DECISION MAKING SUPPORT AT END OF LIFE: ADVANCED DEMENTIA QUALITY OF LIFE

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Disclosures

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Financial Disclosures

• None of the planners, speakers, and/or members of the CME committee have any relevant financial relationships to disclose.
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Objectives

• Discuss the concept of **dementia as a terminal illness**, future policy and research directions
• Understand decisions faced by patients and families as dementia progresses
• Utilize new evidence on intervention options to better support decision making
• Identify and apply advanced care planning principles to maximize quality of life and reduce burden for the patient and family
DEFINITION

• An acquired syndrome of decline in memory and other cognitive functions sufficient to affect daily life in an alert patient

• Progressive and disabling

• *Not* normal aging
THE IMPACT OF DEMENTIA

Economic

• $604 billion annually for direct costs of medical and social care and informal care
• Medicare, Medicaid, private insurance provide much of the direct costs — remaining costs with families and/or caregivers ($202.6 billion)

Emotional

• Direct toll on patients
• Nearly half of caregivers suffer psychological distress, especially depression
THE LANDSCAPE
Parallel Research Efforts

Dementia

- Prevention
- Diagnosis
- Treatment

- Improve quality of care
- Advanced Care Planning
- End of Life
GOAL OF MANAGEMENT

• Enhance quality of life
• Maximize functional performance by improving cognition, mood, and behavior

• No cure
• Support caregivers
• Reduce symptom burden
DEFINING MOMENT
The Clinical Course of Advanced Dementia


ABSTRACT

BACKGROUND
Dementia is a leading cause of death in the United States but is underrecognized as a terminal illness. The clinical course of nursing home residents with advanced dementia has not been well described.

METHODS
We followed 323 nursing home residents with advanced dementia and their health care proxies for 18 months in 22 nursing homes. Data were collected to characterize the residents’ survival, clinical complications, symptoms, and treatments and to determine the proxies’ understanding of the residents’ prognosis and the clinical complications expected in patients with advanced dementia.
Study Design

- Prospective cohort study
- Nursing home residents with advanced dementia
- Funded by NIH
- Goal: address gaps in knowledge concerning patients with advanced dementia
- Part of CASCADE study (Choices, Attitudes, and Strategies for Care of Advanced Dementia at the End-of-Life)
Results

- 323 NHR’s with advanced dementia (CPS 5 or 6)
  - 18 month tracking period
  - 22 nursing homes
- Incidence of death: 54.8%
- Probability of:
  - pneumonia 41%
  - fever 52%
  - eating problem 86%
- Adjusted 6 month mortality rates 39-47%
- During last 3 months of life 41% underwent a burdensome intervention
Pneumonia

Febrile Episode

Feeding Difficulty

Other findings

- Distressing symptoms reported over the 18 months:
  - Dyspnea 46%
  - Pain 39%
  - Pressure ulcers 39%
  - Agitation 54%
  - Aspiration 41%
Re-evaluating Care

• Lessons learned – patients are at the end stages of disease when they manifest these symptoms
• Patients do not show alteration in trajectory with treatments
  • Antibiotics
  • Feeding tubes
  • Transitions to higher level of care
• Patient are suffering
• Families express desire for comfort as the goal of care
End-of-Life Transitions among Nursing Home Residents with Cognitive Issues

Pedro Gozalo, Ph.D., Joan M. Teno, M.D., Susan L. Mitchell, M.D., M.P.H.,
Jon Skinner, Ph.D., Julie Bynum, M.D., M.P.H., Denise Tyler, Ph.D.,
and Vincent Mor, Ph.D.

ABSTRACT

BACKGROUND
Health care transitions in the last months of life can be burdensome and potentially of limited clinical benefit for patients with advanced cognitive and functional impairment.

METHODS
To examine health care transitions among Medicare decedents with advanced cognitive and functional impairment who were nursing home residents 120 days before death, we linked nationwide data from the Medicare Minimum Data Set and claims files from 2000 through 2007. We defined patterns of transition as burdensome if they occurred in the last 3 days of life, if there was a lack of continuity in nursing homes after hospitalization in the last 90 days of life, or if there were multiple hospitalizations in the last 90 days of life. We also considered various factors explaining variation in these rates of burdensome transition. We examined whether there was an association between regional rates of burdensome transition and the
Study Design

- Examined health care transitions among Medicare decedents with advanced cognitive impairment (ACI)
- Residents of nursing home 120 days prior to death
- Nationwide Medicare Minimum Data Set and Medicare claims files from 2000-2007
Definition

• Burdensome transition
  • Occurred in the last 3 days of life
  • Lack of continuity of nursing home before and after hospitalization in last 90 days of life
  • Multiple hospitalizations in the last 90 days of life
Results

• 474,829 NHR with ACI
• 19% had at least one burdensome transition in the last 90 days of life
• Wide state to state variation
• Over the span of several years, the number of transitions increased
  • 17% in 2000 to 19.6% in 2007
State Variation of Burdensome Transition -
Ranges from 2% - 40%

Figure 1. State Variations in the Proportion of Nursing Home Residents with Advanced Cognitive Impairment Who Had at Least One Burdensome Transition.
Results

• Higher transition rates associated with markers of poor quality care
  • Increased rate of feeding tube insertion
  • Higher rates of ICU admission
  • Higher rates of stage IV pressure ulcers
  • Late hospice enrollment
FEEDING TUBES
Background

• Longstanding debate
• Several landmark reviews demonstrated no improved survival or prevention of aspiration
• Cochrane review 2009 supported above and added that evidence on healing of pressure ulcers was inconclusive
Background Study - Design

• Interviewed 486 family members representing 9,652 relatives who died of dementia.
• Mortality follow back survey
• Examined in 5 states using state wide variation noted in previous PEG research
• High feeding tube inserting states (AL, FL, TX) vs low users (MN, MA)
Background Study - Results

- > 11% had feeding tube inserted
- 14% no MD discussion before insertion
- 38% said MD recommended feeding tube
- 11% felt pressured by MD
- 26% patients restrained after insertion
- 29% patients sedated after insertion
Statewide variation of feeding tube insertion

Feeding Tubes and the Prevention or Healing of Pressure Ulcers

Joan M. Teno, MD, MS; Pedro Gozalo, PhD; Susan L. Mitchell, MD, MPH; Sylvia Kuo, PhD; Ana T. Fulton, MD; Vincent Mor, PhD

Background: The evidence regarding the use of feeding tubes in persons with advanced dementia to prevent or heal pressure ulcers is conflicting. Using national data, we set out to determine whether percutaneous endoscopic gastrostomy (PEG) tubes prevent or help heal pressure ulcers in nursing home (NH) residents with advanced cognitive impairment (ACI).

Methods: A propensity-matched cohort study of NH residents with ACI and recent need for assistance in eating was conducted by matching each NH resident who had a feeding tube inserted during a hospitalization to 3 without a PEG tube inserted. Using the Minimum Data Set (MDS), we examined 2 outcomes: first, whether residents without a pressure ulcer developed a stage 2 or higher pressure ulcer (n=1124 with PEG insertion); and second, whether NH residents with a pressure ulcer (n=461) experienced improvement of the pressure ulcer by their first posthospitalization MDS assessment (mean [SD] time between evaluations, 24.6 [32.7] days).

Results: Matched residents with and without a PEG insertion showed comparable sociodemographic characteristic, rates of feeding tube risk factors, and mortality. Adjusted for risk factors, hospitalized NH residents receiving a PEG tube were 2.27 times more likely to develop a new pressure ulcer (95% CI, 1.95-2.65). Conversely, those with a pressure ulcer were less likely to have the ulcer heal when they had a PEG tube inserted (OR 0.70 [95% CI, 0.55-0.89]).

Conclusions: Feeding tubes are not associated with prevention or improved healing of a pressure ulcer. Rather, our findings suggest that the use of PEG tube is associated with increased risk of pressure ulcers among NH residents with ACI.

Arch Intern Med. 2012;172(9):697-701

Dementia is the sixth leading cause of death in the United States, and although the use of feeding tubes is common, the role of feeding tubes in preventing or healing pressure ulcers is controversial.
Study design

• Propensity matched cohort study
• Sample derived from MDS national repository and merged with Medicare claims files 1999-2007
• Restricted to NH residents who had been hospitalized at least once within the first year of entering the cohort.
• Also restricted to “severe” cognitive impairment (CPS score of 6 – need assistance in eating)
Results

• Looked at 2 outcomes:
  • Residents without ulcers – Did they develop a stage 2 or higher after PEG?
  • Residents with ulcers – Did the ulcer improve after PEG?
• 36% of those with PEG had new PU (19% in those w/o PEG)
• With a PEG tube: 2.27 times more likely to develop a new pressure ulcer
Results

• Those with a pressure ulcer were less likely to have the ulcer heal when a PEG tube was inserted

• 27% of those with pre-existing ulcers showed improvement after PEG (35% in those without PEG)

• Adjusted OR for pressure ulcer improving while PEG in place was 0.70
Take home

- No evidence of healing
- Evidence of harm
- Etiology of harm? Diarrhea, Restraints
- Why do we still use them? 74.6% physicians surveyed list healing pressure ulcer as reason for PEG
DECISION MAKING SUPPORT

Improving advance care planning
Advanced Care Planning

• Not just “DNR”
• Not just “Advanced Directives”
• Remove barriers
Care Coordination

- Transitions
- Continuity of care
- Earlier involvement of palliative care & hospice
Priorities

• Prevent unnecessary care or transitions in patients whose goal is comfort
• Support advanced care planning
• Educate families and physicians on risk/benefits
• Incentivize high quality care
• Provide evidence based dementia care; nationwide
• Create nursing home quality indicators for end of life care
REAL WORLD SITUATIONS
End of life dementia

Dementia, Palliative Care, and End of Life: Are We Doing It Right?

By Jamie Wilson
Mrs. G

- 89 year old woman living in a dementia care unit at an assisted living facility. She is married and has 3 children. Her medical history includes hypertension, congestive heart failure, dementia of the Alzheimer’s type, and osteoporosis. She is able to walk with a walker around the unit, is able to speak about 10-20 words, seems to enjoy interactions with family though she often doesn’t recognize them. She likes to listen to music and eat ice cream. Her weight has been steadily declining and she requires 1:1 feeding and encouragement.
Mrs. G continued

• She gets up one night without assistance and before staff can reach her she falls on the way to the bathroom. She is in pain and is unable to move. She is sent to the ER for evaluation.
• Mrs. G is found to have a L femoral neck fracture.
• The medical team calls the family in for a discussion about treatment options.
Group discussion

• Pre fracture functional status?
• Family’s understanding of her wishes?
• Hopes for repair/surgical intervention – ambulation? Pain control?
Mr. B

- Mr. B is a 91 year old man who is a retired Navy captain, he is widowed and lives at the Veteran’s home. His 2 children provide care and are his decision makers. He has had several strokes, and has moderate dementia. He is wheelchair bound and spends most of his days watching television or listening to groups. He has some residual weakness and word finding difficulty. He does enjoy visits from his sons and grandchildren, he still eats well with some assistance. His sons completed advanced directives at the NH to indicate that they would not want resuscitation or breathing support in the event of cardiac arrest.
Mr. B

- Mr. B is noted to have increased coughing and secretions with meals. The NH staff suggest thickening of liquids and a change to a soft diet. Mr. B begins to eat less, and refuse meals.
- The NH team requests a family meeting to discuss concerns for aspiration risk, dysphagia and now refusal to eat.
Group discussion

• Assess family’s understanding of his condition and prognosis
• Do they know what his wishes were or would be?
• Describe risk and benefits of feeding tubes compared to careful hand feeding
• Describe role of comfort feeding
Summary Themes

- Dementia under recognized as terminal illness
  - Patients have untreated pain
  - lack advanced care planning
  - underuse of hospice and palliative care
- Goals of care are changing
- Increased focus on comfort
- Prevention of burden to patients and family
- Improving coordination of care
- Increased involvement of palliative care
- Improve advanced care planning
“It’s not the years in your life that count. It’s the life in your years”
Abraham Lincoln
Summary Themes

• Improved decision making support
• Better evidence base on interventions
• Broaden patient and provider understanding of dementia trajectory
• System based changes are needed
• State to state variation is a major factor
References


Reminders

• After you close out of this webinar, you will receive a survey.
• Please complete this survey to receive continuing education credits.
• RIGEC has applied for CPEs. For Pharmacy (CPE) information, please email Faith Helm at flees@uri.edu for the CPE approval status, code and instructions for completing a separate program evaluation and reporting CPE data in the URI CPD evaluation system for pharmacists. Evaluations for CPEs must be completed within 30 days.
• RIGEC will email nursing and social work certificates on Mondays. Healthcentric Advisors will email CME certificates on Mondays.
• For questions about CME certificates, please email Susan Midwood at smidwood@healthcentricadvisors.org

Thank you!
Geriatric Education Series

Series aims to enhance geriatric competencies of healthcare providers and professionals serving older populations, particularly those with complex care needs, and includes a total five, topic-focused courses offered annually.

1. **Palliative Care and Hospice** – Course 1 (currently being offered)
   - “Pharmacotherapy Considerations When Managing Pain in Older Adults”
   - Monday, February 27th | 9:00-10:00am EST
   - [https://cc.readytalk.com/registration/#/?meeting=7bittq5sfoz7&campaign=aa3lxnc8358ux](https://cc.readytalk.com/registration/#/?meeting=7bittq5sfoz7&campaign=aa3lxnc8358ux)

2. **Stand Up and Stop Falls! Working Together to Prevent Falls in Older Adults** – Course 2 (March 2017)

3. **Optimal Pharmacotherapy** – Course 3 (April 2017)

4. **Cognitive Dysfunction** – Course 4 (June 2017)

5. **Mental, Social and Behavioral Health** – Course 5 (August 2017)

For more information: