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Medical Remedies and Human Rights: Why Civil Rights Lawyers Must Become Involved in Medical Decision-Making

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The physicians are the natural attorneys of the poor and social problems fall to a large extent within their jurisdiction.

Rudolph Virchow, 1848

As recently as the turn of the century a random patient meeting a random physician had less than a 50:50 chance of benefiting from the encounter. Physicians were just beginning to emerge from the era when they were essentially tradesmen, often with little more to offer their patients than comfort and company during illness and death. The principal causes of mortality were the infectious diseases against which the medical community stood impotent. There were few medical schools, few diagnostic tests, no specific treatment of disease, and no specialization of physicians. In the words of former AMA president Dwight L. Wilbur, "It is difficult to accept that physicians of that day and this were even in the same profession."[1]

Medical progress during the past century has brought about a radical change in the doctor's ability to diagnose and treat disease. Infectious disease has all but been conquered and the chronic diseases, such as heart disease, have become the major killers. Hospitals have replaced "pest houses." Medical education has become increasingly demanding and exact. While the technology of medicine no longer resembles that of a century ago, physicians continue to argue that in many other respects the practice of medicine cannot and should not change. The commonest form of this argument is that the "traditional doctor-patient relationship" must be maintained at all costs. In view of the tremendous changes in the content and context of that relationship over the past century, this argument would seem to be of dubious merit. The advantages of maintaining such a "traditional" relationship in theory if not in actual practice are many, however. Account-

1. D. Wilbur, *Let's Lead Rather Than Be Led*, 62 J. TENN. MED. ASS'N. 607 (1970).

ability for actions is likely to be restricted to peer review. Public scrutiny of medical decision-making is likely to be minimal. Autonomy of action is likely to be maximal. Patient-consumer influence on services rendered is not likely to be significant.

It is the major thesis of this short article that lawyers, who in centuries past have abdicated the role of "attorneys of the poor" to the medical profession and others, have an affirmative duty to insert themselves into the medical care delivery system to insure that human rights are not the victims of medical progress. When individuals are sick, dying, or both they are perhaps least able to protect their own rights. Under these circumstances the lawyer's seeming unwillingness to become involved is all the more inexcusable. To help acquaint civil rights lawyers with some of the areas in which their expertise can be helpful to patients and the public at large, this article will initially discuss the reaction of the medical and legal communities to heart transplants. A set of characteristics of traditional medical decision-making that can be used in analyzing particular decisions will then be presented and illustrated with the examples of genetic counseling and care of the dying patient. Finally the questions of why medical decisions are made the way they are, and what the role of the lawyer might be in insuring that human rights do not become the victims of medical progress, are discussed.

The Heart Transplant Experience

Forensic medicine has traditionally concerned itself solely with the medical specialties of pathology and psychiatry. As to the general question of the impact of medical progress on society, lawyers have as a rule seemed satisfied with the view of Chief Justice Warren Burger that the function of the law is to "evolve slowly," to "respond rather than anticipate."[2] In a speech before a group of physicians just months before the first heart transplant Chief Justice Burger noted that "the prime function of

2. W. Burger, *The Law and Medical Advances*, 67 ANN. INTERN. MED. (Supp.) 17 (1967).

the law [is] to protect basic human values—individual human values—sometimes even at the expense of scientific progress."[3] He saw this as consistent with his view that "it is not the function of the law to keep pace with science."[4] The problem is that if the law does not become involved with scientific advances, and begin to anticipate them and plan for them, scientists and medical investigators will tend to ignore the law during their research phase and make the law *de facto* irrelevant to their discoveries and achievements. This ability was dramatically illustrated by the transplantation of a human heart into the body of Louis Washkansky by Dr. Christian Barnard on December 3, 1967.

The heart transplant operation did at least two major things. First it directly contradicted the law's centuries-old definition of death as heart stoppage. Secondly it unleashed a world-wide stampede to join the "me-too" club of transplanting surgeons. The former left the law unclear, the latter demonstrated the inability of the present system to prevent or control human experimentation on a broad scale. More than 100 heart transplants were done in 1968 alone. The desire for fame, publicity and research funds ran far ahead of scientific realities. The fad ended as quickly as it began and there have not been that many heart transplants performed in the four years since 1968. The experience, however, did at least raise vital social issues in public forums. For example, the potential impact of transplants on medical resource allocation was mammoth. The cost of the average transplant exceeded $25,000 and Lee Boyd's 16 additional months of life under the care of Houston's Dr. Denton Cooley cost $160,000.[5] Since ideal donors were those who were healthy at the time of death, the preferable donor was young and the victim of a violent brain-damaging accident that left the heart beating and intact. Such transplants required a new definition of death and permission of the next of kin. The medical profession did not take long to redefine death in terms of brain function.[6] In this area the doctors felt secure.

3. *Id.* at 18.

4. *Id.* at 16.

5. T. Thompson, HEARTS 198 (1971).

6. *A Definition of Irreversible Coma: Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death*, 205 J.A.M.A. 337 (1968).

In obtaining the consent of the next of kin, on the other hand, many called upon the legal profession for assistance. One was Dr. Francis D. Moore of Boston's Peter Bent Brigham Hospital:

> In seeking the donation of lung, liver, heart, eye or kidney from a recently deceased person, the time/temperature curve begins its inexorable demands the moment circulation has ceased. Every minute spent in seeking permission from each responsible relative, or in telephoning across the country, means a million dead cells. . . . *Here is a field where we need help from legislators and lawyers,* so that previous intent of the patient, his family and his next of kin, may remain binding after death.[7]

Legislators and lawyers rushed to help and the Uniform Anatomical Gift Act was quickly passed in one form or another in over 40 states.[8] The experience was another illustration of two facts: (1) that the medical profession calls upon lawyers only when no other way out of a problem can be seen, and (2) that the legal profession's method of quickly responding to medical progress after the fact ensures that the profession will have no influence in shaping the form or the application of scientific advances.

These problems did not go completely unnoticed. In 1968 Senator Walter Mondale introduced legislation to create a National Advisory Commission on Health, Science and Society "to consider and study the ethical social, and legal implications of advances in biomedical science and technology."[9] While hearings were held on the proposal, the measure never reached the Senate floor. On March 24, 1971 the measure was reintroduced as S. J. Res. 75, but to date no action has been taken on it.

On the academic front reaction was both more positive and more promising. Under the sponsorship of the Ford Foundation, Daniel Callahan established the interdisciplinary Institute of So-

7. F. Moore, GIVE AND TAKE: THE DEVELOPMENT OF TISSUE TRANSPLANTATION 137-138 (1964). [Emphasis supplied.]

8. J. Waltz & F. Inbau, MEDICAL JURISPRUDENCE 220 (1971).

9. 117 *Cong. Rec.* S3708 (daily ed. March 24, 1971) (remarks of Sen. Mondale).

ciety, Ethics and the Life Sciences in Hastings-on-Hudson, New York. The group is currently concentrating its research efforts in the areas of population control, genetic engineering, death and dying, and behavior control. In Boston the March of Dimes provided funds to Boston College Law School and Tufts Medical School to form the more specialized B.C.-Tufts Joint Center for the Study of Law, Medicine, and the Life Sciences. This group has recently expanded its interests into the area of medical ethics and decision-making generally. The Joseph P. Kennedy, Jr. Foundation has given grants to establish a Center for the study of Bioethics at Georgetown University and an Interfaculty Program in Medical Ethics at Harvard University. Both are primarily concerned with teaching. While all these programs are heavily interdisciplinary, only the two smallest, those at Boston College and Harvard University, have had consistent and strong legal inputs.

To summarize, we have a medical system that has undergone rapid technological change but which clings to an archaic model of a "traditional doctor-patient relationship." Beside this medical system, we have a legal system that clings to the age-old common law notion that the law must "react slowly" to change rather than help to shape it. Reality, as daily illustrated in clinics and hospitals, has made the doctors' view as untenable as that of the legal profession. As the first heart transplant illustrated, an unprepared legal profession will not "react slowly" but will either react in the "knee-jerk" manner of the Anatomical Gift Act legislation, or in the epicene bystander manner illustrated by the mass human experimentation involved in the 100 heart transplants that followed. There must be a better way. It is suggested that one way is for lawyers to become involved in the initial stages of medical decision-making, both on an individual patient and societal level. Lawyers, who have in the past been called on only to solve problems after they have developed (e.g. to pass remedial or enabling legislation or defend malpractice actions) must get involved

where the action is—at the decision-making level. One way lawyers can be of assistance to both their clients and society at this level is to identify and expose some of the inherent problems and assumptions in such decision-making. It is in this context that the study of "medical ethics" becomes a legal pursuit. It is a subject that is too important to be left to the academics.

Characteristics of Traditional Medical Decision-Making

The study of medical decision making has come to be called "medical ethics." "Medical-ethical" problems tend to be concentrated at birth and death, the most spectacular events in human life. While illustrations will later be drawn from these temporal poles, the medical decisions that affect us on a day to day basis, like physician availability and amphetamine prescription, may be at least as critical to human rights and certainly demand the lawyer's attention.

Apparently one reason lawyers have not become involved in medical decision-making is that both they and their potential clients are unsure of how to approach the area analytically and thus how to determine when legal intervention is appropriate. It is tentatively suggested that, by viewing a medical decision from the vantage of the following five traditional characteristics, one can decide how much a third party, either a lawyer or other skilled advocate, is needed to protect the interests of the patient, society, or both. In general it can be said that as the number of these characteristics in a decision making context increases, so does the need for legal intervention of some sort.

Table 1

Traditional Characteristics in Medical Decision-Making

1. Ambiguous identification of the decision-maker.

2. Ambiguous identification of the person or entity that commands the decision-maker's loyalty.
3. Control of pertinent medical information by the attending physician.
4. Lack of reporting or review of the ultimate treatment decision.
5. Justification of the decision on the basis of public policy.

There is no claim that this list is either complete or absolute. The only claim is that by using this list as a starting point or checklist the attorney can ask questions that will help to define what actions need to be taken to insure that the decision involved will be in the best interests of his client or clients. Indeed, these traditional characteristics can be re-stated as questions. For example, when a lawyer is representing a patient he must know: 1. Who has the power to make a treatment decision? 2. Where do the decision-maker's loyalties lie? 3. Who controls the pertinent information? 4. Is there any reporting or review of the treatment decision? If so, by whom? 5. On what basis is the treatment decision justified? If not on the basis of the welfare of the patient, whose welfare? If society's, how can this be justified? On a broader basis, using this checklist and viewing society as the "patient," one can begin to analyze legislative proposals in a way that can spotlight potential human rights problems.

The strategy is for the lawyer or "patient advocate" to enter the decision-making process before a "wrong" has been done. Just as preventive medicine produces the most for the money, so this type of "preventive law" should yield more benefits than medical malpractice actions. The types of questions and issues raised by use of the checklist can be illustrated by taking examples from both ends of the life cycle: prenatal genetic counseling and care of the dying.

ILLUSTRATIVE CASE ONE

Amniocentesis: Prenatal Genetic Screening

Amniocentesis is a method used to detect genetic defects in the fetus. A portion of the amniotic fluid is removed sometime after the 15th or 16th week of pregnancy. This fluid is then cultured to determine genetic characteristics of the fetus. Culture and analysis takes between 4 and 6 weeks. Currently only about 40 of the over 1600 known genetic defects can be prenatally diagnosed by amniocentesis. Among these is the relatively common Down's Syndrome or mongolism, the genetic defect which has elicited the most comment in relationship to amniocentesis.[10] In a typical case a woman will seek to have this procedure done if she has a "high risk" of giving birth to a genetically defective child. For example, the procedure is generally recommended for women over 40 who run a "high risk" (about 1 in 50) of giving birth to a child with Down's Syndrome. The philosophy of amniocentesis is one of preventive medicine. The goal is to prevent the birth of children with genetic defects. Thus most doctors will not recommend the procedure for a woman who refuses to agree in advance to have an abortion if the result is positive for the defect sought. The trend seems further to be to implant or reinforce the idea in the parents' minds that they have a "right" to have healthy children and that they should not settle for anything else.

Referring to the checklist, we initially want to determine who is making the decision. Is it the doctor who defines what is "medically indicated," the woman who is given "the right to control her own body," the couple whose potential child is involved, or society which encourages the institutionalization of the genetically defective? The answer, of course, may vary from case to case. The second question can be phrased as "who is the patient?" It is certainly not the fetus for whom the "treatment" is abortion. It can be argued it is the mother, the family unit, the existing children, or society. Most doctors would probably argue that "the proper therapy is for the family."[11]

The third characteristic is information control.

10. *See Symposium on Intrauterine Diagnosis*, 7 BIRTH DEFECTS No. 5 (1971).

11. J. Littlefield, *The Pregnancy at Risk for a Genetic Disorder*, 282 NEW ENG. J. MED. 723 (1969) [hereinafter cited as Littlefield].

How much should the doctor tell? How far should he go in informing the parents of what can and cannot be done for children born with the diagnosed defect? If a defect not looked for, like the XYY chromosome (which may or may not be related to antisocial behavior), is identified, should the parents be informed, since in their quest for genetic purity parents may elect abortion for harmless or relatively minor defects? As Dr. Aubrey Milunsky of the Massachusetts General Hospital's Genetic Unit has noted, all the parents in his experience who had fetuses diagnosed as having any genetic abnormality at all, whether its significance was known or not, elected abortion.[12] The point is that by controlling the information in this case, the doctor-counselor controls the ultimate decision. The decision to abort must be made soon after diagnosis, since the earliest diagnosis will probably not be until about the 22nd week of pregnancy. Thus there is no time to have another test run for confirmation, and no opportunity for any meaningful review of the abortion decision—the fourth characteristic.

The fifth characteristic is illustrated by a statement of perhaps the leading spokesman for the procedure, Dr. John W. Littlefield, Chief of the Genetics Unit at the Massachusetts General Hospital, who justifies the procedure on the basis of a public policy to control population growth.

> The world no longer needs all the individuals we are capable of bringing into it—especially those who are unable to compete and are an unhappy burden to others. If the size of our families must be limited, surely we are entitled to children who are healthy rather than defective.[13]

Before going on to the second illustrative case one possible future use of amniocentesis should at least be mentioned. In 1971 the Massachusetts legislature passed a law making sickle cell testing of black children a prerequisite to attending elementary school.

12. Radio broadcast, WEEI, Boston, Mass., March 19, 1972. *Cf.* A. Milunsky, *Prenatal Genetic Diagnosis*, 283 NEW ENG. J. MED. 1370 (1970); C. Leonard, *Genetic Counseling: A Consumer's View*, 287 NEW ENG. J. MED. 433 (1972).

13. Littlefield.

Scientists believe that they are close to being able to identify sickle cell trait and disease through amniocentesis.[14] Currently genetic counselors are advising black couples who both have the recessive trait not to have children and single blacks with the trait not to marry a person with the trait (marrying a white is a simple but seldom suggested "solution"). Is it too soon to begin to consider the possible consequences of a legislative proposal to require all black couples with sickle cell trait to undergo amniocentesis and abortion on a positive finding in the name of "public health"?[15] Preventive legal action may now be the only thing that can stop the move to make such a measure an accepted form of "preventive medicine."[16] The applicable characteristic would again be justification of a medical measure on the basis of public policy, and appropriate legal intervention would be at the legislative level.

14. Y. Kan, *Detection of the Sickle Gene in the Human Fetus*, 287 NEW ENG. J. MED. 1, 1-5 (1972).

15. *Cf.* H. Kazazran, *Antenatal Detection of Sickle-Cell Anemia*, 287 NEW ENG. J. MED. 41, 41-42 (1972).

16. *Cf.* F. Hecht & L. Holmes, *What We Don't Know About Genetic Counseling*, 287 NEW ENG. J. MED. 464, 464-465 (1972).

ILLUSTRATIVE CASE TWO

Treatment of the Dying

Almost 80% of Americans now die in hospitals or nursing homes. A doctor will thus be involved in some way in the deaths of almost all of us. In the typical case a person will be admitted to the hospital with terminal cancer or with a heart condition. The doctor will have some tests performed and make a diagnosis and prognosis. If the prognosis is "terminal," the doctor is dealing with a dying patient. Medical decisions made in this context can be analyzed by use of the "checklist."

The first problem is to define the decision-maker. In this case it might be the patient, if the doctor explains the options to him fully, but could be the patient's spouse or family, the doctor, or even "society" in the form of an insurance policy that limits the type of care. The "patient" could be the dying person, but the doctor may well owe primary loyalty to and be "treating" the family—who will after all survive to be future patients and who will probably be

paying at least part of the bills of the dying person. It could also be the hospital that needs the bed or society who the doctor believes should not be wasting money or keeping "dead" people "alive."

The third characteristic, information control, is extremely important in this situation. While the limited studies done on this subject can by no means be considered invulnerable, they indicate that about 90% of all patients desire to know if their diagnosis is terminal,[17] while between 60% and 90% of all physicians prefer to withhold a diagnosis of a terminal illness.[18] Also, while doctors steadfastly refuse to disclose even routine diagnosis and treatments on the basis of a confidential "doctor-patient relationship," these same studies show that in the case of a dying patient the doctor as a rule communicates almost exclusively with the patient's family concerning the patient's condition. The "terminal" or "dying" label is seen not only as justification for denying the patient's right to privacy, but it also drastically limits his ability to give "informed" consent to his treatment.

No consent to treatment can, of course, be informed if the patient giving it does not know that his doctor considers his condition terminal. The patient then becomes the unwilling participant in a medical experiment. By controlling information the doctor can usually get the patient to agree to almost anything depending on the way he phrases it. The possibilities for abuse can be illustrated by a highly respected British study of the effect of cholesterol on the survival rate of persons who have suffered one myocardial infarction. The doctors randomly divided their patients into two groups: one ate an ordinary diet, the other substituted a diet low in saturated fats and containing an 85 gram glass of soya-bean oil daily. All participants were in the study at least 2 years. The doctors reported that "a high degree of cooperation was achieved." While there is no indication in the study report of exactly what was said to the 199 patients in the experimental group, cooperation from a

17. J. Aitken-Swan & E. Eassen, *Reactions of Cancer Patients on Being Told Their Diagnosis*, 1959 BRIT. MED. J. 783; C. Branch, *Psychiatric Aspects of Malignant Disease*, 6 BULL. CANCER PROG. 102 (1956); W. Kelly & S. Friesen, *Do Cancer Patients Want To Be Told?*, 27 SURGERY 825 (1950); R. Samp & A. Currieri, *Questionnaire Survey on Public Cancer Education Obtained from Cancer Patients and Their Families*, 10 CANCER 382 (1957).

18. W. Fitts & I. Ravdin, *What Philadelphia Physicians Tell Patients with Cancer*, 153 J.A.M.A. 901 (1953); D. Oken, *What To Tell Cancer Patients*, 175 J.A.M.A. 86 (1961); D. Rennick, *What Should Physicians Tell Cancer Patients*, 2 NEW MED. MATERIAL 51 (1960).

person told, "we're running this experiment to see if not eating meat will increase your chances of survival—we have no reason to believe it will, but we would like you to drink vegetable oil for the rest of your life and not eat meat," will be less likely than from one told, "You've had a serious heart attack—I am putting you on a strict diet to prevent your having another." From the study the doctors learned that this type of diet does not significantly influence recovery or relapse rate.[19] The cost in terms of loss of control over their diets and bodies on the part of the experimental group cannot be known or measured.

The problem, of course, is the potential for abuse and undue influence that absolute control of information brings with it. While this potential has spawned the research review committees now present in most hospitals, their impact on the treatment of individual patients is probably not great. Moreover many physicians continue to believe that what is needed in research situations like the one described is not someone who will insure that the patient is fully informed about what is being done to him, but a scientific committee that monitors the study to determine when the results are good enough to stop the study and treat all participants in accordance with the protocol that has been found most effective.[20] Needless to say, this is not what an attorney would consider an adequate "patient advocate." Dr. Franz J. Ingelfinger, editor of the *New England Journal of Medicine,* makes a persuasive argument that the legal concept of informed consent has little meaning in a hospital setting and that therefore "the subjects' only real protection, the public as well as the medical profession must recognize, depends on the conscience of and compassion of *the investigator and his peers.*"[21] Such "protection" is simply insufficient to protect the human rights of patients.

The fourth characteristic is the lack of reporting and review of decision-making. In this case

19. RESEARCH COMMITTEE, MEDICAL RESEARCH COUNCIL, *Controlled Trial of Soya-Bean Oil in Myocardial Infarction,* 1968 THE LANCET 693.

20. *E.g.,* T. Chalmers, *Controlled Studies in Clinical Cancer Research,* 287 NEW ENG. J. MED. 75, at 75-78 (1972).

21. F. Ingelfinger, *Informed (But Uneducated) Consent,* 287 NEW ENG. J. MED. 466 (1972). [Emphasis supplied.]

there is seldom any reporting to anyone and the treatment is seldom reviewed unless the death is seen to have been "unusual" or "preventable." In this latter case a special committee of the hospital may meet in closed session to discuss the case. Such a session, however, is said to be for internal educational purposes only. No records are kept and disciplinary action, if any, is rare. Again we are left with the private malpractice action as the only meaningful form of accountability.

The last characteristic, justification of decisions on the basis of public policy, is also present. It can be illustrated by the doctor who refuses to be "heroic" or use "extraordinary means" to prolong the life of an elderly patient and justifies inaction with the statement that the patient "will die soon no matter what is done."[22] The rationale seems to be that it is a waste of time, effort, and society's scarce medical resources to squander them to postpone the inevitable for a few hours, days or weeks. It is paradoxical in this context that the great advances in medicine's ability to deal with disease and delay death have simultaneously increased the medical profession's ability to practice "negative euthanasia" by withholding new life-saving techniques and machines. In all of this we are again left with private decisions based on "public policy" with no apparent public accountability or social warrant.

22. E. Cassell, *Treating the Dying—The Doctor vs. The Man Within the Doctor*, MED. DIMENSIONS, March, 1972, at 7.

Why Most Medical Decision Making Continues to Exhibit the Traditional Characteristics

Since formal courses in medical ethics or medical decision-making are almost non-existent, most doctors learn decision-making by observation during their clinical training. The problem with this time-honored method of learning decision-making the same way one learns surgery is that decision-making is not a subject that can be learned exclusively by observation. Circumstances vary, and the interests to be

considered in deciding upon an operation may vary even when the medical indications remain constant. Emulation is also unlikely to be successful when the major "ethic" of medicine is that all ultimate decisions regarding treatment should be left in the exclusive hands of the treating physician—a throwback to the days when medical ethics meant medical etiquette, and it was "unethical" to criticize the decisions of another doctor. This is because a doctor's decision in a specific case might vary depending upon many individual factors such as religion, age, specialty, and perception of the family's wishes. The result is predictably a patchwork.

The Hippocratic Oath, based on Pythagorean theory, cannot, of course serve in dealing with modern problems like amniocentesis and EEG-measured brain death. The AMA's "Principles of Medical Ethics" was never meant to be a decision-making tool and affords little aid. In the words of Dr. Eric J. Cassell of Mount Sinai School of Medicine, "Guidance and experience are considered necessary in making difficult clinical decisions, but in these decisions [involving life and death]—the most difficult of all —most of us have had little guidance and less training."[23] This pattern of peer emulation followed by limited peer review is not an altogether satisfactory method of decision-making when individual rights are affected and public policy arguments are used to justify private medical actions. Nor is the medical profession unaware of public discontent. While the AMA continues to insist that "only doctors are entitled to check on other doctors' performance,"[24] there is evidence of an increasing interest on the part of many physicians to openly discuss their problems in decision-making with members of other professions and disciplines.[25] It is essential to good medical care that lawyers get involved in these discussions as often as the opportunity arises and begin to take the initiatives to make sure the dialogue grows.

23. *Id.*

24. TIME, July 3, 1972, at 34.

25. For example, under the direction of Dr. Melvin Levine, an interdisciplinary group has been studying medical decisions on a weekly case-by-case method at the Children's Hospital Medical Center, Boston. The reception by the medical community has been enthusiastic.

Are Human Rights and Medical Remedies Compatible?

In a society that values both human rights and medical progress, it should be disturbing to civil rights lawyers that the most eloquent voices raising this question come not from the bar but from the scientific community itself. For example, the strongest warnings concerning possible societal implications of "cloning," or duplicating indefinitely the genotype of individual humans, come from Nobel laureate, Dr. James Watson. In one of his statements he argues that the public must get involved and possibly prohibit some forms of experimentation altogether:

> Some governments, upon thoughtful consideration, might wish to ban certain manipulations (e.g. human cloning). But in other cases, there may be general agreement that certain procedures (e.g. test-tube conceptions to overcome infertility due to oviduct blockage) are in the *national interest* and should be actively promoted. In any case, I think *the matter is too important to be left in the hands of scientists whose careers might be made by the achieving of a given experiment.*[26]

Another scientist, Dr. Philip Handler, head of the National Academy of Sciences, has called for a national policy of eliminating defective, unborn babies, to protect the genetic pool of mankind.[27] The rationale Dr. Handler put forth was the "quality of life." Thus we have men of science calling upon society to formulate public policy in the form of legislative action either to prevent further research in potentially dangerous areas or to utilize current knowledge and techniques on a massive scale for social ends.

Civil rights lawyers have a duty to define the implications of scientific developments for the individual and society. If legislation is thought to be desirable, it must be carefully drawn. Testimony on all such biomedical legislation should

26. J. Watson, Washington Post, Feb. 24, 1971, (Letters to the Editor), at 12, col. 3. [Emphasis supplied.]

27. Boston Globe, Oct. 22, 1971, at 1, col. 1.

include projections of the human rights implications. In this country legislation designed for an ostensibly public health purpose often sails through the state legislatures with little or no opposition. In less than two years in the early 1960's, for example, 41 states passed laws making the testing of infants for Phenylketonuria (PKU) mandatory under the pressure of a group of scientists and interested citizens. One study has concluded that "there is no convincing proof" that this mandatory testing has, in the aggregate, been of public health benefit.[28] One of the problems noted by the authors was that no one had the responsibility of informing legislatures of the true state of knowledge regarding PKU.

28. S. Bessman & J. Swazey, *Phenylketonuria: A Study of Biomedical Legislation*, HUMAN ASPECTS OF BIOMEDICAL INNOVATION, 49, at 49-76 (1971).

As for individual patients, the time is long past for civil rights lawyers to begin to study the medical decision-making process to see what, if any, due process safeguards should be added to it to protect the interests of the individuals involved without hampering medical progress or the delivery of high quality medical care. Among the ideas that merit discussion is the concept of a "patient representative"—a person to whom the patient can go with complaints, get action from on a broad range of problems (both in and out of the hospital), and have represent his interests in clinical conferences and other complex medical decisions. While "advocacy" seems to be the magic word these days —from "child advocates" to "patient advocates"—the magic is not in the name but in function and performance.

Some efforts have been made with similar programs in mental institutions, but all of these programs are too new to be judged successes or failures, and experimentation with a number of approaches is probably most advisable. Another possibility is to provide all patients entering any health care institution with a "Patient's Rights Handbook" or pamphlet (analogous to a *Miranda* card) setting forth their rights as patients and the name of a person or organization they can call for assistance if they have

problems or questions. Some patients would feel more secure if they could have a friend or relative in the operating room with them or have the operation video taped. Perhaps this should be a patient "right." Under Medicare Regulations "utilization review" is in the exclusive hands of committees of physicians and health professionals. Perhaps consumers should be added to these and similar committees. Law suits might be brought to challenge regulations that fail to provide for consumer membership on medical committees that deal with patient care. This list could be expanded almost indefinitey.

Two major limitations inherent in any proposal to modify the current medical decision-making process need to be considered. The first is what Professor William J. Curran of the Harvard School of Public Health terms the need for "the development of a more effective 'public philosophy' . . . in the field of medical ethics."[29] The other is the lack of sound empirical data concerning exactly how medical decisions—which usually turn out to be a series of decisions—are made. While these limitations should not inhibit experimentation with various ways of introducing due process into the medical decision-making process, it is a "go slow" signal. Studies are currently underway to attempt to validate or invalidate current "impressionistic" descriptions of decision-making.[30] Whatever their results, society can only serve itself by becoming more involved with medical progress, medical institutions, and the medical profession. Without such involvement society's interests in this area will continue to be defined by the opinions of individual doctors (hardly a representative profession), and the possibilities of introducing due process into medical decision-making will be greatly reduced. It is up to civil rights lawyers especially to become knowledgable enough about medical decision-making to be able to work with doctors toward what must be a common goal: insuring that human rights do not become the victims of medical progress.

29. W. Curran, Letter to the Editor, 287 NEW ENG. J. MED. 569 (1972).

30. *E.g.*, At Children's Hospital in Boston under the direction of Dr. Melvin Levine and at other hospitals in Boston under the direction of Prof. William J. Curran, both as part of the Harvard Inter-Faculty Program in Medical Ethics. The B.C.-Tufts Center for the Study of Law, Medicine, and the Life Sciences is also planning a study of medical decision-making by committee.