Self-management practices associated with quality of life for adults with epilepsy

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1. Introduction

Epilepsy is a chronic neurological disorder that impacts over 3.4 million US residents [1]. The challenges of living with epilepsy extend beyond the constant worry for seizures and complicated treatment regimens to many other domains in the patient's life [2, 3]. Persons with epilepsy report a diminished quality of life (QoL) due to poor seizure control, adverse treatment effects, low social support, diminished self-efficacy, higher perceived stigma, medical comorbidities, and low medication adherence [3–6]. These comorbidities and socioeconomic limitations are also shown to have a larger impact on the QoL of persons with epilepsy than the actual seizures [7–9].

While previous studies have established the positive relationship between self-management practices and QoL in persons with epilepsy, there is limited evidence on which self-management domains are most associated with QoL [2, 3, 10–12]. The majority of these previous studies examined self-management practices and QoL independently or with a focus on demographic factors, psychosocial factors, or self-management program evaluations, rather than assessing specific correlations between self-management and QoL

[10, 11, 13]. Additionally, Johnson et al. reported a clear discordance between provider and patient perspectives on self-management needs and self-management program preferences, highlighting the importance of increased subjective patient reports for guiding clinical recommendations [14]. This emphasizes the need for determining which self-management practices have the largest impact on QoL from a patient's perspective.

The purpose of this study was to identify the relationship between self-management and QoL, with a focus on understanding the specific self-management practices that were most related to QoL. We hypothesized that higher subjective Epilepsy Self-Management Scale (ESMS) ratings would be associated with higher QoL reports. Previous studies demonstrated higher scores in the ESMS subdomains of medication management, safety management and seizure management due to an enhanced emphasis on these practices during every clinic visit [9, 13]. This guided our hypothesis that lifestyle management and information management would be more sensitive metrics for predicting differences in QoL for persons with epilepsy. We also hypothesized that depression, assessed by the Patient-Health Questionnaire-9 (PHQ-9), would be significantly associated with self-management practices and overall QoL. The results of our analyses will guide clinical recommendations and inform the development of future epilepsy self-management programs – ultimately, bridging the gap between patient preferences and provider perceptions.

2. Methods

2.1 Participant characteristics

Data was obtained from self-reported baseline questionnaires of a randomized controlled trial of HOBSCOTCH, a self-management program for cognitive problems in epilepsy, prior to the intervention[15]. 106 subjects were enrolled in the study from epilepsy clinics at Dartmouth-Hitchcock Medical Center, Maine Medical Center, the University of Vermont Medical Center, and the University of Massachusetts Medical School. Participants included consenting subjects aged 18 to 70 years who reported subjective memory complaints, telephone access, literacy, and no major changes in antiepileptic or antidepressant medications for one month. Six subjects were excluded because they withdrew before providing baseline questionnaire data. This resulted in baseline data from 100 subjects for the present analyses.

2.2 Assessments

2.2.1 Epilepsy self-management scale (ESMS)—The ESMS is a patient-reported 38-item scale that evaluates the frequency of self-management practices in epilepsy patients. Nested within this scale are five subscales: medication management, information management, safety management, seizure management, and lifestyle management [16]. The questionnaire is a 5-point Likert scale with 1 as "never do" and 5 as "always do". The total possible score ranged from 38 to 190, with higher overall scores corresponding to more frequent use of self-management strategies. This 38-item scale is based on an original 26-item version, which was assessed for content validity and reliability with alpha coefficients between 0.81 and 0.84 [17, 18].

2.2.2 Quality of life inventory in epilepsy (QOLIE-31)—The QOLIE-31 is a self-reported outcome instrument that was initially designed to assess the effect of treatment on epilepsy-associated issues and the patient's overall health-related quality-of-life (HRQOL) [19, 20]. The questionnaire contains 31 items that examine the past four weeks of a patient's life. The questionnaire is a 6-point Likert scale with 1 as "all of the time" and 5 as "none of the time". The items are stratified into seven subscales, which include: seizure worry, overall quality of life, emotional well-being, energy/fatigue, cognitive functioning, medication effects, and social functioning [21]. The subscale scores are calculated based on the mean of items from each subscale, while the overall score is calculated based on the product of the mean subscale scores and specified weights. The weights were determined by regressing an external measurement of quality of life on the subscale scores [21]. Each of the scores ranged from 0 to 100 with higher scores corresponding to better QoL. The first question within the QOLIE-31 ("Overall, how would you rate your quality of life") is scored from 0 ("Worst possible quality of life") to 10 ("Best possible quality of life"), then multiplied by 10 to produce scores that ranged from 0 to 100. Higher scores for this single QOLIE-31 item indicate a better QoL.

2.2.3 Patient Health Questionnaire-9 (PHQ-9)—Development of the Patient Health Questionnaire-9 (PHQ-9) was based on the DSM-IV criteria for major depressive disorder (MDD) [22]. Each of the nine items are rated on a 4-point scale from 0 to 3, where 0 is "never" and 3 is "nearly every day". The scale assesses patient depression two weeks prior to and including the day of survey completion [23]. The PHQ-9 is a well-established scale for assessing depression in persons with epilepsy. The PHQ-9 scores range from 0 to 27, with higher scores corresponding to increased depression severity [22, 24].

2.3 Statistical analysis

Multivariable linear regression was utilized to assess the relationship between overall quality of life (QOLIE-31 overall score) and self-management practices (ESMS subdomains). This regression model was also used to control for potential confounders. All regression models were run with each of the subscale scores as independent predictors to overcome the issues that arise due to multi-collinearity. We then utilized an ordered logit model to determine the association between each ordinal item within the ESMS and the overall QOLIE-31 score. The QOLIE-31 outcome variable was split into three groups (low, medium and high QOLIE-31 scores) using the 25th and 75th percentiles as cutoffs, in order to aid in the interpretation of the results from this model. Nonparametric correlations (Spearman's p) were utilized to assess the ESMS items for inter-question correlations. We employed a conservative threshold of r =0.50 to remove redundant, correlated items from our model to minimize the effects of multi-collinearity. In a post-hoc analysis, Spearman's p was also utilized to assess the relationship of PHQ-9 scores with QOLIE-31 and ESMS overall scores. Correction for multiple comparisons were employed as appropriate (e.g. Bonferroni). The significance level was set at $P < 0.05$, and all statistical analyses were performed using R version 3.4.1.

3.   Results

Table 1 illustrates the demographic and clinical characteristics of subjects who completed the questionnaires. Participants had a mean age of 46.7 (22–70, SD 11.1), and 36.0% were men. In the sample, 42.0% had an annual income of >$50,000, 56.0% were married, and 59.0% were high school graduates. Age, gender, relationship status, and seizure control were deemed significant confounders for the relationship between self-management practices and overall QoL. In this study, subjects with controlled seizures were defined as not having a seizure in the past 30 days.

The overall QOLIE-31 score and the overall ESMS score demonstrated no significant correlation ($r = −0.11$, $p = 0.26$) (Fig.1). The single quality of life question contained within the QOLIE-31 also showed no significant correlation with the overall ESMS score ($r = −0.13$, $p = 0.19$) (Fig.1). A subsequent analysis examining each of the subscale categories for both the QOLIE-31 and ESMS revealed that several subcategories were correlated (S.Fig. 1).

Our multivariable linear regression with ESMS subscales as the predictors and the overall QOLIE-31 as the outcome revealed that ESMS safety management (Beta = −6.66, $p < 0.01$) and ESMS lifestyle management (Beta = 7.29, $p < 0.01$) were significantly associated with the overall QoL for persons with epilepsy (Table 2). Increased safety management was associated with a lower QoL, while increased lifestyle management was associated with an increased QoL. Following this subscale analysis, we examined the individual items within the ESMS subdomains.

We constructed an ordered logit model utilizing individual ESMS items as predictors and QOLIE-31 as the outcome to identify the ESMS items strongly associated with QoL (Table 3). With regard to the ESMS lifestyle management subdomain, as a patient's response to, "I do things that I enjoy to help manage stress," moves one unit in the positive direction (i.e. from "rarely" to "sometimes"), the odds of reporting better QoL increase 3.66 times ($p < 0.01$) (Fig.2). The significant item within the ESMS safety management subdomain was, "I use power tools such as electric saws, electric hedge trimmers, or electric knives without an automatic shutoff." This item was reverse coded in the original ESMS, so as a patient's response moves one unit in the positive direction (i.e. from "rarely" to "sometimes"), then the odds of reporting better QoL increase 2.70 times ($p < 0.01$) (Fig.2).

The post-hoc correlation analysis demonstrated a strong negative correlation between the QOLIE-31 overall score and the PHQ-9 overall score ($r = −0.78$, $p < 0.001$) (Fig. 3), but no significant correlation was observed between the ESMS overall score and the PHQ-9 overall score ($r = −0.108$, $p = 0.28$) (Fig. 3).

4.   Discussion/Conclusion

Our study provides insight into the relationship between self-management practices and the QoL for persons with epilepsy. We found that despite the lack of an overall relationship between self-management scores and QoL scores, several individual factors measured by the

ESMS were associated with QOLIE-31, indicating that there is a complicated set of self-management practices that impact QoL.

Previous research supports the complexity of these associations, but ultimately proposed that enhanced epilepsy self-management practices were associated with better health status ratings and higher QoL [10, 25]. These studies also demonstrated that patients with higher rated QoL were more likely to implement self-management techniques [12, 26]. Surprisingly, we found no significant correlation between the overall self-management rating and overall QoL. This could be explained by the fact that different studies utilized different instruments to measure QoL and self-management practices for persons with epilepsy. For instance, Escoffery et al. utilized an enhanced Adult Epilepsy Self-Management Measurement Instrument (AESMMI), a 113 item scale with 10 domains, and a single item QoL assessment [25]. Although our global analysis indicated no relationship between overall QoL and ESMS, our subdomain and item-level analyses spotlighted ESMS safety management and ESMS lifestyle management as significant predictors for QoL.

The ESMS safety management items encompass a range of safety practices. These include staying out late at night, consuming alcohol, climbing objects, swimming alone, showering instead of bathing, keeping the water temperature low at home, and checking with the doctor before taking other medications [16]. Interestingly, there was an inverse relationship observed between these safety management practices and QoL. The item-level analysis of safety management revealed that ESMS question 23 ("I use power tools such as electric saws, electric hedge trimmers, or electric knives without an automatic shutoff") was a positive predictor for the overall QoL. These results concur with past findings, which caution against disproportionate restrictions imposed by safety advice due to its negative association with QoL [2, 27, 28].

Difficulty with lifestyle management was also documented as a major concern for persons with epilepsy [13]. ESMS lifestyle management items assess sleep, eating and exercise habits, and techniques for managing stress and seizures [16]. A study by Robinson et al. reported that of these specific lifestyle management practices, stress management, sleep behavior, diet, and exercise are significantly associated with seizure frequency [29]. Moreover, they demonstrated that depressive symptoms and perceived social support impacts self-efficacy, which is an important factor for the regulation of lifestyle management practices [29]. Our study supports an increased emphasis on lifestyle management practices in epilepsy self-management programs – with a special emphasis on stress management techniques.

While information management was not a significant ESMS subdomain, several items within this category were significant predictors for the overall QoL. This is in line with our initial hypothesis that lifestyle management and information management would be associated with QoL [9, 13]. As depicted in Table 3, ESMS question 5 ("I keep a record of the types of seizures that I have") was a positive predictor for the overall QoL, while ESMS question 38 ("I practice what to do during a seizure with my family and friends") was a negative predictor for the overall QoL. These differences could explain the null association observed between overall QoL and the ESMS information management subdomain, and

highlights the importance of an in-depth factor analysis of subjective questionnaires for tailoring self-management programs.

Lastly, we evaluated depression (PHQ-9) given the abundance of literature indicating that psychiatric illnesses contribute largely to the QoL for persons with epilepsy [3, 30–34]. Our findings were consistent with past reports and demonstrated a strong correlation between depression and the QOLIE-31. Akin to Tracy et al., we were able to infer that the PHQ-9 and the QOLIE-31 were either assessing similar subjective patient characteristics or that depression was a strong determinant for QoL in persons with epilepsy [35]. These findings indicate that mood state should be properly controlled in persons with epilepsy, and elucidate the need for quality of life measures that account for variations in mood state.

There are several limitations to this study. First, all information for QoL, self-management practices and depression severity were self-reported, as there is currently no established method for objectively assessing QoL and epilepsy self-management in persons with epilepsy. Our data is, therefore, subject to recall and social desirability biases. Generalizability was limited by our restricted sample (n =100), which was predominantly women with epilepsy in the Northeastern United States. Our sample population also had an underrepresentation of racial and ethnic minorities. Further, while the instruments utilized were previously validated, they are not comprehensive of all areas for assessing QoL and self-management.

Future research should examine the impact that demographic, clinical, and psychosocial factors have on the utilization of self-management skills. A deeper evaluation of the relationships between depression and QoL is also warranted. These characteristic differences may reflect the varied implementation of self-management practices, and should be considered in self-management programs as social determinants of health for persons with epilepsy. Subsequent prospective studies should also evaluate the efficacy of interventions that emphasize the most salient self-management methods to improve QoL.

Findings in our study may be useful in clinical practice, as we demonstrate the complex interactions between self-management practices and quality of life. Our study augments past reports on the close relationship between self-management, quality of life, and depression, by identifying specific self-management practices that have the strongest influence on quality of life [2, 17, 36, 37]. These findings emphasize the potential benefit of targeting specific self-management practices in epilepsy self-management programs to maximize improvements in quality of life.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgements

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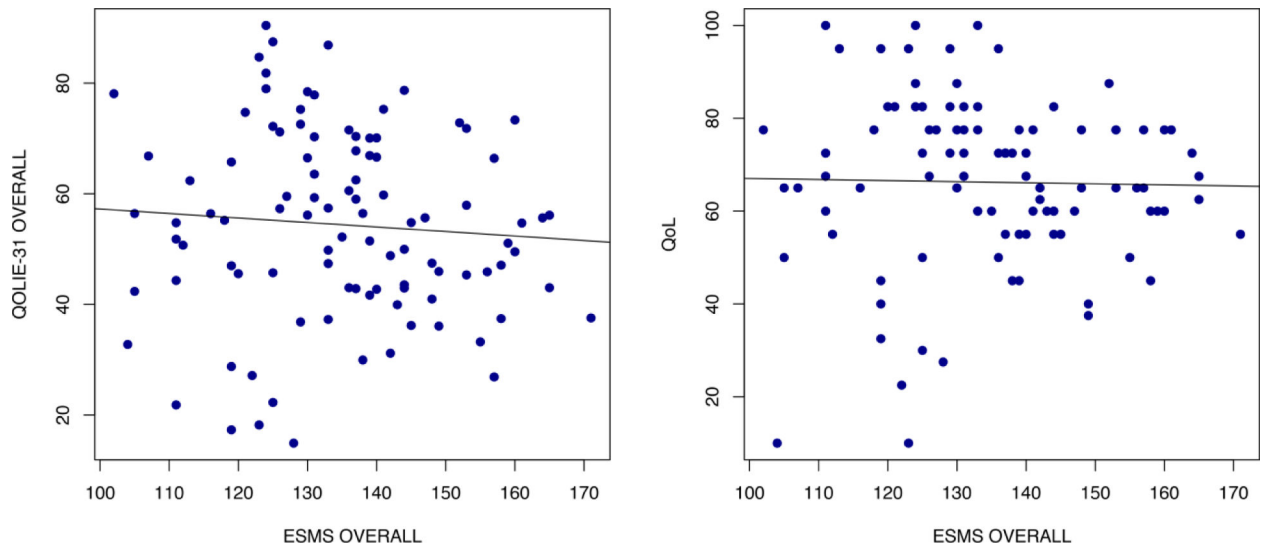
Fig.1.

Correlation between overall quality of life and overall epilepsy self-management ratings. Both the overall QOLIE-31 score (p = 0.26) and the single item QoL score (p = 0.19) demonstrated no significant correlations with ESMS scores (Spearman's correlation coefficient). According to Spearman's correlation coefficient, p < 0.05 was considered significant.

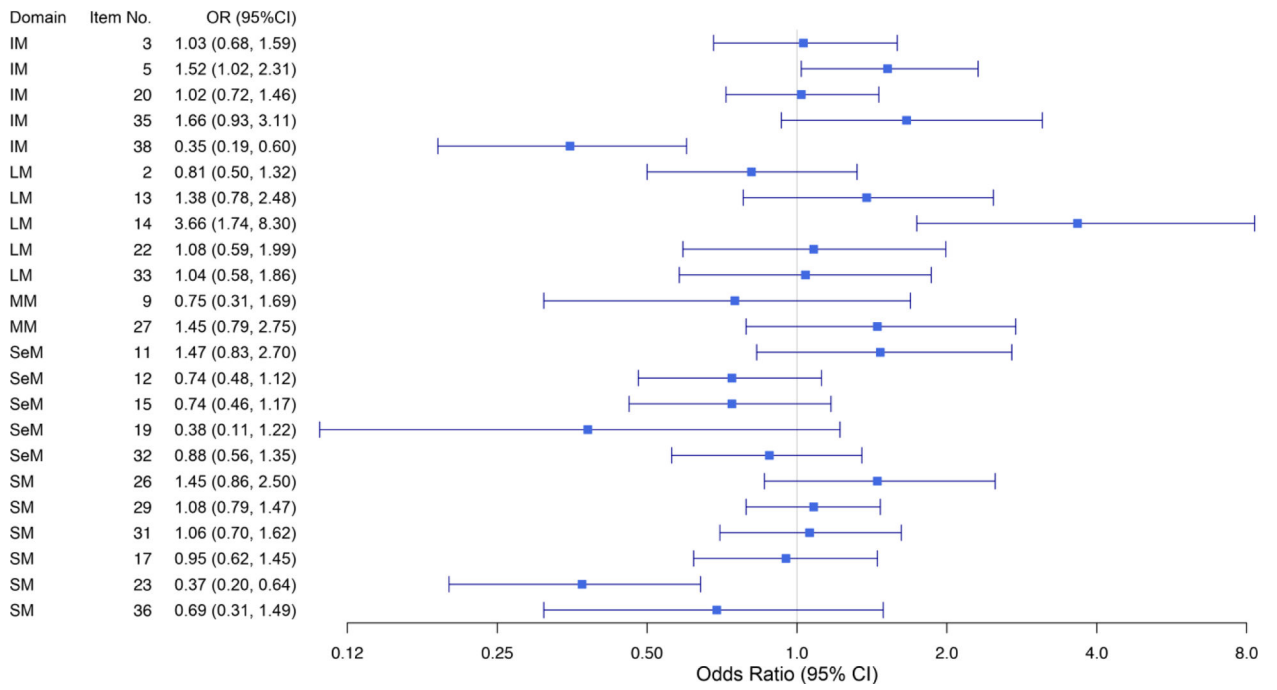| Domain	Item No.	OR (95%CI)
IM	3	1.03 (0.68, 1.59)
IM	5	1.52 (1.02, 2.31)
IM	20	1.02 (0.72, 1.46)
IM	35	1.66 (0.93, 3.11)
IM	38	0.35 (0.19, 0.60)
LM	2	0.81 (0.50, 1.32)
LM	13	1.38 (0.78, 2.48)
LM	14	3.66 (1.74, 8.30)
LM	22	1.08 (0.59, 1.99)
LM	33	1.04 (0.58, 1.86)
MM	9	0.75 (0.31, 1.69)
MM	27	1.45 (0.79, 2.75)
SeM	11	1.47 (0.83, 2.70)
SeM	12	0.74 (0.48, 1.12)
SeM	15	0.74 (0.46, 1.17)
SeM	19	0.38 (0.11, 1.22)
SeM	32	0.88 (0.56, 1.35)
SM	26	1.45 (0.86, 2.50)
SM	29	1.08 (0.79, 1.47)
SM	31	1.06 (0.70, 1.62)
SM	17	0.95 (0.62, 1.45)
SM	23	0.37 (0.20, 0.64)
SM	36	0.69 (0.31, 1.49)

Fig.2.

Assessment of individual ESMS questions with regard to overall quality of life. The ordered logit model revealed ESMS questions 5, 14, 23, and 38 were significant predictors of the overall quality of life.

Fig.3.

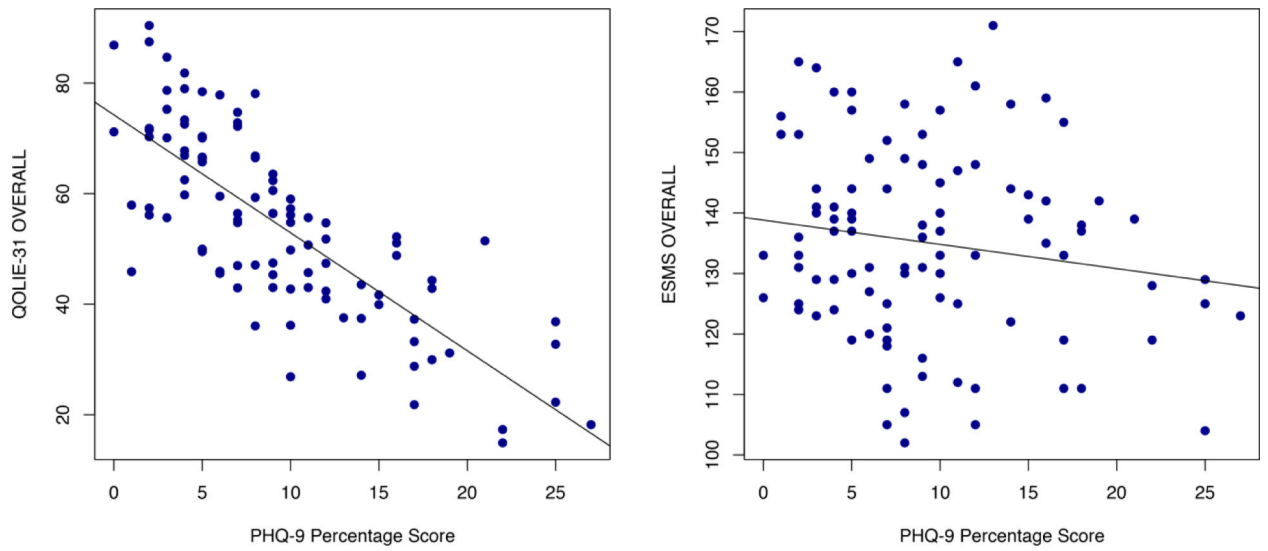PHQ-9 comparison with QOLIE-31 and ESMS overall scores. There was a strong negative correlation between the QOLIE-31 overall score and the PHQ-9 overall score ($p < 0.001$), but no significant correlation between the ESMS overall score and the PHQ-9 overall score ($p = 0.28$) (Spearman's correlation coefficient). According to Spearman's correlation coefficient, $p < 0.01$ was considered significant.

Table 1

Demographic and clinical characteristics of all patients completing the study.

Characteristics	Overall (n = 100)
Age (y)	
Mean (SD)	46.7(11.10)
Gender	
Male	36 (36.0%)
Female	64 (64.0%)
Income	
Less than 24,999	24 (24.0%)
25,000–49,999	22 (22.0%)
50,000+	42 (42.0%)
Missing	12 (12.0%)
Relationship Status	
Married	56 (56.0%)
Unmarried	40 (40.0%
Missing	4 (4.0%)
Education	
No Degree	5 (5.0%)
High School Graduate	59 (59.0%)
College Graduate	34 (34.0%)
Missing	2 (2.0%)
Seizure Control[a]	
Controlled Epilepsy	65 (65.0%)
Uncontrolled Epilepsy	35 (35.0%)
QOLIE-31 Overall Score[b]	
Mean (SD)	54.4(17.01)
ESMS-38 Overall Score[c]	
Mean (SD)	71.1 (8.23)
PHQ-9 Total Score[d]	
Mean (SD)	9.31 (6.19)

[a] Controlled epilepsy refers to a patient that has not had a seizure in the past 30 days.

[b] The QOLIE-31 scores range from 0 to 100, with higher scores reflecting a better quality of life.

[c] The ESMS scores range from 38 to 190, with higher scores reflecting an increased utilization of epilepsy self-management techniques.

[d] Patient Health Questionnaire-9 total scores range from 0 to 27, with higher scores indicating an increased severity of depressive symptoms.

Table 2

Multiple linear regression analysis for QOLIE-31 overall scores and ESMS subscale domains

	β	Std. Error	t-value	p-Value
ESMS Medication Management	7.61	4.20	1.81	0.073
ESMS Safety Management	−6.66	2.39	−2.79	<0.01*
ESMS Lifestyle Management	7.29	2.54	2.87	<0.01*
ESMS Information Management	−1.60	2.09	−0.764	0.45
ESMS Seizure Management	−2.57	3.30	−0.781	0.44

A p-value of less than 0.01 was considered significant with Bonferroni MHC correction.

*β:*Beta regression coefficients

Table 3

Ordered logisitic regression for QOLIE-31 overall scores and ESMS individual questions.

Domain	Item No.	Question	Odds Ratio	95%CI	p-Value
IM	3	I call my doctor when I think I am having side effects from my seizure medication	1.03	(0.68, 1.59)	0.89
IM	5	I keep a record of the types of seizures I have	1.52	(1.02, 2.31)	0.04*
IM	20	I wear or carry information stating that I have epilepsy	1.02	(0.72, 1.46)	0.90
IM	35	I talk with other people who have epilepsy	1.66	(0.93,3.11)	0.10
IM	38	I practice what to do during a seizure with my family and friends	0.35	(0.19,0.60)	<0.01*
LM	2	I do things such as relaxation, guided imagery, and self hypnosis to manage stress	0.81	(0.50, 1.32)	0.40
LM	13	I make sure I get enough sleep	1.38	(0.78, 2.48)	0.27
LM	14	I do things that I enjoy to help manage stress	3.66	(1.74,8.30)	<0.01*
LM	22	I get enough exercise	1.08	(0.59, 1.99)	0.81
LM	33	I eat regular meals	1.04	(0.58, 1.86)	0.88
MM	9	I take my seizure medication the way my doctor orders it	0.75	(0.31, 1.69)	0.51
MM	27	I plan ahead and have my seizure medication refilled before I run out	1.45	(0.79, 2.75)	0.24
SeM	11	If I am going away from home, I take my seizure medication with me	1.47	(0.83, 2.70)	0.20
SeM	12	I call my doctor if I am having more seizures than usual	0.74	(0.48, 1.12)	0.17
SeM	15	I have a way to remind myself to take my seizure medication	0.74	(0.46, 1.17)	0.21
SeM	19	When the doctor orders blood tests, I have them done	0.38	(0.11, 1.22)	0.11
SeM	32	I stay away from things that make me have seizures	0.88	(0.56, 1.35)	0.57
SM	26	I take showers instead of baths	1.45	(0.86, 2.50)	0.17
SM	29	I keep the temperature of the water in my home low enough so I do not get burned	1.08	(0.79, 1.47)	0.65
SM	31	I check with my doctor before taking other medicines	1.06	(0.70, 1.62)	0.79
SM[1]	17	I would go swimming alone	0.95	(0.62, 1.45)	0.82
SM[1]	23	I use power tools such as electric saws, electric hedge trimmers, or electric knives without an automatic shutoff	0.37	(0.20, 0.64)	0.01*
SM[1]	36	I drink a lot of alcoholic beverages such as beer, wine, and whiskey	0.69	(0.31, 1.49)	0.35

[1] Reverse coded items.