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Epilepsy in Adults and Access to Care — United States, 2010

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Epilepsy is a neurologic disorder that negatively affects the quality of life for millions of persons in the United States (*1*); however, nationally representative U.S. estimates of the prevalence of epilepsy are scant (*2*). To determine epilepsy prevalence among adults, assess their access to care, and provide baseline estimates for a *Healthy People 2020* objective ("Increase the proportion of persons with epilepsy and uncontrolled seizures who receive appropriate medical care") (*3*), CDC analyzed data from the 2010 National Health Interview Survey (NHIS). The results of that analysis indicated that, in 2010, an estimated 1.0% of U.S. adults and 1.9% of those with annual family income levels ≤$34,999 had active epilepsy. In addition, only 52.8% of adults with active epilepsy reported seeing a neurologic specialist in the preceding 12 months. Public health agencies can work with Epilepsy Foundation state affiliates and other health and human service providers to eliminate identified barriers to care for persons with epilepsy (*2,4*).

National estimates of epilepsy prevalence using NHIS data have not been reported since 1994 (*5*), and no recent estimates of access to care have been reported using nationally representative samples of adults with epilepsy. To estimate epilepsy prevalence among adults aged ≥18 years, CDC analyzed data from the 2010 NHIS, an annual cross-sectional survey of the civilian, noninstitutionalized U.S. population.* Data were analyzed from the NHIS Sample Adult component, which included supplemental questions on epilepsy.† Adults who responded "yes" to ever having been told by a doctor or other health professional that they had a seizure disorder or epilepsy were considered as having a history of epilepsy ("any epilepsy"). Respondents classified as having "active epilepsy" reported a history of epilepsy and either were currently taking medication to control it, or had one or more seizures in the past year, or both (*6*). Those who had a history of epilepsy but were not taking medication for epilepsy and had not had a seizure in the past year were classified as having "inactive epilepsy" (*6*).§ These case-ascertainment questions and case-classification definitions follow standards for epidemiologic studies of epilepsy (*4*) and have acceptable positive predictive value for identifying clinical cases of epilepsy (*7*).

Epilepsy status was compared across selected demographic and health-care access characteristics: age group, sex, race/ethnicity, education level, and annual family income (using unimputed data). Those with a history of epilepsy were asked about their visits to general doctors and neurologists or epilepsy specialists ("In the past year have you seen a neurologist or epilepsy specialist for your epilepsy or seizure disorder?"). Those without epilepsy were asked about their visits to general doctors. Statistical software was used to account for the complex survey design by using stratification, clustering, and weighting to obtain appropriate population estimates, standard errors, and 95% confidence intervals (CIs). Estimates were considered statistically significantly different if their CIs did not overlap. Prevalence estimates were directly age-adjusted to the 2000 U.S. Census population. Respondent numbers in each group are unweighted; percentage estimates are weighted.

Of 27,139 adults surveyed,¶ 480 (weighted estimate = 1.8%; approximately 4.1 million adults) reported ever being told they had epilepsy (Table 1). Of these, 275 (1.0%; approximately 2.3 million adults) were classified as having active epilepsy, and 198 (0.8%; approximately 1.7 million adults) as having inactive epilepsy. The prevalence of any epilepsy and active epilepsy did not differ significantly by age, sex, or education level. However, those with a history of epilepsy or active epilepsy were significantly more likely to be white or black or live in families at the lowest income level. Among those living in families with annual incomes of ≤$34,999, 1.9% had active epilepsy and 3.1% had any epilepsy.

Significantly more adults with active epilepsy (86.4%) or any epilepsy (76.6%) had visited a general doctor in the past 12 months than those without epilepsy (66.1%) (Table 2). More persons aged ≥65 years with any epilepsy (93.1%) saw a general doctor than those aged 18–34 years with any epilepsy (65.7%).

Among adults with active epilepsy, 52.8% had visited a neurologist or epilepsy specialist in the past 12 months, as had 33.4% of those with any epilepsy (Table 2). The percentage of adults with any epilepsy and active epilepsy who had seen a neurologist or epilepsy specialist in the past 12 months did not differ by age, sex, or race-ethnicity.

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Editorial Note

Epilepsy, or seizure disorder, is a brain disorder characterized by a tendency to have recurrent seizures. New cases of epilepsy are most common in children and older adults because risk factors are most common in these age groups. Preventable causes of epilepsy include traumatic brain injuries, stroke, cerebral infections, lead exposure, and perinatal complications; other causes include neoplasms and disorders of cerebral metabolism (*1*). Although many persons with epilepsy live full, productive lives, some face challenges, including barriers to care, untreated comorbidities, social disadvantages, and public misunderstanding about epilepsy or the abilities of persons with epilepsy (*2*). Such challenges are manifested in lower quality of life of persons with epilepsy (*2,6*).

The findings in this report indicate that estimates of epilepsy prevalence are consistent with previous estimates from the Behavioral Risk Factor Surveillance System (*6*) and other population studies (*8,9*) but slightly higher than other estimates (*10*). Data from NHIS surveys during 1986–1990 indicate an overall prevalence of epilepsy in persons of all ages of 0.47% (*5*). However, the case definitions, sampling strategy, and population distribution differ substantially between that study and this study, limiting comparisons.

Only 52.8% of those with active epilepsy had seen a neurologist or an epilepsy specialist in the past 12 months, confirming a treatment gap related to specialty care in adults with active epilepsy that is consistent with that found in previous reports (*6*). Epilepsy is a spectrum of disorders that require adequate access to appropriate care to ensure effective treatment to improve seizure control and quality of life. Cultural beliefs and practices, referral to and availability of specialty care, transportation barriers, and cost, might affect access to specialty care (*2,4,6*). Increased generalist care among older adults with epilepsy compared with those without epilepsy highlights the likelihood of multiple underlying health problems common with epilepsy (*2*). Increased generalist care among older adults with any epilepsy compared with youngest adults with any epilepsy might result from greater access to health-care coverage in the former.

The findings in this report are subject to at least five limitations. First, because the estimates are based on self-reported data, they might be subject to reporting bias. However, comparability of findings with BRFSS and other population surveys suggests these types of bias might be small. Second, the reported cases of epilepsy are not classified by seizure type, severity, or etiology. Third, certain acute symptomatic seizures or nonepileptic seizures might have been misclassified as epilepsy, thus overestimating prevalence. However, the small percentage of adults with nonepileptic seizures suggests that significant skewing of results is unlikely (*6,7*). Fourth, epilepsy prevalence might be underestimated because of underreporting associated with repercussions in disclosing epilepsy (*1,2*) and because of the exclusion of institutionalized adults from NHIS. Finally, because the questions on access to care in this study provide only limited information on epilepsy care, NHIS can only inform about broader determinants of access to care.

These data provide a baseline estimate to develop a target for a *Healthy People 2020* objective on epilepsy and can be used to monitor progress over the decade. Future studies can further examine associations from this study. Public health agencies can work with Epilepsy Foundation state affiliates and other health and human service providers to eliminate known barriers to care for persons with epilepsy (*4*).

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* Additional information is available at http://www.cdc.gov/nchs/htm.

† The NHIS Sample Adult Component conditional response rate was 77.3%, and the final response rate was 60.8%.

§ Seven cases of epilepsy lacked information on medication usage or on seizure occurrence and could not be classified as either active or inactive.

¶ A total of 18 survey respondents with responses classified as refused or unknown were omitted from analysis.

What is already known on this topic?

Nationally representative data on epilepsy from the National Health Interview Survey (NHIS) have not been reported since 1994, and no recent estimates on access to care have been reported in nationally representative samples of adults with epilepsy.

What is added by this report?

In the 2010 NHIS, an estimated 1.0% of adults reported having active epilepsy. These adults were more likely to live in families with annual incomes ≤$34,999. Only 52.8% of adults with active epilepsy reported having seen a neurologist or epilepsy specialist in the preceding 12 months.

What are the implications for public health practice?

Approximately one in every 100 adults in the United States has active epilepsy, and many adults with active epilepsy might not receive appropriate care. These findings provide a baseline estimate to develop a target for a *Healthy People 2020* objective on epilepsy. Public health agencies can work with Epilepsy Foundation state affiliates and other health and human services providers to eliminate known barriers to care for persons with epilepsy.

TABLE 1. Age-adjusted prevalence of active epilepsy, inactive epilepsy, and any epilepsy, by selected characteristics — National Health Interview Survey, United States, 2010*

Characteristic	**Epilepsy status**†								
	Active epilepsy			**Inactive epilepsy**			**Any epilepsy**		
	No.	**%**	**(95% CI)**	**No.**	**%**	**(95% CI)**	**No.**	**%**	**(95% CI)**
Overall	**275**	**1.0**	**(0.9–1.2)**	**198**	**0.8**	**(0.6–0.9)**	**480**	**1.8**	**(1.6–2.0)**
Age group (yrs)									
18–34	48	0.7	(0.5–1.0)	58	0.9	(0.6–1.1)	108	1.6	(1.3–2.0)
35–54	114	1.1	(0.9–1.3)	85	0.9	(0.6–1.1)	200	2.0	(1.6–2.3)
55–64	62	1.4	(1.0–1.8)	35	0.8	(0.4–1.1)	99	2.2	(1.7–2.7)
≥65	51	1.0	(0.7–1.4)	20	0.3	(0.1–0.4)	73	1.3	(1.0–1.7)
Sex									
Men	102	0.9	(0.7–1.1)	95	0.8	(0.6–1.0)	201	1.7	(1.4–2.0)
Women	173	1.1	(0.9–1.3)	103	0.7	(0.6–0.9)	279	1.9	(1.6–2.1)
Race/Ethnicity§									

White	181	1.2	(1.0–1.4)	135	0.9	(0.7–1.0)	320	2.1	(1.8–2.3)
Black	51	1.0	(0.7–1.3)	34	0.7	(0.4–1.0)	87	1.7	(1.3–2.2)
Other	12	0.5¶	(0.2–0.9)	5	0.1¶	(0.0–0.3)	18	0.7	(0.3–1.1)
Hispanic	31	0.5	(0.3–0.7)	24	0.5	(0.3–0.7)	55	1.0	(0.7–1.2)
Annual family income ($)									
0–34,999	187	1.9	(1.5–2.2)	113	1.2	(0.9–1.4)	304	3.1	(2.7–3.5)
35,000–74,999	58	0.9	(0.6–1.1)	53	0.7	(0.5–0.9)	113	1.6	(1.3–1.9)
75,000–99,999	12	0.5¶	(0.2–0.8)	15	0.6¶	(0.2–0.9)	27	1.1	(0.6–1.5)
≥100,000	10	0.2¶	(0.1–0.4)	12	0.3¶	(0.1–0.5)	22	0.5	(0.3–0.8)
Unknown	8	0.7¶	(0.2–1.3)	5	0.4¶	(0.0–0.8)	14	1.2	(0.4–1.9)
Education level									
Less than high school graduate or GED	153	1.3	(1.0–1.5)	92	0.9	(0.7–1.1)	249	2.2	(1.8–2.5)
Some college or more	120	0.9	(0.7–1.1)	105	0.6	(0.5–0.8)	228	1.5	(1.3–1.8)
Did not answer or unknown	2	1.1¶	(0.0–2.8)	1	0.7¶	(0.0–2.0)	3	1.8¶	(0.0–3.8)

Abbreviations: CI = confidence interval; GED = general equivalency diploma.

* The number of respondents is unweighted; the percentage estimates are weighted.

† Seven cases of epilepsy lacked information on medication usage or on the presence of seizures in the past year and could not be classified as either active or inactive epilepsy.

§ Persons identified as Hispanic might be of any race. Persons identified as white, black, or other are all non-Hispanic. The four racial/ethnic categories are mutually exclusive.

¶ Because the relative standard error exceeds 30%, the estimate is unreliable.

TABLE 2. Adjusted percentage of adults who visited a general doctor, neurologist, or epilepsy specialist in the past 12 months, by epilepsy status and selected characteristics — National Health Interview Survey, United States, 2010*

Characteristic	**Epilepsy status**											
	Active epilepsy			**Inactive epilepsy**			**Any epilepsy**			**No epilepsy**		
	No.	**%**	**(95% CI)**	**No.**	**%**	**(95% CI)**	**No.**	**%**	**(95% CI)**	**No.**	**%**	**(95% CI)**
Visited general doctor in past 12 months												
Overall	**230**	**86.4**	**(81.3–91.5)**	**129**	**63.0**	**(54.7–71.3)**	**365**	**76.6**	**(71.8–81.4)**	**17,478**	**66.1**	**(65.2–66.9)**
Age group (yrs)												
18–34	37	78.9	(64.4–93.4)	31	53.8	(38.0–69.7)	70	65.7	(54.1–77.4)	3,997	53.2	(51.6–54.7)
35–54	95	89.6	(84.0–95.3)	55	62.8	(50.8–74.7)	150	77.6	(70.8–84.3)	5,847	64.0	(62.7–65.2)
55–64	52	82.9	(69.7–96.0)	24	73.1	(56.9–89.2)	78	79.6	(69.5–89.8)	3,125	76.0	(74.5–77.5)
≥65	46	93.2	(86.5–99.9)	19	92.4	(77.3–100.0)	67	93.1	(87.0–99.3)	4,509	84.9	(83.7–86.1)
Sex												
Men	82	85.5	(78.2–92.9)	54	52.8	(40.4–65.2)	140	70.6	(63.1–78.1)	7,125	61.7	(60.5–62.9)
Women	148	87.0	(80.4–93.7)	75	73.4	(63.9–82.9)	225	81.7	(76.3–87.0)	10,353	70.1	(69.1–71.2)
Race/Ethnicity[†]												
White	157	87.4		88	63.4		248	77.2		10,772	69.8	

			(81.3–93.5)			(53.8–72.9)			(71.8–82.6)			(68.8–70.8)
Black	39	82.8	(72.9–92.7)	25	77.2	(62.8–91.6)	66	80.8	(73.1–88.5)	2,856	62.5	(60.6–64.5)
Other	6	63.1§	(28.7–97.4)	3	48.7§	(0.0–98.8)	10	61.1	(32.6–89.6)	1,138	60.1	(57.2–63.1)
Hispanic	28	90.5	(77.6–100.0)	13	44.3	(21.2–67.5)	41	67.4	(51.9–83.0)	2,712	53.1	(51.2–54.9)
Visited neurologist or epilepsy specialist in past 12 months												
Overall	**152**	**52.8**	**(45.7–60.0)**	**14**	**6.9**§	**(2.8–11.1)**	**168**	**33.4**	**(28.3–38.6)**	—¶	—	—
Age group (yrs)												
18–34	30	59.4	(41.1–77.8)	3	5.4§	(0.0–12.1)	34	30.5	(19.3–41.7)	—	—	—
35–54	61	49.2	(38.2–60.2)	4	4.1§	(0.0–8.9)	66	29.5	(21.8–37.2)	—	—	—
55–64	36	54.5	(39.1–70.0)	6	19.8§	(3.3–36.3)	42	42.0	(29.7–54.2)	—	—	—
≥65	25	50.3	(34.1–66.6)	1	2.5§	(0.0–7.4)	26	39.8	(26.0–53.6)	—	—	—
Sex												
Men	53	49.5	(37.6–61.4)	5	5.6§	(0.0–11.6)	59	29.2	(21.4–36.9)	—	—	—
Women	99	55.3	(46.4–64.1)	9	8.3§	(2.2–14.4)	109	37.0	(30.2–43.9)	—	—	—

Race/Ethnicity												
White	94	50.6	(41.9–59.3)	7	6.0[§]	(1.4–10.7)	103	31.8	(25.6–38.0)	—	—	—
Black	30	65.1	(48.4–81.8)	6	12.1[§]	(2.8–21.4)	36	43.5	(30.0–57.0)	—	—	—
Other	9	59.4§	(22.8–96.1)	0	—	—	9	44.4[§]	(16.5–72.3)	—	—	
Hispanic	19	54.4	(32.9–76.0)	1	9.6[§]	(0.0–27.3)	20	32.0	(16.5–47.5)	—	—	—

Abbreviation: CI = confidence interval.

* The number of respondents is unweighted; the percentage estimates are weighted.

[†] Persons identified as Hispanic might be of any race. Persons identified as white, black, or other are all non-Hispanic. The four racial/ethnic categories are mutually exclusive.

[§] Because the relative standard error exceeds 30%, the estimate is unreliable.

[¶] Adults without epilepsy were not asked about visiting a neurologist or epilepsy specialist.

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