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Health literacy and education level correlates of participation and outcome in a remotely delivered epilepsy self-management program

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Abstract

Significance: Health literacy, the ability to understand necessary health information to make proper health decisions, has been linked to greater frequency of hospitalizations. However, there is limited literature on associations between health literacy and outcomes in epilepsy patients, and thus, this secondary analysis investigates associations between health literacy and outcomes in epilepsy patients enrolled in the self-management intervention “Self-management for people with epilepsy and a history of negative events” (SMART). We examined the associations between higher health literacy and higher education level and outcomes of the SMART trial.

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Methods: This is a secondary analysis of data from the SMART self-management intervention, where individuals were randomized to the SMART intervention or a 6-month waitlist control. Health literacy was assessed at baseline before randomization using the Rapid Estimate of Adult Literacy in Medicine (REALM-R). Education level was self-reported by participants at baseline. Pearson correlations between REALM-R scores and continuous demographic and clinical variables were conducted. Point bi-serial Pearson correlations were computed for REALM-R and dichotomous variables. The effect of education on change in negative health events (NHE) counts from baseline to six months was conducted using a linear regression. A logistic regression with health literacy and randomization arm as predictors and improvement in NHE (1=improvement, 0=no change or increased NHEs at 6 months) as the outcome was conducted.

Results: Lower education and lower income were significantly correlated with lower health literacy ($p<0.001$ and $p=0.03$). Higher education level was associated with a greater improvement in 6 month seizure counts ($r_s(105)= 0.29$, $p= 0.002$), and a greater improvement in total 6-month NHEs ($r_s(95)= 0.20$, $p= 0.045$). Health literacy was not associated with change in NHEs or with study retention.

Conclusions: The SMART intervention appears effective for individuals regardless of health literacy competency. Nevertheless, individuals with higher levels of education have fewer epilepsy complications, and thus, those with limited education may still require additional support while participating in epilepsy self-management programs.

Keywords

epilepsy; seizures; self-management; health literacy; education; income

1. Introduction

Epilepsy is one of the most prevalent neurological disorders in the United States affecting approximately 7.1 per 1,000 people [1]. Large epidemiological surveys find the health burden of epilepsy includes educational attainment, lower annual income, and overall poorer health [2–6]. A significant number of people with epilepsy also experience a high burden of negative health events (NHEs) including seizures, accidents, and hospital visits [7–10]. Medication nonadherence, inadequate social support, and mental health illnesses all contribute to poor epilepsy management and NHE [10,11]. To improve outcomes in people with epilepsy we developed an epilepsy self-management intervention called SMART “Self-management for people with epilepsy and a history of negative events” (SMART). SMART is a group-based, self-management, web-based intervention designed to assist vulnerable subgroups with epilepsy by creating an easily accessible space for people with epilepsy to access information, and a social support network. SMART has been demonstrated to reduce NHEs and improve the quality of life in people with epilepsy [12].

Health literacy is the knowledge and ability to understand and obtain necessary health information and services needed to make appropriate health decisions [13]. In the United States, approximately 77 million adults have basic or below basic health literacy, according to a national assessment conducted by the National Assessment of Adult Literacy (NAAL) [13]. Racial minority groups and people with less education and lower-income have the lowest rates of health literacy [13]. People with limited ability to understand and utilize health information and resources may find managing health conditions to be challenging [14]. For example, low health literacy has been associated with higher rates of diabetic foot amputations and poor cardiovascular health [15,16]. Low health literacy has also been linked to a severe economic burden. According to an analysis of the Medical Expenditure Panel Survey and information from the NAAL, low health literacy costs an estimated $106 billion to $236 billion annually [17]. Effects of low health literacy contributing to increased costs include more emergency department usage and more medication errors [18].

As with other chronic health conditions, low health literacy is an obstacle to optimal outcomes among people with epilepsy. Bautista et al found that lower health literacy in epilepsy patients is associated with lower scores on the Quality of Life in Epilepsy-10 (QOLIE-10) inventory [19]. Scrivner and colleagues later expanded on this by finding that a 1% increase in health literacy is associated with a 6.61 point increase in the QOLIE-10 in patients with treatment resistant epilepsy [20]. Epilepsy patients with poor health literacy have also reported higher levels of felt stigma of the disease [21]. Though there are only a limited number of studies specifically investigating associations between health literacy and outcomes such as seizures in epilepsy patients, Paschal and colleagues assessed the health literacy of parents of pediatric epilepsy patients. They discovered a significant association between higher health literacy and fewer missed medication doses and fewer seizures [22].

Given the importance of health literacy in people with epilepsy and the paucity of studies on outcomes, this analysis examined the association between health literacy and outcomes from a randomized control trial (RCT) testing the SMART intervention in a sample with epilepsy. We hypothesized higher educational level and better health literacy would be associated with more robust improvement in people who participated in the SMART intervention. Additionally, we expected that higher educational attainment and better health literacy would be associated with a greater likelihood of intervention engagement.

2. Materials and Methods

2.1 Data Sources

The analysis is a secondary analysis of data from the SMART “Self-management for people with epilepsy and a history of negative health events” (SMART) intervention RCT. Details of the SMART 6-month prospective RCT which involved 120 individuals with epilepsy (N=60 randomized to SMART, N= 60 randomized to wait list (WL) control) are provided elsewhere [12].

2.2 Measures

2.2.1 Education Level and Demographic Data—Education level was self-reported by participants at baseline and was a four level categorical variable with the following categories: some high school, high school graduate, some college, and college graduate [12]. Other demographic data self-reported by participants included the dichotomous variables age (less than 39 or above 39), gender (male or female), ethnicity (Hispanic or not Hispanic), race (nonwhite or white), marital status (married or not married), comorbid health conditions (yes or no), and employment status (employed or not employed). The reference categories for these variables were above age 39, female, not Hispanic, nonwhite, not married, no comorbid health conditions, and not employed respectively.

2.2.2 Health Literacy—

Health literacy was assessed using the Rapid Estimate of Adult Literacy in Medicine (REALM-R), an 8 item survey that evaluates how well patients can read and understand words they commonly encounter during physician visits [23]. Patients were administered the REALM-R before administration of the intervention [12].

Data on the REALM-R was first published in 2003, and it has been correlated with the Wide Range Achievement Test -Revised (r=0.64). The reliability, as measured by Cronbach's alpha, was 0.91 [23].

With the REALM-R, patients sound out the words they recognize on the REALM-R, with a lower number of words indicating a lower score and lower health literacy. While there are 11 words, only 8 are scored, as the first three words are there to reduce patient anxiety. A patient gets one point for each word scored correctly, and a score of 6 or lower indicates lower health literacy [23].

2.2.3 NHEs and Epilepsy Self-Management Attendance and Study Retention—

NHEs were defined as seizures, accidents or traumatic injuries, self-harm attempts, and hospitalizations. NHEs were self-reported by participants, and emergency department visits and hospitalizations were counted to validate self-reported NHEs [12]. Attendance at each of the initial eight SMART sessions over eight to ten weeks was recorded [12]. Study retention was measured by the number of participants present at 6 month follow up.

2.2.4 Secondary Outcomes of Interest—

Measures of secondary outcomes from the original SMART trial were included. All of the following outcomes were self-reported at baseline by participants. Symptoms of depression were self-reported at baseline with the 9-item Patient Health Questionnaire (PHQ-9). Quality of life was assessed with the 10-item Quality of Life in Epilepsy (QOLIE-10) questionnaire. Functional status was measured with the SF-36, a short-form survey with a physical component summary (PCS) and mental component summary (MCS). Lastly, the self-efficacy of patients enrolled in the study was measured with Epilepsy Self-Efficacy Scale (ESES), a 33 item scale with a higher score indicating higher self-efficacy [12].

Secondary clinical variables were derived from a baseline clinical evaluation that assessed duration of epilepsy, number of prescribed anti-epileptic drugs (AEDs), and comorbid medical conditions as assessed by the Charles Comorbidity Index (CCI) [12].

2.3 Data Analysis

The data for this analysis was primarily aimed at assessing the association between REALM-R scores obtained at baseline and the total number of NHEs at 24 weeks. There was no significant difference in baseline health literacy scores for those randomized to the SMART arm (M= 6.52, SD= 2.21) vs. the WL arm (M= 6.41, SD= 2.01; $t(118)= 0.26$, $p=0.80$). Thus, the data in the 2 arms was combined. Participants who did not fill out all clinical or demographic information when self-reporting were excluded from analysis. SPSS version 24.0 (IBM) was used in these analyses.

2.3.1 Correlations between Health Literacy and Demographics and Clinical Characteristics at Baseline—

Pearson correlations between REALM-R scores and continuous demographic and clinical variables were conducted. Point bi-serial Pearson correlations were computed for dichotomous variables. Education was treated continuously.

2.3.2 Higher education level correlations at 6 months—

The effect of education on change in NHE counts from baseline to 6 months was conducted using a Spearman correlation.

2.3.3 Association between Health Literacy and SMART intervention outcomes at 6 months—

The distribution of change in NHE at 6 months was non-normal and left-skewed. Therefore, we created binary variables to determine if REALM-R scores were associated with improvement in NHE (1 = improvement, 0 = no change or increased NHEs at 6 months). A logistic regression was run to determine if health literacy and randomization arm were main effect predictors of total NHE count at 6 months, and if the interaction of the two terms was present.

3. Results

3.1 Baseline Sample Description

The sample is the same as that of the SMART RCT [12], with participants being excluded from analysis if they did not self-report all baseline data. Of the 119 in the analyzed sample, the majority were female (N=81, 68.1%) and African-American (N=79, 69.9%). Mean age was 41.3 years, and only 19 (16%) had less than a high school level of education.

3.2 Health Literacy and Demographic Correlates at baseline

Pearson correlations for continuous variables and point-biserial correlations for dichotomized variables between REALM-R score and demographics and clinical characteristics are listed in Table 1. Notably, lower education and lower income were significantly correlated with lower health literacy ($p<0.001$ and $p= 0.03$, respectively).

3.3 Education Level Associations at 6 months

At 6 months past baseline, higher education level was associated with a greater improvement in 6-month seizure counts ($r_s(105)= 0.29$, $p= 0.002$) and a greater improvement in total 6-month NHEs ($r_s(95)= 0.20$, $p= 0.045$) (Table 2).

3.4 Health literacy correlations with following in 6 month follow-up

There was no association between REALM-R scores and better study retention (Table 3).

3.5 Health Literacy and NHEs

REALM-R scores at baseline were not associated with improvements in NHEs or counts of NHEs in our logistic model, and there was no evidence for interaction between REALM-R and randomization. Randomization was significant for both the unadjusted and adjusted logistic regression.

4. Discussion

While health literacy can have a major negative effect on managing chronic health conditions [16,24], how health literacy might impact people with epilepsy is not well studied [19,22].This secondary analysis from a RCT testing a new epilepsy self-management intervention examined correlates of health literacy at baseline and whether health literacy and/or related variables were associated with change in SMART outcomes at 6-month follow-up. This analysis was completed to test the efficacy of the SMART intervention, which has been shown to reduce NHEs, in patients with lower health literacy and education.

Findings identified that both lower education and lower income were associated with lower health literacy which is consistent with the existing literature. Van der Heide and colleagues studied the relationship between education and health literacy and found that those who had completed tertiary education had higher health literacy than those who had completed upper secondary education [25]. Moreover, in a recent study testing the Short Test of Functional Health Literacy (S-TOHFLA) in Hungary, lower health literacy scores were associated with higher age and lower education [26]. Our results on income and health literacy are also supported by studies finding low income levels to be correlated with lower health literacy [27,28].

Assessment of longitudinal predictors of change in epilepsy outcomes identified several findings of interest with regards to the SMART intervention. First, higher educational level was associated with greater reduction in seizure counts and in NHEs. Second, health literacy was not associated with better retention, and health literacy was not associated with improvements in NHEs, implying that the SMART intervention may be effective regardless of patient’s baseline health literacy. Third, randomization to the SMART or WL arm as a predictor of NHE was significant in our logistic model, supporting the results of the original SMART intervention study [12].

While there is little research looking primarily at education level and reduction in seizure counts, our findings on education levels and epilepsy outcomes aligns with a study conducted by Chen and colleagues. Chen discovered a significant association between education level and reduction in seizures among pregnant women with epilepsy [29].

The literature on associations between health literacy and epilepsy outcomes is more varied. Dash et. al examined the effects of a health education intervention in a randomized controlled trial in Northern India [30]. One hundred eighty patients with low education levels were randomized to either a control group or the intervention group consisting of four health education sessions lasting at least 30 minutes. Secondary analysis indicated a significant increase in the number of patients that experienced a decrease in seizure counts as well as a significant increase in medication adherence in the intervention group. However, the sample’s relatively limited education, and the fact that the intervention was specifically targeted towards individuals with lower education, may limit generalizability of results.

When Bautista et. al investigated associations between health literacy, quality of life, and seizure control in epilepsy patients at an outpatient clinic at the University of Florida, multivariate statistical analysis showed no significant association between health literacy and seizure frequency or severity. Bautista et al proposed that this may be because other factors, such as the pathophysiology of epilepsy, contribute more to the subsequent determinants or correlates of severity [19]. In a different study by Almalag et al, among 102 Arabic speaking adults ages 60 or older, those with a higher baseline level of health literacy were more likely to report adverse effects from anti-epileptic drugs. It was insinuated that this was likely due to better comprehension of medication warnings [31].

This study had a number of limitations including the single-site setting, relatively small sample and the fact that individuals who have volunteered for a research study in the U.S. mid-west, may not fully represent the larger spectrum of individuals with epilepsy. For example, our sample had a relatively high level of education. However, this is not inconsistent with other literature on epilepsy patients. In a survey conducted by the Centers for Disease Control and Education across 19 states, only 16.1% of respondents with a history of epilepsy had less than a high school education [2]. It is also important to note that our study is somewhat unique in that it had a relatively large proportion of African-Americans with epilepsy. This increases the generalizability of findings to a diverse spectrum of individuals with epilepsy.

In conclusion, this analysis suggests that the SMART intervention appears to be effective for individuals regardless of health literacy competency and thus may be a useful treatment for patients across various health literacy levels. The primary study on SMART has indicated that the intervention is effective, leading to a decrease in NHE [12]. Our analysis showed that level of health literacy did not affect changes in NHE, thus insinuating that the intervention is effective regardless of health literacy level. Nevertheless, since individuals with higher levels of education have fewer epilepsy complications, those with less education may still require additional support while they are participating in epilepsy self-management programs.

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Highlights

- “Self-management for people with epilepsy and a history of negative health events” (SMART) is a novel, remotely delivered epilepsy self-management intervention.
- This secondary analysis of the primary outcomes of a 6 month SMART randomized efficacy trial assessed correlations between health literacy and SMART study outcomes and education level and SMART outcomes.
- Education level and income were significantly correlated with health literacy in our sample.
- Higher education level was significantly correlated with a reduction in negative health events (NHEs). There was no significant association between health literacy level and NHEs.
- The health literacy and education levels were not associated with participation in SMART.
- SMART is appropriate for epilepsy patients across a range of health literacy levels.

Table 1:

Pearson and point-biserial correlations between REALM-R scores and demographics and clinical characteristics in a sample of people with epilepsy participating in an epilepsy self-management RCT.

Variables of Interest (n=120)	REALM-R correlation (p value)
Age 39 or older	0.04
Male Gender	0.04
Caucasian (n= 112)	0.12
Hispanic (n= 119)	−0.06
Married	−0.03
Employed	0.14
Annual income greater than $25,000	0.21 [*]
Education level (n= 119)	0.44 [*]
Duration of epilepsy	−0.02
Number of prescribed AEDs[a]	−0.06
30-day seizure count at baseline	−0.11
CCI[b]	−0.05
Total 6 month NHE count at BL[c]	−0.03
Total 6 month seizure count	−0.07
Total 6 month ER and hospitalizations	0.15
MADRS[d]	−0.05
PHQ-9[e]	−0.12
QOLIE-10[f]	−0.06
ESES[g]	−0.05
SF-36 MCS[h]	0.02
SF-36 PCS[i]	0.17
Seizure type	
Generalized seizure (n=89)	0.07
Focal (n=15)	0.16
Unknown/other (n=30)	−0.11
Comorbid health condition	−0.08

[*] Significant at the 0.05 level

Race, African Americans/White; Ethnicity: Hispanic vs. non-Hispanic; Marital status: married/cohabiting vs not married; Employment: employed vs. not employed; Annual income: Below $25,000 vs above $25,000; Comorbid health condition: Yes/No

[a-] Anti Epileptic Drugs;

[b -] Charlson Comorbidity Index;

[c-] NHE = negative health events, BL = baseline,

[d] - Montgomery-Asberg Depression Rating Scale;

[e] - Patient Health Questionnaire-9;

[f] - Quality of Life in Epilepsy-10 Questionnaire;

[g] - Electrical Status Epilepticus in Sleep;

[h] - Short Form Health Survey Mental Component Score;

[i] - Short Form Health Survey Physical Component Score

Table 2:

Pearson and Spearman correlations between education level and epilepsy self-management intervention engagement at 6 months in a sample of people with epilepsy participating in an epilepsy self-management RCT.

	Education level
Likelihood of using web vs phone format	(r(92)= 0.09, p= 0.40)
Attendance	(r(117)= −0.01, p= 0.91)
Study retention	(r(116)= 0.03, p= 0.80)
Change in 30 day seizure counts (24 weeks - BL)*	(r_s(100)= 0.17, p= 0.10)
Change in 6 month seizure counts (24 weeks - BL)*	**(r_s(105)= 0.29, p= 0.002)**
Change in total 6 month NHEs (24 wk - BL)**	**(r_s(95)= 0.20, p= 0.045)**

r_S= Spearman correlation coefficient between education level and epilepsy self-management intervention variables

*BL=Baseline;

**NHE = Negative Health Event

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Table 3:

Pearson and Spearman correlations between health literacy, study attendance and retention rate, and change in NHEs from BL to 6 months

	REALM-R associations
Likelihood of using web vs phone format	($r(92)$= 0.03, p= 0.78)
Attendance	($r(118)$= −0.11, p= 0.24)
Study retention	($r(117)$= −0.06, p= 0.51)
Change in 30 day seizure counts (24wk- BL)*	($r_s(101)$= 0.08, p= 0.41)
Change in 6 month seizure counts (24wk-BL)*	($r_s(106)$= 0.12, p= 0.23)
Change in total NHEs (24wk- BL)**	($r_s(96)$= 0.08, p= 0.43)

r_S= Spearman correlation coefficient between REALM-R scores and change in NHEs and seizure counts

*BL=Baseline;

**NHE = Negative Health Event

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Table 4:

Logistic Regressions with REALM, Randomization, and interaction term as predictors of NHE counts at 6 months

		Estimate	**Standard Error**	**Chi Square**	**P-value**
	Unadjusted Logistic Regression				
Model 1	REALM	0.030	0.102	0.088	0.766
Model 2	Randomization	1.153	0.473	5.951	**0.015**
	Adjusted Logistic Regression				
Model 3	REALM	0.037	0.107	0.121	0.728
	Randomization	1.157	0.473	5.978	**0.015**