



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 epilepsy and those without epilepsy: 1) the Kessler-6 scale of serious psychological distress; 2) cognitive limitation, the duration and 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, 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.

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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 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.

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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 was 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. Material and methods

2.1. Data source

The NHIS is a nationally representative multistage household survey of the civilian noninstitutionalized population of the United States. Administered annually by National Center for Health Statistics, it is used to collect information on the health indicators, health-care utilization and access, and health-related behaviors of the nation [11]. United States 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 component¹ 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 databases) 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 sociodemographic 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"); and 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 for the third question. Five individuals did not meet the case definition of either active or inactive epilepsy and were subsequently excluded 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

2.4.1. 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 to 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 population with epilepsy. Responses were grouped into "a lot," "some or a little," and "not at all" (Table 1).

Self-reported answers to questions regarding the length of time with psychological problems due to "depression/anxiety or emotional problem" (grouped into less than ten years and ten or more years, categorical), 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].

2.4.2. 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 ($n = 6775$) 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,

¹ The family core component allows the NHIS to serve as a sampling frame for additional integrated surveys as needed.

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