A Fresh Look at the Professional Consensus on the Ethics of End of Life Care
What Good Can Ethics Guidelines Do?

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How We Die and the American System of End of Life Care
Managing Our Miracles

• Development of intensive and critical care medicine and life-extending technologies in the 1960s
• “Half-way” technologies (L. Thomas)—greater capacity to prolong biological life functions than to prolong the quality of life
• Not death, but the specific timing and manner of death, became an artifact of explicit decision and choice
• Loss of continuity of care through medical sub-specialization
Sub-specialization and Technology
End of Life Care as a Ethical Issue

End of life care in America today is characterized by:

• Poor quality of medical decisionmaking leading to:
  – violation of individual rights
  – inadequate relief of pain and suffering
  – expensive and dehumanizing overuse of life-sustaining medical technology
  – misallocation of health care resources
  – family burden and avoidable illness

• Restricted access to alternative systems of professional care (hospice and palliative care)

• Lack of social capital and resiliency in community capacity to provide a supportive environment for dying individuals and their families and caregivers
## How Americans Die: A Century of Change

<table>
<thead>
<tr>
<th></th>
<th>1900</th>
<th>2000</th>
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<tbody>
<tr>
<td><strong>Age at death</strong></td>
<td>46 years</td>
<td>78 years</td>
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<tr>
<td><strong>Top Causes</strong></td>
<td>Infection, Accident, Childbirth</td>
<td>Cancer, Organ system failure, Stroke/Dementia</td>
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<tr>
<td><strong>Disability</strong></td>
<td>Not much</td>
<td>2-4 yrs before death</td>
</tr>
<tr>
<td><strong>Financing</strong></td>
<td>Private, modest</td>
<td>Public and substantial- 83% in Medicare, ~½ of women die in Medicaid</td>
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What We Die Of

1. Diseases of heart
2. Malignant neoplasms
3. Chronic lower respiratory diseases
4. Cerebrovascular diseases
5. Accidents (unintentional injuries)
6. Alzheimer’s disease
7. Diabetes mellitus
8. Influenza and pneumonia
9. Nephritis, nephrotic syndrome and nephrosis
10. Intentional self-harm (suicide)

Life expectancy:
Women: 80.2 years  Men: 75.7 years
Source: CDC, National Center for Health Statistics (preliminary 2009 data)
Social Epidemiology of End of Life Care

• 90% of Americans die from chronic, progressive, incurable illnesses

• Patients have high burden of illness
  – Poorly controlled symptoms
  – Psychiatric disorders and psychosocial and spiritual distress
  – Concrete needs in the home
  – Challenges in care coordination, communication, decision making, goal setting
  – Caregiver burden and financial stress
  – Fear about managing the period of active dying
Health Status of the Population
(a conceptual model)

Source: J. Lynn

Healthy

Need acute and preventive care

Chronic Illness consistent with usual role – need acute and preventive care

Chronic, progressive, eventually fatal illness
Need variety of services and priorities
1-2% <65 yo, 5-10% >65 yo
Divisions by Health Status, in the Population and Among Persons with Eventually Fatal Chronic Illness

Source: J. Lynn

Healthy

Chronic, consistent with usual role

Chronic, progressive, eventually fatal illness

A

Cancer

Function

Time

Death

B

Organ System Failure

Function

Time

Death

C

Dementia/Frailty

Function

Time

Death
Quality assessment research on End of Life Care

- After death telephone survey (N=1578 decedents)
- Results
  - About 1/4 reported concerns with physician communication
  - About 1/4 with pain or dyspnea did not receive adequate treatment
  - Insufficient emotional support reported by 1/3 of those cared for by a home health agency, nursing home, or hospital
  - Family satisfaction “excellent”: 50% of those in institutions, 70.7% receiving hospice

(Source: Teno et al, JAMA, 2004)
End of Life care from a health systems standpoint

• The current system of care:
  – Does not adequately address suffering and illness burden of a significant proportion of patients or families despite very high cost
  – Is highly variable, fragmented, and technological, and may increase the potential for inappropriate or unnecessary therapy
  – Has significant disparities in care related to SES, insurance, minority status, cultural differences
The Hastings Center Guidelines

The 1987 Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying, commonly known as the “Hastings Center Guidelines,” broke new ground in end-of-life care. (Cited in Cruzan decision.)

From 2007-2012, we completed a comprehensive review and revision of the 1987 Guidelines to reflect 25 subsequent years of research, innovation, legal and policy developments, and consensus and debates on treatment decision-making and the delivery of good care near the end of life.
Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life (forthcoming Oxford University Press 2013) ©The Hastings Center 2012
Ethical, legal, medical consensus on end of life decisionmaking

Patients with decision-making capacity have a common law and a constitutional right to refuse medical treatment.

Patients who lack decision-making capacity have these same legal rights, exercised through a surrogate.

The basic right to refuse treatment does not depend on prognosis or projected life expectancy.

Withholding (not starting) and withdrawing (stopping) life-sustaining treatment are both forms of forgoing treatment.
Ethical, legal, medical consensus on end of life decisionmaking

No treatment or form of care is intrinsically “ordinary” or “extraordinary.”

Palliative care is integral to good health care.

It is ethically acceptable to properly administer medication to control pain and symptoms even in the rare situation in which this may hasten death.

Forgoing life-sustaining treatment is ethically and legally distinct from suicide, euthanasia, and physician-assisted suicide.
Surrogate decision-making standards

When a patient lacks decision-making capacity, surrogate decision-making follows this sequential order of priority:

1) Patient’s directions: Follow the patient’s explicit treatment directives or other instructions, written or oral.
2) Substituted judgment: If there are no directions allowing the use of the first standard, a surrogate bases decisions on the patient’s own preferences and values, as best they can be inferred from knowledge of and experience with the patient.
3) Best interests: If there are no explicit directions from the patient and the surrogate lacks enough information to use the second standard, the surrogate should choose the treatment option that will be in the patient’s best interests in light of the patient’s diagnosis, prognosis, and treatment options. This sometimes described as choosing what a “reasonable person” would choose if in a situation identical to that of the incapacitated patient.
Why do ethical challenges arise near the end of life?

“The medical environment is very hostile to ambivalence. The legal environment assumes ambivalence doesn’t exist. Public policy assumes you know you want A, B, and C – but everybody’s ambivalent when you get to this point.”

“Somebody is suffering. Somebody else doesn’t know how to make the right decisions about how to relieve this suffering.”

“There is conflict.”
Who uses ethics guidelines?

The new edition of *The Hastings Center Guidelines* is written for:

- Professionals responsible for the care of patients facing decisions about life-sustaining treatment and/or patients who are near the end of life
- Judges and health lawyers and others involved in organizational policymaking
- Leaders of health care organizations providing LST and/or EOL care
- Professional societies in medicine, nursing, social work, chaplaincy, mental health, etc. in the US, other nations
- Journalists, advocates, and others who follow these issues
How can ethics guidelines help?

• Ethics guidelines give clinicians, clinical educators, and organizational policymakers a resource to turn to in uncertain and distressing situations, when “the right thing to do” is unclear.

• They articulate the values that constitute good care.

• They recommend practices and policies that can advance this vision, with reference to evidence and consensus.

• They stay close to bedside realities, and to the needs of good professionals working in flawed systems.
Part One

Part One presents the framework and context for these Guidelines, including the goals of care near the end of life, skills-based ethics competencies for health care professionals, the organizational systems that support good end-of-life care, and social, economic, and legal contexts.
Part Two

Part Two including specific guidelines on:

- the determination of decisionmaking capacity
- advance care planning
- assessing benefit and burden in treatment decisions involving many different types of life-prolonging technology and intervention
- special considerations in pediatric end of life care
- care transitions and institutional transfers
- the determination of death
- institutional policy relating to protocols and cost-containment issues.
Part Three

• Part Three supports implementation of guidelines with additional material on the substance and process of communication in end-of-life care.
Ethics goals for good end-of-life care

- Relieve suffering
- Respect both living and dying
- Promote well-being
- Respect persons
- Respect dignity
- Respect relationships
- Respect difference
- Promote equity
- Preserve professional ethical integrity
- Use organizational systems to support good care and ethical practice
Competencies in end of life care
(Doing right by doing these things well)

• Know the outcomes data on EOL interventions.
• Integrate pain and symptom management into plans.
• Elicit patients’ preferences, establish goals of care, and develop and document care plans.
• Collaborate with patients, surrogates, and loved ones.
• Collaborate with other professionals.
• Recognize common causes of distress.
• Recognize, prevent, and resolve/manage conflict.
• Recognize and correct legal myths.
• Develop capacity for personal and ethical reflection.
Communication: key topics

• Family conferences
• Disagreements among loved ones
• Discussing nutrition and hydration
• Life-sustaining treatment and disabilities
• Communication when a disability affects speech, cognition, or both
• Psychological dimensions of EOL care affecting patients, loved ones, and professionals
• Decision-making concerning specific treatments
• Discussing resource allocation and cost of care
From Decisions to Systems

• If the hospital was once a place of too little choice, lack of transparency, and bald paternalism, in recent years the pendulum has swung to the other extreme, and patients and families are now presented with an excessive menu of complex—always difficult, often bewildering—clinical choices. At an extremely vulnerable time for them, and with little training or support, our system requires people to micromanage a confusing and emotionally explosive set of clinical responses to a recurring series of life-threatening complications within an underlying progressively degenerative and incurable chronic disease. Instead of focusing on how to accommodate the idiosyncratic decisions of individual patient, as it were, one at a time, we should ask what types of needs do dying persons generally have, and how can we design a health care delivery system that will meet most of those needs for most people, most of the time.
The Guidelines’ perspective on hospice and palliative care

• Palliative care is integrated with treatment (not limited to withdrawal of treatment; not incompatible with ongoing life-sustaining treatment).

• Improved communication and access to palliative care and hospice care are needed.

• Attention to challenging topics (palliative sedation, PAS)

• Improve collaboration between hospice programs and specialized medical providers (better referral; improved continuity of care)
The Public Health Dimensions of End of Life Care Guidelines

- Aging societies: How should care for people facing decisions about LST and people near the EOL be organized and financed? How can preventable harms be avoided?

- Primary care and other community-based professionals caring for Medicare-eligible patients: How should advance care planning and treatment decision-making be integrated into these settings?

- Community health centers and chronically ill vulnerable populations: How should safety-net providers collaborate to care for patients with life-threatening conditions and socioeconomic barriers to obtaining potentially beneficial care?
Thank you.
I close with the thought that death is not the worst thing, dying badly is. And while dying is an inevitable part of the human condition, dying badly is not; it is a correctable ethical and system failure.