Dementia & End-of-Life Care: Easing the Transition

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Seminar Objectives

The aim of this case-based workshop is to:

1. Enhance clinicians’ comfort levels in recognizing approaching end-of-life in persons with dementia.

2. Assist clinicians to prepare families for the changes and decision-making that lies ahead.

3. Provide a toolbox of resources to assist in caring for individuals with dementia at the end-of-life.
Stats & Facts

• In 2009, Alzheimer’s disease was the 6th leading cause of death for Canadian’s aged 75 – 84, and the 4th leading cause of death of Canadian’s 85 and over. (Stats Can, 2009).

• An estimated 50% of people with AD are in moderate to advanced stages of the disease at time of diagnosis (Herrmann & Gauthier, 2008).

• Median survival rates range between 3.3 – 4.5 – 6 years (Sampson, et al, 2009; Herrmann & Gauthier, 2008), with a range of 1 – 16 years (Herrmann & Gauthier, 2008).

• ~ 70% with dementia will die in NHs (Mitchell et al, 2006).

• Dying NH residents less likely to have ACP in place, more likely to receive aggressive care (Engel et al, 2006)

• When compared to non-demented pts, pt’s w dementia less likely to be referred to palliative care, less likely to receive palliative drug txs, less likely to have carers involved in decision making (Afzal et al, 2010).
The Clinician’s Role

- Recognize individuals nearing end-of-life
  - Understand disease trajectories
  - Being alert of signs and symptoms of EOL

- Complete holistic assessment
  - Obtain information from multiple sources
  - Use validated tools

- Assess pt/family understanding of illness/situation

- Be alert for factors that influence decision-making

- Support decision making in-line with pt/family values/beliefs/preferences

- Use effective communication when facilitating end-of-life decision making

- Promote quality end of life care

RNAO, 2011
Quality End of Life Care

- Promote comfort: pain and symptom management.
- Avoid inappropriate prolongation of dying
- Promote a sense of control.
- Reduce burden.
- Assist in strengthening the relationships with loved ones.

(RNAO, 2011)
Mrs. A.

- Mrs. A.
  - 76 years young, lived at home w husband until 1 year ago – LTC. (wandering, falls, disorientation); 2 sons living afar; George visits daily at noon.

- PMHx:
  - Hypertension, TIAs, osteoporosis, osteoarthritis-knees, recurrent falls.
  - Alzheimer’s/mixed dementia x 4 years; Last month, MMSE 8/30.
  - Meds: HCTZ, ramipril, atorvastatin, aricept, ASA, calcium TID, residronate, vitamin D, zopiclone, B12 daily, Multivites, Tylenol prn.
  - Advanced Directives: “Full code, send to acute care hospital”

- Issues:
  - Admitted to acute care hospital for aspiration pneumonia, 2\(^{nd}\) time in past year.
  - Baseline past 3 months:
    - Mobility = Requires 1 person assist. Most times in W/C watching others.
    - Intake generally poor; requires feeding, weight loss an issue; chokes easily
    - Not able to recognize family members most times.
    - Behaviours: /screams & strikes out when care given,
Challenges

• Difficulty with prognostication

• Not recognizing dementia as terminal illness

• Patients unable to express preferences

• Families often faced with difficult decisions, emotional stress, q may impede bereavement outcome

Disease Trajectory

(RNAO, 2011, p. 21)
Role of Hospice Palliative Care During Illness

(RNAO, 2011, p. 19)
Domains of Issues Associated with Illness & Bereavement


  
Advanced Dementia

- Severe cognitive impairment
- Unable to ambulate
- Difficulty swallowing
- Decreased appetite/intake
- Dual incontinence
- Unable to function autonomously
- Near-total care; increasingly bedridden
- Corresponds to Global Deterioration Scale 6 – 7
- Severe Dementia (MMSE < 9)
- Very Severe Dementia (< 3). (Lussier et al. 2011)
Clinical Course of Advanced Dementia

Mitchell et al, 2009;
  - US study; Boston; 22 nursing homes.
  - 323 NH residents w advanced dementia & Health Care Proxies
  - Followed x 18 months;

• Survival:
  - 54.8% died over 18 months; adjusted median survival 478 days
  - 6 month probability death = 24.7%; location of death: 93.8% NH

• Complications
  - Pneumonia (41.1%), febrile episode (52.6%), eating problems (85.8%)

• Burdensome Interventions in last 3 months of life
  - Of 177 who died, IV therapy (29.4%), hospitalized (12.4%), ER (2.8%), & 7.2% (13) underwent tube feeding intervention
Proportion of Nursing Home Residents Who Had Distressing Symptoms at Various Intervals before Death (Mitchel et al, 2009. p. 1535)
Mitchell et al. 2009

- Reasons for the 22 hospitalizations in last 3 mons life:
  - Pneumonia (15); other infections (3); CHF (2); hip fracture (1); dehydration (1).

- Hospice Referrals:
  - For 323 residents w AD, 22.3% referred to hospice
  - Of 177 deceased residents, 29.9% (n = 53) received referrals
    - 0 – 7 days = 26.4%
    - 8 – 90 days = 30.2%
    - 91 – 180 days = 17%
    - > 181 days = 26.4%

- “..residents whose health care proxies believed the resident had less than 6 months to live and understood clinical complications expected in advanced dementia were less likely to undergo a burdensome intervention during the final 3 months of life…” (p. 1534)
Challenges in Prognostication

• Predicting prognosis in Dementia is complicated by:
  o Prolonged & progressive disability
  o # Comorbidities
  o Complex age-related care needs

• As outcomes
  o Frequent hospitalization
  o Experience burdensome invasive interventions
    • Feeding tubes, lab tests, restraints
  o Uncontrolled pain

(Brown et al (2012).)
Prognostic Indicators for Dementia from RNAO BPG

“Month to several months of life expected (all predictors should be present):

• Mini-Mental State Examination <12.
• Unable to ambulate without assistance.
• Unable to dress without assistance.
• Unable to bathe without assistance.
• Urinary and fecal incontinence.
• Unable to speak or communicate meaningfully.
• Unable to swallow.
• Increasing frequency of medical complications (e.g. aspiration pneumonia, urinary tract infections, decubitus ulcers).”

(RNAO, 2011, p. 105)
Prognostic Indicators
6 month mortality

Systematic review by Brown et al (2012) supports inclusion of:

- **Measure of dementia severity; no consensus on which scale to use**
  - FAST, MMSE, Medicare Hospice Guidelines
- **Nutritional intake,**
  - anorexia, intake, weight loss, malnutrition
- **Presence of comorbidities**
  - Cancer, Congestive Heart Failure
- **Functional and cognitive impairment**
  - At times measured independently or as part of scale (FAST)
- **Others: Insufficient evidence:**
  - Speech/language difficulties, hematological indices, signs of suffering
Palliative Performance Scale

http://www.viha.ca/NR/rdonlyres/5682D171-DDC8-4A06-8B60-34AF178DBF92/0/PalliativePerformanceScale.pdf
Palliative Performance Index

http://palliative.info/teaching_material/Prognosis.pdf
Preparation the Family: 
Late Stage: What to Expect

• Severe difficulties in memory, thinking, 
  & processing information.
• Speech may be unrecognizable, or doesn’t make sense.
  ◦ Non-verbal important
• Increased difficulties in eating, and swallowing
• Need help toileting; become incontinent
• Require more help walking, or sitting up. Mind seems not able to inform body what to do.
• Explain how do help & interact

Alzheimer Society of Canada, 2013
Decision-Making

• Advanced Care Planning
• Code Status/ CPR
• Tube Feeding
• Hydration
• Treatment of infections
• Acute care hospitalizations
Husband’s concerns

• Nutrition:
  o “She’s not eating enough, she’s going to starve to death. Can you keep her on IV fluids to make sure she’s getting enough?”
  o What about a feeding tube? Would that be safer?
Prevalence of Feeding Tubes

• “As many as 34% of US nursing home residents with advanced dementia have feeding tubes, two-thirds of which are inserted during an acute hospital stay.

• Caregivers report little conversation surrounding tube feeding decisions, and at times families feel pressure for its use.”

Nutrition & Tube Feeds

- Poor intake common in dementia
- Fail to recognize food
- Lose physiological drivers of appetite/satiety r/t changes in limbic/hypothalamic function
- Develop difficulties with swallowing function
  - Unable to manage bolus
  - Aspirate
- Often look at option NG or PEG tube feeding to
  - Prevent aspiration pneumonic
  - Prevent malnutrition
  - Complications of malnutrition (pressure ulcers, infection, starvation, death)
  - Promote comfort & QOL BUT

(Sampson, et al. 2009)
Weighing Pros & Cons

Common Belief

PROs
• ↓ aspiration pneumonia
• ↓ malnutrition
• ↓ complications of malnutrition (pressure ulcers, infection, starvation, death)
• ↑ comfort & QOL

CONs
• ↑ incontinence-pressure ulcers-decrease QOL
• ↑ pulmonary secretions
• PEG invasive w post–op risks:
  o Aspiration pneumonia
  o Oesophageal perforation
  o Migration of tube
  o Haemorrhage
  o Wound infection
  o Restraints
• ↓ QOL

(Sampson, et al. 2009)
The evidence on Tube Feeds & TPN

Cochrane review 2009; (Sampson et al).

- 7 studies; 6 addressed mortality & 1 nutritional
- Inconclusive evidence of benefit re:
  - increased survival in pt receiving TF
  - Nutritional parameters
  - Physical functioning
  - Reduced incidence pressure ulcers

- None assessed QOL
More evidence (Finucaine et al., 1999)

- Hand fed pts w dementia & dysphagia had fewer major aspiration events than tube fed pts.
- No published studies demonstrated less asp pneumonia w tube feeds.
- Despite good intake via TF, subjects still lost weight, and lean/fat body mass.
- Replacement of nutrients in nutritionally deficit pts did not improve meaningful clinical outcomes.
- No survival advantage w tube feeds In pt w dementia.
- No studies re: TF improving function or mitigating decline
- No studies re: TF increasing comfort in demented pts.
NICE Guideline Recommendation

• “…staff should encourage people with dementia to eat and drink by mouth for as long as possible.”

• “Specialist assessment and advice concerning swallowing and feeding in dementia should be available.”

• “Dietary advice…beneficial”

• “Nutritional support, including artificial (tube) feeding, should be considered if dysphagia is thought to be a transient phenomena, but artificial feeding should not generally be used in people with severe dementia for whom dysphagia or disinclination to eat is a manifestation of disease severity….”
  ○ (2006/2012, p. 41-42.)
“Percutaneous feeding tubes are not recommended for older adults with advanced dementia. Careful hand-feeding should be offered;

For persons with advanced dementia, hand feeding is at least as good as tube-feeding for the outcomes of death, aspiration pneumonia, functional status and patient comfort.

Tube feeding is associated with agitation, increased use of physical and chemical restraints, and worsening pressure ulcers.”

Decision-Making Aid
Tube Feeding

Provide Information about:

- common eating and swallowing difficulties.
- Technical aspects of tube insertion
- Role/principles of substitute decision-making
- Risks/benefits of tube
- Options for support/comfort care
- When & how to review/discontinue

Steps to decision-making

- Guide through learning process,
  - check understanding
- How info applies to pt
  - preferences, values and situation
  - Review pt. clinical situation
  - What would pt want?
  - How this decision affects family
  - Invite questions
  - Who decides,
  - When to stop
  - Pt/family thoughts

(Lussier et al, 2011; Mitchell et al, 2001)
A Decision-Making Aid re: feeding options in dementia

http://vimeo.com/51776155
Decision-Making

- Advanced Care Planning
- Code Status/ CPR
- Tube Feeding
- Hydration
- Treatment of infections
- Acute care hospitalizations
## Pain Assessment

### Appendix Q: Pain Assessment in Advanced Dementia (PAINAD)

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breathing, Independent of vocalization</td>
<td>Normal</td>
<td>Occasional labored breathing</td>
<td>Noisy labored breathing. Long period of hyperventilation. Cheyne-stokes respirations</td>
<td></td>
</tr>
<tr>
<td>Negative Vocalization</td>
<td>None</td>
<td>Occasional moan or groan Low level speech with a negative or disapproving quality</td>
<td>Repeated troubled calling out. Loud moaning or groaning. Crying</td>
<td></td>
</tr>
<tr>
<td>Facial expression</td>
<td>Smiling, or unexpressive</td>
<td>Sad. Frightened. Frown</td>
<td>Facial grimacing</td>
<td></td>
</tr>
<tr>
<td>Consolability</td>
<td>No need to console</td>
<td>Distracted or reassured by voice or touch</td>
<td>Unable to console, distract or reassure</td>
<td></td>
</tr>
</tbody>
</table>

TOTAL

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Pain Assessment

SAMPLE 4 - Facial Grimace & Behaviour Checklist Flow Charts

Name: ___________________________________ Active □ Resting □ Time: ___________

0 no pain 2 mild 4 discomforting 6 distressing 8 horrible 10 excruciating

Regular pain Medication: __________________________ Rescue/PRN medication ______________


RNAO (2002, p. 108)
Medications in Advanced Dementia

**Always OK**
- Analgesics
- Antiemetics
- Laxatives
- Eye drops
- Bronchodilators

**Sometimes OK**
- PPI
- BP meds
- DM meds
- Thyroid
- Diuretics
- Anti-anginal
- Anti-psychotics
- Anti-depressants

**Rarely OK**
- Chemo
- Lipid-lowering
- Bladder relaxants
- Biphosphates
- Mineral/Vitamin
- Heparin/Warfarin

Anticipate route change
- SQ, SL

Adapted from Lussier et al, 2011
Preparing the Family
End-of-Life: What to Expect

• Common changes
  o Circulation slows: Skin is cool, nails may be blue
  o Skin may be prone to breakdown/ pressure sores
  o Person no longer accepting food or drink
  o Secretions may pool in back of throat; dry mouth
  o Sleepiness may increase
  o Breathing may become irregular and may pause
  o Person may become agitated or restless
  o Person continues to experience emotion
  o Spirituality may be important

Alzheimer Society of Canada (2013)
The Family: Care for the Caregiver

- Avoid isolation; continue social activities
- Eat, sleep, exercise; take care of health
- Join a caregiver support group
- Be aware of signs of stress
- Talk to your doctor about stress and/or depression
- Ask about setting up a visit schedule (Share-the-Care™)
- Ask about care setting options

Adapted from Alzheimer Society of Canada (2013)
The Resource Toolbox

- Decision Making Aid: Feeding Options in Dementia http://vimeo.com/51776155
- Pain & Symptom Management Program Southwestern Ontario: http://www.palliativecareswo.ca/Resources.htm
- Share-the-Care™ http://caregiverexchange.ca/searchKeyword.aspx?search=share%20the%20care
References


• Hanson, LC, et al. (2011). Improving decision making for feeding options in advanced dementia; A randomized, controlled trial. Journal of American Geriatric Society, 59 (11), p. 1532 -
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