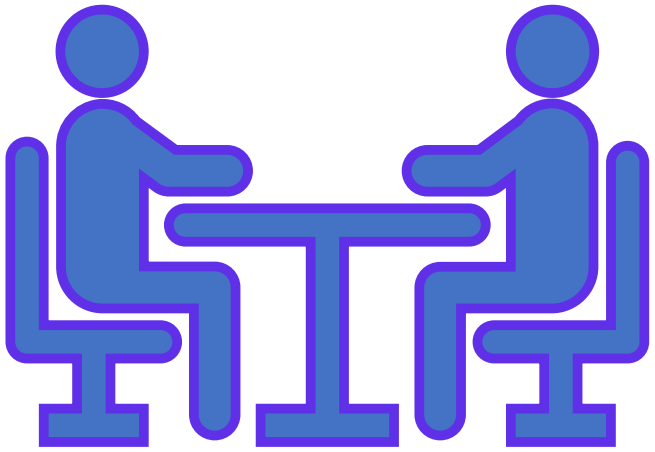
Palliative Medicine Update 2021:

Communicating, Planning and Executing Optimal Palliative Care

Jason R. Beckrow, DO FACOI, HMDC

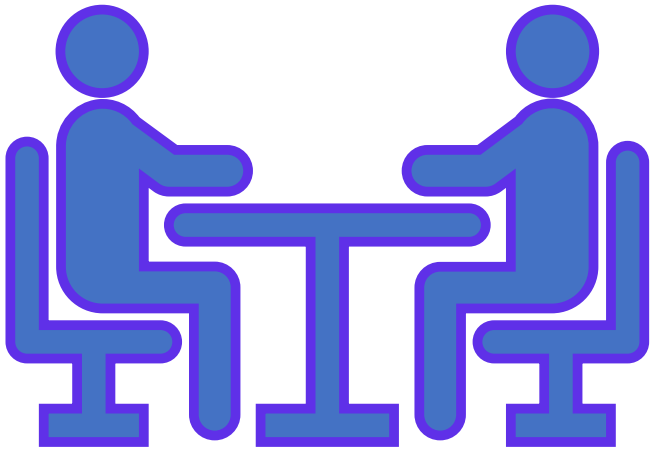
Medical Director, Hospice and Palliative Medicine

Caring Circle, Spectrum Health Lakeland



OBJECTIVES

- Present current state of patient communication
  research and training
- Present Current state of Advance Care Planning (ACP)
- Benefits of longitudinal palliative medicine intervention



DISCLOSURES:

- NONE

SPECIAL ARTICLE

THE NATURE OF SUFFERING AND THE GOALS OF MEDICINE

ERIC J. CASSEL, M.D.

ct The question of suffering and its relation anic illness has rarely been addressed in the al literature. This article offers a descrip- f the nature and causes of suffering in patients going medical treatment. A distinction based inical observations is made between suffering physical distress. Suffering is experienced by ons, not merely by bodies, and has its source allenges that threaten the intactness of the per- as a complex social and psychological enti- ty. Suffering can include physical pain but is by no means limited to it. The relief of suffering and the cure of disease must be seen as twin obligations of a medical profession that is truly dedicated to the care of the sick. Physicians' failure to understand the nature of suffering can result in medical intervention that (though technically adequate) not only fails to relieve suffering but becomes a source of suffering itself. (N Engl J Med. 1982; 306:639-45.)

HE obligation of physicians to relieve human suffering stretches back into antiquity. Despite is fact, little attention is explicitly given to the oblem of suffering in medical education, research, practice. I will begin by focusing on a modern para- ox: Even in the best settings and with the best phy- icians, it is not uncommon for suffering to occur not nly during the course of a disease but also as a result of its treatment. To understand this paradox and its resolution requires an understanding of what suffering is and how it relates to medical care.

Consider this case: A 35-year-old sculptor with metastatic disease of the breast was treated by competent physicians employing advanced knowledge and technology and acting out of kindness and true concern. At every stage, the treatment as well as the disease was a source of suffering to her. She was uncertain and frightened about her future, but she could get little information from her physicians, and what she was told was not always the truth. She had been unaware, for example, that the irradiated breast would be so disfigured. After an oophorectomy and a regimen of medications, she became hirsute, obese, and devoid of libido. With tumor in the supraclavicular fossa, she lost strength in the hand that she had used in sculpturing, and she became profoundly depressed. She had a pathologic fracture of the femur, and treatment was delayed while her physicians openly disagreed about pinning her hip.

Each time her disease responded to therapy and her hope was rekindled, a new manifestation would appear. Thus, when a new course of chemotherapy was started, she was torn between a desire to live and the fear that allowing hope to emerge again would merely expose her to misery if the treatment failed. The nausea and vomiting from the chemotherapy were distressing, but no more so than the anticipation of hair loss. She feared the future. Each tomorrow was seen as heralding increased sickness, pain, or disability, never as the beginning of better times. She felt isolated because she was no longer like other people and could not do what other people did. She feared that her friends would stop visiting her. She was sure that she would die.

This young woman had severe pain and other physical symptoms that caused her suffering. But she also suffered from some threats that were social and from others that were personal and private. She suffered from the effects of the disease and its treatment on her appearance and abilities. She also suffered unremittingly from her perception of the future.

What can this case tell us about the ends of medicine and the relief of suffering? Three facts stand ou The first is that this woman's suffering was not co fined to her physical symptoms. The second is th she suffered not only from her disease but also from treatment. The third is that one could not anticip what she would describe as a source of suffering;

From the Department of Public Health, Cornell University Medical College, New York. Address reprint requests to 411 E. 69th St., New York, NY 10021.

Supported in part by a Sustained Development Award for Ethics and Values in Science and Technology (NSF OSS 80-18086) from the National Science Foundation and the National Endowment for the Humanities.

THE RELIEF OF SUFFERING

- *Physicians' failure to understand the nature of suffering can result in medical intervention that (though technically adequate) not only fails to relieve suffering but becomes a source of suffering itself.*

- *- Eric Cassel, 1982*

"There's no easy way I can tell you this, so I'm sending you to someone who can."

PATIENT COMMUNICATION RESEARCH AND TRAINING: GOALS OF PATIENTS AND PROVIDERS

- What is most important to you?
- Avoiding inappropriate prolongation of dying
- Relieving the burden on the family
- Achieving a sense of control
- Strengthening relationships with loved ones
- Ensuring that all medical options are considered in continuing to fight against the disease

PATIENT COMMUNICATION RESEARCH AND TRAINING: GOALS OF PATIENTS AND PROVIDERS

- ABCs
  - Allyship
  - Build Rapport
  - Cede Power

- **What is most important to you?**
  - May be medical
  - May not

Patient communication:

Discussing Serious News

Serious News vs Bad News

- Any information likely to alter drastically a patient's view of his or her future
- Results in a cognitive, behavioral, or emotional deficit in the person receiving the news that persists for some time after the news is received
- Alternative term for "breaking bad news" is "sharing life-altering information"

Back AL et al 2011
Ptacek JT et al 1996

Patient communication research and training: Discussing Serious News

Patient Preferences:

- Most want to know, but how much?
- Cross Cultural differences,
  - Racial, gender, economic, age, etc.
  - Respect Power Gradient
- How serious news is delivered is as important as what is conveyed.
  - In person vs distant communication.
  - Direct and clear vs. euphemism.
  - Honesty vs hope and optimism.
- Effect on clinicians.
- All efforts augmented by relationship and rapport.

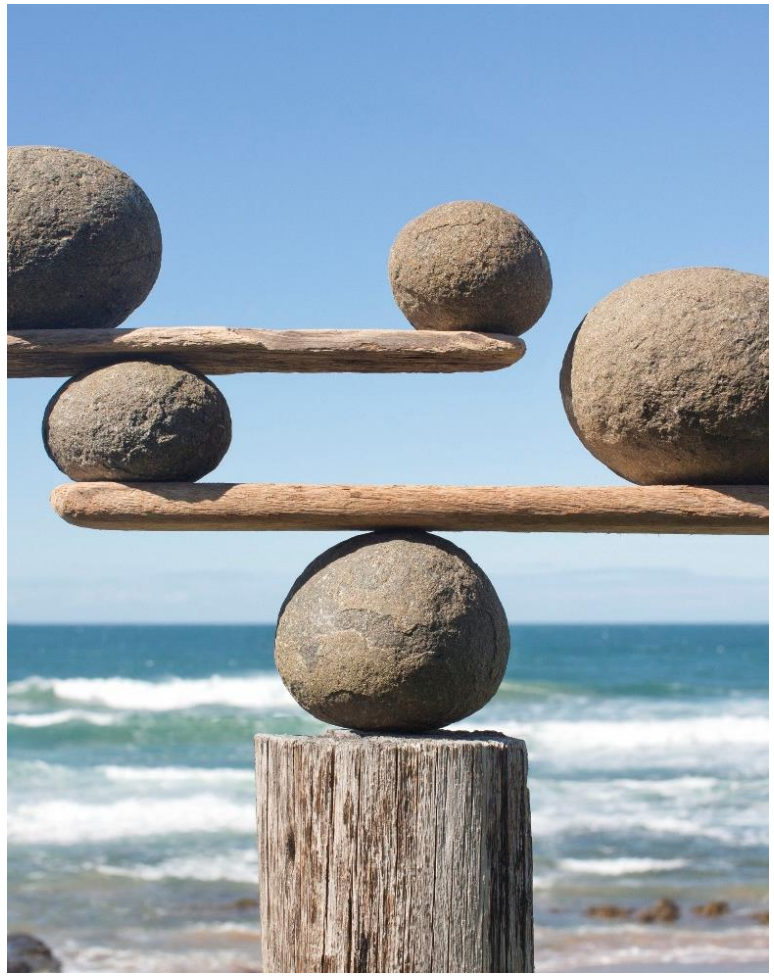
Back AL et al 2011
Ptacek JT et al 1996

Patient communication research and training:

Discussing Serious News: SPIKES

- Setting
- Perception
- Invitation
- Knowledge
- Emotions
- Strategy and Summary

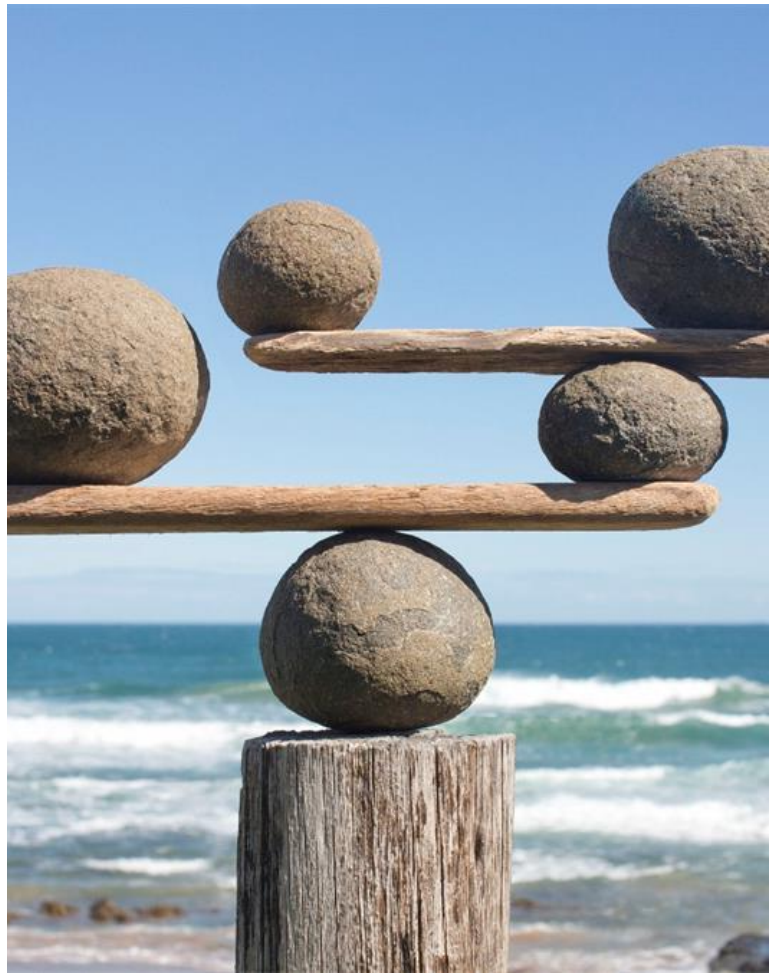
Back AL et al 2011
Ptacek JT et al 1996



PATIENT COMMUNICATION RESEARCH AND TRAINING DISCUSSING SERIOUS NEWS

- Discussing serious news is a common communication process that clinicians and patients can find challenging
- The term “serious news” is preferred to “bad news” as what constitutes “bad news” depends heavily on the patient’s beliefs and perceptions
- In general, patients would like clinicians to share serious news in a quiet, private setting, use straightforward language without medical jargon, offer support, and a clear plan for next steps.

Back AL et al 2011
Ptacek JT et al 1996



PATIENT COMMUNICATION RESEARCH AND TRAINING: DISCUSSING SERIOUS NEWS

- The manner in which serious news is received depends on many factors:
  - Patient expectations
  - Prior Experience
  - Personality and disposition.
- Patient experience and quality outcomes routine fluctuate as a function of communication effectiveness
- Build the Relationship
- Earn the Trust
- Respect the Power Gradient

Back AL et al 2011
Ptacek JT et al 1996

Advance Care Planning (ACP)

Advance care planning (ACP) is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care.

The goal of ACP is to help ensure that people receive medical care that is consistent with their values, goals,
and preferences

Regardless of the clinical scenario, ACP should be proactive, appropriately timed, and integrated into routine care

Sudore, RL et al. 2000

Advance Care Planning (ACP)

- Successful ACP programs not only ensure that doctors, patients, and families talk about future care, but also that the content of those conversations is documented in a fashion that travels with the patient as he or she moves across health care settings

- Documentation can assist greatly in decision-making if the individual loses the ability to participate in medical decision-making in the future

- Ideally, an ACP discussion is followed by specific, actionable medical treatment orders (eg, Do-Not-Resuscitate orders) reflecting a person's treatment preferences and current medical condition

Hickman, SE et al. 2005

Advance Care Planning (ACP)

Benefits and Effectiveness

- Higher rates of completion of ADs
- Higher rates of compliance with patient preferences
- Reduced hospitalization
- Reduction of intensive care utilization
- Increased hospice utilization
- Better patient and family satisfaction
- Improved communication

Hickman, SE et al. 2005

Advance Care Planning
A sense of urgency

Due to a lack of planning, many people receive care that does not align with their preferences and values.

Studies have shown that approximately **80% of Americans would prefer to die at home**, if possible. Despite this, **60% of Americans die in acute care hospitals, 20% in nursing homes and only 20% at home.**

Stanford School of Medicine, Home Care of the Dying Patient, Where do Americans Die?

A 2012 survey found that more than three-quarters of respondents want to talk to their doctors about their wishes, yet **90% said a doctor had never asked them about those issues.**

California HealthCare Foundation, "Final Chapter: Californians' Attitudes and Experiences With Death and Dying" (2012)

Numerous studies demonstrate that even the sickest people rarely discuss their preferences for end-of-life care. **A recent study of patients with advanced cancer found that only 27% had discussed end-of-life issues, and most had never discussed pain management with any doctor.**

Jennifer W. Mack et al., "End-of-Life Discussions Among Patients with Advanced Cancer: A Cohort Study," Annals of Internal Medicine 153, no. 3 (2012)

It's Not About a DNR
It's About Changing Culture

From	To
Advance care planning is end of life care	**ACP is good medicine**
It's about dying	**It's about living**
It's about document completion and checking it off	**Its about meaningful conversations**
ACP starts after the crisis	**ACP anticipates the crisis**
Patient Advocate is the decision-maker: we ask them 'what do you want to do?'	**Patient Advocate is the voice of the patient: we ask them "what would your loved one want?"**
Experiencing a good death	**Experiencing a good life**
ACP means making everyone DNR's	**Protecting their voice, their values; making informed decisions**

Speak for Yourself, Plan Your Care
Southwest Michigan's Advance Care Planning Program

What is the Patient-Physician Gap?

Attribute	Patients	Physicians
Be mentally aware	92%	65%
Be at peace with God	89%	65%
Not be a burden to family	89%	58%
Be able to help others	88%	44%

Speak for Yourself, Plan Your Care
Southwest Michigan's Advance Care Planning Program

Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers. *JAMA*. 2000;284(19):2476-2482. doi:10.1001/jama.284.19.2476

Advance Care Planning

The Process

1. Understand Your Values
2. Discuss Decisions with Your Family

3. Appoint a Health Power of Attorney
4. Appoint a Financial Power of Attorney

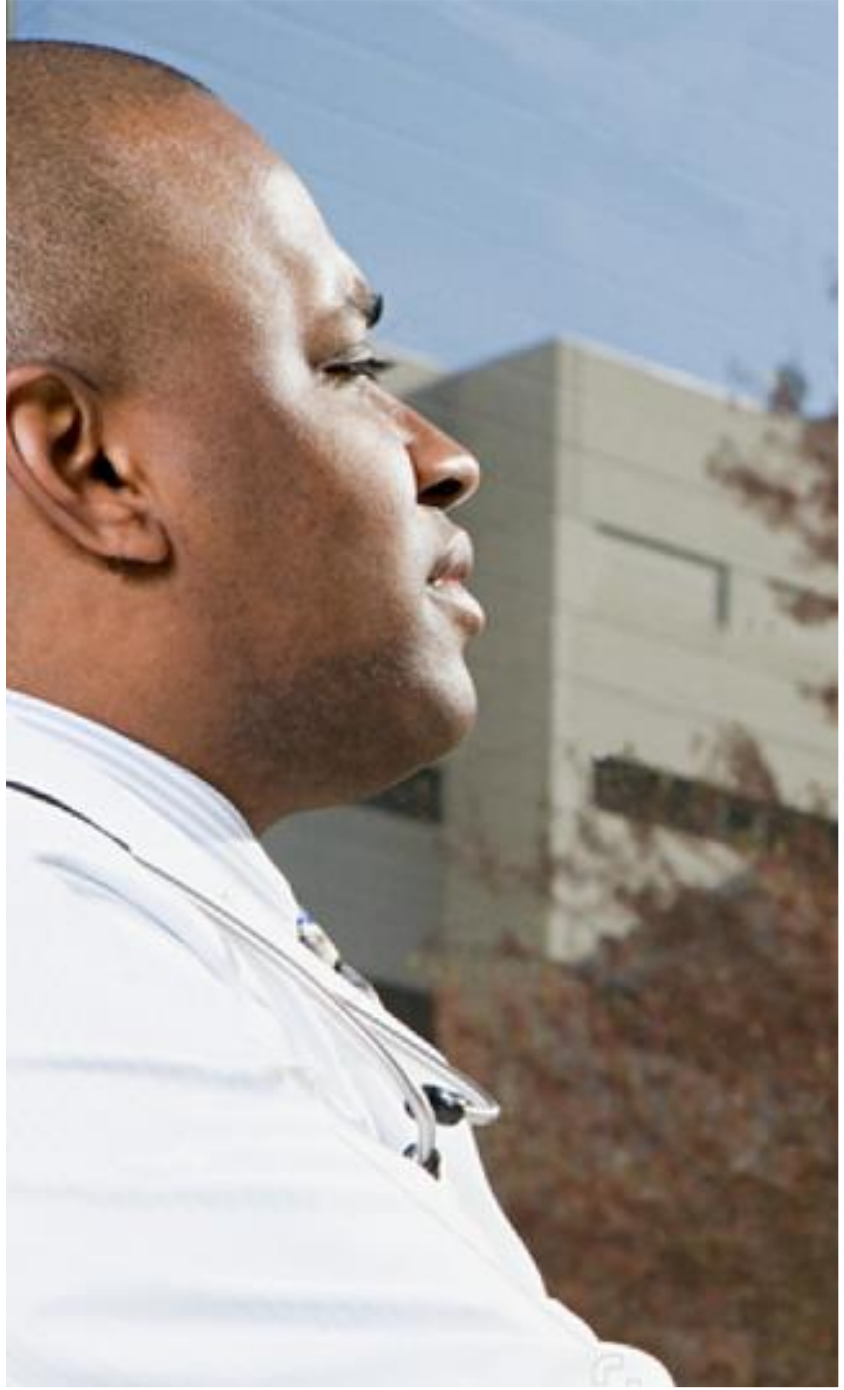
5. Discuss Decisions with Your Doctor
6. Create an Advance Directive or MI-POST

7. Store Your Documents

8. Review Periodically

Purpose of Conversation
Values, wishes and living well

- These conversations explore the participant's perception of living well
- Living well is different for everyone but some perspectives we've had participants share include:
  - Independence
  - Spending quality time with family
  - Participating in meaningful activities/hobbies/interests
  - Having an understanding of who they are, where they are, and who is with them.
  - Helping participants view their decisions based on what brings quality to their lives helps them put treatment decisions into perspective.

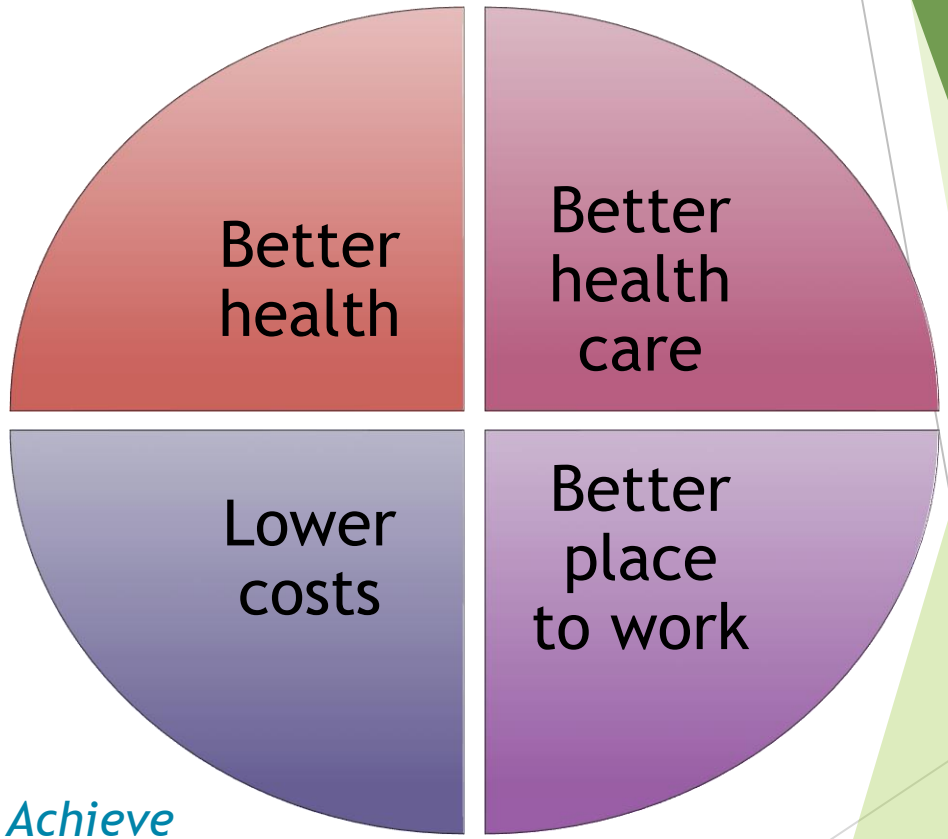


Self-Check

- Do you have a current advanced directive?
- Do your loved ones know what your values and goals are for end-of-life care?
- If yes, does your physician know?
- If you haven’t had this conversation with your family, what are the barriers?

Benefits of longitudinal palliative medicine intervention and advance care planning

- Better Care
- Better Outcomes
- Better Patient and Provider Experience
- Better Value



ACP:
Helping Achieve the Quadruple Aim

What is Palliative Care?

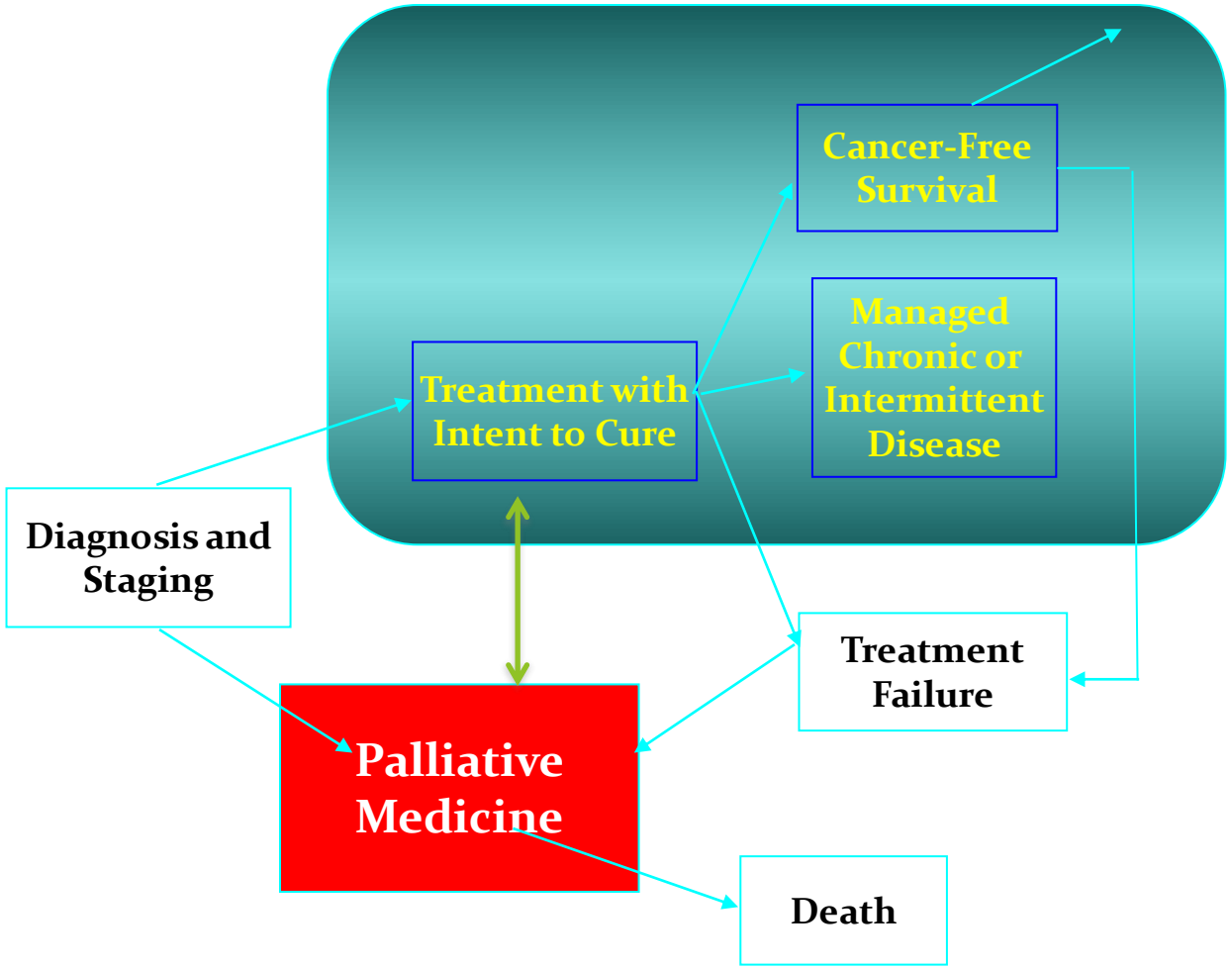
Palliative care means **patient and family-centered care** that **optimizes quality of life** by anticipating, preventing, and treating suffering. **Palliative care throughout the continuum of illness** involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.

— 73 FR 32204, June 5, 2008

Medicare Hospice Conditions of Participation – Final Rule

CENTER TO ADVANCE PALLIATIVE CARE

Community Oncology Offices



- Where majority of cancer care is given today
- Where fewest psychological and social services available

IOM President's Cancer Panel, 2003, 2004
Slide Courtesy of Jimmie Holland, MD
Memorial Sloan Kettering Cancer Center

Nature Of Palliative Chemotherapy

- Which Way are We Going?

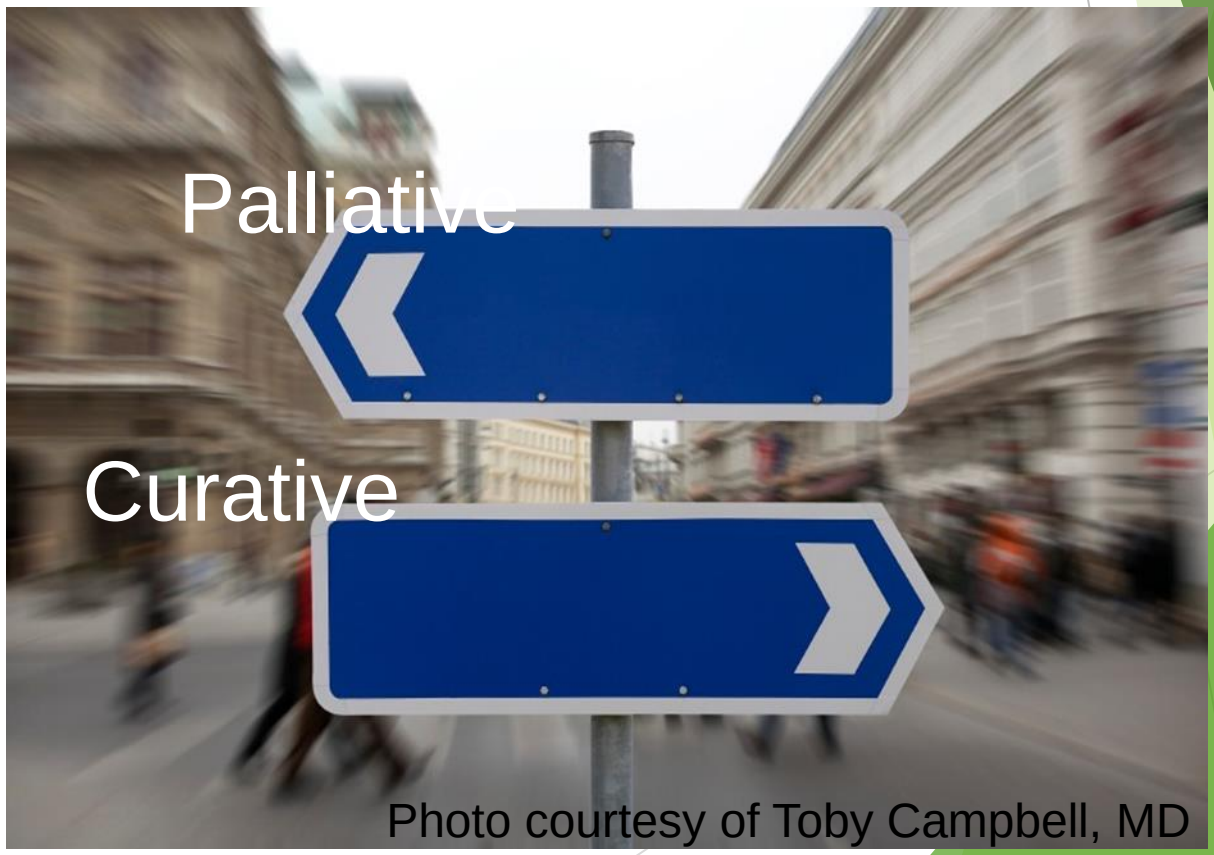
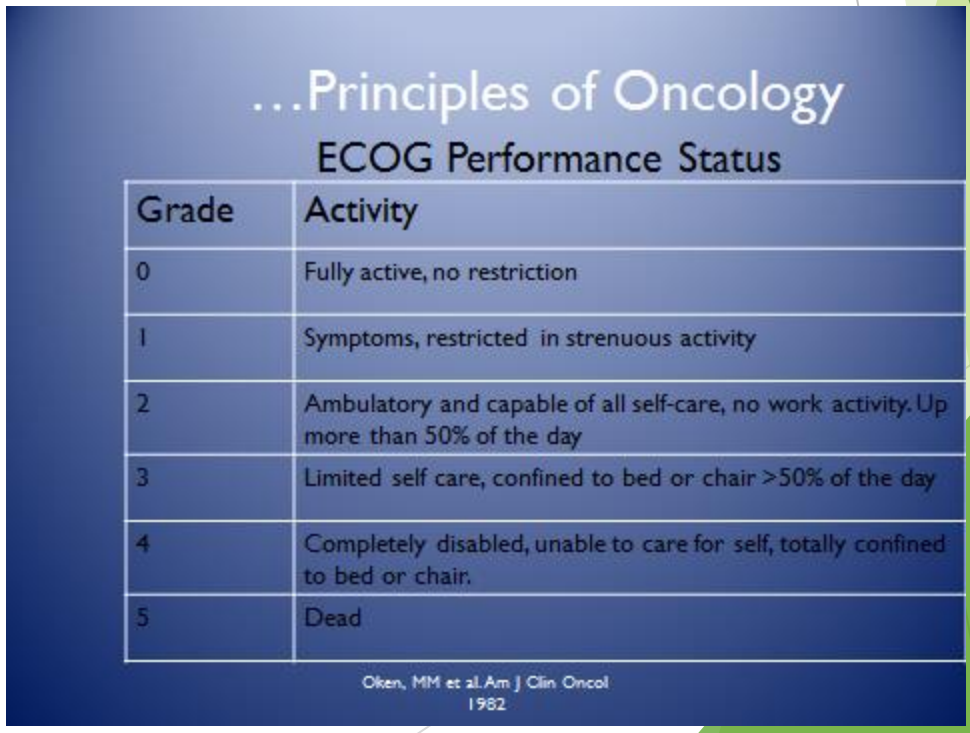


Photo courtesy of Toby Campbell, MD

Nature Of Palliative Chemotherapy

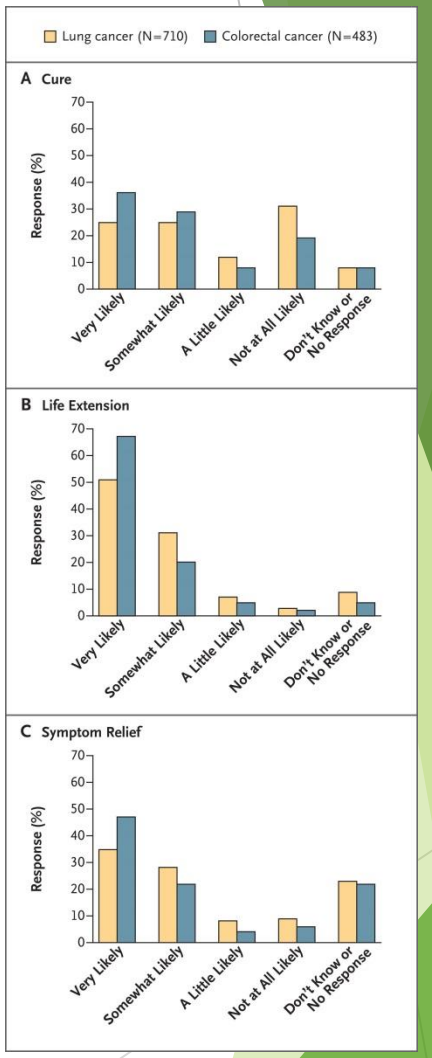
- Symptom Relief Prioritized Over Cure
- Treatment Criteria
  - Tolerable
  - Efficacious



What Patients Believe

- Metastatic Cancer is Curable
- I Must Treat or Quit

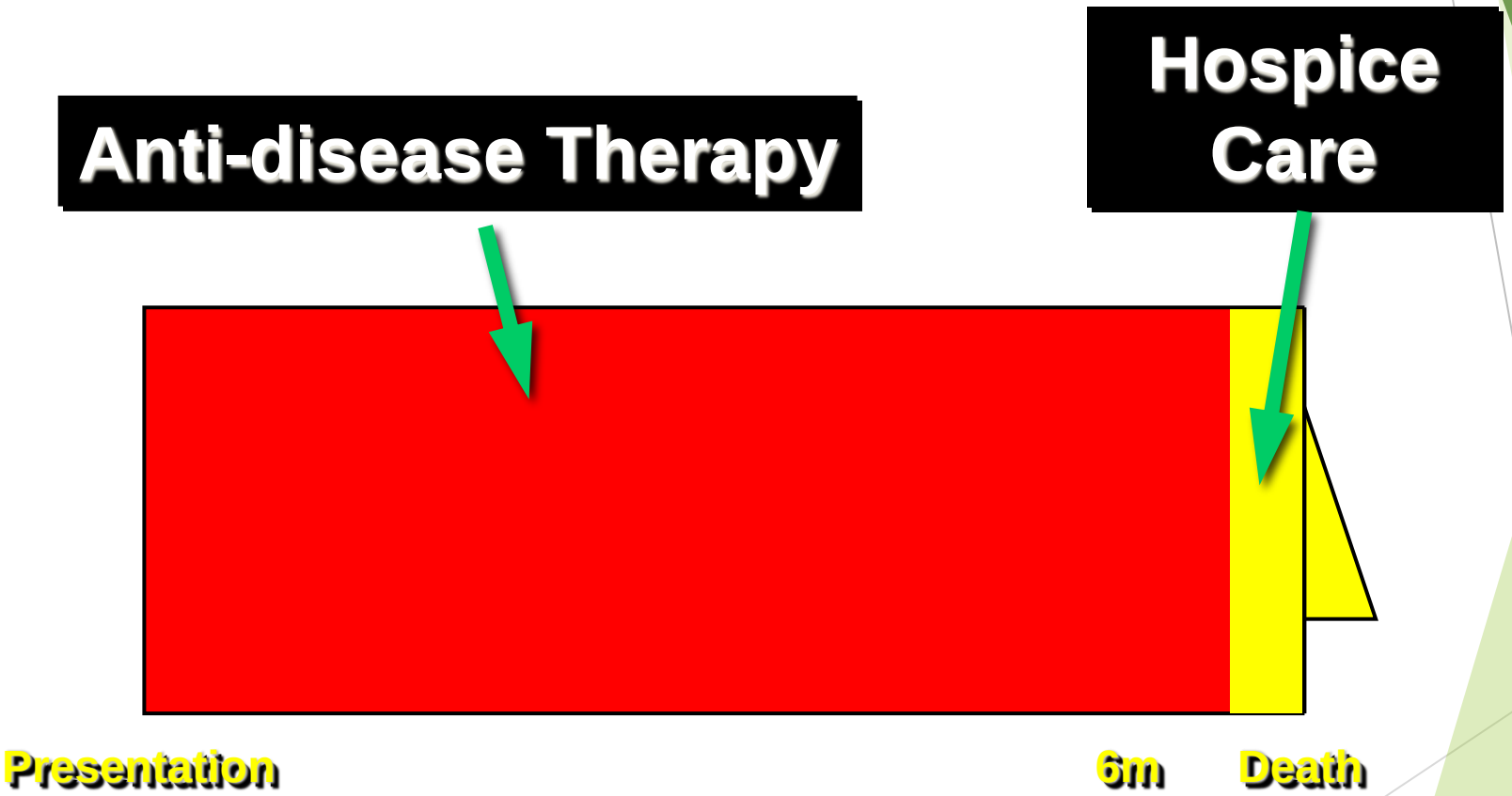
ording to



Weeks JC et al. N Engl J Med 2012;367:1616-1625

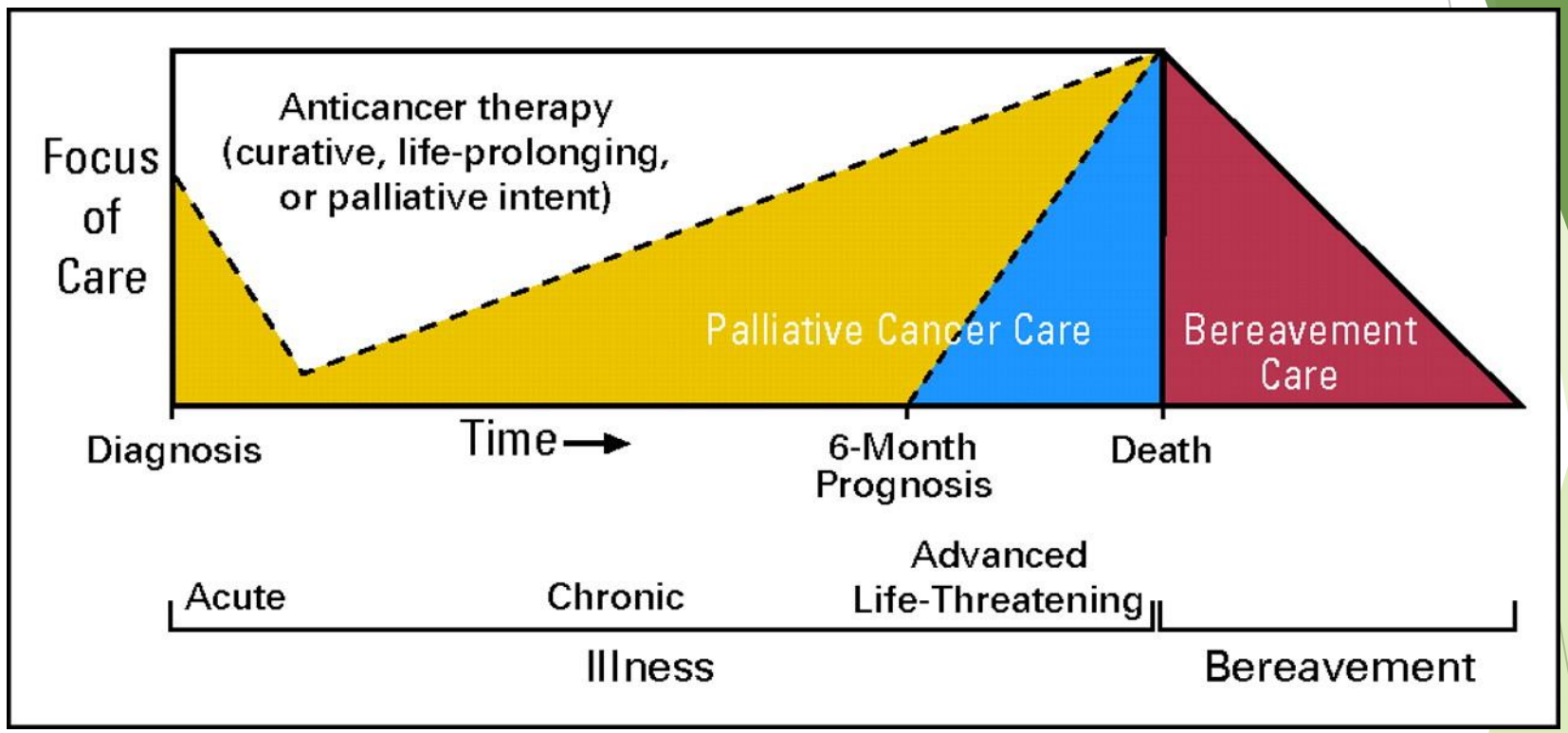
The NEW ENGLAND JOURNAL of MEDICINE

Treat or Quit



Slide Courtesy of Charles von Gunten, MD
Provost, San Diego Hospice

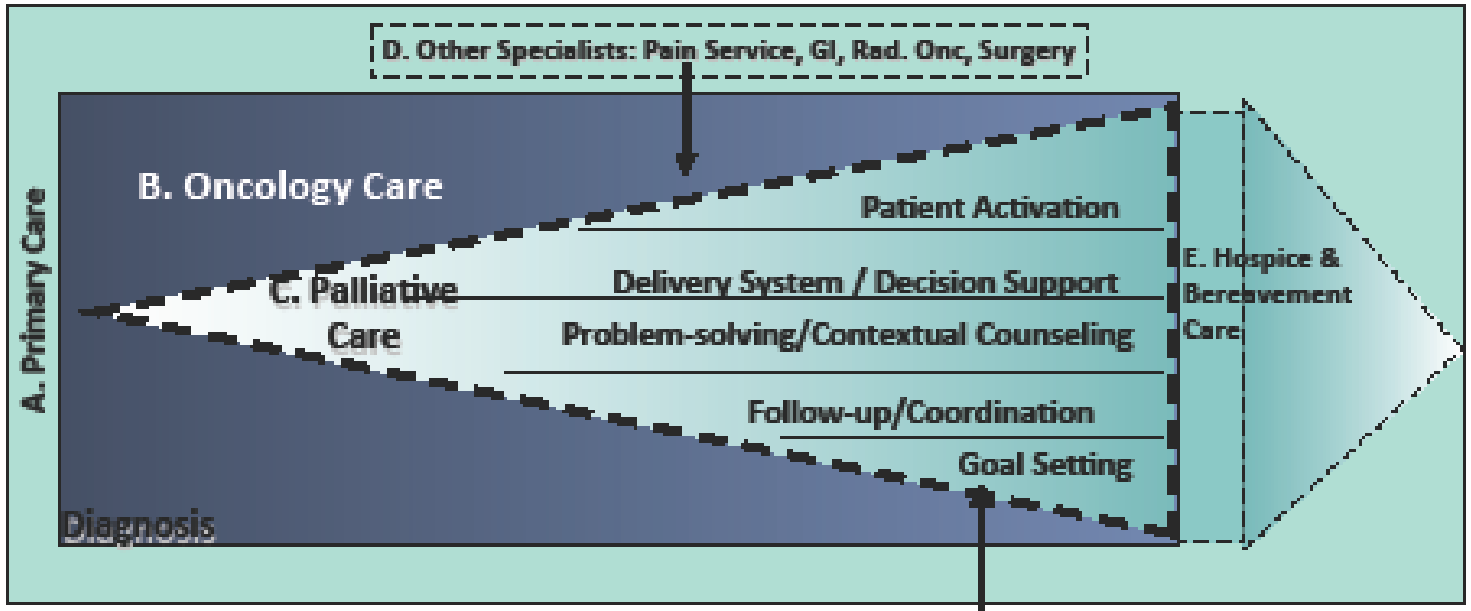
The Power of the Pause Button



Ferris F D et al. JCO 2009;27:3052-3058

JOURNAL OF CLINICAL ONCOLOGY

Conceptual Foundation of the ENABLE III Concurrent Oncology Palliative Care Intervention

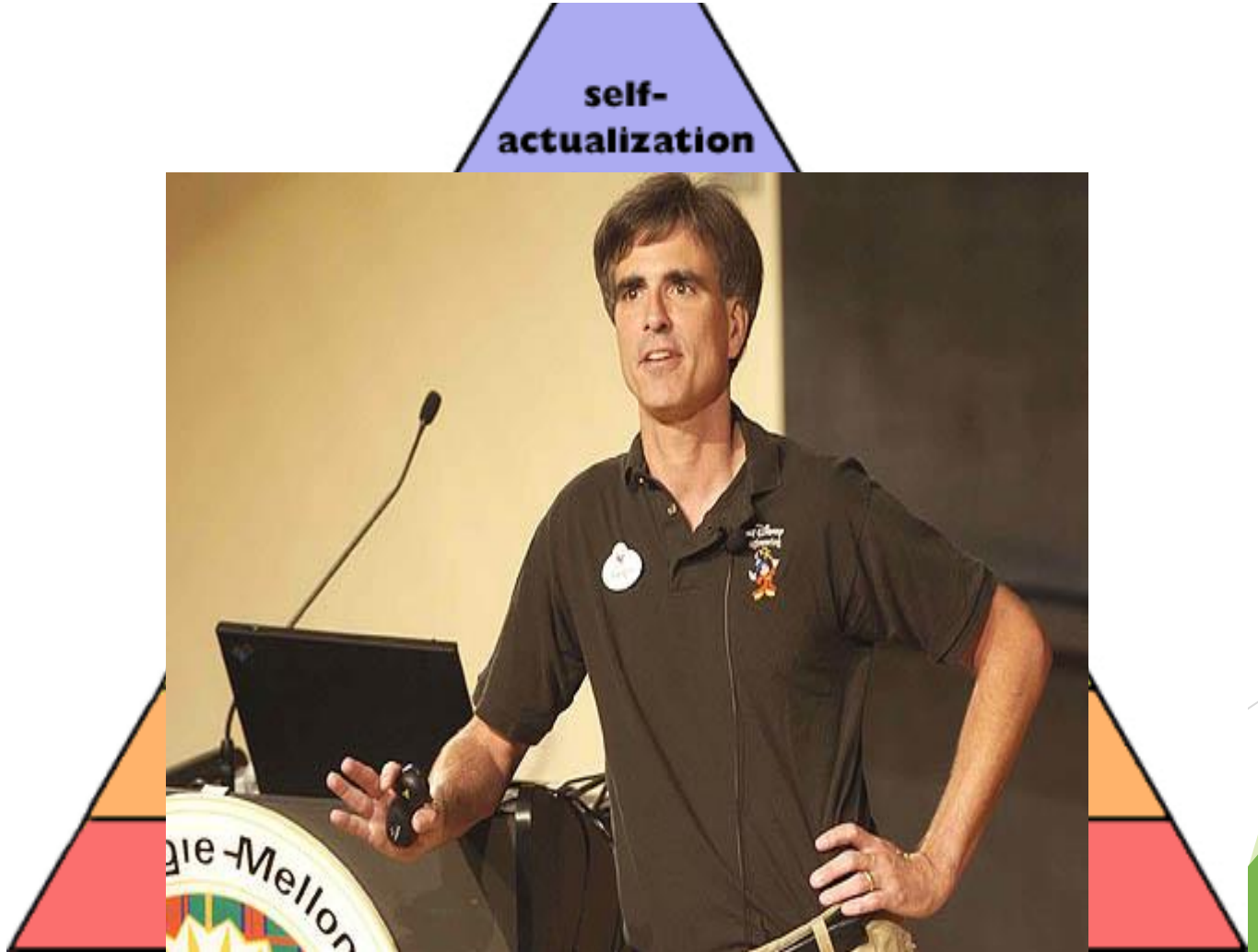


Goals of phone-based palliative nurse coaching

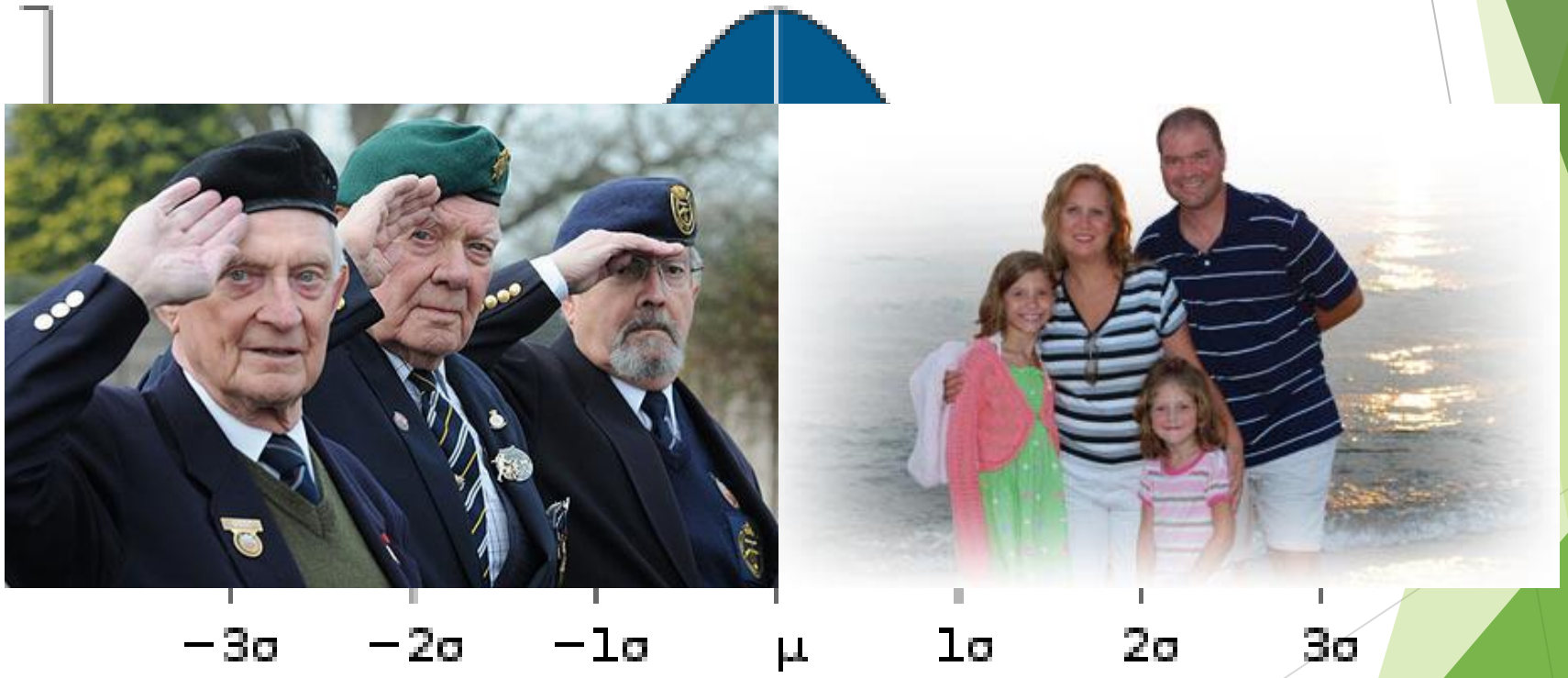
Bakitas et al. Sem Oncology Nursing. 2010

Goals of Palliative Care/Chemotherapy

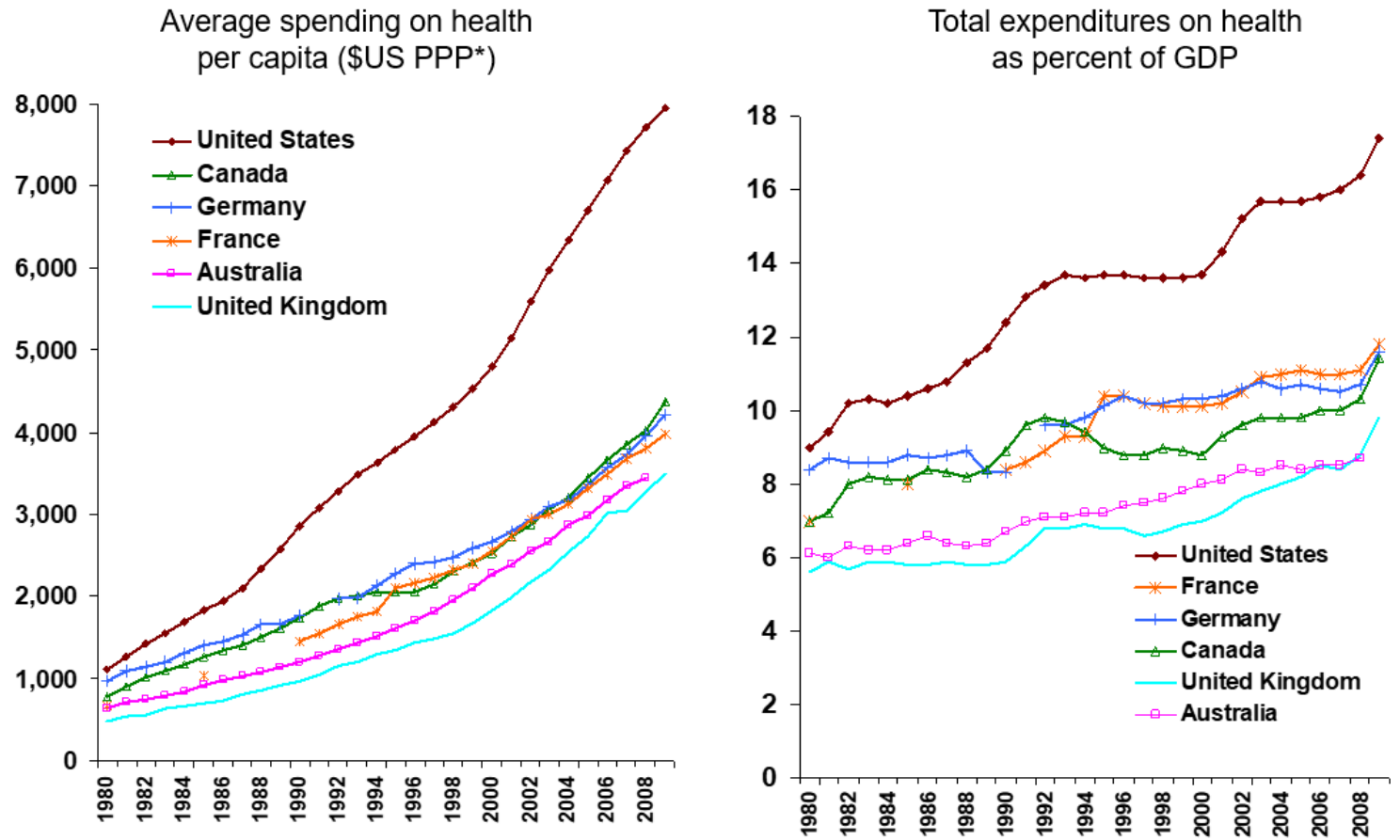
"We can't change the cards we are dealt, only the way we play the hand"
Randy Pausch. 2007



Prepared and Hopeful



International Comparison of Spending on Health, 1980–2009

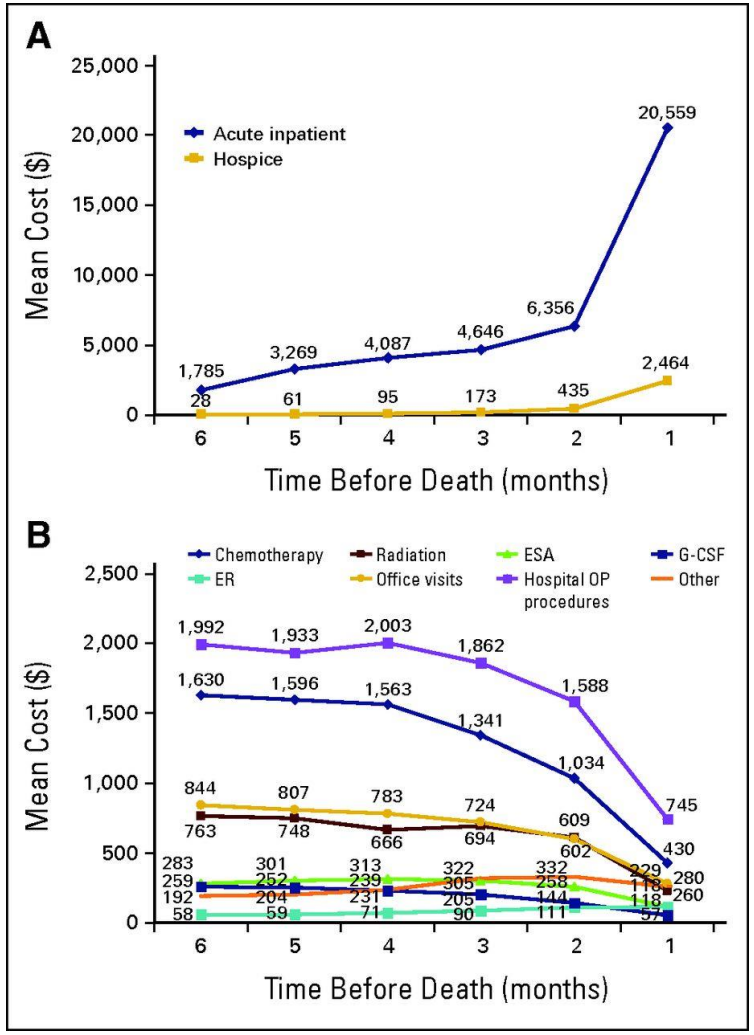


* PPP=Purchasing Power Parity.
Data: OECD Health Data 2011 (database), version 6/2011.

Source: Commonwealth Fund National Scorecard on U.S. Health System Performance, 2011. Slide courtesy of Diane Meier

The Value of Palliative Providers

Mean total cancer-related costs for each of the last 6 months of life for (A) inpatient and hospice and (B) outpatient (OP) services.

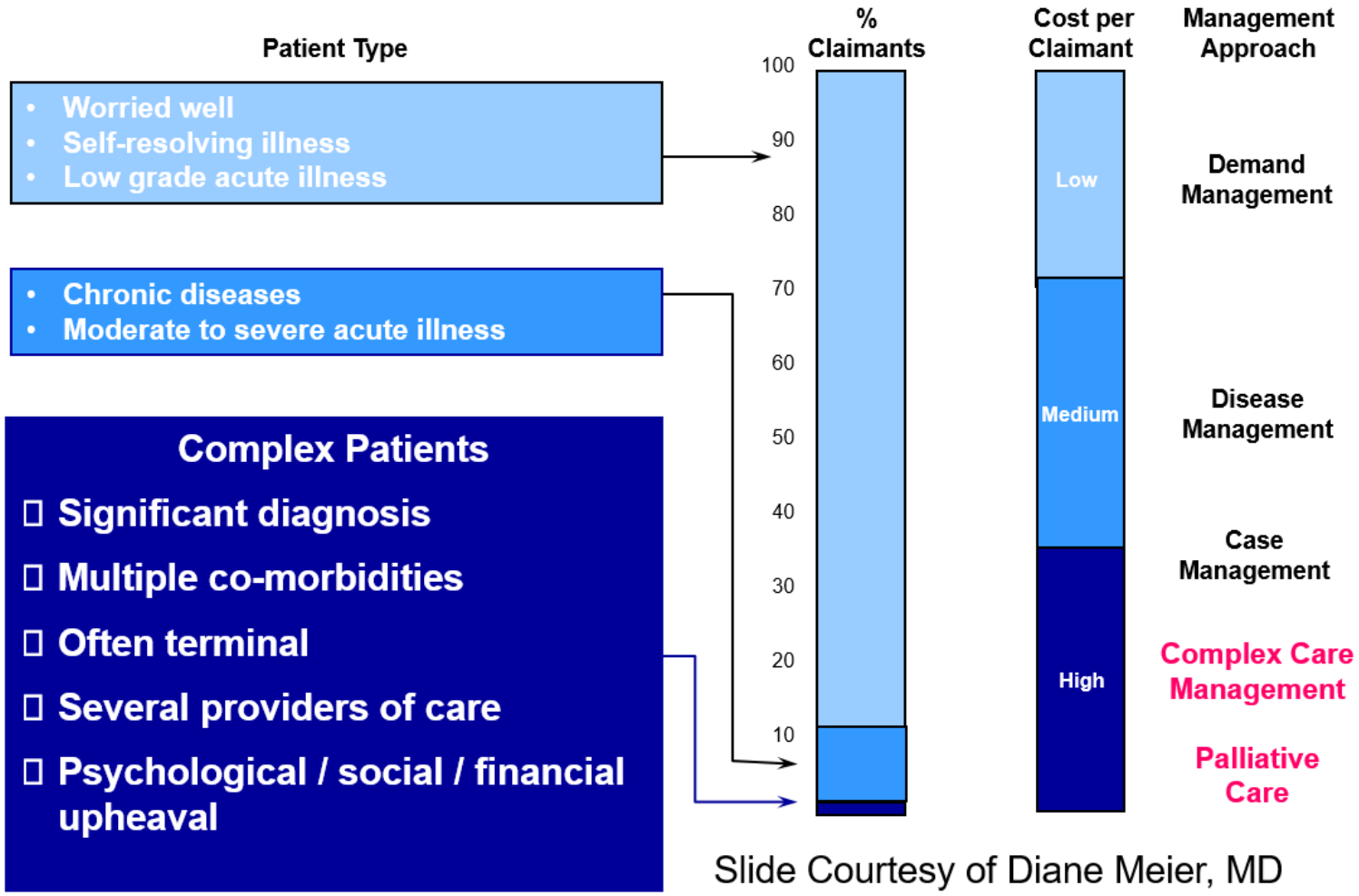


Chastek B et al. JOP 2012;8:75s-80s

JOURNAL OF ONCOLOGY PRACTICE

Payer Perspective:

Care Management Targeted to Needs of Patients



Slide Courtesy of Diane Meier, MD

Palliative Care:

- *To cure sometimes,*
- *To relieve often,*
- *To comfort always.*

CENTER TO ADVANCE PALLIATIVE CARE

References

- Allshouse, KD. Treating patients as individuals. In: Through the Patient's Eyes: Understanding and Promoting Patient-Centered Care, Gerteis, M, Edgman-Levitan, S, Daley, J, Delbanco, TL (Eds), Jossey-Bass Publishers, San Francisco 1993.
- Back AL, Trinidad SB, Hopley EK, et al. What patients value when oncologists give news of cancer recurrence: commentary on specific moments in audio-recorded conversations. Oncologist 2011;
- Hickman SE, Hammes BJ, Moss AH, Tolle SW. Hope for the future: achieving the original intent of advance directives. Hastings Cent Rep 2005
- Ptacek JT, Eberhardt TL. Breaking bad news. A review of the literature. JAMA 1996; 276:496
- Steinhauser KE, Christakis NA, Clipp EC, et al. Factors considered important at the end of life by patients, family, physicians, and other care providers. JAMA 2000; 284:2476
- Sudore RL, Lum HD, You JJ, et al. Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel. J Pain Symptom Manage 2017; 53:821
- Temel JS, Greer JA, El-Jawahri A, et al. Effects of Early Integrated Palliative Care in Patients With Lung and GI Cancer: A Randomized Clinical Trial. J Clin Oncol 2017; 35:834
- Teno JM, Gruneir A, Schwartz Z, et al. Association between advance directives and quality of end-of-life care: a national study. J Am Geriatr Soc 2007; 55: 189
- Umezawa S, Fujimori M, Matsushima E, et al. Preferences of advanced cancer patients for communication on anticancer treatment cessation and the transition to palliative care. Cancer 2015; 121: 4240

Thank you

for your attention

Any Questions?

jason.beckrow@spectrumhealth.org