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.”
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
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

Allshouse, KD et al 1993
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?

- May be medical
- May 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”

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
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 routine 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.

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 (e.g., 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
Future goals of ACP:
Lakeland Health, Southwest Michigan

Speak for Yourself,
Plan Your Care

Southwest Michigan’s Advance Care Planning Program
Advance Care Planning (ACP)

• 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.

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.

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.

Numerous studies demonstrate that even the sickest people rarely discuss their preferences for end-of-life care.

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

A California HealthCare Foundation, “Final Chapter: Californians’ Attitudes and Experiences With Death and Dying” (2012)

# It’s Not About a DNR

## It’s About Changing Culture

<table>
<thead>
<tr>
<th>From</th>
<th>To</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advance care planning is end of life care</td>
<td>ACP is good medicine</td>
</tr>
<tr>
<td>It’s about dying</td>
<td>It’s about living</td>
</tr>
<tr>
<td>It’s about document completion and checking it off</td>
<td>Its about meaningful conversations</td>
</tr>
<tr>
<td>ACP starts after the crisis</td>
<td>ACP anticipates the crisis</td>
</tr>
<tr>
<td>Patient Advocate is the decision-maker: we ask them ‘what do you want to do?’</td>
<td>Patient Advocate is the voice of the patient: we ask them “what would your loved one want?”</td>
</tr>
<tr>
<td>Experiencing a good death</td>
<td>Experiencing a good life</td>
</tr>
<tr>
<td>ACP means making everyone DNR’s</td>
<td>Protecting their voice, their values; making informed decisions</td>
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**Speak for Yourself, Plan Your Care**

Southwest Michigan’s Advance Care Planning Program
What is the Patient-Physician Gap?

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<th>Attribute</th>
<th>Patients</th>
<th>Physicians</th>
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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.

Gunderson Health has developed LaCrosse’s effort into an evidence-based implementation program.
Advance Care Planning

The Process

1-2 Self-Reflection

3-4 Legal

5-6 Medical

7 Storage

8 Review

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?
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
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

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

ACP: Helping Achieve the Quadruple Aim

Better health
Better health care
Lower costs
Better place to work
The Power of the Pause Button

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

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International Comparison of Spending on Health, 1980–2009

Average spending on health per capita ($US PPP*)

- United States
- Canada
- Germany
- France
- Australia
- United Kingdom

* PPP=Purchasing Power Parity.

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

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Payer Perspective: Care Management Targeted to Needs of Patients

Patient Type

- Worried well
- Self-resolving illness
- Low grade acute illness

- Chronic diseases
- Moderate to severe acute illness

Complex Patients

- Significant diagnosis
- Multiple co-morbidities
- Often terminal
- Several providers of care
- Psychological / social / financial upheaval

% Claimants

Cost per Claimant

Management Approach

Demand Management

Disease Management

Case Management

Complex Care Management

Palliative Care

Slide Courtesy of Diane Meier, MD
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Thank you

for your attention

Any Questions?