Detecting health disparities among Caucasians and African-Americans with epilepsy

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A B S T R A C T

Objective: The aim of the study was to determine whether African-Americans and Caucasians who receive care at a tertiary epilepsy center can be distinguished on a variety of demographic, clinical, and psychosocial variables.
Methods: We surveyed 111 consecutive patients followed at a tertiary epilepsy center.
Results: On univariate analysis, African-Americans had significantly more seizures ($P = 0.03$), lower scores on the Beliefs About Medicines Questionnaire—Specific (Necessity minus Concerns) (BMQ-S) ($P = 0.01$), and higher scores on the BMQ—General (BMQ-G) ($P = 0.02$). In binary logistic regression with race as the target variable, higher seizure frequency remained significantly associated with being African-American ($P = 0.04$). After ordinal regression with seizure frequency as the target variable, being African-American ($P = 0.04$) and higher BMQ-G scores ($P = 0.02$) remained significantly associated with increased seizure frequency.
Conclusion: Compared with Caucasians, African-Americans have higher seizure frequency and scores on the BMQ indicating a higher mistrust of medications. Aside from race, attitudes toward medications are also independently associated with seizure control.

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1. Introduction

Health disparities continue to exist in epilepsy care. In a study by Hussain and colleagues [1], the incidence of epilepsy was higher in a cohort of elderly African-Americans when compared with Caucasians. Tragically, the mortality rates from epilepsy are also higher in nonwhite individuals [2].

Although the reason for these disparities may be the disease itself, socioeconomic factors such as decreased financial resources contribute to poor epilepsy care [3]. Standards of epilepsy care still differ between African-Americans and Caucasians. African-Americans are more likely to be diagnosed in an emergency room and nonspecialized setting which increases the chance of receiving suboptimal care [4,5].

An issue that has not been well investigated is the attitude toward medications of minority patients with epilepsy. This is especially relevant in the epilepsy population, in which the vast majority of patients use antiepileptic drugs (AEDs) as their sole method of seizure control [6] and in which the national costs of AED therapy account for up to 30% of the total costs of epilepsy care [7].

In a study of patients with different chronic illnesses (cardiac, renal, asthma, and oncology), it was shown that negative beliefs regarding the importance of medicines resulted in poor adherence, and that medication beliefs were even more powerful predictors of adherence than clinical and sociodemographic factors [8]. Poor adherence to AED treatment is associated with poorer seizure control [9] and increased costs of health care [10].

The aim of this study was to determine whether demographic, clinical, and psychosocial factors distinguish African-American and Caucasians with epilepsy. In particular, we sought to determine whether attitudes toward antiepileptic medications differ between Caucasians and African-Americans with epilepsy followed at a tertiary epilepsy center and if this is associated with more traditional outcomes of care, such as degree of seizure control. The results of this study should provide useful information when developing programs to further narrow the racial disparities in treatment of patients with epilepsy.

2. Methods

This study was approved by the institutional review board of the University of Florida Health Sciences Center/Jacksonville (UFHSCJ). Written consent was obtained from all patients who participated in the study. We performed a direct survey/interview of patients followed at the UFHSCJ Comprehensive Epilepsy Program (CEP) from April to July 2009. This Level 4 epilepsy center is located in downtown Jacksonville, FL, USA, and is a major referral center in the region. About 42% of patients seen at UFHSCJ-CEP are males, 58% are Caucasians, and 31% are African-Americans. A significant portion of patients seen at UFHSCJ-CEP come from the indigent population, and 40% of patients are either uninsured, part of the city's indigent care program, or recipients of

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Medicaid/Medicaid HMO programs. About 5% of patients have undergone epilepsy surgery and/or vagus nerve stimulator implantation. To date, there are more than 3000 patients in our epilepsy database. Physicians from UFHSCJ serve as both primary neurologists and subspecialists to their patients. This allows inclusion in the study of a broad variety of patients with epilepsy, ranging from those with easy-to-control epilepsy to those with refractory seizures.

Only established adult patients with epilepsy seen during their outpatient clinic visit were considered for this study. For study purposes, only Caucasians and African-Americans were considered for the study as other races combined constituted only a small percentage of the patient population. Subjects should not have had any history of psychogenic nonepileptic seizures, should have considered themselves to be their primary caregiver, and should have beeen able to sign the consent form as well as complete the survey without assistance.

We obtained the following information during the survey/interview (Supplementary Material—see Appendix):

1. Demographic information
   a. Age
   b. Gender
   c. Marital status
   d. Race
   e. Educational attainment
   f. Annual household income
   g. Whether they drive
   h. Whether they receive disability benefits
   i. Employment status
2. Disease-related information
   a. Age at seizure onset
   b. Seizure duration
   c. Seizure frequency
   d. Whether they experience convulsions
   e. Whether they experience seizures while awake
   f. Number of AEDs they are currently taking
   g. Severity of side effects from their current AED regimen
3. Psychosocial data
   a. Neurological Institute Disorders Depression Inventory for Epilepsy (NIDDI-E) [11]
   b. Quality of Life in Epilepsy-10 (QOLIE-10) [12]
   c. Beliefs about Medicines Questionnaire (BMQ) [13]

We also performed chart review to determine the patient's primary insurance status and epilepsy classification.

The NIDDI-E is a brief test (six questions) that can be used to rapidly identify patients who have clinical depression. This measure removes the potential effect of confounding variables (such as medication effects and cognitive problems) that influence the diagnosis of depression in patients with epilepsy. A score greater than 15 has a sensitivity of 81%, specificity of 90%, and positive predictive value of 62% for diagnosing major depression [11].

The QOLIE-10 is a short-form measure derived from the widely used QOLIE-89 covering general and epilepsy-targeted aspects of physical and mental health as well as social and role functioning. The test assesses health related quality-of-life issues in patients with epilepsy that fall into three domains: (1) Medication Effects, (2) Mental Health, and (3) Role Functioning and Seizure Worry. Test–retest data reveal significant Pearson's correlations for individual items (range, $r = 0.48$–0.81), and there are high negative correlations with Profile of Mood States Mood Scale, systemic toxicity, neurotoxicity, and seizure frequency [12].

The BMQ is a questionnaire-based method for assessing commonly held beliefs about medicines. Eighteen statements are asked regarding individual attitudes toward their own prescribed medications (BMQ-S, 10 items) and medicines in general (BMQ-G, 8 items). These statements are answered across a 5-point Likert scale. The items on the BMQ-S reflect both patient beliefs in the necessity of their prescribed medications and their concerns about potential adverse effects. In this study, we asked patients to relate their responses to their seizure medications. We obtained a BMQ-S Necessity minus Concerns score, with higher scores indicating stronger patient beliefs in the importance of their seizure medications [13]. High BMQ-S scores are generally associated with good medication adherence [8]. In contrast, responses across the BMQ-G scale were summed. Higher BMQ-G scores correlate with patient beliefs that medications in general are harmful and overused by physicians. It also reflects a tendency to seek alternative remedies [13].

2.1. Statistical analysis

Statistical analysis was performed at a 5% level of significance using a two-tailed test. Descriptive and univariate analysis was performed using SPSS Version 15.0; binary logistic regression was performed using Minitab 15.

Race was the target variable in our study. The remaining demographic, clinical, and psychosocial data gathered during the survey/interview were the predictor variables.

Using univariate analysis, we determined those predictor variables that were significantly associated with race. Testing for the equality of means for interval variables was performed using ANOVA (with transformation of data, if necessary, to satisfy the assumptions of ANOVA). Pairwise comparisons and contrasts were made using methods that control for familywide type I error rates (method of Bonferroni). Ordinal variables were assessed using the Mann–Whitney test, and categorical data were analyzed with the χ^2 test.

We performed multivariate statistics on significant variables identified by univariate analysis ($P < 0.05$) to determine those that retained their significance in the simultaneous context of other variables.

3. Results

More than 80% of patients who met the inclusion criteria and were asked to participate completed the consent form. In all, 111 consecutive consenting patients took the survey/interview and were included in the study. Table 1 details the characteristics of our study population. Seventy-four respondents were Caucasians; the rest were African-Americans. Respondents had a mean age of 41 years, and 44% were males. The majority of respondents had no more than a high school education, and 45% had an annual household income less than $10,000. Most respondents did not operate a motor vehicle. Forty-four percent of our respondents received disability benefits, and the majority were not working. Thirty percent of respondents had commercial insurance/Tricare, 26% were on Medicare, and 16% were on the indigent care program.

The mean age at seizure onset was 23 years, and mean seizure duration was 18 years. Most subjects had fewer than one seizure a year. The majority of subjects experienced generalized tonic–clonic seizures and seizures while awake. Subjects were on a varied number of seizure medications, and although 64% experienced side effects from their medications, only 10% characterized their side effects as a major problem. The mean NIDDI-E and QOLIE-10 scores were 13.9 and 25.2, respectively. The mean BMQ-S score was 3.5, and the mean BMQ-G score was 20.6.

Table 2 outlines the association between race and the various predictor variables. There was a significant association between being African-American and having poorer seizure control ($P = 0.03$). Nearly one-third of African-Americans had more than one seizure a week. In contrast, only 11% of Caucasians had more than one seizure a week. More than a third of Caucasians had fewer than one seizure a year, whereas only a quarter of African-Americans had fewer than

Table 1

Descriptive data ($n = 111$).[a]

Variable	Mean (SD) or number (%)
A. Demographic variables	
Age, years	41.2 (14.9)
Males	44 (36.4%)
Marital status	
Single	57 (47.1%)
Married	39 (32.2%)
Divorced	22 (18.2%)
Widowed	3 (2.5%)
Race	
Caucasian	74 (61.2%)
African-American, non-Hispanic	37 (30.6%)
Other	10 (8.2%)
Highest educational level	
Less than high school	22 (18.5%)
High school, no college	43 (36.1%)
Some college/associate's degree	43 (36.1%)
Bachelor's/technical degree	8 (6.7%)
Graduate/postgraduate degree	3 (2.5%)
Annual household income	
<$10,000	52 (45.2%)
$10,000–$50,000	43 (37.4%)
$50,000–$100,000	17 (14.8%)
>$100,000	3 (2.6%)
Drives a motor vehicle	46 (38.3%)
Receives disability benefits	53 (44.2%)
Work status	
Full-time	21 (17.5%)
Part-time	11 (9.2%)
Unemployed and looking for work	25 (20.8%)
Unemployed and not looking for work	63 (52.5%)
Insurance type	
Uninsured	14 (13%)
Indigent care program	17 (16%)
Medicaid	14 (13%)
Medicare	28 (26%)
Commercial insurance/Tricare	33 (30%)
Other	3 (3%)
B. Clinical variables	
Age at seizure onset, years	22.9 (16.8)
Seizure duration, years	18.4 (15.2)
Seizure frequency	
More than once a week	21 (17.5%)
Less than weekly but at least once a month	11 (9.2%)
Less than monthly but at least once a year	25 (20.8%)
Less than once a year	63 (52.5%)
Currently experiences convulsions	80 (66.7%)
Has seizures while awake	98 (81.0%)
Epilepsy classification[b]	
Localization-related, cryptogenic	73 (66%)
Localization-related, symptomatic	16 (15%)
Generalized, idiopathic	17 (16%)
Undetermined	2 (2%)
Situation related	2 (2%)
Number of AEDs currently taken	
None	2 (1.7%)
One	47 (38.8%)
Two	44 (36.4%)
More than two	28 (23.1%)
Side effects from current AED regimen	
None	55 (45.8%)
Minor inconvenience	63 (44.2%)
Major problem	12 (10%)
C. Psychosocial variables	
Test scores	
Neurological Institute Disorders Depression Inventory for Epilepsy	13.9 (4.2)
Quality of Life in Epilepsy–10 Inventory	25.2 (7.1)
Beliefs About Medicines Questionnaire—Specific (Necessity minus Concerns)	3.5 (5.5)
Beliefs About Medicines Questionnaire—General	20.6 (5.3)

[a] Missing data not included in analysis.
[b] International League Against Epilepsy 1989.

Table 2

Characteristics of Caucasian and African-American individuals with epilepsy.[a]

	Mean (SD) or number (%)		P value
	Caucasians	African-Americans	
Number of subjects	74	37	
Age	40.3 (15.1)	42.9 (14.6)	0.4[b]
Males	29 (39%)	13 (35%)	0.69[c]
Marital status			0.51[c]
Single	37 (50%)	16 (43%)	
Married	21 (28%)	13 (35%)	
Divorced	15 (20%)	6 (16%)	
Widowed	1 (1%)	2 (5%)	
Highest educational level			0.6[d]
Less than high school	13 (18%)	6 (17%)	
High school, no college	28 (38%)	12 (33%)	
Some college/associates degree	27 (37%)	14 (39%)	
Bachelor's/technical degree	4 (5%)	3 (8%)	
Graduate/postgraduate degree	2 (3%)	1 (3%)	
Annual household income			0.89[d]
<$10,000	36 (47%)	16 (47%)	
$10,000–$50,000	27 (37%)	13 (38%)	
$50,000–$100,000	9 (12%)	5 (15%)	
>$100,000	2 (3%)	0	
Drives a motor vehicle, yes	29 (39%)	13 (35%)	0.67[c]
Receives disability benefits, yes	31 (42%)	19 (51%)	0.35[c]
Work status			0.24[c]
Full-time	12 (16%)	6 (16%)	
Part-time	9 (12%)	1 (3%)	
Unemployed and looking for work	13 (17%)	11 (30%)	
Unemployed and not looking for work	40 (54%)	19 (51%)	
Insurance type			
Uninsured	8 (11%)	6 (17%)	0.96[c]
Indigent care program	11 (15%)	6 (17%)	
Medicaid	9 (12%)	5 (14%)	
Medicare	20 (27%)	8 (22%)	
Commercial Insurance/Tricare	23 (32%)	10 (28%)	
Other	2 (3%)	1 (3%)	
Age at seizure onset, years	20.9 (15.9)	26.8 (17.9)	0.06[b,e]
Seizure duration, years	19.5 (15.7)	16.1 (13.9)	0.34[b,e]
Seizure frequency			0.03[c]
More than once a week	8 (11%)	12 (32%)	
Less than weekly but at least once a month	16 (22%)	7 (19%)	
Less than monthly but at least once a year	25 (34%)	9 (24%)	
Less than once a year	25 (34%)	9 (24%)	
Experiences convulsions	49 (66%)	22 (61%)	0.6[c]
Has seizures while awake	60 (81%)	31 (83%)	0.73[c]
Epilepsy classification[f]			
Localization-related, cryptogenic	43 (58%)	30 (83%)	0.08[c]
Localization-related, symptomatic	13 (18%)	3 (8%)	
Generalized, idiopathic	15 (20%)	2 (6%)	
Undetermined	1 (1%)	1 (3%)	
Situation related	2 (3%)	0	
Number of AEDs currently taken			0.76[d]
None	1 (1%)	1 (3%)	
One	28 (38%)	14 (38%)	
Two	31 (42%)	12 (32%)	
More than two	14 (19%)	10 (27%)	
Side effects from current AED regimen			0.82[d]
None	34 (46%)	15 (42%)	
Minor inconvenience	32 (43%)	18 (50%)	
Major problem	8 (11%)	3 (8%)	
Test scores			
Neurological Institute Disorders Depression Inventory for Epilepsy	40.3 (15.1)	42.9 (14.6)	0.78[b]
Quality of Life in Epilepsy-10	24.8 (7%)	26 (17.9)	0.41[b]
Beliefs About Medicines Questionnaire—Specific (Necessity minus Concerns)	4.4 (5)	1.6 (6.1)	0.01[b]
Beliefs about Medicines Questionnaire—General	19.8 (4.9)	22.2 (5.8)	0.02[b]

[a] Missing data not included in analysis.
[b] ANOVA.
[c] χ^2 test.
[d] Kruskal–Wallis test.
[e] Square-root transformation.
[f] International League Against Epilepsy, 1989.

yearly seizures. Compared with Caucasians, African-Americans had significantly lower BMQ-S scores (mean score = 1.6 (SD 6.1) for African-Americans vs 4.4 (SD 5) for Caucasians, $P = 0.01$). African-Americans also had significantly higher BMQ-G scores (mean score = 22.2 (SD 5.8) for African-Americans vs 19.8 (SD 4.9) for Caucasians, $P = 0.02$).

We performed binary logistic regression on predictor variables that were significant on univariate analysis. Of these, only seizure frequency remained independently associated with race ($P = 0.041$); BMQ-S ($P = 0.075$) and BMQ-G ($P = 0.558$) scores were not independently associated with race (Table 3).

Using seizure frequency as the target variable, we performed ordinal logistic regression with race and BMQ-S and BMQ-G scores as predictor variables. Both race ($P = 0.037$) and BMQ-G scores ($P = 0.022$) were independently associated with seizure frequency, whereas BMQ-S scores ($P = 0.335$) were not (Table 4).

4. Discussion

The results of our study indicate that compared with Caucasians, African-Americans have poorer seizure control and this significance is maintained even on multivariate analysis. African-Americans also have significantly lower BMQ-S and higher BMQ-G scores, although this significance is not sustained on multivariate analysis.

The association between race and seizure control has not been firmly established. In a study of pediatric patients, seizure frequency was found not to be significantly different across racial lines [14]. However, other studies have shown that compared with Caucasians, African-Americans have a lower chance of receiving epilepsy surgery [15–17] and generally poorer surgical outcomes [15].

This is the first study to relate scores on the BMQ with race in a group of individuals with epilepsy. Compared with Caucasians, African-Americans had both lower BMQ-S and higher BMQ-G scores, reflecting an increased tendency to view medicines as both harmful and addictive, and to have increased reliance on nontraditional forms of healing [13]. This disparity in BMQ scores was seen even though the races were comparable across age, gender, and educational and income levels. The lower BMQ-S score is concerning and, in other chronic disease states, has been associated with poor medication adherence [13].

The reasons for racial disparities in attitudes toward antiepileptic medications among African-Americans need to be investigated further. Using a focus group, Swarztrauber and colleagues [18] showed that African-American patients with epilepsy have a high degree of mistrust in their health care providers. It has also been shown that a general lack of knowledge about epilepsy still exists among African-Americans [3].

An obvious question is whether the decreased trust in the use of antiepileptic medications results in poorer seizure control among African-Americans. Using ordinal regression with seizure frequency as the target variable, our study indicates that race as well as BMQ-G score is an independent predictor of seizure frequency, indicating that medication attitudes influence seizure control.

Another issue that needs to be addressed is the relationship between attitudes toward medications and medication adherence. This was not directly addressed in our study. In a study of pediatric patients, non-Caucasians, 90% of whom were African-American, had significantly higher levels of undetectable anticonvulsant blood levels, compared with Caucasians [14]. However, variables other than medication attitudes, such as seizure type and financial resources [3], could certainly influence adherence.

This study has several limitations. Our patients were seen at a Level 4 epilepsy center in northeast Florida and were typical of an indigent, urban population. Although seizure frequency varied widely among our patients, the demographic and clinical profiles of our study population may differ from those of other epilepsy programs. Second, data were obtained from a patient survey and were not validated using medical records or actual seizure diaries. Lastly, other variables of interest, such as medication adherence, were not included in this study.

The differences in seizure control among the races studied reflect dissimilar "disease burdens," which is a measure of health disparity. The discrepancy in medication attitudes indicates that there are varying "health damaging behaviors" and is a potential determinant of health disparity [19].

Although our study sheds some light on the disparities that still exist in epilepsy care, it also presents new avenues for further investigation. Previous studies have shown that organized programs can significantly improve patients' attitudes toward medications. A depression care program that educates patients about the disorder and the use of antidepressant therapy has significantly enhanced patients' attitudes toward the use of antidepressants [20]. The use of a pharmacist-led patient educational program also significantly improved patients' beliefs about medications as well as medication adherence across a wide range of medical conditions [21]. Developing programs that successfully improve attitudes toward medications of minority patients should help to decrease health disparities and help realize the goals of Healthy People 2010 [22].

Appendix A. Supplementary data

Supplementary data to this article can be found online at doi:10.1016/j.yebeh.2010.10.016.

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Table 3
Binary logistic regression of variables associated with race.[a]

Variable	B	Significance	Odds ratio	95% CI for odds ratio
Constant	−0.7	0.96		
Seizure frequency	−0.42	0.041	0.65	0.44–0.98
BMQ-S score	−0.08	0.075	0.92	0.83–1.01
BMQ-G score	0.03	0.558	1.03	0.94–1.13

[a] Variables with $P \leq 0.05$ on univariate analysis were included.

Table 4
Ordinal logistic regression of variables associated with seizure frequency.

Variable	B	Significance	Odds ratio	95% CI for odds ratio
Constant (1)	−4.6	<0.001		
Constant (2)	−3.5	0.001		
Constant (3)	−2.1	0.037		
Race	0.8	0.037	2.24	1.05–4.79
BMQ-S score	0.03	0.33	1	0.96–1.12
BMQ-G score	0.09	0.02	1.1	1.01–1.18

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