The Role of Palliative Care in the Demented Patient

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OBJECTIVES

• Describe the Progressive Features of Dementia
• Review of Literature Progression of the Disease and Treatment
• Role of Palliative Care i.e. feeding, mechanical ventilation, comfort and "The Talk"

SPECIAL THANKS

• Dr. Allison Jordan
  Medical Director of Palliative Care, Christian Hospital Northeast, St. Louis, MO
• Dr. Angelo Volandes, Dr. Aretha Davis, ACP Decisions
• Sara Ferguson, RN, Clinical Nurse Manager, Palliative Care, Senior Health, ImPACT, Spartanburg Regional Healthcare System
• Kensey Boyd, BS, Director of Quality and Compliance- Hospice, Palliative, Senior Health, Spartanburg Regional Healthcare System

"The necessity of nature's final victory was expected and accepted in generations before our own. Doctors were far more willing to recognize the signs of defeat and far less arrogant about denying them."

Sherwin Nuland, MD
How We Die
1993

REFLECTIONS OF AN OLDER GENERATION

“Bert, try not to live as long as I have, it’s no fun anymore.”

Dr. Harry Rasor

“Unfortunately, the disease will eventually win out;” said Dr. Nicholas Milano, a neurologist with the Medical University of South Carolina in Charleston.
**ALZHEIMER’S DISEASE**

- The most common form of dementia
  - May be caused by plaques and tangles
- Not a normal part of aging
- Worsens over time
- 6th leading cause of death in the United States
- NO CURE

[https://www.alz.org/](https://www.alz.org/)

**ALZHEIMER’S DISEASE**

- Will affect over 15 MILLION AMERICANS by 2050
- One in ten by age 65/ about 50% over 85
- Currently about 4 MILLION AMERICANS
- About 50% of patients in the NH have dementia
- 70% of patients with dementia will spend the last months of their life in a nursing home

**DEMENTIA**

- A decline in mental ability severe enough to cause impairment in daily life
  - Memory
  - Communication
  - Ability to focus
  - Reasoning and judgement
  - Visual perception
- Term describes a group of symptoms
- Various causes: Vascular, thyroid, vitamin deficiencies

[https://www.alz.org/](https://www.alz.org/)

**DEMENTIA/NORMAL AGE CHANGES**

**Dementia**

- Poor Judgment/ Decision making
- Inability to manage budget
- Losing track of date/ season
- Difficulty having conversation
- Misplacing things and being unable to replace steps to find them (keys in fridge)

**Typical Age-related Changes**

- Making an occasional bad decision
- Missing a monthly payment
- Forgetting which day it is and remembering it later
- Sometimes forgetting which word to use
- Losing things from time to time

**DELIVERING BAD NEWS**

- Delivering a diagnosis of dementia is a delivery of serious news
- Use SPIKES for communication
  - Setting
  - Perception
  - Invitation
  - Knowledge
  - Emotions
  - Summarize and strategize

**VIDEO DECISION SUPPORT**

- Randomized Control Trial
  - 200 Older Patients>65(mean 75)
  - Intervention: verbal narrative alone or video decision support
  - Preferred Goal of Care:
    - Life Prolonging Care(CPR/MV)
    - Limited Care (Hosp.adm./Antibiot.)
    - Comfort Care
  - Preferences after 6 weeks

[BMJ 2009; 338:b1964, doi:10.1136/bmj.b2159](https://www.bmj.com/content/338/b1964)

Baile et al. The Oncologist. 2000
ADVANCE CARE PLANNING - 6 WKS

- Verbal Narrative
  64% Comfort Care/19% Limited Care
  14% Life Prolonging Care/3% ???

- Video Group
  86% Comfort Care/ 9% Limited Care
  4% Life Prolonging Care/ 1% ???


DISEASE PROGRESSION

<table>
<thead>
<tr>
<th>STAGE</th>
<th>COGNITION</th>
<th>FUNCTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>MILD</td>
<td>SHORT-TERM MEMORY</td>
<td>DRIVING/FINANCES</td>
</tr>
<tr>
<td>MODERATE</td>
<td>MEMORY/WORD FINDING</td>
<td>BATHING/DRESSING</td>
</tr>
<tr>
<td>SEVERE</td>
<td>LANGUAGE AND COMPREHENSION LIMITED</td>
<td>CONTINENCE WALKING</td>
</tr>
<tr>
<td>ENDSTAGE</td>
<td>UUTTER FEW WORDS NO FAMILY RECOGNITION</td>
<td>EATING</td>
</tr>
</tbody>
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PHARMACOLOGICAL APPROACH

- Cholinesterase inhibitors
  - Donepezil, galantamine, rivastigmine
  - Work by inhibiting the breakdown of acetylcholine by blocking the enzyme acetylcholinesterase

  - Marginally effective
  - Re-evaluate 12 weeks after starting
  - Significant side effects

Birks, Cochrane Database, Syst Rev. 2006
Cambell, et al. JAGS. 2017

LONG-TERM DONEPEZIL TREATMENT IN ALZHEIMER'S

- Randomized control trial/ 565 patients
- Community residents
- 12 week period randomly allocated donepezil 5mg/day vs placebo
- 486 completed were re-randomized to 5mg, 10mg or placebo
- Endpoints: institutionalized/ progression of disability

Lancet 2004; 363: 2105-15
Non-pharmacologic approach is first line to treat dementia-related behavior

DICE
- Describe the distressing behaviors
- Investigate possible causes
- Create a plan
- Evaluate if plan has been effective

Kafes HC, et al. JAGS. 2014

Antipsychotics
- Long-term increased risk of mortality

Benzodiazepines
- "Cocktail in a pill"

Antidepressants
- Citalopram may have a role in reducing agitation

Dextromethorphan-quinidine
- May help with agitation; increased risk of adverse events

Restraints
- Can worsen agitation

Porsielesson, et al. JAMA. 2014
Cummings, et al. JAMA. 2015

>80% of patients develop feeding difficulty

They include:
- Lose ability to feed oneself
- Food refusal-won’t open mouth/chew
- Dysphagia-difficulty swallowing

Like other terminal conditions weight loss is common and not easily reversible (CANCER/COPD/CARDIAC DISEASE)

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Multiple studies in dementia patients show they DO NOT prolong life and MAY ADVERSELY DECREASE QOL (Decrease human interaction and increase restraints/ pressure sores)

Denies Taste

Reduces Dignity

Adds caregiver responsibility with decreased personal connection

S.C. doctor devised tube technique

SO WHAT ABOUT TUBE FEEDINGS ?????

THE ENJOYMENT OF FOOD IS SO AMERICAN AND YET...

PEG TUBES IN DEMENTIA
Tube feedings in the United States nursing home residents with advanced dementia, 2000-2014

- Rates declined from 8.6% to 3.1% in white residents
- Rates declined from 37.5% to 17.5% in black residents


GOOD NEWS!

South Carolina is still near the top of the country in tube feeding rates in nursing homes.

Nationwide, mechanical ventilation rates are still a problem.

BAD NEWS!

Association of Increasing Use of Mechanical Ventilation Among Nursing Home Residents With Advanced Dementia and Intensive Care Unit Beds

- Attempted to describe the use and outcomes of mechanical ventilation and its association with increasing ICU beds in the US for patients with advanced dementia residing in nursing homes 120 days before hospital admission
- Study from 2000-2013, noted 635,000 hospitalizations of 380,000 patients (30.5% male, 69.5% female, mean age: 84)


MECHANICAL VENTILATION WITH ADVANCED DEMENTIA

Findings:

- Use of mechanical ventilation increased from 39 per 1000 hospitalizations in 2000 to 78 per 1000 hospitalizations in 2013
- As the number of ICU beds in a hospital increased, patients with advanced dementia were more likely to receive mechanical ventilation
- Over the 10+ years, no significant improvement in one year mortality (65.2% vs 64%)


MECHANICAL VENTILATION WITH ADVANCED DEMENTIA

PALLIATIVE PILOT IN SKILLED NURSING FACILITIES

Jan 2017 - June 2018
- 66 patients seen by APRN
  - 71% (15/21) changed to DNR from Full Code
  - 71% (25/35) hospice ordered of hospice appropriate
  - Prevented 26 readmissions

"Our reluctance to honestly examine the experience of aging and dying has increased the harm we inflict on people and denied them the basic comforts they most need."

Atul Gawande, MD
PATIENT RESOURCES

Ira Byock, MD. *Dying Well: Peace and Possibilities at the End of Life;* (Riverhead Books, 1997)

“EXTREMIS” Documentary film, ACADEMY AWARD NOMINEE featuring Critical Care Physician Dr. Jessica Zitter—Netflix/UTUBE


The Conversation Project (theconversationproject.org)

Prepare (prepareforyourcare.org)

ACADEMIC REFERENCES


Campbell ML; Guzman JA. A Proactive Approach to Improve End-of-Life Care in a Medical Intensive Care Unit for Patients with Terminal Dementia. *Critical Care Medicine.* 2004;32:1839-1843