Understanding Palliative Care and Hospice

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Disclosures

• No significant financial relationships to disclose

Objectives

• Define Palliative Care (PC)

• Understand the impact Palliative Care can have on Quality and Healthcare Delivery

• Differentiate Palliative care from Hospice

• 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 an ECOG of 1 (fully ambulatory) but has some dyspnea upon exertion and pain
- 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 and shortness of breath”
  - “But don’t worry…it’s not hospice”
- The patient is scared thinking “it is over” because of the conversation and when she Googled “Palliative care”, hospice was almost always mentioned in conjunction with palliative care

What Are The Roadblocks?

- Provider misunderstanding of PC
- Patient/Family fears of PC
- Lack of cultural humility
- Time limitations
- Providers “Fighting” the resistance
- Lack of true dialogue

Palliative Care:
A Real Need For Image Re-Branding
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 it not always our goal 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
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.

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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

Old

Life Prolonging Care

Medicare Hospice Benefit

New

Life Prolonging Care

Palliative Care

Hospice Care

Dx Death

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Courtesy of Diane Meier, MD, Making The Case 2010.
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True or False:
Early Palliative Care Involvement may Improve Mortality

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 and costs
- Improvement in Advance Care Planning
- Increased likelihood of death occurring outside the hospital
- No change in mortality and possible an improvement in mortality rates

Kavaliratos JAMA 2016
Disparity of Healthcare Costs

- As of 2011, 5% of patients in the United States accounted for 60% of healthcare spending
- 30% of Medicare expenditures are attributed to 5% of beneficiaries who die each year
- About 1/3 of the expenditures in the last year of life is spent in the last month

Economics of Palliative Care

- Meta analysis looking at six studies
- 93% of patients analyzed discharged alive
- PC Consultation within 3 days of admission and estimated direct cost savings per case:
  - $4251 per case for cancer diagnoses
  - $2105 per case for non-cancer diagnosis
  - Greater reduction in costs with 4 or more comorbidities

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

<table>
<thead>
<tr>
<th>Outcome measure</th>
<th>Early palliative care, n=92 (%)</th>
<th>Late palliative care, n=208 (%)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Utilization in the last month of life</td>
<td>10 (35)</td>
<td>14 (71)</td>
<td>&lt; 0.01</td>
</tr>
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<td>Hospital stay and inhospitalisation</td>
<td>10 (35)</td>
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<td>&lt; 0.01</td>
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<td>Emergency department/1 visit</td>
<td>7 (25)</td>
<td>29 (14)</td>
<td>&lt; 0.01</td>
</tr>
<tr>
<td>Discharge to hospital</td>
<td>7 (25)</td>
<td>76 (37)</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Medicare hospital cases</td>
<td>7 (25)</td>
<td>76 (37)</td>
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<tr>
<td>Direct costs in the last 6-months of life</td>
<td>$15,907</td>
<td>$22,754</td>
<td>0.006</td>
</tr>
<tr>
<td>Inpatient care</td>
<td>$12,894</td>
<td>$12,569</td>
<td>0.85</td>
</tr>
<tr>
<td>Outpatient and outpatient care</td>
<td>$12,894</td>
<td>$12,569</td>
<td>0.85</td>
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*Actual Quality of Care Measures/Early vs. Late Palliative Care
Consequences of a Late Referral to Palliative Care

Serious Adverse Outcomes for Bereaved Caregivers:
- Compared to care at home with hospice,
  - Care in ICU associated with 5.6X family risk of Post Traumatic Stress Disorder; and
  - Care in hospital associated with 8.8X family risk of prolonged grief disorder

— Wright A et al. Place of death: Correlation with quality of life of patients with cancer and predictors of bereaved caregivers mental health. JCG 2010, Sept 13, epub ahead of print

Does Having a EOL Discussion Help with Use of Burdensome Interventions?

| Table 1. Medical Care Received in the Last Week of Life by End-of-Life Discussions |
|---------------------------------|---------|--------|----------------|
|                                 | Total   | Yes    | No     |
| Medical care received (n=200)   | 126 (63) | 117 (58) | 9 (5) |
| ICU admission                   | 31 (16)  | 25 (12) | 6 (3) |
| Transfers to ICU                | 30 (15)  | 24 (12) | 6 (3) |
| Respiratory                     | 16 (8)   | 12 (6)  | 4 (2) |
| Chemotherapy                    | 14 (7)   | 11 (5)  | 3 (2) |
| Feeding tube                     | 26 (13)  | 21 (11) | 5 (2) |
| Outpatient hospice use           | 316.36 ± 62.32 | 213.4 ± 42.43 | 102.96 ± 39.95 |

Increase in burdensome interventions:
- Transitions in last 3 days of life
  - 70% of these transitions were to hospice
  - 1/3 of these hospice admissions were to General Inpatient hospice care
  - Increase in multiple hospitalizations in last 30 days of life from 2000 to 2009

Changes in Health Care Utilization: Did We Really Improve?

<table>
<thead>
<tr>
<th></th>
<th>2000</th>
<th>2005</th>
<th>2009</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. of decedents</td>
<td>270,202</td>
<td>291,019</td>
<td>290,262</td>
</tr>
<tr>
<td>Deaths in acute care hospitals, % (95% CI)</td>
<td>32.5 (32.4-32.6)</td>
<td>35.9 (35.7-36.1)</td>
<td>24.5 (24.5-25.0)</td>
</tr>
<tr>
<td>ICU use in last month of life, % (95% CI)</td>
<td>24.3 (24.1-24.5)</td>
<td>26.3 (26.1-26.5)</td>
<td>25.2 (25.0-25.5)</td>
</tr>
<tr>
<td>Hospital use at time of death, % (95% CI)</td>
<td>21.6 (21.4-21.7)</td>
<td>30.3 (30.1-30.5)</td>
<td>32.3 (32.0-32.5)</td>
</tr>
<tr>
<td>Health care transitions in last 90 d of life, % (95% CI)</td>
<td>2.1 (1.9-2.3)</td>
<td>2.8 (2.6-3.0)</td>
<td>3.1 (2.9-3.3)</td>
</tr>
<tr>
<td>Health care transitions in last 3 days of life, % (95% CI)</td>
<td>10.3 (10.1-10.6)</td>
<td>12.8 (12.3-13.2)</td>
<td>14.2 (14.0-14.5)</td>
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</table>
Terminal Cancer Patients
Do early PC interventions help improve QOL and Survival?

- Those assigned to earlier intervention had statistically significant improvement in QOL scores and decreased levels of depression
- 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

**Case Continued**

- Disease progresses despite chemotherapy
- Your patient has a great rapport with the palliative care team and is seen regularly in clinic and opts out of more chemotherapy
- 3 months later her performance status is worse with an ECOG of 3 (>50% of time in bed) and she is asking if she should enroll in hospice

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HOSPICE IS NOT A PLACE

It is intense palliative care that requires a terminal condition and a physician certification of a 6 month prognosis.

It is an insurance benefit that allows more services and medications to be provided in the home to improve quality of life.

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Palliative Care as Compared with Hospice

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<tr>
<th>Characteristics</th>
<th>Palliative Care</th>
<th>Hospice</th>
</tr>
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<tbody>
<tr>
<td>Model of Care</td>
<td>Interdisciplinary team, including physicians, nurses, social workers, spiritual counselors, and other health professionals, with the primary goal being improved quality of life.</td>
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<tr>
<td>Eligibility</td>
<td>Patients of all ages with any diagnosis or stage of illness. Palliative care focuses on symptom relief and end-of-life care.</td>
<td>Patients of all ages who have a terminal illness. Palliative care focuses on symptom relief and end-of-life care.</td>
</tr>
<tr>
<td>Place</td>
<td>Hospitals, physician offices, hospices, home settings, community settings.</td>
<td>Hospices, hospice centers, home settings.</td>
</tr>
<tr>
<td>Payment</td>
<td>Physician and nurse practitioners are covered by Medicare Part B for insulin or other injectable drugs. Other drugs are often covered by Medicare Part D or by other insurance. Out-of-pocket expenses are often covered by hospice care. Family members may pay for home health aids, supplies, or other expenses.</td>
<td>Medicare hospice benefit. Expense for hospice patients is usually covered by Medicare, although some expenses related to care may be covered by personal insurance, Medicaid, or other commercial payers.</td>
</tr>
</tbody>
</table>

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Conceptual Understanding of Hospice

- Hospice is a philosophy and concept of care—Not a place or a building.
- Hospice will not seek to hasten death.
- The clinical goals are symptom relief and comprehensive support of the patient and family as a whole unit.
- Psychological and spiritual pain are as significant as physical pain.
- 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

Hospice Interdisciplinary Team Members

- **Hospice Nurse**
- **Hospice Medical Director**
- **Attending Physician**
- **Social Worker**
- **Counseling services:**
  - Bereavement
  - Spiritual Counseling
- **Home Health Aide**
- **Therapists**
- **Volunteers**

Levels of Hospice Care

- **Routine Home Care**
- **Continuous Home Care**
- **Respite Inpatient Care**
- **General inpatient care**
Levels of Hospice Care:
Routine Home Care

- Family and friends remain primary caregivers
- Hired caregivers
  - Cost NOT covered by hospice or medical insurance
- Home can be at a nursing home
- Nurse can visit as many times in the week as necessary based on medical necessity

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
- Medicaid pays for custodial care so a nursing home (room and board) is covered if a patient is enrolled in hospice

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
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
• 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”
• Must require a SKILLED need that necessitates being in the hospital like uncontrolled pain or terminal agitation that can not be managed at home
  – Custodial issues are NOT a skilled need
  – Imminent death is NOT appropriate for inpatient hospice

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
  – Hospice medical director can fill in as the Attending of record
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Hospice: Fact or Fiction

• Patients can not be on inotropes for advanced heart failure on hospice

• Hospice means giving up hope

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

Hospice: Fact or Fiction

• Once a patient opts out of hospice, they can not re-enroll in hospice

• Patients MUST be DNR

• Patients can not be on tube feeds nor get IV fluids

• Patients can not see their PCP or specialist in clinic
### Hospice: Fact or Fiction

- Infections can not be treated on hospice
- Only medications used in hospice are opiates, benzodiazepines and anti-psychotics
- Hospice patients cannot get dialysis
- Patients need to be home bound

### Hospice: Fact or Fiction

- Patients can never come back to the hospital
- Patients must opt out of hospice to get hospitalized for an unrelated condition to the terminal illness
- Physician goes to jail if they certify patients that live past 6 months

### In Summary

- Remember to divorce palliative care from hospice in the same sentence
- Palliative care should be offered at any stage of a serious illness
- Hospice is simply a form of palliative care for patients who have a terminal illness allowing for more benefits to be delivered at home