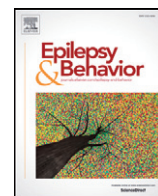




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Correlates of quality of life among individuals with epilepsy enrolled in self-management research From the US Centers for Disease Control and Prevention Managing Epilepsy Well Network

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ABSTRACT

Rationale: Epilepsy is a chronic neurological condition that causes substantial burden on patients and families. Quality of life may be reduced due to the stress of coping with epilepsy. For nearly a decade, the Centers for Disease Control (CDC) Prevention Research Center's Managing Epilepsy Well (MEW) Network has been conducting research on epilepsy self-management to address research and practice gaps. Studies have been conducted by independent centers across the U.S. Recently, the MEW Network sites, collaboratively, began compiling an integrated database to facilitate aggregate secondary analysis of completed and ongoing studies. In this preliminary analysis, correlates of quality of life in people with epilepsy (PWE) were analyzed from pooled baseline data from the MEW Network.

Methods: For this analysis, data originated from 6 epilepsy studies conducted across 4 research sites and comprised 459 PWE. Descriptive comparisons assessed common data elements that included gender, age, ethnicity, race, education, employment, income, seizure frequency, quality of life, and depression. Standardized rating scales were used for quality of life (QOLIE-10) and for depression (Patient Health Questionnaire, PHQ-9).

Results: While not all datasets included all common data elements, baseline descriptive analysis found a mean age of 42 (SD 13.22), 289 women (63.0%), 59 African Americans (13.7%), and 58 Hispanics (18.5%). Most, 422 (92.8%), completed at least high school, while 169 (61.7%) were unmarried, divorced/separated, or widowed. Median 30-day seizure frequency was 0.71 (range 0–308). Depression at baseline was common, with a mean PHQ-9 score of 8.32 (SD 6.04); 69 (29.0%) had depression in the mild range (PHQ-9 score 5–9) and 92 (38.7%) had depression in the moderate to severe range (PHQ-9 score >9). Lower baseline quality of life was associated with greater depressive severity ($p < .001$), more frequent seizures ($p < .04$) and lower income ($p < .05$).

Conclusions: The MEW Network Integrated Database offers a unique opportunity for secondary analysis of data from multiple community-based epilepsy research studies. While findings must be tempered by potential sample bias, i.e. a relative under-representation of men and relatively small sample of some racial/ethnic subgroups, results of analyses derived from this first integrated epilepsy self-management database have potential to be useful to the field. Associations between depression severity and lower QOL in PWE are consistent with previous studies derived from clinical samples. Self-management efforts that focus on mental health comorbidity and seizure control may be one way to address modifiable factors that affect quality of life in PWE.

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1. Introduction

Epilepsy self-management is a behavioral approach that can improve a variety of health outcomes in people with epilepsy [1–7]. In 2007, the Centers for Disease Control and Prevention (CDC) established the Prevention Research Centers' Managing Epilepsy Well (MEW) Network to develop, test, and disseminate epilepsy self-management interventions [3]. Between 2007 and 2015, the MEW Network has incrementally grown to include 8 geographically distinct sites conducting epilepsy self-management research [8]. This thematic research network promotes collaboration on epilepsy self-management, with a focus on gaps in knowledge or on research related to public health practice. Sites are tasked with developing and implementing a coordinated, applied research agenda; conducting research activities that promote epilepsy self-management and quality of life; and identifying and collaborating with public health, mental health, and other service agencies.

Over the last several years, the MEW Network has developed an integrated database (MEW DB) that pools and harmonizes data from past and ongoing epilepsy self-management studies [9,10] in order to conduct aggregate and secondary analysis that might provide information that is not readily derived from small and independently conducted epilepsy self-management studies. The MEW DB is a supplemental voluntary activity supported across MEW Network sites to enhance the cumulative impact of the research.

Quality of life (QOL) is often impaired among individuals with epilepsy [11] for a variety of reasons including complications due to seizures and having a chronic health condition, stigma, and social isolation. In this analysis, using baseline data from the MEW DB, correlates of QOL in people with epilepsy were analyzed in relation to selected standardized demographic and clinical variables available across epilepsy self-management research studies.

2. Material and methods

2.1. Dataset

Details on the MEW Network and the research community providing data have been described elsewhere [9,12,13]. For this analysis, the data used originated from 6 epilepsy self-management studies conducted across 4 research sites and comprised 459 PWE. Only studies that included the variable of QOL in the data dictionary were included in this analysis.

The WebEase study involved 148 individuals participating in an online epilepsy self-management randomized controlled trial [14]. The FOCUS studies, a pilot project and a larger randomized controlled trial, tested a hybrid in-person and phone-based program intended to improve self-regulation skills in both PWE and a key friend or family member who provides support [3]. The TIME study was a randomized controlled trial of an in-person, community-based intervention to improve mood and epilepsy outcomes in PWE with comorbid serious mental illnesses, like schizophrenia, bipolar disorder, and depression [8]. The MORE study was a cross-sectional analysis of 77 socio-economically and racially/ethnically diverse English and Spanish speaking PWE in a single, large urban public hospital [15]. The study examined factors related to medication non-adherence and mood-related quality of life in this underserved patient population. The FACES pilot enrolled 16 Chinese-Americans from the New York University (NYU) Comprehensive Epilepsy Center to examine psychosocial and disease related factors associated with adherence, mood, and quality of life in this under-studied patient population (*unpublished*). The MORE and FACES studies were not CDC-funded studies, but as they were conducted by MEW Network investigators within approximately the same time-frame as their CDC-funded project, were intended to inform epilepsy self-management research, and included data on minority PWE, they have been included in the MEW DB.

2.2. Data cleaning and harmonization

All MEW-DB data are linked to a study protocol and a data dictionary that provides labels for data variables. Study datasets were first evaluated to confirm that data dictionary variables clearly delineated dataset content and assessment timing. Data mapping was done to allow integration between study-specific variables and the MEW common terminology system, and involved reconciling differences in both data values as well as interval values used to categorize the data elements [9]. For example, the first three categorical values for the education variable in the database are “Never attended school”, “grades 1 through 8”, and “grades 9 through 11”. The same categories are used in the TIME study, but, in contrast, the WebEase study used a single category of “School from 1 through 11”. Thus, in the mapping process used for the MEW-DB secondary analysis, the education values of “1”, “2”, and “3” in TIME correspond to a value of “1” in WebEase, but the inverse is not true. To address this issue, mappings were defined to map value “1” in WebEase to value “3” in the integrated database [12].

Another example of original dataset heterogeneity that required harmonization was pro-rating the differential index periods for seizure frequency assessment. The common terminology system evaluates seizures in the last 30 days; however, the studies might have used different observational time-points, for example last 90 days or last year.

2.3. Data analysis

While the MEW-DB contains studies that have repeated measure methodology, only baseline data from all studies was used for this analysis. Descriptive comparisons on common data elements that included gender, age, ethnicity, race, education, employment, annual income, frequency of seizures, quality of life, and depression were done. Standardized rating scales were used for quality of life (Quality of Life in Epilepsy, QOLIE-10) [16] and for depression (Patient Health Questionnaire, PHQ-9) [17]. Statistical analysis was performed using SPSS software version 22 (IBM Corporation, NY). Spearman correlations were computed and group comparisons of QOLIE-10 distributions were conducted across categorical variables using nonparametric methods such as Kruskal–Wallis tests.

3. Results

3.1. Overall sample description

Table 1 illustrates baseline descriptive and clinical variables of studies in the MEW DB that had QOL data. While not all datasets included all common data elements, descriptive analysis found that MEW Network study participants had a mean age of 42 (SD 13.22), and included 289 women (63.0%), 59 African Americans (13.7%), and 58 Hispanics (18.5%). In the total sample, 422 completed at least high school (92.8%), and 169 (61.7%) were unmarried, divorced/separated, or widowed. Income tended to be low in PWE, with over 55% of individuals having an annual income of ≤U.S. \$25,000.

With respect to clinical variables, median seizure frequency in the last 30 days was 0.71 (range 0–308). Depression was common in this sample of PWE, with a mean score of 8.32 (SD 6.04) on the PHQ-9; 69 (29.0%) individuals had mild depression (PHQ-9 score 5–9) and 92 (38.7%) had moderate or more severe depression (PHQ-9 score >9).

3.2. Correlates of quality of life in PWE

With respect to categorical variables in the dataset, there were few demographic and clinical variables that were associated with quality of life in PWE. Neither race, ethnicity, education, or marital status were correlated with QOL, while income was positively correlated with QOL (higher income = higher QOL) ($p = .025$).

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