The Nature of Suffering and the Goals of Medicine - Eric J. Cassell

The relief of suffering and the cure of disease must be seen as twin obligations of a medical profession that is truly dedicated to the care of the sick. Physicians’ failure to understand the nature of suffering can result in medical intervention that (though technically adequate) not only fails to relieve suffering but becomes a source of suffering itself.

Objectives:
By the end of this session, you will be able to:

- Describe How & Where We Are Dying in the U.S.
- Define Palliative Care
- Practice Setting Goals of Care
- Discuss systems in which Palliative Care is delivered
- Define Hospice and when a patient is appropriate for hospice referral
- Compare & contrast different Advance Care Planning documents
- Start thinking about selected legal issues in palliative care

Leading Causes of Death: 1997

- Heart disease: 31%
- Malignant neoplasm: 23%
- Cerebrovascular disease: 7.0%
- COPD: 4.7%
- Accidents: 4.1%
- Pneumonia: 3.7%

Account for 75% of all deaths

Symptoms at the End of Life: Cancer vs. Other Causes of Death

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Cancer</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>84%</td>
<td>67%</td>
</tr>
<tr>
<td>Trouble breathing</td>
<td>47%</td>
<td>49%</td>
</tr>
<tr>
<td>Nausea and vomiting</td>
<td>51%</td>
<td>27%</td>
</tr>
<tr>
<td>Sleeplessness</td>
<td>51%</td>
<td>36%</td>
</tr>
<tr>
<td>Confusion</td>
<td>33%</td>
<td>39%</td>
</tr>
<tr>
<td>Depression</td>
<td>38%</td>
<td>36%</td>
</tr>
<tr>
<td>Loss of appetite</td>
<td>71%</td>
<td>38%</td>
</tr>
<tr>
<td>Constipation</td>
<td>47%</td>
<td>32%</td>
</tr>
<tr>
<td>Bedsores</td>
<td>28%</td>
<td>14%</td>
</tr>
<tr>
<td>Incontinence</td>
<td>37%</td>
<td>20%</td>
</tr>
</tbody>
</table>

Seale and Cartwright, 1994
Who is dying in the U.S.?

- Median age of death is 77 years.
- Among survivors to age 65, median age at death is 84 for women, and 80 for men.
- In the frail elderly death follows a long period of progressive functional decline and loss of organ reserve accompanied by specific disease processes.

Site of Death

- Hospitals: 56%
- Nursing homes: 19%
- Home: 21%
- Other: 4%

(1993 National Mortality Followback Survey)

Palliative Care

"The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social, and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and families."

(WHO, 1990)

Mrs. A: What is her prognosis?

- 94 y/o with congestive heart failure, severe peripheral vascular disease, a systolic blood pressure of 100, and shortness of breath at rest or with mild exertion. She is treated judiciously with medications.

Is this patient terminally ill?

Mrs. A: Is this patient terminally ill?

Prognosis Can Be Difficult to Predict

Life Defining Illness — Actively Dying

Curative vs. Palliative Model of Care

Curative | Palliative
Restoring the Balance

Continuum of Care Model

Disease Progression

Palliative Care is Guided by Goals

Potential Goals of Care

Goals May Change Near the End of Life

Palliative Care...

- Cure of disease
- Avoidance of premature death
- Maintenance or improvement in function
- Prolong life
- Relief of suffering
- Quality of life
- Staying in control
- A good death
- Support for families and loved ones

- Some goals may take priority over others
- The shift in the focus of care
  - is gradual
  - is an expected part of the continuum of medical care
- Review goals with any change in
  - health/functional status (e.g. advancing illness)
  - setting of care
  - treatment preferences

- Focuses on relieving suffering, improving quality of life
  - affirms life, sees death as a personal and natural process
  - many diagnoses
  - appropriate early in course of illness
  - patient and family preferences respected
  - may be combined with curative therapies or may be the focus of care

What are some potential goals of care?

- Cure of disease
- Avoidance of premature death
- Maintenance or improvement in function
- Prolong life
- Relief of suffering
- Quality of life
- Staying in control
- A good death
- Support for families and loved ones

Some goals may take priority over others

The shift in the focus of care
- is gradual
- is an expected part of the continuum of medical care

Review goals with any change in
- health/functional status (e.g. advancing illness)
- setting of care
- treatment preferences

Focuses on relieving suffering, improving quality of life
- affirms life, sees death as a personal and natural process
- many diagnoses
- appropriate early in course of illness
- patient and family preferences respected
- may be combined with curative therapies or may be the focus of care
Palliative Care
- Interdisciplinary care of the patient and family
- Pain and symptom management
- May include disease-modifying treatments
- Psychological, social, spiritual support
- Bereavement support

Delivery of Palliative Care
- Hospital-Based
  - Primary care
  - Consultation
  - In-Patient Unit
- Nursing Home
- Hospice
  - Home Hospice
  - Hospital In-Patient
  - Hospice In-Patient

What Is Hospice?
- A reimbursement benefit for patients who have a limited prognosis or life expectancy
- Primarily community-based
- Care for severely ill patients and their families
- Team of professionals and trained volunteers
- Focus is on care, not cure.
- Goals:
  - Relief of pain and other symptoms
  - Psycho-social support

Hospice Care Provides:
- Patient control over decisions about care
- Family involvement
- Specialized services
  - Pharmaceuticals and home supplies/equipment
  - Pastoral support
  - Grief counseling
  - Volunteer support
- Option for patient to die at home

Conditions for Hospice Eligibility Under Medicare
- Limited life expectancy (generally 6 months or less) - certified by physician
- Patient chooses hospice benefits rather than standard Medicare*
- Patient chooses palliation as goal, rather than cure
- Care provided by Medicare-certified hospice program
- A physician to direct care
- Available/able/willing caregiver at home
*Patient may choose to stop Hospice Care and revert to Cure-Oriented Care at any time

Comparing Hospice vs. Palliative Care

Hospice
- Prognosis of 6 months or less
- Focus on comfort care
- Medicare hospice benefit
- Volunteers integral and required aspect of the program

Palliative Care
- Any time during illness
- May be combined with curative care
- Independent of payer
- Health care professionals
### Objectives

- How And Where We Are Dying
- What Is Palliative Care?
- Setting Goals of Care
- Delivery of Palliative Care
- What is Hospice?
- Advance Care Planning
- Selected Legal Issues

### What is Advance Care Planning (ACP)

- Planning for future medical care in the event a patient is unable to make own decisions
- Should be updated regularly
- Values/goals are explored & documented
- Designate surrogate decision-maker
- It is a process, not an event
- Reduces confusion & conflict

### Instruments Used in Advance Care Planning (ACP)

- Instructions for Medical Care
  - Living will
  - Verbal statements
  - Personal letter or value statement stating preferences
- Designation of decision maker
  - Health Care Proxy or Agent
  - Durable Power of Attorney for Health Care

"Advance Directives"

### Patient Barriers to Completion of Advance Directives

- Belief that physicians should initiate discussions
- Procrastination
- Apathy
- Belief that family should decide
- Family would be upset by the planning process
- Fear of burdening family members
- Discomfort with the topic

### Physician Barriers to Advance Care Planning

- Belief that patients should initiate discussions.
- Discomfort with the topic.
- Time constraints.
- Lack of knowledge about AD’s.
- Negative attitude.

(Morrison et al, Arch Intern Med, 1994)

### Fostering Advance Directive Discussions

- Make it routine
  - "This is something I discuss with all my patients"
- Elicit important values
  - "What makes life worth living for you?"
  - "What makes life NOT worth living for you?"
- Address a limited number of issues
  - CPR, Artificial nutrition and hydration
- Complete documents
- Review/update documents regularly
<table>
<thead>
<tr>
<th>Objectives</th>
<th>Selected Legal Issues in End-of-life Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>- How And Where We Are Dying</td>
<td>- Capacity determination</td>
</tr>
<tr>
<td>- What Is Palliative Care?</td>
<td>- Withdrawal vs. Withholding of life sustaining treatments</td>
</tr>
<tr>
<td>- Setting Goals of Care</td>
<td>- Artificial nutrition and hydration</td>
</tr>
<tr>
<td>- Delivery of Palliative Care</td>
<td></td>
</tr>
<tr>
<td>- What is Hospice?</td>
<td></td>
</tr>
<tr>
<td>- Advance Care Planning</td>
<td></td>
</tr>
<tr>
<td>- Selected Legal Issues</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Determining Capacity</th>
<th>Limiting treatment at the end of life</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Capacity is issue specific</td>
<td>- All patients have rights, even if incapacitated</td>
</tr>
<tr>
<td>- How to determine capacity</td>
<td>- Right to refuse any intervention</td>
</tr>
<tr>
<td>» Is there a decision?</td>
<td>- Withdrawing / withdrawing</td>
</tr>
<tr>
<td>» Is the information understood?</td>
<td>» NOT homicide or suicide</td>
</tr>
<tr>
<td>» Is the reasoning logical and with appreciation for consequences?</td>
<td>» orders to do so are valid</td>
</tr>
<tr>
<td>» Is the decision sensible?</td>
<td>- Courts need not be involved</td>
</tr>
<tr>
<td>- Reassess for each decision</td>
<td></td>
</tr>
<tr>
<td>- Capacity is different from competency</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Life-sustaining treatments</th>
<th>Withdrawal vs Withholding of life sustaining treatments</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Resuscitation</td>
<td>- Legally, there is no difference between withdrawal vs withholding of life sustaining treatments</td>
</tr>
<tr>
<td>- Elective intubation</td>
<td>- However, psychological, emotional, or religious constraints may exist for family.</td>
</tr>
<tr>
<td>- Surgery</td>
<td></td>
</tr>
<tr>
<td>- Dialysis</td>
<td></td>
</tr>
<tr>
<td>- Blood transfusions, blood products</td>
<td></td>
</tr>
<tr>
<td>- Diagnostic tests</td>
<td></td>
</tr>
<tr>
<td>- Artificial nutrition &amp; hydration</td>
<td></td>
</tr>
<tr>
<td>- Antibiotics</td>
<td></td>
</tr>
<tr>
<td>- Other treatments</td>
<td></td>
</tr>
<tr>
<td>- Future hospital or ICU admissions</td>
<td></td>
</tr>
</tbody>
</table>
Artificial nutrition and hydration (ANH)

- States have different laws guiding care surrounding ANH
- Benefits vs burdens of ANH
- What are the goals of ANH?

Common concerns

- Legally required to “do everything?”
- Does withdrawal/withholding constitute euthanasia?
- Are you killing the patient when you remove a ventilator?
- Is the use of opioids to control symptoms at the end of life euthanasia?

What is the patient’s good?

“If medicine takes aim at death prevention, rather than at health and relief of suffering, if it regards every death as premature, as a failure of today’s medicine - but avoidable by tomorrow’s - then it is tacitly asserting that its true goal is bodily immortality...Physicians should try to keep their eyes on the main business, restoring and correcting what can be corrected and restored, always acknowledging that death will and must come, that health is a mortal good, and that as embodied beings we are fragile beings that must stop sooner or later, medicine or no medicine.”

(Kass LR. JAMA 1980;244:1947)

Summary

- Palliative care is guided by patients’ goals
- Advance directives clarify patients’ goals of care
- Setting clear goals guides the direction & plan of care
- Hospice is a way of delivering palliative care
- Palliative care should be introduced early in the course of life-threatening illness and is compatible with curative care.

Questions???