Fundamentals of Ethics at EOL

“Live one day at a time emphasizing ethics rather than rules” – Wayne Dyer

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Goal

• To educate healthcare professionals on the fundamentals of ethics and to ensure high quality care and a heightened sense of ethical awareness when providing services to hospice patients and their families
Objectives
- Define ethics and bioethics.
- Discuss history of bioethics via court cases/legislation.
- Discuss differences between:
  - Morals and ethics/ethical and legal.
- Define ethical conflict.
- Identify the purpose of Ethics Committees.
- Review the bioethical principles.
- List end-of-life ethical issues.

What is Ethics?
- Discipline concerned with right and wrong conduct; what should or should not be done.
- Typical ethics questions:
  - What is the “right” or “good” act and why?
  - How do we create a meaningful life that doesn’t infringe on the rights of others?
  - How do we achieve fairness for all people?
  - How should people treat one another?

What is Bioethics?
- Effect of technology and research on humans:
  - Nazi human experiments.
  - Tuskegee experiment; curable syphilis was not treated.
- Increased patient demand to participate in medical decision-making - diminished physician authority.
- Cultural Pluralism - different values collide in healthcare decision-making.
- Searching for answers to life/death questions in medicine/technology rather than religion.
Court Cases and Legislation

- 1976 Karen Ann Quinlan: Court let father of brain-dead daughter remove life support; EOL committee formed.
- 1977 Natural Death Act: Right to die without artificial prolongation of life.
- 1982 Baby Doe: Parents of a Down's baby opted out of treatment, court voted not to interfere.
- 1990 Nancy Cruzan: Based on Cruzan's prior statements, Judge ruled feeding tube removed.
- 1991 Patient Self Determination Act: Requires institutions receiving Medicare/Medicaid recipients to educate patients of rights to make medical decisions.

Court Cases and Legislation (Cont.)

- Terri Schiavo:
  - Michael Schiavo, petitioned to have feeding tube removed; Claimed Terri would not want to live in a permanent vegetative state.
  - Terri's parents strongly disagreed.
  - Judge ruled in favor of Schiavo after many years of repeated motions, petitions, and appeals.
  - Terri died on March 31, 2005, 13 days after the doctors removed the feeding tube.

The one sure lesson to be learned is that each one of us should have a living will and advance directives.

Morals vs. Ethics

- Morals: belief about what is the right thing to do.
  - It comes from religious traditions, family rules, cultural, and professional codes.
  - Due to pluralistic society, differing moral values
  - Morals are based on beliefs that change
- Ethics: The right and good action in a given situation according to an ideal standard.
- A standardized method for studying moral questions.
Ethical vs. Legal

• Laws are made via a democratic process.
  – Minimum standard of ethical behavior.
• What is ethically justifiable in a given circumstance may not be legal.
  – What is legal may be open to ethical debate (i.e. slavery was legal).

What is an Ethical Conflict?

• Ethical conflicts occur when there is:
  – A conflict of values.
  – No clear right and wrong.
  – An action that is both right and wrong.
  – No single acceptable code of behavior.
• Conflicts may create an inability to make a morally-correct decision, which can cause negative feelings for patients, families, and providers alike.

Ethics Committee’s Mission

“The primary purpose of an ethics committee is to provide a formal mechanism for all involved within a healthcare organization to confront, discuss and ideally to resolve ethical issues or perceived ethical issues that arise within the context of delivery of healthcare. This resource should be available not just for healthcare professionals across disciplines, but also for other staff, patients and families.”

NHPCO Ethical Principles, 2006
Ethics Case Consultation

- Gathers all medical facts, furthers communication and discusses the ethical issues related to the problem.
- Ethics discussion involves two core features:
  1. Identifying/analyzing the ethical conflict.
  2. Facilitating the building of consensus.
- Committee members identify treatment alternatives.
- Bioethical principles are applied and options weighed.
- Consensus develops and a recommendation is made to the interested parties.

Ethical Theories

- **Classical**
  - A right action is right regardless of the consequences (Deontological).
  - An action is right or wrong based solely on the consequences of the action (Consequentialist).
  - An action is justified if it produces more good than an alternative action (Utilitarian).
- **Modern**
  - An action is compared to a similar action where moral consensus was achieved (Casuistry).
  - Principalism theory: there are principles (rules) from which all other rules of right and wrong actions are derived.
  - Examples: respect for autonomy, beneficence, nonmaleficence and justice.

Bioethical Principles

"The principles of medical ethics are statements of the right and good that derive from the end and purposes of medical activity—healing, helping, and caring in a special kind of human relationship."

Author Unknown
Bioethical Principles (Cont.)

• Beneficence: Do Good.
• Non-maleficence: Do No Harm.
• Justice: Treat like cases alike - fairness, impartiality, consistency.
• Veracity: Obligation to tell the truth.
• Fidelity: Obligation to keep a promise and maintain confidentiality, non-abandonment of a patient.
• Professional Integrity: Obligation to act according to standards of a profession.

Bioethical Principles (Cont.)

• Autonomy: Right of autonomous individuals to self-determination - free from controlling influences and personal limitations. Includes:
  – Informed consent and advanced directives.
  – Treatment refusal.
  – Competency and capacity.
• Barriers to Autonomy may include:
  – Actions that would cause self harm or harm to others.
  – Receiving treatment that is not effective.
  – Refusing undeniably effective treatments.
  – Demands that require HC provider to violate his/her ethics.

End-of-Life Ethical Issues

• Competency / Capacity.
• Informed Consent.
• Advance Directives.
• Surrogate Decision Makers.
• Withholding / Withdrawing Treatment.
• Futility / Usefulness of Treatment.
• Cultural and Religious Influences.
• The Double Effect Principle.
Competency and Capacity

- **Competency**: a legal term; does patient have the ability to function independently (autonomy) to make healthcare decisions?
- **Capacity**: a medical judgment; does the patient have the capacity to understand treatment options?
- A person may:
  - Be competent but lack capacity to understand options.
  - Not be competent to make decisions in some areas but may have capacity to make decisions about their body.

Capacity

- In order to have decision-making capacity, the patient must be able to:
  - Communicate effectively about the treatment.
  - Understand the risks and benefits.
  - Demonstrate ability to be free/voluntary in the decision.
  - Understand the outcomes of the choices they make.

Informed Consent is...

- Ability for a competent patient to accept/refuse medical treatment based on what they feel is in their best interest.
  - Patient must have correct information about diagnosis, prognosis, alternative treatments, possible consequences.
  - Explanations should be tailored to patient's level of understanding.
Advance Directives

• Patient’s instructions describing wishes for medical care in the event that he/she cannot advocate for self.
• Established before the need for medical treatment and while patient has capacity.
• Allows informed consent by a surrogate/proxy (if specified) when patient is no longer able to give consent.
• Surrogate/proxy has been informed by patient of his/her values regarding quality of life and desired care interventions.

Advance Directives (Cont.)

• Living Will:
  – Allows one to accept or refuse treatment.
  – May include desire for analgesia, antibiotics, hydration, feeding, the use of ventilators or CPR.
• Medical Power of Attorney:
  – Appoints a healthcare proxy, healthcare agent or durable power of attorney to make medical decisions.
  – Holds true anytime, not just in end-of-life situations.
  – Can specify certain treatments in certain situations.

Advance Directives Limitations

• Can be vague and difficult to interpret.
• Hard to think about hypothetical situations.
• Despite the 1991 Self-Determination Act, many people do not fill them out.
• Family members or surrogate may not agree with the patient’s wishes and may ignore them.
• Directives may not be communicated between healthcare providers or between patient/family.
Surrogate Decision Makers

- **Order of Preference:**
  - Appointed guardian.
  - Durable Power of Attorney (POA) for healthcare.
  - Spouse.
  - Adult children (18-years old).
  - Older adult parents.
  - Adult brothers and sisters.
  - If none of the above, a guardian can be appointed.

Withhold/Withdraw Treatment

- Cultural/religious variations.
- No legal/ethical difference - withdrawing can be more emotionally laden than withholding.
- Artificial nutrition/hydration may be legally withheld/withdrawn.
- Artificial nutrition/hydration are generally not palliative interventions.
  - May require physical restraints; result in increased infection, fluid overload, etc.
- Refusal of life-sustaining treatment does not depend on patient's life expectancy or on being "terminally ill".

**Euthanasia/assisted suicide are morally and legally distinct from withholding or withdrawing treatment.**

Futility = No Useful Results

- **Futile treatment:**
  - Will not stop the inevitability of death.
  - Will not affect the specific condition.
  - Will not produce the desired benefit.
  - Are physiologically unsound.
- An intervention is not futile if it enhances quality of life.
- Differing opinions between patient/family; healthcare professional about what is a benefit vs. burden.
  - Physicians are not obligated to provide treatments outside of professional standards of care.

**Ask: “What is ordinarily done for patients in similar situations?”**
Cultural or Religious Influences

- Cultural values can affect veracity (truth telling) related to disclosing diagnoses and prognoses.
- Hispanics and African Americans may prefer that healthcare providers refrain from speaking to patients directly about death and dying.
- In some Asian cultures if one speaks truthfully about death and dying, it is believed they might bring about the patient's death.
- Some may prefer to withhold information even if the patient can understand and make decisions.

The Double Effect Principle

- When a treatment with a potentially-adverse (unfavorable) side effect is given with the intention of relieving suffering, it is permissible to perform the act if:
  - The main intent is only the good effect.
  - The action was only way to achieve the good effect.
  - The good effect morally outweighs the bad effect.

Conclusion

- It is helpful to understand both the history of the bioethics movement in the U.S. as well as the various principles and paradigms of ethical reasoning in order to come closest to the right and good decisions for the complicated ethical issues that patients, families, and healthcare professionals face at the end-of-life.
References


References (Cont.)

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