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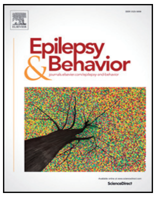

Clinical Research

Self-management skills and behaviors, self-efficacy, and quality of life in people with epilepsy from underserved populations

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ABSTRACT

Purpose: People with epilepsy (PWE) from underserved populations face significant barriers to epilepsy management and therefore may lack knowledge about epilepsy and self-management (SM) of epilepsy. This paper evaluates SM practices, self-efficacy, outcome expectancy, quality of life, and personal impact of epilepsy in PWE from underserved populations as compared with all PWE.

Methods: Recruitment for the Managing Epilepsy Well (MEW) Network PAUSE to Learn Your Epilepsy study occurred from October 2015 to March 2019. Participants were assessed at baseline; after SM education intervention; and 6-, 9-, and 15-month postbaseline assessment. Baseline data from 112 PWE were analyzed for this report.

Results: Study population was diverse: 63% were women, 47.3% were non-Hispanic black, 24.1% were Hispanic, and 57.4% had public healthcare coverage. Participants on average had epilepsy for 14 years, and 49.1% reported at least one seizure within the past month, but only 27% reported having used a seizure diary or calendar for seizure tracking. Self-management practices & behaviors were significantly lower among PWE from underserved populations than all PWE, though self-efficacy among PWE from underserved populations was significantly higher.

Conclusion: This study identifies the unique epilepsy SM needs of PWE from underserved populations. We discuss the need for a personalized approach for developing SM skills and behaviors among these PWE.

1. Introduction

Epilepsy is a common and complex neurologic disorder affecting 1.1% of all adults, approximately 3.4 million in the U.S. [1]. Annual epilepsy specific costs ranged from $1022 to $19,749 per person (in 2013 dollars); 56% of these costs come from outpatient treatment and antiseizure drugs (ASDs) [2]. Epilepsy presents many challenges for those affected by the disease and their healthcare providers. About one-third of all people with epilepsy (PWE) have seizures that are resistant to treatment, and a significant percentage have developmental, cognitive, and psychiatric comorbidities. This patient population represents a large portion of epilepsy specialty clinics and is by far the most difficult to manage.

Two national conferences on public health and epilepsy, Living Well with Epilepsy (LWE) I in 1997 and LWE II in 2003, identified a gap in epilepsy treatment and gave recommendations for research into the need for epilepsy self-management (SM). Self-management for epilepsy is defined as "the sum total of steps a person takes to control seizures and to control the effects of having a seizure disorder" [3] and includes the information and resources PWE need to develop skills and behaviors that enable them to participate actively in patient-centered care. Information offered through a SM education system provides a good foundation for self-efficacy, a social cognitive construct defined by Bandura as "people's beliefs about their capabilities to produce designated levels of performance" and "determine[s] how people feel, think, motivate themselves, and behave" [4].

In practice, healthcare providers routinely educate and counsel patients on epilepsy and related health issues. However, during clinical encounters, providers spend time on medical management, focusing on ASDs, and may have insufficient time to fully address patient-specific epilepsy SM education [5]. Introducing and encouraging access to SM education can address these gaps in care, ultimately transferring "ownership" of care from provider to patient and facilitating shared decision-making [6,7]. The Centers for Disease Control and Prevention (CDC) translated LWE conferences recommendations into the development of the Managing Epilepsy Well Network (MEW) in 2007 [8]. A later 2012 Institute of Medicine (IOM) report, "Epilepsy across the Spectrum," emphasized the "development, evaluation, replication, and expanded use of self-management and educational programs" to

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improve health outcomes and quality of life for PWE [9]. “Epilepsy self-management extends beyond the health care system into the patient's home and community”, and ultimately empowers PWE to an active role for their health through improved communication, behaviors to manage seizures, and safety [10].

The current evidence-based epilepsy SM programs from MEW have shown success [11] Many studies focus on targeted subpopulations of PWE: the Home-Based Self-Management and Cognitive Training Changes lives (HOBSCOTCH) program improved quality of life among PWE with memory and attention complaints [12], Program to Encourage Active Rewarding Lives (PEARLS) reduced suicidal ideation and depressive symptoms among clinically depressed PWE [13], Targeted Self-Management for Epilepsy and Mental Illness (TIME) reduced depressive symptoms among PWE with severe mental illness [14], and Using Practice and Learning to Increase Favorable Thoughts (UPLIFT) reduced depressive episodes/symptoms and increased life satisfaction among PWE with mild-to-moderate depressive symptoms [15]. Other MEW studies work with all PWE; for example, Web Epilepsy, Awareness, Support, and Education (WebEase) was found to increase self-efficacy [16]. The Program of Active Consumer Engagement in Self-management in epilepsy (PACES) program improved SM behaviors and self-efficacy [17]. Self-Management Epilepsy Decision Support for Adult People with Epilepsy and Their providers (MINDSET) was found to assist PWE in identifying personalized goals and improving communication with healthcare providers [18]. The Self-Management for People with Epilepsy and a History of Negative Health Events (SMART) study reduced negative health events and improved mood, quality of life, and health functioning [19].

The ongoing PAUSE (**P**ersonalized internet **A**ssisted **U**nderserved **S**elf-management of **E**pilepsy) to Learn Your Epilepsy program addresses the need for broad patient-centered and patient-specific education interventions that encompass the needs of all PWE. It addresses varying types of seizures and comorbidities, as well as socioeconomic and cultural barriers. It was developed and implemented with the central goal of providing epilepsy SM education tailored to an individual's educational needs, including those from underserved populations. The overall objective of PAUSE, a MEW Network collaborating center, is to examine the effectiveness of personalized SM education on the development of SM practices, outcome expectancy, and self-efficacy to improve epilepsy outcomes, including the personal impact of epilepsy on life, quality of life, and epilepsy health measures.

Participants of PAUSE included those recruited from the Epilepsy Foundation of Greater Chicago (EFGC) and the University of Illinois Health and Hospital System (UIH) epilepsy specialty clinics in Chicago, Illinois. The UIH patient service area covers 24 of the 77 Chicago community areas. These community areas have higher rates of social and economic hardship with a large proportion of individuals who live below the federal poverty line. Many are uninsured and have limited access to healthcare, food, and housing security [20].

People with epilepsy from underserved populations are often hard to treat and hard to reach. This patient population includes those with uncontrolled epilepsy, having failed several ASDs, and are less likely to show significant improvement with additional drugs. In addition to the treatment-resistant nature of their epilepsy, these patients may also suffer from other comorbidities, including psychiatric illnesses that may impact their adherence and ultimately their response to therapy. In addition, PWE from underserved populations are difficult to reach because of their lack of access to social services and face greater barriers in epilepsy management including cost of care, lack of transportation, limited education and employment, lack of awareness of healthcare needs, and lack of internet access [21–23]. At times, they may lose their medical insurance and face challenges in reinstating it, may not have a functioning phone or stable living arrangement, or may be incarcerated. All of these impact both their adherence and response to treatment.

Even those who have access to medical care and SM information may have additional challenges: many may find the process overwhelming, may lack knowledge about their disease to find appropriate information, and may encounter inaccurate or misleading resources. There is lack of knowledge regarding personal epilepsy SM practices, outcome expectancy, and self-efficacy in this patient population. A greater understanding of these factors from underserved populations can inform providers on the resources and efforts needed for epilepsy SM education in this population, with the ultimate goal of providing optimal epilepsy care.

In this paper, we evaluated the SM skills & behaviors, outcome expectancy, and health outcomes of PAUSE participants recruited from epilepsy specialty clinics compared with similar measures from published reports. We also described PAUSE recruitment, SM, and epilepsy outcome measures, methods for education intervention, and baseline characteristics of participants.

2. Materials and methods

The PAUSE study was designed to develop and assess the effectiveness of a personalized SM education using mobile technology to improve the SM skills & behaviors, quality of life, personal impact of epilepsy, and health-related outcomes of PWE. Study protocol, including recruitment from the UIH subspecialty clinic and from the community via EFGC, for the PAUSE to Learn Your Epilepsy was approved by the University of Illinois at Chicago Institutional Review Board.

2.1. Theoretical model

The PAUSE SM education intervention is based on the collaborative care model where SM education needs are identified from shared inputs from the PWE and their healthcare provider. It is theorized that personalized SM education and resources, such as PAUSE, work via enhancing an individual's self-efficacy to improve symptom management, adhere to treatment regimens, make healthier lifestyle choices, and ultimately improve their quality of life [24,25]. Improvements in SM skills are associated with improvements in SM behaviors, which can increase the individual's sense of empowerment, promote positive adaptation to the chronic condition, and enhance overall quality of life [26]. The IOM Committee On The Public Health Dimensions Of The Epilepsies in IOM 2012 report envisioned that “access to relevant and usable knowledge for all individuals with epilepsy and their families that meets their individual needs and allows them to participate effectively in patient-centered care, to achieve optimal self-management of their epilepsy, and to attain the highest possible physical and emotional well-being” [9].

2.2. Study framework

The PAUSE study framework is shown in Fig. 1.

2.3. Study design

Fig. 2 shows PAUSE recruitment, intervention, and follow-up flow.

2.3.1. Recruitment

Study participants were recruited between October 2015 and March 2019 from the outpatient clinics at the UIH epilepsy specialty clinics and from the community via the EFGC following human subjects' research approval.

People with epilepsy recruited through UIH were screened for study eligibility by the epilepsy subspecialty providers (e.g., epileptologists, nurse, pharmacist) which included the following: 1) aged 18 years and older with diagnosed epilepsy, 2) speak and understand English, and 3) absence of any severe or unstable medical comorbidities that would cause harm or prevent participation. Those interested in participating were administered informed consent by PAUSE study staff. After informed consent was obtained, PAUSE study staff assessed inclusion

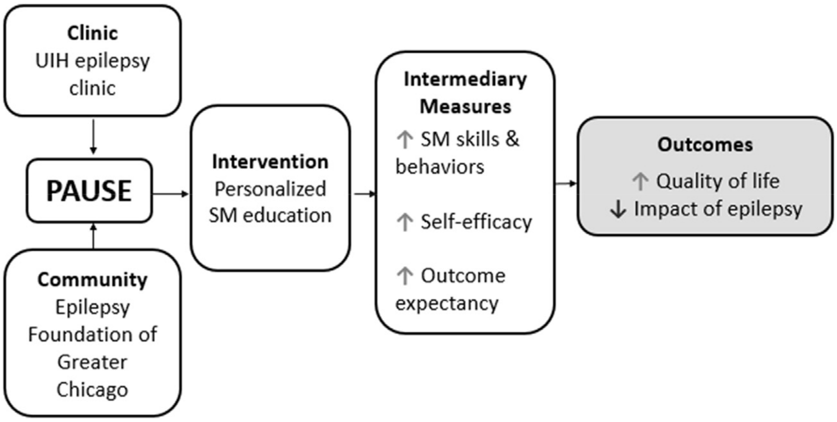

Fig. 1. PAUSE study framework.

criteria: 1) ability to read at a minimum of an eighth grade level as assessed by the Wide Range Achievement Test–4 Reading subtest (WRAT-4 Reading) [27], 2) access to a telephone, 3) had not undergone brain surgery for epilepsy in the past six months, and 4) no plan to undergo brain surgery for epilepsy during the course of the study. Study participants who did not meet the minimum reading criteria were given the opportunity to have an adult caregiver or family member assist with the SM education, provided the caregiver met the minimum reading criteria. All participants who met study inclusion criteria were enrolled. Participants completed all baseline study questionnaires, and the referring healthcare provider was asked to identify SM learning needs tailored to the PWE.

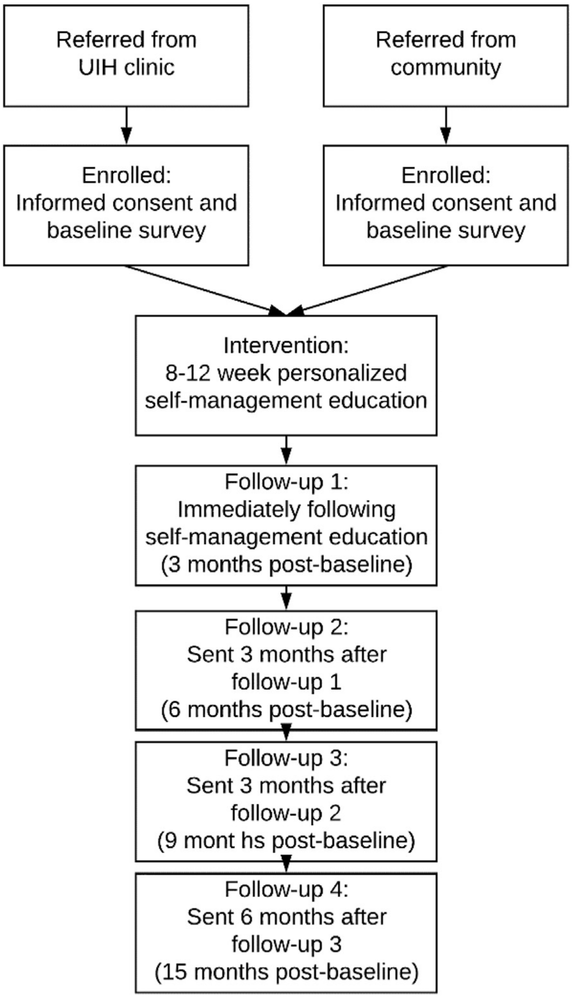

Fig. 2. PAUSE study flowchart.

People with epilepsy recruited through EFGC were screened for study eligibility and study inclusion criteria by EFGC case managers. Case managers also administered informed consent. All participants who met study inclusion criteria were enrolled. Participants completed all baseline study questionnaires, and case managers identified SM learning needs tailored to the PWE. All baseline assessments and case manager-identified SM learning needs were mailed to the PAUSE central office at UIC.

2.3.2. Intervention

An Android-based application to provide tailored SM education was developed for PAUSE. The app was housed on 4G internet-connected tablets. An individualized educational program was developed for each participant, based on SM education modules selected by inputs from both the PWE and their healthcare provider(s). Appropriate learning modules were then loaded onto each tablet. A kiosk-locking program was used to block access to all applications besides the PAUSE and video-conferencing tools, as well as allowed for remote tablet locking and location tracking.

For the duration of the 8–12-week education intervention, participants were instructed to progress through the learning modules at their own pace. Study participants were assisted via weekly one-on-one video calls with a PAUSE education facilitator. Video calls helped maintain participant engagement in the study, allowed education facilitators to answer any questions, and gave participants the opportunity to share their experiences about living with epilepsy.

Tablets were returned to the PAUSE central office and reprogramed and reused once participants completed the SM education intervention.

Self-management educational modules were assembled from publicly available content on the Epilepsy Foundation website, epilepsy.com, in consultation with the website's associate editor. Modules included the following: New diagnosis, Managing Seizures/Epilepsy (including seizure tracking, recognizing triggers, seizure response plans), Impact of Epilepsy (including seizure emergencies, physical and mental side effects, sleep), Managing Treatments (including medication adherence, epilepsy surgery, epilepsy devices), Staying Safe (including risks, seizure first aid, driving), Coping and Living with Epilepsy (including family life, employment, stress), and Specific Audiences (including specific information for women and seniors). An epilepsy healthcare provider, with input from PWE, selected appropriate modules for each participant based on the SM Learning Needs Checklist.

2.3.3. Follow-up

Follow-up questionnaires contain all intermediary and outcome measures. All follow-up measures were mailed to participants along with a prepaid, preaddressed return envelope. Participants were asked to complete these measures at each of the 4 follow-up time points. Median time to return each follow-up questionnaire was assessed.

2.4. Assessments and measures

2.4.1. Participant reading ability was assessed by WRAT-4 Reading [27]

The WRAT-4 Reading is an evaluation that assesses word recognition. Participants are asked to read aloud from a list of 55 words; those who are unable to correctly read at least 38 words have not met 8th grade reading level criteria.

2.4.2. Self-reported sociodemographic and background health data

At enrollment, participants completed sociodemographic and background health questionnaires. Sociodemographic information included age, sex, race/ethnicity, education level, employment status, personal/household income, household composition, and relationship status. The background health questionnaires included primary epilepsy healthcare provider, years treated at epilepsy clinic, age diagnosed with epilepsy, duration of seizures, seizure type, antiseizure medications, and epilepsy-related health status [number of seizures/hospitalizations/emergency department (ED) visits], time of last seizure, and seizure tracking/recording habits. At each follow-up time point, information about epilepsy-related health status was collected.

2.4.3. Self-reported symptoms of depression were assessed using the Patient Health Questionnaire (PHQ-9) [28]

The PHQ-9 is a 9-item measure. All items are scored on a 4-point scale from "not at all" (0) to "nearly every day" (3). A sample item is "Over the last 2 weeks, how often have you been bothered by feeling down, depressed, or hopeless?" For analysis, scores are summed for total scores ranging from 0 to 27, where higher scores indicate a higher number of depressive symptoms.

2.4.4. Epilepsy medication noncompliance was measured using the Epilepsy Adherence questionnaire

The Epilepsy Adherence questionnaire is a 20-item questionnaire created by Colleen DiIorio. The first 14 questions ask about reasons for missing medication doses and are scored on a 4-point scale from "never" (0) to "often" (3) with an option for "refuse to answer" (8). A sample item is, "In the past 30 days, how often have you missed taking your epilepsy medications because you felt sick or ill?" The next question asks "When was the last time you missed taking any of your epilepsy medications?" It is scored on a 6-point scale from "never" (0) to "within the past week" (5) with an option for "refuse to answer" (8) and "N/A" (9). The last 5 questions ask about participant feelings on taking epilepsy medications and are scored on a 6-point scale from "none of the time" (1) to "all of the time" (6) with an option for "refuse to answer" (9). A sample item is, "I found it easy to take my epilepsy medications as the healthcare provider advised."

2.4.5. Electronic Medical Record (EMR) health data

Participants consented to allow study staff to access their EMR data. Study staff collected data for height and weight, insurance, primary care provider, comorbidities, current ASDs and prescribed dosages, and seizure frequency.

2.4.6. Intermediary measures

Participants completed intermediary measurements at all time points, including baseline and four follow-ups. We measured SM practices, outcome expectancy, and self-efficacy using the previously published and validated assessments described below.

2.4.6.1. Self-management practices were measured using the Adult Epilepsy Self-Management Measurement Instrument (AESMMI-65) [29]. The AESMMI-65 is a 65-item assessment of frequency of use of epilepsy SM practices. All items are scored on a 5-point Likert scale from (1) to (5) ("never" to "all the time", "never" to "always", "not at all" to "completely true"), with an option for "not applicable" (8). A sample item is "I keep track of the side effects of my seizure medication." For analysis, item scores are summed for a maximum total score of 325, with "not applicable" treated as missing values. Higher scores indicate more frequent use of SM practices. The AESMMI-65 contains 11 independent domains: Coping (10 items), Healthcare Communication (14 items), Medication Adherence (4 items), Proactivity (3 items), Safety (4 items), Seizure Response (3 items), Seizure Tracking (3 items), Social Support (7 items), Stress Management (3 items), Treatment Management (11 items), and Wellness (3 items).

2.4.8. Self-efficacy was measured using the Epilepsy Self-Efficacy Scale (ESES) [30,31]

The ESES is a 33-item measure of self-reported self-efficacy of epilepsy SM skills. All items are scored on an 11-point scale from "I cannot do at all" (0) to "sure I can do" (10). A sample item is, "I always carry personal identification in case I have a seizure." For analysis, the sum item score for nonmissing values is calculated for scores ranging from 0 to 330, where higher scores indicate higher self-efficacy.

2.4.9. Outcome expectancy was measured using the Epilepsy Outcome Expectancy Scale (EOES) [32]

The EOES determines PWE judgment of likely consequences of epilepsy and is grouped into three scales: Treatment Outcomes, Seizure Outcomes, and Epilepsy Management. All items are scored on a 5-point scale from "Strongly disagree" (1) to "strongly agree" (5).

Treatment Outcomes is a 12-item domain; a sample item is, "If I follow the treatment for my seizures, I will feel more confident." For analysis, the mean item score is calculated for scores ranging from 1 to 5, where higher scores indicate more positive outcome expectancy about epilepsy treatment.

Seizure Outcomes is a 17-item domain; a sample item is, "If I have a seizure, I will be frightened." For analysis, the mean item score is calculated for scores ranging from 1 to 5, where higher scores indicate more negative expected outcomes resulting from seizures.

Epilepsy Management is an 8-item domain; a sample item is, "If I can manage my seizures well, I will feel more satisfied with my life in general." For analysis, the mean item score is calculated for scores ranging from 1 to 5, where higher scores indicate more positive outcomes related to epilepsy management.

2.4.10. Outcome measures

Participants completed outcome measurements at all time points, including baseline and four follow-ups. We measured quality of life and impact of epilepsy on life using the previously published and validated assessments described below.

2.4.11. Quality of life was measured using the Quality of Life in Epilepsy (QOLIE-10) and Patient Weighted Quality of Life in Epilepsy (QOLIE-10-P) [33]

The QOLIE-10 is a 10-item measure that determines health-related quality of life for adults with epilepsy. A sample item is, "How much do work limitations bother you?" For analysis, total scores are calculated according to the scoring manual V2 (2016) from the QOLIE Development Group [34] with scores ranging from 0 to 100, where higher scores indicated increased quality of life.

A patient-weighted version of this measure, QOLIE-10-P, includes an 11th question used to weight the overall score. The final question, "How much does the state of your epilepsy-related quality of life distress you overall?" is scored from "Not at all" (1) to "Very much" (5). For analysis, patient-weighted total scores are calculated according to the scoring manual from the QOLIE Development Group with scores ranging from 0 to 100, where higher scores indicated increased quality of life.

2.4.12. Impact of epilepsy on life was measured using the Personal Impact of Epilepsy Scale (PIES) [35]

The PIES is a 25-item measure that determines the overall negative impact from epilepsy on the life of PWE. The PIES is separated into 3 domains: Seizures, Adverse Effects, and Mood & Social Situations. Items are scored on a 5-point scale from Very Much/Very Often (1) to Not at All/Never (5) total scores that are calculated according to the scoring manual from the PIES Development Group [36] with scores ranging from 0 to 100, where higher scores indicate less negative impact of epilepsy on life.

2.5. Statistical analysis

Statistical analysis was performed with STATA 15.0 [37]. Descriptive statistics was performed to examine distribution of the data, kurtosis, and skewness.

As instructed by the QOLIE Development Group Scoring Manual, for quality of life measures, when only one item was missing, the missing item score was imputed based on the remaining 9 items. In order to calculate the imputed value for missing item, j ($1 \le j \le 10$), a fraction number $s_i = \frac{n_i}{d_i}$ is given to each of the 9 answered items before rescoring, where the numerator n_i is an integer from 1 to d_i reflecting the patient's response to the item and d_i is the number of choices for question i ($i = 1, \ldots, 10$). As a result, the fraction $S_i = \frac{1}{d_i}$ is the smallest fraction meaning the worst, and $s_i = 1$ is the largest value meaning the best. After obtaining the fraction number s_i for all of the 9 items, an arithmetic average is calculated and the imputed value is calculated by $\bar{s} \times d_j$. Out of 112, 9 (8.0%) participants had one missing value that was imputed. If more than one item was missing, the missing item value was not imputed or replaced, and the score became invalid. Only 3 out of 112 (2.7%) had more than one missing value.

We used t-test with unequal variances for 2-sample analysis of summary measures (mean, standard deviation (SD), and sample size) to analyze how intermediary and outcome measure mean values for PAUSE clinic participants compared with similar measures from published reports. Correlates of SM skills & behaviors, quality of life, personal impact of epilepsy, and depression symptoms measures were examined using pairwise correlation analysis. Statistical significance was examined at $\alpha \le 0.05$.

3. Results

A total of 208 patients referred to PAUSE from the UIH specialty clinics, 137 (66%) provided consent to participate; of these, 101 participants (74%) completed baseline questionnaires. From the community, 11 PWE were enrolled, provided consent, and completed baseline questionnaires. Data collection for follow-up assessments is ongoing. For this report, baseline assessments for a total 112 participants were examined.

3.1. Sociodemographic characteristics of study population

Study participants were diverse in regard to age, gender, race and ethnicity, and income status (Table 1). Ages ranged from 18 to 74 years [mean: 37.6 (12.3)]; 63% were women, 47.3% were non-Hispanic black, and 24.1% were Hispanic. The majority (61.6%) of study participants had some college education, though approximately only one-third were either part- or full-time employed. A majority did not report household income; however, 57.4% had public healthcare coverage.

3.2. Epilepsy and health characteristics of study population

Participants had been living with epilepsy on average for 14 years (SD: 14.3, range: 0–53) (Table 2); 49.1% reported at least one seizure within the past month, and 45% were treated for seizures (or seizure-related injury) at an ED within the past year. While 26.8% reported having used a seizure diary or calendar for seizure tracking, the majority reported only using handwritten diaries or calendars. Fewer than 4% of participants report using online seizure tracking tools. Less than a quarter of participants, 17%, had visited the epilepsy.com website more than a moderate amount. About 55% had focal epilepsy, and almost half were on 2 or more ASDs. On average, PWE reported 13 seizures (SD: 36.3) in the past six months.

Table 1
Baseline sociodemographic characteristics of all PAUSE participants (n = 112).

Characteristic	n (%)
Age in years, mean (SD)	37.6 (12.3)
Female	71 (63.4)
Race/ethnicity	
Non-Hispanic White	24 (21.4)
Non-Hispanic Black	53 (47.3)
Hispanic	27 (24.1)
Other	8 (7.1)
Education	
Less than high school	5 (4.5)
High school/High school or equivalent	31 (27.7)
At least some college	69 (61.6)
Unknown/not reported	7 (6.3)
Employment status	
Employed (part- or full-time)	34 (30.4)
Unable to work[a]	35 (31.3)
Unemployed	27 (24.1)
Other[b]	16 (14.3)
Household income	
Less than $25,000	38 (33.9)
$25,000–$49,999	14 (12.5)
$50,000 or more	14 (12.5)
Unknown/not reported	46 (41.1)
Insurance status (n = 101)[c]	
Uninsured/unknown	8 (7.9)
Medicaid	58 (57.4)
Medicare	7 (6.9)
Private	28 (27.7)
Lives alone	19 (17.0)

[a] Includes disabled, permanently, or temporarily.
[b] Includes students, retirees, and homemakers.
[c] Data from EMR, includes clinic participants only.

3.3. Correlates of self-management and self-efficacy

Self-efficacy scores were significantly positively correlated with SM practices (r = 0.43); personal impact of epilepsy (r = 0.47); QOLIE-10 (r = 0.39) and QOLIE-10P (r = 0.37); and outcome expectancy for treatment (r = 0.37) and management (r = 0.33) (Table 3). Self-efficacy scores were significantly negatively correlated with depression symptoms (r = −0.45) and outcome expectancy for seizures (r = −0.40).

Depression symptom scores were negatively associated with personal impact of epilepsy (r = −0.46), QOLIE-10 (r = −0.31), and QOLIE-10P (r = −0.48). Depression symptom scores were positively correlated with outcome expectancy for seizures (r = 0.42).

Self-management practice scores were positively correlated with outcome expectancy for management (r = 0.28). Personal impact of epilepsy scores were negatively correlated with outcome expectancy for seizures (r = −0.34).

Quality of life scores were positively correlated with personal impact of epilepsy scores (QOLIE-10: r = 0.57; QOLIE-10-P: r = 0.68) but were negatively correlated with outcome expectancy for seizures (QOLIE-10: r = −0.45; QOLIE-10-P: r = −0.39).

3.4. Intermediary measures

Mean values for SM skills & behaviors were lower among PAUSE participants from UIH than PWE in published reports [29]; all were

Table 2
Baseline seizure and health characteristics of all PAUSE participants (n = 112).

Self-reported characteristics	n (%)
Age diagnosed with epilepsy[a], mean (SD), range in years	23.5 (14.2), 0–74
Duration of epilepsy[a], mean (SD), range in years	14.0 (14.3), 0–53
Reported last seizure	
Within past month	55 (49.1)
1–3 months ago	18 (16.1)
4–12 months ago	25 (22.3)
Over 1 year ago	13 (11.6)
Unknown	1 (0.9)
Reports moderate to severe depressive symptoms[b]	55 (49.1)
Uses seizure tracking tool	
Handwritten calendar/diary only	27 (24.1)
Online tool/diary only	3 (2.7)
Both handwritten and online	1 (0.9)
None	81 (72.3)
Has visited epilepsy.com	
Yes, a lot	7 (6.3)
Yes a moderate amount	12 (10.7)
Yes, a little	22 (19.6)
No	71 (63.4)
Characteristics from EMR (n = 101)	
Has a primary care provider	66 (65.3)
BMI ≥ 25[c]	62 (66.7)
Epilepsy type	
Focal	55 (54.5)
Generalized	23 (22.8)
Focal to bilateral tonic–clonic	21 (20.8)
Unknown	2 (2.0)
No. of current ASD medications	
1	49 (48.5)
2	33 (32.7)
3	13 (12.9)
4+	2 (2.0)
Unknown	4 (4.0)
Seizure frequency in past month, mean (SD), range[d]	2 (6.1), 0–30
Seizure frequency in past 6 months, mean (SD), range[d]	13 (36.3), 0–190

BMI = Body mass index
[a] Data available for n = 110; 2 participants did not report.
[b] As measured by PHQ-9 score ≥ 10.
[c] Data available for n = 93; BMI ≥ 25 indicates overweight, BMI ≥ 30 indicates obese.
[d] Data available for n = 98.

Table 4
Mean values of epilepsy SM skills, outcome expectancy, and depressive symptoms for PAUSE clinic participants (n = 101) compared with similar measures from published reports.

Intermediary measure	PAUSE findings		Published report		p value
	n	Mean (SD)	n	Mean (SD)	
AESMMI-65, overall[a]	101	221.20 (44.98)	422	245.32 (33.63)	<**0.001**[*]
Coping	101	34.24 (9.80)	422	35.21 (7.78)	0.356
Healthcare Communication	101	43.05 (17.33)	422	52.26 (12.14)	<**0.001**[*]
Medication Adherence	101	16.44 (3.56)	422	17.40 (2.59)	**0.012**[*]
Proactivity	101	10.73 (3.67)	422	12.48 (2.44)	<**0.001**[*]
Safety	101	11.29 (4.92)	422	12.23 (3.84)	0.075
Seizure Response	101	8.36 (3.80)	422	9.10 (3.16)	0.072
Seizure Tracking	101	9.69 (4.57)	422	12.00 (3.40)	<**0.001**[*]
Social Support	101	24.05 (7.69)	422	25.10 (6.02)	0.202
Stress Management	101	6.25 (3.75)	422	7.73 (3.15)	<**0.001**[*]
Treatment	101	48.52 (8.44)	422	51.29 (5.23)	**0.002**[*]
Wellness	101	8.58 (2.97)	422	10.52 (2.74)	<**0.001**[*]
Epilepsy self-efficacy[b]	101	242.78 (49.31)	70	178.95 (32.94)	<**0.001**[*]
Outcome expectancy	–	–	–	–	–
Treatment[c]	101	3.66 (0.77)	317	3.79 (0.69)	0.132
Seizures[c]	101	3.09 (0.68)	317	2.86 (0.70)	**0.004**[*]
Management[d]	101	4.18 (0.64)	29	4.00 (0.24)	**0.022**[*]
Depression symptoms[e]	98	10.07 (7.14)	436	9.8 (6.9)	0.734

Published reports n, mean, and SD:
[a] AESMMI and domains, Escoffery et al. [29].
[b] Epilepsy Self-Efficacy, DiIorio et al. [16].
[c] Outcome Expectancy Treatment & Seizures, DiIorio et al. [38].
[d] Outcome Expectancy Management, DiIorio et al. [39].
[e] PHQ-9 for Depression Symptoms, Begley et al. [40].
[*] Correlation significant at the .05 level shown in bold.

significantly lower except for mean values for Coping and Social Support (Table 4). Self-efficacy among PAUSE UIH participants was significantly higher as compared with published reports [16]. The PAUSE UIH participant mean values for outcome expectancy for seizures were significantly higher, indicating that they expected worse outcomes resulting from seizures, than PWE from published reports [38]; mean values for outcome expectancy for management were also significantly higher [39], indicating they expected better outcomes resulting from medication adherence. The mean score for depression symptoms was not significantly different in participants from the UIH than PWE in general population [40].

3.5. Outcome measures

Personal impact of epilepsy scores for all study participants ranged from 44 to 286 (mean: 185.84 ± 59.29); per item subscale scores ranged from 6 to 100 (mean: 59.38 ± 26.90) for seizures, 14 to 100 (mean: 68.42 ± 22.81) for adverse effects of ASDs, and 11 to 100 (mean: 58.05 ± 22.95) for mood & social situations (Table 5). The QOLIE-10 scores ranged from 11.5 to 95.5 (mean: 55.71 ± 17.20), and QOLIE-10-P ranged from 2.0 to 96.0 (mean: 33.39 ± 22.91).

4. Discussion

1. **PAUSE participants are very diverse and represent underserved and minority populations of PWE**, as compared with many other SM studies that have a high representation of nonminority, wealthier, and higher educated PWE [13,15–17,40]. The racial and ethnic characteristics of the PAUSE study sample are nearly identical to the racial/ethnic breakdown of the city of Chicago [41]. Of the 17% of PAUSE participants who report living alone, 47% have had at least one seizure in the past 6 months and 42% have either generalized or focal to bilateral tonic–clonic seizures. Though PAUSE participants were found to be relatively educated, with 68% having at least some college education, this higher education level can be attributed to our exclusion criteria eliminating participants who were below grade 8 education level and may not be indicative of the UIH epilepsy subspecialty clinics population. Even with higher education, 55% of participants report being unemployed or disabled, which is significantly higher than the current US unemployment rate, where only 3.5% of individuals with at least some college education are

Table 3
Correlation coefficients (and p-values) of SM skills & behaviors, outcome expectancy, and quality of life measures of all PAUSE participants (n = 112).

	AESMMI-65	PIES	QOLIE	QOLIE-P	PHQ-9	EOES: Trt	EOES: Seiz	EOES: Mang
Self-efficacy	**0.43 (0.00)**[*]	**0.47 (0.00)**[*]	**0.39 (0.00)**[*]	**0.37 (0.00)**[*]	**−0.45 (0.00)**[*]	**0.37 (0.00)**[*]	**−0.40 (0.00)**[*]	**0.33 (0.00)**[*]
AESMMI-65 total		0.04 (0.69)	0.01 (0.90)	0.01 (0.91)	−0.14 (0.16)	0.11 (0.23)	−0.15 (0.11)	**0.28 (0.00)**[*]
PIES sum			**0.57 (0.00)**[*]	**0.68 (0.00)**[*]	**−0.46 (0.00)**[*]	**0.34 (0.00)**[*]	**−0.43 (0.00)**[*]	0.18 (0.06)
QOLIE-10				**0.78 (0.00)**[*]	**−0.31 (0.00)**[*]	0.18 (0.06)	**−0.45 (0.00)**[*]	0.00 (0.97)
QOLIE-10-P					**−0.48 (0.00)**[*]	0.19 (0.06)	**−0.39 (0.00)**[*]	0.05 (0.59)
PHQ-9						−0.16 (0.11)	**0.42 (0.00)**[*]	−0.01 (0.89)

[*] Correlation significant at the .05 level shown in bold.

Table 5
Baseline quality of life and personal impact of epilepsy for PAUSE clinic participants (n = 101).

Outcome measure	No. of items	Score range	PAUSE median value (range)
PIES (overall)	25	0–300	196.0 (44.2–286.1)
Seizures	9	0–100	58.3 (5.6–100.0)
Adverse events	7	0–100	67.9 (14.3–100.0)
Mood & social situation	8	0–100	58.3 (11.1–100.0)
QOLIE-10	10	0–100	54.9 (11.5–95.5)
QOLIE-10-P	11	0–100	27.0 (2.0–96.0)

unemployed or unable to work [42]. This emphasizes greater importance of improved SM education, especially among PWE who live alone and therefore cannot rely on partners or other family members for assistance or those who are unemployed, which could increase reliance on others, increase poverty, and create a larger burden on the PWE's family and community. Additionally, 57% of PAUSE participants relied on Medicaid for health insurance, much higher than National Health Interview Survey data that report 33% of PWE who are on Medicaid [43].

Most of the study participants were either overweight or obese, and 35% lacked a primary care provider. This study highlights the additional health challenges and comorbid burdens PWE face, as well as the fact that many do not have adequate healthcare. This identifies an important gap in healthcare management for PWE. Participants of PAUSE were comparable with other epilepsy SM education studies in relation to epilepsy and health characteristics [14,16,44]. Moreover, 50% of the study participants indicated having had at least one seizure in the past month, but only 27% reported seizure tracking. A low percentage of participants report having visited epilepsy.com for epilepsy resources. Increased use of accurate epilepsy education sources may improve SM skills & behaviors, increase epilepsy knowledge, improve communication with healthcare providers, and improve overall epilepsy outcomes.

2. **Correlational analysis shows significant association between PIES and QOLIE-10-P** with $r > 0.6$, indicating that more negative impact of epilepsy is associated with reduced quality of life. To our knowledge, PAUSE is the only study to look into the correlates of personal impact of epilepsy and self-efficacy with SM practices. Our findings provide information on PWE quality of life and personal impact of epilepsy prior to targeted SM education. This can be used to compare how epilepsy affects PWE based on their sociodemographic and health characteristics. We could not compare our quality of life results to any published epilepsy SM studies, as other studies did not use the scoring manual as suggested by the QOLIE Development Group. The SMILE study used the 31-item version of the QOLIE measure, QOLIE-31 and QOLIE-31-P, to examine quality of life among PWE with poorly controlled epilepsy (≥2 seizures in the past 12 months) [45]. Compared with their findings, quality of life among PAUSE participants was lower (SMILE: 66.0 in QOLIE-31-P and 62.0 in QOLIE-31 vs. PAUSE: 27.0 in QOLIE-10-P and 54.9 in QOLIE-10). The lower QOLIE-10 and QOLIE-10-P scores in this population may be due to their lower SM behaviors and/or their higher number of depressive symptoms. It has been shown that individuals who report better quality of life are engaged more in SM behaviors [29].
3. **There is a need for a personalized approach for developing SM behaviors among PWE from underserved population**. The PAUSE study confirms that self-efficacy was correlated with better SM practices and behaviors, as well as with stronger belief that epilepsy treatment and management would lead to more positive epilepsy outcomes for PWE. It also showed that lower self-efficacy among PAUSE participants was associated with a higher number of depressive symptoms and a greater belief that seizures would lead to negative epilepsy outcomes. This supports the findings reported in Project EASE [38], where increased self-efficacy was associated with more positive outcome expectations, improved medication management, and fewer depressive symptoms. However, the findings of this study also showed that while SM practices & behaviors and outcome expectancy were significantly lower among PAUSE participants, self-efficacy was significantly higher. This is in contrast to findings seen in the MINDSET study that compared PWE from a public county hospital serving mainly low-income, uninsured, and Medicaid-covered patients with PWE from a multispecialty medical organization serving mostly middle-class patients with health maintenance organization (HMO) insurance [46]. The MINDSET study found that lower self-efficacy among public county hospital patients was significantly associated with lower SM practices. This indicates the possibility that, while PAUSE participants have high self-efficacy and therefore have strong beliefs that they are capable of improving their quality of life, they may not have the knowledge and/or ability to do so, as evidenced by low SM practices. This underscores the significant need for targeted SM education for underserved and minority populations, which can help providers better direct resources and efforts for epilepsy SM education.

4.1. Limitations of this study

Findings cannot be generalized and can only be compared with studies that have similar sociodemographic participant characteristics. As SM resources at epilepsy.com are only available in English, only English-speaking patients were enrolled, and therefore, participants may not be entirely representative of the large Spanish-speaking patient population at UIH. Also, those who had low reading scores and no assistance from an adult caregiver or family member may not have been able to participate in the study because of the publicly available SM education material being written at an 8th-grade reading level. No monetary incentive was given at enrollment; participants were only given a small $10 compensation for completion of follow-up questionnaires. Participants of PAUSE had higher self-efficacy than PWE in other published reports; it is possible that those who elected to participate may be more interested in SM education and access to SM resources and, therefore, may be more motivated to improve their SM practices than those who did not elect to participate who may have worse self-efficacy and SM practices. Self-reported responses can be affected by recall and social–desirability biases, including tendency for exaggeration in favor of desired outcomes to not seem irresponsible or noncompliant to providers or caregivers. Study protocol attempted to mitigate this as a limitation by using only verified and reliable tools and measures. All measures used in this study were previously assessed for reliability and validity among PWE.

5. Conclusion

The PAUSE study results provide information on how underserved and minority status can specifically affect epilepsy SM skills & behaviors and how to best address these unique needs. People with epilepsy from underserved populations have significantly lower SM practices & behaviors and outcome expectancy, as compared with PWE from the general population, but higher self-efficacy. Participants of PAUSE showed a wide variability in scores, demonstrating a need for personalized SM programs designed such that those with greater needs can also have meaningful improvement following SM education interventions.

These findings underscore the need for future research examining delivery of SM education to a wider range of PWE, especially those from various epilepsy centers, those from minority/underserved populations, and PWE from rural communities. There is also a need for examination of improved methods for SM education, including more streamlined access to learning modules and increased motivation for participation in SM education. Future research should look into the impact of sharing results of SM education and improvements in SM practices to PWE and their healthcare team. It should also determine what resources may be needed at epilepsy subspecialty clinics serving underserved populations.

If successful, the PAUSE program, because of the technology used and the publicly available educational resources provided, is cost-effective and can be easily disseminated in the clinic to provide SM education to PWE from underserved populations.

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Declaration of competing interests statement

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

References

[1] Tian N, Boring M, Kobau R, Zack MM, Croft J. Active epilepsy and seizure control in adults — United States, 2013 and 2015. MMWR Morb Mortal Wkly Rep 2018;67(15):437–42.
[2] Begley CE, Durgin TL. The direct cost of epilepsy in the United States: a systematic review of estimates. Epilepsia 2015;56(9):1376–87.
[3] DiIorio C. Handbook of health behavior research II: provider determinants. New York: Plenum Press; 1997; 213–30.
[4] Bandura A. Self-efficacy. In: Ramachaudran VS, editor. Encyclopedia of human behavior (Vol. 4, pp. 71–81). New York: Academic Press. Reprinted in H. Friedman [Ed.], Encyclopedia of Mental Health. San Diego: Academic Press; 1994. p. 1998.
[5] Clark N, Stoll S, Youatt EJ, Sweetman M, Derry R, Gorelick A. Fostering epilepsy self-management: the perspective of professionals. Epilepsy and Behavior 2010;19:225–63.
[6] Brady TJ. Chronic disease self-management support: public health perspectives. Frontiers in Public Health; 2015.
[7] Quality: crossing the quality chasm: a new health system for the 21st century, JAMA 2002;287(5):646–7.
[8] DiIorio C, Bamps Y, Edwards A, Escoffery C, Thompson N, Begley C, et al. The Prevention Research Centers' Managing Epilepsy Well Network. Epilepsy and Behavior 2010;19(3):218–24.
[9] England MJ, Liverman CT, Schultz AM, Strawbridge LM. Epilepsy across the spectrum: promoting health and understanding. A summary of the institute of medicine report. Epilepsy Behav 2012;25(2):266.
[10] Helmers SL, Kobau R, Sajatovic M, Jobst BC, Privitera M, Devinsky O, et al. Self-management in epilepsy: why and how you should incorporate self-management in your practice. Epilepsy Behav 2017;68:220–4.
[11] Sajatovic M, Jobst BC, Shegog R, Bamps YA, Begley CE, Fraser RT, et al. The Managing Epilepsy Well Network: advancing epilepsy self-management. Am J Prev Med 2017;52(3):S241–5.
[12] Caller TA, Secore KL, Ferguson RJ, Roth RM, Secore KL, Alexandre FP, et al. A cognitive-behavioral intervention (HOBSCOTCH) improves quality of life and attention in epilepsy: a pilot study. Epilepsy Behav 2016;57:111–7.
[13] Chaytor N, Ciechanowski P, Miller JW, Fraser R, Russo J, Unutzer J, et al. Long-term outcomes from the PEARLS randomized trial for the treatment of depression in patients with epilepsy. Epilepsy Behav 2011;20(3):545–9.
[14] Sajatovic M, Tatsuoka C, Welter E, Perzynski AT, Colon-Zimmermann K, Van Doren JR, et al. Targeted self-management of epilepsy and mental illness for individuals with epilepsy and psychiatric comorbidity. Epilepsy Behav 2016;64(Pt A):152–9.
[15] Thompson NJ, Walker ER, Obolensky N, Winning A, Barmon C, DiIorio C, et al. Distance delivery of mindfulness-based cognitive therapy for depression: project UPLIFT. Epilepsy Behav 2010;19(3):247–54.
[16] DiIorio C, Bamps Y, Walker ER, Escoffery C. Results of a research study evaluating WebEase, an online epilepsy self-management program. Epilepsy Behav 2011;22(3):469–74.
[17] Fraser RT, Johnson EK, Lashley S, Barber J, Chaytor N, Miller JW, et al. PACES in epilepsy: results of a self-management randomized controlled trial. Epilepsia 2015;56(8):1264–74.
[18] Begley C, Shegog R, Harding A, Goldsmith C, Hope O, Newmark M. Longitudinal feasibility of MINDSET: a clinic decision aid for epilepsy self-management. Epilepsy Behav 2015;44:143–50.
[19] Sajatovic M, Colon-Zimmerman K, Kahriman M, Fuentes-Casiano E, Liu H, Tatsuoka C, et al. A 6-month prospective randomized controlled trial of remotely delivered group format epilepsy self-management versus waitlist control for high-risk people with epilepsy. Epilepsia 2018;59(9):1684–95.
[20] University of Illinois Hospital & Health Sciences System. University of Illinois Community Assessment of Needs (UI-CAN) 2016: toward health equity. Available from: https://oceanhp.uic.edu/wp-content/uploads/2016/07/CHNA-UIHealth.pdf; 2016.
[21] Owens S, Sirven JI, Shafer PO, Fishman J, Wild I, Findley M, et al. Innovative approaches reaching underserved and rural communities to improve epilepsy care: a review of the methodology of the connectors project. Epilepsy Behav 2019;90:273–83.
[22] Zach L, Dalrymple PW, Rogers ML, Williver-Farr H. Assessing internet access and use in a medically underserved population: implications for providing enhanced health information services. Health Info Libr J 2012;29(1):61–71.
[23] Ahmed S, Lemkau JP, Nealeigh N, Mann B. Barriers to healthcare in a non-elderly urban poor American population. Health and Social Care 2002;9(6):445–53.
[24] DiIorio C, Faherty B, Manteuffel B. Epilepsy self-management: partial replication and extension. Res Nurs Health 1994;17(3):167–74.
[25] DiIorio C, Hennessy M, Manteuffel B. Epilepsy self-management: a test of a theoretical model. Nurs Res 1996;45(4):211–7.
[26] Couldridge L, Kendall S, March A. 'A systematic overview — a decade of research'. The information and counseling needs of people with epilepsy. Seizure 2001;10:605–14.
[27] Wilkinson GS, Robertson GJ. WRAT-4: wide range achievement test; professional manual. . 4th ed.Psychological Assessment Resources, Inc.; 2006
[28] Kroenke K, Spitzer RL, Williams JBW. The PHQ-9: validity of a brief depression severity measure. J Gen Intern Med 2001;16(9):606–13.
[29] Escoffery C, Bamps Y, LaFrance WC, Stoll S, Shegog R, Buelow J, et al. Factor analyses of an adult epilepsy self-management measurement instrument (AESMMI). Epilepsy Behav 2015;50:184–9.
[30] Robinson E, DiIorio C, DePadilla L, McCarty F, Yeager K, Henry T, et al. Psychosocial predictors of lifestyle management in adults with epilepsy. Epilepsy Behav 2008;13(3):523–8.
[31] DiIorio C, Shafer PO, Letz R, Henry TR, Schomer DL, Yeager K. Behavioral, social, and affective factors associated with self-efficacy for self-management among people with epilepsy. Epilepsy Behav 2006;9:158–63.
[32] DiIorio C, Shafer P, Letz R, Henry T, Schomer D, Yeager K. The association of stigma with self-management and perceptions of health care among adults with epilepsy. Epilepsy Behav 2003;4(3):259–67.
[33] Cramer JA, Perrine K, Dvinsky O, Meador K. A brief questionnaire to screen for quality of life in epilepsy: the QOLIE-10. Epilepsia 1996;37(6):577–82.
[34] Cramer J. Quality of life in epilepsy (QOLIE-10-P) scoring instructions. QOLIE Development Group.
[35] Fisher RS, Nune G, Roberts SE, Cramer JA. The personal impact of epilepsy scale (PIES). Epilepsy Behav 2015;42:140–6.
[36] Fisher R. Scoring manual for the personal impact of epilepsy scale (PIES). PIES Development Group. V.2; 2016.
[37] StataCorp. Stata statistical software: Release 15. College Station, TX: StataCorp LLC; 2017.
[38] DiIorio C, Shafer PO, Letz R, Henry TR, Schomer DL, Yeager K, et al. Project EASE: a study to test a psychosocial model of epilepsy medication management. Epilepsy Behav 2004;5(6):926–36.
[39] DiIorio C, Escoffery C, McCarty F, Yeager KA, Henry TR, Koganti A, et al. Evaluation of WebEase: an epilepsy self-management web site. Health Ed Research 2008;24(2):185–97.
[40] Begley C, Shegog R, Liu H, Tatsuoka C, Spruill TM, Friedman D, et al. Correlates of epilepsy self-management in MEW network participants. Epilepsy Behav 2018;85:243–7.
[41] United States Census Bureau. Quick facts: Chicago City, Illinois. Available from: https://www.census.gov/quickfacts/fact/table/chicagocityillinois; 2017.
[42] National Bureau of Economic Research. Unemployment Rate 2.1 Percent for College Grads, 4.3 Percent for High School Grads in April 2018. US Bureau of Labor Statistics; 2018.
[43] Thurman DJ, Kobau R, Luo Y, Helmers SL, Zack MM. Healthcare access among adults with epilepsy: the US National Interview Survey, 2010 and 2013. Epilepsy and Behavior 2016;55:184–8.
[44] Bautista RE. Understanding the self-management skills of persons with epilepsy. Epilepsy Behav 2017;69:7–11.
[45] Ridsdale L, Wojewodka G, Robinson EJ, Noble AJ, Morgan M, Taylor SJC, et al. The effectiveness of a group self-management education course for adults with poorly controlled epilepsy, SMILE (UK): a randomized controlled trial. Epilepsia 2018;59:1048–61.
[46] Begley CE, Shegog R, Iyagba B, Chen V, Talluri K, Dubinsky S, et al. Socioeconomic status and self-management in epilepsy: comparison of diverse clinical populations in Houston Texas. Epilepsy Behav 2010;19:232–8.