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Correlates of quality of life among individuals with epilepsy enrolled in self-management research: Findings from the MEW Network Integrated Database

Martha Sajatovic, MD [Professor],
Department of Psychiatry & of Neurology, Case Western Reserve University School of Medicine, Neurological and Behavioral Outcomes Center University Hospitals Cleveland Medical Center, Cleveland, Ohio

Curtis Tatsuoka, PhD,
Department of Neurology, Case Western Reserve University School of Medicine, Neurological and Behavioral Outcomes Center, University Hospitals Cleveland Medical Center, Cleveland, Ohio

Elisabeth Welter, MS, MA,
Department of Neurology, Case Western Reserve University School of Medicine, Neurological and Behavioral Outcomes Center, University Hospitals Cleveland Medical Center, Cleveland, Ohio

Daniel Friedman, MD,
Department of Neurology, New York University School of Medicine, New York, New York

Tanya M. Spruill, PhD,
Department of Population Health, New York University School of Medicine, New York, New York

Shelley Stoll, MPH,
Center for Managing Chronic Disease, University of Michigan, Ann Arbor, Michigan

Satya S. Sahoo, PhD,
Department of Epidemiology and Biostatistics, of Neurology, & of Electrical Engineering and Computer Science Department, School of Medicine, Case Western Reserve University, Cleveland, Ohio

Ashley Bukach, BA,
Department of Psychiatry and Neurology, Case Western Reserve University School of Medicine, Neurological and Behavioral Outcomes Center, University Hospitals Cleveland Medical Center, Cleveland, Ohio

Yvan A. Bamps, PhD,
Senior Research Project Coordinator, Emory University Rollins School of Public Health, Atlanta, Georgia

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Corresponding Author: Martha Sajatovic, M.D., Professor of Psychiatry and of Neurology, Case Western Reserve University School of Medicine, Affiliated Faculty, Prevention Research Center at Case Western Reserve University, Director, Neurological and Behavioral Outcomes Center, University Hospitals Cleveland Medical Center, 10524 Euclid Avenue, Cleveland, Ohio 44106, Tel. 216/844-2808, Fax 216/844-2742, Martha.sajatovic@uhhospitals.org.

Joshua Valdez, and
Department of Epidemiology and Biostatistics, School of Medicine, Case Western Reserve University, Cleveland, Ohio

Barbara C. Jobst, MD
Professor, Department of Neurology, Geisel School of Medicine at Dartmouth, Dartmouth College, Lebanon, New Hampshire

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%), 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.

Keywords

epilepsy; self-management; quality of life; secondary analysis; database

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 services 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 quality of life (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 has 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 adults with epilepsy 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 people with epilepsy and 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 PWEs, 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 studies might have used different observational time-points, for example last 9 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%), 58 Hispanics (18.5%). In the total sample, 422 completed at least high school (92.8%), 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 data set, 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)

As noted in Table 2, evaluation of correlations of QOL and the continuous variables of age, seizure frequency and PHQ-9 found some significant relationships. QOLIE-10 scores were not associated with age, but were positively associated with seizure frequency (0.163), p-value = .003. QOLIE-10 scores were also positively associated with PHQ-9 scores (.621), p-value = <.001.

4. Discussion

This analysis was derived from a unique data set that pools data from multiple epilepsy self-management studies done across the United States. Self-management has been described as a care approach that focuses on developing the abilities of patients to undertake effective self-management through education, training and support to develop knowledge, skills or psychological and social resources. [18] However, the potential positive impact of self-management approaches can be limited by the numbers of patients able or willing to access and engage with available interventions. [19, 20] Consistent with observations by single-site investigators, the majority of epilepsy self-management studies in the MEW Network have a slight preponderance of women patients. Other investigators have noted that men are often under-represented in chronic illness self-management studies. [20, 21] A goal for future epilepsy self-management research is to enroll male PWE as much as possible and identify approaches that can help them to actively engage in self-management.

Minority representation among PWE varied greatly by study in the MEW –DB, but representation of African-American and Hispanic populations paralleled their distribution in the U.S. population, [22] suggesting outreach strategies for study recruitment are effective in reaching these groups. However, other minority subgroups (e.g., Asians, American Indian, Pacific Islanders) are under-represented. This analysis did not find lower QOL in minority groups. It is possible that the overall sample of minorities may still be too small to permit accurate detection of health disparities. A systematic review by the North American Commission of the International League against Epilepsy [23] suggested that minority PWE may be receiving lower levels of care than the non-minority white population in North America. The authors of the systematic review noted that this is a concern for advocates and policy-makers seeking to eliminate inequalities in national health systems. Consistent with community-based participatory research, the MEW Network continues to target minority PWE (African-Americans, Hispanics) to augment their participation in epilepsy self-management research. It will be of interest to see if minority group differences in QOL and other health outcomes differ when larger samples of minority PWE are added to the MEW DB.

The findings that PWE who have more frequent seizures and greater depression severity have lower QOL aligns with previous research. [24–26] While antiepileptic drugs successfully help control seizures in many PWE, it is increasingly recognized that non-pharmacologic strategies such as training in self-management, stress-reduction and arousal-based strategies [8, 26] may help improve QOL in PWE. Given the known heavy burden caused by depression in PWE, the MEW Network has prioritized targeting depression in epilepsy by developing and testing a number of self-management programs that focus on PWE and mental illness. [8]

The finding of worse QOL with lower income is consistent with studies of individuals with chronic health conditions and functional impairment. [27, 28] Given the early onset of epilepsy in the lives of many PWE, it is perhaps not surprising that the burden of managing epilepsy impedes the attainment of occupational goals and adequate financial resources. [29] It is possible that evidence-based approaches for epilepsy self-management initiated early, for instance in adolescence and emerging adulthood, may help with maximizing occupational achievement and future income levels for PWE.

Summative findings from this pooled novel dataset derived from multiple epilepsy self-management studies suggest directions for future research that include outreach to minority PWE, engaging men with epilepsy, and continuing to target depression and other psychiatric comorbidities. The power of larger samples is also expected to facilitate insight from longitudinal studies on sub-groups of PWE that will ideally advance care for PWE more broadly.

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Table 1:

Baseline demographic and clinical variables among participants included in the Managing Epilepsy Well (MEW) Network Integrated Database

Variable	**Total Sample N=459**	**Study 1 WebEase N= 148**	**Study 2 FOCUS Pilot N= 21**	**Study 3 FOCUS RCT N= 159**	**Study 4 TIME N= 44**	**Study 5 MORE N= 71**	**Study 6 FACES N=16**
Age - Mean(SD)	41.68 (13.22)	40.87 (13.32)	45.05 (12.75)	41.70 (13.85)	48.25 (11.82)	38.36 (10.80)	41.00 (14.70)
Female – N (%)	289 (63.0%)	109 (73.6%)	12 (57.1%)	99 (62.3%)	26 (59.1%)	33 (46.5%)	10 (62.5%)
Race – N (%)							
White	313 (71.3%)	132 (95.7%)	14 (66.7%)	126 (79.2%)	16 (36.4%)	25 (46.3%)	0 (0.0%)
African American	59 (13.4%)	2 (1.4%)	5 (23.8%)	17 (10.7%)	25 (56.8%)	10 (18.5%)	0 (0.0%)
Asian	26 (5.9%)	3 (2.2%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	7 (13.0%)	16 (100%)
Other	33 (7.5%)	1 (0.7%)	2 (9.5%)	16 (10.0%)	3 (6.8%)	12 (22.2%)	0 (0.0%)
Unknown	27 (5.9%)	10 (6.8%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	17 (23.9%)	0 (0.0%)
Ethnicity- N (%)							
Not Hispanic	256 (81.5%)	141 (95.3%)	20 (95.2%)	150 (94.9%)	41 (93.2%)	31 (44.9%)	14 (93.3%)
Hispanic	58 (18.5%)	7 (4.7%)	1 (4.8%)	8 (5.1%)	3 (6.8%)	38 (55.1%)	1 (6.7%)
Unknown	145 (31.6%)	0 (0.0%)	0 (0.0%)	1 (0.6%)	0 (0.0%)	2 (2.8%)	1 (6.3%)
Education – N (%)							
College ≥4 yrs	190 (41.8%)	77 (52.7%)	9 (42.9%)	66 (42.0%)	4 (9.1%)	22 (31.0%)	12 (75.0%)
College 1-3 yrs	167 (36.7%)	68 (46.6%)	6 (28.6%)	60 (38.2%)	21 (47.7%)	11 (15.5%)	1 (6.3%)
High school	65 (14.3%)	-	6 (28.6%)	27 (17.2%)	8 (18.2%)	22 (31.0%)	2 (12.5%)
Some HS	31 (6.8%)	-	0 (0.0%)	3 (1.9%)	11 (25.0%)	16 (22.5%)	1 (6.3%)
Unknown	4 (0.9%)	2 (1.4%)	0 (0.0%)	2 (1.3%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Income – N (%)							
< $25K	114 (55.6%)	-	9 (42.9%)	59 (47.2%)	42 (95.5%)	-	4 (26.7%)
$25-50K	34 (16.6%)	-	5 (23.8%)	24 (19.2%)	2 (4.5%)	-	3 (20.0%)
> $50K	57 (27.8%)	-	7 (33.3%)	42 (33.6%)	0 (0.0%)	-	8 (53.3%)
Unknown	254 (55.3%)	-	0 (0.0%)	34 (21.4%)	0 (0.0%)	-	1 (6.3%)
Marital status - N (%)							

Variable	**Total Sample N=459**	**Study 1 WebEase N= 148**	**Study 2 FOCUS Pilot N= 21**	**Study 3 FOCUS RCT N= 159**	**Study 4 TIME N= 44**	**Study 5 MORE N= 71**	**Study 6 FACES N=16**
Married	105 (38.3%)	69 (48.3%)	-	-	4 (9.1%)	27 (38.0%)	5 (31.3%)
Unmarried couple	14 (5.1%)	12 (8.4%)	-	-	2 (4.5%)	0 (0.0%)	0 (0.0%)
Single, never married	105 (38.3%)	36 (25.2%)	-	-	21 (47.7%)	37 (52.1%)	11 (68.8%)
Divorced	42 (15.3%)	22 (15.4%)	-	-	14 (31.8%)	6 (8.5%)	0 (0.0%)
Widowed	5 (1.8%)	3 (2.1%)	-	-	1 (2.3%)	1 (1.4%)	0 (0.0%)
Separated	3 (1.1%)	1 (0.7%)	-	-	2 (4.5%)	0 (0.0%)	0 (0.0%)
Unknown	185 (40.3%)	5 (3.4%)	-	-	0 (0.0%)	0 (0.0%)	0 (0.0%)
30-day seizure frequency [*]- Mean (SD)	7.36 (26.50)	7.10 (20.79)	1.57 (1.62)	7.99 (33.73)	6.44 (23.03)	-	15.18 (26.91)
QOLIE-10 –Mean (SD)	2.50 (0.73)	2.80 (0.89)	3.60 (0.63)	2.88 (0.90)	3.02 (0.88)	3.04 (0.74)	2.50 (0.73)
PHQ-9 – Mean (SD)	8.32 (6.04)	-	11.24 (6.66)	7.45 (5.90)	10.83 (5.62)	-	6.63 (4.99)

[*] Seizure frequencies were standardized to a consistent time period (30 days). For example, if a study reported number of seizures an individual experienced over a 3-month period the number of seizures reported is divided by 3 to derive a 30-day frequency count.

QOLIE-10: 10-item Quality of Life in Epilepsy. Lower scores indicate better quality of life.

PHQ-9: Patient Health Questionnaire 9-item version. Higher scores indicate worse depression.

RCT= Randomized Controlled Trial

Table 2:

Correlation between quality of life, age, seizure frequency and depression severity in PWE included in the Managing Epilepsy Well (MEW) Network Integrated Database

Item	QOLIE-10	Age	Seizure Frequency	PHQ-9
QOLIE-10	1	−.051	.163[*] (.003)	.621[*] (<.001)
Age	-	1	−.016	−.082
Seizure Frequency	-	-	1	.148[*] (.041)
PHQ-9	-	-	-	1

[*] Correlation is significant at the .05 level (2-tailed)

QOLIE-10: 10-item Quality of Life in Epilepsy. Lower scores indicate better quality of life.

PHQ-9: Patient Health Questionnaire 9-item version. Higher scores indicate worse depression.