



Research Collaborations: Building Bridges and Effecting Change

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Plan for the Hour



- The State of Healthcare for the Seriously Ill in the United States
- Strategies to Effect Change
- A Model of Research Collaboration: The Center To Advance Palliative Care & The National Palliative Care Research Center
- Discussion



"I'd have been here sooner if it hadn't been for early detection."



U.S. Life Expectancy in 2009



- Median age of death is 78 years.
- Among survivors to age 65, median age at death is 82 years.
- Among survivors to age 80, median age at death is 88 years
- The number of people over age 85 will double to 9 million by the year 2030 (CDC)





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*"I would embrace the aging process
if I could lift my arms."*

- Vascular Dementia
- Type II DM
- Oxygen dependent COPD
- CHF
- OA
- Dependent in ADLs
- 4 hospitalizations in past year
- 1 of 8 million Americans now
- 1 of 14 million Americans in 2030





Symptom Burden of Patients Hospitalized With Serious Illness at 5 U.S. Academic Medical Centers



Patients With Mod-Severe Pain Between Hospital Days 8-12

Colon cancer	60%
Liver failure	60%
Lung cancer	57%
End-organ failure + cancer	53%
End-organ failure + sepsis	52%
COPD	44%
CHF	43%

Source: Desbiens & Wu. JAGS



Impact of Serious Illness on Patients' Families



Needed large amount of family caregiving	34%
Lost most family savings	31%
Lost major source of income	29%
Major life change for family member	20%
Other family illness from stress	12%
At least one of the above	55%

Source: SUPPORT, JAMA, 1994



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 the dying process: 50%

Not enough emotional support (family): 38%

Not enough help with symptoms: 19%

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

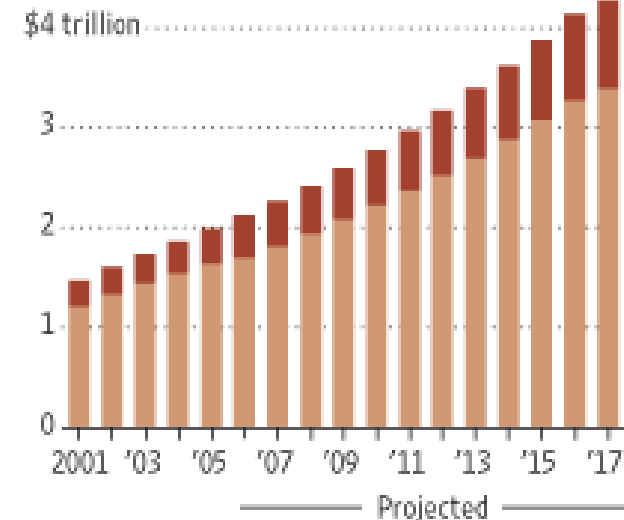
The Financial Landscape of U.S. Healthcare

- \$2.2 trillion dollars spent in 2007 on healthcare
- 16.3% of the GDP
- Projected growth of 6.7% year
- Medicare spending expected to increase from \$426 in 2007 to \$844 billion in 2017
- 5% of sickest Medicare enrollees account for over 50% of expenditures

Footing the Bill

The cost of insuring aging baby boomers will help push up national health expenditures in the next decade

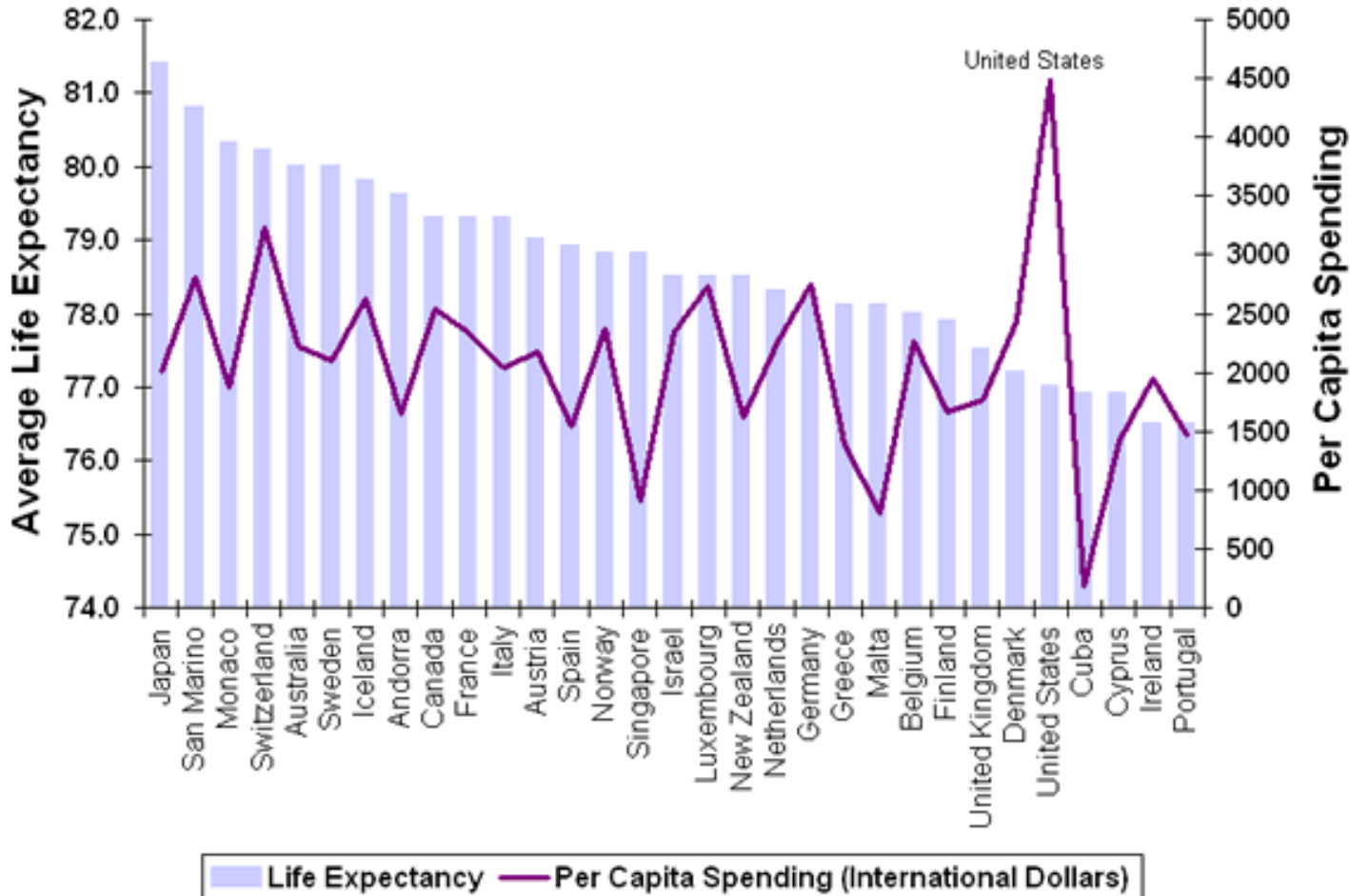
Total health-care spending [— Medicare]



Source: Centers for Medicare & Medicaid Services

Source: WSJ, 2/26/2008

Healthcare Spending & Longevity: January 2008





"It is thornlike in appearance, but I need to order a battery of tests."



Healthcare in the United States



“The American health care delivery system is in need of fundamental change....Health care today harms too frequently and routinely fails to deliver its potential benefits... Quality problems are everywhere, affecting many patients. Between the health care we have and the care we could have lies not just a gap, but a chasm.”

Institute of Medicine: Crossing the Quality Chasm: A New Health System for the 21st Century.

“We have reached a point in this country where the rising cost of health care has put too many families and businesses on a collision course with financial ruin and left too many without coverage at all”

President Barack Obama



Care For the Seriously Ill at the Turn of the Century (2000)



- Unprecedented gains in life expectancy: exponential rise in number and needs of frail elderly and their caregivers
- Cause of death shifted from acute sudden illness to chronic episodic disease
- Untreated physical symptoms
- Unmet patient/family needs
- Disparities in access to care
- Inadequately trained health care professionals
- An unresponsive health care system facing enormous and increasing expenditures



The Medicare Hospice Benefit



- Enacted in 1982
- Provides palliative care coverage to Medicare beneficiaries who:
 - Relinquish Medicare Part A (coverage for hospitalizations and acute care)
 - Have <6 months to live as certified by a physician and willing to relinquish curative treatments
- Covered by most third party insurances and most State Medicaid plans
- Median length of stay on hospice <3 weeks, less than 40% of all deaths



The Medicare Hospice Benefit



**Life
Prolonging/Curative
Care**

**End of
Life Care
(Hospice)**

D

E

A

T

H

Disease Progression



Language Matters



I don't want to achieve immortality through my work. I'd rather achieve it by not dying.

Woody Allen



Language Matters

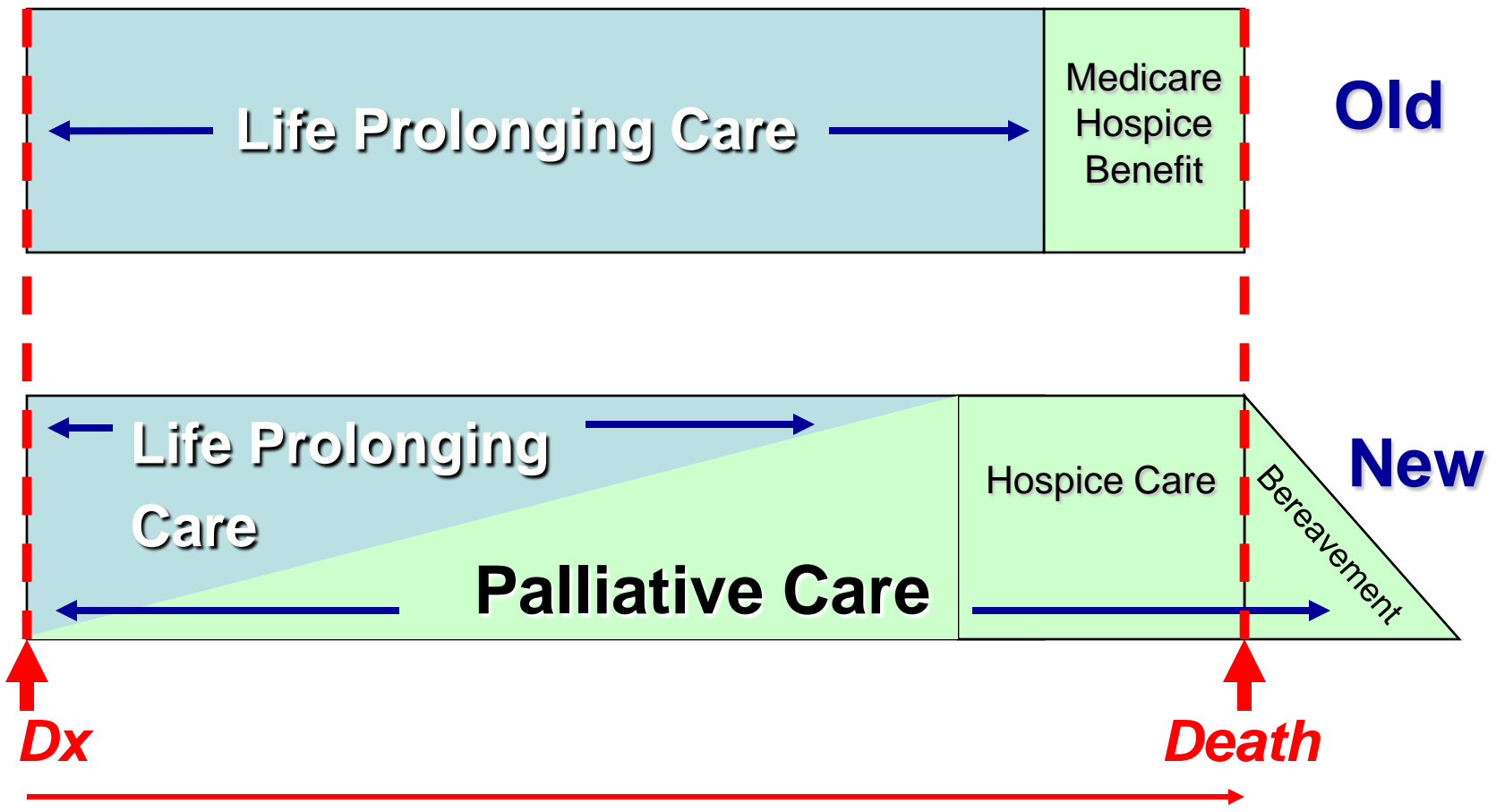


If our goal is to provide a patient-centred approach to improving care of seriously ill...the major barrier we face is self-imposed.

Many people who need palliative care are not dying. Even among the subset that are, no-one wants to die, and very few, including clinicians, are able to accept that they are dying until death is imminent.

Solution- decouple palliative care from end of life care or care of the dying

Modern US Palliative Care



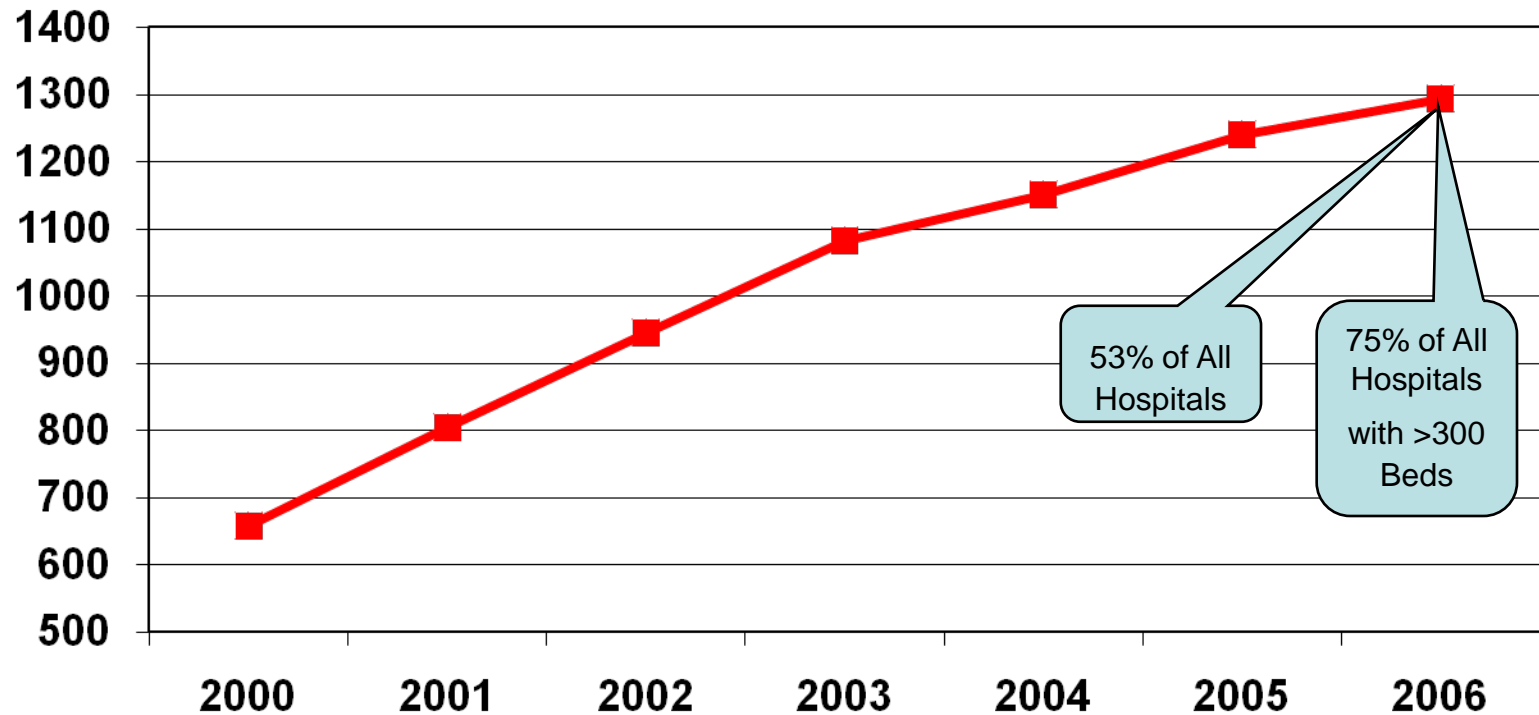


Where is Palliative Care in the US in 2009?



- Hospital palliative care programs: 1314 (53% of hospitals)
- ABHPM certified MDs: 2,678
- HPNA certified nurses: 15,133 (10,000 RNs)
- ABMS-approved subspecialty of 10 parent Boards, 1st board exam Oct. 2008
- National Quality Forum- 2008: chooses palliative care as 1 of 7 actionable top priorities for rapid improvement in US hospitals
- Joint Commission Certificate Program launch forthcoming

Palliative Care is Becoming the Norm in US Hospitals





How Did We Get Here?



All this progress did not occur by accident

It is the result of the collaborative efforts of health professionals (clinicians and researchers), private sector philanthropy, and organized medicine



Creating Social Change...Moving Palliative Care Beyond Hospice

The Center to Advance Palliative Care
(www.capc.org)

&

The National Palliative Care Research Center
(www.nprc.org)



CAPC



- Established in 1999 as a Robert Wood Johnson National Program Office at the Mount Sinai School of Medicine, New York
- Now supported by a consortium of 10 philanthropic foundations
- Director: Diane E. Meier
- Audience: Hospitals and health systems, clinicians, policy makers



NPCRC



- Established in 2005 by the Kornfeld Foundation at the Mount Sinai School of Medicine, New York
- Now supported by a consortium of 9 philanthropic foundations
- Director: R. Sean Morrison, MD
- Audience: Academic institutions, researchers, policy makers



Collaborative Vision and Mission



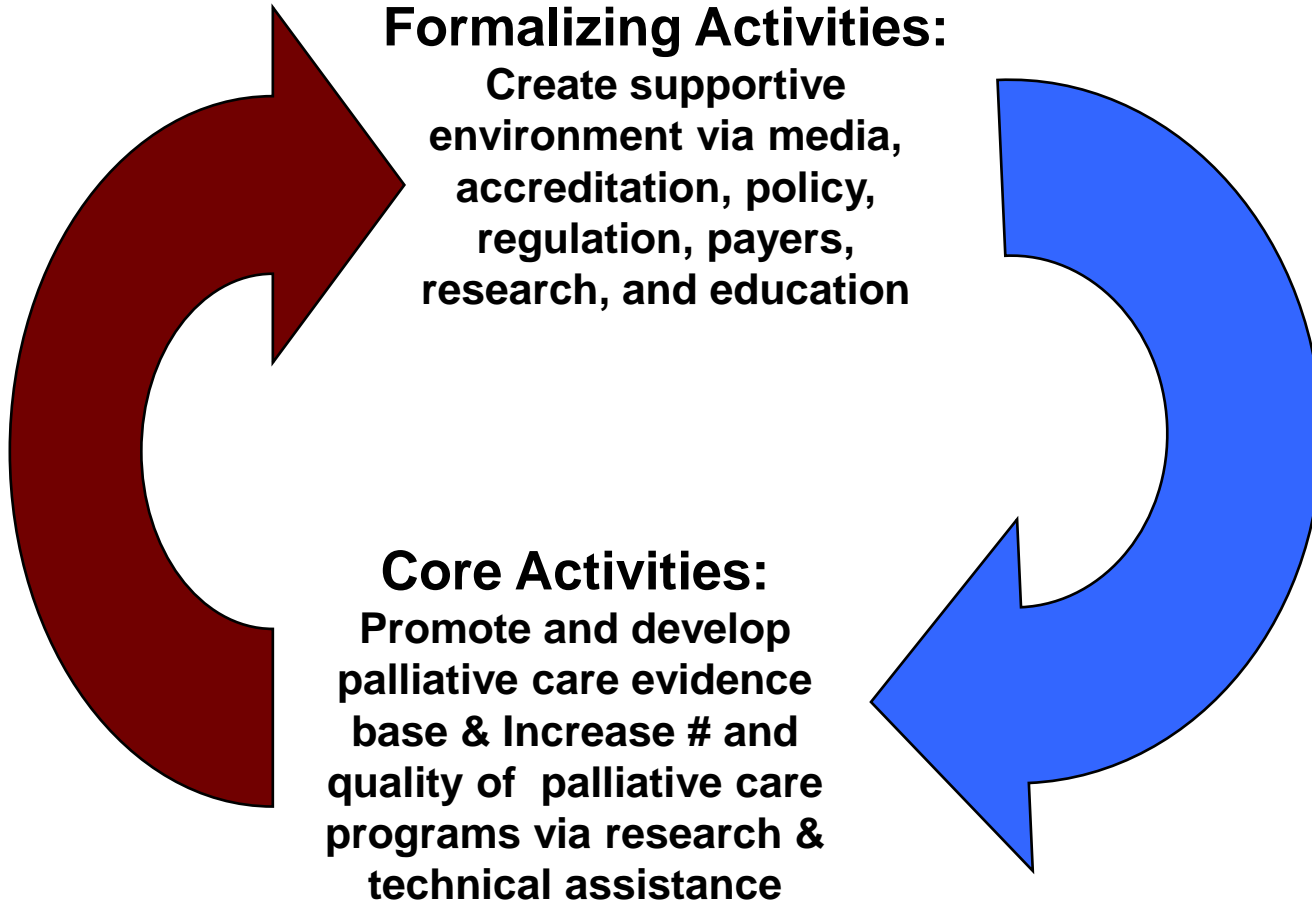
Vision:

- All patients with advanced illness and their families will have access to quality palliative care throughout the disease course and across care settings

Mission:

- To ensure that patients and families know to request palliative care
- To ensure that medical professionals have the knowledge and skills to provide palliative care
- To ensure that hospitals and other healthcare institutions are equipped to deliver and support quality palliative care services

Strategies: Top-Down, Bottom Up





The Top Down Strategy: Formalization via Alignment



- Creating a supportive environment by embedding palliative care in the health care system through alignment with major health care organizations, health policy efforts, educational standards, payment mechanisms, research funding, and accrediting bodies.
- Policy: payment, regulation, accreditation, loan forgiveness, education, research
- Public education: driving the demand side
- Research: academic legitimacy
- Quality: measure and improve it, get paid for providing it
- Access: every hospital
- Efficiency, effectiveness: Better care costs less



Collaborative Tactics



Social change theory and the diffusion of innovation

Tools and technical assistance: web, print, meetings, mentoring, research

Social marketing: audience specific messaging and materials.

"Reason you became a doctor/nurse/researcher" for professionals

"Business + quality case" for administrators, policy makers

"Service message" for colleagues

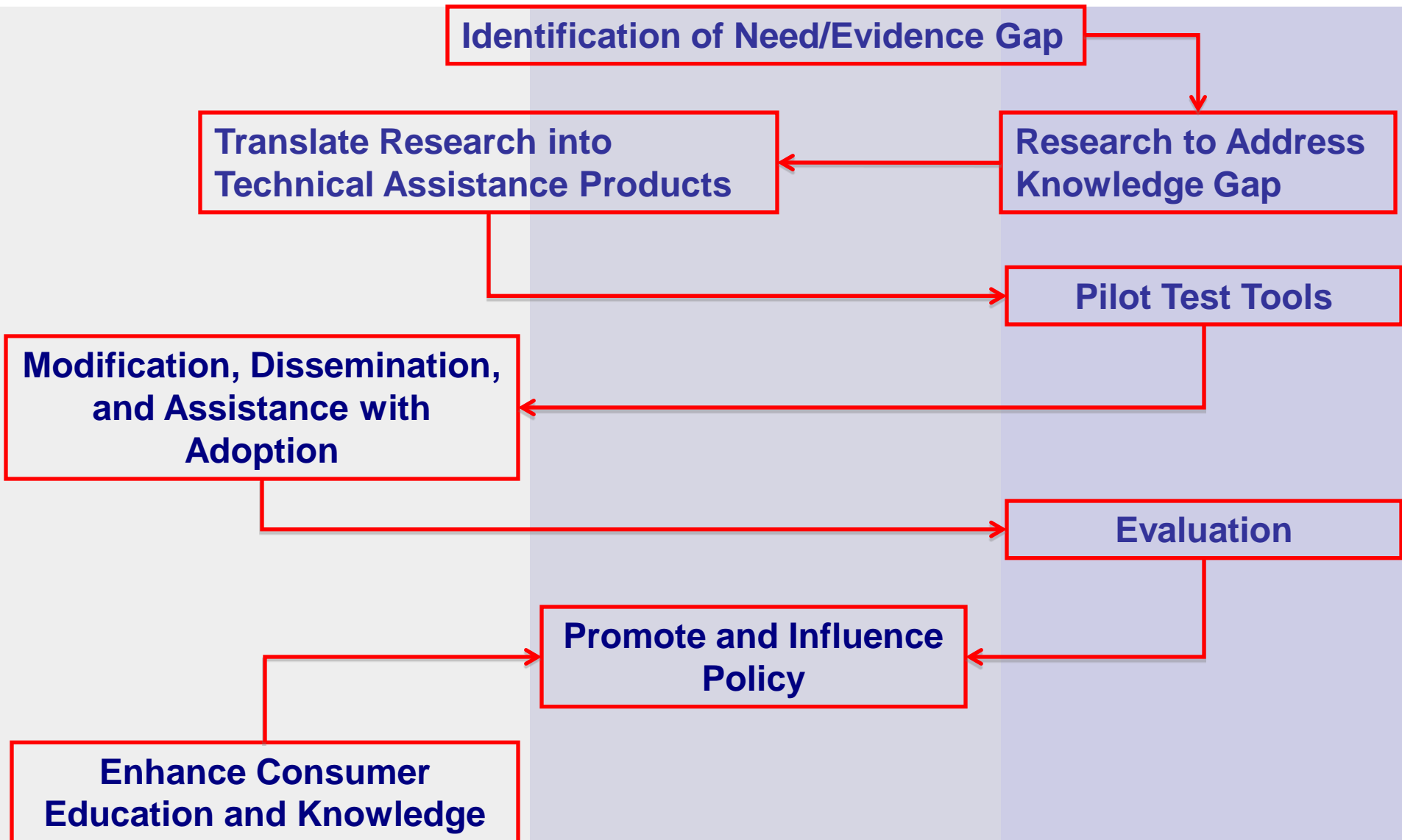
"Best quality care added to appropriate treatment" patients and families

Business case: improves capacity, throughput, efficiency

Outcomes driven: tracking and measurement to assure achievement of the mission

Evidence based: developing and incorporating new science

Organizational partnerships and collaboration





Research Development: NPCRC



- Well documented need for increased palliative care evidence base and palliative care research
 - Reports from Institute of Medicine (4), American Academy of Hospice and Palliative Medicine research task force, NIH State of the Science Conference (2)
- Barriers:
 - Lack of research funding
 - Federal budget cuts combined with withdrawal of major foundation support for palliative care resulted in a withdrawal rather than an increase in support for palliative care research.
 - Lack of Investigators (junior, mid-career, senior)
 - 5 major palliative care research centers in the United States
 - Lack of Mentors for new investigators
 - Absence of a palliative care research community



NPCRC History



- Center developed in response to the:
 - Shortage of palliative care funding structures;
 - Shortage of palliative care investigators;
 - Need for a national organizational home for palliative care research.
- Primary mission is to improve quality of care for patients with serious illness and the needs of their caregivers by promoting palliative care research and translating research results into clinical practice.



NPCRC Products and Activities



- Career development awards
 - Developing a new generation of researchers
- Pilot exploratory grants
 - Giving experienced investigators the pilot data they need to compete for federal research \$
- Consultancy program
 - Giving investigators the tools they need to develop research grants and protocols



NPCRC Products and Activities



- Research community
 - NPCRC website and annual research retreat
 - Scientific Review Committee, Scientific Advisory Council
- Clearinghouse and tracking of research funding and publications in palliative care
- Instrument repository
- Collaborative Partnerships
 - American Cancer Society, American Geriatrics Society, Foundations, American Academy of Hospice and Palliative Medicine, Hospice and Palliative Nurses Association, National Hospice and Palliative Care Organization, Hole in the Wall Gang Camps, EAPC



Knowledge Dissemination and Technical Assistance: CAPC



- Well documented delays in translating knowledge into practice
- Practical generalizable products: no reinvention of the wheel
- Audience specific messages
- Learner specific tools and interventions
- Evidence-based



Technical Assistance: CAPC



Palliative Care Leadership Centers

- Nine Palliative Care Leadership Centers:
 - New Programs
 - 2 ½ day training in programmatic development
 - Year-long mentorship
 - Established Programs
 - In depth needs assessment, individualized curriculum + reverse site visits.
- 691 teams and 3,577 individual visitors have been trained
- 58% of PCLC trainees have a program up and running at the 12 month mark, 76% at the 2 year mark



Technical Assistance: CAPC



National Seminars

- Since 2000, CAPC has held 17 national seminars attended by over 3,365 individuals and 1250 institutions

CAPCconnect™ Forum

- Palliative care threaded discussion forum for clinicians – share info, exchange ideas, get advice.
- Launched October 2007.
- 1,649 registrants

CAPC.org

- 196,716 visits in 2008
- Customizable tools, sample brochures and marketing materials
standardized clinical and data entry tools, audience-specific messages, training and educational resources



Technical Assistance: CAPC



CAPC Campus Online™

- Using the internet to improve access to technical assistance tutorials
- Launched January 2009
- 8 on-line courses
 - Hospital Cost Avoidance Calculating Staffing Needs; Billing and Coding; Philanthropy; The Business Plan; Strategic Planning; Planning for Growth
 - Future topics – increasing referrals through marketing, education and consultation etiquette; measurement; pediatrics

Print Products

- Top Tools Toolkit: collection of customizable data collection instruments
- A Guide to Building a Hospital-Based Palliative Care Program
- The Case for Hospital-Based Palliative Care



Technical Assistance: CAPC



CAPC.org

- In 2008: 196,716 visits were recorded. 42% increase in web traffic since 2006
- Customizable tools
- Financial spread sheets to make the case and track outcomes
- Sample brochures and marketing materials
- Standardized clinical and data entry tools
- Recommended quality and utilization measures
- Audience-specific messages
- Clearinghouse for training and educational resources



Technical Assistance: CAPC



getpalliativecare.org

- Consumer website
- Discusses palliative care from the time of diagnosis – not just at the end of life
- **Palliative Care Directory of Hospitals** - locate hospitals that have a palliative care program based on NPCRC/CAPC research
- In 2008: 112,112 unique visitors



Knowledge Translation: CAPC/NPCRC



- Cost savings associated with hospital palliative care
- State report card on non-hospice palliative care
- National registry of non-hospice palliative care programs

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 of \$1696 in direct costs per admission ($P = .004$) and \$279 in direct costs per day ($P < .001$) including sig-

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.

Arch Intern Med. 2008;168(16):1783-1790



Cost Savings Associated with Hospital Palliative Care Consultation



- Designed and conducted to:
 - Identify and quantify cost-savings that palliative care programs provide to hospitals
 - Apply propensity score methods to palliative care research
 - Provide national normative cost data for hospitals
- Collaboration of 5 palliative care leadership centers and Mount Sinai Medical Center
 - 3/6 non-academic institutions
- Results – Cost savings of:
 - \$170/day and \$1696/admission for patients discharged alive
 - \$374/day and \$4908/admission for patients who died in hospital



Cost Savings Associated with Hospital Palliative Care Consultation



Media Highlights:

- **Crain's New York.com:** "Cheaper care" 9.12.08
- **Forbes.com:** ""Better care of sickest patients can actually save hospitals money, says biggest study of its kind" 9.8.08
- **Reuters:** "Special care teams help U.S. Patients, hospitals" 9.10.08
- **Modern Healthcare.com:** "Study finds cost-savings with palliative care" 9.10.08
- **US News.com:** "Palliative care programs could boost hospitals' bottom line – Better treatment of sickest patients can save more than \$300 a day, a study says" 9.12.08

Estimated Reach from All Sources: 3,000,000

Variability in Access to Hospital Palliative Care in the United States

Benjamin Goldsmith, B.A.,^{1,2} Jessica Dietrich, M.P.H.,³ Qingling Du, M.S.,¹ and R. Sean Morrison, M.D.¹⁻⁴

Abstract

Background: Hospital palliative care programs provide high-quality, comprehensive care for seriously ill patients and their families.

Objective: To examine geographic variation in patient and medical trainee access to hospital palliative care and to examine predictors of these programs.

Methods: Primary and secondary analyses of national survey and census data. Hospital data including hospital palliative care programs were obtained from the American Hospital Association (AHA) Annual Survey Database™ for fiscal year 2006 supplemented by mailed surveys. Medical school-affiliated hospitals were obtained from the American Association of Medical Colleges, Web-site review, and telephone survey. Health care utilization data were obtained from the *Dartmouth Atlas of Health Care 2008*. Multivariate logistic regression was used to identify characteristics significantly associated with the presence of hospital palliative care.

Results: A total of 52.8% of hospitals with 50 or more total facility beds reported hospital palliative care with considerable variation by state; 40.9% (144/352) of public hospitals, 20.3% (84/413) of for-profit hospitals, and 28.8% (160/554) of Medicare sole community providers reported hospital palliative care. A total of 84.5% of medical schools were associated with at least one hospital palliative care program. Factors significantly associated ($p < 0.05$) with hospital palliative care included geographic location, owning a hospice program, having an American College of Surgery approved cancer program, percent of persons in the county with a university education, and medical school affiliation. For-profit and public hospitals were significantly less likely to have hospital palliative care when compared with nonprofit institutions. States with higher hospital palliative care penetration rates were observed to have fewer Medicare hospital deaths, fewer intensive care unit/cardiac care unit (ICU/CCU) days and admissions during the last 6 months of life, fewer ICU/CCU admission during terminal hospitalizations, and lower overall Medicare spending/enrollee.

Discussion: This study represents the most recent estimate to date of the prevalence of hospital palliative care in the United States. There is wide geographic variation in access to palliative care services although factors predicting hospital palliative care have not changed since 2005. Overall, medical students have high rates of access to hospital palliative care although complete penetration into academic settings has not occurred. The association between hospital palliative care penetration and lower Medicare costs is intriguing and deserving of further study.



Access to Hospital Palliative Care



- Designed and conducted to:
 - Examine state-wide variation in access to non-hospice palliative care
 - Examine medical student access to hospital palliative care
 - Serve as the scientific foundation for state by state report card on non-hospice palliative care
- Collaboration between CAPC, NPCRC, American Hospital Association
 - Study led by 3rd year medical student
- Results
 - 53% of hospitals with more than 50 beds have a palliative care program (75% with over 300 beds)
 - 84% primary teaching hospitals for US allopathic medical school's report a palliative care program
 - 5 private medical school main teaching hospitals did not have a program – Albany Medical College, BU, Meharry, Tufts, Yale
 - 4 states did not contain a state-funded medical school affiliated with a non-hospice palliative care program – CT, MI, NE, NV

To learn more about palliative care, visit:



To read the study, visit:

Journal of Palliative Medicine

AMERICA'S CARE OF SERIOUS ILLNESS:
A State-by-State Report Card on Access to Palliative Care
in Our Nation's Hospitals

Home

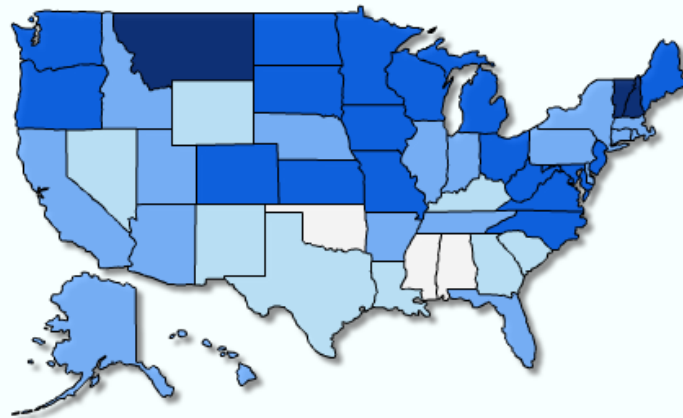
Summary

Key Findings

Top Ten

Recommendations

How Does Your State Rate?



United States

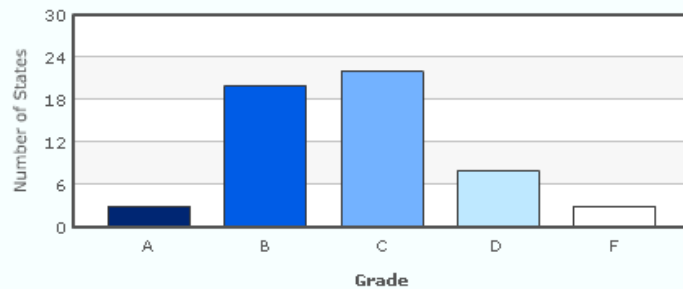
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[Choose State] ▾

Percentage of mid-size and large hospitals with a palliative care program (50+ beds)
(Click on a state for more details)

Choose another national map:

State-by-State Report Card ▾





Report Card



Media Highlights:

- **Washington Post.com:** “National scorecard ranks palliative care across country” 10.2.08
- **Associated Press:** “State gets failing grade in caring for sick” 10.4.08
- **Forbes.com:** “National scorecard ranks palliative care across country” 10.2.08
- **US News.com:** “National scorecard ranks palliative care across country: Availability varies widely, and South comes out worst, researchers say” 10.2.08
- **St. Paul Pioneer Press:** “Minnesota gets a ‘B’ for palliative care: But programs at Fairview, Children’s are national models” 10.2.08

Estimated Reach From All Sources: 9,500,000



National Registry of Non-Hospice Palliative Care Programs



- Purpose
 - To develop a national database of key structure and process measures in order to promote HPC benchmarking
 - To understand the core structures and processes of HPC programs
 - To allow individual hospitals to compare their programs to national averages for similar hospitals
- Methods
 - Interviews with key constituents (program directors, hospital administrators)
 - Survey of existing PCLC programs to populate the database
 - Database development
 - Ongoing recruitment of hospitals with HPC programs to further database development

Welcome to the National Palliative Care Registry[™]

The Registry was created by CAPC and the NPCRC to guide local palliative care leaders in the development and sustainability of their programs. By submitting your data online, you will help standardize structures and processes of care and demonstrate the reach and impact of palliative care in the nation's hospitals and beyond.

Contribute to the growth of palliative care. Become part of it's DNA!

Want to register your
program?

Register Now

Already started your
registration?

Log In

Not sure if your
program is registered?

Search Programs

When you register your program, you'll be able to:

- Receive a premium listing in the www.getpalliativecare.org Provider Directory. Your listing will be highlighted and will have more complete information than a regular listing
- Track your program's structure and operation, year after year
- Be included in CAPC and NPCRC prevalence studies
- Generate in-depth, customized reports comparing your program to your peers' through Palliative Care COMPARE[™] (COMING 2010!)



Influence Health Policy: NPCRC/ CAPC



- National quality initiatives
 - National Quality Forum
 - Joint Commission
 - Center for Medicare and Medicaid
 - American Cancer Society
- National Institutes of Health
 - Research funding (Top-Down)
 - Peer review (Bottom-Up)
- Health Care Reform
 - American Cancer Society
 - American Association of Retired Persons



Future Activities: CAPC/NPCRC



- Build teaching and research capacity
- Catalyze NIH funded palliative care research
- Establish a national research infrastructure
- Promote cross-discipline collaboration
- Identify key characteristics of program quality
- Engage state policy makers
- Empower consumers



Thank you!