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Adherence to Antiepileptic Drugs and Beliefs about Medication Among Predominantly Ethnic Minority Patients with Epilepsy

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Abstract

The current study examined beliefs about medication and their association with adherence to antiepileptic drugs (AEDs) among predominantly ethnic minority, low-income patients with epilepsy (PWE). Seventy-two PWE completed standardized questionnaires. The Beliefs about Medicines Questionnaire was used to assess perceptions about AEDs and medications in general. Adherence was measured with the Morisky 4-item scale and via participant self-rating. On the Morisky scale, 63% of patients endorsed at least one item for nonadherence. There was a significant relationship between seizure frequency and adherence (Morisky: $r = 0.33$, $p = 0.006$; Self-rating: $r = -0.35$; $p = 0.003$). Patients with lower self-rated adherence expressed greater concerns about AEDs ($r = -0.25$, $p = .036$) and beliefs that medications, in general, may be intrinsically harmful ($r = -0.26$; $p = 0.032$) and minimally beneficial ($r = 0.36$; $p < 0.002$), as compared to more adherent patients. These findings inform future educational interventions in this population of PWE.

Keywords

epilepsy; medication adherence; beliefs about medicines

1. Introduction

Antiepileptic drugs (AEDs) can prevent seizures in approximately 70% of adult patients with epilepsy (PWE).[1] However, AED nonadherence is highly prevalent, with estimates ranging from 20 to 80%.[2] Nonadherence is associated with increased risk of mortality, and a higher incidence of ED visits, hospital admissions, injuries, and fractures.[3,4] Yet, little is known about the extent of nonadherence and its association with seizure control in

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populations at high-risk for poor health outcomes, such as economically disadvantaged ethnic minorities. Even less is known about the underlying factors that contribute to nonadherence.

Previous research in predominantly minority and low-income patients from our epilepsy center revealed an extraordinary fear and skepticism of brain surgery as a treatment option; most patients would not consider surgery even if guaranteed seizure freedom without any lasting deficits.[5] The current study aimed to examine beliefs about medication and the association between treatment perceptions and AED adherence in this patient population.

2. Methods

2.1. Participants

Seventy-two adult patients were recruited from a sub-specialty epilepsy clinic attended by predominantly ethnic minority, low-income patients at SUNY Downstate Medical Center in Brooklyn, New York. Epilepsy patients in this convenience sample completed standardized questionnaires anonymously. The study was approved by the institutional IRB.

2.2. Measures

Seizure control—Number of seizures during the past month was self-reported, often with reference to seizure diaries.

AED adherence—The Morisky 4-item scale was used to assess AED adherence,[6] with higher scores (range 0–4) indicating worse adherence (Cronbach’s alpha 0.40). This scale has demonstrated validity based on its relationship with clinical outcomes in various chronic illness populations. However, previous research failed to demonstrate a relationship between the Morisky score and seizure control in PWE.[7] Patients also rated their ability to take their AEDs as prescribed over the past 4 weeks (from ‘1-very poor’ to ‘6-excellent’). This measure is drawn from validation research where it demonstrated close concordance with electronically monitored adherence in HIV/AIDS.[8]

Beliefs about medicines—The Beliefs about Medicines Questionnaire (BMQ) [9] assessed perceptions about AEDs and medications in general. An adapted version, based on confirmatory factor analysis and previously shown ability to predict treatment adherence in HIV/AIDS, [10] was used in the current study. Subscales assess general perceptions of 1) the benefit of medications, 2) harm associated with taking medications, and 3) overuse of prescribed medications by doctors. Specific beliefs about AEDs were assessed by perceived necessity of AEDs and concerns about the negative consequences of AEDs. Responses ranged from ‘1 - strongly disagree’ to ‘5 - strongly agree’. Cronbach’s alpha range: 0.63 – 0.84.

Additional variables—Race, ethnicity, gender, years of education, and household income were obtained via self-report.

2.3. Statistical Analyses

All analyses were conducted using SPSS version 18 (SPSS Inc., Chicago, IL, U.S.A.). Because seizure frequency was significantly skewed and kurtotic, prior to analyses data were transformed using the square root. We first examined the relationships of potential covariates (education, age, gender, race, ethnicity, income, number of AEDs) with AED adherence and seizure frequency. Variables trending to a significant ($p < .10$) relationship with adherence or seizure control would be retained for multivariate analyses. Next, we evaluated the relationships of our two measures of AED adherence to seizure frequency to

assess criterion validity. Finally, we examined the relationship between beliefs about medication and 1) AED adherence and 2) seizure frequency, using Pearson correlations.

3. Results

Sample characteristics are summarized in Table 1. Univariate analyses demonstrated no significant differences between gender, race/ethnicity, or any other potential covariate and either measure of reported AED adherence or seizure frequency (all p 's > .158). Therefore, no covariates were included in the following analyses.

AED adherence—Sixty-three percent of respondents endorsed at least one of the Morisky items for AED nonadherence. Forgetfulness was the most often (50% of participants) endorsed reason for nonadherence, followed by occasional carelessness (29.2%), stopping AEDs when feeling worse (12.5%), and stopping AEDs when feeling better (8.2%). The average score on the AED adherence self-rating item was 4.82 (SD=1.17), nearly corresponding to a rating of ‘very good.’ Morisky total score significantly correlated with self-rated adherence ($r = -.52$, $p < .001$), indicating 27% shared variance. There was a significant relationship between seizure frequency and self-rated adherence ($r = -0.35$; $p = 0.003$), providing evidence for the validity of AED adherence self-ratings. The Morisky score was similarly associated with seizure frequency ($r = 0.33$, $p = 0.006$).

Beliefs about medicines—Table 2 shows that several beliefs were significantly associated with self-rated AED adherence, although none with the Morisky score. Patients with lower adherence expressed stronger beliefs that medications, in general, may be intrinsically harmful ($r = -0.26$; $p = 0.032$) and minimally beneficial ($r = 0.36$; $p < 0.002$), as compared to more adherent patients. Increased concern about the negative consequences of taking AEDs was associated with worse adherence ($r = -.25$, $p = .036$). Concerns about AEDs were also significantly associated with increased seizure frequency ($r = .37$, $p = .002$), while believing that medicines are generally beneficial was associated with fewer seizures ($r = -.26$, $p = .036$). Perceptions regarding the necessity of taking AEDs were not related to adherence.

On average, patients were ‘uncertain’ about whether medications were intrinsically harmful or overused by doctors. For example, 74% reported agreement with the item, “Most medicines are addictive” and 53.5% with, “If doctors had more time with patients, they would prescribe fewer medicines.” At the same time, they tended to ‘agree’ that medications were beneficial; 56.3% agreed that, “Medicines help many people to live longer.” Regarding AEDs in particular, patients tended to ‘agree’ with their necessity (e.g., “My health, at present, depends on these medicines”; 77.5%) but were ‘uncertain’ about concerns regarding negative consequences (e.g., “I sometimes worry about long-term effects of these medicines”; 60%).

4. Discussion

This study examined beliefs about medications in relation to AED adherence and seizure control among economically disadvantaged, predominantly ethnic minority PWE. We found that the majority (63%) of patients endorsed AED nonadherence as measured by the Morisky scale. Perceptions that medicines were either generally harmful or generally beneficial were associated with self-rated AED adherence. Concerns about AEDs were also associated with nonadherence. Furthermore, perceptions regarding the benefits of medicines and concerns about AEDs were related to seizure frequency, suggesting that the impact of these beliefs is robust enough to potentially impact treatment outcomes.

We are aware of only three other studies that evaluated beliefs about medication in PWE using standardized instruments. Jones et al. [7] found that PWE with poorly controlled seizures had stronger beliefs in the necessity of AEDs than well-controlled patients, and found a trend for a relationship between AED concerns and poorer control. Kemp et al. [11] found no relationship between AED beliefs and adherence. Both of these studies from the UK enrolled fewer patients, and did not report ethnic background and socioeconomic status. In a recent study, Bautista and Jain [12] compared seizure frequency and beliefs about medications in Caucasian and African American PWE at an urban medical center's tertiary epilepsy clinic in Jacksonville, Florida. They found a disparity in BMQ scores, reflecting an increased tendency to view medicines as harmful and overused, as well as a greater level of concern relative to perceived necessity of AEDs among African American patients. African American patients were also found to experience worse seizure control relative to Caucasian patients, however, medication adherence was not investigated. Our current study suggests that in a sample that was comparable to that of Bautista and Jain [12] in age, education, employment status, and income, negative beliefs about medicines are significantly associated with medication adherence. While African American/African Caribbean ethnicity was not found to be significantly associated with the patient beliefs about medicines in our study, this may be due to the small number of individuals of other ethnicities represented in our sample.

Our findings on the relationship between beliefs about medication and treatment adherence are consistent with the wider literature in chronic illness populations. For example, both treatment-specific beliefs and beliefs about medications in general predicted adherence to antiretroviral medication over time in a sample of patients with HIV/AIDS. [10] Doubts about the necessity of medication and concerns about its potential adverse effects predicted nonadherence to preventer medication in asthma.[13] While beliefs about the necessity of AEDs were not associated with adherence in our study, contrasting with this literature, this finding points to the greater role of concerns about AED treatment in nonadherence and has important implications for educational interventions with epilepsy patients. Our findings also underscore the importance of beliefs about medication, relative to education level and other demographic factors, in explaining AED nonadherence. Therefore, assessing patient beliefs about medications in clinical practice, irrespective of patient education level is recommended, as evaluation of these beliefs may provide an important opportunity to intervene and correct misconceptions, possibly resulting in improved outcomes.

It should be noted that beliefs about medicines were not associated with adherence as measured by the Morisky scale. Unlike the self-rating scale, the Morisky items specify limited reasons for nonadherence, and this may explain the discrepancy in our findings. The Morisky also had low internal reliability in our sample. The self-rating scale may be a more valid measure of adherence, based on the evidence of its validity when compared directly to objectively monitored adherence in HIV/AIDS.[8] This easily administered one-item measure may be useful in clinical practice in PWE with low levels of education/literacy and could identify patients at risk for poor treatment outcomes.

In addition to the influence of patient beliefs, ability to manage epilepsy treatment and adhere to medication regimens may be impacted by cognitive and emotional problems, which are highly prevalent in PWE.[14] In fact, 50% of PWE in our sample reported forgetfulness as a reason for nonadherence. The current study did not examine the impact of cognitive and emotional variables on adherence or beliefs about epilepsy treatment. Future research should elucidate the role played by these factors.

5. Conclusion

This study demonstrates that misconceptions about medicines are prevalent among economically disadvantaged, predominantly minority PWE. These inaccurate beliefs are associated with low AED adherence and interfere with effective treatment. In addition, many patients reported forgetfulness as a barrier to adherence. The study findings suggest that these potentially modifiable factors should be targeted in future educational interventions for PWE, with the goal of increasing treatment adherence and improving seizure control.

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Table 1

Sample Characteristics

	<i>N</i> (%)
Total number of patients	72
Age, mean (SD)	44 (14.2)
Gender	
Male	27 (37.5)
Female	45 (62.5)
Ethnicity, <i>n</i> = 71	
African-American/African-Caribbean	54 (76.1)
White	9 (12.7)
Asian/Pacific Islander	1 (1.4)
Other	7 (9.9)
Hispanic or Latino	12 (17)
Education, <i>n</i> = 71	
< 12 years	18 (25.4)
High school graduate or equivalency	25 (35.2)
Some college	20 (28.2)
College degree	8 (11.2)
Employed, <i>n</i> = 68	12 (17)
Household income, <i>n</i> = 59	
\$0–\$10,000	34 (57.6)
\$11,000–20,000	7 (11.9)
\$21,000–50,000	15 (25.4)
>\$50,000	3 (5.1)
Number of seizures (past month), mean (SD)	2.2 (3.9)
Number of AEDs (<i>n</i> = 36), mean (SD)	2 (1.1)

Table 2
Beliefs About Medications: Correlations With Seizure Frequency and Adherence

BMQ Scale	Seizure Frequency ¹		Adherence Rating Past 4 Weeks ²		Morisky Score ³	
	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>	<i>R</i>	<i>p</i>
Harm	0.21	0.085	-0.26	0.032	0.07	0.565
Overuse	0.08	0.537	-0.07	0.546	0.10	0.418
Benefit	-0.26	0.036	0.36	0.002	-0.14	0.242
Necessity	-0.07	0.546	-0.01	0.918	-0.09	0.457
Concern	0.37	0.002	-0.25	0.036	0.10	0.432

¹ Patient self-reported seizure frequency over the past 4 weeks

² Adherence rating: range 1 – 6 (i.e., 1 = very poor, 6 = excellent)

³ Morisky score: range 1 – 4 (higher score is indicative of worse adherence)