American Bioethics
UHC PH101
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Course Description

Bioethics is the systematic study of the moral dimensions of the life sciences and health care. American bioethics is a product of American healthcare and American law, which in turn reflect four deeply-ingrained American characteristics: we are individualistic, technology-driven, death-denying, and wasteful. These characteristics make “reforming” American healthcare extremely contentious. No medical technology is as emblematic of American bioethics and healthcare as the artificial heart. An exploration of its 40 year history as reflected in American medicine, public health, law, human rights, bioengineering, and economics helps explain both how the American bioethics “works” and why our “best in the world” healthcare system is so resistant to change.

Course Objectives

Upon completion of this course you should be able to:
1. Explain the difference between medical ethics and bioethics, and why the field is dominated by the doctor-patient relationship and medical research;
2. Identify key issues that consistently arise in the practice of medicine and medical research;
3. Explain why resolving ethical issues in medicine is so difficult;
4. Identify the major barriers to enacting healthcare reform in the United States;
5. Explain the links between American bioethics and American law;
6. Participate constructively in discussions of bioethics and law;
7. Demonstrate critical reasoning skills.

Course Requirements

Required Reading and Texts

Textbook:
(Widely available used, e.g. on Amazon.com)

Course Blackboard Site:
Assigned readings are listed in the course readings section below; with the exception of the text, they will be posted on the course’s Blackboard site (blackboard.bu.edu), as will supplementary readings not handed out in class.

Course Grading
There are two short (3-4 pages) papers, a midterm exam, and a final exam. Due dates will be announced at least 2 weeks in advance and late papers will lose 2 points for every day they are late.

Relative contributions to the final grade:
- 2 short papers: 30% (15% each)
- Midterm Exam: 30%
- Final Examination: 40%

Attendance
Attendance in class is required; only 2 unexcused absences will be permitted.

Academic Dishonesty
http://www.bu.edu/uhc/current-students/policies

Course Outline & Readings

Week 1. Introduction to Bioethics, Medical Ethics, Health Law, & Human Rights (Sept. 6 & 8)
Differentiating bioethics from medical ethics, law, and human rights, and how each apply to American healthcare and discussion of recommended summer readings.

Standard of Care: Introduction


Week 2. Heart transplantation and the dead donor rule (Sept. 13 & 15)
Heart transplantation and the “dead donor” rule; the supply and demand problem in organ transplantation; organ donation and “brain death.”

Standard of Care: Ch. 14, “From Canada with Love: Death and Organ Donation”

A Definition of Irreversible Coma: Report of the Ad hoc Committee off the Harvard Medical School to Examine the Definition of Brain Death, JAMA 1968; 205: 337-40; and The Uniform Definition of Death Act

Week 3. The “bridge to transplant” use of the artificial heart (Sept. 20 & 22)
The “bridge to transplant” artificial heart: first time human experiments at the end of life (including the case of Karp v. Cooley); regulating human experimentation by surgeons.

**Standard of Care:** Ch. 7, “The Insane Root” and Ch. 8, “In Thunder, Lightning, or in Rain”


**Week 4.**  **Rationing hearts (Sept. 27 & 29)**

Rationing hearts (including End Stage Renal Disease, dialysis, the “God Committee,” and the Arizona Medicaid rule); analogies and lessons from lifeboat ethics, conjoined twins, and trapped miners.

**Standard of Care:** Ch.16, “Rationing Medical Care” and Ch. 17, “Minerva v. National Health Agency (2020)”


**Week 5.**  **Informed Consent to the Jarvik 7 (Oct. 4 & 6)**

Informed consent to the Jarvik 7 (especially Barney Clark and Bill Schroeder and the general problem of informed consent to extreme, life-and-death, human experiments); the Walter Reed yellow fever experiments.

**Standard of Care:** Ch. 15, “Death and the Magic Machine: Consent to the Artificial Heart”

Barney Clark consent form (reprinted in Shaw, *After Barney Clark*, 1987)

Readings from *The Bill Schroeder Story*; and D. Breo, *Extraordinary Care* (1986)

**Week 6.**  **The Jarvik 7: Lessons (Oct. 11 & 13)**

Lessons from the Jarvik 7 (continued) Hype and hope in medicine, goals of medicine; Cancer research and the human genome project; how much is an extra month of life worth? Who decides?
Standard of Care: Ch. 9, “Not Saints but Healers: Legal Duties of Physicians in the AIDS Epidemic” and Ch. 10, “Faith (Healing), Hope, and Charity at the FDA: The Politics of AIDS Drug Trials”

Week 7. Midterm Exam (Oct. 18)

Week 7. Government regulation of human experimentation (Oct. 20)

Government regulation of human experimentation The Nuremberg Code and Helsinki; the FDA and IRBs; federal regulations; and “death panels.”

Standard of Care: Ch. 13, “The Politics of Fetal Tissue Transplants”

The Nuremberg Code; The Declaration of Helsinki; and selections from the federal regulations on human experimentation.

United States v. Rutherford, 442 U.S. 544 (1979)

Week 8. The Abiomed heart (Oct. 25 & 27)

The Abiomed artificial heart experience (2004-10); quality versus quantity of life; the coming epidemic of dementia in the elderly; emergency research and community consultation.

Standard of Care: Ch. 19, “Killing Machines”

Fox & Swazey article on abiomed heart


Week 9. Alternatives to the artificial heart (Nov. 1 & 3)

Alternatives to the artificial heart (LVADs, xenografts, tissue/organ replacement and cloning); is doing nothing ever a real alternative?

Standard of Care: Ch. 11, “Mapping the Human Genome and the Meaning of Monster Mythology” and Ch. 12, “Outrageous Fortune: Selling Other People’s Cells”

Week 10.  **Artificial hearts in imagination (Nov. 8 & 10)**

Artificial Hearts in Imagination (art, medicine, and science)

*Standard of Care:* Ch. 3, “She’s Going to Die: The Tragedy of Angela Carder”

Vonnegut, *Fortitude* (a play) in *Wampeters, Foma, & Granfalloons* (1968)


Week 11.  **Defining the goals of American medicine (Nov. 15 & 17)**

Defining the goals of American medicine (cost, quality, and access yes, but what about immortality?)

*Standard of Care:* Ch. 1, “Brave New Medicine” and Ch. 20, “Health Law and Bioethics at the Millennium”


Week 12 and 13.  **Bioethics lessons from the Affordable Care Act (Nov. 22, 29 & Dec. 1)**

Political lessons from the Affordable Care Act (including federalism, medical licensure, and mandating private insurance coverage). Why does medical care cost so much?

*Standard of Care:* Ch. 4, “The Supreme Court, Privacy, and Abortion”


Selections from Appeals Court Decisions on the Constitutionality of the Affordable Care Act.

Week 14.  **American Bioethics and the International “Right to Health” (Dec. 6 & 8)**

The International “Right to Health” and its meaning in a globalized medical world; social justice and human rights for the poor.


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Dec. 20: FINAL EXAM