

Cochrane Database of Systematic Reviews - - Cochrane Review

Cost effectiveness of newborn screening for cystic fibrosis: a simulation study

Code: NHSEED-22013052127 **Year:** 2013 **Date:** 2011 - updated: 25 JUL 2014

Author: Nshimyumukiza L

Study design (if review, criteria of inclusion for studies)

Randomised controlled trials, quasi-randomised controlled trials or controlled clinical trials comparing different types of self-management education for cystic fibrosis or comparing self-management education with standard care or no intervention.

List of included studies (4)

Cottrell 1996; Downs 2006; Stapleton 2001; Watson 2008

Participants

Individuals of all ages with a diagnosis of CF (diagnosed clinically and by sweat or genetic testing) or family members, or both.

Interventions

Disease-specific nutrition education ('Go and Grow with CF'); General and disease-specific nutrition education ('Eat Well with CF'); Self-management education on aerosol and airway clearance treatments ('Airways'); Self-management training

Outcome measures

Primary outcomes 1. Pulmonary function (FEV1, FVC, residual volume/total lung capacity (RV/TLC), FEF25[~]75%); 2. Indices of nutritional health or growth (change in height and in weight, BMI, z score, any other indices of nutritional health)

Main results

Four trials (involving a total of 269 participants) were included. The participants were children with cystic fibrosis and their parents or caregivers in three trials and adults with cystic fibrosis in one trial. The trials compared four different self-management education interventions versus standard treatment: (1) a training programme for managing cystic fibrosis in general; (2) education specific to aerosol and airway clearance treatments; (3) disease-specific nutrition education; and (4) general and disease-specific nutrition education. Training children to manage cystic fibrosis in general had no statistically significant effects on weight after six to eight weeks, mean difference -7.74 lb (95% confidence interval -35.18 to 19.70). General and disease-specific nutrition education for adults had no statistically significant effects on: pulmonary function (forced expiratory volume at one second), mean difference -5.00 % (95% confidence interval -18.10 to 8.10) at six months and mean difference -5.50 % (95% confidence interval -18.46 to 7.46) at 12 months; or weight, mean difference -0.70 kg (95% confidence interval -6.58 to 5.18) at six months and mean difference -0.70 kg (95% confidence interval -6.62 to 5.22) at 12 months; or dietary fat intake scores, mean difference 1.60 (85% confidence interval -2.90 to 6.10) at six months and mean difference 0.20 (95% confidence interval -4.08 to 4.48) at 12 months. There is some limited evidence to suggest that self-management education may improve knowledge in patients with cystic fibrosis but not in parents or caregivers. There is also some limited evidence to suggest that self-management education may result in positively changing a small number of behaviours in both patients and caregivers.

Authors' conclusions

The available evidence from this review is of insufficient quantity and quality to draw any firm conclusions about the effects of self-management education for cystic fibrosis. Further trials are needed to investigate the effects of self-management education on a range of clinical and behavioural outcomes in children, adolescents and adults with cystic fibrosis and their caregivers.

<http://www.cysticfibrosisjournal.com/article/S1569-1993%2813%2900169-0/abstract>

See also

J Cyst Fibros. 2013 Nov 12. pii: S1569-1993(13)00169-0. doi: 10.1016/j.jcf.2013.10.012.

Keywords

Adolescent; Adult; Caregivers; Child; non pharmacological intervention - diet; non pharmacological intervention - psycho-soc-edu-org;
Self-Management; Behavioural interventions;