

Self-care support for children and adolescents with long-term conditions: the REfOCUS evidence synthesis

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Scientific summary

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Background

Commensurate with trends in the adult population, long-term conditions (LTCs) in children and young people are increasing and there is growing international emphasis on developing effective, efficient and person-centred models of service delivery to meet the needs of this patient group. Health-care providers are faced with the growing need to deliver high-quality services in a way that maximises available financial resources without compromising care quality or health outcomes for children and young people. Self-care support interventions offer a potential solution to this problem and are intended to enhance the self-care capacities of children, young people and their families, while simultaneously reducing the fiscal burden facing contemporary health-care systems.

Self-care can be defined as the actions that people take to maintain their physical and mental health; meet social and psychological needs; prevent illness or accidents; and maintain their health and well-being. Self-care support refers to the role played by health-care professionals (or other self-care support agents, such as teachers or peers), in supporting the individual and/or their families to take control of a health condition through developing their confidence, knowledge and skills, and their psychological and social resources.

An implicit assumption underlying self-care support is that it can help people to avoid unnecessary crises and prevent more extensive health services utilisation by managing patients' problems more effectively. Children diagnosed with LTCs face a lifetime of symptom management, and the extent to which they and their families negotiate this in childhood is likely to influence their longer-term health outcomes, life chances and subsequent patterns of health service utilisation. Providing optimal, evidence-based support for self-care thus has the potential to make significant and sustained contributions to NHS efficiency, as well as improving quality of care and health outcomes.

Objectives

To determine which models of self-care support for LTC management are associated with significant reductions in health services utilisation and cost, without compromising quality of life (QoL) or health status outcomes for children and young people.

Methods

We conducted a systematic review with meta-analysis. We defined self-care support as 'any intervention primarily designed to develop the abilities of children and young people (and/or their adult carers) to undertake management of their long-term health condition through education, training and support to develop their knowledge, skills or psychological and social resources'. Our review inclusion criteria were as follows:

- population – children and young people aged 0–18 years with a long-term physical or mental health condition
- intervention – self-care support delivered in a health, social care, educational or community setting
- comparator – usual care, including more intensive usual care (e.g. clinic or inpatient management)
- outcomes – quantitative measures of generic, health-related QoL or disease-specific symptom measures or events and health service utilisation or costs
- design – randomised trials, non-randomised trials, controlled before-and-after studies, interrupted time series designs.

To identify relevant literature, we searched multiple electronic databases: MEDLINE, EMBASE, PsycINFO, Cumulative Index to Nursing and Allied Health Literature, ISI Web of Science (including Social Sciences Citation Index and Science Citation Index Expanded), NHS Economic Evaluation Database, The Cochrane Library (including Cochrane Database of Systematic Reviews, Database of Abstracts of Reviews of Effects and Cochrane Central Register of Controlled Trials), Health Technology Assessment database, Paediatric Economic Database Evaluation and IDEAS. All databases were searched from inception to March 2015. No language restrictions were applied. Additional search strategies included scanning the bibliographies of all relevant retrieved articles, targeted author searches and forward citation searching.

Data were extracted on populations, interventions, study quality and outcomes. We extracted data that allowed us to report a measure of the magnitude of effects [a standardised 'effect size' (ES)] for both health outcomes and costs. We conducted meta-analyses and presented the results of the included studies according to a permutation plot, simultaneously plotting the effect of interventions on service utilisation and health. Each plot gives a visual impression of the distribution of studies across the cost-effectiveness plane, distinguishing between studies that reduce costs without compromising outcomes and those that reduce costs but also compromise outcomes, or those that compromise both outcomes and costs.

We analysed data for included studies as a whole and then conducted meaningful subgroup analyses for level of evidence quality (defined as the adequacy of allocation concealment), age of the children and young people, type of LTC and the setting and type of self-care support intervention that was evaluated (i.e. intervention target, format, delivery method and intensity).

Results

We screened 36,493 unique records for eligibility; 97 studies reporting on 114 interventions were included in our review. Thirty-seven trials (38% of all included studies) were rated as being of high quality (i.e. at a low risk of bias) on the basis of adequate randomisation and allocation concealment. Fourteen studies (14%) were conducted in the UK.

The vast majority of included studies recruited children and young people with asthma ($n = 66$, 68%) or long-term mental health conditions ($n = 18$, 19%). Fewer studies included children with diabetes ($n = 6$), other physical health conditions ($n = 2$) and behavioural difficulties ($n = 5$). The mean age of the children and young people participating in the primary studies was 10.12 years (standard deviation 3.9 years). Of the interventions, 4% were categorised as pure self-care (i.e. delivered through a health technology without any additional support), 23% as facilitated self-care (< 2 hours'/four sessions' support), 65% as intensively facilitated self-care (> 2 hours'/four sessions' support) and 8% as 'case management' (> 2 hours' support including input from a multidisciplinary team).

The majority of self-care support interventions targeted adult caregivers, either together or in parallel with children and young people. These interventions were most typically delivered face to face to individuals, or individual families, in either an outpatient setting or a patient's home.

A moderately sized evidence base enabled meaningful assessments of the effect of self-care support interventions on children and young people's health and QoL (77 comparisons), hospital admissions (65 comparisons) and emergency department (ED) visits (57 comparisons). Other forms of health service use (e.g. primary care visits) were inconsistently reported and were not amenable to meta-analysis. There was a comparative lack of data demonstrating the effects of self-care support on total health service costs (10 comparisons) and variability across studies reporting total cost outcomes was high.

Self-care support interventions have significant but minimal benefits for children and young people's QoL [ES -0.17, 95% confidence interval (CI) -0.23 to -0.11], but lack clear benefits for hospital admissions (ES -0.05, 95% CI -0.12 to 0.03) and total health-care costs (ES -0.11, 95% CI -0.47 to 0.25). Minimal

reductions in ED use were observed (ES -0.11 , 95% CI -0.17 to -0.04). Data on QoL outcomes suggest the possibility of small study bias. Sensitivity analyses that restricted evidence to high-quality trials confirmed that the findings were robust.

Subgroup analyses revealed statistically significant, minimal reductions in emergency use for children aged ≤ 13 years (ES -0.10 , 95% CI -0.17 to -0.04), children and young people with asthma (ES -0.12 , 95% CI -0.18 to -0.06) and children and young people receiving ≥ 2 hours per four sessions of support (ES -0.10 , 95% CI -0.17 to -0.03). The different ESs observed in these subgroup analyses will, in part, reflect differences in the number of studies available and the precision of pooled effects; additional evidence is required to confirm or reject these hypotheses.

Preliminary analyses suggest that the effects of self-care support on children and young people's QoL and ED visits may be optimised by interventions that include the child or young person and deliver at least some of their content to an individual or individual family. Group-based delivery may be more advantageous in reducing hospital admissions, although effects are likely to remain small.

Self-care support interventions for children and young people can vary considerably in the extent to which they target different service utilisation behaviours and it is possible that this influence is meaningful. It is plausible, for instance, that although written action plans to control asthma exacerbations may play a direct role in reducing ED visits, self-care support for mental health may be focused on longer-term recovery and service user empowerment.

Preliminary data in our permutation plots suggest that self-care support for asthma is capable of reducing some aspects of health utilisation for children and young people, but high variability in patient outcomes means that compromises in health status cannot definitively be ruled out. Self-care support interventions that reduce health utilisation for children and young people with mental health conditions may be less likely to compromise patient outcomes, but limited data, and pooling across different conditions, mean that these results must be treated with caution. Lack of data prevented permutation plots being generated for other LTCs.

Conclusions

Self-care support for children and young people is advocated as a key method of increasing service efficiency, but there remains some uncertainty regarding the scale of the contribution that can be made. Current evidence suggests that self-care support interventions will have positive but minimal effects on children and young people's QoL, but may have a limited impact on health utilisation and costs. Self-care support for children and young people is associated with significant but small reductions in ED use, particularly in relation to asthma. Models of self-care support that reduce utilisation do not routinely compromise patient outcomes. However, the effects are highly variable and compromises in children and young people's QoL cannot be definitively ruled out.

New primary research is urgently needed to ascertain the effects of self-care support across a wider range of LTCs and to explore if, and which, models of self-care support can achieve more powerful, consistent effects on health service utilisation.

Future studies should adopt clear and consistent standards of data reporting, including comprehensive reporting of patient outcomes, utilisation and costs. New research should adopt innovative methods of patient recruitment to maximise intervention reach and consider the feasibility of longer-term follow-up to explore potential differences in the shorter- and longer-term effects of self-care support for children and young people.

Study registration

This study is registered as PROSPERO CRD42014015452.

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