



Cystic Fibrosis Research News

Title:

Web-based Symptom Screening in Cystic Fibrosis Patients: A Feasibility Study

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What was your research question?

Our study looked at whether it is feasible to use a monthly online survey to routinely screen for common physical and psychological symptoms that adult patients with cystic fibrosis may experience.

Why is this important?

Understanding when people with CF need immediate care for their symptoms, and when doctors should intervene, may be challenging, especially since a disease like CF can change quickly. The system that we have developed can identify when patients may benefit from immediate care for their symptoms or distress. One important feature is that patients complete the surveys online, on their computers or mobile devices, and their responses are shared directly with their physician and care team. Most similar existing systems have been created for patients with cancer and this is among the first to be created specifically for people with CF.

What did you do?

We created a survey asking patients about their overall distress, pain or shortness of breath, and feelings of anxiety or depression. We also asked patients whether they had ever discussed advance care planning with a healthcare professional, a caregiver or someone else, and whether they felt it would be helpful to do so. Patients completed surveys every 30 days over 9 months. Their responses were reviewed by a social worker who decided if patients

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should be offered an early evaluation by their physician. Patients were also given the social workers phone number in case they had any concerns they wanted to discuss before their next appointment.

What did you find?

The study is ongoing, but the screening system's early results show promise. In total, 74 patients completed 81% of the surveys they received over the 9-month period. Further, the surveys were useful in identifying unmet needs for many patients requiring assistance. For example, 23.0% of patients who completed surveys reported overall distress, 10.8% had severe distress from pain, 9.5% had severe distress from shortness of breath, and 12.2% reported anxiety or depressive symptoms. Finally, more than half (58.1%) were interested in discussing advance care planning with their physician. This suggests that the system is feasible and useful for routine care.

What does this mean and reasons for caution?

Despite some conflicting results from earlier studies on the feasibility of monitoring systems like ours, our results suggest that online surveys can help identify clinical problems among people with CF. However, there are limitations of our work. We did not ask patients about their satisfaction with the system, but plan to do so in the future. Further, while patients completed a fairly large number of surveys, they required a significant number of reminders. Finally, patients in our study may not be representative of other groups of people with CF, and in future larger studies should be done with both adults and children with CF.

What's next?

We'll develop strategies to address problems experienced by people with CF, including physical symptoms, psychological distress, and quality of life. This system is part of an early intervention model for palliative care to improve symptom distress, quality of life, increase discussions of advance care planning, and reduce caregiver distress.

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