

Evaluating the Implementation of a Pharmacist-Driven Epilepsy Telehealth Education Program in an Epilepsy Specialty Clinic

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In 2015, the Centers for Disease Control and Prevention estimated that 3.4 million people in the United States were living with epilepsy, the majority of whom are adults.¹ In addition, an estimated \$US 15.5 billion are spent yearly on healthcare costs in this patient population. In the veteran population, epilepsy is more common because of the higher incidence of traumatic brain injury (TBI), which is one of the risk factors in developing this disease. Post-traumatic epilepsy was reported in 35% to 45% of veterans with combat-related TBI during World War I, World War II, and the Korean War.² High rates of post-traumatic epilepsy were also found in veterans of Afghanistan and Iraq with TBI following Operation Enduring Freedom and Operation Iraqi Freedom, respectively. In this veteran population, the estimated risk for epilepsy among those with penetrating TBI was nearly 18 times greater than among those without TBI.³

It is well documented that patients with epilepsy often lack the support and information necessary to properly self-manage their disease. Studies have shown a significant knowledge gap between what patients and their caregivers wish to learn about epilepsy-related morbidity and mortality and the information that is shared with them by their healthcare providers.⁴⁻⁶ In a cross-sectional study, low levels of disease understanding among patients with epilepsy were reflected by low general knowledge as well as limited details of the patient's own epilepsy diagnosis (e.g., etiology, seizure type).⁷ Other studies have reported low understanding of epilepsy-related information and lifestyle management,⁸ and low self-management practices among patients from underserved populations.⁹ Shortcomings in disease self-management contribute to suboptimal outcomes for patients. For instance, patients

Abstract

Objective: In patients with epilepsy, disease self-management skills may improve seizure control, quality of life, and medication adherence. A patient education and adherence program was developed to empower patients to manage their epilepsy. This pilot assessed the feasibility of implementing the five-module educational book series (Exploring Epilepsy) as a pharmacist-driven telehealth program in an ambulatory care epilepsy clinic and its effect on clinical outcomes.

Methods: This was a prospective cohort study of patients who were enrolled at the William S. Middleton Memorial Veterans Hospital Epilepsy Clinic in Madison, WI. A study pharmacist scheduled and conducted five telephone encounters to review the educational modules. Clinical assessments compared baseline to 3 months post-intervention: Epilepsy Self-Efficacy Scale (ESES), Epilepsy Self-Management Scale (ESMS), Patient Weighted Quality of Life in Epilepsy inventory-10 (QOLIE-10-P), Generalized Anxiety Disorder-7 (GAD-7), Neurological Disorders Depression Inventory in Epilepsy (NDDI-E), and a modified Patient-Physician Interactions survey.

Results: Twenty patients were enrolled; 14 (70%) completed the five-module series. Appointments lasted on average 25±9 minutes. There were no statistically significant differences in ESES, ESMS, QOLIE-10-P, GAD-7, nor NDDI-E (n=10). All participants completing assessments found the facilitator helpful. At least 70% of patients reported improved comfort in discussing epilepsy and understanding various self-management aspects of epilepsy.

Conclusion: Implementation of this epilepsy education program is feasible in a clinic setting. Patients reported high satisfaction with the service and endorsed enhanced understanding of self-management strategies. Although there were no statistical improvements in clinical questionnaires, the small sample size is not powered to detect clinically significant differences. Future investigations could consider organizing the program in a group setting to facilitate peer support and discussion.

with epilepsy often struggle to take their medications consistently and adherence rates can be as low as 30% to 50%.¹⁰ This low adherence results in poor patient outcomes including decreased quality of life, limited seizure control, increased morbidity and mortality including sudden

unexpected death in epilepsy,¹¹ and a significant increase in health-care costs. In a claims database analysis, medication nonadherence among patients with epilepsy increased the risk of mortality (hazard ratio [HR] 3.32, 95% confidence interval [CI] 3.11-3.54), emergency department visits

(relative risk [RR] 1.50, 95% CI, 1.49-1.52), and hospital admissions (RR 1.86, 95% CI 1.84-1.88).¹⁰ Taken together, these findings highlight the need for educational interventions in epilepsy management, including the creation of seizure action plans that can improve key elements of patient and caregiver education and help patients and caregivers better manage their epilepsy.^{12,13} Community and ambulatory care pharmacists are well positioned to provide such interventions because they are accessible health-care providers who routinely interact with patients with chronic diseases without requiring formal appointments. Pharmacist involvement in chronic disease state management has been shown to improve patient outcomes.¹⁴⁻¹⁶ Unfortunately, epilepsy has not been a focus of pharmacist-driven medication therapy management (MTM) programs in the past.

Educational programs can help patients with epilepsy improve self-management of their condition as well as medication adherence. A 2017 meta-analysis investigated various educational interventions in patients with epilepsy and measured their effects on adherence rates.¹⁷ Two trials included in the analysis showed a significant benefit of these educational programs, such as improved adherence rates and improved scores on an adherence questionnaire.^{18,19} Interventions included one-on-one educational sessions with providers, online educational sessions, and full-day group sessions with providers. The programs helped educate patients with epilepsy to better understand their condition and improve their epilepsy management. However, pharmacists were involved in only one of the included studies.²⁰ Pharmacists are medication experts and if patients struggle with medication use and adherence, pharmacists can play a vital role in improving these aspects of treatment. If it is feasible for pharmacists to implement an educational program into a clinical practice, it could help patients with epilepsy improve their self-care and ultimately reduce morbidity, mortality, and health-care costs. To evaluate the health benefits a pharmacist-run educational program can make in patients with epilepsy, it is first important to measure if it is feasible to incorporate these programs into clinic workflow, including barriers and perceived benefits.²¹

TABLE 1. Patient Toolkit: Exploring Epilepsy Modules

<i>Section</i>	<i>Content</i>
Module 1: Epilepsy 101	Overview of epilepsy including pathophysiology, types, signs and symptoms, concerns across the lifespan, healthcare team members, and questions to ask health-care professionals
Module 2: Epilepsy Medication Therapy	Overview of the medications for epilepsy, treatment goals and challenges, ways to optimize treatment
Module 3: Epilepsy Support and Non-Medication Management	Overview of non-medication strategies to optimize well-being, including potential safety issues, managing lifestyle, understanding triggers and risk factors, improving quality of life, and establishing a community of support
Module 4: Medication Action Plan	Introduces an individual MAP developed by the patient to ensure adherence and compliance to the treatment regimen
Module 5: Follow-up Pharmacotherapy Consultation	Guidance for discussion with health-care professional for one-on-one follow-up to continue to discuss the MAP and make any necessary changes
<i>MAP = Medical Action Plan.</i>	

The primary objective of this prospective cohort study was to determine the feasibility, including barriers and perceived benefits, of implementing Exploring Epilepsy as a pharmacist-driven program for patients with epilepsy within an ambulatory care clinic. Secondary objectives included assessing patient acceptability of this intervention and the effect on patient clinical outcomes.

Methods

Exploring Epilepsy Program Development

Human-centered design is a problem-solving methodology that uses co-creation with end users or those impacted by the product, service, system or process to develop a solution. In this study, the materials were developed with a diverse working group including patients, pharmacists and physicians. In the first phase of Exploring Epilepsy development, a working group was convened of patients with epilepsy, clinical pharmacists, nurses, nurse practitioners, physician assistants who work in or have expertise in epilepsy, and physicians or health-care professionals actively involved in educational programs for patients with epilepsy. This group worked with the UCB Pharma team over a 3-month period to identify unmet needs in the epilepsy journey leveraging MTM programs in other disease states as a foundation, with input from involved parties (i.e. patients with epilepsy and health-care providers). The working group

held two virtual meetings and one in-person meeting to discuss the program outline, content type, topics, program operations and delivery, as well as outcome measures of interest. The feedback was integrated into the final program pilot, ensuring that the participant experience and quality of care was aligned with program expectations.

These collaborations resulted in the creation of modular content during phase 2 development, yielding the Exploring Epilepsy Patient Toolkit and a Facilitator's Guide. The Exploring Epilepsy Patient Toolkit comprised an educational book series with five modules: Epilepsy 101, Medication Therapy Review, Disease Management Support, Medication Action Plan, and Follow-up Pharmacotherapy Consultation (Table 1). The Toolkit contained resources specifically designed to aid patients as they progress through their journey in living with epilepsy. The content of the patient toolkit was visually stimulating, included videos, and was designed to tell a visual story across ability levels (e.g. to those with impaired cognition, low general and health literacy, those who speak English as a second language, and older adults; thus, written at a 6th- to 8th-grade literacy level) to activate patient empowerment and enhance self-management through pharmacist-facilitated discussions, disease education, a personalized action plan, and a high level of interactivity. The Facilitator's Guide for the health-care professionals administering

the program was created to provide detailed guidance and tips for leading patients through the program. The guide also provided health literacy and plain-language tips for communicating with patients, and useful links including a patient welcome letter, patient baseline self-questionnaires, reporting for adverse events, a shared decision-making approach, and a teach-back method for patients to demonstrate their understanding of the content (Table 2).

In the third phase of program development, a secure, interactive website was created to house the patient toolkit as an eBook. Materials are publicly available at <https://www.exploringepilepsytoday.com/> and include modules 1 through 3 as of December 2022. In the fourth stage of development, the program was piloted in an ambulatory setting, with a target enrollment of 35 participants.

Clinical Setting

This pilot study was conducted at the Epilepsy Center of Excellence (ECoE), William S. Middleton Memorial Veterans Hospital, Madison, Wisconsin (hereinafter referred to as the Madison VA). The Veterans Affairs (VA) health-care system offers numerous services to their patients through the ECoE. The ECoE at the Madison VA is one of 17 VA ECoEs across the country that provide patient and clinician education regarding epilepsy treatment and disease management. The ECoE at the Madison VA provides epilepsy care to approximately 400 veterans each year. As a Level 4 Epilepsy Center, the ECoE receives referrals from other VA centers and provides high-quality epilepsy care, including treatment with new antiseizure medications (ASMs), neuromodulation devices, and resective surgeries. A Clinical Pharmacist Practitioner (CPP), epileptologist, psychiatrist, medical and pharmacy fellows and residents, medical support assistants, nurse practitioner, and nurses are members of a multidisciplinary team providing individualized care. Integrated into the Madison VA Epilepsy Clinic in 1991, the CPP works at the highest level of clinical practice, providing comprehensive medication management following initial epilepsy diagnosis (e.g. prescribing medications, ordering laboratory tests and diagnostic studies, performing physical assessments, counseling, mental

TABLE 2. Facilitator Guide

Section	Content
Introduction to the Exploring Epilepsy Program	<ul style="list-style-type: none"> • Purpose/Objectives/Appropriate Patients • Overview of Exploring Epilepsy Program • Program Execution Timing • Program Logistics and Patient Flow • Patient Communication Tips and Tools
Module 1: Epilepsy 101	<ul style="list-style-type: none"> • Exploring Epilepsy program content, with guidance and tips to help lead patients through the program • Health literacy and plain-language tips for communicating with patients
Module 2: Epilepsy Medication Therapy	
Module 3: Epilepsy Support and Non-Medication Management	
Module 4: Medication Action Plan	
Module 5: Follow-up Pharmacotherapy Consultation	

health triage, and referral). The Madison VA Epilepsy Clinic meets 1 day per week for 4 hours, during which 14 in-person patient and telehealth appointments are available.

Recruitment

Patients with diagnosed epilepsy established at the Madison VA Epilepsy Clinic who were at least 18 years of age and had provided informed consent during regularly scheduled appointments with the epilepsy clinic were eligible for participation in the Exploring Epilepsy pilot. Those enrolled in another study or without functional capacity as determined by their health-care provider were excluded. This study received approval from the University of Wisconsin-Madison Institutional Review Board and the Madison VA Research and Development Committee.

Study Design: 12-week Education Intervention

Upon enrollment, patients received the Exploring Epilepsy Patient Toolkit from a health-care professional. Enrolled patients were scheduled for five, individualized 30-minute educational sessions with the pharmacist via telephone. The purpose of these sessions was to review each of the five modules. Appointments for module review were scheduled every 2 weeks, with the intention of the program being completed within a 12-week period from enrollment. Patients were discharged from the study after three consecutive, failed attempts at scheduling session phone appointments.

In leveraging the expertise and

availability of pharmacist practitioners during the one-on-one consultations, patients received a customized, co-created action plan by the end of the module appointments. Throughout the program, participants received tips on how to enhance other health-care provider discussions, a holistic approach to epilepsy management, and how to educate others in the event of a seizure.

Outcome Measures

The primary outcome was the feasibility of program implementation,²² which was measured by encounter completion time, patient completion rates, and proportion of patients requiring appointment rescheduling.

Secondary assessments included four validated surveys that patients completed regarding their epilepsy at baseline and at 3 months after completing the Exploring Epilepsy education series. Change in survey results from baseline to 3 months post-intervention was used to assess the effect of Exploring Epilepsy on clinical outcomes and acceptability. The four epilepsy-related patient surveys were the Epilepsy Self-Efficacy Scale (ESES), the Epilepsy Self-Management Scale (ESMS), the Patient Weighted Quality of Life in Epilepsy inventory-10 (QOLIE-10-P), and the Neurological Disorders Depression Inventory in Epilepsy (NDDI-E). The ESES is a 33-item questionnaire using an 11-point Likert scale with 0 being “I cannot do at all” to 10 being “sure I can do,” with higher scores indicating increased self-

efficacy.²³ The ESMS is a 38-item survey with a five-point rating scale, with 1 being “never” and 5 being “always”; higher scores indicate increased frequency in epilepsy self-management behaviors.²⁴ The QOLIE-10-P is a 10-item survey that measures a patient’s perceived effect of epilepsy on quality of life,²⁵ and the NDDI-E is a six-item tool scored over the previous 2 weeks using a four-point scale, with 4 being “always or often” and 1 being “never.”²⁶ NDDI-E scores over 13 indicate potential major depressive disorder.²⁷

Patients completed three additional surveys. The first was the Generalized Anxiety Disorder-7 (GAD-7), a validated seven-item survey where patients indicate the effect of symptoms over the previous 2 weeks using a four-point scale, with 0 being “not at all” and 3 being “nearly every day,” with a total score of 5 indicating mild anxiety.²⁸ The Perceived Efficacy in Patient-Physician Interactions (PEPPI) instrument, which measures older adults’ self-efficacy in interacting with physicians,²⁹ has been previously modified to describe interactions with pharmacists and includes the addition of several questions with good reliability, as shown by Cronbach’s alpha ranging from 0.94 to 0.97.³⁰ This modified PEPPI instrument was used to assess patient-pharmacist interactions. After series completion, patients evaluated the program using a patient satisfaction and perception

survey that contained nine questions about various aspects of Exploring Epilepsy delivery. The survey used a four-point Likert scale of “strongly agree” to “strongly disagree,” and also allowed participants to report no opinion.

Individuals identified through NDDI-E or GAD-7 scores as at risk of major depression or anxiety, respectively, were referred to appropriate resources for intervention.

Statistical Analysis

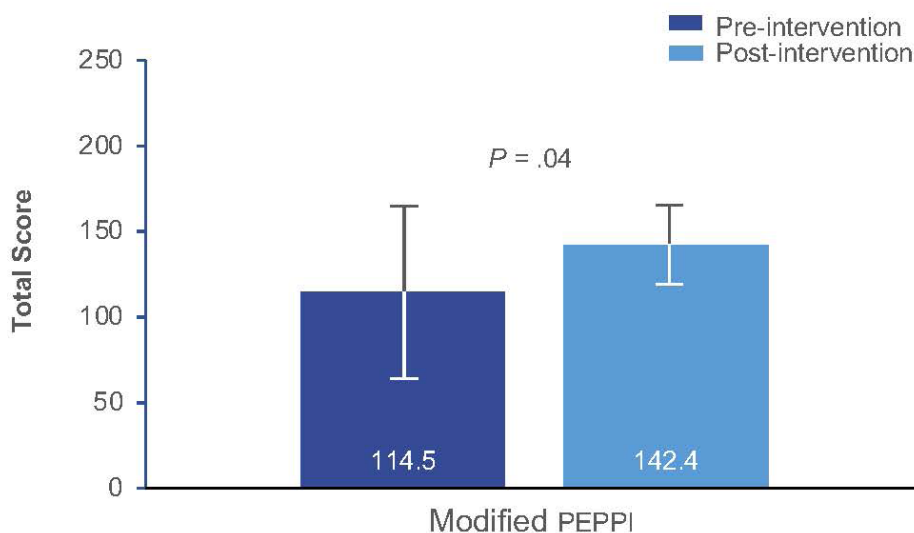
Statistical analyses were performed using STATA version 14.2 (StataCorp LP, College Station, TX, USA). Descriptive statistics were used as appropriate (i.e. means, standard deviations, and proportions). Continuous variables were assessed with the Wilcoxon Signed-Rank test. Imputation was used to manage missing data and was conducted through averaging the patient’s score from the remaining questions on the scale. Results were tested for statistical significance using a two-sided alpha level of 0.05 without adjustment for repeated testing.

Results

Feasibility of Implementation

Between February 2019 and October 2019, a total of 20 patients were enrolled in the Exploring Epilepsy pilot program at the VA ambulatory clinic. Participants

FIGURE 1. Total Scores for Epilepsy and Quality of Life Assessments (n = 10)



ESSES = Epilepsy Self-Efficacy Scale; ESMS = Epilepsy Self-Management Scale; QOLIE-10-P = Patient Weighted Quality of Life in Epilepsy inventory-10.

TABLE 3. Demographic and Clinical Characteristics at Baseline (2019)

Characteristic	Value (n = 20)
Age (years), mean (SD)	57.8 (12.3)
Male, n (%)	17 (85)
Race and ethnicity, n (%)	
American Indian/Native Hawaiian	1 (5)
Hispanic/Latino	1 (5)
White	16 (80)
Declined to answer	2 (10)
Medications, mean (SD)	
Scheduled	7.8 (5.6)
As needed	1.4 (1.7)
Specific comorbid conditions,^a n (%)	
Depression	7 (35)
Hearing loss	7 (35)
Osteoporosis	2 (10)
Post-traumatic stress disorder	2 (10)
Traumatic brain injury	2 (10)
Health-care utilization in past 12 months, n (%)	
Emergency Department	11 (55)
Hospitalization	3 (15)
ASM use, mean (SD)	1.6 (0.8)
Patients on specific ASM, n (%)	
Levetiracetam	8 (40)
Gabapentin	4 (20)
Lamotrigine	3 (15)
Brivaracetam	2 (10)
Carbamazepine	2 (10)
Divalproex sodium	2 (10)
Lacosamide	2 (10)
Perampanel	2 (10)
Phenytoin	2 (10)
Cannabidiol	1 (5)
Valproic acid	1 (5)

ASM = antiseizure medication; SD = standard deviation; VA = Veterans Administration.
^aReflect comorbid conditions that are common (depression), important for telephonic delivery (hearing loss), possibly induced by epilepsy/ASM (osteoporosis), and common to the VA population (post-traumatic stress disorder, traumatic brain injury).

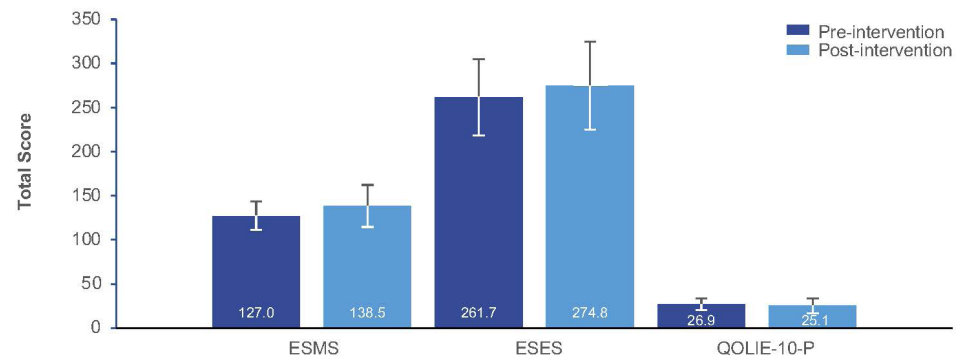
were primarily White men, as is typical for the Madison VA population. Additional baseline characteristics including specific comorbidities and ASM use are summarized in Table 3.

The five-module series was completed by 14 participants (70%). One patient withdrew consent for participating in the program, and five patients were discharged after three consecutive failed attempts at scheduling follow-up. The average time for module session completion was 25±9 minutes. Most patients (13/20; 65%) required rescheduling efforts for at least one of their scheduled sessions.

Clinical Outcomes

Total survey scores pre-intervention and post-intervention were compared for the 10 patients who completed the questionnaires assessing clinical outcomes. Numerical improvements in pre-intervention versus post-intervention scores were noted for the ESMS and the ESES; however, the differences were not statistically significant (Figure 1). No significant differences between pre- and post-intervention scores were noted for the QOLIE-10-P (Figure 1). There were no significant changes in depression and anxiety scores (NADDI-E, 9.0 [5.6] vs 11.4 [4.4], $p=0.73$; and GAD-7, 4.7 [4.1] vs 4.8 [4.2], $p=1.0$) pre- versus post-intervention. The modified PEPPI, assessing interactions with pharmacists,

FIGURE 2. Total Score for Patient-Pharmacist Interactions (n = 10)



PEPPI = Perceived Efficacy in Patient-Physician Interactions.

increased significantly from pre- to post-assessment ($p=0.04$) (Figure 2).

Patient Acceptance

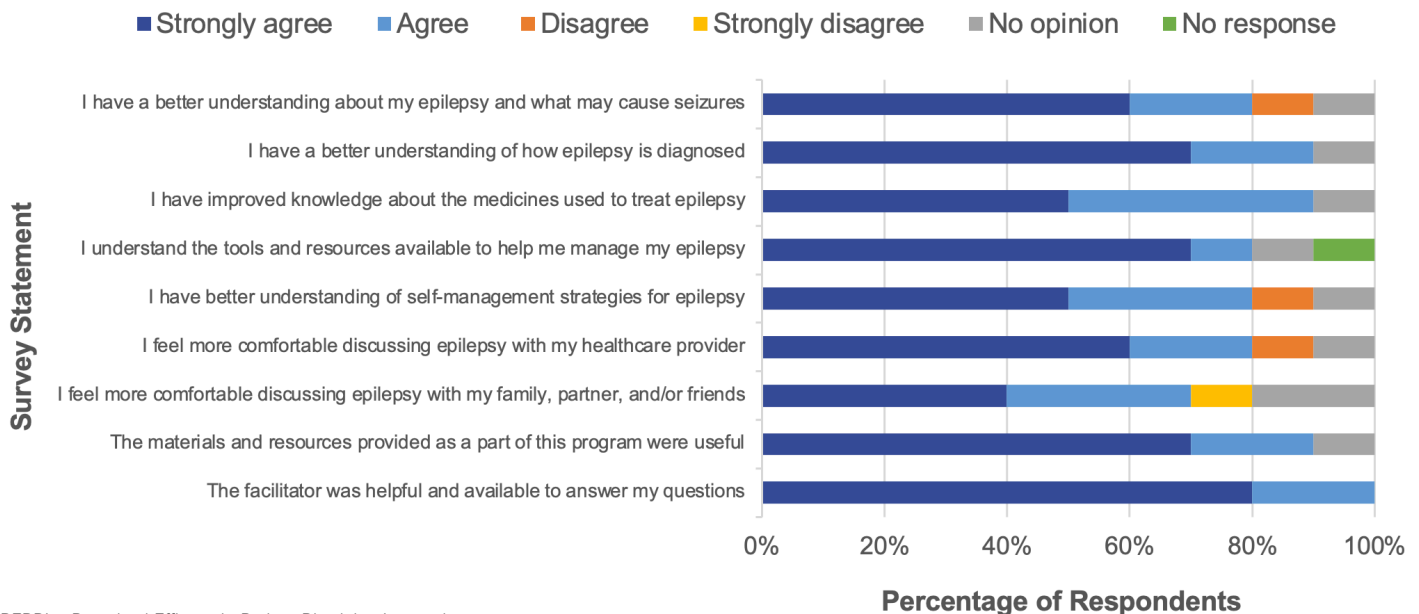
Ten patients completed the patient satisfaction and perception survey after completion of the Exploring Epilepsy pilot study. Based on the Likert scale, a large percentage (70-100%) of patients “strongly agreed” or “agreed” with statements about their level of comfort discussing epilepsy with others or understanding various self-management strategies as a result of their participation in Exploring Epilepsy (Figure 3). All patients “strongly agreed” or “agreed” that the materials were useful. Most patients (90%) “strongly agreed” or “agreed” that the facilitator was useful.

Discussion

Feasibility of Exploring Epilepsy Use in an Ambulatory Clinic

Our analysis of the implementation of Exploring Epilepsy shows that pharmacists can effectively lead an epilepsy education program within an ambulatory clinic setting. In the VA ambulatory clinic, 70% of enrolled patients completed the five-module series that was based on newly developed materials focusing on facilitating discussion with the patient. Patients attended scheduled telephone appointments with the pharmacist, though rescheduling efforts were needed for over half of the patients. The average time spent on these appointments was in line with facility standards for patient care appointments, which typically allot 30 minutes for an

FIGURE 3. Patient Satisfaction and Perception Survey (n = 10)



PEPPI = Perceived Efficacy in Patient-Physician Interactions

office visit.^{31,32} Several strategies can be employed to increase pharmacist time for direct patient care activities, including using administrative staff support to handle appointment scheduling responsibilities.

The majority of patients who completed the program evaluation questionnaire “strongly agreed” or “agreed” that the pharmacist facilitators as well as the educational material were helpful. Participants found the telephone format acceptable despite over 30% of participants having some level of hearing loss. Additionally, over 70% of patients completing post-intervention questionnaires “strongly agreed” or “agreed” that the program increased patient understanding of various aspects of self-management strategies and aspects of epilepsy management. These findings suggest that participants found this program beneficial in promoting various aspects of self-management skills. An increase in the modified PEPPI score was also observed, indicating increasing participant confidence in interacting with the pharmacist over the course of the five telephone discussions. This result is consistent with the post-intervention question regarding finding the facilitator (i.e.

pharmacist) helpful.

There were no statistically significant differences found between various epilepsy-specific clinical questionnaires. There was an improvement in self-management, self-efficacy, and quality of life scores; however, these were not statistically significant, likely because of the small sample size. No improvements in the anxiety and depression scale scores post-intervention were anticipated because this program was not designed to improve these areas; i.e. it did not employ psychotherapy approaches such as mindfulness exercises, which have been shown to be beneficial for anxiety and depression in patients with epilepsy.³³ In addition, a longer study would be needed to observe changes in these areas.

This program was conducted before the significant changes that occurred in health-care delivery as a result of the COVID-19 pandemic, which necessitated a shift to telemedicine. This shift is reflected by results from a survey of neurology providers; whereas less than 40% of providers used

telehealth before the pandemic, nearly 90% used it after pandemic onset.³⁴ As telehealth has become a common modality for health-care interactions since COVID-19 onset, it is interesting to speculate whether this increased familiarity with telehealth would help to improve response rates in the Exploring Epilepsy program.

Limitations

This pilot program had several limitations. First, participants were selected from normal clinic flow for inclusion in the study; however, recruitment was difficult given the time-intensive baseline questionnaires that had to be completed. Thus, the sample size for this feasibility study was limited and did not reach the target enrollment number. This lower than anticipated sample size also left this study underpowered. Additionally, some questionnaires were missing answers, which were completed using imputation.

This approach potentially limits the validity of the available data. Given the chronic nature



of epilepsy, a longer study may be needed to reveal continued changes over time, particularly with anxiety and depression. The study showed the feasibility of the program within a VA population; however, this population may not be representative of patients with epilepsy in general, and the sub-specialty focus of the clinic may be different from general neurology or primary care clinics.

Future Directions

Data from this pilot program can be compared with those from other sites to assess common themes in the larger epilepsy population. It would be interesting to examine the effect of Exploring Epilepsy in populations with psychiatric comorbidities, as well as to repeat questionnaires after a longer duration post-intervention to assess longer-term effects on patient outcomes. It would be advantageous to conduct this study with a larger, appropriately powered sample, potentially across multiple VAs confirm the benefit of the Exploring Epilepsy program. Additionally, it would be useful to complete an analysis quantifying the effect on medication adherence rate and other health outcomes following the intervention on self-management strategies. Finally, this program could be explored in a group clinic setting to maximize pharmacist time while facilitating dialogue between patients.

Pharmacists are underutilized health-care providers who can effectively facilitate patient-centered learning about various self-management strategies. This pilot program shows that a pharmacist-led epilepsy education initiative is feasible with appropriate planning and that patients are highly satisfied with the service.

Conclusion

Implementation of Exploring Epilepsy within an epilepsy clinic is feasible through telehealth modalities. Patients reported high satisfaction with the service and enhanced understanding of various self-management strategies. Although preliminary data did not show statistical improvements in various clinical questionnaires, the sample size of this feasibility study is small and not powered to detect clinically significant differences. Future considerations for operationalizing this program include leveraging the clinic scheduling team for

administrative tasks that would maximize the health-care professional's time on direct patient care activities. Additional considerations include organizing the program in a group setting to facilitate peer support and discussion.

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Data-sharing statement
Data from noninterventional studies is outside of UCB Pharma's data-sharing policy and is unavailable for sharing.

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2023 PSW ANNUAL MEETING

Soaring to New Heights



Thursday-Saturday, August 24-26, 2023
La Crosse Center, La Crosse