



Review

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



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ABSTRACT

Background: Despite recognition that psychosocial interventions can improve quality of life and mental health, there continues to be a lack of clarity and guidance around effective psychosocial interventions for children and young people with epilepsy. This review utilizes specific quality criteria to systematically identify and appraise the evidence for the effectiveness of psychosocial interventions for children and young people with epilepsy.

Methods: A systematic search of six electronic databases was conducted using predefined eligibility criteria. The reference lists of previous review papers were also manually searched. Seventeen studies met the inclusion and exclusion criteria. A quality appraisal checklist, the 'Crowe Critical Appraisal Tool' (CCAT) (Crowe, 2013) [1] was applied to the included articles, and effect sizes were calculated when not provided in the papers.

Results: Methodological quality of the majority of studies included was moderate, with only three studies rated as high quality. Meta-analysis was not conducted as the studies used heterogeneous methodologies and lacked consistency in outcome measures. Limited evidence was found for interventions improving epilepsy knowledge, quality of life, and psychological outcomes.

Conclusions: Psychosocial interventions may provide clinical benefit although further research is needed to clarify the most effective treatment components, delivery methods, and measurement of intervention outcomes. The existing evidence base for children and young people is limited by methodological issues such as the use of small samples, inadequate power, and a lack of controlled studies.

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1. Introduction

Epilepsy is the most common neurological disorder in children in the UK [2] and is defined by the presence of recurrent seizures, resulting from abnormal electrical activity in the nerve cells of the cerebral cortex. Approximately 63,400 children and young people aged 18 years and under in the UK have a diagnosis of epilepsy and take antiepileptic drugs (AED), equivalent to approximately 1 in 220 children [3].

Epilepsy is associated with a range of psychosocial difficulties and cognitive deficits. Baker [4] highlighted that although strong correlations have been found between epilepsy and depression in adolescents, mental health problems are underdiagnosed and undertreated in this population. Children with epilepsy have been found to be

almost five times more likely to have behavioral problems than healthy controls [5]. Dunn and Austin [6] reported younger age at onset of seizures, lower socioeconomic status, and family stress as predictors of behavioral problems in children and young people with epilepsy (CYPE). Neuropsychological assessment and parental questionnaires within the first year of diagnosis have demonstrated that significantly more children with epilepsy require special educational assistance than matched classmate controls [7]. Children with epilepsy also obtained worse scores in behavioral and cognitive domains.

Given the potential for psychosocial difficulties related to epilepsy, the impact on quality of life (QoL) has been researched. In adult studies, depression and anxiety were found to explain more variance in QoL than seizure control/frequency or demographic variables [8,9]. In Baker et al.'s [10] international questionnaire study, more than one-third of CYPE who responded expected the condition to hinder their lives in the future, with 36% keeping their epilepsy a secret from others from fear of being treated differently. Taylor et al. [11] found that when compared with healthy children and children with asthma, children with newly diagnosed epilepsy had significantly poorer QoL across multiple domains. In children with new-onset epilepsy, QoL

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was significantly poorer. The study also noted that parents of children with epilepsy reported reduced QoL. They suggest that QoL could be improved in adolescents with newly diagnosed epilepsy through psychosocial interventions focussed on increasing self-esteem [11]. Involvement of parents in these interventions was also advocated to maintain healthy and positive parent–child relationships. The literature indicates that both psychosocial and seizure factors affect on the wellbeing of CYPE, and that cognitive and academic functioning and psychosocial adjustment can be negatively impacted by epilepsy, underlining the need for early intervention.

Dunn and Austin [6] found that children with a more positive response and attitude toward illness and increased sense of control over their epilepsy had a reduced risk of developing behavioral problems, depression, and poor self-concept. Ostrom et al. [7] reported that epilepsy syndrome, use of AED, and seizure control were not significantly related to the cognitive or behavioral findings. Rather, the child's prediagnostic learning and behavioral histories and the parents' ability to continue their habitual parenting postepilepsy diagnosis were associated with cognitive and behavioral functioning [12]. However, Hermann et al. [13] found that inadequate seizure control (frequency and severity) was the best predictor of behavioral problems in 6- to 11-year-old children. Much of the literature has used self- and carer-reported QoL via standardized questionnaires, but some have used qualitative techniques to develop a better understanding of the issues and concerns directly expressed by CYPE [14,15]. These studies have used the young people's own perspectives to develop a biopsychosocial model of the impact of epilepsy on the lives of young people and have been used by the current authors to develop a manualized psychosocial intervention (the PIE trial).

The recent NICE guidelines on the management of epilepsy by healthcare professionals promote the consideration of the physical, psychological, and social needs of CYPE, highlighting that particular attention should be paid to their relationships with family and friends, and at school [16]. It is also recommended that CYPE should be given information on general issues with epilepsy, ranging from treatment options to the impact on lifestyle, e.g., effects of sleep deprivation [16].

Within the last fifteen years, research developing psychosocial interventions for CYPE has increased, with the majority using group educational programs and cognitive and behavioral interventions. Several reviews have been carried out in this area in the past ten years, but often, they do not meet the requirements of a *systematic* review [17–19]. The focus of most has been on adult populations, although two do include child and adolescent studies [20,21]. A more recent Cochrane systematic review examined the effectiveness of specialist service models for children with epilepsy and their families [22]. Although the Cochrane paper reviewed some of the studies that will be included in the current review, it focussed on comparing the effectiveness of specialist teams/individuals in the care of children with epilepsy with usual care services and only included controlled studies. It was, therefore, considered timely to review the literature on psychosocial interventions for CYPE, incorporating a wider range of methodologies and also including studies published since 2010. This systematic review aimed to synthesize and analyze the research that investigates psychosocial interventions for CYPE. In addition to a summary of study findings, it critically assesses the quality of the evidence. An evaluation of the literature will help determine the effectiveness of interventions for CYPE and may help to develop guidelines on their use.

For the purpose of this review, a psychosocial intervention is defined as a therapeutic intervention, without a pharmacological component, focussing on psychological, relational, and social functioning. They can include formal psychological interventions, e.g., CBT and health education-based programs, as well as those with an emphasis on developing social interaction skills. Interventions with physical exercise content can also be considered under this definition if the aims

are to improve psychosocial wellbeing through physical activity and the associated physical and social benefits.

1.1. Review aims

1. To establish if there is any evidence for the efficacy of psychosocial interventions for CYPE.
2. To identify specific treatment components or methods of delivery that may increase the efficacy of these interventions.
3. To identify whether study intervention goals were clearly specified and how these were measured.

2. Method

The PRISMA statement [23] was used as guidance for the undertaking and reporting of this systematic review.

2.1. Search strategy

The following electronic databases were systematically searched on 28th November 2014 to identify studies: CINAHL, PsychInfo, and Psychology & Behavioral Sciences Collection (via EBSCO host); Embase and Medline (via OVID online); and Web of Science (via Web of Knowledge).

The following search terms were used, both as key words and as Medical Subject Headings (MeSH), creating four search strings (using the Boolean operators 'OR' to combine searches within strings and 'AND' to combine search strings).

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Exp Epilepsy OR Epilep*
AND
Psychosocial OR Psychoeducation* OR Psycholog* OR Psychotherap*
OR Exp Psychotherapy
AND
Interven* OR Treat* OR Therap*
*Signifies truncations or possible extra letters in the term to be included within the search. 'Exp' indicates the term was exploded.
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Searches were limited to those published in English with human subjects. An age limit was not set as this could have excluded some studies meeting inclusion criteria. Hand searches were also carried out on reference lists of 7 review papers in addition to the electronic search [17–22,24]. Duplicate entries were removed. Where more than one paper reported on the same participant sample within the same follow-up timeframe, all papers were selected for inclusion. The following selection criteria were applied. Inclusion criteria: (1) studies published in English from any country, (2) studies published in peer reviewed journals, (3) studies published between 1989 and 2014, (4) studies describing original data, and (5) studies including children and young people aged 0–19 years with a diagnosis of any type of epilepsy.¹ Exclusion criteria: (1) drug/animal studies, (2) studies including participants without an epilepsy diagnosis, (3) studies including participants with learning disabilities, (4) studies including children and adolescents within an adult population, and (5) studies with a ketogenic diet as the sole content. The following categories of article were also excluded: case studies, qualitative studies, book sections, systematic reviews, literature reviews, meta-analyses, dissertations, conference presentations/abstracts, guidelines, and commentaries.

¹ In the UK, child and adolescent health services typically provide care for children up to age 18 years (or age 16 years in some pediatric hospital settings). The age of adolescence is currently debated with regard to brain and social development, with some now arguing that it continues into a person's twenties [25,26]. However, it was decided that this review would use the World Health Organization and UNICEF's definition of adolescence of any person between ages 10 and 19 years. A participant age range from 0 to 19 years was, therefore, set [27].

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