Controversies at the end of life: the ethics of lamentation

Center for Palliative Care
University of Virginia
School of Medicine

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The Nature of Suffering and the Goals of Medicine - Eric J. Cassell

The relief of suffering and the cure of disease must be seen as twin obligations of a medical profession that is truly dedicated to the care of the sick. Physicians’ failure to understand the nature of suffering can result in medical intervention that (though technically adequate) not only fails to relieve suffering but becomes a source of suffering itself.

The voices of moral discourse

- The prophetic voice
- The narrative voice
- The ethical voice
- The policy voice

The prophetic voice

- Language of exhortation and command
  - The prophets of the Hebrew scriptures
  - Martin Luther King, Desmond Tutu, for example
- Seeks not to persuade, but to point to a larger vision, almost always at odds with prevailing cultural sentiments

The narrative voice

- The language of myth, legends, stories
  - foundational or creation stories
  - the history of a culture, or the history of a profession
- The power of the narrative voice lies both in its details, and its universal application
- The power lies in the telling of the story

The ethical voice

- Uses the language of reason, rationality
- Is argumentative
- Is a suasive voice
- Seeks justification for its own position (or criticism of another position) on the basis of internal and external consistency
The policy voice

- The voice of regulations, laws, codes, protocols
  - Example: institutional DNR policies
  - Reimbursement schemes
- Assumes agreement on principles; takes up the regulatory task of implementation

What has been the dominant voice of discourse in end-of-life care?

An historical overview

- Legal
- Ethical
- Clinical protocols

Legal approach

- Predated clinical practice
- Concerns over (at least) two issues:
  - State interest in protecting life
  - Constitutional interest in protecting autonomy
- Presented initially as a problem in conflicting rights

Legal approach

For example:
- Quinlan, 1976
- Brophy, 1980
- Wanglie, 1987
- Cruzan, 1990
- Patient Self-determination Act, 1996

Primary concerns...

- Over permissibility of certain practices
- Documentation and clinical protocols
  - Office of Technology Assessment
  - Living Will Legislation
- Establishing the outer parameters of care
What was missing...

- The actual details of good (best) practices
- We went about with certain assumptions
  » Physician behavior, knowledge, prognostication
  » Patient knowledge, behavior

SUPPORT and the limits of the rational model

- Landmark study (10 years, $28 M)
- Prospective data
- Well-defined population
- Well-established prognostic, policy, legal, ethical criteria
  » Apache III
  » DNR/DNI
  » Advance directives

SUPPORT Results

- No difference between control and study groups
- No difference in secular trends
- No differences in mortality
- A third of patients died in moderate to severe pain
- A third were “coded” against expressed and documented wishes
- A third to one half had no advance directives noted in the chart

Leading Causes of Death: 1997

- Heart disease: 31%
- Malignant neoplasm: 23%
- Cerebrovascular disease: 7.0%
- COPD: 4.7%
- Accidents: 4.1%
- Pneumonia: 3.7%

Account for 75% of all deaths, and there has been no appreciable change in the last 20 years


Issues addressed

- Withdrawal of life-sustaining treatments
- DNR orders
- Hydration and nutrition
- Proxy determinations in PVS
- Treatment futility
- Physician-assisted suicide

Who is dying in the U.S.?

- Median age of death is 77 years.
- Among survivors to age 65, median age at death is 84 for women, and 80 for men.
- In the frail elderly death follows a long period of progressive functional decline and loss of organ reserve accompanied by specific disease processes.
Prognostication and the limits of rationality

- Recent data from Christakis\(^1\) on prognostication on hospice patients
  - Patients already “terminally ill,” less than six months to live
  - Systematic bias in overestimating prognosis

\(^1\)Christakis, N. *A Death Foretold* (2001)

Further limits to rationality

- Prognostic data were confidential, not given to patients
- No difference between “experienced” and “novice” practitioners
- No difference in age, gender, diagnosis
- There was a difference in how long the physician had known the patient
  - The longer the relationship, the likelier the practitioner was to overestimate the amount of time to death

Mrs. A: What is her prognosis?

94 y/o with congestive heart failure, severe peripheral vascular disease, a systolic blood pressure of 100, and shortness of breath at rest or with mild exertion. She is treated judiciously with medications. Is this patient terminally ill?

Mrs. A: What is her prognosis?

Not an interesting question

- What if Mrs. A were 54, instead of 94?
- What if Ms. A were 5 or 4 years old?
- What if Mr. A were 40, and were the sole breadwinner, and had three small children, and a wife who was physically disabled?

Moral discourse and the nature of lamentation

Lament:

(v): to feel or express deep sorrow for . . .

(n): an outward expression of sorrow; lamentation; wail

Moral discourse and the nature of lamentation

- The voice of lamentation is distinct from (but not opposed to) the rational, ethical, legal, policy voice
- The power of lamentation lies both in its details, and its universal application
- The power lies in the telling of the story
Lamentations

- The story is told in non-technical, lay language
  - The voice of the subject, or narrator, is critical
  - The details, however idiosyncratic, are important
- Examples of life reviews in hospice patients, for instance

The narratives of lamentation

- The experience or the meaning of the experience takes precedent over the disease
  - What did I feel? I died when they told me I had cancer
  - What did I know? What is a malignancy, anyway?
  - How did I change? Everyone dies; I just had to face the fact that everyone, now, was me

The narratives of lamentation

- At one level, it is reactive
  - No doctor ever listened to my pain
  - Why would I have ever agreed to a transplant if they had told me the truth
  - Is anyone in this hospital ever going to let my mother die in peace?

At another level, it tells a different story

- You know, doc, this really isn't about you; it's about me
- I don't care what my white count is; I need to get out of here to go to my son's birthday party
- He's worried about an infection; I'm worried about whether I'll live to see my daughter go out on her first date

Likely to talk about suffering instead of pain

- I don't hurt anymore, I just can't stand this any longer
- The pain’s not so bad anymore if I lay still. Who wants to lay still until they die?
- Do I always have to come to the clinic when something goes wrong?

Mr. F is a 45 year old man with a squamous cell tumor eroding into his hypopharynx

- Admitted for pain control
- Comes in on dilaudid, 15mg/h, per infusion device
- Patient is wide-awake, wide-eyed, agitated
- Writes on a piece of paper: “If you can’t make this go away, I’m going to blow my brains out.”
Management of intractable pain

- Evaluate the nature (quality) of the patient’s pain:
  - Burning, shooting, “tingling,” lancinating pain suggest neuropathic pain
  - Less responsive (no dose response curve) to opiates
- Consider change to alternative opiate

Management of intractable pain

- Consider adjuvants:
  - Anticonvulsants (valproate, gabapentin, etc.)
  - Lidocaine (available orally as mexilitene)
  - Tricyclics (amitryptiline, desimpramine)
- Consider anxiolytics
  - NOTE: Some anxiolytics (e.g., lorazepam) can actually lower pain threshold
- Consider SSRI’s, mixed agents

Management of intractable pain

- But most patients will not respond to these measures, or their pain is so severe that you do not have time to titrate and wait for effect

Management of intractable pain

- Consider:
  - IV methadone – has activity against neuropathic pain, fast onset
  - Needs to be titrated carefully
  - May need to be adjusted downward
  - Can be converted to oral regimen (1:1) if patient gets relief

Management of intractable pain

- Consider
  - Ketamine: may be given IV or orally
  - Oral dose is safer, has excellent absorption
  - Order via MIS as ketamine injection, but specify that nurse is to give orally
  - Would use only on palliative care unit, or an ICU
  - Can lower BP, cause hallucinations

The medical narrative

- The archetypal story is the clinical presentation (the chart, or the story on rounds):
  - “This unfortunate 44 yowm, with end-stage leukemia, who failed induction x 2, not an appropriate candidate for transplant, with palliative CHOP and XRT for bony pain, comes in with a fever of unclear origin. . . .”
Patient Barriers to Completion of Advance Directives

- Belief that physicians should initiate discussions
- Procrastination
- Apathy
- Belief that family should decide
- Family would be upset by the planning process
- Fear of burdening family members
- Discomfort with the topic

Physician Barriers to Advance Care Planning

- Belief that patients should initiate discussions.
- Discomfort with the topic.
- Time constraints.
- Lack of knowledge about AD’s.
- Negative attitude.

Selected Legal Issues in End-of-life Care

- Capacity determination
- Withdrawal vs. Withholding of life sustaining treatments
- Artificial nutrition and hydration

Withdrawal vs Withholding of life sustaining treatments

- Legally, there is no difference between withdrawal vs withholding of life sustaining treatments
- However, psychological, emotional, or religious constraints may exist for family.

Artificial nutrition and hydration (ANH)

- States have different laws guiding care surrounding ANH
- Benefits vs burdens of ANH
- What are the goals of ANH?

Case Presentation

90 yo AA female is sent to the emergency room from her nursing home.

Brief History:
She was discharged from the neurology service one week prior after a massive MCA stroke which left her minimally responsive.
**Case Presentation**

90 yo AA female is sent to the emergency room from her nursing home.

Brief History:
- She was discharged from the neurology service one week prior after a massive MCA stroke which left her minimally responsive.
- Given the poor prognosis, the patient was referred to Hospice by the neurology service. Her family agreed upon end of life care. She was sent to a nursing home without IV fluids or tube feeds. The family expected her to pass within several days.

**Hospital Course**

- Her family was concerned that she had not received any food or water for the past week. They feared she was suffering from starvation. In addition, they rescinded her DNR/DNI code status.
- The patient was admitted that night for PEG tube placement.

**Clinical Judgment**

- As there had been no improvement in her neurological status, we felt strongly that the patient would not benefit from the insertion of a PEG tube.
- Despite the team’s concern, the family demanded that the patient be fed.

**Outcome**

- Upon the family’s insistence, the patient was fed and rehydrated. A PEG tube was inserted and tube feeds begun. She expired 2 days later, in the Palliative Care Unit, from an aspiration pneumonia.

**Outcomes**

- No study has demonstrated decreased pneumonia through tube feeds
- No randomized studies
- Swallowing studies lack both specificity and sensitivity in predicting who will aspirate

*(Croghan, 1994)*
Outcomes

- Where tube feedings likely to prolong life
  - Reversible catabolic illness (sepsis, burn, post-surgery)
  - H & N tumors with proximal OP involvement
  - Chemo or XRT involving proximal gut

- Recent prospective data
  (Meier, et al., Arch Int Med, 2001)
  - 192 patients eligible
  - 99 enrolled (10 PCP’s refused, no surrogate found for 89)
  - Randomly assigned to intervention or control

Outcomes

- Median age: 84.0 yrs
- Females: 81%
- Length of stay: 12 d (2-93)
- Number with tubes placed: 51%

- Intervention (counseling on palliative care) had no effect on any outcomes
- Factors associated with tube placement:
  - African American (hazard ratio 9.4)
  - Nursing home resident (4.9)

Outcomes

- More than half of all patients could not be enrolled because of a lack of surrogate
- 50% 6-month mortality irrespective of tube placement

Common concerns

- Legally required to “do everything?”
- Does withdrawal/withholding constitute euthanasia?
- Are you killing the patient when you remove a ventilator?
- Is the use of opioids to control symptoms at the end of life euthanasia?
What is the patient’s good?

“If medicine takes aim at death prevention, rather than at health and relief of suffering, if it regards every death as premature, as a failure of today’s medicine - but avoidable by tomorrow’s - then it is tacitly asserting that its true goal is bodily immortality...Physicians should try to keep their eyes on the main business, restoring and correcting what can be corrected and restored, always acknowledging that death will and must come, that health is a mortal good, and that as embodied beings we are fragile beings that must stop sooner or later, medicine or no medicine.”

(Kass LR. JAMA 1980;244:1947)