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DOES ADMINISTERING A PARENT REPORTED OUTCOME MEASURE DURING THE ANNUAL REVIEW PROCESS IMPROVE THE SELF-EFFICACY OF CARERS OF CHILDREN WITH CYSTIC FIBROSIS

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Background and aims: Cystic fibrosis (CF) is the most common life limiting, inherited disease to affect the Caucasian population. Medical advances have resulted in a longer life expectancy, at the expense of an intensive and often time-consuming treatment regime for patients. Children with CF rely on their primary care givers for adequate treatment. The 'Challenges of Living with Cystic Fibrosis Questionnaire' (CLCF-Q) has been developed as a tool to measure the burden of caring for a child with CF. The aim of this study is to identify whether the self-efficacy, as measured by the 'Cystic Fibrosis Self-Efficacy Questionnaire' (CFSE-Q), can be improved by administering the CLCF-Q to the carer during the child's annual review.

Methods: This is a single centre, randomised control trial. Participants randomised to Group1 (intervention group) receive the CLCF-Q during the annual review. Group 2 is the control group. Those in Group 1 receive feedback based on their answers from the CLCF-Q. All participants complete the CFSE-Q at the beginning and end of the study (Phase I and Phase II respectively).

Results: Interim analysis demonstrates that participants in Group 1 (n=11) have a significantly greater improvement in their self-efficacy scores than Group 2 participants (n=15), at the end of phase II of the trial (Median (IQR) change in self-efficacy score 1 (-1 to 4) versus -2 (-4 to 1); U=41.000, p=0.031).

Conclusions: This study suggests that self-efficacy in carers of children with CF can be improved by administering and giving feedback on the CLCF-Q.