Ethics in Hospice & Palliative Care

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Criteria for Successful Completion of this Program...

• Be sure to sign the attendance sheet.
  – Print your name and address clearly
• You must remain for the entire program in order to receive 1 contact hour credit for CE.
• Participate in the post test discussion.
• Complete and submit the evaluation form
Objectives
- By the end of this session, participants will be able to:
  - Identify the 4 basic ethical principles
  - Distinguish the differences between law and ethics
  - Identify when withholding or withdrawing treatment is ethically sound
  - Recognize the benefit vs. burden of artificial hydration and nutrition
  - Understand the legal ramifications of terminal sedation

Ethical Considerations
- The ethics of care requires a delicate balance between the conventional practice of medicine and the wishes of the patient, appreciating that each human situation is unique.
- Not only should treatment options and likely outcomes be considered, but also patient values, hopes and beliefs.
- Patients and families must be properly informed to make appropriate treatment decisions and help reset the goals of care at all stages of the illness.

What does the term “Ethics” mean?
- “Ethics” is a generic term for different ways to examine moral life.
- Clinical ethics is a “practical discipline that provides a structural approach to decision-making that can assist health professionals to identify, analyze, and resolve ethical issues in clinical medicine” (Jensen, 1992).
- The ethics of a case arises out of the facts and values embedded in the case itself.
Ethics Defined

- Ethics in palliative care is a matter of “practical reasoning” about individual patients.
- Although there are many approaches proposed by ethicists for the analysis and resolution of difficult situations, the most commonly used are organized around principles, such as respect for autonomy, beneficence, non-maleficence and justice.
- The principles are balanced and weighed in any particular ethical situation. Sometimes they come into conflict and create an ethical dilemma.

Basic Ethical Principles: Autonomy

- **Autonomy** recognizes the right and ability of an individual to decide for himself or herself based on his or her own values, beliefs and life span. This implies that the patient may choose a treatment that might differ from the advised course of care.
- The patient’s decision should be informed and well-considered, reflecting his/her values. Many factors interfere with the expression and appreciation of the patient’s preferences: compromised competence of the patient, stress of illness, comprehension difficulty, etc.
- Respect for autonomy implies truth telling and exchange of accurate information about status, goals of care, options and expectations.

Basic Ethical Principles: Beneficence

- **Beneficence** requires that the physician prevent or remove harm, while doing or promoting good. It is the most commonly used principle in the application of care.
- It implies that the health care team should do positive acts in maximizing the benefits of treatment.
- Examples include: delivering effective and beneficial treatments for pain or other symptoms, providing sensitive support, and assisting patients and families in any way possible.
Basic Ethical Principles: Non-Maleficence

- **NON-MALEFICENCE** supposes that "one ought not to inflict harm deliberately."
- Violation of this concept may include:
  - offering information in an insensitive way,
  - providing inappropriate treatment of pain or other symptoms,
  - continuing aggressive treatment not suitable to the patient's condition, providing unwanted sedation, or withholding or withdrawing treatment.

Basic Ethical Principles: Justice

- **JUSTICE** relates to fairness in the application of care. It implies that patients receive care to which they are entitled medically and legally.
- Justice can be translated into "give to each equally" or "to each according to need" or "to each his due."
- Different theories of justice debate what is "due," "equally," or "priority."
- Organ transplantation, selection in the emergency room or admission to the inpatient or outpatient hospice unit are applications of this principle. Who should have priority?
- The principle of justice implies a consideration for a common good and societal considerations.

How Law differs from Ethics

- In the administration of care, one cannot ignore the different legal requirements relevant to each situation. Although some cases might be defensible under ethical principles, they might not be permissible under legal provisions.
- Law is defined as minimal ethics, in the sense that it is based on the values of a society. It is also the reflection of a societal consensus on particular issues. It varies from society to society, from state to state.
Law

- In the U.S., law is divided into two systems: federal (across the states) and state (within the state). It can be made by:
  - Judges (common law)
    - Example: Supreme Court of the United States recognition for the right to refuse medical care
  - Legislatures (statutory law)
    - Example: Uniform Definition of Death Act
  - Executive agencies (regulatory law)
    - Example: Regulations for Protection of Human Subjects of Research

Legal Considerations

- Most end-of-life issues fall under common law (case by case decided by the tribunals, such as consent/withholding or withdrawal of treatment) or statutory law (different state law, e.g., physician-assisted suicide/do-not-resuscitate law).
- Legal provisions impose limits on decisions that might be ethically sound but nevertheless risky. They provide a framework to guide certain decisions or practices. This framework is defined in terms of requirements that need to be fulfilled in order to avoid liability.

Case Example

- Every palliative case presents its own ethical dimensions and dilemmas. The following case illustrates the diverse ethical and legal issues embedded in a common palliative care situation.
  - The following case example was provided by Beth Israel Medical Center (2005).
Mr. W. was a 50-year-old construction worker, separated from his wife (though still legally married) and with a teenage child. He had a history of laryngeal carcinoma diagnosed one year before. He had a total laryngectomy and received radiation therapy, but the disease recurred. He was admitted to the hospital for what turned out to be a final 7 weeks of hospitalization. His admission was initially prompted by increased shortness of breath and facial swelling following chemotherapy. His hospital stay was complicated by a left carotid erosion for which he had a bedside carotid ligation. He spent 2 weeks in the medical intensive care unit (MICU) for stabilization and treatment of pneumonia. Mr. W. had elected the “Do-Not-Resuscitate” option.

His hospital course was marked by increased pain, facial swelling, periodic seizures, a second pneumonia and progressive weakness. At all times, he was bed bound and artificially fed. His pain was relatively well controlled but the facial swelling was uncontrollable. Communication was possible to some extent through hand signals. Decisions were made after lengthy explanations to the patient and his wife, his designated health care agent.

In the final weeks of life, Mr. W.’s condition further deteriorated. His ability to communicate markedly decreased. In response to his enormous suffering, palliative care staff recommended sedation for Mr. W. Although his wife supported the decision, several nurses and house officers were concerned that such an intervention would go beyond the boundaries of appropriate symptom management. Mr. W.’s feeding tube was withdrawn, in accord with symptom control, comfort measures and the patient’s wishes.

The patient, completely unresponsive in the last 5 days of his life, died very peacefully.
In this complex case, many questions can be raised:

• What are the ethical issues?
• What constitutes an ethical problem?
• Are ethical questions different from legal questions?
• Who decides?
• How do we define consent?
• Are advance directives necessary?
• What does it mean to be DNR (do not resuscitate)?
• Is withholding and withdrawal of treatment identical?
• Are they ever acceptable?
• Can we ever stop artificial nutrition and hydration?
• Is sedation an option at the end of life?
• How does sedation differ from physician-assisted suicide (PAS) or euthanasia?

Case Summary: How did you answer the Ethical Questions?

• This case suggests many more questions than answers. Although the following overview might simplify the understanding of the multiple issues embedded in a clinical case, one should remember that ethics cannot be equated with an “easy recipe” for solving problems. Ethics is a complex domain and needs ongoing learning, discussion and reflection, essential to the practice of good medicine.
• Since ethical decisions are sometimes complex and difficult, an ethics committee is available to guide the medical team in the decision-making process. The modalities of access vary according to the facility. Most ethics committees are accessible to families, patients and medical teams.

Ethical Issues: Withholding & Withdrawal of Treatment

• When treatment is considered to be ineffective, disproportionate or of no value to the patient's quality of life, it may be withdrawn or withheld.
• Withdrawal of treatment is defined as the ending of treatment that is medically futile in promoting an eventual cure or a possible control of the disease.
• Withholding of a treatment occurs when this type of treatment is not provided at all.
• Both practices refer to the proportionality of treatment under the circumstances: it is no longer reasonable or beneficial to fight the disease with aggressive medical interventions, since it cannot be controlled.
Withholding & Withdrawal

- Although withholding and withdrawal of therapies have been described mainly in situations related to technical interventions (ventilator, hemodialysis), they can also be applied by extension to chemotherapy, artificial hydration and nutrition as long as the aim of these therapies is to prolong life beyond expectation, to delay death.
- Goals of care must be clarified.
- Discussions regarding withholding or withdrawal require a great deal of sensitivity and care.

CPR & Advanced Illness

- In contrast to popular belief, resuscitation is not an easy procedure or one with a high success rate. It is now known that the survival rate of CPR is about 15% under the best circumstances (good health status and CPR started early after the arrest). The survival rate is related to the underlying disease. Almost no patient with advanced cancer survives to leave the hospital: It is almost never successful in patients with chronic debilitating illnesses (1%-4%).

CPR & Level of Care

The DNR order is only one element of the care plan. DNR does not preclude the administration of other therapies. A patient with a DNR order can still continue intravenous fluids, antibiotics or any other indicated treatments. In each case, adequate information on the various options should be discussed with the patient or decision-maker. The discussion about resuscitation should be placed in the broader context of life-prolonging therapies.
Artificial Hydration & Nutrition

- Withholding or withdrawing artificial hydration or nutrition is difficult to address with the patient or the family because nutrition has such a high symbolic value (it seems to mean caring, and withdrawal is seen as starvation), and because of numerous misperceptions. Withholding nutrition can be perceived as neglect, abandonment or hastening death. An open discussion about the advantages and side effects of artificial nutrition will help to correct the misconceptions and reassure families in their decision process. The discourse is rarely neutral and should take into account emotions, passions, religious beliefs, and the overall goals of care.

Artificial Hydration & Nutrition

- As with any treatment, nutrition and hydration have indications and contraindications. The difficulty is to recognize the appropriateness of these therapies.
- In advanced cancer or other debilitating illnesses, some patients benefit subjectively from artificial nutrition or hydration and others do not. Improvement in quality of life or survival has not been proven. In certain cases, it becomes clearly detrimental since it can contribute to increased swelling, increased pulmonary or other secretions, and worsen the shortness of breath. Each case is unique and deserves an individual approach.

Sedation for the imminently dying (a.k.a. “terminal sedation”)

- Terminal sedation is defined as the action of deliberately inducing unconsciousness without deliberately causing death, in order to relieve intractable symptoms. The treatment is considered for a "refractory symptom," when all other means have failed and a patient is believed to be imminently dying. The prevalence of terminal sedation is unknown; a literature survey shows a frequency ranging from 5% to 52%.
Terminal Sedation & Ethics

- The ethical justification for sedation is based on the principle of double effect. It applies to situations where a desirable effect (good) is linked to an undesirable effect (bad). To be morally acceptable, such an action must comply with the following requirements:
  - the treatment proposed must be beneficial or at least neutral
  - only the good effect should be intended and must be achieved directly
  - the beneficial result must outweigh the untoward outcome

Legal Issues of Terminal Sedation

- Sedation, as a mean to relieve intractable symptoms, possibly to the point of hastening death, has been acknowledged as justifiable by various medical societies, bioethics, and more recently, by the United States Supreme Court.
- To be legally acceptable, sedation should be carried out in a manner consistent with the intent of relieving suffering. The action should reflect the purpose. Sedation in the imminently dying recognizes the right of patients to good palliative care.

Terminal Sedation vs. Euthanasia

- Although some have considered sedation in the imminently dying as a form of euthanasia “in disguise,” the two are quite different.
- They differ in their intent: death is the unintended, although foreseen result in sedation, as opposed to the intended result in PAS and euthanasia.
- They also differ in action: a sedative dose is not a killing dose. PAS and euthanasia imply recognition not only of the right to be relieved of suffering, but also of the right to die.
Treatment Decisions

• In the course of an illness, patients and health care agents will need to decide which treatments they want to pursue. The right to decide has been well acknowledged by the courts and affirmed by ethics through the recognition of the autonomy principle. The patient or agent may refuse a treatment or request the cessation of therapy. Treatment decisions are made according to the goals of care, which vary with the progression of the disease.

• When is it time for palliation? Did we reach the end-of-life phase? Is there still a place for active treatment?

References

• Beth Israel Medical Center (2005). www.stoppain.org; retrieved 10/24/07.

Post Test

• What are the four core ethical principles?
  – A. trust, honesty, loyalty, and care
  – B. lawful, moral, truthful, and collaborative
  – C. autonomy, beneficence, non-maleficence, and justice

• What are the differences between law and ethics?
  – A. something can be legal but not ethical
  – B. something can be illegal and ethical
  – C. something can be legal and ethical
  – D. all of the above

• When is withholding or withdrawing treatment ethically sound?
• What are the burdens of artificial hydration and nutrition?
• Terminal sedation is akin to euthanasia and has been deemed illegal by the US Supreme Court. True or False?