The End of Life
Controversial Conversations

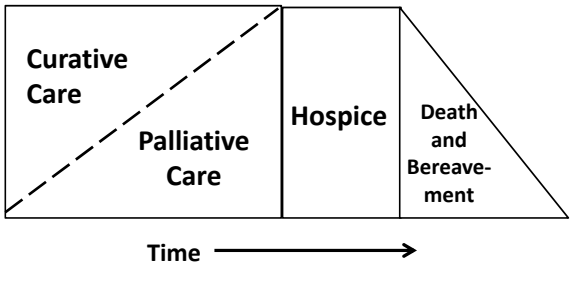
Lisa Anderson-Shaw, DrPH, MA, MSN
September 12, 2015

Speaker has no conflicts of interest to disclose

Objectives

1. **Define end-of-life care options for terminally ill patients.**
2. Describe common myths about palliative sedation.
3. Discuss the clinical and ethical controversies surrounding palliative sedation and other difficult medical decisions at the end-of-life.

End-of-Life Care Options



Adapted from *Hastings Cent Rep* 2005; Spec No: S14-18

Palliative Care Definition

- **Palliative Care** is:

  "patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information and choice"

  -National Hospice and Palliative Care Organization (NHPCO)

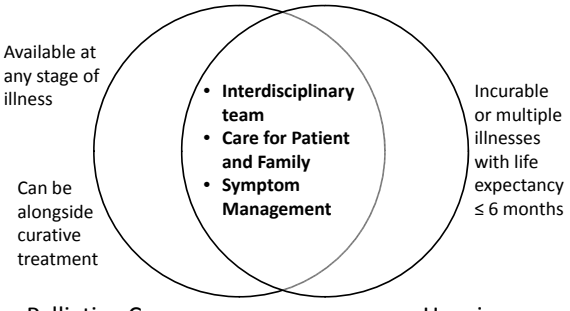
http://www.nhpco.org/palliative-care-4

Key Features of Palliative Care Philosophy

Team	• Care is provided by an interdisciplinary team • Patients, families, and non-palliative care providers collaborate
Care	• Palliative care services may be provided alongside curative care
Support	• Patient and family are supported through illness, the dying process, and after death

http://www.nhpco.org/palliative-care-4

Palliative Care and Hospice



Transition from Hospital to Home

- Clinical Ethics
- Ethics Consultation Service
- Hospital Ethics Committee (HEC)
- Palliative Care Service

Care Near the End of Life

- Goals of care conversations: with patient, family, care team members
  - (MD, APN, nurses, home care, pharmacist, others)
  - When cure is no longer possible, comfort and quality of life remain the goal
  - Family goals may be different than care team goals

Case Example

Ethical Obligation

- Principles of Ethics:
  - Respect for autonomy
  - Beneficence
  - Nonmaleficence
  - Justice (social, distributive, stewardship)
    - Veracity
    - Fidelity
      - Standard of Care

Tools

- Do – Not-Attempt-Resuscitation
- Power of Attorney for Health Care
- Living Will
- POLST (Practitioner orders for Life Sustaining Treatment) (www.POLST.ORG)
- Practitioner conversation and guidance (Key to all of the above)_

Barriers to Quality End of Life Care:

- Practitioner training
- Fear of taking away hope
- Patient fear of talking with family about end of life topics in general
- General lack of awareness related to Advance Directives by public and practitioners

Take-Home Thoughts

- Patients and family need informed guidance when a life limiting diagnosis has been made
- All care team members are in a position to begin education on end of life care
- Resources such as palliative care, Ethics Consultation and Pastoral Care are often available to patient, team and family

The End of Life Controversial Conversations: Options of Last Resort

Laura Meyer-Junco, PharmD, BCPS, CPE
September 12, 2015

Speaker has no conflicts of interest to disclose

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2. **Describe common myths about palliative sedation.**
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The "Right to Die" Movement

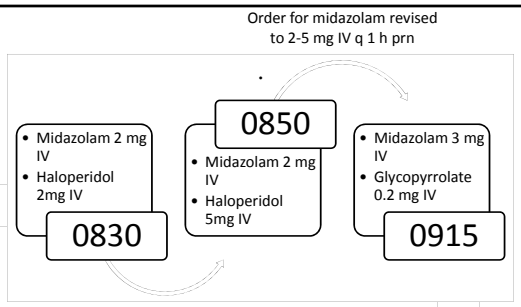
- Campaigns for physician-assisted death are gaining momentum across the United States
- In a recent poll, three-fifths of Americans support legalizing physician-assisted death
- What are potential interventions of last resort for terminally ill patients?

http://www.economist.com/node/21656253

Patient #1: Walter

- 79 year old male with large subdural hematoma after falling off of a ladder and hitting his head
  - Admitted to the hospital; neurosurgery consulted
- Walter was deemed unlikely to recover and continued to decline
  - Increasing restlessness
- Palliative Care was consulted
  - Goals of care discussed with family
  - Comfort care was agreed upon

Walter's Final Hours…



Am J Hosp Palliat Care 2012; 29(7) 522-524

0930 Restlessness improved

- Walter was no longer trying to pull out IV or get out of bed
- Morphine 4 mg IV given

1030 Restlessness returned

- Walter was waving his arms up and down around his head
- Daughter pleaded for "something for the restlessness" before the grandchildren saw him
- Midazolam 5 mg IV bolus; midazolam 0.5 mg/hr infusion

2200 Walter rests

- Family at bedside
- Death was pronounced

https://www.fraserhealth.ca/media/07EHSymptomGuidelinesDelirium.pdf

Patient #2: Carl

- 65 year old male with metastatic colon cancer refractory to treatment.
- Multiple admissions to the inpatient palliative care unit with severe debilitating pain.
- On his last admission, Carl was weak, jaundiced, and in severe distress from painful metastases to his spine, pelvis, and liver.
- Attempts to control his pain this time were unsuccessful, and Carl was becoming increasingly confused and agitated.
- Decision was to pursue sedation after team meeting and discussion with family.

Quill TE, Miller FG. (2014). *Palliative Care and Ethics.*

Carl's Final Days

- Midazolam was added to his analgesic medications:
  - Midazolam 5 mg bolus x1
  - Midazolam 1 mg/hr infusion
- Within 5 minutes he was sedated, but after 30 minutes he was arousable and still in distress
- A second bolus of midazolam was administered and the infusion increased to 2 mg/hr.
- The infusion was titrated over the next several hours to midazolam 5 mg/hr
- He died 2 days later, sedated, comfortable, and with his family.

J Support Oncol 2004;2:181–186

Walter received which of the following?

A. Management of Terminal Restlessness
B. Palliative Sedation
C. Euthanasia
D. Physician Assisted Suicide or Physician Aid-in-Dying

Carl received which of the following?

A. Ordinary Sedation
B. Palliative Sedation
C. Euthanasia
D. Physician Assisted Suicide or Physician Aid-in-Dying

Myth #1:

PALLIATIVE SEDATION IS EUTHANASIA

What is Palliative Sedation (PS)?

- Several Definitions by Professional Societies (partial list)
  - American Academy of Hospice and Palliative Medicine (AAHPM)
  - Hospice and Palliative Nurses Association (HPNA)
  - American Medical Association (AMA)
  - European Association for Palliative Care (EAPC)
  - National Hospice and Palliative Care Organization (NHPCO)

Am J Hosp Palliat Care 2015; 32: 660-671

The Clearest Distinction is INTENT

Palliative Sedation (PS):
"The monitored use of medications intended to induce a state of decreased or absent awareness (unconsciousness) in order to relieve the burden of otherwise intractable suffering in a manner that is ethically acceptable to the patient, family, and healthcare providers."

-European Association for Palliative Care, 2009

Physician-assisted suicide and euthanasia:
deliberately intend to shorten life and cause death, and thus "categorically distinct" from palliative sedation.

-National Hospice and Palliative Care Organization, 2010

Palliat Med 2009; 23 (7): 581-593 *J Pain Symptom Manage* 2010; 39(5): 914-923

More Definitions..

Euthanasia

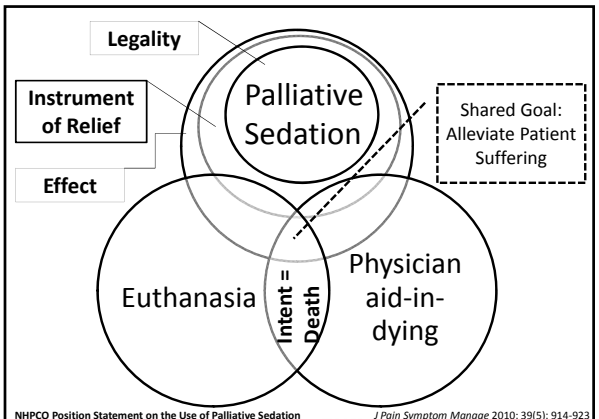
- Also known as: voluntary active euthanasia (VAE)
- "Administration of a **lethal agent** by another person to a patient for the purpose of relieving the patient's intolerable and incurable suffering"
  - AMA Code of Medical Ethics
- Competent patient requested
- **Intent: death**

Physician Aid-in-Dying (PAD)

- Also called: physician-assisted suicide (PAS)
- A physician prescribes a **lethal dose** of medication that is self-administered by the patient
- Competent patient requested
- **Intent: death**

Palliative Medicine 2003; **17:** 97 -101

http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion221.page



NHPCO Position Statement on the Use of Palliative Sedation *J Pain Symptom Manage* 2010; 39(5): 914-923

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~~Lethal~~ Agents for Palliative Sedation

Medication	Starting Dose	Usual Maintenance Dose
Midazolam (Palliative Sedation)	0.5-5 mg IV or SC bolus, then 0.5-1 mg/hr	0.5-10 mg/hr
Midazolam (Endoscopy)	0.5-2 mg IV PRN	Usual Total Dose: 2.5 -5 mg *Gastrointest Endosc* 2003; 58: 317-322
Midazolam (mechanical ventilation)	0.01 to 0.05mg/kg (0.5 to 4 mg) IV PRN	0.02-0.1 mg/kg/hr (1-7 mg/hr) *Crit Care Med* 2013; 41: 263-306

Am J Hosp Palliat Care 2002 19(5):295-297 *J Pain Palliat Care Pharmacother* 2012; 26:30-39

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Medication	Starting Dose	Usual Maintenance Dose
Propofol	20-50 mg IV bolus (may repeat), then 5-10 mg/hr	10-200 mg/hr
Pentobarbital*	1-3 mg/kg IV slow bolus (≥ 50 mg/min)	1-2 mg/kg/hr and titrate to desired level of sedation
Phenobarbital*	200 mg bolus SC or IV (may repeat q 10-15 min)	0.5 -1 mg/kg/hr (25-50 mg/hr) and titrate to effect

*Barbiturates may be used for refractory symptoms not relieved by other agents or in patients with extreme tolerance to other agents.

* Last resort option due to rapid onset of unconsciousness and long duration of action.

J Pain Palliat Care Pharmacother 2012; 26:30-39
Palliat Med 2009; 23 (7): 581-593 www.capc.org/fast-facts/107-controlled-sedation-refractory-suffering-part-ii

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Intermittent Dosing

- Location of care (non-ICU) may preclude use of continuous infusions of PS agents per hospital policy
- Transfer to ICU may not be feasible or desirable for patient/family

Mayo Clin Proc 2010; 85: 949-954

Intermittent Medication	Starting Dose	Usual Maintenance Dose
Lorazepam	0.5-2 mg every 1–2 hr (IV/SC, PO, or SL) *Am J Hosp Palliat Care* 2002 19(5):295-297	0.5-10 mg every 1-4 hours *J Pain Palliat Care Pharmacother* 2012; 26:30-39

"Instrument of Relief" aka Principles and Procedures

Double Effect

- A **double effect** refers to one action that has both a good and bad effect
- High doses for sedation (or opioids for analgesia) are permissible if:
  - the primary intention is to relieve suffering
  - the bad effect (death or respiratory depression) is not the means of achieving relief

Proportionality

- Sedation should be titrated to the **minimum** level needed to render symptoms tolerable
- For some, this may be total unconsciousness
- For most, relief is achieved when patients are sleepy but arousable

J Pain Symptom Manage 2010; 39(5): 914-923
J Pain Palliat Care Pharmacother 2012; 26:30-39

Types of Palliative Sedation

Ann Intern Med. 2009;151:421-424.

- Proportionate Palliative Sedation (PPS)
  - Uses the minimum amount of sedation necessary to relieve suffering at the end-of-life
  - Titration based on symptom relief
  - Unconsciousness is not the goal, but may be required if lower levels of sedation are ineffective

- Palliative Sedation to Unconsciousness (PSU)
  - Unconsciousness is the goal
  - For severe physical, refractory symptoms where continuing consciousness would be intolerable
  - Sedation rapidly escalated over minutes to a few hours until the patient is unresponsive
    - Level of sedation held there until the patient passes

Legal Basis for "Terminal Sedation"

- Supported by the United States Supreme Court in 1997
  - "terminal sedation" not clearly defined

Vacco v. Quill, 1997
Washington v. Glucksberg, 1997

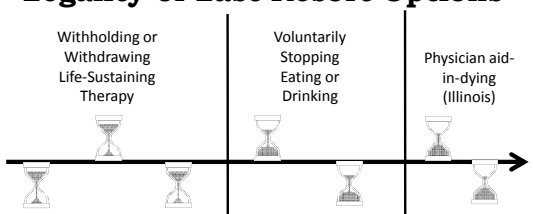
"…A patient who is suffering from a terminal illness and who is experiencing great pain has no legal barriers to obtaining medication from qualified physicians, even to the point of causing unconsciousness and hastening death"

-Justice O'Connor, Washington v. Glucksberg, 1997

Ann Intern Med. 2009;151:421-424. *J Pain Palliat Care Pharmacother* 2012; 26:30-39

Adapted from: Quill TE, Miller FG. (2014). *Palliative Care and Ethics.*

Legality of Last Resort Options



Legal and Widely Accepted	Legal, Mostly Accepted	Illegal

Myth #2:

PALLIATIVE SEDATION HASTENS DEATH

Impact on Survival

Annals of Oncology 2009; 20:1163-1169

Sedation Features	
Duration	4 days (mean)
Mild	62.2%
Deep	37.8%
BZDs	54.3%
Neuroleptics	84.2%
Opioids	25.5%
>2 Drugs	50.6%

+PS: 267 patients — Survival: 12 days (median)

-PS: 251 patients — Survival: 9 days (median)

P=0.330

"…Patients with poorly controlled pain, shortness of breath, and agitation actually die sooner because of the stress caused by this suffering. Studies clearly demonstrate that palliative sedation does not hasten death."
–Center to Advance Palliative Care, 2010

https://www.capc.org/about/press-media/press-releases/2010-1-6/palliative-sedation-myth-vs-fact/

Myth #3:

PALLIATIVE SEDATION (AND PHYSICIAN AID-IN-DYING) ARE COMMON PRACTICES

Frequency of Use

- "Palliative sedation is a treatment of last resort when symptom distress cannot be relieved using standard methods. It is used extremely rarely because the vast majority of patients get acceptable relief without sedation."
  - Center to Advance Palliative Care (CAPC), 2010
- Prevalence of palliative sedation
  - 1% to 50% of terminally ill patients
  - Great variability in the literature
  - Universial definition of palliative sedation lacking

J Pain Symptom Manage 2010; 39(5): 914-923 *J Pain Symptom Manage* 2008; 36:310-333
https://www.capc.org/about/press-media/press-releases/2010-1-6/palliative-sedation-myth-vs-fact/ *Curr Opin Oncol* 2014; 26: 389-394

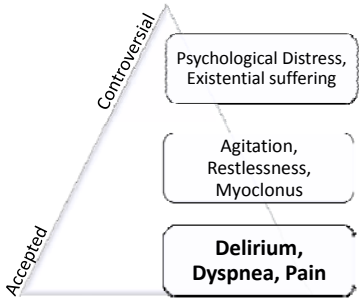
When is Palliative Sedation Appropriate?

Refractory Symptoms	• Aggressive efforts fail to alleviate the symptom • Label as "refractory" only after interdisciplinary evaluation and treatment by experts in palliative and pain management • Psychological and spiritual assessment performed by skilled clinician and chaplain (non-physical symptoms)
Informed Consent	The aims, benefits, and risks of palliative sedation have been discussed with the patient and/or family.
Imminent Death*	The patient is close to death. Prognosis of death within 14 days per NHPCO

*EAPC states that transient or "respite" sedation may be appropriate earlier

J Pain Symptom Manage 2010; 39(5): 914-923 *Palliat Med* 2009; 23 (7): 581-593 *J Palliat Med* 2003; 6 (3):345-50.

Indications for Palliative Sedation:



J Pain Symptom Manage 2008;36: 310-333 *Curr Opin Oncol* 2014; 26: 398-394

Legalized Physician Aid-in-Dying (PAD)

http://www.deathwithdignity.org/advocates/national

Oregon Death with Dignity Act 1997-2014

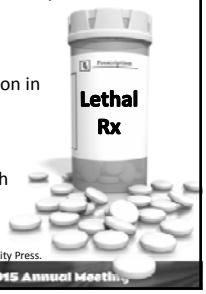
http://public.health.oregon.gov

1,327

Since becoming legal, 1327 Oregonians have had a lethal prescription written. 859 have died.

3 in 1000

Three in 1000 deaths in Oregon in 2014 were due to PAD.



1%

Only 1% of Oregonians who die each year request PAD. Fewer than that actually die by lethal ingestion.

Quill TE, Miller FG. (2014). *Palliative Care and Ethics.* New York, NY: Oxford University Press.

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Physician Aid-in-Dying (PAD)

Requirements	Barriers to Patient	Concerns
Competent at time of request		Competent when ingested?
Terminal illness (≤6 months left)		Expertise in terminal illness not required.
Patient must make two oral requests (15 days apart) and one written request, then wait 48 hours for prescription	Many obstacles to obtaining PAD. Death may occur before completing requirements.	Intolerable suffering is not required; Patients often request PAD before symptoms develop.
Two physicians must certify that patient is eligible	Many physicians decline to participate.	
Must be able to self-administer and ingest Rx	May become unable to swallow	

Quill TE, Miller FG. (2014). *Palliative Care and Ethics.*

http://www.deathwithdignity.org/access-acts

In 2014, 105 Oregon residents died from PAD. What is the most common reason these patients requested PAD?

A. Pain
B. Dyspnea
C. Depression
D. Loss of Autonomy

http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year17.pdf

Journal of Pain and Symptom Management 2015; 49: 555-560

J Gen Intern Med 2007; 23: 154-7

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SUMMARY	Palliative Sedation	Euthanasia (VAE)	Physician Aid-in-Dying
Intent to hasten death?	No	Yes	Yes
Legal in United States?	Yes	No (only in Netherlands and Belgium)	Oregon Washington Vermont (Montana) (New Mexico)
Option if decisional capacity is lost?	Yes (consent from family)	No	No
Death must be imminent?	Yes	No	No (terminal)
Reason for Use	Physical	N/A	Existential
Most Common Agent	Midazolam	Barbiturate + Paralytic	Secobarbital Pentobarbital

Palliative Medicine 2003; 17: 97 -101 http://public.health.oregon.gov

Take-Home Thoughts

- Palliative interventions (including hospice referrals) result in some patients rescinding their requests for physician aid-in-dying/euthanasia.
  - *Journal of Clinical Ethics* 2004; 15:119-122
- Increasing the availability of end-of-life care (palliative/hospice) may just be the most "powerful alternative to calls for legalization of euthanasia and physician-assisted suicide."
  - EAPC Ethics Task Force, *Palliative Medicine* 2003; 17: 97-101
- "Pharmacists should ensure the rights of competent patients to know about all legally available treatment options while communicating to patients…the overall duty of health care professionals to preserve life."
  - ASHP Statement on Pharmacist's Decision-Making on Assisted Suicide* *Am J Health-Syst Pharm* 1999; 56:1661–4.

*"It is hoped that this framework…will virtually eliminate a patient's request for assisted suicide."

Resources for Patients

- Compassion and Choices
  - https://www.compassionandchoices.org
- Death with Dignity National Center
  - http://www.deathwithdignity.org/

Resources for Pharmacist

- Compassion and Choices
  - https://www.compassionandchoices.org/what-you-can-do/in-your-state/oregon/resource-for-healthcare-providers/resources-for-oregon-pharmacists/
- Compassion and Choices of Washington
  - http://compassionwa.org/wp-content/uploads/2012/09/Pharmacists-Guide-2.2015.pdf

Questions?

“The End of Life Controversial Conversations”

Post-test Questions:

1. Palliative can be distinguished from hospice by which of the following:

   A. Care provided by an interdisciplinary team
   B. Care provided alongside curative care
   C. Patients and families are supported
   D. Symptom management

2. Which of the following is a barrier to quality end-of-life care?

   A. Increased public awareness of palliative care
   B. Medicare coverage for hospice services
   C. Lack of practitioner training
   D. Utilizing interdisciplinary teams for delivery of care

3. Which of the following statements is correct?
   A. Palliative sedation is euthanasia
   B. Proportionate palliative sedation hastens death
   C. Palliative sedation is illegal in the United States
   D. The intention of palliative sedation is to relieve intractable suffering

4. The most commonly used agent in palliative sedation is: _____
   A. Midazolam
   B. Phenobarbital
   C. Secobarbital
   D. Propofol

5. Which of the following is a requirement for patients requesting Physician Aid-in-Dying (PAD)?
   A. The patient must be imminently dying (prognosis of death within 14 days)
   B. The patient must make one oral and one written request, 30 days apart
   C. Two physicians must certify that the patient is eligible and competent
   D. The patient must live in Illinois, Indiana, or Ohio.