Finding Meaning and Purpose in Palliative Care

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PALLIATIVE CARE – WHAT IS IT?

Palliative Care - What is it?

• Palliative Care
  – deriv. from pallium, “to cloak”
  – How do you pronounce “palliative”?

Palliative Care

• medical specialty focused on improving overall quality of life for patients and families facing serious illness
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Palliative Care

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Palliative Care

- Services
  - Experienced communication to ensure treatment matches patient preferences
  - Coordination of care and help in navigating the often-complex health care system
  - Relief of suffering
    - physical, psychological, social, spiritual
  - Enhanced quality of life
  - Support for patients and families

Palliative Care - What is it?

- Palliative Care
  - Provided by interdisciplinary team

Palliative Care - What is it?

- Palliative Care
  - Provided wherever the patient is
    - Inpatient
    - Home
    - Skilled nursing facility
MYTH:
PALLIATIVE CARE = HOSPICE

Hospice = Palliative Care for the terminally ill

Hospice
• Place
• Philosophy of care
• Payment benefit

PALLIATIVE CARE – WHY NOW?

Palliative Care – Why now?

Changes in Lifespan over Two Millennia

Lifespan (yrs)

Cause of death: Infection, trauma, childbirth

Year (C.E.)
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**Palliative Care – Why now?**

**Changes in Lifespan over Two Millennia**

- **Cause of death: Chronic illness**
- **Cause of death: Infection, trauma, childbirth**

**Lifespan (yrs)**

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<th>500</th>
<th>1000</th>
<th>1500</th>
<th>2000</th>
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<tbody>
<tr>
<td>Lifespan (yrs)</td>
<td>20</td>
<td>40</td>
<td>60</td>
<td>80</td>
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**Palliative Care – Why now?**

- **The promise of Modern Medicine**
  - Health maintained through most of life
  - Morbidity compressed
  - Peaceful death

**Palliative Care – Why now?**

- **The reality of Modern Medicine**
  - US adults healthy slightly longer, but
  - Spend more time in progressive debility
  - 85% die in hospitals or NH
  - At time of death
    - 75% non-ambulatory
    - 30% incontinent
    - 40% cognitively impaired

**Trajectory of life (ideal)**

**Trajectory of incurable illness - Cancer**

**Trajectory of incurable illness - Dementia**

BMJ 2005;330:1007-1011

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**Palliative Care – Why now?**

Trajectory of incurable illness – COPD, CHF, etc

MYTH: PALLIATIVE CARE IS ONLY AVAILABLE AT A FEW HOSPITALS

- 1988: First U.S. hospital-based palliative care program
- 2008: Palliative care recognized as a medical sub-specialty by ABMS
- 2011: 88% of hospitals with 300+ beds have Palliative Care teams
- 2014: 84% of hospitals with 50+ beds have Palliative Care teams


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**MYTH:**
PALLIATIVE CARE IS ONLY FOR PEOPLE WITH CANCER

**MYTH:**
PALLIATIVE CARE IS ONLY FOR THE ELDERLY

Palliative Care – Who Needs It?
- Common diagnoses appropriate for referral
  - Severe COPD
  - Severe CHF
  - Dementia
  - Cancer
  - Kidney failure
  - Liver failure
  - ALS
  - Neurologic disease

**PALLIATIVE CARE – WHEN?**

Palliative Care – When?

BMJ 2005;330:1007-1011

Hospice: Diagnosis

BMJ 2005;330:1007-1011

Palliative Care: Diagnosis

Hospice: Death

IF NOT NOW..... WHEN?
MYTH: PALLIATIVE CARE HASTENS DEATH

MYTH: PALLIATIVE CARE MEANS GIVING UP TREATMENT

Palliative Care

% of focus

Time

Curative Care

Palliative Care

MYTH: PALLIATIVE CARE MEANS GIVING UP MY PHYSICIAN(S)

Palliative Care Consultation

Finding Purpose in Palliative Care
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**Finding Purpose in Palliative Care**

- Palliative Care
  - Advance Care Planning
  - Support for caregivers
  - Psychosocial and spiritual support
  - Relief of physical symptoms

**Relief of physical symptoms**

- Dyspnea
- Pain
- Anxiety
- Depression
- Poor sleep
- Fatigue
- Anorexia
- Constipation

**Relief of physical symptoms**

- Uncontrolled symptoms
- Progressive functional decline
- Poor quality of life
- Increasing dependence on caregivers
- Increasing use of healthcare system

**Physician-patient disconnect**

- Most physicians do not discuss prognosis with patients
- Most patients want information regarding prognosis


**Advance Care Planning**

- Best-case scenario
  - Patient, family and clinician discuss together treatment options and preferences and document patient’s wishes
Advance Care Planning

• Reality
  – 99% of patients desire AD discussions
  – Only 19% had AD discussions
    • Only 15.2% had discussed life support
    • Only 14.3% thought MDs understood their wishes

• Barriers
  – Providers have limited time
  – Providers have limited expertise
  – No one is in charge
  – No one wants to discuss patient’s declining health and approaching death
  – Providers prefer to offer comfort, hope, medical technology rather than “let people die”
  – Patients and families believe that resuscitation will restore health

What do patients want?
Rated as extremely important
• not being kept alive on life support with “little hope for meaningful recovery”
• symptom relief
• provision of care after discharge
• trust and confidence in physicians
• not being burden on caregivers

Finding Purpose in Palliative Care

Caring for caregivers

• Challenges
  – Advance Care Planning
  – Continuity of care
  – Information and communication
  – Emotional, psychological, spiritual support
  – Education / Training for patient management
  – Access to support services
  – End of life care
  – Follow-up bereavement support

• Assume care in sudden and extreme circumstances
• Little understanding about disease and how to provide care
• Costly in terms of time, money, energy
• Increased risk of mental and physical health problems and death

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