Introduction to Medical Ethics for Students at the Medical College of Georgia

Phase 1 and Phase 2

Ethics is the discipline that systematically analyzes and rationally justifies our moral choices (Pellegrino). Knowledge of ethics is critical to the professional development of the physician (Hafferty).

*Ethical decision making deals with concrete judgments in situations in which action must be taken despite uncertainty.*

This course of study is designed for all four years of medical school. The purpose of this course is to teach the skills necessary for the student to identify, analyze and resolve ethical problems in patient care situations, and choose among the options that can be done and those that ought to be done, for a given patient in a given clinical setting. We will help the student gain insight into the patient-physician relationship from the patient's perspective as well as the physician's. Finally, by introducing this course of study in the preclinical years, we hope to make the transition from a morally responsible student to a morally responsible physician more logical, more meaningful, and more certain.

The course consists of a one-hour group lecture/interactive discussion for Phase 1 and 2. This will be followed by 6 hour and a half workshops. In these workshops, we will discuss and analyze all issues described in the course content. Each workshop will have 10-12 students and one faculty facilitator; and will consist of case discussions, clinical vignettes, role-playing to enhance the skills of proper physician/patient communication regarding sensitive issues, and audiovisual presentations modeling appropriate and inappropriate professional behavior in clinical situations followed by feedback. In addition, there will be ethical grand rounds and vertical insertion of appropriate ethical issues into
preexisting lectures. For example, in a neuroscience lecture dealing with brain function/death or persistent vegetative state, issues regarding care of the dying patient/family, could be discussed. Finally, ethical issues of specific cases being considered in preexisting groups such as problem-based learning, problem solving, and the "standardized patient" could be expanded upon through use of prepared packets of materials.

**Phase 3** core clerkships will include monthly one-hour workshops in which each student would be expected to present an ethical dilemma he/she has faced and a resolution reached. This format is ideally suited to small-group discussions (i.e., 10-30 students) and techniques such as role-playing, use of standardized patients, prepared scenarios, videos of simulated ward teams in action will be used.

Other venues in Phase 3 include:

1. departmental didactic lectures
2. departmental grand rounds
3. departmental daily ward rounds

**Year 4**
An elective in Medical Ethics is offered on a monthly basis to medical students. This course consists of intensive, case-oriented discussion of important issues confronted by all students in the clinical setting. An interdisciplinary elective is planned for the spring semester and will include students from medicine, nursing and the allied health sciences. These students will have the opportunity to explore a special ethical issue and present their research in a grand rounds format for the student body/faculty at large.

**Contents**
Medical students must be prepared and knowledgeable regarding the following issues:

1. Informed consent, including assessment of the comprehension of the patient and shared decision making.
2. Confidentiality and when it can justifiably be
breached.
3. Competency assessment-factors of decision making for the incompetent patient.
5. Futile versus curative therapy.
6. Advance Directives.
7. CPR.
8. DNR issues.
11. Quality of life issues.
12. Euthanasia and assisted suicide.
14. HIV issues.
15. Care of the dying patient and learning the distinction between: (a) withholding and withdrawing life sustaining medical intervention, including nutrition and hydration; (b) "Ordinary" and "extraordinary" care; (c) hastening the death process versus allowing to die; (d) assisted suicide and euthanasia; (e) brain death and persistent vegetative state.
16. Ward Team Ethics: to help the student prepare for his/her clinical education (i.e., the ward team experience) where there is no written curriculum, and to help the student make the transition from classroom to patient care and to discuss pressures of being a team member. In particular, the pressure to learn, be part of the team, achieve good grades, deal with making mistakes, and witnessing other team members making mistakes, handling differences of opinion among ward team members, and learning the paramount importance of keeping the welfare of the patient as first and foremost priority; being perceptive of ethical issues that arise while on the ward, and, above all maintain and enhance his/her individual integrity and moral values regardless of the manifold ward team pressures and influence not withstanding.
17. Genetic testing and genetic manipulation
Issues.
18. Impaired physician issues.
19. Ethical, moral, cultural, religious differences regarding such issues as reproductive technology, abortion, gender differentiation, contraception and birth control. In view of these differences the ever present duty to properly fulfill the physician's fiduciary and moral responsibility to his/her patient in areas of clinical decision making and counseling; to define the responsibility of the physician to appropriately help the patient make a reasonable decision as to his/her course of action regarding these difficult, controversial issues, regardless of the physician's personal moral preference.

Objectives
At the conclusion of this course, the student should:

1. Be thoroughly familiar with the criteria necessary for him/her to make sound ethical decisions.
2. To know the moral aspects of medical practice and to have a clear decision making strategy for clinical-ethical problems in medicine. These criteria will include an understanding of: (a) Beneficence; (b) Non-maleficence; (c) Autonomy; (d) Distributive justice; (e) Medical indications; (f) Patient preferences; (g) Quality of life preferences; (h) Other factors.
3. Know how to obtain informed voluntary consent.
5. Know what to do about incompetent patients.
6. Know when it is morally justified to withhold information.
7. Know when breaching confidentiality is justified.
8. Know how to manage patients with poor prognoses.
9. Know how to manage medical resources wisely.
10. Gain detailed knowledge of advance directives and the legal issues involved.
11. Understand the basis of the physician's
obligation to care for particular patients
13. Learn distinction between withholding and withdrawing life sustaining medical intervention; brain death, persistent vegetative state, and coma; assisted suicide and euthanasia versus allowing to die.
14. Appropriate care of HIV test, notification of third parties exposed to HIV, and maintaining confidentiality of HIV test results.

Finally, to teach skills of ethical analysis essential to making medical moral choices; raise responsibility of ethical issues in every day clinical practice and enhance critical reflection of one's personal values and obligations as a physician. In short, to educate students in proper professional behavior and to endow them with the practice, wisdom, and informed ability to exercise proper moral and ethical judgment in clinical management.

Concept Inventory
Level I: Concepts that the student should be thoroughly familiar with:

- The meaning of professional integrity and the moral basis of medical practice including conflicting moral values and importance of patient preference.
- Ethical principles of beneficence and nonmaleficence.
- Strategy for ethical clinical decision-making and ability to apply this strategy with understanding of the principles of medical indications, patient preference, quality of life factors and other external factors.
- Voluntary informed consent.
- Patient refusal of recommended treatment including life-sustaining treatment and making ethical decisions related to cardio-pulmonary resuscitation and life support.
- Competency and incompetency.
- Moral justification of withholding information.
- Principles of confidentiality and when
breaching confidentiality is justified.

- HIV tests, confidentiality of tests results and legal/ethical issues regarding third parties exposed to HIV.
- Proper professional behavior in dealing with patients, colleagues and co-workers.

**Level 2: Concepts that the student should be familiar with but in-depth knowledge is not necessary.**

- Advance directives and legal instruments in the State of Georgia.
- Principles determining "futile therapy," terminal care vs. futile care and understanding the limits of patient demands for "non-indicated" therapy.
- Specific gender, cultural and ethnic issues; religious beliefs and sexual preferences that affect medical decisions.
- Statutory law and legal restrictions for surrogate decision-making, including treatment of minors.
- MCG policies and procedures.
- Impaired physician issues.
- Genetic testing, genetic manipulation issues.
- Multi-cultural, multi-religious, multi-ethnic differences regarding abortions, contraception, in vitro procedures of conception and birth control.

**Level 3: Concepts that the student should know exist but need not know in-depth.**

- Principle of distributive justice and how it applies to allocating limited or scarce resources and issues of health care reform and access to health care.
- When and how to obtain an ethics consultation and be knowledgeable of the function of MCG's Ethics Committee.

**Evaluation of Students**

1. Knowledge
   - Written evaluation by faculty, following case discussions, workshops, etc.
   - Self-evaluation.
2. Practice Skills
   - Written evaluation by clinic faculty, following direct observation.
   - Written evaluation by faculty ethicists following role playing in workshops.
   - Written evaluation by faculty attending on the in-patient service.

3. Attitudes, values, habits
   - Written evaluation by faculty following direct observation in clinics, in-patient ward service and in-patient rounds.
   - Self-assessment.
   - Nursing survey.
   - Record number of formal and informal bioethics consultations and ethical dilemmas submitted.

Evaluation of curriculum and faculty

1. Written and oral feedback from students.
2. Survey students regarding faculty role modeling of practice skills, attitudes, values, and overall performance behavior.
3. Survey of students after several years following completion of medical school as to how well they have put into practice what they have learned.

Learning Opportunities

1. Lectures
2. Group workshops for interactive discussion, role-playing, problem-oriented.
3. Seminars and case presentations.
4. Audio-visual depictions of professional behavior scenarios followed by feedback sessions.
5. Handouts, referral to specific reference material.
6. Ethical grand rounds.
7. Bedside ethical rounds.
8. Submission in writing of an ethical dilemma faced by a student with interactive group discussion and resolution.
10. Standardized patients.
11. Problem-Based Learning.

Literature Cited


List of References

Phase 1 Medical Ethics for Students at the Medical College of Georgia

Preface

The Medical College of Georgia (MCG) firmly believes that ethics education must be an integral part of the medical school curriculum. As an applied human science, the study of ethics is as fundamental to the education of a physician as the "hard sciences” such as anatomy, physiology, or pathology.

Ethics is a necessary complement in producing physicians with the essential humanistic skills. The science of moral reasoning is founded on basic principles and assumptions about which there is wide consensus. It is a teachable subject with a discrete curriculum and meaningful criteria for evaluation. ¹ With this goal in mind, MCG introduces this four-year longitudinal Ethics curriculum.

The preparers of this syllabus would like to express their deep appreciation to the many people who had the foresight and courage to propose this project and to support and nurture it in its earliest developmental phase and to give the curriculum committee a virtual free hand in the process. Without such patient, enthusiastic support, advice and continued commitment, this process could not have been done.

Alan Roberts, MD, FACP
Chair, Ethics Curriculum Committee

Phase 1 Objectives

Introduction to Medical Ethics

To provide a foundation for subsequent discussions by introducing the appropriate glossary, technique and substantive resources for clinical ethics discourse. To introduce a standard format and method for discussion and provide an opportunity for practice.

Genetic Testing, Genetic Screening, Gene Therapy

To explore the use of new diagnostic and intervention technologies, i.e., decisions about screening, the disclosure of test results to patients or others, and the relative risks and benefits of genetic therapy.

The Human Context of the Practice of Medicine: Self-awareness

To explore the students' own values and their function and significance for clinical decision-making--what they believe and what difference that makes.

The Pediatric Patient: Personhood, Parents and Principles

To explore the physician's responsibility to the child as patient and the role/rights of the parents, and ethical and legal principles which inform decisions when they are in conflict.

The Physician's Obligation to Society: Resource Allocation

To explore the physician's
responsibility and informing principles regarding the efficient and just use of limited clinical resources. Help the students to understand the various interests involved, the areas of controversy and conflict and what is expected of the student in preparation for his/her role as a physician.

**The Patient as Person: Responses to Illness, Living, Dying and Bereavement**

To explore the personal and sociological effects of illness in the life of a patient, productive and nonproductive means of coping with those effects, and the role of the physician in this process. To explore the impact of dying and death upon the students/physicians, patients and their families, and the difficult decisions concerning the treatment of the dying patient.

**Informed Consent and Confidentiality**

To explore the physician's ethical and legal responsibilities for informed, voluntary consent and confidentiality of patient information; and circumstances in which disclosure can be made to others who are likely to be affected (i.e., breaching confidentiality).

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Please email comments, suggestions or questions to:
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October 13, 1999
The Language of Bioethics

**Advance Directive:** a document in which a person gives advance directions about medical care, or designates who should make medical decisions for the person if he/she should lose decision-making capacity, or both. There are two types of advance directives: treatment directives (Living Wills), and proxy directives (Healthcare Power of Attorney).

**Artificial Feeding:** procedures in which a person (patient) is fed by means other than self administration in an oral-ental process. This may include medical enteral procedures (gastrostomy tube, nasogastric tube, transpyloric or transcutaneous enteral tubes), or parenteral nutrition (IV hydration/dextrose or total parenteral nutrition/hyperalimentation to include proteins and lipids.

**Assent:** a concept which applies to children (minors) and refers to their right to have their own perspective represented in all decision-making about his/her health care. The elements of assent include: a) a developmentally appropriate understanding of the nature of one's illness; b) a description of the proposed treatment and the experience it will involve for the child; c) an effort to solicit the willingness of the child to participate in the treatment.

**Baby Doe Regulations:** refers to federal legislation under DHHS: Child Abuse and Neglect Prevention and Treatment Program Federal Register 1985, 50:1478-901, implemented in October of 1985. Addresses standards of care for sick/handicapped infants and limits acceptable withholding of treatment to situations in which: a) the infant is chronically and irreversibly comatose; b) treatment would prolong dying or not correct all life-threatening conditions; c) treatment would
Be futile and inhumane.

**Best Interest Standard**: an assessment of what is good for a patient, typically the incompetent patient/child/infant, in a particular clinical situation which respects the patient's dignity and worth as a person but which does not rely on the patient's own concept of his/her good. In the case of children, parents are presumed to have an important (but not necessarily sole) role in determining their child's best interest.

**Brain Death**: cerebral functions are absent (deep coma or cerebral unreceptivity and unresponsivity and brainstem functions are absent (brain stem reflexes, respiration).

**Capacity**: a clinical judgement that addresses whether or not a person is capable of understanding health care options and participating in decision-making about one's own health care.

**Cardiopulmonary Resuscitation (CPR)**: an array of interventions undertaken at the time of a cardiac or respiratory arrest in order to reestablish vital signs and bodily functions.

**Competence**: a term which may be viewed in a psychological sense to infer a necessary condition of acting voluntarily and apprehending information. Judgement of competence always requires a context. One legal concept of competence presumes that someone over the age of 18 year has the right to make decisions about his/her health care unless a judge has determined otherwise. This right includes refusing treatment even when others consider it to be in the person's best interest. Other legal standards cluster about various abilities to comprehend and process information and to reason about the consequences of one's actions.

**Consent**: refers to the self-determined decisions concerning one's own health care made by a
person with the capacity and legal competence to make such decisions. The right of consent continues even when one is not conscious.

"Do Not Resuscitate" (DNR) Order: a signed order directing that no resuscitation efforts (CPR) are to be undertaken in the event of a cardiac or respiratory arrest.

Dilemma: moral obligations to others exist on both sides of the choice; ethical reasons that support choosing both alternatives.

Durable Power of Attorney: an individual's written designation of another person to act on his or her behalf, when the designation is authorized by a state's durable power of attorney statute. Under state law, a power of attorney terminated when the designating individual loses decision-making capacity, whereas the durable power of attorney does not.

Due Care: The care which a person should exercise in choosing and acting in order to have reasonable grounds to expect his/her action to have results in accord with his/her intention and his/her obligation to other people.

Duty: The conduct or action required of a person on moral grounds.

Emancipated minor: through the courts: if pregnant, married, in military or self-supporting.

Emergency: A sudden, acute medical crisis in the condition of a patient, requiring immediate medical attention in order to avoid injury, impairment, or death.

Ethics Committee: a committee composed of persons from multiple disciplines, which usually directs its attention to one or more of the following: education of hospital staff and/or community on issues in bioethics; policy development or adaptation for procedures or guidelines in patient care and hospital practice.
which impact on bioethical issues; and case consultation in patient care which poses ethical problems.

**Ethics**: refers to principles of morality and right and wrong conduct. The study of moral conduct, systems, and ideas. Medical ethics refers generically to physician, nursing, and healthcare ethics.

**Euthanasia**: (Literally “good dying”); modern usage refers to the physician allowing death to take place without intervening (passive), or actively doing something to bring about death (active), in instances where medical care is concerned; often termed "mercy killing". Also considered in terms of being voluntary (at patient's informed, competent and uncoerced request;), or nonvoluntary.

**Fidelity**: truth telling.

**Fiduciary**: (Based upon trust); specifically, the nature of the relationship between the physician and patient based upon the patient's trust that the physician will act responsibly, that he will help and not harm, that she will advocate the patient's "good" at all times.

**Formalism**: a philosophical view that certain types of acts follow fixed moral principles (or rules) such that circumstances, including consequences, do not alter cases; deontology.

**Futility**: a term dealing with the hopelessly ill and dying; at least three meanings bear consideration:

- **Physiologic futility**—the proposed intervention or continued treatment cannot reverse a physiologic condition in the patient that is leading to death. This strict definition of futility means that the intended medical effect of the treatment is not likely to occur, as
determined by scientific evidence or local medical experience.

**Personal futility**-the proposed intervention or continued treatment may have the desired medical effect, but the resulting benefit does not outweigh the burden of continued life. This "best interest" or "disproportionate burden" definition of futility may mean that consciousness of the patient is not restored, or he/she will not leave the ICU, or that severe suffering will persist.

**Social futility**-the proposed intervention or continued treatment may have the desired medical effect, and personal benefit may outweigh the burden, but the treatment is not available, as determined by the social consensus, due to scarce resources.

**Hospice**: supportive and palliative care of the dying and terminally ill patient for whom curative intervention is no longer relevant. Hospice care may be provided in a facility such as a hospital or long-term care facility (nursing home), or the patient's home, and involves multiple disciplines which contribute extensive support services.

**Institutional Review Board (IRB)**: a hospital committee concerned with the review, revision, and implementation of research protocols which address implications for human research and ethical issues of research in general. IRBs are regulated by federal guidelines.

**Living Will**: a written treatment directive (advance directive) directing what forms of medical treatment the individual wishes to receive or forego should he/she be in given (stated) medical conditions (typically irreversible coma, severe dementia, or terminal
illness), and lack decision-making capacity.

**Mature minor**: 14 years of age, able to understand the nature and consequences of medical treatment; must consult parents if a life-threatening or life-sustaining treatment involved—unless get a court order. Examples: STDs, pregnancy, birth control.

**Morals**: the conduct and codes of conduct of individuals and groups. Three popular uses exist: a) in contrast to immoral (right versus wrong); b) in contrast to nonmoral (actions which have no bearing or question of right or wrong); c) "morals"... the behavior pattern of an individual or group.

**Palliative Care**: medical interventions intended, to alleviate suffering, discomfort, and dysfunction but not to cure (such as pain medication or treatment of an annoying infection).

**Persistent Vegetative State (PVS)**: a condition following significant brain injury in which the patient is permanently unconscious, comatose, but retains "vegetative" (autonomic) functions for a prolonged (perhaps indefinite) period. Neocortical functions are irreversibly lost.

**Physician-assisted Suicide**: the assisted (facilitated) suicide of a patient by a physician; the patient commits suicide by some means provided by, or with instructions from, the physician.

**Proxy Decision Maker**: a designated person who will act on behalf of an individual who become incapable of making decisions. Such an individual may be designated by an advance directive (Durable Power of Attorney for Health Care).

**Reasonable Person Standard**: a standard used when neither substituted judgement nor the best interests standard is applicable in decision
making. The patient (typically incompetent or never competent, i.e. infant or mentally impaired) has never previously expressed their wishes. Two situations generally require that this standard be applied: 1) some permanently unconscious patients (e.g. some patient in PVS) who have no interests in the usual sense of the word and cannot be benefited or burdened; 2) some incapacitated dying patients left on life support to preserve organs for transplantation.

Rights: those things to which people have a just claim; a claim to a condition to which the individual is entitled.

Substituted Judgement: the use of previously expressed (written, spoken or implied) directions by an appointed proxy or surrogate to carry out the patient's wishes for health care when the patient is unable to participate actively in decision-making. These substituted "judgements" (directions/decisions) are actually those of the patient, or consistent with what he/she would make, and are only communicated by the proxy.

Surrogate: an individual whose role it is to make health care decisions for another person (e.g. parent, spouse, designated proxy).

Surrogate Mother: a woman to agrees to carry the developing fetus of which is not the biologic contributor of the ovum; pregnancy is typically the result of implantation of an early dividing conceptus from two donor's gametes fertilized under in vitro conditions.

Terminally Ill: having an incurable or irreversible condition that has a high probability of causing death within a relatively short period of time with or without treatment (e.g. 6-12 months).

Thanatology: the study of death and dying.

Truthtelling: Reflects the general rule to
always tell the truth to patients, families, and colleagues. Temptations to avoid truth telling can take forms of: flawed disclosure and/or deception, use of medical jargon, hope for a breakthrough (too much optimism); omission-intentional failure to disclose (a form of lying); evasion (avoidance of truth telling).

Values: those things which have worth or are desirable to an individual or group; the feelings, habits and behaviors that create a "good" life.

References

Schedule of Classes for Phase 1

Classes will take place from 1:00-3:00 PM on the following dates:

Thursday, August 12, 1999 (Meet in CL-1101)

Thursday, August 19, 1999

Thursday, August 26, 1999

Thursday, September 2, 1999

Thursday, September 9, 1999

Thursday, September 16, 1999

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Please email comments, suggestions or questions to:
Kenda Rindt, krindt@mail.mcg.edu
October 13, 1999
Requirements for Phase 1

The grade assigned for this course will be "pass/fail" and will be based upon participation and final examination.

Attendance and Participation

- In order to pass this course, every student must attend and participate in all of the class sessions.
- No unexcused absences are allowed.
- Excuses for unavoidable absences shall be submitted in writing within seven (7) days to the Course Director for his consideration.
- Remediation of excused absences must be completed before the final examination under the direction of the faculty facilitator.

The Final Examination

- In order to pass this course, every student must pass the final examination.
- The examination will be given 1:00-3:00 p.m. on Thursday, September 23, 1999 in CL-1101.
- It will consist of multiple choice, USMLE-type questions based upon the required and suggested resources referenced in the Student Syllabus.
- To receive a passing grade, every student must score 70% correct answers on the final exam.

Remediation of Failures

- This course is a required course and therefore every student must successfully complete all of its requirements to be promoted to Phase II.
- All failures shall be remediated according to Promotions Committee Policy, Criteria for Promotion, Graduation and Dismissal, section IV, in a manner determined by the
Introduction to Medical Ethics and Genetic Testing, Screening and Gene Therapy

Introduction to Medical Ethics

To provide a foundation for subsequent discussions by introducing the appropriate glossary, technique and substantive resources for clinical ethics discourse. To introduce a standard format and method for discussion and provide an opportunity for practice.

Genetic Testing and Technologies

Objectives

To explore the use of new diagnostic and intervention technologies, i.e., decisions about screening, the disclosure of test results to patients or others, the relative risks and benefits of gene therapy, and issues of genetic privacy and nondiscrimination such as may occur in the workplace or in insurability.

Goals

1. Identify major ethical issues of genetic testing, screening and gene therapy.
2. Understand confidentiality and disclosure issues related to genetic testing.
3. Understand the obligations of the physician to his patient regarding genetic testing.
4. Understand that identification of a genetic disorder is not always in an individual patient’s best interest.
5. Appreciate the need for skilled genetic counseling.

Required Reading

Clinical Vignettes

Vignette #1

A patient is tested for the gene for Huntington's Disease and is positive. The test also revealed the fact that the father was not the biologic father. Does the physician need to tell the patient this information?

Vignette #2

The genetic cause of mental retardation of a man in his mid-40's is determined. The man's sister is his guardian and has two daughters. The physician wants to warn the two daughters they are at risk for bearing a retarded child. The mother refuses to let the physician do so because she does not want to be party to giving them information that might lead to an abortion. What does the physician do?

Vignette #3

The mother in the family has had both uterine and colon cancer at an early age and is found to have a MLHI gene mutation which increases the risk of colon cancer to 85-90%. There are four adult children. Should they be advised to have testing for this mutation and run the risk of not being able to obtain health insurance?

Video-A Question of Genes: Inherited Risks

Key Terms

- Genetic testing: the use of specific assays to determine the genetic status of individuals already suspected to be at high risk for a particular inherited condition.
- Genetic screening: distinguished from
genetic testing by its target population. It is the systematic search of populations for persons with latent, early or asymptomatic diseases.

- Gene therapy: the use of genetically altered material to favorably treat illness in humans.

Clinical genetics encompasses all ethical issues in medicine and health care. Major ethical issues deal with:

- Truth-telling
- Paternalism
- Confidentiality
- Rationing
- Role of the genetic counselor

Neutrality vs. Expressing Opinion

1. Is the physician expressing an opinion in genetic issues different, for example, than expressing an opinion regarding toxic chemotherapy for cancer? 
2. Should neutrality be maintained if a woman knows her fetus is affected with Tay-Sachs disease or Lesch-Nyhan syndrome and asks for advice? 
3. Should the counselor be open and direct about his biases rather than conceal them behind a cloak of neutrality?

In summary, genetic counseling should serve the patient's interest and values but be balanced with legitimate societal needs and wants, including the general public health. (e.g., to screen all pregnant women for carriage of cystic fibrosis gene might cost in excess of one billion dollars annually.

Genetic Screening

- Purpose
1. Identify patients who may benefit from pre-symptomatic treatment
2. Identify persons at risk for having an affected child
3. Research purposes

- Pitfalls
  
  1. Failure to recognize the heterogeneity of the disorder (e.g., in the early days of phenylalanine screening, infants were falsely labeled because of high phenylalanine levels as having the disease).
  2. Failure to test efficacy of the intervention with properly designed and peer-reviewed studies.
  3. Failure to inform prospective patients or their parents that the program is experimental.

- Essential Components of the Ethically Defensible Mass Screening Program

  1. Clear statement of purposes and goals
  2. Peer-reviewed pilot studies showing that stated goals can be achieved with acceptable costs and adverse effects.
  3. Education of the target population
  4. Attention to traditional standards of informed consent (avoiding mandatory programs except when compelling argument exists for doing so)
  5. Respect for confidentiality of potentially stigmatizing information
  6. Prenatal diagnosis and termination of pregnancy option exists
  7. Can prenatal diagnosis be
Genetic Therapy: Complex Ethical Issues

1. Whether to restrict initial efforts to patients with the capacity to consent.
2. Whether to do first trials on patients with end stage disease who have little to lose, or patients early in their course who have the greatest potential for a successful outcome.
3. Whether to try treatments that could prolong the life of patients with severe neurologic impairment, possibly without improving their condition.
4. Somatic gene therapies pose new ethical issues for the individual patient but germ-cell therapies, such as inserting genes into fertilized eggs, affects not only the life of that individual but the potential of all his or her offspring, thus introducing additional complex ethical issues.

Proposed International Code of Ethics for Medical Genetics: Based on Eight Ethical Issues

1. Equitable distribution of genetic services (i.e., access to/demand for)
2. Respect for and safeguarding of personal and parental choices (i.e., reproductive choices, including the choice of termination of the pregnancy). Reproductive decisions should be the province of those who will be directly responsible for the social and biological aspects of childbearing and child rearing. The woman should make the final decision among reproductive options without coercion from her partner, her doctor or the law. Choice should include the economic and social ability to act upon a decision, including decisions to terminate a pregnancy or to raise a child with a disability.
3. Confidentiality when other family members are at high risk. Family members have a moral obligation to share genetic
information with each other.
4. Protection of privacy from institutional third parties. Insurers, employers, schools, government agencies should have no access to genetics information about an individual without the person's fully informed consent and should not be permitted to require genetic tests without informed consent.
5. Full disclosure of clinically relevant information to patients, a prerequisite for free choice.
6. Prenatal diagnosis should be performed only for reasons relevant to the health of the fetus or the mother (i.e., not for sex selection, or to solely benefit a third party).
7. A voluntary approach to genetic services, including genetic counseling, testing, prenatal diagnosis, pre symptomatic testing, and screening in the workplace for susceptibility to occupationally related diseases. The only exception to the rule of voluntary screening should be newborns only if early treatment is available that would benefit the newborn (i.e., then screening should be mandatory).
8. Emphasis on non-directive counseling.


*(None thus far enacted)*

1. Legislative protection: grants a proprietary interest in one's own genetic material, protects individual rights and simultaneously promotes continued research and development by establishing clear rules on which investors and the biotechnology industry may rely.
2. Addresses disclosures and limitations regarding genetic information; prohibits disclosure of an individual's genetic information without written consent.
3. Exception: permits disclosure if it pertains to authorized paternity testing, medical testing of a descendant's relatives,
identification of bodies, court-ordered disclosure, and if it furthers authorized moral investigation.

4. Prohibits employers from obtaining genetic information for purposes of discrimination or restricting rights or benefits of current or prospective employees.

5. Prohibits health insurance providers from using genetic information to affect health insurance in any way and prevents use of genetic information as inducement to purchase insurance.

**Human Genome Project: In process of mapping the entire human gene system.**

**Gene Therapy**

Ashanti/NIH: First approved gene therapy procedure on 4-year old with rare genetic disease, severe combined immune deficiency (SCID). Her own white blood cells were genetically modified and infused back into her blood stream.

*Distinction between therapy on somatic (non-reproductive) cells and germ (reproductive) cells. Only germ cells carry the genes that will be passed on to the next generation.*

- Arguments in favor of Gene Therapy:
  1. Potential for treating ill patients or preventing onset of severe illness (when conventional therapy has failed).
  2. Somatic-cell gene therapy is like any other new medical technology
  3. To prevent research on gene therapy is to infringe upon intellectual freedom of researchers.
  4. With current rate of progress in gene therapy techniques risks become more identifiable and outcomes can be predicted rather precisely.
  5. Germ-line gene therapy: offers true cure; may be only effective way of addressing some genetic diseases by
preventing transmission of diseased genes. The expense of somatic-cell therapy for multiple generations is avoided; medicine should respond to the reproductive health needs of prospective parents at risk for transmitting serious genetic diseases; scientific community has a right to free inquiry within the bounds of acceptable human research.

• Arguments against gene therapy:
  1. "Slippery slope:" can we distinguish between "good" and "bad" uses of gene modification techniques?
  2. Potential for harmful abuse of the technology
  3. Difficulty in following patients in long-term clinical research, including surveillance of future generations.
  4. Many gene therapy candidates are children who are too young to understand ramifications of gene therapy
  5. Potential conflicts of interest versus interests of insurance companies or society in not bearing the financial burdens of caring for children with serious genetic defects.
  6. Issues of justice and allocation: can we afford the expense?
  7. Who should receive gene therapy? If only those who can afford it, where is the principle of justice? Could we skew the distribution of desirable biological traits?
  8. Long-term effects of germ-line therapy not known.
  9. Opens the door to attempts at altering human traits not associated with disease (i.e., eugenics).
  10. Violates rights of future generations to inherit a genetic endowment which has not been intentionally modified.
  11. Too expensive.
  12. Essentially mates generations of
unconsenting research subjects (i.e., germ-line therapy involves research on early embryos and affects their offspring).

- AMA Position Paper on Gene Therapy
  1. Research must conform to AMA
  2. Council on Ethical and Judicial Affairs guidelines on clinical investigations.
  3. Gene Therapy must adhere to stringent safety considerations.
  4. Gene therapy should be utilized for therapeutic purposes in the treatment of human disorders and not for eugenic purposes.

**Genetic Disorders: A Special Use?**

1. With regard to single gene disorders, there is nothing the individual could do to avoid inheriting the gene: one's genotype is immutable and gene expression is unavoidable in spite of improving treatment prospects for some disorders; with few exceptions (e.g., phenylketonuria and dietary changes), no environmental, lifestyle or dietary change can help the individual avoid the effects of a purely genetic disorder; society would consider individuals with genetic diseases more deserving of societal support than medical-conditions attributable to behaviors (e.g., cigarette smoking, alcohol and substance abuse)
2. There is a family stigma associated with genetic disorders
3. Genetic traits sometimes fall along the line of race and ethnicity: mandatory genetic testing and disqualification from life insurance on basis of sickle cell disease, thalassemia, etc. that primarily affect certain racial and ethnic groups raise troubling policy issues.
4. Given the history of eugenics (e.g. Nazi Germany) there is reluctance to embrace any program of systematic application of genetic criteria.
Topical Questions

1. Should the six million women who become pregnant each year be routinely tested for cystic fibrosis carrier state? If so, who will pay for this?
2. Should all women be tested for the genetic mutations linked to breast cancer?
3. Are there differences of ethical issues in somatic-cell gene therapy and germ-cell gene therapy?
4. Should only those who can afford it receive gene therapy?

Suggested Reading
Note: These articles can be found through Ovid and will require an ID and password.

The Human Context of the Practice of Medicine: Self-Awareness

The Physician's Own Perspective and Consideration as Person

Objectives

To explore the students' own values and their function and significance for clinical decision-making--what they believe and what difference that makes.

Goals

1. State how the physician's perspective of the sick role ("how patients are supposed to act") and their own desired role as a physician may be borne out in a clinical encounter, or challenged.
2. Describe what you would believe to be "acceptable" and "unacceptable" physician behavior as it relates to patient conduct, compliance with prescribed care, and family and social dynamics. What criteria do you use?
3. How "involved" should a physician get in the life of his/her patients? What limits? Why?

Required Reading

   Introduction (p 1-15)
   Professional Ethics (p 287-300)

Clinical Vignette

*Sex and the Single Physician,*
excerpted from Case History and Commentary by Janet Weiner, MPH, and Susan W. Tolle, MD, FACP
Leonard Sullivan, MD, age 59, has been one of three general internists in Pumpkin Hills, Wyoming, for the past 30 years. He came to Pumpkin Hills immediately after his residency, married a local woman, and raised two children who are now away at college. Dr. Sullivan's wife died of breast cancer one year ago.

Margaret Dinardo, age 60, has spent her life in Pumpkin Hills and has been a patient of Dr. Sullivan's for nearly 20 years. Her husband died two years ago, and her children are now married with families of their own.

Ms. Dinardo returns for her yearly visit with Dr. Sullivan. He finds her in continued good health, renews her Feldene prescription for mild osteoarthritis, and schedules her yearly mammogram. Dr. Sullivan reviews the results of his clinical exam, and they talk about general preventive care measures. He notices that he feels uplifted by Ms. Dinardo's presence.

"Enough about me, Leonard," Ms. Dinardo says finally. "How have you been since Diane passed on?"

"It's been difficult, although the children have been a great help," he responds. Ms. Dinardo touches his shoulders, saying, "I know exactly what you mean," and leaves.

About a week later, Ms. Dinardo calls Dr. Sullivan at home and invites him over for dinner. "I bet you don't get many home-cooked meals these days," she says. He accepts the invitation, and they spend the evening talking. Dr. Sullivan tells her about his life now and the trouble he has had coping with
his wife's death. In Margaret Dinardo he finds an understanding and compassionate listener, who shares the experiences she has had since losing her spouse. "Thank you, Margaret...I feel so much better talking to you," he says.

"Any time, Leonard," she responds. "Call me and maybe we'll catch a movie."

In the next few months, Dr. Sullivan and Ms. Dinardo see each other regularly. They enjoy each other's company and consider their relationship to be an evolution of their long-standing friendship. But Dr. Sullivan begins to notice that he feels romantically inclined toward Ms. Dinardo and wonders if she feels the same way. One evening, Ms. Dinardo says, "Leonard, what is the matter with you? You've been fidgeting since you got here." He blurs out that he feels attracted to her romantically, and she replies, "Well, it's about time! I was beginning to think you were just too old for me!"

They kiss passionately, well into the evening. He reluctantly draws away from her and heads toward the door. "I really should be getting home. I have a busy day tomorrow at the office. Good night, Margaret."

"Oh, well, your duty calls. Good night, Dr. Sullivan," she replies.

He does not sleep at all, feeling strangely disquieted by the word "doctor." All day, he is troubled by Ms. Dinardo's use of "Dr. Sullivan." After a long day at the office, he decides to talk to her about it. "You
know, I was always taught that a sexual relationship between a doctor and a patient is wrong," he explains. "If we're going to start something here, maybe you should consider becoming Dr. Voorhee's patient."

Ms. Dinardo reacts with surprise and anger. "Leonard Sullivan, you have been my doctor for 20 years. I trust you—that doesn't just go away because we kissed. How can you even think such a thing?" She refuses to consider seeing another internist. "Listen, we kissed yesterday, and you expect me to give you up as a doctor? You must be kidding!"

What should Dr. Sullivan do?

On Physicians Being Human

1. The patient and physician are "more simply human than otherwise." HS Sullivan (1953)

2. Two key components of the physician's humanity:
   a. Emotional responsiveness
      1. Not only the patient is a person, so is the physician
      2. Not only does the patient react to the physician, the physician reacts to the patient
         a. Positive emotions, drive, passion
         b. Negative/detracting emotions
c. Preoccupation with emotions

b. The physician's need to nurture

1. Talmudic aphorism, "More than the calf wishes to suck, does the cow yearn to suckle."

2. This very human, indeed biologic (instinctive vs. learned), need to help allows the physician to respond in the clinical encounter to a patient's needs on a purely human level-this augments, and at times may exceed, the technical components of the encounter.

3. "Care givers need the virtue of humility as an antidote to the arrogance of power. They are receivers, as well as givers, in the professional relationship."
   Wm F. May (1985)

**Professional Responsibility**

1. Defining a "Profession"

   a. Special knowledge

   b. Special responsibilities

   c. A trustworthy trustee

2. Professing to have the above, one makes an avowal of commitment and responsibility

   a. Self is subordinated to the needs of the healing relationship
b. Transformation of self, character, direction of activities

3. Five Views of Medicine

Suggested Reading
Note: These articles can be found through Ovid and will require an ID and password.

The Pediatric Patient
Personhood, Parents, and Principles

Objectives

To explore the physician's responsibility to the child as patient, the role and rights of parents, and ethical and legal principles which guide decisions when they are in conflict.

Goals

1. Describe what makes caring for pediatric patients unique, or different from caring for adults.
2. What is the "best interests" standard? Who determines the child's best interests? Are there problems with this standard of decision making?
3. What role(s) does (do) the physician caring for children fulfill?

Required Reading

   "Decisions about Treatment in Newborns, Infants and children,"
   p 181-204

Unique Aspects for Ethics in Pediatrics

1. Children, infants and fetuses are recipients of care and cannot express their preferences in management
   A. Inability to participate in decision-making
      1. Immaturity
         a. Generally presumed
         b. Exception may
be made in the case of the developmentally maturing and cognitively more capable pre-adolescent and adolescent who can be included in the decisional process...pediatric "assent," permission, versus "consent"

c. Legal concept of the "mature minor"

2. Uncertainty as to future individual values, preferences, qualities and capabilities

B. Dependence upon others

1. Parent/guardian with extensive [though not absolute] legal and moral responsibility

2. Welfare of the patient influenced by the family situation and concurrent multiple obligations

3. In regard to fetus, it may be difficult to determine who the primary patient is (mother/fetus), the moral and legal status of the fetus, and how these are balanced

C. Children are the population of the future; policies and decisions about their
Responsibility of the Physician in Pediatric Care

1. Benefit the patient
   
   A. Standard of the patient's best interests
      
      1. Occasionally difficult to ascertain
      
      2. May prove difficult to apply
      
      2. Refrain from harm

Goals of Medicine in Pediatrics

1. Maintenance and restoration of health
2. Relief of symptoms
3. Restoration of impaired function
4. Saving and prolonging endangered life

Clinical Vignette

Taken from "Active Euthanasia with Parental Consent" by Leake, III, HC. The Hastings Center Report 1979(October): 19-21.

Andrea was a 9 year-old girl who had been diagnosed as having cystic fibrosis at the age of 13 months. Since then she had been hospitalized twelve times, eight times during the last year.

When admitted for the last time she was already receiving an experimental antibiotic, which was being administered in an attempt to control a resistant pneumonia superimposed on severely damaged lungs, a result of her underlying disease. She was at the time a severely ill, emaciated child with moderately labored breathing. She seemed to have no interest in her
environment and refused to communicate with anyone but her mother.

Because of the severity of the child's illness and because the parents had accurately perceived that the experimental antibiotic was a "last ditch" attempt to control her pulmonary infection, the physicians discussed with the parents their perception of "extreme medical measure" and the significance of a "no code" order. The parents indicated that in the event of a cardiac or respiratory arrest, they did not want their child to be resuscitated and the appropriate "no code" order was written. The child was not involved in these conversations or subsequent decision making, nor had the mother previously been able to answer her daughter's questions about death and dying.

As the child's condition continued to decline, the parents asked how much longer she would live and how she would die. At one point the father said: "watching your own child die is worse than dying yourself." This comment led to a discussion of active euthanasia utilizing intravenous potassium chloride or a similar drug. The physicians pointed out that no matter how hopeless a situation that the patient and family were enduring, the law prohibits the active taking of a patient's life. They refused to consider this option.

The following day Andrea's heart began to fail. Her condition became progressively worse, and she died approximately 48 hours later. During these last two days her parents were appalled by her grotesque appearance, with "eyes bulged out like a frog," and were in great despair because of her
steadily deteriorating condition. They felt helpless and impotent to alleviate their daughter's distress. Medical treatment was continued to the end, and no measures were taken to hasten Andrea's death.

Approximately two months after her death, the mother was asked if she would still have given permission for active euthanasia if she had been offered that option. She replied, "Yes."

- Should active euthanasia be permitted to spare the patient and family from suffering when death is inevitable?
- Is palliative care necessary for comfort and pain control of the dying patient acceptable even if it results in an earlier death?

Discussion Questions

1. Describe the Best Interests standard. Can you think of problems in its application?
2. Describe the concept of pediatric assent to medical care.
3. Consider the role of pediatric health care professionals in being advocates for the child patient.

- What does being an advocate mean to the physician?
- Aren't parents advocates too?
- What effects on being an advocate do the following considerations have:
  a) Disease condition (severity)
  b) Uncertainty in
outcome

c) Terminal illness

Suggested Reading

Resource Allocation
The Physician's Obligation to Society:
Management and Allocation of Medical Resources in Relation to Clinical Decisions

Objectives

Explore informing principles and the physician's responsibility regarding the efficient and just use of limited clinical resources. Help the student understand the various interests involved, the areas of controversy and conflict and what is expected of the student in preparation for his/her role as a physician.

Goals

1. Discuss how the physician can be an advocate for the care that best serves the interests of his/her patients in a resource limited environment.
2. Discuss where health care stands in contrast to other competing societal goods. How do you prioritize resource allocation?
3. Examine the different conceptual models of the doctor-patient relationship and how these are sustained or challenged in a resource-conscious healthcare system.

Required Reading

3. Code of Medical Ethics, American Medical Association “Allocation of Limited Medical Resources," 2.03
   "The Provision of Adequate Health Care," 2.095
   "Caring for the Poor," 9.065

Note: Many of these AMA statements are in
Concept of Justice

1. Fair, equitable and appropriate distribution in society determined by justified norms that structure the terms of social cooperation
2. Problems arise under conditions of society and competition
3. Weighing alternatives-
   - Aggregate risks
   - Costs
   - Benefits of various alternatives
   - Distribution through society

Principle of Formal Justice

1. Equals must be treated equally and unequals must be treated unequally
2. Problems with above: who is equal and who is unequal?

Material Principles of Justice

1. Those that specify the relevant characteristics for equal treatment

2. Need versus free-market distribution

3. Valid material principles of distributive justice-
   - to each person an equal share
   - to each person according to need
   - to each person according to effort
   - to each person according to contribution
   - to each person according to merit
   - to each person according to free market exchanges

4. Relevant properties that persons must possess to qualify for a particular distribution
   - Established by tradition, moral, legal principles
   - Changing relevancy: i.e., what was considered
relevant is now considered irrelevant and Visa-versa

Theories of Distributive Justice

1. Utilitarian: criteria that maximize public utility.
2. Libertarian: emphasize rights to social and economic liberty (invoking fair procedures rather than substantive outcomes).
3. Communitarian: stresses principles and practices of justice that evolve through tradition in a community.
4. Egalitarian: equal access to goods in life that every rational person values.

Fair-Opportunity Rule

No person granted social benefits as basis of underserved advantageous properties (because no persons are responsible for having these properties) and no person denied social benefits on basis of underserved disadvantageous properties (because they are also not responsible for these properties).

Choosing Between Person Competing for Basic Health Care Services

1. What moral calculus exists to tip the scale in favor of one person over another?

2. How do we weigh competing claims to life or health?

A. Consequentialist principles-

1. Priority given to those for whom treatment has highest probability of medical success
2. Principle of immediate usefulness: priority given to most useful under the immediate circumstances
3. Principle of conservation: priority given to those who require proportionately smaller amounts of resources
4. Principle of parental role: priority given to those who have largest responsibilities to dependents.
5. Principle of general social value: priority given to those believed to have the greatest social worth (prior, current, and potential).

B. Egalitarian principles-

1. Principle of saving no one: none should be saved if not all can be saved.
2. Principle of medical neediness: priority given to the medically neediest.
3. Principle of general neediness: priority given to the most helpless or the generally neediest.
5. Principle of random selection: priority given to those selected by chance.

Allocation of Health Care Resources

1. Rationing of health care: allocation of scarce health care resources among competing individuals. Occurs when not all care expected to be beneficial is provided to all patients.
2. No ultimately correct theoretical approach: use story of St. Martin of Tours
3. Allocation decisions rest on following tenets:

   • What kinds of health care services will exist in a society?
   • Who will receive them and on what basis?
   • Who will deliver them?
   • How will the power and control of those services be distributed?

Rules of Exclusion

1. Constituency Factor: sets patient-centered
boundaries, e.g., geographic region, age group, ability to pay
2. Progress of Science Factor: may exclude or admit patients in experimental trials based on such contingencies as disease process, sex, age.
3. Prospect of Success Factor: exclude those with least chance of successful outcome.

**Physician as Gatekeeper: A Dubious Moral Role**

Physician must use the patient's and society's resources optimally. Physician uses only those measures appropriate to the cure of the patient or alleviation of the patient's suffering. What the physician recommends must be effective and beneficial. Physicians must use their knowledge to practice competent, scientifically rational medicine using the right degree of economy of means of diagnosis and providing just those treatments that are demonstrably beneficial and effective.

**Economics of Health Care**

Causes of continually increasing health care costs:

- General inflation based on overall increase in Consumer Price Index
- Population increase
- Medical inflation
- New technologies, new procedures, personnel and other resources (intensity)

**Major Health Care System Changes Under Consideration**

1. Single payor system
2. Fee-for-service system with reform of bureaucracy and insurance reform
3. Managed care contractual model of payment for medical care
   - Health care insurers or groups of patients contract with individual or groups of health care "providers" to provide a specified level of health
Preferred provider refers to a participating health care provider listed with the plan to whom the plan member can receive care.

- Capitation: the provider receives a yearly fee for each managed care patient
- Provider is guaranteed a specified number of patients in return for a discounted fee.
- Primary care physicians serve as "gatekeeper": all care provided by the particular managed care plan must be approved by the "provider" (i.e., all diagnostic test including x-rays and all referrals to medical specialists).

Clinical Vignette

Patient A

A 25 year-old unemployed man with a history of migraine consulted his general practitioner with a specific request that he should be prescribed the drug Imigran®, having it recommended to him by a relative. The general practitioner, working to an evidence-based practice protocol for the management of migraine, told the patient that his present medication was the right approach for his problem. The patient became angry, demanded the drug and maintained that he was entitled to the best regardless of cost. The doctor persisted with the clinical decision even though she found the intervention difficult to handle. The patient invoked the Government's Patient's Charter and told the doctor he would be making a formal complaint.
Patient B

A 76 year-old retired mine worker, recently widowed, had end-stage renal failure and was being maintained on hospital dialysis. He had been asked to become the head of a major new community program to help unemployed young people. He also wanted to marry again. He sought an appointment with the Consultant Physician who was supervising his care to ask that he might be considered for renal transplant. The Consultant's renal replacement program was cash-limited to a certain number of transplants a year; moreover, there were problems with limited availability of donor organs. The patient's request was denied on the grounds of his age.

Topical Questions

1. How is the traditional role of the physician as patient advocate being challenged by societal decisions of resource allocation?
2. What responsibility does the physician have in use of all health-related resources?
3. How do decisions on resource allocation differ from the traditional context of the individual patient-physician encounter?
4. How does the physician safeguard the interests of patients when decisions regarding resource allocations are made at the societal level?
5. Within the context of limited medical resources, how does the physician deal with such issues as aging, rationing, futility therapy and caring for the poor and still maintain the fundamental elements of the patient-physician relationship?
The Patient as Person
Responses to Illness, Living, Dying and Bereavement

Objectives

To explore the personal and psychosocial effects of illness in the life of a patient, productive and nonproductive means of coping with those effects, and the role of the physician in this process.

To explore the impact of dying and death upon the students/physicians, patients and their families, and the difficult decisions concerning the treatment of the dying patient.

Goals

1. Recognize the patient's emotional reaction, his illness, his family and his physician.
2. Understand physician's responsibility toward his ill patient.
3. Recognize the influences of age, culture, ethnicity, education on patient response to and manner of coping with illness.
4. Recognize the impact of death and dying on the physician and patient/family.

Required Reading

   "Treatment Refusals by Patients and Clinicians," p 109-125
2. Excerpts provided with this outline, from Paul Ramsey's *The Patient as Person* and William May's *The Patient's Ordeal*.

The Patient's Emotional Reaction to Illness

- Loss
- Identity
- Suffering
The Physician's Responsibility

- Determine the cause of the illness
- Treat the symptoms
- Understand and support the human being who is experiencing those symptoms

Clinical Vignettes

The following reading is taken from the Preface to Ramsey's *The Patient as Person* (1970).

These are by no means technical problems on which only the expert (in this case the physician) can have an opinion. They are rather the problems of human beings in situations in which medical care is needed. Birth and death, illness and injury are not simply events the doctor attends. They are common moments in every human life. The doctor makes decisions as an expert but also as a man...and his patient is a human being coming to his birth or to his death, or being rescued from illness or injury or in between.

Therefore, the doctor who attends the case has reason to be attentive to the patient as person. Resonating throughout his professional actions, and crucial in some of them, will be a view of man, an understanding of the meaning of the life at whose first and second exodus he is present, a care for the life he attends in its afflictions. In this respect the doctor is quite like the rest of us, who must yet depend wholly on him to diagnose the options, perhaps the narrow range of options, and to conduct us through the one that is taken.

The next reading is from the Introduction to May's *The Patient's Ordeal* (1991).
Pregnancy and birth pose for the young mother and father a series of signs marking discrete tasks to perform and apparent crisis to learn how to take in their stride...But birthing and parenting, at their deepest levels, profoundly assault and alter human identity; they limit and redefine the parents' freedom and their future; the advent of the child suddenly converts the couple's pad into a nest and reminds the parents of their own impinging mortality.

Health crisis...confront their victims with things to do; but far more profoundly, as such crisis assault identity, they force their victims to decide who and how they will be. The successful businessman who ponders how to save his limited and valuable time puts a telephone in his Mercedes. It lets him pursue his business and care for its details even while stalled in a traffic jam. But suddenly a blood clot stalls in his coronary artery; the rescue unit pulls him out of his care and wheels him into an intensive care unit. Suddenly he finds his time even more limited than he thought. The catastrophe confronts him with problems to solve; but these problems pale before the deeper question: who and what is he now that he has suffered this explosion from within?

Accustomed to commanding his world, the patient suddenly finds himself helpless in the hands of nurses down the hospital corridor; used to total obedience from his subordinates, he discovers that the very humblest of his subordinates, his own body, has rebelled against him.

The language of the surgery team reflects the profound changes the patient undergoes. Staff members regularly identify surgery patients as
pre-op day one, post-op day two, or post-op day four. These designations serve the staff functionally and prosaically to flag the services scheduled for a particular day and to mark the standards for the patient's progress and recovery. Symbolically, however, the marking of the calendar can also signify a great deal more for the patient. It reflects the patient's sense of a changed and often reconceived and reordered life. Surgery and serious illness traumatize the calendar. The woman refers to "before my surgery last October" or "before my stroke last summer." The man thinks, "before my heart attack last February." The crisis divides and reorders time. It can loom, in the personal scheme of things, as large as 4 B.C. and A.D. 30 or A.D. 1990. The crisis serves as sacred event in the sense that it galvanizes time around it-before and after.

The doctor, the plumber, and the expert may puzzle to solve problems. Once they solve a problem, they move on to other, perhaps different, certainly new quandaries. As they handle cases, they enhance their expertise and sharpen their skills, but, traditionally conceived, they themselves do not usually change. In a sense, qua expert, they have little history; self-transformation is not usually an issue.

The person, however, who experiences a catastrophe moves from life through a kind of death into some sort of new identity. She participates in making history. She partly shapes her own narrative in response to fateful events. In the course of that shaping, she will need to solve problems. But those problems do not pose the real issue. She herself is the problem.
When the medical staff has finished its work and snatched the patient from the jaws of biological death, the agony has just begun to some of the patients...

Discussion Questions

1. If the physician, as "expert" in Ramsey's writing, is one of many who holds an opinion about the person who's case he attends, what other opinions are relevant?
2. How do the physician's opinion interact with the patient's, especially in view of May's accounting of patient perspectives and ordeals?
3. What is considered by you to be a "normal" response to illness? If you have experienced significant illness, been hospitalized or had surgery, what affected your own response to your diagnosis? Your condition?
4. What is the physician's responsibility in knowing and responding to the patient's perceptions and reactions to illness?
5. Relate how any experience with the death of someone you've known has been revealing of the impact that death and dying can have on you, or on others who've known the deceased.
6. What is the likely impact that having no experience with death and dying prior to medical school will make on a medical student? Intern?

Suggested Reading
Note: Articles 1-3 can be found through Ovid and will require an ID and password.

4. *The Doctor's Dilemma* by Martin, Reese,
Browne and Baros-Johnson
"Miller Case"

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Informed Consent and Confidentiality

Objectives

To explore the physician's ethical and legal responsibilities for informed, voluntary consent and confidentiality of patient information; and circumstances in which disclosure can be made to others who are likely to be affected (i.e., breaching confidentiality).

Goals

1. To understand the purpose of the consent process.
2. To understand competency and non-competent patients, the concepts of best interest, substituted judgement and surrogate consent.
3. To understand the right of the patient to self determination including refusal of treatment.
4. To understand the limits of confidentiality and when it can be breached.

Required Reading

   "Respecting Privacy and Confidentiality," p 41-53
   "Communications, Truth-telling, and Disclosure," p55-70
   "Determining Patient Capacity to Share Decision Making," p 71-88
   "The Process of Informed Consent," p 89-105
2. Code of Medical Ethics, American Medical Association
   "Principles of Medical Ethics," p. xiv
   "Fundamental Elements of the Patient-Physician Relationship," p. xxi-xl
   "Informed Consent," 8.08
   "Confidentiality," 5.05 ff

Note: Many of these AMA statements are in Doctor's Dilemma
Clinical Vignettes

1. Competent Refusal, 2.4.1; p 58-59.
2. Refusal on Grounds of Unusual Belief, 2.4.2; 59-60.
3. Enigmatic Refusal, 2.5.3; p 77-80.

Informed Consent

1. Functional definition of informed consent

   A. Disclosure of all pertinent information

      1. Physician's responsibility for expertise

      2. Determination of what is clinically significant

   B. Content of Disclosure

      1. Current medical status and likely course if no treatment

      2. Interventions that might improve prognosis-risks, benefits, probabilities and uncertainties of these interventions

      3. Opinion of alternative interventions

      4. Recommendation based on physician's best clinical judgement

      5. Interventions will vary depending on whether the clinical condition is emergent, semi-emergent or elective.

      6. Research
C. Information must be understood by the patient

1. Comprehensive explanation in patient's vernacular if necessary

2. Patient competence

3. The role of surrogate decision-makers

D. Voluntary, freely given

1. Coercive effect of trust in and dependency upon the physician

2. Family and social pressures

E. Patient competence--the ability to make autonomous, intelligent decisions

1. Ability to understand

2. Ability to evaluate

3. Ability to communicate

F. General purpose of the consent process: To provide as much information as possible and assure intelligent and voluntary decisions to accept or reject proffered care.

2. Ethical Bases

Respect for the human dignity of each patient and the patient's bodily, psychological and emotional integrity.

A. Respect for the full dignity of human life

B. A balance of autonomy and beneficence, and non-maleficence
C. Physician's fiduciary responsibility

D. Professional guidelines

3. Legal Expression

A. Battery--Requirement for legal authorization

B. Informed Consent Doctrine--Legal duties and remedies

C. Georgia's Medical Consent Law

1. Who may consent?

2. What must be disclosed?

3. Exceptions to the rule

Confidentiality

1. Basic elements

A. Respect for patient's privacy and autonomy

B. Prevention of harm to patients

C. Fiduciary relationship between patient and physician

D. Service to the common good

2. Obligations to respect confidentiality

A. Professional ethical guidelines

B. Legal standards

C. Important exceptions

Clinical Vignettes

Competent Refusal

Ms. T.O. is a 49-year-old surgical nurse. Five years ago, she had a resection of a
stage I infiltrating ductal carcinoma. She visits her physician after discovering a mass in the contralateral breast and noting axillary swelling. Studies reveal stage II breast cancer with involved nodes. Following surgery, 10/16 nodes were positive. Chemotherapy and radiation are recommended and Ms. T.O. is told that the statistics for her condition suggest that, with treatment she can expect a disease-free survival rate at 10 years of 50 percent; without treatment, she has a 10 percent chance. She accepts chemotherapy, but after the first course, during which she has experienced significant toxicity, she informs her physician that she no longer wants any treatment. After extensive discussions with her physician and with her two daughters, she reaffirms her refusal of chemotherapy.

Refusal on Grounds of Unusual Belief

Mr. G. comes to a physician for treatment of peptic ulcer. He says he is a Jehovah's Witness. He is firm believer and knows his disease is one that may eventually require administration of blood. He quotes the biblical passage on which he bases his belief: "That ye abstain from meats offered to idols and from blood..." (Acts 15:28). The physician inquires of her Episcopal clergyman about the interpretation of this passage. He reports, after some research, that no Christian denomination except the Jehovah's Witnesses takes it to prohibit transfusion. The physician considers her patient's preferences impose an inferior standard of care. She wonders whether she should accept this patient under her care.
Enigmatic Refusal

Mr. Cure presented with signs and symptoms suggestive of bacterial meningitis. When he was told his diagnosis and told he would be admitted to the hospital for treatment with antibiotics, he refused further care, without giving a reason. The physician explained the extreme dangers of going untreated and the minimal risk of treatment. The young man persisted in his refusal. Other than this strange adamancy, he exhibited no evidence of mental derangement or altered mental status that would suggest decisional incapacity.

Topical Questions

1. What should patients be told about treatment procedures proposed to them? How much detail and how should it be communicated?
2. What if a patient is not very sophisticated? What if he is likely to be frightened or refuse treatment that is in his best interest?
3. Should an adult ever be treated without or against his consent? If not, why? If so, when?
4. Is fully informed, voluntary consent ever possible? How can it best be approximated?
5. What are physicians’ professional responsibilities to patients for confidentiality?
6. Should a patient's enigmatic refusal be accepted? Should there be some inquiry to determine some [hidden] rationale?

Suggested Readings/References

1. *The Doctor's Dilemma* by Martin, Reese, Browne and Baros-Johnson
   "Bowsher Case"
   "Harper Case"
   "King Case"
2. *The Hippocratic Oath* (Located within *Doctor's Dilemma*)
   "Physician and Patient"
"The Physician and Society"
"Conflicts of Interest"
"Consent"
"Confidentiality"
"Decisions about Reproduction"
6. MCG Hospital and Clinics Policies and Procedures, "Request and Informed Consent to Surgical and/or Diagnostic Procedure."

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Please email comments, suggestions or questions to:
Kenda Rindt, krindt@mail.mcg.edu
October 13, 1999
Facilitator's Name:
My Name:

*For the first five questions, choose the extent to which this faculty facilitator engaged in the noted behaviors in your small-group.*

To what extent did the faculty facilitator do the following?

1. Make adequate preparations for the small group session?
   - Regularly (during most sessions)
   - Occasionally (some sessions)
   - Never

2. Lead actively in discussions; framing the issue or question in such a manner as to engender productive discussions?
   - Regularly (during most sessions)
   - Occasionally (some sessions)
   - Never

3. Help me to identify and examine my own values?
   - Regularly (during most sessions)
   - Occasionally (some sessions)
   - Never

4. Help me to identify and examine my own assumptions?
   - Regularly (during most sessions)
   - Occasionally (some sessions)
   - Never
5. Communicate clearly and with sensitivity; giving an equal ear to varied viewpoints while still helping to distinguish between defensible values and simple assumptions or unsubstantiated opinions?

_ Regularly (during most sessions)
_ Occasionally (some sessions)
_ Never

Briefly answer the following:

6. What specifically did this facilitator do to contribute to the learning of others in the group?

7. What specifically did this facilitator do, if anything, that appeared to block learning in the group?

8. What recommendations for change in course content would you make?

9. Discussed with Faculty? _ Yes _ No

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October 13, 1999
Phase 2 Medical Ethics for
Students at the Medical College of
Georgia

Now that you have completed the Phase 1 Ethics course you are beginning the Phase 2 or second year program. In Phase 1, you were exposed to the following six subsequent workshops. The topics covered were:

2. The Human Context of the Practice of Medicine: Self-Awareness.
5. The Patient as Person: Responses to Illness, Living, Dying and Bereavement.

With this background accomplished, you are now ready to begin Year 2 of your medical ethics curriculum.

The schedule for Phase 2 curriculum is as follows:

- Plenary session: a brief reprise of Phase I followed by a discussion of **Lesson 1:**
- **Ward Team Ethics.**
  Objective: To explore the dynamics of the ward team and its impact upon the medical student and his early clinical education, the silent or hidden curriculum that is extant in ward team functioning and the personal interrelationship and psychodynamics of ward team members.

- **Lesson 2: Truth-telling and the Pediatric Patient: Helping, hurting, or honoring children?**
  Objective: To explore the physician's responsibility to the child as a patient when conveying information about their health status, care plans, and prognosis. And look at truth-telling as it pertains to informed consent in pediatrics.
Lesson 3: Informed Consent and Confidentiality.
Objective: To explore the physician's ethical and legal responsibilities for informed, voluntary consent and confidentiality of patient information.

Lesson 4: Impaired Colleague.
Objective: To explore the effects of substance abuse upon the physician, patients and colleagues; professional, ethical and legal responsibilities to all affected, and a practical approach to the problem.

Lesson 5: Reproductive Health Issues.
Objective: To explore the interaction of physician and patient in the arena of reproduction, within pluralistic society, with consideration of increasing technologies requiring a host of moral and ethical decisions, and involving interaction of women, their partners, health care providers and government.

Lesson 6: Death and Dying.
Objectives: To explore the impact of the dying process upon the student/physicians, their patients and families, and the difficult decisions that must be made.
Schedule of Classes for Phase 2

Classes will take place from 8:00-10:00 am on the following dates:

• **Monday, October 4, 1999**
  Plenary Session (Ward Team Ethics)-Will take place in CL-1103 from 8:00-9:00 am. A one-hour workshop (Truthtelling & Pediatric Patient: Helping, Hurting, or Honoring Children) will take place in the Resource Rooms for Medical Students located on the Third floor of the CJ building following the plenary session.

• **Monday, October 11, 1999** (Informed Consent & Confidentiality)

• **Monday, October 18, 1999** (The Impaired Colleague)

• **Monday, October 25, 1999** (Reproductive Health Issues)

• **Monday, November 1, 1999** (Death & Dying)

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Please email comments, suggestions or questions to:
Kenda Rindt, krindt@mail.mcg.edu
October 13, 1999
Requirements for Phase 2

The grade assigned for this course will be "pass/fail" and will be based upon participation and final examination.

**Attendance and Participation**

- In order to pass this course, every student must attend and participate in all of the class sessions.
- No unexcused absences are allowed.
- Excuses for unavoidable absences shall be submitted in writing within seven (7) days to the Course Director for his consideration.
- Remediation of excused absences must be completed before the final examination under the direction of the faculty facilitator.

**The Final Examination**

The final exam will consist of a paper that must be handed in on or before November 1, 1999. The paper can be on any subject covered in the syllabus, an ethical analysis of a case presentation of your choosing, or your own rendition of a professional code of ethic analogous to the "Hippocratic Oath." The paper should be no longer than four double-spaced, typed pages.

**Remediation of Failures**

- This course is a required course and therefore every student must successfully complete all of its requirements.
- All failures shall be remediated according to *Promotions Committee Policy, Criteria for Promotion, Graduation and Dismissal*, section IV, in a manner determined by the Ethics Curriculum Committee.
Ward Team Ethics

Objectives

Explore the complex interactions of members of the ward team, the lack of a formal curriculum, the need to bring context into the process and the manner in which this process of clinical medical education influences the development of a work ethic and code of ethical conduct that will influence the student throughout his professional life. This ward team structure and function is of major importance in the moral development of medical students. This medical team is an early site of ethical behavior in the actual practice of medicine and compliments the learning in the classroom (e.g., study of presented classical ethical dilemmas and textbook bioethics). Finally, the informal curriculum of the ward team is at least as relevant to the moral and professional development of students as the formal curriculum designed by the schools of medicine and the residency programs.

Goals

1. To help the medical student better understand ethical dilemmas he/she may face during clinical clerkships, the relevance of such dilemmas and their potential resolution.
2. To orient the medical student to those ethical dilemmas peculiar to the student as part of the inpatient ward team and how the resolution of such dilemmas will help to develop each student's eventual ethical, professional behavior as house officers and physicians.
3. To help the medical student understand the dynamics of the ward team and how it functions without a formal curriculum.
4. To make the student aware of the risk of ethical erosion as a clinical clerk.

Required Reading

2. *Code of Medical Ethics*, American Medical Association,
   "Sexual Harassment and Exploitation Between
Items for Discussion

1. Is there an "unwritten code" for ethical conduct for medical students and other members of the team? If so, what is it, who decides what it is and how does it come to be?
2. What is a ward team?
3. How does it function?
4. What makes a good "team?"
5. What makes a good faculty attending?
6. Does a ward team have a code of ethics?
7. How do individual members of the team learn their respective roles?
8. How does the team deal with a team member who is not a "team player?"
9. How do we deal with issues of integrity of team members?
10. Who teaches whom, and how do we learn to teach?
11. How are concepts of appropriate conduct conveyed, rewarded or sanctioned?
12. What should be changed and what should be retained?

Clinical Vignettes

In reading and discussing the following vignettes, ask yourself how you would manage these seemingly conflicting roles of being your patients' physician and your maintaining loyalty to the health care team.

Ethical dilemma #1

When you are the junior medical student assisting in a procedure that is sterile and the intern accidentally breaks sterility, but acts like he did not. In the room with the junior medical students are two
residents, a nurse, and the attending.

Issues the student asks about:

1. patient safety
2. making your intern look bad

Ethical dilemma #2

I found myself an observer of an "unethical" situation during my surgical rotation. My patient was a 59 year old woman who had to be admitted one night through the ER for small bowel obstruction-secondary to advanced colon cancer. This patient had been diagnosed with cancer approximately 3 year prior and had elected not to undergo surgery at that time. She strongly believed in alternative medicine and self-healing and felt that if she believed in the healing power of the mind enough, she could overcome the ravages of her disease. Indeed she had been living a fairly comfortable, functional life until her bowel obstructed. She was very anxious about the inevitability of surgery, but reluctantly agreed after making one request-she asked the surgeons to assure her that during surgery even as she lie unconscious form anesthesia, that no one would speak negatively about her cancer or her prognosis. The surgeons, of course, agreed. As I stood by her side during the operation, I listened to a barrage of comments concerning the hopelessness of her situation and how foolish this woman was for refusing surgery in the first place.

Several nights later, while on call, I went to the patient's room and found her lying in the dark crying. She told me that in the recovery room she heard the surgeon approach the bed and tell her nurse how extensive the cancer was and that she was not expected to live more than a few months at best. She told me that she
wanted to open her eyes and tell him that she was awake, but the residual anesthesia wouldn't allow it.

**Ethical dilemma #3**

While on a surgical service, I was taking care of a 38 year old white man who was admitted for a procedure in good general health. The patient had undergone similar operations in the past.

During the operation, the dural covering of the spinal cord was nicked with a subsequent small CSF leak. The incident took place despite careful dissection and meticulous technique. The defect was easily repaired and the rest of the operation went without complication.

Post operatively, the patient was closely monitored with special attention to signs and symptoms of further CSF leakage. The patient's hospitalization was extended slightly more than what he expected and was longer than prior post-op stays. None of the housestaff or faculty mentioned the intraoperative incident.

On the day of his discharge, the patient was very appreciative of my care and asked if anything had happened during the operation. He was mildly suspicious based on his post-op stay and the team's questions. We had developed a good rapport, and the patient had spoken openly to me about very personal issues. Although the CSF leak was accidental and did not have serious adverse consequences, I felt uncertain whether a student should be the correct person to inform the patient.

The rest of the team had already seen the patient on rounds and were busy in the operating room.
Suggested Reading/References

Note: These articles can be found through Ovid and will require an ID and password.


Truth- Telling and the Pediatric Patient
Helping, Hurting, or Honoring Children?

Objective

To explore the physician's responsibility to the child as a patient when conveying information about their health status, care plans, and prognosis. And look at truth-telling as it pertains to informed consent in pediatrics.

Goals

1. List three reasons that truth-telling by a physician to a child might be considered "unethical" or unnecessary. What principles support these arguments?
2. List three reasons that truth-telling by a physician to A child might be considered beneficial. What principles support these arguments?

Required Reading

   "Capacity in Older Children and Adolescents," p 77-78.

Clinical Vignette


KG, a 16 year-old young lady was injured in a motor vehicle accident. Both of her parents were in the car at the time of the accident. Each of the three were transported from the scene to three different area hospitals in different ambulances--unconscious at the time. Unknown to the girl, her mother was pronounced dead at the scene. Her father is in an ICU at another hospital, but is stable.
Within 36 hours of admission to the ICU, KG is alert and out of danger. Her grasp of reality is appropriate and she is psychologically stable enough to be confronted with the terrible news of her mother's death, but her family insists that this information be withheld...at least until KG is discharged from the hospital and reunited with her father. The staff, especially some of the nurses, have spoken extensively about disclosure of the facts to KG with the extended family, in particular an apparent spokesperson who is KG's maternal uncle. But the uncle insisted on delaying such disclosure.

This disturbed some of the nurses who were being confronted with very pointed questions by KG, clearly indicating her awareness and anxiety. Tension arose as the staff was torn between covering up the truth to respect the family's wishes and respecting KG's need to know--and, hence, her being spared unnecessary anxiety. In the meantime, visiting family members were so bold as to wear mourning black! When her sister, having been told of her mother's impending funeral, arrived from afar, she did not even tell KG of her loss! Finally the nursing staff became insistent and gave the uncle an ultimatum. While initially trying to get the staff to tell KG (they refused) he finally responded...scarcely in time for KG to arrange for someone to bring flowers to her mother's funeral as her representative.

**Discussion Questions**

1. Does KG have the right to the truth? Do others (e.g. family members, health care professionals) have a duty to tell KG the truth?
2. Is it KG's "best interests" to be told the truth? Why? Why not?
3. When should family wishes be respected? Should the nurses have insisted that KG be told the truth or respected the family's wish?
4. Who is best suited for telling? What constitutes "best" in this sense... Efficiency? Humaneness? Compassion? From whose perspective should this be judged, or determined...the person being told or
5. When is disclosure by physicians a professional act? When might it simply be an act of mercy, thus taking the burden off of the family?

Substitute a younger child with a lethal diagnosis (HIV, terminal CF or cancer), for whom the parents request nondisclosure and work through these questions.

Tell all the Truth but tell it slant-
   Success in Circuit lies
Too bright for our infirm Delight
   The Truth 's superb surprise
As Lightening to the Children eased
   With explanation kind
The Truth must dazzle gradually
   Or every man be blind-

Emily Dickenson

Truth-Telling (Disclosure) to Children

1. Two-fold purpose of disclosure:
   • To inform patients properly
   • To enable motivated patients to make informed decisions

2. Seven reasons for telling the truth
   • Promotes the patient's well being
   • Furthers the patient's life choices
   • Emphasizes the importance of good communication skills
   • Shows respect for persons
   • Prevents having to lie
   • Reduces the risks of harm to patients
   • Reduces the physician's liability

3. Considerations in pediatric cases
   • Age and cognitive development of the child- capacity to understand
   • Assessment of "benefit" to child-need to know, and when
   • Prerogative of parents to disclose or withhold information
• Determination of "therapeutic privilege" - withholding truth because of expected harm

4. Role of the pediatric health care professional - advocacy

5. Models of dealing with truth-telling to children (see Table)

   A. Protector (based on beneficence; old model of paternalism)

   B. Liberator (based on principle of autonomy)

1. Autonomy states that the individual:

   - Knows his/her feelings best
   - "Owns" his/her body and information about it
   - Cannot defend him/herself against invasion of privacy without knowing truth
   - Must bear the burden of consequences of decisions about them, and thereby is entitled to the truth

2. Respecting the autonomy of children presupposes that children are separate and distinct individuals, with a just claim to rights as full moral and legal "persons."

C. Educator (based on role of advocacy, respect of developing person, child's best interests)
### Three Models of the Pediatric Professional’s Role in Truth-Telling

<table>
<thead>
<tr>
<th><strong>Protector</strong>-argues against truth-telling to children</th>
<th><strong>Liberator</strong>-the truth respects the child’s autonomy and therefore must be told</th>
<th><strong>Educator</strong>-as an advocate, fosters autonomy &amp; educates children in the means necessary to become decision makers</th>
</tr>
</thead>
<tbody>
<tr>
<td>It is <em>harmful</em>-producing unnecessary suffering</td>
<td><em>Not</em> harmful-disclosure brings child/family/professional together, sharing truth &amp; burdens</td>
<td>Prepares child in a progressive manner for responsibilities of being an adult</td>
</tr>
<tr>
<td>It is <em>useless</em>-children don’t/can’t make decisions anyway</td>
<td><em>Not</em> useless-lets child be himself (they find out the truth anyway)</td>
<td>Increase child’s self-esteem</td>
</tr>
<tr>
<td>It is <em>irresponsible</em>-responsible care givers (parents) should bear the burden of truth</td>
<td><em>Not</em> irresponsible-make everyone face the truth &amp; avoid deception (including family/MDs)</td>
<td>Promotes children taking more responsibility for their life/health</td>
</tr>
<tr>
<td>It is <em>impossible</em>-children cannot understand the facts/deliberate about difficult choices</td>
<td><em>Not</em> impossible-children do understand (more than we realize?) especially by age 7</td>
<td>Increases the child’s sense of being in control (security)</td>
</tr>
</tbody>
</table>

### Suggested Reading

*Note: These articles can be found through Ovid and will require an ID and password.*


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Please email comments, suggestions or questions to:

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October 13, 1999
Informed Consent and Confidentiality

Objectives

To explore the physician's ethical and legal responsibilities for informed, voluntary consent and confidentiality of patient information.

Goals

Each student will understand and apply the following in discussion of cases:

1. The purpose and essential elements of fully informed and voluntary consent.
2. Legal authority to give effective consent for self or others.
3. Basic clinical criteria for competence to consent.
4. Requirements for and limitations to patient-physician confidentiality; and when it is acceptable to breach confidentiality.
5. The primary ethical, legal and professional guidelines for these topics.

Required Reading

1. Introduction to Clinical Ethics by Fletcher, Miller, Lombardo and Marshall. Second Edition
"Respecting Privacy and Confidentiality," p. 41-53
"Determining Patients' Capacity to Share in Decision Making," p. 71-88

Note: This article can be found through Ovid and will require an ID and password.

Clinical Vignettes

Bobby Raines: Don't Tell My Mom

Bobby Raines is a 16 year old, African American young man who is
in his junior year at City Technical High School. He has a history of risk taking behavior that many would say is characteristic of his age group. He states (brags actually) that he became sexually active at the age of 13, having had 8-10 partners in the last 3 years. He seldom uses condoms, stating that they are unnecessary, diminish his pleasure and "performance", and that birth control is the woman's responsibility. Last week he was informed that a woman with whom he had sexual contact about a year ago has tested positive for HIV during a recent prenatal visit, so he came in for a physical exam and an HIV test.

Results from the physical exam were-within normal limits. He appears to be in good general health. After appropriate counseling, blood was drawn and sent to the lab. He was given the standard packet of information on HIV, other SDS, and birth control.

The lab report is positive for HIV. Bobby was contacted through his beeper, and is returning for the test results this morning.

**Script**

Dr. Newman: Hello, Bobby. We received the results of your HIV tests, and I'm terribly sorry to tell you that it's not good news. The tests show conclusively that you are infected with the HIV virus. We discussed last week what these results mean and the available treatments. I know there is a lot for you to think about, and we can go over any question you might have. I can help you connect to many forms of assistance when you need them.
Bobby: Wow! I can't believe this! Man, I never even believed for a minute that this could happen to me. I read all that stuff you gave me last week. I don't want to die!

Dr. Newman: Now calm down a little, Bobby. Get a grip. We might not have a cure right now, but good care...that means you taking your prescriptions and changing your lifestyle...can significantly prolong your life even after symptoms appear. And we don't know how long it will be before the disease starts to cause you significant problems. Sometimes it takes years. Research suggests that several promising new drugs are being developed, so it is impossible to say exactly what your odds are.

Bobby: I'm not sure I know what to do about treatment just yet. I hardly know what to think...I still can't believe it. Let's deal with that stuff later.

Dr. Newman: Of course, but there are some things we need to discuss even now. We will need to notify the women you've had sexual contact with in the last year; we certainly don't want this to spread. And if there is anyone important to you, like your parents, you should consider telling them.

Bobby: I can try to give you the names of the girls, uh, I mean women, that I've been with in the last year. But I sure as heck don't want you, or anyone else to tell my parents, especially my mom! Man, that would kill her. She doesn't know about, you know, my goin' out. I don't even want to think about all this stuff. How can I Tell anyone about this?! You've been my doctor for over 10 years, I want
you to take care of me...hopefully for another 10. But promise me you won't tell my mom.

Now, what do you do?
Continue to role play to complete this interaction. Remain in character and improvise.

Refusing Consent for Lumbar Puncture

Mrs. K is a 45 year old woman who is seen in the Acute Care Clinic with a complaint of headache of recent onset. She states that her only other episodes of headache were associated with eyestrain, usually when she needed her glasses changed. The last time was about two years ago. She reports that this is different, but she has difficulty describing any of her symptoms, just that this one is "real bad and won't go away." In general, she is a poor historian.

On physical examination, she is a morbidly obese female in some distress. Her exam is unremarkable except for moderate hypertension and pronounced bilateral papilledema. Neurology is consulted, and she is admitted for observation and tests, including a lumbar puncture.

Several attempts at the spinal tap are unsuccessful because of Mrs. K's obesity. She was cooperative through the ordeal of initial attempts, but when the resident approaches her later to try again, she refuses the test. When asked for the reason for her refusal she states that it was very painful the first time, and her sister has told her about someone their cousin once heard of who had had a lumbar puncture and had been paralyzed. The resident told her that
her papilledema could be a sign of "a serious, life-threatening problem" and that the tap was "absolutely necessary to diagnose and treat" that problem. She further states that "there is absolutely no danger of paralysis from the procedure." During the next three days, the resident tries repeatedly to convince Mrs. K to cooperate, but she continues to refuse. When the resident informs her of her option to sign out "against medical advice," she does so. She does not respond to multiple requests for her to return to be seen in the clinic and is lost to follow-up.

Informed Consent

I. An informed competent patient's preference to accept or refuse medically indicated treatment. This requires information to allow a reasonable person to make prudent choices in his/her behalf.

II. Four basic elements:

1. Disclosure
2. Comprehension
3. Competency
4. Voluntary choice

Disclosure: must be truthful and includes:

- Current medical status and likely course if no treatment.
- Interventions that might improve prognosis-risks, benefits, probabilities and uncertainties of these interventions.
- Opinion of alternatives.
- Recommendation based on physician's
best clinical judgement.

• Details vary depending on emergency, elective or in-between.
• Research

Comprehension

• Physician must make reasonable efforts to assure comprehension.
• Requires dialogue between physician and patient.

Competency

• Mental capacity to understand and make choices.
• Ability to understand relevant information, appreciate one's medical condition and its consequences, to communicate a choice and to rationally be able to discuss one's own values in relation to treatment options.
• Surrogate decision-makers (family members, etc.).
• Determination of incompetence may require legal Determination.

Voluntary Choice

• Competent refusal of treatment must be respected.
• Refusal on grounds of belief.
• Enigmatic refusal.

III. Significance

1. Ethical: Self-determination

   A. Autonomy: moral right to choose and follow one's own plan of life and actions

2. Legal

   A. Each person has fundamental right to control his own body and the right to be protected against unwanted intrusions or unconsented touchings. Explicit consent offers this protection

   B. Patient-physician relationship is a fiduciary one, i.e., physician must promote best interests of the patient.

3. Psychological: Self-worth demand ability to express preferences and have other respect them.

IV. Issues Related to Informed Consent

1. Therapeutic privilege

   A. When to breach:

      1. In an emergency when time required for full disclosure might jeopardize patient's health
2. When patient would not want to know certain particulars

3. When release of information is judged to pose a threat to public health and welfare

B. Treatment refusal

1. Competency

2. Enigmatic

3. Special circumstances (unusual beliefs)

C. ResearchEthical principles stem from Nuremberg Trials after WWII.

Confidentiality

I. Basic Elements

1. Respect for patient's privacy and autonomy
2. Prevention of harm to patients
3. Fiduciary relationship between patient and physician
4. Service to the common good (i.e., confidentiality is good for society in general)

II. Obligations to Respect Confidentiality

1. Professional ethical guidelines
2. Legal standards
3. Important exceptions
4. Comparison of confidentiality in Codes of Medical Ethics
A. World Medical 
Association. A doctor 
owes to his patient 
absolute secrecy on all 
which has been confided 
to him or which he knows 
because of the confidence 
entrusted to him.

B. Declaration of Geneva. 
I will hold in confidence 
all that my patient confides 
In me.

C. Hippocratic Oath: 
Whatever, in connection 
with my professional 
practice, or not in 
connection with it, I see or 
hear, in the life of men, 
which ought not to be 
spoken abroad, I will not 
divulge, as reckoning that 
all such should be kept 
secret.

D. British Medical 
Association. It is a 
practitioner's obligation to 
observe the rule of 
professional secrecy by 
refraining from 
disclosing...(save with 
statutory sanction) to any 
third party information 
which has learnt in his 
professional relationship 
with the patient...On 
certain occasions it may be 
necessary to acquiesce in 
some modification. 
Always, however, the 
overriding consideration 
must be adoption of a line 
of conduct that will benefit 
the patient, or protect his 
interest.
E. American Medical Association Principles of Medical Ethics. A physician may not reveal the confidences entrusted to him in the course of medical attendance, or the deficiencies he may observe in the character of his patients, unless he is required to do so by law or unless it becomes necessary in order to protect the welfare of the individual or of the society.

But what if the best interest of the patient is illegal or prevents justice? What counts, and when is it sufficient to breach confidentiality? Either one of two approaches is usually taken.

5. Generally accepted exceptions to confidentiality

A. When the law requires it (e.g., gunshot wounds, infectious diseases, suspected child abuse, dog bites)

B. When it is in the best interest of the patient (e.g., to prevent suicide)

C. When it is in the best interest of society (e.g., Typhoid Mary-type cases or the patient is planning a homicide)

D. What if the best interest of the patient is illegal or prevents justice and is not required to be reported by law? If there are to be exceptions, under what conditions do you breach
6. Conditions for breach of confidentiality

The principle of confidentiality should not be breached unless all the following conditions are met simultaneously:

A. Its maintenance would clearly result in damage that outweighs the damage done by the breach.

B. There is no other way that does not involve a breach of confidentiality to avoid the damage.

C. The breach is the least possible that will prevent the damage or is the one with the least harmful consequences to the patient.

D. The patient is informed, preferably before the breach.

Topical Questions

1. What should patients be told about treatment procedures proposed to them? How much detail and how should it be communicated?
2. What if a patient is not very sophisticated? What if he is likely to be frightened or refuse treatment that is in his best interest?
3. Should an adult ever be treated without or against his consent? If not, why? If so, when?

Suggested Readings/References

1. Code of Medical Ethics, American Medical Association
"Principles of Medical Ethics," p xiv-xxxviii
"Fundamental Elements of the Patient-Physician Relationship," p xxxix-xl
"Informed Consent," 8.08
"Confidential Care for Minors," 5.055
"Physician and Patient"
"The Physician and Society"
"Conflicts of Interest"
"Consent"
"Confidentiality"
"Decisions about Reproduction"
3. The Doctor's Dilemma
"Bowsher Case"
"Harper Case"
"King Case"
5. The Hippocratic Oath (Located within Doctor's Dilemma)
6. Official Code of Georgia
31-9-1 through 31-9-6.1 and 24-9-40.
8. Medical College of Georgia Hospitals and Clinics, Request and Informed Consent to Surgical and/or Diagnostic Procedure.

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October 13, 1999
The Impaired Colleague

Objectives

To explore the effects of substance abuse upon the physician, patients and colleagues; professional, ethical and legal responsibilities to all affected, and a practical approach to the problem.

Goals

Each student will understand and apply the following in discussion of cases:

1. The definition of impairment and its major forms.
2. How impairment might be manifested in Medical students, housestaff, and practitioners.
3. One's ethical obligations to colleague, patients and the profession.
4. Practical approaches to an impaired colleague and resources available
5. The primary ethical, legal and professional guidelines for these topics.

Required Reading

1. *Code of Medical Ethics*, American Medical Association "Reporting Impaired, Incompetent, or Unethical Colleagues," 9.031  
   Note: Many of these AMA statements are in Doctor's Dilemma  
   "Impaired Physician"  
   Note: This article can be found through Ovid and will require an ID and password.

Outline of Issues

I. The problem physician
   A. Impairment due to substance abuse
   B. Other reportable problems:
incompetence and unethical conduct

II. General obligations of physicians to report

A. Owed to the profession
B. To the community
C. To one's patients
D. To the colleague

III. Effects of a physician's impairment

A. On the integrity of the profession
B. On the health and welfare of the community
C. On safety of your patients
D. On the impaired colleague

IV. Effects of your choice to report a colleague

V. Guidelines for the appropriate course of action

A. When to act

1. Common signs of physician impairment
2. How serious must the abuse be

B. Confronting your colleague-The process

C. Due process for the reported physician

1. To whom reports should be made
2. Assuring a fair hearing for your colleague

D. Impaired physician programs

1. The objective--Rehabilitating a valued colleague
2. Guidelines for impaired physicians
3. The recovery contract

Clinical Vignettes
Arthur Jones

When Arthur Jones became a medical student, he was 35 years old and married with two children. He had been a civil engineer with a small land surveying company and, by all accounts, was a hard worker and devoted father. At first, he had some difficulty adjusting to the role of a medical student, particularly to the small amount of time his studies left for his family. He was advised at one point that he was in jeopardy of failing Anatomy. By the middle of the year, however, he had managed to pull his grades up and was expected to pass all of his courses. When Phase I was completed, Arthur had completed the requirements for promotion, but just barely. Throughout his trials at school, he seemed to maintain a very positive and confident attitude about his future. He made friends easily with his classmates, particularly his study partners. After their intense study sessions, they would often relax together at a local bar frequented by medical students.

Arthur and his family moved back to Atlanta for the summer and he worked at his old trade to try to replenish his dwindling bank account. He did not return to Augusta until the first day of classes. He left his family in Atlanta.

From the first day, it was apparent that Arthur had somehow changed. He no longer met with his old study group. In fact, he was seldom seen outside of class. After the first two weeks, he began missing most classes, even the ones that had a reputation for being particularly helpful or entertaining. When he did attend, he seemed inattentive or frequently dozed off. One morning he asks you, a friend and member of his old group, for a ride to Atlanta. He explains
that his car is in the shop there, and he
needs to check on his family. You detect
the distinct odor of Scotch as he speaks.
During the trip, he confides that his
driver's license had been revoked, and
that he is thinking of dropping out of
school.

Discussion Questions

1. How does a medical student deal
with a colleague who is impaired by
the abuse of alcohol or other drugs?
2. What are the consequences of
taking or not taking action in the
case?
3. What responsibility does the student
have for the interests of the
impaired colleague and his/her
patients?
4. What guiding principles determine
the appropriate response and how is
it to be executed?

Dr. Fred Williams

Dr. Fred Williams is a 2nd year Resident
on-service in the Ambulatory Pediatric
Clinic in July. He has a reputation of
being very outgoing, and even for being
"a party animal," his antics winning him
praise and laughs at the Intern's year-end
party last month. He takes night call
every 4th night in the Pediatric ICU
(PICU) and, generally, loves the scope of
practice opportunity each week holds
between clinic patients by day and
hospital patients at night. However, this
past weekend things became difficult
when his maternal grandmother, who
raised him, had a stroke in her home five
hours away. On Sunday she was
reportedly doing better, and being moved
out of the ICU to an inpatient ward in her
local hospital. Dr. Williams knows she
had an underlying arrhythmia and may
yet have circulatory or coagulation
problems.
Monday morning Dr. Williams' car gives him fits and he barely makes it on time to Morning Report, where he delivers a poor case presentation and is cornered by his attending, Dr. Yoo, who gently suggests he be better prepared next time. After a particularly frustrating day in the clinic, Dr. Williams' car overheats on the way home. He calls for a lift from Dr. Jim Hines, one of his Interns, who picks him up and offers to buy him a beer on the way home. They stop at a local club and an hour turns into four. Jim finally gets Fred, who is now drunk, to get into the car and drives him home promising to be back by at 6:30 am to pick him up in the morning.

Tuesday morning Fred oversleeps. He and Jim are both an hour late to work. Dr. Yoo arranged cross-coverage for the first hour of clinic and makes a note to speak with Drs. Williams and Hines. But very quickly after clinic is over they leave to pickup Fred’s car. Fred asks Jim if he wants to join him at the club for a few drinks. Jim says no and they go their separate ways. Dr. Williams goes out for a round and gets home about 11:45 p.m.

Wednesday sees Dr. Williams late again, this time for Morbidity & Mortality Conference at 7:30am. Dr. Hines overhears Dr. Williams explain to an attending (the Residency Program Director) that he is simply stressed because of his grandmother's condition. The Program Director tells Dr. Williams to take care of personal matters that day, but reminds him that he is on PICU call that night, "Be here at 4:30 for sign-out rounds, Fred."

Dr. Williams returns at 4:30 PM. A Nurse asks him if he got any sleep lately. One of his Resident colleagues tells him he smells like a beer and urges him to clean up before rounds begin, and even then to
speak as little as possible. That night Dr. Williams attends to problem ventilators, low potassium levels and a vomiting child. He has no new admissions. His clinic goes well Thursday morning and he has lunch with Dr. Jim Hines, asks him over for dinner, and then goes home.

At home, Fred crashes for a few hours sleep. Then he gets up and grabs a beer. The phone rings, his grandmother is back in the ICU. As he gets off the phone, and grabs a second beer, the doorbell rings. Jim Hines is there with some favorite take-out Chinese food. "Hey, I think I have some Chinese beer in here!" says Fred. "Don't bother," says Jim, "Besides, after what I heard about your appearance at sign-out rounds yesterday, you'd better watch it." Somehow the dinner was cut short and Jim left within the hour.

Dr. Williams' next call night doesn't go so smoothly. He admits 3 patients to the PICU. A Respiratory Therapist has to call Dr. Williams' attending, Dr. Yoo, to get what he believes are appropriate ventilator settings for a patient in status asthmaticus who has developed a pneumothorax after Dr. Williams placed him on inappropriately high pressures. A Nurse files an Incident Report for an IV Potassium bolus Dr. Williams ordered, which she refused to give, because it was a tenfold dosing error; and the Pharmacy failed to catch a dosing error in dexamethasone that Dr. Williams ordered, thus allowing a neurosurgical patient with cerebral swelling to develop marked hypertension. Luckily, the Neurosurgery Resident reacted quickly and brought the patient's BP under control, much to the surprise of a seemingly confused Dr. Williams.

Discussion Questions

1. What response do you have to Dr.
Williams' actions?
2. Does he have a problem?
3. Is he impaired?
4. What responsibilities exist for each of the following persons, and why?

Dr. Fred Williams, PL2

Dr. Jim Hines, Intern (PL1)

Dr. Yoo (the Attending)

You, as a medical student on-service or on-call with Dr. Williams and knowing of his drinking patterns?

5. What risks are taken by impaired physicians?
6. What potential harms must be considered in dealing with physician impairment?

Suggested Readings/References

1. *Code of Medical Ethics*, American Medical Association
   "Principles of Medical Ethics," p xiv-xxxviii
   "Fundamental Elements of the Patient-Physician Relationship," p xxxix-xlir
   "Discipline and Medicine," 9.04
   "Due Process," 9.05
   "Substance Abuse," 8.15
   "Reporting Impaired, Incompetent, or Unethical Colleagues," 9.031

   "The Physician and the Patient"
   "Physician and Society"
   "Impaired Physician"

3. *The Doctor's Dilemma*
   "Dr. Paul Williams Case"
Index under "Problem Physicians"
Impaired Physician Programs
Guidelines for Problem Physicians
Physician Well-being Program Contract, Med.
Reproductive Health Issues

Objectives

To explore the interaction of physician and patient in the arena of reproduction, within a pluralistic society, with consideration of increasing technologies requiring a host of moral and ethical decisions, and involving interaction of women, their partners, health care providers and government.

Goals

1. To understand the physician's ethical obligation
   To discuss all reproductive health options with his/her patient (i.e., full informed consent)
2. To understand the issues of maternal and fetal rights and when there may be a conflict.

Required Reading

   “Decisions about Reproduction”
2. Code of Medical Ethics, American Medical Association,
   "Abortion," 2.01
   "Mandatory Parental Consent to Abortion," 2.015
   "Artificial Insemination by Anonymous Donor," 2.05
   "In Vitro Fertilization," 2.14
   "Frozen Pre-Embryos," 2.141
   "Pre-Embryo Splitting," 2.145
   "Surrogate Mothers," 2.18
   Note: Many of these AMA statements are in Doctor's Dilemma.
   "Reproductive Issues," p 205-225

Discussion Questions

1. Does a pregnant woman have the right to make reproductive choices including termination of the pregnancy?
2. Is the fetus "a person" with interests and rights that must be protected?
3. Do the rights of the pregnant woman override the fetus' "right to life?"
4. Can the state intervene to protect the fetus from "irresponsible" harm by actions of the pregnant woman?
5. Who bears the responsibility for contraception? Have reversible contraceptive techniques for men kept pace with that for women?
6. What obligations exist for physicians to offer all available assisted reproductive technologies to infertile couples?

Clinical Vignettes


The Case of Angela Carder
Adapted from the Journal of Medical Ethics. 1996; 22: 327-333.

In 1987, Angela Carder was diagnosed as having terminal cancer of the lung. She was twenty-five weeks pregnant and it was expected that she would only survive for a week. Angela had lived under the shadow of cancer since she was thirteen, but had thought herself to be in remission when she planned her pregnancy. Whilst insisting that her own comfort must be the primary consideration, she agreed in principle to consent to any treatment which might enhance the survival prospects for her baby. Her husband, parents and physician were in full agreement with these wishes. Almost a week later, she refused her consent for a caesarean section and the hospital decided to seek legal advice. Angela believed that it was unlikely that such an immature fetus would survive, and that if it did, it would be likely to suffer multiple disabilities. Emmett Sullivan, the judge appointed to the case, decided that the pivotal issue was the fetus's chances of survival and what was in it's best interest granted it's mother's Terminal condition. He ordered the caesarean section to take place. Angela still refused to consent so Sullivan again listened to both counsels but reaffirmed his
original decision. Less than one hour later and with the c-section planned to occur within fifteen minutes, Angela's counsel argued that the operation would shorten her life and was not therefore in her best interest. Against this it was argued that she had no interest as she was dying. Sullivan cut across the ensuing argument by asking who had the best chances of surviving, the mother or the child. The answer was that the baby did and so he again ordered the operation to take place. The non-viable fetus died two hours after the caesarean was performed. Angela died two days later. At no point in the proceedings did Sullivan speak to Angela personally. In 1990, two appeal hearings later, the District of Columbia Court of Appeal reversed Sullivan's decision, not for the benefit of Angela, but to avoid setting a precedent for future cases.

**HIV and Pregnancy**

Ms C is a 25 year-old HIV -positive mother of a two-year old child. When she presented to her primary care physician at 20 weeks' gestation for her first prenatal visit, she encouraged her to start taking AZT to prevent or minimize the risk of HIV transmission to the fetus *in utero* or at the time of delivery. She refused to take AZT, and had only one additional prenatal visit at 28 weeks. Ms C, pregnant in her 34th week, presented today in preterm labor; her membranes rupture 8 hours before she came to the clinic. She is admitted and delivers her preterm infant who weighs 2,000 grams. The baby has respiratory distress, hypotension, and cyanosis. Management for respiratory distress, hypotension, and presumed sepsis are only marginally effective in improving the baby's status. An echocardiogram is performed and reveals an underlying cyanotic congenital heart lesion requiring urgent palliative surgery and possible transplantation in the long term in order to
offer any hope of continued survival. Any heart surgery will have to be performed at another institution, located some 500 miles away and out-of-state. Ms C's primary care physician, her baby's Pediatrician and her baby's Cardiologist are not in agreement about what the best course of action is at this point.

**Fetal Distress at Term**

Mrs. D is a 30 year old mother of twins who is pregnant with a singleton at 39 weeks' gestation. She presented with regular contractions last night; her cervix, however, has failed to dilate beyond 3cm. She desires a "natural childbirth" without analgesics, episiotomy, or any operative assistance (to include forceps delivery or cesarean section). Her physician has gone along with this plan but always maintained during prenatal visits that she must consider the "second" patient...Mrs. D's unborn infant...should any problems develop. Mrs. D never understood what "problems" her physician might be alluding to, but reiterated "No medication, no surgery."

Late in the evening, after laboring for more than 20 hours there fetal heart rate tracing became concerning. Mrs. D's physician informed her that the baby may be in jeopardy and could encounter a problem with its circulation or oxygen delivery if the monitoring strip did not change. She performs a pelvic exam, still finding the cervix at less than 4cm. She initiates some "non-invasive" conservative measures for Mrs. D and then witnesses a sharp decline in fetal heart rate. Concerned about placental abruption and bad outcome for the fetus/newborn, she recommends a STAT cesarean section in view fetal distress. Mrs. D insists "No surgery."

**Maternal-Fetal Conflicts**

A moral dilemma exists when a physician believes he
has a moral obligation to follow two conflicting courses of action, such as when the physician believes he must respect a pregnant woman's decision (autonomy) when the decision conflicts with the physician's obligation to protect the fetus. (non-maleficence and perceived best interest)

**Principle of Reproductive Freedom**

A woman has the right to make her own reproductive choices, including termination of pregnancy. Conflict arises as some feel this principle is morally objectionable, and overrides any "right to life" of the fetus. This view, rests on the controversial presumption that the fetus is a person. Finally, if a pregnant woman does decide to carry her pregnancy to term, she has by this act implied obligations to the fetus.

**Ethical Issues Related to Assisted Reproduction Techniques**

1. What is the role of the government in intervening in any of the following situations?
   - Refusal of HIV testing
   - Substance abuse
   - Voluntary v. non-voluntary intervention
   - Infringement of personal autonomy to promote fetal well-being.

2. What is the role of third-party payors in assisted reproductive processes such as genetic material donation, surrogacy, genetic manipulation, pre-embryo research and splitting, cryo preservation of oocytes, sperm, pre-embryos?

3. Does a woman have absolute autonomy over body?

4. Provision of abortion services by trained OB/GYN physicians in the United States (many training programs don't teach this procedure).

**Major Contributors to the Discussion of Reproductive Health and Technology Issues**

1. Pregnant woman
2. Infertile woman
3. Prospective father
4. Pre-embryo/fetus
5. Physicians
6. State/society

Guiding Legal Principles

Roe v. Wade Balancing test

1. Should respect for the pregnant woman's autonomy when she refuses a medical intervention preclude any approach other than to accept her decision?
2. Should caregivers have recourse to coercive techniques of persuasion?
3. When is there justification for court-ordered intervention?

Suggested Reading/References

1. Flagler E, Baylis F, Rogers S. Bioethics for Clinicians: 12. Ethical dilemmas that arise in the care of pregnant women: rethinking maternal-fetal conflicts. Can Med Assoc J, June 15, 1997; 156(12): 1729-1732. Note: This article can be found through Ovid and will require an ID and password.
2. The Doctor's Dilemma
"Roe v. Wade"
"Bowser Case"
"Juarez Case"

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Please email comments, suggestions or questions to:
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Death and Dying

Objectives

To explore the impact of the dying process upon the student/physicians, their patients and families, and the difficult decisions that must be made.

Goals

1. Understand the terms advance directives, health care proxy, living will, durable power of attorney for health care.
2. Understand the role of surrogates in end-of-life decision-making.
3. Understand the terms physician-assisted suicide, active and passive euthanasia; withholding and/or terminating life-sustaining treatment including nutrition and hydration and differences between them.

Required Reading

"Death and Dying" p. 127-153
“Euthanasia,” 2.21
"Physician-Assisted Suicide," 2.211
"Treatment Decisions for Seriously Ill Newborns," 2.215
"Do Not Resuscitate Orders," 2.22
Note: Many of these AMA statements are in Doctor's Dilemma

Discussion Questions

1. Relate how any experience with the death of someone you've known has revealed to you the
impact that death and dying can have on you,
and on others who have known the deceased.
2. What is the likely impact that having no
experience with death and dying prior to
medical school will have on a medical student?
3. Explore, as time allows, study questions 3-7 on
page 135 of Fletcher's text.

Clinical Vignettes

A video presentation will be given to the entire class
on October 4, 1999 at 8:00 a.m. in CJ-1103. The
class will be released into respective workshops
following the video presentation.

Advance Directives

The term "advance directive" refers to legal means
by which individuals can express and, within certain
limits, enforce their wishes regarding health care in
the event that they become unconscious or otherwise
mentally incapacitated. Common examples of such
include living wills (which direct families and
physicians to withhold or withdraw life sustaining
treatment if the testator is terminally ill and
permanently unconscious) and durable powers of
attorney (which appoint and invest third parties with
full authority to make decisions for incapacitated
patients). When properly executed, these documents
provide those who, in good faith, follow their
provisions, with protection from prosecution and
civil suit.

Living Will: This advance directive allows a
competent adult to direct his or her physician to
withhold or withdraw life-sustaining procedures in
the event of a terminal condition when the patient is
no longer able to participate in decision-making.

A "Durable Power of Attorney for Health Care" is
a written document whereby the patient (the
"principle") appoints a third party (the "agent") to
direct the course of the patient’s personal and
medical care if the patient is unable to make these
decisions for himself or herself; for example, if he or
she is unconscious. The law requires the agent to try
to make the health care decisions that the principle
would make if able. The agent has priority over all
other surrogate decision-makers.

**Points to Remember about Advance Directives**

In critical care settings, advance directives can provide direction for physicians regarding a patient's treatment choices. Keep in mind:

1. Whenever possible, review advance directives with a patient before the person is admitted to an intensive care unit (ICU). In less stressful settings, the patient has time to think clearly, ask questions, and consult with others.
2. When a patient who has decisional capacity enters an ICU with an advance directive, review the contents of the directive carefully with the person and, if at all possible, with the surrogate named and family members.
3. If a patient does not have an advance directive but still has the capacity to make health care decisions, determine the patient's wishes and assist the person in executing directives if he or she so chooses.
4. If a patient is admitted to an ICU without decisional capacity but with an advance directive or if an advance directive is in effect for a patient, carefully follow the instructions specified in the directive and/or the decisions of the agent appointed to ensure that the patient's wishes about care are implemented.
5. If a patient lacks decisional capacity and has not provided formal advance directives, learn as much as possible about the patient's wishes so that they may be followed.
6. You are not obligated to follow a patient's directive in the presence of a moral or professional conflict. However, so that the patient is not abandoned, assist him or her in obtaining the services of another physician.
7. If in doubt about a particular case, seek ethical and/or legal guidance.

**Life-Sustaining Procedures**

The AMA defines life-sustaining treatment as follows: "Life-sustaining treatment is any treatment that serves to prolong life without reversing the underlying medical condition. Life-sustaining
treatment may include, but is not limited to, mechanical ventilation, renal dialysis, chemotherapy, antibiotics, and artificial nutrition and hydration." [From the AMA's Withholding or Withdrawing Life-Sustaining Medical Treatment.]

The Ethics Manual of the American College of Physicians presents its position on this matter in a section on "Dilemmas Regarding Life-Sustaining Treatments," particularly in subsections on "terminally ill patients" and "intravenous fluids and artificial feedings."

**Surrogate Decision-Makers**

The law recognizes the natural rights and concern of family members (and the concerns of others in some states) for the best interest of the patients and authorizes them to provide consent for medical treatment on their behalf when they are unable to consent for themselves. These surrogate decision-makers are empowered in order of how closely they are related to the patients. The purpose of all this is to preserve the patient's autonomy by providing for substituted judgement via those who understand his or her intentions and wishes regarding medical treatment.

**Function of the Surrogate Decision-Maker**

*Code of Medical Ethics, American Medical Association*

If the patient receiving life-sustaining treatment is incompetent, a surrogate decision-maker should be identified...physicians should provide all relevant medical information and explain to surrogate decision-makers that decisions regarding withholding or withdrawing life-sustaining treatment should be based on substituted judgement (what the patient would have decided) when there is evidence of the patient's preferences and values. In making a substituted judgement, decision-makers may consider the patient's advance directive (if any), the patient's values about life and the way it should be lived, and the patient's attitudes toward sickness, suffering, medical procedures, and death. If there is no adequate evidence of the incompetent patient's
preferences and values, the decision should be based on the best interests of the patient (what outcome would most likely promote the patient's well-being).

The American College of Physicians' Ethics Manual has a rather comprehensive section on "decisions near the end of life." Of particular interest are the subsections on "who should make the decision" and "criteria for decisions."

2.20 Withholding or Withdrawing Life-Sustaining Treatment

*Code of Medical Ethics*, American Medical Association

The social commitment of the physician is to sustain life and relieve suffering. Where the performance of one duty conflicts with the other, the preferences of the patient should prevail. The principle of patient autonomy requires that physicians respect the decision to forego life-sustaining treatment of a patient who possesses decision-making capacity ... There is not an ethical distinction between withdrawing and withholding life-sustaining treatment.

A competent, adult patient may, in advance, formulate and provide a valid consent to the withholding or withdrawal of life-support systems in the event that injury or illness renders that individual incompetent to make such a decision.

If the patient receiving life-sustaining treatment is incompetent, a surrogate decision-maker should be identified. Without an advanced directive that designates a proxy, the patient's family should become the surrogate decision-maker. Family includes person with whom the patient is closely associated. In the case when there is no person closely associated with the patient, but there are persons who both care about the patient and have sufficient relevant knowledge of the patient, such persons may be appropriate surrogates. Physicians should provide relevant medical information and explain to the surrogate decision-makers that decisions regarding the withholding or withdrawing life-sustaining treatment should be based on
substituted judgement (what the patient would have decided) when there is evidence of the patient's preferences and values. In making a substituted judgement, decision-makers may consider the patient’s advance directive (if any); that patient's values about life and the way it should be lived; and the patient's attitude toward sickness, suffering, medical procedures, and death. If there is no adequate evidence of the incompetent patient's preferences and values, the decision should be based on the best interests of the patient (what outcome would most likely promote the patient's well-being).

Though the surrogate's decision for the incompetent patient should almost always be accepted by the physician, there are four situations that may require either institutional or judicial review and/or intervention in the decision-making process:

1. There is no available family member willing to be the patient's surrogate decision-maker
2. There is a dispute among family members and there is no decision-maker designated in an advance directive
3. A health care provider believes that the family's decision is clearly not what the patient would have decided if competent
4. A health care provider believes that the decision is not a decision that would reasonably be judged to be in the patient's best interests.

When there are disputes among family members or between family and health care providers, the use of ethics committees specifically designed to facilitate sound decision-making is recommended before resorting to the courts.

When a permanently unconscious patient had not left any evidence of previous preferences or values, since there is no objective way to ascertain the best interests of the patient, the surrogate's decision should not be challenged as long as the decision is based on the decision-maker's true concern for what would be best for the patient.

Physicians have an obligation to relieve pain and suffering and to promote the dignity and autonomy
of dying patients in their care. This includes providing effective palliative treatment even though it may foreseeably hasten death.

Even if the patient is not terminally ill or permanently unconscious, it is not unethical to discontinue all means of life-sustaining medical treatment in accordance with a proper substituted judgement or best interests analysis. (Principles I, III, IV and V) Updated June 1994.

Who Should Make the Decision?

Patients who have decision-making capacity and who are adequately informed of their clinical situation and options have the right to refuse any recommended medical treatment, including life-sustaining treatment, except in rare circumstances when the law forces a patient to accept treatment. The patient's right is based on the philosophical concept of autonomy, the common law right of self-determination, and the patient's liberty interest under the Constitution in refusing unwanted medical care. The crux of the issue is that the patient's (rather than the physician's) assessment of the benefits and burdens of treatment should determine what treatment is administered or withheld.

Criteria for Decisions

_Ethics Manual, American College of Physicians_

In order of priority, decisions should be based on advance directives, substituted judgements, and the best interests of the patient. Patients' informed goals and choices should be respected even if they no longer have decision-making capacity. Through advance directives, competent patients state what treatments they would accept or decline if they lost decision making capacity. In giving advance directives, patients should also indicate their general goals for care and their choice of surrogate.

Oral statement to family members, friends, and health care professionals are the most common form of advance directive. However, oral statements are
problematic if they are vague and ambiguous or if they were casual comments rather than seriously intended directives. Because some states regard oral advance directives as untrustworthy, written advance directives have several advantages. Living wills can have a narrow scope of application, in most states providing guidance only for terminal conditions, the definition of which varies; they may not apply to patients in a persistent vegetative state. Living wills generally are limited to the refusal of interventions that would only prolong the process of dying. Some states explicitly exclude intravenous fluids and tube feedings from the interventions that may be refused, although courts might rule that such an exclusion violates patient rights.

The durable power of attorney for health care can be more comprehensive and flexible than the living will; the patient appoints a surrogate (also called an agent) to make decisions if the patient becomes unable to do so. The surrogate is required to act in accordance with the patient's previously expressed preferences or best interests. Patients can usually indicate specific treatments they would accept or refuse in various situations. Different states have specific procedures for appointing surrogates. Some have durable power of attorney for health care or health care proxy laws for the appointment of surrogates, whereas others allow appointments as part of living wills. Physicians need to be familiar with state laws. Copies of written advance directives should be placed in the patient's medical record.

Physicians should raise the issue of advance directives routinely with competent adult patients in outpatient visits and encourage them to provide advance directives and to discuss their preferences with their surrogate and family members. In addition, the Patient Self-Determination Act of 1990 requires hospitals, nursing homes, health maintenance organizations, and hospices that participate in Medicare and Medicaid programs to provide patients, on admission or enrollment, with information about their right to provide advance directives. These health care institutions are required to respect advance directives to the fullest extent permitted under state law. Discussions between physicians and patients let the physician know the
patient's preferences and values, enable physicians to check that choices are informed and up-to-date, and reassure patients that the physician is willing to discuss these sensitive issues and will respect their choices. Discussions about patient preferences should be documented in the medical record.

Two standards have been developed for surrogate decision making in cases where the patient has not left an advance directive. In a substituted judgement, the surrogate attempts to make the judgement that the patient, if competent, would have made. This approach is feasible and desirable when the surrogate knows the patient's goals, values, and choices.

If the patient's values and preferences are unknown or unclear, decisions should be based on the patient's best interests. In making decisions about their care, patients often take into account their current and projected quality of life. For patients who lack decision making capacity, quality of life may also be an integral aspect of their best interests. Assessments of quality of life according to the patient's perspective and values should be respected. Quality-of-life judgements made by a person not familiar with the patient's perspective should be suspect. Because family members and health care workers may project their own values onto the incapacitated patient, there is a significant risk of bias and discrimination. In the current medical environment, which emphasizes cost containment, physicians should not use quality-of-life standards that may lead to various groups of patients being denied appropriate treatments.

**Suggested Readings/References**
*Note: These articles can be found through Ovid and will require an ID and password.*

3. Cassell EJ. The nature of suffering and the
goals of medicine. *N Engl J Med*
4. *The Doctor's Dilemma*
"Miller Case"