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Cystic Fibrosis Research News

Title:

Measuring Recovery in Health-Related Quality of Life During and After Pulmonary Exacerbations in Patients with Cystic Fibrosis

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What was your research question?

We wanted to measure how pulmonary exacerbations (a flare up of symptoms) impacted quality of life at different stages of the exacerbation (before, during, and after).

Why is this important?

We know a great deal about how lung function is affected by an exacerbation and how much it recovers and how quickly, and we appreciate that aspects of quality of life are also affected, but we know little of their recovery. By knowing how long a person's quality of life is affected, we should be able to provide patients with realistic expectations of when they will recover relative to treatment. Some effects might take longer to return to normal.

What did you do?

We used data from a large clinical trial that measured quality of life scores calculated at pre-specified time points. We identified pulmonary exacerbations that occurred in individuals treated with placebo (a dummy treatment) and evaluated their quality of life scores before, during, and after the week of the pulmonary exacerbation. We also looked at the site and type of treatment for their pulmonary exacerbation (hospitalization, IV antibiotics, or other) and their association with quality of life scores.

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What did you find?

Prior to a pulmonary exacerbation, quality of life scores were stable. There was a reduction in many, but not all, areas of quality of life when there was an exacerbation. The extent of this reduction was greater in those hospitalized compared to those treated at home. For many of these areas, complete recovery from the event may take up to eight weeks, even though lung function recovered in two to four weeks

What does this mean and reasons for caution?

Patients should be informed that some symptoms take longer to recover than others; this can help them manage their recovery expectations.

What's next?

In addition to monitoring lung function for recovery following a pulmonary exacerbation, the patient's quality of life perspective should be monitored as well. Future research should evaluate the potential impact that treatment choice has on the quality of life during recovery. Another area to explore would be the effect, if any, CFTR modulators may have on these outcomes.

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