologic care broadly impacts the other markers of quality care, including increasing the odds of receiving diagnostic evaluation and being adherent. This work underscores the need to further understand the causes of disparities in these markers of quality care for newly diagnosed PWE, while also reinforcing the importance of the consideration of comorbidities in the treatment and management of epilepsy.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Reference

1. Institute of Medicine. Epilepsy Across the Spectrum: Promoting Health and Understanding. Washington, DC: The National Academies Press; 2012.
2. Centers for Disease Control and Prevention. Epilepsy at a Glance. https://www.cdc.gov/chronicdisease/resources/publications/aag/epilepsy.htm. Published 2017. Updated 8/9/2017. Accessed.
3. 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):821–825. [PubMed: 28796763]
4. Wilner AN, Sharma BK, Thompson A, Soucy A, Krueger A. Diagnoses, procedures, drug utilization, comorbidities, and cost of health care for people with epilepsy in 2012. Epilepsy Behav. 2014;41:83–90. [PubMed: 25461195]
5. Keezer MR, Sisodiya SM, Sander JW. Comorbidities of epilepsy: current concepts and future perspectives. The Lancet Neurology. 2016;15(1):106–115. [PubMed: 26549780]

6. Blank LJ, Crispo JAG, Thibault DP, Davis KA, Litt B, Willis AW. Readmission after seizure discharge in a nationally representative sample. Neurology. 2018.
7. Elixhauser A, Steiner C. Statistical Brief #153: Readmission to U.S. Hospitals by Diagnosis, 2010. Agency for Healthcare Research and Quality;2013.
8. Schiltz NK, Koroukian SM, Singer ME, Love TE, Kaiboriboon K. Disparities in access to specialized epilepsy care. Epilepsy Res. 2013;107(1-2):172–180. [PubMed: 24008077]
9. Szaflarski JP, Rackley AY, Lindsell CJ, Szaflarski M, Yates SL. Seizure control in patients with epilepsy: the physician vs. medication factors. BMC Health Serv Res. 2008;8:264. [PubMed: 19094222]
10. Scheuer ML, Pedley TA. The evaluation and treatment of seizures. N Engl J Med. 1990;323(21):1468–1474. [PubMed: 2233919]
11. Ney JP, Johnson B, Knabel T, Craft K, Kaufman J. Neurologist ambulatory care, health care utilization, and costs in a large commercial dataset. Neurology. 2016;86(4):367–374. [PubMed: 26701378]
12. Labiner DM, Bagic AI, Herman ST, et al. Essential services, personnel, and facilities in specialized epilepsy centers--revised 2010 guidelines. Epilepsia. 2010;51(11):2322–2333. [PubMed: 20561026]
13. Hill CE, Lin CC, Burke JF, et al. Claims data analyses unable to properly characterize the value of neurologists in epilepsy care. Neurology. 2019;92(9):e973–e987. [PubMed: 30674587]
14. Sharma S, Chen Z, Rychkova M, et al. Treatment initiation decisions in newly diagnosed epilepsy-A longitudinal cohort study. Epilepsia. 2020.
15. Jette N, Meador KJ, Kwon CS. Readmitted after a seizure-related hospitalization: Deja vu. Neurology. 2018.
16. Fingar KR, Barrett ML, Jiang JH. A Comparison of All-Cause 7-Day and 30-Day Readmissions, 2014. Rockville, Maryland: Agency for Healthcare Research and Quality;2017.
17. Thurman DJ, Kobau R, Luo YH, Helmers SL, Zack MM. Health-care access among adults with epilepsy: The U.S. National Health Interview Survey, 2010 and 2013. Epilepsy Behav. 2016;55:184–188. [PubMed: 26627980]
18. Research Data Assistance Center. Recipient Indicator. https://www.resdac.org/cms-data/variables/recipient-indicator. Published 2020. Accessed Oct 10, 2020.
19. Bakaki PM, Koroukian SM, Jackson LW, Albert JM, Kaiboriboon K. Defining incident cases of epilepsy in administrative data. Epilepsy Res. 2013;106(1-2):273–279. [PubMed: 23791310]
20. Vossler D, Weingarten M, Gidal B. Current Review in Clinical Science: Summary of Antiepileptic Drugs Available in the United States of America. American Epilepsy Society;2018.
21. Karve S, Cleves MA, Helm M, Hudson TJ, West DS, Martin BC. Good and poor adherence: optimal cut-point for adherence measures using administrative claims data. Current Medical Research and Opinion. 2009;25(9):2303–2310. [PubMed: 19635045]
22. Chu L-H, Kawatkar A, Gu A. A SAS® Macro Program to Calculate Medication Adherence Rate for Single and Multiple Medication Use. https://www.lexjansen.com/wuss/2011/hoc/Papers_Chu_L_74886.pdf. Accessed2020.
23. Goodman MJ, Durkin M, Forlenza J, Ye X, Brixner DI. Assessing adherence-based quality measures in epilepsy. Int J Qual Health Care. 2012;24(3):293–300. [PubMed: 22507847]
24. Sikka R, Xia F, Aubert RE. Estimating medication persistency using administrative claims data. American Journal of Managed Care. 2005;11(7):453–460.
25. Steiner JF, Prochazka AV. The assessment of refill compliance using pharmacy records: Methods, validity, and applications. J Clin Epidemiol. 1997;50(1):105–116. [PubMed: 9048695]
26. Cramer JA, Benedict A, Muszbek N, Keskinaslan A, Khan ZM. The significance of compliance and persistence in the treatment of diabetes, hypertension and dyslipidaemia: a review. Int J Clin Pract. 2008;62(1):76–87. [PubMed: 17983433]
27. Hart LG, Larson EH, Lishner DM. Rural definitions for health policy and research. Am J Public Health. 2005;95(7):1149–1155. [PubMed: 15983270]

28. United States Department of Agriculture Economic Research Service. Rural-Urban Continuum Codes. https://www.ers.usda.gov/data-products/rural-urban-continuum-codes/documentation/. Published 2013. Accessed 26 February, 2020.
29. Koroukian SM, Xu F, Murray P. Ability of Medicare claims data to identify nursing home patients: a validation study. Med Care. 2008;46(11):1184–1187. [PubMed: 18953230]
30. Centers for Medicare and Medicaid Services. Nursing Home CPT Codes. https://www.cms.gov/Regulations-and-Guidance/Guidance/Transmittals/2006-Transmittals-Items/CMS060675. Accessed 22 March, 2021.
31. Elixhauser A, Steiner C, Harris DR, Coffey RN. Comorbidity measures for use with administrative data. Med Care. 1998;36(1):8–27. [PubMed: 9431328]
32. Beta Elixhauser Comorbidity Software for ICD-10-CM. Healthcare Cost and Utilization Project, Agency for Healthcare Research and Quality. https://hcup-us.ahrq.gov/toolssoftware/comorbidityicd10/comorbidity_icd10.jsp. Accessed.
33. Tirschwell DL, Longstreth WT Jr. Validating administrative data in stroke research. Stroke. 2002;33(10):2465–2470. [PubMed: 12364739]
34. Mitra M, Parish SL, Clements KM, Zhang J, Simas TAM. Antenatal Hospitalization Among U.S. Women With Intellectual and Developmental Disabilities: A Retrospective Cohort Study. Am J Intellect Dev Disabil. 2018;123(5):399–411. [PubMed: 30198766]
35. Faul M, Xu L, Wald MM, Coronado VG. Traumatic Brain Injury in the United States: Emergency Department Visits, Hospitalizations and Deaths 2002-2006. Centers for Disease Control and PRevention, National Center for Injury Prevention and Control;2010.
36. Kwan P, Arzimanoglou A, Berg AT, et al. Definition of drug resistant epilepsy: consensus proposal by the ad hoc Task Force of the ILAE Commission on Therapeutic Strategies. Epilepsia. 2010;51(6):1069–1077. [PubMed: 19889013]
37. Kwan P, Brodie MJ. Early identification of refractory epilepsy. N Engl J Med. 2000;342(5):314–319. [PubMed: 10660394]
38. Pisu M, Richman JS, Martin RC, et al. Diagnostic tests and neurology care for Medicare beneficiaries with seizures: differences across racial groups. Med Care. 2012;50(8):730–736. [PubMed: 22781710]
39. Boyd RW, Lindo EG, Weeks LD, R MM. On Racism: A New Standard For Publishing On Racial Health Inequities. Health Affairs Blog. 2020.
40. Josephson CB, Lowerison M, Vallerand I, et al. Association of Depression and Treated Depression With Epilepsy and Seizure Outcomes: A Multicohort Analysis. JAMA Neurol. 2017;74(5):533–539. [PubMed: 28241168]
41. Sajatovic M, Welter E, Tatsuoka C, Perzynski AT, Einstadter D. Electronic medical record analysis of emergency room visits and hospitalizations in individuals with epilepsy and mental illness comorbidity. Epilepsy Behav. 2015;50:55–60. [PubMed: 26119621]
42. Khalid Z, Momotaz H, Briggs F, et al. Depressive Symptoms in Older versus Younger People with Epilepsy: Findings from an Integrated Epilepsy Self-Management Clinical Research Dataset. J Multidiscip Healthc. 2019;12:981–988. [PubMed: 31839708]
43. Quarells RC, Spruill TM, Escoffery C, et al. Depression self-management in people with epilepsy: Adapting project UPLIFT for underserved populations. Epilepsy Behav. 2019;99:106422. [PubMed: 31371202]
44. Thompson NJ, McGee RE, Garcia-Williams A, et al. The impact of a depression self-management intervention on seizure activity. Epilepsy Behav. 2020;103(Pt A):106504. [PubMed: 31648928]

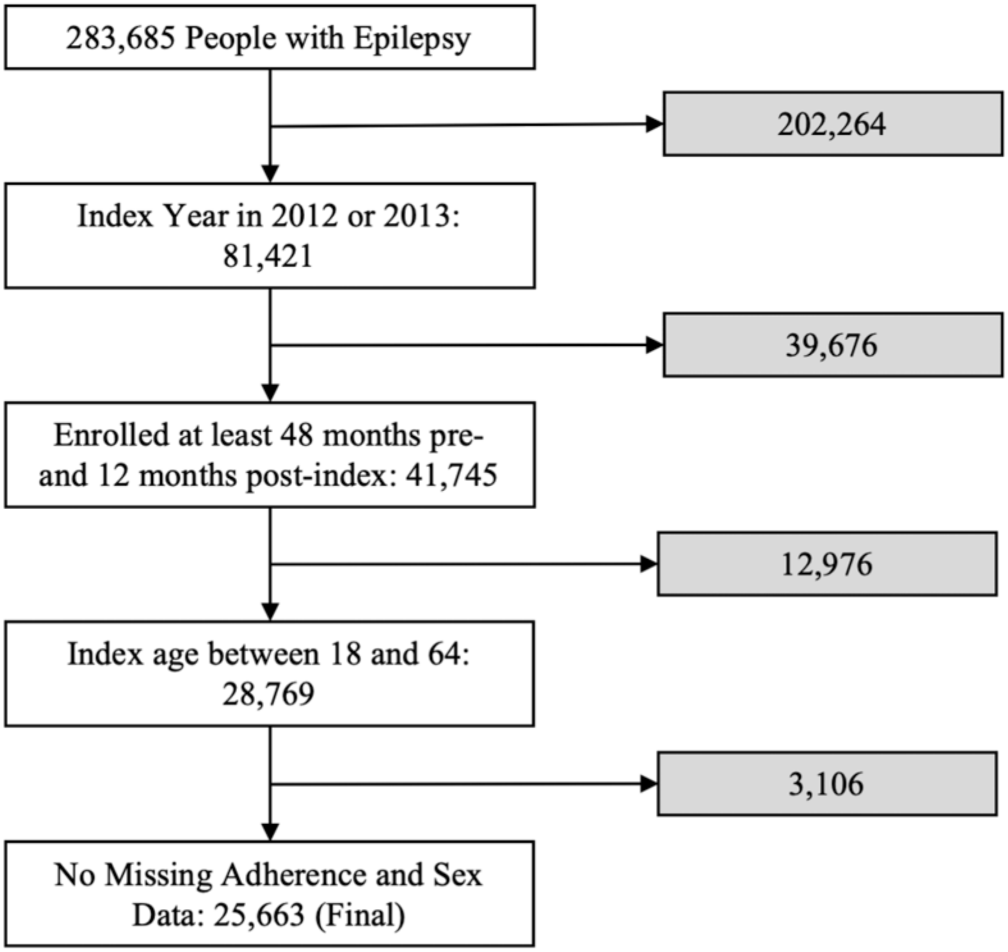

Figure 1.

Flow diagram of study inclusion criteria, the gray boxes represent the number of individuals removed at each step along the path.

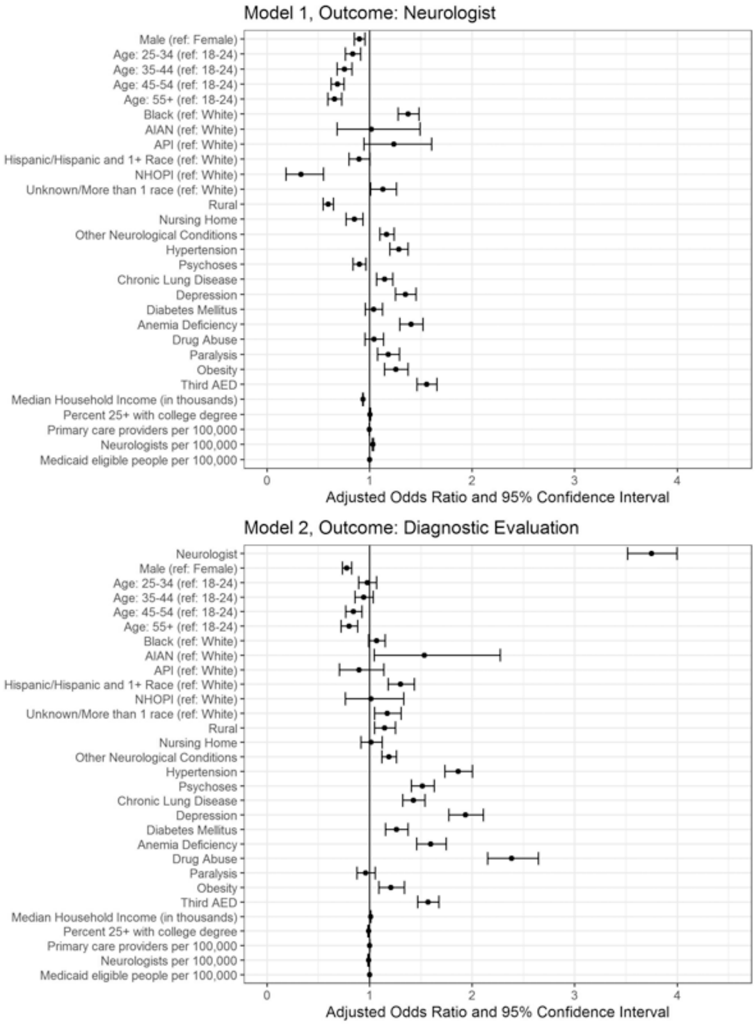

Figure 2.

Logistic regression models 1 and 2, if the person ever saw a neurologist and if they received diagnostic evaluation respectively. Reference levels are given for multi-categorical variables, while the other factor variables represent the odds ratio for “yes”. AIAN: American Indian, Alaskan Native; API: Asian, Pacific Islander; NHOPI: Native Hawaiians and Other Pacific Islander. Other neurological conditions: cerebrovascular disease, cerebral palsy, intellectual and developmental disabilities, traumatic brain injury. AED: anti-epileptic drug.

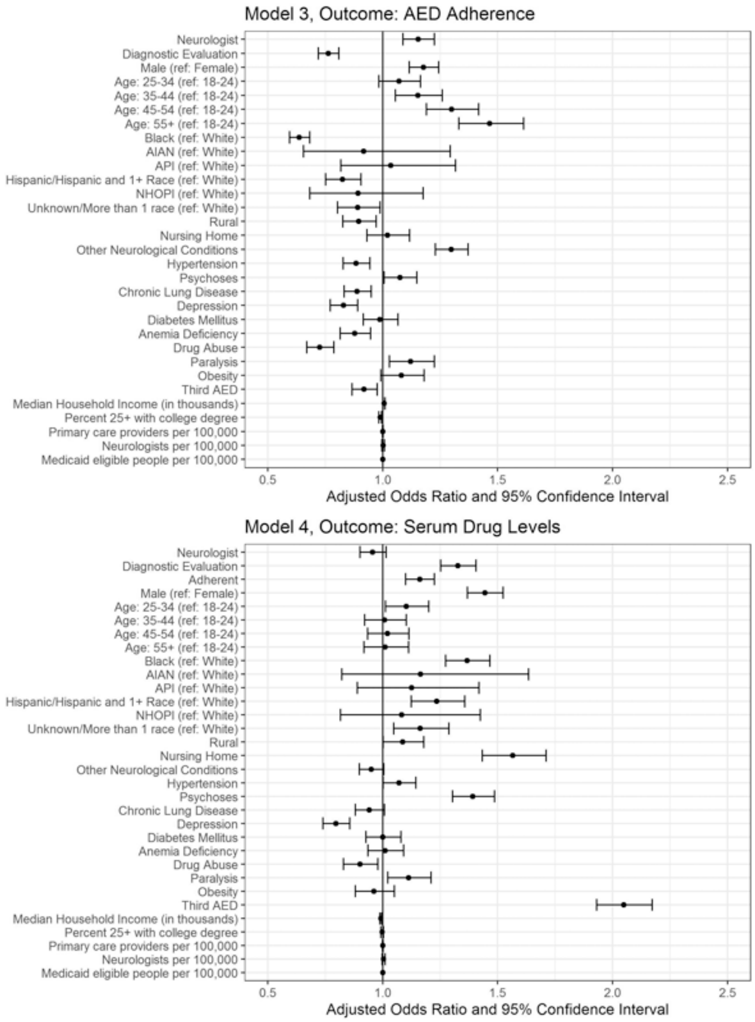

Figure 3.

Logistic regression models 3 and 4, if the person was adherent to anti-epileptic drugs (AEDs) and had serum drug levels checked respectively. Reference levels are given for multi-categorical variables, while the other factor variables represent the odds ratio for “yes”. AIAN: American Indian, Alaskan Native; API: Asian, Pacific Islander; NHOPI: Native Hawaiians and Other Pacific Islander. Other neurological conditions: cerebrovascular disease, cerebral palsy, intellectual and developmental disabilities, traumatic brain injury. AED: anti-epileptic drug.

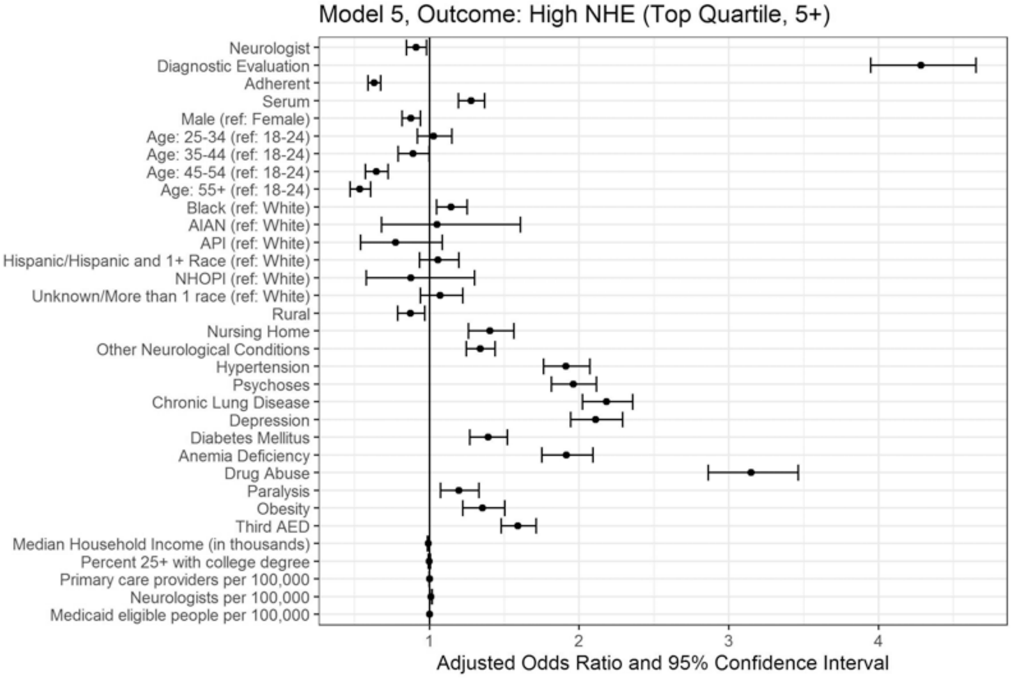

Figure 4.

Logistic regression model 5, where the outcome is in being in the top quartile of negative health events (emergency department visits and hospitalizations post-index date). Reference levels are given for multi-categorical variables, while the other factor variables represent the odds ratio for “yes”. AIAN: American Indian, Alaskan Native; API: Asian, Pacific Islander; NHOPI: Native Hawaiians and Other Pacific Islander. Other neurological conditions: cerebrovascular disease, cerebral palsy, intellectual and developmental disabilities, traumatic brain injury. AED: anti-epileptic drug.

Table 1.

Characteristics of the 25,663 individuals identified with incident epilepsy in Medicaid claims data.

	Total n = 25,663
Female n (%)	14,755 (57.5)
Rural n (%)	4,287 (16.7)
Nursing home n (%)	2,826 (11.0)
Race/Ethnicity n (%)	
White	14,778 (57.6)
Black	5,654 (22.0)
American Indian/Alaskan Native	149 (0.6)
Asian Pacific Islander	334 (1.3)
Hispanic/Hispanic and 1+ Race	2,681 (10.4)
Native Hawaiians and Other Pacific Islander	242 (0.9)
Unknown/More than 1 race	1,825 (7.1)
Age in years (at index date) n (%)	
18-24	4,233 (16.5)
25-34	5,472 (21.3)
35-44	4,917 (19.2)
45-54	6,205 (24.2)
55+	4,836 (18.8)
Median [IQR]	41.5 [23.6]
Comorbidities n (%)	
Other neurological conditions	15,575 (60.7)
Hypertension	8,820 (34.4)
Psychoses	5,871 (22.9)
Chronic pulmonary disease	5,710 (22.2)
Depression	4,584 (17.9)
Diabetes mellitus	4,272 (16.6)
Deficiency anemias	3,814 (14.9)
Substance abuse	3,233 (12.6)
Paralysis	2,959 (11.5)
Obesity	2,682 (10.5)
Third AED n (%)	6,809 (26.5)
County-level care availability median [IQR]	
Median Household Income	$50,094 [$15,050]
Percent of individuals over 25 with a college degree	25.4 [13.4]
Primary care providers per 100,000 population	70.2 [32.3]
Neurologists per 100,000 population	3.9 [4.6]

	Total n = 25,663
Number of Medicaid-eligible per 100,000 population	25,298 [13,826]
Neurologist n (%)	9,584 (37.3)
Diagnostic evaluation n (%)	14,785 (57.6)
Adherent to AED n (%)	15,880 (61.9)
Serum levels checked n (%)	10,263 (40.0)
Negative health events median [IQR]	2.0 [5.0]

Other neurological conditions: cerebrovascular disease, cerebral palsy, intellectual and developmental disabilities, traumatic brain injury. AED: anti-epileptic drug.

[1] Median household income was scaled to thousands for the logistic regression models, therefore the odds ratio would represent the odds given a difference of $1,000.

[2] 571 individuals had an encounter with a neurologist prior to their index date, but none subsequent. For this study they were counted as not having a neurologist visit.