Communication Skill Development with Special Populations: Dementia, End Stage Renal Disease, and Young Parents with Advanced Cancer

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The Coleman Palliative Medicine Training Program
Communication Skills Development with Special Populations: Patients with Dementia

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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%)

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

<table>
<thead>
<tr>
<th>Perception</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduced aspiration pneumonia</td>
<td>76%</td>
</tr>
<tr>
<td>Improved pressure ulcer healing</td>
<td>75%</td>
</tr>
<tr>
<td>Improved survival</td>
<td>61%</td>
</tr>
<tr>
<td>Improved nutritional status</td>
<td>94%</td>
</tr>
<tr>
<td>Dementia is a terminal diagnosis</td>
<td>78%</td>
</tr>
<tr>
<td>PEG is standard of care</td>
<td>51%</td>
</tr>
<tr>
<td>PEG should be standard of care</td>
<td>26%</td>
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</table>
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 agnosia/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

• For clinicians
  - http://www.compassionandsupport.org
  - Choosing Wisely – AAHPM, AGS
Communication Skill Development with Special Populations: Patients with End Stage Renal Failure

Aziz Ansari, D.O., F.H.M.
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Hemodialysis in the Elderly: Is It Always About Fixing That Number?
Disclosures

• No significant financial relationships to disclose
Objectives

• **Identify the Scope of the Problem**

• Review the effects on Functional Status when Starting Hemodialysis (HD) in the Elderly

• Discuss data regarding goals of care discussions in this patient population
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, falls and Stage V CKD who is on the verge of requiring HD

• His daughter is insistent on starting HD, because “we have to do everything you all can 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?
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

- No significant survival difference seen when starting HD on patients > 75 years of age who have significant co-morbidities such as ischemic heart disease

- “Frail” patients on HD have poor survival outcomes compared to those who have better functional status

Murtagh et al. 2007
Johansen et al. 2007
Using Charlson Co-Morbidity Index

- 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 patients increased with at least 1 fall

**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%)

Bereger JR, Hedayati ss, CIASN 2012
Wesibord et al JASN 2005
Objectives

- Identify the Scope of the Problem

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- Discuss data regarding goals of care discussions in this patient population
Functional status maintained at 12 months in only 13% of patients (comes out to 1 out of 8 patients)

- Cumulative decrease in functional status of 29% at 1 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.
Why do patients decline on HD?

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

- Coexisting conditions, e.g:
  - Dementia
  - CVA
  - Diabetes
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 or the primary reason?
  - Is HD going to solve the underlying problem?
  - Is the disability a consequence of clinical events more related to coexisting conditions?
What about functional status and NOT starting HD?

- Longitudinal cohort study in the UK looking at functional status in patients opting for conservative management.

- 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
Outcomes of Conservative Treatment

• Medical management group had longer survival times than previous studies with a median survival of 13.9 months (compared to 2-46 days)

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

• Medical management group had a greater likelihood of dying at home or in hospice compared to HD group (Odds Ratio of 4.15)

Carson et al. CJASN 2009
Objectives

- Identify the Scope of the Problem

- Review the effects on Functional Status when Starting Hemodialysis (HD) in the Elderly

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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
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.
Advanced care planning and HD

• A study of 400 HD patients showed that only 51% had completed an advance 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 do patients want?

- 61% regretted their decision to start HD
  - 52% reported it was the doctor’s wish

- 83.4% were unaware of palliative care

- Only 38.2% had completed an advance directive

- 52% had not had discussions on end of life care preferences with their physician
  - 90.4% 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

• 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

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

• Conservative and HD therapy may have similar outcomes especially when patients have co-morbidities

• 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
Case resolution

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

• His daughter is insistent on starting HD, because “we have to do everything you all can 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?
Young Parents with Advanced Cancer:

Tips and techniques for communication with children and families.

Lauren Kessler, L.C.S.W.
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Objectives

• Understand the unique challenges present in caring for young parents with cancer and their children
• Understand the various ways children understand illness and death in relation to their developmental age
• Become more confident in responding to team members concerns about communicating to children and families
• Develop the tools necessary to facilitate family meetings within this specific population
• Understand the available resources to refer to families after initial support and guidance is provided
Recent research estimates that 18% of newly diagnosed cancer patients are parents to 1+ minor children
- 1/3 of those patients are caring for children under 6
- Approx. 2.85 million children in the US have a parent in some stage of cancer

This cohort “represents a hidden high risk group whose problems are [minimized] by overwhelmed parents and unknown to medical staff who seldom serve them”
Important Role of Medical Team

- Patients often look to their medical team for guidance around these conversations
  - Do not dismiss their concerns and need for support

- Do not immediately refer to Child Life or psychosocial team member
  - There are some basic things that can be said to help alleviate worries and guide them through conversations

- Often times just looking for emotional support - just “being” with them with their worries, fears, concerns.
Too Little, Too Late?

- The conversation is often avoided until a crisis occurs or it is too late

- Children experience more anxiety when they are not given information or included in discussions

- Children may be “confused, stressed, and isolated by a parent’s inability to confront and converse about life threatening illness” (NASW, March 2005)
Fears and Myths Around Disclosure

- The child doesn’t know
  - Often they know more than we think
  - Can create their own story if no information is given

- They’re too young to understand
  - You can bring it down to their developmental level

- Nothing is better than the wrong thing
  - Nothing can actually be very harmful
  - In an effort to “protect” we end up harming
Fears & Myths Continued

- Waiting for the “right time” to talk
  - There is never a right time

- They will not be able to go about their daily life if they know
  - Children are more resilient than we give them credit for
  - They thrive on routine
Developmental Considerations

Significant age groups and what to expect:

- Toddler through preschool (Roughly ages 2-6)
- Latency (School age, 5/6-12)
- Adolescence - Teenage years

- In general, the first and third groups need “the most delicate handling”, however every child and situation is different. Remind the parents that they know their children best
Developmental Considerations

• Tips for Preschoolers:
  • Explain the disease in concrete terms and use their language: “Daddy has a booboo on his head”
  • May use play as a tool
  • Keep it short and be aware of their limited ability to stay concentrated.
    • May mean repeating the conversation many times
  • Tell the truth, but be mindful not to share all the details for younger kids.
Developmental Considerations

- Talking to 6-12 year olds
  - More interested in the details
    - Increased awareness of and interest in bodies around age 6
    - Very important to tell the truth, without hesitation or embarrassment
    - Ask if they want to see the treatment room, talk to the doctors, see the medical tools (within reason)

  - Helps to normalize, reduce fears/anxieties around unknown and ensure they feel included in the process
Developmental Considerations

• Talking to Teenagers
  • Bottom line – teenagers may have the most difficult time and it is often hard to predict how they will respond/react
  • Want LOTS of information
    • Diagnosis, medical terms, survival rates
    • Follow their lead! Do not hide information
  • Want to be treated as adults
  • Respect their need for privacy – disclose the information and give them space to process
    • Let them feel safe to talk to you afterwards, but if they do not feel comfortable at first, be sure that have someone safe to confide in and process with.
Inevitable Questions to Expect from Young Children

The 3 C’s:

1. Did I Cause it?

2. Is it Contagious?

3. Who will take Care of me?
What to say/ What not to say

- Clarify: Start with asking what they know, if anything
- Encourage questions and sharing concerns
- Validate fears/worries
- Be honest, clear and concrete
- Honesty sometimes means saying “I don’t know”
- Ok to instill hope
  - even in terminal cases, there is always hope
- Be prepared for the question “Will you die?”
  - What are your beliefs about death and what happens afterwards – they may want to know and may be comforted by your response
Helpful Books For Communicating with Children About Illness and Death


• Stickney, D. (1970). *Waterbugs and Dragonflies: Explaining Death to Young Children*
Resources for Parents/Adults

• Hamilton, Joan. (2011). *When a Parent is Sick: Helping Parents Explain Serious Illness to Children*

• Silverman, P. R. (1999). *Never Too Young to Know: Death in Children’s Lives.*

• McCue, Kathleen. (1994). *How to Help Children Through a Parent’s Serious Illness: Supportive Practical Advice from a Leading Child Life Specialist*

• American Cancer Society (2015). *Helping Children When a Family Member has Cancer: Dealing with a Parent’s Terminal Illness*
Reference List

American Cancer Society. (2015). *Helping Children When a Family Member Has Cancer: Dealing with a Parent’s Terminal Illness*


