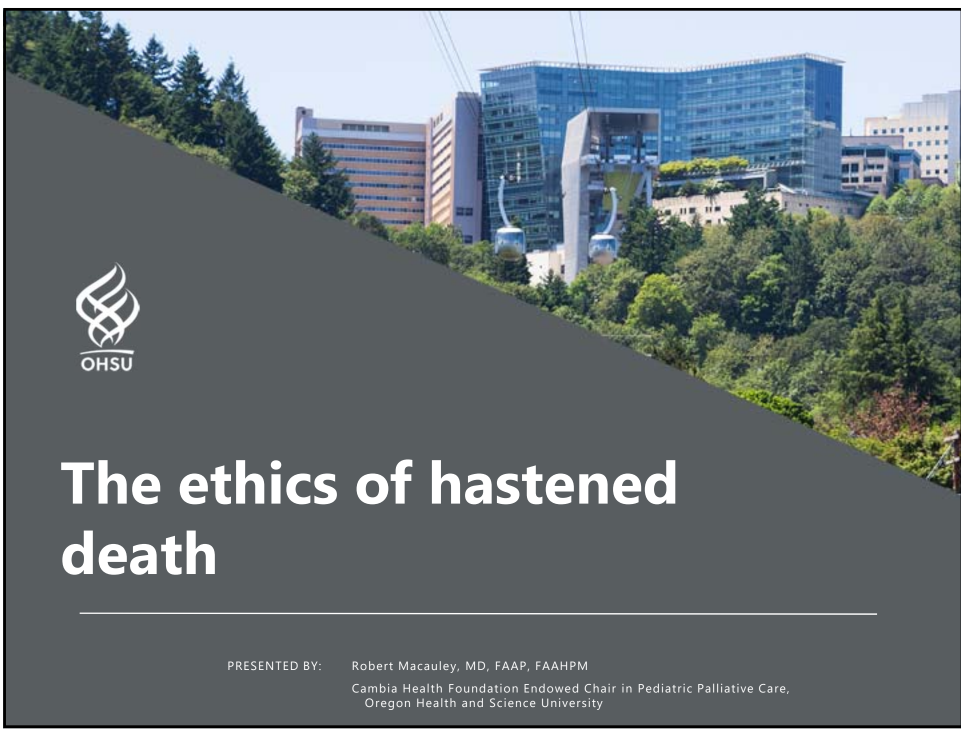

Disclosure of ABIM Service: Robert Macauley, MD

- I am a current member of the Test-Writing Committee on Hospice and Palliative Medicine.
- To protect the integrity of certification, ABIM enforces strict confidentiality and ownership of exam content.
- As a current member of the Test-Writing Committee on Hospice and Palliative Medicine, I agree to keep exam information confidential.
- ***No exam questions will be disclosed in my presentation.***

EXIT
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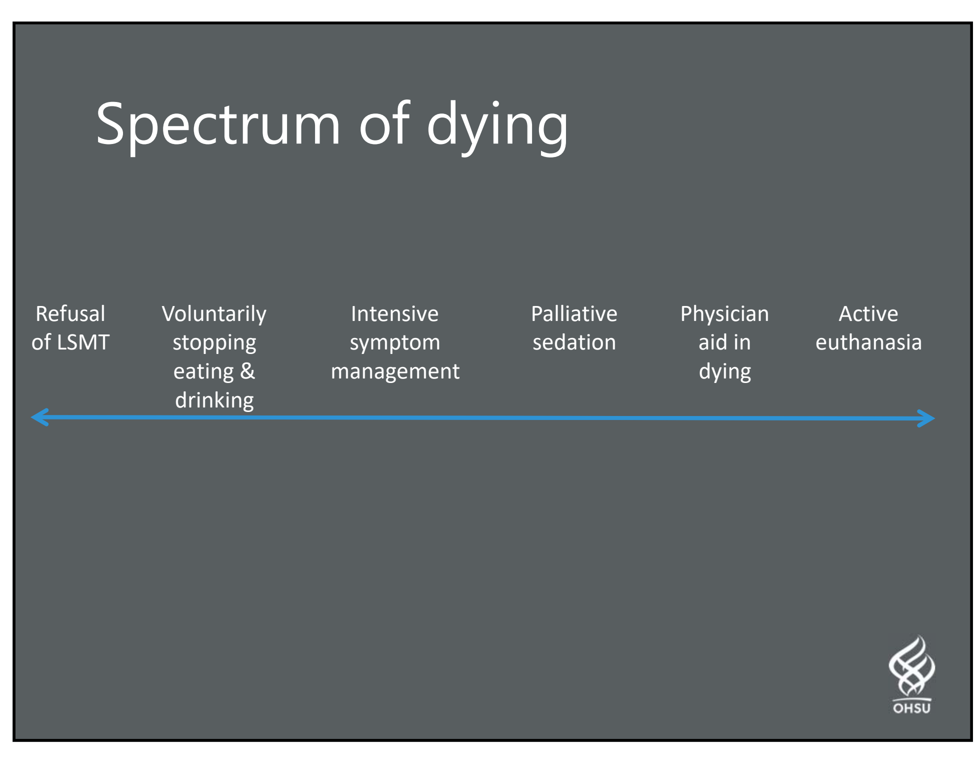
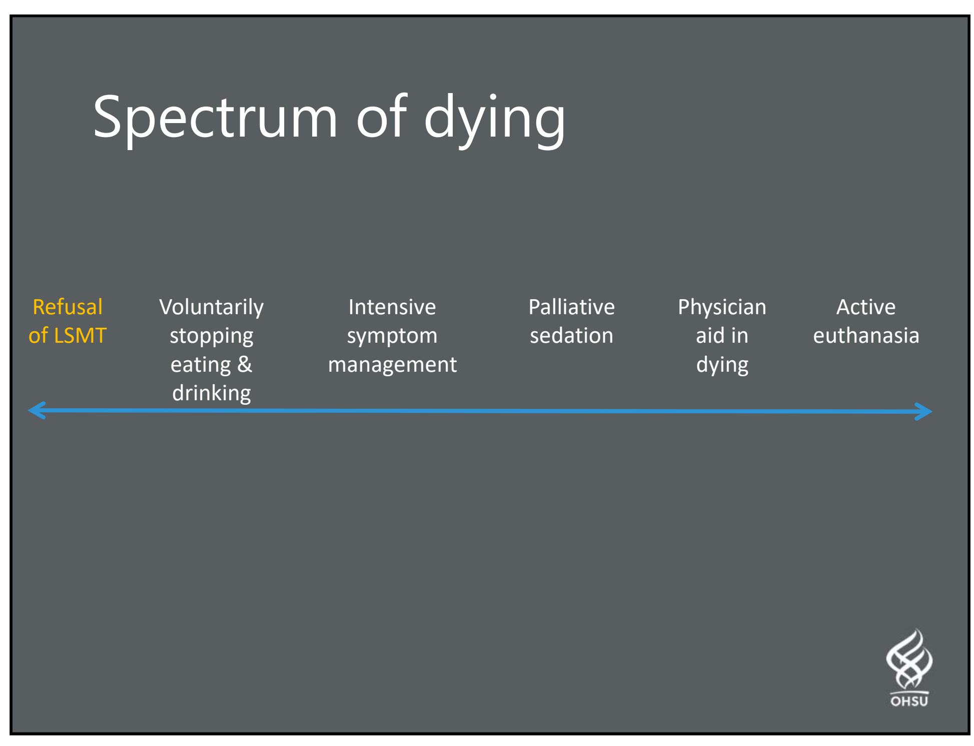

Spectrum of dying
Refusal of LSMT
Voluntarily stopping eating & drinking
Intensive symptom management
Palliative sedation
Physician aid in dying
Active euthanasia
OHSU



Refusal of life-sustaining medical treatment

- For most of the history of Western medicine, LSMT was assumed to be mandatory (beneficence)
- As technology expanded, increased possibility of sustained life with poor benefit/burden ratio
- Refusal of LSMT originally called “passive euthanasia”
- Led to the “Right to Die” movement

6

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"Right to die"

- Predicated on the difference between "active" (bad) and "passive" (acceptable) euthanasia
- Not everyone acknowledged the distinction
  - James Rachels: A man plotted to drown his young nephew in order to gain an inheritance. But before he could, he discovered the boy submerged in a bathtub and did nothing to help. Even though this was "passive," is it not morally reprehensible? (*NEJM* 1975, **292**, 78-80)

Defense of active/passive distinction

- Forgoing LSMT only leads to death in a patient *dependent* on LSMT (and thus the disease is the cause of death)
- Inaccurate analogy: the boy wanted to live, while the patient is refusing LSMT
- Reductio ad absurdum: If not providing a treatment is equivalent to euthanasia, then maximal treatment becomes a moral obligation and honoring a patient's refusal would be akin to murder.

“Right to die” movement in U.S.

- Right to refuse LSMT
  - California Natural Death Act (1976)
  - *In re Quinlan* (New Jersey Supreme Court, 1976)
  - President’s Commission (1983)
  - Hastings Center Guidelines (1987)
- Right to forgo artificially administered nutrition and hydration
  - *Cruzan v. Superintendent, Missouri Department of Health* (1990)

Spectrum of dying

Refusal of LSMT | Voluntarily stopping eating & drinking | Intensive symptom management | Palliative sedation | Physician aid in dying | Active euthanasia

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VSED

- Also called voluntary refusal of food and fluids, terminal dehydration, voluntary palliated starvation
- Clinically, does not entail suffering

Table 3. Nurses' Assessment of the Quality of the Last Two Weeks of Life for Patients Who Died by Stopping Food and Fluids and Those Who Died by Physician-Assisted Suicide.

Variable	Stopped Food and Fluids (N=102)	Physician-Assisted Suicide (N=55)	P Value*
Suffering†			0.007
Median	3	4	
Interquartile range	2–5	2–7	
Pain‡			0.13
Median	2	3	
Interquartile range	1–4	2–4	
Peacefulness§			0.04
Median	2	5	
Interquartile range	1–5	1–7	
Overall quality of death¶			0.95
Median	8	8	
Interquartile range	7–9	6–9	

Ganzini, N Engl J Med 2003; 349:359-365

Ethics of VSED

- In favor
  – Logical extension of right to refuse LSMT
  – Need not involve the physician
  – Informed consent assured and stable over time
- Opposed
  – Need not be terminally ill
  – Risk of coercion
  – Are food and drink “basic human care”?

13

Spectrum of dying

Refusal of LSMT ↔ Voluntarily stopping eating & drinking ↔ Intensive symptom management ↔ Palliative sedation ↔ Physician aid in dying ↔ Active euthanasia

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Intensive symptom management

- Concern
  - Opioids can cause respiratory depression
  - At high doses—as is often used at the end of life—could hasten death
  - Clearly <u>not</u> passive

Typical defense: Rule of Double Effect

- To determine whether an act with a good effect and a bad effect is permissible
- Four components:
  1. Act itself must be, at worst, morally neutral.
  2. The bad effect cannot be the means to the good effect.
  3. The good effect must outweigh the bad effect (principle of proportionality).
  4. The agent must only intend the good effect, although the bad effect may be foreseen.

Criticisms of the RDE

- Physician's intention is multifaceted
- People are usually held responsible for the results of their actions, not just what they "intend"
- Prioritizes physician's professional responsibility over the patient's autonomy
- Could *impede* optimal pain management, by falsely equating intensive pain treatment with hastened death

17

Defenses of intensive symptom management

- Appropriate symptom management may prolong life, rather than hasten death
  - "Morphine kills the pain, not the patient." (Sykes, *Lancet*, 2007)
- Appealing to the RDE might not only be counter-productive, but also unnecessary
  - RDE designed to justify actions with two inevitable effects, but hastened death is actually rather rare
  - "I can't think of any other area in medicine in which such an extravagant concern for side effects so drastically limits treatment." (Angell, *NEJM*, 1982)

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18

Intensive symptom management

- Eventually widely accepted
  - President's Commission 1983
  - Hasting's Center 1987
  - American Medical Association 1992
  - U.S. Supreme Court (*Vacco v. Quill*, 1997)
    - "It is widely recognized that the provision of pain medication is ethically and professionally acceptable even when the treatment may hasten the patient's death if the medication is *intended to alleviate pain and severe discomfort*, not to cause death."

19

Spectrum of dying

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Palliative sedation

- Definition: depressing level of consciousness to ameliorate suffering that is intolerable and refractory
- Different levels (mild/moderate/deep) and durations (emergency/respite/continuous)
- Only continuous sedation to unconsciousness (CSU) is ethically controversial
  - Inability to interact
  - Inability to eat/drink (and MANH usually refused)
  - Impact on life expectancy

Law and ethics

- U.S. Supreme Court (*Washington v. Glucksberg*, 1997): "A patient who is suffering from terminal illness and who is experiencing great pain has no legal barriers to obtaining medication…to alleviate that suffering, even to the point of causing unconsciousness and hastening death."
- Ethically permissible
  - American Medical Association
  - American College of Physicians
  - American Academy of Hospice and Palliative Medicine
  - National Hospice and Palliative Care Organization

Controversial areas

- In situations where life expectancy is weeks or longer
- Palliative sedation for "existential distress"

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- Palliative sedation for "existential distress"

PS and life expectancy

- Some studies suggest PS does not shorten life

Palliative Sedation and Survival in Patients With Cancer

Table 3. Survival in Days From Admission: Sedated Versus Nonsedated Patients

Study	Sedated Patients					Nonsedated Patients					
	Mean	SE/SD	Median	Range	90%/95% CI	Mean	SE/SD	Median	Range	90%/95% CI	*P*
Ventafridda et al[5]			25	NR				23	NR		.57
Stone et al[6]	18.6	NR				19.1	NR				> .2
Fainsinger et al[7]	9	5	8	2-16		6	7	4	1-33		.09
Chiu et al[8]	28.5	36.4				24.7	30.9				.430
Muller-Busch et al[9]	21.5	20.3	15.5	1-109		21.1	23.6	14.0	0-199		NR
Sykes et al[10]											.23
48-hour sedation	14.3		7.0	1-182	11.2 to 17.4	14.2		7.0	1-80	12.7 to 15.7	
7-day sedation	36.6		34.5	7-86	31.5 to 41.7	14.2		7.0	1-80	12.7 to 15.7	
Kohara et al[11]	28.9	25.8				39.5	43.7				.10
Vitetta et al[12]	36.5				20.4 to 52.7	17				2.2 to 31.8	.1
Rietjens et al[13]			8	0-38				7	0-38		.12
Mercadante et al[14]	6.6	4.6				3.3	2.8				.003
Maltoni et al[15]			12		10 to 14			9		8 to 10	.330

Abbreviation: NR, not reported.

Maltoni et al., *J Clin Onc* (2012)

PS and life expectancy

- Some studies suggest PS does not shorten life
  - But that likely has to do with the selection criteria for PS
- Distinguishing between PS and forgoing MANH

AAHPM

Palliative sedation is ethically defensible when used

1) after careful interdisciplinary evaluation and treatment of the patient, and
2) when palliative treatments that are not intended to affect consciousness have failed or, in the judgment of the clinician, are very likely to fail
3) where its use is not expected to shorten the patient's time to death, and
4) only for the actual or expected duration of symptoms

27

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28

Controversial areas

- In situations where life expectancy is weeks or longer
- Palliative sedation for "existential distress"

29

PS for existential distress

- Definition: "The experience of agony and distress that results from living in an unbearable state of existence including…death anxiety, isolation, and loss of control." (American Medical Association)
- May prompt requests for palliative sedation

30

PS for existential distress

It's not that I'm afraid to die, I just don't want to be there when it happens.

(Woody Allen)

izquotes.com

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Ethical complexity

- Clinicians are less comfortable with PS for existential distress
  - May fall outside the boundaries of "medicine"
  - May risk hastening death
- Rejected by American College of Physicians and Veterans Health Administration
- AAHPM: "If palliative sedation is used for truly refractory existential suffering, as for its use for physical symptoms, it should not shorten survival."

32

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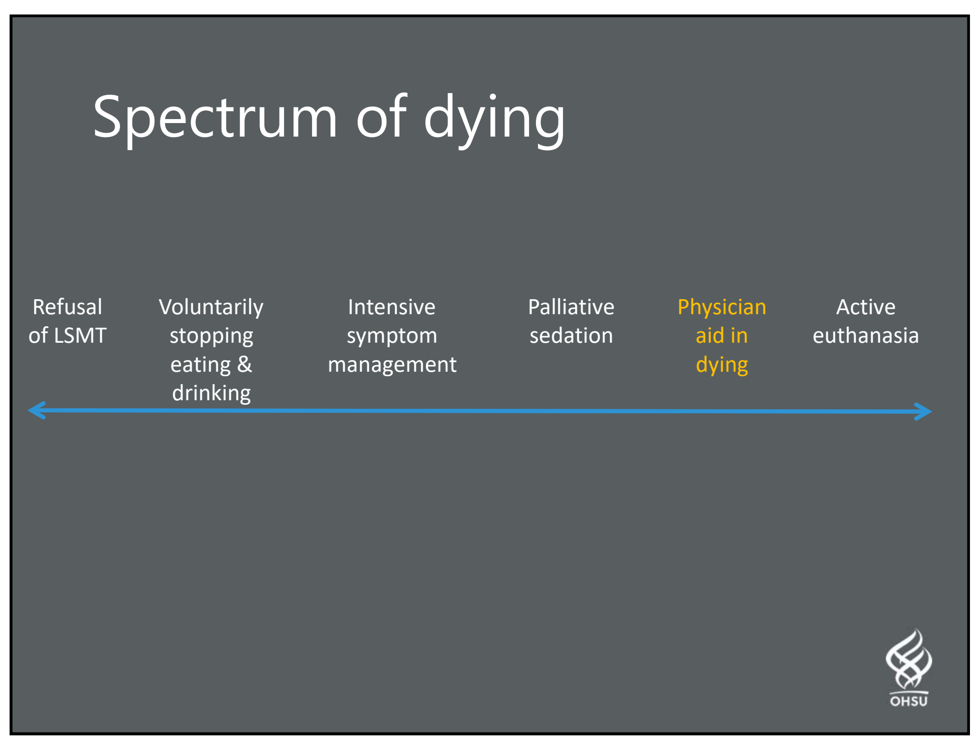

PAD

- Prescribing a lethal dose to a competent, terminally ill adult who can choose to self-administer

34

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PAD

- Prescribing a lethal dose to a competent, terminally ill adult who can choose to self-administer

35

PAD

- Prescribing a lethal dose to a competent, terminally ill adult who can choose to self-administer

36

PAD

- Prescribing a lethal dose to a competent, terminally ill adult who can choose to self-administer
- Requirements
  - Life expectancy < 6 months, confirmed by 2nd physician
  - One written request
  - Two oral requests, separated by at least 15 days

37

Arguments re: PAD

- For
  - Autonomy/compassion
  - Justice
  - Non-abandonment
  - Transparency
- Against
  - Wrongness of killing
  - Physician-patient relationship
  - Exploitation of vulnerable
  - Slippery slope

38

Legal evolution

- Legalized by voter referendum in Oregon in 1994
  - Implementation deferred
- Supreme Court cases (1997)
  - *Vacco v. Quill*: Based on equal protection clause in U.S. Constitution, because patients dependent on LSMT can hasten death through refusal
    - Court response (9-0): there is a difference between forgoing LSMT and actively hastening death
  - *Washington v. Glucksberg*: Based on due process clause in U.S. Constitution
    - Court response (9-0): there are compelling state interests to prohibit PAD (sanctity of life, concern for coercion)
  - So while there is no constitutional right to PAD, states can choose to legalize it

39

PAD laws in the United States

State laws regarding assisted suicide in the United States

- Legal
- Legal under court ruling[1]
- Illegal

[1] In some states assisted suicide is protected through court ruling even though specific legislation allowing it does not exist.

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What does PAD look like?

- 1,750 deaths in Oregon over first 20 years (1 out of 300 total deaths)
- Demographics
  - Mostly cancer patients
  - Highly educated
  - Most enrolled in hospice
  - Primary reasons: loss of autonomy and decreasing ability to engage in enjoyable activities
    - Pain reported by <25%
  - Not everyone qualifies for a prescription, and not everyone who receives one uses it
- Problems
  - Decreasing frequency of psychiatric evaluation (30%→4%)
  - Time from first request to lethal ingestion: 15-1,009 days

41

Spectrum of dying

Refusal of LSMT ← Voluntarily stopping eating & drinking — Intensive symptom management — Palliative sedation — Physician aid in dying — Active euthanasia →

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Active euthanasia

- Currently legal in the Netherlands, Belgium, Luxembourg, Colombia, and Canada
- Arguments against
  - Non-maleficence (first, do no harm)
  - Professionalism
  - Slippery slope
- Arguments for
  - Autonomy (positive right to die)
  - Beneficence
  - Ethical equivalence to already-accepted means of hastening death

43

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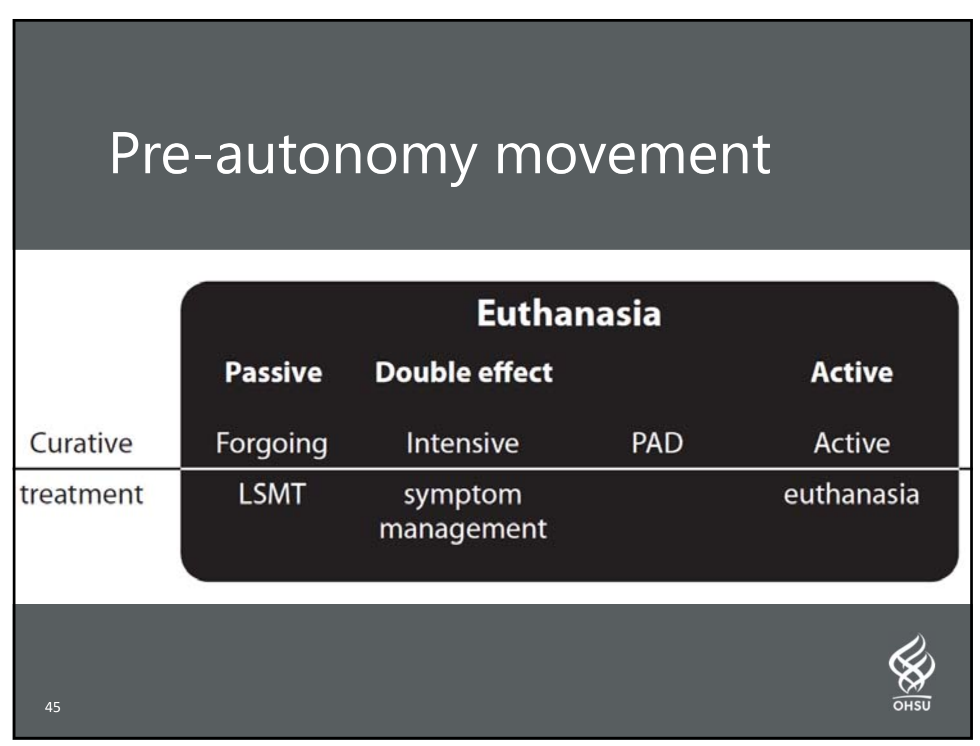
44


Pre-autonomy movement
Euthanasia
Passive
Double effect
Active
Curative
treatment
Forgoing
LSMT
Intensive
symptom
management
PAD
Active
euthanasia
45
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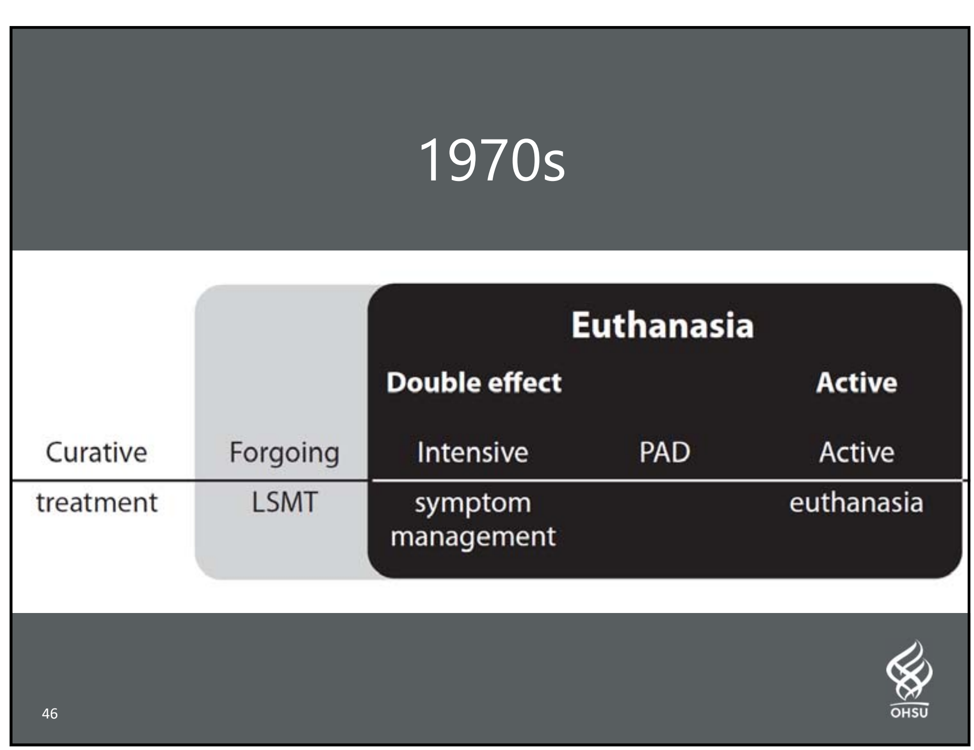
1970s
Euthanasia
Double effect
Active
Curative
treatment
Forgoing
LSMT
Intensive
symptom
management
PAD
Active
euthanasia
46
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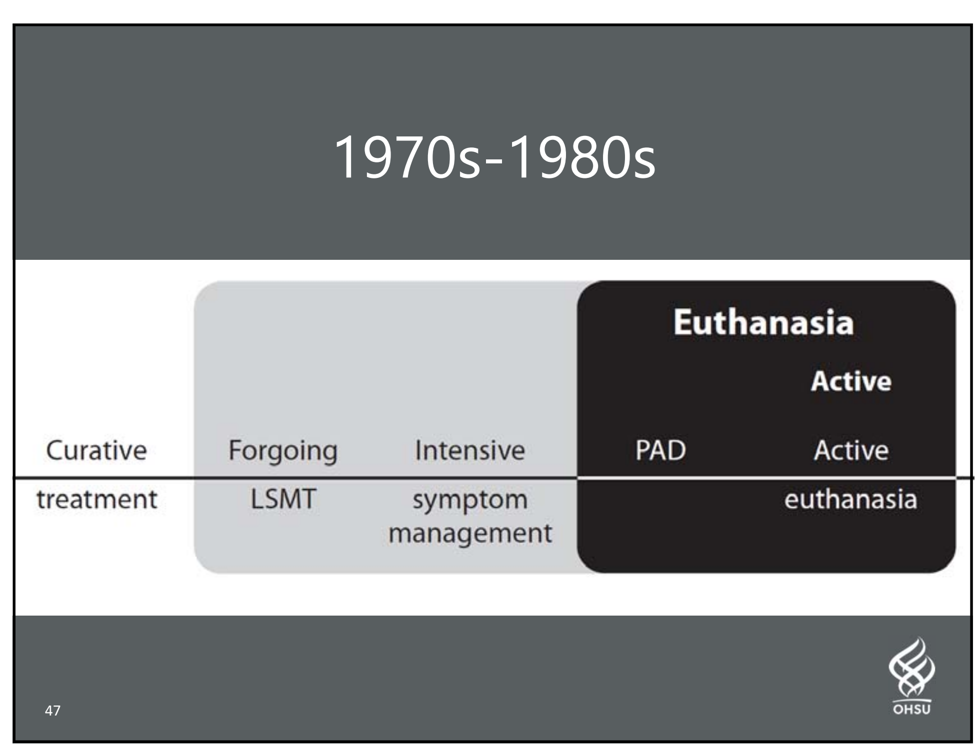
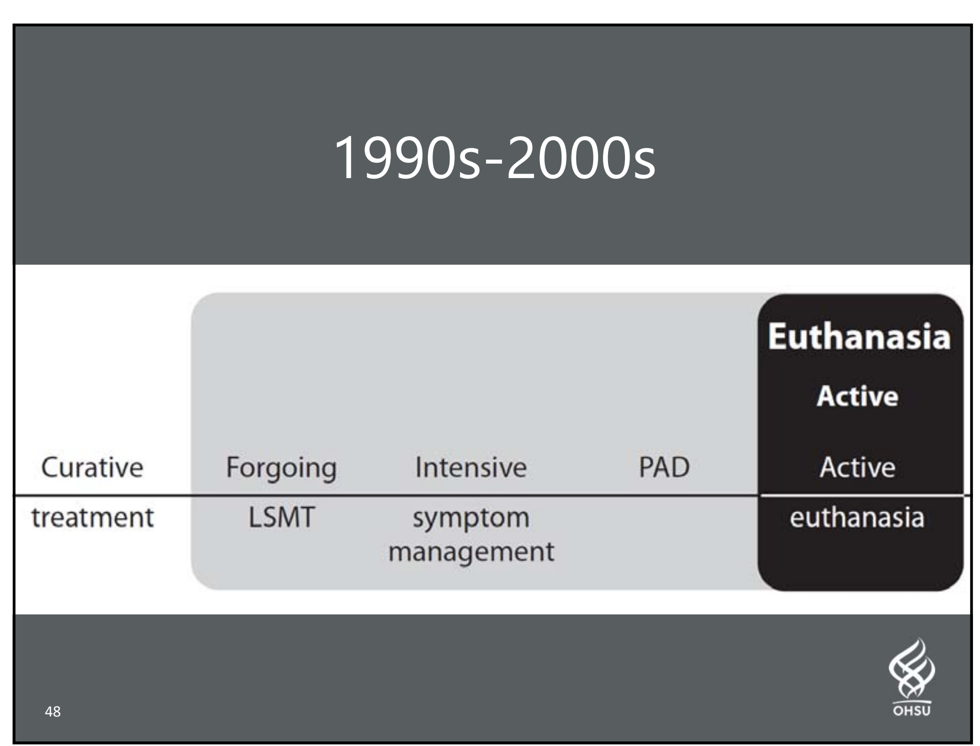
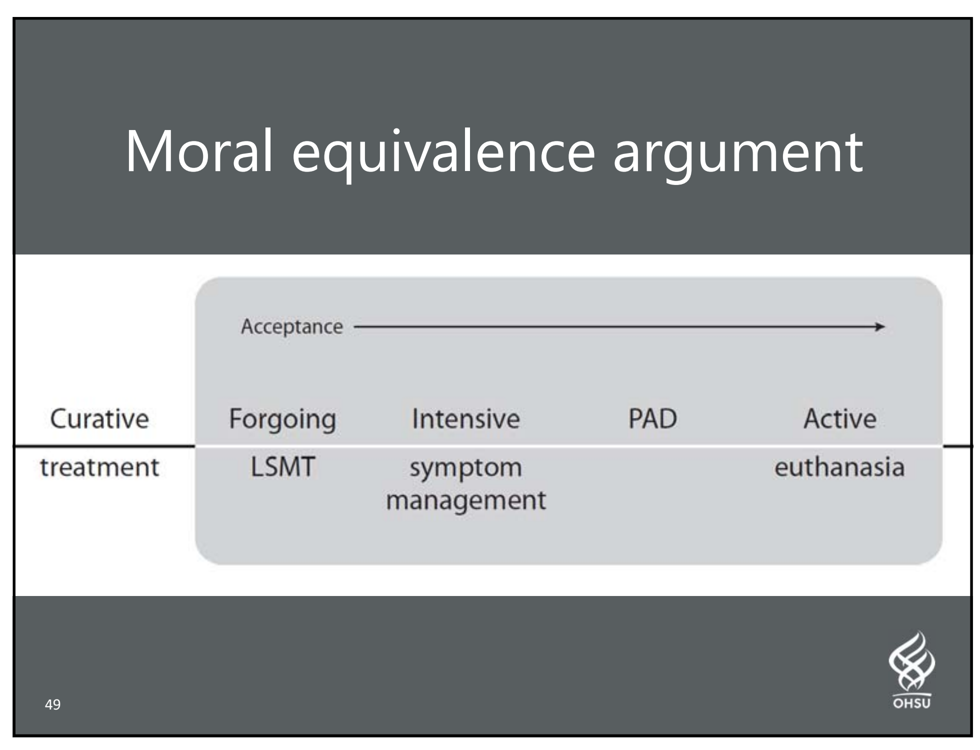
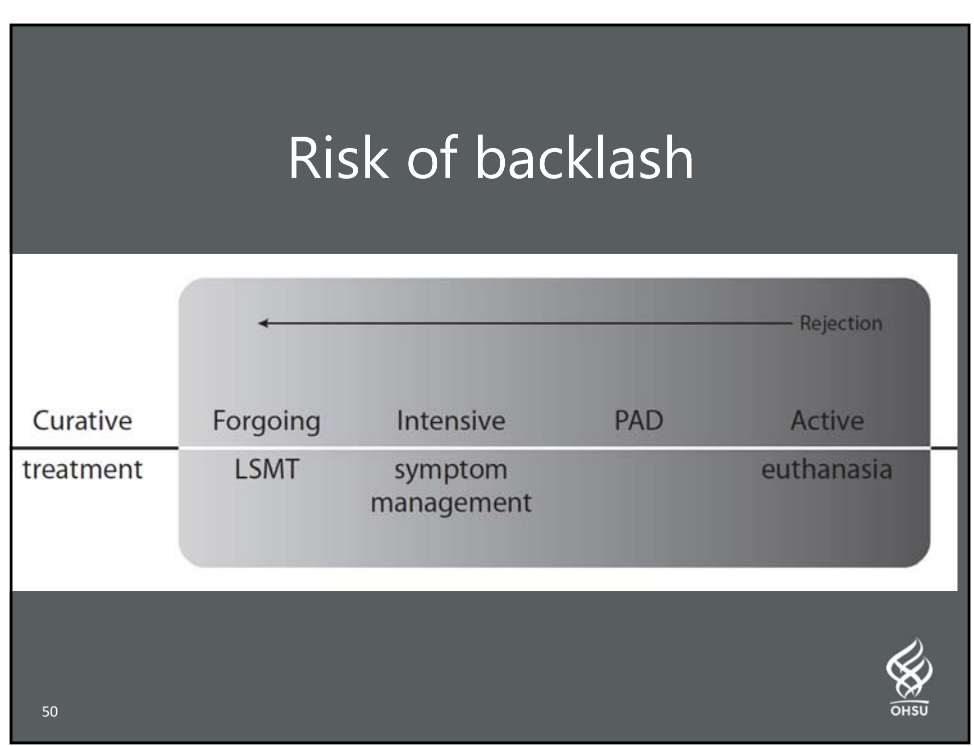
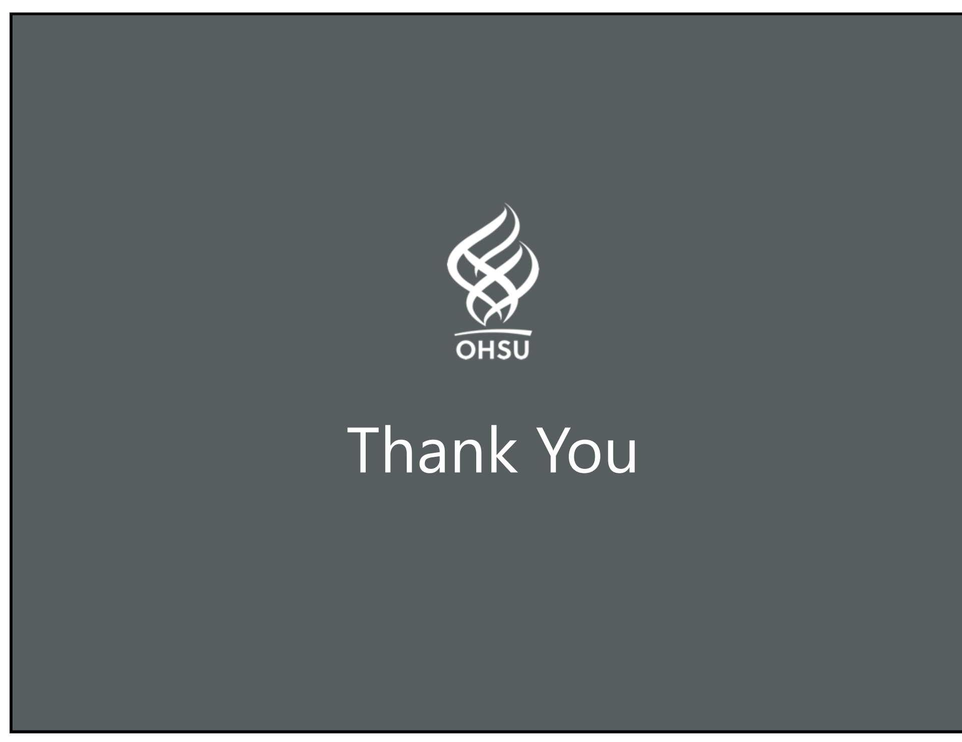

1970s-1980s
Euthanasia
Active
Curative
treatment
Forgoing
LSMT
Intensive
symptom
management
PAD
Active
euthanasia
47
OHSU


1990s-2000s
Euthanasia
Active
Curative
treatment
Forgoing
LSMT
Intensive
symptom
management
PAD
Active
euthanasia
48
OHSU


Moral equivalence argument
Acceptance
Curative
treatment
Forgoing
LSMT
Intensive
symptom
management
PAD
Active
euthanasia
49
OHSU


Risk of backlash
Rejection
Curative
treatment
Forgoing
LSMT
Intensive
symptom
management
PAD
Active
euthanasia
50
OHSU



Case

- A 77-year-old man has prostate cancer that is metastatic to bone. Escalating doses of opioids can usually control his pain, but he often feels sedated. He is unable to do the things in life that he most loves—like taking walks and visiting his grandchildren—and he does not want to “wither away.”
- “I just want this to end, Doc,” he says. “Can’t you do something?”

Case

1. What other questions should you ask?
2. What options are available to you?
3. Even if a clinical practice is illegal, are there times you would consider doing it, if you felt it was justified for a patient?