

ety as a supportive mechanism. Death has always been distasteful to man and probably always will be.

When Christ was going to the cross, he cried, "Father, if it be possible, let this cup pass from me," because he too had to die in order that we may inherit eternal life, which was God's original plan for man.

It is inconceivable for us to see ourselves dying a natural death because of aging. We associate death with a bad act or retribution and punishment. We ought to remember this from the mental facts as essential in understanding some of the most important and otherwise unintelligible communications of our patients. We need to discuss this in our everyday life by making death a part of life, thus decreasing the traumatizing factor.

Man is fearful of death and its frightening experience. This is universal, even if we think we have mastered it at many levels. If we take a look into society, we would question ourselves. What is happening in our world of medicine? Is medicine still a humanitarian, respected profession, or is it a depersonalized science in which it is better to prolong life rather than to diminish human suffering?

We direct our attention to the adjustment of the machine, while ignoring the patient's facial expressions, by which we determine their discomfort and pain and meet the patients' needs.

In conclusion, very important, last but not least: the patient's spiritual needs. This is where the chaplain and the social worker play an important role.

The dying person may be concerned about some unfinished commitment, possibly a retarded child whose needs will have to be taken care of, which will result in the fear of death.

The respect of the patient's soul is primarily the chaplain's role but I, as a nurse and very often the closest person to the patient, have a twofold responsibility of dedication to my patient's natural and spiritual needs.

Therefore, I make myself available to perceive what that need is. If the patients need prayers, I pray with them. At times, a little cuddling does a miraculous healing. I do care, and realize that they may have the need to verbalize whatever is in their minds and hearts; I allow them to do so and know I am there for them.

Patient Choices and Medical Decision-Making: The Ideal versus the Reality

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Introduction

Today we are concerned with the issue of self-determination—how individuals express their freedom of choice in difficult clinical situations.

I write as a physician. It is easy to become defensive or cynical about the behavior of hospitals, doctors, and other caregivers; yet most of us try to care for patients in such a way that they believe what we do to be in their best interests. I can write these words easily but the actual task of caring may be more difficult to carry out. There are a number of reasons for the difficulty.

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The first is that sickness changes people; it changes their goals and their values. The second is that sickness changes cognitive function, not just in the frail elderly, but in everybody. Sick people are not the same as healthy people. To understand what is in somebody's best interest in acute illness, we cannot simply go to that person and ask, "What do you want us to do?" Those who are sick may need a caregiver who can help the patient make decisions. In other words, the goal of acting in the best interest of patients, as patients see themselves, requires the active participation of physicians.

It requires the active participation of us as caregivers to help patients know what we think is in their best interest and also what their daughters or sons think is in their best interests, and in addition, what the patients believe to be the case.

The Right to Refuse Treatment

The remainder of this discussion focuses on the right to refuse treatment, particularly in the critical care environment where we have so many problems. One reason for our difficulty is that patients may have living wills or proxy statements, but when patients flop on the floor and somebody calls 911, all those advance directives get forgotten, pushed aside, or lost. The next thing they know, they are in an intensive care unit with tubes and all the rest. Then the problem becomes trying to discontinue their treatment. All their previous attempts at self-determination go by the board. That just cannot be acceptable. We have to see, however, why this situation comes about in the first place.

First of all, it is hard for physicians and other caregivers to achieve a state of mind that places the patient's freedom of choice above almost any other value in the intensive care unit. The change that has taken

place in the nature of medicine, in particular, has made this extremely difficult. Second, knowing what the patient believes to be in his or her best interests can be difficult because situations change so rapidly. Many well-meaning physicians don't understand that their job is to facilitate the patient's choices. Our job is to reach a state of mind in which we are an agent of a sick person in every act.

In other words, we are not merely trying to pay lip service to our patients' wishes that they will never want to be resuscitated, nor are we allowing their desires to go by the wayside the minute the decision gets tough. Rather, we are trying to ensure that the person—now a patient in a difficult environment—remains in control to the extent possible. It cannot be through their own agency, as in everyday life, because they cannot act in their own best behalf. It must be through the agency of others—us. To do that, we (not simply the physicians, but the social workers and nurses as well) have to step aside from the way we have been trained, each in our own discipline and each with the ideology of our discipline. We must step aside from our training because medical science, knowledge, and technology, the way nurses are trained and the way social workers are trained, all lead us to believe that we know best. If we add to that another idea we all grew up with—preserve life at all costs—then we understand why patient self-determination meets so many obstacles.

Times are changing, of course. The doctor knows best days are over. Patients have become more educated. Diverse cultural values are acting. We are a nation now that prides ourselves on difference, not necessarily on sameness. Diversity is what we are interested in. There have been fundamental changes in what we mean by the word *person*. All of these points lead us into a climate in which the simple matter of deciding what to do or not do has become difficult.

Is Informed Consent Useless?

The situation is confounded further by the

fact that, as studies on obtaining informed consent have shown, when patients are queried about the issues a period of time after they've signed consent forms, they remember nothing about the issues involved. On the basis of these results, many have suggested that informed consent is useless. Patients should not be asked to sign any forms because they know so little about technical matters. That may be true, but it is irrelevant; irrelevant because the kind of information that is most important only patients can know. We can know in our own fields what the correct technical interventions are, but the crucial fact is that we cannot know the most crucial information vis-à-vis every decision about a patient (except the most trivial). What is in the patient's mind is the most important personal determinant of a decision. I can know for myself what I think is important. I can't know for you.

Another issue cannot be minimized. We don't get into trouble because bad guys do bad things in respect to patients' wishes for self-determination. Bad guys have done bad things from the beginning of time. Rather, it is interesting when good guys with good intentions step all over their patients' rights. So we have to see how that could happen. The first reason has to do with the effect of critical care technology. This is 1993. By now we know that technology is not employed merely because it is appropriate. There is no such thing as a free-standing technological capability. All technologies have staff trained and devoted to their use, they occupy space and represent political power and prestige in an institution. So when a technology is used, it will not necessarily be in the best interests of the patient as the patient sees those interests, but also because there are staff who define their functions in terms of the technological actions for which they were trained, in a physical space devoted to the technology, and in an institution that still measures relative clout by technology—not by accession to patients' wishes (or even rights).

So when somebody comes into an intensive care environment and critical care interventions are brought to bear in a way that

seems to insult the very being of the person who is treated, it isn't because somebody is being bad. What is being realized is the whole environment in which the interventions exist and the kind of thinking that goes with them. But having acknowledged the technological imperative and the forces that drive its use, we can also say that there is a very important distinction between using critical care technology appropriately or inappropriately. For example, it is absolutely appropriate where it's employed (with the patient's consent) for sick persons who have a chance to return to everyday life and function after the acute situation has passed. This is as true for the frail elderly as for others who might have had a myocardial infarction or a pulmonary embolism or have sepsis. We must believe that if we can support such patients over relatively short periods of time, they will return to the functions that were important to them prior to their illness and our intervention. We can anticipate that such persons will not only go home from the hospital, but they will be the persons that they were before they entered the hospital. That kind of intervention is appropriate for critical care, as most of us would agree, for ourselves and for others for whom we care.

Unfortunately we also use the technology for itself or to support a physiological function apart from the needs, chances for recovery, or rights of the patient in whom the physiological function is found. For example, patients may be resuscitated not because they will return to health, but because they had cardiac arrest. Why is this person with end-stage pulmonary disease on a respirator? Because his blood gases have gone sour. Why are you supporting this person's blood pressure? Because the pressure dropped. In those instances we are not treating persons with interventions primarily related to returning them to function as persons. Instead, we are treating physiological functions and using equipment because the equipment can be used.

An Outside Chance

Sometimes we intervene because we think

the person has an outside chance of "making it." After all, if we don't do something, death is certain. So we justify our actions on the theory of the long shot: What have we got to lose? Let's give it a run. But this isn't a "nothing ventured, nothing gained; something ventured, nothing lost" situation. These are "go for broke" situations. And they are special. We generally ask for permission on the basis of the long shot. If we don't do this, death is certain, as if there is nothing worse than death. But if, by definition, "go for broke" represents the short end of the odds, our request for permission should be based on the greater probability *things will go bad*. The greatest probability is failure. In many situations we find ourselves trying to figure out how the patient got into the awful situation of being on a machine that no one will take her off when she made it so clear that she did not want anything of the sort to be done for her. To understand why, we must remember that somebody said to some other family member, "You know, we must try this because she will die otherwise." When consent was being obtained, to repeat, it was not consent for the probability of failure, but for the possibility of success. *It is the higher probability (failure and its consequences, no matter how awful) that requires consent, not the smaller possibility.* So when the probability is failure, we say to patients and their families, "This is what will happen if we fail. Your mother will be on a respirator and we have to be prepared to take her off and stop life support. Are you prepared for that? Because if you are not, and that scenario is most probable, we should not undertake this 'go for broke' intervention."

Often I am asked by physicians, "How can you really know? You didn't know he was going to die." No, but I had a very good idea. Besides which, we don't live in a vacuum of information. In critical care situations, patients and families can query physicians about what they think the probability of success or failure is, and can expect to have an honest answer. There are data available that allow predictive

judgments about specific circumstances. Physicians are members of a data-driven profession now. We are not in a "wish" profession. We're not living in the 1940s or the 1960s. We swim in information today.

This is a complex matter. The biggest problem that faces us in acute care medicine is not simply finding a vein to put a line in. Some medical students' whole lives are devoted to having a chance to do just that. No, our biggest problem is deciding what is the appropriate use of technology for the appropriate patient at the appropriate time. That is our problem. In the case of the frail elderly, where we inappropriately use this technology for the inappropriate patient and at an inappropriate time, it is no mystery that we get into trouble and are sorry we ever started it.

In no situation is this problem as common as in the critical care of the frail elderly. It is fair to say that in every hospital or nursing home, there should be discussions to establish standards of intervention and nonintervention. What will we decide is an appropriate intervention, and what is not, and for which patient? How will we discuss these issues with our patients, and when? I think if we did that in our institutions, we would have a lot less trouble. There would be a lot fewer tense discussions and confrontations outside of intensive care units early in the morning between families and house staff.

Starting or Stopping: The Moral Difference

Another issue that frequently causes difficulty is whether there is a moral difference between not starting or stopping an intervention. Ethicists have made it clear that there is no ethical difference. Despite the fact that the two options—not starting and stopping—have been known to be morally equivalent for almost two decades this issue still causes difficulties. There may be no moral difference, but there is a clear-cut psychological difference. Doctors who take a person off a respirator to die seem to think that they killed the patient. This is an instance of mistaken belief in one's own

power. Take somebody off the respirator and the disease, not the doctor, is the cause of death. It is only an exaggerated sense of our own power that might make us believe otherwise. But this issue must also be worked out in each institution, especially in intensive care units and with both the doctors and the nurses. And it ought to be discussed again, and again, and again until everybody is clear on the subject.

An interesting example of this dilemma is the case of Barney Clark, the first recipient of an artificial heart. The staff in Utah were very scrupulous about the moral issues in the case. They were particularly concerned because the consent form that he had to sign (like all research consent forms) had the phrase, "I understand that if I refuse to continue my participation in this project, I will not compromise my care in any way." But, they pointed out, if he refuses to continue his participation, he stops the heart and dies. Isn't he committing suicide? For those Mormons, that was a big problem. Why wouldn't Barney Clark be committing suicide if he said that he wanted to stop? They understood, finally, that if he stopped participating, it wasn't Barney Clark that killed himself, it was his disease. They reached this realization because they accepted the fact that they didn't think he would be committing suicide if he didn't say yes in the first place; that wouldn't be suicide. It wouldn't be suicide if he stopped the heart because it would put Barney Clark back to where he was before he gave the consent.

When we place patients on a respirator and then take them off, we do the same thing. We bring them back to that stage at which the disease threatened them with an inevitable death. The respirator, in these instances, may postpone the inevitable but does not eliminate it. Once again, these issues have to be worked out in each institution and in the units where the problems most frequently present themselves.

Next, there is the problem of eliciting the patient's preference. The classic approach is to present the best we have to offer, in technical terms, in the hope of

getting consent. We generally list all the problems, possibilities, and circumstances in our technical language. Rather than making self-determination possible, the patient is frequently paralyzed. The patient says, "Doctor, what do you think I should do?" I'm happy to give advice, but that question frequently reveals an overwhelmed patient. Rather than making it possible to find out what is really in their best interests as they know their interests, we have made it impossible because of the manner in which we relayed the information. This comes about because, too often, patients are asked their preferences for technical interventions such as respirators or dialysis. That is not their expertise, it is ours. Trying to get consent for specific technologies is the error. That is not what the patient knows. Patients' expertise, and nobody knows better, is what matters to them. We should try to get from patients what they believe is important. How do they feel about coming back out of the hospital more of an invalid than when they went in? How would they feel if they never left the hospital again? How would they feel if they could not watch television again? What is important to this patient, that's what the consent is all about. It's not for going on respirators, for being resuscitated, for all the big fancy words. It's for what is important in the living of their lives.

The same point is central to all of us. For one person, for example, it may be a matter of being able to read and write again. "If you think I won't be able to do that, forget it; I don't want the intervention. If you're not sure, start the intervention and if, as time goes on, it becomes clear that my desire will be impossible, stop the intervention." This puts a much heavier burden on the physician than merely asking patients if they wish to be resuscitated. But that is our job. If physicians don't know how to find these things out, they must learn, just as they learned to do all sorts of unhappy and difficult things.

Of course, if doctors wait until the last moment to find out what is important to patients, the task is doubly difficult. But then we shouldn't pretend that the problem

is impossible, but rather admit that it is a matter of proper timing. It's very hard to ask a family standing outside the CCU with no advance warning whether to place the mother on a respirator or resuscitate her. That's like asking, "Is it all right if I kill your mother?" That is a very uncomfortable situation. Nobody ever asks that but they frequently do come out and say, "We have put your mother on a respirator." "But she said she didn't want a respirator." "Yes, but you know if we don't put your mother on a respirator, she is going to die. You don't want that to happen, do you?" That is very uncomfortable. That is actually what we do, that is actually the kind of choice we are asking people to make. That is the trouble with last-minute decisions. Therefore we should have advance directives. That is what living wills are all about.

Pieces of Paper

Living wills, proxy statements, and other written advance directives are merely forms, pieces of paper that have come into being, in part, because physicians have failed to carry out their responsibilities. We must come to understand that it is fundamental to the nature of the profession itself that in the care of a patient, the doctor is an agent for the patient.

Sometimes doctors say, "Well, how do we know what he said two months ago is still true now? Maybe the patient changed his mind." Yes, maybe he did and maybe he didn't. We don't ask, what if the hematocrit changes, because we always check for such things. Why can't we make sure we are current about what is important to the patient. All we have to do is ask. But what if they did make an earlier choice that led to a death when a change of mind might have occurred. What if the person dies and they really wouldn't have wanted to? Then, the patient will die. That is the way it goes. Provide the opportunity for patients to make meaningful choices and provide opportunity to review those choices as time goes by. Yes, an occasional person will die who might have changed his mind if he or she

had the cognitive function to know what was happening. Instead of that we have thousands of people dying deaths that no one would choose because they never had the opportunity to make choices when they could or because their caretakers overrode their wishes.

A Final Point

Everybody has something to teach their children at every stage of life. They have something to teach their families; they have something to teach their caregivers, always. Often at the very last moment, when people are trying to be who they are, as difficult as it is in late age to be who you are, and show the rest of the world what it means to be a living person until the last minute of life, we ruin it by overriding their wishes. There are certain essential values that we care about. I want my family to know that I really tried to die in the same way I led my

life, that I wasn't just talking for all these years. I don't want any doctor taking that away from me on the last day. A lot of people are like that. We don't want the person's ability to teach their family and their children what it means to die or live in old age taken away by some act that may at best return life for a relatively short time.

The object of every medical and every other care intervention is that the sick person in all his or her individual particularity remain the person he or she is within the constraints of fate or despite them. Nobody can do that alone. For this ideal, dear to all of us, to be a reality, we need the help of our doctors and other caregivers. All of us live in a community of others. When we are needy in this way, it is not for the community to take over for us. It is for the community to understand and ensure that we remain the individuals that we are, no matter what.

The Real World Experience: Death of Homebound Elderly Persons

Views from Emergency Medicine: Our Problem

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Our Problem

I remember in 1968 working as a 23-year-old medical student in a rural hospital, walking on the floor for the first time, and having every nurse stand up. That hasn't happened since. That event is from another era, an era in which doctors made decisions about who should live or who died.

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I started out in emergency medicine in 1970, when it was viewed as second-class medicine. It was only when emergency medicine started to make a clinical impact and the media started to get involved that it began to receive more resources. Its success probably stole from home care and long-term care, but that is the way of our world. In 1978, I became involved with emergency medical services in the state of Maryland and in 1981 I became vice president of the Health and Hospitals Corporation. I was in that role for about 10 years. Every few weeks I would find myself speaking about issues of home health care. That was because I came to New York City just as the AIDS epidemic began to have a clinical impact and just as we started to struggle with how our prehospital providers would relate to those patients.

It is frustrating when 911 is called for a homebound patient. After 911 is accessed, it is virtually impossible to turn the rescue process off, unless a written document makes it very clear that the will of the patient is to forego resuscitation. Emergency medical services (EMS) lawyers tell us to resuscitate unless the advance directive is physically present and absolutely clear. To my knowledge, no one has been successfully attacked in a lawsuit for starting resuscitation.

When a pedestrian collapses, the EMS system is activated and there is often not time to ask if an advanced directive exists