Palliative Care: Myths vs. Reality in the New Era of Healthcare

Purpose

- The participant will learn how palliative medical care services need to be explored as viable options in reducing re-hospitalizations and in effectively managing residents at the end stages of chronic disease. We will discuss how the future of healthcare reform and palliative medical care services will focus on quality of life, a resident-centered plan of care, and support the resident and their loved ones through the process of understanding the prognosis.

Objectives

- Describe medical-based Palliative Care in the new era of healthcare delivery.
- Explain the myths and reality of a medically-based, physician-driven, Palliative Care program.
- Explain COPD, CHF and dementia in the new healthcare era.
**Palliative Care**

- **Definition (World Health Organization)**
  Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

**Palliative Care - Definition**

- Palliative care is specialized medical care for people with serious illnesses. It focuses on providing patients with relief from the symptoms, pain, 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 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.
- http://www.getpalliativecare.org/whatis/

**Palliative Care - Definition**

- Palliative care focuses on symptoms such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite, difficulty sleeping and depression.
- It helps you have more control over your care by improving communication so that you can better understand your choices for treatment.
- Affirms life and regards dying as a normal process, and intends neither to hasten nor postpone death.
- http://www.getpalliativecare.org/whatis/
Aspects of Outpatient Palliative Care

- Billed under Part B as a fee-for-service consultation visit
- Covers physician extenders such as Nurse Practitioners
- Has a benefit for Social Work (not Spiritual Care...yet)

Myths of Palliative Care

- Does NOT change the patient’s pharmacy benefit or exclude medications, oncological treatments or surgical procedures
- Is NOT equivalent to hospice, which is a Medicare A benefit reimbursed on a daily rate
- Does NOT change the patient’s primary provider

Patient “goals of care”

- BEFORE decisions have to be made, these inquiries need to occur, regardless of the questioner:
  - What is their understanding of their prognosis?
  - Informed consent
  - What are their concerns about what lies ahead?
  - Medical, financial, and psychosocial fears
  - Who do they want to make decisions when they can’t?
  - Advance Care Planning
Top needs of terminally ill patients (Sharma et al, 2012)

Top 5
1. Sharing your thoughts and feelings with people close to you
2. Finding meaning in your experience of illness
3. Finding hope
4. Worries you have about your family
5. Finding peace of mind

Bottom 5
- Someone to bring you spiritual texts such as Koran, Bible, Torah, etc.
- Visits from fellow members of your faith community
- Visits from a hospital chaplain
- Death and dying
- Getting in touch with other patients with similar illnesses

Many clinicians are not comfortable giving prognostic information

Focus the discussion on treatment

Give no prognostic information
- In one survey, 23% of physicians planned to give no prognostic information to their cancer patients (Lamont et al. Annals Int Med 2001; 134:1096)

Discuss prognosis in vague or overly pessimistic terms
- 60% of oncologists did not discuss code status, advance directives, or hospice until there were no more treatments to give (Kuechting et al. Arch Intern Med 162:1954-1962)
Prognostication for the Doctor

Would you be surprised if this patient died within the next year?

Lynn, 2005

Utilization of Palliative Services

- To, TH et al. (Intern Med J, 2011)
  - One-third of all patients admitted to hospital had goals of care consistent with palliative care but only 20% of these were offered consultation.

- Berger et al. (Arch Intern Med 2011)
  - Only 8% of California hospitals offer an outpatient palliative service.
When to Utilize Palliative

- Palliative care consultation services
  - In response to a physical symptom(s) of progressive life-limiting illness
  - If patient or provider are unsure about continuing aggressive care
  - To establish the patient's goals of care when in doubt
  - To add psycho-social support for patients with coping difficulties
  - To assist with financial resources if needed

How Dying Has Changed - US

<table>
<thead>
<tr>
<th>1900</th>
<th>2009</th>
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<tbody>
<tr>
<td>1. Pneumonia</td>
<td>1. Heart Disease</td>
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<tr>
<td>2. Tuberculosis</td>
<td>2. Cancer</td>
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<tr>
<td>3. Diarrhea and Enteritis</td>
<td>3. Stroke</td>
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Life expectancy: 47 years
Disability: Days to Weeks
78.7 years (2009)
Weeks to Years

Why Palliative is Needed

- Nearly 1 in 2 Americans has a chronic disease
- Projected to increase – 117 million Americans by 2020; 171 million by 2030
- Americans are living longer – from 2010 to 2030, 65 years old increase 13.2% to 20%
- 90% seniors have at least one chronic disease, 77% have 2
- 5% of all patients are responsible for HALF of all US healthcare costs
- 27% of all Medicare spending is in the last 30 days of life
- Chronic Conditions: Making the case for ongoing care, RWJ – 9/2004 update
Why Palliative is needed

- Trying to provide long-term chronic care management in a system designed to deliver short-term acute care
- We need to go from an acute and reactionary model...
- ...to a planned and proactive approach

Palliative Care Outcomes

- Temel, et al. (NEJM 2010)
  - Randomized controlled trial of outpatient palliative care for NSCLC
  - Average of four outpatient visits per patient during the course of the study

- Results:
  - Improved QOL (FACT-L score 91.5 vs 91.3, P=0.007)
  - Fewer depression symptoms (34% vs. 50%, P=0.01)
  - Improved survival (11.6 months vs. 8.9 months, P=0.02)
- These results were achieved despite reduced aggressiveness of end-of-life care (33% vs. 54%, P=0.05)

Prognostic awareness associated with improved outcomes

- Multisite, longitudinal study of 332 advanced cancer patient-family dyads

- Cancer patients who understood terminal prognosis had:
  - Better mental health
  - Better quality of death
  - Caregivers with better bereavement adjustment
Palliative Care Outcomes

- Hospital admission rates are reduced for palliative patients
  - Ranganathan et al., J Palliative Med 2013
  - Study of 390 patients receiving home care with or without palliative care
  - 30 day re-hospitalization rates for home care patients:
    - With palliative visits - 9.1%
    - Without palliative care - 17.4%

“The Talk”

- A patient and family meeting is a procedure
- It is helping people negotiate the OVERWHELMING anxiety about death
- Can’t be done in one conversation
- Facing one’s mortality and understanding the limits of medicine is a PROCESS, not an epiphany
- Multiple sessions over time

Barriers to Good Communication

- Not being prepared
- Not being present and engaged
- Making assumptions
- Feeling responsible for maintaining the patient’s hope
- Ignoring your own feelings
- Talking too much
Prognostic information precipitates emotion
Unrealistic Hope ---Reality
Emotion Sadness, anger, or disbelief.

Advance Care Planning
- A process aimed at extending the rights of competent adults to guide their medical care through periods of decisional incapacity.
- The process, when accomplished comprehensively, involves three steps:
  1. thinking through one’s values and preferences,
  2. talking about one’s values and preferences with others,
  3. documenting them.

Advance Care Planning
- How is advance care planning different from advance directives?
- Advance care planning is the process
- **Advance directives**
  - the written documents that provide information about the patient’s wishes and/or her designated spokesperson.
  - If official forms are not used, health care providers should document the result of their advance care planning conversations in a medical record progress note.
Advance Care Planning

- Predicting what treatments patients will want at the end of life is complicated by:
  - The patient’s age.
  - The nature of the illness.
  - The ability of medicine to sustain life.
  - The emotions families endure when their loved ones are sick and possibly dying.

Advance Care Planning

- Components include:
  - Identifiable outcome
  - Comprehension of the medical condition trajectory
  - Planning for expected outcomes:
    - Early disease course
    - Mid course
    - End stages
  - Decision making models

"How can a 'care planning system' improve care?"
Hammes, B PhD, CAPC Dallas 2013
**Disease Trajectories**

**Function**
- Death (mostly heart and lung failure)
- Multiple hospitalizations
- Death usually follows disease exacerbation

**Organ System Failure Trajectory**
- Time frame: usually 2-5 years

**Frailty / Dementia Trajectory**
- Time frame: usually 6-8 years
- High dependence on ADLs early in disease course
- Slow decline

**Prognosis**

Important factors to consider:
- Co-morbid illnesses
- Rate of decline
- Nutritional status
- Functional status
- Number of hospitalizations in past year
- Other (psychosocial, emotional and spiritual)
- Will to live
- Cognitive status
- Age and gender
Heart Disease

- Arrhythmias
- Atherosclerotic Heart Disease
- Chronic Heart Failure

Recent cardiac hospitalization (3 x 1 yr mortality)
- Elevated creatinine > 1.4
- SBP < 100 or tachycardia > 100 (2 x 1 yr mortality)
- LVEF < 40%
- Ventricular dysrhythmias
- Anemia
- Hyponatremia
- Cachexia
- Reduced functional state
- Co-morbid illnesses

Cardiovascular Disease

Most patients with ASHD or CHF have a 4 or 5 drug course of therapy (ACE, Beta blocker, Aspirin, statin, diuretic)
- Most will have a cardiologist and a primary care physician involved regularly

What is the palliative role in medical therapy? Same as with other diseases
- Compliance assessment
- Goals of therapy
Pulmonary Disease
Chronic Obstructive Pulmonary Disease
Pulmonary Fibrosis
Asthma

COPD - Prognosis
BODE - point system
- Body mass index (BMI < 21)
- Obstruction – FEV1
- Dyspnoea scale (MMRC)
- Exercise capacity – 6 min distance walked
Better predictor than FEV1 alone, but still not predictive of 6-month prognosis

http://www.icumedicus.com/clinical_criteria/bode.php
NEJM, 2004 150 (10) 1005-1012

COPD - Problems
- Inspiratory force for some MDIs need to exceed 60 LPM - unlikely that GOLD stage IV patients will be able to sustain this
- Current guidelines, as well as prognostic indices, do not account for inhaler technique, compliance and associated comorbidities in a dynamic fashion
Dementia

Alzheimer’s

Lewey Body

Fronto-Temporal

Multi Infarct or Vascular

Pick’s Disease

Various Neurologic entities

Prognosis in Dementia

- FAST 7c
  - 39.5% mortality in 6 mo (poor selectivity)
  - 22.2% who died had FAST 7c (poor sensitivity)
- Excluded a substantial portion of patients who died in 6 months – 77.8%

Mortality Risk Index - Dementia

- Complete dependence with ADLs: 1.9
- Male Gender: 1.9
- Cancer: 1.7
- CHF: 1.6
- Oxygen therapy past 14 days: 1.6
- SOB: 1.5
- <25% po intake: 1.5
- Unstable medical condition: 1.5
- Bowel incontinence: 1.5
- Bedfast: 1.5
- Age > 83 yrs: 1.4
- Sleeps most of the day: 1.4
Mortality Risk Index

Risk of estimate of death in 6 months

- 0  69.0%
- 1-2 11.8%
- 3-5 22.2%
- 6-8 45.4%
- 9-11 57.0%
- >12 70.0%


Prognosis in Dementia

- Hospitalized with pneumonia
  - 53% 6-month mortality vs. 13% cognitively intact
- Hospitalized with hip fracture
  - 59% 6-month mortality vs. 12% cognitively intact

Morrison RS, JAMA 2000;284:47-52

Cancer
Cancer Prognosis

Prognosis with Advanced Solid Tumors
- 177 patients, with metastatic inoperable tumors
- Factors negatively affecting survival:
  - 2 or more metastatic sites
    - 32 days median survival vs 119 days
  - Cerebral metastases
    - 23 days vs 70 days

Karnofsky performance scale
- 70% or greater: 146 days
- 40-60%: 39 days
- 30% or less: 14 days

Serum albumin
- 3.4 or greater: 126 days
- 2.4 - 3.3: 50 days
- 2.3 or less: 30 days

Barbot et al. Assessing 2 month clinical prognosis in hospitalized patients with advanced solid tumors; J Clin Oncol; 26(15); 2008 2538-43

What is the Clinical Course?

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<thead>
<tr>
<th></th>
<th>Disease - Stable</th>
<th>Years</th>
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<tbody>
<tr>
<td>A</td>
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<td>C</td>
<td>Deteriorating, Exacerbations</td>
<td>Weeks</td>
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<tr>
<td>D</td>
<td>End of Life</td>
<td>Days</td>
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</table>

Acceptance of one’s own mortality is a process, not an epiphany

R. Krakauer, MD

References

- Lamont et al. Prognostic Disclosure to Patients with Cancer near the End of Life; Annals Int Med 2001; 134:1096
- Battersby M, PhD et al, Twelve Evidence-Based Principles for Implementing Self-Management Support in Primary Care; Joint Commission Journal on Quality and Patient Safety Vol. 36 No. 12, 2010; 561–570
- Hoeksema et al, Improving Medication Reconciliation in an Outpatient Palliative Medicine Clinic: A Quality Improvement Study; Journal Pain and Symptom Management; Vol. 43 No. 2; Feb 2012
- Morrison RS Survival in end-stage dementia following acute illness; JAMA 2000;264:51–52
- Barbot et al. Assessing 2 month clinical prognosis of hospitalized patients with advanced illness when j Clin Oncol 26(15); 2008 2538-2543

Resources

Fast facts for prognostication and palliation
www.eperc.mcw.edu

Resource for palliative tools and guidelines
www.capc.com