DEATH WITH DIGNITY

An Inquiry Into Related Public Issues

HEARINGS

BEFORE THE

SPECIAL COMMITTEE ON AGING

UNITED STATES SENATE

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[1] Senator Winston Prouty, Vermont, served as ranking minority member of the committee from September 1969, until his death September 10, 1971. Senator Robert T. Stafford, Vermont, was appointed to fill the vacancy on September 17, 1971.

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DEATH WITH DIGNITY

An Inquiry Into Related Public Issues

TUESDAY, AUGUST 8, 1972

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Washington, D.C.

The committee met at 10 a.m. pursuant to call, in room 1224, New Senate Office Building, Senator Hiram L. Fong, presiding.

Present: Senators Fong, Church and Kennedy.

Staff members present: William E. Oriol, staff director; Patricia Callahan, professional staff member; Robert M. M. Seto, minority counsel; Gerald Strickler, printing assistant; and Janet Neigh, Clerk.

OPENING STATEMENT BY SENATOR HIRAM L. FONG

Senator FONG. We will now begin our hearings. Dr. Poe, will you please come forward.

Senator Church has been called to the Committee on Foreign Relations and will not be here until 10:30 or 11 o'clock. I will conduct the meeting until 11 o'clock at which time I will have to proceed to the Appropriations Committee.

Dr. Poe is from Durham, N.C. He is the assistant professor in the Department of Community Health Services, Duke University, and he is the author of "The Old Person in Your Home."

Dr. Poe, thank you for coming today, you may proceed as you desire.

STATEMENT OF WILLIAM D. POE, M.D., ASSISTANT PROFESSOR, DEPARTMENT OF COMMUNITY HEALTH SCIENCES, DUKE UNIVERSITY MEDICAL CENTER, DURHAM, N.C.

Dr. POE. My name is William Poe. I am an assistant professor in the Department of Community Medicine at Duke University. By experience and inclination I am a family doctor. In my private practice years I estimate I made 20,000 house calls, many on elderly people.

My present work is personally caring for about 300 nursing home patients in and around Durham, N.C. I hope to generate among the young an interest in caring for the old. There is no dearth of people who make profound studies and then retreat from meeting needs after a report is written or an experiment is finished. Often such studies are critical of people who day-in and day-out care for the feeble of mind and body. I don't believe the public yet realizes that if anyone lives long enough he eventually becomes dependent. For this reason I am honored to be asked to appear before this committee.

A few facts need to be faced:

1. Medicare, Medicaid and medical skill have undoubtedly prolonged the act of dying. Indeed, our youth-oriented culture has somehow made death seem ignoble. We as a society find death unacceptable. To drive the point home, when a person reads of the care an elderly statesman receives in the intensive care unit of the Walter Reed General Hospital he naturally assumes that anything less elaborate is due to his poverty or to lack of medical concern.

2. The physician's functions are often in conflict. To prolong life and to relieve suffering become confused. We sometimes only prolong the act of dying and inflict suffering. The semantics of this statement are highly emotional, but I advocate no course of action except the restraint that is necessary to a well-ordered society.

3. There is a strong tendency for many people, including physicians, to assume that medical intervention is always helpful to the patient. Insurance schemes have fostered this notion and, though difficult to prove because we don't like to document unwise treatment, many people are harmed by too much treatment. This is particularly true of old people whose health balance may be exceedingly delicate. Many people have medical intervention mainly to assuage guilt feelings of those who care for them.

4. Doctors generally don't like to treat old people, particularly those in nursing homes. Ours is an achievement-oriented society, and we all like to win. Continually losing our patients depresses us and we are apt to feel guilt-ridden. To give dignity to those of us who care for nursing home patients I suggested the words *Marantology* and *Marantologist* as a philosophical concept. Yet, if such terms would help young physicians to be willing to take care of the elderly and dying perhaps they may have some useful function.

5. Nursing homes suffer from too much criticism and not enough encouragement.

Senator FONG. What do you mean by Marantology?

Dr. POE. There is an addendum[1] to my statement which would explain this but it derives from a Greek word meaning old or withered or faded or turned. If one wants to give dignity to a particular profession he sometimes can achieve this by giving it a term.

A Marantologist might be a person who was able to simply make an elderly person comfortable, to accept him as he is rather than trying by heroic means to change his status. It is a philosophical concept and not a plan of action. Does that answer your question, sir?

Senator FONG. Yes, thank you.

Dr. POE. Since we all must die, and if we cannot die comfortably at home, it is possible we may die more comfortably in a nursing home than in a general hospital. Death needs to be talked about: It is a respectable aspect of life.

Since we all must die, there should be no stigma attached to it if one dies outside of a general hospital. I think that when we get to health matters there is a natural tendency to make doctors policemen of any medical system and then to blame them when things go wrong.

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[1] See p. 47.

Doctors cannot bestow meaning or help in every instance but we can try to relieve the pain that living and dying inflict. Finally, I believe we need more and better nursing homes. Nursing homes are no substitute for good treatment elsewhere and indeed frequently are the last move before death, but by then for many death is no enemy.

Thank you for allowing me to express myself. I hope my views are worthwhile.

(The addendum referred to follows:)

ADDENDUM

[From the New England Journal of Medicine, Jan. 13, 1972]

MARANTOLOGY, A NEEDED SPECIALTY

(By William D. Poe, M.D.)

Doing good these days grows more difficult. To do good and survive requires an organization that confines doing good to a narrow field and sets rigid rules by which good is done. When the institution is built, complete with boards of directors, constitutions and bylaws, and executive secretaries, then, and only then, can one go about doing good. But, unfortuately, in becoming part of the superstructure, the person who would go about doing good has become a dogooder with labels and degrees and obscure initials that he puts after his signature.

Pity the poor emergency-room physician at the average hospital. How often someone dumps a poor wretch at his door almost as if unloading excrement on his front porch! Who will care, and how will the emergency-room physician respond? If the patient is an impoverished paraplegic with bedsores and a severe urinary infection who will take him?

Urology does not want such a patient. Plastic surgery does not have an empty bed because this is face-lifting week and the patient smells bad. Neurosurgery did all it could way back when the fellow had hospital insurance.

The emergency doctor wants to do good. But how? After sundown he sneaks the patient on the service of the chief with the least imperious manner, with the least seniority and the mildest temper. Anyway, he'll catch hell, and wants it to be as short and as mild as possible.

Wherever the patient goes he is emotionally an orphan, unloved, unappreciated and unwanted. There are thousands of such patients; castoffs from rheumatology, cardiology, gastroenterology, and even dermatology and pediatrics. They are labeled by such unbecoming terms as crock, crud and crap. They are the true wretched of the earth. They have committed the sin of remaining alive but not yielding to our manipulations. They endure as daily reminders of our failures, and, like football players or business tycoons, we all want to be winners.

When confronted with losing we do all kinds of things to prove we are trying to do good, do-gooders that we are. Surgical residents do radical neck dissections on octogenarians. We put feeding tubes in poor old bodies that should be allowed to die. Rehabilitation people break their backs to get old hemiplegics to take feeble steps for no purpose. We cannot even admit to ourselves that death is a part of living.

Most medical specialties have started doing good by staking out a claim on the patients or parts of patients that no one wanted. Psychiatry started presumably because many doctors did not want anything to do with deranged minds. Physiatry staked its claim on rehabilitation with the grudging acceptance of the orthopedists. And so it was with proctologists, gynecologists and so forth.

Now, there is need for another specialty to stake its claim. Marantology seems to be a good word, suggested by my minister. It is derived from the Greek word *marantos*, meaning, literally, withered, faded, turned, as leaves become withered in the autumn. It has the advantage that marantic and marasmus are already good medical words derived from the same root.

The first tenet of marantology would be that it would not accept any patient anyone else wanted. It would be a boon to our emergency-room physician, who could slip in the paraplegic with infected kidneys and bedsores during normal working hours. Marantology would welcome the double amputee with a nasty disposition and the patient with advanced tuberculosis. It would glory in an incontinent oldster who drooled through rotten teeth.

Anyone who wants to see the kinds of patients marantologists could love should go to almost any nursing home supported by the public. They are all losing and rejected, but they are human and are due care by specialists.

Marantologists could do good by avoiding certain mistakes other specialties have made. It should be remembered that the tendency for people who want to do good is to become do-gooders. This tendency must be avoided at all costs.

To avoid becoming do-gooders marantology should not establish canons that measure performance by the preconceived notions of an American Board of Marantology or an International College of Marantology. Then, the loyalty is to the Board or College rather than to the old bed wetter with the big hemorrhoids.

Marantology should overcome, the winning psychology of most specialties. It should help people endure losing. It should not use silly euphemism such as rehabilitation and convalescence for its losing patients. It should not send its dear old people to intensive-care units to be treated as winners. It should not embarrass or tempt surgeons to do dramatic things such as operating on dissecting aneurisms.

Who would make good marantologists? Certainly, the specialty is no place for charisma and youthful dynamism. It is no place for avid manipulators of the status quo. Its practitioners should know that gross abnormalties of fluid, electrolytes and blood count can become almost physiologic for a particular person. The marantologist could be curious without satisfying his curiosity. Brain scans and barium enemas are of little use unless they influence the management of the patient. The emphasis is on peace and comfort rather than on diagnostic activism.

Marantologists are not winners; they have become good losers. Maybe they should be people who could not make the team. Maybe they flunked the examination of the American Board of Internal Medicine, were passed over for a faculty promotion or never could write well enough to get a paper published: losers all, but with spirits that endure like the bodies of their patients. They should be losers who remain undefeated, who have known defeat well enough to become philosophers.

There are thousands of highly motivated and intelligent people who could never fit into a winner's mold. Marantologists would not always look upon death as an enemy but often as a friend. They would have their vision extend beyond life into eternity.

There should be an American Journal of Marantology with contributions such as "The Uselessness of Speech Therapy in Mute Octogenarians." It would have philosphical treatises about treating all people as children of God. It would explore the role of marantic patients in training physicians. It would ask about the use of stomach tubes to prolong the life of mindless bodies.

What satisfaction could a marantologist get in his work? He could see better than any other specialist the natural history of disease. He could, to himself at least, debunk any number of doctrines propounded by haughty professors who never saw the true end results of their work. He could face honestly the fact of dying and death that our profession as a whole has not yet faced. He could see his specialty as the true medical museum that it is.

Among his patients he could find beautiful antiques among creaky bodies. I have been blessed to know a former university president, a physician who hacked out a hospital in the Belgian Congo, and a rebel priest of the 1920's among my old patients. I have found any number of schoolteachers and missionaries among my dear old losers. By no means are all unwanted patients repulsive; many of them do more for me spiritually than I do for them.

The individual patient could seldom pay his physician, but with increasing public and philanthropic support, the physician could be well paid. A not infrequent occurrence is being able to return a patient, wanted, to another service. Recently, I was able to see that one of my patients did not behave like her contemporaries. Though 78, she was too euphoric; her affect was not that of an old woman—her behavior was bizarre for a senile brain. She had a curable meningioma. A marantology service is no place for the doctor to take life easy and stop thinking.

How could a marantology service help a hospital or medical school? Obviously, it could be a place where a person could die in dignity without all the bother death engenders elsewhere. Such a service is an excellent place for enthusiastic surgeons to study some of the results of their art. Bodies that live more by doctors' reflexes than by their own are fit subjects for study of the meaning of life.

If I were a dictator, I would dictate that the entire profession have grand rounds in a marantology ward each fortnight to get a maintenance dose of humility. (This sounds terribly self-righteous but demonstrates the ease with which discipline falls into the trap of building itself up by tearing somebody else's down. Look! I'm more humble than you are!)

Marantology is a broad and needed specialty. Its practitioners seek to do good without becoming arrogant do-gooders. They will not be too busy attending meetings and studying ways and means of getting others to help bloody beggars beside the road to help bloody beggars beside the road.

Senator FONG. How long have you been practicing, Doctor?

Dr. POE. It has been 30 years since I finished medical school.

Senator FONG. You are now taking care of 300 nursing home patients?

Dr. POE. Indeed, yes.

Senator FONG. While you feel that doctors have a very special function here, and that is to try to relieve pain and to try to cure a person, but actually when it comes to the question of dying, how much does a doctor get into that field, Dr. Poe?

Dr. POE. I think that as one becomes older and perhaps more of a philosopher he is more apt to question the wisdom of unrestrained medical action. By that I mean removing some person with several organ systems that aren't functioning properly and putting him in an intensive care unit, away from his friends or wife or family, merely to prolong his misery, as it quite often works out.

ELDERLY DREAD SUFFERING AND DEPENDENCY

Senator FONG. Do you feel that many of these people who are dying accept death as a natural thing or are they really afraid of death?

Dr. POE. I think old people—many of them are my friends and I have talked intimately with many of them—do not dread death nearly so much as they dread suffering and dependency.

In other words, I believe that to the very old, death is far more acceptable than we are willing to recognize.

Senator FONG. They fear more the neglect and the insecurity that comes with old age, the lack of security that comes with old age. This is their great fear, isn't it? The care and comfort, aren't these the things that they are really more afraid of?

Dr. POE. That is true and, also, I think that many old people are just tired of suffering.

Senator FONG. In your experience with these people in the nursing home how many of them do have friends and relatives or members of the family that come to see them, console them, and comfort them. Do you find many of them are neglected?

Dr. POE. In my particular situation many of the people are the sole survivors in their own families and are brought to the Durham, N.C. area from outlying counties. Indeed, many of them are pretty well ignored or neglected by their own people.

Senator FONG. Do you feel that society should encourage organizations, to encourage people to visit, or to make periodic visits to these older people to cheer them up?

Dr. **Poe.** I think any contact with the outside world, even though it may seem antagonistic, probably is a wholesome thing. Many church and fraternal organizations, labor unions and so forth do make a concerted effort to keep in touch with elderly people. I think this is altogether wholesome.

Senator **Fong.** Do you think there is great need for that?

Dr. **Poe.** Indeed, yes.

Senator **Fong.** Do you feel that because of our achievement-oriented society that we don't give enough attention to old people?

Dr. **Poe.** I think there is a prejudice against older people. I don't think this is any particular insight of my own, but I think it is true. People don't like to have gray hair even. Plastic surgery thrives on people who don't want to appear even to be old, and so it goes. I think this is a youth-oriented society in which to achieve a ripe old age is somehow unrespectable except in the quaint sense of the word.

Senator **Fong.** Doctor, why do you feel that many elderly, especially the wealthy elderly, regard the institution as a desirable place to die? For example, is that responding to a status symbol?

Dr. **Poe.** Of course, I think when we read in the newspapers and see on television the extreme care and the extreme length to which important people in public life are treated, naturally in this egalitarian age I think that everyone tends to assume this is the way to do it. I think this is open to question. It does tend to become something of a status symbol.

Senator **Fong.** Do you believe that health care really should be in the homes rather than in the institutions?

Dr. **Poe.** To an increasing extent, I do, yes.

Senator **Fong.** Have you visited the Far East, for example, Singapore? I was there and they have places like dying homes where people have no families and they have no one to take care of them go to a dying home right in the middle of town and they sleep on their mats there. They are very, very poor people and there they pass their last days. Have you seen that?

HOSPICE FOR THE TERMINALLY ILL

Dr. **Poe.** I have never been in the Far East, sir. I do think that in Great Britain, for example, and I have heard from one of the doctors there, they have what they call a hospice where they treat terminally ill people with dignity and it is accepted. We tend to say a death house as if there were some stigma attached to this and what I am trying to do is to overcome the stigma of a person dying. There should be no stigma to a nursing home making a person's death easy. Death is perfectly acceptable.

We have all got to do it. I am respectable, I hope, and I am sure many people in this room are, so I think this should be an accepted matter for discussion and for decision at the proper time.

Senator **Fong.** Do you think that we should have nursing homes specifically for those who feel that they are going to pass away in a very short period?

Dr. **Poe.** I do not think they should be exclusively for immediate death. However, I think that if a family is unable or unwilling to cope with it I think it is far better to have a person in a nursing home than it is in an intensive care unit unless there is a reasonable chance that that person will make a reasonable recovery to a life from which he can get some enjoyment and fulfillment.

Senator FONG. Doctor, going back to the question of whether doctors are equipped to deal with dying patients; as a member of the academic community, have you observed or do you advocate changes in the educational system that would enable the medical profession to better respond to the needs of dying patients?

Dr. POE. I think this is coming to be recognized by a number of people in my profession at several medical centers throughout the country. However, to make an impact on the medical educational system requires a good bit of time.

It requires money. It requires a push which has not gained the momentum that I would hope. I think that medical students and young doctors ought to be taught that death under certain circumstances is an honorable alternative to prolonged dying.

Senator FONG. I understand that social workers are given some training along that line.

Dr. POE. Indeed, yes.

Senator FONG. And do you think doctors should have some of that training?

Dr. POE. Indeed I do.

Senator FONG. You have brought up the word "marantology." Within the framework of that discipline, within which profession should that be stressed? Do you advocate the separate facilities for the dying patients or rather should we attempt to change certain attitudes that would make medicine want to treat the feeble and the dying?

Dr. POE. The second one of your propositions is what I had in mind. It was a bit of a philosophical concept that would lead, I hope, the medical profession to accept death. Many people, surgeons and physicians who are used to crisis medicine, sometimes prolong life not for the benefit of the life they are prolonging but simply to cause them to feel good. I don't think that a person ought to be required to live to make a doctor feel good.

Senator FONG. The doctor feels that he is accomplishing something if he can continue life, doesn't he?

Dr. POE. Right. I mean it makes certain doctors feel triumphant to keep a miserable person breathing an extra 24 or 48 hours or even a month or two.

Senator FONG. Don't some of them feel they are impelled to do that because they don't know whether death is certain that sometimes some miracle could happen?

Dr. POE. Indeed, and I don't want to leave the impression that this is a black and white proposition. Even under extreme circumstances it is not an easy decision to make. I think that it should be made in view of many factors.

Family feelings, where one is, the acceptance that a person himself may have of his own demise are factors. So, it isn't an easy question, although for the sake of rhetoric I may seem to make it a black and white proposition.

Senator FONG. I have talked to many doctors, especially those in internal medicine and those that are in heart medicine, and they tell me many doctors dump their patients on them when things seem hopeless.

Marantology will become a function of medical discipline. Do you think there might be a tendency for certain doctors to dump the hopeless patients on specialists?

Dr. POE. I think this is a tendency but, of course, in my original essay I said that marantologists won't take a patient anyone else wanted because I think that it takes a philosophy and degree of maturity irrespective of the age of the doctor to accept a patient as he is with his limited capacity for getting better.

Senator FONG. Mr. Oriol, do you have a few questions?

Mr. ORIOL. Thank you, Senator.

DEPENDENCE ON INSTITUTIONS

Dr. Poe, my name is Oriol. I am the staff director for the majority. Several witnesses yesterday expressed the opinion that Medicare and Medicaid have perhaps intensified the problem we are discussing here today by increasing dependence on institutions. Do you have any thoughts on that matter?

Dr. POE. I don't think there is much doubt about this. Before entering in my present work a few years ago, I was in private medical practice for nearly 17 years, and as I said, I guess I have made 20,000 house calls in my life. Quite often the statement would be, should we send father to the hospital, and I would point out—this was in the days before Medicare—that this would be rather costly. I didn't think I had a whole lot to offer and if there were a third party the family would say, "Well, we have got insurance." I believe still, when you see people under such circumstances, there is an illusion that things are free when they really aren't.

Mr. ORIOL. Do you have any suggestions to what could be done about it to overcome this trend?

Dr. POE. Well, for one thing what we were talking about with the Senator here. I think the nursing homes are far less expensive than hospitals with their operating rooms, et cetera. Nursing homes may be an alternative.

Second, I think that such discussion as this and the publication of the books by other witnesses, if death can be made respectable, I think people will be more inclined to say, "Let's keep father at home or mother at home." So, I think it is a matter of public sentiment as well as limitation of some insurance benefits. I know that Medicare now is beginning to question the use of expensive hospital facilities.

Mr. ORIOL. Do you think there should be a 3-day hospitalization requirement before a patient can go to a nursing home under Medicare?

Dr. POE. I think this was a good, well-intended regulation, but I think it causes needles hauling of poor, feeble old people, so I am against that. I don't think that this should be.

Mr. ORIOL. You said nursing homes need encouragement. Now, do you mean that in terms of more reimbursement or do you mean this in better definition of mission, overall improvement of standards, or do you, perhaps, see a way in which nursing homes and home health care services can be married together a little more efficiently than they now are?

Dr. Poe. I think that any orientation away from hospitals is probably a wholesome development. I think, as I say, that nursing homes should be made respectable.

It is depressing to go into a nursing home if you don't know what to expect and many layman who visit there are repelled by seeing the poor old people who can't get well and they tend to go out and write reports that are highly critical of nursing homes when people are really doing a pretty good job in nursing homes day in and day out.

This is not something that is youthful and blooming and budding and pretty. This is a sad aspect of life and to try to give some meaning to it, to me, is a very worthy objective. I think that when we go in nitpicking and fault-finding, this tends to degrade people who work in nursing homes in their own eyes. I think this is bad.

Mr. Oriol. What do you think should be done to make nursing homes respectable?

Dr. Poe. I think to try to get physicians to give inservice training to people who work in nursing homes. This is something I have been thinking about and in a sense butting my head against the wall for, because I think it ought to be made respectable. As my essay said, when psychiatry started out, it was a highly unrespectable profession, it has become so, simply because people became interested in it because over a period of years, it gained public support. I think that if we are going to overcome this winning culture that all of us share, we have got to make nursing homes seem fashionable, respectable, and rewarding.

Disciplines of Marantology

Mr. Oriol. To build upon what Senator Fong mentioned before, this question of: Will other practioners, if there were disciplines of marantology, would they tend to send their "Hopeless" inpatients to the marantologists? Your essay says the first tenet of marantology would be that it would not accept any patient anyone else wanted.

Dr. Poe. Well, this is what happens in effect now, except many of these patients are accepted by people who have lost their self-respect or their dignity or their feeling that they are on a par with anybody else on the medical scene. So this happens in effect now, but not in a way that results in the best care for elderly patients.

Mr. Oriol. It is a hopeless feeling within the patient as well as within the practioner?

Dr. Poe. Yes, and I am sure that many patients feel that they are being passed from their doctors not to more able doctors but to less able doctors, and this, indeed, does happen quite often, and it shouldn't happen. A person should be passed from one who is less able to look after his needs to one who is more able rather than the other way around.

Mr. Oriol. Your essay is angry, and I think at times very ironic, and I wonder whether you really want a new discipline of marantology or you just want to get these concepts throughout the field of medicine?

Dr. Poe. I am not an angry man. Sometimes people mistake forthrightness for a degree of anger, but as I say it was written as a philosophical concept, but if somebody wants to make it a plan of action, that is all right with me, too.

Mr. Oriol. One line says, "If I were a dictator, I would dictate that the entire profession would have grand rounds in a marantology ward each fortnight to get a maintenance dose of humility."

In previous hearings and in a Government budgeting office audit for this committee, it was indicated that doctors don't view bodies of patients who have died in nursing homes. We have even heard an instance where a physician signed a certificate in advance so he won't have to come back. How important is it to see patients before signing certificates?

Is there a possibility that death could occur by extraordinary means if the physician isn't there at the necessary time?

Dr. Poe. For the record if you would, please, read the next sentence. "This sounded terribly self-righteous but demonstrates the ease with which each discipline falls into the trap of building itself up by tearing somebody else's down. Look, I am more humble than you are." So I don't want to be in the position of being overly proud of humility. So I am not an angry man. These things do occur, and I think that even in a large medical center where I have been a relatively short while that merely talking and achieving a degree of publicity on this point has lead some of the young physicians with whom I am associated to look upon my views with increased respect, so I think that this can be very profitable.

Mr. Oriol. With due humility, those are all the questions I have, Senator.

Senator Fong. Thank you, Doctor. Thank you for giving us the benefit of your thinking.

Our next witness will be Dr. Henry K. Beecher from Boston, Mass., who is with the Harvard Medical School.

Dr. Beecher has had several audiences with the late Pope Pius XII and made numerous inquiries into medical and ethical application of human experimentation. Welcome, Dr. Beecher. You may proceed as you desire, doctor.

STATEMENT OF HENRY K. BEECHER, M.D., HARVARD MEDICAL SCHOOL

Dr. Beecher. Thank you, Senator. In "King Lear," Shakespeare wrote, "Vex not his ghost: O, let him pass! he hates him That would upon the rack of this tough world Stretch him out longer."

As physicians we are concerned with life, its protection and prolongation and, when it is attacked by disease, our charge is to lessen or relieve or cure the disease. We could find many a "medical mission unfulfilled" in these areas.

But a coin, like life itself, has two sides. There is the life side and the death side. Today I am going to talk about death. There are a number of urgent problems, inescapable problems, concerning death which we as physicians must examine and study and finally resolve. The field is wide.

Now, let us raise some questions related to the irretrievably injured man who is kept "alive" only by extraordinary means. Four very different kinds of questions arise from this situation.

1. Under what circumstances, if ever, shall extraordinary means of support be terminated, with death to follow?
2. From the earliest times the moment of death has been recognized as the time the heart beat ceased. Is there adequate evidence now that the "moment of death" should be advanced to coincide with brain death while the heart continues to beat?
3. When, if ever, and under what circumstances is it right to use for transplantation the tissues and organs of a hopelessly unconscious patient?
4. Can society afford to discard the tissues and organs of the hopelessly unconscious patient when they could be used to restore the otherwise hopelessly ill but still salvageable individual?

These matters are pertinent to the theme of our common interest for the ever broadening experimentation in the transplantation of tissues and organs has already led to the use of organs of hopelessly unconscious patients while their hearts were still beating. The ethics of this have been questioned. There is, therefore, some urgency to face up to the problems mentioned.

In Judge Cooley's memorable phrase (1888) there is "the right to be let alone." Implicit in this is the right to live and the right to die. There is also the opposite right, to communicate. The individual's right to be let alone conflicts with the advancement of society based upon scientific research.

The development of science requires reasonable freedom for the investigator; at the same time a healthy society imposes restraints on him for the sake of the individual. Thus tension exists between society and scientific man. "This tension between society and science extends to all disciplines in the social, physical, and life sciences. It affects the practitioner as well as the research investigator." There is also the "conflict of science and scientific research with the right of private personality," as stated by the President's Committee on Privacy and Behavioral Research (1967). The committee (*loc. cit.*) concluded that "neither the principle of privacy nor the need to discover new knowledge can supervene universally." As with other conflicts in our society, there is need for adjustment and compromise in determining which value is to govern a given situation. Their view is that the cost in privacy is balanced against the gain in knowledge. But the rights of privacy are so important and complicated we will have to leave them for another time. I would hope that this group might perhaps deal with those matters at a subsequent session.

These thoughts and others to come are relevant to this presentation because of the pressures to use the hopelessly unconscious patent's tissues and organs in an attempt to help the otherwise hopelessly ill but still salvageable patient in certain experimental procedures.

The moment of death can have legal importance, but the criteria by which death is established must depend upon medical evidence. Granted that there may be a time when it is good—appropriate to die—but when is that moment? What are its criteria?

Starzl (1966, p. 98) has spoken of "the declining curve of life," implying that as the end approaches there is less and less life in the individual, that there is present a quantitative factor, a sort of death by inches. To a certain point this is supportable in that all organ and nerve centers do not become irreversibly damaged simultaneously; consciousness as a brain function is often irretriveably destroyed months before the respiratory and vasometor centers fail. At the same time, one can insist that "a coordinating vital principle exists which is either there or not there." This vital principle comes into being when the sperm fertilizes the ovum until life no longer is present. The moment of death can only be approximated.

DEATH OCCURS AT SEVERAL LEVELS

Or, to phrase it differently, death occurs at several levels: There is cellular death. Human cells can be maintained alive in tissue cultures for years; so we cannot define death as the loss of all vital functions. There is "physiological" death when the vital activities have ceased; that is, death occurs when integrated tissue and organ functions cease. There is intellectual death, spiritual death and social death (*cf.* Pickering, 1966). Or to approach the problem with more generality: There is subcellular and cellular life, life of organs, life of the indivdual and beyond this, life of the individual as a member of the commuity. However, it is phrased, our basic concern is with the presence or absence of physiological life, especially neurological life. The lack of an accepted definition of death handicaps many of the activities within the hospital, the cadaver transplant problem. This is a medicolegal problem; it is also a sociolegal problem.

Now a few words about death and the church. In an address on "The Prolongation of Life," Pope Pius XII (1957) raised many questions; some conclusions stand out: (1) In a deeply unconscious individual whose vital functions are maintained over a prolonged period only by extraordinary means, "the soul may already have left the body." As mentioned, verification of the moment of death can be determined if at all only by a physician. It is not "within the competence of the church" to decide this. The presumption is that as long as vital functions persist spontaneously or even with the help of artificial processes, life is present. (2) It is incumbent on the physician to take all reasonable ordinary means of restoring the spontaneous vital functions and consciousness, and to employ such extraordinary means as are available to him to this end. It is not obligatory, however, to continue to use extraordinary means indefinitely in hopeless cases. "But normally one is held to use only ordinary means—according to circumstances of persons, places, times, and cultures—that is to say, means that do not involve any grave burden for oneself or another." There comes a time when resuscitative efforts should stop and death be unopposed, in my view.

VESTED INTERESTS

Vested interests impinge on most moral choices. This situation is not different. It will be best to consider whence these pressures come. Their presence calls for caution.

The unconscious patient with overwhelming brain damage can be maintained only by extraordinary means. When it becomes evident that the brain is dead, there is an obligation to discontinue extraordinary supports. But one must remember that the termination of extraordinary care even for just reasons, with death to ensue, can have a shocking effect on observers.

I want to bear this in mind in communicating such a point of view. The family of the patient very often want to terminate their agonizing death watch; they urge a discontinuance of extraordinary measures.

ORGAN TRANSPLANTATION

Some of those who have an interest in organ transplantation press for a new appraisal of what constitutes death so the organ sought may be taken while circulation continues.

The hospital and society in general have a vested interest in terminating the appallingly costly and useless procedure in hopeless cases. Occupancy of such a bed jeopardizes the salvageable who may need that bed and can't get into it because it is filled by this hopelessly injured man.

The presence of vested interests, however correct, raises the possibility of selfish rationalization and is a warning of the need for caution. Then, too, a new definition of death, when there are those who have a vested interest in it, could lead to public questioning and doubt and an unfortunate blurring of the line between this and euthanasia.

It would be a grave mistake to underrate the attitude of the public as to the inviolability of the body. Doubtless in many cases, this is based upon religious beliefs concerning the resurrection of the body. The Roman Catholics and strict, Orthodox Jews oppose cremation; but this feeling about the body is prevalent in some atheistic societies, too.

Perhaps the theologian, with his distinction between ordinary and extraordinary means of sustaining human life, will also say with Arthur Hugh Clough, ironically or not, "Thou shalt not kill; but need'st not strive Officiously to keep alive."

With the developments of recent years, there has been an extraordinary increase in the power of the doctor and with this increase new and unexpected dilemmas and moral choices emerge. They require decision and action. A major difficulty lies in the fact that choice must often be made among values that are not really measurable or of clearly comparable moral weight. With progress in medicine, technical decisions become easier while moral problems become increasingly significant and difficult.

Two yardsticks must be recognized: the one measuring the welfare of the individual, the other the welfare of science, which is to say, in the best sense, the welfare of society.

(a) It is clear beyond question that a time comes when it is no longer appropriate to continue extraordinary means of support for the hopelessly unconscious patient. Pope Pius XII spelled this out.

(b) A strong case can be made that society can ill afford to discard the tissues and organs of hopelessly unconscious patients. Thank you.

Senator FONG. Doctor, there is an implication in your statement that society has a vested interest in the organs of the individual. Now, we have not gone that far yet, have we? We have stated that we realize that if a person wanted to will parts of his body to others that that will be done; but for those who have not consented or whose families have not consented, we have not forced the yielding of parts of their body for science.

Dr. **Beecher.** As an example, Senator, I think this might be the case. For example, we say we don't have enough dialysis machines so we let people with kidney diseases die right and left. At the same time we spend much more than this on mental diseases and hopelessly incurable individuals.

It seems to me there is something very wrong about that. We know how to preserve the life of these kidney patients and yet we expend these vast sums and say we don't have enough money for the dialysis machines. I don't believe that.

Senator **Fong.** You believe that it is a question of priorities?

Dr. **Beecher.** Certainly. In its heyday when tuberculosis was a common disease, vast sums were spent on looking after these individuals with tuberculosis. It isn't so much of a problem now, but mental disease is surely a problem. We can spend untold sums there but not enough for dialysis. I think there is something wrong with that.

Senator **Fong.** What you are thinking is relative to society's right or society's means of achieving the end, thus raising the question of whether these organs should be preserved for society? Do you feel that society has a right to demand that, or to say that regardless whether you give your consent, that we will take your heart, or we will take your kidneys, and use it for another individual?

Dr. **Beecher.** I am not in favor of actions of that kind. I think that one must have consent insofar as one can approach consent and, of course, many of us have signed cards and carry them in our wallets saying that our body may be used when we are hopelessly unconscious.

This throwing into the grave of these perfectly good tissues that could maintain life in another individual, I think, is wrong. Paul Ramsey, of Princeton, doesn't agree with me but I think I know more about this than he does.

Senator **Fong.** You have raised a question in your statement about the welfare of society, and then you make a statement now that we should not use these parts of the human body unless there is consent; is that correct?

Dr. **Beecher.** Unless there is a kind of consent. It can be indirect.

Senator **Fong.** Now, do you go as far as saying that this consent can be given by the immediate members of the family?

Dr. **Beecher.** It is not necessary in some States for the family to do it. Recent legislation, in several States at least allows a man to determine what may happen to his body after death despite his family's objections.

Senator **Fong.** No. I mean if a man has not consented to give any parts of his body, but his family believes that it should be done and they give their consent. Do you go that far, that society should accept this?

Dr. **Beecher.** Well, that is a tricky business. It is much more complicated than the simple statement would sound. I don't think I can answer that short of a long discussion.

"LIVING WILL" LEGISLATION

Senator FONG. Now, a representative in the Florida Legislature appeared before us yesterday and he has a bill before the Florida Legislature saying that we should have living wills and that if a person is not lucid and is in a state of coma, for example, that immediate members of his family would tell the doctor that they should not prolong his life, or that two physicians appointed by the State can get together and say that this life should not be prolonged.

What do you think of that bill?

Dr. BEECHER. Well, I think we have very much the same thing, at least those of us who carry in our wallets this blanket privilege of using our bodies. I have one in my pocket right now. I know thousands of people who do. I think the time will come when almost everybody will accept that.

Senator FONG. Right of privacy as you said, is a very, very dear right and yet when a man passes away, we have seen fit to do an autopsy on him and we feel that society has that right against the right of privacy. That is true, isn't it?

Dr. BEECHER. Yes, I think so.

Senator FONG. Now, do you feel that when brain damage is such that he cannot recover and he is unconscious and the brain is dead that that time should be considered a time of death?

Dr. BEECHER. Yes. Once that is decided by two physicians one of whom should be a neurosurgeon or a neurologist.

Senator FONG. Regardless whether the heart is beating?

Dr. BEECHER. Regardless of whether the heart is beating.

Senator FONG. That is, the brain is dead and therefore the patient is dead?

Dr. BEECHER. Yes. We have 128 very carefully studied cases, studied before death and after death, and in every one of these the brain is just a mish-mash; the subject couldn't conceivably have recovered.

Senator FONG. Have you seen any cases in which the brain had been declared dead and that the person had been revived?

Dr. BEECHER. No. Individuals under heavy sedation of barbiturates, for example, may recover and seem to fulfill the other criteria, also individuals who are very cold, whose body temperature is below 90 degrees Fahrenheit. The same applies. All you have to do in those cases is to wait for the barbiturate to be eliminated or wait for the body to be warmed up.

I am dismayed, sir, by the attempts of many people to shorten this process. In the Harvard Committee of which I am the chairman, we thought it took 24 hours at least to be sure what you are doing. Now a group has come along that says an electroencephalogram is quite adequate.

Well, I won't argue with that. I mean we never thought it was necessary. We thought it added supplemental interest and support, but the electroencephalogram is a very tricky tool. It can get out of whack without ordinary people being aware of it. And if you trust your technicians implicitly, if you trust the operators and apparatus implicitly, then I think that the electroencephalogram can have real value.

As a matter of fact, some 3,000 cases have been collected in a study and there has not been a single recovery among those who had flat electroencephalograms except two individuals, both of whom were under heavy sedation and did not fill the criteria we specify. So perhaps we will have to weaken our attitude toward the electroencephalogram, but we wanted very much to have it possible for individuals in the smaller hospitals who do not have access to the electroencephalogram to be able to make sure of irreversible coma, it is tantamount to death.

Senator FONG. Now you have stated that we lack money to do things which could save lives, for example, the kidney patient who needs a dialysis machine. What is the solution there?

Dr. BEECHER. Well, I think the dialysis situation is a scandal. I think it will be recognized as such in 5 to 10 years.

Senator FONG. In what respect is it a scandal?

Dr. BEECHER. We are letting people die for lack of funds or supposed lack of funds.

Senator FONG. And now, the second part of the question: when these people are in irreversible coma, how would you treat that patient?

Dr. BEECHER. Who are in irreversible coma?

Senator FONG. Yes.

Dr. BEECHER. Treat him as a dead man. I didn't mean to be flippant with that answer, but that is really what you are dealing with. I think you can come back to me and say, "Well, would you bury a man whose heart was still beating?"

Senator FONG. Well, I won't go that far.

Dr. BEECHER. I think I would temporize a little.

Senator FONG. So you think that if he is in an irreversible coma that we shouldn't try to prolong his life?

Dr. BEECHER. Well, if you have need for his organs, I think you might. He is not alive; you are treating a corpse, actually. I think, despite Paul Ramsey, the distinguished theologian, that these organs should be used. I think it is a criminal waste to allow a man to die who could be saved by a kidney transplant.

Senator FONG. Now, if a man consents to the use of his organs—and this is where you would stop—if he hasn't given his consent, you would not use his organs. Is that correct?

Dr. BEECHER. If he had not, then I would go to his family and if they consented, yes, I would want to be very certain. I don't want another Dallas on my hands.

Senator FONG. So if the man consents to the use of his organs, or if the family consents to have the organs used, then the taking of the organ would natually precede "death," wouldn't it?

Dr. BEECHER. Well, it wouldn't necessarily with double organs such as kidneys. It certainly would with the lungs and the heart and the liver.

Senator FONG. So when do you go in and take the organ?

Dr. BEECHER. When the man has fulfilled these criteria I mentioned, which takes 24 hours.

Senator FONG. That would be difficult to say when is the proper time to go in?

Dr. BEECHER. No, I don't believe it is so difficult. If you maintain the respiration artifically, the heart is still beating.

Senator FONG. But for all practical purposes, the man is dead?

Dr. BEECHER. For all practical purposes, the man is dead.

Senator FONG. And you have only sustained him because you want to keep the organs alive.

Dr. BEECHER. Yes.

Senator FONG. Any questions, Mr. Oriol?

DEFINITION OF DEATH

Mr. ORIOL. Professor Beecher, I was wondering whether you could give us a description of the proper tools or apparatus it would take to arrive at a uniform definition of death throughout the United States, or is it a State-by-State matter? Just what are the mechanics here?

Dr. BEECHER. I don't think you need any instruments beyond the simplest kind of thing.

Mr. ORIOL. I mean whether it is a legal matter or a medical matter. What would it take to arrive at a definition of death that would be a standard definition throughout the United States?

Dr. BEECHER. I am afraid it is going to take a great deal of time. I think this will become possible only when bold individuals go ahead and work on these principles I mentioned. That is being done along the eastern seaboard very freely. As I understand it, it is not being done with equal freedom on the western seaboard, and one reason for that is there are so many lawsuits in California. They seem to be "lawsuit mad" out there, and it is a disgrace, I think, when laws determine what kind of care able doctors want.

For example, spinal anaesthesia is practically never utilized in California because of the fear of lawsuits. I don't think lawyers ought to have a right to determine what medical care should be, and yet I would go right along if I lived in California. I wouldn't want a $500,000 suit against me when I am completely innocent.

Mr. ORIOL. Is there anything that could be done at the Federal level? Do you think that would help?

Dr. BEECHER. Well, it depends on how, Mr. Oriol. I think I'd rather keep this out of the legislative process. I have no doubt that the three simple criteria that our group in Harvard set down will be shortened. I haven't seen any data yet that convinces me that it is time now to do that.

Mr. ORIOL. I see. Professor Beecher, you said in your statement: "There comes a time when resuscitative efforts should stop and death be unopposed." And later you pointed out that there is an interest—the hospital and society in general have a vested interest in terminating the appallingly costly and useless procedure in hopeless cases, but you warn that there might result an unfortunate blurring of the line between this and euthanasia. Could you make that distinction? Senator Church mentioned several times yesterday that the primary concern of these hearings was not euthanasia. I think it is an important point.

Dr. BEECHER. I think this is not—well, euthanasia is quite another matter. I have withdrawn supporting fluids from an individual who was hopeless, just as the Pope suggested was possible. I mention that in here, and perhaps it was indiscreet to have done so, but in conversations with various individuals they include this.

It is amazing, of course. We are dealing with corpses when we are dealing with those in whom the brain is dead. It might have been better if I had left that sentence out, although it is perfectly tenable.

EXPERIMENTAL DRUGS AND TECHNIQUES

Mr. ORIOL. Dr. Beecher, is there any reason to believe that elderly patients in isolated cases, or maybe even more than that, have been the recipients of drugs or techniques which could be accurately described as still in the experimental stage?

Dr. BEECHER. Oh, all the time. Or drugs being withheld, which is equally bad, like the syphilis cases in Alabama.

Dr. DuVal said very bravely these things couldn't happen now, but I would like to invite his attention to what happened in San Antonio, where a series of Mexican-American women were given placebo contraceptives. That is a very recent thing.

I suppose Dr. DuVal has to speak for the NIH, but I must say I disagree very strongly with some of his statements, and this in particular.

Of course these things are going on. I could give you hundreds of examples.

Mr. ORIOL. I was asking whether there was any reason to believe that the elderly may be disproportionately affected by this practice because of the helpless condition of so many of them.

Dr. BEECHER. Well, there was the notorious case in New York where Dr. Southam from the Memorial Hospital injected live cancer cells into sick old people in Brooklyn, but how common this is I don't know, and I don't think anybody knows.

Mr. ORIOL. I have no other questions.

Senator CHURCH (presiding). Dr. Beecher, I am sorry I was unable to be here during your testimony. I had an engagement with another committee I had to attend earlier.

There are two statements you have made that I would like to ask about, reading from your text.

One is: "The lack of an accepted definition of death handicaps many of the activities within the hospital; compare the cadaver transplant problem. This is a medicolegal problem; it is also a sociolegal problem."

Could you amplify that for me?

Dr. BEECHER. Yes. I think the problem is more on the west coast than it is on the east coast. On the east coast, almost everybody that I know of has accepted our definition of brain death as death indeed. On the west coast, I understand that is not the case.

Senator CHURCH. Well, now, when you say "accepted," you mean—

Dr. BEECHER. Acting on it.

Senator CHURCH (continuing). Mean accepted by the medical profession or do you mean accepted as a matter of legal definition of death?

Dr. BEECHER. No, accepted as the explanation for what they actually do.

Senator CHURCH. What they actually do?

Dr. BEECHER. Yes.

DEATH BY LEGAL DEFINITION

Senator CHURCH. I believe we are going to have testimony from a lawyer here in just a moment. Perhaps I should address this question to him, but does the law make clear exactly what constitutes death by legal definition?

Dr. BEECHER. Black's Law Dictionary makes it clear, if you can accept that. I cannot, I think it is an outrageous statement.

Senator CHURCH. It is a kind of medieval——

Dr. BEECHER. "Medieval" is right.

Senator CHURCH. Of course, that is the source of Black's Law Dictionary.

Dr. BEECHER. This can only be resolved, I think, when men of courage will go ahead and act on the fact rather than the law. Of course, that is a dangerous business.

Senator CHURCH. That is exactly the point. Do you think that since so much of our law, the definition of terms in our law, is based on the common law and not necessarily on statutory law, then a medieval understanding of death might very well be held by a given court to constitute——

Dr. BEECHER. And is.

Senator CHURCH (continuing). A definition?

Dr. BEECHER. There is nothing hypothetical about that.

Senator CHURCH. Yes. Well, then, do you think that it will be helpful if State legislatures were to define death in this more sophisticated way?

Dr. BEECHER. I think it would be helpful, but I would be reluctant to see it done yet, because I think our definition of brain damage will be improved upon, and I do not like to see this business frozen at the present time in law. That is my opinion. I think it is too soon for legislation.

I think it is better for doctors to risk their necks, go ahead and carry out what they believe to be right, with the hope that sooner or later this——

Senator CHURCH. Even though this might involve some jeopardy to them in terms of legal liability?

Dr. BEECHER. It does involve jeopardy.

Senator CHURCH. Now, the other statement that you made, it has been called to my attention, is the following: "There comes a time when resuscitative efforts should stop and death be unopposed, in my view."

Dr. BEECHER. I was really quoting Pius XII on that, who made it very clear that when one has reached the stage in treating illness where one is utterly convinced that there is no hope for recovery, then, the Pope says very clearly, there is no necessity for carrying out further attempts at treatments and wasting precious materials that can be used for other individuals. He is very explicit about that.

Senator CHURCH. That is very interesting. I don't think that is well known. Can you document it?

Dr. BEECHER. Can I document it?

Senator CHURCH. Yes.

Dr. BEECHER. Oh, Yes.

Senator CHURCH. Would you document it for the committee, because I have a feeling that perhaps it is utterly unknown that the Pope took such a position on the question of death.

Dr. BEECHER. Oh, he did. I talked with him.

Senator CHURCH. I am not questioning the veracity of your statement. I am simply saying it would be helpful because I think it is utterly unknown to the country.

Dr. BEECHER. I have the English translation of the Italian.

Senator CHURCH. Could you place that in the record?

Dr. BEECHER. Yes, I would be glad to.

Senator CHURCH. Would you submit that for the record?

Dr. BEECHER. That was in 1957. The Pope said:

> It is incumbent on the physician to take all reasonable, ordinary means of restoring the spontaneous vital functions and consciousness, and to employ such extraordinary means as are available to him to this end. It is not obligatory, however, to continue to use extraordinary means indefinitely in hopeless cases. "But normally one is held to use only ordinary means—according to circumstances of persons, places, times, and cultures—that is to say, means that do not involve any grave burden for oneself or another."

I don't see how it could be more clear. I will be glad to send that.

Senator CHURCH. Thank you very much. I think that will be very helpful.

(The information follows:)

HARVARD MEDICAL SCHOOL,
Boston, Mass., August 8, 1972.

Senator FRANK CHURCH,
U.S. Senate,
Special Committee on Aging, Washington, D.C.

DEAR SENATOR CHURCH: You have asked for a reference to the Pope's statement: Pius XII, The Prolongation of Life, an Address to an International Congress of Anesthesiologists on November 24, 1957, *Osservatore Domano 4* : 393–398, 1958.

I think the crucial statement that you were interested in says: ***But normally one is held to use only ordinary means—according to circumstances of persons, places, times, and culture—that is to say, means that do not involve any grave burden for oneself or another.*** A more strict obligation would be too burdensome for most men and would render the attainment of the higher, more important good too difficult. Life, health, all temporal activities are in fact subordinated to spiritual ends. ***On the other hand, one is not forbidden to take more than the strictly necessary steps to preserve life and health, as long as he does not fail in some more more serious duty.*** [Emphasis mine]

Very sincerely,

HENRY K. BEECHER, M.D.

Senator CHURCH. Our next witness is Warren T. Reich, senior research scholar of the Kennedy Center for Bioethics, here in the District of Columbia.

Mr. Reich.

STATEMENT OF WARREN T. REICH, PH. D., SENIOR RESEARCH SCHOLAR, KENNEDY CENTER FOR BIOETHICS, GEORGETOWN UNIVERSITY, WASHINGTON, D.C.

Mr. REICH. Thank you, Mr. Church. I am pleased to be invited. I have submitted a copy of my statement to your staff.

Throughout all ages man has struggled to avoid, deny, or embellish death, for death has always been regarded as a personal enigma which defies explanation. Although some religions have brought death and its surrounding fears into the open and offered transcendent reasons for accepting it, by and large it has remained a taboo topic. Men have feared to discuss it openly and to acknowledge that death is part of life.

Yet in the past few years in this country, for reasons which are difficult to detect, death is being faced with an honesty, an openness, and seemingly with an equanimity that has rarely been witnessed. We may be turning our attention more openly toward death because of the experience of a protracted and what seems to be an unending war in which Americans are killing routinely.

Perhaps as a nation we are reacting to the grinding destructiveness of that war by asking ourselves: Why should life and death be so trivial? So that is one suggestion that comes to mind as to why we are more concerned about death today.

A second reason may be found in the fact that the medical sciences and medical technology have greatly extended the average life expectancy of our people, while our economic situation leads us to retire these people not at a later age as might be expected, but always earlier.

Consequently, a healthy, alert and rather large aging segment of our population is led to reflect on what will be next. They are raising questions about what it will mean to be dependent when most of their powers have wained, what it will mean to die, how they will be treated when they are dying, and whether they will be permitted to determine the conditions under which they will die.

The problem of "death with dignity" is no longer just a question for private speculation and personal struggles; it has become a topic of widespread public concern.

The Right To Die With Dignity

I would like to suggest—and, incidentally, it turns out very much along the lines of Professor Beecher, who has just testified—that a very helpful principle in determining what "death with dignity" should mean, a principle that has more relevance today because of the existence of machines which take over some vital functions, is the principle that states that we must use all ordinary means for preserving life, even if there is no real hope of recovery; but extraordinary means need not always be used when no cure is possible.

This principle, if you dig a little more deeply, clearly implies that life itself is a fundamental good—a sacred value which ought to be maintained and preserved—but that life is not to be maintained outside every other consideration. This means that "ordinarily" all reasonable efforts should be made to preserve human life, but that it is not unethical to permit a person to die by not using extraordinary means.[2]

Consequently, it can be said that the duty to preserve life is not absolute; it is relative. Even the questions as to what constitutes an ordinary means and what must be counted as extraordinary means are quite relative.

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[2] Kieran Nolan, "The Problem of Care for the Dying," in *Absolutes in Moral Theology.* Charles E. Curran, ed.; Washington-Cleveland: Corpus Books, 1968.

There was a time when the respirator was an uncommon device, yet today it is very common. However, what is "common" or commonly available for medical care may not be an "ordinary" means in an ethical sense. In other words, an "established" medical procedure may not be one which absolutely must be used to preserve the life of a particular patient.

Some conditions relative to the patient may make the use of the respirator "extraordinary," at least in the ethical sense. For instance, use of the respirator might not hold out "reasonable hope of success" for a certain patient; it might serve only to maintain the signs of life without the consciousness and other qualities of life associated with the distinctively human. Therefore, it may be an "extraordinary" means of preserving his life because of the futility of the attempt, as well as due to such factors as the strain and expense involved.

Consequently, it is not always easy to determine what is an "extraordinary means" for preserving life, which may be omitted so as to permit a person to die with dignity. Several variable factors may make an effort "extraordinary." We have already mentioned the "reasonable hope of success" in reference to the quality of the life which will be preserved. Five other factors relative to individual patients can be listed:

1. *The strain, pain, and discomfort accompanying some treatment.*—This varies a great deal from individual to individual, and I would like to point out that all of these explanations add up to this, that one never knows and therefore cannot set a very determined policy, whether for a medical institution or for society at large, as to what does in fact constitute extraordinary means for keeping a person alive, because it is so relative to the individual.

For example, whereas for some people their psychological state of mind makes a terror of all surgery, others can sustain pain with considerable equanimity over a long period of time; for others, suffering may have a positive moral and spiritual value, and for still others, the strain and depression involved in seeing one's own life become the extension of a machine such as the "kidney machine" can make that procedure an "extraordinary means."

2. *The need for consciousness in one's terminal condition.*—There can be personal, family, and spiritual reasons for foregoing some medical treatment. This omission will have the negative effect of shortening one's life but at the same time what may be an overriding positive effect of retaining as much consciousness as possible .

Then too, the terminally ill may have the legitimate desire "to go home and die in peace with their family." Because this personal preference can be both legitimate and strong, the customary medical treatment the patient would have received in the hospital can become an "extraordinary means" for preserving his life. Yet it frequently happens that physicians will resist and refuse this request with what I believe is an unjustifiable resistance.

3. *The cost of the procedure.*—It is part of the definition, you see, of the principle of "extraordinary means" that some measures may be considered "extraordinary" if they are too costly. In a way, it seems to me this goes contrary to common sense which tells us that money should, generally speaking, not be an obstacle to rescuing and support-

ing the life of a fellow human being; yet we know that it is, and sometimes understandably so.

If a man would have to spend $35,000 a year to maintain indefinitely the life of his wife who was afflicted with irreversible brain damage, and in so doing would have to go deep in debt, thus jeopardizing his own future medical care and that of his children, the cost would soon make her medical care an "extraordinary means" of preserving her life.

It is obvious that the business of sustaining human lives is a very frail endeavor, which depends on many contingencies. One of those contingencies is the availability of resources. Much as we may regret it, we will never have a situation in which all possible resources are available to every person—geographically, technically, and financially.

It is unrealistic to think that, simply because a life-support system such as the kidney dialysis machine has been developed, it ought to be made available to every person in every circumstance, together with all required professional assistance, regardless of even the most exorbitant costs.

It seems to me, then, that cost is necessarily a factor, and that some people will unavoidably die because the cost of keeping them alive really is excessive. But "excessive" in relation to what? To other priorities? How can we in good conscience say that a kidney machine is too expensive to keep a deserving and otherwise healthy person alive, because we must spend millions of dollars daily to destroy lives, cities, and human environment in South Vietnam, North Vietnam, Cambodia, and Laos? What kind of priorities do we have when our health expenditures are only a fraction of the billions of dollars spent annually on the war in Southeast Asia?

4. *External factors.*—Such as preservation of the life of a person to assure just inheritance, or for the "common good"; and

5. *Special reasons of conscience.*—Such as the religious conviction of Jehovah's Witnesses that blood transfusions are prohibited.

It might be helpful to make an additional comment at this point on the principle of ordinary and extraordinary means. The distinction between ordinary means which must be employed to preserve life and extraordinary means which need not be employed is not an objective, unchanging list of "do's and don'ts." It is a guide which is helpful in prodding people to evaluate very closely the total human situation so as to arrive at just and humane decisions which will protect both the right to live in dignity and the right to die in dignity.

A good practical knowledge of what may constitute ordinary and extraordinary means facilitates the decisionmaking process but doesn't necessarily make the decision an easy one. It is one thing to start a respirator and quite another thing to turn it off. When the patient is put on the respirator, the action may be more than a benign one—it may be quite correct ethically, because it is an ordinary means for preserving the life of someone who has a right to life.

Once a person has made the ethical decision that it is indeed ethical to terminate some care, it may be difficult to carry through on that. Yet, to turn off a respirator may also be both benign and ethical—ethical because continued use of the machine has become an extraordinary means for preserving the life—or signs of life—of someone who has the right to die. It may not always be easy to turn off the respirator—guilt feelings may linger and law suits may threaten. But it becomes somewhat easier to do if you know it can be ethically correct.

More clarity is needed on this point, and there is need for more counseling of physicians and hospital staffs on the moral issues concerning dying. In one hospital, when a decision is reached to turn off a respirator, several staff members pull the cord simultaneously so that no one person feels entirely responsible. Rather than using a roulette method for shifting guilt to an unknown accomplice, or for sharing responsibility artificially with a larger group, it would seem more rational to confront the issue itself and make a decision on the basis of whether one does indeed have the obligation of preserving life "at all costs."

The problem of when and how to turn off the machine might not be so acute if there were greater acceptance of the more fundamental notion that there comes a time when a person can and should be permitted to die—in dignity.

To say that ordinary means should be used to preserve life is to say that it is unethical to neglect ordinary means. This also implies that (active) "euthanasia" is rejected as unethical on grounds that this would be an unjust and direct killing of an aged or ill person by someone who does not have the moral right to make such a disposition of human life. The term "euthanasia"—from the Greek, meaning "to die well"—has commonly taken on this meaning of "mercy killing," or of direct killing "for humane motives," or, more euphemistically, "the painless inducement of death."

Next, I think it may be helpful to make a distinction between euthanasia and some other terms.

UNDERSTANDING THE TERM "EUTHANASIA"

Senator CHURCH. May I just interrupt at that point, please, but I agree wholeheartedly with what you are saying. There is a popular understanding of the term "euthanasia" which relates to the latter definition, that is, some affirmative act on the part of the physician that induces a death, and that has often been called "mercy killing," and I agree with you. Ethically I have great problems with that, and I think most people do; not only ethical problems, but also highly practical considerations like those that were brought up yesterday by Senator Percy. Who can be trusted under the circumstances to administer the blow, when so many might be motivated by selfish considerations and/or pecuniary considerations and not really by the good of the patient?

So I have all kinds of problems with this popular understanding of the term "euthanasia." I tried to stress yesterday when these hearings began that this was not an inquiry into that kind of understanding of euthanasia, that it had nothing to do with that kind of euthanasia, and yet I noticed in the New York Times today, its story unfortunately, I think, places the whole emphasis on euthanasia as though this were—despite every effort we made to make it clear that it was not—an inquiry into the propriety of euthanasia.

Now I don't mean to single out one newspaper, but I do think it important that we try to keep this hearing on track so that these misconceptions are not broadcast to the country at large, and I have emphasized this particular aspect over and over, and I have to do it again today.

By contrast, I thought that the article in the Washington Post was a very well-balanced presentation of the subject as the committee is endeavoring to inquire into it, so I just take this opportunity, because you have made such an explicit contrast between the two understandings of euthanasia, the two contrasting understandings of euthanasia, I think it is an appropriate place to insert in the appendix to the record these two stories, and for that reason I have interrupted your testimony.

(See appendix A, p. 96.)

Mr. Reich. Thank you, Mr. Church, for the clarification.

As a matter of fact, I can also add that this was my understanding of the purpose of the inquiry here, so let me say for the record for purposes of clarification that the entire second part of my statement should be considered simply as an explanation of the main point of my statement, which is this: that "death with dignity" should mean permitting a person to die with dignity, which means to live with dignity in his terminal days, and that this may indeed be called "dying well."

So it is on the notion of "dying well"—"death with dignity" meaning "dying well"—that I thought perhaps at least as a footnote the clarification of terms may be helpful, and perhaps even a substitution of terms.

Euthanasia vs. Benemortasia

"Euthanasia" can also mean "passive euthanasia," or the right to be permitted to die in dignity, as this paper has proposed. There is a major difference between these two kinds of "euthanasia," and that difference can be expressed in the following way. A physician may not take a life, but he does not have to preserve it in all circumstances.

Because the term "euthanasia" when used alone has commonly taken on the more active meaning of "voluntary euthanasia," or taking the life of a person, some believe that a different term should be used to refer to a good death, without the term implying whether a good death must be painless and/or induced. For this reason, Prof. Arthur Dyck of Harvard has recently coined the term "benemortasia" (from the Latin, *bene mori*, to die well).[3]

The ethical distinction between "active euthanasia" and "passive euthanasia," or between "euthanasia" and "benemortasia," is a significant one, even though the difference between permitting death—morally acceptable—and directly causing death—morally unacceptable—is not always a convincing one. To stop dialysis, to turn off a respirator, or to withdraw intravenous feeding may seem to be active, death-inducing actions, at least from a utilitarian point of view. The pain is relieved, the inability of the dying person to communicate is removed, and the person ends up just as surely dead as when life is deliberately terminated.

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[3] Arthur J. Dyck, "An Alternative to the Ethic of Euthanasia," in *To Live or To Die: When, How and Why*, Robert H. Williams, ed.; to be published, Fall 1972.

But it does make a difference how a person engages himself in causing a death. Deliberately to terminate a human life by employing a lethal instrument or substance in an action which has precisely this immediate purpose is ethically objectionable in a way that is not true of the refusal of techniques for prolonging life. The reason for this is that man, by nature, does not have a complete moral right to death control. Every human life has some worth. "Thou shalt not kill" is an indispensable prerequisite for preventing the destruction of the human community, for preserving the meaning and worth of one's own life, and for signifying the fact that others always have a stake in each human life.

Although some acts of killing may be justified, no society can be indifferent about the taking of human life. An act of self-defense which results in the death of the attacker can be morally justified precisely because it is an act of saving a life. Active euthanasia, even for motives of compassion, is an affront against human life itself which is something of intrinsic worth.

It is true that people in the profession of medicine and ethics who favor voluntary euthanasia do so out of compassion for those who are painfully and terminally ill, as well as out of concern for their dignity and freedom of self-determination in choosing how and when they will die. But compassion can be shown and freedom can be enhanced in different ways.

An ethic of benemortasia can be explained in terms of a "passive euthanasia," which actually enhances the freedom of the patient, who is free to accept his own dying and to decide whether he will have any particular medical care. A decision to withhold dialysis, for example, can actually be seen as a freedom-enhancing, pro-life action, because it is the means whereby the patient (assisted by the physician) removes what has become an unnecessary burden (the "extraordinary means"), thus making it possible for him to live the remainder of his life, no matter how brief, in what for him is greater dignity, and to live in dignity during the dying process.[4]

Briefly, a good death or "death with dignity" is one which enhances the freedom of the individual in choosing how to live while dying, and at the same time affirms the value of life, even the waning phases of life.

PATIENT VS. PHYSICIAN?

Among the many obstacles preventing "death with dignity," one set of problems can be singled out: those surrounding the practice of medicine. We will not even mention the harm that would be done to the patient and to society by legalized voluntary euthanasia, when the physician is given the power and the duty to take someone else's life and is encouraged to decide that someone else's life is no longer worth living.

If we turn our attention to "death with dignity," or "passive euthanasia," we see that among the principal obstacles preventing a dignified death are the competing priorities which influence the physician's decisions to treat the patient.

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[4] Cf. John Cavanagh, M.D., "Bene Mori: The Right of the Patient to Die with Dignity." *The Linacre Quarterly* 30 (May 1963), 60 ff.

The terminal patient may desperately want rest, peace, and dignity; yet he may receive only infusions, transfusions, a heart machine, and a team of experts all busily occupied with his heart rate, his pulmonary functions, and his secretions, but not with him as a person.

Why are the terminally ill not more highly respected as persons? It is due, at least in large part, to the vitalistic urge of the medical profession which makes biological continuance the absolute good, even when the price of its continuance is the loss of the dignity of the individual. Medical schools produce competent technicians who view the body as a highly sophisticated machine. Disease is a challenge—something gone wrong in the system. Medicine is a contest, a struggle to set it right again with technical know-how.

Death is the ultimate defeat, a sign of failure. Little is done in medical schools to develop in physicians and surgeons the attitude that sickness and death are aspects of human experience.

Consequently, many physicians are ill at ease with death and dying. The result is that physicians are frequently inclined to struggle to prolong the life of a hopelessly ill patient "for 24 more hours," even against the best interests and explicit wishes of the patient. This vitalistic conviction, which makes it difficult if not impossible for many physicians to see limits to the role of medicine, may also explain why death increasingly occurs in larger metropolitan institutions, where dying is more lonely and more dehumanized than at home.

There are probably many physicians who sense the abuses inherent in the relentless drive to preserve life at all costs, but who are reluctant to admit it or to act always according to their convictions.

Senator CHURCH. Doesn't it follow that if we were to succeed in stopping death medically that we would then have to stop birth? We live on a contained planet, and obviously if death were stopped and births were not, the survival of the human race would be just a matter of mathematical computation.

Mr. REICH. I think the question is highly speculative and has very little practical import at the present time.

Senator CHURCH. Oh, I know that. That was a purely academic question. I don't think we are about to accomplish this, but I am just saying if we were, it is obvious that having accomplished that, we would then have to face the other side of the coin.

Mr. REICH. Oh, of course. If for no other reason, for mathematical reasons.

Senator CHURCH. Sure. We would have to stop birth.

Mr. REICH. But my point was that research into the causes of aging and alteration of the process of aging, you can scarcely say it has begun, and men of science, I understand, are not quite sure where to begin, what the key to it might be.

Senator CHURCH. Well, I am not even certain that it is an objective that we ought to undertake, even assuming that we are nowhere near accomplishing it or reaching it. It seems to me that each one of us as individuals has a right to live a certain length of time, but there are our progeny that ought to have a similar right, and that is that. So let's direct our scientific efforts to more rational goals.

Mr. REICH. Another comment about the problem of the medical profession at times creating obstacles to death with dignity. It must be admitted frankly that there is a fear of malpractice suits. Public censure puts physicians in a position of great stress and prevents them from practicing more humane medicine.

COURT DECISIONS

A similar kind of pressure is put on the practice of medicine by court decisions which recently have opposed death with dignity because of the vitalistic urge. For example, last January New York City's Cornell Medical Center won court permission to install new batteries in a 79-year-old man's pacemaker over his wife's objections. The State supreme court justice, in declaring the patient incompetent, named the hospital director his guardian "to protect or sustain his life."

Another cause of serious violations of the right to die with dignity is the pressure to learn from experience in teaching hospitals. Particularly in intensive care units, patients who have a right to die peacefully—who are very old or who have terminal cancer or whose brain is irreversibly damaged—are given treatment that is more heroic than humane. A similar obstacle to the humane practice of medicine comes in the form of experimentation on the dying. Scientific, educational, and financial pressures combine to push medical personnel and medical institutions into some depersonalized and even violent treatment of the dying as a part of some research project.

All these cases which have involved abuses of the right to die with dignity focus on a major underlying cause: the mistaken notion that it is the physician's task to determine who shall receive what care, when, how, under what circumstances and at how much cost. There is an urgent need today to reassert the fundamental right of the patient to determine his own care. For too long it has been assumed that the physician makes all major decisions about treatment, including whether there should be any treatment at all, and then, when necessary, obtains the consent of the patient—or, more accurately perhaps, manages to obtain an expression of the patient's concurrence in the physician's decision, which is quite a different matter.

It is true that the physician's knowledge of the case and his diagnosis place him in a key position in the decisionmaking process—and sometimes, because of the complexity of the case and the disadvantaged condition of the patient, his responsibility may be heightened. But this should not alter the presumption in every case of the need for informed consent. Frequently it is only the patient who knows when the physician's act of prolonging life has become a technique for prolonging or deferring the act of dying.

The tradition of informed consent is clear—in ethics, law, and in medical experimentation. But often that right seems to vanish when the same patient is dying and neither he nor his family is informed that he will become an appendage of a machine. It is utterly essential that the practice of medicine once again become more patient centered and that to accomplish this we take much more seriously the right of the patient to determine his own care by informed consent.

If this right is to be more fully respected, a change of attitude will be required on the part of much of the medical profession. For, instead of being an elitist profession, it must be a service profession.

Instead of autocratically determining how the sick and dying are to benefit from medicine, physicians must show more respect for the discretion of the individual.

If, up to now, the physician has exercised a somewhat too extensive autonomy in the decisionmaking surrounding treatment—particularly in the case of "surgical autocracy"—it should be recalled that there are at least two other major "autonomies" of his which have supported the first one and which also are now being challenged: (1) the physician's right to select his patient, and (2) his right to set his own fee.

These three major autonomies are now seen to be conflicting with the right of the public to quality medical care. I believe that the entire question of the right of the patient to consent to, and in this sense determine, his own medical care, is very much dependent on the larger question of the extent of the right of the public to a just distribution of quality health care.

Certainly the power created by these three medical autonomies must be radically redistributed, if the rights of all are to be respected. Even before all the practical questions of medical and health care distribution are settled I believe a helpful attitude can be learned from the example of other countries: that medical care is not the dispensing of a privilege but the rendering of a service.

A RIGHT TO LIVE AND A RIGHT TO DIE

I would like to make a concluding remark and that is this: There is a right to live and a right to die. Neither of these rights comes from human legislation; and public enactments, no matter how wise, responsive, and circumspect they may be, can never completely and infallibly guarantee these rights.

But much can be done in our contemporary American society to create attitudes that are favorable to the right to die with dignity which, after all, is not very different from the right to live with dignity.

Much can be done to educate the public on the right of the patient to consent to his own treatment and to decide—when necessary, assisted by close relatives in consultation with the physician—when death should be accepted.

But there are many obstacles which make this task difficult in American society today. For how do you create American attitudes favorable to death with dignity while the same country, its men and its resources, are turned toward making war and killing countless millions without the slightest semblance of dignity? How should the American be taught to have a noble attitude toward the quality of life of the dying person in this country while he is being taught to have a callously ignoble attitude toward people being killed by us abroad?

If we are concerned about the public conscience of this Nation and have its social interests at heart, how can we go about creating a "selective indignation" which requires that we deplore the circumstances under which people die of natural causes in this country, while we sanction one Hiroshima after another, week after week, in tonnage of munitions dropped on anonymous millions in Southeast Asia?

As a nation we should be deeply concerned about death with dignity. But that will first require the development of a more sensitive larger conscience that shows more signs of being sensitive to the value of all human life.

Senator CHURCH. Thank you very much for an excellent statement.

I agree, of course, completely in your appraisal of the immorality of the war in which we are engaged in Southeast Asia. But I do also believe that we also observe a double standard as compared to the ethics that apply to individual conduct and the ethics that apply to national conduct.

"Thou shalt not kill," for example, though applicable to individual conduct within the Nation, has never been held applicable to national conduct.

Otherwise, of course, war itself would be prohibited by that commandment. So, historically, we have applied quite a different standard to national conduct.

Now, that may be a mistaken application of ethics, but it is nonetheless a historical fact, and it continues to be, but aside from that aspect of your testimony, I think you made an extremely fine analysis of the problem as it affects the question of death with dignity.

I think there has been a consensus in the last day or two of these hearings that nearly everyone—at least our witnesses who disagreed on other matters all seemed to agree with the proposition that a patient has the right to determine whether or not he will accept medical care in the first place, and, if he does, what type of treatment he will accept, and he always has the right of refusal. I don't think there has been any serious problem on that score.

But what happens, the argument begins to develop at the point where the patient himself is no longer capable of making that decision, either because he is not fully informed by his doctor and therefore cannot make an informed judgment in his own case and thus exercises no decision, or because he has been rendered by his affliction unconscious or irrational and therefore incapable of judging.

Now, that is the focus of the argument really. What happens in those cases?

I noted in your testimony you said, "There are probably many physicians who sense the abuses inherent in the relentless drive to preserve life at all costs, but who are reluctant to admit it or to act always according to their convictions. A fear of malpractice suits and public censure puts physicians in a position of great stress and prevents them from practicing more humane medicine. A similar kind of pressure is put on the practice of medicine by court decisions which recently have opposed death with dignity because of the vitalistic urge. For example, last January New York City's Cornell Medical Center won court permission to install new batteries in a 79-year-old man's pacemaker over his wife's objections. The State supreme court justice, in declaring the patient incompetent, named the hospital director his guardian 'to protect or sustain his life.' "

Thus taking the matter out of the hands of his wife and placing it in the hands of the hospital itself.

CHANGE IN THE LAW

How do we ever establish death with dignity until we begin to cope with the problem of the law and the concepts of the law, the decision of the courts, if this case is going to characterize court decisions? I don't know that it does, but if it does, then surely we are going to have to consider changes in the law itself before we are ever going to accomplish the goal. Doesn't that follow?

Mr. REICH. I am not so sure that a change in the law is always either the necessary step or the key to the problem, since this is not a statutory problem usually, but is a matter of the court decisions, and, as a matter of fact, whereas this decision was unfavorable to death with dignity, some court decisions are far more favorable, insisting on the right of the individual to choose not to be treated or the right of the next of kin, so there is an inconsistency here in these decisions, and I think it is highly unfortunate and it is an instance of a kind of a phobia that seems to be spreading through the country.

Dr. Beecher spoke just a few moments ago about two different brands of medicine in this country: East coast and west coast.

I find that highly scandalous for the same reasons which perhaps your question is implying, that the pressure is bad enough from the written or unwritten standards of the medical profession, but it is exacerbated by these court decisions and other pressures all out of a fear of suits.

Senator CHURCH. Well, if it is exacerbated by these court decisions and if there is this common fear that malpractice suits might follow, then how can you say that more precise definitions of the death and the more precise guidelines with respect to permissible medical practices as applied to terminal illness would not be advisable?

Mr. REICH. I believe I stated not that they would not be advisable, but that they are impossible to set out in great detail, either in legislation or even in hospital policy or other such devices such as codes of medical ethics. But they can, indeed, be set forth in terms of medical ethics or as guidelines for the practice of medicine which can influence the decision of physicians, but I would like to insist once again that decision is not primarily that of the physician, but of the patient.

It calls for a great deal of education to accomplish, I think, what you are striving for. Legal enactment may be somewhat helpful for other legal devices.

For example, the very possibility of committing a patient to the protection of a court is, itself, a legal device to protect the freedom and the dignity of an individual, and I believe a case of that would be the child of the Jehovah's Witness for whom or on whose behalf the parents attempt to refuse a blood transfusion. Whereas, the courts would be faulty in forcing an adult to receive a blood transfusion, they are correct, I believe, in restraining the adult from prohibiting the infant from receiving such a blood transfusion; and for those kinds of things a court decision, or law, is very helpful, but I would like to propose that the protections which you seem to be seeking and which I surely am seeking have to be obtained within the medical profession itself, and I believe that the broad cross-section of the medical profession has to simply start acting on these convictions about what constitutes the dignity of life and what constitutes the right of the patient in the circumstances to determine that for himself.

Senator CHURCH. Senator Kennedy?

Senator KENNEDY. I first of all want to commend Senator Church for this series of hearings, and I regret very much being unable to be here earlier, Doctor, to hear your testimony, but I do want to commend our chairman for having these hearings and for the leadership he is providing in all matters affecting the elderly.

ADVISORY COMMISSION ON HEALTH SCIENCE AND SOCIETY

Doctor, we in the Senate have considered and passed a resolution to establish on Advisory Commission on Health Science and Society. The Commission would consist of 15 presidentially appointed board members from the general public in a variety of professions, and the Commission has been authorized $1 million a year for 2 years.

I don't know if you would like to make any comment about the usefulness of this type of study in making recommendations to us or ought we to be thinking in other terms. I speak now as the chairman of the health subcommittee which has been interested in this problem as to what we might do legislatively to try and ventilate it, beyond the extraordinary useful work of this set of hearings. I am just wondering whether you had thought about what you would urge the Congress to do on this subject.

Mr. REICH. Yes, Mr. Kennedy, I have thought about this, and those of us who are concerned in the area of medical ethics or bioethics have a very great concern about these questions about science and society, and medicine and society, and I believe something could be said positively about this and perhaps also of caution.

I believe it would be highly desirable for this National Advisory Commission on Health Science and Society to be set up. I would see as its main purpose the gathering of essential information, some of which has never been done before, and I don't see how a profession or a nation can make wise and prudent decisions without the kind of information and evaluation that this kind of commission might establish.

Furthermore, I think its purpose would be the education of the public by calling to the attention of the public many of the issues surrounding life and death and many of the criteria upon which decisions are made like who shall be permitted to live and not live. These decisions are being made, and I think it would benefit the public to know on what criteria these decisions are made.

So I think it would be a highly desirable Commission to set up, much as this particular special committee is accomplishing, I think, a very fine purpose in its educational pursuits.

I would add a word of caution, though, and I don't know if this word of caution would apply to the Congress, but it would apply to those of us who would be affected by this Commission, that there would be some fears—not certainly grave fears—about Government involvement in delicate decisions regarding life and death, Government involvement in the priorities of science and medicine.

I don't worry too much about these, particularly on the basis of the description of what such a commission would be, what its scope would be, its temporary nature and so on. So I am just mentioning that some people in the profession of medicine and ethics may feel some slight intrusion on their autonomy, but I feel the majority would welcome it.

Senator KENNEDY. I think about, for example, our manpower legislation where we have outlined a series of suggested areas of interest, although we didn't require medical schools to move into those areas at this time.

The Senate bill initially passed provided the requirement that they develop a plan which would include seven different areas of concern including use of paramedical personnel. However, that was dropped as a requirement in the conference with the House.

But I am just wondering, for example, in health manpower whether we ought to be trying to provide some incentives to medical schools to begin to develop training programs or curricula in this area.

KIDNEY DIALYSIS MACHINES

And I think of another area which I am sure you are familiar with. The question of our responsibility raised by the kidney dialysis machines, where we provide a certain number, and in some States they are provided under the Medicaid program but in other States they are not included. Now we find cutbacks in the Medicaid program. For example, in New York City we had a brewery worker who just could not afford to have it any longer, and just told us with the cutbacks that he was going to die.

We had another witness who said that they didn't want to face the continuing financial drain—you know how costly it is for a kidney dialysis machine. Even just the medicines cost perhaps $2,500, $3,000 a year. Facing the never-ending draining of their financial resources, they requested the machine be unplugged and he just asked to be left to die with dignity.

And you know, I don't know how HEW, decides who is going to get those machines and who is not, what criteria they are going to use, what they are going to advise the States. I am just trying to think of what areas we in the Congress must explore. What kind of studies, what kind of information should we really seek out, so that we can provide either the incentives or the rewards to the various institutions within our society, theological, medical and public groups, to fulfill our responsibilities. What we are perhaps trying to do now is to identify some of those areas.

I know this was at least the thought behind the introduction of this resolution which has passed the Senate and is now before the House. This was with the initiative of Senator Mondale of Minnesota. I was interested in your reaction to our particular dilemma in this area.

Mr. REICH. I think some of the dilemmas are of direct concern to the Congress and to the public and perhaps others not so directly. The question of manpower and medicine, I think is an acute one, and although I cannot speak from the field of community medicine, I am acutely aware of the fact that in ethics a very important principle is that of distributive justice or, translated into the field of medicine, it would mean that the public has a right, in my view, to a just, and wide, and equitable distribution of quality health care, and I just don't see how that can be accomplished unless there are some adjustments in our medical delivery systems as well as in the manpower that is used, particularly by way of encouraging some of the newer medical professions.

There is another point that I mentioned, Mr. Kennedy, having to do with the renal dialysis and there are two questions here that are of great concern to the public, that I think very much should be called to the attention of the public and perhaps the Congress can do something that would be helpful.

I have mentioned in my statement, a copy of which has been submitted, in what I thought was rather strong terms— I intended it to be very strong in any case—that cost ought not be the determining factor in deciding who will live with dignity and who will die with dignity as it is.

I do admit and have admitted in my statement that cost is necessarily a factor. One cannot assume that as soon as some new technique or instrument is devised for the improvement of health care that it immediately ought to be made available geographically, technically, and financially to everyone who might benefit by it, but there are certain more accepted means of supporting health and life, at least for a temporary period, and under that category would come the machines for renal dialysis.

I think it is scandalous, publicly scandalous to say that those who otherwise would be healthy and deserving are not able to have the benefit of renal dialysis of the kidney machine simply because it is too costly, when in fact our expenditures are far too high in other pursuits, particularly in the pursuit of war.

I notice that Professor Beecher of Harvard who has preceded me in testimony said almost the same thing, singling out other medical problems receive care disproportionately higher than that for acute renal failure.

Another issue that this brings up, I believe, that should be of concern to the public, and that is the question you asked about how does one decide who shall benefit by the use of a kidney machine when not all can live because not all can have access to it.

There are criteria that single out in a wrong way, I think, social worth of an individual as a criterion for determining who shall benefit by it. It comes under different names, but it frequently amounts to the question of the social worth, worthiness of the individual, which is not very different, you know, from the question of what will his productivity be, productivity being kind of the number one criterion for usefulness of so many of our citizens, and I think that this is unfortunate because it singles out a very false primary value. Furthermore it is an invitation to discrimination against those who are weaker, those who are not so advantaged socially, racially, and economically, and so forth.

So I think these are among the many issues that ought to be singled out and identified in a public way for the benefit of the American public.

Senator KENNEDY. Just on this last point, there are a number of communities in the renal dialysis area where they set up different groups to make decisions as to who would get the machines and who would not. But it has turned out almost uniformly that they are going to the younger rather than to the older.

As you mentioned here, these false standards being established brought about enormous consternation among many of the groups after they reviewed their experiences on these panels for a year. They were deeply distressed that they were playing God and felt that they were obviously lacking any ethical guidelines to assist themselves. It brought enormous confusion and self-doubt to the individuals who were involved, let alone the people that were being affected. I think it is a forceful reminder for all of us that we must address ourselves to the problem and try in a conscionable way to help ourselves as a people and as a society to come to grips with it. For far too long we have not.

I want to thank you very much for appearing here and for your comments, and again thank the Chair.

Senator CHURCH. Thank you, Senator.

Thank you very much, Dr. Reich, for your testimony. It has been most helpful.

Our last witness this morning is Alexander Capron of Philadelphia, assistant professor of law at the University of Pennsylvania. We have been looking for a lawyer for 2 days because this certainly crops up in all of the testimony.

I am happy to welcome you here and urge you to proceed with your statement.

STATEMENT OF ALEXANDER MORGAN CAPRON, THE UNIVERSITY OF PENNSYLVANIA SCHOOL OF LAW, PHILADELPHIA, PA.

Mr. CAPRON. Thank you, Mr. Chairman. It is a pleasure for me to present some brief remarks this morning in response to your request for a preliminary review of the legal aspects of "death with dignity." My comments are brief, and I shall rely on your questions to direct my attention to areas in which you are interested that I may have overlooked.

A RIGHT TO DIE?

These hearings pose the question: Is there a right to die? This may sound rhetorical, since death is an inevitable part of existence and perhaps even an essential one. Indeed, without "death" one would be hard pressed to define human "life." Yet, the continuing advance of medical science makes the question of a right to die increasingly less hyperbolic.

You are already familiar with some of medicine's growing arsenal in its struggle against death: artificial respirators, pacemakers, heart-lung machines, hemodialyzers, wonder drugs, intravenous sustenance, and replacement organs, both natural and man made. The prospect that these new theraputic devices will come into wider use raises many fascinating problems, among them the need to reexamine the "definition of death" and the implications for population and economic policy resulting from a general prolongation of average life span through medical intervention with the elderly.

Time does not permit an exploration of these issues here. One—the "definition of death"—is discussed in an article that I recently authored on behalf of the Institute of Society, Ethics, and the Life Sciences which will appear in the November issue of the University of Pennsylvania Law Review.

I might say here, Senator Church, that I had intended only an aside on the question of the "definition of death," but I would be happy to go into this because Senator Fong's questioning of Dr. Beecher earlier raised some confusion in this area. I would be glad to comment on the need for a statutory definition.

As I see it, the issue which the growing biomedical capacities raise for your committee is who should have what authority in deciding either to continue or to cease and abstain from treating a dying patient.

Before indicating what the law's response to that question has been, I would like to be clear about a few background, definitional points.

First, I take it that this inquiry is concerned with the treatment of protracted terminal illness, primarily but not exclusively among elderly people. At least for the moment, we need not discuss the question whether a competent adult in the ordinary doctor-patient relationship has a right to refuse treatment for an injury which does not threaten his life, nor are we addressing the case of sudden, emergency treatment for accident victims.

Senator CHURCH. That is correct.

CEASING TREATMENT

Mr. CAPRON. A second definitional point concerns how one should describe the actions involved in not proceeding with treatment. I do not believe it is particularly worthwhile to distinguish between ceasing to continue a therapeutic modality and abstaining from instituting one. In some situations the distinction may suggest itself, and the personnel giving treatment may employ it to ease their ethical burdens. But it is of doubtful legal usefulness, since it casts such great weight onto what appear to be spurious differences and it would turn medicine into an attenuated game of linedrawing. If legal rights were made to turn on the cease/abstain distinction an official opinion would, for example, be necessary on whether each injection of a drug or intervention of any sort were part of a new attempt to save a patient's life or merely a continuation of existing attempts. Moreover, emphasizing this distinction only obscures the real issue which is whether attempts—be they "new" or "continuing"—should be made to save the patient. Consequently, I employ interchangeably a number of terms to indicate that treatment should be halted.

A final point which should be clarified at the outset is determining what is meant when one speaks of "dignity" in this context. I would like to suggest that this is really a matter for self-definition in each case—in other words, that there is no particular treatment format which should be considered "dignified" for all patients.

This leads to a related point which involves the role of physicians and other treatment personnel. The very fact that these hearings are being held demonstrates a concern that people are not able to die in a fitting manner at the present time in this country. It would be unfortunate if this were taken as implying that doctors want death to be undignified and unnecessarily unpleasant for patients and their families. What they want, of course, is to save lives.

The crux of the problem, then, is whether dignified death is inconsistent with good medical care. There is a pressing need to make clear that these are consistent and indeed that good medical care is a means to achieving a dignified death as well as a dignified life.

If there is an inconsistency between what medicine ought to be doing and present practices, at least part of the blame can be laid at the door of the law. So far as I know there are no clear and certain answers to such questions as:

1. When can a dying patient choose to cease being treated?
2. Who else can exercise that authority on the patient's behalf?
3. What interests do physicians and the State have in prolonging treatment and what weight do these interests carry compared with others?
4. What action could be taken against a physician who—on his own initiative or at the request of a patient or his relatives—ceased treatment?

The law's initial answers to these questions are contained in a group of cases that arose from refusals by Jehovah's Witnesses to accept blood transfusions which physicians believed were necessary to save the patients' lives. American courts are divided in their response.

In one leading case, *In re Brooks Estate*, 32 Ill. 2d 361, 205 N.E. 435 (1965), the Illinois Supreme Court held that a competent adult who steadfastly opposed blood transfusions for her chronic peptic ulcer should not have been compelled to receive blood under a court order. Unfortunately, the appellate court's reasoning is not particularly useful for this discussion because it was grounded in the patient's first amendment right to free exercise of her religion.

A number of courts have reached an opposite conclusion. For examine in *application of President and Directors of Georgetown College*, 331 F.2d 1000 (D.C. Cir.), *cert. denied*, 377 U.S. 978 (1964), Judge J. Skelly Wright, sitting alone on an emergency appeal, ruled that a hospital was entitled to an order permitting it to administer blood over the patient's objections. While I disagree with the action taken by Judge Wright, this case is still useful for the issues it raises which, aside from the religious factor, seem very similar to those raised in the death with dignity situation. I would like to canvass these briefly.

THE HOSPITAL'S RESPONSIBILITY

1. *The hospital's responsibility.*—Judge Wright noted that: "Mrs. Jones was brought to the hospital by her husband for emergency care, having lost two thirds of her body's blood supply with a ruptured ulcer. She had no personal physician and relied solely on the hospital staff. She was a total hospital responsibility."

It is difficult, however, to see why the fact that Mrs. Jones "placed on the hospital the legal responsibility for her proper care" compels the conclusion that a transfusion must be ordered. It is understandable that the hospital and its staff feared civil and criminal liability and therefore "sought judicial direction," but the court's reasoning from the existence of a generalized "responsibility" to the ordering of a transfusion is less understandable. This has particular relevance for these hearings since an increasing number of patients die in hospitals.

A number of choices present themselves——

Senator CHURCH. Let me interrupt because that is a rollcall vote and I am pretty much in the position of the justice of the peace out in Idaho who in the midst of the case said, "Just go ahead with your testimony. I have go to go out and irrigate the north 40."

I think maybe in this case you can go ahead with your testimony. I will go and vote. I will read the balance of your statement en route and then I will come back and hopefully by then you will be finished with your statement and then I will ask you some questions.

Mr. CAPRON. A. Legal and economic steps could be taken to encourage the treatment of the terminally ill in their homes since the question of forcing a patient to receive unwanted treatment does not seem to arise in that context, for medical, legal, and psychological reasons.

B. If home treatment is considered medically or socially unacceptable the use of hospice-type facilities should be considered, with it clearly understood that patients in such facilities would not expect to have their lives prolonged by certain treatments.

C. Through legislation or judicial decision the responsibility of hospitals could be defined to remove the specter of liability where treatment was withheld at the patient's request.

THE ANALOGY TO SUICIDE

2. *The analogy to suicide.*—The creation of an explicit legal right for patients to decline potentially lifesaving treatment presents a second issue discussed in the *Georgetown* case: the court's analogizing of the refusal to be treated with "self-homocide."

Accepting, *arguendo*, that the State has a legitimate interest in prohibiting suicide, I do not believe that this interest or its rationale should be extended to preclude the choice of a dignified death. Suicide concerns the State because it devalues life as much as any form of murder and because attempts at suicide so often imperil the lives of other people. The same cannot be said of a dying patient, for he is not rejecting life but only declining further treatment with the recognition that death is inevitable.

In another case, *John F. Kennedy Hospital* v. *Heston*, 58 N.J. 576, 279 A. 2d 670 (1971), in upholding the appointment of a guardian to consent to blood transfusions for a Jehovah's Witness who needed an operation for a ruptured spleen, the New Jersey Supreme Court equated refusal to receive blood with suicide and declared that "there is no constitutional right to choose to die." Chief Justice Weintraub wrote that, "If the State may interrupt one mode of self-destruction, it may with equal authority interfere with the other." He then continued with *obiter dictum* which is highly relevant to this discussion:

> It is arguably different when an individual, overtaken by illness, decides to let it run a fatal course. But unless the medical option itself is laden with the risk of death or of serious informity, the State's interest in sustaining life in such circumstances is hardly distinguishable from it interests in the case of suicide.

While this statement seems to recognize a qualified right in certain circumstances for a patient to decline treatment, it is unfortunately very vague and continues to equate refusals on one side of its indistinct dividing line with suicide. Clearly, this is another area where much greater legal precision is necessary if medical personnel, patients and their relatives are to have a clear idea of the options open to them and their relative authority to exercise these options.

INCOMPETENCE

3. *Incompetence.*—The question of exercising choice brings me to the third point which I would like to draw from these cases. In the transfusion cases the patients were, on account of their medical conditions, apparently unable to make choices at the time court orders were sought. Moreover, the courts seem to have regarded the very refusal of treatment as an indication of incompetence.

Drawing again on the analogy to suicide, Chief Justice Weintraub observed in *Heston* that it is difficult to know "whether a decision to die is firmly held. . . . Then, too, there is the question whether in any event the person was and continues to be competent—a difficult concept in this area—to choose to die."

If the law on the right to refuse treatment were clarified as I have suggested, it would, of course, be impermissible for a court to infer that a dying patient who refused treatment was therefore incompetent. The problem of incompetence brought on by a debilitating illness would still remain, however. One way to lessen this difficulty would be to encourage people to discuss with their physician in advance the manner in which they want their terminal treatment to be handled.

Mr. ORIOL. How far in advance would that be? Before the illness begins?

Mr. CAPRON. I suppose it would depend on the individual situation. On the one hand, some people say that if you ask a person to contemplate what kind of treatment he would want when he is dying when in fact he is well, he is not going to be able to come up with any real understanding of what he is saying.

On the other hand, if you wait until a person is already terminally ill, you are faced with the pressures that operate on the dying patient, primarily pressures of concern for family, which goes both ways, both concern that they don't want to impose a burden on the family and also that they don't want to seem to abandon the family.

I personally would suggest that the discussion be carried on so that people are aware of this, and as early as possible they begin to discuss with their physicians and draw up a statement and discuss with their family what they would like to have done.

Mr. ORIOL. As something similar to the living will?

Mr. CAPRON. Perhaps something similar to that. Perhaps Dr. Poe can comment on a statement which appeared in the Medical World News last April which quoted a physician—I believe at Duke—who had drawn up instructions to his physician and an unnamed physician.

(The statement follows:)

[From the Medical World News, April 1971]

PHYSICIAN'S INSTRUCTIONS ON FINAL CARE

A major problem in management of the terminal or "vegetable" patient is determining what he himself would want done. His relatives may want to let him die, but even if the physician is inclined to agree, there is the possibility that the patient may be aware of what is happening and be lying there in mute, motionless outrage at what is to be done—or not done—to him.

To resolve any such doubts that might someday arise in his own demise, a noted Duke University professor of medicine wrote the following, with copies to be filed by his wife and his attorney:

"If I become ill and unable to manage my own affairs, I want you to be responsible for my care. To make matters as simple as possible, I will leave certain specific instructions with you.

"In event of unconsciousness from an automobile accident, I do not wish to remain in a hospital for longer than two weeks without full recovery of my mental faculties. While I realize the recovery might still be possible, the risk of living without recovery is still greater. At home, I want only one practical nurse. I do not wish to be tube-fed or given intravenous fluids at home.

"In the event of a cerebral accident, other than a subarachnoid hemorrhage I want no treatment of any kind until it is clear that I will be able to think effectively. This means no stomach tube and no intravenous fluids.

"In the event of a subarachnoid hemorrhage, use your own judgment in the acute stage. If there is considerable brain damage, send me home with one practical nurse.

"If, in spite of the above care, I become mentally incapacitated and have remained in good physical condition, I do not want money spent on private care. I prefer to be institutionalized, preferably in a state hospital.

"If any other things happen, this will serve as a guide to my own thinking.

"Go ahead with an autopsy with as little worry to my wife as possible. The anatomy crematory [at the medical school] seems a good final solution."

His statement was based on the kind of information and understanding which only a physician would have. But I think a statement with less detail in it providing what sort of cerebral accident would preclude the person wanting to be given further treatment would be possible on the part of nonphysicians as well if they discuss it ahead of time with their doctor and he explains what it means to be without circulation of the brain for 3 minutes, 5 minutes, or 7 minutes and what the likelihood of recovery in that situation is if resuscitative measures are applied for a day, a week or a year.

Mr. ORIOL. It is difficult for a healthy person to project his own terminal illness.

Mr. CAPRON. It is difficult but, of course, in many situations illness or advanced age is apparent before the final terminal illness; that is, patients with cancer may know that there is no great probability of treatment and they may be continuing for a while with treatment but they can foresee that within a certain amount of time—if the doctor discloses this—they can foresee that death will come. At that point, with death in mind, they may instruct their physician. If our society approached this as though death were not a taboo subject, an elderly person could discuss this with her or his physician and family—because it often will be the family that will be put in the position of making some choices once the person is so debilitated he won't be able to choose for himself—so it would be possible for that person to make an intelligent, incisive statement as to what sort of treatment ought to be undertaken once the final decline begins.

For the remaining cases where a prior specification of the patient's wishes could not be, or at least was not, made there will be need for criteria and procedures for others, such as relatives and physicians, to be able to step in. Present judicial decisions in this area, for example, *Petition of Nemser*, 51 Misc. 2d 616,273 N.Y.S. 2d 624 (Sup. Ct., 1966), suggest that a legislative solution will be needed.

I have tried here in cursory fashion to indicate that the law in this area is in a rather rudimentary and confused state. The cases closest on point are divided but excluding the religious factor the leading cases hold that a dying patient has no right to refuse the treatment chosen by his physicians. Yet, these cases also seem to recognize that a line must be drawn somewhere that some therapy is so risky, arduous or experimental that a patient may decline it. It seems to me that this line should be drawn quite close in; that is, the usual right of a patient to decline any treatment should not be negated by the imminence of death. If anything, we should be more solicitous of the wishes of the dying patient. The role of the law here can be to facilitate good medical care and to make clear that physicians are not liable criminally, civilly or administratively, if they follow their patients' wishes to forego some or all of the miracles of modern science.

We must relieve the pressure on physicians to overtreat and instead encourage them to counsel patients and their families and reassure them that refusal to accept life-prolonging treatment will not lead to their being abandoned medically and left without medical support for relief of the pain of dying, by which I mean both the physical and the psychological. In sum, the law needs to look for ways of clarifying the right of patients to a dignified death and at the same time it must be mindful of our tendency to neglect the dying and be vigilant against the consequent potential for abuse of the system.

UNIFORM DEFINITION OF DEATH

Mr. ORIOL. Thank you for a very helpful and much needed statement, as Senator Church said. I know that on the Senator's mind are questions about present liability of the physician, but perhaps while we are waiting for him to come back I could ask you what you believe should be the procedure for arriving at a uniform definition of death.

Is it a matter of State statute, changes in medical ethics, some Federal action, or perhaps a combination of all?

Mr. CAPRON. The reference I made earlier to an article in this area would help to clarify this. This is an article which I have drafted on behalf of the Task Force on Death and Dying of the Institute of Society, Ethics, and the Life Sciences, on which Dr. Beecher also serves, which will be appearing in the University of Pennsylvania Law Review in the fall. I will be happy to send you a copy then.

Dr. Beecher and I actually disagree on this point. This is not a statement which has been adopted by this task force. Dr. Beecher expressed the viewpoint that we can rely on physicians and their practices, particularly in adopting the so-called Harvard criteria for bringing about an adequate solution to this problem.

I don't believe that is so, and I think that the case down in Virginia against Dr. Lower and the other transplant surgeons which arose from a 1968 transplant illustrates the problem. In that case a heart was taken from an accident victim and the brother of the victim ended up suing.

He sued on two grounds. First, he claimed that no one had given consent, which was not contested, but the doctors claimed they had made adequate efforts to locate the next of kin and they were unable to do so. The second point raised was whether or not the man from whom the heart was taken was dead at the time.

The doctors had applied basically the Harvard criteria here; that is, that the man did not have any neurological activity. When the case came to trial the judge declined to adopt the medical or so-called Harvard definition of brain damage as the definition in a preliminary ruling.

By the time the case went to the jury, however, he modified his view. I don't have a copy of his charge but basically he permitted the jurors to consider all the medical testimony in deciding whether or not the person was dead, although he read them Black's Law Dictionary which says that it is incomplete until the cessation of all vital functions, which, of course, would include circulation and respiration as well as mental function.

The jury acquitted the doctors. This, I think, is a very ambiguous result. It is not clear what the jury did. It is certainly not clear what the judge did. Of course, that is only a trial decision.

Mr. ORIOL. In the layman's mind that case is usually regarded as establishing brain death as actual death.

Mr. CAPRON. It certainly does not do that. He refused explicitly earlier in the trial on a motion that he was being asked to charge the jury in brain death and he declined to do that. The defendants sought to dismiss the case because they said the testimony had shown that the man was dead and there was no cause there. The judge said he had to stick by Black's Law Dictionary. Yet, when it went to the jury both definitions went in.

The result of the verdict in that sort of case is, of course, unfathomable and the plaintiff has appealed the case, and the Virginia Supreme Court may adopt explicitly one definition or the other. The fact that the brain definition was used at all is a grounds of complaint, as I understand it, on the appeal.

I don't think it is fair to doctors. Dr. Beecher commented on this. I certainly don't think it is fair to the patients, either. We not only have to be concerned, as he said, with the "doctor's neck" but with the patients' lives. You may have some patients who are alive by what is the generally socially accepted legal definition and if that definition is going to be changed, I think it should be changed by law.

I do think, however, that if we adopt statutes these would probably be State statutes. The commissioners on uniform State laws did a very excellent job on promulgating the Uniform Anatomical Gift Act. That has been adopted in all the States and the District of Columbia so that provides a good indication that in this area we can get uniformity without having Federal legislation. I think it would be odd to have Federal legislation here but I don't believe that it will be adequate to rely on court decisions because you will have great uncertainty.

MODEL STATUTE—HARVARD CRITERIA

The law that should be adopted, it seems to me, need not contain the Harvard criteria.

The model statue which we set forth in the article suggests merely that in the cases where the traditional criteria have been obscured by artificial means of maintenance, (primarily in the respirator, which keeps the lungs going and therefore keeps the heart going); the fear has risen that you are basically ventilating a corpse; and the law would permit the physician to rely on the total and permanent cessation of brain function. Yet it won't write in any particular criteria just general standards.

It seems to me to be proper for the law to speak on that level. The kind of questions that arose not only at the time of the *Lower* case in Virginia but in a number of other transplant situations show that there was a great public unrest and disquiet.

If there is going to be a change in such a fundamental concern as what is a dead or living person, it seems to me that that should come about through some sort of public debate and official action.

Senator CHURCH. Did you have some sort of proposal in the way of a statute?

Mr. CAPRON. Yes, I do. I mentioned it before, Senator. The reference early on in the testimony is to an article which will be appearing this fall in the University of Pennsylvania Law Review which I have drafted on behalf of the Task Force on Death and Dying at the Institute of Society, Ethics, and the Life Sciences, and I would be happy to submit a copy of that to you, but on the request of the editors of the law review that it not be published as of yet, so it may appear in their review, and, of course, it also will be undergoing final editing.

The thesis of that article—I will summarize it briefly for you—is that there is need for public action, that we cannot rely, as Dr. Beecher suggested, on physicians changing their practices. And, it is not an area where the public will be satisfied with incomplete decisions, which there are sure to be.

Second, that the public action should come through the State legislatures because the common law method is quite uncertain, quite slow and very risky for the individuals involved. I do not think we should be encouraging individual physicians just to act out their own definition of death and then say, well, the brave ones who want to take a chance of a criminal suit or million dollar judgment can do it, and the other ones will use some other criteria.

In determining if a person is dead, the criteria should be available for everybody.

Senator CHURCH. Now, aside from defining death in this new way, what else would your model statute do?

Mr. CAPRON. It primarily clarifies the traditional definition of death, and then offers the absence of brain functioning as a standard to be applied when the traditional criteria, which are adequate in most all situations of course, are obscured by artificial means of maintenance. This is in the case of a patient sustained by a fairly massive amount of aid.

Senator CHURCH. That is all it does?

Mr. CAPRON. Yes, now it does not address the question which is really the topic of this hearing. That is why I had put it in my original testimony just as an aside. The question for these hearings is not. "Who is alive?" but "Who is being maintained?" and that is extremely difficult.

I gather that is what concerns you because you often have patients in that situation. Now, if the patient himself is still able to make chocies and is not comatose or anything, I think, as I suggested in the testimony, that it is for him to make the decision.

Senator CHURCH. Now, suppose under the present state of the law, and since your model statute does not come to grips with this question, what would happen if a patient, knowing that he had a terminal illness, and having been so advised by his doctor, knowing the type of treatment that was proposed for him, and being rational by every reasonable accepted test, asks not to receive the treatment in order that he will die naturally. And, the doctor complies with this request so he is in the doctor's care and he is the doctor's responsibility. Let us say, he is hospitalized. Do you think the doctor, under the present state of the law, could be held liable for malpractice if he did not insist upon administering the available care, the normal care that would be given in this case?

Mr. CAPRON. I do not think that I can give you a precise answer on that. I wish that I could, and I think the gist of my testimony is that there is no answer to that question now. On the one hand, I know of no case in which a patient, who meets the description that you just suggested, has been ordered to take treatment, which is sort of the reverse side of the coin.

Senator CHURCH. Do you know of any case where a doctor has been held liable for complying with his patient's request?

Mr. CAPRON. No, I do not, but it is clear that the counsel in many hospitals advise the physicians and staff and residents that they could be liable, and that is why they so often go to the courts to seek the advice.

Senator CHURCH. Now, let's take the next case. Suppose you had a patient in similar circumstances who asked not to be treated without having been fully informed by the doctor about the nature of the treatment or probabilities for extending his life if the treatment is offered, and the doctor, without having given him this information, complies with his desire.

LIKLIHOOD OF MALPRACTICE SUITS?

Do you know of any cases where doctors have been held guilty of malpractice?

Mr. CAPRON. No, but I think that you are treading on an area where there is much more likelihood of a suit in this day and age.

Senator CHURCH. And much more likelihood of liability?

Mr. Capron. Yes, and justifiably so.

Senator Church. I agree with you. Now, assume the next case; that the person is receiving treatment and loses consciousness and is no longer able to make a decision on his own, but that his nearest relatives, sensing the hopelessness of the case, being informed of the hopelessness of the case, and believing that the patient is in some physical distress, asked the doctor to refrain from further treatment so that death may occur naturally.

Now, in that case, the doctor complies. What is the state of the law there with respect to his possible liability if some other member of the family, let us say representing the estate, perhaps, were to sue?

Mr. Capron. Well, if he were relying on what appeared to be valid instructions from the next of kin, unless there were a conflict, for instance, between people of equal relationship to the patient, I do not see that that would be a problem for him.

I do not know of any cases in which that has arisen, in which a physician has been sued. It clearly poses the most difficult problem because, as a matter of policy, we usually allow the next of kin to make decisions for people who are incompetent, children, and those who are mentally incompetent although adults.

In the case of the dying patient, there are such terrible conflicting pressures, and as I understand it—I guess the question is better addressed to one of our physician witnesses—medical practice and medical ethics is that the physician should not impose on the family the burden of making the decision when to cease making the treatment.

I find that hard to understand, although I can certainly see why, out of compassion, this has been the practice.

Senator Church. But, is it really compassion for the dying person, or is it compassion for the feelings of the living?

Mr. Capron. It is more for the feelings of the living in that decision, and it is another example of the conflict between the interests of the dying and the living, who on the one hand probably do not want to see the family fortune go down the drain, and on the other, feel all sorts of pressures against doing something which seems terrible, which is to say we are no longer going to support you when you are the sickest you have ever been, because of the judgment perfectly validly reached that that support is not useful to you as a person.

Now, that is the kind of bind that the family is caught in, and I suppose the physician attempts to avoid that. It also, I would suggest, is a physician's avoidance of the burden that is placed on him in having really to confront the family.

Senator Church. Well, can it then be argued that because of the ambiguity of the law, and because of the question that must be in the physician's mind, or indeed the hospital administrators mind, that there might be liability, doesn't that in turn lead to a general failure of communication between doctor and patient and family and all concerned?

Mr. Capron. Yes, I think that is a fair summation of the state of present practice.

UNIFORM ANATOMICAL GIFT ACT

Could I comment on one thing that occurred before you were here in the exchange between Senator Fong and Dr. Beecher? Some questions came up about the state of the law on the donation of organs since so often the dying are the source of organs, and Dr. Beecher made reference in response to a question about the living will to the card which he carries with him.

The card that he was referring to is Uniform Anatomical Gift Act card which provides that once a person is dead, his organs may be removed for transplantation, educational purposes and the like. That should not be confused, it seems to me, with the living will because that relates to what happens with a still living person as to the termination of care. The Uniform Anatomical Gift Act, as I mentioned, is in force in all the States, so in answer to Senator Fong's earlier question to Dr. Beecher we do permit relatives to make the donation.

As I understand it from talking with transplant surgeons, still by far the majority of organs that are given, are given by someone other than the actual person from whom they are taken. That is to say, most people do not yet make the necessary provisions before death. So often the best organs come from young accident victims who have head injuries, and these people are less likely to be carrying cards. This is probably the sort of thing that comes with thinking about death and passing on, so old people are more likely to carry them.

Usually, in those cases, it is a relative who is asked, and that is quite within the provisions of the act to have relatives donate the organs.

Senator CHURCH. Well, in the light of your answers to my questions, do you think something more is needed in the way of a uniform act clearing up these ambiguities that we have discussed than the one that you are offering?

Mr. CAPRON. Oh, I was not offering the act in response to the subject of this inquiry. In the article we attempt to make very clear that there are two issues, and the definition of death is such an important issue that it seems to us that it should be laid to rest, and we should have a socially agreed upon definition because that is, in some ways, preliminary to a discussion of what to do with a person who is dying, but not yet dead.

If you cannot say whether or not a person is dead, you are in a pickle, I guess you might say.

Senator CHURCH. Do you have any further questions?

HOME HEALTH CARE FOR TERMINALLY ILL

Mr. ORIOL. In your statement, in discussing the choices other than institutionalization, you call for legal and economic steps to encourage the treatment of terminally ill in their own homes. Since this committee is so concerned about home health care, for the record, we would like more information on what legal and economic steps should be taken.

Mr. CAPRON. I am not familiar with all the provisions of Medicare and the like, but with the sorts of proposal that Senators Long and

Kennedy and others have put forward for the treatment of catastrophic illness and the like, they seem to continue the general thrust of Federal fund allocation which is to give funds for treatment that is received in institutions particularly in hospitals and to emphasize this kind of massive care rather than emphasizing care that could be given in the home. So that is the sort of legal and economic step that I would have in mind.

In other words, drafting a law to provide for practical nurses or whatever for the patient who decides to remain at home and spend the last days there. I realize in this day and age it would probably be a very difficult step to accomplish. That is to say we have moved so far from the pattern that prevailed even 40 years ago where elderly people were at home because they lived with the family right along and many of them would never go to the hospital because the hospital, in fact, represented fear to them. We have now turned that on its head, and I am not sure that many people wouldn't think that if their relatives stayed at home that they were being neglected and they were not being offered a great deal of care. This will take a good deal of discussion and education.

I am not sure whether making a specialty out of it is the sort of thing you want to do. The British have made some attempts at hospices——

Mr. ORIOL. That is the next thing I want to ask you about. Your next alternative is hospice. One of our witnesses tomorrow will talk about hospices but you describe one of the necessities for a hospice to work is that it clearly be understood that patients in such facilities would not expect to have their lives prolonged by certain treatments.

Now, would any change in existing law or practices be needed to make this sort of arrangement work without any danger of legal roadblocks?

Mr. CAPRON. We have the basic point which Senator Church has raised and that is that the law at the moment is unclear as to what liability would arise if a physician were to follow his patient's wishes. My emphasis here was simply that it should be clearly understood that there are different alternatives, that not every patient has to choose the same sort of alternative, and that these be clearly spelled out.

So if the patient says, "I want home care," he knows what that is going to mean and what that means, of course, is that a patient should be free to say at a time when illness is upon him, "I have changed my mind. I want to either step back to less intensive care" or, "I am now worried. I want more intensive care. Please take me to the hospital." But as to the hospice itself, it would be understood that this would not be merely another hospital for old people where we carry on the same kind of treatment.

ABUSES IN TEACHING HOSPITALS

As has been mentioned by both Dr. Reich and Dr. Beecher probably some of the worse abuses occur because we have teaching hospitals which do a very excellent job but must, to a certain extent, exploit their patients.

Now, that is something I suppose is somewhat clear but not entirely clear to patients when they enter a teaching hospital, that they are going to get the best care, but also they are going to be human guinea pigs. I don't say that pejoratively because it seems to me it is perfectly proper to use human beings in experimentation provided that they have given a fully informed consent to this. For some people an opportunity to participate in an experiment can offer great meaning to the end of life, or if not a dying patient, just to life, as has been illustrated by countless people.

Dr. Jay Katz has just put out a casebook with which I assisted, at Yale where I was before on "*Experimentation With Human Beings*" (Russell Sage Foundation, 1972), which has a chapter on experimentation of the dying. Dr. Beecher's pioneering work in this area also covers that. It has been made clear that so often the patients involved have no knowledge of what is going on or are not given a true knowledge of what is going on. This is the sort of thing which seems to me ought to be avoided by making clear what use of the different facilities entails.

Senator CHURCH. Mr. Capron, I would like to read to you from your final page of testimony. Because I personally have much in accord with what you said. I think it is a summation of your whole testimony.

You say the law in this area is in a rather rudimenatry and confused state and the cases closest on point are divided, but excluding the religious factor the leading cases hold that a dying patient has no right to refuse treatment chosen by his physician. Yet, these cases also seem to recognize that a line must be drawn somewhere that some therapy is so risky, arduous, or experimental that a patient may decline it.

It seems to me that this line should be drawn quite close in, that is, the usual right of a patient to decline any treatment should not be negated by the imminence of death. If anything, we should be more solicitous of the wishes of the dying patient. The role of the law here can be to facilitate good medical care and to make clear that physicians are not liable criminally or civilly if they follow their patients' wishes to forego some of or all of the miracles of modern science.

We must relieve the pressure on physicians to overtreat and instead encourage them to counsel patients and their families and reassure them that refusal to accept life-prolonging treatment will not lead to their being abandoned medically and left without medical support for the relief of the pain of dying. In sum the law needs to look for ways of clarifying the right of patients to a dignified death and at the same time it must be mindful of our tendency to neglect the dying.

Now, I think the principles you state here are perfectly sound. I think most people would agree with that. Why don't you try to write a model statute that encompasses these principles to circulate it through the various State legislatures for their consideration. Why don't you make this an undertaking in your career as a professor of the law?

Mr. CAPRON. I thank you for the suggestion. I would hope that if I were to undertake such a task I would be able to interest many other people in this task. I agree with you, it is a very important one.

Senator CHURCH. You proceed any way you think best and of course you should counsel with as many people as possible for direction and advice but it seems to me that you are sufficiently involved in this area of the law that this would be a most important contribution that you could make, to cope with what is now an utter incomplete, obscure, and ambiguous situation that works to no one's advantage.

If you have no further questions, we will adjourn. We have run out of time for the panel. We will conclude the hearings today and reopen them tomorrow at 10 o'clock.

(Whereupon, at 1:10 p.m., the hearing adjourned, to reconvene at 10 a.m., Wednesday, August 9, 1972.)

APPENDIX A

ITEM 1. ARTICLE FROM THE NEW YORK TIMES,* "DOCTORS DIVIDED OVER EUTHANASIA," AUGUST 8, 1972

[From the New York Times, August 8, 1972]

DOCTORS DIVIDED OVER EUTHANASIA

PHYSICIANS TESTIFY BEFORE SENATE PANEL ON AGING

A group of physicians, including one who said he had allowed "hundreds of terminally ill patients" to die, disagreed at a Senate hearing today on whether terminally ill or injured persons had a right to euthanasia.

Dr. Walter W. Sackett Jr., a physician who is a member of the Florida Legislature, promoted legislation he had introduced in his state to empower adults to execute a document directing the discontinuation of medical treatment in cases of terminal illness or injury when such treatment is designed solely to sustain life.

Dr. Sackett testified at the first of three days of hearings on "Death with Dignity" by the Special Senate Committee on Aging.

Dr. Sackett, who said he had "allowed hundreds of terminally ill patients to die," said his legislation would take effect only after a patient had been declared terminally ill or injured by two licensed doctors.

A spouse or first degree relative would give the authorization if the patient was mentally or physically incapable of doing so. In cases where no relative could be found within 30 days, a panel of three doctors would have authority to decide that continued medical treatment would be useless, he said.

TUBE FED AND UNAWARE

Dr. Sackett said his data indicated that it would cost $5-billion in his state alone to allow "1,500 individuals retarded to the point that they are bedridden, diapered, tube-fed and completely unaware, to live out artificial lives prolonged by the marvels of science."

"The money," he said, "could better be used on persons with illnesses that could be cured, such as those that need kidney transplants."

Dr. Laurance V. Foye Jr., Director of Education Service for the Veterans Administration, disagreed, saying, "Neither I nor anyone else knows how to decide when being alive becomes useless. The right to die concept implies that if death is certain and immediate we have the right to make it even more immediate. We must never forget that on occasion patients, their families and their physicians will conclude that a disease has reached the hopeless stage and death is imminent—and be wrong."

"Only when death beats a patient should we give up. We should never give the game away," Dr. Foye said.

EUTHANASIA BACKED

Dr. Elisabeth Kubler-Ross, a physician and author of "On Death and Dying," said that she supported euthanasia though it must be accompanied by safeguards.

Dr. Kubler-Ross said that her mother had been bed ridden in an institution for the last two years.

"She has begged that she be allowed to die," the physician said.

In her book, Dr. Kubler-Ross wrote: "He [the terminally ill patient] may cry for rest, peace and dignity but he will get infusions, transfusions, a heart machine or tracheotomy, if necessary. Those who consider the person first may lose precious time to save his life."

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*See discussion by Senator Church of this article, pp. 68–69.

Dr. Kubler-Ross contends that modern medical institutions sometimes crush the dignity and comfort of a patient even while working to save his life.

Arthur E. Morgan, the 94-year-old former president of Antioch College in Ohio, testified that legislation bearing upon the right to live should be as effective in protecting life as in providing for the ending of life where this conclusion is called for.

ITEM 2. ARTICLE FROM THE WASHINGTON POST,* "DEATH AND DYING," AUGUST 8, 1972

[From the Washington Post, Aug. 8, 1972]

DEATH AND DYING

(By Nancy L. Ross)

Who should be allowed to die? When? How?

The once-taboo subject of death and dying is now being widely discussed in this country. Yesterday the Senate Special Committee on Aging began its own inquiry into the public issues related to death with dignity, the popular phrase for refusing to prolong life by extraordinary means when there is no hope of recovery.

From the start, witnessses hotly disagreed on fundamental questions. A physician holding the conventional view of doing everything to save lives through the use of equipment and drugs was pitted against a psychiatrist's pleading that the dying be treated like people, instead of medical pincushions, and allowed to die at home in peace. The psychiatrist in turn opposed a state legislator's proposal that the right to die and the right to decide who should live or die be codified into law.

Yet there was a common bond among witnesses and senators alike as one after the other recounted poignant cases of dying and death which had touched them personally or professionally. There was 94-year-old Dr. Arthur E. Morgan, former president of Antioch College, who wept when he told of how nurses forced his dying wife's jaw open to make her eat. There was the committee chairman, Sen. Frank Church (D-Idaho), who recalled how doctors had given him six months to live back in 1947 when he had cancer.

There was Swiss-born psychiatrist Elisabeth Kubler-Ross, who has interviewed over 500 dying patients and is the author of the movement's bible, "On Death and Dying," telling how her own mother has lain moribund and completely incapacitated in a hospital for two years because nurses are not available for round-the-clock home care. Dr. Walter W. Sackett, a Florida state representative, said 125 otherwise healthy victims of kidney disease in his state died for lack of dialysis machines because "somebody" decided the money was better spent maintaining severely mentally and physically retarded individuals in institutions.

These hearings, Sen. Church emphasized, are not for the purpose of "floating trial balloons on proposals for governmental action." They are rather to gain a "greater public understanding of the issues before we can even begin to think about changes in public policy."

Yet five state legislatures—Florida, Wisconsin, Utah, Hawaii and Montana—according to Sackett, have already debated the advisability of legislating death. Sackett has repeatedy but unsuccessfully introduced a bill which would allow a person to sign a legal document asking to be allowed to die under certain circumstances. Such a measure, the sponsor reasons, would among other things tend to relieve the physician's possible liability in cases where active treatment is stopped.

Sackett estimates 75 per cent of today's physicians already practice death with dignity.

It would allow a close relative to make the life or death decision when the patient is mentally incompetent. When such a patient has no relatives or guardian, Sackett would permit three members of the staff of any recognized hospital to say an individual's life should not be prolonged by what he called "heroic methods."

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*See discussion by Senator Church of this article, pp. 68–69.

This last proposal was strongly contested by Sen. Charles Percy (R-Ill.). "Human nature being what it is" he said, "you can always find unscrupulous physicians, clergy and family willing to shut off medical care to people in intensive care" (in the hope of monetary gain).

Dr. Laurance V. Foye Jr., director of the Education Service of the Veterans Administration, vigorously opposed what he called "passive and occasionally active euthanasia in hopeless cases. If a physician withholds maximum effort from patients he considers hopelessly ill, he will unavoidably withhold maximum effort from an occasional patient who could have been saved . . . The physician's hands may be tied (by the proposed law) in just those cases where his skill and modern technology can make the greatest contribution to the saving of lives and the control of disease."

Eighty per cent of all Americans now die in institutions. "The worst place to die is a large teaching hospital," stated Dr. Kubler-Ross. If physicians cannot learn from the dying, she explained, the patients cease to be medically interesting and are shunted off to the custodial care of students.

Medicare and Medicaid, she believes, tend to institutionalize the patient, thus increasing treatment costs and family anxiety. Dr. Kubler-Ross feels part of the money should be spent instead for home care and financial support for the family. Death at home, the psychiatrist reasons, helps the family as well as the patient to better get through what she calls the five stages of dying: denial, anger, bargaining with God, depression and final acceptance.

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