



MASSACHUSETTS
GENERAL HOSPITAL

DIVISION OF PALLIATIVE CARE
AND GERIATRIC MEDICINE

Quality of Life and Interstitial Lung Disease: *Palliative care along the trajectory of illness*

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Project Echo for Interstitial Lung Disease
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Disclosure


- I have nothing to disclose.

Goals for this morning:

- The practice of palliative care:
 - Definition
 - Access
- Functional status:
 - Important marker of QoL and symptom burden
 - Objective assessments across clinic visits

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



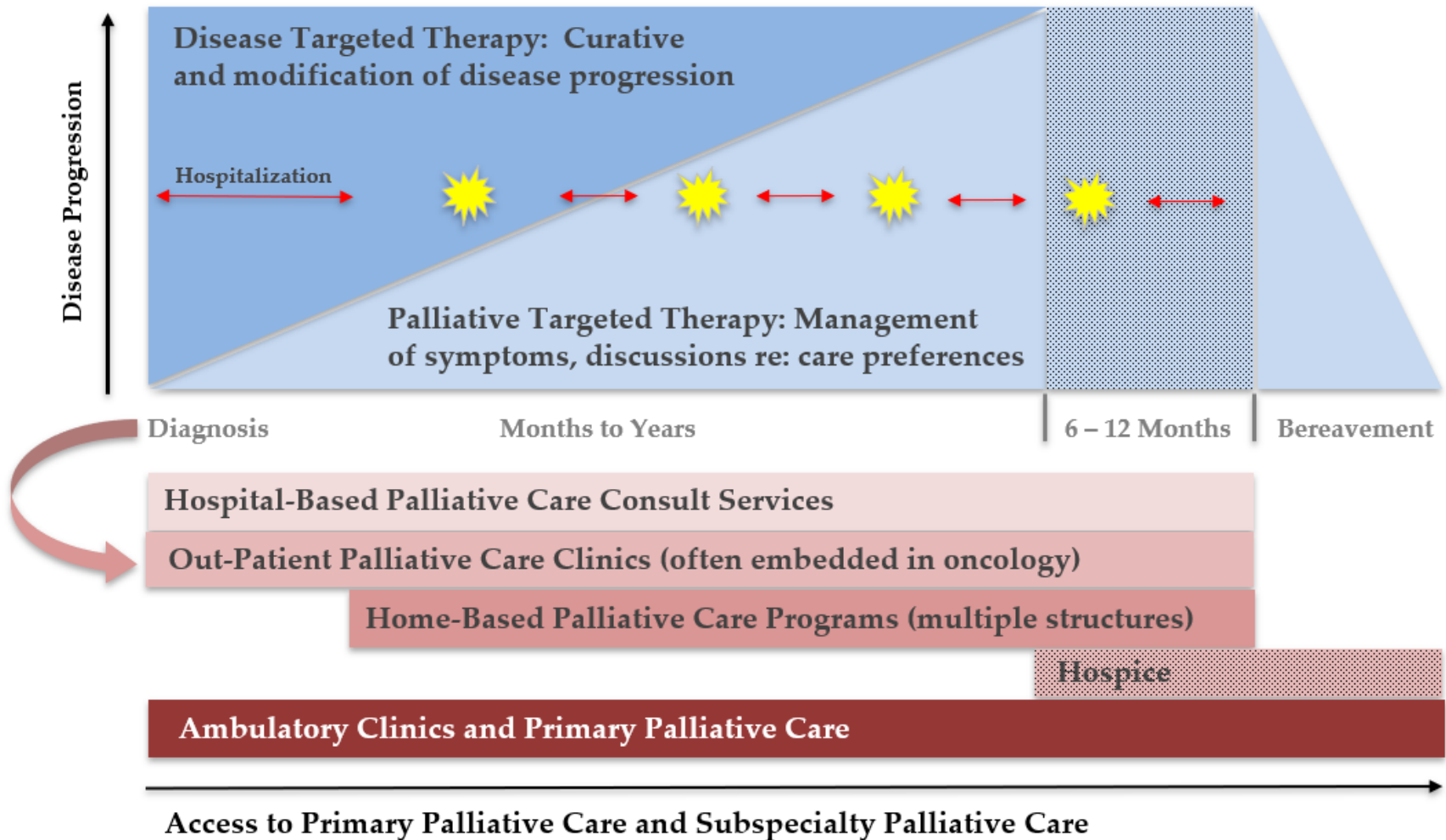
Social and/or Cultural:

- Family/caregiver support
- Relationships
- Rituals, values

Spiritual:

- Sense of meaning
- Existential questioning
- Life transitions

Palliative Care: Accessing Primary and Subspecialty Palliative Care



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.
 - Taylor, Clare J., et al. "Trends in survival after a diagnosis of heart failure in the United Kingdom 2000-2017: population-based cohort study." *BMJ* 364 (2019).
- Dementia is a life limiting illness with well understood markers of a shift to a shorter prognosis.
 - Sampson, E.L., et. al., 2018. *Living and dying with advanced dementia: a prospective cohort study of symptoms, service use and care at the end of life. Palliative medicine*, 32(3), pp.668-681.
- ILDs are a heterogenous group of disorders and pose diagnostic and prognostic challenges.
 - Guler, S.A., et al, 2018. Heterogeneity in unclassifiable interstitial lung disease. A systematic review and meta-analysis. *Annals of the American Thoracic Society*, 15(7), pp.854-863

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.

Schulz, VM et al. "Beyond Simple Planning: Existential Dimensions of Conversations With Patients at Risk of Dying From Heart Failure." JPSM 2017.

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

Functional Status:

Objective measures and relationship to QoL



Gradual restriction of activity

Reporting prior level of activity

Lived experience versus imaging

Functional Status:

Objective measures and relationship to QoL



Number of sit-to-stands before patient experiences dyspnea

Timed get-up-and-go (TUG) and patient rating of dyspnea

Distanced walked before O2 sat declines or patient reports dyspnea

Pulling it all together:



Palliative care is not hospice and Serious Illness Conversations are not always about GOC.



The prognostic uncertainty inherent in ILD should drive both primary and subspecialty palliative care further upstream in the management of these patients.



Use of functional assessment tools may allow for early identification of declines in oxygenation and objective measures of the burden of dyspnea.

Thank you:

Questions, thoughts?

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