

Cystic Fibrosis Research News

Title:

When is too little care, too much harm in cystic fibrosis? Psychological and ethical approaches to the problem.

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What was your research question?

The idea of this paper was to explore a part of CF care that is difficult for clinic staff to deal with, namely when parents do not follow the recommended advice given.

Why is this important?

The importance of this work is to help the CF team see the care of children with CF from a different perspective. CF care should be a partnership between the family, CF team and the child as he or she matures.

What did you do?

In this paper we presented three (fictionalised) scenarios which represented various levels of harm to the child with CF as a result of parents not being willing to follow standard medical advice about CF care. The first case described a family that refused to give any CF care, including enzymes, vitamins and salt replacement. In the next case the family had refused to give antibiotics for treatment over many years, with the consequence that the child's lung disease was more advanced than expected for his age. The third case was similar, although the child was still a pre-schooler and there hadn't been such significant development of structural lung damage (bronchiectasis).



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What did you find?

We did a psychological and ethical analysis of these cases. The psychological analysis described an "Illness Representation model" to help understand the parents' perspective. This can be a helpful tool for the CF team to consider why families may not be willing to follow recommended treatment advice. The ethical analysis used the reflective tool called the "zone of parental discretion" that allows parents to make a range of decisions for their child as long as there is no significant harm to the child.

What Does This mean and Reasons for Caution?

This paper highlights the complexity of the relationship between the CF team, parents and child and the need to develop a clear understanding of individual perspectives in order to work together for the best outcomes for the child.

What's next?

Further research is required into the difficult issue of parent and patient adherence with therapies. In particular the research should focus understanding the difficulties faced by parents asked to administer complex CF-related cares for their child. Further research could also examine the attitudes of the CF team towards parents who find adherence difficult.

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