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

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[Intervention Protocol]

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

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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 children 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 own or their child's epilepsy.

How services are delivered impacts on the effectiveness, efficiency and equity of health systems and affect health outcomes for children, young people and parents of children 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 children 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 control of their condition, reduce impacts on their health and cope with psychosocial impacts of their condition (Clark 1991).

Interventions 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 an interest and confidence in shared decision-making and adopting behaviours that promote a person'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 with epilepsy (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 children 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 (RCTs).

A related review on care delivery and self-management for children with epilepsy identified RCTs of education and counselling programmes for children, and children and their parents (Fleeman 2018). It concluded that whilst each intervention had benefits for children with epilepsy, none had been evaluated outside single studies.

In order to improve the quality of care for children 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 RCTs.

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 children 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. 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 younger than 18 years with any clinical diagnosis of new or recurrent epilepsy. If the study is a mixture of adults, young people and children, we will consider the study for inclusion if: 1. results are reported separately for those younger than 18 years, 2. at least 50% or greater subset of population are younger than 18 years or 3. if no data report on percent younger than 18 years, we will consider studies reporting mean age younger than 18 years. In this latter scenario, we will consult with clinical experts to agree that the interventions are applicable to children.

For service delivery, we will include models delivered specifically for children. We will exclude models targeted for adults. Models for a range of ages groups will be carefully considered for inclusion based on 50% being participants younger than 18 years or mean age younger than 18 years. Models that do not specify a focus on children 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 children 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 or counselling 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 children with epilepsy. Where possible, we will compare one group of behavioural interventions with another group or compare 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 children 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 clinician 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.

For outcomes 2. to 6., parent assessments may have been carried out on behalf of young children.

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 specialised Registers of Cochrane Review Groups including Epilepsy, 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 do 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/). We will group multiple reports and papers related to a single study 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. We will initially pilot the data extraction form on a selection of included studies from the original Cochrane Review's 'Characteristics of included studies' table (Fleeman 2018).

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. We will transfer data 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 inventions 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 assess 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. We will assess bias for each of the parameters ('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% CIs. 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. In the case of any cross-over trials, we will extract data from the first treatment period only.
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 calculate missing data using data from other trials 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, including population factors, interventions and study design between studies. We will evaluate statistical heterogeneity using the I^2 statistic. We will interpret the I^2 statistic as:

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 between trials (i.e. I^2 greater than 75%), we will not conduct 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 an analysis, we will assess funnel plot asymmetry.

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 the *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 find evidence of statistical heterogeneity, we will consider conducting 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.

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 post-hoc sensitivity analyses where appropriate and where the data allow.

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

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- 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

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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 children with epilepsy (Protocol)

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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"

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MP: none.

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NOTES

This protocol supersedes a published Cochrane Review ([Fleeman 2018](#)).