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

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
Goals of Care

- Understanding a patient’s goals allows clinicians to align care provided with what is most important to the patient, and their family
- 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 → 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

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
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

Symptom Palliation

- Palliative
  - Latin – Pallium
  - To Cloak

- Palliation
  - To cloak over
  - To relieve/eliminate the effects if the underlying cause cannot be "fixed"

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**

- Other Pharmacologic agents:
  - Anti-tussives can help with cough
  - Anticholinergics (e.g. scopolamine) can help reduce oral secretions
  - Anxiolytics (e.g. lorazepam) can reduce the anxiety component of dyspnea

- Specific disease modifying effects
  - Include diuretics, bronchodilators, and corticosteroids

**Putting it together:**

A 66-year old with metastatic ovarian cancer has increasing dyspnea.

Develop an assessment and management plan

A. Ambulatory, getting palliative chemotherapy, daughter is getting married next week
B. Ambulatory, has coagulopathy from liver dysfunction due to innumerable liver metastases
C. Largely bedbound, decreasing appetite, increasing weakness, hoping to spend last Christmas awake with family
D. Bedbound, minimally responsive, has not had any PO intake x 5 days

**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
Cessation of Life-Sustaining Therapies

• A treatment can be stopped when it is no longer achieving a meaningful goal for the patient
  • Explore reasons for cessation
  • Examine expectations
  • Discuss symptoms that may result from cessation

• A patient’s right to request withdrawal of life sustaining interventions is both legal and ethical; this is not physician-assisted suicide or euthanasia

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

• Pronounce the patient dead
• Communicate with next of kin (family)
• Determine if Medical Examiner should be notified
• Request Autopsy
• Complete Death Certificate
• Collaborate with Gift of Hope re Organ Donation
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
- Ask if family has any questions
  - Answer simply, accurately
- Offer condolences
  - “I’m sorry for your loss...” Or – “This must be very difficult for you...”
When to Contact ME Office?

- Violent deaths
  - trauma of any type
- Under influence of anesthesia, within 24 hours of anesthesia.
- Within 24 hours of admission
- Industrial environment suspected as cause of the terminal disease
- Illness began on the job
- "Dead on Arrival" in the Emergency Department
- Attending physician has no adequate or reasonable explanation of the cause of death.
- Addiction to alcohol or any drug contributory cause.
- Decedent was not attended by a licensed physician within the last 30 days.
- All deaths due to burns.
- Unexpected deaths.

Request for a medical autopsy

- Provide time for family to process death before requesting
- Request autopsy on ALL patients

Completing Death Certificate
Complete the death certificate

**CASE HISTORY #1**

- **Age:** 58 years
- **Sex:** Male
- **Race:** White
- **Address:** 123 Main St, Anytown, IL
- **Date of Death:** 12/5/2018

**Medical History:**
- Hypertension
- Diabetes
- Coronary artery disease
- Congestive heart failure
- Chronic obstructive pulmonary disease
- Stroke

**Clinical Manifestations:**
- Coma
- Seizures
- Respiratory failure

**Immediate Cause of Death:**
- Cardiac arrest

**Final or Immediate Cause of Death:**
- Myocardial infarction

**Notes for Case History:**
- Admission of patient to hospital
- Treatment administered
- Outcome of treatment
Case Scenario

• A 36-year old woman sustained multiple injuries in a motor vehicle accident.
• She undergoes multiple surgeries requiring multiple units of blood products
• On hospital day #13 she develops dyspnea and acute hypoxia with sinus tachycardia
• PE is strongly suspected. En-route to the CT scanner she develops asystole. Resuscitation efforts are unsuccessful.

Complete the death certificate

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
Major organs that can be donated for transplant
- liver, heart, lungs, kidneys, pancreas and small intestine

Tissues that can be donated include
- corneas, bone, saphenous and femoral veins, heart valves and skin

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 condition and history to establish initial eligibility.

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 meet with family members at the appropriate and most sensitive time to discuss 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 needs. If the patient is not a registered donor, we discuss the option of donation, as required by state and federal regulations. Our Donation Specialist, in conjunction with hospital staff, discusses these options with the family and requests authorization for donation.

Final Topic

Hope
Question

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
• Evolution of the Dying Process
• Physician tasks after a patient dies
• Hope