“Cure, Comfort…… ……or Kill? An Inside Look at Physician-Assisted Suicide”

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American Association of Colleges of Osteopathic Medicine

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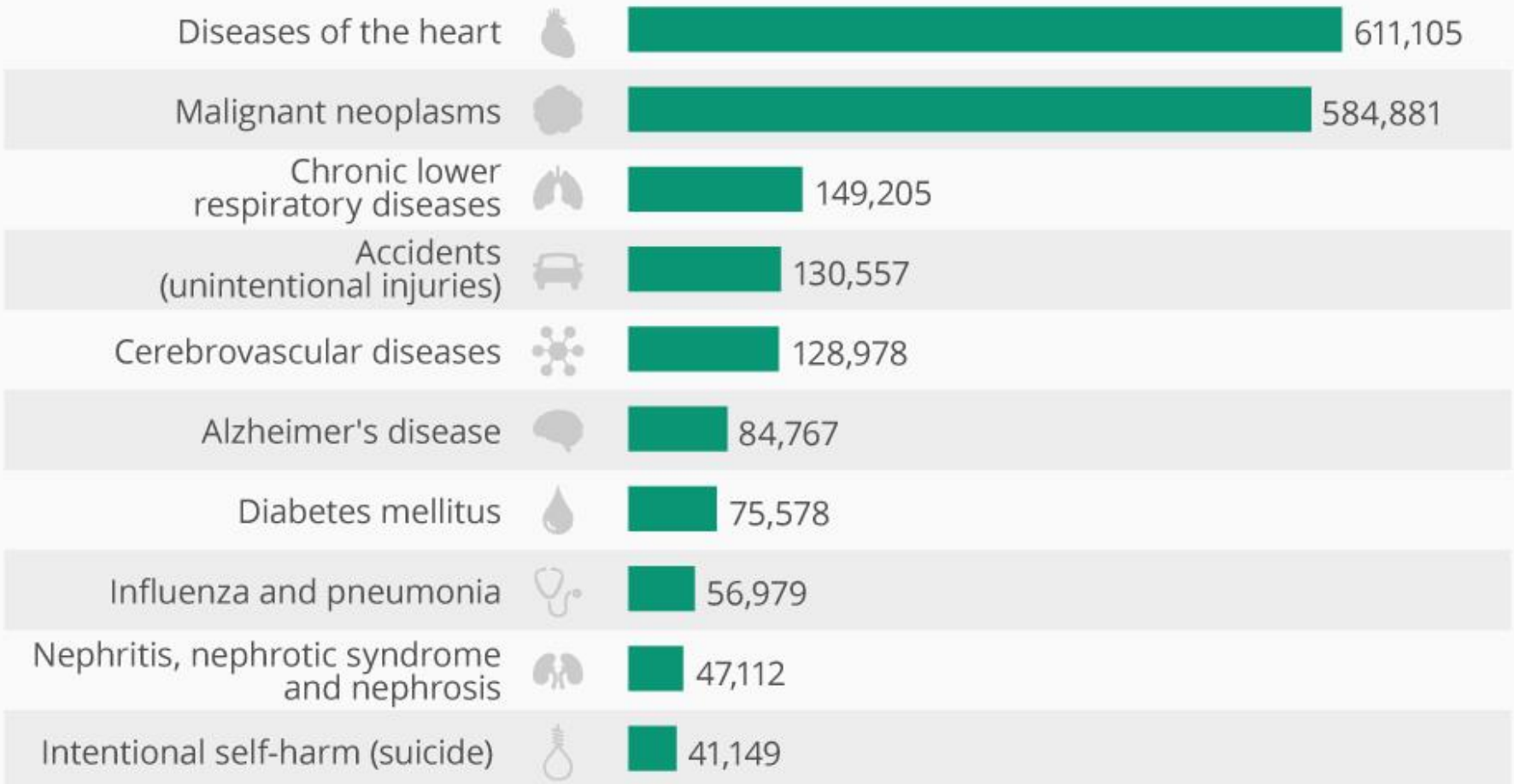
I speak as a physician from my personal experience and study as a specialist in Internal Medicine

Warning!!

What are YOU going to die of?

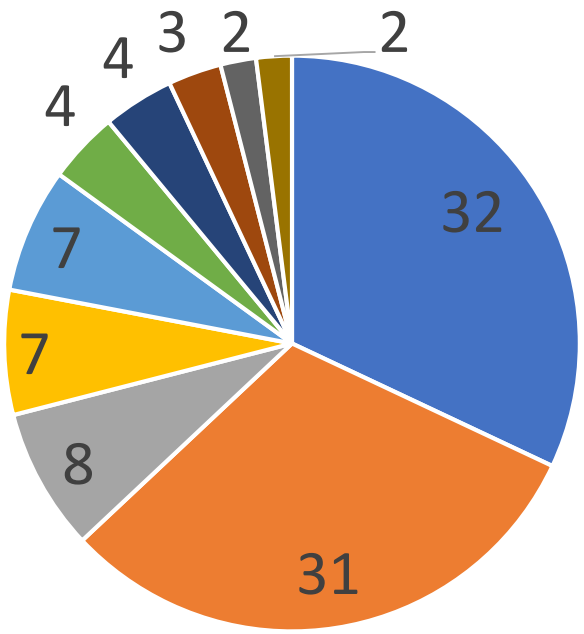
What Kills Americans?

Leading causes of death among people in the United States in 2013

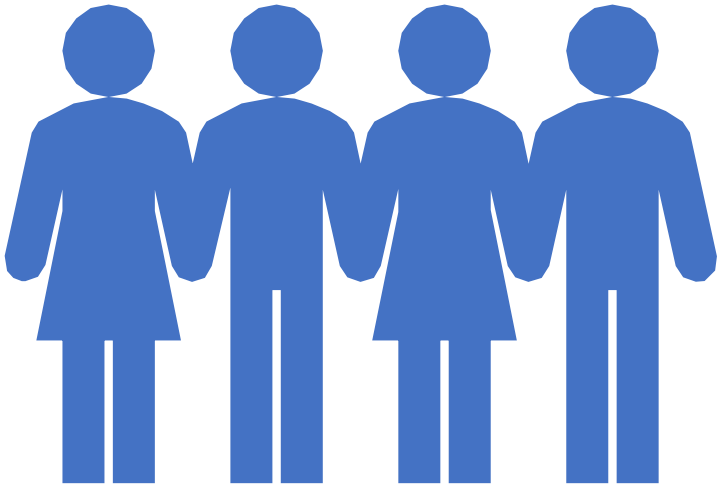


 Source: CDC

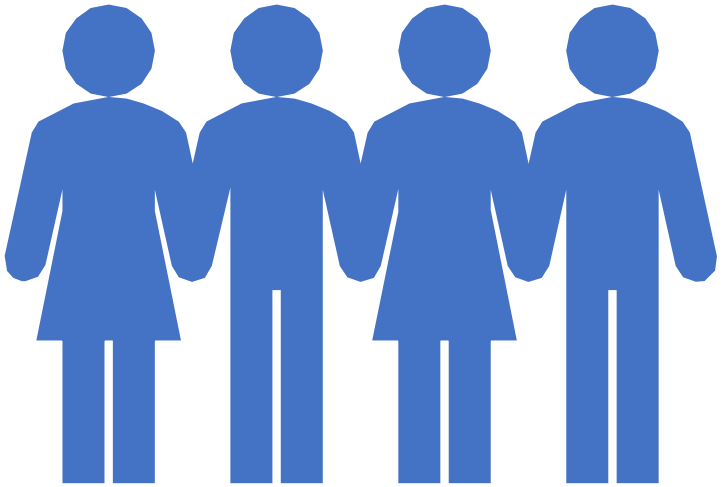
Causes of Death, Americans, 2013, %



Heart Disease
Cancer
Lung Disease
Accidents
Strokes
Dementia
Diabetes
Flu/pneumonia
Kidney Disease
Suicide



We ALL die!



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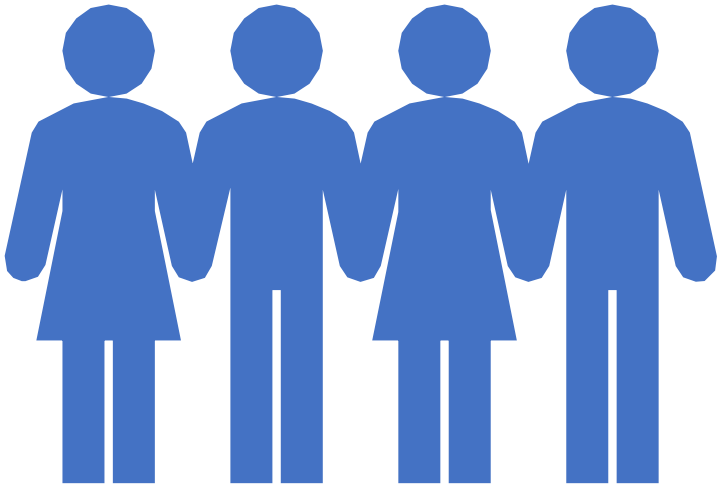
- One of two “universal” human experiences



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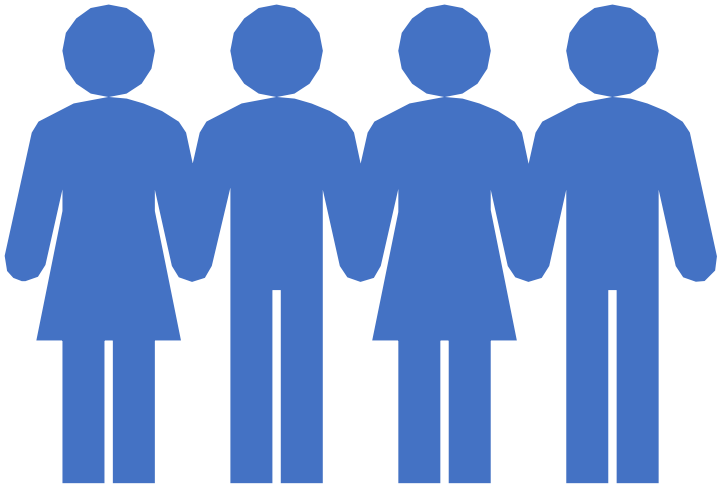

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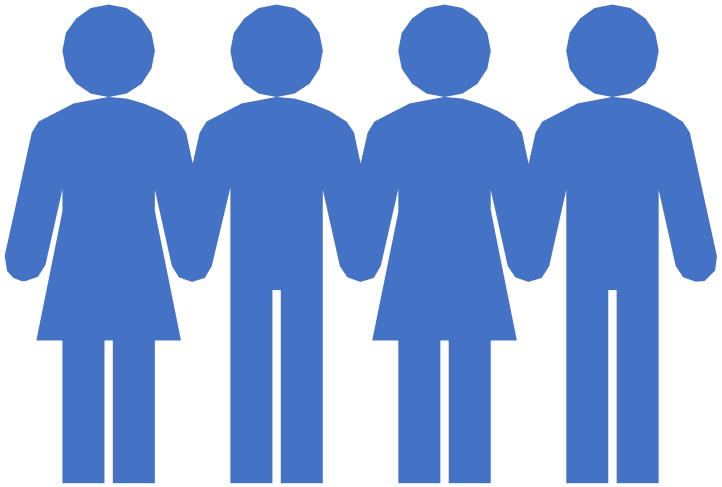


We ALL die!

- One of two “universal” human experiences
- How can death be bad?
- Implications of where we die…
- It is HOW we die that is the question.

- Is Physician-Assisted Suicide the Answer???

- What is the issue?
- What is the definition?
- Where is this legal?
- What has been the experience in Oregon?
- Why do patients request assistance?
- What are the problems?
- What are the alternatives?
- What is our ultimate goal?

- “I’d rather die while I’m alive, than live when I’m dead.”
  - Jimmy Buffet

- “Assisted suicide promotes the belief that people would rather be dead than disabled.”
  - John Kelly, quadriplegic

- “Ethics is about what we do when what to do is up to us.”
  - Aristotle (paraphrased)

What is the issue?

- To relieve suffering

What is the definition?

SUICIDE

- “The act of taking one’s own life voluntarily and intentionally”

Cognitive illusion

- “the effect of using different terminology to describe the same outcome”

- “…the phrase ‘physician-assisted death’ is both euphemistic and ambiguous. We are not talking about assisting dying. We are talking about …. intentionally helping someone to end their own life.”
    - John Keown
        - Rose Kennedy Professor
        - Kennedy Institute of Ethics
        - Georgetown University

Where is it legal?

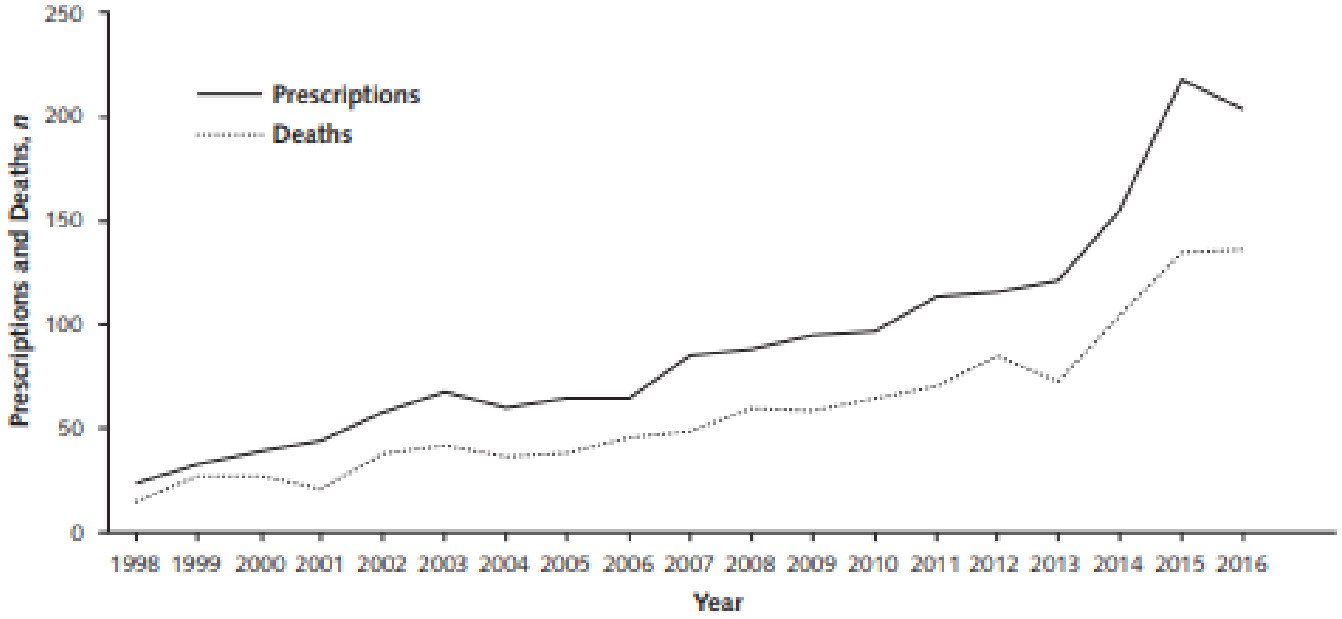
- Oregon
- Washington
- Montana
- Vermont
- California
- Colorado
- Washington, DC
- Hawaii

	CO	OR	WA	CA	VT	DC	MT
Diagnosis	x	x	x	x	x	x	
Patient ELC Concerns?		x	x	x			
In Hospice		x	x	x			
In Hospice at death			x	x			
Health status			x				
Demographics		x	x	x		x	
Which medication?	x	x	x	x			
Psychological report?	x	x	x			x	
Interpreter used?				x			
Physician specialty			x				
Duration of physician/patient relationship		x	x				
Physician/professional present?		x	x	x			

What has been the experience in Oregon?

“20 Years of Oregon’s DWDA”

Figure. DWDA prescriptions and deaths, 1998 to 2016.



DWDA = Death With Dignity Act.

Statistics - 20 years

- Written prescriptions – 1967
- Taken medications – 1275 (65%)
- 0.2% of deaths in OR
- Median age: 72
- Majority over 55
- Diagnosis:
  - Cancer – 78%
- With same underlying disease
  - College/graduate degrees predominate

Statistics - 2000-2017

- 90% in hospice
- Median time from ingestion to death
  - 25 minutes (1 minute to 104 hours)
  - GI cancers
- Seven regained consciousness
- Strongest predictor of request for PAS
  - Low self-assessed spirituality score

Statistics - 2000-2017

- 0.6% all licensed OR physicians wrote at least one script (max: 85)
- 22 were reported to Oregon Medical Board (all exonerated)
  - Incorrect documentation
  - Incomplete written consent
  - Lack of 2 witnesses
  - Not following mandated waiting period
- Psychological assessment referrals – 5% and declining

Why do patients request assistance?

- Existential
  - Loss of autonomy
  - Inability to participate
    - enjoyable desired activities
  - Loss of dignity
  - Spiritual suffering
- Fear of pain
- Fear of the unknown
- “A cry for help”
- “Are you going to help me or are you just going to kill me?”

Reasons for Oregon PAS Requests

- 89% - loss of autonomy
- 89% - inability to engage in activities that make life enjoyable
- 77% - loss of dignity
- 48% - loss of bodily control
- 42% - burdensome to family
- 25% - inadequate pain control
- 4% - financial concerns
    - <2% lacked health insurance

Two sides of the question

- Opponents
  - Look for evidence of abuse
- Proponents
  - Look for signs of reassurance

Physician Assisted Suicide Requirements

- Terminal illness with six month prognosis
- Competence and intact judgment
- Voluntariness
- Ability to perform the life-shortening act

First Requirement: Six month prognosis

- Imprecise
- Not clearly distinguishing
- Who is included/excluded?
- Definition options:
- A – This specific person is nearly certain to die in six months?
- B – This specific person is very likely to die within six months?
- C – This specific person is more likely than not to die within six months?
- D – 51% of people with a similar condition will be dead within six months?

Second Requirement:

Possesses decision-making capacity (competence/intact judgment)

- Assessment based on:
  - Understanding
  - Reasoning
  - Appreciation of consequences
- 2/3 consulting psychiatrists
  - “decision-making evaluation is more challenging than other types of evaluation”
- 54% hospice patients (IP/OP)
  - Significant cognitive impairment
- Unique tool set
  - Prolonging health vs. hastening death

Assessing decision-making capacity

- Inter-rater variability
  - Reflects different training backgrounds
- Low reliability in middle of distribution curve
- High reliability at tails of distribution curve
- Low- vs high-threshold evaluators
- What about the “unbefriended?”
  - Substituted Judgment
    - Living Will/DMPOA-Health Affairs
  - Best Interests

Assessing decision-making capacity

- What is method for evaluation?
  - Standard checklist?
  - In-depth interview?
  - Private stand-alone community physician vs. institution's systematic procedure
- Process: (not required for any other procedure)
  - 1-Mental disorder?
  - 2-Impaired judgment?
  - 3-Causally linked?

Psychiatric/psychological evaluations

- 2.3% receiving lethal prescriptions for PAS in Oregon were referred

Third Requirement: Voluntariness

- Two conditions:
  - Intentionality
  - Freedom from controlling influences (Coercion)
    - Illness itself may be considered coercive
- Difference:
  - Voluntariness to consent to physician-PROPOSED procedure
    - GOAL = health
  - Voluntariness to consent to patient-DESIRED procedure
    - GOAL = death

Fourth Requirement: Ability to Self-Administer

- Paralyzed
- ALS
- Can’t swallow
- GI Cancers

What are the problems?

More issues….

Governmental involvement

- “This method of relieving suffering puts the state government in the position of deciding who must live and who may die based on judgments about the patient’s life.”
    - David Orentlicher, Lobeaga Law Firm
        - Professor, University of Nevada, Las Vegas
- If PAS is a “right,” is it still a medical practice?
    - If a LEGAL right, why are physicians the chosen instrument for the task?
    - “Assisted-suicide practitioners”

Monitor system

- Laws
  - Protection for physicians
    - Protected exception to criminal prohibition against homicide
- No state has a monitoring system
  - Self-reporting of PAS

Extension/ Expansion

- Extending/expanding
  - To vulnerable populations?
  - Open to abuse?
- What about marginalized populations?
  - Providing PAS may increase distrust

The Disabled

- “Ableism”
  - Defining an individual by their disabilities
  - German eugenics - WWII
- Unjust discrimination
  - What about those with the inability to self-administer medication?
  - Why deny incompetent patients a “merciful” death?
- May coerce terminally-ill individuals
  - Progressive deterioration of bodily control
    - Shorten lives prematurely
    - To maintain options

Potential abuse

- Any doctor may prescribe
  - Doesn’t need to:
    - know the patient
    - have expertise in psychological evaluation
    - be independent from second assessing physician
- Diabolical opportunity for abuse
  - Encouragement to make request
  - Physician not need to know patient
  - Sign forms as witness
  - Pick up script
  - Administer drug without witness

Cost of medication

Secobarbital - $3000-5000 for a lethal dose

Reason for PAS request?

- "…the fact that dependence on others has become a socially sanctioned reason to be made dead is *itself* a threat to their dignity even if they are not themselves seeking assisted suicide."
    - Daniel Sulmasy
        - Andre' Hellegers Professor
        - Kennedy Institute of Ethics
        - Georgetown University

Reason for PAS request?

- Control
  - (the only time a patient may truly be in control?)
- Autonomy
- Peace of mind knowing the option is available
- Loss of abilities
- Feeling like a burden
- Avoid indignity of being disabled and dependent on others

Dignity

- Less human due to?
  - Bouts of incontinence
  - Momentarily forget names of their children
  - Unable to drive car
- “I trust that it does not mean that indignities in any sense destroy our basic dignity.”
  - Daniel Callahan
    - Co-founder and President Emeritus
    - Hastings Center

Public/physician attitude change?

- "…ethical issues should be decided based on ethical arguments, not polls…"
- "Journal editors have a bias toward what is new. That means defense of the status quo is not new and does not get published."

Daniel Sulmasy

- Andre' Hellegers Professor
- Kennedy Institute of Ethics
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The effects on families, doctors, social policy

- Patients who oppose PAS may fear physician may encourage them to consider
- Physician response
  - Not providing PAS script – abandonment
  - Writing a PAS script – encouragement
- Unintended consequences on relationships?
  - Medicine/society
  - Patient/physician
  - Perceived/actual integrity of medical profession
- Physician burnout?

Not a crisis

- Detracts from improving health care for aging population
- Number of reported cases
  - Low
- Patients
  - White, wealthy, educated individuals
- Few psychiatric referrals
- Reasons
  - Autonomy, independence, control
- 1/3 with a filled lethal prescription die without taking drugs

Therapeutic imperative

Just because we physicians can assist our patients in committing suicide, should we?

If this is just normal medicine….

- …then why not do randomized controlled trials?
  - Best practice?
  - Most cost effective?

“Where you stand depends on where you sit”

- “A terminally ill person who applied for physician-assisted death is not choosing between living and dying, but between two different methods of dying. One is gentle, peaceful. *The other would be struggling and in pain.”*
  - Dan Diaz, Latino Leadership Council, “Compassion and Choices”
  - Husband of Brittany Maynard

What are the alternatives?

- “Look for ways to respond to request that respects patient values.”
- Hospice
- Voluntarily stopping eating and drinking (VSED)
- Stopping life-sustaining therapies
- Proportional palliative sedation
- Palliative sedation to unconsciousness

Responding to a question/request for PAS

- Not every question about PAS is a request for PAS
- “I’ll be glad to answer that question, but first please tell me what led you to ask.”
  - Seeking information
  - Talking through concerns about dying process
  - Expressing distress
  - Trying to ascertain physician’s views

Responding to a question/request for PAS

- Open-ended questions
- Respond with empathy and respect, non-judgmentally
- Re-evaluate/modify treatments/medications
- Identify depression, anxiety, spiritual suffering
- Consult as indicated
- Commit to work to mutually acceptable solution for patient's suffering

Voluntarily Stopping Eating and Drinking

Self-initiated to accelerate dying

Patients have right to refuse life-sustaining treatment

Screen for:

- unaddressed desires/needs
- psychiatric conditions
- unaddressed symptoms
- existential suffering
- evidence of coercion

Most common symptoms:

- Thirst
- Hunger
- Dysuria
- Weakness
- Delirium
- Somnolence

Stopping Life Sustaining Therapies Interventions

- "…the refusal of care is not logically equivalent to a right to hasten death and that to equate the two is to conflate two very different things, both morally and legally."
    - Neil Gorsuch, JD

Proportional Palliative Sedation

- Sedate for pain and dyspnea relief

Palliative Sedation to Unconsciousness

- “intentional lowering of awareness towards, and including, unconsciousness”
- When all other options are exhausted
- Patient may be sedated to unconsciousness
- May hasten death
  - “Double Effect”
    - May hasten death, but is not the INTENT to do so
    - Monitoring BP, HR, RR, consciousness level
  - Removing anxiety
  - Supplements “voluntarily stopping eating and drinking”

Important questions

- What role did depression play in patients who actually took the medications??
- Were alternative options fully presented?
- To what extent were family members unduly influencing patient choices?
- Did prescribing physician consult with PCP, if not the same?
- Do insurance companies have a conflict of interest, $$?
- What % of cases were reported?

Further discussions needed

- How is PAS different from/similar to suicide in other contexts?
- Do any patients access PAS because their symptoms are not being managed?

Further discussions needed

- What harms occur due to physicians opting out of PAS?
- How do prices of PAS drugs affect people of different socio-economic status make decisions about PAS?
- How often are patients referred to “low-threshold” physicians who are more likely to participate in PAS?

Further discussions needed

- What is the effect of PAS on patients with psychiatric disorders? Does publicity about PAS trigger an increase in suicides?

Further discussions needed

- Is there a difference in the grief process for survivors of a person who completed PAS, compared to person who died a “natural” death, who stopped eating and drinking, or who committed suicide by more violent means?
- What is the psychological effect on physicians who participate in PAS?
- Does the lack of PAS laws create a more dangerous underground practice?
- Is the public interest in legalizing PAS part of a broader set of issues involving lack of trust in the health care system?

What is our ultimate goal?

- To provide palliative, empathetic care
- To provide reassurance that symptoms can be addressed
- “Quality of life is a deeply personal topic that should be discussed between the patient and doctor, yet rarely is.”
  - Omega Silva
    - Professor Emeritus
    - George Washington University

What are you going to die of?

What are you going to die of?

How do you want to die?

References

- American Academy of Hospice and Palliative Medicine, “Statement on Physician-Assisted Dying,” June 24, 2016.
- Armentrout, J. Gitlin, D. Gutheil, T, “Do consultation psychiatrists, forensic psychiatrists, psychiatry trainees and health care lawyers differ in opinion on gray area decision-making capacity cases? A vignette-based survey.” 2016. Psychosomatics 57(5):472-479.
- Burt, RA. “Death is That Man Taking Names,” 2002, University of California Press, Berkley CA.
- Burton, CZ. etal, “Undetected cognitive impairment and decision-making capacity in patients receiving hospice care.” 2012. Am Journ Geriatric Psychiatry 20(4):306-316.
- Dugdale, LS. Callahan, D. “Assisted death and the public good.” 2017. Southern Medical Journal 110(9):559-561.
- English, RA. Liverman, CR. Cilio, CM. Alper, J. “Physician-Assisted Death: Scanning the Landscape: Proceedings of a Workshop,” National Academies Press, 2018
- Emanuel, EJ. Onwuteaka-Philipsen, BD. Urwin, JW. Cohen, J. “Attitudes and practices of euthanasia and physician-assisted suicide in the US, Canada and Europe.” 2016. JAMA, 316(1):79-90.

References

- Ganzini, L. etal, “Physicians’ experiences with the Oregon Death with Dignity Act.” 2000. NEJM 342: 557-63.
- Ganzini, L. etal “Oregon physicians’ attitudes about and experiences with end-of-life care since passage of the Oregon DWDA,” 2001. JAMA 285(18):2363-2369.
- Ganzini, L. Goy, ER. Dobscha, SK. “Oregonians’ reasons for requesting physician aid in dying. 2009. Arch Internal Medicine 169(5):489-492.
- Garrison, M. “The empire of illness: Competence and coercion in health-care decision making.” 2007. William and Mary Law Review 49(781):781-843.
- Gorsuch, NM. “The future of assisted suicide and euthanasia.” 2006 Princeton, NJ: Princeton University Press.
- Hedberg, K. “Oregon’s Death With Dignity Act: 20 Years of Experience to Inform the Debate.” 2017. Annals of Internal Medicine 167:579-583.

References

- Institute of Medicine: Dying in America: improving quality and honoring individual preferences near the end of life. Washington, DC: National Academies Press, 2015.
- Kim, SY. “Variability of judgments of capacity: Experience of capacity evaluators in a study of research consent capacity.” 2011. Psychosomatics 54(4):346-353.
- Kim, SY. Evaluation of capacity to consent to treatment and research, New York: Oxford University Press, 2010.
- Lo, B. “Beyond Legalization – Dilemmas Physicians Confront Regarding Aid in Dying,” 2018. NEJM 378(22):2060-2062.
- Nelson, RM. etal “The concept of voluntary consent.” 2011. Am Journ of Bioethics 11(8):6-16.
- O’Brien, A. “Suicide rate is up 1.2% according to most recent CDC data (year 2016)”. In Lifesaver News. American Foundation for Suicide Prevention. https://afsp.org/suicide-rate-1-8-%-according-recent-cdc-data-year-2016 (accessed April 23, 2018).

References

- Oregon Health Authority. 2018. “Oregon Death with Dignity Act 2017 data summary.” Salem, OR: Oregon Health Authority.
- Sessums, LL, Zembrzuska, H. Jackson, JL. “Does this patient have medical decision-making capacity?” 2011. JAMA 306(4)420-427.
- Seyfried, L. Ryan, KA. Kim, SY. “Assessment of decision-making capacity: Views and experiences of consultation psychiatrists.” 2013. Psychosomatics, 54(2):115-123.
- Tolle, SW. “Lessons from Oregon in Embracing Complexity in End-of-Life Care.” 2017. NEJM, 376(11):1078-1082.
- Wagner, J. Muller, J. Maercker, A. “Death by request in Switzerland: Posttraumatic stress disorder and complicated grief after witnessing assisted suicide.” 2012. European Psychiatry 27(7):542-546.
- Wax, JW. Amy, AW. Kosier, N. Quill, TE. “Voluntary Stopping Eating and Drinking.” J Am Geriatr Soc, 2018; 66(3):441-445.