European Cystic Fibrosis Society

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Cystic Fibrosis Research News

Title:

ADAPTING THE CYSTIC FIBROSIS CARE MODEL: PERSPECTIVES FROM PEOPLE WITH CF, CAREGIVERS, AND MEMBERS OF CF CARE TEAMS

Lay title:

People with cystic fibrosis and care teams share how CF care can change to meet patient needs.

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What was your research question?

What do people with cystic fibrosis (pwCF), caregivers, and CF providers think about the care that pwCF receive and should this care change as pwCF live longer?

Why was this important?

As more pwCF experience better health and live longer, we need to review the care provided at CF Foundation-accredited care centers. While some pwCF may need more care to maintain their health, others may benefit from new approaches to changing needs. Potential changes could include how often pwCF come to CF clinic, what happens during and between visits, the use of telehealth, and how the roles of those within the CF care team and other, including primary care and specialty, can be adjusted.

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What did you do?

A *Care Model Committee* of CF care team members, parents, and adults living with CF was formed to develop interim guidance for the care of pwCF. Understanding what matters to pwCF, caregivers, and CF providers is important to this work. To improve our understanding, we developed and analyzed results from a national survey, “Adapting CF Care Survey,” provided in English and Spanish. Participants in focus groups, including those from the US Adult CF Association (USACFA) and National Organization of African Americans with CF (NOAACF), helped develop and share the survey as broadly as possible.

What did you find?

Responses exceeded expectations, with 1,700 participants and a completion rate of 76%. Despite no incentives, respondents spent 10-12 minutes sharing their perspectives.
Responders felt in-person, routine visits with the CF care team were valuable. While many supported reducing in-person visits from the standard every three-months, they also thought more frequent visits were needed with a new diagnosis, life transition, and pregnancy. Respondents thought telehealth and remote monitoring, like home spirometry, could be used between visits. More pwCF reported seeing primary care providers (PCPs) outside of the CF team than the CF care team members estimated. Respondents preferred PCPs close to home with knowledge about CF and good communication with their CF team.

What does this mean and reasons for caution?

Key issues identified were visit frequency and team structure. It is important to note that the findings represent only those who participated in the survey. They may not represent all pwCF, caregivers, and CF providers. Also, there were enough responses from pwCF not on modulators, those post-lung transplant, and those from Spanish-speaking backgrounds for analysis – but not from people from Black communities. Of the CF providers who responded, representation from some roles was low, particularly among subspecialists, but every interdisciplinary core team role was at least represented.

What’s next?

These insights were shared with the *Care Model Committee* to help develop guidance on issues important to CF care: visit frequency and team structure. This guidance was published in two papers, alongside this paper on the survey results. Although every center is different, all care teams will need time to review and implement the updated guidance, where applicable, using shared decision-making with patients and families based on their individual needs and priorities.

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