Cystic Fibrosis Research News

Title:
Racial Disparities in Lung Transplantation for People with Cystic Fibrosis in the Era of Highly Effective Modulator Therapy

Lay Title:
Racial Disparities in Lung Transplantation for People with Cystic Fibrosis

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What was your research question?
Recently, new medications called CFTR modulators have transformed the way cystic fibrosis is managed. Our research question was whether these new medications, like Trikafta (ETI, elexacaftor-tezacaftor-ivacaftor), have made health differences worse between people of white race and those of racial and ethnic minority groups.

Why is this important?
Breakthroughs in treatment for people with cystic fibrosis have improved their quality of life and reduced the need for lung transplants for many people. However, ETI and similar treatments do not work for all gene mutations that can cause CF. Unfortunately, many of the people whose gene mutations do not respond to ETI are from racial and ethnic minorities. These populations have historically had worse health outcomes related to cystic fibrosis. Now,

there are concerns that these disparities in health outcomes for people with CF who are of racial and ethnic minorities may have worsened since the introduction of treatments like ETI.

What did you do?

Our research group looked at national data on people with CF whose disease was so severe they had to be listed for a lung transplant and examined whether there were changes in how often they were being transplanted or dying while waiting for an organ by their race/ethnicity before and after ETI treatment became available.

We were able to access data for over 30,000 lung transplants that occurred between 2005 and 2022 in the United States, including over 3,800 transplants performed for people with cystic fibrosis.

What did you find?

First, we found that fewer patients with CF were being listed for and receiving lung transplants since ETI treatment became available, likely because ETI treatment was helping prevent people's disease from getting severe enough to need a transplant. This has changed the racial/ethnic makeup of both the lung transplant waitlist (transplant candidates) and the group of people receiving lung transplants (transplant recipients) each year for cystic fibrosis. Among both candidates and recipients with cystic fibrosis, the percentage of White race decreased, while the percentage of Black race or Hispanic ethnicity increased.

What does this mean and reasons for caution?

Our findings suggest that ETI treatment has dramatically improved outcomes for patients with cystic fibrosis, including helping to prevent many from needing a lung transplant. However, White people with cystic fibrosis appear to have benefitted more from these new medications than people of other races and ethnicities, probably because they are more likely to have genes that respond to these medications. Therefore, while we should celebrate the benefits of these new medications, we need to continue to work on other treatments that will help people who currently are not eligible for these treatments because of their different cystic fibrosis gene mutations.

What's next?

Fortunately, there is work underway to bridge this gap. The Cystic Fibrosis Foundation is testing existing medications on some of the rarer genetic mutations, which has led to new treatment possibilities for over 600 patients, and there is also work underway to create new medications.

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