

Cystic Fibrosis Research News

Title:

Predictors of non-referral of patients with cystic fibrosis for lung transplant evaluation in the United States

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What was your research question?

For people with cystic fibrosis (CF) and advanced lung disease, are there certain characteristics that are more often associated with those who are not referred for a lung transplant evaluation compared to those who are?

Why is this important?

Lung transplantation is a treatment option for certain people with CF and advanced lung disease. Lung transplantation improves survival and quality of life for appropriately chosen people with CF. Identifying predictors of not being referred for lung transplant evaluation (despite meeting lung function guidelines for referral) could help with recognition of people with CF who may have missed an opportunity for referral.

What did you do?

Using the Cystic Fibrosis Foundation Patient Registry (CFFPR), we analysed data from 1240 adults (age 18 years and over) in the registry between 2001 and 2008. All participants in our study had advanced lung disease, which we defined as two consecutive years of significantly decreased lung function (forced expiratory volume in 1 second (FEV1) <30% predicted). We



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determined whether each individual had been referred for lung transplant evaluation based on annual data entries in the CFFPR. We used statistics to determine if there were any characteristics associated with not being referred for transplant evaluation.

What did you find?

Among the 1240 participants, only 809 (65%) with advanced lung disease were referred for lung transplant evaluation. Those who were not referred were more likely to have Medicaid insurance, lack a high school graduate education, be older and have a sputum culture positive for *Burkholderia cepacia* complex. Individuals were more likely to be referred if they had a supplemental oxygen requirement or a higher number of pulmonary exacerbations per year. People with Medicaid insurance tended to be younger and sicker (based on markers of disease measured in the CFFPR).

What does this mean and reasons for caution?

Despite meeting lung function criteria, 35% of adults in the CFFPR with advanced lung disease were not referred for lung transplant evaluation. Those who were not referred were more likely to have Medicaid insurance and lack a high school graduate education, which highlights potential disparities in access to healthcare among people of lower socioeconomic status. These findings reveal a group of individuals with CF who could potentially benefit from targeted attempts at referral for lung transplant evaluation. The study is unable to describe why those with advanced lung disease are not referred - physician decision versus individual preference.

What's next?

Future studies should evaluate the health outcomes for those with advanced lung disease who are not referred for lung transplant evaluation. It is possible that deferring transplant evaluation is appropriate in a certain sub-group of the CF population. Additionally, work should focus on reasons for non-referral.

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