



St. Louis University
Medical Center

SAINT LOUIS UNIVERSITY

SCHOOL OF MEDICINE

BASIC CONCEPTS OF MEDICAL ETHICS

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BASIC CONCEPTS OF MEDICAL ETHICS -- 1985

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INTRODUCTION

i

This course is a first introduction to ethical issues in medicine. It will examine the foundations of ethics and the essential relationship between ethics and medicine. In addition one methodology of resolving ethical dilemmas will be proposed. This method will be used in resolving issues presented in case studies designed to explore some of the basic principles used in medical ethics, such as informed consent, proxy consent, allowing to die, and access to health care.

Specific course objectives are:

1. to enable the student to recognize and delineate ethical issues when encountered in research and patient care;
2. to provide students with the tools to answer ethical questions using a logical and scientifically grounded system which integrates recognized ethical norms and personal values;
3. to dispose students to understand, respect, and protect the rights of fellow health care professionals, of patients, and of research subjects;
4. to prepare students to handle future ethical issues which will arise because of advanced technology and economic limitations;
5. to introduce students to the current literature in medical ethics and to provide resource information for resolving future ethical issues.

The course is a combination of lectures, readings, case studies and discussion, at times with clinical specialists, examining the basic issues of medical ethics. The syllabus contains readings for each class, case studies where necessary, and supplemental readings which can be used for further study.

Material presented in the syllabus should be read and cases examined before class. This will facilitate better discussion.

During the normal examination period at the end of the first trimester, there will be an examination: November 19, 1985, 1:00pm.

The material presented in class this year comes from various sources. There is a small bibliography in the Appendix which attempts to familiarize the reader with the sources of research in medical ethics and the basic or most prominent writings of other authors. For those who wish to pursue a particular area of interest this list should provide a starting point.

In addition there are a series of books listed under the title, President's Commission. Some explanation of this Commission and its work is in order. This Commission's work as represented in the syllabus summarizes some of the most basic issues that confront the physician and society in this area, and has had an impact upon many legislative and judiciary bodies as they have deliberated about some of the medical ethical problems that confront society.

SUMMARY OF PERTINENT FACTS CONCERNING THE PRESIDENT'S COMMISSION
FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL
AND BEHAVIORAL RESEARCH

I. Purpose and Publications

Although public awareness of bioethics has been galvanized by the dramatic achievements that emerge from hospitals and research laboratories—and occasionally by reports of research abuses—the concerns are not just monetary ones, nor are they necessarily best addressed in the context of particular revelations or discoveries, however startling. For these reasons, the U.S. Congress in November 1978 authorized the creation of a presidential commission with continuing responsibility to study and report on the ethical and legal implications of a number of issues in medicine and research. The Commission functioned from 1979-1981.

The Commission was charged with studying problems whose value components are at least as important as their technical aspects. In effect, the Commission was instructed to bring ethical analysis of the implications of medical practice and research out of the classrooms, the hospital wards, and the scholarly journals and into a public forum. Since mid-1981 the Commission has published most of its findings and conclusions in a series of nine reports.

The Commission prepared five reports on topics related to the provision of health care: Defining Death (July 1981); Making Health Care Decisions (October 1982); Screening and Counseling for Genetic Conditions (February 1983); Securing Access to Health Care (March 1983); and Deciding to Forego Life-Sustaining Treatment (March 1983). The first four topics were assigned to the Commission by the Congress; the fifth was added early in the Commission's tenure when it arose during the study on the "definition" of death and because it applied several areas of the Commission's work to a set of ethical problems of great importance and immediacy. In addition, as part of its statutory mandate, the Commission studied the ethical aspects of privacy and confidentiality in the health field. In Splicing Life (1983) the Commission reported on the current developments in genetic engineering as they apply to human beings and considered the social and ethical implications of this rapidly evolving field. As with any research that involves human subjects, careful attention must be paid to both the immediate and the long-term impacts. Issues such as these were taken up by the Commission in two Biennial Reports required by its Congressional mandate, Protecting Human Subjects (1981) and Implementing Human Research Regulations (1983). The research side of the Commission's mandate was also addressed through a report on Compensating for Research Injuries (1982), in a cosponsored workshop on Whistleblowing in Biomedical Research (the proceedings of which were published in 1982), and in The Official IRB Guidebook (1983), a project on which the Food and Drug Administration and the Office for Protection from Research Risks, NIH, cooperated (cf. Summing Up, President's Commission, 1983).

II. Predecessor Commission

National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (1974-1978) produced some valuable works on informed consent, fetal research and psychosurgery.

III. Value of these Two Commissions

Their studies offer some general ethical principles, using reasoned analysis as a basis for development, for medical and health care in a pluralistic society. Though one need not agree with all ethical statements of the Commission, one must consider them and be prepared to offer counter-arguments based upon reasoned analysis before rejecting any one of them.

- IV. The studies of the Commission may be obtained by writing: United States Government Printing Office, Washington, DC, 20402.

As stated earlier, this course is a first introduction and will be complimented by other offerings in the following years of medical education. An elective is offered for first and second year students which examines selected ethical issues in greater depth. A fourth year elective enables students to examine ethical issues as they arose in the clinical years. In addition, ethical issues are also examined in certain classes such as Death and Dying, Human Sexuality, and Genetics. Grand Rounds in various services and rounds in certain clerkships are also offered. This course is designed to prepare you for some of these latter experiences.

CLASS 1: INTRODUCTION TO MEDICAL ETHICS

September 13, 1985

8:00-10:00am

Required Reading:

1. "On the Definition and Teaching of the Medical Ethic," by Carleton B. Chapman, Md. NEW ENGLAND JOURNAL OF MEDICINE (NEJM), Vol.301, No.12, Sept. 20, 1979; pp.630-634.
2. "Professing Ethically: On the Place of Ethics in in Defining Medicine," by Leon R. Kass, MD, PhD. JAMA, Vol.249, No.10, Mar. 11, 1983; pp.1305-1310.
3. "Ethical Dilemmas in the Care of the Ill," by Leon R. Kass, MD, PhD. JAMA, Vol.244, No.16, Oct. 17, 1980; pp.1811-1816.
4. Pelligrino and Thomasma, A PHILOSOPHICAL BASIS OF MEDICAL PRACTICE. New York: Oxford University Press, 1981; pp. 170-191.

CLASS 2: ETHICAL ISSUES IN ACCESS TO HEALTH CARE

September 20, 1985

8:00-10:00am

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<u>Case:</u> "Medical Care in the South Bronx"	3

Required Reading:

1. SECURING ACCESS TO HEALTH CARE by President's Commission for Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (hereafter known as President's Commission). Washington, DC: US Govt. Printing Office, March 1983; pp. 11-47.

MEDICAL CARE IN THE SOUTH BRONX

The South Bronx in New York City is one of the most crowded poor areas in America. In health-planning area 21.02 there, 9,000 people live without even one physician. Two storefront clinics dispense minimal care, but they are closed at night. What happens when patients have medical emergencies at night? The administrator of one clinic answered, "We don't know, because we're not there."

One night, Joseph Hernandez's friend, Bernie, was hit by a car and hurt. Joseph called the city-wide emergency telephone number, but no one came. Finally, 14-year-old Joseph ran home, got his bicycle, and somehow managed to ride himself and Bernie to Jacobi Hospital—a mile away. People like Joseph are forced to rely on emergency rooms of faraway hospitals.

One Bronx mother took her son to Lincoln Hospital for treatment of sickle-cell anemia, went to Bronx-Lebanon Hospital for a hysterectomy, to Jacobi Hospital for a gallstone operation, and to another branch of Bronx-Lebanon to take her sick daughter. Another woman was referred to a specialist five miles away and never went. Asked why, she said, "It's too far. I waited a couple of days, then it went away. I got a lot of medicine around. When I feel sick, then I take one of those." A very old resident of the neighborhood, who had seen the area in better times, said, "There won't be doctors here again, unless they build up the neighborhood. I'll be dead by then."

The above cases aren't rare in this country. In another city, where there's no publicly financed ambulance system, a young black woman who had been shot in the stomach bled to death. Her mother couldn't find \$50 for the ambulance. The driver refused to take the girl to the hospital without advance cash payment. Similarly, many rural people with medical problems haven't seen a physician in years. Without care, these people may suffer and their lives may be shortened.

Initially, it seems that the above cases of medical need should be prevented by a national health system in which equal medical care would be a right. However, the air of obvious justification vanishes when we consider how the medical need would have to be satisfied. Obviously, no physician is now voluntarily in area 21.02 in the Bronx; how do we get good physicians to go there to render good care? Should physicians be forced to go there in violation of their rights to live and work where they choose? So if satisfying the right to medical care means forcing physicians to provide it, two rights conflict.

Perhaps physicians shouldn't be forced to go to the Bronx, but merely encouraged to do so. One way to encourage them is to pay the tuition of poor medical students in return for later service in areas such as the Bronx. This plan has several problems. Not enough medical students may take the offer. They may not need the money since private banks lend enormous sums to medical student, knowing that their future

earnings will be very high. Students willing at age 22 to go into such service may later regret what they have done and put in their time grudgingly. Moreover, residents of places classified as needing physicians may not like the ones assigned to their areas. Will they be forced to go only to these physicians? In short, the initial plausibility of a universal right to medical care now seems less obvious.

* * *

CLASS 3: THE PRINCIPLE OF INFORMED CONSENT

September 27, 1985

8:00-9:00am

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"Consent for Routine Laboratory Tests"	8
<u>Ethics Work-up for Case Studies</u>	9

Required Reading:

MAKING HEALTH CARE DECISIONS by The President's Commission.
Washington, DC: US Govt. Printing Office, October 1982;
pp.15-51.

INFORMED CONSENT FOR MEDICAL CARE

Canterbury vs. Spence

Canterbury is a nineteen-year-old man suffering from back pain between his shoulder blades. After a few weeks of this discomfort he consulted two general practitioners who prescribed medication which did not relieve the pain. He then made an appointment with a neurosurgeon, Dr. Spence, who examined the young man in his office and found nothing wrong. Since bone disease disorders are not always immediately diagnosed in such a situation, he suggested that Canterbury have a myelogram—a procedure in which dye is injected into the spinal column and traced to find evidence of a disease or disorder. The young man entered the hospital where it was discovered that there was a "filling defect" in the region of the fourth thoracic vertebra. The doctor then told Canterbury that he would have to undergo an operation called a laminectomy in order to correct what the doctor suspected was a ruptured disc. Canterbury raised no objection to the surgical procedure but he also asked no questions. Dr. Spence said nothing more about the surgery and inquired about his parents since the young man was a minor.

Mrs. Canterbury lived in West Virginia, had little money and could only be reached through a neighbor's phone. When her son called to tell of the recent developments and the needed operation she was not at home. He left Dr. Spence's phone number. Mrs. Canterbury made contact with the doctor who explained that surgery was scheduled for the next day for a suspected ruptured disc. He explained that he knew that she did not have a great deal of money and that she was not needed in Washington, DC, where the operation was to take place. Mrs. Canterbury asked if the operation was serious and the doctor responded, "Not any more than any other operation." Later he was to say, "I feel that any operation is serious. I think that I would not tell my patients that they might be paralyzed because of the small percentage, one per cent, that might exist. There would be a tremendous percentage of people who would not have surgery and would not therefore be benefitted by it, the tremendous percentage that get along very well, 99 per cent." Mrs. Canterbury arrived in Washington the day of surgery but after it was completed. She then signed a consent form.

The first post-operative day saw seemingly normal recovery. The doctor had ordered that bathroom needs would have to be performed in bed. However, the chart for the patient recorded a change in that order. While Mr. Canterbury was voiding that first day he fell off the edge of the bed. There was no rail on the bed and there was no nurse or other staff person there to assist him. A few hours after he was placed back in bed he felt paralysis in his lower legs and experienced respiratory distress. It was discovered that he had to undergo surgery again. Dr. Spence had Mrs. Canterbury sign another consent form and performed the second operation. During this operation he created a gusset to allow the spinal cord to pulsate, something which the spinal cord had not been able to do before the first operation. Some of his leg muscles improved but he had a series of urologic complications. Further surgery was required for bladder stones and he was released from the hospital three months after his initial entry for the myelogram.

The final result of the medical care that Mr. Canterbury received was parital paralysis requiring the use of crutches, urinal incontinence, bowel paralysis and the need for a penile clamp. This greatly affected his job possibilities, social life and earnings. Mr. Canterbury is suing Dr. Spence for malpractice of a negligently performed operation and for failure and negligence in disclosing serious risk of disability.

* * *

CONSENT FOR ROUTINE LABORARY TESTS

Pauline Jaffe had moved to Chicago earlier in the year to become a graduate student at the university, studying anthropology. She thought that she needed a complete physical examination, for it had been over six years since her last one. She discussed it with a neighbor, who referred her to Dr. Mary Vaccaro, a general practitioner whom the neighbor had seen on a number of occasions. Ms. Jaffe called for an appointment and was told that the cost for the physical examination would be \$100. She was quite satisfied with the exam, after which Dr. Vaccaro told her she was perfectly healthy except that she should lose ten pounds. She paid Dr. Vaccaro's receptionist by check as she left.

She was surprised when three weeks later two bills came from Diagnostic Labs, Inc., one for \$15 labeled "profile number one" and another for \$6 labeled "cervical cytology." She assumed that the bills were connected with her visit to Dr. Vaccaro but was troubled because she had not been told that any special laboratory work would be done or that she would be billed separately. Dr. Vaccaro had taken 10 cc's of blood and a pap smear during the exam, telling Ms. Jaffe that they were for "routine tests." Ms. Jaffe called the physician after receiving the bills for an explanation of the additional charge, but also wanting to know what tests had been done and why she had not been informed of the results. Further, she had not authorized the performing of the analyses outside the doctor's office. Dr. Vaccaro explained to her that sending out lab specimens was routine, that the information was kept confidential, that separate billing was required by law, and that there was no reason anyone would want the information anyway.

Ms. Jaffe at this point became more and more distressed. She knew that the right of the patient-consumer to select her own medical providers is considered sacred by the American Medical Association and is a fundamental principle of American business. She also recalled that a student friend of hers worked in some medical lab on a part-time basis, though she was not really worried about disclosure of the data. She wondered why the patient's right to consent to medical treatment would not apply to the choice of lab tests and the lab to perform the tests. While she recognized that she did not have much of a basis to make such a choice, she felt that she should, in principle, be the one to authorize the procedures. The extra \$21 medical bill bothered her, but the main worry was that a diagnostic procedure had been done without her consent by a group of people she did not even know.

Ms. Jaffe called the lab and asked for copies of the finding, claiming that if she was paying the bill, she was at least entitled to the results. She was told that the lab could give the results only to the physician who had asked that the tests be done. The regulation, the company explained, was for the patient's own protection. There might be something in the data that might upset the patient. The doctor should be the one to decide whether the patient should be told. Ms. Jaffe was confused. She knew that in theory she should consent for medical treatment or diagnosis, yet she could not recall ever hearing of anyone giving consent for lab tests.

ETHICS WORK-UP FOR CASE STUDIES

The following three steps are designed to help you reflect critically upon the ethical issues (value conflicts) that can arise in medicine and which need to be resolved.

1. Identify the issues that are raised by the case.

The issues that are raised may affect the behavior, values and relationship of the patient, the health care provider, the relevant members of the patient's family and the health care institution.

The issues that are raised may come from conflicts and involve medical facts, family history, religious beliefs, social environment, and other factors which must be analyzed carefully.

2. Evaluate the values in conflict and map a course of action which should be followed:

The evaluation of the conflict requires that one set priorities for the values (which ought to be realized in this situation) where not all values can be realized.

3. Justify the choice you have made.

Justification requires that you identify the principles that you are following. Which ethical principles, norms, rules, are you following and WHY?

Would this choice be universalizable--that is, would you choose to respond in this way in all similar cases?

CLASS 4: THE PRINCIPLE OF PROXY CONSENT

October 4, 1985

8:00-10:00am

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<u>Cases:</u> "The Child as a Kidney Donor"	11
"Case Study No. 2"	12
"Faith Healing for Childhood Leukemia"	13

Required Reading:

1. President's Commission, MAKING HEALTH CARE DECISIONS, VOLUME 1; Washington, DC: US Government Printing Office, October 1982; pp. 55-68.
2. "Proxy Consent in the Experimentation Situation," by Richard A. McCormick, SJ; PROSPECTIVES IN BIOLOGY AND MEDICINE, Autumn 1974; pp. 2-20.

THE CHILD AS A KIDNEY DONOR

Diane and Dione DeLeon were identical twins born eight years ago. Dione was now suffering from a progressively serious kidney disease, hemolytic uremic syndrome. On December 8, 1971, she began hemodialysis or kidney machine treatments along with other treatments. By February 1, 1972, her kidney was biopsied for a second time because of the onset of a malignant type of blood pressure elevation. The decision was made that the kidneys had to be removed.

Both Dione's parents volunteered to donate kidneys for transplant but were rejected because of a tissue incompatibility. No other related donors were available except Diane who, being an identical twin, would make the ideal donor. There is virtually no risk of failure for transplants from identical twins, but for transplants from an unrelated cadaver source, which is the only other possibility, the rejection risk after three years is estimated to be about 50 percent.

Mr. and Mrs. DeLeon were horrified at the decision they had to make. They agonized with the alternatives in a long counseling session with their minister. He thought that authorizing the transplant between the twin daughters was a morally sound decision. Pressured by knowledge that Dione's condition was deteriorating rapidly, the parents, together with the physicians, decided they should obtain a declaratory judgment from the court to authorize the donation.

The court appointed an independent guardian for Diane who, after spending a great deal of time talking with the child, concluded that she understood to the limits of her age and agreed with what was being asked of her. The guardian consented to the donation. A psychiatrist examined Diane and found that she had a strong identification with her sister and apparently desired to help her without having received undue pressure from the others in the family.

There had been previous cases involving minor identical twin donations, but these involved teenage minors who had a great deal more capacity to understand the procedure. There had also been a case involving a mentally retarded twin donor. He, however, was 28 years old and so utterly dependent upon the brother needing the kidney that a strong case was made that he would benefit more by keeping his brother alive than by having the second kidney. In this case while some possible benefit to Diane was recognized, all agreed that it was not a major consideration. The problem facing the judge was whether to permit the parents to approve the transplant, which would be of immense benefit to the recipient, but of some risk and limited benefit to the donor, who was not herself competent to consent.

* * *

CASE STUDY No.2

Mrs. B. is 77 years old and has been in a nursing home for the past three years following a stroke. Her speech is largely unintelligible and she is occasionally incontinent of urine and stool. Her family (consisting of a son, daughter and three grandchildren) visit periodically, but she rarely shows any signs of recognition. Mrs.B. can feed and dress herself with assistance.

Last evening, Mrs.B began vomiting large amounts of coffee ground material, evidence of bleeding in the upper gastrointestinal tract. She was taken to the local hospital where here hemoglobin was found to be 7 (normal = 3) and x-ray and endoscopic studies confirmed the diagnosis of gastric ulcer. By morning, the bleeding had stopped and she had received a blood transfusion. A biopsy taken at the time of endoscopy was suggestive but not diagnostic of cancer.

Because Mrs. B. was judged not to be competent, the surgeon approached the son and daughter for operative consent. The doctors reasoned that the ulcer had a high likelihood of being malignant and an operation was needed to remove the ulcer which could rebleed, and also to determine the extent and spread of any cancer. The operative risks were significant, with possibility of death or extension of the stroke area but, in the surgeon's opinion, not prohibitive.

With only medical management, two outcomes were possible: If the ulcer was not malignant, it might heal with medication; however, if cancerous, it would continue to erode and eventually cause a massive hemorrhage and probable death. The family refused surgery and Mrs.B. was returned to the nursing home where she died one week later from a massive GI hemorrhage.

* * *

FAITH HEALING FOR CHILDHOOD LEUKEMIA

Within twenty-four hours a ten-month-old boy was transferred from a small local hospital to a university hospital and then to its affiliated cancer center with a presumptive diagnosis of leukemia. Because the diagnosis had not been confirmed by bone marrow examination, information on the type of leukemia—needed for an outline of a specific therapy and a more accurate prognosis—was not available.

When the baby was admitted on a Saturday afternoon, only his mother was present. The child was not acutely ill, and the severe anemia that had concerned the referring physician had been corrected by transfusion before the transfer. The baby seemed much better, according to his mother. However, there were significant signs of tumor. The medical approach currently considered optimal is hydration, medication to counteract excess uric acid, and careful characterization of the leukemia. After that, specific therapy can be offered. The characterization could not begin until after the weekend but some therapy could begin immediately.

This information was explained to the mother, and a few hours later to the father. After two hours of deliberation, they told the attending physician that they refused therapy. They would, they said, place their faith in God. They had recently seen sight restored in the baby's great-grandmother when she was taken to a healing service after a debilitating stroke.

They felt that all the cancer center measures would very likely fail and they would then take the child to a faith-healing service. It made more sense to them to refuse the therapy and take the child to a faith-healing service right away. They had prayed for a sign from God to help them make this decision, and took the nurse's failure to start an intravenous infusion on the first attempt as just such a sign.

The physician asked the father why God would allow cancer centers to exist if prayer were a more appropriate mode of exercising parental responsibility. The father replied, "Cancer centers are part of God's plan, so that children of parents who do not believe still have a chance." The parents were then asked whether they could muster a perfect enough faith to mediate the healing. The answer was that such a faith was not necessary—they had a perfect God. The child was discharged without therapy with a return appointment at the center's clinic, but the family did not keep the appointment.

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CLASS 5: THE ETHICS OF RESEARCH WITH HUMAN SUBJECTS

October 18, 1985

8:00-9:00am

Cases:

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| 1. "Experimenting or Just Fooling Around" | 15 |
| 2. "Benefitting Mentally Retarded Children by Giving Them Hepatitis" | 16 |

Required Reading:

1. THE BELMONT REPORT; Washington, DC; DHEW (HHS) Publication (OS) 78-0012); 1978.
2. U.S. GUIDELINES ON HUMAN EXPERIMENTATION (Institutional Guide to DHEW Policy on Protection of Human Subjects): Washington, DC; US Government Printing Office; 1971.

EXPERIMENTING OR JUST FOOLING AROUND

George Martin, a second-year medical student working in the clinical chemistry lab in the summer, was running the glucose machine when he noticed that the lab had received from the clinic five samples of amniotic fluid, the fluid surrounding a fetus, for glucose tolerance tests. He knew from his summer's experience that they usually received about one a week from the clinic.

He mentioned the extra tests of amniotic fluid to his supervisor, who seemed upset and said she would speak to the clinic about it. The next week when the student was back in the lab, he noticed that this time they had received no amniotic fluids from the clinic, which he remarked to his supervisor. She told him that someone had again sent five amniotic fluid samples that morning from the clinic and the clinic director had told him to stop. A physician in the clinic had simply had an idea about the relation of the glucose tolerance to some aspect of fetal health and thought he would try out his idea on a small scale before designing a formal experiment on the idea.

* * *

BENEFITTING MENTALLY RETARDED CHILDREN BY GIVING THEM HEPATITIS

Willowbrook State Hospital is an institution for the care of the mentally retarded in Staten Island, New York. In 1972 there were 5200 residents, 3800 severely retarded, with IQs of less than 20. In 1954 Dr. Saul Krugman was appointed as a consultant in pediatrics and in infectious diseases. When he began work, he discovered that such diseases were very much prevalent at Willowbrook, including hepatitis, measles, shingellosis, parasitic infections, and respiratory infections. Dr. Krugman and his colleagues began a number of studies of those diseases, including research on measles vaccine and hepatitis.

In 1956 Dr. Krugman, together with Drs. Joan Giles and Jack Hammond, began studies on hepatitis. Four times a year from then until 1970 they admitted approximately 12-15 children into their research unit, for a total of 700-800 children out of the 10,000 admissions to the hospital. The researchers injected infected serum to produce hepatitis in the patient-subjects in their research unit. The objective was to gain a better understanding of the disease and possibly to develop methods of immunization against hepatitis. The research was approved by the Armed Forces Epidemiological Board, one of the funders of the research, the executive faculty and the Committee on Human Experimentation of New York University, where Dr. Krugman held a faculty position, and the New York State Department of Mental Health.

The researchers defended their decision to expose the children to strains of hepatitis virus on the following grounds:

- (1) they were bound to be exposed to the same strains under the natural conditions existing in the institution;
- (2) they would be admitted to a special, well-equipped, and well-staffed unit where they would be isolated from exposure to other infectious diseases which were prevalent in the institution—namely, shigellosis, parasitic infections, and respiratory infections—thus, their exposure in the hepatitis unit would be associated with less risk than the type of institutional exposure where multiple infections could occur;
- (3) they were likely to have a sub-clinical infection followed by immunity to the particular hepatitis virus;
- and (4) only children with parents who gave their informed consent would be included.

* * *

CLASS 6: BRAIN DEATH: ETHICAL SIGNIFICANCE

October 25, 1985

8:00-9:00am

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Cases:

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| 1. "Brain Death: Welcome Definition or Dangerous Judgment" | 18 |
| 2. "Case Study No. 1" | 19 |

Required Reading:

1. President's Commission, DEFINING DEATH. Washington, DC: US Government Printing Office, July 1981; pp.21-43.

BRAIN DEATH: WELCOME DEFINITION OR DANGEROUS JUDGMENT

On May 25, 1968, at the beginning of the era of transplantation, Bruce Tucker was brought into the operating room of the hospital of the Medical College of Virginia. Mr. Tucker, a 56-year-old black laborer, had suffered a massive brain injury in a fall. He sustained a lateral basilar skull fracture on the right side, subdural hematoma on the left, and brain stem contusion.

The following timetable was included in the summary of the case by Judge A. Christian Compton:

- 6:05 P.M. Admitted to the hospital.
- 11:00 P.M. Emergency right temporoparietal craniotomy and right parietal burr hole.
- 2:05 A.M. Operation complete; patient fed intravenous and received "medication" each hour.
- 11:30 A.M. Placed on respirator, which kept him "mechanically alive."
- 11:45 A.M. Treating physician noted "prognosis for recovery is nil and death imminent."
- 1:00 P.M. Neurologist called to obtain an EEG (electroencephalogram) with the results showing "flat lines with occasional artifact. He found no clinical evidence of viability and no evidence of cortical activity."
- 2:45 P.M. Mr. Tucker taken to the operating room. From this time until 3:30 P.M. "he maintained vital signs of life, that is, he maintained, for the most part, normal body temperature, normal pulse, normal blood pressure and normal rate of respiration."
- 3:30 P.M. Respirator cut off.
- 3:33 P.M. Incision made in Joseph Klett, heart recipient.
- 3:35 P.M. Incision made to remove Tucker's heart.
- 4:42 P.M. Heart taken out.
- 4:43 P.M. Incision made to remove decedent's kidneys.

Tucker's heart and kidneys were then removed by the surgical team. The heart was transplanted to Joseph G. Klett, who died about one week later.

William E. Tucker, brother of the dead man, sued for \$100,000 damages, charging the transplant team was engaged in a "systematic and nefarious scheme to use Bruce Tucker's heart and had hastened his death by shutting off the mechanical means of support." According to the judge's summary, "a close friend of the deceased was searching for him and made an inquiry at three of the hospital information desks, all without success." Tucker's brother, William, was "at his place of business, left his business to go find his brother in the afternoon when he heard he had been injured. Among the personal effects turned over to the brother later was a business card which the decedent had in his wallet which showed the plaintiff's (brother's) name, business address and telephone number thereon." The suit charged that the removal of organs was carried out with only minimal attempts to notify the victim's family and obtain permission for use of his organs.

CASE STUDY No. 1

Jack is 14 years old. He was brought into the intensive care unit of the local community hospital after an accident while playing football. He has been in a coma and on a respirator since the accident two months ago. Jack's father is manager of a local discount store. His mother is active in church and busy with five other children, all younger than Jack. The youngest has Down's Syndrome and attends a special class at the local public school. The nurses know that Jack's hospitalization is a terrible drain on this family, financially and economically.

Jack's mother has asked one of the night nurses to "just unplug the respirator sometime when you're on duty. Who's to know?" Jack meets the Harvard brain death criterion. The legislature in Jack's state has recently authorized the criterion as a "legally" acceptable basis for "pulling the plug." The physician has not discussed this with Jack's parents and has adopted a "wait and see" attitude because he knows of a similar case where a patient on a respirator for eight months is now back in school.

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CLASS 7: ORGAN TRANSPLANTATION

November 1, 1985

9:00-10:00am

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Cases:

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| 1. "The Adult Kidney Donor" | 21 |
| 2. "Ethical Options" | 23 |

Required Reading:

1. Ashley & O'Rourke, HEALTH CARE ETHICS, SECOND EDITION.
St. Louis: Catholic Health Assn., 1982; pp.308-312.
2. "Harvesting the Dead," by W. Gaylin. HARPER'S MAGAZINE,
Sept. 1974; pp.413-423.

THE ADULT KIDNEY DONOR

Dr. Maxwell Firman was medical director of the Scheller Kidney Center, one of the most distinguished kidney research centers in the country. For some time he had been seeing Audrey Poland, a middle-aged woman, for chronic renal disease. She was almost to the point where some medical action would have to be taken. He had discussed both transplantation and dialysis with her many times. Mrs. Poland, like many patients in kidney failure, strongly preferred a transplant, not wanting to spend the rest of her life attached to a dialysis machine six hours a day, three days a week.

At the most recent visit, Mrs. Poland seemed happy and said that her sister, Ruth Hamill, had volunteered to donate a kidney to her. Dr. Firman explained to her again the importance of tissue typing in a sibling-to-sibling transplant: that is, if the typing is identical, the chance of a successful transplant is about 90 percent, but if the match is less close, the chance of success is less. Poor matches will have no greater chance than with a cadaver graft, or about 50 percent. In that case Dr. Firman would not recommend such a procedure. Mrs. Poland said that she would arrange for her sister to accompany her on her next visit and have the requisite tests performed.

The following day Dr. Firman received a telephone call from the potential donor's husband, who wanted urgently to see him that day. He arranged for an appointment. Mr. Hamill said that he understood that his sister-in-law had spoken to the doctor about Ruth being a kidney donor. Dr. Firman indicated that Mrs. Poland had said Mrs. Hamill was considering such a donation. Mr. Hamill replied that he was glad she had said "considering," because she certainly was nowhere close to making such a decision. Mr. Hamill thought that it would be the completely wrong decision to make. He explained to Dr. Firman the active life that his wife led, with several young children at home to take care of and a deep involvement in other activities, some of which were reaching a professional culmination for her. He described some medical problems that he thought might rule her out as a donor in any case. He vividly contrasted his wife's life style with that of the patient, who was sedentary owing to her chronic disease; and he saw no reason why his sister-in-law would not do well on chronic dialysis. Mr. Hamill said his wife was deeply disturbed at the prospect of having to confront her sister with a decision not to donate a kidney for her.

Dr. Firman reassured the potential donor's husband that the medical team would do nothing against his wife's wishes in terms of her decision to donate or not to donate, and that if her decision was not to donate, they would make every effort to explain the situation to Mrs. Poland in such a way that it would not jeopardize their relationship.

During the next appointment Dr. Firmin had an opportunity to discuss the donation privately with Mrs. Hamill, the potential donor. She expressed great concern about her sister's health and indicated she wanted to do what she could to help. She asked repeatedly about the risks involved in the donation. She seemed tense during the long conversation. She brought up the subject of the suitability of cadaver kidneys for transplant and at one time said, "Would the kidney machine really be that bad for her?" Later consultation with a psychiatrist indicated that Mrs. Hamill seemed anxious, but there was no evidence of present or past mental disturbance. Still Dr. Firmin had real doubts about her willingness to give the kidney freely.

Dr. Firmin considered four alternatives when he got back the tissue-typing which indicated an ideal match: tell Mrs. Hamill of the good match; tell Mrs. Hamill of the good match but express a willingness to suggest to her sister that the match was not acceptable; tell Mrs. Hamill that the tissue match was unacceptable; or tell Mrs. Hamill that the match was good but that he refused to perform the transplant at this time because he was not convinced of her willingness to give the organ freely.

* * *

ETHICAL OPTIONS

Carl Fuchs, a 59-year-old truck driver, sits in his living room one night watching television with his wife, Marie, and two daughters. Suddenly, Fuchs becomes dizzy and loses consciousness. The alarmed family fail to revive him, and Marie calls an ambulance. Fuch is taken to the nearest hospital. He has had a subarachnoid hemorrhage, a progressive problem often leading to death. After three days, his EEG reading is flat.

During this time, an aunt of Carl calls Marie Fuchs. The aunt has heard of the tragedy and is very sorry; in addition, she has a very delicate matter to bring up. Her 34-year-old daughter, Carolyn, lost her kidneys at 31 and is now doing badly on hemodialysis. Carolyn hopes for a kidney transplant to restore normal life. Chances are greater with good tissue matches, and such matches are more likely among relatives. Would Marie consider, the aunt asks, a tissue test on Carl to judge transplant possibilities?

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CLASS 8: ALLOWING TO DIE

November 8, 1985

8:00-10:00am

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<u>Case Studies</u>	
1. "Case Study No. 3"	25
2. "Was It Murder?"	26
3. "When Suicide Prevention Becomes Brutality"	27

Required Reading:

1. "To Save or Let Die," by Richard A. McCormick, SJ:
JAMA, Vol.229, No.2, July 8, 1974; pp.172-176.
2. "In the Matter of Claire Conroy," Superior Court of
New Jersey, Essex County, Docket No. P-19083E,
decided February 2, 1983.
3. "The Physician's Responsibility Toward Hopelessly Ill
Patients" by Sidney H. Wanzer, MD, et al. NEJM,
Vol.310, No.15, April 12, 1984; pp.955-959.
4. "The Care of the Terminally Ill: Morality and Economics,"
by Ronald Bayer, PhD, et al. NEJM, Vol.309, No.24,
Dec. 15, 1983; pp.1490-1494.

CASE STUDY NO. 3Chronology of Events:

1. A patient, dying of cancer for six months, is admitted to the hospital for terminal care. There does not seem to be any treatment that will arrest the cancer nor any that would restore him to health. The attending physician has known the patient for only two months, the original family doctor having moved to California.
2. The family of the patient, of modest means, consists of three teenage children and his wife. The doctor overhears them saying that they think it would be a blessing if their father died because it would save them a great deal of money—money that could be used for the children's education.
3. The patient has developed tolerance to drugs and even increased doses of any drug gives only a brief respite from the ever-recurring pain. Because the patient has a strong heart and no other serious maladies, the physician is convinced the patient could continue to suffer for another six to eight weeks.
4. The physician does not believe in mercy killing but he does think that "something should be done" in order to alleviate the man's suffering and save the family's savings. Surveying the situation, he determines that it would ethically permissible to discontinue the intravenous feeding because it is only prolonging death.
5. He suggests this plan to the wife of the patient, who is not sure what to do but is inclined to accept the suggestion since it comes from a physician. The wife agrees with this suggestion.
6. The physician issues the order, stating that intravenous feeding should be discontinued permanently. The nurse on duty does not think this is the right treatment, however, and she reports the order to the hospital administrator. The hospital administrator calls a meeting of the physician, the chief of staff, and the chaplain, seeking to determine what should be done.

* * *

WAS IT MURDER?

Clarence Herbert, a 55-year-old man, went to the Kaiser Foundation Hospital in Harbor City, California, for routine surgery, suffered a cardiopulmonary arrest in the recovery room, was successfully resuscitated but remained in a coma from which he never awakened, and died 11 days later.

Believing that Mr. Herbert's condition was hopeless and influenced by his wife and eight children not to prolong his death by artificial methods, his physicians, Drs. Barber and Nejd1, wrote orders at 42 hours after the cardiopulmonary arrest not to resuscitate or treat heart problems, at three days to remove the respirator, and at five days to remove the IVs.

Another order, not to use an endotracheal misting device after the patient's respirator was disconnected, triggered a loud and violent argument between one of the physicians and a nurse.

The nurse copied all of the patient's charts and went to the authorities, starting a chain of events that brought the case to the nation's attention. The physicians called it mercy, the nurse called it bad medicine, the district attorney called it murder. The prosecutor charged the MDs, the nurse and the widow sued the hospital. Though the physicians were acquitted twice of criminal charges, civil suits for malpractice have been filed against the physicians and the hospital.

Because physicians deal daily with these types of issues, the California case is of great significance. At the same time, the lessons to be learned indicate that none of what is going on in the Los Angeles courts needed to have happened.

* * *

WHEN SUICIDE PREVENTION BECOMES BRUTALITY

Elizabeth Bouvia is a woman who desires to starve herself to death. Cerebral palsy has left her with virtually no motor function in any of her limbs or other skeletal muscles. She retains some limited control over the movement of her right hand (sufficient to operate an electrically powered wheelchair), and enough control over her facial muscles to eat when someone else feeds her and to speak. She has completed a BS degree in social work, has been married for more than a year, has attempted to have a child, and has lived independently with the help of her relatives or a personal care attendant. But within the last year her husband left her, she dropped out of school, and she lost her state assistance for transportation. Realizing that she would never be able to find employment, she concluded that she could never live without almost total reliance on someone else.

On September 3, 1983, she asked her father to drive her from Oregon to the Riverside County General Hospital (she had previously lived in Riverside, was a California resident, and had Medi-Cal) where she arranged for a voluntary psychiatric admission on the grounds that she was suicidal. Her plan was to get admitted to a place where she would "just be left alone and not bothered by friends or family or anyone else and to ultimately starve to death." She had allegedly attempted suicide on at least one, and possibly more, previous occasions. At Riverside she refused to eat solid food. After her attending physician threatened to have her certified as mentally ill and dangerous to herself so she could be force-fed, she phoned the local newspapers in an attempt to get legal assistance.

Short after, the American Civil Liberties Union entered the case, with doctory-lawyer Richard Stanley Scott in charge. He persuaded her to continue to take nourishment while he applied for a court order restraining the hospital from either discharging her or force-feeding her. A hearing on these requested orders was held in December.

At the hearing, Mrs. Bouvia testified that she was no longer willing to live completely dependent upon other people. "I hate to have someone care for every personal need... it's humilitating. It's disgusting, and I choose to no longer do that, no longer to be dependent on someone to take care of me in that manner ... I am choosing this course of action due to my physical limitation and disability."

The chief of psychiatry at the hospital, Dr. Donald E. Fisher, testified that he would force-feed her with a nasogastric tube even if the court ordered him not to. At closing arguments, attorney Scott argued that her decision was "exactly medically and morally analogous to the patient deciding to forego further kidney dialysis." The county argued, on the other hand, that the question was whether an individual had a right to commit suicide in a county hospital, with "the forbearance of the medical personnel."

Appendix

- A. Oath of Hippocrates
- B. Principles of Medical Ethics. (Chicago: American Medical Association).
- C. A Patient's Bill of Rights. (Chicago: American Medical Association) 1973.
- D. Ethical and Religious Directives for Catholic Health Facilities. (Washington, DC: United States Catholic Conference) 1977.

SELECTED READINGS FOR FURTHER STUDY

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COMPENSATING FOR RESEARCH INJURIES, Vol. II: Appendices, 1982.

WHISTLEBLOWING IN BIOMEDICAL RESEARCH, 1982.

DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT, 1983.

DEFINING DEATH, 1981.

IMPLEMENTING HUMAN RESEARCH REGULATIONS, 1983.

MAKING HEALTH CARE DECISIONS, Vol. I, Report, 1982..1982.

MAKING HEALTH CARE DECISIONS, Vol. II, Appendices - Empirical Studies of Informed Consent. 1982.

MAKING HEALTH CARE DECISIONS, Vol. III, Appendices - Studies on the Foundations of Informed Consent, 1982.

PROTECTING HUMAN SUBJECTS, 1981.

SCREENING AND COUNSELING FOR GENETIC CONDITIONS, 1983.

SPLICING LIFE, 1983.

SECURING ACCESS TO HEALTH CARE, Vol. I, Report, 1983.

SECURING ACCESS TO HEALTH CARE, Vol. II, Appendices - Sociocultural and Philosophical Studies, 1983.

SECURING ACCESS TO HEALTH CARE, Vol. III, Appendices - Empirical, Legal and Conceptual Studies, 1983.

SUMMING UP: THE FINAL REPORT, 1983.

ENCYCLOPEDIA OF BIOETHICS, edited by Warren Reich; (New York: The Free Press) 1978. Concise articles around basic ethical issues and principles. Presents general theory and information. Small bibliography for further study accompanies each article.

BIOETHICS REPORTER. Monthly publication containing major articles, research findings, bibliography and legal briefs centered on a particular theme. Theme changes each month. (Available in SLU Medical School Library).

GENERAL STUDIES

- Ashley and O'Rourke, HEALTH CARE ETHICS: A THEOLOGICAL ANALYSIS, Second Edition; St. Louis: Catholic Health Association; 1982.
- Beauchamp and Childress, PRINCIPLES OF BIOMEDICAL ETHICS, Second Edition; New York: Oxford University Press; 1983.
- Childress, PRIORITIES IN BIOMEDICAL ETHICS; Philadelphia: Westminster; 1981.
- Culver, Gert, PHILOSOPHY IN MEDICINE; New York: Oxford; 1982.
- Pelligrino and Thomasma, A PHILOSOPHICAL BASIS OF MEDICAL PRACTICE; TOWARD A PHILOSOPHY AND ETHICS OF THE HEALING PROFESSIONS; New York: Oxford Press; 1981.
- Ramsey, Paul, THE PATIENT AS PERSON; New Haven: Yale University Press; 1970.
- Veatch, Robert, A THEORY OF MEDICAL ETHICS; New York: Basic Books; 1981.

BOOKS OF INTEREST

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Fuchs, Victor, WHO SHALL LIVE: HEALTH ECONOMICS AND SOCIAL CHOICE;
New York: Basic Books; 1974.

Starr, Paul, THE SOCIAL TRANSFORMATION OF AMERICAN MEDICINE; New York:
Basic Books; 1982.

Cranford and Doudera, INSTITUTIONAL ETHICS COMMITTEES AND HEALTH CARE
DECISION MAKING; Boston: Boston: ASLM; 1983

Most articles pertaining to medical ethics appear in various medical journals on a regular basis. In addition, the HASTING CENTER REPORT, dedicated solely to these issues, appears bi-monthly.