III

APPENDIX A. SEARCH STRATEGIES

PubMed: April 13, 2018 and October 31, 2018

Set	Terms	Results
#1	"Epilepsy"[Mesh] OR epilepsy[tiab] OR epilepsies[tiab] OR epileptic[tiab] OR	139,312
	epileptics[tiab] OR epilepsia[tiab]	
#2	"Self-Management"[Mesh] OR "Self Care"[Mesh] OR "Self-Control"[Mesh] OR	646,690
	self[tiab] OR selfcare[tiab] OR selfmanagement[tiab] OR selftreatment[tiab] OR	
	selfcontrol[tiab] OR selfhelp[tiab]	
#3	"Patient Compliance"[Mesh] OR "Medication Adherence"[tiab] OR "Medication	162,567
	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]	
#4	"Behavior Therapy"[Mesh] OR behavior therap*[tiab] OR behaviour therap*[tiab] OR behavioral therap*[tiab] OR behavioural therap*[tiab] OR "anger management"[tiab]	125,605
	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]	0.007
#5	#1 AND (#2 OR #3 OR #4) AND English[lang]	3,887
#6	#5 NOT (animals[mh] NOT humans[mh]) NOT (("Adolescent"[Mesh] OR "Child"[Mesh]	3,080
#7	OR "Infant"[Mesh]) NOT "Adult"[Mesh])	4 605
#7	#6 AND (("randomized controlled trial"[ptyp] OR "controlled clinical trial"[ptyp] OR randomized[tiab] OR randomised[tiab] OR randomisation[tiab]	1,695
	OR placebo[tiab] OR random/sed[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]))	

Set	Terms	Results
#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 postimplementation[tiab] OR uptake[tiab] OR preimplementation[tiab] OR facilitator*[tiab] OR feasible[tiab] OR uptake[tiab] OR effective[tiab] OR effectiveness[tiab] OR barrier[tiab] OR barriers[tiab] OR benefits[tiab] OR effectiveness[tiab] OR barrier[tiab] OR benefit[tiab] OR benefits[tiab]))	568
#9	#7 OR #8	1,860

Cochrane Central: April 13, 2018

Set	Terms	Results
#1	[mh Epilepsy] OR (epilepsy or epilepsies or epileptic or epileptics or epilepsia):ti,ab,kw	5,832
#2	[mh "Self-Management"] OR [mh "Self Care"] OR [mh "Self-Control"] OR (self OR	62,762
	selfcare OR selfmanagement OR selftreatment OR selfcontrol OR selfhelp):ti,ab,kw	
#3	[mh "Patient Compliance"] OR [mh "Health Knowledge, Attitudes, Practice"] OR	18,270
	("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	
#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 "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 reducers" OR "stress reducins" OR "stress reduces" OR "stress reducers" OR "stress "stress reducing" OR "stress reducers" OR "stress reducers" OR	37,550
	reductive"):ti,ab,kw	400
#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

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PsycINFO: April 13, 2018

Set	Terms	Results
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 Noncompliance" 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 "relaxation technique" OR meditate OR meditates OR "implosive therap*" OR "relaxation techniques" OR "relaxation techniques" OR "relaxation technique" OR meditation OR medicine" OR "breathing exercise" OR "breathing exercises" OR "respiratory muscle training" OR "breathing exercise" OR "breathing exercises" OR "respiratory muscle training" OR "stress reducer" OR "stress reducers" OR "stress reduced" OR "stress reducer" OR "stress reducers" OR "neuro feedback" OR neurofeedback OR "wofeedback OR "physiological feedback" OR meuto therap*" OR "anger management" OR biofeedback OR "bio-feedback" OR meuto feedback OR myofeedback OR "physiological feedback" OR "neuro feedback" OR neurofeedback OR "cognitive therap*" OR "cognition therap*" OR "acceptance therap*" OR "relaxation therap*" OR "relaxation techniques" OR "neurofeedback OR myofeedback OR "physiological feedback" OR "neurofeedback" OR neurofeedback OR "cognitive therap*" OR "cognition therap*" OR "stress reducers" OR "relaxation therap*" OR "rel	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: April 13, 2018

Set	Terms	Results
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 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
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 techniques" OR "relaxation technique" OR meditate OR meditate 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 "stress reduced" OR "stress reducer" OR "stress reducers" OR "stress reduced" OR "stress reducer" OR "stress reducers" OR "behaviour therap*" OR "anger management" OR biofeedback OR "bio-feedback" OR myobiofeedback OR myofeedback OR "physiological feedback" OR meuro feedback" OR neurofeedback OR "cognitive therap*" OR "cognition therap*" OR "acceptance therap*" OR "reaming OR "implosive therap*" OR "acceptance therap*" OR "behaviour therap*" OR "cognition therap*" OR "acceptance 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 "stress reduced" OR "psychological desensitization" OR "Eye Movement Desensitization and Processing" OR EMDR OR "implosive therap*" OR "ceptosure therap*" OR "relaxation therap*" OR "relaxation techniques" OR "stress reducers" OR meditate OR meditates OR "mind body therapy" OR "mind body therapies" OR "relaxation therap*" OR "relaxation techniques" OR "stress reducers" OR meditate OR meditates OR	71,641
S5	S1 AND (S2 OR S3 OR S4) Limiters - English Language; Age Groups: All Adult;	238
	Publication Type: Journal Article	

Searches retrieved 2,996 records before duplicates were removed.

APPENDIX B. PEER REVIEW COMMENTS/AUTHOR RESPONSES

Question Text	Reviewer Number	Comment	Response
Are the	1	Yes	Acknowledged
objectives,	2	Yes	Acknowledged
scope, and	3	Yes	Acknowledged
methods for	4	Yes	Acknowledged
this review	6	Yes	Acknowledged
clearly described?	7	Yes	Acknowledged
Is there any	1	No	Acknowledged
indication of	2	No	Acknowledged
bias in our	3	No	Acknowledged
synthesis of	4	No	Acknowledged
the	6	No	Acknowledged
evidence?	7	No	Acknowledged
Are there	1	No	Acknowledged
any	2	No	Acknowledged
<u>published</u> or <u>unpublished</u> studies that we may	3	Yes - Would consider an addendum to include the Sajatovic et al study in Epilepsia Sept 2018, 1684-95. This study appears to have a positive outcome and may offset some to the disappointment of the other negative or inconclusive studies reviewed.	Thank you. We identified this study when we updated our search and it is included in the final report.
have	4	No	Acknowledged
overlooked?	6	Yes - Sajatovic M et al. A 6-month prospective randomized controlled trial of remotely delivered group format epilepsy self-management versus waitlist control for high-risk people with epilepsy. Epilepsia. 2018;59 (9):1684–1695)	Thank you. We identified this study when we updated our search and it is included in the final report.
	7	There are a number of published studies that would make the case for why this is important based on data for Veterans.	We cite Veteran-specific data obtained from the Epilepsy Centers of Excellence.
Additional suggestions or	1	Recommend clearly defining "self-efficacy" and how this differs from self-management.	Self-management is carefully defined in the report. We have added a definition for self-efficacy.
comments can be provided below. If applicable,		On page 3 (and elsewhere) it is stated that 6 educational interventions and 8 psychosocial therapy interventions were included for review in KQ1; however, the Table lists these numbers as 6 and 12 respectively. Please clarify the reason for this difference.	This apparent discrepancy relates to the number of studies using the interventions versus the number of intervention arms using the

Question Text	Reviewer Number	Comment	Response
please indicate the			interventions. We have carefully edited to specify studies or intervention arms.
page and line numbers from the draft report.	2	Document is quite thorough, well-written and clear. Though it does not directly address patient centered care or Whole Health, findings regarding the importance of personalization for implementation are relevant. Pg. 50, lines 9-11; Suggested rewording: Self-management of chronic illness that is aligned with an individual's values and preferences is considered an important component in delivering patient-centered care in VHA, and is a pillar of VHA's Patient Aligned Care Teams (PACT). I am unfamiliar with the reference cited (#75) and am not sure that it is reflective of current perspectives re. Whole Health and PCC in VHA. The Office of Patient Centered Care and Cultural Transformation website is:	Thank you. The suggested edit has been made. We think the reference is relevant. We have added a link to the Office of Patient Centered Care and Cultural Transformation.
	3	https://vaww.va.gov/patientcenteredcare/ Reference 2 is not sited properly (ref 2 on page 9 does not seem to match ref 2 on page 48). Could not find a definition regarding how a setting was deemed eligible.	Thank you for detecting this citation error. The citation has been updated (Rehman et al., 2015). Setting is described in Table 1 (Eligibility Criteria). "Setting" is this instance refers to eligible modes of delivery, rather than a physical location.
	4		
	6	It is well written and valuable to providers in VAH. I found following descriptions that may be revised if the most recent publication (see below) will be included. Page 8 (p 2) Data Sources and Searches We searched MEDLINE (via PubMed), PsycINFO, and CINAHL from inception through April 13, 2018. We also examined the bibliographies of recent reviews for additional relevant studies.	Thank you. Thank you. Except as noted, these statements were revised after the addition of the Sajatovic study. This statement is accurate.

Question Text	Reviewer Number	Comment	Response
		Page 12 (p 6) "No studies directly addressed facilitators and barriers to implementing and adopting self-management interventions for patients with epilepsy in the VHA or other large health systems. No studies directly enrolled Veterans with epilepsy."	These statements about educational interventions were updated.
		Page 12 (p6) "We found limited evidence for benefit on selected primary or secondary outcomes. Educational self-management interventions may improve the use of self- management practices. Sparse evidence suggested possible benefit of psychosocial therapy interventions on self efficacy. Self-management interventions did not improve other outcomes but the certainty of evidence for these finding was often low."	
		Page 13 (p7) "None of the included studies were conducted in VHA or specifically with Veterans."	This statement remains accurate.
		Page 13 (p7) Conclusions "These self-management interventions showed clinically important benefit for only a limited number of outcomes, but the confidence in these findings was mostly low."	
		There is a recent article published in Epilepsia September issue of 2018 (Sajatovic M, Colon-Zimmermann K, Kahriman M, Fuentes-Casiano E, Liu H, Tatsuoka C, Cassidy KA, Lhatoo S, Einstadter D, Chen P. A 6-month prospective randomized controlled trial of remotely delivered group format epilepsy self-management versus waitlist control for high-risk people with epilepsy. Epilepsia. 2018;59 (9):1684–1695)	This study is included in the final report.
		This study, if included in this review, will enhance the quality of current review and alter narratives described above in executive summary and through the rest of manuscript of review.	
		This study was conducted at the Cleveland VA Medical Center, and University Hospitals of Cleveland Neurological Institute, with subjects including veterans. I would recommend to include this study in this review. It is a randomized controlled trial using remotely delivered group format epilepsy self-management (n=60) versus waitlist control (n=6) for	

Question Text	Reviewer Number	Comment	Response
		high risk individuals with epilepsy. This study will help in addressing all 3 questions this review intended to answer, and will enhance the quality of this review.	
		Summary of this study is as below. Objective: Despite advances in care, many people with epilepsy have negative health events (NHEs) such as accidents, emergency department visits, and poor quality of life. Self-management for people with epilepsy and a history of negative health events"(SMART) is a novel group format epilepsy self-management intervention. A community participatory approach informed the refinement of SMART, which was then tested in a 6-month randomized controlled trial of SMART (n = 60) versus waitlist control (WL, n = 60).	
		Methods: Participants were adults aged ≥18 years with epilepsy and an NHE within the past 6 months (seizure, accident, self-harm attempt, emergency department visit, or hospitalization). Assessments were conducted at screening, baseline, 10 weeks, and 24 weeks (6 months). Primary outcome was 6-month change in total NHE count. Additional outcomes included depression on the nine-item Patient Health Questionnaire and Montgomery-Asberg Depression Rating Scale, quality of life on the 10-item Quality of Life in Epilepsy, functioning on the 36-item Short-Form Health Survey, and seizure severity on the Liverpool Seizure Severity Scale.	
		Results: Mean age was 41.3 years (SD = 11.82), 69.9% were African American, 74.2% were unemployed, and 87.4% had an annual income < US\$25 000; 57.5% had a seizure within 30 days of enrollment. Most NHEs were seizures. Six-month study attrition was 14.2% overall and similar between arms. Individuals randomized to SMART had greater reduction in total median NHEs from baseline to 6 months compared to WL (P = 0.04). SMART was also associated with improved nine-item Patient Health Questionnaire (P = 0.032), Montgomery-Asberg Depression Rating Scale (P = 0.002), 10-item Quality of Life in Epilepsy (P < 0.001), and 36-item Short-Form Health Survey (P = 0.015 physical health, P = 0.003 mental health) versus WL. There was no difference in seizure severity.	

Question Text	Reviewer Number	Comment	Response
		Significance: SMART is associated with reduced health complications and improved mood, quality of life, and health functioning in high-risk people with epilepsy. Additional efforts are needed to investigate potential for scale-up.	
		Curriculum of "Self-management for people with epilepsy and a history of negative health events" (SMART)	
		Session 1 Orientation and introductions; Emphasize ground rules; Establishment of a therapeutic relationship; Facts and myths about epilepsy and general epilepsy management principles Session 2 Relationship of epilepsy and stress; Stigma and "double stigma"; Strategies to cope with stigma; Introduction to personal goal- setting Session 3 Treatments for epilepsy; Complications of epilepsy; Minimizing epilepsy complications; The importance of daily routine and good sleep habits Session 4 Problem-solving skills and the IDEA approach (Identify the problem, Define possible solutions, Evaluate the solutions, Act on the best solution); Talking with your health care providers; Role play of communication with care providers Session 5 Nutrition for best physical and emotional health; Substance abuse and its effects on epilepsy; Specific stress- management approaches Session 6 Effects of exercise and being outdoors on physical and emotional health; Medication routines; Prioritizing medication side effects and discussing it with your clinician Session 7 Social supports and using your available supports; Advocacy groups for epilepsy; A personal care plan to take care of the mind and the body	
		Session 8 Normalizing your life in spite of having a chronic but unpredictable condition; Self- management as a life-style; Acknowledgement of group progress; Setting the stage for Ongoing Illness Management and Recovery (Step 2)	
	7	The references in the body of the document seemed to be the wrong references.	Thank you, the references have been updated.

APPENDIX C. INTERVENTION CHARACTERISTICS TABLES

For full study citations in this appendix, please refer to the report's main reference list.

RANDOMIZED TRIALS

Study	Setting/Delivery Mode Intervention Target	Type of Provider Specialized Training	Intervention Skills	Intervention Techniques Goal-setting	Frequency/ Duration of Contact Comparator
Educational Self-	management Interventi	ons	•	•	
Dilorio, 2011 ⁴⁷	Asynchronous internet- based delivery ^a Patient targeted	Peer online discussion forum, electronic-based delivery No special training	 Knowledge Symptom-monitoring using MyLog 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 weeks; length of sessions not specified Waitlist control
Fraser, 2015 ⁴⁸	 Group-based intervention, with 1 peer with epilepsy as the leader^a Additional written information via workbook and mailed materials Patient targeted 	 Peer with epilepsy, 7 years' 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 individuals' goals 	 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-minute sessions Waitlist control

Study	Setting/Delivery Mode Intervention Target	Type of Provider Specialized Training	Intervention Skills	Intervention Techniques Goal-setting	Frequency/ Duration of Contact Comparator
			 Medication adherence: "managing my epilepsy" care module 		
Helgeson,1990 ⁵¹	Large group-based intervention with multimedia presentation ^a Patient targeted, but family invited to attend	Not reported	 Explicit knowledge Problem-solving, 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, 2002 ⁵³	 Group-based intervention with 2 instructors^a Written manual also provided Patient targeted 	Any professionals or peers are 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-related 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 hours Waitlist control

Study	Setting/Delivery Mode Intervention Target	Type of Provider Specialized Training	Intervention Skills	Intervention Techniques Goal-setting	Frequency/ Duration of Contact Comparator
Ridsdale, 2018 ⁵⁷	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 of how to self-monitor and record symptoms Discussion of problem- solving for seizure risk factors Discussion for gaining self-efficacy of seizure control Discussion of stress management Discussion of safety, including preventing injuries 	 Explicit education and didactic discussions Multicomponent intervention with CBT-related 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 hours Waitlist control

Study	Setting/Delivery Mode Intervention Target	Type of Provider Specialized Training	Intervention Skills	Intervention Techniques Goal-setting	Frequency/ Duration of Contact Comparator
Sajatovic 2018 ⁵⁸	 Group-based intervention with in-person, 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 one nurse educator and one 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 side-effects management 	 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 weeks of group sessions, where the first in- person session was 60-90 minutes, followed by 6 phone calls over 12 weeks of 10-15 minutes each Waitlist control
Psychosocial Th	erapy Self-management	Interventions			
Caller, 2016 ⁴⁶ Arm 1=PST	 In-person group orientation Telephonic individual sessions, with memory coach^a 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 minute sessions Active comparator and waitlist control
Caller, 2016 ⁴⁶	In-person group	Epilepsy specialized	Explicit knowledge	Explicit education	· Eight 45-60
Arm 2=PST plus	orientation	nurse (RN or ARNP)	 Problem-solving therapy for 	 Problem-solving therapy 	minute sessions

Study	Setting/Delivery Mode Intervention Target	Type of Provider Specialized Training	Intervention Skills	Intervention Techniques Goal-setting	Frequency/ Duration of Contact Comparator
	 Telephonic individual sessions, with memory coach^a Asynchronous training on commercial gaming device^a Written educational materials Patient targeted 	No training required	organizational skills, seizure management, and social skills • Cognitive training with gaming console	 Cognitive training via gaming console Collaborative goal- setting 	 8 weeks of 20- 40 minutes of training on gaming console 5 times/week (40 sessions) Active comparator and waitlist control
Gandy, 2014 ⁴⁹	 In-person introductory sessions Individual in- person sessions^a Patient targeted 	 Predoctoral clinical psychology interns One-day 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 hour introductory session 8 weeks for 60 minutes each Waitlist control
Haut, 2018 ⁵⁰	 In-person training session and refresher session Smartphone- assisted asynchronous 2-3 times daily communication 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-hour training sessions 12 weeks of twice daily PMR for a total of 20 minutes/day 3 times/day e- diary reporting

Study	Study Setting/Delivery Mode Intervention Target		Intervention Skills	Intervention Techniques Goal-setting	Frequency/ Duration of Contact Comparator
					 Additional e- diary reporting based on seizure events Active focused- attention
Leenen, 2018 ⁵²	 In-person group sessions led by 2 nurse- practitioners^a Smartphone- assisted tracking via Eppy app MEMS Caps Patient targeted but family invited to attend 	Nurse practitioners 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 Proactive coping with stressors training Medication management and monitoring Collaborative goal- setting 	 5 weekly 2-hour sessions and one 2-hour booster Eppy app tracking, time not reported Treatment as usual
McLaughlin, 2011 ⁵⁴ Arm 1=CBT	 In-person group sessions led by a psychologist^a 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 utilizing social supports 	 Explicit education and didactic discussions Multicomponent group CBT Symptom/seizure tracking Medication management and monitoring Goal-setting not presented 	Six 2-hour weekly sessions Active relaxation

Study	Setting/Delivery Mode Intervention Target	Type of Provider Specialized Training	Intervention Skills	Intervention Techniques Goal-setting	Frequency/ Duration of Contact Comparator
McLaughlin, 2011 ⁵⁴ Arm 2=Relaxation	 In-person group sessions, led by a psychologist^a Audiotapes of relaxation exercises Daily seizure diary Patient targeted 	Psychologist No training specified	 Medication management Explicit knowledge Symptom/seizure tracking Relaxation training 	 Explicit education and didactic discussions Relaxation training (reported as not PMR but appears to be PMR) Symptom/seizure tracking Goal-setting not presented 	 Six 1-hour weekly sessions Audiotapes with no time specified Active relaxation
Puskarich, 1992 ⁵⁵	 In-person sessions (unclear if group or individual)^a Assigned at-home relaxation practice Patient targeted 	Not reported	 Implicit knowledge Relaxation training via PMR 	PMR Prescribed goal-setting	 6 sessions (first=60 minutes, second and third=50 minutes, fourth=40 minutes, fifth=20 minutes, sixth=15 minutes) At-home practice 2 times/day for 20 minutes each for 3 weeks Inactive control: quiet sitting



Study	Setting/Delivery Mode Intervention Target	Type of Provider Specialized Training	Intervention Skills	Intervention Techniques Goal-setting	Frequency/ Duration of Contact Comparator
Tan, 1986 ⁵⁶	 In-person group sessions^a 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-hour sessions Active supportive counseling and waitlist control

^a Primary target of the intervention.

Abbreviations: ARNP=advanced registered nurse practitioner; CBT=cognitive behavioral therapy; MEM=Medication Event Monitoring System; MOSES=Modular Service Package Epilepsy; NP=nurse practitioner; PMR=progressive muscle relaxation; PST=problem-solving therapy; SMILE=Stress Management Intervention for Living with Epilepsy; RN=registered nurse

NONRANDOMIZED TRIALS

Study	Setting/Delivery Mode Intervention Target	Type of Provider Specialized Training	Intervention Skills	Intervention Techniques Goal-setting	Frequency/ Duration of Contact Comparator
Educational S	Self-management Intervent	ions			
Gunter, 2004 ⁶⁰	 Education workbook^a In-person educational class, led by neurology nurse practitioner 	Neurology nurse practitioner	 Explicit knowledge Symptom/seizure tracking 	 Explicit education and didactic discussions Symptom/seizure tracking 	Optional monthly 1-hour group education; maximum study duration 3 years and 5 months

Study	Setting/Delivery Mode Intervention Target	Type of Provider Specialized Training	Intervention Skills	Intervention Techniques Goal-setting	Frequency/ Duration of Contact Comparator
	 Seizure diary Patient ID card with condition information Resource list from Epilepsy Foundation of America 	No training specified		Goal-setting not presented	Inactive treatment as usual at 3 nonrandomly selected control sites
	Patient targeted				
Psychosocial	I Therapy Self-managemen	t Interventions	;		
Gillham,1990 ⁵⁹ Arm 1=Self- control of seizure treatment only	In-person individual sessions ^a 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-hour session, followed by two 1-hour sessions for self-control of seizure treatment
Gillham,1990 ⁵⁹ Arms 2 and 3= Psychologica I treatment and self- control treatment	In-person individual sessions ^a Patient targeted; relatives involved in identifying psychiatric/social issues, but not clear that they were targeted for treatment	Not reported	 Explicit knowledge Stress management for various comorbid psychological problems (<i>eg</i>, 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-hour sessions for psychological problems Followed by initial 2-hour session followed by two 1-hour sessions for self- control of seizure treatment Order of treatment targets was balanced across 2 different treatment arms

^a Primary target of the intervention. Abbreviation: CBT=cognitive behavioral therapy

APPENDIX D. STUDY CHARACTERISTICS TABLE

For full study citations in this appendix, please refer to the report's main reference list.

Study Country # Enrolled # Arms	Eligibility	Study Acronym Intervention Comparator	Mean Age % Female % Race Marital Status Medication Adherence	Occupational Status Epilepsy Type Time Since Diagnosis Seizure Frequency	Outcomes Reported Primary Outcome Timing	Risk of Bias
Caller, 2016 ⁴⁶ USA 66 3	Inclusion: Patients age 18-65 with epilepsy (controlled or uncontrolled) and with subjective memory complaints Exclusion: Severe mental impairment or IQ <70, visual impairment that precluded reading or writing, no reliable phone access	No acronym Multidimensional psychoeducational and problem-solving intervention for cognitive difficulties through in-person group orientation and telephonic individual sessions with a trained memory coach. One of 3 arms delivered PST and working memory training on a gaming device Comparators: PST+ cognitive training vs PST only vs treatment as usual	45.8 (SD 9.9) 70% female Race: NR Marital status: NR	38% employed Generalized: 9 Time since diagnosis: NR 59% with seizure in the last month	Depressive symptoms QOL: QOLIE-31 Primary outcome: QOLIE-31 Timing: 8 weeks	Objective: High Patient- reported: High
Dilorio, 2011 ⁴⁷ USA 194 2	Inclusion: Adult patients with epilepsy; have taken AEDs for at least 3 months; can read and speak English; have internet access with no prior experience with WebEase	WebEase (Epilepsy Awareness, Support, and Education) study Web program tailored to patient's stage of change; each module patients asked to assess current status, reflect on current behaviors, decide if change is needed,	40.9 (SD 13.27) 74% female 84.3% white 48% married	50% employed Focal: 60 Generalized: 76 Unknown seizure: 6 Time since diagnosis: NR	Distress symptoms QOL: QOLIE-10 Disease knowledge Medication adherence: MAS Self-efficacy: ESES Self-management: ESMS	Objective: NA Patient- reported: High

Study Country # Enrolled # Arms	Eligibility	Study Acronym Intervention Comparator	Mean Age % Female % Race Marital Status Medication Adherence	Occupational Status Epilepsy Type Time Since Diagnosis Seizure Frequency	Outcomes Reported Primary Outcome Timing	Risk of Bias
		and make a goal/action plan to change Comparator: waitlist control		Mean seizure frequency: 10.0 in past 30 days (SD 29.42)	Primary outcome: NR Timing: Baseline, 6 weeks,12 weeks	
Fraser, 2015 ⁴⁸ USA 92 2	Inclusion: Age ≥18, with epilepsy for ≥6 months and MOCA >21; fluent in English Exclusion: Active serious mental illness; IQ <70 or known cognitive impairment (MOCA ≤21)	PACES (Program for Active Consumer Engagement in Self-management) 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	45.2 (SD 12.5) 55% female Race: 81% white 36% married	41% employed Focal: 58 Generalized: 44 Unknown seizure: 4 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 weeks, 6 months	Objective: NA Patient- reported: Unclear
Gandy, 2014 ⁴⁹ Australia 59 2	Inclusion: Adults (18- 65) with formal diagnosis of epilepsy confirmed by treating neurologist; at least low average intelligence	CBT (Cognitive Behavior Therapy to Improve Mood in People with Epilepsy) Included CBT and self- management of epilepsy: psychoeducation, managing triggers, enhancing problem	39.3 (SD 12.57) 64% female Race: NR 60% married, cohabiting	64% employed Focal: 35 Generalized: 10 Mean time since diagnosis: 13.3 years (SD 10.95)	Anxiety symptoms Depressive symptoms QOL: QOLIE-31	Objective: NA Patient- reported: High

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Study Country # Enrolled # Arms	Eligibility	Study Acronym Intervention Comparator	Mean Age % Female % Race Marital Status Medication Adherence	Occupational Status Epilepsy Type Time Since Diagnosis Seizure Frequency	Outcomes Reported Primary Outcome Timing	Risk of Bias
	Exclusion: Psychotic disorder; acutely suicidal; severe personality disorder; about to undergo epilepsy surgery	solving, managing medication adherence; delivered by trained psychology doctoral- level interns Comparator: waitlist	40% divorced, widowed, single	Seizure frequency: NR	Primary outcome: Depressive symptoms Timing: Pretreatment, 2 months; post- treatment, 3 months	
Gillham,1990 ⁵⁹ Europe 59 3	Inclusion: Clinical diagnosis of epilepsy; rated by self and clinician as inadequately controlled; averaged ≥2 seizures per week in the previous 2 months with no trend toward improvement	No acronym 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	31.7 (SD 12.1) 58% female Race: NR 41% married	Employment: NR Focal: 26 Generalized: 29 Unknown seizure: 4 Mean tine since diagnosis: 17.9 years (SD 11.7) Seizure frequency: NR	Anxiety symptoms Depressive symptoms Seizure rate Primary outcome: Seizure rate Timing: Baseline, 42 weeks	Objective: NA Patient- reported: High

Study Country # Enrolled # Arms	Eligibility	Study Acronym Intervention Comparator	Mean Age % Female % Race Marital Status Medication Adherence	Occupational Status Epilepsy Type Time Since Diagnosis Seizure Frequency	Outcomes Reported Primary Outcome Timing	Risk of Bias
Gunter, 2004 ⁶⁰ USA 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 individuals identified as not having epilepsy)	Seizure Disorder Episodes of Care (no acronym) The intervention consisted of both physician resources and direct-to-patient resources; patient resources included an education workbook, a monthly hour-long seizure education class led by a neurology nurse practitioner, and a seizure diary Comparator: treatment as usual	54 (SD NR) % Female NR Race: 68.4% White Marital status: NR	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: Pre- intervention and 12 months post- implementation	Objective: NA Patient- reported: High
Haut, 2018 ⁵⁰ USA 67 2	Inclusion: Age ≥18, medication resistant (≥4 seizures during 56- day baseline period), stable AED regimen; awareness of triggers, premonitory features, and/or ability to self- predict seizures, focal epilepsy, able to maintain e-diary Exclusion: suicide attempt within 2 years or suicidal ideation, status epilepticus w/in 6 months; stress reduction intervention	No acronym Intervention was 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 weeks later Comparator: Active focused- attention	37.2 (SD 24) 62.5% female Race: NR Marital status: NR	Employment: NR Focal: 64 Mean time since diagnosis: 26 years (SD 13.7) Mean seizure frequency: 11.42/month (SD 15.83)	Anxiety symptoms Depressive symptoms Distress symptoms Seizure frequency Primary outcome: Seizure frequency Timing: daily for 12 weeks	Objective: NA Patient- reported: Low

Study Country # Enrolled # Arms	Eligibility	Study Acronym Intervention Comparator	Mean Age % Female % Race Marital Status Medication Adherence	Occupational Status Epilepsy Type Time Since Diagnosis Seizure Frequency	Outcomes Reported Primary Outcome Timing	Risk of Bias
	w/in 3 months or failed prior stress reduction					
Helgeson,1990 ⁵¹ USA 100 2	Inclusion: Epilepsy diagnosis and receiving AEDs Exclusion: Mentally retarded, demented, or psychotic patients	Sepulveda Epilepsy Education program (SEE) 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	37.3 (SD 11.85) 74% Female Race: NR Marital status: NR Med adherence: NR	Employment: NR Focal: 11 Generalized: 12 Mean time since diagnosis: 16.5 years (SD 10.95) Mean seizure frequency: 2.3/month (SD 4.35)	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 months	Objective: High Patient- reported: High
Leenen, 2018 ⁵² Europe 103 2	Inclusion: Adult patients with epilepsy using AED; understood Dutch; could participate in sessions/e-health devices Exclusion: Unwilling or unable to participate in group sessions or felt to be unable to comprehend the topics discussed in sessions	ZMILE Group sessions led by nurse practitioners aimed at improving knowledge, recognition, self-monitoring, and proactive coping Comparator: treatment as usual	41.7 (SD 14.7) 51% female Race: NR 51% married	34.3% employed Epilepsy type: NR Mean time since diagnosis: 20.1 years (SD 15.01) Mean seizure frequency: 5.1/4 weeks (SD 11.15)	Anxiety symptoms Depressive symptoms Seizure rate/frequency Seizure severity QOL: QOLIE-31 Medication toxicity Medication adherence: MARS Self-efficacy: ESES	Objective: NA Patient- reported: Low

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Study Country # Enrolled # Arms	Eligibility	Study Acronym Intervention Comparator	Mean Age % Female % Race Marital Status Medication Adherence	Occupational Status Epilepsy Type Time Since Diagnosis Seizure Frequency	Outcomes Reported Primary Outcome Timing	Risk of Bias
					Primary outcome: ESES Timing: Baseline, 3 months, 6 months	
May, 2002 ⁵³ Europe 383 2	Inclusion: Patients with epilepsy age ≥16 who agreed to participate Exclusion: Mental retardation, acute psychiatric illness; non- epileptic seizures only	MOSES (Modular Service Package Epilepsy) Intervention involved discussion of factors: education about epilepsy; ways to emotionally cope with epilepsy, monitor symptoms and seizures, plan for or actively cope with pre-seizure symptoms/auras, and cooperating with clinicians and taking medications as prescribed Comparator: waitlist	38.0 (SD 13.59) 57% female Race: NR Marital status: NR	41% employed Focal: 152 Generalized: 43 Unknown seizure: 44 Median time since diagnosis: Arm 1: 13.5 years (IQR 4.7 to 26.2) Arm 2: 18.2 years (IQR 8.5 to 29.6) 76% with at least 1 seizure in the past 6 months	Depressive symptoms Seizure rate/frequency Social functioning: Restrictions in daily living QOL: SF36 Disease knowledge Self-management: Coping with Epilepsy Primary outcome: Restrictions in daily living, SF36, disease knowledge, Coping with Epilepsy Timing: Baseline, 6 months post-course completion	Objective: NA Patient- reported: High
McLaughlin, 2011 ⁵⁴ Australia 37 2	Inclusion: English- speaking adults, age ≥60 with confirmed diagnosis of epilepsy, who were able to attend weekly group sessions; must have	No acronym A manualized, in-person, group CBT intervention delivered by a psychologist; self-management elements include psychoeducation,	67.5 (SD 7.37) 51% female Race: NR Marital status: NR	Employment: NR Focal: 20 Generalized: 17	Depressive symptoms Seizure rate/frequency Social functioning: Washington	Objective: NA Patient- reported: Unclear



Study Country # Enrolled # Arms	Eligibility	Study Acronym Intervention Comparator	Mean Age % Female % Race Marital Status Medication Adherence	Occupational Status Epilepsy Type Time Since Diagnosis Seizure Frequency	Outcomes Reported Primary Outcome Timing	Risk of Bias
	MMSE ≥24, and able to provide information on physical and medical status	seizure diaries, CBT to reduce triggers, physical and emotional wellness (including medication management), seizure management Comparator: active relaxation		Mean time since diagnosis: 27.2 years (SD 27.22) Seizure frequency: NR	Psychosocial Seizure Inventory Primary Outcome: NR Timing: 6 weeks, 3 months	
Puskarich, 1992 ⁵⁵ USA 53 2	Inclusion: Epilepsy diagnosis, 6 seizures during a run-in 8 week period with awareness of every seizure by self or witness, normal intellectual function, English-speaking	No acronym Progressive muscle relaxation training; Subjects were encouraged to practice the relaxation techniques at home twice a day for 20 min Comparator: quiet sitting	39.4 (SD NR) 67% female Race: 62% white Marital status: NR	Employment: NR Focal: 21 Generalized: 3 Mean time since diagnosis 22 years (SD NR) Seizure frequency: NR	Seizure rate Primary outcome: Seizure rate Timing: 8 weeks	Objective: NA Patient- reported: High

Study Country # Enrolled # Arms	Eligibility	Study Acronym Intervention Comparator	Mean Age % Female % Race Marital Status Medication Adherence	Occupational Status Epilepsy Type Time Since Diagnosis Seizure Frequency	Outcomes Reported Primary Outcome Timing	Risk of Bias
Ridsdale, 2018 ⁵⁷ Europe 404 2	Inclusion: Age ≥16 with epilepsy ≥1 year, diagnosed by specialist, on AED, ≥2 seizures in past year, understand English; able to attend 2-day course Exclusion: Psychogenic seizures; substance misuse; serious psych illness; terminal illness	SMILE-UK (Self-management education for adults with poorly controlled epilepsy) Intervention based on MOSES. 9 module group education; focused on patients with epilepsy, caregivers also invited Comparator: treatment as usual	41.7 (SD 14.1) 54.2% female Race: 75.2% White 38.1% married	41.8% employed Epilepsy type: NR Median time since diagnosis: 18 (IQR 8 to 32) Median seizure frequency: 34/last 12 months (IQR 18 to 63)	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 Timing: Baseline, 6 months, 12 months	Objective: NA Patient- reported: Low
Sajatovic, 2018 ⁵⁸ USA 120 2	Inclusion: Self-reported epilepsy, age ≥18, ≥1 negative health event (seizure, accident or traumatic injury, self- harm attempt, ED visit or hospitalization) in past 6 months Exclusion: Immediate risk of self-harm; dementia; pregnancy; unable to read/understand English	SMART (Self-management for people with epilepsy) Group-based, in-person, 60- to 90-minute session delivered collaboratively by a nurse educator-peer educator dyad. Then, 7 group format sessions delivered ~weekly via the internet on computer tablets using posters/graphics and emphasizing interactive discussion. Following the group sessions, 6 telephone maintenance sessions	41.3 (SD 11.8) 68.1% female Race: 30.1% White 31.7% married	25.8% employed Focal: 4 Generalized: 85 Mean time since diagnosis: 20.6 (SD 15.2) Seizure frequency: 2.2/30 days (SD 4.9)	Depressive symptoms Seizure rate/frequency Seizure severity QOL: QOLIE-10 Negative health events Self-efficacy: ESES Self-management: ESMS ED visit for epilepsy Hospitalization f(any cause)	Objective: Unclear Patient- reported: Unclear

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Study Country # Enrolled # Arms	Eligibility	Study Acronym Intervention Comparator	Mean Age % Female % Race Marital Status Medication Adherence	Occupational Status Epilepsy Type Time Since Diagnosis Seizure Frequency	Outcomes Reported Primary Outcome Timing	Risk of Bias
		(approximately every 2 weeks) with the peer educator and the nurse educator alternating calls.			Primary outcome: change in total negative health events	
		Comparator: Waitlist control group, allowed to continue treatment as usual with providers, and received intervention after 6-month follow-up with treatment group.			Timing: 24 weeks	
Tan, 1986 ⁵⁶ Canada 30 3	Inclusion: Adult epilepsy patients with significant psychosocial problems and inadequate seizure control (as judged by neurologist) Exclusion: Mentally retarded; psychotic	No acronym 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	33.4 (SD 11.1) 63% female Race: NR Marital status: NR	Employment: NR Focal: 22 Generalized: 5 Mean time since diagnosis: 15.5 (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: pre- intervention, post-	Objective: NA Patient- reported: High

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Study Country # Enrolled # Arms	Eligibility	Study Acronym Intervention Comparator	Mean Age % Female % Race Marital Status Medication Adherence	Occupational Status Epilepsy Type Time Since Diagnosis Seizure Frequency	Outcomes Reported Primary Outcome Timing	Risk of Bias
					intervention, 4 months	

Abbreviations: AED=antiepileptic drug; CBT=cognitive behavioral therapy; ED=emergency department; ESES= Epilepsy Self-Efficacy Scale; ESMS=Epilepsy Self-Management Scale; IQR=interquartile range; MMSE=Mini-Mental State Examination; MOCA=Montreal Cognitive Assessment; MOSES=Modular Service Package Epilepsy; NA=not applicable; NR=not reported; SD=standard deviation

APPENDIX E. EXCLUDED STUDIES

Study	Not full publication	Not eligible country	Not population of interest	Not eligible setting	Not eligible intervention	Not eligible design	Not eligible outcome
Aliasgharpour, 2013 ¹		Х					
Caller, 2016 ²	Х						
Cervenka, 2012 ³					Х		
Chappell, 1999 ⁴					Х		
Clark, 2001 ⁵			Х				
Cole, 2015 ⁶					Х		
Collard, 2017 ⁷						Х	
Crooks, 2017 ⁸			Х				
Davis, 2004 ⁹				Х			
De Barros, 2018 ¹⁰			Х				
Dilorio, 2011 ¹¹	Х						
Dilorio, 2009 ¹²						Х	
Dilorio, 2009 ¹³						Х	
Dilorio, 1992 ¹⁴					Х		
Elsas, 2011 ¹⁵						Х	
Endermann, 2015 ¹⁶			Х				
Engelberts, 2002 ¹⁷					Х		
Groenewegen, 2014 ¹⁸				Х			
Helde, 2003 ¹⁹					Х		
Helde, 2005 ²⁰					Х		
Helmstaedter, 2008 ²¹					Х		
Hixson, 2015 ²²						Х	
Hixson, 2015 ²³				Х			
Kobau, 2003 ²⁴				Х			
Kotchoubey, 2001 ²⁵						Х	
Krakow, 1999 ²⁶				Х			
Kralj-Hans, 2014 ²⁷					Х		
Kumar, 2018 ²⁸					Х		



Study	Not full publication	Not eligible country	Not population of interest	Not eligible setting	Not eligible intervention	Not eligible design	Not eligible outcome
Lai, 2018 ²⁹		Х					
Leenen, 2014 ³⁰				Х			
Losada-Camacho, 2014 ³¹		Х					
Lua, 2013 ³²		Х					
Lundgren, 2008 ³³		Х					
Lundgren, 2006 ³⁴		Х					
Martinovic, 2001 ³⁵		Х					
McAuley, 2001 ³⁶					Х		
Mejdahl, 2017 ³⁷					Х		
Minshall, 2008 ³⁸			Х				
Mody, 2016 ³⁹					Х		
Myers, 2017 ⁴⁰				Х			
Newman, 2016 ⁴¹						Х	
Noble, 2014 ⁴²						Х	
Ogata, 2000 ⁴³					Х		
Pakpour, 201544		Х					
Peterson, 1984 ⁴⁵					Х		
Peterson, 1982 ⁴⁶					Х		
Pfeifer, 200547					Х		
Pramuka, 2007 ⁴⁸						Х	
Privitera, 201449					Х		
Radford, 2011 ⁵⁰					Х		
Rajesh, 2006 ⁵¹		Х					
Ridsdale, 2013 ⁵²						Х	
Ridsdale, 2002 ⁵³			Х				
Ridsdale, 2000 ⁵⁴					Х		
Ridsdale, 1999 ⁵⁵					Х		
Ridsdale, 1996 ⁵⁶				Х			
Rockstroh, 199357					Х		
Roth, 1994 ⁵⁸					Х		

Study	Not full publication	Not eligible country	Not population of interest	Not eligible setting	Not eligible intervention	Not eligible design	Not eligible outcome
Sahoo, 2016 ⁵⁹					Х		
Sajatovic, 201760						Х	
Saramma, 2014 ⁶¹		Х					
Sathyaprabha, 200862		Х					
Sawangchareon, 201363		Х					
Schougaard, 2017 ⁶⁴						Х	
Schroder, 2014 ⁶⁵					Х		
Schröder, 2014 ⁶⁶					Х		
Shaw, 2010 ⁶⁷	Х						
Shaw, 2007 ⁶⁸						Х	
Shegog, 2017 ⁶⁹						Х	
Smith, 2017 ⁷⁰						Х	
Smithson, 2013 ⁷¹					Х		
Spector, 1999 ⁷²						Х	
Staniszewska, 201773					Х		
Strehl, 2014 ⁷⁴						Х	
Sung, 2017 ⁷⁵			Х				
Tang, 2015 ⁷⁶		Х					
Tatum, 2008 ⁷⁷					Х		
Thompson, 2010 ⁷⁸			Х				
Trostle, 1983 ⁷⁹					Х		
CDC Epilepsy Program ⁸⁰					Х		
Walker, 2010 ⁸¹			Х				
Walker, 2009 ⁸²						Х	
Wood, 2017 ⁸³						Х	
Yardi, 2001 ⁸⁴						Х	

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APPENDIX F. GLOSSARY

For full study citations in this appendix, please refer to the report's main reference list.

Term			finition				
Certainty of			of Recommendations Assessment,				
evidence (COE)	Development and	Development and Evaluation (GRADE) approach ³⁷ for 4 domains:					
	Domain	Rating	How Assessed				
	Risk of bias	Low	Assessed primarily through study				
		Unclear	design and aggregate study quality				
		High					
	Consistency	Consistent	Assessed primarily through whether				
		Inconsistent	effect sizes are generally on the				
		Unknown/NA	same side of "no effect," the overall				
			range of effect sizes, and statistical				
			measures of heterogeneity				
	Directness	Direct	Assessed by whether the evidence				
		Indirect	involves direct comparisons or				
			indirect comparisons through use of				
			surrogate outcomes or use of separate bodies of evidence				
	Precision	Precise	Based primarily on the size of the				
	1100131011	Imprecise	confidence intervals of effect				
		mprociso	estimates, the optimal information				
			size and considerations of whether				
			the confidence interval crossed the				
			clinical decision threshold for using a				
			therapy				
	Summary COE ratings for a body of evidence:						
	of the effect.		rue effect lies close to that of the estimate				
		ose to the estimate	e in the effect estimate. The true effect is of the effect, but there is a possibility that it				
			effect estimate. The true effect may be stimate of the effect.				
			in the effect estimate. The true effect is from the estimate of effect.				
	Insufficient— insufficient is		dent to rate. In these situations, a rating of				
Cognitive	Psychological trea	tment that addresse	es unhelpful ways of thinking and unhelpful				
behavioral therapy	behavior.						
(CBT)							
Hierarchical stress			ensitize individuals to anxiety-producing				
inoculation			d coping with increasing stress.				
Objective outcomes			ge degree of individual interpretation and				
(<i>ie</i> , non-patient-			oss patients in a study, by different health				
reported outcomes) Patient-reported	care providers, an		y the patient without interpretation of the				
outcomes			yone else and pertains to the patient's				
		by a onnoidh or an	yono oloo ana portaino to trie patiento				



Term	Definition					
	health, quality of life, or functional status associated with health care or treatment.					
Problem solving therapy (PST)	Psychological treatment that teaches management of negative effects of stressful life events. Goals of PST include identifying types of stressors that trigger emotion and better understanding and management of negative emotions.					
Progressive muscle relaxation (PMR)	A relaxation technique that involves tensing and relaxing muscle groups to reduce body tension.					
Risk of bias (ROB)	An assessment of study quality. We used the following guidance in this report.					
	(1) For KQ 1 and KQ 2, we used the Cochrane EPOC ROB tool, which is applicable to randomized and nonrandomized studies ²⁸ :					
	 Randomization and allocation concealment Comparability of groups at baseline Blinded outcomes assessment Completeness of follow-up and differential loss to follow-up Whether incomplete data were addressed appropriately Protection against contamination Selective outcomes reporting 					
	Summary ROB ratings for a study:					
	 Low ROB—Bias, if present, is unlikely to alter the results seriously Unclear ROB—Bias that raises some doubts about the results High ROB—Bias that may alter the results seriously 					
	(2) We used the Critical Appraisal Skills Programme (CASP) criteria to evaluate the ROB for qualitative study designs ³⁰ :					
	 Clear statement of aims Appropriate qualitative methodology Appropriate research design Appropriate recruitment Appropriate data collection Consideration of ethical issues Sufficiently rigorous data analysis Clear statement of findings Valuable of the research 					
	(3) We used the Mixed Methods Appraisal Tool (MMAT) 5 items specific to descriptive studies to evaluate the ROB for quantitative descriptive designs ³¹ :					
	 Relevant sampling strategy Representative sample Appropriate measures Risk of non-response bias Appropriate statistical analysis 					
	We also used the MMAT 5 items for mixed methods to evaluate the ROB for mixed-methods studies ³¹ :					
	 Adequate rationale for using a mixed-methods design Effective integration of the different components Adequate interpretation of the integration of qualitative and quantitative comments 					



₩ 4

Term	Definition
	 Adequately addressed inconsistencies between quantitative and qualitative results Adherence of the different components to the quality criteria of each method
	No summary ROB was possible for the CASP or MMAT.
Standardized mean difference (SMD)	The difference in outcomes between the intervention and comparator, divided by the pooled standard deviation.