Ethical Issues in End-of-Life Care of the Cancer Patient

Michel Daher, MD, FACS
President, Lebanese Society for General Surgery
President, Lebanese Cancer Society
Professor of Surgery, University of Balamand
Director, Medical Ethics Teaching Program, University of Balamand
Saint George Hospital, Beirut - Lebanon

UOB - March 2008
Objectives...

1) Define major ethical principles that are relevant to care at the end of life.
2) Understand the principle of Autonomy and its application to advanced directives, informed consent, and medical futility.
3) Understand the differences between withholding/withdrawing care and physician-assisted death.
Objectives

• 4) Be able to apply the principle of “double effect” and the other major ethical principles in the care of patients.

• 5) Be able to discuss the ethical reasons for integrating palliative care with acute care for the critically ill patient.
How people died in the past . . .

• Early 1900s
  - average life expectancy 50 years
  - childhood mortality high
  - People died quickly
    • infectious disease
    • accidents

• Medicine focused on caring, comfort

• Sick cared for at home
  - with cultural variations
End of life today

• Modern health care
  – only a few cures
  – live much longer with chronic illness
  – dying process also prolonged
Sudden death, unexpected cause...

- < 10%, MI, accident, etc
Protracted life-threatening illness..

- > 90%
  - predictable steady decline with a relatively short “terminal” phase
    - Cancer..
  - slow decline punctuated by periodic crises
    - CHF, emphysema, Alzheimer’s-type dementia..
Steady decline, short terminal phase
Slow decline, periodic crises, sudden death
Potential goals of care

- Cure of disease
- Avoidance of premature death
- Maintenance or improvement in function
- Prolongation of life
- Relief of suffering
- Quality of life
- Staying in control
- A good death
- Support for families and loved ones
Balancing Benefit and Burden

**Benefit**
- Longer life
- Comfort
- Relationships
- Community
- Communication
- etc.

**Burden**
- Pain
- Suffering
- Technology dependency
- Isolation
- Immobility
- etc.
Ethics and End-of-Life Care

Major Principles...

- **Nonmaleficence** - Hippocratic principle, “first do no harm”
- **Beneficence** - a duty to do good (not just avoid harm)
- **Autonomy** - the recognition of the right of self-determination, establishing one’s own goals of care
- **Justice** - the equitable distribution of often limited healthcare resources
Informed Consent

• A competent patient should agree with the plan of care.

• Providers are under no ethical obligation to provide futile treatment(s); however futility is in the eye of the beholder.

• Tell the truth. Patients have the right to know or refuse to know.
Pain Relief in Cancer

The size of the problem:

Every year:
- 7 M new cancer cases
- 5 M die from cancer
- 4 M have pain
- 2 M does not have adequate pain relief
Pain Is...

- "An unpleasant sensory and emotional experience associated with actual or potential tissue damage" (IASP)

- "What the person says it is..." (McCaffery)
Barriers to Pain Relief

• Importance of discussing barriers
• Specific barriers
  • Professionals
    • Poor assessment
    • Lack of knowledge
  • Health care systems
    • Regulatory oversight
  • Patients
    • Fear of addiction
    • Tolerance
    • Adverse effects
Patients at Risk for Undertreatment

- Children and elderly
- Cognitively impaired
- Patients who deny pain
- Different cultures
- History of substance abuse
- Uninsured and poor
Dimensions of suffering...

- Physical
- Spiritual
- Affective
- Cognitive
- Existential
Symptoms, suffering . . .

• Multiple physical symptoms
  – pain, nausea / vomiting, constipation, breathlessness
  – weight loss, weakness / fatigue, loss of function
Symptoms, suffering

- Psychological distress
  - anxiety, depression,
  - worry, fear,
  - sadness,
  - hopelessness, etc
- 40% worry about “being a burden”
Spiritual suffering

- Existential concerns
- Meaning, value, purpose in life
- Abandoned, punished by God
  - questions faith, religious beliefs
  - anger
Conclusion on Pain Relief

• Pain relief is contingent on adequate assessment and use of both drug and non-drug therapies
• Pain extends beyond physical causes to other causes of suffering and existential distress
• Interdisciplinary care
Balancing Benefit and Burden

**Benefit**
- Longer life
- Comfort
- Relationships
- Community
- Communication
- etc.

**Burden**
- Pain
- Suffering
- Technology dependency
- Isolation
- Immobility
- etc.
Place of death . . .

- 90% of respondents to NHO Gallup survey want to die at home
- Death in institutions
  - 1949 – 50% of deaths
  - 1958 – 61%
  - 1980 to present – 74%
  - 57% hospitals, 17% nursing homes, 20% home, 6% other (1992)
## Gaps between reality and desire

<table>
<thead>
<tr>
<th>Fears</th>
<th>Desires</th>
</tr>
</thead>
<tbody>
<tr>
<td>Die on a machine</td>
<td>Die not on a ventilator</td>
</tr>
<tr>
<td>Die in discomfort</td>
<td>Die in comfort</td>
</tr>
<tr>
<td>Be a burden</td>
<td>Die with family / friends</td>
</tr>
<tr>
<td>Die in institution</td>
<td>Die at home</td>
</tr>
</tbody>
</table>
Ethical Dilemmas - Examples

- Withholding/Withdrawing Treatment
  - Balance of benefit vs burden
- Do Not Attempt Resuscitation
  - Written MD order required
- Aggressive pain management, as a manifestation of the “double effect”.
  “Last Dose Syndrome”
The Principle of “Double Effect”

- A treatment (e.g., opioid administration in the terminally ill) that is intended to do good and not harm the patient (i.e., relieve pain) is ethically acceptable even if a potential consequence of its administration is to shorten the life of the patient (e.g., by respiratory depression).
Ethical Dilemmas - Examples (Cont.)

• **Assisted Suicide**
  
  physician provides
  
  the means, patient acts

• **Euthanasia**
  
  act by which the causative agent of death is administered by another with the intent to end life
  
  Requests are a sign of patient crisis
Why patients ask for PAS...

Asking for help

- Physical suffering: Inadequately treated physical symptoms (e.g., pain)
- Untreated clinical depression
- Fear of loss of control (autonomy)
- Fear of being a burden
- Existential/spiritual distress
Inherent conflict of interest for physicians

• Physicians cannot be trusted advocates for the life/health of their patients if they also may be the means of terminating that same life.

• With rising health care costs (particularly at the end of life), the pressure for more “cost effective” solutions (e.g., physician-assisted death) will mount.

• Physician-assisted death is in direct conflict with the Hippocratic oath and tradition.
The legal and ethical debate . . .

- Principles
  - obligation to relieve pain and suffering
  - respect decisions to forgo life-sustaining treatment
- No right to PAS
- Right to palliative care
Ethical

- “Physicians have an obligation to relieve pain and suffering and to promote the dignity and autonomy of dying patients in their care.

This include providing effective palliative treatment even thought it may foreseeably hasten death”.

Code of Medical Ethics
“The reason also support the distinction between assistance to suicide, which is banned, and practices such as termination of artificial life support and death-hastening pain medication, which are permitted”
When Ethical Dilemmas Occur..

- Physicians as advocate to insure understanding of options, clarification of preferences/values, communication with care team
- Ethics Committee involvement
Making good palliative care is the best defense of all...
Palliative Care: Definition

• “The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families…”

(WHO 1990)
Palliative care – expanded definition

- Affirms life, regards dying as a normal process
- Neither hastens nor postpones death
- Provides relief from pain, other symptoms
- Integrates psychological and spiritual care
- Interdisciplinary team
- Support system for the family

WHO 1990
Palliative care

- Not the absence of care
- More powerful than ever in the history of medicine
- A positive, humanistic philosophy
- Technically sophisticated area of expertise
Everyone must work to live, but the purpose of life is to serve and to show compassion and the will to help others. Only then have we ourselves become true human beings.

Albert Schweitzer
"We can have limits for CURE but there is no limit for CARE."
To cure sometimes
To relieve often
To comfort always

Anonymous 16th century aphorism
Palliative care

• Relieving suffering
• Improving quality of life

*Pain Relief and Palliative Care Group under the auspices of the Lebanese Cancer Society*