Case Studies in Palliative Medicine

Seuli Bose Brill, MD, FAAP, FACP
Director, Pragmatic Clinical Trials Network
Research Dir., Division of General Internal Medicine
Assistant Professor, Clinical
Department of Internal Medicine/Pediatrics
The Ohio State University Wexner Medical Center

Learning Objectives

- Identify the generalist's role in palliative medicine in patients across the chronic disease trajectory (sub-clinical, symptomatic, and end-stage).
- Develop systematic strategies for serious illness communication (Advance Care Planning) in primary care for healthy, sick, and dying patients.
- Understand prognosis prediction tools for patients in primary care and subspecialty settings.
- Identify disease trajectories that require additional palliative medicine intervention.

Generalist Role in Palliative Medicine

"Some people mistakenly believe that palliative care is only for patients who are incurably ill. The goal of palliative care is to provide relief from symptoms and stress of illness."

Raymond Yung, M.D.

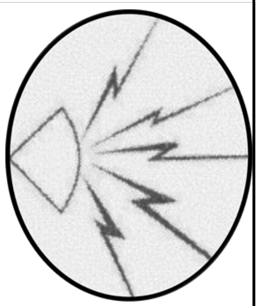
What is Palliative Care?

- Serious illness distress prevention and relief.
- Supports patients and families
  - (e.g. psychological, spiritual)
- Enhances quality of life.
- Positively impacts disease (when possible).
- Starts in early stages of illness (ideally).
- Treats dying as a normal process.

WHO Definition of Palliative Care, http://www.who.int/cancer/palliative/definition/en/; Accessed May 3, 2017.

Patient responses to palliative care

- Patient and providers find the term “palliative care” distressing.
- Societal and personal associations with close impending death.
- Early palliative medicine may be associated with longer survival.



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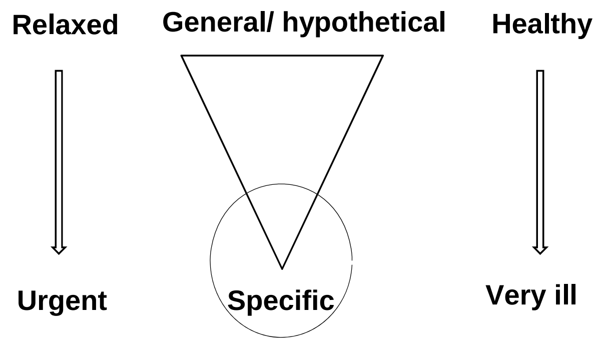
Illness and Palliative Communication: Advance Care Planning



G Modan and S Brill. Engaging death: Narrative and constructed dialogue in Advance Care Planning discussions. Communication in Medicine. Vol 11, No 2 (2014)

Case Previews- Primary Care

- 57 year old “healthy” female with hyperlipidemia and pre-diabetes.
- 65 year old male with physical disability, history of resected brain tumor, and poorly controlled HTN.
- 80 year old male with homebound patient with advanced COPD, persistent dyspnea, continuous O2 dependence.

Case # 1

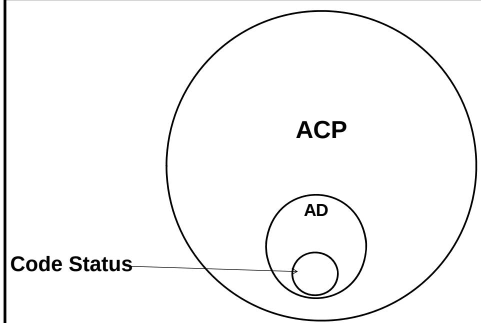
57 year old married female with hyperlipidemia and pre-diabetes who is seeing you for a wellness visit. She appears much younger than stated age and has no medical problems.

- Which palliative medicine concepts should be introduced to this patient?
- What questions should you ask her about her future care?

What is Advance Care Planning (ACP)?

Identify and prepare patient's preferred decision maker to carry out a patient's wishes for <u>a future time</u> when s/he cannot self-advocate.

Advance Directives (AD) and ACP



The Institute of Medicine Report: Dying in America (2014) and ACP

- **Gaps**
  - **> 25% of adults over 75 year "no thought" to end-of-life.**
  - **"Even fewer" have written down preferences or discussed with family or medical providers.**
  - **Patient/ provider communication about end-of-life care is "poor."**
- **Recommendations**
  - **Early, frequent ACP discussions.**
  - **Frequent updates to individualize care plan over time.**
  - **Changes to billing structure (Medicare reimbursement).**
  - **Provider education.**

Tulsky, James A. "Improving quality of care for serious illness: findings and recommendations of the Institute of Medicine report on dying in America." *JAMA internal medicine* 175.5 (2015): 840-841.

Medicare ACP Billing

- **Medicare Reimbursed**
- **99497- ACP 1st 30 minutes**
- **99498-Each subsequent 30 minutes.**
- **Incident-to billing language**
  - **Team-based care.**
- **Can be billed annually.**

Case # 1

57 year old married female with hyperlipidemia and pre-diabetes who is seeing you for a wellness visit. She appears much younger than stated age and has no other medical problems.

Which palliative medicine concepts should be introduced to this patient?

- Incorporating family.
- Death as a normal process.

How should you approach discussing her future care goals?

- Identify preferred health care agent/ family conversations.
  - http://www.nhdd.org/
- Advance Directives.
- Elicit concerns/ fears.
- Acknowledge current health and normalize future decline.

Case # 2

You are caring for a 55 year old who is 10 years s/p subtotal meningioma resection who is here for hypertension follow up. This patient has difficulty with ambulation and has limitations in ADLs, but lives at home with 24 hour assistance from aide. Residual tumor volume has been stable. However, he has major depressive disorder and poorly controlled HTN.

How do you determine his palliative needs?

High Value Care

- Promotes health
- Avoids harms
- Reduces wasteful practices
- American College of Physicians
  - Serious Illness Communication
  - Best practices
  - Physician training and patient handouts.
  - https://www.acponline.org/clinical-information/guidelines (End of Life Care)

Bernacki RE, Block SD, for the American College of Physicians High Value Care Task Force. Communication About Serious Illness Care Goals
A Review and Synthesis of Best Practices. JAMA Intern Med. 2014;174(12):1994-2003. doi:10.1001/jamainternmed.2014.5271

What are Serious Illness Communication Best Practices?

- Multiple conversations over time.
- Starting early in chronic illness.
- PCP responsible.
- Checklist driven.
- Individualized for prognosis.
- Advance directive forms are not enough.
- Clearly documented in a consistent location.

Bernacki, Rachelle E., and Susan D. Block. "Communication about serious illness care goals: a review and synthesis of best practices." *JAMA internal medicine* 174.12 (2014): 1994-2003.

Barriers

- Patient: anxiety, denial, family concerns.
- Clinician: lack of training, discomfort, and limited time, prognostic uncertainty.
- Health System: interventionist culture, no systems for communication and documentation, numerous physicians.

Failure in Serious Illness Communication

- Worse quality of life.
- Prolonged death with increased suffering (with shorter lifespan).
- Worse bereavement outcomes for family members.
- Increased costs without benefit to patients.

Systematic Serious Illness Communication

- Systematic identification of patients.
  - Pre-visit planning
- Intentional time set aside to discuss goals.
  - Scheduling.
- Clear, caring communication.
  - Provider training.
  - Checklist.
- Consistent documentation.
  - Electronic health record systems.

Systematic identification of patients.

- Registry based (Cancer, COPD, CHF, Dementia)
  - Population health.
  - Severity matters.
- Event based (Hospitalization, new diagnosis)
- Age based (e.g > 75)
- Prognosis based: “Would you be surprised if this patient died in the next year?”
  - Additional disease specific prognostic tools that are used in subspecialty setting

Communication Principles

- Schedule templates for ACP (longer visits).
- Practice to overcome discomfort.
- Visit communication:
  - Acknowledge anxiety.
  - Ask patient questions (patient/ family understanding, concerns, goals of treatment).
  - Prognosis.
  - Listen (more than you talk).

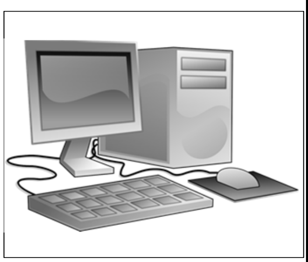
Prognosis: Prediction, Prophecy, Probability?

- Leading area of discomfort in ACP.
- Clinician's gestalt is evidence based.
- Mortality risk calculator.
  - www.eprognosis.org

Glare, Paul, et al. "Predicting survival in patients with advanced disease." *European journal of cancer* 44.8 (2008): 1146-1156.
Moss AH, Lunney JR, Culp S, et al. Prognostic significance of the "surprise" question in cancer patients. *J Palliat Med*. 2010;13(7):837-840.

Documentation

- No best practice guidelines.
- Currently throughout electronic health record.
- Inconsistent.
- Pick a place (easy to find).
- Health system consensus.



Wilson CJ, Newman J, Tapper S, et al. Multiple locations of advance care planning documentation in an electronic health record: are they easy to find? *J Palliat Med*. 2013;16(9):1089-1094.

Case #3

You are seeing an 80 year old patient with advanced COPD, on continuous O2 (4 LPM) for hospital follow up. He lives alone. Other co-morbidities include HTN, DM, Hep C with cirrhosis, and a chronic occult lower GI bleeding. He was admitted for a COPD exacerbation and reports that he was "almost put on a breathing machine." He felt "terrified." Unprompted, he says, "I don't know what I'd do if I had to be on one of these breathing machines, but I am really afraid to die."

How do you meet this patient's palliative care needs?

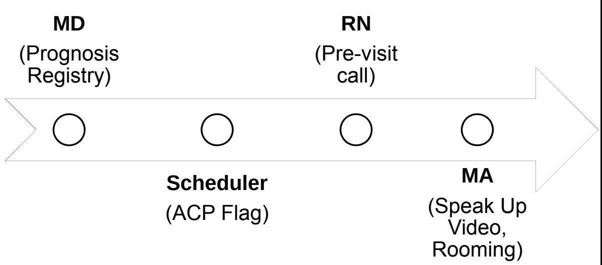
- Moss AH, Ganjoo J, Sharma S, et al. Utility of the “surprise” question to identify dialysis patients with high mortality. *Clin J Am Soc Nephrol*. 2008;3(5):1379-1384.

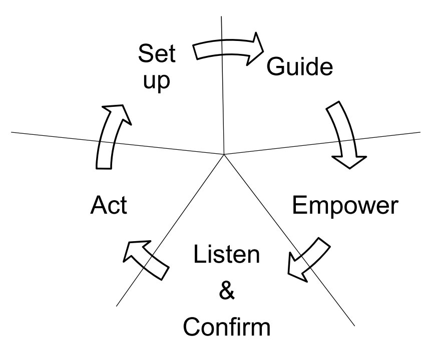
Bernacki, Rachelle E., and Susan D. Block. "Serious illness communications checklist." *Virtual Mentor* 15.12 (2013): 1045.

Pre-visit Planning in Primary Care

- **Built upon registry.**
- **Team based.**
- **No one absolved.**
- **Normalization.**
- **Gentle preparation of patient.**

ACP Registry Based Pre-Visit Workflow





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Case Studies in Palliative Medicine

Todd Barrett, MD
Director of Palliative Medicine Ross Heart Hospital
Assistant Professor - Clinical
Department of Internal Medicine
Division of Palliative Medicine
The Ohio State University Wexner Medical Center

Objectives

- Define Palliative Care
- Understand the Role of POLST
- Review Illness Trajectories
- Four Box Model for Medical Ethics
- Learn Simple Tool for Assessing Goals of Care

25% of deaths occur at home - more than 70% of Americans would prefer to die at home

(Robert Wood Johnson Foundation)

Modern End of Life=Protracted Course

- **85% of people in the US will experience one of these trajectories at the "end of life"**
  - **20% Cancer**
  - **25% Organ Failure**
  - **40% Dementia/Frailty**
- **Average American 2-4 years of disability before death**

POLST

- **Physician Order for Life Sustaining Treatment**
- **Unique Feature – PHYSICIAN ORDER**
- **2006 National Quality Forum named POLST as an Advance Directive the most thoroughly addresses patient preference.**

- **Started in 1991 in Oregon**
- **Over 20 states have adopted POLST**
- **Intended for patients with advanced illness.**

- ***National Quality Forum (2006). A National framework and preferred practices for palliative and hospice care quality. Washington D.C.[dead link]***
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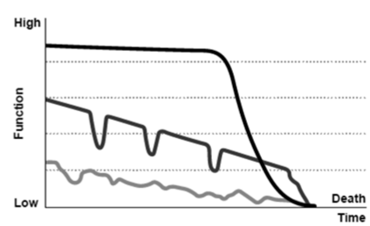
Trajectory of Illness



WHO Definition of Palliative Care

Palliative care:
- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;

- http://www.who.int/cancer/palliative/definition/en/.

Who Provides Palliative Care?

- Interdisciplinary
- Key members
  - Doctors
  - Nurses
  - Social Workers
  - Chaplains

What do we really do???

- Assess prognostic awareness
- Assimilate medical information for the family
- Assess and treat symptoms
- Assess quality of life goals and facilitate patient centered decision making
- Psychosocial assessment and make referrals

Palliative vs. Hospice Care

- Division made between these two terms in the United States
- Hospice is a “type” of palliative care for those who are at the end of their lives.

http://www.ersj.org.uk/content/32/3/796.full

Hospice

- Provides support and care for those in the last phases of life-limiting illness
- Recognizes dying as part of the normal process of living
- Affirms life and neither hastens nor postpones death
- Focuses on quality of life for individuals and their family caregivers

Hospice Team Members

- The patient's personal physician
- Hospice physician (medical director)
- Nurses
- Home health aides
- Social workers
- Clergy or other counselors
- Trained volunteers
- Speech, physical, and occupational therapists

Who Pays?

- Medicare
- Medicaid
- Insurance
- Private pay
- Sometimes a combination of these…

Medicare

- Medicare Part A
  - Hospitalizations and Hospice
- Medicare Part B
  - Durable equipment, outpatient care, ambulanced
  - “Medically necessary services”
  - Hospice paid as per diem

Admission Criteria

- General
  - Life-limiting illness, prognosis is 6 months or less if disease takes normal course
  - Live in service area
  - Consent to accept services

Prognostication

- It is HARD! One of the most biggest challenges in out specialty.

Four Box Model

Medical Indications The diagnostic and therapeutic interventions that are being used to evaluate and treat a problem.	Patient Preferences The express choices of a patient about their treatment or decisions or the decisions of a surrogate.
Quality of Life Describes features of the patient's life prior to and following treatment, insofar as they pertain to decision making.	Contextual Features Identify familial, social, institutional, financial, and legal settings within the case that pertain to decision making.

Jonsen et al. (2010)

Four Box Model

Medical Indications What are the goals of treatment? In what circumstance is treatment not indicated?	Patient Preferences Has the patient been informed of the benefits and risks, understood this information, and given informed consent?
Quality of Life	Contextual Features

Jonsen et al. (2010)

Medical Decision Making:
In what circumstance is treatment not indicated?

- "Medically indicated" describes what a sound clinical judgment determines to be physiologically and medically appropriate
- When not indicated
  - No scientifically demonstrated effect
  - Interventions known to be efficacious but have individual differences in individual patients
  - A treatment indicated earlier in the course in not indicated later

Patient Preferences

- The choices that persons make when they are faced with decisions about health and medical treatment
- Principle of autonomy - the moral right of every individual to choose and follow his or her own plan of life and actions

Patient Preferences: Informed Consent

- Has the patient been informed of the benefits and risks, understood this information, and given informed consent?
- Mutual participation, good communication, mutual respect, shared decision making
- Reciprocal relationship that benefits both the physician and the patient

Beauchamp & Childress (2009)

How to avoid ethical dilemmas?

- Clearly defined goals of care which are readdressed frequently across disease spectrum
- Clear informed consent

Exploring Goals of Care: Cardinal Questions

1. **Who is your loved one (as a person)?**
2. **What is your understanding of your loved one's illness? What does the illness mean to you and your family?**
3. **In light of your understanding, what is most important regarding your loved one's care?**
4. **What are your hopes for your child? What are your fears and concerns regarding your loved one?**
5. **Where do you find support and strength?**