Course Objectives
Upon completion of this course the student will:

1. Demonstrate knowledge in special problems in bioethics in the following ways:
   a. Know the main problems of moral choice faced by decision-makers in nine settings of contemporary research and medical practice.
   b. Know the dominant approach to what the instructor believes to be the most important problem in each setting.
   c. Know the major objections to the dominant approach
   d. Know the best study of the consequences--pro or con-- of the dominant approach.
   e. Examine the long-range consequences, in terms of ethical principles, of following the dominant approach.

2. Examine the levels of moral reasoning critically and be able to use this approach (properly revised) to assess a particular problem of moral choice.

3. Know the major claims of contemporary deontological and utilitarian ethical theories.

Course requirements

other readings: Assigned reprints and handout materials.

Semester assignments: (1) Each student will prepare a statement of 250 words or less to describe his or her ethical perspective. The student will share his views with the class on May 14. One week prior, on May 7th the student should bring a copy of the statement for each student and the instructor for class review by 5/14.

(2) The student taking this course for credit will prepare a final take-home examination or final term paper. The length of the paper should be no less than ten pages and no more than fifteen pages. By March 26 the instructor should be informed of the student's intent to write a paper or take the final exam. The instructor is available to assist with term paper topic selection. The term paper should be fully referenced.

Course grade distribution: 50% statement of views, class participation

50% final paper/exam

Attendance is expected at all class sessions. If a student must be absent please notify Dr. Fletcher's office.
<table>
<thead>
<tr>
<th>Date</th>
<th>Topic</th>
<th>Readings</th>
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<tr>
<td>2/05</td>
<td>Morality and Ethics: How To Begin</td>
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<tr>
<td>2/12</td>
<td>Review and Discussion of assigned readings</td>
<td>Chap. 1; reprints 6,7</td>
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<tr>
<td>2/19</td>
<td>Prenatal Diagnosis</td>
<td>Chap. 3; reprint 6</td>
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<tr>
<td>2/26</td>
<td>Treatment of Genetic Disorders-- Human Gene Therapy</td>
<td>Chap. 5; reprints 1,3</td>
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<tr>
<td>3/05</td>
<td>Genomics and predictive Genetic Screening</td>
<td>Chap. 4</td>
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<td>3/12</td>
<td>In Vitro Fertilization</td>
<td>reprint 11</td>
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<td>3/19</td>
<td>Animal and Human Research</td>
<td>reprint 4, 10</td>
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<td>3/26</td>
<td>Euthanasia</td>
<td>Chap. 5; reprint 5</td>
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<td>4/02</td>
<td>Do Not Resuscitate Choices To Forego Treatment</td>
<td>Chaps. 4 &amp; 5; reprint 2</td>
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<tr>
<td>4/09</td>
<td>Neonatal Intensive Care</td>
<td>reprint 12</td>
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<td>4/16</td>
<td>Class Choice</td>
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<td>4/23</td>
<td>Critiques of Bioethics</td>
<td>Chap. 8; reprints 8, 9</td>
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<td>Utilitarian Ethics</td>
<td>Chap. 2</td>
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<td>5/07</td>
<td>Deontological Ethics</td>
<td>Chap. 2</td>
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<td>Class essays</td>
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<td>5/21</td>
<td>Final Exam/Paper Due</td>
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<td>5/28</td>
<td>Class Dinner Party</td>
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Additional Reading Materials


7. Fletcher, JC. Ethical Considerations In Pediatric Oncology. (In Press)


Lecture #2 Review: Morality and Ethics- how to begin

1. a) Moral dilemmas (B&C p.4)
   b) Problems of moral choice (J.F. Ped. Onc. p.1; J.F. PN. Dx. p. 823)

2. Case study:
   You are an Obstetrician-gynecologist with an inner city tertiary care outpatient clinic. Your 18 year old, 20 week pregnant, patient is referred to you by a blood bank after testing sero-positive for HIV antibodies while trying to donate blood for money. The patient lives at home with her parents. She was exposed to the antibodies by the father of the baby—a 20 year old IV drug abuser. She denies IV drug abuse and says she is afraid to tell her parents because she is afraid of what her father will do. She has no income and is totally dependent upon her parents.
   What ought you to do in this situation?

3. a) Diagram (B&C p. 5)

4. Ethical Theories
   4.1 Principles

5. Three characteristics of moral action guides (B&C p.14-16)
   1. overridingness
   2. universalizability
   3. other-regardingness

6. Conclusion: Compare slide Dimensions with Diagram (B&C p.5)
A. Background Information in Genetic Disease

B. Five Problems of Moral Choice in Prenatal Diagnosis

1. Abortion Choices
   1.1 The Moral Status of The Fetus at Midtrimester
   1.2 Wide Spectrum of Severity
   1.3 Treatability of Genetic Disorders
   1.4 Selective Feticide and Selective Birth In Twin Pregnancies
   1.5 Selective Abortion and Decisions About Treatment of Handicapped Newborns

2. Controversial Indications For Prenatal Diagnosis
   2.1 Maternal Anxiety and Indication For Maternal Age
   2.2 Sex Choice Unrelated to Sex-linked Disorder
   2.3 Refusal of Abortion In Advance of Prenatal Diagnosis

3. Problems In Disclosure of Findings
   3.1 Fetal Sex
   3.2 Findings of Questionable or Potentially Harmful Significance
   3.3 False Paternity
   3.4 When the Patient Objects To Disclosure To Others At Risk
   3.5 Implications of Prenatal Diagnosis of Huntington Disease

4. Risks, Benefits, and Research In Prenatal Diagnosis
   4.1 Amniocentesis and Chorionic Villus Sampling
   4.2 Fetoscopy
   4.3 Ultrasonography

5. Problems In Access to and Distribution of Service

C. The Major Problem of Moral Choice in Prenatal Diagnosis-- Abortion

1. The Dominant Approach To Abortion

   International Study of Medical Genetics:  
   Problem #6 XYY  
   Problem #9 Maternal Anxiety  
   Problem #12 Sex Selection

   The Principle of Autonomy ( B&C pgs. 60-61)

2. The Major Objections to The Dominant Approach
   (1) A basic purpose of medicine--to save life-- is violated by the practice of abortion
   (2) While some abortions may be justified, the use of prenatal diagnosis tends to set apart certain fetuses as deserving of abortion and thus treats fetuses unequally and unjustly
3. The Only Study of the Consequences of the Dominant Approach

John Fletcher's International Study of Medical Genetics

- increase in non-indicated procedures
- increase in scope of screening
- increase in lack of access for deserving pregnancies (highest risk)
- lack of clear line between cases of real suffering and cases of meeting desires to improve normal state (Rifkin objection)
- increase in complex ethical issues requiring societal involvement beyond autonomy

4. Long-Range Consequences (Ethical Principles)

Beneficence: Little population, general screening

Non-maleficence: Less "saying no" in cases risking abortion of normal fetus

Justice: Access; little outreach to highest risk, underserved, under referred

Speakers for next week:

Alan Schechter, M.D.
Chief, Laboratory of Chemical Biology
NIDDK
Bldg 10 9N 30

Robert Cook-Deegan, Ph.D.
Office of Technology Assessment
Biological Application
U.S. Congress
Washington, D.C.
Session #5       Predictive Genetic Screening

Lecture outline

A. Background Information

1. Technological Advances
2. Changing Role of Medical Geneticists
3. Issues Facing Medical Geneticists
   a. Genetic Screening in the Workplace
   b. Screening for Genetic Susceptibility to Common Diseases, e.g.,
      Cancer, Heart Disease
   C. Screening For Genetic Diseases of Late Onset, e.g., Huntington
      Disease, Alzheimer(?)

B. The Major Problems of Moral Choice in Predictive Genetic Screening:
   1. Confidentiality/ genetic discrimination (access to test results)
   2. Disclosure Issues (to tell or not to tell children or those who
do not want to know)
   3. Voluntary/Mandatory Approaches to Screening

C. The Dominant Approach To Predictive Genetic Screening

   1. Voluntary rather than mandatory approach to genetic screening
      except for newborns when treatment is available
   2. A duty to provide full disclosure of test results including
      colleague disagreements
   3. Respect for parental autonomy
   4. An obligation, in cases presented to medical geneticists,
      to reduce or prevent the suffering caused by genetic disease,
on the condition that patient/parental autonomy is respected
in the process

Four questions about predictive genetic screening:
1. voluntary/mandatory screening in the workplace #18
2. Who should have access to results of genetic screening for
   occupational susceptibility? # 19
3. What is the best approach for genetic screening for CF carriers?
   #20
4. Who should have access to results of predictive genetic screening
D. The Emergent Dominant Approach to Predictive Genetic Screening
(extension of the present dominant approach to genetic screening)

Five main features:

1. voluntary rather than mandatory approach
2. informed consent
3. full disclosure including colleague disagreements
4. no access to test results to third parties without consent of
   patient (uncertainties about spouse, relatives, epidemiologists)
5. an obligation, in cases presented to medical geneticists, to reduce
   or prevent the suffering caused by genetic disease, on the
   condition that patient/parental autonomy is respected in the
   process

E. The Major Objections To The Dominant Approach

1. Insufficient positive beneficence
2. Insufficient Utility (cost benefit consideration)
3. Paternalistic

F. Long-Range Consequences of the Dominant Approach

1. Excessive Individualism
2. Increased Genetic Risks
3. Increased Societal Conflicts
4. Long-Range Eugenic Concerns
IN VITRO FERTILIZATION (IVF) AND EMBRYO TRANSFER (ET)

1. Background information on IVF-ET
   Safety, Efficacy?

2. Survey of major moral positions (Walters' chart)
   A. Natural reproduction only (Vatican)
   B. Clinical IVF only and only within the family unit
   C. Clinical IVF, donation oocytes permissible
   D. Clinical IVF and laboratory research with early (preimplantation) human embryos

3. Ethics and public policy questions relating to position D
   Clinical IVF-ET
   1. The discard question
   2. Freezing and storage of embryos
   3. Donation and sale of embryos & gametes
   4. Preimplantation diagnosis
   5. Research involving human embryos
      a. Only those post IVF-ET
      b. Donated gametes + IVF for research only

4. Major moral problems of IVF-ET
   a. Moral status of the human embryo****
   b. Surrogate Parents (AID; Gestational)****
   c. Access to IVF-ET*
      1) Costs
      2) Unmarried Persons
   d. Natural vs. Unnatural (technology influencing procreation)

5. Three Views of the moral status of the fetus
   a. The “potential person/equal protection" view
      (Vatican, National Ethics Committee of France, etc.)
   b. No special status or protection needed
      (Lockwood; Singer/Wells)
   c. The "developmental" (graded) view (EAB-HEW, Dunstan, Warnock, etc.)
(Deserves respect, protection, but limited research allowed; mandatory prior group review; 14-day rule; no sale

6. Is there a “dominant moral approach?” (e.g., cultural differences in ethics)

a. UK - Voluntary scientific association’s oversight using Warnock’s rules

b. US

1) IVF-ET: to treat human infertility is morally commendable, restricted to lawfully married couples

2) Freezing/Storage: morally commendable to spare women the risk of + laparoscopy

3) Donating human embryos for the sake of research is morally questionable and objectable until common ground can be found to debate the issues and test approaches, etc.

7. Major objections to the dominant approach (Vatican/ Singer-Wells)

1. Natural reproduction only is morally permissible

2. Safety & efficacy of IVF-ET is unknown
   a) for chromosomal & genetic damage
   b) spontaneous abortion rate / IVF

8. Long range consequences

1. Access limited (Justice)

2. Less beneficence (if donation restricted)

3. Limits research (social benefits fewer)
SESSION # 7  RESEARCH INVOLVING HUMAN SUBJECTS

LECTURE OUTLINE

A. Problems of Moral Choice

1. Who Decides Whether Research Should Start In Humans?
2. Informed Consent of Subjects
3. Selection of Subjects
4. Protection of Especially Vulnerable Subjects, e.g., children, fetuses, pregnant women, prisoners, institutionalized mentally infirmed
5. Privacy and Confidentiality
6. Research Strategies, e.g., randomization, placebos

B. Major Problems of Moral Choice

1. Who Decides When To Begin?
2. Informed Consent

C. The Dominant Approach

1. Research involving human beings of any age group should not occur without prior consideration of a group of informed and impartial peers who determine potential benefits, of the research with such subjects, to the individual and society, and the risks to the subjects.

   2. The informed consent of the prospective (capable) research subject is non-negotiable; the informed consent of legally authorized representatives of the incapable research subject is non-negotiable.

D. The Major Objections To The Dominant Approach

1. Science is impaired by too much regulation and society is deprived of benefits.

2. Informed consent is at best a myth and at worse a charade.

E. Studies about the dominant approach

F. Long-Range Consequences

1. The rapid advances in science and technology may make it improbable to keep regulations on human research relevant and effective.

2. You can do good science with regulations in place.
March 19, 1987

ETHICAL VIEWS AND RESEARCH WITH ANIMALS

I. Introduction: Why is this important?

Transition from "intuitive" to "critical level" of ethics.

II. Three Views

A. Primacy of human interests

B. Animal utilitarianism
   Type 1: Permissive
   Type 2: Restrictive

C. Animal rights
   The justification for killing an animal must be
   the same as for killing a human being.

III. Any View Must Consider

A. The Moral Status of Animals
B. Pain and Suffering
C. Mental Development
D. Purpose of the Study

   1) Benefits to animals
   2) Benefits to humans
   3) Benefits to science and knowledge

IV. Problems with "Rights" Approach

Rights: Powers or privileges to which an individual has a
just claim;

   • involve a mutual recognition on part of each
     individual of the claims or rights of others;

   • rights are correlative with duties.
Bibliography


# Outline of Presentation

<table>
<thead>
<tr>
<th>SLIDES</th>
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<tr>
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<td>CARETAKER, HELP ME TO DIE</td>
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<tr>
<td>2.</td>
<td>EUTHANASIA: PRO AND CON</td>
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<tr>
<td>3.</td>
<td>DEFINITION</td>
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<td>Euthanasia (&quot;good death&quot;) is the act of causing a person's death for compassionate motives.</td>
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<td>4.</td>
<td>EUTHANASIA VS. ALLOWING TO DIE</td>
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<td>5.</td>
<td>&quot;Allowing to die&quot; is foregoing life-sustaining treatment so death can occur.</td>
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<td>6.</td>
<td>ARGUMENTS FOR EUTHANASIA</td>
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<tr>
<td></td>
<td>1. Cruelty of prolonging life with suffering</td>
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<td>2. Violation of autonomy/self-determination</td>
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<td></td>
<td>3. Acts vs. omission distinction (outworn)</td>
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<td></td>
<td>4. &quot;Invisible acts&quot; will be open</td>
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<td></td>
<td>5. Relieve burdens of family; irrational costs</td>
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</table>
7. VOLUNTARY EUTHANASIA (NETHERLANDS)
   1. Enduring and well-considered request
   2. Patient understands situation
   3. Unbearable suffering; irreversible situation
   4. No other alternatives acceptable to patient
   5. Only qualified physician can perform euthanasia
   6. A second physician must consult and concur
   7. Due care and review before giving euthanasia

8. ARGUMENTS AGAINST EUTHANASIA
   1. Pain and suffering can be relieved (Hospice approach)
   2. Will erode trust between physician-patients
   3. Slippery slope ("wedge") argument
      a) Moral reasoning ("hammer")dangerous
      b) Culture will abuse it (burden, costs)
   4. Possibility of coercion
   5. Encourages suicide
   6. Wrong diagnosis; new treatments

9. OUTWORN DISTINCTIONS
   1. To act vs. omitting to act
   2. Withholding vs. withdrawing treatment
   3. Intended vs. unintended but foreseeable consequences
   4. Ordinary vs. extraordinary treatments
10. CASES AND DECISIONS TO FOREGO

<table>
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<tr>
<th>Year</th>
<th>Name</th>
<th>Location</th>
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<tr>
<td>1976</td>
<td>Quinlan</td>
<td>NJ</td>
<td>Ventilator</td>
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<td>Saikewicz</td>
<td>MA</td>
<td>Chemotherapy</td>
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<td>Dinnerstein</td>
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<td>Ventilator, IVs</td>
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<td>Conroy</td>
<td>NJ</td>
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<td>1986</td>
<td>Jobes</td>
<td>NJ</td>
<td>G-tube</td>
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11. NEGOTIATED DEATH

Between technological imperialism and voluntary euthanasia

12. CULTURAL AND INSTITUTIONAL REFORMS (U.S./U.K.)

1. Hospice Care
2. Living Will
3. Durable Power of Attorney
4. Hospital Ethics Committee/Consultant
5. Patient Representative

13. WHY THE DIFFERENCES BETWEEN NETHERLANDS AND THE UNITED STATES?

1. Cultural and religious differences
2. Strong voluntary euthanasia movement
3. Differences in pluralism, population
4. Which approach is ethically best?
You are on the faculty of one of the leading medical schools in the country. There is a proposal to invite a speaker to present a discussion on euthanasia. You are invited to debate who the speaker, to be invited, should be. Should the speaker be for or against euthanasia?

Each participant is assigned a number 1 or 2. A coin is tossed to determine which number–1 or 2– will be pro euthanasia. Participants with same number will organize in a group and prepare a debate. The group members should first select an individual to represent the group’s opinion and serve as the debator. Once the spokesperson is selected, the group prepares the points of the debate.

45 minutes will be allotted to prepare for the debate. After a 5 minute break, the class will meet to hear the two positions. Each spokesperson will have 10 minutes to state his position. There will be a three minute opportunity for each group to offer rebuttal comments.

The debate will be closed and called to a vote. Depending on the outcome of the vote a guest speaker will be invited to address the medical school audience.
SESSION #9  CHOICES TO FOREGO LIFE-SUSTAINING TREATMENTS

A. Background Information

1. Life-Sustaining Technologies, e.g., CPR, Hemodialysis, Antibiotics, feeding, hydration
2. Patients are less able to communicate their desires
3. Concept of "Negotiated Death"

B. The Major Problems of Moral Choice In Decisions To Forego Life-Sustaining Treatment

1. On what basis ought decisions to forego life-sustaining treatments be made, given the alternatives: (a) cost-benefit analysis; (b) full court press; (c) benefit-burden option?
2. Problems introduced by patient incapacity to participate in the decision making process
3. Should physicians always acquiesce to the patient's desires and preferences? or the family's, if the patient is incapable?
4. Euthanasia vs Allowing to Die

C. The Major Problem of Moral Choice

On what basis ought decisions to forego life-sustaining treatment be made?

D. The Dominant Approach

The President's Commission For the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (March, 1983)

1. Decisions about health care finally rest with capable patients in a context of mutual decision-making with physician and family.
2. The criterion to apply in these choices is the degree to which the patient will benefit or be burdened by the proposed treatment.
E. The Major Objections to the Dominant Approach

Traditional Distinctions

1. To Act vs Omitting to Act
2. Withholding vs Withdrawing Treatment
3. Intended vs Unintended but foreseeable consequences
4. Ordinary vs Extraordinary Treatments

F. The Best "Study" of The Dominant Approach
Cases and Decisions to Forego Treatment

G. Long-Range Consequences of the Dominant Approach
Benefit-Burden

1. Autonomy is respected;
2. Beneficence is less--technology could do more;
3. Non-Maleficence decreases harm that could be done through aggressive treatment and paternalism
4. Justice in health care is increased
Lecture Outline

Session #10 Neonatal Intensive Care

A. Background Information

1. Technological Advances in the Care of the Neonate
2. Development of the Neonatal Intensive Care Unit
3. Sec. 504 The Rehabilitation Act 1973
4. The President's Commission for the Study of Ethical Problems in Medicine and Biomedical Behavioral Research, Forgoing Life-Sustaining Treatment, 1983
5. The Child Abuse Amendment and Final Rule 1984

B. Problems of Moral Choice

1. Withholding Treatment to Full Court Press
2. Parental Autonomy
3. Benefit–Burden
4. Infant's Autonomy
5. Quality of Life

C. The Major Problem of Moral Choice

Is it ethically justified to withhold medical or surgical procedures which are clearly futile and will only prolong the act of dying?

D. The Dominant Approach

All disabled infants with life-threatening conditions must be given medically indicated treatment.

1. when medical / surgical care is clearly beneficial it should always be provided.
2. in cases where it is uncertain whether medical treatment will be beneficial, a person's disability must not be the basis for decision to withhold treatment.
3. when doubt exists at any time whether to treat, a presumption always should be in favor of treatment.
Parents are the legal decisionmakers regarding their child's care unless there is judicial intervention.

E. The Major Objections to The Dominant Approach

Quality of Life Issues

Proportionality	cost/benefit
Nonmaleficence	active euthanasia
Justice	parents have the right to greater say so

F. The Study on The Dominant Approach

Literature Review on Very Low Birth Weight Babies
Session # 11 AIDS: Beyond The Basics

1. Background Information

2. Problems of Moral Choice
   
   A. Confidentiality
   B. Screening/Contact Issues
   C. End of Life Issues

3. The Major Problem of Moral Choice
   
   Screening For Antibodies to HIV/ Contact tracing

4. The Dominant Approach
   
   Voluntary Screening/Voluntary Contact Tracing

   Rules of Liberty
   a. freedom of association
   b. privacy
   c. confidentiality

   Principles
   a. Respect for persons
   b. Confidentiality

5. The Major Objection To The Dominant Approach

   There ought to be routine or mandatory screening to at-risk individuals/groups

   Reasons offered:
   a. some apparent violations of rules may not really be violations;
   b. none of these rules can be considered as absolutes;
   c. each of these rules can be justifiably overridden in order to protect the public health under some circumstances

   Conditions Necessary To Justify Infringement of The Rules of Liberty:
   
   a. Effectiveness and Proportionality
   b. Last Resort-- no feasible alternative
   c. Least Restrictive Alternatives
   d. Prior Notice to the Infringed

6. Long-Range Consequences
   
   a. not enough prevention of harm
   b. too much respect for some persons at the risk of harm to others
LECTURE OUTLINE

SESSION #12  Critiques of Bioethics

A. Definition of Bioethics

B. There are three types of critiques to be considered:

   Type 1 Ideological Critique
   (Responses from professionals in the profession)

   Type 11 Cultural Critique

   Type III Post Ethical Critique

Type 1 Ideological Critique ("The New Medical Ethics: A Second Opinion")

Errors In Logical Argument

1. Ignorantia Elenchi (missing the point)
2. Rhetoric and Prejudicial
3. Romanticizing The Past
4. Genetic Fallacy
5. Inaccurate
6. Petitio Principii
7. Attributing and Attacking A Position No One holds
8. Misplaced Pair

Type 11 Cultural Critique

(Medical Morality Is Not Bioethics- Medical Ethics in China and The United States article by Fox and Swazey, 1984)

United States: The ordering of the Principles of Bioethics; treatment of Autonomy as most important principle (pp.339) Lack of relationships;
The "cultural revolution" influence on medical morality; "Scale the Heights" on modern medicine morality, pp.340

China: The Ordering of the bioethical principles; virtues of the chinese: Modesty; self-criticism; and, generosity are the cornerstones of medical morality (pp.343); Dynamic Complementarity, relationship to others
Can "ethics" ever achieve closure on any moral problem in our society?

Is applied ethics based on a mistake?

Poor Moral Arguments in Contemporary Discourse


1. Confusion of Parenetic Discourse With Normative Discourse

In normative discourse you deal with the pros and cons of a certain precept or prohibition; parenetic discourse does not treat the pros and cons of a precept or prohibition. It takes it for granted. To exhort to a form of conduct or pass judgement on it: "Love is patient; Love is not jealous..."

2. Rhetoric as a normative argument

Blatant use of parenesis with normative discourse: i.e., "We must not tamper with nature" The result of this "argument" is ignorantia elenchi (missing the point)

3. The Straightforward Petitio Principii

(Begging the question) A logical fallacy in which a premise is assumed to be true without warrant or in which what is to be proved is implicitly taken for granted.

4. Confusing Authority for Argument

Authoritative assertions can never replace moral arguments

i.e., Theologians issue personal opinions, the Pope
issues authentic teachings.

5. Various forms of the “genetic fallacy”

If the arguer is labeled "deviant" that is enough to refute what he/she says

6. Misplaced or misnamed pairs

A poor contrast; i.e., to contrast the abstract with the historical. Such a contrast ignores the fact that a norm can be both abstract and historical at the same time. The proper contrast is abstract and concrete.

7. Post Hoc Ergo Propter Hoc

Contraception-sterilization-abortion are seen along a psychological continuum. If a person is determined not to have a baby, when contraception fails, the individual is ready for abortion. Therefore, the prevalence of abortion is used as a form of argument to reject every contraceptive act as intrinsically evil. Such an argument is a non-argument.

8. Attributing and Attacking positions No One Holds
Session #13 Utilitarian Ethics

I. Introduction
   a. definition
   b. characteristics
   c. moral vs. nonmoral

II. Case #1
   Hastings Center Report, Feb. 1987, vol. 17, no. 1
   "AIDS and a Duty to Protect"

   Mr. B, age twenty-eight, reported to the community health center of a large city teaching hospital for counseling after being confidentially informed that his blood test was positive for antibodies to the Human Immune Deficiency Virus (HIV), the virus that causes AIDS. The patient had no symptoms.

   Dr. T informed Mr. B that although he did not have AIDS, there was between a 5 and 35 percent probability that he would develop the disease within the next five years. He was also told that he could probably infect others through sexual contact, by sharing needles, or by donating blood and blood products. He was counseled not to donate blood, and to engage in "safe sex," that is, sex that does not involve the exchange of bodily fluids such as semen.

   Mr. B then revealed he was bisexual, and that he believed he had contracted the infection during one of his homosexual encounters. He also said that he was engaged. Dr. T advised him to inform his fiancee of his diagnosis. But Mr. B refused to do so, saying that it would ruin his marriage plans.

   Should Dr. T inform her of his patient's test results, or should he protect the confidentiality of the therapeutic relationship?

III. Discussion

IV. Case #2
   Hastings Center Report. April 1986, vol. 16, no. 2
   "The Anencephalic Newborn as Organ Donor"

   Mrs. Z, a young, pregnant women with no children underwent an ultrasound examination. Her baby girl was overdue and the ultrasound revealed that she was anencephalic. There appeared to be no brain tissue present except for portions of the brain stem. The parents were told of this tragic diagnosis and immediately decided to volunteer the baby as an organ donor. The obstetrician in charge of Mrs. Z's care decided to contact a large, tertiary
care facility nearby in order to ascertain their interests in utilizing the child as a donor.

Two thirds of children who suffer from anencephaly are stillborn. Many of the organ systems in such children are underdeveloped, but it is possible to utilize both the heart and the kidneys for transplantation to other children. The obstetrician and the pediatrician agreed that it would soon be necessary to induce labor. However, if organ procurement was to be undertaken, it seemed reasonable to transfer her to the large tertiary care hospital and to induce labor there.

The rest of the medical staff was uncertain whether to proceed. If they accepted the mother's wish to have the baby be an organ donor, were they under an obligation to try to resuscitate the infant if it was stillborn? What steps should they take to try and support the child considering that babies with this condition normally receive no aggressive treatment in the neonatal nursery? Perhaps most confusing was the question of when death should and could be pronounced.

Should Mrs. Z be transferred to the large medical center? Should the physicians accept the wishes of Mr. and Mrs. Z to have their child serve as an organ donor? If they do, what steps would be morally permissible to help increase the chances of allowing the child to serve as an organ donor?

V. Discussion

VI. Summary Points
## PROCEDURAL RULES IN UTILITARIAN ETHICS

### UTILITY PRINCIPLE

<table>
<thead>
<tr>
<th>ACT</th>
<th>RULE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Considers the consequences of each particular act</td>
<td>1. considers the consequences of generally observing a rule</td>
</tr>
<tr>
<td>2. observances of a general rule would sometimes not be for the general good</td>
<td>2. observances of rules that pass the test of utility are almost always for the general good</td>
</tr>
<tr>
<td>3. the act utilitarian is willing to challenge ordinary convictions</td>
<td>3. the rule utilitarian teaches respect for ordinary moral rules</td>
</tr>
<tr>
<td>4. the beneficial consequences of the act alone makes it right</td>
<td>4. the conformity of an act to a valuable rule makes the action right</td>
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LECTURE OUTLINE

Session #14 Deontological Ethical Theories

I. Introduction

II. Definition

“...to qualify as a deontologist, one must hold that at least some acts are wrong and others right independent of their consequences.” p. 33

III. Characteristics

a. monistic deontologist
b. pluralistic deontologist

IV. Case 1. (See attached sheet)

V. Case 2.

An agency of the U.S. Government is authorized to conduct national studies, based on probability sampling, to collect a broad range of morbidity data and related health information. The agency is planning in FY88-89 a new study involving a sample of 60,000 Americans. 45,000 of the sampled subjects will receive a physical examination and they will be asked to donate a blood sample.

When the study was originally designed in 1982 analysis of the blood sample for HIV infection was not included. Scientists in the agency have recently posed the question to themselves and to the NIH whether it would be ethically acceptable—in the interest of a scientifically valid prevalence study—to inform the study subjects that the blood was to be tested for HIV infection.

A. How would a deontologist view this issue?
B. On what grounds could a deontologist justify the study, if at all?
A MODIFIED RULE UTILITARIANISM
An Ethics of Responsibility

Among the terms used in the past to explore the moral life (e.g. virtue, duty, law, goodness, morality), a relatively new term has emerged, "responsibility".

Using idea of responsibility, further the two purposes of ethics:

1) Gnothi seauton ("know thyself") (What are we like in all our actions?)
2) Seek guidance for decisions, choices, commitments (What ought we to do?)

Two dominant symbols in historic Western ethics:

I. TELEOLOGY (self-as-maker, fashioners)

Aristotle: "Every art and every inquiry and similarly every action and pursuit, is thought to aim at some good" Ethics.

Acting purposively, future-oriented; teleology is concerned with the highest good to which it subordinates the right (e.g. eugenics; euthanasia).

What shall I do? Answer: "What is my goal, ideal, or telos".

II. Deontology (Self-as-citizen, living under a law)

Life is more like politics than art, and politics is the art of the possible; self-understanding as a political image; we should rule ourselves as being ruled.

Mores, commandments, rules, directions, permissions.

Self-government and the government of the many; consistent deontology is concerned with the right; no matter what happens to our goods (e.g. abortion; prolongation of life).

What shall I do? Answer: "What is the law and what is the first law of my life?"
III. Responsibility  (self-as-answerer, in dialogue, acting in response to action)

Since the 19th Century:

Interactionist psychology, biology, sociology: we are beings in the midst of a field of natural and social forces, acted upon and reacting.

We are responsive beings, who in all our actions answer to action upon us in accordance with our interpretation of such action.

What shall I do? Ask first: "What is going on?", Then answer with actions that seek to do the good, the right, and the fitting.

The fitting action is the one that fits into a total interaction as response and as anticipation of further response; the fitting action will be more conducive to the good and the right (e.g. history of policy to protect human subjects in research; genetic engineering; hospice movement; prenatal diagnosis and fetal therapy).

Four elements in a theory of responsibility:

1. Response: all action, including moral action, is response to action upon us; everything that is has both self-determination and the power to influence others.

2. Response to interpreted action upon us

   What is going on?
   What is being done to me? What is the motivation of the others?

3. Accountability: Our actions are responsible not only as reactions to interpreted actions upon us, but also as they are made in anticipation of answers to our answers

   An agent's action is like a statement in a dialogue
   Responsibility lies in the agent who stays with his/her action, expecting a further answer

4. Social solidarity: Our action is responsible when it is response to action upon us in a continuing discourse or interaction among others forming a continuing society

   A continuity of a self with a relatively consistent scheme of interpretations of what it is reacting to

   Continuity in the community of agents to which response is being made
The fitting act is made to fit into a situation that is defined by more than one measurement (the good, the right)

Analogy: Driving a car

- the rules of the road
- the goal (destination)
- the forty decisions the driver makes each minute

**Rule Utilitarianism**

1. Begin with moral rules (e.g. do no harm, keep your promises, obey the law, do not lie) that apply to all equally; a floor for everyday life. The source of the "right".

2. Also teach the principles that if consistently followed in the majority of cases will lead to the most good for the society and individuals; e.g. beneficience, non-maleficience, autonomy, justice, utility. A mixed set of principles. Principles are used in analysis of types of moral problems that emerge as controversial, about which there is an issue or conflict. The source of the good.

3. Admit that in certain special cases, there are circumstances that might allow for exceptions from the rules; but that these cases are not normative in the sense of shaping our motivation for the vast majority of cases

4. A choice exists, beyond the moral rules and ethical principles, to interpret one action upon us, in the midst of all other actions, as a source of unity for the self that holds it together in the midst of all (and conflicting) actions upon it. We respond to this unifying action as we also respond to all others.
Final Examination

Instructions: Review the text by Beauchamp-Childress (B&C) and the handouts for each class. However, the exam should be taken as "closed book." This method gives the best measure of what you know objectively about the subject matter of the course.

Part I. Ethical Theory

1. B & C diagram their approach to moral reasoning in the form of hierarchical levels. Fill in the blanks with the proper words:
   4.
   3.
   2.
   1.

2. John C. Fletcher diagrams his approach to moral reasoning in the form of dimensions of moral experience. Draw the diagram and label the dimensions.

3. Define: "nonmoral reason" in 25 words or less.

4. The 3 characteristics of moral action guides are:
   1.
   2.
   3.

5. Characteristics of the moral level distinguished from the ethical level are:
   1.
   2.
   3.
6. Characteristics of the ethical level distinguished from the moral level are:
   1. 
   2. 
   3. 
   4. 
   5. 

7. In addition to the principle of utility Beauchamp and Childress recommend four basic ethical principles as normative for biomedical ethics. Name these principles.
   1. 
   2. 
   3. 
   4. 

8. Define in 25 words or less:
   1. Descriptive Ethics

   2. Metaethics

   3. General Normative Ethics

   4. Applied Normative Ethics
9. What are the 5 tests of ethical theories as recommended by Beauchamp and Childress?

   1.
   2.
   3.
   4.
   5.

10. Give the names of at least 3 well-known codes of medical ethics.

   1.
   2.
   3.

Part II Special Problems in Bioethics

A. Prenatal Diagnosis

1. What are the 5 main problems of moral choice in prenatal diagnosis?

   1.
   2.
   3.
   4.
   5.

2. Chorionic villus sampling is as safe and accurate as amniocentesis.

   _____ True _____ False

3. Give 5 reasons why abortion choices after prenatal diagnosis are so difficult.

   1.
   2.
   3.
   4.
   5.
4. Give the 3 controversial indications for prenatal diagnosis.
   1. 
   2. 
   3. 

5. What are the 5 most difficult problems of moral choice in disclosing findings in prenatal diagnosis?
   1. 
   2. 
   3. 
   4. 
   5. 

6. What is the dominant approach to the moral problem of abortion in prenatal diagnosis? 25 words or less.

7. What are the 2 major objections of abortion in prenatal diagnosis?
   1. 
   2. 

8. According to empirical research, what is the most controversial issue in the world regarding prenatal diagnosis?

B. Human Gene Therapy

1. Has human gene therapy ever been attempted?
   _____ Yes    _____ No

2. What are the 3 prerequisites before human gene therapy can be considered ethical?
   1. 
   2. 
   3.
3. What disorder is likely to be the first candidate for human gene therapy?

4. Local IRBs have the authority to approve gene therapy experiments in humans, assuming the recombinant DNA use has had prior approval by an Institutional Biosafety Committee.

______ True  ______ False

C. Predictive Genetic Screening

1. Name three issues facing medical geneticists who use predictive genetic screening
   1.
   2.
   3.

2. What are the 3 major problems of moral choice in predictive genetic screening?
   1.
   2.
   3.

3. What are the 5 facets of an emerging dominant approach to predictive genetic screening?
   1.
   2.
   3.
   4.
   5.

4. According to empirical research, medical geneticists strongly agree that spouses and relatives should not have access to results of genetic screening without the patients consent.

______ True  ______ False
D. In Vitro Fertilization and Embryo Transfer (IVF-ET)

1. A ban exists in the U.S. on federal funding for research on IVF.
   _____ True   _____ False

2. Between _____ % and _____ % of Americans of reproductive age are infertile.

3. What is the major moral problem of IVF-ET?

4. What are 3 other moral problems of IVF-ET
   1. 
   2. 
   3. 

5. Describe the dominant approach to clinical IVF (the use of IVF to treat infertility (25 words or less)

6. Describe the dominant moral approach to fertilization of human embryos for research only

E. Animal and Human Research

Animal Research

1. What are the three major views of the morality of research with animals?
   1. 
   2. 
   3. 

2. What are the four moral problems of animal research (what any view must consider)?
   1. 
   2.
3. What is the dominant approach to the morality of animal research?

4. What is the major objection to this approach?

F. Human Research

1. Give 4 of the 6 moral problems in research with human subjects.
   1.
   2.
   3.
   4.

2. What are the two major problems of moral choice in research involving human subjects? Rank them.
   1.
   2.

3. What are the dominant approaches to the two problems?
   1.
   2.

4. Give two objections to the dominant approach
   1.
   2.
**G. Euthanasia**

1. Define: "Euthanasia"

2. Define: "Allowing to Die"

3. Give three reasons why euthanasia can be morally justified.
   1. 
   2. 
   3. 

4. Give three reasons why euthanasia can be morally objectionable?
   1. 
   2. 
   3. 

5. Euthanasia in the U.S. is illegal!
   ________True ________False

6. Euthanasia in the Netherlands is illegal but permitted with self reporting and judicial review.
   ________True ________False

7. Define: "Negotiated Death"

8. Give three cultural and institutional reforms necessary in the U.S. to promote "negotiated death."

**H. Do Not Recuscite**

1. What are the 4 problems of moral choice in decisions to forego lifesustaining treatment?
   1. 
2. What is the major problem of moral choice?

3. What are the two features of the dominant approach to the major problem?

4. Which ought to be morally harder to justify:
   A. Withholding a life sustaining treatment
   B. Withdrawing a life sustaining treatment

1. Neonatal Intensive Care

1. There is no federal law bearing on the subject of selective nontreatment of newborns.
   
   __________True __________False

2. Give three of the five problems of moral choice frequently faced in the neonatal intensive care setting.
   
   1.
   2.
   3.

3. What is the major problem of moral choice in the neonatal intensive care setting.

4. What is the dominant approach to the major problem of moral choice.

5. Give at least two major objections to the dominant approach.
   
   1.
   2.
J. AIDS

1. What are the three problems of moral choice in coping with AIDS?
   1.
   2.
   3.

2. What is the major problem of moral choice?

3. What is the dominant approach to the major problem of moral choice?

4. What is the major objection to the dominant approach?

5. How many cases of AIDS have been reported to date in the U.S.?

6. Between 1.5 and 2.0 million Americans are infected with the AIDS virus.
   _______ True _______ False

Part 3 Ethical Theory

1. Name the 3 types of critiques of bioethics
   1.
   2.
   3.

2. Give the name of one author representative of each of the three types of critiques.
   1.
   2.
   3.
3. List four common errors in logical argument frequently found in the ethics literature.

1. 
2. 
3. 
4. 

4. How would B&C's four principles be ranked in terms of importance:

   (A) United States
   
   1. 
   2. 
   3. 
   4. 

   (B) Peoples Republic of China
   
   1. 
   2. 
   3. 
   4. 

**Utilitarian Ethics**

1. Name three philosophers representative of utilitarian ethics.

   1. 
   2. 
   3. 

2. Define the principle of utility (25 words or less)


   1. 
   2. 
   3. 
   4.
4. Give 4 procedural rules for rule utilitarianism

1. 
2. 
3. 
4. 

5. After a moral choice has been made, what is the best test to determine whether it has been made on utilitarian grounds?

**Deontological Ethics**

1. Name 3 philosophers or theologians representative of deontological thought.

   1. 
   2. 
   3. 

2. Define the deontological position in ethics in 25 words or less.

3. What is the difference between an act and a rule deontologist?

4. What is the difference between a monistic and a pluralistic deontologist?