The Future of Palliative Care

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An aging population and the need for change

Palliative care: A potential solution

Steps towards implementation
Life Expectancy in Western Europe (2014)

- Median age of death is 80 years.
- Among survivors to age 65, median age at death is 84 years.
- Among survivors to age 84, median age at death is 90 years.
- Doubling of the population over age 80 by 2030

Eurostat
Growth of the Aging Population in Europe

(2013, 2020, 2030, 2040, 2050, 2060, 2070, 2080)

- 80+ years
- 65–79 years
- 15–64 years
- 0–14 years

Source: Eurostat (online data codes: demo_pjangroup and proj_13npms)

(*) 2020–80: projections (EUROPOP2013)
"I would embrace the aging process if I could lift my arms."
• Breast cancer
• Mixed dementia
• Type II DM
• CHF
• COPD
• OA
• Dependent in most ADLs

Estimated that most older adults will spend at least 7 years with one or more major ADL deficiencies.
Symptom Burden of Community Dwelling Older Adults with Serious Illness

75% or more reported symptom as bothersome

Percent of patients reporting symptom

- Ltd Activity
- Fatigue
- Discomfort
- SOB
- Pain
- Lack Well Being
- Appetite
- Insomnia
- Weakness
- Depression
- Anxiety

Walke L et al, JPSM, 2006
The Family Burden of Serious Illness

• 65 million caregivers deliver care at home to a seriously ill relative
  – 40% deliver 20 or more hours of unpaid care
  – 87% state they need more help
  – 33% in poor health themselves
• Stressed caregivers are at significantly increased risk of death, major depression, reduced quality of life, and loss of work
• Economic costs: $375 billion/year (US)

• 5% of persons >65 have dementia
• 1 in 3 >85 have dementia
• 5.3 million Americans
• 90% require a caregiver
• Dementia triples healthcare costs for those >65
• 5th leading cause of death for those >65

Superman in his later years
Prevalence of Distressing Symptoms in Dementia

International Comparison of Spending on Health, 1980–2009

Average spending on health per capita ($US PPP*)

Total expenditures on health as percent of GDP

* PPP=Purchasing Power Parity.

Source: Commonwealth Fund National Scorecard on U.S. Health System Performance, 2011.
Palliative Care: A Possible Solution?

- Multiple studies know show:
  - Improves patients quality of life
    - Reduces pain and other symptoms
    - Addresses patients goals of care
  - Improves family satisfaction/well-being
  - Reduces resource utilization and costs
    - Matches treatments to goals
    - Allows provision of higher quality care in more appropriate, often less costly, settings.
Why is Palliative Care Important To Aging Populations?

Concentration of health expenditures for the U.S. Medicare population, by magnitude of expenditure, 2009

Source: Agency for Healthcare Research and Quality analysis of 2009 Medical Expenditure Panel Survey.
2020 Goals

• All patients and families will know to request palliative care in the setting of serious illness.
• All healthcare professionals will have the knowledge and skills to provide palliative care.
• All healthcare institutions in the area will be able to support and deliver high quality palliative care.
How Do We Get There?

• Workforce
• Evidence base
• Access and quality
• Public and professional attitudes and beliefs
• Current problem:
  – 1 palliative medicine MD for every 1,300 persons with serious illness in the U.S.
  • Compare to 1 oncologist per 145 newly diagnosed cancer patients or 1 cardiologist per 71 MI victims
  – Palliative medicine training is not required in the majority of European and U.S. medical schools and graduate (post-graduate) training programs
Evidence Base: Research Publications in Oncology and Palliative Care

391 unique grants to 294 investigators (0.2% of all NIH grants)

- 125 (32%) were funded by NCI (0.4% of all NCI research grants awarded)
- 123 (31.5%) were funded by NINR (7.6% of all NINR grants)
- 71 (18.2%) were funded by NIA (0.8% of all NIA grants)
- 6 (1.5%) were funded by NIMH (0.04% of all NIMH grants)

Gelfman, Du, Morrison, JPM, 2012
The Result:

- Current palliative care practice is guided by:
  - Data from other populations
  - Results from small series of patients from single institutions
  - Anecdote and hearsay

- Is this the type of care that we want for our parents or for ourselves?
What Is Needed

• Palliative medicine specialist training
  • Teachers, researchers, role models
• Promote ‘generalist level’ palliative care through undergraduate, graduate, and mid career training
• Support for palliative medicine researchers within academic medical centers
• Real investment in palliative care research
Patient Centered Care

- Advanced Organ Failure
- Chronic Critical Illness
- Frailty
- Dementia
- Cancer
- Stroke

Geriatrics:
- Well Older Adults
- Gait Disorders
- Preventive care
- Stable chronic dx
- Geriatric syndromes
- Peri-operative care
- Osteoporosis

Palliative Care:
- AIDS
- Cancer (<65)
- Genetic/Developmental Disorders
- Pediatric Oncology
- Cystic Fibrosis
- TBI

Icahn School of Medicine at Mount Sinai
National Palliative Care Research Center
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Palliative Care
Access: Europe

Map 3.
Services per inhabitants

TOTAL SERVICES PER MILLION INHABITANTS (adults)
- 1/16
- 1/32
- 1/64
- 1/128
- 1/256
- 1/512

Legend:
- No services
What is Needed

• Integrated healthcare delivery systems that focus on patient and family need
• New delivery models that recognize workforce gaps and fiscal realities
  – Quality and business case
• Focus on generalist palliative care training
• Integration of geriatrics and palliative care
• Quality metrics that integrate into routine care and are appropriate for improvement and accountability
NHS End of Life Care Strategy:

“To tackle the taboo on discussing death, the Strategy proposed ‘A national coalition to raise the profile of end of life care and to change attitudes to death and dying in society.’” The National Council for Palliative Care has set up the Dying Matters coalition.
Changing Attitudes: US

- 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

Total Investment: Over $300 million.
People have an abiding desire not to be dead….

“Better to flee from death than feel its grip.”

Homer, Greek poet

“The weariest and most loathed worldly life that age, ache, penury, and imprisonment can lay on nature is a paradise to what we fear of death.”

William Shakespeare, English playwright

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

Woody Allen, American humourist and filmmaker
It’s Not About the End of Life: Top 5% of Spenders

- Population at the end of life: 11%
- Population with persistently high costs: 49%
- Population with a discrete high-cost event: 40%

Source: Aldridge, Kelley, 2014: Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life, IOM Report
If our goal is to improve care of the 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 really wants to die and many are unable to accept that they are dying until death is imminent.

We need to decouple palliative care from end-of-life and terminal care.
Palliative Care: A Patient Centred Definition

- Specialized medical care for people with serious illnesses that provides an added layer of support to improve quality of life for patient and caregivers - whatever the diagnosis.
- Provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an extra layer of support.
- Appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatments.
Public Attitudes Towards Palliative Care

Telephone survey of 800 Americans

- **95%** of respondents believe patients with serious illness and their families should be educated about palliative care.
- **92%** of respondents say they would want palliative care for themselves or a loved one if they had a serious illness.
- **92%** of respondents say palliative care services be available at all hospitals.

Palliative Care in Transition

Old

Life Prolonging Care

Medicare Hospice Benefit

New

Disease Directed Care

Hospice Care

Bereavement

Dx

Death

Palliative Care
Summary

• The needs of an aging society demand changes in how we deliver healthcare
• Palliative care impacts on the value of health care by improving quality
• Better quality reduces need for acute, high cost care
• Palliative care integration in health systems is essential for improved care of the seriously ill
Do the right thing. It will gratify some people and astonish the rest.

Mark Twain (1835 - 1910)