



# ADVANCE LUNG DISEASE PLANNING

INTEGRATING PALLIATIVE CARE IN ADVANCE LUNG DISEASE

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# OUTLINE

1. Review current data on palliative care in pulmonary medicine
  - Patient and physician perspectives
2. When should palliative care be introduced in advance lung diseases and outcomes
3. Introducing palliative care into outpatient pulmonary medicine
  - Blended/collaborative practices

## HISTORY ON PALLIATION

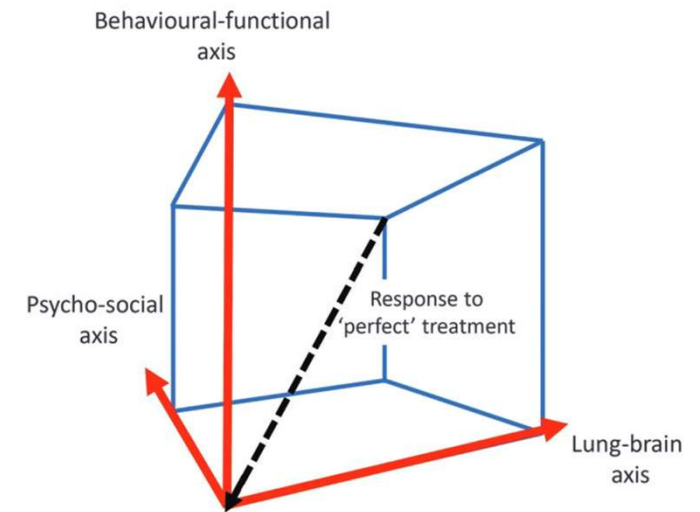
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Seeing the patient beyond their disease and focus on symptomatic relief and stress of illness while providing quality of life to patient and their family.

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# PALLIATION IN PULMONARY MEDICINE

- “I can’t breathe, I need air”...
- Despite advances in disease treatment, symptoms are still a significant burden.
- High rates of resource used. **\$18 billion in 2012**
- Palliation addresses patients as a whole
  - Symptomatic management of dyspnea involves multiple aspects.



<p><b>Triggered, normal breathless level</b></p> <p>Late onset, quick recovery</p> <p>(e.g, heavy exertion, getting very excited)</p>	<p><b>Triggered, predictable</b> (typical for exertional breathlessness)</p> <p>Always triggered – certain level of trigger causes predictable severity of breathlessness</p> <p>“still able to breathe.”</p>	<p><b>Triggered, unpredictable</b></p> <p>Triggered but unpredictable, not related to level of trigger</p> <p>“it’s unpredictable.”</p>	<p><b>Non-triggered: attack-like</b></p> <p>Non-triggered (unpredictable), out-of-the-blue, no warning – quick onset, often severe</p> <p>“it hits you.”</p>	<p><b>Non-triggered or triggered: wave-like</b> (COPD specific)</p> <p>Gradually onset, mostly severe, “don’t panic”</p> <p>“You can’t stop it.”</p>
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# CHALLENGES FOR PHYSICIANS





- Barriers to communication and opportunities
  - Fear of opening the discussion
  - Time constraint
- Lack of knowledge and expertise among providers HOW to recognize patient in need
  - No clear guidelines
    - When to initiate in patient COPD diagnosis vs ILD vs Pulmonary hypertension
- How to engage in the conversation
  - How do I even bring it up
- WIDESPREAD misconception
  - Often hear palliation and hospice as interchangeable words within our own community
  - Are we giving up?
- **AVAILABILITY**

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Diffuse Lung Disease: Original Research

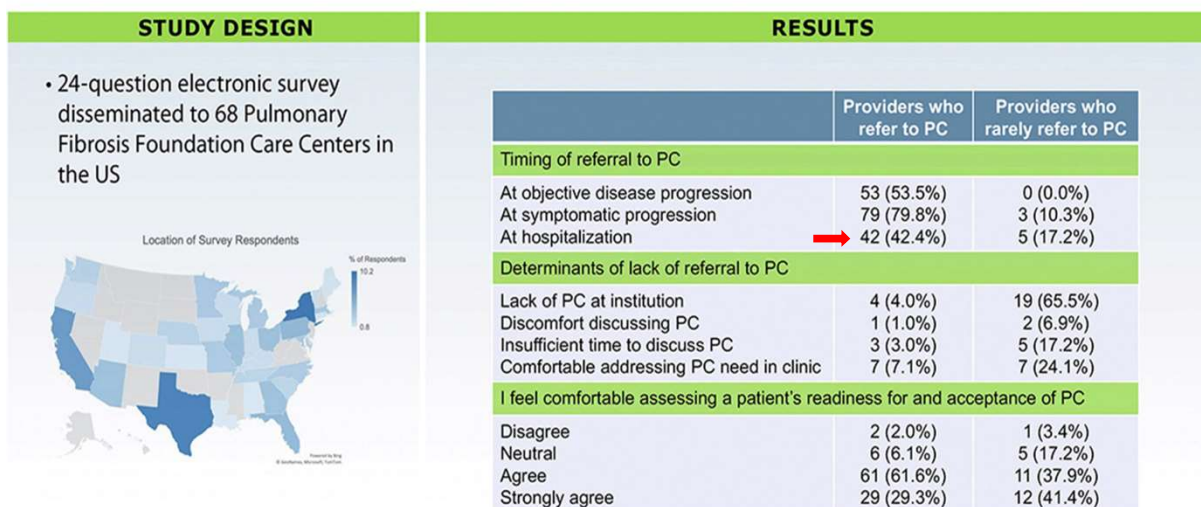
# Provider Perspectives on and Access to Palliative Care for Patients With Interstitial Lung Disease

The abstract of this paper was presented virtually at the American Thoracic Society Annual Meeting, May 14-19, 2021.

Rebecca A. Gersten MD <sup>a</sup>  , Bhavna Seth MBBS, MHS <sup>a</sup>, Luis Arellano BA <sup>b</sup>, Jessica Shore PhD, RN <sup>b</sup>, Lanier O'Hare MSN, CRNP <sup>c</sup>, Nina Patel MD <sup>d</sup>, Zeenat Safdar MD, FCCP <sup>e</sup>, Rachana Krishna MD <sup>f</sup>, Yolanda Mageto MD, MPH <sup>g</sup>, Darlene Cochran <sup>b</sup>, Kathleen Lindell PhD, RN <sup>h</sup>, Sonye K. Danoff MD, PhD <sup>a, b</sup>

Pulmonary Fibrosis Foundation\*

## What Are the Perspectives on Palliative Care (PC) in Interstitial Lung Disease (ILD) Providers?



- 128 completed surveys, all 68 Fibrosis Foundation Care Center Networks
- Referrals made at symptomatic/objective clinical disease progression
- Rarely referred due to lack of local palliative care (PC)
- Difficulties discussing
- Lack of STANDARD measures of disease specific symptoms, burden, health related quality of life.
- Discordance between self reported and actual use of services (inpt and outpt)

Most ILD providers exhibit knowledge regarding PC and agree with PC for their patients with ILD.

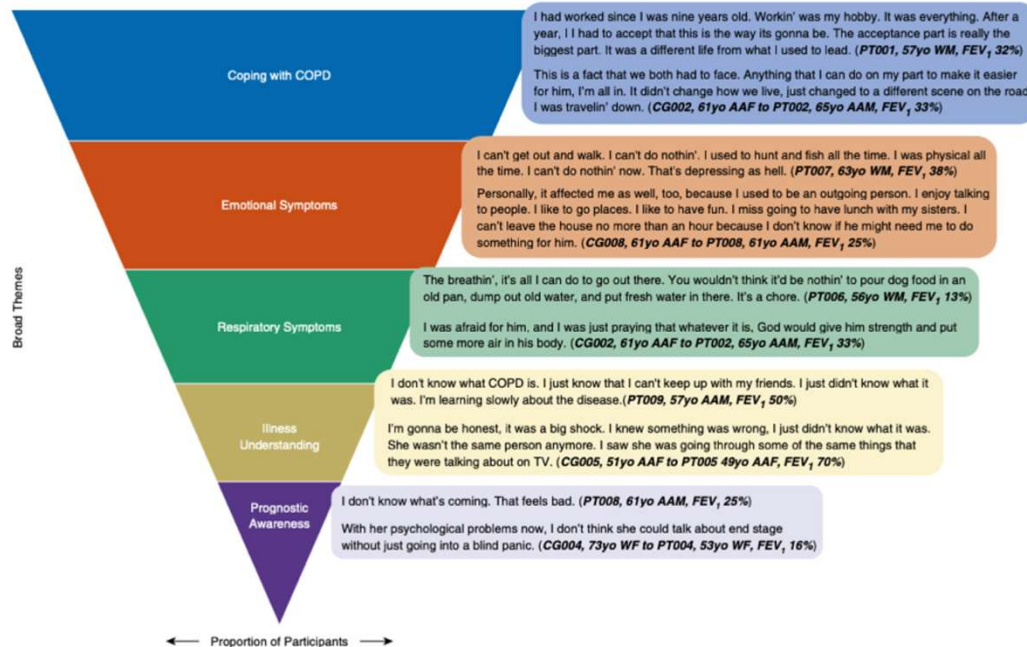


## MISSED OPPORTUNITY

Yes, that train has left the station. No, there won't be another one.



# CHALLENGES FOR PATIENTS



- 1.7% referral to palliative care when hospitalized
- Lack of accessibility
  - Current availability overburden or non-existing
  - Outpatient referrals?

## ORIGINAL RESEARCH

### **A Formative Evaluation of Patient and Family Caregiver Perspectives on Early Palliative Care in Chronic Obstructive Pulmonary Disease across Disease Severity**

Anand S. Iyer<sup>1,2,3</sup>, J. Nicholas Dionne-Odom<sup>4,5</sup>, Stephanie M. Ford<sup>3,4</sup>, Sheri L. Crump Tims<sup>4,5</sup>, Elizabeth D. Sockwell<sup>4,5</sup>, Nataliya V. Ivankova<sup>6,5</sup>, Cynthia J. Brown<sup>4,7</sup>, Rodney O. Tucker<sup>4</sup>, Mark T. Dransfield<sup>1,3,7</sup>, and Marie A. Bakitas<sup>4,5</sup>

<sup>1</sup>Division of Pulmonary, Allergy, and Critical Care Medicine, <sup>2</sup>Health Services, Outcomes, and Effectiveness Research Training Program, <sup>3</sup>Lung Health Center, <sup>4</sup>Division of Gerontology, Geriatrics, and Palliative Care, Department of Medicine, <sup>5</sup>School of Nursing, and <sup>6</sup>School of Health Professions, University of Alabama at Birmingham, Birmingham, Alabama; and <sup>7</sup>Birmingham Veterans Affairs Medical Center, Birmingham, Alabama

1. Understanding of palliative care: 30% have heard
2. Using standardized explanation: All participants were receptive
3. Timing of care: GOLD II-III
4. All stages:
  1. Common theme: Coping
  2. GOLD IV: prognostication awareness





WHEN SHOULD PALLIATION BE INTRODUCED IN COPD?



## A Qualitative Study of Pulmonary and Palliative Care Clinician Perspectives on Early Palliative Care in Chronic Obstructive Pulmonary Disease

Anand S. Iyer, MD, MSPH,<sup>1-3</sup> James Nicholas Dionne-Odom, PhD, RN,<sup>4,5</sup> Dina M. Khateeb, DO,<sup>6</sup>  
Lanier O'Hare, MSN, CRNP, NP-C,<sup>1</sup> Rodney O. Tucker, MD,<sup>4</sup> Cynthia J. Brown, MD, MSPH,<sup>4,7</sup>  
Mark T. Dransfield, MD,<sup>1,3,7</sup> and Marie A. Bakitas, DNSc, CRNP<sup>4,5</sup>

- 12 physicians (pulmonary and palliative)
- Shared concerns for misconception = end of life
- Pulm: symptom management
  - Concerns using benzodiazepines and opiates (self and by palliative care)
- Specialties agree need more consensus on role, referral criteria, delivery models
  - Operational barriers
    - Influx of early referral
    - Nurse led? Telehealth?
  - # hospitalization and emotional symptoms
- Advance planning is rare



WHEN SHOULD PALLIATION BE INTRODUCED IN ILD?



Review Article

## When should palliative care be introduced for people with progressive fibrotic interstitial lung disease? A meta-ethnography of the experiences of people with end-stage interstitial lung disease and their family carers

Evelyn Palmer<sup>1,2,3</sup> , Emily Kavanagh<sup>2</sup>, Shelina Visram<sup>3</sup>, Anne-Marie Bourke<sup>1,2</sup>, Ian Forrest<sup>1</sup> and Catherine Exley<sup>3</sup>



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- IPF still carry only 3-5 years life expectancy
- Often referred too late or not at all.
- 2022 PM study using 5 electronic database, 11 final studies (2013-2021) used with 118 pt and 118 caregivers reviewed: across 5 countries
  1. Information seeking
  2. Grief and acceptance
  3. Fear of the future

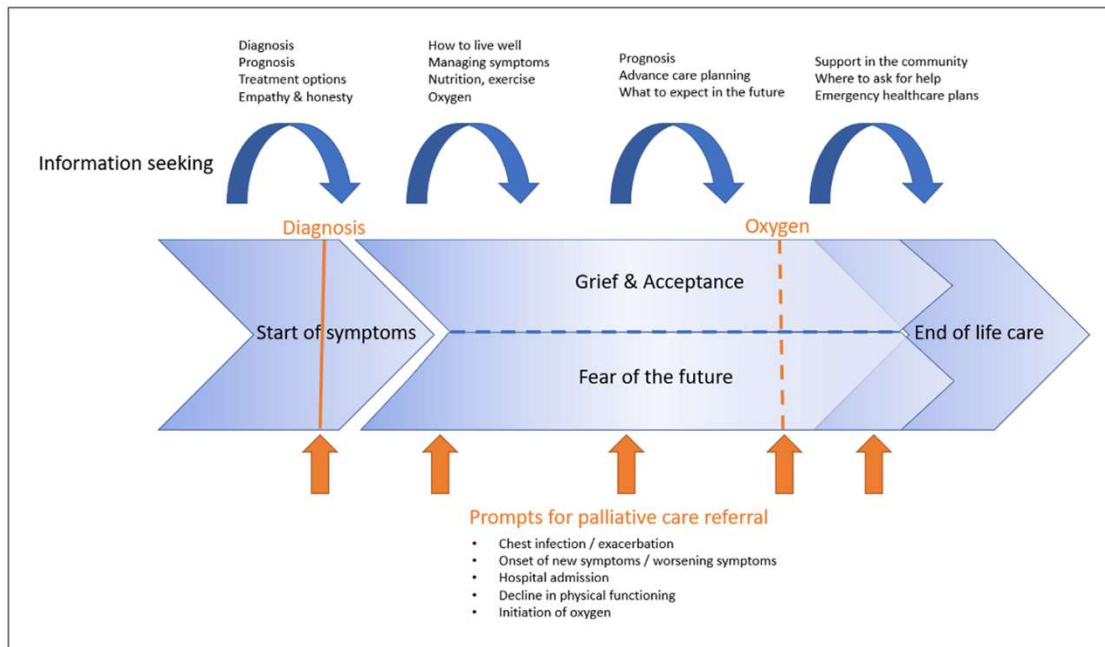


Figure 4. The patient journey and prompts for considering palliative care referral.

#### Information seeking:

- Frustration of length and complicated diagnosis process.
- Want more information at time of diagnosis
  - Preferably written
  - Self research information felt confusion and “worst case”
  - Dissatisfied with specialty clinic education
  - Stagnant info
  - Pulmonary rehab: positive intervention
- More confident patients able to shift perspective **to focus on living well** with disease
- More specific info about disease management at end of life
- Identifying desynchrony needs between patient and carers.



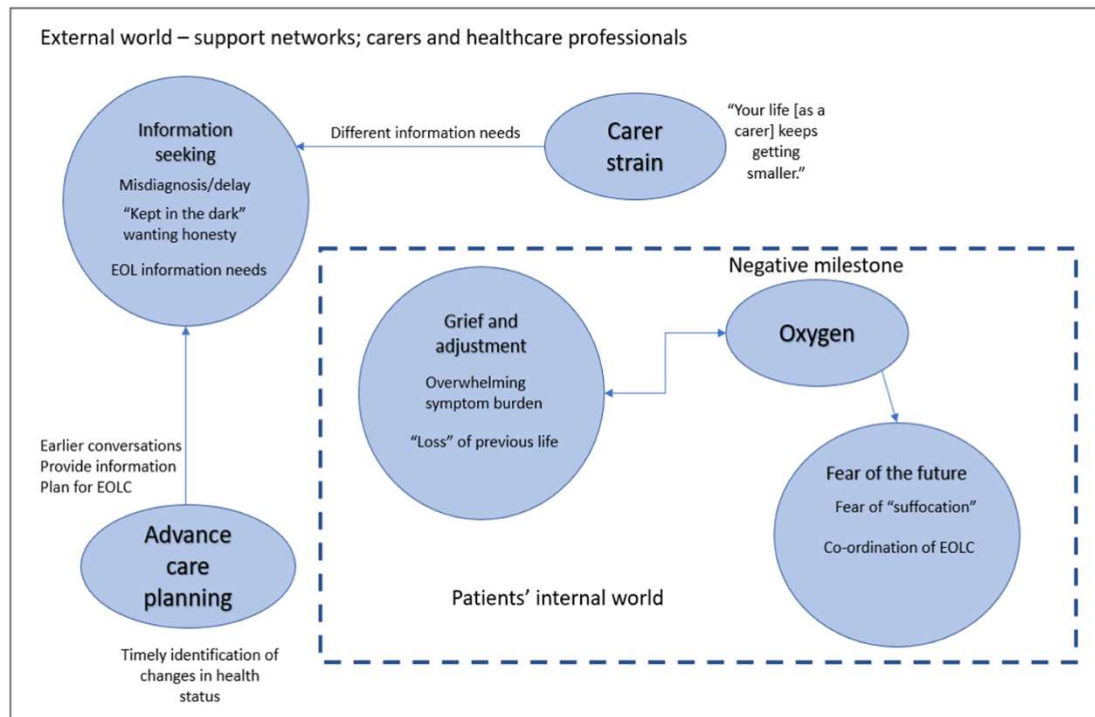


Figure 3. Conceptual model of lines of argument synthesis.

UNCLEAR optimal timing of palliative conversation.

- Patient's living alone want more detail and direct conversations
- Pace of information given varies
- Only small percentage preferred speaking with specialist

Grief adjustment

- Time to review and understand disease and impact

Fear of the future

- Not adequately addressed in clinic
- Oxygen viewed as negative milestone
- Accepting of fatality of disease but fear process
- Carers whose family died in the hospital appeared less prepared for the death



# ADVANCE LUNG DISEASE CLINIC

- Pulmonologists as gatekeepers
  - Bridging the gap
  - ? Re-imburement for physician
    - Save ~\$3,237/pt per hospital stay
- Early relationship development
  - Medical management
  - Education of illness
  - Normalizing conversations
  - Pulm rehab
  - Breathlessness plan
- Progress to more diverse need of social and emotional needs
  - Assist carers
  - Assist with further palliative referral and eventually hospice care



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*Original Article*

**The preferences of patients with chronic obstructive pulmonary disease are to discuss palliative care plans with familiar respiratory clinicians, but to delay conversations until their condition deteriorates: A study guided by interpretative phenomenological analysis**

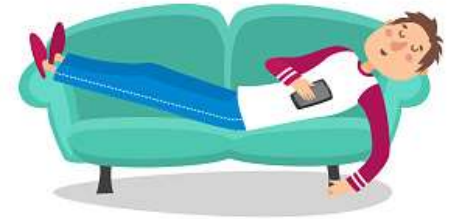
Nuno Tavares <sup>1,2,3</sup>, Katherine J Hunt <sup>3</sup>, Nikki Jarrett<sup>4</sup>, and Tom MA Wilkinson<sup>2,3,5</sup>

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> [J Palliat Care](#). 2022 Apr;37(2):125-133. doi: 10.1177/0825859719851486. Epub 2019 Jul 2.

## Longer Duration of Palliative Care in Patients With COPD Is Associated With Death Outside the Hospital

Valeri Kraskovsky <sup>1</sup>, Jaclyn Schneider <sup>2</sup> <sup>3</sup>, M Jeffery Mador <sup>4</sup> <sup>5</sup>, Karin A Provost <sup>4</sup> <sup>5</sup>





**Table 1.** Demographics of Currently Living Patients With Palliative Care as Compared to Deceased Patients Who Received Palliative Care.<sup>a</sup>

Demographics	Living With Palliative Care	Deceased With Palliative Care	P Value
Number of patients, (male:female)	30 (30:0)	114 (113:1)	
Race, (C:AA:other)	24:6:0	101:13:0	
Age at consult, mean (SD)	70 (8.4)	75 (9.1)	<i>P</i> = .03
FEV1%, mean (SD)	33% (14)	44% (20)	<i>P</i> = .005
DLCO (%), mean (SD)	36% (12)	42% (19)	<i>P</i> = .20
CWIC (IQR)	2 (2-4)	3 (2-4)	<i>P</i> = .04
Disease exacerbations in the year preceding palliative care consult, mean (SD)	1.5 (1.4)	1.1 (1.3)	<i>P</i> = .09

Abbreviations: AA, African American; C, Caucasian; CWIC, Charlson Weighted Index of Comorbidity; DLCO, diffusion capacity for carbon monoxide; FEV1%, forced expiratory volume in 1 second, percent predicted; IQR, interquartile range; SD, standard deviation.

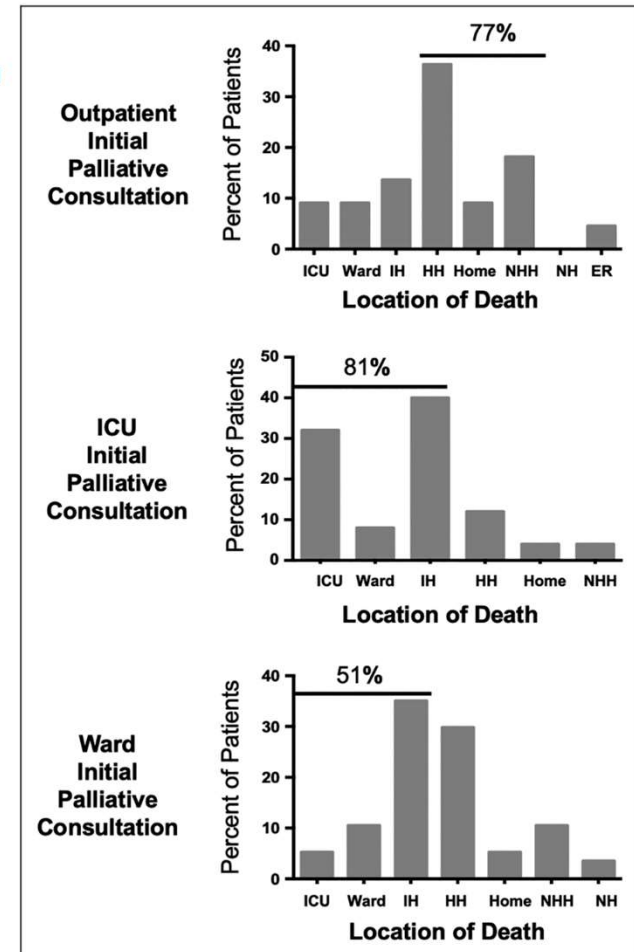
<sup>a</sup>Analysis by Mann-Whitney *U* test. FEV1% is reflective of severity of obstructive lung disease. Diffusion capacity for carbon monoxide is reflective of alveolar gas transfer efficiency. Reduction in DLCO, in the context of tobacco use and reduction in FEV1%, is suggestive of the presence of emphysema.

**Table 2.** Demographics of Deceased Patients Who Received Palliative Care as Compared to Those Who Did Not Receive Palliative Care.

Demographics	Deceased Without Palliative Care	Deceased With Palliative Care	P Value
Number of patients (male:female)	30 (28:2)	114 (113:1)	
Race, (C:AA:other)	28:2:0	101:13:0	
Age at consult, mean (SD)	75 (10)	75 (9.1)	<i>P</i> = .72
FEV1%, mean (SD)	48% (18)	44% (20)	<i>P</i> = .22
DLCO (%), mean (SD)	52% (15)	42% (19)	<i>P</i> = .01
CWIC (IQR)	6 (5-9)	3 (2-4)	<i>P</i> < .0001
Disease exacerbations in the year preceding palliative care consult, mean (SD)	0.6 (1.2)	1.1 (1.3)	<i>P</i> = .01

Abbreviations: AA, African American; C, Caucasian; CWIC, Charlson Weighted Index of Comorbidity; DLCO, diffusion capacity for carbon monoxide; FEV1%, forced expiratory volume in 1 second, percent predicted; IQR, interquartile range; SD, standard deviation.

<sup>a</sup>Analysis by Mann-Whitney *U* test. FEV1% is reflective of severity of obstructive lung disease. Diffusion capacity for carbon monoxide is reflective of alveolar gas transfer efficiency. Reduction in DLCO, in the context of tobacco use and reduction in FEV1%, is suggestive of the presence of emphysema.



**Figure 5.** Outpatient initial palliative care consultation was associated with death in a home-like environment. Patients whose initial palliative care contact occurred in the outpatient setting were more likely to die in a home environment (HH, NH, or Home) than any of the other groups. ER, emergency room; HH, home hospice; ICU, intensive care unit; IH, inpatient hospice; NH, nursing home; NHH, nursing home with hospice.

## National Consensus Project Domains for Quality Palliative Care Applied to COPD

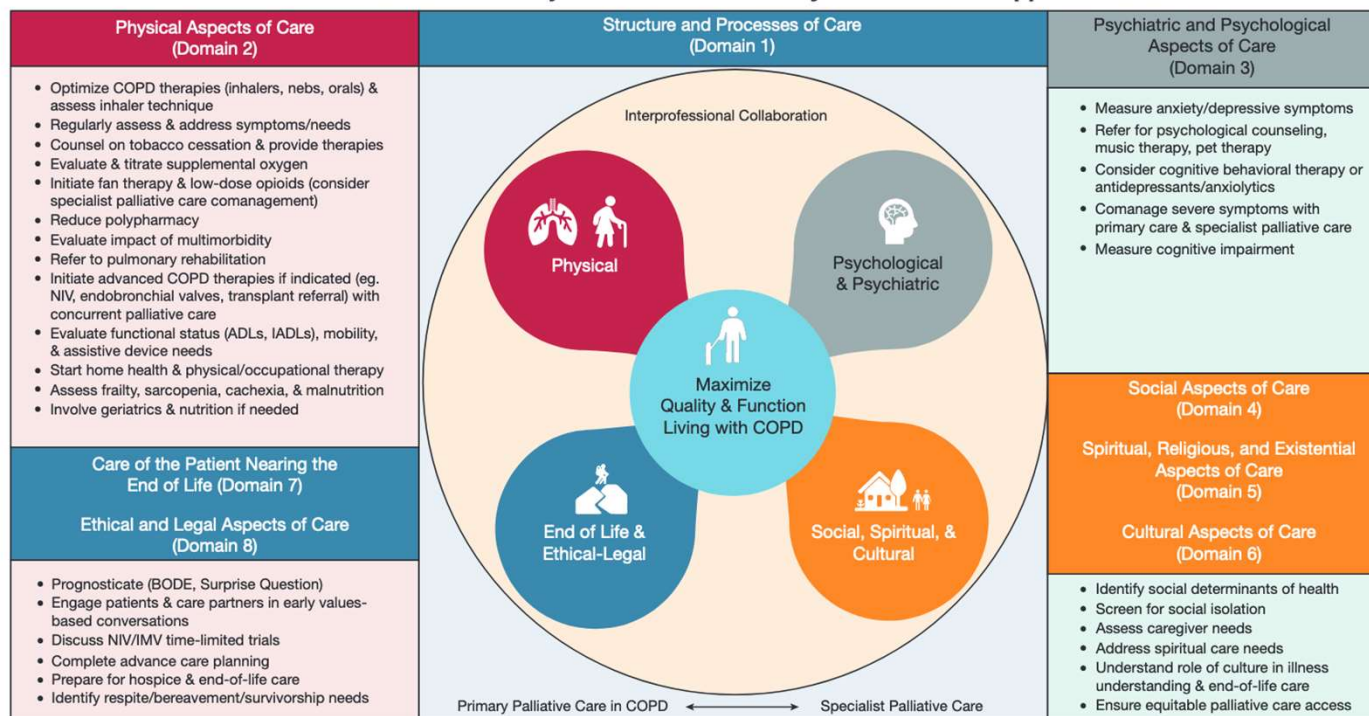


Figure 2 – Diagram showing the eight National Consensus Project Domains for Quality Palliative Care applied to COPD. We provide recommendations within each domain on how to integrate key aspects into routine COPD practice using interprofessional collaboration, a balance between primary and specialist palliative care, and a focus on maximizing quality of life and function. ADL = activities of daily living; BODE = Body Mass Index, Airflow Obstruction, Dyspnea, and Exercise Tolerance; IADL = instrumental activities of daily living; IMV = invasive mechanical ventilation; NIV = noninvasive ventilation.

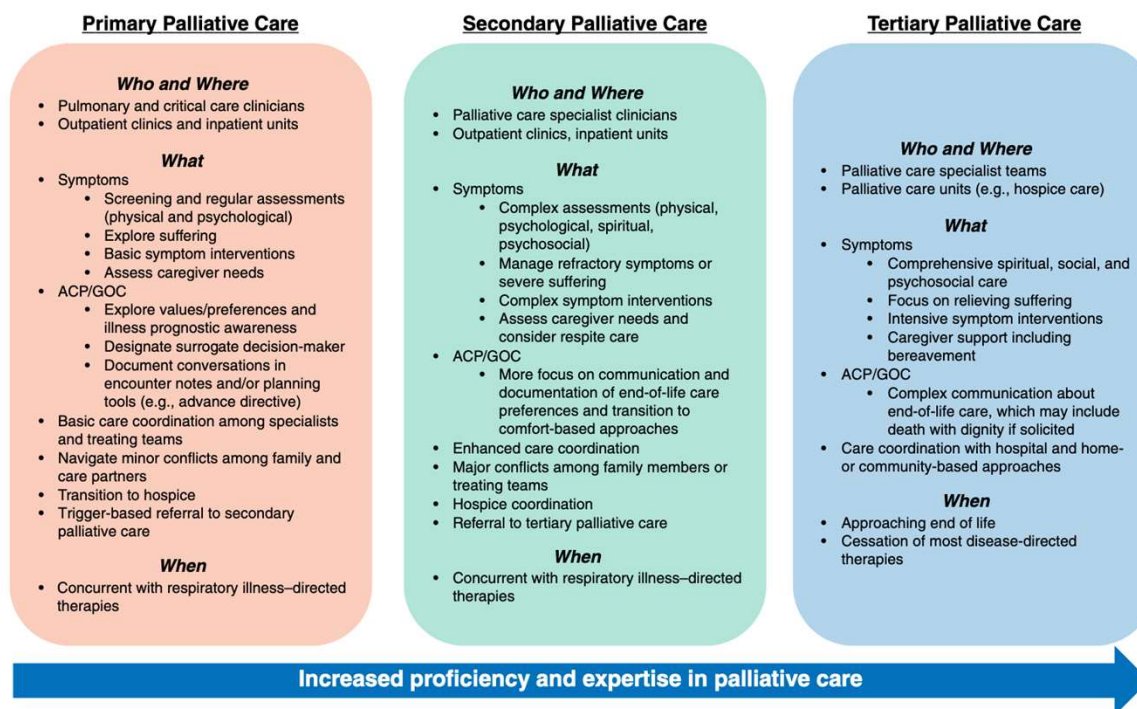
**TABLE 2 ]** How a Comprehensive COPD Palliative Care Assessment Can Enhance Traditional COPD-Focused Assessments

COPD-Focused Assessment	COPD Palliative Care Assessment
<p>Comprehensive COPD assessment:</p> <ul style="list-style-type: none"> <li>• Respiratory symptoms, exposures, tobacco use, vaccinations, inhalers, exacerbations</li> <li>• Spirometry, imaging (CT scan), blood biomarkers (eosinophils)</li> <li>• Supplemental oxygen evaluation</li> <li>• Pulmonary rehabilitation</li> </ul>	<p>Comprehensive COPD-palliative care assessment (patient and family):</p> <ul style="list-style-type: none"> <li>• Broader physical symptoms, pain, refractory breathlessness, cough (eg, CAT, SNAP)</li> <li>• Functional status (eg, ADL, IADL)</li> <li>• Emotional symptoms (eg, HADS, PHQ-9)</li> <li>• Nutrition, unintentional weight loss (eg, malnutrition screening tool)</li> <li>• Spiritual needs, social support</li> <li>• Family and care partner needs</li> </ul>
<p>Focused comorbidities: coronary artery disease, heart failure, pulmonary hypertension, OSA, gastroesophageal reflux disease</p>	<p>Broader evaluation of multimorbidity, frailty, and psychiatric conditions</p>
<p>COPD-directed therapies:</p> <ul style="list-style-type: none"> <li>• Inhalers, nebulizers</li> <li>• Oral medications (eg, azithromycin or phosphodiesterase 4 inhibitors)</li> <li>• Advanced therapies: endobronchial valves, NIV, lung transplant referral</li> </ul>	<ul style="list-style-type: none"> <li>• Broad assessment of medications and polypharmacy, opioids, antidepressants, and anxiolytics</li> <li>• Inhaler adherence and barriers such as cognitive impairment and physical limitations</li> <li>• Gaps in the setting after acute care and home safety evaluation after hospitalization</li> <li>• Home health</li> <li>• Physical and occupational therapy</li> </ul>
<p>Prognosis-based discussions</p>	<ul style="list-style-type: none"> <li>• Gauge prognostic awareness</li> <li>• Values-based discussions</li> <li>• Advance directives, living will, surrogate decision-maker</li> <li>• Respite and bereavement care needs</li> </ul>

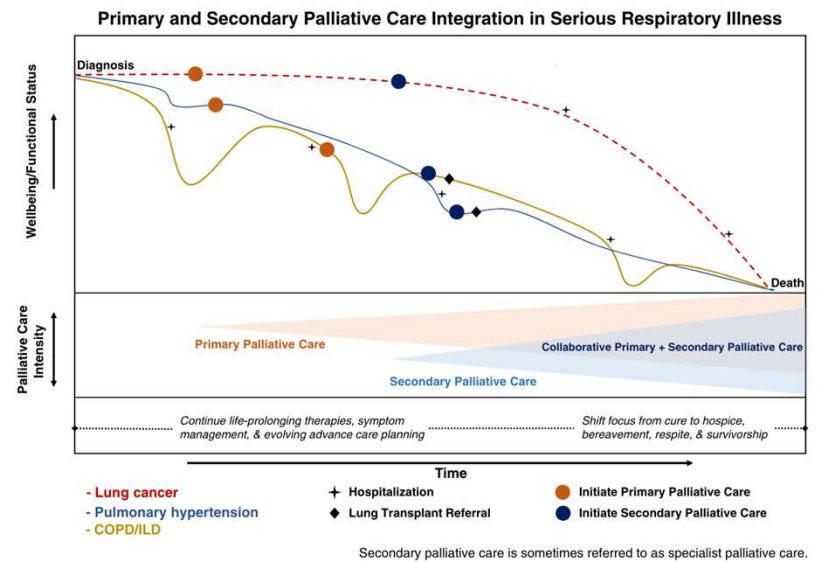
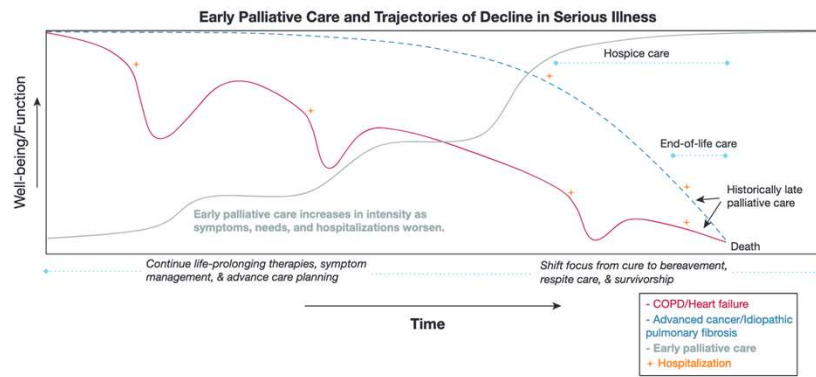
ADL = activities of daily living; CAT = COPD Assessment Test; HADS = Hospital Anxiety and Depression Scale; IADL = instrumental activities of daily living; NIV = noninvasive ventilation; PHQ-9 = Patient Health Questionnaire 9; SNAP = Support Needs Approach for Patients.



## AMERICAN THORACIC SOCIETY DOCUMENTS

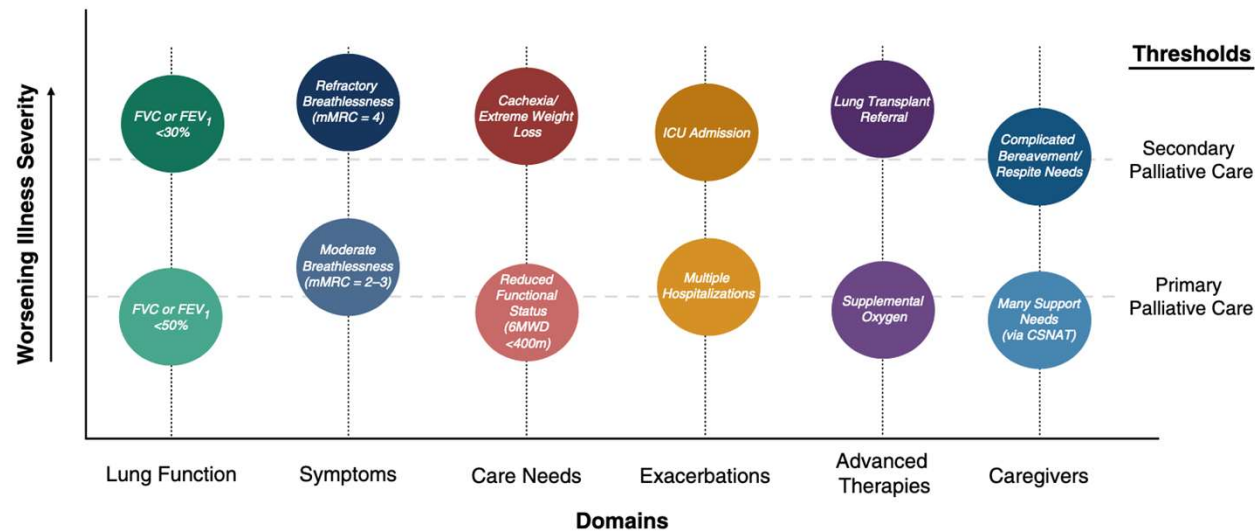


**Figure 1.** Levels of palliative care. This figure illustrates the who, where, what, and when of palliative care across three levels of increasing proficiency and expertise (primary, secondary or specialist, and tertiary palliative care). ACP = advanced care planning; GOC = goals of care.



## AMERICAN THORACIC SOCIETY DOCUMENTS

### Triggers for Initiating Primary and Secondary Palliative Care in Serious Respiratory Illness: The Levers Model



Secondary palliative care is sometimes referred to as specialist palliative care.



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