WHAT MATTERS IN THE END:
How Physicians Can Help Patients at the End-of-Life

Geriatric Grand Rounds
UCD, Division of Geriatric Medicine

Karen M. Wyatt MD – April 2, 2015

Objectives:
At the end of the presentation participants will be able to:

- Recognize the need for improved physician engagement in end-of-life issues.
- Understand the obstacles for physicians in engaging in end-of-life care and how to overcome them.
- Utilize simple tools to assist in the care of patients and loved ones at the end-of-life.

Times are Changing

The aging of the Baby Boom generation is ushering in new attitudes about the end-of-life.

What's New?

- Death Cafés
- The Conversation Project
- Death Over Dinner
- Blog: Confessions of a Funeral Director
- Natural Dying Movement
- Death Midwives and Death Doulas
- Home Funerals
- Green Burials

On-line Interview Series

End-of-Life University
Resources and Inspiration for the End-of-Life

Online Interview Series

www.eoluniversity.com

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The Medical Profession is not well represented in these movements. Patient needs are not being met.

The Recommendation:

Guidelines published in the Canadian Medical Association Journal\(^1\) and by the AHRQ\(^2\) recommend that:

Hospice be discussed as an option with patients who are expected to live less than a year.


The Problem: Delayed or Absent Conversations

December 16, 2013 JAMA Internal Medicine:

86% of doctors surveyed agreed strongly or somewhat that they would enroll in hospice care if they themselves were terminally ill.

But only 27% would discuss hospice “now” with a patient with cancer who was expected to live for another 4 to 6 months.

The Problem: Unmet Needs of Patients

2011 Nebraska End-of-Life Survey Results:

“70 percent of patients surveyed want their doctors to discuss their end-of-life care options, yet only 21 percent had heard about hospice care from a doctor.”


The Problem: Late Referrals

Centers for Disease Control:

Good News: “Hospice use at the time of death increased from 21.6% in 2000 to 42.2% in 2009.”

Twice as many patients referred!

Bad News: “28.4% of those hospice patients referred in 2009 received 3 days or less of hospice care.”

Too little care to make an impact.


The Problem: False Hopes

Dana-Farber Cancer Institute:

Of 1,274 stage IV lung and colon cancer patients in the study who were receiving chemotherapy “69% of the lung cancer patients and 81% of the colon cancer patients did not understand that the chemotherapy they were receiving was not likely to cure their disease.”

The Problem: Missed Opportunities

Dana-Farber Cancer Institute:

“Terminally ill patients who talk to their doctors about EOL care at least a month before they die are more likely to choose therapy that is less aggressive—therapy aimed more at making them feel better than at prolonging life.”


Why should physicians address the end-of-life with patients?

Because they trust us to be their health advisors at ALL stages of life.

Being Mortal – Atul Gawande, MD

“Sometimes we can offer a cure, sometimes only a salve, sometimes not even that. But whatever we can offer, our interventions, and the risks and sacrifices they entail, are justified only if they serve the larger aims of a person’s life. When we forget that, the suffering we inflict can be barbaric. When we remember it the good we do can be breathtaking.”

Obstacles

Obstacles for Physicians:

1. Lack of training in how to discuss the end-of-life.
2. Lack of time.
3. Uncertainty about prognostication and when to discuss the end-of-life.
4. Fear of a negative impact on the patient.
5. Feeling of hopelessness because death seems like a failure.

Adopt a new standard of care for all patients:
End-of-Life – Informed Care

1. Defining the End-of-Life
2. When to discuss the End-of-Life
3. When to refer to Palliative Care/Hospice
4. Tools for talking to patients
5. Finding hope and meaning in the end-of-life

Think of the End-of-Life as the final stage of normal human development.

The Terminal Phase of the End-of-Life Stage occurs just before Death.

Criteria for “End-of-Life” Stage
- Diagnosis of advanced, progressive life-limiting illness
  OR
- Presence of irreversible decline

Defining the End-of-Life: Stages of Human Development
Three Possible Trajectories of Decline at the End-of-Life

When to discuss the End-of-Life: Trajectory 1 - Cancer

“Most patients/caregivers wanted at least some discussion of these [end-of-life] topics at the time of diagnosis of an advanced, progressive, life-limiting illness, or shortly after.”


When to discuss the End-of-Life: Trajectory 2 – Organ Failure

- Persistent decline in organ function
- Multiple hospitalizations for acute exacerbations of chronic illness

When to discuss the End-of-Life: Trajectory 3 – Frailty

- Increasing dependency in Activities of Daily Living
  - Walking short distances
  - Bathing
  - Grooming
  - Dressing
  - Eating
  - Transferring from bed to chair
  - Using the toilet
  - Nursing home stay
  - Multiple hospitalizations


Overcoming the Obstacles

When to refer to Palliative Care/Hospice
**When to refer to Palliative Care/Hospice: Definitions**

- **Palliative Care:** throughout the continuum of illness involves addressing physical, intellectual, emotional, social and spiritual needs of the patient in tandem with curative therapies.

- **Hospice Care:** a special level of palliative care provided when life expectancy is 6 months or less.

**When to refer:**

<table>
<thead>
<tr>
<th>Integrated Palliative Care Model</th>
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**Overcoming the Obstacles**

**Tools for talking to patients**

**Tools: Conversation Project Starter Kit**

- Self-guided document for patients
- Download for free from [www.theconversationproject.org](http://www.theconversationproject.org)
- Helps patients clarify their own thoughts and feelings about the end-of-life
- Encourages conversations between patients and their loved ones

**Tools: BE Ready Checklist**

- List of important information for patients to gather and make available for their loved ones as they age
Tools: Palliative Care Guideline

- Created by Health Teamworks
- Explains the difference between the Traditional Care Model and the Integrated Palliative Care Model
- Graphs three possible trajectories of decline at the end-of-life
- Shows Hospice Care as a component of Palliative Care

Tools: Trigger Questions

- “I’d like to make sure that you experience the best possible quality of life, no matter how many days of life you have.”
- “Have you thought about the options for the last stage of your life? Would you like to discuss them?"”
- “It’s a good idea for all of us to do some planning for the end-of-life, because studies show that things go better when we are prepared. I can talk with you about that whenever you are ready.”

Tools: Colorado Advance Directive

- Includes:
  - Colorado Medical Durable Power of Attorney
  - Colorado Declaration – living will
  - Colorado Organ Donation Form

Tools: MOST Form (Medical Orders for Scope of Treatment)

- Appropriate for any individual with a chronic, serious, or life-limiting condition
- “Consolidates and summarizes patient wishes for key life-sustaining treatments.”
- CPR
- General scope of treatment
- Antibiotics
- Artificial Nutrition and Hydration
- Completed by patient and provider
- Must be signed by provider
- Download at www.LifeQualityInstitute.org

Time-Based Billing for Advance Care Planning – MOST Form

- Prolonged Service CPT Codes:
  - 99354-Prolonged physician service office/outpatient direct contact-1st hour
  - 99355-Prolonged physician service office/outpatient direct contact- each additional 30 minutes
- For companion codes: 99201-99215-Office or other Outpatient Services-New and Established 99326-99337-Domicillary, Rest Home (Boarding Home), or Custodial Care Services-New and Established 99341-99350-Home Services- New and Established
- Prolonged Service CPT Codes:
  - 99356-Prolonged physician service, inpatient, requiring unit/floor time- 1st hour
  - 99357-Prolonged physician service, inpatient, requiring unit/floor time- each additional 30 minutes
- For companion codes: 99221-99233-Hospital Care-Initial and Subsequent; New or Established 99304-99310-Nursing Facility Care-Initial and Subsequent; New or Established

Overcoming the Obstacles

Finding hope and meaning in the end-of-life
Finding Hope and Meaning: Changing Our Attitudes

Old Mindset
- “Death is a failure.”
- “Death is inevitable.”
- “Dying is the final stage of human development.”
- “Death makes life more precious.”

New Mindset
- “Dying is hopeless and tragic.”
- “Dying can provide an opportunity for growth and transformation.”
- “Palliative and hospice care provide hope.”

Finding Hope and Meaning: Increased Survival

New England Journal of Medicine:

“Patients receiving early palliative care had less aggressive care at the end of life but longer survival [11.6 mo. vs. 8.9 mo].”

August 19, 2010DOI: 10.1056/NEJMoa1000678

National Hospice and Palliative Care Organization:

“the mean survival was 29 days longer for hospice patients than for non-hospice patients.”


Finding Hope and Meaning: Improved Quality of Life

Harvard University:

“Advanced cancer patients who avoid hospitalizations and the intensive care unit, who are less worried, who pray or meditate, who are visited by a pastor in the hospital/clinic, and who feel a therapeutic alliance with their physicians have the highest QOL at the EOL.”

Conclusion: Refer to Palliative/Hospice Care early


5 Keys to A Peaceful Passing

- 1. Physical comfort
- 2. Love
- 3. Forgiveness
- 4. Enjoyment of every moment
- 5. Meaning
Summary

How to provide “EOL-Informed Care” for your patients.

End-of-Life Conversation Checklist

- Determine if patient is entering the End-of-Life Stage
- Make appropriate referral to HOSPICE or PALLIATIVE CARE
- Offer handouts to patient (Starter Kit, BE Ready Checklist, NC Advance Directive)
- Schedule follow up appointment to talk about preferences
- Use Trigger Questions to initiate discussion
- Suggest family conference
- Reevaluate treatment goals and EOL plans over time

One more “Why?”

Why should we physicians take the time and effort to engage in end-of-life issues?

Because someday, we are going to lose the ones we love …

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Thank you for this opportunity to share stories and thoughts with you!

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