Palliative Medicine and Shared Decision Making

Danielle J. Doberman, MD, MPH
Director, Palliative Medicine Program
George Washington University Hospital
Assistant Professor of Medicine, GWUSOM
ddoberman@mfa.gwu.edu
What healthcare options exist?

- Bob is a 72 y/o man with diabetes, hypertension and stage 4 colon cancer
- He had a hemi-colectomy with positive nodes three years ago
- He has a seizure at work and is diagnosed with new metastasis in his liver, bone and brain
What healthcare options exist?

- Millie is a 94 y/o nursing home resident with dementia, congestive heart failure, and recurrent infections.
- She is treated with spoon feeding, bisphosphonates, ACE inhibitor, beta blocker, and diuretics.
- She has had 4 hospitalizations in 6 months, for UTI, CHF, and aspiration PNA.
What healthcare options exist?

- George is a 64 y/o man with diabetes, HTN, CAD, ESRD on HD with an AICD.
- He has arthritic pain in his knees and hips, neuropathy in his feet, and his AICD recently fired.
- He wants a TKA
Palliative Care:

- Specialized medical care for people with serious illness.
  - Primary vs. secondary palliative medicine
- Focused on providing relief from symptoms, pain and stressors of a serious illness, no matter what the diagnosis.
- Goal is to improve quality of life for both patient and family.
- Care is provided by a team who work with the patient’s current doctors to provide an extra layer of support
- Palliative care is appropriate at any age and at any stage in a serious illness.
- Can be provided together with curative treatments.
Hospice vs. Palliative Care

**Palliative Care**
- Any time during illness
- May be combined with curative care
- Independent of insurer
- Complementary therapies often included

**Hospice**
- Prognosis of < 6 mo
- Focus on comfort care
- Medicare hospice benefit
- Volunteers integral & required aspect of the program

“Hospice is for the predictably dying”
Traditional View of Illness

Curative Treatments

Hospice

6m

Diagnosis

Death

Bereavement Care

Institute of Medicine
Trajectory View of Illness

- **Diagnosis**
- **Curative Treatments**
- **Hospice Appropriately**
- **Actively Dying**
- **Palliative Medicine** (relieve suffering, improve quality of life)
- **Bereavement Care**

6m
Why Palliative Medicine? Why Now in US Hospitals?

1) Healthcare improvements
2) Societal Demographics
3) State of dying in US
Societal Demographics

- Society is aging
- Life expectancy has increased
- Patients live longer with chronic diseases
- Health care costs are increasing
Number of people age 65 and over, by age group, selected years 1900-2000 and projected 2010-2050

- #s over 65:
  - 35 million in 2000
  - 71 million in 2030
- #s over 80:
  - 9.3 million in 2000
  - 19.5 million in 2030

Note: Data for 2010-2050 are projections of the population.
Reference population: These data refer to the resident population.
Source: U.S. Census Bureau, Decennial Census and Projections.
Health improvements – Effects: Patients are older and sicker

When does chronic debility become dying?
Healthcare Today:

Quality Improvements:
- Hospitalist movement
- Intensivist movement
- Resident work hour restrictions
- Sub-specialization of medicine

Consequences/Patients View:
Fractured Patient Care
Healthcare Today: Technology
Healthcare Today
Healthcare Today: Patient Perspective

- “Who is my doctor?”
- “Why doesn't my regular doctor ever come?”
  - “Has anyone called their office?”
  - “Do they know I am here?”
  - JAMA “My Turn”
- “Mom hasn’t been good for a while…”
  - Take the long view
  - When do debility & chronic decline become dying?
Trajectories of Illness

When does chronic decline become dying?

Cancer
CHF/COPD
Dementia

Case Scenarios:

- 56 y/o Stage 2 colon CA pt with intractable nausea and mucositis following chemo.
- 39 y/o with PCP pneumonia & newly dx’d HIV+, CD4 150. Struggling how to tell family of illness.
- 67 y/o pt with COPD intubated for fourth time in a year.
- 89 y/o pt with Parkinson’s dementia, hospitalized for third aspiration PNA in 6 months, now bed-bound. “Difficult family.”
What does a palliative medicine clinician do?

The family meeting is our procedure!
Communication is Key!

- Communication with patients is the core skill of palliative medicine
- In a typical visit, physicians elicit less than half a patients’ concerns, and consistently fail to discuss their values, goals of care, and treatment preferences
- Information gathered by PM consultant is shared with PMD

Tulsky JA. Geriatric Palliative Care. 2003
Common reasons for consultation:

1. Discussion of medical treatment options and goals of care
2. Pain and symptom management
3. Psychosocial, practical support and care coordination
4. Bereavement services for patient/family
“There’s no easy way I can tell you this, so I’m sending you to someone who can.”
What healthcare options exist?

- Bob is a 72 y/o man with diabetes, hypertension and stage 4 colon cancer.
- He had a hemi-colectomy with positive nodes three years ago.
- He has a seizure at work and is diagnosed with new metastasis in his liver, bone and brain.

What does Bob want?
Comprehensive Palliative Assessment:

- Systematic evaluation like other disciplines
  - Inventories:
    - Edmonton System Assessment System
    - Memorial Symptom Assessment Scale – Short Form

- Broader view of “symptoms”

- Goal is to relieve suffering and pain
  - Differential diagnosis of suffering and pain
  - Dame Cicely Saunders’ concept of “Total Pain”
Comprehensive Palliative Assessment

- Dame Saunders’ concept of “Total Pain and Suffering”

- 4 domains:
  - Physical Pain
  - Psychological Pain
  - Social Pain
  - Existential or Spiritual Pain
Values & Goals Assessment

“I want to help you achieve what you want out of your health care, and I have some questions to ask:”

“What are your most important hopes? What are your biggest fears about your health?”

“Given the severity of your illness, what is most important for you to achieve?”
Statements to Consider:

- “What makes life worth living? What if you could no longer do these things?”
- “Would there be any circumstances under which you would find life not worth living?”
- “Has anyone close to you ever died? What are your feelings about that experience?”
- “In terms of your treatments, what are your thoughts about balancing quality of life with length of life in terms of your treatments?”

Quill JAMA 2000
#1: Determine patient goals and values

What Do Patients with Serious Illnesses Want?

- Pain and symptom control
- Avoidance of a prolonged dying process
- Achieve a sense of control
- Relieve burdens on family
- Strengthen relationships with loved ones

Common causes of suffering in seriously ill:

- Pain
- Dyspnea
- Nausea/vomiting
- Weakness & fatigue
- Insomnia
- Anorexia +/- cachexia
- Incontinence
- Constipation
- Agitation/Delirium
- Anxiety
- Depression

- Sense of well-being
- Uncertainty about future
- Fear of disability
- Fear of death
- Hopelessness
- Remorse
- Loneliness
- Loss of
  - Meaning/Role
  - Control
  - Dignity
  - Autonomy
What are “Goals of Care?”
Goals of Care = Patient Values

- Cure disease
- Avoid early death
- Maintain or improve function
- Prolong life
- Avoid pain
- Avoid dependence
- Improve life quality
- Stay in control
- Support family

*Goals may change as illness evolves*
Goals of Care Family Meeting

- Convey to patient/family:
  - Scope of illness & usual course
  - Limits of technology
  - Prognosis
- Define “acceptable” and “unacceptable” quality of life from patients view
- Suggest which treatments will help achieve patient’s stated goals
  - OK to give an opinion!
"Moms living will"

This is to ask you—should there be a medical emergency—if the situation is such that recovery will leave me a vegetable—please give me the right to die as I choose—well dignity if possible. A long drawn out affair that is offensive and heart-breaking to everyone. This note is to remove the responsibility of the choice from your hands and leave it in mine—

P.S. Remember—no plastic flowers or—stem back—1-11-78 1-15-77

Pearl 5-4-75

Elizabeth J. Wheer 1-1-90
Elizabeth J. Wheer 1-1-91

Elizabeth J. Wheer 1-1-92
Elizabeth J. Wheer 1-1-93

Elizabeth J. Wheer 1-1-94
Elizabeth J. Wheer 1-1-95

Elizabeth J. Wheer 1-1-96
Elizabeth J. Wheer 1-1-97

Elizabeth J. Wheer 1-1-98
Elizabeth J. Wheer 1-1-99

Elizabeth J. Wheer 1-1-00
Elizabeth J. Wheer 1-1-01

Elizabeth J. Wheer 1-1-02
Elizabeth J. Wheer 1-1-03

Elizabeth J. Wheer 1-1-04
Elizabeth J. Wheer 1-1-05

Elizabeth J. Wheer 1-1-06
Elizabeth J. Wheer 1-1-07

Elizabeth J. Wheer 1-1-08
Elizabeth J. Wheer 1-1-09

Elizabeth J. Wheer 1-1-10
Elizabeth J. Wheer 1-1-11

Elizabeth J. Wheer 1-1-12

Elizabeth J. Wheer 1-1-13

Elizabeth J. Wheer 1-1-14
Beyond DNR to QOL

2. Declaration of Wishes.

I desire not to prolong my life through medical intervention if, after such intervention, I would reasonably be expected for the foreseeable future (i) to live in intractable pain, (ii) to be substantially dependent upon others in order to accomplish the basic life functions of eating, communicating or maintaining personal hygiene, (iii) not to be able to exchange affection with my loved ones, (iv) not to be able to regain substantial cognitive, communicative and interactive faculties, or (v) to be in such other circumstance that, in the opinion of my Agent, the burden of sustaining my life degrades my humanity. It is also my express and deeply held desire not to exist in a persistent vegetative state. It is my intention that this health care proxy and declaration shall be honored by my Agent, my family and my attending physician and other health care providers as the final expression of my legal right to refuse medical or surgical treatment and my acceptance of the consequences of such refusal.

“Goals of Care”
American Bar Association’s Commission on Law & Aging, Consumer’s Tool Kit for Health Care Advance Planning:
http://www.abanet.org/aging/toolkit/
Are Some Conditions Worse Than Death?

What is QOL?

What is suffering?

http://www.abanet.org/aging/toolkit/

This worksheet helps you to think about situations in which you would not want medical treatments intended to keep you alive. These days, many treatments can keep people alive even if there is no chance that the treatment will reverse or improve their condition. Ask yourself what you would want in the situations described below if the treatment would not reverse or improve your condition.

Directions: Circle the number from 1 to 5 that best indicates the strength and direction of your desire. If you wish, you can add additional thoughts on the Comment lines.

1 --- Definitely want treatments that might keep you alive.
2 --- Probably would want treatments that might keep you alive.
3 --- Unsure of what you want.
4 --- Probably would NOT want treatments that might keep you alive.
5 --- Definitely do NOT want treatments that might keep you alive.

What If You...

a. No longer can recognize or interact with family or friends.
   Comment
   1 2 3 4 5

b. No longer can think or talk clearly.
   Comment
   1 2 3 4 5

c. No longer can respond to commands or requests.
   Comment
   1 2 3 4 5

d. No longer can walk but can get around in a wheelchair.
   Comment
   1 2 3 4 5

e. No longer can get outside and must spend all day at home.
   Comment
   1 2 3 4 5

f. Are in severe, untreatable pain most of the time.
   Comment
   1 2 3 4 5
What treatment would you want if:

- You could no longer talk or think clearly?
- You could no longer recognize or interact with your family?
- You couldn’t swallow safely and a feeding tube was suggested?
- You couldn’t breathe and needed a breathing machine indefinitely to keep you alive?
- You could no longer control your bowel or bladder?
- You lived in a nursing home?
- You had pain most of the time?

http://www.abanet.org/aging/toolkit/
## Goals of Care Grid:

<table>
<thead>
<tr>
<th></th>
<th>CPR</th>
<th>Ventilator</th>
<th>Surgery</th>
<th>Blood Transfusion</th>
<th>Antibiotics</th>
<th>Feeding tube</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Current state of health</strong></td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Trial</td>
</tr>
<tr>
<td><strong>Chronic illness with physical disability</strong></td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Trial</td>
</tr>
<tr>
<td><strong>Mild Dementia</strong></td>
<td>Yes</td>
<td>Trial</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td><strong>Severe dementia</strong></td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Undecided</td>
<td>Undecided</td>
<td>No</td>
</tr>
<tr>
<td><strong>Total dependence for care</strong></td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>
Putting it all together …

What might a palliative medicine consult mean for you?
Your patients?
The Patient Perspective

Palliative medicine can:

- Relieve pain and non-pain symptoms
- Increase understanding the plan of care
- Coordinate care between settings & specialists
- Provide practical and emotional support for exhausted family caregivers
- Occur simultaneously with disease modifying treatments
  - no requirement to give up curative care
The Clinician Perspective

- Palliative medicine can:
  - Save time by helping with repeated, intense patient-family communications, and coordination of care across settings
  - Bedside management of pain and distress of highly symptomatic and complex cases, thus supporting the treatment plan of the primary physician
  - Promote patient and family satisfaction with the quality of care
The Hospital Perspective

Palliative Medicine can:

- provide service oriented, patient-centered care
- increase patient and family satisfaction
- improve staff satisfaction and retention
- meet JCAHO quality standards
- rationalize the use of hospital resources
- increase capacity, reduce costs
Does my pt need a consult?

“Would I be surprised if this person died in the next year?”

- If the answer is “NO,” they need an advanced directive
- Primary team can accomplish this

Consider Palliative Consult:

- If you are having difficulty creating an advanced directive
- If you are having difficulty controlling symptoms
- If your patient takes up large amounts of your time wanting to talk about death, dying and their spiritual and existential angst.
What healthcare options exist?

- Bob is a 72 y/o man with diabetes, hypertension and stage 4 colon cancer
- He had a hemi-colectomy with positive nodes three years ago
- He has a seizure at work and is diagnosed with new metastasis in his liver, bone and brain
What healthcare options exist?

- Millie is a 94 y/o nursing home resident with dementia, congestive heart failure, and recurrent infections.
- She is treated with spoon feeding, bisphosphonates, ACE inhibitor, beta blocker, and diuretics.
- She has had 4 hospitalizations in 6 months, for UTI, CHF, and aspiration PNA.
What healthcare options exist?

- George is a 64 y/o man with diabetes, HTN, CAD, ESRD on HD with an AICD.
- He has arthritic pain in his knees and hips, neuropathy in his feet, and his AICD recently fired.
- He wants a TKA
Summary

- Palliative medicine is guided by patients’ goals
  - It is “Patient-centered” and “Patient-driven”
- Hospice is one form of palliative medicine
- Palliative medicine should be introduced early in the course of life-threatening illnesses and is compatible with curative care.
“A good doctor takes care of the disease.

A great doctor takes care of the patient.”

Sir William Osler
“How people die remains in the memories of those who live on.”

Dame Cicely Saunders
Thank you for listening!

Questions?

Danielle J. Doberman, MD, MPH
ddoberman@mfa.gwu.edu