Quality of Life and Interstitial Lung Disease: 
*The role of palliative care along the trajectory of illness*

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Disclosure

- I have nothing to disclose.
Overview

- Review the differences between palliative care and hospice.
- Review how palliative care and hospice can help support a patient and family across the trajectory of ILD.
- Review how to access these services in the community.
Palliative care versus hospice:
Intertwined yet distinct

Palliative Care:
Clinical Interdisciplinary Care
Based on Need

Hospice:
Insurance Benefit
Based on Prognosis
An interdisciplinary approach to care:
Understanding the domains of suffering

Physical:
- Disease management
- Symptom management
- Functional status

Psychological:
- Coping in response to illness
- Dignity and control
- Managing grief and/or loss

Social and/or Cultural:
- Family/caregiver support
- Relationships
- Rituals, values

Spiritual:
- Sense of meaning
- Existential questioning
- Life transitions
Palliative Care: Accessing Primary and Subspecialty Palliative Care

Disease Targeted Therapy: Curative and modification of disease progression

Palliative Targeted Therapy: Management of symptoms, discussions re: care preferences

Hospitalization

Diagnosis Months to Years 6 – 12 Months Bereavement

Hospital-Based Palliative Care Consult Services

Out-Patient Palliative Care Clinics (often embedded in oncology)

Home-Based Palliative Care Programs (multiple structures)

Ambulatory Clinics and Primary Palliative Care

Access to Primary Palliative Care and Subspecialty Palliative Care
Putting a conceptual fire wall between PC and Hospice: How might that be helpful?

- Despite advances, 2 out of 5 patients with heart failure will die within five years of their diagnosis.

- Dementia is a life limiting illness with well understood markers of a shift to a shorter prognosis.

- ILDs are a heterogenous group of disorders and pose diagnostic and prognostic challenges.
Putting a conceptual fire wall between PC and Hospice: Managing diagnostic and prognostic uncertainty…and symptoms

Interstitial Lung Disease

- Autoimmune Related
- Smoking Related
- Occupation Related
- Medication Induced
- Hypersensitivity Pneumonitis
- Idiopathic Pulmonary Fibrosis
Serious Illness and GOC Conversations:
Intertwined yet distinct

- **Serious Illness Conversations**
  - Take place longitudinally.
  - Explore illness understanding, hopes/worries and goals/values.
  - Clarify what matters most to a patient should their health worsen.

- **Goals of Care Conversations**
  - A medical decision that needs to be made in response to a change in a patient’s clinical status or to a shift in a patient’s goals/values.

The Relationship:
Serious Illness and Goals of Care Conversations

Serious Illness:
Exploring Goals/Values and Hopes/Worries *Longitudinally*

GOC:
Medical Decision Making at a *Point in Time*
The Relationship: Serious Illness and Goals of Care Conversations

At the time of diagnosis: what’s your understanding of your illness (SIC)?

Disease progression: discussion about burden and benefits of second-line chemotherapy (GOC)

Functional decline: What are you hoping for? What worries you? What matters most? (SIC)

Goals & Values

CHF exacerbation: discussion and evaluation for a left ventricular assist device/LVAD (GOC)

Goals of Care

Multiple hospitalizations for CHF: What are you hoping for? What worries you? What matters most? (SIC)

Time

Function

Cancer

CHF, COPD, dementia
Earlier conversations about patient values and goals: The link to better serious illness care

- Increased goal-concordant care
  - Understanding what matters most when talking about clinical decision making (medications, starting 02, trials)
- Improved quality of life and patient sense of well-being
  - Addressing each of the domains of suffering
- Better patient and family coping
  - Lower rates of depression and anxiety
- Fewer hospitalizations
  - Anticipatory planning for expected clinical complications
- More frequent and earlier enrollment in hospice care
  - Anticipatory planning for when disease modifying therapies are no longer providing benefit

Mack JCO 2010; Wright JAMA 2008; Chiarchiaro AATS 2015; Detering BMJ 2010; Zhang Annals 2009
Involving subspecialty Palliative Care:
Where along the trajectory of illness and by whom?

- Where along the trajectory of illness?
  - Well...
    - I would say at the beginning with an introduction as part of the care team although we’re not there yet.
  - Second best option:
    - if hospitalizations increase, medications stopped or adjusted because not as effective, initiation of O2.
Involving subspecialty Palliative Care: Where along the trajectory of illness and by whom?

- **By whom?**
  - **Hospital-based:**
    - Symptom management, clarify goals/values, community resources.
  - **Clinic-based:**
    - Most palliative care clinics are (currently) embedded in oncology although they may be able to accommodate a handful of visits.
  - **Home-based:**
    - Available resources not well understood which leads to confusion;
    - Most programs are a part of a home health or hospice agency.
      - The MGB HBPaIC Program is NOT part of home health or hospice. MGB HBPaIC is a clinical service line within the MGH Division of Palliative Care and Geriatric Medicine.
      - The Hospice and Palliative Care Federation of MA (HPCFMA) has a hospice locator on its website, and you can select for palliative care and town to find resources.
    - There is NO home-bound requirement. Some programs are linked to an agency’s home health services which *do require* a patient to be homebound.
Thank you:
Questions, thoughts?

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