



American Academy of
Hospice and Palliative Medicine

DEMENTIA

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AAHPM Intensive Board Review Course

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Dementia

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Disclosure Information

Joseph W. Shega, MD
Has no relevant financial relationship to disclose

Objectives

- Appreciate dementia as a terminal illness
- Recognize common ethical issues that arise while caring for persons with dementia, particularly tube feeding
- Identify and manage agitation in persons with dementia
- Appreciate unique care giving and bereavement trajectories in dementia

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Dementia: Epidemiology

- Current estimate: 4 million in US
- Projected for 2050: 16 million
- 1 in 3 women will develop dementia during her lifetime
- Almost half of people over age 85 have dementia
- Someone new develops dementia every 72 seconds in the US

Evans DA, Scherr PA, Smith LA, et al. Aging 1990;2(3):298-302.
 Alzheimer's Association. Available at http://www.alz.org/news_and_events_rates_rise.asp.

Dementia at the End of Life

- 5th leading cause of death in persons over the age of 65
- Centers for Disease Control and Prevention 2000-2004
 - Dementia deaths rose by 33%
 - Deaths from cardiac disease and many cancers decreased
- Roughly 1 in 10 persons dying with dementia enrolled in hospice

Most Common Etiologies of Dementia in the United States

Dementia Diagnosis	Relative Frequency	Pathophysiology
Alzheimer's disease	35-50%	amyloid plaques and neurofibrillary tangles
Mixed-vascular and Alzheimer's disease	15-25%	Combination of Alzheimer's disease and vascular disease
Lewy Body Dementia	15%	alpha-synuclein protein
Vascular Dementia	10-20%	cortical infarcts, subcortical infarcts, and leukoariosis
Frontotemporal Dementia	<5%	Tau protein

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Common Characteristics of Dementia

Diagnosis	Characteristics	Trajectory
Alzheimer's Disease	Memory loss, language, and visuospatial	4-6 yrs, slowly progressive
Vascular Dementia	Heterogeneous (macrovascular, microvascular, subcortical)	variable
Lewy Body Dementia	Parkinsonian, VH, and fluctuations	4-10 yrs, slowly progressive
Frontotemporal	Personality changes, emotional lability, loss of insight, perseveration	Early onset, 8-11 years, some rapidly progressive

Disease Trajectory

Stage	Cognition	Function
Mild (MMSE >20)	Short-term memory	Driving Finances
Moderate (MMSE 20-10)	Memory, Word finding, Comprehension	Bathing Dressing
Severe (MMSE <10)	Language and Comprehension limited	Continence Walking
Endstage MMSE 0	Utter few words No family recognition	Eating

Dementia as the Cause of Death

Complication	Cause of Death	Mode of Death
Acute Infection	Malnutrition Muscle weakness Immobility	Pneumonia Urinary tract infection
Swallowing Difficulties	Malnutrition Dysphagia	Aspiration pneumonia Electrolyte imbalance
Injuries Trauma	Immobility/Atrophy Osteoporosis	Hip fracture Other fracture
Vascular disease	Inflammation Amyloid deposition	Seizure Stroke

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Natural History Advanced Dementia

- Over 80% develop eating difficulty
 - Part of the disease process, last stage terminal illness
- Pneumonia and febrile illnesses common
 - Each associated with about 50% mortality 6 months later
- Appreciation of prognosis and clinical complications decreased burdensome interventions (TF, hospital, ED, IV's)

Mitchell, S.L. et al. The clinical course of advanced dementia. NEJM 2009; 361(16). 1529-1538.

Prognosis

FAST scale

1. No difficulties
2. Subjective forgetfulness
3. Decreased job functioning and organizational capacity
4. Difficulty with complex tasks, instrumental ADLs
5. Requires supervision with ADLs
6. Impaired ADLs, with incontinence
7.
 - A. Ability to speak limited to six words
 - B. Ability to speak limited to single word
 - C. Loss of ambulation
 - D. Inability to sit
 - E. Inability to smile
 - F. Inability to hold head up

Mortality Risk Index Score

- Complete dependence with ADLs
- Male gender
- Cancer
- Congestive heart failure
- O2 therapy needed w/in 14 day
- Shortness of breath
- <25% of food eaten at most meals
- Unstable medical condition
- Bowel incontinence
- Bedfast
- Age > 83 y
- Not awake most of the day

From Functional Assessment Staging (FAST), by B Reisberg, 1988, Psychopharmacol Bull, 24:653-659. ©1984 by Barry Reisberg, MD. All rights reserved. Reproduced with permission.
Mitchell SL, Kiely DK, Hamel MB, et al. Estimating prognosis for nursing home residents with advanced dementia. JAMA. 2004; 291:2734-2740.

Hospice Criteria

1. Dementia of sufficient severity
 - Can not ambulate independently or carry on conversation, lost ability most ADL's, and occasionally incontinent urine or stool
2. Occurrence of medical complications
 - aspiration pneumonia, UTI, weight loss 10% 6 months, worsening multiple pressure sores (3-4 stage), or recurrent fever after antibiotics

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Treatment Decisions

- Tube feeding
- Cardiopulmonary Resuscitation
- Renal dialysis
- Antibiotics
- IVF
- Hospitalization
- Hip fracture repair
- Decision making capacity

Natural History Swallowing and Dementia

How common?

> 80% of advanced dementia patients develop feeding difficulty

What are they?

Lose ability to feed oneself

Food refusal- won't open mouth or chew

Dysphagia- difficulty with swallowing

Volicer L et al Eating Difficulties in Patients With Probable Dementia of the Alzheimer Type, Journal of Geriatric Psychiatry and neurology 1989

The refusal of food

Dislike the food?

Failure to recognize edible objects as food?

Loss of sense of thirst and/or hunger?

Mouth issues-dentition, ulcers, dry, thrush?

Medication- digoxin, theophylline, amioderone?

Other medical condition – impaction, diverticulitis?

Depression or anxiety?

Last stage of a terminal disease?

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Questions Generated

Do feeding tubes:

- prevent aspiration pneumonia?
- prevent malnutrition?
- decrease the mortality rate?
- prevent pressure sores or hasten their healing?
- improve patient comfort?
- improve functional status?

Studies of Tube Feeding and Aspiration Pneumonia

Aspiration pneumonia rates in tube fed vs orally fed:

<u>Study</u>	<u>Pts</u>	<u>F/U</u>	<u>Tube</u>	<u>Oral</u>
Croghan	22	1yr	66.6%	14.3%
Peck	104	6mo	58%	17.0%

Finucane TE, et al. Use of Tube Feeding to Prevent Aspiration Pneumonia. Lancet 1996

Effect of History of Aspiration Pneumonia in Tube Fed Patients

Aspiration pneumonia rates in tube fed patients by history of prior aspiration or not:

<u>Study</u>	<u>Pts</u>	<u>F/U</u>	<u>+ History</u>	<u>- History</u>
Jamagin	60	6mo	37.5%	11.1%
Weltz	100	Death	11.1%	7.3%
Cogen	109	Var	40.7%	17.0%
Hassett	87	54mo	62.1%	29.3%

Finucane TE, et al. Use of Tube Feeding to Prevent Aspiration Pneumonia. Lancet 1996

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Studies of Tube Feeding and nutrition

- 126 pts receive a PEG, 75% neurologically impaired and dependent in ADL's
- Over 1 year, improvement in albumin of 1g/dl occurred in only 13.4% of pts; 5% had a decline
- No significant improvement in any nutritional parameters
- Stabilization of nutritional status may have occurred

Callahan C. Et al. Outcomes of PEG Among Older Adults in a Community Setting. JAGS 2000

Survival Between Residents With and Without Feeding Tube

- No published studies suggest tube feeding prolongs survival in dementia patients with dysphagia
- Mortality rates following PEG decision in older adults with significant neurologic burden remains consistently high
 - 30-day 20-40%
 - 6-month 50%
 - Median survival 7.5 months

Mitchell SL et al. Arch Intern Med 1997

Does Tube Feeding Prevent or Help Heal Pressure Sores - No

- No published studies suggest that tube feeding improves pressure sore outcome
- Database of 800 tube fed patients followed for 6 months
- Tube feeding not associated with ulcer healing nor protection from new ones.

Berlowitz et al. Predictors of pressure ulcer healing among LTC residents. JAGS, 1997

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Feeding Tube Complication

- **PEG short-term**
- Local irritation
- Infection 4-16%
- Peg Occlusion 2-34%
- Aspiration 0-66%
- Bleeding
- Reflux
- Diarrhea 12%
- Tube migration
- **PEG long-term**
- Restraint use
- Diminished QOL
- Frequent replacement/removal
- No oral intake
- Limit socialization
- Poor mouth care

Decision-Making and Outcomes

- | Decision Itself | Adverse Outcomes |
|---|----------------------------|
| • 71.6% reported no conversation about tube | • Improved QOL 32.9% |
| • Risks not discussed 1/3 cases | • Patient bothered 39.8% |
| • Discussion shorter 15 minutes | • Physical restraint 25.9% |
| • 51.8% thought MD strongly in favor tube | • Chemical restraint 29.2% |
| • 12.6% felt pressure by MD to place tube | – Either 34.9% |
| • Worse end of life care | • ED due to tube 26.8% |
| | • Feelings related to tube |
| | – Regret 23.4% |
| | – Right decision 61.9% |

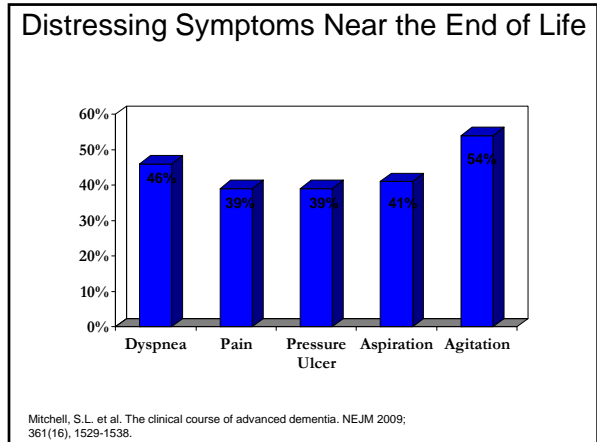
Teno J et al. JAGS 2011

Decision-Making

1. Review the clinical situation
2. Establish the Goals of Care
3. Present options to manage feeding problem
4. Weighing risks and benefits with values and preferences
5. How is the decision affecting the family member
6. Offer additional sources of decisional support
7. Provide ongoing support and recognize the need to revisit the decision

Cervo et al. Geriatrics 2006

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Contributors to Agitation

Contributor	Causes	Approach
Physical Symptom	Pain, SOB	Opioid
Psychological symptom	Depression, Anxiety	SSRI CBT
Medical Illness	Delirium, infection, constipation	Treat condition
Unmet Need	Hunger, thirst, cold	Attend to need
Sensory impairment	Poor vision/hearing	Adaptive
Environment	Under/over stimulation	Modify
Pharmacologic	Dig, caffeine, benzo	Taper
Dementia	AD, Mixed, LBD	AchEI

Treatment of Agitation

Therapeutic Class	Trial	Side effects
Anti psychotics	RTC	Stroke, death...
Trazodone	RCT	Sedation, Hypotension
SSRI (citalopram)	RCT	Nausea, diarrhea
Carbamazepine	RCT	Sedation, anemia, liver toxic
Valproic acid	RCT	Liver toxic, sedation
Lorazepam	RCT	Sedation, falls, ataxia, agitation
NMDA antagonist	RCT	Constipation, dizziness
AChEI	RCT	Nausea, dizziness, weight loss

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Antipsychotics

Antipsychotic	Recommended Dose	Formulations	Frequency	Characteristics
risperidone	0.5-2.0mg	Tab, liquid, IM	twice daily	Extrapyramidal symptoms
olanzapine	2.5-15mg	tab	daily	Wt gain, inc sugar
quetiapine	25-400mg	tab	Three times daily (unless ER)	Sedating, least extrapyramidal
aripiprazole	5-30mg	Tab, liquid, IM	daily	Less QT
haloperidol	0.5-5mg	Tab, liquid, IM, IV, sub q	Twice daily to four times daily	
Chlorpromazine	10-200mg	Tab, liquid, IV, rectal	Twice to three times daily	Very sedating

Black Box Warning: Not approved for use in persons with dementia for agitation and psychosis, increased risk of stroke and death

Medications Used to Treat Dementia

Medication	Severity	Dose	Side Effects
Donepezil (Aricept)	Mild to severe	5-10mg; 23mg	*Nightmares
Rivastigmine (Exelon)	Mild to moderate	4.6 & 9.5mg patch	*Weight loss
Galantamine (Razadyne)	Mild to moderate	8-24mg	*
Memantine (Namenda)	Moderate to severe	10mg BID	Constipation, dizziness, HA

*Cholinesterase inhibitors: Nausea, vomiting, diarrhea, dizziness

Caregiver Burden

- Multiple roles/protracted period of time- "24/7"
 - Direct care
 - Decision-maker
 - Relationship role
- High personal satisfaction, yet notable costs
 - Greater physical/emotional strain
 - Fewer vacations/time for hobbies
 - Less contact other family and friends
 - Put off medical/preventive care
- Caregivers who reported strain had a 63% higher mortality compared to no strain

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Financial Cost

- Annual cost to US- at least 100 billion
- Cost to American business- 36.5 billion
- Cost to families
 - 70% of patients live at home
 - 75% of care form family and friends
 - 12,500/yr in paid care (families pay half)

Caregiving at the End of Life

Variable	Median (Interquartile Range)
Years of caregiving	3 (2-5)
Help with ADLs and IADLs*	4 (3-5)
No. of ADLs	7 (6-8)
No. of IADLs	11 (7-14)
Hours per wk helping with ADLs†	39 (21-56)
Hours per wk "on duty"‡	24 (14-34)
Hours per day must be in room§	22 (12-24)
Hours per day must be at home¶	21 (12-21)
Burden on caregiver according to RMSPC	12 (5-21)

Effect on working caregivers
 Had to reduce hours worked¶
 Had to stop working
 Patient institutionalized during study

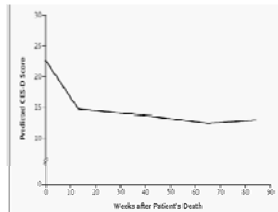


Figure 1. Changes in Levels of Depressive Symptoms According to Center for Epidemiologic Studies Depression Scale (CES-D) Scores among 217 Caregivers in the Weeks after the Patient's Death.
 Before the death, the average CES-D score among caregivers was 15.8. Scores on this scale range from 0 to 60, with higher scores indicating more depressive symptoms.

From End-of-life care and the effects of bereavement on family caregivers of persons with dementia, by R Schulz, AB Mendelsohn, WE Haley, et al., 2003, N Engl J Med, 349(20):1936-1942. ©2003 by the Massachusetts Medical Society. Reproduced with permission.

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Table 2. Levels of In-Home Care Provided to 217 Patients with Dementia.

Variable	Median (Interquartile Range)
Years of caregiving	3 (2–5)
Help with ADLs and IADLs*	
No. of ADLs	4 (3–5)
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Hours per wk helping with IADLs	35 (21–56)
Hours per day “on duty”	24 (14–24)
Hours per day must be in room‡	23 (21–24)
Hours per day must be at home	24 (23–24)
Burden on caregiver according to RMBPC§	12 (5–21)
	Number (Percent)
Effect on working caregivers	
Had to reduce hours worked¶	27 (48.2)
Had to stop working	39 (18.0)
Patient institutionalized during study	57 (26.3)

* Caregivers were asked about the need to help with the six activities of daily living (ADLs) and the eight instrumental activities of daily living (IADLs).

† Data were available for 214 caregiver–recipient pairs.

‡ Data were available for 216 caregiver–recipient pairs.

§ Scores on the Revised Memory and Behavior Problems Checklist (RMBPC) range from 0 to 96, with higher values indicating greater burden.

¶ Data were available for 56 working caregivers.

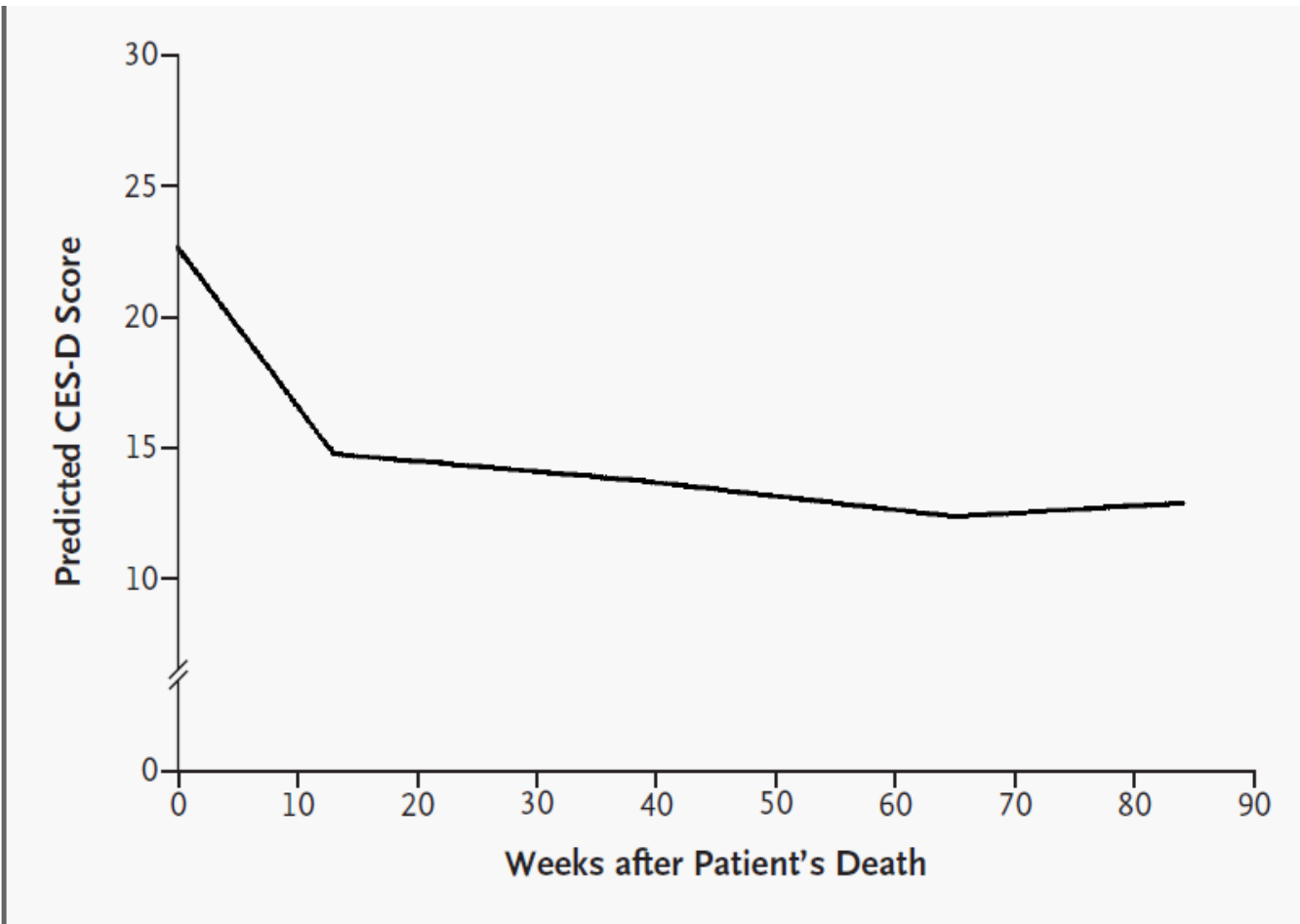


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Dementia

References

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