End of Life Pearls for Primary Care

2015 Massachusetts Chapter Scientific Meeting
November 7, 2015
• *I intend to live forever, or die trying.*
  -----Groucho Marx

• *I am not afraid of death, I just don't want to be there when it happens.*
  -----Woody Allen
Objectives

- Improve understanding of role of palliative care consultation
- Improve understanding of advanced care planning discussions and completing MOLST
- Improve understanding of hospice in the community setting
Case

- 79 year old woman with HTN, CHF, venous insufficiency, osteoarthritis admitted to the hospital with severe heart failure exacerbation. This is her fourth ED visit for shortness of breath in the past 6 months. She notes that she has had 20 lb wt loss over last 6 months, increasing epigastric pain, nausea, and loss of appetite.
Case

- Imaging shows large mass on head of pancreas and liver masses suspicious for metastatic disease
- The primary team consults Oncology and Palliative Care
In an ideal world, would the timing of this palliative care consult be considered:

A. Too early?

A. Too late?

B. Just right?
Too late! Why?

• 79 yo with multiple co-morbidities, including a life-limiting illness
• 4 ED visits in 6 months for dyspnea
• Now with pain, nausea, anorexia in the context of likely metastatic disease
What is palliative care?

• Palliative care is specialized medical care for people living with serious illness. It focuses on providing relief from the symptoms and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family.

• Palliative care is provided by a team of palliative care doctors, nurses and other specialists who work together with a patient’s other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.
Palliative Care as Terminal Care
(old model)

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November 7, 2015
Palliative Care as part of Total Care (newer model)

Disease Modifying Therapy

Palliative Care

Hospice

Bereavement

Acute

Chronic

Advanced

Death

Diagnosis Life-Limiting Illness

Last Hours

Life Closure

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November 7, 2015
Palliative care operating principles

• Maximize comfort
  • Address “total pain”

• Match treatment plan to patient’s priorities

• Reshape goals of treatment as disease progresses

• Provide longitudinal support to patients and families

• Help people live as well as possible for as long as possible
Misconception #1

Palliative care is for patients who have run out of treatment options.

- The World Health Organization advocates early involvement of palliative care in tandem with therapies intended to prolong life, describing palliative care as an essential part of cancer control.
- American Society of Clinical Oncology recommends that palliative care be integrated early in the illness for patients with metastatic cancer and/or high symptom burden.
- The benefit is increasingly recognized by a variety of specialty societies calling for early palliative care integration, e.g., American Thoracic Society, American College of Chest Physicians.
Misconception #2
Palliative care means choosing quality over quantity of life.

Palliative Care = 11.6 months
Standard Care = 8.9 months

NEJM 2010
Misconception #3

Referring patients to palliative care takes away hope.
Does referring to palliative care take away hope?

No.

- Prospective, multi-site longitudinal cohort study of patients with cancer followed 332 patients and caregivers from enrollment until death, and caregivers during bereavement.
  - 37% patients reported having EOL discussions before baseline.
  - No association with increased MDD or worry.
  - EOL discussion were associated with less aggressive medical care near death and earlier hospice referrals. Aggressive care is associated with worse patient QoL and worse bereavement adjustment.

- Survey of 194 parents of children with cancer in 1st year of treatment, and their oncologists
  - Findings: Receiving greater number of elements of prognostic disclosure = greater hope, even when prognosis was poor.
  - Conclusion: Disclosure of prognosis by physician can support hope, even when prognosis is poor.

Palliative care take home points

- Helps with stress and symptoms associated with serious illness
- Can be helpful at any age, any stage of illness
- Can be given concurrently with curative treatment
- Can enhance both quality and quantity of life
- Can support hope in seriously ill patients and their families
Case

- Patient returns to her PCP for hospital follow up and recounts what happened in the hospital and expresses how overwhelmed and sad she is with this new information.
- She asks her PCP: “what should I do?”
Advanced Care Planning

• This is the perfect time to have a goals of care discussion – recent changes in the patient’s health care needs set the tone for re-evaluating appropriate goals of care
• Ask yourself “Would I be surprised if this patient died within the next year?”
• Assess patient’s understanding (“What do you already know about your condition?”), emotional state (“What does it mean to you?” “What has the past year been like for you?” “What do you worry about?”)
• and readiness to engage in the discussion

• Determine patient preferences – what and how much information the patient wants to know (“Some of my patients prefer hearing only the big picture, whereas others want a lot of details. Which do you prefer?”)

• What if they are not ready?

• Appeal to benefits of having the conversation such as reducing the burden of substitute decision-makers and maintaining control of their future care
End of Life Trajectories

Reaching a decision

- Invite HCP to be present in discussion
- Ensure open disclosure of prognostic information and the risks/benefits of treatment
- Assess preferred mode of decision making
  - Informed consumer model – patient decides
  - Paternalistic model – health care team decides
- Involve the family whenever possible (and to the extent desired by patient)
• Although goals of care discussions will improve common understanding, they do not guarantee that conflict over the most appropriate care plan will not arise.
• When patients are capable of directing their own care, invite them to take part in decision-making.
• When patients are incapable of decision-making or defer the responsibility to others, HCPs have a responsibility to act in accordance with patients’ stated or understood beliefs, values and wishes.
• Make the distinction between the HCP “doing what the patient would want me to do” and from “doing what I want for the patient.”

You JJ, et al. CMAJ 2014
How should these decisions be documented?

- MOLST
  - Highly visible, transportable
  - Discuss the risks/benefits of life sustaining therapy

- Include values that have informed these choices by using examples and the patient’s own words
Case

- Patient is seen at home over the next 2 weeks by her hospice interdisciplinary team which includes an MD, RN, LicSW, and Chaplain
- She is anxious: “I don’t want to suffer”
- She asks: “how much time do I have?”
Hospice

• Formally established in US in 1982 as Medicare Benefit
• 4 levels of care with capitated payment: Respite, Routine, General Inpatient, Continuous Care
Hospice Team

- **Primary Care Physician**
- Hospice interdisciplinary team: RN, SW, Chaplain, HHA, Volunteers
- Bereavement support for 13 months
- MD available for consultation and ongoing benefit recertification, Medicare compliance
- Occasionally specialists are still involved for disease management
Why Hospice

  - 67% survey participants expressed a wish to die at home
  - < 25% of Massachusetts residents die at home
  - >70% of Massachusetts residents die in hospitals or nursing homes
Care Transitions at EOL

In patients with cancer, care is transitioned to hospice at the end of life.

In patients with COPD, care is transitioned to acute care hospital at the end of life.

JAMA. 2013 Feb 6;309(5):470
When to order hospice

• When the focus of care has shifted from cure to care and comfort.

• When pain and symptom management is needed for the patient.

• When support is needed for family and caregivers.
How to Order Hospice

- Referring **physician** (not mid-level provider) must provide Certification of Terminal Illness (COTI)
- Best guess that patient likely to die within 6 months if the disease continues on its natural course
- No penalty for patients living beyond 6 months
- Hospice Medical Director provides second COTI base on chart review and RN assessment
How much time?

- Palliative Performance Scale (PPS) 100-0
- Ambulation: Full to Bed Bound
- Activity Level: Normal to None due to extensive disease
- Self-care: Full ADLS to Dependent on ADLS
- PO Intake: Normal to minimal
- Level of consciousness: Normal to Confused to Drowsy
  - Score >60, 100-200 days life expectancy
  - Score < 30, 30-5 days life expectancy
What does hospice provide?

- Symptom management: pain, dyspnea, anxiety
- Medical equipment
- Spiritual support
- Psychosocial support
- Bereavement support
Case

- The patient’s symptoms are managed with
  - Low dose methadone with short-acting morphine for breakthrough pain or dyspnea
  - Haloperidol 0.5 mg q 8 hours for nausea
- Oxygen, hospital bed, walker, and bathroom safety rails are provided in the home
- Home health aid assists patient with ADLs 5 days per week
- Social worker meets with patient and family regularly to help with plan of decline and pre-bereavement support
CODING Tips

• Advanced care planning *(effective by CMS January 2016)*
  • 99497 for first 30 minutes
  • 99498 for additional 30 minutes
• CARE PLAN OVERSIGHT (CPO)
  • VNA
    • 99374 for 15 to 29
    • 99375 for 30 minutes or more
• Hospice Care
  • 99377 for 15 to 29 minutes
  • 99378 for 30 minutes or more
• Patient care visit (need to add modifier)
  • Hospice related
  • Non-hospice related