DEMENTIA DIAGNOSIS, MANAGEMENT AND PROGNOSIS FOR HOSPICE CARE PRACTITIONERS

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WHY DISCUSS DEMENTIA?

► Dementia patients represent a large percentage of patients cared for in facilities
► Dementia is increasing in prevalence in our society (although it declined a bit this year) (6th leading cause of death)
► Dementia poses a huge caregiver burden that facility care can help relieve
DEMENTIA DEFINED

- Evidence from the history and clinical assessment that indicates significant cognitive impairment in at least one of the following cognitive domains:
  - Learning and memory
  - Language
  - Executive function
  - Complex attention
  - Perceptual-motor function
  - Social cognition

- The impairment must be acquired and represent a significant decline from a previous level of functioning
- The cognitive deficits must interfere with independence in everyday activities
- In the case of neurodegenerative dementias such as Alzheimer disease, the disturbances are of insidious onset and are progressive, based on evidence from the history or serial mental-status examinations
- The disturbances are not occurring exclusively during the course of delirium
- The disturbances are not better accounted for by another mental disorder (e.g., major depressive disorder, schizophrenia)
Patients with dementia may have difficulty with one or more of the following:

● Retaining new information (e.g., trouble remembering events)
● Handling complex tasks (e.g., balancing a checkbook)
● Reasoning (e.g., unable to cope with unexpected events)
● Spatial ability and orientation (e.g., getting lost in familiar places)
● Language (e.g., word finding)
● Behavior
DEMENTIA ≠ DELIRIUM

Delirium is usually acute or subacute in onset and is associated with a clouding of the sensorium; patients have fluctuations in their level of consciousness and have difficulty maintaining attention and concentration. Delirium and dementia can overlap, making the distinction difficult and sometimes impossible.

DEPRESSION ≠ DEMENTIA

Patients with depression are more likely to complain about memory loss than those with dementia; the latter are frequently brought to physicians by their families, while depressed patients often present by themselves. Patients with depression may have signs of psychomotor slowing and give poor effort on testing (“I just can’t do this”), while those with dementia often try hard but respond with incorrect answers. It is important to ask the test administrator to estimate the effort given by the patient. Depression and dementia may occur in the same patient.
The Scope of Dementia

- Alzheimers Dementia (60-80% of dementias) commonly occurs as a spectrum of disease beginning with early symptoms and progressing to death over 4-8 years
- Brain pathologic changes often occur years before symptoms develop
- 5.3 million individuals suffer with Alzheimer's in America, the vast majority being over 65 years old (5.1 million)
- Two-thirds of these patients are women
- By 2050 the number of individuals with dementia diagnoses is expected to rise to 13.8 million!

CAREGIVER BURDEN

- Many families give up an entire income to care for a loved one, or, to add to their stress, continue with all of their child care, work demands, and care for a loved one with dementia
- Many have given up work entirely, reduced social activities, exercise, and other family responsibilities
- Most of the care goes to a parent, parent-in-law, or grandparent. Only 6% involved spousal care
- Impaired cognition, judgement, and other medical problems add to the already-difficult tasks of bathing, toileting, medicating, feeding, dressing, undressing, and care
- Few are able to collect financial help for services
THE MAJOR DEMENTIA SYNDROMES

- Alzheimer's disease
- Dementia with Lewy bodies
- Frontotemporal dementia
- Vascular (multi-infarct) dementia
- Parkinson disease with dementia
STAGES OF DEMENTIA

- Mild Cognitive Impairment
- Mild dementia
- Moderate dementia
- Severe dementia

Early Onset Dementias (age 18-65)

- Incidence of 40-100/100,000 population in developed countries
- Dementias due to Down Syndrome, TBI, Vascular dementias may or may not be counted in these studies
- Neurodegenerative disease, approx. 30%, autoimmune/inflammatory disease, 21%, unknown cause, 18%, metabolic diseases including mitochondrial/storage dis. 11%
- Alzheimer Disease, Frontotemporal dementia, alcohol-related, and vascular dementia account for almost all of the neurodegenerative dementia. Chronic Traumatic Encephalopathy may increase based on so many young people with concussions
Rare Causes of Early-Onset Dementias

Alzheimers
- Presenilin-1
- Presenilin-2
- Amyloid Precursor Protein
- Frontotemporal Dementia (behavioral problems, compulsivity)
- Dementia with Lewy Bodies (Visual hallucinations, Parkinsonian tremor, REM behavior disorder)
- Neurodegerative disease associated with tau (Corticobasal syndrome, Progressive supranuclear palsy, Posterior Cortical Atrophy)
- Parkinson disease with dementia (80% of Parkinson’s patients)
- Vascular Dementia (many presentations related to location of infarcts)
- Infectious Disease-related Prion, HIV, Neurosyphilis, Herpes simplex-1, Progressive multifocal encephalopathy

More Causes of Early Onset Dementia

- Multiple Sclerosis
- Neurometabolic disorders: Mitochondrial disease, Leukodystrophy, Adult neuronal ceroid lipofuscinosis
- Complications of alcohol abuse
- Chronic traumatic encephalopathy
- Paraneoplastic syndromes
- Encephalopathy associated with autoimmune disease (SLE, etc)
- Normal pressure hydrocephalus
- Huntington Disease
- Wilson disease
DIFFERENTIATION BETWEEN THE DEMENTIAS

- Age of Onset, Family History, rate of progression, Clinical presentation
- Presence of motor abnormalities (think Parkinson’s)
- Behavioral issues (think Frontotemporal and Lewy Body)
- History of drug/alcohol use
- History of hypertension with mini-strokes ("etat lacunae")
- Tumors
- Obstructive sleep apnea
- Psychiatric disease, especially depression
- CT, MRI, PET, Lumbar Puncture, blood work, Neuropsych eval, PSG, all may have a role in DDx
Dementia prevention strategies

- Brain training/exercises
- Medications
- Dietary Supplements
- Physical Exercise
- Reversal of treatable dementias (vitamin deficiencies, depression, substance abuse abstention)

Is prevention possible?

- Risk Factor modification—BP, Sugar control, Smoking avoidance, regular exercise (brisk walking), Maintenance of social interaction most and brisk walking most helpful
- Vitamins & Supplements: E, B12, Fish oil, Ginkgo biloba—no convincing evidence
- Antioxidants—minimal evidence and only for foods (not supplements)
- Mediterranean diet rich in olive oil, fruits, nuts, whole grains, beans, seeds, vegetables—minimal evidence
- Statins—cardiovascular benefit, no definite dementia benefit
- NSAID’s—unclear benefit
FACTORS THAT INCREASE DEMENTIA RISK

Blood Pressure  
Blood Sugar  
Belly Size  
Inflammation  
Cortisol  
Stress  
Genetics  
Sedentary Lifestyle

Dementia
Dementia Treatments

- Medications
- Home Care
- Institutional Care
- Hospice Care

Medications for Dementia (& Mild Cognitive Impairment)

- Cholinesterase inhibitors
  - Donepezil (Aricept), 5-10mg daily
  - Rivastigmine (Exelon), 1.5 bid to 6 mg bid
  - Galantamine (Razadine), 6-24mg daily in divided doses

N-Methyl-D-Aspartate Receptor Antagonists
  - Memantine (Namenda), 5-20mg qd-bid

Definitely show benefit in early dementia, questionable value later in the course—wean slowly but be willing to resume if patient declines
HOSPICE CARE FOR DEMENTIA

- Medicare Criteria for enrollment of patients in facilities
- Benefits of Hospice for Dementia Patients
- The Family communication/support piece
Prognostication-ADEPT

- length of stay
- age, male
- dyspnea
- pressure ulcers
- total functional dependence
- bedfast

- insufficient intake
- bowel incontinence
- body mass index
- weight loss
- congestive heart failure

PROGNOSTICATION-FAST-I

- Unable to ambulate without assistance;
- Unable to dress without assistance;
- Unable to bathe without assistance;
- Urinary and fecal incontinence, intermittent or constant;
- No consistently meaningful verbal communication (stereotypical phrases only or the ability to speak is limited to six or fewer intelligible words)
FAST-II

- The occurrence of at least one of six specified medical complications in the prior year:
  - Aspiration pneumonia
  - Pyelonephritis
  - Septicemia
  - Multiple decubitus ulcers ≥ stage
  - Recurrent fever after antibiotics
  - Inability to maintain sufficient fluid and calorie intake with 10 percent weight loss during the previous six months or serum albumin <2.5 g/dL

Fast-III

Alternatively, patients are considered to have a life expectancy of ≤ 6 months by Medicare if they meet specific criteria for a decline in clinical status that is not considered to be reversible, independent of the underlying diagnosis.
Decline in clinical status guidelines

A. Progression of disease as documented by worsening clinical status, symptoms, signs and laboratory results.

Clinical status:
1. Recurrent or intractable serious infections such as pneumonia, sepsis or pyelonephritis.
2. Progressive inanition as documented by:
   a. Weight loss of at least 10 percent body weight in the prior six months, not due to reversible causes (e.g., depression, use of diuretics).
   b. Measurements (mid-arm circumference, abdominal girth), not due to reversible causes (e.g., depression or use of diuretics).
   c. Observation of ill-fitting clothes, decrease in skin turgor, increasing skin folds or other observation of weight loss in a patient without a documented weight.
   d. Decreasing serum albumin or cholesterol.
   e. Dysphagia leading to recurrent aspiration and/or inadequate oral intake documented by decreasing food portion consumption.

Symptoms:

a. Dyspnea with increasing respiratory rate.

b. Cough, intractable.

c. Nausea/vomiting poorly responsive to treatment.

d. Diarrhea, intractable.

 e. Pain requiring increasing doses of major analgesics more than briefly.
Signs:

a. Decline in systolic blood pressure to below 90 or progressive postural hypotension.
b. Ascites.
c. Venous, arterial, or lymphatic obstruction due to local progression or metastatic disease.
d. Edema.
e. Pleural/pericardial effusion.
f. Weakness.
g. Change in level of consciousness.

Laboratory (when available; lab testing is not required to establish hospice eligibility):

a. Increasing pCO2 or decreasing pO2 or decreasing SaO2.
b. Increasing calcium, creatinine, or liver function studies.
c. Increasing tumor markers (e.g., CEA, PSA).
d. Progressively decreasing or increasing serum sodium or increasing serum potassium.

B. Decline in Karnofsky Performance Status (KPS) or Palliative Performance Score (PPS) due to progression of disease.

C. Progressive decline in Functional Assessment Staging (FAST) for dementia (from 7A on the FAST).

D. Progression to dependence on assistance with additional activities of daily living (see part II, below).

E. Progressive stage 3-4 pressure ulcers in spite of optimal care.

F. History of increasing ER visits, hospitalizations, or physician visits related to the hospice primary diagnosis prior to election of the hospice benefit.
Non-disease specific baseline guidelines (both A & B should be met)

A. Physiologic impairment of functional status as demonstrated by KPS or PPS <70 percent. Note that two of the disease specific guidelines (HIV and stroke/coma) establish a lower qualifying KPS or PPS.

B. Dependence on assistance for two or more activities of daily living (ADLs):

1. Feeding.
2. Ambulation.
3. Continence.
4. Transfer.

Comorbidities

Although not the primary hospice diagnosis, the presence of comorbid disease which is likely to contribute to a life expectancy of six months or less should be considered for hospice eligibility. Comorbid diseases may include:

- Chronic obstructive pulmonary disease.
- Congestive heart failure.
- Ischemic heart disease.
- Diabetes mellitus.
- Neurologic disease (CVA, ALS, MS, Parkinson).
- Renal failure.
- Liver disease.
- Neoplasia.
- Acquired immune deficiency syndrome/HIV.
- Dementia.
- Refractory severe autoimmune disease (eg, Lupus or rheumatoid arthritis).
What about tube feeding?

► To feed or not to feed?
► What are the benefits? None!!
► What are the risks?
  Dislodgement, need for restraints, aspiration
► Are we starving our loved one?
  No evidence of benefit
Management of Neuropsychiatric Symptoms in Dementia

- Common in dementia and often more-distressing than memory loss
- Agitation
- Aggression, picking at things, destroying objects, fighting
- Delusions, sometimes with paranoid ideation
- Hallucinations
- Wandering, Pacing, Restlessness
- Depression
- Apathy
- Disinhibition/Sexual hyperactivity
- Sleep disturbances

Treatment of Neuropsych Sx

- Best if medications can be avoided
- Often symptoms worse in late afternoon/evening
- Look for an underlying cause: medication side effects, delirium, UTI, fecal impaction, pain, fear, confusion, poor sleep
- Patients often cannot express symptoms, and non-verbal cues are critical
- Redirection, a quiet environment, feed in patient room rather than meal room) caregiver education (including just talking to patients), exercise training, massage, music therapy, aromatherapy (lemon balm/lavender), pet therapy, avoid sudden environmental changes
Pain Management in Dementia

- Prescribe a trial of scheduled analgesics.
- Use a stepped-care approach to analgesic prescribing.
- Start low, go slowly, but use enough.
- Monitor the patient carefully to balance risks and benefits of pain treatment versus persistent pain.
- Adequate pain control may be observed as improvements in behavior and function.

Medications to Consider for NP Sx

- Anti-dementia drugs have added benefit of increased cognition
- SSRI antidepressants (esp Citalopram (Celexa) may be helpful
- Probably to be avoided: Carbamazepine, Valproate, Gabapentin, Lamotrigine showed minimal if any benefit
- Melatonin, 1.5-10mg given at *time, may help sleep disturbance
- Diphenhydramine (Benadryl) discouraged due to anticholinergic SE
- Methyphenidate (Ritalin), 10-60mg SR helps apathy but might increase anxiety/agitation and decrease appetite
Rx of Severe or Refractory NP Sx

- Benzodiazipines (Lorazepam, others) to be avoided if possible
- No single approach will necessarily work
- Efficacy is seldom complete
- Often treatment is at the cost of side effects including >mortality
- Use one drug at a time, start with a low dose, titrate slowly
- Involve families in decision-making, be willing to stop a drug and try another
- Always look for a concomitant medical illness, uncontrolled pain, medication toxicity, or other causes of delirium

Atypical Antipsychotic Medications, etc

- Dextromethorphan 20/Quinidine 10 (Nuedexta) daily x 1 week then bid
- Quetiapine, (Seroquel) 25 qhs, titrating up to 75g bid
- Olanzapine, (Zyprexa) 2.5mg daily titrating up to 5mg bid
- Risperidone, (Risperdal, Risperdone) no more than 1mg daily (more can cause drug-induced parkinsonism)
- Clozapine (Clozari; FazaClo; Versaclo)(must do frequent blood work for neutropenia)
- Attempts to wean these most often result in relapse of behaviors
Typical Antipsychotic (Neuroleptic) Meds

- Chlorpromazine
- Thioidazine
- Haloperidol
- Fluphenazine
- These should not be used. They can cause worsening memory and sedation and Haldol may produce extrapyramidal effects and prolong QT interval
Why Utilize Hospice in Dementia?

- Multidisciplinary care planning
- Assistance with ADL's, Medication choices
- Communication with Family
- Addition of SW, Chaplain, Volunteer, Aide services
- Bereavement
- Patients receiving hospice benefits live longer and better and families are happier

So When to Do Hospice/Palliative Care??

- Given the challenge of accurately predicting the six month survival likelihood, access to hospice and palliative care should be based on a desire (by caregivers and family) for comfort care, rather than prognostic estimates. Can always revoke & return prn.