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LEGAL PERCEPTIONS AND MEDICAL DECISIONMAKING

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TABLE OF CONTENTS

THE LAW/MEDICINE RELATIONSHIPSHIP	2
HEALTH PROFESSIONALS' PERCEPTIONS OF THE LAW	6
Differing Perceptions of the Law	6
Physicians and Nurses	6
Other Professionals Whose Views Affect Perceptions	11
Influence of Delivery Setting	14
Sources of Perceptions	18
Medical Education and the Legal Community	18
The Professional and Popular Media	22
Uncertainty in the Law	26
Myths About the Law	30
The Myth of Simplicity	31
The Myth of Intrusion	32
The Myth of Unreasonableness	35
The Myth of Inflexibility	39
The Myth of Lethargy	40
INFLUENCE OF MEDICAL DECISIONS ON PERCEPTIONS ABOUT THE LAW	42
Physicians' Responses to Perceptions of the Law	42
Inconsistencies Between Law and Medical Practice	44
POLICY ISSUES	50
Alternatives to Court	50
Potential for Federal Legislation	55
REFERENCES	62

LEGAL PERCEPTIONS AND MEDICAL DECISIONMAKING

In March 1983, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (hereinafter referred to as President's Commission) transmitted to the President and Congress a report entitled Deciding to Forego Life-Sustaining Treatment: Ethical, Medical, and Legal Issues in Treatment Decisions. In his cover letter, Commission Chair Morris Abram stated (President's Commission, 1983):

Although our study has done nothing to decrease our estimation of the importance of this subject to physicians, patients, and their families, we have concluded that the cases that involve true ethical difficulties are many fewer than commonly believed and that the perception of difficulties occurs primarily because of misunderstandings about the dictates of law and ethics. Neither criminal nor civil law precludes health care practitioners or their patients and relatives from reaching ethically and medically appropriate decisions about when to engage in or to forego efforts to sustain the lives of dying patients.

Nonetheless, misperceptions of the law persist, influence medical decisionmaking and action, and often have a negative impact on the care of dying patients, especially the elderly. Undue concern with imagined legal requirements and consequences may cause physicians to neglect or disvalue other, seriously significant factors that should figure prominently in the calculus of withholding or withdrawing life-sustaining treatment. Hence, this sort of approach is likely to yield neither an optimum decisionmaking process nor the "best" substantive decisions (Annas, 1981; Burt, 1981; Kapp, in press; Rothenberg, 1982).

This paper examines the influence of legal perceptions on medical decisionmaking, focusing on care concerned with life-sustaining technologies and the elderly. The extent of this influence, the accuracy of the medical community's legal perceptions, and reasons for misperceptions are discussed. Potential Federal policies for addressing this important topic are identified.

THE LAW/MEDICINE RELATIONSHIP

Traditionally, law and medicine have not had an antagonistic relationship. Rather, the relationship has been fundamentally a symbiotic, mutual, and cooperative one (Kapp, 1985b). In fact, the medical profession has aggressively co-opted the legal system over the years and used the law's authority to serve its own ends. Illustrations of this interaction include the medical profession's traditional power to determine for itself the standards of care to be applied in a malpractice action, the standards of information disclosure that constitute informed consent, and licensure/discipline standards for determining who is allowed to be part of the medical profession. The role of government in influencing such standards has historically been negligible.

Today, however, both attorneys (Kapp, 1985b) and physicians (Stone, 1985) perceive that the traditional symbiotic law/medicine relationship is under challenge, for a variety of reasons. The law is both a product of, and a contributor to, myriad other social forces that help to bring about the present tension.

First, authority in our society is no longer automatically accepted by everyone. There is a new-found expectation of, and demand for, the public accountability of professionals, both collectively and individually. The medical profession is no exception.

A second factor exerting pressure to reexamine and redefine the law/medicine relationship is the civil rights movement. Beginning with a narrow focus on racial justice, this movement succeeded in creating a mind-set that led to a more expansive generalization of rights. This notion of the value of personal rights spread eventually to health care, in terms of both broad "patients' rights" and particular, identifiable groups of health care consumers such as the handicapped or elderly. In the realm of health care, as elsewhere, people today have gone from marching in the streets to marching through

the legislatures, administrative agencies, and courts.

Third, consumerism as a movement has progressed beyond Ralph Nader and specific cases to a more general rejection of unbridled professional dominance. The doctrine of caveat emptor has been substantially weakened, as witnessed by, for example, the proliferation of "second opinion" programs. The patient is now called a "client" or "consumer" and is no longer a passive part of a unilateral transaction. The physician/patient relationship today approaches more of an equal partnership.

Finally, government and public funds have become involved in the social financing of health care, especially in the last 20 years, through entitlement programs such as Medicare and Medicaid. This development has given the public an immediate financial stake, as well as an equally real but less tangible ethical interest, in the rights of patients within the health care system, in the access of persons to health care, and in societal control over the system's costs. This stake has compelled the legal system to become actively involved in surveillance of the quality of health care that is purchased with taxpayers' dollars.

Until relatively recently, the main focus of medicine in the United States was on the control and cure of acute, episodic medical problems, such as infectious diseases. Most patients got sick, were treated, and either got better or died quickly. Today, concern for acute medical problems, such as heart attacks or traumatic injuries, is still an important component of medical care. However, advances in medical technology and the aging of the population (a related trend) are slowly shifting some of the emphasis in contemporary medicine from acute to chronic, long-term problems and their care. Many patients now have significant medical difficulties (such as hypertension or other heart disease, cancer, or pulmonary disease) that persist and require medical attention over a long period of time. The medical profession is still learning how to expand from an exclusively acute orientation to include a concern for chronic disabilities as well.

In addition, several age-related illnesses (e.g., Alzheimer's disease and other forms of dementia) diminish mental capacity. These deficits often make medical decisionmaking more difficult and strain further the medicine/law relationship.

A related phenomenon is the advent of "halfway" technology. Technologies have been developed that can keep alive certain patients who previously would have succumbed, but that often are not capable of curing these individuals or restoring them to normal functional status. Ventilators, artificial means of feeding, and sophisticated antibiotics are well-known examples. The result is a sizable number of patients who exist in a status of mental and physical "limbo," neither dead, on one hand, nor healthy and able to participate fully in life, on the other hand. Although this phenomenon is not age-related per se, many of the patients who occupy this middle status are elderly.

Nonetheless, as technological developments have occurred and become publicized, the demand for the use of such life-sustaining technologies has grown among physicians and the public alike. One explanation for the popularity of "high-tech" medicine is the "technological imperative," the (often unconscious) philosophy that simply because a particular technology exists, it must be used. Put differently, there is a reluctance to permit technology that has been developed at great cost and effort to ever sit idle. Another explanation is that it is impossible to predict accurately when sophisticated technological interventions will be successful not only in keeping the patient alive but in restoring the person to some degree of meaningful functional capacity. There is a strong presumption toward applying fully any available technology that holds any potential for benefiting a patient.

The combination of an aging population and advances in medical technology has had an enormous impact on increasing total health care costs in the past 20 years. Providing more units of more sophisticated (as well as routine) care has resulted in an ever-larger public and private economic investment in the health care industry. A concerted effort

is under way in this Nation to attempt to curb excessive health care spending, through, for example, reimbursing hospitals prospectively for Medicare patients under a diagnosis-related group formula. But increasing quality for increasing numbers of older, sicker patients costs a great deal. The delicate cost containment/quality balance carries the potential for further challenging the medicine/law relationship.

All the changes arising out of demographic and technological trends have affected the modern relationship between medicine and law. They have raised new substantive medicolegal questions, and fostered new legal approaches or processes to address them. There was no need to determine the appropriateness of withholding or withdrawing life-sustaining technologies such as ventilators, feeding tubes, and antibiotics when these technologies did not exist. There was no need to determine the legal status of a person with irreversible cessation of brain activities but artificially maintained breathing and heartbeat at a time when most patients either clearly died or clearly recovered. There was no need to agonize over forcing hemodialysis on a demented, unwilling patient before that technology became available (and before the aging of the population contributed to so many patients falling into that category).

We have new legal issues because we have options today that previously did not exist; our modern medicolegal dilemmas are largely the product of our successes. It is not that the law today intrudes into matters that were previously resolved privately; the law gets involved today in many matters that formerly did not come up at all and therefore did not need to be resolved, privately or publicly.

Thus, medicine and law are more closely intertwined than ever before, particularly regarding issues of life-sustaining technologies and the elderly. How this intertwining is perceived will largely determine whether it acts as a positive or negative force in making and acting on decisions.

HEALTH PROFESSIONALS' PERCEPTIONS OF THE LAW

Differing Perceptions of the Law

Physicians and Nurses

Physicians fear liability for civil suits or criminal charges. Rising malpractice settlements and insurance premiums in the 1980s have increased physicians' concern about malpractice suits. Articles entitled "Diary of an Unfounded Malpractice Suit" (Riccardi, 1985), "Who Can Sue You for Not Rendering Care" (Horsley, 1984), and "How a Lawyer Decides Whether to Sue You for Malpractice" (Rheingold, 1985) convey this sense of fear and threat. Physicians worry that plaintiffs' attorneys can bring suits, even if there have been no medical or ethical mistakes.

Criminal liability for withholding life-sustaining treatment also concerns caregivers. In 1982, two California physicians were charged with first degree murder after discontinuing mechanical ventilation and intravenous fluids on a patient who remained comatose after a cardiac arrest (Barber and Nejd v. Superior Court of the State of California, 1983; Lo, 1984). The family had asked that this treatment be withdrawn. These unprecedented criminal charges were dismissed by a court of appeals. But many physicians feared that they could face similar criminal charges, even if they follow ethical and medical guidelines.

Concerns about criminal liability may persist even though such prosecutions are extremely rare and would be unlikely to succeed (Green, 1984; Oakes, 1982). Even a slight risk of criminal charges, with adverse publicity and stigma, may influence physician behavior. Physicians' worries increase when district attorneys make such statements as: "Take away food and water and I'll prosecute to the fullest" (Ginex,

1982). Later, after attending a medicolegal conference, this prosecutor said that he had changed his mind. But such incidents may only reinforce physicians' fears that the law is inconsistent and that lawyers are uninformed about life-sustaining treatment. Resulting perceptions may compel the provision of medically futile, purposeless treatment to a dying patient, or might lead to maintaining someone on artificial life-support systems even after brain death has been clinically observed, until a court order for treatment cessation has been obtained.

Some physicians believe the law impedes good medical care for patients. Doctors who feel that they make complicated life-and-death decisions under great time pressures may resent having their decisions later second-guessed by judges and lawyers. Some physicians understandably doubt that judges and lawyers can make good decisions about patient care, because the legal system seems too slow for the exigencies of these situations. When decisions are appealed, maximal care is usually continued, and patients often die during the appeals process. The most forceful expression of such physician hostility toward the law was an editorial in the prestigious New England Journal of Medicine concerning the Saikewicz case: "To judges, in Massachusetts or elsewhere, who believe that the judiciary should routinely take responsibility for life-or-death decisions in the incompetent terminally ill patient, I respectfully suggest a guided visit to a large acute-care hospital, particularly to the pediatric and adult intensive-care units, where they can take sober cognizance of the numbers of urgent and complex medical problems that would have to be adjudicated in their courts" (Relman, 1978). An experienced and respected health care lawyer has also warned of the intrusion of law into medical practice: "Few trial court judges regard their role as necessarily positive, either for the patient or the legal process.... Our legal system, with all of its very positive virtues, cannot replace the more intimate struggle among those caring for the patient and those who care about the patient, to resolve many of these questions" (Rothenberg, 1982).

Physicians are often antagonistic toward judges and lawyers as well. They blame judges for rulings that undercut physicians' ability to practice medicine. Similarly, they blame plaintiffs' lawyers for bringing unfounded civil suits. Such hostility by physicians toward another profession may be an attempt to assign blame for their own decreased autonomy and authority. Although the rhetoric is phrased in terms of benefiting the patient, an underlying issue may be loss of control and power by physicians, or even economic gain by the continuation of services.

The apparent inconsistency in the common law often confuses physicians. As discussed later in this paper, case decisions in different States about life-sustaining treatment may be susceptible to different interpretations on such issues as whether physicians and families of incompetent patients can decide to withhold such treatment without going to court. Furthermore, the common law is unavoidably uncertain in the mediolegal sphere, as in other areas. If the clinical circumstances of a case differ from the situations in previously decided cases, physicians cannot be sure that the previous rulings apply. In addition, in some states there are no test cases and therefore no precedents about life-sustaining treatment. Such uncertainty may frustrate physicians who seek guarantees that they will not face liability for withholding treatment.

Physicians are bothered not only by case law, but also by administrative regulations and statutory law that carry out political decisions. They believe such legislation imposes some unrealistic demands and embodies unwise social policies. For example, Medicare regulations for Federally funded hospice programs require physicians to certify that patients are terminally ill and will not survive more than 6 months (Brody and Lynn, 1984; Fraser, 1985). If patients survive longer than this, the hospice bears financial responsibility for their care. Such accurate prognostication, however, is beyond the scope of medical knowledge. In order to avoid admitting patients to hospice who survive longer than 6 months, physicians would have to admit only those they expect to survive 2

or 3 months. As a result, many patients who will in fact live only 6 months are denied hospice care until the final stages of their illness. Furthermore, Federal regulations impose costly programmatic requirements on hospices that receive Medicare payments, replace volunteerism with bureaucracy, and introduce financial incentives that conflict with hospice philosophy. For these reasons, most hospices have elected not to seek certification for Medicare reimbursement (Fraser, 1985). Many physicians believe these Federal regulations carry out unsound policy decisions that compromise the goal of hospice to provide supportive care.

Given these legal fears and uncertainty, physicians may seek prior assurance in the courts that their proposed actions will not expose them to liability. Ironically, when physicians or hospitals seek declaratory relief from courts, they exacerbate the very situations they decry: slow judicial decisions that intrude on medical practice.

Nurses have different perceptions of the law than physicians do. They may face legal liability if they carry out physicians' orders that violate ethical or legal principles. They have become increasingly concerned about their own legal responsibility and liability. Nurses implement do not resuscitate (DNR) orders. They are usually the first people to respond to a cardiac arrest and initiate resuscitation. If an order not to resuscitate the patient is made against the wishes of the patient or the family (and contrary to ethical and legal principles), the nurse may bear legal responsibility for withholding resuscitation. Conversely, if a nurse knows that the patient does not want resuscitation but the physician declines to write a DNR order, the nurse could be in legal jeopardy for carrying out resuscitation. An even more difficult situation occurs when the physician gives an oral order not to resuscitate the patient, but deliberately does not write a formal order in the chart. Nurses who follow such oral orders have no documentation that physicians told them not to resuscitate, and hence they risk legal liability. For these reasons, nurses may request that a hospital set up explicit DNR

policies.

For nurses, ethical dilemmas usually involve disagreements with physicians (Howell, et al., in press). Nurses increasingly seek a more active role in patient care (Prescott and Bowen, 1985). They believe that since they spend more time with patients and families, they may know better than physicians what patients want or what is best for patients. One philosopher has suggested that an important change has occurred in the role of nurses (Winslow, 1984). Previously the metaphor of loyalty to a commander was used. But now, rather than playing a subordinate role to doctors, nurses are seeking the role of patient advocate.

This new role, however, may clash with the hierarchical power structure of hospitals. It may be difficult for nurses to question orders by physicians. Ironically, nurses may find that their concerns over their own legal liability provide an effective way to play a more active role. They have been able to change hospital policy, for example, in setting up formal policies for DNR orders. In turn, the existence of these policies may allow nurses to raise ethical concerns in particular cases and thus play a more active role in decisions.

A dramatic example of this is the Barber and Nejd case (Barber and Nejd v. Superior Court of the State of California, 1983). As mentioned earlier, two physicians were charged with first degree murder after discontinuing life-sustaining treatment on a patient who was comatose after a cardiac arrest. The case was brought to the attention of the district attorney by a nurse from the intensive care unit. She had insisted that the attending physicians, not the nurse, disconnect the ventilator. Later, when the patient continued to breathe by himself, she asked the physicians to order a misting device. The nurse and one of the physicians had a vehement public confrontation over whether a misting device was necessary. The physician believed that the nurse was insubordinate, while the nurse believed that the physician was belittling her suggestions to improve

patient care. Her recourse to the legal system was a dramatic response to this disagreement. Although all legal issues were ultimately settled in favor of the physician-defendants, this case illustrates how poor working relationships with nurses may increase legal problems for physicians.

Other Professionals Whose Views Affect Perceptions

Others in the health care system may have different perceptions of the law. Hospital administrators wish to minimize legal problems, the cost of defending lawsuits, and bad publicity. Their primary responsibility is to the hospital corporation, not to its physicians, nurses, or patients. They may be unwilling to accept even minimal legal uncertainty over withholding life-sustaining treatment, and may recommend continuing such treatment or may insist on going to court for prior legal clarification, as happened in the Bartling case (Bartling v. Superior Court of California, 1984).

Often administrators are more concerned about the legal risk of withholding life-sustaining treatment than of continuing possibly inappropriate treatment. Although the patients or their families have brought several suits against physicians and hospitals to have treatments discontinued or alleging battery for unconsented-to treatment, hospital administrators seem more willing to accept these legal risks. In general, neither adverse publicity nor large monetary settlements have been the outcome. In one recent case, an Ohio Common Pleas Court (trial level) allowed mechanical ventilation to be discontinued on a woman with amyotrophic lateral sclerosis who was in a persistent vegetative state after a cardiac arrest (Leach v. Akron General Medical Center, 1980). The patient's husband subsequently also brought a civil suit alleging battery for treatment inflicted over family objections, which was dismissed (Estate of Leach v. Shapiro, 1984). Hospitals and physicians can justify to themselves their actions in continuing life-sustaining treatment; in trying to benefit their patients, they believe it is appropriate to err on the

side of continuing life in difficult cases. The public (and judges) seem willing thus far to accept this justification.

Administrators are concerned about the legal liability of the institution, as contrasted with physicians' concerns about their individual liability. Lack of formal institutional policies, for example about DNR orders, may create liability for the institution. Thus, administrators may be more concerned than physicians are about instituting hospital policies. Indeed, some physicians may be cynical about such guidelines, considering them impractical or even counterproductive. In such disagreements, the law may become a scapegoat.

Administrators also must deal with regulations and financial pressures that affect physicians only indirectly. For example, when a patient is decertified by Medicaid as not needing acute care hospitalization, the hospital will not be reimbursed for that patient's care. Physicians may feel trapped because their responsibility not to harm the patient conflicts with their responsibility to maintain the fiscal integrity of the hospital.

Similarly, under prospective payment by Medicare diagnosis-related groups, the hospital has financial incentives to discharge or transfer terminally or chronically ill patients out of the hospital as early as possible. However, the physician who actually orders the transfer does not face the same direct financial pressures. Under current prospective reimbursement systems, the hospital bears the direct financial risk, not the physician. While the hospital is given a fixed sum regardless of the length of hospitalization, physicians can charge professional fees for each day of hospitalization. Caregivers may believe such transfers harm terminally ill patients by disrupting continuity of care and causing psychological harm (Lind, 1984). This difference in perspectives may lead to clashes between physicians and hospital administrators, with both parties blaming the legal or political systems.

Lawyers may perceive their role in different ways, depending on the identity of their client. Some lawyers may wish to help physicians and administrators minimize liability. They may point out all legal risks and recommend the course of actions that poses the least legal risk. For these lawyers, patient and family welfare is of secondary, if any, importance. Others may view their role as helping to weigh the legal liability or uncertainty against other considerations, such as ethical and medical principles for decisionmaking. Still others may see their task as preparing to defend the decisions made by physicians in good faith and in accordance with institutional and professional guidelines.

Hospital lawyers are more likely than physicians' lawyers to be consulted when the withholding of life-sustaining treatment is being considered. Few physicians retain lawyers whom they can consult about possible legal risks before they make such decisions. But it may be unwise for physicians to rely on hospital attorneys for legal advice. Hospitals may have different legal liabilities and concerns. There may even be a conflict over whether the hospital or the physician is liable. Indeed, when faced with a malpractice suit, physicians frequently are advised to obtain legal counsel that is separate from the hospital counsel (Kaplan, 1984). This potential conflict of interest may be especially common when physicians have their malpractice premiums paid by the institution, as in health maintenance organizations or university teaching hospitals.

Risk managers (many of whom have not been to law school or had other training in legal matters) are hired by hospitals to minimize financial and legal liability for the hospital. Their work includes implementing quality assurance programs, identifying potential problem areas, investigating accidents or incidents, and determining when to negotiate out-of-court settlements. When a lawsuit is brought, the risk manager prepares or coordinates litigation. Fearing large settlements by sympathetic juries, risk managers may wish to settle some suits out of court for low payments even if claims may

not be meritorious. This approach may seem more cost-effective than spending money for legal fees and risking a larger settlement in court (Danzon, 1985).

Risk managers also give a great deal of prospective advice to medical and nursing staff on how to avoid legal difficulties. For many physicians and nurses, risk managers are the chief source of "legal" guidance. Such guidance is usually biased toward continuation of life-sustaining treatment for the dying patient.

Insurance companies wish to minimize their expenditures for defending against and compensating patients who bring suit. Hence, they too may seek to settle some cases out of court even when the plaintiff does not have a strong case, rather than bear the expense of litigation and risk larger verdicts by a jury. Although this strategy is pragmatic and reasonable from the viewpoint of the insurance company, some physicians named in questionable suits may wish to pursue a different strategy. Physicians do not pay the costs of the settlement or verdict directly and some may be concerned about vindicating their reputations. If they are outraged by what they consider unfounded suits, they may seek exoneration in court. Physicians may perceive out-of-court settlements of unfounded suits as yet another example of how the "legal" system puts them in jeopardy even when they may not be at fault.

Influence of Delivery Setting

Perceptions of the law differ in various sites of practice. In teaching hospitals, responsibility for decisions may be diffused among many caregivers. Attending physicians on the faculty may not be as involved in decisions as are residents, interns, and medical students. In one study, attending physicians, who have legal responsibility for patient care, were involved in decisions to withhold cardiopulmonary resuscitation (CPR) in only 39 percent of cases (Uhlmann, et al., 1984). In the other cases, residents and interns made these important decisions.

Yet, inexperienced physicians and students in teaching hospitals may not appreciate legal and ethical guidelines about life-sustaining treatment. The New York state grand jury in 1983 investigated a case in which a decision to withhold cardiopulmonary resuscitation from an elderly woman was made inappropriately by a medical student without regard to her preferences and without discussing the decision with more senior physicians (Supreme Court of the State of New York, 1983). The grand jury found that the lack of a formal hospital DNR policy contributed to this violation of ethical and legal standards.

Physicians in training may feel insulated from legal concerns for several reasons. They may not understand the relevant ethical and legal issues about life-sustaining treatment. Their malpractice premiums are usually paid by the hospital. The likelihood of their involvement in a future lawsuit seems remote, and attending physicians have ultimate legal responsibility for decisions.

One component of the delivery setting that can influence physicians' perceptions of the law is the reimbursement system. Fee-for-service and prepaid health care systems have different financial incentives, including incentives regarding life-sustaining treatments (McPhee, et al., 1984). In turn, these economic incentives may influence physicians' willingness to assume legal risks. In fee-for-service medicine, life-sustaining treatment generates income for both the hospital and the physician. Hence, physicians may be more likely to continue life-sustaining treatment than to go to court or accept even a small risk of legal liability for discontinuation. In contrast, in prepaid care under prospective or capitation payments, the physician and the hospital may suffer financially if expensive forms of life-sustaining treatment are continued for a long time. This economic incentive may encourage the physicians to withhold life-sustaining treatment even when there is some legal risk. Prepaid systems, however, are sensitive to charges that they would discontinue treatment to save money for the providers. Such charges

were alleged, for example, in the Barber and Nejd case. In reaction, prepaid systems may be very conservative about discontinuing treatment.

Physicians who are salaried and whose malpractice premiums are paid by employers, as in health maintenance organizations or in academic medical centers, may be willing to accept some legal uncertainty in decisions about life-sustaining treatment. In contrast, those in fee-for-service practice, who pay malpractice premiums from their gross income, may be more concerned about increases in premiums for bad ratings. They may also be more concerned about how adverse publicity may affect their practice. In turn, they may be unwilling to accept even minimal legal uncertainty.

Many decisions about life-sustaining treatment for elderly incompetent patients are made in nursing homes rather than acute care hospitals, and there may be a great discrepancy between actual practice in nursing homes and ethical and legal ideals. More than in acute care hospitals, decisions in nursing homes may be made informally without standard procedures or even open discussion among those involved. Anecdotal evidence (Hilfiker, 1983) suggests that decisions about transfer to acute care hospitals or about treatment of infections with antibiotics are often made unilaterally by physicians. Few nursing homes have policies about cardiopulmonary resuscitation or about withholding care (Miles and Crimmins, 1985). Even if such policies exist, they are often vague and poorly disseminated, and compliance may be poor. Physicians spend little time in these facilities. They may visit patients only the once a month that is required by Medicare or Medicaid, unless they are employed directly by the nursing home as medical director. Because they are not actively involved in the nursing home, physicians may regard guidelines about DNR orders and withholding treatment as bureaucratic impositions that do not improve patient care.

Nurses, too, may play a different role in these settings. Because physicians are not as available, nurses may have more responsibility and discretion. To decrease their own legal liability, they may want more explicit procedures for making decisions about life-sustaining treatment and formal, written orders rather than oral ones. Once again, the threat of legal difficulties may lead people to place blame on the legal system, rather than recognizing the underlying ethical problems or institutional shortcomings.

Nursing home administrators have particular concerns with elder abuse laws and licensing requirements. Decisions about life-sustaining treatment undoubtedly will be increasingly scrutinized because of concern about the quality of care in nursing homes and the vulnerability of frail elderly nursing home patients. The New Jersey Supreme Court, in the Conroy decision, noted that nursing home patients may have no family, do not have a close relationship with their physicians, and may be victims of abuse (In the Matter of Claire C. Conroy, 1985). The Conroy ruling declared that every time the withholding of treatment from incompetent nursing home patients is considered in New Jersey the situation has to be investigated by the State Ombudsman as a possible case of elder abuse. The court intended these procedures to protect frail nursing home residents. Nursing home administrators may wish to avoid such investigations, which may be long and expensive and generate adverse publicity.

In response to these dilemmas, nursing home administrators may adopt a legally conservative policy. If there is any perceived risk of legal liability for withholding life-sustaining treatment, they may urge that treatment be given. Alternatively, they may encourage the transfer of patients to acute care hospitals when a medical crisis like pneumonia develops, rather than deciding the question of withholding treatment in the nursing home. Such decisions may not be consistent, however, with the patient's wishes or interests.

Sources of Perceptions

Medical Education and the Legal Community

Medical education gives little attention to ethical and legal issues, especially during the clinical years of medical school and residency. In the preclinical years, there may be courses on medical ethics or, much less commonly, on medical law. But clinical medicine is learned on a case-by-case basis from more senior physicians. Discussions of individual cases on "rounds" and in conferences focus on the biotechnical aspects of medicine, such as what tests would provide the most diagnostic information and what medications would be most effective in a given situation. Legal and ethical issues often are not discussed. Only infrequently are lectures about law and ethics presented during clinical training. Even less frequently are students introduced to the analytical methods and approaches of law and ethics. Most physicians report that they developed their approach to ethical dilemmas through clinical experience, observation of role models, and interactions with medical peers, not through formal coursework, seminars, or conferences (Pellegrino, et al., 1985). Interdisciplinary exposure to legal and ethical analysis is scarce.

Not only is there little attention to the substance or the analytical approach of the law in medical education, but there is also scant attention to physicians' attitudes toward the law and toward legal risk. Medicine is an art involving probability and uncertainty, not an exact science. Medical education is only beginning to deal with probabilities in diagnosis and treatment in a systematic way through techniques like decision analysis. Little attempt is made, however, to teach students and physicians how to approach the uncertainty inherent in ethical dilemmas. As a result, physicians may unrealistically expect more certainty from the law than they do from medical science. At the same time, ironically, they tend to praise medical science as "hard" and condemn law and

ethics as "soft."

Few continuing medical education courses devote much attention to legal aspects of medicine. One notable exception is the course recertifying physicians in cardiopulmonary resuscitation, run by the American Heart Association (AHA). Many physicians are required to take this course each year to renew their hospital privileges or medical licenses. The AHA handbook about CPR has a chapter entitled "Medicolegal Aspects of Cardiopulmonary Resuscitation (CPR) and Emergency Cardiac Care (ECC)" (McIntyre, 1983). Its legal advice is conservative and may be at odds with clinical practice. The handbook advises that CPR be administered to almost all cardiac arrest victims who are brought to the emergency room without prehospital CPR, unless an order not to resuscitate has already been appropriately made. Formerly, such patients were designated "dead on arrival." The AHA considers this term an anachronism, because it may be impossible to determine that circulatory arrest has been present for such a long time that recovery of brain function would be impossible: "The argument that the patient could have collapsed. . . and continued to have cardiac activity at a level sufficient to sustain the brain until the victim was rushed through the door of the emergency facility may be an insurmountable one."

The Association suggests it is unwise for physicians to withhold resuscitation based on reports of laypeople who witnessed the arrest and who report long delays in resuscitation: "Armed with the experience that weak or slow pulses may be missed by inexperienced observers, a plaintiff's attorney may inquire as to the person upon whom the physician should reasonably rely as his witness to the onset and progression of the process of brain death" (McIntyre, 1983). Furthermore, an apparently dead patient who has ingested drugs or is hypothermic can sometimes be successfully resuscitated.

The AHA also addresses the question of when resuscitation efforts should be terminated. Often caregivers are concerned that even if the heart is successfully resuscitated, severe irreversible brain damage has already occurred. But there are no reliable criteria that allow caregivers to predict during resuscitation the patient's neurological outcome. The AHA recommends that only failure to restore circulation after basic and advanced cardiac life support is an appropriate reason for stopping resuscitative efforts because of medical futility. The handbook notes that "the concern for guidelines for the cessation of CPR has been strengthened by the reality that litigation is more likely to follow when the patient survives with permanent brain damage than when the patient dies" (McIntyre, 1983).

One major source of information about the law is hospital lawyers and risk managers. Yet, their advice may be incorrect and misleading, as for example after the Saikewicz ruling by the Massachusetts Supreme Court in 1977 (*Superintendent of Belchertown State School v. Saikewicz*, 1977). Joseph Saikewicz, who had been severely retarded since birth, developed acute myeloblastic leukemia. Using a "substituted judgment" standard, the court ruled that he need not undergo chemotherapy for leukemia. The most controversial part of the decision concerned the proper procedure to be followed in decisions about life-sustaining treatment for mentally incompetent patients. Some lawyers recommended to clients that the decision required that all such decisions be taken prospectively to probate court. Other legal scholars believed that the decision required physicians to go to court only if the case involved a "substituted judgment" or if they desired advance assurances of legal immunity. One expert in health care law objected that "many lawyers advising Massachusetts hospitals on the law of the Saikewicz case lack experience and training in health law and have little familiarity with either medical practice or hospital procedures" (Annas, 1982).

After the Saikewicz decision, physicians in Massachusetts were confused about orders not to resuscitate patients in case of cardiopulmonary arrest. Some legal commentators believed that the Saikewicz decision did not preclude the physician and family from making such orders. However, other lawyers advised that no treatment could be withheld from incompetent patients without a prior court order. The Dinnerstein decision by the Massachusetts Appeals Court in 1978 resolved this legal uncertainty over DNR orders, ruling that the physician and family could appropriately agree on such an order without advance recourse to the probate court (In re Dinnerstein, 1978).

Many attorneys and others (such as ethicists and nonattorney risk managers) who purport to give, or who are interpreted as giving, legal advice to medical professionals about life-sustaining technologies send out mixed and inconsistent signals. This is a complex and rapidly changing subject area, where up-to-the-minute information (about, for instance, trial level action or a proposed bill in another jurisdiction) is frequently difficult to monitor and rumors and misinformation abound. Unless attorneys and other advisors have a proper background in the first place (and some people question whether nonattorneys have a sufficient background) and put substantial time and effort into continuing educational pursuits about legal issues surrounding life-sustaining technologies, it is easy for confusion and misunderstanding to develop among advisors. This confusion is often transmitted to medical professionals in the form of ambiguous (both actual and perceived) legal advice, which tends to diminish confidence in the law.

In addition, ambiguity in legal advice may also translate into legal ultraconservatism and risk management at any price. It is certainly understandable that medical professionals and institutional administrators and trustees who stand on the firing line daily encountering the perplexing dilemmas of decisionmaking about life-sustaining technologies are deeply interested in preserving their own legal integrity--that

is, in avoiding lawsuits (or, at least, successful lawsuits). One can also appreciate the legal prophylaxis orientation--and consequently the highly conservative bias--of professionals who must advise medical professionals on how to minimize their potential exposure to legal risks. The appeal of security and risk avoidance, the quest for a zone of legal "comfort" (Annas, 1984a), is self-evident. Since medical professionals value advance legal certainty and protection so highly, it is not surprising that those who provide risk management counsel regularly issue advice that exhibits a heavy, arguably excessive, prejudice toward narrow and conservative solutions (that is, tending to rely on the advance assurances available only through the formal, legal, adversarial process) (Kapp, 1985a; Kapp, in press).

The Professional and Popular Media

Articles in medical journals about the Saikewicz and Dinnerstein decisions purported to inform many physicians about these rulings. Such articles, however, may be incorrect. One legal scholar attacked legal advice columns as "casual, offhand, misleading, or just plain wrong" (Annas, 1982).

Statutory law as well as case law can be presented incorrectly in medical journals. One article on advance directives, for example, did not realize that under the California statute on the durable power of attorney for health care, surrogate decisionmakers must follow the previously expressed wishes of patients (Schneiderman and Arras, 1985). The article therefore incorrectly criticized the durable power of attorney for health care for not respecting patients' preferences regarding treatment.

Articles about the law are often found in "throw-away" journals that are commonly funded by drug companies and do not have a peer-review system (Kaplan, 1984; Rheingold, 1985; Riccardi, 1985). The articles may highlight concerns about a malpractice crisis and polarize attitudes toward attorneys; they often suggest that even

if physicians practice good medicine, they may be trapped into lawsuits by unscrupulous attorneys or greedy patients. Hence, these articles may heighten physicians' fears and sense of powerlessness.

The lay press, which often gives extensive immediate but not continuing coverage to "landmark" cases, shapes professional and public perceptions about the law. Publicity often heightens physicians' perceptions about the hardships of legal proceedings. For example, Drs. Barber and Nejd, who were indicted for murder for discontinuing life-sustaining treatment, received great publicity, some at the urging of their defense attorneys who believed informing the public about the issues would increase their chances for acquittal (Lo, 1984). This publicity, however, brought with it severe personal and professional burdens. Other physicians, fearing such disruption of their private lives and careers, may be reluctant to make medical decisions that entail even a slight risk of legal charges.

Publicity may also polarize disagreements about life-sustaining treatment, as in the case of Elizabeth Bouvia (*Elizabeth Bouvia v. County of Riverside*, 1984; Steinbrook and Lo, 1986). Bouvia is a woman, almost quadriplegic from cerebral palsy, who entered a California hospital in 1983 at the age of 26, saying that she wanted to starve to death. Her physicians and the county hospital believed that her request would involve caregivers in a suicide and that it violated the rights of other patients who were in the hospital and who had chronic diseases. A court rejected her petition to prevent feeding against her will and later authorized involuntary tube feedings. Under the glare of publicity, hostility and confrontation developed. Disabled individuals held vigils at the hospital to convince her to change her mind. Nurses took notes on her visitors and her telephone calls, which were later used as evidence against Bouvia in court. A national columnist's offer to raise funds for her medical treatment was rebuffed.

An escalating cycle of opposition and polarization developed. Physicians and hospital administrators reading the news stories might well conclude that such cases are time-consuming, stressful, and best avoided. The course of events seemed beyond the control of physicians and administrators; turning to the courts for a solution seemed the only recourse. But press coverage did not suggest how physicians and administrators might have managed the case without going to court.

With difficult, hostile, or demanding patients, effective care requires a partnership between the doctor and patient. In the Bouvia case, such a partnership appeared difficult or impossible. But it was essential to try to build it, because the alternative of having the courts decide was unsatisfactory. In general, physicians can take steps to try to establish a therapeutic relationship. Spending time listening uncritically to the patient may be useful. If the patient's requests contradict good medical practice or ethical guidelines, physicians need to define their limits sympathetically. In discussing shared and realistic goals, physicians might stress their empathy for the patient's symptoms and frustration. In the Bouvia case, these principles may have been overlooked. Her physical limitations made it difficult for her to have a sense of partnership in her care. But such patients might be given control over the hospital routine, such as the timing of blood tests and toilet care. Enhancing a patient's sense of control may lead to agreement over a plan of care. Physicians reading about the Bouvia case in the newspapers might have overlooked the therapeutic value of the doctor-patient relationship. In turn, they might have inferred that only the courts can resolve such difficult cases.

Media coverage of the Bartling case also suggested that physicians cannot resolve ethical dilemmas, and that only the courts can decide (*Bartling v. Superior Court of California*, 1984a; Lo, 1986). William Bartling was a 70-year-old man with chronic obstructive lung disease who was admitted to the hospital for depression and chronic back pain. When a chest x ray showed a new pulmonary nodule, a needle aspiration was

performed, which showed carcinoma of the lung. After the procedure, he required mechanical ventilation. Over the next 2 months, he could not be weaned from the ventilator. He and his family asked that the ventilator be discontinued. The hospital and his physicians refused, and he went to court.

A deposition by the patient was videotaped and televised by "60 Minutes." Bartling nodded yes when asked if he wanted to live, but not on a ventilator, and when asked if he understood that if the ventilator was discontinued, he would die. This brief interview seemed to establish the patient's wishes. However, caregivers claimed that Bartling changed his mind about the ventilator, depending on whether or not he was depressed. The questioning in the deposition did not check whether he had changed his mind or was ambivalent, whereas such questions would be customary in a clinical interview. Since these issues were not raised, the possibility that the disagreement might be resolved if his depression could be effectively treated was also not considered.

Physicians may have felt uncomfortable that the legal system did not consider the medical issues in as much detail as a medical conference would. They might object that the ruling seemed based on an inadequate discussion of the medical situation. Caregivers then might fault the legal system as medically naive and inaccurate.

The presentation of the case in the media implied that court action was the only way to resolve the disagreement. It did not present a less dramatic alternative—that agreement might be possible through improved communication between caregivers and the patient or by psychological treatments. On the one hand, Bartling might agree to treatment for his depression. On the other hand, if physicians were convinced that his refusal of treatment was truly informed and consistent, they might be willing to accept his wishes. In summary, accounts of dramatic cases in the media do not indicate how physicians, using their skills of interviewing and counseling, might resolve disagreements with patients. Thus the media implicitly suggest that the only way to resolve ethical

dilemmas in clinical medicine is to let the courts decide. At the same time, physicians may infer that legal rulings are not based on an adequate assessment of the medical issues.

Uncertainty in the Law

Current law is less than certain and definite concerning life-sustaining technologies or almost any other topic. This lack of certainty affects the way that medical professionals perceive the law and its impact in this area.

First, there is general agreement across legal jurisdictions (i.e., among the different States) on the substantive issues. In the absence of countervailing compelling State interests, a competent adult has the right to accept or refuse any medical treatment, including life-sustaining technologies; the wishes of a previously competent patient, to the extent that they can be reasonably discerned, should govern the medical treatment of that individual (known as substituted judgment); and where there is no factual basis for engaging in substituted judgment (i.e., it is impossible to know what the patient would have chosen if able to make a choice), the best interests of the patient, as judged according to the proportionality or benefit/burden test, should control treatment decisions. (For a fuller discussion of these principles, see the paper by Buchanan, et al. in this volume.) The countervailing State interests that have been identified as potentially compelling, depending on the facts of the particular case, are prevention of suicide, preservation of life, protection of innocent third parties, and maintenance of the ethical integrity of the health professions (see, e.g., *Bartling v. Superior Court of California*, 1984a).

There is a good deal of variation, however, among legal jurisdictions regarding procedural issues—who should make decisions when the patient cannot communicate and under what process surrogate decisionmaking should be made. This variation contributes

to anxiety and apprehension in the way the medical professional perceives legal requirements.

A number of legal jurisdictions have not dealt with life-sustaining technology issues at all, leaving a perceived vacuum. Thirty-six States had enacted natural death or living will statutes by the end of 1985 (Society for the Right to Die, 1985); although there are similarities among most of these statutes, there are notable differences as well. Differences also exist among jurisdictions concerning use of the durable power of attorney for health care decisionmaking. A few States have enacted statutes specifically making the durable power of attorney applicable to health care, a few have included the naming of proxies in their living will statutes and thus arguably make it applicable only to terminally ill patients, and many States have not made any attempt to define the scope or limits of the durable power of attorney vis-à-vis health care.

Among the State court cases that have grappled with life-sustaining technology issues, numerous procedural approaches have developed on either a voluntary or mandatory basis: prognosis committees (In re Quinlan, 1976; In re Colyer, 1983), institutional ethics committees (In re Torres, 1984), nursing home ombudsmen (In re Conroy, 1985), the involvement of county coroners and prosecutors (Leach v. Akron General Medical Center, 1980), reliance on family and physician (Barber and Nejd v. Superior Court, 1983; Matter of Dinnerstein, 1978; Matter of Spring, 1980), use solely of the patient's prior statements (In re Eichner, 1981; In re Storar, 1981), reliance just on the court as decisionmaker (Superintendent of Belchertown State School v. Saikewicz, 1977), and so on.

Understandably, medical professionals may feel confused and intimidated by this plurality of legal approaches. Several particular issues stand out. Jurisdictions apparently disagree on whether the withholding or withdrawing of artificial methods of feeding and hydration from incompetent patients is ever appropriate. In at least two

states, courts have ruled (*Barber and Nejd v. Superior Court*, 1983; *In re Conroy*, 1985) that artificial feeding and hydration are to be considered exactly like any other life-sustaining medical intervention, susceptible to being withheld or withdrawn under the substituted judgment and proportionality standards. Yet, 17 of the States with living will statutes have provisions in those acts that make the status of artificial nutrition and hydration problematic (*Society for the Right to Die*, 1985). Most of the statutes (those of Colorado, Connecticut, Florida, Georgia, Illinois, Indiana, Iowa, Maine, Maryland, Missouri, New Hampshire, Oklahoma, Tennessee, Utah, Wisconsin, and Wyoming) specify that artificial nutrition and hydration are not included in the definition of life-sustaining treatments that may be withheld or withdrawn.

A recent Florida court decision (*Corbett v. D'Allesandro*, 1985; *Whiteneck*, 1985) refused to permit withdrawal of artificial feeding and hydration from a patient because the state living will statute expressly excluded these procedures. At least one living will statute (Arizona's) appears to say that artificial nutrition and hydration needed for patient comfort may not be withheld or withdrawn, implying that, when it is not necessary for patient comfort (i.e., when the patient cannot experience hunger or thirst), it may be withdrawn. There has been no judicial clarification of this point as yet. A further complicating factor is the Federal "Baby Doe" regulations (50 FR 14878; 45 CFR 1340), which forbid the "inappropriate" withholding or withdrawing of artificial feeding or hydration from a handicapped newborn, without further definition.

The legal authority of the family to make decisions on behalf of an incompetent patient is another issue that illustrates an inconsistency across legal jurisdictions that contributes to medical professionals' unease and defensiveness. As a general matter, in the absence of a court order finding a person mentally incompetent and appointing another to act as guardian, neither the family as a whole nor any of its individual members have any special legal authority to make decisions on behalf of a family

member who cannot communicate decisions (Ad Hoc Committee on Medical Ethics, 1984). Nonetheless, it has long been the medical convention to rely on families as decisionmakers for incompetent patients, even in the absence of express legal power.

A number of States now formally recognize the family role. Courts in at least five States have explicitly recognized the authority of the family to exercise the incompetent patient's rights on that person's behalf. Eight of the existing living will statutes expressly provide for termination of treatment of incompetent patients who have not executed an advance directive (living will or durable power of attorney) (Society for The Right to Die, 1985). The decision under these statutes typically is made with the agreement of the attending physician and, in a stated order of preference, the family members.

It should be borne in mind that inconsistencies among States are mitigated greatly by the fact that most physicians practice medicine in only a single legal jurisdiction. Thus, as long as the physician understands the law in his or her own State, the fact that other States may have different rules is of little practical consequence in the physician's daily activities.

Even in the absence of explicit judicial or legislative authorization in a particular State, a medical professional's legal risk for a good faith decision made in conjunction with an incompetent patient's family is virtually nil. Nevertheless, such decisions are, in legal jurisdictions that have not yet ruled on this subject, made and implemented under a cloud of some uncertainty that raises the anxiety level of medical professionals.

Myths About the Law

There are several possible explanations for the growth of erroneous and negative perceptions concerning the law's impact on decisions about life-sustaining technologies. (Kapp, 1986). First, as noted earlier, many medical professionals labor under an honest but unfortunate misunderstanding of what the law is and what it requires. Legal pronouncements often are attributed to courts and legislatures that have no basis in fact.

Second, as indicated, many attorneys and risk managers who advise medical professionals and institutions in life-sustaining situations err greatly on the side of legal conservatism, to the point where their caution in seeking absolute legal immunity before any action is taken wastes time, energy, and emotion in a way that is a disservice to both the client and affected patients and families (Annas, 1984b; Kapp, 1985a; Kapp, 1986).

A conservative, formality-based bias toward risk management in situations of decisionmaking concerning life-sustaining technologies is simple to comprehend, but it is also deeply unfortunate. In a number of ways, such an approach neglects or devalues other, seriously significant factors that should figure prominently in the calculus of withholding or withdrawing life-sustaining treatment. Hence, this sort of approach is likely to yield neither an optimal decisionmaking process nor the "best" substantive decisions (Annas, 1981; Burt, 1981; Rothenberg, 1982). Perhaps the worse effect of such an approach is that medical professionals may become imbued with the false belief that the formal, legalistic manner of dealing with difficult medical decisions is the best, or even the only, course of action.

Third, and perhaps most importantly, the tendency to blame the law for intractable decisionmaking problems partially represents a conscious (though more often an unconscious) attempt to circumvent the difficult and fundamental ethical, social, psychological, and economic issues that are implicated in decisions about life-sustaining

technologies, instead of directly confronting those issues (Cassel, 1985; Kerschner, 1985). The law may be a more attractive opponent to face than the patient's incurable condition, as well as a source of social validation ("hand holding") for decisions for which the physician does not wish to bear responsibility alone (Cassel, 1985). Physicians are professionally conditioned to feel a sense of personal failure when a patient dies. The law is often cited, and lawsuits threatened, to promote the personal emotional needs and agendas of the participants, as a way to flex muscles and let out frustrations (Hofmann and Smott, 1985). It is instructive that in Canada, where a different legal system makes the fear of malpractice actions much less of a factor, issues and practices in decisionmaking about life-sustaining technologies seem just as troubled and unclear as in the United States (Clayton, 1985; Law Reform Commission of Canada, 1979). This phenomenon underscores the argument that the central issues and practices are fundamentally ethical rather than legal.

Whatever the cause, it is easy for the law to become a scapegoat and the focal point of several myths that may interfere with good medical decisionmaking and practice. Many of these commonly heard myths are both wrong and internally inconsistent. The best interests of both medical professionals and their patients compel a critical analysis and refutation of some of the more prominent ones.

The Myth of Simplicity

First, decisionmaking concerning life-sustaining technologies is expected to be clear, unambiguous, and straightforward, and legal interference in medical affairs is thought to make that process unnecessarily and counterproductively complex, uncertain, and difficult. The short answer to this attitude is that irreversible life-and-death decisions are and should be agonizing and gut-wrenching, dealing as they do with the most basic of human values and concerns. Such decisions should never become

commonplace, facile, or matter-of-fact (Meier and Cassel, 1983). "The awesome and unsettling power to influence when death comes to another human being should be exercised with the greatest care" (Dresser and Boisaubin, 1985).

To a certain extent, a degree of ambiguity in the law is unavoidable and healthy. There are no absolute guarantees in law, any more than there are perfect guarantees in medical care. Here, as elsewhere, law and medicine operate in parallel. Uncertainties exist in all parts of life; we can to a large extent identify, soften, and prepare for those uncertainties, but we can never completely eliminate them. If medical professionals refused to proceed in the face of clinical uncertainty, no patient would ever be treated; every intervention involves medical risk. Similarly, every intervention involves legal risk as well, but the risk is reasonable and manageable. Particularly in a part of the universe as dependent on human value judgments as our legal system is, some risk can never be obliterated, nor should it be. To the extent that the law contributes to a careful and cautious consideration of all relevant issues and perspectives, to the extent that the law poses questions that would not otherwise have been posed, it makes a valuable and positive contribution to sound decisionmaking (Baron, 1984; Burt, 1984).

The Myth of Intrusion

One widely shared belief is that gratuitous, unwanted, inappropriate legal involvement pervades and intrudes into virtually every aspect and instance of decisionmaking concerning life-sustaining technologies. While it is true that every aspect and instance of medical care (and of every other human activity in complex modern society) entails potential legal implications to which participants must be sensitive, legal intrusion in this sphere cannot fairly be characterized as either gratuitous or pervasive.

First, it is understandable that a few well-publicized legal cases, especially when they yield seemingly conflicting conclusions, are capable of generating substantial anxiety and overcautiousness and increasing the medical professional's normal propensity to practice defensively. However, an examination of the numbers belies the paranoia. Such cases are indeed few and far between. (See report by Annas and Glantz in this volume, and Helm, 1985.) Given the predictable regularity with which decisions concerning life-sustaining technologies are made every day in hospitals and nursing homes across the country — when treatment is either instituted, continued, withheld, or withdrawn — the number of situations in which the legal system becomes actively involved is relatively small. The possibility of a physician, nurse, or health care administrator becoming an involuntary litigant based on a decision concerning life-sustaining treatment of a patient pales in comparison to the ordinary malpractice exposure encountered in standard, run-of-the-mill medical practice.

On the criminal side, both case law and scholarly commentary opine that there is little realistic risk of prosecution or liability whether life-sustaining treatment is or is not given, as long as the decision leading to that result has been made in good faith and according to reasonable professional standards and judgment (Matter of Spring, 1980; President's Commission, 1983; Oakes, 1982; Wilson, 1985; see also Annas and Glantz in this volume). Much media attention surrounded the only criminal prosecution brought against physicians for withdrawing life-sustaining treatment from a comatose, terminally ill patient (discussed earlier) (Barber and Nejdil v. Superior Court, 1983), but many seem to forget that this case ended in complete legal vindication for the accused physicians and an admonition that criminal prosecution was inappropriate.

The bulk of litigated cases fall within the civil sphere. Few involve an after-the-fact allegation of professional malpractice and a demand for substantial monetary damages (but see Estate of Leach v. Shapiro, 1984). Instead, most civil cases involving

life-sustaining technologies treat the rare situation of unreconciled differences between participants as to the appropriate course of conduct to follow, and take the form of before-the-fact actions for declaratory and injunctive relief brought by physicians or health care administrators to obtain advance legal prophylaxis or by patients or their families to compel providers to take or to refrain from taking certain actions.

In this regard, it is important to remember that the law is not a self-initiating or enforcing process; it does not simply "happen." Judges do not randomly roam the halls of intensive care units in sweeping black robes with law books under their arms looking for new cases to decide. On the contrary, a tradition of judicial deference is well-established, and a court becomes involved only when an issue is brought to it by an interested party. In many respects, resort to the courts represents a regrettable failure of informal means of resolving such deeply personal dilemmas (Rothenberg, 1982), and challenges responsible medical professionals, patients, and families to devise and implement better means of informal communication, cooperation, and issue resolution (Hofmann and Smott, 1985; Mariner, 1984). In the vast majority of situations, such procedures are not only achievable, but are already being carried out daily (American Geriatrics Society, 1985; Bollet, 1985; U.S.Congress, 1984).

It should also be noted that, even for the small percentage of disputes about life-sustaining technology that become legal cases, not all involve the debilitated elderly. Many have involved young or middle-aged adults, or minors whose parents have refused treatment for them (*In re Quinlan*, 1976; *Brophy vs. New England Sinai Hospital*, 1985; Classen, 1985). In fact, older persons are vastly underrepresented as malpractice plaintiffs generally, since their cases represent difficult evidence problems regarding damages and causation.

There will be some circumstances where differences involving issues that raise fundamental values, rights, and interests cannot be satisfactorily reconciled by the

parties themselves. Impasses may result from a clash between sincere but uncompromising positions held by different parties, or because of hidden agendas promoted by persons who do not have the patient's best interests foremost at heart. In either case (and such impasses are relatively rare), the judicial system may be the most appropriate decisionmaking forum of last resort—not because judges are automatically imbued with greater wisdom than others, but because the courts can provide a degree of objectivity, fairness, and authority that is unmatched by any other societal or individual formal arena of issue resolution (Baron, 1984; Dresser, 1985).

The Myth of Unreasonableness

Another myth holds that the law surrounding decisionmaking about life-sustaining technologies is basically inconsistent with sound clinical judgment, reason, and ethical imperatives; that it is formulated in a vacuum, based solely on abstract theory, and out of touch with clinical realities. The assumption is that "changes in the law" (generally unspecified) are needed to allow more ethically and clinically reasonable care (Sherlock and Dingus, 1985). As one author prefaced her call for such changes, "Since [the law] does not consider patient sensibilities or base decisions on individual need and sound bioethical principles, . . ." (Whiteneck, 1985).

We hear voiced a lack of faith in the ability of the political system (e.g., hospice statute and regulations) and the common law (law as announced by courts in the context of individual lawsuits, with decisions based on general societal principles, customs, traditions, and legal precedent in similar factual cases) to adapt reasonably to emerging issues concerning the use of life-sustaining technologies. It is not unusual today to hear criticisms by medical professionals, in response to their interpretations of legal decisions, that the law, legal system, and lawyers act as an essentially negative force in medical decisionmaking, a force that often flies in the face of good clinical judgment,

sound ethical principles, and human compassion (Connery, 1980). We hear complaints often about the unnecessary cost and turmoil of "defensive medicine" and the need to "treat the attorney" rather than the patient or the family. One influential group of physicians who are quite familiar with life-sustaining technology issues has written that "fear of legal liability often interferes with the physician's ability to make the best choice for the patient" (Wanzer, 1984).

Certainly, in the area of life-sustaining technologies, the state of the law is not definitively settled, and anomalous legal decisions may occur in any sphere of developing, evolving social policy. For the most part, though, the developing law concerning life-sustaining technologies appears to be highly consistent with, and supportive of, clinical judgment, reason, shared ethical precepts, and compassion for the emotional and spiritual well-being of all participants in this human drama (Ball, 1984; Baron, 1984; Lo, 1984; Dresser, 1985; Dresser and Boisaubin, 1985).

To begin, judges recognize that good law, as well as good ethics, depends in the first instance on the collection and analysis of good facts. Particularly in a scientifically sophisticated field such as life-sustaining technologies, therefore, courts look carefully and respectfully to the clinicians most directly involved in a patient's care to inform the legal process concerning relevant clinical facts about the patient's condition and prognosis. Courts use provider-supplied clinical data as the basic building blocks upon which legal rules and social policy are constructed, as the legal process strives to draw legally and ethically meaningful analogies and distinctions among cases presenting different facts. Some of the most recent judicial decisions have been well-publicized as inconsistencies — for example, the purportedly conflicting results in the Bartling (Bartling v. Superior Court, 1984b; see Scherer, 1985; Lo, 1986) and Bouvia (Elizabeth Bouvia v. County of Riverside, 1984) cases, both of which involved a competent adult, and the inconsistent legal outcomes between the Barber (Barber and Nejd v. Superior

Court, 1983) case and the Conroy (In re Conroy, 1983) intermediate appellate decision (which many overlook was later reversed on appeal) (In re Conroy, 1985; see Cantor, 1985; Curran, 1985), both of which involved withdrawal of tube feeding from an incompetent person. But these may be due not to the respective courts being ignorant of the clinical realities, but precisely to those courts being attuned to the differing physical and mental conditions of the involved patients and the different types of proposed medical interventions (Annas, 1983).

One illustration of the use of clinical data in judicial decisionmaking is the way that courts handle the highly controversial "quality of life" issue. Courts that have considered this issue have unanimously rejected the concept as a valid criterion in treatment decisionmaking for an incompetent patient, maintaining that each person's life is of infinite worth. However, most judicial opinions in this area implicitly consider this factor anyway, but in the guise of the patient's "persistent vegetative state" (In re Quinlan, 1976) or irreversible absence of cognition or sapience. In other words, the same issue is framed in medical, rather than moral, terms, for psychological reasons. Regardless of how the issue is described, the courts need and use clinical data in order to arrive at just, humane conclusions.

The problem faced by the courts here is the same as that encountered by clinicians, patients, and families — namely, good facts upon which to build good law and good ethics may at times be exceedingly difficult to obtain. Making and communicating diagnoses and prognoses in the context of life-sustaining technologies is frequently an uncertain and imprecise process more dependent on art than on science (Meier and Cassel, 1983; Lo, 1984; Billings, 1985) and incapable of giving the courts clear and unequivocal facts for their decisions. Nonetheless, courts faced with difficult decisions concerning the care of critically ill patients uniformly turn to clinicians for an account of the clinical data to be considered in fashioning sound remedies and rules.

Beyond the evolving law's general consistency with such clinical data as are available, there also appears to be a strong congruency between the great bulk of published legal opinions and the emerging (although not unanimous) ethical consensus (see discussion of voluntary guidelines later in this paper) on issues concerning life-sustaining technologies. The ethical emphasis on patient autonomy and self-determination in medical decisionmaking is at the heart of every judicial decision in this area, as courts have held that the right to make decisions about one's own medical care is embodied in both the common law right to bodily integrity and the constitutional right to privacy (and, in some cases, in the constitutional protection of religious freedom as well). Except for a few cases where the interests of third parties were deemed compelling (*John F. Kennedy Memorial Hospital v. Heston*, 1971), the courts have consistently ruled that mentally competent adults possess the right to decline even life-saving medical interventions, while the autonomy of incompetent patients has been safeguarded by application of the "substituted judgment" test that asks what the individual would have wanted if personally capable of deciding. There is nothing unsound, unreasonable, or unethical about this legal approach.

Procedurally, the courts (e.g., *Matter of Spring*, 1980; *Leach v. Akron General Medical Center*, 1980; *Severns v. Wilmington Medical Center, Inc.*, 1980) have overwhelmingly — with the notable exceptions of the Saikewicz case, which was severely limited by subsequent Massachusetts decisions (*Matter of Spring*, 1980), and of the Eichner and Storar cases from New York, which allow for no substitute decisionmakers — recognized and encouraged the vital role of family members and attending clinicians in exercising an incompetent patient's rights on his or her behalf. (On the importance, including the legal value, of encouraging family involvement in medical decisionmaking for an incompetent patient, see Brody, 1985; Erstling, 1985; Sherlock and Dingus, 1985; see also Ad Hoc Committee on Medical Ethics, 1984, on why the family has no legal status in decisionmaking when the patient is competent.)

Substantively, the judiciary has adopted guidelines for the surrogate exercise of such rights according to the generally endorsed ethical principle of proportionality or benefit/burden ratio. It cannot credibly be claimed that these legal developments constrain desirable decisionmaking concerning life-sustaining technologies or that they compel the opposite, although cases like Saikewicz, Eichner, and Storar do foster the medical profession's impression of the law as inconsistent and complex.

In addition, the law affirmatively encourages, and in an increasing number of States expressly enables, cooperation and collaboration among patient, family, and caregivers in a process of advance health care planning designed to avoid many of the difficult and emotion-laden dilemmas that arise in critical care medicine where adequate advance planning has not occurred. Most deaths today happen in health care institutions and a majority of these deaths are expected by physicians (Tolle, et al., 1985). Legal enablement of advance health planning takes the form of legislative and/or judicial recognition of legal instruments such as living wills and durable powers of attorney to effectuate the wishes of a once-competent patient in the event of subsequent incompetence (see President's Commission, 1983; Kapp and Bigot, 1985). Again, such legal developments are well in line with the weight of current professional judgment, ethical analysis, and public opinion.

The Myth of Inflexibility

The common lament that legal requirements are too simpleminded, rigid, and inflexible to accommodate easily to clinical realities and contingencies is the flip side of the previously discussed myth that the law is too ambiguous and nondefinitive to provide sufficient guidance to participants involved in decisions concerning life-sustaining technologies. The inflexibility myth misjudges both the intent and the effect of the law in general, and in this sphere particularly.

It is true that legal rules that are too rigidly and inflexibly drawn and interpreted will necessarily fail, for at least two reasons. First, it is not humanly possible for a lawmaking body (or a medical professional) to anticipate all contingencies that might arise concerning life-sustaining technologies (or any other matter) and to draft definitive laws comprehensive enough to directly cover them. Any attempt to do so would impose unnecessary constraints without corresponding benefits. Second, excessively inflexible legal requirements erode the exercise of discretion and judgment by the actors, and thus impinge on the autonomy of patient and family and on the professionalism of the caregivers. It is by asking for cut-and-dried, risk-free legal answers that medical professionals risk forfeiting their ethical and clinical freedom (Whiteneck, 1985).

Legislators and jurists are cognizant of these inherent limitations of the law. What is developing, therefore, is the legal setting of broad boundaries, beyond which lies conduct that most people would agree is unacceptable, but within which the participants are afforded substantial leeway to exercise judgment and discretion based on personal values and aspirations (President's Commission, 1983). For medical professionals, the crux is not to curse the law for manufactured defects, but rather to know its limits and to acknowledge and embrace the discretion that the law permits and even promotes among medical professionals, patients, and families. While it is the role of law to establish societal rules, it is ordinarily the physician's role, in consultation with patient and family, to apply society's rules to particular circumstances.

The Myth of Lethargy

The final myth explored in this paper is the claim that the law is too slow and lethargic in responding to emerging clinical controversies. This is the mirror image of the complaint that the legal system is too anxious and quick to gratuitously intrude into private, personal matters. Many who eagerly criticize the ubiquitous presence and

expanding role of attorneys in contemporary society are the same persons who shout that "there ought to be a law" as a means to "escape from [the] freedom" (Fromm, 1941) that is imposed by the awesome responsibility to exercise judgment and discretion in life-and-death affairs. It is a paradox that no one wants to be told what to do, but everyone desires the security that comes with clear prescriptions and proscriptions.

The law does react slowly to emerging clinical controversies, but this is not a sign of lethargy. Rather, it is (at least ideally) an indication of deliberation and care. Such a methodically paced process is more likely to produce better legal outcomes, allowing for a greater opportunity to gather evidence, hear arguments from interested parties, and engage in more thoughtful analysis of and reflections about competing points and perspectives (Siegler and Weisbard, 1985). Too, the law generally attains a larger degree of public acceptance and respect when it follows and codifies a widespread ethical consensus on a sensitive issue. Problems with public respect for the law often arise when the law makes the error of moving out ahead of the general community too far and too fast in the absence of substantial ethical agreement. We can avoid or minimize the harm of this happening in the realm of life-sustaining technologies by withholding criticism of the law for patiently and cautiously embodying, rather than trying to anticipate, the growing ethical consensus surrounding the delivery or termination of various types of medical care to critically ill persons. The law must react when needed, not preempt merely for the sake of activity.

One further point is in order. While the law is properly deliberate in developing broad rules and policies, expeditious hearings to apply the rules to particular patients can frequently be obtained. For example, hospital attorneys are adept at getting emergency court orders authorizing treatment for incompetent patients or minors.

INFLUENCE OF MEDICAL DECISIONS ON PERCEPTIONS ABOUT THE LAW

Physicians' Responses to Perceptions of the Law

Because of their fears and uncertainty about the law, physicians sometimes make decisions out of public view. They may attempt to avoid justifying or documenting decisions. In a study of DNR orders in San Francisco, physicians in 4 of the 136 cases studied gave oral orders to nurses not to resuscitate patients in case of cardiopulmonary arrest, but purposely did not write the orders in the medical records. In these four cases, the physicians disagreed with the families of incompetent patients about the decisions (Lo, et al., 1985).

In six cases, the physicians gave "limited," "slow," or "partial" code orders (Lo, et al., 1985). These orders meant that basic cardiopulmonary resuscitation would be started, but that advanced cardiac life support, such as intubation and mechanical ventilation, would be withheld. Again, these decisions generally were used in cases of disagreement with patients or families. Such limited or oral orders may cause confusion, however, and create legal jeopardy for nurses. In addition, they greatly decrease the likelihood of successful resuscitation. Limited attempts at resuscitation may seek to convince the family that "everything was done." But they provide no benefit to the patient and cause cynicism among the nursing and medical staff (Lo and Steinbrook, 1983). Thus they cannot be justified, unless the patient agrees with them.

Physicians may believe that their risk of liability is decreased if they do not give written orders or discuss their decisions in the medical records. This belief is unsound risk management policy. Moreover, it violates the ethical ideal that difficult decisions should be made openly and justified.

Another effect of these perceptions about the law is that life-sustaining treatment may be continued on incompetent patients, whether or not it is medically or ethically appropriate. After the Saikewicz case in Massachusetts, many incompetent patients had life-sustaining treatment applied or continued. One expert in health law described a dying woman who was resuscitated 70 times in a 24-hour period, a brain-dead patient in whom placement of a cardiac pacemaker was planned, and family members who had to bar the door of a patient's room to prevent resuscitation (Annas, 1982). In all cases, the treatment was recommended by hospital counsel. The expert wrote, "Physicians should know at least enough law to be able to tell when the advice their lawyers are giving them is so incredible that it is most likely wrong" (Annas, 1982).

Similarly, while Drs. Barber and Nejdli faced criminal charges for discontinuing intravenous fluids on a comatose patient, many physicians in California were reluctant to discontinue any life-sustaining treatment on incompetent patients. An expert in bioethics said that the prosecution created "terror" among physicians who must decide about life-sustaining treatment for comatose patients (Rohrlich, 1983). He cited a case in which physicians refused to disconnect a ventilator from a brain-dead patient, even though this procedure is expressly permitted by California law (and the law of most other States as well).

There are several reasons why physicians generally are less concerned about legal jeopardy for continuing life-sustaining treatment over objections than they are about legal liability for withholding life-sustaining treatment. Hospital administrators similarly seem less concerned about the legal risks of continuing life-sustaining treatment, as discussed earlier. Court proceedings initiated by patients and families to require physicians to withhold or withdraw life-sustaining treatment have not generated much adverse publicity for the physicians. Similarly, the possibility of civil malpractice actions seems remote and unlikely to stigmatize physicians. The public seems willing to

accept physicians' justification that in questionable or doubtful cases, they should continue life-sustaining treatment rather than allow a patient to die.

Physicians' perceptions of the law may also cause them to practice defensive medicine. They may order additional tests or follow-up visits. The American Medical Association claims that defensive medicine may be costing as much as \$24 billion a year (AMA Special Task Force on Professional Liability and Insurance, 1985). But it is difficult to define defensive medicine exactly: "Does the term cover all tests and procedures, however medically defensible, if the principal motivation of the provider in calling for these measures is a fear of litigation? Or, does it, rather, encompass only measures which have no medical justification and thus, are undertaken solely to guard against legal liability?" (Rosoff, 1985). Moreover, there are little good data on the scope of defensive medicine. One 1980 study reported that medicolegal considerations are a contributing factor in only 1 percent of all test orders (Wertman, et al., 1980).

Inconsistencies Between Law and Medical Practice

Medical practice is inconsistent with the law in fundamental ways. For example, clinical assessment of whether a patient is mentally incompetent may differ markedly from legal requirements. Strictly speaking, competence is a legal concept. An adult person is presumed to be competent until the courts declare that person incompetent and appoint a guardian. But in medical practice such legal proceedings are rarely initiated. Instead, if an elderly person is deemed incompetent by caregivers, family members are usually asked to make decisions on behalf of the patient. It is not clear why clinical practice so diverges from legal standards. Physicians may be ignorant about the precise legal definition of competency or may regard legal proceedings as too cumbersome and time-consuming, with insufficient benefits to justify the costs.

The danger of such informal assessments of competency is that elderly patients

may be inappropriately denied control over decisions about their medical care. This possibility is especially worrisome because caregivers may apply standards of competency that are quite different than the legal ones. While there are no rigorous studies on the issue, often these assessments of competency are based on the mental status examination, which tests whether the patient is oriented, has intact memory, and can perform simple calculations. If there is a question about a patient's competence, it is far more likely that a psychiatrist will be asked to see the patient and do a more elaborate mental status test than that the courts will be asked to settle the question. But using the mental status test to assess competency may be inappropriate. From a legal and ethical perspective, the correct standard for incompetence is that the patient is unable to comprehend the nature of the tests or treatment, the risks and benefits, the alternatives, and the likely consequences of his or her decision.

A fundamental question is who should make decisions for incompetent patients about life-sustaining treatment. As discussed in the other papers in this volume, the competent patient should make decisions. If the patient is incompetent, a representative of the patient should decide. The presumption is that the family of an incompetent patient should make decisions. In some cases, it is appropriate for the courts to appoint a legal guardian.

Medical practice, however, may be inconsistent with this standard; patients and families often are not involved in decisions about life-sustaining treatment. The study of DNR orders in three San Francisco teaching hospitals illustrates this problem. DNR orders had been considered in 136 of 3,282 patients admitted to the medical services; 18 percent of competent patients did not participate in such decisions. Reasons given by physicians for not involving patients in decisions were family requests that the patient not be involved and the belief that the patients' wishes were already known (Lo, et al., 1985). Physicians are unable to determine accurately patient preferences about

resuscitation, however, without asking them directly (Bedell and Delbanco, 1984). Similarly, in two other studies of DNR orders, 18 to 20 percent of competent patients did not participate in decisionmaking (Evans and Brody, 1985).

When patients are considered incompetent, families often do not participate in decisions. In the study of DNR orders in San Francisco, families of incompetent patients participated in decisions in only 81 percent of the cases. Physicians' reasons for not involving families in decisions included a fear that families would disagree with the DNR order; difficulties physicians had talking with families; the belief that medical indications were decisive; and the patient's prior request that the family not be involved (Lo, et al., 1985).

Thus, there is a significant discrepancy between legal and ethical guidelines about life-sustaining treatment and actual practice. The lack of involvement by families of incompetent patients in decisions is particularly worrisome because the courts are also not involved in these decisions. In the San Francisco study, the courts were not involved in any of the 136 cases in which DNR orders were considered, even though patients were regarded as incompetent in 56 percent of the cases (Lo, et al, 1985).

In some situations, the courts may not need to appoint a guardian to make such decisions regarding incompetent patients. Specifically, several courts have ruled that guardianship proceedings are not required if the patient is in a persistent vegetative state, and if all family members and the physician agree with the decision. It seems that it might be prudent to go to court if there is no family or if family members disagree among themselves or with the physician. (For further discussion of these situations, see the other papers in this volume.)

Once again, medical practice may not be consistent with these legal and ethical recommendations. In the study of DNR orders in San Francisco, 20 cases involving incompetent patients fit these standards for judicial review (Lo, et al., 1985). In 12 cases, the patient was incompetent and there was no family. In 4 cases, the family disagreed with the physician, and in 2 other cases, the family members could not agree among themselves. Thus in 20 of 3,282 hospital admissions to the medical service (0.6 percent), ethical and legal guidelines would recommend involving the courts. This did not happen, however. Instead, physicians made decisions unilaterally in these cases and in no case was the physician charged with civil or criminal liability. Although it is not clear why these cases were not taken to court, physician concerns about the delays in the legal system probably were an important factor.

Another inconsistency is that certain distinctions traditionally made in the law are not accepted in medical practice. The distinction between stopping treatment and not starting it troubles many caregivers, even though philosophers have argued that there is no significant moral difference (Burt, 1981; Lo, 1986). A reason that justifies not starting a treatment also justifies stopping it. Moreover, accepting this distinction may have unintended and undesirable consequences. Caregivers may be reluctant to initiate a potentially useful treatment because they fear that they will have to continue it indefinitely. Recent court decisions also have rejected this distinction (Barber v. Superior Court of the State of California, 1983; In the Matter of Claire C. Conroy, 1985).

Ironically, arguments to discontinue treatment may be more compelling than arguments not to initiate treatment. If a treatment has been started and proved unsuccessful, it can be discontinued because it provides no medical benefit to the patient. However, caregivers often are reluctant to discontinue life-sustaining treatment, even though they would not start the treatment under similar circumstances. They may even feel that stopping treatment is a direct action that kills

the patient.

A 1983 case in Washington, DC, illustrates the reluctance of caregivers to discontinue treatment (Weiser, 1984). Nurses in the intensive care unit felt uncomfortable discontinuing the ventilator from a young patient whose coma was judged irreversible by the attending physicians and whose family wanted treatment discontinued. The nurses refused to physically discontinue the ventilator; their disagreement required the chief of medicine and the chief of nursing to intervene in the case. After an emergency weekend meeting, the attending physician himself had to disconnect the ventilator. Similarly, caregivers may be reluctant to discontinue intravenous fluids or tube feedings once they have been started.

The distinction between ordinary and extraordinary care illustrates another difference between clinical practice and law. Clinicians commonly refer to expensive, highly technological, unusual, or experimental treatments, such as artificial hearts, as extraordinary or heroic. In contrast, simpler, more common treatments like intravenous fluids may be considered ordinary care. Recent court decisions have rejected this distinction (Jonsen, 1984). In agreement with philosophical arguments, the courts have ruled that all treatments may have both therapeutic effects and side effects. If the burdens of treatment outweigh the benefits to the individual patient, then the treatment is disproportionate and not appropriate (*Barber v. Superior Court of the State of California*, 1983; *In the Matter of Claire C. Conroy*, 1985). Thus, to decide whether a treatment is appropriate we must look at the benefits and burdens to an individual patient, not at the nature of the technology. In other words, one cannot say that a ventilator is "heroic" rather than "ordinary." For some patients, like the postoperative individual, mechanical ventilation is indicated, because its benefits are far greater than the burdens. For an irreversibly comatose patient, however, the benefits of mechanical ventilation are few, and the treatment is usually not indicated.

Yet, the terms "benefits" and "burdens" are ambiguous and rarely used by clinicians. While caregivers may use the terms risks and benefits, these terms are usually applied only to medical effects and complications, such as the risk of bleeding or infection. Clinicians usually do not use "risk" to refer to loss of dignity or privacy, which may be important considerations to many patients.

The belief that artificial feedings, such as through nasogastric or gastrostomy tubes, are "ordinary" care is particularly persistent (Callahan, 1983; Lo and Dornbrand, 1984; Dresser, 1985; Meyers, 1985; Siegler, 1985). Some caregivers may consider feeding to be basic, humane care, like a warm, clean bed, that must always be given. Undoubtedly feeding has emotional and symbolic significance as nourishment and affection. Some writers acknowledge philosophical arguments against regarding feeding as ordinary care but are reluctant to withhold artificial feeding on a wide scale (Siegler, 1985). However, as noted earlier, the courts have rejected the claim that feeding is ordinary care (Barber v. Superior Court of the State of California, 1983; In the Matter of Claire C. Conroy, 1985; see also Dresser, 1985; Meyers, 1985). For each patient, the burdens and benefits of artificial feedings must be weighed. Like any other medical intervention, feedings by nasogastric or gastrostomy tubes or intravenous lines may cause complications. Moreover, for patients with severe dementia or irreversible coma, the benefits may be slim (Lo and Dornbrand, 1984).

Another inconsistency between law and medical practice is in the use of ambiguous phrases or slogans (Jonsen, et al., 1982; President's Commission, 1983). These terms cause confusion and misunderstanding because physicians and the law may use them in different ways, or there may be no explicit definition.

The term "terminal illness" presents many problems. As mentioned already, the definition of terminal illness adopted by Medicare (6 months' survival) may be impractical because physicians cannot predict a prognosis accurately. There are also

more fundamental problems with this term. The Medicare definition is arbitrary and may not be accepted by many caregivers or patients. Some people may consider a person who is expected to live 6 months terminal, while others may regard a patient as terminal only when survival is expected to be 1 month or 1 week. Some physicians consider patients terminally ill only when they are moribund and will die in a few days no matter what treatment is given. Some people may consider a patient terminal when cancer is first diagnosed, while others apply this label only after metastases develop or a relapse occurs after treatment.

Although the phrase "terminal illness" is often used in living will, it is usually not defined. Under the California law, for example, two physicians must certify that the patient is terminal, but the criteria for such certification are not specified. Reasonable people may disagree on these interpretations. For living wills, the most important interpretation may be that of the patient. A patient who feels that life is valuable may not regard himself or herself as terminally ill, although others do.

POLICY ISSUES

Alternatives to Court

Because of problems with asking the courts routinely to decide cases involving life-sustaining treatment for patients who are incompetent, policies that permit alternatives to court would be useful. (For a review of the two main alternatives, living wills and durable powers of attorney for health care, see the paper by Annas and Glantz in this volume.)

Other alternatives to the courts for resolving disagreements over life-sustaining treatment for incompetent patients include institutional ethics committees, proposed as forums for discussing difficult cases and for resolving disagreements between caregivers

and families of incompetent patients (Cranford and Doudera, 1984; Fost and Cranford, 1985). Among other functions, ethics committees may review and make recommendations. However, there are many unanswered questions about them. There is no evidence that ethics committees are effective in resolving disagreements or that their recommendations are consistent with ethical guidelines. Recommendations by a majority of a committee need not necessarily be consistent with the ethical and legal principles of following the preferences or best interests of patients.

Moreover, important procedural questions need to be answered, such as who may bring cases to the committee and whether patients may be represented before the committee. Although little is known about how ethics committees currently function, some may not adequately protect the interests of patients. In a 1982 survey, only 25 percent of ethics committees that reviewed cases allowed patients to bring cases to the committees. Only 19 percent allowed patients to attend committee meetings and 44 percent allowed families to do so. Limiting access to ethics committees, however, may cause patients or families to object that decisions about their medical care are being made without their participation.

The legal status of ethics committees is uncertain, although many legal experts feel that advice from an ethics committee may help caregivers in the courts. Seeking consultation with an ethics committee may demonstrate that the caregivers were willing to discuss decisions openly and to follow ethical principles agreed upon. The Torres case in Minnesota illustrates how the legal status of ethics committees needs to be clarified (In the Matter of the Conservatorship of Rudolfo Torres, 1984). Torres was in a persistent vegetative state following cardiopulmonary arrest. The appeal questioned whether a court-appointed conservator could authorize removal of his ventilator. Evidence introduced indicated that three area ethics committees would favor removal of the ventilator. The hospital hoped that such evidence would establish a community

standard for appropriate decisionmaking and treatment for such patients. The Minnesota Supreme Court affirmed a lower court ruling allowing removal of the ventilator. The decision affirmed that a court order was not necessary in this case but did not comment on how ethics committees might serve a positive role in such cases. Thus, it remains unclear how ethics committees might avoid court involvement or delays.

Another alternative to regular court involvement exists. In response, at least in part, to the perception and fear of legal intrusion into medical matters, a number of voluntary (i.e., nongovernmental) guidelines for decisionmaking concerning life-sustaining technologies have been developed. These voluntary guidelines take a number of different forms: statements by official professional organizations (e.g., JAMA, 1980; American Geriatrics Society, 1985; JAMA, 1985) and by ad hoc groups of individuals (Concern for Dying, 1983; Wanzer, et al., 1984; Smith and Bodai, 1985), which sometimes have an interdisciplinary composition (e.g., Hoyt and Davies, 1984; Task Force on Supportive Care, 1984; Crawshaw, et al., 1985); statements on the broad area of life-sustaining technologies (e.g., Wanzer, et al., 1984) or with a narrower concentration, usually DNR orders or artificial feeding (President's Commission, 1983, p. 493; Evans and Brody, 1985; Miles and Crimmins, 1985); and statements that are concerned with substantive principles alone (e.g., Miles and Ryden, 1985), with procedures alone (e.g., President's Commission, 1983, pp. 439-442), or with a combination of the two (e.g., President's Commission, 1983, pp. 501-505).

There is another way to characterize voluntary guidelines in this area. A distinction may be drawn between voluntary guidelines that attempt to codify and restate current law, on one hand, and those guidelines that consciously go beyond (but not necessarily in opposition to) existing law, and therefore attempt to stimulate (rather than quell) legal debate and influence the development (or the clarification and precision) of the law, on the other hand.

Most voluntary guidelines fall within the first category, as attempts to codify and restate the group's understanding of current legal boundaries (e.g., Ad Hoc Committee on Medical Ethics, 1984). It is widely accepted, and experience appears to confirm, that institutional adoption of guidelines concerning the use of life-sustaining technologies can protect the health care institution and involved professionals from legal liability for decisions made and actions taken in accordance with those guidelines (U.S. Congress, 1984; Evans and Brody, 1985; Miles and Crimmins, 1985; Miles and Ryden, 1985). Such policies should be clear, reasonable, and legally consistent (to the extent the jurisdiction's law can be ascertained), and implemented in a fair, good faith, documented manner. Institutions have been urged to adopt and implement such internal guidelines (Clayton, 1985; Hirsch, 1985; Miles and Ryden, 1985).

Voluntary guidelines that purposely and conservatively embody existing law are not without criticism. Cassel has warned of the danger that voluntary guidelines that too closely resemble regulations may be more motivated by risk management avoidance of lawsuit considerations (i.e., primarily economic incentives) than by concern for the patient (Cassel, 1984). She urged that guidelines be motivated by ethical convictions rather than risk management precepts, an admonition echoed by Hunter (Hunter, 1985), who argues that a policy and process that devolve to mere risk management is too one-dimensional, ignoring important ethical and emotional concerns. But, she adds, adoption and implementation of a fair, reasonable policy will — incidentally — be a good hedge as well (see also Kapp, in press). Keeney (in Childress, 1984/85) has observed that, while conservative guidelines are useful, difficult life-sustaining technology issues cannot be decided by a "cookbook" approach; rather these cases should remain hard, but not impossible.

Some voluntary guidelines consciously go beyond current legal boundaries (to the extent that they have been enunciated), for the purpose of influencing changes in the law (Lynn, 1984; Wanser, et al., 1984; Gordon and Hurowitz, 1985). The Harvard brain death criteria are an excellent example of this. There is a recognition that the law should unfold by slow evolution, following and embodying formation of an ethical consensus (U.S. Congress, 1984), and such voluntary guidelines try to promote that evolution by providing evidence of a fermenting ethical consensus.

The physician who acts in accordance with voluntary guidelines that purposely go beyond enunciated legal boundaries (e.g., by removing a feeding tube from a non-terminally ill patient in the absence of a statute or judicial decision explicitly authorizing such action in that particular jurisdiction) perhaps operates at higher legal risk than the physician who follows (and documents compliance with) voluntary guidelines that specifically track applicable statutes or court decisions. Nonetheless, there are no reported legal cases where after-the-fact liability has been alleged (much less found) against a physician or other health care provider or institution for rendering care that was inconsistent with relevant voluntary guidelines. And by fostering such guidelines, the physician may be helping to improve medical care and legal and ethical standards. Although declaratory and injunctive relief have been sought a few times against formal or ad hoc institutional policies (e.g., *Bartling v. Superior Court*, 1984b; *Elizabeth Bouvia v. County of Riverside*, 1984), arguably the existence of such policies allowed disagreements to be resolved prospectively, rather than retrospectively through malpractice suits for damages.

Potential for Federal Legislation

The President's Commission observed that "very little attention has been given to providing programmatic incentives for good decisionmaking practices or disincentives against inadequate ones" (1983). There may be a role for legislation in molding those incentives, especially in light of many court decisions that urge boundary setting by the legislature as preferable to broad precedent announcements by the judiciary (Barber and Nejdil v. Superior Court, 1983; In re Conroy, 1985). It may be possible for legislation to narrow the gap between legal perceptions and medical decisionmaking, and thus positively contribute to more humane and sensible use of life-sustaining technologies.

Mechanisms for Action

For the Congress, there are two types of action that can be taken: direct command and control requirements, and requirements tied to financing.

Congress could enact direct command and control requirements governing medical care that is both directly financed and provided by the Federal Government. This would include medical care provided through the military, Veterans' Administration, Public Health Service, and Indian Health Service.

For non-Federal health care institutions, Federal attempts to control medical practice through direct command and control regulation would be problematic from both a legal and a policy viewpoint. Legally, the regulation of medical practice has traditionally been considered a power constitutionally reserved to the States (e.g., professional licensure and discipline, definition of medical malpractice standards and informed consent requirements, delineation of physician/patient confidentiality, or determination of patient competency). Congress would be hard-pressed to persuasively cite Constitutional authority empowering direct Federal intrusion into medical practice

via straight command and control requirements.

Direct Federal command and control requirements are also inadvisable as a policy matter. Some degree of uniformity across jurisdictions is desirable, both to alleviate part of the anxiety created by inconsistencies among jurisdictions and to deal with potentially troubling conflict of law situations. (For example, when an Indiana citizen executes a durable power of attorney naming a son in Ohio as attorney-in-fact, but then become terminally ill in Florida, the law of which jurisdiction applies?) However, notwithstanding this need for uniformity, individual States should still be given substantial room for innovation and experimentation in testing different approaches to the diverse issues raised by life-sustaining technologies, so that out of these State laboratories we may distill the most successful answers.

Federal legislation tied to Federal health care financing, under Congress' Constitutional taxing and spending power, is a more appropriate mechanism for the Federal Government to use to influence decisionmaking concerning life-sustaining technologies. In contrast to direct command and control requirements, such legislation could create strong economic and political incentives encouraging action, by attaching certain conditions or strings to the receipt of health care dollars under certain categorical Federal programs (e.g., Medicare, Medicaid, CHAMPUS, or elder abuse grants). Since the recipients of Federal health dollars are diverse, legislatively created incentives encouraging specific action could be aimed at States, at individual medical professionals and health care institutions, and at private institutions and organizations.

Examples of Legislation

Federally enacted incentives for specific action could take a variety of forms. The eight examples here are intended to be illustrative to provoke discussion only; they are by no means comprehensive, and no particular endorsement or disavowal should be inferred.

Federal legislation might require, as a condition of State receipt of Federal health dollars (e.g., by attaching to Medicaid grants), that each State enact a natural death or living will statute. Either a single model could be specified (such models currently exist; see National Conference of Commissioners on Uniform State Laws, 1985) or each State could develop its own unique statute. Thirty-six States have already done so. The conflict of laws problem could be addressed by requiring each State to include a provision honoring living wills validly executed in another State. Several living will statutes contain such a reciprocity provision (e.g., Maine Rev. Stat. Ann. Title 22, ch. 710-A, sect. 2930; Maryland Health General Code Ann. sect. 5-612), which treats the living will no differently than any other kind of contract.

Federal legislation might require, as a condition of State receipt of Federal health dollars, that each State enact a durable power of attorney for health care statute. Again, either a single model (Uniform Durable Power of Attorney Act, 1982) or individual State experimentation could be encouraged, and a mandatory reciprocity requirement could be imposed to deal with the conflict of laws issue.

Federal legislation might create incentives for the setting up of Institutional Ethics Committees (IECs) (Cranford and Doudera, 1984). This could be accomplished either by conditioning State receipt of Federal health dollars on the enactment of State statutes mandating that health care institutions set up such committees, or by directly conditioning a health care institution's receipt of Federal dollars upon its establishment

of an IEC. The Model Infant Care Review Committee (50 FR 14893-14901) found in the Federal "Baby Doe" regulations protecting handicapped newborns against discrimination in medical care might be a source of guidance in this regard, with appropriate modifications to reflect geriatric concerns. Although attracting substantial criticism, the final version of these regulations represents the political compromise of diverse professional and advocacy interest groups, and affected institutions have thus far experienced little difficulty in living with these regulations.

Federal legislation already requires health care institutions, as a condition of the receipt of Medicare funds, to have contracts with federally approved statewide Peer Review Organizations (PROs) (Mihalski, 1984) to review the necessity, appropriateness, and quality of medical care provided to Medicare beneficiaries. The legislation creating PROs could be amended to expand the role of these bodies and involve them in prospective, concurrent, and retrospective review of cases raising legal and ethical life-sustaining technology issues, with reimbursement for the care of individual patients dependent upon satisfactory handling of those issues.

Federal legislation could condition State receipt of Federal domestic violence or elder abuse grant dollars on enactment or amendment of an elder abuse and neglect statute that clarifies issues of liability either for withholding or withdrawing life-sustaining treatment, on one hand, or for treating against the patient's wishes, on the other, under that State's criminal and civil law. Such statutes could be encouraged on a uniform basis, on a completely individualized basis, or on an individualized basis within specified Federal boundaries. Again, one model might be the Federal "Baby Doe" legislation (Public Law 98-457) and regulations (50 FR 14878-14892), which tie protection of handicapped newborns into each State's existing child abuse and neglect system and which purport to strike a balance between the sanctity of life and the recognition that in some circumstances medical care may be so futile or disproportionately burdensome as

to be nonobligatory. (The regulations specifically disclaim applicability to adult patients, but there is no logical reason they could not be adapted to adults.)

The value of voluntary, privately derived guidelines regarding the use of life-sustaining technologies was discussed earlier. Federal legislation could create grant programs to fund private groups, especially professional associations, to develop and disseminate applicable policies among medical professionals.

Probably the greatest single need in this area is for education of medical and legal professionals regarding the legal, ethical, and economic issues involved in decisionmaking concerning life-sustaining technologies. Federal legislation could create grant programs to fund medical schools, law schools, health care institutions, and professional associations to develop and implement educational programs for the teaching of health law, medical ethics, and medical economics to medical students, medical residents, practicing physicians, law students, practicing lawyers, and judges, with special emphasis on life-sustaining technology issues.

Federal legislation could create grant programs to fund educational institutions, professional associations, health care institutions, and other private groups for special research and demonstration projects designed to address the issues raised in this paper.

Policy Arguments Regarding Federal Involvement

As these suggested strategies indicate, a number of mechanisms exist for Federal involvement in attempting to reconcile legal perceptions and medical decisionmaking concerning life-sustaining technologies. There are both advantages and disadvantages of such involvement.

One advantage of Federal involvement might be the opportunity for a clarification of the applicable substantive and procedural law. Removing medical professionals' doubt,

ambiguity, and distrust of the law should lead to better substantive decisions and to decisionmaking processes that are more just. Clarification of the law should lead to greater confidence by medical professionals, and should make resort to the courts for advance legal prophylaxis an even less common occurrence than it is presently.

Federal involvement could produce uniformity in the law, which would alleviate confusion and counterproductive action engendered by current inconsistencies among jurisdictions. Even if uniformity is not achieved, Federal legislation could encourage reciprocity among States, so that, for example, there would be no doubt (for patient, family, or medical professional) regarding the legal validity of an advance directive executed in State A by a patient who becomes critically ill in State B.

In the area of grants for policy formulation, education, and other research and demonstration projects, the Federal Government is an appropriate source of funding and of delineation of its goals and objectives. Finally, to the extent that tension between legal perceptions and medical decisionmaking exists and exerts a negative influence over medical care, particularly care involving life-sustaining technologies for the Nation's elderly citizens, both the public and the medical profession look to the Federal Government as a source of legal and moral leadership to help resolve that tension and to facilitate more humane and rational care of the elderly.

There are also counterarguments to Federal involvement at this time. As noted earlier, it may be best to wait for definitive legal enactments until society has reached consensus on the ethical stance regarding life-sustaining technologies. Although such a consensus appears to be forming, arguably we are not at the point yet where it has been adequately achieved.

As also noted above, uniformity in the law may stifle State and institutional experimentation with different approaches to these complex issues -- experimentation from which valuable ideas and models may eventually emerge. A plurality of approaches, at least at this relatively early stage of grappling with these issues, may be preferable to mandating a single model.

New grant programs may unduly burden an already strained Federal budget. Although the potential benefits of funding efforts in policy formulation and professional education are obvious, these benefits may not exceed the pressing current need to control Federal expenditures.

The role the Federal Government could play in addressing the tension that now exists between legal perceptions and medical decisionmaking regarding life-sustaining technologies deserves further thought and discussion. Federal activity can best take the form of encouraging individual States, health care institutions, and professional associations to address the difficult issues raised and to devise innovative policies and mechanisms for resolving those issues. This paper suggests a number of potential avenues of Federal involvement that are consistent with this philosophy.

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**PHILOSOPHICAL ISSUES CONCERNING THE RIGHTS OF PATIENTS
SUFFERING SERIOUS PERMANENT DEMENTIA**

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