Palliative Care of the Person with Dementia

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Scope of Problem

- By 2050 more than 13 million people in US will have AD
- Annual mortality rate from AD rising while mortality rates from cancer, heart disease and stroke are declining
- Median survival after diagnosis shorter than thought-3 to 6 years
- 70% of persons with dementia die in nursing homes

Mitchell, S. A 93-year-old man with advanced dementia and eating problems. JAMA 2007 298(21) 2527-2536
Determining Prognosis in Dementia

• FAST: Functional Assessment Staging Scale
  – Seven major stages, with stage 7 having six sub stages
  – Hospice eligibility-must be at or beyond stage 7c and show all features of states 6a through 7c.

• Medical condition
  – At least one of the following over the past year
    • Aspiration pneumonia
    • Septicemia
    • Pressure ulcer stage 3-4
    • Recurrent fever after antibiotic treatment
    • Eating problems such that food/fluid intake is insufficient to sustain life. If tube fed, weight loss greater than 10 over six months or serum albumin less than 2.5 g/dL.
Other Tests to Predict Prognosis

• Minimum Data Set-did predict six month prognosis more accurately than FAST in newly admitted NH residents with advanced dementia

• Mini-Suffering State Examination (MSSE)-high suffering associated with shorter survival period (Aminoff and Adunsky, 2006)
• End of Life Dementia Scale
  – Three scales for satisfaction with terminal care (SWC-EOLD), symptom management (SN-EOLD) and comfort around dying over last seven days of life (CAD-EOLD)

  – Kiely, Volicer, Teno, Jones, Prigerson and Mitchell, The validity and reliability of scales for the evaluation of end-of-life care in advanced demenatia. 2006, Alzheimer's disease Association Disorders 20 (3)
Benefits of Hospice in Dementia

• Lower probability of hospitalization during last 30 days of life
• Higher probability of pain and symptom management in last 30 days of life
• Survey of 77123 family members who received care from 796 hospices for loved one with dementia found 73% rated service as excellent-similar to cancer and other terminal conditions
Pain and Symptom Management in the Person with Dementia

• Pharmacotherapy
• Eating problems
Eating Problems

• Last ADL to be lost prior to death
• Characterized by oral dysphagia, pharyngeal dysphagia, disinterest in food, lack of hunger
• Goal of oral feeding palliation is to allow the pleasure of tasting food, not to provide adequate caloric intake. Requires intensive hand feeding.
• Goal of tube feeding is to prolong live, improve nutrition, prevent aspiration and provide comfort
What Does the Data Say About Tube Feeding in End Stage Dementia?

• No randomized controlled studies of tube feeding in advanced dementia

• Observational studies seem to show:
  – Does not prolong survival
  – Does not improve nutritional status or clinical consequences of malnutrition
  – Does not prevent aspiration
  – May increase decline from restraint use, adverse GI effects,
Talking with Families about Feeding Decisions

1. Clarify the clinical situation (terminal)
2. Establish primary goals of care (promoting comfort, prolonging life, maximizing function)
3. Present treatment options, risks and benefits
4. Weight the options against values and preferences (what would person want, advance directives, cultural concerns)
5. Provide additional and ongoing decision support (readdress as needed, interdisciplinary approach, education)

Mitchell, 2007
Pharmacotherapy