Caring for Older Adults at Life’s End: An Introduction to Palliative

Amy Corcoran, MD
Alicia Marini, MSW LSW

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Objectives

• By the end of this program, the participant will be able to:
  – Discuss the context for dying and death in America;
  – Describe the needs of persons with life-threatening illness and their families;
  – Define hospice and palliative care in lay language;
  – Explain hospice eligibility guidelines;
  – Discuss the importance of advance directives
Warm up exercise

What words would you use to describe a “good” death?
Discuss the context for dying and death in America
Death and Dying in America

• In the early 1900’s most Americans died from acute infections

• In 1900, the average life expectancy at birth was 47 years

• Most deaths took place at home; family were in attendance
Death and Dying in America

In contrast, most older Americans today live with one of more chronic illnesses, and most will die from a chronic illness

- In 2004, the average life expectancy was 77.9 years
  - In 2004, persons reaching age 65 had an average life expectancy of an additional 18.7 years (20.0 years for females and 17.1 years for males).
- Far fewer deaths take place at home; family are often little more than spectators
- By 1998, the nursing home surpassed hospital as place of death
- Death often follows a long period of functional dependence
What are the Barriers to Improving Palliative and End-of-life Care?

- The culture surrounding death
- Predominance of the curative model of medical care
- Health care provider education and skill
- Lack of coordination/communication among health care team members
- Inadequacy of reimbursement mechanisms
The Current Context for Palliative and End of Life Care

- Aging of the population
- Chronic illness continuum
- The “technological imperative”
- Location for death
- Advance directives
- Consumerism and self-determination
Aging of the Population

- **Adults >65**
  - increase from 35 M in 2000
  - to 40 M in 2010 (a 15% increase)
  - to 55 M in 2020 (a 36% increase for that decade).

- **2030 ~ 71.5 M older persons**, almost twice their number in 2005.

- **The 85+ population is projected to increase from**
  - 4.2 million in 2000 to
  - 6.1 million in 2010 (40%) and then to
  - 7.3 million in 2020 (44% for that decade).
Figure 1: Number of Persons 65+, 1900 - 2030 (numbers in millions)

Year (as of July 1)

20% of the population
Minority Older Adult Population

- Minority populations are projected to increase from
  - 5.7 million in 2000 (16.4% of the elderly population) to
  - 8.1 million in 2010 (20.1% of the elderly) and then to
  - 12.9 million in 2020 (23.6% of the elderly).
- Between 2004 and 2030, the white** population
  65+ is projected to increase by 74% compared
  with 183% for older minorities,
  including
  - Hispanics (254%),
  - African-Americans** (147%),
  - American Indians, Eskimos, and Aleuts**
    (143%), and
  - Asians and Pacific Islanders** (208%).
Chronic Illness

• 82% of Medicare beneficiaries have one of more chronic conditions\(^1\)
• 65% have multiple chronic conditions\(^1\)
• Medicare beneficiaries with 4 or more chronic conditions were 99% more likely to be hospitalized\(^1\)
• 75% of health care expenditures related to chronic conditions\(^2\)
• By 2020, approx. 50% of the population projected to have at least one chronic condition\(^3\)

Chronic Illness and End of Life: Functional Decline in Last Year

• Pattern of precipitous decline are seen in end stage cancer
• Higher level of functional impairment and more gradual decline in non-cancer end stage processes
  – > 40% of decedents with DM, CHF, COPD and CVA had ADL impairment 1 year prior to death

Technology as Companion at the End of Life

• In 1989, the majority of Americans (64.1%) who died from a chronic illness (CI) died in an acute care hospital.

• Hospital remains the most common site of death for persons with CI, but the proportion of hospital deaths is declining.
  – 1997: hospital death proportion had dropped to 51.8%
  – 2001: continued drop to 49.2%.

• An increasing proportion of people die at home and in nursing homes.

http://www.chcr.brown.edu/dying/USASTATISTICS.HTM
# Site of Death Changes

**Pennsylvania/ United States**

<table>
<thead>
<tr>
<th>Site of Death</th>
<th>1989</th>
<th>1997</th>
<th>2001</th>
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</thead>
<tbody>
<tr>
<td><strong>Home (%)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PA</td>
<td>17.2</td>
<td>21.5</td>
<td><strong>21.4</strong></td>
</tr>
<tr>
<td>US</td>
<td>16.2</td>
<td>22.5</td>
<td>23.2</td>
</tr>
<tr>
<td><strong>Nursing Home (%)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PA</td>
<td>20</td>
<td>27.9</td>
<td><strong>30.3</strong></td>
</tr>
<tr>
<td>US</td>
<td>17.7</td>
<td>23</td>
<td>23.7</td>
</tr>
<tr>
<td><strong>Hospital (%)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PA</td>
<td>61.4</td>
<td>49.0</td>
<td><strong>46.5</strong></td>
</tr>
<tr>
<td>US</td>
<td>63.4</td>
<td>51.7</td>
<td>49.2</td>
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Hospice Use in the United States

The number of Americans enrolling in hospice continues to grow, but the length of stay on a hospice program is short – approximately three weeks.

- An estimated 1.3 million patients received services from hospice in 2006
  - This is a 162% increase in 10 years
- Approximately 36% of all deaths in 2006 were under the care of a hospice program.
- The average length of stay (2006) was 59.8 days
- The median length of stay was just 21 days

NHPCO. (2007). Facts and figures: Hospice care in America. Available at:
Mr. Jones Case

85 year old veteran with end stage lung disease on continuous oxygen who presents to his physician’s office complaining of a “tooth ache”.

Upon inspection found to have abscess behind his last right upper molar.

Oral surgery fellow performs I&D and patient is sent home on antibiotics.
The “abscess” persists and Mr. Jones undergoes a biopsy. Found to have highly undifferentiated adenocarcinoma.
Describe the needs of persons with life-threatening illness and their families
Public values concerning at the end of life: What do “consumers” want?

- The management of symptoms
- Spiritual and personal growth
- A familiar setting; surrounded by loved ones
- Understandable information to guide decision-making and planning
- Confidence that one will not be a financial, emotional, or physical burden to family members;
- The right to self-determination and control of treatment choices

Quality End-of-Life Care: Patients' Perspectives

- Receiving adequate pain and symptom management
- Avoiding inappropriate prolongation of dying
- Achieving a sense of control
- Relieving the burden on loved ones
- Strengthening relationships with loved ones

Prevalence of Symptoms at the End of Life

- Asthenia/fatigue: 90%
- Anorexia: 85%
- Pain: 75%
- Nausea: 68%
- Constipation: 65%
- Sedation and confusion: 60%
- Terminal dyspnea/secretions: 56-92%
- Dyspnea: 12-77%
- Xerostomia: 7-10%

- Brant, 1998
Define hospice and palliative care in lay language
What is Palliative Care?

• Previously: an “either/or” –
  – “an approach to the management of a terminal illness that focuses on symptom control and support rather than on cure or prolonging life”¹

• Current definition: appropriate across the continuum of serious illness –
  – “…an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other… physical, psychosocial and spiritual (problems).”²

What Is Palliative Care?

- Comprehensive management of physical, psychological, social, spiritual and existential needs
- Control pain and other symptoms
- Relieve suffering
## Markers for Initiation of Palliative Care in Geriatrics

<table>
<thead>
<tr>
<th>Disease-Independent Markers</th>
<th>Disease-Specific Markers</th>
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</thead>
<tbody>
<tr>
<td>Frailty</td>
<td>Symptomatic CHF</td>
</tr>
<tr>
<td>Functional dependence</td>
<td>Chronic lung disease</td>
</tr>
<tr>
<td>Cognitive impairment</td>
<td>Dementia</td>
</tr>
<tr>
<td>Symptom distress</td>
<td>Stroke</td>
</tr>
<tr>
<td>Family support needs</td>
<td>Cancer</td>
</tr>
<tr>
<td></td>
<td>Recurrent infection</td>
</tr>
<tr>
<td></td>
<td>DJD causing functional impairment and chronic pain</td>
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Palliative Care and Hospice Care at the End of Life

• When is the “end of life”?  
  – “the period during which an individual copes with declining health from an ultimately terminal illness, from a serious though perhaps chronic illness, or from the frailties associated with advanced age – even if death is not clearly imminent.”

What is Hospice?

- Hospice focuses on caring, not curing and, in most cases; care is provided in the person’s home.
- Hospice care also is provided in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities.
- Hospice services are available to patients of any age, religion, race, or illness.
- Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations.

Source: NHPCO Caring Connections. Available at: http://www.caringinfo.org/LivingWithAnIllness/Hospice.htm
Hospice History

• “Grass roots” spiritually-based and volunteer-centric movement that emerged as alternative to technological imperative and institutional death
• Hospice is patient/family centered, intensive, interdisciplinary care management and support for persons with serious, progressive illness who are approaching the end of life
• First US Hospice (Yale) – 1974
• Medicare reimbursement - 1982
History of Hospice Care

• Derived from “hospes”, meaning “host”
• Defined classically as a “house of shelter or rest for pilgrims, especially one kept by a religious order”
• St. Christopher’s Hospice founded by Dame Cicely Saunders in 1967
Medicare Hospice Benefit

- Implemented in 1983
- Administered through Medicare-certified hospices
- Per diem reimbursement and capitated
- Medicare Part A benefit
- Standard Medicare benefits are waived for the terminal illness when the patient elects hospice
Basic Premises...

• We have a right to choose where and how we shall live, which includes a choice of when and how we shall die

• Dying is a process, similar in some ways to the birth process, which can be facilitated by skilled practitioners

• Death takes but an instant; every preceding moment is a moment of living (Kübler-Ross)
Goals of Hospice Care

- To support individuals and families coping with dying
- To enhance quality of life through comfort care rather than treatment focused on cure
- To aggressively treat and expertly manage all pain and physical symptoms associated with an individual's dying
- To care for the whole person, addressing physical, emotional, psychological, spiritual, and social needs through an interdisciplinary team approach
- To confirm the individual's and family's sense of self worth, individuality, autonomy, and security
- To acknowledge and offer support for individuals and their family members facing the losses and grief associated with dying and the death of a loved one
- To extend bereavement support for family members following the death of their loved one
- To be a positive influence upon the understanding, compassionate treatment, and care of the dying and bereaved

Myths about hospice care

✓ Hospice is only for patients with cancer
✓ Hospice is only for patients who are actively dying
✓ Patients can “use up” their Medicare Hospice benefits
✓ Patients “give up” Medicare benefits to enroll in hospice
✓ The patient who lives longer than 6 months will be discharged
✓ The physician must be certain that the patient’s life expectancy is 6 months
Hospice: Treatment for Suffering

• Physical pain and other symptoms of a disease
• Psychosocial concerns
  – Disability
  – Dependence
  – Loss of role
• Spiritual concerns
  – Fear of the future
  – Fear of death
Qualities of suffering…

- Suffering is not confined to physical symptoms
- Suffering results from the disease as well as its treatment
- Clinicians need to ask patients about the sources of their suffering

Mr. Jones (continued)

- He is also found to have a solitary lung nodule and is seen by both ENT and Pulmonary at this point.
- He is usually home bound and is not interested in aggressive therapies (i.e. surgery or radiation).
Patient Eligibility for Hospice

• Progressive, irreversible illness
• Limited life expectancy (typically 6 months)
• Goals are palliative rather than curative
• Patient chooses hospice care
• Two physicians certify illness and prognosis
Hospice eligibility ARE guidelines!
General Core Indicators

- Life-limiting condition with clinical progression (may be due to a specific diagnosis, a combination of diseases, or there may be no specific diagnosis defined)
- Weight loss >10% over 6 months
- Serum Albumin < 2.5 gm/dl
- Dependence in most Activities of Daily Living (dressing, bathing, feeding, continence of urine and stool, transfers, and ambulation to bathroom)
- **Karnofsky Performance Status** < 50%
The Medicare Hospice Benefit: Levels of Care

• Routine Home Care
  – Home
  – Nursing home
  – Inpatient facility (Hospice residence)

• Continuous care

• Inpatient respite care

• General inpatient care
Hospice Per diem reimbursement: How it works

- 24 hr. on call
- Nursing visits
- Nutrition counseling
- Medical equipment
- Supplies
- Medications
- Bereavement care
- Volunteers
- Home health aide/homemaker
- Spiritual counseling
- Medical oversight
- PT, OT, Speech
- Social work and counseling

~$150 per patient per day
Overview:
Palliative Care/Hospice Care in Context

• **Palliative Care**
  - An approach to care that emphasizes choice, control, and comfort *at any point on an illness trajectory*
  - *No current reimbursement* model
  - Interdisciplinary care that addresses to patient/family’s physical, psychosocial, spiritual and financial needs

• **Hospice Care**
  - An approach to care at the *end of life* (last 6 months) that emphasizes choice, control and comfort
  - Reimbursed under the *Medicare* program and subject to Medicare regulations
  - Interdisciplinary care that addresses to patient/family’s physical, psychosocial, spiritual and financial needs
Discuss the importance of advance directives
Who in this room has an advanced directive?
Patient Self-Determination Act (PSDA)
Passed by congress in 1990

The law mandates that, in those healthcare institutions which receive Medicare or Medicaid funding, patients must be informed in writing upon admission of:

1. their right to accept or refuse treatment
2. their rights under existing state laws regarding advance directives
3. any policies which the institution has regarding the withholding or withdrawing of life-sustaining treatments

Types of Advance Directives

What is a Living Will?

- usually covers specific directives as to the course of treatment that is to be taken by caregivers, or, in particular, in some cases forbidding treatment (i.e. intravenous fluids or tube feeding) when someone is incapacitated due to a terminal illness

What is a Healthcare Power of Attorney?

- appoints an individual (a proxy) to direct health care decisions should the principal be unable to do so (or not want to), usually a family member or close friend
Why is communication so important?

• The common pathway to relief of suffering
• Generates the most gratitude (and complaints)

Clues to the Patient’s Perspective on Illness

- Direct statements
- Expression of feelings
- Attempts to explain
- Speech clues
- Sharing a personal story
- Behavior clues

Lang, Floyd, & Beine (1999). Archives of Family Medicine, 9, 222-227.
Cultural Context: Influence of Ethnicity and Race

- **Autonomy**
  - “Truth-telling”
  - Communication of preferences

- **Preferences for Life-sustaining Treatment**
  - Mistrust
  - Fear of abandonment
  - Unfamiliarity with options
  - Values related to aggressive support
5 Wishes

1. Which person you want to make health care decisions for you when you can't make them.

2. The kind of medical treatment you want or don't want.

3. How comfortable you want to be.

4. How you want people to treat you.

5. What you want your loved ones to know.
Case Follow-up

• Mr. Jones is currently on the home hospice Medicare benefit. His goals of care are focused solely on comfort and symptom management.
What does the future hold for end of life care in the United States?
How can we meet the needs of greater numbers of patients?

• Minority patients are more likely to die in the hospital

• Medicare beneficiaries who live in poverty areas have higher end of life costs and are less likely to use hospice

• Nearly 1/3 of all Medicare decedents spend all or part of the year of death in a facility (typically a nursing home)
  – Annual mortality rate for Medicare-covered facility residents exceeds 20%
  – More than half of full-year facility residents are dually eligible Medicare/Medicaid

(MedPAC, 2000)
End Of Life is a Public Health Issue

• Considerable burden for patients and caregivers
  – Threatens the health and well-being of a large population of people
• Social and economic costs
• Potential for both promotion of optimal health and prevention of disease-related suffering and morbidity
• Need for improvements in health care systems to address the issue, e.g.
  – Large scale education programs
  – Population-based strategies to destigmatize death

(D’Onofrio & Ryndes, 2007; Singer & Bowman, 2002; Rao, Anderson & Smith, 2002).
“Every patient deserves a peaceful and dignified death.”

- A. Corcoran
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