Washington's Experience with the Death with Dignity Act 2009-2014

HMC Ethics Forum
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Session overview

- Review arguments pro/con aid-in-dying
- Describe legal requirements for patients making a request & logistical process at HMC
- Examine data on prescription use over time
- Discuss access issues & resources
- Review narrative process for evaluating a request and exploring end-of-life worries, concerns and hopes

The debate on physician aid in dying

PRO

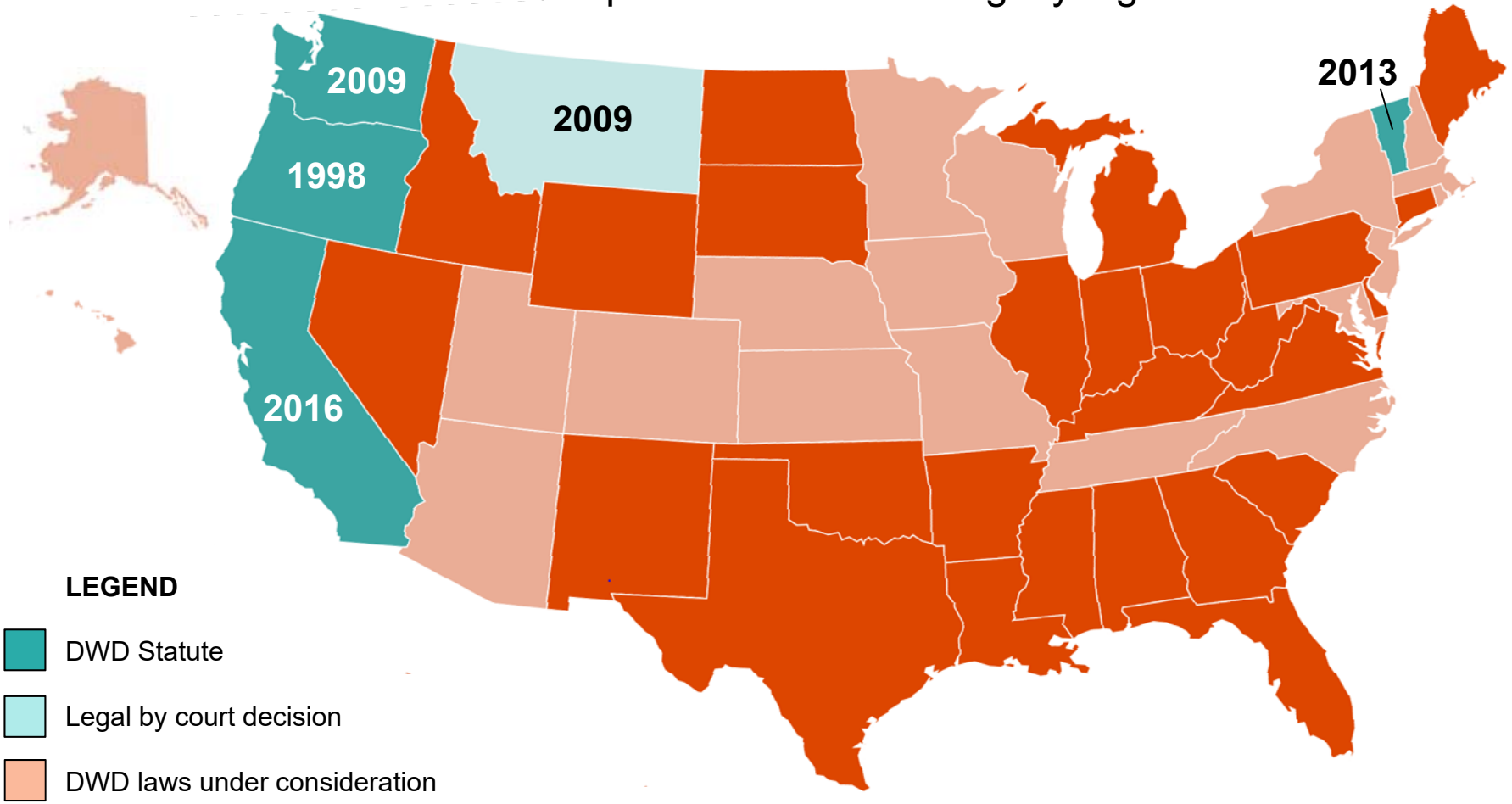
- Self-determination / autonomy
- Merciful act
- Physicians' role to relieve suffering
- Quality of life more important than quantity of life
- Safer and better procedures due to safeguards
- Indirectly promotes better palliative end-of-life care
- Improves quality of dying
- One of many options

CON

- Not ours to decide – up to God to decide time of death
- Seen as killing = morally wrong
- Physicians' role to do no harm
- Band-aid for societal ailments
- Slippery slope
- Worries about coercion/ vulnerable populations
- Economic incentives to hasten death given expense at EOL
- Undermines trust
- Unnecessary with good hospice/palliative care

Death with Dignity around the US

https://www.deathwithdignity.org/take-action/



MD perceptions of Oregon patients

- Very independent / value independence
- Strong personality
- Used to getting things his/her own way
- In control
- Determined
- Up front
- Inflexible about request

Ganzini et al, 2003, J Palliative Med

PAD and vulnerable patients

- Examination of patients in Oregon & the Netherlands to identify differential use of PAD by vulnerable patients
- No heightened risk as compared to all other deaths
  - Elderly (> age 80)
  - Women
  - People with low educational status
  - The uninsured
  - The poor
  - Racial/ethnic minorities
- Elevated risk for persons with HIV/AIDS (pre-ART)

Battin et al, 2007, J Med Ethics

Definitions

- Physician-assisted death (PAD)
  - Request for MD to prescribe medications **that the patient self-administers** with the primary intention of ending her life
- Euthanasia
  - Request for the **MD to inject medications** with the primary intention of ending the patient's life
    - *Voluntary*: At the patient's request and with consent
    - *Involuntary*: Done to a patient who has made a prior request but has now lost capacity to give consent
    - *Nonvoluntary*: Done to a patient who has lost (or never had) capacity to give consent and never made a prior request

Washington Death with Dignity Act

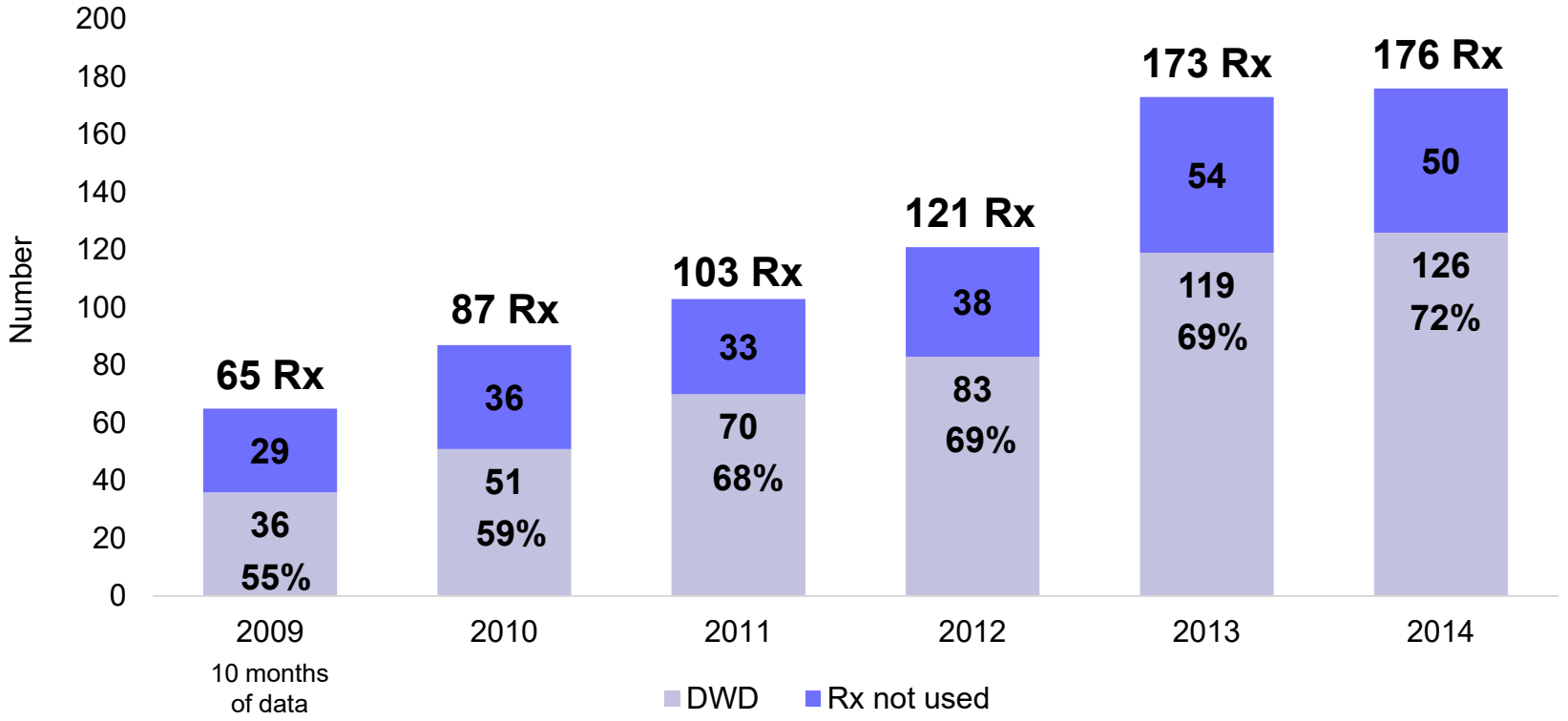
- Terminally ill, competent, adult Washington residents
- Medically predicted to die within six months
- Request & self-administer lethal medication prescribed by a physician
- Two oral and one written request
- A 15-day waiting period between oral requests
- 2 physicians diagnose the patient and determine the patient is competent and making an informed decision
- Optional referral to a psychologist/psychiatrist if concerned about mental health affecting competency
- Physicians, patients and others acting in good faith have criminal and civil immunity

Washington Death with Dignity Act

- Not considered suicide
  - No benefits lost for using the Act
- Underlying illness is noted as the cause of death on the certificate, not lethal meds
- Recommendations
  - Notify next of kin/family
  - Avoid doing this in a public place
  - Make prior arrangements with funeral home, hospice, coroner/medical examiner to establish expected death & know who to call to pick up the body

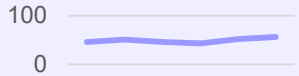
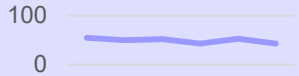
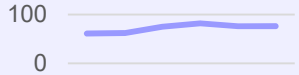
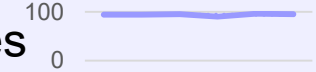
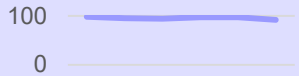
6 years in Washington

Number of DWDA Rx Recipients and Deaths, by Year, 2009-2014
(n = 485 Deaths / 725 Prescriptions Written, Average = 67%)

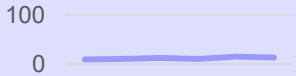
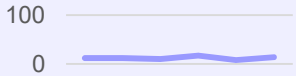


	2009	2010	2011	2012	2013	2014
MDs writing scripts	53	68	80	87	89	109
Pharmacies dispensing	NA	40	46	30	23	57

WA patients 2009-2014

Characteristic (%)	2009	2010	2011	2012	2013	2014
Age range	48-95	52-99	41-101	35-95	29-95	21-101
Married 	46	51	46	43	52	56
Male 	55	50	52	43	53	43
Some college 	61	62	75	82	76	76
Enrolled in hospice 	72	84	83	92	86	68
Insurance 	89	88	87	89	95	93
Died at home 	94	90	93	89	84	92
West of the Cascades 	94	94	95	90	96	95
White 	98	95	94	97	97	92

WA patients 2009-2014

Characteristic (%)	2009	2010	2011	2012	2013	2014
Primary Diagnosis						
Cancer 	79	78	78	73	77	73
Neurodegenerative 	9	10	12	10	15	13
COPD/Heart/Other 	12	12	10	17	8	14
Reason for DWD – Concern about:						
Autonomy [a] 	100	90	87	94	91	89
Dignity [b] 	82	64	79	84	79	79
Enjoyment [c] 	91	87	89	90	89	94

[a] …his or her terminal condition representing a steady loss of autonomy
[b] ...a loss of dignity
[c] ...the decreasing ability to participate in activities that made life enjoyable

Access issues

- 94% requests from West of the Cascades
- Number of participating pharmacies going down across the state
- Valeant Pharmaceuticals acquired rights to manufacture Seconal (secobarbital) in 2015
  - Now an orphan drug
  - Was $150 per 10-gram lethal dose
  - Within 1 year of acquisition, increased to $1500, then $3000
- New concoctions being tried that are cheaper but more unpleasant

http://www.seattletimes.com/seattle-news/health/death-with-dignity-doctors-thwart-steep-price-hike-for-lethal-drug/
http://www.npr.org/sections/health-shots/2016/03/23/471595323/drug-company-jacks-up-cost-of-aid-in-dying-medication

Mr. James

- Retired from his own successful business
- Mouth cancer that was treated and in remission for 12 years
- Recurrence in April with tumors in the roof of his mouth causing severe pain and nasal congestion
- Trajectory of illness
  - Tumors will block his esophagus
  - Soon he won't be able to swallow, speak or breath

Mr. James

- Asked about Death with Dignity Act if treating the recurrence failed to shrink tumors
- Reasons for considering DWD:
  - Always been hardworking, independent and proud
  - Didn't want to live out what time he had left in pain, with a feeding tube and a tracheostomy
  - Didn't want his family to watch him become an invalid and unable to care for himself

Mr. James

- What happened?
  - By July, tumors blocked his airway
  - Got a feeding tube AND tracheostomy
  - Unable to speak; all communication in writing
  - Decided it was time to start DwDA process
- Doctor was initially ambivalent, became supportive watching his patient accept treatments he didn't want, so agreed to help
- Fulfilled legal requirements, got a prescription, died peacefully at home surrounded by family in August

Insights into Hastened Death Study

Investigators:

- Robert Pearlman, MD MPH *Geriatrics, Ethics, Health Svcs*
- Judith Gordon, PhD *Psychology*
- Helene Starks, PhD MPH *Communication, Health Svcs, Ethics*
- Tony Back, MD *Oncology*
- Clarissa Hsu, PhD *Anthropology*
- Ashok Bharucha, MD *Geropsychiatry*
- Barbara Koenig, PhD *Anthropology, Nursing, Ethics*
- Margaret P. Battin, PhD, *Philosophy, Ethics*

Funded by Greenwall & Walter & Elise Haas Foundations 1997-2001

Hastened Death Study Papers

Back AL et al. ***Clinician-patient interactions about requests for physician-assisted suicide: A patient and family view***. Arch Intern Med, 2002; 162(11):1257-65.

Bharucha AJ et al. ***The pursuit of physician-assisted suicide: Role of psychiatric factors.*** J Pall Med, 2003; 6(6):873-83.

Pearlman RA et al. ***Motivations for physician-assisted suicide: Patient and family voices.*** J Gen Intern Med, 2005; 20(3):234-39.

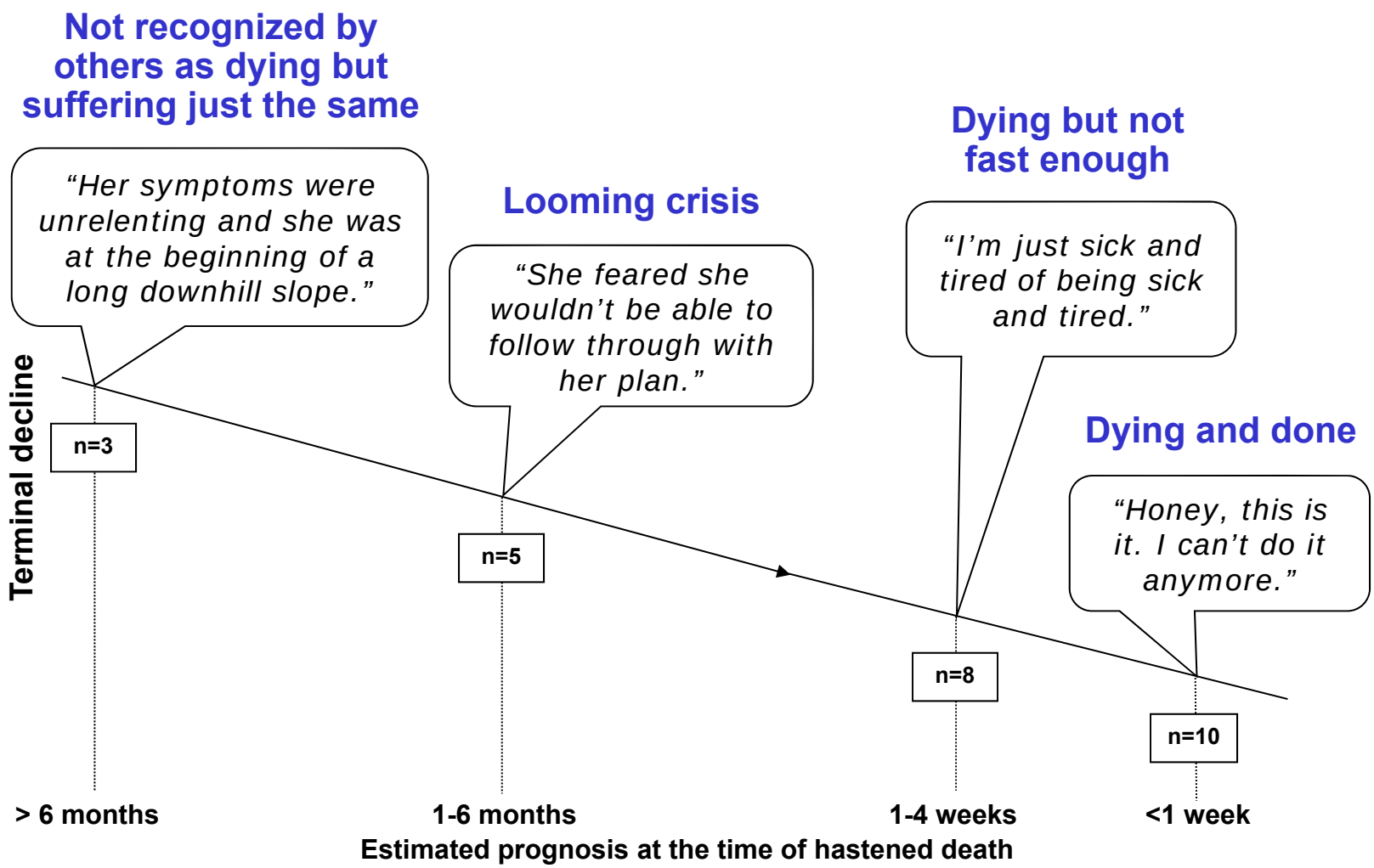
Starks H et al. ***Why now? Timing and circumstances of hastened deaths***. J Pain Symptom Manage, 2005; 30(3):215-26.

Starks H et al. ***Family member involvement in hastened death***. Death Studies, 2007; 31(2)105-130.

Motivating factors for requests

- Illness-related experiences
  - Feeling weak, tired and uncomfortable
  - Pain and/or side-effects of pain medications
  - Loss of function
- Sense of self
  - Loss of sense of self
  - Desire for control
- Fears about the future
  - Fears about future quality of life and dying
  - Negative past experiences with dying

Timing & Circumstances of Death



Looming crisis: Spinal metastases

She knew...she'd be somewhere down on the curve, that she had given up so many things that it wasn't okay.

And rather than wait to get there and have to figure out where that point was, she wanted to just die before it got any worse…when her spine started to go, of course, the big threat was losing control of her bowels, and that was clearly not acceptable.

But if the question is as clear cut as did she commit suicide because she was out of money, the answer is absolutely no. She committed suicide because she was out of body.

Families are part of it too

We kept vigil for eight hours. We just had candles and stayed with him that whole time. It was a really incredibly spiritual thing. We were all talking about him and praying and meditating and crying and being together and noticing. And somebody always had a hand on him. And then about 4:00 in the morning he died.

It was a really good death. It was extremely bonding for our family, the people who were there. It was the strongest, most powerful experience of my life, including the birth of my children. It was more powerful than that. I think it asked more of both of us, maybe, is why.

We had a really good marriage, and maybe it was even better and more intimate because of all that—everything we had to go through together. I mean, we did not just do soul searching, we did soul scouring with each other.

Lessons from the Hastened Death study

- PAD is a gateway to talking about dying
  - Clinicians open to discussions about this are probably open to talking about any/all concerns about dying
  - Maintaining a therapeutic patient-clinician relationship is most important—even when patients and clinicians disagree about PAD
- Need to explore experience with & tolerance for different kinds of suffering
  - Physical, psychological, existential, spiritual, social
  - Need for control & maintaining independence
  - Comfort with the pace of dying
  - Fears about the future

Evaluating requests

- Everyone has a story
  - Your job is to learn what that story is
- Many more will request a R_x than use it
  - 'Insurance' aspect of access to medications gives many patients courage to keep living
  - Engaging in a discussion **IS** an intervention
- You have time to talk and explore options, especially if you start early and invest in good advance care planning
  - Patients are rarely in a hurry to die

Evaluating requests

- Clarify which question is being asked before responding
- Evaluate the patient's decision-making capacity
- Explore all potential dimensions of the patient's unbearable suffering
  - Could be from physical, emotional, psychological, social, spiritual, or existential sources
- Recognize and respond to the associated emotions for the patient and you
  - May be strong and conflicted
  - Distinguish your own feelings and reactions from your patient's

Quill & Arnold, J Pall Med, 2008, 11(8): 1151-1152

7 Questions to Elicit a Patient's Story

1. How do you see the situation you and your family face? (Understanding)
2. What are your past experiences in caring for others who are seriously ill or have died? (Past experiences with illness/death)
3. What are you hoping for in the coming days? Weeks? Months? (Hopes)
4. What are you concerned about (worried) (afraid of)? (Fears)
5. Where do you draw strength to get through each day? (Coping)
6. Do you have a core "family" who supports you through your illness? (Important relationships)
7. Is there anything else about who you are or what you believe that we should know? (Beliefs/values)

Handling requests at HMC

- Call SW as first contact
  - Appropriate for unofficial inquiries and official requests
- Notify Medical Director's office to deploy team
- Team includes
  - SW, Attending MD, Consulting MD, Pharmacist, Risk Mgmt, Medical Director
- Might also include
  - Palliative care, Ethics consultant, Consulting psychiatrist /psychologist, Nurse manager, Spiritual care
- Details in Administrative Policies & Procedures

https://hmc.uwmedicine.org/sites/policiesprocedures/Pages/DEATHWITHDIGNITYACT8037.aspx

Responding to requests

- Have a detailed conversation regarding the risks and benefits of the different possibilities
- Counsel on what to expect, how to prepare meds, involve family, avoid public places
- Learn about the alternatives
  - Withholding/withdrawal of life-sustaining treatments
  - Hospice & palliative care
  - Voluntary withdrawal of oral intake
  - Palliative sedation for severe intractable symptoms

Quill & Arnold, J Pall Med, 2008, 11(8): 1152-1153

Responding to requests

- Reflect on your personal feelings about the request
  - Discuss with other professionals
  - Compassion & Choices Doc-to-Doc program
- Seek out consultation/second opinion
  - Utilize palliative care and ethics consult services
- Balance integrity and non-abandonment
  - Be as specific as possible about what you can/cannot do, explain why
  - Search in earnest with the patient and family for alternative options that might be mutually acceptable
  - Refer to other clinicians for what you cannot do

Quill & Arnold, J Pall Med, 2008, 11(8): 1152-1153

Role of other health care providers

- Psychiatry
  - Evaluate decisional capacity
- Nurses, Social Workers, Spiritual Care
  - Educate about all end-of-life options
  - Evaluate patient and family psychosocial concerns, reasons for request
  - Address health, social, spiritual concerns
  - Counsel and support patients and family members
  - Facilitate family meetings, expect differences of opinion and willingness to participate
- Pharmacists
  - Educate about medications

Conclusions

- Patients may present as ambivalent
  - Narrative approaches engage existential issues and explore quality of life trade offs
- Acknowledge your own discomfort with the process
  - This is your narrative too
  - Examine where you draw the line
  - What influences your moral deliberation
- Seek out colleagues for support
  - Medical Director's office
  - EOL WA: Doc-to-doc outreach program

Resources

- Washington State Dept of Health
  - www.doh.wa.gov/dwda/
- OHSU Guidebook
  - www.ohsu.edu/ethics/guidebook.pdf
- End of Life WA (formerly Compassion & Choices)
  - http://endoflifewa.org/
- Washington State Hospital Association
  - www.wsha.org/