Care of the Patient with Advanced Dementia: What Providers Need to Know

Susan L. Mitchell MD, MPH
Goals

• Describe clinical course of advanced dementia
• Present most common complications
• Outline an approach to decision-making
Public Health Impact

- ~800,000 Canadians have dementia, increase to 1.3 million by 2013
- ~20-25% in advanced stage
- Annual total costs $33 billion, increase to $300 billion by 2040
- 7th leading cause of death in Canada
Change in Number of Deaths Between 2000 and 2010

- Breast Cancer: -2%
- Prostate Cancer: -8%
- Heart Disease: -16%
- Stroke: -23%
- HIV: -42%
- Alzheimer's Disease: -68%
Under-reporting of dementia on death certificates

Wachterman et al, JAMA 2009

Immediate (16%)
Underlying (35%)
Contributing (16%)
Not mentioned (37%)

James et al., Neurology 2014
- 2010 reported vs. estimated deaths: ~84,000 vs. 500,000
Advanced Dementia

Global Deterioration Scale Stage 7
– Do not recognize family
– Loss of all verbal abilities
– Non-ambulatory
– Incontinent

*Reisberg B, J Psychiatry 1982*
Background

• Palliative care sub-optimal across care settings:
  – Under-recognition as a terminal condition
  – Prognostication
  – Lack of high quality research
  – (Under-utilization of hospice)
Cancer

Chronic disease
**Advanced Dementia Prognostic Tool**

**Goal:** Develop and prospectively validate a 6-month mortality risk score in advanced dementia

**Findings:** ADEPT tool ability to predict 6 month survival is modest: AUROC = 0.68) (vs. hospice eligibility = 0.55)

**Implications:** Access to palliative care should be based on preference not prognosis

*Mitchell SL et al, JAMA 2010*
Clinical Course

- **CASCADE**: 18 months prospective study
  - 323 patients advanced dementia
  - Mortality rate: 55%
  - Most common complications
    - ~ 90% eating problems
    - ~ 50% recurrent infections/fever
    - Others rare (stroke, fracture, MI)
Decision-Making

Proxy’s participated in 126 decisions

- Eating problem (29%)
- Pneumonia (19%)
- Febrile illness (6%)
- Pain Rx (18%)
- Dyspnea Rx (10%)
- Behavior Rx (10%)
- Seizure Rx (6%)
- Other (2%)

Givens JL, JAGS 2009
Decision-Making

- Advance care planning is critical
- Opportunity to discuss early
  - Prepare family for what to expect in advanced stages
  - Elicit wishes
  - Set the stage for future discussions
Ethical Framework

- Beneficence
- Non-maleficence
- Autonomy
- Justice
Steps to Operationalize Ethical Decision-Making

1. Clarify clinical situation
2. Determine primary goal of care
3. Present treatment options
4. Weigh options against perceived values
Step 1: Clarify Clinical Situation

- Eating problems
  - Very common in end-stage
  - Last activity of daily living to be lost
Step 2: Goals of Care

- Life prolongation
- Maintain function
- Comfort

Gillick MR, JAMDA 2001
Step 3: Present Options

- Supportive care vs. long-term tube-feeding (PEG or J-tube)
Ranking the Evidence

1st
- Randomized controlled trial
- None!

2nd
- Cohort studies
- Few
- Selection bias

3rd
- Case series (many)
- Prognostic information
- No control group
Options: Hand-Feeding

- Provide food and drink to the extent that is enjoyable
- Sub-optimal nutrition in favor of comfort
- Palliative care
- Nutritional supplements can increase weight
Options: Tube-Feeding

• No demonstrable benefits
  – Prevent Aspiration NO
  – Heal Malnutrition/Pressure Ulcers NO
  – Improve Survival NO
  – Promote Comfort NO

• Risks
A 24-month survival comparison of residents with severe cognitive impairment with (dotted line) and without (dashed line) feeding tubes.

1 Year Survival from Baseline by FT Status

Arch Intern Med; 1997

JAGS; 2012
Tube-Feeding: Risks

- Relatively safe procedure
- Special considerations
  - Agitation
  - Hospital transfer for complications
  - Pressure ulcers: increased risk and poorer healing
    - *Teno et al, Arch Intern Med; 2012*
Step 4: Weigh Options

<table>
<thead>
<tr>
<th>Options</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hand-feeding</td>
<td>Tastes food</td>
<td>Takes Time</td>
</tr>
<tr>
<td></td>
<td>Social Interaction</td>
<td>Inconsistent Intake</td>
</tr>
<tr>
<td></td>
<td>Focus on comfort</td>
<td></td>
</tr>
<tr>
<td>Tube-feeding</td>
<td>Nutrition delivered</td>
<td>No Clear Benefits</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Complications</td>
</tr>
</tbody>
</table>
Step 4: Weigh Options

• Align with goal of care
  – Comfort → Hand-Feeding
  – Prolong life → ???
Step 4: Weigh Options

• Expert opinion and multiple position statements
  – tube-feeding has no demonstrable benefits and should not be offered

*Gillick MR, NEJM 2000    #Finucane T et al, JAMA 1999
Pneumonia
Step 1: Clarify Clinical Situation

- Very common in end-stage dementia: ~ 50% last 90 days
- High mortality
- Discomfort:
  - symptoms* and treatment

*van der Steen et al, JAGS 2002
Step 2: Goals of Care

• Life prolongation
• Maintain function
• Comfort

Gillick MR, JAMDA 2001
Step 3: Present Options
Antimicrobial Exposure

% residents getting antimicrobial

Days prior to death

56-43
42-29
28-15
14-0

*D'Agata EMD, Mitchell SL Arch Int Med 2007*
Pneumonia: survival

*Adjusted for age, gender, race, functional status, suspected aspiration, congestive heart failure, hospice referral, do-not-hospitalize order, and chest x-ray having been obtained.

*Givens JL Arch Int Med 2010
Pneumonia: Comfort

Mean SM_EOLD*

Antibiotic treatment

None | Oral | IM | IV or hospital

P\text{\_trend} = 0.01

\*Symptom Management at the End-of-Life in Dementia, range=0-45, higher score means more comfort
Antimicrobial Resistance

• Nursing home prevalence study (N=84)
  – 64% advanced dementia colonized
  – 3 times higher than other residents

• Nursing home residents bring resistant bacteria into hospitals

• Public health issue

*Pop-Vicas A, J Am Geriatr Soc 2008*
Antimicrobial Resistance

- Study of Pathogen Resistance and Exposure to Antimicrobials in Dementia (SPREAD)
- 362 NH residents with advanced dementia
- 12 months follow-up
- Outcomes
  - Antimicrobial use
  - Multi-drug resistant organisms (MDRO)
# Antimicrobial use

## Development of Minimum Criteria for the Initiation of Antibiotics in Residents of Long-Term–Care Facilities: Results of a Consensus Conference

### TABLE 3. Minimal Criteria for Initiation of Empiric Antimicrobial Treatment

<table>
<thead>
<tr>
<th>Respiratory Tract</th>
<th>Urinary Tract</th>
<th>Skin/soft tissue</th>
<th>Febrile unknown source</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>a. Temperature &gt; 38.9°C</td>
<td>a. An indwelling Foley catheter</td>
<td>New or increased purulent drainage</td>
</tr>
<tr>
<td>&gt; 1 of following:</td>
<td>Acute dysuria concentrates OR Temperature &gt; 37.9°C</td>
<td>OR ≥ 1 of following:</td>
<td>AND ≥ 1 of following:</td>
</tr>
<tr>
<td>1. Respiratory rate &gt; 25 breaths/minute</td>
<td>AND ≥ 1 of following:</td>
<td>1. Temperature &gt; 37.9°C</td>
<td>1. Change in mental status¹</td>
</tr>
<tr>
<td>b. Temperature &gt; 37.9°C (&lt;38.9°C)</td>
<td>3. New or increased swelling</td>
<td>3. Unstable vital signs³</td>
<td>4. Warmth</td>
</tr>
<tr>
<td>New productive cough AND ≥ 1 of the following:</td>
<td>5. Tenderness²</td>
<td>5. Tenderness²</td>
<td></td>
</tr>
<tr>
<td>1. Pulse &gt; 100 beats/minute</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Respiratory rate &gt; 25 breaths/minute</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Rigid</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Change in mental status¹</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c. Atelectasis with COPD</td>
<td>b. Indwelling Foley catheter</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New increased cough with purulent sputum</td>
<td>AND ≥ 1 of following:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>d. Atelectasis without COPD</td>
<td>1. Temperature &gt; 37.9°C</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New productive cough AND &gt; 1 of the following:</td>
<td>2. Rigid</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Respiratory rate &gt; 25 breaths/minute</td>
<td>3. Change in mental status¹</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Change in mental status¹</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

¹. Diagnostic criteria for delirium can be difficult to evaluate in advanced dementia, therefore any change from baseline mental status will be considered.

². Urgency, frequency, skin tenderness, costovertebral tenderness and suprapubic pain may be difficult to evaluate in advanced dementia but will be accepted criteria if present.

³. Unstable vital signs = systolic blood pressure < 90 mmHg systolic OR heart rate ≥ 100 beats/minute OR respiratory rate ≥ 25 breaths/minute.
## SPREAD: Rx of Episodes

<table>
<thead>
<tr>
<th>Source of suspected infectious episodes</th>
<th>All</th>
<th>LRI</th>
<th>UTI</th>
<th>Skin</th>
<th>Fever only</th>
</tr>
</thead>
<tbody>
<tr>
<td>Episodes, No.</td>
<td>486</td>
<td>144</td>
<td>193</td>
<td>68</td>
<td>81</td>
</tr>
<tr>
<td>Treated with antimicrobials, No. (%)</td>
<td>354 (73)</td>
<td>103 (72)</td>
<td>145 (75)</td>
<td>65 (96)</td>
<td>41 (51)</td>
</tr>
<tr>
<td>Minimal criteria met, No. (%)</td>
<td>157 (44)</td>
<td>35 (34)</td>
<td>28 (19)</td>
<td>62 (95)</td>
<td>32 (78)</td>
</tr>
</tbody>
</table>
### SPREAD: MDRO

Multi drug resistant gram negative = MDRGN

Methicillin-resistant *Staphylococcus aureus* = MRSA

<table>
<thead>
<tr>
<th>MDRO</th>
<th>Residents, % (N=362)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Baseline</strong></td>
</tr>
<tr>
<td>Either MDRGN or MRSA</td>
<td>43</td>
</tr>
<tr>
<td>MDRGN</td>
<td>35</td>
</tr>
<tr>
<td>MRSA</td>
<td>12</td>
</tr>
</tbody>
</table>
MDRO Acquisition

Cumulative Incidence of MDRO Colonization
N=152

Cumulative Incidence of MDRGN Colonization
N=174

Cumulative Incidence of MRSA Colonization
N=238

No. at risk
152  94  67  42  37

0  3  6  9  12  Months

Cumulative incidence (%)

No. at risk
174  118  84  54  40

0  3  6  9  12  Months

Cumulative incidence (%)

No. at risk
238  173  131  95  90

0  3  6  9  12  Months

Cumulative incidence (%)

Step 4: Weigh Options

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<tr>
<th>Options</th>
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<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>No antibiotics/palliation</td>
<td>Greater Comfort</td>
<td>Shorter Survival</td>
</tr>
<tr>
<td>Antibiotics</td>
<td>Prolong Survival</td>
<td>Greater Discomfort Cost Antimicrobial Resistance</td>
</tr>
</tbody>
</table>
Step 4: Weigh Options

• Align with goal of care
  – Comfort → Palliation only
  – Prolong life → Antibiotics
    BUT…
    Oral may be adequate
# CASCADE: Hospital Transfers

<table>
<thead>
<tr>
<th>Admissions (N=74)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infections</td>
<td>59</td>
</tr>
<tr>
<td>GI Bleed</td>
<td>8</td>
</tr>
<tr>
<td>Dyspnea</td>
<td>7</td>
</tr>
<tr>
<td>Fracture</td>
<td>5</td>
</tr>
<tr>
<td>Heart Failure</td>
<td>3</td>
</tr>
<tr>
<td>Dehydration</td>
<td>3</td>
</tr>
<tr>
<td>Feeding Tube Cx</td>
<td>3</td>
</tr>
<tr>
<td>Other</td>
<td>12</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ER Visits (N=60)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeding Tube Cx</td>
<td>47</td>
</tr>
<tr>
<td>Infection</td>
<td>27</td>
</tr>
<tr>
<td>Fall</td>
<td>15</td>
</tr>
<tr>
<td>Fracture</td>
<td>3</td>
</tr>
<tr>
<td>Mental Status Change</td>
<td>2</td>
</tr>
<tr>
<td>Chest Pain</td>
<td>2</td>
</tr>
<tr>
<td>IV insertion</td>
<td>2</td>
</tr>
<tr>
<td>Jaundice</td>
<td>2</td>
</tr>
</tbody>
</table>
Decision to Hospitalize

• What is the goal of care?
  – Survival ↔ Comfort
  – 95% of proxies state comfort

• Does hospitalization meet that goal?
Outcomes: Patients

- Most (> 75%) hospital transfers of NH advanced dementia are avoidable...

  Managed same efficacy in nursing home
  OR
  Not consistent with goal of care/preferences
Summary

• Dementia is terminal illness
• Feeding problems and infections are most common complications and decisions
• Aggressive interventions are less likely when families have a better understanding of prognosis and expected complications
• Ethical decision-making
  ➢ informed, guided by the goals of care
• Tube-feeding has no demonstrable benefits and should not be offered
• Antimicrobial treatment of pneumonia may prolong life but also cause more discomfort
• Most hospitalizations avoidable
Take home points

• Opportunity for advance care planning
• Focus on goals of care
• Do not feel compelled to offer everything
• Be knowledgeable about the best evidence
• Use decision support tools/geriatric consults/team
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Les soins de confort
DE FIN DE VIE
DANS LA MALADIE D'ALZHEIMER
ET LES AUTRES
maladies dégénératives du cerveau

A guide
pour les proches

Comfort Care
AT THE END OF LIFE
FOR PERSONS WITH ALZHEIMER'S DISEASE
OR OTHER
Degenerative Diseases of the Brain

A Guide
for Caregivers

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