PRIMARY PALLIATIVE CARE

“An Evolution”

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No financial disclosures
# Objectives

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<td>The current state of end-of-life care</td>
<td>Gaps in care, current challenges, areas of progress</td>
<td>IOM report and the national dialogue</td>
<td>“Primary” Palliative Care</td>
<td>Next steps</td>
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- The current state of end-of-life care
- Gaps in care, current challenges, areas of progress
- IOM report and the national dialogue
- “Primary” Palliative Care
- Next steps
Do you know enough about end of life care?

Take the Quiz →
Most people nearing the end of life are capable of making their own decisions about care.

True
False
CORRECT!

Most people nearing the end of life are not physically, mentally, or cognitively able to make their own decisions about treatment. As a result, advance care planning is essential to ensure that people receive care that reflects their values, goals, and informed preferences.

Next Question →
What is palliative care?

A. Care that provides symptom relief and other supports for people with serious illness
B. Another term for hospice
C. The default care choice when it is no longer possible to cure an illness
D. Care that comes only when people die
CORRECT!
Palliative care is defined by the IOM committee as care that provides relief from pain and other symptoms, supports quality of life, and is focused on patients with serious advanced illness and their families. Palliative care begins early in the course of treatment for a serious illness. Hospice is a type of palliative care.
Which groups are responsible for delivering care at the end of life?

A. Physicians, nurses, pharmacists, rehabilitation therapists, and other clinicians
B. Social workers and spiritual counselors
C. Family members
D. All of the above
CORRECT!

End-of-life care is the responsibility of an interdisciplinary team that includes clinicians at all levels, social workers, spiritual counselors, pharmacists, and, in many ways most importantly, family members.
When should advance care planning begin?

A. 6 months before death
B. Upon diagnosis with a serious illness
C. It is never too early
D. At age 50
CORRECT!

Every American, no matter his or her age or health status, should discuss end-of-life care preferences with family members, health care agents, and care providers. The course of injury or illness cannot be predicted, and preferences may change, so it is important to have the conversation often.
How many Americans age 65 and older die in the hospital?

A. Nearly 1 out of 4  
B. Nearly 1 out of 2  
C. Nearly 2 out of 3  
D. Nearly 9 out of 10
CORRECT!

About 1 in 4 Americans 65 and older dies in a hospital. One in three died at home. The majority of Americans express a preference for dying at home, which for some people may be an assisted living residence, nursing home, or skilled nursing facility.

Get Your Results →
Evolution?

“Let me order more tests”
Or De-evolution?

“Meaningful Use”
Definitions

• Evolution
  • “a process of continuous change from a lower, simpler, or worse to a higher, more complex, or better state: growth (2): a process of gradual and relatively peaceful social, political, and economic advance”

Merriam-Webster
Definitions

• Primary Care

  • Primary care is that care provided by **physicians specifically trained for and skilled in comprehensive first contact and continuing care** for persons with any undiagnosed sign, symptom, or health concern (the "undifferentiated" patient) not limited by problem origin (biological, behavioral, or social), organ system, or diagnosis.

  • Primary care includes health promotion, disease prevention, health maintenance, counseling, patient education, diagnosis and treatment of acute and chronic illnesses in **a variety of health care settings** (e.g., office, inpatient, critical care, long-term care, home care, day care, etc.). Primary care is performed and managed by a personal physician often collaborating with other health professionals, and utilizing consultation or referral as appropriate. **Primary care provides patient advocacy** in the health care system **to accomplish cost-effective care by coordination of health care services.** Primary care promotes effective communication with patients and encourages the role of the patient as a partner in health care.
Definitions

• Palliative Care
  • “Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

WHO
Definitions

• “Primary” Palliative Care

  “Primary palliative care refers to the basic competencies required of all physicians and health care workers” and is germane to any clinical practice, especially those that care for chronically or terminally ill patients

von Gunten, JAMA 2002
Self-reflection...
Fighting to Honor a Father’s Last Wish: To Die at Home

Maureen Stefanides at NewYork-Presbyterian Hospital with her father, Joseph Andrey, waiting to move to a nursing home despite their efforts to arrange for 24-hour care at his apartment. Victor J. Blue for The New York Times
The Predicament

• “I want to go home to my books and music.”
• Aging population with increased co-morbidities
• Undesired transfers between facilities
• Multiple re-hospitalization
• Fragmented home care services
• Exorbitant costs, excess of $1,000,000 over the last year
• “He didn’t die in his bed, and that’s what he wanted…”
The Rising Cost of Living Longer
Analysis of Medicare Spending by Age for Beneficiaries in Traditional Medicare
Average Health Care Spending per Capita, 1980–2012
Adjusted for Differences in Cost of Living

Source: OECD Health Data 2014
Medical spending in the U.S.

- $3.06 trillion in 2014
- Costliest 5% account for 50% of all health care spending
- 14% of Americans with both chronic conditions and functional limitations account for 56%
FIGURE 1-1 Population and health care costs for people with chronic conditions and functional limitations, 2010-2011.
...increased transitions

From: Change in End-of-Life Care for Medicare Beneficiaries: Site of Death, Place of Care, and Health Care Transitions in 2000, 2005, and 2009

Overall, nearly one-half of decedents experienced a transition in the last 2 weeks of life. Decedents with a diagnosis of cancer experienced increases in the use of hospice services, especially in the last week of life, while decedents with a diagnosis of chronic obstructive pulmonary disease (COPD) often transitioned to an acute care hospital. Decedents with dementia were predominantly in a nursing home with transitions to hospice services in last week of life.
# Care at Life’s End

In their last days, older patients are increasingly likely to be shuttled among hospitals, nursing homes and hospices in pursuit of Medicare and Medicaid coverage. Ultimately, most die in an institution, rather than at home.

_Among Medicare beneficiaries over 65 who died*

<table>
<thead>
<tr>
<th>Place of care</th>
<th>Transfers</th>
<th>Place of death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage receiving treatment in last days**</td>
<td>Among facilities and home, average number in last 90 days</td>
<td><strong>Place of death</strong></td>
</tr>
<tr>
<td><strong>Hospital</strong></td>
<td><strong>3</strong></td>
<td><strong>31%</strong></td>
</tr>
<tr>
<td><strong>Nursing home</strong></td>
<td><strong>2</strong></td>
<td><strong>35%</strong></td>
</tr>
<tr>
<td><strong>Hospice</strong></td>
<td><strong>1</strong></td>
<td><strong>34%</strong></td>
</tr>
<tr>
<td><strong>Intensive care unit</strong></td>
<td><strong>1</strong></td>
<td><strong>33%</strong></td>
</tr>
</tbody>
</table>

*Excludes Medicare Advantage members. **Patients may get care in more than one place. Those receiving hospice care may get it anywhere, not just in a stand-alone hospice.

Source: Journal of the American Medical Association
TABLE 1-4 Growth in the U.S. Elderly Population, 1960-2050 (projection)

<table>
<thead>
<tr>
<th>Age Group</th>
<th>1960</th>
<th>2000</th>
<th>2010</th>
<th>2050 (est.)</th>
</tr>
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<tbody>
<tr>
<td>65+: number</td>
<td>16.6 million (9.2)</td>
<td>35 million (12.4)</td>
<td>40.3 million (13.0)</td>
<td>88.5 million (19.8)</td>
</tr>
<tr>
<td>(% of total population)</td>
<td></td>
<td></td>
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<tr>
<td>85+: number</td>
<td>929,000 (0.5)</td>
<td>4.2 million (1.5)</td>
<td>5.5 million (1.7)</td>
<td>19 million (4.2)</td>
</tr>
</tbody>
</table>


TABLE 1-5 Average Medicare Expenditures per Fee-for-Service Beneficiary, by Number of Chronic Conditions, 2010

<table>
<thead>
<tr>
<th>Number of Chronic Conditions</th>
<th>Average Expenditure ($)</th>
</tr>
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<tbody>
<tr>
<td>0-1</td>
<td>2,025</td>
</tr>
<tr>
<td>2-3</td>
<td>5,698</td>
</tr>
<tr>
<td>4-5</td>
<td>12,174</td>
</tr>
<tr>
<td>6 or more</td>
<td>32,658</td>
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</tbody>
</table>
Fragmented Care

- 1/3 of patients with chronic illness and hospitalization had no post discharge follow-up arrangements
- Less than ½ of PCPs were provided discharge information or medications
- 3% of PCPs are involved in discussions with hospitalists regarding patients discharge plans
- PCPs are infrequently notified that patients are discharged

Bodenheimer NEJM 2008
Readmissions

- 1 in 5 Medicare patients are re-hospitalized within 30 days of discharge
- Half of these occurred before seeing an outpatient provider
- Estimated cost 17.4 billion

Jencks et al. NEJM 2009
Many of these patients have palliative care needs.
Transitioning Model of Care

Old

Life Prolonging Care

Medicare Hospice Benefit

New

Life Prolonging Care

Palliative Care

Hospice Care

Dx

Death

Bereavement
Newest

1. Incompatible Domains of Curative Versus Palliative Care:
   - Curative Care
   - Palliative Care

2. Competing Domains of Curative Versus Palliative Care:
   - Curative Care
   - Palliative Care

3. Complementary and Concurrent Components of Care:
   - Cure-Seeking Care
   - Life-Extending Care
   - Quality-of-Life and Comfort Maximizing Care
   - Family Supportive and "Grief and Other Emotions" Care
   - Health Care Staff Supportive and "Grief and Other Emotions" Care

FIGURE F-17 Palliative care as patient-centered complementary and concurrent modes of care.

SOURCE: A version of this figure appears in Feudtner, 2007.
Gaps in Traditional Care

Adapted from Kamal AH, Currow DC, et. al.  Community-based palliative care: the natural evolution for the palliative Care deliver in the US.  J Pain and Symptom Management. 2012
Keep the Patient at the Center of Care

- What do patients want?
  - Pain and symptom control
  - Avoid inappropriate prolongation of the dying process
  - Achieve a sense of control
  - Relieve burdens on family
  - Strengthen relationships with loved ones


- Do we know how and where they want help with this?
  
[We doubt it is only when in the hospital…]
The Good News

• Relatively rapid expansion of Specialist Palliative Care
  • ABMS recognized in 2006, AOA in 2007
  • Majority of hospitals with formalized inpatient programs
  • Fellowship program expansion, >100 nationwide
  • Growing “acceptance” of palliative care

• Beaumont Health
  • Inpatient care available at most/if not all hospitals
  • >2000 inpatient consultations in 2014 across the system and growing
Inpatient Programs

Prevalence of Palliative Care (2000–2011) in U.S. Hospitals with 50 or More Beds

- Programs (#)
- Prevalence (%)
“Proven” Benefits

Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer

Jennifer S. Temel, M.D., Joseph A. Greer, Ph.D., Alona Muzikansky, M.A.,
Emily R. Gallagher, R.N., Sonal Admame, M.B., B.S., M.P.H.,
Vicki A. Jackson, M.D., M.P.H., Constance M. Dahlin, A.P.N.,
Craig D. Blinderman, M.D., Juliet Jacobsen, M.D., William F. Pirl, M.D., M.P.H.,
J. Andrew Billings, M.D., and Thomas J. Lynch, M.D.

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

Mean Change in Quality-of-Life Scores from Baseline to 12 Weeks

Twelve week outcomes of assessments of mood

- A FACT-L
- B LCS
- C TOI

Comparison of outcomes between Standard Care and Early Palliative Care.

Graph showing patients with mood symptoms (%)
- HADS-D
- HADS-A
- PHQ-9
Survival Functions

Median Survival
Early palliative care
11.6 mo
Standard care
8.9 mo
p=0.02
Increased Satisfaction with Care and Lower Costs: Results of a Randomized Trial of In-Home Palliative Care

Richard Brumley, MD,* Susan Enguidanos, PhD, MPH,† Paula Jamison, BA,† Rae Seitz, MD,‡ Nora Morgenstern, MD,§ Sherry Saito, MD,*, Jan McIvor, MSW,§ Kristine Hillary, RNP,*, and Jorge Gonzalez, BA†

OBJECTIVES: To determine whether an in-home palliative care intervention for terminally ill patients can improve patient satisfaction, reduce medical care costs, and increase the proportion of patients dying at home.

DESIGN: A randomized, controlled trial.

SETTING: Two health maintenance organizations in two states.

PARTICIPANTS: Homebound, terminally ill patients (N = 298) with a prognosis of approximately 1 year or less to live plus one or more hospital or emergency department visits in the previous 12 months.

INTERVENTION: Usual versus in-home palliative care plus usual care delivered by an interdisciplinary team providing pain and symptom relief, patient and family education and training, and an array of medical and social support services.

MEASUREMENTS: Measured outcomes were satisfaction with care, use of medical services, site of death, and costs of care.

RESULTS: Patients randomized to in-home palliative care reported greater improvement in satisfaction with care at 30 and 90 days after enrollment (P < .05) and were more likely to die at home than those receiving usual care (P < .001). In addition, in-home palliative care subjects were less likely to visit the emergency department (P = .01) or be admitted to the hospital than those receiving usual care (P < .001), resulting in significantly lower costs of care for intervention patients (P = .03).


Key words: palliative care; in-home services; patient satisfaction; end-of-life care

It has been widely recognized that our current medical care structure is inadequate in meeting the needs of terminally ill patients and reducing the cost of care at the end of life.† Despite the existence of hospice as a Medicare benefit for nearly 2 decades, the program remains underused. Approximately 60% of all deaths occur in the hospital,‡ yet most patients express a preference to die at home.¶ Although hospice programs aim to provide palliative services in the last 6 months of life, the median length of stay in the program is 22 days, and 35% of patients die within the first 7 days after hospice admission.¶ Hospice patients with a short length of stay often require intensive care to initiate the care plan, resulting in higher per diem costs of care than for patients who receive longer periods of stabilized, low-cost palliative care.¶ The low enrollment in hospice services and the short length of time enrolled before death attest to the need for end-of-life care programs that address these access barriers. In addition, recent studies have found that more end-of-life programs are needed to provide alternatives to hospice that do not require forgoing life-sustaining treatment.¶

Although several studies have reported that end-of-life care programs improve patient outcomes, these studies have significant methodological weaknesses, limiting their en-

In-home Palliative Care

- Increased patient satisfaction
- Reduced use of medical services and costs at the end of life
- More likely to die at home
Figure 2. Percentage very satisfied at enrollment (n = 277), 30 days (n = 216), 60 days (n = 168), and 90 days postenrollment (n = 149) according to study group.

Figure 3. Average adjusted cost of care per day according to study group (n = 297).
Palliative Care at Home for the Chronically Ill Markedly Reduces Utilization

Service Use Among Patients Who Died from Heart Failure, Chronic Obstructive Pulmonary Disease, or Cancer While Enrolled in a Palliative Care Intervention or Receiving Usual Care, 1999–2000

Data: Adjusted service use rates were based on administrative records. SNF = skilled nursing facility. (Brumley, R.D. et al. JAGS 2007)
How we are addressing gaps...

• Outpatient consultations (limited to $\frac{1}{2}$ day at RO, some “as needed,” referral to outside resources)
• Home-based Palliative Care (newly launched)
Care & TLC—Treatment for Lifelong Conditions™; seamless care across care settings

Care & Treatment for Lifelong Conditions

- Palliative Care @home
- CHF @home
- COPD @home
- ESRD @home
- Diabetes @home
WHAT ELSE…

What about the rest?
Changing Gears…
IOM has now made clear (in 6 reports): Palliative care IS essential to quality
IOM Key Domains

- Delivery of Person-Centered, Family-Oriented (palliative) Care
- Clinician-Patient Communication and Advance Care Planning
- Professional Education and Development
- Policies and Payment Systems
- Public Education and Engagement
Policies and Payment Systems

- Misaligned incentives
- Cost reductions
- Improved outcomes and quality

Recommendations:
- Federal, state and private insurance and health care delivery programs should integrate the financing and delivery of medical and social services
- Require public reporting of quality and costs near the end of life
Delivery of Care

- Multiple transitions, high hospitalization rates, fragmented care
- **Palliative care is associated with higher quality of life, perhaps increased longevity**
- Recommendation
  - All payers should provide comprehensive care for individuals nearing the end of life
Clinician-Patient Communication and ACP

- Most people nearing the end-of-life are not physically, mentally or cognitively able to make their own decisions
- **Most choose care focused on alleviating symptoms and suffering, not “acute” care**
- Limited access to end-of-life conversation
- Recommendations
  - Develop standards for clinician-patient communication and ACP that are measurable, actionable, and evidence based
  - Adherence should be tied to credentialing, licensing and reimbursement
“There's no easy way I can tell you this, so I'm sending you to someone who can.”
Why This Wisconsin City Is The Best Place To Die

NOVEMBER 16, 2009  4:00 PM ET

Sandra Colbert sits propped up in a hospital bed at Gundersen Lutheran Hospital in La Crosse, Wis., connected by tubes to oxygen and IV fluids. Doctors have told her she didn’t have a heart attack. But it sure felt that way when she collapsed at the gym a few hours earlier. "It felt like my heart exploded," she says, then adds. "I thought I was going to die."

She’s not going to die, the doctor reassured her. But now nurses are asking her to think about dying. Or, more specifically, they’ve asked her to fill out a living will.

It might seem almost rude to ask a woman who just a few hours ago had reason to fear she was about to die — but who now knows she’s OK — to think about how she does want to die some day. Yet it’s a routine question in this Midwestern city on the Mississippi River.

The specially trained nurse, in this case a woman named Laura Wiedman, will spend more than an hour with Colbert — and her husband Jim — and help them both think through the treatment they’d want at the end of life.

Respecting Choices

http://www.cbsnews.com/news/being-prepared-for-the-final-days/
One of the best-known advance directive initiatives is Respecting Choices®.

Institute of Medicine report

Respecting Choices®
ADVANCE CARE PLANNING

Respecting Choices® Advance Care Planning

Gundersen Health System is leading the nation with its innovative advance care planning program—Respecting Choices®. The Respecting Choices’ evidence-based model leads to high-quality care for patients and the population while at the same time reduces healthcare costs.

Advance care planning, as defined by Respecting Choices, is a person-centered, ongoing process of
MI-POST is a program designed to help healthcare professionals honor the treatment decisions of their patients. MI-POST is a part of the National POLST Paradigm.

**View the MI-POST In Action Video**
This video is for general provider education and does not address the differences in Emergency Medical Services procedures for pilot and non-pilot communities.

(Note: The law in the video referenced is the Michigan DNR Procedures Act (PA 193), which is specific to the out-of-hospital DNR and does not address MI-POST in name.)

MI-POST is a tool for translating patient’s goals of care into medical orders so that they are easily located and portable across care settings. MI-POST is not just a specific set of medical orders documented on a form; it is also an approach to end-of-life planning based on conversations between patients, loved ones, and medical providers.

### Michigan Physician Orders for Scope of Treatment (MI-POST)

First follow these orders, then contact physician. This is a Medical Order Sheet based on the person’s medical condition and treatment decisions. Any section not completed does not invalidate the form and implies full treatment for that section.

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<th>Last Name</th>
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<tbody>
<tr>
<td>First Name/Middle Initial</td>
</tr>
<tr>
<td>Date of Birth (mm/dd/yyyy)</td>
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</table>

**CARDIOPULMONARY RESUSCITATION (CPR): Person has no pulse AND is not breathing.**

- [ ] Attempt Resuscitation/CPR
- [ ] DO NOT Attempt Resuscitation/CPR (DNR/No CPR)

(Note: If “Attempt Resuscitation/CPR” is checked in Section A, “Advanced Interventions” must also be checked in Section B.)

**MEDICAL INTERVENTIONS: Person has pulse and/or is breathing.**

All patients will receive comfort measures.

- [ ] Advanced Interventions: Use intubation, advanced invasive airway interventions, mechanical ventilation, cardioversion and other advance interventions as medically indicated. *Transfer to hospital if indicated; includes intensive care.*
- [ ] Limited Interventions: DO NOT use intubation, advanced invasive airway interventions, or mechanical ventilation. Use medical treatment, IV fluids and cardiac monitor as indicated. *Transfer to hospital if indicated. Avoid intensive care.*
- [ ] Comfort Measures Only: Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction manual treatment of airway obstruction and non-

https://www.youtube.com/watch?v=PkAQC4wmjSU
What are we doing?

- Ongoing active dialogue throughout the system
- Exploring ACP options, best-practices, strategic planning and goal alignment
- Focused discussion today…
Public Education and Engagement

- Overall **lack of knowledge** about end of life choices
- Need for **normalization of conversations** about death and dying
- Recognized **growing awareness**
- Recommendations:
  - “Every element of society should engage their constituents and provide factual information about the care of people with advances serious illness, encourage advance care planning and informed choice based on the needs and values of the individuals”
“Death Panels”
Optics in Washington:
> 1/3 of all seniors say new health law includes a government panel to make end-of-life care decisions

To the best of your knowledge, would you say the new law does or does not allow a government panel to make decisions about end-of-life care for people on Medicare?

- Yes, law does this: 36%
- No, law does not do this: 48%
- Don't know: 17%

NOTE: Percentages do not sum to 100 percent due to rounding.
CHANGING DIALOGUE...
Atul Gawande’s ‘Being Mortal’

By SHERI FINK  NOV. 6, 2014

It began with a tingle in the surgeon’s fingers and a pain in his neck. A couple of years later, he learned he had a tumor inside his spinal cord. That was when the difficult choices began. Should he have it removed right away in a risky operation, as his doctor recommended? Or should he take time to consider this question: At what point would the expanding tumor cause debility bad enough to justify the risk of greater debility or even death in trying to fight it?

The surgeon in the story is the father of Atul Gawande, who is also a surgeon as well as a writer for The New Yorker. His new book, “Being Mortal,” is a personal meditation on how we can better live with age-related frailty, serious illness and approaching death.
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<thead>
<tr>
<th>HARD COVER NONFICTION</th>
<th>WEEKS ON LIST</th>
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<tbody>
<tr>
<td><strong>1</strong></td>
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<tr>
<td><strong>KILLING PATTON,</strong> by Bill O'Reilly and Martin Dugard. (Holt.) The host of “The O’Reilly Factor” recounts the death of Gen. George S. Patton in December 1945.</td>
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<td><strong>2</strong></td>
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<td><strong>NOT THAT KIND OF GIRL,</strong> by Lena Dunham. (Random House.) A collection of revealing and often humorous personal essays from the creator and star of “Girls.”</td>
<td>2</td>
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<tr>
<td><strong>3</strong></td>
<td></td>
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<tr>
<td><strong>BEING MORTAL,</strong> by Atul Gawande. (Metropolitan/ Holt.) The surgeon and New Yorker writer considers how doctors fail patients at the end of life, and how they can do better.</td>
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</tr>
</tbody>
</table>
BEING MORTAL
Feb. 10, 2015

(54:11) FRONTLINE explores the intersection of life, death, medicine and what matters in the end.

http://www.pbs.org/wgbh/pages/frontline/being-mortal/
“We think it’s really important to incentivize this kind of care,” said Dr. Barbara Levy, chairwoman of the A.M.A. committee that submits reimbursement recommendations to Medicare. “The idea is to make sure patients and their families understand the consequences, the pros and cons and options so they can make the best decision for them.”
Before I Die...

- Created by artist Candy Chang in New Orleans
- Response to personal loss
- World wide spread
  - 550 walls
  - 70 countries
  - 35 languages
Savannah, Georgia

Pohang City, South Korea

Najaf, Iraq
Treating the person beyond the disease...
Professional Education and Development

• Recognized critical step in development of hospice and palliative care specialty
• Deficiencies remain in formal medical education, in communication skills development in general
• Health professionals are not prepared to deliver basic, or “primary” palliative care

Recommendations:
• Strengthen the palliative care knowledge and skills of all clinicians
• All clinicians should be competent in basic palliative care, including communication skills, inter-professional collaboration and symptom management
What are we doing…

• Annual Palliative Care Conference
• Longitudinal educational sessions throughout our system, including a “PC 101” presented to learners and staff across disciplines
• Established curricular components for OUWB students
• Could there be more? (YES)

• What about “Primary” Palliative Care?
“Primary” Palliative Care

Generalist plus Specialist Palliative Care — Creating a More Sustainable Model
Timothy E. Quill, M.D., and Amy P. Abernethy, M.D.

Palliative care, a medical field that has been practiced informally for centuries, was recently granted formal specialty status by the American Board of Medical Specialties. The demand for palliative care specialists is growing rapidly, since timely palliative care consultations have been shown to improve the quality of care, reduce overall costs, and sometimes even increase longevity. The field grew out of a hospice tradition in which palliative treatment was delivered only at the end of life, but its role has expanded so that palliative care specialists now also provide palliative treatment in the earlier stages of disease alongside disease-directed medical care, improving quality of care and medical decision making regardless of the stage of illness. In an era when health care organizations may soon receive capitated payments for all services that patients receive, many are investing in palliative care to improve overall value.

Although this trend has fostered rapid growth of the palliative care specialty, the current model adds another layer of specialized care for seriously ill patients on top of an already complex, expensive health care environment. As in any medical discipline, some core elements of palliative care, such as aligning treatment with a patient’s goals and basic symptom management, should be routine aspects of care delivered by any practitioner. Other skills are more complex and take years of training to learn and apply, such as negotiating a difficult family meeting, addressing veiled existential distress, and managing refractory symptoms. Now that the value of palliative care has been recognized, specialists are sometimes called on for all palliative needs, regardless of complexity.

Although it may theoretically seem optimal for palliative medicine specialists to take on all palliative aspects of care, this model has negative consequences. First, the increasing demand for palliative care will soon outstrip the supply of providers. Second, many elements of palliative care can be provided by existing specialist or generalist clinicians regardless of discipline, adding another specialty team to address all suffering may unintentionally undermine existing therapeutic relationships. Third, if palliative care specialists take on all palliative care tasks, primary care clinicians and other specialists may begin to be

Representative Skill Sets for Primary and Specialty Palliative Care

Primary Palliative Care
- Basic management of pain and symptoms
- Basic management of depression and anxiety
- Basic discussions about
  - Prognosis
  - Goals of treatment
  - Suffering
  - Code status

Specialty Palliative Care
- Management of refractory pain or other symptoms
- Management of more complex depression, anxiety, grief, and existential distress
- Assistance with conflict resolution regarding goals or methods of treatment
  - Within families
  - Between staff and families
  - Among treatment teams
- Assistance in addressing cases of near futility

N ENGL J MED 368:13 NEJM.ORG MARCH 28, 2013
The New England Journal of Medicine
The “Next Gen”

• “generalist clinicians will need competency-based education”
• “grounded in basic palliative care skills”
Potential Benefits of Outpatient Primary Palliative Care

- Honors clinician-patient relationship
- Timely critical conversations from a trusted source
- Earlier and continuous involvement in disease management (improved clinical outcomes)
- Improves quality of care
- Offers follow-up continuity (to inpatient care) - good for both patients and clinicians
- Strengthens/builds relationship before a crisis
- Reduces hospitalizations/re-admissions
- May increase skills of other caregivers & providers (formally or informally)
- May increase consumer awareness (earlier)
- May open doors for system redesign/ process improvement
- Involves concurrent initiatives/trends: PCMH-N, ACOs, Bundled Payments
Further arguments for primary Palliative Care…

- “Delivery of basic palliative care by primary care and regular specialist physicians would help meet the rising demand that exceeds the supply of palliative care specialists” (Quill, 2013)
- “advanced lung cancer patients who were seen by their usual primary care provider during their final hospitalization had 25 % reduced odds of admission to critical care units” (Sharma et al., 2009)
- “preliminary evidence that the continued involvement of primary care physicians in cancer care is valued by patients, may influence care experiences and outcomes, and serves to meet patients’ needs for communication and emotional support” (Han and Rayson, 2010)
- **Patient Centered Medical Home mandate**, “The personal physician is responsible for providing for all the patient’s health care needs or taking responsibility for appropriately arranging care with other qualified professionals. This includes care for all stages of life; acute care, chronic care, preventive services, and end of life care” (AAFP et al., 2007)
Next Steps…

- Learn
  - Critical conversations
  - ACP
  - Basic clinical skills
- Enhance your own self-awareness and decide
  - Engage your patients
  - Talk with your colleagues
  - Promote the “end-of-life dialogue”
  - Advocate for policy change
Evolution - Primary Palliative Care

“How can we alleviate suffering?”
QUESTIONS?