The effectiveness of self-care support interventions for children and young people with long-term conditions: a systematic review

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CRD summary
This review concluded that there was strong evidence for the effectiveness of self-care support interventions that targeted children/young people using e-health or group methods in community settings but not those that targeted parents or delivered in hospital settings. Limitations in the quality of trials and synthesis methods mean the conclusions do not appear sufficiently cautious and may not be reliable.

Authors' objectives
To review the published evidence on the effectiveness of self-care support interventions for children and young people with asthma, cystic fibrosis and diabetes.

Searching
Seventeen electronic databases including MEDLINE, EMBASE, The Cochrane Library and Social Sciences Citation Index were searched from January 1995 to September 2010 for relevant publications in English. Search terms were reported. Reference lists of retrieved studies and reviews were searched to identify further relevant evidence.

Study selection
Randomised controlled trials were eligible for inclusion if they evaluated interventions to help children or young people take control of and manage their condition, promote their capacity for self care and/or improve their health. Eligible studies had to actively involve participants (aged up to 16 years) diagnosed with asthma, cystic fibrosis or diabetes, their parents, peers or related professionals.

Included trials evaluated interventions intended to enhance self-management, develop coping/problem-solving/social skills, improve communication skills or reduce health service use. Interventions were predominately provided to individual children (aged two to 18 years) or families in hospital, community/home or school settings. Most interventions focused on asthma and had no explicit underlying theoretical basis.

Two reviewers independently selected studies for inclusion. Disagreements were resolved by discussion or arbitration by a third reviewer.

Assessment of study quality
Included studies were assessed on the basis of randomisation, concealment of allocation, blinding of assessor/data analyst, sample size and reporting of a power calculation, baseline comparability, length of follow-up, attrition rate and use of intention-to-treat analysis.

Two reviewers independently performed the assessment. Disagreements were resolved by discussion or arbitration by a third reviewer.

Data extraction
Data were extracted on the number of studies that reported an association between certain study characteristics (setting, mode of delivery, target of the intervention) and outcomes (health status, psychosocial well-being, knowledge, health care use, satisfaction).

It was not clear how many reviewers performed the data extraction.

Methods of synthesis
The studies were combined in a narrative synthesis, grouped by outcome.

Results of the review
Fifteen articles describing 13 studies were included in the review. Sample sizes ranged from 47 to 1,033. Length of follow-up ranged from two months to two years. Around half of the studies reported adequate blinding of outcome assessors and allocation concealment, 12 out of 13 studies adequately reported adequate randomisation methods and all studies were considered to have comparable groups at baseline. Seven studies conducted an intention-to-treat analysis and attrition was generally low.

Six of the seven studies that evaluated interventions delivered in the home/community setting reported some improvements in health status.

Both of the two studies that evaluated group-based interventions reported improvements in health status, psychological well-being and reduced health care use.

All five studies that evaluated e-health modes of delivery reported improvements in psychosocial well-being.

All five studies that evaluated interventions in which children or young people were the target of the intervention reported improvements in psychosocial well-being.

The relationship between other characteristics and outcomes were less consistent across studies.

Cost information
Two USA studies that evaluated asthma-focused interventions in inner city children and ethnic minority families reported cost effectiveness outcomes. One of these studies found intervention to be particularly cost-effective in children with the most severe asthma and the other reported cost savings for all participants, with an overall cost saving of $46.16 per child per month for high-level participants.

Authors’ conclusions
There was strong evidence for the effectiveness of interventions targeting children/young people using e-health or group based methods delivered in community settings. There was no evidence that interventions focusing solely on parents or delivered in hospital settings were effective.

CRD commentary
This review addressed a broadly defined research question supported by appropriate inclusion criteria. The authors made efforts to identify all the relevant publications in English and minimised potential for errors and bias in the selection of these publications. Potential for language bias and publication bias remains and null or negative trials could have been overlooked. Included studies had several limitations: almost half failed to report appropriate methods to conceal treatment allocation, many outcomes were self-reported and participants and personnel were unlikely to be blinded due to the nature of the intervention. Most participants were diagnosed with asthma but the breadth of the research question meant that the included studies differed widely in intervention components and reported outcomes. The decision not to pool all the included studies appeared appropriate. The authors’ conclusions about the strength and/or absence of evidence for each intervention characteristic was based largely on counting the proportion of studies that reported a positive association for five broadly-defined outcomes. As well as raising concerns about the possible impact of incomplete reporting of outcomes, the synthesis did not sufficiently take into account the clinical significance of these associations and their comparability across studies.

Limitations in the quality of the trials and synthesis methods mean that the conclusions do not appear to be sufficiently cautious and so may not be reliable.

Implications of the review for practice and research
Practice: The authors did not state any implications for practice.

Research: The authors discussed several implications for research and emphasised a need for well-designed trials of interventions that are informed by theory and use outcomes that are relevant to children/young people, transferable to real-life settings and involve parents and children in their development.

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