

Hospice and Palliative Care for Patients With Dementia

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Learning Objectives

At the end of this educational activity, participants should be able to

- Identify the challenges faced by health care professionals when managing dementia patients
- Recognize the impact of palliative care in helping dementia patients achieve the best possible quality of life with an effective pain and symptom management program
- Explain how hospice care can help dementia patients and provide their families greater satisfaction with end-of-life care

The Silver Tsunami

- People age 65 years or older
 - 11% of world population in year 2000
 - 22% in 2050
- Age-related diseases
 - Increasing prevalence, morbidity and cost

Dementia: Prevalence & Costs

- Dementia
 - 5-10% of people > age 65
 - 50% of people > age 85
 - 5.4 million Americans
 - 6th leading cause of death
 - \$200 billion in 2012

Alzheimer's Association 2014 Alzheimer's disease facts & figure

Risk Factors

- Dementia
 - Older age
 - Family history
 - Genetic factors (ApoE4)
 - Head trauma
 - Cardiovascular disease

The Stages of Dementia

- Mild or Early-Stage Dementia
 - Forgetfulness of recent events
 - Difficulty with complex tasks
 - E.g. planning dinner for guests, paying bills or managing finances
 - Forgetfulness about one's own personal history
 - Becoming moody or withdrawn
 - Especially in socially or mentally challenging situations

Source: Alzheimer's Association; accessed Sept 10, 2015:
http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp

The Stages of Dementia

- Moderate or Mid-Stage Dementia

- Cannot recall address or telephone number or the name of high school or college
- Become confused about where they are or what day it is
- Need help choosing proper clothing for the season or the occasion
- Still remember significant details about themselves and their family
- Still require no assistance with eating or using the toilet

Source: Alzheimer's Association; accessed Sept 10, 2015:
http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp

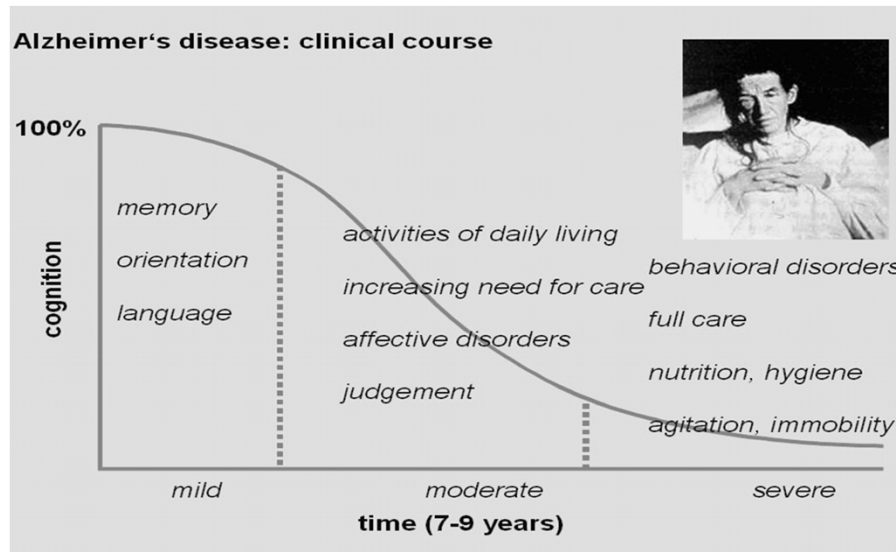
The Stages of Dementia

- Severe or Late-Stage Dementia

- Remember their own name but have difficulty with their personal history
- Trouble remembering the name of a spouse or caregiver
- Need help dressing properly
- Major changes in sleep patterns — sleeping during the day and becoming restless at night
- Need help with toileting and continence
- Personality and behavioral changes, including suspiciousness and delusions
- Tend to wander or become lost

Source: Alzheimer's Association; accessed Sept 10, 2015:
http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp

The Course of Dementia



Nitsch, R. (2004). *Alzheimer's Disease: Clinical Course Diagram Transparency*. BrainFair 2004, Zurich. Retrieved on November 17 at <http://www.ethlife.ethz.ch/e/articles/sciencelife/alzheimerimpfung.html>.

Dying with Advanced Dementia

- Study of 1609 persons 65 years or older with advanced dementia admitted to a nursing home
- Minimum Data Set (MDS) to describe end-of-life experiences
- Results:
 - 1.1% perceived to have <6 month life expectancy
 - 71% died within 6 months of nursing home admit
 - 55.1% had a do-not-resuscitate (DNR) order
 - 1.4% had a do-not-hospitalize (DNH) order

Mitchell S, et al. Arch Intern Med, 164 (3) (2004), pp. 321–326

Dying with Advanced Dementia

- Results:
 - 25% received tube feeding
 - 49.2% had laboratory testing
 - 11.2% had restraints
 - 10.1% had IV therapy

Mitchell S, et al. Arch Intern Med, 164 (3) (2004), pp. 321–326

Palliative Care

- Interdisciplinary medical specialty that focuses on:
 - preventing and relieving suffering
 - supporting the best possible quality of life for patients facing a serious illness and their families
- Benefits of Palliative Care
 - Improve patient symptoms
 - Lessen caregiver burden
 - Match resources/treatment with goals of care and needs

Palliative Care

- Recognized medical subspecialty in US, Canada, England, Ireland, Australia, and New Zealand
- Focuses on:
 - Symptom management
 - Establishing goals of care
 - Regular communication with patient/family
 - Care coordination across care sites
 - Relieve suffering in all its forms: physical, psychosocial, and spiritual

Hospice

- One word, 4 different meanings
 - Site of care of dying patients
 - Unit within hospital/nursing home or free-standing facility
 - Organization that provides care for dying patients
 - Approach to care of dying patients
 - Medicare benefit for beneficiaries with limited life expectancy

Palliative Care vs. Hospice

- Palliative care patients may NOT have a terminal diagnosis
- All patients in hospice care are dying
- Thus, any patient with a serious illness will be appropriate for palliative care

BUT....

Is Hospice Appropriate?

- Is Life Expectancy <6 months?
- Is there functional and physiologic decline?
- Have there been multiple hospital admissions or ER visits?
- Are there physiologic markers of decline
 - Low albumin (<2.5)
 - Weight loss of 10% over 6 months
 - Bed sores

Is Hospice Appropriate?

- Does patient/proxy understand that he has a life-limiting condition?
- Is the goal of care comfort rather than cure?

The Global Deterioration Scale (GDS)

- Validated instrument to assess the clinical progression of dementia
- Score ranges from 1 – 7 (higher = severe)
- GDS 7
 - all verbal abilities lost over this stage
 - Incontinent; requires assistance with toileting and feeding; loss of basic psychomotor skills (e.g. walking)
- http://www.mirecc.va.gov/visn21/pdf/GDS_Basic_Package.pdf

Reisberg B, Ferris SH, de Leon MJ, Crook T SOAm J Psychiatry. 1982 Sep;139(9):1136-9

Advanced Dementia Prognostic Tool (ADEPT)

- Validated tool based on Minimum Data Set
- 12-item score including:
 - Patient age
 - Gender
 - Functional dependence
 - Nutritional status
 - Medical conditions and symptoms
- Good specificity (89%); Low sensitivity (20%)

Mitchell SL, et al. J Pain Symptom Manage. 2010 Nov; 40(5): 639–651.

The Functional Assessment Staging (FAST) Criteria

FAST Scale Item	Activity Limitation Associated with AD
Stage 1	No difficulty, either subjectively or objectively
Stage 2	Complains of forgetting location of objects; subjective work difficulties
Stage 3	Decreased job functioning evident to coworkers; difficulty in traveling to new locations
Stage 4	Decreased ability to perform complex tasks (eg, planning dinner for guests, handling finances)
Stage 5	Requires assistance in choosing proper clothing
Stage 6	Decreased ability to dress, bathe, and toilet independently
Substage 6a	Difficulty putting clothing on properly
Substage 6b	Unable to bathe properly, may develop fear of bathing
Substage 6c	Inability to handle mechanics of toileting (ie, forgets to flush, does not wipe properly)
Substage 6d	Urinary incontinence
Substage 6e	Fecal incontinence
Stage 7	Loss of speech, locomotion, and consciousness
Substage 7a	Ability to speak limited (1–5 words a day)
Substage 7b	All intelligible vocabulary lost
Substage 7c	Nonambulatory
Substage 7d	Unable to smile
Substage 7e	Unable to hold head up

Reisberg B. Psychopharmacol Bull. 1988;24(4):653-9.

Progression of Advanced Dementia

- CASCADE Study
 - 323 nursing home residents with advanced dementia followed for 18 months
 - Results:
 - 55% died (median survival 1.3 years)
 - 41% had pneumonia; 51% fever; 86% eating problem
 - 6-month mortality rates
 - Pneumonia = 47%
 - Fever = 45%
 - Eating problem = 39%

Mitchell SL, et al. N Engl J Med. 2009;361(16):1529

Medicare Hospice Eligibility Guidelines

- FAST Stage 7c or beyond
 - Dependent on all ADLs
 - Occasionally or regularly incontinent of urine and stool
 - Unable to ambulate without assistance
 - No consistently meaningful verbal communication
- AND at least one of six medical complications in the prior year:
 - Aspiration pneumonia
 - Pyelonephritis or other upper UTI
 - Septicemia
 - Multiple decubitus ulcers stage 3-4
 - Recurrent fever after antibiotics
 - Inability to maintain sufficient fluid and calorie intake with 10% weight loss in the previous 6 months or serum albumin <2.5 g/dl.

Life Expectancy for Non-malignant Disease: Trigger Question

“Would you be surprised if this patient were to die in the next 6-12 months?”

Decision Making Steps in Advanced Dementia

1. Clarify the clinical situation
 - Educate health proxy about advanced dementia
2. Establish the preferred level or goal of care
 - Base care decisions on preferences
 - Comfort, Prolong Life, or ‘Middle of the Road’
3. Align treatment options with preferred level or goal of care

Mitchell SL. NEJM 2015;372:2533-2540

Hospice Care

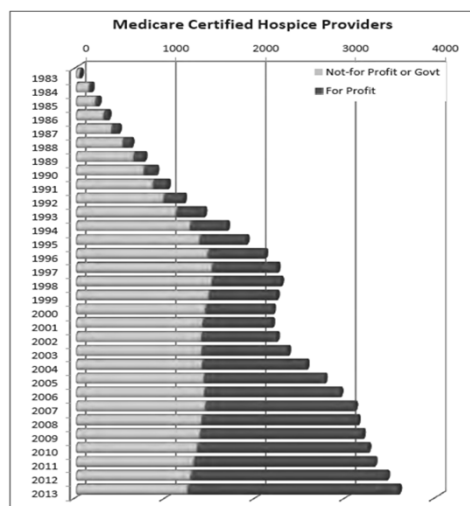
- Per diem:
 - Medicare – Part A (84% of hospice patients)
 - Physician fees – Part B
 - Medicaid (MediCal) – 47 states plus DC covers it
 - Private insurers – most but not all cover it; some cost-sharing possible
- Routine home care, inpatient respite and general inpatient care
- May be renewed if patient still alive in 6 months

http://www.nhpco.org/sites/default/files/public/Statistics_Research/2014_Facts_Figures.pdf

Medicare Hospice Benefit

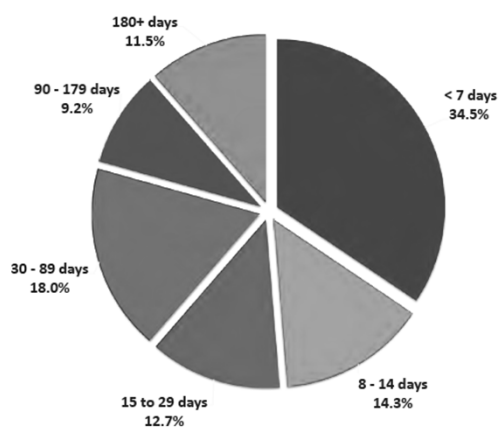
- Nursing care
- Medications
- 4 hours/day custodial home-health services
- Medical equipment/supplies
- Physical and occupational therapy
- Short-term inpatient care for symptom management or family respite
- Bereavement services

Growth in Medicare-Certified Hospice Providers



http://www.nhpco.org/sites/default/files/public/Statistics_Research/2014_Facts_Figures.pdf

Proportion of Patients by Lengths of Service (2013)



http://www.nhpco.org/sites/default/files/public/Statistics_Research/2014_Facts_Figures.pdf

Palliative Care for Dementia

- Family education
 - Site of care
 - Withdrawal of non-essential interventions
 - What to expect
 - Behavioral issues, Eating problems, Weight loss
 - Negotiate interventions for illnesses/discomfort
 - Mode of death

Palliative Care for Dementia

- Site of Care
 - Home
 - Family able to provide adequate care
 - Assisted living facilities
 - Skilled nursing facilities
 - Long-term care facilities
 - Inpatient hospice/ hospital

Palliative Care for Dementia

- Medication review
 - Reduce tablet burden
 - Withdraw superfluous medications
 - Calcium supplements
 - Statins
 - Reduce dose, wean off if possible (e.g. antipsychotics)

Immobility

- Monitor for pressure sores
 - Prevention is key; treatment may be difficult
 - Frequent changes in position
 - Minimize moisture from sweat/urine
 - Avoid friction when moving
 - Pressure-reducing surfaces
- Avoid blood clots
 - Walk if possible
 - Active/passive arm or leg movements

Weight Loss/Cachexia

- Liberalize Diet
- Manage constipation
- Consider medication side effects
 - Cholinesterase Inhibitors – loss of appetite
 - Diuretics – dry mouth

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Anorexia and Cachexia

- Assess, manage comorbid conditions
- Educate, empower, support
- Favorite foods/nutritional supplements
- Others:
 - Alcohol
 - Dexamethasone
 - Megestrol acetate
 - Tetrahydrocannabinol (THC)
 - Androgens

Anorexia and Cachexia

- Corticosteroids may have appetite-stimulating effects and positive effects on mood and energy
 - Dexamethasone and megestrol have been used as appetite stimulant, but not enough evidence to recommend
 - Consider risks vs. benefits
 - E.g. Risk of blood clot (megestrol); mood changes/sleep disturbances/fluid retention (dexamethasone)

Anorexia and Cachexia

- The cannabinoids (e.g., tetrahydrocannabinol [THC]) shown to promote weight gain in patients with AIDS and cancer.
- The androgens (e.g., oxandrolone, nandrolone, etc.) currently under investigation for their effects on appetite and weight.
- Consider side effects (e.g. virilization, alopecia, hirsutism, etc.)

Tube feeding

- Percutaneous endoscopic gastrostomy (PEG)
- No clear evidence of health benefit
 - Prevention of aspiration pneumonia
 - Reduction of pressure sores
 - Palliation
 - Prolong survival
- Risks
 - Tube dislodgement/blockage/leakage
 - Need for physical/chemical restraints

Gillick MR. N Engl J Med. 2000;342(3):206.

Tips for Safe Swallowing

- Very Small Bites
- Thickened liquids
- Slow Feeding
- Upright positioning
- Proper consistency
- No speaking while eating
- Avoid straws

Breathlessness

- **Management of breathlessness:**
- Treat the underlying cause
- Symptomatic management
 - oxygen
 - opioids
 - anxiolytics
- Nonpharmacologic interventions

Breathlessness

- Consider treatment of other contributors
 - bronchospasm (albuterol, steroids, ipratropium)
 - secretions
 - pleural effusion (thoracentesis, catheter drainage, pleurodesis)
 - anemia (transfusion)
 - airway obstruction (clean out tracheostomies, steroids)

Breathlessness: Environmental/Behavioral Interventions

- Reassurance of patient
- Educate the family; limit people in the room
- Open window, increase airflow (fans, O2 by nasal cannula, etc.)
- Eliminate environmental irritants (i.e., noisy machines)
- Reduce the room temperature; provide humidifier
- Reposition (elevate head of bed, turning from one side to another)
- Behavioral approaches, e.g., relaxation, distraction, hypnosis

Delirium

- Common in elderly terminally ill patients
- Distressing to both patients and family members
- Identify potentially reversible causes
 - Infection, impaction, uncontrolled pain, urinary retention
- Consider medications if distressing/risk of harm
 - Benzodiazepines may cause paradoxical agitation and worsen delirium in older adults

Dementia: Cause of Death

- Autopsy study of 524 patients with dementia (1974-2004)
 - Respiratory (45.8%) and Circulatory (37.4%) account of majority of deaths
- Bronchopneumonia: 38.4%
 - Most common cause
- Ischemic heart disease: 23.1%
- Other causes
 - Pulmonary embolism
 - Neoplasm
 - Digestive diseases
 - Traumatic (falls)

Brunnstrom HR and Englund EM. European J of Neurology 2009, 16:488-492

NICE Guidelines on Dementia: Key Palliative Care Components

- Dementia care should incorporate a palliative care approach
- Advance care planning should be utilized by health and social care professionals, guided by the patient and/or care giver where appropriate.
- Palliative care services should be available to people with dementia in the same way that they are available to people who do not have dementia.

NICE, National Institute for Health and Clinical Excellence

NICE Guidelines on Dementia: Key Palliative Care Components

- Artificial feeding, antibiotics for fever and cardiopulmonary resuscitation are generally not appropriate in the terminal stages of dementia.
- If people with dementia have unexplained changes in behavior they should be assessed to see whether they are experiencing pain, potentially by the use of an observational pain assessment tool.

NICE, National Institute for Health and Clinical Excellence

The UCLA Alzheimer's and Dementia Care Program: Visit Us...



dementia.uclahealth.org