Holistic Palliative Care for Alzheimer/Dementia Patients

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Objectives

- Describe the clinical indicators associated with end-stage Alzheimer’s disease and other types of dementia
- Identify pharmacological and non-pharmacological treatment options in patients with advanced dementia
- Describe components of modern palliative therapy for these patients
- Discuss the role of the interdisciplinary team in providing end-of-life care to patients with advanced dementia

Prognosis in Alzheimer’s Disease

- Over 5 million today, to increase by 50% by 2030
- Dementia is a progressive terminal illness
- Life expectancy from symptom onset varies from 3-10 years
- Average life expectancy after diagnosis is 4-6 years
- Predicting the last few months of life is difficult and not well studied

Poor Prognostic Factors

- Male gender
- Behavioral and psychiatric symptoms
- Gait abnormalities
- Loss of > 3 MMSE points per year
- Single or widowed marital status
- Institutionalization
- Malnutrition or obesity
- Comorbid medical conditions

Prognosis and Age of Onset

- Median Survival Time
  - 65 years: 8.3 years
  - 90 years: 3.4 years

Prognosis in Dementia Patients in Nursing Homes

- 2004 retrospective cohort study of data from MDS in 6800 nursing home residents in Michigan and New York
- 12 variables from the MDS correlated with a six-month or less prognosis
- These variables were superior to the FAST score in predicting poor prognosis

Poor Prognostic Variables in Dementia

- Total care in activities of daily living
- Male gender
- Cancer
- Oxygen required in last 14 days
- Congestive Heart Failure
- Shortness of Breath
- <25% of Food Eaten at Most Meals
- Unstable Medical Condition
- Bowel Incontinence
- Bedfast
- Age >83 years
- Not Awake Most of the Day

Medicare Hospice Guidelines for Dementia

- FAST score of 7a or worse
- and one or more of the following in the preceding 6 months that indicate a terminal prognosis:
  - Significant comorbid condition(s)
    - Not directly related to the dementia
  - Significant secondary condition(s)
    - Diagnoses related to the dementia

Functional Assessment Staging (FAST)

- 6a: needs assistance putting on clothes
- 6b: unable to bathe properly
- 6c: inability to handle the mechanics of toileting occasionally or more frequently recently
- 6d: occasional or more frequent urinary incontinence
- 6e: occasional or more frequent fecal incontinence
- 7a: Ability to speak limited to six words or less
- 7b: Intelligible vocabulary limited to one word
- 7c: Non-ambulatory
- 7d: Unable to sit up independently
- 7e: Unable to smile
- 7f: Unable to hold head up

“Ultimately, the combined effects of Alzheimer’s Disease and any comorbid or secondary condition should be such that most beneficiaries with similar impairments would have a prognosis of six months or less.”

Typical Secondary Conditions

- Aspiration Pneumonia
- Pyelonephritis or other UTI
- Septicemia
- Multiple stage 3 or 4 decubitus ulcers
- Fever recurrent after antibiotics
- Insufficient fluid or calorie intake with 10% wt loss during previous 6 months or serum albumin < 2.5 g

Pharmacotherapy in Severe AD

- Cholinesterase inhibitors are widely used to treat AD
- In pharmaceutical company-sponsored trials of patients with mild to moderate dementia, ChEIs:
  - provide cognitive benefits
  - slow functional decline
  - help behavioral symptoms
  - allow patients to stay at home longer
- Some research exists for patients with moderate-severe dementia
- Should these medications be continued into end-stage?
Memantine with Donepezil in Severe AD Summary

• Combination therapy with donepezil in moderate to severe AD was associated with improvement in cognition, function, behavior and global change
• Patients were ambulatory and community-dwelling
• Clinical significance of changes are uncertain

CHEIs and Memantine in Severe AD

• The studies show extremely subtle improvement in cognition and ADLs in patients with moderate to severe dementia
• The improvement has questionable clinical significance
• There is no research on AD patients who would normally be eligible for hospice
  – MMSE scores less than 5
  – FAST scores of >=7

So, what should we do for our patients on donepezil and memantine?

• Discuss the literature and the lack of evidence in patients with advanced dementia
• Empathize
• Feel free to advise stopping these medications
  – A “vacation” from the medications
  – Develop a therapeutic relationship
• If the patient continues the medications, hospice is responsible for covering them

Pain in Advanced Dementia

• Pain is common in advanced dementia patients
  – Chronic musculoskeletal pain
  – Pain from bed-fast state and contractures
• Under recognized
  – 45-84% of nursing home patients have pain
  – 40-78% of nursing home patients have dementia

Pain Assessment – Pain in Advanced Dementia Scale

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Breathing</strong></td>
<td>Normal</td>
<td>Occasional labored breathing, short period of hyperventilation</td>
<td>Deep labored breathing, long period of hyperventilation</td>
</tr>
<tr>
<td><strong>Negative vocalization</strong></td>
<td>None</td>
<td>Occasional moan or groan, low-level speech with a neg. quality</td>
<td>Repeated calling out, loud moaning, groaning, crying</td>
</tr>
<tr>
<td><strong>Facial Expression</strong></td>
<td>Relaxed</td>
<td>Facial grimacing</td>
<td>Facial grimacing</td>
</tr>
<tr>
<td><strong>Body Language</strong></td>
<td>Relaxed</td>
<td>Rigid, fists clenched, hips flexed, pushing, pulling, striking out</td>
<td>Rigid, fists clenched, hips flexed, pushing, pulling, striking out</td>
</tr>
<tr>
<td><strong>Consolability</strong></td>
<td>No need to console</td>
<td>Distracted or resistant by voice or touch</td>
<td>Unable to console, distract or reassure</td>
</tr>
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Agitation and Pain in Dementia

• Nursing home patients with advanced dementia and agitation
• Refractory to treatment with psychotropic drugs
• Randomized to a low-dose, long-acting opioid vs. placebo
• Agitation was significantly lower in the opioid group even after adjusting for sedation

### Neuropsychiatric (NP) Symptoms in Dementia

- Agitation, aggression, delusions, hallucinations, repetitive vocalizations, wandering
- Observed in 60-98% of patients with dementia
- Associated with caregiver stress, depression, reduced employment and income

### Neuropsychiatric Symptom Burden

- Increases hospital length of stay
- Leads to nursing home placement
- 30% of cost of caring for dementia patients is attributed to management of neuropsychiatric symptoms

### A review of the literature on the pharmacologic treatment of neuropsychiatric (NP) Symptoms


### Pharmacologic Treatments Reviewed in the Paper

- Typical and atypical antipsychotics
- Antidepressants
- Anticonvulsants (mood stabilizers)
- Benzodiazepines
- Cholinesterase inhibitors
- Memantine

### Summary of Pharmacological Treatment of NP Symptoms

- High quality evidence for effectiveness for all of the major classes of drugs is sparse
- Haloperidol or an atypical antipsychotic may be a consideration, while recognizing the risk
- Adverse effects such as sedation may be more acceptable to family members of patients with a limited prognosis

### Summary of Pharmacological Treatment of NP Symptoms

- Cholinesterase inhibitors may show a very small effect
- Benzodiazepines can be used acutely with caution
- Always consider the diagnostic possibility of dementia with Lewy Bodies or delirium
FDA “Consideration for Healthcare Professionals”

- Elderly patients with dementia-related psychosis treated with conventional or atypical antipsychotic drugs are at an increased risk of death.
- Antipsychotic drugs are not approved for the treatment of dementia-related psychosis. Furthermore, there is no approved drug for the treatment of dementia-related psychosis. Healthcare professionals should consider other management options.
- Physicians who prescribe antipsychotics to elderly patients with dementia-related psychosis should discuss this risk of increased mortality with their patients, patients’ families, and caregivers.

FDA Information for Healthcare Professionals: Conventional Antipsychotics, last updated 3/02/11

Non-pharmacological Treatment

- Considering the risk and general ineffectiveness of pharmacologic treatment for behavioral issues in dementia patients, a non-pharmacologic approach is critical
- Hospice and palliative care teams should provide that therapy and teach families coping strategies and therapeutic techniques

Antipsychotics and Increased Risk of Death Dementia Patients

- A 2005 analysis of 17 placebo-controlled trials of patients with dementia-related behavioral disorders treated with atypical antipsychotics revealed a 1.6-1.7 times increased risk of death
- Two observational Canadian studies in 2007 found increased death rates in dementia patients treated with typical and atypical antipsychotics
- Increased death rate was seen as early as 30 days after initiation of the drug

What is Anxiety and Agitation

- Anxiety is a feeling of uneasiness, upset, uncertainty and fear thinking that there is a threat or danger. Anxiety is often mental, and not in response to real or actual events.
- Agitation is the state of continuous restlessness, usually characterized by voluntary movements that express emotional tension. The voluntary movements often serve no purpose.

What is Aggression

- Aggression can be lashing out at people or objects
- Overreacting to a situation or minor set back
- Aggression may be expressed verbally or physically
- When expressed verbally the patient may curse, shout or name call
- When expressed physically the patient may hit, pinch or punch others

Common Causes for Behavioral Issues

- Fear - anything that induces fear can lead to behavioral issues. Remember this is a perceived threat.
- Humiliation - patients often feel humiliated that they need assistance with ADLs and loss of control
- Feeling frustrated - having difficulty understanding others or making themselves understood.
- Loss of judgment or self-control due to the progression of dementia.
Common Causes for Behavioral Issues

- **Loss of inhibition** or awareness of the rules for appropriate learned behavior
- **Pain**
- Anything that increases stress on the patient can lead to behavior outburst-tired, thirsty, being in an unfamiliar environment, or too much stimulation such as too much noise or too much people

How to Respond to Behavioral Issues

- **Remind** family not to take the behaviors personally-the patient is reacting to a situation
- **Try to identify the immediate cause of the outburst**-if family can identify the triggers for this behavior, they can avoid the triggers
- **Rule out pain** as a possible cause for the behaviors
- **Remind** family to try not to become upset by the behaviors, instruct family to remain calm, speak softly and slowly to the patient.

How to Respond to Behavioral Issues

- **Never argue**-it will only aggravate the situation
- **Reassure** the patient and acknowledge that you understand they are upset
- **If the patient can verbalize the cause for their outburst**, listen and try to understand
- **Try distraction techniques** to take the focus from the present situation, if needed take them away from the present situation

How to Respond to Behavioral Issues

- If the patient is violent-keep an arms length away
- Keep dangerous objects away from the patient
- If you were trying to do something, ask if this has to be done at this time, you can try again in 5 or 10 minutes
- Limit excessive stimulation, not too many people or activities at the same time or in a day
- Keep clutter to a minimum

How to Respond to Behavioral Issues

- Keep a consistent daily schedule, this helps to decrease stress if the patient knows what to expect next
- Keep demands on the patient to a minimum, make sure family gives the patient significant time to do expected activities
- The patient may require scheduled naps
- If the patient has restless energy, give them an outlet such as a safe physical activity

Case Study

- Mrs. Mattie is a 78 year old AAF who lives alone at home. She is widowed and childless, but has 2 nieces who check on her regularly. She has a PMHx of HTN and dyslipidemia. Family assumed everything was fine with Mrs. Mattie until one day she went to the next door neighbor’s home with a gun. Police where called. She told the police that the neighbors were breaking in to her home and stealing money and jewelry. The police took her to a local hospital for further evaluation. Labs were drawn, a UA and CT of head. Mrs. Mattie had a UTI, mildly dehydrated, malnutrition and the CT was negative. She was admitted for UTI and AMS. She was underweight at 5’10” and 118 lbs, BMI 16.9. Her MMSE was 17.
Case Study

• Her FAST was 6B, she required assistance with bathing and dressing but is able to feed herself. She is continent of B&B and ambulatory w/cane. Mrs. Mattie was oriented x2 and difficulty with short term memory. Mrs. Mattie was diagnosed with moderate Alzheimer’s dementia. She was started on Aricept and Namenda while in the hospital. Family decided to place her in an assisted living facility with a palliative care consult. At first, Mrs. Mattie seemed to adjust well to the new environment, but then developed trust issues with the nursing staff. She thought the staff was taking her purse and stealing money.

What is Suspicion and its Causes

• Suspicion is distrust of others, ideas or objects
• Unfortunately this is common with dementia patients
• It is common for dementia patients to accuse others of theft when they misplace or lose objects
• Other common accusations are infidelity, attempted poisoning (through food, drink or medications) or other improper behaviors
• As the patient’s memory loss and confusion progress, they perceive things in different and unusual ways

How to Respond to Suspicion

• Use the same nursing interventions from the prior slides on how to respond to behavioral issues
• Keep any answers you give the patient simple, lengthy explanations can overwhelm the patient
• Check the trash before taking it out
• Try to keep duplicates of items more likely to be misplaced

Case Study

Which intervention would you recommend to the family and nursing staff at the facility?
A. Explain to Mrs. Mattie that she does not need money in the facility and that her nieces are taking care of all her bills.
B. Have the family explain to Mrs. Mattie that the staff are not stealing from her.
C. Have family bring her a purse and put a few dollars in a wallet for her to keep and examine when she wants.
D. Order a short acting PRN antianxiety medication for her behaviors.

Case Study, Part 2

• Mrs. Mary is an 80 year old CF who lives at home w/ her husband in a lake house. She has a PMHx of breast CA, HTN, DM and Alzheimer’s dementia. She is on Aricept and Namenda. Her PCP recommended a palliative care consult. Her husband requested a late visit and had to meet the nurse practitioner at the main road to guide her to the home. When they returned, Mrs. Mary was not in the home. It was winter and dark. The nurse and the husband spent close to 40 min searching the property and lake before they found Mrs. Mary, who was only in her nightgown. Mrs. Mary reported she was looking for the dog. The dog had died 15 years ago.
Case Study, Part 2

A prudent palliative care practitioner would recommend to family which of the following:

A. Install an alarm system and have it on at all times.
B. Hire private duty sitters to be with Mrs. Mary 24/7.
C. Install and use dead bolts on all exit doors at all times when in the home.
D. Put child safety door handle covers on all exit door handles.

Wandering and its Causes

- There are many different reasons for dementia patients to wander and get lost.
- Often, they forget where they are.
- They may be trying to recreate a familiar routine, such as going to work or the store. Halfway through the familiar routine they forget where they are going or what they were doing and become lost.
- The patient may have increased stress or anxiety, and wandering is form of expression.

How to Respond to Wandering

- Disguise or block the exits in the home. You can put screens, drapes or mirrors in front of or on the exit doors or stop sign.
- Mayo Clinic recommends you place a picture of a toilet on the bathroom door and picture of food on the kitchen door. Label all rooms.
- Place a black mat in front of the exit doors, the patient may think it is a hole and not try to pass.

How to Respond to Wandering

- Move the locks to the exit doors to the bottom of the door.
- Dead bolt all exits doors in the home, keep a key around you neck at all times.
- Never lock the patient in the home by themselves.
- Have an alarm system installed and keep it on at all times when at home.
- Put child safe plastic covers over all exit door nobs.

How to Respond to Wandering

- Encourage safe activities. Have the patient engage in washing dishes, vacuuming and folding laundry.
- Take the patient for a walk.
- If they have a fenced and locked yard, allow the patient to walk in the yard by themselves.
- Have the patient wear an ID bracelet at all times with name, address and telephone numbers.

How to Respond to Wandering

- Family can enroll the patient in the MedicAlert+Alzheimer’s Association Safe Return.
- If family can afford the expense, there are multiple high tech devices to monitor wandering patients, such as GPS shoes, LoJack wristbands and monitoring sensors in the home.
Monitoring Devices for Wandering Patients

Safety and Dementia Patients
• Remove flammable liquids from the home
• Keep a set of house keys on your person at all times, incase the patient locks you out of the house
• Child proof plug covers on unused outlets
• Keep extension cords to a minimum-tripping hazard
• Ensure adequate lighting
• Keep medications locked up and use child safety caps

Safety and Dementia Patients
• Keep all poisons inaccessible to the patient (bug spray, cleaning chemicals, paint, etc. al.)
• Avoid clutter and keep walkways clear
• Remove firearms and power tools or lock them up
• Use night lights
• Remove space heaters-dementia patients often have difficulty in judging temperature
• Remove scatter/throw rugs

Safety and Dementia Patients
• Place nonskid strips in the bathtub and shower
• Place grab bars in the bathtub and shower
• Shower chair and hand held shower head will make bathing easier
• Set the water heater to 120 degrees F
• Remove nob from the stove, washer and dryer
• Consider using a baby monitor
• Consider using child safety locks on kitchen cabinets

Safety and Dementia Patients
### Common Causes of Behavioral Disturbances
- Fear
- Humiliation
- Frustration
- Loss of judgment or self-control
- Loss of inhibition
- Pain
- Stress

### Responding in a crisis situation
- Remain calm
- Never argue
- Reassure the patient
- Try distraction techniques
- Be safe
- If everything else fails, try coming back in 5 to 10 minutes

### The Team Approach to Dementia Patients and Their Families

### Social Worker’s Duties
- They perform a psychosocial evaluation, identify potential problems and help to meet needs.
- They find available local and national resources for families.
- They provide counseling services to the patient and family.
- They help to coordinate patient care with the interdisciplinary team.
- They help to educate patient and family.

### What About Advance Dementia Patients?
- When patients are admitted to hospice with dementia, the majority of information is gathered from the family and primary caregivers.
- The majority of social worker services are aimed towards meeting caregiver’s needs and finding resources available in the community.
- When patients are in a facility, social workers often keep family updated on their loved one and coordinate care with the facility.

### Chaplain’s Duties
- They perform a spiritual assessment when a patient is admitted to hospice.
- They provide spiritual care and end of life counsel to patient and family.
- They coordinate care with other spiritual counselors.
- They participate in the interdisciplinary team meetings.
- When requested, they conduct or help arrange funeral or memorial services.
What about Advance Dementia Patients?

- Chaplains will gather the majority of patient information from the family and primary caregiver.
- Focus will often be on meeting the spiritual needs of the family and primary caregiver, due to the patient cognitively limited.
- Many chaplains will sing hymnals, read from religious texts and pray with dementia patients.
- Families are often grieving the death of the patient before the death.

Questions?

Answers?

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- [www.alz.org](http://www.alz.org)
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