Feeding Tubes in Patients with Dementia: Providing Clarity Amongst the Confusion

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Disclosures

• No significant financial relationships to disclose
Objectives

• Review epidemiology of dementia and eating issues

• Discuss evidence regarding tube feeding in persons with advanced dementia

• Describe evaluation and management, including communication strategies, when caring for patients with advanced dementia and eating issues
Case Presentation

- 87 year male with hypertension and advanced dementia (x 10 years), bedbound, full care by his daughter, including hand feeding

- Brought in through ER with intermittent refusal to eat or drink, inconsistently swallowing medications, pocketing food and found to have aspiration pneumonia

- On exam cachectic elderly male, contracted, non-verbal, stage 2 sacral pressure ulcer, coarse rhonchi right lung

- Labs: WBC 20 K, Na=155, BUN/Cr (50/1.6), increased from baseline
Case Presentation

• Eating issues emerged 6 months ago when he was residing in a nursing facility

• Daughter felt pressure from facility to place a percutaneous gastric tube amid concerns of weight loss

• She ultimately decided to retire from work and become her father’s full-time caregiver

• No known advance directives about his wishes related to nutrition at EOL

• She is second-guessing her decision to forgo feeding tube

• Palliative care consulted to review goals with daughter
Epidemiology

• Dementia prevalence United States: 4.4 million (2010) → 11 million (2050)

• U.S. (2010): 5\textsuperscript{th} leading cause of death age 65 and older

• Median survival: onset = 3-12 yrs; diagnosis = 3-7 yrs

• NH residents  \textit{Mitchell NEJM 2009}
  -38\% develop eating issues last 6 months of life
  -1/3 have feeding tubes, 10 fold regional variation
Influences for Tube Placement

• Local practice culture and physician preference

• Caregiver preference and emotions

• Presence or absence of advance directives

• Legal, regulatory issues

• Clinical concerns
  - malnutrition, medications, aspiration, pressure ulcers, starvation and death, quality of life, comfort
Summary of the Evidence

• Cochrane review 2009
  -Limited data: No RCTs, 6 observational studies

• No evidence that enteral feeding prolongs survival, improves quality of life, enhances nutrition, or decreases the risk of pressure ulcers in patients with advanced dementia
Summary of the Evidence

- Prospective cohort study, 1999-2007
  - 36,000 U.S. NH residents
  - Propensity matched: tube fed vs no tube fed

- Neither insertion of tube nor timing of insertion affected survival (6 months) *J Teno J Am Geriatri Soc 2012*

- Tube fed patients 2.27 times more likely develop pressure ulcers and 30% less likely to heal existing ulcers *J Teno Arch Intern Med 2012*
Summary of the Evidence

• No study has shown decrease in risk of aspiration pneumonia from PEG placement

• Doesn’t prevent aspiration of oral secretions

• Refluxed gastric contents can still be aspirated
  – Enteral feeding may increase risk of aspiration (data mixed)
  – Lower esophageal pressure is decreased in tube fed patients
  – Jejunostomy tubes may not be better than gastrostomy tubes

Finucane TE. JAMA 1999; Dharmarajan TS. Am J Gastroenterology 2001
Summary of the Evidence

• Studies of dying cancer or ALS patients with anorexia:
  – Little hunger or thirst
    • Any thirst can be treated with mouth swabs and ice chips
  – Sense of euphoria (endorphins)
    • Goes away if fed
  – Patients were left alone more

Gillick MR. NEJM, 2000; McCann RM, JAMA, 1994
Feeding Tubes Risks and QOL Issues

• Periprocedural mortality 6-28%
• Mortality in year after placement (64%), median 56 days
• Replacement/repositioning (20%), median 145 days
• Average 9 hospitalized days/patient year after placement
• Increase social isolation by removing contact at mealtime
• Increase use of physical and chemical restraints (30%)

_S Merel Clin Geriatr Med 2014_
The Cost of Feeding Tubes

- Initial placement $2200/person
- Complications one year after insertion $2449/person
- New feeding tubes qualify for 100 days of Medicare skilled nursing benefits
- Medicaid per diem reimbursement higher for persons with TF ($190 vs. $151/day)

Physician Barriers to Limiting PEG Placement

- Survey 500 primary care physicians
- AMA masterfile
- Response rate 47%
- 87% took care of dementia patients in past year
- 75% had discussed PEG issue

Physicians’ Perceptions on Tube Feeding

- Reduced aspiration pneumonia  76%
- Improved pressure ulcer healing  75%
- Improved survival  61%
- Improved nutritional status  94%
- Dementia is a terminal diagnosis  78%
- PEG is standard of care  51%
- PEG should be standard of care  26%
Feeding Tube Discussions with Provider

- Caregiver follow-back survey 486 family members

- Of the 10% with feeding tubes:
  - 13% had no discussion about insertion
  - 41% had discussion lasting <15 minutes
  - Risks not discussed in 1/3 cases
  - 52% felt clinician strongly favored insertion

- Loved ones of those who died with feeding tube less likely to report excellent EOL care

When Dementia Patient Is not Eating

Consider this:

Anorexia vs
dysphagia vs
taglossia/apraxia vs
agitation

• Acute vs Chronic
  – acute (then can treat underlying cause?)
  – chronic (due to dementia itself?)
Reframing the Discussion: “Comfort Feeding Only”

- Provides active language

- “Comfort” means:
  - Hand feeding as long as patient not showing signs of distress (e.g. coughing, choking)
  - Least invasive and most satisfying way that attempts nutrition
  - If hand feeding stopped, continue engaging with oral care, reading/talking, therapeutic touch

- Goal: social and physical contact more than nutritional health

*Palecek J Am Geriatr Soc 2010*
Value-based Communication Tips

- Set up the interview
- Obtain caregiver’s perception of illness
  - Obtain observational and emotional data
- Give relevant data, best available evidence
- Elicit concerns, values and goals
- Be mindful of prognostic uncertainty
- Make a recommendation
- Present goals and plan for each goal based on caregiver’s values
- Balance realism and hope
Revisiting our Case

• 87 year male with advanced dementia, bedbound, full care by his daughter

• Intermittent refusal to eat or drink, inconsistently swallowing medications, pocketing food and found to have aspiration pneumonia

• Daughter felt pressure from facility to place feeding tube and is now second guessing her decision

• No advance directives in place

How would you manage this case?
Resources

• For caregivers
  • https://decisionaid.ohri.ca/docs/das/Feeding_Options.pdf
  • https://www.compassionandsupport.org/index.php/for_patients_families/life-sustaining_treatment/artificial_hydration_and_nutrition

• For clinicians
  • http://www.compassionandsupport.org
  • Choosing Wisely – AAHPM, AGS
  • http://www.choosingwisely.org/patient-resources/feeding-tubes-for-people-with-alzheimers/
Hemodialysis (HD) in the Elderly: Is It Always About Fixing that Number?

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Disclosures

• No significant financial relationships to disclose

• I do not play a comedian on TV
Objectives

• Identify the impact of initiating dialysis in patients with ESRD with multiple co-morbidities

• Review the effects on functional status after starting dialysis in the elderly

• Discuss challenges regarding advance care planning in patients with ESRD
Let’s Begin with a Case

• You have a 81 year old male with moderate dementia, PVD, CAD, chronic systolic heart failure with an EF of 25%, diabetes, and Stage V CKD who may be on the verge of starting dialysis

• His daughter is insistent on starting HD, because “we have to do everything you can doctor to save his life”

• He has multiple ADL impairments including requiring a cane to ambulate and assistance with dressing and bathing

• What do you recommend?
What is the one year mortality when starting HD in patients older than 70 years of age?
The Scope of the Problem

• Age group > 75 years are the fastest growing group of incident ESRD patients

• Mortality in the first year after starting dialysis exceeds 35% among patients older than 70 years of age
  – Exceeds 50% among patients older than 80 years of age
The Scope of the Problem: A Comparative Survival Study

- A retrospective analysis of the survival of 129 patients > 75 years of age starting HD

- The Dialysis group (n=52) had a one and two year survival of 84% and 76% respectively

- The Conservative group (n=77) had a one and two year survival of 68% and 47% respectively

- So this means that HD saves lives in all types of patients, right?
True or False:

When facing co-morbidities in the elderly, HD survival differences are less evident compared to conservative therapy...
Kaplan–Meier survival curves for those with high comorbidity (score = 2), comparing dialysis and conservative groups (log rank statistic <0.001, df 1, P = 0.98).

Co morbidity scores of 2 especially when including ischemic heart disease did not show a survival difference.

Time to death in “Frail patients”

Kirsten L. Johansen et al. JASN 2007;18:2960-2967

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What About Conservative Treatment?

• Single Center study in the UK of 202 ESRD patients > 70 years of age
  – Conservative therapy (MCM) → 29 patients
  – RRT → 173 patients

• Median survival:
  – 37.8 months in the RRT group vs. 13.9 months in the MCM group
  – MCM group however had longer survival times compared to previous studies (ranging from 2-46 days)

• RRT group had higher rates of hospitalizations (25 days/pt/year vs. 16 days/pt/year)

• MCM group had a Odds Ratio of 4.15 greater likelihood of dying at home or in hospice compared to RRT group

Carson et al. CJASN 2009
A Recent Study on Comparative Survival

• Dutch study where 107 patients chose conservative management (CM) and 204 chose RRT with similar co-morbidity scores

• Survival advantage seen in the RRT group

• However after 80 years of age, the survival advantage was no longer observed (p=0.08)

• Patients over 70 years of age with co-morbidities, especially cardiovascular issues, had decreased survival advantages (though RRT group still had a statistically significant advantage for survival)

Verberne, et al. CJASN March 2016
Using the Charlson Co-Morbidity Index

- 268 patients on HD observed in one study

- The higher the CCI, the higher risk of hospital admissions and mortality (HR 1.24)

- Patients with very high scores ≥ 8 have 1 year mortality of 48%
The Scope Of The Problem Beyond Survival

• Falls:
  – >45% of elderly dialysis patients have ≥ 1 fall a year
  – Mortality in HD increased with at least 1 fall (HR 1.63)

• Cognitive Impairment:
  – Cognitive impairment and dementia twice higher in ESRD patients than in the general population
  – Faster rates of cognitive decline

• Pain:
  – Chronic pain in 50-79% of dialysis patients (compared to general population with chronic pain around 2-45%)
Objectives

• Identify the impact of initiating dialysis in patients with ESRD with multiple co-morbidities

• **Review the effects on functional status after starting dialysis in the elderly**

• Discuss challenges regarding advance care planning in patients with ESRD
What happens to Functional status after initiating HD in the elderly?

- Increases
- Decreases
- Stays the Same
• Retrospective study looked at 3702 NH residents starting HD between June 1998 and October 2000

• Aim was to study trajectory of functional status before and after initiation of dialysis among elderly NH patients

Table 1. Characteristics of the Subjects at the Initiation of Dialysis.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Subjects†</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (yr)</td>
<td>73.4±10.9</td>
</tr>
<tr>
<td>Estimated glomerular filtration rate (ml/min/1.73 m² of body surface area)</td>
<td>10.7±4.9</td>
</tr>
<tr>
<td>Albumin (g/dl)</td>
<td>2.9±0.6</td>
</tr>
<tr>
<td>Female sex (%)</td>
<td>60</td>
</tr>
<tr>
<td>Race (%)‡</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>64</td>
</tr>
<tr>
<td>Black</td>
<td>32</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
</tr>
<tr>
<td>Coexisting condition (%)</td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td>68</td>
</tr>
<tr>
<td>Congestive heart failure</td>
<td>66</td>
</tr>
<tr>
<td>Coronary artery disease</td>
<td>44</td>
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<tr>
<td>Peripheral vascular disease</td>
<td>37</td>
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<tr>
<td>Cerebrovascular disease</td>
<td>39</td>
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<tr>
<td>Chronic obstructive pulmonary disease</td>
<td>24</td>
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<tr>
<td>Cancer</td>
<td>12</td>
</tr>
<tr>
<td>Dementia</td>
<td>22</td>
</tr>
<tr>
<td>Depression</td>
<td>35</td>
</tr>
<tr>
<td>Hemodialysis (vs. peritoneal dialysis) (%)</td>
<td>95</td>
</tr>
<tr>
<td>Hospitalized at initiation of dialysis (%)</td>
<td>69</td>
</tr>
</tbody>
</table>

* Plus–minus values are means ±SD.
† Data shown are for 3702 subjects, except for the estimated glomerular filtration rate (3577 subjects) and albumin concentration (2654 subjects).
‡ Race was reported in the U.S. Renal Data System database.
Change in Functional Status after Initiation of Dialysis

- Functional status maintained at 12 months in only 13% of patients (1 out of 8 patients)

- Cumulative decrease in functional status of 29% at one year

- Cumulative mortality rate of 59% at 1 year

- Worse ADL scores 3 months after initiation of HD
Functional Status Decline

- Initiation of Dialysis (period encompassing 3 months before and 1 month after starting HD) was associated with a decline in functional status.

- Coexisting medical conditions such as CVA, dementia, hospitalizations, and low albumin levels were associated with lower odds of maintaining pre-dialysis functional status at 1 year.

- No data to show that functional status improved with HD.
So Why do Patients Decline on HD?

• High prevalence of baseline disability such as tendency for falls and cognitive dysfunction

• Coexisting conditions:
  – Dementia
  – CVA
  – Diabetes
So Why do Patients Decline on HD?

- Physical and psychosocial risks of HD
  - Vascular access and line infections
  - Less time for physical therapy
  - Symptoms from HD such as dizziness and low blood pressure

- Is kidney failure a consequence of terminal multi organ dysfunction?
  - Is HD going to solve the underlying problem?
  - Is the disability a consequence of clinical events more related to coexisting conditions?
What happens to Functional Status for those patients who do NOT start HD?

It declines as quickly as those who start HD

It declines but NOT as quickly as those who start HD
What about Functional Status and NOT starting HD?

- Longitudinal cohort study of 75 patients in the UK looking at functional status in patients opting for conservative management
- 66% died during follow up
- Functional status remained stable during the last year of life but declined steeply in the last month of life (compared to the previous study which showed a decline in functional status when starting HD)

Murtagh et al. JAGS 2011
Objectives

• Identify the impact of initiating dialysis in patients with ESRD with multiple co-morbidities

• Review the effects on functional status after starting dialysis in the elderly

• Discuss challenges regarding advance care planning in patients with ESRD
Summary of Shared Decision Making Guidelines

- **Shared Decision Making**
  - Involve the patient

- **Informed Consent or Refusal**
  - Give the patient all options including time limited trials
  - Patient understands consequences of decisions

- **Estimating Prognosis**
  - Discuss life expectancy and quality of life

- **Conflict Resolution**
  - What happens when there is a disagreement
Summary of Shared Decision Making Guidelines

• **Advanced Directives**
  – Obtain advanced directives from all dialysis patients

• **Withholding or Withdrawing Dialysis**
  – Ethically the same

• **Special patient groups**
  – Reasonable not to initiate dialysis on patients with a terminal illness from a non-renal cause

• **Time limited trials**
  – Can be useful when there is uncertainty

• **Palliative Care**
  – Can be offered at all times even when on HD
True or False:

In ESRD patients with written advanced directives, when to stop dialysis occurs a majority of the time.
How are we doing in discussing goals of care in these patients?

• 30% of patients older than 75 years of age withdraw from dialysis which is a high percentage showing that the ability to counsel patients about foregoing HD should be a core competency

• Physicians may be unaware of these national guidelines on shared decision making regarding initiation and withdrawal of dialysis

• Only 22% of nephrology fellows reported being taught on how to tell a patient that he or she is dying
  – 32% conducted less than 2 family meetings during their training

Arnold, R. NEJM 2009
Advanced Care Planning and HD

- A study of 400 HD patients showed that only 51% had completed an advanced directive.

- Overall most patients had not discussed wishes for specific interventions in the event of a permanent coma:
  - Only 25% had discussed CPR
  - Only 18% had discussed stopping dialysis

- Even in those patients that completed a living will and proxy, stopping dialysis was the least often discussed topic:
  - 69% had discussed mechanical ventilation compared to only 31% who had discussed stopping dialysis.

What percentage of patients had a discussion with their nephrologist on end of life issues?
What Do Patients Want?
A Canadian Study

• A study of 584 stage IV/V CKD patients surveyed in a Canadian university based program January-April 2008

• 61% regretted their decision to start HD
  – When asked why, 52% reported that it was their doctor’s wish

• 83% were unaware of palliative care

• Only 38% of patients had completed an advanced directive

• 52% had not had discussions on end of life care preferences with their physician
  – 90% of patients reported that a nephrologist had not had a end of life discussion with them
A joint collaboration between renal and PC in Australia

- Patients enrolled in:
  - Pre-dialysis clinic (routine pathway where basic education provided)
  - Referred to a renal supportive care (RSC) clinic
  - Attended neither clinic but started HD

- Mean adjusted survival was 20 months in the RSC group compared to 33 months in the pre-dialysis group
  - However, no difference in survival when looking at patients > 75 years of age with 2 or more co-morbidities (one of them being CHF or CAD)

- 32% of patients in the RSC group survived > 12 months after eGFR fell below 10

- Symptoms and quality of life scores were stable or improved over time and there was no difference between the pre dialysis and RSC groups

Brown et al. CJASN 2015
Summary

• Elderly patients on HD with significant co-morbidities have a high mortality rate and may not have a survival difference compared to conservative treatment.

• Functional status declines dramatically in elderly NH patients who start HD and does not improve.

• Functional status may be better maintained by not starting HD.

• Advance care planning occurs infrequently but can be improved by training others in shared decision making guidelines.

• PC collaboration with nephrology is promising and can potentially improve symptoms and quality of life.
Back To Our Case

• You have a 81 year old male with moderate dementia, PVD, CAD, chronic systolic heart failure with an EF of 25%, diabetes, and Stage V CKD who may be on the verge of starting dialysis

• His daughter is insistent on starting HD, because “we have to do everything you can doctor to save his life”

• He has multiple ADL impairments including requiring a cane to ambulate and assistance with dressing and bathing
How Would You Approach This Conversation?
What Actually Happened...

• You have just paid very close attention to this talk and learn that HD may not be in this patient’s best interest and would not improve his functional status

• You obtain a PC consultation

• After a goals of care discussion, the goals of the daughter are more towards comfort and she doesn’t want to “see her father suffer”

• The decision is made to forgo dialysis and he continues to live a comfortable life for the next several months until he is hospitalized for a heart failure exacerbation and then eventually chooses hospice
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