

#### **Understanding Hospice and Palliative Care**

Aziz Ansari DO, SFHM, FACP
Associate Professor of Medicine
Associate Director, Division of Hospital Medicine
Medical Director, Loyola Home Hospice
aansar1@lumc.edu

#### **Disclosures**

No significant financial relationships to disclose

#### **Objectives**

- Define Hospice and differentiate from Palliative care
  - Understand what defines Palliative Care
  - Explain the Medicare Home Hospice Benefit and its limitations

 Identify common misconceptions of Hospice Care

#### Let's Begin With A Case

- 62 year old woman with metastatic lung cancer
- Receiving second line chemotherapy with decent functional status and you expect her prognosis to be about a year because she is young and no other chronic medical problems
- The oncologist refers to Palliative Care Clinic for symptom management saying:
  - "I am going to refer you to Palliative Care who specialize in end of life care"
  - "This is a team that will talk about goals of care and help control your pain"
  - "But don't worry...it's not hospice"
- The patient is scared thinking "this is over" because of the conversation and when she "Googled" Palliative care, hospice was almost always mentioned in conjunction with palliative care

# Palliative Care: A Real Need For Image Re-Branding



### Palliative Care and Proximity Of Words: What Patients See and Hear

Palliative Care is a specialized medical care for people living with advanced illnesses. It focuses on symptom management. While hospice and palliative care both focus on relief of symptoms, palliative care goes beyond end-of-life care. It is different from hospice, where a patient has to have a 6 month or less prognosis, in that it can be offered at anytime of an advanced illness

# Palliative Care And Proximity Of Words: People will Remember the "Negative"

 Proximity of "Hospice" and "terminal" and "6" month prognosis" with palliative

- "Advanced Illness"
  - Synonymous with "death and dying" or "end stage" or "terminal"
- "Goals of care"
  - ???→Is not the Goal always to care??



#### What is Palliative Care? Let's Try This Again

- A recognized specialty with an expertise in the medical care for people with serious illnesses provided by an interdisciplinary team of physicians, advanced practice nurses, and other specialists
- It focuses on relief of symptoms, pain and stress of a serious illness
- It is supportive care in collaboration with the patient's other physicians that aims to improve the quality of life for both the patient and family and ensures that care is being delivered in accordance with the patient's values and preferences



## What is Palliative Care? One-Liner

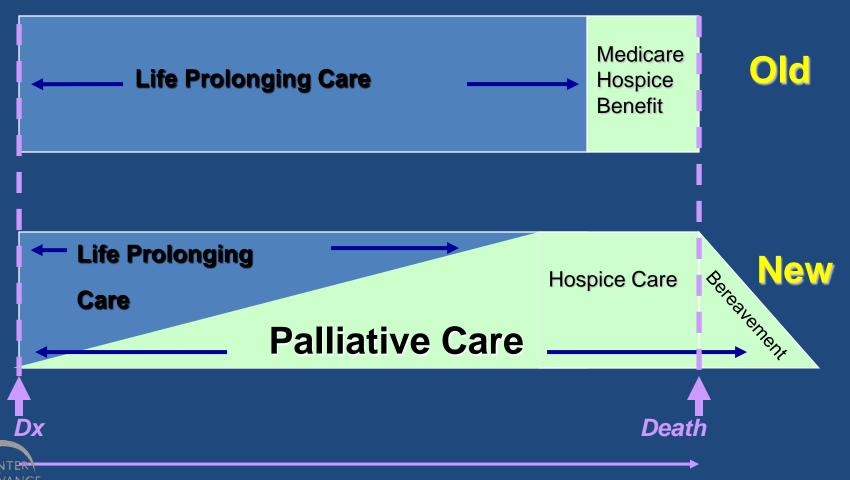
Palliative Care can be delivered at any stage of a serious illness and can be provided together with curative and life prolonging interventions

#### **BOTTOM LINE:**

We need to talk about what Palliative Care IS and NOT what it is not



#### **Conceptual Shift for Palliative Care**



Courtesy of Diane Meier, MD, Making The Case 2010



### The Effects of PC on Quality of Patient Care: A Systematic Review of the Evidence

- Improved pain and symptom distress
- Improved quality of life
- Higher patient satisfaction
- Decreased hospital utilization
- Improvement in Advance Care Planning
- Increased likelihood of death occurring outside the hospital
- No change in mortality and possible an improvement in mortality rates



#### Early vs. Late Palliative Care

 UCSF study looking at outcomes on solid tumor cancer patients receiving early PC (> 90 days) or late PC ( < 90 days) before death</li>

Table 2. Quality and Utilization Measures among Decedents (n = 922)

Outcome measure	Early palliative care, n=93 (%)	Late palliative care, n=204 (%)	p
Utilization in the last month of life			
Inpatient admission	31 (33)	135 (66)	< 0.01
Intensive care unit admission <sup>a</sup>	5 (5)	40 (20)	< 0.01
Emergency department visit	32 (34)	110 (54)	0.02
Emergency department, >1 visit <sup>a</sup>	5 (5%)	28 (14)	< 0.01
Deaths			
In hospital	14 (15)	70 (34)	0.001
30-day mortality cases	31 (33)	135 (66)	< 0.001
Within 3 days of hospital discharge	15 (16)	80 (39)	< 0.001
Direct costs in the last 6 months of life			
Inpatient care	\$19,067	\$25,754	0.006
Outpatient care	\$13,040	\$11,549	0.85
Combined inpatient and outpatient care	\$32,095	\$37,293	< 0.01

aNational Quality Forum Measure/ Bold p value = statistically significant.



### PC and Quality Do early PC interventions help improve QOL and Survival?

 Those assigned to earlier intervention had statistically significant improvement in QOL scores with a decrease in the control group

 Statistically significant decreased levels of major depression in the palliative care group

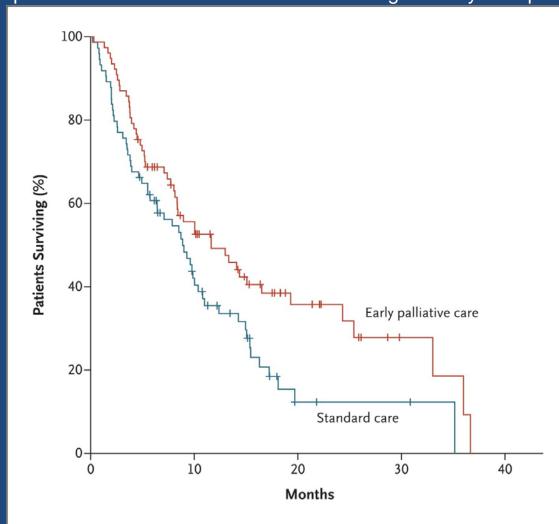




#### **Aggressiveness of Care and Survival**

Kaplan–Meier Estimates of Survival According to Study Group

- Even with less aggressive end of life care, the PC group had a longer survival
  - •Median survival 11.6 months vs. 8.9 months
    (p=0.02)→2.7 months
- PC group had more frequent documentation of resuscitation preferences





#### **Case Continued**

Disease progresses despite chemotherapy

 Your patient has a great rapport with the palliative care team and is seen regularly in clinic

 10 months later her quality of life is waning due to poor performance status and she is asking if she should enroll in hospice



#### **Palliative Care as Compared with Hospice**

Table 1. Palliative Care as Compared with Hospice.*			
Characteristic	Palliative Care	Hospice	
Model of care	Interdisciplinary team, including physicians, nurses, social workers, chaplains, and staff from other disciplines as needed; primary goal is improved quality of life	Interdisciplinary team, including physicians, nurses, social workers, chaplains, and volunteers, as dictated by statute; primary goals are improved quality of life and relief of suffering (physical, emotional, and spiritual)	
Eligibility	Patients of all ages and with any diagnosis or stage of illness; patients may continue all life-prolonging and disease-directed treatments	Patients of all ages who have a prognosis of survival of ≤6 mo, if the disease follows its usual course; patients must forgo Medicare coverage for curative and other treatments related to terminal illness	
Place	Hospitals (most common), hospital clinics, group practices, cancer centers, home care programs, or nursing homes	Home (most common), assisted-living facilities, nursing homes, residential hospice facilities, inpatient hospice units, or hospice-contracted inpatient beds	
Payment	Physician and nurse practitioner fees covered by Medicare Part B for inpatient or outpa- tient care; hospital teams are included with- in Medicare Part A or commercial insur- ance payments to hospitals for care epi- sodes; flexible bundled payments under Medicare Advantage, Managed Medicaid, ACOs, and other commercial payers	Medicare hospice benefit; standard hospice benefit from commercial payers is usually modeled after Medicare; Medicaid, although coverage varies by state; medication costs are included for illnesses related to the terminal illness	

<sup>\*</sup> ACO denotes accountable care organization.



### HOSPICE IS NOT A PLACE

#### **Conceptual Understanding of Hospice**

- Hospice is a philosophy and concept of care
  - Not a place or a building
  - Not a hospital "service"
- The concept evolved from the ethical selfobligation of caregivers and as a response to the "medicalization" of death

 Hospice embraces death as a natural part of life in contrast to conventional medicine, in which death is often the ultimate failure

#### **Conceptual Understanding of Hospice**

 Hospice will not seek to hasten or postpone death and more treat the process as a natural part of the cycle of life

 The clinical goals are symptom relief and comprehensive support of the patient and family

 Psychological and spiritual pain are as significant as physical pain

#### **Conceptual Understanding of Hospice**

Addressing all three requires an interdisciplinary team

 Patients, their families, and their loved ones are the unit of care

 Bereavement care is critical to supporting surviving family members and friends



### What Does the "Medicare Hospice Benefit" Cover?

- Interdisciplinary team care enacted in 1982
- Medical equipment related to the palliation of the terminal illness
- Medications for symptom management related to the terminal illness
- Around the clock availability of staff for phone consultation
- Hospice Agencies do NOT provide for 24 hour in-home care or caregiver support

#### **Levels of Hospice Care**

Routine Home Care

Continuous Home Care

Respite Inpatient Care

General inpatient care

#### Levels of Hospice Care: The Home

- Patient's Home
  - Family and friends remain primary caregivers
  - Hired caregivers
    - Cost NOT covered by hospice or medical insurance
  - Home can be at a nursing home

# Hospice in a Nursing Home Why the Barriers?

- Long term care facilities
  - Services = Home services
  - Therefore Medicare Hospice Benefit does NOT pay room and board expenses at a skilled nursing facility since the routine care benefit is intended for HOME use

 IL Medicaid DOES pay for Room and Board at a nursing home if a patient is enrolled in hospice under the Medicaid Hospice Benefit because Medicaid pays for custodial care at a facility

#### Levels of Hospice Care: Continuous Home Care

- Periods of *intense* nursing needs in a patient's home > 8 hours
  - 51% of this care MUST be provided by a RN and the rest can be provided by home health aides
  - Not commonly invoked

### Levels of Hospice Care: Respite Care

 To relieve family members who are caring for the individual

- No more than 5 consecutive days at a time per benefit period
  - Often this takes place in a nursing home

## Levels of Care General Inpatient Care (Inpatient Hospice)

- Can be provided in a hospital or free standing inpatient hospice facility
  - Hospitals can have a dedicated "unit" or on a private floor bed ensuring nursing competencies
- Available to manage a crisis that can not be managed at home
  - Must require a SKILLED need that necessitates being in the hospital like uncontrolled pain or terminal agitation
  - Custodial issues are NOT a skilled need
  - Imminent death is NOT appropriate for inpatient hospice

#### **Hospice Interdisciplinary Team Members**

- Hospice Medical Director
- Attending Physician
- Hospice Nurse
- Social Worker
- Home Health Aide
- Spiritual Caregiver
- Bereavement Counselor
- Therapists
- Pharmacists
- Volunteers

#### Different types of Hospice Physicians

- Medical Director
  - Direct relationship with the hospice

- Attending of record
  - Physician most involved with the treatment of the hospice diagnosis
    - PCP, Oncologist, other...

### Hospice Interdisciplinary Team: Nurses

- Spend significant time with the patient, family, caregivers
- Hold expertise in assessing symptoms
  - Verbal and non-verbal
  - Physical and emotional comfort
- Anticipate immediate care needs
- Provide support and education to patient and family
- Visit patient as clinical condition warrants

### Hospice Interdisciplinary Team: Social Workers

- Psychosocial issues can be immense
  - Financial concerns
  - Family matters
  - Environmental concerns
  - Grief
  - Counseling

#### **Hospice Interdisciplinary Team**

- Spiritual Caregivers (Chaplains)
  - Address and coordinate spiritual needs

Address religious needs if applicable

Differentiating spirituality from "religiosity"

### Hospice Interdisciplinary Team: Volunteers

 Volunteers required by the Medicare Hospice Benefit

- Undergo screening, training
  - Offer companionship
  - Run errands
  - Give caregivers a chance to leave home
  - Light household chores
  - Bereavement visits

### Hospice Interdisciplinary Team: Bereavement Counselors

 Bereavement services provided to family up to one year after patient's death

Develop and facilitate support groups

Coordinate memorial services

#### **Case Continued**

Everything seems to be OK and the process has started for hospice but the son-in-law, a Beverly Hills attorney, flies in from Southern California and has "lots of questions"

#### **Objectives**

- Define Hospice and differentiate from Palliative care
  - Understand what defines Palliative Care
  - Explain the Medicare Home Hospice Benefit and its limitations

 Identify common misconceptions of Hospice Care

Patients MUST be DNR

Patients can not be on tube feeds nor get IV fluids

 Patients lose their PCP, oncologist and/or can not go to their office

Infections can not be treated on hospice

Medications can not be continued in hospice

Hospice patients cannot get dialysis

Patients need to be home bound

 Patients can never come back to the hospital and must always remain in hospice

 Physician goes to jail if they certify patients and they live past 6 months

Patients really need to die within 6 months

Patients can not get physical therapy in hospice

Hospice means giving up hope

 Hospice is a place where there are rows of patients in cots waiting to die

### **Questions or Comments?**

