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We will discuss today:

- **Suffering:**
 - *What is it? How is it similar to and different from pain?*
 - *Manifestations and expectations*
 - *Alleviation of suffering*
- **Controversial EOL Options:**
 - *Palliative sedation*
 - *“Conventional” suicide*
 - *Voluntarily stopping eating and drinking*
 - *Medical aid-in-dying*
 - *Voluntary Euthanasia*

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Suffering

- Dreaded
- Can arise from physical symptoms
- Can be independent of physical symptoms
- Essentially a human experience
- Difficult to define, but we know it when we experience it

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Cassell: *The Nature of Suffering and the Goals of Medicine*, 1991

- Only a person can suffer
- Suffering encounters the meaning of what is being experienced
- Forward-looking focus
 - *“If this keeps up, I will not be able to endure it.”*
- Fear of being overcome by distress

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Expectations of the sufferer

- We are intrigued by but turn away from suffering
- Dignity ≈ not showing distress
- Daudet: *“Pain is always new to the sufferer, but loses its originality for those around him.”*
- Redemptive nature of suffering?
- Snippets from the tradition:
 - *Isaiah 53:7*
 - *BCP 461*

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Measuring Suffering

- The only one who can assess suffering is the person enduring it
- Self-questioning
 - *“Maybe I’m making too much of this.”*

DWE:

“When a dying patient is told to try to not talk about it or to look on the bright side, it adds yet another layer to the suffering, that of loneliness.”

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Alleviation of Suffering

<p>“Professional”</p> <ul style="list-style-type: none"> • <i>Palliation of physical symptoms</i> • <i>Spiritual counseling</i> • <i>Psychological therapy</i> • <i>Healing relationships</i> • <i>Dignity therapy</i> • <i>Expressive therapies</i> • <i>Legacy, “ethical will”</i> 	<p>“But what can I do?”</p> <ul style="list-style-type: none"> • <i>Be present</i> <ul style="list-style-type: none"> • <i>Job 2:13</i> • <i>Listen</i> • <i>Compassion</i>
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...but those all take energy and time...

- ...and that is just what many people at the very end of life do not possess
- What options are available to achieve relief from that which is unbearable?
- Interventions to lessen awareness or shorten duration of suffering

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Controversial options...

- *Palliative sedation*
- *“Conventional” suicide*
- *Voluntarily stopping eating and drinking*
- *Medical aid-in-dying*
- *Voluntary Euthanasia*

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Reasons given for choosing these

- Intractable symptoms and/or unbearable suffering
- Fear of worsening symptoms / suffering
- Fear of loss of control / autonomy
- Fear of loss of dignity

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Palliative Sedation

The use of sedating medications to relieve intractable symptoms and/or unbearable suffering by reduction in patient consciousness.

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Palliative Sedation

- Temporary or “respite” sedation
 - *≤ 72 hours duration*
 - *Allow effect of medication / intervention*
 - *Good night’s sleep, “reset” coping ability*
- Continuous sedation until death
 - *Survival prognosis ≤ 14 days*
 - *Titrate to desired level of sedation*
 - *Inability to eat or drink*
 - *Minimal to no ability to communicate*

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Palliative Sedation: Ethics & Law in 13th Century

Aquinas - Principle of double effect:
 An action that has two foreseeable outcomes, one desired (relief of suffering) and one undesired (death) can be moral if:

1. *The action itself is morally positive or neutral*
2. *The desired and not the undesired effect is intended*
3. *The desired effect is not achieved by the undesired effect*
4. *There is proportionality between the desired and undesired effects*

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Palliative sedation: Ethics & Law in 20th Century

SCOTUS, *Vacco v. Quill* (1997):

- Found no “right to die”
- Permitted aggressive palliative care that risked death, provided the physician’s intent was alleviation of pain and suffering

Practical answer: No evidence that palliative sedation in appropriate patients (survival prognosis ≤ 14 days) shortens survival

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Voluntarily shortening life

- Intractable symptoms and/or unbearable suffering
- Fear of worsening symptoms / suffering
- Fear of loss of control / autonomy
- Fear of loss of dignity
- Lessen the duration of suffering
- Avoid future suffering or anticipated intolerable situation

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Suicide

<p>“Conventional” suicide</p> <ul style="list-style-type: none"> • Usually performed alone, in secret • Antithetical to the “good death,” dignified ending most people desire 	<p>Voluntarily stopping eating & drinking (VSED)</p> <ul style="list-style-type: none"> • Anorexia common • Hunger & thirst issues • Usually takes longer than anticipated
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Medical Aid-In-Dying (MAID)

- Previously called “Physician-assisted-suicide” & others
- Suicide is legal throughout the US, but assisting a suicide is homicide
- MAID is currently legal in 9 states, DC, and Canada
- Longest experience is in Oregon (1997)

MAID States

CA
CO
HI
MT
ME
NJ
OR
VT
WA

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Oregon Death With Dignity Act: Requirements

- Oregon resident ≥ 18
- Able to make and communicate decisions
- Terminal illness, prognosis ≤ 6 months
- Capable of swallowing fatal dose
- Verbally request assisted dying twice, ≥ 15 days apart
- Provide signed and witnessed request
- Consult 2nd physician to confirm terminal state and decision-making capacity
- Psychiatry consultation if either physician suspects depression / mental illness
- Mandatory physician reporting

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Oregon death with dignity act: outcomes

- Through 2019, 1657 Oregonians died from lethal dose of medication
 - (-0.5% of deaths)
- 1^o diagnosis: Cancer (76%)
- neurologic diseases (like ALS) disproportionately represented
- No evidence of “slippery slope”
- Increased cost, lack of availability of secobarbital (preferred drug)
- Novel “cocktails” developed

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MAID in Ohio

- MAID not legal in Ohio
- Current legislature and Governor not favorable
- Education & advocacy group: <https://ohiooptions.org/>

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Voluntary Euthanasia

- Ending a person's life at their request
 - Like "putting a dog to sleep"
- Not legal anywhere in the United States
- Practiced in a few European nations; The Netherlands has the most experience
 - Only open to citizens
 - (Switzerland allows MAID and voluntary euthanasia for non-citizens)

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Summary

- Suffering may derive from physical symptoms, but related to the meaning of the symptoms and experience
- Alleviation of suffering requires acknowledgment, affirmation, and empathy
- A dying person may experience intolerable distress they have neither time nor energy to address
- For someone enduring unbearable suffering near the end of life, aggressive but controversial options exist
- Palliative sedation is legal and can be appropriate for the last few days of life
- Medical Aid-in-Dying is variably available, but involves strict eligibility and procedures

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