# Palliative Care 101 (these days)

BJ Miller Zen Hospice Project Feb 23, 2015

# Today

- History + definition of terms
- Need for PC
- Impact
- Challenges + Opportunities

# **History and definitions**

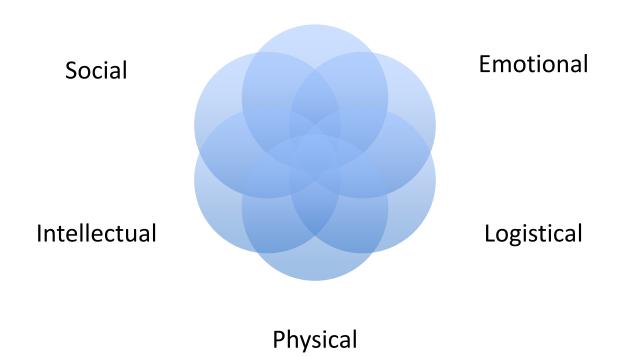
### **Definition:**

## 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



# **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

\*Palliative Care in Hospitals Continues Rapid Growth Trend, According to Latest CAPC Analysis. Accessed from: http://www.capc.org/news-and-events/releases/03-29-13



## 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:



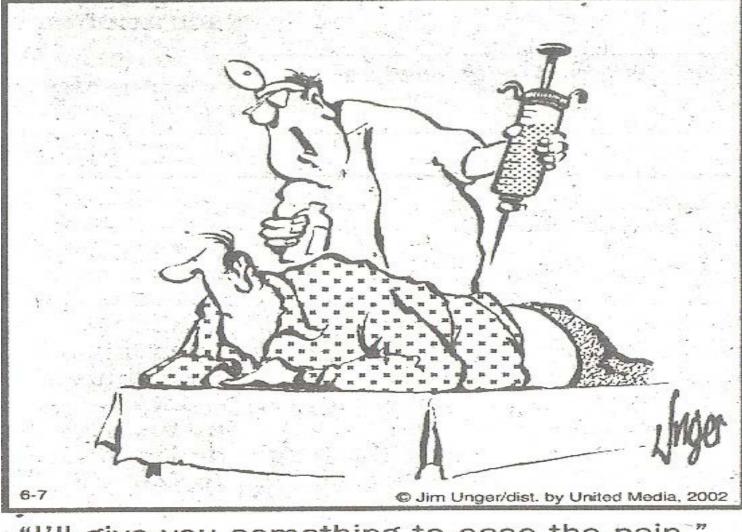
- Team-based care
- Focus on improving quality of life and relieving suffering for patients with serious illness
- Care focus on patient and family
- Many shared competencies

## Some ways PC and hospice differ

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

\*National Hospice and Palliative Care Organization Facts and Figures Hospice Care in America 2013 http://www.nhpco.org/sites/default/files/public/Statistics\_Research/2013\_Facts\_Figures.pdf

### HERMAN By Jim Unger

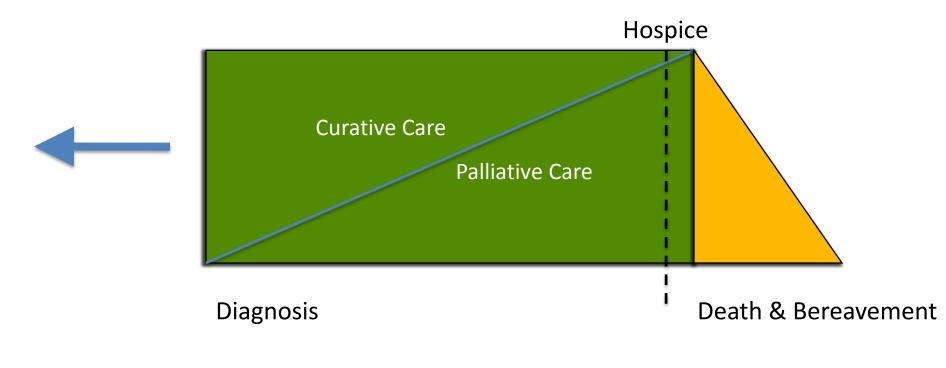


"I'll give you something to ease the pain."

## Timeline – PC in US

- 1974
- 1982
- 1991
- 1995
- 1997

## Services across the disease trajectory



(Progression / Time)

# 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

# Amonical of Chinical Oncology RQW IAL ARTICLE

#### American Society of Clinical Oncology Provisional Clinical Opinion: The Integration of Palliative Care into Standard Oncology Care

Thomas J. Smith, Sarah Temin, Erin R. Alesi, Amy P. Abernethy, Tracy A. Balboni, Ethan M. Basch, Betty R. Ferrell, Matt Loscalzo, Diane E. Meier, Judith A. Paice, Jeffrey M. Peppercorn, Mark Somerfield, Ellen Stovall, and Jamie H. Von Roenn

"...combined standard oncology care and palliative care should be considered early in the course of illness for <u>any</u> patient with metastatic cancer and/or high symptom burden."

## If you want to learn more

1. NCP Guidelines: <u>http://nationalconsensusproject.org/Guidelines\_Download2.aspx</u>

2. NQF Preferred Practices: http://www.qualityforum.org/Publications/2006/12/A National Framework and Preferr ed Practices for Palliative and Hospice Care Quality.aspx

3. TJC Certification in PC: <a href="http://www.jointcommission.org/certification/palliative">http://www.jointcommission.org/certification/palliative</a> care.aspx

4. NQF Endorsed Measures: <u>http://www.qualityforum.org/Projects/Palliative Care and End-of-Life Care.aspx</u>

5. COC Standards:

https://www.facs.org/quality-programs/cancer/coc/standards

6. ASCO Provisional Clinical Opinion: <u>http://jco.ascopubs.org/content/30/8/880.full</u>

7. Issue Brief describing changing payer approaches to end-of-life care in California: <a href="http://www.chcf.org/publications/2013/04/better-benefit-health-plans">http://www.chcf.org/publications/2013/04/better-benefit-health-plans</a>

# Irreducible features

- Suffering
- [Patient + Family]
- Subjectivity
- Interdisciplinary
- Time



# <u>Need</u>

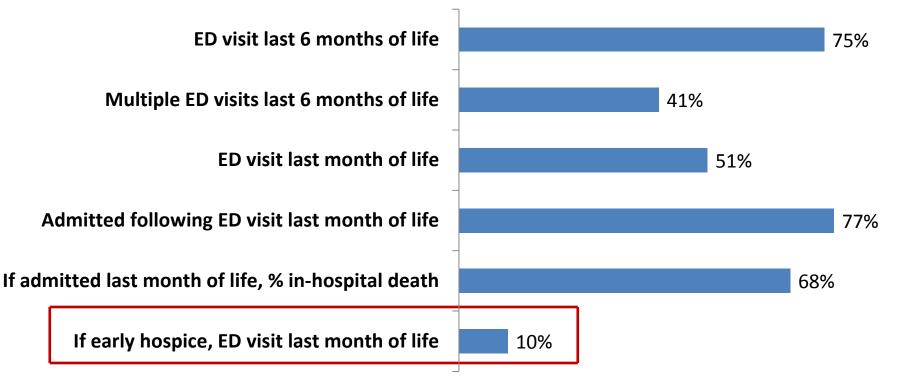
### Importance of Issues at EOL

Don't want to burden family w/finances				
Want to be without pain				
Being at peace spiritually				
Don't want to burden family w/tough decisions 60				
Having loved ones around me 6				
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



## 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

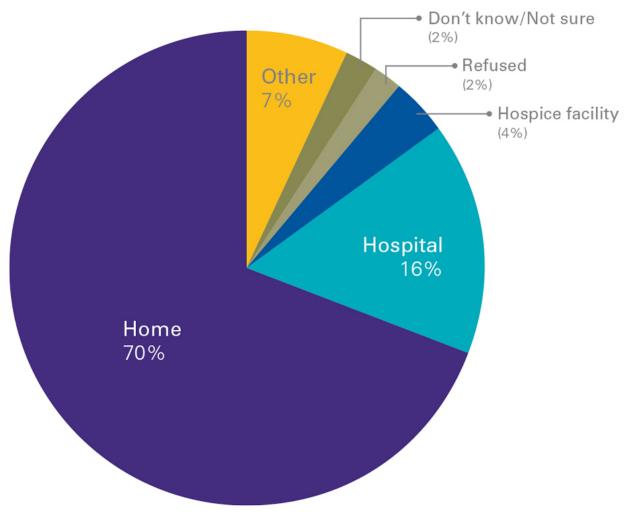
	2000 (n=270,202)	2005 (n=291,819)	2009 (n=286,282)
Deaths in acute care hospitals, %	32.6	26.9	24.6
ICU use last month of life, %	24.3	26.3	29.3
Hospice use at time of death, %	21.6	32.3	42.0*
Health care transitions in last 3 days of life, %	10.3	12.4	14.2

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

Teno et al. Change in End-of-Life Care for Medicare Beneficiaries Site of Death, Place of Care, and Health Care Transitions in 2000, 2005, and 2009. JAMA. 2013;309(5):470-477.

#### Preferred Location of Death,

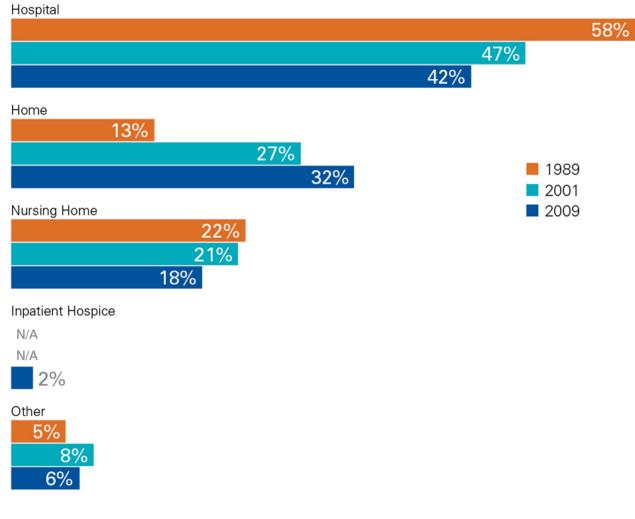
#### California, 2011



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.

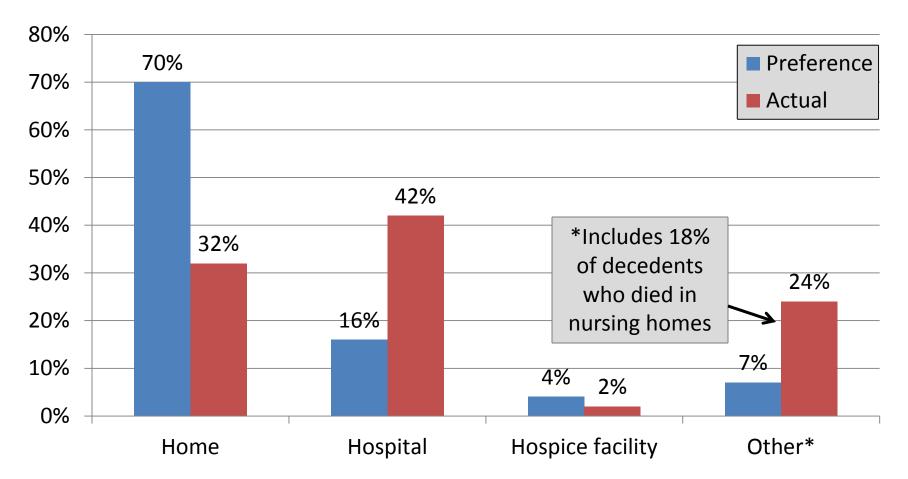
#### **Location of Deaths,** California, 1989, 2001, 2009



Source: State of California, Department of Public Health, Death Records, 2011.

## 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



California HealthCare Foundation. Final Chapter: Californian's Attitudes and Experiences with Death and Dying. Feb 2012. Accessed 27 from: http://www.chcf.org/publications/2012/02/final-chapter-death-dying



# **Impact**

## Proven Benefits (most data from cancer)

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

Morrison, Annals Intern Med, 2008; Teno et al, JAMA, 2004; Christakis & Iwashyna, Soc Sci Med, 2003; Miller et al, JPSM, 2003; Connor et al, JPSM, 2007. Jordhay et al Lancet 2000; Higginson et al, JPSM, 2003; Finlay et al, Ann Oncol 2002; Higginson et al, JPSM 2002, Zimmerrman, JAMA 2008; Follwell, J Clin Onc, 2008; Rabow, Arch Intern Med, 2004; Temel, NEJM, 2010; Rabow J Palliative Med, 2013.

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

Matched cohort study: hospice use or not. 4493 Medicare patients, 2095 (47%) received hospice care for at least one day, 1999

Disease	Added survival	
CHF	+ 81 days, P = 0.0540	
Lung cancer	+ 39 days, P < 0.0001	
Pancreatic cancer	+ 21 days, P = 0.0102	
Colon cancer	+ 33 days, P = 0.0792	
Breast	+ 12 days, P = 0.6136	
Prostate	+ 4 days, P = 0.8266	

# Prolonged Survival with Early PC

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

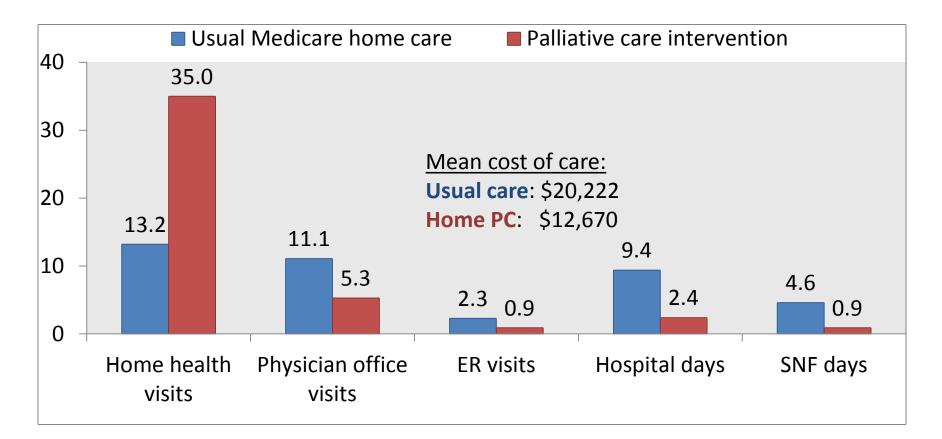
Early pc patients with...

- 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)

*Temel J et al, NEJM, 2010; Greer JA, et al, J Clin Oncol 2012;30:394-400; Greer, JA et al, J Clin Oncol 30, 2012 (suppl;abstr 6004)* 

### RCT: Palliative Care at Home for the Chronically III

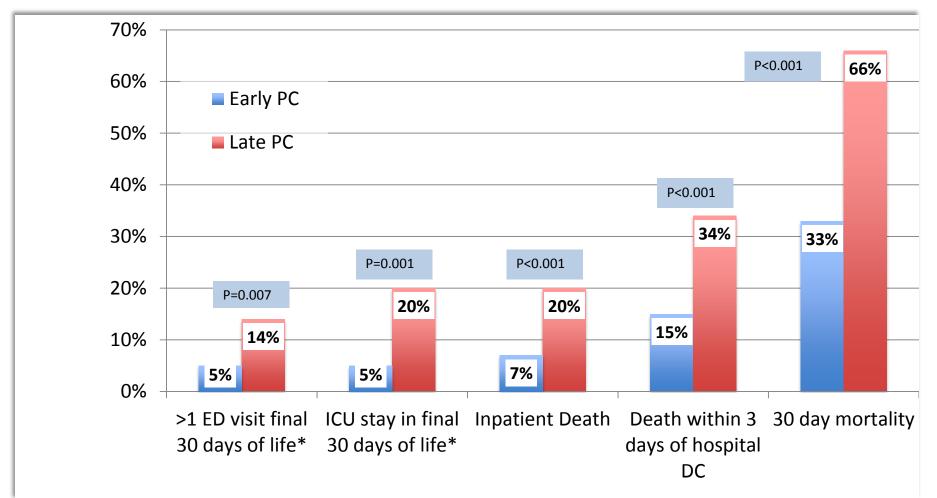
RCT of Service Use Among Heart Failure, Chronic Obstructive Pulmonary Disease, or Cancer Patients While Enrolled in a Home Palliative Care Intervention or Receiving Usual Home Care, 1999–2000



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

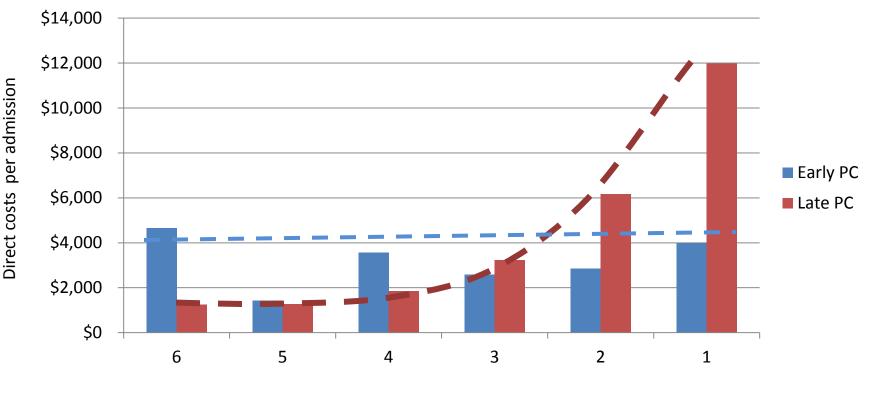
*Early-PC associated with better performance on EOL quality measures* Cancer patients who received Early-PC vs Late-PC at an academic medical center



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

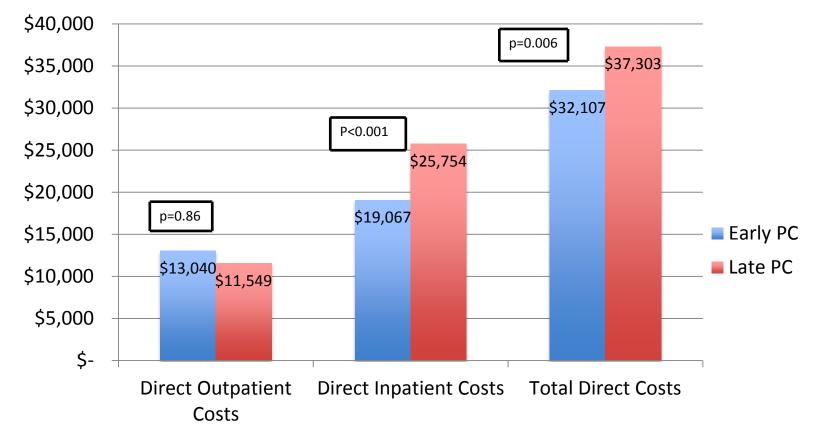


Month preceding death

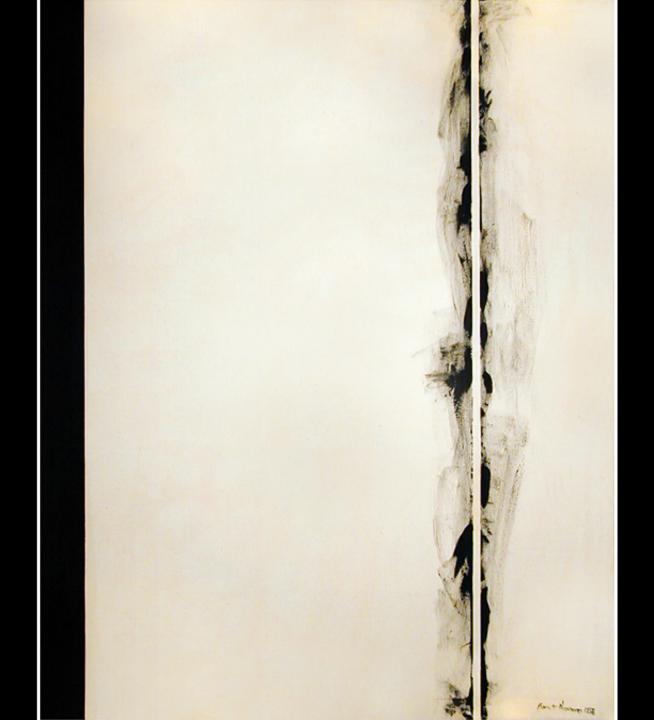
Scibetta C et al. Care Quality and Cost Implications of the Timing of Palliative Care Consultation among Patients with Advanced Cancer. Palliative Care in Oncology Symposium. Boston, MA 2014

### Early PC = economic impact

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 III 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

\* See: 1) Let's Get Health California. 2) Berkeley Forum: A New Vision for California's Healthcare System. 3) California HHS Agency: California State Health Care Innovation Grant. And 4) IOM report: Dying in America

## Challenges

- Lack of knowledge regarding magnitude of need
- 2. Awareness
- 3. Workforce
- 4. Policy/Payment

#### Awareness of End-of-Life Terms, California, 2011

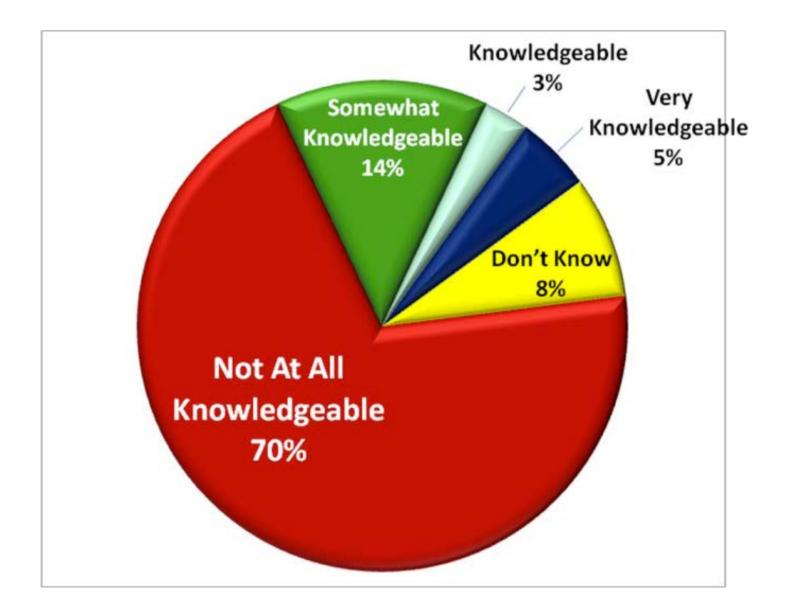
PERCENT SAYING THEY HAVE HEARD OF THESE TERMS

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 indicate his/her wishes.

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.

#### **Public Perception**

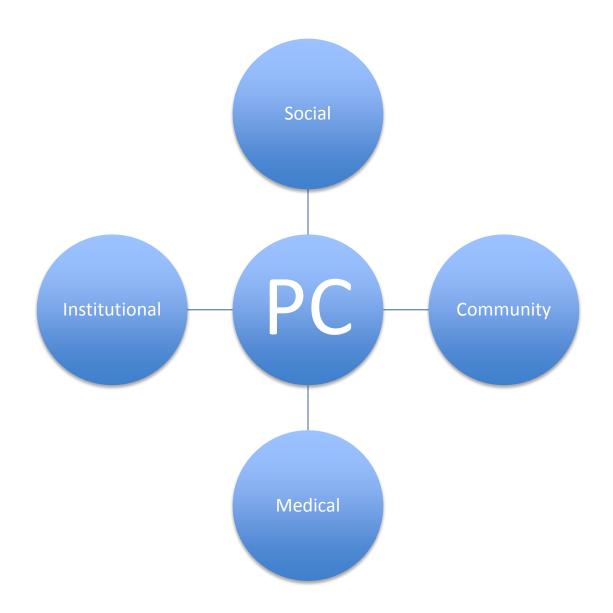


#### Once They Know About Palliative Care...

- 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

# Big picture (external)

- 1. Unmet needs
- 2. Aging US Population: Preparing for 'silver tsunami'
- 3. Affordable Care Act
  - Continuum of care (instead of episodic care)
  - Bundled payment



## Big picture (internal)

- 1. Scope of practice
- 2. Workforce
- 3. Sites of care
- 4. Public awareness

#### California's PC Workforce (2012 Estimate)

Discipline	In California	In Palliative Care	Certified/Desig nated
Physicians	100,544	No reliable data	914 (0.9%)
Nurses	262,658	3,861	789 (0.3%)
Certified Nursing Assistants	166,122	1,899	170 (1.1%)
Social Workers	47,639	993	43 (2.1%)
Chaplains	No reliable data	456	171

## 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)

