A Patient's Last Chapter: Ethical Considerations for VSED, Euthanasia, and MAID

Joel Wu JD MPH MA HEC-C

August 27, 2024

CENTER FOR BIOETHICS

UNIVERSITY OF MINNESOTA

Objectives:

- Describe the interests of patients in being able to make choices about the time and manner of their deaths at the end of life.
- Define and distinguish between treatment options for potentially hastening death at the end of life.
- Describe ethical principles and commitments that justify or limit clinician involvement in interventions that might hasten death.

Questions:

- Is suicide always unethical or morally problematic? (Yes/No)
- Is it always unethical for clinicians to allow a person to cause their own death?
- Is it always unethical for clinicians to assist a person in causing their own death?

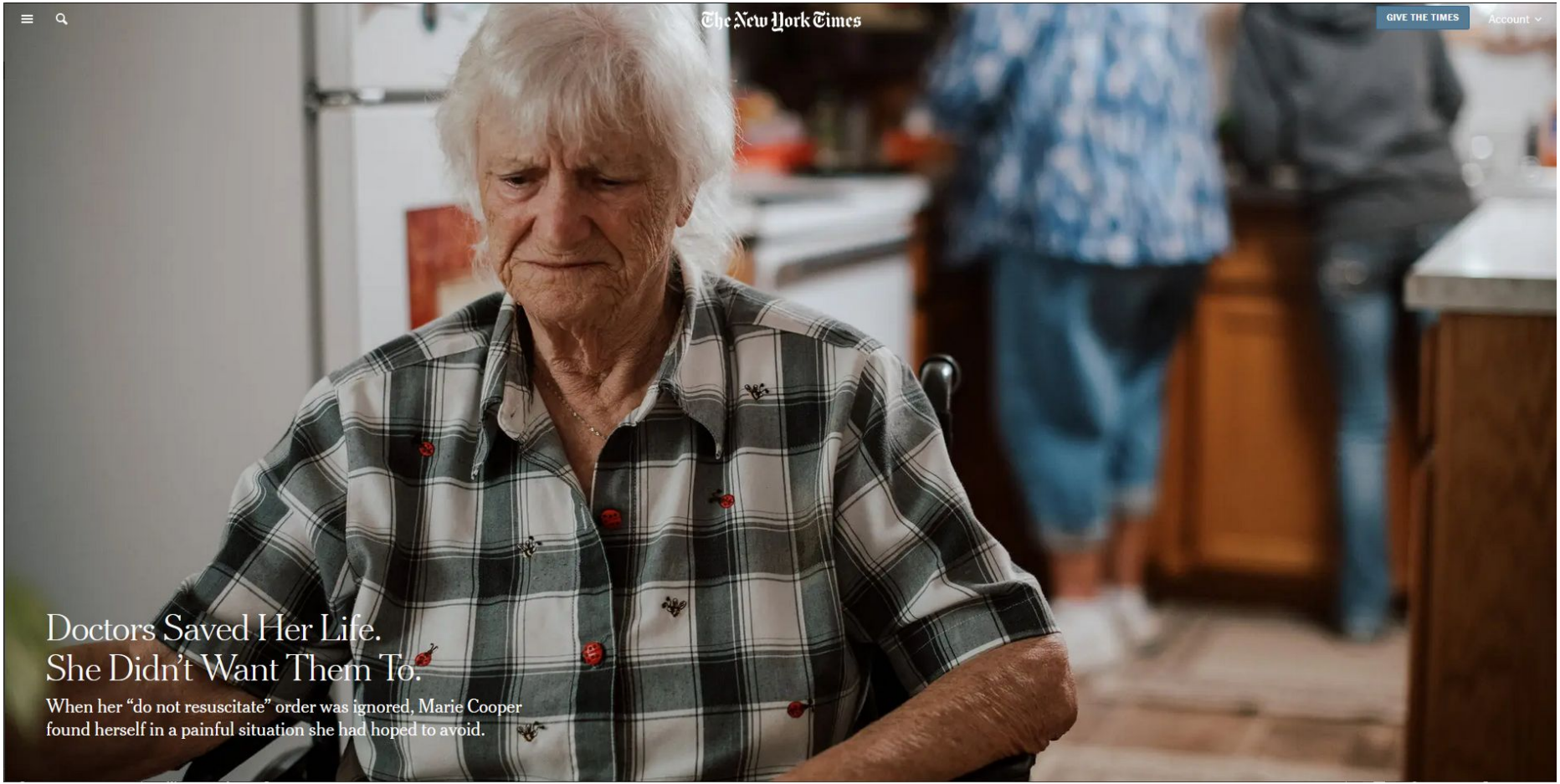
Question: Do distinctions matter?

Regarding “suicide” generally:

- Does distinguishing between the cause of death matter?
  - Does it matter if the cause of death is an underlying disease or a separate new cause of death?
- Does distinguishing between who the final actor is matter?
  - Does it matter if it is the patient themselves or someone else (e.g. a clinician) who is the final actor?
- Does it matter if the person who is hastening or causing their own death has decision making capacity?
- Does it matter if the person is terminally ill (and will die in 6 months?)

Not all actions that hasten death are "suicides"

- Not all actions that hasten death are the same
- Not all actions that hasten death are unethical
- Distinctions matter
  - Obfuscating the differences with inaccurate or misleading terminology is problematic ethically and legally


The New York Times
GIVE THE TIMES
Account
Doctors Saved Her Life.
She Didn't Want Them To.
When her "do not resuscitate" order was ignored, Marie Cooper found herself in a painful situation she had hoped to avoid.

Last winter, doctors found cancer cells in her stomach. She'd had "do not resuscitate" and "do not intubate" orders on file for decades and had just filled out new copies, instructing medical staff to withhold measures to restart her heart if it stopped, and to never give her a breathing tube.

In February, Ms. Cooper walked into the hospital for a routine stomach scope to determine the severity of the cancer. After the procedure, Ms. Uphold visited her mother in the recovery room and saw her in a panic. Despite having an oxygen tube in her nose, Ms. Cooper was gesturing as if she could not breathe. She was able to force out just one word at a time.

Ms. Uphold called for help and was ushered to a waiting room while the medical team called an emergency code. Ms. Cooper grew even more distressed and "uncooperative," according to medical records. Doctors restrained her and inserted a breathing tube down her throat, violating the wishes outlined in her medical chart.

Ms. Uphold, livid, confronted the doctors, who could not explain why Ms. Cooper had been intubated. When Ms. Cooper awoke, she tried to pull at the tubes and IV lines protruding from her body. She motioned to her daughter and the doctors that she desperately wanted her breathing tube removed. "They had me tied down," Ms. Cooper said. "I was scared to death." Ms. Uphold found herself in a situation she and her mother had always wanted to avoid.

"If you take that out, you're committing suicide," Ms. Uphold told her mother, "And if I take it out, I'm murdering you. I won't do that." Ms. Cooper nodded and squeezed her daughter's hand to show she understood.

Not debating legalization or public policy.

We're talking about ***ethics reasons for*** or ***against*** clinicians assisting patients with affecting the timing and manner of their deaths.

Outline

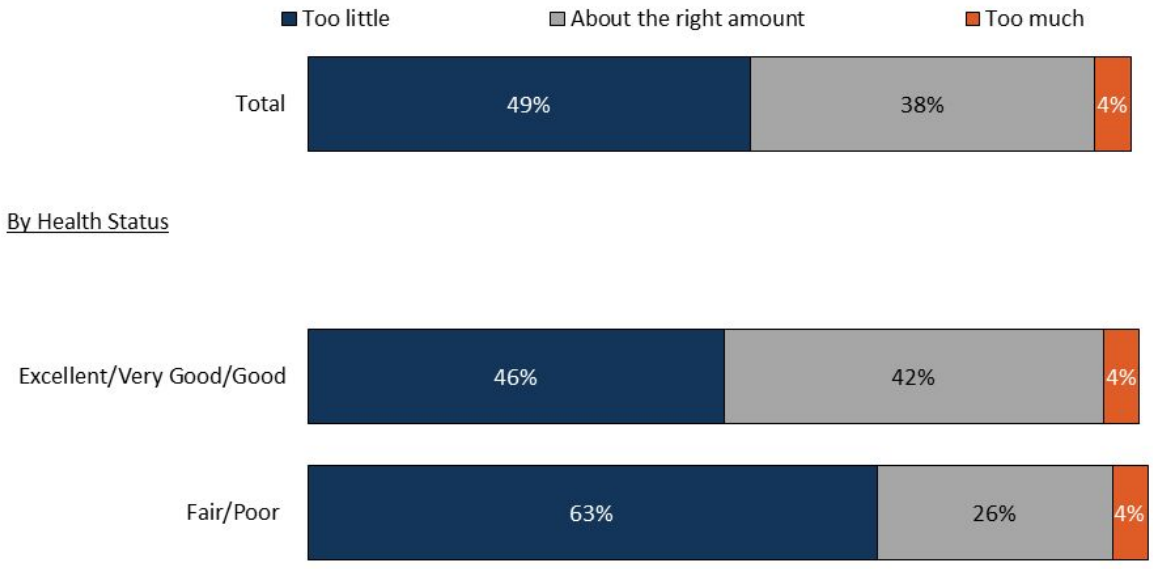
- Patient interests in the timing and manner of their death
- Options that may hasten death at the end of life
- For each option:
  - Define and distinguish from others
  - Specify ethical reasons for or against clinician participation in hastening death
  - Case illustrations

Patient interests in the timing and manner of death at the end of life

Figure 7

About Half Believe Patients Have Too Little Control Over Medical Decisions; Higher Among Those in Poor Health

In general, do you think most people in the U.S. have too much, too little, or about the right amount of control over decisions about their own medical care at the end of life?



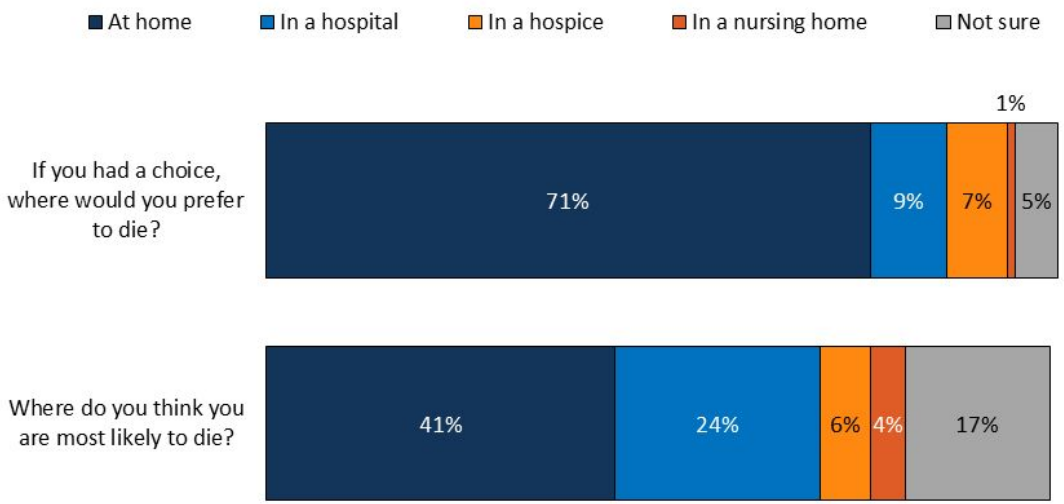
SOURCE: Kaiser Family Foundation/The Economist Four-Country Survey of Aging and End-of-Life Medical Care (conducted March 30-May 29, 2016)

THE HENRY J. KAISER FAMILY FOUNDATION

https://www.kff.org/report-section/views-and-experiences-with-end-of-life-medical-care-in-the-us-findings/

Figure 13

Seven in Ten Americans Would Prefer to Die at Home; Four in Ten Think They Are Likely to Die at Home



NOTE: Somewhere else (Vol.) and Depends (Vol.) responses not shown.
SOURCE: Kaiser Family Foundation/The Economist Four-Country Survey of Aging and End-of-Life Medical Care (conducted March 30-May 29, 2016)

THE HENRY J. KAISER FAMILY FOUNDATION

Non-medical harms at the end of life

- Is it harmful to patients if their death occurs in an unwanted setting?
- Is it harmful to patients if their death occurs sooner or later than they desired?

“Losing control of the last chapter”

- The harms of the dying process are not reducible to the physiological;
- Autonomy, dignity, social/relational interests, and narrative interests have weight.
- Patient choices may be in tension with the professional powers and obligations of clinicians.

Parties: the patient

- Rights:
  - Medically indicated and legal treatment
  - Palliation of symptoms
  - Autonomy: Refusals of unwanted treatment
- Duties:
  - Participation in a plan of care
- No positive right to illegal or ineffective treatment

Parties: the clinician

- Rights:
  - No obligation to provide ineffective or illegal treatment
  - No obligation to provide harmful treatment
  - Conscientious objections/refusals
- Duties:
  - Provide legal, medically indicated treatment including palliation
  - Respect patient autonomy

Ethics of suffering and palliation

- “The duty to relieve pain and suffering is central to the physician’s role as healer and is an obligation physicians have to their patients.”

  AMA Code of Medical Ethics Opinion 5.6

Treatment options that may hasten death at the end of life

Options for affecting the time and manner of a patient's death

- Legal:
  - **Refusals**
    - Non-initiation or withholding;
    - Withdrawal of life sustaining treatment
  - **Palliative Sedation to unconsciousness**
    - **Double effect**
  - **Voluntarily Stopping Eating and Drinking**

- Legal in 11 states:
  - **Medical Aid In Dying (or physician assisted suicide)**
- Legal in 9 countries:
  - **Voluntary active euthanasia**

Specific requirements/exclusions

- Decision making capacity
  - Excludes psychiatric crisis, psychiatric conditions
- Terminal condition
  - Excludes existential suffering, circumstantial suffering
- Imminent death (“final stages”)
  - Not expected to survive longer than 6 months

The key distinctions

- **Cause of Death**
  - Non-interference of an underlying process
    - Terminal disease
    - Dehydration
  - Actions that introduce a new process to hasten or cause death
    - Lethal medications

The key distinctions

- **Final actor**
  - The patient themselves
  - A clinician

- **Decision making capacity at initiation** is also a key distinction, but excluded here.

Refusals and withdrawals of LST

	Cause of Death	Final actor
Refusal of life sustaining treatment	Underlying disease	Patient and Clinician
Withdrawal of life sustaining treatment	Underlying disease	Patient and Clinician

- Ethics justifications
  - Respect for patient autonomy
    - Patient's may decide whether burdens of treatment exceed benefits
  - Involuntary treatment is ethically problematic
    - Non-maleficence and Beneficence do not supersede autonomy

Refusal Case:

- VAD deactivation:
  - 75 F, non-ischemic cardiomyopathy complicated by cardiogenic shock, s/p LVAD, complicated by RV failure, respiratory failure. History of breast cancer, colitis, arthritis.
  - Has decision making capacity
  - Husband recently deceased; 2 adult sons support of deactivation.

Mueller, P. S., Swetz, K. M., Freeman, M. R., Carter, K. A., Crowley, M. E., Severson, C. J. A., ... & Sulmasy, D. P. (2010, September). Ethical analysis of withdrawing ventricular assist device support. In Mayo Clinic Proceedings (Vol. 85, No. 9, pp. 791-797). Elsevier.

VSED

	Cause of Death	Final actor
Voluntarily stopping of eating and drinking	Dehydration	Patient

- Ethics justifications
  - Respect for patient autonomy
  - Relief of suffering
  - Mercy and non-abandonment
- Ethics limitations
  - Complicity in supporting suicide by alleviating symptoms only.

VSED

- Palliation of symptoms and complicity:
  - No distinctions between palliation of a terminal illness and VSED

    vs.
  - Assisting, complicit in act of suicide by alleviating attendant symptoms (which is always immoral)

VSED Case:

Case 1.2 in Quill et al.

- 55 M, metastatic breast cancer; bed bound and dependent on others for care
- Possessed decision making capacity. Long held view regarding independence and end of life choices.
- No other life sustaining treatment, PS not an option.
- Sought MAID
- Chose VSED. 12 days.

Palliative sedation to unconsciousness

	Cause of Death	Final actor
Palliative sedation to unconsciousness	Underlying disease and/or dehydration	Clinician

- Ethics justifications
  - Respect for patient autonomy
  - Palliation
  - Double Effect
    - *Intent* is palliation
- Ethics limitations
  - Causing loss of consciousness like causing death
  - Increasing degree of interference/intervention

“Classic” Double effect

- Action is ethical provided that:
  - that the action in itself from its very object be good or at least indifferent;
  - that the good effect and not the evil effect be intended;
  - that the good effect be not produced by means of the evil effect;
  - that there be a proportionately grave reason for permitting the evil effect

Mangan, Joseph, 1949. “An Historical Analysis of the Principle of Double Effect,” Theological Studies, 10: 41–61.

Palliative sedation case

- 50 M, terminal lung cancer, home hospice
- Physically and psychologically unacceptable condition
- Requested “total sedation”
- Hospice disenrolled, patient could not be moved.
- Sedating medication was prescribed, administered in a “stepwise fashion” by palliative care physician resulting in unconsciousness; died 4 days after loss of consciousness.

Quill, T. E., Lo, B., Brock, D. W., & Meisel, A. (2009). Last-resort options for palliative sedation. *Annals of Internal Medicine*, *151*(6), 421-424.

Medical aid in dying

	Cause of Death	Final actor
Medical Aid in Dying	Lethal drug	Patient

- Ethics justifications
  - Respect for patient autonomy
  - More goods than harms
    - Mercy
    - Non-abandonment
- Ethics limitations
  - Intentionally facilitating death violates professional obligations (Benefit through death, intent for death)
  - More harms than goods
  - Justice and disability concerns
  - Slippery slope issues

MAID Ethics issues

- Patient interests in the manner of their death; correlated duties on clinicians.
  - From non-interference of patient choices to participation
    - Provision of aid in dying medication
    - Final act and requirement of “self-administration” and “unassisted.”
  - From underlying cause of death unimpeded, to a new cause of death
- Ethics concerns:
  - Non-maleficence and justice

MAID Case

- Brittany Maynard:
  - Grade 4 glioblastoma recurrence
  - 6 month prognosis
  - Moved from CA to OR to meet residency requirements
  - Death by self-administered, physician prescribed aid in dying drugs.

CNN Opinion Political Op-Eds Social Commentary

My right to death with dignity at 29

Brittany Maynard

4 minute read · Updated 10:44 PM EST, Sun November 2, 2014

Brittany Maynard's journey Courtesy Britanny Maynard 1028

1 of 7

Brittany Maynard's journey — Brittany Maynard with her dog Charley in San Francisco. Maynard, a 29-year-old with terminal brain cancer, has died, advocacy group Compassion and Choices said in a Facebook post on Sunday. Click through to see more photos of Maynard's life.

Editor's Note: Brittany Maynard worked as a volunteer advocate for the nation's leading end-of-life choice organization, Compassion and Choices. She lived in Portland, Oregon, with her husband, Dan Diaz, and mother, Debbie Ziegler. Watch Brittany and her family tell her story at www.thebrittanyfund.org. The opinions expressed in this commentary are solely those of the author.

(CNN) — On New Year's Day, after months of suffering from debilitating headaches, I learned that I had brain cancer.

Voluntary Active Euthanasia

	Cause of Death	Final actor
Voluntary Active Euthanasia	Lethal drug	Clinician

- Ethics justifications
  - Respect for patient autonomy
  - Mercy and Non-abandonment
- Ethics limitations
  - Professional intentionally, directly causing death violates professional duties
  - Intent: Benefit is through death
  - Justice issues

Euthanasia Case

- Thomas Youk and Jack Kevorkian
  - 52 M, Amyotrophic lateral sclerosis, “Lou Gehrig’s”
  - Youk requested euthanasia
  - Kevorkian injected barbiturates and potassium chloride.

“I, Thomas Youk, the undersigned, entirely voluntarily, without any reservation, external persuasion, pressure or duress, and after prolonged and thorough deliberation, hereby consent to the following medical procedure of my choosing, and that you have chosen direct injection, or what they call active euthanasia, to be administered by a competent medical professional, in order to end with certainty my intolerable and hopelessly incurable suffering.”

Conclusions:

- Patient's have an interest in the timing and manner of their deaths
- Distinctions matter:
  - **Cause of death**
  - **Final actor**
- Intent matters
- Failure to distinguish obscures meaningful ethical differences and causes harm

	Cause of Death	Final actor
Refusal of life sustaining treatment	Underlying disease	Patient and Clinician
Withdrawal of life sustaining treatment	Underlying disease	Patient and Clinician
Voluntarily stopping of eating and drinking	Dehydration	Patient
Palliative sedation to unconsciousness	Underlying disease and/or dehydration	Clinician
Medical Aid in Dying	Lethal drug	Patient
Voluntary Active Euthanasia	Lethal drug	Clinician

Q & A

Key references/resources:

Quill, T. E., Menzel, P. T., Pope, T., & Schwarz, J. K. (Eds.). (2021). *Voluntarily stopping eating and drinking: A compassionate, widely-available option for hastening death*. Oxford University Press.

Quill, T. E., Lo, B., Lo, B., & Brock, D. W. (1997). Palliative options of last resort: a comparison of voluntarily stopping eating and drinking, terminal sedation, physician-assisted suicide, and voluntary active euthanasia. Jama, 278(23), 2099-2104.

https://www.thehastingscenter.org/briefingbook/physician-assisted-death/

“Classic” Double effect

- McIntyre, Alison, "Doctrine of Double Effect", *The Stanford Encyclopedia of Philosophy* (Winter 2023 Edition), Edward N. Zalta & Uri Nodelman (eds.), URL = <https://plato.stanford.edu/archives/win2023/entries/double-effect/>.
- Takla, A., Savulescu, J., & Wilkinson, D. J. (2021). A conscious choice: Is it ethical to aim for unconsciousness at the end of life?. *Bioethics*, *35*(3), 284-291.
- Sulmasy, D. P. (2018). Sedation and care at the end of life. Theoretical Medicine and Bioethics, 39, 171-180.