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## **Serious psychological distress among adults with active epilepsy in all racial/ethnic groups and among adults with inactive epilepsy in non-Hispanic whites is significantly higher than among adults without epilepsy—U.S. National Health Interview Survey, 2010, 2013, 2015, and 2017**

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### **Abstract**

Serious psychological distress (SPD) includes mental health problems severe enough to cause moderate-to-serious impairment in daily activities and to require treatment. Serious psychological distress is based on answers to six survey questions from the Kessler-6 scale used internationally in public health surveillance systems to assess recent feelings of sadness, restlessness, hopelessness, nervousness, worthlessness, and the sense that everything is an effort. We combined nationally representative samples in the National Health Interview Survey (NHIS) from 2010 (N = 27,157), 2013 (N = 34,557), 2015 (N = 33,672), and 2017 (N = 26,742). We used a validated surveillance case definition to classify adults as having epilepsy if they reported a history of doctor-diagnosed epilepsy or seizure disorder (n = 2251). We further classified those with epilepsy as having active epilepsy (n = 1380) if they reported either taking epilepsy medications or having at least one seizure in the past 12 months or as having inactive epilepsy (n = 871) if they did not take epilepsy medication and had not had any seizures in the past 12 months. We used an NHIS recoded variable that classifies adults by Hispanic origin and race. Following age adjustment, among adults with active epilepsy, SPD prevalence was 13.7% among non-Hispanic white adults, 11.2% among non-Hispanic black adults, 20.7% among Hispanic adults, and 17.5% among non-Hispanic other adults. Compared with adults without epilepsy, adults with active epilepsy were 4.8 times more likely, and adults with inactive epilepsy 2.6 times more likely, to report SPD. In each racial/ethnic group, SPD among adults with active epilepsy is significantly higher than in adults without epilepsy. Among adults with active epilepsy, SPD prevalence did not differ by racial/ethnic groups. However, only among non-Hispanic white adults with inactive epilepsy

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Conflict of interest

The authors have no conflict of interest to report.

did SPD prevalence significantly exceed that among non-Hispanic white adults without epilepsy. Epilepsy stakeholders can use these estimates to target culturally appropriate community-based and clinic-based interventions to reduce the high burden of psychological distress among adults with active epilepsy and inactive epilepsy.

## Keywords

Epilepsy; Population study; Race; Ethnicity; Psychological distress; Mood disorder

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## 1. Background

Psychological distress and psychiatric comorbidity are more common in people with epilepsy compared with those without the disorder, but little is known about how these vary by subgroups of people with epilepsy including by race/ethnicity [1,2]. Serious psychological distress (SPD) is an indicator of mental health problems that can result in moderate-to-serious impairment and that may require treatment [3]. Serious psychological distress is based on answers to six survey questions from the Kessler-6 scale used internationally in public health surveillance systems to assess recent symptoms of sadness, restlessness, hopelessness, nervousness, worthlessness, and the sense that everything is an effort [4-6]. Serious psychological distress is used to effectively discriminate between cases and noncases of DSM-IV mood disorders but cannot discriminate which specific disorder (such as clinical depression, generalized anxiety disorder) that any given survey respondent may have [3-7]. In 2017, following age adjustment, 3.3% of U.S. adults reported SPD, including 1.2% of Asians, 3.7% of Hispanic or Latinos, 3.2% of non-Hispanic blacks or African Americans, and 3.4% of non-Hispanic whites [8]. Although a few population-based studies have reported substantially higher levels of SPD among adults with seizures or active epilepsy than among adults without these conditions, none examined SPD prevalence among adults with epilepsy by race/ethnicity [1,2,9]. This study examines SPD prevalence among adults with active and inactive epilepsy by race/ethnicity in nationally representative data from the 2010, 2013, 2015, and 2017 U.S. National Health Interview Survey (NHIS).

## 2. Methods

National Health Interview Survey is a household survey that provides nationally representative estimates on many different health topics for the civilian, noninstitutionalized population [10]. The Centers for Disease Control and Prevention (CDC) Epilepsy Program included supplemental questions on epilepsy on the Sample Adult Core component of the survey in 2010, 2013, 2015, and 2017. We combined samples of adults 18 years old or older in the NHIS [10,11] from 2010 (N = 27,157), 2013 (N = 34,557), 2015 (N = 33,672), and 2017 (N = 26,742). We used validated case-ascertainment questions based on three survey questions about epilepsy [12]. We classified adults as having epilepsy if they reported a history of doctor-diagnosed epilepsy or seizure disorder (n = 2251). We further classified those with epilepsy as having active epilepsy (n = 1380) if they reported either taking epilepsy medications or having at least one seizure in the past 12 months or as having inactive epilepsy (n = 871) if they did not take epilepsy medication and had not had any

seizures in the past 12 months [1]. We used the NHIS recoded variable for race and Hispanic origin to classify respondents by race and ethnicity.

The Kessler-6 scale asks respondents about the frequency with which they have experienced six symptoms of psychological distress in the past 30 days, including feeling 1) nervous, 2) hopeless, 3) restless or fidgety, 4) so sad or depressed that nothing could cheer the respondent up, 5) that everything is an effort, and 6) worthless. Responses are “none of the time”, “a little of the time”, “some of the time”, “most of the time”, or “all of the time” [13]. Scoring of individual items is based on a 0- to 4-point scale, yielding a total six-item score ranging from 0 to 24. A score of  $\geq 13$  indicates SPD [4]. Respondents with missing values for any of the items were excluded from the analyses.

We used SAS-callable SUDAAN SAS® 9.4 statistical software (SAS Institute Inc., Cary, NC, USA) to account for the NHIS's complex survey design, using stratification, clustering, and weighting to estimate SPD prevalence in adults with active epilepsy, inactive epilepsy, and no history of epilepsy overall and by the following four racial/ethnic groups: non-Hispanic whites, non-Hispanic blacks, Hispanics, and non-Hispanics of other races. We used logistic regression to adjust all model estimates for age as well as for socioeconomic characteristics known to be associated with SPD, including marital status, education level, and health insurance coverage—the latter two serving as proxies for income. Accounting for multiple comparisons, we considered differences in estimates significantly different at a significance level of 0.003 using a z-test.

### 3. Results

Serious psychological distress prevalence following adjustment for socioeconomic characteristics did not differ much from the age-adjusted estimates (data not shown); therefore, the latter are reported and presented. During 2010–2017, about 14% of adults with active epilepsy, 9% of adults with inactive epilepsy, and 3% of adults without epilepsy had SPD (Fig. 1). Compared with adults without epilepsy, SPD occurred significantly more often in adults with active epilepsy (odds ratio [OR] = 4.80; 95% confidence interval [CI] = 3.95–5.83) and inactive epilepsy (OR = 2.65; 95% CI = 1.86–3.77) (Fig. 1). Compared with adults with inactive epilepsy, SPD occurred significantly more often in adults with active epilepsy (OR = 1.81; 95% CI = 1.23–2.66). Among non-Hispanic white adults with active epilepsy, age-adjusted SPD prevalence was 13.7% (95% CI = 11.2%–16.8%); among non-Hispanic black adults, 11.2% (95% CI = 7.4%–16.7%); among Hispanic adults, 20.7% (95% CI = 13.7%–30.0%); and among non-Hispanic others, 17.5% (95% CI = 10.0%–29.3%) ( $p = 0.10$ ) [Fig. 1]. Only among non-Hispanic white adults with inactive epilepsy did SPD prevalence significantly exceed that among non-Hispanic white adults without epilepsy ( $p = 0.003$ ).

### 4. Discussion

To our knowledge, this is the first study to examine SPD among U.S. adults with active or inactive epilepsy by race/ethnicity. The higher burden of SPD among adults with active and inactive epilepsy was evident among all racial/ethnic groups. Although population-

based literature on racial/ethnic differences in mood disorder or emotional distress among people with epilepsy is sparse, Hispanic immigrants with epilepsy in a recent clinic-based study were more likely to be moderately to severely depressed and to report worry about seizures than their non-Hispanic counterparts [14]. Serious psychological distress prevalence decreases with increasing income [3], but we controlled for marital status, education level, and health insurance coverage and found little impact on SPD prevalence among adults with active epilepsy. These findings likely reflect the higher burden of mood disorder, cognitive impairment, limitations in social participation, and other social disparities (e.g., unemployment, low income) associated with epilepsy and that may increase emotional distress [1,15,16]. The lack of any differences in SPD prevalence among racial/ethnic groups in adults with active epilepsy requires more study.

Among California adults with psychological distress and epilepsy, 84% perceived a need for mental healthcare in the past year, but only 57% had seen a mental health provider during that time, suggesting a mental health treatment gap [17]. Management of mood or affective disorders remains suboptimal despite screening recommendations, the availability of clinical practice tools, psychotherapy, and self-management programs that provide mental health skills training [18-21].

Future studies can examine different patterns in responses to the Kessler-6 scale items to uncover particular problematic symptoms. For example, among the general U.S. population in 2017, smaller percentages of non-Hispanic blacks reported feeling nervous some of the time compared with non-Hispanic whites, whereas larger percentages of non-Hispanic whites reported feeling restless some of the time than Hispanic or Latinos [8]. Examining such patterns of responses in relation to epilepsy-related factors (e.g., seizure frequency, medication adherence, comorbidity) and social factors (e.g., employment status, social isolation, access to mental healthcare) might identify high-risk groups who would benefit from tailored interventions. That such a high percentage of adults with inactive epilepsy still report SPD suggests that epilepsy continues to have a long-term impact even after the seizures no longer occur [22]. The difference in SPD prevalence between whites with inactive and no epilepsy requires more study.

This study has several strengths. It is based on nationally representative, civilian noninstitutionalized samples of more than 122,000 U.S. adults, more than 2000 with a history of doctor-diagnosed epilepsy or seizure disorder and of whom two-thirds still reported taking epilepsy medications or having had at least one seizure in the past 12 months. The availability of responses to the validated Kessler-6 scale in such large samples enabled comparisons of SPD prevalence by epilepsy status among racial/ethnic groups after adjustment for age and also for socioeconomic characteristics.

This study also has several limitations. Although SPD can distinguish between those with mood disorders and those without such disorders, it cannot distinguish among specific disorders. The symptoms and the intensity of the symptoms associated with the Kessler-6 scale items were not validated from independent reports (e.g., medical records). The cross-sectional nature of the NHIS makes it difficult to determine whether the occurrence of SPD preceded or followed the onset of epilepsy. Limited differences in SPD prevalence among

adults with/without epilepsy within racial/ethnic groups might have been associated with relatively small sample sizes precluding statistical significance. Finally, potential stigma associated with disclosure of epilepsy and psychological distress may have underestimated how often they have occurred together [1].

This is the first large population-based study in the United States examining psychological distress among adults with active and inactive epilepsy by race/ethnicity. Epilepsy stakeholders can use these estimates to target culturally appropriate community-based and clinic-based interventions to reduce the high burden of psychological distress among adults with active epilepsy and inactive epilepsy. National Health Interview Survey data on epilepsy, when available, can track the effectiveness of these efforts over time.

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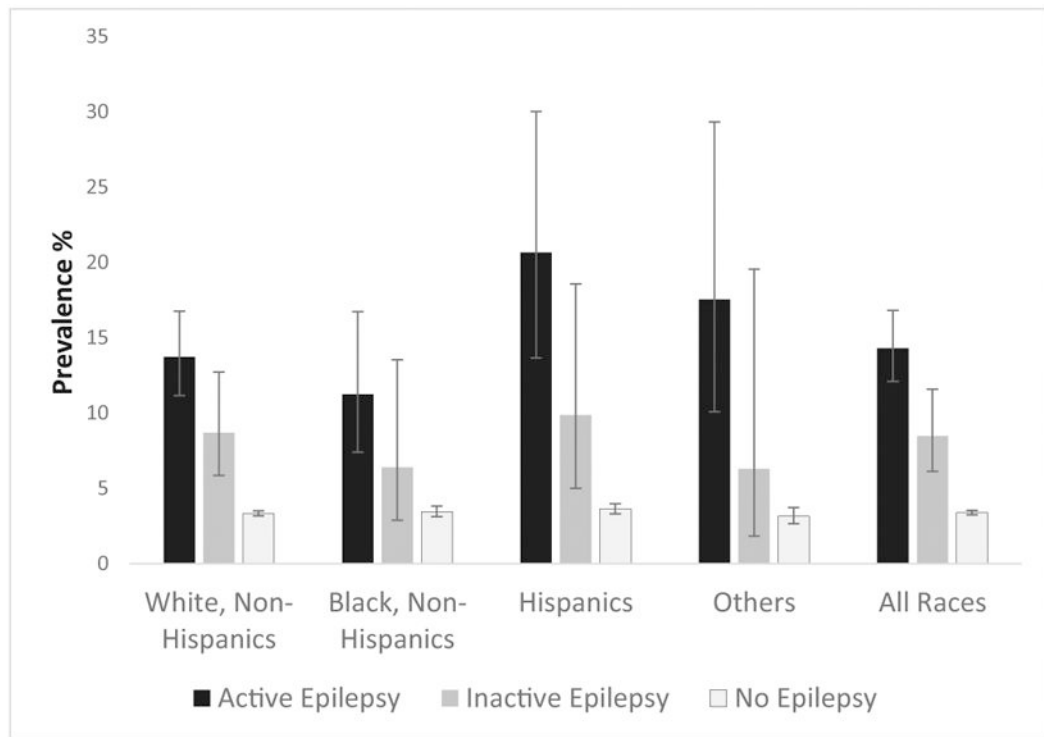
## Disclaimer

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

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**Fig. 1.** Age-adjusted estimated prevalence and 95% confidence interval of serious psychological distress (SPD) among those who are living with active epilepsy, inactive epilepsy, and no epilepsy, by race and ethnicity, U.S. National Health Interview Survey, 2010, 2013, 2015, and 2017.