Palliative Care & Hospice

David Pratt, MD, MPH

Wednesday, Dec. 7
12:15-1:45 PM

Wm. K. Sanford Town Library
625 Albany Shaker Rd., Albany, NY
Today’s Presentation Outline

- Palliative care defined
- Demography, dollars and reality
- A (brief) history of palliative care
- The clinicians’ view
- Efficacy
- The Benefit
- Trends
- Individuals’ actions
- Summary
Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems physical, psychosocial and spiritual’

2002
All of Hospice is Palliative Care but not all Palliative Care is Hospice
Venues for Palliative Care

- Hospital
- Home
- Hospice

Home (or Community)
How Big is the Need?
The Silver Tsunami in America
The Boomers are turning 65 at a rate of 8,000 to 10,000 per day and will do so for 16 additional years.
As We Age We Spend More on Health Care

Figure 3:
A Person’s Health Care Spending Increases with Age

The Case for Palliative Care

Demography → Demand

Demand → Dollars

This logic explains the growing interest from the government and private insurance companies in palliative care.
A Snapshot: Dementia and Total Expenditures

- 2010: $215 billion/yr

- By comparison: heart disease $102 billion; cancer $77 billion

- 2040 estimates: > $375 billion/yr

Hurd MD et al. NEJM 2013;368:1326-34.
The Decline Ritual:
Via the ED and the ICU

• Half of older Americans visited ED in last month of life and 75% did so in their last 6 months of life.

• 90% of ED visits in those >65 due to symptom distress.

• 50% increase in ICU admissions from ED in people >85 years.

A British estimate is that 65% of all those who die each year would be better served if palliative care was involved.
Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life

www/iom.edu/endoflife

Key Findings and Recommendations

1. Person-centered, family oriented care – continuum
2. Communication and Advance Care Planning
3. Professional Education and Development
4. Policies and Payment Systems
5. Public Education and Engagement

www.iom.edu/reports
A (brief) Palliative Care History
History of Palliative Care

• Antiquity: caring for each other
• Middle Ages: convents, hostels, hospitality inns - Martigny CH
• Early years of medicine: symptom management, comfort, sitting bedside
• Modern era: treatment and cure over comfort
• Modern Hospice Movement 1970’s
  – Dame Cicely Saunders in the United Kingdom
History of Palliative Care

- **Hospice in the USA**
  - Volunteer Team to provide supportive care for cancer patients, in their homes: late 1970’s, early 1980’s.
  - Medicare Hospice Benefit: 1980’s

- **Non-Cancer diagnoses now more frequent than cancer diagnosis for hospice care.**

- **Palliative Medicine: recognized specialty for**
  - physicians
  - nurse practitioners, nurses
  - Certified Nurse Assistants
How do US Experts Define Palliative Care?

• Specialized or generalist medical care for people and their families with serious illness
• Focused on improving quality of life as defined by patients and families.
• Provided by an interdisciplinary team that works with patients, families, and other healthcare professionals to provide an added layer of support.
• Appropriate at any age, for any diagnosis, at any stage in a serious illness, and is provided together with curative and life-prolonging treatments.

“Don’t ask what’s the matter with me. Ask what matters to me.”

Palliative Care Teams Address 3 Domains

1. Physical, emotional, and spiritual distress
2. Patient-family-professional communication about achievable goals for care and the decision-making that follows
3. Coordinated, communicated, continuity of care and support for social and practical needs of both patients and families across settings
Some of the Domains of Suffering

- Physical
- Emotional
- Social
- Spiritual
The Tools of Palliative Care are Defined by the Goals of that Care

1. The first goal is healing not curing - patient and family
2. Relief of suffering from any source is the daily work
3. The most powerful intervention is presence with compassion
4. The palliative care team steps into the suffering
Does Palliative Care Work?

Randomized Trial of Advance Care Planning Among 309 Elderly

- Hospitalized patients age >80 randomized to ACP by trained facilitator vs. usual care
- 81% received ACP; 56% completed AD
  - Facilitator used “Respecting Patient Choices”
  - ACP in collaboration with physician
  - Families present for 72%
  - Sessions took median 60 minutes

# Randomized Trial of Advance Care Planning Among 309 Elderly

<table>
<thead>
<tr>
<th>Outcome (%)</th>
<th>ACP</th>
<th>Control</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Death in ICU</td>
<td>0</td>
<td>14</td>
<td>0.03</td>
</tr>
<tr>
<td>PTSD in family</td>
<td>0</td>
<td>14</td>
<td>0.03</td>
</tr>
<tr>
<td>Depression in family</td>
<td>0</td>
<td>30</td>
<td>0.002</td>
</tr>
<tr>
<td>Anxiety in family</td>
<td>0</td>
<td>19</td>
<td>0.02</td>
</tr>
<tr>
<td>Satisfied with death</td>
<td>80</td>
<td>68</td>
<td>0.02</td>
</tr>
<tr>
<td>Satisfied with care</td>
<td>93</td>
<td>65</td>
<td>0.001</td>
</tr>
</tbody>
</table>

...Improves Survival

Average number and type of hospital admissions pre- and post-enrollment to *Care Choices*

<table>
<thead>
<tr>
<th>Hospitalization</th>
<th>Pre M(SD)</th>
<th>Post M(SD)</th>
<th>t</th>
<th>df</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emergency Room</td>
<td>1.79(1.46)</td>
<td>1.00(1.08)</td>
<td>4.46</td>
<td>80</td>
<td>0.000***</td>
</tr>
<tr>
<td>Inpatient</td>
<td>1.21(1.02)</td>
<td>0.38(0.70)</td>
<td>6.54</td>
<td>80</td>
<td>0.000***</td>
</tr>
</tbody>
</table>

* p<.05  
** p<.01  
*** p<.001
Growth of PC Programs Nationally

Prevalence of U.S. Hospital Palliative Care Teams: 2000–2012

Number of Hospitals (50+ Beds) with Palliative Care Teams

- 2000: 658
- 2003: 1082
- 2006: 1357
- 2009: 1568
- 2012: 1734

CAMBIA PALLIATIVE CARE CENTER OF EXCELLENCE
UNIVERSITY of WASHINGTON
The Benefit
Benefits of Palliative Care

• Honors residents’ wishes for dignity
• Provides evidence based measures for good symptom management
• Demonstrates partnering and collaboration with:
  – resident, family, staff, and palliative care team
• Provides a common platform to discuss
  – Goals of Care
  – Advanced Directives
Many private insurance companies and health maintenance organizations (HMOs) offer palliative care and hospice benefits. Medicare (mostly for people 65 and older) offers hospice benefits, and the extra Medicare plan (Part B) offers some palliative care benefits. Medicaid coverage of hospice and palliative care for people of limited incomes varies by state.

The trend in palliative care is for more coverage not less.
Medicare Hospice Benefit

- Established in 1982 for high-quality end-of-life care

- Eligibility
  - Medicare Part A
  - Terminal illness (6 months or less if illness runs its natural course)
  - Forgo intensive medical interventions of curative intent

- Benefit Period
  - Two 90 day periods, followed by unlimited 60 day periods
  - Initial certification by two physicians
  - Recertification by hospice physician
How Reimbursement Currently Works

• All-inclusive per diem rate
  – Routine home care**
  – General inpatient care
  – Continuous care
  – Respite care

• Not adjusted for case-mix or NH setting

• Medicare caps aggregate payments

Proposed Changes to Reimbursement

- Move away from flat per diem rate
- Consideration for different payment structure for hospice care in the nursing home (being studied)

Medpac Report to the Congress. Reforming Medicare’s Hospice Benefits 2009; Chap 6:347-376
Concurrent Care Demonstration

Old concept

Curative

Hospice Care

Better concept

Curative

6 months

Hospice Care

No Time Requirement
Persisting Issues with the Hospice Benefit
(after 2015 changes)

The barriers to care posed by current hospice eligibility Standards (continued chemotherapy)

The exclusion of hospice from Medicare Advantage and other integrated payment models

The poor fit of the current hospice benefit for nursing home residents.
Hospice Trends in the US
Total US Patients Served by Year

NHPCO data 2015
### Table 6. Percentage of Hospice Admissions by Primary Diagnosis

<table>
<thead>
<tr>
<th>Primary Diagnosis</th>
<th>2014</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>36.6%</td>
<td>36.5%</td>
</tr>
<tr>
<td>Non-Cancer Diagnoses</td>
<td>63.4%</td>
<td>63.5%</td>
</tr>
<tr>
<td>Dementia</td>
<td>14.8%</td>
<td>15.2%</td>
</tr>
<tr>
<td>Heart Disease</td>
<td>14.7%</td>
<td>13.4%</td>
</tr>
<tr>
<td>Lung Disease</td>
<td>9.3%</td>
<td>9.9%</td>
</tr>
<tr>
<td>Other</td>
<td>8.3%</td>
<td>6.9%</td>
</tr>
<tr>
<td>Stroke or Coma</td>
<td>6.4%</td>
<td>5.2%</td>
</tr>
<tr>
<td>Kidney Disease (ESRD)</td>
<td>3.0%</td>
<td>3.0%</td>
</tr>
<tr>
<td>Liver Disease</td>
<td>2.3%</td>
<td>2.1%</td>
</tr>
<tr>
<td>Non-ALS Motor Neuron</td>
<td>2.1%</td>
<td>1.8%</td>
</tr>
<tr>
<td>Debility Unspecified</td>
<td>1.9%</td>
<td>5.4%</td>
</tr>
<tr>
<td>Amyotrophic Lateral Sclerosis (ALS)</td>
<td>0.4%</td>
<td>0.4%</td>
</tr>
<tr>
<td>HIV / AIDS</td>
<td>0.2%</td>
<td>0.2%</td>
</tr>
</tbody>
</table>
Patients’ Average Time on Hospice Service

![Pie chart showing the proportion of patients by length of service in 2014](image)

*Figure 5. Proportion of Patients by Length of Service in 2014*
The Shifting Trend Towards for Profit Hospice Centers
Who Pays for Hospice Care?

<table>
<thead>
<tr>
<th>Payer</th>
<th>2014</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicare Hospice Benefit</td>
<td>85.5%</td>
<td>87.2%</td>
</tr>
<tr>
<td>Managed Care or Private Insurance</td>
<td>6.9%</td>
<td>6.2%</td>
</tr>
<tr>
<td>Medicaid Hospice Benefit</td>
<td>5.0%</td>
<td>3.8%</td>
</tr>
<tr>
<td>Uncompensated or Charity Care</td>
<td>0.7%</td>
<td>0.9%</td>
</tr>
<tr>
<td>Self Pay</td>
<td>0.8%</td>
<td>0.8%</td>
</tr>
<tr>
<td>Other Payment Source</td>
<td>1.2%</td>
<td>1.2%</td>
</tr>
</tbody>
</table>
Certified Hospice Programs by State 2014

Figure 9. Medicare-Certified Hospices by State
Individual’s Responsibility
What can people do to ensure they receive the care they want?

• Advance Directives
  – Living will
  – Durable Power of Attorney for Health Care
  – Physician Order for Life-sustaining Treatments (POLST)

• Advance Care Planning
  – Communication with family and doctors about goals, values, and preferences
Welcome to the Conversation Starter Kit

It’s not easy to talk about how you want the end of your life to be. But it’s one of the most important conversations you can have with your loved ones.

This Starter Kit will help you get your thoughts together and then have the conversation.

This isn’t about filling out Advance Directives or other medical forms. It’s about talking to your loved ones about what you or they want for end-of-life care.

www.theconversationproject.org
What are advance directives good for?

- As a tool for raising the discussion
- Good for some specific situations:
  - If there is a specific treatment you know you don’t want
  - If you don’t want your legal next of kin to be making decisions for you
- Advance directives can ease the burden on your family
Preparing for a Discussion About End-of-life Care with Your Doctor

- Advance preparations
  - Who should be there?
  - What do you want to know?
  - Bring in your documents

- Think about the things you might want
  - Specific treatments you don’t want
  - Aspects of health important to you: independence, ability to communicate
  - Consider adaptation
Understanding the Discomfort

- Discomfort discussing dying is universal
  - Patient and family fears
  - Clinician fears and concerns of inadequacy
- Recognizing the discomfort can help us work through it
  - Consider talking about the discomfort with the doctor
Communication With Patients: Competencies

- Listens to patients
- Encourages questions from the patient
- Talks with patients in an honest and straightforward way
- Gives bad news in a sensitive way
- Willing to talk about dying
- Sensitive to when patients are ready to talk about death

Curtis, J Gen Intern Med, 2000;16:41
Thanks to:

J Randall Curtis, MD, MPH
Cambia Medical Center University of Washington

Diane Meier, MD Professor of Geriatrics
Director of CAPC

Phil DiSorbo MSW Care Choices

George Giokas, MD Community Hospice

Center to Advance Palliative Care (CAPC)
Begin doing what you want to do now.

We are not living in eternity.

We have only this moment, sparkling like a star in our hand--and melting like a snowflake.

Francis Bacon