Research Paper

Experiences of using the MINDSET Self-Management mobile health app among Hispanic Patients:Results of a qualitative study

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A B S T R A C T

Background: Interventions focusing on epilepsy self-management (ESM) are vital for promoting the health of people living with epilepsy. E-technology and mobile health (mHealth) tools are becoming increasingly integrated into practice to promote self-management strategies for chronic diseases, enhance care delivery, and reduce health disparities. Management Information and Decision Support Epilepsy Tool (MINDSET), a bilingual decision support tool (available in English and Spanish), was found to be both feasible and effective in facilitating goal-based ESM in the clinic.
Purpose: To assess the experience of using MINDSET as an ESM intervention among Hispanic patients with epilepsy to inform future interventional studies.
Methods: This study used a *Qualitative Descriptive (QD)* framework to provide a rich and straightforward description of patients' subjective experiences using MINDSET. Participants were enrolled in the intervention group of a larger parent study (RCT) to assess the efficacy of MINDSET among Hispanic People with Epilepsy (PWE). The purposive, convenient, criterion-based sample for this qualitative analysis comprised of 42 patients who agreed to participate in a semi-structured interview at the end of the larger RCT. This RCT was conducted between August 2017 and January 2019. Spanish and English-speaking Hispanic adult patients (n = 94) with epilepsy in Arizona (n = 53) and Texas (n = 41) were randomly assigned within 6 neurology clinics to treatment (MINDSET plus Usual Care, hereafter referred to as MINDSET; n = 46) and comparison (Usual Care Only; n = 48) conditions.
Results: Patient demographics, epilepsy conditions, and ESM behavioral characteristics were representative of the intervention group. Study participants were Hispanic, mainly of Mexican descent (94 %), with a mean age of 39 years, mostly female (53 %), and most of the participants reported having had one or more seizures per month (54 %). The MINDSET intervention revealed five ESM themes: (1) Awareness and Realization of Epilepsy Self-Management, (2) Communication and Partnership with Health Care Providers HCP, (3) Epilepsy Self-Management and Quality of Life, (4) Seizure Control, and (5) Optimism and Agency.
Conclusion: The participants who used MINDSET as a self-management intervention reported an overall positive experience. Qualitative data in this study show that MINDSET is a valuable ESM tool for Hispanic patients with epilepsy. Findings from this qualitative study were consistent with results from a larger parent study that recognized MINDSET as an effective platform for improving epilepsy self-management adherence.

1. Introduction

1.1. Epilepsy among Hispanics

Among the nation's 3.4 million people with epilepsy (PWE), 400,000 are Hispanic[1], yet disparities exist in the access to, and quality of, epilepsy care [2–4]. Hispanic patients are seeking specialized neurological epilepsy care from outpatient clinics rather than from emergency departments[5], but there are disparities in the receipt of care as well as undertreatment of depressive comorbidities[6]. For example, Hispanic adults with epilepsy in Arizona-Mexico border communities are significantly less likely to have received epilepsy care in the past three months compared to non-Hispanic Whites[7]. Barriers to care appear to be similar between Hispanics and other ethnic groups,[4] and include inter-related factors of language barriers[8], lack of knowledge in the community about epilepsy[9], and misperceptions about anti-seizure medications [10]. This contributes to low self-efficacy about epilepsy management, and low medication adherence, and compromises the effectiveness of the epilepsy treatment that is received and, ultimately, the outcomes of care[11,12].

Epilepsy affects the QOL of patients in the Hispanic community through psychological, physical, and social sequelae and comorbidities of anxiety, depression, and cognitive dysfunction[9,13 14,15]. Hispanic communities with lower socioeconomic status may lack knowledge about seizures and have false perceptions of epilepsy[16]. Hispanic populations with less than a high school education are more likely to believe that epilepsy is contagious or a sin, perceiving that exorcism would be a good remedy for epilepsy[9]. These perceptions can lead to perceived stigma because of their condition. This and limited education regarding epilepsy can limit diagnosis and treatment, as well as self-efficacy to manage the condition, all associated with reduced outcomes in healthcare in Hispanic communities[17].

1.2. Epilepsy Self-Management (ESM) among Hispanics

Epilepsy self-management refers to the variety of behaviors that PWE engage in to treat their condition and prevent seizure onset [18]. Epilepsy self-management (ESM) is associated with greater epilepsy control, reduced seizure frequency, and increased QoL[19] ESM encompasses domains of medication management (e.g., adherence to epilepsy medication and clinical visit regimens), seizure management (e.g., preparation for and response to seizure episodes), and lifestyle management (e.g., altering behaviors to avoid seizure triggers and/or adverse consequences of seizures, conveying and sharing information about seizures and epilepsy)[20,21]. PWE report more ESM behaviors for seizures and medication than other ESM domains (e.g. lifestyle, safety) and ESM is associated with demographic and clinical variables (e.g. age, depression)[22].

Optimal self-management is determined by an interplay of predisposing, reinforcing, and enabling factors (Fig. 1) [23]. Predisposing factors of ESM behavior include the patient's acceptance of their epilepsy diagnosis, knowledge of the disease and its management, self-efficacy, and skills to perform ESM behaviors (e.g., goal setting, monitoring medication adherence, and monitoring environmental and lifestyle seizure triggers), perceived positive outcome expectations regarding the utility of ESM, perceived attributions regarding the value of personal effort in independent management, and perceived stigma related to epilepsy[24–26]. Enabling factors for ESM include the varied skills required for competent ESM by individuals and families, access to medical care, information, and training[27]. Reinforcing factors of ESM behaviors include an active partnership between the health care provider (HCP), the patient, and the patient's family or significant others to aid in adherence to the treatment plan and stimulate improvements in management[23].

Data from the Managing Epilepsy Well (MEW) research network database on 436 PWE participating in five studies across the U.S. indicated that competencies in information and lifestyle management were significantly lower than medication, safety, and seizure management for PWE[28]. The findings from this national sample were consistent across sites and with existing theory and prior empirical studies. Few studies have focused on ESM among Hispanic PWE in the United States and studies that do have had small study samples and have lacked measurement focus on ESM. It has been challenging, therefore, to draw meaningful empirical conclusions on Hispanic ESM practices. Analysis of aggregate data within the Managing Epilepsy Well Network Integrated Database (MEW-DB) with a sample of 212 Hispanic PWE from 9 studies of 5 MEW interventions indicated that Hispanic PWE appear relatively more competent in managing the medical aspects of their condition than in managing broader, and perhaps more challenging, lifestyle and informational issues. Subscale scores were highest for medication, seizure, and safety management and lowest for information and lifestyle management.

There is also growing evidence that demographic factors and clinical variables are associated with ESM in Hispanics with epilepsy[13,22]. ESM is greater among females but, for those reporting depression, medication, lifestyle, and information management are lower. In adjusted multivariate modeling, being retired is associated with greater medication management while depression and never having been married are inversely associated. Being unemployed (unable to work) is associated with better lifestyle management while being female and reporting depression are inversely associated.

Psychological triggers of epilepsy-related seizures include stress, anxiety, and anger[24]. Cross-sectional analysis of pooled data from 10 studies from the Managing Epilepsy Well Network determined that Spanish-speaking Hispanics were less likely than English-speaking Hispanics to report elevated depressive symptoms [22]. However, Hispanics who reported fair or poor health status had a four-fold higher depression prevalence compared to those in the referent group who reported excellent or very good health status. The authors suggested that future studies should include acculturation data to better screen for depression and suicidal ideation risk and optimize interventions for Hispanic PWE. Information management was associated with being born in the U.S.
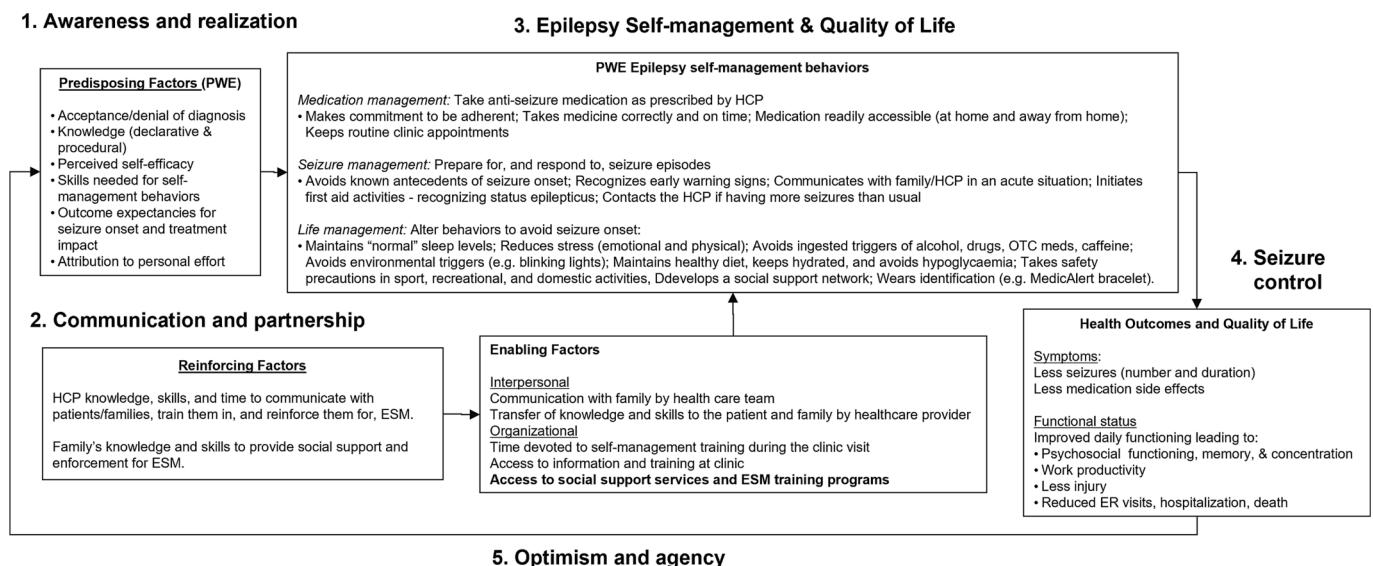

1. Awareness and realization

3. Epilepsy Self-management & Quality of Life

PWE Epilepsy self-management behaviors

Predisposing Factors (PWE)
- Acceptance/denial of diagnosis
- Knowledge (declarative & procedural)
- Perceived self-efficacy
- Skills needed for self-management behaviors
- Outcome expectancies for seizure onset and treatment impact
- Attribution to personal effort

Medication management: Take anti-seizure medication as prescribed by HCP
- Makes commitment to be adherent; Takes medicine correctly and on time; Medication readily accessible (at home and away from home); Keeps routine clinic appointments

Seizure management: Prepare for, and respond to, seizure episodes
- Avoids known antecedents of seizure onset; Recognizes early warning signs; Communicates with family/HCP in an acute situation; Initiates first aid activities - recognizing status epilepticus; Contacts the HCP if having more seizures than usual

Life management: Alter behaviors to avoid seizure onset:
- Maintains "normal" sleep levels; Reduces stress (emotional and physical); Avoids ingested triggers of alcohol, drugs, OTC meds, caffeine; Avoids environmental triggers (e.g. blinking lights); Maintains healthy diet, keeps hydrated, and avoids hypoglycaemia; Takes safety precautions in sport, recreational, and domestic activities, Ddevelops a social support network; Wears identification (e.g. MedicAlert bracelet).

4. Seizure control

2. Communication and partnership

Reinforcing Factors

HCP knowledge, skills, and time to communicate with patients/families, train them in, and reinforce them for, ESM.

Family's knowledge and skills to provide social support and enforcement for ESM.

Enabling Factors

Interpersonal
Communication with family by health care team
Transfer of knowledge and skills to the patient and family by healthcare provider
Organizational
Time devoted to self-management training during the clinic visit
Access to information and training at clinic
Access to social support services and ESM training programs

Health Outcomes and Quality of Life

Symptoms:
Less seizures (number and duration)
Less medication side effects

Functional status
Improved daily functioning leading to:
- Psychosocial functioning, memory, & concentration
- Work productivity
- Less injury
- Reduced ER visits, hospitalization, death

5. Optimism and agency

Fig. 1. Epilepsy self-management framework with emergent themes. [24] Adapted from Shegog & Begley, Frontiers, 2017, 5, 256.

1.3. Digital behavior change interventions for ESM decision support

The use of digital behavior change interventions (DBCIs) in healthcare to improve provider decision-making and patient ESM has increased rapidly[29]. PWE have shown a willingness to use digital technology[30] and have expressed an inclination for a tool with features that may allow them to improve diagnosis, treatment, and ESM [31]. Despite the increased use of DBCI's in healthcare, there is a dearth of research on the attitudes of Hispanic PWE toward this technology.

1.4. MINDSET (Bilingual English/Spanish)

The Management Information & Decision Support Epilepsy Tool (MINDSET) is a bilingual decision support tool (available in both English and Spanish) designed to assist PWE and HCPs to quickly assess ESM needs, identify strategies for improvement, and monitor progress during clinic visits[32]. MINDSET is founded on existing quality of care criteria and clinical guidelines for epilepsy[33], Social Cognitive Theory, self-regulation theory[34], motivational enhancement strategies[35], and the 5A Model (Ask, Assess, Advise, Assist, Arrange)[36,37]. MINDSET incorporates validated scales to assess self-management behavior[20], self-efficacy[21], depression[34,38] and epilepsy medication side effects[2639 40].

Patients' complete MINDSET prior to their clinic visit, and a summarized profile is created to assist patients and HCP discussions. MINDSET inquires on a set of topics, including seizure history, medication, and ESM behaviors. ESM behaviors identified as non-adherent are flagged for possible goal setting. Patients select up to three goals from non-adherent behaviors, one from each ESM domain (seizure, medication, and lifestyle management). MINSET facilitates communication and shared informed decision making between patients and their HCP. The theory and features of MINDSET were developed in collaboration with a patient provider advisory group (PPAG), and its function, feasibility, acceptability, and perceived value among Hispanic patients during clinic visits have been demonstrated previously[28].

A two-group RCT was conducted between August 2017 and February 2019 to assess the efficacy of MINDSET among Hispanic PWE over 3 consecutive clinic visits [42]. Ninety-four Spanish- and English-speaking Hispanic adult patients with epilepsy in Arizona (n = 53) and Texas (n = 41) were randomly assigned within 6 neurology clinics to treatment (MINDSET plus Usual Care; n = 46) and comparison (Usual Care only; n = 48) conditions. Previously reported quantitative results demonstrated the efficacy of MINDSET to increase adherence to ESM behaviors and established the benefits of selecting behavior-specific goals to establish this change [41].

2. Purpose

The purpose of this study was to describe how a digital behavioral change intervention skills training (MINDSET) influences ESM perceptions and behavior for Hispanic PWE. Understanding patient experiences with online decision support applications can inform future development and implementation among this population. This study addresses the need for a clinic-based decision-support tool to assist clinicians in profiling their Hispanic Spanish-speaking patients' ESM needs and to identify a salient, tailored intervention in clinic encounters. This represents an innovative and significant contribution to the field of ESM education for Spanish-speaking patients with epilepsy and their HCPs.

3. Materials and methods

3.1. Study design

This study was a qualitative descriptive (QD) analysis of exit interviews from 46 Hispanic PWE who participated in the intervention group of the RCT [42]. A brief description of the study and study protocol is described below. A full description of the RCT has been previously published [24].

3.2. Clinic settings

The study was conducted at three neurology clinics in Tucson Arizona, which are affiliated with The University of Arizona and the Banner University Medical Center, and two clinics in Texas operated by the Epilepsy Foundation of Central and South Texas (EFCST), which are staffed by the University of Texas School of Medicine in San Antonio, Department of Neurology. In Arizona, the Banner University Medical Center in Tucson serves many Hispanic epilepsy patients. Across Banner University clinics, approximately 30 % of all Hispanic patients prefer to speak Spanish. The patients are diverse in terms of age and socioeconomic status. In Texas, the two EFCST clinics, located in Harlingen and San Antonio, are outreach clinics for low-income and uninsured PWE in the service area (Central and South Texas) who do not otherwise have access to specialized care. Most patients in both locations were Spanish-speaking [28].

3.3. Study participants

The study sample comprised 46 participants in the intervention arm of the RCT. The participants were adult Hispanic patients (≥18 years) with a diagnosis of epilepsy who were making regular visits to the clinic and were willing and able to complete MINDSET. Participants exhibited no rapidly progressive neurological or medical disorders, other major neurological impairments, motor disorders (e.g., hemiplegia), learning difficulties, or psychiatric/behavioral problems (e.g., autism or attention-deficit disorder) that would inhibit the ability to use the tablet, answer survey questions, or perform SM activities. Participating HCPs included two neurologists in Arizona, two neurologists in Texas, and an assistant director from the Epilepsy Foundation of Central and South Texas (EFCST). One neurologist (Arizona) and the assistant director from the EFCST were members of the research team and were involved in the study design.

3.4. Recruitment

Eligible patients were identified by the healthcare providers at each participating clinic. HCPs were asked to identify patients scheduled for medical appointments, determine if they met the eligibility criteria of the study, and send letters to patients inviting them to participate. In the letter, the patients were asked to call or return a signed "consent to contact" form if they were interested in being called by a research staff member with more information about the study [42]. If the patient returned the form or returned a phone call, the research staff described the study to them and gave them detailed explanations of the study and consent documents for them to review. Research staff met patients who agreed to participate at their next clinic visit and advised them of informed consent procedures. After patient questions were answered and informed consent documents signed, those who agreed to participate completed a contact form and demographic questionnaire. Patients were then shown how to use the MINDSET tablet and told to contact staff if they had any questions or difficulties. Following their visit, patients were provided with a $20 cash incentive for each of the three visits for a total of $60. For the qualitative study, only patients enrolled in the intervention group of the larger RCT were invited to participate in the exit interviews. Exit interviews were conducted at the end of the third visit of the larger RCT. The study was approved by the institutional review boards of human subjects from both the University of Arizona, College of Medicine, and the University of Texas, Health Sciences Center School of Public Health at Houston.

3.5. MINDSET use

During the first clinic visit, participants in both groups (intervention and comparison) were assigned a personal non-identifiable number to access MINDSET for baseline data collection, log on to MINDSET, and choose their preferred language (English or Spanish). They then answered questions about their epilepsy condition (e.g., seizure frequency and type), current anti-seizure medications, medication adherence (e.g., missed doses), and depressive symptoms using the 7-item NIDDI-E depression scale [32,43]. ESM behaviors were assessed using a modified 36-item version of the ESM Scale, requesting responses on three self-management domains: seizure, medication, lifestyle, safety, and information management[24,35]. Following data collection, participants in the intervention group (MINDSET plus usual care) continued to use MINDSET to develop a goal-based Action Plan, while those in the comparison (Usual Care only) group continued to their usual visit (Fig. 2).

Intervention participants received feedback on their ESM adherence and reviewed their non-adherent behaviors in each of the three ESM domains. They then selected up to three corresponding ESM behavioral goals (one from each domain) to be completed before the next clinic visit. Participants selected behavioral strategies to meet the chosen goals, indicated their self-efficacy in performing these behaviors, and listed any perceived barriers to successfully performing these behaviors.

A printed copy of the action plan (AP) in PDF format was provided to both the participant and the HCP, which comprised a summary of the participant's medications, past side effects, seizure history, and an overall assessment of current ESM behaviors (Fig. 3). In addition, dedicated single-page sections included the participant's self-selected behavioral goals, self-selected ratings of self-efficacy to meet each goal, and self-selected strategies to achieve each goal. During the clinic, both participants and HCP reviewed and discussed the AP content regarding selected goals, strategies, confidence, and ways to overcome any barriers to achieving goals. Two weeks after the clinic visit intervention participants received a 'booster' phone call from clinic staff enquiring about the use of the Action Plan and to troubleshoot any barriers to Action Plan implementation.

3.6. Measurement

3.6.1. Patient experience

This study was informed by a *Qualitative Descriptive (QD)* framework. QD research is designed to create an intimate description of participants' subjective experiences[44–46] through a naturalistic inquiry method that uses low-inference interpretation to present results in everyday language[41]. QD can therefore present a rich, yet straightforward, description of an experience or event. It is a helpful method to examine health problems of vulnerable populations with complex cultural and clinical factors affecting their health outcomes and their interaction with their HCPs and the health care system[41,47]. Exit interviews were designed to be implemented at the close of the RCT to gain an understanding of these factors from the perspective of the people living with epilepsy as a means of improving interventions and clinical care. The interview method followed a semi-structured interview guide that allowed for both formal and informal communication between the interviewer and the participant, led by the participant response. Two researchers, one from Arizona (RSEP) and one from Texas (KM) interviewed 42 of the 46 intervention participants individually in approximately 15–30-minute-long semi-structured interviews at the conclusion of the study.

The interviews examined: (i) patients' overall perceptions with the MINDSET intervention; (ii) what they valued and found most useful about MINDSET (including what they learned most about MINDSET and ESM); (iii) what they liked best and least about the program and most challenging about MINDSET; (iv) recommendations for improvement; (v) how the intervention assisted in communication with their HCP and healthcare team; (vi) whether and in what ways they continued to make use of the knowledge that they had obtained from the program after the intervention; (vii) if any content made them feel upset, embarrassed, or uncomfortable; and (viii) what they would tell other patients about MINDSET[28].

3.6.2. Analysis

Qualitative analysis of the interview transcripts was conducted using thematic content analysis methods as described by Miles and Huberman [48], organized using computerized qualitative data analysis software (NVivo, QSR International Pty Ltd; version 12, 2018). To ensure methodological rigor, two bilingual research team members independently translated the data from Spanish into English (RSEP and TN). The final translation was reviewed and consolidated by an additional researcher (SS), with a final consensus from the rest of the research team. The analysis started with individual open coding based on the exit interview questions by two of the reviewers (including RSEP, who had conducted the interviews), comparing and contrasting, transcribing after collaborative discussion, and finally clustering pertinent codes into common themes. The primary investigator (DL) and RSEP met frequently during the coding process to review it and resolve discrepancies through discussion. Three of the researchers had expertise in qualitative methodologies (JC, RS, and TN). Themes were categorized and relationships between themes were identified through a constant comparison of the codes and categories. Themes were then discussed and reviewed by an additional peer reviewer, the principal investigator (DL). Saturation was determined when information obtained from participants became redundant and no further thematic observations could be determined [444950].

4. Results

4.1. Patient demographics

Most participants (91.3 %) agreed to be interviewed. One patient refused to be interviewed. Three other patients did not complete the study because of relocation or death. Participant demographics, epilepsy conditions, and ESM behavioral characteristics were representative of the RCT intervention group (Table 1). The final analytic sample (N = 46) was Hispanic, mainly of Mexican descent (94 %), with a mean age of 37.48 ($\pm$14.2) years, equally female and male, and most reported having had one or more seizures per month (54 %). The average time between visits 1 and 3 was 350 +/-79 days with a retention of 96.8 %.
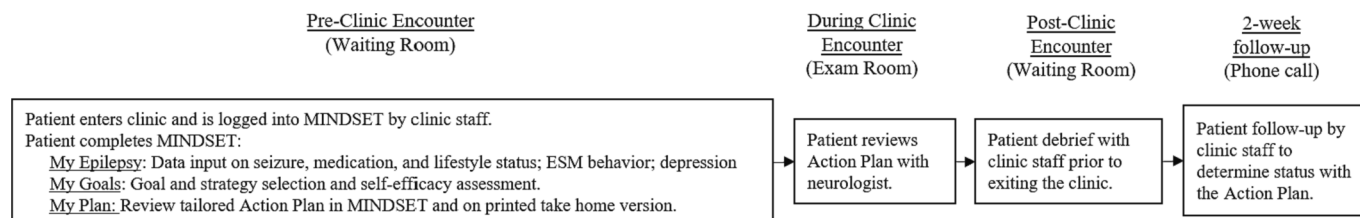

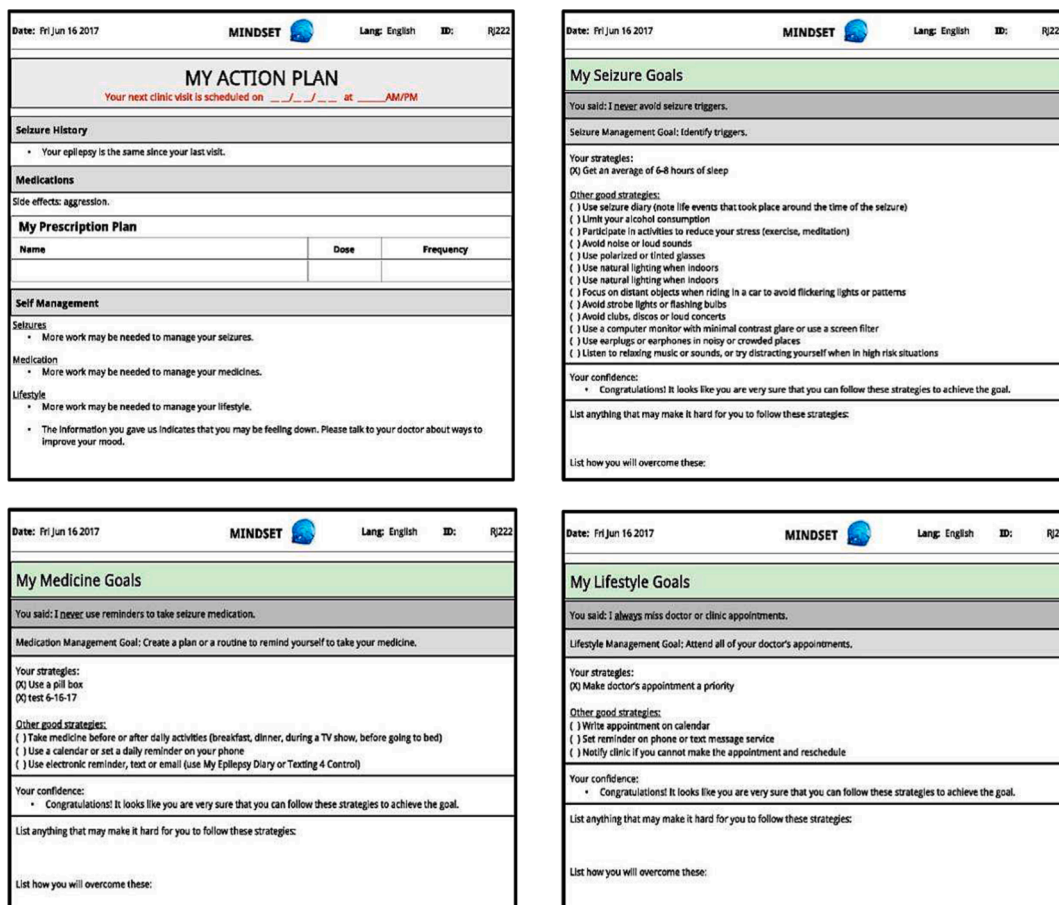**Fig. 2.** Use of MINDSET in the context of the clinic visit.

Fig. 3. Action Plan Pages Include (a) a Summary page of the patient's seizure history, current prescription plan, and ESM behaviors; (b-d) Selected behavioral goals with strategies, self-efficacy, and barriers assessment for mutual review and discussion with the healthcare provider.

Table 1
Demographic Characteristics of the Study Sample.

Category	n (%)	
Gender	Male	23 (24.47)
	Female	23 (27.47)
Language	English	39 (41.49)
	Spanish	7 (7.45)
Age	Years (Mean ± SD)	37.48 (14.20)
Race/ Ethnicity	Hispanic	46 (48.94)
	Non-Hispanic	0 (0.00)
Lived in US	Years (Mean ± SD)	32.48 (±13.99)
Education	No GED	7 (7.45)
	GED or higher	39 (41.49)
	No College	22 (23.40)
	College	24 (25.53)
Marital Status	Married/has partner	26 (27.66)
	No partner	20 (21.28)
Income	Less than $10,000	10 (10.64)
	$10,000-24,999	24 (25.53)
	$25,000 or greater	12 (12.77)
Employment	Employed	4 (4.26)
	Unemployed	23 (24.47)
	Homemaker/retired/ unable to work/ student	19 (20.21)
Coverage	Public	23 (24.47)
	Private	10 (10.64)
	No Coverage	8 (8.51)
	Other	5 (5.32)

*Table adapted from previously reported (Epilepsy and Behavior. 2018 Nov; 88:218–226).

4.2. Study themes (Patients' perceptions of MINDSET)

Five themes emerged from the qualitative analysis, describing the experiences of participants using MINDSET: (1) Awareness and Realization of ESM, (2) Communication and Partnership with HCPs, (3) Improved ESM to QOL, (4), Seizure Control Outcomes, and (5) Optimism and Agency (Fig. 1). The implementation of MINDSET was not without criticism. A considerable number of patients (n = 12) agreed that MINDSET required more clinic time than the usual clinic visits. Others have indicated that MINDSET asked various questions unrelated to their situation. A suggestion for future applications was to have patients complete online questions in advance of their appointment.

4.2.1. THEME #1: Awareness and Realization of epilepsy Self-Management

Participants noted that by using MINDSET, they became "in tune" with their epilepsy, learned about potential seizure triggers, and understood the significance of safe ESM practices in their everyday lives.

"MINDSET made me more aware that I should always have some kind of planning for myself, including monitoring my seizures and any potential side effects.".

[Participant 07; Female; Age 33].

""The program really does make one realize several things that one normally would not take into consideration, like proper medication adherence, diet, and exercise.".

[Participant 23; Male; Age 26].

MINDSET motivated PWE to inspire self-monitor as a critical element of the ESM. Several participants noted that they were inspired to begin monitoring their epilepsy because of MINDSET.

"The program made me take better care of myself by paying closer attention to my seizure management to try and avoid any seizure triggers.".
[Participant 11; Female; Age 42].

""MINDSET allowed me to identify several potential risk factors that could trigger my seizures that I had never thought about. Most of these had to do with my daily lifestyle activities like staying out late at night or drinking beer.".
[Participant 30; Male; Age 28].

One patient stated that by using MINDSET to monitor all elements of his health, including ESM behaviors, he felt a new sense of awareness and comfort.

"The program really made me realize things that I had never taken into consideration. After using the program, I now feel more aware about my condition, and I feel more comfortable about what I know about my condition and how to properly care for myself.".
[Participant 36; Male; Age 56].

Another participant spoke about how MINDSET made him aware of the potential side effects associated with commonly prescribed anti-epileptic drugs (AEDs).

"I was not aware of many of the medication side effects until I completed the program. Thanks to MINDSET I learned about these side effects, and I was able to discuss these with my doctor. Without MINDSET I would have never associated many of the side effects that I was experiencing with my medication but rather the actual seizures themselves" [Participant 42; Male; Age 35.].

Several participants suggested that the learning opportunities afforded by MINDSET were shared with other patients.

"I would tell other patients to try MINDSET! I am sure everyone living with epilepsy will learn so much about their seizures and how to better manage them."
[Participant 3; Female; Age 60].

"I would tell other patients that they would be really surprised to learn how much control they actually have over their seizures and the impact on their overall health."
[Participant 15; Male; Age 29].

"I am really thankful with my doctor and his team for giving me the opportunity to use MINDSET. Thanks to MINDSET, I learned so much about how to better manage my epilepsy. I would love for others to have the opportunity to use MINDSET to help them learn more about how to better control their seizures."
[Participant 2; Female; Age 48].

4.2.2. THEME #2: Communication and Partnership with HCPs

Participants noted that their relationship with their physicians and medical team also improved after using MINDSET, as they were more empowered with knowledge and information about their health. Patients acknowledged that MINDSET helped them speak up on open discussions about their epilepsy.

"MINDSET helped me feel like I was a part of my treatment plan process. By giving me the opportunity and a voice to select goals and strategies to improve in the self-management of my epilepsy, I felt that I was given an opportunity to decide how I wished to move forward. In addition, MINDSET gave me the opportunity to flag side effects in my current medication plan and discuss these with my doctor".
[Participant 9; Female, 52].

To provide HCPs with the essential health information needed for proper care, one participant noted:

"Because of MINDSET, my doctor learned about many of my other health problems, which he later explained may be associated with my seizures."
[Participant 29; Male; Age 32]

Other participants noted how MINDSET encouraged them to ask questions to overcome reticence and contact their medical team when needed:

"MINDSET made me more open-minded into asking questions that troubled me. Before using MINDSET, I was embarrassed about asking what I thought may have been useless questions. Before MINDSET I also tended to keep myself from asking questions as I did not want to waste my doctor's time."
[Participant 2; Male; Age 28].

"The program really helped me be a bit more responsible with calling my doctor's office with information on my seizures and epilepsy. My doctor has always encouraged me to contact his nurse or medical assistant to inform him of any changes in my seizure frequency or new symptoms and side effects. Prior to using MINDSET, I never thought about calling my doctor about any changes to my health until my next office visit."
[Participant 15; Male; Age 27].

Another participant noted that MINDSET helped him disclose to his physician that he was not taking anti-epileptic drugs (AEDs) as prescribed:

"MINDSET helped me open to my doctor in many ways that I had never talked to him about. For instance, one of the main things that I discussed with my doctor was my reason why I would not follow my medication plan as prescribed. Thanks to my action plan, I was able to tell my doctor that I would only take half of the dose of my medication because of the side effects associated with the medication. I would usually feel very tired and exhausted if I took my full dose which would keep me from working or living a normal life. After bringing this to my doctor's attention he suggested a new medication which had fewer side effects. A couple of months ago I started on my new medication. Since then, I have not experienced any side effects and my seizure activity has reduced by more than half".
[Participant 6; Male; 53].

Another participant highlighted how MINDSET allowed her to discuss her reasons for not maintaining a proper record of her seizure frequency.

"I never really kept a record of my seizures nor reported them out to my doctor because I have always thought it was really depressing to keep track of an illness. Whenever I have a seizure, I tend to feel tired and a little down and the last thing that crosses my mind is to keep track of the seizure. Because MINDSET was able to identify this is an issue that I was doing wrong, I was able to bring the topic to discussion with my physician who then explained to me the importance of keeping a record of my number of seizures".
[Participant 34; Female; Age 22]

4.2.3. THEME #3: Improved epilepsy Self-Management Behavior(s) to QOL

Participants noted that they had changed various lifestyle behaviors because of the information obtained in MINDSET, which ultimately helped them improve both their epilepsy and overall quality of life (QOL).

One participant noted that he was inspired to begin making changes to his lifestyle behaviors to improve both his epilepsy and overall health.

"MINDSET really got me thinking about several possible risk factors that could trigger my seizures that I had never thought about. Most of these had to do with my daily lifestyle activities like staying out late at night with my friends and drinking. MINDSET made me appreciate the importance of proper sleep and the risk of drinking for people in my situation. Since I've learned about these issues, I have challenged myself to follow a regular sleep routine and avoid any alcohol. I am now sleeping at least 6–7 h a night and have stopped drinking completely. Aside from my seizures, I have really started to feel much better with my overall health. I feel less tired, more alert, and less stressed.
[Participant 17; Male; Age 31]

Another younger participant noted that MINDSET encouraged him to

start working out and make changes to his diet:

"Thanks to the action plan that I received from MINDSET, I was able to challenge myself and commit to a regular exercise schedule and a better healthier diet. Having a copy of the action plan in hand helped remind me of the goals that I had committed myself to in the program. Before learning about the benefits of exercising in patients with epilepsy, I never really thought that my level of activity and diet habits would have such a big impact on my seizure control. Since I started on my new diet and exercise plan, I feel so much more relaxed and healthier. I have also lost more than 15 lb in the last 6 months, which makes me feel more confident in myself and my self-esteem. While I may not be able prove that my new exercise and diet plan has helped reduce my number of seizures, I can certainly say that I feel that my mental health and anxiety has improved. Both of which I am personally convinced have helped me control my seizures".
[Participant 19; Male; Age 23]

4.2.4. THEME #4: Seizure control outcomes

As participants began to incorporate ESM practices and interact more strongly with their HCPs, they also noticed that these behaviors were correlated with an improvement in their seizure frequency. An older patient reported the following:

"Through frequent seizure monitoring, medication adherence, and lifestyle behaviors, I noticed changes to my seizure patterns and frequency. I now keep a record of my seizures, the time and place when and where they happen, I am more careful with taking my medication on time, I avoid skipping any doses, set reminders to take my medication, and sleep well. While I have lived with epilepsy for most of my life, I feel that MINDSET has helped me make simple changes that have started to improve my number of episodes."
[Participant 10; Female; Age 67]

A newly diagnosed patient with epilepsy reported a significant decrease in seizure frequency because of the knowledge he obtained in MINDSET.

"Because of my Mexican decent and my culture, I was unconvinced and unaccepting of my recent diagnosis with epilepsy. I admit that I was in denial, and as such I was reluctant to take the medication prescribed by my doctor. I was also afraid, intimidated, and ashamed of sharing my condition and symptoms with my friends and family. At first, I went to get a spiritual cleaning with church pastor, I then tried some alternative therapies used in older native communities, none of which helped control my seizures. As I finally began to accept my condition I agreed to participate and take part in the MINDSET study. I have since began taking my medication as prescribed and have not had a single seizure in the last year."
[Participant 4; Male; Age 28]

A middle-aged patient who had lived with epilepsy for more than 30 years learned about seizure rescue medications for the first time in his epilepsy care because of a conversation he had with his neurologist that was prompted using MINDSET. The patient started a new prescription plan, including the use of rescue medications, which significantly reduced his seizures.

"Prior to MINDSET, my doctor was not aware of the high number of back-to-back partial seizures that I would have in a given day. On occasion, I would have anywhere between three and four partial seizures in a single day, which would ultimately lead to a grand mal seizure. My doctor informed me about the use of rescue medications and initiated a new treatment plan. Since starting my rescue medication, I have not experienced any grand mal seizures, as I will take the medication after I begin having partial seizures. My overall number of partial seizures has also reduced significantly."
[Participant 14; Male; Age 57]

4.2.5. THEME #5: Optimism and Agency

Many individuals with chronic illnesses, including epilepsy, have low confidence and do not believe that their health will improve. Participants noted that, while their epilepsy, including seizure frequency and symptoms, improved, it became evident that the ESM behaviors they had learned from using MINDSET were critical towards their goal of improving their epilepsy. One participant noted:

"As a woman of faith, I believe that MINDSET has been sent to me as sign of hope! I have learned so much about my condition and self-management behaviors to overcome my epilepsy. During these last 9 months, I have seen a great improvement in my health, but most importantly, I am truly excited and optimistic about defeating my epilepsy. I am hopeful and pray that many of my other brothers and sisters suffering from epilepsy will have access to the program to help them overcome their epilepsy".
[Participant 42; Female; Age 44]

Another patient noted improvement in his mood, depression, and mental state:

"For the longest time I have experienced mild depression, mood and personality changes, and low self-confidence and hope. As a Hispanic male, I was always embarrassed and intimidated about sharing my feelings and sense of guilt with others, including my family and my doctor. Thanks to MINDSET I was able to communicate with my doctor, which helped me better understand and help me with what I was feeling and experiencing. While I recognize that I have a long way to go, I am now starting to see a light at the end of this journey. It has greatly helped to share my feelings and thoughts with my family and close friends which have been supportive. I now feel mentally stronger and more hopeful about the future, and I trust that I will win this battle".
[Participant 13; Male; Age 46].

5. Discussion

Participants' experience using MINDSET positively enhanced their ESM. This work demonstrates that self-regulation principles can be operationalized, and training provided for Hispanic PWE within the context of the clinic visit. It supports the utility of online digital behavior change interventions for this population. The five emergent themes of 1) Awareness and Realization of ESM, 2) Communication and Partnership with HCPs, 3) Improved ESM Behaviors to QOL, 4) Seizure Control Outcomes, and 5) Optimism and Agency corresponded to core components of epilepsy self-management (Fig. 1). Qualitative inquiry provides more granular and deeper subjective perspectives of individual patients that are valid expressions of the therapeutic journey but are often less reported in the epilepsy literature and often not readily captured in group-based quantitative analytics.

The theme 'Awareness and Realization of Epilepsy Self-Management' and the related increased knowledge regarding the condition of epilepsy and ESM is a fundamental predisposing factor for expert self-management[9]. Lack of information and/or misinformation among people with epilepsy is common, especially Hispanic people with epilepsy[51]. In the study participants acknowledged that they lacked understanding of the scope of self-management, a realization only occurring after exposure to the behavioral inventory and Action Plan feedback provided in MINDSET. The self-assessment and feedback function in MINDSET gave participants an opportunity to practice monitoring their own behaviors by completing a seizure, medication, and lifestyle ESM behavior inventory [31]. This enabled participants to gain awareness of comprehensive ESM practices in the context of assessing their own self-management data. Self-monitoring of symptoms, medication practice, and environmental triggers has been demonstrated as an important component of successful chronic disease self-management practice [44]. The approach of awareness raising in context of self-assessment and feedback provided a pragmatic and readily digestible presentation of educational content that appeared less overwhelming to participants than a more intense training program.

The theme '*Communication and Partnership with Health Care Providers*' reflected participants' reports of improved communication with the health care team through MINDSET use that aided in developing a partnership and a mutually agreed on treatment plan. Patient-provider communication lacks a standard approach to ensure a full range of topics are covered, that the patient's needs are heard, and that patients understand and retain the information discussed to translate to daily practice[51]. Groenewegen et al. (2024) determined that seizures, treatment, and side effects were not always discussed during visits, and patients often disagreed with their specialists regarding the topics that were discussed[52]. A comprehensive needs assessment of practicing HCPs working with epilepsy patients reported a primary goal to improve patient adherence to treatment protocols and advised that patient communication workshops were needed to improve HCP skills to address patient needs in a timely manner [53]. The presence of a clinical care team in support of the patient, and effective patient-provider communication to derive mutually agreed on treatment plans, are respective core enabling and reinforcing factors in chronic disease self-management. Decision-support tools such as MINDSET can help to address identified needs [51] This study demonstrated that online decision support such s MINDSET can complement communication between patients and HCPs by offering a printed tailored Action Plan that summarizes the patients' assessment and feedback selected treatment goals in written form to enable 'common ground' on which to focus, guide, and promote communication with HCPs. This approach offers a direct communication pathway of real-time data during face-to-face visits[54–56]. Participants reported feeling empowered to lead conversations and be self-advocates when communicating with their HCPs.

The theme '*Improved ESM Behavior(s) to Quality of Life*' reflected participants' reports of improved lifestyle behaviors that enabled improved overall quality of life. This occurred in patients who realized a correlational link between MINDSET, management of lifestyle behaviors, and improved enhanced overall health. Shifting patient outcome expectations (e.g., that positive health consequences can result from performing self-management behaviors) is a recognized predisposing factor in self-regulation and motivation for behavioral change[34]. This impact is consistent with a recent review of mHealth apps for individuals with chronic diseases[57]. The participants who used MINDSET felt engaged and empowered to manage their ESM behaviors which can help improve their overall quality of life and reduce healthcare utilization [42,58]. The focus of this empowerment were lifestyle behaviors, traditionally less discussed in the context of busy clinic visits when compared to seizure and medication management[23]. This was consistent with results from the quantitative findings from the RCT that demonstrated greatest positive change in the frequency of lifestyle management behaviors. Descriptively, self-management adherence and improvement from visit 1 to visit 3 was higher in the intervention group for four of five behavioral domains (excluding safety)[42]. Increased motivation to engage in positive health-related behaviors, such as increasing physical activity, drinking, dietary behaviors, and medication adherence [59,60] is encouraging but come with the challenge that lifestyle behaviors, while aligning with the broader Healthy People objectives (e.g. dietary guidelines, sleep) are more complex and difficult to sustain in the long term than discrete epilepsy focused treatment-based behaviors (e.g. using a medication pill box, maintaining well visits).

The theme '*Seizure Control Outcomes*' reflected participants' reports that MINDSET helped to reduce seizure frequency and to manage symptoms. Reduction of seizures has primarily been an outcome associated with pharmacotherapeutic or surgical interventions and less reported in relations to educational or ESM interventions. Many participants euphemistically described MINDSET as a "weapon against combatting their epilepsy." When patients attribute successes in chronic disease self-management to internal and controllable factors (i.e., personal effort) and self-management failures to factors that are internal, controllable, and unstable they are likely to be more successful in managing their disease. MINDSET strategies of self-assessment and

feedback and use of self-selected behavioral goals (and strategies to accomplish those goals) that are founded on evidence-based ESM practices may have contributed to this sense of efficacy and control. However, this study was not designed to determine which functions of MINDSET may have contributed to this affect[20]. Despite this, any reduction in seizure frequency that is perceived to be associated with ESM practice will increase perceived efficacy to manage epilepsy and reinforce ESM practice, thus optimizing a change for perpetuation of ESM behaviors. A significant decline in seizure frequency was not evidenced in the RCT quantitative data analysis. The QD approach is useful to understanding the MINDSET-mediated ESM experience at the individual patient level and supports the utility of patient ESM training.

The theme '*Optimism and Agency*' reflects participant reports of affect and mood. There was a sense of increased vigor and motivation about "defeating" their epilepsy and the generation of an optimistic future orientation is particularly important in Hispanic people with epilepsy who have demonstrated co-morbidities of depression, anxiety, cognitive function, suicidality, and stigma[14]. Positive reinforcement from successful ESM practice (i.e., reduced seizure frequency, better health), increased communication and positive feedback from family, and a growing sense of efficacy (described above) may have contributed to promoting this shift. It appears that the 9-month MINDSET experience was contributary but difficult to determine the degree to which components of MINDSET contributed.

5.1. Limitations and future research

Qualitative inquiry enables a deeper understanding of the PWE experience, which can be lost in quantitative inquiry. It provides an opportunity to understand individual cases that are not apparent in comparative between-group analyses in RCTs. Irrespective, these findings need to be interpreted in consideration of the study's limitations. The study sample was limited due to PWE who were mainly Mexican in origin and willing to volunteer to participate in the study. This sample may not be representative of the broader population of patients of Hispanic origin and may have been more experienced in managing epilepsy. More research with broader patient demographics is required. The data assessed in this qualitative study were derived from participants' self-reports. No assessment of changes in clinical characteristics was performed in this study or examination of other clinical variables obtained from electronic medical records. Self-reporting is more subjective and open to responder bias than clinical metrics. Responder bias could occur because of social desirability (to complete the survey optimally), to avoid goal-setting discussions with the HCP by reporting ESM adherence, to be consistent with having set a goal and to demonstrate achievement, and simply give greater focus on the behavior for which the goal was set.

Future research with a larger sample size is required to control potential biases. The sample was goal-directed and convenient to use. Participants were interviewed in person at the end of their third visit in the parent RCT. It is important to learn from all patients, including those who are less engaged and seek strategies to improve programs and their content; likewise, it is imperative to know how MINDSET may benefit specific individuals, such as newly diagnosed children, or those within minority and/or socially marginalized communities. It is also timely to study MINDSET during remote clinical visits, limiting face-to-face contact, considering the recent COVID-19 pandemic and the increased use of telehealth.

Web-based applications have the potential to combine a tailored approach of face-to-face clinical interventions with the scalability of public health interventions. Patients appreciate the accessibility and convenience afforded by web-based applications. MINDSET has been recently redesigned from a *Windows* based application to a modern web-based tool to allow for greater access via multiple platforms (e.g., computers, cellphones, and tablets). The new version of MINDSET also includes decision-support algorithms to provide tailored

recommendations on appropriate CDC Managing Epilepsy Well (MEW) programs (UPLIFT, HOBSCOTCH, and PACES) and prioritized social determinants for PWE[61]. The results of this qualitative study, combined with the parent study's results on the efficacy of the intervention, have been used to inform a larger and fully powered trial currently testing the newly redesigned web-based version of the program. Results of the new version of MINDSET are expected in late 2024.

The findings of this study support the contention that mHealth applications for patients can increase perceptions of their agency as ESM monitors, advocates, communicators, and managers in the long-term self-management of epilepsy.

6. Conclusion

The use of MINDSET can improve the promotion of ESM techniques for PWE. The qualitative evidence in this study suggests that DBCIs like MINDSET can be acceptable ESM tools for Hispanic PWE. This study showed that patients who used MINDSET as an ESM intervention reported an overall positive experience, and that MINDSET was useful in improving ESM adherence. Improving patient participation and commitment to personal care are directly affected by patients' perceptions of the utility and benefits of MINDSET. This helped achieve improved seizure control, QOL, communication, and collaboration. Implementation of MINDSET during regular clinic visits may assist Hispanic PWE to increase their adherence to ESM behaviors and to maintain adherence over time. In this capacity, MINDSET may assist in mitigating disparities in the care of epilepsy among Hispanic PWE.

Future ESM applications must support patient empowerment, resulting in better seizure control and improved QoL. Health care providers must also work with patients in a way that is commensurate with how they integrate self-care into their daily lives, creating and managing their own ESM program. Lastly, future research could well focus on the qualities of patient-HCP relationships that allow for improved communication, transparency, flexibility, reexamination and change over time and how this relates to better seizure control and longer-term health outcomes. Findings from this study have major implications for Hispanics living with epilepsy given the limited availability of ESM programs in Spanish.

This study addresses the need for a clinic-based decision-support tool to assist clinicians in profiling their Hispanic Spanish-speaking patients' ESM needs and to identify a salient, tailored intervention in clinic encounters. This represents an innovative and significant contribution to the field of ESM education for Spanish-speaking patients with epilepsy and their HCPs.

CRediT authorship contribution statement

Refugio Sepulveda: Writing – review & editing, Writing – original draft, Supervision, Resources, Project administration, Methodology, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Jenny Chong:** Writing – review & editing, Writing – original draft, Validation, Supervision, Resources, Project administration, Methodology, Formal analysis. **Ross Shegog:** Writing – review & editing, Writing – original draft, Methodology. **Kimberly Martin:** Writing – review & editing, Writing – original draft, Project administration. **Charles Begley:** Writing – original draft, Supervision, Project administration, Methodology, Formal analysis, Data curation. **Robert Addy:** Writing – review & editing, Writing – original draft, Methodology, Formal analysis. **Omar Rosales:** Project administration. **Tomas Nuño:** Writing – review & editing, Writing – original draft, Methodology, Formal analysis. **Shiela Soto:** . **Cecilia Rosales:** Writing – review & editing, Writing – original draft, Methodology, Formal analysis. **David Labiner:** Writing – review & editing, Writing – original draft, Validation, Supervision, Resources, Project administration, Methodology, Funding acquisition, Formal analysis.

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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