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Title:

THE CF-CARES PRIMARY PALLIATIVE CARE MODEL: A CF-SPECIFIC STRUCTURED ASSESSMENT OF SYMPTOMS, DISTRESS, AND COPING

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What was your research question?

Palliative care has been identified as an important component of CF care, yet limited information is available on how to deliver effective palliative care to this unique patient population. We sought to tailor primary palliative care assessments for the CF population based on patient reporting of symptoms, distress, and ways of coping with the disease.

Why is this important?

Individuals with CF are living longer and as a consequence frequently have distressing chronic symptoms such as pain, poor sleep, and anxiety. High levels of psychological distress can lead to worse CF medical outcomes. Identifying and ameliorating such distress is key to improving the health and quality of life of individuals with CF. The role of palliative care has expanded to focus on improving quality of life at all stages of chronic illness. Identifying distressing symptoms is an important first step to guide a treatment plan and will aid in the development of CF-specific palliative care.

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What did you do?

We developed a CF-specific structured palliative care assessment and administered it to 41 adolescents and adults with CF. The assessment included a questionnaire about CF-associated symptoms such as shortness of breath, pain, and poor sleep, questionnaires about symptoms of depression and anxiety, and a structured interview to gain insight into how well individuals felt they were coping with CF and managing their CF treatments. The assessment culminated in a discussion about options for addressing distressing symptoms. Finally, participants were asked to rate their level of satisfaction with the assessment process.

What did you find?

Participants reported many physical and psychological symptoms. Even though physical CF symptoms such as shortness of breath were reported as more frequent, psychological symptoms (e.g., worrying) were rated as more distressing. Symptoms of anxiety were reported by 34% percent of participants; 44% reported symptoms of depression. The level of anxiety and depression reported was not associated with experience of severe illness. Overall, participants reported a high level of satisfaction with the CF-specific palliative care assessment process.

What does this mean and reasons for caution?

The study showed that individuals with CF face challenges with managing symptoms, distress and coping at all stages of disease, not only during severe disease exacerbations or at end of life. Directly asking individuals with CF about psychological symptoms is an important component of clinical care. Otherwise, providers may not hear about these symptoms during typical clinic appointments that tend to focus on addressing frequently occurring physical symptoms. Early identification and treatment of burdensome chronic symptoms may lead to improved disease management and enhanced quality of life. The CF-specific palliative care assessment model tested in this study may improve communication about distress and coping between providers and individuals with CF.

What's next?

The hypothesis that this CF-specific primary palliative care model can reduce distress and improve quality of life for individuals with CF should be tested more rigorously through larger scale clinical effectiveness studies. In addition, the development of CF-specific interventions to address distressing chronic symptoms may be of benefit.

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