

Cystic Fibrosis Research News

Title:

Management of Cystic Fibrosis during COVID-19: Patient Reported Outcomes based remote follow-up among CF patients in Denmark – a feasibility study.

Lay Title:

Cystic fibrosis patients and health care professionals' evaluation of a remote follow up solution with digital questionnaires and phone consultations developed due to the COVID19 pandemic.

Authors:

Lotte Rodkjær ^{a,b,c}, Majbritt Jeppesen ^{a,b}, Liv Schougaard ^{b, c, d}

Affiliations:

^a Department of Infectious Diseases, Aarhus University Hospital, Denmark

^b Department of Clinical Medicine, Aarhus University, Denmark

^c Research Centre for Patient Involvement, Aarhus University, Central Denmark Region, Denmark

^d AmbuFlex, Center for Patient-reported Outcomes, Regional Hospital West Jutland, Herning, Denmark

What was your research question?

Is remote follow-up using questionnaire and phone consultations acceptable to patients with cystic fibrosis and health care professionals?

Why is this important?

Patients with cystic fibrosis are at risk of complications due to COVID-19 and were advised to isolate in the beginning of the pandemic. Though, frequent outpatient hospital visits with monitoring of symptoms and collection of airway secretion samples are important. We wanted to be able to monitor patients during the pandemic without exposing them to risk of COVID-infection when visiting the hospital. With this study we wanted to learn if it was possible to avoid in-person appointments at the hospital and offer the patients access to care from home using telephone consultations combined with a questionnaire about their health.

What did you do?

In March 2020, we prepared for remote outpatient follow-up for some of the adult patients with cystic fibrosis. Follow-up consultations were changed from in-person visits to telephone

Cystic Fibrosis Research News

consultations combined with a questionnaire. Patients were instructed to fill in an electronic questionnaire 2-3 days before a planned telephone consultation. They also measured their lung function at home and sent a sputum sample to the hospital. The questionnaires were assessed by health care professional before the telephone consultation. We evaluated acceptability of this organisational change by interviewing patients with cystic fibrosis, nurses, and physicians.

What did you find?

Overall, both patients and health care professionals found remote follow-up using questionnaires combined with phone calls acceptable and useful. Patients experienced greater flexibility and found that the questionnaire was relevant and easy to understand. At the same time, they pointed out that they would like questions about their mental health in the questionnaire. They also asked for better information about changes in their follow-up. Health care professionals also found the questionnaire relevant, but pointed out the need for revision of the questionnaire and patient information, and also focus on change in workflow and implementation.

What does this mean and reasons for caution?

An urgent organisational change in outpatient follow-up due to COVID-19 was acceptable in routine clinical practice. However, patient involvement should be a future point of attention to ensure successful implementation. To capture the patient's perspective, it is essential they are involved from the start to identify aspects that matters to patients. We accommodated this by conducting interviews with patients after the first test, which provided knowledge about both the relevance of the current questionnaire and useful changes and additions to the questions.

What's next?

This study provided valuable input from the participants' perspective, which will be used to improve the questionnaire and future implementation in the out-patient clinic.

Original manuscript citation in PubMed

<https://pubmed.ncbi.nlm.nih.gov/34785157/>