Palliative Care 101
(these days)

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Zen Hospice Project
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Today

• History + definition of terms
• Need for PC
• Impact
• Challenges + Opportunities
History and definitions
Definition:
Center for Medicare and Medicaid Services

“Palliative care” means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.
Suffering

Existential/Spiritual

Social

Emotional

Intellectual

Logistical

Physical
Key PC Characteristics

- Care is provided and services are coordinated by an interdisciplinary team;
- Patients, families, palliative and non-palliative health care providers collaborate and communicate about care needs;
- Services are available concurrently with or independent of curative or life-prolonging care;
- Patient and family hopes for peace and dignity are supported throughout the course of illness, during the dying process, and after death.

PC settings and delivery models

**Inpatient PC (IP PC)**
- Inpatient units and consultation service (with consultation services as the most prevalent delivery model)
  - Center to Advance Palliative Care estimates that 80% of acute care hospitals with >50 beds have such services*

**Community-based PC (CBPC)**

Multiple settings:
- Home
- Clinic (stand alone or embedded in another practice)
- Long Term Care / Skilled Nursing Facility & Rehab
- Distance/phone

Provider affiliations:
- Health systems and hospitals
- Hospices
- Medical groups (including specialty PC practices)
- Post-acute care providers

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Palliative Care

Hospice
Palliative Care and Hospice in the US

Hospice is a version of palliative care designed for patients in their last 6 months of life who are not concurrently pursuing disease management or cure; **hospice is distinct from clinical PC, but the two are similar in important ways:**

- Team-based care
- Focus on improving quality of life and relieving suffering for patients with serious illness
- Care focus on patient and family
- Many shared competencies
### Some ways PC and hospice differ

<table>
<thead>
<tr>
<th></th>
<th>Palliative Care Services</th>
<th>Hospice</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Timing</strong></td>
<td>Any stage of serious illness, any prognosis</td>
<td>Life expectancy ≤ 6 months</td>
</tr>
<tr>
<td><strong>Integration with</strong></td>
<td>Can to be delivered concurrently with all other appropriate</td>
<td>In most cases must forego further curative-intent care for</td>
</tr>
<tr>
<td><strong>other health care</strong></td>
<td>treatments/services</td>
<td>terminal illness as condition of enrollment</td>
</tr>
<tr>
<td><strong>Payment</strong></td>
<td>(Mostly) no distinct payment mechanism</td>
<td>Defined benefit from Medicare and nearly all other payers</td>
</tr>
<tr>
<td><strong>Prevalence</strong></td>
<td>Widely available in larger hospitals; no prevalence data on CBPC, but presumed significant shortage vs. demand/need</td>
<td>Widely available (&gt;5,500 in US), but underutilized (60% of enrollees use hospice for &lt;30 days, including 36% with length of service ≤7 days)*</td>
</tr>
</tbody>
</table>

*National Hospice and Palliative Care Organization Facts and Figures Hospice Care in America 2013*  
"I'll give you something to ease the pain."
Timeline – PC in US

• 1974
• 1982
• 1991
• 1995
• 1997
Services across the disease trajectory

- Curative Care
- Palliative Care
- Hospice

Diagnosis → (Progression / Time) → Death & Bereavement
PC is not:

- A replacement for curative care
- A replacement for primary treating physicians
- Only for dying patients
- Only for cancer patients
Timeline, cont.

• 2006
• 2010
• 2011
• 2014
Specialty recognition

2006 ABMS formalizes HPM specialty

• Subspecialty status of 10 boards
• NQF & ACGME formalize practice and education standards
• Fellowship training & board certification
The American Society of Clinical Oncology now recommends concurrent palliative care for seriously ill cancer patients.

“...combined standard oncology care and palliative care should be considered early in the course of illness for any patient with metastatic cancer and/or high symptom burden.”
If you want to learn more


2. NQF Preferred Practices:  

3. TJC Certification in PC:  

4. NQF Endorsed Measures:  
   [http://www.qualityforum.org/Projects/Palliative_Care_and_End-of-Life_Care.aspx](http://www.qualityforum.org/Projects/Palliative_Care_and_End-of-Life_Care.aspx)

5. COC Standards:  

6. ASCO Provisional Clinical Opinion:  [http://jco.ascopubs.org/content/30/8/880.full](http://jco.ascopubs.org/content/30/8/880.full)

7. Issue Brief describing changing payer approaches to end-of-life care in California:  
Irreducible features

- Suffering
- [Patient + Family]
- Subjectivity
- Interdisciplinary
- Time
Need
Importance of Issues at EOL

- Don’t want to burden family w/finances: 67%
- Want to be without pain: 66%
- Being at peace spiritually: 61%
- Don’t want to burden family w/tough decisions: 60%
- Having loved ones around me: 60%
- Being able to pay for the care I need: 58%
- Making sure medical wishes are followed: 57%
- Not feeling alone: 55%
- MDs and nurses understand my cultural beliefs: 44%
- Living as long as possible: 36%
- Being at home: 33%
High EOL Utilization

Smith AK et al. Half Of Older Americans Seen In Emergency Department In Last Month Of Life; Most Admitted To Hospital, And Many Die There. Health Affairs, 31, no.6 (2012):1277-1285

ED Visits and Hospitalizations, 4,158 Decedents Age ≥65

- ED visit last 6 months of life: 75%
- Multiple ED visits last 6 months of life: 41%
- ED visit last month of life: 51%
- Admitted following ED visit last month of life: 77%
- If admitted last month of life, % in-hospital death: 68%
- If early hospice, ED visit last month of life: 10%
Fragmented high-intensity care still common

In-hospital deaths, ICU stays and health care transitions still common at EOL among patients with cancer, COPD, dementia

<table>
<thead>
<tr>
<th></th>
<th>2000 (n=270,202)</th>
<th>2005 (n=291,819)</th>
<th>2009 (n=286,282)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deaths in acute care hospitals, %</td>
<td>32.6</td>
<td>26.9</td>
<td>24.6</td>
</tr>
<tr>
<td>ICU use last month of life, %</td>
<td>24.3</td>
<td>26.3</td>
<td>29.3</td>
</tr>
<tr>
<td>Hospice use at time of death, %</td>
<td>21.6</td>
<td>32.3</td>
<td>42.0*</td>
</tr>
<tr>
<td>Health care transitions in last 3 days of life, %</td>
<td>10.3</td>
<td>12.4</td>
<td>14.2</td>
</tr>
</tbody>
</table>

In 2009, 28.4% of hospice use at the time of death was for 3 days or less; 40.3% of late hospice referrals were preceded by hospitalization with an ICU stay

Preferred Location of Death, California, 2011

- Home: 70%
- Hospital: 16%
- Hospice facility: 4%
- Other: 7%
- Don’t know/Not sure: 2%
- Refused: 2%

Note: Segments may not add to 100% due to rounding.
Source: Californians’ Attitudes Toward End-of-Life Issues, Lake Research Partners, 2011. Statewide survey of 1,669 adult Californians, including 393 respondents who have lost a loved one in the past 12 months.

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### Location of Deaths, California, 1989, 2001, 2009

<table>
<thead>
<tr>
<th>Location</th>
<th>1989</th>
<th>2001</th>
<th>2009</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital</td>
<td>58%</td>
<td>47%</td>
<td>42%</td>
</tr>
<tr>
<td>Home</td>
<td>13%</td>
<td>27%</td>
<td>32%</td>
</tr>
<tr>
<td>Nursing Home</td>
<td>22%</td>
<td>21%</td>
<td>18%</td>
</tr>
<tr>
<td>Inpatient Hospice</td>
<td>N/A</td>
<td>N/A</td>
<td>2%</td>
</tr>
<tr>
<td>Other</td>
<td>5%</td>
<td>8%</td>
<td>6%</td>
</tr>
</tbody>
</table>

Preferred vs actual site of death in California

Preference = survey responses from 1,669 adults asked about preferred site of death
Actual = data from State of California Department of Health death records

- **Home**: 70% preference, 32% actual
- **Hospital**: 42% preference, 16% actual
- **Hospice facility**: 2% preference, 4% actual
- **Other***: 24% preference, 2% actual

*Includes 18% of decedents who died in nursing homes

Impact
Proven Benefits
(most data from cancer)

• Improved patient and family satisfaction
• Reduction in symptom burden
• Prolonged life (hospice, outpatient)
• Improved efficiency/Reduced costs

Prolonged Survival in Hospice
(Connor, J Pain Sx Mgmt, 2007)

<table>
<thead>
<tr>
<th>Disease</th>
<th>Added survival</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHF</td>
<td>+ 81 days,  P = 0.0540</td>
</tr>
<tr>
<td>Lung cancer</td>
<td>+ 39 days,  P &lt; 0.0001</td>
</tr>
<tr>
<td>Pancreatic cancer</td>
<td>+ 21 days,  P = 0.0102</td>
</tr>
<tr>
<td>Colon cancer</td>
<td>+ 33 days,  P = 0.0792</td>
</tr>
<tr>
<td>Breast</td>
<td>+ 12 days,  P = 0.6136</td>
</tr>
<tr>
<td>Prostate</td>
<td>+ 4 days,  P = 0.8266</td>
</tr>
</tbody>
</table>
Prolonged Survival with Early PC

151 patients with NSCLC at Mass General
Immediate vs. delayed PC along with usual oncologic care

Early pc patients with…

• Improved QOL
• Less depression
• Less chemo in last 2 weeks
• Fewer hospitalizations in last month
• Nearly 3 months longer survival (11.6 mos. vs. 8.9 mos., p<0.02)

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

Mean cost of care:
- **Usual care**: $20,222
- **Home PC**: $12,670

Brumley R et al, Increased Satisfaction with Care and Lower Costs: Results of a Randomized Trial of In-Home Palliative Care, J Am Geriatr Soc. 2007 Jul;55(7):993-1000
Early-PC = Better Quality

Early-PC associated with better performance on EOL quality measures
Cancer patients who received Early-PC vs Late-PC at an academic medical center

Scibetta C et al. Care Quality and Cost Implications of the Timing of Palliative Care Consultation among Patients with Advanced Cancer. Palliative Care in Oncology Symposium. Boston, MA 2014
Early PC = less escalation in utilization

Average direct cost per admission by month, final 6 months of life
Cancer patients who received Early-PC vs those who received Late-PC

Scibetta C et al. Care Quality and Cost Implications of the Timing of Palliative Care Consultation among Patients with Advanced Cancer. Palliative Care in Oncology Symposium. Boston, MA 2014
Average direct cost per patient for hospital care, final 6 months of life
Cancer patients who received Early-PC vs those who received Late-PC

Scibetta C et al. Care Quality and Cost Implications of the Timing of Palliative Care Consultation among Patients with Advanced Cancer. Palliative Care in Oncology Symposium. Boston, MA 2014
Challenges and opportunities
The Problem

There is a gap between the care people want and the care they receive

– More invasive, futile, costly care than desired
– Disparities of access across populations, regions, and settings
– ... Squanders time and creates suffering!

See: 1) Tracking Improvement in the Care of Chronically Ill Patients: A Dartmouth Atlas Brief on Medicare Beneficiaries Near the End of Life. And, 2) Measuring Up? End of Life Cancer Care in California
The Solution*

1. Grow and incorporate PC capacity within health systems across the *full continuum* (medical + social, institutional + community-based)

2. Seek and implement new benefit/payment mechanisms for PC

3. Utilize community agency skills/assets

Challenges

1. Lack of knowledge regarding magnitude of need
2. Awareness
3. Workforce
4. Policy/Payment
Awareness of End-of-Life Terms,
California, 2011

PERCENT SAYING THEY HAVE HEARD OF THESE TERMS

Hospice care 73%
Do-not-resuscitate (DNR) order 63%
Advance directive 38%
Palliative care 17%
POLST 13%

Note: POLST is a form that is signed by a patient and his/her doctor, clearly stating what kinds of medical treatment the patient wants toward the end of life. It must be honored by health care providers, even if the patient later loses the ability to indicate his/her wishes.

Source: Californians' Attitudes Toward End-of-Life Issues, Lake Research Partners, 2011. Statewide survey of 1,869 adult Californians, including 393 respondents who have lost a loved one in the past 12 months.

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Public Perception

- Not At All Knowledgeable: 70%
- Somewhat Knowledgeable: 14%
- Knowledgeable: 3%
- Very Knowledgeable: 5%
- Don’t Know: 8%
Once They Know About Palliative Care…

• Extremely positive about it and want access

• >92% say:
  – It is important
  – Patients with serious illness and their families should be educated
  – Likely to consider PC for a loved one
  – It is important that palliative care services be made available at all hospitals
1. Unmet needs


3. Affordable Care Act
   - Continuum of care (instead of episodic care)
   - Bundled payment
PC
Social
Institutional
Medical
Community
Big picture (internal)

1. Scope of practice
2. Workforce
3. Sites of care
4. Public awareness
## California’s PC Workforce (2012 Estimate)

<table>
<thead>
<tr>
<th>Discipline</th>
<th>In California</th>
<th>In Palliative Care</th>
<th>Certified/Designated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physicians</td>
<td>100,544</td>
<td>No reliable data</td>
<td>914 (0.9%)</td>
</tr>
<tr>
<td>Nurses</td>
<td>262,658</td>
<td>3,861</td>
<td>789 (0.3%)</td>
</tr>
<tr>
<td>Certified Nursing Assistants</td>
<td>166,122</td>
<td>1,899</td>
<td>170 (1.1%)</td>
</tr>
<tr>
<td>Social Workers</td>
<td>47,639</td>
<td>993</td>
<td>43 (2.1%)</td>
</tr>
<tr>
<td>Chaplains</td>
<td>No reliable data</td>
<td>456</td>
<td>171</td>
</tr>
</tbody>
</table>
The Workforce Gap

- 1 cardiologist for every 71 heart attacks
- 1 oncologist for every 145 new patients with cancer
- 1 PC doc for every 300 deaths
- 1 PC doc for every 1,300 patients with serious illness
- 1 PC doc for every 20,000 older patient with chronic illness

= 6,000-18,000 projected gap in pc physicians

(Just for hospitals and hospices!)

Lupu, J Pain Sx Mgmt, 2010
Interdisciplinary Team

**A profession**
- Traditional
  - Doc
  - Nurse
  - Social Worker
  - Chaplain

**A Movement**
- Expanded
  - Patient + circle
  - Admin
  - HHA/CNA/PCA
  - Physical therapy
  - Psychologist
  - Pharmacist
  - Volunteer
  - Informal caregiver
  - Lawyer
  - Artist
  - Architect
  - (etc)