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

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Abstract

Children's health policy has highlighted the need to develop self-care programmes. However, there is a lack of evidence on which to base the development of such programmes. This paper reviews the published research on the effectiveness of self-care support interventions for children and young people with asthma, cystic fibrosis and diabetes. A systematic search was conducted of a range of electronic databases, supplemented by searching the reference lists of retrieved papers and published reviews. Retrieved studies were assessed against quality and eligibility criteria by two independent reviewers. The results were narratively synthesized to examine the effectiveness of self-care support interventions on health status, psycho-social well-being, condition-related knowledge, health service use and participant satisfaction. The search strategy identified 4261 papers which were screened against the review inclusion criteria. A total of 194 papers were assessed as being potentially eligible for inclusion with 15 papers being judged as adequate to include in the review. There is strong evidence of the effectiveness of interventions that target children/young people; use e-health or group-based methods; that are delivered in community settings. There is no evidence that interventions that focus on parents alone or are delivered only in hospital settings are effective. While there is some evidence to inform the development of self-care support programmes, there is a need for well-designed trials of interventions that are feasible to transfer into real-life settings and which involve parents and children in their development.

Keywords

adolescents, children, chronic illness, self care, systematic review

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Introduction

Self-care is an important component of health policy internationally due to the increasing prevalence of long-term health conditions, recognition of the importance of user involvement and for its potential contribution to controlling escalating health care costs (Wanless 2002; Department of Health 2005). Self-care has been defined in different ways according to who

engages in self-care behaviours (individual, family, community); what the context is (health promotion, prevention of illness, limitation of the impact of illness, restoration of health); the activities involved and the extent to which health professionals are involved (Barlow *et al.* 2002; Department of Health 2005, 2006). A commonly cited definition reflects this range of potential agents, contexts and activities, defining self-care as:

the actions individuals and carers take for themselves, their children, their families and others to stay fit and maintain good physical and mental health; meet social and psychological needs; prevent illness or accidents; care for minor ailments and long term conditions; and maintain health and wellbeing after an acute illness or discharge from hospital (Department of Health 2005, p. 1).

Although self-care has been mainly examined in terms of individual behaviour, it can be positioned on a continuum, with individually centred components as one end (e.g. health literacy) and social activities at the other (e.g. social capital and public engagement) (Bower *et al.* 2009). Consequently, the factors influencing self-care can be related to wider contextual influences as well as the individual (Bower *et al.* 2009). This conceptualization of self-care is presented in Fig. 1.

The goal of self-care support has been interpreted as enabling patients to perform three sets of tasks: medical management of their condition, carrying out normal roles and activities and managing the emotional impact of their condition (Lorig & Holman 2003). This proposition reflects how self-care support has largely been constructed in terms of the individual patient rather than at the structural constraints influencing self-care. Self care can be supported in a number of ways; through the development of positive patient-professional relationships; provision of accessible information and education to increase knowledge and skills; support in accessing and navigating the service system (including lay/peer support networks) and self-management support via a range of tools and resources (e.g. telephone help lines, computer-based tools, devices for self-monitoring and personalized self-care plans) (Corben & Rosen 2005; Department of Health 2005, 2008). However, the importance of flexibility in provision has been highlighted in order that individual patients/users can access a range of different types of support from both formal and informal self-care resources that takes account of their socio-economic and cultural context (Bury *et al.* 2005). It has also been noted that supporting self-care requires a comprehensive approach, involving interventions that are directed at professionals and health systems as well as patients (Kennedy *et al.* 2007).

Long-term conditions in childhood are increasing in prevalence. Children face a lifetime of condition management and their success in this may influence health outcomes in adulthood. In addition, the self-care context in relation to children is complex due to the role played by parents in managing their children's long-term conditions and the influence of peers (Christian *et al.* 1999; Prout *et al.* 1999; D'Auria *et al.* 2000).

Consequently, the 'self' in this context is a combination of the child/young person and parents.

Although children's health policy has highlighted the need for services to support self-care and for self-care programmes to be developed (Department of Health, Department for Education and Skills 2004; Department of Health 2009) little is known about the appropriateness and effectiveness of self-care support for children. Systematic reviews suggest that there is limited evidence of effectiveness for a range of condition-specific interventions; written asthma action/self-management plans (Toelle & Ram 2004; Bhogal *et al.* 2006), psychosocial interventions in diabetes and asthma (Hampson *et al.* 2001; Yorke *et al.* 2005), diabetes education (Hampson *et al.* 2001; Couch *et al.* 2008) and family therapy in asthma (Yorke & Shuldham 2005). Although there are also reviews that suggest that psychosocial, behavioural and educational interventions may improve outcomes for children with asthma and cystic fibrosis (Wolf *et al.* 2002; Glasscoe & Quittner 2008).

As part of a larger study evaluating self-care support for children and young people with long-term conditions (Kirk *et al.* 2010) a systematic review was conducted to review the published research on the effectiveness of self-care support interventions. The aim of the review was to assess the effectiveness of self-care support interventions (and their components) in relation to childhood long-term conditions. The review question was 'what types of self-care interventions are effective for children/young people aged 0–16 years with the long-term conditions of asthma, cystic fibrosis (CF) and diabetes?' In the context of this review effectiveness was defined as the extent to which an intervention had a beneficial effect on health-related outcomes. Unlike previous reviews, the review reported in this paper aimed to include a range of self-care support interventions in terms of their target (e.g. child, parent, health care professional), location of delivery, leadership (lay or professional) and medium (face-to-face, e-health) in order to compare different approaches. Conditions were selected that differed in terms of the complexity of self-care management and prognosis. We aimed to compare similarities and differences in interventions and their effectiveness in relation to these different conditions and contexts.

Methods

Search methods

A range of electronic databases were searched for relevant studies published between 1 January 1995 and 30 September 2010. These were MEDLINE, PubMed, EMBASE, Scopus, Social

Figure 1. Conceptualizing self-care.

Table 1. MEDLINE search

(self manag\$ OR self care OR self help OR collaborative care OR collaborative manag\$) AND (plan OR checklist OR coach\$ OR educational materials OR goal set\$ OR individual\$ goal\$ OR action plan\$ OR group education OR patient education OR information OR patient held record OR training OR skills train\$ intervention OR program\$ OR patient involv\$ OR patient participat\$ OR share\$ decision making OR decision aid\$ OR diet\$ OR exercise OR telecare OR telehealthcare OR telemedicine OR telemonitor\$ OR home monitor\$ OR telephone support OR virtual communit\$ OR mutual support OR peer support OR self admin\$ OR self monitor\$ OR self medicat\$ OR self diagnosis OR self treatment OR provider training OR provider education) AND (child\$ OR bab\$ OR infant OR toddler OR teenager\$ OR adolescen\$ OR young person OR young people OR youth OR juvenile OR pediatric OR paediatric OR parent\$ OR mother OR father OR guardian OR advocate OR carer OR family) AND (diabet\$ OR cystic fibrosis OR mucoviscidosis OR asthma)

Sciences Citation Index, Sociological Abstracts, Applied Social Sciences Index and Abstracts (ASSIA), Social Care Online, Social Services Abstracts, Child Data, Cumulative Index to Nursing and Allied Health Literature (CINAHL), British Nursing Index, Allied and Complementary Medicine (AMED), PsycInfo, Health Management Information Consortium (HMIC), The Cochrane Library, The North West Grey Literature Service (FADE). The search terms included MeSH and 'free text' terms in combination and was adapted according to the particular database. The MEDLINE search is presented in Table 1. In addition, reference lists of retrieved papers and published reviews were searched for potentially relevant papers. Unpublished data were not sought from authors due to time limitations.

Inclusion criteria

Type of study

- Randomized controlled trials.

Types of participants

- Studies focusing on children and young people aged 0–16 years diagnosed with one of the following long-term conditions: asthma, cystic fibrosis and diabetes.
- Studies involving or focusing on parents, peers or professionals that related to the above long-term conditions and age group.

Types of interventions

- Any intervention aiming to help children/young people take control of and manage their condition, promote their capac-

ity for self-care and/or improve their health. The target of the intervention, needed to be actively involved and engaged in the intervention, rather than be a passive recipient of knowledge or instructions.

Language

- Only studies published in English were included in the review.

Exclusion criteria

- Mean age of children/young people above 16.5 or if any individual young person was older than 21.
- No active involvement of participants in the intervention.

Data extraction and quality review

The abstracts of the retrieved papers were screened to eliminate those that did not meet the review inclusion criteria. If it was unclear from the abstract whether papers met the inclusion criteria full paper manuscripts were obtained. Each paper that passed the initial screening process was read and assessed independently for quality and eligibility by two reviewers from the research team and data were extracted using a detailed data extraction form based on those developed by the Centre for Reviews and Dissemination (2001) and Marshall and colleagues (2005). The methodological quality of studies was assessed in relation to their internal validity and analysis (Centre for Reviews and Dissemination 2001). Any discrepancies in assessments that could not be resolved by discussion and consensus were resolved by arbitration by a third independent reviewer. The quality assessment of the included studies is summarized in Table 2.

Results

The search strategy identified 4261 papers which were screened against the review inclusion criteria. A total of 194 papers were assessed as being potentially eligible for inclusion (Fig. 2). These papers were reviewed for quality and eligibility and 15 papers describing 13 studies were judged as adequate to include in the review. Figure 2 shows the numbers of papers at each stage of the screening and reviewing process.

Description of the included studies

The characteristics of the 13 studies (design, type of intervention and results) are summarized in Table 3. The majority

Table 2. Quality assessment of the included studies ($n = 13$)

Author(s)	Randomization	Concealment	Blinding of outcome assessors and/or data analysts	Sample size		Comparability of groups at baseline	Length of follow-up and attrition	Intention to treat
				Use of power calculation				
Christian & D'Auria 2006	Adequate	Adequate	Adequate	116	Yes	Yes	9 months	Not applicable
Cicutto <i>et al.</i> 2005	Adequate	Adequate	Not reported	Yes			116/116 (100%)	
				239	Not reported	Yes	12 months	Conducted
Davis <i>et al.</i> 2004	Adequate	Adequate	Not reported	47	Not reported	Yes	236/265 (89.1%)	Not applicable
Espinoza-Palma <i>et al.</i> 2009	Adequate	Unclear	Adequate	Not reported		Yes	2-3 months	
				77	Yes	Yes	47/47 (100%)	Not reported
Evans <i>et al.</i> 1999; Sullivan <i>et al.</i> 2002	Adequate	Unclear	Adequate	Yes		Yes	12 months	Not reported
				961	Yes	Yes	77/88 (87.5%)	
Flores <i>et al.</i> 2009	Adequate	Unclear	Adequate	131	Yes	Yes	2 years	Not reported
Franklin <i>et al.</i> 2006	Adequate	Adequate	Not reported	Yes		Yes	961/1033 (93%)	
				78	Yes	Yes	12 months	Conducted
Guendelman <i>et al.</i> 2002, 2004	Adequate	Not reported	Unclear	Yes		Yes	131/220 (60%)	
				128	Yes	Yes	12 months	Conducted
Jan <i>et al.</i> 2007	Adequate	Adequate	Unclear	Yes		Yes	78/92 (84.8%)	
				164	Yes	Yes	12 weeks	Conducted
Stevens <i>et al.</i> 2002	Adequate	Adequate	Adequate	Yes		Yes	128/134 (95.5%)	
				177	Yes	Yes	12 weeks	Not reported
Walders <i>et al.</i> 2006	Unclear	Not reported	Adequate	Yes		Yes	164/179 (91.6%)	
				124	Yes	Yes	12 months	Not reported
Wade <i>et al.</i> 2009	Adequate	Adequate	Unclear	Yes		Yes	177/200 (88.5%)	
				299	Yes	Yes	12 months	Conducted
Wesseldine <i>et al.</i> 1999	Adequate	Not reported	Unclear	Yes		Yes	124/175 (70.6%)	
				150	Yes	Yes	12 months	Conducted
				Yes		Yes	299/415 (72%).	
				Yes		Yes	6 months	Conducted
				Yes		Yes	150/160 (93.8%)

Figure 2. Number of papers screened, assessed and included.

($n = 12$) of studies compared one intervention with one control. One study compared two interventions with one control. Sample sizes ranged from 47 to 1033. Follow-up periods ranged from 2 months to 2 years with the most common follow-up period being between 12 and 14 months ($n = 8$). Six studies were conducted in the USA, three studies in the UK, two in Canada and one in each of Chile and Taiwan.

Participants

Overall, the age-range covered was 2 to 18 years, with one intervention aimed only at children under 6 years old (Stevens *et al.* 2002) and one aimed only at adolescents/teenagers (Franklin *et al.* 2006). Most interventions were aimed at children/young people either within the primary school age range ($n = 4$) or across the primary and secondary school age range ($n = 7$). All studies included both genders. Where data on the gender and ethnicity of participants were clearly reported, the majority of studies had a higher proportion of male children and a higher proportion of White participants in their samples (excluding three studies that focused only on ethnic minority children/young people or those living in inner-city areas).

Self-care interventions

The majority of the studies ($n = 10$) focused on asthma, with two being on cystic fibrosis and one on diabetes. Five studies targeted the child/young person only and seven focussed on the child/young person and their parent/carer. Two asthma studies were targeted at children/young people from urban/inner-city areas (Evans *et al.* 1999; Sullivan *et al.* 2002; Guendelman *et al.* 2002, 2004) and one study focussed only on ethnic minority children/young people (Flores *et al.* 2009).

Studies investigated a wide range of interventions and outcomes but all included some element of education or training of the child, parent/family or professional as an intervention component. Other components included behavioural therapy, enhancing communication between children and parents/health care professionals, problem-solving skills, counselling and support (Table 3). The aims of the interventions can be classified as enhancing self-management ($n = 10$); developing coping/problem-solving/social skills ($n = 2$); improving communication skills ($n = 2$) and reducing health service use ($n = 2$).

The setting for six studies was the hospital, five studies were provided in the home/community and one intervention was school-based (Table 3). In one study elements of the interventions were delivered in both the clinic and home (Christian & D'Auria 2006).

The majority of the interventions ($n = 8$) were delivered to an individual child or family but in two studies the intervention was delivered on a group basis and three interventions used a combination of individual and group processes (Table 3). In five studies the intervention was delivered via an e-health¹ mode of delivery. This included computers (e.g. CD ROMs or Internet), text-messaging systems and telephone support and education.

Ten interventions reported no explicit underlying theoretical basis. Where a theoretical basis was reported the theories identified were social cognitive theory ($n = 2$), self-regulation ($n = 1$), developmental theory ($n = 1$) and social ecological theory ($n = 1$). One intervention was led by trained parent mentors (Flores *et al.* 2009).

Outcomes assessed

The studies assessed a wide range of outcomes in evaluating the effectiveness of the interventions with nine identifying a clear primary outcome. The most commonly assessed outcomes were health status ($n = 11$), health service utilization ($n = 10$),

¹ E-health is the use of emerging information and communications technology, especially the Internet, to improve or enable health and healthcare (Eng 2001).

Table 3. Characteristics of the included studies

Author(s) & country	Design	Participants	Intervention	Outcomes	Summary of findings about effectiveness
Christian & D'Auria 2006 USA	RCT: two arms	116 children recruited, 116 completed study (100%). Gender of children: 49.2% female. Sample mean age: 9.27 years. Ethnicity: 87.9% White. Condition: cystic fibrosis.	The 'Building CF Life Skills' intervention aims to develop problem solving and social skills for children aged 8–12 years. This educational programme is delivered by an individual, tailored home visit using written information and a computer program, followed by a structured, small group session 2 weeks later. Theoretical basis: based on previous qualitative work, developmental frameworks and social ecological theory. Control group: usual care.	Primary outcome: none identified. Others: psychosocial adjustment, functional health status, physiological health status.	The intervention decreased perceived impact of illness and decreased loneliness. There was no effect on perceived support from peers or health status (lung function). Self-worth increased in both the control and intervention groups.
Cicutto <i>et al.</i> 2005 Canada	RCT: two arms	256 children recruited, 239 completed the study (90.2%). Gender of children: 41% female. Sample mean age: 8.6. Ethnicity: not reported. Condition: asthma.	This school-based asthma education programme, 'The Roaring Adventures of Puff', aims to improve children/young people's asthma knowledge and their self-management and communication skills. Certified asthma educators delivered six 50–60 min weekly sessions to children/young people using a variety of methods, including puppetry, games, role playing and discussions. Family-based homework activities were included in the programme to involve parents. Parents only attended the final session which showcased the children's learning. Theoretical basis: social cognitive theory and self regulation. Control: usual care.	Primary outcome: emergency room visits or office visits for acute asthma episodes, quality of life. Others: self-efficacy, school absences days of interrupted activity, parental time off work.	The intervention improved self-efficacy and quality of life; the intervention group had fewer urgent health care visits, days of missed school or interrupted activity. There were no differences for parental time off work. Data on self-efficacy and quality of life were only collected at the 2-month follow-up whereas other measures (e.g. health care utilization) were repeated up to 12 months post intervention.
Davis <i>et al.</i> 2004 USA	RCT: two arms	47 children recruited and 47 completed study (100%). Gender: 38.3% female. Sample mean age: not reported. Ethnicity: not reported. Condition: cystic fibrosis.	A computer program, The 'STARBRIGHT CD-ROM Program: Fitting Cystic Fibrosis into your Life' Everyday, aimed to educate children/young people about cystic fibrosis and develop their coping skills. Children viewed CD while at a clinic visit. The content focuses on eating, breathing and a question and answer element and takes 30 min to complete. Theoretical basis: none reported. Control: usual care.	Primary outcome: none identified. Others: knowledge of cystic fibrosis, coping skills, satisfaction.	The intervention was associated with increasing children's/young people's knowledge of cystic fibrosis and the competency of their coping strategies. Not all the participants completed measures at the same time (time point two ranged from 2 to 3 months post intervention) and it is unclear if all participants completed all the follow-up measures.
Espinoza-Palma <i>et al.</i> 2009 Chile	RCT: two arms	88 children recruited and 77 completed study (87.5%). Gender: 36.4% female. Sample mean age: not reported. Ethnicity: not reported. Condition: asthma.	A hospital-based self-management education programme that aimed to reduce asthma exacerbations. Programme comprised an information booklet, self-management plan and puzzle game for children and parents. Theoretical basis: none reported. Control: standard education (information booklet) and care.	Primary outcome: asthma exacerbations. Others: hospital admissions, ER visits, steroid use.	No statistically significant differences between the intervention and control groups for any outcomes reported. Statistically significant reductions in asthma exacerbations, hospital admissions, ER visits and steroid use reported for both control and interventions groups.

Table 3. *Continued*

Author(s) & country	Design	Participants	Intervention	Outcomes	Summary of findings about effectiveness
Evans <i>et al.</i> 1999; Sullivan <i>et al.</i> 2002 USA	RCT: two arms	1033 children living in an inner-city area recruited, 961 completed the study (93%). Gender of children: not reported. Sample mean age: not reported. Ethnicity: not reported. Condition: asthma.	This intervention focused on families living in inner-city areas and aimed to improve their communication with physicians, help them eliminate asthma triggers, and address any other barriers to effective asthma self-management. Individually tailored to families' needs, trained asthma counsellors worked with caretakers and children on a group and individual basis (contact every 2 months). Caretakers were invited to two group sessions and one individual session. Sessions covered education, communication and problem solving skills. There were also two group sessions for children. There was ongoing monthly contact with the asthma counsellor by telephone or face-to-face for up to a year or as necessary to address individual needs. The programme also included environmental control measures (pillows and mattress covers). Primary care physicians of the children were sent an asthma action plan, spacer, peak flowmeter and the latest asthma treatment guidelines. Theoretical basis: none reported. Based on 'A+ Asthma Program'. Control: usual care.	Primary outcome: self-reported asthma symptom days. Others: hospitalization, unscheduled physician visits, direct medical costs, intervention costs.	The intervention was associated with a reduction in asthma symptom days reported and fewer hospitalizations. Programme was cost-effective particularly for those with more severe asthma. There is some lack of detail regarding the statistical tests used. A cost effectiveness analysis conducted alongside the RCT assessed the intervention to be a cost-effective one particularly for those with the most severe asthma. It improved outcomes at an average additional cost of \$9.20 per symptom free day gained.
Flores <i>et al.</i> 2009 USA	RCT: two arms	220 children recruited and 131 completed study (60%). Gender: 43.6% female. Sample mean age: not reported. Ethnicity: 81.4% African American. Condition: asthma.	The intervention aimed to improve asthma outcomes for ethnic minority families. Parent mentors were trained to act as advocates, resources and peer counsellors for families. They made a home visit within 3 days of a hospital admission or ER visit; facilitated group meetings at local community centres which focused on education of children/parents, socialization and peer support; phoned families monthly for 1 year to provide support; made a home visit at 6 months. In addition families had access to a 24 h help line. Theoretical basis: none reported. Control: usual care.	Primary outcome: none identified. Others: asthma symptoms/exacerbations, missed days at school/work, quality of life, ER visits, hospital admissions, self-efficacy, parent satisfaction with care, health care costs (direct/indirect).	Intention to treat analysis demonstrated that there were statistically significant reductions in asthma exacerbations ($P = 0.01$) and ER visits ($P = 0.03$) for the intervention group. However, this was a within-group analysis. Per protocol, stratified analyses (on basis of level of participation in programme) were conducted on other outcomes.
Franklin <i>et al.</i> 2006 UK	RCT: 3 arms	92 children were recruited and 78 completed the study (84.8%). Gender: 46.2% female. Sample mean age: not reported. Ethnicity: 96.7% Caucasian. Condition: diabetes.	The intervention aimed to support self-management using 'Sweet Talk', a text-messaging support system. Young people received daily text messages, drawn from a database of over 400 messages that were designed to reinforce goals set in clinic. The messages covered topics such as insulin injections, healthy eating and blood glucose testing and provided tips, information or reminders, including a weekly reminder of their personal goal. Occasional text newsletters were sent about topical diabetes issues. Theoretical basis: social cognitive theory. Control: usual care and conventional insulin therapy.	Primary outcomes: HbA1c level (glycaemic control) and 'behavioural change' (self-efficacy, diabetes knowledge, social support). Others: episodes of ketoacidosis, severe hypoglycaemia, BMI, health service utilization, satisfaction	Sweet Talk with intensive insulin therapy improved HbA1c. Sweet Talk with and without intensive insulin therapy improved self-efficacy, self-reported adherence, and social support from the diabetes team. There was no treatment group to assess if intensive insulin therapy alone would have the same effect.

Guendelman <i>et al.</i> 2002, 2004 USA	RCT: two arms	134 inner-city children recruited, 128 completed the study (95.5%). Gender of children: 42.5% female. Sample mean age: not reported. Ethnicity: 76.1% African American. Condition: asthma.	This intervention focused on 8- to 16-year-old inner-city children/young people and aimed to improve their asthma self-management by helping them to become more aware of their asthma symptoms and their monitoring and to gain more control over their asthma. An asthma self management and education programme, 'Health Buddy' was a personal and interactive communication device connected to a home phone. For 12 weeks information and daily questions were sent to children about asthma symptoms, peak flow readings and use of medications and health services. Each answer received a response. Information was automatically transmitted via a data-processing centre to a secure website where a case manager monitored the responses. Theoretical basis: none reported. Control: completed an asthma diary.	Primary outcome: limitation in activity. Others: self-reported asthma symptoms, school absences, peak flow readings, use of health services, self-care behaviours (assessed by parents).	Children in the intervention group reported fewer limitations in activities due to asthma, were less likely to report peak flow recordings in the yellow or red zone and make fewer urgent calls to hospital. Self-care behaviours also improved more for the intervention group. However, it appeared that the 'Health Buddy' only brought about short term improvements as by 12 weeks both intervention and control groups had improved and there was no significant difference between them. There is a lack of well-validated outcome measures in this study (recognized by the authors) and substantial missing data in relation to peak flow measurements.
Jan <i>et al.</i> 2007 Taiwan	RCT: two arms	179 children recruited, 164 completed the study (91.6%). Gender of children: 61.6% female. Sample mean age: not reported. Ethnicity: not reported. Condition: asthma.	'Blue Angel for Asthma Kids' was an Internet-based interactive asthma educational and monitoring programme for children aged 6–12 years old. It aimed to improved symptom monitoring and self-management. Children entered their asthma symptoms, medication use and lung function on a daily basis Adjustments to asthma management (if needed) were determined by a decision support system and by communications from physicians. The system also provided an asthma action plan, information about asthma and allowed the child to keep an electronic asthma diary and to review their data. Theoretical basis: none reported. Control: traditional asthma care plan, information sheets and usual care.	Primary outcome: none identified. Others: asthma symptom scores, peak expiratory flow, asthma monitoring and adherence, asthma knowledge, quality of life, satisfaction with intervention.	The intervention group reported decreased asthma symptoms; improved peak expiratory flow values; increased adherence; improved self-management knowledge; and improved quality of life. In addition it appeared to be a well-accepted technology.
Stevens <i>et al.</i> 2002 UK	RCT: two arms	200 children recruited, 177 completed the study (88.5%). Gender: not reported. Sample mean age: not reported. Ethnicity: not reported. Condition: asthma.	This educational intervention aimed to improve parent's asthma management. Following a child's hospital admission or ER attendance for an asthma exacerbation parents were provided with an asthma education booklet, a written guided self-management plan, and two 20 min structured educational sessions. The first of these was either on the ward prior to discharge or in clinic. The second was 1 month later in clinic. Theoretical basis: none reported. Control: usual care.	Primary outcome: GP consultation rates; hospitalizations; A&E attendance. Others: asthma symptoms, quality of life, care givers knowledge of asthma, parental confidence in caring for child, parental management of asthma changes.	There were no statistically significant differences between the intervention and control groups for any of the outcomes measured.

Table 3. *Continued*

Author(s) & country	Design	Participants	Intervention	Outcomes	Summary of findings about effectiveness
Walders <i>et al.</i> , 2006 USA	RCT: two arms	175 'undertreated' children recruited, 124 completed the study (70.6%). N.B. This is not clearly reported. Gender: 28% female. Sample mean age: not reported. Ethnicity: 85.1% African American. Condition: asthma.	An interdisciplinary intervention that focused on 'undertreated' children/young people who were defined as those without a written treatment plan and at least two asthma-related emergency department visits or at least one hospital admission over the last year. It aimed to reduce asthma symptoms and health care use and improve quality of life. Families received a 1-h asthma education session from an asthma nurse and an asthma risk profile assessment to identify families' specific barriers to asthma management. Families then received a cognitive behavioural problem-solving session tailored to the individual families' barriers to asthma management followed up 4 weeks later by a telephone consultation to reinforce problem solving strategies; access to a 24 h nurse advice line; a written asthma treatment plan; 1 month's medication; a peak flowmeter and an inhaler. Theoretical basis: none reported. Control: usual care; written asthma treatment plan; inhaler; peak flowmeter; 1 month's supply of medication.	Primary outcome: change in asthma symptoms. Others: health care utilization, quality of life.	The intervention group demonstrated less frequent health care utilization. Both groups reported reductions in asthma symptoms and improvements in quality of life (no between group differences).
Wade <i>et al.</i> 2009 Canada	RCT: two arms	415 children recruited and 299 completed study (72%). Gender: not reported. Sample mean age: not reported. Ethnicity: 67.3% White. Condition: asthma.	The intervention appears to aim to increase asthma control by children and parents. The intervention involved participation in a 4-week interactive education programme where groups of six to eight families or adolescents met together to explore different issues each week facilitated by a nurse. Small group interaction was promoted. Families/adolescents were sent personalized information 2, 4, 6 and 12 months after the end of the course to reinforce key messages. Theoretical basis: none reported. Control: usual care.	Primary outcome: ER visits. Others: hospital admissions, quality of life, lung function; use of steroids, days at work missed.	The intervention group reported a statistically significant reduction in ER visits, courses of steroids and missed work days than the control group. There were no statistically significant differences between the groups for lung function or hospital admissions. In both groups quality of life improved.
Wesseldine <i>et al.</i> 1999 UK	RCT: two arms	160 children recruited, 150 completed the study (93.8%). Gender: 38.8% female. Sample mean age: not reported. Ethnicity: not reported. Condition: asthma.	This intervention aimed to improve asthma self-management and reduce hospital readmission and reattendance by providing a structured nurse-led discharge package for children admitted with acute severe asthma. Comprised a 20 min patient education session emphasizing guided self-management for parents and children; an individual self-management plan; asthma education booklet. Theoretical basis: none reported. Control: usual care.	Primary outcome: hospital readmission in the 6 months after discharge. Others: hospital reattendance without admission, GP consultations, school absences.	The intervention reduced hospital readmissions, attendance at A&E departments and visits to GPs for asthma.

A&E, accident and emergency; BMI, body mass index; ER, emergency room; GP, general practitioner; RCT, randomized control trial.

psychosocial well-being ($n = 7$) and condition related knowledge ($n = 4$) (Table 3). Only a minority of studies included an assessment of participant satisfaction ($n = 4$) or health care or intervention costs ($n = 2$).

Methodological quality

The methodological quality assessment of the 13 studies included in the review is presented in Table 2. Twelve studies reported an adequate method of randomization as defined by Higgins and Green (2008). In one study the randomization method was unclear (Walders *et al.* 2006). Seven studies reported their method of allocation concealment in sufficient detail to be reasonably certain of its adequacy. While it may not be possible to fully blind participants to their allocation group in interventions such as these, only four studies described blinding of outcome assessors and/or care providers which is a source of potential bias for studies not assessing outcomes by postal questionnaires. All the included studies provided information on follow-up rates with seven achieving a rate of 90% or over. The conduct of an Intention To Treat analysis was reported in nine studies. All studies reported equivalent study groups at baseline. The length of follow-up was 12 months or more in eight studies. Ten studies reported that a power calculation had been conducted prior to the commencement of the study.

Interventions often incorporated multiple components and as a consequence a wide variety of outcomes were reported. Many studies measured multiple outcomes but only nine clearly identified a primary outcome (Table 3). There was a high reliance on self-report measures without a discussion of their limitations and parents were used as proxies for their children. In some studies it was unclear who administered the questionnaires and measurement tools and who completed them. Only one asthma study took account of seasonal or daily variations in asthma (Evans *et al.* 1999; Sullivan *et al.* 2002). A wide range of tools were used to measure outcomes and in some studies there was a lack of reporting of their reliability and validity. None of the studies included an integral process evaluation and relatively few studies looked at satisfaction or participant views on the intervention. In a number of studies not all the potential benefits of programmes were measured, for example, social support benefits, knowledge gain (e.g. Evans *et al.* 1999; Sullivan *et al.* 2002; Espinoza-Palma *et al.* 2009). Moreover, in a number of studies there was a lack of detail about the interventions themselves and how they were implemented. While many studies included a wide age range of children it was unclear if or how interventions were adapted to make them age appropriate (e.g. Flores *et al.* 2009).

The effect of interventions on outcomes

The heterogeneity of the studies, interventions and outcomes prevented a meta-analysis being conducted and hence the findings from the review are reported as a narrative synthesis. In this section the effectiveness of the interventions will be considered in relation to the outcomes of health status, psychosocial well-being and health behaviour, knowledge, health service utilization and cost-effectiveness and satisfaction.

Health status

Health status was an outcome measured by 11 studies but was conceptualized and measured in different ways in relation to the particular condition (Table 4). The outcomes measured included symptom reduction (asthma), lung function (asthma), limitations on usual activities/physical functioning (asthma, cystic fibrosis) and glycaemic control (diabetes). As shown in Table 4, health status was reported on by children/young people themselves and parents. In one study physiological measures were taken by the researchers. In five studies the intervention was effective in improving health status (Evans *et al.* 1999; Guendelman *et al.* 2002, 2004; Sullivan *et al.* 2002; Cicutto *et al.* 2005; Jan *et al.* 2007; Wade *et al.* 2009). In a further study the intervention was effective when coupled with intensive insulin therapy (Franklin *et al.* 2006). Of the effective interventions, six were delivered in a home/community setting (Evans *et al.* 1999; Guendelman *et al.* 2002, 2004; Sullivan *et al.* 2002; Cicutto *et al.* 2005; Franklin *et al.* 2006; Jan *et al.* 2007), three targeted both children/young people and parents (Evans *et al.* 1999; Sullivan *et al.* 2002; Cicutto *et al.* 2005; Wade *et al.* 2009) and three focused on children/young people alone (Guendelman *et al.* 2002, 2004; Franklin *et al.* 2006; Jan *et al.* 2007) (Table 5). Three of the effective interventions used e-health modes of delivery and included some form of interaction with a health care professional or individualized computerized feedback (Guendelman *et al.* 2002, 2004; Franklin *et al.* 2006; Jan *et al.* 2007).

Psychosocial well-being and health behaviour

A range of different psychosocial aspects of living with a long-term condition were used as outcomes with the commonest being quality of life ($n = 6$) and self-efficacy ($n = 3$). Interventions were associated with improvements in children's/young people's self-efficacy (Cicutto *et al.* 2005; Franklin *et al.* 2006) and quality of life (Cicutto *et al.* 2005; Jan *et al.* 2007; Wade *et al.* 2009) (Table 4). However, three studies found that the

Table 4. Summary of findings on effectiveness (including outcome measurements)

Study	Outcome	Measurement tool	Reporter
Health status Cicutto <i>et al.</i> 2005	Limitations in activity due to asthma	Number of days of interrupted activity in previous 3 months	Parents
	Intervention group reported fewer interrupted activity days (6.2 ± 7.3 ; $P \leq 0.01$) than control group (9.1 ± 10.5).		
Evans <i>et al.</i> 1999; Sullivan <i>et al.</i> 2002	Asthma symptoms	Maximum asthma symptom days in previous 2 weeks averaged across past year	Unclear if parent or child/young person
	Asthma symptoms days significantly lower in intervention ($n = 515$) than control group ($n = 518$) at 1 and 2 years post intervention. One year: intervention (3.51), control (4.06); difference -0.55 ; 95% CI -0.92 , -0.18 ; $P = 0.004$. Two years: intervention (2.64), control (3.16); difference -0.51 ; 95% CI -0.89 , -0.13 ; $P = 0.007$.		
Guendelman <i>et al.</i> 2002, 2004	Limitations in activity due to asthma	Limitations in activity	Parent and child/young person
	Limitations in activity lower in intervention than control group (OR 0.52; 95% CI 0.29, 0.94; $P = 0.03$). Intervention group reported fewer readings in red/yellow zones than control (OR 0.43; 95% CI 0.23, 0.82; $P = 0.01$).	Peak flow in red or yellow zones	
Jan <i>et al.</i> 2007	Lung function	Peak expiratory flow	Unclear if parent or child/young person
	Asthma symptoms	Asthma symptom score	
Franklin <i>et al.</i> 2006	Asthma symptoms significantly lower in intervention than control group (nocturnal $P = 0.028$; daytime $P = 0.009$). No significant differences between groups for lung function.		
	Glycaemic control	HbA _{1c}	Researcher
Stevens <i>et al.</i> 2002	Intervention group 1 = usual therapy and Sweet Talk. Intervention group 2 = intensive insulin therapy and Sweet Talk. Glycaemic control score for control group: $10.3 (\pm 1.7\%)$; intervention group 1: $10.1 (\pm 1.7\%)$; intervention group 2: $9.2 (\pm 2.2\%)$. No significant differences found between intervention group 1 and control (95% CI -0.7 , $+0.7$; $P = 0.99$). Significant differences found between intervention groups 1 and 2 (95% CI -1.9 , $+0.5$; $P \leq 0.001$). Differences between control and intervention group 2 not investigated.		
	Asthma symptoms	Index of Perceived Symptoms in Asthmatic Children	Parents
Christian & D'Auria 2006	No significant differences found between intervention and control groups for daytime symptoms (3 months post intervention $P = 0.95$; 12 months post intervention $P = 0.07$); nocturnal symptoms (3 months post intervention $P = 0.50$; 12 months post intervention $P = 0.20$); perceived disability (3 months post intervention $P = 0.76$; 12 months post intervention $P = 0.53$).		
	Functional health status (cystic fibrosis)	Functional Disability Inventory	Child/young people
Espinoza-Palma <i>et al.</i> 2009	Lung function	FEV ₁ (Forced Expiratory Volume)	
	For functional health status no significant differences reported between intervention and control ($P = 0.379$) or changes over time ($P = 0.052$). No significant differences in lung function reported between intervention and control ($P = 0.297$) although a significant intervention effect by time is reported ($P = 0.010$).		
Flores <i>et al.</i> 2009	Asthma exacerbations	Use of rescue bronchodilators for more than 2 days in the previous year.	Parents
	Use of oral steroids	Number of courses in previous year	Parents
Wade <i>et al.</i> 2009	No statistically significant differences reported between the intervention and control groups for asthma exacerbations ($P = 0.21$) or use of oral steroids ($P = 0.75$). Statistically significant reductions in asthma exacerbations and steroid use reported for both control and intervention groups (asthma exacerbations: control $P = 0.004$; intervention $P = 0.0001$; steroid use: control $P = 0.003$; intervention $P = 0.001$).		
	Asthma exacerbations	Frequency in previous month	Parents
Walders <i>et al.</i> 2006	Asthma symptoms	Frequency in previous month	Parents
	Limitations in activity due to asthma	Missed school and/or parent work days in previous month	Parents
Walders <i>et al.</i> 2006	Statistically significant reductions in asthma exacerbations ($P = 0.01$) and rapid breathing episodes ($P = 0.04$) were reported for the intervention group. There were no statistically significant reductions for other asthma symptoms (wheezing, coughing, chest tightness) or for limitations in activities. However, this was a within-group analysis. A per protocol, stratified analyses (on basis of level of participation in programme) revealed additional significant differences although again this was a within-group analysis.		
	Lung function	FEV ₁	Unclear
	Use of oral steroids	Number of courses	Unclear
Walders <i>et al.</i> 2006	Limitations in activity due to asthma	Total parent work hours missed in the previous month	Parents
	The intervention group reported a statistically significant reduction in courses of steroids ($P = 0.006$) and missed work days than the control group ($P = 0.004$). There were no statistically significant differences between the groups for lung function.		
Walders <i>et al.</i> 2006	Asthma symptoms	Number of days with symptoms in previous 30 days	Unclear
	No statistically significant between group differences reported for symptoms days or symptoms index score. Both intervention and control groups reported reductions in asthma symptoms and symptom scores. Symptoms days decreased from baseline level by an average of 1.84 days in the control group (95% CI 0.53, 3.14; $P = 0.006$) and by an average of 1.99 days in the intervention group (95% CI 0.70, 3.28; $P = 0.003$). Symptoms score decreased from by an average of 0.66 in the control group (95% CI 0.50, 0.83; $P \leq 0.0001$) and by an average of 0.71 in the intervention group (95% CI 0.54, 0.87; $P \leq 0.0001$).	Asthma symptoms index	Unclear

Psychosocial well-being: quality of life and self-efficacy

Cicuto <i>et al.</i> 2005	Self-efficacy Quality of life Intervention group reported higher self efficacy scores (5.5 ± 1.4).	Child Asthma Self-Efficacy Questionnaire Pediatric Asthma Quality of Life Questionnaire (Juniper) Intervention group reported higher self efficacy scores (3.6 ± 0.7 ; $P \leq 0.05$) than the control group (3.8 ± 0.9) and higher quality of life scores (5.0 ± 1.4 ; $P < 0.05$) than the control group (5.5 ± 1.4).	Child/young person Child/young person
Jan <i>et al.</i> 2007	Quality of life Quality of life improved significantly in the intervention group (6.5 ± 0.5 ; $P \leq 0.05$).	Pediatric Asthma Quality of Life Questionnaire (Juniper)	Child/young person and caregivers
Franklin <i>et al.</i> 2006	Self-efficacy Intervention group 1 = usual therapy and Sweet Talk. Intervention group 2 = intensive insulin therapy and Sweet Talk. Intervention group 1 reported to have higher scores [$62.1 (\pm 6.6)$; 95% CI +2.6, +7.5; $P = 0.003$] than the control group [$56 (\pm 13.7)$]. No results reported in relation to intervention group 2.	Self-efficacy for diabetes	Child/young person
Stevens <i>et al.</i> 2002	Quality of Life Mean scores (SD) 3 months post intervention: intervention group 5.41 (1.54); control group 5.38 (1.39); 95% CI -0.45, 0.40; $P = 0.90$ (<i>t</i> -test). Mean scores (SD) 12 months post intervention: intervention group 5.45 (1.45); control group 5.73 (1.28); 95% CI -0.14, 0.69; $P = 0.19$ (<i>t</i> -test).	Pediatric Asthma Caregivers Quality of Life Questionnaire (Juniper)	Parent
Flores <i>et al.</i> 2009	Quality of life Self-efficacy An intention to treat analysis found that there were no statistically significant differences between control and intervention group for quality of life or self-efficacy. However, this was a within-group analysis. A per protocol, stratified analyses (on basis of level of participation in programme) found that high level participants in the intervention reported significant improvements in parental self-efficacy in relation to managing serious breathing problems ($P = 0.01$). However, this was again a within-group analysis and the control group also reported statistically significant improvements in this outcome.	Pediatric Quality of Life Inventory (PedsQL) Pediatric Asthma Caregivers Quality of Life Questionnaire (Juniper) Parent Asthma Management Self-efficacy Scale	Parent Parent Parent
Wade <i>et al.</i> 2009	Quality of life Quality of life improved significantly in both the intervention and control group on both the Pediatric Asthma Quality of Life Questionnaire and the Pediatric Asthma Caregivers Quality of Life Questionnaire. In the symptom domain of the Pediatric Asthma Quality of Life Questionnaire a clinically important significant difference was reported in the intervention group ($P = 0.03$). In the activities domain of the Pediatric Asthma Caregivers Quality of Life Questionnaire a statistically and clinically important difference was found in the intervention group ($P = 0.05$) when compared with the control.	Pediatric Asthma Quality of Life Questionnaire (Juniper) Pediatric Asthma Caregivers Quality of Life Questionnaire (Juniper)	Child/young person Parent
Walders <i>et al.</i> 2006	Quality of life No statistically significant differences between control and intervention group for quality of life. Both groups reported significant improvements in quality of life ($P = 0.05$).	Children's Health Survey for Asthma	Parent

Condition-related knowledge

Davis <i>et al.</i> 2004	Cystic fibrosis Condition related knowledge increased following intervention (combined sample change score 31.4 (SD 17.8); $P \leq 0.001$; effect size (η^2) 1.76)	Cystic Fibrosis Knowledge Questionnaire	Unclear if parent or child/young person
Jan <i>et al.</i> 2007	Asthma knowledge Asthma knowledge scores significantly higher in the intervention group than control group ($P \leq 0.05$)	Asthma knowledge questionnaire (10 items)	Parents or caregivers
Stevens <i>et al.</i> 2002	Asthma knowledge No significant differences in knowledge score between intervention and control group. Median scores: intervention group 35, control group 30; median difference 1.0; 95% CI -2.0, 1.0; $K = 2695$.	Caregivers knowledge of asthma questionnaire (43 items)	Parents or caregivers
Franklin <i>et al.</i> 2006	Diabetes knowledge Intervention group 1 = usual therapy and Sweet Talk. Intervention group 2 = intensive insulin therapy and Sweet Talk. Knowledge scores: control 11.2 ± 1.9 ; intervention group 1 10.7 ± 2.4 ; intervention group 2 11.3 ± 2.0 . No significant differences reported between control and intervention group 1 ($P = 0.3$) or between interventions groups 1 and 2 ($P = 0.58$). Differences between control and intervention group 2 not investigated.	Diabetes Knowledge Score	Child/young person

Health care use

Wesseldine <i>et al.</i> 1999	Readmission to hospital A&E department attendance GP consultation (unplanned) Proportion of children readmitted to hospital significantly lower in intervention group (12, 1.5%, $n = 80$) than control group (30, 37%, $n = 80$) ($\chi^2 = 10.5$, $P = 0.001$). Intervention group had significantly lower (6, 8%, $n = 80$) rate of A&E attendance than control (31, 38%, $n = 80$) ($\chi^2 = 22$, $P \leq 0.001$). GP consultations substantially lower in the intervention group (31, 90%, $n = 78$) than control (72, 90%, $n = 77$) ($\chi^2 = 50$, $P \leq 0.001$).	Number of readmissions within 6 months of discharge Number of attendances within 6 months of discharge Number of consultations within 6 months of discharge	Hospital information system Hospital information system GP records
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Table 4. Continued

Study	Outcome	Measurement tool	Reporter
Cicutto <i>et al.</i> 2005	Urgent health care visits (A&E, GP) Intervention group reported fewer urgent health care visits (1.7 ± 1.9 ; $P < 0.01$) than control group (2.5 ± 2.5).	Number of visits	Parents
Guendelman <i>et al.</i> 2002, 2004	A&E department attendance Admission to hospital Urgent phone calls to hospital No significant differences between intervention group and control group for A&E attendance (OR 0.59; 95% CI 0.26, 1.35; $P = 0.21$) or hospital admissions (OR 0.99; 95% CI 0.25, 3.88; $P = 0.96$). Intervention group made fewer urgent calls to hospital than control (OR 0.43; 95% CI 0.18, 0.99; $P = 0.05$).	Number of visits in last 6 weeks Number of admissions in last 6 weeks Number of urgent calls in last 6 weeks	Parent and child/young person and record review.
Franklin <i>et al.</i> 2006	Clinic visits Emergency hotline contacts Intervention group 1 = usual therapy and Sweet Talk. Intervention group 2 = intensive insulin therapy and Sweet Talk. Clinic visits: no significant differences reported between control (3.0 $\pm$ 0.92) and intervention group 1 (3.3 $\pm$ 1.1; 95% CI -0.3, +0.8; $P = 0.36$) but significant differences reported between intervention group 1 (3.3 $\pm$ 1.1) and intervention group 2 (3.9 $\pm$ 1.0; 95% CI -0.1, +0.46; $P = 0.016$). Emergency hotline contacts: no significant differences reported between control (8) and intervention group 1 (3; 95% CI -33%, +7%; $P = 0.11$) but significant differences reported between intervention group 1 (3) and intervention group 2 (18; 95% CI +33%, +44%; $P = 0.011$). Differences between control and intervention group 2 not investigated.	Number of visits Number of contacts	Hospital records Hospital records
Evans <i>et al.</i> 1999; Sullivan <i>et al.</i> 2002	Admission to hospital No significant differences between intervention group (14.8%, $n = 515$) and control group (18.9%, $n = 518$); difference -4.19; 95% CI -8.75, 0.36; $P = 0.071$ at 1 year. No significant differences between intervention group (10.2%, $n = 515$) and control group (13.8%, $n = 518$) difference -3.72; 95% CI -7.86, 0.41; $P = 0.078$ at 2 years.	One or more hospitalizations in past year (%)	Unclear if parent or child/young person
Stevens <i>et al.</i> 2002	Readmission to hospital A&E department attendance GP consultation (unplanned) No significant difference between intervention and control groups for GP consultation rate [mean (SD) intervention group 3.87 (3.93), control 4.13 (3.63); 95% CI -1.34, 0.81; $P = 0.63$ (t -test)]; hospital admission (intervention group 26, 26%; control group 19, 19%; $\chi^2 = 1.11$, $P = 0.29$, 95% CI -0.03, 0.17); A&E attendance (intervention group 17, 17%; control group 19, 19%; $\chi^2 = 0.02$, $P = 0.88$, 95% CI -0.01, 0.03). Sample size ranged between 91 and 97 for intervention and 94 and 100 for control.	Number of readmissions 12 months post-intervention Number of attendances 12 months post-intervention Number of consultations 12 months post-intervention	Hospital records Hospital records GP records
Espinoza-Palma <i>et al.</i> 2009	Admission to hospital A&E department attendance No statistically significant differences between the intervention and control groups for hospital admissions or A&E visits (data not reported). Statistically significant reductions in hospital admissions and A&E visits reported for both control and intervention groups	Number of admissions to hospital in 12 months Number of A&E attendances in 12 months	Parent Parent
Flores <i>et al.</i> 2009	Admission to hospital A&E department attendance Intention to treat analysis demonstrated that there were statistically significant reductions in A&E visits ($P = 0.03$) for the intervention group. There were no statistically significant reductions in asthma hospitalizations. However, this was a within-group analysis.	Number of admissions to hospital in 12 months Number of A&E attendances in 12 months	Parent (confirmed by record review) Parent (confirmed by record review)
Wade <i>et al.</i> 2009	Admission to hospital A&E department attendance The intervention group reported a statistically significant reduction in ER visits ($P = 0.0037$) when compared with the control group. There were no statistically significant differences between the groups for hospital admissions.	Number of admissions to hospital during the year after the intervention Number of A&E attendances in during the year after the intervention	Unclear Unclear
Walders <i>et al.</i> 2006	Health care utilization The intervention group reported significantly fewer A&E visits and/or hospital admissions for asthma (95% CI 1.00, 3.69; $P = 0.05$).	Number of admissions to hospital in previous 12 months and number of A&E attendances in previous 12 months	Parent (confirmed by record review) Parent (confirmed by record review)

A&E, accident and emergency; GP, general practitioner.

intervention had no effect on parental quality of life (Stevens *et al.* 2002; Walders *et al.* 2006; Flores *et al.* 2009).

In relation to other psychosocial well-being/health behaviour outcomes, one intervention was associated with a short-term (12 week) improvement in adherence to prescribed medications based on caregiver assessments (Guendelman *et al.* 2002, 2004). Similarly, Franklin and colleagues (2006) found improved self-report adherence scores in the groups receiving the intervention. Interventions were also reported to be effective in improving coping skills (Davis *et al.* 2004), perceptions of illness impact (Christian & D'Auria 2006) and loneliness (Christian & D'Auria 2006). Five of the effective interventions were targeted at children/young people only and also used e-health methods (Guendelman *et al.* 2002, 2004; Davis *et al.* 2004; Christian & D'Auria 2006; Franklin *et al.* 2006; Jan *et al.* 2007). Two interventions that were associated with improving psychosocial well-being outcomes were focused on children/young people and parents (Cicutto *et al.* 2005; Wade *et al.* 2009).

Knowledge

All the interventions had an educational element but only four included condition-related knowledge as an outcome (Table 4). Two studies that used e-health type interventions found that children's/young people's knowledge had increased significantly following the intervention (Davis *et al.* 2004; Jan *et al.* 2007). Two studies found no significant increase in parental (Stevens *et al.* 2002) or children's/young people's (Franklin *et al.* 2006) knowledge.

Health care use and costs

The effect of the intervention on health service use was measured in 10 studies largely by parental self-report and record review (Table 4). Four studies found that the intervention had no effect on hospital admission while three others reported either significant reductions in admissions (Wesseldine *et al.* 1999; Walders *et al.* 2006) or reductions approaching statistical significance (Evans *et al.* 1999; Sullivan *et al.* 2002). The effect of interventions on use of Accident and Emergency Department attendance and general practitioner/primary care consultations is mixed with four studies reporting the intervention significantly decreased use (Wesseldine *et al.* 1999; Cicutto *et al.* 2005; Walders *et al.* 2006; Wade *et al.* 2009) and four studies reporting no effect (Guendelman *et al.* 2002, 2004; Stevens *et al.* 2002; Espinoza-Palma *et al.* 2009; Flores *et al.* 2009). Another study reported a significant increase in clinic visits and calls to an

emergency hotline for the intervention group, however, the frequency of visits were within clinical guidelines (Franklin *et al.* 2006). Indeed, this increase was seen in a positive light with the intervention demonstrating its potential to encourage attendance.

Cost-effectiveness was only assessed in two studies (Evans *et al.* 1999; Sullivan *et al.* 2002 and Flores *et al.* 2009). The multi-systemic intervention evaluated by Evans and colleagues (1999)/Sullivan and colleagues (2002) was concluded to be cost-effective particularly for those with the most severe asthma. Flores and colleagues (2009) reported cost savings for all intervention participants, with an overall cost saving of \$46.16 per child per month for high level participants.

Individual experience

Alongside quantitative measures of effectiveness, four studies obtained participants' views on the intervention (Davis *et al.* 2004; Franklin *et al.* 2006; Jan *et al.* 2007; Flores *et al.* 2009). A text messaging service for children/young people with diabetes was seen as helpful by the majority of users (81%, $n = 51$) and 57 (90%) reported that they wanted to continue using it after the end of the trial (Franklin *et al.* 2006). One study which provided children/young people with CDs with information about their condition reported high levels of satisfaction with the intervention (Davis *et al.* 2004) with participants reporting that this method was an appropriate way of obtaining information about their condition. However, limited details are provided by these studies about the conduct of this component of the studies and the results obtained. A study examining parental satisfaction using the Asthma Satisfaction Survey found no significant differences between control and intervention (Flores *et al.* 2009). Another study obtained feedback from children and parents in the form of a post-intervention survey and found that parents were 'reasonably satisfied' with an Internet-based approach (Jan *et al.* 2007).

Effectiveness of different types of interventions

While acknowledging that there are differences in outcome measurement, there is some evidence to suggest that particular interventions may be more effective in improving outcomes (Table 5). It appears that interventions that target children/young people alone or with their parents/families demonstrate effectiveness across all the outcome categories (Table 5). In particular there is strong evidence that interventions that target children/young people are effective in improving psychosocial well-being. There is no evidence that interventions that only focus on parents are effective.

Table 5. Relationship between characteristics of interventions and outcomes

Characteristic	Studies	Relationship to outcomes				
		Health status	Psychosocial well-being	Knowledge	Health care use	Satisfaction
Location of delivery						
Home/community setting	Evans <i>et al.</i> 1999; Guendelman <i>et al.</i> 2002, 2004; Sullivan <i>et al.</i> 2002; Cicutto <i>et al.</i> 2005; Franklin <i>et al.</i> 2006; Jan <i>et al.</i> 2007; Flores <i>et al.</i> 2009	Associated with improvements (n = 6)	Associated with improvements (n = 4)	Associated with improvements (n = 1)	Associated with reduction (n = 2) and increase (n = 1)	Associated with improvements (n = 2)
Hospital (clinic, ward)	Wesseldine <i>et al.</i> 1999; Stevens <i>et al.</i> 2002; Davis <i>et al.</i> 2004; Walders <i>et al.</i> 2006; Espinoza-Palma <i>et al.</i> 2009; Wade <i>et al.</i> 2009	Associated with improvements (n = 1)	Associated with improvements (n = 2)	Associated with improvements (n = 1)	Associated with reduction (n = 3)	Associated with improvements (n = 1)
Combination of settings (home, community, hospital)	Christian & D'Auria 2006	Not associated with improvement	Associated with improvements (n = 1)	Not measured	Not measured	Not measured
Mode of delivery of the intervention						
Individual child/family based (includes interventions that are self-directed/self-study)	Wesseldine <i>et al.</i> 1999; Guendelman <i>et al.</i> 2002, 2004; Stevens <i>et al.</i> 2002; Davis <i>et al.</i> 2004; Franklin <i>et al.</i> 2006; Walders <i>et al.</i> 2006; Jan <i>et al.</i> 2007; Espinoza-Palma <i>et al.</i> 2009	Associated with improvements (n = 3)	Associated with improvements (n = 4)	Associated with improvements (n = 2)	Associated with reduction (n = 2) and increase (n = 1)	Associated with improvements (n = 3)
Group based	Cicutto <i>et al.</i> 2005; Wade <i>et al.</i> 2009	Associated with improvements (n = 2)	Associated with improvements (n = 2)	Not measured	Associated with reduction (n = 2)	Not measured
Combination of individual and group based	Evans <i>et al.</i> 1999; Sullivan <i>et al.</i> 2002; Christian & D'Auria 2006; Flores <i>et al.</i> 2009	Associated with improvements (n = 1)	Associated with improvements (n = 1)	Associated with improvements (n = 1)	No effect	No effect
Use of computer games, Internet, mobile phone technology and other e-health modes of delivery	Guendelman <i>et al.</i> 2002, 2004; Davis <i>et al.</i> 2004; Christian & D'Auria 2006; Franklin <i>et al.</i> 2006; Jan <i>et al.</i> 2007	Associated with improvements (n = 3)	Associated with improvements (n = 5)	Associated with improvements (n = 2)	Associated with increase (n = 1)	Associated with improvements (n = 3)
Target of the intervention						
Children/young people only	Guendelman <i>et al.</i> 2002, 2004; Davis <i>et al.</i> 2004; Christian & D'Auria 2006; Franklin <i>et al.</i> 2006; Jan <i>et al.</i> 2007	Associated with improvements (n = 3)	Associated with improvements (n = 5)	Associated with improvements (n = 2)	Associated with increase (n = 1)	Associated with improvements (n = 3)
Parents only	Stevens <i>et al.</i> 2002	Not associated with improvement	Not associated with improvement	Not associated with improvement	No effect	Not measured
Child and parent/family	Evans <i>et al.</i> 1999; Wesseldine <i>et al.</i> 1999; Sullivan <i>et al.</i> 2002; Cicutto <i>et al.</i> 2005; Walders <i>et al.</i> 2006; Espinoza-Palma <i>et al.</i> 2009; Flores <i>et al.</i> 2009; Wade <i>et al.</i> 2009	Associated with improvements (n = 3)	Associated with improvements (n = 2)	Not measured	Associated with reduction (n = 5)	No effect

E-health interventions demonstrated positive effects on all outcome categories apart from health service use where their effect is less clear (Table 5). There is strong evidence of the effectiveness of this method of self-care support on psychosocial well-being. Although only two of the included studies investigated a purely group-based intervention both these studies demonstrated effectiveness in terms of improving health status and psychosocial well-being and in reducing health service use (Cicutto *et al.* 2005; Wade *et al.* 2009). There is less evidence that interventions that focus on individual children or families are effective (Table 5).

Interventions delivered in the home or in community settings demonstrated effectiveness across all the outcome categories but particularly in relation to health status and psychosocial well-being (Table 5). There is less evidence that combining intervention settings or modes of delivery has a positive effect on outcomes. There is no evidence of the effectiveness of delivering interventions only in hospital settings.

Discussion

This review suggests that self-care support interventions that target children/young people either alone or with their parents can be effective in improving a range of outcomes and that there is strong evidence for the effectiveness of those interventions directed at children/young people in improving psychosocial well-being. In terms of type of self-care support interventions, there is evidence that those using e-health methods are effective particularly in relation to psychosocial well-being. There is also evidence of the effectiveness of group-based interventions in improving health status and psychosocial well-being and in reducing health service use. There is less evidence that interventions that focus on individual children/families or which combine different intervention settings or modes of delivery are effective. In addition, there is no evidence that interventions that only focus on parents or are delivered only in hospital settings are effective.

Within the wider literature there is conflicting evidence regarding the effectiveness of group-based interventions in relation to self-care with some reviews concluding that group-based approaches are more effective than individual approaches (Deakin *et al.* 2005; Loveman *et al.* 2008) and others finding no difference between the two approaches (Barlow *et al.* 2002; Wolf *et al.* 2002; Gary *et al.* 2003). In relation to educational and psychosocial interventions for children with diabetes, beneficial effects have been reported for both individual and group approaches (Hampson *et al.* 2001). Previous research has suggested that young people and parents value the opportunity to

interact with others in a similar situation in order to share common experiences and information (Johnson *et al.* 2001; Bruzzese *et al.* 2004; Trollvik & Severinsson 2005; Barlow *et al.* 2007). However, the potential negative consequences of peer groups in self-care support have also been noted (Rogers *et al.* 2009).

E-health appears to be an effective self-care approach in adult chronic illness (Murray *et al.* 2005; Griffiths & Christensen 2006). Studies suggest that it is a medium that engages children/young people and is perceived to support their self-management (Johnson *et al.* 2001; Gammon *et al.* 2005; Carroll *et al.* 2007; Van der Meer *et al.* 2007). Another review has indicated that while there is evidence to support the provision of self-care support for children in the home there is insufficient evidence in relation to community settings (Norris *et al.* 2002).

Although the level of detail provided about the interventions reviewed in this paper varied, the transferability of some interventions to 'real-life' settings appears to be feasible in terms of the resources required for integration into current practice (Wesseldine *et al.* 1999; Jan *et al.* 2007; Wade *et al.* 2009). However, there were others that appear to demand significant resources (Evans *et al.* 1999; Sullivan *et al.* 2002; Flores *et al.* 2009). The interventions studied have been developed and implemented under experimental conditions which may be very different from the settings or populations in which they would be actually delivered. Another difficulty in assessing transferability is a lack of reporting of sample characteristics to allow assessments to be made about how representative the sample might be of the population in question. It was notable that in a number of studies there were a disproportionately high number of boys and a low proportion of ethnic minority participants. In addition, a number of studies included a wide age range and it was unclear if interventions were adapted for children and young people of different ages. Although the importance of 'whole system' approaches to self-care are increasingly recognized (Kennedy *et al.* 2007), currently there is little evidence of their effectiveness in relation to children.

In terms of methodological quality only 15 of the 194 papers reviewed were assessed as being of sufficient methodological quality to produce reliable results or make firm conclusions on effectiveness. Most of the included studies lacked a theoretical basis to the intervention developed. A theoretical basis is important because it suggests the nature and content of the intervention as well as the appropriate outcomes to measure and at what time points. It also informs predictions about which outcomes are expected to change and which are expected to be stable. In some studies the outcomes measured were unclearly defined and not all identified a primary outcome. Where a primary

outcome was identified this was frequently health status and/or health service. Psychosocial well-being and health behaviour related outcomes were only measured in half of the studies and condition related knowledge in only four studies. However, it can be argued that self-care support interventions are essentially psychosocial and educational interventions concerned with changing self-management behaviours, attitudes and beliefs, which are viewed as being the mediators of improved health status. Therefore, it would seem to be important that intervention studies assess changes in these behavioural and psychological outcomes. Moreover, parents and children/young people are likely to value improvements in their experiences of living with a long-term condition as well as improvements in health status which means that outcomes such as quality of life, self-efficacy and psychological well-being need to be included in assessing the effectiveness of interventions. This suggests that there is a need to ensure that outcome measurement is patient-centred and involves parents and children/young people to ensure interventions are assessed by criteria that are relevant to them. Although some studies included children's/young people's reports, others used parents as proxies without justification even though there is evidence to suggest that parents and children can assess outcomes differently (Upton *et al.* 2005; Palermo *et al.* 2008). In addition, there were studies where it was unclear who had actually completed the measures.

The review has identified that there is a need for well-designed randomized control trials to be conducted which test theoretically informed interventions that have been developed with parents and children/young people and which are feasible to transfer into clinical practice. These should include the measurement of psychosocial outcomes as well as health status, health service use, cost-effectiveness and an assessment of implementation issues in order to inform the development of future self-care interventions for children/young people. In general, the diversity of individuals, families and communities has been neglected in the development of self-care support interventions. Consequently, there is a need for research that investigates what interventions are appropriate for individuals who face barriers due to disability, socio-economic status, education, culture, geography or gender. There has been a lack of a cumulative approach to research and opportunities to learn from studies investigating similar types of interventions but in different conditions appear to have been missed.

Strengths and limitations

This review has contributed to knowledge by evaluating self-care support across different childhood long-term conditions

and by focusing on a broad range of self-care support interventions whereas other reviews have mainly focused on single conditions and on particular types of intervention. In particular, it has aimed to examine the effectiveness of self-care support interventions in relation to their target, location of delivery and the medium used. An explicit and systematic approach was taken to searching and appraisal. However, there are a number of limitations to this review. Authors were not contacted for additional information about studies and non-English language studies were not included in the review. Studies relating to asthma are over-represented in the review because there have been fewer randomized control trials conducted of self-care support interventions for diabetes and cystic fibrosis. In addition, the conclusions made from the review are not based on a meta-analysis but on a narrative synthesis. The self-care interventions reviewed are comprised of different elements and therefore it is difficult to assess the relative benefits of these different components rather than their global effect.

Key messages

- There is a lack of evidence on which to base the development of self-care programmes for children and young people.
- There is strong evidence of the effectiveness of interventions that target children/young people; use e-health or group-based methods; that are delivered in community settings.
- There is no evidence that interventions that focus on parents alone or are delivered only in hospital settings are effective.
- Well-designed trials of interventions are needed which are feasible to transfer into real-life settings and involve parents and children in their development.

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