European Cystic Fibrosis Society

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Cystic Fibrosis Research News

Title:
Telehealth and CFTR modulators: accelerating innovative models of cystic fibrosis care

Lay Title:
How might cystic fibrosis care change because of telehealth and CFTR modulators

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What was your research question?
What did we learn during the SARS-CoV-2 (COVID-19) pandemic when CF care teams used telehealth to deliver healthcare remotely using telephone and telecommunications technology (telehealth) while more people with CF (PwCF) were also experiencing the effects of CFTR modulators such as elexacaftor/tezacaftor/ivacaftor?

Why is this important?
Many PwCF are experiencing better health and living longer with increasingly diverse needs to maintain their health. The rapid rise of telehealth during the pandemic helped monitor the effects of CFTR modulators on the overall health of PwCF, despite disruptions in traditional in-person care. Reviewing implications of shifts from these unprecedented times will inform improvements in coordinated care and disease management. Key to these improvements is the ability to adapt to individual needs of PwCF while ensuring equitable care, especially for a growing number of adults living longer with CF.

What did you do?
Literature and data collected on several metrics, such as use of and attitudes towards telehealth by different populations, especially those related to outcomes during the pandemic, were reviewed. The findings are organized as recommendations for key areas of

change to improve the quality of care and to support PwCF so that they can take on greater responsibility in managing their disease.

What did you find?

Many PwCF experienced changes in health and delivery of care. Before CFTR modulators were available, survival and the numbers of adults with CF were increasing in part due to access to interdisciplinary care teams. Keeping these teams is vital and coordinating with other specialists will be needed as PwCF get older. Telehealth and technology changed how and when PwCF and their team connect with each other. Additional changes are going to be needed in the future and should be based on shared data and partnering with PwCF and their families. It is important to share best practices as care delivery rapidly evolves. It is also essential to support policies that ensure equitable access to care for all PwCF.

What does this mean and reasons for caution?

A diverse and growing population of PwCF requires the continued development of CF care, offering more opportunities to engage PwCF in care planning and coordinating with a broader care team. It also means using technology to integrate virtual visits and improved data systems to store and share information that matters. Caution comes from balancing resources where modulators may reduce need for inpatient care while increasing outpatient care. Rising cost of medications, especially modulators, could shift funding from care teams, and health systems can discourage effective integration of telehealth by providing less financial support for those services.

What's next?

Continue tracking health outcomes of PwCF and their care to determine if and how the recommendations provided in this paper are being implemented and more importantly, how the needs of the growing and increasingly diverse CF population are being met.

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Telehealth and CFTR Modulators: Accelerating Innovative Models of Cystic Fibrosis Care

Better health and longer survival compel the evolution of the CF care model while modulators and the pandemic have catalyzed this change. Herein we review the implications of these shifts and offer recommendations to improve coordinated care and disease management.