Palliative Care for Patients with Advanced Dementia

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Disclosures

- No conflicts of interest to disclose
- I will discuss the off-label use of some medications

Agenda

- Understanding dementia as a terminal illness
- Clinical issues:
  - Ethical issues and decision-making in advance dementia
  - Symptom management in the terminal phase of advanced dementia

Objectives

- To reflect on when we should consider palliative care for this patient population
- To develop an approach to decision-making for patients with advanced dementia
- To learn from participants' experiences of caring for patients with advanced dementia

Do you think of dementia as a terminal diagnosis?

Does the way we think about prognosis in patients with dementia influence the care provided to these patients?

Alzheimer's Disease

- Most common type of progressive degenerative dementia
- 2000: 4.5 million Americans diagnosed[1]
- 2050 (expected): ↑300% to 13.2 million individuals[1]

1. Prigerson HG. Cost to society of family caregiving for patients with end-stage Alzheimer's disease. N Engl J Med. 2003; 349(20):1891-1892.

Alzheimer's disease: Diagnosis

- Memory impairment and at least one other cognitive disturbance
- Severe enough to cause significant functional impairment
- Gradual onset and progressive course

Disease trajectory in dementia

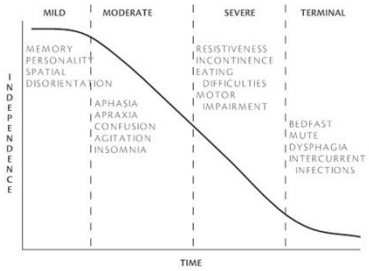
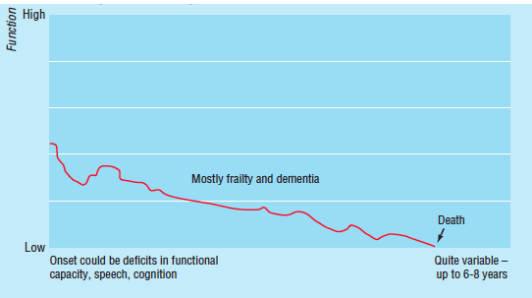


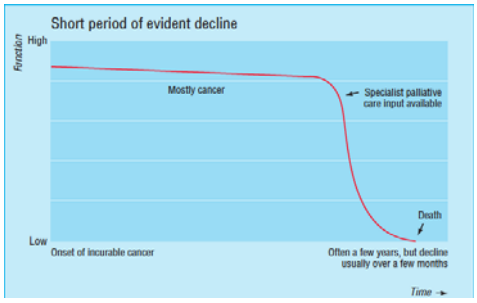
Figure 14.1.1 Course of progressive dementias. Reprinted from Mahoney, E.K. *et al.* (2000) *Management of Challenging Behaviors in Dementia* with Health Professions Press, Baltimore.

Disease trajectory in dementia



Murray SA et al. Illness trajectories and palliative care. BMJ. 2005 Apr 30; 330(7498): 1007–1011

Disease trajectory in cancer



Murray SA et al. Illness trajectories and palliative care. BMJ. 2005 Apr 30; 330(7498): 1007–1011

Prognostication in Dementia

- Very difficult because of the unpredictability of intercurrent diseases (e.g. infections) that are the most common cause of death
- Terminal stage can go unrecognized by clinicians and caregivers

There is a need for palliative care that cannot be based on prognostication

Palliative Care Along the Disease Trajectory

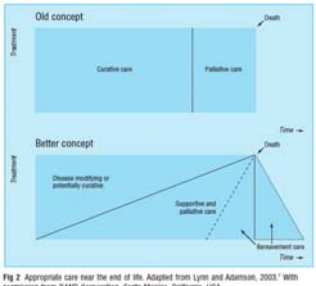


Fig 2 Appropriate care near the end of life. Adapted from Lynn and Adamson, 2003.[1] With permission from RAND Corporation, Santa Monica, California, USA

Murray SA et al. Illness trajectories and palliative care. BMJ. 2005 Apr 30; 330(7498): 1007–1011

Why is defining a terminal stage important?

- Asking 'How long have I got?' = 'What can I expect will happen?'
- Plan for medical and practical care needs
- Discussing illness trajectory allows for a realistic dialogue between patient, caregivers, and professionals
  - Can allow the option of supportive care, focusing on quality of life and symptom control, to be grasped earlier and more frequently

When do we have a discussion about the illness trajectory of dementia?

- At the time of diagnosis
- On-going
- *(At the very least)* When the patient enters the terminal stage

Have you had any experience discussing or observing discussions about prognosis in patients with dementia?

Questions?

Complications in the terminal stage of dementia

- Weight loss
- Infections:
  - Urinary tract, respiratory tract, skin
  - Generalized infections are the most common cause of death

Weight loss in Alzheimer's Disease

- Weight loss/cachexia is common in the later stages dementia
- Weight loss ≥ 5% in any year before death is a significant predictor of mortality[1]

1. White H et al. The association of weight change in Alzhiemer's disease with severity of disease and mortality: a longitudinal analysis. J Am Geriatr Soc. 1998 Oct;46(10):1223-7

Weight loss in Alzheimer's Disease

- Causes:
  - May be due to decreased food intake:
    - Visual spatial problems, inattention
    - Socio-environmental
    - Depression
    - Loss of neuromuscular coordination
  - May be due to increased energy expenditure:
    - Wandering
    - Restlessness

Weight loss in Alzheimer's disease

- Complications:
  - Decreased immunity
  - Loss of muscle mass→functional decline; falls
  - Skin atrophy→ulcers

Difficulties in swallowing

- Major focus of caregivers and healthcare providers
- Dietary modifications or other interventional programs may be effective for a period of time

At some point most patients with dementia will reach a stage when they are no longer able to take oral nutrition

Advanced care planning

…is a process of reflection and communication. It is a time for you [the patient] to reflect on your values and wishes, and let others know what kind of health and personal care you would want in the future if you become incapable of consenting to or refusing treatment or other care.

Speak Up: Advanced Care Planning Workbook, Ontario Ed.

Advanced care planning

- Discussion involving the patient, and the patient's future Substitute Decision Maker (SDM)
  - Required to follow the patient's wishes about treatment, if known, however expressed
    - In advanced dementia, decisions are almost always made with the patient's SDM due to patient's incapacity

Advanced care planning

- Discussion involving the patient, SDM and health care providers
  - Provide accurate medical information on which to make decisions

Active Medical Management and Palliative Care: A continuum

- When receiving palliative care, patients will often be treated for intercurrent or comorbid illnesses, such as urinary tract infections, pneumonia, or heart failure, along with their life-limiting medical conditions
- The objective of such treatment is to reduce physical discomfort and maintain or improve wellbeing;
  - However, the side effect might be that life is prolonged.

Active Medical Management and Palliative Care: A continuum

- Do treatments of comorbid or new conditions have life-prolonging effects that will expose the patient to intolerable symptoms related to the dementia?

  Focus gradually shifts from the quality of life to the quality of death and, at some point, life-extending side effects of medical treatments with a primarily palliative intention might be no longer acceptable.

Factors influencing end-of-life decision-making[1]

- SDM's perception of the patient's quality of life
- The invasiveness of treatments or investigations proposed
- Advanced directives
- Cultural and family context
- Trust or distrust of the medical team

1. Arcand M. End-of-life issues in advanced dementia: Part 1: goals of care, decision-making process, and family education. Can Fam Physician April 2015 61: 330-334.

Has anyone heard of the Speak Up Campaign?

http://www.advancecareplanning.ca/

Common clinical scenario

- Pt from LTC admitted to TWH with a history of fever and hypoxia
- SLP assessment: high-risk for aspiration
- "Patient needs PEG"

Advanced directives?

What are the options?

What are the options for feeding in the terminal stage of dementia?

- Careful hand feeding
  - Feeding carefully, bit by bit, favourite foods
  - Only give as much as the patient wants
  - To alleviate symptoms of dry mouth and thirst:
    - Mouth care consisting of oral cleaning with swabs
    - Lubrication is recommended every 2 hours

What are the benefits and burdens of careful hand feeding?

- Benefits:
  - Gives the patient the opportunity to eat and enjoy food and drink but does not force eating or drinking
  - Can still enjoy the human interaction and taste and feel of food in their mouths at mealtime
- Burdens:
  - Risk of aspiration which can lead to lung infections *continues*
    - Can be reduced

What are the options for feeding in the terminal stage of dementia?

- Tube feeding:
  - Liquid food, fluids and medications via nasogastric tube (temporary) or gastrostomy tube (permanent)

What are the benefits and burdens of tube feeding?

- Benefits:
  - May provide the person with calories if their stomach can absorb nutrition
  - Can reduce the time it takes to feed allowing for more energy for other activities
  - Provides a bypass for the mouth for those who cannot swallow safely
  - Is one of the ways medications can be given

What are the benefits and burdens of tube feeding?

- Burdens:
  - Risk of aspiration *remains*, which can lead to lung infections
  - Insertion of the tube can be painful
  - There is risk of wound infection
  - It may cause a person to become agitated and may increase the use of restraints
  - There is a risk of the tube being pulled out
  - There is risk of the tube blocking

What are the benefits and burdens of tube feeding?

- Burdens, continued:
  - The person may develop abdominal pain or discomfort
  - Tube feeding sometimes causes chronic diarrhea
  - There is no proof that it improves quality of life, thirst or survival in a person with advanced dementia at the end of life
  - May limit enjoyment from taste of food and social interaction with eating
  - Requires maintenance many times in a day

Will there be hunger or thirst?

- As the people reach the final stages of dementia, the body begins to feel less hungry or thirsty
- Studies in patients who are in the final stages of other terminal diseases, and still able to communicate, show that the vast majority of people do not feel hungry or thirsty
- People who do have hunger or thirst experience relief with very small amounts of food/mouth care

Will death come sooner?

- There is no difference in how long people with advanced dementia live when comparing careful hand feeding to tube feeding[1]

1. Finucane TE, Christmas C, Travis K. Tube feeding in patients with advanced dementia: a review of the evidence. JAMA 1999;282(14):1365-70.

American Geriatrics Society Position Statement (2014)

…percutaneous feeding tubes are not recommended for older adults with advanced dementia.

…careful hand-feeing should be offered, because it is at LEAST as good as tube-feeding for the outcomes of death, aspiration pneumonia, functional status and patient comfort.

What challenges and successes have you experienced when talking with caregivers about feeding for patients with advanced dementia?

Symptom Management in the Terminal Phase of Dementia

Box 1. Symptomatic care in advanced dementia: *the low-tech, high-touch approach.*

Elements of the low-tech, high-touch approach include the following:

- Symptom control
- Mouth care
- Regular pain assessment with the appropriate tool (eg, PACSLAC)
- Comfort feeding
- Attention to dignity
- Frequent reassessments
- Comforting measures (eg, touch, music) by family and staff members who know the patient well

PACSLAC—Pain Assessment Checklist for Seniors with Limited Ability to Communicate.

Symptom Management in the Terminal Phase of Dementia

- Constipation
- Pain
- Shortness of breath
- Delirium

Constipation: Etiology

- Decreased oral intake
- Medications
  - Opioids
- Immobility
- Hypomotility

Constipation: Assessment and Treatment

- Assessment:
  - Documentation of bowel movement frequency
- Treatment:
  - Bisacodyl suppository
  - Fleet enema

Pain: Etiology

- Most common: Chronic conditions
  - Arthritis
  - Old fractures
  - Neuropathy
- Acute conditions:
  - Fecal impaction
  - Urinary retention
  - Unrecognized fractures
- Skin ulcers

Pain: Assessment

- Pain Assessment In Advanced Dementia Scale
  - PAINAD Scale
- Observational
- 5 items:
  1. Breathing
  2. Facial expression
  3. Body language
  4. Negative vocalizations
  5. Consolability

- Each item scored 0-2
- Total 0 (no pain) to 10 (severe pain):
  - 1-2 indicates some pain

Available online at http://www.mhpcn.ca/uploads/PAINAD.1276125778.pdf

Pain: Treatment

- Treat the underlying cause
- Tylenol
- Opioids: po (SL) or subcutaneous
  - Regular and prn doses if ≥3 prn doses required
  - E.g. morphine 2.5 mg subcut q4-6h and 1-2.5 mg subcut q1h prn

Shortness of breath: Etiology

- Common:
  - Aspiration pneumonia
  - Pulmonary edema
  - Respiratory muscle weakness

Shortness of breath: Assessment

- Vital signs, including:
  - Temperature
  - Respiratory rate
    - Surrogate maker for dyspnea in non-verbal patient

  (Oxygen saturation, heart rate*)
- Respiratory examination

Shortness of breath: Treatment

- Aspiration pneumonia:
  - Antibiotics *may* increase comfort, but not always
  - Antibiotics *may also extend* the number of days lived in relative discomfort
  - Intravenous lines and/or transfer to hospital may decrease comfort

Shortness of breath: Treatment

- Symptomatic treatment of aspiration pneumonia:
  - Oxygen by nasal prongs if tolerated*
  - Tylenol suppositories
  - Fan at bedside

Shortness of breath: Treatment

- Symptomatic treatment of aspiration pneumonia:
  - Opioids (subcutaneous) for dyspnea prn +/- regular dose
  - Anticholinergic drugs for secretions
    - Atropine SL prn
    - Glycopyrrolate or scopolamine subcut prn
    - Avoid suctioning as this may increase secretions
  - +/- antipsychotics for agitation
  - +/- benzodiazepines for severe respiratory distress or agitation

Shortness of breath: Treatment

- Education of caregivers
  - *Normalcy* of oropharyngeal secretions at end of life
    - Does not cause a sensation of choking in a comatose patient
  - Changes in respiratory pattern at the end-of-life:
    - Apnea
    - Cheynes-Stokes pattern
    - Prominent accessory muscle use
    - Reflex breaths

Delirium: Etiology

- Multicausal etiology; etiology may be unknown
  - Underlying medical condition
    - e.g. pneumonia, renal failure
  - Drugs
    - Withdrawal
  - Urinary retention or constipation

Delirium: Etiology

- Dementia increases risk
  - Restlessness or agitation may be a behaviour of dementia
- Associated with and common in last days of life but not inevitable (‘terminal agitation’)
  - Often irreversible in last days of life

Delirium: Assessment

- DSM-V Criteria for diagnosis
- Observation:
  - Restlessness or agitation, moaning
    - *Does not necessarily indicate pain*
  - Fluctuation in severity throughout day

Delirium: Treatment of restlessness

- Non-pharmacological:
  - Familiar caregivers
  - Limit noise, bright lights and number of visitors
  - Avoid physical restraints
    - Frequent monitoring, prn or regular doses of antipsychotics or benzodiazepines

Delirium: Treatment of restlessness

- Pharmacological:
  - Antipsychotics
  - Benzodiazepines
    - If history of regular use

Delirium: Treatment of restlessness

- Many patients' goals of care at end-of-life include avoiding sedation to allow for meaningful interactions with caregivers
  - This is possible in most cases
- Opioids are used for pain or shortness of breath
  - Can be used without impacting level of alertness

Delirium: Treatment of restlessness

- Sedation may be discussed with a patient's SDM if:
  - The burdens of wakefulness (on-going agitation) outweigh benefits
  - All reasonable non-sedating options for treating agitation have been attempted
  - The goals of care are to maintain comfort and not to prolong life
  - The patient has a prognosis of days to short weeks

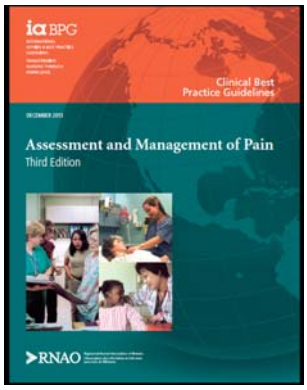
What are your experiences caring for patients with advanced dementia at the end of life?

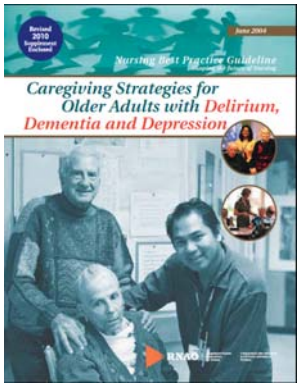
Questions?

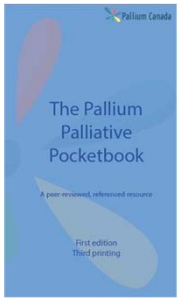
Resources

Geriatrics Cultural Navigator (AGS)

Comfort Care at the End of Life for Persons with Alzheimer's Disease or Other Degenerative Diseases of the Brain – A Guide for Caregivers







Notes re: CPR in Advanced Dementia[1]

- Outside hospital, the chances of survival are low and CPR itself might be harmful and undignified
- Even with the benefits of being in hospital, CPR is 3 times less likely to be successful (survival to discharge) in people with cognitive impairment than in those who are cognitively intact, and the success rate is similar to that found in people with metastatic cancer
- Cardiopulmonary resuscitation attempts in unwitnessed arrests have an extremely low chance of success and, if successful, have a high risk of worsened function from hypoxia