Hospice and Palliative Care in Advanced Dementia

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Dementia

- A disorder characterized by the impairment of memory and at least one other cognitive domain
  - Aphasia, apraxia, agnosia, executive function
- Represents a decline from previous function severe enough to interfere with daily function and independence
  
  DSM IV

Dementia stats (US)

- In 2014, estimated 5 million Alzheimer’s
- “End-Stage” 1.8 million
- 2020 estimated 5.7 million
- 2050 estimated 14 million
- 70% die in nursing homes
- Under-represented Hospice population, many do not receive adequate palliative care, multiple studies support both

Projected Numbers

Projected Number of People Age 65 and Older (Total and by Age Group) in the U.S. Population and Alzheimer’s Disease, 2010 to 2050

Lifetime Risk of Alzheimer's


Dementia Syndromes

- Alzheimer’s Disease — 60-80%
- Vascular dementia — 10-20%
- Dementia with Lewy bodies
- Parkinsons with dementia
- Frontotemporal dementia
- Reversible dementias

Alzheimer’s Disease

- Extracellular deposition of amyloid-beta protein
- Intracellular neurofibrillary tangles
- Loss of neurons

Alzheimer’s Disease

- Diagnostic criteria (DSM IV)
  - Gradual onset and continuing decline in cognitive function
  - Impairment in recent memory and at least one of:
    - Disturbance of language (aphasia)
    - Inability to execute skilled motor activities (apraxia)
    - Disturbances of visual processing (agnosia)
    - Disturbances in executive functioning
  - Cognitive deficit not due to other psychologic, neurologic or systemic disease
  - Does not occur exclusively in the setting of delirium

Vascular Dementia

- No uniform diagnostic criteria
  - Onset of cognitive deficit with stroke
  - Abrupt onset with stepwise decline
  - Findings on neurologic exam c/w stroke
  - Cerebral imaging with infarcts
- Cortical
- Subcortical

Frontotemporal Dementia

- Focal atrophy of frontal and temporal lobes, age 35-75 at onset
- Subtypes
  - Gradual, progressive behavior change
  - Gradual language dysfunction, fluent and non-fluent

Dementia with Parkinsonism

- Parkinson’s disease with dementia (dementia six times more common); parkinsons precedes dementia by years
- Dementia with Lewy Bodies and parkinsonism
  - Gradual
  - Fluctuations in cognition
  - Persistent, well-formed hallucinations
  - Parkinsonism occurs early
- Progressive supranuclear palsy
  - Pseudobulbar palsy
  - Falls, bradykinesia, apathy, disinhibition
  - Frontal lobe type dementia, often later in disease
- Mixed picture
Reversible Dementia

- Normal Pressure Hydrocephalus
  - Dementia
  - Gait disturbance
  - Incontinence

Dementia is a Terminal Disease

- Patients with dementia have a markedly decreased survival at any age
- 2-4 times more likely to die at any age compared to non-demented cohort
- Survival estimates from onset of dementia
  - Women 4.6 years
  - Men 4.1 years
  - Survival influenced by age, prior disability
  

Dementia is a Terminal Disease

- Minimum data set study, 1609 SNF residents with advanced dementia
  
  Arch Int Med. 164:321
  
  - 1.1% felt to have life expectancy < 6 mo.
  - 71% actually died during that period
  - 55% DNR, 25% tube feeds, 11% restraints

Hospice Care in Dementia

- 500 Family members surveyed, 71% would choose a Hospice approach during final stage
  
  Morrison et al. JAMA 284: 47-52
  
  - 1995 Survey, less than 1% hospice admissions with dementia as primary diagnosis
  
  Hanrahan et al. J.Am.Geriatrics.Soc. 43:56-9
  
  - 2005 10% hospice enrollees with dementia
  
  NHPCO
  
  - Medical providers are notoriously poor prognosticators
  
  Christakis et al. BMJ 320: 469-72

NHPCO Guidelines

- FAST score 7C (7A in WNY) or worse
  - Unable to dress or bathe, incontinent, unable to speak or communicate effectively, unable to ambulate without assist
- Presence of one or more complications
  - Aspiration, upper UTI, Sepsis, Decubiti, 
  - Unable to meet caloric needs, intake falling, 10 % weight loss in 6 months, albumin < 2.5

Functional Assessment Staging

- Cannot dress, bathe, urinary and fecal incontinence
  - 7a Six intelligible words over a day
  - 7b Single word
  - 7c Non-ambulatory
  - 7d Cannot sit up independently
  - 7e Cannot smile
  - 7f Cannot hold head up
FAST limitations

- Not all patients progress through the stages as outlined
- Tested in a small population of hospice patients (n=47)
  - Median survival 4 months (7c)
  - 38% lived longer than 6 months (7c)
  - Those not yet at 7c, all lived > 6 months
  - FAST appears to be more sensitive than specific—predicting who will NOT die in 6 months

Palliative Performance Scale

- 466 hospice patients followed 6 months
- PPS more predictive in nursing home residents
- PPS 30% (bedbound, total care, drowsy or confused) 80% 6 month mortality

ADEPT Study

- Developed from MDS data
- 12 items with point scoring, 6 month prediction fair, better than CMS and FAST
  - Recent admit
  - Age, male
  - SOB, skin breakdown, bedbound,
  - BMI < 18.5, CHF, weight loss, falling intake

Hospice Buffalo

- FAST 7A or worse
- PPS 40 or worse
- Co-morbidities important
- Goals of care
  - Limitations of care
  - Tube feeds
  - SNF vs Homecare
  - Discharge “happens”

Pharmacologic Treatment in Dementia

- Cholinesterase inhibitors
  - Dopezril (Aricept)
  - Galantamine (Razadyne)
  - Rivistigmine (Exelon)
  - Tacrine (Cognex)
- Neuropeptide Modifier (NMDA blockade)
  - Memantine (Namenda)

Pharmacologic Treatment in Dementia

- Recent ACP review
- All drugs show improvement in various scoring instruments in early/moderate disease
- Duration of trials generally less than a year
- Clinical significance of “improvement” not understood
- Probably not indicated in “end-stage” disease
## Treatment of Behavioral Symptoms in Dementia

- Agitation
- Aggression
- Delusions
- Hallucinations
- Wandering
- Sleep disorders

## Agitation

- Recent trial of Donepezil (Aricept) no benefit  
  NEJM 357:1382-92
- Carbamazepine (Tegretol)—probably no benefit  
  JAMA 201:566
- Trazodone sometimes helpful
- Caution with benzodiazepines  
  — Paradoxical agitation  
  — Falls
- Don’t forget pain assessment

## Aggression

- Confusion, misunderstanding
- Paranoid delusions
- Can’t express distress in other ways
- Sleep disorders
- Non-pharmacologic  
  — Behavior mod, music, exercise, aromatherapy, environment, pets
- Pharmacologic  
  — Memantine (Namenda)  
  — Valproate

## Neuropsychiatric symptoms

- Delusions more common than hallucinations
- Often paranoid
- Visual hallucinations early in disease suggests Lewy Body dementia
- No treatment if fleeting or non-threatening and don’t interfere with care
- Environmental changes

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**Effect of Dextromethorphan-Quinidine on Agitation in Patients With Alzheimer Disease Dementia A Randomized Clinical Trial**  
JAMA. 2015 Sep;314(12):1242-54
- May be helpful in controlling agitation
- Formulation is expensive (Neudexta)
- Try dextromethorphan oral controlled release liquid 30mg/5ml, 10ml BID alone
- Dextromethorphan-Quinidine can be compounded for $50.00/2 week supply
- Quinidine is added to inhibit cytochrome P450 2D6, adding paroxetine or fluoxetine does the same

**Effect of Citalopram on Agitation in Alzheimer Disease**  
JAMA. 2014;311(7):682-91
- 40% saw significant improvement
- Titrated to 30mg/day
- At least as efficacious as antipsychotics
- Questionably significant decline in cognition and increase in QT
- Lower doses not as effective
Antipsychotics

• Typical antipsychotics
  – Haloperidol, chlorpromazine
• Atypical antipsychotics
  – Clozapine, olanzapine, risperidone, quetiapine
• Little/no data to support routine use though some studies show advantage with atypicals
• Mortality, stroke risk with typical vs atypicals?
  – Black box warning for all antipsychotics

Antipsychotics

• Haldol available PO, liquid and parenteral, inexpensive, fast titration
• Quetiapine useful with sleep disturbance (sedating), slow titration
• Olanzapine available as wafer
• Caveats—haldol/typicals contraindicated in Lewy body dementia, probably all dementias with parkinsonism

Other drugs

• Some have found cholinesterase inhibitors and memantine useful, despite contrary evidence
• SSRI sometimes useful, theoretic serotonin deficit may contribute to psychosis and aggression
• Citalopram (Celexa) favored
• Avoid tricyclics and benzodiazepines
• Trazodone for sleep

Sleep Disorders

• Very common
• Parkinsons patients have shallow sleep, often restless legs, can’t turn over
• Lewy Body dementia have high incidence of REM sleep disorders, increased confusion on awakening
• Low dose clonazepam sometimes useful
• Trazodone

Delirium vs Dementia

<table>
<thead>
<tr>
<th>Delirium</th>
<th>Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Acute onset</td>
<td>1. Insidious onset</td>
</tr>
<tr>
<td>2. Fluctuates</td>
<td>2. Progressive</td>
</tr>
<tr>
<td>3. Duration days to weeks</td>
<td>3. Duration months to years</td>
</tr>
<tr>
<td>5. Impaired attention</td>
<td>5. Normal attention except when severe</td>
</tr>
<tr>
<td>6. Increased or decreased psychomotor</td>
<td>6. Normal psychomotor (usually)</td>
</tr>
<tr>
<td>7. Can be reversible</td>
<td>7. Rarely reversible</td>
</tr>
</tbody>
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CASCADE Study

323 SNF residents with advanced dementia followed for 18 months
• 86% eating problems (39% 6 month mortality)
• 41% pneumonia (47% 6 month mortality)
• 52% febrile episode (45% 6 month mortality)
CASCADE Study

- Distressing symptoms were common
  - 46% dyspnea
  - 39% pain
- 41% of residents underwent a burdensome intervention in last 3 months of life
  - Hospital, ED, IV, tube feed

CASADE Study

- “Residents whose proxies had an understanding of the poor prognosis and clinical complications expected in advanced dementia were much less likely to have burdensome interventions in the last 3 months of life”

Decision Making

- Clarify Clinical Situation
  - Terminal disease, eating and infectious complications expected
- Goals of Care
  - What would the patient want
  - Comfort, life prolongation, middle of the road
- Treatment options based on data

Eating Problems in Advanced Dementia

- Ability to eat independently usually the last ADL to be lost
- Dementia patients can live a long time with very poor oral intake—reduced metabolic requirement? [BMJ 333:1214-15]
- Oropharyngeal dysphagia, inability to interpret hunger

Treatment Options

- Continue hand feeding as tolerated
- Tube feeding

Hand feeding

- Provides food/drink for comfort
- Labor intensive for SNF staff
  - 1/3 SNF residents are tube fed, varies widely among states
- Family interaction
**Percutaneous Endoscopic Gastrostomy tube**

- Gastrostomy tubes in elderly were rare 30 years ago, used for patients with chance for recovery (major surgery)
- PEG first used 1979 for infants
- 1988 60,000 PEGs
- 2006 300,000 PEGs

**Tube feeding misconceptions**

  - Tube feeds prolong life—61%
  - Tube feeds improve nutrition—94%
  - Tube feeds prevent aspiration—76%
- Tube feeds provide comfort

**Tube feeding prolong life?**

- No randomized controlled trials
- Best cohort studies indicate tube feeds do not prolong life in advanced dementia

**Tube feeding prevents aspiration?**

- No evidence that tube feeds improve nutrition or pressure ulcers
  - Patients too debilitated to derive benefit
  - Complications may promote decline
  - Higher rate of new pressure ulcers and less healing

**Hunger and Thirst?**

- Not known if these sensations are appreciated by patients in advanced dementia
- End stage cancer patients report no hunger or thirst as long as mouth is moistened
- Ketosis=hunger suppression
- No measurable discomfort in one study of patients where tube feeds withheld [Arch Int Med 165:1729-35]

**Benefits and Burdens**

- **Benefits**
  - Maintain appearance of life sustaining sustenance?
  - Hope for future cognitive improvement
  - Guilt avoidance
- **Burdens**
  - Long term complication rate 30-72%
  - Restraints, chemical and physical
  - Pain of the procedure
  - No oral gratification
  - Wound infections
  - Diarrhea
  - Indignity
  - Few, if any, proven benefits
  - National organizations advise against tube feeding in advanced dementia
Ethical Principles

• No ethical or medical mandate to provide non-oral nutrition when burden/risk is greater than benefit
• Tube feeding is a medical treatment, not “ordinary care”
• Withholding or withdrawing tube feeds is not euthanasia
• High calorie shots, protein supplements etc. are “artificial”

I won’t let my mother starve!

• Approach the discussion in way that minimizes surrogate/family guilt
  – Consider advance directives, if any
    • Choice already made by patient, surrogate is honoring that choice
  – In the absence of directives
    • What would the patient want/decide?
    • Previous conversations?

Benefits and Burdens

• Ask family/surrogate what their understanding is of benefits/burdens of tube feeds
• Carefully explain the lack of benefit weighed against potential burdens
• Render an opinion, don’t say “what do you want us to do?”
• Offer spiritual input

Catch phrases

• “tube feedings will not improve quality of life, but may prolong dying and suffering”
• “we will continue to do everything necessary to provide comfort”
• “feeding by hand is still possible” “tube feeding is not the same as eating”
• “your mother is dying of dementia (brain failure), not starvation”
• “most dying patients lose interest in eating and drinking in the weeks leading to death”

SNF Confounders

• Some states reimburse higher for tube fed patients, use varies widely by state
  – 2006 MDS data, 8.1% New York
  – Nebraska 3.8%
  – District of Columbia 44.8%
• Hand feeding is labor intensive
• Publicly available quality indicators include “weight loss”

If a tube is placed..

• Try to establish what the goals are
  – Weight gain, improved function
• Set a time-frame for re-evaluation to see if goals are being met, revisit benefits and burdens
• Majority of proxies surveyed regretted decision to initiate tube feeding
  J. Am. Ger. Soc. 48:391-397
Infections

- 50% of dementia patients have pneumonia in last 2 weeks of life
- 6 month mortality (all cause) after pneumonia is 50%
- CASCADE study
  - Pneumonia treated with antibiotics lived 273 days longer with increasing discomfort scores

Infections

- Set goals and expectations with families
  - Comfort vs life prolongation (vs prolongation of the dying process)
  - Assure symptomatic treatment for patients who’s proxies forgo antibiotics

Hip Fracture

AJMA 284:47-52

- 6 month mortality with advanced dementia is 55% (12% cognitively intact)

Re-certification in advanced dementia

AJMA 335:172-78

- Medicare benefit periods
  - First: 90 days
  - Second: 90 days
  - “Unlimited” 60 day periods
- 1996 study of 6451 hospice enrollees
  - Median survival in dementia 74 days
  - 32% lived longer than 6 months

Re-certification in Advanced Dementia

- Need to document decline
- Measures and numbers important
  - PPS (often “stuck” at 30)
  - FAST score, eating problems
  - Weight or arm/thigh circumference, temporal wasting, loss of thenar eminence,
  - Infections, worsening decubiti
  - Eating problems, pocketing, cough, aspiration
- Limitations of care in place?
  - Antibiotics for life threatening infections
  - Hospitalization, tube feeds, MOLST

Summary

- Dementia (brain failure) is a terminal disease
- Hospice is underutilized, but getting better
- There is little evidence to guide pharmacologic treatment
- There is evidence to support burdens>benefits for tube feeding in most cases
- Proxies who are well informed make better decisions
- Dementia patients typically have a longer length of stay, but can remain in program if decline is carefully documented.
Questions and Comments

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