

New Horizons in End of Life and Palliative Care Ethics

Bruce Jennings
The Hastings Center
Yale University School of Public Health

*Beth Israel Medical Center
Department of Pain Medicine and Palliative Care
New York, NY
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I have no conflicts of interest to disclose
(wish I did).

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On Facts and Beliefs

“Facts do not find their way into the world in which our beliefs reside; they did not produce our beliefs, they do not destroy them; they may inflict on them the most constant refutations without weakening them, and an avalanche of afflictions or ailments succeeding one another without interruption in a family will not make it doubt the goodness of its God or the talent of its doctor.”

--Marcel Proust

Objectives

- Review Ethical/Legal Framework for end of life decisionmaking and care
- Identify unresolved problems in applying the framework in clinical settings
- Discuss possible future approaches to improving end of life care for patients and families

Part one

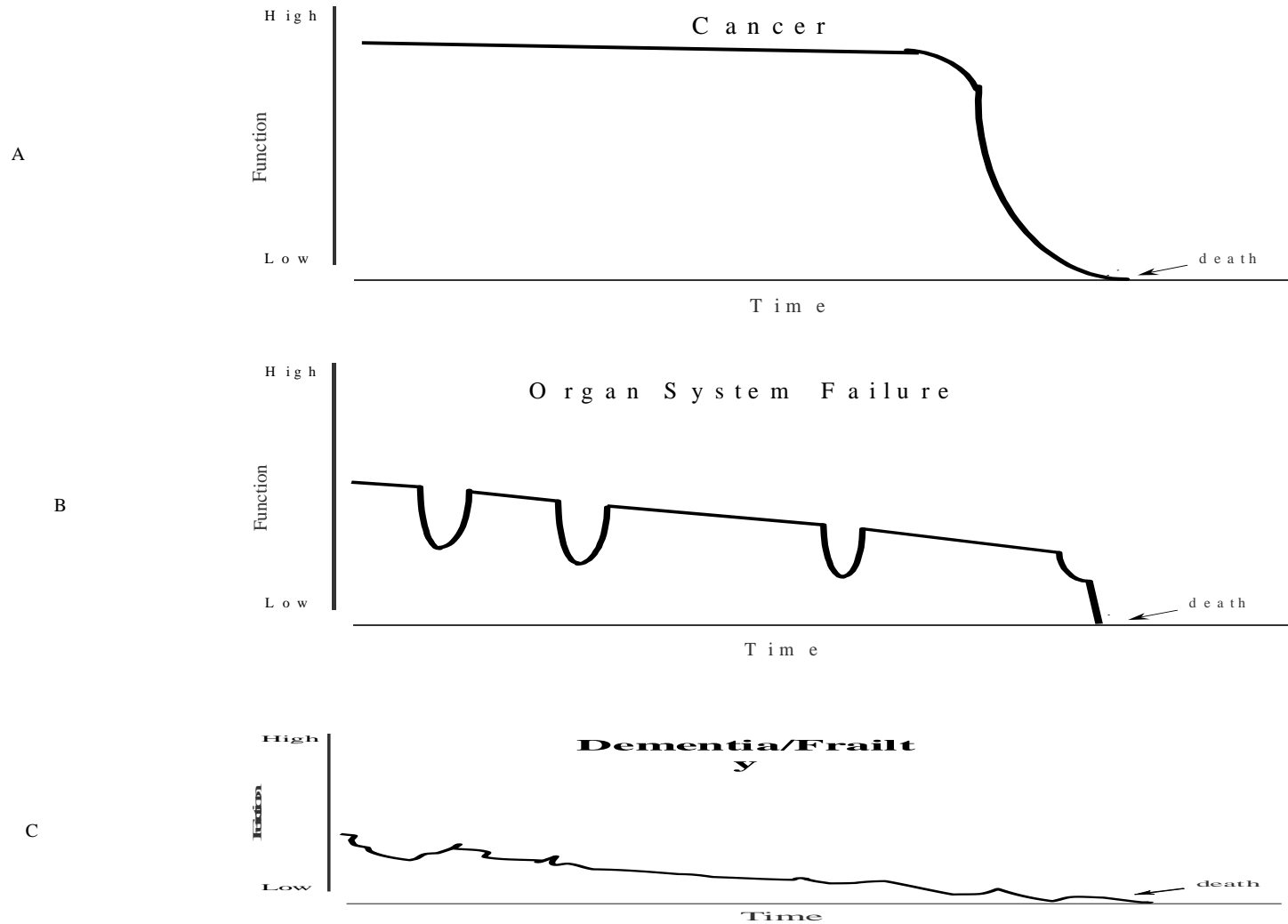
The Ethical-Legal Framework

1975-1990

Quinlan to Cruzan

General Trajectories of Function over Time in Eventually Fatal Chronic Illnesses

Source: Joanne Lynn in Jennings, et al 2005



Legal Framework General Principles

- **Persons with decisionmaking capacity** have a common law and a Constitutional right to refuse treatment.
- **Incapacitated patients** have the same rights as competent patients; however, the manner in which these rights are exercised is different.
- The right to refuse life-sustaining medical treatment does **not** depend on the patient's length of life expectancy or being "terminally ill."
- There is no ethical difference between **withholding or withdrawing** life-sustaining medical treatment.

Quinlan to Cruzan

Legal Framework Decision-Making Process

- The decisionmaking process should generally occur in the clinical setting **without recourse to the courts.**
- The best arrangement is for the person to authorize someone (an “agent”) in advance to make medical decisions should the person lose capacity. The legal instrument for doing so is a durable power of attorney for health care (health care proxy). An advance treatment directive (living will) is also a legal document in most states.
- In making decisions for incompetent patients, surrogate decisionmakers should apply the following standards (in order):
 - **Subjective standard (follow the patient’s treatment directive)**
 - **Substituted judgment test (do what you can infer the pt would want done)**
 - **Best interest test (do what the hypothetical “reasonable person” would want under the circumstances)**
 - **None of these = do what the agent wants done**

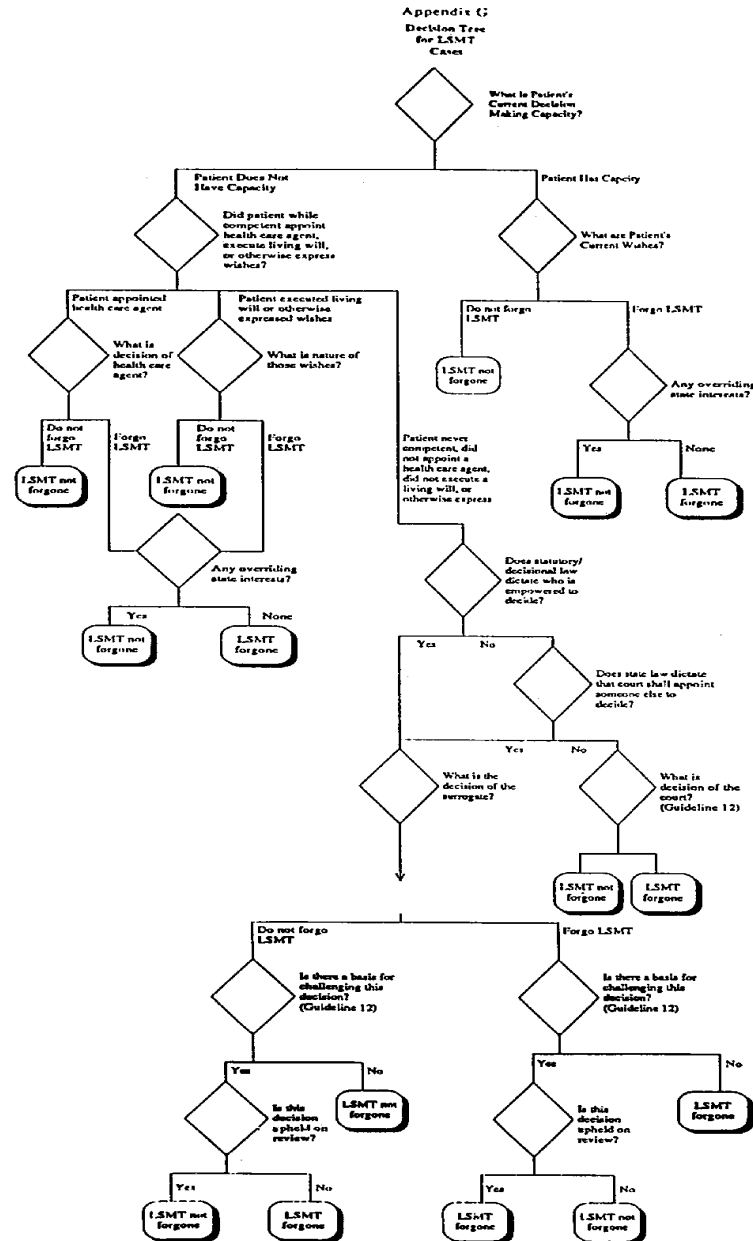
Quinlan to Cruzan

Legal/Ethical/Professional Consensus
Pain Management & Hastening Death

- Artificial nutrition and hydration is a medical treatment and may be withheld or withdrawn under the same conditions as any other form of medical treatment.
- It is acceptable to provide pain medication sufficient to control a patient's pain even if that may **foreseeably** hasten the patient's death.
- Active euthanasia and assisted suicide are morally and legally distinct from forgoing life-sustaining treatment. **Refusing life-sustaining treatment is not the same as committing suicide; honoring such a refusal is not the same as assisting suicide.**

Sample Decision Tree: End of Life Decisionmaking

[Source: National Center for State Courts 1993]



Part two

Practical Problems in Applying the
Framework
1990-2008

Problems with the Framework: Advance Directives

- Limited use of Advance Directives—**Particularly Living Wills**
 - Too vague when they are done.
 - Too often not done at all:
 - **Reason:** The Scarlet O’Hara Syndrome: “I won’t think about it today. I’ll go crazy if I do. I’ll think about it tomorrow.”
 - **Result:** The Blanche DuBois Syndrome: “I have always depended on the kindness of strangers.”
 - Even if done, they are not followed.
 - Physician compliance as a Field of (Bad) Dreams- “If you build it, they still won’t come.”
- We have failed to integrate advance directives into more comprehensive advance care planning and case management.

Problems with the Framework: Futility

- Proving too much: the right to refuse and the right to demand
- The problem with families
- Technical expertise vs. ethical professionalism
- Justice and the allocation of scarce resources

Problems with the Framework: Cultural Diversity

- Protecting rights vs. respecting diversity
- Universal ethics or WASP/middle class bias?
- What is rational?
- What is autonomy?
- Is there a right not to plan?
- Mistrust and the underserved

See Leslie J. Blackhall, Sheila T. Murphy, Gelya Frank, Vicki Michel, and Stanley Azen, "Ethnicity and Attitudes toward Patient Autonomy," Journal of the American Medical Association, 274: 10 (1995), 820-25.

Problems with the Framework: The Right to Life Movement

- Legacy of the abortion controversy
- Seeing end of life care as a part of a broader agenda of cultural and religious revitalization— “The Culture of Death”
- Original intent was to create a subjective, person-centered, treatment and quality of life “neutral” decisionmaking process

Problems with the Framework: The Disability Critique

- Lingering questions about the notion of quality of life
- The validity of advance directives imposed by the past, able-bodied self or the present, impaired self
- What kind of burden does life-sustaining treatment impose?
- Symbolic and social messages

Problems with the Framework: Physician Assisted Suicide

- The ambiguities of autonomy or “self-determination”
 - What is the right to refuse treatment a right to, exactly?
 - Being **free from** unwanted bodily invasion vs. **controlling** the circumstances and timing of one’s death.
- PAS in Oregon and Washington and the Netherlands:
 - How far will the legalization movement go?
 - Advance directives? Psychiatric dxs? Children?

Part three

Where Do We Go From Here?
2008--

Further Work is Needed to Correct

- The excessive rationalism of the framework
- The excessive individualism of the framework
- Sources of bias within the framework
- The misdiagnosis of the problem

Excessive Rationalism

- The consensus works best for those who plan ahead for their terminal illness.
- Most Americans find that exceedingly hard to do. The denial of death and the reluctance to engage in advance planning remain strong
- We don't feel comfortable acknowledging limits

Excessive Individualism

- Patient autonomy is the cornerstone, but:
- The end of life is not the best time to wage battles on behalf of autonomy.
- Caring, family, mutual respect and love, and attentiveness to the dying person are the qualities most needed then.
- Our consensus has been rather distrusting of families, and they become empty conduits of the patient's wishes.
- Mothers and fathers, brothers and sisters, relatives lose their names and become "surrogates" or "proxies," appropriately cold terms to denote an impersonal role.

Sources of Bias

- This framework for decisionmaking at the end of life does not travel well across cultures and traditions within our increasingly pluralistic society.
- Is planning and decisionmaking the only or the most appropriate response to the recognition that one is dying?
- Is everyone's first thought a concern to protect the family from being burdened?
- How best to respond to the suspicion, built up over a lifetime of experiencing discrimination that some patients and families bring to end-of-life care?
- Able-bodied perspectives on the quality of disabled living.

From Decisions to Systems

- The fundamental problem with end-of-life care, however, may be structural and institutional in nature.
- Perhaps a countervailing system—one oriented toward palliative and hospice care—needs to be created to give at least one real alternative to patients and families.

Patients' Rights and Hospice Movements Compared: Legal vs. System Approaches

- Roughly the same period: first US Hospice 1973; Quinlan 1976.
- Both grassroots movements growing out of patient and family dissatisfaction with mainstream health care system.
- **Rights approach.** Legal empowerment to protect individual against the technological imperative. Judicial and legislative reform strategies. Institutional education and new decisionmaking mechanisms (consultation teams; ethics committees).
- **Hospice approach.** Alternative model of cancer care to better meet the needs of patients and families who were being abandoned by mainstream treatment systems. Not for profit and volunteer care delivery agencies in the community. Charitable funding until creation of Medicare Hospice Benefit in 1983; increasing professionalization and business orientation since then. Parallel palliative care movement in the 1990s.

Elements (“Cs”) of and End of Life Care System

- It provides the **care**, not necessarily the disease modifying treatment, that most people want, most of the time in the last year (or two) of life.
- It responds to the overall **condition** of the person (not just disease or the symptoms of the patient) —the person in **context**, not the individuated body.
- It provides **continuity** of care and manages transitions well.
- It integrates care giving, **community**, and **culture** (meaning).

Thank you, and remember...

As Proust said, even "...an avalanche of afflictions or ailments in a family will not make it doubt ...the talent of its doctor."

Part four

Ethical Issues in Palliative Care

Definitions of Palliative Care 1

- “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 possible quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with anticancer treatment.”

Source: WHO, *Cancer Pain Relief and Palliative Care* (1990)

Definitions of Palliative Care 2

- “The study and management of patients with active, progressive, far-advanced disease for whom the prognosis is limited and the focus of care is the quality of life.”

Source: D. Doyle, et al, eds. *Oxford Textbook of Palliative Medicine* (1993)

Definitions of Palliative Care 3

- “Comprehensive care, provided by an interdisciplinary team, for patients and families living with a life-threatening or terminal illness, particularly where care is focused on alleviating suffering and promoting quality of life. Major concerns are pain and symptom management, information sharing and advance care planning, psychosocial and spiritual support, and coordination of care, including arranging for excellent services in the community.”

Source: J. Andrew Billings, “What is Palliative Care?” *Journal of Palliative Medicine* 1:1 (1998)

Barriers to Good Care

- Professional Training and Attitudes
- Social Attitudes
- Legal Barriers
- Myths
- Ethical Concerns

Professional Training and Attitudes

- Bifurcating therapeutic and palliative care
- History of hospice
- Palliation as second class medicine
- Research biases and priorities
- Professional status

Social and Cultural Attitudes

- Stigma of narcotics
- Fear of addiction
- Hold out as long as you can (courage)
- Pain don't hurt (stoicism)
- Suffer in silence (patience)
- Self-rationing

Legal Barriers

- Clashing perspectives--the clinical and law enforcement
- Fear of sanction
- Fear of investigation
- Burdensome regulation

Myths in Palliative Care

- Pain is natural
- Palliative care requires no special expertise
- Special assessment techniques are not necessary
- Pain is linear
- The patient will become “addicted”
- Use of high dosage opioids is illegal and is euthanasia
- Treatment should be “as needed”

Barriers to Cancer Pain Management 1

Problems related to health professionals

- Inadequate knowledge of pain management
- Poor assessment
- Concern about use of controlled substances
- Fear of patient addiction
- Concern about side effects of analgesics
- Concern about pts becoming tolerant

Source: Agency for Health Care Policy and Research [now Agency for Healthcare Research and Quality], Clinical Practice Guideline Number 9: Management of Cancer Pain. Rockville, MD: AHCPH Publication No. 94-0592,1994.

Barriers to Cancer Pain Management 2

Problems Related to Patients

Reluctance to report pain

- Fear of distracting physicians from other treatments
- Fear of what pain means
- Desire to be a “good” patient

Reluctance to take pain medications

- Fear of addiction or stigma
- Worries about side effects or tolerance

Barriers to Cancer Pain Management 3

Problems Related to the health care system

- Low priority given to cancer pain treatment
- Inadequate reimbursement
- Restrictive regulation of controlled substances
- Problems of availability and access

Ethical Concerns

- Hastening death and the problem of double effect
- Total sedation
- Consciousness versus comfort
- Family needs versus patient best interest

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