Purpose

The national conversation around this topic is especially charged as it extends past politics, past legalities, and into the heart of what we believe about the extent (or limits) of dignity, self-determination, sanctity of life, and who gets to decide when and how it’s “ok” to die. How do professionals and agencies respond when the professional ethics honoring patient choice conflicts with personal morals—ours or others? Exploring research from areas in which PAD is legal, this presentation will invite dialogue about how we feel, what we think, and how we can prepare for the future.
Objectives

Discuss current legalities and ethics

List research findings

Define personal struggles

Analyze an ethical response
Overview

Legalities and Ethics
  History
  Current legislation
  Ethical considerations
  What language communicates (to us/ others)

Research
  Patients
  Families
  Teams
Overview

What’s hard for us...

An Ethical Response

Therapeutic poker face—shame, judgment, shock
Process under content—what they really want
Sometimes a question is just a question
Due diligence—assessments involved.
The History

Euthanasia—Greek for “good death”
First bill drafted in Ohio (1906)
Kevorkian (1990s)
Maynard (2014)

https://www.deathwithdignity.org/assisted-dying-chronology/
Current Legislation


Montana (2009)—*Baxter v. Montana*

Under review in Tennessee, Maryland, New Jersey, New York, Connecticut, Rhode Island

New Mexico—January 2014 legalized in Bernalillo Co., overturned August 2015, under review by state supreme court
Current Legislation

**VSED** (Voluntarily Stopping Eating and Drinking)

Legal in all 50 states.

Patients who have decision-making capacity can make a considered choice to stop eating and drinking.
PAD Position Statements

AAHPM
HPNA
NASW
APC
ADEC
NHPCO

“Studied Neutrality”
Ethical Considerations

**Personal autonomy**

“Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent, commits an assault.”

*Scholendorff v. Society of the NY Hospital, 1914*
Ethical Considerations

Self determination
A decisionally capable person is allowed to refuse any unwanted treatment, even if that refusal will result in death.

“It is the individual who is the subject of a medical decision who has the final say” (Right of pt to refuse potentially life-saving blood transfusion upheld.)

Erickson v. Dillgard, 1962
What Language Communicates

Rational suicide
Euthanasia

PAS—Physician Assisted Suicide
PAD—Physician Aid in Dying
MAD—Medical Aid in Dying
DwD—Death with Dignity

What terms can create safest space for pts/families to approach us about the topic?
Research

Impact on:

Patients

Families

Teams


Straw Poll

If it were legal and you were asked by a patient to help them pursue PAD, what would you do?”

1. I would conscientiously object

2. I would be willing to serve, but would hope they would change their mind

3. I would be willing to serve, and would completely honor their choice
Check-in

Right now, how’s your breathing, heart rate, body temperature (face, hands, feet, etc), muscle tension?

Regarding the process (not content), what was the most challenging part of that discussion?

Regarding the process (not content), what was the easiest part of the discussion?
What’s Hard for Us?

Our ethics:

- Autonomy and dignity
- Palliative ethic to comfort
- Patriarchy in palliative care
- The power of power/Values-neutral care

“But sometimes, my ethics and my morality conflict”
What’s Hard for Us?

Our morals:

Sanctity of life
What defines “life”?  
Quality vs. Quantity?  
Difference between surviving and living?  
Is it a sin or an act of mercy?

Who gets to decide another’s “quality”?
What’s Hard for Us?

Our professional ethos: *(which we take personally)*

Professional responsibility
Does it mean we’ve failed?
*(co-dependence and boundaries)*
Neither prolong life nor hasten death
Long history of distancing from Kevorkian
An Ethical Response

Therapeutic poker face
Judgment
Shock
Personal offense = Shame

Be aware of our biases
Be aware of the stories we’re telling ourselves
Process under content—what they really want
(not an invitation to dismiss them)
An Ethical Response

Sometimes a question is just a question

Get curious—“Would you say more about that?”
“I want to really understand…”

Purpose is to increase understanding

Look for common ground

Explore feasible solutions
An Ethical Response

Find your feet, get grounded
Take a breath and pause

Notice the energy that comes up inside
It’s just information, don’t tell yourself a story

Find common ground—“I want your suffering over, too.”

Keep doors open—“Let’s see what solutions we can find.”
An Ethical Response

Consider their bravery

Honor their trust in you

Honor their honest seeking

Even if they come across as flippant, this is no casual question
An Ethical Response

Don’t deflect—“You don’t mean that!”

“Once we get your sx managed you’ll feel differently.”

Don’t minimize—“Well, at least...”

Don’t scold/shame—“Think of your family...”

“You mustn’t be selfish”
An Ethical Response

Don’t theologize:

“God knows best”

“God has a plan/purpose for your life/suffering”

“God’s time, not ours”

“God never gives us more than we can handle”
An Ethical Response

Pushing back risks:
   Shame
   Distrust
   Non-compliance
   Raising their defenses
   Digging in their heels

Listen until they feel heard
Ask for time to explore options *(but DO come back!)*
An Ethical Response

Due diligence—assessments involved

Competence
Symptom control
Grief
Depression
Psychosocial dynamics
Spiritual issues/views
An Ethical Response

Ahead of time, discern policies/protocol

Duty to warn?

Conscientious objection
   Slippery slope or reasonable respect?
An Ethical Response

Listen

Understand

Validate and Normalize

Keep biases to yourself!
Exercise—VSED Case Study

VSED and Hospice Care: A Case Study

By Patrick T. Smith; Elizabeth Collins; Tim Cox; Deborah Jacques; Bonnie Meyer; and Kate Pepin
(NHPCO Newsline, September, 2013)

If a patient decides to forgo eating and drinking in order to hasten his or her own death, how should a hospice respond?

From a legal standpoint, “voluntarily stopping eating and drinking” (VSED) is an option for individuals in all 50 states and distinct from the natural reduction in nutritional intake that accompanies the dying process. It is a voluntary decision by patients with decision-making capacity, with the explicit intention of hastening death(1).
While legal, however, the peer-reviewed literature does not reflect strong ethical consensus about whether, how, and for what reasons hospices should or should not participate in patients’ care decisions about VSED.

The NHPCO Ethics Advisory Council offers the following case study and questions in the spirit of fostering robust discussion on this difficult ethical issue. The Council also encourages each hospice to explore these questions in their organizational ethics committees, with the ultimate goal of establishing a policy or guidelines to address VSED so staff is prepared when such situations arise. Some resources that may help inform these internal discussions are provided at the end of this article.
The Case of Dr. S

1. Given the hospice philosophy of supporting the goals of the patient, what ethical issues do you think emerge in the case of Dr. S?

2. When he began his fast, Dr. S’s death was not imminent; his functional decline was accelerating, but he had a prognosis of several months until death. Is a patient’s projected time until death ethically relevant when considering if and how hospice teams should support a choice to begin VSED? Why or why not?

3. The hospice staff in this case honored the wishes of Dr. S by not placing trays of food in front of him. However, the staff did ask him three times a day if he wanted food just in case he changed his mind. Does this response by the care team cross the line in not respecting Dr. S’s wishes? Why or why not?
Check-in

Right now, how’s your breathing, heart rate, body temperature (face, hands, feet, etc), muscle tension?

Regarding the process (not content), what was the most challenging part of that discussion?

Regarding the process (not content), what was the easiest part of the discussion?
Where do we go from here?

Education

Development of policies

Dialogue

On-going reflection and practice
VSED Resources


Compassion and Choices downloadable book
VSED Resources

KNMG Article, “Caring for people who consciously choose not to eat and drink so as to hasten the end of life”

http://www.knmg.nl/Over-KNMG/about-knmg.htm

On right hand banner under articles in English, look for VSED/voluntary stopping eating and drinking: Caring for people who consciously choose not to eat and drink so as to hasten the end of life (2015)
VSED Resources


http://law.hamline.edu/WorkArea/DownloadAsset.aspx?id=4294999578
VSED Resources


http://widenerlawreview.org/files/2011/07/03-pope2.pdf&embedded=true
VSED Resources

Compassion and Choices is fairly aggressive in protecting persons' rights around their end of life and has information and tools related to Advance Directives and other means of clarifying wishes:  https://www.compassionandchoices.org/eolc-tools/

Death with Dignity is also a group that very strongly advocates for a person's right to choose. You can find information here: https://www.deathwithdignity.org/options-to-hasten-death/
VSED Resources


A Dying Wish documentary about a surgeon who made this choice. http://www.dyingwishmedia.com/

An organization that has strong concerns about any form of aid in dying has information they share, to explore both sides of the issue. Some of their information is here: http://www.patientsrightscouncil.org/site/wp-content/uploads/2013/03/VSED_Questions.pdf
PAD Resources

EOL Option Act Task Force website that contains multiple videos, including this 14-minute segment from The End of Life Option Act Response Conference called “Explanation of the Law”
http://www.eolooptionacttaskforce.org/
PAD Resources

This two-page fact sheet from the UCSF/UC Hastings Consortium on Law, Science, & Health Policy also highlights the protocol for patients and physicians:


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