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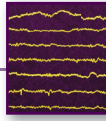
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Self-Management in Epilepsy Care: Untapped Opportunities

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Constant accessibility, rapid scalability, and modest costs make digital and mobile epilepsy self-management platforms an attractive alternative to resource-intensive in-person programs.

Epilepsy is a chronic neurologic condition defined by recurrent seizures not provoked by an environmental or a reversible trigger. About 1% of the US population has an epilepsy diagnosis, and an even higher percentage of the world's population has seizures.¹ For the many US soldiers who sustain blast- and concussion-related injuries, posttraumatic epilepsy is a potential risk.² Although the risk of epilepsy remains unknown, the Veterans Health Administration (VHA) prioritizes diagnosis and management of the condition. Fortunately, antiepileptic therapies are effective for most patients. About 65% of patients can be free of seizures with use of a single daily medication.³ Although the other 35% often experience refractory seizures, advanced medication regimens, surgical approaches, and innovative devices can effect improvement in some cases.

Increasingly, patients are urged to practice epilepsy self-management. The idea of self-managing epilepsy, which has existed for decades, is supported primarily by a theory of robust patient education intended to increase disease knowledge and improve decision making. Multiple formal self-management programs have been developed and academically tested for patients with epilepsy. In a 2013 report, the Institute of Medicine emphasized the importance of research on the effects of behavioral self-management interventions on health outcomes and quality of life for people with epilepsy. The report recommended improving and expanding educational opportunities for patients.⁴ Nevertheless, self-

management programs have not found widespread traction in mainstream clinical use.

This article provides a review of chronic disease self-management with a focus on its application and study in epilepsy. The authors discuss self-management, including underlying theory, definitions, and various tools. The principal formal epilepsy programs that have been studied and published are highlighted and summarized. This review also includes a discussion of the potential barriers to successful implementation of these epilepsy programs along with emerging solutions and tools for addressing these barriers.

SELF-MANAGEMENT THEORY

Disease self-management originated in social cognitive theory, which addresses the cognitive, emotional, and behavioral aspects of behavior change and is relevant to managing chronic illness.^{5,6} Self-management of chronic illness is defined as the daily actions that people take to keep their illness under control, to minimize its impact on physical health status and functioning, and to cope with psychosocial sequelae.⁷ These actions include making informed decisions about care, performing activities intended to manage the condition, and applying the necessary skills to maintain adequate psychosocial functioning.⁷

Related to self-management is self-efficacy, people's confidence in their ability to engage in these actions.⁷ Evidence-based self-management and self-efficacy

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strategies are recognized as central in managing a variety of chronic diseases by improving the medical, emotional, and social role that management demands of chronic conditions.⁸

Self-management and self-efficacy have been explored in patients with epilepsy for decades, with various approaches being developed, implemented, and tested. Findings of several historical studies discussed in this review indicate that patients with epilepsy and high levels of self-efficacy are more successful in performing self-care tasks.⁹ This growing body of evidence led to the establishment of the Managing Epilepsy Well network in 2007.¹⁰ The Centers for Disease Control and Prevention created the network to expand epilepsy self-management research. Since 2007, more research has been focused on the potential for online and mobile health approaches in supporting epilepsy self-management and on intervention studies evaluating e-tools.

Elements of Epilepsy Self-Management

The first element of an epilepsy-specific self-management program is formal education on the diagnosis, treatment, and psychosocial impact of epilepsy and on strategies for coping with it. This element usually includes tools for evaluating and understanding epilepsy, with the goal of empowering patients to become actively engaged in managing and coping with their epilepsy diagnosis. Medication adherence is key in the optimal management of epilepsy. This point is evident in the development of a validated metric for self-efficacy: the Epilepsy Self-Efficacy Scale (ESES).¹¹ Of the 33 items on the ESES, 14 are devoted to aspects of medication management. Other crucial behavioral elements for epilepsy self-management relate to lifestyle issues, such as safety, diet, exercise, sleep, and stress management.

Various self-management programs have incorporated tracking systems for these lifestyle elements as well as epilepsy-specific measures, such as seizure frequency, duration, and type. In addition, social support is an important factor in chronic illness self-management. Results of several studies support the hypothesis that higher levels of social support, particularly disease- and regimen-specific support, are related to better self-management behaviors.¹² An increasing number of formal epilepsy self-management programs include peer support platforms and peer navigator features in their suite of services.

Patient Education and Self-Management Programs

Over the past several decades, multiple research groups have developed, implemented, and tested formal self-management platforms for patients with epilepsy. Designs and results of prominent studies are summarized in the Table. Most programs include the common elements and tools already described, and each program is discussed in detail later. Overall, 3 studies used in-person formal and curriculum-based educational programs.¹³⁻¹⁵ Other programs used an online approach to present individual patients with similar curriculum-based content.¹¹

More recent programs also included a focus on peer-to-peer support and patient-driven content within the educational curriculum.^{16,17} In 2015, Hixson and colleagues used an entirely patient-driven online platform.¹⁸ Unlike the programs described thus far, this platform made educational modules available and did not require that patients complete them. Peer-to-peer support and self-tracking tools were prominently featured, and patients used them. In addition, this intervention focused exclusively on a group of US veterans with epilepsy.

Tools for Improving Self-Management

Self-management programs for patients with epilepsy historically have involved formalized programs conducted face-to-face with other patients, with professional moderators, and perhaps with caregivers. These programs depended entirely on in-person educational sessions and in-person support groups and were found to be very effective in improving self-management skills, though they were labor-intensive and logistically challenging for both practitioners and patients.

Since the advent of the Internet and mobile connectivity, many programs have incorporated the same elements in more accessible form. Educational content appears in live webinars and asynchronous video educational modules; the latter are attractive because patients and caregivers can access them independently at any time. Also readily available are tools for day-to-day self-management of medical conditions. These tools include mobile and online diaries for tracking seizure metrics and medication adherence reminder systems. Last, a variety of online and mobile disease-specific social networking platforms allow patients to connect directly to others without having to travel long distances to meet in-person. Although these digital solutions may not provide the exact experience offered by an in-person

Table. Self-Management Interventions for Patients With Epilepsy

Studies, y	Design	Patients, No.	Interventions	Results
Helgeson and colleagues (SEE), 1990 ¹³	Controlled outcome design	20 treatment 18 control	In-person psychoeducational program to increase knowledge of epilepsy	Significant increase in overall understanding of epilepsy, fear of seizures, and hazardous medical self-management practices
May and Pfäfflin (MOSES), 2002 ¹⁴	Randomized controlled	113 treatment 129 control	14 in-person lessons (1 h each)	Treatment group improved significantly in knowledge, coping, seizures, and satisfaction with therapy
Aliasgharpour, 2013 ¹⁵	Randomized controlled	30 treatment 30 control	4 in-person educational sessions	Treatment group's self-management scores improved significantly
Fraser and colleagues (PACES), 2015 ¹⁶	Randomized controlled	38 treatment 40 control	8 weekly sessions (75 min each) co-led by psychologist and trained peer with epilepsy	Treatment group showed significant improvement on several outcome measures
Laybourne and colleagues (SMILE), 2015 ¹⁷	Pilot study	10 total	2-d patient education session (9 modules)	Participants described powerful peer support, feeling better equipped to discuss condition with providers, and having increased confidence in living with epilepsy
Dilorio and colleagues (WebEase), 2011 ¹¹	Randomized controlled	70 treatment 78 control	Completion of WebEase online program by each patient over 6 wk	Compared with control group, treatment group reported higher levels of self-efficacy, medication adherence, self-management, and knowledge and lower level of stress
Hixson and colleagues (POEM), 2015 ¹⁸	Prospective, within-subject comparison	249 total 92 completers	Unmoderated participation in online patient community, with access to self-tracking tools and educational resources	Study completers demonstrated statistically significant improvement in epilepsy self-efficacy and epilepsy self-management, particularly on Information Management subscale of Epilepsy Self-Management Scale

support group, the promise of superior accessibility creates an advantage in terms of accessibility and flexibility.

SELF-MANAGEMENT IN THE LITERATURE

In a recent review of care delivery and self-management strategies for adults with epilepsy, Bradley and colleagues analyzed 18 different studies of 16 separate interventions and concluded that 2 interventions, the specialist epilepsy nurse and self-management education, had some evidence of benefit. Four studies, detailed next, had the highest quality design, based on a focus on epilepsy self-management specifically, a prospective hypothesis-driven approach, and rigorous methodology.¹⁹

In 1990, Helgeson and colleagues evaluated Sepulveda Epilepsy Education, a 2-day in-person program designed to provide medical education and psychosocial therapy to patients with an epilepsy diagnosis.¹³ The program was based on the theory that having a better understanding of their epilepsy helps people cope with the condition. Medical, social, and emotional topics are covered. Medical topics include epilepsy and how it may change

over time, as well as diagnosis, treatment, and first aid; social and emotional topics include coping with the psychological aspects of epilepsy, family, social aspects, and employment. In this small study (38 patients total), compared with the control group (18 patients), the treatment group (20 patients) demonstrated a significant reduction in the level of fear of death and brain damage caused by seizures, a significant decrease in hazardous medical self-management practices, and a significant decrease in misconceptions about epilepsy. The treatment group also increased their medication adherence, as determined by serum drug levels. In addition, statistically nonsignificant trends were shown by the treatment group toward improved emotional, interpersonal, and vocational functioning; improved adjustment to seizures; and improved overall psychosocial functioning.

In 2002, May and Pfäfflin evaluated the efficacy of the Modular Service Package Epilepsy (MOSES) educational program.¹⁴ This program was specifically developed to improve patient knowledge about epilepsy and its consequences and diagnostic and therapeutic measures, and to improve patient understanding of

psychosocial and occupational problems. It was the first comprehensive program used in German-speaking countries. It had 9 modules: coping with epilepsy, epidemiology, basic knowledge, diagnostics, therapy, self-control, prognosis, psychosocial aspects, and network. To complete the program, patients work through about fourteen 1-hour lessons. The controlled, randomized study by May and Pfäfflin involved 242 patients (113 treatment, 129 control) aged 16 to 80 years. Patients in the treatment (MOSES) group demonstrated significant improvements in 2 of the 9 modules (knowledge, coping with epilepsy), had improved self-reported seizure outcomes, were more satisfied with therapy, experienced better tolerability of antiepileptic drugs with fewer adverse effects (AEs), and were highly satisfied with the program. The researchers concluded that educational programs, such as MOSES, should become a standard service for specialized epilepsy care.

Developed over many years, WebEase is an online epilepsy self-management program that supports education on medication, stress, and sleep management. In 2011, DiIorio and colleagues reported on a WebEase trial in which 194 patients were randomly assigned to either a treatment group ($n = 96$) or a wait-list control group ($n = 96$), and 2 were lost to follow up.¹¹ After accounting for study criteria and study drop out, 70 participants completed the treatment arm, and 78 completed the control arm. The study measured the impact of the platform on multiple outcome metrics, including 3 behavioral areas of focus. At follow-up, self-reported levels of medication adherence were higher for patients in the treatment group than for those in the control group. Analyses also compared patients who completed WebEase modules with those who did not. Patients who completed at least some WebEase modules reported higher levels of self-efficacy, and a trend toward significance was found for medication adherence, perceived stress, self-management, and knowledge. The authors concluded that online tools that support epilepsy self-management could be effective.¹¹

In 2015, Fraser and colleagues reported the results of the Program for Active Consumer Engagement in Self-Management in Epilepsy (PACES in Epilepsy), a consumer-generated self-management program.¹⁶ In the trial, 83 adults with chronic epilepsy were initially assigned either to an in-person intervention or to treatment as usual. After study drop outs, 38 patients remained in the intervention arm, with 40 in the control arm. In the intervention, 6 to 8 adults met for a 75-minute group session 1 evening per week for 8 weeks; these sessions were co-led by a psychologist and a trained peer with epilepsy.

Topics included medical, psychosocial, cognitive, and self-management aspects of epilepsy, in addition to community integration and optimization of epilepsy-related communication. Outcomes were measured with various instruments, including the ESES, the Quality of Life in Epilepsy-31 (QOLIE-31), the Epilepsy Self-Management Scale (ESMS), the Patient Health Questionnaire-9, and the Generalized Anxiety Disorder-7. Each test was administered at baseline and after intervention. Outcomes were assessed immediately after program completion (8 weeks) and at follow-up 6 months later.

Findings suggested a substantial positive impact on epilepsy self-management capacities at program completion. In addition, benefit was sustained, particularly for epilepsy information management, over the 6 months after program completion. On the QOLIE-31 at 6 months, management of medication AEs also remained significantly improved, and fatigue management was improved at the $P < .05$ level. The researchers concluded that the PACES in Epilepsy program might have a more sustained impact on management of disability than on mood. They also noted that the effect was greater immediately after program completion than at 6 months. Patients gave the PACES program high satisfaction ratings.

Although these programs take slightly different approaches to epilepsy self-management, they have a similar focus: directed patient education. Furthermore, most of these programs are conducted in person, usually in a support group setting. In the WebEase trial, patients seem to have completed the online modules in a study setting, and a peer support component was not included. Overall, all programs successfully demonstrated various benefits for trial patients. These outcomes suggest that despite their subtle differences in approach, formal self-management programs are benefiting patients.

None of these platforms was designed for or specifically tested veterans with epilepsy. Although veterans theoretically would benefit from the same tools used by nonveterans, Iraq and Afghanistan veterans with epilepsy are more likely than are those without epilepsy to have mental and physical comorbidities and significantly higher mortality.² Therefore, veterans potentially could benefit more from evidence-based chronic disease self-management programs designed to reduce physical and psychiatric comorbidities. Furthermore, programs that incorporate peer-to-peer support and direct links to VA care teams and mental health providers could be valuable.¹⁸

One research effort that directly addressed these issues is the Policy for Optimized Epilepsy Management (POEM) study, conducted by Hixson and colleagues in

2015.¹⁸ This study, not included in the review by Bradley and colleagues, used a purely online- and mobile-based social networking platform to promote self-management practices.¹⁹ Unlike the other programs described here, POEM did not require that patients view or attend formal educational seminars, though these seminars were available through the online platform for patient self-directed viewing. In addition, the intervention heavily promoted peer-to-peer engagement and disease tracking as means of increasing self-knowledge and activation. This study was unlike the other platforms in another way: It specifically focused on veterans with epilepsy, based on the idea that many veterans had a shared experience that would optimize a peer support approach.

The POEM investigators did not use a controlled design but found a significant benefit for both ESES and ESMS metrics on within-subject comparisons. Similar to the PACES in Epilepsy study, the POEM study found the highest benefit on the information management subscale of the ESMS.¹⁶ Practically speaking, this means patients were better able to use and manage digital and mobile information resources for controlling epilepsy. The POEM study results further reinforced the idea that epilepsy self-management programs are beneficial and expanded on earlier research to emphasize the value of peer support networks and digital interventions that can be used by patients at their convenience. These features provide greater access to more patients and maintain the crucial elements of peer-to-peer learning and counseling.

IMPLEMENTATION BARRIERS

Confirming the effectiveness of self-management programs is only the beginning of formal implementation and adoption. The real-world success of patient self-management programs has been documented for a few chronic diseases, including epilepsy. However, there is little research or commentary on lessons learned or on the challenges encountered with wide implementation of these programs.

Initial Setup and Sponsorship

To promote wider adoption, researchers should include commentary on initial setup, ongoing patient acceptance, and continual provider support. Many of the initial challenges in self-management programs involve a changing paradigm in the delivery and economics of health care. The transition to a more consumer-oriented health model with an emphasis on outcomes and patient-reported variables likely will support self-management strategies but is only slowly evolving. Many health care

providers, hospitals, and payers may not be familiar with or have proper incentives to explore self-management tools even when proven effective.

More specifically, these epilepsy self-management programs are treatment adjuncts well suited to military and veteran health care systems. Self-management closely aligns with the overall VHA mission, vision, and values, including formal Department of Veteran Affairs (VA) goals and the MyVA priorities that collectively embrace improvement in access, a veteran-centric approach, and quality for improvement of the entire VA experience. Self-management platforms in the VA are recognized as empowering veterans and are thought to indirectly improve access to health care.^{20,21}

The barriers of sponsorship and financial support likely will persist in the private health care sector but are less likely to significantly affect the VHA. Self-management programs have been researched and implemented for many health conditions across the VHA. For example, the VA Talent Management System course Patient Self-Management: Skill Building (TMS 6467) offers education and training to all clinical practitioners and managers involved in patient education and self-management activities for a variety of chronic medical conditions. Regarding epilepsy self-management more specifically, a patient brochure on the practice is distributed by the VHA Epilepsy Centers of Excellence (ECoEs) and an associated consortium.²² Last, a national provider educational lecture series has a corresponding patient and caregiver lecture set that emphasizes education and self-management behaviors.

Labor, Time, and Resource Needs

The most time-intensive aspect of designing self-management programs is developing the tool that allows clinicians and patients to work together. From a program perspective, the tool must be available and helpful not only to patients and specialists, but also to primary care providers. Tertiary-care centers usually accept the responsibility for program initiation, including patient recruitment, logistics coordination, and health care professional staffing. For epilepsy, the small pool of relevant specialists and centers limits the number of self-management education sessions that can be hosted and increases the need for complex travel and scheduling tasks. However, ECoE communication lines provide a basic infrastructure for collaboration and for development of tools that can be helpful to all clinicians treating veterans with epilepsy.²³

Given the issues with coordinating the logistics of in-person programs at brick-and-mortar sites, this type

of program may not be the best option for some patients and facilities. Alternative approaches, such as telehealth and asynchronous digital platforms, could expand access and increase convenience. Even though remotely administered programs may not be as powerful for some patients, the promise of scalable access supports consideration of these approaches.

Patient and Caregiver Logistics

Veterans with epilepsy may also have comorbid traumatic brain injury (TBI) and posttraumatic stress disorder, which can complicate self-managed care. In addition, many veterans live in rural areas and have limited travel options. All these factors challenge the success of epilepsy self-management programs. However, the network of ECoEs and associated consortium facilities can step up to deliver self-management tools and information.

The infrastructure of the VHA patient aligned care team (PACT) also contributes to the integration of self-management training. The PACT model takes a personalized, comprehensive, coordinated approach to promote team-based, veteran-centric care and actively partners with other VHA offices to incorporate alternative care services, including peer support and self-management platforms. The combination represents fertile ground for implementation and promotion of self-management tools in the VHA epilepsy population.

Health Care Economics

Given the uncertainties of the US health care economy, it is not surprising that many experts advocate a fundamental redesign of the health care team relationship and information infrastructure.²⁴ This realignment includes partnering directly with patients and their families to encourage more reliance on self-management practices. Unfortunately, this approach does not lend itself to the well-entrenched business model on which most community medical practices are based. Health system leadership often must be convinced there are potential cost savings or a return on investment for new programs. As there is no consistent, comprehensive reimbursement policy for programs focused on self-management, health care systems must be creative and innovative when appraising the financial consequences of such programs.

Epilepsy remains a huge burden. In 2000, the annual total cost of epilepsy treatment in the US was \$362 million for new patients and \$2 billion for existing cases.²⁵ Within the VHA, the occurrence of posttraumatic epilepsy among the increasing number of veterans with

TBI contributes to the burden, and posttraumatic epilepsy and psychogenic nonepileptic seizures complicate treatment approaches. The incidence of comorbidities, including anxiety and depression, has been as high as 50%.²³ Epilepsy health care programs are evaluating ways to validate their ability to minimize cost, improve access, and maintain quality of service. Integration of self-management should be included in these efforts.

The VHA represents a unique health care environment for testing and implementing self-management programs. Although the VHA is not immune to the traditional business models of medicine, it is less dependent on them, and it disproportionately cares for patients for long spans of time. From the health care team perspective, data indicate that ECoE physicians represent a high percentage of VHA epilepsy specialists but directly see only about 20% of veterans with an epilepsy or seizure-associated diagnosis. Therefore, future collaboration and connectivity of consortium sites can have a broader impact on self-management—highlighting the fact that concerted, scaled self-management programs have an important role in the VHA health care delivery system and should be promoted.²⁶

FINAL INSIGHTS AND OPPORTUNITIES

Despite the barriers to adoption, formal epilepsy self-management programs are making gains in maturity and academic credibility. As the health care economy gradually shifts to more outcomes-based models, these offerings likely will become more valued, particularly by health care organizations focused on cost sharing, by large self-insuring employers, or organizations like the VHA where patients maintain a long-term relationship. Nevertheless, for the more resource-intensive, in-person self-management programs, adoption may remain constrained. Digital and mobile platforms should serve as more accessible entry points, with lower costs and more rapid scaling potential. Even though these online platforms may not have the same impact as intensive face-to-face programs, their scalability and constant accessibility should make them attractive, and the relatively modest cost of implementing self-guided programs should reduce barriers to adoption.

Integrated health care systems, such as the VHA and various European health systems, can serve as models for self-management implementation. Incorporating a live clinical implementation into parallel research efforts can continue to produce vital academic information on the real-world impact of these solutions, and this evidence in turn can be used to support policies that foster widespread adoption. More specifically, the ECoE model

represents a clear opportunity to promote widespread implementation of self-management. The ECoEs are already publishing self-management materials that health care teams can use in patient counseling, and several self-care studies are being conducted within the network.²² In this model, compared with private sector health systems, ECoEs are well positioned to advance the use of formal self-management strategies.

The proposed epilepsy self-management model for ECoEs would be based on an iterative program that incorporates best practices from each of the research studies discussed earlier. With the publication of new research, successful self-management tools would be incorporated into the programs. From a curriculum perspective, educational platforms on medication adherence, seizure safety, and information/data management should be included. Evidence is increasing that peer support and use of licensed peer navigators should be incorporated as well. Last, flexible and asynchronous digital methods should be added to self-management platforms to maximize patient access. These features build on the growing body of evidence to maximize the likelihood of a successful and sustainable self-management strategy for patients with epilepsy.

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Disclaimer

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