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## Ethnicity and health outcomes among people with epilepsy participating in an epilepsy self-management RCT☆☆☆

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### ABSTRACT

People with epilepsy (PWE) may experience negative health events (NHEs) such as seizures, emergency room visits, and hospitalizations, with ethnic and racial minorities disproportionately affected. Epilepsy self-management may reduce NHEs; however, few reports examine self-management outcomes in racial minorities. Using data from a longitudinal 6-month randomized controlled trial (RCT) of 120 PWE, this analysis compared African-American and Whites at baseline, 10 weeks and 24 weeks after receiving the “Self-management for people with epilepsy (SMART) and a history of NHEs” self-management program. The primary RCT outcome was number of NHEs. At baseline, compared to Whites, African-Americans had less education ( $p = 0.02$ ) and greater depressive severity ( $p = 0.04$ ). Both African-American and Whites generally improved with SMART, and there were no racial differences in NHE counts or other outcomes' responses. Given known racial disparities in epilepsy care, it may be particularly important to reach out to minority PWE with self-management programs.

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### 1. Introduction

People with epilepsy (PWE) experience more serious adverse health outcomes compared to the general population [1]. Racial and ethnic minorities are disproportionately affected, with African-Americans reporting higher frequencies of seizures [2], hospitalizations, emergency room (ER) visits, and lower antiepileptic drug (AED) adherence [3] than Whites. Data collected by the Center for Disease Control and Prevention (CDC) from 2005–2014 found that in 2014, non-Hispanic African-Americans with epilepsy had a higher mortality rate /were more likely to die compared to other ethnicities [4]. African-Americans also exhibited a lower utilization of health services, as evidenced by their lower rates of epilepsy surgery [5]. However, it remains difficult to fully understand the causes of racial disparities in epilepsy outcomes

as socioeconomic status (SES) and educational level often differ between racial groups and are related to health outcomes [5].

Despite the clear need for research on racial disparities in PWE, the existing literature is limited [6,7]. A 2004 study of 318 epilepsy clinical trials found only 1.9% ( $N = 6$ ) attempted to analyze differences between participants of different ethnicities [8]. Although epilepsy self-management programs generally demonstrate benefits in terms of better patient outcomes, increasing patients' skills, confidence in problem-solving, goal setting, communicating, and adopting healthy behaviors to improve quality of life, there are few studies that particularly assess racial and ethnic differences in outcomes of these programs [9]. A recent epilepsy-self management intervention study by Luedke identified 13 randomized and 2 nonrandomized studies involving a total of 2514 PWE [10]. Notably, most studies enrolled middle-aged adults with at least some college education. Nine out of 15 studies (60%) did not report race or ethnicity. Health literacy was not reported by any study.

Given the paucity of evidence on race/ethnicity as it relates to epilepsy care and epilepsy self-management specifically, this secondary analysis of a 6-month prospective randomized controlled trial (RCT) for a new remotely-delivered (internet or phone) epilepsy self-management program compared clinical and demographical characteristics of African-American and White PWE at baseline and at 6-month follow-up. The analysis compared primary and secondary outcomes by race over time in order to better understand how racial minority PWEs may respond to a curriculum-driven self-management program. It is

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especially important to observe the differences in study outcomes by racial groups given the clear disparities that racial and ethnic minority PWE face. We expect that our findings would be helpful for healthcare professionals and social support agencies that provide support and services to diverse groups of PWE.

## 2. Methods

### 2.1. Data source

This report is an analysis of baseline and 24-week data from a larger 6-month prospective RCT that tested a novel intervention “Self-management for people with epilepsy (SMART) and a history of negative health events (NHEs)” in PWE. The larger RCT methods and results are detailed elsewhere [11]. Briefly, SMART consists of 1 group-based 60- to 90-min session followed by 7 online or telephone 60-min sessions that encourage interactive discussion. Groups consist of 6–10 PWE and are co-led by a nurse and by a peer educator (PWE who is trained to deliver the program). After the group sessions were done, individuals who participated in SMART received brief (10–15 min) telephone maintenance calls approximately monthly for a total of approximately 3 additional months. Adherence was measured by recording attendance for each SMART session. Unfortunately, We did not assess whether individuals might have ever had or currently have difficulties in care access.

### 2.2. Study design

The original study design was a prospective 6-month randomized comparison of SMART (N=60) vs 6-month wait-list control (N = 60) with a total sample of 120. For this secondary analysis, given the small number of Hispanic PWE, we analyzed only the African-American (N = 79) and non-Hispanic White (N = 33) subgroups with a total sample size of 112. Recruitment occurred in an urban setting in northeastern Ohio. Negative health event counts were self-reported and defined as seizures, accidents or traumatic injury, self-harm attempts, emergency department (ED) visits, and hospitalizations. Study inclusion criteria included a self-reported diagnosis of epilepsy, adults 18 years of age and older, experiencing an NHE within the last 6 months of initial contact/screen, and providing written informed consent. There were no inclusion or exclusion criteria based on demographic criteria beyond the fact that individuals needed to be adults. Study exclusion criteria included participants at immediate risk of self-harm, participants with dementia, pregnant participants, or those unable to read and/or understand English. The study was approved by the local Institutional Review board (IRB).

### 2.3. Assessments

This analysis used screening and baseline data collected immediately prior to intervention randomization in this RCT as well as data at 10-weeks and endpoint data after the 6-month intervention. Information collected included demographic and epilepsy characteristics and other clinical factors.

#### 2.3.1. Health literacy

Health literacy was measured by the Rapid Estimate of Adult Literacy in Medicine (REALM-R), an 8-item instrument based off of the longer REALM questionnaire of 125 items [12]. Based on the number of words correctly pronounced, the participant was sorted into one of 4 reading levels: 3rd grade and below, 4th–6th grade, 7th–8th grade, and 9th grade or above. According to the authors, patients with a less than 9th grade level would have difficulty comprehending education materials [13]. In the REALM-R, a similar concept was used, with the respondent being asked to pronounce eight specific words chosen to minimize bias unrelated to literacy [14]. Studies validating the REALM-R have used populations without epilepsy but with demographic

variables similar to our study. The pilot study that validated REALM-R as a reasonable screening tool for identifying patients with potential health literacy problems showed that 27.5% had received a college education, and 45% had public health insurance such as Medicare or Medicaid [12]. Another study of individuals with cancer also had similar demographics compared to our study with the majority female (56.1%) and a significant number of African-Americans (36.3%).

#### 2.3.2. Physical and mental health comorbidity

Comorbidity was measured with the self-reported version Charlson Comorbidity Index (CCI), widely utilized by health researchers to measure disease burden and case mix [15]. Mental health comorbidity was identified via patient self-report using a checklist format. Comorbidities included depression, anxiety, bipolar disorder, panic disorder, schizophrenia, obsessive-compulsive disorder (OCD), attention deficit hyperactive disorder (ADHD), posttraumatic stress disorder (PTSD), and “other” disorders including schizoaffective disorder, unspecified mood disorder, agoraphobia, and personality disorder.

#### 2.3.3. Depression

Depressive symptoms were measured with the self-reported Patient Health Questionnaire-9 (PHQ-9), based on the diagnostic criteria for diagnosing major depressive disorder based on the Diagnostic and Statistical Manual of Mental Disorders-5 (DSM-5) [16]. Scaled from 0 to 27, with increasing scores indicating more severe depression, the PHQ-9 categorizes depression severity in five categories: 1–4 as minimal, 5–9 as mild, 10–14 as moderate, 15–19 as moderately severe, and 20–27 as severe. In PWE, the PHQ-9 is efficient and displays accuracy and validity [17,18]. Depression was also assessed with the rater-administered Montgomery-Asberg Depression Rating Scale (MADRS), a ten-item rater-administered questionnaire with scores ranging from 0 to 60 [19]. Like the PHQ-9, higher scores indicate worse depression severity.

#### 2.3.4. Quality of life

Quality of life was assessed with the ten-item Quality of Life in Epilepsy (QOLIE-10) instrument which groups epilepsy-specific domains into three factors: mental health, epilepsy effects, and role functioning [20]. The QOLIE-10 has been widely used in studies of PWE [21]. For this analysis, the QOLIE-10 was calibrated with scores from 1 to 5, with higher scores indicating a worse quality of life.

#### 2.3.5. Functional status

The 36-item Short Form Health Survey (SF-36) is a multipurpose, short-form health survey that yields two psychometrically based components: a physical component summary (PCS) and mental component summary (MCS) [22]. Scores range from 0 (lowest possible level of functioning) to 100 (highest possible level of functioning).

#### 2.3.6. Epilepsy severity

Epilepsy severity was assessed with the standardized 12-item Liverpool Seizure Severity Scale (LSSS) [23]. The LSSS is only conducted in individuals who have had a reported seizure in the last 30 day. Scores range from 1 to 40, with lower scores indicating more severe seizures.

## 2.4. Statistical analysis

Statistical analysis was performed using Statistical Package for the Social Sciences (SPSS) software version 24 (IBM Corporation, NY). Descriptive analyses were summarized for demographic and clinical variables. Two-tailed t-tests and chi-squares were computed to detect significant differences between race on demographic and clinical variables. We did not prespecify secondary analysis based on racial or ethnic status. A repeated measure analysis of variance (ANOVA) with a post hoc comparison was used with a Bonferroni correction to determine differences in clinical outcome response between racial groups and across time, adjusting for educational level. A  $2 \times 2 \times 3$  ANOVA was conducted

**Table 1**  
Baseline characteristics of African-American and White PWE in the SMART RCT.

Variable	Overall sample N = 112	Non-Hispanic White N = 33	African-American N = 79	Statistics <sup>a</sup>
Age (n = 110) (mean, SD)	41.06 (11.91)	43.33 (11.24)	40.09 (12.12)	t(108) = -1.31, p = 0.19
Gender (N, %)				
Male	38 (33.9)	9 (27.3)	29 (36.7)	x <sup>2</sup> [1] = 0.93, p = 0.34
Female	74 (66.1)	24 (72.7)	50 (63.3)	
Education (N, %)				
College > 4 yrs	13 (11.6)	8 (24.2)	5 (6.3)	x <sup>2</sup> (2) = 7.43, p = 0.02
College < 1-3 yrs	51 (45.5)	12 (36.4)	39 (49.4)	
High school education or less (High School/GED + Some HS)	48 (42.9)	13 (39.4)	35 (44.3)	
Employment (N,%)				
Employed (Employed for wages + Self-employed)	24 (21.4)	8 (24.2)	16 (20.3)	x <sup>2</sup> [3] = 4.85, p = 0.18
Unemployed (Out of work for 1 year or more + Out of work for less than 1 year)	19 (17.0)	3 (9.1)	16 (20.3)	
Unable to work	55 (49.1)	15 (45.5)	40 (50.6)	
Other (Retired + A homemaker + A student)	14 (12.5)	7 (21.2)	7 (8.9)	
Income (n = 111), (N,%)				
<\$25 K	97 (86.6)	27 (81.8)	70 (88.6)	x <sup>2</sup> [2] = 0.38, p = 0.83
\$25-50 K	11 (9.8)	4 (12.1)	7 (8.9)	
>50 K	3 (2.7)	1 (3.0)	2 (2.5)	
Marital status (N, %)				
Single, never married	56 (50.0)	12 (36.4)	44 (55.7)	x <sup>2</sup> [3] = 3.66, p = 0.30
Married	17 (15.2)	7 (21.2)	10 (12.7)	
Unmarried couple	19 (17.0)	7 (21.2)	12 (15.2)	
Divorced + Separated + Widowed	20 (17.9)	7 (21.2)	13 (16.5)	
Epilepsy characteristics				
Duration of epilepsy in years (mean, SD) (n = 106)	20.41 (15.14)	24.21 (15.96)	18.68 (14.54), n = 73	t(104) = -1.76, p = 0.08
Number of prescribed AEDs <sup>d</sup> (mean, SD) (n = 109)	1.65 (0.84)	1.76 (0.94)	1.61 (0.80), n = 76	t(107) = -0.87, p = 0.39
Epilepsy type - (n = 110)				
Generalized	65 (58.0)	17 (51.5)	48 (60.8)	x <sup>2</sup> [5] = 1.15, p = 0.95
Generalized nonconvulsive	4 (3.6)	1 (3.0)	3 (3.8)	
Focal	7 (6.3)	3 (9.1)	4 (5.1)	
Focal with loss of consciousness	6 (5.4)	2 (6.1)	4 (5.1)	
Don't know	13 (11.6)	4 (12.1)	9 (11.4)	
Other	15 (13.4)	5 (15.2)	10 (12.7)	
30-day seizure count at baseline (mean, SD) (n = 111)	2.26 (5.06), median = 1.00	2.03 (2.39), median = 2.00	2.36 (5.85), median = 1.00, n = 78	t(109) = 0.31, p = 0.76
Other clinical characteristics				
Charlson Comorbidity Index (mean, SD)	2.10 (2.53)	2.64 (3.06)	1.87 (2.26)	x <sup>2</sup> [1] = 2.13, p = 0.15
Comorbid mental health condition- N (%)				
Yes	76 (67.9)	25 (75.8)	51 (64.6)	x <sup>2</sup> [1] = 1.34, p = 0.25
No	36 (32.1)	8 (24.2)	28 (35.4)	
Mental health comorbidities- N (%) ** (n = 80)				
Depression	20 (25.0)	3 (12.0)	17 (34.0)	x <sup>2</sup> (7) = 16.02, p = 0.02
Anxiety	14 (17.5)	7 (28.0)	7 (14.0)	
Bipolar	11 (13.8)	6 (24.0)	5 (10.0)	
Panic disorder	5 (6.3)	1 (4.0)	4 (8.0)	
Schizophrenia	3 (3.75)	0 (0.0)	2 (4.0)	
Obsessive compulsive disorder	0 (0.0)	0 (0.0)	0 (0.0)	
ADHD	6 (7.5)	0 (0.0)	6 (12.0)	
PTSD	12 (15.0)	3 (12.0)	7 (14.0)	
Other	9 (11.3)	5 (20.0)	2 (4.0)	
REALM-R <sup>b</sup> Health literacy (mean, SD)	6.52 (2.06)	6.35 (2.04)	6.91 (2.08)	t(110) = -1.31, p = 0.20
Total 6-month NHE <sup>c</sup> count at baseline (mean, SD) (n = 107)	15.99 (35.40), median = 4.00	14.48 (18.99), median = 4.00, n = 31	16.61 (40.32), median = 5.00, n = 76	t(105) = 0.28, p = 0.78
Total 6-month seizure count (mean, SD) (n = 111)	13.71 (34.20), median = 3.00	10.79 (14.52), median = 3.00	14.95 (39.73), median = 3.00, n = 78	t(109) = 0.58, p = 0.56
Total 6-month ER visits and hospitalizations (mean, SD) (n = 107)	1.93 (7.24), median = 0.00	9.81 (12.94), median = 0.00, n = 31	1.16 (2.27), median = 0.50, n = 76	t(105) = -1.73, p = 0.09

Bold data indicates significant p-value.

<sup>a</sup> Comparing non-Hispanic White to African-American.<sup>b</sup> REALM-R: Rapid Estimate of Adult Literacy in Medicine-Revised: scores range from 0 to 7 with higher scores indicating better health literacy.<sup>c</sup> NHEs: Negative Health Events, calculated by adding seizure count, hospitalizations, self-harm attempts, accidents, and ER visits.

to examine the effects of race, education, and randomization on each of the different clinical scales. Data were normally distributed, and there was homogeneity of variances.

### 3. Results

#### 3.1. Overall sample description

Table 1 illustrates baseline descriptive and clinical variables of the African-American (N = 79, 70.5%) and White (33, 9.5%) groups. The mean age was 41.06 (SD 11.91) and predominantly female (N = 74, 66.1%). The majority had attended some college (N = 51, 45.5%), were unable to work (N = 55, 49.1%), made less than \$25,000 (N = 97, 86.6%), and were single (N = 56, 50.0%). The mean baseline 30-day seizure count was 2.26 (SD 5.06). The mean 6-month NHE count at baseline was 15.99 (SD 35.40). Most had a comorbid mental health condition (N = 76, 67.9%) with depression being the most common (N = 65, 58.0%). The mean REALM-R score was 6.52 (SD 2.06).

Table 2 shows scores at baseline for standardized scales including the QOLIE-10, PHQ-9, MADRS, SF-36, and LSSS. The mean QOLIE-10 score was 2.98 (SD 0.91), the mean PHQ-9 score was 10.67 (SD 7.17) with mild levels of depression the most common (N = 29, 25.9%), the mean MADRS score was 17.73 (SD 11.07), and the mean LSSS was 31.45 (SD 31.79). On the SF-36, the mean MCS was 39.98 (SD 13.08), and the mean PCS was 42.39 (10.39).

#### 3.2. Racial differences

As noted in Tables 1 and 2, the samples of African-American and Whites were more alike than different. Differences included that Whites had higher education levels compared to African-Americans ( $p = 0.02$ ). Whites were also more likely than African-Americans to indicate their mental health comorbidity as "other" ( $p = 0.01$ ). African-Americans reported higher PHQ-9 levels indicating greater severity of depressive symptoms ( $p = 0.04$ ). The  $2 \times 2 \times 3$  ANOVA did not parse out any racial interactions or main effects for any of the clinical scales.

In regard to drop out rates, 15 (13.4%) of African-Americans and 4 (12.1%) of Whites did not attend the week 24 visit.

Table 3 records total NHEs in the past 6 months, the QOLIE-10, PHQ-9, MADRS, LSSS, and both components of the SF-36 in African-Americans and Whites at baseline, 10 weeks, and 24 weeks after the start of the SMART intervention. The statistics column shows the result of the repeated measures ANOVA, which compares outcomes among White

and African-American participants accounting for educational level. Our results show that there is no change in any of the outcomes over time when adjusting for race and education level.

### 4. Discussion

This secondary analysis from a 6-month prospective RCT that enrolled PWE who experienced NHEs within the past 6 months investigated differences between Whites and African-Americans at baseline, 10 weeks and 24 weeks after participation in the SMART epilepsy self-management program. The African-American and White samples were largely similar at baseline. African-Americans had lower levels of education and reported greater depression severity as measured by the PHQ-9. However, our analysis generally found no difference in RCT treatment outcomes between Whites and African-Americans.

Our results did not suggest that African-American and White PWE responded differently to the SMART intervention. Begley et al. examined correlates of epilepsy self-management competency in a pooled sample of PWE from epilepsy self-management programs [24]. In the report by Begley, self-management competency differed by gender, and somewhat surprisingly by education (women had better self-management skills as did those with lower levels of education), but similar to our results, there were no differences by race or ethnicity [24]. There is evidence that remotely-delivered self-management may be particularly helpful for minority patients. Bosworth et al. found that combining a telephone-tailored behavioral intervention with home blood pressure monitoring resulted in significantly lowering blood pressure in non-White patients compared to Whites [25]. The findings by Bosworth et al. could reflect underlying disparities in care access, which might have allowed non-Whites to make substantial gains once they received more intensive support. It is possible that African-Americans who volunteer for an epilepsy self-management study represent a group of PWE who are more help-seeking than the general population. Indeed, the SMART RCT sample was notable for having a majority of African-Americans and while their baseline educational level was somewhat lower than Whites enrolled in the trial, their health literacy and other markers of neurological and medical health were very similar.

While our study did not show any differences in outcomes between racial groups, the evidence base on racial disparities in epilepsy care remains an issue that needs clinical focus and additional research. One recommendation informed by our findings is that interventions, particularly those that are more complex, should be tailored to the educational level and health literacy capacities of the specific individual.

**Table 2**  
Baseline depression, general health and seizure severity in African-American and White PWE in the SMART RCT.

	Overall sample N = 112	Non-Hispanic White N = 33	African-American N = 79	Statistics <sup>a</sup>
QOLIE-10 <sup>b</sup> (mean, SD)	2.98 (0.91)	3.03 (0.90)	2.95 (0.92)	$t(110) = -0.42, p = 0.67$
PHQ-9 <sup>c</sup> (mean, SD)	10.67 (7.17)	10.30 (6.81)	10.82 (7.35)	$t(110) = 0.35, p = 0.73$
Level of depressive symptoms (PHQ-9 <sup>c</sup> ) (N, %)				
Minimal (scores 0–4)	26 (23.2)	7 (21.2)	19 (24.1)	
Mild (scores 5–9)	29 (25.9)	12 (36.4)	17 (21.5)	<b><math>\chi^2(4) = 9.86, p = 0.04</math></b>
Moderate (scores 10–14)	25 (22.3)	3 (9.1)	22 (27.8)	
Moderately severe (scores 15–19)	16 (14.3)	8 (24.2)	8 (10.1)	
Severe (scores 20–27)	16 (14.3)	3 (9.1)	13 (16.5)	
MADRS <sup>d</sup> (mean, SD)	17.73 (11.07)	16.79 (10.60)	18.13 (11.30)	
SF-36 <sup>e</sup> (mean, SD)				
MCS	39.98 (13.08)	40.95 (14.17)	39.58 (12.67)	$t(110) = -0.50, p = 0.62$
PCS	42.39 (10.39)	42.44 (9.89)	42.37 (10.65)	$t(110) = -0.03, p = 0.97$
LSSS <sup>f</sup> (mean, SD)	31.45 (31.79)	30.41 (32.01)	33.94 (31.60)	$t(110) = -0.53, p = 0.60$

Bold data indicates significant p-value.

<sup>a</sup> Two-tailed t-test or chi-square where appropriate.

<sup>b</sup> QOLIE-10: Quality of Life in Epilepsy, scores range from 1 to 5 with higher scores indicating worse quality of life.

<sup>c</sup> PHQ-9: Patient Health Questionnaire, scores range from 0 to 27 with higher scores indicating more severe depression.

<sup>d</sup> MADRS: Montgomery-Asberg Depression Rating Scale, scores range from 0 to 60 with higher scores indicating more severe depression.

<sup>e</sup> SF-36: Short-Form 36, MCS: Mental Component Score, scores range from 0 to 100, with 100 being the highest or best possible level of mental functioning. PCS: Physical Component Score, scores range from 0 to 100, with 100 being the highest or best possible level of physical functioning.

<sup>f</sup> LSSS: Liverpool Seizure Severity Scale, scores range from 0 to 100 with higher scores indicating more severe seizures.

**Table 3**  
Response to SMART RCT outcome variables over time in African-American and White PWE.

	Baseline Mean (SD)	10 weeks Mean (SD)	24 weeks Mean (SD)	Statistics <sup>a</sup>	Post hoc
Total NHEs <sup>b</sup> past 6 months					
Non-Hispanic White (n = 26)	13.69 (19.57)	–	8.31 (13.56)	F(1,84) = 2.38, p = 0.13	ns
African-American (n = 64)	14.67 (35.35)		5.45 (8.70)		
QOLIE-10 <sup>c</sup>					
Non-Hispanic White (n = 27)	3.12 (0.93)	2.65 (0.88)	2.86 (0.99)	F(2,162) = 2.63, p = 0.08	ns
African-American (n = 60)	2.99 (0.95)	2.85 (0.97)	2.74 (0.98)		
PHQ-9 <sup>d</sup>					
Non-Hispanic White (n = 27)	10.56 (6.84)	8.15 (6.47)	8.11 (6.90)	F(2,162) = 1.39, p = 0.25	ns
African-American (n = 60)	10.75 (7.35)	10.60 (7.38)	9.67 (7.01)		
MADRS <sup>e</sup>					
Non-Hispanic White (n = 28)	16.29 (10.66)	13.71 (11.11)	14.29 (12.09)	F(2,170) = 2.58, p = 0.08	ns
African-American (n = 63)	17.97 (11.66)	17.89 (12.10)	15.11 (11.95)		
SF-36-MCS <sup>f</sup>					
Non-Hispanic White (n = 28)	40.56 (14.33)	44.00 (13.86)	44.23 (13.27)	F(2,168) = 0.85, p = 0.43	ns
African-American (n = 62)	40.23 (12.77)	39.66 (13.12)	42.12 (13.78)		
SF-36-PCS <sup>g</sup>					
Non-Hispanic White (n = 28)	32.40 (10.52)	44.84 (10.14)	43.86 (11.64)	F(2,168) = 1.66, p = 0.19	ns
African-American (n = 62)	41.65 (10.50)	43.27 (11.12)	43.53 (11.64)		
LSSS <sup>h</sup>					
Non-Hispanic White (n = 27)	36.02 (31.72)	26.39 (29.03)	28.15 (33.38)	F(2,164) = 2.67, p = 0.07	ns
African-American (n = 61)	29.43 (31.62)	28.11 (31.19)	21.89 (30.59)		

<sup>a</sup> Repeated measures ANOVAs. The QOLIE-10 and MADRS were adjusted with Huynh-Feldt for a sphericity violation. The statistic column denotes change from baseline accounting for racial group (African American or non-Hispanic White) and level of education (four years of college or more, 1–3 years of college, or high school or less).

<sup>b</sup> NHE: Negative Health Event, calculated by adding seizure count, hospitalizations, self-harm attempts, accidents, and ER visits.

<sup>c</sup> QOLIE-10: Quality of Life in Epilepsy, scores range from 1 to 5 with higher scores indicating worse quality of life.

<sup>d</sup> PHQ-9: Patient Health Questionnaire, scores range from 0 to 27 with higher scores indicating more severe depression.

<sup>e</sup> MADRS: Montgomery-Asberg Depression Rating Scale, scores range from 0 to 60 with higher scores indicating more severe depression.

<sup>f</sup> SF-36: Short-Form 36 – MCS: Mental Component Score, scores range from 0 to 100, with 100 being the highest or best possible level of mental functioning.

<sup>g</sup> SF-36: Short-Form 36 – PCS: Physical Component Score, scores range from 0 to 100, with 100 being the highest or best possible level of physical functioning.

<sup>h</sup> LSSS: Liverpool Seizure Severity Scale, scores range from 0 to 100 with higher scores indicating more severe seizures.

While African-Americans and Whites had similar levels of health literacy in our study, other studies showed a strong association between African-Americans and lower health literacy [26].

Health access could also be an issue in PWE. Studies show that African-Americans have poorer access to care for their epilepsy and comorbid health conditions, including mental health conditions, which as seen in our study, are quite prevalent in PWE [27]. Most of our sample lived in reduced financial circumstances, which might be expected to limit ability to own a vehicle, pay for transportation, or to be away from home responsibilities such as childcare. The SMART intervention is a web-based online program; therefore, access to transportation and resources was not an issue for our participants. Additionally, for those who did not have web access, telephone participation was encouraged. Thus, an additional recommendation to target racial disparities in epilepsy care is to use on-line or telephone delivered self-management interventions as much as possible to help overcome transportation or logistic barriers for poor and underserved PWE.

This study has a number of limitations including a relatively small sample size and use of self-report to identify medical and psychiatric comorbidities. Self-report may have led to overdiagnosis of psychiatric disorders. While we included identifying individuals with a billing diagnosis of epilepsy as part of our targeted recruitment efforts, epilepsy diagnosis for study enrollment was also self-reported and some participants could have had nonepileptic seizures. Excluding individuals who did not speak or understand English and the small number of Hispanic participants did not allow for an analysis of outcome in this subgroup. Another limitation is that we had a small sample of White respondents (n = 33) compared to African-American respondents (n = 79). This could have led us to conclude that there were no differences in treatment outcomes when differences might have been seen with a larger sample size of White respondents. The REALM-R also has not been specifically tested in PWE of differing races or ethnicities. However, a key strength of the study was the relative homogeneity on demographic and other clinical variables among African-American and White PWE that help support results interpretation that are not being driven

by socioeconomic or other inequities. The findings have important implications for the delivery of epilepsy self-management programs to racial minorities. Based upon these results, African-Americans PWE would be expected to benefit from the SMART intervention. The remote delivery format (web, phone) may be particularly helpful for those PWE who have limitations for travel and transportation access.

## 5. Conclusion

African-American and White PWE may differ in some demographic characteristics and epilepsy-related and physical health variables. However, in this secondary analysis of the SMART RCT, both African-Americans and White PWE showed improvement after participating in a self-management intervention. Given known racial disparities in epilepsy care, it may be particularly important to reach out to minority PWE with self-management programs. While results from this analysis do not suggest a need for differential SMART adaptation for African-Americans, replication and/or larger studies are needed to see if additional refinements to the curriculum might help minority PWE derive even greater gains.

## References

- [1] England MJ, Liverman CT, Schultz AM, Strawbridge LM. Epilepsy across the spectrum: Promoting health and understanding: A summary of the Institute of Medicine report. *Epilepsy Behav* 2012;25(2):266–76.
- [2] Bautista RED, Jain D. Detecting health disparities among Caucasians and African-Americans with epilepsy. *Epilepsy Behav* 2011;20(1):52–6.
- [3] Bautista RED, Graham C, Mukardamwala S. Health disparities in medication adherence between African-Americans and Caucasians with epilepsy. *Epilepsy Behav* 2011;22(3):495–8.
- [4] Greenlund SF, Croft JB, Kobau R. Epilepsy by the numbers: epilepsy deaths by age, race/ethnicity, and gender in the United States significantly increased from 2005 to 2014. *Epilepsy Behav* 2017;69:28–30.
- [5] Burneo JG, Jette N, Theodore W, Begley C, Parko K, Thurman DJ, et al. Disparities in epilepsy: report of a systematic review by the North American Commission of the International League Against Epilepsy. *Epilepsia* 2009;50(10):2285–95.

- [6] Szaflarski M, Szaflarski JP, Privitera MD, Ficker DM, Horner RD. Racial/ethnic disparities in the treatment of epilepsy: what do we know? What do we need to know? *Epilepsy Behav* 2006;9(2):243–64.
- [7] Theodore WH, Spencer SS, Wiebe S, Langfitt JT, Ali A, Shafer PO, et al. Epilepsy in North America: a report prepared under the auspices of the Global Campaign against Epilepsy, the International Bureau for Epilepsy, the International League Against Epilepsy, and the World Health Organization. *Epilepsia* 2006;47(10):1700–22.
- [8] Burneo JG, Martin R. Reporting race/ethnicity in epilepsy clinical trials. *Epilepsy Behav* 2004;5(5):743–5.
- [9] Helmers SL, Kobau R, Sajatovic M, Jobst BC, Privitera M, Devinsky O, et al. Self-management in epilepsy: why and how you should incorporate self-management in your practice. *Epilepsy Behav* 2017;68:220–4.
- [10] Luedke MW, Blalock DV, Lewinski AA, Shapiro A, Drake C, Lewis JD, et al. Self-management of epilepsy. VA ESP project #09-009; 2019.
- [11] Sajatovic M, Colon-Zimmermann K, Kahrman M, Fuentes-Casiano E, Liu H, Tatsuoka C, et al. A 6-month prospective randomized controlled trial of remotely delivered group format epilepsy self-management versus waitlist control for high-risk people with epilepsy. *Epilepsia* 2018;59(9):1684–95.
- [12] Dumenci L, Matsuyama RK, Kuhn L, Perera RA, Siminoff LA. On the validity of the Rapid Estimate of Adult Literacy in Medicine (REALM) Scale as a measure of health literacy. *Commun Methods Meas* 2013;7(2):134–43.
- [13] Murphy PW, Davis TC, Long SW, Jackson RH, Decker BC. Rapid Estimate of Adult Literacy in Medicine (REALM): a quick reading test for patients. *J of Reading* 1993;37:124–30.
- [14] Bass PF, Wilson JF, Griffith CH. A shortened instrument for literacy screening. *J Gen Intern Med* 2003;18(12):1036–8.
- [15] Chaudhry S, Jin L, Meltzer D. Use of a self-report-generated Charlson Comorbidity Index for predicting mortality. *Med Care* 2005;43(6):607–15.
- [16] Carey M, Jones KA, Yoong SL, D'Este C, Boyes AW, Paul C, et al. Comparison of a single self-assessment item with the PHQ-9 for detecting depression in general practice. *Fam Pract* 2014;31(4):483–9.
- [17] Rathore JS, Jehi LE, Fan Y, Patel SI, Foldvary-Schaefer N, Ramirez MJ, et al. Validation of the Patient Health Questionnaire-9 (PHQ-9) for depression screening in adults with epilepsy. *Epilepsy Behav* 2014;37:215–20.
- [18] Seminario NA, Farias ST, Jorgensen J, Bourgeois JA, Seyal M. Determination of prevalence of depression in an epilepsy clinic using a brief DSM-IV-based self-report questionnaire. *Epilepsy Behav* 2009;15(3):362–6.
- [19] Montgomery SA, Asberg M. A new depression scale designed to be sensitive to change. *Br J Psychiatry* 1979;134:382–9.
- [20] Cramer JA, Perrine K, Devinsky O, Meador K. A brief questionnaire to screen for quality of life in epilepsy: the QOLIE-10. *Epilepsia* 1996;37(6):577–82.
- [21] Wang FL, Gu XM, Hao BY, Wang S, Chen Z, Ding CY. Influence of marital status on the quality of life of Chinese adult patients with epilepsy. *Chin Med J (Engl)* 2017;130(1):83–7.
- [22] Ruta D, Garratt A, Abdalla M, Buckingham K, Russell I. The SF 36 health survey questionnaire: a valid measure of health status. *Br Med J* 1993;307(6901):448–9.
- [23] Baker GA, Smith DF, Jacoby A, Hayes JA, Chadwick DW. Liverpool Seizure Severity Scale revisited. *Seizure* 1998;7(3):201–5.
- [24] Begley C, Shegog R, Liu H, Tatsuoka C, Spruill TM, Friedman D, et al. Correlates of epilepsy self-management in MEW Network participants: From the Centers for Disease Control and Prevention managing epilepsy well network. *Epilepsy Behav* 2018;85:243–7.
- [25] Bosworth HB, Olsen MK, Grubber JM, Powers BJ, Oddone EZ. Racial differences in two self-management hypertension interventions. *Am J Med* 2011;124(5):468.e1–8.
- [26] Chaudhry SI, Herrin J, Phillips C, Butler J, Mukerjee S, Murillo J, et al. Racial disparities in health literacy and access to care among patients with heart failure. *J Card Fail* 2010;17(2):122–7.
- [27] Institute of Medicine (US) Committee on the Public Health Dimensions of the Epilepsies. In: England MJ, Liverman CT, Schultz AM, Strawbridge LM, editors. *Epilepsy across the spectrum: promoting health and understanding*. Health care: quality, access, and value Washington (DC): National Academies Press (US); 2012 Available from: <https://www.ncbi.nlm.nih.gov/books/NBK100604/>.