



Cochrane
Library

Cochrane Database of Systematic Reviews

Service delivery, behavioural, and self-management interventions for adults with epilepsy (Protocol)

Huang Y, Fleeman N, Doherty AJ, Wilson N, Boland P, Clegg A, Shaw EJ, Nevitt SJ, Tudur Smith C, Hill RA, Marson AG

Huang Y, Fleeman N, Doherty AJ, Wilson N, Boland P, Clegg A, Shaw EJ, Nevitt SJ, Tudur Smith C, Hill RA, Marson AG. Service delivery, behavioural, and self-management interventions for adults with epilepsy (Protocol). *Cochrane Database of Systematic Reviews* 2023, Issue 3. Art. No.: CD015284. DOI: [10.1002/14651858.CD015284](https://doi.org/10.1002/14651858.CD015284).

www.cochranelibrary.com

Service delivery, behavioural, and self-management interventions for adults with epilepsy (Protocol)

Copyright © 2023 The Cochrane Collaboration. Published by John Wiley & Sons, Ltd.

WILEY

TABLE OF CONTENTS

| | |
|--------------------------------|----|
| ABSTRACT | 1 |
| BACKGROUND | 2 |
| OBJECTIVES | 3 |
| METHODS | 3 |
| ACKNOWLEDGEMENTS | 6 |
| REFERENCES | 7 |
| APPENDICES | 8 |
| CONTRIBUTIONS OF AUTHORS | 16 |
| DECLARATIONS OF INTEREST | 16 |
| SOURCES OF SUPPORT | 16 |
| NOTES | 17 |

[Intervention Protocol]

Service delivery, behavioural, and self-management interventions for adults with epilepsy

Yun Huang¹, Nigel Fleeman², Alison J Doherty³, Neil Wilson³, Paul Boland³, Andrew Clegg³, Elizabeth J Shaw⁴, Sarah J Nevitt⁵, Catrin Tudur Smith⁵, Ruairaidh A Hill², Anthony G Marson^{6,7,8}

¹University of Liverpool, Liverpool, UK. ²Liverpool Reviews and Implementation Group, University of Liverpool, Liverpool, UK.

³University of Central Lancashire, Preston, UK. ⁴National Institute for Health and Care Excellence (NICE), Manchester, UK. ⁵Department of Health Data Science, University of Liverpool, Liverpool, UK. ⁶Department of Pharmacology and Therapeutics, Institute of Systems, Molecular and Integrative Biology, University of Liverpool, Liverpool, UK. ⁷The Walton Centre NHS Foundation Trust, Liverpool, UK.

⁸Liverpool Health Partners, Liverpool, UK

Contact: Ruairaidh A Hill, ruairaidh.hill@liverpool.ac.uk.

Editorial group: Cochrane Epilepsy Group.

Publication status and date: New, published in Issue 3, 2023.

Citation: Huang Y, Fleeman N, Doherty AJ, Wilson N, Boland P, Clegg A, Shaw EJ, Nevitt SJ, Tudur Smith C, Hill RA, Marson AG. Service delivery, behavioural, and self-management interventions for adults with epilepsy (Protocol). *Cochrane Database of Systematic Reviews* 2023, Issue 3. Art. No.: CD015284. DOI: [10.1002/14651858.CD015284](https://doi.org/10.1002/14651858.CD015284).

Copyright © 2023 The Cochrane Collaboration. Published by John Wiley & Sons, Ltd.

ABSTRACT

Objectives

This is a protocol for a Cochrane Review (intervention). The objectives are as follows:

To evaluate the benefits and harms of different behavioural interventions, self-management education and models of service delivery in promoting seizure control and improving quality of life-related outcomes for adults with epilepsy compared to usual care or another behavioural intervention.

BACKGROUND

Description of the condition

Epilepsy is a common condition affecting the central nervous system, with an estimated incidence of around 50 per 100,000 people per year in high-income countries (Thijs 2019). It is defined by a predisposition to generate epileptic seizures, and by the neurobiological, cognitive, psychological and social consequences of this condition (Fisher 2014). Despite treatment with antiepileptic drugs, for 30% of people their epilepsy is drug-resistant (Kwan 2000). People with epilepsy have higher level of stress, anxiety and depression compared to the general population (Beyenburg 2005; Fiest 2013), and chronic stress can be linked to higher frequency of seizures (Maguire 2013). Therefore, there is a focus on developing adjunct therapies that target the cognitive and psychological aspects to improve seizure control for people with epilepsy. These include interventions described as being behaviour focused or centred on education to support people's self-management of their epilepsy.

How services are delivered impacts on the effectiveness, efficiency and equity of health systems and affects health outcomes for people with epilepsy. Models of service delivery, such as how services are organised or staff roles used to deliver the service, are also relevant to supporting people with epilepsy. However, there is uncertainty as to which models of service delivery may affect better outcomes for people with epilepsy.

Description of the intervention

Behavioural interventions can be broadly defined as any type of intervention designed to affect the action of an individual (Culter 2004). This review will focus on behavioural interventions designed to promote seizure control and improve quality of life in adults with epilepsy. Types of behavioural interventions include psychobehavioural interventions (such as cognitive behavioural therapy and mind–body approaches), progressive muscle relaxation, yoga, bio/neurofeedback and creative arts therapy (Haut 2019).

Self-management can be broadly defined as an intervention that aims to increase accurate, condition-related knowledge, build confidence and support the individual to choose behaviours that promote management of their condition and overall well-being (Ozuna 2018). Clark and colleagues has described self-management as daily actions a person undertakes to support and control their condition, reduce impact on their health and cope with psychosocial impacts of their condition (Clark 1991).

Inventions to develop and maintain self-management include educational components that aim to develop condition-related knowledge and promote a patient's engagement in and ownership of the management of their condition (self-efficacy) and shared decision-making about their condition (Clark 2010). Self-management interventions also aim to support medication concordance, which is a key element of epilepsy management, and other aspects of a person's health and well-being such as diet, sleep, stress and appropriate healthcare attendance (NHS RightCare 2020). Self-management may be developed through in-person educational programmes that range in duration or number of sessions, and self-guided use of digital technologies that present educational materials; and may offer inactive advice and feedback

(depending on user inputs) or a means for communities of peers to communicate about their management of their condition and offer support.

A service delivery model describes who provides the service and where it is delivered. A model of service delivery can encompass a whole system of service delivery, consisting of a range of services. It can also be considered in a narrower sense as a small part of the whole system when service delivery is distributed across a single department or unit (Jessup 2020). There are several ways that healthcare delivery may be modified, including changing the physical location (e.g. hospital to home), providing care in individual or group settings, changing which health professionals provide care or using technology to assist with the provision of care (e.g. telehealth).

A range of specialist or dedicated models of service delivery are employed in clinical practice for people with epilepsy. Services may include specialist epilepsy outpatient clinics, nurse-based liaison services between primary (general practitioner) and secondary/tertiary (hospital-based) care and specialist epilepsy multidisciplinary community teams (Culter 2004; Haut 2018; Haut 2019; Tang 2014). Services may also include input from social care or the voluntary sector and target specific groups, such as people with learning disabilities.

How the intervention might work

Behavioural interventions and self-management are theorised to work through a variety of overlapping mechanisms to promote seizure control and overall well-being (Haut 2018).

Psychobehavioural therapies focus on reducing stress and psychiatric comorbidity, while promoting self-efficacy including development of seizure interruption techniques and learning to stop the progression of seizure activity (Tang 2014). Progressive muscle relaxation focuses on stress-reduction (Haut 2018), while yoga may also induce relaxation and stress reduction (Panebianco 2017). Biofeedback is theorised to enhance behavioural self-regulation through operant conditioning, thereby facilitating the voluntary regulation of automatic bodily responses such as cortical electrical activity (Nagai 2011).

Self-management has a base in social cognitive theory, where cognitive (knowledge, understanding and thinking), emotional and behavioural (making decisions, actions) aspects relevant to a person's chronic condition(s) are considered (Ozuna 2018). Educational components of self-management seek to develop knowledge and understanding, and develop an interest and confidence in shared decision-making and adopting behaviours that promote a patient's health and well-being. Interventions may also develop social support, including peer support mechanisms.

Specialist or dedicated models of care may improve the quality of care; promote more systematic multidisciplinary follow-up of individuals; and enhance communication between professionals, patients and other services (Haut 2019). Delivering care in the context of integrated health and social care should better address the wider burden of epilepsy while offering improved psychosocial support (Bell 2015). Importantly, care should enable people with epilepsy to cope with all aspects of the disease including the other interventions considered in this review, and improve self-education and self-management skills (Haut 2019; Panebianco 2017).

Why it is important to do this review

Epilepsy care has been criticised for having limited impact by not fully addressing all the health and social needs of people experiencing it (Betts 1992; Chappell 1992; Elwyn 2003; Thapar 1996).

There is an increasing popularity in the use of a range of behavioural interventions for people with epilepsy. However, there are significant methodological challenges associated with study designs for behavioural interventions and their overall effectiveness in improving seizure control for adults with epilepsy remains uncertain. There remains a need for an up-to-date systematic review to assess the overall level and certainty of evidence for effectiveness of behavioural interventions through randomised controlled trials.

A range of self-management approaches have been studied in people with epilepsy. However, there are significant methodological challenges associated with study designs for self-management and although an existing review by Bradley 2016 concluded that some self-management interventions have evidence of benefit, the overall effectiveness in improving seizure control for adults with epilepsy remains uncertain.

Bradley 2016 also highlighted that there are significant methodological challenges associated with study designs for service delivery. The review identified studies of various models of service delivery including by specialist nurse services, alternative models of care delivery in outpatient clinics, implementing services via the use of risk profiles for adverse events and supplementing clinical guidelines for general practitioners with additional services.

Bradley 2016 concluded that while there was some of evidence of benefit from some behavioural interventions, self-management and models of service delivery, the overall effectiveness in improving seizure control for adults with epilepsy remains uncertain.

In order to improve the quality of care for adults with epilepsy, there remains a need for an up-to-date systematic review to assess the overall level and certainty of evidence for behavioural interventions, self-management education and models of service delivery through randomised controlled trials.

OBJECTIVES

To evaluate the benefits and harms of different behavioural interventions, self-management education and models of service delivery in promoting seizure control and improving quality of life-related outcomes for adults with epilepsy compared to usual care or another behavioural intervention.

METHODS

Criteria for considering studies for this review

Types of studies

We will include the following type of trials.

1. Randomised control trials (RCTs) or quasi-RCTs
2. Double-blinded, single-blinded or unblinded
3. Parallel, cross-over and cluster design

Types of participants

We will consider studies of behavioural intervention or self-management eligible for this review if they include anyone aged over 16 years with any clinical diagnosis of new or recurrent epilepsy. If the study is a mixture of adults and children, we will consider the study for inclusion if: 1. results are reported separately for adults, 2. at least 50% or greater subset of the population are adults (aged older than 16 years) or 3. if no data report on percent aged 16 or older, we will consider studies reporting mean age older than 16 years. In this latter scenario, we will consult with clinical experts to agree that the interventions are applicable to adults.

For service delivery, we will include models delivered specifically for adults. We will exclude models targeted for children. Models for a range of age groups will be carefully considered for inclusion based on 50% being participants older than 16 years or mean age older than 16 years. Models that do not specify a paediatric focus but do not provide information of the range of ages the service is delivered for will be carefully consider for inclusion, consulting clinical experts. If included, we will label studies as 'not specified' in this respect.

We will also consider studies that include epilepsy with other medical conditions if the results are reported separately for each condition.

Types of interventions

We will include any type of behavioural intervention or self-management used to promote seizure control and improve quality of life in adults with epilepsy.

The behavioural interventions for epilepsy can be broadly grouped, but not limited to the following.

1. Psychobehavioural interventions, such as motivational interviewing, psychoeducation interventions and cognitive behavioural therapy
2. Mind-body approaches such as mindfulness, yoga, meditation, exercise programmes, progressive muscle relaxation and neurofeedback
3. Creative arts therapy such as music and art therapy

The self-management interventions for epilepsy can be broadly grouped, but not limited to the following.

1. Educational programmes with provider-led self-management education components and aims to develop knowledge, understanding, decision-making skills, or a combination of these
2. Self-guided self-management materials and health condition tracking, including digital platforms such as Apps with automated interactivity and programmed user outputs
3. Social support from peers; in person or via digital media

We will aim to group behavioural interventions and, separately, self-management by likely mechanism(s) of action and compare different groups of behavioural interventions or self-management with usual care for adults with epilepsy. Where possible, we will compare one group of behavioural interventions with another group or comparing different behavioural interventions within the same group.

There will be no restriction on the mode, setting or duration of delivery of intervention.

We will include models of service delivery intending to improve the quality of care and outcomes for adults with epilepsy. To be eligible for inclusion, the focus of study will be on the efficiency of service delivery model. For example, the same type of intervention delivered by a specialist nurse versus non-specialist nurse or if the same elements of a service are compared in different settings, such as a clinical-based service versus an online service.

For studies where the service delivery model encompasses behavioural intervention or self-management, to be included in the review, a model of service must include information about at least one of the following.

1. Provider – the person(s) delivering the service, that is a comparison between a professional such as use of epilepsy specialist nurses versus the usual model of care.
2. Service model, such a named model of care or recognised service model versus usual model of care.
3. Specific contextual factors, that is comparing different settings for service delivery such as services delivered in a specialist centre, hospital, community urban or rural setting; remotely using information technologies such as secure video conferencing or at different times (timing) along the person's epilepsy pathway or frequency of care contacts.

We will list all treatment arms of each study in the 'Characteristics of included studies' table.

Types of outcome measures

Primary outcomes

1. **Seizure frequency**
 - a. Recorded seizure frequency in a defined period
 - b. Reduction in seizure frequency compared to baseline
 - c. Seizure remission of one year or longer
 - d. Seizure freedom (or remission) for other defined time period

We will present short-term (less than six months) and long-term (six months or longer) primary outcome measurements separately.

Secondary outcomes

1. **Seizure severity**
 - a. Validated measurements of seizure severity
2. **Participant report of health and quality of life using validated scales**
 - a. A validated scale for measuring of quality of life
 - b. Other aspects relating to quality of life can include measures of depression, anxiety, stress, self-efficacy, self-management, self-esteem, disability, stigma, sleep quality, cognitive ability, ability to cope with epilepsy and overall functioning
3. **Appropriateness and volume of medications, including evidence of drug toxicity.** These can include the number of medications prescribed per participant, changes to medications, prescription refill frequency, measurements of blood antiepileptic drug concentrations, participant and clinician reports of medication compliance and adherence, participant or clinicians reports of adverse drug reactions, drug adverse effects and participant's beliefs about medications.

4. **Participant-reported knowledge of information and advice received from professionals.** These can include assessment of participant knowledge about epilepsy (such as Epilepsy Knowledge Scale), their beliefs, awareness, attitudes towards epilepsy and misinformation regarding epilepsy. Advice received from professionals could be self-reported by participants.
5. **Measure of general health status.** These could be measured by self-completed questionnaires, on issues such as the number of attendances to emergency departments in a defined period, injury as result of epilepsy episode and long-term health problems
6. **Measure of social or psychological function.** These could include self-report of impact on social activities, employment status, number of days absent from school or work due to sick leave.

We will assess all outcome measures for reliability and validity, for example, their clinical relevance and whether validated tools were used for outcome measures.

The secondary outcomes (2. to 6.) are likely to be heterogeneous, with respect to different type of metrics and measurement tools used, how measurements are reported and who reported the measurements. Therefore, we anticipate that narrative synthesis will be most appropriate for these outcome measures. Where possible, we will consider meta-analysis for outcomes.

Search methods for identification of studies

Electronic searches

We will search the following databases.

1. Cochrane Register of Studies (CRS Web) using the search strategy shown in [Appendix 1](#). CRS Web includes randomised or quasi-randomised, controlled trials from the Specialised Registers of Cochrane Review Groups including Epilepsy, the Cochrane Central Register of Controlled Trials (CENTRAL), PubMed, Embase, ClinicalTrials.gov and the World Health Organization International Clinical Trials Registry Platform (ICTRP).
2. MEDLINE (Ovid, 1946 to current) using the search strategy shown in [Appendix 2](#).
3. CINAHL Plus (EBSCOhost, 1937 to current) using the search strategy shown in [Appendix 3](#).
4. PsycINFO (EBSCOhost, 1887 to current) using the search strategy shown in [Appendix 4](#)

There will be no language restriction in our searches. The search strategies will not specify any age range, to allow us to capture studies with mixed adult and children populations.

Searching other resources

We will check the reference lists of retrieved studies for additional reports of relevant studies.

Data collection and analysis

Selection of studies

We will merge and deduplicate the search results and use Rayyan to manage the results of our searches ([Ouzzani 2016](#); www.rayyan.ai/).

Multiple reports and papers related to a single study will be grouped under a single reference ID from the first publication of the study. We will screen papers in two stages.

1. At stage one, two review authors will independently screen all titles and abstracts of papers identified by the search of relevance. We will exclude papers that are clearly irrelevant at this stage.
2. At stage two, two review authors will independently screen the full-text papers and assess for eligibility of studies for inclusion.

We will resolve any discrepancies with discussion, if unable, we will involve a third review author. The selection process will be detailed in a PRISMA flow diagram, and we will list all records excluded at stage two in the 'Characteristics of excluded studies' table.

Data extraction and management

Two review authors will independently perform data extraction. Another review author will check data, and we will resolve any potential discrepancies via discussion. We will extract the following information from all studies, using a prepiloted data extraction form. The data extraction form will be initially piloted on a selection of included studies from the original Cochrane Review's 'Characteristics of included studies' table (Bradley 2016).

1. Methods
 - a. Study design
 - b. Date of study
 - c. Method of randomisation
 - d. Allocation concealment
 - e. Blinding
 - f. Duration of participation
2. Participants
 - a. Population characteristics
 - b. Setting
 - c. Method of recruitment
 - d. Total number recruited, randomised and analysed
 - e. Baseline seizure type, seizure frequency and disease duration
3. Interventions
 - a. Detail nature of intervention(s)
 - i. Type
 - ii. Duration
 - iii. Timing
 - iv. Delivery
 - v. Provider
 - vi. Was the delivery to individuals or groups?
 - b. Detailed nature of comparison(s)
4. Outcomes
 - a. Definitions, unit of measurements and person measuring
 - b. Time point measured
 - c. Missing data
5. Notes: any conflict of interest of trial authors

We will identify which studies have data available for numerical meta-analysis, data that need converting for meta-analysis and data that are suitable for a narrative synthesis. Data will be transferred to Review Manager Web (RevMan Web 2022).

Two review authors will extract data. We will resolve any discrepancies through discussion and, if necessary, with an additional review author. We will contact study authors if there is inadequate information within available reports.

We will synthesise the characteristics of all studies that will contribute to each comparison and present these in the 'Characteristics of included studies' table in our full review.

Assessment of risk of bias in included studies

As the review considers diverse interventions with complex pathways between delivery and outcomes and considerable heterogeneity in people and settings studied, interventions, outcomes and outcome assessment, these features will be responsible for underlying uncertainties across the review. Therefore, we will use the original RoB 1 tool to assessment of studies. We will refer to the *Cochrane Handbook for Systematic reviews of Interventions* for assessment of risk of bias in studies (Higgins 2011).

Two review authors will independently assess each study comparing their assessments, with any differences resolved through discussion or recourse to a third review author. The RoB 1 tool examines: random sequence allocation, allocation concealment, blinding of participants and personnel, blinding of outcome assessors, incomplete outcome data, selective outcome reporting and other biases. Bias for each of the parameters will be assessed ('low', 'high' or 'unclear') according to the *Cochrane Handbook for Systematic reviews of Interventions* (Higgins 2011).

We are interested in quantifying the effect of assignment to the interventions at baseline using intention-to-treat analyses. Risk of bias assessment will inform GRADE and the summary of findings table(s).

Measures of treatment effect

For outcome measures reported as continuous data, we will use mean differences with 95% confidence interval (CI) if studies use the same scales, or standardised mean differences with 95% CIs if studies use different scales. For dichotomous/binary data, we will use risk ratios with 95% CI. If this is not possible, we will present the measures of treatment effect or summary statistics narratively as reported in the published papers.

Unit of analysis issues

We will attempt to manage the following unit of analysis issues according to the *Cochrane Handbook for Systematic reviews of Interventions* (Higgins 2022).

1. Cluster and cross-over trials: we will use adjusted effect sizes as reported in included studies. If studies do not report adjusted effect sizes, we report these studies narratively.
2. Multiple arms: we will analyse separate comparisons. We will not attempt to pool treatment arms or split control groups. If studies include different 'doses' or 'intensities' of the same intervention versus a control, then we will attempt to pool intervention arms after consulting with topic experts as to the relevance of this approach to practice.
3. Multiple measurements: we will not attempt to pool multiple measurements over time in meta-analyses. We will present short-term and long-term outcome data separately.

Dealing with missing data

We will contact study authors directly to obtain missing relevant outcome data, and we will calculate missing data using other data from trial where possible as advised in the *Cochrane Handbook for Systematic Reviews of Interventions* (Higgins 2022).

Assessment of heterogeneity

We will assess clinical heterogeneity between studies by reviewing the differences across trials, these include population factors, interventions and study design between studies. We will evaluate statistical heterogeneity using the following I^2 statistic ranges (Higgins 2022):

1. 0% to 40%: might not be important;
2. 30% to 60%: may represent moderate heterogeneity;
3. 50% to 90%: may represent substantial heterogeneity;
4. 75% to 100%: considerable heterogeneity.

If there is considerable clinical heterogeneity in trials (i.e. I^2 greater than 75%), we will not run any meta-analyses.

Assessment of reporting biases

For all studies, we will check whether outcomes intended to be measured (reported in the methods section) were reported in the results section of papers. Where data were missing, we will attempt to contact study authors. If more than 10 studies are included in the review, we will assess funnel plot asymmetry according to the approach outlined in the *Cochrane Handbook for Systematic Reviews of Interventions* (Higgins 2022).

Data synthesis

We will present results of data extraction and quality assessment for each study in structured tables and as a narrative summary. If a meta-analysis is feasible for subsections of the outcome measures (see [Types of outcome measures](#)), we will use a random-effects model. There is a broad range of self-management interventions, and these studies are likely to use a variety of different outcome measures; therefore, the results are likely to follow a distribution across studies rather than a single true effect. Where meta-analysis is not feasible, we will present results for each outcome in a narrative synthesis. We will follow the guidance in Chapter 12 of *Cochrane Handbook for Systematic Reviews of Interventions* on synthesis without meta-analysis (McKenzie 2022).

Subgroup analysis and investigation of heterogeneity

We have not planned any subgroup analysis a priori. If we decide to combine any studies in a meta-analysis and found evidence of statistical heterogeneity, we will consider post-hoc subgroup analyses where appropriate and where the data allow.

We will note data reported by characteristics relevant to potential inequalities (such as gender, ethnicity or socioeconomic status) and discuss any evidence of differential effectiveness (Higgins 2022).

Sensitivity analysis

We have not planned any sensitivity analysis a priori. If we decide to combine any studies in a meta-analysis and find evidence of statistical heterogeneity, we will consider conducting of post-hoc sensitivity analyses where appropriate and where the data allows.

Summary of findings and assessment of the certainty of the evidence

For the summary of findings table(s), we will include the intervention and comparison, the main outcomes, details of scale, number of studies and participants with each outcome, relative and absolute effect (where reported) and GRADE consideration for each study. We will present a separate summary of findings table for each comparison if applicable. We will use the GRADE approach and consider overall risk of bias, consistency of effect, imprecision, indirectness and publication bias in GRADE consideration (Schünemann 2013; Schünemann 2022). Two review authors will independently make judgements, with any differences resolved through discussion or involving a third review author. We will justify all decisions to downgrade the certainty of the evidence using footnotes and make comments to aid reader's understanding of the review where necessary. We will use GRADEpro GDT to create summary of findings table(s) for the following outcomes (GRADEpro GDT).

1. Seizure frequency
2. Participant report of health and quality of life using validated scales

ACKNOWLEDGEMENTS

The following authors are part-funded by the National Institute of Health and Care Research (NIHR) Applied Research Collaboration North West Coast: AJD, AC and PB.

The views expressed are those of the review authors and not necessarily those of the NIHR or the Department of Health and Social Care.

The Cochrane Epilepsy Group supported the authors in the development of this protocol. The following people conducted the editorial process for this protocol.

- Managing Editor (provided editorial guidance to authors, edited the protocol, conducted editorial policy checks): Rachael Kelly
- Information Specialist (conducted electronic literature searches): Graham Chan
- Copy Editor (copy editing and production): Anne Lawson

REFERENCES

Additional references

Bell 2015

Bell GS, Liu RS. Provision of clinical services for people with epilepsy. epilepsysociety.org.uk/sites/default/files/2020-08/Chapter57BellLiu2015.pdf (accessed 21 November 2022).

Betts 1992

Betts T. Epilepsy services. What people need, what they want, what they get. *Acta Neurologica Scandinavica Supplementum* 1992;**140**:95-100. [PMID: 1441915]

Beyenburg 2005

Beyenburg S, Mitchell AJ, Schmidt D, Elger CE, Reuber M. Anxiety in patients with epilepsy: systematic review and suggestions for clinical management. *Epilepsy & Behavior* 2005;**7**(2):161-71. [PMID: 16054870]

Bradley 2016

Bradley PM, Lindsay B, Fleeman N. Care delivery and self management strategies for adults with epilepsy. *Cochrane Database of Systematic Reviews* 2016, Issue 2. Art. No: CD006244. [DOI: [10.1002/14651858.CD006244.pub3](https://doi.org/10.1002/14651858.CD006244.pub3)]

Chappell 1992

Chappell B. Epilepsy: patient views on their condition and treatment. *Seizure* 1992;**1**(2):103-9. [PMID: 1344324]

Clark 1991

Clark NM, Becker MH, Janz NK, Lorig K, Rakowski W, Anderson L. Self-management of chronic disease by older adults: a review and questions for research. *Journal of Aging and Health* 1991;**3**(1):3-27. [DOI: [10.1177/089826439100300101](https://doi.org/10.1177/089826439100300101)]

Clark 2010

Clark NM, Stoll S, Youatt EJ, Sweetman M, Derry R, Gorelick A. Fostering epilepsy self management: the perspectives of professionals. *Epilepsy & Behavior* 2010;**19**(3):255-63. [PMID: 21145491]

Culter 2004

Culter DM. Chapter 17: behavioural health interventions: what works and why? In: Anderson NB, Bulatao RA, Cohen B, editors(s). *Critical Perspectives on Racial and Ethnic Differences in Health in Late Life*. Washington (DC): National Academies Press, 2004:643-74. [ISBN: 0-309-53200-0] [PMID: 20669464] [URL: www.ncbi.nlm.nih.gov/books/NBK25527/]

Elwyn 2003

Elwyn G, Todd S, Hibbs R, Thapar A, Edwards P, Webb A, et al. A 'real puzzle': the views of patients with epilepsy about the organisation of care. *BMC Family Practice* 2003;**4**:4. [PMID: 12709265]

Fiest 2013

Fiest KM, Dykeman J, Patten SB, Wiebe S, Kaplan GG, Maxwell CJ, et al. Depression in epilepsy: a systematic review and meta-analysis. *Neurology* 2013;**80**(6):590-9. [PMID: 23175727]

Fisher 2014

Fisher RS, Acevedo C, Arzimanoglou A, Bogacz A, Cross JH, Elger CE, et al. ILAE official report: a practical clinical definition of epilepsy. *Epilepsia* 2014;**55**(4):475-82. [PMID: 24730690]

Glanville 2019

Glanville J, Dooley G, Wisniewski S, Foxlee R, Noel-Storr A. Development of a search filter to identify reports of controlled clinical trials within CINAHL Plus. *Health Information and Libraries Journal* 2019;**36**(1):73-90. [PMID: 30737884]

GRADEpro GDT [Computer program]

McMaster University (developed by Evidence Prime) GRADEpro GDT. Version accessed 21 November 2022. Hamilton (ON): McMaster University (developed by Evidence Prime). Available at gradepro.org.

Haut 2018

Haut SR, Lipton RB, Cornes S, Dwivedi AK, Wasson R, Cotton S, et al. Behavioral interventions as a treatment for epilepsy: a multicenter randomized controlled trial. *Neurology* 2018;**90**(11):e963-70. [PMID: 29444968]

Haut 2019

Haut SR, Gursky JM, Privitera M. Behavioral interventions in epilepsy. *Current Opinion in Neurology* 2019;**32**(2):227-36. [PMID: 30694921]

Higgins 2011

Higgins JP, Altman DG. Chapter 8. Assessing risk of bias in included studies. In: Higgins JP, Green S, editor(s). *Cochrane Handbook for Systematic Reviews of Interventions* Version 5.1.0 (updated March 2011). The Cochrane Collaboration, 2011. Available from training.cochrane.org/handbook/archive/v5.1/.

Higgins 2022

Higgins JP, Thomas J, Chandler J, Cumpston M, Li T, Page MJ, Welch VA, editor(s). *Cochrane Handbook for Systematic Reviews of Interventions* Version 6.3 (updated February 2022). Cochrane, 2022. Available from training.cochrane.org/handbook.

Jessup 2020

Jessup R, Putrik P, Buchbinder R, Nezon J, Rischin K, Cyril S, et al. Identifying alternative models of healthcare service delivery to inform health system improvement: scoping review of systematic reviews. *BMJ Open* 2020;**10**(3):e036112. [DOI: [10.1136/bmjopen-2019-036112](https://doi.org/10.1136/bmjopen-2019-036112)] [PMID: 32229525]

Kwan 2000

Kwan P, Brodie MJ. Early identification of refractory epilepsy. *New England Journal of Medicine* 2000;**342**(5):314-9. [PMID: 10660394]

Lefebvre 2022

Lefebvre C, Glanville J, Briscoe S, Featherstone R, Littlewood A, Marshall C, et al. Technical Supplement to Chapter 4: Searching for and selecting studies. In: Higgins JP, Thomas J, Chandler J, Cumpston MS, Li T, Page MJ, et al, editor(s). *Cochrane Handbook for Systematic Reviews of Interventions* Version

6.3 (updated February 2022). Cochrane, 2022. Available from training.cochrane.org/handbook.

Maguire 2013

Maguire J, Salpekar JA. Stress, seizures, and hypothalamic-pituitary-adrenal axis targets for the treatment of epilepsy. *Epilepsy & Behavior* 2013;**26**(3):352-62. [PMID: 23200771]

McKenzie 2022

McKenzie JE, Brennan SE. Chapter 12: Synthesizing and presenting findings using other methods. In: Higgins JP, Thomas J, Chandler J, Cumpston M, Li T, Page MJ, et al, editor(s). *Cochrane Handbook for Systematic Reviews of Interventions* Version 6.3 (updated February 2022). Cochrane, 2022. Available from training.cochrane.org/handbook.

Nagai 2011

Nagai Y. Biofeedback and epilepsy. *Current Neurology and Neuroscience Reports* 2011;**11**(4):443-50. [PMID: 21465147]

NHS RightCare 2020

NHS RightCare. Epilepsy toolkit. www.england.nhs.uk/rightcare/toolkits/epilepsy-toolkit/ (accessed 21 November 2022).

Ouzzani 2016

Ouzzani M, Hammady H, Fedorowicz Z, Elmagarmid A. Rayyan – a web and mobile app for systematic reviews. *Systematic Reviews* 2016;**5**(1):210. [PMID: 27919275]

Ozuna 2018

Ozuna J, Kelly P, Towne A, Hixson J. Self-management in epilepsy care: untapped opportunities. *Federal Practitioner* 2018;**35**(Suppl 3):S10-6. [PMID: 30766395]

Panebianco 2017

Panebianco M, Sridharan K, Ramaratnam S. Yoga for epilepsy. *Cochrane Database of Systematic Reviews* 2017, Issue 10. Art. No: CD001524. [DOI: [10.1002/14651858.CD001524.pub3](https://doi.org/10.1002/14651858.CD001524.pub3)]

RevMan Web 2022 [Computer program]

The Cochrane Collaboration Review Manager Web (RevMan Web). Version 4.12.0. The Cochrane Collaboration, 2022. Available at revman.cochrane.org.

Schünemann 2013

Schünemann H, Brožek J, Guyatt G, Oxman A, editor(s). Handbook for grading the quality of evidence and the strength of recommendations using the GRADE approach (updated October 2013). GRADE Working Group, 2013. Available from gdt.guidelinedevelopment.org/app/handbook/handbook.html.

Schünemann 2022

Schünemann HJ, Higgins JP, Vist GE, Glasziou P, Akl EA, Skoetz N, et al. Chapter 14: Completing 'Summary of findings' tables and grading the certainty of the evidence. In: Higgins JP, Thomas J, Chandler J, Cumpston M, Li T, Page MJ, et al, editor(s). *Cochrane Handbook for Systematic Reviews of Interventions* Version 6.3 (updated February 2022). Cochrane, 2022. Available from training.cochrane.org/handbook.

Tang 2014

Tang V, Michaelis R, Kwan P. Psychobehavioral therapy for epilepsy. *Epilepsy & Behavior* 2014;**32**:147-55. [PMID: 24418662]

Thapar 1996

Thapar AK. Care of patients with epilepsy in the community: will new initiatives address old problems? *British Journal of General Practice* 1996;**46**(402):37-42. [PMID: 8745851]

Thijs 2019

Thijs RD, Surges R, O'Brien TJ, Sander JW. Epilepsy in adults. *Lancet* 2019;**393**(10172):689-701. [PMID: 30686584]

APPENDICES

Appendix 1. Cochrane Register of Studies (CRS Web) search strategy

1. MESH DESCRIPTOR Epilepsy EXPLODE ALL AND CENTRAL:TARGET
2. epilep*:AB,KW,KY,MC,MH,TI AND CENTRAL:TARGET
3. #1 OR #2 AND CENTRAL:TARGET
4. MeSH DESCRIPTOR Program Evaluation Explode All AND CENTRAL:TARGET
5. MeSH DESCRIPTOR Delivery of Health Care Explode All AND CENTRAL:TARGET
6. MESH DESCRIPTOR Home Care Services EXPLODE ALL AND CENTRAL:TARGET
7. MeSH DESCRIPTOR Ambulatory Care Explode All AND CENTRAL:TARGET
8. MESH DESCRIPTOR Patient Care Team EXPLODE ALL AND CENTRAL:TARGET
9. MESH DESCRIPTOR patient outcome assessment EXPLODE ALL AND CENTRAL:TARGET
- 10.MESH DESCRIPTOR disease-free survival EXPLODE ALL AND CENTRAL:TARGET
- 11.MESH DESCRIPTOR progression-free survival EXPLODE ALL AND CENTRAL:TARGET
- 12.MESH DESCRIPTOR Process Assessment, Health Care EXPLODE ALL AND CENTRAL:TARGET
- 13.(program* NEAR2 evaluat*):AB,KW,KY,MC,MH,TI AND CENTRAL:TARGET
- 14.((service* or care or healthcare or intervention or treatment) NEAR3 (deliver* or package* or program*)):AB,KW,KY,MC,MH,TI AND CENTRAL:TARGET

- 15.((speciali* or dedicated or home) NEAR3 (nurs* or service* or care or center* or centre* or clinic*)):AB,KW,KY,MC,MH,TI AND CENTRAL:TARGET
- 16.#4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 AND CENTRAL:TARGET
- 17.#3 AND #16 AND CENTRAL:TARGET
- 18.(epilep* NEAR3 specialist*):AB,KW,KY,MC,MH,TI AND CENTRAL:TARGET
- 19.(epilep* NEAR2 nurs*):AB,KW,KY,MC,MH,TI AND CENTRAL:TARGET
- 20.#17 OR #18 OR #19 AND CENTRAL:TARGET
- 21.MESH DESCRIPTOR Self Care EXPLODE ALL AND CENTRAL:TARGET
- 22.MESH DESCRIPTOR Self-Management EXPLODE ALL AND CENTRAL:TARGET
- 23.(self NEAR3 (care or manag*)):AB,KW,KY,MC,MH,TI AND CENTRAL:TARGET
- 24.MESH DESCRIPTOR Health Education EXPLODE ALL AND CENTRAL:TARGET
- 25.MESH DESCRIPTOR Counseling EXPLODE ALL AND CENTRAL:TARGET
- 26.((health* or care) and (advise or advice or counsel*)):AB,KW,KY,MC,MH,TI AND CENTRAL:TARGET
- 27.MESH DESCRIPTOR Monitoring, Ambulatory EXPLODE ALL AND CENTRAL:TARGET
- 28.((ambulator* or health* or home) NEAR3 (monitor* or track*)):AB,KW,KY,MC,MH,TI AND CENTRAL:TARGET
- 29.MESH DESCRIPTOR Social Support EXPLODE ALL AND CENTRAL:TARGET
- 30.((family or social) NEAR3 support):AB,KW,KY,MC,MH,TI AND CENTRAL:TARGET
- 31.#21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30
- 32.#3 AND #31
- 33.MESH DESCRIPTOR Behavior Therapy EXPLODE ALL AND CENTRAL:TARGET
- 34.MESH DESCRIPTOR Conditioning, Psychological EXPLODE ALL AND CENTRAL:TARGET
- 35.((conditioning NEAR2 psychol*) or "classical conditioning" or "operant conditioning"):AB,KW,KY,MC,MH,TI AND CENTRAL:TARGET
- 36.MESH DESCRIPTOR Counseling EXPLODE ALL AND CENTRAL:TARGET
- 37.(counseling or counselling or crisis intervention):AB,KW,KY,MC,MH,TI AND CENTRAL:TARGET
- 38.MESH DESCRIPTOR Early Intervention, Educational EXPLODE ALL AND CENTRAL:TARGET
- 39.((Desensitisation OR Desensitization) NEAR2 psychol*):AB,KW,KY,MC,MH,TI AND CENTRAL:TARGET
- 40.("Early Intervention" OR exercise):AB,KW,KY,MC,MH,TI AND CENTRAL:TARGET
- 41.("Eye Movement" NEAR2 (Desensitisation OR Desensitization OR Reprocessing)):AB,KW,KY,MC,MH,TI AND CENTRAL:TARGET
- 42.MESH DESCRIPTOR Exercise Therapy EXPLODE ALL AND CENTRAL:TARGET
- 43.MESH DESCRIPTOR Mind-Body Therapies EXPLODE ALL AND CENTRAL:TARGET
- 44.MESH DESCRIPTOR Psychotherapy EXPLODE ALL AND CENTRAL:TARGET
- 45.MESH DESCRIPTOR Sensory Art Therapies EXPLODE ALL AND CENTRAL:TARGET
- 46.#33 OR #34 OR #35 OR #36 OR #37 OR #38 OR #39 OR #40 OR #41 OR #42 OR #43 OR #44 OR #45
- 47.((("Acceptance commitment" OR Art OR Arts OR Assertive or autosuggestion or Aversive or Behav*) NEAR2 (therap* or intervention*)):AB,KW,KY,MC,MH,TI AND CENTRAL:TARGET
- 48.((("Client cent*" OR Cognitive or Color OR Colour OR Compassion* or couples or dance or Directive or Family) NEAR2 (therap* or intervention*)):AB,KW,KY,MC,MH,TI AND CENTRAL:TARGET
- 49.((("Human Givens" or Humanistic or implosive or Interpersonal or milieu or nondirective or "non-directive") NEAR2 (therap* or intervention*)):AB,KW,KY,MC,MH,TI AND CENTRAL:TARGET
- 50.((("patient cent*" or "person cent*" or play or socioenvironmental or "socio-environmental" or suggestion or "therapeutic community") NEAR2 (therap* or intervention*)):AB,KW,KY,MC,MH,TI AND CENTRAL:TARGET
- 51.(relax* NEAR3 (therap* or intervention* or treat*)):AB,KW,KY,MC,MH,TI AND CENTRAL:TARGET
- 52.(aromatherap* or asanas or "autogenic train*" or bibliotherap* or (biofeedback NEAR2 psychol*) or "Compassionate Mind Train*" or "Emotional freedom tapping" or Flooding or "free association"):AB,KW,KY,MC,MH,TI AND CENTRAL:TARGET
- 53.(imagery or meditation or Mindfulness or "motivational interview*" or music* or mozart* or neurofeedback or pranayama or "progressive muscle relax*" or "Psychological Adaptation" or "psychological feedback" or "residential treatment*" or "Rewind technique*" or "Stress manag*" or yoga):AB,KW,KY,MC,MH,TI AND CENTRAL:TARGET
- 54.#47 OR #48 OR #49 OR #50 OR #51 OR #52 OR #53
- 55.#46 OR #54
- 56.#3 AND #55
- 57.#20 OR #32 OR #56

Appendix 2. MEDLINE search strategy

This strategy includes a modification of the Cochrane Highly Sensitive Search Strategy for identifying randomised trials ([Lefebvre 2022](#)).

Service delivery, behavioural, and self-management interventions for adults with epilepsy (Protocol)

Copyright © 2023 The Cochrane Collaboration. Published by John Wiley & Sons, Ltd.

1. exp Epilepsy/ or epilep\$.mp.
2. exp Program Evaluation/
3. exp "Delivery of Health Care"/ or exp Home Care Services/
4. exp Ambulatory Care/
5. exp Patient Care Team/
6. exp patient outcome assessment/ or exp disease-free survival/ or exp progression-free survival/
7. exp Process Assessment, Health Care/
8. (program\$ adj2 evaluat\$).mp.
9. ((service\$ or care or healthcare or intervention or treatment) adj3 (deliver\$ or package\$ or program\$)).mp.
10. ((speciali\$ or dedicated or home) adj3 (nurs\$ or service? or care or center? or centre? or clinic?)).mp.
11. or/2-10
12. 1 and 11
13. (epilep\$ adj4 (nurs\$ or specialist?)).mp.
14. 12 or 13
15. exp Self Care/
16. exp Self-Management/
17. (self adj3 (care or manag\$)).mp.
18. exp Health Education/ or exp Counseling/ or ((health\$ or care) and (advise or advice or counsel\$)).mp. or "health education".mp.
19. exp Monitoring, Ambulatory/ or ((ambulator\$ or health\$ or home) adj3 (monitor\$ or track\$)).mp.
20. exp Social Support/ or ((family or social) adj3 support).mp.
21. 15 or 16 or 17 or 18 or 19 or 20
22. 1 and 21
23. exp behavior therapy/
24. exp Conditioning, Psychological/ or (conditioning adj2 psychol\$).mp. or classical conditioning.mp. or operant conditioning.mp.
25. exp Counseling/ or counsel?ing.mp. or crisis intervention.mp.
26. (Desensiti?ation adj2 psychol\$).mp. or exp Early Intervention, Educational/ or Early Intervention.mp. or exp Exercise Therapy/ or exercise.mp.
27. (Eye Movement adj2 (Desensiti?ation or Reprocessing)).mp.
28. exp Mind-Body Therapies/
29. exp Psychotherapy/
30. exp Sensory Art Therapies/
31. ((Acceptance commitment or Art? or Assertive or autosuggestion or Aversive or Behav\$) adj2 (therap\$ or intervention\$)).mp.
32. ((Client cent\$ or Cognitive or Colo?r or Compassion\$ or couples or dance or Directive or Family) adj2 (therap\$ or intervention\$)).mp.
33. ((Human Givens or Humanistic or implosive or Interpersonal or milieu or non?directive or non-directive) adj2 (therap\$ or intervention \$)).mp.

34. ((patient cent\$ or person cent\$ or play or socio?environmental or socio-environmental or suggestion or therapeutic community) adj2 (therap\$ or intervention\$)).mp.
35. (relax\$ adj3 (therap\$ or intervention\$ or treat\$)).mp.
36. (aromatherap\$ or asanas or autogenic train\$ or bibliotherap\$ or (biofeedback adj2 psychol\$) or Compassionate Mind Train\$ or Emotional freedom tapping or Flooding or free association).mp.
37. (imagery or meditation or Mindfulness or motivational interview\$ or mozart\$ or music\$ or neurofeedback or pranayama or progressive muscle relax\$ or Psychological Adaptation or psychological feedback or residential treatment? or Rewind technique? or Stress manag\$ or yoga).mp.
38. or/23-37
39. 1 and 38
40. 14 or 22 or 39
41. exp controlled clinical trial/ or (randomi?ed or placebo or randomly).ab.
42. clinical trials as topic.sh.
43. trial.ti.
44. 41 or 42 or 43
45. exp animals/ not humans.sh.
46. 44 not 45
47. 40 and 46
48. remove duplicates from 47

Appendix 3. CINAHL Plus search strategies

This strategy includes the Cochrane CINAHL Plus search filter ([Glanville 2019](#)).

| | |
|-----|---|
| S64 | S40 AND S63 |
| S63 | S62 NOT S61 |
| S62 | S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50 OR S51 OR S52 OR S53 OR S54 OR S55 |
| S61 | S59 NOT S60 |
| S60 | MH human |
| S59 | S56 OR S57 OR S58 |
| S58 | TI animal model* |
| S57 | MH animal studies |
| S56 | MH animals+ |
| S55 | AB cluster W3 RCT |
| S54 | MH crossover design OR MH comparative studies |

(Continued)

| | |
|-----|---|
| S53 | AB control W5 group |
| S52 | PT randomized controlled trial |
| S51 | MH placebos |
| S50 | MH sample size AND AB (assigned OR allocated OR control) |
| S49 | TI trial |
| S48 | AB random* |
| S47 | TI randomised OR randomized |
| S46 | MH cluster sample |
| S45 | MH pretest-posttest design |
| S44 | MH random assignment |
| S43 | MH single-blind studies |
| S42 | MH double-blind studies |
| S41 | MH randomized controlled trials |
| S40 | S16 OR S26 OR S39 |
| S39 | S3 AND S38 |
| S38 | S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 |
| S37 | ("acceptance commitment" or art# or assertive or autosuggestion or aversive or behav* or (client W1 cent*) or cognitive or colour or compassion* or couples or dance or directive or family or "human givens" or humanistic or implosive or interpersonal or milieu or nondirective or (patient W1 cent*) or (person W1 cent*) or play or socioenvironmental or socio-environmental or suggestion) W2 (therap* or intervention*) |
| S36 | "psychological adaptation" OR aromatherap* OR asanas OR (autogenic W2 train*) OR autosuggest* OR bibliotherap* OR (biofeedback N2 psychol*) OR ("compassionate mind" W2 train*) OR (conditioning N2 psychol*) OR counselling OR "crisis intervention" OR (desensitization N2 psychol*) OR "early intervention" OR "emotional freedom tapping" OR exercise OR ("eye movement" W2 desensitization) OR ("eye movement" W2 reprocessing) OR "psychological feedback" OR flooding OR "free association" OR hypnosis OR imagery OR meditation OR mindfulness OR motivational interview* OR music* OR mozart* OR neurofeedback OR pranayama OR progressive muscle relax* OR (relax* W2 (therap* or intervention* or treat*)) OR "residential treatment" OR "rewind techniques" OR "stress management" OR "therapeutic community" OR yoga |
| S35 | (MH "Psychotherapy+") OR (MH "Mind Body Techniques+") |
| S34 | (MH "Therapeutic Exercise+") |
| S33 | (MH "Early Intervention+") |
| S32 | (MH "Counseling+") |
| S31 | (MH "Color Therapy") |

(Continued)

| | |
|-----|--|
| S30 | (MH "Conditioning (Psychology)+") |
| S29 | (MH "Behavioral (Iowa NIC)+") |
| S28 | (MH "Aromatherapy") |
| S27 | (MH "Adaptation, Psychological+") |
| S26 | S3 AND S25 |
| S25 | S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 |
| S24 | (family or social) N3 support |
| S23 | (MH "Support, Psychosocial+") |
| S22 | (MH "Support, Social+") |
| S21 | (ambulator* OR health OR home) N3 (monitor* OR track*) |
| S20 | (MH "Counseling+") |
| S19 | (MH "Health Education+") OR "health education" OR ((health* OR care) AND (advise OR advice OR counsel*)) |
| S18 | self N3 (care OR manag*) |
| S17 | (MH "Self Care+") |
| S16 | S14 OR S15 |
| S15 | epilep* N3 (nurs* OR specialist*) |
| S14 | S3 AND S13 |
| S13 | S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 |
| S12 | (speciali* OR dedicated OR home) N3 (nurs* OR service OR care OR center OR centre OR clinic) |
| S11 | (service* OR care OR healthcare OR intervention OR treatment) N3 (deliver* OR package* OR program*) |
| S10 | program* N2 evaluat* |
| S9 | (MH "Health Care Delivery+") OR (MH "Home Health Care+") |
| S8 | (MH "Outcomes (Health Care)") OR (MH "Nursing Outcomes") OR (MH "Outcome Assessment") |
| S7 | (MH "Disease Progression+") |
| S6 | (MH "Patient Care+") |
| S5 | (MM "Program Evaluation") |
| S4 | (MM "Ambulatory Care") |

(Continued)

| | |
|----|------------------|
| S3 | S1 OR S2 |
| S2 | epilep* |
| S1 | (MH "Epilepsy+") |

Appendix 4. PsycINFO search strategies

| | |
|-----|---|
| S36 | S27 AND S35 |
| S35 | S33 NOT S34 |
| S34 | PO (animal NOT (human OR inpatient OR outpatient)) |
| S33 | S31 NOT S32 |
| S32 | SU "cluster analysis" |
| S31 | S28 OR S29 OR S30 |
| S30 | TX (randomized controlled OR randomised controlled) |
| S29 | TX ((randomiz* OR randomis* OR controlled OR placebo OR blind* OR unblind* OR "parallel group" OR crossover OR cross-over OR cluster OR "head to head") N3 (analy* OR design OR evaluat* OR investigat* OR method OR procedure OR study OR studies OR trial)) |
| S28 | DE "Randomized Controlled Trials" OR DE "Randomized Clinical Trials" |
| S27 | S11 OR S21 OR S26 |
| S26 | S3 AND S25 |
| S25 | S22 OR S23 OR S24 |
| S24 | DE "Acceptance and Commitment Therapy" OR DE "Adaptive Behavior" OR DE "Adaptive Behavior Measures" OR DE "Adjustment" OR DE "Aromatherapy" OR DE "Art Therapy" OR DE "Assertiveness Training" OR DE "Autogenic Training" OR DE "Aversion Therapy" OR DE "Behavior Modification" OR DE "Behavior Therapy" OR DE "Bibliotherapy" OR DE "Biofeedback" OR DE "Classical Conditioning" OR DE "Client Centered Therapy" OR DE "Cognitive Behavior Therapy" OR DE "Cognitive Therapy" OR DE "Conditioning" OR DE "Conjoint Therapy" OR DE "Counseling" OR DE "Couples Therapy" OR DE "Creative Arts Therapy" OR DE "Crisis Intervention" OR DE "Dance Therapy" OR DE "Early Intervention" OR DE "Emotional Adjustment" OR DE "Exercise" OR DE "Eye Movement Desensitization Therapy" OR DE "Family Therapy" OR DE "Free Association" OR DE "Guided Imagery" OR DE "Human Potential Movement" OR DE "Hypnotherapy" OR DE "Implosive Therapy" OR DE "Interpersonal Psychotherapy" OR DE "Meditation" OR DE "Milieu Therapy" OR DE "Mind Body Therapy" OR DE "Mindfulness-Based Interventions" OR DE "Motivational Interviewing" OR DE "Movement Therapy" OR DE "Music Therapy" OR DE "Occupational Adjustment" OR DE "Operant Conditioning" OR DE "Play Therapy" OR DE "Poetry Therapy" OR DE "Progressive Relaxation Therapy" OR DE "Rational Emotive Behavior Therapy" OR DE "Reality Therapy" OR DE "Recreation Therapy" OR DE "Relaxation Therapy" OR DE "School Adjustment" OR DE "Social Adjustment" OR DE "Sociotherapy" OR DE "Stress Management" OR DE "Systematic Desensitization Therapy" OR DE "Therapeutic Community" OR DE "Yoga" |

(Continued)

| | |
|-----|---|
| S23 | ("acceptance commitment" OR art# OR assertive OR autosuggestion OR aversive OR behav* OR (client W1 cent*) OR cognitive OR colour OR compassion* OR couples OR dance OR directive OR family OR "human givens" OR humanistic OR implosive OR interpersonal OR milieu OR nondirective OR (patient W1 cent*) OR (person W1 cent*) OR play OR socioenvironmental OR socio-environmental OR suggestion) W2 (therap* or intervention*) |
| S22 | "psychological adaptation" OR aromatherap* OR asanas OR (autogenic W2 train*) OR autosuggest* OR bibliotherap* OR (biofeedback N2 psychol*) OR ("compassionate mind" W2 train*) OR (conditioning N2 psychol*) OR counselling OR "crisis intervention" OR (desensitization N2 psychol*) OR "early intervention" OR "emotional freedom tapping" OR exercise OR ("eye movement" W2 desensitization) OR ("eye movement" W2 reprocessing) OR "psychological feedback" OR flooding OR "free association" OR hypnosis OR imagery OR meditation OR mindfulness OR motivational interview* OR music* OR mozart* OR neurofeedback OR pranayama OR progressive muscle relax* OR (relax* W2 (therap* or intervention* or treat*)) OR "residential treatment" OR "rewind techniques" OR "stress management" OR "therapeutic community" OR yoga |
| S21 | S3 AND S20 |
| S20 | S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 |
| S19 | (family or social) N3 support |
| S18 | DE "Social Support" |
| S17 | (ambulator* OR health OR home) N3 (monitor* OR track*) |
| S16 | DE "Counseling" OR DE "Community Counseling" OR DE "Cross Cultural Counseling" OR DE "Educational Counseling" OR DE "Genetic Counseling" OR DE "Gerontological Counseling" OR DE "Grief Counseling" OR DE "Group Counseling" OR DE "Marriage Counseling" OR DE "Microcounseling" OR DE "Multicultural Counseling" OR DE "Occupational Guidance" OR DE "Pastoral Counseling" OR DE "Peer Counseling" OR DE "Premarital Counseling" OR DE "Psychotherapeutic Counseling" OR DE "Rehabilitation Counseling" OR DE "School Counseling" |
| S15 | "health education" OR ((health* OR care) AND (advise OR advice OR counsel*)) |
| S14 | DE "Health Education" OR DE "Drug Education" OR DE "Public Health Campaigns" |
| S13 | self N3 (care OR manag*) |
| S12 | DE "Self-Care" OR DE "Self-Help Techniques" OR DE "Self-Management" |
| S11 | S9 OR S10 |
| S10 | epilep* N3 (nurs* OR specialist*) |
| S9 | S3 AND S8 |
| S8 | S4 OR S5 OR S6 OR S7 |
| S7 | (speciali* OR dedicated OR home) N3 (nurs* OR service OR care OR center OR centre OR clinic) |
| S6 | (service* OR care OR healthcare OR intervention OR treatment) N3 (deliver* OR package* OR program*) |
| S5 | program* N2 evaluat* |
| S4 | DE "Outpatient Treatment" OR DE "Outpatient Commitment" OR DE "Program Evaluation" OR DE "Educational Program Evaluation" OR DE "Mental Health Program Evaluation" OR DE "Caregiving" |

(Continued)

OR DE "Health Care Delivery" OR DE "Clinical Practice" OR DE "Health Care Access" OR DE "Health Care Utilization" OR DE "Quality of Care" OR DE "Quality of Services" OR DE "Treatment Planning" OR DE "Discharge Planning" OR DE "Posttreatment Followup" OR DE "Disease Progression" OR DE "Treatment Outcomes" OR DE "Treatment Compliance" OR DE "Treatment Duration" OR DE "Home Care"

| | |
|----|---|
| S3 | S1 OR S2 |
| S2 | epilep* |
| S1 | MM "Epilepsy" OR MM "Epileptic Seizures" OR MM "Lennox Gastaut Syndrome" OR MM "Grand Mal Seizures" OR MM "Petit Mal Seizures" OR MM "Status Epilepticus" |

CONTRIBUTIONS OF AUTHORS

All review authors contributed to the writing of the protocol.

DECLARATIONS OF INTEREST

YH: none.

NF: none.

AJD: is part funded by the National Institute for Health and Care Research Applied Research Collaboration North West Coast (ARC NWC).

NW: none.

PB: is part funded by the National Institute for Health and Care Research Applied Research Collaboration North West Coast (ARC NWC).

AC: is part funded by the National Institute for Health and Care Research Applied Research Collaboration North West Coast (ARC NWC).

EJS: none.

SJN: none.

CTS: none.

RH: declares a financial – non-personal, non-specific interest, having delivered educational workshops on health economics, medicines management and HTA for cancer specialists supported by unrestricted sponsorship by the pharmaceutical industry and an industry association (March 2019). No fees received personally. Not specific to the topic of the review.

AGM: a consortium of pharmaceutical companies (GSK, Eisai, UCB Pharma) funded the National Audit of Seizure Management in Hospitals (NASH) through grants paid to the University of Liverpool. Professor Marson is funded in part by the NIHR Applied Research Collaboration, North West Coast (NIHR ARC NWC). Professor Marson is a National Institute for Health and Care Research (NIHR) Senior Investigator. The views expressed in this article are those of the author(s) and not necessarily those of the NIHR, or the Department of Health and Social Care. Professor Marson is the Co-ordinating Editor of the Cochrane Epilepsy Group; however, he was not involved in the editorial process of this review update.

SOURCES OF SUPPORT

Internal sources

- No sources of support provided

External sources

- National Institute for Health and Care Research (NIHR), UK

This protocol was supported by the National Institute for Health and Care Research (NIHR), via Cochrane Programme Grant funding (ESPG Project: NIHR133216 – Service delivery interventions for people with epilepsy and for people with epilepsy and intellectual disability) to the Epilepsy Group. The views and opinions expressed herein are those of the review authors and do not necessarily reflect those of the Systematic Reviews Programme, NIHR, National Health Service, or the Department of Health and Social Care.

NOTES

This protocol supersedes a published Cochrane Review ([Bradley 2016](#)).