Introduction to Palliative and End-of-Life Care in PACE

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Learning Objectives

• Address ethical questions that arise when treating the dying patient

• To understand the impact of healthcare decisions

• To provide a starting place for those wishing to explore the complex subject of death and dying
• Death is the point at which our vital physical functions ease.
• In past eras, human death was much easier to define than it is now.
• When our heart or lungs stopped working, we died.
• Sometimes our brain stopped before our heart and lungs did, sometimes after.
• But the cessation of these vital organs occurred close together in time.

“Life support technologies introduced in the 20th century have produced a new kind of patient, one whose brain does not function, but whose heart and lungs continue to work.”
A Good Death

Improving the end of life and advocating for a “good death” has become the mission of many dedicated individuals and organizations, and is also a frequent subject of research and focus for policy improvements. 1
A Good Death

“...too many Americans die unnecessarily bad deaths—deaths with inadequate palliative support, inadequate compassion, and inadequate human presence and anxiety, loneliness, and isolation. Deaths that efface dignity and deny individual self-control and choice.”

Common elements of a good death have been identified as the following: 2,3,4

- Adequate pain and symptom management.
- Avoiding a prolonged dying process.
- Clear communication about decisions by patient, family and physician.
- Adequate preparation for death, for both patient and loved ones.
- Feeling a sense of control.
- Finding a spiritual or emotional sense of completion.
- Affirming the patient as a unique and worthy person.
- Strengthening relationships with loved ones.
- Not being alone.
Many believe that failing to address the suffering of a patient with a terminal illness violates two of the main ethical principles behind health care:

- Providing help or benefit to a patient (beneficence) – Failing to relieve pain and other symptoms does not help the dying patient.

- Not harming a patient (non-maleficence) – Failing to relieve pain and other symptoms can actually harm a patient and the patient’s loved ones.
Pain Management

As a patient with a serious illness nears the end of life, symptoms, including pain, may intensify. A major part of symptom relief is the use of drugs to relieve pain, soothe anxiety, and encourage rest. Many of the ethical dilemmas surrounding hospice and palliative care stem from the use of pain-relieving drugs in terminally ill patients. Questions about the importance of treating symptoms, the value of individual autonomy, and fears of addiction to narcotics all play a role in how people view pain management.⁶
Withholding and Withdrawing Medical Treatment

When seriously injured or ill and approaching death, medical interventions may save or prolong the life of a patient. But patients and loved ones often face decisions about when and if these treatments should be used or if they should be withdrawn.

Most people die in hospitals and long term care facilities, and a majority of deaths in these settings involve withholding or withdrawing at least one of the medical treatments listed above.
The ethical decisions surrounding the major types of medical care at end of life are:

- Resuscitation
- Mechanical ventilation
- Nutrition and Hydration
- Kidney Dialysis
- Antibiotic Treatments
- Medically Futile
- Terminal Sedation
DNR orders might be issued for the following patients:

• Patients for whom CPR may not provide benefit.
• Patients for whom surviving CPR would result in permanent damage, unconsciousness, and poor quality of life.
• Patients who have poor quality of life before CPR is ever needed, and wish to forgo CPR should breathing or heartbeat cease.
Mechanical ventilation is the most common life support treatment withdrawn in anticipation of death. Mechanical ventilation is such a common treatment at the end of life, that some care providers may regard mechanical ventilation as “death-delaying” rather than “life-prolonging.” Some patients become dependent on the ventilator or die while being treated.

Therefore, for some patients ventilation is considered a non-beneficial treatment that negatively affects patients by delaying natural death or requiring families and physicians to decide to withdraw treatment.
Nutrition and Hydration

• Decisions about nutrition and hydration are among the most emotionally and ethically challenging issues in end of life care.
• The main dilemma concerns the nature and social meaning attached to providing people with food and water.

principle of proportionality:

If a dying patient receiving nutrition and hydration suffers burdens that outweigh the benefit of extended life, artificial nutrition and hydration may be ethically withheld or withdrawn – whether or not the patient will die as a result of this action.
Kidney Dialysis

The ethical challenges for dialysis withdrawal arise when stopping dialysis becomes an option patients want to consider.

Withdrawal can occur when patients are either:

- capable of making decisions and decide to forgo dialysis
- a written health care directive expresses a desire to discontinue dialysis
- a health care agent considers discontinuation of dialysis the best course of action
- or when the physician decides dialysis no longer beneficial.
Antibiotic Treatments

• One ethical concern raised by public health professionals is that excessive use of antibiotics can contribute to bacteria that mutate and become resistant to treatments: 10

• Public health professionals express concern that over-prescribing antibiotics may result in resistant bacteria that could be more harmful to future patients – particularly in light of evidence that antibiotics may not be effective for treating infection in terminally ill patients.
Medical Futility

Medically futile treatments are those that are highly unlikely to benefit a patient.

Ethical questions surrounding the concept of medical futility are:

- whether medical futility can be defined at all
- treatments that provide a smaller benefit may be eliminated
- treatments will be labeled futile in order to save money
Terminal Sedation

Some ethical concerns about its use are:

• The unknown effect terminal sedation may have on hastening death.
• The potential for abuse of patients who are unconscious and cannot speak for themselves.
• Use of terminal sedation with patients who either do not require such strong relief or whose suffering is compounded by emotional, psychological, or spiritual suffering.
• How to value consciousness versus suffering.
• How far people should go in an attempt to relieve pain and other uncomfortable symptoms.
References

Center for Bioethics University of Minnesota: Overview Ethics at End of Life


2. Steinhauser KE, Clipp EC, McNeilly M et al. In search of a good death: observations of patients, families, and providers. Annals of Internal Medicine, 2000; 132:825-832.


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