# The Evolving Role of Palliative Care in the U.S. Health System

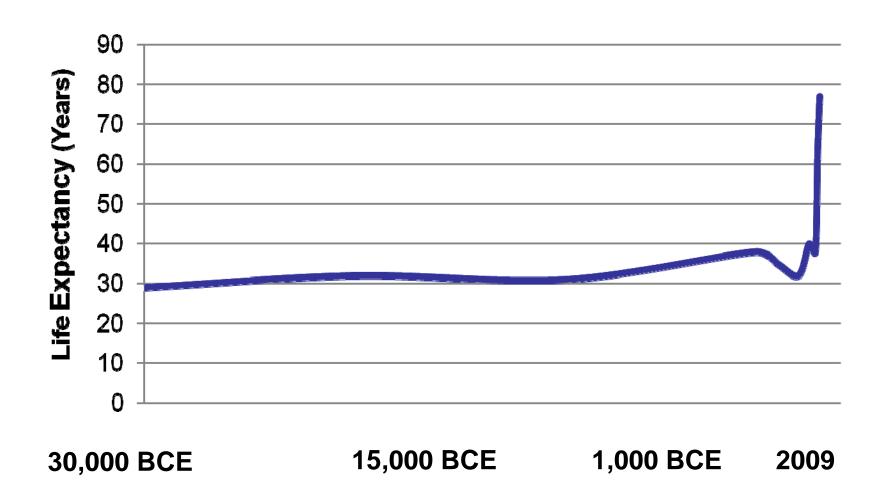


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### Median Life Expectancy in Years





### Life Expectancy in 2011



- 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)





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

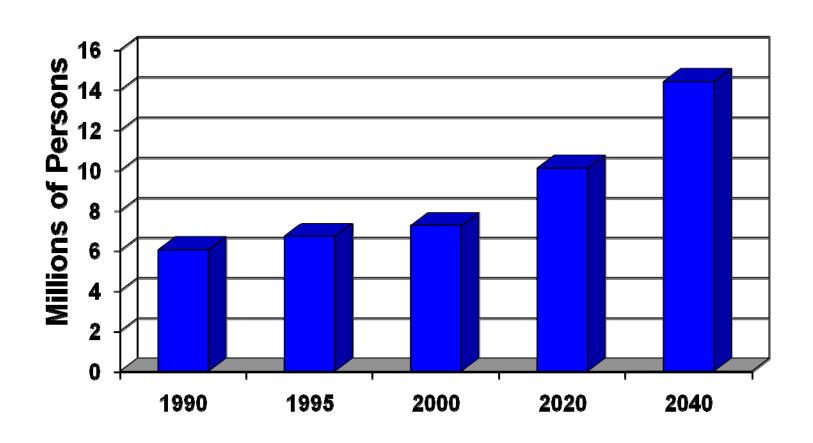




- Vascular Dementia
- Diabetes
- Oxygen dependentCOPD
- Advance heart failure
- Arthritis
- Dependent in activities of daily living
- 4 hospitalizations in past year

# Projections of Noninstitutionalized Population Age 65 and Over with ADL Limitations





# Care For the Seriously III at the Turn of the Century (2000)



- Untreated physical symptoms
- Unmet patient/family needs
- Impoverishment from health care costs
- Inadequately trained health care professionals
- An unresponsive health care system facing enormous and increasing expenditures

#### 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."

IOM: Crossing the Quality Chasm: A New Health System for the 21<sup>st</sup> 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



#### Palliative Care:

A Possible Solution to the Health Care Crisis

### Palliative Care: A Definition



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

Team based care.

Provided simultaneously with all other disease-directed and curative treatments.

# Why is Palliative Care the Solution?

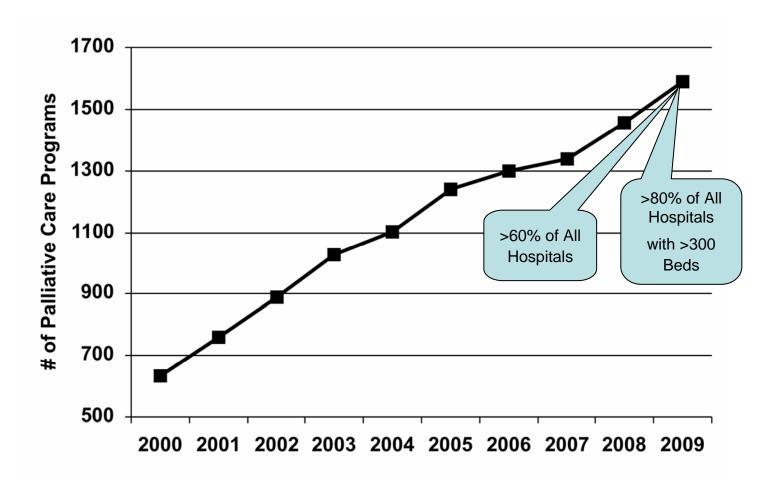


- Improves patients quality of life
  - Reduces pain and other symptoms
  - Addresses patients goals
- Improves family satisfaction and well-being
- Reduces resource utilization and costs by matching treatments to goals

....and does so for the sickest 5% of Medicare beneficiaries driving over 50% of healthcare costs

### Growth of Hospital Palliative Care Teams





# Palliative Care Media Highlights 2010







THE WALL STREET JOURNAL.











Los Angeles Times

The Philadelphia Inquirer



#### How Did We Get Here?



- A clear body of evidence that demonstrated palliative care:
  - -Improves clinical quality
  - Addresses patient and family preferences
  - Assists physicians with their most complex and demanding patients
  - Addresses resource mis-utilization and reduces costs

#### Where Do We Go Next?



#### 2020 Goals

- All patients and families will know to request palliative care in the setting of serious and life-limiting illness
- All healthcare professionals will have the knowledge and skills to provide palliative care
- All healthcare institutions in the US will be able to support and deliver high quality palliative care



# This will require changes in state and federal policy...

#### How Do We Get There?



- Workforce
- Access and Quality
- Evidence base
- Public and professional misconceptions

#### Workforce



- Current problem:
  - 1,300 persons with serious and advanced illness
    - Compare to 1 oncologist per 145 newly diagnosed cancer patients or 1 cardiologist per 71 MI victims
  - 26 states have no GME fellowship training programs in palliative medicine

#### Workforce



- Potential solutions
  - Adjust the GME cap to allow for development and expansion of palliative care fellowship training programs
  - Loan forgiveness programs for palliative care physicians, nurses, and social workers
  - Palliative care academic career development awards (HRSA) to support clinician educators in palliative care
  - Mid-career training awards to support retraining of current workforce in new specialty

### **Access and Quality**



- Current problem
  - 50% of hospitals (20% of hospitals with over 300 beds) lack a palliative care program
  - Standards for palliative care programs are voluntary
  - Business model = cost savings + MD reimbursement (difficult to demonstrate and sustain)

### **Access and Quality**



- Potential solutions
  - Bonus payments/penalties linked to palliative care delivery
  - Link palliative care to bundled payments
  - Establish a palliative care Resource Utilization Group (RUG) for nursing home reimbursement
  - Inclusion of palliative care in medical home models and accountable care organizations
  - Include palliative care in accreditation requirements (Joint Commission)
    - Move beyond certification (10/11)

#### Evidence base



- Current problem
  - Inadequate evidence base to support appropriate care of persons with serious and life-limiting illness
    - NIH Funding in 2009
      - 114 active NIH grants in palliative care
      - \$30,031,914 in FY 09 (.098% of total NIH budget)
        - » NCI: \$13,179,833 (0.27% of NCI budget)
        - » NINR: \$10,679,930 (7.5% of NINR budget)
        - » NIA: \$5,534,584 (0.8% of NIA budget)
  - Lack of junior and mid-career investigators
  - Lack of sustainable research centers

#### Evidence base



- Potential solutions
  - NIH/AHRQ reallocate 2% of current budget to focus on symptom relief, communication in the setting of serious illness, health services/comparative effectiveness research focused on patients with serious and advanced illness
  - Establish specific funding mechanisms in palliative care to support junior investigators and mid-career mentors
  - Establish Office of Palliative Care Research to coordinate research

### Public and Professional Misconceptions



#### Current Problem

- Palliative care is too often confused with "endof-life" care and hospice in the minds of the public, professionals, and policy makers
- Major barrier to ensuring access to high quality medical care for persons with serious and advanced illness

### Efforts to Improve "End-of-Life" Care (1995-2004)



- Project on Death in America
  - Soros's OSI initiative to fund palliative care initiatives
- Promoting Excellence in End-of-Life Care
  - RWJ initiative to support research/education in palliative care
- On our own terms: Moyers on Dying
  - 8 Hour series on palliative care
- Last Acts
  - RWJ consumer advocacy organization
- Approaching Death: Improving care at the end of life
  - IOM report

# Attitudes and Denial of Death:



What tormented Ivan Illych most was the deception, the lie, which for some reason they all accepted, that he was not dying but was simply ill, and that he need only keep quiet and undergo a treatment and then something very good would result.

## People have an abiding desire not to be dead....



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

## Public and Professional Misconceptions



- Potential solutions
  - Language matters!
    - Most 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. This will not change.
    - We cannot talk about "palliative care and end-oflife care" or "palliative care and hospice" together to the public, healthcare professionals, and policy makers – it confuses our audiences

### Final Thoughts



- If we truly want to improve care for persons with serious illness and their families, we need to recognize their values and needs
  - This means moving from "conversion" to "care"
- We need to speak with one voice and one message
  - "Palliative care is about improving quality of life and matching treatment to goals in the setting of serious or life-threatening illness".
  - "death", "end-of-life-care", or "care of the dying"
- We need to support public/private social marketing campaign to appropriately define and educate about palliative care, increase public demand, and promote effective bi-partisan legislation