END OF LIFE DECISIONS: ARTIFICIAL NUTRITION AND HYDRATION

ROSCHELE HEUBERGER, PHD, RD

OUTLINE

• END OF LIFE (EOL) DECISION MAKING
  • CER ETHICS REQUIREMENT
• NUTRITION AND HYDRATION
  • ARTIFICIAL NUTRITION AND HYDRATION (ANH)
  • CAREFUL HAND FEEDING AND LUBRICATION
  • VOLUNTARY REFUSAL OF FOOD AND FLUIDS (VF), DEHYDRATION AND STARVATION, SEDATION
• DETERMINATION OF HEALTH PROFESSIONALS ATTITUDES, KNOWLEDGE AND BELIEFS
  • RESEARCH STUDY
  • ANH IN EOL
    • ETHICAL, LEGAL, FISCAL, RELIGIOUS, CONTEXTUAL, ORGANIZATIONAL, AND OTHER DETERMINANTS
  • CONCLUSIONS, RESOURCES, CONTACT INFORMATION

DEATH AND DYING

• DISCUSSIONS ON DEATH AND DYING ARE AVOIDED
  • CULTURALLY TABOO
  • MEDICAL MODEL
    • TECHNOLOGICAL ADVANCEMENT
    • QUALITY OF LIFE (QOL)
  • BURDEN:
    • FISCAL, EMOTIONAL, PHYSIOLOGICAL, ETHICAL
  • UNITED STATES VERSUS OTHER WESTERN NATIONS
END OF LIFE CARE

• END OF LIFE DECISION MAKING

• DONE IN A CHAOTIC, EMOTIONALLY CHARGED ENVIRONMENT 88% OF THE TIME

DEFINITIONS

• HOSPICE
• PALLIATION
• LIVING WILL
• DURABLE POWER OF ATTORNEY FOR HEALTH CARE
• PERSISTENT VEGETATIVE STATE
• MINIMALLY CONSCIOUS STATE OR LOCKED IN SYNDROME
• COMA

ADVANCED DEMENTIA

• PROGRESSION OF DEMENTIA COMES WITH:
  • DYSPHAGIA
  • FEAR AND AGITATION, CONFUSION AND DISORIENTATION
  • MYOCLONUS, FLAILING
  • DECREASED THIRST AND HUNGER
  • WEIGHT LOSS, LOSS OF LBM
  • FLUID SHIFTS, METABOLIC DYSREGULATION
  • FRAILTY AND VULNERABILITY
  • LOSS OF VOLUNTARY MOTOR CONTROL, SENSORY AND SPEECH CAPABILITIES
ARTIFICIAL NUTRITION

• NUTRIENTS BY ANY ROUTE OTHER THAN ORAL
  • APOPTOSIS > VIABILITY
  • PAIN
  • SYSTEMIC STRESS RESPONSE
  • ASPIRATION, PNEUMONIA, GI DISTRESS
  • LAB INDICES, LBM, INFLAMMATORY RESPONSE
  • PRIMARY OR CO-MORBID CONDITION
  • SURVIVAL TIME

TOTAL PARENTERAL NUTRITION

• CONTRAINDICATED IN THE DYING
  • RISK OUTWEIGHS BENEFITS
  • INFECTION
  • SECRETIONS AND COMPLICATIONS
  • PAIN, DISCOMFORT
  • COSTS
  • SURVIVAL
  • FALSE HOPE IS ETHICALLY QUESTIONABLE

ARTIFICIAL HYDRATION

• ORAL HYDRATION IN EOL VERSUS:
  • HYPODERMOCLYSIS
  • PROCTOCLYSIS
  • TUBE FLUSHES
  • IV FLUIDS
RESTRAINTS

- Restraint Use
- Controversial
- Pulling
- Ethically Questionable
- Expression of Refusal
- Consequences

CONSIDERATIONS

- Careful Hand Feeding
- Lubrication
- Deprivation
- ANH Institution

VOLUNTARY REFUSAL OF FOOD AND FLUIDS

- Food and Fluid Provision
  - Highly charged, emotive subject.
  - Constitutes "standard of care"
- Most see food and fluids as "doing something"
  - VRFF is a legal right for a competent person
  - Most states have statutes for proxy refusal
SEDATION

- PALLIATIVE SEDATION
- DOUBLE JEOPARDY, SLIPPERY SLOPE
- ASSISTED SUICIDE
- VRFF, PALLIATIVE SEDATION AND THE RIGHT TO DIE

[Links to相关网站]

RESEARCH

- SURVEY OF HEALTH PROFESSIONALS
  - RANDOM REPRESENTATIVE SAMPLING
  - DEMOGRAPHICS
  - PRACTICE SETTINGS
  - ORGANIZATIONAL CONSTRUCTS
  - PERSONAL OR PROFESSIONAL EXPERIENCE
  - GNOSIS

CASE STUDY

- ADVANCED DEMENTIA SCENARIO:
  - NON-VERBAL, BEDBOUND, DYSPHAGIC, 89 Y.O., DEVOUT CATHOLIC FEMALE
  - NO LEGALLY DOCUMENTED PREFERENCES ON ANH, THE DECEASED HUSBAND WAS PROXY.
  - SHE IS AGITATED, FLAILS AND MOANS IN DISTRESS, AND OBVIOUS PAIN.
  - HER CHILDREN ARE FIGHTING OVER HOW TO PROCEED AND A PRIEST IS CALLED IN. THE PRIEST INFORMS THE FAMILY THAT THE POPE ISSUED A STATEMENT THAT FOOD AND FLUID PROVIDED THROUGH ANY ROUTE IS CONSIDERED NECESSARY AND IS THE STANDARD OF CARE.
  - THE PATIENT IS SARCOPENIC, DEHYDRATED, HAS ASCITES, MYOCLONUS, A STAGE III DECUBITUS ULCER, ABNORMAL SERUM LABORATORY VALUES, INDICATIVE OF, AMONG OTHER THINGS, HYPERNATREMIA AND PEM.
  - PALLIATIVE SEDATION WITH ANH
  - VRFF
### Semi Skilled Staff

- **Need Fewer Audit**: 
  - D/C Mouth Restraints
  - Dementia
  - ANH
  - Serum Value
  - Myoclonus
  - Improvment
  - Decubitus

- **Less Bad**: 
  - Ascites
  - Mouth
  - LBM

### Scenarios

<table>
<thead>
<tr>
<th>Level</th>
<th>Registered Dietitians % (n=860)</th>
<th>Physicians % (n=73)</th>
<th>All Other Clinical Practitioners % (n=250)</th>
<th>All Ed, Research, Industry % (n=538)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ineff</td>
<td>Opened</td>
<td>In-hour</td>
<td>Uran</td>
<td>Opened</td>
</tr>
<tr>
<td>Insert. PEG</td>
<td>47*</td>
<td>24</td>
<td>5</td>
<td>12*</td>
</tr>
<tr>
<td>Insert. NG</td>
<td>50*</td>
<td>13</td>
<td>7</td>
<td>49*</td>
</tr>
<tr>
<td>TPN</td>
<td>60*</td>
<td>6*</td>
<td>3*</td>
<td>66*</td>
</tr>
<tr>
<td>Ur. Catheter</td>
<td>41*</td>
<td>21</td>
<td>11</td>
<td>40*</td>
</tr>
<tr>
<td>D/C Mouth</td>
<td>64*</td>
<td>8*</td>
<td>8</td>
<td>72*</td>
</tr>
<tr>
<td>Restraints</td>
<td>62*</td>
<td>8*</td>
<td>6</td>
<td>67*</td>
</tr>
<tr>
<td>Sedation</td>
<td>63*</td>
<td>6*</td>
<td>15*</td>
<td>68*</td>
</tr>
</tbody>
</table>

### ANH

<table>
<thead>
<tr>
<th>Initiated</th>
<th>Registered Dietitians % (n=860)</th>
<th>Physicians % (n=73)</th>
<th>All Other Clinical Practitioners % (n=250)</th>
<th>All Ed, Research, Industry % (n=538)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Legal - Facility</td>
<td>19</td>
<td>19</td>
<td>19*</td>
<td>20</td>
</tr>
<tr>
<td>Less Audi Protection</td>
<td>40*</td>
<td>10*</td>
<td>10*</td>
<td>10*</td>
</tr>
<tr>
<td>Less Bed Protection</td>
<td>17*</td>
<td>40*</td>
<td>16*</td>
<td>18*</td>
</tr>
<tr>
<td>Food Fear - Skilled</td>
<td>47*</td>
<td>12*</td>
<td>12*</td>
<td>47*</td>
</tr>
<tr>
<td>Food Fear - Skilled Staff</td>
<td>67*</td>
<td>3*</td>
<td>11*</td>
<td>50*</td>
</tr>
</tbody>
</table>

### PEG Placed

<table>
<thead>
<tr>
<th>Values</th>
<th>Registered Dietitians % (n=860)</th>
<th>Physicians % (n=73)</th>
<th>All Other Clinical Practitioners % (n=250)</th>
<th>All Ed, Research, Industry % (n=538)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improvement</td>
<td>Opened</td>
<td>In-hour</td>
<td>Uran</td>
<td>Opened</td>
</tr>
<tr>
<td>Nutrition</td>
<td>6*</td>
<td>6*</td>
<td>5*</td>
<td>6*</td>
</tr>
<tr>
<td>N/P</td>
<td>20</td>
<td>10</td>
<td>10</td>
<td>20</td>
</tr>
<tr>
<td>NG2</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>NG1</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>D/C Mouth</td>
<td>64*</td>
<td>8*</td>
<td>8</td>
<td>72*</td>
</tr>
<tr>
<td>Restraints</td>
<td>62*</td>
<td>8*</td>
<td>6</td>
<td>67*</td>
</tr>
<tr>
<td>Sedation</td>
<td>63*</td>
<td>6*</td>
<td>15*</td>
<td>68*</td>
</tr>
</tbody>
</table>
FINDINGS

• PROVIDER UNFAMILIARITY

• EDUCATION USING SOUND, RESEARCH BASED INFORMATION LACKING

• INSTITUTIONALIZATION OF TRANSFERABLE DOCUMENTATION
  • WWW.POLST.ORG

• PATIENT WISHES

• DECISIONS

• DIETITIANS HAVE AN OBLIGATION TO BE ADVOCATES

• HUNGER AND THIRST

• COMFORTABLE PASSAGE

• QUALITY OF LIFE

• PROVISION OF FALSE HOPE

• TERMINAL SEDATION WITH DEHYDRATION

• DIRECT EXPRESSION OF WILL

• UNINFORMED INSTITUTION OF ANH

• REFUSE AGGRESSIVE MEASURES

• BIASES
LEGAL

• Patient Self Determination Act of 1991
• The 14th Amendment to the Constitution
• Legal Liability
• The Medical Right
• Right to Know – End of Life Options Act of 2008
• Multiple Supreme Court and International Legal Proceedings

FISCAL

• Institutionalized
• Hospitalization
• Mortality
• Medicare
• Taxpayer Savings
• Limiting Technologies
• Surviving Spouse

RELIGIOUS

• Practitioners, Family and Individuals' Religious Beliefs
• Every Denomination of Every Religion Has a Position
  • ANH Delays Death, Allow Repentance (Fundamentalist Christianity)
  • ANH is Not Extraordinary Intervention, Needs to Be Administered To Decrease Suffering (Pope Francis, John Paul II, Catholicism)
  • ANH Basic Care, As Long As It Does Not Harm (Orthodox Judaism)
  • Life on Earth Is Preparation For Afterlife (Islam)
  • Good Death, Successful Reincarnation (Hinduism)
  • Withhold ANH To Allow Rebirth, Good Death (Buddhism)
PERSONAL & CONTEXTUAL

• CULTURAL DETERMINANTS
• RACIAL DETERMINANTS
• PROVIDER CREDENTIALS
• OCCUPATION
• PATIENT RELATIONSHIP
• PERSONAL BIAS INFLUENCES ADVOCACY

ORGANIZATIONAL DETERMINANTS

• ORGANIZATIONS - ETHICIST, HOSPICE, PALLIATIVE
• ORGANIZATIONS - LAWSUIT
• ORGANIZATIONS - PUBLIC
• ORGANIZATIONS - PATIENT POPULATION
• ORGANIZATIONS - PROVIDERS
• ORGANIZATIONS – NON-TEACHING

CONCLUSIONS

• DIETITIANS:
  • EDUCATION
  • ADVOCACY
  • PERSONAL BIAS
  • ETHICS
  • COST
  • CONSULTATION


RESOURCES

Preedy, Victor. Diet and Nutrition in Palliative Care. 2011, CRC Press, Boca Raton, FL, USA

Berlinger, N, Jennings, B, Wolf, S. The Hastings Center Guidelines for Decisions on Life Sustaining Treatment and Care Near the End of Life. 2nd ed. (2016). Oxford Press. NY, NY, USA

The U.S. National Consensus Project.

Http://www.nationalconsensusproject.org/positionstatements

Palliative Care Guidelines – National Association Consensus Statements.

Http://www.nationalconsensusproject.org/displaypage.asp?topic=Guidelines&Organize=1

The National Hospice and Palliative Care Organization.

Http://www.nhpco.org/policies/policies.asp

The Agency for Health Care Research and Quality.


Hospices and Palliative Care Nurses Association

Http://www.nhpca.org/positions/positionstatement-palliativefeeding-hydration

American Academy of Hospice and Palliative Medicine.

Http://www.aahpm.org/positionstatements

QUESTIONS?
CONTACT INFORMATION

ROSCHIELE HEUBERGER, PhD, RD
PROFESSOR OF NUTRITION
DIRECTOR OF GRADUATE PROGRAMS IN NUTRITION AND DIETETICS
106A WIGHTMAN HALL
CENTRAL MICHIGAN UNIVERSITY
MT. PLEASANT, MI 48859
EMAIL: heube1ra@cmich.edu
PH: 989-774-2571
FAX: 989-774-2433