Evidence-Based Activities for Physicians to Improve End of Life Care

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Learning Objectives

• Update on the trajectories of end of life
• Identify tools for determining prognosis
• Recognize strategies physicians can adopt to improve care of seriously ill patients
Mr. H

- 80 year old married man with a history of CHF. His CHF is well compensated until one day he becomes increasingly dyspneic. He goes to the hospital emergency department.
MY REPORT TODAY ASKS THE QUESTION, "WHERE WILL IT ALL END?"
Facts

• 90 million Americans are living with serious and life threatening illness.
• Number is expected to more than double in the next 25 years (aging baby boomers).
FACTS

• 60% of people say that making sure their family is not burdened by tough decisions is “extremely important”
• 56% have not communicated their end-of-life wishes.

Source: Survey of Californians by the California HealthCare Foundation (2012)
Causes of Death Among U.S. Adults Aged 65 Years or Older, 2006

- Heart Disease: 29.0%
- Cancer: 22.0%
- Stroke: 6.7%
- Chronic Lower Respiratory Diseases: 6.1%
- Alzheimer's Disease: 4.1%
- Diabetes: 3.0%
- Influenza and Pneumonia: 2.8%
- Unintentional Injury: 2.1%
- All Other Causes: 24.2%

Major Medical Conditions Before Death for Medicare Beneficiaries

Lunney et al 2004
### End of Life Experience

<table>
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<tr>
<th></th>
<th>1900</th>
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<tr>
<td>Age at death</td>
<td>47</td>
<td>75</td>
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<tr>
<td>Usual place of death</td>
<td>Home</td>
<td>Hospital</td>
</tr>
<tr>
<td>Coverage for most medical expenses</td>
<td>Family</td>
<td>Medicare</td>
</tr>
<tr>
<td>Disability before death</td>
<td>Usually not much</td>
<td>Two years, on average</td>
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</table>
Figure 5. Trajectories of eventually fatal chronic illnesses. Source: Lynn and Adamson 2003.
SUPPORT
Study to Understand Prognoses and Preferences for Treatment (1995)

• Randomized intervention trial
• Seriously ill patients who had one of 9 index conditions suggesting 50% or more mortality in 6 months.
• 4000 patients at 5 US hospitals
• Usual care or the SUPPORT intervention:
  Physicians in the intervention group received
  – Estimates of probability of survival over 6 months
  – Estimates of outcomes of CPR attempt
  – Estimates of probability of severe functional disability at 2 mos.
  – Documentation of patient and family preferences
  – Access to a nurse interventionist to facilitate communication.
Results of SUPPORT Trial

• Measured outcomes:
  – Earlier writing of DNR orders
  – Physicians’ knowledge of patient preferences for CPR
  – Number of ICU days before death
  – Patient reports of moderate or severe pain
  – Hospital resource utilization

• Results:
  – No change in any of the outcomes
Legacy of SUPPORT

• >100 SUPPORT publications
• Increased our understanding of care at the end of life and the seriously ill
• Comprehensive description of EOL from the perspective of family members
• Prognostic tools to better understand outcomes following non-traumatic coma
• Description of seriously ill patients’ preferences for communication about EOL decisions
Legacy of SUPPORT

• Initiated the downfall of Swan Ganz catheters by showing that patients receiving this device did not have better outcomes – a finding later confirmed in randomized studies.
IOM Reports

• Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life. IOM 2014.

• Last report “Approaching Death: Improving Care at the End of Life”, 1997

• “More than a quarter of all adults have given little or no thought to their end-of-life wishes. Have you?”

• Learn more: iom.edu/endoflife
2014 IOM Report

• Generated a lot of press
• Mostly on how our health care system is broken and not serving the needs of dying patients.
• Recalls “death panels” furor, and subsequent stripping from the Affordable Care Act of proposed Medicare payments to doctors for advance care planning conversations.
2014 IOM Report

• Despite its title, the report is largely about people with serious and chronic illness of indeterminate prognoses, and why the current health care system has largely failed to meet their needs.

• Geriatric palliative care is a major focus, e.g. dying in American is increasingly characterized by a long term progression of chronic conditions and frailty associated with aging.
2014 IOM Report

- Frames optimal care being “patient-centered and family oriented care”.
- Recognizing prognosis (e.g. ePrognosis)
- Advance Care Planning discussion
- Recommendations include:
  - Universal education and training for all health professionals
    - Pain and symptom management,
    - Safe and effective use of opioids,
    - Skilled communication with patients and families to help them determine their goals, how the healthcare system can help them achieve their goals,
    - Seemless, well-coordinated care across multiple settings over time.
  - Coverage of both the social and medical needs of the most serious and complex patients, including greater integration of medical and social services (and payment for such), support for caregivers.
EOL Care in 2014

• Inadequately treated symptoms
• Uncertainty about care coordination due to fragmented systems of care
• Poor communication among clinicians, patients and families
• Enormous strain on family caregivers

• IPAL-EM  CAPC 2011
Palliative Care

Therapies to modify disease

Therapies to relieve suffering and/or improve quality of life

Hospice

Bereavement Care

Presentation

6m Death
What is Palliative Care?

• Specialized **medical care** for people facing serious and chronic illness.

• Focuses on **relief from symptoms, pain and stress**- whatever the diagnosis.

• Goal is to **improve quality of life** for both patient and family.

• Provided by a **team** (physicians, nurses and other specialists) who work with a patient’s own doctor to provide an **extra layer of support**.
Envisioning the Best Scenario:

Seven Promises

• 1. Evidence-based, **appropriate medical treatment**
• 2. Prevention and effective treatment of troubling **symptoms**
• 3. Continuity, coordination, and comprehensiveness, so that essential **services are in place** when you need them
• 4. **Advance care planning** so that common complications of your illness rarely create emergencies
Seven Promises

• 5. Customized care, reflecting your preferences and respecting your wishes
• 6. Thoughtful use of the resources you and your family bring to bear (financial, emotional, and practical)
• 7. Help that allows you to make the best of every day that you live
  – Lynn, Sick To Death, 2004
Surprise Question

• Would you be surprised if your patient died within the next 6 months to a year?
Hospice Medicare Benefit Question

• Do you predict that your patient will die within the next 6 months of their illness?
Hospice vs. Palliative Care

• “hospice insurance benefit”
  – Specified diagnosis
  – Per diem payment
  – For meds, DME, skilled services for that diagnosis

• Physician certifies prognosis of 6 months or less

• No specific insurance benefit
  • Focus on improving quality of life
  • Can be combined with attempts at modifying or curing disease
  • Can be for anyone with serious illness
Outcomes of Palliative Care

1. Better quality of life,
2. Less depressive symptoms,
3. Less aggressive treatment near the end of life
4. Lived longer (?)

Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer (NEJM 2010)
Presence of a Serious Chronic Illness

- Declining ability to complete activities of daily living
- Weight loss
- Multiple hospitalizations
- Difficult to control physical or emotional symptoms related to serious medical illness
- Patient, family or physician uncertainty regarding prognosis or goals of care
Serious Illness, continued

- DNR order conflicts
- Use of tube feeding or TPN in cognitively impaired or seriously ill patients
- Limited social support and serious illness (e.g. homeless, chronic mental illness)
- Patient, family or physician request for information about hospice appropriateness
- Patient or family psychological or spiritual distress.
ICU Criteria

• Admission from a nursing home in the setting of one or more life-limiting conditions (e.g. dementia)
• Two or more ICU admissions within the same hospitalization
• Prolonged or difficult ventilator withdrawal
• Multi-organ failure
• Consideration of ventilator withdrawal with expected death
ICU, continued

- Metastatic cancer
- Anoxic encephalopathy
- Consideration of patient transfer to long term ventilator facility
- Family distress impairing surrogate decision-making
Oncology Criteria

• Metastatic or locally advanced cancer progressing despite systemic treatments with or without weight loss and functional decline.
• Karnofsky <50 or ECOG>3
• Progressive brain metastases following radiation
• New spinal cord compression
• Malignant hypercalcemia
• Progressive pleural/peritoneal or pericardial effusions
Oncology, continue

- Failure of first or second line chemo
- Multiple painful bone metastases
- Consideration of interventional pain management procedures
- Severe prolonged pancytopenia in setting of untreatable hematological problem (e.g. relapsed leukemia)
Emergency Department Criteria

- Multiple recent prior hospitalizations
- Long term care patient with DNR or Comfort Care orders
- Patient previously enrolled in home or residential hospice program
- Patient/caregiver/physician desires hospice but has not been referred
ED Criteria, continued

• Consideration of ICU admission and/or mechanical ventilation in a patient
  – With metastatic cancer and declining function
  – With moderate to severe dementia
  – With one or more chronic diseases and poor functional status at baseline
Physician Resources
Center to Advance Palliative Care (CAPC)

• Provides health care professionals with the tools, training and technical assistance to start and sustain palliative care programs in hospitals and other health care settings.

• National organization dedicated to increasing the availability of high quality palliative care services for people facing serious, complex illness.

• Located at Mount Sinai School of Medicine in New York City
GeriPal

- A Geriatrics and Palliative Care Blog
- Links to multiple other sites and resources
- ePrognosis
- Communication Tools
Communication

• Vitaltalk.org
• Coaching for clinicians and teachers
• Three fundamental skills
  – Tell me more....
  – Ask-tell-ask. “What do you think about...” “Here’s what the tests show..” “Does that make sense..?”
  – “I wish” statements. “I wish I could say that the chemo always works.
Communication: NURSE statements for articulating empathy

• **Naming:** “It sounds like you are frustrated.”

• **Understanding:** “This helps me understand what you are thinking.”

• **Respecting:** “I can see you have really been trying to follow our instructions.”

• **Supporting:** “I will do my best to make sure you have what you need.”

• **Exploring:** “Could you say more about what you mean when you say that...?”
The Conversation Project

- [http://theconversationproject.org](http://theconversationproject.org)
- Ellen Goodman co-founder
- Institute for Health Care Improvement
- Founding funder Cambia Health Foundation
- IHI Open School has course to introduce students and health professionals to basic skills for having conversations with patients and their families about their end of life care preferences.
Mr. H – Advance Care Plan

• Mr. H has mild cognitive impairment and prefers son to guide medical decision-making.

• His DPOA is his son, Mr. H II, telephone 202-123-4567.

• Mr. H and his son have said that all appropriate medical treatments would be desired, but he would not want to be on life support machines if he would be unable to return to his usual level of independent function.
Mr. H

- Hospitalized.
- Treated with diuresis and needing oxygen at times.
- Improved. “I am ready to go!”
- Discharged to home with home RN follow-up scheduled, but caregiver called from the lobby. “He is too short of breath to come home.”
On further assessment, hospitalists recognized Mr. H was fragile with worsening CHF despite medical therapy. His strongest wish was to be at home.
Mr. H wishes for care

- “Mr. H and his son understand the nature of the progressive weakening of his heart muscle despite optimizing medical treatment. His strongest wish is to be home with his wife. We agree that given the severity of his CHF, he would not benefit from CPR or ventilator treatment. They wish to avoid hospitalization unless necessary for comfort.”
Mr. H Care Plan

• Goals of care are comfort and to be at home with his family through the end of life. No CPR. No intubation or ventilator use. Prefer no further hospitalization unless needed for comfort.
Physician Orders for Mr. H

• Hospice referral
• Caregivers at home
• POLST or DC Comfort Care Order
  – Signed by physician and patient/proxy
  – Do not initiate CPR or mechanical ventilation.
  – Do not hospitalize unless needed for comfort.
POLST

• An out-of-hospital physician’s order
• Indicates patient preferences for resuscitation and scope of treatment
• Intended to be completed for seriously ill or frail patients and to be followed by emergency medical providers
• Indicates scope of treatment from full treatment to comfort-focused measures
• To be valid, must be signed by physician and patient (or patient’s legally recognized decision-maker).
• [http://www.polst.org/programs-in-your-state](http://www.polst.org/programs-in-your-state)
Palliative Care

Therapies to modify disease

Therapies to relieve suffering and/or improve quality of life

Hospice

6m Death

Bereavement Care
VA Health System: a model system

• Committed to caring for veterans throughout their life span
• Patient- and family-centered care
• Comprehensive Patient Record System
• Strong emphasis on preventive services, wellness, age- and health-appropriate screening
• Multiple levels of care
• Universal access to palliative care
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<td>Evaluation of + Depression Screen</td>
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Visit 05/28/10

ADVANCE DIRECTIVE DISCUSSION, GERIATRIC P.CARE TELEPHONE-X, ELIZABETH L COBBS

LOCAL TITLE: ADVANCE DIRECTIVE DISCUSSION
STANDARD TITLE: ADVANCE DIRECTIVE DISCUSSION
DATE OF NOTE: MAY 28, 2010@13:57 ENTRY DATE: MAY 28, 2010@13:57:14
AUTHOR: COBBS, ELIZABETH L EXP COSIGNER:
URGENCY:
STATUS: COMPLETED

Check one:
[XX] Veteran has decision making capacity for discussion of advance care planning.
[] Veteran lacks decision making capacity for discussion of advance care planning.

Veteran's health care proxy:
Name: Joe Jones
Relationship: Durable Power of Attorney for Health Care and long time friend
Phone (home): 333-333-3333
Phone (work): 444-444-4444

Additional/alternate proxy (if any): Jane James, friend, 555-555-5555

Summary of discussion of goals and wishes for medical treatments in life threatening conditions: Patient appears fully capable of making his own healthcare decisions. He sets no limits on emergency medical care, but he would not want prolonged treatment with life support machines if he was unable to communicate with his loved ones.

/es/ ELIZABETH L COBBS
ATTENDING
Signed: 05/28/2010 14:11

ESTABLISHED PATIENT Extended Exam
Diagnoses: Cancer* (ICD-9-CM 199.1) (Primary), Dementia NOS* (ICD-9-CM 294.8)
LOCAL TITLE: ADVANCE DIRECTIVE DISCUSSION
STANDARD TITLE: ADVANCE DIRECTIVE DISCUSSION
AUTHOR: COBBS, ELIZABETH L EXP COSIGNER: 
URGENCY: STATUS: COMPLETED

Check one:
[XX] Veteran lacks decision making capacity for discussion of advance care planning due to advanced dementia and inability to speak.

Veteran's healthcare proxy:
Name: Andrew Lawyer Esq
Relationship: Guardian
Phone (home): 202-222-2222
Phone (work): 202-333-3333
Phone (cellular): 202-444-4444

Additional/alternate proxy (if any): none known

Summary of discussion of goals and wishes for medical treatments in life threatening conditions: Patient lacks capacity to make healthcare decision for himself because of advanced dementia and inability to understand or articulate his wishes. He now has widely metastatic cancer of unknown etiology with no option for disease modifying treatment. The guardian and primary care team discussed today, and we agree that goals of care are comfort and to maintain function. Attempts at cardiopulmonary resuscitation and mechanical ventilation are not desired in the event of cardiopulmonary failure. Simple diagnostic and treatment interventions in the nursing home are acceptable, but guardian prefers to avoid hospitalizing patient unless comfort cannot be maintained at home. Home hospice services are being initiated.

/ES/ ELIZABETH L COBBS
ATTENDING
Signed: 05/28/2010 13:51
Atul Gawande

• “In Medicine, we’re good at treating fixable problems...we’re not so good at treating unfixable problems. I felt useless”

• **Being Mortal, 2014**
Summary

• Recognize trajectories associated with nearing the end of life
• Customize care to be person- and family-centered
• Incorporate palliative modalities into attempts at disease-modifying treatments early
• Foster communication and documentation of care planning in a place where others can find it.
Resources and References

• Center to Advance Palliative Care (CAPC)
  – Training for Palliative Care Teams
  – Tools for Palliative Care Programs
  – Resources

• Identifying Patients in Need of a Palliative Care Assessment in the Hospital Setting A Consensus Report from the Center to Advance Palliative Care, Weissman and Meier, J Pall Med, 2011, 14

• Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer, Temel et al, N Engl J Med 2010; 363:733-742

• Components of Early Outpatient Palliative Care Consultation in Patients with Metastatic Nonsmall Cell Lung Cancer, J Pall Med, April 2011 14(4) 459-464