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Reduction of the Adult Epilepsy Self-Management Measure Instrument (AESMMI)

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Abstract

Managing one's own symptoms, medications, treatments, lifestyle, psychological and social aspects of chronic disease is known as self-management. The Institute of Medicine has identified three categories of epilepsy self-management, including medication management, behavior management, and emotional support. Overall, there has been limited research of interventions measuring epilepsy self-management behaviors. The present study aims to develop an abbreviated version of the full, previously published, Adult Epilepsy Self-Management Measurement Instrument (AESMMI) using confirmatory factor analysis. Data come from a cross-sectional survey of people with epilepsy. The sample includes adults with epilepsy (n=422), who reported that a clinician diagnosed them with epilepsy or a seizure disorder. We ran confirmatory factor analyses in testing the abbreviated scale. The scale was reduced using a theory-driven data-informed approach. The full AESMMI length was reduced by 40% (from 65 to 38 items) with an overall internal consistency of 0.912. The abbreviated AESMMI retained the 11 subdomains, with Cronbach's alphas from 0.535 to 0.878. This reduced item scale can be useful for assessing self-management behaviors for people with epilepsy or measuring outcomes in self-management research.

Keywords

epilepsy; self-management; behaviors; adults

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Conflict of Interest
We wish to confirm that there are no known conflicts of interest associated with this publication.

1.0 INTRODUCTION

Individuals with chronic illness who actively manage their symptoms, medications, treatments, lifestyle, psychological and social aspects are performing what is known as self-management [1]. For persons with epilepsy (PWE), self-management specifically includes medication adherence, learning more about their seizures and diagnosis, keeping a seizure diary, or tracking seizures, understanding and avoiding seizure triggers, and reducing stressors that may induce a seizure [2]. The Institute of Medicine's critical goal of epilepsy education identifies three categories of epilepsy self-management, including medication management, behavior changes to help manage epilepsy, and emotional support for dealing with a chronic condition [3]. Epilepsy self-management (eSM) activities have been reported to improve overall quality of life (QoL) by decreasing seizure frequency, reducing health care costs, promoting seizure control, and increasing positive health and social outcomes [4].

Epilepsy self-management activities have been integrated into programs to address various concerns in a PWE's life, including depression and anxiety, memory problems, and social support [5–7]. These programs offer skill-building techniques that have been reported to improve PWE's self-efficacy, medication adherence, mood, memory, and QoL [5–10]. Many of these self-management programs utilize facilitators, co-facilitators, and coaches in either a group setting or through one-on-one sessions to address specific concerns faced by PWE. Several systematic review of adult epilepsy self-management programs have found that they can improve knowledge and behavioral outcomes [11–13], problem solving [12], and symptom monitoring [12], and reduce seizure frequency [11–12]. A review of psychosocial interventions for people with epilepsy found improvements in quality of life [13]. Overall, these reviews have found low to moderate effects of these programs [11–12]. The effectiveness of eSM programs are continuing to show that self-management is an integral part of a PWE's overall care and quality of life [14].

The assessment of self-management also has clinical and practical relevance. Self-management is associated with improvements in QoL across many diseases, as well as epilepsy [10]. One of the first measures of self-management was the Epilepsy Self-Management Scale (ESMS), a 38-item scale that assesses frequency of use of epilepsy self-management practices with a higher score meaning more frequent use of self-management strategies [15]. Items were created and categorized into three areas: a) medication-related, b) safety-related, and c) general lifestyle management [16]. Clinicians may want to assess how patients are doing, managing their daily lives with epilepsy, across various domains. Frequency of conduct of self-management behaviors can inform patient education and referral to services or resources, depending on the scores on different eSM domains. In addition, researchers can employ a self-management scale to assess the impact of eSM programs. Therefore, a short instrument that measures self-management behaviors could make a great contribution to the literature.

The Adult Epilepsy Self-Management Measurement Instrument (AESMMI) was developed as a comprehensive scale covering the most relevant domains of eSM [17]. A Workgroup consisting of experts in public health, clinician and statistics working in epilepsy, engaged in a multiphase process in the creation of the scale including: 1) item generation: an iterative review process, evaluating scales or items based on the working definition of self-management, 2) content validity with a broader panel of epilepsy experts, and 3) testing of the scale [17]. The original scale had 113 items with 10 exploratory domains that were reduced by exploratory factor analyses to 65 items, covering 11 domains [18]. The AESMMI has been used in the evaluation of several self-management programs [19–23].

The present study aims to develop an abbreviated version of the AESMMI using confirmatory factor analysis. Reducing the scale's length has the potential to increase its use in clinical practice and research to measure eSM behaviors of PWE.

METHODS

2.1. Sample

This study is a descriptive analysis of a cross-sectional survey of PWE. The AESMMI sample included adults with epilepsy (n=422) who reported that a clinician diagnosed them with epilepsy or a seizure disorder [17, 18]. Other inclusion criteria for both surveys were participants being at least three months post-diagnosis of epilepsy, residents of the United States, and able to read and write in English.

2.2 Procedures

For this AESMMI study, recruitment occurred in epilepsy clinics in around the U.S. through epilepsy clinics and community outreach and online. The online channels included social media platforms (e.g., Facebook, Instagram, Twitter) and websites (e.g., ResearchMatch, the Epilepsy Foundation of America and their affiliates' web pages). The study was approved by the Emory University Institutional Review Board.

2.3 Measures

Demographics.—Participants responded to questions about their gender, race/ethnicity, income, educational level, employment status and health insurance status.

Epilepsy and medical history.—Participants reported on age of epilepsy diagnosis, type of epilepsy and treatment. Seizure frequency (number of seizures in the past 3 and 12 months) was collected, along with if participants had seen a neurologist in the past year [24]. Quality of life was measured by 10-items assessing the quality of their life during the past 4 weeks on a scale of 1 = very well to 6 = very bad [25].

Self-management behaviors.—The AESMMI consists of items that represent 11 domains of epilepsy self-management including: Healthcare Communication, Treatment, Coping, Social Support, Seizure Tracking, Wellness, Seizure Response, Safety, Medication Adherence, Stress Management, and Proactivity. We developed the scale employing a multiple phase process [17]. The resulting domains were identified through an exploratory factor analysis of the original 113 items [18]. Participants rated the frequency of performing the behaviors related to managing their epilepsy in the past 3 months. Responses were rated on a 5-point Likert scale (i.e., 1=none to 5= all of the time; 1=never to 5=always; 1=not at all to 5=completely true) or "Not applicable" (i.e., missing value). Some behavioral items that were negatively worded behaviors were reverse coded to reflect their frequency. Higher scores on a domain or scale indicated more frequent conduct of the self-management behaviors.

2.4 Data Collection

A total of 422 participants completed online or paper surveys from spring 2017 to fall 2018. Online participants entered the survey data directly into the REDCap Server, a HIPAA-compliant online survey system. Research staff manually entered paper surveys (n=12) into REDCap.

2.5 Analyses

All data were imported into SAS version 9.4 software for data analysis [26]. Descriptive statistics (means, ranges, minimum/maximum scores) were calculated for each item of the 65-item full AESMMI. Then the full scale was reduced using a theory-driven data-informed approach [22]. We retained the factor structure from the full scale. The experts on the team made decisions on excluding items based on low factor loadings as well as differences in behaviors (i.e., removing duplicative items). Additionally, we aimed to have at least three but preferable four or more items per domain remain. The reduced set of items was used for testing the psychometric properties of the shorten instrument.

Descriptive statistics (means, ranges, minimum/maximum scores) were calculated for each subdomain/scale and the overall reduced AESMMI instrument (AESMMI-38). In addition, internal consistency reliability (Cronbach’s alpha) was calculated for the overall AESMMI-38 as well as for the sub-scales. Confirmatory factor analysis was conducted using the same factor structure as for the full scale with the reduced set of items. All scale items were modeled as ordinal and, thus, the WLSMV estimator was used; all data were used in the modeling. Model fit indices used were chi-square ($p<.0001$), RMSEA (0.41(95% CI = [0.37, 0.45]), CFI (0.959), and TLI (0.953) [27, 28]. Confirmatory factor analysis (CFA) was conducted using Mplus 8.4; all other analyses were conducted in SAS version 9.4 [26].

3.0 RESULTS

3.1 Description of Participants

Participants responded to questions about their gender, race/ethnicity, income, educational level, employment status, health care coverage, and source of health insurance. A total of 510 participants completed the online/paper survey; however, we removed 88 online surveys for being duplicate entries (n = 46) or on suspicion of fraudulent participation (n = 42).

3.1.1 Demographics.—Generally, participants (N=422) were female (72.6%) and their ages ranged from 18 to 89 years with a mean age of 41.5 years (SD=13.1) (Table 1). They primarily self-identified as White (82.9%), with fewer identifying as Black/African American (7.6%) or Other race (9.5%). They were mostly from suburban (54.6%) settings, with smaller proportions from urban (23.6%) or rural settings (21.8%). Almost one-fifth had a high school education (19.1%), while more had some college (37.7%), or had obtained a college or higher degree (43.2%). Most participants were employed full-time (35.3%), or unable to work due to disability (32.0%), while a small percentage were currently not working (13.2%); most had annual income below $50,000 (58.1%). Many participants were insured through Medicaid (13.0%) or Medicare (17.2%).

The average age of participants diagnosed with epilepsy was 20.6 (15.0). 37.2% participants reported having seizures in the past 30 days and 77% in the last year. The most common treatments were anti-seizure medication (95.5%), device (10.2%), or other (7.8%). About half of the patients experienced tonic-clonic seizures (51.0%), followed by complex partial (44.6%), and simple partial (34.1%) (Table 2).

3.1.2 Self-management domains—Mean and Cronbach's alpha scores of each self-management domain are found in Table 3. Generally, participants reported conducting self-management behaviors in these domains more frequently: treatment (M=4.70), medication adherence (M=4.57), proactivity (M=4.15), seizure tracking (3.98), healthcare communications (M=3.76), coping (M-3.63), and social support (M=3.59). They performed self-management behaviors related to domains of stress management (M=2.56) and seizure response (M=3.00) least often. Cronbach's alpha for the overall reduced scale (AESMMI-38) was very good at 0.912. The subscales' alphas ranged from 0.535 to 0.878. Most subscales had adequate (>0.7) to good (>0.8) Cronbach's alpha. However, four sub-scales with each three items only (Seizure Response, Safety, Stress Management, & Proactivity) had Cronbach's alphas indicating less than adequate internal consistency.

3.1.3 Confirmatory Factor Analysis Results—The model fit for the proposed reduced scale was good for all fit indices but chi-square, (which is sensitive to large sample sizes, i.e., n>200), indicating that the data fit the model well. Thus, no modifications were made. Standardized factor loadings ranged from .95 to .47 with a mean loading of .75 (SD=.13). Full factor loadings are presented in Table 4. Factor correlations ranged from .025 to .81, with the strongest correlation between treatment and adherence (see supplemental table). Most factor correlations were not statistically significant. In addition, there was a significant correlation of the AESMMI-38 with overall QoL (r=0.272, p<.0001).

DISCUSSION

4.1 General Findings

This analysis developed the reduced, AESMMI-38 scale. The creation of a shorter instrument for measuring epilepsy self-management has several valuable attributes. The new, shorter scale possesses robust dimensional properties and high reliability as the longer AESMMI-65). It also encompasses the same 11 domains as the AESMMI-65 but has the important advantage of being shorter for greater ease and lower respondent burden in patient assessment and research.\

Five domains (stress management, proactivity, seizure response, seizure tracking and wellness) had all 3 items retained. Two domains of safety and medication adherence had 1 item dropped. The four domains of health communications, treatment, coping and social support had 3–7 items dropped based on lower item loadings or concept overlap with other items based on discussions with our team of behavioral scientists and neurologists. For example, for the health communications domain, items were dropped that were related to talking to healthcare providers regarding seizure medications and side effects that overlapped with other items (e.g., information seeking about new treatments) or had a low factor loading. For treatment domain, 7 items were dropped; many were related to the concepts of medication taking or refilling AEDs that were retained in 2 other items related to those concepts.

This research contributes to the existing literature on epilepsy self-management in several important ways. First, the AESMMI-65 length is reduced by more than 40 percent (from 65 to 38 items), while its psychometric properties are improved. As discussed earlier, there is growing interest designing self-management programs and evaluating self-management, and having a shorter scale facilitates its measurement and reduces respondent burden. The shorter AESMMI-38 in this paper will provide researchers with a measure of epilepsy self-management that is faster to administer and score, yet reliable and valid. Second, we showed that the shorter AESMMI-38 is correlated with QoL, indicating that it has construct validity and potential value for studies of epilepsy QoL. This demonstrates concurrent validity of the instrument; future research could examine associations of the AESMMI with other known assessments for people with epilepsy to ascertain if it is performing in the right direction. Finally, we assessed the dimensionality of the AESMMI-38, and re-examined the 11 subscale dimensions found in the AESMMI-65. They represent key self-management behaviors that PWE should perform on a regular basis and that contribute to overall self-management of epilepsy. Previous literature has reported on fewer self-management topics for PWE [3].

Recent reviews of psychosocial or self-management programs for epilepsy report that varied outcomes have been assessed among adults and youth with epilepsy [12–3, 29]. There has been some initial use of the AESSMI-65 with self-management programs [14], but the development of a shorter version may increase its adoption for research and in clinical practice as patient self-assessment. The new 38-item scale should be used in its entirety since the total scale has high reliability for self-management research and could be with relative ease in relation to its longer versions (AESMMI-113, 65). Future research can confirm the reliability of the scale or sub-domains with other population with people with epilepsy.

4.2 Limitations

This study presents the refinement and reduction of a self-management scale for PWE. It employs large sample of PWE; however, the sample is still overwhelming White. However, the study has several limitations. We employed multiple recruitment methods to recruit PWE, but the final sample may not be representative of adults with epilepsy; it likely over-represents whites and women with epilepsy. Online recruitment may yield less diverse populations of people with epilepsy and fraudulent cases that may require a process for review. We used multiple methods to remove potential fraud survey completion (e.g., not describing their seizure in own words, cases taken within minutes of each other in a row) [17]. In addition, because we recruited from Epilepsy Foundation affiliates and clinics, our sample may also over-represent people with access to epilepsy-related resources. In addition, participants self-reported their epilepsy self-management behaviors and seizure history, which may be influenced by bias or problems with recall. In addition, since some AESMMI-38 subdomains had lower reliability, it is advised that health professionals use the entire scale for research purposes. Finally, this scale has only been tested among PWE in the U.S. The present research was designed to provide increasing conceptual and empirical clarification of what different self-management domains and tasks represent, but we do not know the cultural appropriateness of the items and subdimensions of the scale. Further research is needed in global settings. This will enable researchers to determine whether the scale and items can be generalized to other cultures.

4.3 Conclusions

Epilepsy self-management is important to understand and address in patient-centered care and research. This study was conducted to reduce the AESMMI65 and examine the psychometric properties of the reduced AESMMI-38. Results suggest that the AESMMI-38 has high internal consistency and the same factor structure as the longer instrument. Having a shorter, reliable instrument with which to measure ESM may assist in clinical care and patient self-care and facilitate research to improve outcomes for PWE. In addition, this reduced scale can be utilized in research to assess ESM cross-sectionally or over time as a program outcome.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.

Demographic Characteristics of Participants (n=422)

Characteristic	n (%)
Gender, n=419	
Male	115 (27.5%)
Female	304 (72.6%)
Age, n=416	
Mean (SD)	41.5 (13.1)
Range	18–89
Race, n=422	
White	350 (82.9%)
Black	32 (7.6%)
Other	40 (9.5%)
Ethnicity, n=410	
Hispanic/LatinX	28 (6.8%)
Residence location, n=407	
Urban	96 (23.6%)
Suburban	222 (54.6%)
Rural	89 (21.9%)
Education, n=418	
Grade 12 or GED	80 (19.1%)
Some college	158 (37.7%)
College or higher	181 (43.2%)
Employment[1], n=422	
Full-time employee	149 (35.3%)
Part-time employee	60 (14.2%)
Currently not working	55 (13.0%)
Homemaker	34 (8.1%)
Unable to work/disability	135 (32.0%)
Retired	17 (4.0%)
Volunteer	36 (8.5%)
Prefer not to answer	5 (1.2%)
Annual Income, n=365	
Less than $20,000	109 (29.9%)
$20,000-$49,999	103 (28.2%)
$50,000 and above	153 (41.9%)
Insurance, n=414	
Insured	
Medicaid	54 (13.0%)
Medicare	71 (17.2%)
Insurance through work	120 (29.0%)
Insurance through spouse	110 (26.6%)

Characteristic	n (%)
Other private insurance	13 (3.1%)
Military Plan	3 (0.7%)
Insured but not sure how	10 (2.4%)
Not insured	33 (8.0%)
Veteran, n=420	12 (2.9%)

[1] Respondents could check all that apply

Table 2.

Epilepsy History of Participants (n=422)

Variable	n (%)
Age of diagnosis, years, n=405	
Mean (SD)	20.6 (15.0)
Range	0.25–64
Had a Seizure in Last 30 days, n=113	42 (37.2%)
Number of Seizures in Last 30 days M (SD), n=40	2 (1.8)
Range	1–10
Had a Seizure in Last 12 months, n=422	325 (77.0%)
Number of Seizures in Last 12 months M (SD), n=327	65.0 (188.3)
Range	1–1800
Type of Seizure[1], n=422	
Simple partial	144 (34.1%)
Complex partial	188 (44.6%)
Partial with progression to secondarily generalized	80 (19.0%)
Absence (petit mal)	137 (32.5%)
Tonic-clonic (grand mal, convulsive	215 (51.0%)
Atonic (drop attacks)	27 (6.4%)
Other primarily generalized type (myoclonic, clonic, tonic)	60 (14.22%)
I don’t know	23 (5.5%)
Prefer not to answer	5 (1.2%)
Current Treatment[1], n=422	
Antiseizure medications	403 (95.5)
Dietary treatment	15 (3.6)
Device	43 (10.2)
Epilepsy surgery	11 (2.6)
None	12 (2.8)
Other	33 (7.8)

[1] Respondents could check all that apply

Table 3.

Means and Reliability of Domains and Overall AESMMI-38

	N	Mean	Cronbach's Alpha
Health Communication	5	3.76	0.763
Treatment	4	4.70	0.801
Coping	4	3.63	0.821
Social Support	4	3.59	0.728
Seizure Tracking	3	3.98	0.878
Wellness	3	3.50	0.757
Seizure Response	3	3.00	0.676
Safety	3	3.17	0.627
Adherence	3	4.57	0.724
Stress Management	3	2.56	0.637
Proactivity	3	4.15	0.535
Overall AESMMI-38 Scale			0.912

Table 4.

Domains, Items, and Standardized Factor Loadings of the AESSMI-38 (N=422)

Factor and item	Factor loading
Health Communication	
I talk to my health care provider about my emotions.	0.704
I tell my health care provider when I think I am having side-effects from my seizure medicine.	0.751
I talk about how I take my seizure medicine with my health care provider.	0.739
I set treatment goals with my healthcare provider on how to manage my epilepsy/seizures.	0.755
I call my health care provider if I am having more or different seizures than usual	0.668
Treatment	
I plan ahead so that I do not run out of my seizure medicine.	0.825
Before my seizure medicine runs out, I get it refilled.	0.904
I keep healthcare provider or clinic appointments.	0.736
I take my seizure medicine as prescribed even on holidays, birthdays, vacations and other special occasions.	0.842
Coping	
I do things that I enjoy with my family and friends despite my epilepsy/seizures	0.468
I have ways to change my negative thinking.	0.887
I have healthy ways to solve problems related to my epilepsy/seizures	0.832
I have healthy ways to cope when I am feeling sad or down.	0.923
Social Support	
I get the help I need with problems at home, work, school, or other community settings.	0.720
I have ways to get help if I have a seizure.	0.671
I talk with someone about my epilepsy/seizures when I need to	0.757
I talk to my family or my friends about their worries about my epilepsy/seizures.	0.646
Seizure Tracking	
I keep track of when my seizures occur.	0.878
I keep track of how often I have seizures.	0.946
I keep a record of the types of seizures I have.	0.907
Wellness	
I do things to maintain a healthy weight.	0.821

Factor and item	Factor loading
I eat a healthy diet almost every day.	0.793
I exercise at least half an hour most days of the week.	0.683
Seizure Response	
I teach my family and friends what to do during a seizure.	0.864
I teach others not to put something in my mouth when I have a seizure.	0.836
I have seizure drills with my family and friends so that they know what to do when I have a seizure.	0.620
Safety	
I use safety precautions when I cook.	0.591
I use safety precautions if I take a shower.	0.501
I take steps to stay safe when I have a seizure.	0.891
Adherence	
I take my seizure medicine the same way every day.	
I take my seizure medicine at about the same time each day.	0.857
I take my seizure medicine the way my healthcare provider prescribes it.	0.816
	0.821
Stress Management	
I do things such as relaxation or breathing exercises to keep myself from having seizures or to stop them.	0.582
I use/I have used non-medical techniques in addition to my treatment to keep myself from having seizures	0.556
I use some techniques (such as relaxation, guided imagery, and self-hypnosis) to manage stress.	0.857
Proactivity	
I check with my doctor, nurse or pharmacist before taking other medicines.	0.599
I bring an up-to-date list of all my medicine to healthcare provider’s appointments.	0.616
I avoid situations or things that might cause seizures.	0.606

Note: All factor loadings are standardized and all p-values < .0001