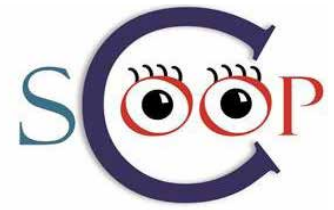


Supporting Children's Physiotherapy for Cystic Fibrosis



Background:

Cystic fibrosis (CF) is an inherited, life-threatening disorder of the lungs and digestive system affecting approximately 1 in 2,500 children in the UK. Chest physiotherapy is a major component in the respiratory management of CF to help prevent lung damage.

Adherence in young children is important because damage occurs rapidly and can be irreversible. However, parents and young children adhere to only 50% of their recommended regimen. Interventions to address this significant problem are lacking.

The SCoop project involved the development and testing of an audio-visual intervention to increase physiotherapy adherence among 0-8 year olds.

Aims and objectives:

The main aim of the studies was to develop and feasibility test a theoretically-informed intervention consisting of a film and family action plan to improve adherence to home chest physiotherapy (CPT) among children aged 0 to 8 years with CF and their parents/carers.

Methods:

The project employed a mixed-methods, two-stage approach.

Stage 1 used an action research approach to develop a short film and family action plan in partnership with 11 paediatric CF clinicians and 18 parents of young children with CF in the UK.

Stage 2 involved a before-and-after repeated measures feasibility study of the intervention with 20 parents in the UK. Quantitative outcomes data collected from parents included physiotherapy adherence, parental depression and anxiety, and burden of care. In-depth qualitative interviews explored experiences and acceptability of the intervention.

Parents were recruited via the NHS and community routes. Parents accessed the film online or via DVD.

Findings:

We designed and tested an audio-visual intervention (a documentary film and action plan) intended to improve adherence to home CPT among young children with CF and their parents.

The documentary film featured seven families, a computer animation of the lungs, and incorporated behavior change techniques.

In the feasibility study, recruitment and retention of NHS research sites and parents were successful:

- 10 out of 14 NHS sites agreed to participate and invited parents to take part in the study
- We recruited our target of 20 parents
- 17 out of 20 parents watched the film and completed data collection

At 8 weeks post intervention there was a trend for:

- increased adherence - although most parents were adherent at baseline
- reduced parental depression and anxiety
- reduced carer burden.



Figure 1. Still images from the documentary film

Qualitative data indicated that the intervention was acceptable, appealing and supportive to parents. The film made them feel less alone. Some parents thought the film was more suited to parents of newly-diagnosed infants despite also featuring older children. Most parents had not used the action plan because of perceived lack of need related to high adherence.

Conclusions:

The intervention appears acceptable and supportive and could enhance physiotherapy adherence in young children with CF and their parents.

Next steps:

Plans for a larger study are underway to definitively decide if the intervention increases adherence.

Funder:

Chief Scientist's Office and the Cystic Fibrosis Trust

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