

How effective are self-management interventions for children with epilepsy? A Cochrane Review summary with commentary



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The aim of this commentary is to discuss from a rehabilitation perspective the published Cochrane Review ‘Care delivery and self-management strategies for children with epilepsy’ by Fleeman and Bradley,¹ under the direct supervision of Cochrane Epilepsy Group. This Cochrane Corner is produced in agreement with *Developmental Medicine & Child Neurology* by Cochrane Rehabilitation.

BACKGROUND

Epilepsy is defined as ‘a brain disease characterized by abnormality in brain activity predisposing to generate seizures which is associated not only with neurological but also with cognitive, psychological, and social consequences’.²

Globally, idiopathic epilepsy is the fifth largest contributor of neurological disability-adjusted life-years with the prevalence being the highest between 5 and 9 years and in those older than 80 years.³ Treatment of epilepsy usually requires uninterrupted pharmacological treatment to control seizures, as well as non-pharmacological approaches including self-management interventions.² Self-management interventions promote active participation of individuals in managing their own health condition through better understanding of the condition and treatment adherence, and the adoption of a healthy lifestyle which may reduce frequency of seizures, and improve functioning and quality of life (QoL).^{2,4} A Cochrane Review,¹ an update of two previous reviews,^{5,6} studied the effectiveness of self-management interventions in the care of children with epilepsy.

This summary is based on a Cochrane Review previously published in the *Cochrane Database of Systematic Reviews* 2018, Issue 3, Art. No.: CD006245. <https://doi.org/10.1002/14651858.CD006245> (see www.cochranelibrary.com for information). Cochrane Reviews are regularly updated as new evidence emerges and in response to feedback, and Cochrane Database of Systematic Reviews should be consulted for the most recent version of the review. The views expressed in the summary with commentary are those of the Cochrane Corner authors and do not represent the Cochrane Library or Wiley.

CARE DELIVERY AND SELF-MANAGEMENT STRATEGIES FOR CHILDREN WITH EPILEPSY¹

What is the aim of this Cochrane Review?

The aim of this Cochrane Review¹ was to evaluate the effects of any dedicated or specialized intervention for epilepsy aiming to improve self-management in children affected by epilepsy and their parents.

What was studied in the Cochrane Review?

Children under 18 years of age with any epilepsy diagnosis (either new or recurrent) were assessed. Any education or counselling intervention aiming to improve self-management of children or adolescents with epilepsy and involving a dedicated or specialized team/person for the care of these children in a variety of settings including hospitals or specialized clinics, community, or care networks were studied. The intervention was compared to usual care. The outcomes studied were seizure severity and frequency, appropriateness and volume of prescribed medication, knowledge of information and advice provided by professionals, health and QoL as reported by child or family, general health status and psychological or social functioning such as sick leave days or school absenteeism, and costs relevant to care or treatment.

Up-to-dateness of the Cochrane Review

The review authors searched for studies that had been published up to 27th September 2016.

What are the main results of the Cochrane Review?

The review¹ included seven trials (five randomized controlled trials⁷⁻¹¹ and two before-and-after controlled trials^{12,13}) and compared six distinct innovative interventions (education, counselling, and training programs) either for children ($n=4$),^{7-9,12} or teenagers ($n=1$),¹¹ or children and adolescents ($n=1$)¹³ and their parents (involved in all interventions) aiming to improve self-management of children with epilepsy. Specifically, the interventions included: (1) ACINDES model, a self-management training program using play techniques for children with chronic conditions (not specific to epilepsy) aiming to improve social functioning and QoL;⁷ (2) the Children’s Epilepsy Program (CEP), an educational program for children and parents

involving sessions on seizure control and coping with and adapting to epilepsy;^{8,9} (3) the Supporting Treatment Adherence Regimen (STAR), an intervention tailored to families aiming to improve antiepileptic drug adherence;¹⁰ (4) Issue-Specific Family Counseling Model (ISFCM), a model involving sessions for teenagers and families to help in attaining counselling aims;¹¹ (5) FAMOSES, a modular educational program for children with epilepsy and their parents to support knowledge development, treatment, and coping and living with epilepsy;¹² and (6) FLIP&FLAP, a program for families involving educational sessions to convey knowledge on epilepsy and its management using an experience-based learning strategy.¹³

The review found the following on specified outcomes when compared with controls (usual care,^{7,10} traditional education,^{8,9} or waiting list controls^{12,13}) and three methods were compared for ISFCM.¹¹

Seizure severity and frequency (two trials)

The ACINDES model⁷ showed a significant reduction in the number of seizures at 12 months and FAMOSES¹² did not make any difference to seizure frequency at 3 months.

Appropriateness and volume of prescribed medication (three trials)

STAR¹⁰ and FAMOSES¹² did not make a difference to antiepileptic drug adherence and tolerability and efficacy, respectively, at 3 months. FLIP&FLAP¹³ significantly improved parent-reported self-management skills of children such as taking medication at 6 months.

Knowledge of information and advice provided by professionals (six trials)

ACINDES⁷ improved knowledge, fears, and anxieties of parents. CEP^{8,9} improved both children's and parents' knowledge gain in general. However, not all of the wide range of questions asked were correctly answered by both children or parents in favor of the intervention group. It seemed CEP significantly improved knowledge on some issues during seizure in children (five items) and some medical issues in parents (three items) and, though not significantly, improved five more items in children and seven in parents such as the importance of taking medicines as prescribed and some during-seizure issues. STAR¹⁰ and FAMOSES¹² significantly increased parents' knowledge of epilepsy. FLIP&FLAP¹³ appeared to improve epilepsy knowledge in children, knowledge of seizure triggers and medical aspects in both adolescents and parents, and social aspects and giving information on epilepsy to others only in parents.

Health and QoL (five trials)

Parents let children stay at friends' homes overnight after participating in ACINDES.⁷ CEP⁸ seemed to improve social, but not academic, athletic, appearance, behavior, or self-esteem competencies. Children receiving CEP⁸ were more prone to describe social skills gain and participation

in everyday activities. CEP⁹ resulted in less anxiety and fear in parents at 5 months. Different delivery types of ISFCM¹¹ (face-to-face, videoconferencing, telephone) did not show a difference regarding perception of frequency and severity of family problems. Prosocial and problem behavior scales scores of teenagers significantly improved as rated by parents and teachers across the three modes both at 1 week and 6 months.¹¹ FAMOSES¹² significantly improved getting used to and anxiety about epilepsy, as well as attendance restrictions among parents and reduced social restrictions among children, while not making a difference to other items such as QoL, anxiety, attitudes, coping, social restrictions, and impact of epilepsy among parents.

General health status

There were no studies reporting objective measures of this outcome.

Social or psychological functioning (four trials)

ACINDES⁷ resulted in significantly fewer emergency visits and less absenteeism from school, but not in regular medical visits when compared to controls. STAR¹⁰ was found to improve parents' self-management significantly, but not social problem-solving or response of the parents to child illness. No differences were found across different delivery modes of ISFCM¹¹ in treatment program adherence. FAMOSES¹² did not make any difference to absenteeism from school.

Costs relevant to care or treatment

There were no studies reporting on this outcome.

Harm

None of the interventions studied created any harm.

How did the authors conclude on the evidence?

The authors concluded that each of the interventions evaluated had some beneficial effects for children with epilepsy; however, no single program was effective on the full range of user outcomes. Currently, the evidence is insufficient to favor and/or recommend any single program due to the large variability and limitations of their effects, as well as very serious methodological flaws in trials compromising their reliability. Given the quality of evidence is poor, there is uncertainty as to which intervention is best.

What are the implications of the Cochrane evidence for practice in rehabilitation?

Although self-management interventions are important in epilepsy care,² it is not clear which specialized intervention is the best. The weakness and uncertainty of the evidence does not allow us to make recommendations on any of the self-management interventions studied. However, the review¹ points to favorable effects of innovative care delivery models on some aspects relevant to the well-being of children or adolescents with epilepsy, and the impact on

parents if delivered in partnership between the users and providers. But, given the heterogeneity of interventions, the results are not generalizable and future research is needed to clarify the effects of these interventions. The review¹ also indicates the lack of independent evaluation of any single intervention in different populations. This raises the important concept of clinical replicability/applicability for complex interventions such as self-management in future studies. Better description of PICO (Population, Intervention, Comparison, and Outcome) questions in future studies could be helpful in varying clinical settings and/or populations.¹⁴ The International Classification of Functioning, Disability and Health (ICF)¹⁵ [Children and Youth version (ICF-CY)¹⁶ in this case] could play a key role for specifying outcomes and standardized reporting of interventions to increase replicability.¹⁷

Health professionals involved in epilepsy care need to conduct future research to provide more conclusive and generalizable evidence on the effectiveness of self-management in epilepsy. The use of ICF-CY¹⁶ when collecting data could help understanding of the effects of interventions on specific functioning categories identified as relevant to epilepsy.¹⁸ Moreover, future research needs to consider which elements of self-management interventions are culture-specific and which are common across different countries and societies.

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