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Tracking Psychosocial Health in Adults with Epilepsy—Estimates from the 2010 National Health Interview Survey

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Abstract

Objective—This study provides population-based estimates of psychosocial health among U.S. adults with epilepsy from the 2010 National Health Interview Survey.

Methods—Multinomial logistic regression was used to estimate the prevalence of the following measures of psychosocial health among adults with and those without epilepsy: 1) the Kessler-6 scale of Serious Psychological Distress; 2) cognitive limitation; the extent of impairments associated with psychological problems; and work limitation; 3) Social participation; and 4) the Patient Reported Outcome Measurement Information System Global Health scale.

Results—Compared with adults without epilepsy, adults with epilepsy, especially those with active epilepsy, reported significantly worse psychological health, more cognitive impairment,

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

Disclosures/Conflict of Interest
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difficulty in participating in some social activities, and reduced health-related quality of life (HRQOL).

Conclusions—These disparities in psychosocial health in U.S. adults with epilepsy serve as baseline national estimates of their HRQOL, consistent with Healthy People 2020 national objectives on HRQOL.

Keywords

Epilepsy; Quality of Life; Social Participation; Cognition; Psychological Distress; Limitations

1.1 Introduction

Living with epilepsy is challenging not only because of the constant uncertainty associated with seizures and complex treatment but also because of limitations on daily activities, cognitive dysfunction, stigma, co-occurring mental illness, and social disadvantages [1, 2]. The 2011 Standards for Epidemiologic Studies and Surveillance of Epilepsy recommends examining health-related quality of life (HRQOL) as an important overall outcome for people with epilepsy [3]. People with epilepsy have a substantial burden of impaired HRQOL [4]. Community-dwelling adults with epilepsy are more dissatisfied with specific life domains, suggesting possible limitations in full participation in many life opportunities [5].

The National Institutes of Health Patient Reported Outcome Measurement Information System (PROMIS) has developed valid, practical, self-rated assessment questions about patients' functional status and well-being that can be used across a wide variety of conditions and disorders [6,7]. Based on advanced psychometric methods, the 10-item PROMIS Global Health Scale examines physical, mental, and social domains of HRQOL [8]. The scale is used to set U.S. population benchmarks and track HRQOL for Healthy People 2020, a national initiative designed to improve population health [9]. As far as we know, no other study has used the PROMIS® Global Health Scale [7,8] to examine HRQOL in a nationally representative sample of adults with epilepsy. The PROMIS Global Health Scale, as well as new questions on social participation, and questions on epilepsy are included on the 2010 National Health Interview Survey (NHIS). The purpose of this study is to provide population-based estimates of psychosocial health, social participation, and HRQOL among nationally representative community-dwelling U.S. adults with epilepsy. These data can inform program development and serve as baseline national estimates of HRQOL in people with epilepsy, consistent with Department of Health and Human Services (DHHS) Healthy People 2020 national objectives established for HRQOL and related Healthy People 2020 objectives [10].

2.0 Material and Methods

2.1 Data Source

The NHIS is a nationally representative multistage household survey of the civilian noninstitutionalized population of the United Stateis. Administered annually by the National Center for Health Statistics, it is used to collect information on health indicators, health care

utilization and access, and health-related behaviors of the nation [11]. U.S. Census Bureau interviewers conduct the NHIS continuously throughout the year by asking questions using computers at respondents' homes.

The NHIS core questionnaire contains three major components: family, sample adult, and sample child [11]. The family component [1] contains three basic level files: household, family, and person. In 2010, of 43,208 households selected for NHIS interviews, about 80% (=34,329) of them participated in the study. The household-level files collect basic household composition information (e.g. types of living quarters) and tracking information used for identification (e.g. linkage to administrative data bases) for these households. The family-level files cover 35,177 families from these households and include family information such as sociodemographic characteristics (e.g. family type, family structure, or annual income), access to care and utilization, and activity limitation status. The person-level files contain personal data on all 89,976 family members. Any adult household member present at the time of interview might take the survey, and a knowledgeable adult household member provided information about adults who did not participate on factors such as health status and activity limitation, health care access and utilization, health insurance, and socio-demographic characteristics. The sample adult component includes data on 27,157 randomly selected adults (only one adult per family, a 77.3% conditional response rate) who answer more specific and detailed questions about many of the same topics as those in the family component. Among these adults, 378 used a knowledgeable proxy because she/he was physically or mentally unable to answer questions for themselves. The final analysis sample for our study includes the 27,139 adults from the sample adult component who provided complete information about their epilepsy status, psychological conditions, social participation level, and health-related quality of life.

2.2 Epilepsy Case Definition

Three case definitions for epilepsy were used in this study based on the following (categorical) questions [2,12]: 1) "Have you ever been told by a doctor or other health professional that you have a seizure disorder or epilepsy?" (response options: "yes," "no," "don't know," and "refused"). Participants who answered "yes" to this question were asked all of the remaining questions: 2) "Are you currently taking any medicine to control your seizure disorder or epilepsy?" (response options: "yes," "no," "don't know," and "refused"); 3) "Today is [fill: Current Date]. Think back to last year about the same time. About how many seizures of any type have you had in the past year?" (response options: "none," "one," "two or three," "between four and ten," "more than ten," "don't know," and "refused"). Those who responded "yes" to the first question were considered as having a history of epilepsy ("any epilepsy"). Respondents with a history of epilepsy were classified as having active epilepsy if they answered "yes" to the second question or if they reported one or more seizures during the past year in response to the third question. Respondents were classified as having inactive epilepsy if they answered "no" or "don't know/refused" to the second question and reported having zero seizures to the third question. Five individuals did not meet the case definition of either active or inactive epilepsy and were subsequently excluded

[1]The Family Core component allows the NHIS to serve as a sampling frame for additional integrated surveys as needed.

from the subgroup analyses. These case-ascertainment questions and case-classification definitions follow standards for epidemiologic studies on epilepsy [3]. They have acceptable positive predictive value (73.5%) for identifying clinical cases of epilepsy, demonstrating their validity in identifying epilepsy at a population level [12, 13].

2.3 Demographic Variables

Demographic variables adjusted for as potential confounders in this study included age (18–85 years, continuous), sex (male or female, categorical), race/ethnicity (Hispanic, non-Hispanic White, non-Hispanic Black, or all other races/ethnicities, categorical), and family income (total household income last year, continuous). These variables were used as adjustments for all model-based prevalence estimates of psychosocial variables, social participation variables, and health-related quality of life measures detailed in the following sections at each level of epilepsy status.

2.4 Psychosocial Variables

2.41 Psychological Distress—The psychosocial variables included the Kessler-6 Serious Psychological Distress (SPD) scale (continuous) from the Sample Adult Core questionnaire [14, 15]. This scale is a validated measure designed to screen for psychological distress associated with mood or anxiety disorders but does not identify a specific mental illness [14, 15]. This scale asks respondents about how often they have experienced the following six feelings during the last 30 days: 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 “all of the time,” “most of the time,” “some of the time,” “a little of the time,” and “none of the time.” Scoring of individual items is based on a 5-point scale ranging from 0 (“none of the time”) to 4 (“all of the time”), yielding a six-item score ranging from 0–24. A score of ≥13 indicates serious psychological distress [15]. The extent to which the previously reported psychological distress interfered with life or activities (categorical) was asked as a follow-up question to the Kessler-6, and was included in this analysis to better understand the impact of psychological distress within the epilepsy population. Responses were grouped into “a lot”, “some or a little”, and “not at all” (Table 1).

Self-reported answers to questions regarding whether respondents were unable to work (categorical), and whether they experienced work or cognitive limitations (categorical) were also included. See Table 1 for each specific survey question and its response options. Answers to questions regarding work limitations and cognitive limitations were retrieved from the Family questionnaire. Questions on limitations have undergone cognitive testing, and have been shown to be valid [16, 17]. For example, in cognitive testing, respondents considered both age-related problems and problems caused by physical, mental, and emotional problems when answering the question on cognitive limitations. People with physical, mental, and emotional problems were able to clearly state whether they had no memory loss or confusion, either memory loss or confusion, or both memory loss and confusion [16].

2.42 Social Participation—The social participation variables (categorical) were retrieved from the NHIS Quality of Life (QOL) supplement [11]. A random sample of about one quarter of the sample adults (n=6,775) answered questions from this supplement. This supplement asked respondents questions about eight activities based on the following format: "For each of the following activities, please tell me if you do the activity, don't do the activity, or are unable to do the activity" (e.g., working outside the home to earn an income; participating in leisure or social activities) (Table 1). Because of small numbers (<10) in some response categories, we recoded "don't do the activity" and "unable to do the activity" as one response category. Additionally, we excluded from the analysis "refused," "not ascertained," or "don't know" answers to these social participation questions (~10%).

2.43 Health-Related Quality of Life—HRQOL was assessed through ten validated PROMIS measures that examine mental, physical, and social health (Table 1) [7,8]. The ten HRQOL items are available on the NHIS Cancer Supplement[2] administered to all sampled adults. Eight of these variables (categorical) were subsequently grouped into global mental and physical health scales [8]. The mental health scale (continuous) included emotional problems in the past seven days, satisfaction with social activities/relationships, general quality of life, and general mental health. The physical health scale (continuous) included fatigue and pain in the past seven days, everyday physical activities, and general physical health. Hayes et al. [8] found that physical health or mental health summary scores can be used, or individual items can be investigated to examine specific information about more specific areas of HRQOL. After recoding and rescoring each PROMIS item based on Hays, et al.'s study [8], both physical and mental scales ranged from 4 to 20 points. To be consistent with scoring methods used to develop Healthy People 2020 national objectives on HRQOL for the U.S. population, we used fifteen points as the cut point for good or better physical health and 14 points as the cut point for good or better mental health [18]. Consistent with Hays' [9] methods, social questions are evaluated as separate individual items.

3.0 Analysis

The person, the sample adult, the quality of life, and five imputed income files from the 2010 NHIS were used for this analysis. All of the files were merged using the person record identifiers. Because of different weighting procedures[3] associated with different survey sections and sampling strategies, sample adult weights were used for the analysis of psychosocial variables (Table 2) and PROMIS HRQOL variables (Table 4), whereas quality of life weights were used for social participation variables (Table 3).

The multinomial logistic regression procedure in SAS-callable SUDAAN was used to obtain the predicted marginal proportions ("adjusted percentages") of each outcome variable (i.e., psychosocial variables, social participation variables, and PROMIS HRQOL variables) for

[2]In 2010, the National Cancer Institute supported the QOL supplement on NHIS, thus leading to its inclusion as a supplemental questionnaire.

[3]The detailed weighting information for 2010 NHIS can be found in the document "2010 National Health Interview Survey (NHIS) Public Use Data Release: NHIS Survey Description." at: ftp://ftp.cdc.gov/pub/Health_Statistics/NCHS/Dataset_Documentation/NHIS/2010/srvydesc.pdf.

the main predictor, the four epilepsy categories (no history of epilepsy, any history of epilepsy, inactive epilepsy, active epilepsy), while adjusting for age, sex, race/ethnicity, and family income (covariates). In all these models, NHIS' complex sampling design was accounted for. Adjusted percentages estimate percentages of different levels of the dependent variable controlling for all other explanatory variables in the model [19]. Adjusted percentages do not lose data as occurs with a calculated measure of association because adjusted percentages present estimates for all levels of an independent variable rather than estimates for all but one level relative to a reference category (e.g., using whites as a reference group) [19]. Non-overlapping 95% confidence intervals of adjusted percentages identify statistically significant differences in such percentages across subgroups, generally comparable to a statistical significance level of 0.007, which also partially adjust for multiple comparisons (similar to adjustment factors used when calculating p-values in multiple comparisons) [20]. We examined relative standard errors (RSE) to judge reliability of estimates. Where the estimates are less than 50%, the RSE is the standard error divided by the estimate, and then multiplied by 100 to obtain a percent. Where the estimates are ≥50% the RSE is the standard error of the estimate/[(100%-value of the estimate)]*100. RSEs ≥30% were considered unreliable [11]. Estimates for which RSEs ≥30% are noted and omitted from the Tables.

We conducted some post-hoc analyses to further examine general patterns of associations with select variables of interest (Table A, Supplemental file).

4.0 Results

Of the 27,139 individuals included in this analysis, 480 (1.8%, 95% CI 1.6–1.9%) reported a history of epilepsy. Among those with a history of epilepsy, 277 (1.0%, 95% CI 0.9–1.2%) reported having active epilepsy.

4.1 Psychosocial Health

The percentage of respondents with active epilepsy who reported having serious psychological distress was significantly higher than those without a history of epilepsy (12.8% vs. 3.2%; Table 2). Significantly more respondents with active epilepsy reported these feelings related to psychological distress interfered with their life activities a lot compared to those without any epilepsy (24.3% vs. 11.3%). This pattern was also seen in those with a history of epilepsy. Significantly more respondents with epilepsy in all categories also reported being unable to work or being limited in work, compared to adults without epilepsy. Individuals with epilepsy in all categories were significantly more likely to report cognitive limitations (17.3% for history of epilepsy; 22.2% for active epilepsy; 9.1% for inactive epilepsy vs. 3.0% for no history of epilepsy [Table 2]).

4.2 Social Participation

Adults with epilepsy reported great challenges when participating in social activities such as leisure or social activities, getting out with friends or family, and using transportation to get to places. For example, 26.9% of adults with active epilepsy reported not participating or being unable to participate in leisure or social activities compared to 14% of those without

epilepsy (Table 3). Significantly more respondents with a history of epilepsy (13.9%) also reported being unable to get out with friends or family compared to those without epilepsy (6.8%). Respondents with active epilepsy reported not using or being unable to use transportation to get to places three and a half times more often (28.9%) than those without epilepsy (8.3%). Across all social participation variables examined, respondents 65 years old or older, both with and without epilepsy, were more likely to report not doing an activity (e.g., working outside the home; going to school) than being unable to do the activity (data not shown). But, adults with epilepsy from 45 through 64 years of age were more likely than adults with epilepsy at other ages to report being unable to do activities (data not shown).

4.3 Health-Related Quality of Life as assessed by PROMIS

On the PROMIS Summary Scales, significantly fewer individuals with active epilepsy reported good or better overall physical (49.9% vs. 79.0%) and mental health (52.1% vs. 79.4%) than those without a history of epilepsy (Table 4). This pattern was repeated for those with a history of epilepsy and inactive epilepsy. When compared with individuals without the disorder, those with active epilepsy reported fair or poor health status significantly more often (36.9% vs. 12.3%) and excellent or very good health status significantly less often (29.9% vs. 60.8%; Table 4). Significantly more adults with active epilepsy or a history of epilepsy also reported experiencing moderate or severe fatigue in the past seven days compared to those without epilepsy. Severe pain was also more common in adults with epilepsy in all categories than in adults without the disorder. Adults with a history of epilepsy and active epilepsy were significantly less likely to report being able to carry out their daily activities. Similar patterns were seen for general physical health, emotional problems in the past seven days, satisfaction with social activities or relationships, overall quality of life, general mental health, and the ability to carry out usual social activities or roles.

4.4 Work limitations by selected psychosocial health factors, social participation variables, and HRQOL

Adults with active epilepsy who had serious psychological distress (64.0% vs. 28.5%), cognitive limitations (71.4% vs. 22.3%), or fair or poor mental health (64.9% vs. 14.3%) were significantly more likely to report being unable to work than adults with epilepsy without these additional psychosocial limitations (Table A, Supplemental file).

5.0 Discussion

Adults with epilepsy in this nationally representative sample from 2010 described substantially and significantly poorer psychological health, cognitive impairment, difficulty in participating in certain social activities, and reduced HRQOL than adults without epilepsy. More than ten percent with a history of epilepsy reported serious psychological distress. These nationally representative findings support Institute of Medicine recommendations to expand surveillance [1] and provide 2010 population estimates of epilepsy burden associated with psychosocial health.

Having work limitations or being unable to work, seen in 45.7% of individuals with active epilepsy, could reflect legal restrictions on driving, lack of access to public transportation, inability to negotiate workplace accommodations, as well as epilepsy or mental health-related challenges (e.g., uncontrolled seizures, depression). Community-based employment programs and training available through the national Epilepsy Foundation can be more widely disseminated to help adults with epilepsy obtain stable and meaningful employment opportunities [21]. The U.S. Department of Labor Job Accommodation Network provides resources to help both employers and job seekers with epilepsy better understand and discuss job accommodations in compliance with Title 1 of the American with Disabilities Act, to help foster stable employment among people with epilepsy [22]. The significant 31.5% work limitations reported in adults with inactive epilepsy might be associated with cumulative past effects of epilepsy diagnosis and treatment, including cognitive impairment that may follow or antedate epilepsy onset [23].

The presence of cognitive limitations, seen in about 1 in 5 adults with active epilepsy is notable and imposes substantial and chronic burden on these adults. Like the percentage in this study, Hermann and colleagues [24] noted that 20% of patients with chronic temporal lobe epilepsy had deficits in memory, in psychomotor or motor abilities, in naming, and in executive functioning. Behavioral, emotional and cognitive problems caused by active epilepsy earlier in life may change brain physiology that affects cognition or mental health that then results in diminished quality of life [4, 23]. Cognitive impairment exacerbates difficulties in psychological coping, obtaining and keeping employment, and maintaining an active and healthy lifestyle—all activities that help epilepsy self-management. Growing research to better understand the nature, the timing, and the course of cognitive impairment associated with epilepsy suggests a need to identify and remediate early neurobehavioral problems, especially because of possible lifelong negative impacts independent of epilepsy remission [23]. The significantly higher rates of self-reported cognitive impairment in adults with a history of epilepsy or those with inactive epilepsy support this point. Bernstein et al., found that the NHIS cognition item produced prevalence estimates of dementia similar to national estimates generated from studies designed to assess clinical dementia [25]. But, our results should be interpreted with caution because respondents with epilepsy might have associated the question phrase “periods of confusion” with seizures including the post-ictal period, leading to overestimates in cognitive impairment. This attribution combined with side-effects of older anti-seizure drugs, sleep insufficiency, and other risk factors more common in people with epilepsy (e.g., physical inactivity, smoking) might also explain findings [26, 27]. Future studies can validate this item in people with epilepsy, and longitudinal epidemiologic studies might examine how the duration of epilepsy and factors are associated with cognitive impairment.

Another intriguing outcome was the burden of severe pain in adults with epilepsy. Pain is one of the most disabling and burdensome conditions that make people seek medical care [28]. Although pain is common in people with epilepsy [26, 29], the association of pain and epilepsy remains largely unexplored. Persons with epilepsy may experience high levels of pain for several reasons. Seizures, particularly generalized tonic-clonic seizures, can cause pain [30]. An injury from seizures or adverse effects of anticonvulsants (e.g., unsteadiness) can lead to traumatic injuries or fractures which result in pain [31]. Moreover, pain,

especially headache and abdominal pain or discomfort, can be a symptom of seizures [32, 33] or adverse effects of antiepileptic medications [34, 35]. The presence of comorbid conditions in people with epilepsy makes it unclear whether and to what extent pain in epilepsy actually results from these comorbid conditions. Several pain conditions such as arthritis, peptic ulcer disease, and back pain are common among people with epilepsy [36–38]. Moreover, other comorbid conditions such as depression and pain might share similar underlying physiological mechanisms including genetic susceptibility [39]. An increased risk of seizures in depression and migraine further supports that these conditions associated with pain are clinically and mechanistically related with seizures [40]. Pain is also common in other psychiatric conditions and complex chronic illnesses associated with epilepsy, such as anxiety [41, 42], traumatic brain injury [43], stroke [44], heart failure, and diabetes [45]. These comorbid conditions, rather than epilepsy itself, are likely the principal contributors of pain in epilepsy. The presence of comorbid conditions, furthermore, might also contribute to overall deficits in quality of life [4].

Those with epilepsy were significantly less likely than those without epilepsy to participate in some social activities—leisure, getting out with friends or family, and using transportation to get to places. Although the 1990 American with Disabilities Act has improved access to public transportation for many people with disabilities, significant gaps remain for people who live in rural areas, those who rely on paratransit to get to work or medical appointments, those who rely on private transportation services, and those with visual or cognitive impairments who rely on bus stop announcements [46]. Communities and stakeholders interested in improving transportation options for people with epilepsy can implement models and initiatives that have improved transportation access for people with disabilities [46]. Uncontrolled seizures and comorbidity including mood disorders might limit social participation in people with epilepsy. Ensuring that those with epilepsy have access to specialty care, including mental health care and support, might help improve their health status and confidence to participate in social activities. Finally, improving public awareness of epilepsy, improving the public’s knowledge and skills for providing seizure first-aid, and highlighting strengths and abilities of people with epilepsy in educational programs might help create a more socially inclusive environment for people with epilepsy.

A strength of this analysis was use of the PROMIS HRQOL measures, a tool usable in clinical practice as well as in epilepsy research. These measures not only identify different health domains but also help distinguish levels of deficit severity and of duration. While this study has not identified causal relationships, individuals with active epilepsy fare worse on the HRQOL measures than individuals with inactive epilepsy, who in turn fare worse than individuals without epilepsy. PROMIS HRQOL findings can be used as population norms with which clinicians or other researchers can compare patient reported scores to explore burden of disease by epilepsy, by comorbidities, and by other social context factors that impact HRQOL [47]. Other study strengths include a large, nationally representative sample of community-dwelling adults with epilepsy allowing for adjustment of potential confounding factors associated with psychosocial health.

This study has several limitations. First, all the outcome measures are self-reported and subject to recall or other response biases. Similarly, epilepsy case definitions are also based

on self-reported data and might be subject to misclassification (e.g., overestimating by survey respondents). However, as previously reported, comparability of findings with BRFSS and other population surveys suggests these types of bias might be small [2, 12]. Second, because these data are cross-sectional, the psychosocial outcomes may not be causally related to epilepsy and its activity. Third, because NHIS requires fluency in English, ability to understand questions, and functional capacity, this study may have excluded some adults with epilepsy with limited education and literacy or severe functional limitations. Fourth, some estimates and findings should be interpreted with caution because small cell sizes may contribute to unreliable estimates.

6.0 Conclusion

Epilepsy negatively impacts physical and mental health, leading to markedly limited vitality and societal roles in individuals who struggle with the disorder [48]. In this study, adults with active epilepsy and those with a history of epilepsy reported worse scores than those without epilepsy across all PROMIS domains and experienced limitations in social participation. This suggests that the effects of epilepsy go beyond seizures. Persons with epilepsy need to manage clinical symptoms, psychosocial difficulties, and mental health issues as well as perceived or actual social disadvantages [2]. Evidence-based self-management interventions to eliminate barriers to care (e.g., lack of access to transportation) can help people with epilepsy better manage their disorder and its effects on psycho social health, mental health and cognitive disability [49]. Future studies combining 2010 and 2013 data can further explore associations among psychological distress, cognitive impairment, work limitations and social participation. Finally, comparing HRQOL in adults with epilepsy to HRQOL in adults without epilepsy is consistent with Healthy People 2020 Objectives on HRQOL and Well-Being [10]. Stakeholders can use these baseline estimates to assess whether programs, interventions, and policies designed to improve health in people with epilepsy will ultimately result in population-level improvements in HRQOL in U.S. adults with epilepsy over the decade.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Variables used in the analysis of adults with epilepsy, 2010 National Health Interview Survey.

Variable	Question Text	Response Categories
Psychosocial Health		
Serious psychological distress (Kessler-6)	During the past 30 days, how often did you feel: …so sad that nothing could cheer you up?	0 = None of the time 1 = A Little of the time 2 = Some of the time 3 = Most of the time 4 = All of the time
	…nervous?	
	…restless or fidgety?	
	…hopeless?	
	…that everything was an effort?	
	…worthless?	
Feelings interfere with life or activities	We just talked about a number of feelings you had during the past 30 days. Altogether, how much did these feelings interfere with your life or activities: a lot, some, a little, or not at all?	1 = A lot 2 = Some or a little 3 = Not at all
Work limitations	Are you limited in the kind or amount of work you do because of a physical, mental or emotional problem?	1 = Unable to Work 2= Limited in work 3= Not limited in work
Cognitive Limitations	Are you limited in any way because of difficulty remembering or because you experience periods of confusion?	1 = Yes 2 = No
Social Participation		
Work outside the home	For each of the following activities, please tell me if you do the activity, don't do the activity, or are unable to do the activity: …Working outside the home to earn an income?	1 = Do the activity 2 = Don't/Unable to do the activity
Go to school/achieving educational goals	…Going to school or achieving your education goals?	
Participate in leisure or social activities	…Participating in leisure or social activities?	
Get out with friends or family	…Getting out with friends or family?	
Do household chores	…Doing household chores such as cooking and cleaning?	
Use transportation to get to places	…Using transportation to get to places you want to go?	
Participate in religious activities	…Participating in religious activities?	
Participate in community gatherings	…Participating in community gatherings?	
Health-Related Quality of Life (PROMIS)		
General health status	Would you say [your] health in general is…?	1 = Excellent/Very Good 2 = Good 3 = Fair/Poor
Fatigue, past 7 days	In the past 7 days, how would you rate your fatigue on average?	1 = None 2 = Mild 3 = Moderate 4 = Severe/Very Severe
Pain, past 7 days	In the past 7 days, how would you rate your pain on average? Use a scale of 0–10 with 0 being no pain and 10 being the worst imaginable pain.	1 = 0 No pain 2 = 1–2 3 = 3–5 4 = 6–10
Ability to carry out everyday physical activities	To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?	1 = Completely 2 = Mostly 3 = Moderately/A little 4 = Not at all
General Physical health status	In general, how would you rate your physical health?	1 = Excellent/Very Good 2 = Good

Variable	Question Text	Response Categories
		3 = Fair/Poor
Emotional problems, past 7 days	In the past 7 days, how often have you been bothered by emotional problems such as feeling anxious, depressed, or irritable?	1 = Never 2 = Rarely 3 = Sometimes 4 = Often/Always
Satisfaction with social activities/ relationships	In general, how would you rate your satisfaction with your social activities and relationships?	1 = Excellent/Very Good 2 = Good 3 = Fair/Poor
General quality of life	In general, would you say your quality of life is...?	1 = Excellent/Very Good 2 = Good 3 = Fair/Poor
General Mental health status	In general, how would you rate your mental health, including your mood and your ability to think?	1 = Excellent/Very Good 2 = Good 3 = Fair/Poor
Ability to carry out social activities	In general, please rate how well you carry out your usual social activities and roles. This includes activities at home, at work and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.	1 = Excellent/Very Good 2 = Good 3 = Fair/Poor

Table 2

Psychosocial health in adults aged 18 years and older by epilepsy status, 2010 National Health Interview Survey[a].

	No History of Epilepsy (n=26,659)		History of Epilepsy (n=480)		Active Epilepsy[b] (n=277)		Inactive Epilepsy[b] (n=198)	
	N	% (95% CI)	N	% (95% CI)	N	% (95% CI)	N	% (95% CI)
Serious Psychological Distress (Kessler-6)								
Yes	962	3.2 (2.9–3.5)	70	10.1 (7.8–13.0)	52	12.8 (9.6–16.9)	17	*
Feeling Interfered with Life Activities								
A lot	1,100	11.3 (10.5–12.1)	67	21.3 (16.0–27.7)	48	24.3 (17.1–33.3)	17	16.1 (10.1–24.7)
Some or a little	4,351	48.2 (46.9–49.5)	144	50.9 (43.7–58.0)	81	48.7 (39.8–57.6)	62	54.5 (42.5–66.0)
Not at all	3,395	40.5 (39.2–41.8)	68	27.8 (21.4–35.3)	44	27.1 (19.3–36.6)	24	29.4 (19.3–42.1)
Work Limitations								
Unable to work	2,281	7.3 (6.9–7.7)	175	26.5 (22.3–31.2)	127	32.5 (26.4–39.2)	45	17.8 (12.7–24.4)
Limited in work	1,290	4.4 (4.1–4.7)	69	13.1 (10.3–16.6)	39	13.2 (9.6–18.0)	30	13.7 (9.4–19.7)
Not limited in work	23,078	88.3 (87.8–88.9)	236	60.4 (55.5–65.1)	111	54.3 (47.4–61.0)	123	68.5 (61.8–74.5)
Cognitive Limitations								
Yes	991	3.0 (2.8–3.3)	118	17.3 (14.3–20.9)	93	22.2 (17.7–27.5)	23	9.1 (5.7–14.2)

[a] The number of respondents in unweighted; the percentage estimates are weighted. Estimates are model-based and adjusted for age, race/ethnicity, sex, and family income.

[b] Those with active or inactive epilepsy are subsets of those with a history of epilepsy. Five adults with epilepsy could not be classified further.

* The estimate is unreliable because the relative standard error ≥30%.

Table 3

Social participation in adults aged 18 years and older by epilepsy status, 2010 National Health Interview Survey[a].

	No History of Epilepsy (n=6,653)		History of Epilepsy (n=116)		Active Epilepsy[b] (n=67)		Inactive Epilepsy[b] (n=47)	
	N	% (95%)	N	% (95%)	N	% (95%)	N	% (95%)
Working outside the home to earn an income								
Don't do/unable to do the activity	2,219	34.5 (32.9–36.1)	53	41.5 (32.3–51.4)	31	40.7 (29.7–52.7)	21	42.4 (28.6–57.5)
Going to school or achieving education goals								
Don't do/unable to do the activity	4,761	79.2 (77.8–80.5)	89	84.6 (73.6–91.6)		*		*
Participating in leisure or social activities								
Don't do/unable to do the activity	982	14.0 (13.0–15.1)	30	25.5 (18.1–34.7)	20	26.9 (17.4–39.1)		*
Getting out with friends or family								
Don't do/unable to do the activity	470	6.8 (6.1–7.6)	19	13.9 (8.9–20.9)		*		*
Doing household chores								
Don't do/unable to do the activity	456	7.4 (6.6–8.3)		*		*		*
Using transportation to get to places								
Don't do/unable to do the activity	575	8.3 (7.5–9.3)	25	25.2 (17.0–35.6)	19	28.9 (18.8–41.7)		*
Participating in religious activities								
Don't do/unable to do the activity	2,166	36.7 (35.0–38.4)	50	45.6 (35.2–56.5)	26	48.3 (34.3–62.5)	22	42.0 (26.1–59.7)
Participating in community gatherings								
Don't do/unable to do the activity	2,534	41.0 (39.3–42.6)	56	48.3 (38.0–58.8)	30	46.2 (33.2–59.7)	25	50.7 (33.5–67.8)

[a] The number of respondents is unweighted; the percentage estimates are weighted. Estimates are model-based and adjusted for age, race/ethnicity, gender, and income.

[b] Those with active or inactive epilepsy are subsets of those with a history of epilepsy. Five adults with epilepsy could not be classified further.

* The estimate is unreliable because the relative standard error ≥30%.

Table 4

Health-Related Quality of Life in adults aged 18 years and older by epilepsy status (assessed with PROMIS measures), 2010 National Health Interview Survey[a].

	No History of Epilepsy (n=26,659)		History of Epilepsy (n=480)		Active Epilepsy[b] (n=277)		Inactive Epilepsy[b] (n=198)	
	N	% (95%)	N	% (95%)	N	% (95%)	N	% (95%)
Summary Scale, Physical Health[c]								
15–20	18,683	79.0 (78.3–79.7)	199	54.2 (49.1–59.3)	96	49.9 (42.7–57.0)	101	59.6 (52.1–66.6)
Summary Scale, Mental Health[d]								
14–20	18,829	79.4 (78.7–80.1)	219	57.8 (52.6–62.8)	106	52.1 (45.1–59.0)	113	65.2 (57.9–71.9)
General Health Status								
Excellent/Very good	15,339	60.8 (60.0–61.7)	129	36.9 (31.6–42.6)	57	29.9 (22.9–37.9)	72	45.4 (38.0–53.1)
Good	7,433	26.9 (26.2–27.5)	161	31.6 (27.0–36.6)	90	33.2 (26.6–40.6)	69	30.7 (24.1–38.2)
Fair/Poor	3,871	12.3 (11.8–12.8)	190	31.5 (27.4–35.9)	130	36.9 (31.1–43.1)	57	23.9 (18.1–30.8)
Past 7 Days, Fatigue								
None	9,347	38.3 (37.5–39.1)	108	29.6 (24.4–35.4)	56	29.0 (22.2–37.0)	52	30.7 (23.6–38.9)
Mild	9,044	38.2 (37.5–38.9)	137	31.6 (26.4–37.4)	68	28.3 (21.8–35.9)	67	35.9 (27.9–44.8)
Moderate	4,818	19.1 (18.5–19.7)	128	27.5 (22.6–33.0)	72	28.7 (22.2–36.2)	56	26.5 (19.5–34.9)
Severe/Very severe	1,167	4.5 (4.2–4.8)	71	11.2 (8.5–14.8)	53	14.0 (10.1–19.1)	15	6.9 (3.9–11.9)
Past 7 Days, Pain level								
0 (no pain)	10,916	44.9 (44.1–45.7)	104	29.6 (24.6–35.2)	50	28.8 (22.2–36.4)	53	30.8 (23.6–39.2)
1–2	5,301	23.2 (22.6–23.9)	70	18.4 (14.4–23.2)	35	16.6 (11.8–22.8)	34	20.5 (14.7–27.9)
3–5	5,012	20.1 (19.4–20.7)	121	24.8 (20.4–29.7)	68	26.5 (20.5–33.5)	53	23.0 (17.3–29.9)
6–10	3,104	11.8 (11.3–12.4)	148	27.2 (23.0–31.7)	95	28.2 (22.7–34.4)	50	25.6 (18.9–33.7)
Ability to carry out every day physical activities.								
Completely	17,349	73.6 (72.8–74.4)	198	52.9 (47.7–58.1)	97	50.3 (42.9–57.7)	100	56.5 (49.2–63.5)
Mostly	3,399	13.3 (12.7–13.8)	73	17.0 (13.5–21.3)	39	15.5 (10.8–21.7)	34	19.8 (14.3–26.7)
Moderately/A little	3,213	11.5 (11.0–12.1)	127	21.7 (18.1–25.9)	79	24.2 (19.0–30.2)	46	18.5 (13.7–24.6)
Not at all	473	1.6 (1.4–1.8)	46	8.3 (5.9–11.6)	35	10.0 (6.6–14.8)		*
General Physical Health Status								
Excellent/Very good	13,178	56.2 (55.4–57.0)	121	33.1 (28.2–38.4)	58	27.5 (21.1–35.0)	63	39.7 (32.2–47.6)

	No History of Epilepsy (n=26,659)		History of Epilepsy (n=480)		Active Epilepsy[b] (n=277)		Inactive Epilepsy[b] (n=198)	
	N	% (95%)	N	% (95%)	N	% (95%)	N	% (95%)
Good	7,683	30.5 (29.8–31.3)	149	36.5 (31.1–42.2)	84	39.7 (32.5–47.4)	63	33.1 (26.0–41.1)
Fair/Poor	3,609	13.3 (12.7–13.8)	175	30.4 (26.4–34.8)	108	32.7 (27.1–39.0)	64	27.2 (21.1–34.3)
Past 7 days, Emotional Problems								
Never	13,990	58.1 (57.3–58.9)	171	42.9 (37.7–48.3)	87	38.5 (30.9–46.7)	83	48.6 (40.9–56.3)
Rarely	4,702	19.4 (18.7–20.1)	80	19.9 (15.9–24.5)	39	19.4 (13.6–26.8)	39	20.2 (14.6–27.3)
Sometimes	4,106	16.3 (15.7–16.8)	100	22.7 (18.3–27.6)	62	24.8 (18.9–31.7)	38	20.3 (14.4–28.0)
Often/Always	1,599	6.2 (5.8–6.6)	90	14.5 (11.3–18.5)	60	17.3 (13.1–22.6)	28	10.9 (6.9–16.8)
Satisfaction with social activities/relationships								
Excellent/Very good	14,754	63.3 (62.4–64.2)	161	45.8 (40.2–51.5)	78	39.3 (32.2–46.8)	83	54.0 (45.4–62.4)
Good	7,061	27.5 (26.8–28.3)	154	34.0 (28.7–39.7)	85	35.9 (28.8–43.6)	69	32.6 (24.9–41.5)
Fair/Poor	2,594	9.2 (8.7–9.7)	128	20.2 (16.7–24.1)	86	24.8 (19.8–30.7)	37	13.3 (9.3–18.8)
General Quality of Life								
Excellent/Very good	15,810	68.1 (67.2–68.9)	187	51.5 (46.2–56.8)	93	44.7 (37.8–51.8)	93	60.0 (52.1–67.5)
Good	6,310	23.7 (23.0–24.4)	144	30.5 (26.0–35.5)	83	34.5 (28.1–41.5)	59	26.1 (19.6–33.8)
Fair/Poor	2,330	8.2 (7.8–8.7)	114	17.9 (14.7–21.7)	74	20.8 (16.1–26.5)	38	13.9 (9.8–19.4)
General Mental Health Status								
Excellent/Very good	15,820	66.7 (65.9–67.5)	161	44.0 (38.9–49.2)	71	35.3 (28.5–42.9)	89	54.3 (46.7–61.7)
Good	6,582	25.8 (25.1–26.5)	144	32.1 (27.2–37.4)	82	36.1 (29.3–43.6)	59	27.6 (21.1–35.2)
Fair/Poor	2,047	7.5 (7.1–7.9)	139	23.9 (20.2–28.1)	97	28.5 (23.4–34.2)	41	18.2 (13.0–24.7)
Ability to carry out usual social activities/roles								
Excellent/Very good	16,122	68.7 (67.9–69.5)	197	50.6 (45.2–56.0)	107	49.4 (42.4–56.4)	90	52.9 (44.4–61.1)
Good	6,557	25.2 (24.6–25.9)	149	33.3 (28.3–38.7)	73	30.8 (24.5–37.9)	74	37.1 (29.2–45.8)
Fair/Poor	1,709	6.0 (5.7–6.4)	97	16.1 (12.8–19.9)	69	19.9 (15.1–25.7)	25	10.0 (6.4–15.4)

[a] The number of respondents is unweighted; the percentage estimates are weighted. Estimates are model-based and adjusted for age, race/ethnicity, gender, and income.

[b] Those with active or inactive epilepsy are subsets of those with a history of epilepsy. Five adults with epilepsy could not be classified further..

[c] Physical health summary measure includes fatigue in the past 7 days, pain in the past 7 days, everyday physical activities, and general physical health.

[d] Mental health summary scale includes emotional problems in the past 7 days, social activity/relationship satisfaction, general quality of life, and general mental health.

* The estimate is unreliable because the relative standard error ≥30%.