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Cystic Fibrosis Research News

Title:
Cystic Fibrosis Foundation position paper: Redefining the CF care model

Lay Title:
CF Care Model- Guidance for an Evolving Model

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The Care Model Position Paper Committee members included:

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What was your research question?

The medical care that most people with CF (pwCF) receive involves routine visits with an interdisciplinary care team to track physical and mental health, and for consultations on treatments and therapies. Should this specialized care pattern change given the changes pwCF are experiencing in their health with aging, modulators and telemedicine?

Why is this important?

This question is important because as pwCF increasingly experience their disease differently from each other with some benefitting from modulators more than others, and technology continues to enable care outside of traditional clinical settings, we are compelled to review how CF care is provided to adapt to these changes.

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This position paper provides reasonable guidance, based on evidence and expert opinion of pwCF and care teams, about how CF care screenings and visits may be tailored to individual patient needs.

What did you do?

To address this question, a committee of interdisciplinary CF care team members, adults with CF, and parents of children with CF was formed to review the CF care model, and determine what, if any, changes should be considered. Through the lens of clinical expertise and lived experiences, the committee reviewed research, services provided by CF programs, and results from a national survey capturing perspectives on CF care. Where research was unavailable, the committee identified areas of agreement. Feedback provided by CF care teams and the community through public comment informed revisions to the draft guidance prior to publication.

What did you find?

PwCF in stable health (pulmonary, gastrointestinal, endocrine, nutritional, mental and social), six years of age or older may be able to attend routine CF clinic less frequently (every 4-6 months vs. every 3 months). To maintain stable health, they should still meet with the full multidisciplinary team once a year, be screened for mental and health-related social needs annually, have in-clinic spirometry 2x a year, and have a CT scan if any concern (vs. a screening chest Xray). Practices that could occur outside of CF clinic are respiratory cultures, home spirometry and telemedicine visits in between clinic visits.

What does this mean and reasons for caution?

The traditional CF care model remains the gold standard; however, tailoring visit frequency and testing may be appropriate with a proposed framework and shared decision-making. For many, routine in-person clinic visits every 3 months or more may be needed, especially given health-related concerns. This includes new CF diagnoses or complications, those who are infants, toddlers, preschoolers, or experiencing transitions (adolescence, pregnancy, parenthood, etc.), or with other specific communication or educational needs. CF centers will have to assess the feasibility of home and local monitoring to maintain respiratory cultures every three months. Telemedicine touchpoints can be considered in between in-person visits.

What's next?

PwCF and their care teams can further adapt care with this guidance in mind to better meet the pwCF's individual needs over longer lifespans. It will be important to track the impact of

changes like reduced visit frequency or screenings on quality of life, health, and longevity in pwCF.

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