Palliative Care in End stage dementia: Providing the right care for the right patient at the right time in the right place

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Which of the following statement about tube feeding in patients with advanced dementia is true?

a) Patients will starve to death unless a feeding tube is placed
b) Tube feedings prevent aspiration pneumonia.
c) Survival is improved in patients who are tube fed
d) Tube feeding increases comfort at the end of life by preventing hunger and thirst.
e) Tube feeding is a risk factor for aspiration pneumonia
Palliative Care aims to improve care in 3 domains:

1. Relieve physical and emotional suffering
2. Improve patient-physician communication and decision-making
3. Coordinate continuity of care across settings
4. Meet the needs of the elderly and others with complex, chronic, and advanced illness
5. And coordinate and rationalize care-

- Providing the right care for the right patient at the right time in the right place
Case #2: Hospital Stay

- Found to have Acute Renal Failure thought to be pre-renal due to dehydration and poor intake - resolves with intravenous fluids.

- As we all likewise in urinary tract infection with antibiotics.

- During her hospitalization he develops a stage 3 pressure ulcer.

- Patient nonolonger able to get out of bed and also not cooperating with physical therapy.
Case #1

- 88 year-old nursing home resident with Alzheimer's Dementia who has lived there for the past 5 years since his wife passed away. He requires assistance for dressing, bathing, and toileting, however eats independently when food is set up in front of him. He is non-ambulatory. He knows his name, but does not know the date or his residence and only sometimes he recognizes his children.
What stage of dementia does this patient have?

a) Mild
b) Moderate
c) Severe
d) Terminal
e) Normal senility due to old age
## Cause of Death: Demographic and Social Trends

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<th>Medicine's Focus</th>
<th>Early 1900s</th>
<th>Current</th>
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<td>Relatively Short</td>
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Administration on Aging, 2009; Arias et al., 2003; Minino et al., 2007
The Reality of the Last Years of Life: Death Is Not Predictable

Functional Assessment Staging Tool
“FAST Scale”

1. No difficulties
2. Subjective forgetfulness
3. Decreased job functioning and organizational capacity
4. Difficulty with complex tasks, instrumental ADLs
5. Requires supervision with ADLs
6. Impaired ADLs, with incontinence
7. Assistance with all ADL’s

Functional Assessment Staging Tool

6d. Urinary incontinence.
6e. Fecal incontinence.
7a. Ability to speak limited (1 to 5 words a day).
7b. All intelligible vocabulary lost.
7c. Nonambulatory
7d. Unable to sit up independently.
7e. Unable to smile.
7f. Unable to hold head up.

Case #2

- 84 year old female with PMH of dementia, HTN, and urinary incontinence who lives in assisted living.
- She has round the clock paid caregiver support through the ALF (Assisted Living Facility) and a daughter who visits regularly.
- ALF staff found the patient more confused than usual and sent her to the ER for evaluation.
- She was admitted to the hospital for new onset confusion.
Case #2: Previous 6 months

- Functional decline noted by both daughter and caregivers
- Less cooperative with care
- Less talkative and less appropriate with answers
- Needing more assistance with all basic Activities of Daily Living (ADLs)
- He has lost 20 pounds over the past 6 months
Clinical Course of Advanced Dementia

- NH residents over 18 months (N = 323)
  - pneumonia 41.1%;
  - febrile episode 52.6%;
  - eating problem 85.8%
- 6-month mortality rate for residents who had
  - pneumonia 46.7%;
  - a febrile episode 44.5%;
  - and an eating problem 38.6%
- Distressing symptoms
  - dyspnea 46.0%
  - pain 39.1%

Mitchell S et al. The Clinical Course of Advanced Dementia. NEJM. 2009; 361:1529-38
In the last 3 months of life, 40.7% of residents underwent at least one burdensome intervention:
- hospitalization, emergency room visit, parenteral therapy, or tube feeding

Residents whose proxies had an understanding of the poor prognosis and clinical complications expected in advanced dementia were much less likely to have burdensome interventions in the last 3 months of life.

Case #2: Hospital Stay

- Found to have Acute Renal Failure thought to be pre-renal azotemia due to dehydration
  - resolves with intravenous fluids.
- Also urinary tract infection
  - resolves with antibiotics.
- During her hospitalization she develops a stage 3 pressure ulcer.
- Patient no longer able to get out of bed and requires maximum assistance with all ADLs.
- She is also not cooperating with physical therapy.
What is the appropriate next step?

a) Place a feeding tube to prevent her from starving to death.

b) Get a video-swallowing study

c) Begin speech therapy to retrain her swallowing reflex

d) Move her to the inpatient hospice unit that your hospital just opened

e) Talk to her daughter
Case #2: Back to Our Patient

- She is enrolled in home hospice at the ALF.
- She receives home visits from RN 1-2x/week and agency caregiver for 8 hours/week from hospice.
- She dies comfortably in her apartment in 3 months. She has no further hospitalizations during that time.
Criteria for Enrolling Dementia Patients In Hospice

- Studied the relationship of FAST to survival
  - 47 patients with advanced dementia and 1 or more dementia related co-morbidity
- Median survival time all patients = 6.9 months
- 37% survived longer than 6 months
- For those who could be assigned a FAST stage (n=17):
  - Score 7C or greater: mean survival 3.2 months
  - Score less than 7C: mean survival 18 months

Luchinset et al AM J HOSP PALLIAT CARE January 1999 vol. 16 no. 1 395-400
Dementia Hospice Eligibility

- Stage 7c or beyond according to the FAST scale
- Plus one of the following within the past 12 months:
  - Aspiration pneumonia
  - Pyelonephritis or other upper UTI
  - Septicemia
  - Multiple stage 3 or 4 decubitus ulcers
  - Fever that recurs after antibiotic therapy
  - Inability to maintain sufficient fluid and calorie intake, with 10 percent weight loss during the previous six months or serum albumin level less than 2.5 g per dL

Case #3

- A 68-year-old cachectic female with a history of Alzheimer’s dementia presents with a slowly progressive decline in functional status. She is bed bound, minimally verbal, and has lost interest in eating.
- Her problems with decreased oral intake started when her diet was changed to nectar-thickened liquids. This change was made after the patient was hospitalized multiple times for aspiration pneumonia and she underwent a fluoroscopic swallowing evaluation that revealed aspiration of thin liquids. The patient’s husband requests that a feeding tube be placed so his wife doesn’t “die of pneumonia or starve to death.”
No evidence that tube feeding in patients with advanced dementia:

- Improves function
- Provides comfort
- Prolongs survival
- Prevents aspiration pneumonia
- Reduces the risk of pressure sores or infections
- No evidence tube feeding prevents pneumonia

Use of Feeding Tubes Among Persons with Severe Cognitive Impairment 2001

Prepared by Brown Medical School
Center for Gerontology & Health Care Research
Gastrostomy placement rates per 1000 eligible Medicare beneficiaries in 1991 according to age, race, and sex

High Short-term Mortality in Hospitalized Patients With Advanced Dementia Lack of Benefit of Tube Feeding

Diane E. Meier, MD; Judith C. Ahronheim, MD; Jane Morris, RN; Shari Baskin-Lyons, MPH; R. Sean Morrison, MD


Hospital Characteristics & Feeding Tube Placement (Teno et al 2010)

- 2797 Acute care hospitals
- >280,000 admissions among 163,022 NH residents with advanced cognitive impairment
- Identify characteristics associated with higher rates of feeding tube insertion in NH residents with advanced CI (cognitive impairment)
- For-Profit, larger hospital size, and greater ICU use associated with increased rates of feeding tube insertion

Dementia and tube feeding

- Feeding tubes in demented patients are associated with significant increases in:
  - Restraint use
  - ER utilization
  - Hospitalization

“There’s no easy way I can tell you this, so I’m sending you to someone who can.”
Case #3 - Family Discussion

- Palliative Care consult is ordered
- Family does not wish to pursue aggressive work-up.
- Due to the progressive decline over the past 6 months the team discusses options, including hospice.
- Healthcare-proxy, his daughter, feels that hospice is the most appropriate and would support her father's previously expressed wishes
Conclusion

- Universal human experience and universal health professional obligation.
- Palliative care improves quality of care for our sickest and most vulnerable patients and families.
- Palliative care is an integral part of geriatric medicine, contributes to goal of achieving best possible quality of life.
“The American high tech way of death is a blemish on the integrity of the medical and nursing profession and this charade costs the US 1.2 trillion dollars per year.”

Damiano de Sano Iocovozzi MSN FNP CNS
Sooner or Later: Restoring Sanity to Your End of Life Care
Publisher: Transformation Media Books; (April 2, 2010)