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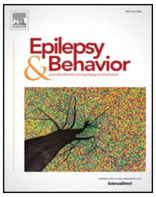

Epilepsy by the Numbers — from the US Centers for Disease Control and Prevention

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☆

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ABSTRACT

Epilepsy is more common among children and adults living in households at lowest incomes. Like those living with any complex chronic condition, people with epilepsy need quality healthcare to improve their health and social outcomes. The purpose of this study was to use the latest national data to provide updated estimates of the percentages of adults aged 18–64 years with active epilepsy who were uninsured in 2010, 2013, 2015, and 2017 and to examine changes in health insurance coverage during these years. We analyzed nationally representative samples of adults (aged 18–64 years) from the 2010, 2013, 2015, and 2017 National Health Interview Survey (NHIS). We used a validated epilepsy surveillance case definition to classify adults as having active epilepsy during 2010 and 2013 (n = 507) and during 2015 and 2017 (n = 582). We used the NHIS recode variables available in each year that account for a series of questions posed to respondents to confirm coverage and that ultimately classify respondents with different healthcare coverage types. Overall, the percentage of uninsured adults among respondents aged 18–64 years with active epilepsy decreased by more than half (59%), from 17.7% (95% confidence interval [CI] = 13.6%–22.7%) in 2010 and 2013 to 7.3% (95% CI = 4.8%–10.7%) in 2015 and 2017. The decrease in the percentage of uninsured adults with active epilepsy after 2010 and 2013 was balanced by a similar increase in public insurance coverage and private insurance coverage in 2015 and 2017.
Epilepsy stakeholders can ensure that all uninsured adults with epilepsy obtain access to health insurance coverage. National Health Interview Survey data on epilepsy, when available, can be used to monitor trends in insurance status in the new decade.

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1. Introduction

Epilepsy is more common among children and adults living in households with the lowest incomes [1–4]. Adults with epilepsy living in the U.S. report suboptimal physical and mental health relative to national health goals for 2020 [5]. Like those living with any complex chronic condition, people with epilepsy need quality healthcare to improve their health and social outcomes [6]. Compared with US adults without the disorder, adults with active epilepsy are over three times more likely to be insured by Medicaid but less likely to have private insurance, consistent with the higher rates of unemployment for this population [7]. Adults with epilepsy are more likely to report cost and inaccessible transportation as barriers to healthcare [7,8]. The last national estimates of health insurance coverage for U.S. adults ≥18 years old with active epilepsy are based on data from 2010 and 2013 [7]. The purpose of this study was to use the latest national data to provide updated estimates of the percentages of adults aged 18–64 years with active epilepsy who were uninsured in 2010, 2013, 2015, and 2017 and to examine changes in health insurance coverage during those years.

2. Methods

The National Health Interview Survey (NHIS) is conducted through personal household interviews, and it provides nationally representative estimates for the civilian, noninstitutionalized US population on

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health status, selected conditions, insurance coverage, and numerous other health topics [9]. The Centers for Disease Control and Prevention's Epilepsy Program included supplemental questions on epilepsy on the Sample Adult Core component of the survey in 2010, 2013, 2015, and 2017 [9]. We analyzed nationally representative samples of adults aged 18–64 years in combined samples from the NHIS from 2010 (n = 27,157), 2013 (n = 34,557), 2015 (n = 33,672), to 2017 (n = 26,742). We restricted our analyses to adults aged 18–64 years because at least 99% of those ≥65 years have health insurance [10], and data on active epilepsy in children are not collected by the NHIS. We used a validated case definition for community-based surveillance of epilepsy to classify adults with active epilepsy if they reported doctor-diagnosed epilepsy or seizure disorder, and reported either taking medication for their epilepsy/seizure disorder or having had one or more seizures in the past year [11]. For the combined 2010 and 2013 samples, we classified 507 respondents with active epilepsy. For the combined 2015 and 2017 samples, we classified 582 respondents with active epilepsy.

Health insurance coverage was assessed with a question in each survey year that asked a respondent, answering on behalf of all family members, “What kind of health insurance or health care coverage do you have?” A respondent could select one or more of the following response options: Private health insurance, Medicare, Medi-Gap, Medicaid, Military healthcare (TRICARE/VA/CHAMP-VA), Indian Health Service, State-sponsored health plan, Other government program, Single service plan (e.g., dental, vision, prescriptions), No coverage of any type, Refused, or Don't know [9]. We used the NHIS recode variables available in each year (e.g., “PRIVATE”, “MEDICARE”, “MEDICAID”, “MILCARE”) that account for additional follow-up questions posed to respondents to confirm coverage and that ultimately classify respondents with different healthcare coverage types [9]. We identified uninsured adults aged 18–64 years as those who reported “No coverage of any type” using the variable “NOTCOV” [9]. We excluded respondents who refused to answer the insurance question or who did not know the answer at the time of the interview. The NHIS health insurance questions have a low-item nonresponse rate (~1%) [10].

We used SAS-callable SUDAAN® (version 9.4) statistical software to account for the NHIS's complex survey design, using stratification, clustering, and weighting. We estimated the percentage who were uninsured among adults aged 18–64 years with active epilepsy for each year and for two combined periods (2010 and 2013; 2015 and 2017). For the aggregated time periods, we classified respondents into three groups: uninsured (based on the “NOTCOV” variable), private health insurance (based on the “PRIVATE” variable), or public health insurance (based on the variables, “MEDICARE,” “MEDICAID,” “OTHPUB,” “OTHGOV,” or “MILCARE”) [9]. We accounted for a change in the NHIS survey design in 2016 by revaluing the stratifications of NHIS data from 2017 and merging them with data from 2010, 2013, and 2015 [9]. We used logistic regression to adjust all model estimates for age, and then for selected sociodemographic characteristics, including marital status and education level. We considered differences in estimates significantly different at 0.05 using a Z test. In post hoc analyses, we used logistic regression to examine changes in the distribution of respondents with active epilepsy by insurance coverage type, adjusting for age, for the periods 2010–2013 and 2015–2017.

3. Results

Because changes in health insurance coverage following adjustment for sociodemographic characteristics did not differ much from the age-adjusted estimates alone (data not shown), we report only the latter. Overall, the age-adjusted percentage of uninsured among adults aged 18–64 years with active epilepsy in 2010 was 18.8% [95% confidence interval (CI) = 12.8%–26.7%; weighted estimate = 346,000 adults]; in 2013, 16.6% [95% CI = 11.4%–23.6%; weighted estimate = 299,000 adults]; in 2015, 7.5% [95% CI = 4.4%–12.4%; weighted estimate = 190,000 adults]; and in 2017, 7.1% [95% CI = 3.8%–12.6%; weighted estimate = 184,000 adults].[1]

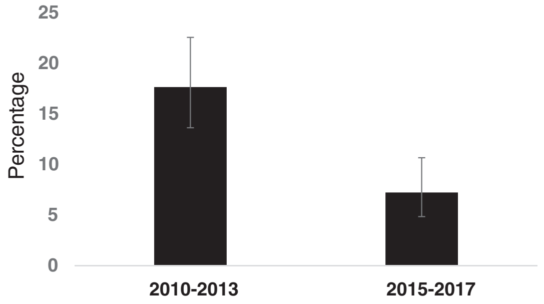

Fig. 1. Age-adjusted percentages and 95% confidence intervals of uninsured among adults aged 18–64 years with active epilepsy—National Health Interview Survey 2010 and 2013 and 2015 and 2017.

Overall, the percentage of uninsured adults among respondents aged 18–64 years with active epilepsy decreased by more than half (59%), from 17.7% [95% CI = 13.6%–22.7%] in 2010 and 2013 to 7.3% [95% CI = 4.8%–10.7%] in 2015 and 2017 ($p < 0.05$) (Fig. 1). The decrease in the percentage of uninsured adults with active epilepsy after 2010 and 2013 was balanced by a similar increase in public insurance coverage and private insurance coverage in 2015 and 2017. For example, in 2015 and 2017, about 53% (95% CI = 46%–59%) of adults with active epilepsy had public health insurance compared with 48% (95% CI = 42%–54%) in 2010 and 2013; and in 2015 and 2017 40% (95% CI = 34%–45%) had private insurance compared with 35% (95% CI = 28%–40%) in 2010 and 2013.

4. Discussion

The percentage of uninsured US adults aged 18–64 years with active epilepsy significantly decreased from the early to the middle part of the decade. However, 7.1% (95% CI = 3.8–12.6) of this population was still uninsured in 2017, highlighting a group at high risk for adverse outcomes. The substantial decrease in the percentage of uninsured adults aged 18–64 years with active epilepsy from 2010 to 2017 parallels trends in the general population aged 18–64 years [10]. During these time periods, health insurance coverage and healthcare access varied substantially by state, state Medicaid expansion status, household income, race/ethnicity, and other factors [10,12–14]. How these changes affected the subpopulation of adults with epilepsy was unknown. Studies evaluating different health insurance coverage plans generally demonstrate that health insurance coverage fosters use of preventive care, chronic illness treatment, and regular care and improves patients' perception of care, especially among people with lower socioeconomic status [13,14]. Such healthcare services may benefit people with epilepsy. For example, adults with epilepsy who are at risk of, or living with, comorbidity may benefit from regular preventive care (e.g., cholesterol screenings to reduce cardiovascular disease risk), or from more frequent and affordable specialty care that provides individualized treatment. But, more research may be needed to evaluate how different health insurance coverage plans affect health outcomes for people with epilepsy.

Our study found that the decrease in uninsured among adults aged 18–64 years with active epilepsy resulted from more people enrolling in both public and private plans. Reasons for enrolling in these plans may include changes in disability status, changes in eligibility for Medicaid in states with Medicaid expansion, increased affordability of private plans in state exchanges, removal of preexisting condition exclusions, or other factors. Uninsured adults with active epilepsy are a priority group that could benefit from efforts to ensure that they have

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[1] Weighted estimates rounded to nearest thousand.

access to appropriate healthcare coverage.

This study has several strengths. It is based on nationally representative samples of more than 122,000 US civilian, noninstitutionalized adults, of whom more than 1000 had active epilepsy. To our knowledge, it is the first study to examine changes in insurance status among U.S. adults with epilepsy and provides information about a critical determinant of healthcare access and health status. This study also has several limitations. Because it is based on self-reports, it is subject to recall bias, interviewer effects, misclassification of epilepsy, and reluctance to disclose epilepsy because of its repercussions (e.g., driver's license restrictions) [1]. However, as previously reported, such biases may have limited effects on the overall findings [1,7]. Although a previous study on insurance status among adults with epilepsy using the 2010 and 2013 NHIS data reported a slightly different estimate [7], this difference is likely due to the previous study examining all adult age groups and other differences in methodology. Subgroup analysis of adults with active epilepsy produced estimates with large confidence intervals, limiting the ability to find statistically significant differences in population shifts in health plan coverage types by epilepsy status. Finally, some estimates may include double counting because we did not follow a hierarchy of health insurance types based on a variable, COVER, unavailable from the NHIS public use data files before 2015. But, our 2015 and 2017 estimates for the percentage of adults with active epilepsy who were uninsured were similar to that based on the recommended hierarchy.

People with epilepsy face notable and long-standing deficiencies in the level of healthcare they need to address the complex challenges of this disorder, reflected in recent national estimates of impaired health-related quality of life for this population [5,6]. Increasing access to routine general preventive care is fundamental to improving physical and mental health, especially for people with low incomes. Given the shortages of specialists such as neurologists and epileptologists in the US healthcare system [15], ensuring that primary care providers who are more likely to treat adults with epilepsy have access to educational information and decision aids about epilepsy treatment and to guidelines about when to refer patients to specialty care may improve access to quality healthcare. Epilepsy social service providers and other community groups can work to ensure that all uninsured people with epilepsy get access to health insurance coverage. The NHIS data, when available, can be used to monitor trends in insurance status in the future.

Declaration of Competing Interest

The authors have no conflict of interest to report.

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