Ethics of Death with Dignity
from Tim Quill to Washington DC

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Objectives

- Distinguish Death with Dignity (DWD) or physician assisted suicide (PAS) from euthanasia
- List major reasons patients request DWD, and how to respond as a result of legalization
- Define the legal requirements set by DC
- Discuss how religion interacts with patients’ end of life choices
Definitions

- Euthanasia - the deliberate ending of a life by someone other than the patient by introducing a lethal drug (injection, infusion)
  - Legal only in the Netherlands

- Death with Dignity (formerly called Physician-assisted suicide and Physician Aid in Dying) - deliberate ending of a life by the patient taking a lethal drug provided or prescribed by a doctor
  - Legal in Oregon since 1997
  - Since joined by CA, NJ, WA, MT, CO, VT, HI, ME, DC
Two Physicians: a contrast

- Kevorkian’s PAS cases were from 1990-1998.
- He says there were 130, but that’s not certain. Maybe less. (One source says 45 died—perhaps 130 answered his ad but didn’t follow through?)
- In 1990 Tim Quill, a family medicine doc in Rochester NY, gave prescription for sleeping pills and info about a lethal overdose to “Diane” a 45 year old leukemia patient
Civil Disobedience

- Both doctors questioned laws making PAS or DWD illegal
- Quill though didn’t want to get in legal trouble, while Kevorkian seemed to relish it
- Kevorkian in that way maybe a better example of true civil disobedience?
- He wanted to get caught to show law wrong
- But also seemed to like the publicity or wanted to be a martyr (part of personality for civil disobedience?)
Popular support for legalization

- While Kevorkian seemed like a crusader, polls at the time indicated over 50% of the public and over 50% of doctors agreed that PAS should be legal.
- He was tried and acquitted three times, after jury saw video of the patient.
- Oregon first passed a referendum legalizing DWD in 1994; it went into effect after Quill/Glucksberg SCOTUS decision in 1997 said the Constitution does NOT guarantee any such right, and that it is UP TO the states to decide.
When a person has a disease that cannot be cured and is living in severe pain, do you think doctors should or should not be allowed by law to assist the patient to commit suicide if the patient requests it?

1996-1999 WORDING: When a person has a disease that cannot be cured and is living in severe pain, do you think doctors should be allowed by law to assist the patient to commit suicide if the patient requests it, or not?
The Legal and Ethical Debate

- Supreme court: The legal status of PAS/DWD can differ from state to state
- In Glucksberg and Quill Supreme Court supported
  - Right to palliative care (that’s a strong word, legally)
  - State right to control (or prohibit) assisted suicide
  - One justice (O’Connor) warned that failure of former could lead to increased demand for latter
- U.S. Supreme Court (2006): Gonzalez vs Oregon, upheld the ODWDA (i.e. Alberto Gonzales, 43’s Attorney General, lost)
DWD/PAS Court cases


- Outcome: U.S. recognizes state’s right to legalize (Oregon) or ban (New York and Washington) death with dignity.


- *Carter v Canada* (out of BC) also 2016 legalized it in all of Canada.
Oregon Death with Dignity Act *

- Legalized DWD in 1997
- Patient must have capacity to make their own choice
- 6 month prognosis with Dx confirmed by a second doctor who specializes in that disease
- Waiting period of two weeks before prescription written
- Review by a psychologist or psychiatrist only if depression or mental disorder causing impaired judgment is suspected
- In contrast, euthanasia is not legal anywhere in U.S.

*ODWDA, the model for the DC law

- 541 prescriptions provided
- 341 deaths resulted
- Median age – 70 (25-94)
- Dx – Cancer (80%), ALS (8%), COPD (8%) AIDS (2%)
- 68% have college experience or degree
- 90% died at home
- 98% whites, 53% men
- Divorced, 23%, never married, 23%, married 46%
- 99% had insurance, 88% in hospice care

Incidence (2007) - 16/10,000 deaths
Important to note

- 200 prescriptions never taken
- That’s over 33%
- But those patients report comfort from knowing they have control
- Profile of the patients who get prescriptions: educated, insured, want control
- That describes many doctors
- We should be careful before denying to patients something we’d want for ourselves
Why Patients Ask for PAS

- Losing autonomy (86%)
- Decreased ability to participate in activities that make life enjoyable (85%)
- Loss of dignity (78%)
- Losing control of bodily functions (57%)
- Burden on family/CG (37%)
- Pain (22%)—sixth!
- Financial concerns (3%) 

50% had multiple concerns
Pain as a red herring

- Many discussions dwell exclusively on pain
- This is a mistake, as pain is a symptom that can be controlled over 90% of the time
- In worst cases, pain control requires sedation to the point of coma (‘terminal’ or palliative sedation)
- When coma is induced and no feeding tube used, this is sometimes known as “terminal sedation”—legal and ethical (though some people, including Kevorkian, thought DWD preferable)
ODWDA – Death Experience 2007

- 84 deaths - 100% used barbituates
- More get the Rx but don’t take it (1/3 don’t, but report peace of mind from having it)
- Drug effect:
  - Mean 5 min between ingestion and unconsciousness  (Range 2-15 min)
  - Mean 25 min between ingestion and death (Range 5 min-83 hr)
- Complications
  - 3 regurgitated small amount
  - No seizures
  - No EMT calls

California’s sentinel case
DC’s DWD law

Passed by legislature
Began in late 2017
First year: no deaths reported
Second year: 4 prescriptions written, two deaths reported
Likely to increase, but not that much. Perhaps 15-20 requests, and 10-12 deaths per year eventually (in another 10 years?)
Specific requirements in DC

★ Two oral requests at least 15 days apart
★ One written request must be submitted before the second oral request using the “Request to End My Life in a Humane and Peaceful Manner” form at: https://dchealth.dc.gov/page/death-dignity-act-2016
★ The physician is required to upload the form to that same Death with Dignity web portal
★ Prescription must be at least 48 hours after written request (which could be day 15 after first oral request)
★ Prescription must be dispensed by physician or called in to pharmacist by physician (no script)
Who can make the request

- Must have diagnosis of six months or less to live (standard definition of terminal illness)
- Must be at least 18 years old
- Must be resident of DC--physician needs to get two forms of ID that support residency within the past 60 days, like DL, rent receipts, utilities bills.
- No requirement of length of residency (e.g. for 1 year or 2 years)
Who can (and cannot) be witnesses

★ The written request needs two witnesses
★ The attending cannot be a witness
★ One witness can be anyone the patient chooses, other than the physician
★ The second witness cannot be family member, or someone named to inherit money from the estate, or an employee of the facility where the patient gets care or resides
★ Also, the patient must be a DC resident, and the physicians must submit written proof of residency
Important ethical issue: Conscience

- Conscience clauses (or conscientious objection)
- Every state law allows individual physicians to not participate (modeled on abortion law)
- But less clear if hospitals or health systems can invoke that…
- Can just mean they won’t allow it on their property
- not a big problem since 86% (WA)-90% (OR) die at home
- But can they/should they be allowed to forbid all doctors who work for them from every participating?
Conscience creep?

- Ethicists not always big fan of conscience
- Implies ethics from fuzzy inner voice (or ‘yuk factor’) or intuition rather than reason and evidence
- First used as political compromise for abortion
- Has religious feel, and part of ‘religious freedom’ to discriminate against gays, inter-racial marriage, etc.
- Catholic hospitals won’t allow any of their staff to offer DWD…being tested in courts
- GWH and its MFA, Vitas, Sibley allow it
What to say instead of just ‘Yes’

★ I’m sorry that your illness has progressed.
★ If you want this option of DWD, I am willing to support you and fill out the paperwork with you.
★ First I have to make sure you understand the process. It can be a safety net that you never need to use, even if you fill the prescription.
★ I also have to make sure you know all of the reasonable alternatives, like hospice and palliative care.
★ I recommend you let your family know your plans, so they can be emotionally prepared. I hope you can arrange to have some loved ones with you if you do make this choice.
★ My advice: send a condolence note to the family afterwards.
What to say instead of just ‘No’

★ I’m sorry that your illness has progressed.
★ If you want this option of DWD, I am willing to help you find a doctor, but my personal/religious beliefs or my employer won’t let me do this for you.
★ If you don’t choose another doctor, I will remain your doctor for the rest of your life, and will do everything I can to prevent or relieve your suffering, including using hospice and palliative care
★ My advice: send a condolence note to the family afterwards.
An alternative to DWD open to everyone

- Law says you must inform patient of alternatives such as hospice
- Another option is VSED = voluntarily stop eating and drinking
- Does not require 6 month prognosis (or all the paperwork), so option for people with dementia diagnoses
- Has zero failure rate, minor side-effects usually limited to first 48 hours, and gives patient time to change his or her mind
- Usually takes 2 weeks (+/- a few days) if you start w/ normal weight, nutritional status, and metabolism
- Reasonable choice for people w/ swallowing disorders, but anyone can choose it
- Catholic church opposes it too
CME by Movie

- If you watch “You Don’t Know Jack” and want to see how things have evolved since…
- “How to Die in Oregon” is a 2011 documentary film about the Oregon Death with Dignity Act, directed by Peter Richardson. It won the Grand Jury prize for documentary film at the 27th Sundance Film Festival.
- Also interesting: “Extremis” and “Alternate Endings: Six New Ways to Die in America”
Going too far? slippery slopes?

1: mental illness, even if refractory to treatment? It can qualify for PAD or euthanasia in Belgium and Netherlands

But…few here support that, and no law allows it

2: children (severely disabled, unconscious) also would never be allowed in U.S. (but are in Belgium and Netherlands)

Solution: discrete steps prevent slippery slopes
Religious Beliefs about suicide

- Most prohibitions of suicide are from religion, e.g. Roman Catholic, Orthodox Judaism, Evangelicals
- Most philosophers in history, in contrast, have seen suicide as rational in some circumstances
- Eastern religions more like Western philosophers
- Should DWD be called ‘suicide’? DC says No
- Mainstream Protestant and Reform Judaism less likely to oppose (and they are the biggest groups of Christians and Jews in the US, respectively)
Does religious belief reduce or increase suffering?

- Recent studies indicate religious people fear death more than secular people.
- In ICU and hospice you can request psychiatry or pastoral care to help patients with severe anxiety.
- My hypothesis is religious people will rarely request DWD, but will need emotional support.
- If you are religious you may be uncomfortable with death or DWD. You will have to decide whether to help patients, or refer.
The role of psychiatric or psychological assessment for DWD

It is not required unless you aren’t sure if patient is making autonomous decision, not being coerced

☐ focus should be on capacity assessment and informed consent: do they understand their prognosis and all of the reasonable treatment options available to them (and their risks)

☐ normal reactive depression does not rule out capacity

☐ All primary care attendings should be able to assess capacity and depression

☐ DC followed OR —doesn’t want to create a roadblock to vulnerable patients. (i.e. doesn’t want to empower opponents who think this is suicide and all suicide is irrational)
Timing ‘the talk’

- Since Oct. 31, 2015 CMS covers e-o-l discussions: $86 (in hospital) or $80 (office) for first 30m and $75 second 30m
- Not with diagnosis, but promise at diagnosis that you will discuss it with them at the right time
- Work with them on advance directives, and don’t be evasive about e-o-l. Mention DWD option.
- Share story of Ezekiel Emanuel (MD at NIH and Penn) not getting any tests after age 75?
- Can share your own views, but only if asked
Some Classic References

- Tim Murphy, *AJOB* 2011:7, 3-6. A Philosophical Obituary: Dr. Kevorkian Dead at 83, Leaving End of Life Debate in US Forever Changed
More references on DWD/PAD

References on Religion, ICU, Suffering

- Thune-Boyle IC. Terminally ill patients who are supported by religious communities are more likely to receive aggressive end-of-life care rather than hospice care; spiritual support from medical teams may reverse this. Evid Based Nurs 2014 Jul;17(3):101509. Epub 2013 Nov 1.
More references on Religion, ICU, Suffering


- Usha Lee McFarling. Hospitals struggle to address terrifying and long-lasting ‘ICU delirium’ October 14, 2016: https://www.statnews.com/2016/10/14/icu-delirium-hospitals/

Videos on VSED

- Avoiding prolonged dying in Advanced Dementia. How healthcare professionals can help. Dr. Terman and a patient, from Houston ASBH conference 10/22/2015. The 75 minute presentation w/ Q&A on YouTube: https://youtu.be/gBim9UKI2-s

- 30 minute excerpt: Includes only Dr. Terman’s narrated slide presentation. https://youtu.be/d0aSUCHknrI
Fun reading on end of life planning (can recommend to patients)

- “Can’t we talk about something more pleasant?” by Roz Chast. 2014. A graphic novel by a well-known New Yorker magazine cartoonist about her conversations with her parents about advance directives.
5 other acclaimed books on death from the past 8 years

- Christopher Hitchens. Mortality. 2012 (first person account of dying)
- Atul Gawande, MD. Being Mortal. 2014
- Marion Coutts. The Iceberg. 2014 (by the wife, an already established author)
- Paul Kalanithi, MD. When Breath becomes Air. 2016 (first person account of dying)
- And the granddaddy of the field: Sherwin Nuland, MD. How We Die. 1993