

Autonomy in the Intensive Care Unit: The Refusal of Treatment

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The right of competent adults to refuse treatment, whether in a physician's office or an intensive care unit, is now firmly established in American medicine. Nonetheless, discussions of autonomy in a critical care environment are too often like ballet lessons in a fracture ward—demonstrations of impracticality and wishful thinking. This is a pity. Freedom of choice, which is highly valued in this society, is nowhere more important than in matters of life and death—whether and how we live or die. Such questions are the stuff of critical care units.

Despite its inherent complexities, in terms of the care of patients, autonomy is another way of saying self-determination—the choices people make in their own best interest.^{6, 7, 10, 11} The equivalent legal doctrine was clearly stated by Justice Cardozo in 1914, "Every human being of adult years and of sound mind has a right to determine what shall be done with his body" (*Schloendorff v. Society of The New York Hospital*). The problem is simply stated. How are we to act in intensive care environments so that whatever we do for our patients will be seen by them, at that time or in the future, to be in their own best interests?

Although the issue is easy to phrase, its solution is difficult for several reasons. The first reason is the difficulty physicians have in achieving the state of mind that places the patient's freedom of choice above almost any other value in an intensive care unit. The second reason is the subtle change that has taken place in the nature of critical care medicine. Third is the difficulty of knowing what patients believe to be in their own interests, and fourth is that a patient's situation can change very rapidly.

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THE PHYSICIAN'S ATTITUDE TOWARD THE PATIENT'S FREEDOM OF CHOICE

Underlying this discussion is the presumption that the physician understands, right to the center of his or her heart of hearts, that doctors are meant to act to promote the best interests of the patient *as defined by the patient* unless the patient is a minor or legally incompetent, an illegal action is entailed, or the physician cannot in good conscience concur. I am well aware that such a state of mind is not arrived at easily. One of the wonderful things about being a doctor is that one can go about doing good, and even aspiring to be good, with a fair probability of success. However, since the physician works with understandings about disease and medical science that are completely remote from concepts of good (or compassion or caring), what it means to do good is largely derived from general cultural notions and what has been learned by precept and experience. Here there is nothing like the precision of science that exists in other facets of medicine. Further, since doing good in medicine often, paradoxically, involves causing pain, doctors must, out of self-defense, learn to hold fast to the belief that what they think is good for a patient is indeed good for the patient. It is usual and largely necessary that sick people have the same belief because of their inability to think everything through for themselves as they might if they were well. The result of all this is a common presumption on the part of doctors that they really do know what is best for their patients. If physicians act primarily on the presumption that they know what is good for patients or on general rules such as "a doctor's job is to protect life at all costs," conflicts about self-determination in the intensive care unit will arise.

The beliefs—that doctors know what is good for patients and that they should preserve life at all costs—come from earlier times in medicine. Since both notions served medicine well, even though they have now outlived their utility, it is useful to examine them more closely. Changes in the knowledge held by patients, changes in the nature of society, changes in the concept of person (what do I mean when I say "myself"), and increased medical efficacy have outdated the comfortable precept that the doctor knows best.

There was a time when only doctors knew anything about medicine and the body. In those days, physicians' authority about disease and treatment was usually accepted without protest. Modern patients know, or believe they know, a great deal about science, the body, diseases, and treatment options. Whether their knowledge is accurate or not, they are now in the position of having an informed opinion about what should be done for them or their relatives. For this reason, in the decision-making climate of acute care, the opinions of patients must be taken into account. If they are wrongly informed, they must be given correct information; if they lack information, it must be provided in terms understandable to the patient. On no account can patients' opinions be brushed aside or dismissed without chancing enmity or encouraging an adversarial relationship.

In those earlier times, as now, physicians had authority and status and were responsible for the care of persons largely like themselves. In addition,

they provided care to poor and working class patients, often in free clinics. The values of the doctor and his or her paying patients were assumed to be similar (or the patient changed doctors) so that the assumption that the doctor knew best for the patient rested not only on the physician's knowledge of the body but also on a solid social structure. The poor and the working class were believed to be aspiring to the values of the comfortable so that physicians acting on their own values could assure themselves that if their ideas about what was best for patients did not represent what poor patients believed, they were what the poor required. This scenario may seem like a caricature, but it was largely true of the Bellevue Hospital clinics where I served as a student and house officer 30 years ago. We, like generations of physicians before us, hid our cultural biases behind a false belief in the value-free nature of medical science. Indeed, many physicians still wrongly think that science is value free.⁸

Understanding of the uniqueness and worth of the ideas and values of other cultures did not enter American medicine in an important way until after the Second World War. Indeed, the stress placed on cherishing ethnic differences is a relatively recent trend that is continuing to change American society. Physicians can no longer safely assume that their values are the same as those of patients coming from different backgrounds and that therefore their ideas of what is good correspond to these patients' ideas of what is correct.

During the past two generations, changes in the concept of person provide another parallel social transformation that has an impact on decisions made today in critical care units. All of us cherish the idea that we are individual and unique persons, as in the statement, "I want to be treated like a person, not like just a liver or a heart attack." Although the meaning of the words "liver" or "heart attack" is relatively fixed, the meaning of the word "person"—what I mean when I say "I"—is constantly evolving. The importance of the concept of individualism in our heritage is well known, but now the stress is on what might be called "personalized individualism," a me-myself-and-I individualism distinctly different from the political individualism, or individualism of effort, so central to our heritage. Here, the emphasis is on individual differences rather than political equality; on the rich interior of human existence rather than its surface existence. (Has any culture *ever* been so public about its private life?) In view of this social transformation, it is not surprising that Americans are changing their relationship to medicine and to their doctors, wanting to be treated as the persons they are, not primarily as containers of disease, and seeing themselves as partners in, rather than merely objects of, medical care. For these and other reasons, our patients are particularly sensitive about their rights to choose and refuse treatment. This sensitivity, which most physicians share when it comes to themselves, provides another explanation of the physician's definition of what is good for a patient is inadequate unless it is the expression of that patient's own beliefs.

It requires but a moment's reflection to realize that all the freedom of choice in the world is useless unless one has the ability to make choices as well as the ability to act on them. For a sick person in an intensive care unit, neither condition may be satisfied. Further, in order for choice to be

meaningful, a person must have the information on which to base decisions and the cognitive ability to act on this information. In the modern critical care area there is no lack of information. Not only is the patient frequently able to see the monitor readouts, but staff members toss information back and forth to each other like footballs on a practice field. In addition, physicians no longer lie or conceal information as was common in former days but rather share virtually everything that is going on. Unfortunately, too much information may be as paralyzing as too little. The reason is that uncertainty makes us unable to act, or even to think straight. For the sick person, the world is filled with uncertainties, some of them huge ("will I die?") and some of them seemingly small ("what if I have diarrhea again and I can't reach the bedpan?"). It is well to remember that the information that patients receive is meant, above all, to *reduce uncertainty now or in the future*. Since the reduced uncertainty is meant to enable the patient to act in his or her own best interest, information must also *enhance the patient's ability to act*. Remember that making a decision is an action; feeling relieved is an action, as is crying, signing out against advice, and asking that a family member be called. Information also enhances the bond of trust between patient and physician and facilitates the doctor-patient relationship through which all care flows.³ It follows that, if information wisely used can reduce uncertainty, improve the ability to act, and enhance the doctor-patient relationship, then information poorly employed can increase uncertainty, paralyze action, and destroy the relationship between doctor and patient. In a severely ill patient, fear is more often secondary to uncertainty and failures of trust than to the objective circumstances, almost no matter how horrendous they are or what they portend.

Physicians have frequently noted the difficulties posed for informed consent by the cognitive problems of the very ill. It is unquestionably true that the sick think differently than the well.¹ The sick are more concrete and less able to deal with abstract concepts and transitions. They act as though dire remote possibilities are existing threats; they can frequently see things only in terms of themselves and are unable to assume the perspective of others. It is crucial to remember that such changes in cognition do not constitute incompetence. Incompetence is a legal doctrine for which there are specific criteria. Generally, the declaration that a patient is incompetent is best made by a psychiatrist unless the patient is all but unresponsive. These difficulties in thinking do not revoke the patient's right to self-determination and they do not relieve the doctor of the obligation to keep the patient informed; they merely make the task harder. There are a few simple guidelines to follow in discussing a patient's condition with the patient. Whenever a statement about a finding or a symptom is made, it should be followed by an explanation of the thing *in terms of its relevance to this patient*. The explanation should conclude with a statement about what action will be taken. For example, a patient developed the chest pain of pericarditis following an acute myocardial infarction. He was, naturally, concerned that his condition had worsened. The patient was told, "The pain comes from an irritation on the outside of your heart that is called pericarditis. This is very common after a heart attack. The irritation makes the surfaces around your heart rough where they rub together, and

that roughness causes the pain. But neither the roughness nor the pain will do you or your heart any harm. This is not a setback. It will go away by itself, but we are going to give you a blue and white capsule called Indocin that will relieve the irritation and make you feel better." This explanation, plus the answers to some of his questions, was sufficient. As is usually the case, the explanation had to be repeated over the next several days.

What should be avoided at all cost are answers such as, "The pain is from pericarditis. That's an inflammatory reaction that sometimes develops after a transmural infarction. Don't worry about it." Such a response increases the patient's uncertainty because it creates whole new categories for worry—pericarditis, inflammatory reaction, the idea that things are still developing ("what'll come next, I wonder"), and transmural infarction ("I thought I had a myocardial infarction"). The important thing to keep in mind is that the heart attack has reduced the patient's ability to be autonomous through two separate but related mechanisms. The first is the inability to act brought about by the event itself. The second, which is equally potent, is the disruption brought about by the *meaning to the patient* of the event. Frequently, physicians can do little to influence the first, but they always have power to influence the second. My meaning may be clarified if you can imagine yourself hearing about a report on your node biopsy. You are entirely asymptomatic and discovered the isolated cervical node while in the shower. You are told that it is non-Hodgkins lymphoma. Consider the disruption in your thinking and ability to act that would immediately follow such news. The effect in this instance would be solely because of the meaning to you of the disease, since the disease itself is causing you no symptoms.

The patient's ability to act in his or her own best interests is unavoidably interfered with by the physical circumstances of a critical care unit. Telephones are less available, visitors are restricted, and knowledge of the outside world is imperfect. In addition, it is not uncommon for patients to experience hallucinations, which they may call "bad dreams" but which are more real than their other dreams. Such defects in thinking further reduce the patient's self-confidence. The best way to solve such problems is to discharge patients from the unit as soon as possible. One is rarely doing the patient a favor by keeping him or her a few more days "just to be on the safe side." The longer patients have been on the unit, the more important it is to get them off, even though a few extra days does not seem to be too important to the staff, especially after a prolonged stay. *In all of this it is essential to remember that maintaining the patient's autonomy is why we do everything we do for the patient's body.* We all want to be well so that we can pursue our own lives. Therefore, we should be careful that what we do for the patient's body does not unnecessarily interfere with the patient's self-determination.

THE EFFECT OF CRITICAL CARE TECHNOLOGY

Critical care units have come into being as a result of the evolution of a technology and a changed approach to resuscitation. Originally, critical

care medicine arose from the need to maintain patients who were critically ill from illness or intervention and who required more staff time than could be provided on ordinary nursing units. The impetus for the change was increased medical effectiveness. Postsurgical recovery rooms promoted the spread of this idea, which was further encouraged by the occasional early success of cardiac massage for cardiac arrest. The finding that continuous monitoring of patients with acute myocardial infarction provided the opportunity to intervene effectively in life-threatening cardiac arrhythmias firmly established the role of critical care units. Intensive care medicine, however, has changed. The critical care unit is no longer merely a place and its staff are no longer merely staff. It does not merely contain technologic devices, it is a technology—a technology for resuscitation and maintenance of cardiopulmonary-renal function.

For the purposes of this discussion it is important to recognize several facts. First, cardiopulmonary-renal resuscitation and maintenance are complex technologies that require sophistication and skill for their effective deployment. Second, because there are special staff, beds, and equipment devoted to cardiopulmonary-renal resuscitation and maintenance, the technology will tend to be self-perpetuating. Third, cardiopulmonary-renal resuscitation and maintenance are employed for patients who will benefit greatly from them, as well as for patients who can be expected not to benefit; in other words, they are utilized both appropriately and inappropriately. For all of these reasons, as is the case with so many other technologies, critical care technology is no longer used exclusively in the service of its original intention but has created its own function—cardiopulmonary-renal resuscitation and maintenance in the service of itself. Since the distinction is crucial, it should be restated. Cardiopulmonary-renal resuscitation and maintenance are frequently employed for sick persons who have a reasonable chance of return to everyday life and function after the acute situation has passed. Here the intervention is part of the treatment of the underlying disease. On the other hand, cardiopulmonary-renal resuscitation and maintenance are also utilized in circumstances in which the patient has virtually no possibility of returning to everyday life and function. An example of the latter might be a patient who has had a myocardial infarction and has been resuscitated five or six times previously and has not returned to spontaneous vital functions. If the reader believes that I have chosen a poor example I am sure an instance can be brought to mind in which cardiopulmonary-renal resuscitation and maintenance were used where there was no possibility that the patient would ever leave the hospital. I have chosen to call such usage "go-for-broke," in recognition that its employment is determined more by the existence of a probability—no matter how small—that an intervention will work, than by a general consensus that the intervention is useful in the particular circumstance.

In order to understand the issue of autonomy, or self-determination, in critical care units, the problem should be related both to the clearly appropriate and to the "go-for-broke" use of cardiopulmonary-renal resuscitation and maintenance. Further discussion may clarify the distinction between the two. First, let us examine the clearly appropriate use of critical care technology. Severe and immediate threats to life occur in several

diseases or states. The list is not long—myocardial infarction, pulmonary embolus, ventilatory failure, overwhelming sepsis, stroke (and a few other neurologic diseases), trauma, and certain postsurgical states. Reversal of the threat returns the person to his or her previous state, subject to the prognosis of the underlying disease. These threats to life are inherent in the natural history of the disease state, the possibilities that may follow a particular surgical procedure, or the effects of the specific trauma. *Therefore, their nature and probability can be anticipated and discussed in advance.* Since the possibility always exists that a patient who sustains a myocardial infarction will require resuscitation, patients' desires can be determined in advance of the need to resuscitate in most instances. Further, the range of possible outcomes can be known within certain probabilities. Thus, for example, it is possible to state with some assurance that if a person with a myocardial infarct sustains an arrest, the chances of successful resuscitation and return to the previous prognosis are quite good. The probability of discharge from the hospital diminishes with each succeeding resuscitative attempt, becoming nil by, let us say, the third separate arrest. Note the distinction between successful resuscitation and discharge from the hospital. It is the latter that is in the patient's basic interest, not merely the former. Another example is the patient with long-term chronic obstructive pulmonary disease who goes into ventilatory failure. If, after acute problems such as infection or congestive heart failure have been resolved, the patient cannot be maintained off the respirator after two or three tries, the chances are vanishingly small that such a person will be discharged from the hospital. The possibility that the patient could not be removed from the respirator existed, in fact, it was inherent in the patient's requirement for a respirator in the first place. If such a patient undergoes arrest while on the respirator, successful resuscitation does not alter the underlying odds of discharge from the hospital, which continue to depend primarily on the pulmonary disease.

In each instance, I have mentioned the probability of discharge as having bearing on the discussion. Where would one find such probability tables? I know of no source where one could look up the probability that, for example, a 60-year-old man who has required resuscitation on three separate occasions in the course of an acute myocardial infarct will be discharged from the hospital. The data from which such probabilities can be derived exist in virtually every critical care unit but are rarely, to my knowledge, compiled into probability statements. This should be done in retrospect and then maintained. Such information permits rational decision-making by both physicians and patients (and also permits the unit to monitor its own efficacy over time). While other survival (1 and 6 months) and functional status information would be useful, the difficulties in obtaining it are far greater than merely finding out whether patients who had been on the unit left the hospital under their own power.

"Go-for-broke" uses of resuscitation offer difficulties other than the ones just discussed. Frequently, as noted earlier, cardiopulmonary-renal resuscitation is provided to patients who cannot sustain their own vital functions primarily because the technology to do so exists and because it is difficult to withhold the resuscitation from a patient who will obviously die

without it. These are not insurmountable reasons. There are many times when doctors withhold a treatment that exists and without which the patient will die. Surgeons have learned to restrain themselves in such circumstances because they know that, while such patients may die without the operation, they will also die if they are operated upon. Surgery has had a longer history in which to learn such restraints, however, than critical care medicine. Most often the justification for cardiopulmonary-renal resuscitation and maintenance is offered on the basis of the possibility, be it ever so slight, that the patient will achieve meaningful survival. It seems difficult to argue against such a stance; what is there to lose by taking the chance?

First, it must be clear that the chance of success is, by definition, very small. Therefore, like shooting blind at a distant target, the greatest priority must be given to determining what will happen in the most likely event—missing the target.⁵ Here the consequences must be measured both in terms of the patients for whom resuscitation has failed and the staff. It has been my experience that physicians usually do not determine in advance of any resuscitative effort the extent to which they will go. Consequently, failure—defined as the inability of the patient to maintain spontaneous vital functions following the resuscitative effort—is often followed by further interventions to shore up one part after another of a failing physiology. By this point the patient is no longer competent to request that treatment be terminated. If the patient is able to do so, the request seems to many to be tantamount to a request that the patient be killed. These are the situations that cause such anguish for the patient's family members. They may also equate stopping the cardiopulmonary-renal maintenance with killing the patient. In the intense inner conflicts that are inevitably generated by such situations, communication between staff and family may begin to break down. This is particularly unfortunate because an adversary relationship may have developed at a time when the family has most need for the physician's support. Such situations, with all their discomfort, are common. These are the inevitable side effects of the few successful go-for-broke resuscitation attempts. The calculation in such instances should not be in terms of the chance of success in *this* case but in terms of how much suffering in *other* patients and families is justified in order that a rare patient survives and walks out of the hospital? The effect on the staff of the go-for-broke mentality is also poor. It is inevitable in such circumstances that physicians will tend to think about their patients as collections of organ systems to be sustained rather than as sick people needing their care. Such a shift in goals, difficult to resist in many aspects of high technology, further undermines the patient's need (and right) to determine what is to be done with him. In go-for-broke resuscitative efforts, consent should be obtained from the family (the patient is rarely competent at this point) in a manner that stresses both the likelihood and the consequences of failure, as well as the possibility of success. Remember that success in these instances is measured in terms of patients who are discharged from the hospital.

At this point, two vital issues must be noted. Virtually every physician's experience is that it is easier to withhold treatment in the first place than stop it after it has been started. This leads to the intuitive belief that there

is a *moral* distinction between not starting and stopping life-support measures. *There is no moral difference between the two acts.*¹²

Families must be reassured on this point in discussions about stopping cardiopulmonary-renal resuscitation and maintenance. Physicians and families must also be assured that stopping life-sustaining treatment is not homicide when permission is withdrawn by a legal guardian or surrogate, and it is not suicide when permission is withdrawn by the patient.¹²

ELICITING THE PATIENT'S PREFERENCE

People go to hospitals to get better and go home. For patients and their families, however, the possibility of disability or death exists whenever there is illness or surgery. Physicians know that virtually everybody, whatever the facts, acts as though the worst is sure to happen. It is just because of the universality of such fears that doctors from the time of Hippocrates (and following his advice) have presented an optimistic picture of the outcome of treatment. The first inroad into this classic practice came with the legal requirement for informed consent prior to research or therapeutic procedures. Physicians find themselves uncomfortable relating all the possible complications when their desire is to motivate the patient to do what the physician believes, in good faith, to be best. Some have cast doubt on the validity of the requirement for informed consent by noting the impossibility of the patient's being truly informed or by quoting studies that demonstrate that patients frequently forget what they have been told.⁴ However, the patient brings something to the consent procedure that the physician cannot know, and that is an understanding of his or her fears, desires, beliefs, needs, concerns, and individual priorities. That patients deny or forget unpleasant realities in no way detracts from their right to exercise choice or participate in their own care to the degree that they do or do not wish.²

Consent in critical care units may be required for particular procedures and in that regard is no different from informed consent in other aspects of medicine. The issue that is most troubling, however, arises in connection with cardiopulmonary-renal resuscitation and maintenance. The matter is simplified, I believe, by dividing the problem, as discussed earlier, into predetermined and go-for-broke resuscitation. Since, at the present time, consent for both categories of cardiopulmonary-renal resuscitation and maintenance is usually obtained at the moment of need, patients are least able to express their coherent desires, and families, under the gun of an instant consent, are unable to reflect or seek guidance for their decisions. In addition, consent is sought *in terms of the resuscitation rather than the underlying disease*. For neither category of resuscitation is such consent entirely appropriate.

In those situations in which the need for cardiopulmonary-renal resuscitation and maintenance is a realistic possibility, the patient's wishes *should be ascertained prior to the need for consent*. Examples of these categories are shown in Table 1. I am aware that there are clinical situations in which resuscitation may be required that are not included in this list. The vast

Table 1. Patients in Whom the Need for Cardiopulmonary-Renal Resuscitation Is a Realistic Possibility

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1. All patients at the time of admission to a critical care unit or as soon thereafter as is practical
 2. All patients prior to surgery when such patients are routinely admitted to a surgical intensive care unit after operation
 3. All surgical patients whose anticipated operations carry significant mortality
 4. All medical patients with diseases that are immediately life threatening or in whom the prognosis not uncommonly worsens suddenly
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majority of problematic cases, however, fall within these four categories. Further, if an institution has special needs or deals with special patients who may commonly require cardiopulmonary-renal resuscitation and maintenance, other categories may be included. An institution might decide that the preference of *all* patients should be elicited on admission.

The object of the following discussion is not to meet some legalistic requirement for informed consent but to determine what the patient believes to be in his or her own best interests. The reason for this vague but vital requirement is that no consent procedure can possibly cover all the eventualities. Nor would one want to try, considering the potential for unnecessarily frightening the patient. For example, a 62-year-old married woman was admitted to the hospital with a neglected fungating carcinoma of the breast, widespread metastatic disease to the bone, some parenchymal involvement, and a serum calcium level of 14 mg/dl. She sought care because of back pain. The issue was consent for treatment. A good case could be made for no definitive treatment on the basis of her inevitably fatal disease and a serum calcium level that promised to spread a cloak of sedation over her demise. Whatever action was taken required her consent, because even starting corticosteroids would complicate the issue. In the presence of her daughter (and when she was sufficiently alert to converse) she was told that she was very seriously ill from cancer and we wanted to find out what she wanted before we did anything further. Everyone wants to live, we said, but that might not be possible for her because her disease was so bad. She said that she wanted to be able to go home. "Even if you are bedridden or an invalid?" we asked. She stated that if she could have some time at home with her family before she died, even as an invalid, she would be satisfied. She was promptly started on tamoxifen and corticosteroids. After confirming the conversation and our plans with her daughter, a "do not resuscitate" order was written into her chart. The latter action was taken because the chance was nil of her leaving the hospital should she undergo arrest in the course of her treatment.

Resuscitation status should be reviewed as the patient's situation evolves, but it should be remembered that the decision about resuscitation is based primarily upon the prognosis of the underlying disease rather than upon how the patient appears on any particular day. If she had said that she wanted any possible chance at life, no matter what the consequences, then (assuming those consequences had been discussed) she should be resuscitated in case of arrest. The patient's desire for "any chance at life,"

personal qualities, is why patients have the right to know, in terms that they can understand, what will happen to them. It is in the service of these goals that physicians treat the sick. It is in the service of the same goals that physicians must honor the patient's right to refuse treatment.

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prognostication was overly optimistic, all change the patient's outlook. What is less commonly realized is that such changes in prognosis require that *patients be informed so that physicians can find out whether consent for treatment is still valid*. The requirements of informed consent for treatment, it must be emphasized, imply consent for a *particular* treatment based on a *particular* set of circumstances. When circumstances change, it is wrong for doctors to continue as if anything they believe necessary would meet with the patient's approval. Here again, physicians often believe that telling the patient bad news will do harm, whereas false optimism does good. I know of no solid evidence for this opinion and considerable reason to believe it false. It is unquestionably an unpleasant task to be the bearer of unhappy truths, but this is a necessary part of the physician's life. Once again, when such renegotiation of consent is done well (a matter of clear thinking and practice), it is rewarding to both doctor and patient.

Discussions of informed consent and the right to refuse treatment often revolve around the patient's right to determine his or her own goals. It is too frequently forgotten, however, that there are two *separate and distinct* kinds of goals at issue that are too often combined. One set of goals, the most commonly considered, have to do with what the patient wants to be able to do. These are what are referred to when the phrase "meaningful survival" is employed. Will the patient be able to do the things that are important to him? There is another set of goals, however, that are equally important but often confused. These have to do with *personal qualities*.⁹ Will the patient, even though ill, be considered brave or cowardly, strong or weak, active or passive, smart or dumb, quick or slow, a good or bad model for the children, and so forth. The effect of illness and the circumstances of care, particularly critical care, have a profound effect on such qualities and on how the patient will be esteemed by self and others. When physicians discuss the change in prognosis and whether that revokes previous consent with the patient, rather than only with the family, they accord the patient the esteem all of us require. In like manner, when patients refuse further treatment, it may be because they cannot any longer tolerate the idea of themselves as the person such treatment promises to make them. The patient may also wish to die in a manner that will be highly esteemed by friends and family, and this may be the true reason for the refusal of further treatment. Commonly, in discussions of refusal of treatment, we hear that such and such a patient chose to die. Most often this is *not* the case. The last thing the patient wanted to do was die. The patient's choice was *not to live in a particular manner*—a far different choice. The Jehovah's Witness who dies because transfusion is refused did not choose to die; the choice was to not have his or her immortal soul rest in Hell for all eternity, something much worse than death to such a patient. In seeking guidance from the patient about further treatment, doctors may ignore the patient's need for approval or praise at the very moment that the doctors are pressing someone to do something so that they will be esteemed by their colleagues. All of us, sick or well, require approval for what we do and what we are.

The fundamental importance of honoring human values, those concerned with the goals of action and those concerned with the goals of

Table 2. Sample Choices for Patients Who Fail to Spontaneously Express a Preference About Treatment

I only want things done if it looks as though I will leave the hospital alive.	I want my life sustained until there is absolutely no chance that I will leave the hospital alive. I know that may mean being kept alive by machine with little chance of leaving the hospital alive.	I leave the matter entirely in the hands of my doctor.
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make sure that the patient understands serve better than elaborate consents. I cannot emphasize too strongly that what is being elicited is the patient's preferences to serve as a guideline in the event of an arrest. The patient has already given consent for treatment (in one form or another), otherwise no treatment would be possible. Now the patient is providing one of the bases for a decision in the event that consent cannot be requested. The results of the conversation should be entered on the chart. If patients fail to express a preference spontaneously, they should be given choices. Table 2 lists three possible alternatives. When the patient is very ill, it may be best to discuss these issues in the presence of the family. The practice of asking the family for permission or obtaining the family's preference in order to avoid talking to a sick but competent adult is a leftover from the past and should be avoided. Anything that further removes from the sick person the control over his or her own existence deepens and increases the damage of the illness. Patients are perfectly capable of saying, "please discuss that with my wife, I just can't think now."

A question frequently raised by physicians is the durability of patients' choices. How does one know that patients who express a preference not to be maintained on life-sustaining treatment will not change their minds? Perhaps a person in good health a few years ago signed a living will. Now, having just sustained a myocardial infarction, there has been a change of mind and he or she wants to be "kept alive at all costs." The answer is simple. One does not know unless a new preference is expressed. However, the presumption that the patient has not altered his or her position is more acceptable than the presumption that the doctor knows the mind of the patient better than the patient does. If the sick person states a new preference, that must, in a competent adult, take precedence over the previous opinion (even though one may suspect that the illness is now speaking). Many of these problems of the durability of choice will become moot if such issues are discussed with patients when they are admitted.

WHEN THE CLINICAL SITUATION CHANGES

It is inherent in critical care medicine that the patient's circumstance can suddenly worsen. It is well known that the supervention of renal failure, changes in cardiac function, stroke, adult respiratory distress syndrome, or, perhaps most common, the recognition that the original

however, does not relieve the doctor from the responsibility to abstain from truly pointless actions.

Different problems are presented by patients admitted for coronary artery bypass or other cardiac surgery. In order to diminish anxiety and increase compliance, it is usual to explain at length what such patients can expect postoperatively. These conversations are often quite graphic, but because they deal with issues that may already be a source of concern to the patient, they reduce uncertainty and thus generally decrease anxiety. In the same manner, I believe, discussions of attitudes toward resuscitation can relieve rather than enhance distress about this subject. Just as there are patients whose primary concern is that they will "just be kept alive," there are others who fear they will be allowed to die without a "fight to the bitter end." The former have received more notice because the issue of the right to refuse treatment is involved, but the latter deserve as much consideration. Other patients appear to have given the matter no thought, but since they may also be candidates for resuscitation, their attitudes must also be elicited.

These may not be easy conversations to start, but on the basis of my own experience, I believe that with a little practice the results will be gratifying. An example of such a conversation is as follows:

"Mr. Jones, we try very hard to prepare you for your operation by letting you know what to expect, how you can help us, and what we will be doing for you immediately after the surgery in the intensive care unit. If it has not already happened, the nurse will be here to discuss these things with you at length and to answer all your questions. We also want you to know that we try very hard to have our decisions, in the event of an emergency, be guided by your wishes. Although we have no reason to foresee any difficulty, emergency equipment, respirators, and things like that are always standing by. We have learned that people have different attitudes and fears about such matters. Some patients are afraid that they will be just hooked up to machines even though they have no real chance of walking out alive, and others are afraid that we will give up too soon. It is important to find out how you feel, so that we can always be guided by your feelings. We also want you to know that you can discuss this with any of the doctors at any time. Please ask me all the questions you can think of."

In the ensuing conversation the patient's resuscitation status should be elicited. Patients must be reassured that you are not asking these questions because you think they are going to die or that you know something about them that they have not been told.

Although initially the physician may be uncomfortable in such conversations, eventually he or she will discover that this does not frighten but rather calms preoperative patients. This is because the emphasis is on keeping patients in control even when, in an emergency, they no longer have the ability to express themselves directly. One of the worst things about terrible illness is not the threat of death but the total loss of control over one's destiny. Anything that returns a measure of control contributes to the patient's well-being. For that reason, similar conversations on admission to an intensive care unit will help both staff and patients. Remember, however, that the very ill are unable to think in large abstractions. Short, jargon-free, simple sentences with frequent checks to