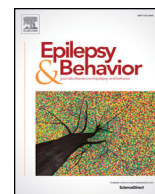




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Epilepsy by the numbers – From the US Centers for Disease Control and Prevention

Six in 10 adults with active epilepsy saw a neurologist or epilepsy specialist in the past year, United States, 2017

Rosemarie Kobau ^{a,*}, Sanjeeb Sapkota ^b, Page B. Pennell ^c, Janet B. Croft ^a

^a Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Division of Population Health, 4770 Buford Highway NE, MS 107-6, Atlanta, GA 30341, USA

^b G2S Corporation, Epilepsy Program, Division of Population Health, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention (CDC), Mail Stop 107-6, 4770 Buford Hwy, 30341, GA, USA

^c Harvard Medical School, Brigham and Women's Hospital, Hale Building for Transformative Medicine, 60 Fenwood Road, Boston, MA 02115, USA

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ABSTRACT

This study used the most recent national data on epilepsy from the 2017 National Health Interview Survey (NHIS) to examine the distribution of types of provider visits in the last 12 months among 2.9 million adult respondents aged ≥ 18 years with active epilepsy (self-reported doctor-diagnosed epilepsy taking antiseizure medications and/or having ≥ 1 seizure in the past year) and compared these estimates with 2010 NHIS data. We calculated age-standardized percentages of visits to a general doctor and an epilepsy specialist during the past 12 months, accounting for the complex survey design. Among US adults with active epilepsy in 2017, 27.1% saw a general doctor only, 9.0% saw a neurologist/epilepsy specialist only, 53.0% visited both a general doctor and a neurologist/epilepsy specialist, and 11.4% did not see either a general doctor or a neurologist/specialist. Overall, 62.0% [95% confidence interval (CI) = 55.2%–67.5%] of adults with active epilepsy visited a neurologist or epilepsy specialist in the past year. A visit in the past 12 months with both provider types was not significantly different in 2017 compared with 2010 (53.0% vs 46.2%) while seeing a general doctor only had declined (41.8% vs 27.1%, $p < 0.05$). Given that 79.8% of US adults with active epilepsy reported being seen by a general doctor within the past 12 months, epilepsy stakeholders have an opportunity to enhance epilepsy care by ensuring that general practitioners have access to the latest information about epilepsy diagnosis and new treatment options. National Health Interview Survey data can be used to track the distribution of provider visits in the coming decade to assess changes in access to primary care, specialty care, or other types of healthcare for people with epilepsy.

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1. Introduction

Many people with epilepsy can obtain seizure control when under the care of a general practitioner, but others require more specialized care from a neurologist or epileptologist [1]. In 2017, the US Health Resources and Services Administration (HRSA) National Center for Workforce Analysis projected that demand would exceed growth in the supply of neurologists by 2025 [2,3]. Based on 2010 National Health Interview Survey (NHIS) data, 86.4% of US adults with active epilepsy (self-reported doctor-diagnosed epilepsy taking antiseizure medications and/or having ≥ 1 seizure in the past year) had visited a general

doctor, and 52.8% had visited a neurologist or epilepsy specialist in the past year [4]. National Health Interview Survey data from 2010 to 2013 indicated that 65.3% of adults with uncontrolled epilepsy (taking medication and ≥ 1 seizure in past year) saw both a general doctor and a specialist in the past year, but 23.2% saw only a general doctor [5]. National Health Interview Survey data from 2013 to 2015 indicated that 67% of respondents with active epilepsy (taking medication or ≥ 1 seizure in past year) had seen a neurologist or an epilepsy specialist in the past year [6]. Understanding the distribution of provider visits among persons with epilepsy can inform clinical care pathways, especially for those with active epilepsy and with uncontrolled seizures who need evaluation by an epilepsy specialist [1]. The primary goal of this study was to use the latest national data on epilepsy to examine the proportion of US adults with active epilepsy who have seen a general practitioner, epilepsy specialist, both, or neither in the past year. A

* Corresponding author at: Division of Population Health, Epilepsy Program, 4770 Buford Highway NE, MS 107-6, Atlanta, GA 30341, USA.

E-mail address: rmk4@cdc.gov (R. Kobau).

secondary goal was to compare the 2017 estimates with 2010 estimates to assess any changes in these outcomes.

2. Methods

Conducted through personal household interviews, the NHIS is an annual, nationally representative, in-person survey of the noninstitutionalized US civilian population that provides estimates on health status, selected conditions, visit to healthcare providers and specialists, and health conditions including epilepsy, hypertension, cancer, diabetes, stroke, and others [7]. The Centers for Disease Control and Prevention (CDC) Epilepsy Program included supplemental questions on epilepsy on the Sample Adult Core component of the survey both in 2010 and 2017. Sample sizes and final response rates for sample adults were 27,157 (60.8%) in 2010 and 26,742 (53.0%) in 2017 [7,8].

We used a validated case definition for community-based surveillance of epilepsy from the Sample Adult component of the 2010 and 2017 survey to classify adults aged ≥ 18 years 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 [9]. For these analyses, active epilepsy was defined for 277 adult respondents in 2010 (weighted estimate = 2.3 million adults) and 335 in 2017 (weighted estimate = 2.9 million adults).

Visit to a general doctor was assessed with the question, “During the past 12 months, have you seen or talked to any of the following healthcare providers about your own health? A general doctor treats a variety of illnesses (a doctor in general practice, family medicine, or internal medicine).” Visit to a neurologist or to an epilepsy specialist was assessed with the question, “In the past 12 months, have you seen a neurologist or epilepsy specialist for your epilepsy or seizure disorder?”

We used SAS® 9.4 statistical software (SAS Institute Inc., Cary, NC, USA) to account for the complex survey design using stratification, clustering, and weighting. This software generates variance estimates based on the assumption that sample respondents from within a known cluster, such as people in households within the same zip code, are not completely independent in their health, attitudes, and risk factors. We estimated age-adjusted percentages of past 12-month visits to a general doctor and an epilepsy specialist using direct age-standardization to the 2000 US projected population using four age groups (18–34, 35–54, 55–64, and ≥ 65). We considered these age-standardized percentages to

differ statistically significantly at a significance level of 0.05 if their 95% confidence intervals (CI) did not overlap.

3. Results

The age-standardized percentage of US adults with active epilepsy in 2017 who saw a general doctor only was 27.1% (95% CI = 22.0%–33.0%; Fig. 1); 9.0% (95% CI = 5.6%–13.7%) saw only a neurologist or an epilepsy specialist; 53.0% [95% CI = 46.3%–59.1%] saw both general doctor and a neurologist or epilepsy specialist in the past year; and 11.4% [95% CI = 7.4%–17.0%] saw neither. Overall, 62.0% [95% CI = 55.2%–67.5%] of adults with active epilepsy visited a neurologist or epilepsy specialist in the past year, and 79.8% (95% CI = 73.4%–85.0%) visited a general doctor in the past year.

In 2017, adults who saw only a general doctor in the past year decreased significantly to 27.1% [95% CI = 22.0%–33.0%] from 41.8% [95% CI = 34.6%–49.3%] in 2010 (Fig. 1). There were no changes over time in the percentages of adults with active epilepsy who saw an epilepsy specialist only or who saw neither a general doctor nor an epilepsy specialist. There was a nonsignificant increase in 2017 in visits to both a general doctor and an epilepsy specialist (53.0% [95% CI = 46.3%–59.1%]) compared with that in 2010 (46.2% [95% CI = 38.2%–54.3%]; Fig. 1).

4. Discussion

In 2017, most US adults with active epilepsy reported being seen by a general doctor within a 12-month period, and more than one-half reported being seen by a neurologist or epilepsy specialist. Still, one in 10 US adults with active epilepsy (about 290,000 adults) did not see a general doctor or an epilepsy specialist within a 12-month period. These results are comparable with previous studies based on NHIS data using the same epilepsy questions [4–6]. Results from the US Healthy People 2020 national objective on epilepsy identified that between 58% and 72% of US adults with epilepsy and uncontrolled seizures had past year visits with a neurologist or epilepsy specialist over the decade, although differences between individual years in which data were collected were not statistically significant [10]. These studies based on NHIS data highlight the ability to examine access to provider type by different subgroups of people with epilepsy. Collectively, these findings suggest that epilepsy stakeholders should continue to ensure that general practitioners have access to the latest information about epilepsy

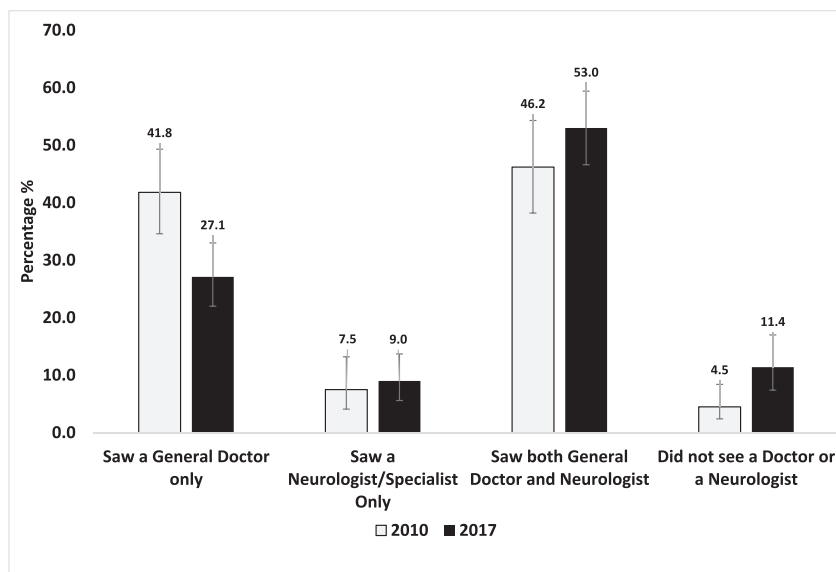


Fig. 1. Age-standardized distribution of types of provider visits in the past 12 months among adults with active epilepsy, by year—National Health Interview Survey United States, 2010 and 2017.

diagnosis and myriad new treatment options [1]. National Health Interview Survey data allow us to see an improvement in visits to neurologists/epilepsy specialists for people with active epilepsy over the decade (53.6% in 2010; 67.0% in 2013 and 2015; 62.0% in 2017), but there is still room for further improvement [1,4–6]. Expanding epilepsy learning collaboratives and use of telementoring programs such as the Extension for Community Healthcare Outcomes (ECHO) epilepsy neurology pilot might supplement traditional provider training approaches [11]. This is especially critical with current and forecasted professional shortages of epilepsy specialists [2,3]. Expanding and sustaining the use of telehealth to conduct virtual neurological visits and exams, as has been done in some settings and more recently in response to the coronavirus disease 2019 pandemic, may also eliminate barriers to specialty care for people with epilepsy [12,13]. To the extent that some adults with epilepsy have seen only an epilepsy specialist in the past 12 months, epilepsy specialists can assess whether their patients have discussed other preventive screening and health concerns with their general doctor to ensure that all health issues of their patients are addressed and do not complicate epilepsy management.

Study limitations include possible recall or reporting biases among survey respondents and the exclusion of adults who do not speak English or Spanish and those in active military service, prison, nursing homes, and other institutionalized settings, which are not captured in the NHIS sample. The NHIS question on visits with a neurologist or epilepsy specialist in the past year does not distinguish between visits with general neurologists and epileptologists or whether only one or multiple visits with these specialists occurred in the 12-month period preceding the survey. This study did not examine all possibilities of health provider visits assessed by NHIS such as those with mental health providers, dentists, and other specialists. These limitations may have underestimated the extent to which adults with epilepsy have seen other medical providers.

National Health Interview Survey data can be used to track the distribution of visits to general practitioners, epilepsy specialists, and potentially other types of provider in the coming decade to assess changes in access to healthcare, specialty care, or other types of healthcare for people with epilepsy.

Disclaimer

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Declaration of competing interest

Rosemarie Kobau has no conflict of interest to report.
Sanjeeb Sapkota has no conflict of interest to report.
Janet B. Croft has no conflict of interest to report.
Page B. Pennell has no conflict of interest to report.

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