Engaging Patients and Families at End of Life:
When, Why and How to have the Talks

Jason R. Beckrow, DO FACOI, HMDC
Medical Director, Hospice and Palliative Medicine
Caring Circle, Lakeland Health

OBJECTIVES

- Discuss best practices for end of life and serious illness communication with patients and families
- Discuss patient experience and quality outcomes as a function of communication effectiveness
- Discuss benefits of longitudinal palliative medicine intervention
- Present Current state of Advance Care Planning (ACP)
- No Disclosures
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
The Benefits of a Trusting Doctor-Patient Relationship

PATIENT COMMUNICATION RESEARCH AND TRAINING: GOALS OF PATIENTS AND PROVIDERS

- What is most important to you?
- 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
- Avoiding inappropriate prolongation of dying

Allshouse, KD et al 1993

The Benefits of a Trusting Doctor-Patient Relationship

- 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
The Benefits of a Trusting Doctor-Patient Relationship

- 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

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

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 false hope.
- All efforts augmented by relationship and rapport.
Patient communication research and training:
Discussing Serious News:
SPIKES-Ask Tell Ask

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

Back AL et al 2011
Ptacek JT et al 1996

The Benefits of Hospice and Palliative Care

- Improved Quality of Life
- Improved Symptom Control
- Improved Length of Life
- Improved Quality of Death
- Improved Grief Support

- Reduced Resource Consumption
- Lower Costs

Keating, NL et al 2018
Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer


ABSTRACT

BACKGROUND

Patients with metastatic non–small-cell lung cancer have a substantial symptom burden and may receive aggressive care at the end of life. We examined the effect of introducing palliative care early after diagnosis on patient-reported outcomes and end-of-life care among ambulatory patients with newly diagnosed disease.

METHODS

We randomly assigned patients with newly diagnosed metastatic non–small-cell lung cancer to receive either early palliative care integrated with standard oncologic care or standard oncologic care alone. Quality of life and mood were assessed at baseline and at 12 weeks with the use of the Functional Assessment of Cancer Therapy–Lung (FACT-L) scale and the Hospital Anxiety and Depression Scale, respectively. The primary outcome was the change in the quality of life at 12 weeks. Data on end-of-life care were collected from electronic medical records.

Study Design

150 patients with newly diagnosed metastatic NSCLC

Randomized

Baseline Data Collection

Early palliative care integrated with standard oncology care

Meet with palliative care within 3 weeks of signing consent and at least monthly thereafter

Meet with palliative care only when requested by patient, family or oncology clinician.

Standard oncology care

Temel et al. NEJM 2010
Study Objectives

Primary Objective:
> Measure the difference in QOL between the two study arms at 12 weeks.

Secondary Objectives:
1. Psychological distress at 12 weeks.
2. Quality of end-of-life care.
3. Resource utilization at the end-of-life.
4. Documentation of resuscitation preference in the medical record.

Temel et al. NEJM 2010

Survival Analysis

Median Survival
- Early palliative care: 11.6 mo
- Standard care: 8.9 mo

Controlling for age, gender and PS, adjusted HR=0.59 (0.40-0.88), p=0.01
Treat or Quit

Anti-disease Therapy

Hospice Care

Presentation 6m 6m Hospice Care Death

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

©2009 by American Society of Clinical Oncology
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

©2012 by American Society of Clinical Oncology
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

- Management Approach:
  - Demand Management
  - Disease Management
  - Case Management
  - Complex Care Management
  - Palliative Care

Source: Commonwealth Fund National Scorecard on U.S. Health System Performance, 2011. Slide courtesy of Diane Meier, MD.
The use of a car is an analogy for setting goals of care.

(A) A hopeful and unrealistic patient focuses on cancer cure and life-prolongation measures, without paying attention to her symptoms and advance care needs.
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.

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.

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.

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.

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.

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>
</tr>
</tbody>
</table>
What is the Patient-Physician Gap?

<table>
<thead>
<tr>
<th>Attribute</th>
<th>Patients</th>
<th>Physicians</th>
</tr>
</thead>
<tbody>
<tr>
<td>Be mentally aware</td>
<td>92%</td>
<td>65%</td>
</tr>
<tr>
<td>Be at peace Spiritually</td>
<td>89%</td>
<td>65%</td>
</tr>
<tr>
<td>Not be a burden to family</td>
<td>89%</td>
<td>58%</td>
</tr>
<tr>
<td>Be able to help others</td>
<td>88%</td>
<td>44%</td>
</tr>
</tbody>
</table>


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:
  o Independence
  o Spending quality time with family
  o Participating in meaningful activities/hobbies/interests
  o Having an understanding of who they are, where they are, and who is with them.
  o 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?
So, what’s the point?

References

- 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
Thank you
for your attention

Any Questions?
jason.beckrow@spectrumhealth.org