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## Introduction and Summary

Americans seem to be increasingly concerned with decisions about death and dying. Why is a subject once thought taboo now so frequently aired by the popular media, debated in academic forums and professional societies, and litigated in well-publicized court cases?

Perhaps it is because death is less of a private matter than it once was. Today, dying more often than not occurs under medical supervision, usually in a hospital or nursing home. Actions that take place in such settings involve more people, and the resolution of disagreements among them is more likely to require formal rules and means of adjudication. Moreover, patients dying in health care institutions today typically have fewer of the sources of nonmedical support, such as family and church, that once helped people in their final days.

Also important, no doubt, are the biomedical developments of the past several decades. Without removing the sense of loss, finality, and mystery that have always accompanied death, these new developments have made death more a matter of deliberate decision. For almost any life-threatening condition, some intervention can now delay the moment of death. Frequent dramatic breakthroughs—insulin, antibiotics, resuscitation, chemotherapy, kidney dialysis, and organ transplantation, to name but a few—have made it possible to retard and even to reverse many conditions that were until recently regarded as fatal. Matters once the province of fate have now become a matter of human choice, a development that has profound ethical and legal implications.

Moreover, medical technology often renders patients less able to communicate or to direct the course of treatment. Even for mentally competent patients, other people must usually assist in making treatment decisions or at least acquiesce in carrying them out. Consequently, in recent years there has

been a continuing clarification of the rights, duties, and liabilities of all concerned, a process in which professionals, ethical and legal commentators, and—with increasing frequency—the courts and legislatures have been involved.

Thus, the Commission found this an appropriate time to reexamine the way decisions are and ought to be made about whether or not to forego life-sustaining treatment.<sup>1</sup> For example, may a patient's withdrawal from treatment ever be forbidden? Should physicians acquiesce in patients' wishes regarding therapy? Should they offer patients the option to forego life-sustaining therapy? Does it make any difference if the treatment has already been started, or involves mechanical systems of life support, or is very costly?

### Summary of Conclusions

Building on a central conclusion of its report on informed consent<sup>2</sup>—that decisions about health care ultimately rest with competent patients—the Commission in this Report examines the situations in which a patient's choice to forego life-sustaining therapy may be limited on moral or legal grounds. In addition to providing clarification of the issues, the Report suggests appropriate procedures for decisions regarding both competent and incompetent patients and scrutinizes the role of various public and private bodies in shaping and regulating the process.

These aims are the only ones that this Commission believes to be within the scope of its role. The Report does not judge any particular future case nor provide a guidebook of the morally correct choice for patients and health care providers who are facing such a decision. Rather, the Commission intends to illuminate the strengths and weaknesses of various considerations and various instruments of social policy. Clarifying the relevant considerations and prohibitions may help decisionmakers, but it may also force them to confront painful realities more directly. The Commission hopes that this Report

<sup>1</sup> "To forego life-sustaining treatment" means to do without a medical intervention that would be expected to extend the length of the patient's life. "Foregoing" includes both the non-initiation of a treatment and the discontinuation of an ongoing treatment. The terms "therapy" and "medical intervention" are used interchangeably with "treatment" in this Report. When a patient's underlying condition is incurable and will probably soon be fatal, "therapy" or "treatment" may not seem entirely apt, because these terms usually imply a curative intervention. Nevertheless, the terms are used here both because no better ones are available and because they are commonly used.

<sup>2</sup> President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, **MAKING HEALTH CARE DECISIONS**, U.S. Government Printing Office, Washington (1982).

will help improve the process, but recognizes that an improved process will not necessarily make decisions easier.

The Report addresses a broad range of problems and patient situations. Serious questions about whether life should be sustained through a particular treatment usually arise when a patient is suffering from a known disease likely to prove fatal in the near future rather than in an unanticipated emergency (where any decisionmaking would necessarily have to be truncated). Life-sustaining treatment, as used here, encompasses all health care interventions that have the effect of increasing the life span of the patient. Although the term includes respirators, kidney machines, and all the paraphernalia of modern medicine, it also includes home physical therapy, nursing support for activities of daily living, and special feeding procedures, provided that one of the effects of the treatment is to prolong a patient's life.

The issues addressed in this Report are complex and their resolution depends not only on the context of particular decisions but also on their relationship to other values and principles. Thus, it is exceptionally difficult to summarize the Commission's conclusions on this subject. The synopsis provided here should be read in the context of the reasoning, elaboration, and qualifications provided in the chapters that follow.

(1) The voluntary choice of a competent and informed patient should determine whether or not life-sustaining therapy will be undertaken, just as such choices provide the basis for other decisions about medical treatment. Health care institutions and professionals should try to enhance patients' abilities to make decisions on their own behalf and to promote understanding of the available treatment options.

(2) Health care professionals serve patients best by maintaining a presumption in favor of sustaining life, while recognizing that competent patients are entitled to choose to forego any treatments, including those that sustain life.

(3) As in medical decisionmaking generally, some constraints on patients' decisions are justified.

- Health care professionals or institutions may decline to provide a particular option because that choice would violate their conscience or professional judgment, though in doing so they may not abandon a patient.
- Health care institutions may justifiably restrict the availability of certain options in order to use limited resources more effectively or to enhance equity in allocating them.
- Society may decide to limit the availability of certain options for care in order to advance equity or the general welfare, but such policies should not be

applied initially nor especially forcefully to medical options that could sustain life.

- Information about the existence and justification of any of these constraints must be available to patients or their surrogates.

(4) Governmental agencies, institutional providers of care, individual practitioners, and the general public should try to improve the medically beneficial options that are available to dying patients. Specific attention should be paid to making respectful, responsive, and competent care available for people who choose to forego life-sustaining therapy or for whom no such therapies are available.

(5) Several distinctions are employed by health care professionals and others in deliberating about whether a choice that leads to an earlier death would be acceptable or unacceptable in a particular case. Unfortunately, people often treat these distinctions—between acts and omissions that cause death, between withholding and withdrawing care, between an intended death and one that is merely foreseeable, and between ordinary and extraordinary treatment—as though applying them decided the issue, which it does not. Although there is a danger that relying on such labels will take the place of analysis, these distinctions can still be helpful if attention is directed to the reasoning behind them, such as the degree to which a patient is benefited or burdened by a treatment.

(6) Achieving medically and morally appropriate decisions does not require changes in statutes concerning homicide or wrongful death, given appropriate prosecutorial discretion and judicial interpretation.

(7) Primary responsibility for ensuring that morally justified processes of decisionmaking are followed lies with physicians. Health care institutions also have a responsibility to ensure that there are appropriate procedures to enhance patients' competence, to provide for designation of surrogates, to guarantee that patients are adequately informed, to overcome the influence of dominant institutional biases, to provide review of decisionmaking, and to refer cases to the courts appropriately. The Commission is not recommending that hospitals and other institutions take over decisions about patient care; there is no substitute for the dedication, compassion, and professional judgment of physicians. Nevertheless, institutions need to develop policies because their decisions have profound effects on patient outcomes, because society looks to these institutions to ensure the means necessary to preserve both health and the value of self-determination, and because they are conveniently situated to provide efficient, confidential, and rapid supervision and review of decisionmaking.

### Incompetent Patients Generally

(8) Physicians who make initial assessments of patients' competence and others who review these assessments should be responsible for judging whether a particular patient's decisionmaking abilities are sufficient to meet the demands of the specific decision at hand.

(9) To protect the interests of patients who have insufficient capacity to make particular decisions and to ensure their well-being and self-determination:

- An appropriate surrogate, ordinarily a family member, should be named to make decisions for such patients. The decisions of surrogates should, when possible, attempt to replicate the ones that the patient would make if capable of doing so. When lack of evidence about the patient's wishes precludes this, decisions by surrogates should seek to protect the patient's best interests.<sup>3</sup> Because such decisions are not instances of self-choice by the patient, the range of acceptable decisions by surrogates is sometimes not as broad as it would be for patients making decisions for themselves.

The medical staff, along with the trustees and administrators of health care institutions, should explore and evaluate various formal and informal administrative arrangements for review and consultation, such as "ethics committees," particularly for decisions that have life-or-death consequences for incompetent patients.

- a State courts and legislatures should consider making provision for advance directives through which people designate others to make health care decisions on their behalf and/or give instructions about their care. Such advance directives provide a means of preserving some self-determination for patients who may lose their decisionmaking capacity. Durable powers of attorney are preferable to "living wills" since they are more generally applicable and provide a better vehicle for patients to exercise self-determination, though experience with both is limited.
- a Health care professionals and institutions should adopt clear, explicit, and publicly available policies regarding how and by whom decisions are to be made

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<sup>3</sup> "Decisionmaking guided by the best interests standard requires a surrogate to do what, from an objective standpoint, appears to promote a patient's good without reference to the patient's actual or supposed preferences." MAKING HEALTH CARE DECISIONS, *supra* note 2, at 179. See also pp. 131-36 *infra*.

for patients who lack adequate decisionmaking capacity.

- Families, health care institutions, and professionals should work together to make decisions for patients who lack decisionmaking capacity. Recourse to the courts should be reserved for the occasions when adjudication is clearly required by state law or when concerned parties have disagreements that they cannot resolve over matters of substantial import. Courts and legislatures should be cautious about requiring judicial review of routine health care decisions for patients with inadequate decisionmaking capacity.

### **Patients with Permanent Loss of Consciousness**

(10) Current understanding of brain functions allows a reliable diagnosis of permanent loss of consciousness for some patients. Whether or not life-sustaining treatment is given is of much less importance to such patients than to others.

(11) The decisions of patients' families should determine what sort of medical care permanently unconscious patients receive. Other than requiring appropriate decisionmaking procedures for these patients, the law does not and should not require any particular therapies to be applied or continued, with the exception of basic nursing care that is needed to ensure dignified and respectful treatment of the patient.

(12) Access to costly care for patients who have permanently lost consciousness may justifiably be restricted on the basis of resource use in two ways: by a physician or institution that otherwise would have to deny significantly beneficial care to another specific patient, or by legitimate mechanisms of policy formulation and application if and only if the provision of certain kinds of care to these patients were clearly causing serious inequities in the use of community resources.

### **Seriously Ill Newborns**

(13) Parents should be the surrogates for a seriously ill newborn unless they are disqualified by decisionmaking incapacity, an unresolvable disagreement between them, or their choice of a course of action that is clearly against the infant's best interests.

(14) Therapies expected to be futile for a seriously ill newborn need not be provided; parents, health care professionals and institutions, and reimbursement sources, however, should ensure the infant's comfort.

(15) Within constraints of equity and availability, infants should receive all therapies that are clearly beneficial to them. For example, an otherwise healthy Down Syndrome child whose life is threatened by a surgically correctable complication should receive the surgery because he or she would clearly benefit from it.

- The concept of benefit necessarily makes reference to the context of the infant's present and future treatment, taking into account such matters as the level of biomedical knowledge and technology and the availability of services necessary for the child's treatment.
- The dependence of benefit upon context underlines society's special obligation to provide necessary services for handicapped children and their families, which rests on the special ethical duties owed to newborns with undeserved disadvantages and on the general ethical duty of the community to ensure equitable access for all persons to an adequate level of health care.<sup>4</sup>

(16) Decisionmakers should have access to the most accurate and up-to-date information as they consider individual cases.

- Physicians should obtain appropriate consultations and referrals.
- The significance of the diagnoses and the prognoses under each treatment option must be conveyed to the parents (or other surrogates).

(17) The medical staff, administrators, and trustees of each institution that provides care to seriously ill newborns should take the responsibility for ensuring good decisionmaking practices. Accrediting bodies may want to require that institutions have appropriate policies in this area.

- An institution should have clear and explicit policies that require prospective or retrospective review of decisions when life-sustaining treatment for an infant might be foregone or when parents and providers disagree about the correct decision for an infant. Certain categories of clearly futile therapies could be explicitly excluded from review.
- The best interests of an infant should be pursued when those interests are clear.
- The policies should allow for the exercise of parental discretion when a child's interests are ambiguous.
- Decisions should be referred to public agencies (including courts) for review when necessary to determine whether parents should be disqualified as decisionmakers and, if so, who should decide the course of

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<sup>4</sup> "A determination of this [adequate] level will take into account the value of various types of health care in relation to each other as well as the value of health care in relation to other important goods for which societal resources are needed." President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *SECURING ACCESS TO HEALTH CARE*, U.S. Government Printing Office, Washington (1983) at 4-5.

treatment that would be in the best interests of their child.

(18) The legal system has various — though limited — roles in ensuring that seriously ill infants receive the correct care.

- Civil courts are ultimately the appropriate decision-makers concerning the disqualification of parents as surrogates and the designation of surrogates to serve in their stead.
- Special statutes requiring providers to bring such cases to the attention of civil authorities do not seem warranted, since state laws already require providers to report cases of child abuse or neglect to social service agencies; nevertheless, educating providers about their responsibilities is important.
- Although criminal penalties should be available to punish serious errors, the ability of the criminal law to ensure good decisionmaking in individual cases is limited.
- Governmental agencies that reimburse for health care may insist that institutions have policies and procedures regarding decisionmaking, but using financial sanctions against institutions to punish an "incorrect" decision in a particular case is likely to be ineffective and to lead to excessively detailed regulations that would involve government reimbursement officials in bedside decisionmaking. Furthermore, such sanctions could actually penalize other patients and providers in an unjust way.

### **Cardiopulmonary Resuscitation**

(19) A presumption favoring resuscitation of hospitalized patients in the event of unexpected cardiac arrest is justified.

(20) A competent and informed patient or an incompetent patient's surrogate is entitled to decide with the attending physician that an order against resuscitation should be written in the chart. When cardiac arrest is likely, a patient (or a surrogate) should usually be informed and offered the chance specifically to decide for or against resuscitation.

(21) Physicians have a duty to assess for each hospitalized patient whether resuscitation is likely, on balance, to benefit the patient, to fail to benefit, or to have uncertain effect.

- When a patient will not benefit from resuscitation, a decision not to resuscitate, with the consent of the patient or surrogate, is justified.
- When a physician's assessment conflicts with a competent patient's decision, further discussion and consultation are appropriate; ultimately the physician must follow the patient's decision or transfer responsibility for that patient to another physician.



- When a physician's assessment conflicts with that of an incompetent patient's surrogate, further discussion, consultation, review by an institutional committee, and, if necessary, judicial review should be sought.

(22) To protect the interests of patients and their families, health care institutions should have explicit policies and procedures governing orders not to resuscitate, and accrediting bodies should require such policies.

Such policies should require that orders not to resuscitate be in written form and that they delineate who has the authority both to write such orders and to stop a resuscitation effort in progress.

- Federal agencies responsible for the direct provision of patient care (such as the Veterans Administration, the Public Health Service, and the Department of Defense) should ensure that their health care facilities adopt appropriate policies.

(23) The entry of an order not to resuscitate holds no necessary implications for any other therapeutic decisions, and the level or extent of health care that will be reimbursed under public or private insurance programs should never be linked to such orders.

(24) The education of health care professionals should ensure that they know how to help patients and family make ethically justified decisions for or against resuscitation; those responsible for professional licensure and certification may want to assess knowledge in these areas.

## The Commission's Inquiry

When the Commission convened in January 1980, it decided to take up first its Congressional mandate to report on "the matter of defining death, including the advisability of developing a uniform definition of death."<sup>5</sup> In July 1981 the Commission reported its conclusions in *Defining Death*<sup>6</sup> and recommended the adoption of the Uniform Determination of Death Act (UDDA), which was developed in collaboration with the American Bar Association, the American Medical Association, and the National Conference of Commissioners on Uniform State Laws.<sup>7</sup>

<sup>5</sup> 42 U.S.C. § 300v-1(a)(1)(B) (Supp. 1981).

<sup>6</sup> President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *DEFINING DEATH*, U.S. Government Printing Office, Washington (1981).

<sup>7</sup> The UDDA states:

An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain

During hearings on this subject, the Commission learned that many people were troubled by the uncertainties about the correct care to provide for patients with serious deficits in "higher brain" functions—such as those required for thinking, communicating, and consciously responding to others or to the environment. Decisions about the care of such patients were seen to be at least as troubling as decisions about those who have permanently lost all brain functions. The most pointed example brought to the attention of the Commission is the group of patients who are so damaged as to be permanently devoid of any consciousness—the most severe brain damage compatible with life.<sup>8</sup> The Commission concluded that the situation of such patients—like Karen Quinlan—merited its attention. In *Defining Death*, the Commission stated an intention to report subsequently on the treatment of patients who are dying but not dead.<sup>9</sup>

The present study was undertaken not merely because of the study on the determination of death but also because of its broader relationship to work done by the Commission in several areas over the past three years. Under its mandate, the Commission is authorized to undertake investigation "of any other appropriate matter...consistent with the purposes of [its authorizing statute] on its own initiative."<sup>10</sup> Decisions about life-sustaining therapy involve the direct and concrete application of the principles of decisionmaking in medicine, which

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stem, is dead. A determination of death must be made in accordance with accepted medical standards.

Ten states and the District of Columbia have enacted the uniform Determination of Death Act by statute. Cal. Uniform Determination of Death Act, amending Health and Safety Code §§ 7180-7183, 1982 New Laws 4451; Colo. Rev. Stat. § 12-36-136 (Supp. 1981); D.C. Code Ann. § 6-2401 (Supp. 1982); Idaho Code § 54-1819 (Supp. 1982); 1982 Md. Laws ch. 327; 1981 Miss. Laws ch. 410; Pa. Uniform Determination of Death Act, Pa. Acts 323 (1982); 1982 R.I. Pub. Laws ch. 411; 1982 Tenn. Pub. Acts ch. 763; Vt. Stat. Ann. tit. 18, § 5218 (Supp. 1981); Wisc. Stat. § 146.71 (Supp. 1982). The UDDA has been "adopted" through the case law by the highest court of two other states. *See Swafford v. State*, 421 N.E.2d 596, 602 (Ind. 1981) (for homicide law); *In re Bowman*, 94 Wash. 2d 407, 421, 617 P.2d 731, 738 (1982). This brings to 37 the number of jurisdictions that have recognized the determination of death through neurological criteria. For a listing of those states with other statutes, *see* DEFINING DEATH, *supra* note 6, at 65, 120-34.

<sup>8</sup> *See, e.g.*, testimony of Dr. Ronald Cranford, transcript of the 3rd meeting of the President's Commission (July 11, 1980) at 20, 23: "The persistent vegetative state...seems to me an even more complex and important issue....these cases of persistent vegetative state are going to become more frequent and they will continue to exist in that state for longer periods of time."

<sup>9</sup> DEFINING DEATH, *supra* note 6, at 4-5.

<sup>10</sup> 42 U.S.C. § 300v-1(a)(2) (Supp. 1981).

was the subject of the Commission's mandated study on informed consent." Such decisions also illustrate the ways questions of equity in the allocation of often scarce and expensive resources are resolved, a subject addressed by the Commission in another mandated study.<sup>12</sup> The present Report thus represents an effort to apply the conclusions of two previous studies to a particular area of current concern, while also responding to some particularly difficult clinical and ethical problems noted in *Defining Death*.

The Commission received testimony and public comment on the subject of this Report at four public hearings in as many cities; witnesses from medicine, nursing, hospital administration, the social sciences, philosophy, theology, and law, as well as patients and family members, testified.<sup>13</sup> It also deliberated on partial drafts of the Report at eight Commission meetings. On December 15, 1982, a final draft was discussed and approved unanimously, subject to editorial corrections.

## Overview of the Report

Part One of the Report examines the considerations common to all decisionmaking about life-sustaining therapy. Chapter One presents historical, cultural, and psychological information to illuminate the social context of the Report. Chapter Two first considers the importance of shared decisionmaking between provider and patient (in which the voluntary decisions of competent patients are ordinarily binding) and the considerations that arise when patients are inadequate decisionmakers, and then discusses constraints imposed by the community's need to ensure that life is protected and that wrongful death is deterred and punished. Traditional distinctions made between acceptable and unacceptable actions to forego treatment are critically scrutinized and their usefulness in sound decisionmaking is evaluated. Chapter Three analyzes additional constraints on patients' choices that arise from the actions of family and care-giving professionals, from society's pursuit of equitable allocation of resources, and from the policies and practices of health care institutions, which are often where these many forces come together.

In Part Two of the Report, several groups of patients whose situations currently raise special public policy concerns are considered. Chapter Four examines decisionmaking for incompetent patients generally, including "living wills" and other advance directives, intrainstitutional review (such as "ethics committees"), and court proceedings. Chapters Five

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<sup>11</sup> MAKING HEALTH CARE DECISIONS, *supra* note 2.

<sup>12</sup> SECURING ACCESS TO HEALTH CARE, *supra* note 4.

<sup>13</sup> A detailed description of the Commission's inquiry appears in Appendix A, pp. 259-74 *infra*.

and Six look at the issues involved in treating two particular categories of incompetent patients—those who have permanently lost all consciousness and seriously ill newborns. Finally, Chapter Seven considers orders not to resuscitate hospitalized patients whose hearts stop beating and recommends institutional policies on such orders.

Extensive appendices follow the Report itself, beginning with a detailed account of the process followed by the Commission in its study. Appendix B reviews some of the medical aspects of caring for dying patients in a format intended to be helpful to clinicians, though it will also be of interest to people concerned with ethics and policy. The remainder of the Appendices consist of various documents that are cited in the text and that might otherwise be difficult for a reader to obtain, including the report of a national survey of hospital ethics committees undertaken for the Commission.

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**Making  
Treatment  
Decisions**

**I**



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# The Setting of the Report

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## The Origins of Public Concern

Death comes to everyone. To a few, it comes suddenly and completely unexpectedly, but to most, it follows an opportunity for leave-taking and for directing to some extent the mode and timing of death.<sup>1</sup> Virtually all people who die in this country will have been under treatment by health care professionals who have, especially in the last four decades, developed powerful means to forestall death. This power is so dramatic that sometimes it seems that medicine aims first and foremost to conquer death. Physicians realize, of course, that the mission of vanquishing death is finally futile, but often they and their patients are quite determined to do all that is possible to postpone the event. Sometimes this objective so dominates care that patients undergo therapies whose effects do not actually advance their own goals and values. Specifically, the drive to sustain life can conflict with another fundamental (and arguably more venerable) objective of medicine—the relief of suffering.<sup>2</sup> Physicians and others who establish health care

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<sup>1</sup> Approximately two million people die each year in the United States. The illnesses causing mortality most often are heart disease (34%), malignancies (22%), and cerebrovascular disease (7%). Traumatic death—including accidents, homicide and suicide—account for 13% of all deaths. Only the relatively few who die very suddenly from accident, heart attack, or stroke are likely to have been without medical attention. Dept. of Health, Education and Welfare, *FACTS OF LIFE AND DEATH*, U.S. Government Printing Office, Washington (1978) at 31-33.

<sup>2</sup> Physicians may not have recognized a duty to prolong life until fairly recently: "The treatise entitled *The Art in the Hippocratic Corpus* defines medicine as having three roles: doing away with the sufferings of the sick, lessening the violence of their diseases, and refusing to treat those who are overmastered by their diseases, realizing that in

policies and practices have come to recognize that the attempt to postpone death should at times yield to other, more important goals of patients.

**Recent Changes in How and Where People Die.** Until this century decisions about medical interventions to prolong life probably appeared more straightforward, for doctors had few effective therapies from which to choose.<sup>3</sup> For most patients, diagnosis of serious illness no longer connotes sure, fairly swift death, requiring of the physician "philosophy and sympathy, not science."<sup>4</sup> Between 1900 and the present, the causes of death have changed dramatically: communicable diseases have declined sharply while chronic, degenerative diseases have become much more prominent. At the turn of the century, influenza and pneumonia were the leading causes of death, followed by tuberculosis and "gastritis."<sup>4</sup> By 1976, these had been supplanted by heart disease, cancer, and cerebrovascular disease<sup>6</sup>—illnesses that occur later in life and that are ordinarily progressive for some years before death. Consequently, those facing death today are more-likely to be aged and to be suffering from one or more ailments for which at least some potentially therapeutic interventions exist. "In this age of surgical derring-do and widespread use of drugs, almost no disease can be said any longer to have a 'natural history'."

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such cases medicine is powerless." Darrell W. Admunsen, *The Physicians' Obligation to Prolong Life: A Medical Duty Without Classical Roots*, 8 **HASTINGS CTR. REP.** 23, 24 (Aug. 1978); Warren T. Reich, *The 'Duty' to Preserve Life*, 5 **HASTINGS CTR. REP.** 14 (April 1975).

One modern formulation of the physician's role toward the terminally ill is found in this statement from the American Medical Association. "The social commitment of the physician is to prolong life and relieve suffering. Where the observance of one conflicts with the other, the physician, patient, and/or family of the patient have the discretion to resolve the conflict." Judicial Council, *CURRENT OPINIONS OF THE JUDICIAL COUNCIL OF THE AMERICAN MEDICAL ASSOCIATION*, American Medical Association, Chicago (1982) at 9, *reprinted in* Appendix C, pp. 299-300 *infra*.

<sup>3</sup> Ivan L. Bennett, Jr., *Technology as a Shaping Force*, in John H. Knowles, ed., *DOING BETTER AND FEELING WORSE: HEALTH IN THE UNITED STATES*, W.W. Norton, New York (1977) at 128-29.

<sup>4</sup> Louis Lasagna, *The Prognosis of Death*, in Orville G. Brim, Jr. et al., eds., *THE DYING PATIENT*, Russell Sage Foundation, New York (1970) at 67, 76.

<sup>5</sup> Monroe Lerner, *When, Why and Where People Die*, in Brim, *supra* note 4, at 5. See also Thomas M. Perry, *The New and Old Diseases: A Study of Mortality Trends in the United States, 1900-1969*, 63 *AM. J. CLINICAL PATHOLOGY* 453 (1975).

<sup>6</sup> *FACTS OF LIFE AND DEATH*, *supra* note 1.

<sup>7</sup> Lasagna, *supra* note 4, at 68.



Just as recent years have seen alterations in the underlying causes of death, the places where people die have also changed. For most of recorded history, deaths (of natural causes) usually occurred in the home.

Everyone knew about death at first hand; there was nothing unfamiliar or even queer about the phenomenon. People seem to have known a lot more about the process itself than is the case today. The "deathbed" was a real place, and the dying person usually knew where he was and when it was time to assemble the family and call for the priest.<sup>8</sup>

Even when people did get admitted to a medical care institution, those whose conditions proved incurable were discharged to the care of their families. This was not only because the health care system could no longer be helpful, but also because alcohol and opiates (the only drugs available to ease pain and suffering) were available without a prescription.<sup>9</sup> Institutional care was reserved for the poor or those without family support; hospitals often aimed more at saving patients' souls than at providing medical care.<sup>10</sup>

As medicine has been able to do more for dying patients, their care has increasingly been delivered in institutional settings. By 1949, institutions were the sites of 50% of all deaths; by 1958, the figure was 61%; and by 1977, over 70%.<sup>11</sup> Perhaps 80% of the deaths in the United States now occur in

<sup>8</sup> Lewis Thomas, *Dying as Failure*, 447 ANNALS AM. ACAD. POL. & SOC. SCI. 1,3 (1980).

<sup>9</sup> The Harrison Act of 1914 restricted access to narcotics, making them available only through a physician's prescription. Harrison Act, 38 Stat. 785 (1914), as amended 26 U.S.C.; Alfred R. Lindesmith, *THE ADDICT AND THE LAW*, Random House, New York (1965) at 3-8. At the turn of the century many of the widely available elixers and patent medicines contained substantial quantities of narcotics. Nicholas N. Kittrie, *THE RIGHT TO BE DIFFERENT*, Johns Hopkins Univ. Press, Baltimore, Md. (1971) at 216-17; James Harvey Young, *THE TOADSTOOL MILLIONAIRES*, Princeton Univ. Press, Princeton, N.J. (1961). See also David E. Kyvig, *REPEALING NATIONAL PROHIBITION*, Univ. of Chicago Press, Chicago (1979) at 33 (describing physicians' reactions to restrictions on medicinal use of alcohol during prohibition).

<sup>10</sup> "The first hospitals for the sick...remained, of course, the least preferred setting for medical treatment, and people with sufficient funds received care at home. But by the end of the colonial period, the almshouse had become a hospital for the poor." David J. Rothman, *THE DISCOVERY OF THE ASYLUM: SOCIAL ORDER AND DISORDER IN THE NEW REPUBLIC*, Little, Brown, Boston (1971) at 43-45. John H. Knowles, *The Hospital*, in *LIFE AND DEATH AND MEDICINE*, W.H. Freeman & Co., San Francisco (1973) at 91.

<sup>11</sup> Lerner, *supra* note 5, at 22; Jack M. Zimmerman, *Experience with a Hospice-Care Program for the Terminally Ill*, 189 ANNALS SURGERY 683 (1979).

hospitals and long-term care institutions, such as nursing homes.<sup>12</sup> The change in where very ill patients are treated permits health care professionals to marshal the instruments of scientific medicine more effectively. But people who are dying may well find such a setting alienating and unsupportive.

Patients who are known to be dying are segregated as much as possible from all the others, and...doctors spend as little time in attendance as they can manage... When [doctors] avert their eyes it is not that they have lost interest, or find their attendance burdensome because wasteful of their talents; it is surely not because of occupational callousness. Although they are familiar with the business, seeing more of it at first hand than anyone else in our kind of society, they never become used to it. Death is shocking, dismaying, even terrifying. A dying patient is a kind of freak. It is the most unacceptable of all abnormalities, an offense against nature itself.<sup>13</sup>

**Meeting Patients' Needs.** With the process of dying prolonged and increasingly institutionalized, new concerns have arisen from and on behalf of dying patients. As in all areas of medicine, care of these patients is shaped by the varying degrees of uncertainty regarding diagnosis and prognosis. On the one hand, for most patients death is not anticipated. One study, for example, found that half the population dies of an illness diagnosed at least 29 months earlier<sup>14</sup>; chronic conditions were the cause of 87% of all deaths in 1978.<sup>15</sup> On the other hand, dying follows no regular path.<sup>16</sup> The varied and somewhat unpredictable nature of the physical course of a

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<sup>12</sup> In a review of 35,381 cancer deaths in Cuyahoga County, Ohio, homes during the period 1957-1974, 65% of the people died in hospitals, 15% in nursing homes, and 20% at home. Arthur Flynn, *Where Do Cancer Patients Die?*, 5 J. COMMUNITY HEALTH 126 (Winter 1979). See also John M. Hinton, *Comparison of Places and Policies for Terminal Care*, 1 LANCET 29 (1979); Roger Pritchard, *Dying: Some Issues and Problems*, 164 ANNALS N.Y. ACAD. SCI. 707 (1969).

<sup>13</sup> Thomas, *supra* note 8, at 2.

<sup>14</sup> Raymond S. Duff and August B. Hollingshead, *SICKNESS AND SOCIETY*, Harper & Row, New York (1968) at 307.

<sup>15</sup> Anne R. Somers, *Long-Term Care for the Elderly and Disabled*, 307 NEW ENG. J. MED. 221 (1982) (quoting Dorothy P. Rice of the National Center for Health Statistics).

<sup>16</sup> Strauss and Glaser have developed a theory involving each patient's "dying trajectory" to describe this process. Barney G. Glaser and Anselm L. Strauss, *TIME FOR DYING*, Aldine Pub. Co., Hawthorne, N.Y. (1968). "It plunges straight down, it moves slowly but steadily downward; it vacillates slowly, moving slightly up and down before diving downward radically; it moves slowly down at first, then hits a long plateau, then plunges abruptly to death." Anselm L. Strauss and Barney G. Glaser, *Patterns of Dying*, in Brim, *supra* note 4, at 129, 131.

dying patient is often a major source of anxiety to the patient, family, and care givers.

Patients frequently are afraid of symptoms and conditions, especially pain,<sup>17</sup> that may accompany the dying process. With appropriate medical management, many of these fears can be allayed. Patients who fear pain do so most often when it is out of control, overwhelming, or chronic, when it comes from an unknown source, or when it warns of devastating injury or death.<sup>18</sup> Each of these sources of fear can be treated. People at the forefront of the hospice movement, for example, have demonstrated that presently available drugs and other techniques can reduce even overwhelming pain to acceptable levels.<sup>19</sup> Some physicians may previously have withheld drugs to control pain out of a fear of addiction,<sup>20</sup> a concern that is unwarranted for dying patients.<sup>21</sup> Moreover, other uncomfortable or dangerous side effects of adequate pain medication can

<sup>17</sup> Peter G. Wilson, *Anxiety and Depression in Elderly and Dying Patients*, in Marcus Reidenberg, ed., *Clinical Pharmacology of Symptom Control*, 66 THE MEDICAL CLINICS OF NORTH AMERICA 1011 (Sept. 1982). See generally, Patrick B. Friel, *Death and Dying*, 97 ANNALS INT. MED. 767 (1982).

<sup>18</sup> Eric J. Cassell, *The Nature of Suffering and the Goals of Medicine*, 306 NEW ENG. J. MED. 639 (1982); Laurence B. McCullough, *Pain, Suffering and Life Extending Technologies*, in Robert M. Veatch, ed., *LIFE SPAN*, Harper & Row, New York (1979) at 118.

<sup>19</sup> Some of the techniques to control pain and other symptoms are given in Appendix B, pp. 275-97 *infra*. St. Christopher's Hospice reports complete control of pain in more than 99% of its dying patients. Cicely M. Saunders, *Current Views on Pain Relief and Terminal Care*, in Martin A. Swerdlow, ed., *THE THERAPY OF PAIN*, J.B. Lippincott Co., Philadelphia (1981) at 215.

Just as people have different understandings of death, so do they view pain differently:

According to Christian teaching, however, suffering, especially during the last moments of life, has a special place in God's saving plan; it is in fact a sharing in Christ's Passion and a union with the redeeming sacrifice which he offered in obedience to the Father's will. Therefore one must not be surprised if some Christians prefer to moderate their use of painkillers, in order to accept voluntarily at least a part of their suffering and thus associate themselves in a conscious way with the sufferings of Christ crucified.

Sacred Congregation for the Doctrine of the Faith, *Declaration on Euthanasia*, Vatican City (1980) at 8; *reprinted in* Appendix C, pp. 300-07 *infra*.

<sup>20</sup> Gerald Klerman has termed this hesitance on the part of physicians, "pharmacological Calvinism." Gerald L. Klerman, *Psychotropic Drugs as Therapeutic Agents*, 2 HASTINGS CTR. STUDIES 80, 91-2 (Jan. 1974).

<sup>21</sup> Marcia Angell, *The Quality of Mercy* (Editorial), 306 NEW ENG. J. MED. 98 (1982); Richard M. Marks and Edward J. Sachar, *Undertreatment of Medical Inpatients with Narcotic Analgesics*, 78 ANNALS INT.

often be mitigated by careful attention to drug schedule, the strength of the medication, or a combination of these.<sup>22</sup> Symptoms such as nausea, anxiety, constipation, insomnia, and shortness of breath can also usually be ameliorated.<sup>23</sup> Simple attention to details such as skin care, oral hygiene, and proper positioning can greatly improve the lives of patients who are dying.

In the past several decades, the emotional and psychic course of dying patients has also received increasing attention.<sup>24</sup> The concern of the public as well as health care professionals has been evidenced by conferences, courses and training seminars, and publications such as *On Death and Dying*, a landmark book by Dr. Elisabeth Kiibler-Ross published in 1969.<sup>25</sup> Critics of her work point out that dying patients do not all pass in lock-step fashion through the five psychological stages (denial and isolation, anger, bargaining, depression, and acceptance) that Dr. Kiibler-Ross observed during counseling sessions, and that her theory has yet to be confirmed by systematic research. Although Dr. Kiibler-Ross emphasized that patients in all stages continue to evidence hope, the very notion of "stages" is potentially misleading since they are not independent, in the sense of a patient being "in" one stage or another. Perhaps most important, experience shows that acceptance is not always possible or appropriate for a patient.<sup>26</sup> Eschewing the theory of stages of death, one thanatologist sees instead "a complicated clustering of intellectual and affective states, some fleeting, lasting for a moment or

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MED. 173 (1973); Jane Porter and Hershel Jick, *Addiction Rate in Patients Treated with Narcotics*, 302 NEW ENG. J. MED. 123 (1980).

<sup>22</sup> Robert G. Twycross, *Relief of Pain*, in Cicely M. Saunders, ed., *THE MANAGEMENT OF TERMINAL DISEASE*, Edward Arnold Publishers, Ltd., London (1978) at 65.

<sup>23</sup> Ned H. Cassem and Rege S. Stewart, *Management and Care of the Dying Patient*, 6 INT'L. J. PSYCHIATRY IN MEDICINE 293, 299 (1975); A.G.O. Crowther, *Management of Other Common Symptoms in the Terminally Ill*, in Eric Wilkes, ed., *THE DYING PATIENT*, George A. Bogden & Son, Inc., Ridgewood, N.J. (1982) at 209; Mary J. Baines, *Control of Other Symptoms*, in Saunders, *supra* note 22, at 99.

<sup>24</sup> Michele Vovelle, *Rediscovery of Death Since 1960*, 447 ANNALS AM. ACAD. POL. & Soc. Sci. 89 (1980).

<sup>25</sup> Elisabeth Kiibler-Ross, *ON DEATH AND DYING*, Macmillan Pub. Co., New York (1969).

<sup>26</sup> Michael A. Simpson, *Therapeutic Uses of Truth*, in Wilkes, *supra* note 23, at 255, 258; Ned H. Cassem, *The Dying Patient*, in Thomas P. Hackett and Ned H. Cassem, eds., *MASSACHUSETTS GENERAL HOSPITAL HANDBOOK OF GENERAL HOSPITAL PSYCHIATRY*. C.V. Mosby Co., St. Louis, Mo. (1978) at 300.

a day or a week, set not unexpectedly against a backdrop of that person's total personality, 'his philosophy of life.'<sup>27</sup>

**Views of Death.** Dying patients often are not entirely averse to the prospect of death,<sup>28</sup> which may be seen as preferable to prolonging an inexorable process of suffering or as less important than other concerns (personal salvation, the welfare of loved ones, and so forth). People's perceptions of the nature and meaning of death, especially in this pluralistic society, are quite diverse. For some, life is infinitely important and death is always to be opposed:

The value of human life is infinite and beyond measure, so that a hundred years and a single second are equally precious.<sup>29</sup>

For some, life is the norm and death an oddity or annoyance:

To make matters worse, the process of dying cannot even be treated as a tragedy since our Doing and mastery-over-Nature values make it seem more like technical failure. Tragedy, in our society, is something that should have been avoided rather than something to be appreciated. The implication is that someone slipped up or that research simply has not yet got around to solving this kind of thing. Thus dying is covered over with optimistic or reassuring statements and the dying person is scarcely given the opportunity to make the most of his position.<sup>30</sup>

All men must die: but for every man his death is an accident and, even if he knows it and consents to it, an unjustifiable violation.<sup>31</sup>

Some have noted that the inevitability of death is what gives life meaning or purpose:

Protect me  
From a body without death. Such indignity  
Would be outcast, like a rock in the sea.

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<sup>27</sup> Edwin S. Shneidman, *Death Work and Stages of Dying*, in Edwin S. Shneidman, ed., *DEATH: CURRENT PERSPECTIVES*, Mayfield Pub. Co., Palo Alto, Calif. (1976) at 446.

<sup>28</sup> See, e.g., C.M. Farquhar, *Attitudes and Beliefs Concerning Life and Death of Elderly Persons*, 92 **NEW ZEALAND MED. J.** 107 (1980); David L. Jackson and Stuart Youngner, *Patient Autonomy and "Death with Dignity"*, 301 **NEW ENG. J. MED.** 404 (1979); L. Witzel, *Behavior of the Dying Patient*, 2 **BRIT. MED. J.** 81 (1975).

<sup>29</sup> Immanuel Jakobovitz, *JEWISH MEDICAL ETHICS*, Bloch Pub. Co., New York (1959) at 46.

<sup>30</sup> John Spiegel, *Cultural Variations in Attitudes Toward Death and Disease*, in George H. Grosser et al., eds., *THE THREAT OF IMPENDING DISASTER*, M.I.T. Press, Cambridge, Mass. (1964) at 297.

<sup>31</sup> Simone de Beauvoir, *A VERY EASY DEATH*, G.P. Putman's Sons, New York (1966), reprinted in Shneidman, *supra* note 27, at 523, 526.

But with death, it can hold  
More than time gives it, or the earth shows it.<sup>32</sup>

Death forces us to shore up, personally and aggregatively, the conviction of life; that we persist and survive, as at least minimally rational creatures, confirms the pragmatic adequacy of our beliefs.<sup>33</sup>

For some, death is the release of the soul from its body:

The soul which is pure at' departing...departs to the invisible world—to the devine and immortal and rational: Hither arriving, she is secure of bliss and is released from the error and folly of men, their fears and wild passions and all other human ills, and forever dwells, as they say of the initiated, in company with the gods.<sup>34</sup>

The perspectives on death are as numerous as the philosophies and religions that give them birth. And for each perspective there is a complementary set of values and priorities in the medical care of dying patients. Someone who holds that every second of life under any circumstances is worth living, for example, will make very different decisions than a person who is accepting of death.<sup>35</sup>

The view that there is no one way to die that is right for all persons has ancient roots:

Just as I choose a ship to sail in or a house to live in, so I choose a death for my passage from life....Nowhere should we indulge the soul more than in dying....A man's life should satisfy other people as well, his death only himself, and whatever sort he likes best.<sup>36</sup>

Under modern conditions, to achieve some harmony between an individual's death and personal values throughout life will probably entail not only awareness of personal values but also

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<sup>32</sup> Christopher Fry, *THE DARK IS LIGHT ENOUGH*, Oxford Univ. Press, London (1954) at 89.

<sup>33</sup> Joseph Margolis, *Death*, in *NEGATIVITIES: THE LIMITS OF LIFE*, Charles E. Merrill Pub. Co., Columbus, Oh, (1975), reprinted in Tom L. Beauchamp and Seymour Perlin, eds., *ETHICAL ISSUES IN DEATH AND DYING*, Prentice-Hall, Inc., Englewood Cliffs, N.J. (1978) at 357, 363.

<sup>34</sup> Plato, *Phaedo*, in Irwin Edman, ed., *THE WORKS OF PLATO*, Modern Library, New York (1928) at 141.

<sup>35</sup> "An appropriate death, in brief, is a death that someone might choose for himself—had he a choice." Avery D. Weisman, *Appropriate and Appropriated Death*, in *ON DYING AND DENYING: A PSYCHIATRIC STUDY OF TERMINALITY*, Behavioral Publications, Inc., New York (1972) at 41; Lauren E. Trombley, *A Psychiatrist's Response to a Life-Threatening Illness*, in Shneidman. *supra* note 27, at 506; H. Tristram Engelhardt, Jr., *Tractatus Artis Bene Moriendi Vivendique: Choosing Styles of Dying and Living*, in Virginia Abernathy, ed., *FRONTIERS IN MEDICAL ETHICS*, Ballinger Pub. Co., Cambridge, Mass. (1980) at 9.

<sup>36</sup> Seneca, *Suicide*, in *THE STOIC PHILOSOPHY OF SENECA*, W.W. Norton, New York (Moses Hadas trans. 1958) at 506.

the sensitivity and compassion of others and the tolerance of a society willing to allow a fair range of choice—both for people to find and create meaning in living while dying, and for survivors to incorporate and interpret their loss.

Achieving this harmony is made more complex because of an apparently unavoidable tension that accompanies the medical care of dying patients. It is a tension that persists even when both the general society and health care professionals agree that avoiding death should not always be the preeminent goal of therapy and that assisting each patient to achieve a personally appropriate death is among the professionals' obligations. Once someone realizes that the time and manner of death are substantially under the control of medical science, he or she wants to be protected against decisions that make death too easy and quick as well as from those that make it too agonizing and prolonged. Yet such a "golden mean" defies ready definition, both in theory and often in practical application in individual cases.<sup>37</sup> Each case is different, both objectively and in the subjective experience of the patient, so definitions of "too quick" and "too long" vary widely. This does not, however, preclude setting forth some general guidelines and policy tools.

### Considerations in Framing Social Policy

The Commission uses the term public policy in its broadest sense, which includes all the various rules, norms, laws, and practices that a society employs in a given area. Regulations may be formal, such as statutes enforced according to specified procedures, or informal, as in the expectations regarding acceptable professional behavior that health care professionals absorb while learning other things.<sup>38</sup> A public policy also exists when society chooses not to intervene in private actions. Indeed, a major issue in establishing wise public policies on life-sustaining treatment is the degree to which the community and its agents should be involved in medical decisionmaking.

Public policy is mediated through a variety of societal practices and institutions: governmental bodies (both legislative and regulatory), health care professionals and institutions (individually and collectively), organized religions, and other social groups. Yet the people who must implement such

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<sup>37</sup> When 205 physicians in one study were presented with a hypothetical case, the range of assessments was striking, with those who favored and those against aggressive treatment offering the same reasons but projecting very different views of the patient's future. Robert A. Pearlman, Thomas S. Inui, and William Carter, *Variability in Physician Bioethical Decisionmaking: A Case Study of Euthanasia*, 97 ANNALS INT. MED. 420 (1982).

<sup>38</sup> See, e.g., Charles L. Bosk, *FORGIVE AND REMEMBER: MANAGING MEDICAL FAILURE*, Univ. of Chicago Press, Chicago (1979).

policies are often the directly affected patients and their families.

**The Disservice Done by Empty Rhetoric.** Discussions of life-sustaining treatment have often been confused by the use of slogans and code words. As a general matter, the issues can be understood much better if the exact meaning of these rhetorical devices is spelled out. Phrases like "right to die," "right to life," "death with dignity," "quality of life," and "euthanasia" have been used in such conflicting ways that their meanings, if they ever were clear, have become hopelessly blurred.

In recent years, for example, many have commented on the claim that patients have a "right to die with dignity."<sup>39</sup> Much can and should be done to ensure that patients are treated with respect and concern throughout life. Insofar as "death with dignity" means that the wishes of dying patients are solicited and respected, it is a concept the Commission endorses.<sup>40</sup> Many who use the phrase seem to go well beyond this, however, to a vision in which everyone is guaranteed a peaceful and aesthetically appealing death. This is clearly beyond reach; a fair proportion of dying patients are confused, nauseated, vomiting, delirious, bleeding, or breathless. Avoiding these distressing symptoms is not always possible; likewise, naturalness may have to be sacrificed since mechanical assistance is sometimes required to ensure comfort at the end of life.<sup>41</sup> Thus, the apparent appeal of the slogan "dignified death" often disappears before the reality of patients' needs and desires. Comparable problems arise with other slogans that are frequently heard in discussions on life-sustaining treatment.<sup>42</sup>

Other phrases — though useful as general descriptions — are similarly unacceptable when an unambiguous definition is

<sup>39</sup> See, e.g., Stephen L. Kuepper, *THE EUTHANASIA MOVEMENT: A BRIEF HISTORY OF THE ORGANIZED EUTHANASIA MOVEMENT IN THE UNITED STATES* (1979) (unpublished manuscript, on file with the Society for the Right to Die, New York); Ivan Illich, *The Political Use of a Natural Death*, 2 *HASTINGS CTR. STUDIES* 3 (Jan. 1974); Marya Mannes, *LAST RIGHTS: A PLEA FOR THE GOOD DEATH*, William Morrow, New York (1974); Patrick Francis Sheehy, *ON DYING WITH DIGNITY*, Pinnacle Books, New York (1981). But see Jackson and Youngner, *supra* note 28.

<sup>40</sup> See pp. 46-51 *infra*.

<sup>41</sup> Robert M. Veatch, *DEATH, DYING AND THE BIOLOGICAL REVOLUTION*, Yale Univ. Press, New Haven, Conn. (1976) at 277-305; Paul Ramsey, *The Indignity of Death with Dignity*, 2 *HASTINGS CTR. REP.* 47 (May 1974). See also Appendix B, pp. 275-97 *infra*.

<sup>42</sup> See, e.g., Daniel Callahan, *Natural Death and Public Policy*, and James Childress, *Further Reflections on Natural Death and Public Policy*, in Robert M. Veatch, ed., *LIFE SPAN: VALUES AND LIFE-EXTENDING TECHNOLOGIES*, Harper & Row, San Francisco (1979) at 162, 176.



required. For example, attempts—such as those in several statutes<sup>43</sup>—make the obligations of patients and providers different when a patient is "terminally ill" are dubious for several reasons. First, although a decision to undertake a life-sustaining treatment will frequently depend on whether the patient believes the treatment is likely to extend life substantially enough to be worth its burdens, patients with similar prognoses evaluate relevant facts very differently. The closeness of death may be strongly felt by someone who has only a remote chance of dying soon, while for another person it may not seem imminent until his or her organs have nearly ceased to function. Moreover, prognostication near the end of life is notoriously uncertain.<sup>44</sup> At best, confidence in predicting death is possible only in the final few hours. Patients with the same

<sup>43</sup> Natural Death Acts have usually tried to define a class of patients who have "incurable injury, diseases, or illness...where the application of life-sustaining procedures would serve only to prolong the dying process." Medical Treatment Decision Act, *reprinted in* Appendix D, pp. 313-17 *infra*. The 1982 amendments to the Medicare program provide much more substantial reimbursement for "palliation and management" of "terminally ill" patients (defined as those for whom death is expected within six months) than for treatment of disease for these patients or for any treatment of other patients. S 122, Part II, Tax Equity and Fiscal Responsibility Act, Pub. L. No. 97-248 (1982). These points are discussed more fully in Chapters Three and Four *infra*. See also Paul Ramsey, *THE PATIENT AS PERSON*, Yale Univ. Press, New Haven, Conn. (1970) at 113.

<sup>44</sup> "Physicians' predictions of prognosis were relatively inaccurate, with actual survival plus or minus one month coinciding with that predicted in only 16% of patients. Except in patients who were very ill and had short prognosis of three to four months, survival was consistently underestimated." Linda J. Aiken and Martita M. Marx, *Hospices: Perspectives on the Public Policy Debate*, 37 AM. PSYCHOLOGIST 1271, 1275 (1982) (reporting data from J.W. Yates, F.P. McKegney and L.E. Kun, *A Comparative Study of Home Nursing Care of Patients with Advanced Cancer*, Proceedings of the Third National Conference on Human Values of Cancer, American Cancer Society, New York, 1982).

The subjective nature of prognoses affects the types of treatment that are encouraged, which in turn affects patients' outcome. In one study, physicians who preferred to intubate and artificially ventilate a patient with severe chronic lung disease projected that the patient would survive about 15 months; other physicians who decided against artificial ventilation when presented with the same case predicted that, even with artificial life support, the patient had only 6 months to live. Pearlman, Inui, and Carter, *supra* note 37. See also J. Englebert Dunphy, *Annual Discourse—On Caring for the Patient with Cancer*, 295 NEW ENG. J. MED. 313, 314 (1976); Mark Siegler, *Pascal's Wager and the Hanging of Crepe*, 293 NEW ENG. J. MED. 853 (1975); cf. Arno G. Motulsky, *Biased Ascertainment and the Natural History of Disease*, 298 NEW ENG. J. MED. 1196 (1978).

stage of a disease but with different family settings, personalities, and "things to live for" actually do live for strikingly varied periods of time.<sup>45</sup> It seems difficult to devise or to justify policies that restrict people's discretion to make appropriate decisions by allowing some choices only to "terminally ill" patients or by denying them other choices.

Although the Commission has attempted to avoid rhetorical slogans so as to escape the ambiguities and misunderstandings that often accompany them, it uses "dying" and "terminally ill" as descriptive terms for certain patients, not as ironclad categories. There seem to be no other terms to use for a patient whose illness is likely to cause death within what is to that person a very short time. Of course, the word "dying" is in some ways an unilluminating modifier for "patient"—since life is always a "terminal" condition—and further refinements, such as "imminently," do little to clarify the situation. Therefore, words like "dying" are used in this Report in their colloquial sense and with a caution against regarding them as a source of precision that is not theirs to bestow.

**Underlying Values.** In its work on the ethical issues in health care the Commission discussed the importance of three basic values: self-determination, well-being, and equity. The concepts are not all-encompassing; nor was any attempt made to relate them in a hierarchical fashion. In *Making Health Care Decisions*, the Commission focused almost entirely upon the values of self-determination and well-being<sup>46</sup>; in *Securing Access to Health Care*, principally upon considerations of equity.<sup>47</sup> In this Report, the Commission examines treatment situations in which all three values are intimately involved.

The primary goal of health care in general is to maximize each patient's well-being. However, merely acting in a patient's best interests without recognizing the individual as the pivotal decisionmaker would fail to respect each person's interest in self-determination—the capacity to form, revise, and pursue his or her own plans for life. Self-determination has both an instrumental value in achieving subjectively defined well-being and an intrinsic value as an element of personal worth and integrity.

Given the special importance of health care in promoting individuals' well-being and opportunities, the Commission also

<sup>45</sup> E. Mansell Pattison, *The Will to Live and the Expectation of Death*, in E. Mansell Pattison, ed., *THE EXPERIENCE OF DYING*, Prentice-Hall, Inc., Englewood Cliffs, N.J. (1977) at 61.

<sup>46</sup> President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *MAKING HEALTH CARE DECISIONS*, U.S. Government Printing Office, Washington (1982).

<sup>47</sup> President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *SECURING ACCESS TO HEALTH CARE*, U.S. Government Printing Office, Washington (1983).

concluded that society has a moral obligation to ensure that everyone has access to an adequate level of care and is able to obtain such care without excessive burdens (in terms of financial or time expenditures). Since differences in health status are largely determined by natural and social contingencies beyond an individual's control and are so unevenly distributed that some people are unable through their own efforts to obtain adequate care, the moral obligation to ensure equitable access rests with society as a whole. This obligation is particularly acute when health care is needed to sustain life itself.

Though a given decision will often serve all relevant values, sometimes conflict occurs. When the conflicts that arise between a competent patient's self-determination and his or her apparent well-being remain unresolved after adequate deliberation, a competent patient's self-determination is and usually should be given greater weight than other people's views on that individual's well-being. Similarly, while a competent patient's choice about treatment is usually more compelling than claims based on resource allocations, considerations of equitable access to health care in society will in fact partially determine the availability of options for a particular patient. Fair treatment of individuals necessitates basing decisions about availability and funding on defensible principles, and then implementing decisions through general rules and institutional policies that are insulated from the subjectivity of ad hoc decisions.

**General Rules and Specific Cases.** Although good public policy should reflect morally sound treatment of the individual cases that the policy concerns, the many distinctions among different cases that might be made in a careful, complete moral analysis cannot usually be included in a manageable public policy. Yet general rules are adopted to govern the behavior of many people with diverse values and goals in a manner that is morally acceptable in the vast majority of cases and that tends to permit only the most acceptable errors. But the weight of certain ethical considerations is changed when they are applied to matters of general public policy instead of merely to the private concerns of individuals. Consequently, policies that are predominantly procedural rather than substantive are often favored as a means of attempting to allocate responsibility in a way that allows decisionmakers to take account of the full range and subtlety of each case's morally relevant features.

As in so many other areas, there is tension between substance and procedures in making policies about foregoing life-sustaining treatment. Decisions are commonly made under adverse conditions; the individuals who make them have varying capacities for judgment and their disinterest and goodwill are sometimes imperfect. Caution is warranted, then,

in considering procedural policies that fail to place some substantive constraints on the decisionmakers. For the same reasons, however, policies that do contain substantive criteria for decisions may be subject to misuse and abuse. To limit the potential for both well-intentioned misapplication and ill-intentioned abuse, justifiable social and legal policies in this area (as elsewhere) may forbid certain classes of actions that include cases in which the forbidden act would actually be morally justified, while at the same time allowing other classes that include cases in which the permitted act would be morally wrong. The problem, then, is determining which guidelines and procedures are most likely to produce optimal decisions—in this case, the best balance between overuse and underuse of life-sustaining treatment.

Consistent with this goal, the conflict between the careful assessments of the concerned parties in a particular case and the demands of public policy should be minimized. Otherwise patients, providers, and families will continually be acting contrary either to generally accepted, and often legally enforced, public policy or to their own responsible assessment of a situation.

**"Slippery Slope" Arguments.** An important concern regarding the potential of any policy to cause unintended harm is captured in the phrase "slippery slope." This argument cautions against taking a first step that is itself ethically justified when doing so is expected to lead to the acceptance of other actions that are not likewise justified.<sup>48</sup> If the slope is indeed slippery and no likely stopping points exist to provide a toehold, then the wisest course may be to avoid taking the first step.

Slippery slope arguments are prominent whenever the protection of human life is at stake. Some people urge, for example, that intentional killing should be allowed if a person who will die very soon of an untreatable illness that is causing great and unrelievable suffering wants to die but is physically incapable of ending his or her own life.<sup>49</sup> This position would

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<sup>48</sup> An interesting view of the "slippery slope" argument in the context of *in vitro* fertilization can be found in Samuel Gorovitz, *In Vitro Fertilization: Sense and Nonsense and a Reply to Leon Kass*, in Ethics Advisory Board, Dept. of Health, Education and Welfare, HEW SUPPORT OF RESEARCH INVOLVING HUMAN IN VITRO FERTILIZATION AND EMBRYO TRANSFER, U.S. Government Printing Office, Washington (1979). See also, Peter Steinfels and Carol Levine, eds., *Biomedical Ethics and the Shadow of Nazism*, 6 HASTINGS CTR. REP. (Special Supp. Aug. 1976).

<sup>49</sup> See, e.g., Marvin Kohl, ed., BENEFICENT EUTHANASIA, Prometheus Books, Buffalo, N.Y. (1975); James Rachels, *Active and Passive Euthanasia*, 292 NEW ENG. J. MED. 78 (1975); Bonnie Steinbock, *The*

clearly be opposed by people who hold that deliberate killing of an innocent person is always wrong.<sup>50</sup> But it would also be opposed by those who might be willing to allow killing in such a situation but who fear that doing so would put society on a slippery slope because it would lead to killing in other, unjustifiable circumstances.<sup>51</sup>

For such an argument to be persuasive, however, much more is needed than merely pointing out that allowing one kind of action (itself justified) could conceivably increase the tendency to allow another action (unjustified). Rather, it must be shown that pressures to allow the unjustified action will become so strong once the initial step is taken that the further steps are likely to occur. Since such evidence is commonly quite limited, slippery slope arguments are themselves subject to abuse in social and legal policy debate.

Obviously, slippery slope arguments must be very carefully employed lest they serve merely as an unthinking defense of the status quo.<sup>52</sup> The cost of accepting such an argument is the

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*Intentional Termination of Life*, 6 **ETHICS, SCI., & MED.** 59 (1979); Derek Humphry, *LET ME DIE BEFORE I WAKE*, Hemlock, Santa Monica, Calif. (1981).

<sup>50</sup> See, e.g., Paul Ramsey, **ETHICS AT THE EDGES OF LIFE**, Yale Univ. Press, New Haven, Conn. (1978); Arthur Dyck, *An Alternative to the Ethic of Euthanasia*, in Robert H. Williams, ed., *TO LIVE AND TO DIE*, Springer-Verlag, New York (1973) at 98; *Declaration on Euthanasia* (1980), reprinted in Appendix C, pp. 300-07 *infra*.

<sup>51</sup> See, e.g., Yale Kamisar, *Euthanasia Legislation: Some Non-Religious Objections*, 42 **MINN. L. REV.** 969 (1958):

<sup>52</sup> I guess the slippery slope must have been the Swiss philosopher's answer to the Arabic philosopher's camel's nose [under the tent]....It seems to me that it is a bogeyman that is brought out in every discussion—again it's part of the hard-case problem....

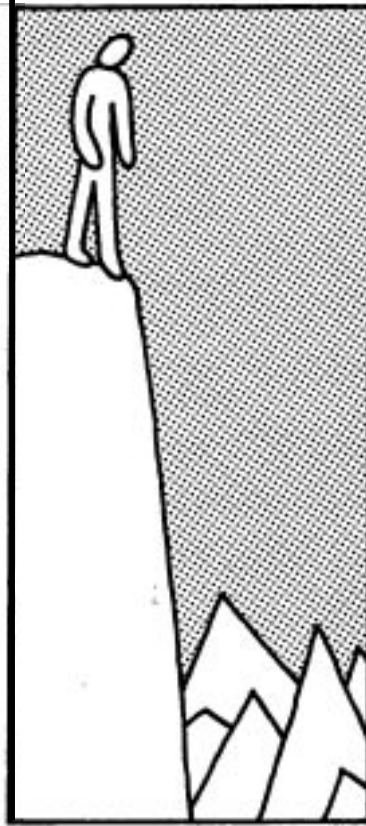
It then occurred to me that there was not a single problem that I was concerned about that didn't exist on a spectrum, and that any time you draw a line on any spectrum some damn fool can get up and point to the two things proximal to that line and say, "You mean, Dr. So-and-so, you think there's a difference between X and Y." And, of course, there isn't a difference between X and Y, because when you're on a spectrum, wherever you draw the line, you're going to find two proximal points that are almost identical.... You ...[run the risk of going] all through your life never drawing a line.

Testimony of Dr. Willard Gaylin, transcript of 21st meeting of the President's Commission (June 10, 1982) at 144-45.

We do not always possess clear natural lines. Such a realization is sometimes thought to imply that all distinctions are useless, so long as they are not mirrored in nature. But it is crucial to see that, even though a line is not drawn in nature, it may well be needed in practice....All social policy requires the

continued prohibition of some conduct that is actually acceptable. Nevertheless, the Commission has found that in the area of concern of this Report, in which human life is at issue, valid concerns warrant being especially cautious before adopting any policy that weakens the protections against taking human life.

**The Role of Law.** Law is one of the basic means through which a society translates its values into policies and applies them to human conduct. Using the general rules embodied in statutes, regulations, and court decisions, society attempts judiciously to balance the degree to which various values may be pursued and to arbitrate situations in which serving one fully justified goal entails failing to serve another. With respect to foregoing life-sustaining treatment, law simultaneously allows such decisions (as an expression of the value of self-determination and well-being), circumscribes the practice (to safeguard well-being), and shapes social institutions and government programs (to advance equity and well-being and to protect self-determination).



The legal system frames these issues in several ways. The outer limits of acceptable behavior are set by the criminal law, which encompasses not merely the rules set forth in the statute books (concerning intentional or negligent homicide, for example) but also the discretion of prosecutors and the decisions of judges and jurors in individual cases. In civil law, comparable rules can be invoked by individuals either after the fact (in

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drawing of lines....Prohibitions have to be established and distinctions made even where human affairs are uncertain and hard to classify.

Sissela Bok. *Death and Dying: Euthanasia and Sustaining Life: Ethical Views*, in 1 *ENCYCLOPEDIA OF BIOETHICS*, The Free Press, New York (1978) at 268, 277.

damage actions) or before a decision is made about treatment (through the appointment of a guardian or through an injunction). Public law, statutory and regulatory, enters in the form of rules on the administration, funding, and regulation of governmental and private programs. Underlying all these areas are claims asserted as constitutional rights, perhaps most importantly the right of privacy, described as the "interest in independence in making certain kinds of important decisions."<sup>53</sup> The constitutional right of privacy encompasses a far broader range of interests than those implicated in health care decisionmaking—so broad that it is probably better to think of it as a variety of privacy interests rather than as one indivisible right.<sup>54</sup>

In its seminal *Quinlan* opinion, the New Jersey Supreme Court used this right as the cornerstone of its reasoning:

It is the issue of the constitutional right of privacy that has given us most concern, in the exceptional circumstances of this case....Supreme Court decisions have recognized that a right of personal privacy exists....Presumably this right is broad enough to encompass a patient's decision to decline medical treatment under certain circumstances.<sup>55</sup>

The *Quinlan* court recognized that although it is substantial, the right of privacy in this context is not absolute and may give way to "interests of the State in...the preservation and sanctity

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<sup>53</sup> *Whalen v. Roe*, 429 U.S. 589, 598 (1977) (footnote omitted). The decisions that have received greatest attention concern marriage and parenting. *See, e.g.*, *Eisenstadt v. Baird*, 405 U.S. 438 (1972) (striking regulation limiting sale of contraceptives to married couples); *Griswold v. Connecticut*, 381 U.S. 479 (1965) (striking state regulation of sale and use of contraceptives by married couples); *Skinner v. Oklahoma*, 405 U.S. 438 (1942) (limited state's use of sterilization); *Pierce v. Society of Sisters*, 268 U.S. 510 (1925) (parental right to direct education and upbringing of children upheld).

<sup>54</sup> Laurence Tribe, *AMERICAN CONSTITUTIONAL LAW*, Foundation Press, Mineola, N.Y. (1978) at 886-990.

<sup>55</sup> *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, 662-63, *cert. denied*, 429 U.S. 922 (1976).

Some commentators have, however, expressed doubts about framing these issues in terms of Constitutional rights.

The *Quinlan* decision seems to have been a premature if reasonably thoughtful constitutionalization of a difficult and still fluid area....Viewed as a prod to intensive legislative consideration, the decision's guidelines seem defensible. But by casting its holding in federal constitutional terms, the New Jersey court may have needlessly foreclosed more intelligent legislative solutions in that state....This case did not involve a law or policy selectively burdening less powerful groups in the society.

Tribe, *supra* note 54, at 937 (citations omitted).

of human life and defense of the right of the physician to administer medical treatment according to his best judgment."<sup>56</sup> In other cases, courts have recognized two more counterweights—the protection of the interests of innocent third parties (especially the financial and emotional interests of minor children) and the societal interest in preventing suicide.<sup>57</sup>

In most decisions to forego life-sustaining treatment, these four state interests are quite attenuated. The preeminent one—that of preserving life—must be considered in concert with concerns about the suffering inflicted upon a dying individual and society's general "regard for human dignity and self-determination."<sup>58</sup> Likewise, the emotional and financial interests of dependents and family members are unlikely to be in opposition to a patient's decision to forego treatment; when they are, those interests are seldom sufficient to outweigh a patient's unwillingness to undergo the suffering or burden of further treatment. Furthermore, provided that personal conscience is respected, the "rights" of health professionals are not jeopardized when they acquiesce in decisions of patients to forego treatment. "Rather...the prevailing ethical practice seems to be to recognize that the dying are more often in need of comfort than treatment."<sup>59</sup> Finally, as a number of courts have recognized, the foregoing of life-sustaining treatment can usually be differentiated from the unreasonable self-destruction involved in suicide, which characteristically warrants state intervention.<sup>60</sup>

Regardless of how interests are weighed in specific cases, a decision to forego life-sustaining treatment has been firmly established as a Constitutionally protected right that can be overcome only by marshalling countervailing considerations of substantial weight.<sup>61</sup> In practice, these countervailing considerations are reflected in and implemented by the sanctions and procedures of criminal, civil, and administrative law.

**Criminal law.** Throughout the ages almost all cultures have regarded the protection of human life as a major aim of their legal systems. In the Anglo-American tradition, proscrip-

<sup>56</sup> *In re Quinlan*, 70 N.J.10, 355 A.2d 647, 663, *cert. denied*, 429 U.S. 922 (1976).

<sup>57</sup> Note, *The Refusal of Life-Saving Treatment vs. The State's Interest in the Preservation of Life: A Clarification of the Interests at Stake*, 58 WASH. U.L.Q. 85 (Winter 1980).

<sup>58</sup> *Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d 417, 424 (1977).

<sup>59</sup> *Id.* at 426.

<sup>60</sup> See pp. 37-38 *infra*.

<sup>61</sup> Not all cases, however, have relied upon a Constitutional claim. See *In re Storar*, 52 N.Y.2d 363, 420 N. 64 (1981), *rev'g In re Storar*, 433 N.Y.S.2d 388 (App. Div. 1980) and *modifying Eichner v. Dillon*, 426 N.Y.S.2d 517 (App. Div. 1980).



tions of homicide and suicide are fundamental components of the criminal law. Yet no such legal proscription is absolute. Self-defense, the defense of others, killing in the conduct of military activities, and capital punishment are among the well-established justifications and excuses for homicide.<sup>62</sup> Criminal law applies these same general norms to physicians and other health care professionals, not only in their capacity as ordinary citizens, but also in their professional capacities.

The criminal law confines people's freedom of action, in order to protect society, in ways that civil law does not. Although a patient's "informed consent" is sufficient authority in the civil law for a medical intervention, consent is never accepted as a defense to the crime of murder.<sup>63</sup> An individual who seeks death at the hands of another, regardless of the reason, does not confer immunity from prosecution on the one who takes the life, because the taking of innocent human life is seen as a wrong to the entire society, not just to the dead person. A physician's shooting or poisoning of a dying patient, even at the patient's request and from merciful motives, falls within the definition of murder.

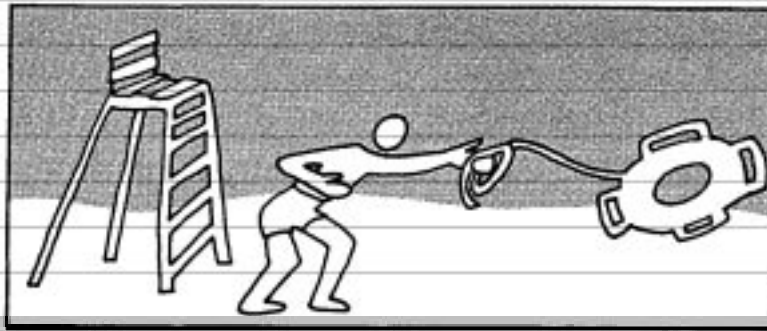
In some situations the criminal law looks to other branches of the law to fill in the details of punishable conduct. The law ordinarily holds individuals liable only for the injurious consequences of their acts, not for the injurious consequences of omissions of action.<sup>64</sup> If someone throws into deep water a person who is known to be unable to swim and the nonswimmer then drowns, criminal and civil liability will be imposed. But if someone merely happens to be present when another is having obvious difficulty swimming in deep water, and if he or she is the only other person present and could rescue the drowning individual, that person ordinarily has no legal obligation to do so—although the failure to rescue may result in a less forgiving moral assessment. In the first case, the person "acts" and is liable; in the second, the person "omits" to act and is not liable. Of course, if a person takes on the responsibilities of a lifeguard, he or she is under a legal

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<sup>62</sup> Wayne R. LaFare and Austin W. Scott, *HANDBOOK ON CRIMINAL LAW*, West Publishing Co., St. Paul, Minn. (1974) at 356-413.

<sup>63</sup> *Id.* at 408-09.

<sup>64</sup> George A. Oakes, *A Prosecutor's View of Treatment Decisions*, and Gregory R. Ginex, *A Prosecutor's View on Liability for Withholding or Withdrawing Medical Care: The Myth and the Reality*, in A. Edward Doudera and J. Douglas Peters, eds., *LEGAL AND ETHICAL ASPECTS OF TREATING CRITICALLY AND TERMINALLY ILL PATIENTS*, AUPHA Press, Ann Arbor, Mich. (1982) at 194, 205; Jerry B. Wilson, *DEATH BY DECISION*, Westminster Press, Philadelphia (1975) at 148-155; LaFare and Scott, *supra* note 62, at 182; Model Penal Code § 2.01(3); Graham Hughes, *CRIMINAL OMISSIONS*, 67 Yale L. J. 590 (1958).



duty to act and an omission of this duty would become the basis of legal liability.<sup>65</sup>

Similarly, the recognized duty of physicians to treat patients with appropriate technologies and methods means that criminal sanctions may be imposed on a physician whose patient died because of the physician's failure to act in circumstances under which no liability would attach for nonphysicians. The *omission* of a duty to take protective action by someone obligated to do so, such as a physician or a parent, is regarded by the law in the same way that an *action* would be that led to the same result.

Despite the fact that there are rather rigid and seemingly ironclad prohibitions against intentionally taking the life of another, the administration of the criminal law allows a great deal of discretion, thereby permitting law to be tempered by justice, mercy—and even empathy.<sup>66</sup> Reported criminal prose-

<sup>65</sup> William L. Prosser, *HANDBOOK OF THE LAW OF TORTS*, West Publishing Co., St. Paul, Minn. (4th ed. 1971) at 338-43. The general rule of no duty to rescue has come under recurrent criticism by legal commentators. See, e.g., Ernest J. Weinrib, *The Case for a Duty to Rescue*, 90 *YALE L.J.* 247 (1980).

<sup>66</sup> The ambivalent position of prosecutors in such cases is evident in the case of Woodrow Collums, a Texan convicted of the shooting death of his 72-year-old brother Jim, who suffered from Alzheimer's disease. Collums was sentenced to probation for ten years and required to spend time as a volunteer in a nursing home. The prosecutor in the case stated:

Personally, emotionally, I am with Woodrow Collums, in that I have three brothers; we're very close, and I'm sure that if I were in the deathbed, or vice versa, I hope one of my brothers would end my suffering. But my position in court is as a prosecutor. And there, it's not that I'm going after Woodrow Collums personally. We have to protect the interest of potential victims out there.

Interview with Mike Sawyer on *60 Minutes*, CBS Network, New York (March 28, 1982) at 4 (transcript).

cutions of health care professionals for killing patients are almost nonexistent.<sup>67</sup> The major reason must be that such killings are rare; when they do occur, some may go undetected, and those that are detected are seldom prosecuted, perhaps because of the difficulty in obtaining a conviction.<sup>68</sup>

Nevertheless, the threat of prosecution provides an appropriate protection against abuse. While "there is precious little precedent" one way or the other, as the Supreme Judicial Court of Massachusetts has observed, "what there is suggests that the doctor will be protected if he acts on a good faith judgment that is not grievously unreasonable by medical standards."<sup>69</sup> Since neither wrongful shortening of life by physicians nor

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<sup>67</sup> Although physicians have been defendants in murder cases in this country and abroad under a variety of circumstances, until recently only two American physicians have ever been tried for "mercy killing"; both were acquitted by juries. In 1973, Dr. Vincent Montemarano was indicted in the death of a 59-year-old comatose cancer patient, charged with causing his death by injection of potassium chloride. He successfully denied any role in the killing and argued that there were numerous other possible causes of death. *People v. Montemarano*, Indictment No. 37707, Nassau County Court, N.Y. (1974).

The other case also involved a cancer patient. In 1950, Dr. Hermann Sander was charged with the murder of Mrs. Abbie Barroto, having recorded in her chart, "patient was 'given 10cc. of air intravenously four times. Expired within ten minutes after this was started.'" Again, acquittal came after the jury found that the cause of death could not be established with sufficient certainty. O. Ruth Russell, *FREEDOM TO DIE: MORAL AND LEGAL ASPECTS OF EUTHANASIA*, Human Sciences Press, New York (1975) at 100-03; Daniel C. Maguire, *DEATH BY CHOICE*, Doubleday & Co., New York (1974) at 20-26.

<sup>68</sup> Cases involving physicians have turned on *factual* innocence. When nonphysicians have been charged with "mercy killings" of close relatives, they have usually relied upon *legal* innocence, asserting defenses of temporary insanity and similar exculpatory claims. Veatch, *supra* note 41, at 80. In a number of cases juries have recognized these defenses and acquitted such defendants. *See, e.g.*, the case of Lester Zygmanski, acquitted on the basis of temporary insanity in shotgun murder done at the request of his brother, paralyzed in an accident four days previously. Paige Mitchell, *ACT OF LOVE: THE KILLING OF GEORGE ZYGMANSKI*, Alfred A. Knopf, New York (1976); R. Johnston, 'Mercy Killer' Acquitted on Insanity Pleas, N.Y. TIMES, Nov. 6, 1973, at A-1. There have been a few convictions; in some of these, however, sentences have been greatly mitigated. *See, Texan Given Probation in Brother's Mercy Death*, N. Y. TIMES, March 5, 1982, at A-12; note 66 *supra*.

<sup>69</sup> *In re Spring*, 405 N.E.2d 115, 121 (Mass.1980). The court also noted that "it is reported that apparently no prosecutor has proceeded to trial in a case where a physician chose to terminate life-preserving treatment or omit emergency treatment in a hopeless case." *Id.* But see note 71 *infra*.

failure to give appropriate medical treatment for fear of the criminal law appears to be prevalent, society seems well served by retaining its criminal prohibition on killing, as interpreted and applied by reasonable members of the community in the form of prosecutors, judges, and jurors.<sup>70</sup> Of course, in an era when medical and community standards are being reevaluated in light of changes in biomedical and sociocultural circumstances, some uncertainty about "reasonable medical standards" is inevitable.<sup>71</sup> If the considerations and procedures

<sup>70</sup> *Martin v. Commonwealth*, 184 Va. 1009, 37 S.E.2d 43 (1946); *Turner v. State*, 119 Tenn. 663, 108 S.W. 1139 (1907); Helen Silving, *Euthanasia: A Study in Comparative Criminal Law*, 103 U. PA. L. REV. 350 (1954); Norman St. John-Stevan, *LIFE, DEATH AND THE LAW*, World Publishing Co., New York (1961) at 262. Many proposals have been made either explicitly to authorize direct killing of certain patients, see Humphry, *supra* note 49, at 6, 94, or to provide physicians with a "mercy defense" to homicide charges. See, e.g., James Rachels, *Euthanasia*, in Tom Regan, ed., *MATTERS OF LIFE AND DEATH*, Temple Univ. Press, Philadelphia (1980) at 28, 63-66; Frederick Stenn, *A Plea for Voluntary Euthanasia* (Letter), 303 NEW ENG. J. MED. 891 (1980). It would be difficult to demonstrate that either reform is likely to reduce the harm of nontreatment without increasing the harm of too rapid death precisely because there is so little evidence of serious systematic abuse at present. See David Brand, *Right to Die Groups Seek Another Right to Aid in Suicide*, WALL ST. J., Sept. 4, 1980, at 1.

The possibilities for civil and criminal liability are enhanced if any of the above conditions are absent—especially if a health care professional were to use means that characteristically are associated with criminal homicide rather than merely cooperating with the patient's refusal of treatment. See Donald G. Colleser, Jr., *Death, Dying and the Law: A Prosecutorial View of the Quinlan Case*, 30 *RUTGER'S L. REV.* 304, 310-11 (1977); John B. Nesbitt, *Terminating Life Support of Mentally Retarded, Critically Ill Patients: The Prosecutor's Perspective*, 3 J. LEGAL MED. 245 (1982); James Vorenberg, *Decent Restraint on Prosecutorial Power*, 94 HARV. L. REV. 1521, 1558 (1981).

A Canadian study commission recommended ensuring prosecutorial caution by adding a provision to the Canadian criminal code that would allow charges of aiding or counseling suicide to be brought against a physician only upon personal written authorization of the Attorney General. Law Reform Commission of Canada, *EUTHANASIA, AIDING SUICIDE AND CESSATION OF TREATMENT*, Minister of Supply and Services, Ottawa (1982) at 68-69.

<sup>71</sup> The possibility of criminal liability for deliberate omissions is demonstrated by the recent indictment of two physicians on charges of murder and conspiracy to commit murder in the case of Clarence H. Herbert, a 55-year-old comatose patient at Kaiser-Permanente Hospital in Harbor-City, California. Ted Rohrlich, *2 Doctors Face Murder Charges in Patient's Death*, L. A. TIMES, Aug. 19, 1982, at A-1; Jonathan Kirsch, *A Death at Kaiser Hospital: How Medical Politics Turned a Clash between Two Doctors and a Nurse into a Case for the District Attorney*, 7 CALIFORNIA 79 (Nov. 1982). The indictments were dismissed after a preliminary hearing. Magistrate's Findings, California

suggested in this Report are taken into account, however, there appears to be no basis for concern that the law provides an inadequate or unsuitable framework within which practitioners, patients, and others can make decisions about life-sustaining care.<sup>72</sup>

Suicide, or "self-killing," could be an issue with a dying patient either through an act or an omission of action. The common law treated suicide as a crime and punished both those who performed (or attempted) it and those who aided the them.<sup>73</sup> Though suicide is no longer punished as a felony, a suicide attempt—regardless of a person's motive—is a basis for active intervention by public officers and for deprivation of liberty (through involuntary psychiatric observation and treatment).<sup>74</sup> Furthermore, a number of states continue to consider the assisting of suicide a crime.<sup>75</sup>

Since this Report is concerned with the ethics of foregoing life-sustaining treatment, the Commission did not investigate the effects any remaining legal rules on suicide have on

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v. Barber and Nejd, No. A 025586 (Los Angeles Mun. Ct., Cal., March 9, 1983). See also David Margolick, *Hospital Is Investigated on Life Support Policy*, N.Y. TIMES, June 20, 1982, at A-34; Loy Wiley, *Liability for Death: Nine Nurses' Legal Ordeals*, 11 NURSING 31 34 (Sept. 1981).

<sup>72</sup> In cases dealing with incompetent patients who have never stated their preferences about the continuation or cessation of a particular treatment, there is considerably more uncertainty about the latitude of permissible actions that physicians may take, and some courts have asserted that treatment may be withheld only after having obtained judicial permission. See pp. 154-57 *infra*. See also 65 Ops. Cal. Att'y Gen. 417 (1982), reprinted in Appendix I, pp. 536-45 *infra*. (Even courts are said to lack power to authorize withdrawal of treatment from incompetent patients.)

<sup>73</sup> Under the English common law, from which a good deal of American law derives, suicide—literally, "self-killing"—was considered a crime. The punishment for suicide was ignominious burial and forfeiture of the individual's property to the Crown. T. Plucknett, *A CONCISE HISTORY OF THE COMMON LAW*, Little, Brown, Boston (1948) at 420. Attempted suicide was a lesser offense. Glanville Williams, *THE SANCTITY OF LIFE AND THE CRIMINAL LAW*, Alfred A. Knopf, New York (1957) at 273-85. Suicide was decriminalized in England in 1961, Suicide Act of 1961, 9 & 10 Eliz. 2, Ch. 60 S1 (1961), and is no longer a crime in any American jurisdiction. Norman L. Cantor, *A Patient's Decision to Decline Life-Saving Medical Treatment: Bodily Integrity versus the Preservation of Life*, 26 RUTGERS L. REV. 228, 246 (1973). However, attempted suicide remains a crime in a few American jurisdictions, although the last reported prosecution was in 1961. See *State v. Willis*, 255 N.C. 473, 121 S.E.2d 854 (1961).

<sup>74</sup> David F. Greenburg, *Involuntary Psychiatric Commitments to Prevent Suicide*, 49 N.Y.U. L. REV. 227 (1974).

<sup>75</sup> Humphry, *supra* note 49, at 94; Richard S. Scott, "Rational Suicide" For the Terminally Ill?, 9 LEGAL ASPECTS MED. PRACTICE 1, 6 n.6 (Nov. 1981) (lists 23 states where assisting suicide remains a crime, although the rules governing liability as an accessory or conspirator differ).

decisions by dying patients to deliberately try to kill themselves. The continuing public policy of condemning suicide has, however, played a role in judicial consideration of cases involving a foregoing of treatment. Although in the 1960s some courts relied on the analogy to suicide when they refused to permit treatment to be foregone,<sup>76</sup> in recent years judges have consistently distinguished between suicide and the refusal of treatment by, or on behalf of, terminally ill patients.<sup>77</sup> Some courts did so by treating the earlier cases as examples of incompetent or unreasonable refusals of "life-saving" treatments (refusals that can legitimately be prevented), as distinct from competent refusals of treatments that are at best "life-prolonging" but not curative. Furthermore, in cases in which treatment refusal has been found to be acceptable, courts have held that death resulted from a "natural cause" — the patient's illness — which means that the patient's death was not considered to result from suicide, since it was neither self-inflicted nor "caused" by health professionals who honored the patient's decision to refuse treatment.<sup>78</sup> The Commission has not found any instances in which criminal or civil liability has been imposed upon health professionals or others (such as

<sup>76</sup> See, e.g., *Application of the President and Directors of Georgetown College Inc.*, 331 F.2d 1000, 1009 (1964).

<sup>77</sup> "There is a real and in this case determinative distinction between the unlawful taking of the life of another and the ending of artificial lifesupport systems as a matter of self-determination." *In re Quinlan*, 70 N.J.10, 355 A.2d 647, 670, *cert. denied*, 429 U.S. 922 (1976).

<sup>78</sup> In the case of the competent adult's refusing medical treatment such an act does not necessarily constitute suicide since (1) in refusing treatment the patient may not have the specific intent to die, and (2) even if he did, to the extent that the cause of death was from natural causes the patient did not set the death producing agent in motion with the intent of causing his own death. Furthermore, the underlying state interest in this area lies in the prevention of irrational self-destruction. What we consider here is a competent, rational decision to refuse treatment when death is inevitable and the treatment offers no hope of cure or preservation of life. There is no connection between the conduct here in issue and any State concern to prevent suicide.

*Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d 417, 426 n.11 (1977) (citations omitted); see also *Satz v. Perlmutter*, 362 So.2d 160 (Fla. App. 1978), *aff'd* 379 So.2d 359 (Fla. 1980).

Since a patient has a right to refuse life-saving treatment, that right necessarily entails a right on the part of others to effectuate the patient's refusal, and no prosecution could occur for aiding an act that is not itself a crime. "The constitutional protection extends to third parties whose action is necessary to effectuate the exercise of that right." *In re Quinlan*, 70 N.J.10, 355 A.2d 647, 670, *cert. denied*, 429 U.S. 922 (1976). The difficulties of relying on attributions of causation to explain the distinction are discussed at pp. 68-70 *infra*.

family members) for acquiescing in a patient's refusal of life-sustaining treatment.<sup>79</sup>

**Civil law.** Rather than punishing people for behavior that offends social norms, civil law strives both to prevent violations of those norms and, when that is not possible, to require the violator to compensate those who have been harmed by the violation. Although the branch of civil law known as the law of torts attempts to protect human life, autonomy, and well-being, it does not bar health care professionals from exposing patients to risk; if it did, many valuable health care services would not be provided.<sup>80</sup> Rather, practitioners may administer treatments (and diagnostic procedures) that subject patients to "reasonable" risks to life and limb, but damages must be paid if death or other harm ensues from practitioners' conduct that violates the standards of reasonable behavior established by the profession or that contravenes any agreement that the professional and the client had about their relationship and mutual duties.<sup>81</sup>

Civil courts also exercise the powers of *parens patriae* to protect individuals who cannot adequately defend their own interests.<sup>82</sup> In this role, courts are the final authority as to who needs such protection, who should provide it (such as a guardian appointed for an incompetent patient), and what standards should be applied.<sup>83</sup>

When a court is faced with a "human being of adult years and sound mind," then its function is to protect that person's "right to determine what shall be done with his body."<sup>84</sup> Determining the exact meaning of this credo, its application in each particular case, and the legitimacy of various encroachments on it has led to (and probably will continue to generate)

<sup>79</sup> See Robert S. Morison, *Alternatives to Striving Too Officiously*, in Franz J. Ingelfinger *et al.*, eds., *CONTROVERSY IN INTERNAL MEDICINE II*, W.B. Saunders, Philadelphia (1974) at 119.

<sup>80</sup> The social benefit that accrues from pursuit of an activity is a legitimate consideration in determining the reasonableness of the activity. *RESTATEMENT (SECOND) OF TORTS*, American Law Institute Publishers, St. Paul, Minn. (1965) at § 292 (a).

■ The risk-taking activities of engineers, accountants, plumbers, and lawyers are all judged by the standards of their respective professions. Prosser, *supra* note 65, at 161-62; James M. Smith, *The Nurses and Orders Not to Resuscitate* (Commentary), 7 *HASTINGS CTR. REP.* 27 (Aug. 1977); Jay Alexander Gold, *Wiser than the Laws?: The Legal Accountability of the Medical Profession*, 7 *AM. J. L. & MED.* 145 (1981).

<sup>82</sup> *Prince v. Massachusetts*, 321 U.S. 158 (1944); *AMERICAN JURISPRUDENCE*, Lawyers Co-Operative Pub. Co., Rochester, N.Y. (2nd ed. 1971) at *Parent and Child* § 1, 9, 10.

<sup>83</sup> For a discussion of guardianship and of the probate function of the courts, see pp. 121-31 *infra*.

<sup>84</sup> *Schloendorff v. Society of New York Hosp.*, 211 N.Y. 125, 129, 105 N.E. 92, 93 (1914).

numerous court cases. These cases have been brought both by patients who seek to compel health care professionals and institutions to take certain steps (for example, to forego treatment) and by professionals and institutions that seek to declare the rights of the parties, particularly when there is doubt about the capacity or authority of a patient to forego treatment.

A number of state legislatures have adopted statutes that would permit dying patients in advance of incompetence to authorize physicians to withhold life-saving treatment without involving the courts, thus specifying the presumptions under which decisions about incompetent patients are to be made. The first and best-known of these "natural death" acts, which was adopted by California in 1976, expressly states that withholding treatment is not to be construed as homicide or suicide.<sup>85</sup> These judicial opinions and legislative declarations are the logical corollary of the doctrine of informed consent, which holds that patients are entitled to choose the treatment option, if any, they wish to pursue. The test of the depth of this commitment comes when the choice may result in or hasten death.<sup>86</sup> Courts faced with these situations have increasingly taken the view that "the value of life...is lessened not by a decision to refuse treatment, but by the failure to allow a competent human being the right of choice."<sup>87</sup>

**Governmental administration and regulation.** A wide range of government activities are aimed at structuring the society so as to advance the general welfare or the welfare of especially disadvantaged persons. Unlike criminal law, these provisions are not principally meant to punish individual wrongdoers. And, unlike the civil law, they do not redress or oversee individual cases. Rather, reductions or expansions of benefits are used to regulate behavior. Thus, for example, a state license to practice medicine can be revoked if a physician demonstrates a pattern of substandard practice, even if there has been no finding in an individual case of criminal wrongdoing or civil liability. Often the power of these laws and regulations are most effectively used to shape institutions and practices and to prevent misuse and error. This is especially true when the withdrawal of benefit because of a particular wrongdoing would actually punish innocent parties more substantially than it would harm those responsible for the wrong.

<sup>85</sup> Cal. Health & Safety Code § 7192(a) (Deering Supp. 1982), *reprinted in* Appendix D, pp. 324-29 *infra*.

<sup>82</sup> A. M. Capron, *Right to Refuse Medical Care*, in 4 **ENCYCLOPEDIA OF BIOETHICS**, The Free Press, New York (1978) at 1498.

<sup>87</sup> *Superintendent of Belchertown State School v. Saikewicz* 370 N.E.2d 417, 426 (1977).



Administrative and regulatory law has been used in health care mainly to expand opportunities for care and to improve its **quality**.<sup>88</sup> Very little attention has been given to providing programmatic incentives for good decisionmaking practices or disincentives against inadequate ones.

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<sup>88</sup> See **SECURING ACCESS TO HEALTH CARE**, *supra* note 47, at 119–82.



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## The Elements of Good Decisionmaking

# 2

Patients whose medical conditions require treatment to sustain life usually want the treatment and benefit from it. Sometimes, however, a treatment is so undesirable in itself or the life it sustains is so brief and burdened that a patient—or a surrogate acting on the patient's behalf—decides that it would be better to forego the treatment. This chapter considers how life-sustaining treatment decisions should be made and the ethical and legal constraints on such decisions that might be warranted.

### Shared Decisionmaking

In considering the issue of informed consent,<sup>1</sup> the Commission recommended that patient and provider collaborate in a continuing process intended to make decisions that will advance the patient's interests both in health (and well-being generally) and in self-determination.<sup>2</sup> The Commission argued that decisions about the treatments that best promote a patient's health and well-being must be based on the particular patient's values and goals; no uniform, objective determination can be adequate—whether defined by society or by health professionals.

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<sup>1</sup> President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *MAKING HEALTH CARE DECISIONS*, U.S. Government Printing Office, Washington (1982). Arguments for the recommendations given here and further elaborations of the consequences can be found in that Report and its two volumes of Appendices.

Self-determination, sometimes called "autonomy," involves a person forming, revising over time, and pursuing his or her own particular plan of life. See John Rawls, *Rational and Full Autonomy*, 77 *J. PHIL.* 524 (1980).

Respect for the self-determination of competent patients is of special importance in decisions to forego life-sustaining treatment because different people will have markedly different needs and concerns during the final period of their lives; living a little longer will be of distinctly different value to them. Decisions about life-sustaining treatment, which commonly affect more than one goal of a patient (for example, prolongation of life and relief of suffering) create special tensions. Nonetheless, a process of collaborating and sharing information and responsibility between care givers and patients generally results in mutually satisfactory decisions.<sup>3</sup> Even when it does not, the primacy of a patient's interests in self-determination and in honoring the patient's own view of well-being warrant leaving with the patient the final authority to decide.

Although competent patients thus have the legal and ethical authority to forego some or all care,<sup>4</sup> this does not mean that patients may insist on particular treatments. The care available from health care professionals is generally limited to what is consistent with role-related professional standards and conscientiously held personal beliefs. A health care professional has an obligation to allow a patient to choose from among medically acceptable treatment options (whether provided by the professional or by appropriate colleagues to whom the patient is referred) or to reject all options. No one, however, has an obligation to provide interventions that would, in his or her judgment, be countertherapeutic.

In most circumstances, patients are presumed to be capable of making decisions about their own care. When a patient's capability to make final decisions is seriously limited, he or she needs to be protected against the adverse consequences of a flawed choice. Yet any mechanism that offers such protection also risks abuse: the individual's ability to direct his or her own life might be frustrated in an unwarranted manner. In its report on informed consent, the Commission recommended that a surrogate—typically a close relative or friend—be named when a patient lacks the capacity to make particular medical decisions.<sup>5</sup> As much as possible, surrogates

<sup>3</sup> See generally Ned H. Cassem, *Procedural Protocol When Illness is Judged Irreversible*, in Edward Rubenstein and Daniel D. Federman, eds., *SCIENTIFIC AMERICAN MEDICINE*, Scientific American, Inc., New York (1980) at 13-V-1; Bernard Lo and Albert Jonsen, *Clinical Decisions to Limit Treatment*, 98 *ANNALS INT. MED.* 764 (1982).

<sup>4</sup> A. M. Capron, *Right to Refuse Medical Care*, in 4 *ENCYCLOPEDIA OF BIOETHICS*, The Free Press, New York (1978) at 1498; Norman L. Cantor, *A Patient's Decision to Refuse Life-Saving Medical Treatment: Bodily Integrity versus the Preservation of Life*, 26 *RUTGERS L. REV.* 228 (1973).

<sup>5</sup> *MAKING HEALTH CARE DECISIONS*, *supra* note 1, at 181-88. The considerations that enter into a decision to turn to a surrogate

and providers of care should then make decisions as the particular patient would have.

**Decisionmaking Capacity.** Determining whether a patient has sufficient decisionmaking capacity to make choices about health care treatment is based on three considerations: the abilities of the patient, the requirements of the task at hand, and the consequences to the patient that are likely to flow from the decision. The individual must have sufficiently stable and developed personal values and goals, an ability to communicate and understand information adequately, and an ability to reason and deliberate sufficiently well about the choices.<sup>6</sup>

Just as for medical treatment generally, deciding about a patient's decisionmaking abilities when the patient is facing a complex and confusing situation or making a decision of great consequence requires both the wise judgment of others and procedures that regularly yield morally and legally acceptable decisions. The Commission has found no reason for decisions about life-sustaining therapy to be considered differently from other treatment decisions. A decision to forego such treatment is awesome because it hastens death, but that does not change the elements of decisionmaking capacity and need not require greater abilities on the part of a patient. Decisions about the length of life are not necessarily more demanding of a patient's capabilities than other important decisions. And decisions that might shorten life are not always regarded by patients as difficult ones: a patient who even with treatment has a very short time to live may find a few additional hours rather unimportant, especially if the person has had a chance to take leave of loved ones and is reconciled to his or her situation.

Thus, determining whether or not a patient lacks the capacity to make a decision to forego life-sustaining treatment will rest on generally applicable principles for making assessments of decisional incapacity in medical care. Of course, when a patient who could have a substantial time to live rejects life-sustaining treatment, close inquiry into the components of that person's decisionmaking capacity is warranted in order to protect the individual from harms that arise from incapacities that themselves diminish the value of self-determination.'

**Voluntariness.** A patient's choice is binding when it is selected freely—that is, when the patient can decide in accord with his or her own values and goals.<sup>8</sup> Selection among options

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(including the steps that are appropriate to overcome the causes of a patient's incapacity) and the procedures and standards for surrogate decisionmaking are also treated in pp. 121-36 *infra*.

<sup>6</sup> MAKING HEALTH CARE DECISIONS, *supra* note 1, at 169-75.

<sup>7</sup> *Id.* at 44-51.

<sup>8</sup> *Id.* at 63-68.

must not be so influenced by others that free choice is precluded, and relevant treatment options must therefore be made available to the patient. Furthermore, the patient must be situated so as to feel that he or she is expected to have the final word in the treatment decision. Of course, patients do not make decisions in isolation from others. Complex networks of relationships and roles make the responses of other parties very important to patients and to their decisionmaking.

One of the things that patients rightly expect from professionals, and that professionals usually expect to provide, is advice rather than neutral information about treatment options and their risks and benefits. However, the way advice is provided can vary substantially. Individual personality styles, both of the professional and of the patient, range from authoritarian through nondirective to dependent.

Drawing the line between influence that is legitimate and that which is not is difficult both conceptually and in practice.<sup>9</sup> Often distinctions are suggested between "coercion," "fraud," "duress," "deceit," and "manipulation" —all of which are said to be unacceptable— and "influence," "persuasion," and "advice" —which are expected, and perhaps even desired. The use of these labels conveys a judgment as to whether an action would interfere with voluntary choice or not, but the categories are too poorly defined to provide a generally accepted basis for judging the difficult cases. It is important, therefore, to develop a fuller understanding of acceptable conduct in the interaction of health care professionals and others with patients.

Professional care givers and a patient's close friends and family<sup>10</sup> have two major roles to play when someone faces a decision about life-sustaining treatment. First, their actions, words, and presence help shape the patient's assessment of the best course of treatment. Second, their ability and willingness to carry out various decisions often define the range of options available to the patient."

***Shaping the patient's deliberations.*** How information is communicated and continuing care is provided can forcefully induce a patient to make certain choices. In many medical care

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<sup>9</sup> *Id.*

<sup>10</sup> "Family" is defined broadly in this Report to include closest relatives and intimate friends, since under some circumstances, particularly when immediate kin are absent, those most concerned for and knowledgeable about the patient may not be actual relatives. See also notes 18, 19 and 20, Chapter Four *infra*.

<sup>11</sup> This second aspect is discussed in pp. 91-94 *infra*.

situations patients are dependent and professionals are relatively powerful.<sup>12</sup> This disparity creates an obligation for professionals to reduce the understandable tendency of some patients to receive and act upon either a distorted understanding of their medical situation or a feeling of powerlessness, so that individuals can truly decide in accord with their own values and goals.<sup>13</sup>

Helping to shape the deliberations of a patient who must decide about the course and duration of his or her life is a complex and weighty obligation. For example, letting a patient know that his or her death is now seen by others to be appropriate—or at least not unexpected—may be "giving permission to die" to a patient who no longer wishes to struggle against overwhelming odds. On the other hand, it may encourage overly rapid acceptance of death by a patient who feels rejected and unimportant.<sup>14</sup>

Deciding on the best response and role is especially difficult for families and often inescapably uncertain. Clearly, family members do best by sustaining the patient's courage and hope, and by advancing the person's interests (and limiting self-serving actions) as much as possible. But family members usually cannot be dispassionate and emotionally uninvolved, nor should they try to be. In addition to any practical effects of the illness, they suffer from fear, anxiety, and grief—often as much or more than the patient. Thus, their ability to respond to the patient's needs is determined by their own capabilities under the circumstances.<sup>15</sup>

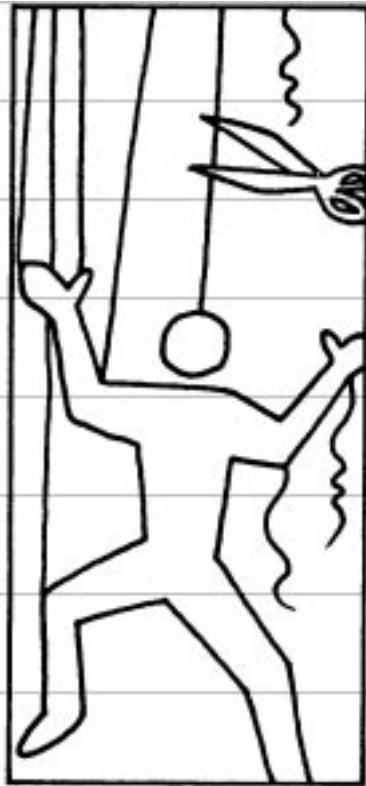
<sup>12</sup> Talcott Parsons, *THE SOCIAL SYSTEM*, The Free Press, New York (1951) at 445; Charles J. Dougherty and Sandra L. Dougherty, *Moral Reconstruction in the Hospital: A Legal and Philosophical Perspective on Patient Rights*, 14 **CREIGHTON L. REV.** 1409, 1423-24 (1981).

<sup>13</sup> This feeling of powerlessness led 27-year-old Ted Vergith, a paralyzed nursing home resident, to resist the recommended appointment of a guardian to consent to treatment for life-threatening infections: "I was not in control and I felt almost like I was being stripped of my dignity. Just because you can't walk anymore doesn't mean you can't think and make decisions for yourself." Although Vergith was successful in resisting the appointment of a guardian, he did accept treatment. 3 **BIOETHICS LETTER** 3 (Dec. 1982).

<sup>14</sup> Antipaternalistic policies may be construed in ways other than their proponents and practitioners intend. For example, if we do not intervene to prevent suicides out of respect for patient autonomy, our nonintervention may be seen as expressing the conviction that these deaths do not matter. A policy that affirms "you should care for yourself" may be interpreted as "we don't care for you."

James F. Childress, *PRIORITIES IN BIOMEDICAL ETHICS*, Westminster Press, Philadelphia (1981) at 32.

<sup>15</sup> Austin H. Kutscher, *Practical Aspects of Bereavement*, in Bernard Schoenberg *et al.*, eds., *LOSS AND GRIEF: PSYCHOLOGICAL MANAGEMENT*



Generally, part of the experience of dying involves withdrawing from some goals and relationships that have become unachievable or unimportant, pursuing other goals that are important to accomplish, providing directions for the future disposition of property and body, and giving advice to friends and families. Each of these practical steps entails reciprocal activities by others in a person's social network---acceptance of disengagement, support in revising priorities, legal counsel in writing a will, gathering for farewells, and so forth.<sup>16</sup>

The roles of health care professionals are different from those of family members. Their personal concerns and predispositions are not supposed to interfere with providing patients with competent care<sup>17</sup>; they are expected to develop

ways to protect themselves from emotional exhaustion without becoming too distant or impersonal to help patients cope with emotional problems.<sup>18</sup>

The individual health care provider is likely to help dying patients most by maintaining a predisposition for sustaining life (while accepting that prolongation of dying may serve no worthwhile purpose for a particular patient). Indeed, this favoring of life is part of society's expectation regarding health care professionals.<sup>19</sup> Commonly, it is supported by a personal

IN *MEDICAL PRACTICE*, Columbia Univ. Press, New York (1970) at 280; Henry J. Heimlich and Austin H. Kutscher, *The Family's Reaction to Terminal Illness*, in *id.* at 270.

<sup>16</sup> Barton E. Bernstein, *Lawyer and Therapist as an Interdisciplinary Team: Serving the Survivors*, 4 *DEATH EDUCATION* 179 (1980); Ann S. Kliman, *The Non-Legal Needs of a Dying Client*, *NAT'L L.J.*, Nov. 24, 1980, at §1-15.

<sup>17</sup> Different physicians often see the same situation quite differently, a fact that physicians ought to try to remedy as otherwise it severely biases patients' ability to choose. Robert A. Pearlman, Thomas S. Inui, and William B. Carter, *Variability in Physician Bioethical Decision-Making: A Case Study of Euthanasia*, 97 *ANNALS INT. MED.* 420 (1982).

<sup>18</sup> See note 57 *infra*.

<sup>19</sup> See, e.g., Donald G. McCarthy, *The Responsibilities of Physicians*,



belief or value commitment and by a recognition of the needs of dying patients for reassurance about the worth of their own lives. Until it is quite clear that a patient is making an informed, deliberate, and voluntary decision to forego specific life-sustaining interventions, health care providers should look for and enhance any feelings the patient has about not yet acquiescing in death. As death comes closer, such sentiments generally recede; until then, there need be no haste to encourage a patient's acceptance of death.<sup>20</sup>

Enhancing the experience of those whose lives are drawing to a close is a worthwhile goal, one that requires skill, compassion, honesty, and humility. Here, various individuals can serve different and valued functions: clergy can attend especially to religious questions and rituals that affirm spiritual and temporal meaning; family members can resolve problems in relationships and reaffirm the importance of the patient's life; and health care professionals can focus on relieving immediate sources of distress and on enhancing the self-respect and courage of the patient.

The complex nature of provider-patient relations—each person influencing the attitudes of the other in ways that neither may fully understand—is illustrated by the case of "David G.," a young man who pleaded articulately with his physicians to cease the painful treatments they were providing for the extensive burns he had suffered.

His sudden and unaccustomed total dependence on others insistently calls into question the psychological basis for common-sense perception that he has an identity separate from other people and from the external world.

The critical ambiguity...goes...to Mr. G.'s conception of himself as a choice maker; that is, it is not clear whether he sees himself as separate from others in exercising choice regarding his future or whether he chooses death because he believes others want that result for him and he feels incapable of extricating himself from their choicemaking for him. Either perspective could lead to the deepest despair; his affliction itself could rob life of

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in Donald G. McCarthy and Albert S. Moraczewski, eds., *MORAL RESPONSIBILITY IN PROLONGING LIFE DECISIONS*, Pope John Center, St. Louis, Mo. (1981) at 255; John Ladd, *Physicians and Society: Tribulations of Power and Responsibility*, in Stuart F. Spicker, Joseph M. Healey, Jr., and H. Tristram Engelhardt, Jr., eds., *THE LAW-MEDICINE RELATIONSHIP: A PHILOSOPHICAL EXPLANATION*, D. Reidel Pub., Boston (1981) at 33.

<sup>20</sup>Ned H. Cassem, *Treatment Decisions in Irreversible Illness*, in Thomas P. Hackett and Ned H. Cassem, eds., *MASSACHUSETTS GENERAL HOSPITAL HANDBOOK OF GENERAL HOSPITAL PSYCHIATRY*, C.V. Mosby Co., St. Louis, Mo. (1978) at 572-73.

all possible meaning for him: his belief that others...wished him dead could do the same. If, however, others were deferring to his wish to die because they conceived that they were honoring his self-determination, it would be critical to establish which of these two perspectives led him to this choice.<sup>21</sup>

**Making choices available.** Providers and others have an obligation to see that patients can choose among a range of available and potentially beneficial treatment.<sup>22</sup> Sometimes the range is limited wrongly because a practitioner is unwilling to make available an option or is ignorant of a possible treatment that is especially pertinent to a particular decision about life-sustaining therapy. Since competent and informed patients ought to be made aware that they can forego medical interventions, the option of no effort at curative therapy should generally be explored with dying patients. Some patients may associate this course with isolation, abandonment, and unmitigated suffering, however, unless supportive care is clearly also made available.

Good medical and nursing care can greatly improve the lives of patients who are dying.<sup>23</sup> Much comfort can be gained by careful attention to such details as proper positioning, vigorous skin care, oral hygiene, disguising of disfigurement, on-demand feeding of preferred foods, and so on. Medical management of symptoms has recently demonstrated that no patient should have to be terrified of physical pain; in fact, presently available drugs and techniques allow pain to be

<sup>21</sup> Robert A. Burt, *TAKING CARE OF STRANGERS*, The Free Press, New York (1979) at 11. See also Robert B. White and H. Tristram Engelhardt, Jr., *A Demand to Die*, 5 *HASTINGS CTR. REP.* 9 (June 1975); Michael Platt, *Commentary: On Asking to Die*, 5 *HASTINGS CTR. REP.* 9 (Dec. 1975).

<sup>22</sup> For a discussion of external sources of unavailability, such as financial limitations on access to care, see Chapter Three *infra*.

<sup>23</sup> See, e.g., Cicely Saunders, ed., *THE MANAGEMENT OF TERMINAL DISEASE*, Edward Arnold Publishers, Ltd., London (1978); E. Mansell Pattison, ed., *THE EXPERIENCE OF DYING*, Prentice-Hall, Inc., Englewood Cliffs, N.J. (1977). See also Appendix B, pp. 275-97 *infra*.

We may do much good by a palliative course, by alleviating pain, procuring sleep, guarding the diet, regulating the alimentary canal—in fine, by obviating such sufferings as admit of mitigation...Lastly, by a just prognosis...we may sustain the patient and his friends during the inevitable course of the disease.

Jacob Bigelow, *Care in the Absence of Cure-1835*, reprinted in 85 *ANNALS INT. MED.* 825 (1976).

reduced to a level acceptable to virtually every patient, usually without unacceptable sedation.<sup>24</sup> Other symptoms, such as nausea, anxiety, constipation, and shortness of breath, usually respond reasonably well to drugs or other procedures.<sup>25</sup> Providers of care have an obligation to ensure that these supportive measures are available to everyone, whether or not a patient has chosen to pursue life-sustaining treatment. To allow such a decision to result in an avoidably harsh existence, or to let the patient believe that it will, is unjustifiable and may render the patient's decision involuntary.

**Nonvoluntary decisionmaking.** Nonvoluntary foregoing of life-sustaining therapy takes place when a patient gives neither effective consent nor refusal. Often this arises because a patient's decisionmaking capacity is inadequate, and then a surrogate will have to decide on behalf of the patient.<sup>26</sup> Sometimes, however, a patient, though competent, is excluded from the decisionmaking process. This is unjustifiable since it demeans the patient by barring self-determination and allows others to shorten the patient's life or establish the burdens under which it will be lived without the assurance (which could be obtained) that the patient concurs in the judgment. Although there may be times when a competent patient would prefer not to be involved in these choices, it is impossible to know in advance which patients would come to this conclusion.<sup>27</sup> And the risk of wrongly abrogating decisionmaking for many patients seems generally more grievous than the pain of confronting some seriously ill patients with choices that they would rather not face. The only time that the Commission finds it justified for a patient who could be informed and involved to be excluded is when that patient freely and knowingly transfers some decisionmaking authority to another.<sup>28</sup>

### Informing and Communicating

**Disclosure.** The extent of the obligation of providers to inform patients so that they can make sound choices is no different for life-sustaining treatment than for any other. In the Commission's view, health professionals should ensure that patients understand (1) their current medical status, including

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<sup>24</sup> Robert G. Twycross, *Relief of Pain*, in Saunders, *supra* note 23, at 65; Ivan K. Goldberg, Sidney Malitz, and Austin H. Kutscher, eds., *PSYCHOPHARMACOLOGIC AGENTS FOR THE TERMINALLY ILL AND BEREAVED*, Columbia Univ. Press, New York (1973).

<sup>25</sup> See, e.g., Mary J. Baines, *Control of Other Symptoms*, in Saunders, *supra* note 23, at 99. See also Appendix B, pp. 275-97 *infra*.

<sup>26</sup> See pp. 126-31 *infra*.

<sup>27</sup> MAKING HEALTH CARE DECISIONS, *supra* note 1, at 94-102. One regular exception to this is that most people willingly let professionals make decisions for them when life-sustaining treatment is needed on an emergency basis. *Id.* at 93.

<sup>28</sup> *Id.* at 50-51.

its likely course if no treatment is pursued; (2) the interventions that might be helpful to the patient, including a description of the procedures involved and the likelihood and effect of associated risks and benefits; and (3) in most cases, a professional opinion as to the best alternative.<sup>29</sup> Each of these elements must be discussed in light of associated uncertainties.<sup>30</sup>

The purpose of such discussions is not to inundate patients with medical facts but rather to give them the information they need in order to assess options realistically and to choose the treatments most consonant with their own values and goals. Inaccurate or incomplete information limits patients' understanding of what is at stake. For any medical intervention to be warranted, a patient must stand to gain more from having the treatment than from not having it. Since the benefit to be gained must be assessed in terms of the patient's own values and goals, practitioners should be cautious not to rule out prematurely a seemingly undesirable or less-than-optimal alternative that might offer what a particular patient would perceive as a benefit.

Physician attitudes toward communication with terminally ill patients have changed dramatically in recent years. Whereas 20 years ago the majority of physicians did not disclose a fatal diagnosis to their patients, most physicians now do so routinely.<sup>31</sup> Yet both behaviors—generally withholding in the 1960s and generally disclosing today—seem to be based on physicians' judgments of what is best for patients rather than on recognition of the value of self-determination per se.

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<sup>29</sup> A physician who merely spreads an array of vendibles in front of the patient and then says, "Go ahead and choose, it's your life," is guilty of shirking his duty, if not of malpractice. The physician, to be sure, should list the alternatives and describe their pros and cons but then, instead of asking the patient to make the choice, the physician should recommend a specific course of action. He must take the responsibility, not shift it onto the shoulders of the patient. The patient may then refuse the recommendation, which is perfectly acceptable, but the physician who would not use his training and experience to recommend the specific action to a patient—or in some cases frankly admit "I don't know"<sup>m</sup>—does not warrant the somewhat tarnished but still distinguished title of doctor.

Franz J. Ingelfinger, *Arrogance*, 303 *NEW ENG. J. MED.* 1507, 1509 (1980). See also MAKING HEALTH CARE DECISIONS, *supra* note 1, at 76-79.

<sup>30</sup> MAKING HEALTH CARE DECISIONS, *supra* note 1, at 85-89. See also Parsons, *supra* note 12, at 449; Renee *of Medical*

*Uncertainty*, 58 *MILBANK MEM. FUND Q./ HEALTH & SOCIETY* 1, 49 (1980).

<sup>31</sup> Dennis H. Novack *et al.*, *Changes in Physicians' Attitudes Toward Telling the Cancer Patient*, 241 *J.A.M.A.* 897 (1979).

Three surveys between 1953 and 1961,<sup>32</sup> for example, found that 69-90% of physicians routinely failed to inform cancer patients of their diagnosis, claiming that the unvarnished truth would be too much for their patients—"a death sentence," "torture," or "hitting the patients with a baseball bat."<sup>33</sup> Those surveyed expressed concern about the psychological damage that could ensue from such revelations<sup>34</sup> and gave that as a reason for a "therapeutic privilege" to exempt them from the requirements of informed consent when caring for terminally ill patients.<sup>35</sup> Yet one researcher found "on closer examination, most of the instances in which unhappy results were reported to follow [disclosure] turned out to be vague accounts from which no reliable inference could be drawn."<sup>36</sup> Fearful of the effects of telling the truth, many physicians relied upon incomplete information and euphemisms, resorting to vague terms such as "lesion" or "mass" or using language only suggestive of malignancy, such as a "suspicious" or "degenerated" tumor.<sup>37</sup>

<sup>32</sup> William T. Fitts, Jr. and I.S. Ravdin, *What Philadelphia Physicians Tell Patients with Cancer*, 153 J.A.M.A. 903 (1953); Dan Rennick, *What Should Physicians Tell Cancer Patients?*, NEW MED. MATERIALS (March 1960); Donald Oken, *What to Tell Cancer Patients: A Study of Medical Attitudes*, 175 J.A.M.A. 1120 (1961).

<sup>33</sup> Oken, *supra* note 32, at 1125.

<sup>34</sup> The reluctance to disclose information shown by the early surveys seemed ironic in the face of the desire expressed by the overwhelming majority of physicians to be told when they themselves confront serious illness. Herman Feifel, *The Function of Attitudes Toward Death*, in DEATH AND DYING: ATTITUDES OF PATIENT AND DOCTOR, Symposium #11, Group for the Advancement of Psychiatry, New York 632, 635 (1965). Interestingly, however, they still would not disclose such information to their physician brethren. Jay Katz and A. M. Capron, CATASTROPHIC DISEASES: WHO DECIDES WHAT?, Russell Sage Foundation, New York (1975) at 101 n.56.

<sup>35</sup> Hubert W. Smith, *Therapeutic Privilege to Withhold Specific Diagnosis from Patient Sick with Serious or Fatal Illness*, 19 TENN. L. REV. 349 (1946).

<sup>36</sup> Oken, *supra* note 32, at 1124.

<sup>37</sup> *Id.* at 1125. The practice of using misleading euphemistic language has apparently long existed, as can be seen in a well-known nineteenth-century work:

The face of a physician, like that of a diplomatist should be impenetrable. Nature is a benevolent old hypocrite; she cheats the sick and dying with illusions better than any anodynes....

Some shrewd old doctors have a few phrases always on hand for patients that will insist on knowing the pathology of their complaints without the slightest capacity of understanding the scientific explanation. I have known the term "spinal irritation" serve well on such occasions, but I think nothing on the whole has covered so much ground, and meant so little, and given such profound satisfaction to all parties, as the magnificent

In a 1978 replication of the 1961 survey, 97% of physicians said they preferred to tell cancer patients of their diagnosis, compared with only 10% of those polled earlier.<sup>38</sup> Physician attitudes thus now seem to be more attuned to current desires of patients, the overwhelming majority of whom want to know the whole truth. Indeed, in the Commission's survey of patient-provider relationships, "the public displayed an unflinching desire for facts about their condition, even dismal facts"; 96% of the public stated specifically that they would want to know of a diagnosis of cancer, and 86% said they would want a realistic prognosis.<sup>39</sup>

There are a number of hypotheses about why physicians' attitudes shifted. When physicians avoided telling patients their prognoses explicitly, they may still have found that patients arrived at quite reliable conclusions about the nearness of death from how sick they were and from the behavior of others. In one study, three-fourths of the patients who had not been fully informed nevertheless knew that they were expected to die soon.<sup>40</sup> When this is the case, the issue of

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phrase "congestion of the portal system."

Oliver Wendell Holmes, *The Young Practitioner*, in *MEDICAL ESSAYS: 1842-1892*, Houghton Mifflin and Co., Boston (1891) at 370, 388-89.

<sup>38</sup> Physicians in the 1978 survey cited the patient's age, intelligence, and emotional stability, in addition to the patient's or relatives' expressed wishes to be told, as factors in deciding whether to disclose. Obviously, reliance on these qualifiers as hurdles patients must overcome to receive information could lead to objectionable paternalism. Novack, *supra* note 31.

Regarding intelligence as a prerequisite, one physician, writing in a popular magazine, had this observation: "To some highly intelligent people—like John Foster Dulles or Robert A. Taft—you can tell the simple truth and know that it is not going to destroy them as human beings. Their minds... are capable of ...adjusting to it rationally." *Discussion, Should Doctors Tell the Truth to a Cancer Patient?*, 78 *LADIES HOME J.* 65, 108 (May 1961). The wiser view would seem to be that "It is very probable that a doctor feels better able to tell an intelligent patient, but this does not necessarily mean that the less intelligent may not cope with this knowledge as well." John M. Hinton, *The Physical and Mental Distress of the Dying*, 32 *Q.J. MED.* 1, 19 (1963). For a critique of paternalistic justifications for withholding information from patients, see Allen E. Buchanan, *Medical Paternalism*, in Marshall Cohen *et al.*, eds., *MEDICINE AND MORAL PHILOSOPHY*, Princeton Univ. Press, Princeton, N.J. (1982) at 214.

<sup>39</sup> Louis Harris and Associates, *Views of Informed Consent and Decisionmaking: Parallel Surveys of Physicians and the Public*, in President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *MAKING HEALTH CARE DECISIONS, VOLUME TWO: APPENDICES (EMPIRICAL STUDIES OF INFORMED CONSENT)*, U.S. Government Printing Office, Washington (1982) at 17.

<sup>40</sup> Hinton, *supra* note 38, at 19.

whether the doctor should tell the patient loses much of its force. Moreover, most of the surveys have dealt with cancer,<sup>41</sup> which may indeed have been very nearly a death sentence as recently as two decades ago. Today remission and even cure is often possible; the disease is not as ominous or stigmatizing as it once was.<sup>42</sup> Since the medical information is more complex, diagnoses today may actually need much more explanation in order for patients to understand the relevant facts.

Physicians may also be giving more information as a function of the increasingly broad and enforced legal duties of disclosure.<sup>43</sup> And many dying patients are part of clinical research in which the obligation to disclose a diagnosis before consent is obtained is carefully enforced by each hospital's institutional review board.<sup>44</sup> Finally, physicians have doubtless been affected by the desire of terminally ill patients for more information, one manifestation of an era marked by consumerism, "patients' rights," and a wariness of the professions generally.

Some physicians are more willing to talk about dying because they have seen the detrimental effects of not doing so. Failure to disclose information to patients who seek it takes a toll in the erosion of trust—the basic bond between physician and patient. This mistrust is likely to be exacerbated and extended to family members if they conspire in keeping silent.<sup>45</sup> For patients whose intuitions tell them they are

<sup>41</sup> See, e.g., notes 21 and 32 *supra*; William D. Kelly and Stanley R. Frisen, *Do Cancer Patients Want to Be Told?*, 27 *SURGERY* 822 (1950); E.M. Litin, *Should the Cancer Patient be Told?*, 28 *POSTGRADUATE MED.* 470 (1960); Robert J. Saup and Anthony R. Curreric, *A Questionnaire Survey on Public Cancer Education Obtained from Cancer Patients and Their Families*, 10 *CANCER* 382 (1957); Lesley A. Slavin, *Communication of the Cancer Diagnosis to Pediatric Patients: Impact on Long-term Adjustment*, 139 *AM. J. PSYCHIATRY* 179 (1982).

<sup>42</sup> For an elucidation of some of the myth, metaphor, and imagery surrounding cancer, see Susan Sontag, *ILLNESS AS METAPHOR*, Farrar, Straus & Giroux, New York (1978).

<sup>43</sup> Note, *Informed Consent and the Dying Patient*, 83 *YALE L. J.* 1632 (1974); Arnold J. Rosoff, *INFORMED CONSENT: A GUIDE FOR HEALTH CARE PROVIDERS*, Aspen Systems Corporation, Rockville, Md. (1981). One example of a statutory duty to disclose a terminal diagnosis is the District of Columbia's Natural Death Act, which requires a physician to inform the patient of his or her terminal condition verbally or in writing so that the Act's provisions have legal force. D.C. Code Ann. tit. 16, § 6-2425(b) (1981), *reprinted in* Appendix D, pp. 335-40 *infra*.

<sup>44</sup> Emil J. Freireich, *Should the Patient Know?* (Editorial), 241 *J.A.M.A.* 928 (1979); President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *THE OFFICIAL IRB GUIDEBOOK*, U.S. Government Printing Office, Washington (1983).

<sup>45</sup> This danger is revealed movingly in the case of Jo Ann Mortenson, a 37-year old woman from whom a diagnosis of brain tumor was withheld. Her family was told the truth; Jo Ann was told she had an

seriously ill, unlikely fabrications or euphemisms may result in fear that the doctor does not know the real diagnosis or that the family cannot cope with it. For many, the worry, conjecture, and degradation that can result from misinformation may be more tormenting than the knowledge of the illness itself.<sup>46</sup> Nondisclosure may inhibit further questions from patients, which would limit their capacity to participate in medical care decisions as well as those on other personal and financial affairs.

The issue of whether to tell patients about a terminal diagnosis is less a choice of "to tell or not to tell" than it is a question of how to gauge how much each patient wants to

"encephalitic scar." She later said:

Imagine taking the parents of a thirty-seven-year-old woman and a man who is the father of five children into a room, hitting them over the head with the truth and then expecting them to take the responsibility for what should be told to the patient. That's not fair. When the doctor takes on the patient in the first place, he is taking the patient on whether that patient lives or dies; and when something unpleasant comes up, it is the doctor's job to tell the patient.

Perhaps he might start off before he knows the results of any tests and ask if the patient wants to know the truth. He can remind the patient that whatever the diagnosis, he is prepared to be available as long as the patient requires, to supply whatever physical and psychological comfort he can.

Gerald Astor, *"What's Really Wrong with Me?", 100 McCALL'S* 52,138 (June 1973). See also Peter Maguire, *The Personal Impact of Dying*, in Eric Wilkes, ed., *THE DYING PATIENT*, George A. Bogden & Son, Inc., Ridgewood, N.J. (1982) at 233, 252; W.P.L. Myers, *The Care of the Patient with Terminal Illness*, in Paul Beeson, Walsh McDermott, and James B. Wyngaarden, eds., *CECIL TEXTBOOK OF MEDICINE*, W.B. Saunders Co., Philadelphia (1979) at 1941, 1944.

<sup>46</sup> What tormented Ivan Ilych most was the deception, the lie, which for some reason they all accepted, that he was not dying but was simply ill, and that he only need keep quiet and undergo a treatment and then something very good would result. He however knew that do what they would nothing would come of it, only still more agonizing suffering and death. This deception tortured him—their not wishing to admit what they all knew and what he knew, but wanting to lie to him concerning his terrible condition, and wishing and forcing him to participate in that lie. Those lies—lies enacted over him on the eve of his death and destined to degrade this awful, solemn act to the level of their visitings, their curtains, their sturgeon for dinner—were a terrible agony for Ivan Ilych.

Leo Tolstoy, *The Death of Ivan Ilych*, in *THE DEATH OF IVAN ILYCH AND OTHER STORIES*, New American Library, New York (Aylmer Maude trans., 1960) at 95, 137. See also William F. May, *On Not Facing Death - Alone*, 1 *HASTINGS CTR. REP.* 8 (June 1971).



know at a particular time. As one experienced physician has noted, "The real question is not 'what do you tell your patients?' but rather 'what do you let your patients tell you?'"<sup>47</sup> In other words, "Now that we tell our patients more, are we also listening more?"<sup>48</sup>

Clearly, doses of truth must be administered with sensitivity, lest they inflict undue psychic trauma upon patients. The dialectic of provider-patient communication is a sensitive one that varies from case to case.<sup>49</sup> Commonly, communication and cues take nonverbal forms, and verbal expressions sometimes are misleading. Meaningful dialogue does not come easily or cheaply:

You have to be prepared to spend an enormous amount of time with that person, exploring and talking and being quiet for periods of time and letting conversation go and coming back to conversation....Expenditure of time is something that is a quite precious commodity in medical care generally, and is in fact ladled out rather sparingly...particularly with dying patients.<sup>50</sup>

A nurse who has worked with parents of seriously ill newborns in a neonatal intensive care unit told the Commission:

Very often parents are not ready to talk a great deal initially about the worst and most horrible possibilities for the future of their child. And so a good deal of time is often spent in early weeks...on what sounds like casual chitchat. I talked a lot about baseball and TV and other things with this family...which really was contributory to building the relationship to use when we needed it.<sup>51</sup>

**Learning to communicate.** For professionals who work with the dying, as well as for families and loved ones, being with patients who are dying can be painful and emotionally exhausting; in truth, it means facing one's own death.

It extracts a cost that is usually overlooked in the training of the professional. In fact, it would be more accurate to say that the cost is known but the student is

<sup>47</sup> Cicely Saunders, *The Moment of Truth: Care of the Dying Person*, in L. Pearson, ed., *DEATH AND DYING*, Case Western Reserve Univ. Press, Cleveland, Ohio (1969) at 49, 59.

<sup>48</sup> Novack, *supra* note 31, at 899. *See also*, E.R. Hillier, *Communication Between Doctor and Patient*, in Robert G. Twycross and Vittorio Ventafridda, eds., *THE CONTINUING CARE OF TERMINAL CANCER PATIENTS*, Pergamon Press, New York (1980) at 37.

<sup>49</sup> *See* Ned H. Cassem, *The Dying Patient*, in Hackett and Cassem, *supra* note 20, at 300.

<sup>50</sup> Testimony of Robert Burt, transcript of 21st meeting of the President's Commission (June 10, 1982) at 169.

<sup>51</sup> Testimony of Carole Kennon, transcript of 16th meeting of the President's Commission [Jan. 9, 1982] at 21-22.

usually warned against paying it. The price of compassion is conveyed by the meaning of the two words, *com* and *passio*, which mean to "suffer with" another person. One must be touched by the tragedy of the patient in a literal way, a process that occurs through experiential identification with the dying person. This process, empathy, when evoked by a person facing death or tragic disability, ordinarily meets strong...resistance. Who can bear the thought of dying at 20?<sup>52</sup>

For some, avoidance is a way to deal with disconcerting aspects of being with dying patients. Such avoidance can be an impersonal or scientific attitude as much as a failing to be physically present.<sup>53</sup> Patients often express concern about loneliness in their final days, and studies have showed that many professionals tend to avoid dying patients." When this occurs, the patient can end up in a netherworld of neglect, feeling lonely and abandoned; possibly foregoing opportunities to receive palliative, comforting measures; perhaps even missing the chance that a mistaken diagnosis will be corrected.<sup>55</sup>

<sup>52</sup> Ned H. Cassem and Rege S. Stewart, *Management and Care of the Dying Patient*, 6 INT'L. J. PSYCHIATRY IN MED. 293, 298 (1975).

<sup>53</sup> To Ivan Ilych only one question was important: was his case serious or not? But the doctor ignored that inappropriate question. From his point of view it was not the one under consideration, the real question was to decide between a floating kidney, chronic catarrh, or appendicitis. It was not a question of Ivan Ilych's life or death.

Tolstoy, *supra* note 46, at 121.

<sup>54</sup> One dying patient stated: "I feel like a railway station that's been closed down—the ward round doesn't stop here any more." Michael A. Simpson, *Therapeutic Uses of Truth*, in Wilkes, *supra* note 45, at 255, 259. See also Barney G. Glaser and Anselm L. Strauss, *Dying on Time*, in Anselm L. Strauss, ed., *WHERE MEDICINE FAILS*, Aldine Pub. Co., Hawthorne, N.Y. (1970) at 131, 139; Donald G. Gallup, Marco Labudovich, and Paul R. Zambito, *The Gynecologist and the Dying Cancer Patient*, 144 AM. J. OBSTET. GYNECOL. 154 (1982); *Physicians Found to Spend Little Time With Oldsters*, 22 MED. WORLD NEWS 48 (Aug. 17, 1981); David Rabin, Pauline L. Rabin, and Roni Rabin, *Compounding the Ordeal of A.L.S.: Isolation from My Fellow Physicians*, 307 NEW ENG. J. MED. 506 (1982).

<sup>55</sup> After the flurry of attention to the diagnosis [carcinoma], ward personnel lost interest. The patient began to be moved further and further from the nursing station at the front of the ward. The withdrawal that our patient experienced was not so much physical absence as uninterest. ...[An autopsy revealed] a tumor that should have readily yielded to the correct neurosurgical attack.

Charles D. Aring, *Intimations of Immortality*, 69 ANNALS INT. MED. 137, 140 (1968).

Of course, dying patients may be difficult to work with and their mental and physical state may be such that communication takes longer than with other patients. Also, avoiding such patients on occasion might be respecting their wish not to be disturbed. Yet if health care professionals recognize that the tendency toward avoidance exists, they can then seek to mitigate its impact themselves and to involve other care givers, including clergy. The importance of teamwork and mutual support among those who work with the dying has been demonstrated in hospices and neonatal intensive care units.<sup>56</sup> Having colleagues who are willing to listen and a forum in which to express one's feelings can help deal with the emotional toll of working with the dying. A tendency to "burnout" after extended periods of such work has been noted, though there are strategies to help cope with this.<sup>57</sup>

Some medical and nursing schools never deal with dying as a subject, and some do so all too shallowly. One professor of psychiatry and family practice reported:

In the School of Nursing I encountered,...the junior nurses were given a half-hour lecture on the Kübler-Ross five, and were then sent to the bedsides of terminally ill patients with the instructions to "get them through to acceptance" in an hour.<sup>58</sup>

The notion that a bit of brief classroom work can transform providers into sensitive humanitarians and effective communicators is, of course, simplistic and dangerous. The training of health care professionals should include serious and systematic attention to the requisite skills for working with dying patients. Whereas only 50 years ago it was the rare household that had not been touched by death, today many students in professional training have not previously been exposed to a dying person. Even medical students and residents are likely during their years of clinical training to miss the chance to attend for any length of time a patient in the shadow of impending death. Indeed, many physicians and nurses have never stayed with a dying patient through the final

<sup>56</sup> Thelma D. Bates, *At Home and in the Ward: The Establishment of a Support Team in an Acute Care General Hospital*, in Wilkes, *supra* note 45, at 263; Kennon, *supra* note 51, at 31; see also note 89, Chapter Six *infra*.

<sup>57</sup> See Stephen B. Shanfield, *The Mourning of the Health Care Professional: An Important Element in Education about Death and Loss*, 4 DEATH EDUCATION 385 (1981); Louis E. LaGrand, *Reducing Burnout in the Hospice and the Death Education Movement*, 4 DEATH EDUCATION 61 (1980); Glaser and Strauss, *supra* note 54, at 34; Richard A. Kolotkin, *Preventing Burn-Out and Reducing Stress in Terminal Care: The Role of Assertive Training*, in Harry J. Sobel, ed., BEHAVIOR THERAPY IN TERMINAL CARE: A HUMANISTIC APPROACH, Ballinger Pub. Co., Cambridge, Mass. (1981) at 229; Cassem, *supra* note 49.

<sup>58</sup> Simpson, *supra* note 54, at 259.

few hours and have never actually seen a patient die except in an unsuccessful resuscitation effort.

Empirical evidence has shown that many of the skills needed to work with the dying can be learned, while undesirable responses and reactions such as avoidance can be "unlearned" or mitigated.<sup>59</sup> Some health care professionals have cited their lack of such training as an impediment in caring for dying patients.<sup>60</sup>

Educating providers to become better communicators is a process that is both explicit and implicit.<sup>61</sup> Work in formal courses is unlikely to have any impact unless it is validated by behaviors at the bedside. Young physicians and nurses need to see their mentors doing the hard work of attending the dying; they are unlikely to learn if all their role models are people only a few years their senior professionally, especially since, as the Commission found, younger physicians are less likely to be comfortable discussing "dismal" news with their patients.<sup>60</sup>

Educational reform must entail greater change than adding a dash of the humanities to already overburdened health care curricula. What is needed instead is systematic attention to the social, ethical, psychological, and organizational aspects of caring for dying patients. Students should also be encouraged to develop an appreciation for different patterns and styles of dying, especially as they arise from different cultures, medical care settings, or religious views.

### **Reexamining the Role of Traditional Moral Distinctions**

Most patients make their decisions about the alternative courses available to them in light of such factors as how many days or months the treatment might add to their lives, the nature of that life (for example, whether treatment will allow or interfere with their pursuit of important goals, such as completing projects and taking leave of loved ones), the degree of suffering involved, and the costs (financial and otherwise) to themselves and others. The relative weight, if any, to be given to each consideration must ultimately be determined by the competent patient.

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<sup>59</sup> Margaret Shandor Miles, *The Effect of a Course on Death and Grief on Nurses' Attitudes Toward Dying Patients and Death*, 4 DEATH EDUCATION 245 (1980); George E. Dickinson, *Death Education in U.S. Medical Schools: 1975-1980*, 56 J.MED. EDUC. 111 (1981).

<sup>60</sup> See, e.g., Loretta Hoggatt and Bernard Spilka, *The Nurse and the Terminally Ill Patient: Some Perspectives and Projected Actions*, 9 OMEGA 255 (1978).

<sup>61</sup> MAKING HEALTH CARE DECISIONS, *supra* note 1, at 135.

<sup>62</sup> *Id.* at 96.

Other bases are sometimes suggested for judging whether life-and-death decisions about medical care are acceptable or unacceptable beyond making sure that the results of the decisions are justified in the patient's view by their expected good. These bases are traditionally presented in the form of opposing categories. Although the categories—causing death by acting versus by omitting to act; withholding versus withdrawing treatment; the intended versus the unintended but foreseeable consequences of a choice; and ordinary versus extraordinary treatment—do reflect factors that can be important in assessing the moral and legal acceptability of decisions to forego life-sustaining treatment, they are inherently unclear. Worse, their invocation is often so mechanical that it neither illuminates an actual case nor provides an ethically persuasive argument.<sup>63</sup>

In considering these distinctions, which are discussed in detail in the remainder of this chapter, the Commission reached the following conclusions, which are particularly relevant to assessing the role of such distinctions in public policies that preclude patients and providers from choosing certain options.

- The distinction between acting and omitting to act provides a useful rule-of-thumb by separating cases that probably deserve more scrutiny from those that are likely not to need it. Although not all decisions to omit treatment and allow death to occur are acceptable, such a choice, when made by a patient or surrogate, is usually morally acceptable and in compliance with the law on homicide; conversely, active steps to end life, such as by administering a poison, are likely to be serious moral and legal wrongs. Nonetheless, the mere difference between acts and omissions—which is often hard to draw in any case—never by itself determines what is morally acceptable. Rather, the acceptability of particular actions or omissions turns on other morally significant considerations, such as the balance of harms and benefits likely to be achieved, the duties owed by others to a dying person, the risks imposed on others in acting or refraining, and the certainty of outcome.
- The distinction between failing to initiate and stopping therapy—that is, withholding versus withdrawing treatment—is not itself of moral importance. A justification that is adequate for not commencing a treatment is also sufficient for ceasing it. Moreover,

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<sup>63</sup> Such terms are also used in varying ways. In particular, some people may use a term (such as "allowing to die" or "artificial means") descriptively while others attach a normative connotation to the same phrase.

erecting a higher requirement for cessation might unjustifiably discourage vigorous initial attempts to treat seriously ill patients that sometimes succeed.

- A distinction is sometimes drawn between giving a pain-relieving medication that will probably have the unintended consequence of hastening a patient's death and giving a poison in order to relieve a patient's suffering by killing the patient. The first is generally acceptable while the latter is against the law. Actions that lead to death must be justified by benefits to the patient that are expected to exceed the negative consequences and ordinarily must be within the person's socially accepted authority. In the case of physicians and nurses, this authority encompasses the use of means, such as pain-relieving medication, that can cure illnesses or relieve suffering but not the use of means, such as weapons or poisons, whose sole effect is viewed as killing a patient.
- Whether care is "ordinary" or "extraordinary" should not determine whether a patient must accept or may decline it. The terms have come to be used in conflicting and confusing ways, reflecting variously such aspects as the usualness, complexity, invasiveness, artificiality, expense, or availability of care. If used in their historic sense, however—to signify whether the burdens a treatment imposes on a patient are or are not disproportionate to its benefits—the terms denote useful concepts. To avoid misunderstanding, public discussion should focus on the underlying reasons for or against a therapy rather than on a simple categorization as "ordinary" or "extraordinary."

The analysis of these four distinctions in this chapter need not be repeated in decisionmaking for each individual patient. Rather, the Commission intends to point to the underlying factors that may be germane and helpful in making decisions about treatment or nontreatment and, conversely, to free individual decisionmaking and public policy from the mistaken limitations imposed when slogans and labels are substituted for the careful reasoning that is required.

**Acting Versus Omitting to Act.** For many dying patients who decide to forego further life-prolonging treatment when its benefits no longer seem to them worth the burdens it creates, cessation of treatment leads rapidly to an end of life and, with that, to a release from their suffering. Others, however, suffer from conditions that would not be immediately fatal were treatment withdrawn. Some of these patients wish that they (or someone acting at their request) could administer a poison to end their suffering more quickly. The Commission does not

believe that society ought to condone the deliberate use of poisons or similar lethal agents in this setting. To do so would certainly risk serious abuse.

Lawyers, health care professionals, and policymakers today are in general accord that treatment refusals by dying patients should be honored.<sup>64</sup> Physicians commonly acquiesce in the wishes of competent patients not to receive specified treatments, even when failure to provide those treatments will increase the chance—or make certain—that the patient will die soon.<sup>65</sup> When some patients are dying of a disease process that cannot be arrested, physicians may, for example, write orders not to provide resuscitation if the heart should stop,<sup>66</sup> forego antibiotic treatment of pneumonia and other infections,<sup>67</sup> cease use of respirators,<sup>68</sup> or withhold aggressive therapy from overwhelmingly burned patients.<sup>69</sup> Courts have sanctioned such decisions by guardians for incompetent patients,<sup>70</sup> as well as by competent patients who might have lived for an indefinite period if treated.<sup>71</sup> Although declining to start or continue life-sustaining treatment is often acceptable, health care providers properly refuse to honor a patient's request to be directly killed. Not only would killing, as by violence or strychnine, be outside the bounds of accepted medical prac-

<sup>64</sup> See, e.g., John A. Robertson, *THE RIGHTS OF THE CRITICALLY ILL*, Bantam Books, New York (1983) at 23; William J. Monahan, *Contemporary American Opinion On Euthanasia*, in McCarthy and Morawski, *supra* note 19, at 180.

<sup>65</sup> See, e.g., Testimony of Dr. Anne Fletcher, transcript of 16th meeting of the President's Commission (Jan. 9, 1982) at 8, 26; Testimony of Dr. Ned Cassem, S.J., transcript of 10th meeting of the President's Commission (June 4, 1981) at 74; Testimony of Dr. Richard Scott, transcript of 12th meeting of the President's Commission (Sept. 12, 1981) at 398.

<sup>66</sup> See pp. 244-47 *infra*.

<sup>67</sup> See Appendix B pp. 275-97 *infra*; Norman K. Brown and Donovan J. Thompson, *Nontreatment of Fever in Extended-Care Facilities*, 300 NEW ENG. J. MED. 1246 (1979).

<sup>68</sup> See, e.g., Ake Grenvik, *Terminal Weaning: Discontinuance of Life-Supporting Therapy in the Terminally Ill Patient*, 11 CRIT. CARE MED. (forthcoming, May 1983). See also, *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, *cert. denied*, 429 U.S. 922 (1976).

<sup>69</sup> Sharon H. Imbus and Bruce E. Zawacki, *Autonomy for Burn Patients When Survival Is Unprecedented*, 297 NEW ENG. J. MED. 308 (1977).

<sup>70</sup> See, e.g., *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, *cert. denied*, 429 U.S. 922 (1976); *In re Dinnerstein*, 380 N.E.2d 134 (Mass. App. Ct. 1978); *Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d 417 (1977). See also David W. Meyers, *MEDICO-LEGAL IMPLICATIONS OF DEATH AND DYING*, The Lawyers Co-operative Pub. Co., Rochester, N.Y. (1981) at 211-62; pp. 121-31 *infra*.

<sup>71</sup> See, e.g., *Satz v. Perlmutter*, 379 So.2d 359 (Fla. 1980); *Lane v. Candura*, 376 N.E.2d 1232 (Mass. App. 1978); *In re Quackenbush*, 383 A.2d 785 (N.J., Morris County Ct. 1978).

tice, but as murder it would be subject to a range of criminal sanctions, regardless of the provider's motives.<sup>72</sup>

In both scholarly and policy discussions, "killing" is often equated with an action causing death, and "allowing to die" with an omission causing death.<sup>73</sup> Killing and allowing to die are then used as merely descriptive terms, leaving open which actual actions that cause death (that is, killings) are morally wrong. Certainly some actions that cause death, such as self-defense, are morally justified. However, particularly in medicine, "killing" is often understood to mean actions that *wrongfully* cause death, and so is never justifiably done by health care providers. Likewise, "allowing to die" is often used to communicate *approval* of accepting that death will occur rather than simply to describe the behavior.<sup>74</sup> In an attempt to avoid confusion that stems from these conflicting usages and to present the important issues clearly, the Commission's discussion employs the descriptive terms—actions that lead to death and omissions that lead to death—rather than mixing the normative and descriptive connotations of the terms killing and allowing to die.

Although the Commission believes that most omissions that lead to death in medical practice are acceptable, it does not believe that the moral distinction between that practice and wrongful killing lies in the difference between actions and omissions per se. Not only is this distinction often difficult to draw in actual practice, it fails to provide an adequate foundation for the moral and legal evaluation of events leading to death. Rather, the acceptability or unacceptability of conduct turns upon other morally significant factors, such as

<sup>72</sup> See p. 33 *supra*.

<sup>73</sup> See, e.g., James Rachels, *Active and Passive Euthanasia*, 292 NEW ENG. J. MED. 78 (1975); Tom Beauchamp, *A Reply to Rachels on Active and Passive Euthanasia*, in Tom Beauchamp and Seymour Perlin, eds., *ETHICAL ISSUES IN DEATH AND DYING*, Prentice-Hall, Inc., Englewood Cliffs, N.J. (1978) at 246; Sisella Bok, *Death and Dying: Euthanasia and Sustaining Life: Ethical Views*, in 1 *ENCYCLOPEDIA OF BIOETHICS*, at 268; Harold F. Moore, *Acting and Refraining*, in *id.* at 38. The philosophical and moral issues concerning the nature and significance of the killing-letting die distinction are extensively explored in Bonnie Steinbock, ed., *KILLING AND LETTING DIE*, Prentice-Hall, Inc., Englewood Cliffs, N.J. (1980); P. J. Fitzgerald, *Acting and Refraining*, in Samuel Gorovitz *et al.*, eds., *MORAL PROBLEMS IN MEDICINE*, Prentice-Hall, Inc., Englewood Cliffs, N. J. (1976) at 284. See also Jonathan Glover, *CAUSING DEATH AND SAVING LIVES*, Penguin Books, New York (1977) at 92.

<sup>74</sup> George Fletcher, *Prolonging Life*, 42 WASH. L. REV. 999 (1967); Edward J. Gurney, *Is There a Right to Die? A Study of the Law of Euthanasia*, 3 Cum.-Sam. L. Rev. 235 (1972); Robert S. Morrison, *Alternatives to Striving Too Officially*, in Franz J. Ingelfinger *et al.*, eds., *CONTROVERSY IN INTERNAL MEDICINE II*, W.B. Saunders, Philadelphia (1974) at 113.



the duties owed to patients, the patients' prospects and wishes, and the risks created for someone who acts or who refrains from acting.

***The difference between actions and omissions that lead to death.*** The distinction between acts and omissions is often easy to draw. A person acts in a way that results in another's death, for example, by fatally poisoning an otherwise healthy person. On the other hand, a person's omission leads to the death of another if the first person knows he or she has the ability and opportunity to act so as to prevent the other dying [at a particular time and in a particular way]<sup>75</sup> but refrains from doing so. For example, an omission leads to death when a person could, but does not, rescue a nearby child who is drowning. The difference, then, is that when A acts to cause B to die, the course of events into which A's action intervenes is otherwise one in which B is not likely to die, whereas when A omits to act and thus causes B to die, the course of events already under way (into which A fails to intervene) includes B's imminent death. Thus, the distinction between a fatal act and a fatal omission depends both upon the difference between a person physically acting and refraining from acting and upon what might be called the background course of events.

If a patient's death is imminent (for example, death is expected within a matter of days) failing to treat and thus hastening death is seen by some not even to be a case of an omission that leads to death—failing to treat is said to be merely "avoiding prolonging the dying process."<sup>76</sup> To hold that such a failure to treat is neither a fatal act nor an omission is wrong and misleading. No one can prevent a person's ever dying; death can only be postponed by preventing it at the moment. Usually, though not always, to postpone death for only a very short time is less important, but that is relevant to whether an omission is wrong and how serious the wrong is, not to whether it is an omission that leads to a patient's death.

Sometimes deciding whether a particular course involves an act or an omission is less clear. Stopping a respirator at the request of a competent patient who could have lived with it for a few years but who will die without it in just a few hours is

<sup>75</sup> More formally, it can be said that the deceased would not have died as and when he or she did had the person responsible not acted in the way he or she did. For death to be a killing by another, that other's action must have changed the cause of the person's death, or have hastened the moment of death, or both.

<sup>76</sup> See, e.g., Glover, *supra* note 73, at 197; James B. Nelson, HUMAN MEDICINE: ETHICAL PERSPECTIVES ON NEW MEDICAL ISSUES, Augsburg Pub. House, Minneapolis, Minn. (1973) at 125; Natural Death statutes for Alabama, the District of Columbia, and Kansas, *reprinted* in Appendix D, pp. 318-23, 335-40, 345-49 *infra*.

such an ambiguous case. Does the physician omit continuing the treatment or act to disconnect it? Discontinuing essential dialysis treatments or choosing not to give the next in a sequence of antibiotic doses are other events that could be described either as acts or omissions.

***The moral significance of the difference.*** Actual instances of actions leading to death, especially outside the medical context, are more likely to be seriously morally wrong than are omissions that lead to death, which, in the medical context, are most often morally justified. Usually, one or more of several factors make fatal actions worse than fatal omissions:

- (1) The motives of an agent who acts to cause death are usually worse (for example, self-interest or malice) than those of someone who omits to act and lets another die.
- (2) A person who is barred from acting to cause another's death is usually thereby placed at no personal risk of harm; whereas, especially outside the medical context, if a person were forced to intercede to save another's life (instead of standing by and omitting to act), he or she would often be put at substantial risk.
- (3) The nature and duration of future life denied to a person whose life is ended by another's act is usually much greater than that denied to a dying person whose death comes slightly more quickly due to an omission of treatment.
- (4) A person, especially a patient, may still have some possibility of surviving if one omits to act, while survival is more often foreclosed by actions that lead to death.

Each of these factors—or several in combination—can make a significant moral difference in the evaluation of any particular instance of acting and omitting to act. Together they help explain why most actions leading to death are correctly considered morally worse than most omissions leading to death. Moreover, the greater stringency of the legal duties to refrain from killing than to intervene to save life reinforces people's view of which conduct is worse morally.<sup>77</sup>

However, the distinction between omissions leading to death and acts leading to death is not a reliable guide to their moral evaluation. In the case of medical treatment, the first and third factors are not likely to provide grounds for a distinction: family members and health professionals could be equally merciful in their intention—either in acting or omit-

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<sup>77</sup> See A. D. Woозley, *Law and the Legislation of Morality*, in Arthur L. Caplan and Daniel Callahan, eds., *ETHICS IN HARD TIMES*, Plenum Press, New York (1981) at 143.

ting—and life may end immediately for some patients after treatment is withdrawn. Likewise, the second factor—based on the usual rule that people have fairly limited duties to save others with whom they stand in no special relation—does not apply in the medical context.<sup>78</sup> Health professionals have a special role-related duty to use their skills, insofar as possible, on behalf of their patients, and this duty removes any distinction between acts and omissions.

Only the final factor—turning the possibility of death into a certainty—can apply as much in medical settings as elsewhere. Indeed, this factor has particular relevance here since the element of uncertainty—whether a patient really will die if treatment is ceased—is sometimes unavoidable in the medical setting. A valid distinction may therefore arise between an act causing certain death (for example, a poisoning) and an omission that hastens or risks death (such as not amputating a gangrenous limb). But sometimes death is as certain following withdrawal of a treatment as following a particular action that is reliably expected to lead to death.

Consequently, merely determining whether what was done involved a fatal act or omission does not establish whether it was morally acceptable. Some actions that lead to death can be acceptable: very dangerous but potentially beneficial surgery or the use of hazardous doses of morphine for severe pain are examples. Some omissions that lead to death are very serious wrongs: deliberately failing to treat an ordinary patient's bacterial pneumonia or ignoring a bleeding patient's pleas for help would be totally unacceptable conduct for that patient's physician.

Not only are there difficult cases to classify as acts or omissions and difficulties in placing moral significance on the distinction, but making the distinction also presupposes an unsound conception of responsibility, namely (1) that human action is an intervention in the existing course of nature, (2) that not acting is not intervening, and (3) that people are responsible only for their interventions (or, at least, are much more responsible for deliberate interventions than for deliberate omissions). The weaknesses of this position include the ambiguous meaning of "intervention" when someone takes an action as part of a plan of nonintervention (such as writing orders not to resuscitate), the inability to define clearly the "course of nature," and the indefensibility of not holding someone responsible for states of affairs that the person could have prevented.

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<sup>78</sup> Ernest J. Weinrib, *The Case for a Duty to Rescue*, 90 *YALE L. J.* 247 (1980); Judith Jarvis Thomson, *Killing, Letting Die, and the Trolley Problem*, 59 *MONIST* 204 (1976). See also pp. 33-34 *supra* for a discussion of role-related obligations to intercede.

In sum, then, actions that lead to death are likely to be serious wrongs, while many omissions in the medical context are quite acceptable. Yet this is not a fixed moral assessment based on the mere descriptive difference between acts and omissions, but a generalization from experience that rests on such factors as whether the decision reflects the pursuit of the patient's ends and values, whether the health care providers have fulfilled their duties, and whether the risk of death has been appropriately considered.

***The cause of death.*** Sometimes acts that lead to death seem to be more seriously wrong than omissions that likewise lead to death because the cause of death in the first instance is seen to be the act while the cause of death in an omission is regarded as the underlying disease. For example, were a physician deliberately to inject a patient with a lethal poison, the physician's action would be the cause of the patient's death. On the other hand, if an otherwise dying patient is not resuscitated in the event of cardiac arrest, or if a pneumonia or kidney failure goes untreated, the underlying disease process is said to be the cause of death. Since people ordinarily feel responsible for their own acts but not for another person's disease, this is a very comforting formulation.

The difference in this common account of causation does not actually explain the different moral assessment—rather, the account of causation *reflects* an underlying assessment of what is right or wrong under the circumstances.<sup>79</sup> Commonly, many factors play some causal role in a person's death. When "the cause" of a patient's death is singled out—for example, to be entered on a death certificate—the decision to designate one or more factors as "the cause(s)" depends upon the normative question at issue. Although the process begins with an empirical inquiry to identify the factors that were actually connected with a particular patient's death, both the process of narrowing to those factors that were "substantial" causes<sup>80</sup>

<sup>79</sup> H.L.A. Hart and A.M. Honore, *CAUSATION IN THE LAW*, Oxford Univ. Press, Oxford, England (1959).

<sup>80</sup> The empirical component of causation is referred to as "actual" cause (or "cause-in-fact"). For A to be the cause of X, one might have to be able to say that "but for" (or, without the existence of) A, X would not have occurred. Where there is more than one causative agent or factor, a different test of "actual" cause must be applied, one called a "substantial factor" or "material factor" test. For instance, if Drs. A and B simultaneously give Patient C a lethal injection, neither A nor B is the "but for" cause of C's death because if A had not given the injection, C would have died anyway (from B's injection), and if B had not given the injection, C still would have died (from A's injection). Since it would be unfair for either A or B to escape liability, which would occur if the "but-for" test were applied, these other tests inquire instead whether A's conduct was a substantial (or material)

and that of deciding which ones should be held legally or morally responsible for the death involve value judgements.<sup>81</sup> In some situations, although one person's action is unquestionably a factual cause of another's death, holding the person responsible for the death is unfair because the death could not reasonably have been foreseen or because the person was under no obligation to prevent the death.<sup>82</sup>

Beyond selecting "the cause" of death from among the many factors empirically determined to have causally contributed to a patient's death, both the legal and the moral inquiry presuppose that some kinds of causal roles in a death are wrong, and then ask whether any person played any of those roles. Therefore, a determination of causation ordinarily must presuppose, and cannot itself justify, the sorts of decisions that ought to be permissible. For example, in a death following nontreatment, designating the disease as the cause not only asserts that a fatal disease process was present but also communicates acceptance of the physician's behavior in foregoing treatment. Conversely, if an otherwise healthy patient who desired treatment died from untreated pneumonia, the physician's failure to treat would be considered to have

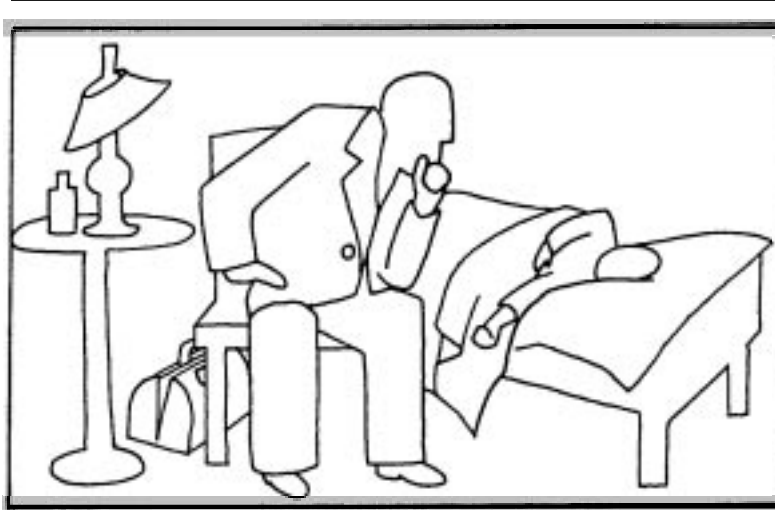
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factor in bringing about C's death. If it was, A is legally culpable—and the same test is applied to B's conduct to establish B's culpability.

■ Once it is established that the defendant's conduct has in fact been one of the causes of the plaintiff's injury, there remains the question whether the defendant should be legally responsible for what he has caused. Unlike the fact of causation, with which it is often hopelessly confused, this is essentially a problem of law.... This becomes essentially a question of whether the policy of the law will extend the responsibility for the conduct to the consequences which have in fact occurred.... The term "proximate cause" is applied by the courts to those more or less undefined considerations which limit liability even where the fact of causation is clearly established.

William L. Prosser, *HANDBOOK OF THE LAW OF TORTS*, West Publishing Co., St. Paul, Minn. 14th ed. 1971 at 244.

<sup>82</sup> For instance, if in parking an automobile, a driver carelessly hits the car in front, he or she will be liable for any damage to the other car. But if the other car explodes because there was a concealed bomb in the trunk that required only a small tap to set it off, the driver may not be liable for the destruction of the car even though "but for" the driver's carelessness, the harm would not have occurred; the harm nevertheless was more substantially caused by the bomb than by the car accident and the explosion could hardly have been foreseen. And further, if several blocks away, a nurse holding a baby is startled by the explosion and drops the infant, who dies, the driver most certainly will not be liable for the infant's death despite the fact that, in the absence of the driver's carelessness, the infant would have lived. See *Palsgraf v. Long Island R.R.*, 248 N.Y. 339, 162 N.E. 99 (1928) (Andrews, J., dissenting).



caused the patient's death. Although pneumonia is among the factual causes of death, one way of stating the physician's responsibility for the death is to identify the physician's omission of his or her duty to treat as the cause of death. As this example shows, the action/omission distinction does not always correspond to the usual understanding of whether the physician or the disease is the cause of death, and so the attribution of what caused a death cannot make acts morally different from omissions.

In addition, the physician's behavior is among the factual causes of a patient's death both in acting and in omitting to act. This is clear enough if a physician were to give a lethal injection—the patient would not have died at that time and in that way if the physician had not given the injection. But exactly the same is true of a physician's omission of treatment: had a physician not refrained from resuscitating or from treating a pneumonia or a kidney failure, a patient would not have died at that time and in that way. In either case, a different choice by the physician would have led to the patient living longer. To refrain from treating is justifiable in some cases—for example, if the patient does not want the treatment, is suffering, and will die very soon whatever is done. But the justification rests on these other reasons, rather than on not classifying a physician's omission as a cause of the patient's death. Thus, calling the disease the cause of death can be misleading but does reflect a sound point: that a physician who omits treatment in such a case is not morally or legally blameworthy.

***The role of the distinction in public policy.*** The moral and legal prohibition against acting to take the life of another human being is deeply rooted in Western society and serves the laudable and extremely important value of protecting and

preserving human life. Although health care professionals and families want to do the best they can for patients, both in respecting patients' self-determination and promoting their well-being, they face troubling conflicts when doing so would involve them in conduct that might be considered as the taking of another's life.

Yet in health care, and especially with critically or terminally ill patients, it is common to make decisions that one knows risk shortening patients' lives and that sometimes turn out to do so. As a result, there is a strong motivation to interpret the actions decided upon and carried out, especially if by people other than the patient, as something other than acts of killing. Thus, the concerned parties very much want these to be regarded as cases of "allowing to die" (rather than "killing"), of "not prolonging the dying process" (instead of "hastening death"), or of "failing to stop a disease from causing death" [rather than "someone's action was the cause of death"].<sup>83</sup> Consequently, these distinctions, while often conceptually unclear and of dubious moral importance in themselves, are useful in facilitating acceptance of sound decisions that would otherwise meet unwarranted resistance. They help people involved to understand, in ways acceptable to them, their proper roles in implementing decisions to forego life-sustaining treatment.

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<sup>83</sup> There would be, indeed, no defense for a doctor who went so far as to take life because in his opinion it was worthless or worse, that is an exercise of power permitted only to Juries and Judges acting through their agent the Sheriff. But to kill is one thing, and to let die is another, with a difference which, though small, is none the less real.

*He Forgets Silence is Golden* (Editorial), *N.Y. TIMES*, July 26, 1917 at A-10 (supporting a physician's decision not to treat a microcephalic child).

Parents of a severely compromised premature newborn have written of the kinds of reasoning that resulted from the desire of their son's doctors to be seen only as "allowing to die":

[His doctor] spoke as if this were the moment he had been waiting for, when he could make a decision on Andrew that found its way past *commission* into *omission*.... They found their loophole. Because of course I shouldn't say they "took him off" [the respirator]—they couldn't do that, since that would be immoral and illegal. They had to hope for an appropriate accident; once Andrew became accidentally detached from the respirator, and had breathed for a couple of minutes, they could declare him "off" and *omit* to put him back on while they wait for his inadequate breathing to kill him. This is the moral, legal, and "dignified" way.

Robert and Peggy Stinson, *THE LONG DYING OF BABY ANDREW*, Little, Brown, Boston (1983) at 343, 345.

Law, as a principal instrument of public policy in this area, has sought an accommodation that adequately protects human life while not resulting in officious overtreatment of dying patients.<sup>84</sup> The present general legal prohibition against deliberate, active killing, reinforced by a strong social and professional presumption in favor of sustaining life, serves as a public affirmation of the high value accorded to each human life. The law, and public policy in general, has not interpreted the termination of life-sustaining treatment, even when it requires active steps such as turning off a respirator, as falling under this general prohibition. For competent patients, the principle of self-determination is understood to include a right to refuse life-sustaining treatment, and to place a duty on providers and others to respect that right. Providers, in turn, are protected from liability when they act to aid a patient in carrying out that right. Active steps to terminate life-sustaining interventions may be permitted, indeed required, by the patient's authority to forego therapy even when such steps lead to death.<sup>85</sup> With adequate procedural safeguards, this right can be extended to incompetent patients through surrogates.<sup>86</sup>

Although there are some cases in which the acting-omitting distinction is difficult to make and although its moral importance originates in other considerations, the commonly accepted prohibition of active killing helps to produce the correct decision in the great majority of cases. Furthermore, weakening the legal prohibition to allow a deliberate taking of life in extreme circumstances would risk allowing wholly unjustified taking of life in less extreme circumstances. Such a risk would be warranted only if there were substantial evidence of serious harms to be relieved by a weakened legal protection of life, which the Commission does not find to be the case. Thus the Commission concludes that the current interpretation of the legal prohibition of active killing should be sustained.<sup>87</sup>

<sup>84</sup> The practice of medicine raises a peculiar problem of policy for the law of homicide. It is the doctor's job to take decisions which may affect the span of human life. Therefore, it is especially important that law be neither too strict nor too lenient. If it is too strict, it will begin to make doctors criminally responsible for man's mortality; if it is too lenient it will give doctors a "license to kill." But whether the law does steer a middle course between these two extremes, or, indeed, is capable of doing so without greatly distorting the general principles of the criminal law, is a different matter.

Helen Beynon, *Doctors as Murderers*, 1982 *CRIM. L. REV.* 17, 17-18.

<sup>85</sup> See, e.g., *State v. Perlmutter*, 379 So.2d 359 (Fla.1980); *In re Quinlan*, 70 N.J. 30, 355 A.2d 647, 671, cert. denied, 429 U.S. 922 (1976).

<sup>86</sup> See Chapter Four *infra*.

<sup>87</sup> Evaluating the policy role of the acting/omitting distinction in



One serious consequence of maintaining the legal prohibition against direct killing of terminally ill patients could be the prolongation of suffering. In the final stages of some diseases, such as cancer, patients may undergo unbearable suffering that only ends with death. Some have claimed that sometimes the only way to improve such patients' lot is to actively and intentionally end their lives.<sup>88</sup> If such steps are forbidden, physicians and family might be forced to deny these patients the relief they seek and to prolong their agony pointlessly.

If this were a common consequence of a policy prohibiting all active termination of human life, it should force a reevaluation of maintaining the prohibition. Rarely, however, does such suffering persist when there is adequate use of pain-relieving drugs and procedures.<sup>89</sup> Health care professionals ought to realize that they are already authorized and obligated to use such means with a patient's or surrogate's consent, even if an earlier death is likely to result. The Commission endorses allowing physicians and patients to select treatments known to risk death in order to relieve suffering as well as to pursue a return to health.

Policies prohibiting direct killing may also conflict with the important value of patient self-determination. This conflict will arise when deliberate actions intended to cause death have been freely chosen by an informed and competent patient as the necessary or preferred means of carrying out his or her wishes, but the patient is unable to kill him or herself unaided, or others prevent the patient from doing so. The frequency with which this conflict occurs is not known, although it is probably rare. The Commission finds this limitation on individual self-determination to be an acceptable cost of securing the general protection of human life afforded by the prohibition of direct killing.

**Withholding Versus Withdrawing Treatment.** A variation on the action/omission distinction sometimes troubles physicians who allow competent patients to refuse a life-sustaining treatment but who are uncomfortable about stopping a treatment that has already been started because doing so seems to

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regulating behavior requires balancing its positive value as a safeguard that protects human life against its negative consequences of contributing to some undesirable decisions. The law has used conceptually unclear reinterpretations to remove most foregoings of life-sustaining treatment from the behaviors that count as "acting" or "wrongful killing." These are important in reducing the frequency of morally undesirable decisions that might otherwise arise.

■ George Fletcher, *Prolonging Life*, 42 *WASH. L. REV.* 999 (1967); Robertson, *supra* note 64, at 20-22; Christian Barnard, *GOOD LIFE/GOOD DEATH*, Prentice-Hall, Inc., Englewood Cliffs, N.J. (1980) at 110-17.

<sup>89</sup> See pp. 19-20 *supra* and Appendix B, pp. 275-97 *infra*.

them to constitute killing the patient. By contrast, not starting a therapy seems acceptable, supposedly because it involves an omission rather than an action.<sup>90</sup>

Although the nature of the distinction between withholding and withdrawing seems clear enough initially, cases that obscure it abound. If a patient is on a respirator, disconnecting would count as stopping. But if the patient is on a respirator and the power fails, does failing to use a manual bellows mechanism count as "stopping" a therapy (artificial respiration) or "not starting" a therapy (manually generated respiration)?<sup>91</sup> Many therapies in medicine require repeated applications of an intervention. Does failing to continue to reapply the intervention count as "stopping" (the series of treatments) or as "not starting" (the next element in the series)? Even when a clear distinction can be drawn between withdrawing and withholding, insofar as the distinction is merely an instance of the acting-omitting distinction it lacks moral significance.<sup>92</sup>

Other considerations may be involved here, however. Even though health care professionals may not be obligated to initiate a therapy with a particular patient, its initiation may create expectations on the part of the patient and others. In some instances these expectations may lead the health care provider to feel obliged not to stop a therapy that initially could have been foregone.<sup>93</sup> (Similarly, a physician, who is under no obligation to accept any particular person as a patient, may not abandon a patient once a physician-patient relationship has been established.<sup>94</sup>)

This observation does not actually argue that stopping a treatment is in itself any more serious than not starting it. What it claims is that if additional obligations to treat have arisen from any expectations created once a treatment has been initiated, then stopping, because it breaches those obligations, is worse than not starting. The expectations, and

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<sup>90</sup> "By not starting a 'routine IV' I am not committed to that modality of therapy. It is easier *not* to start daily intravenous parenteral fluids than to stop them, once begun—just as it is easier not to turn on the respiratory assistance machine than to turn the switch off, once started." Louis Shattluck Baer, *Nontreatment of Some Severe Strokes*, 4 ANNALS NEUROL. 381,382 (Oct. 1978).

<sup>91</sup> See, e.g., Alan J. Weisbard, *On the Bioethics of Jewish Law: The Case of Karen Quinlan*, 14 ISRAEL L. REV. 337,346 (1979).

<sup>92</sup> See pp. 66-68 *supra*.

<sup>93</sup> See, e.g., George J. Annas, *THE RIGHTS OF HOSPITAL PATIENTS*, Avon Books, New York (1975) at 92, 95-96; Albert R. Jonsen, Mark Siegler, and William J. Winslade, *CLINICAL ETHICS*, Macmillan Pub. Co., New York (1982) at 100.

<sup>94</sup> See Jon R. Waltz and Fred E. Inbau, *MEDICAL JURISPRUDENCE*, Macmillan Pub. Co., New York (1971) at 142-51; Angela R. Holder, *MEDICAL MALPRACTICE LAW*, John Wiley & Sons, New York (1975) at 375.

the resultant obligation to continue, create whatever moral difference arises. The definition of the professional-patient relationship and the creation of expectations that care will be continued occur in complex ways—from professional codes, patterns of practice, legal decisions, and physician-patient communications. A particular physician faced with stopping or not starting therapy with a particular patient may have to accept a relationship and expectations that are at least partly givens.

Discussions between a physician and competent patient, however, allow redefinition of their relationship and alteration of their expectations and thus of any resulting obligations. For example, a physician and patient could agree to a time-limited trial of a particular intervention, with an understanding that unless the therapy achieved certain goals it should be stopped. Moreover, these relationships and expectations, with their resultant obligations, need not be treated as fixed when public policy is being made but can be redefined where appropriate. Of course, most withdrawals of treatment involve explicit decisions while withholdings are commonly implicit and not clearly discussed (although, in conformity with the Commission's recommendations, they should be discussed, except in emergency situations).<sup>95</sup> Although this may make the withdrawal of treatment more anguishing, or even more likely to precipitate external review, it does not make it morally different.

Adopting the opposite view—that treatment, once started, cannot be stopped, or that stopping requires much greater justification than not starting—is likely to have serious adverse consequences. Treatment might be continued for longer than is optimal for the patient, even to the point where it is causing positive harm with little or no compensating benefit.<sup>96</sup> An even more troubling wrong occurs when a treatment that might save life or improve health is not started because the health care personnel are afraid that they will find it very difficult to stop the treatment if, as is fairly likely, it proves to be of little benefit and greatly burdens the patient.<sup>97</sup> The Commission

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<sup>95</sup> See p. 51 *supra*.

<sup>96</sup> Such "overtreatment" has resulted in the filing of a lawsuit by a deceased patient's family. *Leach v. Shapiro*, Civ. Action C-81-2559A Summit County, Oh. (1982); *Leach v. Akron General Medical Center*, 426 N.E.2d 809 (Ohio Com. Pl. 1980).

<sup>97</sup> Another problem is whether a distinction should be made between causing someone to die by commission of a positive act and allowing someone to die through inaction, i.e., withholding treatment. Whether one physician would be held criminally liable for "pulling the plug" when another would not be liable for failing to start the initial treatment is unclear. Certainly, however, to maintain that there is a difference in the degree of culpability may have the undesirable effect of

received testimony, for example, that sometimes the view that a therapy that has been started could not be stopped had unduly raised the threshold for initiating some forms of vigorous therapy for newborns.<sup>98</sup> In cases of extremely low birth weight or severe spina bifida, for example, highly aggressive treatment may significantly benefit a small proportion of the infants treated while it prolongs the survival of a great number of newborns for whom treatment turns out to be futile. Fear of being unable to stop treatment in the latter cases—no matter how compelling the reason to stop—can lead to failure to treat the entire group, including the few infants who would have benefited.

Ironically, if there is any call to draw a moral distinction between withholding and withdrawing, it generally cuts the opposite way from the usual formulation: greater justification ought to be required to withhold than to withdraw treatment. Whether a particular treatment will have positive effects is often highly uncertain before the therapy has been tried. If a trial of therapy makes clear that it is not helpful to the patient, this is actual evidence (rather than mere surmise) to support stopping because the therapeutic benefit that earlier was a possibility has been found to be clearly unobtainable.<sup>99</sup>

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promoting nontreatment over treatment.

Comment, *Medico-Legal Implications of "Orders Not to Resuscitate,"* 31 CATH. U.L. REV. 515, 519 n.12 (1982) (citation omitted).

<sup>98</sup> Testimony of Dr. John Freeman, transcript of 16th meeting of the President's Commission (Jan. 9, 1982) at 124-25.

<sup>99</sup> A decision to stop "extraordinary" life-sustaining treatments requires no greater and in fact the same moral warrant as a decision not to begin to use them.... Since a trial treatment is often a part of diagnosis of a patient's condition, one might expect there to be greater reluctance on the part of physicians in not starting than in stopping extraordinary efforts to save life. As I understand them, physicians often have the contrary difficulty.... The reasons for these variations are probably psychological rather than rational.

Paul Ramsey, *THE PATIENT AS PERSON*, Yale Univ. Press, New Haven, Conn. (1970) at 121-22. See also James F. Childress, *PRIORITIES IN BIOMEDICAL ETHICS*, Westminster Press, Philadelphia (1981) at 123, n.10.

Commenting on Judge Robert Meade's ruling in the Brother Fox case that "it is important that the law not create a disincentive to the fullest treatment of patients by making it impossible for them in at least some extreme circumstances to choose to end treatment which has proven unsuccessful," John Paris noted: "With that legal support for the standard that once the patient has been given the benefit of all known procedures and these prove unsuccessful in restoring health, they need not be uselessly continued. It is to be hoped that the legal

Behind the withholding/withdrawing distinction lies the more general acting/omitting distinction in one of its least defensible forms. Given that the Commission considers as unwarranted the view that steps leading to death are always more serious when they involve an act rather than an omission, it also rejects the view that stopping a treatment ("an act") is morally more serious than not starting it ("an omission") could be.

Little if any legal significance attaches to the distinction between withholding and withdrawing. Nothing in law—certainly not in the context of the doctor-patient relationship—makes stopping treatment a more serious legal issue than not starting treatment. In fact, not starting treatment that *might* be in a patient's interests is more likely to be held a civil or criminal wrong than stopping the same treatment when it has proved unavailing.

As is the case with the distinction between acting and omitting, many other factors of moral importance may differentiate the appropriateness of a particular decision not to start from one to stop. Yet whatever considerations justify not starting should justify stopping as well. Thus the Commission concludes that neither law nor public policy should mark a difference in moral seriousness between stopping and not starting treatment.

**Intended Versus Unintended But Foreseeable Consequences.** Since there are sound moral and policy reasons to prohibit such active steps as administering strychnine or using a gun to kill a terminally ill patient, the question arises as to whether physicians should be able to administer a symptom-relieving drug—such as a pain-killer—knowing that the drug may cause or accelerate the patient's death, even though death is not an outcome the physician seeks. The usual answer to this question—that the prohibition against active killing does not bar the use of appropriate medical treatment, such as morphine for pain<sup>100</sup>—is often said to rest on a distinction between the

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recognition of that moral reality will help overcome physician timidity in similar cases." John J. Paris, *Brother Fox: The Courts and Death with Dignity*, 143 *AMERICA* 282, 284 (1980).

<sup>100</sup> In this situation, death occurs because patients in the terminal stages of diseases like cancer sometimes undergo suffering so great that it can only be relieved by doses of morphine that are so large as to induce respiratory depression or to predispose the patient to pneumonia, which may result in an earlier death. The Commission notes that such an occurrence should not be termed an "overdose," with its implications of excessive dosage, since the use of the correct dose of morphine to relieve suffering is really an acceptable practice. On the other hand, relief of pain can extend life: "the relief and comfort given an aged patient often affects the prolongation of life if only by restoring the willingness to live." Alfred Worcester, **THE CARE**

goals physicians seek to achieve or the means they use, on the one hand, and the unintended but foreseeable consequences of their actions on the other.<sup>102</sup>

One problem with assigning moral significance to the traditional distinction is that it is sometimes difficult to determine whether a particular aspect of a course of action ought to be considered to be intended, because it is an inseparable part of the "means" by which the course of action is achieved, or whether it is merely an unintended but foreseeable consequence. In medicine, and especially in the treatment of the critically or terminally ill, many of the courses that might be followed entail a significant risk, sometimes approaching a certainty, of shortening a patient's life. For example, in order to avoid additional suffering or disability, or perhaps to spare loved ones extreme financial or emotional costs, a patient may elect not to have a potentially life-extending operation. Risking earlier death might plausibly be construed as the intended means to these other ends, or as an unintended and "merely foreseeable" consequence. Since there seems to be no generally accepted, principled basis for making the distinction, there is substantial potential for unclear or contested determinations.

Even in cases in which the distinction is clear, however, health care professionals cannot use it to justify a failure to consider all the consequences of their choices.<sup>103</sup> By choosing a course of action, a person knowingly brings about certain effects; other effects could have been caused by deciding differently. The law reflects this moral view and holds people to be equally responsible for all the reasonably foreseeable results of their actions and not just for those results that they acknowledge having intended to achieve.<sup>104</sup> Nevertheless, although medication is commonly used to relieve the suffering of dying patients (even when it causes or risks causing death), physicians are not held to have violated the law. How can this

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OF THE AGED, THE DYING AND THE DEAD, Charles C. Thomas, Springfield, Ill. (1935) *reprinted by* Arno Press, Inc., New York (1977) at 6.

<sup>101</sup> The customary use of "foreseeable" is for those things that would be predicted as possible outcomes by a person exercising reasonable foresight; it is not limited to consequences that are certain or nearly certain to occur.

<sup>102</sup> The moral importance of this distinction is defended in Charles Fried, *RIGHT AND WRONG*, Harvard Univ. Press, Cambridge, Mass. (1978) at 7-53. *But see* Alan Donagan, *THE THEORY OF MORALITY*, Univ. of Chicago Press, Chicago (1977) at 112-71.

<sup>103</sup> Donagan, *supra* note 102, at 164; R.G. Frey, *Some Aspects to the Doctrine of Double Effect*, 5 *CANADIAN J. PHIL.* 259 (1975); Philippa Foot, *The Problem of Abortion and the Doctrine of the Double Effect*, 5 *OXFORD REV.* 5 (1967).

<sup>104</sup> *RESTATEMENT (SECOND) OF TORTS*, American Law Institute Publishers, St. Paul, Minn. (1965) at §§ 289-91.

failure to prosecute be explained, since it does not rest on an explicit waiver of the usual legal rule?

The explanation lies in the importance of defining physicians' responsibilities regarding these choices and of developing an accepted and well-regulated social role that allows the choices to be made with due care. The search for medical treatments that will benefit a patient often involves risk, sometimes great risk, for the patient: for example, some surgery still carries a sizable risk of mortality, as does much of cancer therapy. Furthermore, seeking to cure disease and to prolong life is only a part of the physician's traditional role in caring for patients; another important part is to comfort patients and relieve their suffering.<sup>105</sup> Sometimes these goals conflict, and a physician and patient (or patient's surrogate) have the authority to decide which goal has priority. Medicine's role in relieving suffering is especially important when a patient is going to die soon, since the suffering of such a patient is not an unavoidable aspect of treatment that might restore health, as it might be for a patient with a curable condition.

Consequently, the use of pain-relieving medications is distinguished from the use of poisons, though both may result in death, and society places the former into the category of acceptable treatment while continuing the traditional prohibition against the latter.<sup>106</sup> Indeed, in the Commission's view it is not only possible but desirable to draw this distinction. If physicians (and other health professionals) became the dispensers of "treatments" that could only be understood as deliberate killing of patients, patients' trust in them might be seriously undermined.<sup>107</sup> And irreparable damage could be done to health care professionals' self-image and to their ability to devote themselves wholeheartedly to the often arduous task of treating gravely ill patients. Moreover, whether or not one believes there are some instances in which giving a poison might be morally permissible, the Commission consid-

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<sup>105</sup> Judicial Council, CURRENT OPINIONS OF THE JUDICIAL COUNCIL OF THE AMERICAN MEDICAL ASSOCIATION, American Medical Association, Chicago (1982) at 9, reprinted in Appendix C, pp. 299-300 *infra*.

<sup>106</sup> "Neither will I administer a poison to anybody when asked to do so, nor will I suggest such a course." *Selections from the Hippocratic Corpus: Oath*, in Stanley Joel Reiser, Arthur J. Dyck, and William J. Curran, eds., ETHICS IN MEDICINE, MIT Press, Cambridge, Mass. (1977) at 5.

<sup>107</sup> "Euthanasia would threaten the patient-physician relationship; confidence might give way to suspicion....Can the physician, historic battler for life, become an affirmative agent of death without jeopardizing the trust of his dependents?" David W. Louisell, *Euthanasia and Biathanasia: On Dying and Killing*, 40 LINACRE Q. 234, 243 (1973).

ers that the obvious potential for abuse of a public, legal policy condoning such action argues strongly against it.<sup>108</sup>

For the use of morphine or other pain-relieving medication that can lead to death to be socially and legally acceptable, physicians must act within the socially defined bounds of their role.<sup>109</sup> This means that they are not only proceeding with the necessary agreement of the patient (or surrogate) and in a professionally skillful fashion (for example, by not taking a step that is riskier than necessary), but that there are sufficiently weighty reasons to run the risk of the patient dying.<sup>110</sup> For example, were a person experiencing great pain from a condition that will be cured in a few days, use of morphine at doses that would probably lead to death by inducing respiratory depression would usually be unacceptable. On the other hand, for a patient in great pain—especially from a condition that has proved to be untreatable and that is expected to be rapidly fatal—morphine can be both morally and legally acceptable if pain relief cannot be achieved by less risky means.

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<sup>108</sup> Yale Kamisar, *Some Non-Religious Views Against Proposed 'Mercy-Killing' Legislation*, 42 MINN. L. REV. 969 (1958); Beauchamp, *supra* note 73; John C. Fletcher, *Is Euthanasia Ever Justifiable?*, in Peter H. Wiernik, ed., *CONTROVERSIES IN ONCOLOGY*, John Wiley & Sons, Inc., New York (1982) at 297.

<sup>109</sup> See Dennis Horan, *Euthanasia and Brain Death*, 35 ANNALS N.Y. ACAD. SCI. 363, 374 (1978). Cf. Tamar Lewin, *Execution by Injection: A Dilemma for Prison Doctors*, N.Y. TIMES, Dec. 12, 1982, at E-20; Norman St. John-Stevan, *LIFE, DEATH AND THE LAW*, World Publishing Co., New York (1961) at 276-77.

<sup>110</sup> This consideration plays a prominent part in what is known in Catholic medical ethics as the "doctrine of double effect." This doctrine, which is designed to provide moral guidance for an action that could have at least one bad and one good effect, holds that such an action is permissible if it satisfies these four conditions: (1) the act itself must be morally good or neutral (for example, administering a pain-killer); (2) only the good consequences of the action must be intended (relief of the patient's suffering); (3) the good effect must not be produced by means of the evil effect (the relief of suffering must not be produced by the patient's death); and (4) there must be some weighty reason for permitting the evil (the relief of great suffering, which can only be achieved through a high risk of death). The Commission makes use of many of the moral considerations found in this doctrine, but endorses the conclusion that people are equally responsible for all of the foreseeable effects of their actions, thereby having no need for a policy that separates "means" from "merely foreseen consequences." See, e.g., William E. May, *Double Effect*, in 1 ENCYCLOPEDIA OF BIOETHICS, *supra* note 73, at 316; Joseph T. Mangan, S.J., *An Historical Analysis of the Principle of Double Effect*, 10 THEOLOGICAL STUD. 4 (1949); Donagan, *supra* note 102; Richard A. McCormick, S.J., *AMBIGUITY IN MORAL CHOICE*, Marquette Univ. Press, Milwaukee, Wisc. (1973); J.M. Boyle, *Toward Understanding the Principle of Double Effect*, 90 ETHICS 527 (1980).



This analysis rests on the special role of physicians and on particular professional norms of acceptability that have gained social sanction (such as the difference between morphine, which can relieve pain, and strychnine, which can only cause death).''' Part of acceptable behavior—from the medical as well as the ethical and legal standpoints—is for the physician to take into account all the foreseeable effects, not just the intended goals, in making recommendations and in administering treatment.<sup>112</sup> The degree of care and judgment exercised by the physician should therefore be guided not only by the technical question of whether pain can be relieved but also by the broader question of whether care providers are certain enough of the facts in this case, including the patient's priorities and subjective experience, to risk death in order to relieve suffering. If this can be answered affirmatively, there is no moral or legal objection to using the kinds and amounts of drugs necessary to relieve the patient's pain.

The Commission concludes that the distinction between the decisionmakers' "intending" a patient's death and their "merely foreseeing" that death will occur does not help in

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<sup>111</sup> These issues were addressed in a national survey conducted for the Commission by Louis Harris and Associates. Physicians, especially, distinguished between administering drugs to relieve pain, knowing that the dose might be lethal, and complying with a patient's wish to have his or her life ended. In the case of a patient in severe pain who had, no hope of recovery and who asked to have the pain eased, knowing it might shorten life, 79% of the public and 82% of the physicians said it would be ethically permissible to administer drugs to relieve the pain even at the risk of shortening life. Furthermore, 84% of physicians said they would be likely to administer such drugs under these circumstances. When asked whether the law should allow such treatment, assuming the patient has requested the drug and understands the consequences, 71% of the public and 53% of the physicians said yes. When asked whether a physician would be right or wrong to comply with the wishes of a dying patient in severe pain who directly asks to have his or her life ended, 45% of the public said it would be right. Among physicians, however just 5% thought such compliance was ethically permissible, and a mere 2% said they would comply with such a request. 52% of the public thought the law should allow physicians to comply with a request for mercy killing, but only 26% of physicians thought so. Harris, *supra* note 39, at 217-62.

See also, John M. Ostheimer, *The Polls: Changing Attitudes Toward Euthanasia*, 44 PUB. OPINION Q. 123 (1980).

<sup>112</sup> This is a weighty responsibility, and one that correctly entails serious liabilities for the physician if wrongly carried out. Society does want risky treatments to be offered and suffering to be relieved but wants to circumscribe the authority to risk life or to relieve suffering in ways expected to shorten life. One way to do so is to impose penalties for negligent or otherwise unjustified actions that lead to death, and this is the role of legal proceedings for homicide and wrongful death.

separating unacceptable from acceptable actions that lead to death. But, as proved true of the distinctions already discussed, this does point to ethically and legally significant factors—here, the real and symbolic role traditionally assigned to physicians and other practitioners of the healing arts, who can be expected to have developed special sensitivity and skills regarding the judgments to be made, and who are an identifiable group that can be readily held accountable for serious error.<sup>113</sup> Furthermore, the acceptable treatment options that carry a risk of death are limited to those within the special expertise of health care professionals.

The highly valued traditional professional role is not undermined when a physician, with due care, employs a measure—whether radical surgery or medication to relieve pain—that could lead to the patient's death but that is reasonably likely to cure or relieve pain. The relevant distinction, then, is not really that death is forbidden as a means to relieve suffering but is sometimes acceptable if it is merely a foreseeable consequence. Rather, the moral issue is whether or not the decisionmakers have considered the full range of foreseeable effects, have knowingly accepted whatever risk of death is entailed, and have found the risk to be justified in light of the paucity and undesirability of other options.

**Ordinary Versus Extraordinary Treatment.** In many discussions and decisions about life-sustaining treatment, the distinction between ordinary and extraordinary (also termed "heroic" or "artificial") treatment plays an important role. In its origins within moral theology, the distinction was used to mark the difference between obligatory and nonobligatory care—ordinary care being obligatory for the patient to accept and others to provide, and extraordinary care being optional.<sup>114</sup>

<sup>113</sup> Part of this endeavor is the development by professional groups of standards of practice that can be publicly discussed and modified. See, e.g., the policies of various institutions and professional societies, Appendices C, G, H, and I, pp. 299, 459, 467, 493 *infra*; George P. Fletcher, *Prolonging Life: Some Legal Considerations*, in Edwin S. Shneidman ed., *DEATH: CURRENT PERSPECTIVES*, Mayfield Pub. Co., Palo Alto, Calif. (1976) at 484.

<sup>114</sup> James J. McCartney, *The Development of the Doctrine of Ordinary and Extraordinary Means of Preserving Life in Catholic Moral Theology Before the Karen Quinlan Case*, 47 *LINACRE Q.* 215 (1980). The first treatment of the topic was Soto's in 1582 when he pointed out that superiors could oblige their subjects under religious obedience to use medicine that could be taken without too much difficulty, but they could not oblige them to undergo excruciating pain because nobody is held to preserve life by such means. It was Banez who in 1595 introduced the terms "ordinary" and "extraordinary" into the discussion of the preservation of life. He stated that while it is reasonable to hold that a human being must conserve his or her life, one is not bound

It has also played a role in professional policy statements<sup>115</sup> and recent judicial decisions about life-sustaining treatment for incompetent patient<sup>116</sup>. As with the other terms discussed, defining and applying a distinction between ordinary and extraordinary treatment is both difficult and controversial and can lead to inconsistent results, which makes the terms of questionable value in the formulation of public policy in this area.

**The meaning of the distinction.** "Extraordinary" treatment has an unfortunate array of alternative meanings, as became obvious in an exchange that took place at a Commission hearing concerning a Florida case<sup>117</sup> involving the cessation of life-sustaining treatment at the request of a 76-year-old man dying of amyotrophic lateral sclerosis. The attending physician testified:

I deal with respirators every day of my life. To me, this is not heroic. This is standard procedure....I have other patients who have run large corporations who have been on portable respirators. Other people who have been on them and have done quite well for as long as possible.<sup>118</sup>

By contrast, the trial judge who had decided that the respirator could be withdrawn told the Commission:

Certainly there is no question legally that putting a hole in a man's trachea and inserting a mechanical respirator is extraordinary life-preserving means.

to employ extraordinary means, but only to preserve life by nourishment and clothing common to all, by medicine common to all, and even through some ordinary and common pain or anguish (*dolorem*), but not through any extraordinary or horrible pain or anguish, nor by any undertakings (*suniptos*) extraordinarily disproportionate to one's state in life. Jose Janini, *La operation quirurgica, remedio ordinario*, 18 *REVISTA SPANOLA DE TEOLOGIA* 335 (1958). For the current Catholic view, see note 132 *infra*.

<sup>115</sup> For example, a statement of the House of Delegates of the American Medical Association (December 1973) employs the ordinary/extraordinary language: "The cessation of the employment of extraordinary means to prolong life of the body when there is irrefutable evidence that biological death is imminent is the decision of the patient and/or his immediate family." Quoted in Benedict M. Ashley and Kevin D. O'Rourke, *HEALTH CARE ETHICS: A THEOLOGICAL ANALYSIS*, The Catholic Hospital Association, St. Louis, Missouri (1978) at 390.

<sup>116</sup> *In re Quinlan*, 70 N.J.10, 355 A.2d 647, 667, cert. denied, 429 U.S. 922 (1976); *Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d 417, 424 (1977).

<sup>117</sup> *Satz v. Perlmutter*, 379 So.2d 359 (Fla.1980).

<sup>118</sup> Testimony of Dr. Marshall J. Brumer, transcript of 8th meeting of the President's Commission (April 9, 1981) at 60-61.

I do not think that the doctor would in candor allow that that is not an extraordinary means of preserving life.

I understand that he deals with them every day, but in the sense of ordinary as against extraordinary, I believe it to be extraordinary.

There was no question in this case, nobody ever raised the question that this mechanical respirator was not an extraordinary means of preserving life.<sup>119</sup>

The most natural understanding of the ordinary/extraordinary distinction is as the difference between common and unusual care, with those terms understood as applying to a patient in a particular condition. This interprets the distinction in a literal, statistical sense and, no doubt, is what some of its users intend. Related, though different, is the idea that ordinary care is simple and that extraordinary care is complex, elaborate, or artificial, or that it employs elaborate technology and/or great efforts or expense.<sup>120</sup> With either of these interpretations, for example, the use of antibiotics to fight a life-threatening infection would be considered ordinary treatment. On the statistical interpretation, a complex of resuscitation measures (including physical, chemical, and electrical means) might well be ordinary for a hospital patient, whereas on the technological interpretation, resuscitation would probably be considered extraordinary. Since both common/unusual and simple/complex exist on continuums with no precise dividing line, on either interpretation there will be borderline cases engendering disagreement about whether a particular treatment is ordinary or extraordinary.<sup>121</sup>

A different understanding of the distinction, one that has its origins in moral theology, inquires into the usefulness and burdensomeness of a treatment.<sup>122</sup> Here, too, disagreement

<sup>119</sup> Testimony of Judge John G. Ferris, transcript of 8th meeting of the President's Commission (April 9, 1981) at 124.

<sup>120</sup> See Leslie Steven Rothenberg, *Down's Syndrome Babies: Decisions Not to Feed and the Letter from Washington*, 2 J. CALIF. PERINATAL ASSOC. 73, 77-78 (Fall 1982).

<sup>121</sup> There are some even less understandable uses of the term "extraordinary." In defining the term "extraordinary life support systems or procedures," the formal response to a question directed by a county's attorney to the Attorney General of California states:

We further understand the word "extraordinary" to distinguish those systems or procedures which are utilized on a continuing basis as necessary to the person's health. Thus we are not here concerned with those treatment measures employed to replace or assist a vital function on a continuing basis such as a heart transplant, a pacemaker, kidney dialysis, and the like.

65 Ops. Cal. Att'y Gen. 417, 418 (1982). reprinted in Appendix I, pp. 537-45 *infra*.

<sup>122</sup> The ordinary-extraordinary distinction has had special importance

persists about which outcomes are considered useful or burdensome.<sup>123</sup> Without entering into the complexity of these debates, the Commission notes that any interpretation of the ordinary/extraordinary distinction in terms of usefulness and burdensomeness to an individual patient has an important advantage over the common/unusual or simple/complex interpretations in that judgments about usefulness and burdensomeness rest on morally important differences.

Despite the fact that the distinction between what is ordinary and what is extraordinary is hazy and variably defined, several courts have employed the terms in discussing cases involving the cessation of life-sustaining treatment of incompetent patients. In some cases, the courts used these terms because they were part of the patient's religious tradition.<sup>124</sup> In other cases, the terms have been used to

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and a special meaning within Catholic moral theology. The distinction dates back several centuries, but much of its prominence stems from its use by Pope Pius XII in a 1957 address in which he stated: "But normally one is held to use only ordinary means—according to circumstances of persons, places, times, and culture—means that do not involve any grave burden for oneself or another." *The Prolongation of Life*, 4 THE POPE SPEAKS, Vatican City (1958) at 393, 395-96.

The distinction is here employed within a general theological view of human life as a gift from God that should not be deliberately destroyed by man. As such, it serves to clarify and qualify the absolute obligation to refrain from deliberately taking innocent human life, in light of medical treatments capable of extending a patient's life only by imposing grave burdens on the patient or others. The obligation to sustain life was extended to accepting ordinary, beneficial medical therapies, but not to require extraordinary therapies. For interpretations of the distinction within the Catholic tradition, see Richard A. McCormick, *To Save or Let Die: The Dilemma of Modern Medicine*, 229 J.A.M.A. 172 (1974); Edwin F. Healy, *MEDICAL ETHICS*, Loyola Univ. Press, Chicago (1956); The Linacre Centre, *Prolongation of Life, Paper 3: Ordinary and Extraordinary Means of Prolonging Life*, NTRE, London (1979).

<sup>123</sup> Disagreement persists about which outcomes should count as being useful or burdensome (for example, whether the life that is sustained can itself be burdensome or only the treatment; whether financial costs are relevant burdens; whether evaluations can be specified independent of, or only in light of, a particular patient's circumstances and values; and especially whether benefits and burdens only to the patient or also to others such as the patient's family are relevant). See, e.g., McCartney, *supra* note 114.

<sup>124</sup> For example, in *Quinlan*, the New Jersey Supreme Court dealt with the "Catholic view" only insofar as it related to the "conscience, motivation, and purpose of the intended guardian.., and not as a precedent in terms of civil law." *In re Quinlan*, 70 N.J.10, 355 A.2d 647, 660, *cert. denied*, 429 U.S. 922 (1976). Likewise the Eichner court admitted evidence as to Catholic teachings as "probative of the basis for Brother Fox's state in mind concerning this question." *Eichner v.*

characterize treatments as being required or permissibly foregone. For example, the New Jersey Supreme Court in the *Quinlan* case recognized a distinction based on the possible benefit to the individual patient:

One would have to think that the use of the same respirator or life support could be considered "ordinary" in the context of the possibly curable patient but "extraordinary" in the context of the forced sustaining by cardio-respiratory processes of an irreversibly doomed patient.<sup>125</sup>

Likewise, the Massachusetts Supreme Judicial Court quoted an article in a medical journal concerning the proposition that ordinary treatment could become extraordinary when applied in the context of a patient for whom there is no hope:

We should not use *extraordinary* means of prolonging life or its semblance when, after careful consideration, consultation and application of the most well conceived therapy it becomes apparent that there is no hope for the recovery of the patient. Recovery should not be defined simply as the ability to remain alive; it should mean life without intolerable suffering.<sup>126</sup>

Even if the patient or a designated surrogate is held to be under no obligation to accept "extraordinary" care, there still remains the perplexing issue about what constitutes the dividing line between the two. The courts have most often faced the question of what constitutes "ordinary" care in cases when the respirator was the medical intervention at issue. Generally the courts have recognized, in the words of one judge, that "the act of turning off the respirator is the

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Dillon, 426 N.Y.S.2d 517, 547 (App. Div. 1980), *modified in, In re Storar*, 52 N.Y.2d 363, 420 N.E.2d 64 [1981]. The *Cruse* case also admitted expert testimony on Catholic teaching as evidence of the parents' "good faith" in seeking removal of a respirator. *In re Benjamin Cruse* Nos. J9 14419 and P6 45318, slip op. at 4 (Los Angeles Sup. Ct., Feb. 15, 1979).

<sup>125</sup> *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, 668, *cert. denied*, 429 U.S. 922 (1976).

<sup>126</sup> *Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d 417, 424 (1977) (citing Howard P. Lewis, *Machine Medicine and Its Relation to the Fatally Ill*, 206 J.A.M.A. 387 (1968), citations omitted). The *Dinnerstein* court cited the same source and also relied upon fatal illness as a distinguishing factor.

The essence of this distinction in defining the medical role is to draw the sometimes subtle distinction between those situations in which the withholding of extraordinary measures may be viewed as allowing the disease to take its natural course and those in which the same actions may be deemed to have been the cause of death.

*In re Dinnerstein*, 380 N.E.2d 134, 137 n.7 (Mass. App. Ct. 1978).

termination of an optional, extraordinary medical procedure which will allow nature to take its course." <sup>127</sup>

For many, the harder questions lie in less dramatic interventions, including the use of artificial feeding and antibiotics. In one criminal case involving whether the defendant's robbery and assault killed his victim or whether she died because life-supporting treatments were later withdrawn after severe brain injury was confirmed, the court held that "heroic" (and unnecessary) measures included "infusion of drugs in order to reduce the pressure in the head when there was no obvious response to those measures of therapy."<sup>128</sup> In another case, in which a patient's refusal of an amputation to prevent death from gangrene was overridden, antibiotics were described by the physician "as heroic measures, meaning quantities in highly unusual amounts risking iatrogenic disease in treating gangrene."<sup>129</sup> Here the assessment, in addition to relying on "benefits," also seems to rely to some degree upon the risk and invasiveness of the intervention. One court did begin to get at the scope of the questions underlying the ordinary/extraordinary distinction. Faced with the question of treatment withdrawal for a permanently unconscious automobile accident victim, the Delaware Supreme Court asked what might constitute life-sustaining measures for a person who has been comatose for many months:

Are "medicines" a part of such life-sustaining systems? If so, which medicines? Is food or nourishment a part of such life-sustaining systems? If so, to what extent? What extraordinary measures (or equipment) are a part of such systems? What measures (or equipment) are regarded by the medical profession as not extraordinary under the circumstances? What ordinary equipment is used? How is a respirator regarded in this context?<sup>130</sup>

***The moral significance of the distinction.*** Because of the varied meanings of the distinction, whether or not it has moral significance depends upon the specific meaning assigned to it. The Commission believes there is no basis for holding that whether a treatment is common or unusual, or whether it is simple or complex, is in itself significant to a moral analysis of whether the treatment is warranted or obligatory. An unusual treatment may have a lower success rate than a common one; if so, it is the lower success rate rather than the unusualness of the procedure that is relevant to evaluating the therapy.

<sup>127</sup> *In re Benjamin Cruse*, Nos. J9 14419 and P6 45318, slip op. at 6-7 (Los Angeles Sup. Court, Feb. 15, 1979).

<sup>128</sup> *Parker v. U.S.*, 406 A.2d 1275, 1279 n.1 (D.C. Ct. App., 1979).

<sup>129</sup> *State Department of Human Services v. Northern*, 563 S.W.2d 197 (Tenn. Ct. App. 1978).

<sup>130</sup> *Severns v. Wilmington Medical Center, Inc.*, 421 A.2d 1334, 1349 (Del. 1980).

Likewise, a complex, technological treatment may be costlier than a simple one, and this difference may be relevant to the desirability of the therapy. A patient may choose a complex therapy and shun a simple one, and the patient's choice is always relevant to the moral obligation to provide the therapy.

If the ordinary/extraordinary distinction is understood in terms of the usefulness and burdensomeness of a particular therapy, however, the distinction does have moral significance. When a treatment is deemed extraordinary because it is too burdensome for a particular patient, the individual (or a surrogate) may appropriately decide not to undertake it. The reasonableness of this is evident—a patient should not have to undergo life-prolonging treatment without consideration of the burdens that the treatment would impose. Of course, whether a treatment is warranted depends on its usefulness or benefits as well. Whether serious burdens of treatment (for example, the side effects of chemotherapy treatments for cancer) are worth enduring obviously depends on the expected benefits—how long the treatment will extend life, and under what conditions. Usefulness might be understood as mere extension of life, no matter what the conditions of that life. But so long as mere biological existence is not considered the only value, patients may want to take the nature of that additional life into account as well.<sup>131</sup>

This line of reasoning suggests that extraordinary treatment is that which, in the patient's view, entails significantly greater burdens than benefits and is therefore undesirable and not obligatory, while ordinary treatment is that which, in the patient's view, produces greater benefits than burdens and is therefore reasonably desirable and undertaken. The claim, then, that the treatment is extraordinary is more of an expression of the conclusion than a justification for it.

***The role of the distinction in public policy.*** Despite its long history of frequent use, the distinction between ordinary and extraordinary treatments has now become so confused that its continued use in the formulation of public policy is no longer desirable.<sup>132</sup> Although those who share a common

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<sup>131</sup> Pope Pius XII acknowledged this in his statement that "Life, health, all temporal activities are in fact subordinate to spiritual ends." *The Prolongation of Life*, *supra* note 122. See also Richard McCormick, *The Quality of Life, the Sanctity of Life*, 8 **HASTINGS CTR. REP.** 30 (Feb. 1978); Robert M. Veatch, *DEATH, DYING AND THE BIOLOGICAL REVOLUTION*, Yale Univ. Press, New Haven, Conn. (1976) at 77.

<sup>132</sup> The Commission is not the first to have come to this conclusion. See e.g.: "You do not need to puzzle for very long over the categorical distinction between 'ordinary' and 'extraordinary' means of saving life. By that I mean those terms as classes or categories of treatment are no longer useful." Paul Ramsey, *ETHICS AT THE EDGE OF LIFE*, Yale Univ. Press, New Haven, Conn. (1978) at 153. The overuse and misuse of the term has led the Vatican to question the usefulness of the



understanding of its meaning may still find it helpful in counseling situations, the Commission believes that it is better for those involved in the difficult task of establishing policies and guidelines in the area of treatment decisions to avoid employing these phrases. Clarity and understanding in this area will be enhanced if laws, judicial opinions, regulations, and medical policies speak instead in terms of the proportionate benefit and burdens of treatment as viewed by particular patients. With the reasoning thus clearly articulated, patients will be better able to understand the moral significance of the options and to choose accordingly.

## Conclusions

Good decisionmaking about life-sustaining treatments depends upon the same processes of shared decisionmaking that should be a part of health care in general. The hallmark of an ethically sound process is always that it enables competent and informed patients to reach voluntary decisions about care. With patients who may die, care givers need special skills and sensitivities if the process is to succeed.

A number of constraints on the range of acceptable decisions about life-sustaining treatment have been suggested. They are often presented in the form of dichotomies: an omission of treatment that causes death is acceptable whereas an action that causes death is not; withholding treatment is acceptable whereas withdrawing existing treatment is not; extraordinary treatment may be foregone but ordinary treatment may not; a person is permitted to do something knowing that it will cause death but may not aim to kill. The Commission has concluded that none of these dichotomies should be used to prohibit choosing a course of conduct that falls within the societally defined scope of ethical medical practice. Instead, the Commission has found that a decision to forego treatment is ethically acceptable when it has been made by suitably qualified decisionmakers who have found the risk of death to be justified in light of all the circumstances. Furthermore, the Commission has found that nothing in current law precludes ethically sound decisionmaking. Neither criminal nor civil law—if properly interpreted and applied by lawyers, judges, health care providers, and the general public—forces patients to undergo procedures that will increase their suffer-

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terminology. The *Declaration on Euthanasia* proposes substituting "proportionate" and "disproportionate" for the more traditional, but perhaps outmoded, "ordinary/extraordinary." Sacred Congregation for the Doctrine of the Faith, *Declaration on Euthanasia* (June 26, 1980), reprinted in Appendix C, pp. 300-307 *infra*.

ing when they wish to avoid this by foregoing, life-sustaining treatment.

Since these conclusions recognize the importance of societally defined roles, health care professionals, individually and through their professional associations, will need to become more active in creating, explaining, and justifying their standards regarding appropriate professional roles. Within presently accepted definitions, it is already apparent that health care professionals may provide treatment to relieve the symptoms of dying patients even when that treatment entails substantial risks of causing an earlier death. The Commission has also found no particular treatments—including such "ordinary" hospital interventions as parenteral nutrition or hydration, antibiotics, and transfusions—to be universally warranted and thus obligatory for a patient to accept. Nevertheless, a decision to forego particular life-sustaining treatments is not a ground to withdraw all care—nor should care givers treat it in this way, especially when care is needed to ensure the patient's comfort, dignity, and self-determination.

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## Additional Constraints on a Patient's Decision

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In actual decisionmaking about life-sustaining treatment, various personal and institutional influences and constraints restrict reliance upon the voluntary choice of informed, competent patients. First, other people who become involved may find that a particular choice conflicts with their own values and hence be unwilling to act on a particular decision, which may place pressures on a patient. Second, society in various ways may restrict access to some care for some people in order to allocate scarce resources equitably. Third, the rules and practices—and indeed, the whole ethos—of health care institutions can profoundly affect patients' choices.

### Other People Involved in Patients' Decisions

The people—family and health care professionals—whom patients rely on to provide care and to carry out their decisions influence choices in two ways: first, by their willingness to be agents to implement a particular choice; and, second, by their response to unexpected, especially iatrogenic, complications of treatment that require rapid decisionmaking on behalf of a patient.

**Acting as Agent for a Patient's Decision.** Nearly every decision about life-sustaining treatment involves people other than the patient. Even competent patients making voluntary and informed choices must usually rely on health care personnel to act on those choices and often also need help from family members.

Those who act as agents for patients' decisions will have their own decisions to make. A patient's choice need not be the one that the agent would make under similar circumstances; it need only be seen as an appropriate and reasonable one for this patient. When there is some question on this point, a

person acting as an agent is justified in carefully evaluating the patient's competence, voluntariness, and comprehension, as well as the reliability of the information presented. Yet several other issues are raised by the fact that a patient's decision is to be carried out by another person.

First, the intention of a patient who is capable of carrying out his or her own decision independently is usually expressed directly through the action. When such decisions must be communicated to others, however, they can be seriously misinterpreted. Communication is much more than the mere transmittal of factual information. It conveys the mood and orientation of a patient and provides a means for that person to manipulate and test the environment. These considerations preclude the automatic acceptance of a patient's statements at face value, especially when they are against life-sustaining therapy.<sup>1</sup> Instead, those asked to act (or to refrain from acting) must look carefully for hidden meanings and nonverbal communication that might give a more accurate reading of a patient's declarations. Without any one person intending it, each participant in this decisionmaking process may "choose" according to what is perceived as the outcome desired by the other participants—not according to his or her own values and desires—and each other person may, in turn, be doing the same. Moreover, agents must be cautious not to let their own values dictate their responses, thereby systematically discounting a patient's intentions and explicit declarations.

Second, patients who cannot act on their own decisions lose an important protection—the reluctance individuals ordinarily feel in actually taking steps that will lead to their own demise. Some patients who seem satisfied with continuing artificial life-support stop treatment when they gain control of the situation; conversely, some who claim to want a life-sustaining therapy stopped do not do so when they get the chance.<sup>2</sup> Consequently, anyone who acts for a patient in this regard should carefully consider whether he or she is unduly affecting the patient's decision by being too willing to bear the responsibility for the actual action.

By having to involve others, a patient also risks the loss of privacy. Often a decision to forego treatment will be controver

<sup>1</sup> See pp. 48-49 *supra*. See also David L. Jackson and Stuart Youngner, *Patient Autonomy and 'Death with Dignity? Some Clinical Caveats*, 301 NEW ENG. J. MED. 404 (1979); Ned H. Cassem, *When to Disconnect the Respirator*, 9 PSYCHIATRIC ANN. 84 (1979); Ruth Faden and Alan Faden, *False Belief and the Refusal of Medical Treatment*, 3 J. MED. ETHICS 133 (1977).

<sup>2</sup> Robert B. White and H. Tristram Engelhardt, Jr., *Case Study: A Demand to Die*, 5 HASTINGS CTR. REP. 9 (June 1975); *One of our Newest M.D.'s is a Paraplegic Who Once Sued For the Right to Die*, 3 THE BIOETHICS LETTER 3 (Dec. 1982).

sial among some family members, acquaintances, and others. A patient may well want to exercise his or her prerogative to limit the disclosures made to various people. Such a prohibition, however, can place burdens upon those involved in implementing the decision. These difficulties are usually satisfactorily resolved by the good-faith efforts of all involved. When they are not resolved and when a review of a patient's decision is needed, institutional bodies and the courts will have to take special precautions to preserve privacy interests.<sup>3</sup>

The law regarding decisions about life-sustaining treatment is not clear or uniform in its application.<sup>4</sup> Those involved in carrying out a patient's or a surrogate's decision will want to assess their potential civil or criminal liability and reduce it in a responsible fashion. There is little reason to believe that liability would arise for actions taken on the basis of the decisions of competent patients that are arrived at in an appropriate fashion. Detailed records of the decisionmaking process would often be strong evidence of good medical practice. Liability could attach, however, to compliance with a competent patient's decision—whether it is to undertake or to forego therapy—if the decision was the result of a seriously deficient decisionmaking process.<sup>5</sup> Refusing to comply with a patient's request for termination of treatment out of fear of potential liability is a decision that, for now, will have to be made on a case-by-case basis.<sup>6</sup> Yet it would be most unfortu-

<sup>3</sup> Many of the protracted proceedings held to determine the legal propriety of decisions to forego life-sustaining treatment have been attended by considerable publicity, compounding already tragic situations for families involved. In the Earle Spring case, for example, a nursing home administrator allowed right-to-life advocates to interview the patient without his guardian's consent; the interview was subsequently published in a local newspaper. His widow sued the nursing home and four nurses and was awarded \$2.58 million, including \$2.5 million in damages for violation of the state's fair information practices act. Defense arguments that Spring had become a public figure did not succeed. *Home Loses 'Right to Die' Case*, AM. MED. NEWS, Dec. 10, 1982, at 20. Exactly what privacy protections may be warranted is not yet clear. There may need to be ways of protecting parts of the patient's chart or, sometimes, even the patient's identity. See also pp. 167-68 *infra*.

<sup>4</sup> David W. Meyers, MEDICO-LEGAL IMPLICATIONS OF DEATH AND DYING, Lawyers Co-Operative Publishing Co., Rochester, New York (1981); A. M. Capron, *Euthanasia*, in 2 ENCYCLOPEDIA OF CRIME AND JUSTICE, Macmillan-Free Press, New York (forthcoming). See pp. 30-41 *supra* and pp. 153-60 *infra*.

<sup>5</sup> See pp. 32-34 *supra*.

<sup>6</sup> The situation can be highly influenced by the particular proclivities of local prosecutors and their perceptions of the political climate. For example, an assistant District Attorney in New York informed a large gathering of physicians and attorneys:

nate if this fear prevented physicians and other health care professionals from acting in the manner they believe is appropriate, medically and ethically, in light of a patient's wishes.

Finally, for reasons of personal commitment, value judgment, or professional role, competent patients will sometimes be unable to secure the cooperation of others to implement their informed, voluntary decisions.<sup>7</sup> The resolution of such issues will entail counseling and compromise. In general, either patient or physician (with adequate notice) can withdraw from a relationship, and no one may forcibly undertake or continue interventions over the objections of competent patients or qualified surrogates.<sup>8</sup> However, each party can and often should seek advice within the guidelines of legitimate professional practice and institutional policy—or, where necessary, judicial decree—to resolve any discord.

**Responding to Complications of Treatment.** A particularly troubling, albeit rare, situation arises when a patient who is dying or who has refused specific life-sustaining treatment encounters a life-threatening complication (through an inadvertent or unfortunate side effect) of otherwise warranted therapy. For example, a rather routine therapy, perhaps an antibiotic for an infected tooth, might cause a massive allergic reaction that will be fatal in minutes without resuscitation. This patient may have already indicated a wish not to be revived if an unexpected heart attack were to lead to the same situation; and, given the opportunity to choose a course of action, he or she might even choose not to be resuscitated in this situation. Sometimes an account of the changed situation from the patient's perspective alone would hold that the complication

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As things stand now, withdrawal of life support is homicide....(Although) [t]he majority would not bring charges because they felt no jury would convict a doctor who acted out of humanitarian motives....[t]here are DA's in this state anxious to pursue such a charge. One told me he would see how many are enrolled in the Right to Life Party in his county. And he'd go from there.

David Zinman, *Critical Question of Life/Death*, **NEWSDAY**, Oct. 28, 1981, at 2 (quoting Robert L. Adams).

<sup>7</sup> Francis D. Moore, *Therapeutic Innovation—Ethical Boundaries in the Initial Clinical Trials of New Drugs and Surgical Procedures*, 8 **DAEDALUS** 509 (1969); Paul Heller, *Informed Consent and the Old-Fashioned Conscience of the Physician-Investigator*, 20 **PERSPECTIVES IN BIOLOGY & MED.** 434 (1977); Yashar Hirshaut and David Bleich, *Case Study: Choosing a Therapy When Doctors Disagree*, 5 **HASTINGS CTR. REP.** 19 (April 1975); W. Cole Durham, Mary Anne Q. Wood, and Spencer J. Condie, *Accommodation of Conscientious Objection to Abortion: A Case Study of the Nursing Profession*, 1982 **B.Y.U. L. REV.** 253.

<sup>8</sup> See pp. 43-45 *supra*.

should not be treated, either because the way the patient dies is preferable to the alternatives that he or she otherwise faced or because the necessary ameliorative treatment is intolerable to the patient. Yet two problems with such a decision remain: first, the patient was most likely not asked about this rare and unpredictable complication whose treatment, though dramatic, is most often completely successful; and, second, the professionals who administered the antibiotic will feel responsible for the patient's death in a way they never would have for death from a heart attack.

All such situations will be very difficult, especially if the patient's wishes are uncertain. Each time this conflict arises, the physician in charge faces a dilemma: not wanting to violate a patient's wishes, especially when doing so may well harm the patient, yet not wanting to fail to rescue someone from a death produced by a medical treatment. Public policy is caught in the same dilemma. The motivations for both courses are laudable, yet adopting either course of action as the standard does violence to the values that underlie the other.

The Commission does not propose any uniform resolution of this tension; rather, the resolution in specific cases will depend on the prudent judgment of the people involved in the case. The decision should, as much as possible, be the one the patient would have made. If that is impossible to determine, the presumption in favor of life should tilt toward administering the needed treatment. Again, it would be very unfortunate if the hypothetical threat of liability were to become a major factor in deterring an agent from a course that he or she would otherwise follow.

### **Constraints Imposed to Achieve Equitable Allocation of Resources**

Most patients' decisions about life-sustaining therapy involve the use of societal resources and thus have consequences for many other people. How and to what extent should the decisionmaking process take this into account?

Life-sustaining therapies can be very expensive. Even when a therapy itself is not expensive (such as antibiotic therapy for an infection or temporary intravenous feeding), the total expense of maintaining a patient who would not survive without the therapy can be substantial. Very few patients pay directly for health care. Instead, costs are routinely spread over large groups of people through public and private mechanisms, including private health insurance, government financing programs such as Medicare and Medicaid, and the

provision of free care by governmental and charitable institutions.<sup>9</sup>

The equity issues raised by public and private cost-spreading often seem to differ. A person with private insurance purchased a contract to be reimbursed for the costs of care if the need arises. Since premiums are based on probable use (plus profits and administrative costs), at least for the group of insured persons as a whole, a policyholder can be said to bear the expected cost through payment of premiums. Public programs, however, are supported by taxes that are unrelated to each person's probable use. In fact, these programs are usually explicitly redistributive (wealthier citizens contribute more than the poor, who are often the major beneficiaries). Thus, in public programs it is clearer that others have a reason to be concerned about an individual patient's decision.

In both public payment programs and private insurance, however, an individual's decision about the use of care does have significant effects on the costs borne by others. The resultant potential for conflict of interests could be avoided if people were made to bear all costs directly. But people buy health insurance and support government health care programs partly because they fear that some day they will need clearly beneficial care and be unable to afford it—and because their hearts go out to others who find themselves in that position. Making everyone bear the cost directly is unacceptable because it would deprive people of highly valued personal security and because people do not want a society in which individuals die or suffer substantial harm because they cannot afford necessary health care.

On the other hand, allowing decisions about life-sustaining care to be made with total disregard for the costs they impose on others has equally serious implications. Enormous expenditures may be made for very limited benefits, such as sustaining a painful and burdened life for an individual who has little or no capacity to enjoy it. When medical resources are used without concern for cost, the pattern of expenditures that results does not accurately reflect societal values because the pursuit of other goals remains constrained by costs.

Are there ethically acceptable alternatives to these extremes? The concept of access to an adequate level of health care without excessive burdens set forth in the Commission's

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<sup>9</sup> President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *SECURING ACCESS TO HEALTH CARE*, U.S. Government Printing Office, Washington (1983) at 90-108.



report on equity in access to health care provides a framework for responsibly resolving this difficult question.<sup>10</sup> The Commission held it appropriate to take both the significance of the care to the individual and its cost into account in deciding what constitutes adequate care and what burdens are excessive. Society is not obligated to provide every intervention that the patient or provider believe might be beneficial.

Undeniably, the role that health care plays in sustaining life is very important, but the fact that a therapy is life-sustaining does not automatically create an obligation to provide it. Rather, the therapy must offer benefits proportionate to the costs—financial and otherwise<sup>n</sup>—and the benefit provided must be comparable to that provided other patients in similar circumstances. For example, care for chronic conditions that interfere with the enjoyment of life (for example, arthritis) might be given greater importance than care that merely sustains a very limited existence (such as artificial support of major organ systems for patients who are already bedridden and in pain).

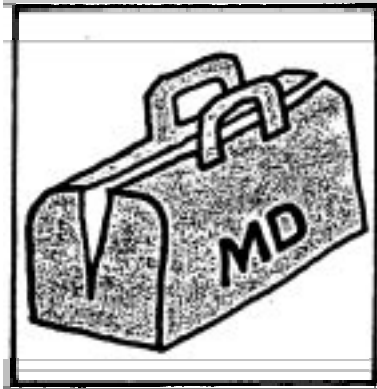
Though it is acceptable in principle—and probably unavoidable in practice—to consider cost in deciding about health care, explicitly restricting treatment decisions on financial grounds poses significant dangers. Because people vary greatly in the value they attach to particular forms of life-extension, uniform rules based on objective measures of disease would create unacceptable consequences in some cases. For example, people differ in their attitudes about life on a respirator—some treasure each additional minute of life, whereas others find the treatment intolerable. And individual views change with time and circumstances; a patient may want very vigorous treatment until a family member who lives far away arrives or a grandchild is born, while finding the same treatment unwarranted thereafter.<sup>12</sup>

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<sup>10</sup> *Id.* at 11-47. See also Testimonies of Norman Daniels and David Gautier, transcript of 13th meeting of the President's Commission (Oct. 22, 1981) at 27-30, 35-37.

<sup>11</sup> The Catholic Church, for example, explicitly includes expense as part of the assessment of whether a treatment is "disproportionate" and thus not obligatory. Sacred Congregation for the Doctrine of the Faith, *Declaration on Euthanasia*, Vatican City (1980), reprinted in Appendix C, pp. 300-07 *infra*.

<sup>12</sup> Private financial arrangements might reasonably encourage consideration of cost while allowing for individual values. For example, the provision of contracts (by insurance companies or other prepayment arrangements) that have different kinds of exclusions and limits might be one way of letting people make their own trade-offs between lower premiums, better coverage of conditions that are not life-threatening, and coverage of certain life-sustaining therapies. In advance, however, it is difficult for people to make such trade-offs reasonably. Decisions about such contracts are often uninformed or severely



Beyond the unfairness of inappropriate application of the rules, there is a danger that rules that denied access to life-prolonging care would be seen to pass a value judgment about the patients as individuals and about their social worth. This is a particular problem in public programs for the poor and the handicapped; if the measures to sustain life under programs like Medicare and Medicaid are much more severely constrained than those available to citizens generally, perceptions of unjustified discrimination and a "devaluation" of the lives of those affected might arise.

Finally, the judgment and cooperation of physicians are crucial for the functioning of a system in which such constraints are imposed. But physicians have few incentives to adopt any role other than that of strong advocates on behalf of each patient. Both their professional ethos and the legal constraints within which they work provide powerful disincentives for a role as allocator of resources. Thus cost constraints that are externally imposed—rather than arising from the profession's ongoing reevaluation of the appropriateness of certain attitudes and practices—are more likely to induce circumvention than compliance on the part of physicians.

There are few instances in which there is a strong societal consensus that cost is so high that care should not be given, even when patients greatly desire it. In many societies, these issues must be faced head-on. Hard choices must be made about the level of life-sustaining care to provide, given the very limited resources available in those societies. In this country, however, discussions of the need to control health care costs—which are occurring with increasing frequency—often are stymied because they first turn to examples involving life-sustaining treatment in which the care does provide significant benefit to the patient but is very costly. The suggestion seems to be that any serious attempt at cost-containment must begin with restrictions on this sort of care. Actually, this would seem to be a poor place to begin. The limitations on access to life-sustaining care that are acceptable in other societies would

constrained by a person's financial or employment situation or by the limited range of alternatives offered. The difficulties are even more severe in the case of public programs in which there is even greater tension between the need for similar treatment of similar cases, for the sake of fairness, and the need to allow for individual variations to reflect differing deeply held values.

probably be found unacceptable in this country. The United States can reasonably afford to include many forms of labor-intensive and high-technology life-support in its definition of adequate care.

In addition, a myriad of "small-ticket" tests and treatments probably account for more expenditures with disproportionately small payoffs than more dramatic forms of treatment do.<sup>13</sup> If cost-control incentives could be increased throughout the existing health care system, a substantial amount of care could be eliminated without substantial consequences for health or life. Reports by the Food and Drug Administration suggest, for example, that about one-third of the 75 million chest X-rays done in 1980 (at a cost of nearly \$2 billion) were unnecessary in that before they were taken it was clear that they were unlikely either to detect disease or affect its outcome.<sup>14</sup> Similarly, although cardiac pacemakers can make the difference between life and death, a recent study suggests that their use in cases in which they are not medically indicated may be adding as much as \$280 million annually to the nation's health care expenditures.<sup>15</sup> At least 25% of "respiratory care" (treatments and tests for breathing now costing \$5 billion annually) is reportedly unnecessary.<sup>16</sup> Numerous other examples of questionable health care expenditures have been documented.<sup>17</sup>

Even when treatment is life-sustaining, in many cases patients and physicians agree that the patient's prognosis makes the treatment of so little benefit that it is not worth pursuing. If decisionmaking about life-saving treatment could be improved along the lines in this Report—by being freed from misunderstanding about the dictates of law and morality—considerable savings might also result, not from explicit limitations on costs but as a consequence of better decision-making that took individual facts and values into account in each case.

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<sup>13</sup>Thomas W. Moloney and David E. Rogers, *Medical Technology—A Different View of the Contentious Debate Over Costs*, 301, **NEW ENG. J. MED.** 1413 (1979).

<sup>14</sup>Jeanne Kassler, *Routine Use of Chest X-Ray is Under Attack*, **N.Y. TIMES**, Aug. 10, 1982, at C-1.

<sup>15</sup>Howie Kurtz, *25% of Pacemakers Unnecessary*, **WASH. POST**, July 8, 1982, at A-6 (reporting joint study by the Health Research Group and Dr. Peter R. Kowey); Philip J. Hilts, *Probe Finds Kickback on Pacemakers*, **WASH. POST**, Sept. 5, 1982, at A-1 (describing investigation into pacemaker industry by Department of Health and Human Services).

<sup>16</sup>Victor Cohn, *Health Insurers Would Stifle Some Respiratory Outlays*, **WASH. POST**, Oct. 21, 1982, at A-3 (quoting Dr. Marvin Shapirc, Chairman of the Board of Blue Cross/Blue Shield).

<sup>17</sup>**SECURING ACCESS TO HEALTH CARE**, *supra* note 9, at 185-90.

Although society might be justified in limiting access for some very costly forms of life-sustaining treatment, the Commission does not believe that it would now be wise to focus decisions about such therapy on the issue of cost-containment. Nor should discussions of cost-containment begin with consideration of life-sustaining treatments.<sup>18</sup> If potential benefits must be foregone, they should first be in areas that allow more dispassionate reflection and opportunity to rectify errors. Where resource allocation policies do limit the availability of life-sustaining therapies, steps should be taken to help patients understand these policies and the reasons they were enacted. This will help patients accept the policies or see the need to seek alternative ways to obtain the desired care. More stringent constraints on the availability of life-sustaining therapies should not be imposed on those who are dependent on public programs than would be found acceptable by Americans who pay for their health care through private insurance coverage.<sup>19</sup>

Meanwhile, efforts should certainly be made to educate the public about the connection between reasonable limits on the use of care, freedom from the fear of overwhelming health care costs, and the ability to obtain care that is of great importance to personal well-being. In the long run, a societal consensus about access to health care, including life-sustaining care, is needed. Rather than beginning with restrictions on life-sustaining care, however, it would be better to develop principles for equitable and acceptable limits on the use of health care generally, and then to apply those principles to issues at the end of life.<sup>20</sup>

### Institutional Rules and Practices

Three-quarters of the deaths in the United States occur in a hospital or long-term care facility.<sup>21</sup> Even if death occurs at

<sup>18</sup> Paul Ramsey, *THE PATIENT AS PERSON*, Yale University Press, New Haven, Conn. (1970) at 117-18; James F. Childress, *Who Shall Live When Not All Can Live?*, 43 *SOUNDINGS* 339 (1970); Guido Calabresi and Philip Bobbitt, *TRAGIC CHOICES*, W.W. Norton, New York (1978).

<sup>19</sup> *SECURING ACCESS TO HEALTH CARE*, *supra* note 9, at 5-6.

<sup>20</sup> Since life-sustaining care is a matter of particular importance with older patients, whose care is largely paid for under public programs (particularly Medicare and Medicaid), restrictions on marginally beneficial use of funds must avoid a real or perceived conflict between the role of the government as articulator of rights and responsibilities (especially regarding the protection of human life) and its role as allocator of collective financial resources. For this reason, too, the Commission hopes that the conclusions and recommendations contained in this Report will stimulate the establishment of good decisionmaking policies by public and private bodies now, before the current debates on cost-containment are resolved.

<sup>21</sup> In a review of 35,381 cancer deaths in Cuyahoga County, Ohio, from

home, treatment of many illnesses, including the leading causes of death (cancer, stroke, trauma, and heart disease), usually involves a period in a health care institution. Thus, the structure, rules, and general character of these institutions have important—though seldom considered—implications for patients' decisionmaking.<sup>22</sup>

Professional traditions and educational norms, societal incentives and disincentives (such as reimbursement rules), and the dictates of administrative convenience and professional needs help to shape the character of each institution, often without particular attention being paid to their effects on decisionmaking by or on behalf of patients. The choices available to patients are affected not only by the ethos of the institution they are in but also by the range of available alternatives to being in that institution. The effects may be so indirect and unstated that patients never really have an opportunity to understand the true impact of a decision to be admitted to a particular health care institution.<sup>23</sup>

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1957-1974, 65% of the people died in hospitals, 15% in nursing homes, and 20% at home. Arthur Flynn, *Where Do Cancer Patients Die?*, 5 J. COMMUNITY HEALTH 126 (Winter 1979). See also John M. Hinton, *Comparison of Places and Policies for Terminal Care*, 1 LANCET 29 (1979); Roger Pritchard, *Dying: Some Issues and Problems*, 164 ANNALS N.Y. ACAD. SCI. 707 (1969).

Hospitals and nursing homes are not the only institutional settings for such decisions—questions about foregoing life-sustaining treatment have also arisen in such settings as mental institutions and prisons. See, e.g., *Commissioner of Corrections v. Meyers*, 399 N.E. 2d 452 (Mass. App. 1979) (dialysis ordered over objection of prisoner noting state interest in preservation of life and orderly operation of penal facilities). But see *Zant v. Prevatte*, 248 Ga. 832, 286 S.E.2d 715 (1982) (prisoner's right to privacy allows refusal of force-feeding during hunger strike).

<sup>22</sup> Robert L. Kane and Rosalie A. Kane, *Care of the Aged: Old Problems in Need of New Solutions*, in Philip H. Abelson, ed., *HEALTH CARE: REGULATION ECONOMICS, ETHICS, PRACTICE*, American Association for the Advancement of Science, Washington (1978) at 100.

<sup>23</sup> The baby must be saved at all costs; anything less is illegal and immoral. That's what they say at Pediatric Hospital [a pseudonymous tertiary care center] anyway.

I'm afraid for Andrew, afraid for us. Afraid and ashamed. Why did we ever sign him into such a place. I don't understand why we had rights at Community and suddenly, we discover, we have no rights at Pediatric. Or why something is morally right at Community and morally wrong when you move some distance away. Legal here and illegal in the city.

Robert and Peggy Stinson, *THE LONG DYING OF BABY ANDREW*, Little, Brown, Boston (1983) at 46-47.

See also *O'Connor v. Donaldson*, 422 U.S. 563 (1975); Note,

Obviously, just being in an institution affects a person's decisionmaking ability. Typically, patients forfeit control over what to wear, when to eat, and when to take medicines, for example. Furthermore, they almost inevitably lose substantial privacy—intimate body parts are examined, highly personal facts are written down, and someone they have never seen before may occupy the next bed. Finally, trust must be placed in strangers selected by the institution: care is given by professional experts who might well be, and who frequently are, substituted freely for one another to accommodate work schedules and educational needs. All these factors serve to isolate patients, rob them of their individuality, foster dependence, and diminish self-respect and self-confidence, even when illness, medication, and surgery have not already had these effects.<sup>24</sup> The situation can seriously impair patients' power to exercise self-determination and, thus, to be active participants in decisionmaking.<sup>25</sup>

Institutions also have customs and procedures that govern lines of authority and that are intended to guarantee the efficient, fair, and effective operation of the organization.<sup>26</sup> These are often largely implicit and informal, and their obscurity and complexity can keep a patient from knowing what policies are in effect and how he or she might affect personally relevant institutional practices.

The first hidden influence on patient choice is that, along with trying to serve individual patient's needs, administrators of health care institutions have other goals. Account books must be balanced; salaries paid; heat, light, and food provided; legal liability limited; research and education carried out; public health needs met; public image maintained; and the future of the institution assured.<sup>27</sup> The effects of national and local regulations, laws, and financial incentives and disincen-

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*Developments in the Law of Civil Commitment of the Mentally Ill*, 87 HARV. L.R. 1190 (1970).

<sup>24</sup> Erving Goffman, *ASYLUMS*, Anchor Books, Garden City, New York (1961) at 18-21; Talcott Parsons, *THE SOCIAL SYSTEM*, The Free Press, New York (1951) at 445-46.

<sup>25</sup> Of course, for some patients, who were debilitated before treatment, the net effect of an institution may be to *increase* the ability to make decisions on their own behalf.

<sup>26</sup> Harvey L. Smith, *Two Lines of Authority: The Hospital's Dilemma*, in E. Gartly Jaco, ed., *PATIENTS, PHYSICIANS AND ILLNESS*, The Free Press, New York (1958) at 468-77.

<sup>27</sup> Reinhold Niebuhr contends that, although individuals may on occasion be capable of a limited degree of altruism, groups or institutions invariably operate exclusively in their own self-interest: "The selfishness of human communities must be regarded as an inevitability." Reinhold Niebuhr, *MORAL MAN AND IMMORAL SOCIETY*, Charles Scribner's Sons, New York (1960) at 272 (originally published in 1932). See also John D. Thompson. *The Hospital—Its Role and*

tives are important in shaping the behavior of health care institutions. In recent years, for example, the rapid increase in health care expenditures has led to increased pressure to hold institutions accountable for the wise use of resources; reimbursement methods are being changed in ways that are intended to cause both profitmaking and nonprofit institutions to alter decisions about patient care.

Second, the character of most health care institutions, shaped by professional norms and societal values, strongly favors extending life whenever possible, regardless of resource use or personal suffering. Thus, the institutional arrangements made by administrators are frequently far from neutral in terms of the choices they leave for individual patients. A patient who chooses to forego aggressive therapy may have trouble finding emotional or material support, in addition to any more formal barriers to such decisions that are erected by the institution. For example, turning down aggressive care may leave no justification for an acute-care-hospital level of reimbursement, prompting the hospital to press for discharge or to inform the patient pointedly as to his or her liability for charges. Also, such a refusal may occasion formal adjudication of competence or of the relative weight of state interests.<sup>28</sup>

**The Extent of Institutional Responsibility for Decisionmaking.** Health care decisionmaking—whether in the context of life-sustaining treatment or otherwise—has traditionally been regarded by physicians as their province. In recent years, the law, medical ethics, and patients themselves have urged a more truly collaborative involvement of patients in the process. However, despite the marked growth in the importance of institutions as the setting of care and of "teams" of professional employees as providers of care, remarkably little consideration has been given to the proper role of hospitals and other institutions in health care decisionmaking. Traditionally, since only physicians—not hospitals—can practice medicine, it has been physicians who have had legal responsibility for the decisionmaking process—that is, for ensuring that patients are adequately informed about treatment options, have the capacity to make the treatment decision at hand, and actually do voluntarily consent. The few attempts by patients to impose liability on hospitals as well as, or instead of, physicians, on

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*Limitations in the Health Care System*, in Lawrence Corey, Michael F. Epstein, and Steven E. Saltman, eds., *MEDICINE IN A CHANGING SOCIETY*, C.V. Mosby Co., St. Louis, Mo. (2ded. 1977) at 107.

<sup>28</sup> See pp. 122-26 *infra* and pp. 31-32 *supra*. See also Willard Gaylin, *Still, A Person Owns Himself*, *N.Y. TIMES*, Dec. 12, 1982, at A-31.

the ground that they were not adequately informed about treatment before consenting to it, have uniformly failed.<sup>29</sup>

Nonetheless, hospitals have long been responsible for the acts and omissions of their employees.<sup>30</sup> If a staff nurse failed to give a medication prescribed by the patient's doctor, for example, the hospital might be liable for harms caused thereby. Similarly, a hospital is liable for the wrongful acts of an employee-physician, including failure to obtain a patient's informed consent to treatment,<sup>31</sup> though it is not liable for the professional defaults of those physicians who practice at the hospital as independent contractors.<sup>32</sup> By virtue of membership on a hospital's medical staff, a physician enjoys the "privilege" of admitting patients to the hospital and using its facilities and employees (such as nurses, technicians, and house staff) to assist in treating patients. Privileges to admit patients are not granted by the hospital as a corporate entity, but by the medical staff of the hospital, which is an independent legal entity composed of and operated by the physician members of the medical staff.

In recent years, the allocation of legal responsibility between the hospital on the one hand and individual physicians and the medical staff on the other has been subject to gradual but continuing redefinition by courts.<sup>33</sup> The unsettled nature of the law regarding an institution's responsibilities concerning patients' decisionmaking provided the backdrop for the Commission's consideration of what the extent of those responsibilities ought to be.

Hospitals are increasingly (though still infrequently) held responsible for defaults committed by physicians treating

<sup>29</sup> See, e.g., *Cooper v. Curry*, 92 N.M. 417, 589 P.2d 201 (Ct. App. 1978); *German v. Nichopolous*, 577 S.W.2d 197 (Tenn. App. 1978); *Parr v. Palmyra Park Hosp.*, 228 S.E.2d 596 (Ga. App. 1976).

<sup>30</sup> Many hospitals were formerly protected from suit by the doctrines of charitable or sovereign immunity. See Angela R. Holder, *MEDICAL MALPRACTICE LAW*, John Wiley & Sons, New York (1975) at 326-29. See also Richard T. DeGeorge, *The Moral Responsibility of the Hospital*, 7 J. MED. & PHIL. 87 (Feb. 1982).

<sup>31</sup> *Cooper v. Curry*, 92 N.M. 417, 589 P.2d 201, 203 (Ct. App. 1978) (by implication).

<sup>32</sup> *Id.*, citing *Schloendorff v. Society of New York Hosp.*, 211 N.Y. 125, 105 N.E. 92 (1914).

<sup>33</sup> The landmark case in this process is *Darling v. Charleston Community Memorial Hosp.*, 50 Ill. App.2d 253, 200 N.E.2d 149 (1964), *aff'd* 33 Ill.2d 326, 211 N.E.2d 253 (1965). See generally Neil L. Chayet and Thomas M. Reardon, *Trouble in the Medical Staff: A Practical Guide to Hospital Initiated Quality Assurance*, 7 AM. J. L. & MED. 301 (1981); Edward E. Hollowell, *Does Hospital Corporate Liability Extend to Medical Staff Supervision?*, 10 L., MED. & HEALTH CARE 225 (1982); Jay Alexander Gold, *Wiser than the Laws?: The Legal Accountability of the Medical Profession*, 7 AM. J. L. & MED. 145 (1981).



patients under their auspices and on their premises in situations in which the hospital's responsible officers (trustees or administrators) knew or reasonably should have known that the physician was not adhering to proper standards of medical practice. In parallel, hospitals are also gradually and increasingly being held legally liable for harmful results that befall patients at the hands of physicians whose lack of skills were not discovered because the medical staff did not adequately investigate into the physician's credentials when staff privileges were applied for and granted.<sup>34</sup>

Few cases have sought to impose liability on a hospital for a physician's failure to make an adequate disclosure of information to a patient, and none has been successful.<sup>35</sup> Nonetheless, as standards for making health care decisions—including decisions to forego life-sustaining treatment—evolve and become an accepted part of medical practice, hospitals are more likely to be held responsible when physicians to whom privileges have been accorded fail to abide by these decision-making procedures, at least in cases in which the hospital authorities knew or should have known of the physician's failure. Some state statutes or regulations now require hospitals to obtain adequate documentation of informed consent.<sup>36</sup> Even in the absence of statutory mandates, health care institutions have assumed some responsibility for the decision-making process, individually or through the accreditation process.<sup>37</sup> For example, the Joint Commission on the Accredita-

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<sup>34</sup> See, e.g., Hollowell, *supra* note 33.

<sup>35</sup> Holding the hospital liable for such negligence has once been expressly rejected. The rationale for rejection—that it "would...interfere in the delicate doctor-patient relationship [by]...discourag[ing] hospitals from allowing physicians to use their facilities for novel or experimental medical procedures and [by]...inducing hospitals to discourage patients from undergoing such operations," *Cooper v. Curry*, 92 N.M. 417, 589 P.2d 201, 204 (Ct. App. 1978)—is not only factually tenuous but illogical and inconsistent with a proper understanding of requirements for informed consent. Hospitals need not discourage "novel or experimental medical procedures" if they were responsible for assuring patients' informed consent to such procedures, since informed consent is already required for nonexperimental as well as experimental procedures. See, e.g., *Demers v. Gerety*, 85 N.M. 641, 515 P.2d 645 (Ct. App. 1973). Further, if adequate disclosure had the consequence of discouraging patients from undergoing experimental (or other) procedures, then it would have fulfilled its purpose of promoting patient self-determination.

<sup>36</sup> See, e.g., Pennsylvania Department of Health, General and Special Hospitals, Patient's Bill of Rights, 10 Pa. Bull. 3761, 3676 § 103.22(8), (9) (Sept. 20, 1980); Minn. Stat. § 144.651(2).

<sup>37</sup> The voluntary assumption of a duty to which one would not otherwise be held often imposes a legal responsibility to comply with that duty. Thus, although hospitals arguably need not provide consent forms, use nurses to have them signed, or make inquiry of patients

tion of Hospitals (JCAH) requires that hospitals have a policy that stipulates when informed consent must be obtained.<sup>38</sup> Most health care institutions provide consent forms for the documentation of informed consent and permit or require employees, usually nurses, to have the patient sign the form; nurses are often cautioned not to allow patients to sign consent forms if they say their physicians have not explained the procedure or if it appears that the patients do not understand the treatment for which consent is sought.<sup>39</sup>

Thus, there is a growing recognition that health care institutions have a legitimate role in ensuring that patients are informed, voluntary decisionmakers, at least to the extent that this goal can be achieved through appropriate institutional supervision of the decisionmaking process. Although hospitals were once seen simply as facilities at which physicians could provide medical care, the responsibility of administrators for many decisions that impinge directly upon patient care is now recognized.<sup>40</sup> The particular dimensions of these responsibilities regarding life-sustaining treatment are still being developed.

**Characteristics of Institutions.** The nature of the major institutions where patients face decisions about life-sustaining treatment varies considerably. For example, acute care hospitals have a dominant predisposition to prolonging life; nursing homes have a weaker and more variable commitment to prolonging life; and hospices are characterized by an acceptance of death.

**Acute care hospitals.** There are over 7000 acute care hospitals in the United States with a total of 1.3 million beds.<sup>41</sup> Each year about one in every eight Americans spends some

about whether the procedure has been explained and whether they understand it, their agreement to do so imposes a duty on them to do so and to do so in a responsible manner.

<sup>38</sup> Joint Commission on Accreditation of Hospitals, *ACCREDITATION MANUAL FOR HOSPITALS*, Chicago (1981) at 84-86.

<sup>39</sup> See Charles Lidz and Alan Meisel, *Informed Consent and the Structure of Medical Care* (1982), in President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *MAKING HEALTH CARE DECISIONS, VOLUME TWO: APPENDICES (EMPIRICAL STUDIES OF INFORMED CONSENT)*, U.S. Government Printing Office, Washington (1982) at 317; *Demers v. Gerety*, 85 N.M. 641, 515 P.2d 645, 648 (Ct. App. 1973).

<sup>40</sup> See, e.g., Barry S. Bader and Andrew Burness, *Ethics: Boards Address Issues Beyond Allocation of Resources*, 35 *TRUSTEE* 14 (Oct. 1982).

<sup>41</sup> Michael Enright and Steven Jonas, *Hospitals*, in Steven Jonas, ed., *HEALTH CARE DELIVERY IN THE UNITED STATES*, Springer Publishing Co., New York (1981) at 169.

time as a hospital patient; it is estimated that 60-70% of the two million Americans who died in 1981 did so in a hospital.<sup>42</sup> In hospitals, a strong commitment to preserving life is combined with readily available means to try to do so. For a patient to decline procedures needed to make a definitive diagnosis, to reject vigorous treatment that might possibly bring longer life, or to find meaning in death and suffering is not only seen by most hospital personnel as aberrant or even suspect behavior, but may actually be very disruptive of the usual institutional routines and assumptions.<sup>43</sup>

The depersonalization and dependency that accompany living for a time in a large institution is particularly pronounced in hospitals. Many routine procedures—for example, denying patients an opportunity to review their charts or not telling them the nature and purpose of diagnostic tests<sup>44</sup>--undermine patient self-determination. Even hospital architecture and personnel patterns may aggravate confusion and depression.<sup>45</sup>

A great deal could be done to ameliorate the detrimental effects and to enhance the potentially beneficial effects of

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<sup>42</sup> See note 21 *supra*.

<sup>43</sup> One response to such disruptive behavior can be seen in the play, *WHOSE LIFE IS IT ANYWAY?*, the story of a paralyzed sculptor and his struggle to gain control over the decisions regarding his care. When his doctor prescribes valium over his objections because he "seems a little agitated," he reacts bitterly to the nurse who brings it:

Because in an hour's time, you'll be bringing round a little white pill that is designed to insert rose-colored filters behind my eyes. It will calm me and soothe me and make me forget for a while that you have a lovely body.

Brian Clark, *WHOSE LIFE IS IT ANYWAY?*, Avon Books, New York (1978) at 17. See also Victor and Rosemary Zorza, *A WAY TO DIE*, Alfred A. Knopf, New York (1980) at 95; Robert M. Veatch, *DEATH, DYING, AND THE BIOLOGICAL REVOLUTION*, Yale Univ. Press, New Haven, Conn. (1976) at 279-87; Elisabeth Kibler-Ross, *ON DEATH AND DYING*, Macmillan Pub. Co., New York (1969) at 195-98.

<sup>44</sup> Budd N. Shenkin and David C. Warner, *Giving the Patient His Medical Record: A Proposal to Improve the System* (Sounding Board), 289 *NEW ENG. J. MED.* 688 (1973); President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *MAKING HEALTH CARE DECISIONS*, U.S. Government Printing Office, Washington (1982) at 80. See also "There are many ways in practice of not respecting a patient. For example, enclosing him in an exclusively technical world which is suitable only for the initiated, a world in which he cannot find any room for himself and his rights, and in which he is unable to influence the course of events." L.M. Cattoretti, *Moral Aspects*, in Robert G. Twycross and Vittorio Ventafridda, eds., *THE CONTINUING CARE OF TERMINAL CANCER PATIENTS*, Pergamon Press, New York (1980) at 7,8.

<sup>45</sup> Gregg A. Warshaw *et al.*, *Functional Disability in the Hospitalized Elderly*, 248 *J.A.M.A.* 847 (1982).

being treated for a life-threatening condition in a hospital. The most important change would be to make these problems more of a priority concern. Hospitals could minimize the institution's depersonalizing effects by, for example, encouraging patients to decorate their rooms or bring in personal items, protect their privacy, wear their own clothes, or even substantially direct their daily schedule. Some patients could go home for a few days to consider treatment options in a less intimidating setting. At the very least, hospital personnel could help patients understand how to function effectively within the institution's organization.

Whether hospitals can or should change their commitment to extending life is a more difficult issue. For the vast majority of patients, the institutions' strong commitment to saving lives is a source of trust and comfort. Even for patients who do not favor such treatment for themselves, encountering some degree of resistance to their wishes is a reminder that their lives are important to others. Nevertheless, patients should not face such marked and regular resistance to a decision to forego life-sustaining treatment as to either rob them of the right to self-determination or damage their mental or physical health, which might happen if others continually questioned the decision. Moreover, there are surely better ways to use institutions' scarce resources than to force them upon patients who truly prefer to forego them. The task facing hospitals and their personnel is to respond sensitively to the varied needs of individual patients in the context of a large, complex, and often overwhelming institution.

**Nursing homes.** Many people will spend some time in a long-term care (LTC) facility, typically a nursing home. The growing number of elderly in the population, the shifts in the composition and roles of families, and the initiation of Federal and state government funding led to a rapid expansion of long-term care facilities in the 1960s and 1970s.<sup>46</sup> Today nursing homes have over 1.4 million beds, and 64% of their residents remain there for more than a year.<sup>47</sup> Of the people residing in nursing homes, almost all are over 65 and 80% are over 75 years old.<sup>48</sup>

Admission to an LTC facility has substantial effects upon a person's prospects for a longer life. For a few patients, usually those subject to substantial abuse or neglect before admission, long-term care provides a chance for a longer and

<sup>46</sup> See e.g., Anne R. Somers, *Marital Status, Health, and the Use of Health: A Predicament for All*, WASH. POST, May 16, 1982, at A-1.

<sup>47</sup> National Center for Health Care Statistics, *THE NATIONAL NURSING HOME SURVEY: 1977 SUMMARY FOR THE UNITED STATES*, U.S. Dept. of Health and Human Services, Washington (1979) at 8, 29.

<sup>48</sup> Bruce C. Vladeck, *UNLOVING CARE: THE NURSING HOME TRAGEDY*, Basic Books, New York (1980) at 13.

better life. For many, however, admission involves leaving a familiar and supportive environment. A change in living arrangements is stressful for anyone; for the frail elderly, being "put into" a nursing home may actually increase the risk of dying in the year after admission.<sup>49</sup> Thus, deciding to enter a nursing home can really be a decision to forego the life-sustaining possibilities of remaining at home. Unfortunately, outpatient support services that would enable some people to continue to live independently are still not widely available, and many families are unable to bear the emotional and financial costs involved in caring for a severely dependent relative at home.<sup>50</sup>

The decision options available to residents in an LTC facility will be affected by a number of institutional and professional responses. Since many of these will never have been formally analyzed and adopted by an institution, there may be no way for a patient or surrogate to review them. Financial incentives and disincentives can make it difficult to obtain unscheduled physician visits, which are underpaid, and too easy to obtain a trip to the local emergency room, which is fairly well reimbursed. Some commentators feel that since rehospitalization usually "requalifies" the patient for (higher) Medicare benefits upon return to the nursing home, there is a substantial incentive for such long-term care facilities to send sick patients back to a hospital whether or not hospitalization offers the patients any benefit.<sup>51</sup>

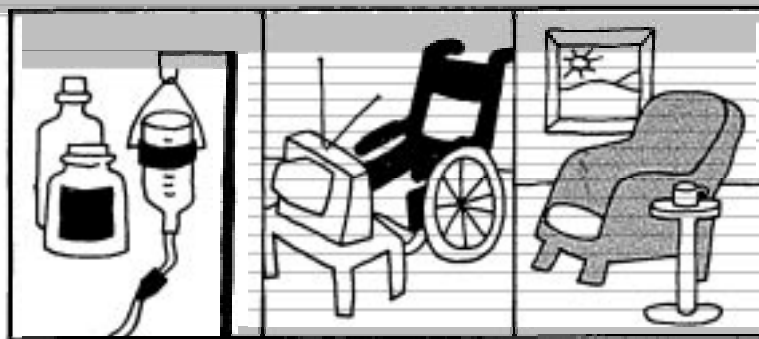
Although all these incentives favor the use of technologically aggressive care, and although it is clear that some LTC institutions follow that course, others appear not to make aggressive care available to some patients. LTC facilities share hospitals' commitment to prolong life, but their bias in that direction is both less strong and less uniform. A study of

<sup>49</sup> See, e.g., Richard T. Smith and Frederick W. Brand, *Effects of Enforced Relocation on Life Adjustment in a Nursing Home*, 6 INT'L J. AGING & HUM. DEV. 249 (1975); Stanislaw V. Kasl, *Physical and Mental Health Effects of Involuntary Relocation and Institutionalization On the Elderly—A Review*, 62 AM. J. PUB. HEALTH 379 (1972).

<sup>50</sup> Elaine M. Brody, *Environmental Factors in Dependency*, in A.N. Exton-Smith and J. Grimley Evans, eds., *CARE OF THE ELDERLY: MEETING THE CHALLENGE OF DEPENDENCY*, Grune and Stratton, New York (1977) at 81, 84; General Accounting Office, *ENTERING A NURSING HOME—COSTLY IMPLICATIONS FOR MEDICAID AND THE ELDERLY*, U.S. Government Printing Office, Washington (1979) at 9; Emmett Keeler and Robert L. Kane, *What is Special About Long-Term Care?*, in Robert L. Kane and Rosalie A. Kane, eds., *VALUES AND LONG-TERM CARE*, Lexington Books, Lexington, Mass. (1982) at 85, 94.

<sup>51</sup> *ENTERING A NURSING HOME—COSTLY IMPLICATIONS FOR MEDICAID AND THE ELDERLY*, *supra* note 50, at 26; James Lubitz and Ronald Deacon, *The Rise in the Incidence of Hospitalizations for the Aged, 1967 to 1979*, 3 HEALTH CARE FINANCING REV. 21, 37 (March 1982).

nontreatment of fever in LTC facilities showed that nearly half the patients with fever were not treated (with antibiotics or otherwise) and that the mortality in this group was—as expected—high (59%).<sup>52</sup> The untreated patients were more likely than others to have malignancies, to be bedridden, to be in pain, and to be residents of smaller facilities. Nontreatment in such settings seemed to be accepted, but the decisionmaking leading to it was rarely the object of scrutiny. (In fact, this is the only published study of nontreatment decisions in LTC facilities.) Although any treatment (or nontreatment) option may well be best for a particular patient, his or her chances of getting any specific choice seem largely to depend on the predilections of the institution's administrators, trustees, and employees, which are seldom made explicit.



The financial incentives established by reimbursement systems are another often unexamined influence on the decisionmaking of patients in LTC facilities. These institutions find it much more profitable, for example, to provide rehabilitation services and skilled care of wounds than psychiatric services and recreation.<sup>53</sup> It is not clear that the services provided are those that patients would choose, but it is clear that patients have little opportunity to alter the mix of services they receive or even to be informed of the importance of these administrative decisions. Thus, the responsibility of providing the most useful mix of services and informing patients and their surrogates of the opportunities that are not available must rest with those who establish the incentives (that is, the administrators of Medicaid programs) and those who respond

<sup>52</sup> Norman K. Brown and Donovan J. Thompson, *Nontreatment of Fever in Extended-Care Facilities*, 300 NEW ENG. J. MED. 1246 (1979).

<sup>53</sup> Such incentives probably contribute to Medicare spending about 6.6 times as much on enrollees who die in a calendar year than on those who live through the year. James Lubitz, Marian Gornick, and Ron Prihoda, *Use and Costs of Medicare Services in the Last Year of Life* (draft), Internal Working Paper, Health Care Financing Administration, Baltimore, Md. (Sept. 21, 1981). See also Human Resources Division, THE ELDERLY REMAIN IN NEED OF MENTAL HEALTH SERVICES, General Accounting Office, Gaithersburg, Md. (Sept. 16, 1982).

to them (predominantly nursing home administrators and trustees, though the patients' physicians and nurses may have a substantial role).

Very little has been done to encourage LTC institutions to develop good decisionmaking practices. Licensure of facilities and accreditation rests on a number of quality control measures but includes no consideration of decisionmaking factors such as the assessment of a patient's competence, the designation of surrogates, or the requirement to abide by a patient's decision.<sup>54</sup> Though residents often receive a "Bill of Rights" they are rarely taught to recognize infringements that occur. Advance directives about the care to be provided or foregone are often discouraged,<sup>55</sup> and serious assessment of the best interests of incompetent patients is often avoided.<sup>56</sup>

Like hospitals, LTC facilities can lessen the tendency of the institution to foster dependency and decisionmaking incapacity and can establish regular procedures for decisionmaking, including the assessment of residents' capacity to participate and the designation of surrogates. Since the practices and prevailing ethos of LTC facilities vary so greatly, they have an obligation to inform patients and families about these matters, both before and during the period of residence.<sup>57</sup> And since their patients are so commonly powerless to change practices, LTC institutions should be especially responsible in protecting the interests of the individual. Finally, improving decisionmaking in LTC facilities will require much further research on present practices and the likely effects of proposed improvements, a field that has received little scholarly attention.

**Hospices.** Whereas patients entering hospitals usually do so expecting to be cured and people entering nursing homes expect to stay for considerable periods of time and may not

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<sup>54</sup> Vladeck, *supra* note 48, at 155-57; *but see* American Health Care Association, *Questionably Competent Long Term Care Residents*, Washington (1982).

<sup>55</sup> *See* pp. 136-53 *infra*.

<sup>56</sup> Concerns that "many residents of long term care facilities exhibit some degree of inability to make, communicate or implement decisions" and a "growing awareness of the inadequacy of existing mechanisms for assuring the authority of decisions made by and on the behalf of questionably competent long term care residents" prompted the American Health Care Association to establish an ad hoc study committee, which published some analysis and tentative recommendations in *Questionably Competent Long Term Care Residents*, *supra* note 54, at 1, 2. *See also* Mary Devitt and Barry Checkoway, *Participation in Nursing Home Resident Councils: Promise and Practice*, 22 THE GERONTOLOGIST 49 (1982).

<sup>57</sup> Steven A. Levenson, Noel D. List, and Bo Zawwain, *Ethical Considerations in Critical and Terminal Illness in the Elderly*, 29 J. AM. GERIATRICS SOC. 563 (1981).

even be sick, people entering hospice programs not only know they are sick but also that their death will occur quite soon.<sup>58</sup> Before 1974 hospices were virtually unknown in the United States. Now this grass-roots movement has spawned an estimated 800 programs across the country.<sup>59</sup> Hospices were developed for the sole purpose of assisting dying patients—typically cancer patients who have exhausted all reasonable forms of curative treatment—to live their remaining weeks or months as free of symptoms and as much in control as possible.<sup>60</sup> They have been deliberately created as an alternative to traditional long-term care institutions.

Hospices are further distinguished from hospitals and nursing homes by several features. First, the term "hospice" refers not to a building, but to a concept of care.<sup>61</sup> Thus a hospice is a social and health care "institution," but not necessarily an inpatient facility. In the United States, most hospice care is delivered to people in their homes and many hospice programs provide only home care.<sup>62</sup> Second, the

<sup>58</sup> Nina Millett, *Hospice: Challenging Society's Approach to Death*, 4 HEALTH & SOC. WORK 131 (1979); Paul M. DuBois, *THE HOSPICE WAY OF DEATH*, Human Sciences Press, New York (1980) at 48-59.

<sup>59</sup> In 1979 the General Accounting Office identified 59 operational hospices and another 73 in the planning stages. General Accounting Office, *HOSPICE CARE—A GROWING CONCEPT IN THE UNITED STATES*, U.S. Government Printing Office, Washington (1979) at 11. By 1980 the Joint Commission on Accreditation of Hospitals found 440 operational hospices (half of which had begun delivering services in that year) and almost 400 others getting ready to provide services. H. Peggy Falknor and Deborah Kugler, *JCAH Hospice Project Interim Report, Phase I*, Chicago, mimeo. (July 1981). Although no more recent surveys have been conducted, the National Hospice Organization estimates that there may now be as many as 800 hospice programs providing services.

<sup>60</sup> Although some hospice programs admit only cancer patients, most admit other patients as well. However, even then the vast majority of patients (estimated at 95% or more) have cancer. The virtual exclusion of other patients from hospices led to a study of the records of patients who died. Only 6 out of the 245 patients who would have been appropriate for hospice care had diseases other than cancer. Charles L. Breindel and Timothy O'Hare, *Analyzing the Hospice Market*, 60 HOSP. PROGRESS 52 (Oct. 1979). Furthermore, hospices' focus on malignant disease may be due to recent advances in pain management, the anxiety people have about cancer, and the severe pain suffered by some cancer patients. Cicely Saunders, *Care for the Dying*, 3 PATIENT CARE 2 (1976).

<sup>61</sup> Marian Osterweis and Daphne S. Champagne, *The U.S. Hospice Movement: Issues in Development*, 69 AM. J. PUB. HEALTH 492 (1979).

<sup>62</sup> The Joint Commission on Accreditation of Hospitals surveyed 440 operational hospice programs in 1980 and found 46% to be hospital-based, most of which also provide care. Falknor and Kugler, *supra* note 59. The General Accounting Office reported that almost half the 59 operating hospices they surveyed in 1979 had no inpatient facilities.



patient and his or her family are considered to be the unit of care. Third, attention is given not only to physical needs, but also to emotional, social, and spiritual needs. Finally, hospice care is delivered by multidisciplinary teams of providers, including volunteers, on whom the hospice movement has depended heavily.<sup>63</sup>

Hospice programs vary substantially in their administrative arrangements and service offerings.<sup>64</sup> However, all hospices share a philosophy of care. Hospice development has been premised on the belief that home is almost always the best place to die<sup>65</sup> and that traditional medical care facilities, especially acute care hospitals, are inappropriate to the needs of the dying as well as unnecessarily costly.<sup>66</sup> They support families not only in their care of the patient but emotionally throughout a period of bereavement.

Like all other institutions, hospices have their particular ethos and operate under some constraints that necessarily impinge on the range of options available to patients and the ease of obtaining them. To their credit, hospices have been more self-conscious and self-critical than traditional institutions about these effects on patients. Because they recognize that their orientation differs from the norm in health care today, most hospices discuss their philosophy and approach with potential patients and their families in order to enhance

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HOSPICE CARE—A GROWING CONCEPT IN THE UNITED STATES, *supra* note 59. Fully 67% of hospices do not accept patients unless they have a primary care giver in the home at least 19 hours a day. Helen Butterfield-Picard and Josefina Magno, *Hospice the Adjective, Not the Noun*, 37 AM. PSYCHOLOGIST 1254,1256 (1982).

<sup>63</sup> National Hospice Organization, *Standards of a Hospice Program of Care*, Washington, mimeo. (1981).

<sup>64</sup> Osterweis and Champagne, *supra* note 61: HOSPICE CARE—A GROWING CONCEPT IN THE UNITED STATES, *supra* note 59. While some programs initiated all their own services, others developed creative links with existing services. Some programs began as information and referral services, some rely at least partially on existing home care services, and others have become certified home health agencies in their own right. Although many hospices do not offer inpatient services, others may offer day care, short-term respite care, or long-term inpatient services. Inpatient care is provided in freestanding hospice facilities, in hospitals (either in special units or by roving hospice teams that care for the patient wherever he or she is), or occasionally in nursing homes.

<sup>65</sup> John M. Hinton, *DYING*, Penguin Books, Middlesex, Eng. (1967) at 148; Judy Alsofrom, *The 'Hospice' Way of Dying—At Home With Friends and Family*, AM. MED. NEWS, Feb. 21, 1977, at 7-9.

<sup>66</sup> Cicely Saunders, *Hospice Care and Cancer*, mimeo. (1976) at 3; Claire F. Ryder and Diane M. Ross, *Terminal Care—Issues and Alternatives*, 92 PUB. HEALTH REP. 20 (1977):Alsofrom, *supra* note 65. at 7.

patient self-determination; many have rather explicit formal consent procedures.<sup>67</sup> Nonetheless, some patients do not realize that hospice admission amounts to a decision to forego many kinds of life-sustaining treatment (such as resuscitation, continuous cardiovascular monitoring, or chemotherapy).<sup>68</sup>

Hospices in this country, as in Great Britain, have deliberately tried to remain separate from traditional institutions.<sup>69</sup> When physically or administratively linked to them, hospices have taken steps to minimize the influence of the parent institutions. Hospice programs do have certain difficulties of their own. First, their institutional separateness can erect a hurdle to patients' reentering the traditional care setting should such a step become necessary or desirable.<sup>70</sup> Second, although

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<sup>67</sup> Patients and their families may be visited by a hospice worker prior to admission to a hospice program to discuss care needs as well as the program's philosophy and services. Although many hospices have no informed consent procedures or forms, others have rather explicit ones: For example, the consent form for the Washington Home Hospice in Washington, D.C., speaks of a "malignant tumor" for which "no further treatment is warranted," and the form for Hospice of Northern Virginia refers to care that is "palliative not curative" for disease with "life-limiting expectancy measured in weeks or months."

<sup>68</sup> Michael Van Scoy-Mosher, *An Oncologist's Case for No-Code Orders*, in A. Edward Doudera and J. Douglas Peters, eds., *LEGAL AND ETHICAL ASPECTS OF TREATING CRITICALLY AND TERMINALLY ILL PATIENTS*, AUPHA Press, Ann Arbor, Mich. (1982) at 16-17. That hospice programs provide symptom relief rather than cure is not always understood, even after signing consent forms that state this directly. Families of patients who died in the Washington Home Hospice were asked about the importance of several considerations in their decision to use the hospice. Almost 18% said the desire for cure was important. Marian Osterweis and Daphne S. Champagne, *The Washington Home Hospice: Case Study of an Inpatient Hospice*, report prepared for the Dreyfus Foundation, Washington (1982) at 19.

<sup>69</sup> In order to have home-like environments, open visiting, and individualized care, hospices have mostly been kept separate from other inpatient facilities. See, e.g., Edward J. Spillane, *An Analysis of Catholic-Sponsored Hospices*, 60 HOSP. PROGRESS 49 (March 1979); Sandol Stoddard, *THE HOSPICE MOVEMENT*, Vintage Books, New York (1978) at 229-30. The first inpatient facilities tended to be freestanding, a trend encouraged by the National Cancer Institute, which undertook the construction costs of four hospices in the late 1970s; see note 72 *infra*.

<sup>70</sup> In its experimental programs to reimburse for hospice care, Blue Cross has required that the hospice physician have admitting privileges at a local hospital and that home care hospices have agreements with hospitals in order to guard against the possibility of isolating the patient from the traditional care system. Neil Hollander and David Ehrenfried, *Reimbursing Hospice Care: A Blue Cross and Blue Shield Perspective*, 60 HOSP. PROGRESS 56, 76 (March 1979); Jack G. Coale, *The Hospice in the Health Care Continuum*, 5 QUALITY REV. BULL. 23 (1979); Glen W. Davidson, *Five Models for Hospice Care*, *id.* at 9.

hospices pride themselves on providing an alternative to the norms embodied in acute care hospitals, their own norms and philosophy of care may make it emotionally (even if not practically) difficult to offer their patients some alternatives. For example, the enthusiasm and personal involvement of care givers—at hospices as at other institutions—can make patients feel guilty if they reject recommendations, resist plans of care, fail to respond to treatment (that is, report symptom relief), or fail to conform to institutional norms (which is a general acceptance of death). In contrast to hospitals that sometimes pressure patients to continue aggressive therapy after it has ceased to be warranted, hospices risk pressuring patients to accept death too readily and to forego potentially life-sustaining therapies too quickly.<sup>71</sup>

Until recently hospices have not had a firm financial base, relying instead on volunteers (both lay and professional), charitable donations, occasional demonstration grants from Federal agencies, and (rarely) reimbursement by third-party payors on an experimental basis.<sup>72</sup> Federal legislation passed in September 1982 will enable hospice services to be reimbursed under Medicare.<sup>73</sup> With this precedent, other third-party payors are expected to follow suit. Unfortunately, the legislation's requirements and incentives are likely to promote substantial and unjustified inequities in access to hospice care.<sup>74</sup> For example, the requirement that, in order to qualify for this coverage, patients must be expected to die within six months, favors hospice care (which is of higher quality than

<sup>71</sup> Although this is a risk, there are no data to substantiate that this actually occurs. Peter Mudd, *High Ideals and Hard Cases: The Evolution of a Hospice*, 12 *HASTINGS CTR. REP.* 11 (April 1982); David J. Smith and Judith A. Granbois, *The American Way of Hospice*, *id.* at 8.

<sup>72</sup> The National Cancer Institute supported the construction, program development, and evaluation of four hospices beginning in 1974. Twenty-six additional hospices are currently being supported by the Health Care Financing Administration in conjunction with the Robert Wood Johnson and John A. Hartford Foundations in the largest demonstration program to date. Private insurers, especially the Blue Cross and Blue Shield Association, have also been experimenting with hospice reimbursement. *Hospice: Medicare's Newest Provider*, *PERSPECTIVE/WASH. REP. ON MED. & HEALTH*, Nov 29, 1982.

<sup>73</sup> Sec. 122 of the Tax Equity and Fiscal Responsibility Act of 1982, Pub. Law No. 97-248, codified as 42 U.S.C.A. §§ 1395c to 1395f (West 1982).

<sup>74</sup> The legislation restricts inpatient hospice care that "may be provided only on an intermittent, nonroutine, and occasional basis and may not be provided consecutively over longer than five days," Pub. Law No. 97-248, § (dd)(1)(G), and further requires "assurances satisfactory to the Secretary that the aggregate number of days of inpatient care... provided in any 12-month period... does not exceed 20 percent" of the total number of hospice days, Pub. Law No. 97-248, § (dd)(2)(A)(iii).

that available to other elderly patients under Medicare). Also, this reimbursement policy will favor cancer patients, since they include the largest group of patients for whom prognostication of death within a few months can be made with acceptable reliability. And the severe limits on inpatient care favor patients who will not need such care because they have substantial and supportive families and homes. Yet there are certainly other patients with comparable medical burdens or with no families who on grounds of equity have a stronger claim to public support.<sup>75</sup>

The present legislation also provides considerable financial incentive for hospices to admit many people into their programs, but for short periods of time, which might mean admission is delayed until it is too late for the person to receive the substantial benefits of the program. Existing barriers to patients reentering traditional care are compounded under the new legislation, since a patient may only go back and forth between hospice and traditional care twice, and each movement results in loss of the benefits remaining in that period. These real and potential limits on patient choice could seriously undermine self-determination.

Several other concerns have been raised as a result of the recent legislation. If hospice programs become readily available, especially as a desirable place to send "failed" patients, hospital physicians and social workers may alter the care of patients in order to qualify them for hospice admission.<sup>76</sup> Commentators also fear that hospices will become big business, as the nursing home industry did when its financial base became secure, and lose their special value for dying patients.<sup>77</sup> In addition, if hospices are more generally available, efforts in traditional institutions to improve care of the dying might be slowed or abandoned altogether. "Experts in dying" may be

<sup>75</sup> The history of hospices in England is of care directed toward middle class and the working poor. Hospices were seen as rescuing decent people from dying in workhouses. To have accepted parish relief (welfare) virtually disqualified an applicant for admission in the hospices established late in the nineteenth century. Carol Levine, *St. Luke's House: A Turn-of-the Century Hospice*, 12 *HASTINGS CTR. REP.* 12 (April 1982); Maureen A. Lally, *The Development of Terminal Care Facilities in England before the Notional Health Service*, Ph.D. Thesis, London School of Economics and Political Science, London (forthcoming).

<sup>76</sup> For example, they may undertake studies just to certify prognosis or to establish a tissue diagnosis. The issues discussed in the remainder of this section were addressed by several people at the National Hospice Organization Annual Meeting, Washington. Nov. 7-10, 1982. See, e.g., Allen Buchanan, Marian Osterweis, and Joanne Lynn, *Ethical Problems in Hospice*, Nov. 10, 1982.

<sup>77</sup> Smith and Granbois, *supra* note 71, at 9.

created, just as experts in caring for the elderly have been, and care could be further fragmented.<sup>78</sup> Moreover, if hospice care is found to be less expensive than traditional care for at least some discernable categories of patients,<sup>79</sup> pressure may build for certain groups of patients to be limited to hospices or to have reimbursement provided at a rate no greater than for hospice care, thereby effectively denying those patients the alternative of more aggressive treatment.

The present virtues of hospices may depend upon the special commitment of dedicated care givers who have pioneered in this field. Mechanisms for careful and sensitive review should be part of present planning efforts if the benefits now offered by hospices are to be maintained when these facilities become a larger feature of patient care. The needed review will be unusual in that it must aim to monitor quality of care in such important but unfamiliar terms as whether the patient's role in decisionmaking is being fostered and whether death is, as far as possible, appropriate to the particular person's situation.

**Summary of Changes Needed.** Some constraints that institutional settings place on patient choice cannot be eliminated and some probably should not be. In the Commission's view, however, the failure to inform patients about limits on the services offered and other biases of an institution is unacceptable because it undermines patient self-determination. The process of decisionmaking should be responsive to individual differences and respectful of all persons, even the severely ill or dependent. The decision about whether to provide aggressive care for a seriously ill, wheelchair-bound, and forgetful person should not depend principally upon the character of the institution where the individual happens to be a patient, especially when this criterion is not the result of patients' and families' choices based on their knowledge of the institution's overall biases and procedures. Rather, the decision should be governed by the principles and practices of good decisionmaking.

The impact of various institutional constraints on patient choice could be diminished by ensuring both that patients are aware of the policies and ethos of the institutions they choose and that health care institutions are more responsive to individual patient needs, particularly through improving decisionmaking practices within the institution. Policymakers in the private as well as the public sector who establish the

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<sup>78</sup> Expertise also may distance family and friends, who may feel less capable of correctly caring for the patients. See Mudd, *supra* note 71.

<sup>79</sup> Although the populations are not matched, it is instructive that one survey showed average costs of the last four weeks for a hospice patient to be \$1290 and for a traditional home/hospital patient to be \$3557. *AM. MED. NEWS*, Dec. 10, 1982, at 23.

financial and legal incentives and disincentives for institutions should be attentive to the effects of their choices on the actions of institutions in regard to patient decisionmaking.