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Understanding the self-management skills of persons with epilepsy

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ABSTRACT

Purpose: To determine whether the self-management skills of persons with epilepsy (PWE) vary across the different domains of the Epilepsy Self-Management Scale (ESMS).
Methods: 172 PWE completed a survey questionnaire as well as the ESMS.
Results: Using ANOVA with pairwise comparison, the mean item scores of the medication, seizure, and safety management subscales of the ESMS were significantly higher than the lifestyle and information management subscales ($p < 0.01$). The mean item score for the lifestyle management subscale was significantly higher than the information management subscale ($p < 0.01$).
Conclusion: PWE in our population performed differently across the various domains of the ESMS and did worse on the lifestyle and information management subscales. We discuss the implications of this on patient counseling and education.

1. Introduction

Epilepsy is a common neurologic disorder that affects up to 1% of the population [1]. It is a medical condition resulting in repeated, oftentimes debilitating seizures that can lead to injury and death. Despite the advances in the various treatment modalities, around one-third of persons with epilepsy (PWE) continue to have difficult-to-control seizures [2].

The importance of good seizure control in PWE cannot be overstated. Individuals with poor seizure control, particularly generalized tonic-clonic seizures, are at increased risk for a condition known as "sudden unexplained death in epilepsy" (SUDEP) [3]. In addition, there are numerous social and societal restrictions imposed on PWE who have ongoing seizures that adversely affect their lifestyle and quality of life.

Poor seizure control has been linked to decreased education and intellectual functioning [4], increased incidence of depression and other mental disorders [5], as well as an increase in family stress [6].

It is also well known that a significant number of PWE remain unemployed [7] and this inability to work has often been cited as a major concern [8,9]. However, it has also been shown that the employment rates for PWE significantly improve if they achieve good seizure control to a degree comparable to individuals who do not have epilepsy [10].

Poor seizure control also results in restricted mobility and the inability to drive. This is a serious concern, especially in regions where public transportation is unreliable, and has been identified as one of the main barriers that prevent full integration into society and the workplace [11].

It is now recognized that for many PWE, to achieve optimal seizure control and to enhance one's quality of life entails a multi-pronged approach that requires practicing excellent self-management skills while taking advantages of the technical advances in diagnostics and therapy [12,13].

Epilepsy self-management is defined as the "ability of patients to adapt and adhere to the behavioral adjustments needed to reduce seizure frequency and improve overall health" [14]. Good epilepsy self-management encompasses a set of skills including good medication adherence, being able to accurately describe and document one's seizures, practicing safety precautions, having adequate rest, and managing one's stress levels.

The Epilepsy Self-Management Scale (ESMS) is a commonly-used and well-validated self-reported scale that assesses the frequency with which individuals perform tasks that are helpful in managing their seizures [15]. It contains 38 statements each rated on a 5-point Likert scale, with responses ranging from "Never" to "Always". The ESMS is divided into 5 subscales that encompass the realms of medication management - i.e. practicing good medication adherence (10 items), information management - i.e. keeping good records of seizures (8 items), safety management - i.e. avoiding alcohol (8 items), seizure management - i.e. contacting physician if having more seizures than usual (6 items), and lifestyle management - i.e. managing stress (6 items). The total possible scores of the ESMS range from 38 to 190 with higher scores indicating greater use of self-management strategies.

In an earlier study, we were able to determine those demographic and clinical factors that are associated with superior self-management skills in our epilepsy population [16]. However, it is important to

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determine how patients employ the various self-management skills and whether some are utilized more than others. This is important because since good epilepsy self-management requires a broad set of skills, knowing whether PWE utilize certain self-management skills more than others helps detect those areas for improvement. This can provide direction when designing and implementing self-management programs in order to help PWE optimize their seizure control and improve their quality of life.

The objective of this study was to determine the patterns of self-management among PWE and whether certain self-management skills are used more often than others.

2. Methods

The Institutional Review Board of the University of Florida Health Sciences Center Jacksonville approved this research.

This study is an extension of an earlier one we conducted at the outpatient clinics of the Comprehensive Epilepsy Program, University of Florida HSC Jacksonville, Florida. In that study, we conducted a direct survey of adult PWE from February to April 2014 and obtained a range of demographic and clinical information as well as psychosocial measures that included the ESMS. We enrolled consenting subjects who were diagnosed with localization-related epilepsy and excluded those with a history of psychogenic, non-epileptic seizures. Subjects considered themselves to be their own primary caregiver and completed the survey without assistance.

In this study, we calculated the mean item score for each subscale (medication, seizures, safety, lifestyle, and information management) of the ESMS by dividing the subscale summated scores by the number of items that comprise each subscale. Because each subscale has a different number of items in the ESMS, determining a subscale's mean item score allows for statistical comparison across subscales.

Statistical analyses were performed using SPSS™ 15.0. All statistical analyses were performed at a 5% level of significance and utilized a 2-tailed test. Tests for skewness and kurtosis were conducted prior to analysis with the intent of transforming the data, if needed, in order to satisfy the assumptions of normality. We then performed one-way ANOVA to determine whether the mean item score for each of the various subscales of the ESMS significantly differed from one another. We employed the Bonferroni correction for pairwise comparison, if necessary.

3. Results

Over 95% of patients who were invited to participate in the study did so. The demographic and clinical characteristics of the population is detailed in Table 1. More than 50% of the respondents were Caucasians and a third were African-Americans. The majority of our respondents had no more than a high school education and an annual household income of less than USD 10,000. The vast majority were unemployed, and more than half received disability benefits.

The average age of seizure onset was 22 years and mean seizure duration was 21 years. Nearly 20% had at least weekly seizures but over 25% had seizures less than once a year. Most patients experienced convulsive seizures and had seizures while awake. Over 95% were taking seizure medications. The majority of patients did not know the cause for their seizures.

Of the 182 subjects who comprised the original study, 172 fully completed the ESMS and were included in the present study. The mean summated ESMS score was 144 (Std Error of the Mean [SEM] 1.15). The mean summated scores on the medication, lifestyle, seizure, safety, and information management subscales were 44.28 (SEM 0.36), 18.55 (SEM 0.3), 25.87 (SEM 0.27), 33.11 (SEM 0.34), and 21.07 (0.56) respectively. Tests for skewness and kurtosis were performed and revealed no significantly departures from normality.

Table 1
Demographic and clinical profiles of study population.

Demographic variables	
Age in years, mean(SD)	42.8(14.2)
Males, n(%)	56(30.8)
Marital status	
Single, n(%)	89(48.9)
Married, n(%)	68(37.8)
Divorced, n(%)	18(9.9)
Widowed, n(%)	7(3.7)
Hispanics, n(%)	5(2.9)
Race	
Caucasian, n(%)	107(56.6)
African-American, n(%)	65(34.4)
Others, n(%)	17(9)
Highest educational level	
Less than high school, n(%)	42(22.2)
High school, no college, n(%)	71(37.6)
Some college/associates degree, n(%)	51(27)
Bachelor's/technical degree and higher, n(%)	25(13.2)
Annual household income	
Less than $10,000, n(%)	85(55.3)
Between $10,000 and $50,000, n(%)	71(39.2)
Between $50,000 and $100,000, n(%)	20(11)
More than $100,000, n(%)	5(2.8)
Drives a motor vehicle, n(%)	44(24.3)
Receives disability benefits, n(%)	106(58.6)
Work status	
Works full-time, n(%)	18(10.1)
Works part-time, n(%)	9(5.1)
Unemployed, n(%)	151(84.8)
Clinical variables	
Age of seizure onset in years, mean(SD)	22(16.8)
Seizure duration in years, mean(SD)	20.6(16.8)
Seizure frequency	
Daily, n(%)	8(4.5)
Less than daily but more than once a week, n(%)	27(15)
Less than weekly but at least once a month, n(%)	53(29.4)
Less than monthly but at least once a year, n(%)	43(23.9)
Less than once a year, n(%)	49(27.2)
Currently experiences convulsions, n(%)	109(60.2)
Have seizures while awake, n(%)	143(79)
Seizure etiology	
Head trauma/brain injury, n(%)	28(14.8)
Stroke/brain tumor, n(%)	27(14.3)
Other causes, n(%)	36(19)
Unknown, n(%)	98(51.9)
Number of antiepileptic drugs (AEDs) currently taking	
None, n(%)	6(3.3)
One AED, n(%)	63(36.4)
Two AEDs, n(%)	65(35.7)
More than two AEDs, n(%)	48(26.4)
Side effects from current AED regimen	
None, n(%)	87(47.8)
Minor inconvenience, n(%)	74(40.7)

The mean item scores for the medication, lifestyle, seizure, safety, and information management subscales were 4.43 (SEM 0.04), 3.1 (SEM 0.05), 4.3 (SEM 0.05), 4.15 (SEM 0.04), and 2.65 (SEM 0.03) respectively. Differences among these scores were statistically significant using one-way ANOVA ($p < 0.01$) (Fig. 1).

Using pairwise correction, the mean item scores for medication, seizure, and safety management were significantly higher than those for lifestyle and information management (all $p < 0.01$ using Bonferroni correction). The mean item score for lifestyle management was also significantly higher than for information management ($p < 0.01$ using Bonferroni correction).