

# Cystic Fibrosis Research News

**Title:**

The impact of the COVID-19 pandemic on the emotional well-being and home treatment of Belgian patients with cystic fibrosis, including transplanted patients and children

**Authors:**

Trudy Havermans<sup>1,2</sup>, Janne Houben<sup>1</sup>, Francois Vermeulen<sup>1</sup>, Mieke Boon<sup>1</sup>, Marijke Proesmans<sup>1</sup>, Natalie Lorent<sup>1</sup>, Erik de Soir<sup>3</sup>, Robin Vos<sup>1,2</sup> and Lieven Dupont<sup>1,2</sup>.

**Affiliations:**

<sup>1</sup> Cystic Fibrosis Centre, University Hospitals Leuven, Belgium

<sup>2</sup> Lung Transplant Centre, University Hospitals Leuven, Belgium

<sup>3</sup> Royal Higher Institute for Defence, Department of Scientific and Technological Research, Brussels, Belgium

**What was your research question?**

We wanted to investigate the early impact of COVID-19 on the psychological well-being of patients (children, adults and transplanted) and parents in our CF and transplant clinic. In addition, we wanted to study how the lock-down in Belgium has changed patients' home therapy.

**Why is this important?**

The COVID-19 pandemic has a great impact on people around the world. Understanding the impact on people with CF and parents may assist health care professionals to recognize problems related to COVID-19 and provide help accordingly. Awareness of the emotional impact and symptoms of post-traumatic stress should lead to preventive support, psychological help or therapy.

Understanding the impact of the pandemic and the lock-down, on people's home therapy may help CF teams to anticipate medical problems, but also to motivate patients to make positive changes.

**What did you do?**

We drew up a questionnaire to measure the impact of the pandemic as reported by the patients. The questionnaire asked about changes in emotions and feelings since the beginning of the pandemic, changes in home therapy, changes in health-related behaviours and questions about COVID-19 testing. Parents reported on their own emotions, but the questions on home therapy concerned their child's therapy. The online questionnaires were sent



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through a secure application, linked to the hospital's electronic medical patient records. We collected the data and calculated the self-reported changes on each item. We then identified where more than 30% of the respondents reported a change.

## **What did you find?**

63% of our patients completed the questionnaire (80 CF, 66 lung transplanted patients and 73 parents). Patients with a wide range of illness severity responded. No one had contracted COVID-19 and everyone followed the social distancing rules. We saw a psychological impact from the start of the pandemic, with many people reporting increased stress, fear and worry about the future. The results did not show much change in self-confidence or decision-making.

Reported changes in treatment were mostly positive, including more and healthier eating, more physiotherapy and better-quality nebulizing. People also reported changes in their routine (e.g. timing of treatment). Many adults and parents cancelled their CF appointments.

## **What does this mean and reasons for caution?**

The reported emotional changes are similar to changes seen among other groups of people, and are normal given the situation. But, one third of the patients reported reactions that may lead to posttraumatic stress and they need to be followed up. The results indicated that most people who completed the questionnaire continued to do their home treatments, and some even better than normal. This points to resilience in self-care, even in difficult circumstances. The cancellation of hospital appointments was worrying because regular follow-up within a CF centre is important. This study included reports from patient from a single centre and caution is needed when generalizing the results to other clinics.

## **What's next?**

Specialized psychological care is needed for those who suffer a prolonged psychological impact related to the COVID-19 pandemic. CF teams need to put the information that patients and parents receive from the media into context and support them to balance the perceived risk with true risk.

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[cfresearchnews@gmail.com](mailto:cfresearchnews@gmail.com)