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REVIEW

Self-management of Epilepsy

A Systematic Review

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Background: Although self-management is recommended for persons with epilepsy, its optimal strategies and effects are uncertain.

Purpose: To evaluate the components and efficacy of self-management interventions in the treatment of epilepsy in community-dwelling persons.

Data Sources: English-language searches of MEDLINE, Cochrane Central Register of Controlled Trials, PsycINFO, and CINAHL in April 2018; the MEDLINE search was updated in March 2019.

Study Selection: Randomized and nonrandomized comparative studies of self-management interventions for adults with epilepsy.

Data Extraction: An investigator assessed study characteristics; intervention details, including 6 components of self-management; and outcomes, which were verified by a second reviewer. Risk of bias (ROB) was assessed independently by 2 investigators.

Data Synthesis: 13 randomized and 2 nonrandomized studies (2514 patients) evaluated self-management interventions. Interventions were delivered primarily in group settings, used a median of 4 components, and followed 2 general strategies: 1 based on education and the other on psychosocial therapy. Education-based approaches improved self-management behaviors (standardized mean difference, 0.52 [95% CI, 0.0 to 1.04]), and psychosocial therapy–based approaches improved quality of life (mean difference, 6.64 [CI, 2.51 to 10.77]). Overall, self-management interventions did not reduce seizure rates, but 1 educational intervention decreased a composite of seizures, emergency department visits, and hospitalizations.

Limitation: High ROB in most studies, incomplete intervention descriptions, and studies limited to English-language publications.

Conclusion: There is limited evidence that self-management strategies modestly improve some patient outcomes that are important to persons with epilepsy. Overall, self-management research in epilepsy is limited by the range of interventions tested, the small number of studies using self-monitoring technology, and uncertainty about components and strategies associated with benefit.

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For author affiliations, see end of text.
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Epilepsy affects about 50 million people worldwide (1), with the highest rates in children and older adults. Persons with epilepsy have higher rates of injury and premature death than the general population, and many face diminished quality of life (QOL), even if their seizures are controlled (2–4). Seizure control and medication adherence are common challenges among patients (5–8). Some forms of epilepsy and many anticonvulsants are associated with cognitive impairment or behavioral issues, complicating care plans and medication adherence. Patient self-management behaviors are important in controlling epilepsy, because decreased patient participation in treatment regimens is a major cause of breakthrough seizures, leading to increased hospital use and mortality (9, 10).

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" (11). Self-management support is a core component of care delivery models for chronic disease and a requirement for participation in some Medicare alternative payment programs (12–16).

Systematic reviews have shown that self-management support for patients with chronic illness improves symptoms and role function, but these positive effects are influenced by the type of chronic illness and the self-management skills taught (17–19). Further, the effectiveness of self-management may be diminished by conditions associated with epilepsy, such as traumatic brain injury or depressive disorders, and by low health literacy. For patients with epilepsy, robust self-management skills may improve self-efficacy and medication adherence, prevent seizure triggers, and increase patient and family knowledge regarding when to seek urgent medical care. Self-management interventions hold promise for patients with epilepsy, although the paroxysmal nature of seizures, along with prevalent comorbid conditions, may attenuate the benefit. We conducted a systematic review to examine the effect of self-management in patients with epilepsy.

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METHODS

Study Design

This work is part of a Veterans Health Administration (VHA)–funded report available online (www.hsrd.research.va.gov/publications/esp). The present analysis addresses 2 questions: For adults with epilepsy, what are the most commonly used components of self-management interventions, and what are the effects of these interventions on self-management skills and self-efficacy, clinical outcomes, and health care use? This review followed a published protocol (PROSPERO: CRD42018098604) developed with input from stakeholders and follows the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) statement (20).

We developed a conceptual framework that outlines the population, intervention, outcomes, and potential effect moderators (Appendix Figure 1, available at Annals.org). Self-management was defined as interventions that aim to equip patients with skills to actively participate in and take responsibility for managing their epilepsy. We adapted an existing operational definition (21) to increase the breadth of eligible interventions (requiring only 1 component beyond knowledge acquisition, instead of 2) to specify that decision-making skills should be aimed at epilepsy-relevant behaviors.

Data Sources and Searches

In collaboration with an expert reference librarian, we searched MEDLINE (via PubMed), the Cochrane Central Register of Controlled Trials, PsycINFO, and CINAHL in April 2018. The MEDLINE search was updated on 25 March 2019 (Appendix Table 1, available at Annals.org). We also screened reference lists from published reviews.

Study Selection

Our prespecified eligibility criteria are listed in Appendix Table 2 (available at Annals.org). Major eligibility criteria were a comparative evaluation of a self-management intervention for adults with epilepsy, delivered in the outpatient setting or by remote technology and using a randomized trial, nonrandomized trial, controlled before–after, or prospective cohort study design. We used artificial intelligence technology (DistillerAI; Evidence Partners) to assist with screening abstracts (22). All citations classified by DistillerAI with certainty (that is, eligible or ineligible) were reviewed by 1 investigator (23). All other citations (50%) underwent abstract screening by 2 investigators. Articles included by an investigator or artificial intelligence algorithm underwent full-text screening by 2 investigators. Disagreements were resolved by consensus between the investigators or by a third investigator.

Data Extraction and Quality Assessment

Data from published reports were abstracted into a customized DistillerSR database by 1 reviewer; a second investigator reviewed these data for accuracy. Data elements included descriptors to assess applicability, study quality, outcomes, and intervention details. Intervention characteristics included interventionist training, family member or caregiver involvement, delivery method, duration or intensity, and peer support. With input from stakeholders, we specified the primary outcomes as self-management behaviors, QOL, and seizure rates. We contacted 1 author to request missing study details but did not receive a response.

Two investigators independently assessed study quality, and disagreements were resolved by consensus or through arbitration by a third investigator. We used the Cochrane Effective Practice and Organisation of Care Risk of Bias (ROB) Tool, which is applicable to randomized and nonrandomized studies (24), and assigned a summary ROB score (low, unclear, or high) to individual studies separately for non–patient-reported outcomes, hereafter referred to as objective outcomes (such as emergency department visits), and patient-reported outcomes (such as QOL).

Data Synthesis and Analysis

We developed summary tables to describe study characteristics. Initially, we planned to categorize studies as those meeting the full definition of self-management (21) and those with fewer components. However, studies were classified more naturally into 2 categories: those emphasizing education and those emphasizing skill acquisition from psychosocial therapy approaches. Although we planned to evaluate the consistency of effects by components of the intervention, the number of studies was insufficient to perform these analyses.

We aggregated outcomes when at least 3 studies were conceptually similar in terms of design, population, intervention, and outcomes. Analyses were stratified by study design (randomized vs. nonrandomized) and by intervention category. When meta-analysis was appropriate, we used random-effects models (DerSimonian–Laird estimator with Knapp–Hartung SE adjustment) to generate a pooled mean difference (MD) or the standardized MD (SMD) when studies used different measures for the same outcome. The SMD is the difference in outcome means between the intervention and the comparator divided by the pooled SD. Cohen (25) suggested the following guidelines for interpreting the magnitude of the SMD: small, 0.2; medium, 0.5; and large, 0.8. We evaluated statistical heterogeneity by using Cochran Q and I^2 statistics. Test statistics for publication bias (such as Begg or Egger regression statistics) perform adequately only if more than 10 studies are included in an analysis. Because no analyses met this threshold, formal analysis for publication bias was not performed.

Certainty of Evidence

The certainty of evidence was assessed by using the GRADE (Grading of Recommendations Assessment, Development and Evaluation) approach (26). We limited GRADE ratings to outcomes identified by the stakeholder and technical expert panel as critical to decision making. In brief, this approach requires assessment of 4 domains: ROB, consistency, directness, and precision. When applicable, we considered the effect of plausible residual confounders, strength of associa-

tion (magnitude of effect), and publication bias. These domains were considered qualitatively, and a summary rating—high, moderate, or low certainty of evidence—was assigned after discussion by 2 investigators.

Role of the Funding Source

The U.S. Department of Veterans Affairs was not involved in the design, conduct, or interpretation of the analyses.

RESULTS

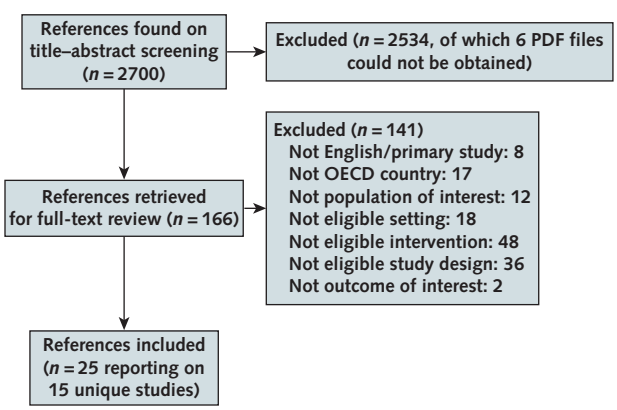
From 2700 citations, we reviewed 166 full-text articles and identified 15 eligible studies (27–41): 13 randomized and 2 nonrandomized (Figure 1). Appendix Tables 3 and 4 (available at Annals.org) summarize the characteristics of the included studies.

Self-management Intervention Components

Interventions were mapped to the 6 components described in the operational definition: knowledge acquisition; stimulation of independent sign or symptom monitoring; medication management; enhancement of problem-solving and decision-making skills for medical treatment management; safety promotion; and changes in physical activity, dietary, or smoking behaviors. Because some studies had more than 1 active intervention group, 18 intervention groups are described across the 15 studies. Each intervention group had a median of 4 self-management components (range, 2 to 6 components). Medication management and safety promotion were the least frequently addressed components (Appendix Tables 3 to 5, available at Annals.org).

We identified 2 distinct groups of interventions, classified by emergent criteria: intervention focus (educational vs. psychosocial therapy) and intervention development (created vs. adapted for patients with epilepsy). The first group focused primarily on educational interventions created explicitly for patients with epilepsy (Figure 2). Seven studies described explicit educational components with the implicit understanding that education may lead to skill acquisition (28, 29, 32, 34, 38, 39, 41). The second group focused primarily on skill acquisition and evaluated interventions adapted for patients with epilepsy from previously existing therapies (Figure 2). Eight studies examining 11 interventions described explicit skill acquisition components from therapeutic techniques; education components were described explicitly in some studies, but were implicit in others (27, 30, 31, 33, 35–37, 40). Within each group of interventions, variation was seen in the duration or intensity of the intervention, composition and training of the intervention delivery team, methods of delivering the intervention, targets of the intervention, and components of self-management addressed.

Figure 1. Evidence search and selection.



OECD = Organisation for Economic Co-operation and Development.

Educational Self-management Interventions

Educational self-management techniques included presentation of modules and didactic discussions aimed at increasing knowledge of symptoms; triggers; and psychological, social, and vocational problems that arise with epilepsy. In addition, modules often addressed coping, problem solving, self-monitoring, and medication management skills; 3 studies incorporated goal setting with patients (28, 29, 39). Five studies explicitly discussed symptom or seizure tracking, but only 2 had participants actively engage in this activity.

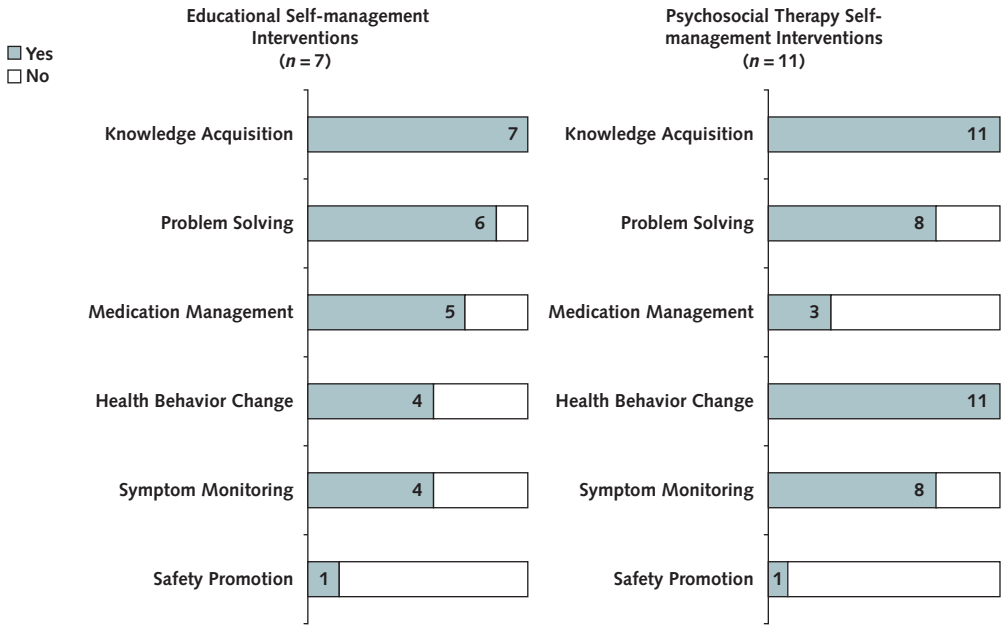
Intervention duration varied considerably, with a median of 14 contact hours (range, 10 to 41 hours [2 studies did not specify duration]) delivered over 2 consecutive days to 8 weekly sessions (29, 39). Interventions primarily comprised in-person, group-based instruction; however, pure Internet-based asynchronous didactic and hybrid models were represented (28, 41). In general, the interventions were provided by peers with epilepsy or a nurse practitioner, both of whom had specific training. Caregivers or family members were allowed to attend group sessions in 3 studies (32, 34, 38).

Psychosocial Therapy Self-management Interventions

Psychosocial interventions included broad multicomponent therapies, such as problem-solving therapy; cognitive behavioral therapy (CBT), alone or paired with specific behavioral activation components or hierarchical stress inoculation; and proactive coping skills, noted as being based on CBT principles. Some interventions used specific techniques, such as progressive muscle relaxation, cognitive training, and brief psychological interventions for anxiety and depression. Six studies (7 interventions) explicitly included some form of symptom or seizure monitoring (30, 31, 33, 35, 37, 40), and 5 studies explicitly discussed goal setting with patients (27, 30, 33, 36, 37).

The duration of the interventions varied between 4 and 40 hours total, with most consisting of weekly treatment with daily at-home skills practice. No intervention had fewer than 4 independent contacts for therapy. The most common method of treatment was in-person

Figure 2. Components addressed in self-management interventions.



Values in the green bars represent the number of interventions using each component.

group sessions, usually led by a nurse practitioner or psychologist, but interventions often included asynchronous technologic support (such as a seizure diary smartphone application) to aid in independent practice of self-management. Two studies allowed caregivers or family members to attend sessions (33) or to help identify psychiatric or social issues for treatment (40). Peer-support features were not explicitly discussed in any intervention.

Comparison of Self-Management Interventions

Self-management was compared with usual care, waitlist, or attention controls in all but 1 randomized study comparing 2 therapy interventions. Of the 2 nonrandomized studies, 1 used a crossover design to compare 2 therapy interventions (40) and the other a cluster design to examine a quality improvement program with prominent educational features versus usual care (41). Table 1 shows the evidence profile for the studies.

Primary Outcomes: Self-management Behaviors, Quality of Life, and Seizure Rate

Educational Self-management Interventions

Four randomized studies reported the effects of educational interventions on self-management behaviors using the Coping With Epilepsy and Adaptation or Epilepsy Self-Management Scale. Three studies provided sufficient information for meta-analysis (29, 34, 39) and showed a moderate increase in self-management behaviors at 6 months of follow-up (SMD, 0.52 [95% CI, 0.0 to 1.04]) (Figure 3). Intervention effects were consistent across studies (Q = 2.8; P = 0.24; I^2 = 29.8%). The fourth high-ROB study reported no improvement in self-management behaviors (P not significant) but did not offer further statistics (28). Overall, educational interventions created for patients with epilepsy suggest a possible benefit for self-reported measures of self-management and were judged as having unclear or high ROB.

Four randomized studies and 1 nonrandomized study reported effects on QOL as assessed by the 10- or 31-item version of the Quality of Life in Epilepsy Inventory. Three randomized studies showed no benefit on QOL (SMD, 0.17 [CI, −0.57 to 0.91]), although intervention effects varied substantially across studies (Q = 5.1; P = 0.078; I^2 = 60.8%) (Figure 3). Two trials showed no intervention effect (31, 38); however, a recent trial examining the novel SMART (Self-Management for People with Epilepsy and a History of Negative Health Events) intervention showed a statistically significant improvement in QOL over the 6-month study period (SMD, 0.53 [CI, 0.14 to 0.93]) (39). A fourth large high-ROB study examined a Web-based educational intervention and reported no effect on QOL (P not significant), but did not provide sufficient data to calculate an intervention effect (28). An additional nonrandomized cluster study reported a small nonsignificant improvement in QOL (MD, 0.5 [CI, −6.4 to 7.4]).

Four randomized studies reported intervention effects on self-reported seizure rates (32, 34, 38, 39). Seizure frequency was assessed by 30-day frequency (32, 39) or by categorical scales that asked about seizures over 6 months (34, 38). These studies, with mixed ROB, demonstrated no effect of group-based educational interventions on seizure frequency (SMD, 0.0 [CI, −0.03 to 0.04]) (Figure 3). Results were consistent across studies (Q = 0.1; P = 1.00; I^2 = 0.0%).

Psychosocial Therapy Self-management Interventions

No studies of psychosocial therapy interventions reported effects on self-management skills. Effects of psychosocial therapy on QOL were reported in 3 studies, all of which measured QOL with the Quality of Life in Epilepsy Inventory, with scores ranging from 0 to 100 points. A larger, low-ROB study showed small improvements in QOL at 3 and 6 months, but the CI included no effect (MD, 4.10 [CI, −1.12 to 9.32]) (33). Two smaller, high-ROB studies reported improvement in QOL at 8 weeks (MD, 7.20 [CI, 0.37 to 14.03]) (27) and at 3 months (MD, 11.98 [CI, 3.16 to 20.80]) (**Figure 3**) (30). A meta-analysis showed a positive effect of psychosocial therapy interventions on QOL (MD, 6.64 [CI, 2.51 to 10.77]; $Q = 2.3$; $P = 0.31$; $I^2 = 14.3\%$). However, an analysis that adjusted the SEs for small study effects resulted in a CI that included no benefit (CI, −2.45 to 15.73).

Four studies, 3 randomized and 1 nonrandomized, compared the effect of interventions with that of controls on seizure rates; 3 enrolled patients with refractory epilepsy (31, 37, 40). One small low-ROB study found no effect from progressive muscle relaxation versus control (SMD, 0.06 [CI, −0.43 to 0.55]) (**Figure 3**) (31). Another small study examining progressive muscle relaxation training demonstrated improvement in seizure rates from baseline but no significant differences versus control (SMD, 0.47 [CI, −0.35 to 1.28]) (**Figure 3**) (36). Although a third small high-ROB trial reported improvement with CBT plus supportive counseling, it did not reach statistical significance and was excluded from the forest plot because of insufficient data (37). A single nonrandomized crossover study examining 2 psychosocial therapy interventions identified similar improvements in seizure rates from baseline to week 42 regardless of the intervention or order of the interventions (40).

Yet another small randomized trial compared CBT with a relaxation therapy control (treated as an active intervention) (35). The study, with unclear ROB, reported significant improvement in seizure control in the CBT versus the control group (Cohen d, 0.63; $P < 0.01$) and a time-dependent increase in improvement in the CBT group over the 3-month follow-up. Overall, these small studies evaluating psychosocial therapy self-management interventions showed no benefit regarding seizure rates.

Table 2 summarizes the certainty of evidence for the effects of self-management interventions on primary outcomes.

Secondary Outcomes: Self-efficacy, Social Function, and Medication Adherence

Educational Self-management Interventions

Four group-based educational self-management studies addressed self-efficacy at intervals of 2 to 12 months (29, 32, 38, 39). Overall, interventions did not improve self-efficacy (SMD, 0.18 [CI, −0.32 to 0.69]), although the effects varied significantly ($Q = 8.0$; $P = 0.045$; $I^2 = 62.7\%$), possibly because of the broad range in timing of outcome assessments. Effects of educational self-management interventions on social function were reported in 3 randomized studies (29, 32, 34) and 1 nonrandomized study (41), demonstrating no significant effects compared with controls (SMD, −0.05 [CI, −0.62 to 0.53]) (**Appendix Figure 2**, available at Annals.org). Two educational self-management studies reported effects on medication adherence by using self-report measures. Neither a Web-based (WebEase [Epilepsy, Awareness, Support, and Education]) (28) nor an in-person educational intervention (SMILE-UK [Self-management Education for Adults With Poorly Controlled Epilepsy]) (38) improved medication adherence, assessed at 6 weeks (SMD, 0.05 [CI, −0.32 to 0.43]) and 12 months (SMD, 0.0 [CI, −0.22 to 0.22]), respectively (**Appendix Figure 2**). A third randomized study inferred drug adherence on the basis of antiepileptic drug levels; although levels were substantially higher in the intervention group, assessment varied across treatment groups, which may have biased the results (32). One education-based self-management study evaluated emergency department and hospital use (39). During 6 months, negative health events (seizures, emergency department visits, and hospitalizations) declined in the SMART intervention group (mean change, −10.16; SD, 39.2) compared with the waitlist control group (mean change, −1.93; SD, 18.6; $P = 0.04$), but no significant improvement was seen in emergency department and hospital use ($P = 0.69$).

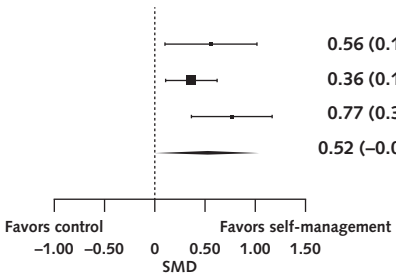
Table 1. Evidence Profile for Studies of Self-management Interventions for Epilepsy ($n = 15$)

Study Characteristic	Data
Studies, *n*	
Design	
Randomized	13
Nonrandomized	2
Enrolled patients with refractory epilepsy	3
Comparator	
Usual care, waitlist, or attention	13
Active	2
ROB of patient-reported outcomes	
Low	3
Unclear	3
High	9
Years	1986–2018
Participants	
Total (range across studies), *n*	2514 (30–747)
Median women (range), %	63 (51–74)
Median age (range), *y*	41 (32–68)
Median proportion with a college education or above (range), %*	52 (15–77)
Median epilepsy duration (range), *y*†	18 (13–27)
Countries	Australia, Austria, Canada, Germany, the Netherlands, Switzerland, United Kingdom, United States

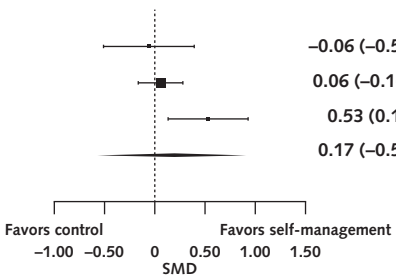
ROB = risk of bias.
* Not reported in 6 studies.
† Not reported in 4 studies.

Figure 3. Forest plot showing primary outcomes for epilepsy self-management interventions.

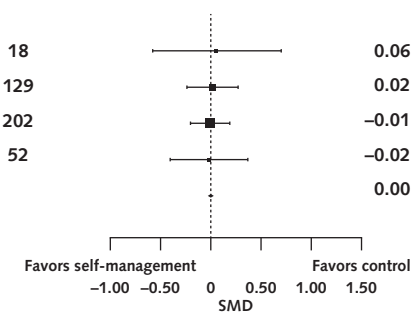
Study, Year (Reference)	Timing, *mo*	ROB	Educational Interventions: Self-management Mean Score (SD)	Self-management Patients, *n*	Control Mean Score (SD)	Control Patients, *n*	SMD (95% CI)
Self-management practices							
Fraser et al, 2015 (29)	6	Unclear	3.9 (0.3)	37	3.7 (0.4)	39	0.56 (0.10–1.02)
May and Pfäfflin, 2002 (34)	6	High	65.6 (16.6)	113	59.9 (14.6)	129	0.36 (0.11–0.62)
Sajatovic et al, 2018 (39)	6	Unclear	152.8 (16.1)	51	139.8 (17.4)	52	0.77 (0.37–1.17)
Summary: $I^2 = 29.8\%$; $Q = 2.8$ ($P = 0.24$)							0.52 (–0.00–1.04)



Study, Year (Reference)	Timing, *mo*	ROB	Self-management Mean Score (SD)	Self-management Patients, *n*	Control Mean Score (SD)	Control Patients, *n*	SMD (95% CI)
QOL							
Fraser et al, 2015 (29)	6	Unclear	61.0 (18.0)	37	62.0 (15.0)	39	–0.06 (–0.51–0.39)
Ridsdale et al, 2018 (38)	6	Low	66.3 (13.0)	153	65.5 (14.0)	160	0.06 (–0.16– 0.28)
Sajatovic et al, 2018 (39)	6	Unclear	–2.5 (1.0)	51	–3.0 (0.9)	52	0.53 (0.14–0.93)
Summary: $I^2 = 60.8\%$; $Q = 5.1$ ($P = 0.078$)							0.17 (–0.57–0.91)



Study, Year (Reference)	Timing, *mo*	ROB	Self-management Mean Seizures (SD)	Self-management Patients, *n*	Control Mean Seizures (SD)	Control Patients, *n*	SMD (95% CI)
Seizure rate*							
Helgeson et al, 1990 (32)	4	High	2.3 (4.0)	20	2.0 (4.7)	18	0.06 (–0.58–0.70)
May and Pfäfflin, 2002 (34)	6	High	2.8 (1.6)	113	2.7 (1.6)	129	0.02 (–0.23–0.27)
Ridsdale et al, 2018 (38)	6	Low	– –	202	– –	202	–0.01 (–0.20–0.19)
Sajatovic et al, 2018 (39)	6	Unclear	–0.2 (8.4)	51	–0.2 (1.8)	52	–0.02 (–0.40–0.37)
Summary: $I^2 = 0.0\%$; $Q = 0.1$ ($P = 1.00$)							0.00 (–0.03–0.04)



Study, Year (Reference)	Therapy	Timing	ROB	Psychosocial Therapy: Self-management Mean Score (SD)	Self-management Patients, *n*	Control Mean Score (SD)	Control Patients, *n*	SMD (95% CI)
QOL								
Caller et al, 2016 (27)	PST	8 wk	High	5.0 (11.8)	29	–2.2 (12.1)	20	7.20 (0.37–14.03)
Gandy et al, 2014 (30)	CBT	8 wk	High	58.4 (11.8)	20	46.4 (18.2)	25	11.98 (3.16–20.80)
Leenen et al, 2018 (33)	Multicomponent	6 mo	Low	69.5 (10.8)	49	65.4 (14.4)	44	4.10 (–1.12–9.32)
Summary: $I^2 = 14.3\%$; $Q = 2.3$ ($P = 0.31$)								6.64 (2.51–10.77)

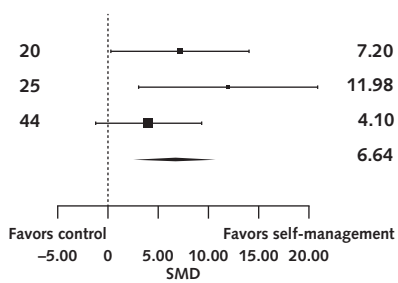


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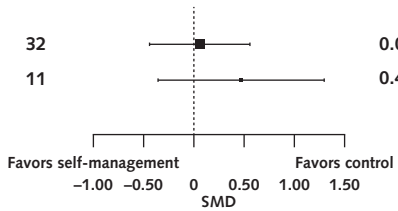
Figure 3—Continued.

Study, Year (Reference)	Therapy	Timing	ROB	Self-management Mean Seizures (SD)	Self-management Patients, *n*	Control Mean Seizures (SD)	Control Patients, *n*	SMD (95% CI)
Seizure rate*								
Haut et al, 2018 (31)	PMR	3 mo	Low	–17.3 (58.9)	32	–20.9 (55.8)	32	0.06 (–0.43–0.55)
Puskarich et al, 1992 (36)	PMR	8 wk	High	12.1 (4.0)	13	10.0 (4.7)	11	0.47 (–0.35–1.28)



For the score measures used in each study, see Appendix Table 4 (available at Annals.org). CBT = cognitive behavioral therapy; MD = mean difference; PMR = progressive muscle relaxation; PST = problem-solving therapy; QOL = quality of life; ROB = risk of bias; SMD = standardized mean difference.
* Seizure frequency measures: 30-d seizure frequency (32, 39); 6-mo categorical measure (34); and Baker scale, a 6-mo categorical measure (38).

Psychosocial Therapy Self-management Interventions

One low-ROB randomized study reporting the effects of a psychosocial therapy intervention on self-efficacy showed a small to moderate improvement (SMD, 0.37 [CI, −0.04 to 0.78]) at 6-month follow-up, but the CI included no effect (33). Two small randomized studies with high ROB reported conflicting effects on social function. Problem-solving therapy with or without cognitive training improved social function compared with control (SMD, 1.08 [CI, 0.47 to 1.69]) at 8 weeks (**Appendix Figure 2**) (27). In contrast, a small high-ROB study comparing CBT with supportive counseling and waitlist controls found no benefit on social function at 4-month follow-up (**Appendix Figure 2**) (37). A third study evaluated 2 active interventions, CBT plus education versus relaxation therapy, and found no differential effect on social function (SMD, 0.15 [CI, −0.79 to 0.50]) (35). Two studies using self-report measures to examine effects on medication adherence found no benefit at 4- or 6-month follow-up (33, 37). However, both studies were relatively small, and the CI included the possibility of a moderate effect.

Quality of Evidence

Among the 13 randomized studies, the ROB for patient-reported outcomes was judged low for 3 (31, 33, 38), unclear for 3 (29, 35, 39), and high for 7 (27, 28, 30, 32, 34, 36, 37). Patterns that led to judgments of higher ROB included inadequate or unclear allocation concealment (n = 10), incomplete outcome data (n = 6), and outcome assessments that were not clearly blind to intervention assignment (n = 5). For the 2 nonrandomized studies, unbalanced provider characteristics, incomplete outcome data, and possible selective outcome reporting, in addition to the lack of randomization, led to a judgment of high ROB. Risk-of-bias ratings for each study are shown in **Appendix Figure 3** (available at Annals.org), and the pattern of ROB assessments across studies is shown in **Appendix Figure 4** (available at Annals.org).

DISCUSSION

We evaluated self-management interventions for patients with epilepsy, examining their effects on a range of outcomes important to patients, clinicians, and policymakers. Our review is unique in its use of a standard definition for self-management and its focus on high-quality study designs. We identified 15 studies addressing the effects of self-management, demonstrating 2 broad categories of self-management interventions: educationally focused interventions created for patients with epilepsy and established psychosocial therapies, such as CBT, that were adapted for people with epilepsy. We found limited evidence for benefit on a priori selected primary or secondary outcomes. Educational approaches may improve the use of self-management practices, and psychosocial therapy approaches may improve QOL. Certainty is low to moderate that the interventions studied do not decrease seizure rates. Sparse evidence suggests that psychosocial therapy interventions may have a benefit on self-efficacy. Effects on health care use were reported in a single study and showed benefit only for a composite measure including seizure rates, hospitalizations, and emergency department visits.

Previous literature reviews focused narrowly on group-based interventions (42); single therapeutic techniques (43); or interventions that would not meet standard definitions for self-management, such as measures to improve antiepileptic drug adherence (44). Other reviews addressed self-management interventions for persons with chronic health conditions more generally (45–47), whereas others examined diverse approaches, including care delivery redesigns (48, 49). A rapid synthesis of 30 previous systematic reviews for long-term conditions (LTCs) concluded, "Supporting self-management is inseparable from the high-quality care for LTCs" (47). Consistent with our findings, authors of previous reviews of epilepsy interventions found limited evidence to support an effect on studied outcomes other than epilepsy self-management. Some reviews reported benefit for outcomes that we did not

Table 2. Certainty of Evidence for Primary Outcomes of Self-management Interventions

Outcome	Studies (Patients), *n*	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 for improved self-management
QOL	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 (−0.3 lower to 0.04 higher)	Moderate certainty for no effect
Psychosocial therapy self-management interventions			
Epilepsy self-management	None	Not applicable	Insufficient
QOL	3 randomized (187)	MD, 6.64 higher (2.51 to 10.77 higher)	Low certainty for improved QOL
Seizure rates	3 randomized (106)	SMD range, 0.06 to 0.47	Low certainty for no clinically important improvement

MD = mean difference; QOL = quality of life; SMD = standardized mean difference.

consider (such as emotional well-being) (42). Authors of earlier reviews elected not to perform meta-analyses because of the diversity of study designs; we established study eligibility criteria that narrowed the scope of eligible studies and conducted limited meta-analyses of randomized trials by intervention category to facilitate understanding of intervention effects.

The studies included in this review varied widely in their design, statistical analysis, and reporting. We highlight the most recent study in the review, the SMART intervention by Sajatovic and colleagues (39), as an example of a well-structured and well-reported study. Notable features of this study were the engagement of stakeholders in developing the intervention and the inclusion of health care use and safety outcomes. Future investigations should consider the SMART trial as a model for study design, and sources of research support could use it as a guide for funding subsequent work in epilepsy self-management.

Our review benefited from being protocol driven, leveraging input from an expert panel, using a conceptual model, identifying recent studies not included in previous reviews, and using a detailed approach to categorizing and defining components of self-management interventions. Despite these strengths, limitations in our approach and the primary literature remain. For example, we excluded studies that required a depression diagnosis or elevated depressive symptoms for enrollment; thus, studies with a depression-specific focus (such as Project Uplift [50]) were excluded. Because of the small number of studies, statistical methods to detect publication bias were not useful. Although no publication bias was detected, qualitative tools for detection were poor. We also were limited by the existing literature. Most studies were assessed as having unclear or high ROB, did not describe patient race, and enrolled fewer than 100 patients. Interventions often were described incompletely, and intervention fidelity frequently was not reported. Some outcomes, such as effects on employment, were not reported. Other self-reported outcomes, particularly seizure rates, were difficult to measure.

Whether epilepsy will respond to self-management training in the same way as other chronic conditions is not clear. Compared with patients who have other chronic diseases, those with epilepsy are more likely to have low socioeconomic status (51). Further, rates of psychiatric disease and poor health care literacy are disproportionately high in this population (5–8). Cognitive dysfunction also is a well-known comorbid condition in persons with epilepsy and may evolve during the course of the disease (52). Many of the trials in this review explicitly excluded patients with cognitive impairment, and our eligibility criteria excluded studies that enrolled patients with severe comorbid psychiatric disease. A separate analysis of barriers to adoption of self-management interventions associated with this review (www.hsrd.research.va.gov/publications/esp) identified cognitive limitations and patient-specific impairments, such as familiarity and access to technology and transportation, as key impediments. Self-management strategies developed specifically with input from patients with epilepsy and tailored to those with cognitive and psychosocial impairment may be necessary to achieve a clinically important effect.

Epilepsy, one of the most common chronic neurologic conditions, has the potential to generate substantial morbidity, impaired QOL, 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 interventions broke down into 2 categories: educational and psychosocial therapy interventions. These self-management approaches showed clinically important benefit for only a few outcomes, but the confidence in these findings was mostly low. Further, the effect of educational interventions on QOL and self-efficacy varied inexplicably. The analysis was limited by the small selection of qualifying studies and by study quality; however, such studies as the recent SMART intervention represent best practices for study design and reporting and may serve as a model for further research in self-management strategies in epilepsy.

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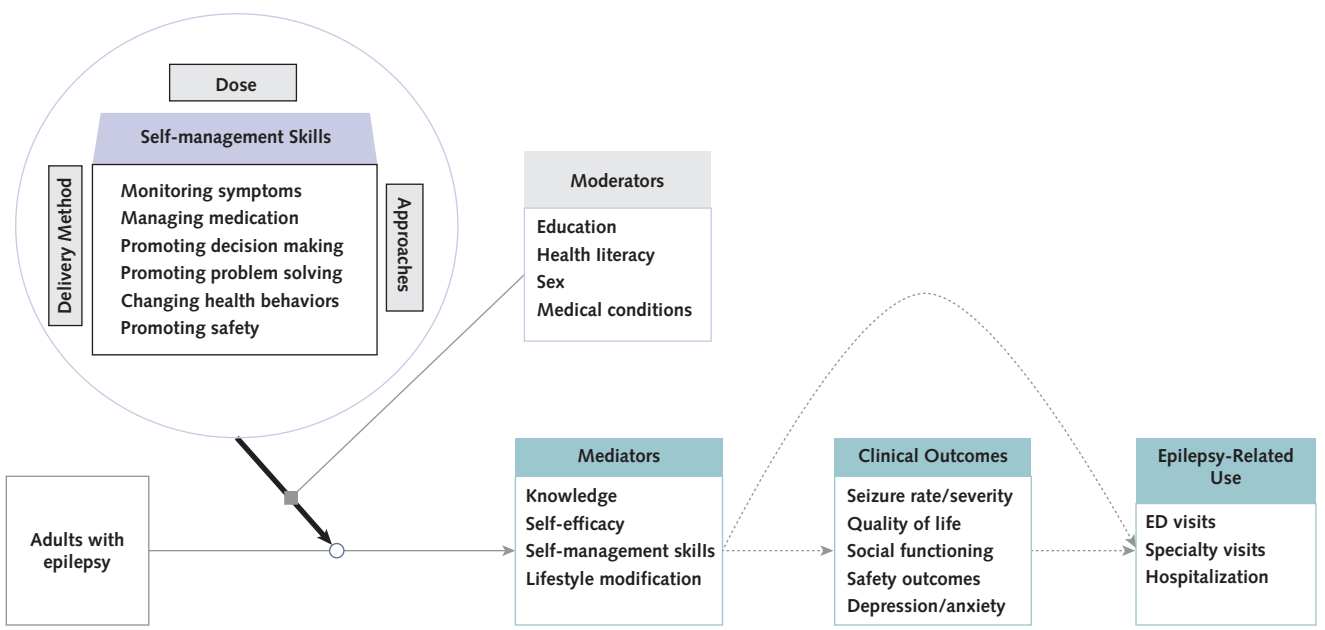
Appendix Figure 1. Conceptual framework.



ED = emergency department.

Appendix Table 1. Search Strategy*

Set	Terms	Results, *n*
PubMed: 13 April 2018 and 25 March 2019		
#1	"Epilepsy"[Mesh] OR epilepsy[tiab] OR epilepsies[tiab] OR epileptic[tiab] OR epileptics[tiab] OR epilepsia[tiab]	145 831
#2	"Self-Management"[Mesh] OR "Self Care"[Mesh] OR "Self-Control"[Mesh] OR self[tiab] OR selfcare[tiab] OR selfmanagement[tiab] OR selftreatment[tiab] OR selfcontrol[tiab] OR selfhelp[tiab]	697 243
#3	"Patient Compliance"[Mesh] OR "Medication Adherence"[tiab] OR "Medication Compliance"[tiab] OR "Medication nonadherence"[tiab] OR "Medication non adherence"[tiab] OR "Medication Noncompliance"[tiab] OR "Medication non compliance"[tiab] OR "Medication Persistence"[tiab] OR "Health Knowledge, Attitudes, Practice"[Mesh]	173 151
#4	"Behavior Therapy"[Mesh] OR behavior therap*[tiab] OR behaviour therap*[tiab] OR behavioral therap*[tiab] OR behavioural therap*[tiab] OR "anger management"[tiab] OR biofeedback[tiab] OR "bio-feedback"[tiab] OR myobiofeedback[tiab] OR myofeedback[tiab] OR "physiological feedback"[tiab] OR "neuro feedback"[tiab] OR neurofeedback[tiab] OR cognitive therap*[tiab] OR cognition therap*[tiab] OR acceptance therap*[tiab] OR commitment therap*[tiab] OR mindfulness[tiab] OR "MBSR"[tiab] OR "psychologic desensitization"[tiab] OR "psychological desensitization"[tiab] OR "Eye Movement Desensitization and Processing"[tiab] OR EMDR[tiab] OR implosive therap*[tiab] OR exposure therap*[tiab] OR relaxation therap*[tiab] OR "relaxation techniques"[tiab] OR "relaxation technique"[tiab] OR "meditation"[tiab] OR meditate[tiab] OR meditates[tiab] OR "Mind-Body Therapies"[Mesh:NoExp] OR "mind body therapy"[tiab] OR "mind body therapies"[tiab] OR "mind body medicine"[tiab] OR "Breathing Exercises"[Mesh] OR "breathing exercise"[tiab] OR "breathing exercises"[tiab] OR "respiratory muscle training"[tiab] OR "paced respiration"[tiab] OR "Imagery (Psychotherapy)"[Mesh] OR "guided imagery"[tiab] OR "Alexander Technique"[tiab] OR problem-solving therap*[tiab] OR psychodynamic therap*[tiab] OR psychotherap*[tiab] OR "stress reduced"[tiab] OR "stress reducer"[tiab] OR" stress reducers"[tiab] OR "stress reducing"[tiab] OR "stress reduction"[tiab] OR "stress reductions"[tiab] OR "stress reductive"[tiab]	132 964
#5	#1 AND (#2 OR #3 OR #4) AND English[lang]	4208
#6	#5 NOT (animals[mh] NOT humans[mh]) NOT (("Adolescent"[Mesh] OR "Child"[Mesh] OR "Infant"[Mesh]) NOT "Adult"[Mesh])	4042
#7	#6 AND (("randomized controlled trial"[ptyp] OR "controlled clinical trial"[ptyp] OR randomized[tiab] OR randomised[tiab] OR randomization[tiab] OR randomisation[tiab] OR placebo[tiab] OR randomly[tiab] OR trial[tiab] OR groups[tiab] OR "Comparative Study"[ptyp] OR "clinical trial"[pt] OR "clinical trial"[tiab] OR "clinical trials"[tiab] OR "evaluation studies"[ptyp] OR "evaluation studies as topic"[MeSH] OR "evaluation study"[tiab] OR "evaluation studies"[tiab] OR drug therapy[sh] OR "intervention study"[tiab] OR "intervention studies"[tiab] OR "cohort studies"[MeSH] OR cohort[tiab] OR "longitudinal studies"[MeSH] OR longitudinal[tiab] OR longitudinally[tiab] OR prospective[tiab] OR prospectively[tiab] OR "follow up"[tiab] OR "comparative study"[pt] OR "comparative studies"[tiab] OR nonrandom[tiab] OR "non-random"[tiab] OR nonrandomized[tiab] OR "non-randomized"[tiab] OR nonrandomised[tiab] OR "non-randomised"[tiab] OR quasi-experiment*[tiab] OR quasiexperiment*[tiab] OR quasirandom*[tiab] OR quasi-random*[tiab] OR quasi-control*[tiab] OR quasicontrol*[tiab] OR (controlled[tiab] AND (trial[tiab] OR study[tiab])) OR "pre-post"[tiab] OR "posttest"[tiab] OR "post-test"[tiab] OR pretest[tiab] OR pre-test[tiab] OR (before[tiab] AND after[tiab]) OR (before[tiab] AND during[tiab])) NOT (Editorial[ptyp] OR Letter[ptyp] OR Comment[ptyp]))	2263
#8	#6 AND (("Delivery of Health Care"[Mesh] OR "healthcare delivery"[tiab] OR "health care delivery"[tiab] OR "healthcare system"[tiab] OR "healthcare systems"[tiab] OR "health care system"[tiab] OR "health care systems"[tiab] OR "Health Facilities"[Mesh] OR outpatient[tiab] OR outpatients[tiab] OR clinic[tiab] OR clinics[tiab] OR "primary care"[tiab] OR program[tiab] OR programs[tiab] OR programme[tiab] OR programmes[tiab] OR protocol[tiab] OR protocols[tiab] OR policy[tiab] OR policies[tiab] OR guideline[tiab] OR guidelines[tiab] OR "standards"[Subheading] OR standard[tiab] OR standards[tiab] OR initiative[tiab] OR initiatives[tiab] OR strategy[tiab] OR strategies[tiab] OR "Evidence-Based Practice"[Mesh]) AND ("Program Evaluation"[Mesh] OR "Outcome and Process Assessment (Health Care)"[Mesh] OR "Diffusion of Innovation"[Mesh] OR implement[tiab] OR implements[tiab] OR implementation[tiab] OR implemented[tiab] OR implementing[tiab] OR preimplementation[tiab] OR postimplementation[tiab] OR uptake[tiab] OR adopt*[tiab] OR adapt*[tiab] OR facilitator*[tiab] OR feasible[tiab] OR feasibility[tiab] OR effective[tiab] OR effectiveness[tiab] OR barrier[tiab] OR barriers[tiab] OR benefit[tiab] OR benefits[tiab]))	763
#9	#7 OR #8	2484
Cochrane Central: 13 April 2018		
#1	[mh Epilepsy] OR (epilepsy or epilepsies or epileptic or epileptics or epilepsia):ti,ab,kw	5832
#2	[mh "Self-Management"] OR [mh "Self Care"] OR [mh "Self-Control"] OR (self OR selfcare OR selfmanagement OR selftreatment OR selfcontrol OR selfhelp):ti,ab,kw	62 762
#3	[mh "Patient Compliance"] OR [mh "Health Knowledge, Attitudes, Practice"] OR ("Medication Adherence" OR "Medication Compliance" OR "Medication nonadherence" OR "Medication non adherence" OR "Medication Noncompliance" OR "Medication non compliance" OR "Medication Persistence"):ti,ab,kw	18 270

Continued on following page

Appendix Table 1–Continued

Set	Terms	Results, *n*
#4	[mh "Behavior Therapy"] OR [mh^ "Mind-Body Therapies"] OR [mh "Breathing Exercises"] OR [mh "Imagery (Psychotherapy)"] OR ((behavior near/2 therap*) or (behaviour near/2 therap*) or (behavioral near/2 therap*) or (behavioural near/2 therap*) OR "anger management" OR biofeedback OR "bio-feedback" OR myobiofeedback OR myofeedback OR "physiological feedback" OR "neuro feedback" OR neurofeedback OR (cognitive NEAR/2 therap*) OR (cognition NEAR/2 therap*) OR (acceptance NEAR/2 therap*) OR (commitment NEAR/2 therap*) OR mindfulness OR MBSR OR "psychologic desensitization" OR "psychological desensitization" OR "Eye Movement Desensitization and Processing" OR EMDR OR (implosive NEAR/2 therap*) OR (exposure NEAR/2 therap*) OR (relaxation NEAR/2 therap*) OR "relaxation techniques" OR "relaxation technique" OR meditation OR meditate OR meditates OR "mind body therapy" OR "mind body therapies" OR "mind body medicine" OR "breathing exercise" OR "breathing exercises" OR "respiratory muscle training" OR "paced respiration" OR "guided imagery" OR "Alexander Technique" OR ("problem-solving" NEAR/2 therap*) OR (psychodynamic NEAR/2 therap*) OR psychotherap* OR "stress reduced" OR "stress reducer" OR "stress reducers" OR "stress reducing" OR "stress reduction" OR "stress reductions" OR "stress reductive"):ti,ab,kw	37 550
#5	#1 AND (#2 OR #3 OR #4) AND English[lang]	432
#6	#5 NOT (([mh Adolescent] OR [mh Child] OR [mh Infant]) NOT [mh Adult])	326
PsycINFO: 13 April 2018		
S1	DE "Epilepsy" OR DE "Epileptic Seizures" OR TI (epilepsy OR epilepsies OR epileptic OR epileptics OR epilepsia) OR AB (epilepsy OR epilepsies OR epileptic OR epileptics OR epilepsia)	38 409
S2	DE "Self-Management" OR DE "Self-Monitoring" OR DE "Self-Control" OR TI (self OR selfcare OR selfmanagement OR selftreatment OR selfcontrol OR selfhelp) OR AB ("self-care*" OR "self-manage*" OR "self-treat*" OR "self-control" OR "self-help" OR "self care" OR "self management" OR "self treatment" OR "self control" OR "self help" OR selfcare OR selfmanagement OR selftreatment OR selfcontrol OR selfhelp)	160 644
S3	DE "Compliance" OR DE "Treatment Compliance" OR DE "Health Attitudes" OR TI ("Medication Adherence" OR "Medication Compliance" OR "Medication nonadherence" OR "Medication non adherence" OR "Medication Noncompliance" OR "Medication non compliance" OR "Medication Persistence") OR AB ("Medication Adherence" OR "Medication Compliance" OR "Medication nonadherence" OR "Medication non adherence" OR "Medication Noncompliance" OR "Medication non compliance" OR "Medication Persistence")	29 260
S4	DE "Behavior Therapy" OR DE "Guided Imagery" OR DE "Alternative Medicine" OR DE "Stress and Coping Measures" OR DE "Stress Management" OR DE "Emotional Control" OR DE "Anger Control" OR DE "Relaxation Therapy" OR DE "Progressive Relaxation Therapy" OR DE "Mindfulness" OR AB ("behavior therap*" OR "behaviour therap*" OR "behavioral therap*" OR "behavioural therap*" OR "anger management" OR biofeedback OR "bio-feedback" OR myobiofeedback OR myofeedback OR "physiological feedback" OR "neuro feedback" OR neurofeedback OR "cognitive therap*" OR "cognition therap*" OR "acceptance therap*" OR "commitment therap*" OR mindfulness OR "MBSR" OR "psychologic desensitization" OR "psychological desensitization" OR "Eye Movement Desensitization and Processing" OR EMDR OR "implosive therap*" OR "exposure therap*" OR "relaxation therap*" OR "relaxation techniques" OR "relaxation technique" OR meditation OR meditate OR meditates OR "mind body therapy" OR "mind body therapies" OR "mind body medicine" OR "breathing exercise" OR "breathing exercises" OR "respiratory muscle training" OR "paced respiration" OR "guided imagery" OR "Alexander Technique" OR "problem-solving therap*" OR "psychodynamic therap*" OR psychotherap* OR "stress reduced" OR "stress reducer" OR "stress reducers" OR "stress reducing" OR "stress reduction" OR "stress reductions" OR "stress reductive") OR TI ("behavior therap*" OR "behaviour therap*" OR "behavioral therap*" OR "behavioural therap*" OR "anger management" OR biofeedback OR "bio-feedback" OR myobiofeedback OR myofeedback OR "physiological feedback" OR "neuro feedback" OR neurofeedback OR "cognitive therap*" OR "cognition therap*" OR "acceptance therap*" OR "commitment therap*" OR mindfulness OR MBSR OR "psychologic desensitization" OR "psychological desensitization" OR "Eye Movement Desensitization and Processing" OR EMDR OR "implosive therap*" OR "exposure therap*" OR "relaxation therap*" OR "relaxation techniques" OR "relaxation technique" OR meditation OR meditate OR meditates OR "mind body therapy" OR "mind body therapies" OR "mind body medicine" OR "breathing exercise" OR "breathing exercises" OR "respiratory muscle training" OR "paced respiration" OR "guided imagery" OR "Alexander Technique" OR "problem-solving therap*" OR "psychodynamic therap*" OR psychotherap* OR "stress reduced" OR "stress reducer" OR "stress reducers" OR "stress reducing" OR "stress reduction" OR "stress reductions" OR "stress reductive")	183 898
S5	S1 AND (S2 OR S3 OR S4) Limiters - Publication Type: All Journals; Language: English; Age Groups: Adulthood (18 yrs & older); Population Group: Human; Document Type: Journal Article; Exclude Dissertations	583
CINAHL: 13 April 2018		
S1	(MH "Epilepsy+") OR TI (epilepsy OR epilepsies OR epileptic OR epileptics OR epilepsia) OR AB (epilepsy OR epilepsies OR epileptic OR epileptics OR epilepsia)	18 173
S2	(MH "Self Care+") OR TI (self OR selfcare OR selfmanagement OR selftreatment OR selfcontrol OR selfhelp) OR AB ("self-care*" OR "self-manage*" OR "self-treat*" OR "self-control" OR "self-help" OR "self care" OR "self management" OR "self treatment" OR "self control" OR "self help" OR selfcare OR selfmanagement OR selftreatment OR selfcontrol OR selfhelp)	97 606
S3	(MH "Patient Compliance+") OR (MH "Attitude to Health+") OR TI ("Medication Adherence" OR "Medication Compliance" OR "Medication nonadherence" OR "Medication non adherence" OR "Medication Noncompliance" OR "Medication non compliance" OR "Medication Persistence") OR AB ("Medication Adherence" OR "Medication Compliance" OR "Medication nonadherence" OR "Medication non adherence" OR "Medication Noncompliance" OR "Medication non compliance" OR "Medication Persistence")	129 591

Continued on following page

Appendix Table 1–Continued

Set	Terms	Results, *n*
S4	(MH "Behavior Modification+") OR (MH "Guided Imagery") OR (MH "Control (Psychology)+") OR (MH "Biofeedback") OR AB ("behavior therap*" OR "behaviour therap*" OR "behavioral therap*" OR "behavioural therap*" OR "anger management" OR biofeedback OR "bio-feedback" OR myobiofeedback OR myofeedback OR "physiological feedback" OR "neuro feedback" OR neurofeedback OR "cognitive therap*" OR "cognition therap*" OR "acceptance therap*" OR "commitment therap*" OR mindfulness OR "MBSR" OR "psychologic desensitization" OR "psychological desensitization" OR "Eye Movement Desensitization and Processing" OR EMDR OR "implosive therap*" OR "exposure therap*" OR "relaxation therap*" OR "relaxation techniques" OR "relaxation technique" OR meditation OR meditate OR meditates OR "mind body therapy" OR "mind body therapies" OR "mind body medicine" OR "breathing exercise" OR "breathing exercises" OR "respiratory muscle training" OR "paced respiration" OR "guided imagery" OR "Alexander Technique" OR "problem-solving therap*" OR "psychodynamic therap*" OR psychotherap* OR "stress reduced" OR "stress reducer" OR "stress reducers" OR "stress reducing" OR "stress reduction" OR "stress reductions" OR "stress reductive") OR TI ("behavior therap*" OR "behaviour therap*" OR "behavioral therap*" OR "behavioural therap*" OR "anger management" OR biofeedback OR "bio-feedback" OR myobiofeedback OR myofeedback OR "physiological feedback" OR "neuro feedback" OR neurofeedback OR "cognitive therap*" OR "cognition therap*" OR "acceptance therap*" OR "commitment therap*" OR mindfulness OR MBSR OR "psychologic desensitization" OR "psychological desensitization" OR "Eye Movement Desensitization and Processing" OR EMDR OR "implosive therap*" OR "exposure therap*" OR "relaxation therap*" OR "relaxation techniques" OR "relaxation technique" OR meditation OR meditate OR meditates OR "mind body therapy" OR "mind body therapies" OR "mind body medicine" OR "breathing exercise" OR "breathing exercises" OR "respiratory muscle training" OR "paced respiration" OR "guided imagery" OR "Alexander Technique" OR "problem-solving therap*" OR "psychodynamic therap*" OR psychotherap* OR "stress reduced" OR "stress reducer" OR "stress reducers" OR "stress reducing" OR "stress reduction" OR "stress reductions" OR "stress reductive")	71 641
S5	S1 AND (S2 OR S3 OR S4) Limiters - English Language; Age Groups: All Adult; Publication Type: Journal Article	238

* Searches retrieved 2996 records before duplicates were removed.

Appendix Table 2. Eligibility Criteria

Study Characteristic	Inclusions	Exclusions
Population	Adults (aged ≥18 y) with new or chronic epilepsy Family members or caregivers of those with epilepsy KQ 3 only: stakeholders involved in implementation (e.g., neurologists, health coaches, nurses, administrators)	Children Populations with <70% adults Severe learning disabilities Nonepileptic (i.e., psychogenic) seizures Populations who were recruited for depression or had major mental illness (e.g., bipolar disorder, major depressive disorder, schizophrenia)
Intervention	Self-management defined as interventions aimed to equip patients with skills to actively participate and take responsibility in managing their epilepsy to function optimally through at least knowledge acquisition and a combination of ≥1 of the following: Stimulation of independent sign/symptom monitoring Medication management Enhancing problem-solving and decision-making skills for epilepsy treatment management, safety promotion (e.g., driving) Changing health behaviors (including stress management, sleep, substance use)* Examples: Psychoeducation (e.g., CBT) Behavioral interventions (e.g., adherence strategy training) Personalized care plan development and coaching	Multicomponent interventions that included self-management but not as the primary intervention CBT focused on comorbid mental illness in patients with epilepsy (e.g., depression in patients with epilepsy) Education-only interventions General care delivery interventions (e.g., introduction of specialist nurse practitioner or implementation of clinical practice guidelines)
Comparator	Any (usual care, attention control, active intervention)	None
Outcomes	Self-management skills/self-efficacy Epilepsy self-efficacy and epilepsy self-management scales† Medication adherence† Disease knowledge Clinical Seizure rate/frequency/severity† QOL† Social function/engagement (e.g., days of work missed, or validated measure)† Psychological symptoms (i.e., distress, depressive, or anxiety symptoms) Safety outcomes (e.g., motor vehicle accidents)† Medication toxicity Health care use Acute care or emergency department visits, hospitalization, or outpatient specialty visits for epilepsy	None
Timing	KQ 1, KQ 2: Must be longitudinal (any length) Assessments at end of treatment and longest follow-up	KQ 1, KQ 2: Cross-sectional or assessments at the time of intervention delivery
Setting	Delivered in person (individual or group) in outpatient setting or remotely via telehealth technology (e.g., mobile device or Internet) Delivered by health care team members or trained lay workers	Inpatient Delivered only in emergency department
Design‡	KQ 1, KQ 2: Randomized trials Nonrandomized trials Controlled before–after studies Prospective cohort study if it included a properly adjusted analysis KQ 3: KQ study designs listed above Qualitative and survey designs if specifically addressing facilitators and barriers to adoption of epilepsy self-management interventions	KQ 1, KQ 2: Self-described pilot studies or sample size Studies with retrospective data collection Interrupted time series Case series Systematic reviews/meta-analyses KQ 3: Reports that do not include primary data on barriers or facilitators
Language	English	Non-English
Countries	OECD§	Non-OECD
Years	Any	None
Publication types	Full publication in a peer-reviewed journal	Letters, editorials, reviews, dissertations, meeting abstracts, protocols without results

CBT = cognitive behavioral therapy; KQ = key question; OECD = Organisation for Economic Co-operation and Development; QOL = quality of life.
* Adapted from reference 21.
† Outcomes prioritized for synthesis. For other outcomes, only the frequency of reporting is described.
‡ See Cochrane Effective Practice and Organisation of Care criteria for definitions and details (24).
§ Includes Australia, Austria, Belgium, Canada, Chile, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Israel, Italy, Japan, Korea, Latvia, Luxembourg, Mexico, the Netherlands, New Zealand, Norway, Poland, Portugal, Slovak Republic, Slovenia, Spain, Sweden, Switzerland, Turkey, United Kingdom, and United States.

Appendix Table 3. Intervention Characteristics

Study, Year (Reference)	Setting/Delivery Mode and Intervention Target	Type of Provider and Specialized Training	Intervention Skills	Intervention Techniques and Goal Setting	Frequency/Duration of Contact	Comparator
Randomized trials						
Educational self-management interventions						
Dilorio et al, 2011 (28)	Asynchronous Internet-based delivery* Patient targeted	Peer online discussion forum, electronic-based delivery No special training	Knowledge Symptom monitoring with MyLog (WebEase) Problem solving, decision making: "planning the next steps" Stress management module Sleep module Medication adherence module	CBT, PST, relaxation technique, sleep intervention, motivational interviewing Collaborative goal setting and automated goal setting	Weekly use of program for 6 wk; length of sessions not specified	Waitlist control
Fraser et al, 2015 (29)	Group-based intervention led by 1 peer with epilepsy* Additional written information via workbook and mailed materials Patient targeted	Peer with epilepsy, 7 y experience as a neurologic employment specialist Social worker delivered: rehabilitation psychologist No special training	Explicit knowledge Problem solving, decision making: assertive communication, "managing my epilepsy" care module Stress management: "dealing with stress and the blues" modules Mailed materials on "safe exercise programs" as related to patient's goals Medication adherence: "managing my epilepsy" care module	Likely CBT based but not explicitly stated Multicomponent intervention with CBT-related skills of problem solving and stress management Collaboratively set weekly personal goals	8 weekly, 75-min sessions	Waitlist control
Helgeson et al, 1990 (32)	Large group-based intervention with multimedia presentation* Patient targeted but family invited to attend	Not reported	Explicit knowledge Problem-solving and decision-making skills to identify and cope with psychological, social, family, and work-related problems Information on compliance issues related to epilepsy	Identification and coping skills presented as "cognitive behavioral" Goal setting not presented	2 consecutive days	Waitlist control
May and Pfäfflin, 2002 (34)	Group-based intervention with 2 instructors* Written manual also provided Patient targeted	Any professionals or peers were eligible but not reported for current study MOSES training required	Explicit knowledge Discussion of how to self-monitor and record symptoms Discussion of problem solving for seizure risk factors Discussion of gaining emotional coping skills Discussion of communication and cooperation with provider, including medication management	Explicit education and didactic discussions Multicomponent intervention with CBT- and PST-related skills of problem solving and stress management CBT and PST not explicitly discussed Goal setting not presented	2 consecutive days totaling 16 h	Waitlist control

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Appendix Table 3–Continued

Study, Year (Reference)	Setting/Delivery Mode and Intervention Target	Type of Provider and Specialized Training	Intervention Skills	Intervention Techniques and Goal Setting	Frequency/Duration of Contact	Comparator
Ridsdale et al, 2018 (38)	Group-based intervention with 2 trained epilepsy nurse specialists Patient targeted but family invited to attend	Epilepsy nurse specialists and clinical psychologists trained in SMILE SMILE specialized training required	Explicit knowledge Discussion on how to self-monitor and record symptoms Discussion of problem solving for seizure risk factors Discussion on gaining self-efficacy of seizure control Discussion of stress management Discussion of safety, including injury prevention	Explicit education and didactic discussions Multicomponent intervention with CBT- and PST-related skills of problem solving and stress management CBT and PST never explicitly discussed Goal setting not presented	2 consecutive days totaling 16 h	Waitlist control
Sajatovic et al, 2018 (39)	Group-based in-person intervention followed by synchronous Internet-based delivery led by 1 trained nurse educator and 1 trained peer educator. Follow-up 1:1 telephone calls with nurse educator and peer educator Patient targeted	2-person interventionist team of 1 nurse educator and 1 peer educator 2-day specialized training and ongoing check-in support	Explicit knowledge Discussion of problem-solving techniques using IDEA framework Discussion of stress management strategies Discussion of physical activity, sleep, and decreased substance abuse benefits Discussion of diet benefits Discussion and role playing of communication with providers Discussion of medication adherence and management of side effects	Explicit education and didactic discussions Problem-solving technique practice via IDEA framework Role-playing communication with providers Patient-driven goal setting and checking on goal progress	Roughly 8 wk of group sessions, with the first in-person session lasting 60–90 min, followed by 6 phone calls of 10–15 min each over 12 wk	Waitlist control
Psychosocial therapy self-management interventions						
Caller et al, 2016 (27)						
Group 1: PST	In-person group orientation Individual telephone sessions with memory coach* Written educational materials Patient targeted	Epilepsy specialized nurse (RN or ARNP) No training required	Explicit knowledge Problem-solving therapy for organizational skills, seizure management, and social skills	Explicit education Problem-solving therapy Collaborative goal setting	Eight 45–60-min sessions	Active comparator and waitlist control
Group 2: PST plus	In-person group orientation Individual telephone sessions with memory coach* Asynchronous training on commercial gaming device* Written educational materials Patient targeted	Epilepsy specialized nurse (RN or ARNP) No training required	Explicit knowledge Problem-solving therapy for organizational skills, seizure management, and social skills Cognitive training with gaming console	Explicit education Problem-solving therapy Cognitive training via gaming console Collaborative goal setting	Eight 45–60-min sessions 20–40 min of training on gaming console 5 times/wk for 8 wk (40 sessions)	Active comparator and waitlist control

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Appendix Table 3–Continued

Study, Year (Reference)	Setting/Delivery Mode and Intervention Target	Type of Provider and Specialized Training	Intervention Skills	Intervention Techniques and Goal Setting	Frequency/Duration of Contact	Comparator
Gandy et al, 2014 (30)	In-person introductory sessions Individual in-person sessions* Patient targeted	Predoctoral clinical psychology interns 1-d treatment manual training	Explicit knowledge Symptom management Problem-solving skills Communication training Coping with anxiety and depression related to epilepsy Medication adherence	Explicit education and didactic discussions Multicomponent CBT Behavioral activation Symptom monitoring Collaborative goal setting	1–2-h introductory session 8 wk for 60 min each	Waitlist control
Haut et al, 2018 (31)	In-person training session and refresher session Smartphone-assisted asynchronous communication 2–3 times daily Patient targeted	Psychologist No training specified	Implicit knowledge Symptom/seizure tracking with e-diary Relaxation training via PMR	PMR Symptom/seizure monitoring Goal setting not presented	Two 1-h training sessions 12 wk of twice-daily PMR for a total of 20 min/d E-diary reporting 3 times/d Additional e-diary reporting based on seizure events	Active focused attention
Leenen et al, 2018 (33)	In-person group sessions led by 2 NPs* Smartphone-assisted tracking via Eppy app MEMS Caps (Aardex Group) Patient targeted but family invited to attend	NPs No training specified	Explicit knowledge Symptom/seizure tracking Stress management via proactive coping Evaluation and management of risks Medication management Decision making and communication with providers	Explicit education and didactic discussions Symptom/seizure monitoring Training on proactive coping with stressors Medication management and monitoring Collaborative goal setting	Five weekly 2-h sessions and one 2-h booster Eppy app tracking, time not reported	Treatment as usual
McLaughlin and McFarland, 2011 (35)						
Group 1: CBT	In-person group sessions led by a psychologist* Daily seizure diary Patient targeted	Psychologist Expertise in CBT for epilepsy	Explicit knowledge Symptom/seizure tracking Symptoms and triggers identification Stress management via cognitive restructuring Information on diet, physical activity, sleep, and substances Information on using social supports Medication management	Explicit education and didactic discussions Multicomponent group CBT Symptom/seizure tracking Medication management and monitoring Goal setting not presented	Six 2-h weekly sessions	Active relaxation
Group 2: relaxation	In-person group sessions, led by a psychologist* Audiotapes of relaxation exercises Daily seizure diary Patient targeted	Psychologist No training specified	Explicit knowledge Symptom/seizure tracking Relaxation training	Explicit education and didactic discussions Relaxation training (reported as not PMR but seems to be PMR) Symptom/seizure tracking Goal setting not presented	Six 1-h weekly sessions Audiotapes with no time specified	Active relaxation
Puskarich et al, 1992 (36)	In-person sessions (unclear whether group or individual)* Assigned at-home relaxation practice Patient targeted	Not reported	Implicit knowledge Relaxation training via PMR	PMR Prescribed goal setting	6 sessions (first, 60 min; second and third, 50 min; fourth, 40 min; fifth, 20 min; sixth, 15 min) At-home practice 2 times/d for 20 min each for 3 wk	Inactive control: quiet sitting

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Appendix Table 3—Continued

Study, Year (Reference)	Setting/Delivery Mode and Intervention Target	Type of Provider and Specialized Training	Intervention Skills	Intervention Techniques and Goal Setting	Frequency/Duration of Contact	Comparator
Tan and Bruni, 1986 (37)	In-person group sessions* Educational materials provided Patient targeted	"Therapist"; otherwise not reported	Explicit knowledge Symptom/seizure tracking Tracking of stress triggers, including events, thoughts, feelings Stress management via stress inoculation and coping skills Relaxation Problem-solving skills, including vocational problems Increasing social skills and assertive communication	Multicomponent CBT Hierarchical exposures (stress inoculation) Symptom/seizure tracking Collaborative goal setting	8 weekly 2-h sessions	Active supportive counseling and waitlist control
Nonrandomized trials						
Educational self-management interventions						
Gunter et al, 2004 (41)	Education workbook* In-person educational class led by neurology NP Seizure diary Patient ID card with condition information Resource list from Epilepsy Foundation of America Patient targeted	Neurology NP No training specified	Explicit knowledge Symptom/seizure tracking	Explicit education and didactic discussions Symptom/seizure tracking Goal setting not presented	Optional monthly 1-h group education; maximum study duration, 3 y and 5 mo	Inactive treatment as usual at 3 nonrandomly selected control sites
Psychosocial therapy self-management interventions						
Gillham, 1990 (40)						
Group 1: self-control of seizure treatment only	In-person individual sessions* Patient targeted	Not reported	Explicit knowledge Symptom/seizure tracking Relaxation via deep breathing Provocation avoidance training	Explicit education and didactic discussions Relaxation training (deep breathing) Goal setting not presented	Initial 2-h session followed by two 1-h sessions for self-control of seizure treatment	–
Groups 2 and 3: psychological treatment and self-control treatment	In-person individual sessions* Patient targeted; relatives involved in identifying psychiatric/social issues, but whether these issues were targeted for treatment is unclear	Not reported	Explicit knowledge Stress management for various comorbid psychological problems (e.g., anxiety, mild depression, family issues) Symptom/seizure tracking Relaxation via deep breathing Provocation avoidance training	Explicit education and didactic discussions Brief psychological intervention (likely CBT-based but not explicitly stated) Relaxation training (deep breathing) Goal setting not presented	Initial 2-hour session followed by two 1-h sessions for psychological problems, then initial 2-h session followed by two 1-h sessions for self-control of seizure treatment Order of treatment targets was balanced across 2 different treatment groups	–

* Primary target of the intervention.

ARNP = advanced registered nurse practitioner; CBT = cognitive behavioral therapy; IDEA = identify the problem, define possible solutions, evaluate the solutions, act on the best solution; MEMS = Medication Event Monitoring System; MOSES = Modular Service Package Epilepsy; NP = nurse practitioner; PMR = progressive muscle relaxation; PST = problem-solving therapy; RN = registered nurse; SMILE = Self-management Education for Adults With Poorly Controlled Epilepsy; WebEase = Epilepsy Awareness, Support, and Education.

Appendix Table 4. Study Characteristics

Study, Year (Reference); Setting	Participants (Groups), *n*	Eligibility	Interventions and Comparators	Participant Characteristics	Epilepsy Type; Time Since Diagnosis; Seizure Frequency	Outcomes and Timing	ROB
Caller et al, 2016 (27); United States	66 (3)	Inclusion: patients aged 18–65 y with epilepsy (controlled or uncontrolled) and subjective memory problems Exclusion: severe mental impairment or IQ	Multidimensional psychoeducational and problem-solving intervention for cognitive difficulties through in-person group orientation and individual telephone sessions with a trained memory coach. One of 3 groups delivered PST and working memory training on a gaming device Comparators: PST + cognitive training vs. PST only vs. treatment as usual	Mean age: 45.8 y (SD, 9.9) Female: 70% Race: NR Marital status: NR Employment status: 38% employed	Epilepsy type: Generalized (9 patients) Time since diagnosis: NR Seizure frequency: 59% with seizure in the past month	Depressive symptoms QOL: QOLIE-31 Primary outcome: QOLIE-31 score Timing: 8 wk	Objective: high Patient-reported: high
DiIorio et al (WebEase study), 2011 (28); United States	194 (2)	Inclusion: adults with epilepsy who had received AEDs for at least 3 mo, could read and speak English, had Internet access, and had no previous experience with WebEase	Web program tailored to patient's stage of change; each module asked patients to assess current status, reflect on current behaviors, decide whether change is needed, and make a goal/action plan to change Comparator: waitlist control	Mean age: 40.9 y (SD, 13.27) Female: 74% Race: 84.3% white Marital status: 48% married Employment status: 50% employed	Epilepsy type: Focal (60 patients), generalized (76 patients), unknown (6 patients) Time since diagnosis: NR Mean seizure frequency: 10.0 (SD, 29.42) in past 30 d	Distress symptoms QOL: QOLIE-10 Disease knowledge Medication adherence: MAS Self-efficacy: ESES Self-management: ESMS Primary outcome: NR Timing: baseline, 6 wk, 12 wk	Objective: NA Patient-reported: high
Fraser et al (PACES), 2015 (29); United States	92 (2)	Inclusion: adults aged ≥18 y with epilepsy for ≥6 mo, MOCA score >21, and fluency in English Exclusion: Active serious mental illness; IQ <70 or known cognitive impairment (MOCA score ≤21)	Group-based psychoeducational intervention based specifically on an initial consumer survey, with sessions led by an epilepsy professional and a peer with epilepsy; participants were mailed informational material related to their specific goals each week and were given a workbook with written materials. Comparator: treatment as usual	Mean age: 45.2 y (SD, 12.5) Female: 55% Race: 81% white Marital status: 36% married Employment status: 41% employed	Epilepsy type: Focal (58 patients), generalized (44 patients), unknown (4 patients) Time since diagnosis: NR Median seizure frequency: 1 (IQR, 1.2)*	Anxiety symptoms Depressive symptoms QOL: QOLIE-31 Self-efficacy: ESES Self-management: ESMS Primary outcome: NR Timing: baseline, 8 wk, 6 mo	Objective: NA Patient-reported: unclear
Gandy et al, 2014 (30); Australia	59 (2)	Inclusion: adults aged 18–65 y with formal diagnosis of epilepsy confirmed by treating neurologist and at least low-average intelligence Exclusion: persons with psychotic disorder; acutely suicidal persons; persons with severe personality disorder; and those about to undergo epilepsy surgery	CBT and self-management of epilepsy Psychoeducation Managing triggers Enhancing problem solving Managing medication adherence Delivered by trained psychology doctoral-level interns Comparator: waitlist	Mean age: 39.3 y (SD, 12.57) Female: 64% Race: NR Marital status: 60% married or cohabiting; 40% divorced, widowed, or single Employment status: 64% employed	Epilepsy type: Focal (35 patients), generalized (10 patients) Mean time since diagnosis: 13.3 y (SD, 10.95) Seizure frequency: NR	Anxiety symptoms Depressive symptoms QOL: QOLIE-31 Primary outcome: depressive symptoms Timing: pretreatment, 2 mo; posttreatment, 3 mo	Objective: NA Patient-reported: high

Continued on following page

Appendix Table 4–Continued

Study, Year (Reference); Setting	Participants (Groups), *n*	Eligibility	Interventions and Comparators	Participant Characteristics	Epilepsy Type; Time Since Diagnosis; Seizure Frequency	Outcomes and Timing	ROB
Gillham, 1990 (40); Europe	59 (3)	Inclusion: Clinical diagnosis of epilepsy, rated by self and clinician as inadequately controlled; average of ≥2 seizures per week in the previous 2 mo with no trend toward improvement	Self-control: identification of seizure semiology, training in identification of seizure symptoms, training in avoidance of provocations, relaxation techniques during prodrome, general relaxation/breathing techniques Psychological intervention: targeted problems, most commonly phobic avoidance, mild depression, and family relationships Comparator: Self-control vs. self-control followed by psychological intervention vs. psychological intervention followed by self-control	Mean age: 31.7 y (SD, 12.1) Female: 58% Race: NR Marital status: 41% married Employment status: NR	Epilepsy type: Focal (26 patients), generalized (29 patients), unknown (4 patients) Mean time since diagnosis: 17.9 y (SD, 11.7) Seizure frequency: NR	Anxiety symptoms Depressive symptoms Seizure rate Primary outcome: seizure rate Timing: baseline, 42 wk	Objective: NA Patient-reported: high
Gunter et al, 2004 (41); United States	747 (2)	Inclusion: electronic medical record identification of potential candidates, followed by physician verification of presence of epilepsy Exclusion: those identified as "do not contact" by primary care physicians (presumed these were persons identified as not having epilepsy)	Physician and direct-to-patient resources; patient resources included an education workbook, a monthly hour-long seizure education class led by a neurology NP, and a seizure diary Comparator: treatment as usual	Mean age: 54 y (SD, NR) Female: NR Race: 68.4% white Marital status: NR Employment status: 50% employed	Epilepsy type: NR Time since diagnosis: NR Seizure frequency: NR	Seizure rate/frequency Seizure severity QOL: QOLIE-31 Primary outcome: QOLIE-31 Timing: before and 12 mo after implementation	Objective: NA Patient-reported: high
Haut et al, 2018 (31); United States	67 (2)	Inclusion: age ≥18 y; medication resistance (≥4 seizures during 56-d baseline period); stable AED regimen; awareness of triggers or premonitory features, or ability to self-predict seizures; focal epilepsy; ability to maintain e-diary. Exclusion: suicide attempt within 2 y or suicidal ideation, status epilepticus within 6 mo, stress reduction intervention within 3 mo, or failed previous stress reduction	Primarily stress management practice through PMR, with additional self-monitoring component based on seizure activity; patients received an in-person training session with a psychologist for PMR and a follow-up training 6 wk later Comparator: active focused attention	Mean age: 37.2 y (SD, 24) Female: 62.5% Race: NR Marital status: NR Employment status: NR	Epilepsy type: Focal (64 patients) Mean time since diagnosis: 26 y (SD, 13.7) Mean seizure frequency: 11.42 (SD, 15.83) per month	Anxiety symptoms Depressive symptoms Distress symptoms Seizure frequency Primary outcome: Seizure frequency Timing: daily for 12 wk	Objective: NA Patient-reported: low
Helgeson et al (SEE program), 1990 (32); United States	100 (2)	Inclusion: epilepsy diagnosis and treatment with AEDs Exclusion: intellectual disability, dementia, or psychosis	Psychoeducational treatment program providing education and psychosocial therapy through cognitive behavioral methods to patients and their families; presented education on medical and compliance issues with epilepsy and modeled skills for identifying and coping with psychological, social, family, and work-related problems of epilepsy Comparator: waitlist	Mean age: 37.3 y (SD, 11.85) Female: 74% Race: NR Marital status: NR Employment status: NR	Epilepsy type: Focal (11 patients), generalized (12 patients) Mean time since diagnosis: 16.5 y (SD, 10.95) Mean seizure frequency: 2.3 (SD, 4.35) per month	Anxiety symptoms Depressive symptoms Seizure rate/frequency Social functioning: Washington Psychosocial Seizure Inventory Disease knowledge Self-efficacy: Sherer self-efficacy scale Primary outcome: NR Timing: baseline and 4 mo	Objective: high Patient-reported: high

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Appendix Table 4–Continued

Study, Year (Reference); Setting	Participants (Groups), *n*	Eligibility	Interventions and Comparators	Participant Characteristics	Epilepsy Type; Time Since Diagnosis; Seizure Frequency	Outcomes and Timing	ROB
Leenen et al (ZMILE), 2018 (33); Europe	103 (2)	Inclusion: adults with epilepsy who were using AEDs, understood Dutch, and could participate in sessions or use e-health devices Exclusion: persons unwilling or unable to participate in group sessions or thought to be unable to comprehend the topics discussed in sessions	NP-led group sessions aimed at improving knowledge, recognition, self-monitoring, and proactive coping Comparator: treatment as usual	Mean age: 41.7 y (SD, 14.7) Female: 51% Race: NR Marital status: 51% married Employment status: 34.3% employed	Epilepsy type: NR Mean time since diagnosis: 20.1 y (SD, 15.01) Mean seizure frequency: 5.1 (SD, 11.15) per 4 wk	Anxiety symptoms Depressive symptoms Seizure rate/frequency Seizure severity QOL: QOLIE-31 Medication toxicity Medication adherence: MARS Self-efficacy: ESES Primary outcome: ESES Timing: baseline, 3 mo, 6 mo	Objective: NA Patient-reported: low
May and Pfäfflin (MOSES), 2002 (34); Europe	383 (2)	Inclusion: patients aged ≥16 y with epilepsy Exclusion: intellectual disability, acute psychiatric illness, nonepileptic seizures only	Discussion of factors: education about epilepsy; ways to emotionally cope with epilepsy, monitor symptoms and seizures, and plan for or actively cope with preseizure symptoms/auras; cooperating with clinicians; and taking medications as prescribed Comparator: waitlist	Mean age: 38.0 y (SD, 13.59) Female: 57% Race: NR Marital status: NR Employment status: 41% employed	Epilepsy type: Focal (152 patients), generalized (43 patients), unknown (44 patients) Median time since diagnosis: group 1: 13.5 y (IQR, 4.7–26.2 y), group 2: 18.2 y (IQR, 8.5–29.6 y) Seizure frequency: 76% with ≥1 seizure in the past 6 mo	Depressive symptoms Seizure rate/frequency Social functioning: Restrictions in daily living QOL: SF-36 Disease knowledge Self-management: Coping With Epilepsy Primary outcome: restrictions in daily living, SF-36, disease knowledge, Coping With Epilepsy Timing: baseline, 6 mo after course completion	Objective: NA Patient-reported: high
McLaughlin and McFarland, 2011 (35); Australia	37 (2)	Inclusion: English-speaking adults aged ≥60 y with confirmed diagnosis of epilepsy, ability to attend weekly group sessions, MMSE score ≥24, and ability to provide information on physical and medical status	Manualized, in-person, group CBT intervention delivered by a psychologist; self-management elements included psychoeducation, seizure diaries, CBT to reduce triggers, physical and emotional wellness (including medication management), and seizure management Comparator: active relaxation	Mean age: 67.5 y (SD, 7.37) Female: 51% Race: NR Marital status: NR Employment status: NR	Epilepsy type: Focal (20 patients), generalized (17 patients) Mean time since diagnosis: 27.2 y (SD, 27.22) Seizure frequency: NR	Depressive symptoms Seizure rate/frequency Social functioning: Washington Psychosocial Seizure Inventory Primary outcome: NR Timing: 6 wk, 3 mo	Objective: NA Patient-reported: unclear
Puskarich et al, 1992 (36); United States	53 (2)	Inclusion: epilepsy diagnosis, 6 seizures during an 8-wk run-in period with awareness of every seizure by self or witness, normal intellectual function, English speaking	PMR training; participants were encouraged to practice the relaxation techniques at home twice a day for 20 min Comparator: quiet sitting	Mean age: 39.4 y (SD, NR) Female: 67% Race: 62% white Marital status: NR Employment status: NR	Epilepsy type: Focal (21 patients), generalized (3 patients) Mean time since diagnosis: 22 y (SD, NR) Seizure frequency: NR	Seizure rate Primary outcome: seizure rate Timing: 8 wk	Objective: NA Patient-reported: high

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Appendix Table 4–Continued

Study, Year (Reference); Setting	Participants (Groups), *n*	Eligibility	Interventions and Comparators	Participant Characteristics	Epilepsy Type; Time Since Diagnosis; Seizure Frequency	Outcomes and Timing	ROB
Ridsdale et al (SMILE-UK), 2018 (38); Europe	404 (2)	Inclusion: persons aged ≥16 y who had specialist-diagnosed epilepsy for ≥1 y, were using AEDs, had ≥2 seizures in the past year, could understand English, and were able to attend the 2-d course Exclusion: psychogenic seizures, substance misuse, serious psychiatric illness, terminal illness	Intervention based on MOSES; 9-module group education focused on patients with epilepsy; caregivers also were invited Comparator: treatment as usual	Mean age: 41.7 y (SD, 14.1) Female: 54.2% Race: 75.2% white Marital status: 38.1% married Employment status: 41.8% employed	Epilepsy type: NR Median time since diagnosis: 18 y (IQR, 8–32 y) Median seizure frequency: 34 (IQR, 18–63) in past 12 mo	Anxiety symptoms Depressive symptoms Seizure rate/frequency QOL: QOLIE-31 Medication toxicity Medication adherence: ESMS Self-efficacy: Self-Mastery and Control scale Primary outcome: QOLIE-31 score Timing: baseline, 6 mo, 12 mo	Objective: NA Patient-reported: low
Sajatovic et al (SMART), 2018 (39); United States	120 (2)	Inclusion: self-reported epilepsy, age ≥18 y, ≥1 negative health event (seizure, accident or traumatic injury, self-harm attempt, ED visit, or hospitalization) in past 6 mo Exclusion: immediate risk for self-harm, dementia, pregnancy, inability to read/understand English	Group-based, in−person, 60–90−min session delivered collaboratively by a nurse educator–peer educator dyad; then 7 group-format sessions delivered approximately weekly via the Internet on computer tablets by using posters/graphics and emphasizing interactive discussion; then 6 telephone maintenance sessions (approximately every 2 wk), with the peer educator and nurse educator alternating calls. Comparator: Waitlist control group, which continued treatment as usual with providers and received intervention after 6-mo follow-up with treatment group	Mean age: 41.3 y (SD, 11.8) Female: 68.1% Race: 30.1% white Marital status: 31.7% married Employment status: 25.8% employed	Epilepsy type: Focal (4 patients), generalized (85 patients) Mean time since diagnosis: 20.6 y (SD, 15.2) Mean seizure frequency: 2.2 (SD, 4.9) per 30 d	Depressive symptoms Seizure rate/frequency Seizure severity QOL: QOLIE-10 Negative health events Self-efficacy: ESES Self-management: ESMS ED visit for epilepsy Hospitalization (any cause) Primary outcome: change in total negative health events Timing: 24 wk	Objective: unclear Patient-reported: unclear
Tan and Bruni, 1986 (37); Canada	30 (3)	Inclusion: adults with epilepsy, substantial psychosocial problems, and inadequate seizure control (as judged by neurologist) Exclusion: persons with intellectual disability or psychosis	CBT-based intervention that included education via explicit readings; symptom monitoring for seizures; problem solving of anticipated seizure-related issues in life; stress management; increasing other healthy activities Comparators: CBT vs. supportive counseling vs. waitlist	Mean age: 33.4 y (SD, 11.1) Female: 63% Race: NR Marital status: NR Employment status: NR	Epilepsy type: Focal (22 patients), generalized (5 patients) Mean time since diagnosis: 15.5 y (SD, 8.9) Seizure frequency: NR	Depressive symptoms Seizure rate/frequency Social functioning: Washington Psychosocial Seizure Inventory Medication adherence: "Compliance with Taking Anticonvulsant Meds" Likert scale 1–5 Primary outcome: NR Timing: preintervention, postintervention, 4 mo	Objective: NA Patient-reported: high

* Score on a 5-point scale (ranging from 0 to 4 points): 0 = no seizures in past 2 years, 1 = 1–11 seizures per year, 2 = 1–3 seizures per month, 3 = ≥1 seizures per week, and 4 = ≥1 seizures per day. Therefore, a median of 1.2 translates to approximately 1 seizure per month.

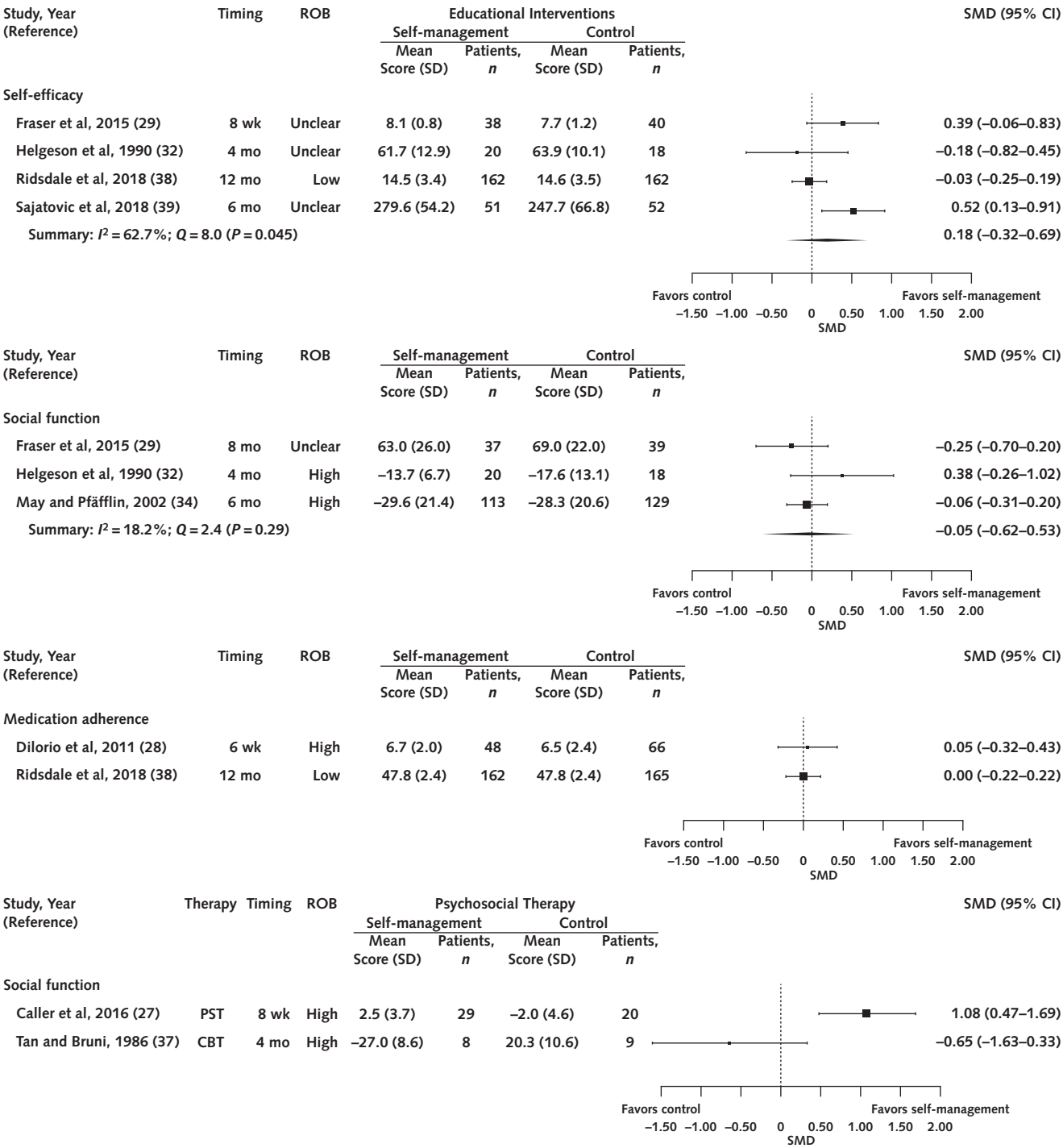
AED = antiepileptic drug; CBT = cognitive behavioral therapy; ED = emergency department; ESES = Epilepsy Self-Efficacy Scale; ESMS = Epilepsy Self-Management Scale; IQR = interquartile range; MAS = Medication Adherence Scale; MMSE = Mini-Mental State Examination; MOCA = Montreal Cognitive Assessment; MOSES = Modular Service Package Epilepsy; NA = not applicable; NP = nurse practitioner; NR = not reported; PACES = Program for Active Consumer Engagement in Self-management; PMR = progressive muscle relaxation; PST = problem-solving therapy; QOL = quality of life; QOLIE = Quality of Life in Epilepsy Inventory; ROB = risk of bias; SEE = Sepulveda Epilepsy Education; SF-36 = Short Form-36 Health Survey; SMART = Self-Management for People with Epilepsy and a History of Negative Health Events; SMILE-UK = Self-management Education for Adults With Poorly Controlled Epilepsy; WebEase = Epilepsy Awareness, Support, and Education; ZMILE = Effectiveness of a Multicomponent Self-management Intervention for Adults With Epilepsy.

Appendix Table 5. Intervention Components Across Studies

Study, Year (Reference); Design	Knowledge	Symptom Monitoring	Medication Management	Problem Solving	Safety	Health Behaviors	Total Components, *n*
Educational self-management interventions							
Dilorio et al (WebEase), 2011 (28); randomized	Yes	Yes	Yes	Yes	No	Yes	5
Ridsdale et al (SMILE-UK), 2018 (38); randomized	Yes	Yes	No	Yes	Yes	Yes	5
Fraser et al (PACES), 2015 (29); randomized	Yes	No	Yes	Yes	No	Yes	4
May and Pfäfflin (MOSES), 2002 (34); randomized	Yes	Yes	Yes	Yes	No	No	4
Sajatovic et al (SMART), 2018 (39); randomized	Yes	No	Yes	Yes	No	Yes	4
Helgeson et al (SEE), 1990 (32); randomized	Yes	No	Yes	Yes	No	No	3
Gunter et al, 2004 (41); nonrandomized	Yes	Yes	No	No	No	No	2
Psychosocial therapy self-management interventions							
Leenen et al (ZMILE), 2018 (33); randomized	Yes	Yes	Yes	Yes	Yes	Yes	6
Gandy et al, 2014 (30); randomized	Yes	Yes	Yes	Yes	No	Yes	5
McLaughlin and McFarland, 2011 (35); randomized							
Group 1	Yes	Yes	Yes	Yes	No	Yes	5
Group 2	Yes	Yes	No	No	No	Yes	3
Gillham, 1990 (40); nonrandomized							
Group 1	Yes	Yes	No	Yes	No	Yes	4
Groups 2 and 3*	Yes	Yes	No	Yes	No	Yes	4
Tan and Bruni, 1986 (37); randomized	Yes	Yes	No	Yes	No	Yes	4
Caller et al (HOBSCOTCH), 2016 (27); randomized							
Group 1	Yes	No	No	Yes	No	Yes	3
Group 2	Yes	No	No	Yes	No	Yes	3
Haut et al, 2018 (31); randomized	Yes	Yes	No	No	No	Yes	3
Puskarich et al, 1992 (36); randomized	Yes	No	No	No	No	Yes	2
Total for all groups	18	12	8	14	2	15	

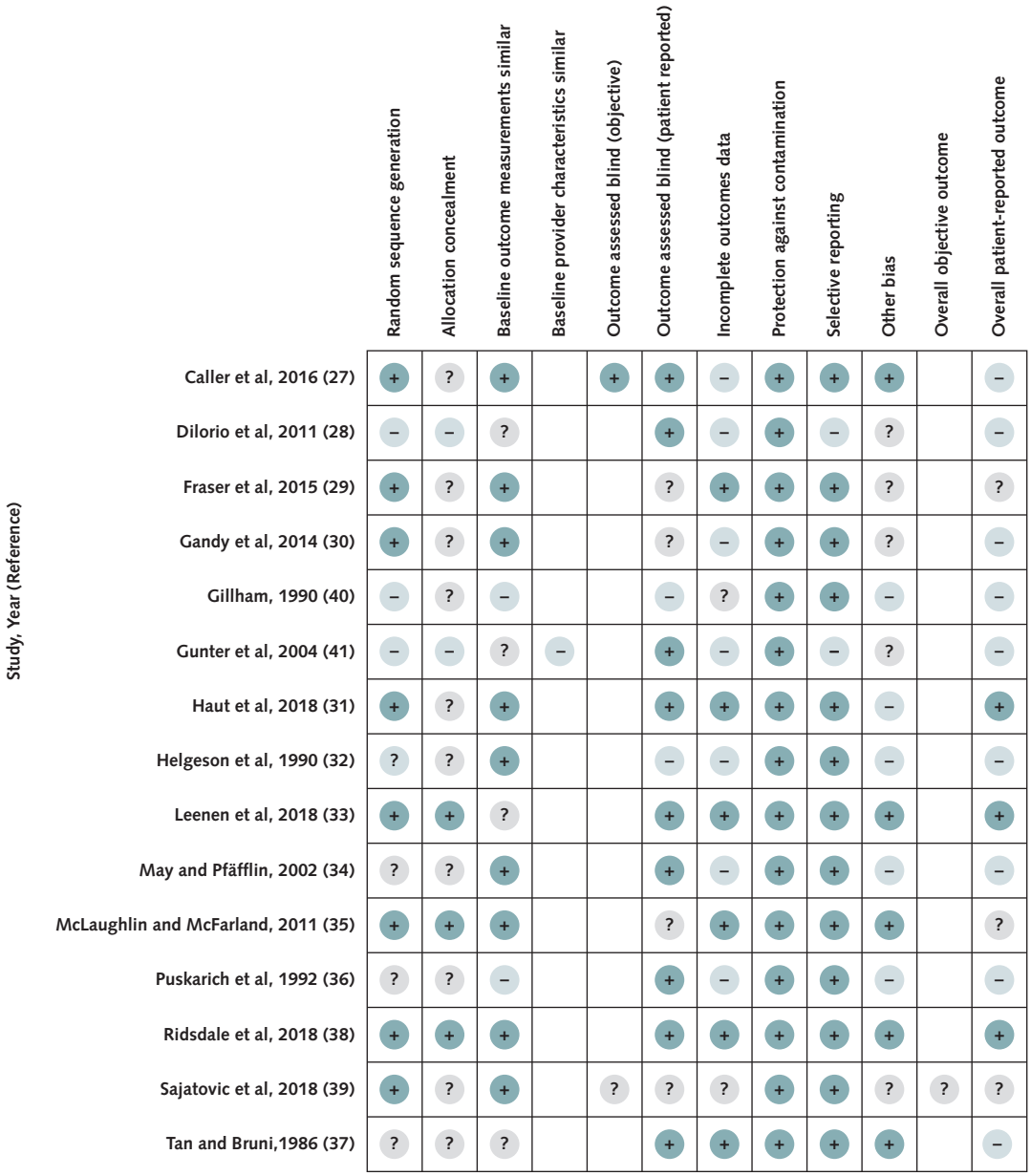
* Groups 2 and 3 were assigned the same intervention in the initial intervention period of this crossover study.
HOBSCOTCH = Home Based Self-management and Cognitive Training Changes Lives; MOSES = Modular Service Package Epilepsy; PACES = Program for Active Consumer Engagement in Self-management; SEE = Sepulveda Epilepsy Education; SMART = Self-Management for People with Epilepsy and a History of Negative Health Events; SMILE-UK = Self-management Education for Adults With Poorly Controlled Epilepsy; WebEase = Epilepsy Awareness, Support, and Education; ZMILE = Effectiveness of a Multicomponent Self-management Intervention for Adults With Epilepsy.

Appendix Figure 2. Forest plot showing secondary outcomes for epilepsy self-management interventions.



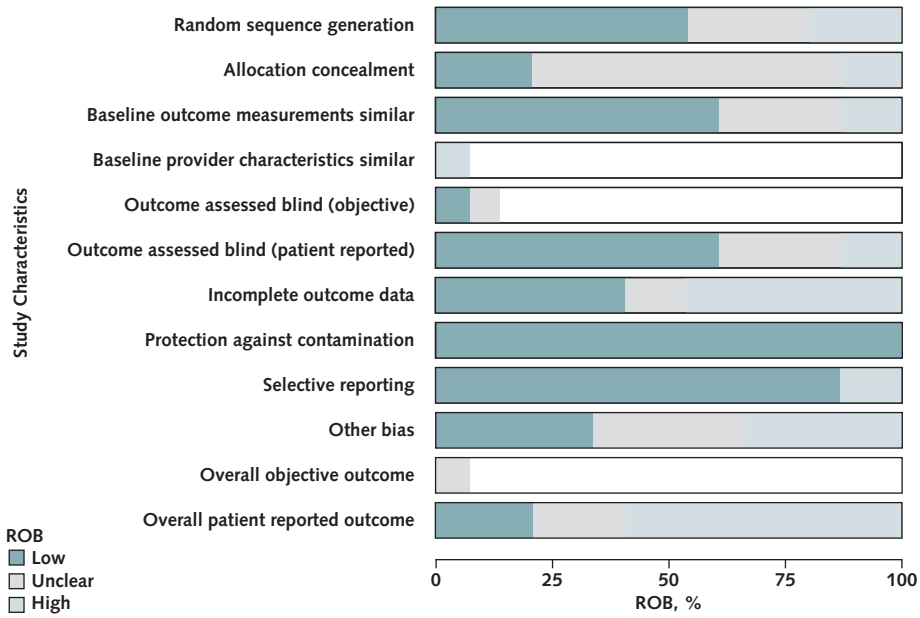
For the score measures used in each study, see Appendix Table 4 (available at Annals.org). CBT = cognitive behavioral therapy; PST = problem-solving therapy; ROB = risk of bias; SMD = standardized mean difference.

Appendix Figure 3. ROB ratings for the included studies.



Blank spaces indicate items that were not applicable. Dark-green circles with plus signs indicate items that were judged low ROB. Light-gray circles with question marks indicate items that were judged unclear ROB. Light-green circles with minus signs indicate items that were judged high ROB. ROB = risk of bias.

Appendix Figure 4. ROB assessment across included studies.



White spaces indicate items that were not applicable. ROB = risk of bias.