Sound Familiar?
- 36-year old wife and mother of 3 refuses further chemo for stage 4 ovarian cancer. Husband insists chemo continue.
- 78-year old woman with dementia and Parkinson’s rushed to ER from nursing home without attention being paid to her advance directive. Family is furious that she is now on a ventilator.
- Patient confides in you that he does not want any further hospitalizations/treatment for stage 4 prostate cancer, as he knows he will bankrupt his family. Oncologist insists on clinical trial.

Definitions
- Ethics is defined as “moral principles that govern a person’s or group’s behavior” or “the branch of knowledge that deals with moral principles”
- Bioethics is “the study of typically controversial ethics brought about by advances in biology and medicine”
- Clinical Ethics “is a structured approach to ethical questions in clinical medicine”

Responding to Ethical Issues in Palliative Care
- Ethical dilemmas emerge daily
- Changes in social/family systems have added to complexity of care
- Landmark cases influence legal/ethical history
- Attention to help patients make fully informed decisions
- Nurses and the palliative care team help patients make fully informed decisions

Historical Perspective
- Landmark Cases
  - Karen Ann Quinlan
  - Nancy Beth Cruzan
  - Terri Schiavo
- Patient Self Determination Act (1990)
  - Patient Rights
    - Right to facilitate their own health care decisions
    - Right to accept or refuse medical treatment
    - Right to make an advance health care directive
- Washington State Natural Death Act (1992)

Standards of Professional Nursing Practice
- Scope of practice & standards of care
- Codes of ethical conduct
- Guidance for responsible end-of-life / palliative practice
- ANA & HPNA Standards
Common Ethical Dilemmas In Nursing
- Euthanasia, Assisted Suicide, Aid in Dying
- Nursing Care and Do Not Resuscitate (DNR)/Code Status
- Forgoing Nutrition and Hydration
- Registered Nurses’ Roles and Responsibilities in Providing Expert Care and Counseling at the End of Life

Clinical Practice Guidelines: Ethical/Legal Aspects of Care
- Goals, preferences, and choices are respected
- Palliative care program identifies, acknowledges, and addresses complex ethical issues
- Provision of palliative care occurs in accordance with professional, state, and federal laws/regulations

Organizational Ethics
Mechanisms to resolve ethical issues:
- Ethics consultation
- Ethics committees
  - Education
  - Policy development
  - Case consultation

Ethical Principles
- Autonomy: Making one’s own decision
- Beneficence: Intending to do good
- Nonmaleficence: Intending to do no harm
- Justice: Providing equal access

Issues of Communication and Shared Decision-Making
- Disclosure
- Confidentiality
- Informed consent
- Decision-making capacity

Decisional Capacity
- Decision-making capacity for marginalized groups
  - Patients with dementia/mental illness
  - Patients with developmental disabilities
  - Prisoners
Physician/Provider Orders for Life-Sustaining Treatment (POLST)

- Standardized medical orders
- Specific types of life-sustaining treatment
- Applicable in life-limiting disease states
- A legal document and part of medical record
- Travels with the patient
- Honored across all care settings
- POLST/MOLST/MOST/POST/SMOST/TPOPP

California HealthCare Foundation, 2011; The California Coalition for Compassionate Care, n.d.

Ethical Issues in Palliative Care

- Prolongation of life: Balancing benefits and burdens
- Withholding/withdrawing medical intervention
- DNR/code status

Ethical Issues in Palliative Care, cont.

- Medical futility
- Principles of double effect
- Assisted death
- Euthanasia
- Research-regulatioin

“Potentially Inappropriate Treatments”

- Preferred terminology
- The Official ATS/AACN/ACCP/ESICM/SCCM Policy Statement: Responding to Requests for Potentially Inappropriate Treatments in Intensive Care Units
  - The term “potentially inappropriate” should be used, rather than futile, to describe treatments that have at least some chance of accomplishing the effect sought by the patient, but clinicians believe that competing ethical considerations justify not providing them. Clinicians should explain and advocate for the treatment plan they believe is appropriate.
  - Use of the term “futile” should be restricted to the rare situations in which surrogates request interventions that simply cannot accomplish their intended physiologic goal. Clinicians should not provide futile interventions.
**Time Limited Trial**

- Can allow for proper diagnosis and prognosis of a condition
- Can allow for perspective of burdens and benefits of a treatment
- Patients and surrogates often feel less stress and more in control if they know that they can reverse a decision
- Allows for the healthcare team to re-evaluate and make new recommendations

**Physician Aide in Dying (DWD)**

- Allows mentally competent, terminally ill state residents to voluntarily request and receive a prescription to hasten their death
- Legal in 3 states
  - Oregon (1997)
  - Washington (2008)
  - Vermont (2013)
- Criteria to qualify in Washington:
  - Washington State resident
  - Competent adult
  - Terminal illness with a prognosis of 6 months or less
  - Able to self-administer medication
- Process takes at least 15 days

**DWD in 2016**

- 248 Participants
  - 240 participants died
    - 152 ingested the medication
    - 18 did not ingest the medication
    - 12 unknown
- Age range: 33–98
- Primary disease:
  - 77% Cancer
  - 8% Neurodegenerative Diseases
  - 15% Other (heart and respiratory)
- Demographics
  - 98% white
  - 53% Male
  - 47% married
  - 76% at least some college education
- Reported concerns
  - Loss of autonomy: 87%
  - Loss of dignity: 66%
  - Loss of ability to participate in activities that make life enjoyable: 84%

**Preventive Ethics**

- Proactively prevent occurrence of conflicts
- Early identification of issues
- Knowledge of the natural history of many illnesses
- Understand wishes of patient/family
- Attention to culture and spirituality
- Build communication skills

**Facilitating Ethical and Legal Practice**

The Four Box Method

- Clinical Indications
- Patient Preferences
- Quality of Life
- Contextual Features

Jonsen et al., 2010
Four Box Method: Clinical Indications
- Indications for and against the intervention
- Reflects the goals of care
- Common ethical dilemmas

Four Box Method: Patient Preferences
- An ongoing, dynamic process of assessment that decreases chance of conflict
- Cultural, ethnic, and age-related differences
- Common ethical dilemmas

Four Box Method: Quality of Life (QOL)
- Evaluation of prior QOL
- Expected QOL with and without treatment
- Common ethical dilemmas addressing QOL

Four Box Method: Contextual Features
- Social, legal, economic, and institutional circumstances
- Context features must be determined and assessed
- Common ethical dilemmas

Case
- In July 1973, Dax Cowart, then a pilot in the Air Force reserve, and his father were visiting a tract of land. The sparking of the ignition set the gas on the floor of the valley ablaze, severely burning both men.
- Cowart’s father died en route to the hospital, but Cowart himself survived. Cowart’s injuries included the loss of both his hands, eyes, and ears, and the loss of skin over 65-68% of his body.
Case

“I was burned so severely and in so much pain that I did not want to live even in the early moments following the explosion. A man who heard my shouts for help came running down the road, I asked him for a gun.” He said, “Why?” I said, “Can’t you see I am a dead man? I am going to die anyway. I need to put myself out of this misery.” In a very kind and compassionate caring way, he said, “I can’t do that.”

Cowart eventually healed enough from his injuries to be released from the hospital. Although blind and without functioning hands, he was able to earn a law degree from Texas Tech University in 1986, and now has his own practice. Cowart’s life and his reflections on what has happened to him continue to challenge medicine’s understanding of itself as a moral practice.

Conclusion

- Ethical discernment, discourse, decision-making
- Address values and understanding of needs
- Advocate for patient/family rights
- Work closely with other disciplines