Cochrane Database of Systematic Reviews - - Cochrane Review

Psychological interventions for individuals with cystic fibrosis and their families

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

Randomised controlled trials of a broad range of psychological interventions in children and adults with CF and their immediate family.

List of included studies (16)

Belsky 1994; Chernoff 2002; Christian 2006; Delk 1994; Goodill 2005; Grasso 2000; Hernandez-Reif 1999; Powers 2003; Powers 2005; Quinn 2004; Stark 1996; Stark 2003; Stark 2009; Taylor 2003; Vandemheen 2009; Wilkinson 2008

Participants

Children and adults diagnosed with CF - individuals of all ages, from any ethnic group, and during all stages of the disease process will be included. Parents or carers or both of a child or adult with CF. Siblings of a child or adult with CF. Nuclear family of a child or adult with CF where the individuals with whom the person with CF lives were identified collectively as a family unit.

Interventions

Behavioral and nutritional intervention (BEH); Behavioural group treatment; Biofeedback assisted breathing re-training (BRT); Community-based support program; Genetic clinic education & carrier testing; Go and Grow with CF; Massage therapy; Music therapy; Nutrional intervention plus behavioural management training (BEH); Self-management education programme 'Airways'; STARBRIGHT CD-ROM; Teaching and drug leaflets

Outcome measures

% Anthropometric; % fat intake; Acceptance of CF carrier testing by relatives of those affected; Activity level; Anthropometric change scores; Anthropometric measures; CF Knowledge score; Child knowledge on ACT questionnaire; Childrenâ€™s feelings about performing daily aerosol and ACT treatments; Cognitive; Educational - knowledge test - while for test results; Educational - patient knowledge; Emotional; Nutrition status; Nutritional and enzyme knowledge score - carers; Nutritional and enzyme knowledge score - children; Nutritional status; Percentage of prescribed aerosols taken; Psychiatric Symptom Index - Anxiety subscale - mother; Pulmonary function; Relational; total energy intake per day (kcal); Use of support service - satisfaction with testing - after results were known

Main results

The review includes 16 studies (eight new studies included in this update) representing data from 556 participants. Studies are diverse in their design and their methods. They cover interventions with generic approaches, as well as interventions developed specifically to target disease-specific symptoms and problems in people with cystic fibrosis. These include cognitive behavioural interventions to improve adherence to nutrition or psychosocial adjustment, cognitive interventions to improve adherence or those associated with decision making in lung transplantation, a community-based support intervention and other interventions, such as self-hypnosis, respiratory muscle biofeedback, music therapy, dance and movement therapy, and a tele-medicine intervention to support patients awaiting transplantation.A substantial proportion of outcomes relate to adherence, changes in physical status or other specific treatment concerns during the chronic phase of the disease.There is some evidence that behavioural interventions targeting nutrition and growth in children (4 to 12 years) with cystic fibrosis are effective in the short term. Evidence was found that providing a structured decision-making tool for patients considering lung transplantation improves patients' knowledge of and expectations about the transplant, and reduces decisional conflict in the short term. One study about training in biofeedback-assisted breathing demonstrated some evidence that it improved some lung function measurements. Currently there is insufficient evidence for interventions aimed at other aspects of the disease process.

Authors' conclusions

Currently, insufficient evidence exists on psychological interventions or approaches to support people with cystic fibrosis and their caregivers, although some of the studies were promising. Due to the heterogeneity between studies, more of each type of intervention are needed to support preliminary evidence. Multicentre studies, with consequent funding implications, are needed to increase the

sample size of these studies and enhance the statistical power and precision to detect important findings. In addition, multicentre studies could improve the generalisation of results by minimizing centre or therapist effects. Psychological interventions should be targeted to illness-specific symptoms or behaviours to demonstrate efficacy.

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See also

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Keywords

Adult; Caregivers; Child; family; Family Therapy; non pharmacological intervention - diet; non pharmacological intervention - psyco-soc-edu-org; pharmacological_intervention; Psychoeducation; training; carrier status; Genetic Predisposition to Disease; Depression; Self-Management; Biofeedback- Psychology; Biofeedback- hypnosis- and relaxation; Systemic interventions; Mental Disease-Psychiatric Conditions; Behavioural interventions;