End of Life Nutrition and Hydration: Optimal Communication and Guidance for Patients and Families

Victor M. Sandler, MD
Medical Director Fairview Home Care and Hospice
Co-chair UMMC Bioethics Committee
President of Hospice and Palliative Care Physicians of Minnesota

April, 2019

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 Physiology of Death and Dying

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

Artificial Nutrition & Hydration

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

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

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

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

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

Factors Leading to FT Placement

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

Presence of:
- Color
- Poverty
- Urban
- For Profit NH

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.”
Reflective Explanations

Reflects good medical judgment:

“Swallowing difficulties and weight loss are symptoms of Advanced Disease” (Advanced Dementia/Heart Disease/Metastatic Cancer). “We see this when people are in the last weeks and months of life.”

“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.”

Case Presentation

93 year old man completely independent, chopping wood and caring for demented wife, fell off exercise machine and suffered spine fracture. Despite rehab for 2-3 months he was unable to recover. He became totally dependent and unable to care for his wife. He decided he did not want to live in this state of ongoing dependency. Under the care of his children, he entered hospice, stopped eating and drinking so that he could die. He died peacefully nine days later in his son’s home.

Case Study

85 yo man with end stage dementia residing in an AL memory care unit. He is cachectic due to dysphagia and poor intake. Through hand feeding administered by staff he continues to survive on decreased intake of a pureed diet. Care conference with his wife and daughter. Wife is his HCA. Both are adamant that he was a proud, independent man who would never want to live on in this condition.
Case Study

80 yo woman with end stage dementia residing in a SNF. She has a flat affect, does not react to speech, non verbal, non ambulatory, and has not appeared to recognize her family for the past two years. She has been hand fed by staff for the past two years. She appears well nourished and has no history of dysphagia. At the care conference her husband and adult children all agree that she would find her current existence repugnant because of her diminished quality of life. They are convinced that she would stop eating if she was able to decide for herself and end her life.

“\n\nA competent patient may refuse any medical intervention, even when such treatment may be life-saving. When patients are not competent to make these decisions for themselves, surrogates are legally empowered to make these decisions on the patient’s behalf.”

“\n\nNo law limits the refusal of treatment to particular diseases or prognoses, and the right to refuse unwanted medical interventions, including tube feedings, extends to those with severe cognitive impairments.”
Argument: Withdrawal of oral food and fluid causes starvation and is therefore cruel and painful.

Reality: Withdrawal of oral or tube feeding causes death by dehydration. It is consistent with natural dying process that is peaceful and without suffering.

Refusal of Hydration and Nutrition

Irrelevance of the “Artificial” vs. Natural distinction

“We propose that under certain circumstances surrogates may choose that all forms of hydration and nutrition be foregone, regardless of whether they are administered artificially (by tube) or naturally (by hand).”
"The justification for the withdrawal of feedings does not hinge on whether feeding is administered artificially or naturally; rather it is based on the fundamental rights to self determination and bodily integrity that permit patients to refuse ANY unwanted intervention.

Terminal Patients Who Die by Cessation of Nutrition and Hydration

89% Hospice Nurses
86% Hospice Physicians

Report peaceful, comfortable deaths.

Comfort Care for Terminally Ill Patients

32 patients, average age 75, mentally aware & competent

Mean Survival – 40 days
63% No hunger
34% Initial hunger
62% No thirst or initial thirst only
100% of patients, symptoms of hunger, thirst easily alleviated
Nurses' Experiences with Hospice Patients Who Refuse Food and Fluids to Hasten Death

<table>
<thead>
<tr>
<th></th>
<th>Stopped Food &amp; Fluids</th>
<th>PAS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suffering</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Pain</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Peacefulness</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Overall quality of death</td>
<td>8</td>
<td>8</td>
</tr>
</tbody>
</table>

Likert 10 point scale

102 patients

Comfort Feeding Only

Dilemma: PEG vs Hand feeding in patients with advanced dementia

Solution: Comfort feeding only (CFO) – attempt to hand feed as long as it is not causing distress

Oral Nutrition and Hydration: The Progression As We Die

- Normal Oral Feeding
  - Dysphagia with Modified Diet
  - Hand Feeding
  - Comfort Feeding Only
- VSED or Cessation of Non voluntary Hand Feeding