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Cystic Fibrosis Research News

Title:

Prevalence of unmet pain and symptom management needs in adults with cystic fibrosis

Lay Title:

How do people with CF experience pain and other symptoms?

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What was your research question?

What types of symptoms and pain are most common, and most burdensome, for people with CF? What is the experience of people with CF seeking treatment for pain and symptoms?

Why is this important?

CF is associated with physical and psychological symptoms, including cough, pain, shortness of breath, and anxiety. These symptoms can reduce quality of life, but people with CF report that their symptoms are not always managed. To improve care, it is important to know what symptoms are most burdensome and how people with CF seek treatment.

What did you do?

We developed a questionnaire about symptoms that people with serious illness often experience. We sent the survey to >300 people with CF through the Cystic Fibrosis Foundation's Community Voice listserv. The survey had both multiple-choice questions and open-ended questions. We used statistics to identify the most common and most burdensome symptoms. We analyzed open question responses to identify the most common themes in how people with CF talked about their symptoms and treatment.

What did you find?

A total of 55 people with CF responded to the survey. Pain was the most common symptom mentioned, and the one participants said was most distressing. People using modulator therapy were less likely than people not using modulator therapy to say their pain caused distress.

Participants said pain and other symptoms are not always recognized or managed by their clinicians. They also said they feared that asking for pain treatment would lead to being labelled a "drug seeker." Participants are concerned about opioids and are interested in multiple ways of treating pain.

What does this mean and reasons for caution?

Results from this study suggest that CF teams can improve how they identify and treat symptoms and pain. This study includes only a small number of people with CF, and their experience and views may not represent those of the full CF population.

What's next?

Future studies should investigate pain and symptoms in a larger pool of people with CF. Research also could look at differences in people who are or aren't using modulator therapies.

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https://pubmed.ncbi.nlm.nih.gov/35973901/