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[Intervention Review]

Care delivery and self-management strategies for children with epilepsy

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Contact: Nigel Fleeman, nigel.fleeman@liverpool.ac.uk.**Editorial group:** Cochrane Epilepsy Group.**Publication status and date:** New search for studies and content updated (no change to conclusions), published in Issue 4, 2022.**Citation:** Fleeman N, Bradley PM, Panebianco M, Sharma A. Care delivery and self-management strategies for children with epilepsy. *Cochrane Database of Systematic Reviews* 2022, Issue 4. Art. No.: CD006245. DOI: [10.1002/14651858.CD006245.pub5](https://doi.org/10.1002/14651858.CD006245.pub5).

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ABSTRACT

Background

Epilepsy is a neurological disorder affecting both children and adults. Epileptic seizures are the result of excessive and abnormal cortical cell electrical activity in the brain. In response to criticism that epilepsy care for children has little impact on long-term outcomes, healthcare professionals and administrators have developed various service models and strategies to address perceived inadequacies.

This is an updated version of a Cochrane Review previously published in 2018.

Objectives

To assess the effects of any specialised or dedicated intervention for epilepsy versus usual care in children and adolescents with epilepsy and their families.

Search methods

We searched the following databases on 14 January 2020: the Cochrane Register of Studies (CRS Web), MEDLINE (Ovid, 1946 to 13 January 2020), PsycINFO (1887 to 14 January 2020), CINAHL Plus (1937 to 14 January 2020), ClinicalTrials.gov, and the World Health Organization International Clinical Trials Registry Platform. The Cochrane Register of Studies (CRS Web) includes the Cochrane Epilepsy Group Specialised Register and the Cochrane Central Register of Controlled Trials (CENTRAL). We also contacted experts in the field seeking information on unpublished and ongoing studies and checked the websites of epilepsy organisations and the reference lists of included studies.

Selection criteria

We included randomised controlled trials recruiting children and adolescents with epilepsy.

Data collection and analysis

Two review authors independently selected trials for inclusion and extracted the relevant data. We assessed the following outcomes: 1. Seizure frequency and severity; 2. Appropriateness and volume of medication prescribed (including evidence of drug toxicity); 3. Participants' reported knowledge of information and advice received from professionals; 4. Participants' reports of health and quality of life; 5. Objective measures of general health status; 6. Objective measures of social or psychological functioning (including the number of days spent on sick leave/absence from school or work, and employment status); and 7. Costs of care or treatment. The results of the data extraction and quality assessment for each study were presented in structured tables and as a narrative summary. All summary statistics were extracted for each outcome.

Main results

We included nine studies of eight interventions in the review, reporting on seven distinct self-management programmes for educating or counselling children with epilepsy and their parents, and one new model of care. Based largely on self-reported outcomes, each programme showed some benefits for the well-being of children with epilepsy; however, all of the included studies had methodological flaws. No single programme was evaluated with different study samples, and in no instance was the same outcome measured and reported in the same way across studies, precluding any possible meta-analysis, even if the interventions were considered sufficiently similar to include in meta-analysis.

We chose the outcomes for which data might be important for decisions about the interventions as per guidance in the *Cochrane Handbook for Systematic Reviews of Interventions*. We found moderate certainty evidence that one of the educational interventions reduced seizure frequency. There was low certainty evidence that two other educational interventions reduced seizure severity, seizure control, and seizure cure rates. The evidence for all other outcomes (drug adherence, knowledge, self-efficacy and self-perception of epilepsy on quality of life) was mixed.

Authors' conclusions

Whilst each of the programmes evaluated in this review showed some benefit to children with epilepsy, their impact was extremely variable. No programme showed benefits across the full range of outcomes, and all studies had methodological problems. There is currently insufficient evidence in favour of any single programme. Further evidence from randomised controlled trials using validated measures and considering clinical meaningfulness as well as statistical significance of results is required.

PLAIN LANGUAGE SUMMARY

Care delivery and self-management strategies for children with epilepsy

Background

Epilepsy is a disorder that affects the nervous system of children and adults. Epileptic seizures (fits) are the result of excessive and abnormal activity in the brain, which are unpredictable in frequency. Most seizures are well controlled with medicines and other types of treatments, although epilepsy can cause problems in social, school, and work situations, making independent living difficult. People with seizures tend to have physical problems (e.g. fractures, bruising, and a slightly increased risk of sudden death) as well as social problems because of the stigma attached to the illness. People with epilepsy and their families may lack social support or experience social isolation, embarrassment, fear, and discrimination, and some parents of children with epilepsy may also feel guilty. Self-management of epilepsy refers to a wide range of health behaviours and activities that a person can learn and adapt to control their seizures and improve their well-being. This approach requires a partnership between the person and the providers of services (e.g. specialist epilepsy outpatient clinics, nurse-based liaison services between family doctors and specialist hospital doctors, specialist epilepsy community teams), as well as targeted services for specific groups (e.g. children, teenagers, and families).

Study characteristics

We searched scientific databases for studies in children and adolescents with epilepsy that looked at the effects of self-management of epilepsy. We wanted to look at several outcomes to see how well people with epilepsy and their families generally cope with the condition.

Search date

We included evidence published up to January 2020.

Key results

This review compared seven education- or counselling-based self-management programmes for children and adolescents with epilepsy, plus one new way of delivering nursing care. Each strategy appeared to improve some of the outcomes studied, although no intervention improved all the outcomes that were measured. The studies also had problems with their methods, which made their results less reliable. Whilst none of the interventions caused any harm, their impact was limited. There is insufficient evidence to support any single strategy as the best one for children with epilepsy.

Quality of the evidence

The quality of the evidence was poor because all of the included studies had problems in how they were run.