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"The soul is the full actualization of a person, incorporating the body, purpose, and ultimately the sum of total operations of being human"

(Aristotle, De Anima, c 350BCE)

## The ethical dilemma in practice - Communication conflict:

- ▶ Daniel's story
- ▶ Perception and perspective
- Attitude
- Your burnout or fatigue may be controlled with professional interaction and empathy

#### Discuss cultural norms

- ▶ Growth in the elderly population
- Average patient comorbidities and number of drugs-chronic and critical
- Average likelihood of end-of-life discussion: when do they occur
- ► A death-denying culture
- ► An imbalance of resources
- ▶ Breaching the walls of the healthcare silos

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- ► Education and the principles
- ▶ What is an ethicist/"exorcist"?
- ➤ Can you relate to your patients and the art of value based ethics: here is my experience, what is yours?
- ▶ Now let's look at application in the environment, then and now.

#### Understanding value based ethics

- Autonomy, but where's justice?
- ▶ Patient's best interest and do no harm, but where's compliance?
- What do you fix, what do you leave alone when all you learned to do is to fix?
- When does discernment replace clinical standards and protocols?

# What is the medicalization of death?

## The acuity in ethics - Reactive issues:

- ▶ 70 yr old female, living with mother, past NH resident
- ► Past CVA, multiple readmissions for respiratory failure/aspiration pneumonia, aphasia, contracted, multiple wounds, non-responsive
- ► Prior trach, current PEG, in through ED, intubated after quick code discussion with mom
- MD writes "inhumane to continue to provide life support...when...coming back and forth...ethics should communicate with patient's mother who does not understand patient's quality of life"

## The acuity in ethics - Reactive issues:

- ▶ 56 yr old male
- ▶ Diagnosed stage IVb lymphoma
- Documented non-compliance all over chart. Did not show up for planned/recommended chemo until acute issues brought her back to ER months following
- Discussion resulted in revelations of financial/resource/advocate distress
- Recommended palliative care, hospice discussion, advance directive completion, SW to follow at home if possible... outcome, 1tx/ death

## The chronicity in ethics - Proactive issues:

- Managing patients instead of just treating patients
- ▶ Population health
  - Social determinants
  - Listening
  - Abandoning the silos
  - Integrating with outreach facilities
- ▶ The Advance Directive comes first.

#### CASE 1

- ▶ 50 yr old male
- ▶ Past diagnoses of Hepatitis C, in remission
- Recently diagnosed with cancer, underwent chemo
- Chemo may have exacerbated Hepatitis C
- Pt expressed desire to live, but refuses to eat
- Pt and family refused hospice, wants aggressive care
- ▶ Pt did not want NG tube placed
- ▶ Pt seemed very depressed
- ► Ethics discusses w/ pt

#### CASE 2

- ▶ 80 yr old female
- Abdominal pain, respiratory distress, gallbladder infection
- ▶ Patient not surgical candidate, at end of life
- ▶ Patient wants DNR, and comfort care. Eventually cannot communicate due to resp. distress
- ▶ Daughter rescinds DNR. MDs concerned about change in care goals
- Daughter cannot let go- will not honor mom's wishes
- Ethical Issues??



- ▶ Let me read you an account of a chosen death
  - 1. Was it autonomous
  - Was the decision maker FULLY informed
  - 3. Was the decision maker legal
  - Was the decision maker making decisions based on emotion or information

ETHICAL
RESOURCES: BOTH
RE-ACTIVE AND
PROACTIVE

## Back to the basics: Proactive ethics is COMMUNICATION

- Listening to patient needs
- ▶ Be unafraid, be uncomfortable, be ok to read the notes
- Understanding patient barriers: language, literacy, home support, surrogate appointment and understanding, knowing hospice concepts
- Scripting the discussion within reason and keeping value based ethics
- ▶ Losing fear of offering opinions at end of life
- ▶ Losing fear that everything is a liability
- Understanding the ethics may be in giving options which are unrealistic and futile

#### Four skills to conquer

- ▶ Compassion is learned
- 1. Remove Personal Guilt
- 2. Let them salvage control
- 3. Don't ignore suffering of any kind
- 4. Things are not black and white at the end



Recognize cultural and faith barriers



Learn the logistics of discharge



► Through the continued success of ethics and palliative care, diagnosis of a terminal and or chronic illness will no longer be considered the end of the line, but simply the beginning of an excellent continuum of care and a good quality of life.

### Kathleen Benton

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#### Resources

- ▶ Institute of medicine, 2014
- ▶ Benton, K. The Skill of End-of-Life Communication: Getting to the Root of the Ethical Dilemma, 2017
- ► Advance Care Planning Decisions Library @copyright 2007
- ▶ Defining Hope, @ 2017 Carolyn jones productions, PBS
- ▶ Rediscovering the Art of Dying, Kenny 2018