European Cystic Fibrosis Society

Journal of Cystic Fibrosis
The Official Journal of the European Cystic Fibrosis Society

Cystic Fibrosis Research News

Title:

Caregiver burden of parents of young children with cystic fibrosis

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What was your research question?

How does the care provided by both mothers and fathers of young children with cystic fibrosis (CF) impact on their lives? Are there any risk factors that are associated with a high impact in parents of young children with CF?

Why is this important?

Informal caregivers provide an important economic and social service in society which is likely to increase due to pressures on healthcare services. The number of, sometimes complicated, treatment schedules needed by children with CF and adherence to these schedules means a large burden of care is placed on their parents or caregivers. They also have to cope with uncertainty about the progression of their child's condition, financial strain due to costs linked to caring for their child, as well as frequent clinic visits and hospitalisation. There is very little research that has examined how this burden of care impacts on the lives of parents and caregivers of young children with CF.

What did you do?

We used the CarerQoL questionnaire, which has not yet been tested specifically in carers of people with CF, although it has been used for other long-term conditions. The questionnaire is made up of two parts; the first part (the CarerQol-7D) describes the care situation in terms of the negative (problems with relationships, mental and physical health) and positive (a feeling of fulfilment or support) effects of caregiving and the second part measures happiness on a scale from 0 (completely unhappy) to 10 (completely happy). Both parts are used to calculate a utility score (US) and a higher US indicates a reduced burden of care. A total of 213 families whose child had been diagnosed with CF were invited to complete the CarerQoL questionnaire and at least one parent from 195 families completed the questionnaire (130 mother-father pairs 189 mothers and 137 fathers).

What did you find?

Fathers had a significantly lower caregiver burden (higher US score) compared to mothers, most of whom described themselves as the primary care-giver. We also found that the caregiver burden increased with the child's age and was linked to the child testing positive for *Pseudomonas*. Most parents did not report any relationship problems with their child. Many parents reported problems with their own mental health (these problems were more common in mothers than fathers). Very few parents reported a lack of fulfilment when carrying out care tasks, the majority of parents reported good support when they needed it to carry out care tasks.

What does this mean and reasons for caution?

This study found that the CarerQol was a brief questionnaire easily completed by parents of children with CF. This was the first time this questionnaire has been used for CF caregivers. The questionnaire was effective in identifying parents of children that were positive for Pa as having higher caregiver burden (it was anticipated that this group of parents would have a higher burden due to the increased treatment burden for Pa), increasing age of the child and being a mother were also found to be associated with high burden. CF is considered a life limiting condition and the burden of care on parents of children with CF can be significant so we anticipated that this would be reflected in the results however caregiver burden and happiness scores were rather higher than anticipated for a condition that carries a daily care burden for parents. It is possible that the results may reflect parent's attitudes that what they face is a challenge rather than a burden. Higher caregiver burden in mothers may be because they are the primary caregivers not because they are mothers.

What's next?

Findings from this study highlight the importance of assessing the psychological well-being of parents of young children with CF and advising parents of the importance of seeking support or counselling if needed. The CarerQol is a generic tool that enables comparisons of the impact of caring between different groups of patients and caregivers however there is a need for a dedicated well validated tool, using items generated by parents of children with CF which could be used in this specific population.

The results from this study are generally quite positive for parents (high median US) although many parents do report problems with their own mental health. It is unclear what specific problems they are experiencing as the questionnaire asks if they have problems with their own mental health (stress fear gloominess depression or concern about the future) it could be that they are concerned about the future given the life limiting condition their child has been diagnosed with. Further research is needed as it is unclear why parents are reporting these problems.

Original manuscript citation in PubMed

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