Improving Care for Seriously and Terminally Ill Patients

Christine Seel Ritchie, MD, MSPH
Division of Geriatrics
University of California San Francisco
Overview

• Chronic serious illness: our new reality

• The value equation: quality and cost in our new reality

• Improving systems of care through integration of palliative care
Figure 3 | Cumulative probabilities of reaching a proportion 60+ of one-third or more for the world and selected world regions by calendar year.
Global Aging

MA = median age

RLE=Remaining Life Expectancy  
Global Aging and the Snake who ate the Rat

Figure 3: Population pyramids for Germany in 1956, 2006, and 2050

Christenson et al. Lancet 2008
The Crisis of Chronic Illness

- Alzheimer's
- Cancer
- DM
- CHD
- OA
- HTN
- CVD

<table>
<thead>
<tr>
<th>Disease</th>
<th>Prevalence Estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic Illness</td>
<td>1 in 3</td>
</tr>
<tr>
<td>CVD</td>
<td>1 in 4</td>
</tr>
<tr>
<td>HTN</td>
<td>1 in 5</td>
</tr>
<tr>
<td>Arthritis</td>
<td>1 in 7</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>1 in 9</td>
</tr>
<tr>
<td>DM</td>
<td>1 in 12</td>
</tr>
<tr>
<td>CHD</td>
<td>1 in 17</td>
</tr>
<tr>
<td>COPD</td>
<td>1 in 20</td>
</tr>
<tr>
<td>Kidney Disease</td>
<td>1 in 26</td>
</tr>
<tr>
<td>Cancer</td>
<td>1 in 30</td>
</tr>
<tr>
<td>Alzheimer’s</td>
<td>1 in 68</td>
</tr>
</tbody>
</table>

Source: Centers for Disease Control; NHLBI, NIAMS
Chronic Illness and Aging

1 or more chronic conditions

Percent with...

Ages 50-64 Ages 65-74 Ages 75-84 Ages 85+

Johns Hopkins Bloomberg School of Public Health analysis Of MEPS, 2005 (Does not include people in institutions)
Chronic Serious Illness

• Longer survival with advanced disease
• High illness and symptom burden
• Management complexity increased
  – Patient/caregiver fatigue
  – Ongoing financial stressors from serious illness
  – Multiple providers
  – Dynamic goals and treatment preferences
  – Conflicting/interacting treatment regimens
Serious Chronic Illnesses in Older Adults: Some examples

- Chronic dialysis
  - 95% of those with chronic kidney disease are over 65 years of age (5.9 million)
  - Geriatric population most rapidly growing kidney failure population in the U.S.
  - In 2008, 80,000 adults 75 years and older received dialysis

Serious Chronic Illnesses in Older Adults: Some examples

• Cancer as a serious chronic illness
  – Breast cancer death rates decreased 31% between 1989 and 2007
  – Lung cancer (in men) death rate decreasing since 1990
  – Colorectal cancer deaths decreased by 3%/yr between 2003 and 2007

Cancer as a Chronic Serious Illness

Chronic Serious Illness: CHF

1-yr risk adjusted mortality rate for CHF

Chen, J. et al. JAMA 2011;306:1669-1678
Disease Trajectory

- Initial Therapy (curative)
- Relapse
- Progression-free
- Progression
- Deterioration
- Salvage Therapy
- Comfort Care (Hospice)
- Death

Illness Burden
The Challenge of Quality and Cost in our new reality

Value = \frac{\text{Quality}}{\text{Cost}}
Our Numerator: Quality

- 100,000 deaths/year from medical errors
- Millions harmed by overuse, underuse, and misuse
- Fragmentation
- Evidence Based Medicine <50% of the time
- U.S. ranks 40th in quality worldwide
Quality:
What Do Patients with Serious Illness 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

Quality:
What Do Patients with Serious Illness Want?

• To have trust and confidence in the doctors looking after you

• Not to be kept alive on life support when little hope for a meaningful recovery

• Information about one’s disease communicated to you by your doctor in a honest manner

Heyland DK et al. CMAJ 2006;174:5
Quality:
What Do Patients with Serious Illness Want?

• To complete things and prepare for life’s end
• To not be a physical/emotional burden to family
• Upon discharge, have an adequate plan of care
• To have relief of symptoms

Heyland DK et al. CMAJ 2006;174:5
Quality: 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
And What They Get …

Mortality follow-back survey of family members or other knowledgeable informants representing 1578 decedents

Not enough …

<table>
<thead>
<tr>
<th>Service</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>contact with physician:</td>
<td>78%</td>
</tr>
<tr>
<td>emotional support (pt):</td>
<td>51%</td>
</tr>
<tr>
<td>information about the dying process:</td>
<td>50%</td>
</tr>
<tr>
<td>emotional support (family):</td>
<td>38%</td>
</tr>
<tr>
<td>help with pain/dyspnea:</td>
<td>19%</td>
</tr>
</tbody>
</table>

And What They Get …

• 94 family members from 4 ICUs (teaching hospital or VA)
• Family perception of patient’s ICU dying and death:
  - Pain under control 47%
  - Keeping dignity and self-respect 32%
  - Breathing comfortably 3%

THANK YOU FOR SUFFERING IN SILENCE
“For people whose diseases will not be cured but instead progress despite aggressive treatments, the very places that are meant to provide the best care can become dystopias of discomfort, false promises, and foreboding.”

-Ira Byock, *The Best Care*
Our Denominator: Cost

- Health premiums for workers have risen 114 percent in the last decade.
- U.S. spending 17% GDP, >$7,000 per capita/yr
- Despite high spending, 15% of our population has no insurance (18% in AK)
- Lack of health coverage contributes to at least 45,000 preventable deaths/year.

Cost of Healthcare

Chart 1 - National Health Expenditures (NHE) as a Percentage of Gross Domestic Product (GDP)
1960-2007

Source: Centers for Medicare & Medicaid Services, Office of the Actuary
Cost of Healthcare

Source: OECD Health Data 2008.
## Multimorbidity and Medicare Expenditures

<table>
<thead>
<tr>
<th>Number of Chronic Conditions</th>
<th>Percent of Beneficiaries 65+</th>
<th>Percent Medicare Expenditures</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>18</td>
<td>1</td>
</tr>
<tr>
<td>1</td>
<td>19</td>
<td>4</td>
</tr>
<tr>
<td>2</td>
<td>21</td>
<td>11</td>
</tr>
<tr>
<td>3</td>
<td>18</td>
<td>18</td>
</tr>
<tr>
<td>4</td>
<td>12</td>
<td>21</td>
</tr>
<tr>
<td>5</td>
<td>7</td>
<td>63%</td>
</tr>
<tr>
<td>6</td>
<td>3</td>
<td>18</td>
</tr>
<tr>
<td>7+</td>
<td>2</td>
<td>24%</td>
</tr>
</tbody>
</table>

Cost: Personal Expenditures

- Private health insurance
- Medicare
- Out-of-pocket
- Medicaid (federal)
- Medicaid (state)

SOURCE: CDC/NCHS, *Health, United States, 2009*, Figure 22. Data from the Centers for Medicare & Medicaid Services.
How does palliative care contribute to the value equation in chronic serious illness?
Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.

73 FR 32204, June 5, 2008 Medicare Hospice Conditions of Participation – Final Rule
Supportive Care = Team Care

- Intake Review
- Tailored Plan of Care, & Referral to Community Resources
- Supportive Care and Counseling
- Spiritual Care
- Financial and Social Support
- Coordination
- Symptom management
- Nutrition Support
- Follow-up

Whole Person Approach

Tailored Interdisciplinary Assessment & Treatment Plan
Conceptual Shift for Palliative Care

Life Prolonging Care  Medicare Hospice Benefit

Old

Life Prolonging Care  Hospice Care  Bereavement

New

Palliative Care

Dx  Death

Copyright 2008 Center to Advance Palliative Care. Reproduction by permission only.
Palliative Care - Dynamic, Not Linear

- Initial Therapy (curative)
- Relapse
- Progression
- Progression-free
- Salvage Therapy
- Diagnosis
- Deterioration
- Comfort Care (Hospice)
- Death

Illness Burden

Burden of illness
Palliative Care and Patient/Caregiver Satisfaction

Mortality follow back survey palliative care vs. usual care (N=524 family survivors)

Overall satisfaction markedly superior in palliative care group, p<.001; Palliative care superior for:

- emotional/spiritual support
- information/communication
- care at time of death
- access to services in community
- pain
- well-being/dignity
- care + setting concordant with patient preference
- PTSD symptoms

Palliative Care, Quality and Costs

• In a prospective multicenter study of 332 seriously ill cancer patients, recall of occurrence of a prognostic/goals conversation was associated with:
  – Better quality of dying and death
  – Lower risk of complicated grief + bereavement
  – Lower costs of care
  – Less ‘aggressive’ care

Palliative Care and Healthcare Utilization

“Expanded” hospice/CM services to 387 Aetna beneficiaries with advanced illness

Spettell CM et al. JPM 2009; 12: 827-832
Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer


ABSTRACT

BACKGROUND
Patients with metastatic non–small-cell lung cancer have a substantial symptom burden and may receive aggressive care at the end of life. We examined the effect of introducing palliative care early after diagnosis on patient-reported outcomes and end-of-life care among ambulatory patients with newly diagnosed disease.

METHODS
We randomly assigned patients with newly diagnosed metastatic non–small-cell lung cancer to receive either early palliative care integrated with standard oncologic care or standard oncologic care alone. Quality of life and mood were assessed at baseline and at 12 weeks with the use of the Functional Assessment of Cancer Treatment.

Effect of Early PC on 12-week Psychological Distress

$\text{Temel J et al. NEJM 2010; 19:733-742.}$
Early palliative care

Median Survival
Early palliative care
11.6 mo
Standard care
8.9 mo
p=0.02

How might palliative care support patient centered care across the continuum?
How might palliative care support patient centered care across the continuum?

• Provider focus- education and specialty access

• System focus- triggers/care transitions

• Integration/technology focus- telehealth
Education in basic palliative care skills

- Advance care planning
  - What are the goals of care?
  - Are treatment options matched to informed patient-centered goals?
  - Has the patient participated in an advance care planning process?
  - Has the patient completed an advance care planning document?

Education in basic palliative care skills

- Communication skills (e.g. giving bad news; empathic opportunities)
  - Does the patient/family understand the current illness, prognostic trajectory and treatment options?
  - Are there significant social/spiritual concerns affecting daily life?

Education in basic palliative care skills

• Symptom assessment/management
  – Are there distressing physical or psychological symptoms?
  – Is there a management plan to address them?

“There’s no easy way I can tell you this, so I’m sending you to someone who can.”
Comanagement and Palliative Care

**concurrent care**

1. operating or occurring at the same time
2. running parallel
3. acting in conjunction
4. exercised over the same matter or area by two different authorities
System Focus: Care gaps in current palliative care delivery models
The Palliative Care Continuum

Triggers for Palliative Care: severity, illness burden, multimorbidity, ↓ function, ↑ utilization

Adapted from/courtesy of J Kutner
Health Status in the Population and Among Persons with Eventually Fatal Chronic Illness

- **Chronic, consistent with usual role**
  - Healthy

- **Chronic, progressive, eventually fatal illness**
  - Cancer
    - Time
    - Function
    - Death
  - Organ System Failure
    - Time
    - Function
    - Death
  - Dementia/Frailty
    - Time
    - Function
    - Death
Triggers for Specialized Palliative Care in the Hospital:

• You would not be surprised if the patient died within 12 months or to adulthood
• Difficult to control physical or psychological symptoms
• ICU stay $\geq 7$ days
• Lack of clarity/documentation re Goals of Care
• Disagreements or uncertainty concerning major med rx decisions

Weissman & Meier JPM 2011; 14:1-7
Triggers for Specialized Palliative Care in any setting:

- Awaiting or deemed ineligible for solid-organ transplantation
- Pt/family/surrogate physical emotional, spiritual or relational distress
- Pt/family/surrogate request for palliative care/hospice services
- Pt/medical team is considering/seeking counsel for feeding tube placement, tracheostomy, dialysis, ethics, LVAD, LTAC

Adapted from Weissman & Meier JPM 2011; 14:1-7
Types of Care Transitions: Settings

- Hospital
- Nursing Home
- Home
- Home with Home Health
- Home with Home Hospice
Types of Care Transitions: Goals

- Curative Care
  - Curative Care with Palliative Support
  - Palliative Care with Life Prolonging Intent
- Chronic Illness
- Non-curative Care
  - Palliative Care with Comfort Intent
Care Transition: A High Risk Event

• Approximately 20% of recently discharged patients experience adverse events, often precipitated by ineffective communication

• Almost 12% report new or worsening symptoms within 3 to 5 days of leaving the hospital

• One-quarter of Medicare beneficiaries post hospitalization experienced a complicated care transition within the first 30 days post-discharge

Care Transitions in Advanced Illness

• Mortality “follow-back” study of 690 pts in the Netherlands
• Died 'totally expectedly and non-suddenly'
• 709 transitions in the last 3 months, which involved a hospital two times out of three, and covered 43 distinct care trajectories
• 46% experienced one or more transitions in their last month of life.

Care Transitions: Last 3 months of Life

Of the 4,158 decedents, 9 percent visited the emergency department on the last day of life, 51 percent had visited it within thirty days before death, and 75 percent had visited within 180 days before death.
Characteristics Associated with ER use in the last month of life

- African American or Latino ethnicity
- Moderate or severe pain were 4 percent
- Patients who did not enroll in hospice early
- ADL dependency
- Lower levels of cognitive impairment

Smith A K et al. Health Aff 2012;31:1277-1285
Risk Factors for Care Transitions (CT) in Advanced Illness

• RF for CT last 30 days of life:
  – Male gender
  – Multi-morbidities,
  – Absence of GP awareness of a patient's wish for place of death

• RF for terminal hospitalization for > or = 7 days:
  – age of < or = 85 years
  – having an infection
  – absence of a palliative-centered treatment goal

Improving Care Transitions: Information Transfer between Providers

- Roles, lines of communication

- Treatment options, patient preferences, and treatment plans (e.g. POLST/MOLST)

- Communication/consensus building regarding relative benefit/burden of specific interventions (e.g. coumadin, statins, acetylcholinesterase inhibitors)
Improving Care Transitions: Patient/Caregiver Information

- What to expect
- What to do
- Who to call
Improving Care Transitions: Self Management Support

- Medications
- Follow-up
- Knowledge by pt/caregiver of red flags
  - Escalation of pain
  - Altered mental status
  - Fever
- Knowledge of “who to call”
Improving CT: Empowerment to Assert Preferences

- Anticipation and management of “what ifs”
- Understanding of what different programs and treatment settings do and don’t provide
- Access to a healthcare provider and decision maker
Care Transitions and Palliative Care

• Transition 1: would my patient benefit from supportive and palliative care to address illness burden?

• Transition 2: would my patient benefit from supportive and palliative care to manage their advanced illness?

• Transition 3: Is my patient reaching the last days of life?

Boyd & Murray. BMJ 2010; 341:c4863
Palliative Care, IT, and Telehealth

- Monitoring
  - Synchronous
  - Asynchronous

- Video-conversing

- Diagnosing

- Treating
A story of a good death…
Comfort, community, dignity...
Summary

• Our new reality of chronic serious illness is stressing our healthcare system

• Integration of palliative care into the continuum of care can positively impact outcomes

• There is an ocean of possibilities for using palliative care to improve the healthcare value equation