



# Cystic Fibrosis Research News

## **Title:**

Defining Palliative Care in Cystic Fibrosis: A Delphi Study

## **Authors:**

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## **What was your research question?**

Palliative care focuses on quality of life and reduction in distressing symptoms and suffering related to serious illness. It is an important aspect of care for people with cystic fibrosis (CF). Some people feel that unique aspects of CF make it different than in other conditions. We aimed to develop a CF-specific definition of palliative care.

## **Why is this important?**

Palliative care focuses on quality of life and is an important part of the care of people with serious illness. There are no specific recommendations for incorporating palliative care into the care of people with CF. As a starting point for developing recommendations, we felt it would be helpful to have key stakeholders in CF care work together to develop a definition of palliative care that feels relevant to CF.

## **What did you do?**

We used a series of surveys that built upon one another to create a definition. We asked individuals with CF, caregivers of individuals with CF, CF care team members, palliative care providers, and researchers to select elements of palliative care that felt relevant to CF. We then asked them to combine these elements into a definition, and to choose the best definition. Along the way, survey participants were asked to share their thoughts and feelings related to specific terms and definitions. We settled on a definition by consensus.

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## **What did you find?**

The preferred definition was, "Palliative care focuses on reducing physical and emotional symptoms and improving quality of life for people with CF throughout their lives. Palliative care occurs alongside usual treatments and is individualized according to the unique goals, hopes and values of each person with CF." Participants wished to emphasize that palliative care is appropriate throughout the lives of people with CF, and decided to omit any language about death and dying.

## **What does this mean and reasons for caution?**

This definition will be used in the development of clinical care guidelines for palliative care in CF, and we hope it will be used broadly in palliative care research and quality improvement projects in CF. We hope that having a standard definition will be a nice starting point for communication between individuals with CF and their caregivers, CF care teams, and palliative care consultants. It should be noted that this definition was chosen by a small group of stakeholders representing only US CF care centers.

## **What's next?**

The members of this research team are involved in additional research about palliative care in CF that we hope will help advance the field and ensure quality palliative care for people with CF through new knowledge and the developmental of clinical care guidelines.

## **Original manuscript citation in PubMed**

<https://www.ncbi.nlm.nih.gov/pubmed/?term=Defining+Palliative+Care+in+Cystic+Fibrosis+%3A+A+Delphi+Study>