The Role of Palliative Care and Hospice in Dementia Care

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Objectives

- Describe the demographics of aging and how this has shaped care needs
- Review evolving models of palliative and hospice care
- Show how palliative care principles inform dementia care, with focus on:
  - Trajectory of illness
  - Prognostication
  - Advance Care Directives
  - End of Life Care and Decision-Making
Why Palliative Care?
US Population > 65 years of age
- 35.6 million Americans total
- Most rapidly increasing sub-group in the population
  - In 2000: 1 out of 8
  - In 2030: 1 out of 5

Seniors living with a spouse
- Two out of three between ages 65–74
- One out of five over age 85

Alzheimer’s disease and other dementias
- 5.4 million in US in 2013; 16 million projected by 2050
- By age 85, 45% of population has dementia
- 5th leading cause of death in those > age 65

CDC, US Census, 2002
Effects of Health Care Changes: Patients Living Longer and Sicker

1900s

Today

Health

Chronic Disability

Years of Age

0

55

60

70

90
Clinical Trends for Older Adults

- Median age of death in US: 78.2yrs and rising
- Majority of deaths occur after 65 years of age
- Multiple chronic illnesses: gradual decline, disability and death (77% non-cancer)
Managing multiple chronic conditions in the community with increasing levels of disability.

Vulnerable due to:
- Strained caregiver systems
- Limited decisional capacity and financial resources.

Lack coordination of care.

Older patients: visits to ED for complaints related to chronic illnesses with limited likelihood of survival.
The Perfect Storm: the Need for Palliative Care

- Older, sicker, chronic patients
- “Under treatment” of pain, esp. in acutely ill patients
  - Appreciation, recognition, treatment
  - “Fifth” vital sign (Joint Commission)
- Consumer movement
- Quality of care movement
- Dramatic increases in cost of care
What is Palliative Care?
What Is Palliative Care?

- Surprisingly difficult to define

- *Not defined by:*
  - *Body system* (compare with dermatology, cardiology)
  - *What is done* (compare with anesthesiology, surgery)
  - *Age* (compare with pediatrics, geriatrics)
  - *Sex* of patient (such as with gynecology)
  - *Location of Care* (compare with ER, critical care)

Any illness, any age, any location…
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
Palliative Care: Key Characteristics

- Patients with serious, progressive and life-threatening medical conditions
- Patients with “life-limiting” conditions
- Focus on symptoms, not the underlying disease
- Focus on quality of life, not longevity
- Unit of care = patient and caregivers
Palliative Care Components

- Advance Directives
- Difficult Decisions
- Pain & Symptom Management
- Goals of Care
- Improve Communication
- Hospice Care
Overall Goal of Palliative Care: Improve Quality of Life

- Eliminate or reduce emotional, spiritual and psychosocial discomfort
- Ameliorate symptoms: mood, pain, fatigue
- Establish goals of care and advance care directives
- Provide End of Life and Bereavement care
- Support for caregivers
Potential Palliative Care Interventions

Control of
- Pain
- Dyspnea
- Nausea
- Vomiting

Support
- Emotional
- Spiritual
- Psychosocial

Variable
- Infections
- Hypercalcemia
- Tube Feeding
- Dialysis

Generally Not Palliative
- CPR
- Ventilation
- Highly burdensome Interventions

Palliative
Palliative Care vs. Hospice

- **Palliative care** is appropriate at any point in a serious illness. It is provided at the same time as life-prolonging treatment. No prognostic requirement, no need to choose between treatment approaches.

- **Hospice is a form of palliative care** that provides care for those in the last weeks/few months of life. Patients must have a 2 physician-certified prognosis of <6 months + abandon Medicare coverage for “non-palliative” treatments in order to be eligible.
Hospice is a “type” of palliative care for those who are at the end of their lives.
Palliative Care vs. Hospice Care

**Palliative Care**
- No life expectancy limit
- Covered under traditional medical insurance or Medicare
- More aggressive treatment of symptoms without compromising quality of life

**Hospice Care**
- Life expectancy of 6 months or less
- Covered under Medicare
- Pain management to allow patient to die with dignity

**Quality of Life**
- Emotional, Physical, & Spiritual Support

This diagram illustrates the key differences between palliative care and hospice care, focusing on important aspects such as life expectancy, coverage, and quality of life support.
Conceptual Shift: Models of Palliative Care
Traditional Model of Illness and Care

- Curative Treatments
- Hospice
- Bereavement Care

Institute of Medicine
Palliative and Disease-Modifying Treatments

- Increasingly, both models are used simultaneously to varying degrees
- Can be combined with any and all other appropriate treatments
- **State of the Art**: Palliative care initiated at the time of diagnosis for life-limiting illness
Trajectory Model of Illness and Care

- Curative Treatments
- Hospice Appropriate
- Actively Dying
- Bereavement Care

Diagnosis

6m

Palliative care

Death
What is the difference between Palliative Care, End-of-Life Care, and Terminal Care?

**Palliative Care**
- Symptom Management
- Quality of Life
- Months to years

**End-of-Life Care**
- Initiate GOC discussions
- Underlying condition is irreversible
- Weeks to months

**Terminal Care**
- Introduction to Palliative Care
- New baseline shows declining function
- Actively Dying
- Terminal Care Orders
- Last hours to days

**Additional Points**
- GOC may fluctuate
- Anyone living with or at risk of a life-limiting illness
Palliative Care and Dementia at End of Life
Causes of “Dying” in the Elderly

- Cardiovascular diseases: CHF, Stroke, MI
- Pulmonary disease: Emphysema, COPD
- Neurodegenerative diseases: Dementia, Parkinson’s, ALS
- Frailty syndrome, also known as senile cachexia, or debility
- Cancers (23%)
Symptom Prevalence in the Geriatric Dying Patient

- Multiple symptoms at end of life
- Symptom prevalence INCREASES with age:
  - 7.4 symptoms in pts over 85 yrs
  - 5.7 symptoms in pts under 65 yrs
- Elderly patients less likely to report their symptoms as very distressing
PROGNOSIS

- More straightforward for cancer diagnosis
- Often unpredictable for chronic disease
  - COPD
  - Alzheimer’s Disease
  - Heart disease
  - Failure to Thrive/ Debilitation
Reality of the Last Years of Life: Death Is Not Predictable

Common Symptoms for Dementia Patients

Below are examples of the most common symptoms experienced by people who have dementia:

- 65% experience pain
- 60% experience confusion
- 80% experience fatigue
- 60% experience depression
- 70% experience incontinence

Faull and Woof 2002
Symptom assessment challenging for patients with dementia

- Patient self report is cornerstone of pain assessment
- Most pain and symptom assessment scales require language and cognitive skills
- In dementia true physical or affective discomfort can present with a wide range of signs and symptoms
  - Increased agitation, fidgeting, repetitive body movements
  - Increased calling out, verbalizations
  - Decreased cognition or functional ability
  - Change in sleep patterns, falls
  - Increased pulse, BP, sweating

Kovach C, et al., J. of Pain and Symptom Management, 1999
Reality of Death in Dementia

- Lengthy period of decline: uneven course
- Difficulty with prognostication
- Multiple chronic medical conditions
- Progressive losses: independence; control
- Heavy burden of symptoms: multifactorial
- Substantial care needs: often overwhelming for family caregivers
The Art of Prognostication

“Well, it’s not a good sign, that’s for sure ...”
Prognostication questions in dementia

- Patient’s question: “How long do I have before my mind is shot?”
- Health professional’s question: “Is s/he eligible for palliative care?”
- Family’s question: “How long does s/he have to live?”
- Caregiver’s question: “I am exhausted. How much longer can I do this?”
Prognosis in Dementia

Multi Infarct Dementia

- 6 year survival 11.9%

Alzheimer's disease

- 6 year survival 21.1%

Mölsä et al. Acta Neurologica Scandanavica Volume 74 Issue 2, Pages 103 – 107
Dementia as a life shortening illness

Little known as to why people with dementia die.

Three main considerations:

1. Death due to unrelated cause
2. Death directly from Dementia
3. Death as a result of interaction between dementia and other disease
Prognostication

- Time course and duration may be inexact
  - Physicians err on the side of being overly optimistic

- Ways clinicians may contemplate prognosis
  - Use Functional abilities
    - ADL’s
  - Use important events
    - Multiple hospitalizations, LTC placement
  - Use Mobility factors
    - Ataxia, falls, immobility, decubitus ulcers, fx
  - Use Nutritional factors
    - Dysphagia, Weight loss, Albumin<2.5
End–Stage Dementia: FAST

- FAST scale 7C (Functional Assessment Staging)
  - Not able to walk, dress, or bathe properly
  - Incontinent of bowel and bladder
  - Ability to speak, less than 5–6 intelligible words
  - Hospitalizations for aspiration pneumonia, sepsis, infected wounds, pylonephritis
  - Difficulty swallowing or taking in adequate nutrition, declining a tube for feeding

- However, FAST was:
  - Validated only with older onset Alzheimer’s dementia
  - Not an accurate assessment for other types of dementia and younger onset dementias
NH patients with dementia

- 1% thought to have prognosis less than 6 months
- 70% were dead in 6 months

Dementia: A Terminal Illness

- Cohort study of 323 NH patients with advanced dementia and their HCPs
- During the 18 month study period
  - 54.8% died
  - 41.1% had pneumonia
  - 52.6% had a febrile episode
  - 85.8% had a feeding problem
Proportion of Nursing Home Residents Who Had Distressing Symptoms at Various Intervals before Death.

Mitchell S., et al., NEJM, 2009
Dementia associated with higher death rate after pneumonia and hip fracture

- Prospective cohort study
- 216 patients, age >70
  - 97 with hip fracture: 59 cognitively intact; 38 with end-stage dementia
  - 119 with pneumonia: 39 cognitively intact; 80 with end-stage dementia
- 6 month mortality (dementia vs. intact cognition)
  - Hip fracture: 55% vs. 12%
  - Pneumonia: 53% vs. 13%

Morrison S and Siu A
JAMA, 2000
Dementia associated with decreased survival from breast, colon and prostate cancer

- Retrospective cohort study
  - 106,061 patients >68; 7% with prior dementia dx.
- Decreased survival with pre-existing diagnosis of dementia
- Increased mortality from cancer and non-cancer causes
- Increased odds of being diagnoses at unknown stage or more advanced stage

Dementia differs from other causes of death
- Prolonged median survival time (generally 4 yrs., but up to 9 yrs in some studies)
- Clinician and caregiver difficulty in viewing dementia as a terminal illness, even in late stages
- Current hospice enrollment criteria poorly predictive of terminal phase
  - Functional dependency
  - Recurrent hospitalizations
  - >10% weight loss

Sachs G, et al., JGIM, 2004
Barriers to excellent end of life care for patients with dementia

- Treatments for co-morbid conditions in dementia (e.g. infection) often psychologically difficult for surrogates to forgo
  - Fairly routine
  - Would not be burdensome to average person
  - Relatively painless
  - Effective in short run

- Institutional and health system factors also promote burdensome treatments

Sachs G, et al., JGIM, 2004
Patient and Caregiver Goals of Care
What Do Patients with Serious Illnesses 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

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 ...

Not enough contact with MD: 78%
Not enough emotional support (pt): 51%
Not enough information about what to expect with the dying process: 50%
Not enough emotional support (family): 38%
Not enough help with pain/SOB: 19%

Advance Care Planning
What is Advance Care Planning?

- Process of planning for future care
- Exploring patients’ goals and values
- Identifying proxy decision-maker(s)
- Proper documentation
- Key component: assessment of decisional capacity
Advance Care Planning

1. Advance Directives
2. Values
3. Goals/Expectations
4. Preferences/Wishes
Advance Directives

- Allow patients to make decisions on health care issues while they still have capacity
- Become effective when the patient loses decision making capacity
- Living will: documents that state the patients desires
Determining Medical Decision-Making Capacity

- Understand the nature of their illness
- Understand the risks and benefits of treatment options
- Able to process this information to make an informed decision
- Able to communicate their decisions
Assessing decision-making capacity

What is decision-making capacity?

- Relates to specific decisions
- Patients may be capable of making some decisions but not others
- May be determined by a physician
- Not the same as “competence”
SOME DEFINITIONS

- **Durable Power of Attorney for Health Care (Health Care Proxy)**
  - Appointing someone to make medical decisions for you if you cannot make them yourself
  - Does not require presence of AD or living will

- **Living Will**
  - Description of wishes about life sustaining medical treatments if one is terminally ill

- **Advance directives**
  - Instructions / guidance for health care should one become incapacitated
  - Can name an “agent” to make decisions for them
  - Wishes stated must be honored by surrogate unless court orders otherwise
  - Can be revoked at any time

Adapted from University of New Mexico Some
<table>
<thead>
<tr>
<th>A</th>
<th>CARDIOPULMONARY RESUSCITATION: for a patient in cardiac or respiratory arrest</th>
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<th>VENTILATION: for a patient in respiratory distress</th>
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<th>D</th>
<th>PATIENT or patient's representative signature</th>
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<td>Select one circle</td>
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Signature of patient confirms this form was signed of patient's own free will and reflects his/her wishes and goals of care as expressed to the Section E signer. Signature by the patient’s representative (indicated above) confirms that this form reflects his/her assessment of the patient’s wishes and goals of care, or if those wishes are unknown, his/her assessment of the patient’s best interests. “A guardian can sign to the extent permitted by MA law. Consult legal counsel with questions about guardian’s authority.”

|   | Signature of Patient (or Person Representing the Patient)  | Date of Signature |

|   | Legible Printed Name of Signer  | Telephone Number of Signer |

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<th>E</th>
<th>CLINICIANS signature</th>
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<td>Signature of physician, nurse practitioner or physician assistant confirms that this form accurately reflects his/her discussion(s) with the signer in Section D.</td>
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|   | Signature of Physician, Nurse Practitioner, or Physician Assistant  | Date of Signature |

|   | Legible Printed Name of Signer  | Telephone Number of Signer |

Optional
Expiration date and other patient care contacts
This form does not expire unless expressly stated. Expiration date (if any) of this form: ____________

Health Care Agent Printed Name: ____________ Telephone Number: ____________
Primary Care Provider Printed Name: ____________ Telephone Number: ____________

SEND THIS FORM WITH THE PATIENT AT ALL TIMES.
HIPAA permits disclosure of MOLST to health care providers as necessary for treatment.
# Proposed Goals of Care Grid

<table>
<thead>
<tr>
<th>Current state of health</th>
<th>CPR</th>
<th>Ventilator</th>
<th>Surgery</th>
<th>Blood Transfusion</th>
<th>Antibiotics</th>
<th>Feeding tube</th>
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<tr>
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<td>Yes</td>
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Advance Directives: benefits for elderly patients

- 3746 subjects >60 who had died 2000–2006
- Part of the Health and Retirement Study
- Proxies (knowledgeable informants) surveyed within 24 months of death re:
  - Prior completion of Living Will or Health Care Proxy
  - Need for decision making near the end of life
  - Loss of decision making capacity near EOL
  - Patients’ wishes regarding EOL care
    - As reported by proxy
    - As outlined in Advance Directives

Silveira MJ, et al. NEJM, 2010
Advance Directives: benefits for elderly patients

Results

◦ Of the 42.5% who required decision making, 70.3% lacked capacity (29.8% of decedents required surrogate decision making at the end of life)
◦ Of those, 67.6% had Advance Directives
◦ Patients with Advance Directives were more likely to receive their preferred level of care at the end of life
  • 89% of proxies reported that Living Will was applicable to most required EOL decisions
  • 50% of patients who requested all care possible received it
  • 80% of patients who requested limited care received it
  • 96% of patients who requested comfort care received it

Silveira MJ, et al. NEJM, 2010
Many patients with dementia lack capacity for ACP and completion of AD

Better disease understanding is associated with less aggressive EOL care

- Intervention showing short video to n=120 healthy patients, changed care preferences \(^1\)
- In study of n=323 NH patients with advanced dementia, health proxies with better understanding of prognosis chose less aggressive care \(^2\)

\(^1\) Volandes A et al. Arch Intern Med 2007
\(^2\) Mitchell et al. NEJM 2009
Caregiver Burden and Palliative Care
Family Caregivers: The Numbers

- 2011 United States estimates: 15 million caregivers deliver care at home to a relative with dementia
  - 17 billion hours of care giving, valued at more than $202 billion
- Unpaid caregivers provide >90% of all at home care for dementia patients
  Alzheimer’s Association, Thies, W etal, 2011;7(2);208–244

- 56% of elderly have incomes under $20,000 and spend >25% of it on healthcare for themselves and family members
  Report to Congress: Medicare Payment Policy Medpac; March 2003 www.medpac.gov

- Caregivers suffer physically and emotionally, incurring $7.9 Billion in additional healthcare costs in 2010
- More than 60% of caregivers report increased stress and 33% increased depression
  Torke etal, Neurology, 1998;51(Suppl):S53–60
Family Caregivers and the SUPPORT study

Patient needed large amount of family caregiving: 34%
Lost most family savings: 31%
Lost major source of income: 29%
Major life change in family: 20%
Other family illness from stress: 12%
At least one of the above: 55%

JAMA 1995;272:1839
900 family caregivers of terminally ill persons at 6 sites across the U.S.

- Women: 72%
- Close family member: 96%
- Over age 65: 33%
- In poor health: 33%

Caregiving Needs among Terminally Ill Persons

Interviews with 900 caregivers of terminally ill persons at 6 U.S. sites

- *need more help*: 87% of families
- transportation: 62%
- homemaking: 55%
- nursing: 28%
- personal care: 26%

Nurses Health Study: prospective study of 54,412 nurses

- Increased risk of MI or cardiac death: RR 1.8 if care giving >9 hrs/wk for ill spouse
  
  Lee et al. Am J Prev Med 2003;24:113

Population based cohort study 400 in-home caregivers + 400 controls

- Increased risk of death: RR 1.6 among caregivers reporting emotional strain
  
Benefits of Palliative Care
Data demonstrate that palliative care:

- Relieves pain and distressing symptoms
- Supports on-going re-evaluations of goals of care and difficult decision-making
- Improves quality of life, satisfaction for patients and their families
- Eases burden on providers and caregivers
- Helps patients complete life prolonging treatments
- Improves transition management
- Increased survival time
How Palliative Care Reduces Length of Stay and Cost

Palliative care:
- Clarifies goals of care with patients and families
- Helps families to select medical treatments and care settings that meet their goals
- Assists with decisions to leave the hospital, or to withhold or withdraw death–prolonging treatments that don’t help to meet their goals
Palliative care lowers costs (for hospitals and payers) by reducing hospital and ICU length of stay, and direct (such as pharmacy) costs.

Palliative care improves continuity between settings and increases hospice/homecare/nursing home referral by supporting appropriate transition management.

Honors residents’ wishes for dignity
Provides evidence based measures for good symptom management
Demonstrates partnering and collaboration with:
  ◦ patient, family, staff, and palliative care team
Provides a common platform to discuss
  ◦ Goals of Care
  ◦ Advanced Directives
What Does All this Mean from the Patient Perspective?

For patients and family, palliative care is a key to:

- relieve symptom distress
- navigate a complex and confusing medical system
- understand the plan of care
- help coordinate and control care options
- allow simultaneous palliation of suffering along with continued disease modifying and rehabilitative treatments (no requirement to give up curative care)
- provide practical and emotional support for exhausted family caregivers
Palliative Care and Hospice in Dementia:
Future Goals and Needs
Future Goals for Palliative Care

- Increase the number community based palliative care programs
- Enhanced reimbursement for community and hospital based palliative programs
- Improved training and education of health care providers
- Development of evidence-based treatment for patients with their dementia and their caregivers.
- Earlier diagnosis, better prognostic measures for dementia patients
- Better outcomes measures and research studies
"You matter because you are you. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but also to live until you die." ~ Dame Cicely Saunders