Managing End of Life Care for Patients with Dementia
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Objectives

1. Recognize Dementia as a Terminal Disease
2. Utility of Hospice/Palliative Care in Managing Advanced Dementia
3. Understand the Importance of Educating Family of the Natural History of Dementia.

Dementia is a Terminal Disease

• Median survival 3 to 6 years
• Prognosis for advanced dementia comparable to severe CHF or metastatic breast cancer.
• Palliative care is the most appropriate care for advanced dementia patients.

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Advanced Dementia

- Profound memory deficits
- Total functional dependence
- No knowledge of recent or past events
- Little to no verbal communication
- Limited ability to ambulate

Mitchell, JAMA, 2007, 298, pp 2527-2536

Mechanical Ventilation Among NH Patients With Advanced Dementia 2000 - 2013

<table>
<thead>
<tr>
<th>Rate of Mechanical Ventilation</th>
<th>Doubles</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Year Mortality</td>
<td>80%</td>
</tr>
<tr>
<td>30 Day Mortality</td>
<td>51%</td>
</tr>
<tr>
<td>ICU Beds and Mechanical Ventilation</td>
<td>Doubles</td>
</tr>
</tbody>
</table>

Teno, JAMA IM, 2016

Mechanical Ventilation Among NH Patients With Advanced Dementia 2000 - 2013

96% Health Care Proxies Say Comfort Care

Goals of Care

POLST

Teno, JAMA IM, 2016
Winzelberg, JAMA IM, 2016
Clinical Complications of Advanced Dementia

- Pneumonia (Aspiration)
- Feeding/Swallowing/Nutrition Issues
- Sepsis

Fever

Antibiotics vs. Palliation

Goals of treatment:
1. Life Prolongation
2. Symptom Control

Risks of Antibiotics:
1. Pain – from injection
2. C-diff
3. Antimicrobial resistance

Prognosis of Advanced Dementia

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>18 Month Mortality</td>
<td>55%</td>
</tr>
<tr>
<td>6 Month Mortality</td>
<td>25%</td>
</tr>
<tr>
<td>6 Month Mortality / Pneumonia</td>
<td>47%</td>
</tr>
<tr>
<td>6 Month Mortality / Febrile Episode</td>
<td>45%</td>
</tr>
<tr>
<td>6 Month Mortality / Eating Problem</td>
<td>39%</td>
</tr>
</tbody>
</table>
Distressing Symptoms in Advanced Dementia

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dyspnea (≥5 days/month)</td>
<td>46%</td>
</tr>
<tr>
<td>Pain (≥5 days/month)</td>
<td>39%</td>
</tr>
<tr>
<td>Pressure Ulcers</td>
<td>39%</td>
</tr>
<tr>
<td>Agitation</td>
<td>54%</td>
</tr>
<tr>
<td>Aspiration</td>
<td>41%</td>
</tr>
</tbody>
</table>

Burdensome Interventions Last 3 Months of Life

<table>
<thead>
<tr>
<th>Believed prognosis</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;6 mos, understood</td>
<td>27%</td>
</tr>
<tr>
<td>&gt;6 mos, did not understand</td>
<td>73%</td>
</tr>
</tbody>
</table>

Hospice Eligibility

**Dementia:**
1. FAST Scale ≥7C
2. Aspiration pneumonia, pyleonephritis, sepsis, multiple decubs > ST 3, recurrent fever after antibiotics, poor nutritional status.

**End Stage Debility:**
1. Degenerative neurologic process
2. Comorbidities
3. Functional and nutritional decline.

**And/or Likelihood of Death in <6 months**
Advanced Dementia Patients

Only 1 in every 10 patients dying with dementia receive Hospice Care.

Why?
1. Prognosis Challenges
2. Lack of recognition of dementia as a terminal disease.

Benefits of Hospice Care for Dementia Patients

- 50% reduction in hospitalization the last 30 days of life.
- Higher rate of regular treatment for daily pain (44% vs. 27%)
- Family support: 73% rating hospice service excellent

Video Assisted ACP in Dementia

120 Subjects, Average Age 58

<table>
<thead>
<tr>
<th>Narrative of Advanced Dementia</th>
<th>Video of Advanced Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comfort Care</td>
<td>50</td>
</tr>
<tr>
<td>Limited Care</td>
<td>18</td>
</tr>
<tr>
<td>Life Prolonging Care</td>
<td>21</td>
</tr>
</tbody>
</table>

VOLANDES, ARCH IM, 04-27-07
**Treatment Preferences**

Median Age 60

<table>
<thead>
<tr>
<th></th>
<th>Dementia: Do not want</th>
<th>Dementia/Terminal Illness: Do not want</th>
</tr>
</thead>
<tbody>
<tr>
<td>CPR</td>
<td>72</td>
<td>84</td>
</tr>
<tr>
<td>Ventilator</td>
<td>75</td>
<td>84</td>
</tr>
<tr>
<td>IVF’s</td>
<td>73</td>
<td>82</td>
</tr>
<tr>
<td>Artificial Nutrition</td>
<td>76</td>
<td>82</td>
</tr>
<tr>
<td>Major Surgery</td>
<td>77</td>
<td>85</td>
</tr>
<tr>
<td>Minor Surgery</td>
<td>71</td>
<td>81</td>
</tr>
</tbody>
</table>

**Video Assisted ACP in Dementia**

“Differences in preferences with regard to race/ethnicity, educational level, and religious attendance disappeared after watching the video.”

**Video Assisted ACP Cancer Patients**

50 Subjects Malignant Glioma

<table>
<thead>
<tr>
<th></th>
<th>Verbal</th>
<th>Video</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life Prolonging</td>
<td>26%</td>
<td>0%</td>
</tr>
<tr>
<td>Basic Medical Care</td>
<td>52%</td>
<td>4%</td>
</tr>
<tr>
<td>Comfort Care</td>
<td>22%</td>
<td>91%</td>
</tr>
</tbody>
</table>

[3/6/2017]
Artificial Nutrition & Hydration

- Intravenous Fluids
- TPN: Total Parenteral Nutrition
- Tube Feeding: Enteral Nutrition

The Physiology of Death and Dying

- Decreased thirst in the elderly
- Terminally ill patients:
  - Decreased hunger (anorexia)
  - Decreased thirst

Sir William Osler’s Philosophy of Death

1900-1904 Survey of 486 Dying Patients

- 90 “Bodily Pain or Distress
- 11 “Mental Apprehension
- 2 “Positive Terror”
- 1 “Spiritual Exaltation
- 1 “Bitter Remorse”

“The majority gave no sign one way or the other; like their birth, their death was a sleep and a forgetting.”

Hoshara, Annals of IM, 1993, 118, pp.638-642
Sir William Osler’s Death

1919 Chronic Bronchitis

“Shunt the whole pharmacopoeia, except opium. It alone in some form does the job. What a comfort it has been.”

Hinohara, Annals IM, 1993, 118, pp 638-642

The Naturalness of Dying

- The Medicalization of death:
  80% Die in institutions

- “Heroic Positivism”:
  A philosophy of medicine in which there is intrinsic value to action.

McCue, JAMA, 273, pp 1038-1043

Artificial Nutrition and Hydration

The Nancy Cruzan Case

Background:
30 year old woman in persistent vegetative state for 7 years.

The Protesters:
“Please Feed Nancy”
“The issue is that a woman is being starved to death”
1990 U.S. Supreme Court:
“The liberty guaranteed by the due process must protect an individual’s deeply personal decision to reject medical treatment, including the artificial delivery of food and water”

Justice Sandra Day O’Connor’s opinion:
“Artificial feeding cannot readily be distinguished from other forms of medical treatment.”

A Sad History: The Feeding Tube

The Gastrostomy = major surgery

The PEG: Percutaneous Endoscopic Gastrostomy
• 1979: Invented by pediatricians for infants
• By 2005: 300,000 a year; 225,000 in patients over 65; 34% of patients with advanced dementia

Advanced Dementia
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Mitchell, JAMA, 2007, 298, pp 2527-2536
The Benefits of ANH

- Permanent vegetative state
- Extreme short bowel syndrome
- ALS
- Head and neck undergoing radiation therapy
- Cancer with proximal bowel obstruction
- Acute phase of stroke or head injury

The Burden of ANH at EOL

- Prolonging the dying process
- Increased oral and pulmonary secretions
- Dyspnea due to pulmonary edema
- Increase urination
- Ascites

Physician Attitudes of FT’s in Patients with Advanced Dementia

<table>
<thead>
<tr>
<th>Survey</th>
<th>Actual</th>
</tr>
</thead>
<tbody>
<tr>
<td>75% Decreases Pneumonia</td>
<td>False</td>
</tr>
<tr>
<td>90% Improves Nutrition</td>
<td>False</td>
</tr>
<tr>
<td>75% Heals Pressure Ulcers</td>
<td>False</td>
</tr>
<tr>
<td>61% Improves Survival</td>
<td>False</td>
</tr>
</tbody>
</table>

Shega, J Fam Med, 2003, 6, pp 895-893
Survival of Patients over 65 Receiving PEG

20-40% 30 day Mortality

50-60% 1 year Mortality

Tube Feeding in Advanced Dementia

“A demented patient with eating difficulties .... A conscientious program of hand feeding is the proper treatment. If the patient continues to decline tube feeding might be considered, however, all who help make the decision should be clearly informed that the best evidence suggests it will not help.”

Factors Leading to FT Placement

Lack of:
• DNR
• Advanced Directive
• Health Care Agent

Presence of:
• Color
• Poverty
• Urban
• For Profit NH
Triple Jeopardy

Physician Ignorance

+ Swallowing Studies

+ Reimbursement Policies

“The Tube Feeding Death Spiral”

Alternatives:

• Swallowing dysfunction marker of dying process
• Assume informed consent: hand feeding, hospice care
• Make clear recommendations to family, support family decision
• Establish goals

The Burdens of ANH

• Physical restraints
• Diarrhea, GI distress
• Patient or accidental removal of FT
• Surgical complications: infection, bowel perforation
• TPN complications: infection, blood clots
The Future

- Education: Health Professionals
- Education: The Public
- Reform: The Regulators (Reimbursement)

Reflective

*Reflects patient wishes:*

“What would your mother have wanted? If she had, in her good mind of 5 or 10 years ago, had seen herself in this condition, with Advanced Dementia, would she have wanted medical treatment to prolong her life?”

“Or, do you think she would have chosen care focused on comfort?”

From Here:
A Loved One with Advanced Dementia

To There:
A Reflective Advanced Directive
Reflective

Reflects good medical judgment:
“I strongly discourage CPR in the nursing home. It rarely provides any benefit. The very few – maybe 1 out of 50 – that survive return in an even more deteriorated condition.”

Reflective

Reflects compassion:
“Hospitalization can be very upsetting for a patient with Advanced Dementia. She could not understand the test or treatments. These can often be uncomfortable and painful. Plus, a hospital is an unfamiliar setting.”

“It is often best to focus on comfort in surroundings that are familiar, by staff that know her.”

Reflective

Reflects good medical judgment:
“Swallowing difficulties and weight loss are symptoms of Advanced Dementia.”

“Comfort can be provided altering the diet, providing foods that are easier to swallow, or hand feeding.”

“When death is near, appetite is lost, comfort can be provided by keeping the mouth moist.”
Reflective

Reflects compassion:

“Since your mother would want her care focused on comfort, I recommend that we consider a hospice evaluation. She is entitled to it; it is a Medicare Benefit.”

“It would provide an additional level of care – here at her home.”

“Nurse, Social Workers, Chaplains, Therapists – all of whom would have the goal of maximizing your mother’s comfort and dignity.”

POLST Form

POLST: Provider Orders for Life Sustaining Treatment

CARDIOPULMONARY RESUSCITATION (CPR): Patient has no pulse and/or is not breathing. See Section A regarding CPR if pulse is lost.

Additional Orders (e.g., Analgesia, etc.):

POLST Form
POLST Form

DIRECTIONS FOR HEALTH CARE PROFESSIONALS

COMPLETING POLST:
- Must be completed by a health care professional based on patient preferences and medical indications.
  - If the goal is to support quality of life in last phases of life, then DNR must be selected in Section A.
  - If the goal is to maintain function and quality of life, then either CODE or DNR may be selected in Section A.
  - If the goal is to live as long as possible, then CPR must be designated in Section A.
  - POLST must be signed by a physician, nurse practitioner, Doctor of Chiropractic, or Physician Assistant (when delegated to be valid).

USING POLST:
- Any section of POLST not completed implies most aggressive treatment for that section.
- An automatic external defibrillator (AED) should not be used for a patient who has chosen "Do Not Attempt Resuscitation." Opioids and nutrition must always be offered if medically feasible.
- A patient with capacity or the surrogate (if patient lacks capacity) can revoke the POLST at any time and request alternative treatment.
- Comfort care only: At this level, provide only palliative measures to enhance comfort, minimize pain, relieve dis- torts, avoid invasive and perhaps futile medical procedures, all while preserving the patient's dignity and wishes during final, last moments of life. This patient must be designated DNR at in section A. A for this choice to be applicable in section B.

1. Limit Interventions and Treat Reversible Decisions: The goal at this level is to provide limited additional interventions aimed at the treatment of new and reversible illness or injury or management of non-life-threatening chronic conditions. Treatment may be tried and discontinued if not effective.

2. Prolong Life-Sustaining Care: The goal at this level is to provide limited additional interventions aimed at the treat- ment of new and reversible illness or injury or management of non-life-threatening chronic conditions. Treatment may be tried and discontinued if not effective.

QUESTIONS?