Where We Are & Where Are We Going

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APPROXIMATELY NINETY MILLION AMERICANS ARE LIVING WITH SERIOUS ILLNESSES...

This number is expected to more than double over the next twenty-five years.

Patients with chronic illness in their last two years of life account for about 32% of total Medicare spending, much of it going toward physician and hospital fees associated with repeated hospitalizations. (Dartmouth Atlas 2015)

Suffering at End of Life

Despite national efforts to improve end-of-life care, proxy reports of pain and other alarming symptoms in the last year of life increased from 1998 to 2010. (Singer et al, 2015)
Hospitals are full, often with people who don’t want to be there.

- Hospitals report 90%+ occupancy.
- More people are using the ICU and dying there. (Lubitz and Reilly, 2011)
- ICUs are profitable. Every hour of ICU diversion costs the health system $1200/hour in profit.
- This is not where people want to be, or die, if one asks. (Mostly)
- Oncologists ask about advance directives only 2% of the time, even though 90% of patients think ADs are important and want to talk about them. (Dow et al. J Clin Oncol 2010)
- The typical patient spends 19.7 days in hospice care, down from 21.3 days in 2008. (AMA 2012)
- 30% of hospice patients are not referred until their last week of life, and 10% in their last twenty-four hours of life too late to have much impact on the experience of their illness. (Teno 2007)

Medicare Beneficiaries End of Life Preferences

- 40.4% concerned about too little treatment
- 45% concerned about too much treatment
- 86% preferred to spend their last days at home
- 83% did not want potentially life-prolonging medications that made them feel worse
- 71.7% wanted palliative medications, even if they might be life-shortening
- 87.4% would not want to be put on a ventilator to gain 1 week of life
- 77.4% would not want to be put on a ventilator to gain 1 month of life

92% of the American public are highly likely to consider palliative care for themselves or their families if they have a serious illness.

92% also said it is important that palliative care services be made available at all hospitals for patients with serious illness and their families throughout the United States. (Public Opinion Strategies Poll, April 2011)
Life Expectancy

- 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.

Symptom Burden of Community Dwelling Older Adults with Serious Illness

- High Cost ≠ High Quality of Care

- Health system facing unprecedented growth of an aging population
- Documented failure to recognize and treat pain and other distressing symptoms
- Widespread use of costly medical technologies that fail to restore health and functional independence
- Exponential cost increases in care
- Dissatisfaction and confusion about medical care and the health system
We spend twice as much on Cancer but have the same survival rate for most diseases

Cancer care costs are rising exponentially
- from $100 to $150 billion due just to more of us
- $173 billion at 2% growth rate, which is likely to be 5 to 10%

Insurance premiums are rising and fewer people can afford them
- Insurance premiums: doubled 2000-10 (Kaiser Fndn).
- Patient responsibility > $4000, 2010
Medicare costs rise as hospice stays lengthen

- Increasingly long hospice stays have nearly doubled the amount Medicare is spending on patients in recent years, according to a new report from the Wall Street Journal.

- Medicare’s hospice coverage program was designed for patients who doctors deemed likely to die within six months, or 180 days. More than 106,000 beneficiaries received care averaging 1,000 days or more between 2005 and 2013, the report found. By that year, hospice spending climbed to $15 billion, almost double the amount eight years earlier.

- Those beneficiaries with extended lengths of hospice care cost Medicare 14% of its hospice spending, although they accounted for slightly above 1% of hospice patients.

- Fifteen years ago, the average length of stay for Medicare beneficiaries in hospice was 54 days, which climbed to an average of 88 days by 2013. At that time, more than a third of Medicare hospice payments were going to patients with at least a year of total hospice care. February 21, 2016

Hospice eligibility criteria restricts access...but do they identify patients with the greatest needs?

The Challenges

- 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

- 5% of persons >65 have dementia

- 1 in 3 >65 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
Palliative Care Workforce

• In next decade, a workforce shortage of approximately 15,000 palliative specialty-trained clinicians is predicted.
• It is critical to educate all health care professionals in palliative care.
• APRNs and PAs are essential to meet some of the demand. However, neither receive the education and training needed to fill those roles.

Deficiencies in Medical Education

• 74% of residencies in U.S. offer no training in end of life care.
• 83% of residencies offer no hospice rotation.
• 41% of medical students never witnessed an attending talking with a dying person or his family, and 35% never discussed the care of a dying patient with a teaching attending.

As of 2010 there were only 73 accredited training fellowship programs in the United States, collectively producing approximately 86 new palliative medicine physicians per year. (www.acgme.org 8/15; Billings & Block JAMA 1997)

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
Nursing Education in Palliative Care

- Over 1/3 Nurses averaged 1 hour per year of education. Most rated this education as fair.
- Communication rated first among needed education.

White, Coyne et al. 2000,2012

NIH Funding For Palliative Care 2006-2010

- 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, JPH, 2012

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?
Overcoming the Identity Problem

It is NOT about giving up!
Palliative Care improves:
• Quality of life and the quality of how people are living
• Communication about personal choice that helps align treatment with values to deliver person-centered and goal-concordant care
• Quality of care that reduces need for acute, high cost hospitals/ER/ICU

Palliative Care is Not Hospice

Acceptance is another frequent stumbling block to palliative care. Physicians practicing non-curative medicine do not always receive support from patients, family members, healthcare professionals or their social peers for their work to reduce suffering and follow patients’ wishes for end-of-life care. Education is therefore a key part of any program.

Finally, acceptance by patients and families is another vital piece of the puzzle. This means education about the purpose and benefits of palliative care. It also means keeping the patient and family informed so that they can be active participants in the plan of care. Understanding and accepting the prognosis early on is the key, because patients generally get the most benefit from palliative care when they enter the program early.

Bringing Palliative Care Everywhere

Who delivers it? Everyone.
• Primary palliative care – Management of common pain and symptoms and common communication skills to achieve goal-concordant treatment
• Specialty palliative care – More complex cases – refractory symptoms, challenging care planning and communication

Where is it delivered?
• In every care setting. Acute care settings, office based settings, home based settings, and long term care settings

When to deliver it?
• Early and often. As part of disease-directed treatment at diagnosis and continually across care continuum
• Screening checklists provide helpful primary palliative care trigger criteria

[Link to primary palliative care trigger criteria]

Disease Course and Care
Potential for PC from Diagnosis through Death

Many Programs Still Focused on EOL Care Today

The number of U.S. hospitals offering palliative care services is growing rapidly, palliative care teams have increased for the 11th consecutive year — from 658 (24.5%) in 2000 to 1,635 (65.7%) in 2010. This represents growth of 148.5%

Prevalence and distribution of palliative care programs in U.S. hospitals with 50 or more beds. States were assigned a letter grade based on the percentage of hospitals with palliative care programs. A grades were assigned to states in which over 80% of hospitals had palliative care programs, B grades to states with 61%-80% of hospitals with palliative care programs, C grades to states with 41%-60% of hospitals having palliative care programs, and D grades to states with 21%-40% of hospitals having palliative care programs.
Palliative Care Growth in the U.S.

- In 2012, hospital programs were serving over 6 Million patients each year.
- Palliative care prevalence and # of patients served has nearly tripled since 2000.
- 100% of the U.S. News 2014 – 2015 Honor Roll Hospitals Have a Palliative Care Team.
- 100% of the U.S. News 2014 – 2015 Honor Roll Children’s Hospitals Have Palliative Care Teams.

We Can Improve Care and Reduce Costs by What We Do and Don’t Do.

Doctors do not always make good transitions to end of life care

When a patient is dying discuss what the future holds.

Only 37% had that discussion. If they did...
- No difference in mental health or worry;
- 52% as likely to have heroic measures
- 4% ventilation
- 27% ICU
- 2.46 x DNR
- 2x hospice


Palliative Care Studies Show Reduced Costs

A number of studies show statistically significant savings – in addition to better care

Comprehensive 2014 literature review of studies, 2002-2011
- 46 studies in total; 31 using US data
- 5 US studies examined impact of hospital-based palliative care on health care expenditure
- Consistent results across studies finding palliative care was associated with significantly lower inpatient costs


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Palliative Care Trigger Tool

- Code status changed to DNR
- Conflict about stopping/starting life-prolonging treatment (e.g. dialysis, chemotherapy)
- Goals of care or code status discussion needed and/or surrogate or proxy distressed about decision-making
- Uncontrolled symptoms (pain, nausea, dyspnea, insomnia, fatigue, weight loss) that interfere with quality of life
- Marked decrease in functional status/ADLs in last 60 days
- Considering PEG tube placement
- Admitted from extended-care facility with ADL dependence or chronic care needs

In building a palliative care program, funding (or lack thereof) is often the most difficult aspect. In the United States, palliative care services are paid for by philanthropy, fee-for-service arrangements or from direct hospital support (unlike hospice care, which is covered by Medicare, Medicaid and most private health insurers).

What is needed

- 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
The Future of Palliative Care:

- Home-based
- Population-centered
- Increasingly integrated with inpatient and outpatient care
- Quality-driven
- Funded by cost-avoidance/gain-sharing

Why is now the time for palliative care?

- The Affordable Care Act
- Goals of Care Payments
- HCAP Measurements
- Patient/Family care is getting wheels
- Team based health care is becoming an expectation

What we must do

- Need to be viewed as public health, an expectation of care
- Outcomes must be measured
- Be innovative ... ie telehealth, home visits, triggers
- We need to be seen as value based, we increase quality while decreasing costs
While there is cost savings, improved pt/family satisfaction, improved survival, our message is...

It’s the right thing to do!

Threats

- Need to measure what matters
- We practice in a medicine culture which may not share our vision
- Lack of trained clinicians

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 primary palliative care
- All healthcare institutions in the will be able to support and deliver high quality palliative care
A Call to Action...

What can we do now?

- A palliative care consult should be obtained at the onset of a life threatening diagnosis or seriously advanced illness. This way, people can receive comfort care while they are being treated for their illness. It will also ease the move to better end of life care once curative treatment is no longer effective. If you or someone you love has a serious illness, insist on a consultation.

- Implore Medicare to remove the six month rule on hospice enrollment. What can you do that won’t take much time? Use social media – tweet to @MedicareGov “Remove six month life expectancy requirements for hospice care. Pay for palliative care at the beginning of a serious illness.”

- Payment systems must change. Fee for service is a problem in all facets of our health care system and per diem fees present a different set of problems. What can you do about this? Nothing yet. I am hopeful the move toward patient centered medical homes will eventually produce solutions.

- Support organizations working on change in advanced care models. The Coalition to Transform Advanced Care is hot on this mission. They have organized hundreds of individuals and organisations to transform the way we help people with serious illness. Their national summit will be held on January 29 and 30 to frame the challenges, present solutions, and create an action plan for results. I look forward to their reports. Carolyn McClanahan 2013

Palliative Care Value Proposition Pyramid

Why Palliative Care is a Solution

- Improves patients’ quality of life
  - Reduces pain and other symptoms
  - Address patients’ goals

- Improves family satisfaction/well-being

- Reduces resource utilisation and costs
  - Matches treatments to goals
  - Allows provision of higher quality care in appropriate, often less costly, settings
Q&A