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.
**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*

**Clinical Complications of Advanced Dementia**

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

**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>

*NEJM, MITCHELL, 10-15-09*
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>Scenario</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Believed prognosis &lt;6 mos, understood clinical complications</td>
<td>27%</td>
</tr>
<tr>
<td>Believed prognosis &gt;6 mos, did not understand clinical complications</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.
4. 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></th>
<th>Narrative of Advanced Dementia</th>
<th>Video of Advanced Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comfort Care</td>
<td>50</td>
<td>89</td>
</tr>
<tr>
<td>Limited Care</td>
<td>18</td>
<td>2.5</td>
</tr>
<tr>
<td>Life Prolonging Care</td>
<td>21</td>
<td>0</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>

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.”

Hinohara, Annals 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
- Profound memory deficits
- Total functional dependence
- No knowledge of recent or past events
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- Limited ability to ambulate

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>


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)
The Benefits of ANH

- Permanent vegetative state
- Extreme short bowel syndrome
- ALS
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- Cancer with proximal bowel obstruction
- Acute phase of stroke or head injury

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>

QUESTIONS?