Fear of disease progression questionnaire for parents: Psychometric properties based on a sample of caregivers of children and adolescents with cystic fibrosis.

Abstract:
Parents caring for a child with a chronic somatic condition are at risk of increased distress and impaired quality of life. Fear of disease progression (FoP) is known to be an important source of distress in patients and their partners, and may be of relevance for parents as well. Existing measures are not applicable to parents. This study describes the adaptation of the FoP questionnaire for parental caregivers and investigated its psychometric properties. Sixteen items appropriate for parents were derived from existing measures and from interviews with clinical experts in family-oriented psychosocial care. Factor structure, internal consistency, validity and sensitivity to change were analyzed in a clinical sample of 162 caregivers (M(age)=42.07 years, SD=6.0 years, 87.8% female) of a child with cystic fibrosis. The exploratory factor analysis revealed a two-factor structure, which was not supported by confirmatory analysis. Cronbach's ? was examined for total score (.91) and significant positive correlations of the total score with anxiety (HADS: r=.70) and depression (CES-D: r=.60, BDI-II: r=.59), and a significant negative correlations with quality of life (r=-.66) could be demonstrated. A significant decrease in FoP was found (d=1.11) in a group of highly distressed caregivers undergoing web-based cognitive behavioral intervention. The FoP questionnaire is a reliable and
valid instrument for parents of children with CF. Further studies in larger samples are needed to clarify dimensionality and validity among parents of children with other chronic conditions.

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