Self-management of Epilepsy: A Systematic Review

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Prepared by:

Evidence Synthesis Program (ESP) Center
Durham Veterans Affairs Healthcare System
Durham, NC
John W. Williams, Jr., MD, MHSc, Director

Authors:

Principal Investigator:
Matthew W. Luedke, MD
Dan V. Blalock, PhD, MA
John W. Williams, Jr., MD, MHS

Co-Investigators:
Allison A. Lewinski, PhD, MPH, RN
Abigail Shapiro, MSPH
Connor Drake, MPA
Jeffrey D. Lewis, PhD, MD
Karen M. Goldstein, MD, MSPH
Aatif M. Husain, MD
Saurabh R. Sinha, MD, PhD
Tung T. Tran, MD
Adelaide M. Gordon, MPH
Andrzej S. Kosinski, PhD
Hayden B Bosworth, PhD

Research Associates:
Avishek Nagi, MS
Robyn E. Fortman, BA
Christiana Oshotse

Medical Editor:
Liz Wing, MA

VA
U.S. Department of Veterans Affairs
Veterans Health Administration
Health Services Research & Development Service

PREFACE

The VA Evidence Synthesis Program (ESP) was established in 2007 to provide timely and accurate syntheses of targeted healthcare topics of importance to clinicians, managers, and policymakers as they work to improve the health and healthcare of Veterans. These reports help:

- Develop clinical policies informed by evidence;
- Implement effective services to improve patient outcomes and to support VA clinical practice guidelines and performance measures; and
- Set the direction for future research to address gaps in clinical knowledge.

The program is comprised of four ESP Centers across the US and a Coordinating Center located in Portland, Oregon. Center Directors are VA clinicians and recognized leaders in the field of evidence synthesis with close ties to the AHRQ Evidence-based Practice Center Program and Cochrane Collaboration. The Coordinating Center was created to manage program operations, ensure methodological consistency and quality of products, and interface with stakeholders. To ensure responsiveness to the needs of decision-makers, the program is governed by a Steering Committee comprised of health system leadership and researchers. The program solicits nominations for review topics several times a year via the program website.

Comments on this evidence report are welcome and can be sent to Nicole Floyd, Deputy Director, ESP Coordinating Center at Nicole.Floyd@va.gov.

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ACKNOWLEDGMENTS

This topic was developed in response to a nomination by Glenn Graham, Deputy National Director of Neurology, and John Hixson, Associate Professor of Neurology, for the purpose of identifying the current evidence base and its quality to support the use of self-management programs aimed at patients with epilepsy; identifying the program components that contribute most to effectiveness; and identifying potential barriers in the adoption of these programs within the VHA system. The scope was further developed with input from the topic nominators (*ie*, Operational Partners), the ESP Coordinating Center, the review team, and the Technical Expert Panel (TEP).

In designing the study questions and methodology at the outset of this report, the ESP consulted several technical and content experts. Broad expertise and perspectives were sought. Divergent and conflicting opinions are common and perceived as healthy scientific discourse that results in a thoughtful, relevant systematic review. Therefore, in the end, study questions, design, methodologic approaches, and/or conclusions do not necessarily represent the views of individual technical and content experts.

The authors gratefully acknowledge the following individuals for their contributions to this project.

Operational Partners

Operational partners are system-level stakeholders who have requested the report to inform decision-making. They recommend TEP participants; assure VA relevance; help develop and approve final project scope and timeframe for completion; provide feedback on the draft report; and provide consultation on strategies for dissemination of the report to field and relevant groups.

Glenn Graham, MD, PhD
Deputy National Director of Neurology

John Hixson, MD
Associate Professor of Neurology
Epilepsy Center of Excellence (ECoE), San Francisco VA Medical Center
Neurology Program Office, VHA

Technical Expert Panel

To ensure robust, scientifically relevant work, the TEP guides topic refinement; provides input on key questions and eligibility criteria, advising on substantive issues or possibly overlooked areas of research; assures VA relevance; and provides feedback on work in progress.

Jennifer Patterson, PhD
Senior Whole Health Consultant
Office of Patient Centered Care & Cultural Transformation
VA Sierra Nevada Health Care System
Reno, Nevada

Paul Rutecki, MD
Neurology Service Chief
William S. Middleton Veterans Hospital
Madison, Wisconsin
National Director VA Epilepsy Centers of Excellence
Professor of Neurology and Neurosurgery
University of Wisconsin-Madison

Peer Reviewers

The Coordinating Center sought input from external peer reviewers to review the draft report and provide feedback on the objectives, scope, methods used, perception of bias, and omitted evidence. Peer reviewers must disclose any relevant financial or nonfinancial conflicts of interest. Because of their unique clinical or content expertise, individuals with potential conflicts may be retained. The Coordinating Center and the ESP Center work to balance, manage, or mitigate any potential nonfinancial conflicts of interest identified.

EXECUTIVE SUMMARY

INTRODUCTION

Epilepsy affects about 50 million people worldwide. In the Veterans Health Administration (VHA), an estimated 79,576 Veterans were treated for epilepsy in 2016. Seizure control and medication adherence are common challenges among patients; decreased health care literacy, poor social support, burdensome side effects, low socioeconomic status, and co-occurring psychiatric disorders are all associated with lower medication adherence. Patient self-management behaviors are important to the management of epilepsy, as decreased patient participation in treatment regimens is a major cause of breakthrough seizures, leading to increased hospital utilization and mortality.

In 2003, the Institute of Medicine defined self-management support as “the systematic provision of education and supportive interventions by health care staff to increase patients’ skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support.” In Veterans Affairs (VA), self-management has an established role in the management of chronic conditions, such as diabetes mellitus, chronic obstructive pulmonary disease, and depressive disorders.

For patients with epilepsy, improved self-management skills could improve self-efficacy, medication adherence, avoidance of seizure triggers, and improve patient and family knowledge about when to seek urgent medical care. A Cochrane review that included literature published through December 2013 evaluated self-management strategies for adults with epilepsy. The review identified only 4 trials and concluded that self-management education has some evidence of benefit but did not find clear evidence of substantially improved outcomes for adults with epilepsy. Prior systematic reviews on this topic were inadequate for the needs of our stakeholders because they do not include recent important studies and did not adequately consider components such as peer support, which has particular relevance to Veterans. This review will address these gaps in evidence, synthesize the current evidence on self-management programs for patients with epilepsy, and identify potential barriers in the adoption of these programs within the VHA system.

At the request of the VA National Neurology Program Office in the Office of Specialty Care Services, we conducted a systematic review and meta-analysis to address the following key questions (KQ):

KQ 1: For adults with epilepsy, what are the most commonly employed components of self-management interventions evaluated in comparative studies?

KQ 2: What are the effects of self-management interventions on self-management skills and self-efficacy, clinical outcomes, and health care utilization?

KQ 3: What are the identified facilitators and barriers that impact the adoption of self-management interventions in large-scale health systems such as the VHA?

METHODS

We developed and followed a standard protocol for this review in collaboration with operational partners and a Technical Expert Panel (PROSPERO registration number CRD42018098604).

Data Sources and Searches

We searched MEDLINE® (via PubMed®), PsycINFO, Cochrane Central Register of Controlled Trials (CENTRAL), and CINAHL from inception through April 13, 2018, and updated the MEDLINE search on October 31, 2018. We also examined the bibliographies of recent reviews for additional relevant studies.

Study Selection

In brief, the major eligibility criteria were randomized or quasi-experimental studies that enrolled adults with epilepsy, evaluated self-management interventions, and reported a relevant clinical, process, or economic outcome. For KQ 3, we also included additional observational designs and qualitative studies addressing facilitators or barriers to adoption or implementation. Self-management interventions were defined operationally as those that aimed to equip patients with skills to actively participate and take responsibility in the management of epilepsy in order to function optimally through at least knowledge acquisition and a combination of 1 or more of the following: stimulation of independent sign/symptom monitoring; medication management; enhancing problem-solving and decision-making skills for epilepsy treatment management; safety promotion (*eg*, driving); and changing health behaviors (*eg*, stress management, sleep, substance use). Using these prespecified inclusion/exclusion criteria, investigators and the DistillerSR Artificial Intelligence tool evaluated titles and abstracts to identify potentially eligible studies. Studies that met all eligibility criteria at full-text review were included for data abstraction.

Data Abstraction and Quality Assessment

Key characteristics abstracted were patient descriptors (*eg*, age, duration of epilepsy), intervention characteristics (*eg*, self-management components, delivery modality, duration/intensity), comparator, and outcomes. For studies relevant to KQ 3, we abstracted barriers (*ie*, description of themes or factors that impeded the use and implementation of the intervention as reported in the study's results and/or findings sections) and facilitators (*ie*, description of themes or factors that aided the use of the intervention as reported in the study's results and/or findings sections) to the implementation of self-management interventions (as distinct from barriers and facilitators of an individual engaging in self-management behaviors).

For KQ 1 and KQ 2 studies, we assessed risk of bias (ROB) using the Effective Practice and Organization of Care (EPOC) guidance. For KQ 3 studies, we used ROB appraisals customized to the specific study design.

Data Synthesis and Analysis

We described the included studies using summary tables and graphical displays. We computed summary effects (*ie*, meta-analysis) when studies were conceptually homogeneous and there were at least 3 studies with the same outcome. When quantitative synthesis was feasible, we combined outcomes using random-effects models and computed summary effects using the standardized mean difference. Analyses were stratified by study design (randomized vs nonrandomized) and by intervention category. When quantitative synthesis was not feasible, we analyzed the data narratively.

We analyzed potential reasons for inconsistency in treatment effects across studies by evaluating differences in the study population, intervention, comparator, and outcome definitions. Confidence of evidence (COE) was assessed for outcomes critical to decision making using the approach described by the Grading of Recommendations Assessment, Development and Evaluation working group (GRADE).

For KQ 3, 2 co-investigators (AAL, AS) with experience in qualitative methodology led the abstraction and analysis of data collected. We analyzed the data using thematic synthesis and the framework method. First, we identified the respondent (*eg*, the patient with epilepsy, caregiver, or health care clinician) for each facilitator and barrier. Then, we created an *a priori* framework that included barriers and facilitators as reported at 1 of 3 levels (*eg*, person, program, site/system) adapted from ecological models of health behavior. The creation and identification of codes and themes was iterative; to ensure rigor and validity of these findings, we independently coded and developed themes and then discussed theme development and identification until we reached agreement between the 2 researchers.

RESULTS

Results of Literature Search

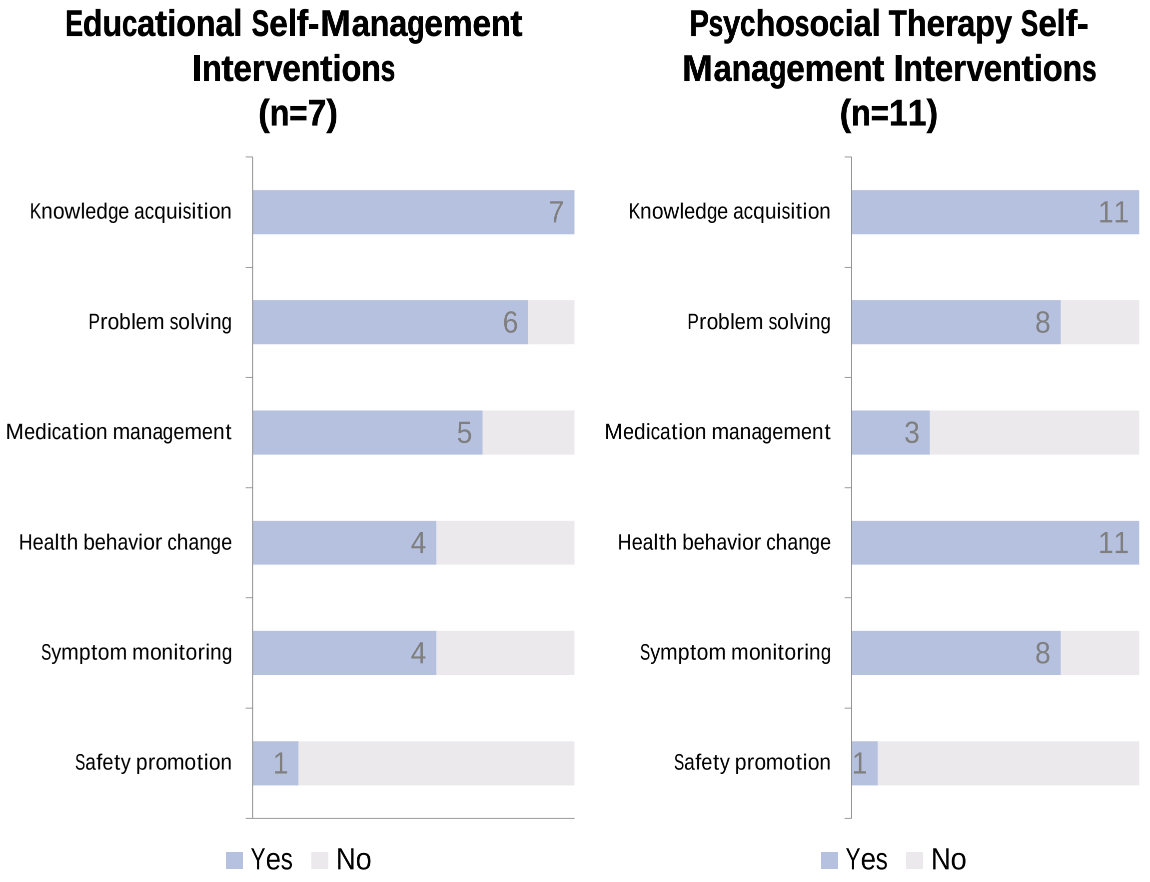
The literature search identified 2,543 citations, of which 161 were reviewed at the full-text stage. Fifteen articles relevant to KQs 1 and 2 were retained for data abstraction, of which 13 were randomized and 2 were nonrandomized; one enrolled Veterans. Because some studies had more than 1 active intervention arm, a total of 18 intervention arms are described across the 15 studies. Thirteen articles relevant to KQ 3 were retained for data abstraction.

Summary of Results for Key Questions

KQ 1

Self-management interventions for adults with epilepsy used 2 main approaches: educational interventions with content created specifically for patients with epilepsy (n=7 studies, 7 intervention arms) and psychosocial therapy interventions (*eg*, cognitive behavioral therapy, problem solving therapy, progressive muscle relaxation) established for other conditions and adapted for patients with epilepsy (n=8 studies, 11 intervention arms). Intervention approaches most commonly addressed education—implicitly or explicitly—as well as stimulation of independent sign/symptom monitoring; enhancing problem-solving and decision-making skills for medical treatment management; and changing physical activity, dietary, and/or smoking behaviors. These intervention components were delivered during 4-41 hours of training over a broad range of times anywhere from 2 days to 3 years. Peer support was only provided explicitly in 1 study, although 3 studies incorporated peers as group leaders. Goal-setting was present in 8 studies.

Self-management Components Addressed in Interventions



KQ 2

Among the interventions that used an educational approach, the use of self-management practices may have improved among people with epilepsy, although the certainty of evidence (COE) is low, and there was no effect on overall quality of life (low COE) or seizure rate (moderate COE). Similarly, there was no overall effect on self-efficacy, social function, or medication adherence. However, a stakeholder-informed, group-based intervention delivered to patients at high risk for poor outcomes (including Veterans) showed moderate benefit for quality of life and self-efficacy. Among interventions that used a psychosocial therapy approach, there was a positive effect on overall quality of life (low COE) but no benefit on seizure rates (low COE), and there was insufficient evidence to determine effects on self-management practices. Additionally, sparse evidence suggested some benefit on self-efficacy; there were inconsistent effects on social function and limited data for no effect on medication adherence. COE was evaluated only for primary outcomes. One study of an intervention using a group-based intervention in high-risk patients found no effect on the combined outcome of emergency department visits and hospitalization. No study reported effects on workplace productivity or employment status. Only one study reported enrolling Veterans.

Certainty of Evidence for Primary Outcomes of Self-management Interventions for Patients with Epilepsy

Outcome	Number of Studies (Patients)	Findings	Certainty of Evidence (Rationale)
Educational Self-management Interventions			
Epilepsy self-management	4 randomized (569)	SMD 0.52 higher (0 to 1.04 higher)	**Low certainty** of improved self-management
Quality of life	4 randomized (492) 1 nonrandomized (747)	SMD 0.17 (0.57 lower to 0.91 higher) MD 0.5 (6.4 lower to 7.4 higher)	**Low certainty** for no effect
Seizure rates	4 randomized (787)	SMD 0.00 (-0.3 lower to 0.04 higher)	**Moderate certainty** for no effect
Psychosocial Therapy Self-management Interventions			
Epilepsy self-management	None	Not applicable	**Insufficient**
Quality of life	3 randomized (187)	MD 6.64 higher (2.51 to 10.77 higher)	**Low certainty** for improved quality of life
Seizure rates	3 randomized (106)	SMD range from 0.06 to 0.47	**Low certainty** for no clinically important improvement

Abbreviations: MD=mean difference; NR=not reported; SMD=standardized mean difference; ROB=risk of bias

KQ 3

Thematic synthesis of the abstracted data identified 5 themes across all KQ 3 studies that could be applied conceptually to facilitators and barriers. The presence of facilitators of epilepsy self-management interventions at any level (*ie*, person, program, site/system) was noted in 11 studies. Two studies did not include any relevant facilitators. The presence of barriers to epilepsy self-management interventions at any level was noted in 11 studies. Two studies did not include any relevant barriers.

Theme	Definition
Relevance	Relevance of intervention content or topics that facilitate the acquisition of self-management skills in patients with epilepsy
Personalization	Intervention components that account for the individual social, physical, and environmental characteristics of the patient
Intervention components	Components and dosing of the intervention
Technology considerations	Considerations that account for patient’s use, familiarity with, and ownership of technology (*eg*, computers, laptops, mobile phones)
Clinician interventionist	Role and preparation of individual who leads the intervention, engages with the patient, and provides self-management education and/or support to the patient

Involving patients with epilepsy in the development of interventions may facilitate implementation by ensuring that the self-management content is relevant to people living with the condition. Including customizable intervention content to allow for tailoring to each individual patient may facilitate implementation. Patients may have cognitive limitations that present a barrier to intervention engagement and adherence. Technology use for self-management is highly dependent on individual characteristics such as familiarity and ownership of technological devices (*eg*, mobile phones, computers). The role of the clinician (*ie*, the individual who interacts with the patient to provide self-management education and support) is important to the implementation of the intervention. The clinician should be appropriately trained, have the duties of the intervention incorporated into their dedicated clinical time, and be provided with clearly written standardized protocols that articulate the clinician interventionist's role in the intervention. No studies directly addressed facilitators and barriers to implementing and adopting self-management interventions for patients with epilepsy in the VHA or other large health systems. No studies intentionally enrolled Veterans with epilepsy.

DISCUSSION

Key Findings

We evaluated self-management interventions for patients with epilepsy, examining effects on a range of outcomes of importance to patients, clinicians, and policymakers. Our review is unique in its use of a standard definition for self-management, focus on high-quality study designs, and rigorous analysis of studies that address facilitators and barriers to implementation and adoption of self-management interventions. We identified 15 studies addressing the effects of self-management and 13 that addressed implementation and adoption. Only 1 specifically included Veterans. We identified 2 broad categories for self-management interventions: educationally focused interventions created for patients with epilepsy, and psychosocial therapies such as cognitive behavioral therapy (CBT) that were adapted for people with epilepsy. We found limited evidence for benefit on selected primary or secondary outcomes. Educational self-management interventions may improve the use of self-management practices, and quality of life may improve with therapy-based self-management approaches. There was low to moderate certainty of no improvement in seizure rates across self-management interventions. Sparse evidence suggested possible benefit of psychosocial therapy interventions on self-efficacy. Effects on employment and health care utilization were not reported.

Studies of barriers and facilitators to implementation and adoption of epilepsy self-management interventions addressed factors primarily at the patient level or program level. No studies directly addressed implementation and adoption issues for large health systems such as the VHA. Important themes that could inform the development, implementation, and/or adoption of future self-management interventions included the desire of patients with epilepsy to be involved in the development of intervention content, recognition that cognitive limitations may affect engagement and adherence, and the need for clinician interventionists who are appropriately trained to provide self-management interventions and whose job function specifically includes this role.

Applicability

Only 1 of the included studies specifically enrolled Veterans. However, we limited eligibility to studies conducted in OECD countries, which improves applicability to the VHA. All intervention studies were conducted in North America, Europe, or Australia. Identified studies included predominantly white samples, and mid-life patients (median age 41 in contrast to the >50% of Veterans with epilepsy who are 65 years of age or older). Although this approach improved applicability of findings to Veterans, it means that potentially relevant studies conducted in non-OECD countries were excluded.

Research Gaps/Future Research

In brief, research is needed with patients who are earlier in their course of illness, and on barriers and facilitators to adoption of self-management interventions in large health systems and with Veterans. Interventions are needed that incorporate patient, caregiver, and clinician interventionist input into the self-management content and delivery design. Self-management programs should account for potential cognitive limitations, incorporate peer support, address other barriers to engagement and adherence, and address the composition of the intervention team as well as the role of technology.

Research is needed on outcomes most valued by patients with epilepsy, and how to best measure these outcomes. Self-management skills can take time to master and may take longer for patients with cognitive difficulty. Consensus, or research, on the time required to acquire self-management skills, and for those skills to affect clinical outcomes, should inform the timing of outcome assessments. Few studies have examined interventions delivered outside of clinical settings. Future research should determine the preferred location for a self-management program for patients with epilepsy and their caregivers.

Conclusions

Epilepsy is one of the most common chronic neurological conditions, with the potential to generate significant morbidity, impaired quality of life, socioeconomic decline, and high health care costs. Self-management is essential for patients who live with a chronic disease, and the VHA and other health systems are interested in offering self-management training to patients with epilepsy. In our protocol-based review, we found that tested interventions broke down into 2 categories: educational and psychosocial therapy interventions. These self-management interventions showed clinically important benefit for only a limited number of outcomes, but the confidence in these findings was mostly low. Further, there is unexplained variability in the effect of education interventions on quality of life and self-efficacy. Findings on facilitators and barriers to the implementation were stronger and point to a clearer path to the design and adoption of self-management interventions, including factors of patient personalization, information delivery, use of technology, and intervention personnel. Future research should be designed to address these implementation issues, and should include standardized outcome measures prioritized by patients and other stakeholders and Veteran populations.

ABBREVIATIONS TABLE

AED	Antiepileptic drug
CBT	Cognitive behavioral therapy
CI	Confidence interval
CINAHL	Cumulative Index to Nursing and Allied Health Literature
COE	Certainty of evidence
ECoE	Epilepsy Centers of Excellence
ESES	Epilepsy Self-Efficacy Scale
ESMS	Epilepsy Self-Management Scale
ESP	Evidence Synthesis Program
HSR&D	Health Services Research & Development
IOM	Institute of Medicine
LTC	Long-term condition
MD	Mean difference
MeSH	Medical Subject Heading
MMAT	Mixed Methods Appraisal Tool
MMSE	Mini-Mental State Examination
MOSES	Modular Service Package for Epilepsy
OECD	Organization for Economic Cooperation and Development
PACES	Program for Active Consumer Engagement in Epilepsy
PACT	Patient-Aligned Care Team
PICOTS	Population, intervention, comparator, outcome, timing, and setting
PMR	Progressive muscle relaxation
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta Analyses
PST	Problem-solving therapy
QOL	Quality of life
QUERI	Quality Enhancement Research Initiative
QUIET	Quality Indicators in Epilepsy Treatment tool
SMD	Standardized mean difference
ROB	Risk of bias
VA	Veterans Affairs
VHA	Veterans Health Administration