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Fleeman N, Bradley PM, Lindsay B

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[Intervention Review]

Care delivery and self management strategies for children with epilepsy

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ABSTRACT

Background

Epilepsy care for children has been criticised for its lack of impact. Various service models and strategies have been developed in response to perceived inadequacies in care provision for children and their families.

Objectives

To compare the effectiveness of any specialised or dedicated intervention for the care of children with epilepsy and their families to the effectiveness of usual care.

Search methods

We searched the Cochrane Epilepsy Group Specialized Register (9 December 2013), the Cochrane Central Register of Controlled Trials (CENTRAL) (*The Cochrane Library*, 2013,Issue 11), MEDLINE (1946 to June week 2, 2013), EMBASE (1988 to week 25, 2013), PsycINFO (1887 to 11 December 2013) and CINAHL Plus (1937 to 11 December 2013). In addition, we contacted experts in the field to seek information on unpublished and ongoing studies, checked the websites of epilepsy organisations and checked the reference lists of included studies.

Selection criteria

We included randomised controlled trials (RCTs), controlled or matched trials, cohort studies or other prospective studies with a control group (controlled before-and-after studies), or time series studies.

Data collection and analysis

Each review author independently selected studies, extracted data and assessed the quality of included studies.

Main results

We included five interventions reported in seven study reports (of which only four studies of three interventions were designed as RCTs) in this review. They reported on different education and counselling programmes for children, children and parents, teenagers and parents, or children, adolescents and their parents. Each programme showed some benefits for the well-being of children with epilepsy, but each study had methodological flaws (e.g. in one of the studies designed as an RCT, randomisation failed) and no single programme was independently evaluated by more than one study.

Authors' conclusions

While each of the programmes in this review showed some benefit to children with epilepsy, their impacts were extremely variable. No programme showed benefits across the full range of outcomes. No study appeared to have demonstrated any detrimental effects but the evidence in favour of any single programme was insufficient to make it possible to recommend one programme rather than another. More studies, carried out by independent research teams, are needed.

PLAIN LANGUAGE SUMMARY

Care delivery and self management strategies for children with epilepsy

Background

Epilepsy is spectrum of disorders in which a person may have seizures (fits) that are unpredictable in frequency. Most seizures are well controlled with medicines and other types of treatments but epilepsy can cause problems in social, school and work situations, and make independent living difficult. People with seizures tend to have physical problems (e.g. fractures and bruising and rarely an increased risk of sudden death) and problems with how the illness is viewed leading to people with epilepsy being 'labelled'. People with epilepsy and their families may then experience a lack of social support, social isolation, embarrassment, fear and discrimination, and some parents may also feel guilt. 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 needs 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 and volunteers), and targeting of services at specific groups (e.g. children, teenagers and the families).

Study characteristics

We searched scientific databases for clinical trials of children (aged 18 years or under) with epilepsy that looked at the effects of self management of epilepsy. The results are current to December 2013. We wanted to look at several outcomes (e.g. how often seizures occurred, how bad they were, how well the medicines worked, how well the child felt, school/work attendance and cost of care) to see how well or badly people and their families cope with epilepsy.

Key results

This review compared five education- or counselling-based interventions (treatments) for children with epilepsy. One intervention was aimed solely at children, two were aimed at children and their parents, one was aimed at teenagers and their parents, and one was aimed at children, adolescents and their parents. Each of the interventions appeared to improve some of the outcomes studied, but no intervention improved all of the outcomes that were measured. The studies also had problems with their methods, which makes their results less reliable. While none of the interventions caused any harm, their impact was limited and we cannot recommend any single intervention as being the best one for children with epilepsy.

Evidence for the best ways to care for children with epilepsy is still unclear.

Quality of the evidence

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

BACKGROUND

Description of the condition

Epilepsy is spectrum of disorders in which a person may experience seizures that are unpredictable in frequency (England 2012). At least 40 different seizure types have been identified (Berg 2010). While for the majority of people seizures are well controlled with

medications and other treatment options, epilepsy can pose challenges in social, school and work situations and for independent living. Not only do people with seizures tend to have more physical problems (such as fractures and bruising and rarely an increased risk of sudden death) but a significant challenge for people with epilepsy is how the condition is perceived (or indeed misperceived) which can lead to people with epilepsy being stigmatised (Bandstra 2008). As a result, both people with epilepsy and their families may experience a lack of social support, social isolation, embarrassment, fear and discrimination, while some parents also report feelings of parental guilt (England 2012). Epilepsy affects around 50 million people worldwide with around 80% of all cases in developing countries (WHO 2012). Epilepsy is most common in children and older adults (Betts 1992; Sander 1990).

Description of the intervention

The self management of epilepsy refers to a wide range of health behaviours and activities that a person can learn and adapt in order to promote seizure control and enhance well-being (Austin 1997). Self management of any condition typically entails a partnership between users and providers of services (Clark 2008). Various dedicated models of service provision may be utilised to improve care networks and self education (Clark 2010; Fitzsimons 2012; SIGN 2003; SIGN 2005). Services may include specialist epilepsy outpatient clinics, nurse-based liaison services between primary (general practitioner; GP) and secondary/tertiary (hospital-based) care and specialist epilepsy multi-disciplinary community teams (Clark 2010; Fitzsimons 2012; SIGN 2003; SIGN 2005). Services may also include input from social care or the voluntary sector (Clark 2010; SIGN 2003; SIGN 2005), and be targeted at specific groups, such as children, teenagers and the families of people with epilepsy.

How the intervention might work

Specialist or dedicated models of care, care networks or self education and self management may improve the quality of care, promote more systematic multi-disciplinary follow-up, and enhance communication among professionals, patients and other services (Fitzsimons 2012). Importantly, it should enable people with epilepsy (and their families) to cope with all aspects of the disease through improved self education and self management (Clark 2008; Fitzsimons 2012).

Why it is important to do this review

Epilepsy care has been criticised as 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). In order to improve the quality of care for people with epilepsy, we aimed to produce a systematic review of the evidence from studies investigating the effectiveness of these service models compared to non-specialist services. This systematic review is an update of the Cochrane review previously published in 2010 (Lindsay 2010).

OBJECTIVES

To compare the effectiveness of any specialised or dedicated intervention for the care of children with epilepsy and their families to the effectiveness of usual care.

METHODS

Criteria for considering studies for this review

Types of studies

We included several study types in the review, as the interventions considered were highly variable and complex. The inclusion criteria for studies were based on those used by The Cochrane Effective Practice and Organisation of Care (EPOC) Group. We included all randomised controlled, controlled or matched trials, cohort or other prospective studies with a control group (controlled before-and-after studies) or time series studies.

Types of participants

We considered studies that included children with any diagnosis of new or recurrent epilepsy aged under 18 years eligible for this review. We included studies incorporating epilepsy with other long-term conditions if results were reported for each condition separately.

Types of interventions

We considered any intervention including a specialised or dedicated team or person for the care of children with epilepsy whether based:

- in hospital (e.g. a specialist epilepsy clinic);
- in the community (e.g. a specialist pharmacist);
- in general practice (e.g. a specialist epilepsy nurse);
- elsewhere (e.g. social worker, the voluntary sector);
- as a care network combining any of these elements;
- on education or counselling for improved self management.

Types of outcome measures

The outcome measures included:

- seizure frequency and severity;
- appropriateness and volume of medication prescribed (including evidence of drug toxicity);
- child or family's reported knowledge of information and advice received from professionals;
- child or family's reports of health and quality of life (including adverse effects of medication);
- objective measures of general health status;
- objective measures of social or psychological functioning (including the number of days spent on sick leave/absence from school and employment status);
- costs of care or treatment.

We assessed all outcome measures for reliability and validity (i.e. for clinical relevance or whether validated tools were used for outcome measurement). If measures were misused (e.g. adults scales used on children), we investigated their effect on study results using a sensitivity analysis.

Search methods for identification of studies

We searched the following databases.

- Cochrane Epilepsy Group Specialized Register (9 December 2013). See Appendix 1 for details of search strategy.
- Cochrane Central Register of Controlled Trials (CENTRAL) (*The Cochrane Library* 2013, Issue 11). See Appendix 2 for details of search strategy.
- MEDLINE (Ovid) (1946 to June week 2, 2013). See Appendix 3 for details of search strategy.
- EMBASE (1988 to week 25, 2013). See Appendix 4 for details of search strategy.
- PsycINFO (EBSCOhost) (1887 to 11 December 2013). See Appendix 5 for details of search strategy.
- CINAHL Plus (EBSCOhost) (1937 to 11 December 2013). See Appendix 6 for details of search strategy.

Finally, we contacted experts in the field to seek information on unpublished and ongoing studies, checked the websites of epilepsy organisations and checked the reference lists of included studies. It should be noted that this review was undertaken at the same time as a review of care delivery and self management strategies for adults with epilepsy. Consequently, the same search strategy was used for both reviews.

Data collection and analysis

Selection of papers

We screened papers in two stages. At stage one, two review authors (PM and BL in the original review, PM and NF in the updated review), independently screened all titles and abstracts of papers identified by the searches for relevance. We excluded only papers that were clearly irrelevant at this stage. At stage two, two review authors (PM and BL in the original review, PM and NF in the updated review) independently screened the full papers, identified relevant studies and assessed eligibility of studies for inclusion. We resolved any disagreements by discussion.

Data extraction

The same review authors extracted the following types of data:

- study characteristics - place of publication, date of publication, population characteristics, setting, detailed nature of intervention, detailed nature of comparator and detailed nature of outcomes. A key purpose of these data was to define unexpected clinical heterogeneity in included studies independently from analysis of results.
- results of included studies with respect to each of the main outcomes indicated in the review question including data on outcomes not considered and to consider the possibility of selective reporting of results on particular outcomes.

We resolved any disagreements when extracting data by discussion. If reports provided inadequate information, we contacted authors for further information.

Assessment of risk of bias of included studies

Two review authors (NF and PB) assessed every study independently using the suggested risk of bias criteria for Cochrane Effective Practice and Organisation of Care (EPOC) reviews (Cochrane EPOC 2012). We resolved any disagreements when assessing risk of bias by discussion. If reports provided inadequate information, we contacted authors for further information.

Data analysis and synthesis

We assessed clinical heterogeneity between studies by reviewing the differences across studies. There was considerable methodological and clinical heterogeneity in the studies so a meta-analysis was not considered appropriate. If we had decided to combine the results of any studies in a meta-analysis, we would have investigated heterogeneity using an I^2 test. If the results had shown heterogeneity, we would have investigated the cause (Higgins 2011).
If studies had been of a suitable quality and sufficiently homogeneous to combine in a meta-analysis, we would have used (standardised) mean differences for continuous variables and risk ratios (including Mantel-Haenszel analysis) for dichotomous variables using either a random-effects or fixed-effect model. For future updates of this review, if the data allow, we will consider sensitivity analyses based on the risk of bias.

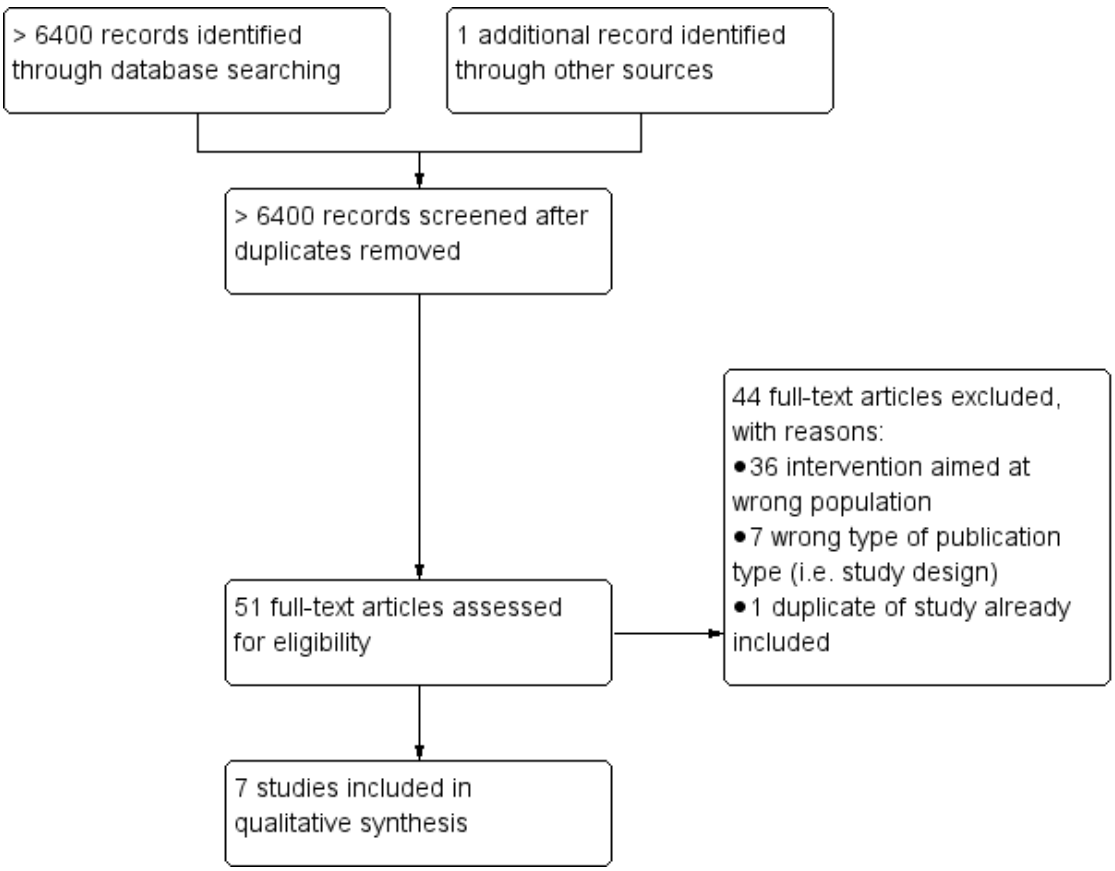
RESULTS

Description of studies

Flow of studies

In the original review, initial searches identified over 4000 papers, including duplicates, of which we included four (Glueckauf 2002; Lewis 1991; Rau 2006; Tieffenberg 2000). We identified a fifth paper (Lewis 1990) from the reference list of Lewis 1991: both of these papers reported on same intervention (the papers focused on the impact on children (Lewis 1990) and parents (Lewis 1991)). The updated searches yielded 2438 additional papers including duplicates plus two studies that were awaiting assessment from the original review (Jantzen 2009; Shore 2008). We included one of these, a controlled before-and-after study, in the review (Jantzen 2009). A further study published after the previous review was published was also included (Pfäfflin 2012). This study evaluated the same intervention as a previously included controlled before-and-after study (Rau 2006), but provided additional information. Thus, in total, we included seven different studies (four designed as randomised controlled trials (RCTs); Glueckauf 2002; Lewis 1990; Lewis 1991; Tieffenberg 2000), and three controlled before-and-after studies (Jantzen 2009; Pfäfflin 2012; Rau 2006)) reporting on five different interventions in the review (Figure 1). The study characteristics are summarised in the Characteristics of included studies table. Overall, we excluded 51 full-text articles (see Characteristics of excluded studies table).

Figure 1. Study flow diagram (original and updated searches).



Included studies

All of the included studies investigated interventions for improved self management: these interventions were identified by the review authors as education, counselling or training. No included study investigated specialist teams of health or social care professionals either in hospital or community settings or as care networks. One intervention included children only (Tieffenberg 2000), two included children and parents (one evaluated by two RCTs (Lewis 1990; Lewis 1991), and one evaluated by two controlled before-and-after studies (Pfäfflin 2012; Rau 2006)), one involved teenagers and parents (Glueckauf 2002), and one involved children, adolescents and parents (Jantzen 2009). The studies provided varying details about the specifics of the interventions. This information is summarised in Appendix 7. With the exception of the controlled before and after evaluation of FAMOSES (Pfäfflin 2012; Rau 2006), all of the interventions were designed, delivered and evaluated by the researchers who authored the reports.

Strategies for children

Tieffenberg 2000 reported on the effects of ACINDES, a model for self management training based on play techniques designed to train children in self management of chronic conditions and is not epilepsy-specific (children with asthma are also included) (see Appendix 7 for details). The model was developed by the researchers specifically for Spanish-speaking children aged six to 15 years.

One RCT used ACINDES to evaluate 355 children in Buenos Aires, Argentina, of whom 167 had epilepsy. Both children and parents were interviewed before the programme and at six and 12 months after its completion. In addition, medical and school records were monitored for emergency and routine visits, hospitalisations and school absenteeism. The intervention group received the ACINDES programme while children and parents in the control group received routine care without additional training.

Strategies for children and parents

Lewis 1990 and Lewis 1991 evaluated the Children's Epilepsy Program (CEP), a child-centred, family-focused educational programme developed at the Medical Center of the University of California in Los Angeles (UCLA) for children and their parents (see Appendix 7 for details). For unreported reasons, the researchers could not recruit a suitable sample from the UCLA Medical Center and so the evaluation of the CEP was undertaken in Santiago, Chile. This required that the CEP was translated into Spanish for the trial. Lewis 1990 reported on the impact of CEP on children and Lewis 1991 reported on the impact of CEP on parents.

The evaluation of CEP was conducted by an RCT that recruited 252 children aged seven to 14 years and 294 parents selected from 1000 families belonging to the Liga Contra Epilepsia in an RCT. Families were randomly allocated in groups of 20 to the intervention and control groups. All participants were tested immediately prior to the first session and tested five months after the end of CEP. The intervention groups of children (n = 123) and parents (n = 185) separately undertook CEP whereas the control groups of children (n = 113) and parents (n = 109) jointly attended three two-hour sessions consisting of lectures and question and answer discussions. This was described as "passive learning" in contrast to the "active learning" of the intervention. Only 78.6% of children in the intervention group and 52% children in the control group attended all the required sessions (Lewis 1990); 73.2% of mothers and 59% of fathers attended all four sessions in the intervention group and 62% of mothers and 49% of fathers attended all three sessions in the control group (Lewis 1991).

Pfäfflin 2012 and Rau 2006 evaluated FAMOSES, a modular educational programme for children with epilepsy and their parents (see Appendix 7 for details). FAMOSES aims to improve knowledge, coping, treatment outcomes and adaptation to epilepsy through a series of educational modules.

FAMOSES was evaluated by a prospective, controlled before-and-after, multicentre study in Germany (Pfäfflin 2012; Rau 2006). Children with epilepsy, aged 7.2 to 15.9 years, and parents were allocated to an intervention group (children, n = 31; parents, n = 55) or waiting list control group (children, n = 19; parents, n = 48). Children and parents completed questionnaires at baseline and then three months after completing FAMOSES.

Strategies for teenagers and parents

Glueckauf 2002 studied the effects of a counselling programme based on counselling via video-conference (VFC) or office-based counselling (OFC) for teenagers and their families based in the rural midwest of the USA (see Appendix 7 for details). The model for the intervention is based on an Issue-Specific Family Counselling Model.

A three-arm RCT was designed to evaluate the counselling programme. A total of 39 families were recruited but 12 dropped out before counselling and five more dropped out prior to six-month follow-up. Hence, 22 teenagers and their 36 parents were randomised as follows: nine teenagers (and their parents) to VFC, six teenagers (and their parents) to OFC and seven teenagers (and their parents) to waiting list control. However, it was established that VFC was not possible for every family allocated to receive it because of a lack of digital services and, as a result, four of the nine families allocated to VFC were instead given counselling by speaker phone (SFC), that is the randomisation failed. Baseline measures required for the conduct the study were completed at the initial session. The participants received questionnaires after their sixth session and at six-month follow-up. Around 10% of study participants exercised their option to continue with two further sessions after the sixth session.

Strategies for children, adolescents and their parents

Jantzen 2009 evaluated the FLIP&FLAP programme (see Appendix 7 for details). The programme is based on an inventory used in family and behaviour therapy including imagination techniques, elaborating resources, role play and teaching problem-solving strategies, using an experience-based learning approach. The FLIP&FLAP programme was assessed utilising a multicentre (10 specialised German epilepsy centres) non-randomised two-group controlled before-and-after study using a waiting-list control group design. Eligible participants were children aged eight to 11 years or adolescents aged 12 to 16 years who were diagnosed with epilepsy, taking epilepsy medication and, along with a parent, were willing to participate in the study. All centres offered two educational courses. Applicants for the first course were assigned to the intervention group; applicants for the second course were assigned to the waiting-list control group; the waiting-list control group then participated in the programme six months later. Assessments were performed at baseline, six months after starting the programme and six weeks after completing the programme (in both groups).

Excluded studies

We excluded one of the studies awaiting classification (Shore 2008) from the previous version of this review (Lindsay 2010), because lacked a control group. It reported a feasibility study of the Seizures and Epilepsy Education (SEE) programme. Similarly, we excluded Austin 2002 for being a pre- and post-test feasibility study lacking a control group. We excluded three other studies in the original review for having the wrong type of study design (Price 2004; Shore 2008; Snead 2004). Although Hallfahrt 2007 reported on the FLIP&FLAP programme, which was an included study, it was confirmed by contact with the author that this did not include any new data (unlike Pfäfflin 2012), and so we excluded it. See Characteristics of excluded studies table.

Ongoing studies

We identified no ongoing studies.

Risk of bias in included studies

There is a potential risk of bias in all the seven included studies (Glueckauf 2002; Jantzen 2009; Lewis 1990; Lewis 1991; Pfäfflin 2012; Rau 2006; Tieffenberg 2000), particularly as three studies were not randomised (Jantzen 2009; Pfäfflin 2012; Rau 2006), and in a fourth, randomisation failed (Glueckauf 2002). Furthermore, it is unclear how participants were allocated to treatment, whether studies were blinded or how drop-outs were accounted for. Indeed, overall, four studies were considered at high risk of bias (Glueckauf 2002; Jantzen 2009; Pfäfflin 2012; Rau 2006), and no study was considered at low risk of bias overall. The assessments for each study are detailed in the Characteristics of included studies table and summarised in Figure 2, Figure 3, and in the text below.

Figure 2. Risk of bias graph: review authors' judgements about each risk of bias item presented as percentages across all included studies.

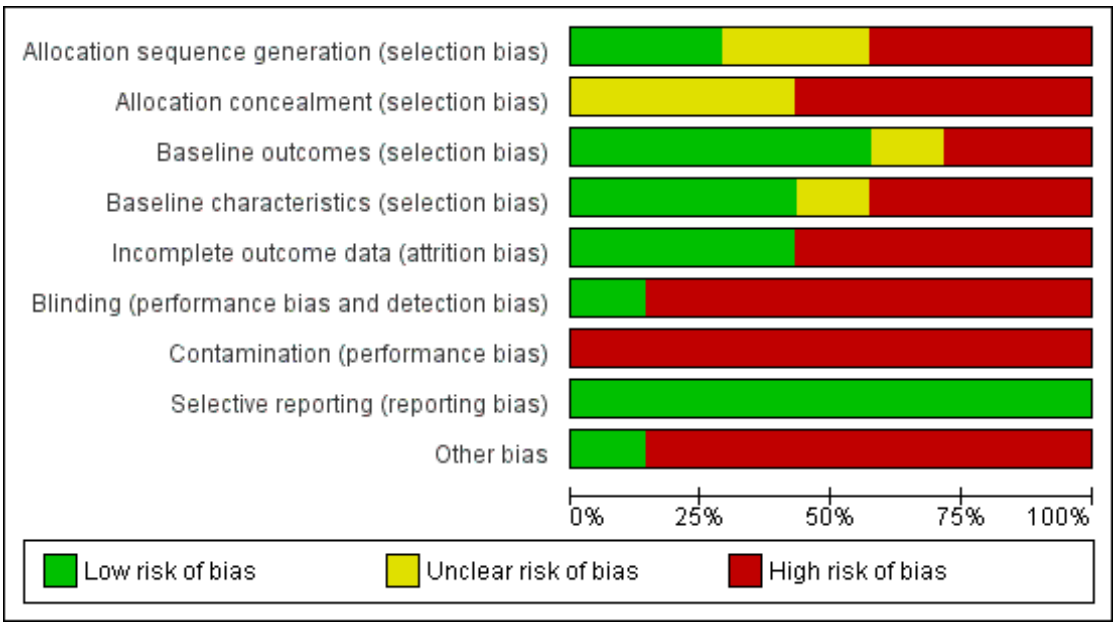
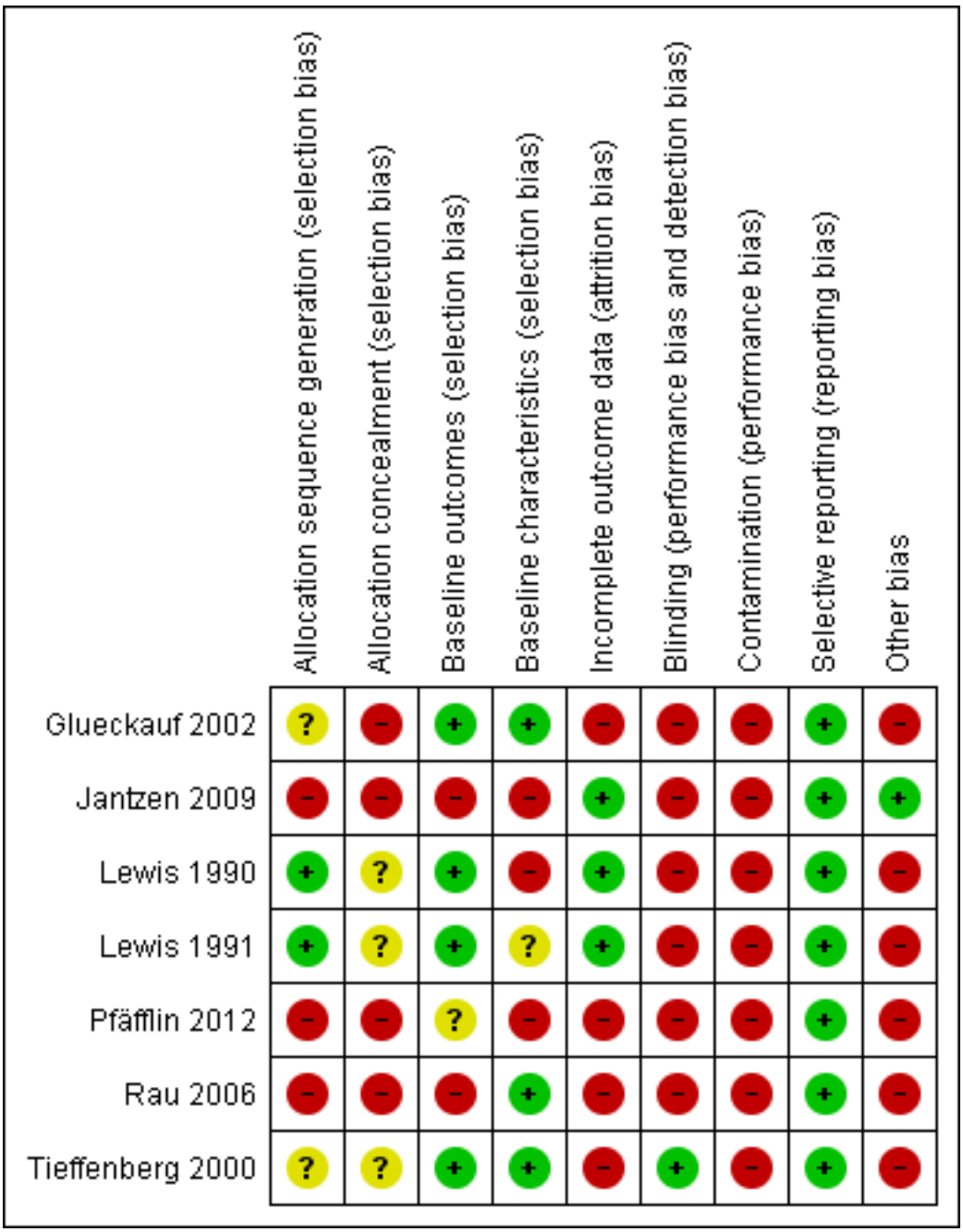


Figure 3. Risk of bias summary: review authors' judgements about each risk of bias item for each included study.



Allocation sequence generation

For four interventions, the risk of bias was high; in three instances because participants were not randomised (Jantzen 2009; Pfäfflin 2012; Rau 2006), and in a fourth because randomisation failed (Glueckauf 2002). In Tieffenberg 2000, the details of randomisation including the 'clustering techniques' were not reported and so we judged this to be of unclear risk of bias. Only the evaluations of CEP, which employed a simple randomisation design for both the evaluation of children with epilepsy and parents of children with epilepsy, were at low risk of bias (Lewis 1990; Lewis 1991).

Allocation concealment

No study adequately reported on allocation concealment. The risk of bias was high in all four of the controlled before-and-after studies (Glueckauf 2002; Jantzen 2009; Pfäfflin 2012; Rau 2006).

Baseline outcomes

Two studies were at high risk of bias for baseline outcomes. In the evaluation of FLIP&FLAP, scores were notably higher at baseline for a number of quality of life outcomes in the control group (Jantzen 2009). Furthermore, the mean contact with healthcare providers in the past six months was 3.32 in the intervention group compared with 2.03 in the control group. More parents in the control group reported a longer seizure-free duration, more parents in the intervention group reported better social knowledge of epilepsy and more contacts with healthcare providers in the last six months. In the evaluation of FAMOSES by Rau 2006, there was no discussion about how baseline potential differences might affect the result of the study before the data were analysed. In the latter evaluation of FAMOSES by Pfäfflin 2012, the risk of bias was unclear because a number of outcomes scores (including 'knowledge') were notably different between groups at baseline, all in favour of the control group; however, an analysis of covariance (ANCOVA) was performed with 'knowledge' at follow-up as dependent variable and 'knowledge' at baseline as covariate confirmed a significant group effect (control versus treatment) at follow-up after adjustment for baseline values. In the other four studies, there were no imbalances in outcomes at baseline and so the risk of bias for these studies was low (Glueckauf 2002; Lewis 1990; Lewis 1991; Tieffenberg 2000).

Baseline characteristics

Five studies were at high risk of bias as a result of imbalances in baseline characteristics. The evaluations of FLIP&FLAP by Jantzen 2009 and FAMOSES by Rau 2006 and Pfäfflin 2012 were at high risk as a result of imbalances at baseline. Both of the RCTs by Lewis 1990 and Lewis 1991, which evaluated CEP in children (Lewis 1990) and parents (Lewis 1991) were also at high risk due to imbalances in demographic characteristics at baseline. Only the studies by Glueckauf 2002 and Tieffenberg 2000 were at low risk of bias due to there being no imbalances in baseline characteristics.

Incomplete outcome data

Loss to follow-up was relatively low in FLIP&FLAP (Jantzen 2009) and CEP (Lewis 1990; Lewis 1991) (lower than 10%). Hence, the evaluations of these two interventions by these three studies were at low risk of bias. In the other four studies, loss to follow-up was relatively high (greater than 10%) (Glueckauf 2002; Pfäfflin 2012; Rau 2006; Tieffenberg 2000). These studies were at high risk of bias.

Blinding

Blinding was not reported for participants, clinicians or assessors in any study. Only the evaluation of ACINDES had lower risk of bias because the outcomes reported were less susceptible to subjective interpretation (i.e. analysis of hospital and school records) (Tieffenberg 2000). Because all outcomes for the other interventions were derived from self report, the lack of blinding was deemed to introduce a high risk of bias (Glueckauf 2002; Jantzen 2009; Lewis 1990; Lewis 1991; Pfäfflin 2012; Rau 2006).

Contamination

All seven studies were at high risk of contamination (Glueckauf 2002; Jantzen 2009; Lewis 1990; Lewis 1991; Pfäfflin 2012; Rau 2006; Tieffenberg 2000). This was because these were all education-based programmes and there was nothing to stop participants of intervention and control groups interacting with each other and sharing knowledge. The fact that blinding was not reported for participants, clinicians or assessors in any study heightened the risk.

Selective reporting

In all studies, the outcomes intended to be measured (reported in the methods sections) were reported (in the findings). Hence, all studies had low risk of bias for selective reporting (Glueckauf 2002; Jantzen 2009; Lewis 1990; Lewis 1991; Pfäfflin 2012; Rau 2006; Tieffenberg 2000).

Effects of interventions

The types of outcomes reported varied considerably between studies, even within apparently similar types of outcomes. We therefore concluded that meta-analysis of the results would be inappropriate and have presented the results of the studies narratively. We have only presented the findings reported that could be considered to match the pre-defined outcomes of our review.

Seizure frequency and severity

From one RCT evaluating ACINDES there was a significant difference (P value = 0.026) in terms of epileptic seizures between groups over time (mean (standard deviation; SD) 0.80 (1.46) at baseline to 0.34 (0.98) at 12 months) compared to control (0.49 (1.15) at baseline to 1.11 (2.77) at 12 months) (Tieffenberg 2000). The controlled before-and-after study by Pfäfflin 2012 reported that seizure frequency decreased significantly over time for children whose parents participated in FAMOSES (P value = 0.037) but not in children of the parents of the control group (P value = 0.156). The rate did not significantly differ between groups at three months (30.8% with FAMOSES versus 20.0% with control; P value = 0.397). None of the other studies reported seizure frequency and severity (Glueckauf 2002; Jantzen 2009; Lewis 1990; Lewis 1991).

At three months, there was a significant difference in seizure management amongst parents between groups participating in FAMOSES and controls, as measured by scores from a questionnaire (P value = 0.029). A five-year follow-up of parents who participated in FAMOSES was also reported by Pfäfflin 2012 indicating an improvement in seizure management and everyday management over time (P value = 0.036). On the contrary, the RCT conducted by Lewis 1991 reported that for CEP, there were no significant changes in answer to the question, "do you deal with your child's seizure disorder differently after the sessions?", where 21% of intervention parents and 29% of control parents answered affirmatively.

Appropriateness and volume of medication prescribed

Two controlled before-and-after studies reported appropriateness and volume of medication prescribed (Jantzen 2009; Pfäfflin 2012). For participants in FAMOSES, the tolerability and efficacy of antiepileptic drugs did not change significantly over time in either group (Pfäfflin 2012). In FLIP&FLAP there were significant differences between groups at six months in terms of child's self management skills (i.e. taking medication) (P value < 0.05) (Jantzen 2009). None of the other studies reported the appropriateness and volume of medication prescribed (Glueckauf 2002; Lewis 1990; Lewis 1991; Pfäfflin 2012; Rau 2006; Tieffenberg 2000).

Knowledge of information and advice received from professionals

At 12 months, the cluster RCT evaluating of ACINDES reported that parents' knowledge improved in the intervention group at 12 months (from 22% to 56%) compared to control (from 8% to 15%, probability of gain = 0.62, variance = 0.0026) and fears and anxieties improved in the intervention group at 12 months (from 69% to 30% for fear of child's death) compared to no change in the control group (from 74% to 65%, probability of gain = 0.63, variance = 0.0026) (Tieffenberg 2000). Similar results also occurred for children with significant improvements in knowledge, beliefs, attitudes and behaviours (probability of gain = 0.69, variance = 0.007).

At five months, the RCT evaluating CEP showed children in the intervention group were more likely to report generic gain in knowledge to the question "what were the important things that you learned" (mean: 64% with intervention versus 47% with control; P value < 0.01) (Lewis 1990). Intervention parents were also more likely to report generic gain in knowledge to the question "what were the important things that you learned" (mean: 59% with intervention versus 48% with control P value < 0.05) (Lewis 1991).

Specifically, Lewis 1990 reported that CEP showed significant differences between groups in percentage of children responding correctly to the following five knowledge items:

- inappropriate to have objects in mouth during seizure (mean baseline to five months: 40.7% to 71.5% with intervention versus 44.3% to 52.2% with control; P value = 0.002);
- inappropriate to restrain during seizure (mean baseline to five months: 34.9% to 79.7% with intervention versus 33.6% to 46.0% with control; P value = 0.001);
- not required to visit emergency department after seizure (mean baseline to five months: 30.9% to 78.1% with intervention versus 29.2% to 52.2% with control; P value = 0.001);
- purpose of electroencephalogram (EEG) (mean baseline to five months: 62.6% to 82.1% with intervention versus 63.7% to 69.0% with control; P value = 0.02);
- restriction of activities should be minimal (mean baseline to five months: 58.5% to 86.2% with intervention versus 58.4% to 68.1% with control; P value = 0.001).

Each group also reported slightly improved scores for the following four knowledge items (although all were reported to be "not significant" between groups):

- importance of taking medicines exactly as prescribed;
- knowledge that seizures start in the brain;
- purpose of drug blood levels to monitor dosage;
- positive effects of participation in sports;
- loss of sleep can trigger seizures.

In relation to specific items for parents, Lewis 1991 reported that CEP showed significant differences between groups in percentage of parents responding correctly to the following three knowledge items:

- loss of sleep can trigger seizures (mean baseline to five months: 62.7% to 50.3% with intervention versus 66.3% to 65.2% with control; P value = 0.005);
- purpose of EEG (mean baseline to five months: 80.0% to 90.3% with intervention versus 81.1% to 83.3% with control; P

value = 0.05);

- purpose of drug blood levels to monitor dosage (mean baseline to five months: 63.4% to 79.6% with intervention versus 67.2% to 87.8% with control; P value = 0.04).

Parents who undertook CEP were also more likely to recognise the importance of medicines (mean: 19% with intervention versus 9% with control; P value < 0.01). However, there were no significant changes for the following seven knowledge items:

- importance of taking medicines exactly as prescribed (mean baseline to five months: 94.6% to 97.3% with intervention versus 97.8% to 99.0% with control);
- inappropriate to have objects in mouth during seizure (mean baseline to five months: 35.3% to 78.8% with intervention versus 35.6% to 76.1% with control);
- inappropriate to restrain during seizure (mean baseline to five months: 52.2% to 76.3% with intervention versus 56.7% to 81.1% with control);
- not required to visit emergency department after seizure (mean baseline to five months: 68.1% to 93.0% with intervention versus 71.1% to 88.3% with control);
- knowledge that seizures start in the brain (mean baseline to five months: 86.0% to 93.5% with intervention versus 86.7% to 90.0% with control;
- restriction of activities should be minimal (mean baseline to five months: 88.6% to 96.7% with intervention versus 93.3% to 97.2% with control;
- positive effects of participation in sports (mean baseline to five months: 80.5% to 95.1% with intervention versus 73.3% to 90.0% with control).

At three months, one controlled before-and-after study of FAMOSES showed significant differences between groups in increased knowledge amongst parents (P value < 0.001) (Pfäfflin 2012; Rau 2006). Parents who participated in FAMOSES were also followed-up after five years by Pfäfflin 2012, where acquisition of new knowledge improved significantly over time (P value < 0.001).

At six months, one controlled before-and-after study of FLIP& FLAP showed significant differences between groups in knowledge of epilepsy amongst children (P value < 0.001) and parents (P value < 0.05) but not adolescents (Jantzen 2009). However, there was an improvement between groups in adolescent's (but not children's) knowledge for medical aspects (P value < 0.001) and seizure triggers (P value < 0.05). There were significant improvements between groups for parents' knowledge for medical aspects (P value < 0.05) and seizure triggers (P value < 0.001). In addition, there were significant improvements between groups for parents' knowledge of social aspects (P value < 0.001) and an improvement in the ability to explain epilepsy to others (P value < 0.001), but not between groups for children or adolescents.

Health and quality of life

Lewis 1990, using Harter's Self-competency Scale, reported that at five months, the RCT evaluating CEP showed significant differences between groups (excluding children under eight years of age) in social competency after scores were adjusted for pre-test values, age and sex (P value < 0.05). There were no significant changes (excluding children under eight years of age) for the following:

- scholastic competency;
- athletic competency;
- appearance competency;
- behaviour competency;
- self esteem competency.

In addition, Lewis 1990 reported that at five months, children in the intervention group were more likely to report gain in social skills (mean: 9% with intervention versus 2% with control; P value < 0.02) and participation in normal activities (mean: 11% with intervention versus 3.5% with control; P value < 0.03). There were "non-significant" changes for children's self care skills or children's reports of parents' behaviours or their disclosure of their epileptic status. Interestingly, two-thirds of children reported doing nothing different as a result of programme participation.

For parents who participated in the CEP, Lewis 1991 reported that there were significant differences between groups in parental anxiety as measured by Taylor Manifest Anxiety Scale. Parents in the intervention group showed greater reduction in anxiety than parents in the control group (P value < 0.01). However, the effect was not significant for fathers of children when analysed alone. At five months, there was a significant difference in the proportion of parents who reported feeling less anxious and fearful after the sessions (mean: 31% with intervention versus 10% with control; P value < 0.001). There were no differences in anxiety scores between people who attended all sessions and people who only attended some sessions.

From a controlled before-and-after study, Rau 2006 reported that at three months, there were no significant differences between participants in the FAMOSES group and the control group in quality of life as assessed by parents and children. However, the same study reported reduced social limitations amongst children (P value = 0.017) and reduced level of supervision needed and need for family resilience amongst parents in the intervention group (P value = 0.031). Pfäfflin 2012 reported three other improvements for parents in the intervention group compared to the control group, namely: improved adaption to epilepsy amongst parents (P value = 0.001); reduced anxiety about epilepsy amongst parents (P value = 0.014), and parental ability to exert rules and limitations for children about need for supervision (P value = 0.031). Other outcome measures relating to quality of life showing significant differences between groups in the FAMOSES group were improved attitudes amongst parents (P value = 0.001) and reduced fears amongst parents (P value = 0.014) (Rau 2006). There were no significant differences for sporting limitations, coping strategies or attitudes. Outcome measures showing no significant differences for parents

were: coping strategies, sporting and social limitations, restrictions because of epilepsy and impact of epilepsy.

The controlled before-and-after study of FLIP&FLAP measured quality of life using the DISABKIDS modular health-related quality of life questionnaire (Jantzen 2009). Between groups, there was improved health-related quality of life in the social exclusion dimension amongst children and adolescents (P value < 0.05) but not parents. There were no significant differences between groups of children, adolescents or parents for the other dimensions of the HRQoL questionnaire: independence, emotion, physical limitation, social inclusion, medication and epilepsy impact social aspects of epilepsy.

The evaluation of counselling interventions used two types of outcome measures (via one RCT in which the randomisation failed) (Glueckauf 2002). First, self perception of severity, frequency and improvement of family problems and second, the improvement with those family problems identified using standardised scales of teenager functioning (pro-social and problem behaviour) in classroom and home settings. At six months, there were no differences in outcome measures between groups for family issue frequency for teenagers or parents, issue severity for teenagers or parents, pro-social behaviour scale for parents or teachers, or problem or behaviour scale for parents or teachers. There were no significant changes in the frequency of family problems over time, while family issue-severity was significantly improved at six months. Scores on the pro-social behaviour and problem behaviour scales were significantly improved at both one week post-treatment and at six months follow-up.

Objective measures of general health status

No studies reported objective measures of general health status.

Objective measures of social or psychological functioning

At 12 months in one cluster RCT, there were significantly fewer emergency visits in children who received the ACINDES programme compared to control (mean at baseline to 12 months: 0.90 (SD 0.95) to 0.22 (SD 0.58) with intervention versus 0.83 (SD 0.95) to 0.46 (SD 0.66) with control; P value = 0.046) (Tieffenberg 2000). The number of regular medical visits was also reduced in each group but the differences were reported as "not significant" (mean at baseline to 12 months: 3.64 (SD 3.01) to 3.06 (SD 2.57) with intervention versus 3.89 (SD 4.47) to 2.91 (SD 3.19) with control). The evaluation of ACINDES also showed significant improvement in school absenteeism (mean number of absences per 100 school days at baseline to 12 months: 10.31 to 6.85 with intervention versus 9.32 to 9.21 with control; P value = 0.011). The controlled before-and-after study by Rau 2006 reported that there was no difference in the number of days missed at school between participants in FAMOSES and the control group. No other studies reported on objective measures of social or psychological functioning

Costs of care or treatment

Glueckauf 2002 measured adherence to the treatment programme (number of missed appointments and the extent of the homework completion) between the three different treatment modalities evaluated. There were no significant differences at six months. However, randomisation failed for this study and so the results should be interpreted with caution. No other study considered the costs of care or treatment.

DISCUSSION

Summary of main results

This review included five interventions and seven study reports, of which four were designed as RCTs (Glueckauf 2002; Lewis 1990; Lewis 1991; Tieffenberg 2000), and three as controlled before-and-after studies (Jantzen 2009; Pfäfflin 2012; Rau 2006). We identified two types of intervention, both of which aimed to improve self management: that is, educational interventions (Jantzen 2009; Lewis 1990 and Lewis 1991; Pfäfflin 2012 and Rau 2006; Tieffenberg 2000), and a counselling intervention (Glueckauf 2002). The studies were undertaken in diverse locations and investigated the use of a range of innovative interventions with children, adolescents and parents. Each study used a unique combination of outcome measures, mostly subjective in nature. No single intervention was consistently effective across the full range of reported outcomes.

Overall completeness and applicability of evidence

One cluster RCT (Tieffenberg 2000) and two controlled before-and-after studies (Pfäfflin 2012; Rau 2006) measured the impact of educational programmes (ACINDES and FAMOSES) on seizure frequency. These interventions suggest that educational interventions may result in seizure frequency decreasing over time in children. Only the controlled before-and-after studies considered the impact of an educational programme on the tolerability and efficacy of antiepileptic medication (Rau 2006; Pfäfflin 2012). This reported no impact. No study reported objective measures of general health status or evaluated the costs of care or treatment.

The majority of outcomes measured in the studies were self reported, considering knowledge about epilepsy or related issues including advice received from professionals. In general, the educational interventions appeared to have a positive impact but the

differences in how outcomes were collected prevented comparison of effectiveness between the studies. Therefore, it is unclear which intervention, if any, may be considered the best at improving these outcomes.

The cluster RCT evaluating ACINDES had a 12-month follow-up (Tieffenberg 2000), while all the studies reported outcomes at between three and six months after the intervention had finished. Therefore, it was impossible to elucidate the impact of any of the interventions on the long-term self management of epilepsy.

Finally, although all of the studies investigated self management improvement strategies, no individual strategy was investigated by more than one study. Therefore, the generalisability of any of the interventions is unclear.

Quality of the evidence

The quality of evidence was generally poor, with all reports containing major methodological problems.

Potential biases in the review process

None identified.

Agreements and disagreements with other studies or reviews

The current review is an update of a review we originally conducted in 2010 (Lindsay 2010). Despite the identification of two additional controlled before-and-after studies (Jantzen 2009; Pfäfflin 2012), the overall findings remain unchanged. This is unsurprising given that one of the additional studies reported on an intervention (FLIP&FLAP) previously evaluated (Pfäfflin 2012), published in German (Rau 2006), and included in our previous review. We are not aware of any other reviews that have considered care delivery and self management strategies specifically for children or adolescents. However, three similar reviews have examined psychosocial treatment programmes in epilepsy (Mittan 2009), evidence-based models of care for people with epilepsy (Fitzsimons 2012), and care delivery and self management strategies for adults with epilepsy (Bradley 2009); the latter of these reviews is currently being updated alongside this update for children (Bradley 2009). The review of care delivery and self management strategies for adults reported that two intervention types, specialist epilepsy nurse and self management education, had some evidence of benefit (Bradley 2009). However, there was no clear evidence that other service models substantially improved outcomes for adults with epilepsy. The two other reviews reported similar findings (Fitzsimons 2012; Mittan 2009). Mittan 2009 suggested that the psychoeducational model, in particular the SEE programme (Helgeson 1990), may be the most promising in terms of delivering knowledge and psychosocial treatment outcomes, as well as being potentially the most cost-effective. It should be noted that the author of this review also developed the SEE programme in the 1980s and is one of the co-authors of the Helgeson 1990 study. However, in a conflict of interest statement at the end of his review he stated that he "had no role in SEE program outcome research cited herein aside from presenting the program for independent researchers." All reviews have noted that there is currently a lack of evidence for the cost-effectiveness of any intervention.

AUTHORS' CONCLUSIONS

Implications for practice

The evidence from this review suggests that innovative models of service delivery may improve some outcomes relating to epilepsy in children and to the impact that epilepsy can have on parents. However, no single strategy improved a comprehensive range of user outcomes and methodological deficiencies within each study mean that the results must be treated with caution.

The evaluation of each programme is based on a single evaluation and in most cases design, delivery and evaluation were undertaken by the same team of researchers. At present there is insufficient evidence in favour of any single programme and so, while no programme was shown to impact negatively on children with epilepsy or their parents, it is not possible to recommend any single programme as being more effective than any other. No programme showed consistent improvement across all of the assessed outcomes. Healthcare professionals and families need to be aware of this when considering any of these strategies for implementation.

Implications for research

This review has identified four distinct programmes for the education or counselling of children with epilepsy and their parents, aimed at improving self management. However, no programme was evaluated in more than one study, and the studies show methodological flaws, were not independently assessed and showed inconsistent results. The evidence from this review suggests that innovative models of service delivery may improve some outcomes relating to epilepsy in children and to the impact that epilepsy can have on parents. However, no single strategy improved a comprehensive range of user outcomes and methodological deficiencies within each study mean that the results must be treated with caution.

As a result, further studies are needed that:

- offer an improved quality of study design and reporting;
- improve generalisability (e.g. include a full description of the intervention, a process evaluation, and a multicentred

assessment of the benefits for more than one population and service provider);

- evaluate the effects of interventions for those subgroups most likely to benefit (e.g. children with newly diagnosed epilepsy, children with learning disabilities);

- consider objective outcomes and the cost-effectiveness of service models shown to be beneficial.

To maximise the potential of future studies for generalisability and to ensure study quality, we would recommend randomised controlled trials rather than observational studies. Studies should also ensure that the interventions are adequately defined and described, and that contextual factors are taken into account in the study design. Where socially complex interventions such as these are under study, sufficient service providers must be included to ensure that individual characteristics do not bias the results.

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* *Indicates the major publication for the study*

CHARACTERISTICS OF STUDIES

Characteristics of included studies *[ordered by study ID]*

Glueckauf 2002

Methods	Randomised controlled trial
Participants	Teenagers (aged 12-19 years) with epilepsy and behaviour problems and their parents
Interventions	Issue Specific Family Counseling Model (ISFCM) delivered via video-conferencing, speakerphone or face-to-face in the counsellor's office
Outcomes	Measures of change in severity and frequency of the behaviour problem; teenager's functional ability in school and home; adherence to intervention activities
Notes	

Risk of bias

Bias	Authors' judgement	Support for judgement
Allocation sequence generation (selection bias)	Unclear risk	No details of how participants were allocated was provided but the randomisation failed in this trial as several families allocated to video-conference-based family counselling (VFC) were unable to support it technically and were offered speakerphone family counselling as an alternative (SFC)
Allocation concealment (selection bias)	High risk	The randomisation failed in this trial as several families allocated to video-conference-based family counselling (VFC) were unable to support it technically and were offered speakerphone family counselling as an alternative (SFC)
Baseline outcomes (selection bias)	Low risk	Outcomes were not imbalanced at baseline
Baseline characteristics (selection bias)	Low risk	No baseline differences between groups were reported
Incomplete outcome data (attrition bias) All outcomes	High risk	31% of families did not attend any counselling and a further 13% did not complete all sessions. Parents in the treatment drop-out group reported a greater mean frequency of pre-test family problems than parents who completed the counselling programme
Blinding (performance bias and detection bias) All outcomes	High risk	None of the participants, clinicians or assessors appeared to have been blinded. The subjective nature of the outcomes measured (all by self reported questionnaire) means this may have introduced bias

Glueckauf 2002 (*Continued*)

Contamination (performance bias)	High risk	Randomisation was potentially done at the patient level, rather than by an independent centre and so there is nothing to stop people in intervention and control groups interacting with each other and sharing knowledge
Selective reporting (reporting bias)	Low risk	All outcomes detailed in the methods were reported in the results
Other bias	High risk	No details of power calculations or required sample size were reported

Jantzen 2009

Methods	Multicentre non-randomised 2-group controlled before-and-after study
Participants	Children (aged 8-11 years) or adolescents (aged 12-16 years) with epilepsy and their parents
Interventions	Educational sessions using age-appropriate material based on an inventory used in family and behaviour therapy
Outcomes	Knowledge of epilepsy; self management skills; epilepsy-related worries; health-related quality of life; communication skills; satisfaction with the intervention
Notes	

Risk of bias

Bias	**Authors' judgement**	**Support for judgement**
Allocation sequence generation (selection bias)	High risk	Controlled before-and-after study
Allocation concealment (selection bias)	High risk	Controlled before-and-after study
Baseline outcomes (selection bias)	High risk	For a number of quality of life outcomes, scores were notably higher in the control group and the mean contact with health-care providers in the past 6 months was 3.32 in the intervention group compared with 2.03 in the control group. More parents in the control group reported a longer seizure-free duration, more parents in the intervention group reported better social knowledge of epilepsy and more contacts with healthcare providers in the last 6 months

Baseline characteristics (selection bias)	High risk	A number of baseline differences were apparent between the 2 groups that were not adjusted for in analysis (however, for 1 of the variables, educational status, and for 1 of the outcomes, epilepsy knowledge, a univariate analysis of variance with repeated measurements was performed with epilepsy knowledge as a dependent variable and time and educational status as independent variables)
Incomplete outcome data (attrition bias) All outcomes	Low risk	It was reported that the loss to follow-up was less than 10% in all subgroups of the sample
Blinding (performance bias and detection bias) All outcomes	High risk	None of the participants, clinicians or assessors appeared to have been blinded. The subjective nature of the outcomes measured (all by self reported questionnaire) means this may have introduced bias
Contamination (performance bias)	High risk	This was a waiting-list comparison and families were recruited from the same centres over Germany, so those in the intervention and control groups would theoretically have been able to share information
Selective reporting (reporting bias)	Low risk	All outcomes detailed in the methods were reported in the results
Other bias	Low risk	A sample size calculation was reported and no other obvious risks of bias were identified

Lewis 1990

Methods	Randomised controlled trial
Participants	Children (aged 7-14 years) with epilepsy
Interventions	Children's Epilepsy Programme, a counselling model based on Rogerian principles
Outcomes	Knowledge about seizures; self perceived competency, knowledge, behaviour and parent's behaviour
Notes	Evaluation of same intervention as Lewis 1991
Risk of bias	

Lewis 1990 (*Continued*)

Bias	Authors' judgement	Support for judgement
Allocation sequence generation (selection bias)	Low risk	From a master list of children aged 7-14 years, groups of 20 families were selected and assigned numbers and randomly selected for the control and intervention groups
Allocation concealment (selection bias)	Unclear risk	The allocation process was not described
Baseline outcomes (selection bias)	Low risk	Outcomes were not imbalanced at baseline
Baseline characteristics (selection bias)	High risk	Some baseline differences were apparent (ordinal position, grades in school, living with both parents and number of siblings)
Incomplete outcome data (attrition bias) All outcomes	Low risk	Only 78.6% of children in the intervention group and 52% of children in the control group attended all the required sessions. However, pre- and post-test data were available for almost 95% of children. No intention-to-treat analysis was explicitly reported, but data were reported for each participant in the final analysis for some, but not all, outcomes despite attendance at the educational programme being incomplete
Blinding (performance bias and detection bias) All outcomes	High risk	Participants and clinicians were not blinded; it is unclear if the trained interviewers were blinded. The subjective nature of the outcomes measured (by self reported questionnaire) means this may have introduced bias
Contamination (performance bias)	High risk	There was nothing to prevent participants in the intervention and control groups interacting with each other and sharing knowledge
Selective reporting (reporting bias)	Low risk	All outcomes detailed in the methods were reported in the results
Other bias	High risk	No details of power calculations or required sample size were reported

Lewis 1991

Methods	Randomised controlled trial
Participants	Parents of children with epilepsy
Interventions	Children's Epilepsy Programme, a counselling model based on Rogerian principles

Lewis 1991 (*Continued*)

Outcomes	Parental knowledge and anxiety; perceptions of the programme's efficacy including parental reactions to child's seizures
Notes	Evaluation of same intervention as Lewis 1990

Risk of bias

Bias	**Authors' judgement**	**Support for judgement**
Allocation sequence generation (selection bias)	Low risk	From a master list of children aged 7-14 years, groups of 20 families were selected and assigned numbers and randomly selected for the control and intervention groups
Allocation concealment (selection bias)	Unclear risk	The allocation process was not described
Baseline outcomes (selection bias)	Low risk	Outcomes were not imbalanced at baseline
Baseline characteristics (selection bias)	Unclear risk	Some baseline differences were apparent (both parents at home, education and occupation of mother and father)
Incomplete outcome data (attrition bias) All outcomes	Low risk	Only 73.2% of mothers and 59% of fathers attended all 4 sessions in the intervention group and 62% of mothers and 49% of fathers attended all 3 sessions in the control group. However, pre- and post-test data were available for almost all parents. No intention-to-treat analysis was explicitly reported, but data were reported for each participant in the final analysis for some, but not all, outcomes despite attendance at the educational programme being incomplete
Blinding (performance bias and detection bias) All outcomes	High risk	Participants and clinicians were not blinded; it is unclear if the trained interviewers were blinded. The subjective nature of the outcomes measured (by self reported questionnaire) means this may have introduced bias
Contamination (performance bias)	High risk	There was nothing to prevent participants in intervention and control groups interacting with each other and sharing knowledge
Selective reporting (reporting bias)	Low risk	All outcomes detailed in the methods were reported in the results
Other bias	High risk	No details of power calculations or required sample size were reported. Some baseline differences were apparent

Pfäfflin 2012

Methods	Controlled before-and-after study
Participants	Children with epilepsy (aged 7-16 years) and their parents
Interventions	Modular Education Programme Epilepsy for Families (FAMOSES)
Outcomes	Epilepsy-specific knowledge; coping with epilepsy; adaption to epilepsy; anxiety; seizure management including parental abilities to deal with child's seizures; seizure frequency and satisfaction with drug therapy; school absenteeism
Notes	Evaluation of same intervention as Rau 2006

Risk of bias

Bias	**Authors' judgement**	**Support for judgement**
Allocation sequence generation (selection bias)	High risk	Controlled before-and-after study
Allocation concealment (selection bias)	High risk	Controlled before-and-after study
Baseline outcomes (selection bias)	Unclear risk	For a number of outcomes (epilepsy knowledge ('knowledge'), adaptation to epilepsy, rules and limitations: attendance, impact of epilepsy), scores were notably different between groups at baseline, all in favour of the control group; however, an analysis of co-variance (ANCOVA) was performed with 'knowledge' at follow-up as dependent variable and 'knowledge' at baseline as covariate confirmed a significant group effect (control vs. treatment) at follow-up after adjustment for baseline values
Baseline characteristics (selection bias)	High risk	A number of baseline demographic differences were apparent between the 2 groups (% female parents, education and employment status of parents, % female children and educational level of children)
Incomplete outcome data (attrition bias) All outcomes	High risk	Only 71.4% of children and 64.7% of adults completed the post-programme evaluation questionnaire and so were included in the analysis. Information on the number of participants lost to follow-up was not provided for adults by treatment group. For children, the drop-out rate in the control group was 40.6% and in the intervention group was 18.4%. Children with other conditions were significantly more common among the non-responders. No details were given of how drop-outs were accounted for, but only participants completing the intervention programme were included in the final

Pfäfflin 2012 (*Continued*)

		analysis and numbers varied for each outcome considered
Blinding (performance bias and detection bias) All outcomes	High risk	None of the participants, clinicians or assessors appear to have been blinded. The subjective nature of the outcomes measured (all by self reported questionnaire) means this may have introduced bias
Contamination (performance bias)	High risk	Families were consecutively allocated to the treatment and control groups and so there was nothing to prevent participants in intervention and control groups interacting with each other and sharing knowledge
Selective reporting (reporting bias)	Low risk	All outcomes detailed in the methods were reported in the results
Other bias	High risk	No details of power calculations or required sample size were reported

Rau 2006

Methods	Controlled before-and-after study
Participants	Children with epilepsy (aged 7-16 years) and their parents
Interventions	Modular Education Programme Epilepsy for Families (FAMOSES)
Outcomes	Knowledge, coping, adaptation of children and parents, school attendance and seizure frequency in the children
Notes	Evaluation of same intervention as Pfäfflin 2012

Risk of bias

Bias	**Authors' judgement**	**Support for judgement**
Allocation sequence generation (selection bias)	High risk	Controlled before-and-after study
Allocation concealment (selection bias)	High risk	Controlled before-and-after study
Baseline outcomes (selection bias)	High risk	There was no discussion about how baseline potential differences might affect the result of the study before the data were analysed

Rau 2006 (*Continued*)

Baseline characteristics (selection bias)	Low risk	Although the groups were not randomised, they did not differ with respect to sociodemographic aspects with the exception of mean age of parents
Incomplete outcome data (attrition bias) All outcomes	High risk	Only 71.4% of children and 64.7% of adults completed the post-programme evaluation questionnaire and so were included in the analysis. Information on the number of participants lost to follow-up was not provided for adults by treatment group. For children, the drop-out rate in the control group was 40.6% and in the intervention group was 18.4%. Children with other conditions were significantly more common among the non-responders. No details were given of how drop-outs were accounted for, but only participants completing the intervention programme were included in the final analysis and numbers varied for each outcome considered
Blinding (performance bias and detection bias) All outcomes	High risk	None of the participants, clinicians or assessors appeared to have been blinded. The subjective nature of the outcomes measured (all by self reported questionnaire) means this may have introduced bias
Contamination (performance bias)	High risk	There was nothing to prevent participants in intervention and control groups interacting with each other and sharing knowledge
Selective reporting (reporting bias)	Low risk	All outcomes detailed in the methods were reported in the results
Other bias	High risk	No details of power calculations or required sample size were reported

Tieffenberg 2000

Methods	Randomised controlled trial
Participants	Children (aged 6-15 years) with asthma or epilepsy and their parents
Interventions	ACINDES: a child-centred training programme
Outcomes	Knowledge, beliefs, attitudes and behaviours of the children; parental knowledge, fear of child death; clinical outcomes including seizure frequency and clinic attendance
Notes	

Risk of bias

Tieffenberg 2000 (*Continued*)

Bias	Authors' judgement	Support for judgement
Allocation sequence generation (selection bias)	Unclear risk	The details of randomisation including the 'clustering techniques' used were not reported
Allocation concealment (selection bias)	Unclear risk	No details of how participants were allocated was provided
Baseline outcomes (selection bias)	Low risk	No baseline differences between groups were reported
Baseline characteristics (selection bias)	Low risk	Outcomes were not imbalanced at baseline
Incomplete outcome data (attrition bias) All outcomes	High risk	For those children with epilepsy, 13.6% of children were lost to follow-up in the intervention group and 29.7% in the control group. No details were provided of families lost to follow-up, but reasons for non-attendance were provided. No details were given of how drop-outs were accounted for. No intention-to-treat analysis was reported
Blinding (performance bias and detection bias) All outcomes	Low risk	None of the participants, clinicians or assessors appeared to have been blinded. However, the outcomes reported were derived from hospital and school records and so less likely to be prone to bias from a lack of blinding
Contamination (performance bias)	High risk	There was a possibility of contamination in both groups as randomisation was not conducted by an independent centre
Selective reporting (reporting bias)	Low risk	All outcomes detailed in the methods were reported in the results
Other bias	High risk	No details of power calculations or required sample size were reported

Characteristics of excluded studies *[ordered by study ID]*

Study	Reason for exclusion
Austin 2002	Pre- and post-test feasibility study lacking a control group
Hallfahrt 2007	Duplicate of included study (Rau 2006) containing no new data
Mar 2005	Audit of documentation and data recording

(*Continued*)

Price 2004	Before-and-after (pre- and post-test) design. Study measured knowledge and skills of educators related to seizure management. No participant-related outcomes
Shore 2008	No control group
Snead 2004	Before-and-after (pre- and post-test) design. Small sample size (7 participants). No control group

DATA AND ANALYSES

This review has no analyses.

APPENDICES

Appendix 1. Cochrane Epilepsy Group Specialized Register search strategy

Review update

#1 MeSH DESCRIPTOR Program Evaluation Explode All WITH EC MT ST SN TD
#2 MeSH DESCRIPTOR Delivery of Health Care Explode All WITH CL EC ES EH HI LJ MA MT OG ST SN TD UT
#3 MeSH DESCRIPTOR Ambulatory Care Explode All WITH CL EC ES HI LJ MA MT OG PX ST SN TD UT
#4 MeSH DESCRIPTOR Outcome and Process Assessment (Health Care) Explode All WITH CL EC ES HI LJ MT OG ST SN TD UT
#5 epilep* NEAR4 (centre* OR center*)
#6 epilep* NEAR3 specialist*
#7 epilep* NEAR2 nurs*
#8 #1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7
#9 #8 AND INREGISTER AND >2011:YR

Appendix 2. Cochrane Central Register of Controlled Trials (CENTRAL) search strategy

Review update

#1 MeSH descriptor: [Epilepsy] explode all trees
#2 epilep*
#3 (#1 or #2)
#4 MeSH descriptor: [Program Evaluation] explode all trees
#5 MeSH descriptor: [Delivery of Health Care] explode all trees
#6 (#4 or #5)
#7 (#3 and #6)
#8 MeSH descriptor: [Ambulatory Care] explode all trees
#9 (#3 and #8)
#10 epilep* near/4 centre*:ti,ab,kw (Word variations have been searched)
#11 epilep* near/4 center*:ti,ab,kw (Word variations have been searched)
#12 epilep* near/3 specialist*:ti,ab,kw (Word variations have been searched)
#13 epilep* near/2 nurs*:ti,ab,kw (Word variations have been searched)
#14 MeSH descriptor: [Outcome and Process Assessment (Health Care)] explode all trees
#15 (#14 and #3)
#16 (#7 or #9 or #10 or #11 or #12 or #13 or #15) from 2012, in Trials

Appendix 3. MEDLINE search strategy

Original review

#1 exp EPILEPSY/
#2 epilep$.tw.
#3 1 or 2
#4 exp Program Evaluation/
#5 exp "Delivery of Health Care"/
#6 4 or 5
#7 3 and 6
#8 exp Ambulatory Care/
#9 3 and 8
#10 (epilep$ adj4 centre$).ab,ti.
#11 (epilep$ adj4 center$).ab,ti.
#12 (epilep$ adj3 specialist$).ab,ti.
#13 (epilep$ adj2 nurs$).ab,ti.
#14 exp "Outcome Assessment (Health Care)"/
#15 14 and 3
#16 7 or 9 or 10 or 11 or 12 or 13 or 15

Review update

#1 exp Epilepsy/
#2 epilep$.mp.
#3 1 or 2
#4 exp Program Evaluation/
#5 exp "Delivery of Health Care"/
#6 exp Ambulatory Care/
#7 *"Outcome Assessment (Health Care)"/
#8 (program$ adj2 evaluat$).mp.
#9 4 or 5 or 6 or 7 or 8
#10 3 and 9
#11 (epilep$ adj4 (centre$ or center$)).mp.
#12 (epilep$ adj3 nurs$).mp.
#13 (epilep$ adj3 specialist$).mp.
#14 11 or 12 or 13
#15 10 and 14
#16 limit 15 to yr="2012 -Current"

Appendix 4. EMBASE search strategy

Original review

#1 exp Epilepsy/
#2 epilep$
#3 1 or 2
#4 exp Ambulatory Care/
#5 exp Institutional Care/
#6 exp Community Care/
#7 exp Health Care Delivery/

#8 *Outcomes Research/
#9 (program$ adj2 evaluat$)
#10 4 or 5 or 6 or 7 or 8 or 9
#11 3 and 10
#12 (center$ or centre$)
#13 nurs$
#14 specialist$
#15 (epilep$ adj4 (centre$ or center$))
#16 (epilep$ adj3 nurs$)
#17 (epilep$ adj3 specialist$)
#18 11 or 15 or 16 or 17

Review update

#1 exp epilepsy/
#2 epilep$.mp.
#3 1 or 2
#4 exp ambulatory care/
#5 exp institutional care/
#6 exp community care/
#7 exp health care delivery/
#8 *outcomes research/
#9 (program$ adj2 evaluat$).mp.
#10 4 or 5 or 6 or 7 or 8 or 9
#11 3 and 10
#12 (epilep$ adj4 (centre$ or center$)).mp.
#13 (epilep$ adj3 nurs$).mp.
#14 (epilep$ adj3 specialist$).mp.
#15 12 or 13 or 14
#16 11 and 15
#17 limit 16 to yr="2012 -Current"

Appendix 5. PsycINFO search strategy

Original review

This search was carried out in two phases. The first search was carried out in May 2006 using the following strategy:
#10 #1 and #9
#9 #2 or #3 or #4 or #5 or #6 or #7 or #8
#8 specialist*
#7 nurs*
#6 centre* or center*
#5 treatment effectiveness evaluation
#4 treatment outcome*
#3 health care delivery
#2 ambulatory care
#1 epilep*

The second search was carried out in March 2010 using the EBSCO host platform for PsycINFO, and the following strategy:
S12 S8 or S9 or S10 or S11
S11 S3 and S7

S10 epilep* N3 specialist*
S9 epilep* N3 nurs*
S8 epilep* N4 center* or epilep* N4 centre*
S7 S4 or S5 or S6
S6 MM “Program Evaluation”
S5 MM “Health Care Delivery”
S4 MM “Outpatient Treatment”
S3 S1 or S2
S2 epilep*
S1 MM “Epilepsy” or DE “Epileptic Seizures” or DE “Grand Mal Seizures” or DE “Petit Mal Seizures”

Review update

S12 S8 OR S9 OR S10 OR S11
Limiters - Publication Year: 2012-
S11 S3 AND S7
S10 TI epilep* N3 specialist* OR AB epilep* N3 specialist* OR SU epilep* N3 specialist*
S9 TI epilep* N3 nurs* OR AB epilep* N3 nurs* OR SU epilep* N3 nurs*
S8 TI (epilep* N4 center* or epilep* N4 centre*) OR AB (epilep* N4 center* or epilep* N4 centre*) OR SU (epilep* N4 center* or epilep* N4 centre*)
S7 S4 OR S5 OR S6
S6 MM “Program Evaluation”
S5 MM “Health Care Delivery”
S4 MM “Outpatient Treatment”
S3 S1 OR S2
S2 epilep*
S1 MM “Epilepsy” OR DE “Epileptic Seizures” OR DE “Grand Mal Seizures” OR DE “Petit Mal Seizures”

Appendix 6. CINAHL search strategy

Original review

This search was carried out in two phases. The first search was carried out in May 2006 using the Ovid platform for CINAHL, and the following strategy:

#1 exp EPILEPSY/
#2 epilep$.tw.
#3 1 or 2
#4 exp Ambulatory Care/
#5 exp Health Care Delivery/
#6 exp Program Evaluation/
#7 exp “Outcomes (Health Care)”/
#8 (epilep$ adj4 (centre$ or center$)).tw.
#9 (epilep$ adj3 nurs$).tw.
#10 (epilep$ adj3 specialist$).tw.
#11 4 or 5 or 6 or 7
#12 3 and 11
#13 8 or 9 or 10 or 12

The second search was carried out in March 2010 using the EBSCO host platform for CINAHL, and the following strategy:
S13 S9 or S10 or S11 or S12

S12 S3 and S8
S11 epilep* N3 specialist*
S10 epilep* N3 nurs*
S9 epilep* N4 centre* or epilep* N4 center*
S8 S4 or S5 or S6 or S7
S7 (MM "Outcomes (Health Care)")
S6 (MM "Program Evaluation")
S5 (MM "Health Care Delivery")
S4 (MM "Ambulatory Care")
S3 S1 or S2
S2 epilep*
S1 (MH "Epilepsy+")

Review update

S13 S9 OR S10 OR S11 OR S12
Limiters - Published: 20120101-
S12 S3 AND S8
S11 epilep* N3 specialist*
S10 epilep* N3 nurs*
S9 (epilep* N4 centre*) or (epilep* N4 center*)
S8 S4 OR S5 OR S6 OR S7
S7 (MM "Outcomes (Health Care)")
S6 (MM "Program Evaluation")
S5 (MM "Health Care Delivery")
S4 (MM "Ambulatory care")
S3 S1 OR S2
S2 epilep*
S1 (MH "Epilepsy+")

Appendix 7. Additional detail about the interventions evaluated

ACINDES (Tieffenberg 2000)

ACINDES is delivered by specially selected and trained teachers to small groups of children (Tieffenberg 2000). The programme consists of 5 x 2-hour meetings, held weekly, plus a "reinforcement meeting" held 2-6 months afterwards. Groups of children are arranged according to age (6-8 years, 9-12 years, 13-15 years) with no more than 10 children per teacher. Parent groups are not arranged according to the ages of the children, and are co-ordinated by 1 or 2 teachers.

Children's Epilepsy Program (CEP) (Lewis 1990; Lewis 1991)

The CEP was initially developed and piloted with 40 children with epilepsy (aged 7-12 years) at the Medical Center of the University of California in Los Angeles (UCLA) (Lewis 1990; Lewis 1991). It consists of 4 sessions, each lasting 1.5 hours and delivered at weekly intervals. Children and parents are taught separately, meeting to share experiences at the end of each session.
Each session has a specific theme:

- session 1, understanding body messages: this uses electronic toys and cartoon drawings to teach children about seizures and to help them identify seizure-related emotions and feelings;
- session 2, controlling seizures with medication: this focuses on seizure-related information, using a card-sorting exercise to separate facts and fictions about seizures. It also teaches seizure management and decision-making skills;
- session 3, telling others in a matter of fact way: children are encouraged to share personal experiences, especially experiences with friends or peers, whether related to epilepsy or not. Children learn how to tell others about their epilepsy;

- session 4, coping and adapting to balance my life: various exercises are used to develop coping skills, including ways of dealing with bullying or taunting or with negative attitudes.

The parental group of the CEP follows the same basic structure as the child-focused group but is based on a Rogerian model of counselling as well as enabling parents to review the children's sessions as described above. The parental sessions for the intervention group are as follows (the paper does not report on who delivers these sessions):

- session 1, telling a story: parents introduce themselves to other group members and share their experiences of their child with epilepsy. A card-sorting exercise to dispel false perceptions or myths is undertaken;
- session 2, making decisions: a decision-making process is used to develop decision-making skills;
- session 3, working as a family system: the group develops their understanding of how a child's epilepsy can impact on family life and discuss their parenting styles;
- session 4, coping and adapting: in this final session parents discuss how to be more open about their child's epilepsy and how to acknowledge the pain and grief that may arise when parenting a child with a chronic condition.

FAMOSES (Rau 2006; Pfäfflin 2012)

While the content of the sessions for parents and children is similar, focusing on topics such as basic knowledge, diagnosis, treatment and living with epilepsy, each group is taught separately (Pfäfflin 2012; Rau 2006). FAMOSES was developed by a multi-disciplinary group of neuropaediatricians, psychologists, social workers and educators. It was designed to be used in different settings (e.g. epilepsy centres, outpatient clinics, inpatient settings and in weekly or weekend courses). The number of participants is restricted to 6 in the children's programme and 12 in the parent's programme, with 2 trainers working with each group. Trainers are physicians, psychologists, social workers, therapeutic educators or electroencephalogram assistants. The co-operation of a physician and a psychologist as co-trainers in the parents' programme are reported to be very useful in covering the medical and emotional aspects (FAMOSES Project Group 2007). The programme was first implemented in Germany and Switzerland in the spring of 2005 and is now reported to be operating in different epilepsy centres in German-speaking countries. Using educational material such as age-related illustrations interrupted by games, the children's content is presented as a virtual journey by sea, in which a virtual crew of "sailors" are accompanied by educated trainers. The virtual journey consists of 7 modules (60-90 minutes each):

- Harbour: group members become acquainted with each other and are motivated to discuss actively their experiences of epilepsy with each other;
- Rock Island: alongside information about the frequency of epilepsy, the influence of the disease on everyday activities and how to react in case of a seizure, children are encouraged to talk about emotions connected with epilepsy and how to deal with them;
- Volcano Island: the pathophysiological background of epilepsy is explained (i.e. causes, types of seizures and what happens in the brain during a seizure);
- Treasure Island: information about important diagnostic tests presented alongside an exploration of children's own experience and feelings with their seizures. Emphasis is placed on the importance of accurate observation and description of seizures;
- Fungus Rock: major aspects of therapy are explored including the aims of medical treatment, the need for active co-operation and therapeutic options if drugs do not work. Focus is given to individual therapeutic aims and children's own impact on managing the seizures and their consequences;
- Holiday Island: children are taught how to talk about epilepsy and how to react properly in the case of an observed seizure;
- Lighthouse Island: the content of the whole course is summarised and in a short ceremony, "sailors" are promoted to "captains" of their own ships. This is considered to be 1 step in managing their own lives with epilepsy.

The adult's content consists of 6 modules (60-90 minutes each):

- module 1, overview: group members become acquainted with each other and are motivated to reflect actively on their own ideas and emotions about epilepsy;
- module 2, basic knowledge: information is given about the causes or pathophysiology of epilepsy, as well as about different seizure types;
- module 3, diagnostic: the role of diagnostic tests in the diagnosis and therapy of epilepsy are explained. The importance of seizure observation, description and documentation, and the need to support children in sensing and describing their own seizures is emphasised;
- module 4, therapy: major aspects of epilepsy therapy are discussed. Medical treatment is the focal point but additional non-medical treatment options are also discussed. Materials to be explored at home are provided;
- module 5, prognosis: the prognosis of different epilepsies with respect to seizure remission and discontinuation of antiepileptic drugs is explored alongside the motor and cognitive development of the child with epilepsy;

- module 6, living with epilepsy: recognition of, and strategies for, coping with epilepsy-related emotional aspects of relationships with parents and siblings are explored. Group members have the opportunity to share their experiences, taking other participants as models to learn from and to be motivated by. Different disease management strategies are discussed, and hints are given on where to get help in critical situations (legal, financial, self help, written and audio-visual information).

Counselling programme based on video-conferencing for teenagers and their families (Glueckauf 2002)

During an initial assessment, a 90-minute video-taped family interview involving a series of open-ended questions about the nature of each family member's concerns is conducted (Glueckauf 2002). 5 family counselling sessions of 1.5-2 hours then follow. Commencing around 2 weeks later, the primary function of the second session is to identify the priorities for counselling and to develop an initial treatment plan, focusing on 2 or 3 priorities for intervention. The following sessions are also typically at intervals of 2 weeks apart. The primary objectives of these sessions are to assist family members in attaining their specific counselling goals. Each session follows a similar format centred on the counselling goals. At the end of the fifth session, family members are asked to consider the option of pursuing further intervention (2 additional sessions) after the sixth session, or terminating the programme after 6 sessions.

FLIP&FLAP programme (Jantzen 2009)

The FLIP&FLAP programme was developed following a 3-stage process (Jantzen 2009). This process included in the first phase, qualitative interviews conducted with 7 children with epilepsy (aged 8-18) and their mothers and information about the most frequent questions and worries of parents and children being reported to the project team from epilepsy specialists. In the second phase, a training guideline was produced and piloted on a children's course, an adolescent's course and 2 adults' courses. From these pilot sessions, in the third phase, the curriculum of the programme was systematically developed using a formative evaluation of 37 children/adolescents and 54 parents conducted in several north German clinics; the results of each evaluation were used to tailor the programme more closely to the needs of the participants and trainers.

The FLIP&FLAP programme is a 2-day or a 2.5-day course, consisting of continuous sessions (14 hours and 16 hours, respectively) in which parents and children (aged 8-11 years) or adolescents (aged 12-16 years) are taught separately from one another in groups of 5-8 families. It consists of detailed manuals for trainers and a diverse range age-related teaching material for participants in order for participants to understand seizures better and to develop a more adequate self concept of the disease. This includes a film about seizures, 2 rag dolls called "FLIP&FLAP", a game about epilepsy facts, a comic book for children and an information booklet for parents. Delivered by 2 trainers (healthcare professionals: nurses, social workers, doctors or psychologists), the courses include the following 7 domains:

- disease knowledge: understanding of the disease through information on the pathophysiology of the condition and treatment appropriate to participants' age and needs;
- disease-related emotions: discussion of shared emotions such as anxiety, guilt or embarrassment and coping strategies;
- communication: dialogue among children, adolescents, parents and healthcare professionals is encouraged;
- self responsibility: children, adolescents and parents are encouraged to share responsibility for managing the disease, particularly to counteract parental tendency for overprotection;
- self management: children and adolescents are encouraged to be self reliant, particularly in relation to taking medication and choice of leisure activities;
- participation: families are encouraged to question their expectations of stigmatisation and to cope with aspects of the disease openly and confidently; children and adolescents are encouraged to participate socially;
- educational insecurity: educational counselling and further information on diagnostic possibilities is provided for parents.

Central to the programme is the FLIP&FLAP story. Using children's expressions and speech patterns, this story is of the teamwork that happens between the "Flaps" (the "clumsy" nerve cells) and the "Flips" (the strong and fit colleagues of the "Flaps"). The children's course deals with all contents through play. In the adolescents' programme, connections are made between the FLIP&FLAP model and more scientific explanations of epilepsy through non-directive learning. Particularly for parents, illustrated exemplary case studies serve as stimulants for discussion and understanding.

WHAT'S NEW

Last assessed as up-to-date: 9 December 2013.

Date	Event	Description
9 December 2013	New citation required but conclusions have not changed	Conclusions remain the same.
9 December 2013	New search has been performed	Searches updated 9 December 2013; two new studies have been included and the review has been extensively re-written by one of the original authors (Peter Bradley) and a new author (Nigel Fleeman) A pre-publication search was carried out on 26 October 2015. The authors will address these search results at a later stage. It is extremely unlikely that these results will change the existing conclusions

CONTRIBUTIONS OF AUTHORS

PB and BL developed the protocol for this review and developed the final systematic review.

NF, PB and BL independently reviewed papers for inclusion using Cochrane EPOC Group criteria.

PB led the analysis of included papers.

BL wrote the original review and NF wrote the updated review.

PB commented on and contributed to the write up of the original and updated review.

DECLARATIONS OF INTEREST

None known.

SOURCES OF SUPPORT

Internal sources

- No sources of support supplied

External sources

- National Institute of Health Research (NIHR), UK.

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DIFFERENCES BETWEEN PROTOCOL AND REVIEW

PB was lead author on the protocol. Review methodology was unchanged from that included in the protocol.

NOTES

A pre-publication search was carried out on 26 October 2015. The authors will address these search results at a later stage. It is extremely unlikely that these results will change the existing conclusions.

INDEX TERMS

Medical Subject Headings (MeSH)

*Delivery of Health Care; *Self Care; Adaptation, Psychological; Controlled Before-After Studies; Counseling; Epilepsy [psychology; *therapy]; Parents [*education]; Patient Education as Topic [*methods]; Randomized Controlled Trials as Topic; Self Disclosure; Treatment Outcome

MeSH check words

Adolescent; Child; Humans