

Washington  
Death with Dignity Act  
Overview of the Law & Report  
of 1<sup>st</sup> Year (2009) Data

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# Washington Death with Dignity Act

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- Terminally ill, competent, adult Washington residents
- Medically predicted to die within six months
- Request & self-administer lethal medication prescribed by a physician
- 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
- Two oral and one written request
- A 15-day waiting period between oral requests
- Physicians, patients and others acting in good faith have criminal and civil immunity



# Washington Death with Dignity Act

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- 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



# Definitions

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- Physician-assisted dying (PAD) (aka physician-assisted suicide – PAS)
  - Request for MD to prescribe medications **that the patient can use** with the intention of ending her life
- Voluntary active euthanasia
  - Request for the **MD to inject medications** with the primary intention of ending the patient's life



# Election results

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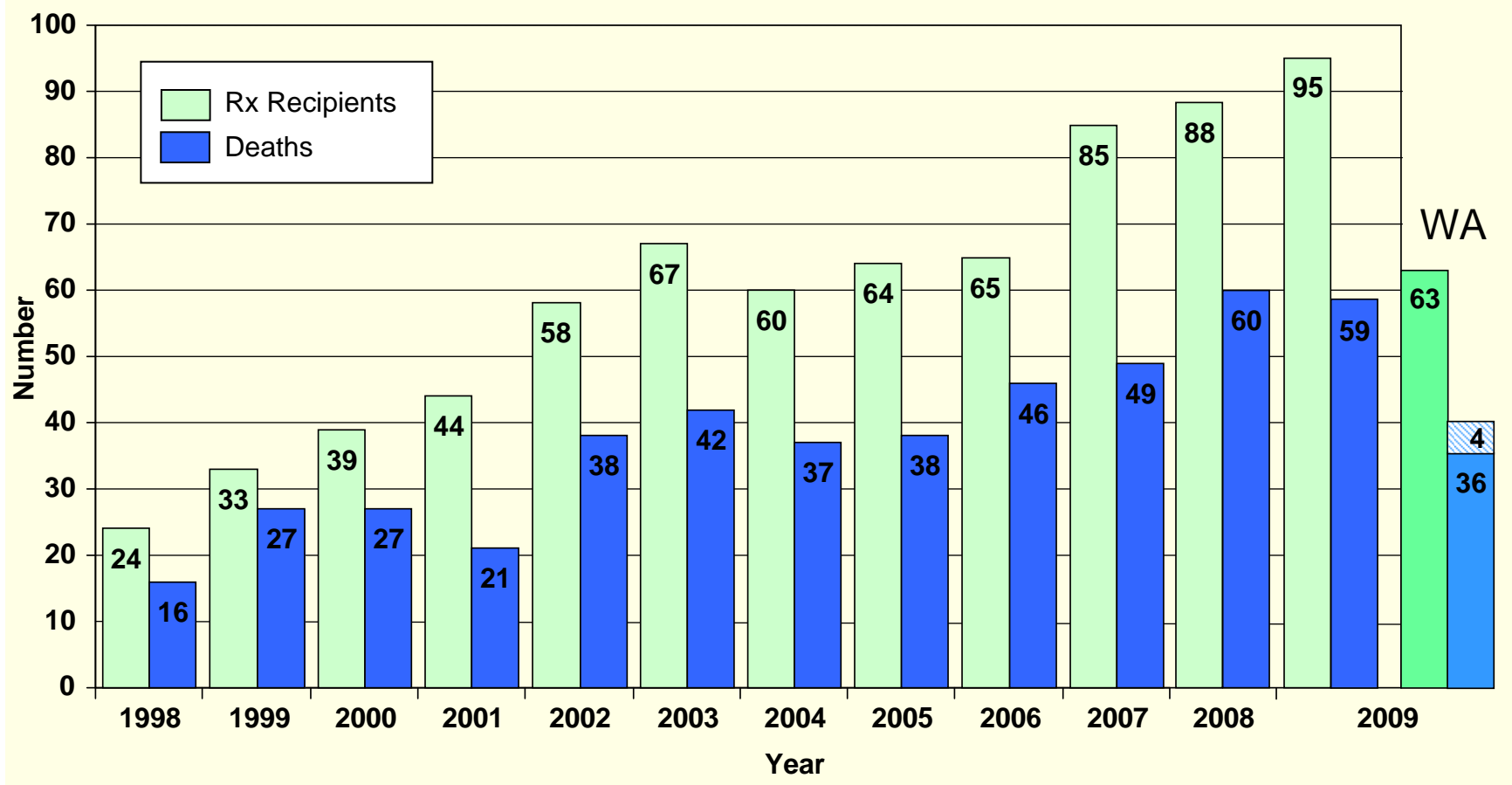
- Voter turnout: 84.6% of registered voters
- Votes cast for I-1000: 96.6% of ballots
  - Yes: 57.8% (1,715,219 votes)
  - No: 42.2% (1,251,255 votes)
- Effective Start Date: March 5, 2009  
(120 days after the measure passed)

# Experience in Oregon & Washington

## DWDA Statistics by Year, 1998-2009

OR Rx Recipients (n=722) and Deaths by medication ingestion (n=460, 64%)

WA Rx Recipients (n=63) and Deaths by medication ingestion (n~40, 63%)





# OR/WA patients 1998-2009

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	<u>Oregon</u>	<u>Washington</u>
■ % of overall deaths	1.5%	0.08%
■ Male	53%	55%
■ Median age	71 (Range: 25-96)	Range: 48-95
■ White	98%	98%
■ Marital status		
● Married	46%	46%
● Widowed	22%	27%
● Divorced	24%	22%
● Never married	8%	5%
■ Enrolled in hospice	88%	72%



# OR/WA patients 1998-2009

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<b>Underlying illness</b>	<u>Oregon</u>	<u>Washington</u>
■ Cancer (malignant neoplasms)	81%	79%
■ Amyotrophic lateral sclerosis	8%	9%
■ Chronic lower respiratory disease	4%	9%
■ HIV/AIDS	2%	no data
■ Other (from Oregon only)	6%	3%
● Includes alcoholic hepatic failure, corticobasal degeneration, diabetes with renal complications, hepatitis C, organ-limited amyloidosis, scleroderma, Shy-Drager syndrome, multiple sclerosis, meningioma, chronic heart failure, and Huntington's disease		
● Other diseases not specified in Washington		





# OR/WA patients 1998-2009

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## Place of death

	<u>Oregon</u>		<u>Washington</u>	
	N	(%)	N	(%)
■ Home	435	(94.6)	34	(94.0)
■ Long term care, assisted living or foster care facility	19	(4.1)	no data	
■ Hospital	1	(0.2)	no data	
■ Other	5	(1.1)	no data	



## Motivations for hastening death, 1998-2009

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	<u>OR</u>	<u>WA</u>
■ Losing autonomy	91%	100%
■ Less able to engage in activities making life enjoyable	87%	91%
■ Loss of dignity	85%	82%
■ Losing control of bodily functions	58%	41%
■ Burden on family, friends/caregivers	37%	23%
■ Inadequate pain control/pain concerns	22%	25%
■ Financial implications of treatment	3%	2%



# PAD and vulnerable patients

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- 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



# MD perceptions of Oregon patients

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- 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



# Attending physician responsibilities

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## ■ Confirm eligibility criteria

- Washington State resident
- Age 18 and older
- Competent (able to make and communicate an informed decision to health care providers)
- Terminally ill (incurable, irreversible disease expected to cause death within six months, as determined by the attending physician and a consulting physician)
- Able to voluntarily express his or her wish to die



# Attending physician responsibilities

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- Assure that it is an informed decision

An appreciation of the relevant facts, after being fully informed about

- Medical diagnosis
- Prognosis
- Potential risks associated with taking the prescribed medication
- Probable result of taking the prescribed medication
- Feasible alternatives including, but not limited to, comfort care, hospice care, and pain control



# Attending physician responsibilities

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- Evaluate request

- Assess reasons
- Explore and recommend alternatives (palliative care, hospice, pain/symptom management, psychosocial and/or spiritual counseling, palliative sedation)

- Counsel patient

- Opportunities to rescind request at any time
- Recommend notifying next of kin
- Importance of having another person present and not taking medications in a public place



# Attending physician responsibilities

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- Refer to a consulting physician for medical confirmation of the diagnosis, competency and voluntariness of the request
- Refer to a counselor if concerned about a psychiatric or psychological disorder or depression causing impaired judgment (optional)
- Work with pharmacists to prescribe/get medications





# Attending physician responsibilities

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- Medical record documentation of all steps
- Sign the death certificate
  - List the underlying terminal disease as the cause of death
- Send a copy of the dispensing record to DOH within 30 days



# Consulting physician responsibilities

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- Examine the patient and his or her relevant medical records
- Confirm, in writing the patient's
  - Prognosis
  - Competency
  - Choice is informed and voluntary



# Protections for physicians

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- No civil or criminal liability or neglect for providers acting in good faith, including being present when patient takes the medication
- No censure, discipline, loss of license, privileges, or membership, or other penalties to members of professional organizations for either participating or not participating



# Opting out

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- Providers may opt out because they are unable or unwilling to participate
- Not required to refer but must transfer relevant medical records at the patient's request, to the new provider of choice
- Can continue to provide other patient services (evaluate requests, address concerns, etc) while abstaining from fulfilling the request



# Institutional prohibitions allowed

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- Institutions may prohibit employees from participating in the act
- Must provide written notice to the employees and the general public regarding its policy
- Policy allows providers to give all other services (evaluate requests, address concerns, etc) while abstaining from participation in fulfilling the request



# Role of other health care providers

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- 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



# Washington's first case

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- Linda Fleming
- Age 66, Sequim resident
- Diagnosed in April 2009 with pancreatic cancer
- Died May 21, 2009
- Increasing difficulty swallowing, keeping food down, stomach pain; losing weight
- "I am a very spiritual person, and it was very important to me to be conscious, clear-minded and alert at the time of my death. The powerful pain medications were making it difficult to maintain the state of mind I wanted to have at my death. And I knew I would have to increase them."



# Evaluating requests

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- 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





# Responding to requests

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- 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



# Responding to requests

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- Reflect on your personal feelings about the request
  - Discuss with other professionals
- 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



# Insights into Hastened Death Study

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## Investigators:

- Robert Pearlman, MD MPH *Geriatrics, Ethics & Health Services*
- Judith Gordon, PhD *Psychology*
- Helene Starks, PhD MPH *Health Services & Ethics*
- Tony Back, MD *Oncology*
- Clarissa Hsu, PhD *Anthropology*
- Ashok Bharucha, MD *Geropsychiatry*

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



# Insights into Hastened Death Study

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- Recruitment in Washington ( $n=29$ ) & Oregon ( $n=6$ )
  - Intermediaries: Advocacy & hospice organizations
  
- 23 retrospective cases
  - After death interviews with 28 family members
- 12 prospective cases
  - Before death interviews with 12 patients and 20 family members
  
- Demographics similar to Oregon patients
  - Cancer ( $n=21, 60\%$ )
  - AIDS ( $n=6, 17\%$ )
  - Neurologic ( $n=5, 14\%$ )
  - Other ( $n=3, 9\%$ )



## Patient characteristics (N=35)

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Manner of death	N	(%)
■ Self-administered medications	17	(49)
■ Self-administered gunshot wound	1	(3)
■ Other-administered medications	8	(23)
● Back-up to complications ( <i>n</i> =1), concurrent consent ( <i>n</i> =3), prior consent ( <i>n</i> =4)		
■ Underlying illness	8	(23)
■ Still alive at end of the study	1	(3)



# Motivating factors for requests

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■ Illness-related experiences	N	(%)
● Feeling weak, tired and uncomfortable	24	(69)
● Pain and/or side-effects of pain medications	14	(40)
● Loss of function	23	(66)
■ Sense of self		
● Loss of sense of self	22	(63)
● Desire for control	21	(60)
■ Fears about the future		
● Fears about future quality of life and dying	21	(60)
● Negative past experiences with dying	17	(49)



# Cancer with spinal metastases

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“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.”



## Feeling weak, tired and uncomfortable

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“In the last 6 months her lungs started giving out... so she was always short of breath, and she found it very hard to even move. And her muscles had gotten so weak that she could not bend over and pick something up off the floor anymore. She had trouble getting in and out of bed and a lot of trouble getting in and out of her car. She knew that any day now she wasn't going to be able to drive anymore and that was going to be it.”





# Pain and side-effects of medications

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“He had been taking Roxicet for months, and so by that time his body had built up a tremendous tolerance. [Hospice] could knock him out; he could be a vegetable, but that was not what he wanted. I mean, if he couldn't function and at least think somewhat clearly, life wasn't worth it. But it got to a point where the pain was just intolerable.”

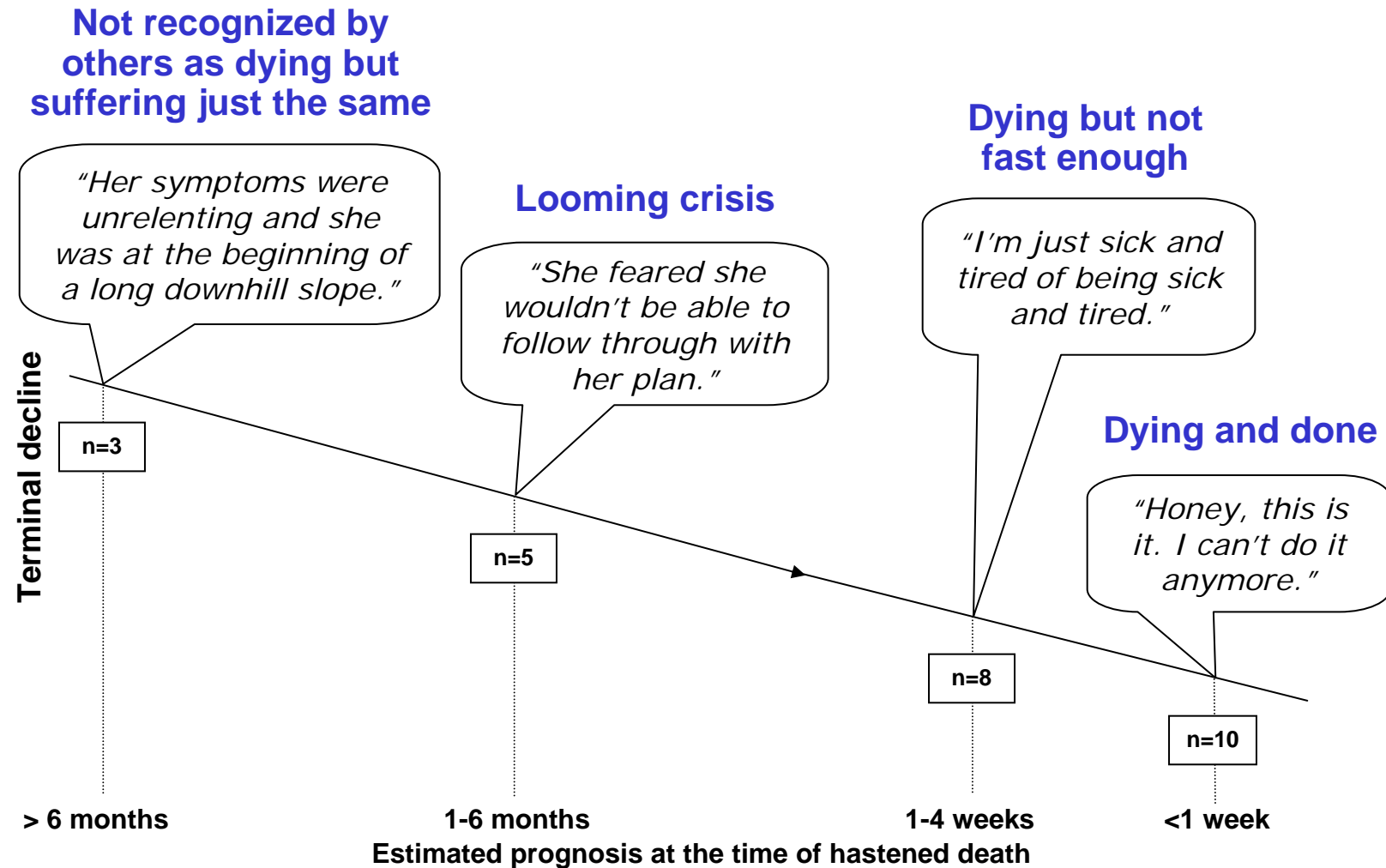


# Loss of sense of self

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“The things that were meaningful to her in her life were her art, her ability to do her art, her friends and spending time with her friends, and cooking and eating. And she was very convinced that when she couldn't do any of those things anymore, her life would be meaningless, and she wouldn't want to live anymore.”

# Timing & Circumstances of Death





# Lessons from this study

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- Qualities valued by patients & families
  - Openness to discussion about aid-in-dying
  - Expertise in dealing with the dying process
  - Maintaining a therapeutic patient-clinician relationship—even when patients and clinicians disagree
- Aid-in-dying is the most taboo topic
  - Clinicians open to discussions about this are probably open to talking about any/all concerns about dying



# Lessons from this study

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- Patients have long-held beliefs about hastened death
  - Some seek this as an option before they are in a terminal stage of illness
- Multiple reasons for wanting to hasten death
  - Most can be addressed & managed
  - Usually require a cumulative set of circumstances before they reach their threshold



# Lessons from this study

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- Lack of openness to discuss PAD may result in a “don't ask, don't tell” policy for both patients & clinicians
  - Could result in less-than-optimal care and the exploration of other possible options
- Acknowledge own discomfort with the process
  - Examine where you draw the line
  - What influences your moral deliberation



# Implications for Health Care Providers

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- Patients & families appreciate expertise with the dying process
  - Good communication skills
  - Setting reasonable expectations
  - Individualizing pain control
  - Knowledge about the lethal potential of commonly used medications
  
- Explore experience with & tolerance for suffering
  - Physical, psychological, existential
  - Need for control & maintaining independence
  - Comfort with the pace of dying
  - Fears about the future



# Implications for Health Care Providers

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- Possible stigma for clinicians if they become known as a willing provider
- Networks needed for support and referral
  - ARNPs not allowed to write Rx
  - May want to involve a team to assure compliance with the law





# Resources

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- Washington State Dept of Health
  - [www.doh.wa.gov/dwda/](http://www.doh.wa.gov/dwda/)
- OHSU Guidebook
  - [www.ohsu.edu/ethics/guidebook.pdf](http://www.ohsu.edu/ethics/guidebook.pdf)
  - Washington supplement in the works
- Compassion & Choices
  - [www.candcofwa.org/](http://www.candcofwa.org/)
- Washington State Hospital Association
  - [www.wsha.org/](http://www.wsha.org/)



# Conclusions

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- Many more will request a R<sub>x</sub> than use it
  - ‘Insurance’ aspect of access to medications gives many patients courage to keep living
- You have time to talk and explore options
  - Patients are rarely in a hurry to die
  - Median time from initial request to death = 43 days
- Involve others as required and desired