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An evaluation of self-management behaviors and medication adherence in patients with epilepsy

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ABSTRACT

Comprehensive treatment of epilepsy involves many facets including self-management behaviors. The primary purpose of this study was to characterize the self-management behaviors of our patients. Additionally, we wanted to assess if the behaviors differed depending on the level of seizure control. Adult patients with epilepsy were recruited for this cross-sectional study. We used two previously validated scales to assess various self-management behaviors and collected clinical data. Our sample consisted of 50 patients (23 women). The mean overall Epilepsy Self-Management Scale (ESMS) question score was 3.72 ± 0.41. The mean question scores on the ESMS subscales Medication Management, Information Management, Safety Management, Seizure Management, and Lifestyle Management were 4.4, 2.7, 3.9, 4.0, and 2.6, respectively. Information Management and Safety Management subscale scores were higher in the patients continuing to have seizures. Based on the Morisky scale, patients fell into either the low ($n = 2$), medium ($n = 27$), or high ($n = 21$) medication-taking behavior category. Self-management skills, beyond medication-taking behaviors, should be emphasized during patient interactions.

1. Introduction

Epilepsy is a common neurological problem affecting 1–2% of the U.S. population. Epilepsy has significant economic and social consequences. These can be minimized by optimal seizure control. Antiepileptic drugs (AEDs) are the mainstay of treatment. Despite the fact that the number of AEDs approved by the Food and Drug Administration has dramatically increased over the last 15 years, it is estimated that seizures in 30–35% of patients being treated for epilepsy may not be well controlled [1]. Poor adherence to treatment is one of many reasons for pharmacological treatment failure.

Much attention has been paid to medication adherence and its role in the therapeutic outcomes of patients with a variety of diseases. Though many different definitions of medication adherence are available, the term can be sufficiently defined as "the taking of prescribed medication at the correct times, in the correct dosage, remembering to take doses, and continuing to take the medication for the duration prescribed" [2]. Over many years, a body of evidence has accumulated indicating that lack of treatment adherence in patients with chronic diseases is a major problem [3]. Lack of adherence not only reduces treatment effectiveness [4], but also increases significantly the financial burden related to management of chronic diseases [5].

A portion of patients with epilepsy, similar to patients with other chronic diseases, have poor medication adherence behavior. One study reported that between 30 and 60% of patients with epilepsy were nonadherent to their AED medication regimens [6]. Prior studies have shown an appreciable correlation between stated AED adherence and resultant seizure control in patients with epilepsy. In one study, 80% of patients with epilepsy who were determined to be adherent through self-completed survey were able to achieve some modicum of seizure control with minimal adverse effects [7]. A recently published study reported that nonadherent patients with epilepsy had a threefold increased risk of mortality compared with adherent patients [8]. Therefore, assessing medication adherence and counseling patients about it are important components of daily clinical practice [9].

However, comprehensive treatment of epilepsy involves many facets beyond medication; this is defined by DiIorio et al. as self-management [10]. Kobau and DiIorio describe behavioral and psychosocial adjustments that patients with epilepsy make to control seizures and attain a higher quality of life [11]. Behavioral adjustments include medication adherence, adequate sleep, good nutrition, and stress reduction. Coping with loss of independence and

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dealing with embarrassment and stigma are psychosocial adjustments. All of these adjustments make up self-management behaviors. Patients' diligence in controlling adherence to their medication regimen as well as non-drug-related behavioral factors, such as management of information, concern for personal safety, management of the seizures themselves, and lifestyle issues, all play an important role in the overall success of epilepsy therapy. The primary purpose of this study was to characterize the self-management behaviors of our patients. Additionally, we wanted to assess if the behaviors differed depending on the patient's level of seizure control.

2. Methods

This cross-sectional, descriptive study was approved by the Ohio State University institutional review board. Fifty-four patients in the Medical Center's Comprehensive Epilepsy Clinic who met the inclusion criteria were recruited to complete two scales. Enrolled patients were required to have a clinical diagnosis of epilepsy, to be at least 18 years of age, to be able to provide consent and complete the scales by themselves, and to have been on AED therapy for at least the past 6 months. After patients signed the consent and confidentiality forms, they were given the option to complete the scales in the clinic or take them home and return them via a prepaid envelope. The two scales were administered one time and took less than 15 minutes to complete.

We used two previously validated scales derived and used by DiIorio and Morisky to differentiate determinants of success in epilepsy therapy. DiIorio's scale was our main tool [12]; we used Morisky's scale to confirm medication adherence [13].

DiIorio et al. have created a series of scales to be used in the clinical setting in an attempt to determine AED adherence in patients with epilepsy and analyze the ability of a patient to manage his or her condition in areas other than their medications. One of these tools, the Epilepsy Self-Management Scale (ESMS), comprises 38 questions [12]. Each question on the scale is rated on a 5-point scale from *never* (1) to *always* (5). The questions are categorized into five subscales: Medication Management (MM, 8 questions), Information Management (IM, 7 questions), Safety Management (SM, 7 questions), Seizure Management (SzM, 7 questions), and Lifestyle Management (LM, 4 questions). Five questions are not categorized into subscales. The higher the total score, the better the self-management practices. The scale has been used in epilepsy self-management studies, with a reliability coefficient ranging from 0.81 to 0.84, indicating uniform consistency in results across and within sample groups [14]. Results of the ESMS have been reported either as a total score [15,16] or a question score (range: 1–5) [14].

Morisky et al. developed a brief, easily understood, and valid scale to be administered to patients in the clinical setting. This scale was very successful in predicting positive therapeutic outcomes by identifying hypertensive patients with good medication adherence [13]. Scores range from 0 to 4, with 4 depicting high and 0 depicting low medication-taking behavior. Patients were categorized into three groups: low (score of 0 or 1), medium (score of 2 or 3), and high (score of 4) scores.

In addition to the two scales, key clinical and demographic information on each patient was gathered at the time of the clinic visit. The clinical data included number of AEDs, seizure activity over the last 3 months (based on patients' calendars and/or recall), and whether their seizures were AED resistant (previously-failed two AEDs).

2.1. Data analysis

The degree of therapeutic outcome was determined by current seizure status because of the cross-sectional method of this study. The analytic plan of this study followed a specific progression. First, descriptive statistics were used to summarize and describe the data. A mean score for each question was determined by dividing the subscale mean score by the number of questions in the subscale. This allowed for a more standardized comparison of the subscales based on a one-sample t test. The MM mean score of 4.5 was used as the test value, which is consistent with previously published results [17]. The next analysis used the ESMS subscale and total scores as the dependent variables. One-way ANOVA was used to determine if there were differences in the independent variables: age, gender, race/ethnicity, education, seizure frequency, and treatment for depression. The nonparametric two-tailed Wilcoxon rank sum test was used for unbalanced sample size comparisons (race/ethnicity and depression) in this analysis. Next, we performed a bivariate (Pearson correlations) analysis to examine relationships between the ESMS subscales and the independent variables: age, number of seizures, number of AEDs, total number of medications, and self-rated health status. Spearman correlation was used for noncontinuous variables (self-rated health status). All analyses were done using SPSS Version 15.0.

3. Results

The total number of patients recruited into the study was 54. Two of the patients never returned the scales via mail as promised. Data from two patients were excluded because of excessive missing data. The total number of patients analyzed was 50.

Demographics of participants and self-rating of health are summarized in Table 1. There was an approximate 50% split between the genders. Patients ranged in age from 20 to 70 years. Of the 50 patients, 46 were Caucasian. Almost half of the patients were currently seizure free at the time the scales were administered. The average total number of medications patients were taking was 4, with a wide range of responses to that question. Almost 70% rated their health to be well or very well.

Mean ESMS total scores and the five subscale scores are listed in Table 2. The MM subscale had the highest mean score per question, and was significantly higher when compared with the other subscales: IM ($t = -14.60$, $P < 0.001$), SM ($t = -6.73$, $P < 0.001$), SzM ($t = -4.61$, $P < 0.001$), and LM ($t = -17.24$, $P < 0.001$). When the MM subscale was compared with the Morisky adherence category, patients who scored high on the Morisky scale also scored high on the MM subscale (Fig. 1).

Table 3 lists scores by demographic groupings. Scores on two of the five ESMS subscales (IM and SM) were higher in the group of patients continuing to have seizures. Patients who were not seizure free at the time they completed the scales scored higher on the IM ($F = 4.14$, $P = 0.048$) and SM ($F = 4.06$, $P = 0.05$) subscales. The older the patient, the higher the ESMS total score ($F = 4.20$, $P = 0.01$). Women scored higher than men on the IM ($F = 4.55$, $P = 0.038$) and SM ($F = 4.68$, $P = 0.036$) subscales. Caucasian patients scored higher on both the MM subscale (Wilcoxon $W = 32.50$ $P = 0.012$) and the Morisky scale. Patients with higher education scored higher on the LM subscale ($F = 5.27$, $P = 0.03$), but scored lower on the SM subscale ($F = 4.72$, $P = 0.04$). Patients with depression scored lower on the MM subscale (Wilcoxon $W = 133.00$, $P = 0.014$).

Demographics were correlated with the total ESMS score and the subscale scores (Table 4). Age was moderately correlated with IM subscale score ($r = 0.28$, $P = 0.048$) and ESMS total score ($r = 0.33$, $P = 0.021$). Number of medications was moderately correlated with IM subscale score ($r = 0.36$, $P = 0.01$), SM subscale score ($r = 0.40$, $P = 0.005$), and ESMS total score ($r = 0.40$, $P = 0.004$). Self-rated health status was moderately correlated with MM subscale score ($\rho = 0.31$, $P = 0.03$). Interestingly, the Morisky score was

Table 1
Demographics of participants

Variable	*N* (%)
Male	27 (54)
Ethnicity	
Caucasian	46 (92)
African-American	3 (6)
Other	1 (2)
Education	
Eighth grade or less	2 (4)
High school or GED	22 (44)
Some college	11 (22)
College graduate	15 (30)
Other medical conditions	
Depression	9 (18)
Hypertension	9 (18)
High cholesterol	6 (12)
Asthma	6 (12)
Anxiety	5 (10)
Arthritis	5 (10)
Gastroesophageal reflux disease	3 (6)
Diabetes	2 (4)
Peptic ulcer disease	2 (4)
Cancer	1 (2)
Allergy	1 (2)
Stroke	1 (2)
Cardiac ischemia	1 (2)
Patients with AED-resistant epilepsy	35 (70)
Reported seizure frequency in last 3 months	
0	23 (47)
1–10	14 (29)
>10	12 (24)
Current number of AEDs	
One	26 (52)
Two	19 (38)
Three	2 (4)
Four	3 (6)
Total number of medications	
One	9 (18)
Two	9 (18)
Three	9 (18)
Four	9 (18)
More than four	13 (25)
Health status self-rating (based on Morisky scale)	
Poor	1 (2)
Fair	14 (29)
Well	25 (51)
Very well	9 (18)

moderately correlated with the ESMS LM subscale score. Of no surprise is the fact that the Morisky score was highly correlated with the ESMS MM subscale score. This supports the idea that they are measuring the same construct.

4. Discussion

This project attempted to characterize the self-management behaviors of our patients and to determine if the behaviors differed depending on the level of seizure control. As a whole, our patients scored high on the medication-taking behavior subscale as compared with the other self-management skills. Despite our initial thinking that the seizure-free patients would report consistently higher self-management behaviors, this was not the case in our patient sample.

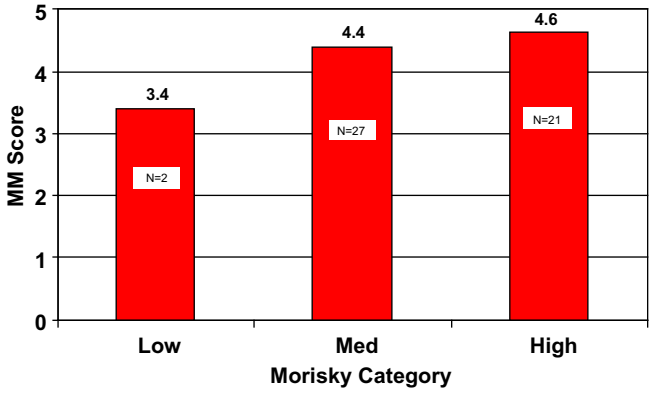

Fig. 1. Medication Management (MM) subscale scores by Morisky category.

Although one would expect correlation between total ESMS score, all subscale scores, and seizure frequency, our study did not show such a correlation, even for medication management. This may be explained by the fact that our study was a cross-sectional study, and seizure frequency was not collected using a prospective method. Another explanation for this finding could be that patients reported themselves to be more adherent than they actually were. Patients may have had a tendency to consciously and/or unconsciously want to show their treating physicians that they are adherent.

An important finding of this study is that patients with epilepsy have better management behaviors with respect to their AEDs than other health aspects related to epilepsy (information, safety, seizure, and lifestyle). A previous study showed that patients with epilepsy may be adherent to medication therapy, but not have healthy lifestyle behaviors [11]. The adherence rates of our patients were high on both the DiIorio and Morisky scales. We do not have published MM subscale scores with which to compare our population with others; however, the mean question score for the total ESMS in our study (3.7 ± 0.4) was very close to that in other studies in patients with epilepsy (4.0 ± 0.5, 4.1 ± 0.5, 3.8 ± 0.4) [14–16]. This leads us to believe that our patient sample was similar to previously studied populations.

An explanation for our results is that patients receive counseling about medication adherence more extensively than other aspects of epilepsy management. We believe this is the case in our and other medical practices. Most practitioners tend to spend more time discussing medication adherence and side effects than discussing other social and safety issues related to epilepsy.

It is routine clinical practice to reinforce medication adherence. This study highlights that other factors should not be ignored. Regular discussions with patients could include, but not be limited to, coping with the loss of independence, dealing with embarrassment, getting proper sleep, eating right, and/or attempting to bet-

Table 2
Mean ESMS subscale and total scores[a]

	MM[b]	IM	SM	SzM	LM	ESMS
Total score	35.8 (3.8)	18.7 (6.1)	27.7 (3.9)	24.0 (4.7)	10.5 (3.1)	141.0 (15.4)
Question score (range: 1–5)	4.4 (0.5)	2.7 (0.9)	3.9 (0.6)	4.0 (0.8)	2.6 (0.8)	3.7 (0.4)

[a] Data expressed as means (SD).
[b] MM, Medication Management subscale (8 questions, total score range: 8–40); IM, Information Management subscale (7 questions, total score range: 7–35); SM, Safety Management Subscale (7 questions, total score range: 7–35); SzM, Seizure Management subscale (6 questions, total score range: 6–30); LM, Lifestyle Management subscale (4 questions, total score range: 4–20); ESMS, Epilepsy Self-Management Scale (38 questions, total score range: 38–190).

Table 3
ESMS Subscale, Total and Morisky Scores by select demographics

Total score range		MM (8–40)	IM (7–35)	SM (7–35)	SzM (6–30)	LM (4–20)	ESMS (38–190)	Morisky (0–4)
Age	*n*							
20–30	13	35.3 (3.7)	16.4 (7.1)	27.6 (3.8)	24.6 (5.4)	10.9 (3.3)	140.2 (15.4)	3.0 (0.8)
31–40	12	35.2 (4.0)	18.5 (7.7)	25.8 (3.9)	22.8 (4.4)	9.8 (3.2)	135.0 (15.8)[b]	3.4 (0.6)
41–50	14	35.2 (4.2)	17.9 (5.0)	26.9 (4.2)	23.1 (4.8)	9.9 (2.4)	136.3 (14.3)[b]	2.9 (0.9)
>51	10	38.5 (2.0)	22.3 (3.6)	30.5 (3.7)	26.0 (3.0)	11.5 (3.7)	154.6 (11.0)[b]	3.7 (0.7)
Gender								
Male	27	36.7 (3.0)	16.9 (6.2)[a]	26.4 (4.6)[a]	23.6 (4.7)	10.1 (2.7)	136.9 (15.2)	3.3 (0.7)
Female	23	34.9 (4.5)	20.5 (5.9)[a]	28.9 (3.2)[a]	24.4 (4.7)	10.9 (3.5)	145.1 (15.6)	3.2 (0.9)
Race/ethnicity								
Caucasian	46	36.3 (3.5)[a]	18.8 (6.3)	27.5 (4.2)	24.0 (4.6)	10.7 (3.0)	141.7 (15.5)	3.3 (0.8)[a]
Non-Caucasian	4	31.3 (4.2)[a]	15.8 (5.7)	28.5 (4.1)	23.3 (5.9)	8.3 (3.9)	128.8 (15.8)	2.3 (1.0)[a]
Education								
High school or less	24	35.4 (4.7)	18.7 (5.8)	28.8 (3.5)[a]	23.0 (5.3)	9.5 (3.3)[a]	138.9 (17.5)	3.1 (1.0)
Some college or college grad	26	36.3 (2.8)	18.4 (6.8)	26.4 (4.4)[a]	24.9 (3.7)	11.4 (2.6)[a]	142.3 (14.1)	3.3 (0.6)
3-Month seizure frequency								
Seizure free	23	36.0 (3.2)	16.7 (6.6)[a]	26.3 (4.3)[a]	24.5 (4.6)	11.0 (2.8)	138.0 (14.5)	3.4 (0.6)
Not seizure free	26	36.2 (3.8)	20.2 (5.7)[a]	28.7 (3.9)[a]	23.9 (4.4)	10.0 (3.4)	144.0 (16.2)	3.1 (0.9)
Report being treated for depression								
No	41	36.4 (3.7)[a]	18.0 (6.5)	27.2 (4.4)	23.9 (5.0)	10.6 (3.1)	140.4 (16.2)	3.3 (0.8)
Yes	9	33.7 (3.4)[a]	21.1 (4.6)	28.9 (2.8)	24.2 (3.0)	9.9 (3.3)	141.9 (14.3)	3.0 (0.9)

Note. Data expressed as means (SD). Analyses were completed through one-way ANOVA, except for race/ethnicity and depression, for which a Mann–Whitney test was used because of unequal sample sizes. MM, Medication Management; IM, Information Management; SM, Safety Management; SzM, Seizure Management; LM, Lifestyle Management; ESMS, Epilepsy Self-Management Scale total score.

[a] $P \leqslant 0.05$.

[b] $P \leqslant 0.01$.

Table 4
Correlation matrix of select demographics by ESMS subscale and total scores

	MM	IM	SM	SzM	LM	ESMS
Age	0.27	0.33[a]	0.15	0.12	0.07	0.28[a]
3-Month seizure frequency	−0.24	0.27	0.19	−0.09	−0.15	0.08
Number of AEDs	0.21	0.11	−0.04	0.003	0.07	0.10
Total number of medications	0.16	0.36[a]	0.40[b]	0.28	−0.14	0.40[b]
Self-rated health status	0.31[a]	0.05	−0.21	0.15	0.18	0.17
Morisky score	0.58[b]	0.14	−0.11	0.19	0.34[a]	0.30[a]

Note. Correlations were calculated using Pearson's *r*, except for self-rated health status, which was calculated using Spearman's ρ. MM, Medication Management; IM, Information Management; SM, Safety Management; SzM, Seizure Management; LM, Lifestyle Management; ESMS, Epilepsy Self-Management Scale total score.

[a] $P \leqslant 0.05$.

[b] $P \leqslant 0.01$.

ter manage stress. Our data indicate where patients' weaknesses lie and therefore may benefit from increased counseling in these other areas. In particular, lifestyle management was consistently the lowest scoring subscale of self-management techniques in patients.

In relation to clinical utility, some practitioners may desire the shorter scale (Morisky) to assess medication adherence due to time constraints. Though it has many more questions, domain-specific scales like the ESMS tend to still be the better choice.

It is important to point out the limitations of our study of medication adherence and self-management techniques. First, the sample size of 50 is relatively small, especially considering the fact that we further broke down the population into smaller categories for analyses. Additionally, this relatively small sample size is rather heterogeneous with respect to age, seizure control, and AED resistance. We also realize that we could have gathered other key demographic data, such as socioeconomic status. A fourth limitation is that the study was a cross-sectional design. Lastly, there is a chance that nonadherence may have been underreported because of the self-reporting nature of the scales.

In conclusion, in our convenience sample of patients with epilepsy, we found that self-management skills, beyond medication-taking behaviors, should be an area of emphasis during patient interactions.

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