

Chapter 7

Health Care

- Four Models of the Physician-Patient Relationship
- Legal and Ethical Myths About Informed Consent
- Physician-Assisted Suicide: Promoting Autonomy or Medicalizing Suicide?
- Reassessing the Reliability of Advance Directives
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- Physicians and Managed Care: Employees or Professionals?

The topic of health care ethics has in recent years produced some of the most discussed issues in all of professional ethics. These include physician-assisted suicide, heartbreaking cases involving the ineffectiveness of advance directives, and the serious lack of health care resources, to name a few. Such cases are often made especially difficult by conflicting intuitions, strong emotional reactions, guidelines provided by various religions, and the changing nature of the health care industry. The complexity of these problems highlights the need for precise and careful attention, and it is no wonder that many scholars have turned their attention toward these difficulties. The large number of ethical issues in the health care profession necessitates the inclusion of more articles here than in other chapters, though a number of topics still remain absent. The first four articles address some central ethical questions regarding the role of physicians in health care ethics. The next two articles are about nursing ethics, while the final two articles address issues in managed care.

A logical starting point in this area is the question of what the ideal physician-patient relationship should be like. Ezekiel J. Emanuel and Linda L. Emanuel outline four competing models: the paternalistic model, the informative model, the interpretive model, and the deliberative model. The paternalistic model defines the interaction in terms of limited patient involvement with medical decisions. The informative model places the responsibility of decision making squarely in the patient's lap, with the physician providing only factual information that will assist the patient in his deliberations. The interpretive model places the physician in a counseling role; she not only must provide facts but also must help the patient to clarify his values, which is thought to be necessary in order to decide what medical therapy to choose. The deliberative model assumes a friendship idea, and the physician and patient should consider together what course of action would be best. Although the authors suggest that under different clinical circumstances any one of the different models may be employed, the ideal relationship is the deliberative model.

A common discussion in the field of health care ethics surrounds the notion of informed consent. It is widely believed that patients are entitled to make their own decisions about their own health care. Such decisions, many believe, should be made under conditions of informed consent: the patient should agree (consent) to a particular treatment option only when she has been fully educated (informed) about the available options, including their prospects for success, side effects, and so on. From this central idea it seems to follow, first, that medical professionals are ethically obligated to fully inform their patients of all information relevant to their decision, and second, that decisions made by patients who are not, or cannot be, fully informed may be overridden for their own good—for reasons of paternalism, in other words. Alan Meisel and Mark Kuczewski explore in more detail this notion of informed consent, and they discuss some of the myths that have arisen as a result of misunderstanding its meaning and implications.

The concept of informed consent requires consideration of autonomy (discussed in various other places in this book) and the question of whether patients enhance their autonomy by making their own decisions. This can be a difficult question, especially in the context of "extreme" decisions patients may make, such as the decision to end one's own life. This bears on the topic of physician-assisted suicide, an issue with which the courts are now struggling and likely will be for some time. Advocates of physician-assisted suicide, those who think the practice is ethically permissible, argue that it promotes patient autonomy in two different ways: first, it puts the very personal decision to end one's own life into the hands of the patient, who after all is the "owner" of the life; and second, it curtails the unrestrained (and very expensive) use of medical technology at the end of life. Tania Salem challenges both of these claims, and in fact argues that just the

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opposite happens: patients lose autonomy. If allowed, suicide will be transformed into a medical event and assisted suicide will become assimilated by the medical establishment.

Another complex issue in health care concerns decisions that must be made on behalf of permanently incapacitated patients, those who are permanently comatose for example. Such patients are heavy burdens on surviving family members, emotionally and perhaps financially as well. Most parties—doctors, family members, friends—want to act in a way that respects the wishes of the patient, but it may be quite difficult to determine which action does this. The typical example is whether to remove a patient from life support or whether to continue with the treatment despite its almost certain futility. Case law makes things worse by requiring evidence of the patient's end-of-life intentions. In recent years part of the burden has been eased with the creation of advance directives. Advance directives allow a competent patient to specify, in advance, the sort of treatment he would want if and when he were to become incapacitated and unable to make a decision at that time. At first glance, advance directives seem like an effective way to respect the patient and determine the action that is most consistent with his autonomy; such directives seem equivalent to decisions made by a competent patient under conditions of informed consent. However, Thomas May takes issue with this reasoning and argues that advance directives are quite different in an ethically important sense. According to May, advance directives help others to identify an incapacitated patient's *preferences*, but they do not reflect the autonomy of the competent patient's wishes.

Issues in health care ethics have traditionally focused on the physician-patient relationship, and the topics described so far illustrate some principal examples of such issues. Ethics in the nursing profession have at times been neglected, but there is certainly reason to address this subject matter. Even though nurses lack the degree of autonomy typically held by other professionals, they can find themselves in any number of ethically difficult situations. They are employees, for example, and owe a duty of loyalty to their employers. Further, they are often instructed merely to assist the doctor, and so they are thought to owe a duty of allegiance to the doctor directly. We often feel, however, that nurses are also obligated to patients directly—that they owe the patients a certain duty of care which includes easing their suffering and taking steps to make them more comfortable. Thus, nurses have a lot of issues to balance. The article by Anthony Tuckett provides a framework for how a nurse ought to go about making ethically difficult decisions. The framework utilizes virtue ethics, but does so in a way that allows room for certain aspects of feminist ethics as well, and so “nursing as caring” might be an accurate way to capture the spirit of Tuckett's approach.

Lucie Ferrell picks up the idea of nursing as caring, and after investigating it in more detail applies it to the question of a nurse refusing an assignment. Although a nurse may only rarely be justified in refusing to perform a task assigned by a doctor or by hospital administration, there are probably some times when it is permissible or even required for a nurse to refuse. One might imagine examples of a doctor who is, say, intoxicated or otherwise incompetent ordering treatment for a patient that is clearly not in that patient's best interests. If this is correct, then at times a nurse's responsibilities to the patient override her responsibilities to the doctor. In addition to potentially conflicting responsibilities, Ferrell discusses some other aspects of health care practice that put considerable strain on nurses, including their relative lack of autonomy, their lack of authority, and their extended workloads which jeopardize the well-being of the numerous patients they are trying to serve. For example, a nurse may be required to care for more babies in a premature pediatric ward than she can handle safely. Ferrell argues that in such a case, a nurse has one of two options: she may take the assignment and risk harming one of the infants, or she may refuse the assignment and risk losing her position. Neither option

seems feasible. Ferrell explores a number of ways such a situation may be handled, which include using a broadly feminist "caring" approach and also a utilitarian approach. At the same time, a third topic has generated increased discussion over the past few years, namely the rising costs of health care. For example, the question of how health care should be delivered—whether, for example, through government programs, as it is in Canada, or perhaps through private businesses, as in the United States—has moved to the forefront. When thinking through such an issue, we tend to agree on the general aims of holding down costs and providing quality treatment to patients, and there is also wide (but not universal) agreement that physician autonomy, in terms of managing each case as the physician deems appropriate (without constraints imposed by insurance companies), is desirable. Attempts to achieve all these aims seem doomed. If we strive for high-quality treatment, for example, then costs will increase; if we hold costs down, then the quality of treatment will decline; if we allow a high degree of physician autonomy, then costs are likely to increase because of the numerous tests and other services that physicians are inclined to use in an effort to promote the well-being of their patients.

In his article, Mark H. Waymack discusses this problem of maintaining a balance among the various desirable aims of a health care system. It comes as no surprise that, on closer inspection of the way health insurance organizations (such as HMOs) happen to operate, certain conflicts of interest emerge. One of the more interesting conflicts is where the welfare of the patient is at stake and where a physician is pressured by the insurance organization, by means of financial incentives, to withhold certain health care services. Many critics argue that such a conflict of interest is unethical because it violates the moral trust a patient places in a physician. In response to this objection, Waymack argues that while such a conflict exists, it is not one that indicates a moral problem. He argues that the objection loses its bite when we understand that consumers purchase the coverage of HMOs with the knowledge that withholding expensive or unnecessary health care services will contain costs. It is, according to Waymack, a choice made by the consumer, and so the consumer is not in a position to come back later and complain about the coverage (or lack thereof) as it relates to a particular medical situation.

In her essay, Kate T. Christensen describes the latest way this problem has been addressed in terms of the creation of for-profit managed care organizations (MCOs) and not-for-profit MCOs. She points out that both kinds of organizations attempt to solve the problems by making a physician an employee of the MCO and then using positive financial incentives to encourage patient welfare and negative financial incentives to discourage overuse of the health plan's resources. However, she argues that only the not-for-profit organizations can maintain a balance that minimizes the problematic consequences mentioned earlier.

Four Models of the Physician-Patient Relationship

EZEKIEL J. EMANUEL AND LINDA L. EMANUEL

DURING THE LAST TWO DECADES OR SO, there has been a struggle over the patient's role in medical decision making that is often characterized as a conflict between autonomy and health, between the values of the patient and the values of the physician. Seeking to curtail physician dominance, many have advocated an ideal of greater patient control. Others question this ideal because it fails to acknowledge the potentially imbalanced nature of this interaction when one party is sick and searching for security, and when judgments entail the interpretation of technical information. Still others are trying to delineate a more mutual relationship. This struggle shapes the expectations of physicians and patients as well as the ethical and legal standards for the physician's duties, informed consent, and medical malpractice. This struggle forces us to ask, What should be the ideal physician-patient relationship?

We shall outline four models of the physician-patient interaction, emphasizing the different understandings of (1) the goals of the physician-patient interaction, (2) the physician's obligations, (3) the role of patient values, and (4) the conception of patient autonomy. To elaborate the abstract description of these four models, we shall indicate the types of response the models might suggest in a clinical situation. Third, we shall also indicate how these models inform the current debate about the ideal physician-patient relationship. Finally, we shall evaluate these models and recommend one as the preferred model.

As outlined, the models are Weberian ideal types. They may not describe any particular physician-patient interactions but they highlight, free from complicating details, different visions of the essential characteristics of the physician-patient interaction. Consequently, they do not embody

minimum ethical or legal standards, but rather constitute regulative ideals that are "higher than the law" but not "above the law."

The Paternalistic Model

First is the *paternalistic* model, sometimes called the parental or priestly model. In this model, the physician-patient interaction ensures that patients receive the interventions that best promote their health and well-being. To this end, physicians use their skills to determine the patient's medical condition and his or her stage in the disease process and to identify the medical tests and treatments most likely to restore the patient's health or ameliorate pain. Then the physician presents the patient with selected information that will encourage the patient to consent to the intervention the physician considers best. At the extreme, the physician authoritatively informs the patient when the intervention will be initiated.

The paternalistic model assumes that there are shared objective criteria for determining what is best. Hence the physician can discern what is in the patient's best interest with limited patient participation. Ultimately, it is assumed that the patient will be thankful for decisions made by the physician even if he or she would not agree to them at the time. In the tension between the patient's autonomy and well-being, between choice and health, the paternalistic physician's main emphasis is toward the latter.

In the paternalistic model, the physician acts as the patient's guardian, articulating and implementing what is best for the patient. As such, the physician has obligations, including that of placing the patient's interest above his or her own and soliciting the views of others when lacking

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adequate knowledge. The conception of patient autonomy is patient assent, either at the time or later, to the physician's determinations of what is best.

The Informative Model

Second is the *informative* model, sometimes called the scientific, engineering, or consumer model. In this model, the objective of the physician-patient interaction is for the physician to provide the patient with all relevant information, for the patient to select the medical interventions he or she wants, and for the physician to execute the selected interventions. To this end, the physician informs the patient of his or her disease state, the nature of possible diagnostic and therapeutic interventions, the nature and probability of risks and benefits associated with the interventions, and any uncertainties of knowledge. At the extreme, patients could come to know all medical information relevant to their disease and available interventions and select the interventions that best realize their values.

The informative model assumes a fairly clear distinction between facts and values. The patient's values are well defined and known; what the patient lacks is facts. It is the physician's obligation to provide all the available facts, and the patient's values then determine what treatments are to be given. There is no role for the physician's values, the physician's understanding of the patient's values, or his or her judgment of the worth of the patient's values. In the informative model, the physician is a purveyor of technical expertise, providing the patient with the means to exercise control. As technical experts, physicians have important obligations to provide truthful information, to maintain competence in their area of expertise, and to consult others when their knowledge or skills are lacking. The conception of patient autonomy is patient control over medical decision making.

The Interpretive Model

The third model is the *interpretive* model. The aim of the physician-patient interaction is to elucidate the patient's values and what he or she actually wants, and to help the patient select the available medical interventions that realize these values.

Like the informative physician, the interpretive physician provides the patient with information on the nature of the condition and the risks and benefits of possible interventions. Beyond this, however, the interpretive physician assists the patient in elucidating and articulating his or her values and in determining what medical interventions best realize the specified values, thus helping to interpret the patient's values for the patient.

According to the interpretive model, the patient's values are not necessarily fixed and known to the patient. They are often inchoate, and the patient may only partially understand them; they may conflict when applied to specific situations. Consequently, the physician working with the patient must elucidate and make coherent these values. To do this, the physician works with the patient to reconstruct the patient's goals and aspirations, commitments and character. At the extreme, the physician must conceive of the patient's life as a narrative whole, and from this specify the patient's values and their priorities. Then the physician determines which tests and treatments best realize these values. Importantly, the physician does not dictate to the patient; it is the patient who ultimately decides which values and course of action best fit who he or she is. Neither is the physician judging the patient's values; he or she helps the patient to understand and use them in the medical situation.

In the interpretive model, the physician is a counselor, analogous to a cabinet minister's advisory role to a head of state, supplying relevant information, helping to elucidate values, and suggesting what medical interventions realize these values. Thus the physician's obligations include those enumerated in the informative model but also require engaging the patient in a joint process of understanding. Accordingly, the conception of patient autonomy is self-understanding; the patient comes to know more clearly who he or she is and how the various medical options bear on his or her identity.

The Deliberative Model

Fourth is the *deliberative* model. The aim of the physician-patient interaction is to help the patient determine and choose the best health-related values that can be realized in the clinical situation. To this end, the physician must delineate information

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on the patient's clinical situation and then help elucidate the types of values embodied in the available options. The physician's objectives include suggesting why certain health-related values are more worthy and should be aspired to. At the extreme, the physician and patient engage in deliberation about what kind of health-related values the patient could and ultimately should pursue. The physician discusses only health-related values, that is, values that affect or are affected by the patient's disease and treatments; he or she recognizes that many elements of morality are unrelated to the patient's disease or treatment and beyond the scope of their professional relationship. Further, the physician aims at no more than moral persuasion; ultimately, coercion is avoided, and the patient must define his or her life and select the ordering of values to be espoused. By engaging in moral deliberation, the physician and patient judge the worthiness and importance of the health-related values.

In the deliberative model, the physician acts as a teacher or friend, engaging the patient in dialogue on what course of action would be best. Not only does the physician indicate what the patient could do, but, knowing the patient and wishing what is best, the physician indicates what the patient should do—what decision regarding medical therapy would be admirable. The conception of patient autonomy is moral self-development; the patient is empowered not simply to follow unexamined preferences or examined values, but to consider, through dialogue, alternative health-related values, their worthiness, and their implications for treatment.

Comparing the Four Models

Importantly, all models have a role for patient autonomy; a main factor that differentiates the models is their particular conceptions of patient autonomy. Therefore, no single model can be endorsed because it alone promotes patient autonomy. Instead the models must be compared and evaluated, at least in part, by evaluating the adequacy of their particular conceptions of patient autonomy.

The four models are not exhaustive. At a minimum, there might be added a fifth: the *instrumental* model. In this model, the patient's values are irrelevant; the physician aims for some goal

independent of the patient, such as the good of society or the furtherance of scientific knowledge. The Tuskegee syphilis experiment and the Willowbrook hepatitis study are examples of this model. As the moral condemnation of these cases reveals, this model is not an ideal, but an aberration. Thus we have not elaborated it herein.

A Clinical Case

To make tangible these abstract descriptions and to crystallize essential differences among the models, we will illustrate the responses they suggest in a clinical situation, that of a 43-year-old premenopausal woman who has recently discovered a breast mass. Surgery reveals a 3.5-cm ductal carcinoma with no lymph node involvement that is estrogen receptor positive. Chest roentgenogram, bone scan, and liver function tests reveal no evidence of metastatic disease. The patient was recently divorced and has gone back to work as a legal aide to support herself. What should the physician say to this patient?

In the paternalistic model a physician might say, "There are two alternative therapies to protect against recurrence of cancer in your breast: mastectomy or radiation. We now know that the survival with lumpectomy combined with radiation therapy is equal to that with mastectomy. Because lumpectomy and radiation offers the best survival and the best cosmetic result, it is to be preferred. I have asked the radiation therapist to come and discuss radiation treatment with you. We also need to protect you against the spread of the cancer to other parts of your body. Even though the chance of recurrence is low, you are young, and we should not leave any therapeutic possibilities untried. Recent studies involving chemotherapy suggest improvements in survival without recurrence of breast cancer. Indeed, the National Cancer Institute (NCI) recommends chemotherapy for women with your type of breast cancer. Chemotherapy has side effects. Nevertheless, a few months of hardship now are worth the potential added years of life without cancer."

In the informative model, a physician might say, "With node-negative breast cancer there are two issues before you: local control and systemic control. For local control, the options are mastectomy or lumpectomy with or without radiation. From many studies we know that mastectomy and

lumpectomy with radiation result in identical overall survival, about 80 percent 10-year survival. Lumpectomy without radiation results in a 30 percent to 40 percent chance of tumor recurrence in the breast. The second issue relates to systemic control. We know that chemotherapy prolongs survival for premenopausal women who have axillary nodes involved with tumor. The role for women with node-negative breast cancer is less clear. Individual studies suggest that chemotherapy is of no benefit in terms of improving overall survival, but a comprehensive review of all studies suggests that there is a survival benefit. Several years ago, the NCI suggested that for women like yourself, chemotherapy can have a positive therapeutic impact. Finally, let me inform you that there are clinical trials, for which you are eligible, to evaluate the benefits of chemotherapy for patients with node-negative breast cancer. I can enroll you in a study if you want. I will be happy to give you any further information you feel you need."

The interpretive physician might outline much of the same information as the informative physician, then engage in discussion to elucidate the patient's wishes, and conclude, "It sounds to me as if you have conflicting wishes. Understandably, you seem uncertain how to balance the demands required for receiving additional treatment, rejuvenating your personal affairs, and maintaining your psychological equilibrium. Let me try to express a perspective that fits your position. Fighting your cancer is important, but it must leave you with a healthy self-image and quality time outside the hospital. This view seems compatible with undergoing radiation therapy but not chemotherapy. A lumpectomy with radiation maximizes your chance of surviving while preserving your breast. Radiotherapy fights your breast cancer without disfigurement. Conversely, chemotherapy would prolong the duration of therapy by many months. Further, the benefits of chemotherapy in terms of survival are smaller and more controversial. Given the recent changes in your life, you have too many new preoccupations to undergo months of chemotherapy for a questionable benefit. Do I understand you? We can talk again in a few days."

The deliberative physician might begin by outlining the same factual information, then engage in a conversation to elucidate the patient's values,

but continue, "It seems clear that you should undergo radiation therapy. It offers maximal survival with minimal risk, disfigurement, and disruption of your life. The issue of chemotherapy is different, fraught with conflicting data. Balancing all the options, I think the best one for you is to enter a trial that is investigating the potential benefit of chemotherapy for women with node-negative breast cancer. First, it ensures that you receive excellent medical care. At this point, we do not know which therapy maximizes survival. In a clinical study the schedule of follow-up visits, tests, and decisions is specified by leading breast cancer experts to ensure that all the women receive care that is the best available anywhere. A second reason to participate in a trial is altruistic; it allows you to contribute something to women with breast cancer in the future who will face difficult choices. Over decades, thousands of women have participated in studies that inform our current treatment practices. Without those women, and the knowledge they made possible, we would probably still be giving you and all other women with breast cancer mastectomies. By enrolling in a trial you participate in a tradition in which women of one generation receive the highest standard of care available but also enhance the care of women in future generations because medicine has learned something about which interventions are better. I must tell you that I am not involved in the study; if you elect to enroll in this trial, you will initially see another breast cancer expert to plan your therapy. I have sought to explain our current knowledge and offer my recommendation so you can make the best possible decision."

Lacking the normal interchange with patients, these statements may seem contrived, even caricatures. Nevertheless, they highlight the essence of each model and suggest how the objectives and assumptions of each inform a physician's approach to his or her patients. Similar statements can be imagined for other clinical situations such as an obstetrician discussing prenatal testing or a cardiologist discussing cholesterol-reducing interventions.

The Current Debate and the Four Models

In recent decades there has been a call for greater patient autonomy or, as some have called it,

"patient sovereignty," conceived as patient *choice* and *control* over medical decisions. This shift toward the informative model is embodied in the adoption of business terms for medicine, as when physicians are described as health care providers and patients as consumers. It can also be found in the propagation of patient rights statements, in the promotion of living-will laws, and in rules regarding human experimentation. For instance, the opening sentences of one law state: "The Rights of the Terminally Ill Act authorizes an adult person to *control* decisions regarding administration of life-sustaining treatment. The Act merely provides one way by which a terminally-ill patient's *desires* regarding the use of life-sustaining procedures can be legally implemented" (emphasis added).¹ Indeed, living-will laws do not require or encourage patients to discuss the issue of terminating care with their physicians before signing such documents. Similarly, decisions in "right-to-die" cases emphasize patient control over medical decisions. As one court put it:

The right to refuse medical treatment is basic and fundamental. . . . Its exercise requires no one's approval. . . . [T]he *controlling decision belongs to a competent informed patient*. . . . It is not a medical decision for her physicians to make. . . . *It is a moral and philosophical decision that, being a competent adult, is [the patient's] alone.*² (emphasis added)

Probably the most forceful endorsement of the informative model as the ideal inheres in informed consent standards. Prior to the 1970s, the standard for informed consent was "physician based." Since 1972 and the *Canterbury* case, however, the emphasis has been on a "patient-oriented" standard of informed consent in which the physician has a "duty" to provide appropriate medical facts to empower the patient to use his or her values to determine what interventions should be implemented.

True consent to what happens to one's self is the informed exercise of a choice, and that entails an opportunity to evaluate knowledge-

ably the options available and the risks attendant upon each. . . . *[I]t is the prerogative of the patient, not the physician, to determine for himself the direction in which his interests seem to lie.* To enable the patient to chart his course understandably, some familiarity with the therapeutic alternatives and their hazards becomes essential.³ (emphasis added)

Shared Decision Making

Despite its dominance, many have found the informative model somewhat "arid."⁴ The President's Commission and others contend that the ideal relationship does not vest moral authority and medical decision-making power exclusively in the patient but must be a process of shared decision making constructed around "mutual participation and respect."⁵ The President's Commission argues that the physician's role is "to help the patient understand the medical situation and available courses of action, and the patient conveys his or her concerns and wishes."⁶ Brock and Wartman⁷ stress this fact-value "division of labor"—having the physician provide information while the patient makes value decisions—by describing "shared decision making" as a collaborative process

in which both physicians and patients make active and essential contributions. Physicians bring their medical training, knowledge, and expertise—including an understanding of the available treatment alternatives—to the diagnosis and management of patients' conditions. Patients bring knowledge of their own subjective aims and values, through which risks and benefits of various treatment options can be evaluated. With this approach, selecting the

³*Canterbury v. Spence*, 464 F2d 772 (D.C. Cir 1972).

⁴President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. *Making Health Care Decisions*. Washington, D.C.; U.S. Government Printing Office; 1982.

⁵*Ibid*; Brock D. The ideal of shared decision-making between physicians and patients. *Kennedy Institute J Ethics*. 1991; 1:28-47.

⁶President's Commission, op. cit.

⁷Brock DW, Wartman SA. When competent patients make irrational choices. *N Engl J Med*. 1990; 322:1595-1599.

¹Uniform Rights of the Terminally Ill Act. In: *Handbook of Living Will Laws*. New York, NY: Society for the Right to Die; 1987:135-147.

²*Bouvia v. Superior Court*, 225 Cal Rptr 297 (1986).

best treatment for a particular patient requires the contribution of both parties.

Similarly, in discussing ideal medical decision making, Eddy⁸ argues for this fact-value division of labor between the physician and patient as the ideal:

It is important to separate the decision process into these two steps. . . . The first step is a question of facts. The anchor is empirical evidence. . . . [T]he second step is a question not of facts but of personal values or preferences. The thought process is not analytic but personal and subjective. . . . [It] is the patient's preferences that should determine the decision. . . . Ideally, you and I [the physicians] are not in the picture. What matters is what Mrs. Smith thinks.

This view of shared decision making seems to vest the medical decision-making authority with the patient while relegating physicians to technicians "transmitting medical information and using their technical skills as the patient directs."⁹ Thus, while the advocates of "shared decision making" may aspire toward a mutual dialogue between physician and patient, the substantive view informing their ideal reembodies the informative model under a different label.

Other commentators have articulated more mutual models of the physician-patient interaction. Prominent among these efforts is Katz's¹⁰ *The Silent World of the Doctor and Patient*. Relying on a Freudian view in which self-knowledge and self-determination are inherently limited because of unconscious influences, Katz views dialogue as a mechanism for greater self-understanding of one's values and objectives. According to Katz, this view places a duty on physicians and patients to reflect and communicate so that patients can gain a greater self-understanding and self-determination. Katz's insight is also available on grounds other than Freudian psychological theory and is consistent with the interpretive model.

⁸ Eddy DM. Anatomy of a decision. *JAMA*. 1990; 263:441-443.

⁹ President's Commission, op. cit.

¹⁰ Katz J. *The Silent World of Doctor and Patient*. New York, NY: Free Press; 1984.

Objections to the Paternalistic Model

It is widely recognized that the paternalistic model is justified during emergencies when the time taken to obtain patient consent might irreversibly harm the patient. Beyond such limited circumstances, however, it is no longer tenable to assume that the physician and patient espouse similar values and views of what constitutes a benefit. Consequently, even physicians rarely advocate the paternalistic model as an ideal for routine physician-patient interactions.

Objections to the Informative Model

The informative model seems both descriptively and prescriptively inaccurate. First, this model seems to have no place for essential qualities of the ideal physician-patient relationship. The informative physician cares for the patient in the sense of competently implementing the patient's selected interventions. However, the informative physician lacks a caring approach that requires understanding what the patient values or should value and how his or her illness impinges on these values. Patients seem to expect their physician to have a caring approach; they deem a technically proficient but detached physician as deficient, and properly condemned. Further, the informative physician is proscribed from giving a recommendation for fear of imposing his or her will on the patient and thereby competing for the decision-making control that has been given to the patient. Yet, if one of the essential qualities of the ideal physician is the ability to assimilate medical facts, prior experience of similar situations, and intimate knowledge of the patient's view into a recommendation designed for the patient's specific medical and personal condition, then the informative physician cannot be ideal.

Second, in the informative model, the ideal physician is a highly trained subspecialist who provides detailed factual information and competently implements the patient's preferred medical intervention. Hence, the informative model perpetuates and accentuates the trend toward specialization and impersonalization within the medical profession.

Most importantly, the informative model's conception of patient autonomy seems philosophically untenable. The informative model presupposes

that persons possess known and fixed values, but this is inaccurate. People are often uncertain about what they actually want. Further, unlike animals, people have what philosophers call "second-order desires,"¹¹ that is, the capacity to reflect on their desires and to revise their own desires and preferences. In fact, freedom of the will and autonomy inhere in having "second-order desires" and being able to change our preferences and modify our identities. Self-reflection and the capacity to change what we want often require a "process" of moral deliberation in which we assess the value of what we want. And this is a process that occurs with other people who know us well and can articulate a vision of who we ought to be that we can assent to. Even though changes in health or implementation of alternative interventions can have profound effects on what we desire and how we realize our desires, self-reflection and deliberation play no essential role in the informative physician-patient interaction. The informative model's conception of autonomy is incompatible with a vision of autonomy that incorporates second-order desires.

Objections to the Interpretive Model

The interpretive model rectifies this deficiency by recognizing that persons have second-order desires and dynamic value structures and placing the elucidation of values in the context of the patient's medical condition at the center of the physician-patient interaction. Nevertheless, there are objections to the interpretive model.

Technical specialization militates against physicians cultivating the skills necessary to the interpretive model. With limited interpretive talents and limited time, physicians may unwittingly impose their own values under the guise of articulating the patient's values. And patients, overwhelmed by their medical condition and uncertain of their own views, may too easily accept this imposition. Such circumstances may push the interpretive model toward the paternalistic model in actual practice.

Further, autonomy viewed as self-understanding excludes evaluative judgment of the patient's

values or attempts to persuade the patient to adopt other values. This constrains the guidance and recommendations the physician can offer. Yet in practice, especially in preventive medicine and risk-reduction interventions, physicians often attempt to persuade patients to adopt particular health-related values. Physicians frequently urge patients with high cholesterol levels who smoke to change their dietary habits, quit smoking, and begin exercise programs before initiating drug therapy. The justification given for these changes is that patients should value their health more than they do. Similarly, physicians are encouraged to persuade their human immunodeficiency virus (HIV)-infected patients who might be engaging in unsafe sexual practices either to abstain or, realistically, to adopt "safer sex" practices. Such appeals are not made to promote the HIV-infected patient's own health, but are grounded on an appeal for the patient to assume responsibility for the good of others. Consequently, by excluding evaluative judgments, the interpretive model seems to characterize inaccurately ideal physician-patient interactions.

Objections to the Deliberative Model

The fundamental objections to the deliberative model focus on whether it is proper for physicians to judge patients' values and promote particular health-related values. First, physicians do not possess privileged knowledge of the priority of health-related values relative to other values. Indeed, since ours is a pluralistic society in which people espouse incommensurable values, it is likely that a physician's values and view of which values are higher will conflict with those of other physicians and those of his or her patients.

Second, the nature of the moral deliberation between physician and patient, the physician's recommended interventions, and the actual treatments used will depend on the values of the particular physician treating the patient. However, recommendations and care provided to patients should not depend on the physician's judgment of the worthiness of the patient's values or on the physician's particular values. As one bioethicist put it:

The hand is broken; the physician can repair the hand; therefore the physician must repair

¹¹Frankfurt H. Freedom of the will and the concept of a person. *J. Philosophy*. 1971; 68:5-20.

the hand—as well as possible—without regard to personal values that might lead the physician to think ill of the patient or of the patient's values. . . . [A]t the level of clinical practice, medicine should be value-free in the sense that the personal values of the physician should not distort the making of medical decisions.¹²

Third, it may be argued that the deliberative model misconstrues the purpose of the physician-patient interaction. Patients see their physicians to receive health care, not to engage in moral deliberation or to revise their values. Finally, like the interpretive model, the deliberative model may easily metamorphose into unintended paternalism, the very practice that generated the public debate over proper physician-patient interaction.

The Preferred Model and the Practical Implications

Clearly, under different clinical circumstances, different models may be appropriate. Indeed, at different times, all four models may justifiably guide physicians and patients. Nevertheless, it is important to specify one model as the shared, paradigmatic reference; exceptions to use other models would not be automatically condemned, but would require justification based on the circumstances of a particular situation. Thus, it is widely agreed that in an emergency where delays in treatment to obtain informed consent might irreversibly harm the patient, the paternalistic model correctly guides physician-patient interactions. Conversely, for patients who have clear but conflicting values, the interpretive model is probably justified. For instance, a 65-year-old woman who has been treated for acute leukemia may have clearly decided against reinduction chemotherapy if she relapses. Several months before the anticipated birth of her first grandchild, the patient relapses. The patient becomes torn about whether to endure the risks of reinduction chemotherapy in order to live to see her first grandchild or whether to refuse therapy, resigning herself to not seeing her grandchild. In such cases, the physician may justifiably adopt the interpretive approach. In

other circumstances, where there is only a one-time physician-patient interaction without an ongoing relationship in which the patient's values can be elucidated and compared with ideals, such as in a walk-in center, the informative model may be justified.

Descriptively and prescriptively, we claim that the ideal physician-patient relationship is the deliberative model. We will adduce six points to justify this claim. First, the deliberative model more nearly embodies our ideal of autonomy. It is an oversimplification and distortion of the Western tradition to view respecting autonomy as simply permitting a person to select, unrestricted by coercion, ignorance, physical interference, and the like, his or her preferred course of action from a comprehensive list of available options. Freedom and control over medical decisions alone do not constitute patient autonomy. Autonomy requires that individuals critically assess their own values and preferences; determine whether they are desirable; affirm, upon reflection, these values as ones that should justify their actions; and then be free to initiate action to realize the values. The process of deliberation integral to the deliberative model is essential for realizing patient autonomy understood in this way.

Second, our society's image of an ideal physician is not limited to one who knows and communicates to the patient relevant factual information and competently implements medical interventions. The ideal physician—often embodied in literature, art, and popular culture—is a caring physician who integrates the information and relevant values to make a recommendation and, through discussion, attempts to persuade the patient to accept this recommendation as the intervention that best promotes his or her overall well-being. Thus, we expect the best physicians to engage their patients in evaluative discussions of health issues and related values. The physician's discussion does not invoke values that are unrelated or tangentially related to the patient's illness and potential therapies. Importantly, these efforts are not restricted to situations in which patients might make "irrational and harmful" choices¹³ but extend to all health care decisions.

¹²Gorovitz S. *Doctors' Dilemmas: Moral Conflict and Medical Care*. New York, NY: Oxford University Press Inc; 1982:chap 6.

¹³Brock, DW, Wartman SA, op. cit.

Third, the deliberative model is not a disguised form of paternalism. Previously there may have been category mistakes in which instances of the deliberative model have been erroneously identified as physician paternalism. And no doubt, in practice, the deliberative physician may occasionally lapse into paternalism. However, like the ideal teacher, the deliberative physician attempts to persuade the patient of the worthiness of certain values, not to impose those values paternalistically; the physician's aim is not to subject the patient to his or her will, but to persuade the patient of a course of action as desirable. In the *Laws*, Plato¹⁴ characterizes this fundamental distinction between persuasion and imposition for medical practice that distinguishes the deliberative from the paternalistic model:

A physician to slaves never gives his patient any account of his illness. . . . [T]he physician offers some orders gleaned from experience with an air of infallible knowledge, in the brusque fashion of a dictator. . . . The free physician, who usually cares for free men, treats their disease first by thoroughly discussing with the patient and his friends his ailment. This way he learns something from the sufferer and simultaneously instructs him. Then the physician does not give his medications until he has persuaded the patient; the physician aims at complete restoration of health by persuading the patient to comply with his therapy.

Fourth, physician values are relevant to patients and do inform their choice of a physician. When a pregnant woman chooses an obstetrician who does not routinely perform a battery of prenatal tests or, alternatively, one who strongly favors them; and when patients seek an aggressive cardiologist who favors procedural interventions or one who concentrates therapy on dietary changes, stress reduction, and life-style modifications, they are, consciously or not, selecting a physician based on the values that guide their medical decisions. And, when disagreements between physicians and patients arise, there are discussions over which values are more important and should be realized in

medical care. Occasionally, when such disagreements undermine the physician-patient relationship and a caring attitude, a patient's care is transferred to another physician. Indeed, in the informative model the grounds for transferring care to a new physician is either the physician's ignorance or incompetence. But patients seem to switch physicians because they do not "like" a particular physician or that physician's attitude or approach.

Fifth, we seem to believe that physicians should not only help fit therapies to the patients' elucidated values, but should also promote health-related values. As noted, we expect physicians to promote certain values, such as "safer sex" for patients with HIV or abstaining from or limiting alcohol use. Similarly, patients are willing to adjust their values and actions to be more compatible with health-promoting values. This is in the nature of seeking a caring medical recommendation.

Finally, it may well be that many physicians currently lack the training and capacity to articulate the values underlying their recommendations and persuade patients that these values are worthy. But, in part, this deficiency is a consequence of the tendencies toward specialization and the avoidance of discussions of values by physicians that are perpetuated and justified by the dominant informative model. Therefore, if the deliberative model seems most appropriate, then we need to implement changes in medical care and education to encourage a more caring approach. We must stress understanding rather than mere provisions of factual information in keeping with the legal standards of informed consent and medical malpractice; we must educate physicians not just to spend more time in physician-patient communication but to elucidate and articulate the values underlying their medical care decisions, including routine ones; we must shift the publicly assumed conception of patient autonomy that shapes both the physician's and the patient's expectations from patient control to moral development. Most important, we must recognize that developing a deliberative physician-patient relationship requires a considerable amount of time. We must develop a health care financing system that properly reimburses—rather than penalizes—physicians for taking the time to discuss values with their patients.

¹⁴Plato; Hamilton E, Cairns H, eds; Emanuel EJ, trans. *Plato: The Collected Dialogues*. Princeton, NJ: Princeton University Press; 1961:720 c-e.

Conclusion

Over the last few decades, the discourse regarding the physician-patient relationship has focused on two extremes: autonomy and paternalism. Many have attacked physicians as paternalistic, urging the empowerment of patients to control their own care. This view, the informative model, has become dominant in bioethics and legal standards. This model embodies a defective conception of patient autonomy, and it reduces the physician's role to that of a technologist. The essence of doctoring is a fabric of knowledge, understanding, teaching, and action, in which the caring physician integrates the patient's medical condition and health-related values, makes a recommendation on

the appropriate course of action, and tries to persuade the patient of the worthiness of this approach and the values it realizes. The physician with a caring attitude is the ideal embodied in the deliberative model, the ideal that should inform laws and policies that regulate the physician-patient interaction.

Finally, it may be worth noting that the four models outlined herein are not limited to the medical realm; they may inform the public conception of other professional interactions as well. We suggest that the ideal relationships between lawyer and client, religious mentor and laity, and educator and student are well described by the deliberative model, at least in some of their essential aspects.

Discussion Questions

1. What are the main distinguishing features of each of the four models of the physician-patient relationship?
2. According to the authors, what should be the ideal physician-patient relationship? To what extent do you agree with their assessment? How does moral theory support your claim?
3. How might one use a moral theory (or theories) to argue against the authors' conclusion? Is there an adequate response to this protest?
4. If you had to choose one of the models to define your relationship with your physician, which model would it be? In light of the authors' claims and your assessment of them, do you think that relationship should change?
5. Which type of professional-client relationship described by Paul Faber (Chapter 4) would the authors think is ethically appropriate for the physician-patient relationship specifically?

Legal and Ethical Myths About Informed Consent

ALAN MEISEL AND MARK KUCZEWSKI

INFORMED CONSENT is a foundational concept of medical ethics. Since its enunciation almost 4 decades ago, it has engendered, and continues to

engender, a great deal of debate and opposition from practicing physicians. We believe that much of the negative reaction to informed consent stems

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from some fundamental misunderstandings about what informed consent requires. This article discusses and refutes several myths about informed consent that have acquired some currency among physicians.

Informed consent has been at the heart of medical ethics in the modern era. In fact, one could argue that the emergence of informed consent is the hallmark of the modern era in medical ethics. Informed consent first guided the evolution of the ethics of biomedical research that arose from the horrors of Nazi medical experimentation. Informed consent came of age in clinical medicine only a few years later.

Moreover, the idea of informed consent has provided the foundation for an evolving ethical and legal consensus in perhaps the best-known area of medical ethics, forgoing life-sustaining treatment. Yet, even though informed consent seems to be well established, strong reactions have continued to surround it.

The purpose of requiring informed consent is to promote autonomy of the individual in medical decision making. The modern concept of autonomy has its philosophical roots in 17th-century political philosophy and its legal roots in even older English legal principles that American democracy has inherited from English law. However, patient autonomy lay dormant in the physician-patient relationship until the beginning of the present century and only developed into fullblown form in the last 4 decades.

The origins of informed consent in medicine are somewhat murky. Its antecedents can be traced to early 20th-century American law. The requirement of *simple* consent to medical treatment was well established in the United States before World War II, and the Nuremberg trials of Nazi physicians made this a requirement of international law. But the *elaboration* of the requirement of consent to medical treatment and its transformation into informed consent, according to Katz,¹ one of the leading authorities on informed consent, "surfaced, seemingly out of nowhere." In attempting to ascertain the origins of the phrase "informed consent," first used in a 1957 California case, he

could unearth no antecedent cases. The entire informed consent paragraph (in the first informed consent case) was adopted verbatim, and without attribution, from the amicus curiae brief submitted by the American College of Surgeons. It is an ironic twist of history that informed consent was dreamed up by lawyers in the employ of physicians.

Some physicians are still mistrustful of the doctrine of informed consent. It has been condemned in the medical literature as a myth and as bad medicine.² It has been the subject of numerous parodies intended to illustrate the absurdities to which it can be carried.³ Most of these attacks are based on the idea that there is a fundamental incompatibility between the patient autonomy that informed consent is intended to promote and physician responsibility for a patient's well-being and on the fear that well-being will be severely compromised.

Recently, more subtle attacks on informed consent have come from well-intentioned medical ethicists. For instance, Veatch⁴ argues that modern medicine has too many treatments available for many conditions for a physician to be able to disclose relevant information about all of them—as would need to be done if the letter of the law were to be observed—and therefore, physicians should disclose only information about those treatments that are consistent with their own values. Veatch somewhat overoptimistically advocates delivery-of-care arrangements that pair physicians and patients who have similar values and treatment dispositions as the solution to this problem.

We think that these critics of informed consent exhibit a variety of misunderstandings. Rather than confuse matters further by analyzing their arguments point by point, we first outline the 2 major approaches to informed consent and the ideals behind them. Then, we examine the most common misunderstandings of informed consent, ie, myths, and suggest more productive conceptions.

¹Katz J. Judges, physicians, and patients. In: *The Silent World of Physician and Patient*. New York, NY: The Free Press; 1984, p. 60.

²Katz RL. Informed consent: Is it bad medicine? *West J Med*. 1977; 126:426-428.

³Meisel A. The legal consensus about forgoing life-sustaining treatment: Its status and its prospects. *Kennedy Inst Ethics J*. 1992; 2:309-345.

⁴Veatch RM. Abandoning informed consent. *Hastings Cent Rep*. 1995; 25:5-12.

Approaches to Informed Consent: Rights vs. Shared Process

Patient autonomy began to grow as an antidote to physician paternalism—the supposed tendency of physicians to assume almost complete responsibility for determining what treatment patients would have—and in recognition of the fact that what treatment patients should have is a normative as well as a scientific determination. Its function in preserving a patient's liberties is probably responsible for the enthusiastic response lawyers have given to informed consent. However, too strong an emphasis on its legal origins and function eclipses the fact that informed consent is not merely a legal concept.

Informed consent is a legal doctrine that also supports many of our cherished ideals about the rights of the individual. The law's rights-oriented approach to informed consent assumes that the individual patient is characterized by a set of personal values that no one but that patient can know. In deciding what treatment, if any, a patient is to receive, the physician is viewed as an expert who should leave his or her values aside and only bring technical expertise into play. In the standard rendition of informed consent, the physician's role is to explain the various possibilities for the diagnosis or treatment of a particular patient's condition, and the patient is to consider this information in the context of his or her own values and then choose a course of treatment suited to him or her.

This approach fits certain cases nicely, for example, religiously based treatment refusals by a competent adult patient. However, mindless application of this approach to all medical decision making is responsible for many of the myths that have developed about informed consent. In the clinical setting, rights often recede into the background, and it is more helpful to approach informed consent as a *shared process* of decision making. A shared process approach does not restrict the physician to providing facts and insists that the patient supply all the values. The physician and patient each have access to interrelated facts and values. The values and thinking of the physician and patient should gradually take shape. They should mutually monitor each other so that their goals, thoughts, and evaluations become transparent to each other.

Conceived as a process of shared decision making, informed consent can accommodate both

patient autonomy and the physician's responsibility for the well-being of the patient. As we explore some of the myths about informed consent, we highlight how a balance should be struck to accommodate both autonomy and beneficence.

Myth 1: A Signed Consent Form Is Informed Consent

Perhaps the most fundamental and pervasive myth about informed consent is that informed consent has been obtained when a patient signs a consent form. Nothing could be further from the truth, as many courts have pointed out to physicians who were only too willing to believe this myth. Consent forms are used as a matter of routine in both treatment and research settings because many hospital administrators, physicians, and their attorneys see these forms as providing protection against liability, despite the fact that they actually provide little protection.

Consent forms do have some value. They create an inference that the patient at least had an opportunity to read the information on it. If the information presented in the consent form contains a description of the risk that actually came to pass and contains other information that is adequate for a patient to make a decision, it will probably be helpful to a physician in the defense of a lawsuit.

On the other hand, if the information on the form is not adequate or is overly complex, the form may provide evidence to support the *patient's* case. If the form merely acknowledges that disclosure was made, but fails to recite the *content* of what should have been disclosed, it is unlikely to provide the physician with any advantage with respect to the main issue in a lawsuit: what was disclosed and whether it was adequate. Contemporary consent forms—often optimistically referred to as “informed consent forms” as if wishing would make it so—provide a false sense of security to physicians and hospital administrators who are led to believe that a signed consent form constitutes informed consent.

Myth 2: Informed Consent Is a Medical Miranda Warning

As practiced, and certainly as symbolized by consent forms, informed consent is often no more than a medical Miranda warning. Just as police are

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required to tell criminal suspects that "you have a right to remain silent, you have a right to a lawyer, and if you choose to speak, anything you say can be used against you," some physicians believe that informed consent has been obtained if they warn patients of the risks of treatment.

Certainly, patients should be told about the risks of treatment. Admittedly, it is difficult to know what risks must be disclosed, but the approach to informed consent that we advocate makes this less important. Rather than focusing on risks, the focus needs to be on therapeutic options. For example, patients with ulcers need to know about medical treatment and surgical treatment. Patients with breast cancer need to know about different kinds and combinations of surgery, radiation, and chemotherapy. All patients always need to know that one of their options is to do nothing.

Knowledge of one's options alone, however, is not meaningful unless one also knows the range of consequences is choosing each option. One facet of information about consequences is the risks of treatment, but there are others such as information about the likely outcomes, including information about mortality, morbidity, and functioning.

Myth 3: Informed Consent Requires That Physicians Operate a Medical Cafeteria

A myth that contradicts the previous one, yet is sometimes held simultaneously with it, is that informed consent requires physicians to operate a medical cafeteria, in which they must set out all the therapeutic options and let patients choose, each according to his or her own appetite. The law clearly does not require this.

Some physicians feel that their ability to practice medicine "the way we used to in the good old days" has been impinged on not only by courts and lawyers but also by third-party payers, health facility administrators, Congress, the state legislature, governmental bureaucrats, and patients incited by Ralph Nader, the consumer advocate. In a sense, this myth about informed consent has arisen as an antidote to the previous one. It is not hard to envision a physician, who has been continually told to provide patients with information about medical options and their consequences, wringing his or her hands in disgust or discouragement and responding with,

Well, damn it, if informed consent is all about letting patients chart their own course in medical matters, then let *them* do it. And if things go wrong, well it's their own fault—both because *they* did the choosing, and because *they* didn't listen to us.

When this attitude is at work, there is a serious sin of omission. What is being omitted is a central part of the physician-patient relationship as both physicians and patients view it—namely, the physician's role as medical adviser.

Patients usually want more than information. They also want advice. They say, "Doctor, if you were in my position, what would you do?" That does not mean they are going to do what their physician would do, nor does it mean that they should have just let the physician decide from the outset. It does not mean that informed consent is a charade. What it means is that informed consent is a process and part of the process is human interaction. Rather than thinking of informed consent as an abstract ideal, what we call informed consent should take the form of a conversation in which patients get information, ask questions, give information, and say "I want to think about it" or "I've thought about it and I can't decide. What do you think I should do?" Thus viewed, informed consent is a process of *shared* or *collaborative* decision making.

Another way of looking at the process of informed consent is that it must mix together treatment goals and particular treatments. Most of the confusion surrounding the cafeteria approach to informed consent assumes that patients wish to micromanage their care. This is rarely the case.⁵ However, patients are entitled to know the goals of therapeutic options and when that goal has changed. Too often, treatments are discussed in detail but patients are not really sure what the treatment is ultimately meant to do. Similarly, when new treatments are introduced and discussed, it is not always clear to the patient that the old goal is no longer realistic, eg, cure is no longer possible, and that this new treatment is directed at a different goal such as minimizing disability or relieving pain. Patients are not experts at treatments; physicians are. However, patients' preferences are central to

⁵Churchill LR. Trust, autonomy, and advance directives. *J Religion Health*. 1989; 28:175-183.

the choice of treatment goals. Thus, in selecting and revising treatment goals, physicians and patients need to form a partnership.

Myth 4: Patients Must Be Told Everything About Treatment

Some believe that the law requires patients be told everything about treatment—the equivalent of giving them the *Physicians' Desk Reference*. Actually, the law requires only that patients be given a reasonable amount of information. In about half the states, the adequacy of disclosure is measured by customary professional practice, which means that patients must be given the information that a reasonable physician would disclose. In the remaining states, the adequacy of disclosure is measured by a so-called legal standard, which requires the provision of that amount and kind of information that a reasonable *patient* would find material to making a decision about treatment.

Because those rules are vague, lawyers cannot provide physicians with specific guidance about how to comply. Therefore, physicians sometimes feel driven back into the corner of disclosing everything, which is unnecessary. Further, it is unwise from a legal perspective because physicians could be held liable (though it is not likely) for intentionally inflicting emotional distress on patients by giving them *too much* information.⁶

Our previous discussions of goals and treatments should provide a minimal checklist. Once a physician and patient have explored all the relatively realistic goals of treatment, the number of therapeutic options and amount of information about those options frequently become relatively minor issues.

Myth 5: Patients Need Full Disclosure About Treatment Only If They Consent

Information about therapeutic options and their consequences to be used by patients in making decisions needs to be provided before, not after, decisions are made. In practice, this is not always the case. One reason is the nature of the process by which physicians conceptualize and solve prob-

lems and formulate recommendations. Physicians acquire information about patients through examination, history, medical records, laboratory tests, and similar processes and then formulate a diagnosis. The physician makes a treatment recommendation to the patient in the form of, "Here's what's wrong with you and this is what we need to do."

Patients are expected to comply with the recommendation although some patients will ask questions, take some time to think about it, seek a second opinion, or even refuse the recommendation or any further medical attention. If the patient decides to follow the recommendation (ie, consents), and especially if the physician has not yet provided much in the way of information, he or she might then receive more information because this decision provides an occasion to discuss the medical malady and its treatment. In other words, much of the information relevant to making a decision actually comes after the decision is made. There is nothing wrong with continuing to provide, reiterate, or recast information at the time the patient consents to treatment. In fact, we recommend it. However, if informed consent was conceived of by physicians as a process of shared decision making, information might more readily flow earlier and more frequently.

The failure to make information available to patients before they decide whether to accept or reject a physician's recommendations is based on the premise that if the patient refuses treatment, it is unnecessary, if not paradoxical, to obtain informed consent. This illustrates how the use of the term *informed consent* is unfortunate, if not dangerous, for it assumes that the process of informing is to eventuate in consent. Physicians also assume that if in fact consent is not forthcoming, information need not be given to patients or if the patient refuses the recommended treatment and settles on an alternative treatment, no information need be provided about the rejected treatment.

In fact, physicians are obligated to obtain not only informed consent but also informed refusal.⁷ This is not as silly as it might at first appear, when one recalls that the most important part of informed consent is information about options

⁶*Ferrara v Galluchio*, 152 NE2d 249 (NY 1958).

⁷*Truman v Thomas*, 611 P2d 902 (Cal 1980).

and their consequences and a refusal of treatment is a choice to do nothing, which has predictable consequences too. This is not a resurrection of the cafeteria approach, nor are we recommending that the physician present the entire treatment menu. What we are saying is that when the physician examines the patient and says, for example, "We'll have to do bypass surgery," and omitted discussion of the choice of goals, he or she has assumed that the patient would agree about the treatment to meet that goal.

Myth 6: Patients Cannot Give Informed Consent Because They Cannot Understand Complex Medical Information

The notion that informed consent is a myth and bad medicine is premised in part on the assumption that providing information to patients frightens them.⁸ These characterizations are also based on the assumed difficulty of transmitting technical information to patients. A typical unspoken thought might go,

Patients can't understand all this medical stuff. Why I have trouble keeping up with my own subspecialty, I've forgotten 95% of what I learned in medical school, and the 5% I remember is now outdated. Even worse, what about all those empirical studies that show that patients who have been given information don't remember it 6 months, 6 days, or even 6 hours or 6 minutes later?

There are at least 2 errors in this reasoning. The first is the equation of recall with understanding. While it might be true that someone who cannot retain information for a few seconds might not be said to understand it, people often make reasonable decisions but cannot later recall the premises that supported the reasoning or the process that led to the conclusion. Nevertheless, they might well have understood it at the time.

The second error is the assumption that patients must understand information in the same way and to the same extent as the physician. It is true that a patient who is totally bereft of understanding lacks decision-making capacity and would

be considered legally incompetent. In such a case, decision making would need to take place with a surrogate decision maker acting on the patient's behalf. The fact that a patient might put an odd gloss on information or might not have a completely accurate factual understanding of the information does not disqualify that patient as a decision maker. To have decision-making capacity, patients do not need to be Jonas Salk. They merely need to be able to understand their options and the potential risks and benefits of these options. Most assuredly the fact that the patient reaches a decision different from the one that the physician would have made does not mean that the patient does not understand the information.

What is critical is that patients be given information and that they have a chance to use it in formulating a decision, to ask questions about it, and to gather further information. It is essential that they be given the context for the proposed treatments, ie, they must be told the physician's goals in making this treatment recommendation. However, within broad limits, patients have the right to set their own goals and to make their own decisions in their own way and for their own reasons, which includes the right *not* to use information that others might think relevant, rational, and even necessary to decision making.

We are steering a course between extremes. One extreme assumes that a patient just cannot understand medical information, and so we should give up on informed consent. On the other end of the spectrum resides the extreme rights-oriented view that a patient's treatment choices should not be challenged. We advocate the middle path: patients' choices should make sense in terms of their values and way of making sense of the world and these decisions should be made in the manner patients normally make similar choices. However, to require "understanding" in the same way and to the same extent that a physician understands the information is as paternalistic as not permitting patients to participate in decision making at all.

Myth 7: Patients Must Be Given Information Whether They Want It or Not

Some patients choose not to participate in the decision-making process at all or may wish to

⁸Katz, Judges, physicians, and patients, pp. 74-76.

participate on a reduced basis. Withholding information from patients when they request that it not be given respects their autonomy as much as providing information to patients who want it. Enabling and permitting patients to make medical decisions is one way of fostering self-determination; respecting their wish not to participate is another. *Compelling* patients to receive information that they do not want or to make decisions that they do not wish to make is to fail to respect their dignity.

Withholding information from patients at their request is a legally recognized exception to informed consent referred to as waiver.⁹ Usually, only by initiating a conversation with a patient can a physician determine that a patient wishes to participate in only a limited way, or not at all, in the decision-making process. In some instances, patients may fully engage in such a conversation and only at the end declare that they do not know what to do and wish to leave the decision to a family member, the physician, or someone else. In such a case, a patient can be said to have waived the right to decide though not the right to be informed. Sometimes patients make it clear that they do not even want to talk about therapeutic options and consequences. They may be willing to make a decision on less, rather than more, information. In such a case, a patient can be said to have waived the right to be informed, though not necessarily the right to decide. Or patients may want neither information nor to decide, again preferring to leave it all to someone else.

Thus, the waiver exception parallels the 2 distinct but related rights that informed consent embodies, the right to be given information and the right to decide. Patients who waive their right to decide do not automatically waive their right to information. There may be good reasons to continue to provide information to such patients. One is that just because patients do not want to make a particular treatment decision does not mean that they will not wish to participate in the future. Furthermore, there are reasons to provide information other than for decision making. Patients also need information to facilitate compliance with treatment decisions. They deserve information

about their treatment as a sign of respect and so that they can be prepared for what is to happen to them.

Myth 8: Information May Be Withheld If It Will Cause the Patient to Refuse Treatment

It is ironic that physicians who profess not to know much about informed consent sometimes do know about the therapeutic privilege, which, like the waiver exception, allows information to be withheld from patients. When information is withheld under the waiver exception, *patients* decide that having information would not serve their ends. By contrast, when the therapeutic privilege is invoked to withhold information, the physician determines that providing the patient with information would undermine, rather than promote, the goals of informed consent.

The purpose of the therapeutic privilege is to allow physicians to honor their "primary duties" to do what is beneficial for the patients and to avoid inflicting harm on them.¹⁰ However, it is far less clear what circumstances justify the physician in withholding information. In general, physicians are permitted to withhold information when its disclosure would seriously harm the patient.

In practice, the therapeutic privilege may legitimate a physician's natural aversion to providing unpleasant information to patients—indeed, almost everyone's natural aversion to providing unpleasant information to anyone else. However, the therapeutic privilege is not a license for physicians to withhold information when they fear, rightly or wrongly, that providing it to patients will lead them to refuse recommended treatment. Such a view of the privilege is paternalistic in the extreme; it threatens to devour any obligation to provide information and would permit physicians to substitute their judgment for the patient's. The more appropriate formulation of the privilege permits physicians to tailor (and even withhold) information when, but only when, its disclosure would so upset a patient that he or she could not rationally engage in a conversation about therapeutic options and consequences.

⁹Meisel A. The "exceptions" to the informed consent doctrine: Striking a balance between competing values in medical decision-making. *Wis Law Rev.* 1979; 413-488.

¹⁰*Nishi v Hartwell*, 473 P2d 116 (Haw 1970).

Conclusion

A number of myths about what the law requires impede the practice of obtaining informed consent. If informed consent is viewed as a process of shared decision making, some of the seeming absurdities and excesses that can be associated with it disappear. In so doing, it might make the practice of medicine more rewarding for physicians. The doctrine of informed consent does not analogize physicians to waiters who take orders from customers. Rather, it recognizes the responsibility of the physician for the patient's well-being.

We are a litigious society, and physicians must be concerned with avoiding lawsuits. The best advice we can give is to treat patients like people, act sensitively and compassionately, and most of all, talk to patients. Have a conversation, have several; remember that this is a process. In this process, you will gradually come to know your patient's decision-making style. Furthermore, do not press patients to decide quickly. Do not make them think that you do not have time for them. Because if you do, regardless of how much information they are given, they are going to be angry, and another name for an angry patient is plaintiff.

Discussion Questions

1. What, exactly, does "informed consent" mean and what is its purpose in the health care profession?
2. What is the moral relevance of informed consent? What moral theory (or theories) would support the obligation of medical professionals to fully inform patients about relevant information associated with various alternatives? What moral theory (or theories) would allow medical professionals to override the stated preferences of patients who are not, or cannot be, autonomous?
3. Of the various myths about informed consent, which do you think is most important ethically? Which do you think is least important ethically? What is the basis for your answers?

Physician-Assisted Suicide: Promoting Autonomy or Medicalizing Suicide?

TANIA SALEM

ASSISTED SUICIDE, many argue, honors self-determination in returning control of their dying to patients themselves. But physician assistance and measures proposed to safeguard patients from coercion in fact return ultimate authority over this "private and deeply personal" decision to medicine and society.

Why have physician-assisted suicide and voluntary active euthanasia taken on such vitality in recent years? Some authors stress the conjunction of powerful medical and cultural trends. The advances of modern medicine in association with its overwhelming bias to treat have engendered widespread and increasing fear. More than death

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itself, what seems frightening is the very real prospect of losing control over one's own dying process. The reaction to this exorbitant sway of medicine has been nourished since the 1970s: patients' empowerment or, more generally, the liberal individualism that has vigorously extended into the medical system. In response, advance directives, health care proxies, and other devices founded on the right to forgo medical treatment aim to "protect" patients from physicians, medicine, and hospitals' institutional imperatives. From the perspective of this recent history, physician-assisted suicide and even voluntary active euthanasia are just one more necessary and justified step in this process. It is as if what modern medicine has expropriated from individuals could be returned to them through physician-assisted suicide: control over their own deaths.

These considerations condense two widespread current assumptions in the debate over aid in dying. The first is that these practices are, for better or for worse, pragmatic expressions of patients' autonomy. Although proponents and opponents evaluate very differently the adequacy and the limits conferred to self-determination in this context, they both endorse this general assertion. The second assumption is that physician-assisted suicide and voluntary active euthanasia are ultimate brakes on the unrestrained use of medical technology at the end of life. They are instruments to promote the "demedicalization" of death.

I propose to challenge these assumptions. I want to argue that physician-assisted suicide does not demedicalize death; rather, it medicalizes suicide. By this I mean it transforms a private act (suicide) into a medical event. Indeed, physician-assisted suicide implies not a resistance to but an extension of medical power over life and death. And second, that instead of asserting an individual's autonomy physician-assisted suicide is in fact an impediment to it.

My analysis accepts the liberal/libertarian presumption that one of the essential attributes of the individual is precisely the liberty to govern oneself free from external constraints. Despite my belief in both the indispensability and inevitability of social constraints, as an analytic device here I will assume radical autonomy to be a moral goal. I will also assume that from the perspective of the physician-patient dyad, more than killing, "assisted suicide"

is literally what the phrase states: suicide with assistance, not only because it is the patient who makes the request, but also because it is she who is responsible for the final deed.

Promoting Autonomy, Demedicalizing Death

Many of those who favor physician-assisted suicide analyze and support it in reference to free choice, individual rights, and moral autonomy. This line of argument rests on a conception of autonomy primarily as "negative liberty": the right to act and govern oneself in accordance with one's own private beliefs, values, and choices without interference as long as one's behavior does not harm others. Proponents assert that this right should encompass patients' control over the timing and circumstances of death up to and including assistance in suicide. So conceived as a "personal and intimate decision," the right to aid in dying refers to a sphere of self-determination that should be left free from any paternalistic interference, whether that interference emanates from the state, from doctors, from family members, or from religious or philosophical orthodoxies. Physician-assisted suicide is, in short, advocated as a "natural" extension of the constitutionally protected "right to privacy," and as a mere specification of the moral right to self-determination.

Opponents of this line of argument contest the pre-eminence conferred on autonomy vis-a-vis other social values and interests. The sanctity of life, the protection of those who are vulnerable to medical or family abuses, the "common good," and the ethical integrity of the medical professional (that is, the preservation of its ancient vow never intentionally to kill) are variously seen as competing values that in fact outweigh individual autonomy. What is contested is not physician-assisted suicide as an instrument of personal autonomy; critics insist that even if assisted suicide does serve autonomy, limits should be imposed on this value for the sake of other goods. Daniel Callahan's argument is illustrative: "the acceptance of euthanasia would sanction a view of autonomy holding that individuals may, in the name of their own private, idiosyncratic view of the good life, call upon others, including such institutions as medicine, to help them to pursue that life, even at

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the risk of common good."¹ Thus though they diverge in respect to how far personal autonomy and self-determination should extend, proponents and opponents converge in assuming that these values are ultimately the major forces driving the movement of physician-assisted suicide.

A second assumption widespread in the literature—particularly among defenders—is that by enhancing the patient's control assisted suicide represents just one more necessary step in the demedicalization of death. With the relationship between patients and doctors increasingly seen as a zero-sum game pitting vulnerable patients against the power of doctors and medicine, demedicalization is regarded as a prerequisite to patients' autonomy and empowerment in the face of death.

Thus proponents uphold physician-assisted suicide as a "natural" and indispensable development of the widely accepted right to refuse and/or withdraw life-sustaining medical treatments. Indeed, Peter Singer argues that the right to refuse is insufficient to grant individuals real control over their dying process. In his own words, "Not killing is not enough. The right to refuse medical treatment can help only in a limited number of cases in which it leads to a swift and painless death. Most cancer patients, for instance, are not in this situation. [This is why] the desire of control over how we die . . . will not be satisfied by the concessions to patient autonomy within the framework of [traditional] ethics."²

Outer Codes, Inner Individuals

Incontestably, from a certain perspective physician-assisted suicide is a dramatic expression of autonomy, empowerment, self-determination, and the like. The contemporary debate about death and dying has shifted focus from medical norms to individual rights, choices, and desires, a shift from outer codes to inner individuals. Michel Foucault argues that every moral system necessarily comprises these two aspects: socially stipulated codes

of conduct, and a relation to oneself as a moral entity who must evaluate and define a personal stance regarding the proposed conduct.³ Outer codes and inner individuals thus point not to a dichotomy but to the predominance of one or the other moral perspective: some moral systems emphasize codes (requiring from the individual a strict conformity to them) while others shift the focus to personal "choices."

There is no doubt that the emphasis on inner individuals prevails in contemporary arguments for physician-assisted suicide. Influences from the outside, whether subtle or blatant, are seen as pernicious in subverting the main goal: the "pure" or "true" choice reached from within that at bottom takes account of the interests of the decisionmaker. This self-centered ethics rests on a nonrelational conception of personhood.

The second—and closely related—pillar of this discourse is the insistence that individuals be radically free to exercise their singularities and idiosyncrasies. In pluralistic societies, it is asserted, "there is far from any agreement, or near-agreement, about how one can establish as canonical a particular normative view of life."⁴ Because personal styles, experiences, and beliefs are radically irreducible, it is impossible to suppose a priori that individual choices will coincide; each must find his or her own way of facing dying and death.

Yet there is a paradox underlying physician-assisted suicide. It is conceived of as an intimate, existential act and indeed a response to modern medicine, but at the same time it is a request for the complicity of physicians (and society). In contemporary Western societies the decision to take death into one's own hands has been construed as an act that is not simply personal, private, and solitary, but contrary to social norms and expectations. From a societal perspective, the individual who commits or attempts suicide is in this sense an outsider.

What seems unusual in the debate about aid in dying is the request for public endorsement and legitimization of the act of suicide. Whereas in

¹Daniel Callahan, "When Self-Determination Runs Amok," *Hastings Center Report* 22, no. 2 (1992): 50–55, at 52.

²Peter Singer, *Rethinking Life and Death: The Collapse of Our Traditional Ethics* (New York: St. Martin's Press, 1994), pp. 194, 147–48.

³Michel Foucault, *History of Sexuality, Vol. 2: The Use of Pleasure* (New York: Vintage Books, 1986), ch. 3.

⁴H. Tristram Engelhardt, Jr., "Fashioning an Ethic for Life and Death in a Post-Modern Society," *Hastings Center Report* 19, no. 1 (1989): S7–S9, at S7.

suicide the individual "drops out" of the social order, in the context of physician-assisted suicide the individual "drops into" a system that recognizes and must even authorize this particular (ostensibly private) choice. In other words, displacing suicide from the private arena to bring it under medicine's stewardship means surrendering suicide to the (medical) "establishment."

Precisely because assisted suicide requires the connivance of others (direct from doctors, indirect from society), it cannot be seen as an act that solely expresses the ideal of individual autonomy. On the contrary, as long as it entails assistance it implies a mutual decision. Additionally, and, even more importantly, more than a mutual decision, assisted suicide presupposes that medicine has passed judgment on the act of suicide. In sum, physician-assisted suicide introduces tensions in the principle of personal autonomy and entails an increase of medical power over death and social morality.

Medicalizing Suicide

Medicalizing suicide encompasses three different (though interrelated) facets: the medicalization of an act, of a practice, and above all of the social ethos of death and suicide.

MEDICALIZING THE ACT OF SUICIDE

In the typical physician-assisted suicide scenario, the patient is responsible both for requesting aid in dying and for performing the final deed, and she or he construes the act basically as suicide. Yet as long as the physician is in charge of assisting the patient—either by his or her physical presence or by supplying the medical means to perform the act—physician-assisted suicide entails the medicalization of the act of suicide.

Ideally, for the physician to assist a patient's suicide the physician must be physically present—as attested in Timothy Quill's regrets for "abandoning" Diane, leaving her to take the prescribed lethal medication alone.⁵ Thus what is intriguing in physician-assisted suicide is not that ventilators, tubes, CPR, and so on are supplanted by "lethal

drugs," but that even in this context the physician and medicine are overwhelmingly present in the setting of death.

Even without the doctor's physical presence in the last scene, as long as physician-assisted suicide presupposes medical assistance it cannot be conceived as immersed in the realm of self-determination. Unless doctors are reduced strictly to being instruments to fulfill their patients' desires, physician-assisted suicide enacts what must be seen as a mutual decision. But what kind of questions are at stake in this joint decision? Proponents of assisted suicide suggest that patient and physician discuss the patient's medical condition and explore alternatives for alleviating pain and suffering. If it comes to it, the physician should provide a prescription for a lethal drug that leads to a "rapid" and "painless" death.⁶ That is, the decision to die by suicide is treated precisely as if it were a set of clinical problems to be solved medically—the "private," "intimate," "self-determining" decision to commit suicide is translated into a clinical event.

MEDICALIZING SUICIDE AS PROFESSIONAL PRACTICE

Medicalizing suicide also points to the fact that if legalized, physician-assisted suicide as a legitimate practice would become the prerogative of physicians. Indeed, Jack Kevorkian has seen the exclusive right as the foundation for a new medical subspecialty of "obituary."⁷

This monopoly leads to the more general question of why aid in dying should be provided only by a medical practitioner. Why, that is, should assistance in suicide be understood as requiring medical authority rather than, for instance, a community of family or friends? The most obvious answer is that physicians—and only physicians—have the necessary technical skills to ensure a "rapid" and "painless" death. But as some critics have noted, "Assisted suicide does not even require medical skill. . . . If freeing up patients

⁵Timothy E. Quill, *Death and Dignity: Making Choices and Taking Charge* (New York: W.W. Norton & Company, 1993).

⁶New York State Task Force on Life and the Law, *When Death Is Sought: Assisted Suicide and Euthanasia in the Medical Context* (Albany, NY: New York State Task Force on Life and the Law, 1994), p. 105.

⁷Jack Kevorkian, *Prescription: Medicine* (New York: Prometheus Books, 1991).

truly is the goal, then assisted suicide's advocates disserve patients when they do not advocate ending the physician's exclusive power to prescribe medication. Ironically, the advocates of patients' rights end up empowering doctors more than they do patients."⁸

Yet even those who maintain that technical knowledge is imperative do not confine their justification of physician-assisted suicide to this reason. Placing suicide under the stewardship of medicine is further defended as a way of "enhancing public accountability of the practice" and "protecting against abuse."⁹ From the patient's perspective, the request for aid in dying may mean a "desire for companionship in pursuing a difficult course of action, a wish for confirmation of a decision about which the patient is unsure or simply a cry for help" (pp. 88-89, note 42). Moreover, since suicide is still stigmatized, "seeking a physician's assistance may be a way of trying to remove that stigma."¹⁰ But inasmuch as cultural preconceptions and loneliness (whatever its source) are far from being exclusively medical issues, we must ask why we expect doctors to respond to them. Two possible answers come to mind: either medicine is moving beyond its proper role, or the scope of medical competence has already been extended beyond appropriate boundaries.

It seems reasonable to conclude that ceding monopoly of assistance in suicide to doctors is anchored in an inflation of the physician's role, as well as in the extreme idealization of physicians' character and the relationships they establish with patients. The bond physicians establish with patients is supposedly effective, collaborative, and committed. Both this idealization and the willingness to delegate to physicians the exclusive right to assist suicide bespeak the social and symbolic power already conferred on medicine and medical professionals in our societies. In other words, it is not (or not only) the need for technical expertise that impels us to physician-assisted suicide. Rather, our culture, so impregnated by medicalization,

takes for granted that assisted suicide should fall under the control and supervision of medicine.

MEDICALIZING THE MORALITY OF SUICIDE

As a legitimate domain of professional practice, then, physician-assisted suicide necessarily involves medicalizing the moral questions surrounding suicide. Physician-assisted suicide presupposes, and ultimately is, a medical judgment about death or suicide; it is a medical evaluation of the fairness and legitimacy of a person's (not simply a patient's) desire or choice to end his or her life.

With some few exceptions, even the most radical advocates of physician-assisted suicide recognize the need to establish protocols and guidelines to prevent abuses, protect the vulnerable, guarantee public accountability, and even to assure the autonomous character of the patient's choice. Surely these aims are respectable and the setting up of criteria just and reasonable. Yet establishing medical guidelines also introduces tensions into the value of autonomy in several ways.

The requisites for physician-assisted suicide (must the patient be terminally ill? which medical specialists are best qualified as consultants?) are still being debated. There is, however, agreement about the moral attributes that the patient and his or her request must evince: the decision to die must be "informed," "rational," "stable," and "fully free" or "voluntary." And there is broad agreement that to ensure that these conditions are fulfilled the patient must submit to screening by a team of doctors (the treating physician, a consulting physician, and a psychiatrist) who would evaluate the request for aid in dying.

This requirement assumes that besides undue external influences, some impulses or dispositions emanating from the patient herself or himself—such as depression or guilt—may threaten "pure choice." "Voluntariness" in this sense must be safeguarded from undue influence stemming not only from outside, but also from within. Ultimately, this is to assume that the inner world may be obscure to the individual, that she or he may be half blind to her or his own choice, desire, or personal truth.

The presumption that the inner world is or may be opaque to the individual suggests a second underlying presupposition: someone other than

⁸Giles R. Scofield, "Privacy (or Liberty) and Assisted Suicide," *Journal of Pain and Symptom Management* 6, no. 5 (1991): 280-88, at 285.

⁹New York State Task Force, *When Death Is Sought*, p. 105.

¹⁰Dan W. Brock, "Voluntary Active Euthanasia," *Hastings Center Report* 22, no. 2 (1992): 10-22, at 21.

the person requesting aid in dying has greater expertise in judging the appropriateness of that request. Medical authority, that is, is assumed to have the proper ability to unveil the "real truth" behind the request to die. The patient's treating physician, along with psychiatric and/or palliative care consultants, is charged to distinguish authentic from distorted choices; that is, to discern whether the request is pertinent or pathological (and if so, whether it is "curable" by medical means).

Both these premises obviously collide with the principles of autonomy and self-determination. Both displace the final decision concerning suicide from the patient to the physician's judgment that the request is appropriate and free from "undue influence."

The insult to autonomy is not exerted through repression, as was the criminalization of suicide. Rather, it is exercised through what Foucault would call the "normalization" of suicide, the subordination to medical scrutiny of this event and the person making the request.¹¹ The "patient" is subjected to observation, examination, and inquiry to confirm the "rationality" and "voluntariness" of his or her request. Thus medicalizing (assisted) suicide jeopardizes autonomy not only when the patient's request is denied for one reason or another. Requiring that the patient submit to medical surveillance is, in itself, an outrage to autonomy as this value is classically defined.

To illustrate how complex is the apparatus through which suicide is normalized, consider guidelines suggested by Frank Miller, Howard Brody, and Timothy Quill, for example. To ensure public accountability for physician-assisted suicide, to guarantee that the procedure is used only as a "last resort," and to assure that the patient's decision is genuinely voluntary, the authors suggest palliative care consultants and regional palliative care committees as the core of a whole supervising system.¹² Thus the primary physician would be prohibited from providing lethal drugs without

prior consultation with a palliative care expert who, based on "examination of medical records and interviews with the treating physician, the patient and the interested members of the patient's family" (p. 121), would assess the authenticity of the request to die. Patients and their physicians would have the right to appeal the consultant's denial of requests for assisted suicide to regional palliative care committees. The bureaucratization of suicide built into such proposals entails serious constraints on patients' self-determination.

Subjecting individuals who request aid in dying to this kind of scrutiny further affronts their dignity in putting all such requests under suspicion. In the name of protecting individuals from irreversible self-harm all are in principle treated as moral patients rather than moral agents and are presumed to be mentally incompetent. The capacity to make autonomous decisions, which is presumed in all other cases unless demonstrated otherwise, is stood on its head in physician-assisted suicide. Patients must prove their decisionmaking capacity from the outset.

Subjecting the individual to medical norms in this way also introduces a tension for one of the central questions of liberal philosophers. If, as the liberal argument claims, the morality or immorality of decisions at the end of life rests on the competent patient's wishes rather than on a distinction between killing and allowing to die, protocols that may ultimately deny a patient's request for assistance in dying assert, in effect, that moral authority resides outside the patient's choice. And if medicine may, morally, reject patients' autonomous requests for aid, in the context of physician-assisted suicide the value of patient autonomy becomes more rhetorical than real.

Admittedly, even liberal theorists emphasize that there are limits to autonomy, and that like other important rights, the right to physician-assisted suicide is not absolute and can properly be restricted under certain circumstances. Indeed, Ronald Dworkin and others argue precisely that because autonomy must be protected and preserved physician-assisted suicide must be regulated. Under certain conditions the state has the power to override individual rights to protect patients from undue pressures, even internal ones.

¹¹On the concept of "normalization," see Michael Foucault, *History of Sexuality, Vol. 1: An Introduction* (New York: Random House, 1978).

¹²Miller, Quill, Brody, "Regulating Physician-Assisted Death," *New England Journal of Medicine* 331 (1994): 119-23.

The tension remains, however. In the context of assisted suicide, how is it possible to reconcile the assertion that paternalistic influences are unacceptable with the concept that in some situations the state (or the medical establishment) may deny assistance in suicide in the name of "what it reasonably judges to be the best interest of the potential suicide"? Alexander Capron has argued that decisions on behalf of others should utilize a best interest standard of what the "average reasonable person would do under the given circumstances."¹³ Doesn't this permit the tyranny of the majority over the individual? Doesn't this menace the right, so praised by liberal theorists, to exercise our singularities in a radical way? As Yale Kamisar has asked, "[I]f self-determination and autonomy is the major force driving the right to assisted suicide, why should a competent person's firm conclusion that life has become unendurable for her have to be 'objectively reasonable'? Why should not a competent person's own evaluation of her situation suffice?"¹⁴ To phrase this in terms of the

argument I make here, is it ever possible to reconcile medicalizing suicide with autonomy?

It could reasonably be argued that guidelines for physician-assisted suicide do not injure the patient's self-determination since the request emanates from a patient who supposedly knows the rules of the game in advance. And, the argument would continue, if one does not wish to submit to those rules, "do it yourself" remains a way out. But this seems to admit that ultimately assisted suicide has to do with something beyond strict self-determination, that autonomy is not the primary moral foundation, or at least that if autonomy is to be exercised it demands constant external oversight.

In sum, although advocated in the name of self-sovereignty, physician-assisted suicide ends up reinforcing a power external to the self. It reinforces medical power at the expense of the individual in a very sensitive realm: one's decision to die.

¹³Alexander M. Capron, "Substituting Our Judgment," *Hastings Center Report* 22, no. 2 (1992): 58-59, at 59.

¹⁴Yale Kamisar, "Physician-Assisted Suicide: The Last Bridge to Voluntary Active Euthanasia," in *Euthanasia*

Examined: Ethical, Clinical and Other Legal Perspectives, ed. John Keown (Cambridge: Cambridge University Press, 1995), pp. 225-60, at 239.

Discussion Questions

1. Salem attempts to persuade us that allowing physician-assisted suicide does not demedicalize death, but instead medicalizes suicide. What, more precisely, does she mean? How does she argue for this point?
2. A number of scholars believe that physician-assisted suicide promotes individual autonomy. Explain why this is so. Explain why Salem believes that physician-assisted suicide is actually an impediment to individual autonomy. Based on your understanding of the notion of autonomy, do you agree with Salem's claims? Why or why not?
3. Helping other people to commit suicide is against the law in most places and is commonly thought to be ethically wrong as well. However, defenders of physician-assisted suicide argue that this is a legitimate exception. Could Kantian deontology support such a view? What other moral theory (or theories) might be used to justify this exception?

Reassessing the Reliability of Advance Directives

THOMAS MAY

Introduction

A competent patient has the right to refuse treatment necessary to sustain life. However, for many end-of-life decisions, we lack direct access to the wishes of a competent patient. Some treatment decisions near the end of life involve patients with severely diminished mental capacity (for example, Alzheimer's patients), some involve patients who are unable to communicate (for example, some stroke victims), and some involve patients who are simply unable or unwilling to participate in decisionmaking due to the nature or severity of their illness.

In response to this, most states have now recognized the extension of a competent patient's right to refuse treatment through advance directives, which allow a competent person to specify in advance an approach to treatment decisionmaking when he or she is unable to directly participate in the decision. Indeed, this extension of a patient's rights has been recognized at a federal level through the Patient Self-Determination Act.

A question remains, however, concerning the extent to which this extension of a competent patient's right to refuse treatment should be recognized. In this paper, I will argue that we should not recognize advance directives as equivalent to the decisions made by a competent patient. While I believe there are good reasons to recognize advance directives in many (perhaps even most) circumstances, I also believe there are good reasons for recognizing the important differences between advance directives and the direct decisions of a competent patient, and to require that additional criteria be met before advance directives become operative in treatment decisionmaking.

Many discussions of advance directives (ADs) and self-determination focus on the question of

personal identity: If the AD is to reflect the patient's autonomy, we must address the question of the identity of the person who issues the AD and his or her relation to the person who is to receive (or not receive) treatment through the application of the AD. While this is surely an important question, it will not be the focus of this paper. Rather, I shall consider whether, given the resolution of problems concerning personal identity, the AD could be considered an embodiment of patient autonomy. Ultimately, I will argue that it cannot. That is, even if the patient who is to receive treatment under the application of the AD can in fact be said to be the same person who issued the AD, because of certain defining characteristics of the application of ADs, the application of the AD must be seen as "binding" the patient in a way that is incompatible with the patient's autonomy.

Because of this focus, I will treat advance directives in a generic fashion. There are several forms that an AD might take. For example, the "living will" and "durable power of attorney" are the most common, but "medical directives" and "values histories" may also be forms an AD might take. I will treat these in generic fashion because each represents, for the purposes of this discussion, a similar phenomenon. Each form of advance directive represents a commitment to a particular strategy for making healthcare treatment decisions when the patient in question is unable to make such decisions directly.

For example, the strategy represented by an AD may take the form of an appeal to a living will, appeal to the judgment of a chosen surrogate decisionmaker, appeal to an articulated medical directive, or an appeal to the values articulated in a values history. Each form of an AD, however, represents a particular strategy to be used to deter-

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"Reassessing the Reliability of Advance Directives," *Cambridge Journal of Healthcare Ethics* 6 (1997), pp. 325-38. Reprinted with kind permission of the author and Cambridge University Press.

mine treatment when the patient is unable to make such decisions directly. The important issue, then, is whether an appeal to such a strategy represents the autonomy of the patient in question. The particular feature that, I will argue below, makes an AD inconsistent with autonomy (namely, the inability to reconsider the commitment to this strategy at the time of application) is a feature common to ADs in generic fashion (whatever particular form the AD might take).

In this context, one more caveat is in order. I do recognize that there are ways in which people may bind themselves that *are* consistent with autonomy. It is important to note, therefore, that it is not *simply* the appeal to a strategy for making healthcare decisions that I find to threaten autonomy. Indeed, as I will discuss below, commitments to certain types of strategies are perfectly consistent with autonomy. For example, a patient might defer to a physician's judgment as an indirect strategy. In normal circumstances, this is perfectly consistent with the patient's autonomy. However, not all cases of "self-binding" behavior are consistent with autonomy, with voluntary slavery serving as but one example. As we shall see below, to remain consistent with an agent's autonomy, the strategy in question must include an ability to reassess one's commitment to the strategy, a characteristic absent (again, by definition) in the application of advance directives, whatever particular form an AD might take.

The above has serious implications for the autonomous determination of action through various formal mechanisms and strategies. As we shall see below, although all formal strategies reflect the agent's *adoption* of that strategy, the ways in which different strategies *operate* within the agent's practical reason can be very different. Some types of formal strategies for determining action are indeed consistent with autonomy, others are not. I will argue that because of certain defining characteristics, advance directives specify *how* the determination of treatment is reached (a formal strategy for determining action), but cannot reflect an *autonomous* determination of treatment. Put differently, because of the conditions that define the application of advance directives, ADs might be taken to reflect the agent's *adoption of a formal strategy for determining action*, but not the *type of formal strategy* that reflects the agent's auton-

omy in determining action itself. To understand this, we must examine how phenomena like advance directives fit into an agent's practical determinations.

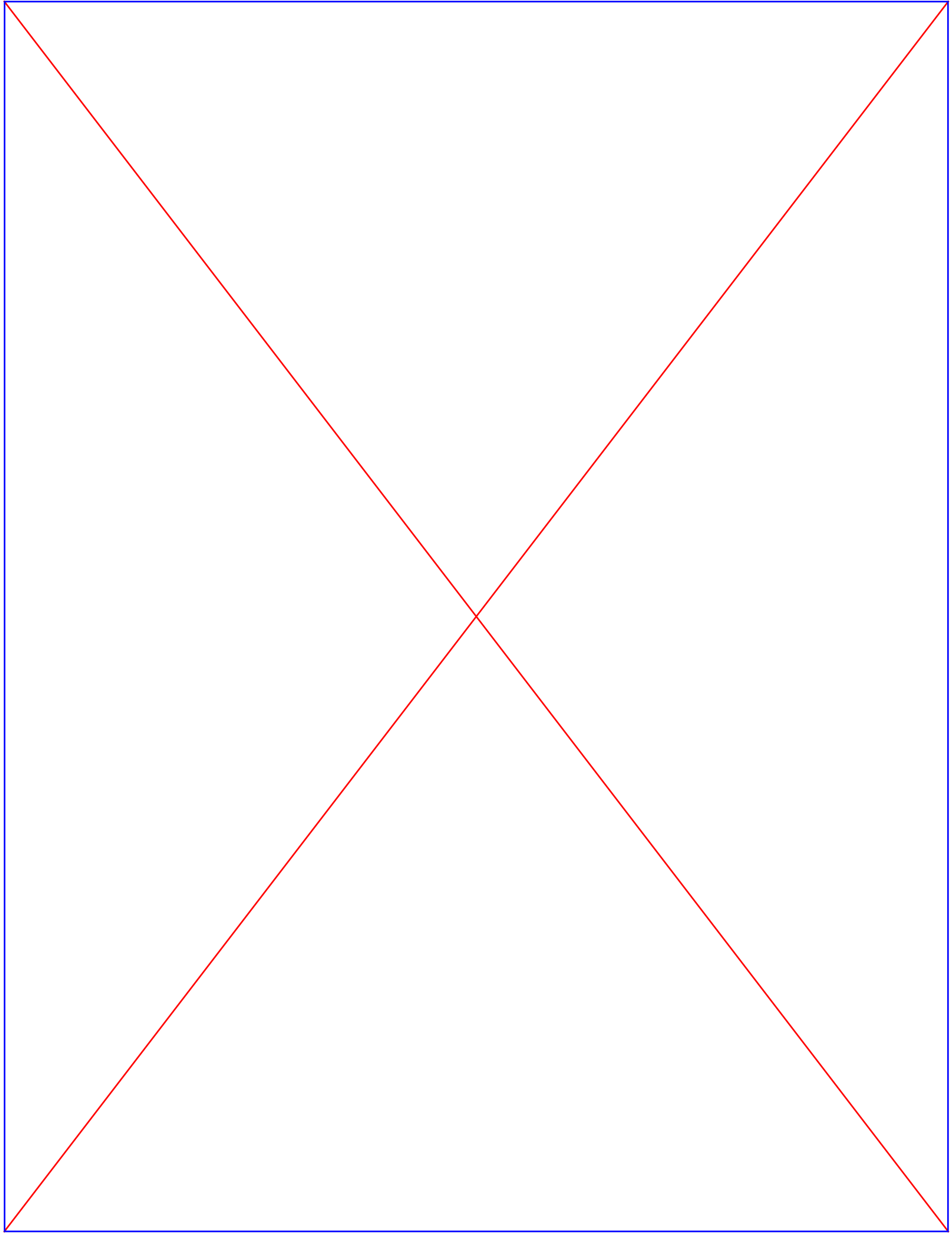
Practical Reasons and Strategies

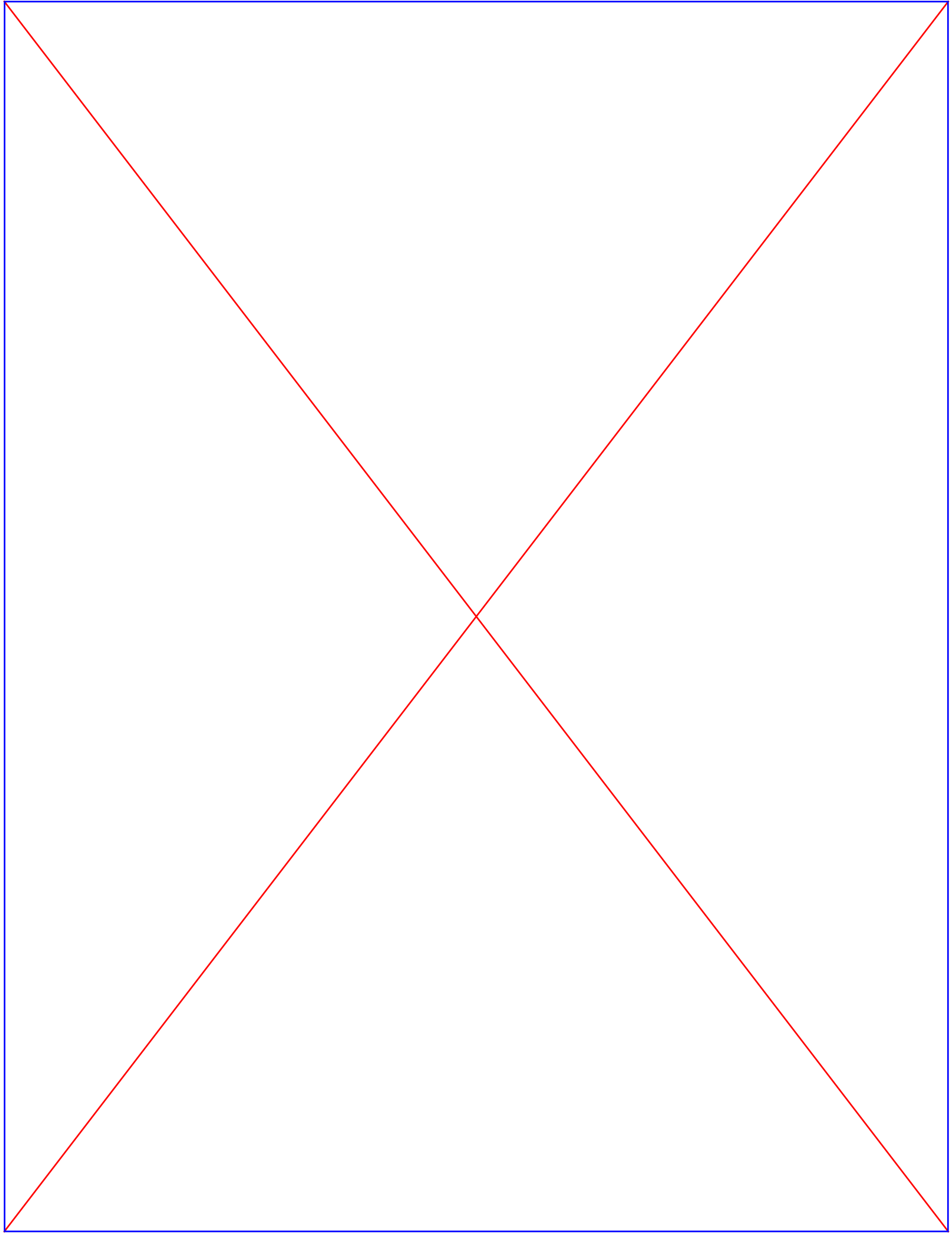
We shall now leave, briefly, the direct examination of ADs per se to come to a better understanding of how strategies of practical reasoning operate in terms of their affect on an agent's autonomy. As we shall see, certain strategies reflect autonomous practical reasoning, but others do not. After we examine how these different types of strategies should be understood, we will return to our focus on advance directives to see why the characteristic features of the type of strategy an AD represents reflect the type of commitment to a strategy that is not consistent with autonomy.

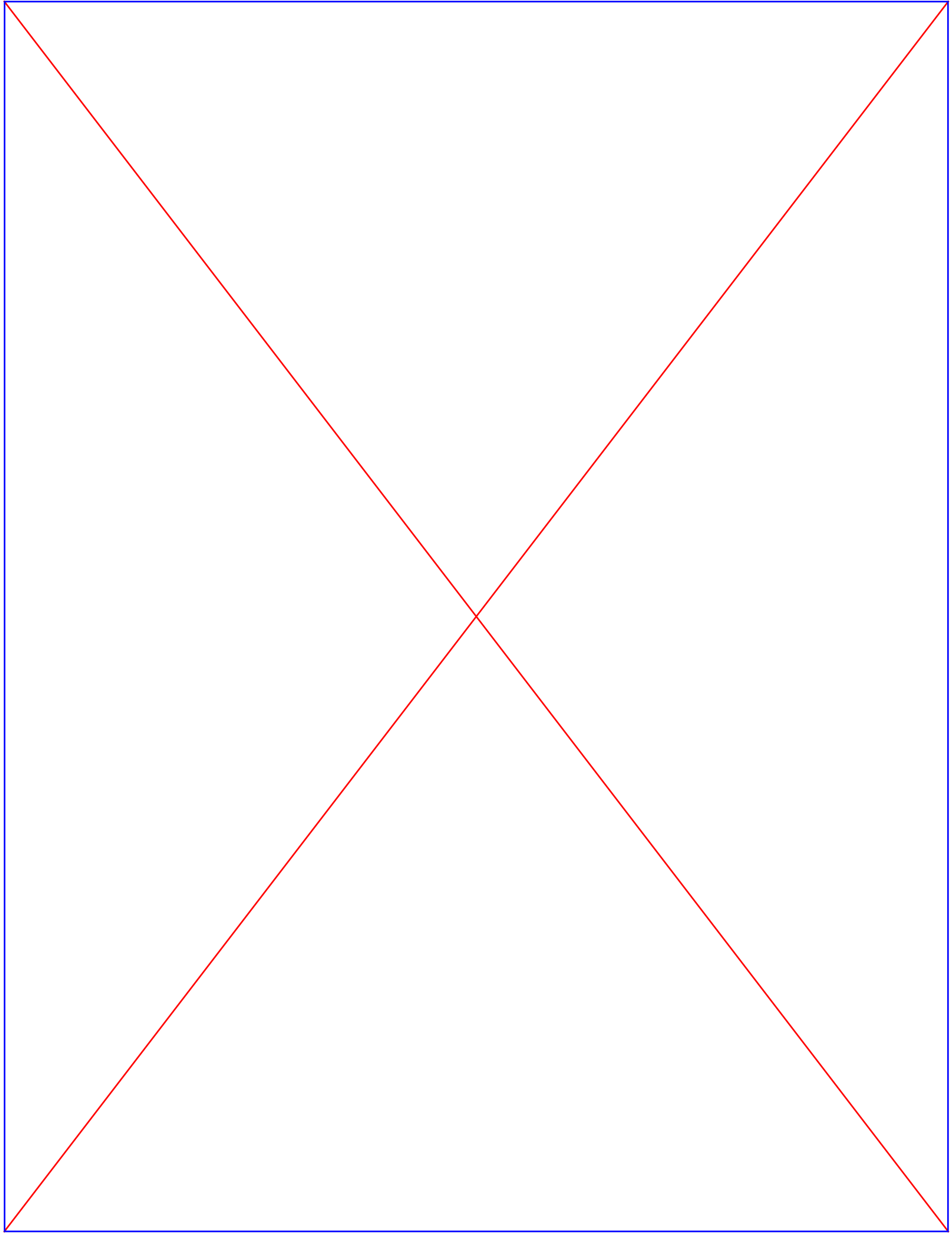
Autonomous decisions reflect the agent's assessment of the balance of reasons for action, "reasons" here construed in the broadest possible sense. But in real life, an agent's determination of action does not always reflect a simple assessment of the balance of reasons. For example, we sometimes use indirect strategies, or adopt rules of thumb that do not fit the model of a simple assessment of reasons (we shall discuss examples of such phenomena below). As we shall see, advance directives look to be phenomena of this sort, allowing the patient to determine treatment through commitment to a particular strategy: by reference to the advance directive. To account for phenomena like indirect strategies and rules of thumb, Joseph Raz devised a model of "second-order reasoning"¹ that we shall examine in detail.

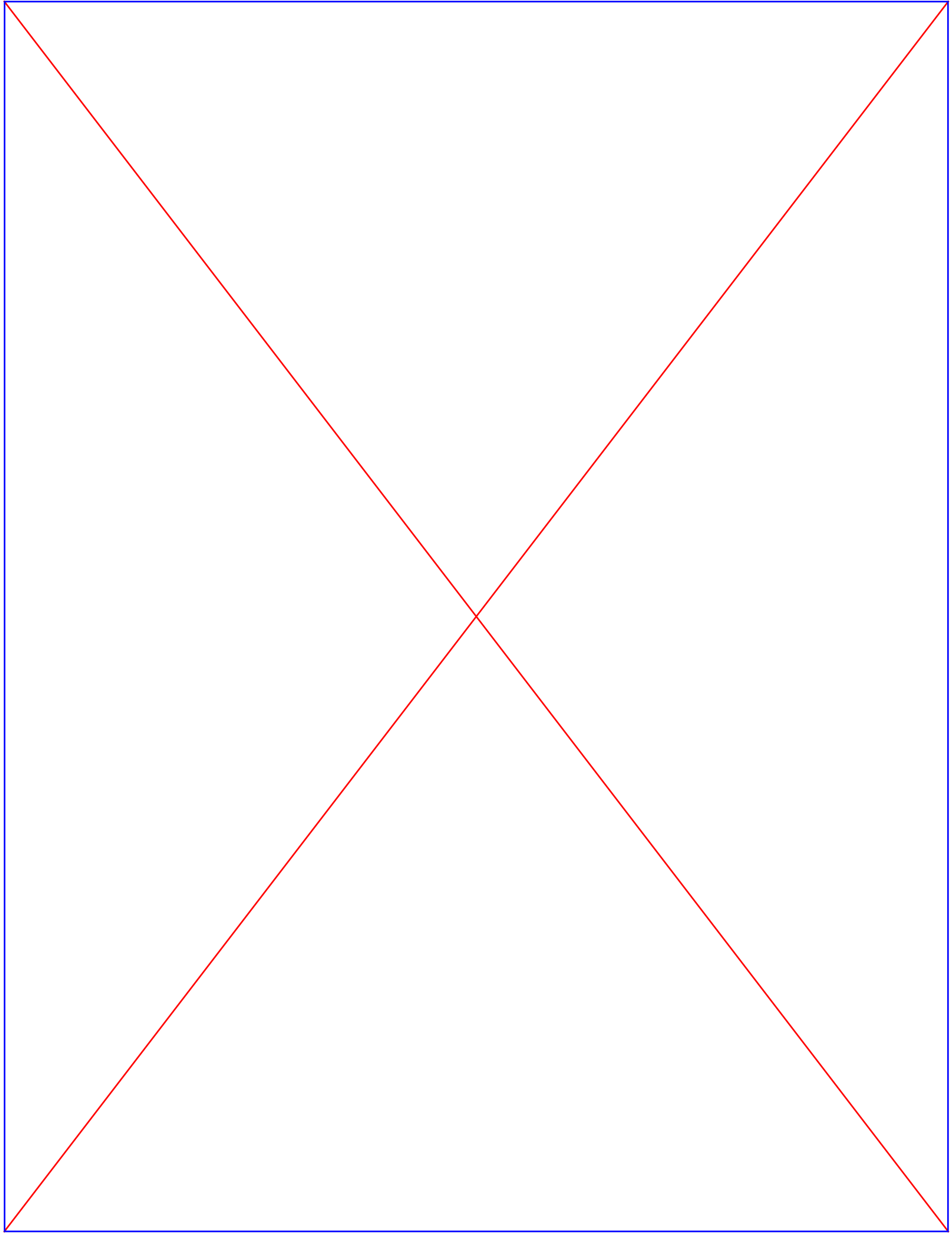
Although the notion of second-order reasons was recognized as a significant contribution to philosophical work in the area of practical reason and action, there remains confusion as to exactly how we are to understand what a second-order reason is, and how it relates to other reasons we have to perform various actions. The various examples used by Raz to illustrate second-order reasoning emphasize different aspects of the relationship of second-order reasons to other reasons for action that we may have; that diversity clouds

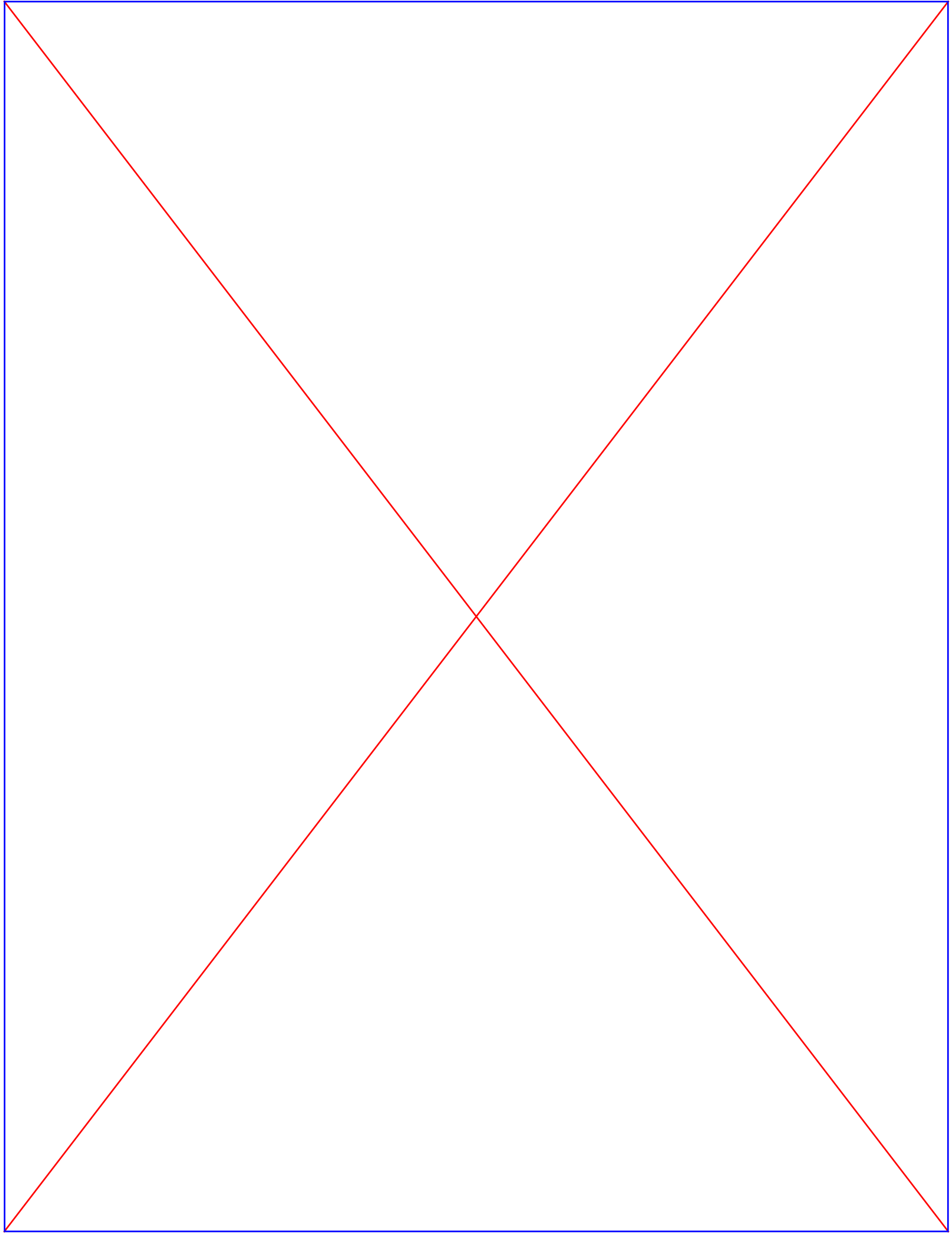
¹Raz J. *Practical Reason and Norms*. Princeton, New Jersey: Princeton University Press, 1990.

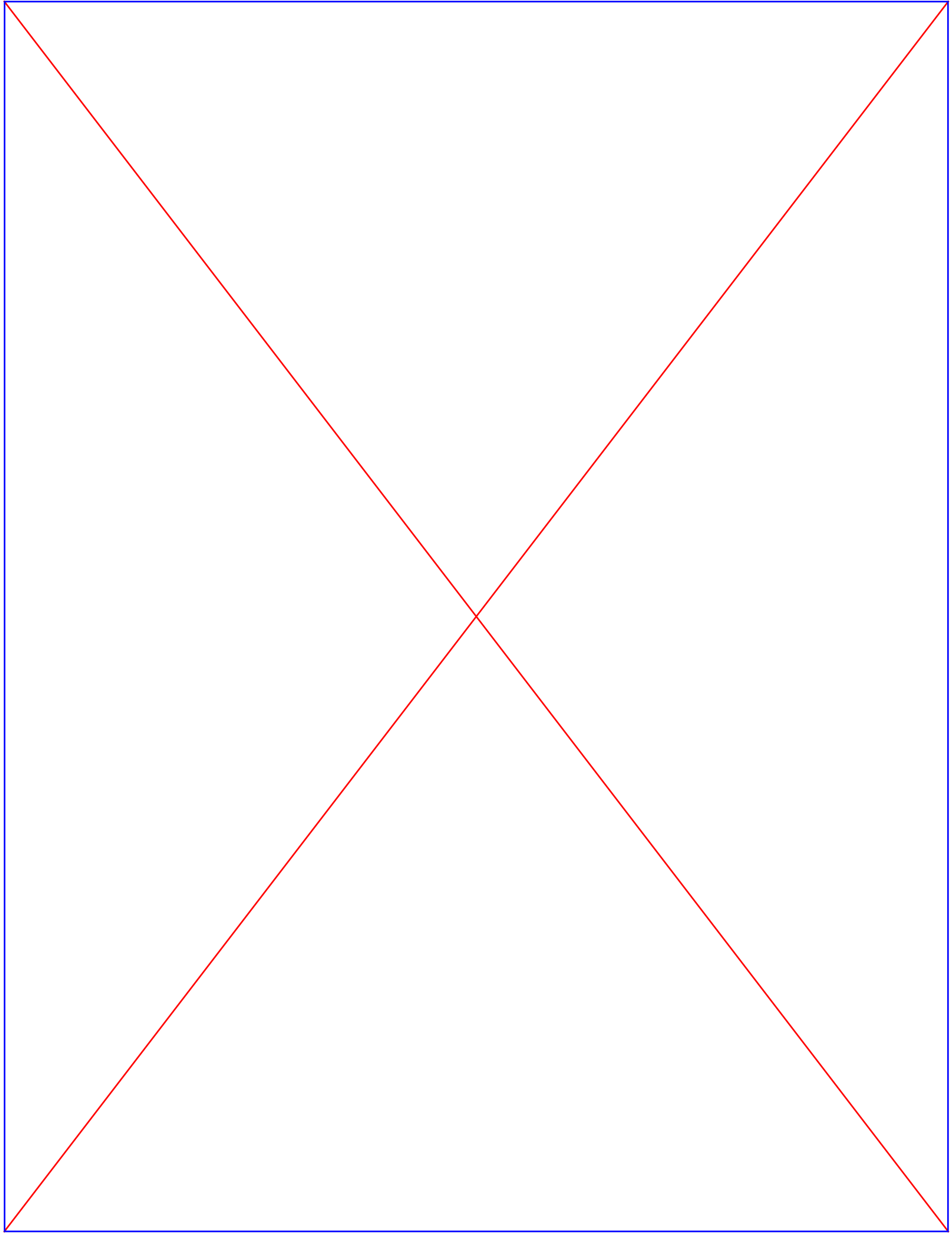


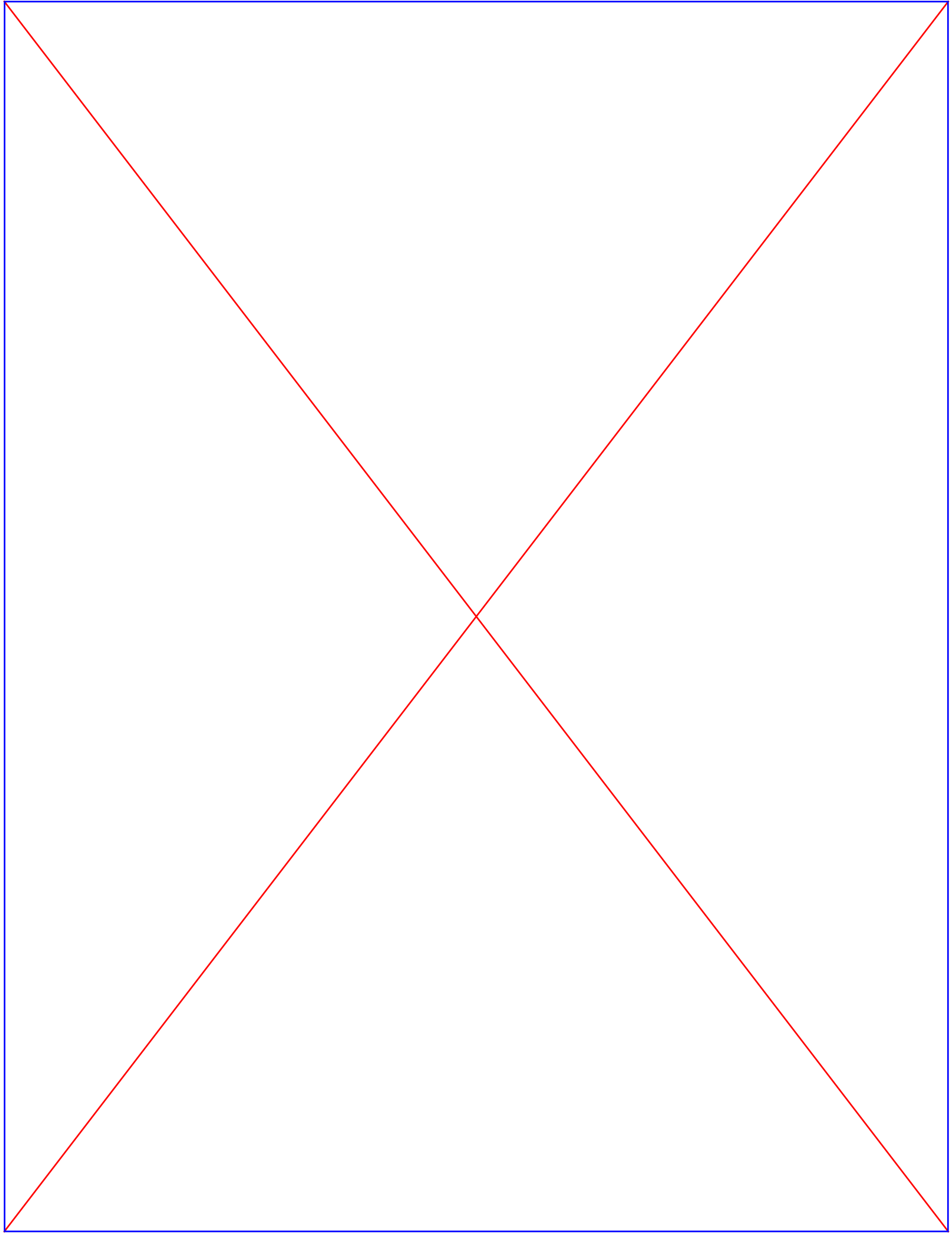












Conclusion

Over the last few decades, the discourse regarding the physician-patient relationship has focused on two extremes: autonomy and paternalism. Many have attacked physicians as paternalistic, urging the empowerment of patients to control their own care. This view, the informative model, has become dominant in bioethics and legal standards. This model embodies a defective conception of patient autonomy, and it reduces the physician's role to that of a technologist. The essence of doctoring is a fabric of knowledge, understanding, teaching, and action, in which the caring physician integrates the patient's medical condition and health-related values, makes a recommendation on

the appropriate course of action, and tries to persuade the patient of the worthiness of this approach and the values it realizes. The physician with a caring attitude is the ideal embodied in the deliberative model, the ideal that should inform laws and policies that regulate the physician-patient interaction.

Finally, it may be worth noting that the four models outlined herein are not limited to the medical realm; they may inform the public conception of other professional interactions as well. We suggest that the ideal relationships between lawyer and client, religious mentor and laity, and educator and student are well described by the deliberative model, at least in some of their essential aspects.

Discussion Questions

1. What are the main distinguishing features of each of the four models of the physician-patient relationship?
2. According to the authors, what should be the ideal physician-patient relationship? To what extent do you agree with their assessment? How does moral theory support your claim?
3. How might one use a moral theory (or theories) to argue against the authors' conclusion? Is there an adequate response to this protest?
4. If you had to choose one of the models to define your relationship with your physician, which model would it be? In light of the authors' claims and your assessment of them, do you think that relationship should change?
5. Which type of professional-client relationship described by Paul Faber (Chapter 4) would the authors think is ethically appropriate for the physician-patient relationship specifically?

Legal and Ethical Myths About Informed Consent

ALAN MEISEL AND MARK KUCZEWSKI

INFORMED CONSENT is a foundational concept of medical ethics. Since its enunciation almost 4 decades ago, it has engendered, and continues to

engender, a great deal of debate and opposition from practicing physicians. We believe that much of the negative reaction to informed consent stems

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"Legal and Ethical Myths About Informed Consent," Archives of Internal Medicine 156 (1996), pp. 2521-26. Reprinted with kind permission of the American Medical Association.

Approaches to Informed Consent: Rights vs. Shared Process

Patient autonomy began to grow as an antidote to physician paternalism—the supposed tendency of physicians to assume almost complete responsibility for determining what treatment patients would have—and in recognition of the fact that what treatment patients should have is a normative as well as a scientific determination. Its function in preserving a patient's liberties is probably responsible for the enthusiastic response lawyers have given to informed consent. However, too strong an emphasis on its legal origins and function eclipses the fact that informed consent is not merely a legal concept.

Informed consent is a legal doctrine that also supports many of our cherished ideals about the rights of the individual. The law's rights-oriented approach to informed consent assumes that the individual patient is characterized by a set of personal values that no one but that patient can know. In deciding what treatment, if any, a patient is to receive, the physician is viewed as an expert who should leave his or her values aside and only bring technical expertise into play. In the standard rendition of informed consent, the physician's role is to explain the various possibilities for the diagnosis or treatment of a particular patient's condition, and the patient is to consider this information in the context of his or her own values and then choose a course of treatment suited to him or her.

This approach fits certain cases nicely, for example, religiously based treatment refusals by a competent adult patient. However, mindless application of this approach to all medical decision making is responsible for many of the myths that have developed about informed consent. In the clinical setting, rights often recede into the background, and it is more helpful to approach informed consent as a *shared process* of decision making. A shared process approach does not restrict the physician to providing facts and insists that the patient supply all the values. The physician and patient each have access to interrelated facts and values. The values and thinking of the physician and patient should gradually take shape. They should mutually monitor each other so that their goals, thoughts, and evaluations become transparent to each other.

Conceived as a process of shared decision making, informed consent can accommodate both

patient autonomy and the physician's responsibility for the well-being of the patient. As we explore some of the myths about informed consent, we highlight how a balance should be struck to accommodate both autonomy and beneficence.

Myth 1: A Signed Consent Form Is Informed Consent

Perhaps the most fundamental and pervasive myth about informed consent is that informed consent has been obtained when a patient signs a consent form. Nothing could be further from the truth, as many courts have pointed out to physicians who were only too willing to believe this myth. Consent forms are used as a matter of routine in both treatment and research settings because many hospital administrators, physicians, and their attorneys see these forms as providing protection against liability, despite the fact that they actually provide little protection.

Consent forms do have some value. They create an inference that the patient at least had an opportunity to read the information on it. If the information presented in the consent form contains a description of the risk that actually came to pass and contains other information that is adequate for a patient to make a decision, it will probably be helpful to a physician in the defense of a lawsuit.

On the other hand, if the information on the form is not adequate or is overly complex, the form may provide evidence to support the *patient's* case. If the form merely acknowledges that disclosure was made, but fails to recite the *content* of what should have been disclosed, it is unlikely to provide the physician with any advantage with respect to the main issue in a lawsuit: what was disclosed and whether it was adequate. Contemporary consent forms—often optimistically referred to as “informed consent forms” as if wishing would make it so—provide a false sense of security to physicians and hospital administrators who are led to believe that a signed consent form constitutes informed consent.

Myth 2: Informed Consent Is a Medical Miranda Warning

As practiced, and certainly as symbolized by consent forms, informed consent is often no more than a medical Miranda warning. Just as police are

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required to tell criminal suspects that "you have a right to remain silent, you have a right to a lawyer, and if you choose to speak, anything you say can be used against you," some physicians believe that informed consent has been obtained if they warn patients of the risks of treatment.

Certainly, patients should be told about the risks of treatment. Admittedly, it is difficult to know what risks must be disclosed, but the approach to informed consent that we advocate makes this less important. Rather than focusing on risks, the focus needs to be on therapeutic options. For example, patients with ulcers need to know about medical treatment and surgical treatment. Patients with breast cancer need to know about different kinds and combinations of surgery, radiation, and chemotherapy. All patients always need to know that one of their options is to do nothing.

Knowledge of one's options alone, however, is not meaningful unless one also knows the range of consequences is choosing each option. One facet of information about consequences is the risks of treatment, but there are others such as information about the likely outcomes, including information about mortality, morbidity, and functioning.

Myth 3: Informed Consent Requires That Physicians Operate a Medical Cafeteria

A myth that contradicts the previous one, yet is sometimes held simultaneously with it, is that informed consent requires physicians to operate a medical cafeteria, in which they must set out all the therapeutic options and let patients choose, each according to his or her own appetite. The law clearly does not require this.

Some physicians feel that their ability to practice medicine "the way we used to in the good old days" has been impinged on not only by courts and lawyers but also by third-party payers, health facility administrators, Congress, the state legislature, governmental bureaucrats, and patients incited by Ralph Nader, the consumer advocate. In a sense, this myth about informed consent has arisen as an antidote to the previous one. It is not hard to envision a physician, who has been continually told to provide patients with information about medical options and their consequences, wringing his or her hands in disgust or discouragement and responding with,

Well, damn it, if informed consent is all about letting patients chart their own course in medical matters, then let *them* do it. And if things go wrong, well it's their own fault—both because *they* did the choosing, and because *they* didn't listen to us.

When this attitude is at work, there is a serious sin of omission. What is being omitted is a central part of the physician-patient relationship as both physicians and patients view it—namely, the physician's role as medical adviser.

Patients usually want more than information. They also want advice. They say, "Doctor, if you were in my position, what would you do?" That does not mean they are going to do what their physician would do, nor does it mean that they should have just let the physician decide from the outset. It does not mean that informed consent is a charade. What it means is that informed consent is a process and part of the process is human interaction. Rather than thinking of informed consent as an abstract ideal, what we call informed consent should take the form of a conversation in which patients get information, ask questions, give information, and say "I want to think about it" or "I've thought about it and I can't decide. What do you think I should do?" Thus viewed, informed consent is a process of *shared* or *collaborative* decision making.

Another way of looking at the process of informed consent is that it must mix together treatment goals and particular treatments. Most of the confusion surrounding the cafeteria approach to informed consent assumes that patients wish to micromanage their care. This is rarely the case.⁵ However, patients are entitled to know the goals of therapeutic options and when that goal has changed. Too often, treatments are discussed in detail but patients are not really sure what the treatment is ultimately meant to do. Similarly, when new treatments are introduced and discussed, it is not always clear to the patient that the old goal is no longer realistic, eg, cure is no longer possible, and that this new treatment is directed at a different goal such as minimizing disability or relieving pain. Patients are not experts at treatments; physicians are. However, patients' preferences are central to

⁵Churchill LR. Trust, autonomy, and advance directives. *J Religion Health*. 1989; 28:175-183.

and their consequences and a refusal of treatment is a choice to do nothing, which has predictable consequences too. This is not a resurrection of the cafeteria approach, nor are we recommending that the physician present the entire treatment menu. What we are saying is that when the physician examines the patient and says, for example, "We'll have to do bypass surgery," and omitted discussion of the choice of goals, he or she has assumed that the patient would agree about the treatment to meet that goal.

Myth 6: Patients Cannot Give Informed Consent Because They Cannot Understand Complex Medical Information

The notion that informed consent is a myth and bad medicine is premised in part on the assumption that providing information to patients frightens them.⁸ These characterizations are also based on the assumed difficulty of transmitting technical information to patients. A typical unspoken thought might go,

Patients can't understand all this medical stuff. Why I have trouble keeping up with my own subspecialty, I've forgotten 95% of what I learned in medical school, and the 5% I remember is now outdated. Even worse, what about all those empirical studies that show that patients who have been given information don't remember it 6 months, 6 days, or even 6 hours or 6 minutes later?

There are at least 2 errors in this reasoning. The first is the equation of recall with understanding. While it might be true that someone who cannot retain information for a few seconds might not be said to understand it, people often make reasonable decisions but cannot later recall the premises that supported the reasoning or the process that led to the conclusion. Nevertheless, they might well have understood it at the time.

The second error is the assumption that patients must understand information in the same way and to the same extent as the physician. It is true that a patient who is totally bereft of understanding lacks decision-making capacity and would

be considered legally incompetent. In such a case, decision making would need to take place with a surrogate decision maker acting on the patient's behalf. The fact that a patient might put an odd gloss on information or might not have a completely accurate factual understanding of the information does not disqualify that patient as a decision maker. To have decision-making capacity, patients do not need to be Jonas Salk. They merely need to be able to understand their options and the potential risks and benefits of these options. Most assuredly the fact that the patient reaches a decision different from the one that the physician would have made does not mean that the patient does not understand the information.

What is critical is that patients be given information and that they have a chance to use it in formulating a decision, to ask questions about it, and to gather further information. It is essential that they be given the context for the proposed treatments, ie, they must be told the physician's goals in making this treatment recommendation. However, within broad limits, patients have the right to set their own goals and to make their own decisions in their own way and for their own reasons, which includes the right *not* to use information that others might think relevant, rational, and even necessary to decision making.

We are steering a course between extremes. One extreme assumes that a patient just cannot understand medical information, and so we should give up on informed consent. On the other end of the spectrum resides the extreme rights-oriented view that a patient's treatment choices should not be challenged. We advocate the middle path: patients' choices should make sense in terms of their values and way of making sense of the world and these decisions should be made in the manner patients normally make similar choices. However, to require "understanding" in the same way and to the same extent that a physician understands the information is as paternalistic as not permitting patients to participate in decision making at all.

Myth 7: Patients Must Be Given Information Whether They Want It or Not

Some patients choose not to participate in the decision-making process at all or may wish to

⁸Katz, Judges, physicians, and patients, pp. 74-76.

participate on a reduced basis. Withholding information from patients when they request that it not be given respects their autonomy as much as providing information to patients who want it. Enabling and permitting patients to make medical decisions is one way of fostering self-determination; respecting their wish not to participate is another. *Compelling* patients to receive information that they do not want or to make decisions that they do not wish to make is to fail to respect their dignity.

Withholding information from patients at their request is a legally recognized exception to informed consent referred to as waiver.⁹ Usually, only by initiating a conversation with a patient can a physician determine that a patient wishes to participate in only a limited way, or not at all, in the decision-making process. In some instances, patients may fully engage in such a conversation and only at the end declare that they do not know what to do and wish to leave the decision to a family member, the physician, or someone else. In such a case, a patient can be said to have waived the right to decide though not the right to be informed. Sometimes patients make it clear that they do not even want to talk about therapeutic options and consequences. They may be willing to make a decision on less, rather than more, information. In such a case, a patient can be said to have waived the right to be informed, though not necessarily the right to decide. Or patients may want neither information nor to decide, again preferring to leave it all to someone else.

Thus, the waiver exception parallels the 2 distinct but related rights that informed consent embodies, the right to be given information and the right to decide. Patients who waive their right to decide do not automatically waive their right to information. There may be good reasons to continue to provide information to such patients. One is that just because patients do not want to make a particular treatment decision does not mean that they will not wish to participate in the future. Furthermore, there are reasons to provide information other than for decision making. Patients also need information to facilitate compliance with treatment decisions. They deserve information

about their treatment as a sign of respect and so that they can be prepared for what is to happen to them.

Myth 8: Information May Be Withheld If It Will Cause the Patient to Refuse Treatment

It is ironic that physicians who profess not to know much about informed consent sometimes do know about the therapeutic privilege, which, like the waiver exception, allows information to be withheld from patients. When information is withheld under the waiver exception, *patients* decide that having information would not serve their ends. By contrast, when the therapeutic privilege is invoked to withhold information, the physician determines that providing the patient with information would undermine, rather than promote, the goals of informed consent.

The purpose of the therapeutic privilege is to allow physicians to honor their "primary duties" to do what is beneficial for the patients and to avoid inflicting harm on them.¹⁰ However, it is far less clear what circumstances justify the physician in withholding information. In general, physicians are permitted to withhold information when its disclosure would seriously harm the patient.

In practice, the therapeutic privilege may legitimate a physician's natural aversion to providing unpleasant information to patients—indeed, almost everyone's natural aversion to providing unpleasant information to anyone else. However, the therapeutic privilege is not a license for physicians to withhold information when they fear, rightly or wrongly, that providing it to patients will lead them to refuse recommended treatment. Such a view of the privilege is paternalistic in the extreme; it threatens to devour any obligation to provide information and would permit physicians to substitute their judgment for the patient's. The more appropriate formulation of the privilege permits physicians to tailor (and even withhold) information when, but only when, its disclosure would so upset a patient that he or she could not rationally engage in a conversation about therapeutic options and consequences.

⁹Meisel A. The "exceptions" to the informed consent doctrine: Striking a balance between competing values in medical decision-making. *Wis Law Rev.* 1979; 413-488.

¹⁰*Nishi v Hartwell*, 473 P2d 116 (Haw 1970).

itself, what seems frightening is the very real prospect of losing control over one's own dying process. The reaction to this exorbitant sway of medicine has been nourished since the 1970s: patients' empowerment or, more generally, the liberal individualism that has vigorously extended into the medical system. In response, advance directives, health care proxies, and other devices founded on the right to forgo medical treatment aim to "protect" patients from physicians, medicine, and hospitals' institutional imperatives. From the perspective of this recent history, physician-assisted suicide and even voluntary active euthanasia are just one more necessary and justified step in this process. It is as if what modern medicine has expropriated from individuals could be returned to them through physician-assisted suicide: control over their own deaths.

These considerations condense two widespread current assumptions in the debate over aid in dying. The first is that these practices are, for better or for worse, pragmatic expressions of patients' autonomy. Although proponents and opponents evaluate very differently the adequacy and the limits conferred to self-determination in this context, they both endorse this general assertion. The second assumption is that physician-assisted suicide and voluntary active euthanasia are ultimate brakes on the unrestrained use of medical technology at the end of life. They are instruments to promote the "demedicalization" of death.

I propose to challenge these assumptions. I want to argue that physician-assisted suicide does not demedicalize death; rather, it medicalizes suicide. By this I mean it transforms a private act (suicide) into a medical event. Indeed, physician-assisted suicide implies not a resistance to but an extension of medical power over life and death. And second, that instead of asserting an individual's autonomy physician-assisted suicide is in fact an impediment to it.

My analysis accepts the liberal/libertarian presumption that one of the essential attributes of the individual is precisely the liberty to govern oneself free from external constraints. Despite my belief in both the indispensability and inevitability of social constraints, as an analytic device here I will assume radical autonomy to be a moral goal. I will also assume that from the perspective of the physician-patient dyad, more than killing, "assisted suicide"

is literally what the phrase states: suicide with assistance, not only because it is the patient who makes the request, but also because it is she who is responsible for the final deed.

Promoting Autonomy, Demedicalizing Death

Many of those who favor physician-assisted suicide analyze and support it in reference to free choice, individual rights, and moral autonomy. This line of argument rests on a conception of autonomy primarily as "negative liberty": the right to act and govern oneself in accordance with one's own private beliefs, values, and choices without interference as long as one's behavior does not harm others. Proponents assert that this right should encompass patients' control over the timing and circumstances of death up to and including assistance in suicide. So conceived as a "personal and intimate decision," the right to aid in dying refers to a sphere of self-determination that should be left free from any paternalistic interference, whether that interference emanates from the state, from doctors, from family members, or from religious or philosophical orthodoxies. Physician-assisted suicide is, in short, advocated as a "natural" extension of the constitutionally protected "right to privacy," and as a mere specification of the moral right to self-determination.

Opponents of this line of argument contest the pre-eminence conferred on autonomy vis-a-vis other social values and interests. The sanctity of life, the protection of those who are vulnerable to medical or family abuses, the "common good," and the ethical integrity of the medical professional (that is, the preservation of its ancient vow never intentionally to kill) are variously seen as competing values that in fact outweigh individual autonomy. What is contested is not physician-assisted suicide as an instrument of personal autonomy; critics insist that even if assisted suicide does serve autonomy, limits should be imposed on this value for the sake of other goods. Daniel Callahan's argument is illustrative: "the acceptance of euthanasia would sanction a view of autonomy holding that individuals may, in the name of their own private, idiosyncratic view of the good life, call upon others, including such institutions as medicine, to help them to pursue that life, even at

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suicide the individual "drops out" of the social order, in the context of physician-assisted suicide the individual "drops into" a system that recognizes and must even authorize this particular (ostensibly private) choice. In other words, displacing suicide from the private arena to bring it under medicine's stewardship means surrendering suicide to the (medical) "establishment."

Precisely because assisted suicide requires the connivance of others (direct from doctors, indirect from society), it cannot be seen as an act that solely expresses the ideal of individual autonomy. On the contrary, as long as it entails assistance it implies a mutual decision. Additionally, and, even more importantly, more than a mutual decision, assisted suicide presupposes that medicine has passed judgment on the act of suicide. In sum, physician-assisted suicide introduces tensions in the principle of personal autonomy and entails an increase of medical power over death and social morality.

Medicalizing Suicide

Medicalizing suicide encompasses three different (though interrelated) facets: the medicalization of an act, of a practice, and above all of the social ethos of death and suicide.

MEDICALIZING THE ACT OF SUICIDE

In the typical physician-assisted suicide scenario, the patient is responsible both for requesting aid in dying and for performing the final deed, and she or he construes the act basically as suicide. Yet as long as the physician is in charge of assisting the patient—either by his or her physical presence or by supplying the medical means to perform the act—physician-assisted suicide entails the medicalization of the act of suicide.

Ideally, for the physician to assist a patient's suicide the physician must be physically present—as attested in Timothy Quill's regrets for "abandoning" Diane, leaving her to take the prescribed lethal medication alone.⁵ Thus what is intriguing in physician-assisted suicide is not that ventilators, tubes, CPR, and so on are supplanted by "lethal

drugs," but that even in this context the physician and medicine are overwhelmingly present in the setting of death.

Even without the doctor's physical presence in the last scene, as long as physician-assisted suicide presupposes medical assistance it cannot be conceived as immersed in the realm of self-determination. Unless doctors are reduced strictly to being instruments to fulfill their patients' desires, physician-assisted suicide enacts what must be seen as a mutual decision. But what kind of questions are at stake in this joint decision? Proponents of assisted suicide suggest that patient and physician discuss the patient's medical condition and explore alternatives for alleviating pain and suffering. If it comes to it, the physician should provide a prescription for a lethal drug that leads to a "rapid" and "painless" death.⁶ That is, the decision to die by suicide is treated precisely as if it were a set of clinical problems to be solved medically—the "private," "intimate," "self-determining" decision to commit suicide is translated into a clinical event.

MEDICALIZING SUICIDE AS PROFESSIONAL PRACTICE

Medicalizing suicide also points to the fact that if legalized, physician-assisted suicide as a legitimate practice would become the prerogative of physicians. Indeed, Jack Kevorkian has seen the exclusive right as the foundation for a new medical subspecialty of "obituary."⁷

This monopoly leads to the more general question of why aid in dying should be provided only by a medical practitioner. Why, that is, should assistance in suicide be understood as requiring medical authority rather than, for instance, a community of family or friends? The most obvious answer is that physicians—and only physicians—have the necessary technical skills to ensure a "rapid" and "painless" death. But as some critics have noted, "Assisted suicide does not even require medical skill. . . . If freeing up patients

⁵Timothy E. Quill, *Death and Dignity: Making Choices and Taking Charge* (New York: W.W. Norton & Company, 1993).

⁶New York State Task Force on Life and the Law, *When Death Is Sought: Assisted Suicide and Euthanasia in the Medical Context* (Albany, NY: New York State Task Force on Life and the Law, 1994), p. 105.

⁷Jack Kevorkian, *Prescription: Medicine* (New York: Prometheus Books, 1991).

truly is the goal, then assisted suicide's advocates disserve patients when they do not advocate ending the physician's exclusive power to prescribe medication. Ironically, the advocates of patients' rights end up empowering doctors more than they do patients."⁸

Yet even those who maintain that technical knowledge is imperative do not confine their justification of physician-assisted suicide to this reason. Placing suicide under the stewardship of medicine is further defended as a way of "enhancing public accountability of the practice" and "protecting against abuse."⁹ From the patient's perspective, the request for aid in dying may mean a "desire for companionship in pursuing a difficult course of action, a wish for confirmation of a decision about which the patient is unsure or simply a cry for help" (pp. 88-89, note 42). Moreover, since suicide is still stigmatized, "seeking a physician's assistance may be a way of trying to remove that stigma."¹⁰ But inasmuch as cultural preconceptions and loneliness (whatever its source) are far from being exclusively medical issues, we must ask why we expect doctors to respond to them. Two possible answers come to mind: either medicine is moving beyond its proper role, or the scope of medical competence has already been extended beyond appropriate boundaries.

It seems reasonable to conclude that ceding monopoly of assistance in suicide to doctors is anchored in an inflation of the physician's role, as well as in the extreme idealization of physicians' character and the relationships they establish with patients. The bond physicians establish with patients is supposedly effective, collaborative, and committed. Both this idealization and the willingness to delegate to physicians the exclusive right to assist suicide bespeak the social and symbolic power already conferred on medicine and medical professionals in our societies. In other words, it is not (or not only) the need for technical expertise that impels us to physician-assisted suicide. Rather, our culture, so impregnated by medicalization,

takes for granted that assisted suicide should fall under the control and supervision of medicine.

MEDICALIZING THE MORALITY OF SUICIDE

As a legitimate domain of professional practice, then, physician-assisted suicide necessarily involves medicalizing the moral questions surrounding suicide. Physician-assisted suicide presupposes, and ultimately is, a medical judgment about death or suicide; it is a medical evaluation of the fairness and legitimacy of a person's (not simply a patient's) desire or choice to end his or her life.

With some few exceptions, even the most radical advocates of physician-assisted suicide recognize the need to establish protocols and guidelines to prevent abuses, protect the vulnerable, guarantee public accountability, and even to assure the autonomous character of the patient's choice. Surely these aims are respectable and the setting up of criteria just and reasonable. Yet establishing medical guidelines also introduces tensions into the value of autonomy in several ways.

The requisites for physician-assisted suicide (must the patient be terminally ill? which medical specialists are best qualified as consultants?) are still being debated. There is, however, agreement about the moral attributes that the patient and his or her request must evince: the decision to die must be "informed," "rational," "stable," and "fully free" or "voluntary." And there is broad agreement that to ensure that these conditions are fulfilled the patient must submit to screening by a team of doctors (the treating physician, a consulting physician, and a psychiatrist) who would evaluate the request for aid in dying.

This requirement assumes that besides undue external influences, some impulses or dispositions emanating from the patient herself or himself—such as depression or guilt—may threaten "pure choice." "Voluntariness" in this sense must be safeguarded from undue influence stemming not only from outside, but also from within. Ultimately, this is to assume that the inner world may be obscure to the individual, that she or he may be half blind to her or his own choice, desire, or personal truth.

The presumption that the inner world is or may be opaque to the individual suggests a second underlying presupposition: someone other than

⁸Giles R. Scofield, "Privacy (or Liberty) and Assisted Suicide," *Journal of Pain and Symptom Management* 6, no. 5 (1991): 280-88, at 285.

⁹New York State Task Force, *When Death Is Sought*, p. 105.

¹⁰Dan W. Brock, "Voluntary Active Euthanasia," *Hastings Center Report* 22, no. 2 (1992): 10-22, at 21.

The tension remains, however. In the context of assisted suicide, how is it possible to reconcile the assertion that paternalistic influences are unacceptable with the concept that in some situations the state (or the medical establishment) may deny assistance in suicide in the name of "what it reasonably judges to be the best interest of the potential suicide"? Alexander Capron has argued that decisions on behalf of others should utilize a best interest standard of what the "average reasonable person would do under the given circumstances."¹³ Doesn't this permit the tyranny of the majority over the individual? Doesn't this menace the right, so praised by liberal theorists, to exercise our singularities in a radical way? As Yale Kamisar has asked, "[I]f self-determination and autonomy is the major force driving the right to assisted suicide, why should a competent person's firm conclusion that life has become unendurable for her have to be 'objectively reasonable'? Why should not a competent person's own evaluation of her situation suffice?"¹⁴ To phrase this in terms of the

argument I make here, is it ever possible to reconcile medicalizing suicide with autonomy?

It could reasonably be argued that guidelines for physician-assisted suicide do not injure the patient's self-determination since the request emanates from a patient who supposedly knows the rules of the game in advance. And, the argument would continue, if one does not wish to submit to those rules, "do it yourself" remains a way out. But this seems to admit that ultimately assisted suicide has to do with something beyond strict self-determination, that autonomy is not the primary moral foundation, or at least that if autonomy is to be exercised it demands constant external oversight.

In sum, although advocated in the name of self-sovereignty, physician-assisted suicide ends up reinforcing a power external to the self. It reinforces medical power at the expense of the individual in a very sensitive realm: one's decision to die.

¹³Alexander M. Capron, "Substituting Our Judgment," *Hastings Center Report* 22, no. 2 (1992): 58-59, at 59.

¹⁴Yale Kamisar, "Physician-Assisted Suicide: The Last Bridge to Voluntary Active Euthanasia," in *Euthanasia*

Examined: Ethical, Clinical and Other Legal Perspectives, ed. John Keown (Cambridge: Cambridge University Press, 1995), pp. 225-60, at 239.

Discussion Questions

1. Salem attempts to persuade us that allowing physician-assisted suicide does not demedicalize death, but instead medicalizes suicide. What, more precisely, does she mean? How does she argue for this point?
2. A number of scholars believe that physician-assisted suicide promotes individual autonomy. Explain why this is so. Explain why Salem believes that physician-assisted suicide is actually an impediment to individual autonomy. Based on your understanding of the notion of autonomy, do you agree with Salem's claims? Why or why not?
3. Helping other people to commit suicide is against the law in most places and is commonly thought to be ethically wrong as well. However, defenders of physician-assisted suicide argue that this is a legitimate exception. Could Kantian deontology support such a view? What other moral theory (or theories) might be used to justify this exception?

Reassessing the Reliability of Advance Directives

THOMAS MAY

Introduction

A competent patient has the right to refuse treatment necessary to sustain life. However, for many end-of-life decisions, we lack direct access to the wishes of a competent patient. Some treatment decisions near the end of life involve patients with severely diminished mental capacity (for example, Alzheimer's patients), some involve patients who are unable to communicate (for example, some stroke victims), and some involve patients who are simply unable or unwilling to participate in decisionmaking due to the nature or severity of their illness.

In response to this, most states have now recognized the extension of a competent patient's right to refuse treatment through advance directives, which allow a competent person to specify in advance an approach to treatment decisionmaking when he or she is unable to directly participate in the decision. Indeed, this extension of a patient's rights has been recognized at a federal level through the Patient Self-Determination Act.

A question remains, however, concerning the extent to which this extension of a competent patient's right to refuse treatment should be recognized. In this paper, I will argue that we should not recognize advance directives as equivalent to the decisions made by a competent patient. While I believe there are good reasons to recognize advance directives in many (perhaps even most) circumstances, I also believe there are good reasons for recognizing the important differences between advance directives and the direct decisions of a competent patient, and to require that additional criteria be met before advance directives become operative in treatment decisionmaking.

Many discussions of advance directives (ADs) and self-determination focus on the question of

personal identity: If the AD is to reflect the patient's autonomy, we must address the question of the identity of the person who issues the AD and his or her relation to the person who is to receive (or not receive) treatment through the application of the AD. While this is surely an important question, it will not be the focus of this paper. Rather, I shall consider whether, given the resolution of problems concerning personal identity, the AD could be considered an embodiment of patient autonomy. Ultimately, I will argue that it cannot. That is, even if the patient who is to receive treatment under the application of the AD can in fact be said to be the same person who issued the AD, because of certain defining characteristics of the application of ADs, the application of the AD must be seen as "binding" the patient in a way that is incompatible with the patient's autonomy.

Because of this focus, I will treat advance directives in a generic fashion. There are several forms that an AD might take. For example, the "living will" and "durable power of attorney" are the most common, but "medical directives" and "values histories" may also be forms an AD might take. I will treat these in generic fashion because each represents, for the purposes of this discussion, a similar phenomenon. Each form of advance directive represents a commitment to a particular strategy for making healthcare treatment decisions when the patient in question is unable to make such decisions directly.

For example, the strategy represented by an AD may take the form of an appeal to a living will, appeal to the judgment of a chosen surrogate decisionmaker, appeal to an articulated medical directive, or an appeal to the values articulated in a values history. Each form of an AD, however, represents a particular strategy to be used to deter-

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