Care for Seriously Ill and Dying Patients: Key Principles for All Physicians

“Goals of Medical Care”
An understanding of what is important to a patient

Goals of Care
- Understanding a patient’s goals allows clinicians to align care with what is most important to the patient
- There are many possible treatment choices
- Decision-making informed by many factors
  - Disease extent and prognosis
  - Side effects of therapies vs benefits
  - Patient’s values and preferences \( \rightarrow \) Reflected as goals for medical care
  - What matters, what matters more, what matters most
Potential Goals of Care

• Take 2 minutes and come up with a list with your neighbors

Question

When should a physician address “goals of care” with a patient in the context of a serious illness?

A. When death is imminent
B. When disease directed treatments are no longer effective
C. Early and often in the course of the illness

Advance Directives

A decision made by a person specifying preferences for medical care in the future if he/she were to lose decisional capacity
Question

In general, are people who are approaching death actually afraid of dying?

A. Yes
B. No

Causes of “Suffering” in Seriously Ill and Dying Patients

- Pain
- Dyspnea
- Nausea, vomiting
- Constipation
- Fatigue
- Anorexia

- Anxiety
- Depression
- Fear of dying
- Fear of leaving loved ones
- Loss of control
- Become a burden

Symptom Palliation

- Palliative
  - Latin – Pallium
    - To cloak

- Palliation
  - To cloak over
    - To relieve/eliminate the effects if the underlying cause cannot be "fixed"
Question
Which best defines symptom “palliation”?

A. Dismiss the symptom since the patient is going to die
B. Fully evaluate the cause of the symptom before initiating any treatment
C. Implement strategies to minimize the discomfort of the symptom

Dyspnea
• Subjective sensation of difficulty breathing
• “Like diving into deep water, trying to swim to the surface, but feeling like you will never get there”

Dyspnea DDX includes:
• Multiple mechanisms
• Wide spectrum of pulmonary and cardiac conditions
• Anemia
• Anxiety
• Chest wall pathology
• Urinary retention or constipation
• Pain
Assessment and Management in Serious Illness and Dying Patients

Potential Goals of Care
- Cure my disease
- Prolong life
- Maintain or improve function
- Not suffer
- Stay in control
- Stay out of the hospital
- See....
- Die peacefully
- Have family cared for

Palliation of Dyspnea

- General measures
  - Positioning (sitting up)
  - Increasing air movement via a fan or open window
  - Use of bedside relaxation techniques

Palliation of Dyspnea

- Treatment with opioids
  - Drugs of choice for dyspnea
    - dyspnea refractory to treatment of the underlying cause
  - Patient, family and caregiver education
Mechanism of Opioid relief of Dyspnea

- Not entirely understood
  - Decreased respiratory output results in decrease in corollary discharge from the brainstem to perceptual areas in the cerebral cortex and thus reduce sensation of breathlessness
  - May blunt perceptual sensitivity to sensations of breathlessness
    - Neuroimaging studies demonstrate that μ opioid receptor agonists can modulate central processing of breathlessness similar to that of pain relief
  - May modulate breathlessness by binding to opioid receptors located in bronchioles and alveolar walls
    - No evidence to use nebulized opioids

Palliation of Dyspnea

- Treatment with oxygen
  - Oxygen is NOT universally helpful
  - Well-designed randomized, controlled trial of oxygen vs ambient air, delivered by nasal cannula, in normoxic patients with advanced illness and dyspnea showed no benefit of oxygen over ambient air delivered by nasal cannula

Palliation of Dyspnea

- Specific disease modifying effects
  - Include diuretics, bronchodilators, and corticosteroids
- Other Pharmacologic agents:
  - Anti-tussives can help with cough
  - Anticholinergics can help reduce oral secretions
  - Anxiolytics (e.g. lorazepam) can reduce the anxiety component of dyspnea
Putting it together:

A 66-year old with metastatic lung cancer develops fever and cough productive of purulent sputum.

Develop an assessment and management plan

A. Ambulatory, getting palliative chemotherapy, working part time, daughter is getting married in 2 weeks
B. Disease progressed on last line chemotherapy, spends majority of day in chair, decreasing appetite, increasing weakness, does not want to be hospitalized, hopes to meet 1st grandchild (due in 7 days)
C. Bedbound, minimally responsive, has not had any PO intake x 5 days
Question

The best approach to understanding an individual's religious views that may influence their end-of-life care is to memorize the previous table.

A. True
B. False

What is the best approach to understanding an individual's religious views that may influence their end of life care?

Evolution of the Dying Process
Question

In the face of serious illness, which of the following can be stopped/removed/deactivated after discussion with a decisional patient or their surrogate decision maker?

A. Defibrillator
B. Hemodialysis
C. Mechanical ventilation
D. Left ventricular assist device
E. All of the above
F. None of the above
Life-Sustaining Therapies

AMA Code of Medical Ethics

• Decisions to withhold or withdraw life-sustaining interventions can be
  ethically and emotionally challenging to all involved.
• A patient who has decision-making capacity appropriate to the decision at
  hand has the right to decline any medical intervention or ask that an
  intervention be stopped...
• While there may be an emotional difference between not initiating an
  intervention at all and discontinuing it later in the course of care, there is
  no ethical difference between withholding and withdrawing treatment.
• When an intervention no longer helps to achieve the patient’s goals for
  care or desired quality of life, it is ethically appropriate for physicians to
  withdraw it.
• Physicians should elicit patient goals of care and preferences regarding
  life-sustaining interventions early in the course of care, including the
  patient’s surrogate in that discussion whenever possible.

Ethical and Religious Directives for Catholic Health Care Services

57 A person may forego extraordinary or disproportionate means of preserving life.
Disproportionate means are those that in the patient’s judgment do not offer a reasonable
hope of benefit or entail an excessive burden, or impose excessive expense on the family
or the community.

• Examine expectations (goals, what is important, fears)
• Explore reasons for cessation (or not initiating)
• Discuss symptoms that may result from cessation (or not initiating)
Question

You have been taking care of a 76-year old woman with advanced heart failure during her hospitalization. The nurse informs you that the patient just died.

Which of the following is NOT part of a physician's responsibilities after a patient dies?
A. Pronounce the patient dead  
B. Complete the death certificate  
C. Ask next of kin for authorization for autopsy  
D. Discuss organ donation with next of kin

Post-Mortem Responsibilities

The Pronouncement

• Identify the patient
• Examination
  • Assess response to verbal, tactile stimuli
  • overtly painful stimuli unnecessary
  • Listen for absence of heart sounds; feel for absence of carotid pulse
  • Look and listen for absence of spontaneous respirations
  • Note position of pupils, absence of pupillary light reflex
  • Record the time at which assessment was completed (time of death)
Question

Which of the following is most appropriate to tell patient’s husband?
A. Your wife has passed on
B. Your wife has died
C. Your wife has expired
D. Your wife has passed away

Communication

• Be straightforward, clear
  • Say “dead” “died”
    • “Expired”, “passed away” can be misinterpreted

• Ok to offer condolences
  • “I’m sorry for your loss...” Or – “I see this is very difficult for you...”

When to Contact ME Office?
Request for a medical autopsy

• Provide time for family to process death before requesting

• Request autopsy on ALL patients

Completing Death Certificate

* Must be Specific
Complete the death certificate

Our patient with metastatic lung cancer (ambulatory, getting chemo, working) is hospitalized, dx with post-obstructive pneumonia, develops sepsis and dies.

Organ Donation

- Gift of Hope
  - Federally designated not-for-profit organ procurement organization
  - Coordinates organ and tissue donation with 180 hospitals in Illinois and northwest Indiana
  - Works with nine transplant centers

Step 1 Referral & Evaluation
- Federal regulations require hospitals to notify Gift of Hope each time a patient dies or is about to die so we can determine if he or she is a potential donor. We review the patient's medical record to check for any clues regarding potential organ and tissue donation.

Step 2 Authorization for Organ and Tissue Donation
- If we determine the patient is medically eligible, a Gift of Hope representative visits the hospital to review the patient chart and meet with the doctors and patient care team. We then recommend the family visit with us in the appropriate and most sensitive time to discuss donation as part of “what comes next.”

Step 3 Family Approach
- If the patient is a registered donor, we review the affidavit of donor registration with the family, explain the donation process, answer questions and provide any support the family may need if the patient is not a registered donor, we will explain the option of donation, among other options, to the family to allow them to make an informed decision. These discussions are then continued with hospital staff, discuss these options with the family and requests authorization for donation.
Multiple studies have shown that discussing prognosis with patients with serious illness takes away hope.

A. True
B. False

- Data suggest that withholding prognosis is NOT viewed as an acceptable way of maintaining hope for most patients
- Prognostic information
  - Helps make emotional, logistic preparations, including for death
HOPE

We do not want to take away hope...we help our patients change what they are hoping for.

Summary

• Goals of care
• Palliation of Dyspnea
• Spiritual/Religious Needs
• Evolution of the Dying Process
• Physician tasks after a patient dies
• Hope

Comments/ Questions?