

The Principles of the Belmont Report Revisited

How Have Respect for Persons, Beneficence,
and Justice Been Applied to Clinical Medicine?

by ERIC J. CASSELL

Although written primarily for medical research, the Belmont principles have permeated clinical medicine as well. In fact, they are part of a broad cultural shift that has dramatically reworked the relationship between doctor and patient. In the early 1950s, medicine was about making the patient better and maintaining optimism when the patient could not get better. By the 1990s, medicine was about the treatment of specific physiological systems, as directed by the patient, but as limited by the society's concern for justice.

In 1954 a man in his fifties was admitted to a teaching hospital with a heart attack of a few hours' duration. He was to be the first subject of an innovative treatment (intravenous streptokinase and streptodornase) to dissolve the thrombosis in his coronary artery.

The patient was chosen because he was a derelict with no living relatives. In the fashion of the day, he was not told what was to be done and no consent was requested or obtained. An attending physician, resident, and medical student were in constant attendance. After a number of hours of receiving the new medication, an irregularity of his heart rhythm developed. The treatment was stopped out of fear for his safety.

In 1997 a thirty-eight-year-old woman with stage IV (metastatic) cancer of the breast received high-dose chemotherapy followed by a bone marrow stem-cell transplant at a major western medical center, after almost three years of continuous disease and multiple treatments. Months later a routine CT scan revealed

what appeared to the transplant oncologist to be recurrent cancer in the spine. The implication was that the chemotherapy and bone marrow transplant had failed.

The transplant oncologist sent the following letter to the patient, her radiation oncologist, and the chief of the breast service at a major cancer center in the patient's home city:

Dear Olga [the patient], Cheryl, and Jimmy:

Enclosed is the relevant bone window from Olga's 11-12-97 CT Scan (as well as the formal reading) demonstrating the new sclerotic focus in the left pedicle of L2. I have circled it in red. It looks real to me and I would have Cheryl buzz [radiate] that area.

Olga, this is our only copy so will you send that one sheet back to us for our files? Hope all is well with the three of you. Talk to you soon.

Sincerely

[Signed]

Associate Director,
Bone Marrow Transplant Program

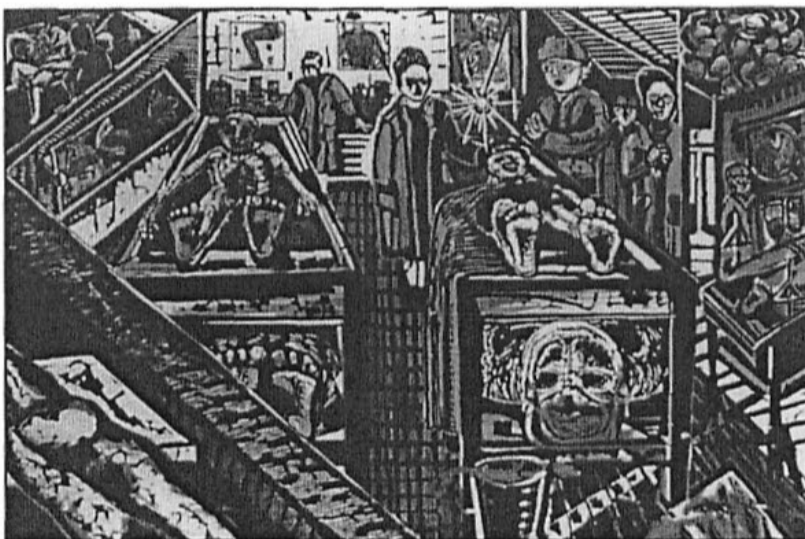
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In the forty-three years between these cases both medicine and the society around it have changed significantly under the influence of complex and intertwining forces. Scientific and technological advance have come to drive medical practice; the organization and financing of medical services have been remodeled in response both to new therapeutic capabilities and to the increasing costs of those therapies; chronic disease has displaced infectious and other acute diseases as the leading reason for seeking medical care and the leading cause of death; and the relationship between the patient and the physician has shifted not only toward "patient-centered" care but equally toward consumerism.

American society, of course, has undergone equally deep changes as government and authority were challenged in the social unrest of the '60s and '70s, rights movements of all kinds (civil rights, women's rights, patients' rights, gay rights, disability rights, and others) have gained prominence, individualism and pride in ethnicity have superseded the metaphor of the American "melting pot," and information technologies and financial and economic forces have captured the social imagination, allowing an ever-widening gap to open between rich and poor.

Like the wider society, neither the profession of medicine nor medical education is what it was a scant four decades ago.

Just about midway through these forty years of transformation, in 1978, the National Commission for the Protection of Human Subjects in Biomedical and Behavioral Research published the *Belmont Report*, introducing the principles of respect for persons, beneficence, and justice into research with human subjects—and foreclosing scenarios like the opening case. The Belmont principles have permeated clinical medicine as well. For example, recognition of the importance of freedom of choice as an aspect of respect for persons is now instantiated in informed consent doc-



Eric Avery, *As It Is*, 1987, five-color lithograph with woodcut overprint, courtesy of the artist.

uments, laws, and court rulings. Similarly, the principles of respect for persons and beneficence are institutionalized in hospital functions that monitor quality of care, such as the tissue committees that insure that surgical procedures are appropriate. Patterns of practice, professional ideals, and the everyday behavior of both doctors and patients also demonstrate the definitions and application of the principles. They show what patients expect or demand and what physicians feel obligated to do. But what the principles mean is closely bound up with the changes in medicine and the social context in which medicine is practiced.

Beneficence

I begin with the principle of beneficence because the place of respect for persons and justice in clinical practice is easier to understand when one becomes aware of the changes since the 1950s in what counts as beneficence in medicine. Beneficent (or benevolent) actions or behaviors are those that actively do good or that actively protect from harm. Initially, the idea of doing good and avoiding harm was seen as resulting from both physicians' personal characteristics and medical effectiveness. The for-

mer, if ideal, would be devoid of overweening pride, venality, impure motives, untrustworthiness, and carelessness. The latter was a function of technical knowledge and proficiency. The physicians of the derelict with the heart attack suffered both moral and technical inadequacies of which they were largely unaware. They were, however, unquestionably aware of the dangers and fearful of harming him.

The intervening period in medicine has seen an explosion of technical capacity and a great increase in moral awareness, but the concept of benevolence has shrunk *pari passu*. The personal characteristics of physicians that served beneficence and were believed to be of great importance in previous generations now serve nostalgia more than clinical medicine.

In the early 1950s, being made better was often defined as having the burdens of disease lifted. Benevolence had to do with making patients better. During my training and early years of medical practice, disease manifestations were treated because they were there. Hernias, hemorrhoids that made any trouble, and most varicose veins of the legs were surgically removed, as were many superficial tumors and abnormalities. By the late 1950s, psychological de-

A Fifty-Year Perspective

Alterations in the relationship between patient and physician over the last fifty years have occurred within a set of large transformations in the medical and social parameters that enframe the relationship. The following changes occurred in medicine:

- Chronic diseases became overwhelmingly the most common cause of death and most frequent reason for seeking medical care, displacing infections and other acute diseases.
- Access to health care came to be considered a right. Most western nations (but not the United States) provided universal access to care.
- The "therapeutic revolution" took place, grounded on progressively greater knowledge of medical science. Technological advance became a driving force.
- The cost of medical care rose worldwide. Economic and legal forces became increasingly important, frequently displacing moral determinants.
- The organization and financing of the delivery of medical services changed. Fee-for-service medicine withered and physicians increasingly became employees of medical care organizations, were paid according to predetermined fee schedules, or received a capitated rate. The political and social power of physicians shrank.
- Physicians' performance was increasingly measured by evidence-based, process, or outcome guidelines.
- The bioethics movement arose in the 1960s and became an influential voice.

- The relationship between patient and physician shifted. Consumerism and ideas such as patient-centered medicine became commonplace. The public became knowledgeable about medicine and medical science.
- The form and content of medical education changed little, although the curriculum was updated to reflect advances in medical science.

The surrounding society was also in flux:

- The social unrest and antiwar protests of the 1960s challenged the social structure of the nation and accompanied a decreased respect for government and authority in general.
- Rights movements came to prominence—civil rights, women's rights, patients' rights, disability rights, and gay rights.
- Pride in ethnicity and diversity and a still greater emphasis on individualism made the "melting pot" metaphor of the United States obsolete.
- Computers and, latterly, the Internet widely disseminated information that was previously available only to professionals.
- The power of the law and financial incentives to influence social behavior and professional relationships increased, overwhelming the established moral order. The bottom line became the bottom line.
- The gap between the rich and the poor grew steadily.

terminants of illness began to be better known, leading to the attribution of many common complaints to psychological causes. With that awareness, the psychotherapies began to displace the sympathetic ear that had been part of medical benevolence since antiquity.

Increasingly, the focus of medicine has come to be understanding functional abnormalities and pathophysiology—the chain of bodily events that lead to and define the abnormal state as well as explaining its manifestations. This important conceptual evolution has been supported by a number of trends. In medical science primacy is given to research on mechanisms of disease, including molecular biology. Newer diagnostic tech-

nologies facilitate study of the body and its parts in motion, replacing the static view of disease afforded by, for example, plain X-rays, electrocardiograms, and biopsies. Pharmacological innovation has produced legions of drugs that give excellent symptom control for complaints as diverse as migraine headaches, angina pectoris, asthma, and panic attacks. The old belief that one should treat the disease not the symptoms gave way to the understanding that in many conditions the symptoms *are* the disease.

The good of patients that was identified with making them better has changed as a structural understanding of disease has been superseded to a large extent by a pathophysiological perspective that focuses

on the function of parts. This encourages measuring benefit by the good done to only a part of the patient. With the rise of scientific medicine, what doctors had long done out of kindness, sympathy, patience, and personal interest—attentions directed solely at the person rather than the disease—were derogated as hand-holding or bedside manner, were not scientific medicine. As therapeutic effectiveness and scientific medicine came into bloom, the sick person lost standing to the body or disease as the place of clinical interventions and was no longer the primary locus of benevolence. The code of what was called medical ethics in times past was devoted to protecting patients (among

other goals). Now termed medical etiquette, it has largely disappeared.

Patients were also gaining power as a result of the rights movements, their increasing knowledge of medicine and science, and of the erosion of respect for authority in general and the authority of physicians specifically. The profession's view of benevolence as the cure of disease or the relief of its manifestations came under public scrutiny, as did the view of physicians as benevolent helpmates in general. For example, the 1973 self-help book *Our Bodies, Our Selves* was published to promote what the authors saw as the need for women to take back their bodies from physicians, whose motives and actions were viewed with increasing suspicion. Doing "what the doctor ordered" without question and out of respect for his or her benevolence and authority had long been the mode when I went into practice in 1961. It was largely gone by the end of the decade and has not returned.

With increasing knowledge about science and medicine, the public bought into medical definitions of treatment, improvement, and cure—largely devoted to parts of the patient rather than to the person of the patient—as evidence of the benevolence of the medical profession. It is, however—if one can imagine such an attribute—a disembodied benevolence. It is not doctors, one might guess from the attitude of the public, but their scientific knowledge and technology that diagnose, treat, and cure diseases. Knowledge of medical science and information about medicine began to pervade the media. With the advent of the Internet, patients have an ever-increasing array of options from which to choose, leading to a kind of evidence-based and guideline-driven "cafeteria medicine." Patients, now at center stage in medicine, define benevolence, while physicians retreat or are forced by managed care to retreat from taking responsibility for the whole patient.

Over the same forty-some years there have been countervailing trends within and outside medicine as well.

Response to wounds suffered during WWII started the rehabilitation medicine movement, which brought new understandings of function, thereafter defined not solely by the action of a body part but by the ability of a person to participate in a social role. Rehabilitation may not correct the underlying pathogenic mechanism, but it can restore function by retraining abnormal parts, utilizing other body mechanisms to compensate for lost function, and teaching persons to accommodate to their impairments.

When the goal is removing diseased tissues or restoring a diseased organ to normal—defined structurally—professional standards can define benevolence. But when the idea is to restore function to a part, or actively relieve symptoms, or return the patient to social function, then the sick person is the final arbiter of success. Only the patient knows when he or she is better.

In the care of the dying, the paradoxes of beneficence are easily seen. The goal of keeping people alive first entered medicine in the nineteenth century, well before the necessary technical capability existed. As time went on doctors became better able to support one physiological function after another apart from the state of the whole patient. Kidney dialysis replaced lost renal function, better ventilators replaced failed lungs and supported oxygenation, pacemakers and defibrillators maintained heart rhythm, total intravenous nutrition took over when oral nutrition failed, various methods of blood pressure support and volume replacement maintained circulation. Transfusions of various blood components as well as means for stimulating production of blood elements allowed for continued function of the blood as an organ. By the 1980s intensive care units contained patients on life support even though they had no chance of returning to meaningful life, whatever the outcome of their therapies. These patients lay alongside others with diseases for which resuscitation and life support were appropriate because, if

they could be maintained long enough, their return to full function was probable. These excesses led to a reaction among the public and physicians. The importance of a good death, first brought to public awareness by Elisabeth Kubler-Ross in her 1972 book *On Death and Dying*, received increasing support and was the subject of widespread discussion. Advance directives and "do not resuscitate" orders became more common, and the assignment of surrogates for medical purposes became easier and more frequent. The hospice movement provided an alternative for the care of the terminally ill and focused attention on the relief of pain. Nonetheless, as in other aspects of medical care, technical proficiency and scientific knowledge continued to define medical benevolence, again most often as the good done to a part. Patients were constantly told what was wrong and what was happening in considerable technical detail, and then given technical options to choose from, as was the case with Olga, the patient with breast cancer mentioned earlier. She, like others with similar end-stage diseases, chose to accept the physicians' recommendations, because choices were described to her only in terms of technical procedures.

The patient has become increasingly central, but codes, guidelines, laws, and legal actions have pushed the notion of wronging the patient to the fore, while the calculus of benefit and harm has receded as physicians have withdrawn even more from the ideals of the past.

Respect for Persons

The physicians of the derelict with the heart attack probably did not entertain the notion that he had a right to decide whether to participate in the experiment or that he was wronged by not having been asked for his consent. They chose a derelict with no family because more sophisticated patients were always wary of being "experimented on." By the

standards of the time they did the right thing: they protected the patient from harm. He was after all a patient, not a person. When persons became patients, their social status changed. In the late 1960s I admitted a mentally fit corporate president with pneumonia to the hospital. After I explained to him what I thought was wrong and what would take place, his wife and I went out into the corridor for a full discussion of his case—a discussion that would not now take place without his participation. Patienthood had in minutes deprived him of his status as a self-determined person. This was the fashion of the times.

The letter to Olga, the young woman with stage IV breast cancer, suggests that to the physicians Olga is clearly a person; it is the sick patient part of her identity that seems to have diminished. She has gained rights as a person, but no longer commands obligations due a patient.

The idea of respect for persons as described in the *Belmont Report*—or even the concept of persons qua persons—was not present in medicine in 1954. Benevolence and the avoidance of harm were the expressions of respect for the humanity of patients. Patients were to be treated as fully human. Persons, in contrast, are not merely human; they are social, moral, legal, and political entities with rights, to whom obligations are due. Because of this persons can not only be harmed, they can be wronged. It seems probable that the idea of person as we use it today—derivative as it is from the evolving concept of atomistic individuality—was just beginning to take full form after WWII. In the time period covered in this essay, the nature of persons changed, society changed, and medicine changed, resulting in a change in the meaning of respect for persons and autonomy. In the 1950s and early 1960s, women in public were not persons in their present sense, nor were people with disabilities, nor gay people. The civil rights movement achieved legal rights for blacks and other ethnic minorities

but also changed their social status by making them persons in the wider American community in a legal and political sense. These changes were not the end of the matter; they were the official beginning of a process that had started well before the civil rights movement and that continues to this day.

In *The Patient as Person: Explorations in Medical Ethics* (published in 1970), Paul Ramsey discusses the bond between physician and patient and how that bond defines both. Before the patient became fully a person, physicians were patients' decision-makers: doctors made decisions about the best thing to do and about what and how to tell patients about their circumstances. It was part of physicians' obligations and part of their patients' expectations. Good physicians knew that patients had to be informed about what was happening because too much uncertainty was considered bad.

But full disclosure of fatal or dangerous diagnoses or situations was thought to be harmful because it would be followed by hopelessness. When one patient I cared for was back in his room after his surgery for inoperable cancer of the stomach, he asked his surgeon what he had found. The surgeon said, "We did a lot of cuttin' and schnitten and removed a lotta junk and you're gonna be fine." I took care of the patient until he died months later. A few days before he died he said, "Sometimes lately I think maybe I'm not getting better."

Medicine was only a few decades into the beginning of the therapeutic revolution that now is taken for granted. Then, despite great expectations of the bounty to be expected from medical science, there was little optimism about the outcome of diseases such as cancer, strokes, heart attacks, heart failure, advanced diabetes, and emphysema. Only for children had everything improved, as their death rates from now curable infectious diseases dropped precipitously in the Western World.

It is important to understand the relation among the fall in death rates, the improvement in health and well-being, the optimism fed by scientific advances, and the notions of respect for persons and freedom of choice. Previously, if you believed that your cancer inevitably meant a hopeless outcome and a painful death, and if your physicians believed that there was nothing beyond surgery that could be done for you, you might not have been so eager for knowledge or the freedom to choose. Beyond refusing or agreeing to (say) surgery, there was not much choice. One did the mastectomy and waited for the patient to get a recurrence and die, or be lucky. So doctors lied, not because they were morally defective but because, in their eyes, all they had to offer was an attitude of optimism and denial of a bad truth. Especially since at that time personal matters that might arise from these illnesses and the doctors' lies—lost hopes, unhappiness, anxieties, sadness, suffering, death, and grief—were personal matters kept from the view of others, even physicians (unless they looked).

On the other hand, if death rates are falling and the expectation of becoming hopelessly ill is disappearing in the face of new treatments, if persons with disabilities are entering active life in increasing numbers, if optimism pervades medicine, and if the world around is encouraging a further blossoming of individualism, then telling the truth and freedom of choice have new meaning.

The effects of the change in disease burden, the advance of medical science, change in social status, and personal freedom are easily seen in the rise of the women's movement. Would the continuing emergence of women to their present social and political state have been possible without a low birthrate, effective contraception, the virtual disappearance of the complications of childbirth, and the increased survival of children? As recently as 1928 Virginia Woolf, in *A Room of One's Own*, could decry the paucity of women in letters or any

other profession. At that time, none of the four benefits mentioned above were available to women. Is widespread freedom of choice possible in their absence? Virginia Woolf did not think so.

Like WWI, WWII had put women in the work force, but I believe it took these medical changes to continue their advance. By the end of the social turmoil of the 1960s, as the women's movement grew, abortion had become legal, common venereal diseases were easily treatable (although new ones were appearing), and the physical constraints on the emergence of women were disappearing. Further, the opinion held by physicians about women gradually changed with the changing social milieu so that their climate of choice was also altered—even in advance of the entrance of large numbers of women into medicine. Women seized the locus of choice from physicians prior, I believe, to a similar change in the general population.

The bioethics movement was also a major force in spreading the importance of patient autonomy in clinical medicine. Publications, public discussions, the education of interested physicians and individuals who were making bioethics their academic field, and increased public interest brought power to the idea of patient autonomy.

By 1997 when Olga came to be making decisions about how her breast cancer would be treated, respect for persons in clinical medicine had become identical in many minds with autonomy defined solely as freedom of choice.

As time went on, the emphasis in the meaning of freedom of choice in medical practice shifted from choice from among the reasonable alternatives offered by physicians to whatever the patient (or surrogate) wanted. This was most evident in intensive care units where unconscious patients with no possibility of survival in the absence of support equipment were kept alive because (the physicians said) the family wanted a "full court

press." It was not unusual at this time for the family and the medical staff to become adversaries. Influential guidelines in the bioethics literature (such as the Hastings Center Guidelines) supported the right of the family or patient to insist on resuscitation no matter what the clinical situation or the patient's prognosis.

In earlier years, learning to base clinical decisions on prognostication—carefully considered alternative possible outcomes (not merely what a physician wanted to do)—had been an important part of clinical training. With freedom of choice, this element began to disappear from clinical medicine. (Surgeons remained constant in this regard. They remained firmly in control of the decision to operate—if the patient agreed.) Absent concern about the impact of the past and the future on a clinical deci-

had clearly shifted to the patient. For many physicians it became easier to acquiesce when patients wanted medications or diagnostic technologies than to assert medical authority or negotiate a middle ground. Patients and the public at large had become so knowledgeable that their choices were often well informed and cogent.

There can be no freedom of choice in the absence of knowledge on which to base choices. As previously noted, until the 1970s physicians commonly withheld the truth from patients who had life-threatening diseases. Earlier, doctors did not tell patients about the facts of their illnesses even when they were not serious. For example, doctors frequently did not reveal blood pressure to patients. Why would they want to know? After all, it was thought, they

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sion (what prognostication is all about), the exercise of autonomy in medicine came to be marked by immediacy.

Issues such as the nature of the person, the impact of illness on decisionmaking capacity, the problems of autonomy that were specific to medicine and care of the sick, and the meaning of autonomy in the context of the special relationship between patient and physician were buried under the tide of legal interpretations of these concepts and rise of the language of rights. As required by law, in every hospital in New York State a "Patients' Bill of Rights" was posted prominently next to elevators or other visible sites. The tone of the document was adversarial, as though everything that could be undertaken by physicians was determined by patient rights and medical obligations rather than patient needs and medical responsibilities. The balance of power

did not know what a specific blood pressure meant. The reasons for a specific medication might be revealed because it had been shown that explanations increased compliance (otherwise only about half of prescriptions were ever filled), not because it was believed that patients wanted to participate in the decision. Why would they? That was the doctor's job. It was commonly believed that doctors did not tell the truth—that they hid bad news. By the late 1970s patients were increasingly told the truth. By the late 1980s, any reticence on the part of the physician about revealing the truth was gone. The criterion for telling something to a patient became its truth.

From the destructiveness of complete lies to the destructiveness of unmediated truth took less than three decades. Attempts to teach the harm that could be done by "truth bombs" and "truth fragments" fell on deaf

ears. But the truth of information is only one of its aspects. Of importance also are accuracy, reliability, and completeness, the meaning to the patient of the information, its relevance to the patient's problem, whether it increases or decreases uncertainty, what it indicates about appropriate or possible action, and what impact it has on the relationship between patient and physician. The understanding that information is a tool that can be used for healing or hurting disappeared under the new avalanche of truth revealed to patients in the service of autonomy. Deciding what should be said when, where, and how requires knowledge of not just the medical facts, but the nature of the sick person and his or her needs beyond the simply "medical." Physicians who have distanced themselves from their patients cannot obtain this kind of personal knowledge.

Decisions made in the name of respect for persons and their autonomy can result in different conclusions about the right thing to do. Consider, for example, the following two cases: A terminally ill patient with terminal respiratory disease decided against further treatment and entered a home hospice program. He soon became very sick and was brought to an emergency room in respiratory failure. Severely short of breath, he chose to go on a respirator despite having previously decided against resuscitation. His request was granted, although he could have been made comfortable without a respirator, and ultimately he will again be in the terminal state he was in before entering the emergency room. The second instance is that of a patient who had been on dialysis for a long time and decided to stop treatment. When he was close to death he requested that he be restarted on dialysis. His physicians chose not to do so and he soon died.

In the first instance the decision was justified by saying that the patient wanted to be resuscitated despite his previous refusal of further treatment. In the second instance the decision was justified by saying that the pa-

tient's previous decision against dialysis carried more weight than his current request for dialysis. The first case probably represents the more common contemporary occurrence. Here the patient's choice is atemporal—as though the person of the past does not count in the present and as if there is no future. Choice is exercised as if it were independent of circumstances, as if the panic of respiratory distress had no impact on the choice and the patient in his profoundly sick circumstances is as representative of the person as the less sick voice of the recent past. It is the immediate, individual choice that counts.

In the second case the physicians take responsibility for deciding that the previous decision to stop dialysis is more representative of the person

In the years since the early 1950s, clinical medicine has moved away from respect for persons expressed primarily by benevolence and the avoidance of harm toward respect for persons defined by autonomous freedom of choice with little regard for other aspects of autonomy. Before the current era, patients were not accorded full status as persons by society—sickness removed them from the community of equals, impaired their autonomy, and required that physicians accept full responsibility for their benevolent treatment. At present, in the absence of obviously diminished mental capacity, the easily demonstrable impairment in the very sick of the ability to make reasoned decisions is essentially denied and they are accorded the full autonomy of normal persons who

The medical industry supports itself by spreading the belief that it is about saving lives and promoting health.

than the current choice to restart dialysis. How do they know that they are correct, that they are not condemning the patient to death based solely on their judgment? They cannot know; it is merely a judgment. Their decision is based on their knowledge of end-stage renal disease, the life of a dialysand, and this patient's previous experience with both. The patient will die of renal disease—no action or decision will change that fact. His previous decision was made over time and was justified over time. No patient is removed from dialysis without a lot of discussion with his or her physicians—it is in the nature of dialysis units. To honor his immediate choice would return him to the situation that he opted to end with death rather than face its continuance. Here the decision acknowledges the effect of illness and, perhaps most important, entwines the acts of the physicians with those of the patient.

make decisions in which their physicians no longer share much responsibility.

Justice

In 1981 I was asked to discuss justice as it applied at the patient's bedside. I argued that "love of humanity, compassion, and mercy, not justice, are the appropriate concepts to guide actions at the bedside."¹ But in the years that have followed, society and medicine itself have come to realize that no nation is rich enough to make available all that medicine has to offer. Accordingly, there have been many discussions of the need for some kinds of rationing or the awareness that covert rationing already exists. With that awakening has come concern for fairness in distribution, whether the problem is seen as one of large-scale social institutions such as governments, or of more local institutions

such as transplant teams, hospitals, or other medical care organizations.

Inevitably, this involves the belief that individual physicians should play a part in preserving society's medical resources. Simply put, this means that the physician should be thinking not solely about a particular patient, but also about how the resources used in that patient's care affect conservation of the general resource supply. Only a few decades ago, such an idea would have met with strong opposition. The ethos held that physicians' primary obligation is to their patients and all else comes second—including physicians themselves, their institutions, and society.

The rise of managed care in the last decade has highlighted the distributive issues that arise when cost becomes the primary value by which services are measured. Eliminating services from a plan's benefit package, reducing the level of reimbursement for specific services, and reducing the time allotted for services can directly reduce costs. Each of these cost-saving strategies raises the question whether these medical services are not merely commodities that can be allocated fairly or unfairly.

It is not surprising that in this changing climate attention has turned to issues of justice arising from the individual physician's attention to an individual patient. The idea of concepts of justice applying to the physician's acts at the bedside, to which I denied legitimacy in 1981, has now become a focus of attention. In *Local Justice*, published in 1992, Jon Elster explores allocation of resources in situations not usually considered matters of justice, including military draft, admission to colleges, and certain larger medical allocation problems such as organ transplantation, which he discusses at some length.¹ Elster cites previous work by others, including Michael Walzer, that has focused on similar local issues. *Local Justice*, however, allows me to demonstrate the application of these ideas to clinical medicine.

The values underlying Elster's arguments are simple: To meet the standard of justice, the distribution of scarce resources should be both equitable and efficient. The existing norms of clinical medicine appear to conflict with justice as a principle of clinical medicine. The following excerpt from Elster makes the point:

In many cases, professional norms are self-explanatory. There is no need to ask why colleges want good students, why firms want to retain the most qualified workers, or why generals want their soldiers to be fit for combat. The norms of medical ethics, however, are somewhat more puzzling. I shall offer some conjectures concerning the origins of two central medical norms with important allocative consequences. Neither norm is outcome oriented, in the sense of aiming at the most efficient use of scarce medical resources. Instead, one might say that the norms are *patient oriented*, in a sense that will become clear in a moment. [Italics in the original.]

The first is what I have called "the norm of compassion," that is, the principle of channeling medical resources toward the critically ill patients, even when they would do more good in others. In addition to spontaneous empathy, I believe some cognitive factors could be involved in this norm. . . . Instead of comparing the fates of different individuals if treated, doctors compare their fates if left untreated. . . .

Next, there is what I shall call "the norm of thoroughness." Rational-choice theory tells us that when allocating scarce resources, whether as input for production or as goods for consumption, one should equalize the marginal productivity or the marginal utility of all units A rational consumer would, therefore, spread his income more thinly over a large number of

goods, rather than concentrate it on just a few.

We can apply similar reasoning to the behavior of doctors. With respect to any given patient, the doctor's time has decreasing marginal productivity, at least beyond a certain point This implies that if a doctor makes a very thorough examination of his patient, his behavior is not instrumentally rational with respect to the objective of saving lives or improving overall health. Other patients might benefit much more from the time he spends on the last and most esoteric tests. Nevertheless, doctors seem to follow a norm of thoroughness, which tells them that once a patient has been admitted, he or she should get "the full treatment." . . .

In Norway, a recent parliamentary commission found that eye specialists tend to admit too few patients and treat each of them excessively thoroughly. When I confronted my own eye doctor with this claim, she refuted it by telling me about a case in which she had been able to diagnose a rare eye disease only after exhaustive examination, thereby saving her patient's sight. I did not remind her of the cases that go undetected because the patient never gets to see a doctor at all. (pp. 146-48)

In the 1950s such an application of economic theory to medicine was unlikely. Even today, many clinicians would be upset at the conclusions Elster has drawn, but he is not alone. As F. H. Bradley once said, "When you are perplexed, you have made an assumption and it is up to you to find out what it is." Elster's assumption, which led to his puzzlement about the norms of medical ethics and on which his argument stands, is that medicine is devoted to saving lives and promoting overall health.

Historically, *clinical* medicine has been devoted to caring for individual

patients, one at a time. Elster can be excused his error. He has probably been reading medicine's public relations slogans, in common with the rest of the population. The medical industry—clinical, teaching, and research—supports itself by spreading the belief that it is about saving lives and promoting health. The error is really an error in systems theory. The level of the medical system devoted to these goals is not medicine as a profession of individual doctors treating individual patients—what most people think of when they speak of medicine. It is medicine as a social system, concerned with keeping the population alive and healthy. The United States does not have an institution responsible for the social system of medicine—certainly it is not the Sur-

tion, in conjunction with various organizations concerned with technology assessment, epidemiology (The Centers for Disease Control), and health policy.

It is probably true that at the present time more than one set of norms are applied to clinical medicine and the care of patients—patients who persist in clinging to historical values in the belief that when they are actively the patient they are their doctor's primary concern. Their health insurance organization is probably dedicated primarily to efficiency and, hopefully, equity—whatever its public advertising may say. But the matter does not end here. A recent paper by Lynn Jansen, a nurse who has a doctorate in political theory, allows us to move a step further.³ Drawing

decisions of individual physicians, then it is entirely appropriate that these decisions be assessed in terms of justice" (*italics in the original*). (In a footnote she states that not every decision by a physician raises an issue of justice.)

Why does it matter whether these local decisions are viewed in terms of justice? "As the case of pain management resources aptly demonstrates, many of these resources cannot be distributed properly according to a uniform policy or guideline. Yet they are sufficiently important to require a stronger distributive justification than simply relying on market forces or professional discretion." And finally, "When decisions . . . come to be viewed in terms of justice, there is greater pressure, both social and legal, for those who make these decisions to defend and justify them in public."

Whether one agrees with Jansen's argument is not the issue; what is important is the concept on which her discussion is based. For Jansen, and for many others in these last decades, the actions of the doctor have become *resources* for which physicians are socially and legally accountable. Take away the concept of resources and the argument that the idea of justice applies at the bedside disappears. The overriding belief that physicians' acts represent the exemplification of the *personal* duties of individual physicians toward individual patients—that this is the moral framework of clinical medicine—has lost considerable currency.

A number of things follow from the shift to a framework of justice. It presupposes people or groups pressing claims for scarce goods as their *right* and justifying those claims by rules or standards. It suggests the utility of rules and guidelines, and evidence-based medicine that can provide the basis for the social and legal evaluation of the distribution of the physicians' resources. It provides a basis for diminishing the importance of the personal judgment of physicians.

The belief that physicians' acts represent the exemplification of the *personal* duties of individual physicians toward individual patients has lost considerable currency.

geon General's Office or the Department of Health and Human Services. The nation depends instead on the outmoded and demonstrably false assumptions that the health of the population is the sum of the health of individuals and that lives are best saved by the actions of individual physicians.

In the last few decades, however, as the economics of medical care have come under increasing scrutiny, addressing questions of equity and efficiency in the care of patients has come to be seen as necessary and reasonable. But the goal has not necessarily been the best medicine for the overall health of the population and the lowest death rate, but the most medical care for the money. Perhaps the closest thing to an arbiter of medicine as a social system has been the Healthcare Financing Administra-

on Elster's work, she applies the concept of local justice to the treatment of pain. As have many others, she finds that pain is under treated. She states that "an important factor affecting the distribution of [pain management] resources was the decisions made by individual clinicians at the bedside. Since these decisions affect the distribution of important health care resources, they should be understood as raising an issue of justice." After citing as an objection to her conclusions the belief of others that individual treatment decisions should be discussed in terms of beneficence, she states, "It is the actual distribution of resources, however, that should be assessed in terms of justice. *Ultimately, what matters from the standpoint of justice is who actually gets what resources.* If, therefore, this distribution is influenced in part by the

In quoting both Jon Elster and Lynn Jansen perhaps I have presented an overdrawn account of the place of justice in contemporary clinical medicine. This idea is not usually so baldly stated because, in a period of changing values, people often talk the old values but act on the new. Whether the word justice is used or not, the idea of physicians' services as scarce commodities discussed in marketplace terms is, by now, widely accepted. Similarly, the utility of guidelines, evidence-based medicine, and rules of practice are increasingly accepted. When physician commentators point out that such a medicine dismisses the importance of the physician's personal judgment based on the evaluation of the individual patient in context, they are correct but they miss the point. To a medicine guided by marketplace principles and the socially based ethics of justice, the loss of the personal is irrelevant. The classical norms of clinical medicine—dedication to the patient, constancy, thoroughness, self-discipline, compassion—are not about saving lives and improving overall health; they are about *this patient's* life and health.

These are the values of a professional ethos that at the moment of action knows no other patient. It is the physician's difficult task, accepted since antiquity, to keep these values in the forefront despite the fact that at any time there are many other patients. They are values that arise in relationships; they presume a relationship between doctor and patient. In this relationship, fairness—justice—is only one duty among others and probably not preeminent, judging from its absence in classical discussions of the obligations of physicians. Although Eric Cassell could rise in outrage at the idea of the concept of justice at the bedside in 1981, less than twenty years later it has a secure place at the head of the patient's bed to insure that the patient gets a fair share (but not more) of the medical resources and that the social system gets its money's worth.

From Treating Patients to Making Treatment Decisions

We no longer understand the Belmont principles as we did in 1978, or 1954. The meaning of benevolence has shifted from acting for the good of the sick person to acting for the good of a body part or physiological system. Respect for persons has been redefined from overriding concern for the sick person (almost solely) to the right of the patient to choose independently from among all options. Justice was originally not seen to apply to clinical medicine; now it is apposite because we no longer understand the medical act as that of an individual clinician caring for an individual patient within a relationship, but as a commodity or a resource within a marketplace.

Their relationship devalued, the actors in the medical drama have become atomistic individuals, and treatment the increasingly successful therapy of body parts or systems. Scientific, legal, and marketplace world views have increasingly defined the participants and their actions, with medicine reflecting changes that have occurred in the surrounding society. There are, of course, countervailing forces in which the patient rather than the disease is the object of medicine, but they offer no more than an alternative viewpoint at this time.

A final case.

A forty-nine-year-old woman developed recurrent breast cancer three years after a lumpectomy, radiation, and chemotherapy. It progressed very rapidly so that within a few weeks she had extensive spread of her cancer to the lungs, bones, and liver. The severity of her liver disease made adequate chemotherapy impossible, but her oncologist continued to talk of cure "once the liver is better." When she became sicker and deeply jaundiced, she was admitted to a major teaching hospital. Because of gross edema and abnormalities of electrolytes, a nephrologist was called who took over the problem of kidney function. Her liver function worsened, but the

oncologist's stated optimism did not wane. The house staff were kind and attentive, but busied themselves with her abnormal liver function. She and her partner, supported by the physicians, continued to make plans for her future and would not hear of the possibility that she might die. Reluctantly, she accepted the advice that her parents be told of her illness. She was discharged from the hospital but was readmitted in three days with a pathologic fracture of the hip. The hip was pinned, but postoperatively her liver function worsened and her blood pressure fell. She was transferred to an intensive care unit. The oncologist said that as soon as the problems with her liver and kidneys were straightened out, he could start treating her cancer. In a few days the nephrologist announced that her kidneys were now doing well. Her sickness deepened and she became confused. The orthopedist came and pronounced the wound healing well. He asked the nurses whether they could get her up and walking. She died the next morning.

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2. J. Elster, *Local Justice: How Institutions Allocate Scarce Goods and Necessary Burdens* (New York: Russell Sage Foundation, 1992).
3. L.A. Jansen, "Local Justice and Health Care: The Case of Pain Management," delivered at a medical ethics meeting at Johns Hopkins University, Baltimore, Maryland, 1999.