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Title:

DEVELOPMENT AND EVALUATION OF A PALLIATIVE CARE CURRICULUM FOR CYSTIC FIBROSIS HEALTHCARE PROVIDERS

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What was your research question?

Does training for CF healthcare providers about CF palliative care topics improve their comfort with palliative care skills? These skills include assessing and treating burdensome chronic symptoms and integrating difficult conversations into regular CF care.

Why is this important?

Many people view palliative care as equivalent to end of life care, or terminal care. However, the role of palliative care has expanded a lot in recent years to focus on treating burdensome symptoms and suffering at all stages of disease. According to the World Health Organization, a palliative care approach should actually be introduced early in the course of illness, to help people more. People with CF are living longer and now have to do more treatments to take care of themselves. People with CF may also have more chronic, distressing symptoms such as pain, shortness of breath, poor sleep, and anxiety. Early introduction of palliative care will help more people with CF to feel more comfortable and



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enjoy life more. Palliative care also helps people think ahead about their health, life goals, and preferred treatments. CF healthcare providers need to become better trained in palliative care, so that palliative care can be used to improve quality of life for people with CF.

What did you do?

Members of our CF care team attended these training sessions. We tested how well the training worked by asking members of our CF care team about their comfort with palliative skills both before and after the trainings. We looked to see if training improved provider comfort with palliative care skills.

What did you find?

After attending the training, CF healthcare providers felt significantly more comfortable with palliative care skills. On average, providers originally felt “neutral” about their comfort with palliative care, but after training they felt “comfortable”. On average, providers felt more comfortable with all types of palliative care skills. These included referring patients to supportive care services (such as acupuncture or cognitive behavioural therapy), managing pain, managing other symptoms such as anxiety and poor sleep, communicating difficult news, and caring for patient’s psychological and social concerns. Most of the CF healthcare providers felt the training was helpful and were likely to recommend it to others.

What does this mean and reasons for caution?

This study showed that CF healthcare providers need and want additional training in palliative care skills. Our training appeared to help providers feel more comfortable with their palliative care knowledge and skills. Providers who are more comfortable with palliative care are more likely to use these skills to improve quality of life and medical care for people with CF. However, more studies are needed to test whether training CF providers in palliative care leads to better outcomes for patients.

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What's next?

Providers at other clinics may find similar palliative care training helpful and can use our curriculum. Another next step is testing programs that use palliative care techniques to directly help patients. The overall goal is to improve lives of people with CF by helping them feel more comfortable and enjoy life more.

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