

Cystic Fibrosis Research News

Title:

Lived experiences of people with cystic fibrosis that were not eligible for elexacaftor-tezacaftor-ivacaftor (ETI): A qualitative study

Lay Title:

Experiences of people with cystic fibrosis living without Trikafta/Kaftrio

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What was your research question?

The research question of this study is what people with cystic fibrosis feel and how they react to not being able to be treated with Trikafta/Kaftrio.

Why is this important?

Currently, 10% of people with cystic fibrosis living in the United States and about 30% of people with cystic fibrosis living in southern European countries cannot take Trikafta/Kaftrio. This study can provide information to the CF care team about their patients' personal experience and what is most important to their patients. This knowledge can inspire physicians, nurses, stakeholders, and the whole cystic fibrosis care team to support this patient group.

What did you do?

We interviewed 13 people with cystic fibrosis who cannot be treated with Trikafta/Kaftrio and asked them to share their personal experience of living without Trikafta/Kaftrio. The interviews were analyzed to identify the most important common experiences shared by the participants.

What did you find?

We identified two main themes and six minor themes. The first main theme (being deemed ineligible for ETI) had four themes (disappointment, information, happiness, and concerns). It involves patients who cannot be treated with Trikafta/Kaftrio experience intense



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disappointment and conflicting emotions about the progressive worsening of their health and happiness when seeing other people benefit from Trikafta/Kaftrio. The second main theme (coping with a life without ETI) had two minor themes (lack of hope and continued hope). It summarizes the views and perspectives perceived by participants in dealing with the future, highlighting a sense of diminishing/renewal hope.

What does this mean and reasons for caution?

People with cystic fibrosis who cannot take Trikafta/Kaftrio experience intense disappointment that can affect their decisions and future expectations.

Participants revealed intense emotions such as fear that their health might deteriorate and happiness at the possibility that other patients had through the Trikafta/Kaftrio. Qualitative research cannot provide information about the prevalence of attitudes or coping strategies and instead aims to in depth evaluation of personal experience, limiting the generalization of the findings.

What's next?

This study identified some of the needs of people with cystic fibrosis who cannot take Trikafta/Kaftrio. The next work will be to use the data to plan specific interventions that can improve the quality of life and health care of these patients.

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<https://pubmed.ncbi.nlm.nih.gov/36549989/>