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Cystic Fibrosis Research News

Title:

Development and outcomes of a patient driven Cystic Fibrosis Quality of Care Improvement project

Lay Title:

The assessment of quality of care from the patient perspective

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What was your research question?

Is it manageable for a patient organisation to develop a quality assessment program from the patient's perspective? Following up on that, can we assess quality of care from the patient's perspective? Which criteria are important to patients with CF? How do we subsequently improve quality of care?

Why is this important?

Patients are the end users of healthcare, and their perspective is important in weighing quality of care. Usually, healthcare professionals decide on the quality of care, from their professional perspective, using guidelines and protocols. It is important however, to define what is important to patients and what lessons can be learned from their observations and perspective.

If we structurally want to implement the patient perspective in a quality improvement program, the patient organisation has a big role to play.

What did you do?

We selected 61 criteria, relevant for all aspects of care, from the patients perspective, together with patients. These related to the workload of the team, hospital facilities, aspects of care, communication and segregation policy. Dutch patients were invited to answer an online questionnaire to assess quality of care in their own CF center, from their perspective; the results were discussed with the CF centers. An on site visitation by the patient organisation was part of the process. The individual CF centers received recommendations for criteria that were not met according to the patients.

What did you find?

The amount of recommendations given to the centers varied from 9 to 16. In total 82 recommendations were given. Most recommendations related to communication, for example: better insight in test results for the patient within short notice or better communication either by phone or mail. After two years more than half of the recommendations was successfully implemented by the centers. General hospital facilities seemed to be most difficult to improve. CF centers thought the procedure to be very effective and doable, and not time consuming.

What does this mean and reasons for caution?

Adding the patient perspective to a quality improvement program gives better quality of those aspects of care that are meaningful for the patients. The assessment can be done in a way that is not time consuming for centers. The patient organisation needs to staff experienced employees with regard to patient participation and quality improvement programs. Having the patient perspective implemented in a quality improvement program means quality of care improves in an effective way.

What's next?

The authors consider a next round of the current quality improvement program. Because of the pandemic, this was not possible so far. It is important to measure whether improvements were sustainable and to detect whether the same set of criteria is of importance to the patients.

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