Ethical Issues at the End-of-Life

Katherine Wasson, PhD, MPH
Associate Professor
Neiswanger Institute for Bioethics
Stritch School of Medicine
Loyola University Chicago
Why is clinical ethics important?

• Death and Dying in Western Society
  • Death = taboo
  • Success of Medicine

• Death is Institutionalized

• Rise of Technology
  • Resist death at all costs?
  • Technological Imperative

• Differing Values --- conflict?
Why is clinical ethics important?

• High Expectations for all
  • Cure vs. Care
  • Death = failure
  • People fear disease, dying process, pain, disability, loss of control
Clinical Ethics Consultation Service

- Ethics Consult: EPIC order or call 708.327.9219
- Levels of Ethics Consultation
  - Clarification or question – usually done by telephone
  - Attend Family Meeting – ethics consultant joins family meeting where ethical issues are present
    - Enters chart note and summary of meeting
  - “Full” Ethics Consultation – ethics consultant facilitates the meeting with patient, family, health care team
    - Enters chart note and makes recommendations
- Ethics committee - retrospective reviews monthly
## Review of Ethics Consultation Cases 2008-2013

<table>
<thead>
<tr>
<th>Mean age (Range) N=156</th>
<th>53.3 (0-98)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age in years – no. (%) N=156</strong></td>
<td></td>
</tr>
<tr>
<td>≤1</td>
<td>7 (4.5)</td>
</tr>
<tr>
<td>2-18</td>
<td>8 (5.1)</td>
</tr>
<tr>
<td>19-49</td>
<td>43 (27.6)</td>
</tr>
<tr>
<td>50-69</td>
<td>60 (38.5)</td>
</tr>
<tr>
<td>≥70</td>
<td>38 (24.4)</td>
</tr>
<tr>
<td><strong>Male sex – no. (%) N=156</strong></td>
<td>87 (55.8)</td>
</tr>
<tr>
<td><strong>Race – no. (%) N=156</strong></td>
<td></td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>4 (2.6)</td>
</tr>
<tr>
<td>White</td>
<td>89 (57.1)</td>
</tr>
<tr>
<td>Black</td>
<td>43 (27.6)</td>
</tr>
<tr>
<td>Other/Unknown</td>
<td>20 (12.8)</td>
</tr>
<tr>
<td><strong>Ethnicity — no. (%) N=156</strong></td>
<td></td>
</tr>
<tr>
<td>Hispanic Origin</td>
<td>20 (12.8)</td>
</tr>
<tr>
<td>Non-Hispanic Origin</td>
<td>134 (85.9)</td>
</tr>
<tr>
<td>Unknown</td>
<td>2 (1.3)</td>
</tr>
<tr>
<td><strong>Religion — no. (%) N=156</strong></td>
<td></td>
</tr>
<tr>
<td>Roman Catholic</td>
<td>68 (43.6)</td>
</tr>
<tr>
<td>Non-Catholic Christian</td>
<td>56 (35.9)</td>
</tr>
<tr>
<td>None/No Affiliation</td>
<td>15 (9.6)</td>
</tr>
<tr>
<td>Other</td>
<td>17 (10.3)</td>
</tr>
</tbody>
</table>
## Frequency of Ethical Issues at LUHS 2008-13 (N=156)

<table>
<thead>
<tr>
<th>Ethical Issues</th>
<th>Frequency N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Capacity</td>
<td>89 (57.1)</td>
</tr>
<tr>
<td>Patient’s wishes/Autonomy</td>
<td>85 (54.5)</td>
</tr>
<tr>
<td>Surrogate Decision Maker</td>
<td>80 (51.3)</td>
</tr>
<tr>
<td>Withholding/Withdrawing</td>
<td>67 (42.9)</td>
</tr>
<tr>
<td>Comfort/Palliative Care</td>
<td>67 (42.9)</td>
</tr>
<tr>
<td>DNR/Resuscitation Issues</td>
<td>65 (41.7)</td>
</tr>
<tr>
<td>Benefits &amp; Burdens/Harms</td>
<td>62 (39.7)</td>
</tr>
<tr>
<td>Advanced Directives/POA</td>
<td>53 (34.0)</td>
</tr>
<tr>
<td>Discharge</td>
<td>42 (26.9)</td>
</tr>
<tr>
<td>Legal/Regulatory</td>
<td>41 (26.3)</td>
</tr>
</tbody>
</table>

Wasson et al 2015
Ethical Issues at the End of Life

- Surrogate decision making
- Advanced Directives
- Withholding and Withdrawing
- Goals of Care and Futility
- Physician Assisted Suicide
Case Study

- 50 y/o female with a history of gastric bypass surgery 7 years ago
  - Multiple complications
- Surgery 4 mo ago and still has “ostomy” bag and open wound
- Can eat only small amounts, in pain
Case Study

- Admitted to hospital for infection
- Discussed w/ physician she wanted to have a DNR Order (Do Not Resuscitate Order)
- Infection becomes more serious, intubated
- Unable to communicate regularly
- Team treats with multiple antibiotics, infections begins to improve
Case Study

- Family begins to say “she would not want to live like this” and “It’s time to let her go”
- Team believes further surgery can help
- Family disagrees – mother, aunt, uncle and cousin
  - Two adult children are not present
- Ethics consultation is called

- What are the ethical issues?
- What should the ethics consultant do?
Surrogate Decision Making

- Gold Standard = obtaining wishes directly from patient with decision making capacity

- If not possible, then ethically appropriate decision maker should be identified
  - POA for Healthcare
  - Surrogate decision maker
Surrogate Decision-Making

• Advanced Directives
  • Durable Power of Attorney for Healthcare – patient appoints a person to make decisions for her when unable to speak for herself
    • Legally documented
    • Request documents for chart
  • Living Will – document which outlines patient’s wishes regarding end-of-life decisions
    • Gives instruction or indication of patient’s wishes, i.e. “do everything” or “let me go”
Surrogate Decision-Making

- Illinois Healthcare Surrogate Act: Qualifying Conditions for withdrawal of LST
  - Terminal condition
  - Permanent unconsciousness
  - Incurable or irreversible condition

- Surrogate Decision-Makers
  - Guardian, spouse, adult child, parent, adult sibling, adult grandchild, close friend, guardian of estate

- Other states – unspecified order of surrogates, next of kin, consensus
Surrogate Decision-Making

• **Substituted Judgment Standard**
  • Incompetent patient cannot express his/her wishes
  • What would the patient want in this circumstance?
  • **Not** – What does surrogate want for the patient?

• **Best interests Standard**
  • Incompetent patient with unknown preferences
  • Surrogate should determine highest net benefit of options given patient’s known wishes, values
  • Assess risks/burdens/benefits

Beauchamp and Childress 2013, pp. 226-29
Withholding/Withdrawing LST

• AMA – no ethical distinction
  • EOL dialysis, artificial feeding/hydration, ventilator

• Withdrawing
  • Rationale: Why at this point?
    • Burdens vs. benefits
    • Patient/family choice
    • Professional/clinical assessment: short and long term
Withholding/Withdrawing LST

• Act vs. Omission Debate
  • May *feel* different to families or healthcare practitioners
  • Ethical reasoning: burdens vs. benefits, patient’s wishes, surrogate

• Stop vs. not start
  • May need to start to see if patient improves
  • Time-limited trial
Ethical and Religious Directives for Catholic Health Care Services

• 56. A person has a moral obligation to use ordinary or proportionate means of preserving his/her life. Proportionate means are those that in the judgment of the patient offer a reasonable hope of benefit and do not entail an excessive burden or impose excessive expense on the family or community.

• 57. A person may forgo extraordinary or disproportionate means of preserving life. Disproportionate means are those that in the patient’s judgment do not offer a reasonable hope of benefit or entail an excessive burden, or impose excessive expense on the family or community.
Case Study

- Mother tested positive for illegal substance
  - Documented substance abuse

- Orthopedic spinal surgery to stabilize the spine was discussed initially, but now surgeon does not think it will provide any benefit
  - Family still want it
Case Study

- 35 y/o female and 4 y/o male admitted to ED after car accident where mother was driving
- Mother has broken leg and arm
- Son has fractured spine, comatose (possible PVS), ventilated
- Extremely poor prognosis
Case Study

- Mother and grandmother want surgery and all aggressive measures
  - Feeding tube and tracheotomy
- Other family members argue for withdrawal based on the “extremely poor prognosis”
- Surgeon strongly believes that spinal surgery presents risks and no benefit
Case Study

• Health care team is divided – most think he will not recover while some think it is too early to determine his prognosis.
• Some express suspicion and frustration stating the mother is unfit, protecting herself legally, and should not be making decisions for the son.

• What should the ethics consultant recommend?
What are the Goals of Care?

• Quality vs quantity of life
• Benefits vs burdens
• Short and long term goals
• Hopes and expectations
Case Study

• Mr. Mendez 82 y/o man
• CHF, Type 2 diabetes, declining kidney function, sepsis, UTI
• Admitted from nursing home
• Daughter, Maria, claims to be POAHC
• 3 other male siblings
• Mr. Mendez agreed to DNR upon admission
• Maria rescinded it
Case Study

• Maria rescinded DNR, requests more consults from cardiology and renal
• Friend also present with Maria pressing for further interventions
• Clinical team indicates Mr. Mendez is dying
• Want to withdraw interventions (not care)
• Maria does not agree
Case Study

• Who is the appropriate decision maker?
• How should the team approach the DNR order? Other current interventions?
• What ethical issues should be addressed?
Considerations of Futility

• “Futility” = “...used to describe any effort to achieve a result that is possible but that reasoning or experience suggests is highly improbable and that cannot be systematically produced.”

• Quantitative vs. Qualitative
• Shift to “Potentially Inappropriate Treatment”
  • ATS/AACN/ACCP/ESICM/SCCM


Schneidermann et al 1990
Futility

• Merriam Webster – “useless act or gesture”

• Medical Futility
  • Physician judges that in last 100 cases treatment has been useless (less than 1% chance of success)
  • ‘Effect’ of treatment = limited to one part of the body
  • ‘Benefit’ = improves patient as a whole
  • Schneidermann et al 1990

• AMA Code of Medical Ethics opinion on futile care: “Physicians are not ethically obligated to deliver care that, in their best professional judgment, will not have a reasonable chance of benefiting their patients. Patients should not be given treatments simply because they demand them.”
Medically Futile Resuscitation

“Physicians are not obliged to initiate or continue medically useless resuscitation. When death is imminent for a terminally ill patient, or it is clear that resuscitation efforts will not be effective in resuscitating the patient, resuscitation can be omitted. The family should be informed that resuscitation would be ineffective and will not be considered owing to the burdens it would impose on the patient without any expectation of medical benefit. The consent of the family is not needed for the attending physician to discontinue or withhold resuscitation that is deemed to be medically futile. Medically futile resuscitation does not include treatment that is provided for a patient’s comfort, care, or alleviation of pain. This decision should be documented by the Physician in the patient medical record.” [#RES-005]
End-of-Life Issues and Wider Society
Physician Assisted Suicide (PAS) and Euthanasia

• Euthanasia = “mercy killing”
• PAS = physician provides drugs, patient takes them
  • Legal in CA, OR, VT, WA, DC, HI, MT*
  • Oregon was first 1997 (Death with Dignity Act)
  • 38 states have laws prohibiting assisted suicide
Physician Assisted Suicide

• Arguments For

• Arguments Against
Physician Assisted Suicide

• Arguments For
  • Individual Autonomy
  • Dignity
  • Compassion

• Arguments Against
  • Sanctity of Life
  • Common Good/Harm
  • Palliative Care
60. Euthanasia is an action or omission that of itself or by intention causes death in order to alleviate suffering. Catholic health care institutions may never condone or participate in euthanasia or assisted suicide in any way. Dying patients who request euthanasia should receive loving care, psychological and spiritual support, and appropriate remedies for pain and other symptoms so that they can live with dignity until the time of natural death.
Approaches to Ethical Decision-Making

- Principles
- Consequences
- Virtue Theory
- Other

What approach do you take to decision making?
- Is it consistent?
Summary

- Ethical decisions at the end of life are common and often complex
- Try to determine patient’s wishes, values, choices
- Help surrogate and families process information, identify ethical issues, options for ways forward
- Give them time to consider

- What approach do you take to decision making?
  - Is it consistent?