

Cystic Fibrosis Research News

Title:

Symptoms and Quality of Life in Adults with Cystic Fibrosis: A Cross-Sectional Analysis of the InSPIRe:CF Trial

Lay Title:

What symptoms are most common and most bothersome for people living with cystic fibrosis?

Authors:

Natalia Smirnova MD¹, Jane Lowers PhD², Alexandre Cammarata-Mouchtouris PhD^{2, 5}, Elisabeth P Dellon MD⁴, Anne Fitzpatrick PhD⁵, Dio Kavalieratos PhD^{2, 3, 5}

Affiliations:

1. Division of Pulmonary, Allergy, Critical Care, and Sleep Medicine, Department of Medicine, Emory University, Atlanta, GA, United States.
2. Division of Palliative Medicine, Department of Family and Preventive Medicine, Emory University, Atlanta, GA, United States.
3. Rollins School of Public Health, Emory University, Atlanta, GA, United States
4. Department of Pediatrics, UNC Chapel Hill, Chapel Hill, NC, United States.
5. Department of Pediatrics, Emory University, Atlanta, GA, United States.

What was your research question?

What symptoms are most common and most bothersome for people living with cystic fibrosis?

Why is this important?

We know that people living with cystic fibrosis suffer from many symptoms such as shortness of breath, cough, anxiety, depression, and pain, that impair their quality of life. However, we don't know if the symptom experience has changed now that modulator therapy is common. In order to figure out how to best improve quality of life for adults living with CF, we need to better understand what symptoms are now common, and what symptoms are associated with decreased quality of life.

What did you do?

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We used data from the first visit from the first palliative care trial for adults with cystic fibrosis. The trial is called “Integrating specialist palliative care to improve care and reduce suffering: cystic fibrosis,” or InSPIRe:CF for short. We looked at symptoms and quality of life scores.

What did you find?

- 262 adults with CF participated. Their median age was 33 years old, 78% were on modulator therapy.
- The most common symptoms included lack of energy and cough.
- The most distressing symptoms were difficulty sleeping and pain
- The symptoms that were associated with the lowest quality of life were not related to the lungs: lack of energy, feeling sad, worrying, feeling irritable, and pain.

What does this mean and reasons for caution?

Based on our findings, screening for common symptoms that affect quality of life the most (lack of energy, worrying, feeling sad, feeling irritable, and shortness of breath) and a less common symptom that is also strongly associated with decreased quality of life (pain) could help identify people living with CF who are most at risk for a decreased quality of life and may benefit from additional support.

What's next?

Next, we will look at symptom clusters (groups of two or more symptoms) and quality of life.

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