

**Codebook for Content Analysis: Assessing Practices, Beliefs and Attitudes about Palliative Care among People with CF, Their Caregivers, and Clinicians**

<b>Code</b>	<b>Definition</b>	<b>Sample Text</b>
<b>Primary Category 1: Stakeholder Perceptions of Palliative Care for CF</b>		
E-o-L	References to: Hospice or end of life care, end stage, getting sicker etc.	A tool to discuss various medical therapeutic options in the context of end of life care
Physical/Q-o-L	References to: Physical symptom management, support, and quality of life, providing comfort care	emphasizing quality of life as a first priority when addressing treatment strategy
MH/Coping	References to: Mental healing transplanth, stress, anxiety, coping, emotional distress	As people with CF are living longer, we must have individuals that are better trained with handling & helping with depression, coping in society with CF and also help understanding everything.
ACP/GoC	References to: Goals of care, advance care planning, decision making, communication	Finding out exactly what the patient needs to meet their goals for treatment. What are their goals and what steps do they want to take with treatment, this may differ from what the physicians have in mind but by getting what they want this will <u>maximize the life they have.</u>
Families	References to: Support for families or that PC is also for families	It is a life long support for patients, caregivers and family members
Holistic	References to: Holistic – “whole person” approach, tailored to individual patient, dynamic, changes over time	The combined mission should be a focus on emotional, spiritual and physical well-being. The process is tailored to the individual person and their story.
CF Unique	References to: fact that CF is unique - lifelong, complex, uncertain course, progressive	Assisting patients with addressing the unique needs of a chronic and life threatening disease with changing needs in regards to life decisions and goals of care and treatment.
Misunderstand PC	Misunderstood - when respondent states that others have confusion about or misunderstand PC	In my institution, it is very poor. Great confusion as to what palliative care is and what it is not. Most professionals still assume that palliative and hospice are the same thing.
Not sick enough	Not sick enough to need it - particularly parents of peds people or younger adult lung transplants	This is a great idea, along transplanth though my children are young and doing great, when it comes time this service would help emotionally in a huge way!
<b>Primary Category 2: Delivering PC to People with CF</b>		

PC Specialists	References to: Palliative care specialists - clinicians palliative care brought in, consulting transplanted - outside of CF care, done by others	I prefer to leave that discussion to a specialist since I do not see myself discussing the issue and not able to answer properly the questions, by fear of adding to their mental healing transplanth issues.
PC Integrated Care	References to: PC being integrated within CF care teams - part of regular CF Care - fully integrated, approach to CF care	I think it should go hand in hand, and always be a part of the care given.
PC Supplemental	References to: PC being supplemental, alongside of, MADE AVAILABLE but concurrent to regular CF Care	Palliative Care is an amazing way to offer extra layers of support and resources alongside traditional CF therapies that can improve quality of life for patients and their families.
<b>Primary Category 3: Conversations about Palliative Care for CF</b>		
Intro Early/Lifespan	References to: Introducing PC early and making available across the lifespan allowing for changes over time	providing guidance assistance and support through a life long illness from diagnosis through death
Intro CF Progressing	References to: PC when CF is starting to Progress, as person gets older	As CF disease progresses, the ability of the care team and patient and caregivers to manage goals, symptoms and make sure the patients wishes are followed not the people involved in their care.
Intro E-o-L	References to: offering PC at the end of life	Palliative Care has only been utilized at our center when the patient is hospitalized and actively dying.
<b>Primary Category 4: Perceptions that PC Services are Underutilized for People with CF</b>		
CF Provider Training	References to: CF providers needing better training, CF providers lack training to administer PC	I haven't needed much palliative care, but when I have, the providers were sometimes not good at talking about it or didn't have options I liked (not necessarily their faulung transplant).
Access	References to: Lack of PC access, underutilized, not brought up to patients or families, denied due to financial issues	I haven't needed much palliative care, but when I have, the providers were sometimes not good at talking about it or didn't have options I liked (not necessarily their faulung transplant).
Delays	References to: Delays In offering PC for CF - providers wait too long to introduce etc.	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
PCs Don't Understand CF	PC specialists don't understand complexities of CF	It's tricky! In my experience most palliative care providers who don't know CF don't understand the need of patients to stay positive and focused on transplant vs. end of life planning.
<b>Primary Category 5: Beliefs that PC Services are Critical for People with CF Considering or Pursuing Lung Transplant</b>		

No lung transplant	When lung transplant is not an option	I think palliative care should be offered for those patients that will not qualify for a lung transplant
lung transplant Life course	Lung transplant as one component of the life course where PC is needed, i.e. just as important for lung transplant	if palliative care is not end of life, than lung transplant is another facet to disease that palliative care would come in handy for
lung transplant DM	PC for lung transplant decision making, advance care planning, goals of care	Regarding Lung transplant there are choices and some times CF patients don't feel like they have choices. patients need help to decide if lung transplant is the right decision for them.
lung transplant Unique	Lung transplant unique PC needs to be part of the process	There must be major physical and emotional symptoms during the transplant process, and palliative care would be extremely valuable
EoL vs Life Extend	PC lung transplant misconception - mutually exclusive e-o-l vs. extending life	It makes the timing difficult lung transplant; planning for a transplant is creating hope and palliative care often implies lack of hope
lung transplant no Opioids	PC lung transplant misconception - mutually exclusive- opioids for pain management	There seems to be a perception that the palliative care team will put our patients on too many pain meds, which will make it harder for them to get approved for transplant
lung transplant Uncertainty	PC important because of the uncertainty of lung transplant outcomes- don't know what might happen,	Not all patients are able to make it through the lung transplant workup or being listed, so I do believe Palliative Care has a place with these patients.
Teams not contact	CF teams Lose Contact with Patients once they are referred to lung transplant	There is a huge disconnect between our center and transplant. Once we refer a patient to transplant, they seem to "fall into outer space" as the transplant centers limit their conversations/communications with the CF team. That is a huge problem.