

ATTENTION

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GPTN Webinar Series

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Talking with Your Seriously Ill Patients About Their Goals of Care, and Accessing Palliative or Hospice Care

Presented by

Stephen Goldfine, MD

Chief Medical Officer

Samaritan Healthcare & Hospice

SamaritanNJ.org



Objectives

Attendees will be better able to:

- Define palliative care and its role in the value-based care continuum
- Demonstrate improved speaking and listening skills.
- Articulate ways to discuss goals of care, including hospice and palliative care.
- Incorporate effective palliative practices into patient care



Outcome #1

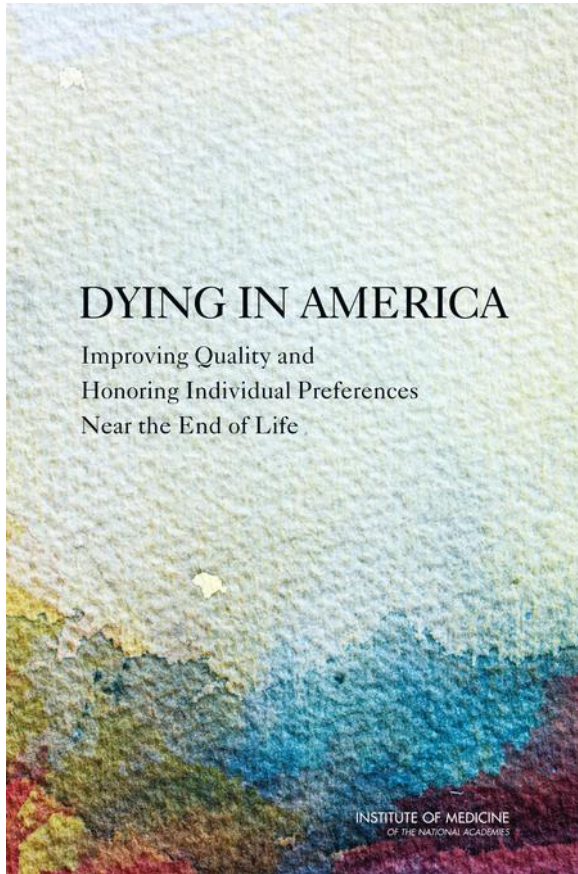
Healthcare professionals should be able to have comfortable, mindful conversations with patients concerning prognosis, treatment goals, etc. from diagnosis through end of life.



Outcome #2

Healthcare professionals should be able to incorporate the benefits of palliative care into their practices and understand when to trigger palliative specialist referrals to improve their patients' and families' healthcare experience and quality of life.

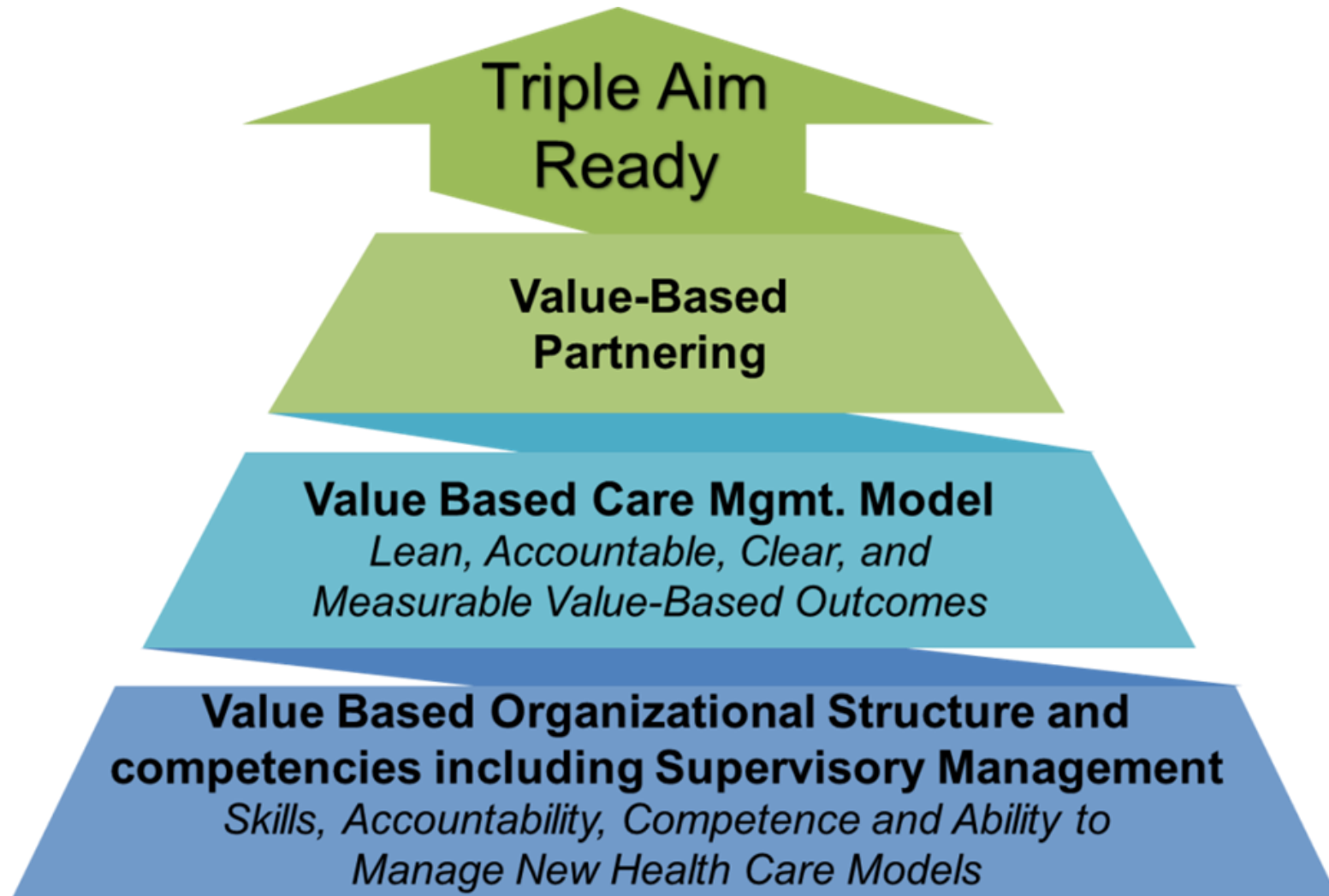
Setting the Stage: Institute of Medicine



- 2.5 million deaths in US in 2011
- Life expectancy increasing
- Multiple chronic conditions
- Fastest growing age 85
- 2/3 of population over 65
- Causes of death
 - 58.3%: heart disease, cancer, CVA, pulmonary disease
 - 4.9 %: unintentional injuries

Source: *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, Institute of Medicine (2015)

Healthcare's Shared Goals



Shift from Volume to Value-based Care?

Volume

- Fragmented providers and payments
- No uniform quality
- Fees for volume
- Demand increasing

Value

- Collaboration, connectivity
- Clinical, financial data, analysis
- Optimize outcomes
- Accountable care

Troubling Care Gap

What People Want

1. Be at home with family, friends
2. Have pain, symptoms managed
3. Have spiritual needs addressed
4. Avoid being a burden to family

What They Get

Multiple hospital admissions

Often unwanted, ineffective treatment

Often die in hospital, in pain and isolation

At great cost to families and the nation.

Financial Impact

Consider this:

Patients with chronic illness in their last two years of life account for about **32% of total Medicare spending**, much of it going toward physician and hospital fees associated with **repeated hospitalizations**.

Source: Dartmouth Atlas Project

A dubious distinction!

New Jersey consistently ranks among the highest/lowest against key benchmarks.

Dartmouth Atlas Report

Dartmouth Atlas Study 2006 vs 2014

Factor	NJ 2006	NJ 2014	US Avg. 2006	US Avg. 2014	NJ Rank among 50 states (incl. DC) 2006	NJ Rank among 50 states (incl. DC) 2014
Hospital days per decedent during last 6 months of life	15.2	10.6	11.7	7.9	49	50
ICU days per decedent during last 6 months of life	4.6	5.7	3.2	3.5	50 (tie)	51
Physician visits per decedent during last 6 months of life	41.5	40.1	29.0	26.5	51	51
% deaths associated with admission to intensive care	25.1	20.2	18.5	14.7	51	51
% enrolled in hospice	23.5	47.8	27.2	52.0	32 (tie)	39
Days spend in hospice	12.7	19.6	17.0	23.3	42	31
Medicare spending & resource inputs during last 2 years of life	\$39,810	\$83,996	\$29,199	\$69,289	51	50

A New Approach to the Continuum

Traditional medical model:

- Treats disease; feelings, pain/symptoms often not addressed
- Families often secondary consideration
- Doctors trained to “fix” problems.
- Nurses and other healthcare professionals trained to care for whole patient but also want to “fix” patients

Palliative Care: Beyond the Fixable Model

As population ages, more chronic conditions NOT fixable :

- COPD & other chronic lung diseases
- CAD
- PVD (wounds, phlebitis)
- Damage from diabetes
- Cancer
- The list goes on

Palliative Medicine

All hospice care is palliative. Not all palliative care is hospice.

What it is:

- Expert treatment of pain and symptoms
- Listening and answering patient/family questions about disease and treatment options
- Matching treatments to patient's goals
- Helping to coordinate and share information with patient's other doctors and health care providers

What it's not:*

- **Only** provided during hospice care
- A signal that treatment isn't working
- Morphine-only treatment
- Something you should wait to ask for

**American Lung Association*

Palliative Medicine Goals

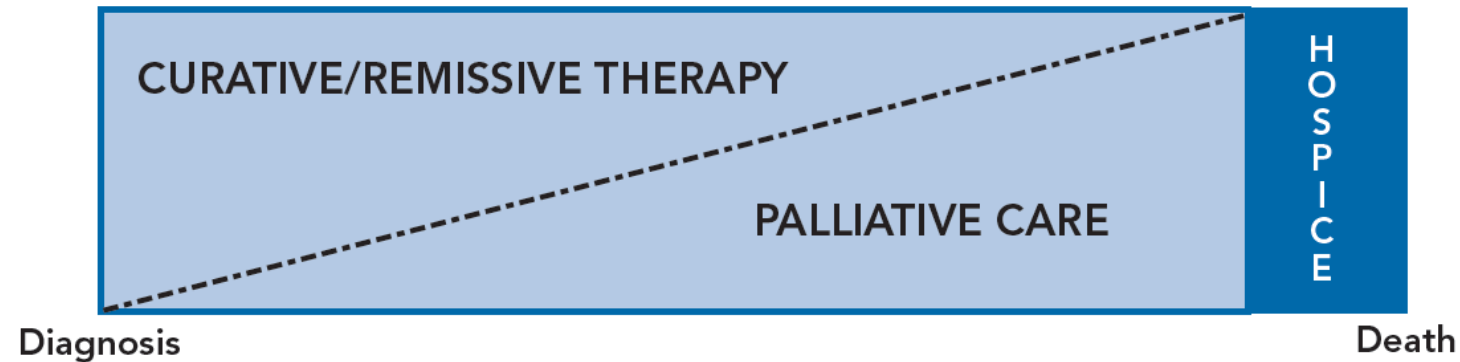
- **Improve quality of life** by addressing physical, spiritual, emotional needs
- Help patient & family better **understand patient's condition and choices for care**
- Improve patient's **ability to tolerate medical treatments**
- Enable patient & family to **carry on** with everyday life

The Need: Broadening E-O-L Focus

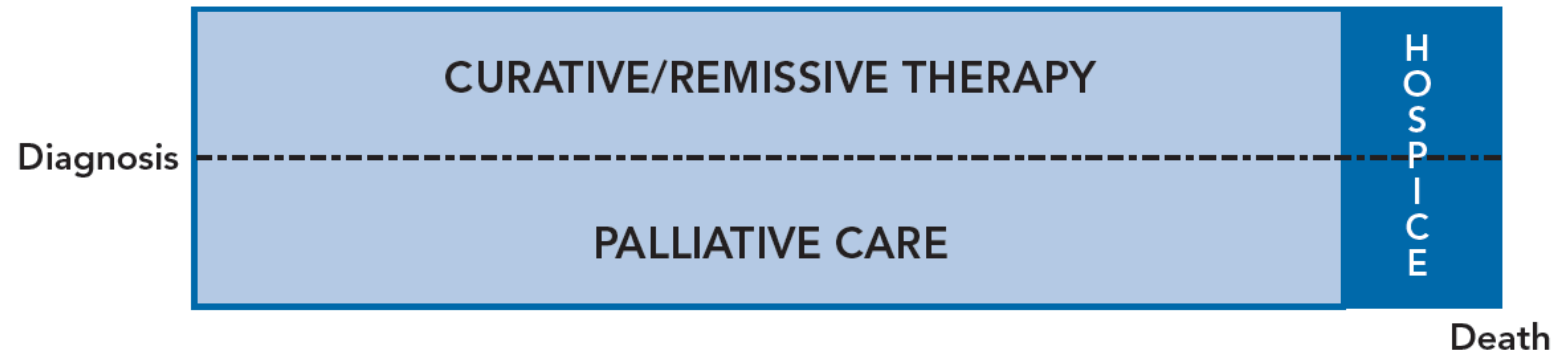
- Differentiating palliative medicine vs. hospice care
- **Making the case for community based palliative care across the continuum**

Current vs. Ideal

CURRENT USE OF PALLIATIVE CARE

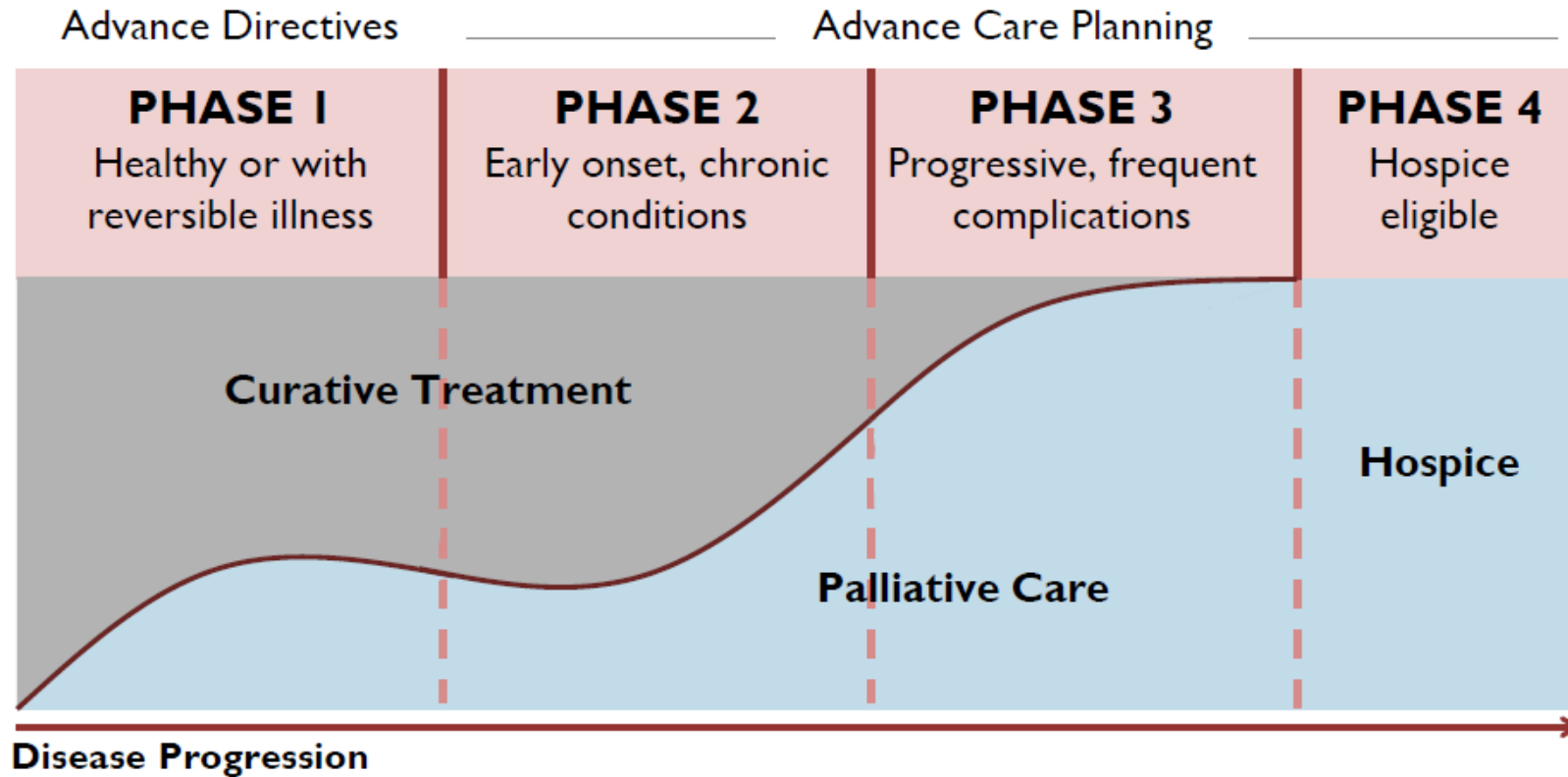


IDEAL USE OF PALLIATIVE CARE



Advanced Illness Management (AIM)

Phases of AIM



Source: AHA CPI analysis, 2012, with contributions from 2012 C-TAC data and 2011 Center to Advance Palliative Care data.

Addressing Physician Shortage

Primary vs. Secondary Palliative Care:

- Palliative Medicine part of “good medical care” for primary care or primary specialist (e.g. pulmonologist or oncologist)
- Sub-specialty palliative care needed for:
 - complex pain
 - non-pain symptoms
 - conflict-rich communications
 - complicated psychosocial and/or spiritual distress

Source: Strand et al., Mayo Clinic, August 2013

General Palliative Criteria

A Palliative Care Consult should be considered in any of the following contexts:

A. Primary Disease Process	B. Concomitant Factors	C. Other Criteria to Consider	D. Call Consult Before Discussions About:
<ul style="list-style-type: none"> • Cancer (Active/Metastatic/Recurrent) • Advanced COPD • Advanced CHF (EF<25%) • Cardio-Respiratory Arrest with Cerebral Hypoxia/Anoxia • Shock with Multiple Organ Dysfunction Syndrome (MODS) • Advanced Neurodegenerative Disease (e.g., Dementia, Parkinson's, Amyotrophic Lateral Sclerosis ALS) • ESRD and/or ESLD • Stroke with at least 50% decreased functional ability • Actively dying patient 	<ul style="list-style-type: none"> • Hemodialysis • Liver Disease • Moderate CHF, Coronary Artery Disease (CAD), Severe Valvular Disease, Cardiomyopathy, Pulmonary Hypertension • Bed-bound/Dysphagia/Failure to Thrive/Functional Decline/Pressure Ulcers • Complex medical decision making/Family disagreements/Conflicts about care • Patients from Long-Term Care Centers • Patients on home hospice 	<p>The Patient is/has:</p> <ul style="list-style-type: none"> • A life-limiting illness • Unacceptable level of pain > 24 hours • Uncontrolled symptoms (i.e., dyspnea, nausea, vomiting, anxiety) • Frequent visits to the ER • More than one hospital admission for the same diagnosis in the last 30 days • Prolonged intensive care unit (ICU)/hospital stay without evidence of progress or improvement • Transferred from hospital floor to ICU • S/P cardiorespiratory arrest • Medical Futility 	<ul style="list-style-type: none"> • PEG tube for artificial nutrition • Tracheostomy for prolonged mechanical ventilation • Shiley or Permacath for Hemodialysis • Withdrawal of ventilatory support

Palliative vs. Hospice Care

All hospice care is palliative.
Not all palliative care is hospice.

Palliative Medicine:

- Treats *symptoms* across spectrum of chronic disease
- Does not require a terminal diagnosis
- Benefits patients before or after treatments

Hospice:

- *Branch of palliative medicine reserved for those with prognosis of 6 months or less*
- *A Medicare and insurance benefit that participants are entitled to*

Benefits of Good Communication

“Without clear, goal-directed communication, care loses its purpose. When the purpose of care (aggressive treatment or quality-of-life preservation) becomes muddled or even lost in an unfortunate battle of wills, distress is certain to occur in patients, families, and caregivers.”

Marcus & Mott (2014). Difficult Conversations: From Diagnosis to Death, The Ochsner Journal, 14:712



National Room for Improvement

- A recent study shows that approximately **42% of individuals** have had discussions on end-of-life issues.
- Yet **only 23%** put their wishes in writing and/or legal/medical documentation e.g. POLST, Five Wishes, etc.
- And **90%** said that their physicians never asked about this issue – despite CMS reimbursement since 2016!

Source: John H. Hartford Foundation

Work to Do in New Jersey

April 2014 NJ poll:

- 38% - **never** discussed end-of-life wishes with their families
- 54% - **no** written document for end-of-life wishes



Source: "Health Matters" poll conducted by New Jersey Health Care Quality Institute and Monmouth University Polling Institute

Benefits of Good Communication

- Improve accuracy of diagnosis and quality of management * **
- Improve eliciting and imparting of information
- Improve patients' understanding, retention of information, compliance **
- Reduce anxiety, uncertainty , and litigation *
- Improve doctor and patient satisfaction *

*Dias et al. (2003). Breaking Bad News: A Patient's Perspective, The Oncologist, 8:592.

** Belanger et al. (2014). Initiating decision-making conversations in palliative care: an ethnographic discourse analysis. BMC Palliative Care, 13:63.



Communication in End-of-Life Care

- Fundamental aspect of palliative care
- Ethical obligation*
- Advanced or terminal illness is a family experience
- Is a major area of need
- Requires interdisciplinary collaboration

* Lenherr, G., Meyer-Zehnder, B., Kressig, R., Reiter-Theil, S. (April 5, 2012). To speak, or not to speak – do clinicians speak about dying and death with geriatric patients at the end of life? *Swiss Med Wkly*, 142: w13563, p. 1



Factors Influencing Communication

- **Patient/Family**

- Family systems/culture
- Financial/educational
- Physical/cognitive limitations *(Lenherr et al., p. 4)*
- Coping/grief

Factors Influencing Communication

- **Health care professionals**

- Fear of own mortality
- Discomfort /lack of confidence to give bad news
(Lenherr et al., p.4)
- Inaccuracy of prognostication
- Fear of patient thinking doctor has “given up”
(Lenherr et al., p. 5)
- Fear of removing patient’s hope *(Pino et al., p.2)*

Factors Influencing Communication

- **Health care professionals (cont.)**
 - Lack of cultural understanding
 - Lack of training
 - Lack of time
 - Gender differences



Other Barriers

- Lack of privacy
- Interruptions & distractions
- Palliative care stigma*
- Ageism of healthcare workers**
- Overprotectiveness of family**

All contribute to stress.

*Granek, L., Krzyzanowska, M., Tozer, R., Mazzotta, P. (July 2013). Oncologists' Strategies and Barriers to Effective Communication About the End of Life, jop.ascopubs.org, p. e132. Downloaded February 24, 2015.

** Lloyd A., Kendall M., Carduff, E., Cavers, D., Kimbell, B., Murray, S.A.. (2016) Why do older people "get less palliative care than younger people?", European Journal of Palliative Care, 23(3).



Communication Process

- **The Message**

- Most difficult aspect in end of life discussions
 - Doctors poor prognosticators; tend to avoid subject
 - Influenced by culture

- **The Speaker**

- Clear, sensitive, and have proper vocabulary
 - Be direct, but not excessively blunt
 - Balance honesty/realism with sensitivity/support
 - Give *realistic* hope (for comfort if not cure)
 - Convey that patient/family will not be abandoned (*Dias et al.*)

Broaching the Topic of Hospice and Palliative Care

- Initiate conversation early in disease course, when patient is still feeling well *
- Ask what the patient/family already know and how much they want to know
- Advanced age, level of depression etc. may limit what patient wants to know (*Dias et al.*)
- Use language they understand

*Ngo-Metzler, Q., August, K., Srinivasan, M., Liao, S., Meyskens, F. (January 15, 2008). End-of-Life Care: Guidelines for Patient-Centered Communication, *American Family Physician*, 77(2): 168. Downloaded February 24, 2015.



Broaching the Topic of Hospice and Palliative Care

Studies indicate:

- Patients and families value being able to prepare for death
- Delays in discussions often lead to later hospice admission, and fewer opportunities to say goodbye, complete personal and financial arrangements, and plan for last phase of patient's life.

Cherlin et al.

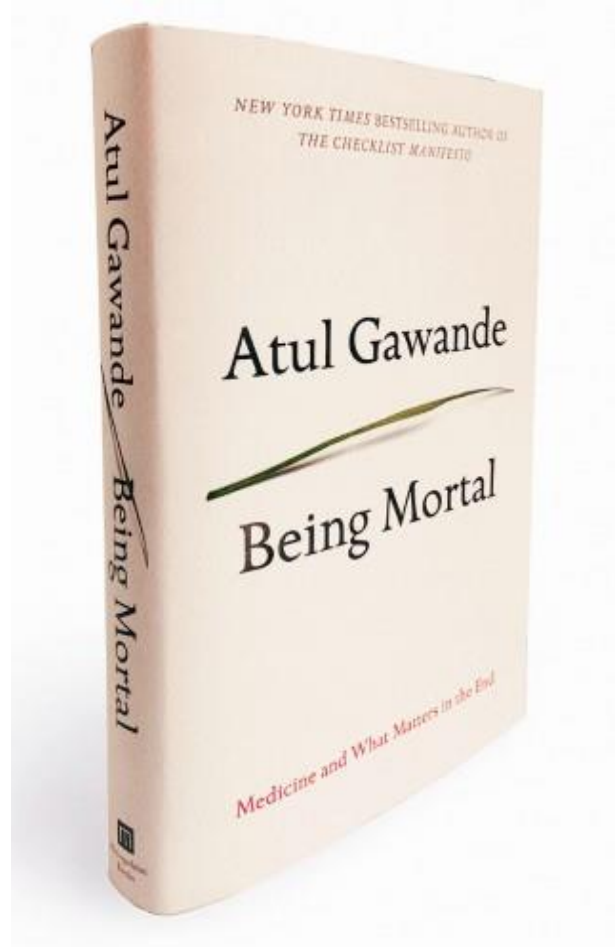


Broaching the Topic of Hospice and Palliative Care

- **Review the goals of palliative care**
 - Symptom management
 - Achieve the best quality of life for the patient and his or her family
 - Address all needs: physical, emotional, spiritual



Atul Gawande's 5 Basic Questions



What is your understanding of your health or your condition at this point?

What are your fears and worries for the future?

What are your goals or priorities if time becomes short?

What outcomes are unacceptable to you?

What does a good day look like?

Broaching the Topic of Hospice and Palliative Care

Physicians' Dilemma:

Denying patient/family opportunity to plan
vs. taking away hope.

One solution: Elaboration solicitations

- Fishing questions
- “You said”-prefaced paraphrases
- Floating a possible end of life thoughts

“SPIKES”

S	Setting & Set-up
P	Patient’s perception
I	Invitation
K	Knowledge (imparting)
E	Empathetic response
S	Summary/Strategy

(Baile WF et al., 2000)

“SPIKES”

Setting & Set-up

- **Who:** Assemble the important people
- **What:** Get the facts straight, key informants
- **When:** Find time, don't rush
- **Where:** Quiet, private room (*in the ED?!);* minimize interruptions
- **Why:** Purpose of the meeting

“SPIKES” Perception

What does the patient know?

“What have the other doctors told you?”

“Tell me what you understand...”

“Just to make sure we’re on the same page, ...”

Sometimes patient gives/knows the bad news

“When you think of becoming critically ill, what worries you most?”

Observe for emotion

“SPIKES” Invitation

- **Ask permission**
“Would it be ok to discuss the results of your CT...?”
- **Ask for preferences**
 - How much detail?
 - Who else present?
 - *“Have you thought about who should speak for you if you were unable to speak for yourself?”*
 - Goals of Care
 - *“How do you define quality of life?”*
 - *“Have you thought about whether you’d want CPR if you were to stop breathing? May I discuss potential CPR outcomes with you?”*
 - Cultural considerations

“SPIKES” Knowledge

- Give information clearly, in small chunk(s)
- Focus on big picture and what info means
- Use plain English, no jargon
- Then stop talking!

“SPIKES”

Empathy

- Silence
- Acknowledge Emotion:
N-U-R-S-E statements (for all clinicians)
 - Naming-*“it sounds like you're are frustrated”*
 - Understand-*“this helps me understand what...”*
 - Respecting-*“I can see you have done what was asked”*
 - Supporting-*“I'll make sure you have what you need”*
 - Exploring-*“Could you say more about that?”*

“SPIKES” Summary

- Confirm understanding
 - “What questions do you have?”*
 - “I want to be sure I explained this well, can you tell me what you understand?”*
- Make a plan for follow-up / next steps

Common Statements to Avoid

- *“There’s nothing we can do for you.”*
- *“It’s time to think about withdrawal of care.”*
- *“You’ve failed the treatment.”*
- *“I think you should consider hospice.”*

Alternatives: Statements to Use

- *“We can offer many options to control your symptoms and make you feel better.”*
- *“Do you think it’s time to consider a different type of treatment, which focuses on your symptoms? I’ll be here with you no matter what you decide.”*
- *“I want to provide intense, coordinated care with a team of professionals who will treat your symptoms and help you stay comfortable.”*



General Tips: Discussing Difficult Topics

- Prioritize 2 - 4 key points patient should retain
- Coordinate key prognosis points with all providers, for consistent messages
- Multiple visits may be needed *(Ngo-Metzger et al.)*
- Continually probe patient's understanding
- Ask patient how he/she feels
- Leave time for questions *(Dias et al.)*



Bob D's Story: One Patient's Palliative Experience



Why it matters

Providing high-quality care for people who are nearing the end of life is a matter of professional commitment and responsibility.... [that] could not only enhance quality of life through the end of life, but may also contribute to a more sustainable care system.

*Source: Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life
Institute of Medicine of the National Academies*

Questions?



Hackensack
Meridian Health
JFK Medical Center

Preliminary Announcement

The Office of CME & the Bioethics Committee of Hackensack Meridian Health (HMH), JFK Medical Center invite you to attend:

***Decision-Making in Medicine: Using a Four-Step Approach to Improving Care
- An Introduction to the NJ POLST Form****

Keynote Speaker: David Barile, MD

Founder and Executive Medical Director, Goals of Care, Princeton, NJ

Date: Wednesday Evening, October 3, 2018

Location: HMH, JFK Conference Center; Time: 5:00-8:45-pm

Audience

Physicians and Dentists in All Specialties, nurses, social workers, long term care administrators, and other health professionals.

Educational Objectives

At the conclusion of this CME activity, participants should be able to:

1. Apply effective communication strategies and more comfortably engage in discussions of end of life issues with patients, families, and professional colleagues.
2. Identify barriers to good decision-making at end-of-life.
3. Discuss the importance of prognostication in decision-making.
4. Incorporate the NJ POLST form during end-of-life discussions.
5. Problem solve approaches to clinical and ethical dilemmas in care of patients at end of life.

Program

5:00-5:25 Registration & Dinner Buffet

5:25-5:30 Opening Remarks/Introduction: *Robin O. Winter, MD*

5:30-6:30 Interactive Activity: Strategies for Effective Communication – *Tracy Grafton, LCSW*

6:30-8:30 **Keynote Presentation: “Decision-Making in Medicine: Using a Four-Step Approach to Improving Care – *David Barile, MD***

8:30-8:45 Q & A / Closing Remarks – *Robin O. Winter, MD, Tracy Grafton, LCSW*

Your cooperation in confirming attendance by phoning Mary

Ann Laurita at 732-632-1564

**or emailing mlaurita@jfkhealth.org by September 28 is
appreciated.**



Tyla Housman

Vice President of External Affairs

thousman@njhcqi.org

<http://www.njhcqi.org/>