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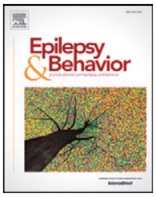

Health literacy and quality of life in patients with treatment-resistant epilepsy

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ABSTRACT

This exploratory study examined the impact of health literacy on quality of life (QoL) in patients with treatment-resistant epilepsy (TRE). Health literacy is a discrete form of literacy in which an individual can readily interpret prose and apply that skill to understand medical, pharmaceutical, and self-management information. From the perspectives of cultural health capital (CHC) and social disability theory, we hypothesized that greater levels of health literacy would be associated with a higher QoL score. The sample ($n = 79$) included adult patients with TRE enrolled in the University of Alabama at Birmingham Cannabidiol Program. The data were analyzed by using nested linear regression. Respondents aged 19–63 years (mean, standard deviation [SD] = 32.9 [13.65]) and were 92% white; 44% of patients were in Special Education until age 21 years, and 29% reported a total annual family income of less than $25,000. Significant bivariate relationships were found between health literacy and QoL ($p = .004$), age ($p = .0001$), and income ($p = .036$). There was a significant difference in health literacy scores for patients who completed high school or less (mean [SD] = 0.68 [0.86]) and those with any postsecondary education (mean [SD] = 1.59 [1.0]). The regression results showed health literacy to be positively associated with QoL where a 1% increase in health literacy was associated with a 6.61-point increase in QoL ($p = .004$), and this pattern persisted through each addition of other independent factors and control variables. This is one of the first studies investigating the role of health literacy in QoL among patients with TRE. The results suggest that health literacy is important and may function as a tool through which healthcare participation is expanded. Further research is needed with larger, more diverse, and longitudinal samples to accurately model the development of health literacy and its impact on QoL in this population.

1. Introduction

Health literacy has been conceptualized as the degree to which an individual can obtain, process, and understand basic health information [1]. Over the past twenty years, health literacy and its influence on health outcomes has been paid increasingly more attention [1–3]. It has been proposed that globalization and the relative abundance of health-promoting technology could serve as a mechanism for increased self-mastery and improved patient engagement. However, the rise in internet-based health information sources has not contributed to a decrease in healthcare disparities. Instead, gaps in access and varying levels of comprehensibility of health information have resulted in unequal benefits for individual self-care [4]. Low levels of health literacy are consistently associated with more hospitalizations, less preventative healthcare, poorer medical adherence, and – among elderly persons – lower health status and higher mortality [3].

Most health literacy research has focused on clinical outcomes and the ways health literacy shapes patient involvement in medical care. The research examining the impact of health literacy on quality of life (QoL) is growing, but remains sparse when investigating people with a neurological disorder. Bautista et al. [5] conducted the first study establishing a link between health literacy and QoL in people with epilepsy (PWE). Bautista et al.'s findings provided a foundation from which to consider diverse interpretations of the fundamental question, “How does heath literacy impact QoL for PWE?” This study takes a step further and addresses this question in patients with treatment-resistant epilepsy (TRE), whose greater degree of disability might shape health literacy as well as its association with QoL in unique ways.

1.1. Disparities in care

There is ample literature linking socioeconomic status (SES) and health outcomes [6]. This is particularly important for PWE, as the

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incidence and prevalence of epilepsy is associated with socioeconomic deprivation [7]. Furthermore, compared with individuals with other chronic conditions, PWE have reported lower levels of physical and mental health [8]. Using data from the National Health Interview Surveys, Thurman and colleagues [9] found that, compared with people with no history of epilepsy, PWE are *less likely* to be employed and to have private health insurance, and they are *more likely* to be disabled and to be insured under Medicaid. This and other research [9–11] have also documented that PWE have lower levels of education and household income, that they cite transportation as a barrier to healthcare, and that they have lower medication adherence. For example, Elliott et al. [11] analyzed data from the California Health Interview Survey to examine how the social determinants of health impact epilepsy prevalence and reported medication use. Their results suggest that PWE living in poverty are less likely to report taking medication for epilepsy than PWE not living in poverty.

These significant barriers to equitable healthcare require further research to assess the needs for intervention to close the gaps due to social inequalities.

1.2. Health literacy

Public health expert Don Nutbeam [1] explored how health literacy has evolved in its definition and application. Formerly, health literacy was defined as the “degree to which individuals have the *capacity* to obtain, process, and understand basic health information and services needed to make appropriate health decisions” ([1]: 2073). Contemporary definitions discard the term “capacity” as overly individualist and a reductionist disregard for broader social factors, and in its place, the use of “can” has been recommended in an effort to distinguish between intelligence (capacity) and health literacy as an ability [12,13]. This is an important distinction, as an ability denotes an actual skill set that one acquires or develops, whereas capacity refers to an individual's potential. Modifying the language to be reflective of abilities versus innate characteristics highlights the levels of power constraining an individual's health choices. More specific to this study, health literacy is a discrete form of literacy in which an individual can readily interpret prose and apply that skill to understand medical, pharmaceutical, and self-management information (including consent forms, inserts, and directions) [12,14]. Health literacy is an extension of self-efficacy because it functions as a tool that helps patients interact with their providers.

Unequal levels of health literacy contribute to healthcare disparities (the differences in the quality of healthcare that are not due to access-related factors or clinical needs, preferences, or appropriateness of intervention) by denying full health benefits to portions of the population [15,16]. Paasche-Orlow and Wolf [17] found that individuals with low levels of health literacy not only have less information about their disease, but also have less information about practical/instrumental self-management care. Further, low levels of health literacy are associated with poor health outcomes: more hospitalizations, higher use of emergency care, less medical compliance, poor ability to understand labels and health messages, and higher all-cause mortality [3,18].

1.3. Quality of life

Health-related quality of life (HRQoL), or quality of life (Qol), is a matrix of important, valued dimensions of life that influence health. It is a patient-centered assessment that combines self-reports of social, emotional, and physical well-being is crucial because diagnostic or clinical indicators may be helpful for healthcare providers, but do not usually address what is important to a patient (e.g., well-being and functionality). Further, QoL is essential for deciphering why patients with the same or similar clinical indicators exhibit different QoL outcomes [19]. In studies of QoL in patients with TRE, mood states and adverse events were found to be the strongest predictors of QoL [20]. Other disability research has noted an inverse relationship between multimorbidity in chronic disease and QoL [21]. Health literacy as an extension of self-efficacy is a modifiable factor that could likely impact QoL for the population with TRE.

1.4. Cultural health capital

Pierre Bourdieu theorized cultural capital as the accumulation of behaviors, tastes, and competencies that an individual can use to demonstrate social status or power [22–24]. Following Bourdieu, *cultural health capital* (CHC) has been defined as the constellation of skills, attitudes, behaviors, attributes, and interaction styles adopted, utilized, and leveraged by both patients and providers [25]. This skill set has been posited to be socially derived and contributing to the hierarchical power differential that impacts health outcomes. The CHC framework provides a lens to understand how broad social inequalities are manifested in patient–clinician interactions [25]. Specifically, CHC is a context-specific set of resources allowing for more effective healthcare interaction (e.g., instrumental approach to self-management, biomedical verbal competency, and information seeking behavior). Cultural health capital does not assume the leveraging of resources to be a purposeful action by patients exercising agency. Rather, the development of CHC occurs through repeated health-related practices and clinician interactions where the reciprocal interplay of choice and constraint become embodied by and embedded in an individual's habitus [22,25]. The development of adequate health literacy can be considered an achievement of the transactional nature of CHC in two ways: first, patients who interact with clinicians using accepted medical terminology establish themselves as informed and facilitate communication; second, healthcare providers may interpret the leveraging of such skills as a sign of a patient's adherence to ideal standards of patient compliance, and result in material benefits in care [25]. Gage-Bouchard [26] examined the role of CHC through clinical observation, in-depth interviews with 80 parents of pediatric patients with cancer and members of the pediatric oncology team. She found that parents who had social support via personal networks could adopt a more conspicuous role in their child's care. Parental ability to function in a role visible to the oncology team maximized communication and built trust with clinicians. This process of aligning values and preferences through interaction between patients and providers reinforces the patient-centeredness of treatment.

1.5. Study aim and hypotheses

This study seeks to investigate a third possible outcome where the benefits gained from CHC result in nonmaterial benefits. Specifically, CHC in the form of health literacy is assumed to positively impact QoL. Considering the past theory and research, we hypothesized that higher health literacy is associated with improved QoL in patients with TRE and that greater health literacy is associated with enhanced QoL in this group of patients independent of mood states, adverse effects, and sociodemographic and economic factors.

2. Material and methods

2.1. Data

The study design was cross-sectional and included 79 patients with TRE (ages 19–74 years) enrolled in the University of Alabama at Birmingham Cannabidiol (CBD) Program between 4/1/2015 and 7/18/2018 [27–30]. Each patient was referred to the study by their neurologist; inclusion was conditioned upon committee review of the physician-submitted application packet including a medical history, video-electroencephalogram (VEEG) confirming the epilepsy diagnosis, laboratory tests (complete blood count [CBC], metabolic panel [CMP], and urinalysis), previous and current antiseizure drug (ASD) list, and a calendar documenting seizure activity (uab.edu/cbd). Quality of life, mood states, and adverse events were assessed at the patient's first visit using standardized instruments (see Measures below).

In addition, social and psychosocial data were collected through a face-to-face interview conducted by a trained interviewer also at the patient's first visit. The interview included 27 structured items assessing the patient's sociodemographics (age, gender, and race), socioeconomic background (education, family income, and financial strains), self-reported health, health literacy, and other social/psychosocial factors. Two versions of the interview schedule were available for administration: one version was used with patients responding for themselves (48%); the second version was used when the patient was unable (due to poor cognitive or seizure status) to respond for themselves, and a caregiver report was used as a proxy (52%). Patients with TRE rely heavily on their caregivers for their basic social and physical needs, and we expected the caregivers to have good knowledge of the patient's personal and social circumstances. In our analyses, we included a control for the type of report: patient- versus caregiver-based. The average interview lasted 20 min.

This study was approved by the Institutional Review Board at the University of Alabama at Birmingham.

2.2. Measures

2.2.1. Dependent variable

Quality of life was assessed using the Quality of Life in Epilepsy-89 (QOLIE-89), a comprehensive instrument developed to gauge QoL in PWE [31]. An overall QoL score based on 17 subscales with 4 underlying dimensions was used as the dependent variable. Higher scores on the QOLIE-89 overall score indicate better QoL.

2.2.2. Main independent variable

Health literacy was assessed with three questions. Questions 1) "How often does patient have someone help him/her read hospital materials?" and 2) "How often does patient have problems learning about his/her medical condition?" had five response choices: "never", "occasionally", "sometimes", "often", and "always". These items were reverse coded from 0 "always" to 4 "never" and treated as continuous. Question 3) "How confident is patient filling out forms by him/herself?" had the following five response choices: "not at all", "a little bit", "somewhat", "quite a bit", and "extremely"; responses were coded from 0 "not at all" to 4 "extremely" (Appendix A, Table A-1). The three items were used to create a summative composite scale (Cronbach's $\alpha = 0.9$) with possible values 0–12, where a higher score is indicative of a higher level of health literacy. Because of the positive skew of the distribution (Appendix A), the variable was transformed by natural logarithm to account for this skewness.

2.2.3. Independent factors

Socioeconomic and demographic factors included total family income, financial strain, education, race, and gender. Total family income was measured with the question "Can you tell me which category on this card best represents your total combined family income in the last 12 months?" Respondents chose from 21 possible response categories ranging from "Less than $5000" to "$200,000+", and the variable was treated as continuous (0–21).

Financial strain was assessed by using three items: 1) "How would you describe the money situation in your household right now?" with response categories "comfortable with extra", "enough, but no extra", "have to cut back", and "cannot make ends meet". This variable was coded 0 = "comfortable with extra" to 3 = "cannot make ends meet" and was treated as continuous. 2) "In the past 12 months, how often has the following statement been true in your household '*the food we bought ran out and we didn't have money to get more*'", with response options: "never true", "sometimes true", or "often true". This variable was dichotomized with "never true" as the reference category. The remaining values were combined into a "sometimes or often true" category. 3) "In the past 12 months, how often have you had problems covering the cost of your epilepsy medications?" Response categories included "never true", "sometimes true", and "often true". This variable was also dichotomized with "never true" as the reference category, and the remaining values were combined into a "sometimes or often true" category.

Education was measured by asking "What is the highest grade or year of school that you have completed?" The ten response categories ranging from "Completed grade 3 or 4" to "Completed graduate or professional degree" were used to create a binary education variable with "graduated high school" or less as the reference and all postsecondary education as 1.

Race was treated as binary and coded 0 for white (reference) and 1 for nonwhite. Nonwhite patients were all Black/African American except one American Indian/Alaskan Native. Gender/sex was also binary: female (reference) versus male.

Self-reported health status was assessed using the question "In general, would you say your health is excellent, very good, good, fair, or poor?" This variable was coded 0 "poor" to 4 "excellent" and treated as continuous.

2.2.4. Controls

Mood states were assessed by using the Profile of Mood States (POMS), a widely-used instrument composed of 65 mood-related items in six dimensions: tension/anxiety, depression, anger/hostility, vigor/activity, fatigue, and confusion/bewilderment [32]. The Total Mood Disturbance (TMD) value is a composite score used in this analysis and was calculated by summing respondent subscale scores and subtracting vigor/activity. Adverse effects were evaluated using the Adverse Events Profile, a 19-item inventory assessing medication side effects where higher scores indicate more severe medication adverse effects [33].

A binary patient versus caregiver response variable was created with patient response as the reference group.

2.2.5. Analysis

Analyses were performed using Stata 15.1 [34]. Descriptive analysis included summarization of sociodemographic factors, health literacy scores, QOLIE-89 values, and controls (percentage distribution for categorical variables, and mean/median, standard deviation, and range for continuous variables), bivariate analyses—Pearson correlations for continuous variables, t-tests for pairs of categorical and continuous variables, Chi-square tests for pairs of categorical variables, as well as multivariable nested ordinary-least-squares (OLS) regression, with independent and control variables included in theoretically relevant blocks (see Results, Models 1–4). The significance level of alpha = 0.05 was used.

3. Results

The sample was 54% female and 92% white. The mean age was 33 years, and about 78% of the patients finished high school or less (Table 1). Significant positive bivariate associations were found between health literacy and QoL ($r = 0.324$, $p = .004$), age ($r = 0.415$, $p = .0001$), and income ($r = -0.235$, $p = .036$; Tables 2 & 3). An independent-samples t-test was conducted to compare health literacy scores across educational levels. There was a significant difference in health literacy scores for patients who completed high school or less (mean [SD] = 0.68 [0.86]) and those with any postsecondary education (mean [SD] = 1.59 [1.0]; Appendix B). Positive associations were found between money situation and food availability ($p < .0001$) and ASD affordability ($p = .008$). Perception of money situation was worse for white participants, compared with black participants ($r = -0.256$, $p = .023$).

To formally evaluate our hypotheses, we estimated nested linear regression models of the effects of health literacy on QoL including all

Table 1
Descriptive statistics for the epilepsy sample (n = 79).

Variable	Mean or proportion	SD	Min	Max
Outcome variable				
QOLIE-89 overall score	48.87	19.59	2	85
Explanatory variable				
Health literacy index[a]	2.79	3.72	0	12
Independent variables				
Age	32.91	13.65	19	74
Race[b]	0.924			
Sex[c]	0.544			
Education[d]	0.785			
Income[e]	11.6	5.28	3	21
Self-rated health	2.06	1.11	0	4
Money situation	2.05	0.999	0	3
Food availability[f]	0.165			
ASD affordability[g]	0.114			
Control variables				
TMD	46.06	34.58	0	156
AEP	41.37	10.35	19	65

QOLIE-89 = Quality of Life in Epilepsy-89, ASD = antiseizure drug, TMD = Total Mood Disturbance, AEP = Adverse Effects Profile.

[a] Logged additive composite of health literacy items: confidence filling out forms, problems reading, and has help reading.

[b] 1 white, else 0.

[c] 1 female, else 0.

[d] 1graduated high school or less, else 0.

[e] Total annual family income levels treated as continuous from 0 ("Less than $5000") to 21 ("200,000 or more").

[f] 1 sometimes/often food runs out, else 0.

[g] 1 sometimes/often problems affording ASDs, else 0.

independent variables tested in the bivariate analyses to account for potential spurious relationships (Table 4). Model 1 shows a positive association between health literacy and QoL where a 1% increase in health literacy is associated with a 6.61-point increase in QoL ($b = 6.61$, $p = .004$). The effect of health literacy on QoL continued to be positive and significant through the addition of age, race, and sex in Model 2 ($b = 6.89$, $p = .006$); the inclusion of income and education values in Model 3 ($b = 8.76$, $p = .001$); measures of financial strain in Model 4 ($b = 8.48$, $p = .002$); self-rated health in Model 5 ($b = 8.32$, $p = .003$); or when controlling for mood states and adverse effects in the final model ($b = 8.22$, $p = .002$). Thus, these results support our hypotheses that health literacy positively impacts QoL and does so after the addition of other independent variables and controls.

In our preliminary analyses, we controlled for caregiver-based response, which resulted in a small reduction of the coefficient for health literacy (i.e., 16% of the association between health literacy and QoL is accounted for by whether the respondent has a caretaker) and much larger standard errors resulting in loss of significance. However, the large increase in the standard errors suggested issues of multicollinearity. To examine this further, supplementary analyses (Appendix C) included two additional nested multivariable linear regression models: the first included only patients who responded to the interview themselves; the second sample was comprised of caregiver-based response only. The results show that for those who do not have a caregiver and who are active directors of their own care, the effect is stronger and more significant than for those who do not. However, the pattern is similar for both groups. Thus, the supplementary results add to the finding from the main analysis that health literacy is a crucial contributor to QoL among PWE.

Table 2
Pearson correlations among continuous study variables (n = 79).

	QOLIE-89	Age	Income	Self-rated health	AEP	TMD
Health literacy index[a]	0.324[**]	0.415[***]	−0.235[*]	−0.114	0.009	0.055
QOLIE-89	1.00	0.19	0.103	0.127	−0.189	−0.214
Age			−0.109	−0.267[*]	−0.137	−0.087
Income				0.210	−0.026	0.027
Self-rated health					−0.014	0.045
AEP						0.461[***]
TMD						1.00

QOLIE-89 = Quality of Life in Epilepsy-89 (overall score), ASD = antiseizure drug, TMD = Total Mood Disturbance, AEP = Adverse Effects Profile.

[a] Logged additive composite of health literacy items: confidence filling out forms, problems reading, and has help reading.

[***] $p < .001$.

[**] $p < .01$.

[*] $p < .05$.

Table 3
Bivariate associations among categorical independent variables (n = 79).

	Race	Sex	Education	Money situation	Food availability	ASD affordability
Race[a]	1.00	0.392	0.091	−0.256[*]	5.31[*]	3.1
Sex[b]			0.169	−0.21	1.37	4.86[*]
Education[c]				1.53	0.347	0.840
Money situation					29.52[***]	11.94[**]
Food availability[d]						11.3[**]
ASD affordability[e]						1.00

ASD = antiseizure drug.

Note: Chi-square values are presented and noted where significant.

[a] 1 white, else 0.

[b] 1 female, else 0.

[c] 1graduated high school or less, else 0.

[d] 1 sometimes/often food runs out, else 0.

[e] 1 sometimes/often problems affording ASDs.

[***] $p < .001$.

[**] $p < .01$.

[*] $p < .05$.

4. Discussion

This study is an attempt to build on the limited research examining whether, for patients with TRE, QoL can be improved by strengthening health literacy. Current disability research and advocacy promotes health literacy as a tool to provide access to disabled individuals—both physical access and long-term assurance of competent, coordinated care [35]. In this study, health literacy remained a statistically significant predictor of QoL through each addition of independent factors, including the addition of adverse effects and total mood states, and is especially interesting given the spectrum of disability represented by the sample: mean seizure frequency 45.7 ± 121.5, seizure severity 83.7 ± 49.1 [28,29]. This seems to support the CHC, social disability, and contemporary advocacy perspectives that when provided with access to appropriate resources, individuals can participate more fully in social interactions (such as interactions in clinical settings), which can enhance their QoL.

Health literacy is, at its core, an issue of communication. Health literacy can function as a bridge between social class and health by influencing the quality of care and engagement in healthcare settings [36]. Clinical setting communication styles are indicative of CHC: patterns of behaviors, attitudes, and interactions that are valued and leveraged by both patients and providers in a healthcare setting [37]. From this stance, previous research supports low levels of CHC impacting health literacy in two ways. First, most healthcare professionals are not aware of their patients' low levels of health literacy [16]. This could be a result of cultural factors, communication styles/interview techniques, or simply the imposed time constraints of clinical interactions. Second, most patients report being too embarrassed to admit to their healthcare providers that they do not fully understand their instructions; patients with low levels of functional health literacy report shame and may not confide in family, caregivers, or clinicians about their struggles [38].

Table 4
Nested multiple regression models predicting QOLIE-89 overall score in patients with TRE (n = 79).

QOLIE-89	Model 1	SE	Model 2	SE	Model 3	SE	Model 4	SE	Model 5	SE	Model 6	SE
	b		b		b		b		b		b	
Explanatory variable												
Health literacy index[a]	6.61**	2.20	6.89**	2.46	8.76**	2.58	8.48**	2.64	8.32**	2.66	8.22**	2.60
Independent factors												
Age			0.04*	0.172***	0.108	0.173	0.07	0.186	0.09	0.189	0.034	0.191
Race[b]			−11.3	8.05	−9.27	8.10	−9.40	8.41	−9.47	8.44	−4.53	8.52
Sex[c]			−4.52	4.23	−3.93	4.18	−3.99	4.43	−3.87	4.44	−3.08	4.40
Income					0.662	0.414	0.389	0.533	0.41	0.535	0.420	0.527
Education[d]					8.79	5.60	8.32	5.69	7.23	5.90	4.90	5.85
Money situation							3.39	2.98	2.71	3.13	4.16	3.16
Food availability[e]							1.17	7.17	1.66	7.22	4.88	7.20
ASD affordability[f]							7.05	7.87	6.90	7.90	8.97	7.82
Self-rated health									1.62	2.19	1.73	2.16
Control variables												
AEP											−0.211	0.238
TMD											−0.112	0.07
R^2	0.105		0.146		0.196		0.218		0.225		0.283	
F for change in R^2	9.01**		1.20		2.22		0.66		0.54		2.69	

QOLIE - 89 = Quality of life in Epilepsy - 89, TRE = treatment-resistant epilepsy, ASD = anti-seizure drug, AEP = Adverse Effects Profile, TMD = Total Mood Disturbance" to reflect table order.

[a] Logged additive composite of health literacy items: confidence filling out forms, problems reading, and has help reading.
[b] 1 white, else 0.
[c] 1 female, else 0.
[d] 1 graduated high school or less, else 0.
[e] 1 sometimes/often food runs out, else 0.
[f] 1 sometimes/often problems affording ASD, else 0.
*** $p < .001$.
** $p < .01$.
* $p < .05$.

This disconnect could be associated with a less activated, more passive patient–physician interaction resulting in miscommunication [17]. It is perhaps due to CHC inequalities similar to those found in other studies where women of lower SES were less likely to use interpersonal sources for healthcare because of limited social networks [39] and were more apt to adopt a passive approach to healthcare information absorption, incorporating ideas heard on television rather than actively seeking aid from people (medical and nonmedical) or health-oriented literature [40].

Previous research has noted health literacy to be positively associated with income, education, and QoL, but negatively associated with advanced age and racial minority status [41]. Our findings support this notion with the finding that higher education was found to be associated with improved health literacy. This is somewhat intuitive, as the development of health literacy is an educational process. Further, results are consistent with the original findings from Bautista et al. [5] where health literacy was positively associated with QoL. However, our results also indicate that age is a positive indicator of health literacy which is inconsistent with previous reports that older or elderly individuals have less knowledge of their disease [16,41]. Our finding supports the CHC perspective wherein continuous interaction with a clinician is assumed to result in greater health capital gains (i.e., health literacy). This explanation is strengthened by the independent associations between age and education, affordability of epilepsy medications, and its negative association with self-rated health. A possible explanation for these associations is that older individuals have more resources and have developed the self-management skills needed to enhance their QoL.

While prior research cites low SES as an indicator of diminished health literacy [16], our bivariate findings indicate a negative relationship between income and health. This finding may be a result of our interview question that aimed at determining “total family income in the last year including all sources of income from all individuals living in the household.” Of the participants who are nonverbal and whose caregiver responded to the survey, many live at home with parents. For the outcome variable, QoL, our results were consistent with previous QoL for PWE studies that found a negative correlation between QoL and adverse medication effects and mood states in PWE [20,42]. In our study, QoL was most strongly associated with health literacy.

Many of the variables used in our analysis had a moderately strong bivariate relation with our main independent variable. After all independent and control variables were included through each conceptual step in the multivariable regression analysis, only health literacy remained statistically associated with QoL. These results support both our hypothesis that a relationship exists, and our theoretical stance that health literacy, derived via clinical transaction, serves as a bridge between disability and agency of care.

Our findings are not generalizable to the larger population of U.S. adults living with epilepsy. The sample is limited and composed of patients with TRE participating in a CBD study. Further, participation in the study is restricted to the state of Alabama, and this may introduce sociodemographic characteristics that are not reflected in the broader population with epilepsy (e.g., the sample is only 7.6% Black or African-American despite the state of Alabama reporting a 26.8% Black or African-American population) [43]. While income was evenly distributed, it is notable that nearly 30% of the sample had a total family income of less than $25,000 annually in a state with a median yearly income of $46,472 [43]. However, this distribution is consistent with other studies conducted in the Deep South [44]. Previous analyses on this sample have not found a significant relationship between income and QoL for PWE [10], and our results support those findings. All patients in the study have health insurance, which is not always the case for all epilepsy social research [45]. Research examining the incidence and prevalence of epilepsy have found the rates to be highest for individuals under the age of 5 years and over the age of 60 years [46]. In our sample, there was no one under the age of 19 years, and less than 7% of the sample was aged 60 years and above; thus, our sample may be further specialized. Finally, a theoretical limitation of our study is that health literacy is operationalized as a static concept within this study. Future research testing the theory of CHC as an achievement of clinical interactions should consider health literacy a dynamic concept requiring assessments over time.

5. Conclusion

This study has shown that health literacy is an important factor contributing to QoL in patients with TRE. More research is needed to determine if health literacy impacts QoL for larger, more diverse populations of PWE. Future directions of this study include comparisons across different locations to investigate potential differences in rural versus urban environments and the respective impacts on QoL for PWE. Also, analysis of longitudinal data would allow a fuller examination of health literacy as an evolving and growing capacity borne of clinical interaction. The clinical and institutional shift toward collaborative patient-centered care is made stronger and more efficient with a culture of health literacy and patient advocacy. Clinicians have the opportunity to grow patient knowledge and, in turn, provide optimal care by ensuring understanding, encouraging compliance and adherence, and promoting improved self-management. This approach would help to reduce healthcare costs and improve QoL for PWE, particularly in rural or underserved areas where access to specialized care is not readily available.

Declaration of competing interest

JPS, PI of the UAB CBD Program, and BS received salary support from the program. MS has received funding from Greenwich Biosciences, Inc. EHB reports no conflicts of interest. CBD (Epidiolex®) was provided by GW Pharmaceuticals, Inc. free of charge to the patients.

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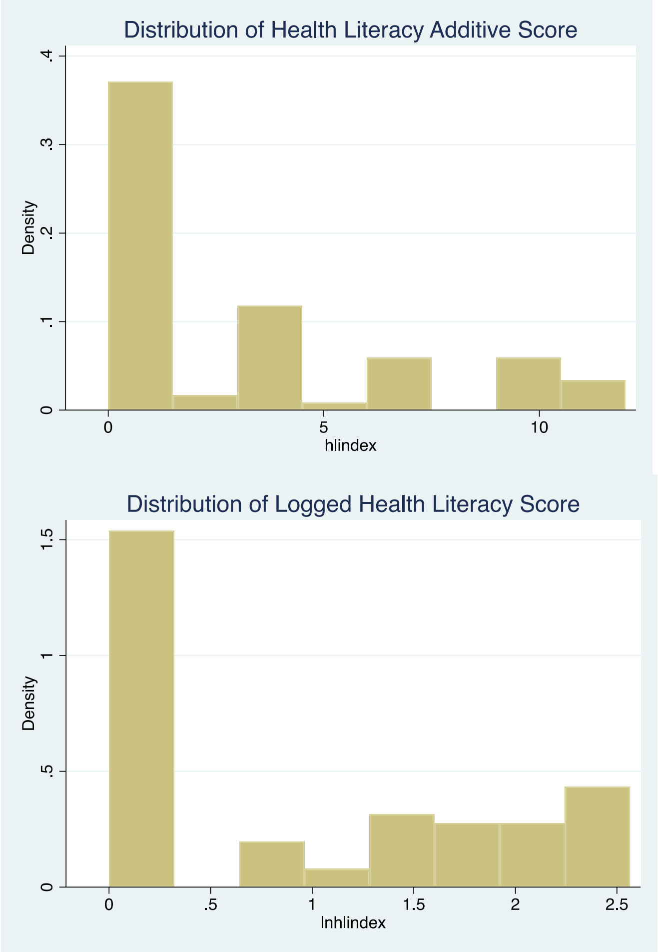
Preliminary findings were presented at the Annual Meeting of the Southern Sociological Society (New Orleans, April 2018), and additional analyses were presented at the American Epilepsy Society's Annual Meeting (New Orleans, December 2018).

Appendix A. Health literacy transformation

Supplementary graphs and statistical tests were used when transforming the health literacy measures from a three-question categorical variable to a logged additive composite. Single health literacy item linear regressions were performed to determine if single items were more important than the overall health literacy construct.



Distribution of Health Literacy Additive Score

Distribution of Logged Health Literacy Score

Fig. A-1. Distribution of health literacy index vs logged variable.

Table A-1
Descriptive statistics for categorical health literacy measures (n = 79).

Variable	Mean (%)	SD	Min	Max
How often does patient have someone help them read hospital materials?	0.823	1.33	0	4
Never	8.86			
Occasionally	5.06			
Sometimes	11.39			
Often	8.86			
Always	65.82			
How often does patient have problems learning about their medical condition?	1.10	1.43	0	4
Never	11.39			
Occasionally	8.86			
Sometimes	11.39			
Often	15.19			
Always	53.16			
How confident is patient filling out medical forms by themselves?	0.873	1.29	0	4
Not at all	63.29			
A little bit	7.59			
Somewhat	12.66			
Quite a bit	11.39			
Extremely	5.06			

Table A-2
Linear regression: reading help.

QOLIE-89	b	SE	t	p	95% CI	
Reading help[a]	5.77	2.01	2.86	.006	1.745071	9.79085
Age	0.002	0.194	0.01	.992	−0.3849844	0.388992
Race[b]	−4.16	8.62	−0.48	.631	−21.37779	13.05838
Sex[c]	−3.30	4.43	−0.75	.459	−12.14581	5.542573
Annual family income[d]	1.19	3.45	0.34	.732	−5.709941	8.083948
Education	−1.27	2.11	−0.60	.550	−5.488003	2.947141
Money situation	5.03	3.07	1.64	.106	−1.106342	11.16907
Food availability[e]	6.35	7.22	0.88	.382	−8.055979	20.76063
ASD affordability[f]	12.2	8.10	1.51	.137	−3.968642	28.35847
Self-rated health	1.60	2.13	0.75	.456	−2.667676	5.871398
AEP	−0.223	0.240	−0.93	.357	−0.7023125	0.2564461
TMD	−0.105	0.071	−1.49	.141	−0.2466244	0.035699

QOLIE - 89 = Quality of life in Epilepsy - 89, CI = Confidence Interval, ASD = anti-seizure drug, AEP = Adverse Effects Profile, TMD = Total Mood Disturbance.

[a] Patient report of difficulty learning about medical condition(s) due to reading difficulties.

[b] 1 if white, else 0.

[c] 1 male, else 0.

[d] Reference group $8000–$25,000/year.

[e] 1 sometimes/often food runs out, else 0.

[f] 1 sometimes/often problems affording ASDs, else 0.

Table A-3
Linear regression: forms confidence.

QOLIE-89	b	SE	t	p	95% CI	
Forms confidence[a]	4.96	1.99	2.49	.015	0.9770542	8.94129
Age	0.085	0.190	0.45	.654	−0.2934319	0.4641406
Race[b]	−3.17	8.72	−0.36	.718	−20.574	14.24249
Sex[c]	−2.95	4.48	4.48	.513	−11.89718	6.00468
Annual family income[d]	0.622	3.49	0.18	.859	−6.340913	7.584004
Education	−0.583	2.08	−0.28	.780	−4.734276	3.568387
Money situation	4.48	3.13	1.43	.158	−1.775598	10.72857
Food availability[e]	3.86	7.54	0.51	.610	−11.19319	18.91322
ASD affordability[f]	8.10	8.02	1.01	.316	−7.91556	24.11721
Self-rated health	2.18	2.15	1.01	.315	−2.116507	6.476912
AEP	−0.198	0.244	−0.81	.418	−0.6844384	0.2878985
TMD	−0.110	0.072	−1.54	.130	−0.2529372	0.0330439

QOLIE - 89 = Quality of life in Epilepsy - 89, CI = Confidence Interval, ASD = anti-seizure drug, AEP = Adverse Effects Profile, TMD = Total Mood Disturbance.

[a] Patient report of difficulty learning about medical condition(s) due to reading difficulties.

[b] 1 if white, else 0.

[c] 1 male, else 0.

[d] Reference group $8000–$25,000/year.

[e] 1 sometimes/often food runs out, else 0.

[f] 1 sometimes/often problems affording ASDs, else 0.

Table A-4
Linear regression: problems reading.

QOLIE-89	b	SE	t	p	95% CI	
Problems reading[a]	3.52	1.75	2.02	.048	0.0344214	7.00502
Age	0.081	0.195	0.41	.680	−0.3090383	0.4707274
Race[b]	−3.90	8.90	−0.44	.662	−21.67173	13.86479
Sex[c]	−2.94	4.56	−0.64	.521	−12.05083	6.169412
Annual family income[d]	0.589	3.54	0.17	.869	−6.482218	4.410851
Education	0.422	1.99	0.21	.833	−3.567024	4.410851
Money situation	4.86	3.17	1.53	.130	−1.467565	11.18482
Food availability[e]	6.36	7.48	0.85	.398	−8.571306	21.28674
ASD affordability[f]	9.63	8.22	1.17	.246	−6.793399	26.04355
Self-rated health	2.64	2.19	1.21	.232	−1.726172	7.005733
AEP	−0.216	0.247	−0.88	.385	−0.7095186	0.2770253
TMD	−0.120	0.073	−1.65	.104	−0.2647298	0.0253033

QOLIE - 89 = Quality of life in Epilepsy - 89, CI = Confidence Interval, ASD = anti-seizure drug, AEP = Adverse Effects Profile, TMD = Total Mood Disturbance.

[a] Patient report of difficulty learning about medical condition(s) due to reading difficulties.

[b] 1 if white, else 0.

[c] 1 male, else 0.

[d] Reference group $8000–$25,000/year.

[e] 1 sometimes/often food runs out, else 0.

[f] 1 sometimes/often problems affording ASDs, else 0.

Appendix B. t-Test results for associations between health literacy and categorical independent factors

Results of t-test: race									
	Sex						95% CI for mean difference	t	df
	White			Black/African-American					
	M	SD	n	M	SD	n			
Health literacy index	0.842	0.956	73	1.23	1.01	6	−1.20, 0.424	−0.95[NS]	77
Results of t-test: sex									
	Sex						95% CI for mean difference	t	df
	Female			Male					
	M	SD	n	M	SD	n			
Health literacy index	0.942	0.928	43	0.787	0.928	36	−0.585, 0.278	−0.71[NS]	77
Results of t-test: food availability									
	Food has run out						95% CI for mean difference	t	df
	Never true			Sometimes/often true					
	M	SD	n	M	SD	n			
Health literacy index	0.791	0.949	66	1.28	0.941	13	−1.06,0.082	−1.71[*]	77
Results of t-test: ASD affordability									
	Has had trouble paying for ASD						95% CI for mean difference	t	df
	Never true			Sometimes/often true					
	M	SD	n	M	SD	n			
Health literacy index	0.806	0.958	70	1.38	0.849	9	−1.24,0.095	−1.71[*]	77
ASD = antiseizure drug.									
Results of t-test: caregiver proxy respondent									
	Respondent						95% CI for mean difference	t	df
	Patient			Caregiver					
	M	SD	n	M	SD	n			
Health literacy index	1.60	0.799	38	0.201	0.496	41	1.10, 1.69	9.39[***]	77
Results of t-test: education (binary)									
	Respondent						95% CI for mean difference	t	df
	HS or less			Postsecondary or more					
	M	SD	n	M	SD	n			
Health literacy index	0.678	0.858	62	1.58	1.00	17	0.415, 1.39[**]	3.69[***]	77

NS = not significant.

[***] p < .001.

[**] p < .01.

[*] p < .05.

Appendix C. Supplementary regression tables

In C-1, items were standardized after regression to examine their weights within the model.

C-2 and C-3 are the full nested linear regression model results showing the differences in patients who responded to their interviews themselves and those who had caregiver proxies respond.

Table C-1
Linear regression model with standardized coefficients (n = 79).

	b	t	P > t	bStdX	bStdY	bStdXY	SDofX
Health literacy[a]	8.2211	3.163	0.002	7.885	0.420	0.402	0.959
Age	0.0340	0.181	0.857	0.464	0.002	0.024	13.652
Race[b]	−4.5278	−0.531	0.597	−1.207	−0.231	−0.062	0.267
Sex[c]	−3.0795	−0.701	0.486	−1.543	−0.157	−0.079	0.501
Income	0.4198	0.797	0.429	2.230	0.021	0.114	5.311
Education[d]	4.8977	0.837	0.406	2.026	0.250	0.103	0.414
Money situation	4.1590	1.316	0.193	4.154	0.212	0.212	0.999
ASD affordability[e]	8.9730	1.147	0.256	2.869	0.458	0.146	0.320
Food availability[f]	4.8762	0.677	0.501	1.820	0.249	0.093	0.373
Self-rated health	1.7333	0.803	0.425	1.930	0.088	0.098	1.113
AEP	−0.2105	−0.884	0.380	−2.178	−0.011	−0.111	10.346
TMD	−0.1123	−1.613	0.111	−3.882	−0.006	−0.198	34.580
Constant	38.3886	2.220	0.030	.	.	.	.

ASD = antiseizure drug, AEP = Adverse Effects Profile, TMD = Total Mood Disturbance.

[a] Logged additive composite of health literacy items: confidence filling out forms, problems reading, and has help reading.

[b] 1 if white, else 0.

[c] 1 male, else 0.

[d] 1 graduated high school or less, else 0.

[e] 1 sometimes/often problems affording ASDs, else 0.

[f] Sometimes/often food runs out, else 0.

Table C-2
Nested linear regression model with caretaker (N = 41).

QOLIE-89	Model 1 *b*	SE	Model 2 *b*	SE	Model 3 *b*	SE	Model 4 *b*	SE	Model 5 *b*	SE	Model 6 *b*	SE
Explanatory variable												
Health literacy index[a]	6.51	6.43	6.47	6.66	4.84	6.90	5.80	2.73	5.65	7.33	3.99	7.67
Independent factors												
Age			0.295	0.407	0.336	0.413	0.332	0.429	0.324	0.437	0.172	0.479
Race[b]			−2.83	15.17	0.173	16.2	−0.746	16.98	−0.247	17.4	3.61	18.2
Sex[c]			−1.92	6.72	−2.28	6.83	−2.93	7.06	−2.56	7.33	−1.09	7.64
Income					5.49	5.04	1.30	6.88	1.55	7.06	2.77	7.46
Education					3.43	5.61	1.33	6.11	1.48	6.24	2.37	6.42
Money situation[d]							5.56	5.53	5.86	5.75	6.59	5.95
Food availability[f]							0.141	16.9	−0.454	17.4	−3.56	18.1
ASD affordability[e]							12.7	22.8	13.3	23.3	6.89	24.7
Self-rated health									−0.933	3.87	−1.72	4.09
Control variables												
AEP											−0.391	0.472
TMD											−0.024	0.143
R^2	0.026		0.046		0.095		0.132		0.134		0.161	
F for change in R^2	1.02		0.26		0.93		0.44		0.06		0.46	

QOLIE - 89 = Quality of life in Epilepsy - 89, ASD = anti-seizure drug, AEP = Adverse Effects Profile, TMD = Total Mood Disturbance..

[a] Logged additive composite of health literacy items: confidence filling out forms, problems reading, and has help reading.

[b] 1 if white, else 0.

[c] 1 male, else 0.

[d] Reference group $8000–$25,000/year.

[e] 1 sometimes/often problems affording ASDs, else 0.

[f] Sometimes/often food runs out, else 0.

Table C-3

Nested linear regression model without caretaker (n = 41).

QOLIE-89	Model 1 *b*	SE	Model 2 *b*	SE	Model 3 *b*	SE	Model 4 *b*	SE	Model 5 *b*	SE	Model 6 *b*	SE
Explanatory variable												
Health literacy index[a]	6.86	3.59	8.53*	3.61	8.93*	3.78	9.37*	3.95	8.75*	3.99	7.20	3.70
Independent factors												
Age			−0.068	0.198	−0.025	0.208	−0.101	0.236	−0.032	0.245	−0.081	0.230
Race[b]			−17.7	9.50	−18.5	9.92	−19.9	11.1	−18.3	11.1	−8.41	11.0
Sex[c]			−5.98	5.68	−6.50	5.88	−6.88	6.86	−3.70	7.46	−3.38	6.91
Income[d]					0.617	4.16	0.407	4.17	1.04	4.94	1.83	4.54
Education					−1.86	2.24	−1.84	2.45	−0.990	2.57	−1.09	2.41
Money situation							1.96	3.98	1.38	4.01	3.30	3.76
Food availability[e]							−0.069	9.01	1.57	9.12	5.79	8.65
ASD affordability[f]							8.26	9.08	8.04	9.06	10.5	8.87
Self-rated health									3.63	3.31	3.03	3.03
Control variables												
AEP											−0.310	0.313
TMD											−0.163***	0.088
R^2	0.064		0.178		0.702		0.785		0.296		0.043**	
F for change in R^2	3.66		0.26		0.93		0.44		0.06		0.46*	

ASD = antiseizure drug, TMD = Total Mood Disturbance, AEP = Adverse Effects Profile.

[a] Logged additive composite of health literacy items: confidence filling out forms, problems reading, and has help reading.

[b] 1 if white, else 0.

[c] 1 male, else 0.

[d] Reference group $8000–$25,000/year.

[e] 1 sometimes/often problems affording ASDs, else 0.

[f] Sometimes/often food runs out, else 0.

* $p < .05$.

** $p < .01$.

*** $p < .001$.

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