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

Rev. Thomas F. Bracken, Jr. D Min

NATIONAL PACE ASSOCIATION
Advancing Programs of All-inclusive Care for the Elderly
www.NPAonline.org | (703) 535-1565
As medical knowledge and technology increase, so do options for healthcare. When decisions arise concerning the treatment of dying patients, these options present complex ethical dilemmas. Many are faced with decisions about the best treatment to ease a patient’s final suffering. Perhaps a decision will need to be made about whether to allow a patient’s life to end by terminating treatment altogether. These decisions—regarding their own care or the care of a dying loved one—confront people from all walks of life.
Defining the End of Life and Declaring Death

- 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:

- 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.
For dying patients, palliative treatment provides relief of suffering from pain and other symptoms.
Narcotics are controlled addictive substances derived from opium. They act on the brain and spinal cord to relieve pain, reduce cough, and alleviate diarrhea. Side effects include drowsiness, an inability to focus, constipation, and – most seriously – respiratory depression. Physicians are sometimes wary of legal and criminal scrutiny and punishment from prescribing narcotics excessively or to the wrong person.

Morphine is the most commonly used narcotic for treating pain and other symptoms experienced by seriously ill patients. Morphine is particularly good at relieving the two most common symptoms experienced by dying patients – pain and shortness of breath. The fear that respiratory depression, a side-effect of morphine, will be severe and result in death may cause a physician to under-prescribe the drug, even to terminally ill patients suffering intense pain.
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. 7
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
Whether or not it is ethical to apply CPR to all patients who stop breathing has become a subject of debate. One argument suggests that DNR orders would not be necessary if CPR was limited to those cases where it is a potentially beneficial treatment.  

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.
Approximately 75% of dying patients experience breathlessness, or dyspnea, as they die. The feeling can be uncomfortable to patients and frightening for loved ones to witness. Ventilation may be given to these patients, not to extend life but to help with breathlessness. Ventilation may help them sleep better, experience less anxiety, and eat and drink more comfortably.
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.
Dialysis is a time consuming and physical burden for patients with end stage renal disease. Some patients may eventually decide that this burden outweighs the benefits and then wish to discontinue this treatment. Today, discontinuing dialysis is considered an appropriate treatment option that respects a patient’s autonomy and ability for self-direction.

Shared decision making between the patient and physician must occur, and if the patient lacks decision-making capacity, the health care agent should be involved.

Physicians should provide patients with all available information – including available treatment options, consequences of dialysis withdrawal, and other end of life care options – like hospice and palliative care.
Dying patients are susceptible to infection. For many patients with life-threatening diseases, infection will affect their final days, and antibiotics may be given as a result. Anywhere between 32% and 88% of terminally ill patients receive antibiotics. Antibiotic treatments may not cure an underlying cause of illness, but rather alleviate symptoms. Treating an infection may extend life in circumstances under which a patient may not wish to continue.

Physicians often find it difficult to withhold antibiotic treatment from patients. Some believe that antibiotics are part of routine care and should not be denied to patients simply because they have a life-threatening condition. Others may consider an infection a “treatable” condition and not related to the “untreatable” and underlying, terminal illness.

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<th>Antibiotic Treatments</th>
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<td>• 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</td>
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<td>• 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.</td>
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advocates wishing to limit medically futile care argue that:

Futility can be defined using measures that include prognosis, estimates of the likelihood of recovery, and functional status. Not all medical treatments are beneficial. Health professionals would never label a beneficial treatment as futile. Futile treatments are expensive and an inefficient use of resources. By addressing medical futility, patients may be more appropriately cared for with other programs, such as hospice care.
For some dying patients, agonal suffering—the profound pain that may occur when dying—may not be relievable by any means other than terminal sedation. Terminal sedation uses sedatives to make a patient unconscious until death occurs from the underlying illness.
References


Contact Information

Rev. Thomas F. Bracken, Jr.  D Min
Community LIFE
Pittsburgh, PA
brackentf@upmc.edu

Rev. Bracken is the Senior Chaplain of Community LIFE and is a member of the ethics committees of several hospitals in the Pittsburgh area. He also serves as a Pennsylvania State Police Chaplain and is the proud recipient of the Pastor of the Year: Servants Heart Award 2013.