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Review Article

# A systematic review of psychosocial interventions for children and young people with epilepsy

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ABSTRACT

*Background:* Epilepsy is a lifelong neurological disorder that has a profound impact on the lives of millions of children and young people throughout the world, and is linked with mental ill-health and a poorer quality of life. Psychosocial interventions have showed promise for children and young people with epilepsy (CYPE), however there is an absence of large-scale RCT's that would add robustness to the evidence base. The present systematic review provides an update and extension of findings from an earlier review by Corrigan et al. to assess the state of the literature in 2023.

*Methods:* The present systematic review carried out a search of six electronic databases. Forward and backward chaining was carried out on review articles as well as the studies returned through the search to source additional studies. In total, ten articles were included in this review and appraised for quality using the Crowe Critical Appraisal Tool (CCAT).

*Results:* Forty percent (4/10) of the included studies were rated as high quality according to the CCAT, which represents a significant proportional increase since Corrigan et al.'s review. A meta-analysis of results was not possible due to significant methodological heterogeneity, and the variability of outcome measures, however effect sizes were reported or calculated for the majority of studies (7/10), which facilitated comparison. Despite the issues of relatively small samples, there are promising findings with regard to psychosocial interventions increasing epilepsy knowledge, coping strategies, self-efficacy, and quality of life markers.

*Conclusions:* There is a growing evidence base supporting the efficacy of psychosocial interventions for children and young people with epilepsy. This evidence base is also increasing in quality. Particular components of treatment that prove to be effective include psychoeducation, components based on cognitive behavioural therapy principles, as well as mindfulness techniques. This aligns with the evidence-based recommendations for adult populations. Intervention goals centre around improving quality of life, reducing symptom distress, and increasing knowledge and skills. The instruments used to measure these outcomes are predominantly standardised, however remain heterogeneous between studies which impacts the overall robustness of the evidence base.

## 1. Introduction

### 1.1. Background and prevalence

Epilepsy is a neurological disorder that has a profound impact on the lives of millions of children and adolescents throughout the world. It has a reported prevalence of between 0.5 and 1%, and is the most present chronic neurological condition in children and adolescents [1].

### 1.2. Seizure prevention

Seizure prevention is an important aspect of care for many people with epilepsy, and this is managed predominantly through pharmaceutical interventions. These interventions are considered successful for the majority of patients from either the first or second antiseizure medication trialled [2]. For those who do not respond favourably to the first two trials of medication, there are alternatives that have a proven evidence base, such as the ketogenic diet [3], and for those with disabling focal onset seizures surgical resection can be considered.

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'Seizure freedom' has been found to be highly correlated with an improved quality of life in people with epilepsy [4].

### 1.3. Psychosocial issues associated with epilepsy

Beyond the psychopharmaceutical needs of people with epilepsy, there are often also associated psychological and psychosocial challenges. These can have several causes from an acute fear response associated with seizures [5], to the avoidance of activities associated with positive mental health such as exercise, due to epilepsy-related fears [6].

Children and young people with epilepsy (CYPE) are known to have higher incidence of mental health and neurodevelopmental challenges. A recent meta analysis found a pooled prevalence of anxiety in 18.9% and depression in 13.5% of children with epilepsy [7]; in addition, an ILAE paediatric commission systematic review found a 2.5–5.5 times higher rate of ADHD compared to healthy controls [8]. CYPE also often become adults with epilepsy and have to contend with a wide range of mental health comorbidities across the lifespan. A very large (36,984 participant) population-based study [9] found that the lifetime prevalence for any mental health disorder for those without epilepsy was 20.7% (95% CI = 19.5–20.7), whereas people with epilepsy faced a significantly increased risk of mental health disorders across their lifespan (35.5%, 95% CI = 25.9–44.0). Depressive disorders have been found to be the mental health disorder with the highest co-morbidity with epilepsy [10,11]. Given the ramifications of untreated mental health difficulties among CYPE, it is important that any evidence based early interventions that can improve the mental health of CYPE are understood and more widely accessible.

In their large sample (n = 250) study, Pham et al. [12] found that people with epilepsy were significantly more likely to experience anxiety, and that this was associated with several negative outcomes, including a lower quality of life. Even when isolating other factors, such as frequency and severity of seizures, mental health remains a significant predictor of quality of life in adolescents with epilepsy [13], highlighting a need for evidenced psychological interventions. In their qualitative study, Fayed et al. [14] found that the main theme with regard to dealing with the anxiety and uncertainty caused by epilepsy for adolescents was "to adapt or not to adapt" with the subthemes of this being "leave me alone" versus "sharing knowledge, empowering self". This emphasises the role for CYPE to engage them and support the development of adaptive strategies to meet the challenges that they face.

The goals associated with any intervention for CYPE should address these factors, namely attitudes towards seizures, issues with mental health, deterioration in quality of life, and training/skill learning needs.

### 1.4. Psychosocial interventions for people with epilepsy

Psychosocial interventions have consistently been shown to be effective in reducing depression symptoms within the child and adolescent population, albeit with questions arising relating to the longevity of the treatment effect [15]. This is also the case for anxiety [16]. As CYPE experience elevated levels of depression and anxiety, this suggests a role for psychosocial interventions within this population. This need is supported by the evidence-based recommendations for psychological treatments for people with epilepsy [17].

The NICE guidelines [18] recommend ongoing clinical discussions about the cognitive and mental health challenges that children and young people face, which can be associated with their epilepsy and/or treatment. In addition to this, there is specific mention within the NICE guidelines of the common neurobehavioural disorders that are frequently comorbid with epilepsy, such as attention deficit hyperactivity disorder (ADHD) and autism spectrum disorder (ASD). The prevalence of ADHD and ASD amongst people with epilepsy adds to the case for psychological interventions, and may require specific modifications to the delivery of these interventions. A diagnosis of ASD, for example, is associated with a higher risk of depression (see Ref. [19] for a review for adolescent population), however therapeutic work must be cognisant of the challenges presented with a poorer self-recognition of emotional states within the ASD population [20] as well as challenges with cognitive flexibility [21]. In their Cochrane review of psychotherapy (predominantly CBT) for anxiety, however, James et al. [16] found no significant differences in treatment effects between ASD and non-ASD populations.

Previous research has suggested that epilepsy is more prevalent in areas of social deprivation within England [22], as well as among people with lower incomes within the United Kingdom [23]. Such findings present context for psychological treatment work with people with epilepsy. Indeed, a recent prospective population-level study in Scotland concluded that "There is a clear social gradient to the incidence of early childhood epilepsies", suggesting significantly higher incidence of childhood epilepsy in areas of social deprivation [24].

### 1.5. Research landscape

The earlier review by Corrigan et al. [25] noted that psychological interventions for people with epilepsy was a growing area of research, however that the primary focus was on adult populations. Michaelis & colleagues have recently provided several important Cochrane systematic reviews in this area [26,27], supporting the creation of evidence-based practice guidelines [17]. Whilst these reviews did include studies with child and adolescent populations, the vast majority of studies contained adult only populations (e.g., 75% within [26]).

Systematic reviews have also evaluated the efficacy of specific treatment deliveries for the adult population, for example group self-management interventions [28], however this has not been extended to children and adolescents. Indeed, a more recent review concerning the child and adolescent population focussed on parenting interventions and parental outcomes [29]. Further research into the specific components of direct treatment that are most efficacious for CYPE would facilitate the development of evidence-based practice, improving outcomes for this population specifically. Research into the methods of delivery that yield the best results is also important, as remote delivery (e.g. teletherapy and online interventions) and group-based interventions offer cost savings when compared to individual psychotherapy, if found to be suitably efficacious.

We therefore believe that the present review represents a timely update to the previous review [25]. We have set a lower methodological threshold for study inclusion than the Cochrane reviews [26,27], allowing the inclusion of studies beyond randomised controlled trials (RCT's). The focus of this review is exclusively on the child and adolescent population, whereas this was a minority aspect of the Cochrane reviews. We will also focus on direct interventions that contain outcome data for the children and adolescents, rather than the indirect intervention focus used by Kaye [29] or the narrower scope of care delivery and self-management strategies found in Fleeman et al.'s [30] Cochrane review.

### 1.6. Definition of psychosocial/psychological therapies

We have defined a psychosocial intervention in the following way for the purpose of this review: "A direct intervention that is primarily therapeutic, without a pharmacological or dietary-based element, that yields psychosocial outcome data (e.g. quality of life, reduction of distress)."

Studies can therefore include recognised evidence-based psychological interventions (e.g. Cognitive Behavioural Therapy, Acceptance and Commitment Therapy), as well as psychosocial interventions that develop communication skills, and health-education programmes that have direct delivery (i.e. to the child and adolescent population), and have psychosocial outcome measurements.

This would not include studies where the primary focus is cognitive

rehabilitation, for example using computer software for attention retraining. Studies where the intervention was indirect (e.g. delivered to parents with parental outcomes) were also not included in the current review. Studies that did not yield psychosocial outcome data (e.g. psychoeducational interventions that only measure the assimilation of epilepsy-based knowledge) were not included.

### 1.7. Review questions/aims

The previous review concluded that there was "limited but promising evidence that psychosocial interventions can be of benefit to CYPE improving mood, quality of life, and epilepsy knowledge. However, there is a need for further good quality studies using randomized controlled trial designs with larger samples." [25]. The present review aims to evaluate the research evidence published since 2014, providing an overview of recent progress in this important area of healthcare for young people with chronic health problems.

The research questions and aims of the previous review [25] are retained to facilitate comparison between time periods.

1. Is there any evidence that psychosocial interventions are effective for children or young people with epilepsy?
2. Are there specific treatment components or methods of delivery that may increase the effectiveness of these interventions?
3. Are there clear intervention goals and how effectively are these measured?

## 2. Method

The present systematic review followed the PRISMA statement for guidance and structure throughout the process [31] (Appendix A).

This review provides an update and extension to the systematic search conducted by Corrigan et al. [25]. One key change is that the search strategy has been updated for greater sensitivity. The search strategy was developed to facilitate the inclusion of specific therapies that have been used for people with epilepsy within the search terms. The included therapeutic terms were taken from review articles [26,27,32].

### 2.1. Search strategy

The electronic databases from the previous review [25] were retained in this review. This meant that the following were utilised Embase, Medline, and PsychInfo (via OVID online); CINAHL, and Psychology & Behavioral Sciences Collection (via EBSCO host); and Web of Science Core Collection (via Web of Knowledge). Final searches were conducted on 30th May 2023.

The search terms for the present review, as used for OVID: Medline and Embase is presented below.

1. exp Epilepsy
2. Epilep*.ti,ab,kw
3. 1 OR 2
4. exp child/
5. exp adolescent/
6. (Child* OR Adolescen* OR Young Person OR Young People OR Kids OR Minor* OR Youth* OR Paediatri* OR Pediatri*).ti,ab,kw
7. 4 OR 5 OR 6
8. ((Psychosocial OR Psychoeducation* OR Psycholog* OR Psychotherap* OR Mental Health) adj3 (Interven* OR Treat* OR Therap*)).ti,ab,kw
9. exp psychotherapy
10. exp cognitive therapy
11. exp cognitive behavioral therapy
12. (education program* OR behavioural strateg* OR behavioral strateg* OR motivational interviewing OR epilepsy education OR self-management OR cognitive behavioural therap* OR cognitive behavioral therap* OR CBT OR acceptance and commitment therapy OR ACT OR behavioural activation OR behavioral activation OR cognitive therap* OR cognitive restructuring OR stress management OR communication skills OR mindfulness).ti,ab,kw
13. 8 OR 9 OR 10 OR 11 OR 12
14. 1 AND 7 AND 13

A date range was also applied to the searches, so that only results published since the previous review were retuned. The date range for the present review succeeds the date range from the previous review [25], which were 1st January 1989 and 28th November 2014.

Limits were applied to the searches so that only English language studies (any territory) with human participants were returned.

Age filters were not applied to the search results, as the factor of age was addressed through the search strategy. The age ranges from the previous review [25] were retained, meaning that the World Health Organisation definition of 'adolescence' was adopted [33].

Duplicate studies were removed using the in-built tool within Microsoft EndNote, as well as through methodical manualised sorting.

Inclusion criteria:

- Published in English language
- Published in a peer-reviewed journal
- Studies published between 29th November 2014 and 30th May 2023
- Studies containing original data
- Intervention participants must be between ages of 0 and 19 years
- Intervention participants have a diagnosis of epilepsy

Exclusion criteria:

- Intervention participants are non-human
- Intervention participants do not have a diagnosis of epilepsy
- Intervention participants have a diagnosis of a learning disability
- Intervention participants are adult
- Studies without psychosocial intervention
- Studies without psychosocial outcome measurements

The following types of research article were also not included; qualitative studies, review studies (systematic, literature) and meta-analyses, case studies, conference abstracts or presentations, book sections, and commentaries or opinion pieces. These were retained from the earlier review.

In addition to the systematic search, manual searches were carried out using the reference lists from selected reviews [26,27,32], as well as forward and backward chaining from the final included studies. This led to the inclusion of one additional study for full text review.

### 2.2. Quality assessment

To facilitate comparison between the present review and the previous review [25], we retained the use of the Crowe Critical Appraisal Tool (CCAT) [34], which remains in version 1.4. This quality assessment tool for systematic reviews supports the evaluation of included studies based on their reporting and methodology.

The previous review [25] transposed the scores obtained from applying the CCAT to the studies, which are out of 40, to percentages. Studies were then categorised according to their percentage score as

**Table 1.1**
CCAT scoring key.

| Quality Rating | Percentage | Equivalent CCAT Score |
|---|---|---|
| **Poor Quality** | ≤50 | 20/40 or less |
| **Acceptable Quality** | 51–74 | 21/40 to 29/40 |
| **High Quality** | ≥75 | 30/40 and above |

shown in Table 1.1.

We have retained this scoring and rating system for the present review so as to facilitate comparisons between the research landscapes at each time period. The transposition of scores to percentages is supported by the author of the CCAT [34].

## 3. Results

### 3.1. Search results

The search selection process is presented in Fig. 1.1. A random sample of 10% (136/1356) of the records that were title and abstract screened for full text review were also blind rated by a second rater to determine inter-rater reliability. This returned an initial score of $\kappa = 0.699$ representing 'substantial agreement' [35]. In practice, this related to four incidences of disagreement which were resolved through discussion.

### 3.2. Quality rating results

Studies were assessed for quality using the CCAT. Table 1.2 details the scores for each study across the 8 domains of the CCAT, as well as the total score, a transposed percentage, and the associated quality rating.

All ten included studies were rated using the CCAT by the lead author and an additional blind-rater, thus forming a 'rating pair'. The rating pair had an initial agreement of $\kappa = 0.878$, which represented one disagreement (1/10). Weighted Cohen's kappa was used as the categories (CCAT classifications) were ordered. Using Landis & Koch's [35] benchmarks, this represents 'almost perfect agreement'. After discussion between raters, perfect agreement was attained for all articles.

A summary of the ten studies included in the present review is provided in Table 1.3.

### 3.3. Sample size and characteristics

All studies required a diagnosis of epilepsy from a healthcare professional for participation. The characteristics of the sample did however

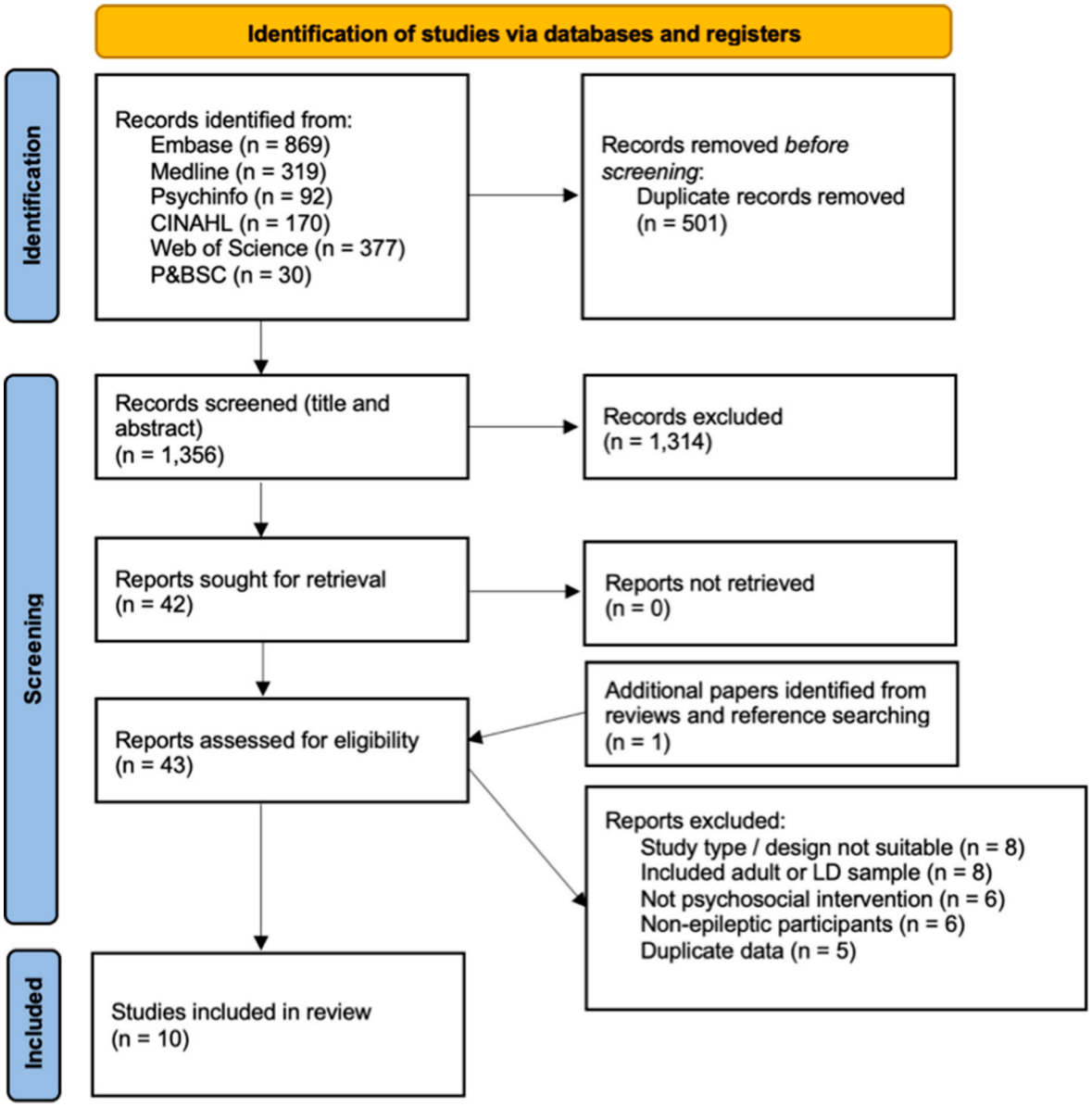


**Fig. 1.1.** PRISMA Diagram: Adapted from Page et al. (2021).

**Table 1.2**
CCAT quality ratings.

| Study | Preliminary | Introduction | Design | Sampling | Data Collection | Ethical Matters | Results | Discussion | Total Score (%) | Rating |
|---|---|---|---|---|---|---|---|---|---|---|
| Batista et al. (2015) | 3 | 2 | 2 | 1 | 2 | 1 | 3 | 3 | 42.5 | Poor |
| Brown et al. (2019) | 5 | 5 | 3 | 3 | 3 | 4 | 4 | 5 | 80 | High |
| Dorris et al. (2017) | 4 | 5 | 4 | 4 | 4 | 4 | 4 | 5 | 85 | High |
| Eom et al. (2016) | 2 | 2 | 2 | 1 | 1 | 2 | 3 | 4 | 42.5 | Poor |
| Gurhopur et al. (2018) | 3 | 3 | 4 | 3 | 3 | 2 | 3 | 4 | 62.5 | Acceptable |
| Guven et al. (2020) | 4 | 5 | 4 | 5 | 4 | 3 | 4 | 4 | 82.5 | High |
| Rizou et al. (2017) | 3 | 3 | 3 | 3 | 2 | 3 | 2 | 4 | 57.5 | Acceptable |
| Schaffer et al. (2017) | 3 | 4 | 4 | 3 | 3 | 3 | 5 | 5 | 75 | High |
| Svanstrom et al. (2023) | 5 | 5 | 2 | 2 | 2 | 3 | 4 | 5 | 70 | Acceptable |
| Tajrishi et al. (2015) | 2 | 2 | 4 | 4 | 2 | 2 | 3 | 4 | 57.5 | Acceptable |

vary in their presentation, with differences between studies with regard to their inclusion and exclusion criteria relating to time since last seizure.

Only three studies [37,41,45] calculated power sizes to determine an appropriate sample size which informed participant recruitment. One study provided a justification for not using a power calculation to guide recruitment [38].

There was variability in the overall sample sizes (including control conditions) for the studies. One study recruited a large sample of over 100 participants [37]. Five studies had a sample size of less than or equal to 30.

It is also of note that inclusion and exclusion criteria were inconsistent between studies with regard to cognitive ability. For example, Svanstrom et al. [44] applied an inclusion criterion of FSIQ $\geq$85 but based this on clinical judgement, whereas Schaffer et al. [43] used a prediction of IQ (ESIQ) based on the completion of a WISC subtest (block design) and used a cut-off of $\leq$79 for exclusion.

Seven of the ten included studies included a control group, and five of these seven studies used randomisation [37,38,40,41,45].

### 3.4. Effect size

Effect sizes were provided for two of the ten included studies [38,44]. For studies that provided means and standard deviations, however not an effect size, these were calculated for the main significant findings [39–42,45]. Effect sizes were calculated using the formula:

$$d \Big/ g = \frac{M^1 - M^2}{SD_{pooled}}$$

This was used for within subjects and between subjects comparisons. A recent analytic review highlights that this is the optimum calculation [46].

Effect sizes were interpreted using Cohen's [47] benchmarks of 0.2 (small), 0.5 (medium), and 0.8 (large). Where participant numbers were low (fewer than 30), 'Hedge's g' was favoured over 'Cohen's d' [48]. If effect sizes were provided within the study, these were not transposed based on sample size criteria.

### 3.5. High quality studies

Of the four high quality studies, three were RCT's [37,38,41], whereas one utilised a matched pairs design [43]. Only one high quality study [43] explicitly used a blinding process within their methodology, and one study provided a justification for not using blinding [38].

Two of the studies carried out a power calculation before proceeding with recruitment [37,41] and another provided a justification for not conducting a power calculation to inform recruitment [38].

None of the studies rated as high quality explicitly stated any potential harms that may have arisen from participation in the intervention, which is considered as part of the rating using the CCAT.

#### 3.5.1. Intervention outcomes

Two studies rated as high quality focussed their outcome measures on quality of life and the reduction of distress (i.e. anxiety, depression, emotional distress) [37,38]. One of these studies also measured changes in self-efficacy and epilepsy knowledge [38].

Guven et al. [41] had self-efficacy and epilepsy knowledge as intervention goals, as well as changing their participants attitudes towards illness. Schaffer et al.'s [43] study focussed on self-efficacy and attitudes towards life (i.e. optimistic or pessimistic) as the psychosocial aspects of their intervention. They also collected neuropsychological outcomes (memory-based, and executive function) as part of their study, commenting on the moderation effects that these may play.

All high-quality studies used validated and standardised psychosocial measures. These were used in addition to measures that were created for the purpose of the research. Brown et al. [37] captured physical activity markers in their study, creating a tool to do this. Dorris et al. [38] created participant and parent questionnaires for their study, which enabled the collection of qualitative and feasibility data.

#### 3.5.2. Intervention methods

Two of the studies used a modular CBT group therapy intervention using multiple sessions [38,43]. Schaffer et al. [43] also included modular skills training for memory and executive function difficulties in their intervention.

Of the two studies that did not contain a primary CBT-based element, one [37] implemented a longitudinal exercise-based intervention, which included weekly or fortnightly sessions with the research team that utilised behaviour change techniques. There was also a psychoeducational aspect of this intervention. The final intervention [41] saw participants being given access to a web-based educational platform for 12 weeks, alongside reminders to use the platform and virtual technical support. There was no therapeutic intervention delivered by a clinician in this study, rather it was a remote psychoeducational intervention.

#### 3.5.3. Intervention effectiveness

Only one of the high-quality studies provided effect sizes for their main findings [38]. One further study provided means and standard deviations for the primary findings, which enabled calculation of effect sizes [41]. The remaining two studies did not provide effect sizes or sufficient data to calculate these for their primary findings [37,43].

Of the studies for which effect sizes are calculated, Dorris et al. (2017) found a significant improvement in epilepsy knowledge after their CBT-based intervention which included psychoeducational components (small effect size). This increased at three-month follow-up (medium effect size) suggesting that participants had continued to independently learn more about their epilepsy. There were no changes on measures of anxiety/depression likely reflecting the low baseline scores on these measures. The authors also reported very high acceptability and feasibility data including significant improvements in self-reported confidence in speaking to others about their epilepsy. Guven et al. [41] reported significant results across all outcome measures for their web-based psychoeducational intervention. This included a

**Table 1.3**
Data extraction: Summary of 10 included studies that met criteria.

| Study | Sample | Design | Intervention Delivery | Psychosocial Outcome Measures | Analysis | Main Findings (Child/ Young Person) |
|---|---|---|---|---|---|---|
| Batista et al. (2015) [36] | 17 children, 9–17 years. Epilepsy diagnosis >1 year. Purposive sample. Croatia. | One group, pre-test/ post-test. No follow-up. | Manualised computer-assisted CBT delivered in a residential setting. Team included paediatricians, psychologists, and nurses. CBT intervention had six modules; three on epilepsy education, three on coping strategies. | Scale of Coping with Stress (SUO) and author created two knowledge tests; one for general epilepsy knowledge, and one for epilepsy and coping. | Related samples Wilcoxon signed rank test. | Significantly higher epilepsy knowledge post-intervention ($p < 0.01$). Significantly higher scores on stress knowledge and coping with stress quiz post-intervention ($p < 0.01$). Significantly higher ($min = p < 0.05$) usage frequency and effectiveness of 4 strategies on the SUO (problem solving, seeking help from friends, seeking help from family, and cognitive restructuring). |
| Brown et al. (2019) [37] | 115 children, 8–14 years. >1 seizure in past 12 months. Convenience sample. Canada. | RCT (conformed to CONSORT 2017 guidelines). 6-month follow-up period. | Intervention group had physical activity behaviour-change counselling, which were motivational and psychoeducational (self-regulatory skills). | Physical activity markers. Childhood epilepsy quality of life scale (CEQOL). KIDSCREEN-27 which measures health-related quality of life. The Children's depression inventory-short (CDI-S). | Linear regression model, independent t-tests, Chi-square. | No significant differences between groups for condition specific quality of life ($p > 0.07$), health-related quality of life ($p > 0.15$), or depressive symptoms ($p > 0.07$). No significant difference between groups for physical activity ($p = 0.67$). |
| Dorris et al. (2017) [38] | 83 children, 12–17 years. Epilepsy diagnosis >6 months. Convenience sample. United Kingdom. | RCT using a waiting list control group. Follow-up at three and six months. | Intervention delivered in groups by healthcare professionals (epilepsy nurse and clinical psychologist). Weekly sessions, manualised delivery based on CBT and mindfulness techniques | Paediatric Quality of Life Inventory (PedsQL), Glasgow Epilepsy Outcome Scale for Young Persons (GEOS-YP), Epilepsy Knowledge Profile-General (EKP-G), the Seizure Self Efficacy Scale for Children (SSEC-C), the Brief - Illness Representations Questionnaire (B-IPQ), Paediatric Index of Emotional Distress (PI-ED) as well as participant and caregiver questionnaires created for the study. | T-tests, Mann-Whitney test, McNemar's test. | Significant increase in epilepsy knowledge in experimental group after intervention ($p = 0.04$, $d = 0.25$), and at three-month follow-up ($p = 0.02$, $d = 0.58$). Positive changes noted in GEOS-YP, BPIQ, PI-ED, and SSEC for intervention group, however these changes did not reach significance post-intervention or at follow-up. |
| Eom et al. (2016) [39] | 10 children, 8–12 years. Benign epilepsy diagnosis. Convenience sample. Korea. | One group, pre-test/ post-test. No follow-up. | 35-week exercise program. Gym and home-based. Parents received psycho-educational input from healthcare professionals, including clinical psychologists. | Korea–Child Behavior Checklist (K-CBCL) and the Korean version of the Quality of Life in Childhood Epilepsy Questionnaire (K-QOLCE). | Wilcoxon signed-rank test. Outliers were removed for some analyses. | Significant improvement in general health ($p = 0.018$, $g = 2.62$), and quality of life ($p = 0.017$, $g = 2.47$) post intervention on the QOLCE. A reduction in behaviour problems post-intervention, however non-significant (K-CBCL). No significant change was noted for competence post-intervention (K-CBCL). |
| Gurhopur et al. (2018) [40] | 92 children, 7–18 years. Epilepsy diagnosis >6 months. Convenience sample. Turkey. | RCT. Follow-up at one and three months. | Modular education program. Activities included discussions, brainstorming, Q&A, role playing, and playing games. | The Epilepsy Knowledge Test for Children (EKTC), the Seizure Self-efficacy Scale for Children (SSES-C), the Quality of Life in Epilepsy Inventory (QOLIE-48). | Chi-square, t-tests, Kolmogorov-Smirnov test. | Scores on the EKTC ($p < 0.001$, $d = 0.92$), SSES-C ($p < 0.001$, $d = 0.27$), and QOLIE-48 ($p < 0.001$, $d = 0.34$) increased significantly post-intervention for the intervention group. |
| Guven et al. (2020) [41] | 69 children, 9–18 years. Epilepsy diagnosis >6 months. Convenience sample. Turkey. | RCT. No follow-up. | Access to a web-based epilepsy education program (WEEP) for 12 weeks. Sent weekly reminders to use the website. | Epilepsy Knowledge Test (EKT), Seizure Self-Efficacy Scale for Children (SSES-C), Child Attitude Toward Illness Scale (CATIS), the e-Health Literacy Scale (eHEALS). | Chi-square, t-tests. | Intervention group had statistically different post-test scores (within group) for all measures ($p < 0.05$). EKT ($p = <0.0001$, $d = 1.32$). SSES-C ($p = <0.0001$, $d = 1.48$). CATIS ($p = <0.0001$, $d = 0.97$). |

(*continued on next page*)

**Table 1.3** (*continued*)

| Study | Sample | Design | Intervention Delivery | Psychosocial Outcome Measures | Analysis | Main Findings (Child/ Young Person) |
|---|---|---|---|---|---|---|
| | | | | | | eHEALS ($p = <0.0001$, $d = 1.01$). |
| Rizou et al. (2017) [42] | 24 children, 12–17 years. >1 seizure in past 12 months. Purposive sample. Greece. | Matched pairs design. Epilepsy control group. Follow-up at 3 months. | Brief self-regulation-based intervention, one 4-h group session. Psycho-educational component, relaxation, and storytelling. | Brief Illness Perceptions Questionnaire (BIPQ), Revised Children's Anxiety and Depression Scale (RCADS), Athens Insomnia Scale (AIS), and the somatization scale of the validated Symptom Checklist (SCL-90-R). | ANCOVA | Significant main effects noted for psychological distress levels ($p = 0.005$, $g = 1.37$), and sleep problems ($p = 0.003$, $g = 1.83$), as well as the 'coherence' scale of the BIPQ ($p = 0.02$, $g = 1.70$). Effect sizes provided are within group calculations. |
| Schaffer et al. (2017) [43] | 33 children, 9–14 years. <1 seizure in past 12 months. Purposive sample. Israel. | Matched pairs design. Non-epilepsy control group. No follow-up. | Modular intervention with 2 five-week modules; memory skills training, and psychosocial training informed by CBT methods and techniques. | Youth self-report subtest (YSR), General Perceived Self-Efficiency scale (GSE), Children's Self-Control scale (CSC), and the Youth Life Orientation Test (YLOT). Parents completed the Child Behavior checklist parents form (CBCL). | ANOVA, Chi-square. | Between subject analysis showed modest intervention effect for optimism (YLOT) ($p < 0.05$) as well as self-efficacy (GSE) ($p < 0.05$). |
| Svanstrom et al. (2023) [44] | 15 children, 8–13 years. 2+ historical seizures, medication controlled. Convenience sample. Sweden. | One group, pre-test/ post-test (before intervention and 3-month follow-up). | Psychoeducational intervention delivered by psychologists in groups (3–5 children). Mixed in-person and online delivery due to COVID-19 related restrictions. | ADHD-RS-IV Inattention subscale, the Behavior Rating Inventory of Executive Function, Second Edition (BRIEF2), Strengths and Difficulties Questionnaire (SDQ), DISABKIDS generic, and DISABKIDS epilepsy. | Paired sample t-tests. | Statistically significant reduction in self-identified executive function difficulties ($p = 0.03$, $d = 1.10$), as well as generic quality of life for self-report ($p = 0.043$, $d = 0.57$) and parent report ($p < 0.001$, $d = 1.40$) measures. |
| Tajrishi et al. (2015) [45] | 30 children, 14–18 years. No seizure in past 6 months. Medication controlled. Convenience sample. Iran. | Semi-experimental design with pre-test and post-test measures. Control group. Follow-up at six weeks. | Intervention group attended 11 sessions (2x per week, 45 min) and received an attribution retraining program, as well as communication training, anger management, and life skills training. Attribution retraining program based on Bandura, Seligman, and Wiener's models. | General Health Questionnaire (GHQ). | ANCOVA | Statistically significant reduction in mental health difficulties in all subscales of the GHQ; physical symptoms ($p = 0.01$, $g = 1.86$), anxiety and insomnia ($p = 0.01$, $g = 2.26$), social dysfunction ($p = 0.01$, $g = 2.03$), depression ($p = 0.01$, $g = 2.56$), as well as the overall index ($p = 0.01$, $g = 2.62$). Within-subjects effect sizes provided. |

significant increase in epilepsy knowledge (large effect size), seizure self-efficacy (large effect size), positive attitudes towards health (large effect size), as well as health literacy (large effect size).

Of the studies for which effect size was not calculated, Brown et al. [37] did not report any significant results for their physical activity intervention. The research team discussed the high baseline scores for physical activity in the intervention group as a possible factor as to why changes did not reach significance. Schaffer et al. [43] reported significant results for between subject analysis for their neuropsychological and CBT-based intervention for self-efficacy and optimism.

### 3.6. Acceptable quality studies

Of the four acceptable quality studies, one was a randomised controlled trial [40], two used a quasi-experimental design [42,45] with non-randomised control groups, and one used a single system pre-test, post-test design [44].

One acceptable quality study calculated power sizes to determine their sample size prior to data collection [45], none of the other studies rated as acceptable did this [40,42,44].

#### 3.6.1. Intervention outcomes

Out of the four acceptable quality studies, two were primarily concerned with the reduction of distress/mental ill-health [42,45], and two were primarily concerned with increasing quality of life [40,44]. One study was also focussed on the reduction of executive function difficulties, and this was reflected in their sampling inclusion criteria [44].

All four studies used clinically valid and standardised instruments to measure the impact of their interventions. Three studies exclusively used self-report measures, two for children alone [42,45], and one [40] used child self-report and parental-self report measures, as they included parental participants. One study [44] used informant (parental plus teacher) report measures, in addition to self-report measures. The use of informant measures represents a methodological strength, reducing bias.

#### 3.6.2. Intervention methods

Three of the studies used a psycho-educational approach for intervention [40,42,44]. Rizou et al. [42] furthered this approach by using a Socratic exploration of participant fears about epilepsy. One of these three studies carried out the intervention in one 4-h session after consultation with parents that this would be the most practical approach [42], whereas the other two studies operated a modular design with multiple intervention sessions [40,44]. One study also ran a parallel modular education program for parents alongside the children's programme [40].

Tajrishi et al. [45] used a skills training approach for their intervention, with a focus on attribution retraining. Limited information is

provided about the development or adaption of this program, beyond that it had been previously used in the same country (Iran) for children with dyscalculia. The course was delivered across 11 sessions, each lasting 45 min.

#### 3.6.3. Intervention effectiveness

Only one of the acceptable quality studies [44] reported effect sizes. The three other acceptable quality studies [40,42,45] did however all provide means and standard deviations, which enabled the calculation of effect sizes. Gurhopur et al. [40] found that their modular education programme significantly increased children's epilepsy knowledge (large effect size), whilst also significantly increasing their seizure self-efficacy and quality of life, however the effect sizes for these were small. Rizou et al. [42] found that their brief self-regulation intervention (one session, 4 h) significantly reduced psychological distress and sleep problems (both large effect sizes). The very small sample size (n = 12 in the intervention condition) limits the generalisability of these findings. Svanstrom et al.'s [44] psychoeducational intervention significantly reduced self-reported attentional difficulties (large effect size) and significantly increased self-reported quality of life (medium effect size). The parental (informant) reported quality of life also increased significantly (large effect size). Tajrishi et al.'s [45] attribution retraining program led to a significant reduction in mental health difficulties (large effect size). The post-test in their study was conducted at six weeks, which provides some insight into longitudinal benefits of the intervention, however it is limited by the small sample size (n = 15 in the intervention condition).

### 3.7. Poor quality studies

Owing to methodological weaknesses, the two poor quality studies [36,39] in this review will be described in limited detail. Both studies utilised a single system research design (one group, pre-test and post-test), with no longer term follow-up. This reduces the validity and practical application of the findings, as no certainty can be drawn with regard to whether the intervention was the agent of change. These issues are exacerbated by low sample sizes of 17 [36] and 10 [39] respectively. No power analysis was carried out to determine an appropriate sample size in either study. Batista et al. [36] created two outcome measures used in their study, which means that they were not validated or standardised, whereas Eom et al. [39] exclusively used validated measures.

Batista et al. [36] found that delivering manualised computer-assisted CBT increased children's epilepsy knowledge and stress knowledge. It also increased their frequency in using positive strategies for coping with stress. They did not, however, provide effect sizes for these and the lack of reported means and standard deviations meant that these could also not be calculated. Eom et al. [39] found that a 35-week exercise programme significantly increased participants general health and quality of life. Effect sizes were not provided in the study, however we were able to calculate them (g = 2.62 for general health; g = 2.47 for quality of life). These represent (very) large effect sizes, however the aforementioned methodological weaknesses impact the internal and external validity of both of these studies, and so these significant findings should be interpreted with caution.

## 4. Discussion

### 4.1. Evidence for psychosocial interventions

The present review demonstrates that the evidence base for psychosocial interventions for CYPE continues to grow and develop. The findings are promising with regard to the psychoeducational aspect of interventions increasing participants epilepsy knowledge, with four of the included studies reporting significant changes in this regard [36,38,40,41]. The present review also highlights the role of psychosocial interventions in increasing the quality of life of CYPE, with significant findings found in three of the studies [39,40,44]. Limited, missing, or non-significant longitudinal data within the included studies limits the extent to which the longevity of these changes can be assessed. Other significant outcomes included the reduction of distress [41,45] as well as increased self-efficacy and problem-solving skills [36,41,43], and improved confidence in talking about epilepsy with others [38].

The robustness of the evidence base is impacted by a tendency for participants to be recruited through convenience or purposive sampling as a result of receiving hospital care (100% of studies included in the present review). This adds bias into the sample, and it is important that there is transparency around how samples are selected from treatment databases, particularly with a purposive sample. In addition, when interventions are delivered as part of clinical practice within a treatment setting it is often impractical or impossible to blind participants (e.g. if they are part of a waiting list control group), which limits the internal validity of the research.

### 4.2. Treatment components

The majority of studies included in the present review utilised evidence-based treatment components, which are supported by the literature. The most common component within the interventions was psychoeducation (9/10 studies), which meets the evidence-based practice suggestion that "each patient with epilepsy should receive psychoeducation" [17].

With regard to affective challenges for people with epilepsy (e.g. depression and anxiety), the studies included in the present review utilised behavioural and skill-based approaches in addition to interventions informed by CBT and mindfulness practices. This aligns with the evidence-based practice suggestion from Michaelis et al. [17] that "treatment components may include behavioural intervention (e.g. social activation) and skill-based interventions (e.g. problem solving, social skills training)" when working with depression, and with regard to anxiety "the highest level of evidence pertains to the implementation of mindfulness exercises." Six of the ten studies included in the present reviewincluded a direct skill-training element, which could include mindfulness-based exercises.

Cognitive behavioural therapy continues to be a leading evidence-based intervention for people with epilepsy, with a recent systematic review and meta-analysis suggesting CBT-based interventions have led to better outcomes with regard to depression and quality of life [49]. Four of the ten studies included in the present review had an explicitly stated CBT-based approach to their intervention. Interestingly, the same authors [49] found that CBT delivered in an individual capacity had a larger effect size than group-based CBT. In the present review, CBT-based interventions were delivered in group settings, including in the two CBT-based studies rated as high quality [38,43].

### 4.3. Intervention goals and outcome measures

Studies included interventions that aimed to increase epilepsy knowledge, increase quality of life, reduce distress, and develop skills and self-efficacy. Across the ten included studies, these intervention goals were operationalised through diverse interventions limiting the generalisability of findings and clinical applicability.

All ten of the included studies utilised standardised outcome measures for a substantial part of their data collection and analysis. Only one study relied on bespoke measures for most of their outcome data [36]. This represents a positive change since the earlier review [25]. Outcome measures were however heterogenous, which presents a challenge when comparing results between studies and developing a coherent and consistent evidence base. For example, in this review we saw three different quality of life outcome measures, each using different items and constructs. Adopting a consensus on outcome measures between research groups would support higher quality research, as well as the ongoing standardisation of those measures. In their systematic review of quality of

life instruments for children with epilepsy, Crudgington et al. [50] recommend the use of the Quality of Life in Childhood Epilepsy Questionnaire (QoLCE-55) and the Health-Related Quality of Life Measure for Children with Epilepsy (CHEQoL). Of these, the CHEQoL is the only one that provides a child self-reported health-related quality of life score, and so perhaps should be favoured. Cultural differences in the concept of quality of life may however limit global adoption of a single measure.

Of the ten included studies, only two reported longitudinal outcome data beyond 4 months [37,38], four studies had no follow-up data, and four studies did not have a follow-up after 4 months. Dorris et al. [38] showed sustained treatment effects at 6-month follow-up in relation to increased epilepsy knowledge and in confidence talking about epilepsy. Longer term follow-up periods should perhaps be a greater methodological consideration when constructing interventions and research studies focussed on psychosocial interventions for CYPE, given the evidence base for accelerated forgetting in this population more broadly (see Ref. [51] for a review). One of the included studies combined a memory training program with their psychosocial intervention [43], however there was no longer-term follow-up.

### 4.4. Future research

The included studies varied significantly between their inclusion and exclusion criteria, such as the extent to which participants were seizure free or experiencing active seizures. For example, Brown et al. [37] and Rizou et al. [42] required participants to have experienced a seizure in the past 12 months, whereas other studies required differing periods of seizure-free status prior to participating, or for epilepsy to be medically controlled. One study actively included participants with neurodevelopmental difficulties (relating to attention), whereas other studies specifically excluded CYPE who had neurodevelopmental co-morbidities. A solution to this could be to encourage agreement between researchers for a collective set of parameters, which could be achieved through large-scale multi-centre research collaborations.

When the collective sample between studies does not combine into a homogenous group, the rationale for excluding people with cognitive impairment could be called into question. For example, Svanstrom et al. [44] stated their exclusion criteria for 8–11-year-olds of an IQ $< 85$ was a "pragmatic decision based on the clinical judgment that they were likely to have difficulties accessing the content of the intervention due to cognitive and reading ability". Such views have been challenged within the adult population by reviews of the evidence base, such as Vereenooghe & Langdon [52], who found a moderate effect size for psychological therapies for people with intellectual disabilities. Although excluded from the present review due to the sample containing participants with a learning disability (legacy exclusion criteria), we scored one promising study using the CCAT and found that it would have been included as a high-quality study (Appendix B). Bennett et al. [53] found significant improvements in self-reported mental health problems, the impact of mental health problems, anxiety and depression symptoms, as well as quality of life (all medium effect size) for CYPE. Their sample contained 9/23 children with a learning disability (39.1%). Although the sample size was small, this tentatively suggests that children and young people with a learning disability may positively respond to a phone-based CBT intervention, and reduces the rationale for their exclusion in other studies. This is a point of consideration, should this review be updated in the future, as well as for the research area as a whole. It is, however, notable that clinical practice favours a systemic approach to psychosocial support for children with intellectual disabilities. This may be due to the additional support needs of the children, and a greater need to train and educate parents. It may therefore be the case that a distinct systematic review for this population is warranted.

As previously stated, the standardisation of outcome measures across studies would also strengthen the evidence base. If there could be agreed guidelines for which outcome measures to use, then this would support good practice. There are existing systematic reviews that can guide this process (e.g. Ref. [50]), however this needs to be developed for all outcome measures.

### 4.5. Limitations and strengths

There are a number of limitations of the present review. The review is subject to publication bias, in that studies with significant findings are more likely to be published and therefore included in this review. Only one included study did not report any significant results [37]. The heterogeneity of the included studies also presents a limitation, as the differences in populations, interventions, and outcome measures mean limits the extent to which pooling the results leads to a coherent picture of the research landscape. This heterogeneity also restricted our ability to perform a meta-analysis, which represents a weakness of the present review. In addition, whilst the proportion of high-quality studies (40.0%) has increased since the earlier review (17.6% in Corrigan et al. [25]), 60% of the included studies were either of poor or acceptable quality and as such there are notable methodological weaknesses that negatively impact their internal and external validity.

Strengths of the present review include the use of the CCAT, which enables a quality appraisal of studies with a variety of methodologies and was developed to address the lack of consistent reliability and validity data among critical appraisal tools [54]. The CCAT is also accompanied by user guidance which adds to its validity through increasing the uniformity of its application. Rating pairs were also used in the present review at two stages; title and abstract searching, and during quality rating. This strengthens the present review through the reduction of subjectivity bias, errors, and increasing transparency. As with any critical appraisal tool, and despite attempts to address this through the creation of detailed guidance, the CCAT can be influenced by the level of experience of individual raters leading to bias in appraising quality.

### 4.6. Summary and conclusions

There is an expanding body of research that underscores the efficacy of psychological interventions for children and adolescents diagnosed with epilepsy. This body of evidence is steadily improving in terms of both quantity and quality. Effective elements within these interventions include psychoeducation, strategies grounded in cognitive-behavioural therapy principles, and mindfulness techniques. This aligns with the evidence-based guidelines established for adult populations. Treatment goals for these interventions focus on enhancing the overall quality of life, mitigating symptom-related distress, and bolstering knowledge and skills. The instruments used to measure these outcomes are predominantly standardised, however remain heterogeneous between studies, which introduces a degree of variability that may affect the overall strength of the evidence base.

Since the previous review there have been a number of studies employing an RCT design, which represents progression for research into the efficacy of psychosocial interventions for CYPE. The proportion of studies that have been rated as high quality has also increased significantly since the previous review, so too has the proportion of studies using standardised outcome measures. The evidence base continues to be limited by the heterogeneity of the samples, reliance on convenience and purposive sampling, as well as significant variability in the outcome measures used. The earlier review concluded that "the adoption of multi-centre collaborations may overcome many of the methodological limitations observed in the current evidence base" [25], which remains true today.

### Declaration of interests

The authors declare that they have no known competing financial or personal interests. This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

### 4.7. Other information

This systematic review is registered on PROSPERO, reference: CRD42023424140.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ejpn.2024.02.002.

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