



# Hospice, Palliative Care and Health Care Reform: beyond “end of life” to quality of life

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# + Your thoughts -

- How do *you* define a “good death”?



# Defining the Problem



the human  
condition –  
+ mortality inevitable

# Change in Cause of Death

| Rank | 1990                 | 2000                           |
|------|----------------------|--------------------------------|
| 1    | Pneumonia            | Heart Disease                  |
| 2    | Tuberculosis         | Cancer                         |
| 3    | Diarrhea & enteritis | Stroke                         |
| 4    | Heart disease        | Emphysema & chronic bronchitis |
| 5    | Liver disease        | Unintentional injuries         |
| 6    | Injuries             | Diabetes                       |
| 7    | Stroke               | Pneumonia & influenza          |
| 8    | Cancer               | Alzheimer's disease            |
| 9    | Senility             | Kidney Failure                 |
| 10   | Diphtheria           | Septicemia                     |

Source: Lynn, Sick to Death Univ of CA Press  
2004. p. 6

# + One century of difference

|                                    | <b>1900</b>      | <b>200</b>           |
|------------------------------------|------------------|----------------------|
| Age at death                       | 47               | 75                   |
| Usual place of death               | home             | hospital             |
| Coverage for most medical expenses | family           | Medicare             |
| Disability before death            | Usually not much | Two years on average |



# The Demographic Imperative: Chronically Ill, Aging Population Is Growing



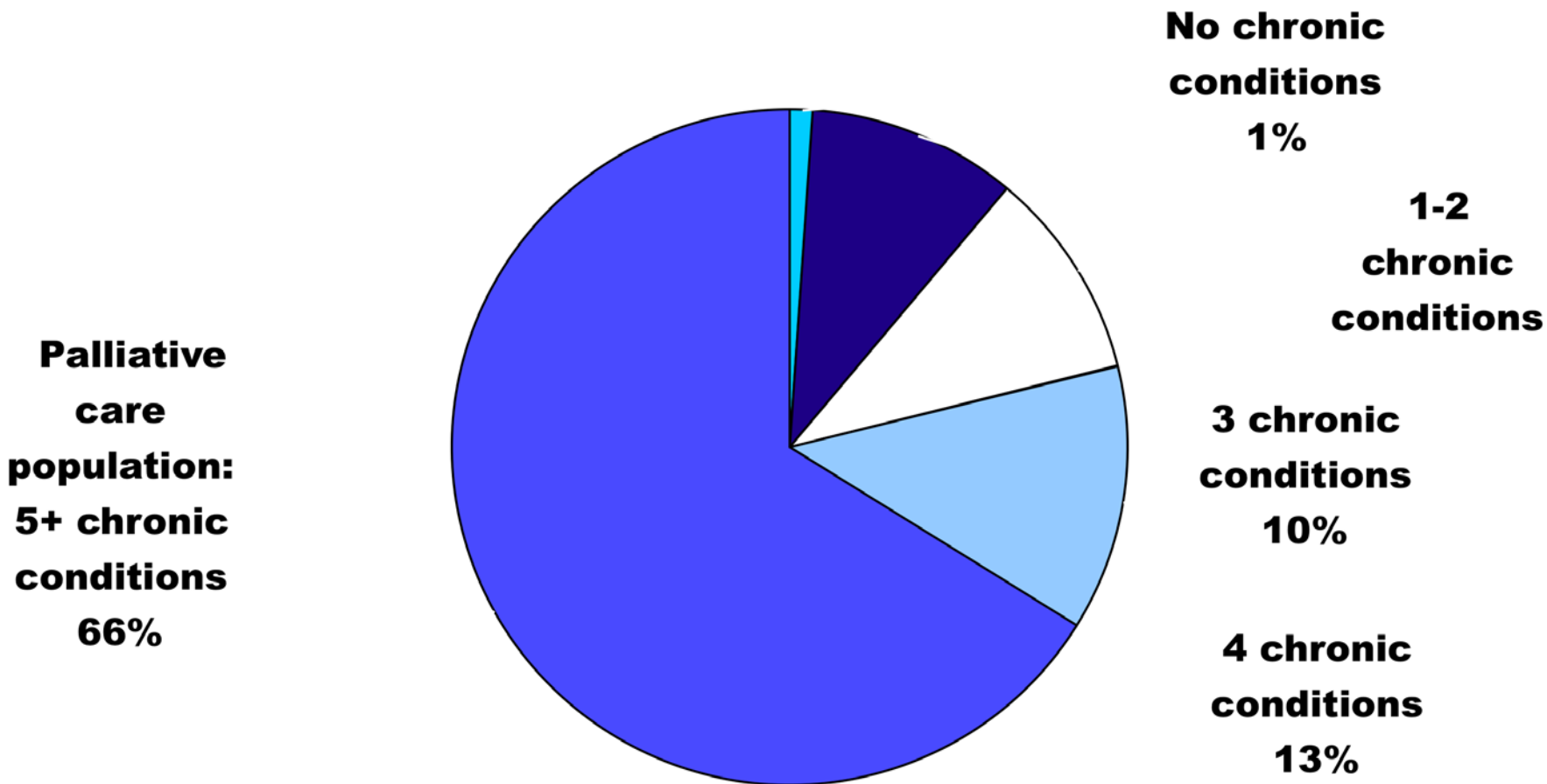
- The number of people over age 85 will double to 10 million by the year 2030.
- The 23% of Medicare patients with >4 chronic conditions account for 68% of all Medicare spending.

US Census Bureau, CDC, 2003. Anderson GF. NEJM 2005;353:305

CBO High Cost Medicare Beneficiaries May 2005



# The 10% of Medicare Beneficiaries Driving 2/3rds of Medicare Spending are Those with $\geq 5$ Chronic Conditions





# Why is Palliative Care Important to Health Care Reform?



- >95% of all health care spending is for the chronically ill
- 64% of all Medicare spending goes to the 10% of beneficiaries with 5 or more chronic conditions
- Despite high spending, evidence of poor quality of care





## What Do Patients with Serious Illness 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

Singer et al. *JAMA* 1999;281(2):163-168.



## And What They Get: Suffering in U.S. Hospitals



### National Data on the Experience of Advanced Illness in 5 Tertiary Care Teaching Hospitals:

- 9000 patients with life-threatening illness, 50% died within 6 months of entry
- Half of patients had moderate-severe pain >50% of last 3 days of life.
- 38% of those who died spent >10 days in ICU, in coma, or on a ventilator.



# What Do Family Caregivers Want?

2000 Mortality follow-back survey, n=1578 decedents

Study of 475 family members 1-2 years after bereavement:

- Loved one's wishes honored
- Inclusion in decision processes
- Support/assistance at home
- Practical help (transportation, medicines, equipment)
- Personal care needs (bathing, feeding, toileting)
- Honest information
- 24/7 access
- To be listened to
- Privacy
- To be remembered and contacted after the death

Tolle et al. Oregon report card. 1999 [www.ohsu.edu/ethics](http://www.ohsu.edu/ethics)



## And What They Get: Family Satisfaction with Hospitals as the Last Place of Care

2000 Mortality follow-back survey, n=1578 decedents

- Not enough contact with MD: 78%
- Not enough emotional support (pt): 51%
- Not enough information about what to expect with the dying process: 50%
- Not enough emotional support (family): 38%
- Not enough help with pain/SOB: 19%

Teno et al. JAMA 2004;291:88-93.



# Dartmouth Atlas:

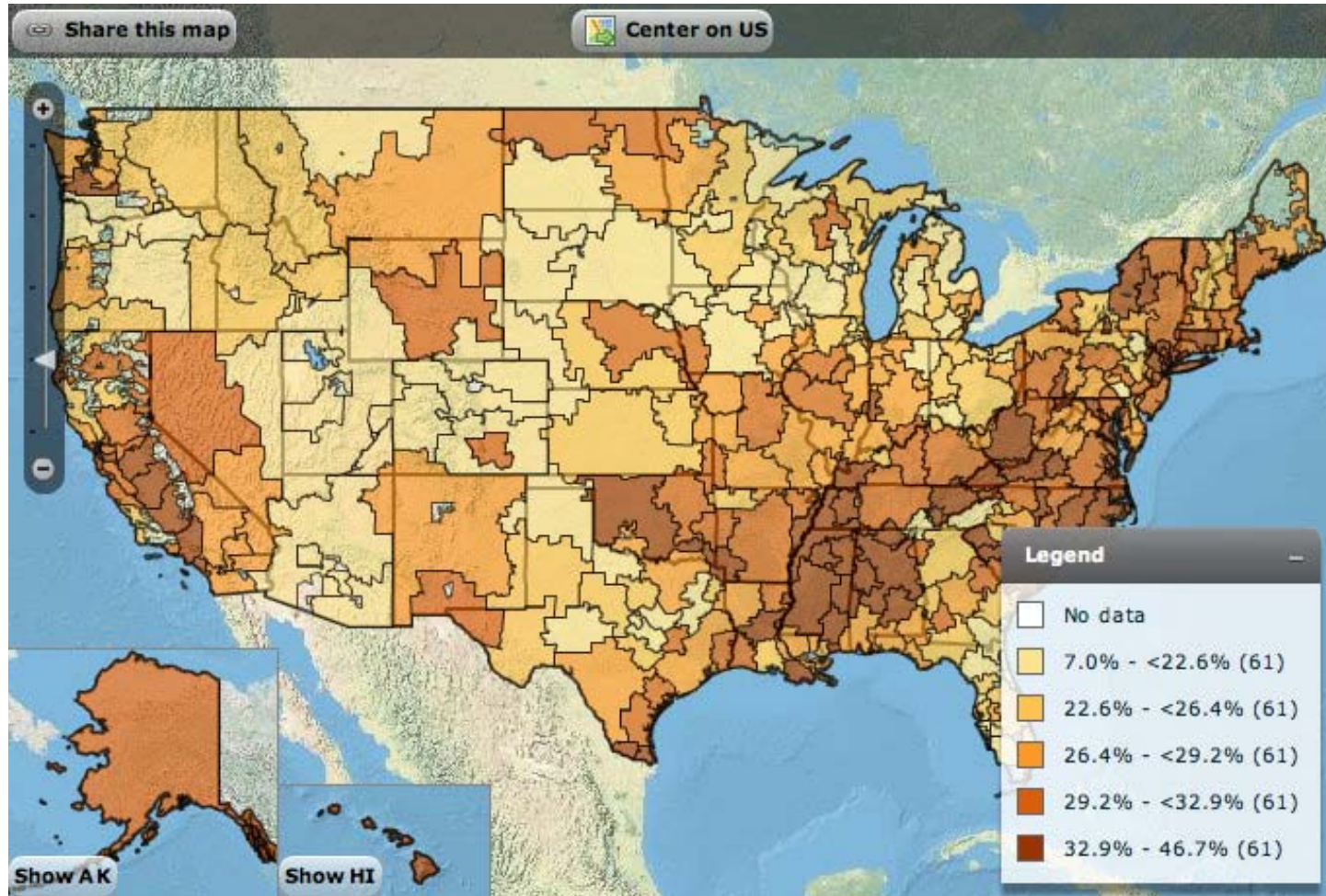
## Quality of End-of-Life Cancer Care for Medicare Beneficiaries



- November 2010 report:  
<http://www.dartmouthatlas.org/data/map.aspx?ind=176>
- Medicare patients over age 65 with cancers that have a poor prognosis
- Care varies markedly by region
- 10 indicators examined – overuse and underuse



# Percent of Cancer Patients Dying in Hospital (2003-2007)





# Overuse in last month of life



Percent of poor prognosis patients over 65:

- Dying in hospital (7% in Mason City, Iowa to 46.7% in Manhattan)
- One or more hospitalizations (7% in Mason City, Iowa to 70.2% in Detroit)
- Number hospital (3.5 days in Salt Lake City to 7.3 days in Manhattan)
- Admissions to intensive (6% in Mason City, Iowa to 42.4% in Huntsville, Alabama)
- Number of ICU days (0.1 days in Mason City, Iowa and Appleton, Wisconsin to 3.1 days in Huntsville, Alabama)

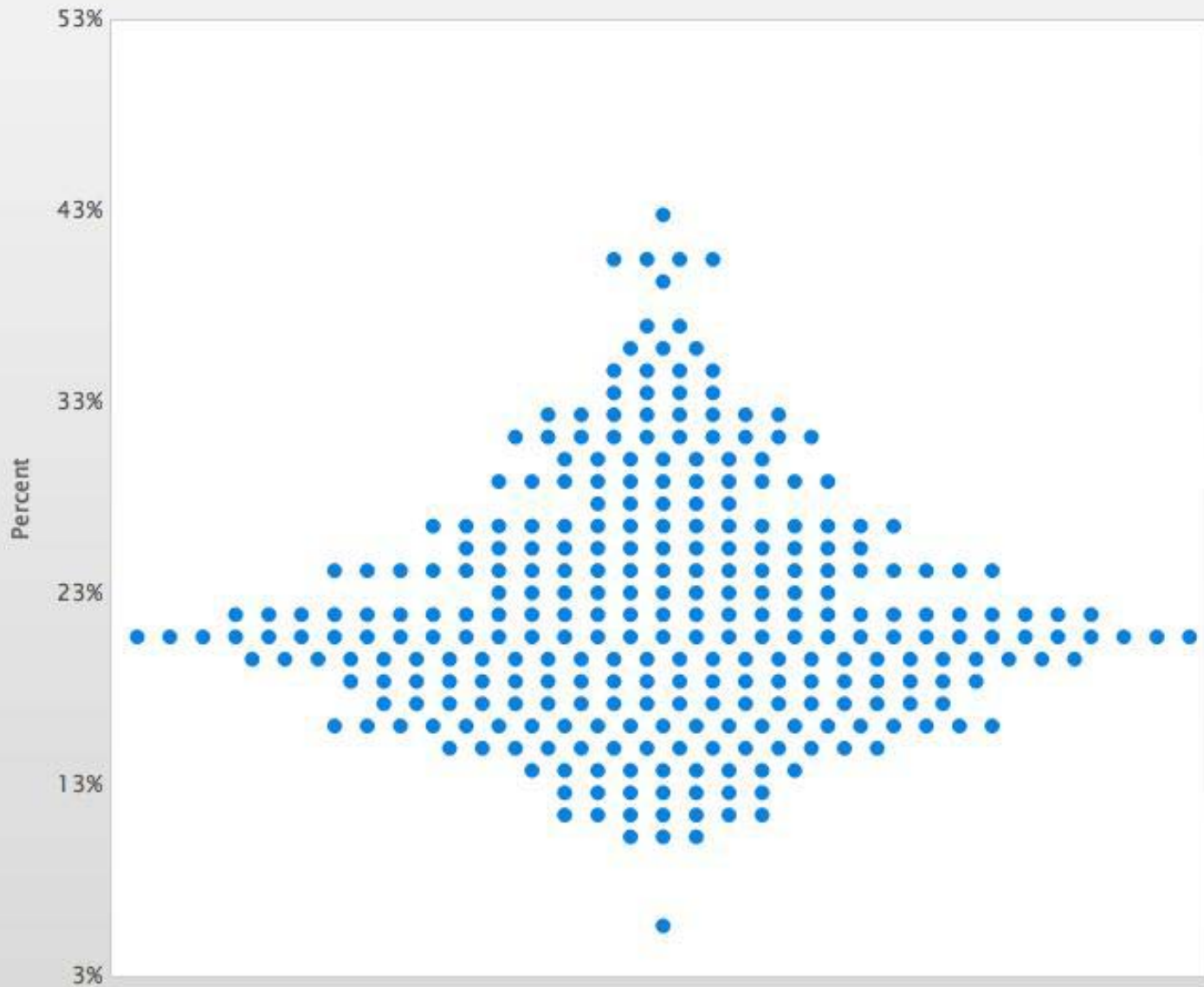
# + Overuse



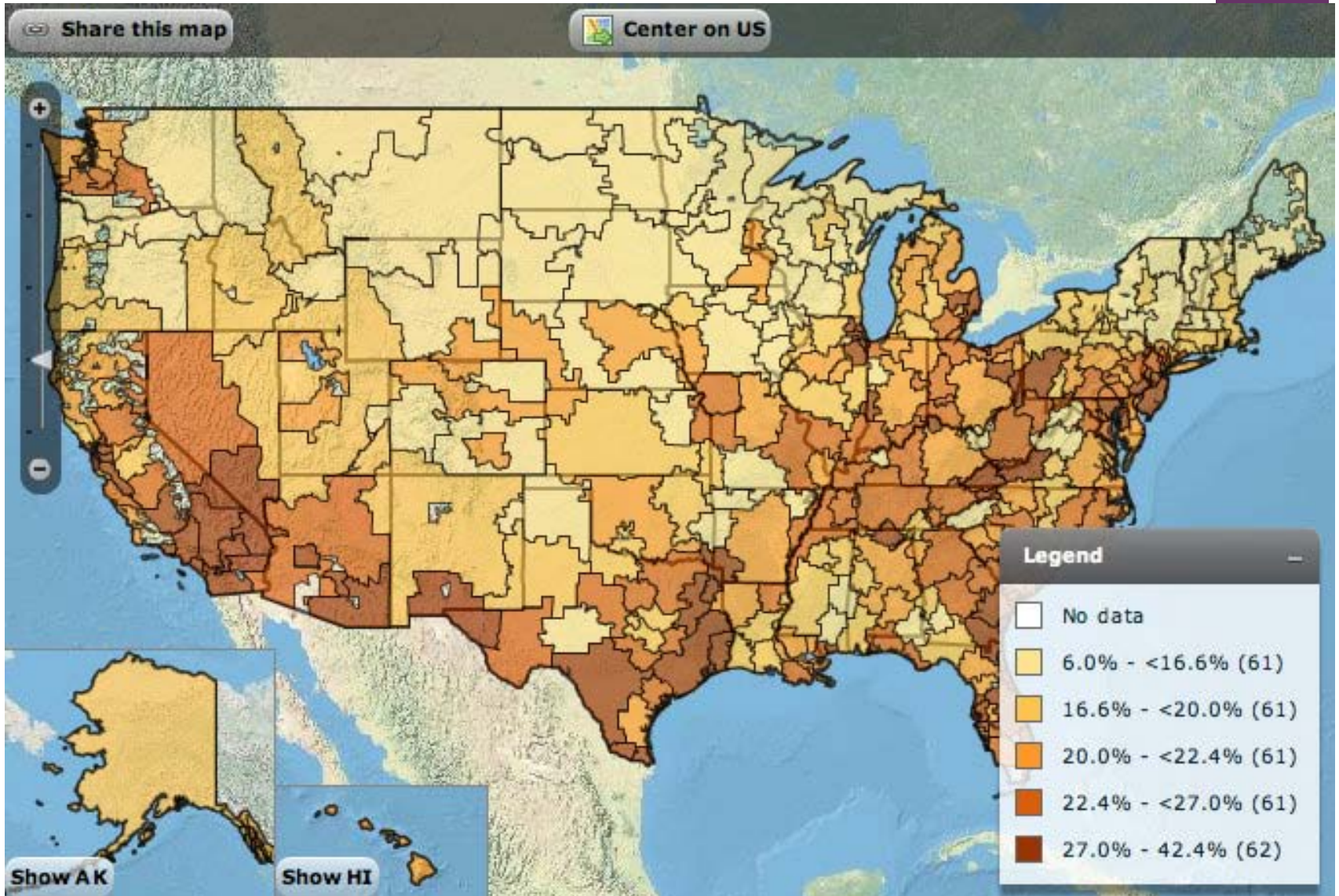
- Percent of patients receiving endotracheal intubation, feeding tube placement and cardiopulmonary resuscitation (CPR) in last month (3.9% in Minneapolis to 17.5% in Los Angeles)
- Percent of patients receiving chemotherapy in the last two weeks of life (About 3% in Worcester, Massachusetts and Baton Rouge, Louisiana to 12.6% in Olympia, Washington)



Percent of Cancer Patients Admitted to ICU during the Last Month of Life  
(2003-2007)

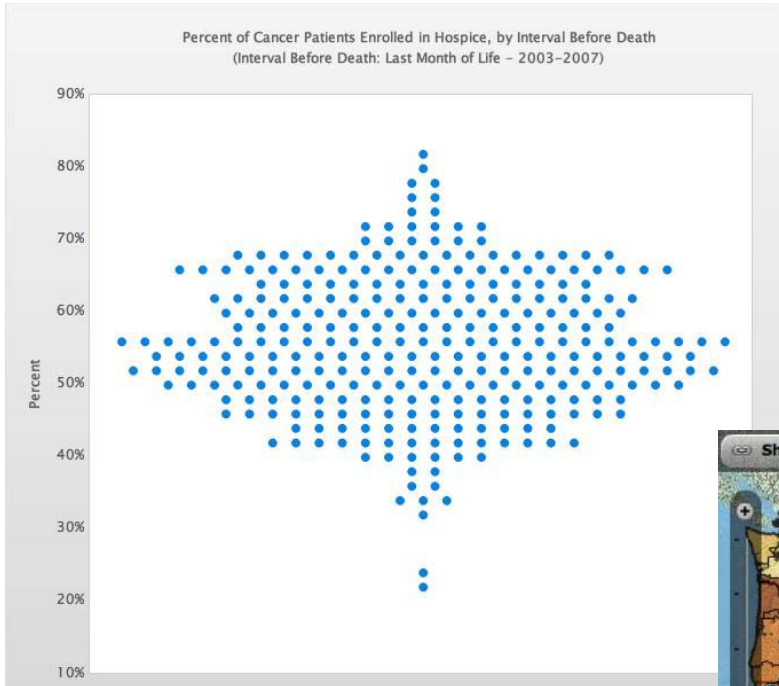


# + Cancer pts admitted to ICU in last month of life

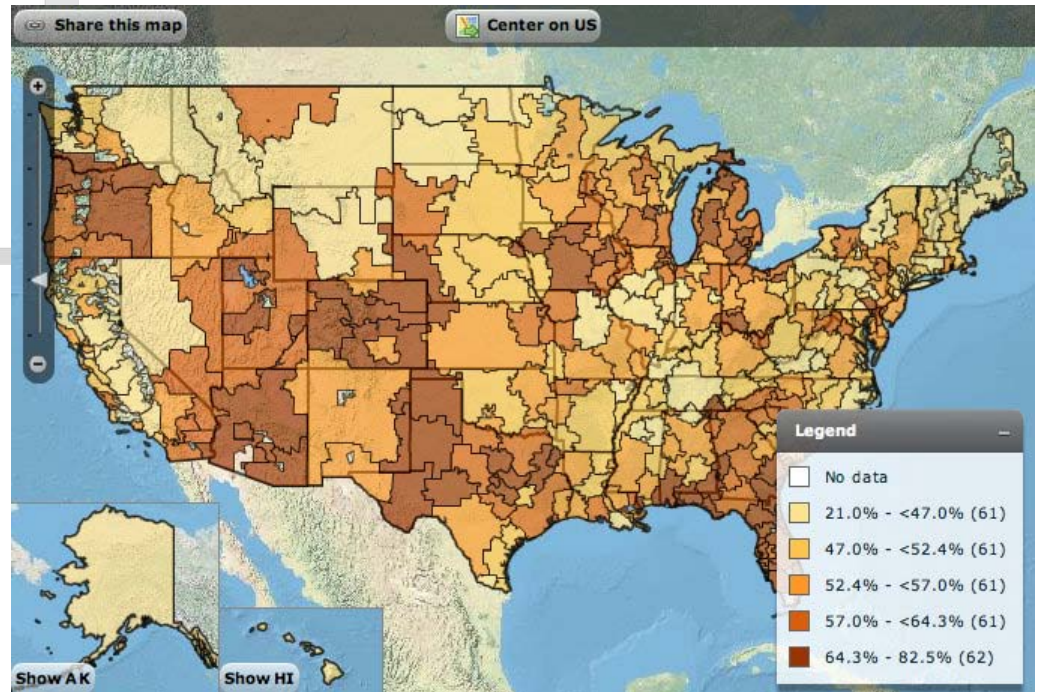




# Hospice use in last month of life

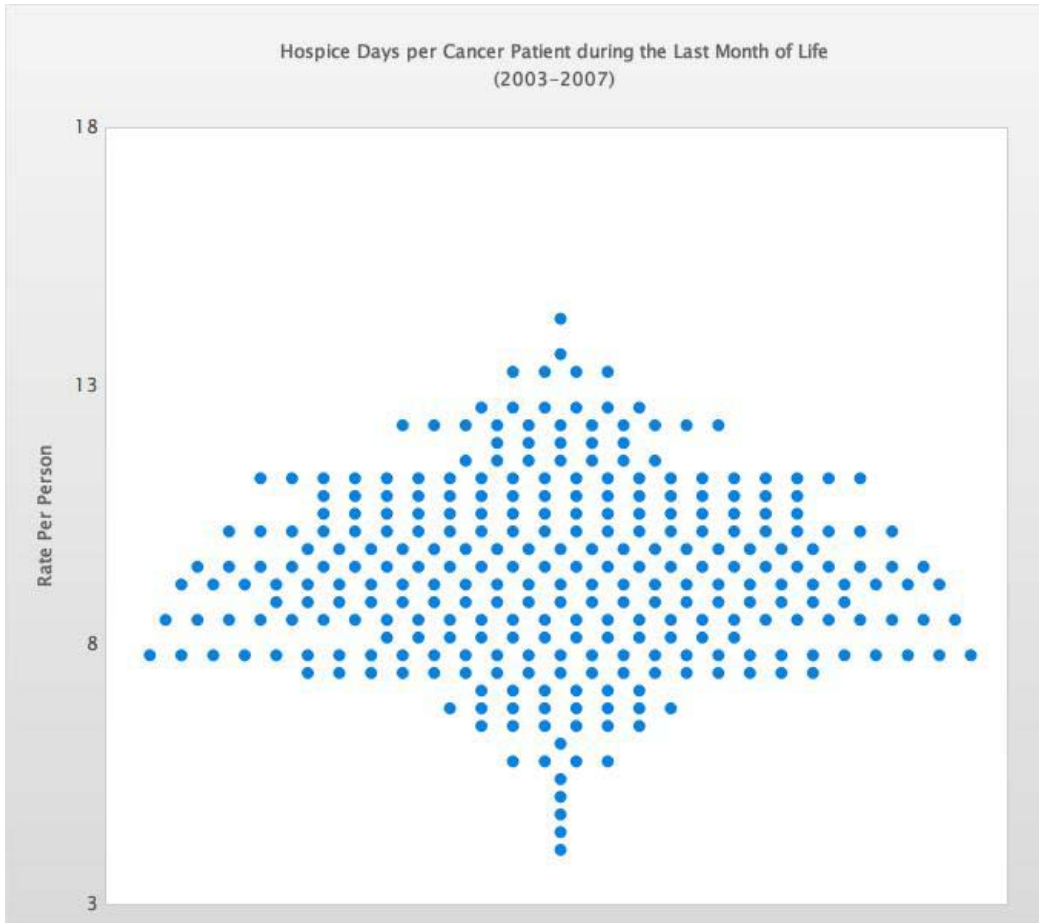


Range: 21% to 82%





# Average number of days in hospice in last month of life



■ Range: 3.9 to 14.4 days

■ Average: 8.7 days

# + How did we get here?

The lack of a public health approach

- Focus on clinical and individual decision-making
- Ignoring the systemic forces





# Default option

## Retirement fund contributions



- automatic enrollment for new hires:
  - plan participation rate 35 percentage points higher after three months
  - remained 25 points higher after two years.
  
- Beshears J. et al. "The Importance of Default Options for Retirement Savings Outcomes: Evidence from the United States" (NBER Working Paper [12009](#)).



+ Martha, 86 dementia patient in ICU, Mt. Sinai  
Hospital, NY

PBS Frontline program: Facing Death, November  
2010

# + Disconnect Between Health Care System and Needs at End of Life



| <b>Health Care System Provides and Pays For</b> | <b>End-of-Life Care Needs</b> |
|---|-------------------------------|
| Procedures                                      | Caregiving                    |
| Chemotherapy                                    | Communication<br>Pain control |
| Clinic visits                                   | Home visits                   |
| Emergency room                                  | 24-hour on-call nursing       |





# Solutions?



Hospice – starting in the late ‘70’s

Palliative care (hospital based) grew in the ‘00s

# + Two approaches

- Specialty programs that people opt into – hospice and palliative care
- Integration of palliative approach throughout the system



# + Hospice



- Medicare benefit - Separate, per diem
- Most patients cared for at home
  - Nursing homes, inpatient hospice
- Prognosis < 6 months (predictable course)
  - Goals of care:
    - Comfort and quality of life
    - Avoid further hospitalizations
    - Usually, avoid expensive care

# + Hospice provides:

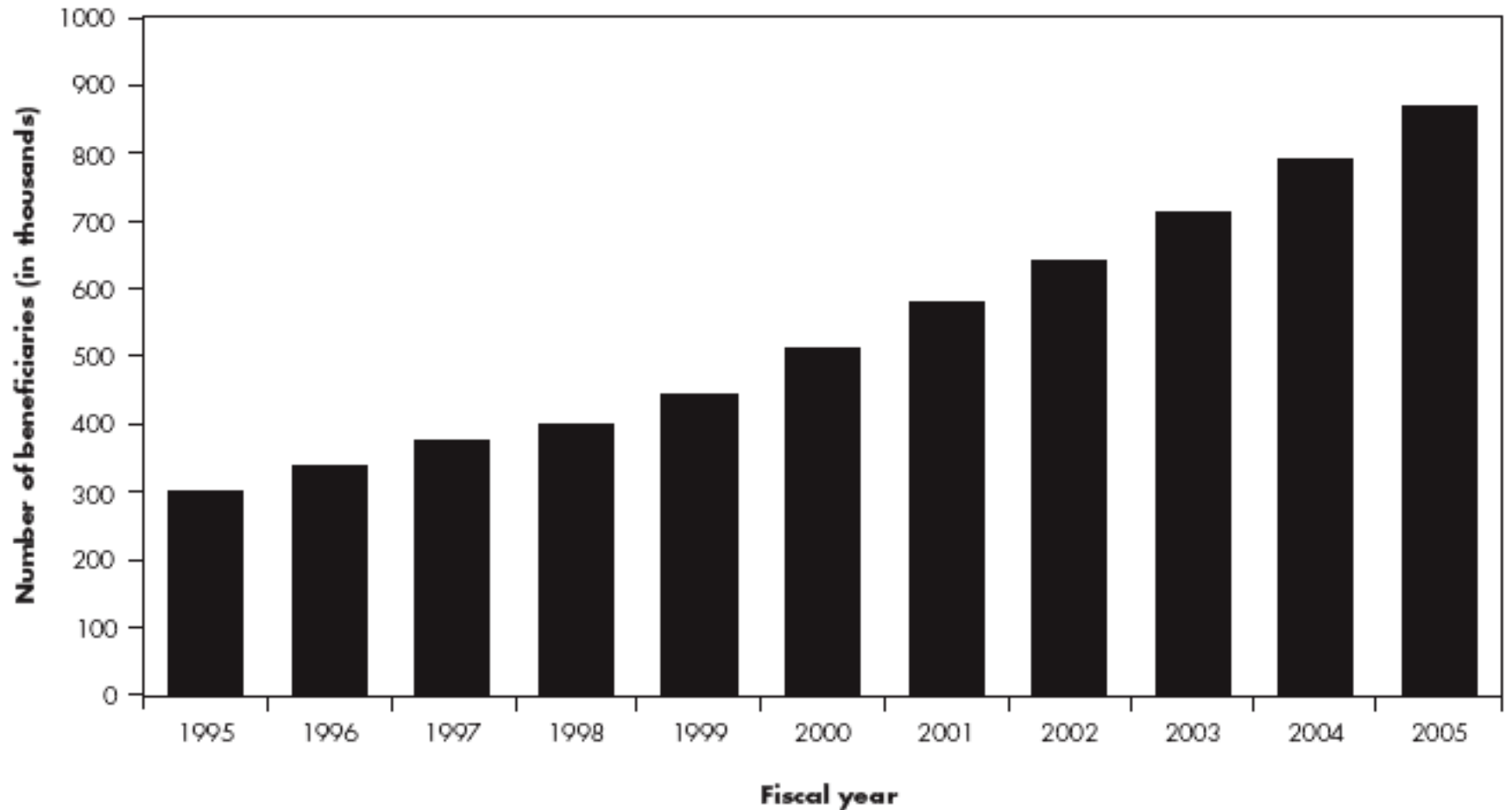
- 24-hour on-call nursing care
  - Includes visits
- Home health aides (1-2 hrs/day)
- Chaplain, social work, volunteers in home
- Multidisciplinary team management
- Consultation with physician by phone
  - Sometimes includes physician home visits



# + Hospice growth – now serves 40% of dying Medicare patients

- But median length of stay short
- Entry of new providers may signal quality problems
- Financing model incentives problematic





Source: CMS 2007. [http://www.cms.hhs.gov/PropMedicareFeeSvcPmtGen/downloads/FY05update\\_hospice\\_expenditures\\_and\\_units\\_of\\_care.pdf](http://www.cms.hhs.gov/PropMedicareFeeSvcPmtGen/downloads/FY05update_hospice_expenditures_and_units_of_care.pdf)

## Chart 12-8. Medicare hospice use and spending grew substantially from 2000 to 2008

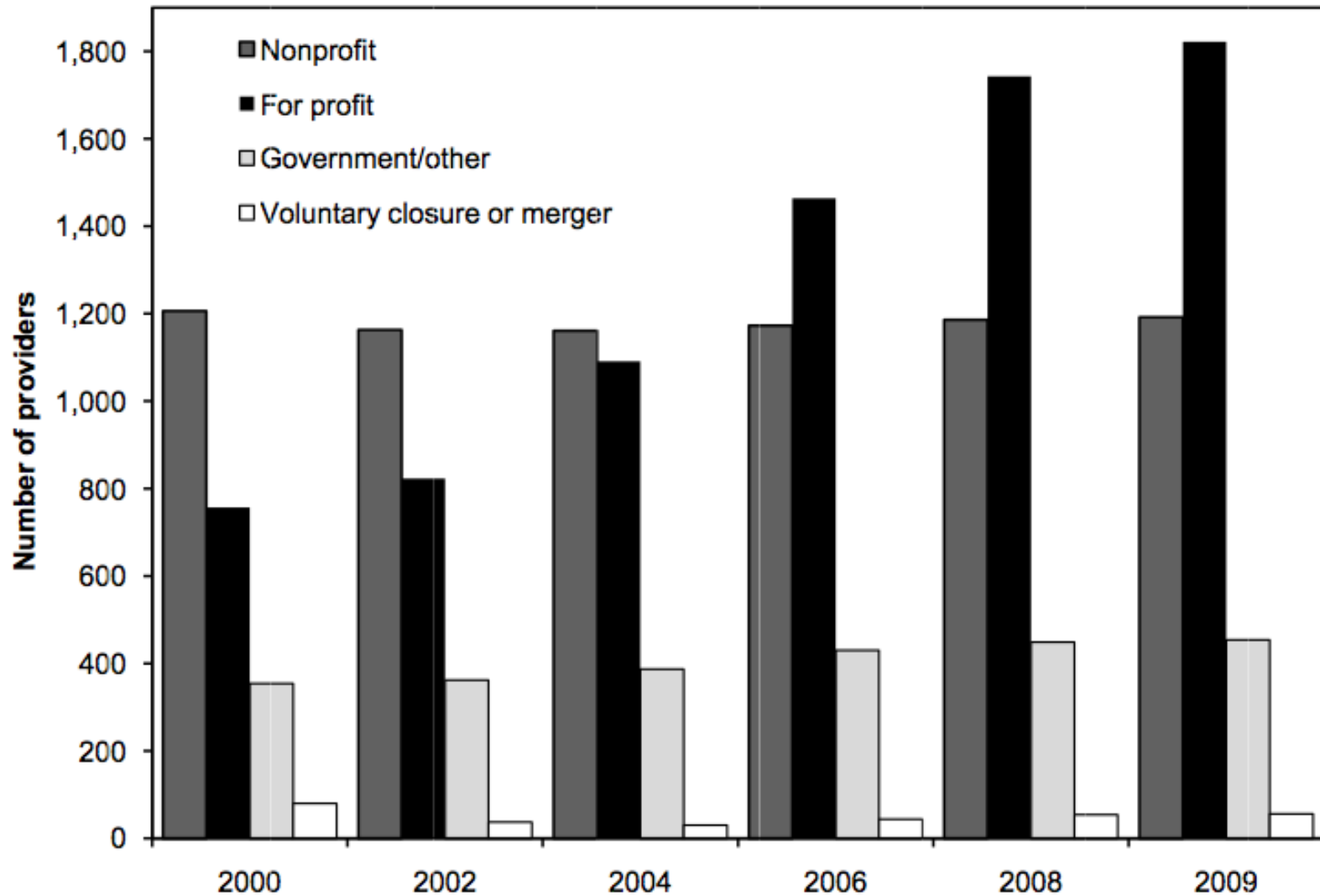
|  | 2000    | 2007      | 2008      | Average annual percent change 2000–2007 | Percent change 2007–2008 |
|--|---------|-----------|-----------|---|--------------------------|
| Beneficiaries in hospice                         | 513,000 | 1,000,000 | 1,055,000 | 10.0%                                   | 5.5%                     |
| Average length of stay among decedents (in days) | 54      | 80        | 83        | 5.8                                     | 3.8                      |
| Medicare payments (in billions)                  | \$2.9   | \$10.3    | \$11.2    | 19.8                                    | 8.7                      |

Note: Average length of stay reflects the average number of days a Medicare decedent who used hospice was enrolled in the Medicare hospice benefit during his/her lifetime.

Source: 2000 data on number of beneficiaries and payments from CMS analysis of 100 percent hospice claims Standard Analytic File: [http://www.cms.gov/PropMedicareFeeSvcPmtGen/downloads/FY05update\\_hospice\\_expenditures\\_and\\_units\\_of\\_care.pdf](http://www.cms.gov/PropMedicareFeeSvcPmtGen/downloads/FY05update_hospice_expenditures_and_units_of_care.pdf). All other numbers are based on MedPAC analysis of the denominator file, the Medicare Beneficiary Database, and the 100 percent hospice claims Standard Analytic File from CMS.

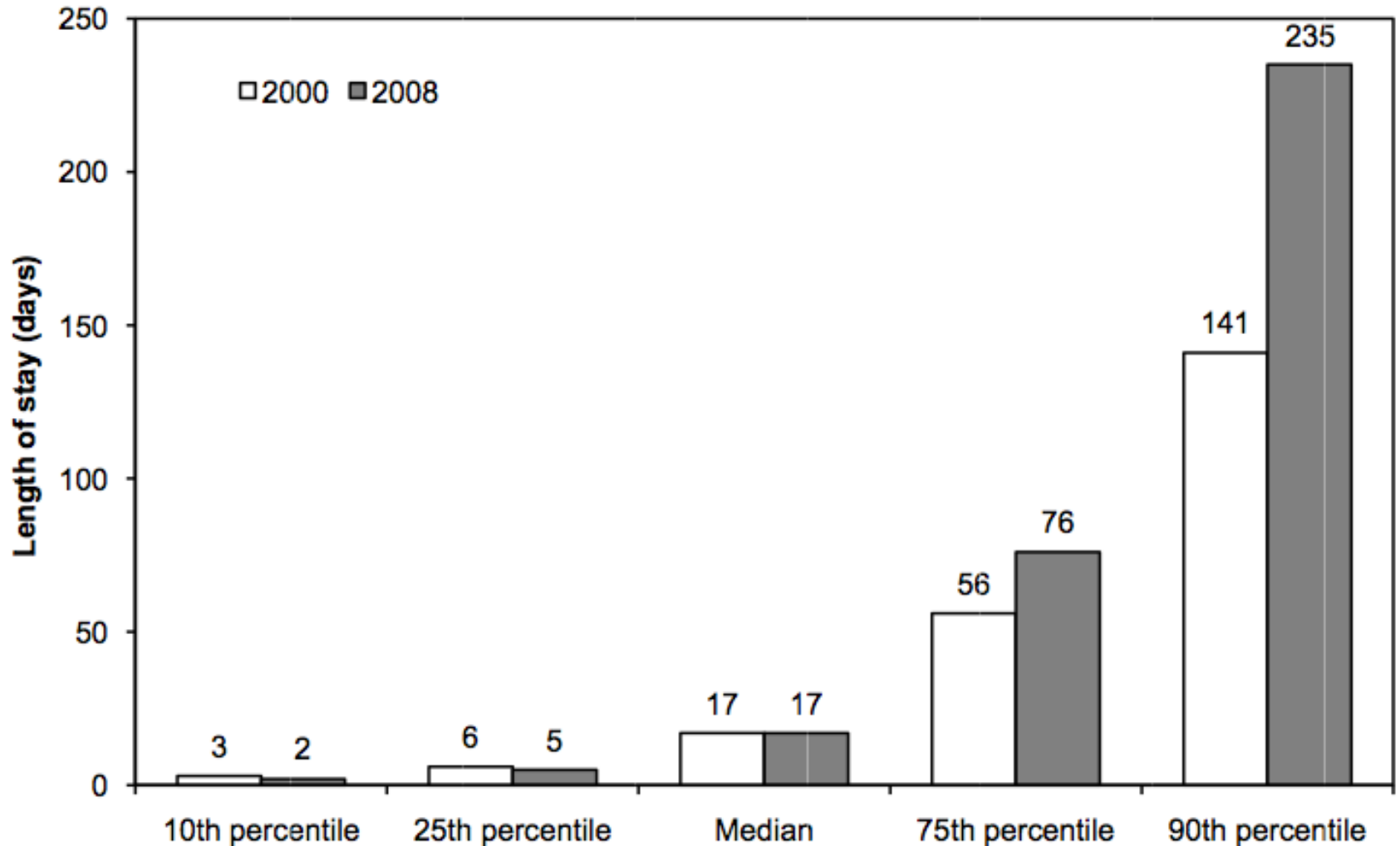
Medpac: A Data Book: Healthcare Spending and the Medicare Program (June 2010) p. 206

**Chart 12-10. Number of Medicare-participating hospices has increased, largely driven by for-profit hospices**





**Chart 12-13. Long hospice stays are getting longer, while short stays remain virtually unchanged**



Note: Data reflect hospice length of stay for Medicare decedents who used hospice at the time of death or before death. Length of stay reflects the total number of days the decedent was enrolled in the Medicare hospice benefit during his/her lifetime.

Source: MedPAC analysis of the denominator file and the Medicare Beneficiary Database from CMS.

# + Hospital based palliative care

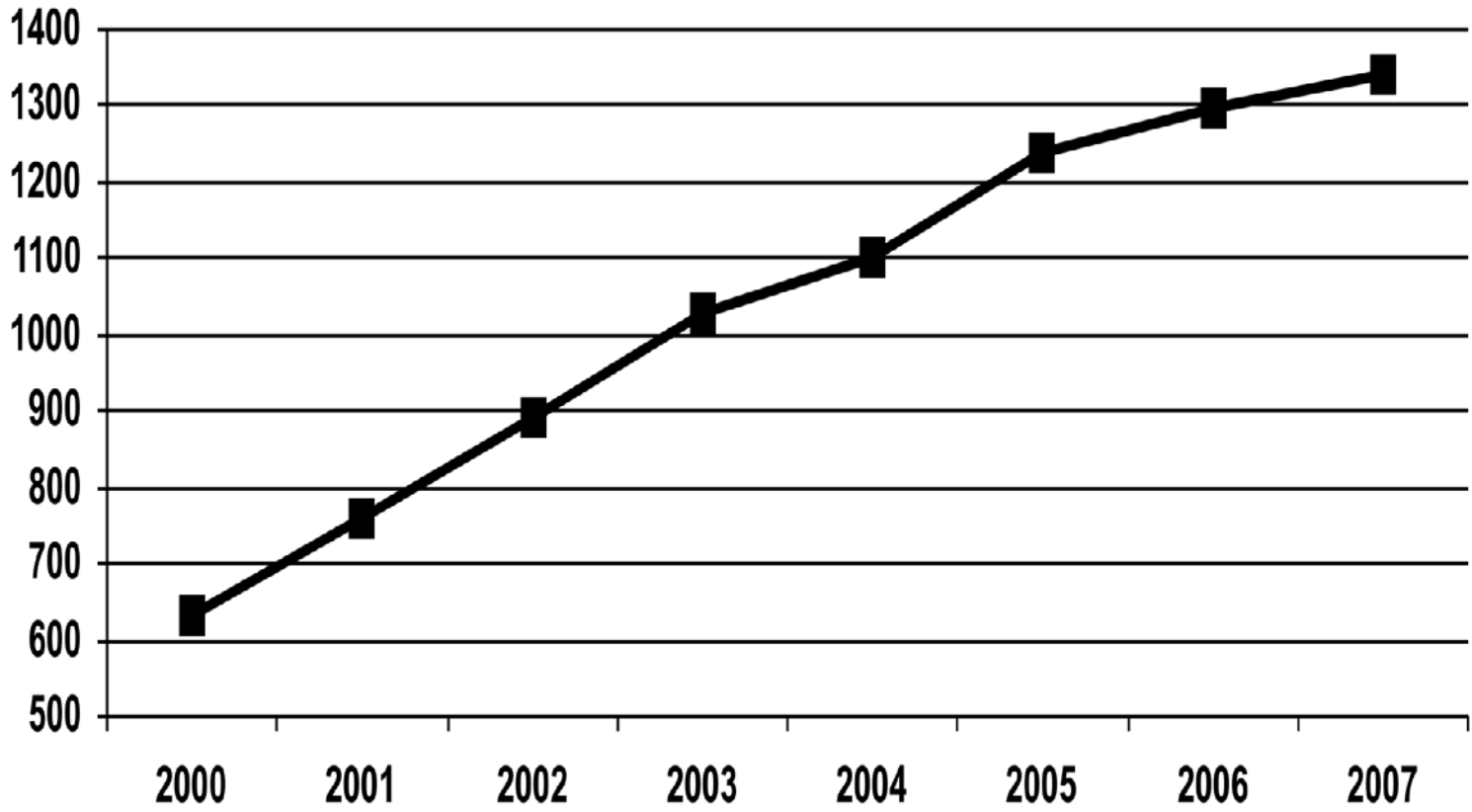
- Model of care began to diffuse in last 10 years
- Consultation teams, some units
- No enforcement of quality standards



# Access to U.S. Hospital Palliative Care Programs

# hospitals w/ palliative care programs

Goldsmith B et al. J Palliat Med 2008



# + Palliative Care Is Beneficial



Mortality follow back survey palliative care vs. usual care  
Casarett et al. J Am Geriatr Soc 2008;56:593-99.

- N=524 family survivors
- Overall **satisfaction markedly superior** in palliative care group,  $p < .001$
- Palliative care superior for:
  - emotional/spiritual support
  - information/communication
  - care at time of death
  - access to services in community
  - well-being/dignity
  - care + setting concordant with patient preference
  - pain
  - PTSD symptoms



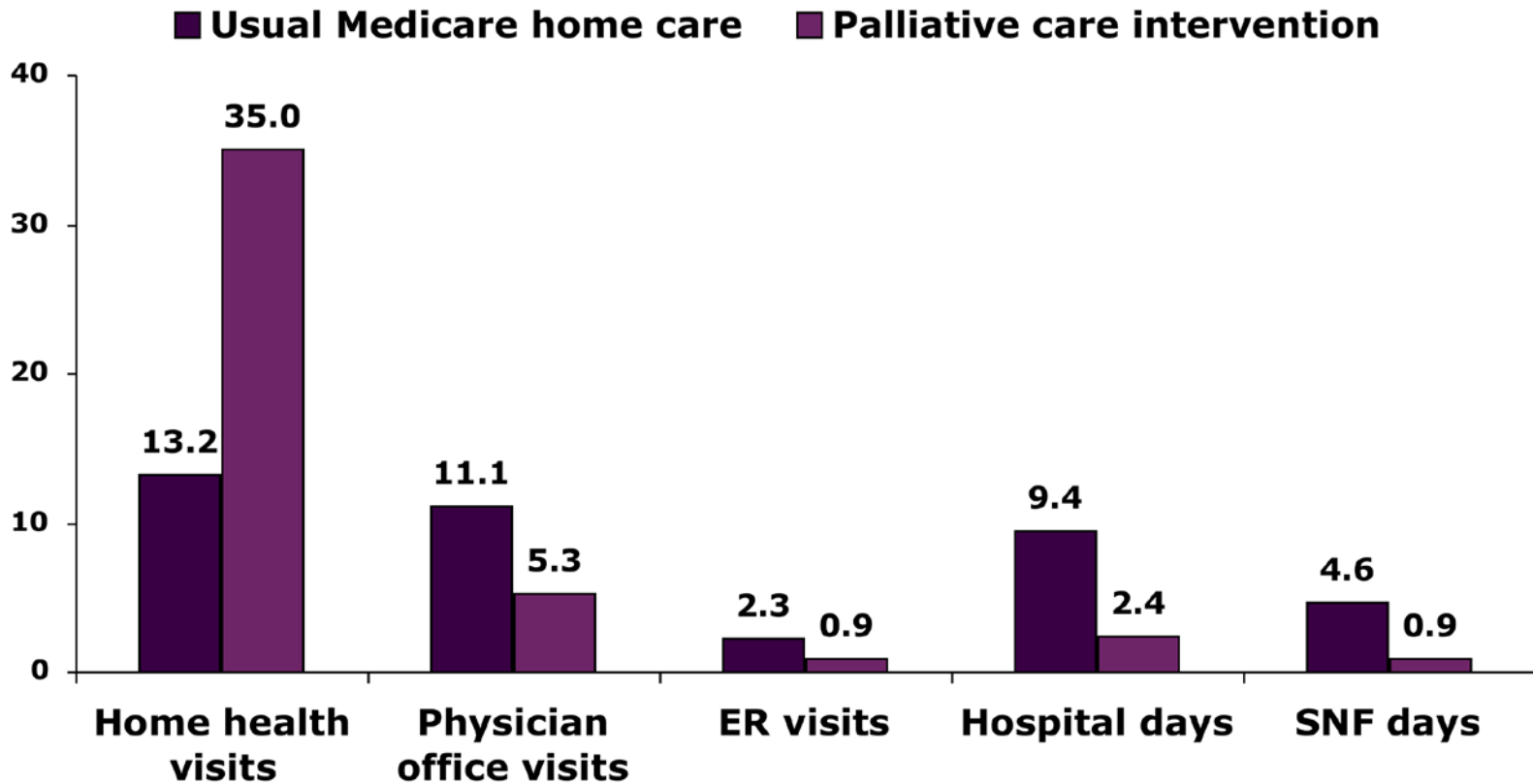
# + Early palliative care benefits QOL and length of life

**Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer, Tanel, NEJM 2010; 363:733-742** [August 19, 2010](#)

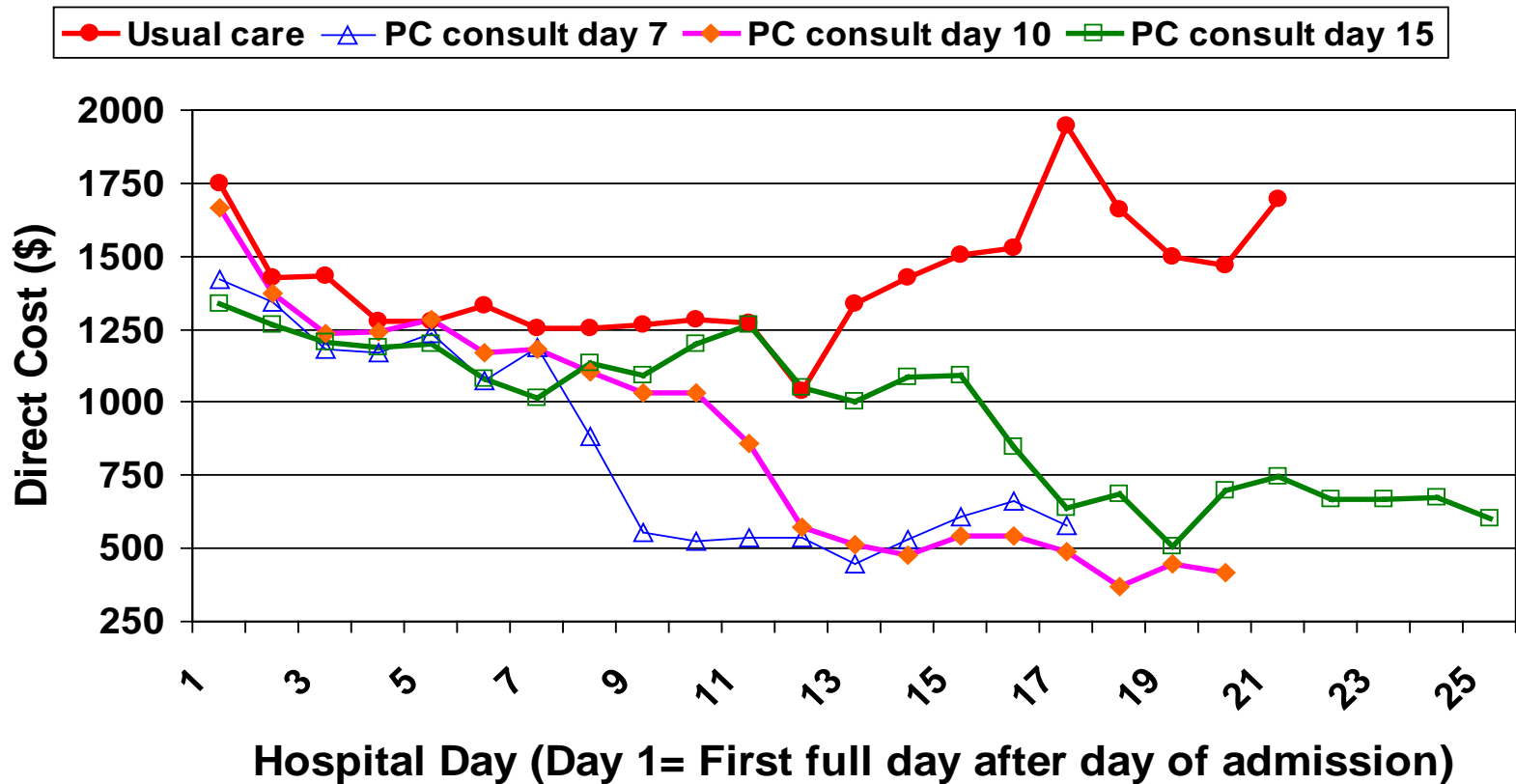
- RCT of early palliative care along with usual oncologic care vs. only usual oncologic care in newly diagnosed metastatic non-small cell lung cancer patients n=151
- Findings: Palliative care patients
  - had higher quality of life
  - had lower depression rates at 12 weeks after diagnosis
  - used less aggressive care
  - used more hospice care (median 11 days pal care vs. 4 days usual)
  - Lived longer - median survival, 11.6 vs. 8.9 months; P=0.02

# Palliative Care Shifts Care Out of Hospital to Home

Service Use Among Patients Who Died from CHF, COPD, or Cancer Palliative Home Care versus Usual Care, 1999–2000

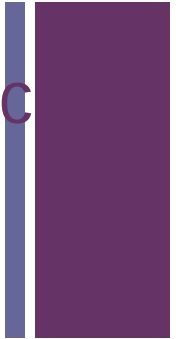


## Mean direct costs/day for patients who died and who received palliative care consultation versus matched usual care patients





# How Palliative Care Improves Care While Reducing Hospital & ICU Length of Stay



## Palliative care:

- Clarifies goals of care with patients and families
- Helps families to select medical treatments and care settings that meet their goals
- Assists with decisions to leave the hospital, or to withhold or withdraw death-prolonging treatments that don't help to meet their goals

capc.org/research-and-references-for-palliative-care/citations Lilly et al, Am J Med, 2000; Dowdy et al, Crit Care Med, 1998; Carlson et al, JAMA, 1988; Campbell et al, Heart Lung, 1991; Campbell et al, Crit Care Med, 1997; Bruera et al, J Pall Med, 2000; Finn et al, ASCO, 2002; Goldstein et al, Sup Care Cancer, 1996; Advisory Board 2002; Davis et al J Support Oncol 2005; Smeenk et al Pat Educ Couns 2000; Von Gunten JAMA 2002; Schneiderman et al JAMA 2003; Campbell and Guzman, Chest 2003; Smith et al. JPM 2003; Smith, Hillner JCO 2002; [www.capc.org](http://www.capc.org); Gilmer et al. Health Affairs 2005. Campbell et al. Ann Int Med.2004; Health Care Advisory Board. *The New Medical Enterprise 2004*. Elsayem et al, JPM 2006; Fromme et al, JPM 2006; Penrod et al, JPM 2006; Gozalo and Miller, HSR 2006; White et al, JHCM 2006; Morrison RS et al Arch Int Med 2008







New Delivery  
and Payment  
Models  
Need  
Palliative Care

## **Policy Goal:**

**Add palliative care and hospice to the eligibility/specifications/metrics for medical homes, accountable care organizations, and bundling strategies.**

# + New Models + Relevance to Palliative Care and Hospice

## Accountable Care Organizations:

- groups of providers receiving set fees to deliver *coordinated quality* care to a select group of patients (not a demo).
- ACO must agree to be **fully accountable for the overall care of their Medicare beneficiaries**

## Bundled payments:

- pilots to develop and evaluate paying a **single bundled payment for all services**
- begins three days prior to a hospitalization and spans 30 days following discharge

# + New Models: Relevance to Palliative Care and Hospice

## Medical Homes:

- "an approach to providing comprehensive primary care that facilitates partnerships between individual patients and their personal providers and when appropriate, the patient's family."
- CMS Medicare demonstration provides a **care management fee to physician practices serving "high need" patients**, who must use health assessment, integrated care plans, tracking of tests and providers, review of all medications, and tracking of referrals (Tier 1), and should develop an EHR, coordinate care across settings, and employ performance metrics and reporting (Tier 2).
- Per member per month payment.



New Models

Relevance to Palliative Care and Hospice

## **Independence at Home (Demo)**

- Testing the provision of MD and NP-directed home-based primary care and care coordination across all treatment settings.
- Eligible beneficiaries: 2 or more chronic conditions, a nonelective hospital admission in last year, prior rehabilitation, and 2 or more functional dependencies.
- **Shared savings.**



# Paying for Value

Assessing Quality in Hospice and Palliative Care

- Quality reporting requirement for hospices beginning 2014
- Need accreditation standards for palliative care



# Hospice – public accountability



## Hospice Report Card

HOME

CONTACT US

AHF strives to improve access to quality hospice care through public education, professional training, and advocacy on behalf of consumers.

To learn more, [click here](#).

LEARN ABOUT HOSPICE CARE

LEARN ABOUT COMPARING HOSPICE QUALITY

Start Comparing Hospice Quality

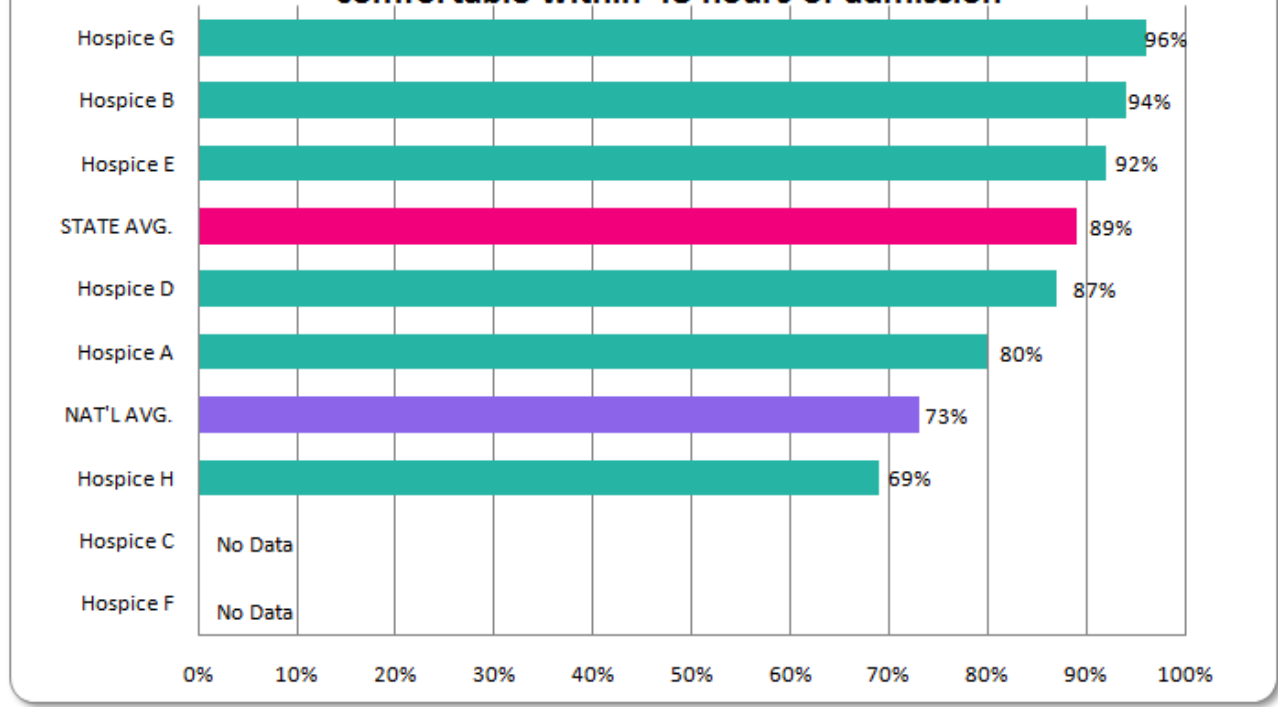
**Options for:**  
**Comparing Hospice Quality**

Pain and symptom management

## Pain and Symptom Management

Please select a measure with a higher score on this

### The percent of patients admitted in pain who reported being comfortable within 48 hours of admission



[How did we get the results for this graph?](#)



## Policy challenge:

- Strengthen specialty level programs (hospice, hospital-based palliative care, LTC palliative care)
- Integrate palliative care approach into all systems
- Public health approach – Individual choices take place in the context of systems that shape those choices. Build systems that make it routine to put patient and family comfort and dignity in the center of care.
- Make the individual's choice “opt out” of palliative care rather than “opt out” of aggressive care.

Hospice & Palliative Care  
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