



Serious psychological distress and health outcomes for persons with epilepsy in poverty

John O. Elliott ^{a,*}, Christine Charyton ^b, Bo Lu ^{c,1}, J. Layne Moore ^{a,2}

^a The Ohio State University, Department of Neurology, 430 Means Hall, 1654 Upham Drive, Columbus, OH 43210, United States

^b Ohio State University, Department of Psychology, 130 Lazenby Hall, 1827 Neil Avenue, Columbus, OH 43210, United States

^c The Ohio State University, College of Public Health – Division of Biostatistics, B-110 Starling-Loving Hall, 320 W 10th Avenue, Columbus, OH 43210, United States

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ABSTRACT

Epidemiology literature demonstrates socioeconomic status as an important variable for outcomes in persons with epilepsy. However, no previous studies have analyzed the association between poverty and epilepsy in the United States. Forty-one percent (246/604) of persons with a history of epilepsy (PWHE) in the 2005 California Health Interview Survey ($n = 43,020$) had an annual income <200% Federal Poverty Level (FPL), adjusted lifetime prevalence rate 0.5% [98.33% CI 0.4–0.7]. Four groups are presented in the analyses: (1) those with a history of epilepsy <200% FPL, (2) those with a history of epilepsy \geq 200% FPL, (3) those not reporting a history of epilepsy <200% FPL and (4) those not reporting a history of epilepsy \geq 200% FPL. PWHE in poverty reported significantly higher amounts of serious psychological distress, based on the validated Kessler 6 (K6) scale, than both non-epilepsy populations. After adjusting for demographics and other comorbid conditions, logistic regression analyses show PWHE in poverty are significantly more likely to report fair or poor self-rated health status when compared to the PWHE not in poverty and both non-epilepsy populations. PWHE in poverty are also more likely to report \geq 14 generally unhealthy days and \geq 14 physically unhealthy days in the past 30 days compared to the PWHE not in poverty and both non-epilepsy populations. Psychological well-being needs to be incorporated into any comprehensive treatment strategy for managing epilepsy.

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1. Background

Epilepsy affects many areas of function; education, employment, family relations, recreation and social activities.¹ Persons with epilepsy also face stigma, discrimination and fear of embarrassment which all create problems for self-esteem.² Persons with epilepsy are also more likely to be economically disadvantaged.^{3–5} To identify differential needs in health care, it is imperative to identify conditions that disproportionately affect socio-economically deprived people. In the U.S., state-based programs typically focus on the most prevalent conditions such as cancer, diabetes and cardiovascular disease. However, a recent publication by the Centers for Disease Control (CDC) has acknowledged the importance of less prevalent conditions, such as epilepsy.⁶ Objectives of the U.S. government's report *Healthy People 2010* include increasing both the quality and years of healthy life and to eliminate health disparities.⁷ The limited knowledge between epilepsy and low socioeconomic status has

been highlighted at two U.S. conferences held in conjunction with Centers for Disease Control in 1995 and 2003.⁸

In a recent examination of the 2001–2004 National Health Interview Survey ($n = 123,610$) the prevalence of serious psychological distress was higher in females, those with less than a high school diploma and those in poverty. Persons with serious psychological distress were less likely to be married, more likely to be obese, more likely to be current smokers and more likely to have a history of heart disease, diabetes, arthritis and stroke than persons without serious psychological distress.⁹ Persons with epilepsy report significantly higher rates of these same issues.^{10–15}

Persons with epilepsy are at higher risk for developing mood disorders than the general population.¹⁶ Moreover, the incidence of depression in epilepsy is higher than that of other chronic health conditions, such as asthma.¹⁷ Anxiety also has a significant impact on health-related quality of life (HRQOL) and is commonly comorbid with epilepsy.^{18,19} The under-recognition and under-treatment of mood disorders in persons with epilepsy is likely due to the rather atypical presentation of symptoms.²⁰ Kanner et al. found 71% of epilepsy patients with depression failed to meet DSM-IV criteria, but complained of anhedonia, fatigue, anxiety, irritability, frustration, crying and mood lability.²¹

* Corresponding author. Tel.: +1 614 293 6219; fax: +1 614 293 4688.

E-mail addresses: john.elliott@osumc.edu (J.O. Elliott), charyton.1@osu.edu (C. Charyton), blu@cph.osu.edu (B. Lu), j.layne.moore@osumc.edu (J.L. Moore).

¹ Tel.: +1 614 293 3906.

² Tel.: +1 614 293 4882; fax: +1 614 293 4688.

Treatment strategies that focus solely on seizure reduction are inadequate and unsuccessful for up to one half of patients with epilepsy.² In one investigation psychological distress, loneliness, adjustment and coping, and stigma perception were the most significant predictors of self-rated HRQOL. When psychosocial and clinical variables were examined in combination none of the clinical variables (onset, seizure frequency, side effects of antiepileptic drugs (AEDs)) contributed significantly to patients' HRQOL judgement.²² In another study seizure severity, seizure frequency, antiepileptic drug polytherapy and duration of epilepsy were not substantially associated with depression or anxiety when regressed against Beck Depression Inventory (BDI) scores, or the Symptom Checklist-90 for anxiety and depression in persons with temporal lobe epilepsy.²³ This suggests that anxiety and depression exert independent, adverse effects on HRQOL.

Issues related to poverty and serious psychological distress have not been studied in epilepsy. The goal of this study was to examine the prevalence of self-reported serious psychological distress and poor health-related quality of life in persons with a history of epilepsy (PWHE) in poverty. The axiom of "treating the whole patient" requires examining the relationship between poverty, serious psychological distress and poor HRQOL. It is theorized that persons with both epilepsy and poverty are likely to suffer more due to the combination of these problems than people suffering from either one (or none) of these problems alone. Such research may provide healthcare practitioners and state-based epilepsy advocacy organizations better information to coordinate care.

2. Methods

The California Health Interview Survey (CHIS) is a geographically stratified, random-digit dialed, two-stage telephone survey conducted on a biennial state-basis of non-institutionalized persons in California, over the age of 18. CHIS data have been used to address many chronic health problems^{24–28} and risk factors, such as obesity²⁹ and smoking.³⁰ The CHIS is conducted by the Center for Health Policy Research at the University of California at Los Angeles (UCLA) and is the largest state-based health survey in the United States. A full description of the topics, questionnaires, survey methodology and sample design are described on the CHIS website hosted by the UCLA Center for Health Policy at http://www.askchis.org/methods_main.html. The household response rate was 29.5% for the 2005 CHIS. This is comparable to response rates from the 2005 California Behavioral Risk Factor Surveillance System (BRFSS) Survey of 29.2%. The 2005 data and codebooks were obtained through the CHIS website. The Ohio State University Institutional Review Board deemed the research exempt prior to analyses being completed.

To assess lifetime epilepsy prevalence (history of epilepsy), we used the question "Have you ever been told by a doctor that you have a seizure disorder or epilepsy?" Demographics (gender, age, race/ethnicity, marital status, educational attainment and employment status), serious psychological distress, as defined by the Kessler 6 (K6), and HRQOL were analyzed. Poverty was defined in the CHIS by reported annual income levels, total household size and number of children. In 2005, <200% Federal Poverty Level (FPL) was defined by the U.S. government as \$38,700 for a family of four.³¹

The U.S. Department of Health and Human Services poverty guidelines (or various percentage multiples of them) are used as eligibility criteria for means-tested federal programs (eligibility for benefits is determined by property or wealth). These include the Low Income-Home Energy Assistance Program, Community Food and Nutrition Program, Job Opportunities for Low-Income Individuals and the subsidized portion of the Medicare Prescription Drug Program. However, some means tested programs do not use poverty guidelines such as Supplemental Security Income,

Earned Income Tax Credit, Medicaid and low-rent public housing. Since there is no standard definition of income for all program eligibility purposes, we defined poverty status as <200% Federal Poverty Level in order to include individuals who may fall on the cusp for public assistance eligibility (i.e., State Children's Health Insurance Program).

An extensive number of tools exist in the literature to assess mental health,³² however, most are too long to be administered in large epidemiological studies designed to study multiple health conditions.⁹ The K6 is a brief epidemiological screening tool developed to identify persons with a high likelihood of having diagnosable psychological distress severe enough to cause moderate to serious impairment in social, occupational or school functioning using the least amount of questions as possible. A score ≥ 13 is used to indicate serious psychological distress with a range of scores from 0 to 24.⁹ This is the optimal cut point which equalizes false-positive and false-negative results. The K6 was found to be the most efficient screening tool with a sensitivity of 0.36 and a specificity of 0.96, and total classification accuracy of 0.96 as compared with other instruments such as the World Health Organization's Disability Assessment Schedule.³³

HRQOL measures used in the CHIS are based on a set of healthy days assessments (general, physical and mental) as well as normal activity limitation days that were developed and validated by the CDC. These questions are often used in surveys, surveillance systems and population level prevention research.³⁴ Despite their brevity these questions have construct validity³⁵ and criterion validity in both healthy and disabled populations,^{36–38} as well as excellent retest reliability.³⁹

3. Data analysis

All analyses were conducted with Stata Version 9.2 (Stata Corp. LP, College Station, TX) using replicate weights to achieve corrected variance estimates.^{40,41} Data were weighted to obtain appropriate estimates, standard errors and confidence intervals. Replicate weights are a series of weight variables that contain the information necessary for correctly computing (via the replicate weight method) the standard errors of point estimates when analyzing survey data. Weighting procedures compensate for differential probabilities of selection to reduce bias that may occur. Weighting also adjusts for undercoverage to reduce the variance of the estimates by using auxiliary information. An adult final weight was created for each adult who completed the adult extended interview. The initial adult weight is the product of the final household weight and the reciprocal of the probability of selecting the adult from all adults in the household. In subsequent steps, the initial adult weight is adjusted for non-response and raked (a multidimensional post-stratification procedure) to known control totals. To compensate for undercoverage of adults that could not be interviewed because they reside in households without a landline telephone, the raking adjustment included a dimension designed to reduce the undercoverage bias.

Four populations are presented in the analyses: (1) PWHE <200% FPL, (2) PWHE $\geq 200\%$ FPL, (3) those not reporting a history of epilepsy <200% FPL and (4) those not reporting a history of epilepsy $\geq 200\%$ FPL. Both numerical counts and percentages were reported for each population. Comparisons across populations were made using PWHE in poverty as the reference group. To adjust for the multiple comparisons in statistical testing, a Bonferroni correction was used. With an overall type I error at 0.05, an $\alpha = 0.0167$ was used for each individual two-group comparison. Both percents and 98.33% confidence intervals are provided in reporting population level prevalence estimates. Results are considered significantly different and marked with asterisks in the tables when the 98.33% confidence intervals do not overlap.

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