



Cystic Fibrosis Research News

Title:

Prevalence of Unmet Palliative Care Needs in Adults with Cystic Fibrosis

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What was your research question?

How common are unmet care needs due to the physical, emotional, and social burdens of adults with cystic fibrosis (CF)? Do these adults want help with their unmet needs? Which individuals are most likely to have unmet needs?

Why is this important?

Palliative care is an overall approach to care that improves quality of life and symptom burden. Many individuals with CF have physical, psychological, and social burdens that may be improved by palliative care services. While the needs of individuals with CF may be different than in other diseases, research in CF-specific palliative care is lacking. Before CF-specific programs can be developed, we must understand the complete spectrum of unmet needs in CF and learn which individuals most require additional support.

What did you do?

We surveyed 164 adults with CF from the University of Pittsburgh Medical Center Adult CF Clinic. We assessed their unmet palliative care needs using a survey that asked about 34 needs across five different need domains (physical & daily living, psychological, health system & information, patient care & support, and sexuality). We also assessed their current symptom burden and gathered additional patient information, such as age, lung function, and history of anxiety or depression.

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What did you find?

Most adults with CF (78%) reported at least one unmet need with which they wanted help. They were most likely to report physical (72%) and psychological (66%) needs, such as “lack of energy/tiredness” (65%), “feeling unwell a lot of the time” (52%), and “fears about my CF getting worse” (50%). People with poorer lung function were likelier to have greater physical and psychological needs, while those with higher symptom burden were likelier to have greater needs across all five need domains.

What does this mean and reasons for caution?

Adults with CF have substantial unmet palliative care needs—especially physical and psychological needs—and they want help with these needs. Because the most common unmet needs, such as fatigue and feeling unwell, are core aspects of palliative care services, palliative care may be beneficial to adults with CF. To identify who can most benefit from palliative care services, CF care centers should routinely ask patients about symptoms, emotional health, and other palliative needs. Similarly, patients and families should feel free to have open and honest communication with their care teams when they feel like their needs aren't being met.

What's next?

Our data can help CF clinics identify who might benefit from extra support. In addition, these data have informed upcoming research to understand how palliative care specialist clinicians can work with CF care teams to effectively support adults with CF and their families.

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