

Assessing Practices, Beliefs, and Attitudes about Palliative Care among People with Cystic Fibrosis, Their Caregivers, and Clinicians: Results of a Content Analysis

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Abstract

Background: Individuals with cystic fibrosis (CF) experience symptoms affecting quality of life and may benefit from palliative care (PC).

Objectives: To present results of content analysis from open-ended survey questions assessing knowledge and experiences with PC among CF stakeholders.

Design, Setting, Subjects: Online surveys were sent to CF stakeholders through CF-specific listservs predominantly in the United States.

Measurements: Responses to five open-ended questions about CF PC—delivery, health care provider training, and lung transplant—underwent content analysis. Responses were coded using NVivo12 Software™.

Results: Forty-eight CF adults, 59 caregivers, and 229 providers responded to the open-ended survey questions. Analysis showed 5 primary categories related to CF PC: (1) stakeholder perceptions of PC for CF, (2) delivering PC to people with CF, (3) conversations about PC for CF, (4) perceptions that PC services are underutilized for people with CF, and (5) beliefs that PC services are critical for people with CF considering or pursuing lung transplant. Analysis showed variation among and within groups in defining PC for CF, when, and how to deliver it. Many respondents felt PC was underutilized in CF. Most saw PC as particularly important when considering lung transplant, managing anxiety around transplant, and for goals of care discussions. Some believed PC and lung transplant were mutually exclusive.

Conclusion: Respondents felt PC is underutilized for CF, and that people with CF may miss out on the benefits of PC. Among stakeholders, respondents felt people with CF would benefit from access to primary and secondary PC services.

Keywords: cystic fibrosis; primary palliative care; qualitative methods

Introduction

IN RECENT YEARS, treatment advances and evidence-based guidelines for daily self-care have enabled many people with cystic fibrosis (CF) to live longer.^{1–5} However, this increased life expectancy has not eliminated prevalent and

distressing symptoms,^{6,7} and has increased the daily treatment burden among this population, affecting both individuals with CF and their families.⁸ Therefore, resources addressing physical and mental health symptoms, advance care planning (ACP), and decision making about life-extending interventions such as lung transplant and family

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Accepted February 24, 2021.

support are vital to quality of life for people with CF and their families. Palliative care (PC) may address many of these needs.

Although the field of PC originated with the hospice movement, there has been an overall shift in recent years toward improving the quality of life of individuals with chronic illnesses and their families by focusing on alleviating suffering throughout the lifespan.⁹ However, misconceptions equating PC with end-of-life care and hospice remain one of the key barriers to offering early PC services.¹⁰ Similarly, earlier studies among the CF population showed PC discussions often take place within the last few days of life, when patients were too sick to participate.¹¹ Prior studies also show that CF providers were hesitant to discuss PC earlier on as they felt uneasy about initiating discussions that might dampen their patients' hopes.¹²

There are several existing models available for offering PC services to people with CF and their families. These include: (1) primary PC, which encourages non-PC specialists to attend to basic palliative needs including pain and symptom management, and ACP and goals of care discussions with referral to specialty PC services if needed.¹³ (2) Specialty PC that can be administered by clinicians with PC training who can offer assessment and management of complex or intractable pain and other physical symptoms, mental health care, and assist patients in decision making about complex treatments and goals of care.¹⁴ (3) PC services may also be offered through embedding PC specialists within CF care teams,¹⁵ or (4) through consultative services whereby PC specialists are brought in for those patients who require additional care.¹⁶ (5) Finally, there are also hybrid models combining primary and specialty PC services.¹⁷

There are a limited number of studies exploring multi-stakeholder perceptions and utilization of PC services for CF.^{18,19} However, until recently, there has been no consensus regarding appropriate models of PC for people with CF. To address these issues, we developed and administered online surveys comprising open- and closed-ended questions to a variety of CF stakeholder groups nationwide including adults with CF, family caregivers, and CF team members. We sought to assess frequency of PC service delivery by CF care teams, perceived skill of CF care team members to deliver PC services, knowledge of existing PC resources, experience with PC training and tools among providers, and specific concerns related to

PC services for people exploring lung transplant across the three stakeholder groups. The surveys were one component used to inform the development of consensus guidelines for CF-specific PC models.²⁰ Herein, we present the results from content analysis of responses to the open-ended questions. Analysis of the closed-ended questions has been previously published.¹⁸⁻²¹

Methods

Survey design and administration

Modeled on a format used by a previous team to develop guidelines for CF-specific anxiety and depression screening,^{22,23} we undertook a similar process to design parallel surveys for the three stakeholder groups (i.e., adults with CF, family caregivers, CF health care providers). We conducted a literature review on general and CF-specific PC and engaged various CF and PC experts to develop open- and closed-ended survey questions tailored to the stakeholder groups.¹⁸ The open-ended questions were further reviewed by two members of the study team with expertise in design of qualitative research studies (Table 1). In addition, included in the survey introduction was the following definition of PC that was developed by several members of the research team through a Delphi Survey: "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."^{18,21}

This definition of PC differs from more generally accepted definitions of PC, for example, that was put forth by the World Health Organization—"WHO defines PC as the prevention and relief of suffering of adult and paediatric patients and their families facing the problems associated with life-threatening illness. These problems include physical, psychological, social and spiritual suffering of patients and psychological, social and spiritual suffering of family members,"²⁴ in that it is focused specifically on PC for people with CF. It is similar to recent definitions of PC in its emphasis on the continuous delivery of PC throughout the life course, concurrent care, symptom management, and focus on what is important to the individual patient. Our definition has been tailored specially to CF.

Surveys were administered using the Qualtrics™ (Qualtrics, Provo, UT; <https://www.qualtrics.com>) platform and widely

TABLE 1. OPEN-ENDED SURVEY QUESTIONS ASKED BY STAKEHOLDER GROUP

<i>Questions</i>	<i>Adults with CF</i>	<i>Caregivers of people with CF</i>	<i>CF providers</i>
Do you think CF providers should receive more training in PC?	x	x	
Does the availability of lung transplant for some people with CF affect whether and how they receive PC?	x	x	
In your own words, how would you describe PC in the context of CF care delivery?			x
In your opinion, how does PC fit into CF care in the context of the availability of lung transplant for select patients? Does it change your approach to providing PC or referring patients to PC consultants? Please consider all elements of PC, including symptom management, advance care planning, goals of care, decision making, and end of life, in your response.			x
Please share additional thoughts about any of the questions in this survey.	x	x	x

CF, cystic fibrosis; PC, palliative care.

disseminated through U.S.-based CF Foundation patient/family and clinician listservs. All participants received electronic consent forms with language stating that completing the surveys implied consent. The surveys were made available between July and August 2017. This study was approved by the University of North Carolina Institutional Review Board (No. 17-1510).

Qualitative data analysis

To explore topics of importance for CF-specific PC among our survey respondents, we undertook content analysis of the open-ended questions.^{18,25} The goal was to identify and categorize topics that were mentioned with high frequency among respondents. Before undertaking our content analysis, all open-ended responses (i.e., the raw data) were sorted first by stakeholder group and clustered by question (Supplementary Appendix Table SA1: Survey Responses).

Our content analysis was primarily guided by a deductive orientation reflecting the study team's interests in determining whether or not: (1) among providers, there was variation, including possible misconceptions, in understanding what PC for CF; (2) among people with CF and their caregivers, there were perceptions that CF care teams may need additional training in basic PC services based on our definition of PC provided in the survey; and (3) among all respondents, there was a perception that there were features unique to people with CF considering lung transplant that may impact PC delivery. These areas of interest are reflected in the *a priori* codes that were included in our codebook. We also applied an inductive approach to our data analysis allowing us to identify and include additional, new topics of importance from the open-ended responses.

Two qualitative researchers (M.B., M.R.H.) undertook the content analysis whereby all survey responses were read independently, with each researcher inductively adding to the *a priori* list of codes. Through iterative discussion and comparison, a final list of codes was agreed upon, including both the *a priori* codes (e.g., CF unique, PC Misunderstood, PC Primary Training, and Lung Transplant Unique) and inductively derived codes (e.g., Opioid use was a contraindication for lung transplant, PC specialists don't understand CF), and further organized with codes categorized as primary or secondary. A codebook was then developed (L.J.), which comprised the full list of codes, their definitions, and example quotes from the responses (Supplementary Appendix Table SA2: Codebook). Using this codebook, one qualitative researcher (M.B.) initially coded all responses using NVivo12™ Software.

To confirm accuracy and to reduce single-coder subjectivity, a second coder (M.R.H.) then randomly coded 20% of the responses with 84% accuracy achieved between the two coders indicating high agreement. The NVivo database presents classification of responses by stakeholder type, allowing us to see the total number of times a response was tagged to a specific code by each stakeholder group. Our goal for the content analysis was to capture the many ways in which respondents discussed PC in the context of CF. Because most individual responses encompassed multiple topics of importance, we allowed for co-coding of responses, and therefore, we did not use inclusion or exclusion criteria in the codebook. For example, the response that PC is "helping patients and families cope with diagnosis and its affects throughout lifespan" was co-coded as (1) Mental Health/Coping, (2) Families, and (3) Intro Early/Lifespan.

Results

Participant demographics

Surveys were sent to 11 CF-provider listservs with a total of 3500 subscribers, and to a CF patient and caregiver listserv with 210 CF patients and 290 family caregivers subscribed. However, for the provider listservs, overlap among subscribers to each listserv prevents us from calculating an accurate response rate for our provider respondents. The total number of responses received was 520 (70 CF adults, 100 CF caregivers, and 350 CF health care providers). Of these survey respondents, there were 48 CF adults, 59 caregivers, and 229 clinicians who responded to at least 1 open-ended question. Table 2 shows the breakdown of participants' characteristics organized by stakeholder for both total respondents, and open-ended-only respondents. Characteristics are summarized descriptively.

Content analysis

Responses to the open-ended survey questions are organized into five primary categories based on frequency. Within each primary category, the secondary categories are summarized hereunder, and includes sample quotes for select secondary categories. Supplementary Appendix Table SA3 includes relevant sample quotes for all secondary categories taken from survey responses, and a breakdown of the frequency of responses for each category per each stakeholder group. (See Supplementary Appendix Table SA1: Survey Responses for complete version of stakeholder responses to open-ended questions.)

Category 1: Stakeholder perceptions of PC for CF.

The majority of statements related to stakeholder perceptions of PC indicated that respondents associated PC for CF with: (1) physical symptom management and improving quality of life; (2) ACP and communicating goals of care; (3) mental health and coping with the emotional distress of CF; (4) family support; (5) others emphasized the holistic nature of CF, using terms like "whole person" care; (6) several responses highlighted the importance of PC given the complex and uncertain nature of CF; (7) a limited number of responses linked PC with hospice or end-of-life care, and the idea that some people with CF were not "sick enough" to need it, and other responses focused on difficulties administering PC for CF because of associations of PC with end-of-life care. For example:

1. Physical/Q-o-L: Having CF is an everyday battle having help dealing with all the side effects both physically and emotionally is necessary. (Adult with CF)
2. ACP and communicating goals of care: CF providers often form life-long bonds with us as patients, and in some ways provide emotional support and help with difficult decisions. (Adult with CF)
3. Mental health and coping: PC is very helpful with patients who have trouble coping with the disease and its progression. (CF Provider)

Category 2: Delivering PC to people with CF. There was variation in respondents' perceptions about how to provide PC to people with CF. Some respondents viewed PC as something external, either with (1) PC specialists being

TABLE 2. PARTICIPANT DEMOGRAPHICS²²

Characteristic	n (%)	n (%) of those responding to at least 1 of the open-ended responses
Patients (N=70)		N=48
Followed by adult (vs. pediatric) CF care team	67 (96)	44 (92)
Lung transplant recipient	11 (15)	8 (17)
Previous experience with PC	33 (47)	21 (44)
Personal experience	5 (7)	3 (6)
Family or friend received PC	21 (27)	14 (29)
Professional/work experience	2 (3)	1 (2)
Caregivers (N=100)		N=59
Relationship to individual with CF		
Parent	89 (89)	50 (85)
Has 2 or more children with CF	17 (19)	10 (17)
Partner or spouse	5 (5)	5 (8)
Other relative	6 (6)	4 (7)
Individual with CF receives care from adult CF team	17 (17)	10 (17)
Individual with CF is a lung transplant recipient	5 (5)	4 (7)
Previous experience with PC	50 (50)	25 (42)
Personal experience	5 (5)	0
Family or friend received PC	29 (28)	20 (34)
Professional/work experience	10 (10)	3 (5)
Providers (N=350)		N=229
Role on CF care team		
Physician	72 (22)	41 (18)
Social worker	65 (19)	37 (16)
Nurse	58 (16)	40 (17)
Advanced practice nurse or physician assistant	39 (11)	27 (12)
Dietitian	37 (11)	23 (10)
Physical therapist	26 (7)	16 (7)
Respiratory therapist	15 (4)	11 (5)
Pharmacist	13 (4)	7 (3)
Other	25 (7)	27 (12)
Pediatric or adult CF care team member		
Pediatric	129 (37)	87 (38)
Adult	129 (37)	78 (34)
Both	90 (26)	59 (26)
Also a lung transplant team member	37 (11)	21 (9)
Also a PC provider/team member	10 (3)	n/a
Someone on CF care team has attended PC training session(s)	69 (20)	34 (15)
Personally attended PC training session(s)	53 (15)	5 (2)

n/a, not available.

“brought in” to provide a service, or “sending” patients with CF to see PC specialists when needed. A variation to this approach involved offering PC “alongside” or (2) supplemental to usual CF care—sometimes referred to as “concurrent care.” Here, PC was seen as a service provided by others, that is, not by the CF clinical team. Other respondents saw PC as something that should be part of usual or (3) integrated into regular CF care, or as an approach to providing CF care with CF clinicians providing primary PC or initiating PC conversations. For example:

1. PC specialists: There should be a program/person for this. CF Docs have a lot to be on their plate already. (CF Caregiver)
2. PC supplemental: [PC as] Added layers of support for medically complex patients. (CF Provider)
3. PC integrated care: Basic PC is the responsibility of every CF provider at every point in the disease. (CF Provider)

Category 3: Conversations about PC for CF. Respondents varied on when PC should be introduced to people with CF, perhaps because they had different views on what PC for CF is. Most participants felt that PC should be (1) introduced early and made available across the lifespan, accommodating individual-level changes in condition and needs over time. Others felt PC should be (2) introduced during the teenage years, when a person was either becoming older or owing to illness progression. In both instances, the idea was to expand ideas about PC away from end-of-life care to make people with CF feel more comfortable with PC. By contrast, others felt that (3) PC should be introduced at end of life or end stage. For example:

1. Intro early/lifespan: Most of us think of PC as easing pain and suffering at end-of-life times, but the toll CF takes on a patient begins much, much earlier. (CF Caregiver)
2. Getting older: As a CF patient we go through so many ups and downs in our care. It would be nice to in-

corporate PC as part of our treatment especially as we get older. (Adult with CF)

3. End of life: PC has only been utilized at our center when the patient is hospitalized and actively dying. This has resulted in family feeling poorly educated on what to expect and unprepared for the actual dying process. (CF Provider)

Category 4: Perceptions that PC is underutilized for people with CF. Many respondents felt that CF clinicians would benefit from receiving (1) primary PC training, stating that sometimes CF providers were uncomfortable discussing PC with their patients. Several respondents also stated that PC services were either (2) underutilized (e.g., services were either lacking at their centers, or PC was not discussed). A limited number of CF providers felt there were (3) delays in offering PC, or that PC specialists did not always understand the complexities of CF. For example:

1. Primary PC training: Continuing professional development in all aspects of CF should be required for all members of the CF team. (CF Caregiver)
2. Underutilized: My CF clinic has never mentioned PC to me. (Adult with CF)
3. Delays: It is often introduced too late so patients think they must be dying to get it. One patient called Pall Care “Dr. Death.” We are getting better but not good enough. (CF Provider)

Category 5: Beliefs that PC services are critical for people with CF considering or pursuing lung transplant. When responding to questions about how lung transplant for CF might affect the delivery of PC services to this population, respondents raised several topics. For some, (1) lung transplant was seen as a single time point in the life course of a person with CF where PC would be needed. Several respondents felt that PC was important for (2) lung transplant decision making and goals of care discussions. A number of respondents expressed the idea that (3) lung transplant is a unique time where PC services were of particular importance, and similarly, many respondents brought up that (4) lung transplant itself was fraught with uncertainty. Among such responses, there was concern that those pursuing transplant might not survive, and for this reason, PC is necessary. Others saw (5) PC as important for those patients for whom lung transplant was not an option, either because they could not pursue it or had decided against it.

There were two themes related to misconceptions about PC for lung transplant. Both implied that lung transplant and PC were mutually exclusive: (6) the need to avoid opioids or other pain medications in preparation for transplant, or (7) people saw lung transplant as extending life, and PC as being for end of life. Finally, a limited number of providers mentioned the fact that (8) they were not aware of PC services associated with transplant because CF teams often lose contact with patients once they are referred to transplant teams. For example:

1. Lung transplant life course: If PC is not end of life, then lung transplant is another facet to disease that PC would come in handy for. (Adult with CF)

2. Lung transplant decision making: I think PC could be helpful to patients considering transplant for discussing whether or not the patient really wants one. (CF Provider)
3. Lung transplant unique: There must be major physical and emotional symptoms during the transplant process, and PC would be extremely valuable. (CF Caregiver)

Discussion

Our qualitative study showed within group variation among the three stakeholder respondent groups regarding specific delivery models for CF PC. Differences emerged regarding who should administer it and when, and these were related to the existing models of PC offered to people with CF. Although most respondents saw PC as something that could improve quality of life across the lifespan, other participants inappropriately equated PC with hospice, or end-of-life care. We saw greater homogeneity with regard to PC for lung transplant with the majority of respondents believing that PC was critical for patients with CF who are considering transplant, particularly for decision making, symptom management, mental health, and support amidst uncertainty. A limited number of respondents expressed the belief that PC and lung transplant were mutually exclusive, either because of the fear that patients may feel clinicians have given up hope if PC is offered or because opioids or other pain medications are thought to be a contraindication for transplant.

Our study also found variation in perceptions about how PC services should be provided to people with CF. Among our respondents, particularly among the providers, some felt PC was something that should be brought in as needed, or that people with CF should be sent to PC specialists. These beliefs and practices indicate that in many cases, PC is not part of usual CF care. In contrast, other respondents either stated that CF providers should be trained to offer at least primary PC to patients or that PC specialists should be part of CF care teams. With this approach, people with CF are offered PC as part of usual care, enabling PC providers to offer services tailored to specific needs of people with CF. It may also help move the CF community away from the notion that PC is only appropriate when someone with CF is nearing end of life. This is of particular importance because it has been shown in studies of PC among non-CF populations that frequent association of PC with end-of-life care and hospice led to delays in service and anxiety around PC discussions.^{26–28}

Most respondents saw PC as something that should be offered throughout the life course, including during lung transplant. This would encourage a CF-specific PC model that can tailor care to each individual’s disease course. It recognizes that each person’s needs will change over time, including physical and mental health symptoms, and goals of care—whether or not that includes lung transplant. Expanding stakeholder views of what PC is and encouraging PC as part of usual care may help move toward those models of PC care that encourage ongoing access to PC services—either by embedding PC providers into care teams¹⁵ or ensuring primary PC can be delivered by CF providers.^{13,29} This would mean providing training in primary PC to CF clinicians, which clinicians have cited as being an area in which they would like to receive training.³⁰ Here, PC offered

as part of primary CF services, would begin at diagnosis by CF clinicians trained in PC, with avenues for also addressing the needs of family members who are involved in providing care to their CF loved ones.

We note several strengths and limitations of our study. Strengths include (1) the large sample size for a qualitative study, (2) nationwide administration of the survey, and (3) the inclusion of key CF stakeholders, namely adults with CF, caregivers of people with CF, and CF providers. This large and diverse sample allows us to assess the experiences of key stakeholder groups on a wide scale. Limitations include the following: (1) inability to determine exactly how many individuals had access to the survey owing to cross-posting of the survey on multiple listservs, (2) responses heavily weighted toward providers, (3) a possible risk of reporting bias as those choosing to respond to specific open-ended questions about PC may have had more experiences with PC services. However, many respondents made statements indicating that they did not have prior knowledge or experiences with PC, so we believe participant responses to the open-ended questions reflect a broad range of exposure and experiences with PC, (4) having only one primary coder.

To help address concerns regarding single coder subjectivity, we had a second coder randomly code 20% of the responses to assess accuracy and identify possible single-coder subjectivity, and were able to achieve 84% coder agreement indicating high agreement. We have also provided in the Supplementary Material both the codebook and all stakeholder survey responses. In addition, we include the breakdown of response in the content analysis table (Supplementary Appendix Table SA3), including the denominators for each group. This allows us to isolate the responses by stakeholder group.

It is important to note that while stakeholder groups were asked different questions, preventing comparisons among the three groups, we did ultimately find that most responses fit well into the pooled content analysis categories. Finally, (5) we note the inherent limitation of the use of open-ended questions administered through an online survey as a qualitative method, particularly without the chance to follow-up with respondents for clarification, or the ability of respondents to ask for clarification about the questions from the study team. In addition, the questions were not pilot tested before administration. Therefore, we cannot know whether any respondents may have misunderstood the questions, and the impact that this could have had on their responses.

Conclusion

Among stakeholders, there were varied beliefs and practices about PC as it relates to the CF population. As a result, many people with CF may not be receiving PC across the spectrum of their disease. Education and outreach are needed to increase access to quality PC for individuals with CF. PC could become integrated into usual CF care either by increasing PC training among CF care teams, establishing partnerships between CF and PC teams, and/or by having PC specialists embedded in CF care teams.

Acknowledgments

The authors thank the Cystic Fibrosis Foundation and their Community Voice Team for their support, and all of the individuals who responded to the survey.

Funding Information

Author Disclosure Statement

M.B.: Receives research support from the Cystic Fibrosis Foundation (20K0 2020) outside the submitted work, and a grant from a federal source (Agency for Healthcare Research and Quality [AHRQ] 1R03HS026970-01A1), outside the submitted work.

L.J., M.R.H., J.L.G., E.C., S.E.H., and A.F.: Nothing to disclose.

E.P.D.: receives research support from the Cystic Fibrosis Foundation.

A.M.G.: reports grants and personal fees from Vertex Pharmaceuticals, outside the submitted work; grants, personal fees, and nonfinancial support from the Cystic Fibrosis Foundation, outside the submitted work, grant funding from the Dutch Cystic Fibrosis Foundation, outside the submitted work; personal fees and nonfinancial support from Cystic Fibrosis Australia, outside the submitted work; nonfinancial support from the European Cystic Fibrosis Society, outside the submitted work; personal fees from Johns Hopkins University/DKBmed, outside the submitted work.

C.H.G.: reports grants, personal fees and nonfinancial support from the Cystic Fibrosis Foundation, grants from the Federal sources (UM1HL119073, UL1TR000423, P30 DK 089507, R01FD003704 and R01FD006848), personal fees and honoraria from Vertex Pharmaceuticals (Participation in UK LEAD conference), clinical trial contract and personal fees from Boehringer Ingelheim while serving as the National PI for a phase 2 study, honoraria from Gilead Sciences for serving as a Chair of a grant review committee, and honoraria from Novartis for serving as a DSMB Chair for a joint Novartis/European Commission trial.

D.K.: received research funding during the conduct of this study from the NIH/National Heart Lung and Blood Institute (K01HL133466), and the Cystic Fibrosis Foundation (KA-VAL19QI0).

Supplementary Material

Supplementary Appendix Table SA1
Supplementary Appendix Table SA2
Supplementary Appendix Table SA3

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