Published in final edited form as:

Epilepsia. 2022 August ; 63(8): 2144–2154. doi:10.1111/epi.17305.

Drivers of US health care spending for persons with seizures and/or epilepsies, 2010–2018

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Abstract

Objective: This study was undertaken to characterize spending for persons classified with seizure or epilepsy and to determine whether spending has increased over time.

Methods: In this cross-sectional study, we pooled data from the Medical Expenditure Panel Survey (MEPS) household component files for 2010–2018. We matched cases to controls on age and sex of a population-based sample of MEPS respondents (community-dwelling persons of all ages) with records associated with a medical event (e.g., outpatient visit, hospital inpatient) for seizure, epilepsy, or both. Outcomes were weighted to be representative of the civilian, non-institutionalized population. We estimated the treated prevalence of epilepsy and seizure, health care spending overall and by site of care, and trends in spending growth.

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AUTHOR CONTRIBUTIONS

Lidia M. V. R. Moura contributed to study design and conceptualization, data analysis, interpretation of data, and original draft of the manuscript. Ioannis Karakis contributed to data interpretation and drafting of the manuscript for intellectual content. Matthew M. Zack contributed to study design, data interpretation, and revision of the manuscript for intellectual content. Niu Tian contributed to study design, interpretation of data, and revision of the manuscript for intellectual content. Rosemarie Kobau contributed to study design, interpretation of data, and revising the manuscript for intellectual content. David Howard contributed to study design and conceptualization, data analysis, interpretation of data, and revising the manuscript for intellectual content. Statistical analysis was conducted by Lidia M. V. R. Moura and David Howard.

CONFLICT OF INTEREST

L.M.V.R.M. receives support from the Centers for Diseases Control and Prevention (U48DP006377), the National Institutes of Health (NIH-NIA 5K08AG053380–02, NIH-NIA 5R01AG062282–02, NIH-NIA 2P01AG032952–11), and the Epilepsy Foundation of America, and reports no conflict of interest. I.K. receives support from the Centers for Diseases Control and Prevention (U48DP006377) and NIH (R01 NS110347–01A1) and reports no conflict of interest. M.M.Z., N.T., and R.K. are employees of the Centers for Diseases Control and Prevention and report no conflicts of interest (U48DP006377). D.H. receives support from the Centers for Diseases Control and Prevention (U48DP006377) and reports no conflict of interest. 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.

SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher’s website.

Results: We identified 1078 epilepsy cases and 2344 seizure cases. Treated prevalence was .38% (95% confidence interval [CI] = .34–.41) for epilepsy, .76% (95% CI = .71–.81) for seizure, and 1.14% (95% CI = 1.08–1.20) for epilepsy or seizure. The difference in annual spending for cases compared to controls was $4580 (95% CI = $3362–$5798) for epilepsy, $7935 (95% CI, $6237–$9634) for seizure, and $6853 (95% CI = $5623–$8084) for epilepsy or seizure, translating into aggregate costs of $5.4 billion, $19.0 billion, and $24.5 billion. From 2010 to 2018, the annual growth rate in total spending incurred for seizures and/or epilepsies was 7.6% compared to 3.6% among controls.

Significance: US economic burden of seizures and/or epilepsies is substantial and warrants interventions focused on their unique and overlapping causes.

Keywords

burden; cost; drugs; epilepsy; MEPS

1 | INTRODUCTION

Understanding the economic costs associated with epilepsy is important for assessing the value of policies to reduce the burden of the disease and the value of medical interventions designed to reduce symptoms. Community-based surveillance of active epilepsy or seizure disorder (self-reported doctor-diagnosed epilepsy and either currently taking antiseizure medication or experiencing one or more seizures in the past year) indicates about 1.2% of the US population (3.4 million people) live with active epilepsy.[1] Approximately 10% of people will experience a seizure, a sudden abnormal surge of electrical activity in the brain.[1,2] There are many types of seizures (e.g., provoked vs. unprovoked), and some patients may ultimately meet the clinical definition of epilepsy (i.e., at least two unprovoked seizures ≥24 h apart; one unprovoked seizure and ≥60% probability of another within 10 years; or epilepsy syndrome).[3]

The evaluation and management of persons with suspected or definite seizures and/or epilepsies typically overlap in many aspects (e.g., tests, providers, care setting), particularly during initial evaluation of a new onset seizure. Studies show median delays of 12–19 months in epilepsy diagnosis following an incident seizure.[4–6] Some patients may prefer the term “seizure disorder” to avoid epilepsy stigma and associated restrictions, and in some cases epilepsy is misdiagnosed.[5]

Epilepsy is associated with significant health and socioeconomic disparities, and patients may not disclose their condition due to stigma.[7–11] Among 19 studies published between 1999 and 2014 included in Begley and Durgin’s systematic review,[12] the direct costs attributable to epilepsy ranged from $1022 to $19 749 (2013 dollars). The wide range of estimates indicates how differences in period, data source, cost attribution method (e.g., select cost components vs. total direct costs), subpopulations, and covariates can affect estimates of epilepsy-specific costs. Patients with milder cases that allow continued employment may be overrepresented in claims from employer-based health plans.[4,6,13] We expect that costs have increased over time due to the adoption of new technology (e.g., laser ablation and neurostimulation approaches for drug-resistant epilepsies), new drugs, and increases in insurance coverage following the Affordable Care Act.[8] Patients' out-of-pocket costs have not been as widely studied,[14] but are an important area for research given the growth of high-deductible health plans.

In this study, we estimated the prevalence of and characterized health care spending for persons classified with seizure or epilepsy using 2010–2018 Medical Expenditure Panel Survey (MEPS) data—a set of large-scale surveys of noninstitutionalized individuals, their medical providers (doctors, hospitals, pharmacies, etc.), and employers across the United States. We examined both conditions to account for the diagnostic and management overlap of epilepsy and seizure.

2 | MATERIALS AND METHODS

Emory University's institutional review board approved this study, informed consent was waved due to the nature of the study, and we followed STROBE Reporting Guidelines (Table S1).[15–17] We used MEPS as a repeated cross-sectional survey from 2010 to 2018 to identify survey participants classified with seizures, epilepsies, or seizures or epilepsies, to estimate differential health care spending (i.e., emergency department visits, inpatient care, prescription drugs, out-of-pocket cost) among cases and matched controls based on pertinent sociodemographic and clinical characteristics.[9,18–21]

2.1 | Data sources and sampling approach

MEPS is a set of surveys that collects data on health services that people use, their costs, payers, health insurance status of participants, and related data to generate nationally representative estimates of health care costs (the sum of direct payments for health care provided during the year)[22] for the civilian, noninstitutionalized population.[23–27] We used the MEPS Household Component and Condition files. The former is drawn from households that participated in the previous year's National Health Interview Survey.[27] Households are surveyed over five rounds over a 2-year period, and information is collected from about 13 000 households and 30 000 individuals annually. Asian, Black, and Hispanic individuals are oversampled. Data are collected via computer-assisted personal interviewing. The response rate to the full-year file, the main source of information about health care spending, was about 44% in 2017.[28]

2.2 | Definition of epilepsy and seizures

We identified respondents with records in the MEPS condition files for epilepsy or seizure. Respondents were asked to self-report conditions that bothered them and were associated with a health care encounter, prescription drug, or a disability day. More than 95% of the condition records for epilepsy and seizure were associated with a medical encounter or a prescription drug. Respondents' descriptions of their conditions were recorded verbatim during the household interview and then translated to International Classification of Diseases codes at the three-digit level by professional coders. Interviewers prompt respondents to provide specific diagnoses rather than symptoms. Of MEPS respondents with an epilepsy diagnosis recorded in their medical record, 78.9% have a condition record associated with a medical event for epilepsy (operationalized in MEPS as "treated prevalence").[19,20]

To examine whether the MEPS condition records miss patients with epilepsy when a single definition is adopted,[20] we examined the proportion of respondents receiving antiseizure medications generally (e.g., prescribed for pain or anxiety, like benzodiazepines or gabapentin) and medications prescribed primarily for an epilepsy diagnosis (e.g., levetiracetam, lacosamide).[21]

2.3 | Health care spending

Health care represented costs for physician office, hospital, emergency department, outpatient, home health, and dental services and prescription drugs and medical equipment. Costs represented payments from insurers to providers and respondents' out-of-pocket costs. MEPS obtains payment amounts directly from respondents' providers and pharmacies. We updated health care costs to 2019 US dollars using the Medicare Economic Index. We winsorized each cost category at the 99th percentile to downweight outliers.

2.4 | Additional demographic and clinical characteristics

We used the MEPS condition files to identify respondents with comorbid conditions (e.g., emphysema, diabetes) and known risk factors (e.g., traumatic brain injury, cerebrovascular accident) that would have an expected association with higher health care spending. We measured insurance status using the "INSCOV" variable, which indicates whether the respondent had any private or public coverage during the prior year. Otherwise, respondents were classified as being uninsured the entire year. Inclusion of insurance status and type in our study is important given the associations between socioeconomic factors, health care use, and shifting insurance status among epilepsy and seizure patients.[8,29]

2.5 | Statistical analysis

Records for respondents included in the MEPS for 2 consecutive years were treated as independent observations. The MEPS stratum and primary sampling unit variables account for clustering at the respondent level. We matched each respondent with a condition record for seizures, epilepsies, or seizure or epilepsies to 10 control respondents based on age and sex. We performed all analyses in Stata version 16.0 (StataCorp). All analyses were weighted for the MEPS complex survey design.

We compared spending between cases and controls using generalized linear models with a Gamma distribution and a log link. For each condition and cost category (e.g., overall, inpatient), we estimated three models. The first included only a constant term, the second adjusted for patient demographic characteristics (age group, sex, race/ethnicity, marital status, region) and education level, and the third further adjusted for comorbidities (Table S2).

We omitted insurance status as a covariate, because it was not independent. Seizures or epilepsies may cause persons to lose employment and lose access to employer-sponsored insurance. Conversely, people with seizures or epilepsy may be more likely to buy individual coverage or enroll in government programs to obtain care.[8]

Comparing estimates across models allowed us to assess the sensitivity of estimated cost differences to patient characteristics. We reported marginal effects (or “predicted marginals”), which represented the expected difference in spending following adjustment. Using the full model, we also compared total expenditures between cases and controls by subgroups. We combined estimates of the prevalence of persons with seizures, epilepsies, or seizures or epilepsies with estimates of the average and incremental costs per case and the total population covered by MEPS to calculate the aggregate annual cost of each condition.

We estimated annual growth rates by estimating two-part models separately for cases and controls that included a time trend variable. We divided the marginal effect of the time trend variable by average spending across the entire period to calculate growth rates. We evaluated the significance of differences in growth rates by estimating two-part models on the entire sample (cases and controls) that included separate time trend variables for cases and controls. We used a Wald test to examine the significance of these differences in the time trend. We estimated total spending by multiplying estimates of disease prevalence by regression-adjusted estimates of spending attributable to epilepsy or seizure.

2.6 | Data availability

Researchers and users with approved research projects can access MEPS data files that have not been publicly released for reasons of confidentiality.[19,20]

3 | RESULTS

3.1 | Population characteristics

We identified 2344 persons with a condition record for seizure, and 1078 persons with condition records for epilepsy. Few respondents, 89 for seizure and 53 for epilepsy, had a condition record that was not associated with a medical event. A total of 3422 respondents had either a record for epilepsy or seizure.

Among respondents with seizures (no epilepsy code), 1359 (58.0%) had a prescription for antiseizure medication and 867 (37.0%) had a prescription for a drug used in patients with epilepsy (e.g., levetiracetam). Among respondents with epilepsy, 729 (67.6%) had a prescription for antiseizure medication and 558 (51.8%) had a prescription for a drug used in patients with epilepsy (Table S3). Among the 290 791 respondents without condition records for epilepsy or seizure, 19 557 (6.8%) received an antiseizure medication and 2187 (.8%) had a prescription for a drug used in patients with epilepsy.

3.2 | Treated prevalence

Seizure prevalence was .76 (95% confidence interval [CI] = .71–.81), and epilepsy prevalence was .38% (95% CI = .34–.41; Table S4). The treated prevalence of epilepsy or seizure was 1.14% (95% CI = 1.08–1.20).

3.3 | Covariate balance

After matching on age and sex, the distributions of cases and controls across age and sex groups were similar (Table 1). Remaining differences were likely due to sample weights to the matched sample. Epilepsy cases were more likely to be non-Hispanic White, to be married, and to have graduated from high school but not college.[30] Comorbidities were more common among epilepsy and seizure cases than controls (Table S2).

Compared to their controls, a similar proportion of respondents with epilepsy were uninsured for the entire year, 8.4% versus 10.8% (estimates reflect sample weights). Respondents with epilepsy were more likely to have public coverage (37.2% vs. 21.4%) but less likely to have private coverage (54.4% vs. 67.8%). The proportion of respondents with epilepsy who were uninsured declined from 12.8% in 2010 to 3.4% in 2018 (Table S5).

3.4 | Spending

Average annual spending was $11 333 for persons with epilepsy, $16 951 for persons with seizures, and $15 096 for persons with epilepsy or seizures (Table 2). Regression-adjusted differences in spending between cases and controls declined as more covariates were added to the model. The unadjusted difference in spending between epilepsy or seizure cases and controls was $9385, and the regression-adjusted difference from the model that included all controls was $6835 (95% CI = $5623–$8084; Table S6). Adjusted differences from the full model were $4580 (95% CI = $3362–$5798) for epilepsy cases versus controls and $7935 (95% CI = $6237–$9634) for seizure cases versus controls (Table S6).

Spending in the “other” category, which includes outpatient care, accounted for roughly $3052 (95% CI = $2176–$3929) of the difference in overall spending between epilepsy or seizure cases versus controls, and inpatient care and prescription drugs accounted for equal amounts (approximately $1400; Table 2). Average out-of-pocket costs for epilepsy or seizure cases were $991, and the difference in out-of-pocket costs between cases and controls was $213.

3.5 | Time trend

Spending overall, and prescription drug and outpatient costs were significantly higher in 2012 and in subsequent years among epilepsy cases versus controls (Figure 1A–D). Annualized growth rates over the period 2010–2018 were higher for cases compared to controls (Table 2). For example, the growth rate in total spending incurred by epilepsy or seizure cases was 7.6% compared to 3.6% among controls. Differences in spending growth between cases and controls were especially large for inpatient care (15.1% vs. 5.0%) and prescription drugs (8.8% vs. 1.9%; Table 2). Out-of-pocket spending did not change much over the study period.

3.6 | National economic burden estimate

Multiplying our estimates of prevalence (first row of Table S5) by our estimates of the incremental cost per case from the regression model that includes all covariates (Model 3 in Table 2) and by the population covered by MEPS (314 million), we estimate that total costs for persons with epilepsy or seizure was $54.0 billion nationally (Figure 2). Incremental costs, which capture the added contribution of epilepsy or seizure, were $24.5 billion.

4 | DISCUSSION

Based on nationally representative US data from 2010–2018, direct health care spending was $6853 ($5623–$8084) higher annually among persons with seizures and/or epilepsies compared to controls, adjusting for sociodemographic and clinical factors, corresponding to aggregate total health care spending of $5.4 billion for epilepsy, $19.0 billion for seizure, and $24.5 billion for epilepsy or seizure. Our study updates findings from Dieleman et al., who reported that epilepsy-attributable personal health care spending in 2013 was $4.3 billion by using not only more recent expenditure data, but a more sensitive case ascertainment approach (i.e., persons with seizures or epilepsies),[20] yielding lower and upper bounds of epilepsy- and seizure-attributable costs. The wide range of epilepsy-attributable cost estimates in previously published studies between 1999 and 2014 (e.g., $2050 [2013 dollars] to $19 800 per patient)[31,32] is at least in part explained by variability in data sources, study design, and other factors like age ranges and care setting. For instance, a study using institutionalized Medicare data by Fitch et al.[33] reported that the risk-adjusted incremental cost of epilepsy averaged $6087.6 (annually). Lekobou et al.[34] studied a similar age range without restriction to institutionalized patients and obtained a lower averaged adjusted incremental health care cost associated with epilepsy ($4595). Our study is therefore consistent with previous US-based data but is based on a nationally representative community-dwelling population. MEPS data, however, underestimates all health care spending, because MEPS methodology excludes institutionalized persons, more likely to have a higher prevalence of epilepsy, and additional costs (e.g., transportation to health care). Additional studies of epilepsy- or seizure-attributable direct (health care spending, informal caregiving) and indirect (e.g., lost productivity) costs are warranted to demonstrate the total burden of these conditions.

Although a subset of total population prevalence, the treated prevalence estimate (based only on condition records with medical events) is slightly lower, but within the range of the recently published Centers for Disease Control and Prevention total population prevalence estimate for active epilepsy (1.2% [95% CI = 1.1–1.4]).[1] Treated prevalence may approximate total population prevalence for conditions that require ongoing treatment, such as epilepsy.[19] Treated epilepsy prevalence was lower among Black, non-Hispanic persons, but seizure prevalence was higher, suggesting underreporting of medical events attributable to epilepsy versus seizures, inequities in accessing health care, or that epilepsy may be underdiagnosed or underreported in this population.

A substantial proportion of respondents reported only seizures but had a corresponding record for epilepsy-specific antiseizure medication like leveti-racetam. These are likely persons with epilepsy (or at least treated for epilepsy) who attributed the cause of their medical event to “seizure.” Respondents who experienced events that were the direct result of a seizure (e.g., a fall) may have been more likely to attribute the event to a diagnosis of “seizure” rather than a diagnosis of “epilepsy.” We expected average costs to be higher in this group (seizure, no epilepsy), because treatment for seizure-related events, as opposed to the underlying diagnosis, is more likely to occur in the inpatient and emergency department settings.

Spending for patients with epilepsy, especially among select sociodemographic subgroups, has increased over time. Increases may be due to increases in insurance coverage and adoption of new technologies. Consistent with a previous report,[8] we found a significant decline in the proportion of people with epilepsy or seizure who were uninsured. Use of in-hospital and ambulatory video-electroencephalographic (EEG) monitoring has increased, both of which have also been supported by hospital administrators and an expanding literature demonstrating the accuracy of multiple EEG modalities for detection of subclinical seizures, functional spells, and other findings.[35] However, previous studies have yet to demonstrate an association between the detection of abnormalities and improvement in outcomes for patients with epilepsy (e.g., quality of life, seizure control).

Our study contributes novel and valuable information on the alarming difference in growth rates for “other” spending (e.g., dental services, home health care). Our study aligns with national projections in growing health spending for various services.[36] We also showed a substantial difference in epilepsy-a ttributable inpatient care (7.7% for epilepsy or seizure vs. −1.0% for controls). Inpatient care for epilepsy and/or seizures includes urgent admissions for breakthrough seizures, elective admissions for diagnostic neurophysiologic investigation, presurgical evaluations, and admissions for surgical procedures. This finding is also concordant with existing literature using the MEPS data that revealed an increasing growth in inpatient hospital care spending for those with private insurance.[37]

This study also highlighted the rising prescription drug costs associated with persons with epilepsy or seizure. Increasing use of drugs approved during the study period, such as clobazam and lacosamide, may contribute to the increase in costs. Average out-of-pocket spending was almost $1000 among persons with epilepsy or seizure, but attributable out-of-pocket spending ($200) was modest. We expected out-of-pocket spending to increase alongside total spending, but that was not the case, probably due to the increase in insurance coverage. Also, out-of-pocket maximums in private plans insulate patients from increases in spending to some degree.

Health care innovations and studies that account for both health care spending and epilepsy-related outcomes are needed with particular attention to social vulnerability and the effect of cost-sharing among people with epilepsy or seizures.[31]

4.1 | Limitations and future directions

This study has several limitations contributing to an underestimation of costs.

4.1.1 | Generalizability, selection, and reporting biases—Although MEPS sample weights produce estimates representative of the community-dwelling population, MEPS is also subject to nonresponse bias, social desirability biases in self-reporting conditions, including those attributable to medical events. With population aging, there is a growing cohort of institutionalized individuals with seizures or epilepsy who were excluded from MEPS. Understandably, the cost of epilepsy care is higher in institutionalized patients, as the prevalence of seizure and/or epilepsy in this population is seven times higher than community-dwelling patients.[12]

4.1.2 | Confounding—

Comparisons of cases and controls assume that, after matching and regression adjustment, there are no factors related to both a condition record for epilepsy or seizure and health care spending. As we added controls to regressions comparing spending, estimates of the impact of epilepsy or seizure on spending became smaller. This pattern suggests that unobserved factors operated in the same direction, that is, that our spending estimates were biased upward. Residual confounding may result from factors unaccounted for through matching (e.g., baseline diagnoses of insufficiently treated mental health conditions that may contribute to increased health care spending).[32,38]

4.1.3 | Effect measure modification—

The health care costs attributable to evaluation and management of epilepsy vary based on seizure types and levels of seizure control.[39] Future studies may use claims-based approaches for defining seizure control and stratifying by epilepsy subgroups.[40] Our study could not differentiate patients with prevalent versus incident epilepsy, or well-controlled epilepsy versus refractory epilepsy. These subgroups differ because they are often subject to different diagnostic and therapeutic approaches, and therefore health care costs. This study also focused on direct costs but not on indirect costs like loss of productivity and early retirement. Medicaid, Medicare, and all-payer state databases permit longitudinal tracking of patients, which would greatly improve case identification, and allow for estimation of incidence and study designs that, if properly conducted, may allow for more sensible causal inference.

5 | CONCLUSIONS

Understanding the health care costs associated with epilepsy and seizure is important for assessing the value of efforts to prevent and treat these conditions. We estimate that direct health care spending for the 3.4 million community-dwelling individuals with epilepsy and seizures was approximately $24.5 billion annually over the period 2010–2018. Spending for epilepsy and/or seizures is rising at approximately twice the rate as spending overall, although most of the increase has been borne by payers, not patients.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

ACKNOWLEDGMENTS

This publication was supported by Grant or Cooperative Agreement Number U48DP006377 (total awarded: $1 508 482), with 100% funded by the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the US Department of Health and Human Services.

Funding information

This study was funded by the Centers for Disease Control and Prevention of the US Department of Health and Human Services (Cooperative Agreement Number U48DP006377), to design and conduct all aspects of the study (i.e., data collection and management, data analysis and interpretation, manuscript preparation and review)

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. 10.15585/mmwr.mm6631a1 [PubMed: 28796763]
2. Hauser WA, Annegers JF, Rocca WA. Descriptive epidemiology of epilepsy: contributions of population-based studies from Rochester, Minnesota. Mayo Clin Proc. 1996;71(6):576–86. 10.4065/71.6.576 [PubMed: 8642887]
3. Scheffer IE, Berkovic S, Capovilla G, Connolly MB, French J, Guilhoto L, et al. ILAE classification of the epilepsies: position paper of the ILAE commission for classification and terminology. Epilepsia. 2017;58(4):512–21. 10.1111/epi.13709 [PubMed: 28276062]
4. Bensken WP, Navale SM, Andrew AS, Jobst BC, Sajatovic M, Koroukian SM. Delays and disparities in diagnosis for adults with epilepsy: findings from U.S. Medicaid data. Epilepsy Res. 2020;166:106406. 10.1016/j.eplepsyres.2020.106406
5. Parviainen L, Kalviainen R, Jutila L. Impact of diagnostic delay on seizure outcome in newly diagnosed focal epilepsy. Epilepsia Open. 2020;5(4):605–10. 10.1002/epi4.12443 [PubMed: 33336131]
6. Bensken WP, Navale SM, Andrew AS, Jobst BC, Sajatovic M, Koroukian SM. Markers of quality care for newly diagnosed people with epilepsy on Medicaid. Med Care. 2021;59:588–96. 10.1097/MLR.0000000000001541 [PubMed: 33797505]
7. Cui W, Kobau R, Zack MM, Buelow JM, Austin JK. Recent changes in attitudes of US adults toward people with epilepsy—results from the 2005 SummerStyles and 2013 FallStyles surveys. Epilepsy Behav. 2015;52(Pt A):108–18. 10.1016/j.yebeh.2015.08.040 [PubMed: 26409138]
8. Kobau R, Sapkota S, Koh HK, Zack MM. National declines in the percentages of uninsured among adults aged 18–64 years with active epilepsy, 2010 and 2013 to 2015 and 2017—U.S. national health interview survey. Epilepsy Behav. 2019;97:316–8. [PubMed: 31255566]
9. Tellez-Zenteno JF, Patten SB, Jetté N, Williams J, Wiebe S. Psychiatric comorbidity in epilepsy: a population-based analysis. Epilepsia. 2007;48(12):2336–44. [PubMed: 17662062]
10. Lu E, Pyatka N, Burant CJ, Sajatovic M. Systematic literature review of psychiatric comorbidities in adults with epilepsy. J Clin Neurol. 2021;17(2):176. [PubMed: 33835737]
11. Subota A, Jetté N, Josephson CB, McMillan J, Keezer MR, Gonzalez-Izquierdo A, et al. Risk factors for dementia development, frailty, and mortality in older adults with epilepsy—a population-based analysis. Epilepsy Behav. 2021;120:108006.
12. Begley CE, Durgin TL. The direct cost of epilepsy in the United States: a systematic review of estimates. Epilepsia. 2015;56(9):1376–87. [PubMed: 26216617]
13. Kobau R, Boring M, Zack MM, Croft JB. In 2016, Medicaid and Medicare paid about 65% of all inpatient hospitalization costs for all-age persons hospitalized with epilepsy as the principal diagnosis. Epilepsy Behav. 2021;114(Pt. A):107601. 10.1016/j.yebeh.2020.107601
14. Allers K, Essue BM, Hackett ML, Muhunthan J, Anderson CS, Pickles K, et al. The economic impact of epilepsy: a systematic review. BMC Neurol. 2015;15(1):1–16. [PubMed: 25595849]
15. Yu TC, Wu TE, Wang YS, Cheng SF, Liou SW. A STROBE-compliant case-control study: effects of cumulative doses of topical atropine on intraocular pressure and myopia progression. Medicine (Baltimore). 2020;99(48):e22745. 10.1097/MD.0000000000022745
16. Avery L, Rotondi M. More comprehensive reporting of methods in studies using respondent driven sampling is required: a systematic review of the uptake of the STROBE-RDS guidelines. J Clin Epidemiol. 2020;117:68–77. 10.1016/j.jclinepi.2019.09.024 [PubMed: 31589951]
17. White RG, Hakim AJ, Salganik MJ, Spiller MW, Johnston LG, Kerr L, et al. Strengthening the reporting of observational studies in epidemiology for respondent-d riven sampling studies: "STROBE-RDS" statement. J Clin Epidemiol. 2015;68(12):1463–71. 10.1016/j.jclinepi.2015.04.002 [PubMed: 26112433]
18. Machlin S, Cohen J, Elixhauser A, Beauregard K, Steiner C. Sensitivity of household reported medical conditions in the medical expenditure panel survey. Med Care. 2009;47(6):618–25. 10.1097/MLR.0b013e318195fa79 [PubMed: 19433993]

19. Machlin S, Soni A, Fang Z. Understanding and analyzing MEPS household component medical condition data. MEPS: Medical Expenditure Panel Survey. Maryland: Agency for Healthcare Research and Quality. Available from: https://www.meps.ahrq.gov/survey_comp/MEPS_condition_data.pdf. Accessed 27 May 2022.
20. Dieleman JL, Cao J, Chapin A, Chen C, Li Z, Liu A, et al. US health care spending by payer and health condition, 1996– 2016. JAMA. 2020;323(9):863–84. 10.1001/jama.2020.0734 [PubMed: 32125402]
21. Moura LMVR, Smith JR, Blacker D, Vogeli C, Schwamm LH, Cole AJ, et al. Epilepsy among elderly medicare beneficiaries: a validated approach to identify prevalent and incident epilepsy. Med Care. 2019;57(4):318–24. 10.1097/mlr.0000000000001072 [PubMed: 30762723]
22. Blewett LA, Drew JAR, Griffin R, Williams KCW. IPUMS health surveys: medical expenditure panel survey, version 1.1 [dataset]. Minnesota Population Center. Minneapolis, MN: University of Minnesota. Available from:. https://meps.ipums.org. Accessed 27 May 2022.
23. Williams JS, Egede LE. Differences in medical expenditures for men and women with diabetes in the Medical Expenditure Panel Survey, 2008–2016. Womens Health Rep (New Rochelle). 2020;1(1):345–53. 10.1089/whr.2020.0050 [PubMed: 33786499]
24. Gawron AJ, Staub J, Bielefeldt K. Impact of health insurance, poverty, and comorbidities on colorectal cancer screening: insights from the Medical Expenditure Panel Survey. Dig Dis Sci. 2021;66(1):70–7. 10.1007/s10620-020-06541-7 [PubMed: 32816210]
25. Mitchell JA, Williams EG, Li Y, Tarraf W. Identifying disparities in patient-centered care experiences between non-Latino White and Black men: results from the 2008–2016 Medical Expenditure Panel Survey. BMC Health Serv Res. 2020;20(1):495. 10.1186/s12913-020-05357-5 [PubMed: 32493469]
26. Lekoubou A, Bishu KG, Ovbiagele B. Nationwide trends in medical expenditures among adults with epilepsy: 2003–2014. J Neurol Sci. 2018;384:113–20. 10.1016/j.jns.2017.11.025 [PubMed: 29249368]
27. Agency for Healthcare Research and Quality. MEPS survey background. Available from: https://www.meps.ahrq.gov/mepsweb/about_meps/survey_back.jsp. Accessed 26 Dec 2022.
28. Agency for Healthcare Research and Quality. MEPS-HC response rates by panel [cited 2021 Jul 23]. Available from: https://meps.ahrq.gov/survey_comp/hc_response_rate.jsp
29. Groover O, Morton ML, Janocko NJ, Teagarden DL, Villarreal HK, Drane DL, et al. Mind the gap: health disparities in families living with epilepsy are significant and linked to socioeconomic status. Epileptic Disord. 2020;22(6):782–9. 10.1684/epd.2020.1229 [PubMed: 33337334]
30. de Boer MR, Waterlander WE, Kuijper LD, Steenhuis IH, Twisk JW. Testing for baseline differences in randomized controlled trials: an unhealthy research behavior that is hard to eradicate. Int J Behav Nutr Phys Act. 2015;12:4. 10.1186/s12966-015-0162-z [PubMed: 25616598]
31. Donahue MA, Herman ST, Dass D, Farrell K, Kukla A, Abend NS, et al. Establishing a learning healthcare system to improve health outcomes for people with epilepsy. Epilepsy Behav. 2021;117:107805. 10.1016/j.yebeh.2021.107805
32. Seneviratne U, Low ZM, Low ZX, Hehir A, Paramaswaran S, Foong M, et al. Medical health care utilization cost of patients presenting with psychogenic nonepileptic seizures. Epilepsia. 2019;60(2):349–57. 10.1111/epi.14625 [PubMed: 30577087]
33. Fitch K, Pan X, Lau J, Engel T, & Rajagopalan K. Prevalence and economic burden of epilepsy in the institutionalized medicare fee-for-service population. Am Health Drug Benefits. 2019;12(3):151–158. https://www.jns-journal.com/article/S0022-510X(17)34457-X/fulltext [PubMed: 31346367]
34. Lekoubou A, Bishu KG, Ovbiagele B. Nationwide trends in medical expenditures among adults with epilepsy: 2003–2014. Journal of the Neurological Sciences. 2018;384:113–120. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6611517/ [PubMed: 29249368]
35. Dash D, Hernandez-Ronquillo L, Moien-Afshari F, Tellez-Zenteno JF. Ambulatory EEG: a cost-effective alternative to inpatient video-EEG in adult patients. Epileptic Disord. 2012;14(3):290–7. 10.1684/epd.2012.0529 [PubMed: 22963900]

36. Keehan SP, Cuckler GA, Sisko AM, Madison AJ, Smith SD, Stone DA, et al. National health expenditure projections, 2014–24: spending growth faster than recent trends. Health Aff (Millwood). 2015;34(8):1407–17. 10.1377/hlthaff.2015.0600 [PubMed: 26220668]
37. Callison K, Nguyen BT. The effect of Medicaid physician fee increases on health care access, utilization, and expenditures. Health Serv Res. 2018;53(2):690–710. 10.1111/1475-6773.12698 [PubMed: 28419487]
38. Lekoubou A, Bishu KG, Ovbiagele B. Costs and cost-drivers of a diagnosis of depression among adults with epilepsy in the United States. Epilepsy Behav. 2019;98(Pt A):96–100. 10.1016/j.yebeh.2019.04.047 [PubMed: 31301456]
39. Begley CE, Lairson DR, Reynolds TF, Coan S. Early treatment cost in epilepsy and how it varies with seizure type and frequency. Epilepsy Res. 2001;47(3):205–15. 10.1016/s0920-1211(01)00310-2 [PubMed: 11738928]
40. Smith JR, Jones FJS, Fureman BE, Buchhalter JR, Herman ST, Ayub N, et al. Accuracy of ICD-10-CM claims-based definitions for epilepsy and seizure type. Epilepsy Res.2020;166:106414. 10.1016/j.eplepsyres.2020.106414

Key Points

- From 2010–2018, direct health care spending was $6853 (95% CI = $5623–$8084) higher annually among persons with seizures and/or epilepsies compared to controls, adjusting for sociodemographic and clinical factors
- This corresponds to $24.5 billion direct US health care spending attributable to seizures or epilepsy
- Health care spending for persons with seizures and/or epilepsies is substantial and growing

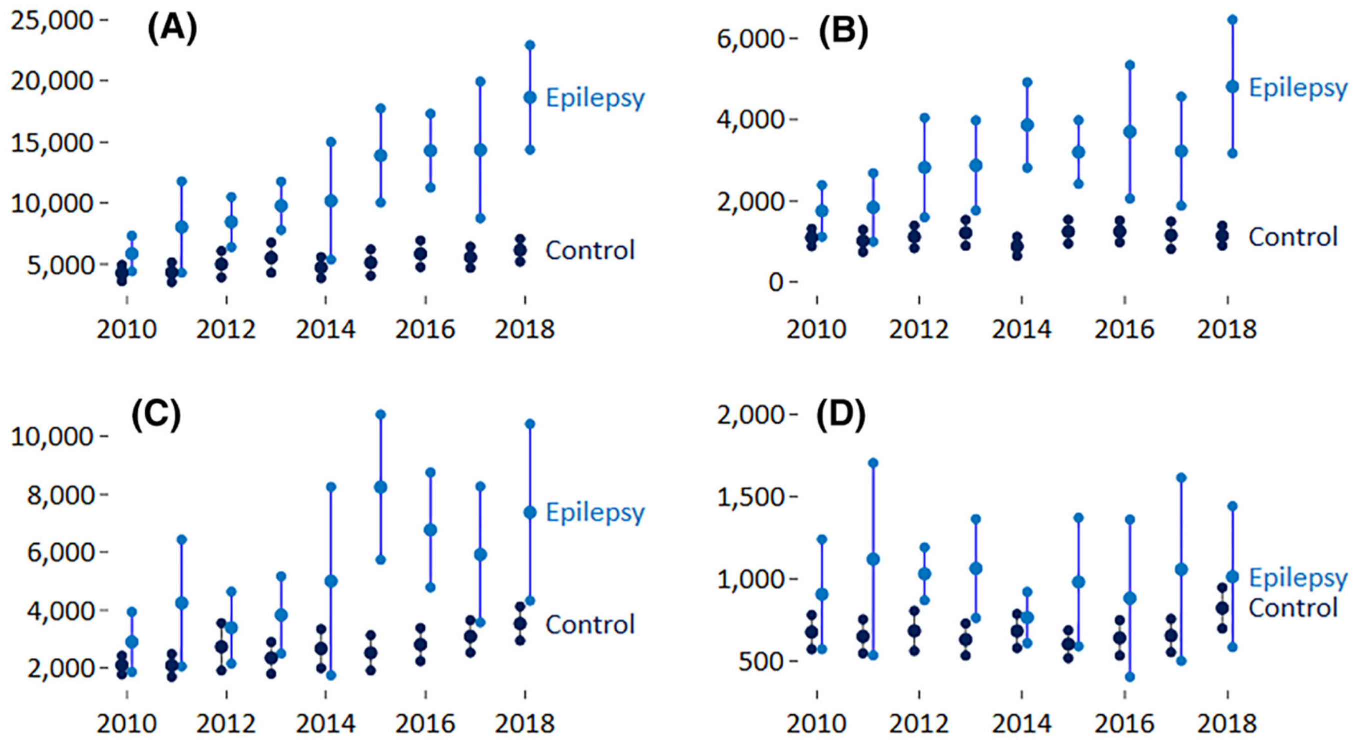

FIGURE 1.

(A) Trends in average costs: total spending. (B) Trends in average costs: prescription drugs. (C). Trends in average costs: outpatient/physician/other spending. (D) Trends in average costs: out-of-pocket spending. The graph shows means and 95% confidence intervals. Spending was winsorized at the 99th percentile. Estimates are based on the medical expenditure panel survey for 2010 through 2018 and weighted to be representative of the noninstitutionalized, community-d welling population. Confidence intervals account for the complex survey design.

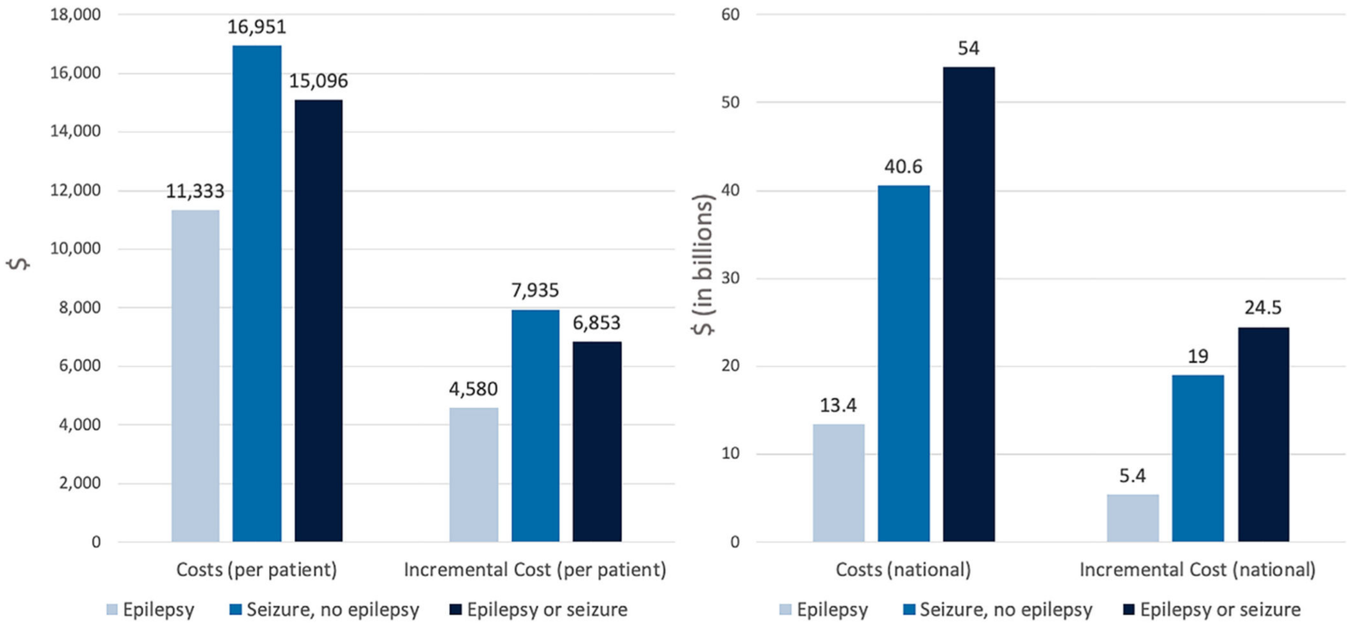

FIGURE 2.

The total burden of epilepsy and/or seizure costs (per patient and national). The estimations of the national burden of epilepsy and/or seizure assume a population size of 314 million noninstitutionalized, community-dwelling persons, and prevalence of epilepsy, seizure, and epilepsy or seizure of .38%, .76%, and 1.14%, respectively.

TABLE 1

Comparison of demographic and socioeconomic characteristics between cases and matched controls, 2010–2018

	Epilepsy		Seizure, no epilepsy		Epilepsy or seizure	
Characteristic	**Cases**	**Controls**	**Cases**	**Controls**	**Cases**	**Controls**
Age group						
0–24	326 (27.0)	978 (26.1)	661 (24.7)	1983 (24.6)	987 (25.4)	2961 (25.0)
25–49	406 (34.6)	1218 (38.4)	719 (30.0)	2157 (30.4)	1125 (31.5)	3375 (32.8)
50–64	237 (25.7)	711 (24.3)	527 (24.0)	1581 (24.3)	764 (24.6)	2292 (24.3)
65+	109 (12.6)	327 (11.2)	437 (21.3)	1311 (20.8)	546 (18.5)	1638 (17.8)
Sex						
Male	589 (53.9)	1767 (54.1)	1306 (54.5)	3918 (55.1)	1895 (54.3)	5685 (54.8)
Female	489 (46.1)	1467 (45.9)	1038 (45.5)	3114 (44.9)	1527 (45.7)	4581 (45.2)
Race/ethnicity						
White, non-Hispanic	517 (68.4)	1267 (59.9)	1003 (62.5)	3023 (64.0)	1520 (64.4)	4290 (62.7)
Black, non-Hispanic	155 (8.9)	653 (13.8)	684 (18.2)	1360 (12.0)	839 (15.1)	2013 (12.5)
Hispanic	319 (15.9)	966 (17.6)	493 (13.2)	1945 (16.0)	812 (14.1)	2911 (16.5)
Other	87 (6.8)	348 (8.8)	164 (6.2)	704 (8.1)	251 (6.4)	1052 (8.3)
Marital status						
Currently married	776 (68.8)	1985 (56.3)	1677 (64.3)	4222 (55.3)	2453 (65.8)	6207 (55.6)
Other	302 (31.2)	1249 (43.7)	667 (35.7)	2810 (44.7)	969 (34.2)	4059 (44.4)
Education level						
Less than high school	548 (42.4)	1642 (43.9)	1206 (45.2)	3713 (45.9)	1754 (44.3)	5355 (45.3)
High school graduate/GED	323 (34.3)	803 (25.1)	776 (35.8)	1734 (25.5)	1099 (35.3)	2537 (25.4)
Some college or more	207 (23.3)	789 (31.1)	362 (19.0)	1585 (28.6)	569 (20.4)	2374 (29.3)
Region						
Northeast	153 (14.4)	491 (18.1)	345 (16.3)	1173 (18.6)	498 (15.7)	1664 (18.4)
Midwest	257 (26.4)	609 (20.7)	471 (21.1)	1359 (21.7)	728 (22.8)	1968 (21.4)
South	373 (34.7)	1202 (37.1)	1017 (42.4)	2668 (36.3)	1390 (39.8)	3870 (36.5)
West	295 (24.5)	932 (24.1)	511 (20.2)	1832 (23.4)	806 (21.6)	2764 (23.6)
n	1078	10 780	2344	23 440	3422	34 220

Note: Data are presented as *n* (%). Characteristics of cases (epilepsy, seizure with no epilepsy record, and epilepsy or seizure) and controls are matched on a 1– 10 basis on age and sex. Estimates are based on the Medical Expenditure Panel Survey for 2010 through 2018 and weighted to be representative of the noninstitutionalized, community-dwelling population.

Abbreviation: GED, Graduate Equivalency Degree/General Education Diploma.

TABLE 2

Impact of epilepsy and seizure on health care spending by spending category, 2010–2018

	Average annual spending			Regression-adjusted differences			Annualized growth rate^b	
				Model 1^a	Model 2^a	Model 3^a		
	Case	Control	Difference	No covariates	Demographics/ education	Demographics/ education/comorbidities	Cases	Controls
Total spending								
Epilepsy	11333	5197	6136	5990 (4656–7325)	5486(4072–6901)	4580 (3362–5798)	10.5%	4.3%
Seizure, no epilepsy	16951	5942	11008	10551 (8719–12383)	10278(8473–12082)	7935 (6237–9634)	6.9%	3.3%
Epilepsy or Seizure	15096	5711	9385	9018(7746–10290)	8728(7466–9989)	6853(5623–8084)	7.6%	3.6%
Components of total spending								
Spending on emergency department services								
Epilepsy	452	201	251	189(110–269)	184(107–260)	157(89–226)	5.8%	4.2%
Seizure, no epilepsy	661	196	465	304 (264–345)	296 (255–338)	256 (216–297)	7.1%	2.2%
Epilepsy or seizure	592	198	394	269(234–304)	262 (227–298)	223 (188–258)	6.5%	2.9%
Spending on inpatient care								
Epilepsy	2597	1202	1395	1047 (720–1374)	1054(730–1378)	865 (475–1255)	15.1%	5.0%
Seizure, no epilepsy	5199	1504	3695	2339 (1913–2765)	2354 (1931–2777)	1749 (1357–2141)	5.8%	−3.2%
Epilepsy or seizure	4340	1410	2930	1935 (1608–2261)	1962 (1638–2285)	1489 (1171–1806)	7.7%	−1.0%
Spending on prescription drugs								
Epilepsy	3062	1123	1939	1756 (1387–2125)	1597 (1219–1974)	1385 (1043–1727)	8.8%	1.9%
Seizure, no epilepsy	3485	1291	2194	1952 (1644–2260)	1830 (1538–2123)	1312(1047–1577)	7.6%	4.7%
Epilepsy or seizure	3345	1239	2107	1880(1646–2114)	1752 (1527–1978)	1344 (1133–1556)	7.7%	4.0%
Other spending								
Epilepsy	5222	2671	2551	2437(1455–3420)	2284 (1245–3324)	1941(1025–2858)	93%	5.6%
Seizure, no epilepsy	7606	2952	4654	4404 (3110–5697)	4370(3083–5658)	3601 (2305–4897)	7.8%	5.8%
Epilepsy or seizure	6819	2865	3954	3747 (2866–4629)	3699 (2820–4577)	3052 (2176–3929)	7.8%	5.8%
Out-of-pocket spending^c								
Epilepsy	982	676	307	315(162–468)	282(134–430)	246 (104–389)	−1.4%	2.0%
Seizure, no epilepsy	996	739	257	264 (163–366)	284 (189–379)	199 (102–295)	1.3%	1.6%
Epilepsy or seizure	991	719	272	280 (204–356)	282 (213–352)	213 (142–283)	.8%	1.7%

Note: Regression-adjusted differences are marginal effects from a two-part model. The second part is a generalized linear model with a gamma distribution and a log link. Costs are in 2019 US dollars. Estimates are based on the Medical Expenditure Panel Survey for 2010 through 2018 and weighted to be representative of the noninstitutionalized, community-dwelling population. Confidence intervals account for the complex survey design.

[a] The first model does not include covariates and the second adjusts for age group, sex, race/ethnicity, marital status, region, and education level. The third adds controls for comorbidities.

[b] All differences were significant at the 1% level.

[c] Out-of-pocket spending is included in total spending. It includes out-of-pocket spending for emergency department services, inpatient care, prescription drugs, and other services.