

Cystic Fibrosis Research News

Title:

Addressing the Burden of Illness in Adults with Cystic Fibrosis with Screening and Triage: An Early Intervention Model of Palliative Care

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What was your research question?

The study's aim was to determine whether a model involving monthly online screening used by adults with cystic fibrosis (CF) can identify those who are suffering from physical or psychological symptom distress, or those who wish to discuss advance care planning, and help them quickly access palliative care interventions to address their needs.

Why is this important?

While better treatments have greatly increased the lifespan for people with CF, living with CF means experiencing varying levels of distress and disability over the years. Palliative care improves the quality of life for patients with chronic illness, from the time of diagnosis to the end of life, by providing care that focuses on preventing or relieving the causes of physical, emotional, and spiritual/existential suffering of the patient and caregiver. However, individuals with CF can only benefit from palliative care when their needs are promptly identified, and services are available.

What did you do?

A CF Center partnered with palliative care specialists to create a new care model for prompt access to treatments and services that could address causes of distress or illness burden. We



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developed a 12-item online survey to assess common problems experienced in CF and emailed it to patients each month. Completed surveys were promptly reviewed by the Center's social worker who, based on specific scores, telephoned patients and evaluated whether the results were of concern and needed follow-up. The social worker either scheduled a prompt follow-up for palliative care or informed patients that issues would be addressed at their next regular visit.

What did you find?

We found that 80% of the online surveys were completed. Based on specific criteria, about one-third of the screenings required outreach by the social worker. Of these assessments, 39 patients required prompt follow-up: 22 for medical interventions, mostly for pain, breathing difficulty, or transplant needs; 11 were referred for psychosocial services; and 6 needed other services. When compared to information collected at the start of the study, we learned that older patients and those with higher initial distress were most likely to require prompt follow-up. Interestingly, many requested advance care planning, which suggests that patients want to discuss their care preferences with CF Care Teams.

What does this mean and reasons for caution?

Monthly online screening has the potential to identify people with CF whose problems may benefit from prompt attention by CF Care Teams. The teams can manage many sources of distress or illness burden; and provide '*generalist palliative care*.' Repeated screening also identifies patients who have persistent unmet needs requiring a more comprehensive assessment. However, there are limitations of our study. We only studied patients in one CF Center and didn't compare our study with other populations and methods. Screening identified a relatively low number of problems experienced by patients, so other models that use less frequent or briefer assessments should be tested.

What's next?

Multicenter, controlled studies with more diverse populations are needed so that the relationship between initial symptom distress and distress over time can be better understood, and whether our screening-and-triage model can improve the ability to detect concerns and improve outcomes for people with CF and their families.

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