

Palliative Medicine Update 2018:

Communicating, Planning and
Executing Optimal Care at End of Life

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Objectives

- Present current state of patient communication research and training
- Discuss patient experience and quality outcomes as a function of communication effectiveness
- Present Current state of Advance Care Planning (ACP)
- Futures goals of ACP
- Benefits of longitudinal palliative medicine intervention



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

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

SPECIAL ARTICLE

THE NATURE OF SUFFERING AND THE GOALS OF MEDICINE

ERIC J. CASSEL, M.D.

Abstract The question of suffering and its relation to organic illness has rarely been addressed in the medical literature. This article offers a description of the nature and causes of suffering in patients undergoing medical treatment. A distinction based on clinical observations is made between suffering and physical distress. Suffering is experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person 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.)

THE obligation of physicians to relieve human suffering stretches back into antiquity. Despite this fact, little attention is explicitly given to the problem of suffering in medical education, research, or practice. I will begin by focusing on a modern paradox: Even in the best settings and with the best physicians, it is not uncommon for suffering to occur not only 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 de-

pressed. 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 out: The first is that this woman's suffering was not confined to her physical symptoms. The second is that she suffered not only from her disease but also from its treatment. The third is that one could not anticipate what she would describe as a source of suffering; like

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Patient communication research and training: Patient Centered Concerns, Relationship Building

- Respect for patients' values, preferences, and expressed needs
- Coordination of care and integration of services within the clinical setting
- Communication between patient and providers: dissemination of accurate, timely, and appropriate information, and education about the long-term implications of disease and illness

Allshouse, KD et al 1993



Patient communication research and training: Patient Centered Concerns, Relationship Building

- Enhancing physical comfort
- Involvement of family and friends
- Transition and continuity from one locus of care to another
- Emotional support and alleviation of fears, anxiety and suffering



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

- What is most important to you?
 - Maybe Medical
 - Maybe not



Patient communication research and training: 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”



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



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.

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 routinely fluctuate as a function of communication effectiveness
- Build the Relationship
- Earn the Trust
- Respect the Power Gradient

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

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

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

Futures goals of ACP: Lakeland Health, Southwest Michigan

Speak for Yourself, Plan Your Care

Southwest Michigan's Advance Care Planning Program

Advance Healthcare Planning

- What is most important to you about your medical care?
- What is most important to you about your care providers and how they treat you?
- What will your choices be if you have a chronic, serious, and/or terminal illness?
- How will you assure your choices are honored?

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

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%

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

The Value of Informed Consent



- Why Doctors Die Differently
- Wall Street Journal
- 25 February 2012

What's unusual about doctors is not how much treatment they get compared with most Americans, but how little.

With our patients we hit the accelerator. Privately we use and value the brakes.



LaCrosse, Wisconsin: *the Little Town that Could*

Bud Hammes, a medical ethicist at Gundersen Health System, spoke with families for years who were trying to decide what to do next when a loved one had a stroke, was in a coma, on machines. These conversations were excruciating.

Most of the conversations were about people who had been ill for a long time. Why not talk earlier?

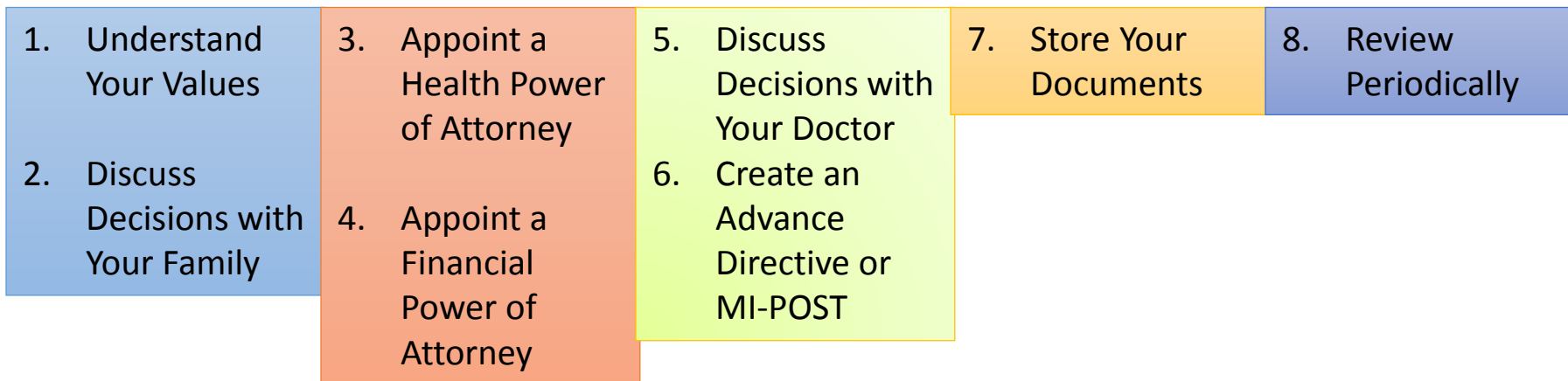
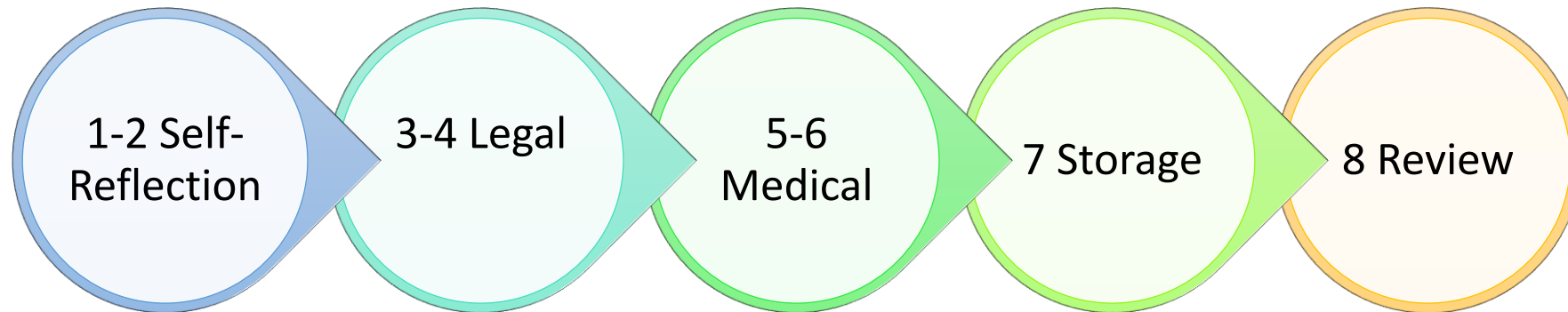
Bud trained nurses to ask if people would like to fill out an advance directive. Through consistent asking at every touchpoint, it became normalized.

Today, 96% of people who die in LaCrosse have an advance directive.

Gundersen Health has developed LaCrosse's effort into an evidence-based implementation program.

Advance Care Planning

The Process



Speak for Yourself,
Plan Your Care

Southwest Michigan's Advance Care Planning Program

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?

Myths - We Have Work To Do!!

- You will die 30 minutes after you sign it
- Choosing “comfort care only” means no one will do anything for you anymore.....they have given up on you.
- Others??

Barriers to Talking

- Most families find bringing up the topic is the hardest part. Once everyone gets past the initial discomfort, they're relieved.
- Though 75% of Americans say they're in favor of Advance Directives, only 30-35% of them write one. The biggest barrier: **Procrastination**

When Family Members Disagree

This situation is uncomfortable for families, and makes things difficult for the professionals trying to deliver care. If all the paperwork is complete and available, there is no question – the patient's wishes will be honored.

After completion of Advance Directives

Make several copies and distribute them liberally so they are not difficult to find when they are needed.

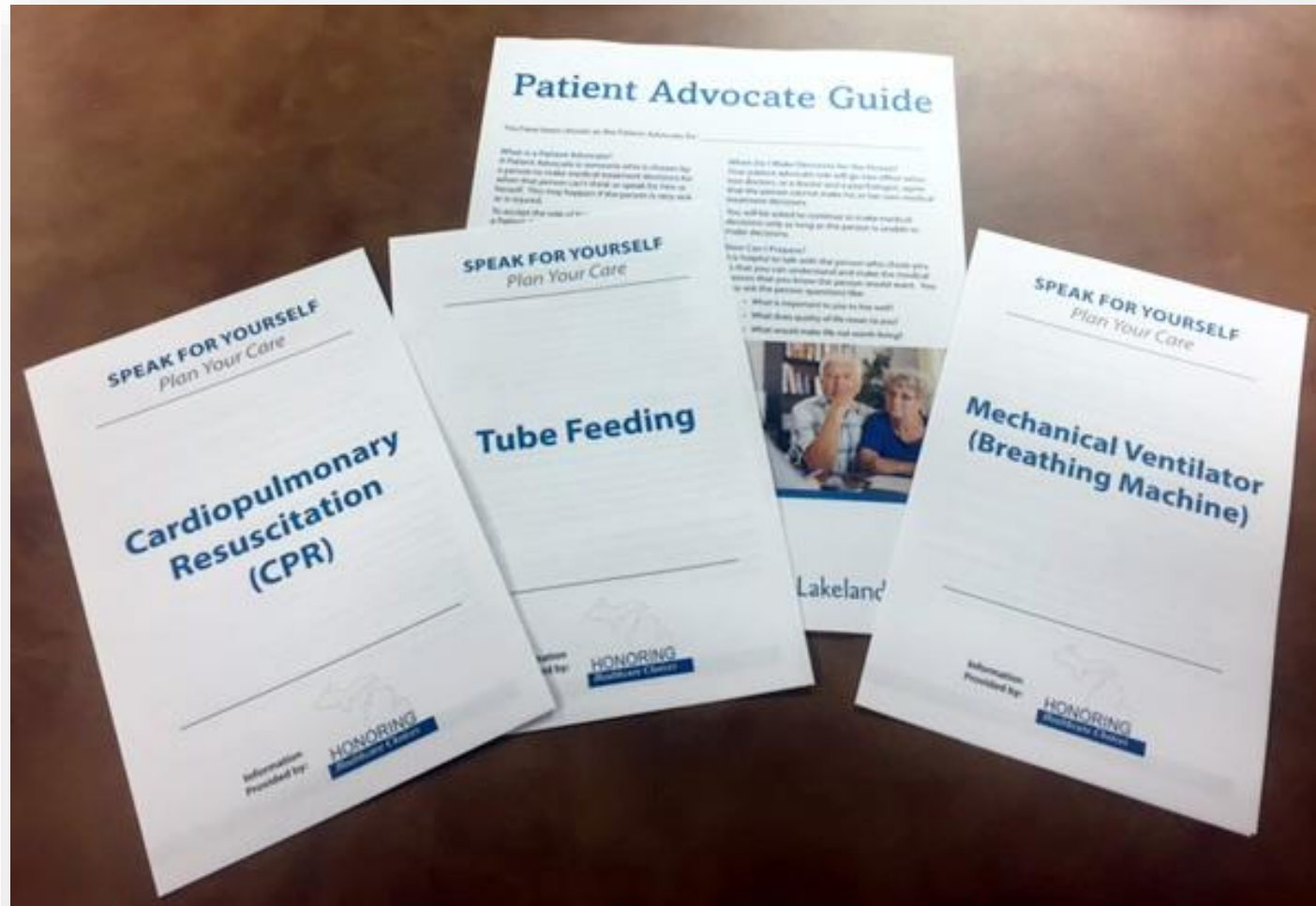
Who should have copies:

- Your doctor
- Your lawyer
- Your patient advocate
- Your local hospital
- If the person you care for is homebound, keep a copy in a drawer by the bedside

The “5 D’s” of Conversations: Make or review your plan...

- Every new ***Decade*** of your life
- After the ***Death*** of a loved one
- After a ***Divorce***
- After any significant ***Diagnosis***
- After any significant ***Decline*** in functioning

What Speak for Yourself is Using



Speak for Yourself,
Plan Your Care

Southwest Michigan's Advance Care Planning Program

Community Partners

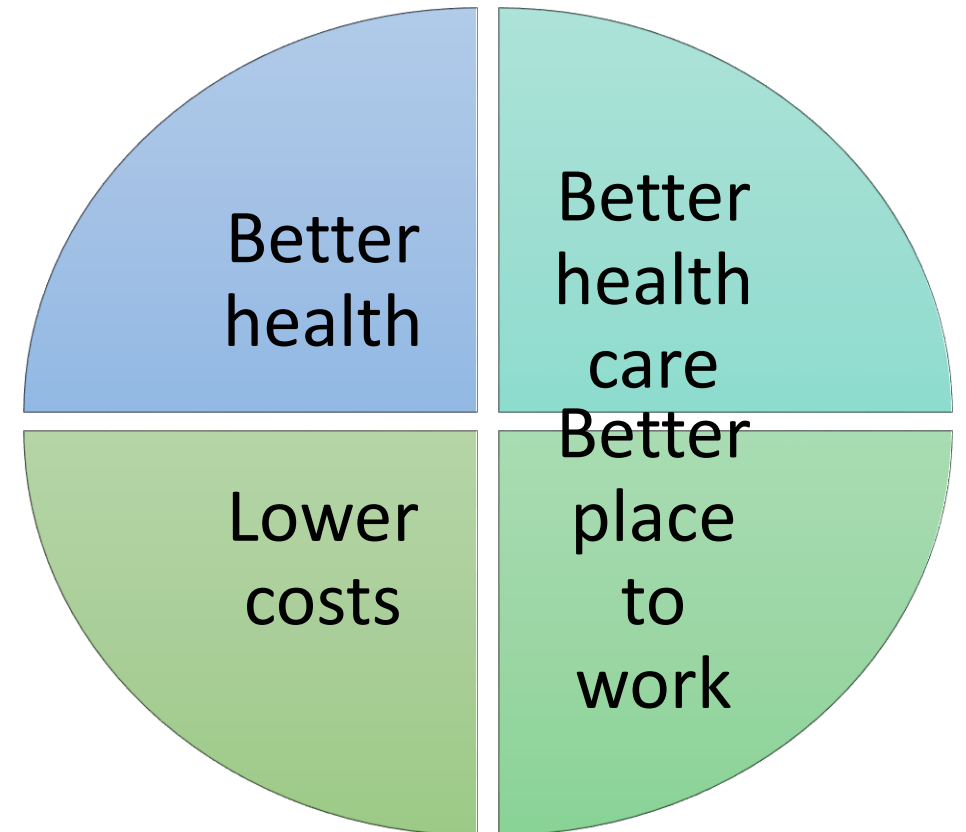
- Area Agency on Aging
- Caring Circle
- Community Volunteers
- Edgewater Family Medicine
- Fresenius Dialysis Centers
- Great Lakes Heart & Vascular
- HouseCalls
- Lakeland Family Medicine, Niles
- Lakeland HomeCare
- Lakeland Medical Center
- Lakeland Medical Practices, Watervliet
- Marie Yeager Cancer Center
- PACE of southwest Michigan
- Parish Nurses
- Pine Ridge Nursing and Rehabilitation Center
- Southwestern Medical Clinic, Bridgman
- Southwestern Medical Clinic, Stevensville
- Strong Women of Faith
- West Woods of Niles

Benefits of longitudinal palliative medicine intervention and advance care planning.

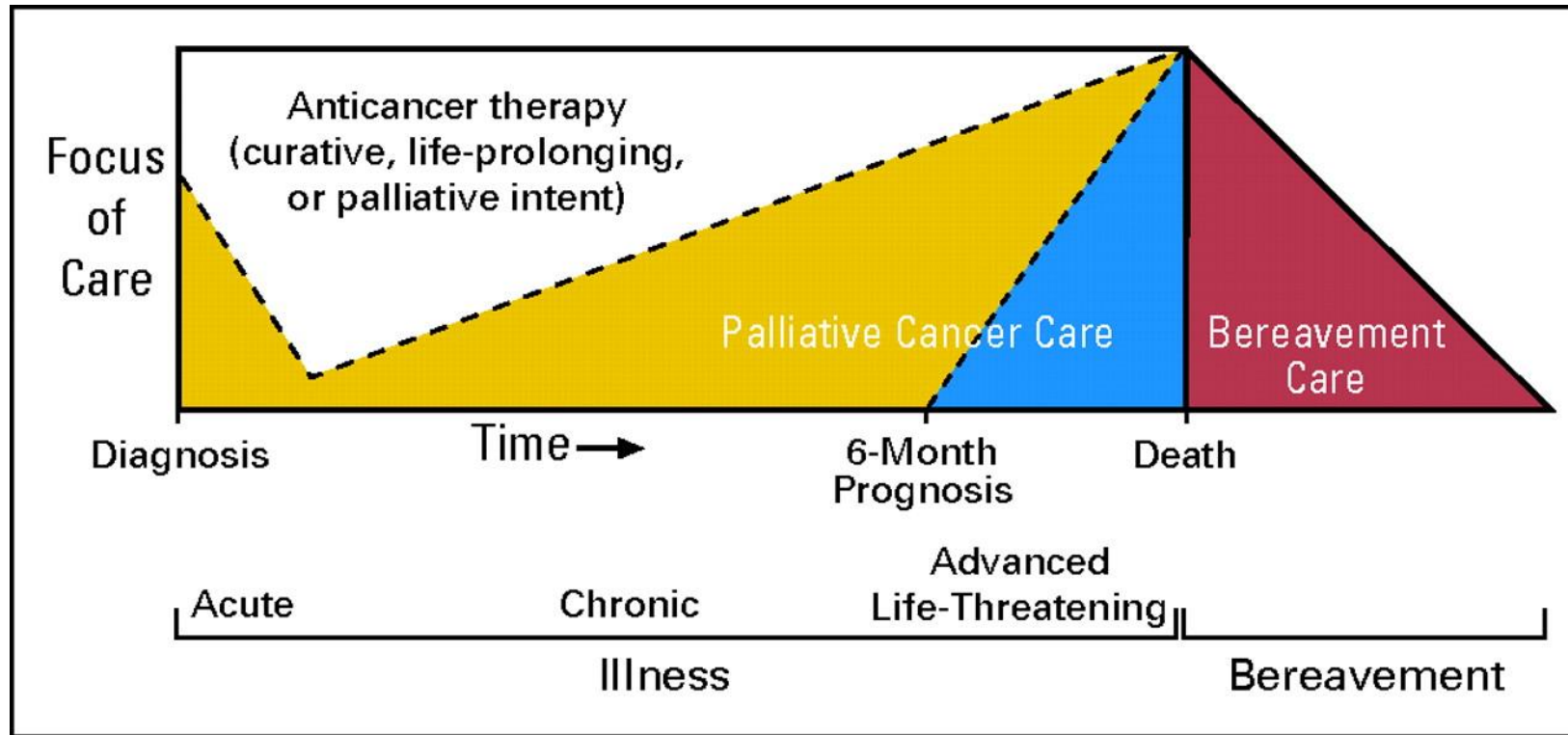
ACP:

*Helping Achieve
the Quadruple Aim*

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



The Power of the Pause Button

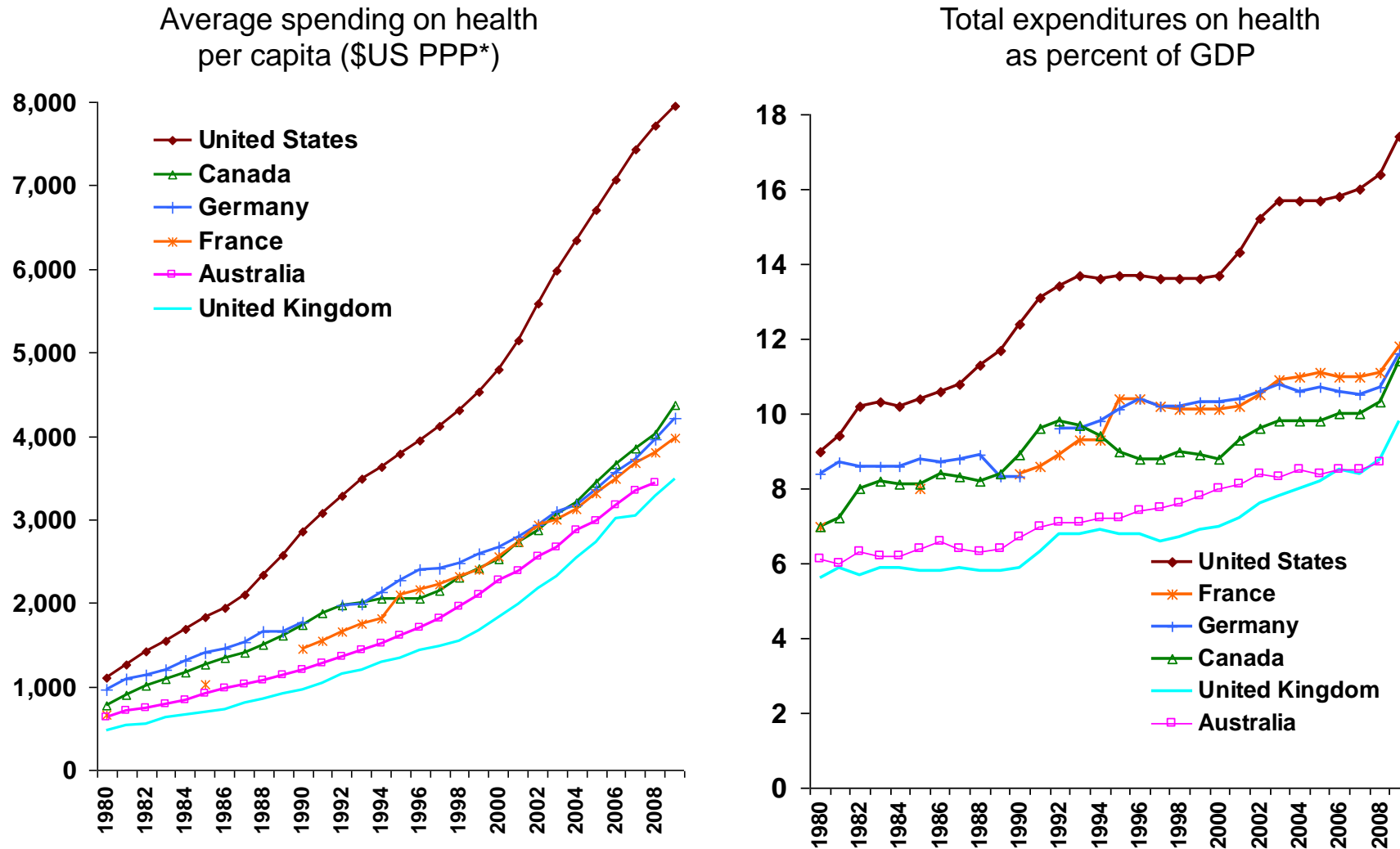


Ferris F D et al. JCO 2009;27:3052-3058

JOURNAL OF CLINICAL ONCOLOGY

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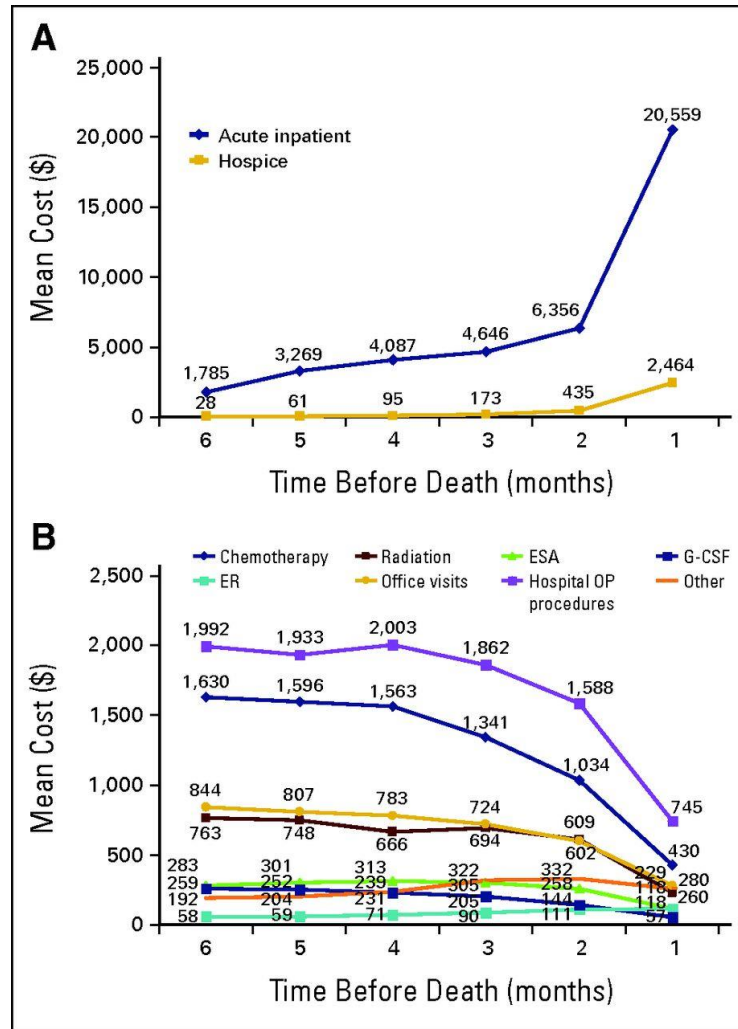
International Comparison of Spending on Health, 1980-2009



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

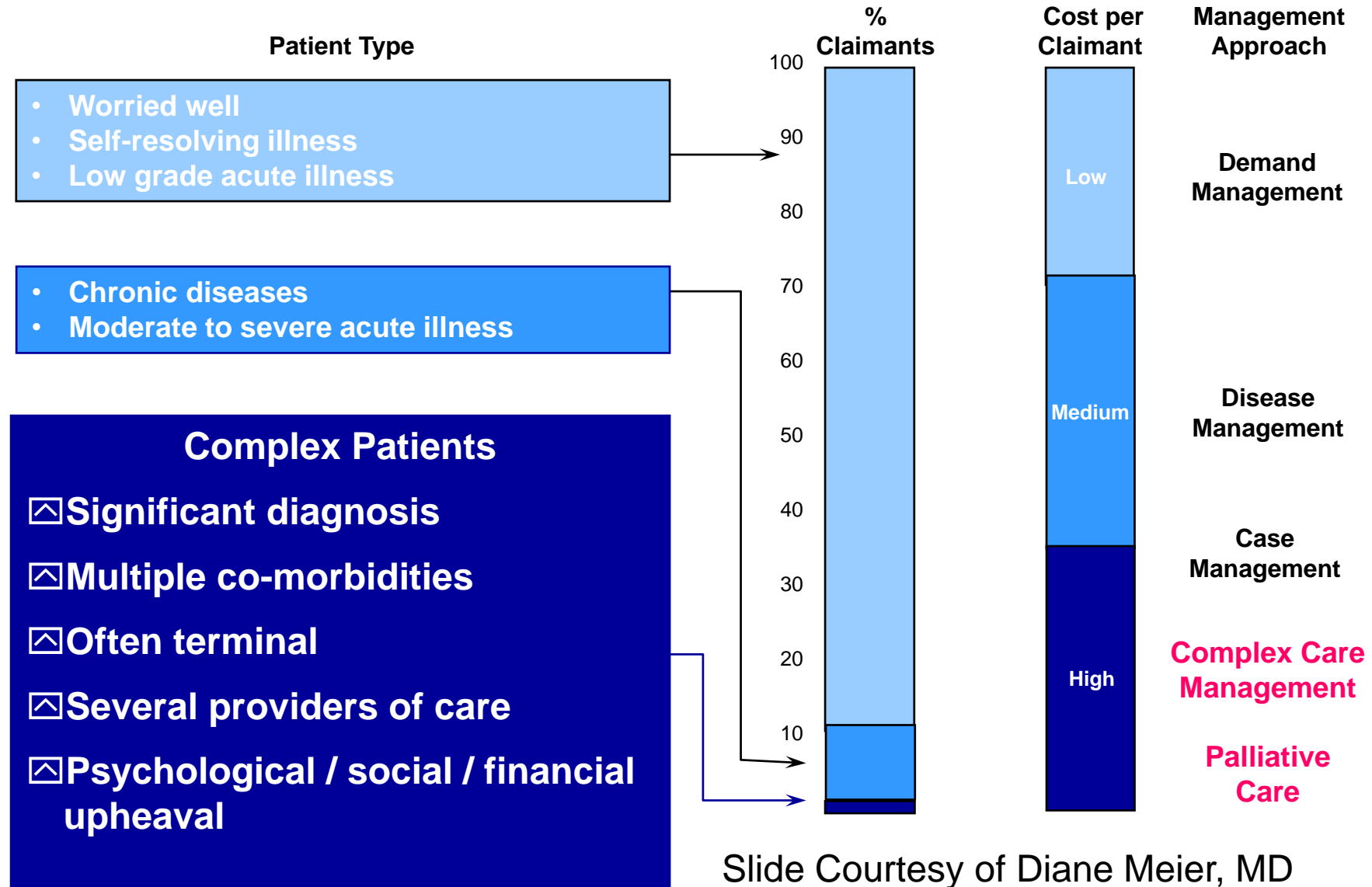
The Value Of Palliative Providers

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



Payer Perspective:

Care Management Targeted to Needs of Patients



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Thank you for your attention.

- Any Questions?