



## Original Article

## Defining palliative care in cystic fibrosis: A Delphi study

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**Abstract**

**Background:** The goal of palliative care is to improve quality of life for people with serious illness. We aimed to create a cystic fibrosis (CF)-specific definition of palliative care.

**Methods:** A working group of 36 CF care providers, researchers, palliative care providers, quality improvement experts, individuals with CF, and CF caregivers completed a series of questionnaires to rate the value of each of 22 attributes of palliative care, rank top attributes to construct definitions of palliative care, and then rate proposed definitions.

**Results:** An average of 28 participants completed each of four questionnaires, with consistent distribution of stakeholder roles across questionnaires. Many identified overlaps in routine CF care and palliative care and highlighted the importance of a definition that feels relevant across the lifespan.

**Conclusion:** Modified Delphi methodology was used to define palliative care in CF. The definition will be used as the foundation for development of CF-specific palliative care guidelines.

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**Keywords:** Palliative care; Cystic fibrosis; Quality of life

**1. Introduction**

Palliative care aims to improve quality of life for people of any age with serious illness [1]. While there is no single, standard definition of palliative care, it is widely accepted that palliative care is appropriate from the time of diagnosis of a serious medical condition, can be offered alongside standard, disease-specific treatments, and can be provided in any setting: hospital, outpatient, or home [2]. Cystic fibrosis (CF) is a serious illness for which palliative care is appropriate [3,4].

Palliative care for individuals with CF of any age may differ from palliative care for children or adults with other serious

illnesses. CF is a genetic disease that currently has no cure, is typically diagnosed in infancy, and is heterogeneous in its manifestations and course, making prognostication for individuals with CF challenging [5]. As a result of better therapies, the population of adults with CF now exceeds that of children with CF in the US [6], and therapies targeting the basic defect in CF are available to an increasing proportion of those living with the disease [7]. While the long term impact of disease modifying therapies is unknown, their availability amplifies hope for marked improvements in quality of life and longevity. Even with these therapeutic advances, and regardless of the severity of lung disease, CF is a complex and burdensome condition that affects both physical and emotional functioning, thus affecting quality of life. People with CF commonly report pain [8,9] and experience depression and anxiety at higher rates than healthy peers [10,11].

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As the disease progresses, they must make increasingly complex decisions about medical treatments and end of life much earlier than those without lifelong serious illness.

The current model of CF care, with quarterly outpatient visits and care coordination among clinicians from multiple disciplines, invites inclusion of palliative care practices. Palliative care specialists with knowledge of CF can help address needs of select patients that are better met by those with specific training in specialist palliative care skills [12]. How palliative care fits into CF care is yet to be defined.

A Cystic Fibrosis Foundation-sponsored 36-member palliative care working group consisting of CF care team members, researchers, palliative care providers, health care quality improvement experts, individuals with CF, and caregivers of individuals with CF from across the US convened in July 2016 to discuss current practices in palliative care for people with CF and to plan for the development of clinical practice guidelines for palliative care in CF. The group determined that establishing an agenda to inform standards of care would be helped by a clear definition of palliative care that feels relevant to this unique population. We aimed to develop a CF-specific palliative care definition using Delphi methodology [13]. This process is intended for decisions that are made by a diverse group of experts or stakeholders. We determined that this methodology would be an effective tool to explore the meaning of palliative care in CF, where patient and family-centered care is emphasized and provided by a multidisciplinary CF care team.

## 2. Materials and methods

A subgroup of the palliative care working group conducted an online search for definitions of palliative care offered by health care organizations and professional groups recognized by members of the research team as reliable, publicly available sources of information about palliative care [2,14–19]. Specific attributes of palliative care were extracted verbatim from these definitions with the intent to identify the most valuable and relevant attributes from existing, widely accepted definitions of palliative care for inclusion in a consensus definition of palliative care in CF. As we selected elements of standard definitions verbatim, we opted not to separate attributes when they were closely linked. These attributes were used to construct questions

in the initial anonymous online questionnaire, which informed a multistep, iterative Delphi survey process [13,20].

A total of four questionnaires were sent to the members of the working group, and participants were asked to identify their role(s) in CF care. A participant's role was grouped into four stakeholder groups: palliative care provider (palliative care provider and/or researcher), CF care team member (CF care provider and/or researcher), researcher, or individual with CF/caregiver of an individual with CF. Any of the four stakeholder groups could include a quality improvement expert. After each questionnaire, the subgroup of the palliative care working group reviewed results, developed the next questionnaire, and determined when consensus was reached. The study was approved by the Institutional Review Board at the University of North Carolina. Questionnaire administration occurred between December 2016 and April 2017.

In the first questionnaire, participants rated 22 attributes of palliative care on a 5-point Likert scale, from “very high value/should be included in the definition of palliative care” (most positive response) to “no value/definitely should not be included.” In assessing value of the attribute, participants were asked to consider whether the attribute was sufficiently clear to be understood by all stakeholders - individuals with CF, family caregivers, CF care team members, lung transplant providers, and palliative care providers - and whether the attribute could be helpful in prioritizing strategies for providing effective palliative care to people with CF. Three summary statistics were used to identify the attributes of highest value: 1) percent most positive response, 2) percent most positive response stratified by the four stakeholder groups, and 3) a divergent metric,\* which was the sum of the absolute differences between each stakeholder group. Attributes with concordant value rankings among stakeholder groups were maintained (higher value) or removed (lower value), and those with divergence among stakeholder groups were removed unless supportive statements provided rationale for maintaining the attribute.

In the second questionnaire, participants reviewed the 12 most valuable attributes identified in the first questionnaire and ranked a minimum of five and maximum of seven attributes that should be included in the definition of palliative care. They also listed up to five attributes to exclude from the definition, again considering clarity and utility of the attributes. Three

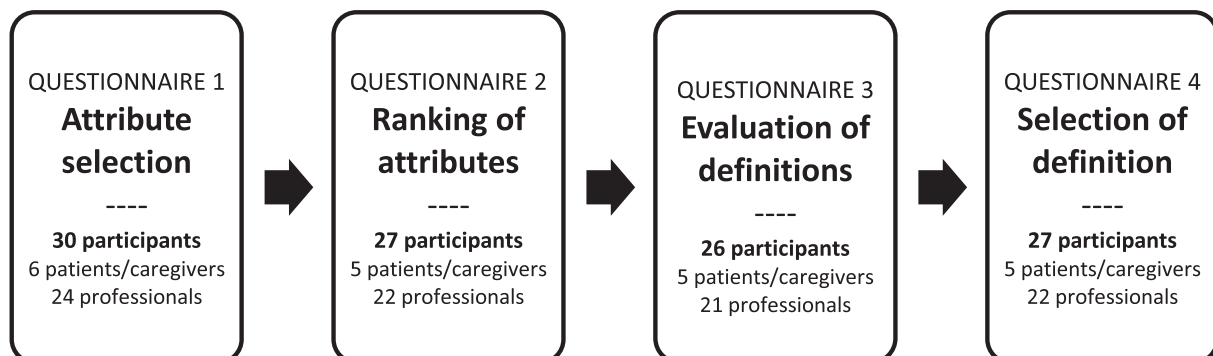


Fig. 1. Delphi process participation. “Professionals” include three stakeholder groups: CF care team members, palliative care providers, researchers.

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