Scottish Government Health Directorates Chief Scientist Office

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DEVELOPMENT OF AN INTERVENTION TO INCREASE PHYSIOTHERAPY ADHERENCE AMONG YOUNG CHILDREN WITH CYSTIC FIBROSIS: A MEDICAL RESEARCH COUNCIL COMPLEX INTERVENTION FRAMEWORK DEVELOPMENT AND FEASIBILITY STUDY

Researchers

PI: Dr Emma France. Co-Applicants: Dr Gaylor Hoskins; Prof. Suzanne Hagen; Elaine Dhouieb; Steve Cunningham; Prof. Eleanor Main; Prof. Chris Rowland; Prof. Shaun Treweek; Dr John McGhee; Dr Claire Glasscoe; Dr Janet Marjorie Allen; Prof. Pat Hoddinott; Prof. Brian Williams. Researchers: Dr Karen Semple, Dr Mark Grindle, Kieran Duncan.

Aim

To develop and test an intervention based on what we know works and consisting of a film and family action plan to improve adherence to home chest physiotherapy (CPT) among children aged 0 to 8 years with cystic fibrosis (CF) and their parents.

Project Outline/Methodology

This study took a two-stage approach using qualitative and quantitative methods.

Stage 1. A cyclical qualitative action research approach was used to develop a documentary film, including a lung computer animation, and action plan in partnership with paediatric CF clinicians and parents of young children with CF. This process drew on the 'development' and 'feasibility/piloting' stages of the 2008 version of the Medical Research Council Framework for the Development of Complex Interventions. Twenty-nine participants - 18 parents and 11 clinicians - took part in online interaction and telephone interviews over 8 months.

Stage 2. Design: a before-and-after repeated measures feasibility study of the intervention with 20 parents in the UK. Quantitative data on adherence (primary outcome), parental depression/anxiety and burden of care (secondary outcomes) were collected from parents (the main family caregiver) by telephone at three points – baseline, 4 weeks and 8 weeks post intervention. Post-intervention, in-depth qualitative interviews explored experiences and acceptability of the intervention.

Key Results

We designed and tested an intervention (film and action plan) intended to improve adherence to home CPT among young children with CF and their parents. In the feasibility study, 20 parents of children with CF took part. Recruitment and retention of NHS research sites and parents were successful. Seventeen of 20 parents completed data collection and watched the film but only seven used the action plan. Number of CPT sessions completed was a better adherence indicator than session length. There was a trend for increased adherence - although most parents were adherent at baseline - and for improved parental mood and burden 8 weeks post intervention. Where parents shared CPT administration, there were missing adherence data. Qualitative data indicated that the intervention was acceptable, appealing and supportive to parents. Some parents thought the film was more suited to parents of newly-diagnosed infants despite also featuring older children. Most parents could not recall the action plan. The intervention is likely to be used by parents without formal clinician input, accessed online or by DVD.

Conclusions

The proposed intervention holds promise as an inexpensive, acceptable, appealing and supportive intervention to be used by parents. We consider that the intervention warrants a larger-scale study to definitively decide if the intervention increases adherence. A future study should: target low-moderate adherent parents, collect outcomes data from all caregivers who administer home CPT, and modify the action plan to improve its salience and use.

What does this study add to the field?

The study suggests that a documentary film and accompanying action plan are acceptable and could potentially enhance CPT adherence in young children with CF and their parents.

Implications for Practice or Policy

If it proves successful after a future larger-scale study, this intervention could contribute to an increase in CPT treatment adherence in young children with CF, with potential to decrease the likelihood of lung damage and medical complications, reducing both health burden and costs to families and the NHS.

Where to next?

Some refinements should be made to the intervention and study processes in a further feasibility study including pilot study prior to applying for funding for a larger-scale study.

Further details from:

Dr Emma France: NMAHP-RU, School of Health Sciences, University of Stirling.
Email: emma.france@stir.ac.uk