Alzheimer's Dementia: Disease Trajectory and Hospice Eligibility

Terri L. Maxwell PhD, APRN
VP, Strategic Initiatives
Weatherbee Resources
Hospice Education Network

Course Materials & Disclosure

Course materials including handout(s) and conflict of interest disclosure statement are available to download with this course.

This presentation is for educational and informational purposes only. It is not intended to provide legal, technical or other professional services or advice.

Objectives

Describe the epidemiology and pathophysiology of dementia

Identify “secondary” and “co-morbid” conditions commonly associated with dementia

Recognize the body structure(s) and body function(s) related to dementia

Recognize activity/participation and environmental components related to dementia

Describe clinical documentation that supports medical necessity and substantiates hospice eligibility for patients with dementia
**International Classification of Functioning, Disability & Health (ICF)**

- Structure
- Function
- Activity
- Participation
- Environment

---

**Overview of Dementia**

- Irreversible, progressive brain disease that slowly destroys memory, thinking, and motor skills.
- Caused by various diseases and conditions

---

**Dementia Subtypes**

- Alzheimer's-
  - Most common type of dementia
  - 60-80% of cases
- Vascular dementia (multi-infarct dementia)
  - 15-30% cases
### Dementia Subtypes
- **Lewy Body dementia**
  - 10-15% cases
- **Frontotemporal dementia**
  - <1% cases
- **Parkinson’s Disease with dementia**
  - Occurs in 20-40% of patients with PD
  - Risk rises in patients with PD for > 8 yrs

### Prevalence of AD
- Estimated 5.4 million Americans have AD (2012)
- 1 in 8 older Americans age 65+
- More prevalent in women
  - Differences are due to women living longer, not due to true gender differences
- African Americans and Hispanics more likely to develop dementia

2012 Alzheimer's Disease Facts and Figures

### Projected Numbers of People Diagnosed with Dementia

![Bar chart showing projected numbers of people diagnosed with dementia from 2000 to 2056.]

By 2030, the number of people with AD is expected to double

2011 Alzheimer's Disease Facts and Figures
Dementia and Hospice

- 2nd most common primary non-cancer diagnosis in hospice
- 12.5% hospice admissions

NHPCO Facts and Figures, 2012

Common Hospice Dementia Diagnoses

- 331.0 Alzheimer's Disease
- 331.82 Dementia with Lewy Body
- 294.21 Dementia, Unspecified with Behavioral Disturbances
- 294.20 Dementia, Unspecified without Behavioral Disturbances
- 290.4 Vascular Dementia (Multi-infarct Dementia)

Pathophysiology of Alzheimer's Dementia (AD)

- The brain has billions of neurons, each with an axon and many dendrites.
- To stay healthy, neurons must communicate with each other, carry out metabolism, and repair themselves.
- AD disrupts all three of these essential jobs.
Pathophysiology of AD cont’d

- People with AD have an abundance of two brains:
- Beta-amyloid plaques
- Neurofibrillary tau tangles leading to…
  Neurodegenerative changes eventually resulting in clinical symptoms

Neuronal Cell Death in AD

Clinical Symptoms Vary Depending on Region of Brain Affected

- Regions of the brain most affected
  - Hippocampus
  - Amygdala
  - Temporal lobe
  - Frontal lobes

- Regions of brain spared
  - Occipital
  - Primary sensory and motor

Regions of the brain most affected

- Hippocampus
- Amygdala
- Temporal lobe
- Frontal lobes

Regions of brain spared

- Occipital
- Primary sensory and motor
AD and the Brain

In severe AD, extreme brain shrinkage occurs. Patients become completely dependent on others for care.

Symptoms of AD

- Neurocognitive
  - Memory loss
  - Cognitive deficits
  - Confusion/disorientation
  - Combativeness/agitation
  - Loss of speech
  - Incoherence
  - Unresponsive

- Functional
  - Loss of mobility
  - Inability to carry out ADLs

- Nutritional
  - Loss of appetite
  - Loss of ability to swallow

Natural History of AD Progression
Dementia/Frailty Trajectory

Onset could be deficits in ADL, speech, ambulation

Quite variable - up to 6-8 years

Death

Function

+ FAST Scale - Functional Assessment Stage

<table>
<thead>
<tr>
<th>FAST Scale Stage</th>
<th>Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>1...normal adult</td>
<td>No functional decline</td>
</tr>
<tr>
<td>2...normal older adult</td>
<td>Personal awareness of some functional decline</td>
</tr>
<tr>
<td>3...early Alzheimer’s Disease</td>
<td>Noticeable deficits in demanding job situations</td>
</tr>
<tr>
<td>4...mild Alzheimer’s</td>
<td>Requires assistance in complicated tasks such as handling finances, planning parties, etc.</td>
</tr>
<tr>
<td>5...moderate Alzheimer’s</td>
<td>Requires assistance in choosing appropriate attire</td>
</tr>
<tr>
<td>6...moderately severe Alzheimer’s</td>
<td>Requires assistance dressing, bathing, toileting, urinary/rectal incontinence</td>
</tr>
<tr>
<td>7...severe Alzheimer’s</td>
<td>Able to speak only half-dozen intelligible words. Progressive loss in ability to walk, sit up, smile, and hold head up.</td>
</tr>
</tbody>
</table>

Reisberg, 1988; Psychopharmacology Bulletin

+ FAST Scale cont’d

Stage 7 subscales:

a. Ability to speak limited to 6 words
b. Ability to speak limited to 1 word
c. Loss of ambulation
d. Inability to sit
e. Inability to smile
f. Inability to hold head up
Prognosis

- Median survival 5-9 years but actual prognosis may be worse
- Younger patients and females have slightly longer survival
- Presence of behavioral and psychiatric symptoms *not* associated with worse survival

Dementia Subtypes

Vascular (multi-infarct) Dementia

- History: sudden onset, follows stroke or TIA
- Clinical features: similar to AD; depends upon region of the brain affected
- Early presence of gait disturbances
- History of unsteadiness and falls
- Incontinence
- Personality and mood changes
- Memory problems may be less compared to AD
Vascular Dementia (two types)

1) Multi-infarct dementia
   - Sudden onset
   - Focal neurological signs and symptoms
   - Cognitive deficits variable

2) White matter changes and subcortical infarct
   - Gradual onset
   - No focal signs and symptoms
   - Memory loss, slowness of thought with motor slowing

Lewy Body Dementia

- Results from Lewy Body deposits in brain
- Clinical symptoms
  - AD-type signs—confusion, problems with memory and judgment
  - Visual hallucinations common
  - Parkinsonian signs—rigid muscles, slowed movement, shuffling walk and tremors
  - Alertness and cognitive symptoms may fluctuate daily

Lewy Body Dementia cont’d

- Prognosis—typically 5-7 yrs.

Clinical Note: Anti-psychotics used to treat psychiatric symptoms may worsen Lewy Body symptoms and can be life-threatening.
Frontotemporal Dementia

- Cellular damage is concentrated in the front and side regions of the brain
- Typical symptom patterns:
  - Changes in personality and behavior
  - Difficulty with language
- Pick’s disease is a type of frontotemporal dementia

Parkinson's Disease with Dementia

- Parkinson's Disease:
  - Progressive disorder associated with dopamine deficiency
  - Characteristic signs: resting tremor, rigidity, gait disturbance
- Parkinson's Dementia:
  - Compared to AD: more hallucinations, greater visuospatial defects, greater fluctuating attention

Final Stages of Dementia

Final Stages of Dementia

- **Neurocognitive**
  - Progressive worsening of memory and other cognitive deficits
  - Profound confusion, disorientation
  - Behavioral changes: combativeness, resistance giving way to apathy, coma
  - Worsening speech: incoherence, eventually mute

Final Stages of Dementia cont’d

- **Nutritional**
  - Progressive loss of appetite
  - Progressive loss of ability to swallow
  - Aspiration risk increases

Final Stages of Dementia cont’d

- **Functional**
  - Motor system preserved until advanced stage
  - Independent mobility eventually lost: bedbound
  - Capacity for self care progressively lost: patient becomes totally dependent
+ Final Stages of Dementia cont’d

- Death results from the deterioration of the “mind-body connection” and is usually a consequence of secondary impairments
- Bowel and bladder incontinence
- Malnutrition
- Fevers and infections (pneumonia, UTIs, sepsis)
- Decubitus ulcers
- Falls


+ End Stage Issues in Patients with Dementia

- Use of aggressive, life-prolonging medical care
- CPR – Studies demonstrate pts with dementia do very poorly after CPR
- Nutrition and hydration
  - Repeated bouts of aspiration do not benefit from PEG tube insertion
- Need for proxy decision-making

Li, 2002; Am Family Phys

+ End Stage Issues in Patients with Dementia cont’d

- Treatment of infections
- Use of antibiotics is controversial; antibiotics are frequently used in patients with dementia in the final few weeks of life
- Need to weigh risk vs. benefit and patient’s goals of care

End Stage Issues in Patients with Dementia cont’d

- Management of behavioral problems
- Controversial role of cholinesterase inhibitors and NMDA receptor antagonists in hospice
- Non-pharmacologic approaches
- Pharmacologic management - antipsychotics should be prescribed based upon the goals of care and after weighing risk versus benefit

Potential Benefits of Hospice

- Higher satisfaction with care
- More likely to report unmet need related to pain
- Rated peacefulness of dying and quality of dying more positively compared to families without hospice
- Provision of bereavement services

Barriers to Hospice Enrollment

- Dementia not viewed as terminal illness
- Prognostic challenges
- Nature of disease course
- Treatment decisions
Prognostic Factors

- Co-morbidities:
  - DM, CHF, COPD, cancer, cardiac dysrhythmias, etc.

- Signs:
  - Aspiration
  - Peripheral edema
  - Recent weight loss
  - Bowel incontinence
  - Seizures
  - Dehydration
  - Pressure ulcers

- Symptoms:
  - Fever
  - Shortness of breath
  - Dysphagia
  - Pain

Guidelines for Hospice Eligibility

LCD for Alzheimer’s Disease and Related Disorders (31395)

+ Palmetto Alzheimer’s & Related Disorders Guideline (L31395)

- Documentation of:
  - Structural/functional impairments & activity limitations
  - Co-morbid and secondary conditions
  - Intervention strategies
  - Outcomes of interventions

“Documentation of these variables is thus essential in the determination of reasonable and necessary Medicare Hospice Services”
+ Alzheimer’s & Related Disorders
Patients with dementia should show all the following characteristics:
  a. FAST score of 7a or beyond
  b. Unable to ambulate without assistance
  c. Unable to dress without assistance
  d. Unable to bathe without assistance
  e. Urinary and fecal incontinence
  f. No consistently meaningful verbal communication: stereotypical phrases only or the ability to speak is limited to 6 or fewer intelligible words

+ Co-morbid Conditions
  - CHF
  - Renal disease
  - Stroke
  - Cancer
  - COPD, etc.

+ Secondary Conditions
  - Describe by defining structural and functional impairments- together with limitations in activity related to the secondary condition.
  - Impairments in mental functioning and movement lead to:
    - Memory impairment (Mental function)
    - Delirium (Mental functions)
    - Pressure ulcers (Skin & related structure functions)
    - Difficulty swallowing (GI)
    - Difficulty speaking (Voice/speech function)
    - Bowel and bladder incontinence (GU/GI)
### IDT Assessment and Documentation

- Cognitive status (behavior, communication, LOC)
- Nutritional status (height, weight, BMI calculation, meal percentages, calorie approximations, hydration)
- Risk factors (fall/safety, aspiration)
- Skin issues (pressure ulcers, wounds, turgor)
- Infections/treatments (if any)

### Supporting/Ongoing Documentation

- Family/caregiver’s psychosocial/spiritual needs
- Increased service utilization
- Need for more frequent visits
- Greater involvement by members of IDT
- Changes in signs/symptoms
- Dietary changes
- Medication changes - addition/discontinuation/titration/route of administration, etc.

### Dementia Case Example

Mrs. Doe: 96 yr old with Alzheimer’s Disease who lives in a nursing home
- PCG: facility staff and granddaughter
- PTA: aspiration pneumonia; refusing food, 5’9”, 89 lbs, BMI=13%
- Secondary: cachexia & 2 Stage III Decubitus ulcers
- Co-morbid: cardiac disease and NIDDM
**Admission Documentation**

"Granddaughter states that patient no longer makes eye contact and is very upset re: recent loss of communication. Pt occasionally turns head when name is called, but speaks < 6 intelligible words/day. Pt frequently pushes away food and pockets food with episodes of coughing. Was hospitalized 1 month ago with aspiration pneumonia. Very cachectic as evidenced by sunken cheeks, severe muscle wasting… FAST 7a, KPS 40…”

**Mrs. Doe**

**DX: Dementia, SOC: 2/28/12**

<table>
<thead>
<tr>
<th>MEASURE</th>
<th>PTA</th>
<th>2/28/12</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weight / BMI (5’ 9&quot;)</td>
<td>-</td>
<td>89 / 13.5%</td>
</tr>
<tr>
<td>KPS</td>
<td>-</td>
<td>40%</td>
</tr>
<tr>
<td>NYHA or FAST</td>
<td>-</td>
<td>7a</td>
</tr>
<tr>
<td>ADLs</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>Amb, transfer w/1, incontinent of B&amp;B</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skin</td>
<td>Stage III (R) shoulder, hip &amp; heel</td>
<td>Stage II (R) shoulder, hip &amp; heel</td>
</tr>
<tr>
<td>Infection</td>
<td>Aspiration pneumonia</td>
<td>-</td>
</tr>
</tbody>
</table>

**Mrs. Doe DX: Alzheimer's disease**

<table>
<thead>
<tr>
<th>DATA</th>
<th>PTA</th>
<th>SOC</th>
<th>1st RECERT</th>
<th>2nd RECERT</th>
</tr>
</thead>
<tbody>
<tr>
<td>KPS / PPS</td>
<td>-</td>
<td>50%</td>
<td>50%</td>
<td>50%</td>
</tr>
<tr>
<td>FAST</td>
<td>-</td>
<td>7a</td>
<td>7a</td>
<td>7a</td>
</tr>
<tr>
<td>NYHA</td>
<td>-</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>ADLs</td>
<td>3.6</td>
<td>3.6</td>
<td>3.6</td>
<td>3.6</td>
</tr>
<tr>
<td>Skin</td>
<td>3 Stage III</td>
<td>3 Stage III</td>
<td>Intact</td>
<td>Stage II</td>
</tr>
<tr>
<td>Wt (5’ 9&quot;)</td>
<td>-</td>
<td>89</td>
<td>95</td>
<td>89</td>
</tr>
<tr>
<td>BMI</td>
<td>-</td>
<td>13.5%</td>
<td>14.4%</td>
<td>13.5%</td>
</tr>
<tr>
<td>Infection</td>
<td>Pneumonia</td>
<td>-</td>
<td>-</td>
<td>Cough/congestion</td>
</tr>
<tr>
<td>O2</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>
**Mrs. Doe**  
**Clinical Documentation**

**Nursing:**
Dementia AEB ↓ ability to verbalize…
speech garbled…inappropriate
responses…requires frequent cues to
eat…finger foods only…takes one hour to
eat meal…loss of six lbs in past
month…facility RN indicated pt having
congestion, coughing…afebrile

---

**Mrs. Doe**  
**Clinical Documentation cont’d**

**Social Work:**
Met w/ family to discuss their financial
concerns…application for Medicaid initiated since
funds are more limited…spent time with
pt…unable to verbalize anything other than
repeating "Help me! Help me!" Appears to have
lost weight AEB baggy clothes, unable to keep
dentures in her mouth…facility nurse reports she is
eating less…coughing

---

**Mrs. Doe**  
**Clinical Documentation cont’d**

**Volunteer:**
Spent time today with Mrs. Doe…unable to
communicate except to repeat the words "Help me!
Help me!" …assisted her with her lunch- she
chewed food but did not swallow…appears to have
lost weight…
Conclusion

- Dementia patients benefit from hospice care, but 6 month prognosis is difficult to estimate.
- Hospice eligibility and recertification is based on the description of effects of dementia on the structural, functional, activity, participation and environmental domains, plus documentation of secondary and co-morbid conditions.

Course Evaluation & Post-Test

Thank you for viewing this course on the Hospice Education Network.

To conclude this course and to obtain a certificate of completion, you must finish the evaluation and post-test.

Questions? Contact me:
Terri Maxwell PhD, APRN
terrimaxwell@weatherbeeresources.com