AMAZING THINGS ARE HAPPENING HERE

Improving EOL Care: Understanding disparities, current barriers, and finding a way forward

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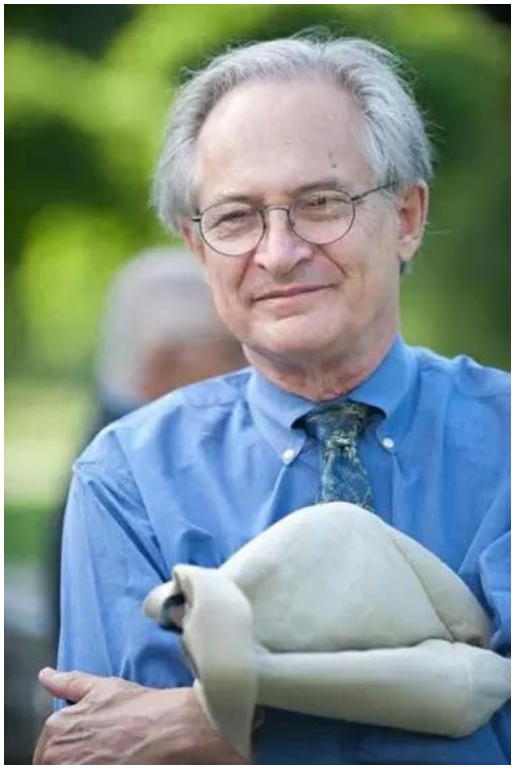
Disclosures

A) Relationship with companies who manufacture products used in the treatment of the subjects under discussion: No

B) Relationships with any of the commercial supporters of this CME activity: No

C) Discussion of unlabeled uses: No

With gratitude, and in memoriam



J. Andrew Billings, MD
(Sept 7, 1945 – Sept 6, 2015)

Outline

- The Problem: Providing Goal Concordant Care
- Dying in America
- Disparities in End of Life Care
- Barriers to Hospice Utilization
- The Role and Impact of Palliative Care in the US
- Palliative Care at CUMC—Where have we come from? Where are we now?
- Recommendations for improving EOL Care: Summary of the IOM Report

The Problem

Providing Goal Concordant Care

What Experienced 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

Steinhauser, et al. Ann Intern Med. 2000;132: 825-832.
Singer, et al. JAMA. 1999;281:163-168

Most people want to die at home surrounded by loved ones

Robert Wood Johnson Foundation
>70% of people would prefer to die at home

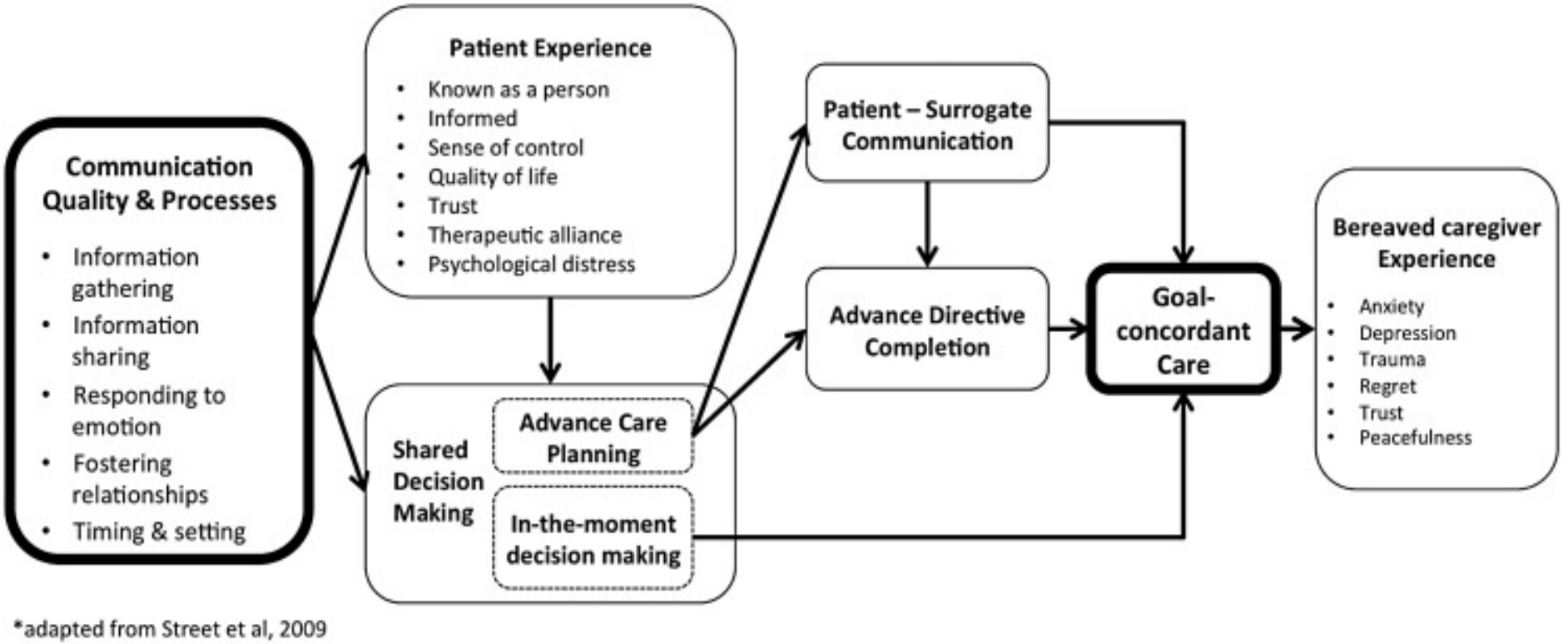
Most patients prefer to spend time with family and loved ones at the end of life

Goal Concordant Care: An Ethical Imperative

- High-quality care for seriously ill patients aligns treatment with their goals and values.
- Failure to achieve “goal-concordant” care is a medical error that can harm patients and families.
- Because communication between clinicians and patients enables goal concordance and also affects the illness experience, healthcare systems should endeavor to measure communication and its outcomes as a quality assessment.
- Measuring patient experience and receipt of goal-concordant care should be our highest priority.

Sanders JJ, et al. J Palliat Med. 2018 Mar 1; 21(Suppl 2): S-17–S-27.

Goal concordant care: A conceptual model



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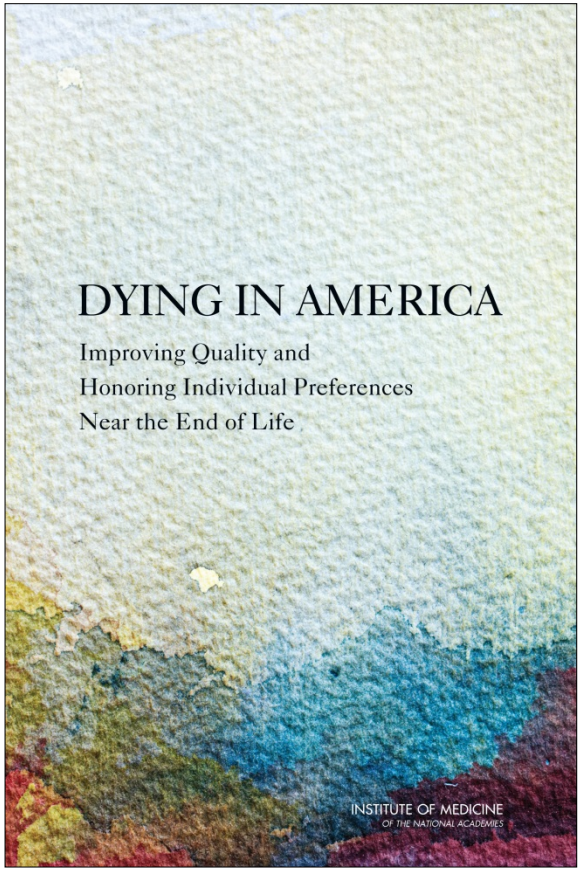
Dying in America

Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life

www/iom.edu/endoflife



Suggested citation: IOM (Institute of Medicine). 2014. *Dying in America: Improving quality and honoring individual preferences near the end of life.* Washington, DC: The National Academies Press.

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The Problem with End of Life Care Reflects Problems in our Health Care System

- Barriers in access to care that disadvantage certain groups
- A mismatch between the services patients and families need and the services they can obtain.
    - Improving the quality and availability of medical and social services for patients and their families could not only enhance quality of life through the end of life, but may also contribute to a more sustainable care system.
- Inadequate numbers of palliative care specialists and too little palliative care knowledge among other clinicians who care for individuals with serious advanced illness
- A fragmented care delivery system, spurred by perverse financial incentives, that contributes to the lack of service coordination across programs and unsustainable growth in costs.

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Teno J, et al JAMA. 2013;309(5):470-477. doi:10.1001/jama.2012.207624

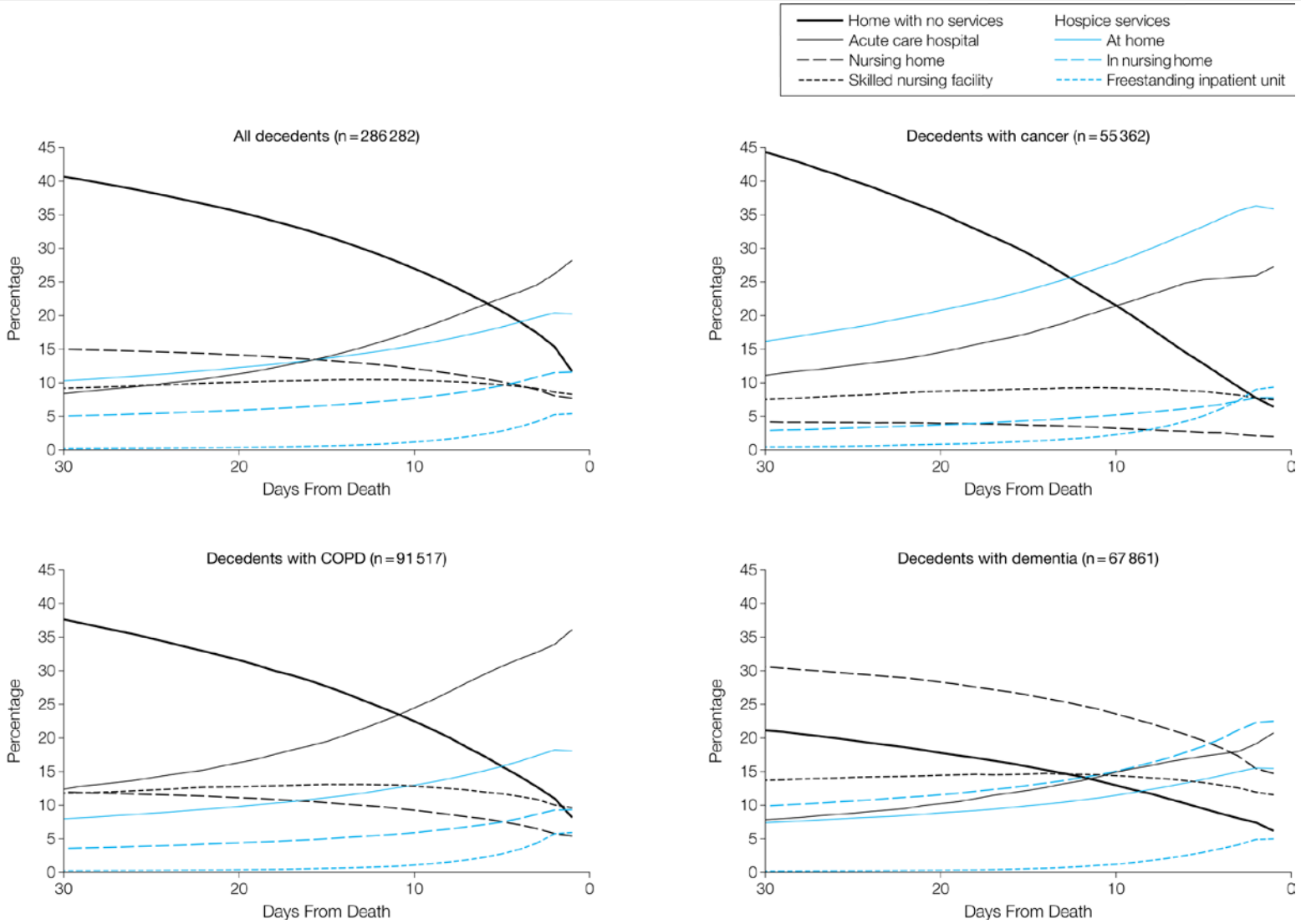

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Table 2. Trends in Site of Death, Place of Care, and Transitions Between 2000, 2005, and 2009[a]

	% (95% CI)								
	All Decedents			Cancer		COPD		Dementia	
	2000 (n = 270 202)	2005 (n = 291 819)	2009 (n = 286 282)	2000 (n = 49 735)	2009 (n = 55 362)	2000 (n = 79 284)	2009 (n = 91 517)	2000 (n = 59 065)	2009 (n = 67 861)
Site of death[b]									
Home	30.7 (30.6-30.9)	34.9 (35.7-35.1)	33.5 (33.3-33.6)	41.5 (41.1-41.9)	43.4 (43.0-43.8)	24.0 (23.7-24.3)	28.0 (27.8-28.3)	19.9 (19.6-20.2)	22.8 (22.4-23.1)
Acute care hospital	32.6 (32.4-32.8)	26.9 (26.7-27.1)	24.6 (24.5-24.8)	30.1 (29.7-30.5)	22.1 (21.7-22.4)	44.2 (43.9-44.6)	31.7 (31.4-32.0)	28.6 (28.3-29.0)	17.5 (17.2-17.7)
Nursing home	27.2 (27.0-27.3)	25.3 (25.1-25.4)	27.6 (27.4-27.8)	17.0 (16.7-17.3)	17.1 (16.8-17.5)	22.3 (22.0-22.6)	24.3 (24.0-24.6)	45.6 (45.1-46.0)	48.8 (48.4-49.1)
Place of care[c]									
Hospice at time of death	21.6 (21.4-21.7)	32.3 (32.1-32.5)	42.2 (42.0-42.4)	45.1 (44.6-45.5)	59.5 (59.1-59.9)	19.5 (19.2-19.8)	39.0 (38.7-39.3)	19.5 (19.2-19.8)	48.3 (48.0-48.7)
Hospice ≤3 d	4.6 (4.5-4.7)	7.6 (7.5-7.7)	9.8 (9.7-10.0)	7.6 (7.4-7.8)	12.7 (12.5-13.0)	5.0 (4.9-5.2)	11.5 (11.3-11.7)	5.2 (5.0-5.3)	10.5 (10.3-10.8)
GIP level of hospice care in last mo	3.9 (3.8-4.0)	8.0 (7.9-8.1)	11.3 (11.1-11.4)	8.4 (8.2-8.7)	17.8 (17.5-18.2)	4.2 (4.1-4.4)	12.6 (12.4-12.9)	3.7 (3.5-3.8)	11.4 (11.1-11.6)
Continuous care level of hospice care in last mo	0.94 (0.91-0.98)	2.3 (2.2-2.3)	3.1 (3.0-3.1)	1.8 (1.6-1.9)	4.2 (4.0-4.4)	0.83 (0.77-0.90)	2.9 (2.8-3.0)	0.91 (0.83-0.99)	3.9 (3.7-4.0)
Nursing home stay in last 90 d	42.8 (42.6-43.0)	42.2 (42.0-42.4)	45.0 (44.8-45.2)	28.6 (28.2-29.0)	31.3 (30.9-31.7)	42.2 (41.9-42.6)	47.4 (47.1-47.7)	70.9 (70.5-71.3)	72.1 (71.8-72.5)
Hospitalization in last 90 d	62.9 (62.7-63.1)	62.8 (62.7-63.0)	69.3 (69.2-69.6)	75.0 (74.6-75.4)	80.3 (80.0-80.6)	81.6 (81.4-81.9)	82.8 (82.6-83.1)	69.9 (69.5-70.2)	65.2 (64.8-65.6)
ICU in last 30 d	24.3 (24.1-24.5)	26.3 (26.1-26.5)	29.2 (29.0-29.3)	19.9 (19.6-20.3)	26.8 (26.5-27.2)	36.6 (36.3-37.0)	39.9 (39.6-40.2)	18.6 (18.3-18.9)	21.8 (21.5-22.2)
Transitions[c]									
Rate in last 90 d per decedent, mean (median) (IQR)	2.1 (1.0) (0-3.0)	2.8 (2.0) (1.0-4.0)	3.1 (2.0) (1.0-5.0)	2.8 (2.0) (1.0-4.0)	4.1 (4.0) (2.0-6.0)	2.8 (2.0) (1.0-4.0)	3.9 (3.0) (1.0-6.0)	2.4 (2.0) (1.0-4.0)	3.1 (3.0) (1.0-5.0)
Transition in last 3 d	10.3 (10.1-10.4)	12.4 (12.3-12.5)	14.2 (14.0-14.3)	11.0 (10.7-11.3)	15.5 (15.2-15.8)	12.1 (11.9-12.3)	17.1 (16.8-17.3)	15.2 (15.0-15.5)	16.5 (16.3-16.8)
≥3 Hospitalizations in last 90 d	10.3 (10.2-10.4)	10.9 (10.8-11.0)	11.5 (11.4-11.6)	13.2 (12.9-13.5)	14.4 (14.1-14.7)	17.9 (17.6-18.1)	19.1 (18.8-19.3)	12.0 (11.7-12.3)	10.7 (10.5-11.0)
Utilization measures[c]									
Mechanical ventilation in last 30 d	8.3 (8.2-8.4)	8.6 (8.4-8.6)	9.3 (9.2-9.4)	5.9 (5.7-6.1)	6.7 (6.4-6.8)	13.3 (13.1-13.5)	13.0 (12.7-13.2)	5.1 (4.9-5.3)	5.2 (5.0-5.4)
Hospital days, mean (median) (IQR)									
Last 30 d	4.9 (1.0) (0-8.0)	4.8 (1.0) (0-7.0)	4.6 (1.0) (0-7.0)	6.0 (3.0) (0-9.0)	5.3 (3.0) (0-8.0)	7.5 (5.0) (0-12.0)	6.6 (4.0) (0-10.0)	5.1 (2.0) (0-8.0)	4.0 (0) (0-6.0)
Last 90 d	8.5 (4.0) (0-12.0)	8.5 (4.0) (0-12.0)	8.2 (4.0) (0-11.0)	10.8 (7.0) (2.0-15.0)	9.7 (6.0) (1.0-13.0)	13.2 (9.0) (3.0-18.0)	12.0 (7.0) (2.0-17.0)	9.5 (6.0) (0-13.0)	7.7 (4.0) (0-10.0)
ICU days, mean (median) (IQR)									
Last 30 d	1.5 (0) (0-0)	1.7 (0) (0-1.0)	1.8 (0) (0-1.0)	1.2 (0) (0-1.0)	1.6 (0) (0-1.0)	2.6 (0) (0-3.0)	2.8 (0) (0-3.0)	0.9 (0) (0-0)	1.2 (0) (0-0)
Last 90 d	2.3 (0) (0-1.0)	2.7 (0) (0-2.0)	2.9 (0) (0-3.0)	1.9 (0) (0-5.0)	2.7 (0) (0-6.0)	4.1 (0) (0-1.0)	4.7 (0) (0-1.0)	1.6 (0) (0-1.0)	2.1 (0) (0-1.0)

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Last 90 d	8.5 (4.0) (0-12.0)	8.5 (4.0) (0-12.0)	8.2 (4.0) (0-11.0)	10.8 (7.0) (2.0-15.0)	9.7 (6.0) (1.0-13.0)	13.2 (9.0) (3.0-18.0)	12.0 (7.0) (2.0-17.0)	9.5 (6.0) (0-13.0)	7.7 (4.0) (0-10.0)
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Last 90 d	2.3 (0) (0-1.0)	2.7 (0) (0-2.0)	2.9 (0) (0-3.0)	1.9 (0) (0-5.0)	2.7 (0) (0-6.0)	4.1 (0) (0-1.0)	4.7 (0) (0-1.0)	1.6 (0) (0-1.0)	2.1 (0) (0-1.0)

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Nursing home	27.2	25.3	27.6	17.0	17.1	22.3	24.3	45.6	48.8
Place of care[c]									
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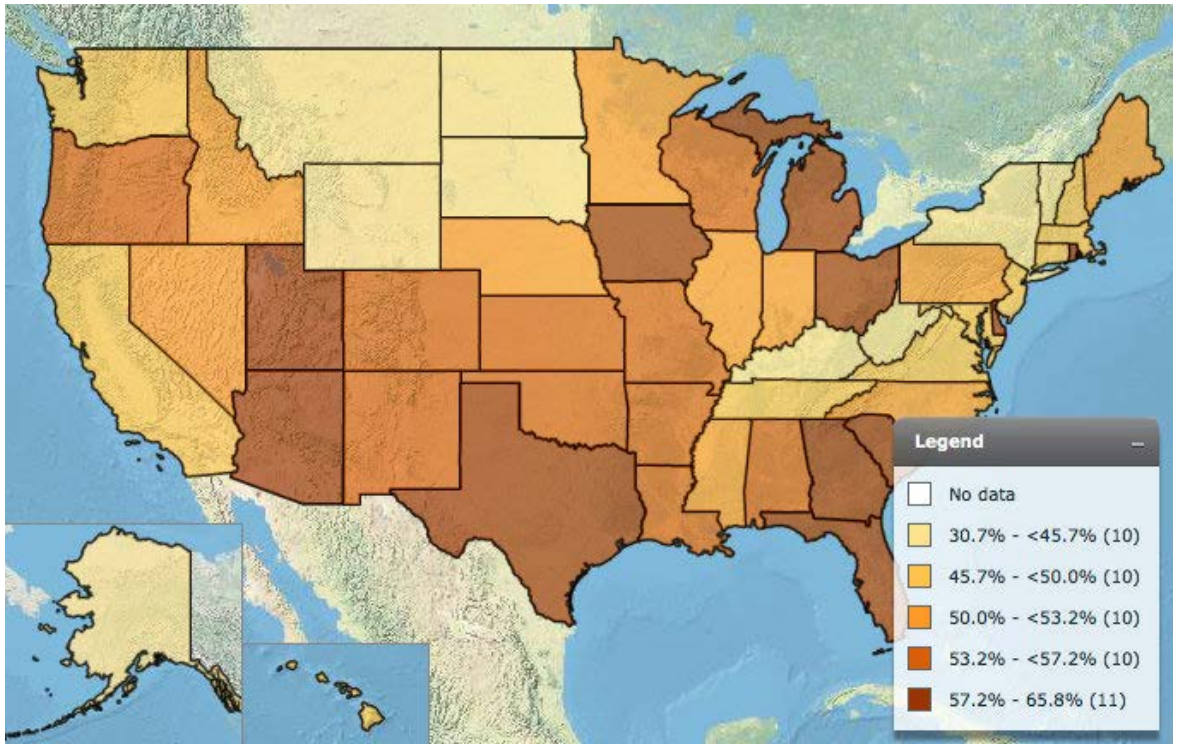
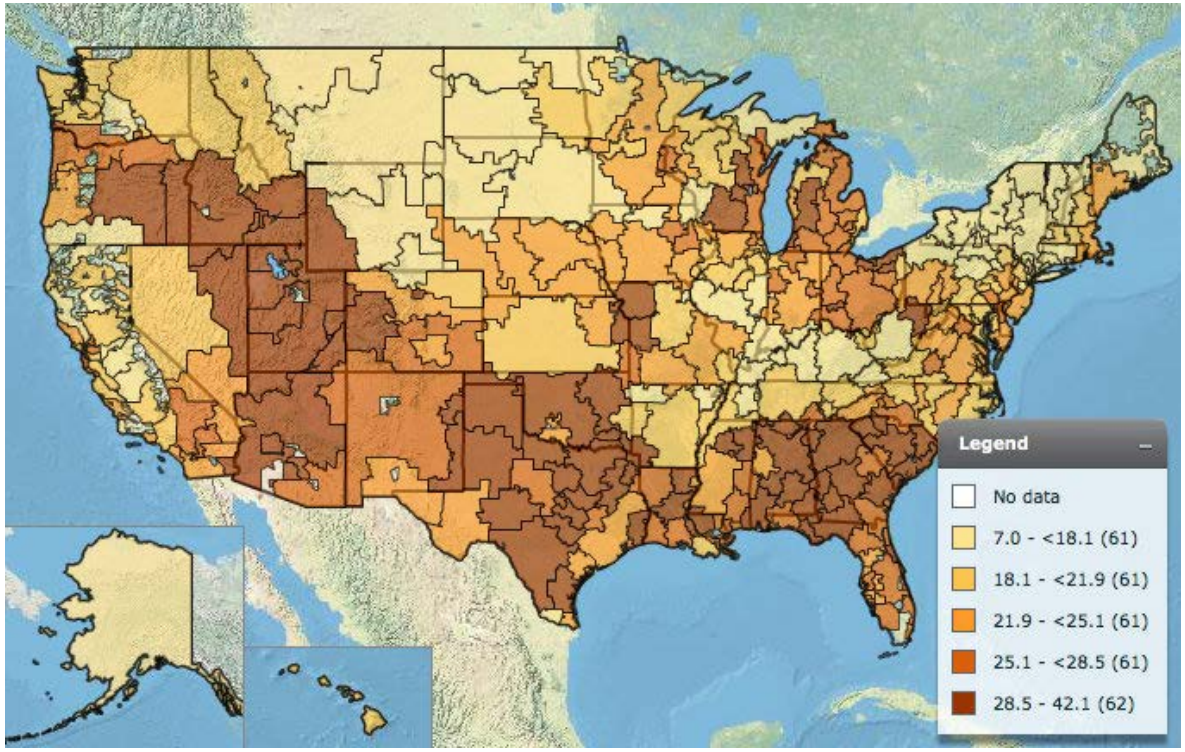
Hospitalization in last 90 d	62.9	62.8	69.3	75.0	80.3	81.6	82.8	69.9	65.2
ICU in last 30 d	24.3 (24.1-24.5)	26.3 (26.1-26.5)	29.2 (29.0-29.3)	19.9 (19.6-20.3)	26.8 (26.5-27.2)	36.6 (36.3-37.0)	39.9 (39.6-40.2)	18.6 (18.3-18.9)	21.8 (21.5-22.2)
Rate in last 90 d per decedent, mean (median) (IQR)	2.1 (1.0) (0-3.0)	2.8 (2.0) (1.0-4.0)	3.1 (2.0) (1.0-5.0)	2.8 (2.0) (1.0-4.0)	4.1 (4.0) (2.0-6.0)	2.8 (2.0) (1.0-4.0)	3.9 (3.0) (1.0-6.0)	2.4 (2.0) (1.0-4.0)	3.1 (3.0) (1.0-5.0)
Transition in last 3 d	10.3 (10.1-10.4)	12.4 (12.3-12.5)	14.2 (14.0-14.3)	11.0 (10.7-11.3)	15.5 (15.2-15.8)	12.1 (11.9-12.3)	17.1 (16.8-17.3)	15.2 (15.0-15.5)	16.5 (16.3-16.8)
≥3 Hospitalizations in last 90 d	10.3 (10.2-10.4)	10.9 (10.8-11.0)	11.5 (11.4-11.6)	13.2 (12.9-13.5)	14.4 (14.1-14.7)	17.9 (17.6-18.1)	19.1 (18.8-19.3)	12.0 (11.7-12.3)	10.7 (10.5-11.0)
Utilization measures[c]									
Mechanical ventilation in last 30 d	8.3 (8.2-8.4)	8.6 (8.4-8.6)	9.3 (9.2-9.4)	5.9 (5.7-6.1)	6.7 (6.4-6.8)	13.3 (13.1-13.5)	13.0 (12.7-13.2)	5.1 (4.9-5.3)	5.2 (5.0-5.4)
Hospital days, mean (median) (IQR)									
Last 30 d	4.9 (1.0) (0-8.0)	4.8 (1.0) (0-7.0)	4.6 (1.0) (0-7.0)	6.0 (3.0) (0-9.0)	5.3 (3.0) (0-8.0)	7.5 (5.0) (0-12.0)	6.6 (4.0) (0-10.0)	5.1 (2.0) (0-8.0)	4.0 (0) (0-6.0)
Last 90 d	8.5 (4.0) (0-12.0)	8.5 (4.0) (0-12.0)	8.2 (4.0) (0-11.0)	10.8 (7.0) (2.0-15.0)	9.7 (6.0) (1.0-13.0)	13.2 (9.0) (3.0-18.0)	12.0 (7.0) (2.0-17.0)	9.5 (6.0) (0-13.0)	7.7 (4.0) (0-10.0)
ICU days, mean (median) (IQR)									
Last 30 d	1.5 (0) (0-0)	1.7 (0) (0-1.0)	1.8 (0) (0-1.0)	1.2 (0) (0-1.0)	1.6 (0) (0-1.0)	2.6 (0) (0-3.0)	2.8 (0) (0-3.0)	0.9 (0) (0-0)	1.2 (0) (0-0)
Last 90 d	2.3 (0) (0-1.0)	2.7 (0) (0-2.0)	2.9 (0) (0-3.0)	1.9 (0) (0-5.0)	2.7 (0) (0-6.0)	4.1 (0) (0-1.0)	4.7 (0) (0-1.0)	1.6 (0) (0-1.0)	2.1 (0) (0-1.0)

PERCENT OF DECEDENTS ENROLLED IN HOSPICE DURING THE LAST SIX MONTHS OF LIFE (Year: 2014; Region Level: HRR)

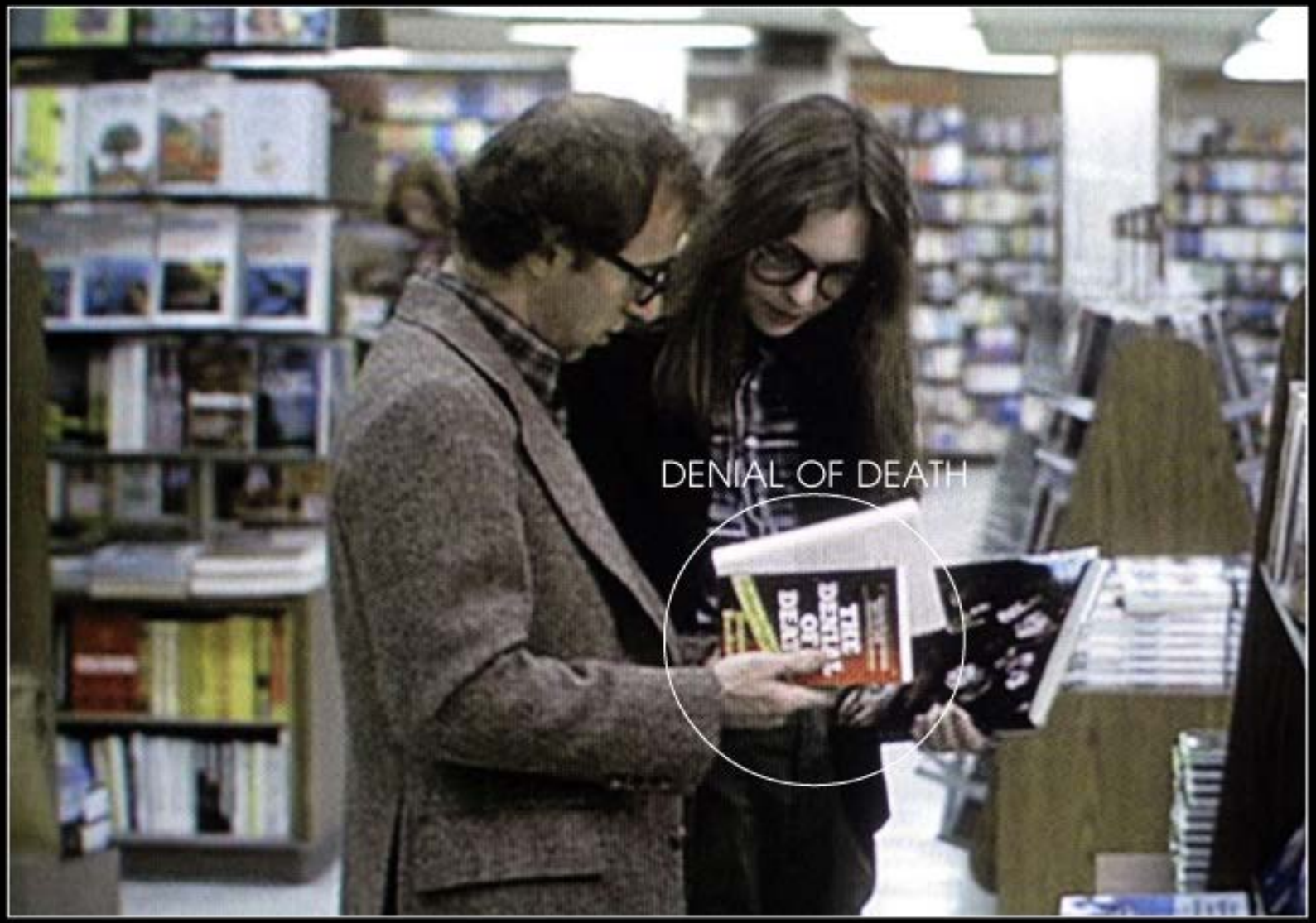


THE DARTMOUTH INSTITUTE
FOR HEALTH POLICY & CLINICAL PRACTICE

HOSPICE DAYS PER DECEDENT DURING THE LAST SIX MONTHS OF LIFE (Year: 2014; Region Level: HRR)

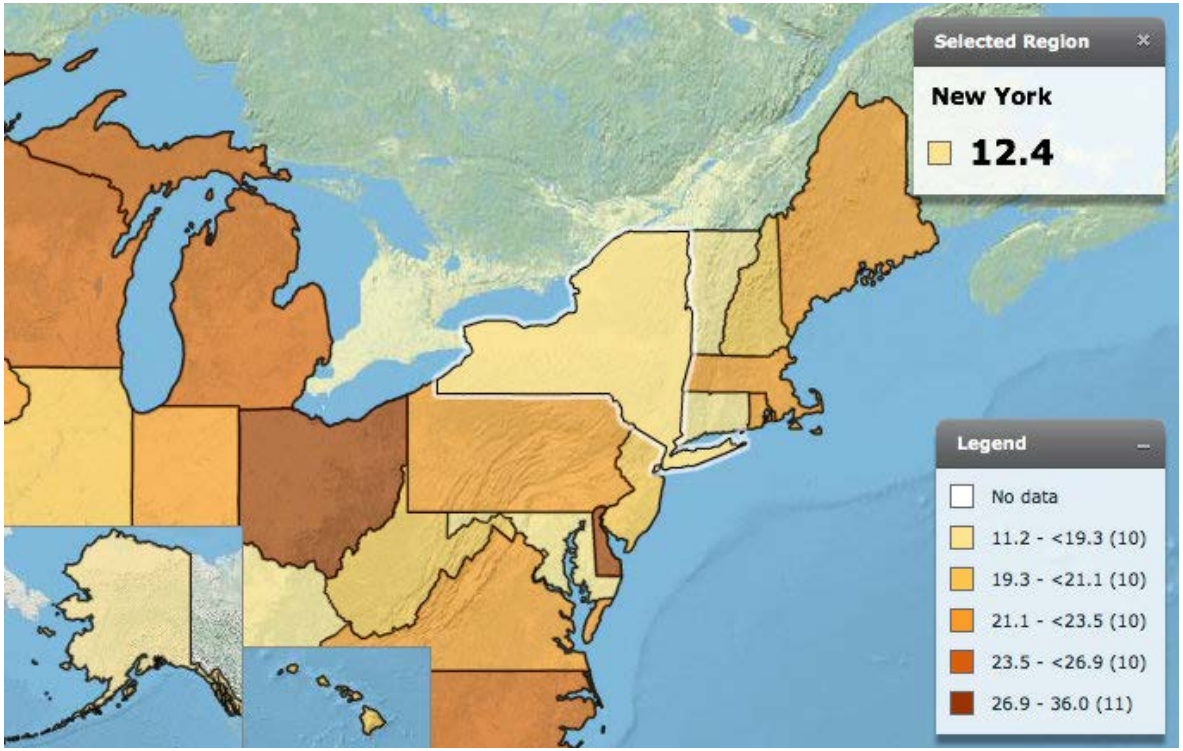


THE DARTMOUTH INSTITUTE
FOR HEALTH POLICY & CLINICAL PRACTICE



"I'm not afraid to die. I just don't want to be around when it happens."

NEW YORK STATE HAS 12.4 HOSPICE DAYS PER DECEDENT DURING THE LAST SIX MONTHS OF LIFE (Year: 2014; Region Level: HRR)



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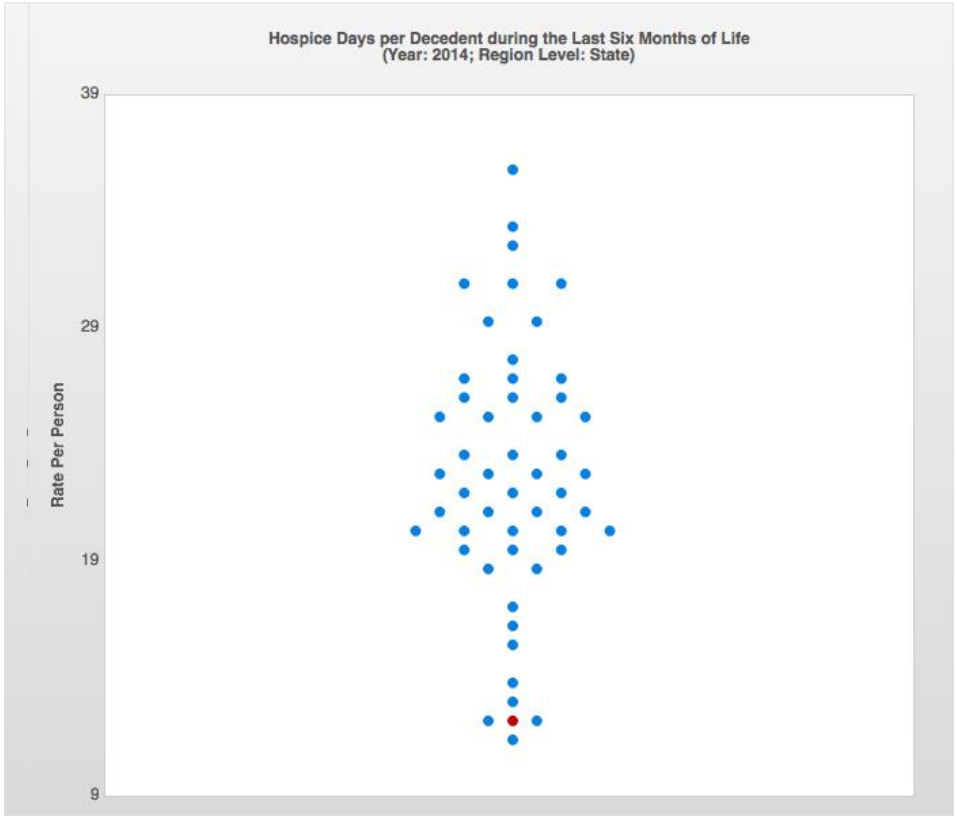
New York State has one of the lowest number of hospice days for decedents



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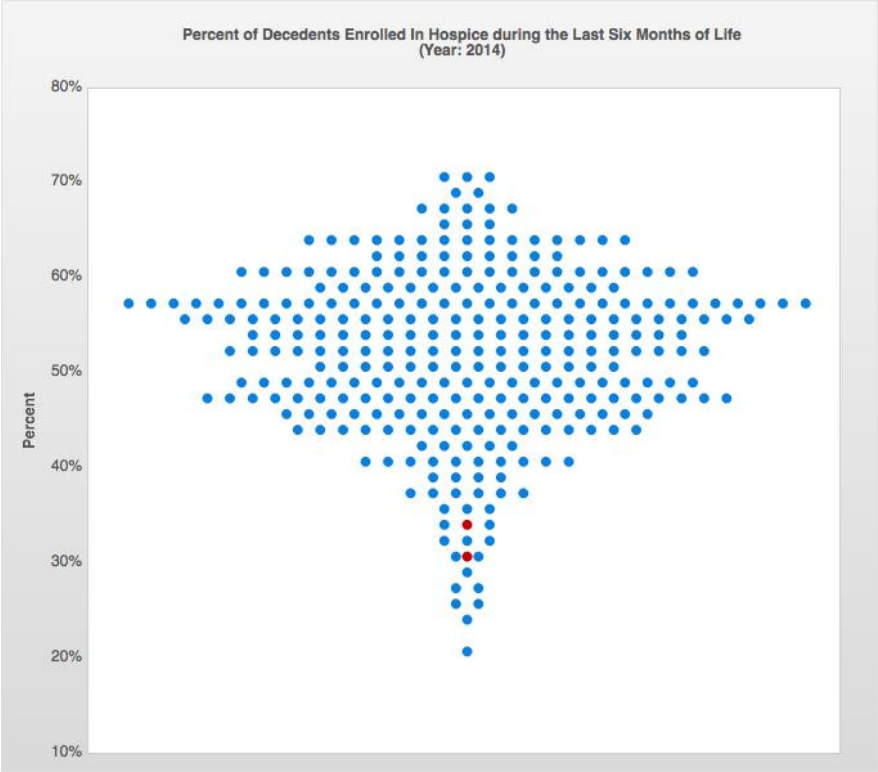
New York City has one of the lowest percent of decedents enrolled in hospice during the last 6 months of life



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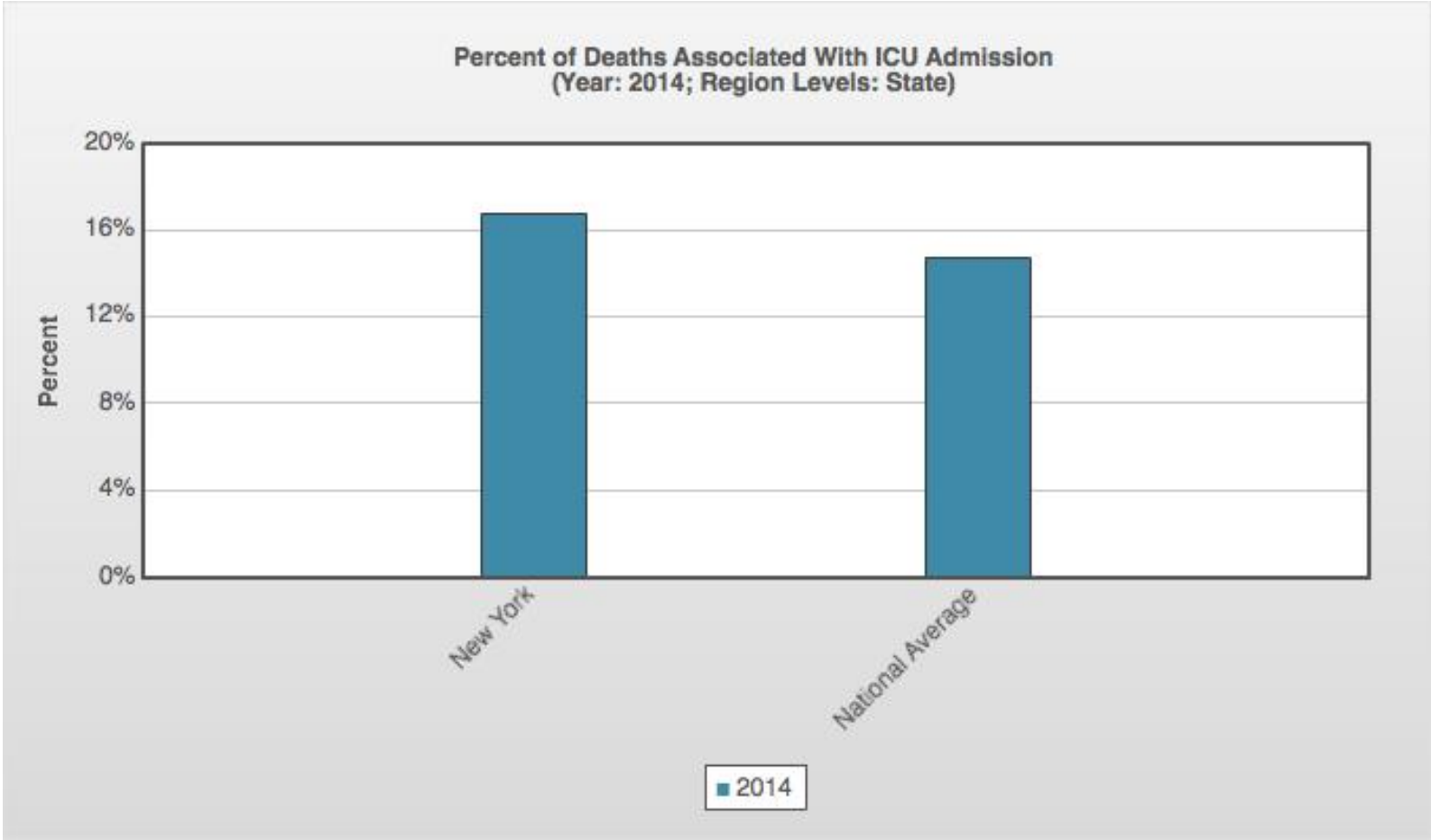

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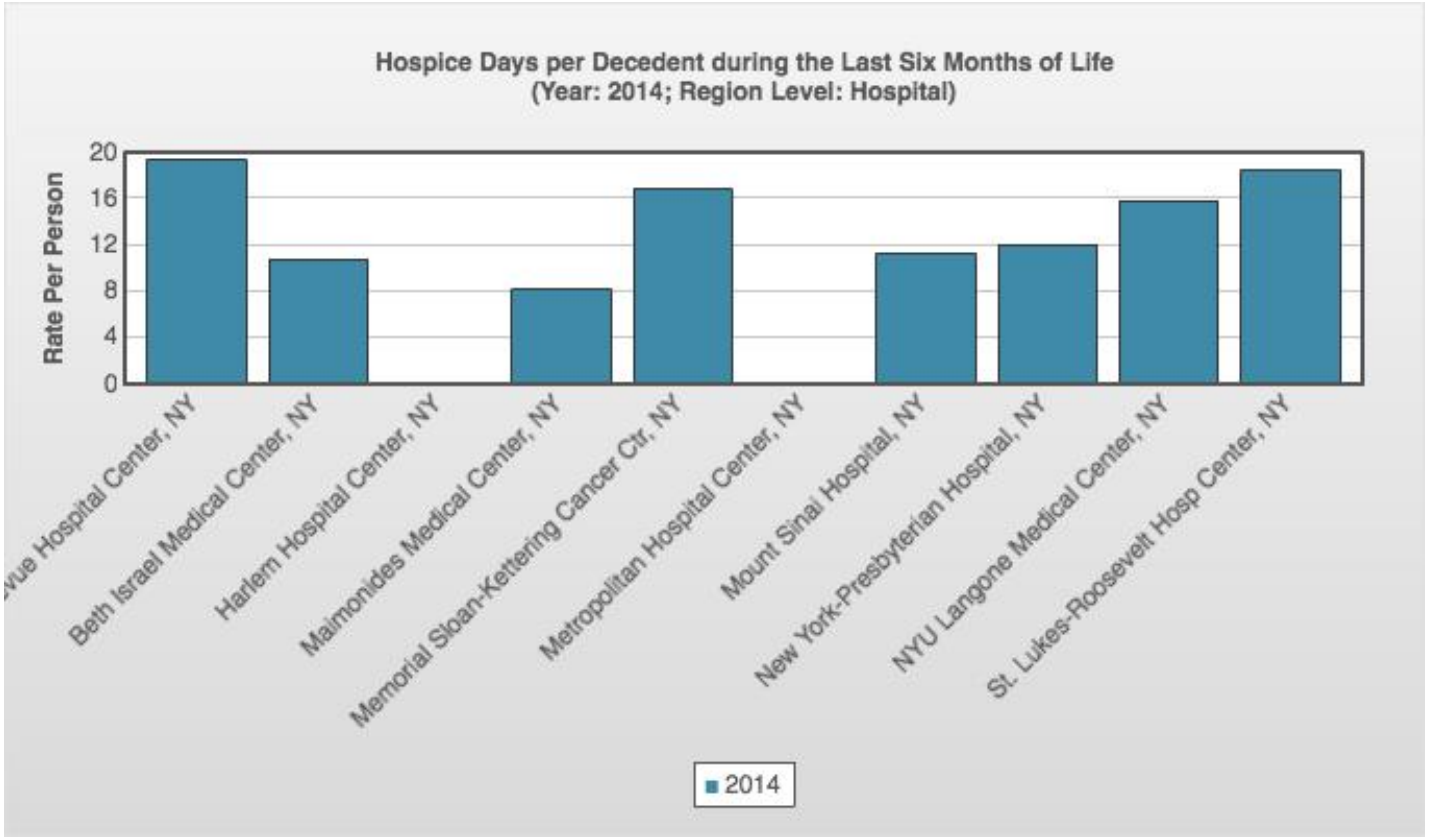
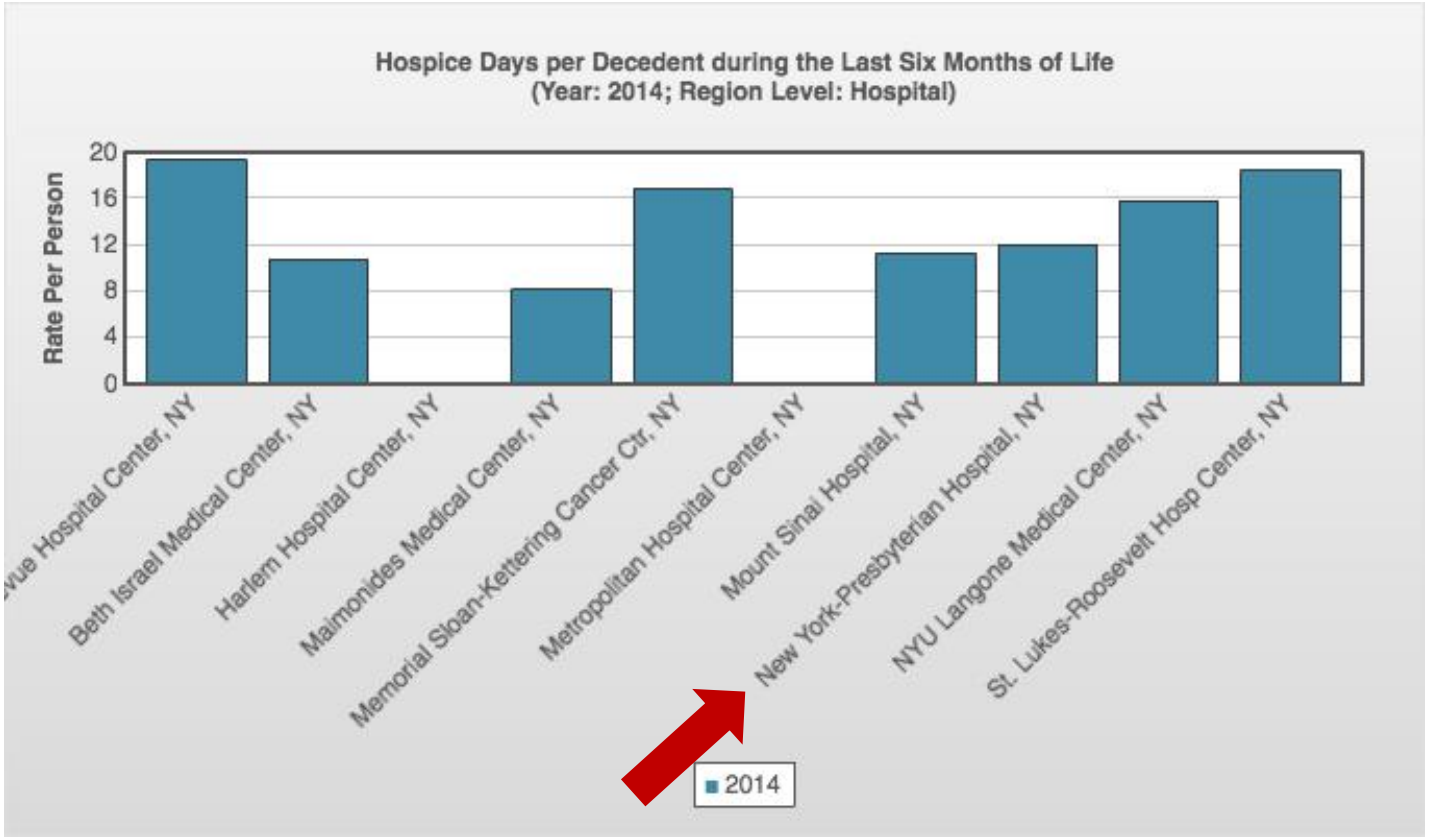
HOSPICE DAYS PER DECEDENT DURING THE LAST SIX MONTHS OF LIFE IN NYC HOSPITALS



HOSPICE DAYS PER DECEDENT DURING THE LAST SIX MONTHS OF LIFE IN NYC HOSPITALS



THE DARTMOUTH ATLAS OF HEALTH CARE

HOSPICE DAYS PER DECEDENT DURING THE LAST SIX MONTHS OF LIFE

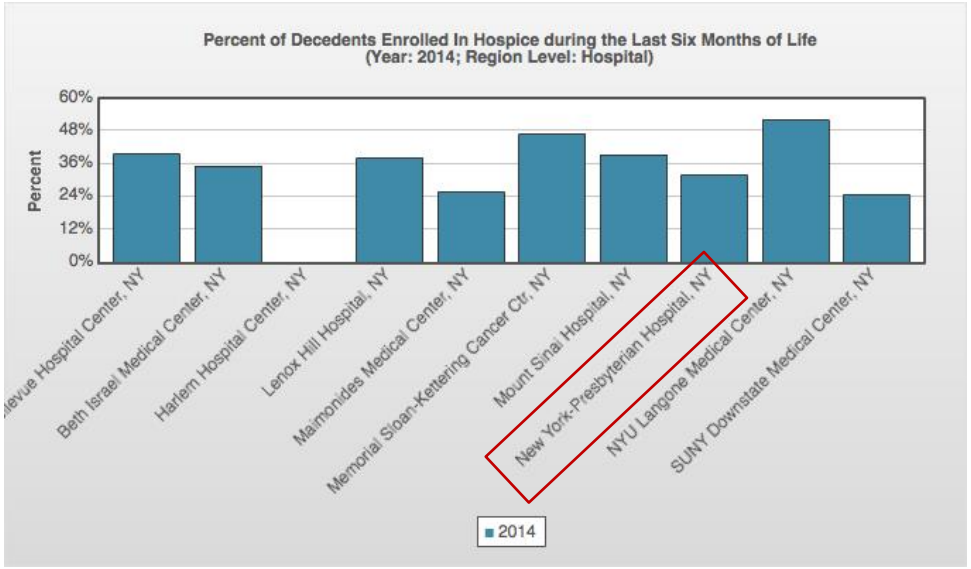
	Hospice Days per Decedent during the Last Six Months of Life (Year: 2014; Region Levels: Hospital)
Bellevue Hospital Center, (New York, NY)	19.5
St. Lukes-Roosevelt Hosp Center, (New York, NY)	18.4
Memorial Sloan-Kettering Cancer Ctr, (New York, NY)	16.8
NYU Langone Medical Center, (New York, NY)	15.9
New York-Presbyterian Hospital, (New York, NY)	12.1
Mount Sinai Hospital, (New York, NY)	11.2
Beth Israel Medical Center, (New York, NY)	10.8
Maimonides Medical Center, (Brooklyn, NY)	8.3
National Average	23.3
90th Percentile	29.5
50th Percentile	20.1
10th Percentile	11.7

NYPH is < 10th percentile for decedents enrolled in hospice during the last 6 months of life

THE DARTMOUTH ATLAS OF HEALTH CARE

PERCENT OF DECEDENTS ENROLLED IN HOSPICE DURING THE LAST SIX MONTHS OF LIFE

	Percent of Decedents Enrolled In Hospice during the Last Six Months of Life (Year: 2014; Region Levels: State, Hospital)
New York	
New York-Presbyterian Hospital, (New York, NY)	31.8%
National Average	52.6%
90th Percentile	66.8%
50th Percentile	53.7%
10th Percentile	35.4%



DENOMINATOR DEFINITION:
Click here to read about changes in methods between the 2001–05 and 2003–07 analyses. The study population includes beneficiaries with one of nine chronic conditions who were enrolled in traditional (fee-for-service) Medicare and died during the measurement period. To allow for two years of follow-back for all patients, the population is restricted to those whose age on the date of death was 67 to 99 years, and to those having full Part A and Part B entitlement throughout the last two years of life. Persons enrolled in managed care organizations were excluded from the analysis. For the hospital-specific analyses, patients had to be hospitalized for chronic illness at least once during their last two years of life to be included. For regional analyses, all patients diagnosed with a chronic illness were included.

NUMERATOR DEFINITION:
Number of beneficiaries with one or more claims in the Hospice file.

ADJUSTMENTS:
Rates are adjusted for age, sex, race, primary chronic condition, and the presence of more than one chronic condition using ordinary least squares regression.

The Dartmouth Atlas of Health Care is based at The Dartmouth Institute for Health Policy and Clinical Practice and is supported by a coalition of funders led by the Robert Wood Johnson Foundation, including the WellPoint Foundation, the United Health Foundation, the California HealthCare Foundation, and the Charles H. Hood Foundation.

NewYork-Presbyterian
Columbia University Medical Center

Palliative Care Information Act (PHL Section 2997)
February 9, 2011

Public Health Law section 2997-c requires the "attending health care practitioner" to offer to provide patients with a terminal illness with information and counseling regarding palliative care and end-of-life options appropriate to the patient, including:

- Prognosis
- Range of options appropriate to the patient
- Risks and benefits of various options
- Patient's "legal rights to comprehensive pain and symptom management at the end of life."

Palliative Care Access Act (PHL Section 2997-d)

April 1, 2011

- Requires that hospitals, nursing homes, home care agencies, special needs assisted living residences, and enhanced assisted living residences, provide access to information and counseling regarding options for palliative care appropriate to patients with advanced life limiting conditions and illnesses.
- These providers and residences must also facilitate access to appropriate palliative care consultation and services, including associated pain management consultation and services, consistent with the patient needs and preferences.

What is hospice?

- Health care benefit for terminally ill patients
- Focus is relief of distressing symptoms
- Goal is to improve quality of life
- Eligibility:
  - Terminal phase of illness (< 6 month prognosis)
  - No further disease modifying therapy
- Care can be provided anywhere
  - Home, long term care, hospice residence, inpatient

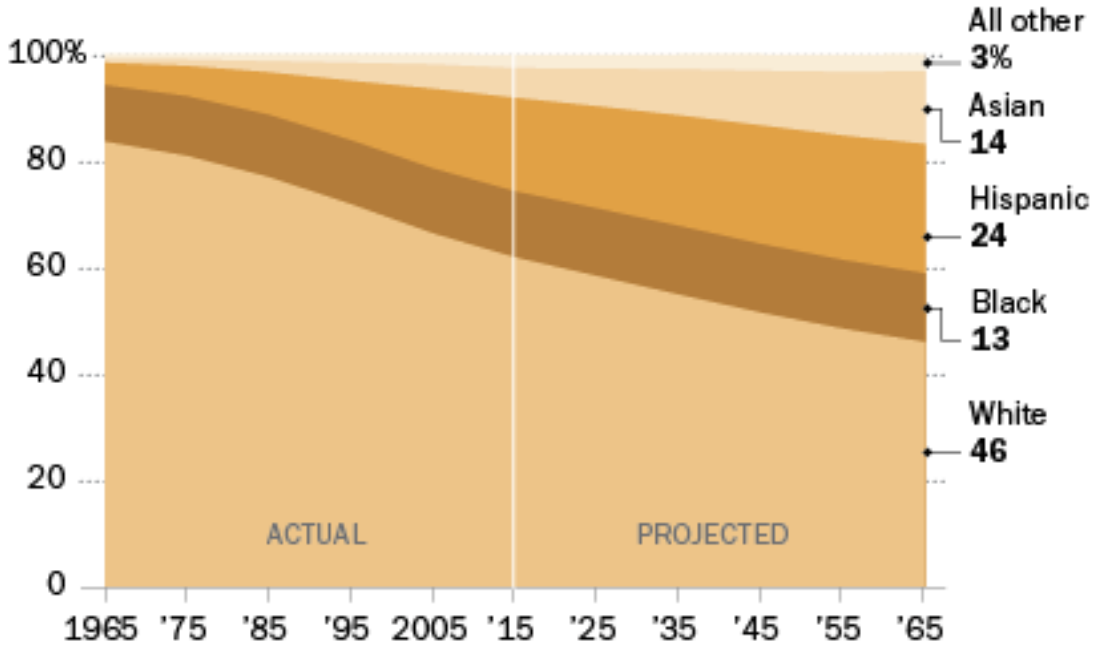
What is the Hospice Benefit?

- Under Medicare Part A
- Available under most health care plans
- Consists of an interdisciplinary team
  - Nurse visit (1x/week if stable)
  - 24/7 access to nurse/ doctor
  - Social worker
  - Chaplain
  - Home attendant (up to 20h/week)
  - Bereavement for 13 months
- Levels of care:
  - Home care
  - Inpatient (GIP)
  - Respite
  - Continuous care

Disparities in EOL Care

The changing face of America, 1965–2065

% of the total population



Note: Whites, blacks and Asians include only single-race non-Hispanics; Asians include Pacific Islanders. Hispanics can be of any race.
Source: Pew Research Center 2015 report, "Modern Immigration Wave Brings 59 Million to US, Driving Population Growth and Change Through 2065"

PEW RESEARCH CENTER

Current Hospice Utilization

- The National Hospice & Palliative Care Organization Facts and Figures October 2015 report…
- Although ethnic minorities constitute more than 25% of the U.S. population, they represent only 18% of patients enrolled in hospice

Table 4. Percentage of Hospice Patients by Ethnicity[1]

Patient Ethnicity	2014	2013
Non-Hispanic or Latino origin	92.9%	93.2%
Hispanic or Latino origin	7.1%	6.8%

Table 5. Percentage of Hospice Patients by Race[1]

Patient Race	2014	2013
White/Caucasian	76.0%	80.9%
Multiracial or Other Race	13.1%	7.5%
Black/African American	7.6%	8.4%
Asian, Hawaiian, Other Pacific Islander	3.1%	2.9%
American Indian or Alaskan Native	0.3%	0.3%

An Evidence Based Summary of the Ethnic and Racial Disparities in EOL Care

- African American and Hispanic individuals utilize advance-care planning and hospice far less than whites.
- Hospice was most used among Whites, followed by use among Hispanics, and least used by African and Asian Americans.
- African Americans perceived a greater need for hospice, yet more frequently had inadequate knowledge.
- African Americans preferred aggressive treatment, yet EOL care provided was often inconsistent with preferences.
- Hispanics and African Americans less often documented advance care plans, citing religious coping and spirituality as factors.

LoPresti MA, et al. End-of-Life Care for People With Cancer From Ethnic Minority Groups A Systematic Review. *Am J of Hospice and Palliative Med, 2016*

African Americans are less likely to utilize hospice

- In a retrospective analysis of more than one million Medicare enrollees, Virnig et. al. found that the **rate of hospice use was significantly lower for blacks than for non-black**s- *J Am Geriatric Society* 2000
- Even though blacks made up **13.2 % of the population** of the United States in 2014, and **have excessive mortality from almost all causes of death,** they accounted for **only 7.66 % of hospice admissions** for that year

Latino Disparities in ACP/ EOL Care

- Latinos are *more likely* than non Latinos to:
  - Have a burdensome, futile aggressive EOL (9.1% vs 4.1)
  - Die in the ICU (49% vs 36%)
- Latinos are *less likely* than non Latinos to engage in ACP:

  -Completion of Advance Directives (9% vs 67%)

  -Name a HCP (4% vs 59%)

  -Have end of life discussions (32% vs 85%)

Carr D. Racial differences in end-of-life planning: Why don't Blacks and Latinos prepare for the inevitable? OMEGA--Journal of Death and Dying. 2011;63(1):1-20.

Lackan NA, Eschbach K, Stimpson JP, Freeman JL, Goodwin JS. Ethnic differences in in-hospital place of death among older adults in California: effects of individual and contextual characteristics and medical resource supply. Medical care. 2009;47(2):138-145.

Asian American & Pacific Islanders (AAPI)

J Am Geriatr Soc. 2008 Jan;56(1):139-44. Epub 2007 Nov 27.

Ethnic disparities in hospice use among Asian-American and Pacific Islander patients dying with cancer.

Ngo-Metzger Q[1], Phillips RS, McCarthy EP.

- Fewer than 2% of hospice patients are AAPIs, although they represent approximately 5% of the U.S. population
- **All AAPI subgroups studied had lower rates of hospice use**
  - Chinese Japanese Filipino, Hawaiian/Pacific Islanders and other Asians less than white patients
  - Overall, approximately 20% of patients enrolled **within 7 days of death**, and only **6%** had hospice stays that were **longer than 2 months**,

Native American are less likely to be enrolled in Hospice

Ethn Dis. 2014 Autumn;24(4):393-8.

Disparities in hospice utilization among American Indian Medicare beneficiaries dying of cancer.

Guadagnolo BA, Huo J, Buchholz TA, Petereit DG.

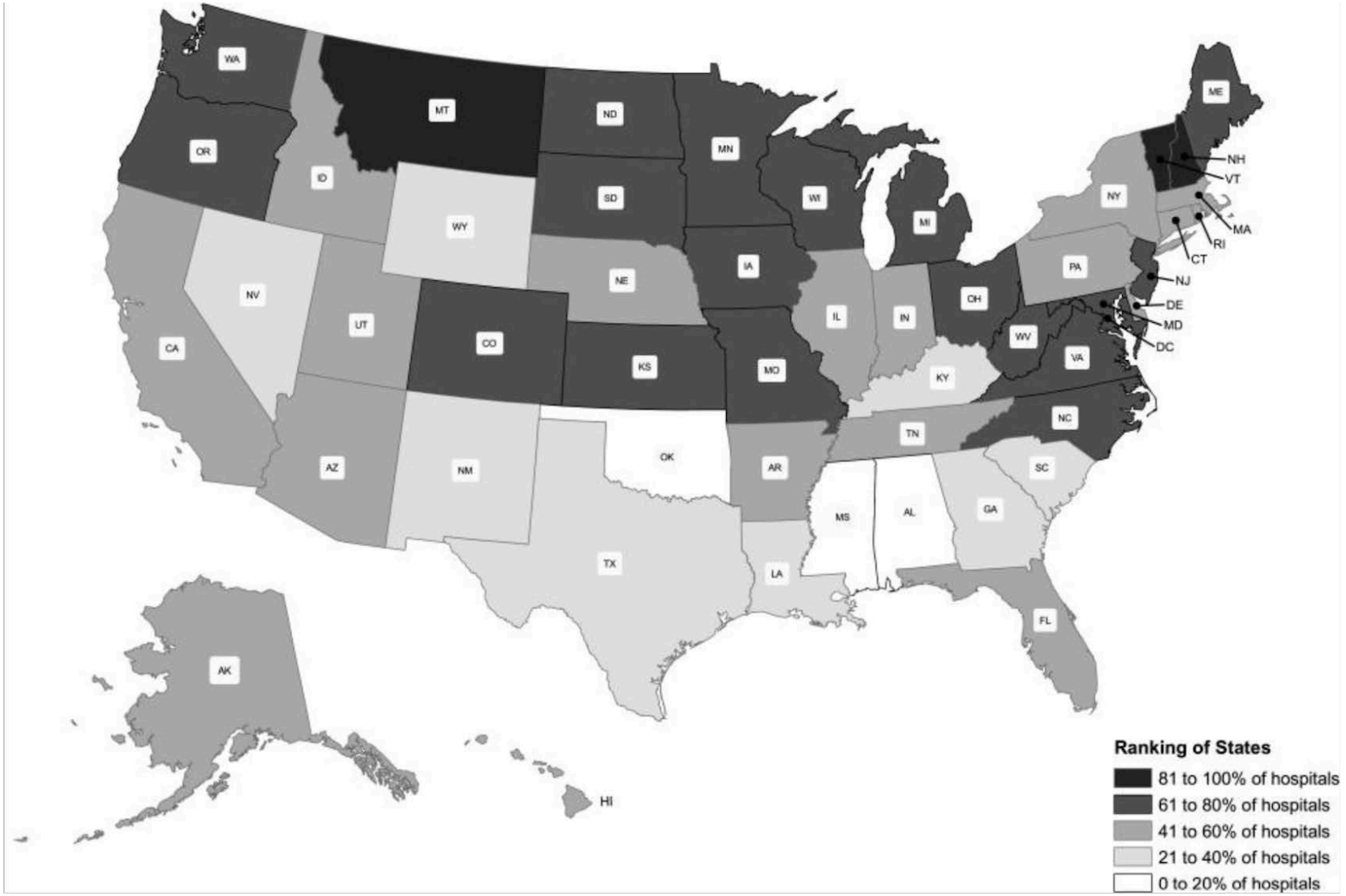
- ↓American Indians enrolled in hospice compared to White patients (54% vs 65%, respectively).
- Proportion of American Indian patients using hospice care remained unchanged throughout the years of study.

Geographical Disparities

Cross-sectional study of geographic access to U.S. hospices using the 2008 Medicare Provider of Services data found that:

- Hospice utilization is higher in urban areas and lower in rural areas
- 11-fold increase in hospice use in metropolitan vs. rural areas

Geographic disparity in distribution of hospital palliative care programs in the U.S.



Barriers to Hospice Utilization

A Summary of the Barriers to Hospice

- cultural or religious beliefs
- preferences for end-of-life care
- socioeconomic factors
- disparities in access to care or information about hospice
- mistrust of the medical system

J Palliat Med. 2004 Apr;7(2):247-56.

Knowledge, attitudes, and beliefs about end-of-life care among inner-city African Americans and Latinos.

Born W[1], Greiner KA, Sylvia E, Butler J, Ahluwalia JS.

Barnato et al. 2009, Cohen 2008, Crawley et al. 2000

Specific Barriers to Using Hospice Among Latinos

- Knowledge of hospice care / Health Literacy
- Language barriers
  - “Hospicio” – a charitable establishment where abandoned, orphaned, or poor children are raised; designed to shelter the poor and pilgrims
- Lack of insurance
- Greater desire for life-sustaining treatments (also associated with higher religiosity)
- Difference in Cultural Norms/Decision Making
  - Latino culture values a collective decision-making that emphasizes family participation in EoL care
- Concerns about revealing immigration status
- Distrust of medical system

Do minorities prefer for more aggressive care?

Am J Hosp Palliat Care. 2015 Mar;32(2):233-7. doi: 10.1177/1049909113511144. Epub 2013 Nov 7.

Racial disparities in receipt of hospice services among nursing home residents.

Frahm KA[1], Brown LM[2], Hyer K[2].

- Black, Hispanic, and Asian residents who received hospice services were significantly less likely overall to have documented advance directives.
- All racial groups were also more likely to experience hospitalization while on hospice, regardless of whether they had a documented “do not hospitalize” order.
- **Shen et al. Cancer 2016**- Compared with non-Latino, white patients with advanced cancer, Latino patients with advanced cancer are less likely to sign do-not-resuscitate (DNR) orders.
  - **Latino patients who had an EOL discussion were >10 times more likely to complete a DNR order than those who had not, and were found to be equally as likely to complete a DNR order as white patients.**

Socioeconomic factors may be mitigated by increased awareness of hospice care

- Series of studies by Virnig et al.,
  - Greater hospice use among managed care enrollees vs. Fee For Service **and** Medicare, married, younger, of non-black race, those living in areas with greater population density, and those with **higher income** and **greater educational attainment**.
- Lackan et. al.
  - Medicare database: hospice utilization in 51,345 subjects 67 and older diagnosed with breast, colorectal, lung, or prostate cancer from 1991-1996 and who died 1991-1999.
  - "The **decreased variation** in the use of hospice care **over time** by other patient characteristics such as type of insurance, marital status, urban versus rural residence, and income can be attributed to **increased availability and awareness of hospice care"**

Impact and Role of Palliative Care

Are there benefits to having end of life discussions?

Wright A, et al. *JAMA* 300(14):2008

Are there benefits to having end of life discussions?

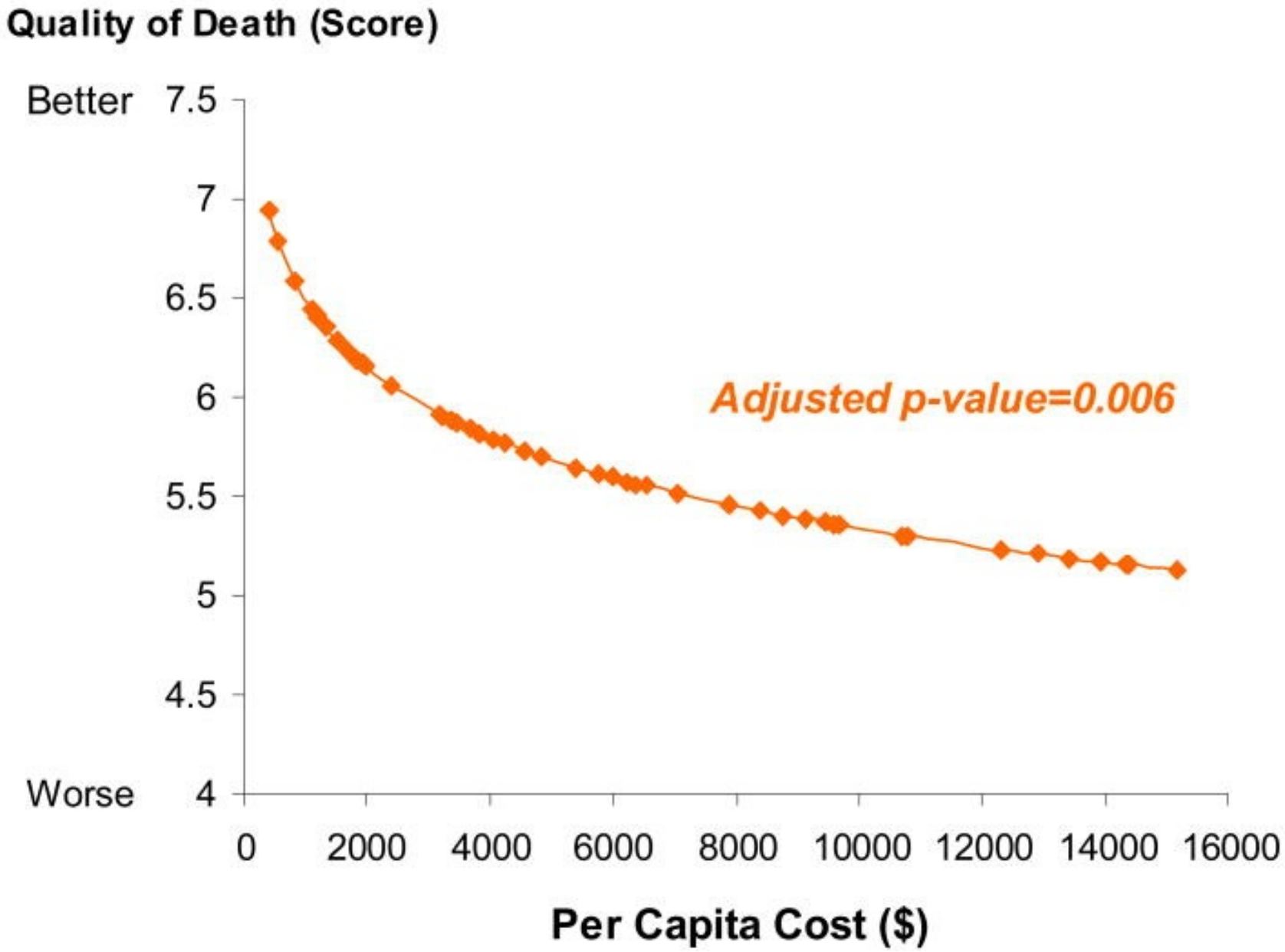
- Fewer aggressive, life-extending interventions (e.g., mechanical ventilation and resuscitation)
- End of life care that is consistent with the patient's preferences
- Fewer deaths in the intensive care unit
- Earlier referral to a hospice

Wright AA, Zhang B, et al. *JAMA* 2008;300(14):1665-73
Mack JW, Weeks JC, et al. *J Clin Oncol* 2010;28:1203-8.

Advanced cancer patients who reported EOL conversations with physicians had significantly lower health care costs in their final week of life.

Higher costs were associated with worse quality of death.

Zhang B, et al *Arch Int Med* 2009 Mar 9;169(5):480-8.



Zhang B, et al *Arch Int Med* 2009 Mar 9;169(5):480-8.

Effect of Palliative Care on Hospital Costs

ORIGINAL INVESTIGATION

Cost Savings Associated With US Hospital Palliative Care Consultation Programs

R. Sean Morrison, MD; Joan D. Penrod, PhD; J. Brian Cassel, PhD; Melissa Caust-Ellenbogen, MS; Ann Litke, MFA; Lynn Spragens, MBA; Diane E. Meier, MD; for the Palliative Care Leadership Centers' Outcomes Group

Background: Hospital palliative care consultation teams have been shown to improve care for adults with serious illness. This study examined the effect of palliative care teams on hospital costs.

Methods: We analyzed administrative data from 8 hospitals with established palliative care programs for the years 2002 through 2004. Patients receiving palliative care were matched by propensity score to patients receiving usual care. Generalized linear models were estimated for costs per admission and per hospital day.

Results: Of the 2966 palliative care patients who were discharged alive, 2630 palliative care patients (89%) were matched to 18 427 usual care patients, and of the 2388 palliative care patients who died, 2278 (95%) were matched to 2124 usual care patients. The palliative care patients who were discharged alive had an adjusted net savings o
and $279 nificant reductions in laboratory and intensive care unit costs compared with usual care patients. The palliative care patients who died had an adjusted net savings of $4908 in direct costs per admission ($P=.003$) and $374 in direct costs per day ($P<.001$) including significant reductions in pharmacy, laboratory, and intensive care unit costs compared with usual care patients. Two confirmatory analyses were performed. Including mean costs per day before palliative care and before a comparable reference day for usual care patients in the propensity score models resulted in similar results. Estimating costs for palliative care patients assuming that they did not receive palliative care resulted in projected costs that were not significantly different from usual care costs.

Conclusion: Hospital palliative care consultation teams are associated with significant hospital cost savings.

THE CARE SPAN

By R. Sean Morrison, Jessica Dietrich, Susan Ladwig, Timothy Quill, Joseph Sacco, John Tangeman, and Diane E. Meier

DOI: 10.1377/hlthaff.2010.0929
HEALTH AFFAIRS 30,
NO. 3 (2011): 454–463

THE CARE SPAN

Palliative Care Consultation Teams Cut Hospital Costs For Medicaid Beneficiaries

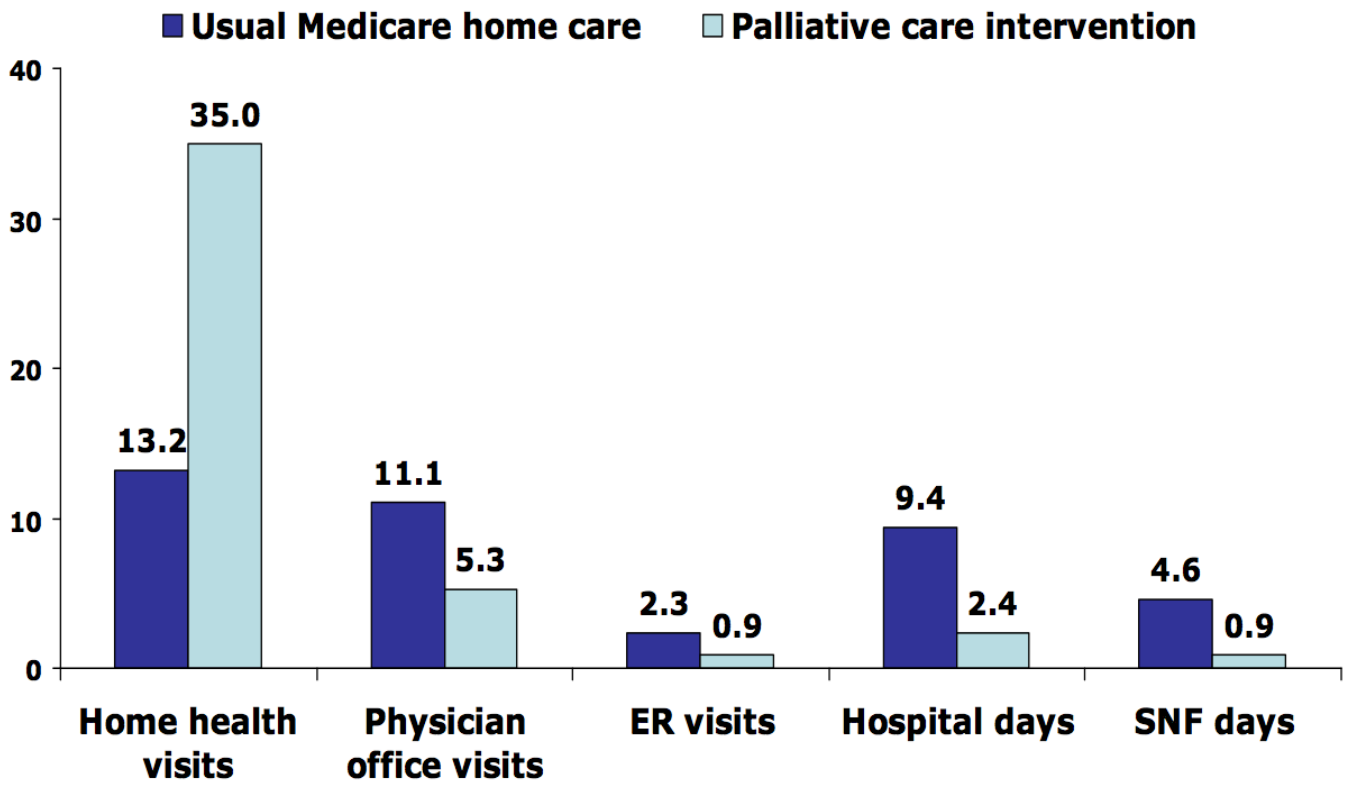
HealthAffairs

At the Intersection of Health, Health Care and Policy

Palliative Care at Home for the Chronically Ill
Improves Quality, Markedly Reduces Cost

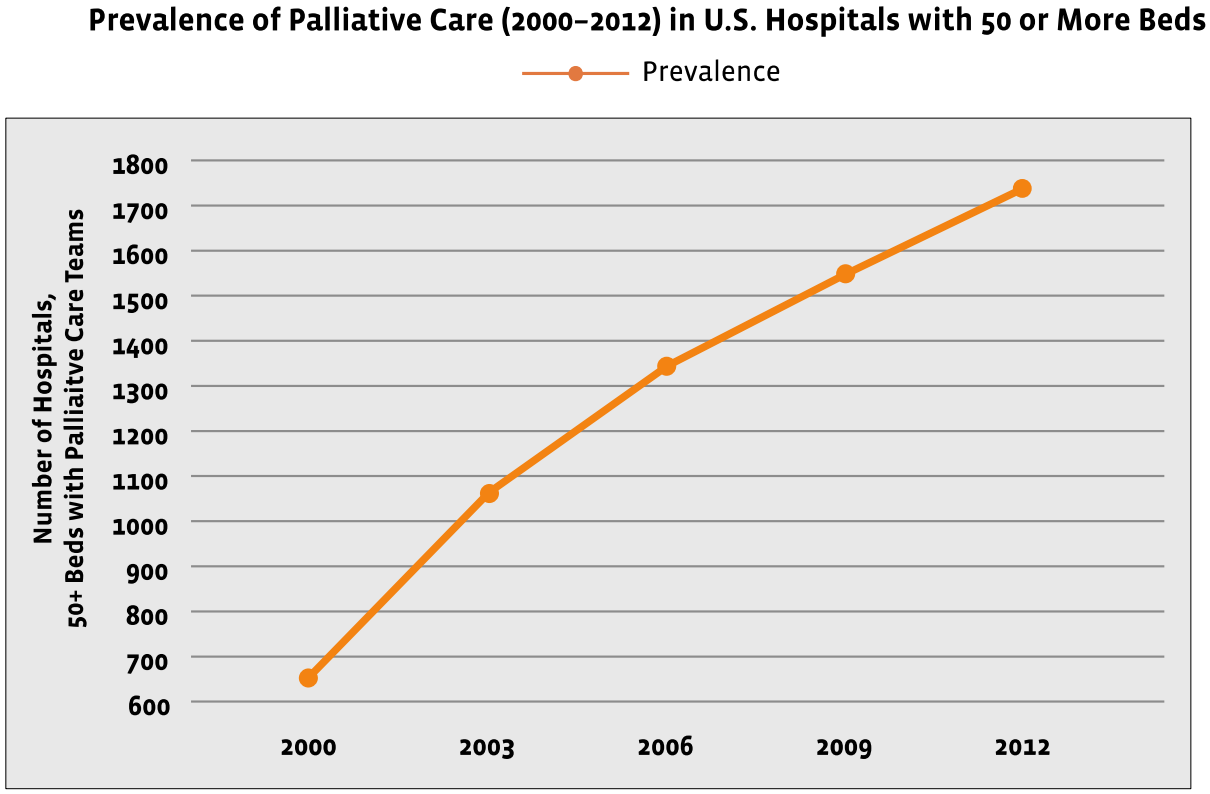
RCT of Service Use Among Heart Failure, Chronic Obstructive Pulmonary Disease, or Cancer Patients While Enrolled in a Home Palliative Care Intervention or Receiving Usual Home Care, 1999–2000

KP Study Brumley, R.D. et al. JAGS 2007



ACCESS TO PALLIATIVE CARE IN THE U.S.

Palliative care prevalence in U.S. hospitals has increased 164% over the past 12 years, to 61% of hospitals with 50 or more beds. In 2000, less than one-quarter of these hospitals (658) had a palliative care program, compared with more than two-thirds (1,734) in 2012. If current trends continue, by 2015, eight in ten U.S. hospitals with 50 or more beds will have a palliative care program.



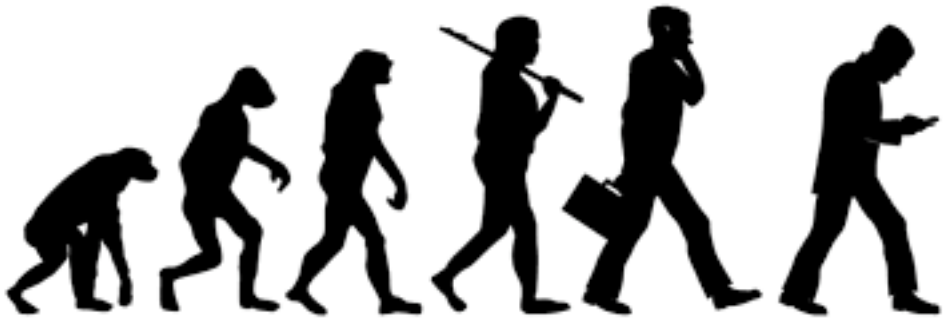
Source: Center to Advance Palliative Care, July 2014

History of Palliative Care at NYP/CUMC

Where did we come from?

History of Palliative Care at NYP/CUMC

Where did we come from?



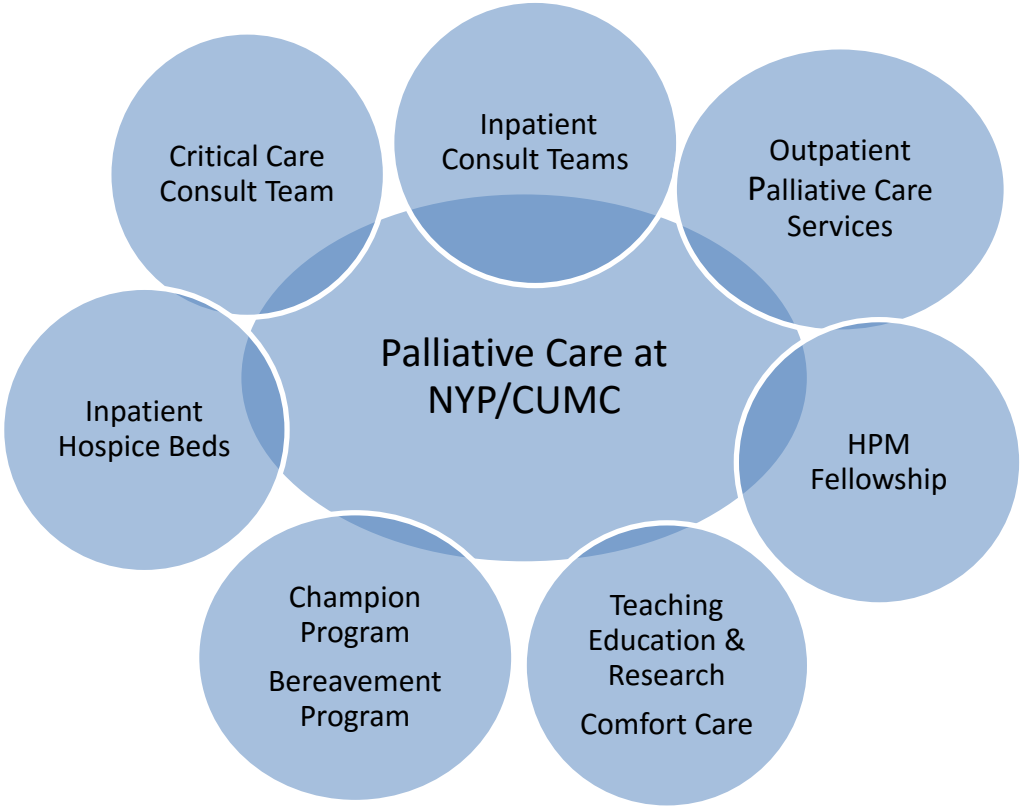
History of Palliative Care at CUMC/NYP

- **2006-2010**
  - Inpatient Palliative Care services launched
  - Multidisciplinary model of NP/SW
  - MD coverage provided part-time by Dr. Weinberger (Anesthesia)
- **2010-2012**
  - Expansion of consult service with MD leadership
  - Development of HPM Fellowship
- **2013 Expansion in Department of Medicine**
  - Addition of ICU dedicated consult team and outpatient team
  - Outpatient program started

NYP/CUMC Palliative Care Update

Where are we now?

Scope of Palliative Care Services, Interventions, and Projects at NYP/CUMC

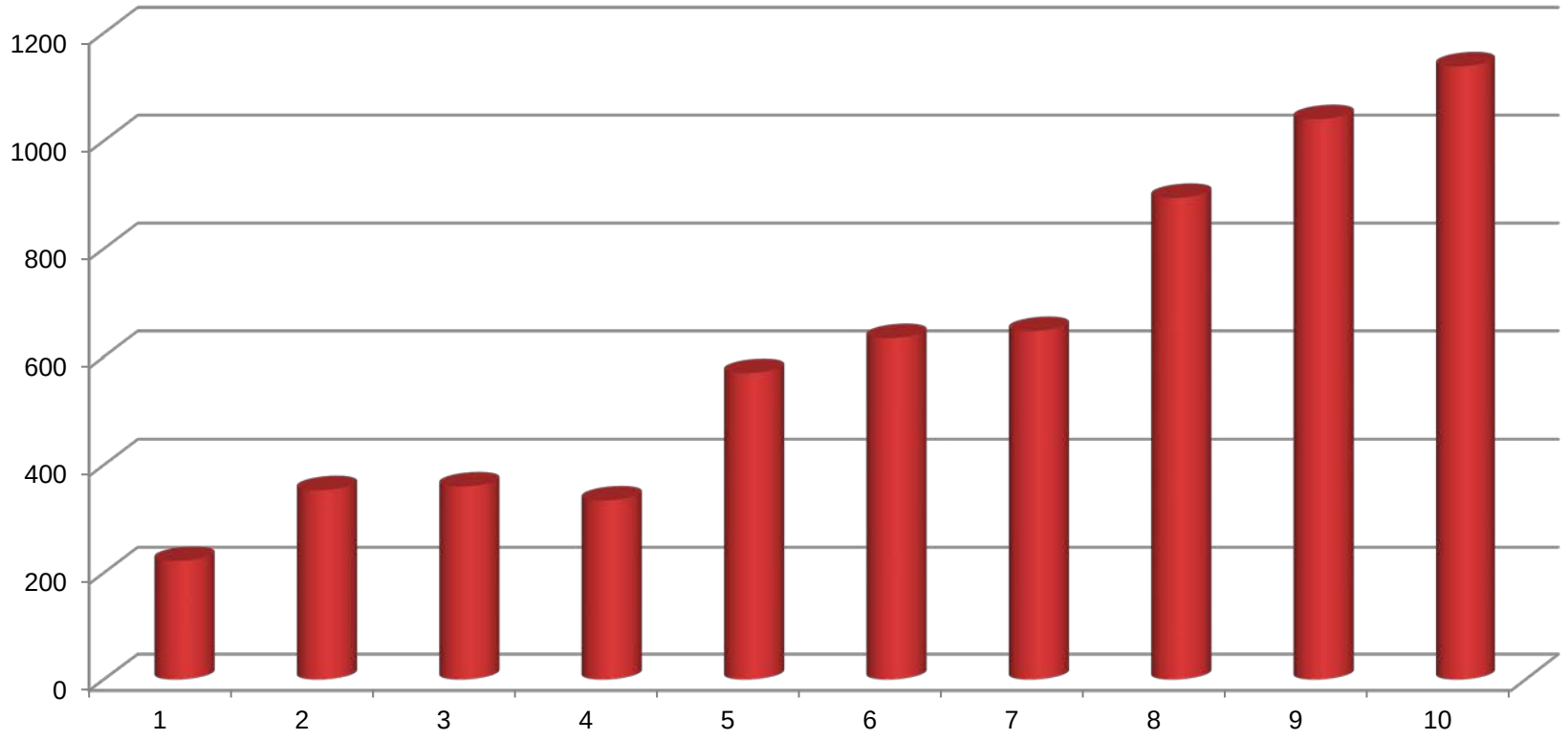


Palliative Care Clinical Program at NYP/CUMC

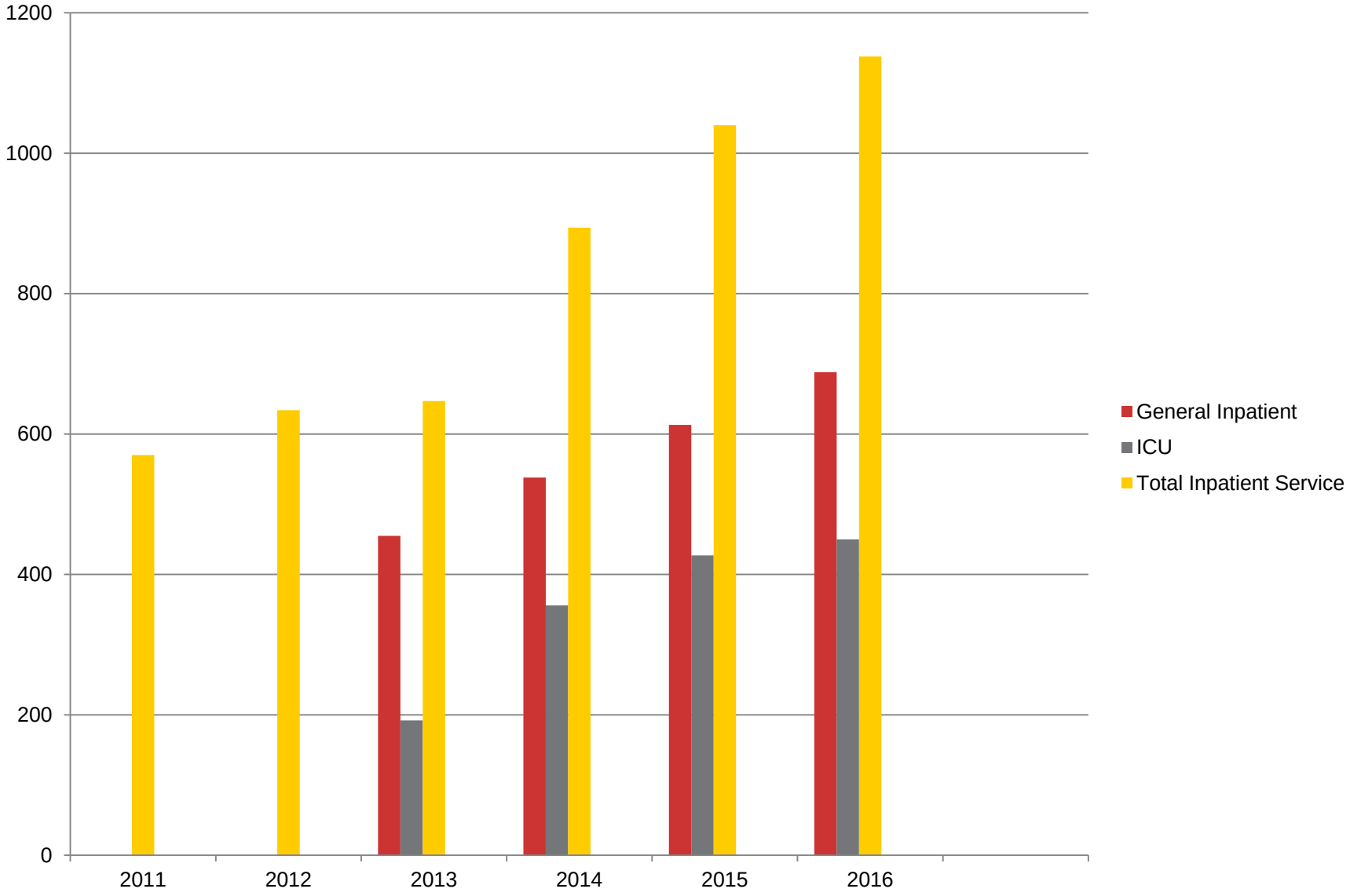
- General inpatient and Critical Care Consult Service
- Piloting Early Intervention Palliative Care
- Outpatient—Cancer Center and ACN
- Services provided:
  - ❖ Pain and Symptom Management
  - ❖ Facilitating Goals of Care Discussions
  - ❖ Patient & Family Support
  - ❖ Coordination of Care
  - ❖ Staff Education and Support

2006 – 2016 : The 10 year retrospective & growth

Number of patient discharges seen by palliative care



Growth of Palliative Care Inpatient Services at NYP/CUMC



Summary of our success to date

- Culture change with growing acceptance and recognized need for palliative care
  - No longer just for “end of life care,” but increasingly recognized as beneficial for patients with advanced illnesses
- Consulted earlier in course of patient’s illness and hospitalization
- 2016: achieved national benchmark of 5% hospital penetration
- Significant and Steady Growth of Program:
  - 2013 to 2016: almost DOUBLE rate of growth with 1200 inpatients projected in 2016
  - ICU volumes higher than initial projections
  - Development and Growth of Outpatient Services (over 400 patients on our active census)
- Inpatient hospice program established

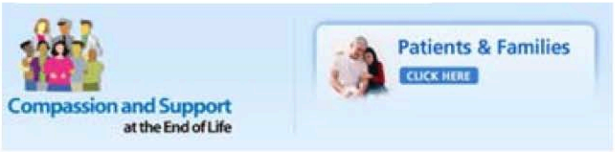
The Future

Hospital and Payers Need to Partner with Hospice

How Do We Build a Better Hospice / Hospital-Based Palliative Care Partnership?

- Identify champion clinicians acceptable to both sides
- Identify common goals and challenges
- Share clinical tools/checklists
- Regular intra-organizational educational and partnership opportunities
- Identify and adopt QI measures to enhance quality of care
  - E.g. hospice patients going to the ED / Identifying patients eligible for hospice in the ED

Payers linking up with palliative and hospice / end of life care programs to improve quality and decrease costs



Public Service Announcements on End-of-Life Care Earn Bronze Telly

CMS.gov

Medicare Care Choices Model

- According to Medicare claims data, only 44% of Medicare patients use the hospice benefit at the end of life, and most only for a short period of time.

- This model enables beneficiaries to receive palliative care services that are provided by the Medicare Care Choices Model participating hospices *concurrently* with services from their curative provider.

Institute of Medicine Recommendations

Improving Care at the End of Life

Care Delivery

- Multiple transitions between health care settings can fragment delivery of care and create burdens for patients and families
- Demand for family caregiving and the responsibilities of family caregivers are increasing
- Palliative care enhances quality of life, reflects patient choices, and supports families
- Widespread timely referral to palliative care appears slow

Recommendation

Government health insurers and care delivery programs, as well as private health insurers, should cover the provision of comprehensive care for individuals with advanced serious illness who are nearing the end of life.

Clinician-Patient Communication

- Most people nearing the end of life are not physically, mentally, or cognitively able to make their own decisions about care.
- Of people who indicate their EOL care preferences, most choose care focused on alleviating pain and suffering.
- Frequent clinician-patient conversations about EOL care values, goals, and preferences are necessary to avoid unwanted treatment.
- Incentives, quality standards, and system support are needed to promote improved communication skills and more frequent conversations.

Recommendation

Professional societies and other organizations that establish quality standards should develop standards for clinician–patient communication and advance care planning that are measurable, actionable, and evidence based.

These standards should change as needed to reflect the evolving population and health system needs and be consistent with emerging evidence, methods, and technologies.

Payers and health care delivery organizations should adopt these standards and their supporting processes, and integrate them into assessments, care plans, and the reporting of health care quality.

Professional Education

- The establishment of specialty practice in hospice and palliative medicine is a major improvement in the education of health professionals.
- Three problems remain:
  - Insufficient attention to palliative care in medical and nursing school curricula
  - Educational siloes the impede development of interprofessional teams
  - Deficits in equipping providers with sufficient communication skills
- Health professionals are not always adequately prepared to deliver “basic” or “primary” palliative care

Recommendation

Educational institutions, credentialing bodies, accrediting boards, state regulatory agencies, and health care delivery organizations should establish the appropriate training, certification, and/or licensure requirements to strengthen the palliative care knowledge and skills of all clinicians who care for individuals with advanced serious illness who are nearing the end of life.

Policies and Payment Systems

- Incentives under fee-for-service Medicare result in more use of services, more transitions among care settings, and late enrollment in hospice.
- Programs that integrate health care and long-term social services may reduce hospitalizations and health care costs while improving patients' quality of life.
- Changes are needed throughout the health care system to incentivize provision of comprehensive palliative care.
- Quality standards and measures are needed to ensure that changes in payment systems, particularly those under ACA, do not adversely affect EOL care quality.

Recommendation

Federal, state, and private insurance and health care delivery pro-grams should integrate the financing of medical and social services to support the provision of quality care consistent with the values, goals, and informed preferences of people with advanced serious illness nearing the end of life.

To the extent that additional legislation is necessary to implement this recommendation, the administration should seek and Congress should enact such legislation. In addition, the federal government should require public reporting on quality measures, outcomes, and costs regarding care near the end of life (e.g., in the last year of life) for programs it funds or administers (e.g., Medicare, Medicaid, the Department of Veterans Affairs). The federal government should encourage all other payment and health care delivery systems to do the same.

Public Education and Engagement

- Need for public education and engagement is manifest at the societal, community/family, and individual levels.
- Most Americans lack knowledge about EOL care choices, and the health community and other leaders have not fully utilized strategies to make that knowledge available, meaningful, and relevant across diverse groups.
- Efforts are needed to normalize conversations about death and dying.
- Several social trends suggest that the time is right for a national dialogue on this issue.

Recommendation

Civic leaders, public health and other governmental agencies, community-based organizations, faith-based organizations, consumer groups, health care delivery organizations, payers, employers, and professional societies should engage their constituents and provide fact-based information about care of people with advanced serious illness to encourage advance care planning and informed choice based on the needs and values of individuals.

Questions?


AMAZING
THINGS
ARE
APPENING
HERE