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S. HRG. 103-1008

END OF LIFE ISSUES AND IMPLEMENTATION OF ADVANCE DIRECTIVES UNDER HEALTH CARE REFORM

Y 4. F 49: S. HRG. 103-1008

End of Life Issues and Implementati...

HEARING

BEFORE THE

COMMITTEE ON FINANCE
UNITED STATES SENATE

ONE HUNDRED THIRD CONGRESS

SECOND SESSION

MAY 5, 1994

Printed for the use of the Committee on Finance

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COMMUNICATIONS

END OF LIFE ISSUES AND IMPLEMENTATION OF ADVANCE DIRECTIVES UNDER HEALTH CARE REFORM

THURSDAY, MAY 5, 1994

U.S. SENATE,
COMMITTEE ON FINANCE,
Washington, DC.

The hearing was convened, pursuant to notice, at 10:00 a.m., in room SD–215, Dirksen Senate Office Building, Hon. Daniel Patrick Moynihan (chairman of the committee) presiding.

Also present: Senators Rockefeller, Conrad, Dole, Danforth, Chafee, Durenberger, and Grassley.

[The press release announcing the hearing follows:]

[Press Release No. H–32, May 4, 1994]

FINANCE COMMITTEE SETS HEARING ON HEALTH CARE AT THE END OF LIFE

WASHINGTON, DC.—Senator Daniel Patrick Moynihan (D–NY), Chairman of the Senate Committee on Finance, announced today that the Committee will continue its examination of health care issues with a hearing on health care at the end of life and implementation of advance directives such as living wills.

The hearing will begin at *10:00 A.M. on Thursday, May 5, 1994,* in room SD–215 of the Dirksen Senate Office Building.

"Most medical care is received at the end of one's life," Senator Moynihan said in announcing the hearing. "Often such care involves very expensive and invasive procedures. The Committee will examine questions as to the appropriateness of aggressive treatments that have little chance of success for dying patients, and the efficacy of living wills."

OPENING STATEMENT OF HON. DANIEL PATRICK MOYNIHAN, A U.S. SENATOR FROM NEW YORK, CHAIRMAN, COMMITTEE ON FINANCE

The CHAIRMAN. A very good morning to our most distinguished panel and to our most welcome guests. This is the latest in the sequence of hearings on health care issues which the Committee on Finance has been conducting for the better part of a year now.

In this instance we return to a subject which has been of great concern to a number of Senators and in particular to Senator Danforth. We have held hearings in the previous Congress, we have considered legislation, and we continue to do so with the extra emphasis that we are going to have some general health care legislation this year. There ought to be a place in it for the issues that Senator Danforth terms the end of life issues. This is something that has concerned us in a whole manner of ways, not the least is the extraordinary advances in technology that keep intruding on

what had been thought to be a life span, such that the issue has been hugely transformed in the course of a single generation.

There is not a day goes by we do not encounter some phenomenon on which we would not have been able to compose a sentence very effectively 30 years ago, but one reads this morning that several doctors have determined what precise form of cancer Hubert Humphrey died from, simply by analyzing a urine sample that has been preserved from 20 years past.

I mean that sort of technology just did not exist. Now it does. It has consequences. We are here to learn from some very experienced and learned practitioners what advice they have for us.

Might I say on a happy note that Senator Packwood is in Oregon today for the wedding of his daughter and will not be in attendance, but will be attentive to what the record shows.

Good morning to you all. The Republican Leader is here and as is the courtesy of the committee we would like to ask if you would like to make an opening statement.

Senator DOLE. No, I do not have a statement. I just walked in and I said, gee, I do not see anybody in the hall. They said, well, lobbyists are not concerned with dying. [Laughter.]

Senator DOLE. So I came on in anyway.

The CHAIRMAN. It was you who named it Gucci Gulch and not without reason.

As I observed, Senator Danforth has had a particular interest in this matter. Senator Danforth?

OPENING STATEMENT OF HON. JOHN C. DANFORTH, A U.S. SENATOR FROM MISSOURI

Senator DANFORTH. Mr. Chairman, thank you very much for holding this hearing. We have had a long series of hearings on various aspects of health care under your chairmanship and I do not think that any series of hearings on this general subject of health care would be complete without getting into the whole issue of the end of life problem.

In 1990, Mr. Chairman, with your co-sponsorship the Congress enacted the Patient Self-Determination Act. And the theory of the Patient Self-Determination Act was very simple. It is that with the advances in technology there are going to be more and more circumstances where it will be possible to keep people going, breathing and yet not in a position where they can think or speak or make decisions.

Often times people are kept going under these circumstances in a condition which they would never choose for themselves. It is a basic right. It is recognized in every State in the union that if a person does not want a kind of medical treatment, then that person cannot be treated against his or her will.

In fact, it would give rise to a lawsuit to treat somebody against that person's stated will. It will be a common law battery. So a person who is conscious and a person who is able to make a statement can just say to the medical professionals do not treat me. But a person who is comatose cannot say such a thing.

So we have this situation now where people who are comatose can be kept going under circumstances which they would never have permitted for themselves. They would have said no, it is un-

thinkable. It is totally unthinkable to treat me that way. Do not do it. But they did not think about it. And they were involved in, say, a car wreck and their brains are gone; and yet they are kept alive.

So we have had these dreadful situations. Several of them happen to have been in my State, which have been litigated where the families and have tried to stop it and there is no basis for stopping it. So we got into the issue, you and I, Mr. Chairman, and back in the 1990 the Patient Self-Determination Act was passed and it was a very simple premise. It did not force anybody to do anything, except that it asked the hospitals, it did require the hospitals and the health care providers, to give people information when they checked into the hospital that they had a right to make their wishes known in advance of getting in a position where they can no longer convey their wishes. That was the Patient Self—Determination Act.

It said simply that when you check in the hospital you are simply given the information. That you can execute a living will or you can provide a durable Power of Attorney so that people can make decisions for you if you are no longer able to make them yourself.

This legislation was very largely the work of a wonderful staff person in my office at that time named Liz McCloskey. She is now raising her two sons and working for an organization that deals in questions of medical ethics. But she really conceived of this idea and had the perseverance to get it through the legislative process.

All of the indications that I have had from the hospitals is that it really is a terrific blessing to have this, that it really has worked very well, not perfectly. There are questions as to when people should be given this information. I mean, obviously there are problems when somebody is admitted to a hospital and given a stack of forms.

And if a person is in desperate condition and you are giving a person a form while on the gurney, I mean, that clearly is a problem. Maybe there are better ways of providing the information. But the basic point is to create the knowledge that people have this kind of decision that they can make for themselves.

There are a lot of organizations that have been active in trying to provide this knowledge in addition to the form that is made available under the Patient Self—Determination Act—an organization called Choice in Dying, the American Association of Retired Persons, the American Bar Association's Commission on Legal Problems for the Elderly, the American Hospital Association, the American Medical Association, the people who are here today.

All of these organizations and individuals have been very instrumental in creating the kind of public attention so that people know that this is their right and it is something that they can do. And it, in fact, is a fairly simple matter to do it.

So the point of this hearing is to find out how the patient Self-Determination Act is working, how it can be improved, and also what I would like to get into is a question that you and I, Mr. Chairman, and Dr. Marks of Memorial Sloan-Kettering spoke about a couple of weeks ago—that is whether there is any possibility on a more systematic basis of dialogue between patients and their physicians.

Because it is one thing to be given a form, but the health care people, doctors, are trained to keep people alive. Sometimes they do not do a terribly good job of really communicating the real choices that are available to human beings.

So one thing that I would appreciate hearing from the panel is the views of the people present today as to what, if anything, could be done to encourage real communications.

I know that Dr. Marks sent me, in fact, the forms that are used at Memorial Sloan-Kettering. One of the forms that they already use is a very simple acknowledgement of discussion between patients and physicians, just a little simple one-page piece of paper.

The CHAIRMAN. Why do we not place that in the record?

Senator DANFORTH. All right. I appreciate that and that will be submitted for the record.

[The information follows:]

[SAMPLE OF PATIENT ACKNOWLEDGEMENT OF DISCUSSION]

I have discussed with my physician, my diagnosis, prognosis and treatment options. My physician has communicated the expected risks and benefits of my treatment options to me and the advantages and disadvantages of the proposed plan of care. I have been given the opportunity to ask questions about all of the foregoing and my questions have been answered satisfactorily.

Signature of Patient or Agent _____ Date _____ Signature of Physician _____

I choose not to discuss my diagnosis, prognosis or treatment options and hereby designate the person named below to have these discussions, on my behalf, with my physician.

Name of Person Designated as Agent: _____

Signature of Patient _____ Signature of Witness (over the age of 18) _____

Senator DANFORTH. So, again, Mr. Chairman, I appreciate all of the members of the panel for being here, their work on this subject, and your holding the hearing.

The CHAIRMAN. Thank you, Senator Danforth.

Senator Grassley?

Senator GRASSLEY. Mr. Chairman, no opening statement.

The CHAIRMAN. Good. There will be no flashing lights up here. We might ask our panelists to be fairly concise so that we can ask questions, which is what we are here for. We are here to learn and we are very happy to have you.

We will start with Dr. Cassel, who is the Professor of Medicine at the University of Chicago and Director of the Center on Aging, Health and Society.

All statements will be placed in the record as if read. Just proceed exactly as you wish.

STATEMENT OF CHRISTINE K. CASSEL, M.D., CHIEF, SECTION OF GENERAL INTERNAL MEDICINE, DIRECTOR, CENTER ON AGING, HEALTH, AND SOCIETY, DIRECTOR, CENTER FOR HEALTH POLICY RESEARCH, AND PROFESSOR OF MEDICINE, UNIVERSITY OF CHICAGO, CHICAGO, IL

Dr. CASSEL. Thank you, Senator Moynihan, and members of the committee. I would like to say in spite of the absence of lobbyists in the hallway, I think this is probably one of the most important issues that you face, particularly in the context of health care reform.

I have been asked to present an overview of what some of those issues are and some of the specific aspects of those will be gone into in more detail by some others on the panel.

I am Chief of the Section of General Internal Medicine at the University of Chicago and am also Chairman of the Health and Public Policy Committee of the American College of Physicians and a member of the Board of Directors of the American Board of Internal Medicine.

So in these various capacities I am aware that this issue is an issue whose time has come. I think the passage of the patient Self-Determination Act began and was one of the many events that started to get people in medicine as well as people in public policy to take this issue seriously. It has been too long neglected.

Some examples of what I mean. Just within the past year the American Board of Internal Medicine has constituted a committee to define the areas of clinical competence that it will require of residents in internal medicine around the care of dying patients. They have never done that before. So this is a new set of requirements for internal medicine trainees.

The Institute of Medicine just completed a feasibility study in which they recommended a major research program about the quality of care and the process of decision making around the end of life. I was asked last week to chair a project on the policy dimensions of improving the care of terminally ill patients that will be launched by the Millbank Fund in New York.

It seems to me that these are indications that major groups concerned with medicine and health care are turning their attention to this area. So it is very timely. The entire nation learned an important lesson about this from former-President Richard Nixon two weeks ago.

As his last days were reported in the press, it was one of the most important efforts in public education about what death with dignity can mean. It was widely known that President Nixon had a living will, that he did not want heroic measures if his life was

not going to be meaningful on his own terms. He was never placed on a ventilator and when his heart did stop beating, no resuscitation was attempted.

So this was an important example, I think, that really all of America looked to. Unfortunately, there are many and increasing numbers of people who would prefer to exit this world with the same kind of dignity that President Nixon did, but somehow the system prevents this from happening.

As we move into an era of health care reform, we have an opportunity to improve this situation. This requires widespread changes in medical practice, in medical education and training and in health care financing.

Dr. Lewis Thomas, who preceded Dr. Marks as President of the Memorial Sloan-Kettering Cancer Research Center, and was a noted author on medicine in society also died this year. And he was one of many who eloquently pointed out that progress of medical technology in medical science has led to a culture of medicine where the death of a patient is seen as a failure, a personal and professional failure of the physician, leading to attempts, often futile attempts, which are made to prolong life in the face of common sense evidence that these attempts are futile.

And in the process, and this is what I think we really ought to concentrate on, patient suffer needlessly pain, discomfort and fear.

The health care environment is part of society. So it is the result not only of the culture within medicine but also the culture within which we all live, where there is a great deal of denial of mortality, denial of aging, and I think an overly strong belief in the miracles that modern medicine can produce.

It is also the case that patients too often are made to feel that their only choice in the face of critical illness is intensive care or abandonment. And, indeed, in most of our major hospitals we do not offer a real alternative. We do not offer comfort care in every sense of that word.

What we should instead offer is something like what the hospice movement has done so well. But unfortunately hospice has not infiltrated the mainstream of medical practice. It is still the case that the majority of people die in hospitals, in nursing homes, where it is rare that true hospice care is being delivered.

So I think some requirements for optimal care at the end of life include the following. One, that medical professionals understand the limits of medicine and learn to view death when it is appropriate as an inevitable and personally meaningful chapter in the life of their patients.

Second, that the knowledge of the principles and scientific basis of palliative medicine be widespread among physicians and nurses. Palliative medicine is indeed a medical specialty focused on comfort care and relief of suffering rather than on the prolongation of life.

We have made important steps at limiting the use of unwanted and unnecessary medical technology at the end of life. But that is only the first step. We have a much more in some ways difficult and important job in providing adequate comfort care to those patients.

Hospitals, including emergency rooms and nursing homes should be structured to make this kind of palliative care available to a pa-

tient wherever he or she may be. It should not be necessary, for example, to transfer a patient to hospice in order to get this kind of care. You ought to be able to do it everywhere.

And related to this reimbursement for services should not be dependent on acute curative care being offered, which is too often now the case. The hospitals will say, we cannot afford to provide comfort care because it is not reimbursed.

I think to deliver on the promise of the Patient Self—Determination Act we should emphasize the necessity for primary care physicians to be the major source of this communication between doctor and patient about end of life care. It is, in fact, as Senator Danforth said, not the optimal time to have this conversation when you are first coming in to an acute care hospital.

So as we think about health care reform, we must not construct a situation in which the doctor/patient relationship is going to be disrupted, for example as employers change plans 1 year or another and then destroys the continuity in which that relationship is so important.

A couple of suggestions in terms of health care reform along these lines. One, payment for health care services needs to be flexible enough to allow palliative care to occur wherever the patient is being cared for. We also need to put in place numbers of ways to reenforce this need for better training and understanding of palliative medicine.

Federal initiatives could help here, for example, to encourage and examine innovative approaches to the delivery of end of life care, to the measurement of quality of care at the end of life which we now do very little of and then to the clinical use of those measures so that patients know what they should expect as they die.

We need much more extensive training of physicians, especially those in primary care, in both the science and the art of palliative medicine and we need to encourage hospitals and physicians to talk more openly about death and dying and the approaches to setting limits on life sustaining treatment.

Here I want to make two final points. The physician needs to be comfortable taking back some of the burden of decision making on his or her own shoulders. As I have traveled in Europe, in Scandinavia, for example, where they have a very good health care system and spend a lot of money on it, but they do not use all this unneeded and unwarranted technology at the end of life.

If you ask one of the physicians about how do they make these decisions, they will say, well, it is just common sense. So there is a sense that the physician has and exercises some common sense judgment in interacting with the patient about these.

I think that the tremendously adversarial environment that the current malpractice crisis in our profession has created makes American physicians want to get a contract from their patients. So they turn the whole decision over to the family or the patient, which then makes the family feel like it is their fault that the patient died, rather than the more comforting notion of a physician who is brave enough to put her arm around somebody's shoulder and say, medical science cannot keep your mother alive much longer, but she will not suffer and we will take good care of her.

This would be much more comforting to families and I think much more keeping in the traditional and important role that physicians can offer.

Finally, let me just say a few words about this brave new world of managed care, which most health care reform initiatives are heading towards and which even as we speak health care itself is changing to, regardless of what happens with health care reform, I think.

Now I am a big fan of managed care. I think prepaid approaches to health care have been shown to be ways of providing more comprehensive services with more accountability for cost containment in areas where they have had long experience with this, where there are stable and large organizations. But that still is not most of the United States.

As we move into what will be a new world for most health care providers in the United States, we need to be cautious and aware of the tremendous differences in the ethical context that managed care presents to the physician. The traditional role of the physician is to do whatever is the right thing for the patient regardless of cost.

All too often it has been easier to substitute more ineffective technology for the much tougher task of sitting down and really facing the limits with the patient and their family.

Now that we are putting an additional responsibility in front of the patient, the fiduciary responsibility of practicing medicine prudently in order to conserve resources for all the beneficiaries in that plan, we still do not have an ethical and legal environment which really supports the physician in doing that.

So I think this is not an insoluble problem, but requires that we explicitly define these new rules that we are asking physicians to take and support them with some clear standards and relief again from unnecessary legal threats.

So in conclusion I want to point out perhaps something which is obvious, which is that the end of life is something all of us will face, and, therefore, interest in improving the quality of care at this time is not the province of any particular interest group, any particular medical specialty or any particular disease advocates.

Every aspect of our health care system, including medical education and training, structures of systems of care and approaches to financing and reimbursement, as well as the agendas of our research institutions ought to be included in this vitally important effort.

Thank you.

The CHAIRMAN. Thank you, Doctor. That was hugely helpful. We have come upon this question of the changed sets of incentives that managed care brings about in ways that are not always reassuring. We appreciate your term, palliative medicine.

We have got to deal with this. You have given us a context in which to think about malpractice that I do not think we have had, this adversarial culture which is associated with this subject, which is a new one.

[The prepared statement of Dr. Cassel appears in the appendix.]

The CHAIRMAN. And now, Dr. Eric Cassell, a good friend, Professor of Public Health at Cornell University and a member of the

Board of Directors of the Hastings Center in New York, who comes to us in both capacities. We welcome you, Doctor.

STATEMENT OF ERIC J. CASSELL, M.D., CLINICAL PROFESSOR OF PUBLIC HEALTH, CORNELL UNIVERSITY MEDICAL COLLEGE, AND MEMBER, BOARD OF DIRECTORS, THE HASTINGS CENTER, NEW YORK, NY

Dr. CASSELL. Thank you, Mr. Chairman, Senator Danforth. I did testify 30 years ago in the Senate in a, if you will excuse the expression, previous incarnation and at that time——

The CHAIRMAN. Well, would you define that? [Laughter.]

Dr. CASSELL. It was in air pollution in those days and the halls were also empty. But look what happened in the 30 years that have followed that. So although the halls may be empty now, I think that what we are talking about brings us to a changing understanding of medicine.

We are at an ultimate of high technology, high specialty medicine. We are beginning to see a change, however. That is really what underlines one of the things we are talking about. What brings it to the floor is the fact that there are three groups of patients in the United States who die nothing less than bad deaths.

One group is patients who are inappropriately resuscitated and maintained on life support. Those are people who would have died without the resuscitation anyway. Their disease is progressive. Resuscitation offers them nothing except to extend their dying.

The second group of patients are those with late stage dementias, like Alzheimers Disease, and the inevitable physical decline that comes with that disease. They enter hospitals unable to talk to anybody, to make contact, to interact and are treated for one infection after another until they finally peter out, dying a death that no one would choose for themselves—no one would choose for themselves.

And the final group are patients who die suffering in pain, unrelieved pain and other symptoms from diseases—cancer is the one we talk about the most, but it is not the only one—and whose care is inadequate for what their problem is.

Now the first two groups, people who are inappropriately resuscitated and the end stage dementias, the problem with their deaths could be or can be resolved in part by advanced directives. When the Patient Self—Determination Act came along, I, along with a lot of other people thought this is the push we needed. This is going to make a huge difference. Unfortunately it has not made as big a difference as we wanted it to.

Patients are coming onto the floors of the New York Hospital, unlike Mr. Nixon, they do not all have advanced directives and that piece of paper that they get as they come in the front door is one of 100 other pieces of paper and it is too often not signed.

Now there are some reasons for this—why they do not tell us what they do not want done and why they do not tell us who should speak for them when they no longer have a voice. For one thing, there is inertia, inevitable inertia. There is apathy. They have other things on their mind. They are indifferent to this concern. They are also frightened, like people who do not write wills because they do not want to talk about death in the first place and

they do not want to consider their death coming into a hospital, so they do not want to sign a document that appears to be a document directed only at their death.

There are lack of incentives. There are ways of making people do things that they otherwise would not do and there are some direct incentives. I just might say one of them—that if Medicare reimbursed physicians for the visit in which an advanced directive is signed and that had a code, we would have more advanced directives signed.

There is ignorance by both physicians and patients about what this whole thing is really about. There are administrative difficulties. In the New York Hospital, as I say, the piece of paper is presented as part of the admission procedure. It ought to be on the chart. It ought to be in the front of the chart. And it ought to stay on the front of that chart until it is either signed or declined and so it has impact.

But there is one final thing that gets in the way, and that is the wrong idea of what an advanced directive should do. I would like to concentrate on that if I could for the moment.

The widespread idea that people have is, and it is a wrong one, that an advance directive is meant to exercise the patient's right to refuse treatment. As we know, this started out in the age where autonomy was coming up as a major issue—patient's autonomy—in the face of an aggressive and imperialistic medicine so that it looked like the thing to do was to be able to refuse treatment.

Doctors pursue disease and hold off death at all costs, grinding patients under their goals and patients defend themselves by exercising their right to refuse treatment. Well, that is a strange picture of the care of the sick, that there is an aggressive doctor here and you defend yourself unless you happen to be lucky enough to have shared goals.

And despite the fact that I have exaggerated somewhat to make the point, it is too often true. I think we must change the focus of our advanced directives from refusing treatment to choosing treatment.

The purpose of an advanced directive is to move away from an adversarial stance between patients and doctors to an active involvement of the physician with the patient on the patient's making a choice about what is important to that patient in his or her care. Not merely if they are going to die, but in any case.

Now we say the patient chooses their treatment when they can and they have a voice. But we really want their doctor and them involved at all times in the evolution of care. People die and so in choosing treatment we are also choosing how we want to die. It should be something over which we have considerable choice.

The ability to do it is there. It is not really either advanced technological medicine or palliative care. They are all part of a seamless continuum of medicine when medicine is practiced to meet the needs of sick persons.

What kind of an end of life best meets the patients needs, as the patient knows those needs, is a concern of physicians and patients together. It requires an enhanced relationship between doctor and patient. It requires a shift in the orientation of the physician from

a primary concern with diseases and technology to a primary concern with sick persons.

Whatever health care law is enacted in relationship to any aspect of health care, even patient self-direction—I mean patient's advanced directive—has an impact on the doctor/patient relationship. It either encourages it or it discourages it. There is no neutral stance.

It is only by a return to the historical basis of medicine—that the relationship between doctor and patient—that we can help patients make meaningful choices and make physicians aware of their responsibilities for the quality of living as well as the quality of dying.

Only here will we be able to resolve the third kind of bad death, a death of suffering, and again make appropriate care of the dying and relief of suffering one of the fundamental goals of medicine.

Thank you.

[The prepared statement of Dr. Cassell appears in the appendix.]

The CHAIRMAN. We thank you, Dr. Cassell, most emphatically. The notion that the advance directive needs to shift from being seen as a matter of refusing treatment to a matter of choosing it is very helpful, at least to this Senator. I appreciate that very much.

We welcome Senator Chafee this morning.

Dr. Ezekiel Emanuel is a Medical Oncologist at the Dana-Farber Cancer Institute and a Professor of Medicine at Harvard Medical School. We welcome you, Doctor.

STATEMENT OF EZEKIEL J. EMANUEL, M.D., PH.D., MEDICAL ONCOLOGIST, DANA-FARBER CANCER INSTITUTE, AND ASSISTANT PROFESSOR OF MEDICINE, HARVARD MEDICAL SCHOOL, BOSTON, MA

Dr. EMANUEL. Thank you, Mr. Chairman. Thank you, Senators, for having me. I am an oncologist and I take care of mainly breast cancer patients. I am also a medical ethicist. Last spring I worked as an ethicist on President Clinton's health care task force and have been interested in the area of advanced directives for about the last 8 or 10 years, and with my wife created The Medical Directive, which is a kind of advanced care directive that combines precisely the wishes of whether you actually want treatment and proxies.

I am going to talk to you today for a moment about the widespread perception in our society on the part of doctors, health policymakers, the media, the public, may I even say Senators, that were spending too much money on the care of dying patients. We find this view almost everywhere.

Recently there was an Op. Editorial in the Washington Post entitled "Final Savings from Living Wills," which promulgated this idea.

I want to ask first the question, where does this perception come from. I think it rests on three ideas. The first idea is from very good data from the Medicare system provided by HCFA that shows—and it is actually illustrated on this poster here—that around 5 percent of Medicare beneficiaries each year die. Those 5 percent consume about 27 percent of the Medicare budget.

That proportion has stayed the same from 1976 to 1988. 1988, by the way, is the last year for which we have statistics available. That is 6 years ago.

The CHAIRMAN. That is a stable ratio, is it not?

Dr. EMANUEL. Yes. And actually, that ratio can be shown to project back into the early 1960's—the same ratio.

So it appears that we are spending a huge amount of money on the care of dying patients. Second, it is claimed that the vast majority of Americans do not want aggressive end of life care. They would rather refuse treatments, just as President Nixon did.

We, like many of the people at this table, have conducted a number of studies of patients and the general public and have substantiated that when asked 73 percent of patients and members of the public did not want a respirator at the end of life and 74 percent did not want artificial feeding and nutrition at the end of life.

If you portray the most extreme scenarios, if patients are in a persistent vegetated state, the number goes to 80 percent who do not want these aggressive treatments. Thus, many people take a look at that 28 percent and they say, well, 70 percent of people do not want aggressive treatments. Well, 27 percent of the health care budget this year is around $230 billion. If we assume we can save 70 percent of that, maybe we can save about $110 billion on end of life care.

Such calculations have been made. They have been made by physicians in the literature and, dare I say, they have been made by senior advisers to our President who have been quoted and I have heard make such statements.

The CHAIRMAN. We have heard that, too, actually.

Dr. EMANUEL. Are these estimates true? And do they reflect reality? I want to suggest for three reasons I do not think they are true. In fact, I do not think we are actually spending that much on health care at the end of life.

The first point I would make to you is that while the Medicare data is very good data, it distorts reality. Five percent of the Medicare beneficiaries die each year. But in America only 2.2 million or so people die each year, less than 1 percent of the population dies.

It is highly unlikely that that 1 percent is going to consume 27 percent of the whole national health care budget. As a matter of fact, our calculations, which are on the high end, suggest that dying patients in America consume only around 10 percent of the total national health care expenditures.

As a matter of fact, the HCFA data, the people I have talked with in HCFA, suggest that it may be lower, at 7 or 8 percent. I think the reason we have that distortion is because two-thirds of people who die in America die on Medicare. So there are very few other people dying.

Second, the idea that most Americans want to refuse treatment I think is true. But we cannot extrapolate the data so easily. For one thing we know as a result of many studies now that despite the fact that there has been a lot of media publicity to advance care directives, despite the fact that they are widely available, despite the fact that you now have to get them in hospitals, despite the fact that they are cheap, only around 25 percent of Americans have ever completed an advanced care directive.

Indeed, as I think Dr. Cassell has mentioned, there are enormous barriers, not just practical, but actually psychological, for completing advance care directives. When you consider that only half of Americans have ever filled out a regular estate will, you can realize what the barriers are.

More importantly I think, we need to remember that from survey after survey roughly 20 percent of Americans want everything done for them no matter what. They are very committed to getting everything modern medicine has to offer, even at the end of life.

There are also important segments of our population who want lots of medical treatment. AIDS patients, very costly patients, represent such a group. Many surveys have shown that around 50 percent of AIDS patients want everything done, including intensive care units, if in fact they still have a low chance of survival.

I was recently reading my alumni book from Amherst College and happened to look at an obituary of a classmate of mine from the Class of 1979 who died of AIDS. Here is what it said. "He told his family he wanted them to take whatever measures were available to sustain his life. He told me he felt robbed of the virus and refused to succumb. Until the very end, he stubbornly clung to life and tried to hang on as long as possible".

I am sure he does not represent a majority of Americans. But I am sure he does represent a significant minority. That is one reason again that we cannot necessarily reduce medical care costs at the end of life.

Finally, I want to suggest the idea that we can save a lot of money through the use of advanced directives, hospice and other things does not have a lot of empirical support.

If you can flip to the third poster there. I have summarized on this poster for you many of the recent studies about the use of advanced directives and hospice to save money. In the top panel are the three studies that exist about saving money through advanced care directives. The first one is from California. The second one is from five places around the country; and the third one is from Philadelphia.

The first two suggest that you cannot save any money from greater use of advanced care directives. And, in fact, the very first one looked not just at the final hospitalization but the last 6 months of life and suggested that there was not a significant amount of money to be saved by patients who used advanced care directives in California.

The last one is the most recent study that showed we could save 68 percent, but they were looking at only the terminal hospitalization. I do not think any of these studies are definitive. I do not believe that they show you can save anything. But I do think——

The CHAIRMAN. That last one is Chambers, 474 Medicare patients in Philadelphia.

Dr. EMANUEL. Correct. Over 3 years.

But I think the important point is, it is not obvious you can save a lot of money. I think that they suggest there is less to be saved than we believe.

Another place that we have good data on is in the whole area of hospice care. That is the bottom panel here. In the early 1980's

there was a big push before Medicare fully covered hospice to study the use of hospice in this country.

There was a VA study which randomized patients either to hospice or not, patients who had cancer. It showed that you could not save any money by using home hospice. Then there was a very big national hospice study between 1980 and 1983 in cooperation with the HCFA and the Robert Wood Johnson Foundation and it showed that in the last month of life you could save 40 percent by having people in hospice.

But as people stayed in hospice longer and longer the savings decreased, such that in the last 6 months of life you could only save 27 percent of the end of life care cost by using hospice.

Now I would remind you of current statistics. In 1992 now the average length of stay of a Medicare patient on hospice has risen to 57 days. That is about the break even point.

Also importantly, more than a quarter of patients on hospice still require hospitalization for treatment of complications and other problems.

In addition to these studies there are other studies among cancer patients, for example, showing that if you give patients with metastatic lung cancer either chemotherapy or best supportive care and no chemotherapy, you do not save a whole lot of money either. So I think the idea that we are going to save a lot of money is doubtful.

I have made sort of a wild estimate of how much could we save if every American executed an advanced directive, every American accepted palliative care in hospice and wanted to die at home rather than get aggressive care. That is the next panel.

I am not going to go through the details of it, since as you might imagine there are a lot of assumptions and complicated calculations. But we can show, I think, that assuming you can save 27 percent of the health care dollar by using these services, the most you are going to save is 3.3 percent of health care spending and 6 percent of Medicare.

From one perspective these figures might seem trivial, from another perspective they represent $30 billion. And dare I say in the Everett Dirksen Building, I should not trivialize a few billion dollars here and a few billion dollars there.

But the fact of the matter is that it is highly dubious all Americans are going to use those interventions—living wills and hospice. More importantly, as I am sure you appreciate, you cannot flip a switch, such that tomorrow we can collect the $30 billion. It will dribble in over time and it to actually get it represents a huge shift in the practice of American care. Probably a shift that would require almost a decade to accomplish.

Finally, let me address myself to why I think the total savings are probably less than we anticipate. First, I want to reemphasize the point that Medicare gives us an inflated view of how much we are actually spending on the dying people. If we spend 10 percent of national health care expenditures on dying patients we simply cannot save that much on such a small percentage.

Second, and very importantly, I want to emphasize to you that we already are doing a lot to stop aggressive end of life care. Many studies can show you now that 80 percent of Americans who die

in big hospitals do not get resuscitated anymore. And if it is cancer patients we are talking about, a recent study from the Cleveland Clinic demonstrates that 97% of patients do not get resuscitated at the end of life.

Doctors in the last 10 years have had a dramatic shift in the way they treat patients. Importantly, I also think if you found other statistics, we are withdrawing a lot of other treatments, not just cardiopulmonary resuscitation. The idea that we do everything, I think, is old. It is certainly a decade out of date.

Fourth, I would emphasize that we cannot predict who is going to die. So it is hard to decide from which patients we should withdraw care. Until the very last moments.

The only cases where we really have good predictability are cancer and AIDS, but they account for only about a quarter of all deaths. That means three-quarters of the dying patients we do not have an ability to predict when the death will occur with any precision.

Who would have known that Richard Nixon would have died in April 1994? It might have been 1995. It might have been 1996. If some illness would have come up, would we have withheld treatment from him?

Finally, I want to emphasize one very, very important point. We talk about palliative care. Even if we stop aggressive end of life care it does not mean the patient immediately dies and we do not provide good medical care. Providing good palliative care is still expensive. It is labor intensive. You need to provide someone who turns a patient, who can adjust the pain medications, maybe gives them radiation therapy to a painful bone metastasis or other things. That kind of care is not cheap.

If we are going to urge doctors to provide high quality end of life care then we have to recognize it does not come for free, even if it is not high tech. Therefore, I think we are not going to save nearly as much on this to finance universal coverage as many people would anticipate. I do not think there is nearly as much waste in the system as we might believe.

Thank you.

The CHAIRMAN. Thank you, Dr. Emanuel.

[The prepared statement of Dr. Emanuel appears in the appendix.]

The CHAIRMAN. Once again, to say, as Dr. Cassel observed, that nothing has been more emphatic in our hearings than the repeated reports of how medicine is changing right before us. To some extent we have to watch that we do not repair a system that no longer exists. But that has happened before.

Welcome, Senator Rockefeller. It is good to see you here.

Senator ROCKEFELLER. Thank you, Mr. Chairman.

The CHAIRMAN. Dr. Melvin Konner is one of those, I dare not say over educated, but superbly educated persons, who is both a professor——

Dr. KONNER. Over educated is fine.

The CHAIRMAN. A Professor of Anthropology and of Psychiatry and Neurology at Emory University, an absorbing and rare combination. We welcome you, Dr. Konner.

STATEMENT OF MELVIN KONNER, M.D., PH.D., SAMUEL CANDLER DOBBS PROFESSOR OF ANTHROPOLOGY, AND ASSOCIATE PROFESSOR OF PSYCHIATRY AND NEUROLOGY, EMORY UNIVERSITY, ATLANTA, GA

Dr. KONNER. Thank you very much. It is a privilege to be here. My name is Melvin Konner and I hold Ph.D. and M.D. degrees. To my mother's disappointment, I do not practice medicine but teach and write about medicine in society. I sympathize with the practicing physician, but I get no part of my income from the delivery of care.

Due to several serious illnesses in my family I also know how it feels to be at the other end of the stethoscope.

Robert Frost is known for many serious works, but my favorite may be the following two-line poem. "Forgive oh Lord my little jokes on thee and I will forgive thy great big one on me." The big joke is mortality. And although the almighty may sometimes find it funny, we humans rarely do. In fact, we spend our lives in a massive effort to postpone them in denial.

Certainly in medicine the assault on mortality is our mission, obsession and dream. But what happens when we have so much control that the idea of natural order loses its meaning?

There is agreement that competent adults may refuse treatment and a growing acceptance of advanced directives. Activists have tried to extend patient rights to encompass a right to die and even a right to a physician's help in dying.

A series of average Americans, most recently this week, have refused to punish such acts when they seem human. And only yesterday a Federal Judge in Washington State ruled a ban on assisted suicide unconstitutional.

But as Dr. Christine Cassel has said, it is one thing to let people die because their lives are an inconvenience to them. Quite another to let them die because they are an inconvenience to us. Surely we do not want to create a moral realm in which seriously ill people, guilty over the burden they cause, choose death when life still appeals to them.

Dr. Carlos Gomez studied youth in Asia in the Netherlands and found inadequate treatment of pain and depression. Before we help people die we had better be sure we have done enough to help them want to live. Yet, a rational fatally ill person may choose death and leaders of medicine recognize that assisted suicide does and probably should sometimes happen.

We owe it to physicians, patients and families to share the burden of this secret. But the ethics of the ice flow also evokes the specter of explicit rationing. Nobody wants it, but in fact we have rationing now.

The CHAIRMAN. Did we hear you sir? The ethics of the ice flow.

Dr. KONNER. The ethics of the ice flow, yes.

Nobody wants rationing, but in fact we have rationing now. As a medical student in some of our Nation's best hospitals, I saw it in action as poor people waited in pain for so many hours that they left without treatment.

We saw rationing, too, when thousands of children contracted measles in a completely unnecessary epidemic a few years ago and

some died of it because of the shameful inadequacy of our vaccination programs. This is simply irrational rationing.

We accept the process of triage and war or disaster when we must choose whom we will treat. We may be facing triage as a nation. Americans say that we spend too much on health, yet 35 million people have been left out.

The people of Oregon have tried to set priorities and a bipartisan plan designed by physician legislators after countless town meetings and with the Governor's support, they ranked medical treatments by value and effectiveness. They did not find this easy, nor did they think they had done it perfectly. They can be criticized for singling out people on Medicaid, but their plan should be studied by all who care about health.

If we set priorities, how do we view the end of life. To focus on the last year misses the point in two ways. First, there are wasted treatments throughout life. Tens of thousands of unwarranted coronary bypasses, hysterectomies, prostatectomies, caesarean sections, the list goes on. These treatments may be wanted but that does not make them good medicine and the money they waste is drawn from other needed treatments.

Second, the last year does not exhaust the end of life issues. Consider my mother's final illness. A large stroke left her bedridden and unable to speak. She had made it clear that she would not want to live in such a condition. Still, we fought to give her every chance of recovery. But after a second stroke we faced a sad choice.

Specialists wanted to implant a gastric feeding tube. Her family doctor, a friend, advised against it. It could have kept her alive for years in a very grim condition. We knew what she would have wanted. No tubes she had said again and again. Still, we agonized about it and even consulted a lawyer. We decided not to place the tube and her doctor discharged her to hospice care at home where she died gently a few weeks later.

With the tube she might have survived for years of indignity and distress without hope of improvement. She would have also incurred many medical expenses, most of which would not have been in the last year of her life. But,of course, we were not trying to save money.

Indeed, while we were aiming for recovery, we spent Medicare's money with impunity and so I hope with everyone. I call this the what if it is your mother rule.

As awareness of new technology spreads, the what if it is your mother rule will continue to drive up costs. Only a broad social consensus eventually embodied in law can slow down this process. Not all treatments of patients demand have equal value and some have none. Courts have ordered hospitals to provide against their best judgment expensive treatments with no proven merit in a vain attempt to control what cannot be controlled. We sorely need more and better outcome studies to give us practice guidelines.

If we do not set priorities, then our effort for denial of death will come back to haunt our children as they struggle to find the values that we lack the courage to bequeath them.

The CHAIRMAN. Thank you very much, Dr. Konner.

[The prepared statement of Dr. Konner appears in the appendix.]

The CHAIRMAN. That was very moving. Of course, we are not going to change the advance of that technology, are we?

Dr. KONNER. Certainly not.

The CHAIRMAN. Although that is one of the dilemmas we deal with. We will get to that in general questioning.

Dr. Lynn, good morning. Professor Joanne Lynn, a Professor of Medicine at the Dartmouth Medical School. We welcome you.

Dr. LYNN. Thank you.

The CHAIRMAN. I think I am going to ask that those somewhat intimidating charts be taken away. They seem from the perspective of the camera and the light—no, we will do it for you—we do not want to have you sitting there with those charts glaring at you.

Good morning.

STATEMENT OF JOANNE LYNN, M.D., PROFESSOR OF MEDICINE, AND OF COMMUNITY AND FAMILY MEDICINE, DARTMOUTH MEDICAL SCHOOL, HANOVER, NH

Dr. LYNN. Good morning. Much to the surprise of most Americans, dying is not optional. It is the one minority group to which we can all aspire—to be very old, very sick, and dying. And not only that, we will mostly get the chance. It is the case that most of us who are alive long enough to be in this room will spend time seriously ill with an illness that will eventuate in our death. The major success of modern medicine can be said to be the creation of serious chronic disease eventuating in death, but later—not at the time when it would have killed us in an earlier era.

The usual person dying of illness in the United States faces an extraordinarily high likelihood of dying in pain, alone, isolated, at great expense, devoid of meaningfulness, without grace or dignity.

My background in this regard arises mainly from having been a physician to some 2,000 patients who have died, mostly in this city. I was the main hospice physician for Washington, D.C. for more than a dozen years and I have served a number of patients in nursing homes and in home care. I also have worked a great deal with ethics, having been a part of the President's Commission on Ethics in Medicine when it was alive and well in the early 1980's, and I have worked with a number of legal organizations in trying to work on these issues.

It is striking that, at least in this arena, there are not adversarial groups. We all can see where we ought to end up. The struggle is, how can we get there? It is not really that there are parties in opposition. This ought to give us tremendous opportunities for achieving what we hope to achieve.

But we have a long history to live down. Modern medicine has almost completely lost even basic descriptive knowledge of how it is that we die. The last sequential study of dying patients in hospitals was done by Sir William Osler at the turn of the century. You cannot say with any authority today how many people die in a hospital. Although I have helped create some of the estimates, it is still the case that we do not have even that basic information.

We do not know how many people die unconscious, how many people have seizures, how many have pain, how many have family in attendance, how many are abandoned. The basic work of under-

standing what it is to die has been abandoned by modern medicine and by the culture that modern medicine serves.

If you look at a textbook of modern medicine at the turn of the century, you will find virtually every disease described in its gory detail through to death, with advice to the practitioner as to how they will recognize that things are getting worse and what small things can be done to try to assuage the pain and suffering that is thereby entailed.

In a modern medical textbook you are lucky to find acknowledgement that the disease will eventuate in death. You can go hundreds of pages in descriptions of congestive heart failure or cancer without noting that these are the diseases that take most of us.

That sort of reorientation is going to take substantial sea change in how it is that we view ourselves, our lives, and our lives coming to a close. People routinely think that doctors know how to prognosticate, how to assuage pain, and generally how to serve dying persons. Nothing could be farther from the truth.

This culture has been so thoroughly death-denying that we have not even described our course to death, nor have we developed the professional skills to provide service to these patients. It is probably true that we are gradually learning how to forego inflicting unjustified technology upon dying persons, but we clearly do not know how to see to it that most of us—and most of our parents—will get excellent care shaped to our needs and responsive to our symptoms.

The care system that we have developed has serious barriers to adequate care of the dying. Reimbursement is not regularly available for services that merely mitigate suffering. An automatic denial of a hospital stay happens if you are not doing something more aggressive than merely to have somebody be comfortable. And yet that is, after all, what one most hopes for as one comes close to dying.

Even hospice is really available only to the middle class with solid cancers and predictable courses to death. It is not regularly available to the poor, the homeless, persons without adequate wealth and families.

The usual person dying and in need is not in the same condition as was probably the case in 1950 or 1955 when we really shaped the current health care system. The usual patient is not the 55-year-old male legislator who is worried about a heart attack. The usual person dying now is an elderly person with multiple illnesses, most commonly afraid of bankruptcy, most commonly with very little family resources, with no regular physician who is following through to death, and whose fears are homelessness, hunger, pain, and isolation, not the absence of access to coronary artery bypass grafts.

All of these terrors can be mitigated. We do know how to do this. But doing so will require substantial reorientation of the care system so that continuity and support become priorities. And to that end, what is done in regard to the end of life must be integrated completely into the reforms now being considered for the care system as a whole.

In regard to the Patient Self-Determination Act, I think that the Patient Self-Determination Act has done a great deal of good. I was

something of a skeptic at the time it was enacted. I think that, as it has played itself out, it has done a great deal of good.

I want to review just briefly some of the things it has done. One of the small provisions of the Act which has received very little attention was that the Act required that States say what their law was. Now that sounds fairly simple. It turned out to be enormously complicated.

I brought along some examples of what Vermont did, for example, in putting together an intelligible way of patients and doctors understanding what it is they could and were free to do. And, in doing that, cosortiums had to develop in every State, involving people from quite diverse fields, who had to try to make sense of what were ordinarily quite a disparate and incoherent set of statutes.

Thirty-three States enacted legislation to improve their statutes out of that endeavor. Forty-eight States developed intelligible consumer oriented information that is now in use in those States to try to make clear what you can do with regard to medical decision making, including using advance directives, but not limited to advance directives. That provision of the PSDA was stunningly effective and with very little cost.

There is perhaps a more checkered balance sheet in regard to the mandatory notice. The centerpiece of the PSDA is that patients must be told at various points as they come in and out of the health care system about their opportunities to make advanced directives and to control their care.

In the support project, which I am one of the co—leaders of, we have had the opportunity to study advanced directive use among very seriously ill patients in five U.S. hospitals before and after implementation of the PSDA. Before the PSDA about one in five of our patients said they had an advanced directive. There were few that were mentioned in the medical records—on the order of 80 out of 400—and there were none that were recorded in the medical charts. Advance directives themselves—there were none at all.

After the PSDA, the proportion of patients who have an advance directive has gone up almost not at all, only a very small amount. But now one in three are mentioned in the records and almost all of those actually have the document. Our experiences are echoed in the work of others, who are finding many more advance directives showing up in the charts and being discussed there.

However, the evidence that advanced directives are changing how patients are cared for is less clear. In support, we can find virtually no effect of having a living will or a durable power of attorney. You are equally as likely to have a "do not resuscitate" order with or without one. You are equally likely to have the timing of your "do not resuscitate" order at a certain date with or without a durable power of attorney or a living will.

Even among patients who have living wills and who have expressed a preference not to be resuscitated, only half have an order or a discussion of an order documented in the chart. So there is a staggering inability of the care system still to deal with this issue. We have patients who are very sick—in our study all the patients are very sick and most will die within 6 months—and they have a living will. Furthermore, they tell us in an interview that they do not want to be resuscitated. Yet, the care system is only ad-

dressing that in less than half of the cases. So there are still miles to go.

I think as Ezekiel has already said, the evidence that we have a substantial effect on costs with advance directive is fairly small. On the other hand, we are early in this process. This is a C change. This requires a lot of changes down the line and maybe over time we will really see some substantial effects. This is very early in the process. There are lots of things yet to be done.

One of the more striking changes which may or may not have to do with the Patient Self-Determination Act is the enormous increase in do not resuscitate orders and in orders against hospitalization in nursing homes. That may have as much to do with the OBRA regulations requiring that those be documented. But in either case, those have gone up enormously, on the order of tripling in many States.

But advance directives have not delivered on the promise that we thought they would have in 1990 of a blossoming affect of communication, a burgeoning of advanced care planning for seriously ill patients and a curtailing of worthless and desired life prolonging care for dying persons in hospitals.

Why is this? I think it is for three reasons. One is that most advance directives just say to do what it is you would already be doing. That is, turning to the next of kin in the case of a durable power of attorney or stopping at some point for almost everybody else—and that is what almost everybody wants. In those cases you would not expect an advanced directive to change much.

A second reason is that patients, doctors, and the patients' families do not really understand when these should be used and have the sense they should be used essentially as the patient is dying, as their blood pressure is sinking, not two or 3 months or 6 months or 2 years earlier when they really could have a substantial impact on the shaping of a long plan of care.

This may have to do also with the fact that patients and families especially do not understand prognosis. Even though they are told—it is rather like the story of asking a lot of people whether they are good drivers and how they would rate their driving. It turns out that everybody in America is a better than average driver. Well, if you ask people who are very sick how long they are going to live, everybody thinks they have at least 90 percent chance of making it to 2 months, even if they are likely to die this week.

So that is a really fundamental change in how it is we come upon our dying to acknowledge that we are probably not greatly different from the statistical mean and we probably are not all going to beat the odds. Unless we get to the point of understanding that, some of these things are not going to change dramatically.

A final consideration is that very few interventions are actually being implemented that are really stupid anymore. We are down to around 10 percent of people get a resuscitation tried as they die. We are not having huge amounts of people kept in ICUs who have no chance of successful treatment. Most Nancy Cruzans do have their treatment stopped very early.

What should you do? What should we do about improving the things that are yet to be improved? Well, that takes some careful thought because it is not only a question of what should be done,

but what should be done at the Federal level. And so much of this is the matter of changing 1,000 little things in the lives of doctors, patients, nurses, hospitals. We have to be very careful as to where it is we step in to shape the system so that we do not create more problems than were there to begin with.

I think that the advent of managed care and of thinking systemically about health care creates a tremendous opening wedge for improved care of the dying by simply requiring there to be measures of how well we are doing, and requiring a reporting of that.

Now we do not have those measures today but we could develop those and we could require the regional health alliances or health plans to know how they are doing. And those that are doing badly, presumably, would be motivated to improve that.

We also could require that organizations like professional groups and IOM, the Institute of Medicine, would generate guidelines on what it is that is good care. And that might stand to help make coherent what right now are very difficult, conflicting mandates at the Federal level. For example, we are required to treat all persons as if we are blind to disability and the fact of illness on the one hand and on the other hand to notice that we are not doing very much good at some level of disability if we drag out life for a little longer.

That incoherent mandate needs to be brought together in very concrete guidelines and a group like the Institute of Medicine or perhaps leading professional groups could take a lead in that. But they would have to be mandated to do so and given some learning room. Because right now I as a practitioner do not know how I should try to bring those together.

We could make Medicare Part A and graduate medical education funds contingent upon better education of doctors at least in regard to care of the dying. We could encourage innovations in Medicare that would broaden the scope of potential services at the cost of reducing aggressive care so that people could get services that are tailored to that 85-year-old woman dying at home alone and scared rather than a Medicare program which really was tailored to the fears of people who were afraid they could not get hernias repaired or cataracts extracted. That is the fear of most 65-year-olds, but it is not the fear of most 85-year-olds. There probably ought to be an innovative program under Medicare that would make that possible.

We could require that the institutes in the National Institutes of Health that have under their purview the major killers actually come to terms with that fact. They must support research on how it is that one comes to die of heart disease, of lung disease, of liver disease, of cancer and to present reports on how well we are doing and what we could do to improve those rather than to treat the fact of dying as an orphan phenomenon that we are going to continue to ignore forever.

[The prepared statement of Joanne Lynn appears in the appendix.]

The CHAIRMAN. Why do we not just take that as a healthy list of suggestions and we will hold it right there. Listening to you I thought will there emerge a national malaise called longing for pneumonia. [Laughter.]

But your reference to Sir William Osler's compendium on dying makes me think of Lewis Thomas a little earlier on the hundredth anniversary of the first publication of the journal Science, which is the Journal of the American Association for the Advancement of Science.

They had a series of very brief articles on the big events of the last century. Lewis Thomas had an article on medicine. It had as its feature that wonderful portrait, which got the Victorian painter knighted, called "The Doctor" by Sir Luke Filk. I think you all recognize it. You have seen it in calendars that pharmaceutical companies send you.

The doctor is sitting there. He is bearded. He is intelligently looking at this child who is sort of sprawled off the couch and in the back you see a father and a mother hovering. And Thomas explains that that doctor almost certainly knows what is wrong with that child and he knows exactly how the disease will progress. And he also knows that there is nothing he can do about it and that it took a century of medicine to get to that point.

What has changed in the interval is that now you can do something and that has produced the ailments for which you say we will all expire. Whereas, formerly pneumonia came along rather briefly.

But that is the condition we are in and we are asked both to deal with it and to legislate on it. We have had wonderful testimony. I want to thank you all and turn now to the Republican Leader.

Senator DOLE. Are these advanced directives portable or do you have to make one in Kansas and one in Tennessee?

Dr. LYNN. They are probably portable in that they would be overwhelmingly persuasive evidence of the patient's intent and it is exceedingly unlikely that anyone would fail to follow one that was clear just because it did not meet the requirements of any one State.

On the other hand, the state-to-state distinctions are really silly. In one State you require a notary public and in another State two witnesses. And sometimes the witnesses cannot be employees of health care institutions and sometimes they can. You know, trying to get through the morass of the small differences is really silly and sometimes looks as if you cannot rely on it.

I think the ruling in Cruzan makes it fairly clear that courts would rely on even a letter. For example, I write a letter to my child. Courts would probably rely on it. But doctors might not believe that. And it would be a mercy for the providers of this country if we were freely able to transport formal advance directives.

The CHAIRMAN. Dr. Konner is agreeing.

Dr. KONNER. Yes. My experience is that today an advanced directive from another State would be more than most hospitals and physicians would require to assume that they know what the patient's wishes were. Really the problem is with the great majority of people who do not have advanced directives and for whom the actual character of their wishes is very debatable.

Senator DOLE. Could I ask Dr. Emanuel, I guess the point you are making is not an economic issue. You are not suggesting it is not a good idea.

Dr. EMANUEL. Right. I have worked in this area for almost a decade now trying to improve the documents, trying to improve ways

for physicians and patients to communicate, trying to get legislation passed, trying to study how we use them.

So I think it is a fantastic idea. I spend a lot of my time campaigning for greater use of advance care directives. But I think the under current, which has risen closer to the surface over the last few years is that advance care directives are also going to be a great economic tool and I think that is a very sad mistake, both because we are not likely to realize much savings and also because I think it distorts their purpose.

I might mention that there are some consultants running around advising insurance companies and HMOs to give a 5 percent discount to anyone who fills out an advanced directive. I do not know how they get the statistics on which to make such a recommendation. Nothing suggests that is anywhere near right. But you can see that it has become much more material.

Senator DOLE. Are there any statistics that——

The CHAIRMAN. Five percent?

Dr. EMANUEL. A 5 percent discount.

The CHAIRMAN. Well, Kaiser might be making money.

Dr. LYNN. It does select for the well off.

Senator DOLE. Are there any statistics available on people who might have an advanced directive or people who are comatose and then suddenly one morning, you know, they are back on the road to recovery? Does that happen very often? I mean we talk about living wills and advanced directives. You just roll the dice and 99 percent of the time you are going to die anyway or what?

Dr. CASSELL. Do you mean are there people who have an advanced directive, would withdraw treatment, and then one morning would wake up and are alive again?

Senator DOLE. Yes, get better. Does that happen very often?

Dr. EMANUEL. We do not have good statistics on that.

Dr. CASSELL. But the point is that prognosis is not a blind. You do not have to look into a crystal ball to find out whether somebody with advanced metastatic cancer is going to die. They are going to die.

There are other conditions in which whether somebody is going to die is doubtful—comatose, people who are comatose through accidents may, in fact, come back. But the vast majority of people who die do not have a disease in which it all of a sudden reverses itself. But it is brought up as an argument that supposing, just supposing this person could live, well, that is interesting. But then we have to ask how many other people are going to be subjected to an awful lot of awful care in order that this one person might 1 day rise up out of their bed and come alive again.

So it is not only that one person might come back to life. It is all the other people we treat wrongly or inadequately just so the one might rise.

Dr. EMANUEL. There are also some interesting stories about people who did have an advanced directive, it was not known, they were treated, they did recover and they resented having recovered because they are left with some disabilities, because they had lived out the life they wanted to and now they were not in the condition they wanted.

You asked for statistics, statistics we do not have. But we do have stories that it is not everyone's wish, as we know, to live ad infinitum. Many people think they have lived a sufficient life and enough is enough.

The CHAIRMAN. We have a rule in this committee which is that data is the plural of anecdote. So you need not fear. [Laughter.]

Dr. Cassel.

Dr. CASSEL. I just wanted to add to this that that is part of what I meant by the fact that we are always going to be dealing with some degree of uncertainty. There is a movement in medical ethics to search for perfect futility data so that we will know which treatment or in which patients treatment will be 100 percent futile.

I think there are very few such arenas. Most of medicine is based on probability. But the point is that when we talk about these unpredicted recoveries, it is not that someone gets up and goes back to the golf course. There are intermediate consequences which I discuss with my patients when they face major surgery, for example, at the age of 90 years old.

They are not worried about dying on the table. They are worried about having a stroke during the operation and then surviving with that. That is much more worrisome to them than the possible risk that they might die.

So I think that is what we have to deal with. Remember, Karen Ann Quinlan who is one of the first people who brought this to our attention was thought to be certainly going to stop breathing when her ventilator was stopped in 1976. She did not. She lived for eight more years with a feeding tube in place.

Nancy Kruzan's parents thought that Nancy would not want those additional years of life with the feeding tube. So it shows that our ability to prognosticate is not perfect, nonetheless the quality of that life is something that I think we can predict pretty clearly.

Senator DOLE. You would not compare this to what Kevorkian does, right?

Dr. CASSEL. Not what mostly we are talking about. I think Dr. Konner did raise that issue. I think that one of the reasons there is such tremendous public clamor for the right to assisted suicide and assisted dying right now in this country is not because the majority of Americans want to commit suicide. That is not what they are saying. What they are saying is, they are afraid to die in our hospitals because they are afraid they will not be comforted and they will not receive the kind of care that palliative medicine requires.

Therefore, they want to have that option in case they should need it. So I think the message to us as a health care system is much more importantly to improve the quality of care.

Dr. LYNN. On the question of prognostication, may I jump in just briefly?

Senator DOLE. Yes, because I saw in your statement about how doctors really do not know.

Dr. LYNN. Right. It is a very profound question and terribly important. I think it is an embarrassment to the body politic that we managed to debate hospice with the prognosis at 6 months with no one ever having pointed out how different the population could be

if we meant that 99 percent had to be dead at 6 months compared to 50 percent at 6 months.

The elementary statistics of what it is we can do with data are very poorly understood, even by doctors. Your question has a couple of interesting ramifications, if I may explain just very briefly. If you look at the very best studied populations, find those who die, and look at what you could have prognosticated two weeks to four weeks earlier you will have a middling prognosis—50/50 of living 2 months.

Picking out the people who are almost certain to die can be done, but selects a tiny population. Most of us a week or two before we die will have something like a 50/50 prognosis of making it 2 months. Because our course to dying is rather like we are walking a tightrope in a wind storm. You know you are going to fall off if you go long enough but it is very hard to know exactly how far you will get.

We really have to come to terms with that basic limitation of what data can do for us. So I can tell you a population. Out of the support project I can show you very good data that I can find a population that has less than 1 percent chance of living for 2 months. It is 115 people out of 4,300 people, most of whom die within a year. It is a tiny population for whom I could ever be that precise.

The reverse is what you really want. You want to know, for those people who die, how bad do they look two weeks earlier or four weeks earlier so that we can change what we do for them.

Dr. CASSELL. Thirty-three years of practicing medicine confirms that you cannot know for sure when somebody is going to die. But you must understand that prognosis is a process. If you are trying to figure out how many people will be dead at day one, day five, and you can only make one guess and you make it only today, you stand a very, very good chance of being wrong a lot of times.

But if you understand you are watching the process of an illness unfold and that the question is not will this person die a week from Tuesday, although that may come up, the question is, what kind of care do they need now so that this evolution of this disease allows them to be who they are for the longest period of time and what kind of resources have to go into that.

Prognosis is not just the moment of death, it is also will they return to the golf course, will they be an active participant in the family, can they go back to work. For those things prognosis can be done very well, if you understand it is always evolving over time, that you get to correct like any course correction.

There are very few of us who are required to make the NASA type of calculations. We get to correct our course as we go along. If you do it that way,then prognosis becomes much, much more accurate.

The CHAIRMAN. Thank you, Senator Dole.

Senator Danforth?

Senator DANFORTH. I want to thank all members of the panel and first say to Dr. Emanuel I think that the end of life question is both an important ethical question and an economic question. But with respect to the issue of advanced directives, I have not linked the two.

In other words, I would never argue for the Patient Self-Determination Act that we have to save the money and, therefore, it is the duty of people to drop like leaves from the trees.

Dr. EMANUEL. I never suggested you did. But it is in the air. We have a former-Governor of Colorado and many other people making such statements in and about this city and the country.

Senator DANFORTH. Right. But I mean my point is simply the question of a person saying, here is what kind of treatment I want and here is what kind of treatment I do not want. And anybody can make that while conscious.

So the question is, well, how do you extend that capacity to make a decision or to give some communication to the physician when a person is no longer conscious. I just view the advanced directive question as an extension of something that anybody can do in any event. It just creates a mechanism for doing it.

So the Patient Self-Determination Act was really a mechanism to aid a mechanism. It was really to say, here, let us inform people that they can write a document and the document becomes a mechanism to express in advance what your wishes were if certain events happened.

Dr. Cassel, when you communicate with patients, conscious patients, you tell them what you do, I guess, is you give them your best judgment, based on all you know and your expertise as to what is going to happen to them.

Dr. CASSEL. That is right. And I also often, and maybe because I work predominantly in geriatrics, I deal with a different cohort of patients, but I find that the current mode of negotiating with the patient, that is to say here are the list of things we could do, what do you want us to do, does not work with someone who is 85 years old. What they want to know is, what do I think, what is my advice to them.

Now they may choose not to take that advice, but that is one of the things they expect from a physician is to get a well-educated piece of advice. So I feel that that is part of my responsibility to them, even about these life and death issues.

Senator DANFORTH. Well, the point was made by Dr. Emanuel and also by Dr. Lynn that the cases of hospitals and doctors doing just crazy things is declining. It is not that heavy a percentage.

Dr. CASSEL. It is declining. It is not gone though I would say.

Senator DANFORTH. But I take it that health care is not on a purely mechanical basis. I mean, there are judgments to be made. You are not on automatic pilot.

Dr. CASSEL. Absolutely. I think that—and where I think some of the most tragic mistakes happen is in the misinterpretation of the notion of patient autonomy. As you pointed out, the advanced directive is an instrument to promote communication. It is not an end in itself.

So, unfortunately, we have created a new problem in medical care, especially in our academic centers, known as the unreasonable family. The way that comes about is that a young physician in training will go to a family of someone who is critically ill, perhaps in the intensive care unit, and say, do you want us to do everything for your mother.

Well, now, who would not say yes? Right? I mean, what kind of a son or daughter are you if you do not say yes? Then the resident goes back to the attending physician and says this is a really unreasonable family, they want us to do everything.

So a lot of this has to do with communication skills and what really are you saying to the family about what is possible and are you presenting them with real choices. And unless we change the culture of medicine so that those physicians can use the word death in the presence of the family and say, you know, it is likely that your mother is going to die and we can make her comfortable and make sure that she does not suffer and that she will not be alone, then you can start having that conversation.

But if instead you put it in this unrealistic choice framework, then you are going to produce these demanding families.

Senator DANFORTH. But there are choices to be made?

Dr. CASSEL. Often indeed there are choices along the way and that is why you would like the family to be there with you as you move along. As Eric said, the prognostication occurs over time. It is not an all or nothing thing at one point.

Senator DANFORTH. Well, I want to ask Dr. Cassell because you emphasized the patient/doctor communication, but is there something we should be doing that would encourage that? I mean, for example, the Memorial Sloan-Kettering simple sheet which says that when there is a change in the patient's condition, the patient issues in health care is let us get out of the hair of physicians, they should have less forms to fill out and people are filling out too many forms now.

I have a daughter who is a hospice nurse. She tells me that half of her time is spent filling out forms. I mean, that is clearly crazy. We do not want to give people a lot of forms to fill out.

On the other hand, is there anything we could do or anything systematically that could be done such as the Patient Self-Determination Act was designed to be a system to at least present decisions to people. Is there anything systematic we could do to encourage physicians to talk to patients about these issues?

Dr. CASSELL. I think there are. The problem of—I phrase it somewhat differently. It is the resident who comes out and says, is it all right if we kill your mother. What they actually say is, if we do not put your mother on the respirator she will die. Should we put your mother on the respirator? Which translates, should we kill mom.

And, of course, at the moment then, of course, the family says, well, we want full court press and all those funny words you hear. But, in fact, you might say to the resident, this lady has been in the hospital since a week ago Monday, how come nobody had this discussion with the family and with her when she came in the hospital. Well, we did not want to bring it up, we did not want to frighten her and so forth.

Yes, I think you can make that document which you have already got in the law, can become part of the chart and the physician's responsibility, not the admitting office. The physician's responsibility to have the discussion and that the thing stays in the chart from the beginning.

If you do that, then it is something that has to be worked out. It is there. Now it is not another form. The form already sits there. It is already in the hospital system. So that on the short term you are requiring this as part of that patient's care—the discussion about outcome.

So that is the first thing. The second thing, I think we can educate——

Senator DANFORTH. So you would just require that something appear on the patient's chart one way or another?

Dr. CASSELL. Yes, and that it be a part of the beginning of that chart and does not move from the beginning until it has been dealt with. It should actually stay there.

But the second thing is, one of the forces that makes for communication between doctors and patients is patients asking questions. So I think that there ought to be as part of the act educational programs, just as we are now educating people about condoms when nobody would have dreamed that that was going to be part of public education before.

It might be just as reasonable that we educate people on an ongoing basis about end of life decisions, about the fact that they have these rights that we should be discussing these matters with their physicians, that they should not be waiting until the last minute, that they are not being asked to say I want a respirator or I do not want a respirator but what is important to me.

I tell people in lectures all the time. If I drop in front of you now, if you do not believe that I am going to go out of your hospital able to read and write or return to reading and writing, please stop treating me. It is your problem how you do that.

Patients have to know that is part of the ongoing discussions. They ask for pap smears. They can be asking for that. But to do that, it has to be a continuous educational process. They have to see the literature. They have to see the documents. They have to become aware of it.

Senator DANFORTH. How do we do that?

Dr. CASSELL. Well, how do we educate about breast cancer screening and condoms and pap smears? HHS has educational programs. They have public service spot announcements that come on television. It costs money but it is effective. And we have a very knowledgeable patient population.

The days of there-there dear are gone. Our patients know a lot about medicine. So we are trying to get them to know this about medicine. This is part of medicine too, not merely drugs and treatment.

Dr. EMANUEL. Can I make three suggestions? First, many years ago—six or so years ago—we had suggested——

Senator CHAFEE. Many years ago? Six or seven?

Dr. EMANUEL. Well, what Dr. Cassell had suggested in his testimony, which is that you make discussing advanced care directives a reimbursable office visit because it takes away the number of incentives that are against it. Right? If it takes time and I can't get reimbursed for it as a physician, it is hard to do.

In addition to being economically difficult, it is a psychologically difficult topic to raise with patients. I can assure you of that. It is important to at least line up some of the incentives in the right di-

rection. I think making it a Medicare reimbursable issue is one possibility.

Second, as I think has been suggested around the table, there is a lot of control in this committee over education in medical schools, by indirect and direct medical financing. It seems to me that more emphasis on education in medical schools on these subjects is very important.

I had not one single lecture, not one single minute in my medical school training at Harvard Medical School about these issues. You were sent in and you learned how to discuss dying and stopping treatments by trial and error. It was baptism by fire, as much of medical school still is. That is not very helpful. There are things that can be taught before students get into patients rooms.

The third thing I would suggest is that a very important element of this whole issue is continuity of care, having the same physician treat the same patient over time. I have a great luxury. I have cancer patients who I follow from the diagnosis all the way until the end. We develop a relationship over years and because it is cancer it is very intense. I see them much more frequently than most primary care doctors see their patients.

I think when we consider health care reform we have to consider how it is going to have an impact on the continuity of care. The proposals, for example, of managed competition are likely to have a very deleterious affect on continuity of care.

They encourage people to switch every year to the cheapest health plan. We already know, for example, that people who switch to HMOs have a much shorter time with the same physician, compared to people who are in fee-for-service. We know also that Medicare people in this country, almost half of them have been with the same doctor for 10 years. They have an enduring relationship.

That is very important for two reasons. First, it is important for me as a doctor to feel comfortable to introduce the subject of end of life care. Second of all, I see over time how the patient reacts to a variety of health crises. So we have addressed the issue over and over. I know the family. I know a lot about their decision making.

If we have a system which is going to chop up this continuity of care and make each patient go to a doctor for a year or 2 years and then have to switch, I think we are going to disrupt more than anything else the possibility of having a discussion about end of life care over time.

I think probably the common theme from all of us, certainly in our practice as doctors, is that continuity is a very critical issue to end of life care decision making.

The CHAIRMAN. And you got on that task force?

Dr. EMANUEL. This is one of the things I have written about and argued with the White House. I kept saying that this disruption was a very pernicious aspect of managed competition.

Senator DANFORTH. I have two more questions, Mr. Chairman, but I will wait until everybody takes a turn.

The CHAIRMAN. Fine. Would you do that? Senator Rockefeller has been very patient.

Senator ROCKEFELLER. Thank you, Mr. Chairman.

I would address this, I guess, to anybody who wants to answer it. The question of continuity of care, seeing the same person is a very interesting point. Dr. Emanuel, you brought up managed competition, HMOs already exist; managed care already exists. Managed care can be invasive of continuity of physician if you are forced to leave your physician to join a managed care plan.

Physicians sometimes are made nervous by expanded scope of practice for nurses. I am interested in what part nurses and other providers can plan in dealing with patients about these matters. Physicians may usually be brought in at critical points and crisis points but they may also be there at routine points. But nurses have quite constant contact.

Dr. EMANUEL. It depends on whether the decision making is being made in the hospital or in the office.

Senator ROCKEFELLER. I am not talking about decision making. I am talking about the evaluation, the evolution of judgment, available to the patient and to the caregivers.

The CHAIRMAN. That is a good point.

Dr. LYNN. There actually is some evidence out of our study on the question of nurses. Nurses in the hospital know less about the patient's preferences and desires than do their house staff and do interns. So the image that just because nurses are there a lot, that they know a lot is appealing but it is not very well borne out.

On the other hand, in working as I have done in home care and long term and institutional long term care, it becomes very clear that the doctor ought to be a relatively modest part of the health care team and not the leader or the dominant force.

I think when it comes my time to be sick unto death, I am hoping most for a very good nurse. You know, a very good nurse will often know when a very good doctor will make a difference, will have that doctor be much less a part of the care presence.

I think we need the opportunity to innovate more about what it is that really must be done by physicians or must be done by nurses or can be shared freely. For that matter, I would include in that mix social workers and certain other kinds of therapists. And a well functioning hospice team, I think we end up about 75 percent cross—trained, so we often have nurses effectively telling me exactly what I am supposed to order for medications and likewise I know how to call in social supports and to get financial services arranged for a patient.

So I think very good, well-functioning care teams will see that doctor's incomes will go down, doctor's predominance will go down relative at least to other parties in the system and that the important roles that nurses especially can play will be very important in the care of very seriously, chronically ill patients and dying persons because of the skills that they mostly need.

Senator ROCKEFELLER. At the risk of cutting other members off, I only have five minutes and I want to ask others.

The CHAIRMAN. Jay, take all the time you need.

Senator ROCKEFELLER. Well, I want to ask a final question, because I think I already have a sense of what you would say. You have given me both limits and scope in your answers.

Jack Danforth and I have discussed this question a number of times. I remember a year-and-a-half ago when my mother died

from Alzheimers. In the last several weeks of her life when she developed pneumonia and her lungs were filling up with fluid, I and my sisters went up to the New York Hospital.

I was fascinated. Maybe, Dr. Emanuel, you have spoken on this already. The very first thing that the physician said to me was, I do not want you to worry, and this was a rather young doctor. I would say maybe late thirties or earlier forties. I trusted him. There was an automatic chemistry.

He said, we have gotten very good at these things these days. I do not want you to worry that we are going to over extend or try to do too much. And it was in a sense almost as if he was predicting my concern.

Now my mother had a living will which we actually did not discover until just a few days before her death. So this never came into play. I was comforted by that. Then in returning I saw that my mother was having suction tubes down her nose, in her mouth and she was resisting. Of course, if you have Alzheimers you do not think as well, but you can feel. So she would bite down upon those tubes, at least the ones in her mouth.

It was very clear that she did not want to go on. It was very clear to all of her siblings that we did not want that to happen. We knew what her life had been like and we understood what she wanted.

So we said basically that is enough. We took her home and we started using morphine. The attending physician remained the same attending physician. My mother was a strong woman, a big woman. She did not respond to morphine, so the physician increased the dosage of morphine.

I remember a series of discussions I had with the doctor in which there were actual little beads of perspiration on his forehead as he began to discuss with me concerns about cause and effect as interpreted by New York State law.

What I came to discover was that it was the siblings who really took over the medical care and the physician in this case was kind of the reluctant partner, in some cases made to relax by us rather than the other way around. All of which brings me to the question of the training of the physician and what you said about not a single day.

How widespread is that? We have medical ethics being taught in medical schools more now. There is a lot of writing on it. But you still do not hear very much about it. I want to know what is happening and how do you teach something like that. What does a course like that say?

Dr. CASSELL. Well, at the New York Hospital we do not teach communication between doctor and patient. It would have permitted the physician coming up now to know how to have a discussion about this subject with you or your family.

But the story you tell also makes it clear that we do not take care of a patient. We take care of a patient and a family in an environment. And knowledge that medicine is context related, that it happens in this environment, is not a knowledge we teach. We have expected doctoring to be learned by experience.

Well, as you point out, that is not adequate anymore. Doctoring is too complex to learn just by experience. We do not ask pilots to learn just by——

The CHAIRMAN. You mean medical schools teach medicine and doctoring is something else.

Dr. CASSELL. We teach basic science, but. Now there are places where this is starting. I mean, there are schools where there is beginning to be teaching and some of it is quite good. But it is early because the same kind of disciplined knowledge about what you are talking about does not exist as exists for the liver. It is not that it cannot. It is that it does not. We would have trouble getting adequate funding again and again not to have discipline knowledge on the same basis that we now have knowledge about molecular biology.

So while there are starts and while we can find schools where there is interesting and even very good things being done, the impact on medicine, broadening the funding base for teaching this kind of thing would be profound.

Dr. CASSEL. But it is also true that we do know more than you are giving us credit for. There is a huge and authoritative textbook—the Oxford Textbook of Palliative Medicine. And yet what we teach in medical schools is only curative medicine.

When the patient becomes sick enough to begin dying and when we transfer that patient to hospice, the patient is transferred off the teaching surface as if, and I have heard this said, there is nothing more to learn from this. So it is almost as if when you stop trying to prolong life, it is no longer important for the student or hospice to learn this.

The CHAIRMAN. Could I just interrupt? Dr. Cassel, you mean that the young medical interns leave that person who is going off to hospice.

Dr. CASSEL. Is less interested. That is right.

The CHAIRMAN. You are not going to learn anything there.

Dr. CASSEL. And in some ways it is—to get to Senator Rockefeller's point, in some ways it is because of the curative culture of medicine and our focus on the dramatic scientific advances. But it is also because a lot of it, not all of it, but a lot of it is nursing and that is undervalued and under appreciated, this team work concept that is so essential to palliative medicine.

So, therefore, we assume, oh, this is something for the nurses to do. This is not the doctor's business. And, of course, much of it is essential. For example, the correct dose of morphine and understanding how to use that and other kinds of symptom control, as well as the importance of this ongoing relationship.

Dr. EMANUEL. Can I just make one brief observation? We have no National Institutes of medical ethics and within the Cancer Institute where you might expect a big research endeavor in palliative care since still about 40 percent of people who have cancer will die of their cancer, we do not have such a significant endeavor.

You know, doctors are like many other people and they follow some incentives. The idea that we are going to both generate important research so we understand this process and we train people so that they can teach communication about these issues has not yet happened.

I think if your question is how can the Senators in this committee room make an impact on this, I think the idea of persuading the medical schools of this country who train our doctors that this is a legitimate area for research and a legitimate area to get time in the first 4 years of medical school, these national institutes are a very powerful message, especially in this era when we are debating where medical education funds are going to come from and research funds are going to come from. It is that simple.

Senator ROCKEFELLER. Another very powerful tool is the $5.5 billion that comes from Medicare to medical education.

Dr. EMANUEL. Right.

Senator ROCKEFELLER. I am wondering out loud whether that is something we ought to think about. Give a Federal directive that medical schools need to develop ethical training or whatever the word would be.

Dr. CASSEL. Not just ethics, but the clinical care of the dying patient.

Senator DANFORTH. It is much more than ethics.

Senator ROCKEFELLER. Tell me what the word should be.

Dr. CASSELL. If you make palliative care just another specialty you will once again separate off the dying from the rest of people.

Dr. CASSEL. No, you do not have to be dying to get comfort.

Dr. EMANUEL. I think you need three areas—medical ethics, communication skills and palliative care. I do not think that restricts you only to the dying, because you have emphasized communication and you have emphasized medical ethics which have wide ranges. But it also does indicate that it is not just sort of broad principles.

There are actually important skills that people can learn about how to communicate more effectively and information about medical ethics and basic information about palliative care which they need to treat anyone.

The CHAIRMAN. Could I ask that Dr. Konner be allowed to get a word in here?

Dr. KONNER. Thank you very much. I have written a book on medical education that has been widely read and praised, to some extent, by leaders of medical education. I take a dim view of the term process of medical education and training. I think that the problems are far more pervasive and serious and can be addressed by more courses in medical ethics or a course in palliative care.

I have been teaching pre-medical students and to some extent medical students for many years. I think that many of the wrong people are being brought into medicine and they are then being trained in very counterproductive ways.

I think the distinction between medicine and doctoring is a valuable one and that the concept of doctoring covers many virtues, including doctor/patient communication, including the concept of caring, the concept of palliative care and nursing and the process of ethical judgments, which really boils down to a kind of sensitivity that modern physicians have lost.

I think that the Federal involvement in funding of medical education is certainly a powerful instrument for changing the way these things are done. But I would focus on two things.

First of all, the extreme emphasis on science as the basis for medicine, which has I think done great things for us, but which is not all there is to medicine. And second, I think the process of residency training is so brutal that people cannot come out of it without resentments,angers and insensitivities that have been ingrained in them.

And adding courses to medical schools simply will not do the trick, because medical students know very, very, very well that they are not being taught in medical school to become doctors. They are taught to become house officers—interns and residents, that is what they are being trained up for. They are scared and well they should be because their survival depends on their adopting the skills that are being modeled for them by these young people who are being brutalized and who are in the most stressful phase of their professional careers.

They are the models for medical students, not doctors who are fully trained and practicing in a more humane way.

Senator ROCKEFELLER. I have taken too much time, Mr. Chairman.

The CHAIRMAN. Thank you, Senator Rockefeller. We want to get to Senator Chafee.

Could I make just one point before we go by though? When we speak of medical ethics, let us not raise the subject, but let us certainly acknowledge it. The profound, perhaps the most profound, vision in American life today is the division over the issue of abortion, the issue of medical ethics, and it is not resolved. Medical ethics is not molecular biology in which you can take down the book and say, here it is now, learn it. There are choices that are anguished and unresolved and probably unresolvable.

Senator Chafee?

Senator CHAFEE. Thank you, Mr. Chairman. I think this is a fine panel. I must say this group represents the University of Chicago, Cornell University, Harvard Medical School, Emory University, and Dartmouth Medical School and if they cannot do something about medical education, I do not know who can.

The CHAIRMAN. I think they have been teaching us a lot.

Senator CHAFEE. Well, that is quite a cross section.

Now, what I would like to do, gentlemen and ladies, is to take the recommendations of Dr. Lynn and if you could just say yes or no; do you agree or not agree with Dr. Lynn's recommendations. What I am seeking here is some guidance of what we ought to do.

I will start on page 11-C of Dr. Lynn's testimony. It is a yes or no, no maybes, if you would, please.

Change Medicare reimbursement to require advanced care planning in the managed care package and to allow it to be billed in fee-for-service Medicare.

The CHAIRMAN. I think we are going to have to be systematic about this. Dr. Cassel?

Senator CHAFEE. Did everybody get the question? I want to make sure we all understand the question. Change Medicare reimbursement—and, Dr. Lynn, you may have to help me—to require advanced care planning—this is what we have been talking about today—in the managed care package and to allow it to be billed in fee-for—service Medicare. That last part I am not sure.

Dr. LYNN. Well, it is either fee-for-service or managed care.

Senator CHAFEE. In other words, it is adding a fee-for-service part to managed care to cover this particular item?

Dr. LYNN. If you have a managed care system you have to include it; and if you have a fee-for-service system it has to be billable.

Senator CHAFEE. OK.

Dr. LYNN. It gets it either way.

Senator CHAFEE. Either way. All right. Start.

Dr. CASSEL. Yes.

Dr. CASSELL. Yes.

Dr. EMANUEL. Yes.

Dr. KONNER. Yes.

Dr. LYNN. Sure.

Senator CHAFEE. You wrote it. I would be surprised if you disagreed with it. [Laughter.]

Senator CHAFEE. Now, next, change physician experience toward long-term care of seriously ill patients by paying more for persistent care by the same practitioner than for acute care by a shifting cast and by mandating training of generalists through regulating graduate medical education payments under Medicare. I think that should be divided in two.

First, change physician experience toward long-term care of seriously ill patients by paying more for persistent care by the same practitioner. That is the point, I guess—who was making?

The CHAIRMAN. I think Dr. Emanuel was making.

Senator CHAFEE.—Dr. Emanuel was making. Does everybody agree?

The CHAIRMAN. Let us go in sequence.

Dr. CASSEL. Yes, very important.

Senator CHAFEE. Dr. Cassell?

Dr. CASSELL. Yes.

Dr. EMANUEL. Yes.

Dr. KONNER. Excellent idea.

Senator CHAFEE. Excellent. And Dr. Lynn is finding all this very agreeable.

Now the next part of that. Mandating training of generalists through regulating medical education payments under Medicare. What exactly does that mean?

Dr. LYNN. Medicare pays a huge proportion of graduate medical education costs through essentially a capitation, GME payments.

Senator CHAFEE. So you would mandate the training of generalists?

Dr. LYNN. Something like the American College of Physicians' recommendation of at least 50 percent of all slots being aimed toward primary care. Some such real goal.

Senator CHAFEE. So you would mandate—I am not sure I vote yes on that part. [Laughter.]

Dr. LYNN. You would not have to go with that particular scheme. But somehow to use the leverage of the payment scheme for house staff to see that you get the doctors who can provide this service rather than to see that you get whatever it is that people choose to train themselves into, which is what you get now.

Dr. KONNER. Could I point out that for 25 years leaders of American medical education have decried the crisis in primary care in the United States and have mounted programs to increase the number of medical school graduates who go into primary care. And during all those 25 years the percentage of medical students who elect primary care has gone down and down and down. The opposite of what they were trying to accomplish in their stated purpose and their programs.

Senator CHAFEE. All right, next. Encourage innovations to develop Medicare benefits which would provide managed care of the broader scope, but limited to hospital and emergency services.

Encourage innovations to develop Medicare benefits which would provide managed care of the broader scope.

Dr. LYNN. This is a reflection of something we are spearheading at Dartmouth with funding from Robert Wood Johnson, trying to sort out what it is that the benefit would look like if very seriously disabled, very elderly persons were to write it.

What we are finding in focus groups around the country, people from all kinds of socio-economic backgrounds, is that by the time you reach 85 most people are scared that they have food, that they have shelter, that they have comfort, that they have somebody who will respond in the case of an emergency. They want protected against most surgeries unless it is going to relieve them of pain. They want to stay out of hospitals if at all possible.

These people need something like a hospice benefit. But unlike hospice, they cannot promise to die soon. So they need a hospice benefit that is tailored to the possibility that they may live six or eight or 10 years. What we are looking for then is to work on the innovations that would allow a flexible benefit that would not make resuscitation and surgery a high priority, but would instead make supportive services and enabling services a high priority.

I do not know how they will end up costing out or who will end up wanting them.

Senator CHAFEE. The second part of that, but limited hospital and emergency services. How could you limit those?

Dr. LYNN. In our hospice work here in Washington, we almost cut out all use of emergency services just by having very good nurses available 24 hours a day. People do not want to have to call 9-1-1. They call 9-1-1 because that is the only thing they have. So if you provide excellent backup services for things that scare you, then you can stay out of the emergency medical system largely.

If you have a way of getting good nursing aides into the home quickly, you can keep people from coming into the hospitals. Two years ago when I left here, I would not hospitalize very elderly disabled persons with heart attacks. I would be able to mobilize enough services to take care of them in their homes.

That is the kind of innovation that I am looking for—the possibility of providing some alternatives other than the routine use of a hospital just because it is there.

Senator CHAFEE. Now, would they call, for instance if this was provided through an HMO, would they call an HMO, they would have a relationship, and then a nurse would come out?

Dr. LYNN. Yes, or would at least decide who needs to come out.

Senator CHAFEE. Yes.

Dr. LYNN. Very often I would be there. The doctor has to be willing to go to the home to make this work.

Senator CHAFEE. Let us go to the next one. As I understood in your testimony, Dr. Lynn, you said the last decent work on preparing for death and what diseases would have you die was by Sir William Osler at the turn of the century.

Dr. LYNN. The last sequential study of hospital deaths. It is a little more narrow than you said. But, yes. Basically we have ignored the field.

Senator CHAFEE. Now what you have suggested here in your next recommendation is to mandate each Institute in the NIH which has as its purview one or more substantial causes of death, to report about the costs of death for each major disease and what can be done. This is your medical training. Again, reflecting back to what was previously said, I guess by Dr. Emanuel, when he went through Harvard Medical School he had no courses in this.

You would have this compiled so that a doctor would have the information available?

Dr. LYNN. Right. At the present time you cannot say what the usual course to death is for congestive heart failure and a third of us will die of it. You cannot say what the usual course to death is of Alzheimers Disease and yet about 50 percent of people who make it to 80 years old are going to have some kind of dementing illness.

That kind of basic descriptive work has been ignored by our National Institutes funding research. It is not terribly expensive.

Dr. KONNER. Natural history.

Dr. LYNN. The unnatural history. The history——

Dr. KONNER. Current unnatural history.

Dr. LYNN. As currently shaped by our care system.

Senator CHAFEE. Does everybody agree with that last one? Yes or no.

Dr. CASSEL. I would add also the treatment of those illnesses at the end of life, symptomatic treatment, not just describing the natural course, but looking at places where it makes sense to make the patient more comfortable.

See, there is an anti-science bent off into how people think about this end of life care issue which I think is wrong. In fact, there is a great deal that modern science can do to make people comfortable and not unnecessarily prolong life.

We ought to charge the National Institutes of Health to do more work in that as well.

Senator CHAFEE. All right. Doctor? Yes or no?

Dr. CASSELL. No, as stated. I mean, the problem is not simply knowing the natural history.

Senator CHAFEE. All right.

Dr. CASSELL. Or separating off end of life issues from other care issues. It is being concerned with the care of a patient from the beginning of an illness to the end of the illness and the changes in treatment that are required during that period of time. So we are not merely talking about the biology of the disease but the care of the disease.

Senator CHAFEE. Dr. Emanuel?

Dr. EMANUEL. I think the point that has been made, the natural history description is simply insufficient is correct. So as stated I could not possibly endorse that.

Senator CHAFEE. But you would agree with Dr. Cassel?

Dr. EMANUEL. Right. I think we need a broader view of what we are going to describe, which includes the care that should be provided.

Senator CHAFEE. All right.

Dr. KONNER. I disagree with it as stated. I think that separating this out into all the different Institutes because you die this way of emphysema and that way of breast cancer, that is not the point. I think maybe we should have a National Institute of Pain and Suffering. Maybe we should have a National Institute of End of Life Care.

The CHAIRMAN. Dr. Lynn, you have won 80 percent of your points.

Senator CHAFEE. I was going to say, Dr. Lynn is batting about 750 here, doing pretty well. If you want a couple minutes to respond. Make it a minute.

Dr. LYNN. Only that I think everyone is agreeing that we need more information. Exactly how to craft the Federal level response which could generate that information might take some further work. I think all of us would agree, we need to know how the disease evolves and what we can do that actually makes people's lives better, reasonably efficiently, and that can be delivered within a system of care.

Exactly how to do that, whether it would be in a separate institute or this institute, I do not care, I just want it to be there.

Senator CHAFEE. Thank you very much.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Senator Chafee.

Senator Danforth, you had some questions.

Senator DANFORTH. Yes, thank you, Mr. Chairman.

First, Senator Hatch had an opening statement which he would like entered into the record.

The CHAIRMAN. We will place it in the record.

[The prepared statement of Senator Hatch appears in the appendix.]

Senator DANFORTH. I just have two questions. First, Dr. Lynn, you said that only a third of the advance directives find their way into the patients' charts. Then you said further that they do not appear to have much of an affect on how the patient is treated. That is an amazing statement.

Dr. Cassell said that he thought that one of the things we might be thinking about is how to make sure that there is something in the charts, one way or the other.

Is this in your opinion an area that we should be dealing with?

Dr. LYNN. Well, my history in this regard is quite troubled, since I was the principal author of the President's Commission Report that advocated formal advance directives and that really gave this field a start. I use them a lot in my practice, not necessarily written or formal, but an agreement between me and the patient in regard to what kind of care should be done.

I believe in advance care planning. I think that, in an era of chronic disease, people should have the authority to shape how their care will unfold. On the other hand, the raw evidence is that we do not do very well at it and that the kinds of things that are in the advance directives at this point are often terribly frail. They do not really direct care.

A standard form living will really says that, like almost everyone else in the country, there is some point where I want you to draw the line. But it does not really give very specific advice about what that is.

What we should do in regard to that is somehow to find the ways and the leverage points that yield effective communication. I am not sure how much more can be done with the generation of documentation. But the effect of communication is striking. Perhaps we can really encourage longitudinal care. Maybe one of the answers to Senator Rockefeller would be to mandate through GME that physicians in training have to follow people through to death, because we do that very little in our care schemes.

Maybe there are some other ways of leverage.

Senator DANFORTH. The least we could do is to make sure that there is something one way or the other in the patients' charts. Otherwise people have filled out a document and they may as well not have done it, even if it is an adequate document.

Dr. LYNN. A standard form living will is almost never adequate, unless it is not used as a springboard for communication, which I think is its major use. Other than that use, I think standard living wills are almost irrelevant to care because the directive does not determine any real decision.

Senator DANFORTH. Let me just say this. Before we get to the quality of the living will,and I understand that point, but your first statement was that even if it was the highest quality or the most precise living will you could have, two-thirds of them are just gone somewhere. They are in the file drawers or some place. They are lost.

Dr. LYNN. We do not actually know how that works after the PSDA. In our study we have 800 actual recent documents now to study. Of those, I think about 40 or 50 have specific instruction that would shape a specific decision. We have not looked at whether that subset is better known in the medical record.

Senator DANFORTH. May I interrupt you? It seems to me you are making two points. One is that they are insufficiently precise to shape decisions. I understand that point. I would like to take that point for a minute and put it to the side.

I would like to get to the first question. Even if you had the ideal living will, where is it? I think you said that only a third of them are even on a patient's charts.

Dr. LYNN. What I was trying to say, I think, is that if we had ideal living wills they could only have resulted from effective communication because it is the only way you could get there. You must have talked about what it is that you as a patient really face and come to some accord on what makes sense to do.

That process is terribly important. And if we then documented it in a living will, my guess is that those living wills would be much more effectively used. I do not know that yet.

Senator DANFORTH. I think Dr. Cassell has said that the chart at least should have something on it.

Dr. CASSELL. Right.

Senator DANFORTH. I mean, that would be a forcing mechanism, just as the admissions process now is designed to be a forcing mechanism to have the patient focus on something. You could have the chart being a focus mechanism.

I am only talking about something mechanical for the time being, not the quality of the living will. But it seems to me that if the mechanics were that the chart had to have on it something that would tend to open up the communications that led to the something that was to be in the chart.

Dr. LYNN. Maybe there are two points of leverage to achieve what you are trying to get. One is that in a hospital people care terribly about the resuscitation decision. Now we specifically exlude some people from resuscitation.

We could instead require an affirmative decision about resuscitation. The doctor would have to state definitely whether the person will be or will not have an effort at resuscitation. That would be a very useful leverage point.

The second point of leverage would be to require advance planning to be entered on the chart, whether that will make sense, we have now under study. I will not know for a couple of months whether we made a difference by doing that. My sense is that, if you have somebody who is mandated to make sure that plans are made and known, you do get an effect, but I do not know that for sure yet.

Success would require not only that plans get on the chart, but that somebody have to have made acknowledgement of it beyond a clerk. There has to be a doctor or a nurse. Exactly how to do that is not entirely clear.

Senator DANFORTH. I think Memorial Hospital does that.

Dr. LYNN. I think we do it very well at the hospital I am now working in. But still on the whole, I cannot show that it is being done well.

Dr. EMANUEL. Senator Danforth, I would just suggest that we not over focus on just the piece of paper in the chart. Almost all of us who work in this area believe that this piece of paper is effective only as a vehicle to communication.

One of the problems is not to have the communication. To keep emphasizing the chart though keeps putting it back on the inpatient at the hospital standpoint of entry into the medical system. I think that is probably not the best time to begin the discussion or the communication about end of life care. The best time is probably in the physician's office.

That way you have a very good lever. Right? The lever is, make it a reimbursable issue. Make the physician want to have that discussion, want to bring it up. I do not think you have to mandate that something be done in the chart where the discussion will not happen.

I mean, there is much evidence that if it is brought up in the hospital patients do not remember. Even being introduced to the Patient Self-Determination Act because they come in, they are concerned about other things, as Dr. Cassell mentioned. That even if

they go home and have remembered they actually do not complete these documents.

I think the better time is to take them when there is no crisis. That way the patient's mind is clear. That is the office setting. And we do have a mechanism—a Medicare easy mandate.

Dr. CASSELL. But it is not either or. Obviously, the document on the chart is more easily handled if there has already been a discussion in the office. Further, the discussion in the office will not have an impact on the in-hospital care unless there is something on that chart that indicates what that discussion was.

And in the best of all possible worlds—we will have the best of all possible worlds, but we do not—so we will do the best to push people into a discussion which they are presently not having and documents tend to do that, just as reimbursement incentives will help us get that to happen in the office.

Senator DANFORTH. I like they are two good complimentary ideas.

I have one other question, Mr. Chairman.

The CHAIRMAN. You may surely do.

Senator DANFORTH. On the issue of medical malpractice——

The CHAIRMAN. That is what I was going to ask.

Senator DANFORTH. All right.

The CHAIRMAN. No, I think that is what we want. We do not want to let that go by.

Senator DANFORTH. Well, the question is, is this an important issue to deal with in connection with the subject we have been talking about today.

Dr. CASSEL. Let me start addressing that. I think it important not because there is a huge risk to physicians in this area but because physicians feel like there is. All the evidence is that very few physicians are charged either with malpractice or what we are being feared more extensively, which is homicide charges, for example.

The CHAIRMAN. That fellow with the beads of sweat.

Dr. CASSEL. The fellow with the beds of sweat on his forehead.

The CHAIRMAN. He knew that so much more pain is okay.

Dr. CASSEL. Exactly. If I give this patient too much morphine I am going to be accused of killing her. While the recent trial of Dr. Kevorkian tells us that most juries in this country would never convict a doctor in a situation where they felt like this might be something that they would want, the fact of the matter is that those laws are still there and those malpractice threats are still there; and physicians are made very anxious by this.

You see it constantly in discussions about decision making that people will not aggressively treat pain and symptoms because they are fearful of crossing over that line.

So I think that doing something about relieving that fear, whatever mechanism that takes, is going to be very important to freeing the physician up to take a more active role here.

Dr. EMANUEL. And in part many of those laws vary State by State. And ironically New York actually has some of the most confusing and restrictive laws on the end of life care issues, which is why I was not surprised that that happened in New York.

Senator DANFORTH. Are we talking about the general malpractice issue or is this a subcategory? In other words, the trial lawyers, it is tough to have any kind of tort reform because of general opposition.

Dr. EMANUEL. I do not think this is general.

Senator DANFORTH. But is this like a subgroup which could be dealt with in a discreet manner?

Dr. LYNN. Actually, a parallel issue of criminal law.

Dr. CASSELL. Well, the problem often is that physicians hide behind their fear of malpractice any time an uncomfortable circumstance comes up. Doctors all make very bad lawyers, but that does not stop us from talking about it all the time. So doctors are always saying, I do not want to be sued, and beads of sweat are quite common.

But they will be glad to point out to you, if you think the conversation makes beads of sweat, an indictment makes even more sweat. So if they are relieved of fear in a particular area, even if, in fact, malpractice is not a big problem as Chris has pointed out, they are relieved of fear, then they are obligated really to deal with the problem rather than to hide behind that fear.

Dr. LYNN. I should tell you that when I first spoke publicly about withdrawing feeding tubes, an issue that you in Missouri have had a lot of familiarity with, prosecuting attorneys in various regions offered their view to such esteemed publications as USA Today, that such actions in their jurisdiction would lead to criminal indictment, that they would have to test whether withdrawing a feeding tube from a dying patient counted as homicide.

I think we are at the same boundary now with very vigorous treatment of severe dyspnea, where I have said publicly that I treat severe dyspnea with sedation so people do not suffocate to death.

But there are certainly prosecutors who think that the care might well be contrary to the criminal law. I do not think that the Federal level can solve that problem directly but could sponsor the appropriate consensus and guidelines endeavors that would provide the kind of backup that Chris and Eric have given voice to.

If the IOM or AHCPR or some other, you know, esteemed body came out with saying, well, cases like this really should not raise these concerns, there are an awful lot of front-line doctors and nurses who would behave much better.

Dr. KONNER. I think that there has been the clear evidence in court decisions recently that prosecutors' attitudes are out of line with what the average American thinks about this subject.

The CHAIRMAN. It is surely a small consolation to doctors to know the jury will let him go.

Dr. KONNER. Well, what I was about to say was that I think you gentlemen have perhaps a role to play in making the prosecutors a little bit less zealous.

The CHAIRMAN. Well, how do you feel about that? You were one of those, your grace. [Laughter.]

Senator DANFORTH. I think it is easier for us in Congress to deal with the tort question than the criminal law question because the criminal law question is simply a State matter.

I guess we could maybe, you know, I mean use our handle on Medicaid or something to get them to do something. But I just really have not thought it out.

Dr. LYNN. Just providing funding for the State Justice Institute to run an RFA on establishing guidelines for prosecutions of medical practice.

Senator DANFORTH. But it is the State Legislature that is going to determine it.

Dr. LYNN. It is not the legislation; it is an interpretation that we need. The legislation can stay exactly as it is.

Senator DANFORTH. I know. But I mean it is the State Legislator, plus the prosecutor. I do not think they are going to pay much attention to anything we do. I just have not thought it out.

Dr. LYNN. Tort reform would help, too.

Senator DANFORTH. Sorry?

Dr. LYNN. Tort reform would help, too. Because part of this is—particularly with the family, the complex family situation where there is always son or daughter in Colorado who comes in at the last minute and has a different opinion about things and leads to less security of doing what you think is the right thing and what you worked out with the patient is the right thing.

So I think there is always going to be that dimension to it, which especially in this issue that I raised at the end about managed care and the different environment of that I think some effort towards tort reform would go a long way towards freeing physicians to do what they need to do.

Dr. KONNER. We have not said much about the durable Power of Attorney for health care and I think it is important to stress that as a different instrument, which many of the concern for dying organizations feel is more useful and binding than the living will, that is to designate officially someone who will have the decision making power in the even that you lose it. Then you obviate some of these conflicts among family members and so on.

The CHAIRMAN. I would like to say because our caucus is to begin very shortly now, Senator Danforth, I thought we were pretty well agreed we were going to try to do something in tort reform.

Senator DANFORTH. Right.

The CHAIRMAN. Is there a model statute equivalent? I mean, has anyone tried to tell us what we should do? I do not think so.

Senator DANFORTH. One thing that was just suggested to me was the possibility that practice guidelines could be used as presumptive defenses.

Dr. KONNER. If we got serious about practice guidelines they could then be used in that way. But we have not gotten serious about it yet.

Dr. EMANUEL. Every major medical organization in this area does have agreement on what the appropriate practice is and that increasing morphine, for example, is completely acceptable. So I do not think in terms of strict practice guidelines that is the problem.

Senator DANFORTH. I mean, if we created as a matter of law there was a defense——

Dr. EMANUEL. Oh, yes.

Senator DANFORTH.—that if you followed the practice guidelines——

Dr. EMANUEL. On palliative care, right.

Senator DANFORTH. Right.

Dr. EMANUEL. That would help a lot.

Dr. KONNER. You know, a sitting Surgeon General, Dr. Sullivan, a few years ago issued a report saying that American doctors are inept in their handling of pain and urged improvements in training and practice. As far as I know there were not very many consequences of that reported.

Dr. CASSELL. There is a practice guideline on the treatment of acute and chronic pain now.

Dr. EMANUEL. Just issued by the AHCPR.

Senator DANFORTH. So if you said well if you follow that guideline that is the defense.

Dr. CASSEL. Well, you need to do more about the end of life context because that guideline does not specifically address that issue. And it is not just pain, that we are dealing with other symptoms, too.

Dr. KONNER. And the defense does not protect you from the indictment.

Senator DANFORTH. No, this is just simple liability. I do not know how to do the criminal. I mean, we can think about it but it just does not occur to me right now.

Dr. KONNER. Well, the defense does not protect you from the suit either. I mean, it protects you from the losses, but you have already been put through the probably experience——

Senator DANFORTH. I think you could have it on summary judgment. I mean, you could get it pretty quickly decided if you had a ready defense.

Dr. LYNN. Remember, you are tackling chimera, that in regard to the care of the dying there are no cases. I really mean that there are, effectively, no cases. The last time I checked there were none against hospice practice. Malpractice cases are almost impossible on end of life care, unless you reach the level of punitive damages, because conventional damages are so small.

The tort system does not serve very sick people well because they do not have productivity and other serious financial damages. What you are tackling is the doctor's perception that there is a real risk. You just have to make the doctor comfortable that liability would be limited if it ever arose. Interesting psychology.

The CHAIRMAN. Doctors have a right to be comforted. [Laughter.]

Dr. LYNN. Palliative care for doctors.

The CHAIRMAN. We are going to have to close now after an absorbing 2½ hours.

Senator Danforth, you know, we are going to look to you on this matter. I think we should legislate, do you not?

Senator DANFORTH. Yes, I do. I think we did a lot in 1990 and that it was a big step forward and there is more to do.

The CHAIRMAN. We have the possibility, which certainly we would desire, of legislation which basically looks to the profession to set the details. If there is a standard practice promulgated by the associations we would like to point to that, because that can change a lot faster and be a lot more informed than our art.

As Senator Chafee says it, the horror we are involved in with Medicaid. Medicare has 300,000 pages of rules. What was it John

Chafee was saying yesterday, at 4:00 in the morning some years back he and Pete Stark were in a corner of the room on the House side of the Capitol deciding how much someone should be paid for reading an EKG. We want less of that and more of the kind of concerns you have raised.

We want to thank you very much. You have come great distances with wonderful testimony. We are much in your debt, as are, we hope, the people who will live with the legislation we are trying to produce. With that, we are thanking our reporter and thanking your grace.

[Whereupon, at 12:28 p.m., the hearing was adjourned.]

APPENDIX

ADDITIONAL MATERIAL SUBMITTED

PREPARED STATEMENT OF CHRISTINE K. CASSEL, M.D.

Senator Moynihan and members of the Committee and members of the Staff. My name is Dr. Christine Cassel. I am an internist with special training in Geriatric Medicine and Medical Ethics. I am Chief of the Section of General Internal Medicine and Director of the Center on Health Policy Research at The University of Chicago where I am also Professor of Medicine and Public Policy. I am Chairman of the Health and Public Policy Committee of the American College of Physicians and a member of the Board of Directors of the American Board of Internal Medicine. I am pleased to be able to testify this morning on the important topic of end of life care in the context of health care reform.

Care at the end of life is a neglected issue which has finally come to the attention of many people in the field of medicine and health care. I believe that this attention is long overdue and much needed. Just within the past year the American Board of Internal Medicine has constituted a committee to define the areas of clinical competence in the care of dying patients that should be required of internal medicine trainees. The Institute of Medicine of the National Academy of Sciences has completed a feasibility study recommending that The Institute of Medicine launch a major research program about the quality of care and process of decision making around the end of life. I was asked last week to chair a project on the policy dimensions of improving the care of terminally ill patients to be launched by the Milbank Fund in New York. These are indications that major groups concerned with health care in The United States are turning their attention to this important issue.

The entire nation learned an important lesson from former President Richard Nixon. As his last days were reported by the press, President Nixon had made it known to his physicians that he did not want to be kept alive by heroic measures that would not be likely to return him to meaningful life. Therefore after suffering a major stroke drugs were given to reduce the swelling of his brain, but he was never placed on a ventilator and when his heart did stop beating, no attempt at resuscitation was made. These events were reported by the news media and an example was given to the American people of how a dignified death can be conducted even within the context of modern medical technology. Contrast this with a case that became widely known several years ago of Helga Wanglie, an 85 year old woman in Minnesota who had total loss of conscious brain function and was kept alive in an intensive care unit on a ventilator for almost a year before her death because her husband was hoping for a miracle. The difference between these two cases reflects the totally divergent personal views of the patient and demonstrates the ability of the current health care system to respect those personal views. Unfortunately, there are still many and increasing numbers of people who would prefer to exit the world more like President Nixon; but events and "the system" prevent this from happening. As we move into an era of health care reform we have an opportunity to improve the care of patients at the end of life. To make these improvements requires changes in medical practice, medical training and health care financing.

It is commonly thought that a great deal of money is spent on patients in the last days and weeks of life that could easily be saved if we simply encourage patients to execute advance directives and stopped the use of futile interventions. A number of experts question this view. I believe that it is still controversial exactly how much potential savings in the health care system there might be if extraordinary efforts at prolonging life were able to be discontinued earlier or not started. But regardless of the answer to that question, there is a more important issue here, which is the

quality of care of dying patients and the culture of care for the dying within American medicine.

Dr. Lewis Thomas, an eminent New York physician also died this year. He was President of The Memorial Sloan Kettering Cancer Research Center and a noted author on medicine and society. He along with many others—pointed out that the progress of medical technology and medical science has led to a culture where the death of a patient is too often viewed as a failure. Attempts are made to prolong life in the face of common sense evidence that such attempts are futile. Patients and families are not brought into the honest discussion of the relative burdens and benefits of potential life sustaining treatment. Public awareness of advance directives has grown and the 1990 Patient Self Determination Act has contributed to that growing awareness. But it has not changed the culture of dying in many of our hospitals.

I have a close friend whose mother died in a cardiac care unit three weeks ago. Her suffering was mercifully short, but my friend said afterwards that her main impression from that experience was that the physicians were completely unwilling to sit down and talk with her about the fact that her mother was dying. That word was never used. Instead, euphemisms and evasions surrounded the decisions that were presented to her. The Patient Self Determination Act has not solved this problem.

The health care environment is the result of social forces as well as medical attitudes. The cultural context supports the denial of our mortality, and thus, we have created a system in which patients all too often feel that the only option other than intensive care is abandonment. Instead we need to offer aggressive comfort are throughout the health care system code, that says to the patients and family that we will not abandon you, you will not suffer, and you can exit this world on your own terms with personal dignity and meaning. The Hospice movement has allowed this to occur for a minority of patients who have access to Hospice, but the mainstream of medicine still does not allow this approach. It is still the case that a majority of people die in hospitals and nursing homes where it is rare under current circumstances that a hospice approach can be applied.

Requirements for optimal end of life care Include the following:

1. Medical professionals need to understand the limits of medicine and to view death, when appropriate, as an inevitable and personally meaningful chapter in the life of their patients. They should not consider the death of a patient a personal failure.
2. knowledge of the principles and scientific basis of palliative medicine among physicians and nurses should be widespread. Palliative medicine is a specialty focused on comfort care and relief of suffering rather than prolongation of life.
3. Hospitals (including emergency rooms) and nursing homes should be structured to make optimal palliative care available to a patient wherever he or she may be. It should not be necessary to "transfer" to hospice in order to get this kind of care.
4. Reimbursement for services should not be dependent on acute curative care being attempted.
5. Home hospice care should be widely available with seamless continuity between hospitals and nursing homes, in the case that home care becomes more difficult than the family can manage
6. A culture of medicine and society that allows, even enhances, open discussions between patients, families and providers about the risks facing patients with serious disease and the options of comfort care.
7. Enhanced avenues of communication for patients to make known their values and preferences in end of life care, and for physicians to honor those wishes. Building on the PSDA, it is necessary for primary care physicians who have long term relationship with patients to remain involved with their care to the end.

What are the barriers to better care of dying patients that health care reform might address?

1. Payment for health care services needs to be flexible enough to allow palliative care to occur wherever the patient is being cared for. Currently many insurance companies, Medicare included, will not allow payment for patient care in the hospital if "only comfort" is provided. Many patients do not have the support at home necessary for hospice care as it is defined under current Medicare rules and many people in the United States cannot deal with the care of a dying patient in their homes. We should allow patients to be able to die with comfort care in hospitals or nursing homes or where ever they may be.

2. We need a better understanding of the best approaches to palliative care, within the framework of medical interventions as well as within the framework of systems of health care. Federal initiatives framed by health care reform could support initiatives to encourage and examine innovative approaches to the delivery of end of life care, to the measurement of quality of care and to the clinical use of those measures.

3. We need more extensive training of all physicians, especially those in primary care, in the science and art of palliative medicine. Physicians are not generally well trained in comfort care techniques, symptom evaluation and symptom control. These areas of expertise are currently the realm of only a small number of physicians and nurses who specialize in hospice care. Many of these providers focus entirely on patients dying of cancer. This type of care should be available to patients dying from heart failure, lung disease or any other illness.

4. We need to encourage hospitals and physicians to talk more openly about death and dying and approaches to setting limits on life sustaining treatment. While important research is being done that will give us more information about the likelihood of success with many of these life sustaining treatments, it is unlikely in most cases that we will ever have the full knowledge necessary to define futility in most cases. Thus, we will always be dealing with uncertainty. But if our patients understand that our concern is for their comfort and dignity at the end of life, then it is much less likely that they or their families will demand unreasonable interventions.

5. The physician needs to feel comfortable taking some of the burden of decision making on his or her own shoulders. The family should not be made to feel that it was because of their decision that a family member died, but rather that clear comfort was offered by a physician who was brave enough to say "medical science cannot keep your mother alive much longer, but she will not suffer and we will take good care of her." To allow this to happen requires that physicians be relieved of the anxiety of the tremendously adversarial environment that our current malpractice crisis has created. While many legal scholars will argue that physicians who make these decisions have little risk of being sued, it is nonetheless a terrible fear that physicians live with day in and day out. It is around these most sensitive and challenging situations that that fear is most harmful to the optimal care of patients and the comfort of their families. Thus significant tort reform would go a long way towards creating a better environment for physicians and patients around end of life care.

6. Finally, let me say a few words about the brave new world of managed care which is the direction that most health reform proposals are leading, and towards which the health care industry is progressing even as we speak. Prepaid approaches to health care financing have been shown to provide more comprehensive benefits and more accountability for health care costs than fee for service medicine. There are many examples of successful and high quality managed care organizations. Nonetheless, most of the United States still does not have extensive experience with this approach to health care financing and as we move to managed care, we should be cautious and aware of the tremendous differences in the ethical context it presents to the physician. The traditional role of the physician is to do whatever is the right thing for the patient, regardless of cost. Managed care gives the physician an additional fiduciary responsibility to the patient and to the group of patients who have enrolled in that system to be prudent in the use of medical care and to reduce unnecessary costs. If the beneficiaries are trusting the physician to do this, they must realize that there are times when this situation will put the physician in an irresolvable double bind, unless changes in the legal and institutional context occur. There would be no such problems if all patients were like Richard Nixon. But if Helga Wanglie's family belonged to an HMO and demanded that she be kept alive on a ventilator as long as possible and that attempts be made to restart her heart when it stopped, even though her brain had totally ceased functioning, the other beneficiaries would have to pay for this care. If a physician or the system took the stance that this was not fair allocation of resources, the legal system would not back them up. Thus, the physician would still be vulnerable to malpractice claims if he decided to discontinue life sustaining treatment in this case and if he did not, he would be vulnerable to being fired by the insurance company or the HMO because he was using too many resources unnecessarily. This is an untenable situation for physicians. It is not insoluble but it requires that we explicitly define new roles that we are asking physicians to take, and then support them in those roles with clear ethical standards and relief from trivial or unnecessary threats of malpractice.

CONCLUSION

The end of life is something all of us will face. What we may not know is the disease or event which will cause our death, or where it might happen. We stand a better than 50/50 chance that our deaths will occur in a health care institution, and a far greater likelihood that the world of medicine and health care will somehow define our last days or weeks. Interest in improving the quality of this care is thus not the province of any particular interest group, medical specialty or disease advocates. Every aspect of our health care system—including medical education and training, structures of systems of care, approaches to financing and reimbursement and the agendas of our research institutions ought to be included in this vitally important effort.

PREPARED STATEMENT OF ERIC J. CASSELL, MD

The right to refuse treatment is a principle that is firmly established in American medicine. While it has been part of the law for almost a century, it has been an everyday reality for only the last few decades. The increasing strength of the concept can be attributed to the rising legal and social status of patients, who, with other groups such as persons with disabilities have finally achieved full personhood. The idea that patients should play a major part in decisions about their treatment has been a focus of the bioethics movement since its inception twenty-five years ago. The Patient Self-Determination Act of 1990 has been an important force in ensuring that patients have an opportunity to both make their wishes known and to provide for someone who can speak for them should they lose the capacity to decide for themselves.

It remains true, however, that many Americans die in a manner that almost none of them would have chosen while they were well. Three kinds of death are both common and particularly unfortunate. The first group is made up of patients who are resuscitated after cardiopulmonary arrest and do not live to get off the respirator or other support technology. The second group who endure a bad death is made up of failed old people whose dementia has run its inevitable course into profound physical decline, and who are treated successfully for one complication after another long after they have lost the capacity to speak or represent themselves, to interact with persons around them, or to be themselves in any manner that their families or friends want to remember. Patients who die with their pain inadequately treated, whose other physical symptoms and disabilities are not properly addressed, and whose suffering from any source is not the active and unremitting focus of their physicians' and other caregivers' attention make up the last group whose members also die a death for which the word bad does not seem large enough.

In neither of the first two groups does a bad death come about because of bad behavior on the part of caregivers. In the past patients with disease states like heart attacks, clots in the lung, profound infections, extensive pneumonias, or certain kinds of trauma commonly died from failure of their hearts. or lungs but are now saved by resuscitation and cardiopulmonary support that sustains them until they recover from their underlying disease and return to their former life. Of course, not all of them recover. In which case they remain on life support technologies until they die—which can be a long time—or until someone finally discontinues the respirator. Another group of patients are also too often resuscitated. They are persons with diseases which would not have improved even if they had not had a cardiopulmonary arrest—for example, patients with advanced cancers, profound strokes, or end-stage pulmonary disease. These people, as well, often die an unpleasant death. They are resuscitated not because it is believed that they will return to health and independent living, but because resuscitation has become something that is considered necessary for any patient who will otherwise die, unless the patient refuses, has left an advance directive so stating, or has a designated surrogate who refuses permission for resuscitation.

The unfortunate deaths in the second group come about because of a quandary. The increasing number of old and very old persons in the United States that has changed our demographic pattern is attributable, in part, to the successful treatment of numbers of diseases—including respiratory and cardiac diseases—that were common causes of death among older persons in times past. The aged not only survive their heart attacks and pneumonias, but lead active lives based on high functional capacity that was not common among the aged in previous eras. It is the treatment of these same diseases and the support of temporarily inadequate cardiac, renal or respiratory functions in the totally failed elderly—unless contravened by

advance directives or surrogates—that produces wards full of old people neither dead nor alive, who will never be better and who finally die, usually within months.

It has been interesting for me to see the changing attitudes of medical students about these cases where resuscitation or continued treatment seems futile—particularly in advanced dementia. A few years back most students were vehement in their belief that doctors must treat every infection, use feeding tubes, and deploy almost every available therapy. Now they are doubtful. Some still want to treat aggressively, others to stop treatment, but most are doubtful and cannot agree on what criteria should guide their decisions in the absence of formal advanced directives or a trustworthy knowledge of what the patient wants. Although they talk a great deal about something called "quality of life," (as though everything a doctor does is not related to the quality of patients' lives) almost none of them have been taught that the quality of the patients death is one of the responsibilities of a physician. That is about where the rest of the profession finds itself.

The same technology and the same actions by physicians and other caregivers that in some instances returns a wonderful gift of life, in other cases produces miserable deaths, special sadness and misgivings in the survivors. Sometimes the bad death cannot be helped, not everyone appropriately resuscitated survives. Those who do not will die in intensive care units usually still connected to the respirator. In many cases, however, the bad death is entirely predictable, even probable. As it began to become clear the amount of harm that was being done by resuscitating every dying patient, and as fear began to subside of legal action for failing to resuscitate patients for whom it offered no advantage, physicians began looking for criteria that might relieve them of the necessity for doing something they did not think proper. Increasingly patients and families were asked for permission not to resuscitate. In some jurisdictions this is a relatively simple matter, in others it is more complex. New York State has a particularly bizarre law which provides for seven different kinds of Do Not Resuscitate (DNR) forms, depending on the cognitive state of the patient, the presence of surrogates, and etc. While it may be important that a dying patient not be resuscitated, that is hardly the criterion for good care at the end of life.

With this background, the right to refuse treatment seems like a curious right. As though there are two distinct situations, a sick person may either accept treatment and receive it or refuse treatment and not receive it. As long as someone is receiving medical care, they receive treatment. There is no such thing as no treatment. Treatments are not merely technologies or drugs, virtually everything done to or for a sick person is part of the treatment. If you think this is an exaggeration, what would you think of your treatment if you were left to lie all night on a stretcher in the hallway of the hospital? If you think, further, that this is a different use of the word treatment, what would such treatment do to your trust and acceptance of treatment in the conventional medical sense. It is time for us to extend our understanding to the fact that patients have a right not only to refuse treatment, but to choose treatment. To call this a *right* implies that someone might choose any treatment they wanted. Clearly, that is not possible. Not everything is available, or possible, or appropriate; there are always limits to choice. So the right must be amended to say that they should be able to choose treatment within the constraints of fate and the capacities of medicine. Once that is done, persons can no longer make their choice by themselves. They require the assistance of physicians to tell them what fate means in their instance—their diseases and prognoses—and what medicine has to offer them. All rights have corollary obligations, but this is different. The information the physician provides must be tuned to *this patricular patient* to be of value, just general information will be inadequate. In order to do that, the doctor must have some knowledge of the patient, and have a relationship of trust with the patient. Without a basis in trust (trust does not mean blind trust) the physician would not be able to find out much about the patient and the patient would not be able to trust the information given. Finally, the physicians information must be given in such a manner that the patient, no matter how sick, will be able to make choices.

The right to choose treatment puts a different cast on things than the right to refuse treatment. The biggest difference is that the idea of an independent, autonomous patient exercising his or her right is replaced by two people in community with a common goal, deciding what treatment that is possible best suits the needs of the patient as the patient understands those needs. As the discussion continues, keep in mind that our goal is to go further than the usual idea of advance directives.

Inappropriate resuscitation and other end-of-life treatment producing unnecessary suffering and bad deaths continues to be an all too common problem, mocking the triumphalism of high technology medicine.

Nothing insures better than advance directives that patients with life-threatening disease, terminal illness, or the final stages of inevitably progressive dementias will receive treatment appropriate to their disease, the capacities of medicine, and their wishes. In spite of the Patient's Self-Determination Act which should apply to the vast majority of patients in the United States, only a minority of patients have them. Why, when they are so crucial, is that the case. There are several reasons.

1. Inertia, apathy, indifference, and fear on the part of patients.
2. Ignorance among patients, physicians, and other caregivers.
3. Lack of incentives for physicians and other caregivers.
4. Administrative and other difficulties.
5. A wrong idea of what an advance directive should do.

Many Americans, who do not sign an advance directive, are aware of the problem of inappropriate resuscitation, life support or treatment at the end of life. Court cases have received publicity, television and print media commonly discuss these issues, and people discuss them with their friends and family. When it comes time to sign an advance directive or appoint a surrogate, many seem to hold back. People know that everybody dies, but it is as if it is an event, something that will just happen. They do not seem to see their deaths as something in which they can play a part, which, because of their actions could be better or worse, or even come about in a desirable manner. I routinely ask my patients to appoint a Health-Care Proxy according to New York State law. The procedure is simple, the document is straight forward, and I strongly encourage it. Surprisingly often, the document does not get filled out. Sometimes people think I am covertly telling them something negative about their prognosis and have to be reassured. We must accept the existence of these impediments to advance directives as a problem to be solved.

Despite the currency of the problem in American life, there is considerable ignorance about the availability, the importance, and the effect of an advance directive and the appointment of a surrogate decision-maker. People must understand that this is not only something that they do for themselves, but for their family. Like estate planning, many family difficulties can be resolved—even money saved—by an advance directive. Physicians are often as ignorant as their patients about the uses of advanced directive, ignorant of the fact that a surrogate speaks with the patient's voice when the patient has lost capacity, or that when a patient chooses not to be resuscitated, he or she has not chosen not to be treated. Advance directives should be the subject of a sophisticated, widespread, and continuing educational program. Patient education always ends up educating physicians. When patients in sufficient numbers ask their doctors for the forms, they will be available.

Incentives get things done. Medicare should have a procedure code that applies to obtaining an advanced directive. The procedure should be reimbursable apart from the visit in which it occurs. The reimbursement should be adequate. It will save Medicare money in the long run. Other third-party payors should do the same thing, they too will save money.

It appeared that the Patient Self-Determination Act would succeed since it was to become part of the procedure of being admitted to the hospital or other health care facility. This has not worked. The document should be part of the patient's record, in front of the chart, until its purpose has been accomplished or the patient declines. It should be the responsibility of the attending physician or the physician of record.

Finally, the object of these documents should not primarily be finding out what the patient does not want, or refuses—for example resuscitation, respirators, or feeding tubes—although such information might be important, but what kind of care the patient does want and what is important to the patient. Too often sick persons are asked to make choices about technical issues concerning resuscitation, respirators, and the like about which they know very little. On the other hand, the thing they, *and only they,* know about, what matters to them, gets left off. My advance directive says that if and when my physicians no longer believe, with reasonable certainty, that I can return home able to read and write or with that fair expectation, they should discontinue treatment. The technical issues in those decisions are both their expertise and their problem, not mine. Other patients say that they want to be able to think, or at least remain conscious and aware of their surroundings. A rare patient wants to remain alive no matter state he or she is in. I believe it is my obligation to act on those wishes, and the obligation of every physician. It is much easier to ask the questions that gets that information than asking whether they want to be resuscitated. Usually that follows from what the patient says. In general, the process of finding out about end of life care is continuous with all other diagnostic and therapeutic decisions in which the patient should be playing an active part.

No administrative solution exists to remedy the too frequent problem of death after unrelieved suffering. The understanding that effective pain control is the sine que non of adequate care of the dying has begun.to spread around the country. The technology and medications necessary to achieve that goal are ubiquitous and inexpensive. Death after unrelieved pain, however, remains too common. Further, the concepts that provide the basis for pain control are usually not extended to other symptoms. Suffering itself, a distress distinct from but often elicited by pain and other symptoms, is rarely explicitly addressed. Suffering is always lonely, unique in its fashion to the individual, and arising from the sick person as a person. It puts to lie any attempt to separate mind from body, the psychological from the physical, the personal from the social. There are no technologies for its relief, it can only be treated by physicians or other caregivers explicitly devoting themselves to the relief of suffering. Virtually all of the goals of the care of the dying are exemplified by the hospice movement. Its ideas, knowledge, and skills are as applicable to the care of any sick person as to the terminally ill, yet these have not spread to the rest of medicine.

For physicians to properly care for the dying in any setting as well as helping the patient choose treatment requires a therapeutic relationship between doctor and patient. While it is desirable to establish a long lasting relationship with a physician, that is not necessary, the relationship can be of recent origin. The physician must understand his or her functions as always arising from a therapeutic relationship. This is an understanding that must be taught during medical training and reinforced at every opportunity.

The Senate Finance Committee will soon be considering legislation that will have an enormous impact on the possibility for physicians to form and maintain therapeutic relationships with their patients. The structure of health care reform will either encourage doctor-patient relationships in which patients' right to choose in concert with their physicians can become a reality or discourage such crucial bonds. There is no neutral stance. Medicine cannot move forward past its present over-utilization of technology and subspeciality medicine without a return to its fundamental basis in the relationship between patient and doctor. The present problem with end of life decisions is merely one symptom of our departure from that foundation of medical care.

Just because we are spending a lot of money on patients who die, does not mean that we can save a lot of money on end of life care.

* * * * *

There is a widespread perception that the medical care we provide Americans at the end of life is irrational and unjustifiable; both ethical and economic considerations urge us to reduce medical interventions for dying patients.

One can find this view expressed by prominent physicians, leading health policy analysts, members of the lay public, and throughout the media.[1,2,3,4,5,6,7] For example, George Lundberg, editor of JAMA has written:

> I believe that by developing and implementing such guidelines to prevent futile care, everyone wins--the patient, the family, and society as a whole. the financial savings (in addition to the obvious humanitarian benefits) resulting from widespread implementation of such policies is impossible to predict, but certainly tens and probably scores of billions of dollars annually could be saved.[8]

Leading health economists such as Eli Ginzberg of Columbia have decried "the high cost of dying." Our current Surgeon General is quoted as saying that: "[S]ome 70 to 90 percent of our health-care dollar is spent on the last few months of life."[9] And at least one leading member of President Clinton's Health Care Task Force argued during some of the debates last spring that reducing medical interventions for dying patients was one of the two main mechanisms to cut the waste out of the medical care system and finance universal coverage.

Op-ed page editorials that have appeared in The New York Times and The Washington Post within the last 9 months have proclaimed: "Good ethics, good health economics" and argued that the use of living wills is key to saving the health care system finances.[10,11]

Is this widespread perception true? Are we wasting scores of billions of dollars on dying patients which could otherwise be spent on providing care for the uninsured?

WHAT DATA SUPPORT THE CLAIM THAT WE ARE WASTING MONEY ON DYING PATIENTS?

Where does this perception that we are spending too much on dying patients come from?

It rests on three related claims. First, it is claimed we are spending too much money on medical care for dying patients. The data used to support this idea comes from excellent studies on Medicare expenditures for dying patients. A series of studies dating back to the late 1970s and most recently reviewing Medicare expenditures for 1988 demonstrate 1) that

between 5 and 6% of all Medicare beneficiaries die each year and 2) that these dying patients consume between 27 and 30% of the entire Medicare budget.[12,13,14] The latest available figures indicate that in 1988 mean Medicare payments for the last year of life of Medicare decedents was $13,316, compared to $1,924 for all Medicare beneficiaries (a ratio of 6.9). Indeed, the use of medical resources rises significantly as patients approach death, such that fully 40% of all spending in the last year of a patient's life occurs in the last 30 days of life. Importantly, these trends and ratios are not new. Similar figures date back to the early 1960s and the implementation of Medicare.

These data on Medicare expenditures for dying patients are the best data available in the United States and they have shaped our view of how much we spend on the medical care at the end of life. (It is worth noting that the best available data is now 6 years old--a period in which health care expenditures nearly doubled going from $544 billion in 1988 to almost $1 trillion in 1994. This is a sad comment on our system's ability to provide accurate data for health policy decision-making.)

Second, it is claimed that the vast majority of Americans actually want fewer medical interventions at the end of life--that is do not want to be attached to respirators and other machines prolonging life. Consequently, their autonomy and satisfaction with medical care will actually be enhanced with fewer treatments at the end of life. We have studied patients at the Massachusetts General Hospital and members of the general public in Boston and found that on average 73% of both patients and the public did not want a respirator and 74% did not want artificial feedings. In the worst prognosis situation, persistent vegetative state 80% of respondents refused respirators and artificial feedings.[15]

Many other studies, from opinion polls of the general public to more focused interviews of patients, have demonstrated slightly different results depending upon the study population, the specific wording of the question, and the interventions being considered. Without summarizing the numerous studies, it is fair to say that between 60 and 80% of Americans would refuse medical interventions at the end of life with older patients tending to want more treatments--or defer to their physician or family more often--than younger patients.

Third, it is claimed that we can save a significant amount of money by reducing medical care for dying patients. Most of the support for this claim comes from combining information on the amount we spend on the medical care of patients who die and their preference for not wanting life-sustaining medical interventions. For instance, the most sophisticated version attempting to quantify how much could be saved comes from Drs. Singer and Lowy in which they "performed a thought experiment examining the cost impact of offering advance directives to the general public."[16] They argue that in 1990 the U.S. spend $661 billion on health care.

> [Using the Medicare data showing that] 27.9% of annual health spending flows to the 5.9% of enrollees who die in that year, approximately $184 billion was spent in 1990 on patients who died [and] $109 billion was spent in 1990 on patients who, if asked, would have declined life-sustaining treatments....If we assume an average 50% reduction in costs for patients who choose to forego life-sustaining treatments, then $55 billion might have been saved in 1990 U.S. health spending ...from a policy of asking all patients about their wishes regarding life-sustaining treatment and incorporating those wishes into advance directives.

ARE WE WASTING MONEY ON MEDICAL CARE FOR THE DYING? ARE THESE ESTIMATES SHOWING WE CAN SAVE MONEY AT THE END OF LIFE TRUE?

First, it should be noted that the Medicare data provides us with a distorted and biased view of how much we spend on medical care for dying patients. The Medicare data is for patients 65 years and older--a segment of the population more likely to die. Thus between 5 and 6% of Medicare beneficiaries die each year and constitute almost 70% of all Americans who die. By contrast, less than 1% of all Americans die. This means that we cannot simply extrapolate, as many have done, the 27 to 30% of the Medicare budget paying for patients who die to the entire medical care system and assert that 27% of all $1 trillion spent on health care goes to dying patients. While 5% of Medicare beneficiaries who die may consume 27% of the Medicare budget, it is highly unlikely that less than 1% of Americans who die consume 27% of all health care spending. By our estimate (which is higher than the estimate of some senior analysts at HCFA), the 1% of Americans who die in any calendar year use approximately 10% of health care spending.

In addition, it is important to note that Medicare does not cover all health care costs even for those over 65 years of age. Medicare does not pay for nursing home care, prescription drugs, many physician office visits and other medical services. Indeed, Medicare covers only 45% of the health care costs of Medicare beneficiaries. Patients who do not die may very well use more of these uncovered services than patients who do die. This again may inflate the proportion of health care expenditures going to patients who die.

Second, while in survey questions the majority of Americans want to forego life-sustaining treatments, we must be hesitant about extrapolating these data too easily. It is now fashionable to refuse life-sustaining care; it is the default answer in our popular culture. Yet we know that there is a big difference between answering these questions in a survey and taking such action. For instance, despite the fact that more than 70% of Americans say they want living wills or other form of advance care directives, despite the fact that these

documents have received extensive media publicity, are readily available at little or no cost, and are given out during hospital admissions, only 25% of the population and patients recently discharged from the hospital has completed such advance care documents.[17] Completing an advance care directive and actually refusing care is much more difficult--psychologically, emotionally and it seems practically--than answering a question in a survey. This casts doubt on the likelihood of such a large majority of Americans refusing life-sustaining medical treatments in actuality.

It also might be compared with the use of hospice among Medicare patients. Since 1982 and the passage of the Tax Equity and Fiscal Responsibility Act, Medicare covers hospice care. In 1992, 154,000 Medicare beneficiaries or roughly 10% of Medicare patients who die utilize hospice care at the end of life (personal communication Paul Eggers, HCFA). This number has been rapidly rising over the last five years, yet it still remains a small proportion of total patients who die.

Furthermore, there are a significant minority of patients who do not want to refuse life-sustaining treatments even under dire--some might say futile--conditions. Many studies have shown that about 20% of Americans want "everything" done even if they are in a persistent vegetative state. Indeed many recent legal cases, from the Wanglie case in Minnesota, to the recent cases of the family who took a brain dead girl home on a respirator, attest to the fact that significant minority of Americans do want life-sustaining treatments come what may. Importantly, surveys among AIDS patients--one of the most costly group of dying patients--show that about 50% want cardio-pulmonary resuscitation and intensive care even under circumstances in which their chances for survival are less than 15%.[18,19] A story may convey the issues as well as any statistics. One of my Amherst College classmates contract AIDS. His obituary tells that

> He told his family he wanted them to take whatever measures were available to sustain his life. He told me he felt robbed by the virus and refused to succumb. Until the very end, he stubbornly clung to life and tried to hang on as long as possible.[20]

Also not all advance care planning is created equal in terms of refusing life-sustaining treatments. Many studies have shown that patients' family members and proxies are more reluctant to stop life-sustaining treatments.[21,22] Therefore, if we advocate proxy decision-making as the best form of advance care planning, as many have done, the proportion of patients for whom we would withdraw treatment will be smaller--probably less than 50%--and the cost savings would be commensurately less.

Finally, there is not much data that supports the notion of significant cost savings by reducing life-sustaining treatments. The studies that are available suggest at best, under the

most wildly optimistic scenario, we could reduce costs during the last 6 months of life by 27% through the use of advance care directives, home hospice, and the elimination of futile care.

Before considering these studies in some detail it is worth noting there is no single reliable and valid study of this issue. All the available studies have significant limitations. few are randomized trials; most are small involving only a few hundred patients; most focus only on the terminal hospitalization rather than total health care costs; and costs are frequently estimated rather than directly measured. Nevertheless, these studies all point in the same direction: there will be little cost savings by limiting end of life care.

Use of Advance Care Directives: Three studies--of which one is randomized--examined whether the use of advance care directives can reduce medical care costs for patients who die. The only randomized trial of use of advance care documents occurred at two hospitals in San Diego and involved only 204 patients.[23] It randomized patients to either receive a discussion by their physician of the California Durable Power of Attorney or no special discussion and assessed the cost of care over the last six months of life. The study had a negative result: "executing the California Durable Power of Attorney for Health Care and having a summary copy placed in the patient's medical record had no significant positive or negative effect on a patient's well-being, health status, medical treatments, or medical treatment charges."[21]

Authors	Year of Study	End of Life Costs with ACD	End of Life Costs without ACD	Percent Savings by Using ACD
Schneiderman et al.	1987-89	$59,000	$42,000	0
Teno et al.		$61,589	$56,300	0
Chambers et al.	1990-92	$30,478	$95,305	68%

The SUPPORT study examined the costs of the final hospitalization of 854 patients who died in five separate hospitals across the United States (Teno et al.). Having an advance directive did not significantly effect the costs of patients' terminal hospitalization. Hospital bills for those without an advance directive were $56,300 versus $61,589 for those with a living will and $58,346 for those with a durable power of attorney.[24]

The study by Chambers et al. retrospectively reviewed the deaths of 474 Medicare patients in Philadelphia and found that the final hospitalization of those patients with an

advance care directive mentioned in the chart cost significantly less than those without one. There is some question whether all patients who had an advance care document were properly classified and it also suggests that sicker patients had an advance care document. While the Chambers study is suggestive it needs to be considered in the perspective of these other studies which showed not savings from use of advance care documents.

Hospice: Hospice patients are known to be terminally ill, refuse life-sustaining medical treatments, and often have care at home. There are several studies on whether the use of hospice care actually saves money.[25,26,27,28,29,30] The one randomized study was conducted at a VA hospital in California. The study involved 247 cancer patients randomized either to hospice or conventional care. It showed that there was no savings from hospice care.

The National Hospice Study was not randomized and studied 5,853 Medicare patients with cancer of which 3,641 used home care hospice. It showed that in the last month of life home hospice was 43% less expensive than conventional medical care. But that the longer patients were in hospice, the savings were much less. So that in the last 6 months of life patient in home hospice saved approximately 27% compared to patients with conventional care, while patients in hospital based hospice saved less than 15%.

Author	Year of Study	End of Life Costs with Hospice	End of Life Costs without Hospice	Percent Savings by Using Hospice
VA Study		$15,262	$15,493	0
National Hospice Study	1980-83	$ 7,719	$11,729	27%

It is worth noting that about 25% of patients on hospice still are hospitalized during their period on hospice. As noted above the use of hospice has significantly grown over the last five years. Medicare data demonstrate that 44,000 Medicare patients used hospice in 1988 and over 150,000 used hospice in 1992. In addition the length of stay on hospice has also significantly increased. In 1988 Medicare hospice patients stayed on hospice for an average just 37 days. In 1992 hospice patients stayed on hospice for 57 days. Remembering that the longer patients stay on hospice after one month the lower the savings, this trend implies lower cost savings per patient than in previous studies.

Eliminating Futile Care: What constitutes futile care is controversial. But there are some areas that seem less controversial than others. For instance, many people claim that resuscitating patients with cancer is futile. While there is there is no cost study of eliminating resuscitation for oncology patients there is a study from the Cleveland Clinic of the cost of care for all patients with Do Not Resuscitate (DNR) orders, almost 25% of whom had cancer. This study involved 852 patients and looked at the cost of the final hospitalization. It found that patients who were DNR cost about the same as non-DNR patients who died: $62,594 for 616 DNR patients versus $57,334 for 219 non-DNR patients who died.[31]

Other people might consider chemotherapy for lung cancer a futile therapy. Chemotherapy for unresectable non-small cell lung cancer is an example of marginal if not entirely futile therapy: it does not seem to systematically enhance longevity, improve quality-of-life or palliate pain.[32,33] A Canadian randomized trial comparing chemotherapy with quality supportive care for patients with non-small cell lung cancer found that the average cost of the supportive care was $8,594.85 (1984 Canadian dollars) while one chemotherapy regimen cost less--$7,645.36--and another regimen cost more--$12,232.45.[34] Aspects of this study are controversial and some costs required approximations because they are "not routinely identified in the Canadian health care system."[38,35] Nevertheless, the authors conclude that even if chemotherapy is expensive, "a policy of supportive care for patients with advanced NSCLC was associated with substantial costs."[38]

HOW MUCH CAN WE SAVE FROM GREATER USE OF ADVANCE CARE DIRECTIVES, HOSPICE, AND FEWER FUTILE INTERVENTIONS?

Predicting how much we could save by wider use of advance care directives, hospice care, and fewer futile interventions is at best speculative, requiring many assumptions, extrapolations from limited data, and educated guessing. But even making the wildly optimistic assumptions that 1) all Americans complete an advance care directive, 2) refuse aggressive life-sustaining interventions, and 3) take terminal care through home hospice the savings are likely to be small.

We know that 2.17 million Americans died in 1988, of which 1.49 million were Medicare beneficiaries. Using the hospice data, let us assume that the maximum we might save in health care costs during the last year of life by reducing end-of-life interventions is 27%.[22,24,26]

Using estimates for the cost of medical care during the last year of life and these assumptions, we can calculate how much can be saved if each of the 2.17 million Americans who died used advance directives, hospice and refused aggressive, in-hospital, end-of-life interventions. As the table shows, the total savings in the health care budget would have

been $18.1 billion in 1988 or 3.3% of all heath care spending. In 1988, the Medicare savings would have been $5.4 billion or 6.1% of expenditures.[36] Since the percent of health dollars spent on decedents has been constant over 30 years, the savings as a percent of the national health budget and Medicare are unlikely to change over time.[37]

	OVERALL HEALTH CARE SYSTEM		MEDICARE
	Under 65	65 and Over	
Number of patients who died in 1988	0.68 million	1.49 million	1.49 million
Average annual health care cost per dying patient	$34,102	$29,295	$13,316
27% savings from use of advance directives, hospice and less aggressive interventions by all patients	$ 9,208	$ 7,910	$ 3,595
Absolute dollar savings from use of advance directives, and hospice and less aggressive interventions by all patients	$ 6.3 billion	$11.8 billion	$ 5.4 billion
1988 Health Care Spending	$546 billion		$88.5 billion
Percentage of health care spending saved from greater use of advance directives, hospice and less aggressive interventions	3.3%		6.1%

Some may look at these figures and conclude that 3.3% of the health care budget amounts to almost $30 billion and is a huge savings. This conclusion is not just a matter of perspective on a set of data. It is taking a fantasy for potential reality. The purpose of this calculation is not to show what is possible if we work hard, but rather how little extra savings can be had even if we could wish our ideal.

For many reasons this fantasy is not likely to develop. As I have already noted, it is highly dubious that all Americans will use advance care directives and refuse life-sustaining care. We already know that at least 20% of Americans reject this. Further, as noted above only about 10% of Medicare beneficiaries us hospice even thought it is available and covered by Medicare and has been for 12 years. Furthermore, even if we could realize these large

savings, there would be no windfall. As the health economist Rashi Fein has noted about other proposed cost saving changes that involve changes in medical practice: "the savings would occur only over a number of years." Achieving 5 or 6 billion in savings each year for five years is significant but likely to be dwarfed by simple health care inflation.

WHY ARE THE SAVINGS AT THE END OF LIFE LESS THAN WE EXPECT?

There are at least five reasons that the prediction of scores of billions of dollars of savings from eliminating wasteful end of life care made by physicians, health policy analysts, the public and the media are wrong. We have already indicated some of them.

First, our best data on cost of care for patients who die comes from Medicare and the Medicare statistics are not readily extrapolated to the whole health care system. Medicare makes us think we are spending a great deal and therefore can save a great deal. We are spending only 10% of all health care expenditures on end of life care. Thus even a large percentage decrease in this spending is a small fraction of the total health care budget.

Second, as we have stated many Americans just do not desire less aggressive medical care at the end of life.

Third, it is worth noting that we have undergone a revolution in the provision of health care to dying patients over the last decade. Currently almost 80% of patients in large hospitals die without "everything" being done for them.[38,39,40] Among cancer patients, in fact, as many as 97.5% die without resuscitation.[41] We are already withdrawing and withholding life-sustaining treatments for the vast majority of people. While there might be more interventions that can be stopped, it is fewer than we think and therefore the savings are likely to be less than we think.

Fourth, death is unpredictable. The statistics we have from Medicare and other studies provide us the cost of patients who died. We know that they die after the fact and then look back to find out how much medical care the used. As Anne Scitovsky has argued:

> Most of these studies deal not with the 'high cost of dying' of ' terminal patients but with medical care expenditures at the end of life, generally in the last six months of life. It is easy enough, of course, to designate a patient as terminal or as dying *retrospectively* but an entirely different matter to do so *prospectively*.

This means that when 1994 started we did not know who would die and who would not. For only a few diseases, most notably some cancers and AIDS, can we accurately predict weeks

or months in advance who will do well and who is likely to die. But for most other causes of death, including heart disease and stroke which account for about half of all deaths, the end is sudden and unpredictable. Indeed who would have predicted Richard Nixon would die in April 1994 of a stroke. And even after the initial stroke who knew with accuracy he would die five days later.

The inability to know who is terminal and likely to die with any accuracy makes it hard to know when to stop medical treatments. In the face of this uncertainty we--physicians, patients, and family--are likely to err on the side of treating and withdraw only after it is clear that the patient is likely to die. This approach means there will be less cost savings that we might predict by looking at the cost figures after we can identify who dies.

Finally and most importantly, just because we are willing to stop providing high-technology life-sustaining care for patients at the end of life does not mean that they require no medical care at all. When we stop life-sustaining treatments patients just do not simply die. Depending upon the disease, patients who refuse life-sustaining care can still live weeks, months even a year. For example, the median survival of patients with metastatic lung cancer is about 6 months. Half will live more than six months even if they refuse life-sustaining care. The dying patients still require high quality, and dignified comfort care over this period. Even if it is not high technology, this comfort care is not cheap. A patient with metastatic lung cancer refusing life-sustaining treatments but getting comfort measures may require radiation therapy for painful bone metastases; intravenous pain medications; supplemental oxygen to reduce air hunger; and other medications and treatments. Such comfort care is labor intensive and not cheap. It may also be useful to note that even among hospice patients about 25% end up using in-hospital services while they are on hospice.

We cannot on the one hand lecture physicians about providing high quality, dignified comfort care and pain management to dying patients and then on the other hand berate them for the fact that medical care for these dying patients will cost significant sums of money.

CONCLUSION

None of the studies of end of life care is definitive. But almost all of them point in the same direction showing that there is unlikely to be a windfall in savings by use of advance care documents, more hospice and less aggressive life-sustaining treatments. We certainly could use better--especially randomized--studies of the cost of dying. Before we have definitive data on this we should not count on this money to finance health care reform.

To reiterate the main point: Just because we spend a lot of money on dying patients does not mean we can save a lot of money.

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PREPARED STATEMENT OF MELVIN KONNER, M.D., PH.D.

My name is Melvin Konner, and I teach human biology and medical anthropology at Emory University in Atlanta. I hold Ph.D. and M.D. degrees from another noted institution of higher learning where, after six years on the faculty, I attended medical school. I have authored three books on the relationship between medicine and society,[1-3] and have taught for many years about it. I understand the viewpoint of the practicing physician, but I get no portion of my income from the delivery of care, and so have no special interest in the economic results of reform. Due to some serious illnesses in my immediate family, I also know how it feels to be on the other end of the stethoscope. My testimony reflects only my own opinion, not that of any institution or organization. It is a privilege to have your attention even briefly.

Robert Frost is known for many serious works, but my favorite may just be the following late, mischievous two-line poem:[4]

> Forgive, O Lord, my little jokes on Thee,
> And I'll forgive Thy great big one on me.

The big joke is, presumably, mortality; and although the Almighty may occasionally find it funny, humans rarely do. In fact, some philosophers have argued that we humans spend our lives, energies, and fortunes in a massive effort that combines postponement with denial. Certainly in medicine the assault on mortality is our mission, our obsession, and our dream. But the philosophical questions remain. What happens when the length of life is at odds with its quality; when, in Hamlet's words, we face the "calamity of so long life?" And who will bear the awesome responsibility of judging when life has been too long?

But modern medicine and its technologies raise a new question, one that Hamlet could not have thought of. What happens when medicine gives us so much control over dying that the idea of a natural order of things slowly loses its meaning? Among the !Kung San, or Bushmen, whom I lived with in Africa, control over dying is so feeble that they would never dream of our problem–an ethical dilemma concerning when to let people die. Indeed, throughout human history until the last few decades, no such conundrum could have existed. Science has presented us with a new kind of dilemma, one that requires a new kind of ethical reasoning.

None of us, of course, would go back in time to an era when mortality made life so precarious. But we do need to realize that it has not been the advance of medical technology that caused most of the reduction in mortality in modern times. Rather, it has been primarily improvements in the quality of life–nutrition, sanitation, housing, work conditions, and so on–that have defeated the great killers of the past. The role of new technologies has been more dramatic, but much less important.

Good people can legitimately differ about how we should view the end of life. There appears to be agreement that competent adults have the right to refuse treatment, a consensus embodied in The Patient Self-Determination Act.[5] There is growing acceptance of legal instruments such as the living will and the durable power of attorney for health care, designed to prevent unwanted treatments in the event of a person's loss of competence.[6] And in some cases, such as that of Nancy Cruzan, courts have accepted other evidence of an incompetent patient's wishes. The Cruzan decision also extended, rightly I think, the boundary of what we view as technological intervention, to include artificial feeding and hydration.[7] Meanwhile, Derek Humphry,[8] the Hemlock Society, and of course Dr. Jack Kevorkian have acted, sometimes with disregard for the law, to try to push the boundaries of the right to refuse treatment until they encompass a right to die, a

right to take one's own life, and even a right to be assisted by a physician in such an act of suicide. And whatever ethicists and legislators may think of these actions, juries of average Americans–most recently just a few days ago–have consistently refused to punish such acts when they are perceived to have a humane motivation.[9]

But as Dr. Christine Cassel has wisely said, "it is one thing to let people die because their lives have become an inconvenience to them; it is quite another to let them die because their lives have become an inconvenience to us."[10] Surely we do not want to create a moral environment in which seriously ill people, guilty over the inconvenience they cause us, chose death at a time when life still appeals to them. The line is easy to cross. Dr. Carlos Gomez, author of *Regulating Death*, reported on twenty-six cases of euthanasia in the Netherlands, where legal strictures against this practice are limited.[11] In too many cases Dr. Gomez found evidence of inadequate treatment of pain, and even more inadequate treatment of depression. In the United States too, it is widely agreed that doctors treat pain and depression inadequately, even in the terminally ill, to the point where a sitting Surgeon General, Dr. Louis Sullivan, was moved to call for a major reform of practice. Dr. Eric Cassell's dismal assessment of modern doctors is that they have lost their ability to address human suffering.[12] The lesson is that before we help people die, we had better be sure that we have done everything reasonable to help them want to live.

Yet there is a point at which a person may really want to die, and leading physicians throughout the nation have explicitly recognized that assisted suicide does and should sometimes happen under the aegis of physicians.[13] We owe it to physicians, to patients, and to families to bring this secret out of the closet, and to debate publicly how we as a society may lift at least part of this dreadful burden from their shoulders.

Dr. Cassel's warning about the ethics of the ice floe brings us to a still more complex problem: the specter of explicit rationing. Nobody wants rationing, but few have faced the fact that we have rationing now.[14] As a medical student working in what many consider our nation's best hospital, I saw this rationing in action, as poor people waited in pain for so many hours that they left without treatment. We saw rationing too, when thousands of children contracted measles in a completely unnecessary epidemic, and some of them, inexcusably, died of it, because of the disgraceful inadequacy of our nation's vaccination programs.

I prefer the rationing to be rational, and I prefer the word triage, because it is one we accept. It comes from the French *triager*, to sort. It is something we know to be ethical in war or accident or natural disaster, when so many cases descend on medical workers that they must choose whom they will treat. This one is serious, but will live for another day. This one is worse off, but nothing I do will help him. And oh yes, here is the one I must care for first, the one who will live only if I do what is needed now. How can we make such decisions? We must, and so we do.

I believe that we are already in a situation of triage at the societal level. Americans have decided that they cannot spend much more on health than they spend now–around a seventh of GNP. Yet forty million people have been left out of the system, without logic, ethics or compassion.

A few years ago the people of Oregon decided to prioritize medical treatments–in effect, to triage. The fact that the Bush administration quashed their effort should not be allowed to obscure what they accomplished. In a bipartisan plan designed by physicians in the state legislature, after consultation with countless town meetings around the state, and with the support of the governor, Oregonians made a list of medical treatments ranked

according to their value and effectiveness. They did not claim that this was easy, nor did they think they had done it perfectly. They can be criticized for prioritizing treatments and rejecting some of them only for those on Medicaid. But their effort needs to be studied by all who care about the health of Americans.[15]

Assuming we become capable of setting priorities, how will we handle end of life issues? Doctors Ezekiel and Linda Emanuel have shown that the savings to be gained by hospice treatment in the last year of life are not great, although even they concede that "reducing health care expenditures by 3.3 percent cannot be dismissed lightly."[16] As your late colleague Senator Dirksen said, "a billion here, a billion there, and pretty soon you're talking about real money." With this saving, a third of the uninsured could be covered.

But to focus on the last year misses the point. There are inappropriate treatments throughout life–tens of thousands of unwarranted coronary bypasses, hysterectomies, prostatectomies, cesarean sections–the list goes on.[17] These excess procedures not only waste tens of billions of dollars, they expose patients to needless risk, discomfort, and opportunity costs of their own. Unquestionably, the money saved from withholding needless treatments could fund coverage for most of the uninsured. Most of these savings would not, in the usual sense, be triggered by end-of-life measures.

But the last year of life does not exhaust the end-of-life issues, and to claim that it does is disingenuous. Consider my mother's final illness. In August 1990, she suffered a large stroke that left her bedridden without speech. She had made it clear that she would not want to live long in that kind of shape. Still, my father, my brother, and I fought to get her into a rehab hospital to give her every chance at recovery. Unfortunately, while there she had a second stroke and was transferred back to the acute care hospital. The rehab hospital would not take her back.

Now came the sad choice. Specialists at the hospital wanted to implant a gastric feeding tube. Her family doctor, a longtime friend, advised against it. It would have kept her alive for years in a humiliating condition. We knew what she would have wanted. We agonized about it for days, and even consulted a lawyer who had argued a "right to die" case before the Florida Supreme Court. We decided not to place the tube. Without it, she could not be accepted by a nursing home, and her doctor discharged her to hospice care at home. She died gently in her own room a few weeks later, appropriately medicated to limit her discomfort.

We had respected her wishes. If we had placed the gastric tube, she might still be alive today, suffering countless indignities and ongoing distress, without hope of improvement or recovery. She would also have incurred many medical expenses, some covered by Medicare, most of which would not have been in the last year of life. Yet they would have resulted from end-of-life issues, since the end of her life did follow our decision not to place the tube–as we had suspected it would. So not just last-year-of-life savings, but perhaps years of savings, resulted from an end-of-life decision.

But of course we did not make it to save money. On the contrary, while we were trying to give her her best shot at recovery, we spent Medicare's money with impunity; and so, I hope, would everyone. I call this the "what-if-it's your mother" rule of expenditure. I know that an MRI scan costs three times as much as a CAT scan, but that it does not yield three times the information. Still, as a good son, I will ignore the cost-benefit ratios and insist on the best. So will all good sons and daughters, and parents, siblings, and spouses too. As awareness of the rapidly moving frontier of technology spreads throughout

society, the "what-if-it's-your-mother" rule will drive up medical costs until they consume so much of our resources that we can't do the rest of what we want and need to do.[18]

Only a broad social consensus, eventually embodied in law, can slow down this process, and that, once again, means triage. Not all treatments that patients demand have equal value, and some have no value. Yet in recent months courts have ordered doctors and hospitals to provide, against their better judgement, expensive treatments that have no proven scientific merit. This is a path that can only lead to disaster, as expanding demand pushes treatment far beyond what is reasonable, in a vain attempt to control completely what, finally, is beyond our control: the hour of our death. We sorely need more and better outcome studies to assess the value of treatments, and practice guidelines to help physicians say no when that is the right answer. We must set clear priorities. If we don't, then our effortful denial of death will come back one day to haunt our children.

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PREPARED STATEMENT OF JOANNE LYNN, M.D., M.A.

I appreciate the opportunity to talk with you this morning about care of persons near the end of their lives and the role of the federal government in improving their situation. I am especially interested in conveying to you results of research by my group and others in regard to the effects of the Patient Self-Determination Act and our observations on the avenues that you might pursue to further improve care for all of us as we die.

I am Joanne Lynn, a physician and Professor of Medicine at Dartmouth Medical School where I also am engaged in researching health services related to dying persons. For many years, I was the main hospice physician for Washington, D.C., the Medical Director of The Washington Home here, and the Director of Aging Studies and Services at The George Washington University. I serve on the Board of Directors and as the Chair of the Ethics Committee of the American Geriatrics Society. I was the Assistant Director of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research in the early 1980's and I have worked extensively on these subjects with the National Center for State Courts, the Commission on Legal Problems of the Elderly of the American Bar Association, and others concerned with the legal, ethical, and health care issues affecting elderly, disabled, and dying persons. Most important, I have cared for some two thousand dying persons and I am leading a major study of decision-making for some ten thousand seriously ill hospitalized patients.

This hearing is intended to review the status of care of the dying, the effects of the Patient Self-Determination Act, and the Federal role in improving the situation. I will organize my comments around three key points:

1. The Patient Self-Determination Act has had important effects on improving state law and perhaps on mitigating costs of certain hospitalizations. Its effects on improving the care of patients are, thus far, difficult to trace in hospitals, though the rate of DNR orders in nursing homes has increased dramatically.

2. The care of dying persons evidences serious and troubling shortcomings, and we do not even have much reliable information about what we face as we die or how to improve care.

3. The Federal government can have important roles in improving the care of dying persons and in enhancing patient participation in shaping the plan of care.

1. THE PATIENT SELF-DETERMINATION ACT—EVALUATION

The PSDA, which was implemented on December 1, 1990, mandated three major endeavors:

a. Most health care providers had to tell patients of their rights under state law to make medical decisions

b. Each state had to articulate a definitive interpretation of relevant law

c. Providers and states were to provide public and professional education about decision-making

a. PSDA Mandatory Notice

The PSDA required that providers give notice to patients about their rights to make decisions, and that providers have policies on how to deal with written advance directives. These notice provisions have almost certainly increased public and professional awareness of formal advance directives. (living wills and durable powers of attorney) and probably has increased completion of these documents. In the SUPPORT project (The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments, the basic study funded by The Robert Wood Johnson Foundation and the work on advance directives funded by The Agency for Health Care Policy and Research), we have had the opportunity to study advance directive use among very seriously ill patients in five U.S. hospitals before and after the implementation of the PSDA. Before the PSDA, about one in five of our patients said they had an advance directive, but only a few advance directives were mentioned in the medical records and none were kept in the permanent records. After the PSDA, the proportion of patients who say that they have made an advanced directive has increased only slightly, but now nearly one in three are mentioned in the records and virtually all of these patients' medical records actually contain the written documents. Our experiences are echoed in the work of others who are finding many more advance directives in medical records, but very little increase in the rate of documents completed.

However, there is little evidence that advance directives are changing patient care in hospitals. In SUPPORT, we can find virtually no important effects of having a living will or a durable power of attorney. Patients with formal advance directives

have the same rates as do those without formal advance directives of orders against trying resuscitation, and of chart documentation of discussions of withholding life-sustaining medical treatments. Even patients who have living wills and have expressed preferences to avoid resuscitation have no increased rate of "do not resuscitate" orders or of discussion of them. Patients with advance directives in the medical record have slightly decreased hospital charges, with a median length of stay for those who died of 16.5 days and hospital charges of $55,000 as compared to a median stay of 18 days and hospital charges of $59,000 for those without documented advance directives.

Other research has also found very little evidence of an effect of having an advance directive. Schniederman, et al., in a randomized trial of counselling for advance directives, found no effect on multiple endpoints such as patient well-being, decisions about trying resuscitation, and resource utilization in the month prior to death. In contrast to our work and Schneiderman's, Chambers et al. reported a substantial effect of advance directives on hospital charges at one hospital, though that study does not allow one to infer that the advance directives caused the savings because one cannot separate decisions to forgo aggressive. treatment from the forces which led to having an advance directive.

If further studies confirm a substantial cost savings, the source will almost certainly be better communication between provider and patient and more acknowledgement of the limited prospects for enhanced health with additional interventions. Certainly there is much room for improvement in communication and understanding. IN SUPPORT, less than half of the advance directive documents placed in the charts by the third hospital day were known to the physician when interviewed on the tenth hospital day. Patients who said they had an advance directive had discussed it with their physician less than 40% of the time. And patients and families routinely projected that the patient was more than 90% likely to survive for two months or more when the patient actually had less than a "50–50" chance to live so long.

If advance care planning is to improve, we probably have to develop ways to improve communication. Recently, we convened thirty-five concerned persons with expertise in sociology, anthropology, medicine, nursing, law, ethics, and related fields in order to settle on priorities for research in this field. This group felt strongly that public policy urgently needs to be guided by reliable evidence as to the potential effectiveness of communication in creating shared decisions and in shaping those decisions so that they reflect the patient's preferences and potential outcomes.

Certainly, advance directives have not delivered on their promises of a blossoming of effective communication, a burgeoning of advance care planning for seriously ill patients, or a curtailing of worthless and undesired life-prolonging care for dying persons in hospitals. In nursing homes, the situation may be different. Certainly, coincident with the PSDA, the rates of "do not resuscitate orders" in nursing homes increased greatly, although states still evidence rates of DNR that vary from 10 to 70%, a probable indication of unjustified variation in practices.

Could advance directives and the PSDA still make a substantial difference? Perhaps. We are still early in the story of responding to the PSDA and the other social incentives to enhance the role of patient preferences and of advance care planning in the shaping of care for dying and seriously ill persons. However, some evidence gives us reason for caution. First, we have collected some 800 advance directives actually written in the care of seriously ill persons. Virtually all of them either name the closest kin as surrogate or state a standard "living will" directive. Neither of these endeavors can be expected to change the care plan substantially. The durable powers of attorney often name the same proxies who would be used if there were no document and the living will language is so vague as to have no real force without interpretation. Furthermore, our experience with patients, families, and physicians shows that many do not understand when and how advance directives should be used, and usually rely upon them only when death is very near at hand. Finally, very few interventions are actually being implemented for persons who are clearly beyond being able to be helped. Only about one in every eight persons who die in SUPPORT have an effort at resuscitation, and these patients have better or more uncertain prognoses or prefer to have resuscitation tried. Just ten years ago, a clear majority of patients would have had efforts to resuscitate. Very few persons with very bad prognoses are kept on life-sustaining treatment. In sum, the rate at which aggressive treatment is thrown at persons who cannot benefit is already greatly curtailed, so one cannot expect a substantial effect of the PSDA in regard to savings.

Not only does PSDA have little effect, it also incurs substantial costs. The one effort to estimate the costs of hospitals' implementing the PSDA shows that minimal compliance (having admissions clerks make inquiry and having the minimally required staff follow-up) will cost the "system" up to $100 million in the first year.

While this may seem to be a small amount, one would want to be more confident than we can be now that the investment is yielding something of importance to patients, or substantial savings, especially before requiring this outlay every year. It may be, for example. that the good to be had through the PSDA can be had by keeping it in place for a limited time.

b. State Articulations of Relevant Law

The PSDA required each state to develop an authoritative statement of the law of that state in regard to patients' rights to make decisions and to utilize advance directives. Working with the Commission on Legal Problems of the Elderly of the American Bar Association and the consumer group Choice in Dying and with the financial support of the Retirement Research Foundation, my research group helped to develop and circulate a guidebook, hoping to raise all the issues and to provide resources to these highly varying teams. We interviewed those involved in the process of writing the interpretation of state law at mid-course and when the documents were completed and we collected all the resulting documents.

In brief, this provision of the PSDA was stunningly effective. Virtually all states developed very useful, consumer oriented materials under the guidance of unusual multi-professional committees including governmental and private participants. These coalitions have often been important in fomenting improvements in law affecting medical decisionmaking generally. A majority of the states actually revised their statutes to address some of the inadequacies that they identified in the existing laws. Also, most states provided fairly authoritative interpretations of ambiguous provisions of state law which had the effect of enabling good decisionmaking.

c. Public and Professional Education

Health care providers and the states were required to provide education by the PSDA. However, no financing or other federal support was provided and no enforcement provisions were implemented. Some health care institutions and some private groups have done substantial educational work nevertheless. The usual health care provider has not made substantial contributions to this endeavor. Probably the most effective educational intervention was the publicity over Richard Nixon's advance directive, but much more could be done!

Although hard to quantify, one of the most important impacts of the PSDA has been its serving as a stimulus for a national discussion among researchers, advocacy groups, and the public regarding end of life decisonmakiing. In anticipation of the PSDA, each of the major medical journals had articles about advance directives. The PSDA has spurred a dialogue among multiple disciplines regarding decision making. For example, the conference we hosted involved 35 experts from diverse backgrounds and regions and was funded by the Greenwall Foundation, the Haas Fund, the Kornfeld Foundation, and the Agency for Health Care Policy and Research. The consensus research priorities will be important in shaping the future of funding strategies, and this would not have occurred without the focus of the PSDA.

2. CARE OF DYING PERSONS

The usual person dying of illness in the United States faces an extraordinarily high likelihood of dying in pain, alone and isolated, at great expense, and devoid of meaningfulness, grace and dignity. Probably three-quarters of us will die in hospitals with our dying having to be a hidden eventuality in a culture that only acknowledges survival as a worthy goal.

There is a widespread myth that enormous resources are wasted on the dying. The evidence for this is actually quite frail. About one quarter of the payments under Medicare are directed at the care of those who die during that year. This seems to be a reasonable proportion—after all, persons are commonly quite sick in the year that they die. Much of the care needed near death is supportive and would be part of any reasonably decent minimum standard of care. Scitovsky's study showed that the ratio of medical services (like hospital care and physician visits) to supportive services (like home care aides and nurses) declined very sharply with age, so that the very old have much more expenses for nursing homes than for intensive care, whereas the young (even below 70 years of age) have the reverse pattern of expenditure. .Very few dying persons now have resuscitation efforts or extended stays in intensive care. However, there may still be important opportunities for savings in care of the dying. Preliminary work by Wennberg and colleagues at Dartmouth shows that excess capacity in hospitals has many troubling effects, including increased use of hospitals for dying persons.

Modern medicine has completely lost even the basic descriptive knowledge about dying that was accumulated at the beginning of this century. Indeed, the last sequential study of persons dying in hospitals was done in the first years of this cen-

tury! Textbooks of that era attended to describing the natural course of diseases through to death. Modern texts often fail to note that most chronic illnesses eventuate in death and they certainly do not instruct practitioners about how to care for persons facing their deaths with each illness. The need for research and education is pervasive.

We do not know how many of us will have pain, or unconsciousness, or disabilities, or other adversity, nor for how long, nor how to address these problems. You may find this hard to believe. People routinely think that doctors know how to prognosticate, how to mitigate pain, and generally how to serve dying persons. Nothing could be farther from the truth. This culture has been so thoroughly death-denying that we have not even described our course to death nor developed professional skills in service to the dying, except for the development of hospice services for certain cancer patients in recent years. It is probably true that we are gradually learning how to forgo inflicting unjustified technology upon dying persons, but we clearly do not know how to see to it that most who die get excellent care, shaped to their needs, and responsive to their symptoms.

The care system that we have developed has serious barriers to adequate care of the dying. Reimbursement is not regularly available for services that merely mitigate suffering or support the daily needs of persons who are too weak or sick to care for themselves. Even hospice is really available only to adults with solid cancers and homes and substantial family wealth. The usual person dying and in need is an elderly woman with one or more chronic diseases, few resources, small families, no regular physician, and fears of homelessness, hunger, pain, isolation, and lack of control. All of these terrors can readily be mitigated, but doing so will require substantial reorientation of the care system so that continuity and support are priorities. To this end, what is done in regard to the end of life must be integrated completely into the reforms now being considered for the care system overall.

3. NEXT STEPS

The PSDA has been an interesting first step, laying some groundwork and accomplishing much. However, more is yet to be done. Communication between patient and physician and the availability of supportive services are the obvious shortcomings. There are no easy, painless, effective correctives for these problems. The following list shows an array of options that I feel might offer possibilities. Some are quite substantial initiatives, others are inexpensive and time-limited. I offer them in hopes that considering them will illuminate some productive avenues for Federal action in a very difficult field.

a. Develop and require implementation of measures of quality of care affecting dying persons, specifically:

—mandate that AHCPR and NIH (or regional health foundations) develop (or fund the development of) measures to assess quality of care for dying persons

—mandate that regional health alliances (or their equivalent in whatever health reform is enacted), or hospitals and other providers, assess quality of care for the dying in each authorized health plan, using the measures developed above.

b. Require that the Secretary of HHS contract the following:

—with the IOM and/or appropriate professional groups to generate guidelines on good palliative care

—with teaching institutions to generate curriculum and evaluation for various kinds of students.

c. Make some Medicare Part A and graduate medical education funds under Medicare become contingent upon public and professional education for care of the dying.

d. Change Medicare reimbursement to require advance care planning in the managed care package and to allow it to be billed in fee-for service Medicare.

e. Change physician experience toward long term care of seriously ill patients by paying more for persistent care by the same practitioner than for acute care by a shifting cast and by mandating training of generalists through regulating graduate medical education payments under Medicare.

f. Encourage innovations to develop Medicare benefits which would provide managed care of the broadest scope, but limited hospital and emergency services.

g. Mandate each Institute in the NIH which has in its purview one or more substantial causes of death to report about the course to death for each major disease and what can be done. When the knowledge base is too inadequate to support this endeavor, expect the Institute to make the generation of that knowledge a high priority.

COMMUNICATIONS

STATEMENT OF THE AMERICAN BAR ASSOCIATION

(BY JOHN H. PICKERING AND CHARLES P. SABATINO)

Mr. Chairman and Members of the Committee: My name is John H. Pickering and I am Special Advisor to the American Bar Association's Commission on Legal Problems of the Elderly. From 1985 to 1993, I was Chair. of that Commission. I am very pleased to submit these remarks regarding the success and impact of the 1990 Patient Self-Determination Act (PSDA). It has been almost four years since our Commission's Assistant Staff Director, Charles P. Sabatino, appeared before this same committee to address the then pending PSDA. Mr. Sabatino joins with me in presenting these comments on behalf of the American Bar Association.

In 1990, the American Bar Association supported the passage of the PSDA, and today we congratulate Senator John Danforth and Senator Daniel Patrick Moynihan for their decisive and creative leadership in establishing this mechanism to inform individuals of their rights to control end-of-life decisions. The PSDA has now been in effect for two and one-half years. Because it is a law calculated to affect the public consciousness and professional practice through ripples of information and discussion over time, rather than through dramatic splashes, it is difficult to point to dramatic, cause-and-effect outcomes of the Act. However, it is possible to identify significant positive changes in state law, medical practice, and education of the public that have occurred over this period of time as a result of the PSDA. Even the tenaciousness of the name "Patient Self-Determination Act" is indicative of the significance attached to the legislation by the medical and legal communities. Enacted as part of the Omnibus Budget Reconciliation Act of 1990, the provisions merely amended the Medicare and Medicaid program. Yet in the vernacular, these provisions have become permanently referred to as the Patient Self-Determination Act.

STATE DESCRIPTIONS OF THE LAW

One important example of positive change resulting directly from the PSDA has come from the mandate that each state develop a written description of the law of the state concerning advance directives to be distributed by providers or organizations under the requirements of the Act. In most states this prompted a remarkable, broad-based and fruitful collaboration among state agencies, medical and health facility associations, bar associations, and consumer groups. By the effective date of the PSDA (December 1, 1991), all states had prepared a written description, and in all but three states these descriptions were written in non-technical language and accessible to the general public. *See* Joan Teno, et al., *The Impact of the Patient Self-Determination Act's Requirement that States Describe Law Concerning Patients' Rights,* 21(1) J. of Law, Medicine & Ethics 102 (1993).

A premier example of the kind of collaboration that resulted from the PSDA is represented by the California Consortium on Patient Self-Determination. Comprised of some 25 diverse groups, the Consortium produced not only a simple, readable statement of one's rights to make decisions about medical treatment, but also multilingual versions of the statement, plus a more detailed question-and-answer booklet, model policies and procedures for health facilities, training materials for staffs and the community, and PSDA handbooks for facilities.

The ABA's Commission on Legal Problems of the Elderly actively supported state level efforts to develop high quality descriptions of patients' medical decisionmaking rights through publication of the *Patient Self-Determination Act State Law Guide* in 1991. The Guide was provided to all the state working groups responsible for developing descriptions of law. Through the distribution system of the American Association of Retired Persons, the ABA Commission has also made available free to the

public a booklet entitled *Health Care Powers of Attorney*. The booklet includes a sample form that can be detached and used by readers of the booklet.

FACILITY PRACTICES

Facility practices illustrate another important area of change affected by the PSDA. The August 1993 report of the Inspector General, Department of Health and Human Services, found that most facilities are indeed complying with the mandates of the PSDA to: (1) develop and provide written materials regarding health care decisionmaking and provide them to patients upon admission, (2) develop written policies and procedures regarding advance directives, (3) provide staff education, and (4) provide community education on the subject. While 1 percent compliance must remain the ultimate criteria for success, it is nevertheless gratifying to see the substantial strides providers have made in fulfilling the informational and educational goals of the Act.

STATE LAW

The same report also reinforces the findings of other studies, showing that while a large majority of individuals have at least a rudimentary understanding of advance directives, only about one out of five have written advance directives. We believe that one of the disincentives of executing advance directives has been the complexity of state law on the topic. Most states have enacted two or more statutes relating to advance directives and surrogate health-care decisionmaking. The legislation has evolved incrementally in fits and starts, resulting in often fragmented, incomplete, and sometimes inconsistent sets of rules even within a single state. In tracking state health decisions law since prior to the PSDA, the ABA Commission has seen encouraging signs of movement among the states during the last four years toward more comprehensive, yet simpler, rules and procedures governing advance directives and medical decisionmaking for persons lacking capacity. One simple but telling hallmark of this trend is the widespread use of the generic term "Advance Directive," formally coined by the PSDA. The term has been important in breaking the narrow "living will" mold of thinking and encouraging the public and providers to think about more comprehensive documents containing both proxy appointments and instructions. The term has become virtually omnipresent in legislation and educational materials since 1991. For further information on state legislative trends, we refer you to the summary of relevant state legislative trends, attached to this testimony as Appendix A.

The recent adoption of the new Uniform Health-Care Decisions Act by the National Conference of Commissioners on Uniform State Laws in August of 1993 will further encourage the trend toward more comprehensive yet simpler legislation in this area. In February of this year, the American Bar Association added its endorsement to this model act.

RECOMMENDATIONS FOR ACTION

On the federal level, an auspicious opportunity exists within the context of national health care reform to advance the original goals of the PSDA to ensure that Americans are informed and educated about their health-care decisionmaking rights, especially with respect to the use of advance medical directives. The ABA suggests that the Congress consider five elements:

First, we assume that the basic PSDA requirements will be made applicable to all health plans under any health reform bill. However, in addition to the basic requirements, the statute should also mandate health plans to offer, as part of their services, periodic opportunities for patients to discuss end-of-life medical choices and preferences with appropriate clinicians. This requirement goes a step further than the current mandate that requires the provision of information to individuals at the time of enrollment. Advance directives work best when they enhance direct communication between patients and health care providers, not when they substitute for face-to-face communication. A better focusing of the PSDA on counseling outside the stressful context of admission will substantially promote the underlying goal of the Act.

Second, the federal government, through its medical education and research funding programs, should explore ways to promote the inclusion of advance directive counseling in medical school curricula, certification programs, and physician practice standards. Physicians who regularly deal with dying patients do not routinely receive training in end-of-life counseling to enable them to initiate and facilitate meaningful discussions with patients and their families about options available to them.

Third, the Congress should provide adequate funding to enable the Secretary of Health and Human Services to carry out effectively the mandate under the PSDA to implement a national campaign to inform the public about advance directives and the patient's right to participate in and direct health care decisions.

Fourth, assuming that some form of health security identification card is included in final health reform legislation, Congress should require that these cards contain a place to note the existence of the individual's advance directive. Alternatively, Congress, through its highway funding programs, could encourage states to provide such a place on all drivers' licenses. Three states, Illinois, South Dakota, and Texas have already taken steps in this direction. The goal is to create a universal, accessible notice that travels with the individual.

Fifth, Congress should ensure that advance directives will be portable—that is, they will be recognized across state lines. Because of the variability of state legislation, individuals frequently express concern about whether their advance directives, executed in one state, will be respected in other states. In a mobile society such as the United States, this is an especially important concern. As to actual practice, we know of no empirical evidence indicating whether or not resistance to out-of-state advance directives is truly widespread. Nevertheless, the concern about it is widespread. We have reviewed the relevant language of state advance laws and found that, in most states, the.language is less than adequate for ensuring the effectiveness of out-of-state directives. Because this is an issue arising from interstate travel, the federal government is uniquely situated to deal with it nationally. The ABA Commission has suggested ways to address portability at the federal level, and we remain available to refine possible solutions.

In closing, we think that it is clear that the PSDA has made a vital contribution to enhancing the knowledge, participation, and control of individuals over end-of-life health-care decisions. The ABA remains committed to these underlying goals of the PSDA and will continue to be available to work with the Senators and staff of this committee to achieve this objective.

APPENDIX A

LEGISLATIVE TRENDS IN HEALTH CARE DECISIONMAKING

A. Four Forces Have Fueled the State Legislative Process on the Subject of Health-Care Decisionmaking.

1. Medical providers prefer-legal safe harbors. Influenced by a technological, cultural, and professional imperatives to keep patients alive, the medical profession is more willing to change course if lawmakers provide clearly defined avenues or bright pathways. (Irony: most advance directive statutes are filled with ambiguities.)

2. The consumer movement in health care continues to champion patient autonomy and choice.

3. The 1990 Nancy Cruzan case, decided by the U.S. Supreme Court, continues to exert a profound influence. Even though dicta, the portions of the Court's opinion indicating acceptance of a constitutional basis for the right to refuse treatment has led states to assume it is so. State legislative developments have shown greater deference to patients' rights.

4. The Patient Self-Determination Act, especially through its requirement for State descriptions of law, has forced states to examine state law and respond to gaps and ambiguities.

B. Trends in Health Decisions Legislation Relevant to the PSDA:

1. Every state has one or more Advance Directive (AD) statutes.

a. All states except three (Massachusetts, Michigan, and New York) have statutes providing for living wills. The three that do not have specific leiving will statutes do recognize living will type instructions under their health care proxy statutes.

b. All states except Alabama have some form of health proxy statute. Most address all health care decisions, although some address only terminal conditions.

c. State Advance Directive legislation has developed in waves.

Living Will legislation spread dramatically between 1976 and mid 80's.
Health Care Power of Attorney (HCPA) or proxy directive legislation has surged mostly 1989–92.

We are now seeing two more waves of materially new legislation: combined or comprehensive acts, and emergency medical services DNR acts, both described below.

2. Combined/Comprehensive Acts Are Replacing Current Statutes.

States are beginning to reassess the piecemeal legislation they have crafted and rewrite it into unified comprehensive statutes—covering Advance Directives, even anatomical gifts, surrogate consent, and emergency medical services.

Aim of Combined or Comprehensive Acts: To recognize a single combined Advance Directive and move away from treating these as separate legal instruments.

NJ was the first to do in '91, starting with a clean legislative slate.

In 1992, VA, FL, and AZ rewrote their statutes to merge Living Wills and HCPAs into a single AD tool. In 1993, MD enacted a comprehensive new act, and CT created comprehensive form but kept 3 separate and somewhat conflicting acts.

In August 1993, the National Conference of Commissioners on Uniform State Law adopted a comprehensive model act entitled the Uniform Health-Care Decisions Act. The American Bar Association endorsed this Act in February 1994.

3. States are taking steps to ensure that terminally ill persons in the community are not resuscitated against their wishes by Emergency Medical Services. (EMS-DNR statutes)

These provisions address Non-Hospital Do Not Resuscitate Orders in the context of emergency medical services (EMS).

a. Background: In the home or community, EMS personnel are generally required to institute cardio-pulmonary resuscitation and other life-saving treatment unless a doctor physically present instructs them not to do so. Without legislation to permit them to comply with Advance Directives requesting no resuscitation, EMS personnel have generally not followed Advance Directives.

b. Starting in 1991 with the enactment of non-hospital DNR laws in IL and NY, 17 states now have such provisions as of January 1994. Some of these statutes, like NY's and AZ's, provide very detailed identification requirements, procedures and protocols. Others, like VA's, simply authorize the health department to develop a process.

The key issues in drafting protocols has been: Key issues:

Under what conditions or circumstances will refusals of treatment be recognized by EMS? Most protocols require that the individual be certified as terminally ill.

How can individuals who have valid non-hospital DNR orders be identified swiftly and accurately by EMS personnel? States are experimenting with special identification bracelets, color coded forms, and computer identification systems.

4. States are Increasingly addressing "Family Consent" or "Surrogate Consent" in the Absence of Advance Directives.

a. Family consent statutes have evolved via four different pathways:

(1) Informed consent laws that emerged in many states in the 1960's and 70's provided for family consent to treatment as a way to facilitate access to care. They are usually silent on the issue of refusals of treatment.

(2) Some Living Will statutes included family consent authority, but these statutes are typically limited to patients in terminal conditions where decisions about life-sustaining treatment are being considered.

(3) New York's family consent provision deals only with do-not-resuscitate orders under the New York DNR statute. This decision-specific approach is unusual.

(4) The growing current trend is to include family/surrogate consent within comprehensive state health-decisions statutes, like those described above.

b. About 30 states have some form of family consent statute (VA, FL, and AZ were among first to realistically merge them into comprehensive acts).

c. All these statutes create a list of permissible surrogates in order of priority. Only recently have these laws begun to address non-conventional family situations, or the total absence of available family.

AZ, FL, IL, CO, and MD include "close friend" in list of permissible surrogates.

AZ also includes "patient's domestic partner" if the patient is unmarried. However, AZ drastically limits the authority of any surrogate not actually appointed by the patient or a court. These surrogates cannot make decisions about nutrition and hydration.

d. States have not addressed what to do if no surrogates on the list of permitted family or friends are available. A few states have taken tentative steps toward prescribing non-judicial means for making decisions for these persons.

5. States Are Just Beginning to Show an Interest in Strategies to Increase Accessibility and Notice.

Only three states have considered using driver's licenses as a means of encouraging the use of Advance Directives and to make them easily available to providers. Also, considering idea of central repository.

Drivers' License Statutes:

IL—1991 III. Legis. Serv. P.A. 87–590 (H.B. 1446) (West) (amending Ch. 95 1/2, par. 6–110) (enacted September 18, 1991, effective January 1, 1992);

ISD—1992 S.D. Laws S.B. 207, approved March 10, 1992.

ITx—1993 Tex. Gen. Laws ch. 190 (HB 502), enacted 5/19/93, eff. 9/1/93, provides that the Department of Public Safety shall print on the reverse side of each driver's license "Directive to physician has been filed at tel. #" followed by a line that the holder of the license may use to indicate the appropriate telephone number.

ND is considering the idea of creating a central repository of Advance Directives:

ND—Sen. Conc. Res. 4013, adopted March 15, 1993, directs the state's Legislative Council to "study the feasibility of establishing a central repository for living wills, documents evidencing anatomical gifts, durable powers of attorney for health care, and other similar documents." The Legislative Council is to report its findings and recommendations to the 1994 legislative assembly.

A few States have information and disclosure provisions roughly parallel to the PSDA. These provisions are usually incorporated into the AD statute.

6. States Have Not Been Clear About the Applicability of Advance Directives to Mental Health Treatment.

Many Advance Directive statutes apply to treatments for any physical or mental condition. However, the interaction of Advance Directive laws with mental health treatment and commitment laws is often uncertain. Minnesota and Oregon have enacted special Advance Directive provisions for mental health treatment.

The Minnesota Commitment Act (M.$. §253B.03) authorizes an Advance Directive which applies only to intrusive mental health treatments, defined as "electroshock therapy and neuroleptic medication." The Advance Directive may include preferences, instructions, and/or the appointment of a proxy.

The Oregon Declaration for Mental Health Treatment (1993 Or. Laws ch. 442) permits instructions and/or designate an attorney-in-fact for mental health treatment. "Mental health treatment" is defined as: "convulsive treatment, treatment of mental illness with psychoactive medication, and admission to and retention in a health care facility for a period not to exceed 17 days for care or treatment of mental illness." Provisions are included for overriding the principal's wishes in limited circumstances.

C. Key Public Policy Issues

1. *What is the goal of Advance Directive legislation?* Simply getting everyone to "have" an Advance Directive is merely a triumph of form over substance. The more difficult goal is getting everyone to "use" an Advance Directive in a way that enhances involvement in health care decisionmaking. Advance Directives cannot be a replacement for good communication. They are best used as tools to stimulate and ensure good communication.

2. *Legislative Fragmentation.* Most states have two or more pieces of legislation addressing different aspects of health-care decisionmaking on behalf of persons unable to speak for themselves. Inconsistencies and gaps are common.

3. *The impact of statutory "protections"* (e.g., required formalities), *restrictions* (e.g., limitations on decisionmaking authority of proxies), *and preconditions*

(e.g., certification of terminal illness or permanent unconsciousness by two physicians) is unclear. Do they protect vulnerable persons or merely discourage the use of Advance Directives?

4. *The Impact of Forms and Formalities.* Mandatory forms limit flexibility and choice. Optional forms may do so indirectly. Complicated witnessing rules may discourage the completion of Advance Directives.

Consider the tyranny of formalities: the story of James Robert Rhea's death, by reporter Denise Gamino in the Austin-American Statesman, May 15, 1992.

Formalities may adversely affect the portability of Advance Directives.

5. *Portability of Advance Directive Across State Lines.* Portability involves three issues.

a. Is the document validly executed?

b. Will the specific wishes or instructions in the Advance Directive be respected in the site state if the instructions are valid in state of origin but not in site state.

c. Which state's presumptions and interpretation rules of Advance Directives applies when they differ?

6. *Emergency Medical Services Do-Not-Resuscitate Directives.* Who should be eligible, and how can they be swiftly and accurately identified by EMS personnel?

7. *Oral directives.* What is the legal status of oral instructions given by the individual to his or her physician? Should the law impose witnessing and documentation requirements on oral instructions?

8. *Patients without Surrogates.* How should decisions be made where there is no close family, friend, or other surrogate with a close relationship to the decisionally incapacitated patient?

CHRONOLOGY OF ADVANCE DIRECTIVE STATUTES

(As of January 1994)

Living Will Statutes:.	
'76– CA	1
'77– AR, ID, NV, NC, NM, OR, TX	7
'78– . . .	0
'79– KS, WA	2
'80– . . .	0
'81– AL, DC	2
'82– DE, VT	2
'83– IL, VA	2
'84– FL, GA, LA, MS, WV, WI, WY	7
'85– AZ, CO, CT, IN, IA, ME, MD, MO, MT, NH, OK, TN, UT	13
'86– AK, HI, SC	3
'87– . . .	0
'88– . . .	0
'89– MN, ND, OH	3
'90– KY	1
'91– NJ, SD	2
'92– NE, PA, RI	3
'93– . . .	0
TOTAL:	48
Health Care Power of Attorney Statutes:.	
'83– CA	1
'84– . . .	0
'85– ME, UT	2
'86– RI	1
'87– IL, NV	2
'88– AK, ID, VT	3
'89– DC, KS, NM, OH, OR, TX, VA, WA	8
'90– CT, FL, GA, KY, LA, MA, MI, MS, NY, SD, TN, WV, WI	13
'91– IN, IA, MO, NH, NJ, NC, ND, WY	8
'92– AZ, CO, HI, NE, OK, SC	6
'93– MD, MN	2
TOTAL:	46

Combined/Comprehensive ADs:	
'91– NJ	1
'92– AZ, FL, OK, VA	4
'93– MD, (CT)	2
TOTAL:	7
EMS/DNR Statutes:	
'91– IL, NY	2
'92– AZ, CO, FL, PA, RI, VA, WA	7
'93– AR, MD, MT, NM, TN, UT, WV, WY	8
TOTAL:	17

COMMUNICATIONS AND THE PATIENT SELF-DETERMINATION ACT
STRATEGIES FOR MEETING THE EDUCATIONAL MANDATE

Findings of a Working Group

November 9-10, 1992
Washington, D.C.

Sponsored by

THE ANNENBERG
WASHINGTON PROGRAM
Communications Policy Studies
Northwestern University

AACN
AMERICAN ASSOCIATION
OF CRITICAL-CARE NURSES

The Patient Self-Determination Act (PSDA) took effect in December 1991 with the goal of ensuring that each individual's right to self-determination in health care decisions be communicated and protected. The Act has three significant provisions.

First, it requires hospitals, skilled nursing facilities, home health agencies, hospice programs, and HMOs which participate in Medicare and Medicaid programs to distribute to every adult patient information describing his or her rights under State law to make decisions concerning medical care, including the right to accept or refuse medical or surgical treatment and the right to formulate advance directives (*e.g.*, a written document such as a living will or durable power of attorney). Health care providers must also document in each patient's record whether or not he or she has executed an advance directive and must provide staff and community education concerning advance directives.

The second principal provision of the Act requires that states develop a written description of their laws concerning advance directives for distribution by health care providers. Third, the Act requires the Secretary of Health and Human Services to implement a national campaign to inform the public and medical professionals of each person's right to make decisions concerning medical care, including the right to accept or refuse medical or surgical treatment, and the existence of advance directives.

STRATEGIES FOR MEETING THE EDUCATIONAL MANDATE

On November 9-10, 1992, The Annenberg Washington Program in Communications Policy Studies of Northwestern University and the American Association of Critical-Care Nurses convened a high-level working group of individuals representing nurses, physicians, ethicists, communications experts, social workers, patients, lawyers, sociologists, and researchers to accomplish three objectives:

1. Examine the principles of public information, communication, and education as they apply to the PSDA;

2. Examine existing educational models developed to implement the PSDA; and

3. Define educational and communication strategies to facilitate nationwide implementation of the Act.

The working group was moderated by Barbara A. Gill, R.N., M.N., a clinical nurse specialist and a Fellow of The Annenberg Washington Program.

This statement reflects the key issues identified by the working group. It does not necessarily reflect the views of the sponsoring organizations, individual participants, or the organizations represented. A companion volume containing the papers presented at the forum will be available from The Annenberg Washington Program. An earlier white paper, *The Patient Self-Determination Act: Implementation Issues and Opportunities*, is currently available from The Annenberg Washington Program.

Working Group Recommendations

The Working Group Recommends:

1. **Health care providers move beyond legal mandates and mere compliance with the letter of the law to treat consideration of advance directives as a process, not a single moment in time (*e.g.*, the receipt of written material or the signing of a document).**

To optimally respond, providers should plan educational initiatives for a variety of times and settings. There is a need to move away from the clinical setting, to introduce end-of-life decisions in less threatening environments, and to reach the many people who have no regular contact with health care institutions. Educational initiatives should embrace community participation.

2. **Health care providers approach advance directives from the patient or decision-maker's point of view, rather than that of a particular profession or professional.**

The complexity of self-determination requires the participation of the broadest possible array of providers as well as interdisciplinary cooperation and collaboration. Individuals must have access to the provider they are most comfortable with, whether lawyer, nurse, physician, or other professional. The information provided must be accurate, relevant, and understandable.

3. **Health care providers create systems for raising the issue of end-of-life decision-making that are sufficiently flexible and broad-based to take into account patients' different sensitivities and needs.**

Clarifying individual values, treatment decisions, and identifying the reasons for these decisions are essential ways to bring forth the intent of the law. The language used in the self-determination process, for example, must be understandable in order to promote effective dialogue among providers, health care recipients, and their significant others.

4. **Health care providers consider the interaction between patient autonomy and other values in health care delivery.**

While both autonomy and patient involvement are extremely important in health care delivery, other values must be explicitly acknowledged. For example, only medically appropriate treatment options should be offered or delivered to a patient. Advance directives should not be used to subjugate the professional judgment of nurses, physicians, and other health care professionals to the wishes of patients.

5. **Quantitative and qualitative studies are needed to analyze the relationship between motivation to establish advance directives and such factors as age, gender, culture, definitions of family, and individual values.**

It is not clear what motivates individuals to establish advance directives. Nor is it clear what motivates professionals to participate in the self-determination process.

6. **Economic issues must be addressed when educational programming for the PSDA is planned.**

Issues to be considered include cost containment by institutions, reimbursement for professional time, and financial expenses of patients and families.

7. **Professional standards for participating in the education and implementation of the PSDA must be established.**

The ongoing monitoring of the PSDA process should utilize a continuous quality improvement model.

8. **A comprehensive, ongoing informational and educational program is necessary to provide the background and support for widespread public and professional participation in the PSDA process.**

SPEAKERS AT THE FORUM

FRED H. CATE, J.D., Director of Research and Projects and Senior Fellow, The Annenberg Washington Program

MARIANNE CHULAY, R.N., DNSc, FCCM, President, American Association of Critical-Care Nurses

SUSAN H. EVANS, PH.D., Research Scientist, The Annenberg School for Communication, University of Southern California

BARBARA A. GILL, R.N., M.N., Fellow, The Annenberg Washington Program and clinical nurse specialist

JOAN KILLION, M.P.A., Director, The Community Advance Directives Project, Midwest Bioethics Center

JOHN LA PUMA, M.D., Director, Center for Clinical Ethics, Lutheran General Hospital

THE HONORABLE SANDER M. LEVIN, J.D. (D-MI), Member of the House Ways and Means Committee as well as the Health and Human Resources Subcommittees

SARAH J. SANFORD, R.N., M.N., CNAA, FAAN, Chief Executive Officer, American Association of Critical-Care Nurses

MICHAEL S. VICTOROFF, M.D., Chair, Department of Family Medicine, Aurora Presbyterian Hospital

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The American Association of Critical-Care Nurses is the world's largest specialty nursing organization with almost 80,000 members and 270 chapters worldwide. It is dedicated to the implementation of a patient driven health care system where critical-care nurses make their optimal contribution. With its wide ranging and well known education programs and its ever-increasing ability to provide scholarships and research grants, the association has directed all of its efforts to the realization of this vision.

The Annenberg Washington Program in Communications Policy Studies of Northwestern University provides a neutral forum, open to diverse opinion, for assessing the impact of communications technologies and public policies. The Program serves as a bridge between policymakers, industry officials, academics, the press and the public.

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DAVID M. ENGLISH,
University of South Dakota, School of Law, May 3, 1994.

Senator JOHN C. DANFORTH
U.S. Senate,
Washington, DC

Re: Hearing on PSDA

Dear Senator Danforth: This letter and the enclosed article is submitted for the record for the May 5 hearing on the Patient Self-Determination Act.

While the PSDA is a federal statute, it seeks to effectuate rights under advance directives, which are creatures of state law. The recently approved Uniform Health-Care Decisions Act, if enacted by the states, will dramatically change the state law on advance directives. This new act was approved by the Uniform Law Commissioners last August, and by the American Bar Association this February. It has also been endorsed by AARP. I served as the Reporter for the Act and was responsible for much of the drafting. Like the PSDA, the primary purpose of this new Uniform Act is to facilitate the making of advance directives.

The following are some highlights of the Act:

—The Act is comprehensive and addresses topics now usually dealt with by separate statue.

Unlike the statutes in most states, the Health-Care Decisions Act covers the subject of advance directives in one place, avoiding a piecemeal approach.

—The Act does not attempt to legislate restrictions on the withholding of life-sustaining treatment.

While the questions of when life-sustaining treatment may be withdrawn is an issue for serious consideration, attempts by the states to legislate in this area have failed. The complex definitions of the categories of patients for whom life-sustaining treatment may be withheld or withdrawn have turned many state statutes into virtual nullities. The Health-Care Decisions Act does not attempt to repeat this failure. It instead leaves the question of withdrawal of life-sustaining treatment where it belongs—with the patient, family, physicians, and the standards of medical ethics.

—The Act keeps execution requirements to an absolute minimum.

The execution requirements for an advance directive in most states are both cumbersome and confusing, requirements that deter the use of this important device. Under the Health-Care Decisions Act, these requirements are largely eliminated. A power of attorney for health care need only be signed. A patients instruction as to future care may be either written or oral.

The Act contains many other provisions other than those summarized above. For a fuller treatment, enclosed is an article I have written, "The Health-Care Decisions Act Represents A Major Advance" which appeared in the May issue of Trusts & Estates.

I hope this letter and the enclosed are of assistance for your upcoming hearing.

The Uniform Laws

The Health-Care Decisions Act Represents A Major Advance

While prospects for a quick and widespread enactment are uncertain, it will likely prove an influential model for many years to come

By **DAVID M. ENGLISH**
University of South Dakota
Vermillion, SD

Planning for health-care decision-making has become a significant component of the estate planning practice in recent years. This increased attention has been fueled by a variety of factors, with changing demographics perhaps being the most important. The number of individuals over age 65 is increasing each year, and the number over age 85 is increasing at an even more rapid rate. But America's population is not aging well. People are living longer but more often in a condition of chronic disability.

Some well-publicized cases also have focused attention on the issue. The widespread interest in living Wills may be traced to the seminal case of *In re Quinlan*,[1] and an increased interest in advance directives generally was fueled by the Supreme Court's ruling in *Cruzan*.[2]

This increase in public interest has led to a flurry of state legislation. *Quinlan* spurred the widespread enactment of living Will statutes, with all but three states now having such legislation on the books.[3] *Cruzan* led to a rapid increase in the number of power of attorney for health care statutes, a device now authorized in all but two states.[4] Furthermore, more than 30 states have enacted statutes allowing family members and, in some instances, close friends to make health-care decisions for individuals who lack capacity.[5]

The state legislation has been a mixed blessing, however. Many of the health-care statutes, while enacted for the purpose of facilitating the making of advance directives, may actually inhibit their use. The execution requirements are often formidable. Restrictions on the types of treatment, which may be withheld or withdrawn, are common. There is little uniformity. The result is a system of legislation that is fragmented, incomplete, and often inconsistent, both among states and even within states.

The Uniform Health-Care Decisions Act, if enacted by the states, would bring order to the present chaos. The primary purpose of the Act, which was approved by the Uniform Law Commissioners in August, 1993, and by the ABA House of Delegates in February, 1994, is to facilitate the making of advance directives. The Act is comprehensive, addresses decisionmaking for those who fail to plan, and eliminates many of the restrictions. It is an Act that is congenial to estate planners, many of whom played a major role in its drafting.[6] Comprehensive articles on the Act will appear elsewhere.[7] The purpose of this article is to describe the Act's innovative features as compared to the existing state legislation.

The Act is comprehensive and addresses topics now usually dealt with by separate statute. While most states have legislation recognizing living Wills, powers of attorney for health care, and a decisionmaking role for the family, the states have usually addressed these topics by separate statute, often in piecemeal fashion. A new approach is beginning to emerge, however. Instead of enacting separate living Will and power of attorney for health care statutes, states are beginning to move toward a combined approach. The 1991 New Jersey statute, for example, governs the creation of both living Wills (referred to as "instruction directives") and powers of attorney for health care (referred to as "proxy directives").[8] The more recently enacted acts in Arizona, Florida, Maryland and Virginia cover in one place not only living Wills and powers of attorney for health care but family decisionmaking as well.[9]

The Uniform Health-Care Decisions Act builds on this trend. Under the Act, any adult or emancipated minor may give an "advance health-care directive," which refers to

either a "power of attorney for health care" or an "individual instruction."[10] Like the New Jersey statute, the Uniform Act deliberately avoids the term "living Will," the drafters concluding that "individual instruction" is more accurate and less confusing.

Should an individual fail to execute a power of attorney for health care or should the agent not be available, the Uniform Act authorizes health-care decisions to be made by a "surrogate," to be selected from a priority list.[11]

The Act, while comprehensive, does not address all conceivable issues. In recent years, many states have begun to address the thorny issue of whether and under what circumstances emergency medical services personnel may recognize do-not-resuscitate orders. The Uniform Act includes do-not-resuscitate orders within the definition of "health-care decision,"[12] and, by extension, authorizes an individual, or his or her agent or surrogate, to give such an order. However, detailed protocols and protections are needed to guide and protect EMS personnel in withholding resuscitation. Given that state legislatures have only begun to tackle this issue, the drafters concluded that it would now be premature to attempt to codify protocols or guidelines in model legislation.[13]

The Act also does not address health-care decisionmaking for unemancipated minors. To have covered the full range of healthcare decisions for unemancipated minors, including the effect of differing parental and custodial arrangements and levels of maturity, would have made the Act unwieldy. However, the drafting committee did recommend that the Commissioners consider developing a separate uniform act on this topic.

The Act does not attempt to legislate restrictions on the withholding or withdrawal of life-sustaining treatment. A majority of the existing power of attorney for health care statutes permit a principal to delegate to an agent the authority to make all health-care decisions. Although held to a standard of care, the agent may act for the principal regardless of the nature of the principal's condition or the type of treatment in question.[14]

The living Will statutes are another matter. The complex definitions of the categories of patients for whom life-sustaining treatment may be withheld or withdrawn, and the prohibitions against the withdrawing or withholding of certain forms of treatment, have rendered many of these statutes into virtual nullities. Prompted by *Cruzan*, a number of living Will statutes have recently been liberalized. Withdrawal or withholding of treatment is permitted not only from patients in a "terminal condition," but also from patients in conditions of "permanent unconsciousness."[15] But while many of the living Will statutes are now less restrictive, a major effect of the recent amendments is to add yet another layer of definitions requiring interpretation.

The drafters of the Uniform Act concluded that the attempts to statutorily prescribe the circumstances when life-sustaining treatment may be withheld or withdrawn unduly restrict, are difficult to apply in a clinical setting, and provide an appearance of precision where none is possible. Under the Act, there are no restrictions. An individual instruction and the authority which may be granted to an agent may extend to all "health-care decisions," a term which is expansively defined to include such matters as approval or disapproval of orders not to resuscitate, and directions to provide, withhold, or withdraw artificial nutrition and hydration and other forms of health care.[16]

While no restrictions are prescribed, certain principles of law and medical practice will impose limits, although indirectly. The Act authorizes the provision, withholding, or withdrawal of health care only to the extent not prohibited by other statutes of the state.[17] Furthermore, a health-care provider or institution may decline to comply with an individual instruction or health-care decision that requires medically ineffective health care or health care contrary to generally accepted health-care standards.[18] Finally, agents and surrogates are subject to a standard of care. An agent or surrogate may not act contrary to the principal's or patient's express wishes, and must otherwise act in the principal's or patient's best interest.[19]

The Act minimizes execution requirements. The execution requirements for an advance directive in most states are both cumbersome and confusing. A substantial majority of the living Will statutes require two witnesses, but Minnesota and New Jersey permit either witnessing or acknowledgment, and South Carolina requires both witnessing and acknowledgment.[20] There is greater variation among the power of attorney for health care statutes. Some statutes require only the principal's signature.[21] Other statutes follow the living Will model by requiring two witnesses.[22] Finally, some statutes require that the power be either witnessed or acknowledged at the principal's option, others that it be both witnessed and acknowledged.[23]

A majority of the living Will and power of attorney for health care statutes also impose witness qualification rules. Some of these lists are quite lengthy. Included on the lists of various states are relatives, in-laws, intestate heirs, Will beneficiaries, creditors, the designated agent, health care providers, and nursing home operators and employees. Under some statutes, the advance directive is invalid if either witness is from one of the proscribed classes. But under other statutes, a prohibited person may act as long as the other witness is independent.[24]

The drafters of the Uniform Act concluded that the cumbersome execution requirements found under many state statutes have done little to deter fraud or prevent overreaching. Rather, their primary effect is to deter the making of advance directives and to invalidate defectively executed directives that otherwise would be reliable indicators of the individual's intent. Consequently, to facilitate the making of advance directives, the Act keeps execution requirements to an absolute minimum. A power of attorney for health care must be written and signed, but need not be witnessed or acknowledged.[25] An individual instruction may be either written or oral.[26]

The statutory recognition of an oral instruction, while relatively rare, is found in both the 1992 Virginia and 1993 Maryland acts.[27] Oral instructions are frequent in clinical practice. Furthermore, case law, the Uniform Act itself, and the statutes in many states require agents and surrogates to honor the principal's and patient's express wishes, which may include oral instructions. It seems nonsensical to require an agent or surrogate to honor an oral

instruction while at the same time denying statutory recognition to an oral instruction given directly to a health-care provider.

The 1993 Maryland act goes even further by authorizing an individual to orally designate an agent.[28] The Uniform Act does not go quite this far. But as described below, the act does allow an individual to orally designate a surrogate.[29]

The Act contains one combined form. The use of statutory forms provide a number of benefits. First, because the form is standard and widely available, individuals who might not otherwise seek professional help may be more inclined to execute an advance directive. Second, the availability of an officially sanctioned form will reduce the reluctance of health-care providers to honor a directive. Furthermore, through continued use providers will hopefully become more familiar with the form's provisions and make more informed decisions.

Nearly all living Will statutes include statutory forms,[30] as do a growing number of power of attorney for health care statutes.[31] The enactment by most states of separate living Will and power of attorney for health care statutes has, perhaps not surprisingly, resulted in the enactment of separate statutory forms. Recently, however, states have begun to enact a combined form, one that allows an individual to both designate an agent and give instructions. The 1993 Connecticut and Oregon acts are notable examples.[32]

The Uniform Act, like Connecticut and Oregon, includes a combined form.[33] Unlike Oregon,[34] however, use of the form is entirely optional. An individual is also free to omit or modify any part of the form. Making the form optional is consistent with the principle of patient autonomy, one of the driving forces behind the Act. It is also of particular importance to adherents of certain religions, such as Christian Science, whose special views would not otherwise be accommodated.

The power of attorney appears first on the form to ensure to the extent possible that it will come to the attention of a casual reader. This reflects the reality that the appointment of an agent is a more comprehensive approach to the making of health-care decisions than is the giving of an individual instruction, which cannot possibly anticipate all circumstances which might arise.

Like most well-drafted attorney forms, space is provided for the individual to designate up to two alternate agents. Furthermore, the agent and alternate agents are automatically nominated to act as guardians, in their order of priority, should the need for guardianship of the person arise. The purpose of this provision is not to encourage the use of guardianship, but to prevent others from using guardianship as a device to thwart the agent's authority. This defense is further buttressed by the Act's provision that a guardian may not revoke an agent's authority without express approval of the appointing court.[35]

More unusual is the provision providing a box to check should the individual wish the authority of the agent to become effective immediately upon execution. Under the Act, while the authority of an agent generally becomes effective only upon a determination that the principal lacks capacity, the principal is free to provide in the power that the authority of the agent becomes effective immediately or upon the happening of some other event.[36]

Because the variety of treatment decisions to which individual instructions may relate is virtually unlimited, the instructions part of the form does not attempt to be comprehensive but is directed at the types of treatment for which an individual is most likely to have special wishes. Space is provided for the individual to express special wishes regarding the provision of pain relief. In addition, artificial nutrition and hydration is to be treated like other forms of health care unless the individual checks a box. Most importantly and most problematical to draft, the form contains language specifying the circumstances when treatment may be withheld or withdrawn.

Two choices are provided, a "Choice Not To Prolong Life," and a "Choice to Prolong Life." The "Choice to Prolong Life" is designed for those wishing maximum treatment. The "Choice Not To Prolong Life" will be the option far more frequently selected. Because the concept of the living Will has become so ingrained, the drafters concluded that it was appropriate to specify in this choice that the individual's life not be prolonged in the event of a "terminal condition" or "condition of permanent unconsciousness," although those precise terms were not used. Limiting withdrawal or withholding of treatment to these two categories, however, would have codified in the statutory form the very restrictions which the drafters had deliberately avoided in the statutory text. Consequently, the drafters added a third more flexible option. Treatment may also be withheld or withdrawn if "the likely risks and burdens of treatment would outweigh the expected benefits." This test is well known to the courts and is one which was advocated in an influential 1983 report of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research.[37]

The form also includes space for an individual to express an intent to make an organ or tissue donation. It is included here because an advance directive is far more likely to be noticed than is a donor card, which rarely comes to light when the need arises.

Finally, the form provides space for an individual to designate his or her "primary physician." The Act specifically avoids use of the term "attending physician," which could be understood to refer to the physician currently providing treatment to the individual, and not to the physician whom the individual would select. Among the functions of an individual's primary physician is the determination of whether the individual has capacity to make his or her own health-care decisions.[38]

The Act contains a comprehensive provision on the authority of surrogates. Despite the wider use of powers of attorney for health care and living Wills, families will continue to play an important role in the making of health-care decisions for an incapacitated relative. A substantial majority of individuals fail to execute advance directives. For these individuals, recourse to the family may be the only realistic method for assuring continuity in decisionmaking. Guardianship is an available option, but the appointment of a guardian is an expensive and cumbersome process that is often ill-suited to the making of health-care decisions, particularly when time may be of the essence.

The traditional reliance of health

providers on the family, however, is often based on little more than medical custom. While there is a recent and growing body of judicial precedent validating a role for the family,[39] many states have no decision on point, and few of the cases address the issue of priority. Perhaps due to these uncertainties, a growing number of states — over 30 to date — have enacted statutes to validate a role for the family.[40]

Most of the statutes tend to be quite limited in scope. The New York statute, for example, applies only to decisions to administer or withhold cardiopulmonary resuscitation.[41] Many others address only the withdrawal or withholding of lifesustaining treatment.[42] Other statutes empower the family to consent to treatment and apply to decisionmaking from the onset of incapacity but fail to specifically address withdrawal or withholding of lifesustaining treatment.[43]

Priority

A substantial majority of the statutes, however, do address the issue of priority. The better and growing approach is to recognize that the family may act only if no guardian or agent has been appointed or is available.[44] Should no agent or guardian be available, the statutes empower the spouse to make the decision. Adult children come next, usually followed by parents. Nontraditional relationships are not generally recognized, but this is beginning to change. Many recent statutes place "close friends" on the list, although normally at the bottom.[45] More significantly, Arizona grants a "domestic partner" a fourth priority, although it failed to define the term.[46]

Section 5 of the Uniform Act, the surrogacy provision, addresses the role of the family and close friends, and responds at least in part to the concerns of those in non-traditional relationships. The section is comprehensive. A surrogate is empowered to make all "health-care decisions" for the affected individual. The right of a surrogate to act is triggered by a determination that the patient lacks capacity to make his or her own health-care decisions. Not all patients are covered, however. A surrogate may make a health-care decision only for an adult or emancipated minor for whom no agent or guardian has been appointed or whose agent or guardian is not reasonably available.[47]

Controversy Developed

The Act, like a majority of the state statutes, prescribes a priority list for who may act as surrogate. Developing the list proved to be quite controversial, however. A majority of the drafting committee concluded that the priority list should consist of specified family members, with the patient's close friends trailing at the end. A majority of the Commissioners thought otherwise, however, and overruled the drafting committee.

The commissioners concluded that a priority list based primarily on closeness of family relationship does not necessarily reflect reality. Unmarried individuals in cohabiting relationships, for example, are much more likely to prefer that their companions act on their behalf. For this reason, appearing first on the priority list is a new type of decisionmaker, the orally designated surrogate. This is to be distinguished from an agent, who can only be appointed in writing signed by the principal, but the function is largely the same. But because of the risk of miscommunication of an individual's oral statement, some reliability of proof is required. An individual may designate a surrogate only by personally informing his or her supervising health-care provider.[48] The health-care provider is then in turn obligated to record the designation in the individual's health-care record.[49] While the Commissioners recognized that written powers of attorney are preferred, they also recognized that many individuals will quite simply fail to prepare the necessary document. Furthermore, oral designations of decisionmakers occur with some frequency in clinical practice.

If an individual has not designated a surrogate, or if the designee is not reasonably available, a rather standard family list is followed: the spouse, followed by an adult child, followed by a parent, followed by an adult brother or sister.[50] Should all classes of family members decline to act or otherwise not be reasonably available, a health-care decision may be made by another relative or friend who has exhibited special care and

concern for the patient and who is familiar with the patient's personal values.[51]

The Uniform Act is in general to be effectuated without litigation, and the surrogacy provision is no exception. A healthcare decision made by a surrogate is effective without judicial approval.[52] Because a surrogate is not usually selected by the patient, however, there has been no consent, expressed or implied, to this informality. Some system of review is appropriate. The Act relies on notice. Upon his or her assumption of authority, a surrogate must communicate that fact to the members of the patient's family who might otherwise be eligible to act as surrogate.[53] Notice to the family will enable them to follow health-care developments with respect to their now incapacitated relative. It also will alert them to take appropriate action should the need arise.

Conclusion

The Uniform Health-Care Decisions Act is not the Commissioners' first venture into the field of health-care decisionmaking. But the previous acts were quite limited in scope. The 1982 Commissioners' Model Health-Care Consent Act[54] focused primarily on the authority of the family to make health-care decisions. The Uniform Rights of the Terminally Ill Act, in both its 1985[55] and 1989 versions,[56] focused exclusively on the withdrawal or withholding of life-sustaining treatment.

The Health-Care Decisions Act represents a major advance over existing law and the prior uniform acts. It is comprehensive: it facilitates the giving of advance health-care directives; it addresses decisionmaking for those who have failed to plan; and it eliminates many of the restrictions. While its prospects for quick and widespread enactment are uncertain, it will likely prove an influential model for many years to come. ◊

FOOTNOTES

1. 355 A.2d 647 (N.J. 1976).

2. *Cruzan v. Director*, Mo. Dept. of Health, 497 U.S. 261 (1990).

3. For a list, see Alan Meisel, The Right to Die Table 11-1 (Supp. 1993) (hereinafter The Right to Die). The exceptions are Massachusetts, Michigan, and New York.

4. The Right to Die Table 10A-1. The exceptions are Alabama and Montana.

5. The Right to Die Table 8-1.

6. Willard H. Pedrick, of Tempe, Arizona, served as Reporter from August, 1991 to August, 1992. I served as reporter from August, 1992, until completion. James N. Zartzman, of Chicago, Illinois, served as ABA Co-Advisor. Francis J. Collin, Jr., of Napa, California, served as Advisor from the ABA Section of Real Property, Probate and Trust Law. Harley J. Spitler, of San Francisco, California, served as Observer for the State Bar of California. Section of Estate Planning, Trust and Probate Law. The Act was unanimously endorsed by the Supervisory Council of the ABA Section of Real Property, Probate and Trust Law, at its October, 1993, meeting.

7. *See* David M. English & Alan Meisel, *The Uniform Health-Care Decisions Act*, 21 Est. Plan. (forthcoming 1994).

8. *See generally* N.J. Stat. Ann. Secs. 26:2H-53 to 26:2H-78 (West Supp. 1993).

9. *See generally* Ariz. Rev. Stat. Ann. Secs. 36-3201 to 36-3262 (1993); Fla. Stat. Ann. Secs. 765.101 to 765.401 (West Supp. 1993); Md. Health-Gen. Code Ann. Secs. 5-601 to 5-618 (1994); Va. Code Ann. Secs. 54.1-2981 to 54.1-2993 (Michie Supp. 1993).

10. Unif. Health-Care Decisions Act ("UHCDA") Sec. 1(1).

11. *See* UHCDA Sec. 5, and *infra* notes 39-53 and accompanying text.

12. UHCDA Sec. 1(6).

13. The first state statutes addressing the honoring of do-not-resuscitate orders by EMS personnel were enacted in 1991 in Illinois and New York. See 210 Ill. Comp. Stat. Ann. 50/10.8 (Smith-Hurd 1993); N.Y. Pub. Health Law Secs. 2960 to 2979 (McKinney 1993). As of January, 1994, 17 states have enacted legislation on this topic, most frequently authorizing a state agency such as the department of health to develop protocols. *See Choice in Dying, Statutes Authorizing Surrogate Decisionmaking*, Right-to-Die Law Digest (Dec. 1993).

14. For a discussion, see David M. English, *The UPC and the New Durable Powers*, 27 R. Prop. Prob. & Tr. J. 333, 395-400 (1992).

15. *See, e.g.*, Cal. Health & Safety Code Sec. 7186(e) (West Supp. 1994) ("permanent unconscious condition"); Haw. Rev. Stat. Sec. 327D-2 (1991) ("persistent vegetative state ... deep coma"); La. Rev. Stat. Ann. Sec. 40:1299.58.2(10) ("profound comatose state") (West 1992); Tenn. Code Ann. Sec. 32-11-103(9) (Supp. 1993) ("coma or persistent vegetative state").

16. UHCDA Sec. 1(6).

17. UHCDA Sec. 13(c).

18. UHCDA Sec. 7(f).

19. UHCDA Sec. 2(e), 5(f).

20. Minn. Stat. Ann. Sec. 145B.03(2)(a) (West Supp. 1994); N.J. Stat. Ann. Sec. 26:2H-56 (West Supp. 1993); S.C. Code Ann. Sec. 44-77-40 (Law Co-Op. Supp. 1993).

21. *See, e.g.*, 755 Ill. Comp. Stat. Ann. 45/4-10 (Smith-Hurd 1992).

22. *See, e.g.*, N.Y. Pub. Health Law Sec. 2981(2) (McKinney 1993).

23. *See, e.g.*, Nev. Rev. Stat. Sec. 449.840(1) (1991) (witnessing or acknowledgment); N.C. Gen. Stat. Sec. 32A-16(3) (1993) (witnessing and acknowledgment).

24. For the witness disqualification rules, see David M. English, *supra* note 14, at 369-72 (power of attorney for health care statutes); The Right to Die Sec. 11.9 (1989 & Supp. 1993) (living Will statutes).

25. UHCDA Sec. 2(b).

26. UHCDA Sec. 2(a).

27. See Va. Code Ann. Sec. 54.1-2983 (Michie Supp. 1993); Md. Health-Gen. Code Ann. Sec. 5-602(d) (1994).

28. Md. Health-Gen. Code Ann. Sec. 5-602(d) (1994).

29. See UHCDA Sec. 5(b), and *infra* notes 39-53 and accompanying text.

30. The exceptions include Delaware, New Mexico and Ohio.

31. According to research conducted by Charles P. Sabatino, Assistant Director of the ABA Commission on Legal Problems of the Elderly, 36 states and the District of Columbia as of 1/1/94 had statutory forms in their power of attorney for health care statutes.

32. Act approved June 29, 1993, P.A. 93-407, 1993 Conn. Legis. Serv. 1323 (West). Act approved Aug. 31, 1993, ch. 767, 1993 Or. Laws.

33. UHCDA Sec. 4.

34. Use of the Oregon form is mandatory.

35. UHCDA Sec. 6(a).

36. UHCDA Sec. 2(c).

37. For a discussion of the cases and the President's Commission report, *see* The Right to Die Secs. 4.17, 9.27-9.32 (1989 & Supp. 1993). The following is the relevant portion of the form:

> (6) END-OF-LIFE DECISIONS. I direct that my health-care providers and others involved in my care provide, withhold, or withdraw treatment in accordance with the choice I have marked below:
>
> [ ] (a) Choice Not to Prolong Life
>
> I do not want my life to be prolonged if (i) I have an incurable and irreversible condition that will result in my death within a relatively short time, (ii) I become unconscious and, to a reasonable degree of medical certainty, I will not regain consciousness, or (iii) the likely risks and burdens of treatment would outweigh the expected benefits, or
>
> [ ] (b) Choice To Prolong Life
>
> I want my life to be prolonged as long as possible within the limits of generally accepted health-care standards.

38. UHCDA Secs. 2(d), 5(a).

39. See Judith Areen, The Legal Status of Consent Obtained from Families of Adult Patients to Withhold or Withdraw Treatment, 258 J. Am. Med. Ass'n 229 (1987).

40. For a list, see The Right to Die Table 8-1 (Supp. 1993).

41. N.Y. Pub. Health Law Sec. 2965(2) (McKinney 1993).

42. *See, e.g.*, Unif. Rights of the Terminally Ill Act (1989) Sec. 7, 9B U.L.A. 122 (1993 Supp.).

43. *See, e.g.*, S.D. Codified Laws Sec. 34-12C (Supp. 1993).

44. *See, e.g.*, 755 Ill. Comp. Stat. Ann. 40/25(a) (Smith-Hurd 1992).

45. See, e.g., Fla. Stat. Ann. Sec. 765.401(1)(g) (West Supp. 1993); 755 Ill. Comp. Stat. Ann. 40/25(a)(7) (Smith-Hurd 1992).

46. *See* Ariz. Rev. Stat. Ann. Sec. 36-3231(A)(4) (1993).

47. UHCDA Sec. 5(a).

48. UHCDA Sec. 5(b).

49. UHCDA Sec. 7(b).

50. UHCDA Sec. 5(b).

51. UHCDA Sec. 5(c).

52. UHCDA Sec. 5(g).

53. UHCDA Sec. 5(d).

54. 9 U.L.A. (Pt. 1) 453 (1985).

55. 9B U.L.A. 609 (1987).

56. 9B U.L.A. 109 (1993 supp.).

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Forum on Health Law — American Bar Association

THE HEALTH LAWYER

Patient Care Issues

The Patient Self-Determination Act: Implementation Issues and Opportunities

Fred H. Cate and Barbara A. Gill[1]

More and more it is arguable that we play God by subjecting people to unwanted and sometimes unnecessary treatment, treatment that unnaturally prolongs the dying process. Our health care system has become obsessed with extending life, at times neglecting the caring component of medicine and trampling on the rights of patients.

— Senator John C. Danforth (R-Mo.)

The Patient Self-Determination Act

Experts estimate that approximately 10,000 Americans currently exist in a persistent vegetative state. The majority of people in this country will at some point during their lifetimes be unable to participate in medical treatment decisions affecting their own care. Chronic or degenerative ailments have replaced infectious diseases in this century as the primary cause of death in the Western world. According to medical ethicist Joseph Fletcher, 80 percent of Americans who die in hospitals are "likely to meet their end . . . 'in a sedated or comatose state; betubed nasally, abdominally and intravenously; and far more like manipulated objects than like moral subjects.' "[2]

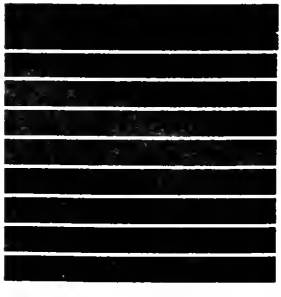
As the baby-boom generation ages and medical technology continues to develop, more and more people will at some point during their lifetimes be incapacitated. This is not a problem only for the elderly: Nancy Cruzan was only 25 when tragedy struck. Knowing these facts, it would seem unavoidable that every person in the United States, regardless of age, should have the meaningful opportunity to make some provision for decision-making about his or her health care in the likely circumstance that he or she is incapacitated.

This is the intent of the Patient Self-Determination Act[3]. The Act, Senate Bill 1766, was introduced in the Senate in October 1989 by Senators John C. Danforth (R-Mo.) and Daniel Patrick Moynihan (D-N.Y.). Rather than legislatively create rights for patients to make health care decisions even if unconscious or incapacitated, the bill reflected a bipartisan effort to assure that patients are given information about the extent to which those rights already exist under applicable state law. As stated in the Act itself, the goal is "to ensure that a patient's right to self-determination in health care decisions be communicated and protected." The bill passed the Senate—and a companion bill passed the House of Representatives—as part of the deficit reduction package and with little comment from either legislators or the press. It was signed into law by President Bush on November 5, 1990. The Act has four significant provisions.

Obligations of Certain Health Care Providers

First, the Act requires hospitals, skilled nursing facilities, home health

(continued on page 3)



agencies, hospice programs and HMOs, which participate in Medicare and Medicaid programs, to maintain written policies and procedures guaranteeing that every adult receiving medical care be given written information concerning patient involvement in treatment decisions. Specifically, the information must describe (i) "an individual's rights under State law (whether statutory or as recognized by the courts of the State) to make decisions concerning such medical care, including the right to accept or refuse medical or surgical treatment and the right to formulate advance directives" (defined as a written document such as a living will or durable power of attorney); and (ii) "the written policies of the provider or organization respecting the implementation of such rights."

This written information must be provided by hospitals "at the time of the individual's admission as an inpatient," by nursing facilities "at the time of the individual's admission as a resident," by a home health agency "in advance of the individual coming under the care of the agency," by a hospice program "at the time of initial receipt of hospice care," and by an HMO "at the time of enrollment of the individual."

In addition to distributing this written information, the health care provider must also document in each patient's medical record whether or not he or she has executed an advance directive. Health care providers are forbidden to "condition the provision of care or otherwise discriminate against an individual based on whether or not the individual has executed an advance directive."

The Act's second principal provision requires the health care providers enumerated above "to provide (individually or with others) for education for staff and the community on issues concerning advance directives." The Act notes, however, that it is not intended to "prohibit the application of a State law which allows for an objection on the basis of conscience for any health care provider or any agent of such provider which, as a matter of conscience, cannot implement an advance directive."

Obligations of States

The third principal provision of the Act requires that states "develop a written description of the law of the State (whether statutory or as recognized by the courts of the State) concerning advance directives that would be distributed by providers."

Obligations of the Secretary of Health and Human Services

The fourth and final significant provision of the Act requires the Secretary of Health and Human Services, "no later than 6 months after the date of enactment of this section, [to] develop and implement a national campaign to inform the public of the option to execute advance directives and of a patient's right to participate and direct health care decisions." This section of the Act also requires the Secretary to "develop or approve nationwide informational materials that would be distributed by the providers . . . to inform the public and the medical and legal profession of each person's right to make decisions concerning medical care, including the right to accept or refuse medical or surgical treatment, and the existence of advance directives." The Secretary is also required to work with the states in preparing material describing applicable state law, to mail information to Social Security recipients, and to add a description of the new law to the Medicare handbook.

In summary, the Act focuses on education and communication, not the creation or modification of substantive legal rights. Each state must provide information about its laws which govern advance directives. Each health care provider receiving Medicare or Medicaid funds must assure that such information is distributed on a timely basis, along with information on the institution's own policies regarding implementation of advance directives. The health care provider must also assure that each patient's medical record reflects whether he or she has completed a living will or designated a proxy decision-maker. Finally, while covered health care providers must provide education for their staffs and the community at large, the Secretary of Health and Human Services is required to develop and implement a nationwide education campaign and appropriate information materials.

The Legal Instruments for Advance Health Care Decision-Making

The Patient Self-Determination Act defines "advance directive" as "a written instruction, such as a living will or durable power of attorney for health care, recognized under State law . . . and relating to the provision of such care when the individual is incapacitated." There are three general types of legal instruments currently available that meet the Act's definition.

Living Wills

The most widely available instrument for recording future health care-related decisions is the living will. The District of Columbia and all but five states have enacted living will statutes, under which a competent adult may prepare a document providing direction as to his or her medical care if he or she is incapacitated or otherwise unable to make decisions personally. Courts in other states—such as New York—have authorized the use of living wills in the absence of action by state legislatures. Only Massachusetts, Michigan, Nebraska and Pennsylvania have apparently made no provision for living wills.

Though legally available in almost every jurisdiction and widely

supported by both health professionals and the public—95 percent of those asked in one recent survey reported that they would like some form of advance directive—living wills have thus far had apparently little impact in clinical practice. As of 1987 only nine percent of Americans had completed a living will. More recent data suggest that as many as 15 percent of the public may have some form of advance directive. But even for that small percentage, the effectiveness of most living wills is significantly diminished by at least three factors. First, many living wills, particularly older ones, use vague and ambiguous language (referring, for example, to "heroic measures"). Second, health care teams seldom ask and are rarely told whether their patients have living wills.

Finally, there is substantial confusion in many states about the scope of living wills—when do they apply and may they be used to justify withholding or withdrawal of nutrition and hydration? It is not clear in those states which provide for living wills whether a form other than that provided in that state's living will statute is valid. Moreover, in a number of states, living will laws may conflict with health proxy laws, apparently giving a health proxy greater rights than the patient himself or herself would have been permitted to exercise. After the Supreme Court's decision in *Cruzan*, there is substantial doubt whether a living will may be restricted by state law from applying to nutrition and hydration, but the issue remains unresolved.

Durable Power of Attorney/Health Care Proxy

A general durable power of attorney enables any competent individual to name someone to exercise decision-making authority, under specified circumstances, on his or her behalf. All states and the District of Columbia provide for a general durable power of attorney. The District of Columbia and all but seven states—Alabama, Alaska, Arizona, Hawaii, Maryland, Nebraska and Oklahoma— have gone further to provide for powers of attorney specifically for health care decision-making. Under these provisions, the state authorizes the appointment of an individual specifically to make personal health care-related decisions for another person who is incapacitated. Many state legislatures have adopted forms, which include specific choices for the conditions under which life-sustaining treatment may be withdrawn; or an individual may specify different conditions altogether. The individual who may be appointed to exercise the power of attorney is usually a spouse, parent, adult child or other adult.

Durable powers of attorney have actually had limited impact with regard to life-support decisions. The proxy decision-maker may not be known to the physician. The decision-maker may not—in fact, studies suggest, frequently does not—know what the person for whom the decision is being made would want in a specific situation. Drs. Linda and Ezekiel Emanuel write: "Furthermore, the proxy's ethical and psychological burden may be overwhelming." In the context of withdrawal of life-support, the willingness to act "decreases from 70% to 46% when the decision is not for oneself but rather for a relative."[4]

Advance Care Medical Directive

A third option for advance health care decision-making is the medical directive, a hybrid of the living will and the durable power of attorney. Under a medical directive an individual, in consultation with his or her physician, relatives or other personal advisors, provides precise instructions for the type of care he or she does or does not want in a number of scenarios. The individual may also use the medical directive to appoint a proxy decision-maker to help interpret the application of the specific instructions or fill in unanticipated gaps. The directive then becomes part of the patient's permanent medical record.

Medical directives have limitations: they may be more time-consuming to complete, and they are more likely to require the assistance of a medical expert. Some people, such as the 34 million Americans without health insurance, do not have regular contact with medical professionals; many others are likely to find such personal discussions difficult or uncomfortable. On the other hand, precisely because of the need for the participation of a health care professional in this discussion, medical directives are far more specific, and someone—a nurse, physician, relative or friend—is more likely to know of the document's existence if and when it is needed.

Implementation of the Patient Self-Determination Act

The Patient Self-Determination Act's requirements became binding on health care provider organizations receiving Medicare or Medicaid funding on December 1, 1991, without further action by the Secretary of Health and Human Services or other federal or state officials. The precise requirements for implementation, however, are not clear from the text of the Act itself; fair and equitable enforcement of the Act is therefore impossible until those requirements are specified.

It is reported that the Health Care Financing Administration, the division of the Department of Health and Human Services that is responsible for administering the Medicare and Medicaid system, is preparing implementation regulations, but it has yet to release any drafts. As a result, though health care providers covered by the Act will be required to comply with its terms, specific compliance and enforcement of that compliance will be impossible.

In addition, the Act burdens each state with providing a written summary of its laws governing

advance directives. The majority of states apparently did not meet the December 1st deadline. Similarly, because the Act contains no provision for funding, the Department of Health and Human Services itself has not met its other obligations under the Act, to work with states in developing those materials and to develop a nationwide educational program.

The slow response of the Department of Health and Human Services and many states has not been reflected by most of the non-governmental entities who are subject to the Act. On the contrary, the Act has sparked a wide variety of energetic and creative responses by both health care providers and professional organizations. The following provides a brief summary of the broad variety of *types* of responses to the Act.

Individual Health Care Provider Responses

Based on a sample of 219 U.S. hospitals prior to passage of the Patient Self-Determination Act, the American Hospital Association reports that 67 percent had a formal policy regarding advance directives; but only four percent of hospitals routinely asked patients if they had an advance directive. With passage of the Act, of course, both of those figures are certain to change: all hospitals receiving Medicare or Medicaid funding will be required both to have a policy regarding advance directives and, as part of that policy, to ask every patient upon admission whether he or she has completed an advance directive.

Although this change may seem simple to accomplish, implementation of the Act by hospitals and other health care providers poses many practical, medical, legal and ethical issues, many of which are detailed in the next section. Within institutional health care settings, these issues are addressed and managed through *institutional protocols*. The goal of these protocols, like all institutional protocols, is to assist staff in making rational and consistent decisions regarding patient care, particularly in the face of complex issues and relationships. In most basic terms, these protocols state the policy of the institution and identify who within the institution is responsible for doing what to whom, how those actions must be documented, and how they are related to other institutional protocols. Protocols focus on *how* a decision is to be made or policy carried out, not on the *substance* or the *outcome* of those decisions or actions.

According to the Office of Technology Assessment's 1988 *Report on Institutional Protocols for Decisions About Life-Sustaining Treatments*, thoughtful institutional protocols should: decrease staff uncertainties about the practices permitted by the institution; reduce stress and conflict among health care professionals, patients and families; reduce "ad hoc" decision-making procedures and arbitrary decisions; increase the involvement of patients and their families in decisions about treatment; and improve the accuracy of decisions about treatment.

In response to the Patient Self-Determination Act and other forces, such as the "patient rights standards" under development by the Joint Commission on Accreditation of Healthcare Organizations, individual hospitals are developing and refining institutional protocols regarding advance directives. These protocols are evolving through a variety of processes involving medical and nursing staff, administration, admitting departments, patient representatives, clergy, legal counsel, ethics committees, and working groups established specifically for the purpose of drafting protocols on advance directives. As might be expected in view of the legal requirements imposed by the Act, these processes are yielding similar protocols.

For example, one major university hospital has promulgated a draft policy concerning the Patient Self-Determination Act with six substantive sections: Purpose, Policy, Persons Affected, Definitions, Responsibilities, and Cross-References. Under the heading "Policy," the hospital identifies three themes common in advance directive protocols:

> [*Encourage use of advance directives*] It is the policy of the Hospital to encourage the execution of advance directives by patients, in order to support patient autonomy and advance patient rights.
>
> [*Comply with state law*] The Hospital shall not discriminate against patients, based on whether or not the patient has executed an advance directive. The Hospital shall ensure compliance with [state] law respecting advance directives.
>
> [*Place responsibility for initiating discussion on the Attending Physician*] It is the responsibility of the Attending Physician to initiate discussion with his/her patient concerning advance directives, when relevant to the patient's medical care. This responsibility cannot be delegated. The Hospital shall make available resources, including persons knowledgeable concerning advance directives, to assist Attending Physicians in carrying out this responsibility.

The majority of the advance directive protocol is comprised of the section headed "Responsibilities" and designates the duties with regard to advance directives of the medical staff, admitting department, nursing staff, human services department, patient representative department, and hospital administration. The most interesting feature of the assignment

of duties, again common in individual institutional protocols concerning advance directives, is that the admitting department is responsible for assuring and documenting technical compliance with the Act, while the medical staff is responsible for initiating and participating in substantive discussions with patients concerning advance directives.

In addition to developing institutional protocols, many health care providers are developing their own brochures and educational materials for patients, staff and the community at large. Although few of these attempt to characterize the current status of state law regarding advance directives, many include either generic living will and health care proxy forms, or the forms set forth in applicable state statutes. A number of institutions are also preparing audiovisual material, particularly short video segments, to be used when introducing patients to advance directives or in staff and community education programs.

Collaborative Health Care Provider Responses

One notable effect of the Patient Self-Determination Act has been the development of collaborative efforts by health care providers. Diverse, often competing institutions, have joined together to prepare model protocols, forms, and informational materials to be given to patients, staff and the public. Each institution must comply with the terms of the Act as an individual matter, but these cooperative activities are efficient and cost-effective—the type of communication the Act was designed to foster.

In many instances, individual hospitals and other health care providers have joined together under the auspices of local and state hospital associations. For example, in the District of Columbia, 17 hospital members of the District of Columbia Hospital Association have joined with nursing homes and HMOs to create a task force charged with developing uniform standards of implementation. In California, 25 organizations—including hospitals, skilled nursing facilities, hospice and home health providers, HMOs, professional and consumer groups, and state government agencies—joined together to form the California Consortium on Patient Self-Determination. The Consortium has developed a variety of written materials, including two brochures for patients and a *PSDA Handbook* to provide relevant information to health care providers in California. The Consortium has also taken an active role in developing training materials and community-oriented education programs about the Patient Self-Determination Act and advance directives generally.

Some institutions have developed a brochure or other material concerning advance directives and made them widely available to other institutions. For example, the Mary Black Foundation, associated with Mary Black Hospital in Spartanburg, South Carolina, developed a series of video segments hosted by Spencer Christian of ABC's *Good Morning America*, entitled *Make Your Wishes Known*. Separate versions, accompanied by both training manuals and brochures, are available for use by (1) hospital and nursing home in-patients; (2) hospital and nursing home staff; (3) physicians with patients; (4) attorneys with clients; (5) businesses with employees; (6) inpatient television systems in hospitals; and (7) television stations as public service announcements. This series is an excellent example of an innovative, cooperative response to the Act, involving both public and private institutions and combining expertise in communications, marketing, and health care.

Professional Organization and Research Institution Responses

A number of national professional societies and organizations specializing in medical ethics and law and medicine have contributed both to the discussion over advance directives and to practical strategies for implementing the Patient Self-Determination Act. For example, the American Hospital Association's guide to advance directives, *Put It in Writing*, originated prior to passage of the Act, but it includes information about the Act and its requirements applicable to hospitals, as well as two sections detailing Communications Strategies and Communications Tools for educating patients, staff, the public and the media about advance directives. The guide also provides sample living will and power of attorney forms, and the texts of three AHA documents concerning ethics committees, patients' rights, and patients' choice of treatment options. The American Hospital Association has also prepared a ten-minute video tape with accompanying written materials, *Advance Directives: Guaranteeing Your Health Care Rights*, and other educational materials.

The American Association of Retired Persons, both on its own and in cooperation with the American Bar Association and the American College of Physicians, has prepared a series of publications dealing with end-of-life decisions, as well as living will and power of attorney forms. Many of these materials were prepared prior to passage of the Act, but they have been widely cited and reproduced in response to the Act.

Choice in Dying (formerly Concern for Dying/Society for the Right to Die), based in New York City, has prepared and distributed a variety of educational and informational resources concerning advance directives and the so-called right to die generally, including more than ten

million living will forms. Choice in Dying will provide anyone who asks, without charge, a copy of a generic living will and a copy of the living will form, if any, provided for in the state law of the requester. Choice in Dying also distributes a variety of video tapes on end-of-life decisions.

Conclusion

Supporters of the Patient Self-Determination Act proclaim it as the emancipator of free choice and open discourse on the subject of a patient's right to choose the extent of medical treatment he or she desires. The Act's focus is on education and communication—the importance of which is increasingly recognized in medicine, particularly with regard to critical health care decisions such as the withdrawal or withholding of life-support. The Patient Self-Determination Act, however, does not resolve any of the complex issues surrounding end-of-life decisions. In fact, the Act poses many clinical, ethical and legal questions that must be answered if we are to realize Senator Danforth's hope of providing all Americans with the information necessary to guarantee them the dignity of deciding their own fate.[9]

Sources for Further Information

American Association of
Critical-Care Nurses
101 Columbia
Aliso Viejo, CA 92656
(714) 362-2000

American Association for Retired Persons
1909 K Street, N.W.
Washington, D.C. 20049
(202) 434-2277

American Bar Association
Commission on Legal Problems
of the Elderly
1800 M Street, N.W.
Washington, D.C. 20036
(202) 331-2200

American Hospital Association
840 N. Lake Shore Dr.
Chicago, IL 60611
(312) 280-6424
(800) AHA-2626

American Nurses' Association
2420 Pershing Road
Kansas City, MO 64108
(816) 474-5720

American Society of Law & Medicine
765 Commonwealth Ave.
Boston, MA 02215
(617) 262-4990

The Annenberg Washington Program
Northwestern University
The Willard Office Building,
Suite 200
1455 Pennsylvania Ave., N.W.
Washington, D.C. 20004
(202) 393-7100
Facsimile (202) 638-2745

Choice in Dying
(formerly Concern for Dying/
Society for the Right to Die)
250 West 57th St.
New York, NY 10107
(212) 246-6962

Senator John C. Danforth (R-Mo.)
249 Russell Building
Washington, D.C. 20510
(Elizabeth L. McCloskey,
Legislative Assistant)

The Hastings Center
255 Elm Road
Briarcliff Manor, NY 10510
(914) 762-8500

Midwest Bioethics Center
410 Archibald, Suite 106
Kansas City, MO 64111
(816) 756-2713

National Center for State Courts
300 Newport Avenue
Williamsburg, VA 23187-8798
(804) 253-2000
Facsimile (804) 220-0449

National Reference Center
for Bioethics Literature
Kennedy Institute of Ethics
Georgetown University
Washington, D.C. 20057
(800) MED-ETHX
(202) 687-3885

Pacific Center for Health Policy
and Ethics
University of Southern California
Los Angeles, CA 90089-0071
(213) 740-2541
Facsimile (213) 740-5502

Selected Bibliography

A Matter of Choice: Planning Ahead for Health Care Decisions (available from the American Association of Retired Persons, in cooperation with the American Bar Association and the American College of Physicians).

Advance Directive Protocols and the Patient Self-Determination Act: A Resource Manual for the Development of Institutional Protocols (available from Concern for Dying).

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Footnotes

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INTRODUCTION

Mr. Chairman, Senator Danforth and members of the United States Committee on Finance, we thank you for the opportunity to submit written statements regarding the implementation of advance directives and its impact on the care of persons at the end of life. Under health care reform, a critical role of the federal government is to ensure that a fundamental right of all persons—the right of self determination—is not abridged.

Our longstanding interest (see Appendix A)[1] as well as our experiences in long term and community health services are germane to the issues before the Committee. This is reflected in the research described below.

STUDY: IMPLEMENTATION OF THE PATIENT SELF DETERMINATION ACT

The Division of Nursing at New York University is conducting research to evaluate the impact of the Patient Self Determination Act ("PSDA") on hospitals and nursing homes in New York City. This project, funded by the Greenwall Foundation, an organization with a special interest in bioethics and medical decisionmaking, has two components: (1) institutional survey of hospitals and nursing homes in New York City; and (2) a consumer survey. (see Appendix B)[1]

FINDINGS

I. THE LETTER OF THE LAW IS BEING MET IN HOSPITALS AND NURSING HOMES

Hospitals and nursing homes are providing patients with written information about their rights under state law; providing written policies regarding those rights; documenting in the medical record whether the patient has an advance directive; avoid discrimination on the basis of presence or absence of an advance directive; and providing some staff and community education. However, because the PSDA provides only "procedural guidelines" for implementation but does not provide the delineation of roles for health care professionals in meeting its legislative mandates, facilities have considerable latitude and discretion in meeting those mandates. For example, who will assume responsibility for dissemination of the information; who will assist in executing the directive; who will witness; and who will provide documentation in the medical record vary according to state and health care setting.

II. THE PSDA IS WORKING DIFFERENTLY IN NURSING HOMES THAN IN HOSPITALS.

Nursing Homes are meeting the spirit as well as the letter of the law. In addition, we found the following:

(a) In nursing homes, the PSDA appears to be have a greater impact than in hospitals. This is noted by the attempts being made to inform residents about their rights pursuant to state law to execute an advance directive and the number of residents who actually execute a directive.

(b) Social Workers are the nursing home professionals who are responsible for meeting the mandates of the PSDA. We recommend that any further education regarding advance directives in nursing homes should be directed to the social worker.

(c) Due to the increasing number of nursing homes with Ethics Committees, these bodies could be useful in conflict resolution, and policy development.

III. THE PSDA NEITHER CREATES NOR CHANGES THE PREVAILING FEDERAL OR STATE REQUIREMENTS FOR INFORMED CONSENT TO MEDICAL CARE OR DETERMINATION OF MENTAL CAPACITY.

There is evidence to suggest that people are not being asked about advance directives because they are perceived to lack decision making capacity. This decision is made on its face and absent a comprehensive medical assessment.

RECOMMENDATIONS

1. Develop specific guidelines regarding staff and community education. Reconsider the flexibility inherent in the PSDA in as much as staff and community education must be ongoing, i.e., done prior to admission.

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[1] Appendxes have been retained in the Committee files.

2. Identify the rights of the patients/residents with and without capacity, and the rights of the resident who lacks capacity and who does not have a directive.
3. Add a requirement that the advance directive must be placed in a specific place in the chart.
4. Seek and publicize "best practices." Identify institutions that are doing well and make their policies and procedures available for other institutions to review. Perhaps this may be facilitated by the Office of Technological Assessment.

COMMENTS

In response to Senator Rockefeller comments regarding the role of the nurse, we have found in some institutions such as, University Hospital Case Western Reserve, that nurses are solely responsible for implementing the PSDA. The leadership in these institutions feel that because the nurse spends more time with the patient than any other health care professional, the nurse should approach the patient about advance directives.

CONCLUSION

Mr. Chairman, we commend you for holding a hearing on the PSDA and end of life issues. We appreciate the efforts members of the Committee and Senator Danforth have made in continuing their commitment to bioethical issues. We join you in support of this effort.

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