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Enhancing epilepsy self-management and quality of life for adults with epilepsy with varying social and educational backgrounds using PAUSE to Learn Your Epilepsy

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ABSTRACT

Purpose: People with epilepsy (PWE) come from a wide variety of social backgrounds and educational skillsets, making self-management (SM) education for improving their condition challenging. Here, we evaluated whether a mobile technology-based personalized epilepsy SM education intervention, PAUSE to Learn Your Epilepsy (PAUSE), improves SM measures such as self-efficacy, epilepsy SM behaviors, epilepsy outcome expectations, quality of life (QOL), and personal impact of epilepsy in adults with epilepsy.

Methods: Recruitment for the PAUSE study occurred from October 2015 to March 2019. Ninety-one PWE were educated using an Internet-enabled computer tablet application that downloads custom, patient-specific educational programs from Epilepsy.com. Validated self-reported questionnaires were used for outcome measures. Participants were assessed at baseline (T0), the first follow-up at completion of the PWE-paced 8–12-week SM education intervention (T1), and the second follow-up at least 3 months after the first follow-up (T2). Multiple linear regression was used to assess within-subject significant changes in outcome measures between these time points.

Results: The study population was diverse and included individuals with a wide variety of SM educational needs and abilities. The median time for the first follow-up assessment (T1) was approximately 4 months following the baseline (T0) and 8 months following baseline for the second follow-up assessment (T2). Participants showed significant improvement in all SM behaviors, self-efficacy, outcome expectancy, QOL, and personal impact of epilepsy measures from T0 to T1. Participants who scored lower at baseline tended to show greater improvement at T1. Similarly, results showed that participant improvement was sustained in the majority of SM measures from T1 to T2.

Conclusion: This study demonstrated that a mobile technology-based personalized SM intervention is feasible to implement. The results provide evidence that epilepsy SM behavior and practices, QOL, outcome expectation for epilepsy treatment and management, self-efficacy, and outcome expectation and impact of epilepsy significantly improve following a personalized SM education intervention. This underscores a greater need for a pragmatic trial to test the effectiveness of personalized SM education, such as PAUSE to Learn Your Epilepsy, in broader settings specifically for the unique needs of the hard-to-reach and hard-to-treat population of PWE.

1. Introduction

Epilepsy, characterized by spontaneous recurrent seizures with unpredictable frequency, is a common and complex neurological disorder that affects the health and quality of life (QOL) of people with epilepsy (PWE) [1]. It is the fourth most common chronic neurological disorder after migraines, Alzheimer's disease, and Parkinson's disease in terms of 1-year prevalence per 1000 in the general population [2]. In 2015, approximately 1.2% of American adults reported living with epilepsy; 68.5% had seen a neurologist or epilepsy specialist; 93% were taking antiseizure medication (ASM), and, among those taking medication to control seizures, only 42.4% were seizure-free in the past year [3]. Epilepsy, especially with uncontrolled seizures, poses an immense burden

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to the people who have it, caregivers, and the society due to a number of factors including associated developmental, cognitive, and psychiatric comorbidities; ASM side effects; higher injury and mortality rates; poorer QOL; and increased financial burden. An estimated 3.0% of global disability-adjusted life years (DALYs) were from neurological disorders in 2010, a quarter of which were from epilepsy; epilepsy was the second-most burdensome chronic neurologic disorder worldwide in terms of DALYs [4].

Self-management (SM) education has shown to improve SM skills & behaviors and QOL in many chronic diseases including heart disease, diabetes, asthma, and arthritis [5,6]. Barlow defines self-management as an individual's ability to manage the symptoms, treatments, physical and psychological consequences, and life style changes inherent in living with a chronic condition [7]. However, successful SM requires sufficient knowledge of the condition, its treatment, and necessary skills to perform SM activities. Like other chronic conditions, day-to-day management of epilepsy shifts from healthcare professionals to PWE. Epilepsy care demands active involvement of PWE in keeping up with the health effects of epilepsy and coping with social (e.g., family/friends, stigma, hobbies), health (e.g., seizure response/tracking, comorbidities such as depression/anxiety, sleep, safety, health literacy), employment (e.g., transportation, disability, absenteeism), and economic (e.g., cost of healthcare and medication) challenges. One can only self-manage their disease if they have the tools to do so, including knowledge, access to information relevant to their specific healthcare needs, and the ability to carry out the SM tasks needed for their condition. Evidence shows that many PWE are not knowledgeable about their disorder or often not educated about the risks of epilepsy, injury, and mortality [1,8]. Education needs also vary between individuals and subgroups of PWE. Women, in particular, may seek information on bone health and the effect of ASM on pregnancy or contraception, while older adults' priorities may relate to fall safety and interactions of ASM with other medications. Existing evidence also reveals that, while patients with chronic diseases are willing to receive SM education materials, perceived information overload (i.e., too much or complex information) negatively influences their usage willingness [9]. Patients with low health literacy are even more susceptible to information overload [10]. The Institute of Medicine recognized SM education gaps for PWE and recommended (Recommendation 9) in its 2012 report, "Epilepsy Across the Spectrum: Promoting Health and Understanding," to improve and expand educational opportunities for PWE and their families, as well as to ensure that all PWE and their families have access to accurate, clearly communicated educational materials and information [1].

Several studies have reported contradictory results after examining the efficacy of SM education interventions in improving PWE's knowledge and understanding of epilepsy and QOL. The Modular Service Package Epilepsy study (MOSES) reported significant improvements in ASM tolerability, epilepsy knowledge, coping with epilepsy, and seizure frequency after 6 months following a 2-day SM education program [11]. Self-management education for people with poorly controlled epilepsy [SMILE (UK)] adapted MOSES for use in the United Kingdom and did not find the 2-day course to be effective in improving QOL or secondary outcome measures (anxiety and depression), after 12 months [12]. Though both MOSES and SMILE were randomized control trials (RCTs), MOSES included all adults with epilepsy whereas SMILE included only adults with chronic epilepsy who had two or more seizures in the prior 12 months. Another RCT compared the effectiveness of a multicomponent SM intervention consisting of five weekly, 2-hour group sessions each followed by a 2-hour group session after three weeks with usual care; they found no difference in measures of self-efficacy, though did find improvements in some epilepsy QOL domains and decreases in measures of ASM side effects [13]. Other studies examining the efficacy of in-person, group-based, online or phone/internet SM interventions, including the Centers for Disease Control and Prevention-supported Managing Epilepsy Well (MEW) network programs, did show improvement in epilepsy SM and QOL [14–18].

In addition to existing group-based programs, which require permission to use and specialized training, there is a greater need for patient-centered and patient-specific individualized education interventions for epilepsy SM that are publicly available, cost-effective, and easily disseminated to clinics or in community. The PAUSE to Learn Your Epilepsy (hereafter referred to as "PAUSE"), a MEW network collaboration center, was developed and implemented to address the needs of all PWE, especially those in underserved populations. This program uses publicly available education information from the Epilepsy Foundation (EF) website, epilepsy.com, linked to a mobile technology-based PAUSE application to provide patient-centered personalized epilepsy SM lesson plan to PWE. Detailed information about PAUSE including study design, recruitment, intervention, and assessments has been published previously [19,20]. We reported significantly lower epilepsy SM practices and behaviors among PWE from an underserved population as compared to all PWE. In this paper, we sought to determine whether the PAUSE intervention significantly improves self-efficacy, SM behavior & skills, QOL, personal impact of epilepsy, and epilepsy outcome expectancies over time in adults with epilepsy. We also assessed whether perceived depression symptoms influence longitudinal changes in SM measures following the PAUSE intervention.

2. Materials and methods

Study protocol, including recruitment from the epilepsy subspecialty clinics and from the community, for PAUSE was approved by the University of Illinois at Chicago (UIC) Institutional Review Board.

2.1. Study design

The study was designed to develop and assess the effect of personalized SM education delivered through mobile technology to improve the SM practices & behaviors, QOL, personal impact of epilepsy, and epilepsy-related outcome expectations of PWE. Within-subject longitudinal assessments were used to test significant change in pre- and postintervention outcome scores and in postintervention scores over time.

2.2. Recruitment

Study participants were recruited between October 2015 and March 2019 via referrals from healthcare providers from the epilepsy specialty clinics at the University of Illinois Hospital and Health System (UIH) or from the Chicago area community via referrals from case managers at the Epilepsy Foundation of Greater Chicago following human subjects' research approval. The PWE were not selected or referred to PAUSE based on any preexisting measures of epilepsy SM. Study eligibility criteria were as follows: PWE 18 years of age and over, who speak and understand the English language, with absence of severe or unstable medical conditions that would harm or prevent participation. Study inclusion criteria were as follows: provided consent to participate, an ability to read at a minimum of eighth grade level or a caregiver who could do so, access to a telephone, and those who had not undergone or planned to undergo brain surgery for epilepsy in past 6 months or next six months, respectively.

2.3. PAUSE app and SM learning modules

2.3.1. PAUSE electronic application

An Android OS compatible software application for PAUSE was developed and housed on internet-connected tablet devices to provide SM education tailored to individual needs of adult PWE. The PAUSE application linked SM education learning modules to publicly available education materials and information from the EF website, epilepsy.com. Tablets were also preprogrammed with video conferencing using a freely available web-conferencing application. Study

Fig. 1. Snapshot of PAUSE study application.

participants were provided internet-enabled PAUSE study tablet devices for the 8- to 12-week duration of the SM educational intervention, and the tablets were returned to the study team at the end of the intervention period. As an example, Fig. 1 shows a snapshot of the PAUSE study application.

2.3.2. Self-management education learning modules

Self-management learning modules were assembled with the EF website's associate editor. An individualized educational program was developed for each participant based on the SM learning modules selected by input from both the PWE and their healthcare provider(s) or case manager at study enrollment. Providers/case managers completed the Epilepsy Self-Management Learning Needs Checklist to indicate which modules should be selected and programmed into the tablet for each individual participant. Participants were given the opportunity to include modules that were not selected by their provider(s). The SM learning modules were as follows: Epilepsy New Diagnosis, Managing Seizures/Epilepsy, Impact of Epilepsy, Managing Treatments, Staying Safe, Coping and Living with Epilepsy, and Special Interests (Women's Issues and Information for Seniors). Descriptions of modules and proportion of PAUSE participants assigned to each module are shown in Table 1.

2.4. Study protocol

2.4.1. 8- to 12- week education intervention

As each participant was assigned a tailored educational program, there was no set curriculum or timeline for PWE to follow. Participants were encouraged to progress through assigned modules at their own pace, on their own time. All educational programs were designed to be able to be completed within the 8- to 12-week timeframe. Participants were given support by an education facilitator via video or telephone conferencing, if they chose. Each call was scheduled to last 10–15 min; during this time, PWE were encouraged to ask study-related questions, identify information that was important or interesting, and share their personal experience living with epilepsy. The facilitators also utilized a collection of additional resources to provide to PWE if they deemed it relevant based on conversations via one-on-one calls, including information on seizure response plans, epilepsy.com forums, EF activities and support groups, and educational resources for family and friends of PWE. Participants returned the tablets upon completion of the intervention and tablets were then reset in preparation for the next participant. Of the 30 tablets used by the PAUSE study, only 4 were reported lost.

2.4.2. Assessments

Fig. 2 shows the PAUSE recruitment, intervention, and follow-up study flow. Assessments were performed using self-reported

Table 1
Description of self-management education modules and proportion of PAUSE participants provided with self-management education information.

Module	Description	N (%)
General Information		
Epilepsy New Diagnosis and Self-Management	Includes information about new diagnosis, as well as general information on epilepsy and epilepsy self-management	12 (17.6)
Managing Seizures/Epilepsy	Includes information on seizure types, epilepsy syndromes, seizure observation & recording, using online seizure diary, recognizing and managing triggers, seizure first aid, seizure emergencies, using seizure response plans, diagnosing seizures and epilepsy, refractory epilepsy, and nonepileptic events	66 (97.1)
Impact of Epilepsy	Includes information on seizure emergencies, thinking and memory, mood and behavior, sleep, and causes of death in epilepsy	66 (97.1)
Managing Treatments	Includes information on seizure medications, adherence and side effects, getting the help you need (new diagnosis, refractory epilepsy, women with epilepsy), surgery for epilepsy (presurgical evaluation and types of surgery), devices for treating epilepsy, and dietary therapy	60 (88.2)
Staying Safe	Includes information on risks, seizure first aid, driving, home life, sleep, work, and exercise/sports	58 (85.3)
Coping and Living with Epilepsy	Includes information on family life, education, employment, and stress and coping	58 (85.3)
Special Interest		
Women's Issues	Includes information relevant for women (menses, contraception, pregnancy, and bone health)	35 (89.7)[a]
Seniors	Includes information relevant for seniors	4 (80)[b]

[a] Includes only female participants, n = 39.
[b] Includes only participants over age 55, n = 5.

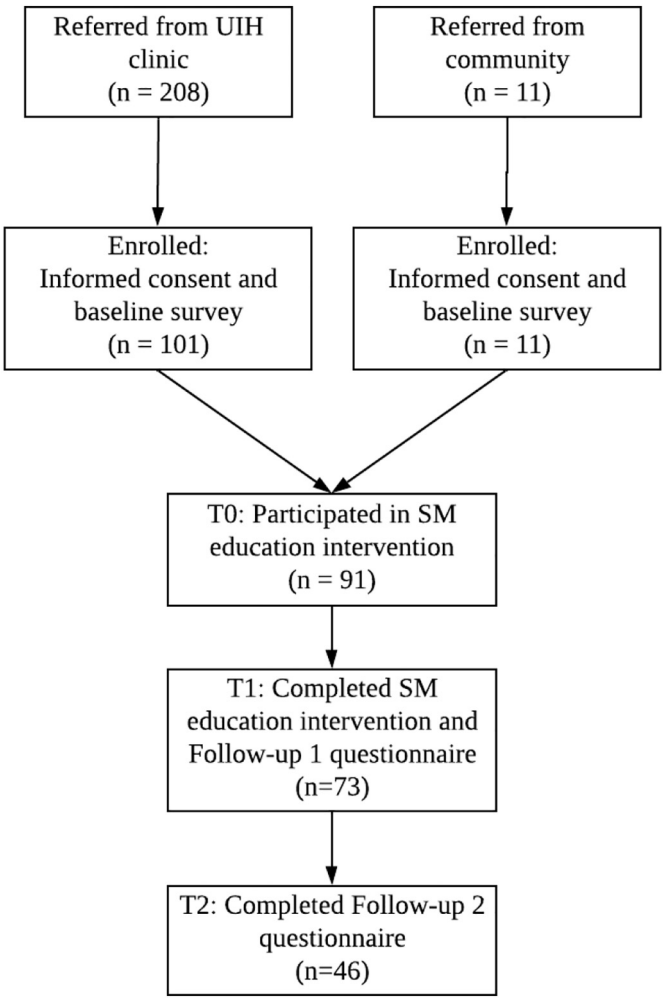

Fig. 2. PAUSE study flowchart.

questionnaires at 5 time points over the course of 15 months; results from three time points are used to evaluate significant change in outcome scores over time in this analysis: at enrollment/baseline (T0), postintervention/follow-up 1 (T1), and at second follow-up/follow-up 2 (T2) data. Of the 112 participants who consented to participate, 91 (81%) agreed and received the PAUSE SM education intervention; 73 (80%) completed and returned at least one follow-up, and 46 (51%) completed and returned at least two follow-up questionnaires.

Participants completed the assessment self-reported questionnaire at enrollment during their clinic visit; because of time constraints (transportation, diagnostic lab tests, electroencephalogram [EEG]), some participants partially completed the remainder of the questionnaire at home and mailed it to the study office. All follow-up assessment questionnaires were mailed to participants along with a prepaid, preaddressed return envelope. Participants were asked to complete these questionnaires at each of the 4 follow-up time points. Follow-up 1 was sent immediately following completion of the SM education intervention and often coincided with tablet return. Follow-up 2 was sent to participants approximately three months following return of the first follow-up assessment. Median time to complete each follow-up questionnaire was assessed as number of weeks following baseline assessments. Median time to return follow-up 1 questionnaires was 17.1 weeks (interquartile range [IQR]: 3.6) and to return follow-up 2 was 34.8 weeks (IQR: 8.2).

Participants received $10 as compensation for completion and return of each follow-up questionnaire.

2.5. Measures

Detailed information on all measures used during the PAUSE study was previously published [19]. Table 2 summarizes all PAUSE measures and scoring.

2.5.1. Sociodemographic and health assessments

Sociodemographic and health data were collected at baseline using sociodemographic and background health questionnaires, as well as the Patient Health Questionnaire (PHQ-9) to assess self-reported symptoms of depression [21]. Participant data for insurance status, epilepsy type, primary care provider, and number of current ASM were also obtained from the electronic medical record.

2.5.2. Epilepsy self-management measures

Participants completed the 65-item Adult Epilepsy Self-Management Measurement Instrument (AESMMI-65) to assess the frequency of use of epilepsy SM practices [22], the 33-item Epilepsy Self-Efficacy Scale to measure self-efficacy of epilepsy SM skills [23,24], and the Epilepsy Outcome Expectancy Scale [25] at all time points.

2.5.3. Quality of life

Quality of life was measured using the QOLIE-10-P instrument [26]; QOLIE-10-P is an 11-item survey questionnaire of which the first 10 items measure health-related quality of life for adults with epilepsy (referred as QOLIE-10), where higher scores indicated increased QOL. The last, 11th item of the QOLIE-10-P includes a patient-reported distress item that is used to weight overall QOLIE scores (referred as QOLIE-10-P). Participants completed QOLIE-10-P questionnaires at all time points. We have described QOLIE-10P in our previous publication [19].

2.5.4. Personal impact of epilepsy measure

Participants completed the 25-item Personal Impact of Epilepsy Scale (PIES) questionnaires at all time points [27]; PIES measures the overall negative impact of epilepsy on life. The PIES scores were calculated using the updated PIES Scoring Manual Version 3.0. Higher scores indicate more negative impact of epilepsy on the life of PWE (in contrast, our earlier publication used PIES Scoring Manual Version 2.0 where higher scores indicate less negative impact of epilepsy on the life of PWE). The Pearson correlation coefficient (and p-value) between PIES and QOLIE-10 is −0.616 (<0.001), and between PIES and QOLIE-10-P is −0.661 (<0.001).

2.6. Statistical analysis

2.6.1. Missing data

2.6.1.1. QOLIE-10 and QOLIE-10-P. Total scores were calculated according to the QOLIE Development Group Scoring Manual. If only one QOLIE item was missing, the missing item score was imputed based on the remaining 9 items following the scoring manual instructions. If more than one item was missing, the score became invalid and was not included in the data analysis. The details of the QOLIE-10 and QOLIE-10-P imputation method are provided in an earlier publication [19].

2.6.1.2. AESMMI-65. The AESMMI-65 domain-specific and overall scores were calculated according to the AESMMI-65 scoring instructions. We imputed missing values as described below. If the item value at both T0 and T1 time points (or both T1 and T2 time points) were missing for any given participant, it was treated as missing data for that participant. If the item value for either T0 or T1 (or T1 or T2) time points was not missing, the missing item value was imputed from the nonmissing value at the corresponding time point. First, we determined the percentile value of the nonmissing item among all participant values at that time point. The missing item value at the corresponding time point was then imputed and replaced by calculating the value at the same

Table 2
Description of PAUSE Self-Management Analysis Measures.

Measure	Higher scores indicate:	No. of Items	Possible max score
PHQ-9	Higher number of depression symptoms	9	27
AESMMI-65	more frequent use of SM strategies	65	325
Healthcare Comm.	more frequent healthcare communication	14	70
Treatment Management	more frequent treatment management	11	55
Coping	more frequent use of coping practices	10	50
Social Support	greater social support	7	35
Seizure Tracking	more frequent seizure tracking	3	15
Wellness	greater wellness	3	15
Seizure Response	more frequent seizure response practices	3	15
Safety	more frequent use of safety practices	4	20
Med. Adherence	greater medication adherence	4	20
Stress Management	greater stress management	3	15
Proactivity	greater proactivity	3	15
Self-Efficacy	higher levels of confidence in ability to manage epilepsy	33	300
PIES	epilepsy has a greater negative impact on PWE life	25	100
Seizures	seizures have a greater negative impact on life	9	100
Adverse Effects	medication adverse effects have a greater negative impact on life	7	100
Mood & Social Situation	mood and social situations have a greater negative impact on life	9	100
QOLIE-10	higher self-reported QOL	10	100
QOLIE-10-P	higher self-reported QOL including self-reported distress	11	100
Outcome Expectancy			
Treatment	higher perceived optimism for treatment outcomes	12	100
Seizures	lower perceived optimism for seizure outcomes	17	100
Management	higher perceived optimism for management outcomes	8	100

percentile level determined earlier for the nonmissing value for that item.

There was very little missing data; imputation was required only for the seizure tracking, wellness, safety, and proactivity domains. For seizure tracking, 3 (4.1%) participants had missing values at T0 and T1, and so, data were not imputed; 3 (4.1%) had missing data at T1 but had available data at T0 and so were imputed. For wellness, 1 (1.4%) participant had missing data at T1 and observed data at T0, so data were imputed. For safety, 1 (1.4%) participant had missing data at T1 and observed data at T0, so data were imputed. For proactivity, 1 (1.4%) participant had missing values at T0 and T1, and so, data were not imputed; 1 (4.1%) participant had missing data at T1 but had available data at T0 and so were imputed.

Similarly, missing values at T2 were imputed only if there was an observed value at T1 for that item. For seizure tracking, a total of 3 (6.5%) participants had missing data at T2 but had available data at T1 and so were imputed.

2.6.2. Data analysis

2.6.2.1. Descriptive statistics. Statistical analysis was performed with STATA 15.0 [28]. Descriptive statistics was performed to examine distribution of the data, kurtosis, and skewness.

2.6.2.2. Multiple regression analysis for estimation of change in response variables (epilepsy SM measures, QOL, and PIES). Linear regression analysis was utilized to test the change in scores for responses from T0 to T1 (Δ_1) with adjustment for T0 scores, and from T1 to T2 (Δ_2) with adjustment for T1 scores. The intercept (β_0) in regression model represents the estimated mean response difference from T0 to T1 (or T1 to T2) if the score at T0 (or T1) was 0, and the slope (β_1) coefficient represents the estimated change in the response variable for a 1 unit change in T0 (or T1) score. Since 0 is not necessarily a possible score for all measures at T0 (or T1), in this analysis, β_0 is the intercept of regression line. One may infer that if $\beta_0 = 0$ is rejected at a significance level of $\alpha = 0.05$ then the mean Δ_1 or Δ_2 values are significantly different than 0 for scores at T0 (or T1). For all outcomes (Δ_1 or Δ_2), with the exception of PIES and outcome expectancy for seizures, a positive β_1 coefficient indicates that an individual who starts with a higher score improves more, on average, than those who start with lower scores at T0 (or T1). In contrast, a negative β_1 coefficient means that an individual who starts with a lower score improves more on average than those who start with higher scores at T0 (or T1). We also evaluated the effect of moderate to severe depression symptoms (PHQ-9 total score > 9, assessed at study enrollment) and the interaction between moderate-to-severe depression symptoms and T0 scores on Δ_1 after adjustment for T0 scores. The moderate to severe depression symptoms variable (depression) was categorized as 0 (PHQ-9 score ≤ 9) and 1 (PHQ-9 score > 9). Here, the slope coefficient (β_2) represents the effect of depression on the change in scores for response variables, and the slope coefficient (β_3) represents the interaction effect between depression and the baseline (T0) response variable score on the change in response variable. The statistical significance was examined with $p < 0.05$.

3. Results

3.1. Sociodemographic characteristics of PAUSE participants

The sociodemographic characteristics of participants ($n = 91$) who completed the SM education intervention are outlined in Table 3. The mean age of participants was 37.8 ($\pm$12.0) years. Over half (61.5%) were women; nearly 40% were non-Hispanic black and 23% were Hispanic. Participants were relatively well-educated, with 66% having had at least some college, yet less than one-third (28.6%) reported being employed either part- or full-time. The majority of participants used either Medicaid (63.1%) or Medicare (6%), and 16% reported living alone.

3.2. Epilepsy-related health characteristics of PAUSE participants

Table 4 shows the seizure and health characteristics of PAUSE participants who completed the SM education intervention. The mean age of epilepsy diagnosis was 24.8 years old, participants had a diagnosis of epilepsy on average 13 years prior to starting the intervention, and 4% reported having kept a seizure diary or calendar. Almost half (49%) reported their most recent seizure had occurred in the past month and only 13.3% had been seizure-free for over one year. One-third (34%) had been hospitalized overnight and nearly half (46%) had visited the ER for epilepsy within the past year. Half of the participants reported moderate to severe depressive symptoms. Over half (64%) of the

Table 3
Sociodemographic characteristics of PAUSE participants (n = 91).

Self-reported characteristic	N (%)
Age, mean (SD)	37.8 (12.0)
Female	56 (61.5)
Race/ethnicity	
Non-Hispanic White	18 (19.8)
Non-Hispanic Black	35 (38.5)
Hispanic	21 (23.1)
Non-Hispanic Other	17 (18.7)
Education	
Less than high school	3 (3.3)
High school/GED	25 (27.5)
At least some college	60 (65.9)
Unknown/Not reported	3 (3.3)
Employment status	
Employed (part- or full-time)	26 (28.6)
Unable to work [a]	31 (34.1)
Unemployed	17 (18.7)
Other/Not Reported [b]	17 (18.7)
Household Income	
Less than $25,000	31 (34.1)
$25,000–$49,999	12 (13.2)
$50,000 or more	11 (12.1)
Unknown/Not reported	37 (40.7)
Lives alone	15 (16.5)
Insurance Status [c]	
Uninsured/Unknown	4 (4.8)
Medicaid	53 (63.1)
Medicare	5 (6.0)
Private	22 (26.2)

[a] Includes disability.
[b] Includes students, retirees, and homemakers.
[c] Data from clinic participant electronic medical record, n = 84.

participants report having had at least one seizure in the past three months, and 48% were taking two or more ASM.

3.3. Change in scores (Δ_1) for SM, QOL, and PIES after adjustment for T0 scores

Results from linear regression analysis for estimated changes in SM, QOL, and PIES measures from T0 to T1 after adjustment for baseline scores are summarized in Table 5. All measures, except PIES and outcome expectancy for seizures, had statistically significant positive intercepts (β_0) and statistically significant negative β_1 coefficients, indicating significant improvement from T0 to T1 (after intervention) and that individuals with lower scores at T0 on average improved significantly more than those with higher T0 scores. Statistically significant positive intercepts (β_0) and statistically significant negative β_1 coefficients for PIES indicate that individuals who experience a higher negative impact of epilepsy on life at T0 show a significant reduction in the negative impact of epilepsy following intervention (from T0 to T1). The outcome expectancy for seizures measure had a statistically significant negative intercept (β_0) and statistically significant negative β_1 coefficient indicating that a participant who had reported less optimism about outcomes resulting from seizures at T0 on average had increased optimism following intervention (from T0 to T1).

3.4. Change in scores (Δ_2) for SM, QOL, and PIES after adjustment for T1 scores

Results from linear regression analysis for estimated changes in SM, QOL, and PIES measures from T1 to T2 after adjustment for T1 scores are summarized in Table 6. Results show statistically significant improvements in the majority of measures (with exceptions for: seizure tracking, wellness, safety, PIES overall and all domains, QOLIE-10-P, outcome expectancy for seizures, and outcome expectancy for management) were sustained at T2 and indicate that individuals with lower scores at T1 on average improved significantly more than individuals who scored higher at T1.

3.5. Δ_1 for SM, QOL, and PIES after adjustment for T0 scores and depression

Multiple linear regression analysis estimated changes in scores from T0 to T1 after adjustment for both T0 scores and depression (0/1), as well as their interaction. Coefficients were considered to have had significant effect on Δ_1 if the interaction term (β_3), along with its 95% confidence interval and with p-value, was significant (with $p < 0.05$). This analysis revealed that change in the AESMMI: safety domain scores was significantly modified by depression at baseline. A positive coefficient for the intercept ($\beta_0 = 5.04$, $p = 0.01$) and for depression ($\beta_2 = 5.56$, $p = 0.02$) and a negative coefficient for T0 score ($\beta_1 = -0.35$, $p = 0.01$) and for the interaction term ($\beta_3 = -0.41$, $p = 0.03$) indicate that individuals with depression would have a larger improvement in utilization of safety practices following the SM education intervention (T0 to T1) than individuals without depression, though this positive effect is reduced for participants with higher T0 scores. Depression did not play a significant role in improvement for other epilepsy SM, QOL, or PIES measures.

Table 4
Seizure and health characteristics of PAUSE participants (n = 91).

Self-reported characteristics	N (%)
Age diagnosed, mean (SD)	24.8 (14.7)
Years since diagnosis, mean (SD)	13.0 (13.7)
Reported last seizure [a]	
Within past month	44 (48.9)
1–3 months ago	14 (15.6)
4–12 months ago	20 (22.2)
Over 1 year ago	12 (13.3)
Hospitalized overnight for epilepsy within past year	31 (34.1)
Visited ED for epilepsy within past year	42 (46.2)
Has a VNS or has undergone surgery for epilepsy	5 (5.5)
Follows a special diet for epilepsy	3 (3.3)
Uses a seizure diary or calendar	4 (4.4)
Reports moderate to severe depressive symptoms [b]	46 (50.5)
Has visited epilepsy.com:	
Yes, a lot	6 (6.6)
Yes, a moderate amount	9 (9.9)
Yes, a little	18 (9.9)
No	58 (63.7)
No. of seizures in past month [c]	
0	45 (52.9)
1–2	19 (22.4)
3+	21 (24.7)
No. of seizures in past 3 months [d]	
0	30 (36.1)
1–2	21 (25.3)
3+	32 (38.6)
Epilepsy Type [e]	
Focal	62 (74.8)
Generalized	22 (26.2)
Has a primary care provider [e]	55 (65.5)
No. of current ASDs [e]	
1	44 (52.4)
2	26 (31.0)
3+	14 (16.7)

[a] 1 participant did not respond, n = 90.
[b] PHQ-9 score ≥ 10.
[c] 6 participants did not respond, n = 85.
[d] 8 participants did not respond, n = 83.
[e] Data from clinic participant electronic medical record, n = 84.

Table 5
Change in self-management assessment scores from T0 to T1 (Δ_1) after adjustment for T0 scores (n = 73).[a]

Measure	Values		Adjusted for T0 scores					
	T0	T1	Intercept (β0)			T0 score (β1)		
	Mean (SD)	Mean (SD)	Coef.	95% CI	p	Coef.	95% CI	p
AESMMI-65	227.99 (37.04)	242.04 (40.44)	83.44	37.45, 129.43	0.001	−0.30	−0.50, −0.11	0.003
Healthcare Communication	44.30 (16.31)	48.00 (14.90)	25.73	17.22, 34.23	0.000	−0.50	−0.68, −0.32	0.000
Treatment Management	50.08 (5.56)	49.67 (6.43)	19.44	7.67, 31.22	0.002	−0.40	−0.63, −0.17	0.001
Coping	34.68 (36.71)	36.71 (9.37)	17.74	10.86, 24.63	0.000	−0.45	−0.64, 0.26	0.000
Social Support	24.82 (8.08)	26.49 (6.59)	15.07	10.92, 19.22	0.000	−0.54	−0.70, −0.38	0.000
Seizure Tracking	10.50 (4.12)	11.97 (3.78)	7.58	5.35, 9.80	0.000	−0.58	−0.78, −0.38	0.000
Wellness	8.82 (3.02)	9.64 (2.91)	3.84	2.29, 5.38	0.000	−0.34	−0.51 -0.18	0.000
Seizure Response	8.78 (3.60)	10.11 (3.40)	5.86	4.04, 7.67	0.000	−0.52	−0.71, −0.32	0.000
Safety	11.75 (4.95)	13.16 (4.30)	7.91	5.67, 10.16	0.000	−0.55	−0.73, −0.38	0.000
Medication Adherence	17.16 (2.89)	17.44 (3.01)	6.87	3.41, 10.33	0.000	−0.38	−0.58, −0.19	0.000
Stress Management	6.32 (3.72)	7.65 (4.02)	3.67	2.14, 5.21	0.000	−0.37	0.58, −0.16	0.001
Proactivity	11.27 (3.36)	11.78 (3.36)	5.46	3.17, 7.76	0.000	−0.44	−0.63, −0.24	0.000
Self-Efficacy	247.84 (48.69)	248.99 (55.21)	140.88	78.33, 203.43	0.000	−0.56	−0.81, −0.32	0.000
PIES	38.11 (21.35)	37.67 (21.83)	9.46	2.18, 16.73	0.012	−0.26	−0.43, −0.09	0.003
Seizures	39.56 (27.51)	36.57 (27.00)	11.29	2.87, 19.70	0.009	−0.36	−0.53, −0.18	0.000
Adverse Events	33.29 (24.90)	36.88 (23.50)	17.17	9.79, 24.55	0.000	−0.41	−0.59, −0.24	0.000
Mood & Social Situation	41.47 (23.41)	39.57 (24.27)	8.98	0.73, 17.24	0.033	−0.27	−0.44, −0.09	0.003
QOLIE-10	53.02 (18.96)	55.46 (17.11)	40.17	28.62, 51.73	0.000	−0.71	−0.92, −0.51	0.000
QOLIE-10-P	30.17 (23.41)	33.08 (23.60)	16.36	8.48, 22.25	0.000	−0.45	−0.66, −0.24	0.000
Outcome Expectancy								
Treatment	3.67 (0.83)	3.58 (0.83)	2.13	1.32, 2.95	0.000	−0.60	−0.82, −0.39	0.000
Seizures	3.10 (0.65)	2.93 (0.67)	−0.82	0.21, 1.42	0.009	−0.32	−0.51, −0.13	0.001
Management	4.23 (0.64)	4.11 (0.64)	2.09	1.19, 2.99	0.000	−0.52	−0.73, −0.31	0.000

[a] Includes only participants who completed both baseline (T0) and follow-up 1 (T1).

4. Discussion

4.1. The PAUSE to Learn Your Epilepsy SM education intervention demonstrates significant improvement in self-efficacy, epilepsy SM behaviors and practices, expected epilepsy outcomes QOL in epilepsy, and personal impact of epilepsy

The PAUSE intervention included education to improve all SM domains including lifestyle, seizure control, safety, medication adherence and compliance, and information management. We found that, for all measures, PAUSE participants showed improvement following SM education. For the majority of measures, participants maintained this level of improvement through the second follow-up at a median of about 35 weeks, or about 8 months. Unlike most other currently available programs, which a Cochrane review concluded are relatively labor- and time-intensive and require substantial investment from the clinical centers, PAUSE is scalable, cost-effective, and can be implemented quickly and easily in clinics [29]. In coordination with clinic and social services

Table 6
Change in self-management assessment scores from T1 to T2 (Δ_2) after adjustment for T1 scores (n = 46).[a]

Measure	Values		Adjusted for T1 Scores					
	T1	T2	Intercept (β0)			T1 Score (β1)		
	Mean (SD)	Mean (SD)	Coef.	95% CI	p	Coef.	95% CI	p
AESMMI-65	242.39 (40.09)	237.20 (39.81)	120.51	55.70, 185.32	0.001	−0.51	−0.78, −0.25	0.000
Healthcare Communication	47.67 (14.24)	47.80 (15.90)	36.08	19.63, 52.53	0.000	−0.75	−1.09, −0.42	0.000
Treatment Management	49.76 (6.27)	49.83 (5.62)	26.89	15.17, 38.61	0.000	−0.54	−0.77, −0.31	0.000
Coping	36.74 (9.70)	36.24 (10.08)	23.07	11.82, 34.32	0.000	−0.64	−0.94, −0.35	0.000
Social Support	26.50 (6.67)	26.41 (6.41)	11.64	5.15, 18.14	0.001	−0.44	−0.68, −0.20	0.001
Seizure Tracking	11.91 (3.82)	10.00 (4.52)	0.21	−3.22, 3.64	0.901	−0.17	−0.45, 0.10	0.207
Wellness	9.57 (2.93)	9.22 (3.16)	2.28	−0.15, 4.72	0.065	−0.27	−0.52, −0.03	0.028
Seizure Response	10.22 (3.39)	9.85 (3.40)	2.27	−0.06, 4.48	0.044	−0.26	−0.46, −0.05	0.015
Safety	13.02 (4.59)	12.22 (5.06)	2.86	−0.65, 6.37	0.108	−0.28	−0.54, −0.03	0.031
Medication Adherence	17.50 (2.98)	16.70 (3.32)	7.67	2.35, 13.00	0.006	−0.48	−0.78, −0.18	0.002
Stress Management	7.98 (4.21)	7.28 (3.57)	−13.07	−15.80, −10.34	0.000	0.36	0.05, 0.66	0.022
Proactivity	12.04 (3.18)	11.65 (3.16)	5.80	2.52, 9.07	0.001	−0.51	−0.78, −0.25	0.000
Self-Efficacy	247.20 (59.27)	248.93 (60.19)	99.44	36.48, 162.39	0.003	−0.40	−0.64, −0.15	0.002
PIES	39.67 (21.74)	39.09 (22.20)	5.60	−2.70, 13.90	0.181	−0.16	−0.34, 0.02	0.088
Seizures	39.67 (26.10)	38.50 (28.96)	3.32	−6.76, 13.40	0.660	−0.12	−0.33, 0.09	0.258
Adverse Events	38.02 (23.40)	37.87 (26.70)	6.91	−4.27, 18.09	0.219	−0.18	−0.44, 0.07	0.145
Mood & Social Situation	41.31 (25.17)	40.89 (24.35)	8.67	0.14, 17.48	0.054	−0.22	−0.41, −0.04	0.018
QOLIE-10	55.45 (17.85)	58.20 (20.64)	22.85	5.94, 39.76	0.009	−0.36	−0.65, −0.07	0.016
QOLIE-10-P	32.83 (24.37)	35.02 (28.12)	10.62	−0.06, 21.30	0.051	−0.24	−0.50, 0.03	0.079
Outcome Expectancy								
Treatment	3.56 (0.86)	3.44 (0.75)	1.94	1.04, 2.84	0.000	−0.58	−0.83, −0.33	0.000
Seizures	2.85 (0.62)	3.04 (0.78)	0.53	−0.27, 1.33	0.191	−0.10	−0.38, 0.17	0.455
Management	4.06 (0.63)	3.86 (0.79)	0.88	−0.49, 2.25	0.200	−0.27	−0.61, 0.06	0.105

[a] Includes only participants who completed both follow-up 1 (T1) and follow-up 2 (T2).

visits, PAUSE can be a very useful tool for healthcare providers and/or case managers who may not have the time during every in-person visit to educate PWE on SM practices; PAUSE uses a patient-centered approach to enable all PWE to address their own unique issues in managing epilepsy independent of environmental barriers, psychological comorbidities, the wide range of epilepsy types and severity, varying lifestyles, and the complexities of healthcare for women. Providers are able to identify the SM education needs of each individual patient during regular clinic visits in less than 5 min and allow PWE to educate themselves on how to self-manage at their own pace. It also allows the patient and provider to have equal input on education modules, giving patients responsibility and ownership over their education and epilepsy SM.

4.2. PAUSE study population is diverse

As shown in our previous publication, the PAUSE study population is very diverse and is a true representation of the racial/ethnic breakdown of underserved areas of Chicago [30]. There was a slightly higher proportion of black participants than can be seen in Chicago and slightly fewer Hispanics, due to the fact that PAUSE is currently only offered in English. However, this demonstrates a need for a Spanish-language version of PAUSE.

4.3. The PAUSE intervention is especially useful for underserved PWE

Many underserved Chicago residents lack access to care and do not have the resources to self-educate, such as reliable internet access. This has been shown dramatically due to the current COVID-19 pandemic, where the Chicago Public School District has demonstrated a lack of computer/Wi-Fi access and a need to provide remote learning devices among many families [31]. These findings demonstrate the limitations of underserved PWE with respect to accessing online epilepsy content and how PAUSE helped them to overcome these barriers; PAUSE is innovative in that it provides a preprogrammed internet-connected tablet device that participants can use on their own time to obtain personalized epilepsy SM information specific to their life and specific needs. This gives a freedom and sense of ownership over SM and education not seen in many other epilepsy education interventions.

4.4. Comparison of PAUSE findings to other epilepsy SM interventions examining improvements in self-efficacy, SM behaviors and practices, and quality of life in epilepsy

Overall, study findings showed that the PAUSE program can be an effective means to provide SM education to PWE during their regular clinic visits. The results indicate that personalized SM education led to a significant increase in self-efficacy among those who were at lower level at baseline. That is, participants showed a more positive attitude towards SM behaviors and more confidence in their ability to engage in these actions. Results demonstrate that a tailored SM education significantly increases the frequency of epilepsy SM behaviors and practices overall and particularly in healthcare communication, treatment management, coping, social support, seizure tracking, wellness, seizure response, safety, medication adherence, stress management, and proactivity. The results also show a significant increase in treatment, and epilepsy outcome expectancies suggesting an increase in PWE judgment of positive outcomes of treatment and epilepsy management. Results also show a significant decrease in seizure outcome expectancy, indicating an expectation of less negative outcomes resulting from epilepsy. A significant increase in quality of life in epilepsy measures following SM education intervention reveal an increase in PWE's subjective perception of overall wellbeing in living with epilepsy. The results of PIES overall and PIES domain measures indicate that PWE who assessed greater negative impact of epilepsy overall and specifically as related to seizures, ASM adverse effects, and comorbidities reported less negative impact following intervention. Taken together, these results demonstrate that a personalized epilepsy SM education approach, such as PAUSE, "improves and expands educational opportunities for PWE and their families, as well as ensures that all PWE and their families have access to accurate, clearly communicated educational materials and information" as suggested in an Institute of Medicine (IOM) report [1]. In a recent review "Self-management in Epilepsy Care", Ozuna J et al. reviewed seven SM interventions for PWE which were delivered by either online or group sessions [15]. Of these, three studies report improvement in self-efficacy [17,18,32], six studies reported improvement in various components of SM behavior and practices [11,14,17,18,32], and one study reported improvement in QOLIE measure [18]. The ZAMILLE study also reported significant improvement in QOLIE-31P in the treatment group compared to the group, which received usual care [13]. The effect of SM intervention on PIES or outcome expectancies has not been examined in previously published reports. In addition, measures used by other studies to assess SM practices and QOL are partially comparable to our study; previously reported studies did not use the AESMI-65 instrument to measure SM behavior and practices.

4.5. Comparison of PAUSE recruitment and retention with other SM intervention studies

We presented recruitment and retention of PAUSE participants in Fig. 2. We noted that 48.6% of those who were referred for SM intervention by epilepsy specialty clinics healthcare providers consented to participate; 81.2% of those who consented participated in SM intervention. For retention, 80.2% returned the postintervention assessments (Follow-up 1). The recruitment and retention of participants is comparable to WebEase, POEM, and ZAMIL [13,17,32]. Low retention at follow-up may be due to lengthy follow-up SM measure questionnaires, which contained approximately 200 items. Recruitment from the community through the EF local chapters/affiliates was less successful than expected. Many PWE from community felt that they already received adequate SM education through EF case managers; PWE mostly visit EF offices for social purposes, such as support groups or local awareness events, so epilepsy treatment and SM education were less of priority. Retention was also challenge in our underserved population due to lack of adequate transportation, frequently disconnected telephone numbers, no-shows at clinic appointments, incarceration, and other personal issues due to their sociodemographic situation.

4.6. Limitations of this study

There are several limitations of the PAUSE intervention. First, it was not a randomized controlled trial. Second, PAUSE assessed improvement in SM and outcome expectancies measure, QOL, and PIES scores following intervention by using within-subject longitudinal assessments to compare a participant's follow-up scores to baseline scores. We acknowledge that this single-group pre- and postintervention design lacked a control group and thus has limited external validity. We explored whether the change is due to a maturation effect or sensitivity to change over time. The immediacy of postintervention measures (median time: 17 weeks) should mitigate this, however. Also, we found that improvement is more significant from baseline (T0) to follow-up 1 (T1) than from follow-up 1 (T1) to follow-up 2 (T2), which is further evidence of the effect of the intervention. The intervention effect would diminish over time but a maturation or time effect would be constant over time.

Another threat to internal validity in a single-group intervention study is statistical regression to the mean. We concluded that the results are not due to "regression to the mean" as mean response variables consistently move to the "improving" direction on all items from T0 to T1 and on most items from T1 to T2. This indicates that the entire distribution shifts toward improvement following intervention. For example,

for AESMMI-65 overall, the mean (and Q1, Q3) prior to intervention at T0 was 228 (210, 252); following intervention at T1, the AESMMI-65 overall mean was 242 (216, 270). For QOLIE-10-P, the mean at T0 was 53 (41, 66) and was 55 (46, 76) at T1. Although, on average, individuals with worse scores improve more than individuals with better scores, the intervention benefits the whole study population, not only individuals who begin with lower scores. Based on these results, we conclude that regression to the mean is not a plausible explanation.

It may also be argued that PWE elected to participate and therefore may be more motivated to improve than PWE as a whole and particularly those who declined participation, though sociodemographic and epilepsy health data for participants did not differ significantly from that of those who elected not to participate [20]. However, our findings show optimistic effects of the PAUSE intervention and provide information about subgroups of PWE who may benefit the most from SM education. Specifically, we found that those who had lower SM measure, QOLIE or PIES scores to begin with had the most improvement; PWE who had mild-to-moderate depression symptoms showed greater improvement in SM behaviors and practices related to safety.

The study findings have limited generalizability and can only be compared to studies with similar sociodemographic participant characteristics. As PAUSE was limited by nonavailability of SM information in Spanish, meaning that Spanish-speaking PWE could not participate in PAUSE, the results could not be generalized to that population. The PWE, or their caregivers, who could not read at an eight-grade reading level were also not included. Nevertheless, PAUSE study findings identify subgroups of PWE who will benefit from the PAUSE intervention. It is also important to recognize that many PAUSE participants were in a "hard to reach and treat" subgroup of PWE where the majority of participants were on public healthcare, had epilepsy for an average of 13 years, and their condition required visits to epileptologists at an epilepsy subspecialty clinic. We noted that requiring education materials to be downloaded from the Internet each time made the PAUSE application unwieldy, slow, and difficult to use. Participants often commented about long lag and wait times for accessing modules, especially PWE who lived in areas with poor 4G service. Slow internet capabilities or loss of internet connection in some urban locations was noted as a limitation to PAUSE as participants may have lost interest in continuing with SM education if they were experiencing technical difficulties. Self-reported responses, recall and social-desirability biases, random responding, and exaggeration toward more desirable outcomes were possible. However, the use of validated questionnaires and a mixture of patient-reported outcome measures (particularly QOLIE and PIES) where a higher vs. lower score indicate better SM mitigates these biases and demonstrates that participants were meaningfully responding to questions. This is the first study to reporting both QOLIE and PIES assessments and therefore provides evidence that PWE perceive better QOL when they view a reduced impact of epilepsy on their life.

It is unlikely that provider relationship with long-term patients had any impact on the outcome of the study. We analyzed self-reported information from participants regarding how long they had been patients at the UIH epilepsy subspecialty clinic. Only 17% of participants reported having seen a provider at UIH for more than five years, and 60% reported having seen a provider at UIH for less than 2 years. It is also important to note that the role of providers in the clinic was solely to identify eligible patients to PAUSE study staff and ask if they would like to learn more about the epilepsy SM education study. Introduction and explanation of PAUSE, informed consent, and all other study-related tasks were handled by the study investigators and research staff who had no clinical relationship with patients.

4.7. There is a greater need for further epilepsy SM education intervention testing in diverse epilepsy clinics and in community settings

Local Epilepsy Foundation center case managers have commented that, in their experience, a much higher proportion of PWE than the reported two-thirds have never accessed web-based resources (reported earlier and here) [19]. The PAUSE staff have reported that many PWE have a need for this personalized approach to improve their knowledge of epilepsy. Further research should attempt to reach a larger and more diverse population of PWE to assess the effectiveness of personalized epilepsy SM education interventions. There should also be additional focus on the effect of health illiteracy on the adoption and use of SM practices among PWE, especially in underserved communities.

5. Conclusion

The results provide evidence for the potential benefit of mobile technology-based personalized SM education, such as PAUSE, that improves epilepsy SM behavior and practices, QOL, improve outcome expectation for treatment and epilepsy management, reduces pessimism related to outcome of seizures, boosts self-efficacy, and reduces negative impact of epilepsy due to seizures, ASM adverse effects, and comorbidities; PAUSE helped underserved PWE overcome educational barriers due to limited access to online epilepsy content; PAUSE can be implemented in a clinical setting or in the community through a partnership with community-based organizations. It is easy-to-use, not labor-intensive, and time-efficient. Healthcare providers and/or case managers, along with PWE, can identify epilepsy SM needs during a regular clinic or social services visit; support staff can then easily select those identified SM needs into a preprogramed tablet device. The strengths of PAUSE include its ability to succeed with a diverse population including many underserved PWE with uncontrolled epilepsy (86.7%). The results should be interpreted with caution, as epilepsy SM measures and outcomes may be sensitive to change over time due to the time-effect. This underscores a greater need for a pragmatic trial to test the effectiveness of mobile technology-based personalized SM education on SM of epilepsy and for improving epilepsy outcomes in broader settings, specifically for the unique needs of the hard-to-reach and hard-to-treat population of PWE.

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Declaration of competing interest

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.

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References

[1] IOM (Institute of Medicine). Epilepsy across spectrum:Promoting health and understanding. Washington, DC: The National Academic Press; 2012.
[2] Hirtz D, Thurman DJ, Gwinn-Hardy K, Mohamed M, Chaudhuri AR, Zalutsky R. How common are the "common" neurologic disorders? Neurology. 2007;68(5):326–37.
[3] Tian N, Boring M, Kobau R, Zack MM, Croft JB. Active epilepsy and seizure control in adults — United States, 2013 and 2015. MMWR Morb Mortal Wkly Rep. 2018;67(15):437–42.
[4] Murray CJ, Vos T, Lozano R, Naghavi M, Flaxman AD, Michaud C, et al. Disability-adjusted life years (DALYs) for 291 diseases and injuries in 21 regions, 1990–2010: a systematic analysis for the Global Burden of Disease Study 2010. Lancet. 2012;380(9859):2197–223.
[5] Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient self-management of chronic disease in primary care. JAMA. 2002;288(19):2469–75.
[6] Newman S, Steed L, Mulligan K. Self-management interventions for chronic illness. Lancet. 2004;364(9444):1523–37.
[7] Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: a review. Patient Educ Couns. 2002;48(2):177–87.
[8] Long L, Reeves AL, Moore JL, Roach J, Pickering CT. An assessment of epilepsy patients' knowledge of their disorder. Epilepsia. 2000;41(6):727–31.
[9] Liu C, Kuo K. Does information overload prevent chronic patients from reading self-management educational materials? Int J Med Inform. 2016;89:1–8.
[10] Khaleel I, Wimmer BC, Peterson GM, Zaidi STR, Roehrer E, Cummings E, et al. Health information overload among health consumers: a scoping review. Patient Educ Couns. 2020;103(1):15–32.
[11] May TW, Pfafflin M. The efficacy of an educational treatment program for patients with epilepsy (MOSES): results of a controlled, randomized study. Modular Service Package Epilepsy Epilepsia. 2002;43(5):539–49.
[12] Ridsdale L, McKinlay A, Wojewodka G, Robinson EJ, Mosweu I, Feehan SJ, et al. Self-Management education for adults with poorly controlled epILEpsy [SMILE (UK)]: a randomised controlled trial. Health Technol Assess. 2018;22(21):1–142.
[13] Leenen LAM, Wijnen BFM, Kessels AGH, Chan H, de Kinderen RJA, Evers SMAA, et al. Effectiveness of a multicomponent self-management intervention for adults with epilepsy (ZMILE study): a randomized controlled trial. Epilepsy Behav. 2018;80:259–65.
[14] Aliasgharpour M, Dehgahn Nayeri N, Yadegary MA, Haghani H. Effects of an educational program on self-management in patients with epilepsy. Seizure. 2013;22(1):48–52.
[15] Ozuna J, Kelly P, Towne A, Hixson J. Self-Management in Epilepsy Care: untapped opportunities. Fed Pract. 2018;35(Suppl. 3):S10–6.
[16] Sajatovic M, Johnson EK, Fraser RT, Cassidy KA, Liu H, Pandey DK, et al. Self-management for adults with epilepsy: Aggregate Managing Epilepsy Well Network findings on depressive symptoms. Epilepsia. 2019;60(9):1921–31.
[17] Dilorio 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.
[18] 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.
[19] Pandey DK, Levy J, Serafini A, Habibi M, Song W, Shafer PO, et al. Self-management skills and behaviors, self-efficacy, and quality of life in people with epilepsy from underserved populations. Epilepsy Behav. 2019;98(Pt A):258–65.
[20] Analysis of Patient Participation in the PAUSE to Learn Your Epilepsy Self-Management Education Study. Research brief no. 113. Illinois prevention research Center, University of Illinois at Chicago. Chicago, IL [internet]. Available from: https://illinoisprc.org/wp-content/uploads/2019/11/Patient_Participation_Epilepsy_PAUSE_508final.pdf; 2019.
[21] Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. J Gen Intern Med. 2001;16(9):606–13.
[22] Escoffery C, Bamps Y, LaFrance Jr 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.
[23] Robinson E, Dilorio 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.
[24] Dilorio C, Shafer PO, Letz R, Henry TR, Schomer DL, Yeager K, et al. Behavioral, social, and affective factors associated with self-efficacy for self-management among people with epilepsy. Epilepsy Behav. 2006;9(1):158–63.
[25] Dilorio C, Osborne Shafer P, Letz R, Henry T, Schomer DL, Yeager K, et al. The association of stigma with self-management and perceptions of health care among adults with epilepsy. Epilepsy Behav. 2003;4(3):259–67.
[26] Cramer JA, Perrine K, Devinsky O, Meador K. A brief questionnaire to screen for quality of life in epilepsy: the QOLIE-10. Epilepsia. 1996;37(6):577–82.
[27] Fisher RS, Nune G, Roberts SE, Cramer JA. The personal impact of epilepsy scale (PIES). Epilepsy Behav. 2015;42:140–6.
[28] StataCorp. Stata statistical software: Release 15. College Station, TX: StataCorp LLC; 2017.
[29] Bradley PM, Lindsay B, Fleeman N. Care delivery and self management strategies for adults with epilepsy. Cochrane Database Syst Rev. 2016;2:CD006244.
[30] University of Illinois Community Assessment of Needs (UI - CAN), Toward Health Equity [Internet]. 2016:2016 Available from: https://oceanhp.red.uic.edu/wp-content/uploads/sites/416/2020/03/CHNA-UIHealth-1.pdf.
[31] No plans for broad E-learning for Chicago public schools [internet]. 2020. Available from: https://www.npr.org/local/309/2020/03/30/824145943/no-plans-for-broad-e-learning-for-chicago-public-schools.
[32] Hixson JD, Barnes D, Parko K, Durgin T, Van Bebber S, Graham A, et al. Patients optimizing epilepsy management via an online community: the POEM study. Neurology. 2015;85(2):129–36.