



Cystic Fibrosis Research News

Title:

Correspondence between Symptoms and Preference-Based Health Status Measures in the STOP Study

Authors:

Laura S. Gold^a, Donald L. Patrick^b, Ryan N. Hansen^c, Valeria Beckett^d, Christopher H. Goss^e and Larry Kessler^b

Affiliations:

^aDepartment of Radiology, University of Washington, Seattle, Washington, United States

^bDepartment of Health Services, University of Washington, Seattle, Washington, United States

^cSchool of Pharmacy, University of Washington, Seattle, Washington, United States

^dSeattle Children's Research Institute, Seattle, Washington, United States

^eDepartments of Medicine and Pediatrics, University of Washington, Seattle, Washington, United States

What was your research question?

We looked for connections between questions about cystic fibrosis symptoms and questions about quality of life. We thought that the symptoms CF patients had during their pulmonary exacerbations would align with their quality of life.

Why is this important?

When new treatments for CF patients are developed, researchers need ways to measure how well they work in terms of both helping CF symptoms and improving quality of life. We wanted to know if measures of CF patients' symptoms and quality of life would show the same results. For example, we expected that CF patients experiencing many symptoms would also experience worse quality of life.

What did you do?

We found 169 patients who answered questions about their symptoms and about their quality of life on the same day during pulmonary exacerbations. We looked to see how closely related their answers to the symptom questions were to the quality of life questions. We also looked at how their lung function improved as their pulmonary exacerbations were treated.

Cystic Fibrosis Research News

cfresearchnews@gmail.com



Cystic Fibrosis Research News

What did you find?

When patients first had their pulmonary exacerbations, their quality of life was lower since they had trouble performing their usual activities and also because they had pain or discomfort. They also complained about CF symptoms like difficulty breathing. By the end of treatment, these had improved, but we did not find that patients who suffered from more CF symptoms had more complaints about their quality of life.

What does this mean and reasons for caution?

Measuring CF patients' quality of life and their symptoms are assessing different aspects of the health of CF patients. While we were surprised that we didn't observe a strong relationship between quality of life and CF symptoms, our research shows that measuring both is important when assessing new treatments for pulmonary exacerbations.

What's next?

In the future, more detailed assessments of the timing and duration of CF symptoms would be helpful to get a better idea of the ways that new treatments affect them. Also, more extensive measures of quality of life might be useful in assessing novel treatments for CF.

Original manuscript citation in PubMed

<https://www.ncbi.nlm.nih.gov/pubmed/?term=Correspondence+between+Symptoms+and+Preference-Based+Health+Status+Measures+in+the+STOP+Study>