

# **Palliative Care: A Standard for Cancer Care**

**Dr. Kathleen M. Foley**

**August 4, 2010**

# 2002 WHO Definition of Palliative Care

*"Palliative care is an approach which improves quality of life of patients and their families facing life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual"*

# Palliative Care as a Public Health Issue

- affects all people
- need for better information on end-of-life care
- potential to prevent suffering
- potential to prevent disease

# Palliative Care as a Prevention Model

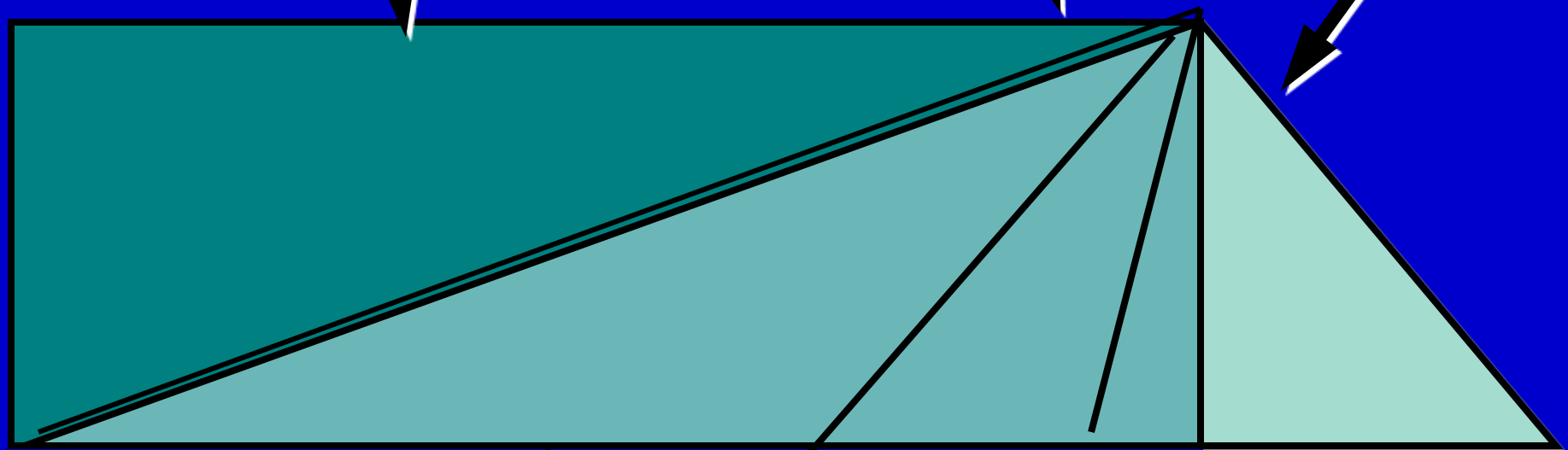
- prevents needless suffering
- provides peer education
- provides patient centered care
- incorporates self-management programs

# The continuum of palliative care

Therapies to modify disease  
(*curative, restorative intent*)

Life  
Closure

Actively  
Dying



Diagnosis

6m

Death

Therapies to relieve suffering,  
improve quality of life

Bereavement  
Care

# The Politics of Palliative Care: Challenges in the US

- Death panel discussions high jacked real issues
- Workforce capacity of palliative care limits access
- Hospice benefit limitations on concurrent active therapies
- Prescription drug abuse impacting end of life pain management

# Advances in Palliative Care in the United States

- In 2010
  - 4700 hospice programs
  - 1.4 million patients/served by hospice
  - 40% of all deaths (excluding accidents and sudden deaths) are served by hospice

# Advances in Palliative Care in the United States

- By 2010
  - 1300 hospital palliative care programs
  - October, 2008, ABMS specialty status for palliative medicine;
  - In 2008, Veterans Administration awarded 20 million dollars to bring palliative care to scale

# Advances in Palliative Care in the United States

- Published second edition National Consensus Project for Quality Palliative Care (2009)
- 2007 National Quality Forum (NQF) framework and Preferred Practices for Palliative Care
  - NQF names palliative care as one of six priorities for improving quality of care in the US through National Priority Partners Institute

# Advances in Palliative Care in the United States

## -Palliative Care Education

- ELNEC trained 5,700 US nurses
- ELNE presented trainings in 61 countries
- EPEC trained >4000 U.S. medical doctors
- EPEC-O curriculum available through NCI

# Advances in Palliative Care in the United States

- National Palliative Care Research Center supports research through collaboration with the American Cancer Society <http://www.npcrc.org/>
- Center to Advance Palliative Care supports the development of palliative care programs in hospitals <http://www.capc.org/>

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# Advances in Palliative Care in the United States

- Economic analysis support cost savings and improved quality of care for patients receiving palliative care services
- Surveys of families of patients who died of cancer report improved pain and symptom management and family satisfaction with palliative care.
- Simultaneous care models of palliative care and cancer care demonstrate earlier referral to hospice and cost savings and improved satisfaction

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pp. 3052-3058 © 2009 [American Society of Clinical Oncology](#).**

## **ASCO SPECIAL ARTICLE**

# **Palliative Cancer Care a Decade Later: Accomplishments, the Need, Next Steps—From the American Society of Clinical Oncology**

**Frank D. Ferris, Eduardo Bruera, Nathan Cherny, Charmaine Cummings, David Currow, Deborah Dudgeon, Nora JanJan, Florian Strasser, Charles F. von Gunten, Jamie H. Von Roenn**

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# ASCO, 1998

“Oncologists’ responsibility to care for a patient in a continuum from diagnosis throughout the course of the illness.

In addition to appropriate anticancer treatment, this includes symptom control and psychosocial support during all phases of care, including those during the last phase of life.”

(J Clin Oncol 1998;16:1986-96)

# 1998 ASCO Survey

- 6,645 oncologists surveyed
- 118 questions
- $n = 3,227$  (48% response rate)
- No significant differences in answers based on oncology specialty

# Source of Information about Palliative Care

- 90% trial and error
- 73% colleagues and role models
- 38% traumatic experience
- Message: No one is teaching this to oncologists

# Inadequate education about palliative care

- 81% inadequate mentor or coaching in how to discuss poor prognosis
- 65% inadequate information about controlling symptoms

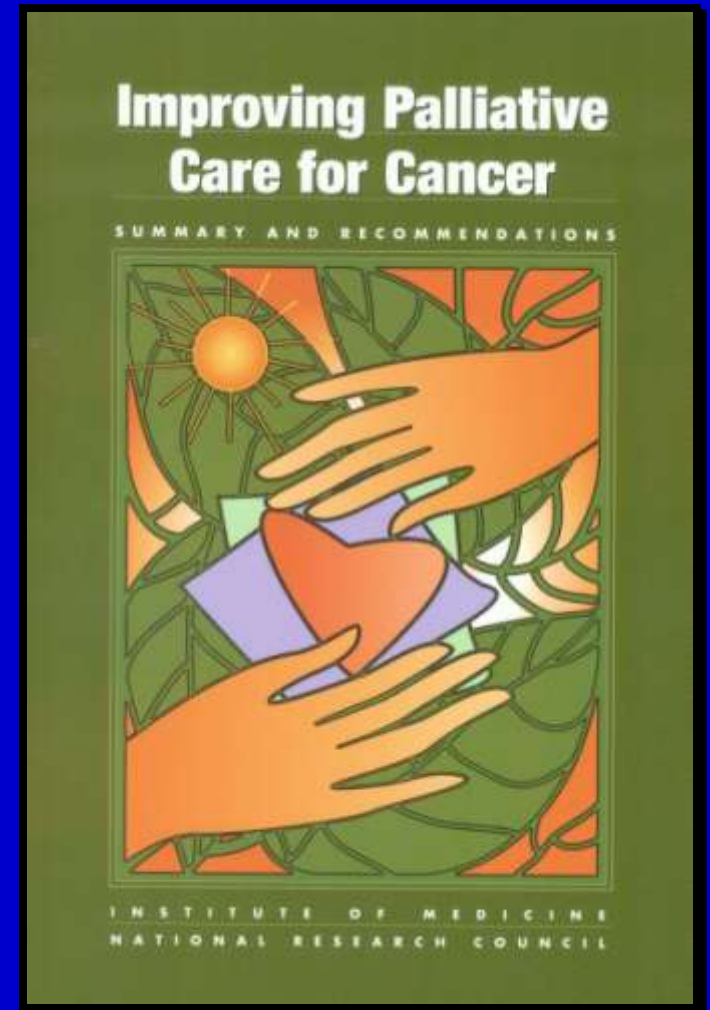
# Personal Failure

- 76% feel some sense of personal failure if patient dies of cancer
- 90% feel at least some anxiety discussing poor prognosis
- 75% feel at least some anxiety discussing symptom control with patients and families

# National Cancer Policy Board Report, 2001

- Summary
- 10 Recommendations

[www.iom.edu](http://www.iom.edu)





NCCN Clinical Practice Guidelines in Oncology™

# Palliative Care

V.1.2010

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[www.nccn.org](http://www.nccn.org)

## PALLIATIVE CARE OVERVIEW

SCREENING<sup>a,b</sup>

Uncontrolled symptoms or Moderate to severe distress related to cancer diagnosis and cancer therapy or Serious comorbid physical and psychosocial conditions or Life expectancy  $\leq 12$  mo or Patient/family concerns about course of disease and decision-making or Patient/family requests palliative care

Present →  
Not present ↓

- Inform patients and families of role and benefits of palliative care services
  - ▶ Discuss anticipation and prevention of symptoms
  - ▶ Rescreen at next visit

## ASSESSMENT

- Benefits/risks of anticancer therapy
- Symptoms
- Psychosocial or spiritual distress
- Personal goals/expectations
- Educational and informational needs
- Cultural factors affecting care
- Criteria for early consultation with palliative care specialist

## ESTIMATED LIFE EXPECTANCY

Years  
Year to months  
Months to weeks  
Weeks to days (Dying patient)

PALLIATIVE CARE INTERVENTIONS<sup>b</sup>

- Anticancer therapy
- Appropriate treatment of comorbid physical and psychosocial conditions
- Promote coordination of care
- Symptom management
- Advance care planning
- Psychosocial and spiritual support
- Culturally appropriate care
- Resource management/social support
- Consultation with palliative care specialist
- Hospice referral
- Response to request to withdraw or withhold life sustaining treatment
- Response to request for physician-assisted suicide and euthanasia
- Care of imminently dying patient
- Palliative sedation

## REASSESSMENT

Satisfactory:  
• Patient satisfied with response to anticancer therapy  
• Adequate pain and symptom control  
• Reduction of patient/family distress  
• Acceptable sense of control  
• Relief of caregiver burden  
• Strengthened relationships  
• Optimized quality of life  
• Personal growth and enhanced meaning

Unsatisfactory ↓

- Intensify palliative care efforts
- Consult or refer to specialized palliative care services or hospice

## AFTER DEATH INTERVENTIONS

Death → (A "good death") →

- For family and caregivers:
- Immediate after-death care
  - Bereavement support
  - Cancer risk assessment and modification
- For healthcare team:
- General support
  - After-death support

Ongoing reassessment ←

Ongoing reassessment ←

<sup>a</sup>Management of any patient with positive screening requires a care plan developed by a interdisciplinary team of physicians, nurses, social workers and other mental health professionals, and chaplains.

<sup>b</sup>Oncologists should integrate palliative care into general oncology care for patients who meet screening criteria. Consultation/collaboration with a palliative care specialist/hospice team is recommended for patients with more complex issues.

Note: All recommendations are category 2A unless otherwise indicated.

Clinical Trials: NCCN believes that the best management of any cancer patient is in a clinical trial. Participation in clinical trials is especially encouraged.

[Palliative Care Assessment \(PAL-3\)](#)

*EPEC - Oncology*  
*Supported by the*  
*National Cancer Institute*  
*American Society for Clinical Oncology*

# **EPEC - O**

**Education on Palliative and End-of-life Care -Oncology**

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Charles F. von Gunten, MD, PhD, Co-principal

# ESMO Survey on Care of Advanced Cancer Patients

- To Evaluate
  - the degree to which ESMO oncologists are involved in the management of advanced cancer
  - the degree with which they collaborate with PC clinicians
  - their personal involvement in PC
  - their attitudes to PC

(Cherny N, Catane R, Schrivvers D, Kloke M, Strasser F. Ann Oncol. 2010;21(2):362-9)

# Demographics 1

- N=895
- European 82.5%
- Sex: F 194 (21.7%) M 701 (78.3%)
- Median age: 45-49 years
- Median experience: 15-19 years

# Discrepancy 1: Belief Practice

- Although, 88.4% agreed medical oncologists should coordinate the care of cancer patients at all stages of disease including end of life care...
- Actual practice seems much less...
  - 43% commonly coordinate the care of cancer patients at all stages of disease including end of life care.
  - 39% commonly coordinate meetings with the family of dying patients
  - 11.8% manage delirium

# Discrepancy 2: Education

- Education
  - 42% reported that they did not receive good training in PC
  - 76% own a textbook of PC
  - 83.6% read journals or article about PC
- Regarding skill levels
  - 60.4% said they were skilled in PC
  - 37% said most oncologists they knew were skilled

# ESMO Program for Integration of Oncology and Palliative Care

- Five year review of program to improve delivery of supportive and palliative care
- 75 centers applied
- 48 accredited including 34 comprehensive cancer centers in general hospitals and 7 free standing CCCs
- Benefits included improved status and role identification of center; positive impact on daily work on business activity and funding for projects

# ASCO Key Findings

- **Supply of oncology visits will rise about 14%**
  - Aging workforce
  - Limited plans for new training slots
- **Demand for visits will be up about 48% by 2020**
  - Aging population (48% increase in incidence)
  - Increased cancer survivorship (81% increase)
- **Challenge for entire oncology care system**
  - Project a shortfall of 2,550 to 4,080 oncologists by 2020
  - Assuring access and quality care will require a concerted and multi-faceted effort and significant changes to practice of oncology

# Oncologists Views on Addressing Shortages

## (Results of 2006 Practitioner Survey)

Increase Efficiency	Reduction of paperwork and regulations	61%
	Improved IT such as electronic medical records	43%
Increase / extend oncology workforce	<b>Increased use of NPs/PAs</b>	<b>36%</b>
	Train more clinical oncologists	34%
	<b>Increased use of oncology nurses and CNS</b>	<b>32%</b>
	Create incentives to delay retirement	28%
Increase use of related care providers	<b>Hospice and palliative care providers</b>	<b>26%</b>
	Social workers, counselors and patient educators	24%
	Hospitalists	20%
	Pain and symptom management specialists	17%
	Primary care providers to care for patients in remission	15%

# Why bother to bring up the “D” word?

People who have a discussion about dying...

- No difference in mental health or hope

- Less likely to want heroic measures

- Undergo ventilation

- ICU

- To admit being terminally ill

- Complete DNR

- Use hospice

- ☺ More family, spiritual, life review opportunities

# Palliative Care at US Cancer Centers

NCI Cancer Centers were more likely to have

- a palliative care program 50/51 (98%) vs 39/50,(78%)
- at least 1 palliative care physician 46/50 (92%)vs 28/38(74%)
- an inpatient palliative care team 47/51(92%) vs 28/50(56%)
- an outpatient palliative care clinic 30/51(59%) vs11/50(22%)
- Few centers had dedicated palliative care beds or an institution-operated hospice

(Ferris D, Bruera E, Cherny N, Cummings C, Currow D, Dudgeon D, Janjan N, Strasser F, von Gunten CF, Von Roenn JH. J Clin Oncol. 2009;27(18):3052-8)

# Discharge Outcomes and Survival from APCU

- APCU discharges from 2003 to 2008 from MD Anderson
- 2568 admitted
- 33% died
- 20% home discharge
- 3% health care facility
- 43% hospice

(Hui D, Elsayem A, Palla S, De La Cruz M, Li Z, Yennurajalingam S, Bruera E. J Palliat Med. 2010;13(1):49-57)

# Supportive vs Palliative Care: What's in a Name

Surveyed 140 med oncologists and midlevel providers:  
80% response rate

- Preferred term supportive care to palliative care. The term palliative care was perceived as more distressing and reducing hope to patients and families.

(Hui D, Elsayem A, De La Cruz M, Berger A, Zhukovsky DS, Palla S, Evans A, Fadul N, Palmer JL, Bruera E. JAMA. 2010;303(11):1054-1061.)

# Palliative Chemotherapy: Balancing Results, Costs, and Hope.

- 24% of Medicare patients receive chemo in last 2 weeks of life, increasing. (Earle C, JCO 2004)
- NSCLC pts 43% chemo within 4 weeks of death, 20% within 2 weeks. (Murillo & Koeller J. Oncologist. 2006)
- 47% of pts receive chemo within 2 weeks of death at one large insurer of 34 million lives (personal communication)

# Palliative Chemotherapy: Balancing Results, Costs, and Hope

- The likelihood of such chemo helping patients within 2 weeks of their death is small.
- Sometimes patients want such therapy, but mostly they don't get any truthful prognostic or effectiveness information from their cancer doctors.

(Matsuyama, Reddy, Smith. JCO 2006)

# Health Care Costs in Last Week of Life

- Patients with advanced cancer who reported having EOL conversations with physicians had significantly lower health care costs (35% lower) in their final week of life.
- Higher costs were associated with worse quality of life.

(Zhang B, Wright AA, Huskamp H, Nilsson ME, Maciejewski ML, Earle CC, Block SD, Maciejewski PK, Prigerson HG. Arch Inter Med. 2009;169(5): 480-484)

# Cost Savings Associated with US Hospital Palliative Care Programs

- Data from 8 US hospitals from 2002 -2004 matching patients receiving palliative care to patients receiving usual care
- The palliative care patients who were discharged alive had adjusted net savings of \$1696 in direct costs per admission and \$279 in direct cost per day
- The palliative care patients who died had adjusted net savings of \$4908 in direct costs and \$374 in direct costs per day including significant reductions in pharmacy, laboratory and intensive care unit costs

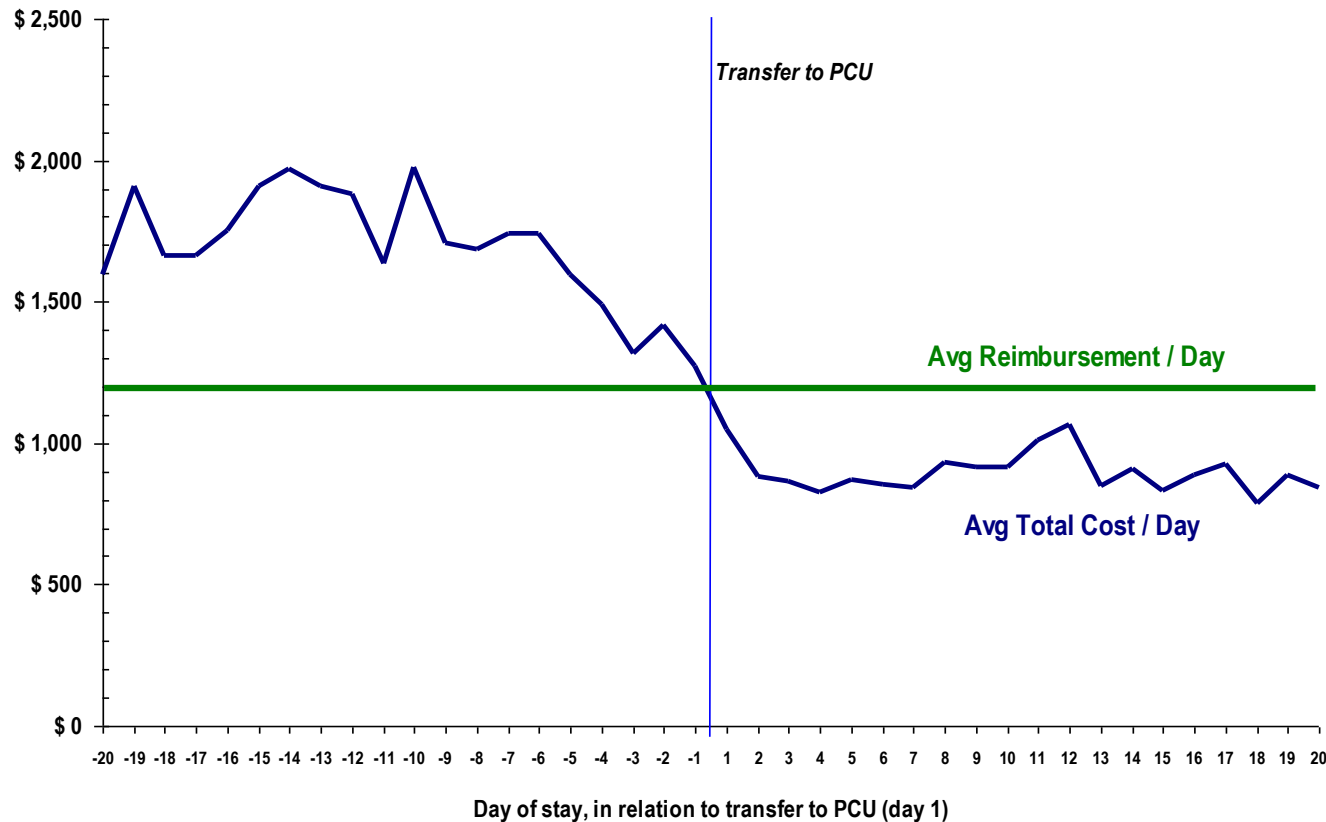
(Morrison SR, Penrod JD, Cassel B, Caust-Ellenbogen M, Lith A, Spragens L, Meier D. Arch Intern Med. 2008;168(16):1783-90)

## Lower Cost Per Day After Transfer To Palliative Care

Cohort study: 60% less cost after transfer

Case Control study: 67% less cost than matches

Smith T, J Pall Med 2003



**Standard algorithms**  
**POS correction**  
*High volume, expert attendings*  
**Review orders**

**Have “the talk”:**  
**oxygen**  
**antibiotics**  
**tube feeds**  
**multiple meds**

# TPCU Fiscal Evaluation

## Smith, Coyne, Cassel, Hager.

(J Pall Med 2003 White K, et al. J Healthcare Mgmt 2006)

- “”””” **Cost avoidance = profit**
  - Transfers from high \$ to low \$ bed
  - Appropriate care
  - opens ICU beds (OHS loses \$1200/hour if on diversion)

### **2008 FY**

profit \$40,000

Contributions ~\$1 million

Cost avoidance ~\$1 million

2 RO1s, 1 endowed professorship, Foundation funding,  
NCI help

Statewide education program (VIPIC, on Massey CC  
website)

# Lower Cost Per Day After Transfer To Palliative Care

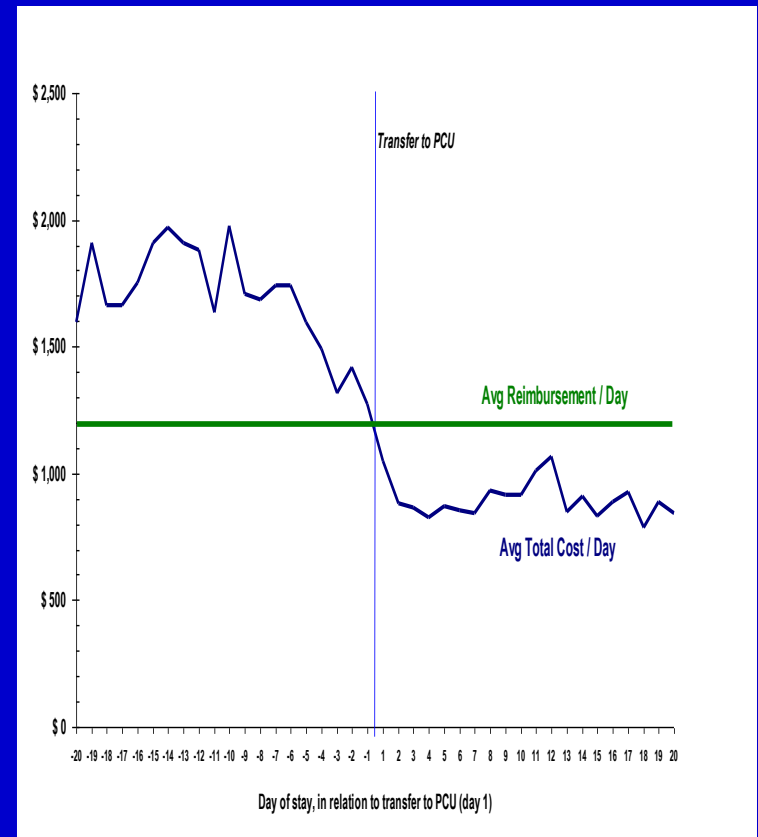
Same pattern observed in 6 other health systems that have started PC consults.

[www.capc.org](http://www.capc.org)

White K, J Health Care Mgmt 2006

MDACC: 38% less daily charges and costs after transfer to PCU + better symptom control. Elsayem A, et al. JCO 2004

\$239/day savings with PC consult. Penrod J. J Pall Med 2006, 9(4): 855-860.



## Project Safe Conduct: Ireland CC + Hospice of Western Reserve.

233 NSCLC pts seen concurrently with HWR  
APN, MSW, chaplain + oncologist  
Hospice use ↑ 13% to 80%, and LOS 10 to 44 days  
*Once project over, ICC hired team from HWR to expand the program*

(Pitorak E, J Pall Med 2003;6: 645-655)

<http://www2.edc.org/lastacts/archives/archivesJuly02/featureinn.asp>

# **RCT of usual oncology care vs. usual oncology + concurrent hospice care.**

**(J Finn, ASCO, 2002)**

167 Pts on concurrent care vs. ONC care  
had preserved QOL longer  
used less chemo  
lived slightly longer  
Caregiver burden less

Intervention saved \$2500/pt in hosp days  
... cost an additional \$17,500/pt

*Need to define what is needed to improve care at a cost society can afford*

# Coordinated Care Models

(Raftery JP, Addington-Hall, et al. Palliat Med 1996;10:151

Desch C, Smith T. J Rural Health 1999)

Intervention: a nurse coordinator in charge

Outcomes did not change for terminally ill cancer patients

Costs reduced from £ 8814 to £4414 (-41%;  $p = 0.006$ )

Savings came from decreased hospital days (24 vs 40), and nursing visits

Keep patients out of the ER

US cost savings 40% for coordinated care between rural hospital and academic center

# Simultaneous Care : A Model Approach Between Investigational Therapy and Palliative Care

- SC enhances patient choice by allowing patients access to two beneficial options.
- SC enhances coordination of care and facilitates patients' explicit transition from curative intent to palliative intent

(Meyers FJ, Linder J, Beckett L, Christensen S, Blais J, Gandara D. J Pain Symptom Manag. 2004;28(6):548-556.)

# Project ENABLE II: Effects of a Palliative Care Intervention

- Patients receiving a nurse-led palliative care focused intervention addressing physical, psychosocial, and care coordination provided concurrently with oncology care had higher scores for quality of life and mood but did not have improvements in symptom intensity scores or reduced days in hospital or ICU or ED departments.

(Bakitas M, Lyons KD, Hegel MT, Balan S, Brokaw FC, Seville J, Hull JG, Li Z, Tosteson TD, Byock IR, Thles TA. JAMA, 2009;302(7): 741-9)

# Integrating Palliative Care Into Outpatient Oncology

- An embedded palliative care clinic integrated into an office-based oncology practice
- resulted in reduction in symptom burden by 21%
- Overall provider satisfaction of 9/10
- Group consultation requests increased by 87%
- Total time saved for oncology practice was over four weeks

(Muir JC, Daly F, Davis MS, Weinberg R, Heintz JS, Palvanas TA, Beveridge R. J Pain Symptom Manage. 2010;40 (1):126-35.)

# Palliative Care Consultation and Hospital Length of Stay

- Review of 12 published studies only show reduced length of stay in 3 of the quasi- experimental studies and one of two randomized trials
- Need for further studies

(Cassell JB, Kerr K, Pantilat S, Smith TJ. J Palliat Med. 2010;13(5):761-7)

# Family Perspectives on End of Life Care at the Last Place of Care

- Family members of patients receiving hospice services were more satisfied with overall quality of care:
  - 70% rated care as excellent compared to less than
  - 50% of those dying in an institutional setting or with home health services

(Teno JM, Clarridge BR, Casey V, Welch LC, Wetle T, Shield R, Mor V. JAMA, 2004;29(1):88-93)