Palliative Care: Making the Case

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Palliative Care

Interdisciplinary care that aims to relieve suffering and improve quality of life for patients with advanced illness and their families.

It is offered simultaneously with all other appropriate medical treatment.

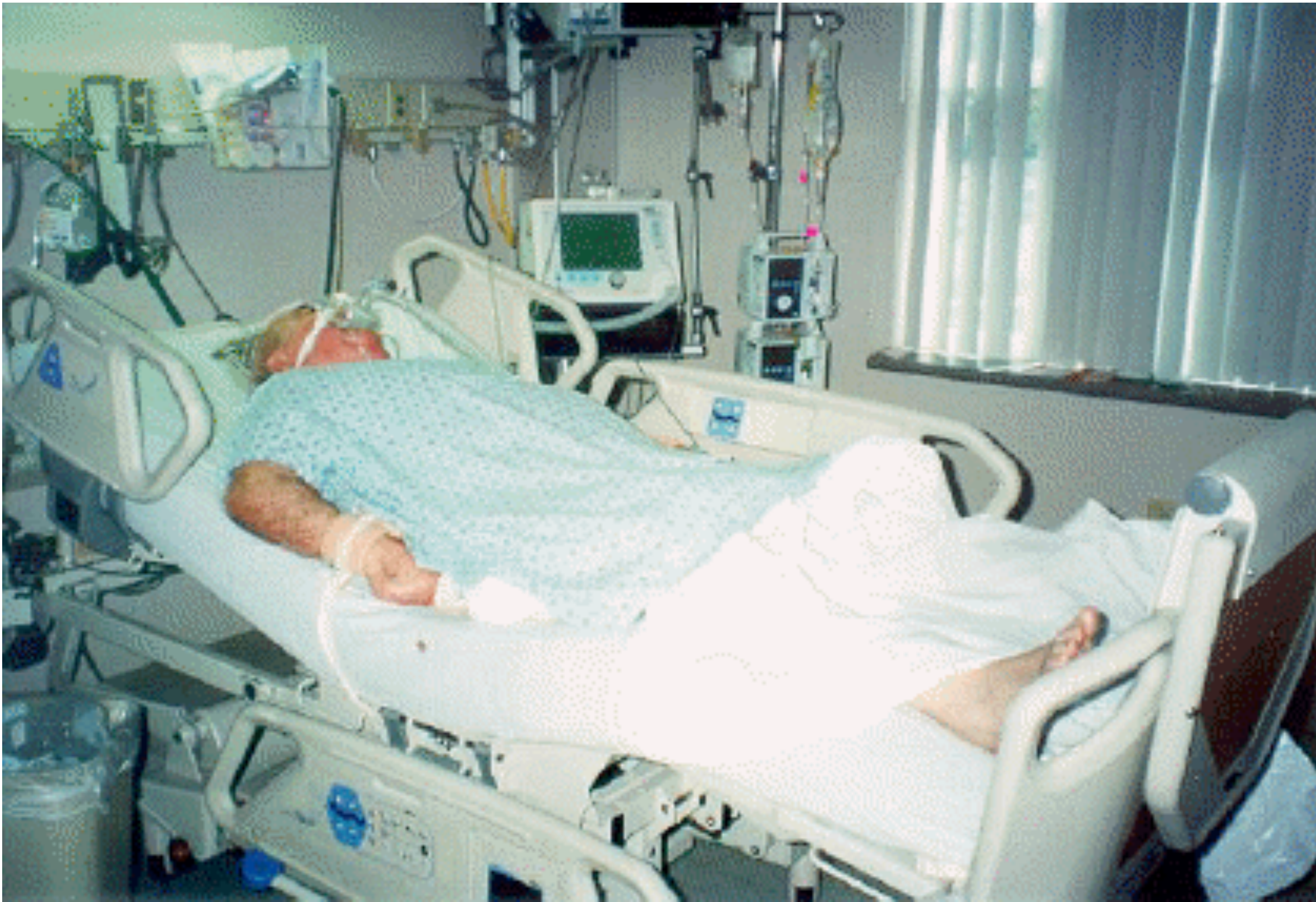
The Cure - Care Model: The Old System

Life Prolonging Care

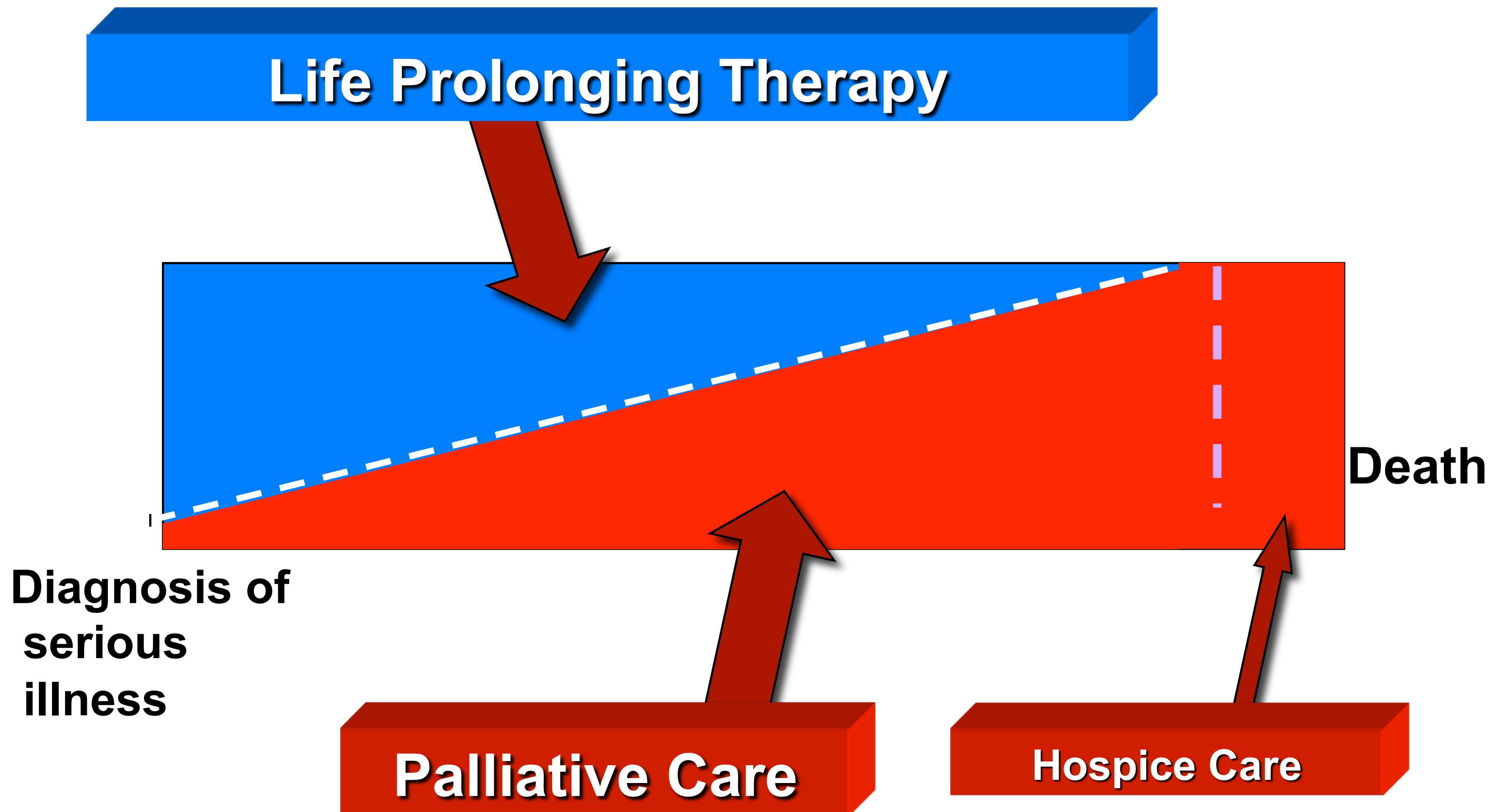
Palliative/ Hospice Care

D E A T H

Disease Progression



Palliative Care's Place in the Course of Illness



Hospital-based Palliative Care: The 5 Main Arguments

1. Clinical quality
2. Patient and family preferences
3. Demographics
4. Education
5. Finances

Why palliative care?

1. Clinical imperative:

The need for a better quality of care for persons with serious and complex illnesses

The Nature of Suffering and the Goals of Medicine

The relief of suffering and the cure of disease must be seen as twin obligations of a medical profession that is truly dedicated to the care of the sick. Physicians' failure to understand the nature of suffering can result in medical intervention that (though technically adequate) not only fails to relieve suffering but becomes a source of suffering itself.

Cassell, Eric NEJM 1982;306:639-45.

Dying in the Hospital:

What do we know about it?

National Data on the Experience of Dying in 5 Tertiary Care Teaching Hospitals

The SUPPORT Study

- Controlled trial to improve care of seriously ill patients
- Multi-center study
- 9000 patients with life threatening illness, 50% died within 6 months of entry

JAMA 1995;274:1591-98

Pain Data from SUPPORT

% of 5176 patients reporting moderate to severe pain between days 8-12 of hospitalization:

colon cancer	60%
liver failure	60%
lung cancer	57%
MOSF + cancer	53%
MOSF + sepsis	52%
COPD	44%
CHF	43%

Desbiens & Wu. JAGS 2000;48:S183-186.

Why palliative care?

2. Concordance with patient and family wishes

What is the impact of serious illness on patients’ families? And what do persons with serious illness say they want from our healthcare system?

Family Caregivers: The Numbers

- 1996 United States estimates: 25 million caregivers deliver care at home to a seriously ill relative
  - Mean hours caregiving per week: 18
  - Cost equivalent of uncompensated care: $194 billion (@ $8/hr)

  Levine C. Loneliness of the long-term caregiver N Engl J Med 1999;340:1587-90.
- Unpaid caregivers provide >70% of all long term care

  Liu et al. Home care expenses for the disabled elderly. H Care Fin Rev 1985;7:51-7
- 56% of elderly have incomes under $20,000 and spend >25% of it on healthcare for themselves and family members

  Report to Congress: Medicare Payment Policy Medpac;March 2003 www.medpac.gov

Caregiver Characteristics

900 family caregivers of terminally ill persons at 6 sites across the U.S.

- Women: 72%
- Close family member: 96%
- Over age 65: 33%
- In poor health: 33%

Emanuel et al. N Engl J Med 1999;341:956.

Caregiving Needs among Terminally Ill Persons

Interviews with 900 caregivers of terminally ill persons at 6 U.S. sites

- ***need more help: 87% of families***
- transportation: 62%
- homemaking: 55%
- nursing: 28%
- personal care: 26%

Emanuel et al. Ann Intern Med2000;132:451

Caregiving Increases Mortality

Nurses Health Study: prospective study of 54,412 nurses

- Increased risk of MI or cardiac death: RR 1.8 if caregiving >9 hrs/wk for ill spouse

Lee et al. Am J Prev Med 2003;24:113

Population based cohort study 400 in-home caregivers + 400 controls

- Increased risk of death: RR 1.6 among caregivers reporting emotional strain

Schulz et al. JAMA 1999;282:2215.

Family Caregivers and the SUPPORT study

Patient needed large amount of family caregiving: 34%

Lost most family savings: 31%

Lost major source of income: 29%

Major life change in family: 20%

Other family illness from stress: 12%

At least one of the above: 55%

JAMA 1995;272:1839

What Do Family Caregivers Want?

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

What Do Patients with Serious Illnesses 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.

Why palliative care?

3. **The demographic imperative**

Hospitals need palliative care to effectively treat the growing number of persons with serious, advanced and complex illnesses.

The Demographic Imperative:

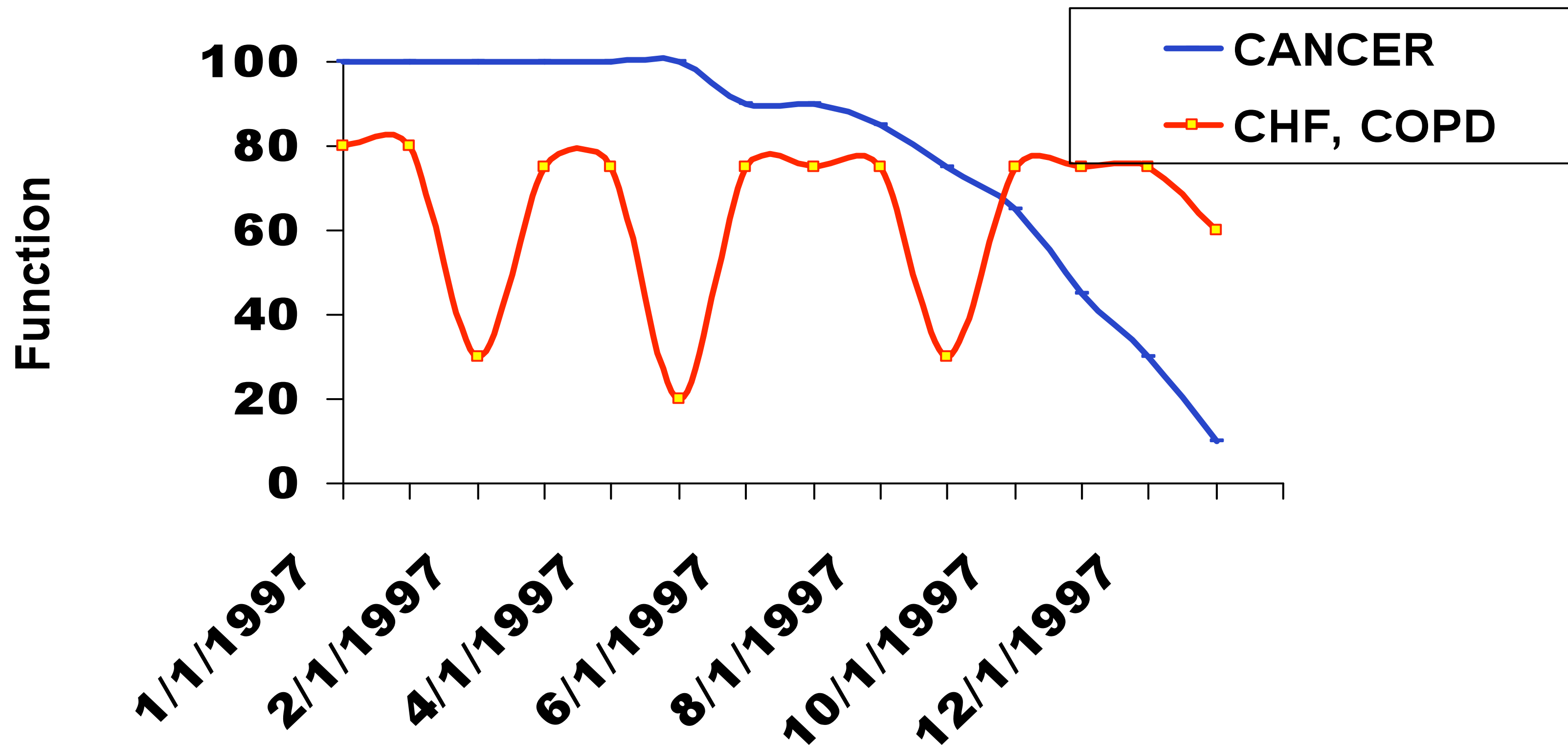
Chronically Ill, Aging Population Is Growing

- The number of people over age 85 will double to 10 million by the year 2030.
- The 63% of elderly patients with 2 or more chronic conditions account for <u>95%</u> of Medicare spending.

US Census Bureau, CDC, 2002.

The Reality of the Last Years of Life: Death Is Not Predictable

(slide courtesy of Joanne Lynn, MD Rand Corp.)
Covinsky et al. JAGS 2003;
Lynn & Adamson RAND 2003.
Morrison & Meier N Engl J Med 2002.



Leading Causes of Death: 77% Are Not Due to Cancer

Heart disease:	33%
Malignant neoplasm:	23%
Cerebrovascular disease:	7%
COPD:	5%
Accidents:	4%
Pneumonia:	4%

Account for 75% of all deaths

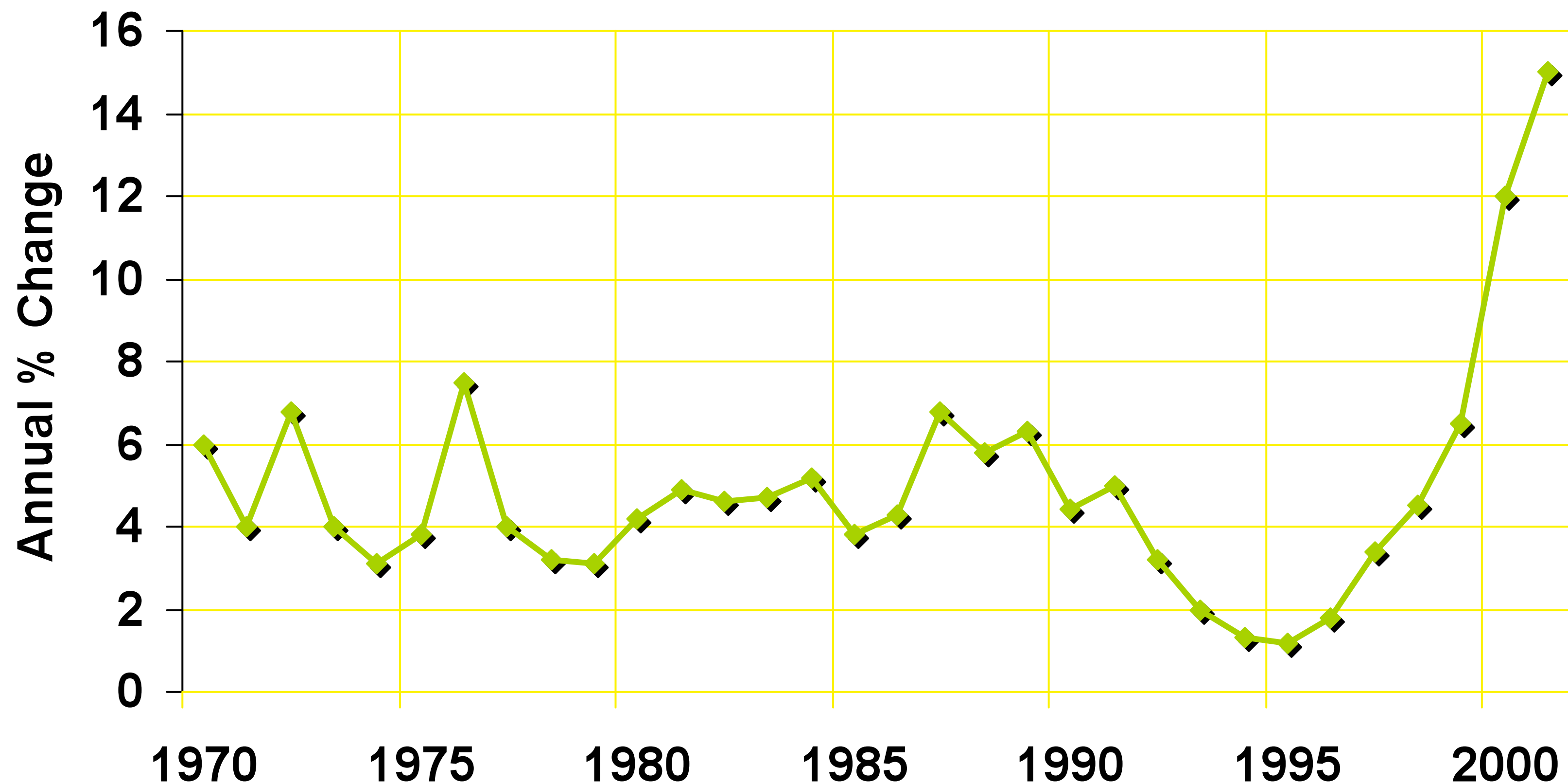
Natl. Ctr. Health Statistics, CDC, 1998

Why palliative care?

5. The fiscal imperative

Population aging + growth in numbers of patients in need + effective new technologies + antiquated payment system = financial crisis for healthcare

National Health Expenditure Growth 1970-2003



HCFA, Office of the Actuary, National Health Statistics Group, 2003

Why Palliative Care?

The Fiscal Imperative

- Exponentially rising costs with effective new technologies, aging population
- Growth in hospital payments in 2001-2003
- 76% of 2002 U.S. Medicare budget spent on hospital care ($198 billion)
- Long, high-intensity hospital stays = fiscal crisis for hospitals
- *Hospital and payor of the future will have to efficiently and effectively treat serious and complex illness in order to survive*

Palliative Care aims to improve care in 3 domains:

1. Relieve physical and emotional suffering
2. Improve patient-physician communication and decision-making
3. Coordinate continuity of care across settings

Case Study: What Actually Happened

82-year-old woman with hypertension, diabetes, renal failure osteoporosis, vision loss.

Cycle of health crises- falls, fractures, pneumonia

- Hospitalized three times in 9 months
- Home with Home Health Agency, discharged from homecare after 4 weeks- new crisis = hip fracture and repeat hospitalization
- In pain, symptoms not managed- long hospital stay, resulting in progressive deconditioning, weakness, functional decline
- Not ready for hospice but in need of more support in hospital and ongoing transition management and care coordination at home

Case Study: What Should Have Happened

Palliative care consultation for:

- Pain and symptom relief - facilitates success of rehabilitation, reduces hospital length of stay
- Patient/family discussions re: needs/goals, advance care planning
- Home needs assessment
- Identification of ongoing support services at home
- Plan for coordination and monitoring after home care; 'skilled need' terminates
- Support for gradual transition to hospice if and when illnesses progress to terminal stage

Benefits of Palliative Care: The Evidence Base

- Reduction in symptom burden
- Improved patient and family satisfaction
- Reduced costs

Palliative Care Improves Quality

Data demonstrate that palliative care:

- Relieves pain and distressing symptoms
- Supports on-going re-evaluations of goals of care and difficult decision-making
- Improves quality of life, satisfaction for patients and their families
- Eases burden on providers and caregivers
- Helps patients complete life prolonging treatments
- Improves transition management

Campbell et al, Heart Lung, 1991; Campbell et al, Crit Care Med, 1997; UC Davis Health System News; 2002; Carr et al, Vitas Healthcare, 1995; Franklin Health, 2001; Dartmouth Atlas, 2000; Micklethwaite, 2002; Du Pen et al, J Clin Oncol, 1999; Finn et al, ASCO, 2002; Francke, Pat Educ Couns, 2000; Advisory Board, 2001; Portenoy, Seminars in Oncol, 1995; Ireland Cancer Center, 2002; Von Roenn et al, Ann Intern Med, 1993; Finn J et al ASCO abstract. 2002; Manfredi et al JPSM 2001; Schneiderman et al. JAMA 2003; Higginson et al JPSM 2002 & 2003; Smith et al. JCO 2002, JPM 2003; Coyne et al. JPSM 2002; www.capc.org.

Palliative Care Is Cost-Saving,

supports transitions to more appropriate care settings

- Palliative care lowers costs (for hospitals and payers) by reducing hospital and ICU length of stay, and direct (such as pharmacy) costs.
- Palliative care improves continuity between settings and increases hospice/homecare/nursing home referral by supporting appropriate transition management.

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; Project Safe Conduct 2002, 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.

How Palliative Care Reduces Length of Stay and Cost

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

Role of the hospital-based palliative care consultation team

- **Client = attending physician**
- Advice and support to ward team on symptom control and psychosocial/existential issues
- Support to families
- Support and advice to staff
- Education of hospital staff
- Liaison between hospital and hospice/home care services or other institutions
- Auditing and research

Dunlop and Hockley 1998

Palliative Care: A Case Example

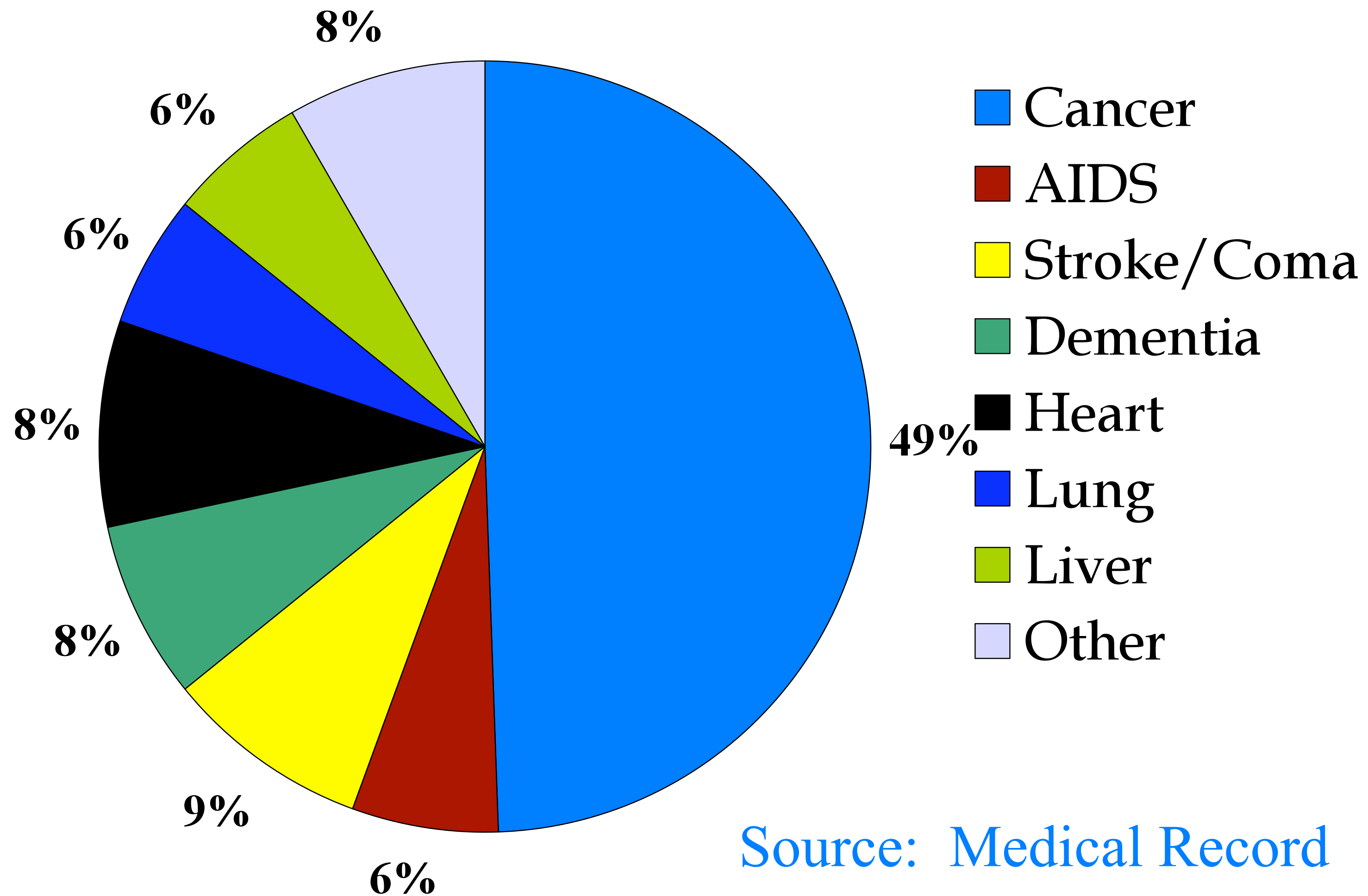
MJ was an 85 year old women with multiple medical problems including moderate dementia, coronary artery disease, renal insufficiency, and peripheral vascular disease who was admitted to Mount Sinai with urosepsis. Her hospital course was complicated by the development of gangrene of her left foot resulting from her vascular disease, candidal sepsis, multiple pressure ulcers, and recurrent infections. She underwent 5 debridements under general anesthesia. When asked by the primary doctor, her family consistently said that they wanted "everything done".

On day 63 of her hospitalization, a palliative care consult was initiated to help clarify the goals of care and to treat the patients' evident pain and discomfort. She was persistently moaning in pain and resisting all efforts to reposition or transfer her or to change her dressings. The palliative care team met with her son (her health care proxy) and her two grandchildren. During a 90 minute discussion, the team explored with the family what they hoped to accomplish for the patient. The team reviewed the hospital course and clarified any confusion about her diagnosis and prognosis. Possible sources of discomfort and pain were identified. A treatment plan was initiated which included morphine sulfate to treat the pain associated with her necrotic foot, discontinuing her antibiotics, withholding hemodialysis for her acute renal failure, treating her fevers with acetaminophen, and transferring her to the palliative care unit. The patient was discharged 2 days later when a bed in a nursing home with a hospice contract became available. The family expressed tremendous satisfaction with the resolution of her hospitalization and continued to visit her daily in the nursing home where she was reported to be interactive and comfortable until her death 2 months later.

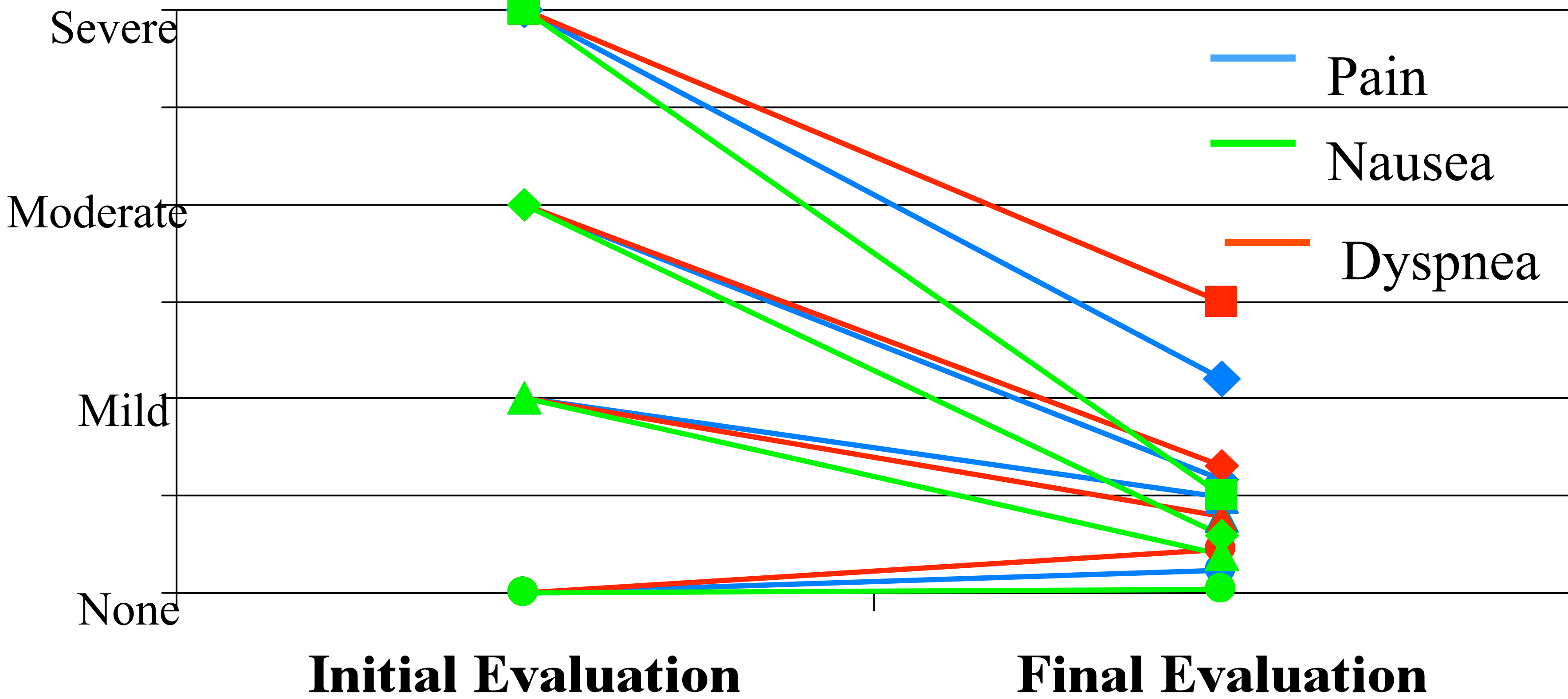
Case 1. Clinical and Financial Impact of Palliative Care Service at Mount Sinai Hospital

- Documentation of patient demographics
- 723 consecutive patients prospectively studied
- Recommendation and implementation rates recorded

Palliative Care Service Diagnoses 4/97 – 3/02



Improvement in Symptoms for 2500 Mount Sinai Hospital Patients Followed by the Palliative Care Service (6/97-10/02)



Percent of Palliative Care Families Satisfied or Very Satisfied Following Their Loved Ones Death With:

- Control of pain - 95%
- Control of non-pain symptoms - 92%
- Support of patient's quality of life - 89%
- Support for family stress/anxiety - 84%
- Manner in which you were told of patient's terminal illness - 88%
- Overall care provided by palliative care program- 95%

Source: Post-Discharge/Death Family Satisfaction Interviews, Mount Sinai Hospital, New York City

What Does All this Mean from the Patient Perspective?

For patients, palliative care is a key to:

- relieve symptom distress
- navigate a complex and confusing medical system
- understand the plan of care
- help coordinate and control care options
- allow simultaneous palliation of suffering along with continued disease modifying treatments (no requirement to give up curative care)
- provide practical and emotional support for exhausted family caregivers

The Clinician Perspective

For clinicians, palliative care is a key tool to:

- Save time by helping to handle repeated, intensive patient-family communications, coordination of care across settings, comprehensive discharge planning
- Bedside management of pain and distress of highly symptomatic and complex cases, 24/7, thus supporting the treatment plan of the primary physician
- Promote patient and family satisfaction with the clinician's quality of care

The Hospital Perspective

For hospitals, palliative care is a key tool to:

- effectively treat the growing number of people with complex advanced illness
- provide service excellence, patient-centered care
- increase patient and family satisfaction
- improve staff satisfaction and retention
- meet quality standards
- rationalize the use of hospital resources
- increase capacity, reduce costs

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The patient's good and the ends of medicine

If medicine takes aim at death prevention, rather than at health and relief of suffering, if it regards every death as premature, as a failure of today's medicine- but avoidable by tomorrow's- then it is tacitly asserting that its true goal is bodily immortality… Physicians should try to keep their eyes on the main business, restoring and correcting what can be corrected and restored, always acknowledging that death will and must come, that health is a mortal good, and that as embodied beings we are fragile beings that must stop sooner or later, medicine or no medicine.

Kass LR. JAMA 1980;244:1947

Summary: *Making the Case*

- Palliative care improves quality of care for our sickest and most vulnerable patients and families.
- Universal human experience and universal health professional obligation.

Although the world is full of suffering, it is also full of the overcoming of it.

Helen Keller

Optimism **1903**

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- Publications:
  - A Guide to Establishing a Hospital-Based Palliative Care Program
  - Hospice-Hospital Partnerships
  - The Case for Hospital Based Palliative Care