



Cystic Fibrosis Research News

Title:

What does it mean to be “healthy” when taking elxacaftor/tezacaftor/ ivacaftor (ETI)? A qualitative study

Lay Title:

What do people with CF think about their health since starting ETI?

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What was your research question?

The goal of this study was to document changes in the health and well-being of people with CF after starting ETI, beyond the positive physical changes experienced.

Why is this important?

Many people with CF are feeling better and experiencing fewer symptoms on ETI. Thus, it may be more challenging for providers and care teams to determine when a person with CF is experiencing slight changes in symptoms or worse overall well-being. Understanding changes in health among people with CF might help identify new ways to measure changes in health or assist providers in asking questions to identify when a person with CF is not doing as well overall.

What did you do?

We completed interviews with 91 people with CF (14 to 67 years old) and 23 caregivers of teenagers. Interviews were about an hour each and participants answered questions about a previous study they had participated in (the SIMPLIFY study), how they communicated with their care teams, and how they defined their health, among other questions. This study was interested in how participants described their health before starting ETI and since starting ETI.

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Researchers organized and analyzed participants' responses to determine how their health had changed since starting ETI.

What did you find?

We found that participants talked most about four main ways that their health had changed since started ETI. This included experiencing major changes in their health, such as being able to focus on the future and living longer. They also noted not having to think as much about having CF as they had before, and being hopeful about the future. They also described being able to focus on other aspects of their health, such as exercise and diet. Finally, participants noted that because their health was more reliable now, they did not have to miss out on social activities.

What does this mean and reasons for caution?

Our study suggests that people with CF may be less occupied everyday by their CF symptoms and thinking about CF. This has allowed them to focus on other aspects of daily life, such as the future, relationships with others, and social activities. Healthcare providers may need to pay closer attention to small changes in a person's physical health, and also ask whether they are having trouble doing other things, like going to work or being with others. Our findings, however, are specific to the people who participated in these interviews and other people with CF may have had different experiences.

What's next?

Next steps include considering whether our measures of respiratory symptoms and well-being need to be changed if people with CF are not experiencing as many negative health symptoms.

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